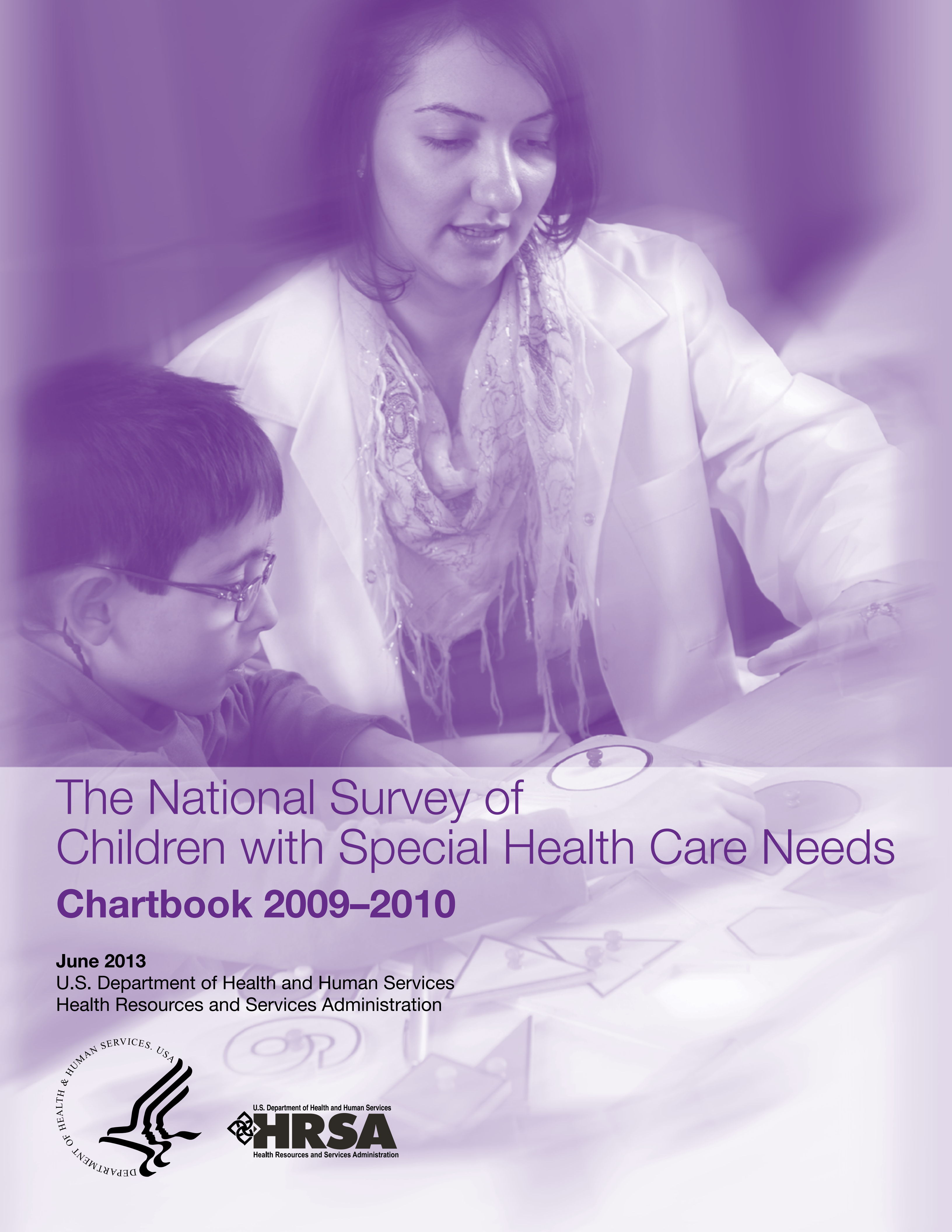

# The National Survey of Children with Special Health Care Needs

## Chartbook 2009–2010

**June 2013**
U.S. Department of Health and Human Services
Health Resources and Services Administration

U.S. Department of Health and Human Services
HRSA
Health Resources and Services Administration

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# Introduction

Children with special health care needs (CSHCN) are defined by the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau 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."*** [1]

This definition is broad and inclusive, and it emphasizes the characteristics held in common by children with a wide range of conditions. The National Survey of Children with Special Health Care Needs (NS-CSHCN) provides a consistent source of both national- and State-level data on the size and characteristics of the population of CSHCN. This survey, sponsored by the Maternal and Child Health Bureau (MCHB) and carried out by the National Center for Health Statistics of the Centers for Disease Control and Prevention, provides detailed information on the prevalence of CSHCN in the Nation and in each State, the demographic characteristics of these children, the types of health and support services they and their families need, and their access to and the quality of the care they receive.

The survey conducted in 2009-2010 represents the third round of the National Survey of CSHCN. While many indicators were measured consistently over the three rounds of the survey, many of the survey's questions were revised or re-ordered, some of the composite indicators have been re-defined, and the sample design was changed to incorporate cell-phone-only households in 2009-2010. Consequently, the indicators described here generally cannot be compared directly with the findings of the previous surveys.

Overall, the survey shows that 15.1 percent of U.S. children, or 11.2 million children, have special health care needs, and 23.0 percent of households with children include at least one child with a special health care need. These rates represent a slight increase from the percentages reported in 2005-2006, which, in turn, represented an increase from 2001. However, the reasons for this trend are unknown. While it is possible that the number of CSHCN is actually increasing, it is equally possible that children's conditions are more likely to be diagnosed, due to increased access to medical care, or growing awareness of these conditions on the part of parents and physicians, or that the changes in the composition of the sample affected the likelihood that CSHCN would be identified by the survey.

Children with special health care needs are as diverse as our Nation, representing all racial and ethnic groups, ages, and family income levels. The children meeting the definition also represent a range of levels of functional abilities, from those who are rarely affected by their conditions to those who are significantly affected. However, what they all share in common is the consequences of their conditions, such as reliance on medications or therapies, special educational services, or assistive devices or equipment. They also share a need for systems of care that are comprehensive, coordinated, community-based, family-centered, and accessible—that is, a medical home and a set of supports that help families to navigate the various services that their children need.

These services include preventive, acute, and chronic medical care; prescription medications; specialty therapies; medical equipment; and mental health services, among others. The survey documents the breadth and extent of these needs, including prescription medications (needed by 86 percent of CSHCN), specialty medical care (48 percent), vision care (35 percent), mental health care (28 percent), specialized therapies (27 percent), and medical equipment (11 percent). Most CSHCN receive the services they need; however, the parents of 24 percent report at least one unmet need for services.

Families of CSHCN often require support in coping with the consequences of their children's conditions. Overall, the parents of 6.7 percent of CSHCN report a need for respite care, 6.5 percent for genetic counseling, and 12 percent need family counseling to help deal with the stresses involved in having a child with special health care needs. Again, while most families receive the services they need, 7.2 percent report at least one unmet support service need.

The MCHB has identified six Core System Outcomes that provide a framework for examining the needs of CSHCN and their families and the quality of the systems that serve them throughout childhood, from screening and identification of special health care needs through transition to adulthood. These are measures that can be used to monitor the Nation's progress toward the goal of a comprehensive, family-centered, community-based, coordinated system of services for children with special health care needs, and the outcomes can be monitored through the questions asked in the National Survey. Moreover, the individual indicators that make up the Core System Outcomes provide useful detail about CSHCN's access to the systems and services they need. For example, one of the Core Outcomes addresses the need among CSHCN for coordinated, comprehensive care within a medical home. Overall, 43 percent of CSHCN receive care that meets this standard. This outcome incorporates a wide range of indicators that provide insight into various aspects of the care that CSHCN receive. Nearly all CSHCN have at least one personal doctor or nurse, the foundation of a medical home, and 75 percent have a usual place they go when they are sick. However, only 56 percent of those who needed coordination among their various sources of care received it, and only 65 percent reported receiving care that was family-centered. Of those CSHCN who needed referrals to specialists, 23 percent had problems receiving them. Thus, while most CSHCN have some basic elements of a medical home—a personal doctor or nurse and a place they go when they are sick—fewer receive care that encompasses all essential elements of the comprehensive medical home.

Another important element of access to care, and one of the Core System Outcomes is the availability and adequacy of health insurance coverage. Children with special health care needs are more likely than the population of children as a whole to have insurance; at the time of the survey, only 3.6 percent of CSHCN were uninsured, and 9.3 percent were uninsured at some time over the previous

## *The Six Core System Outcomes*

1. ***Families of CSHCN partner in decision-making regarding the child's health***
2. ***CSHCN receive coordinated, ongoing, comprehensive care within a medical home***
3. ***Families of CSHCN have adequate public and/or private insurance to pay for needed services***
4. ***Children are screened early and continuously for special health care needs***
5. ***Community-based services are organized so families can use them easily***
6. ***Youth with special health care needs receive the services necessary to make transitions to adult health care***

12 months. However, one-third of insured respondents report that their child's insurance is not always adequate to meet their children's needs, either because the benefits do not meet their needs, the cost-sharing is not reasonable, or they do not have access to the providers they need. Thus, despite the fact that 90 percent of CSHCN have continuous health insurance, only 60 percent met all of the standards for this Core Outcome.

While the NS-CSHCN is not a longitudinal survey, looking at the six Core System Outcomes as snapshots across a child's life span can provide a life-course perspective on the care of CSHCN. Early and continuous screening for special health care needs, which should begin at birth and continue throughout childhood, is the Core Outcome most likely to be achieved, with 78.6 percent of CSHCN meeting the standards. Transition to adulthood, at the other end of childhood, is the outcome that is least often met, with only 40 percent of CSHCN aged 12-17 receiving the services necessary to make transitions to adult health care.

Another important set of indicators reflects the impact of having a child with a special health care need on the family's time, finances, and employment status. The financial impact of the care of CSHCN can be substantial: the families of one-third of CSHCN report that they spend more than $500 per year on their child's care. Moreover, the parents of 22 percent of CSHCN report that their child's condition has caused them financial problems. These problems can be exacerbated if parents must stop working or reduce their work hours to care for their children, as the parents of 25 percent of CSHCN report that they do. Conversely, the parents of 18 percent of CSHCN report that they have avoided changing jobs because they are concerned about losing access to health insurance for their children.

Taken together, the indicators presented here paint a picture of a system of services for CSHCN that meets the needs of many children and their families. However, room for improvement still exists, especially in the systems that serve the most vulnerable children, such as those in low-income families and those who receive coverage through public programs. In addition, the group with the greatest challenges is often the children who are most affected by their conditions in their daily lives. This chartbook presents the major findings of the survey on the national level, stratifying each indicator by selected sociodemographic variables such as age, race/ethnicity, income level, and type of insurance. The specific demographic variables used on each page were selected to highlight those of greatest interest or strongest association with each particular indicator; the full set of findings for each indicator are available at the Data Resource Center for Child and Adolescent Health at http://www.childhealthdata.org.

The second section of this chartbook shows the indicators for each of the 50 States and the District of Columbia. All indicators are displayed for each state, except in cases where the sample size would compromise the respondents' confidentiality. The chartbook concludes with a technical description of the survey methodology.

## 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.

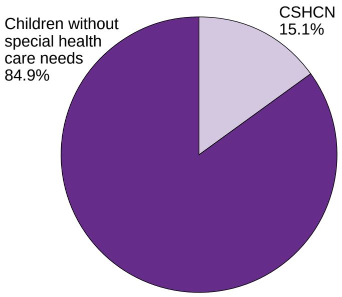
The following section describes the survey's findings about the prevalence of special health care needs among children. Throughout this chartbook, the term "children" is used to refer to children and youth from birth through age 17 unless otherwise specified.

## Prevalence of CSHCN: Individuals and Households

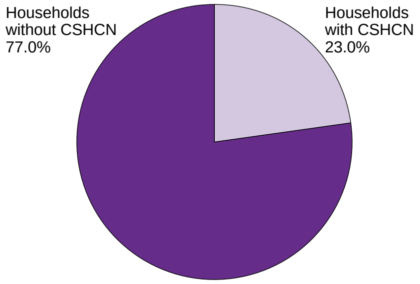
One purpose of the NS-CSHCN is to estimate the prevalence of CSHCN in the population nationally and in each State. The survey identifies CSHCN by asking parents if their child has a medical, behavioral, or other health condition that is expected to last at least one year, and if that condition caused 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 Among Individuals**



**Prevalence of CSHCN Among Households***



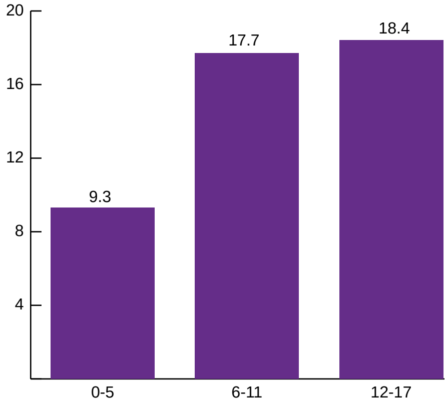
**Includes only households with children.*

## Prevalence of CSHCN: Age and Sex

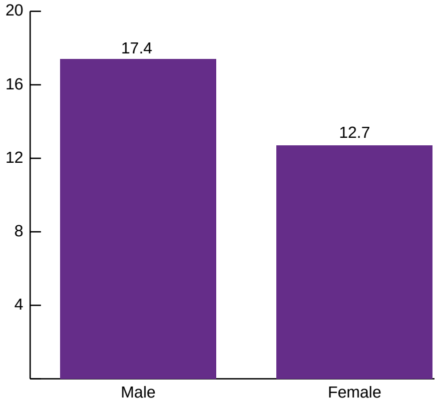
The prevalence of special health care needs among children increases with age. Preschool children (from birth to 5 years of age) have the lowest prevalence of special health care needs (9.3 percent), followed by children aged 6-11 years (17.7 percent). Children in the oldest age group (12-17 years) have 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, by Age**



**Prevalence of CSHCN, by Sex**



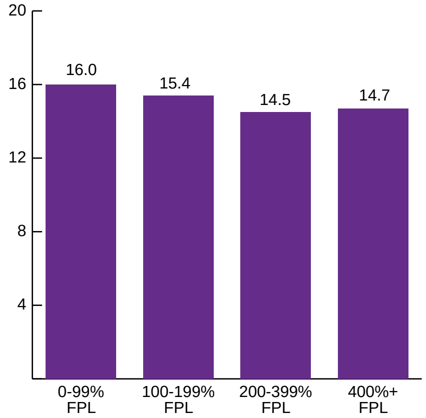
## *Prevalence of CSHCN: Family Income, Race/Ethnicity, and Primary Language*

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.

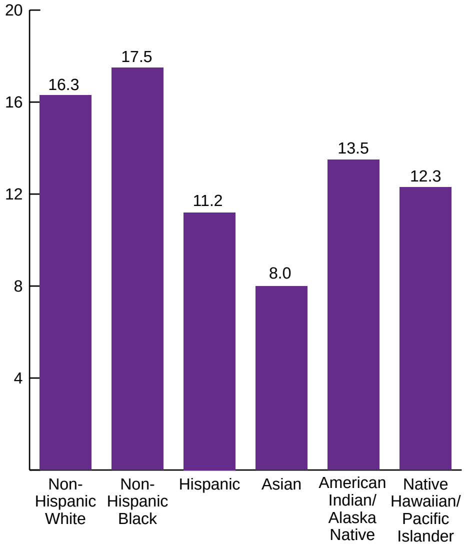
The prevalence of special health care needs also varies by the race/ethnicity of the child. Prevalence is highest among non-Hispanic Black children (17.5 percent), non-Hispanic White children (16.3 percent), American Indian/Alaska Native children (13.5 percent), and Native Hawaiian/Pacific Islander children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

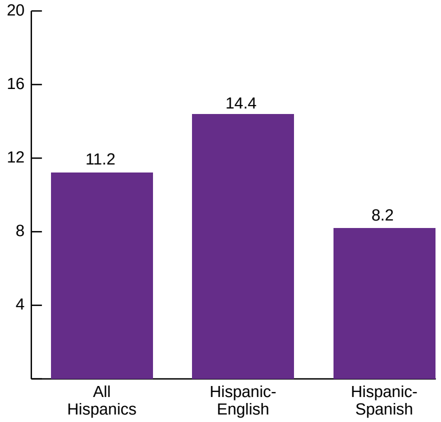
**Prevalence of CSHCN, by Poverty Status**



**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.

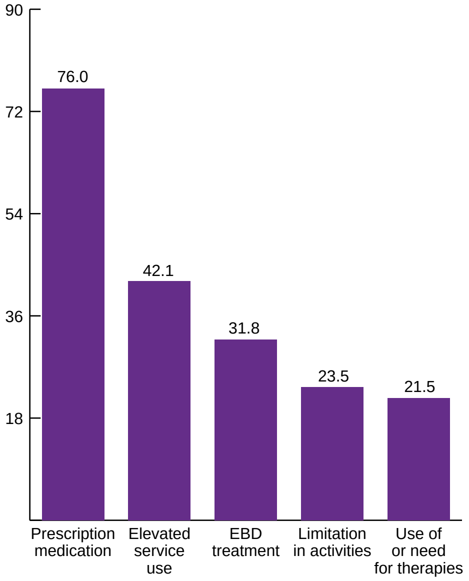
## Consequences of Special Needs

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),

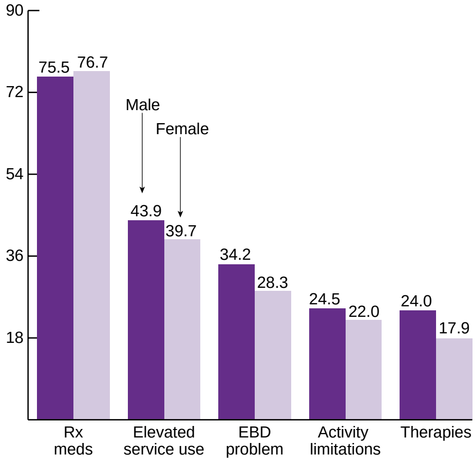
**Percent of CSHCN Experiencing Each Consequence of Special Health Care Needs**



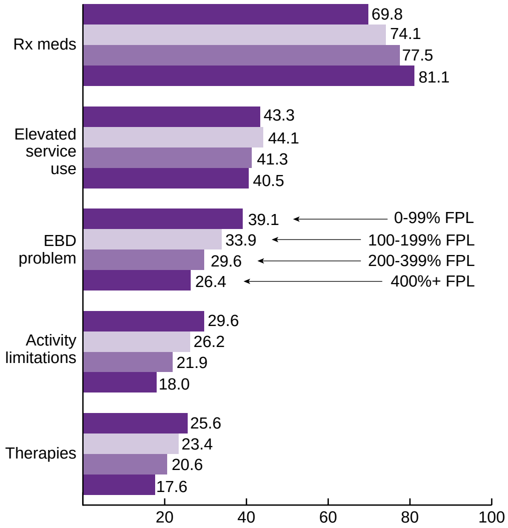
followed by need for or use of services for ongoing emotional, behavioral, or developmental problems (31.8 percent), limitation in activities (23.5 percent), and the use of specialized therapies (21.5 percent). The percentages do not add to 100 because each child may experience more than one consequence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

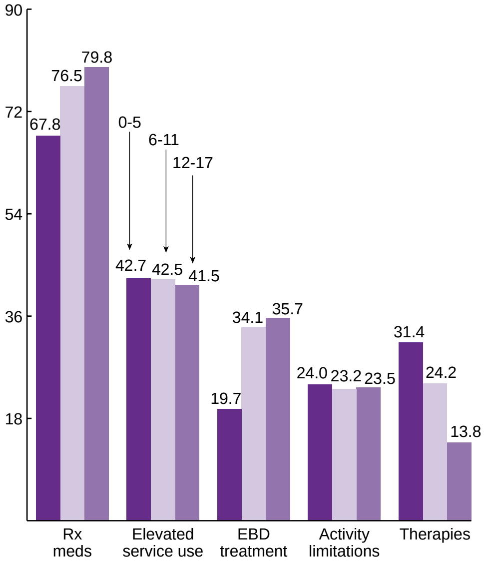
**Percent of CSHCN Experiencing Each Consequence of Special Health Care Needs, by Sex**



**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:

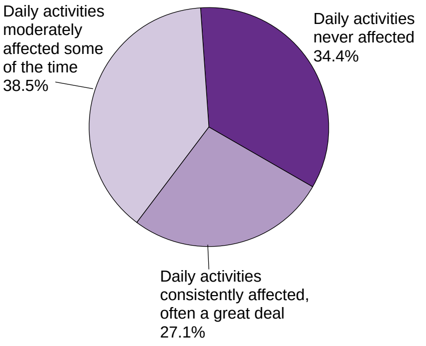
- How often does the child's condition affect his or her ability to do the things other children of the same age do?
- To what degree does the condition affect the child's ability to do those things?

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.

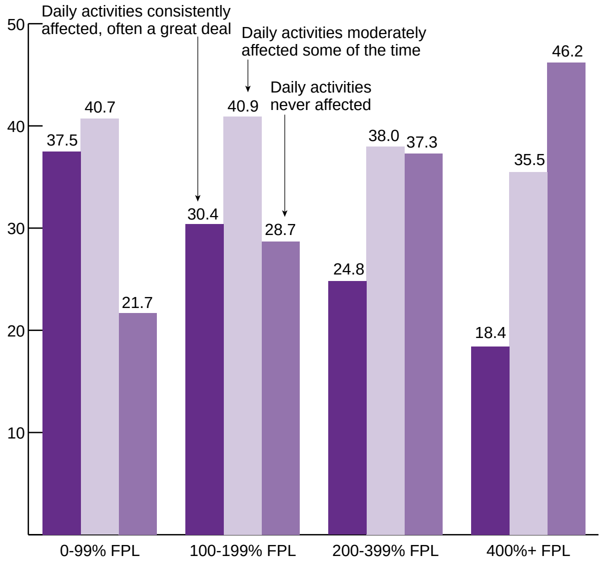
Based on parents' reports, 34.4 percent of CSHCN are never affected in their ability to do things other children do. This may be attributable to the nature of their conditions or to treatment that effectively manages their conditions. Another 38.5 percent are moderately affected some of the time, and 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**

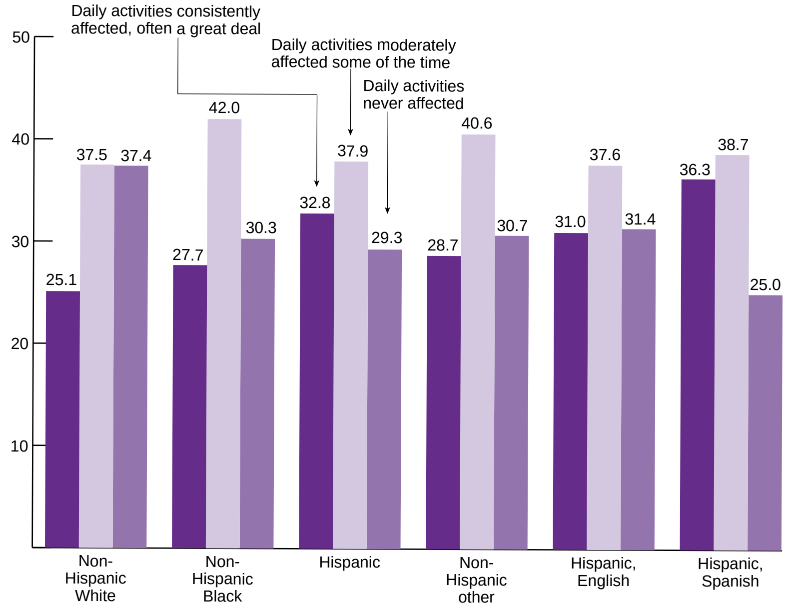


**Impact of Children's Conditions on Their Daily Activities, by Poverty Status**



The 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.

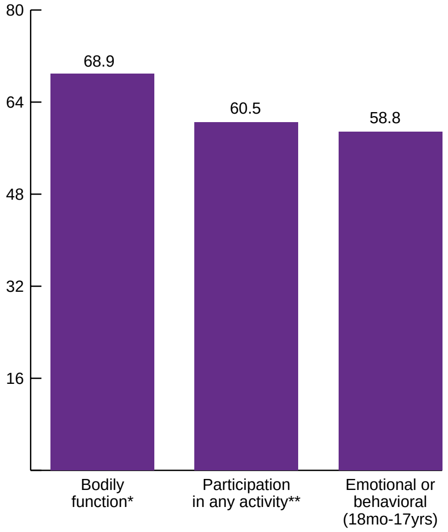
There is some variation in the types of functional difficulties that are evident by racial and ethnic group. Non-Hispanic White children are less likely to have difficulties with bodily functions (65.2 percent) than non-Hispanic Black and Hispanic children, and Hispanic children are the most likely to 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 CSCHN (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.

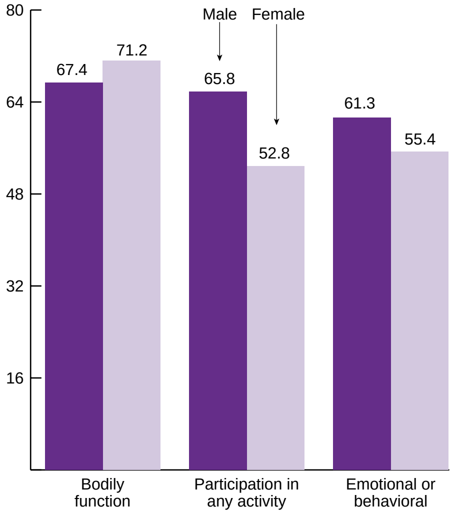
These three categories of functional difficulties — bodily functions, emotions or behavior, and participation in activities — comprise 14 specific difficulties that children may experience as a result of their conditions. For children of all ages, these may include difficulties with vision (even when 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**



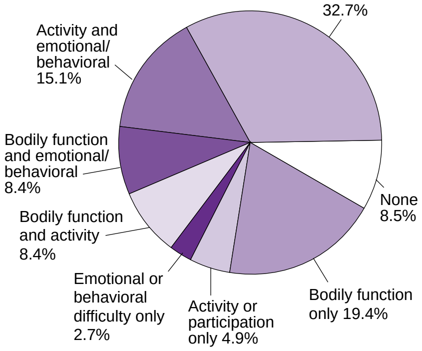
**Breathing or respiration, swallowing or digestion, blood circulation, chronic physical pain including headaches, seeing even when wearing glasses or contacts, hearing even when using a hearing aid. **Self care, coordination or moving around, using hands, learning, understanding or paying attention,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

**Functional Difficulties Among CSHCN, by Sex**

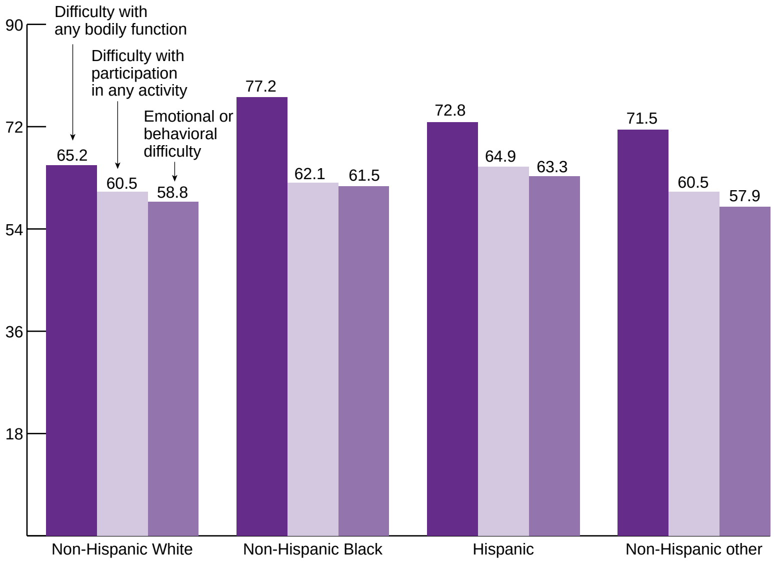


For children aged 1 to 17 years, other potential areas of difficulty include learning, understanding, or paying attention, and speaking, communicating, or being understood. For children aged 18 months to 17 years, additional potential problem areas include anxiety or depression and behavior problems. 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.

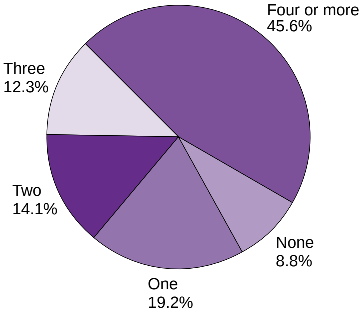
**Distribution of Functional Difficulties Among CSHCN**



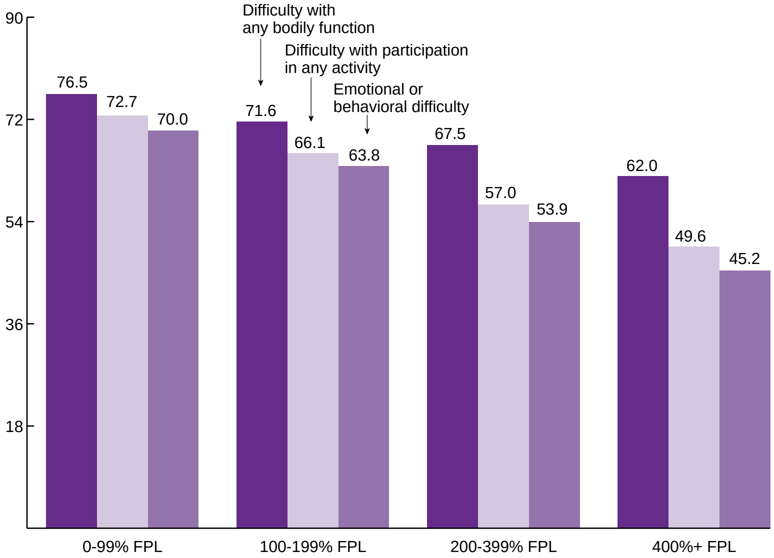
**Functional Difficulties Among CSHCN, by Race/Ethnicity**



**Number of Functional Difficulties Among CSHCN**



**Functional Difficulties Among CSHCN, by Poverty Status**



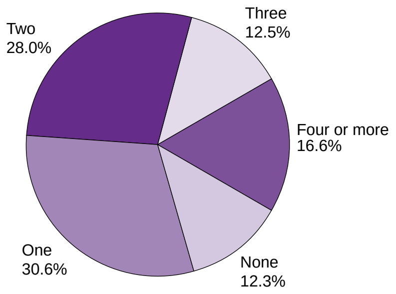
## *Health Conditions*

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**

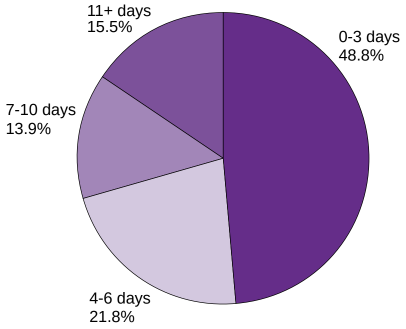
| Conditions | Currently have the condition |
|---|---|
| ADD/ADHD (age 2-17) | 30.2% |
| Allergies | 48.6% |
| Food allergies | 11.9% |
| Anxiety (age 2-17) | 17.1% |
| Arthritis/joint problems | 2.9% |
| Asthma | 35.3% |
| Autism Spectrum Disorders (age 2-17) | 7.9% |
| Behavioral/conduct disorders (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*

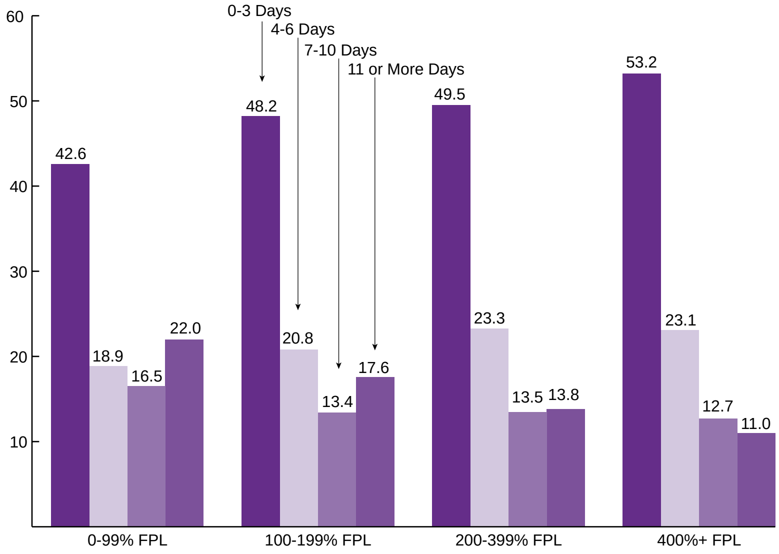
The number of days of school a child misses during the school year is another measure of the impact of a child's condition on his or her ability to function as other children do. In general, the average child misses 3 days of school due to acute conditions. In comparison, among school-aged CSHCN, the 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**

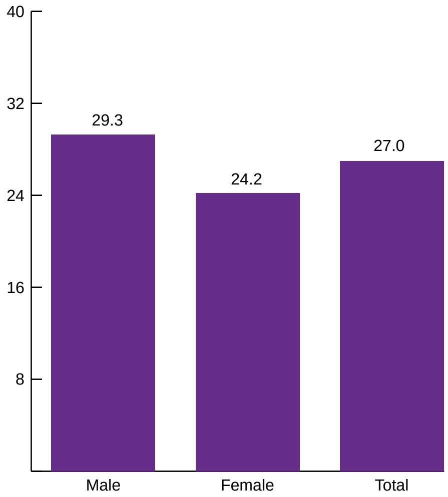


## *Program Participation*

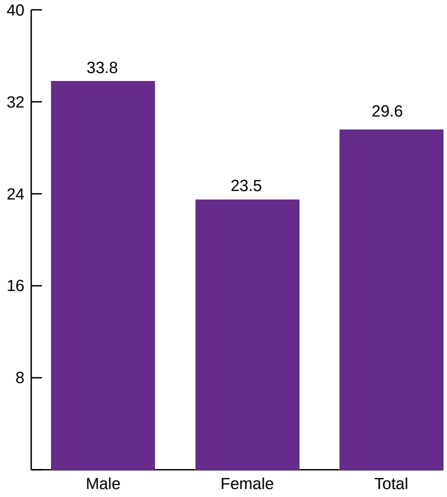
The early development and eventual success in school of CSHCN can be promoted and supported by participation in Early Intervention and Special Education programs. The Individuals with Disabilities Education Act (IDEA) provides specialized therapies to children under age 3 with developmental delays (under 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.

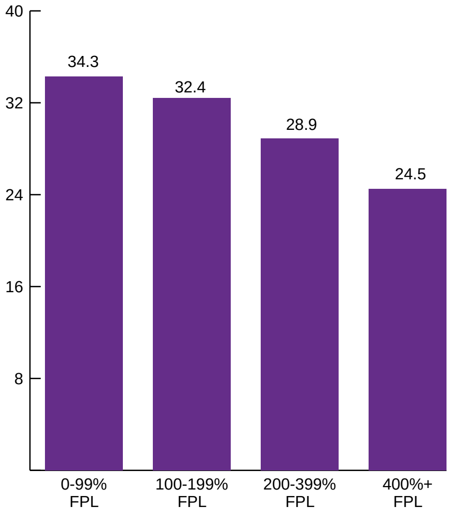
**Participation in Early Intervention Among CSHCN Aged 0-2 Years**



**Participation in Special Education Among CSHCN Aged 3-17 Years**



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



# CSHCN Core System Outcomes – Goals for a System of Care

Since 1989, the goal of the State Title V programs for children with special health care needs (CSHCN) has been to provide and promote family-centered, community-based, coordinated care for children with special health care needs and to facilitate the development of community-based systems of services for such children and their families. The long-term outcome of systems development is that all families are able to access health and related services along the continuum of care in a manner that is both affordable and meets their needs; policies and programs are in place to guarantee that children have access to quality health care; providers are adequately trained; financing issues are equitably addressed; and families play a pivotal role in how services are provided to their children.

A long-term national goal was first articulated in *Healthy People 2000: National Health Promotion and Disease Prevention Objectives*, as follows:

*Increase the proportion of states and territories that have service systems for children with or at risk for chronic and disabling conditions as required by Public Law 101-239.*

The Maternal and Child Health Bureau, together with its partners, has identified core outcomes for the community-based system of services required for all children with special health care needs under Title V, under *Healthy People 2000*, and reiterated under *Healthy People 2010* and *Healthy People 2020*. These outcomes give us a concrete way to measure our progress in making family-centered care a reality and in putting in place the kind of systems all children with special health care needs deserve. Progress toward the overall goal can be measured using these six critical indicators:

- Families of children with special health care needs partner in decision making regarding their child's health;
- Children with special health care needs receive coordinated, ongoing, comprehensive care within a medical home;
- Families of children with special health care needs have adequate private and/or public insurance to pay for needed services;
- Children are screened early and continuously for special health care needs;
- Community-based services are organized so families can use them easily;
- Youth with special health care needs receive the services necessary to make transitions to adult health care.

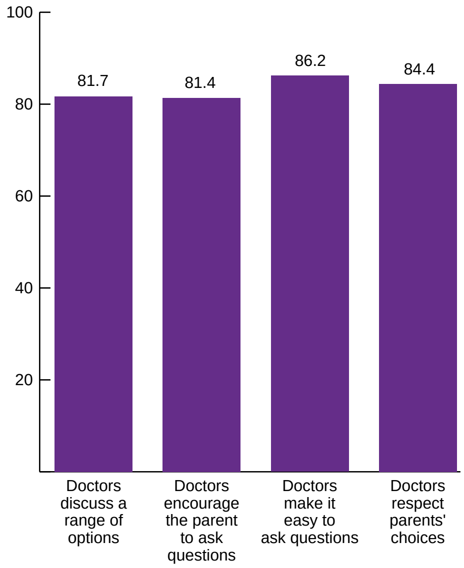
The following sections describe the Nation's progress on each of these indicators, presenting first the individual indicators that make up the outcome measure, followed by any related indicators that are not part of the overall measure. Finally, we discuss the proportion of CSHCN whose care meets each of the six outcome goals.

## *Families of CSHCN partner in decision-making regarding the child's health*

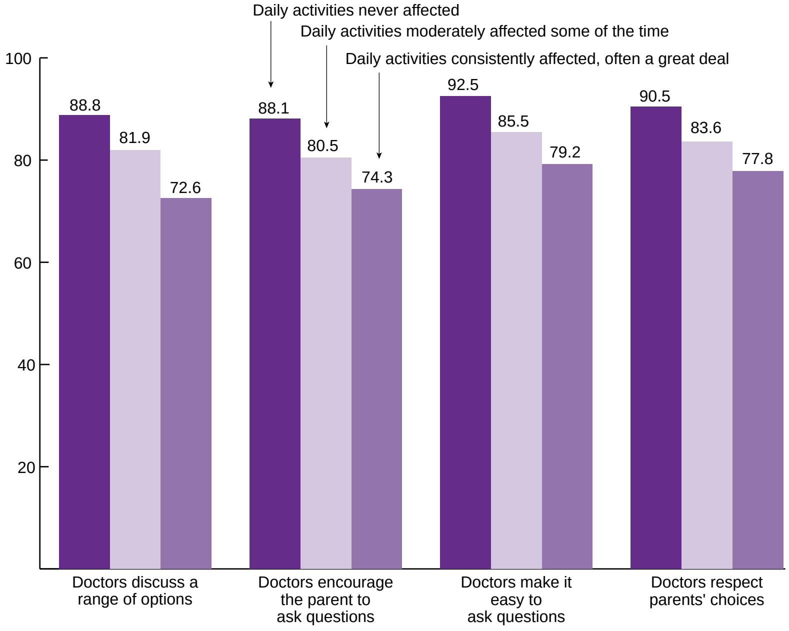
Family-centered care is based on the recognition that children live within the context of families, which may include biological, foster, and adoptive parents, step-parents, grandparents, other family caregivers, and siblings. Family-centered care is a process to ensure that the organization and delivery of services, including health care services, meet the emotional, social, and developmental needs of children; and that the strengths and priorities of their families are integrated into all aspects of the service system. For example, family-centered care supports families as they participate as integral partners in the medical home and work with their children's health care providers in making informed health care decisions. Family-centered care recognizes that families are the ultimate decision-makers for their children, with children gradually taking on more and more of this responsibility as they mature.

The family partnership outcome was evaluated using a series of questions in the NS-CSHCN about families' role in decision-making: how often doctors discuss a range of treatment options with families, how often they encourage parents to ask questions about their child's care, how often they make it easy for parents to ask questions, and how often doctors respect parents' choices about their child's health care. The parents of over 80 percent of CSHCN answered "usually or always" to each of these four questions. This percentage is lower, however, among children whose conditions consistently affect their activity; among these children, the parents of approximately three-quarters reported that their children's providers usually or always meet each criterion for partnership in decision-making.

**Percent of CSHCN Whose Families Usually or Always Are Partners in Decision-Making (components)**



**Components of Partnership in Decision-Making, by Impact of Condition**

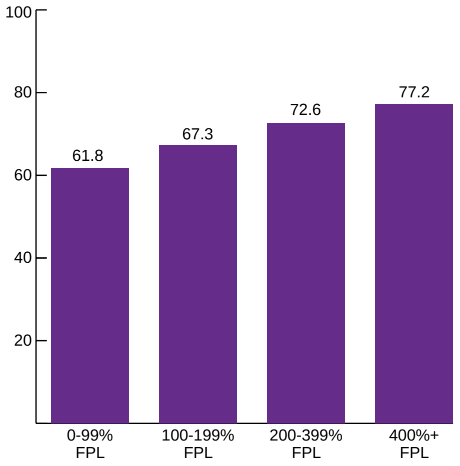


## Core Outcome Summary

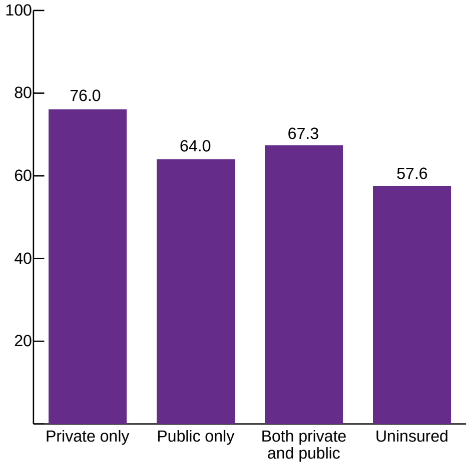
A child was determined to meet the standard for family partnership if their parents answered “usually or always” to all four questions. Overall, 70.3 percent of CSHCN met this standard. This percentage is highest among non-Hispanic White CSHCN (74.2 percent) and lowest among Hispanic CSHCN who primarily speak Spanish at home (59.8 percent). Of children whose daily activities are never affected by their conditions, 79.3 achieved the outcome, compared to 61.1 percent of CSHCN whose activities are consistently affected, often a great deal, by their conditions.

The percentage of CSHCN who achieved this outcome also varies by family income and the child’s insurance status. Of children with no health insurance, 57.6 percent receive family-centered care, compared to 64.0 percent of CSHCN with public insurance and 76.0 percent of those with private insurance. Likewise, of children with family incomes below the Federal Poverty Level (FPL), 61.8 percent achieved this outcome, compared to 77.2 percent of CSHCN with family incomes of 400 percent of the FPL or more.

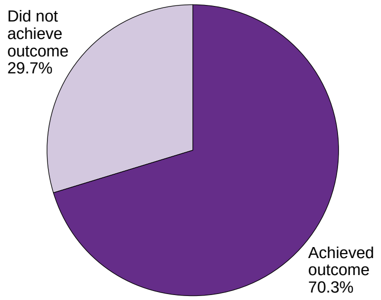
**Percent of CSHCN Whose Families Are Partners in Shared Decision-Making for Child’s Optimal Health, by Poverty Status**



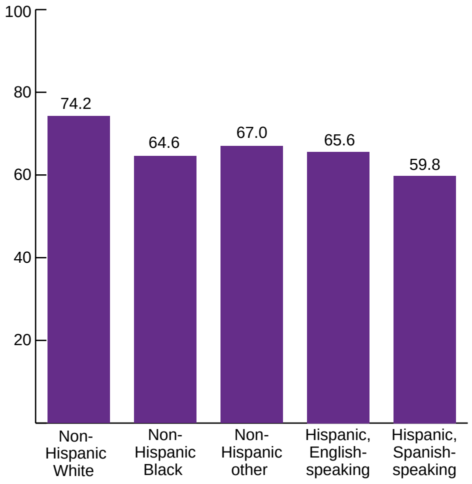
**Percent of CSHCN Whose Families Are Partners in Shared Decision-Making for Child’s Optimal Health, by Insurance Type**



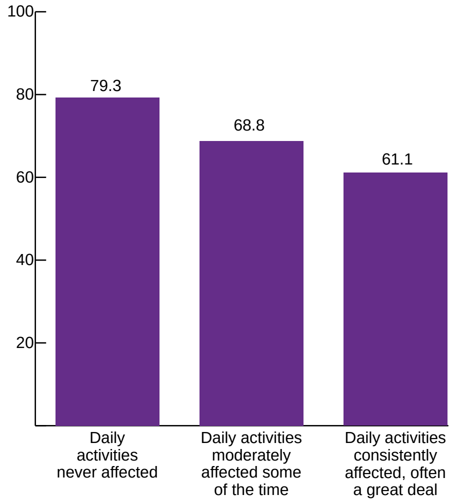
**CSHCN Whose Families Are Partners in Decision-Making Regarding the Child’s Health**



**Percent of CSHCN Whose Families Are Partners in Shared Decision-Making for Child’s Optimal Health, by Race/Ethnicity and Primary Language**



**Percent of CSHCN Whose Families Are Partners in Shared Decision-Making for Child’s Optimal Health, by Impact of Condition**



## *CSHCN receive coordinated, ongoing, comprehensive care within a medical home*

A medical home is a source of ongoing, comprehensive, coordinated, family-centered care in the child's community.[3] Child health care professionals and families agree that medical homes provide important benefits to children and youth with special health care needs.

The medical home can and should provide preventive services, immunizations, growth and developmental assessments, appropriate screening, health care supervision, and counseling for patients and their families about health and psychosocial issues. The medical home also can and should ensure that children have continuity of care from visit to visit, from infancy through transition into adulthood. In addition, the medical home must be supported to provide care coordination services so that each family and the range of professionals serving them work together as an organized team to implement a specific care plan and to address issues as they arise.

Collaboration between the primary, specialty, and subspecialty providers to establish shared management plans in partnership with the child and family, and to clearly articulate each other's role, is a key component of the medical home concept. Equally key is the partnership between the primary care provider and the broad range of other community providers and programs serving CSHCN and their families. The medical home concept includes the responsibility of primary care providers to become knowledgeable about all the community services and organizations families can access.

The presence of a medical home was evaluated using a series of questions from the NS-CSHCN: whether the child has a personal doctor or nurse, whether he or she has a usual source of sick and well-child care; whether the child has had problems obtaining needed referrals; whether the family is satisfied with doctors' communication with each other and with the child's school and other systems; whether the family gets help coordinating the child's care if needed; whether the doctor spends enough time with the child; whether the doctor listens carefully to the parent; whether the doctor is sensitive to the family's customs; whether the doctor provides the family with enough information; and whether the parent feels like a partner in the child's care.

## Usual Source of Care

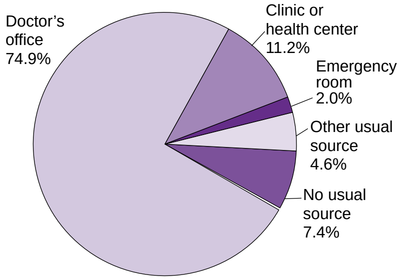
A basic element of a medical home is a regular place that children can go—whether it be a doctor's office, clinic, or health center—when they are sick. The survey asked parents whether there is a place, and what kind of place, the family usually goes when the child is sick or when the family needs advice about the child's health.

Overall, 90.7 percent of CSHCN have a usual source of sick care. For the majority of children (74.9 percent), this is a doctor's office; for 11.2 percent, it is a clinic or health center; and for 4.6 percent it is another setting. The parents of just 7.4 percent of CSHCN report that their child has no usual source of care, and an additional 2.0 percent rely on a hospital emergency department.

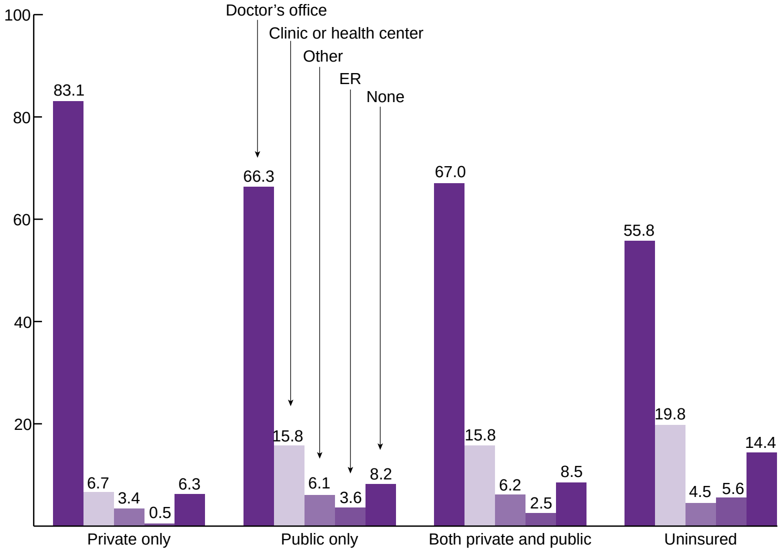
Children with private insurance are more likely than those with public insurance, who in turn are more likely than uninsured children, to have a usual source of care. Of CSHCN with private insurance, 83.1 percent go to a doctor's office and 6.7 percent a clinic or health center, while 6.3 percent are reported to have no usual source of care. Of those with public insurance, whether alone or in combination with private insurance, two-thirds go to a doctor's office and 15.8 percent to a clinic, while approximately 8 percent have no usual source of care. Of uninsured CSHCN, just over half go to a doctor's office and 19.8 percent to a clinic or health center, and 14.4 percent have no usual source of care.

A similar disparity is seen by race and ethnicity. While the majority of children in each racial and ethnic group go to a doctor's office for their regular care, this percentage ranges from 60.8 percent among Hispanic children to 81.4 percent among non-Hispanic Whites. Likewise, the percentage that go to a clinic or health center ranges from 7.6 percent of non-Hispanic White children to 22.5 percent of Hispanics, and the percentage with no usual source of care from 6.3 percent of non-Hispanic Whites to 9.3 percent of non-Hispanic Blacks.

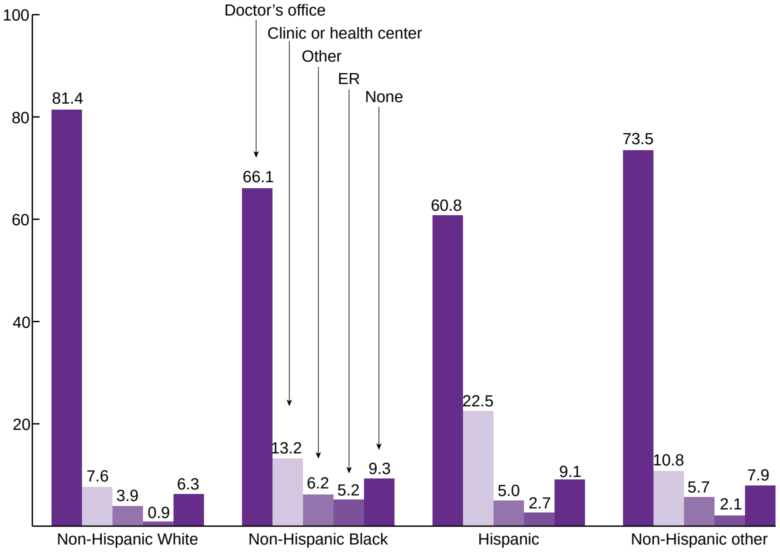
**Usual Source of Sick Care Among CSHCN**



**Usual Source of Care, by Insurance Type**



**Usual Source of Care, by Race/Ethnicity**

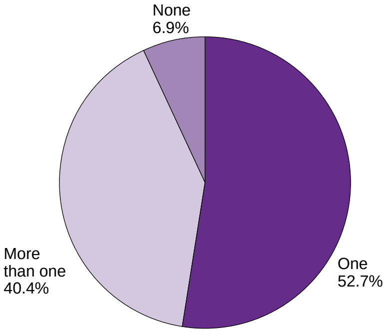


## Personal Doctor or Nurse

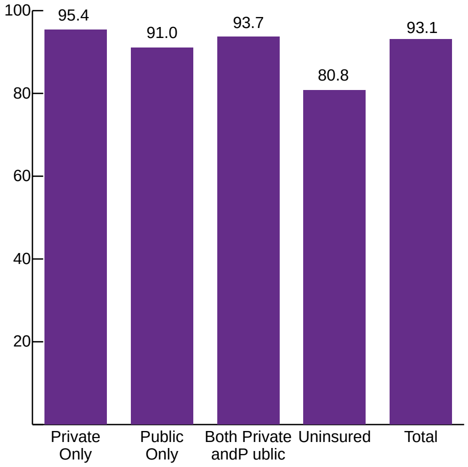
Another essential element of the medical home is having one or more personal doctors or nurses, defined as the health care provider(s) who know the child best. Because the health conditions and risks faced by CSHCN can be complex, having a consistent source of care can be especially important.

Overall, 93.1 percent of CSHCN are reported to have at least one personal doctor or nurse, and 6.9 percent do not have any. The proportion of CSHCN who have a personal doctor or nurse is highest among CSHCN with private insurance (95.4 percent), and lowest among uninsured CSHCN (80.8 percent). Likewise, of children in poverty, only 88.9 percent have at least one personal doctor or nurse, compared to 96.0 percent of children with family incomes of 400 percent of the Federal poverty level or more.

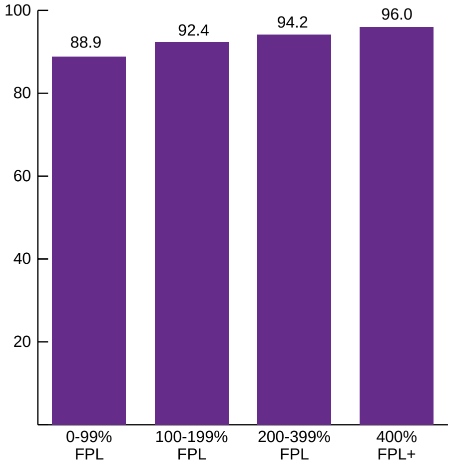
**CSHCN with a Personal Doctor or Nurse**



**One or More Personal Doctor or Nurse, by Insurance Type**



**One or More Personal Doctor or Nurse, by Poverty Status**



## *Care Coordination*

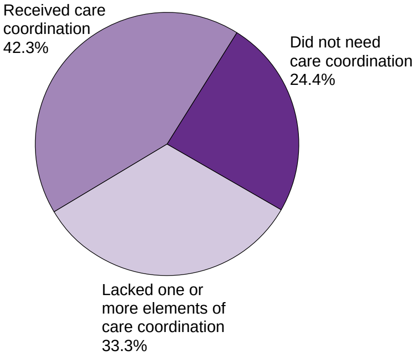
Care coordination has been defined as "a process that links CSHCN to services and resources in a coordinated effort to maximize the potential of children and provide them with optimal health care."[4] The survey addressed the issue of care coordination in two ways. To measure the proportion of CSHCN receiving care coordination services, the survey asked parents whether they received help coordinating their children's care, whether they needed additional help, and whether they got all the help they needed.

In addition, to measure how well care for CSHCN was coordinated, parents were asked about their satisfaction with the communication among the child's doctors and other providers, as well as their satisfaction with the communication between health care providers and schools and other systems that serve their children.

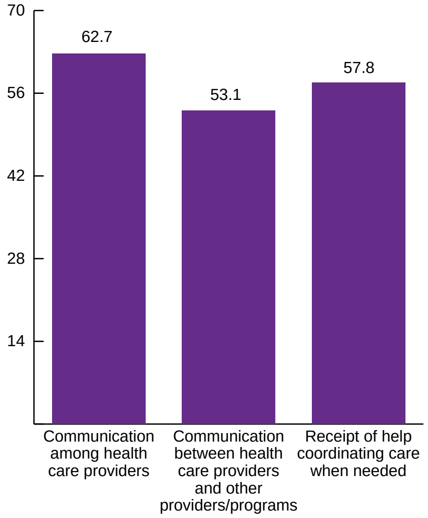
For a child to qualify as receiving coordinated care, the parent had to report that they usually received help when needed, and that they were "very satisfied" with communication among providers (when needed) and communication between providers and other programs (when needed). Overall, 42.3 percent of CSHCN received coordinated care by this definition. Of the three elements of coordinated care, the one that is most often met is communication among health care providers; the parents of 62.7 percent of CSHCN report that they are "very satisfied" on this item. However, fewer (53.1 percent) are satisfied with communication between health care providers and other systems, and the parents of 57.8 percent report that they received help coordinating their child's care when it was needed.

Among the 75.6 percent of CSHCN who needed care coordination, 56.0 percent were reported to receive all needed components of coordinated care. This percentage was highest among CSHCN with private insurance, of whom 60.8 percent received effective care coordination when needed. Among uninsured CSHCN, only 37.7 percent received coordinated care.

**Receipt of Coordinated Care Among CSHCN**

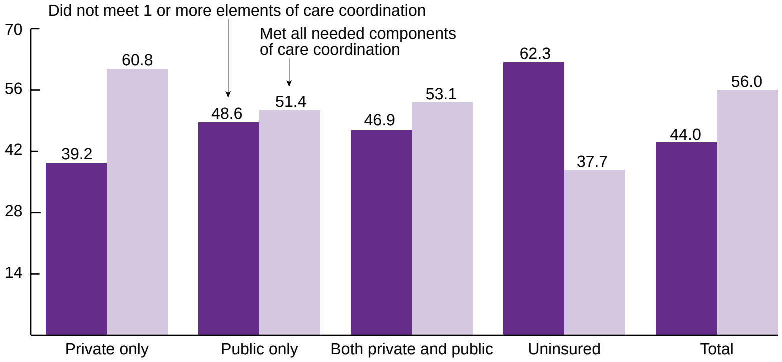


**Percent of CSHCN Whose Care Met Individual Care Coordination Components***



**Parents reported that they were "very satisfied" with communication components (when such communication was needed) or usually got help when needed.*

**Receipt of Effective Care Coordination,* Among CSHCN Who Needed Care Coordination, by Insurance Type**



**Includes help with coordination of care and satisfaction with communication among providers.*

## *Family-Centered Care*

Family-centered care is an approach to the planning, delivery, and evaluation of health care whose cornerstone is active participation between families and professionals. Family-centered care helps support the family's relationship with the child's health care providers and recognizes the importance of the family's customs and values in the child's care. To measure family-centeredness of care, the survey asked parents whether their child's providers spend enough time with the family, listen carefully to the parents, make the parents feel like a partner in their child's care, are sensitive to the family's customs and values, and provide the specific information that the parent needs.

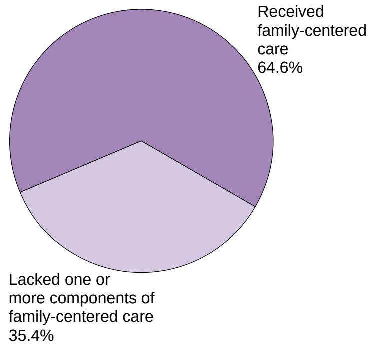
For a child's care to qualify as family-centered, the parent needed to answer "usually or always" to each of the above elements. Overall, 64.6 percent of CSHCN received care that met all of the components of family-centered care.

More than three-quarters of CSHCN receive care that meets each criterion for family-centeredness. The component that is most often met is sensitivities to families' values and customs, which was usually or always the case for 88.9 percent of CSHCN. The criterion that providers usually or always spend enough time with the child, on the other hand, was met for 77.5 percent of children.

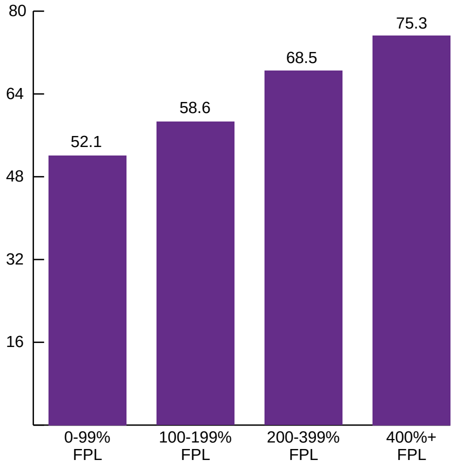
Children's receipt of family-centered care varies by family income, with those in the lower income categories being less likely to receive care that meets all criteria for family-centeredness. Of CSHCN with family incomes below the Federal Poverty Level (FPL), 52.1 percent received family-centered care, compared to 75.3 percent of children with family incomes of 400 percent of the FPL or more.

Race/ethnicity is also a factor in children's receipt of family-centered care. Non-Hispanic White children are the most likely (71.1 percent), and non-Hispanic Black children the least likely (51.6 percent), to receive care that met all of the criteria for family-centeredness.

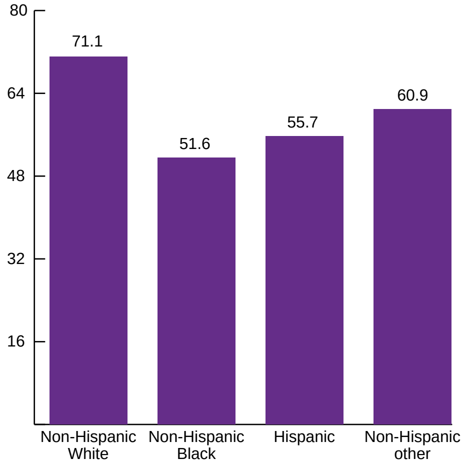
**Receipt of Family-Centered Care Among CSHCN**



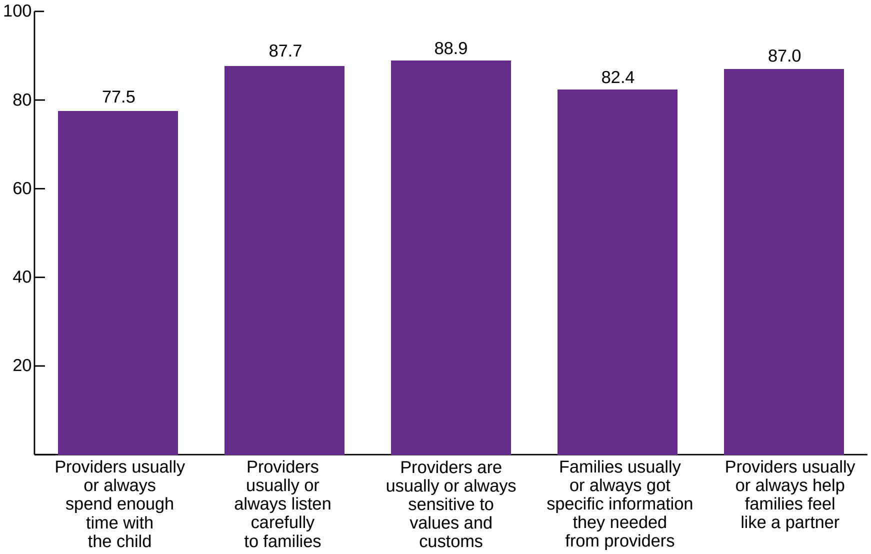
**Receipt of Family-Centered Care, by Poverty Status**



**Receipt of Family-Centered Care, by Race/Ethnicity**



**Components of Family-Centered Care**



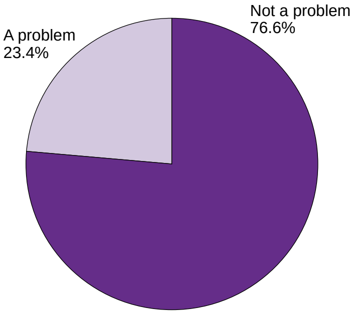
## Getting Needed Referrals

Another aspect of the medical home is the provision of referrals to specialty services. Parents who reported that their children needed a referral in order to see another doctor or receive services were asked how much of a problem it was to get such a referral for their children over the past 12 months.

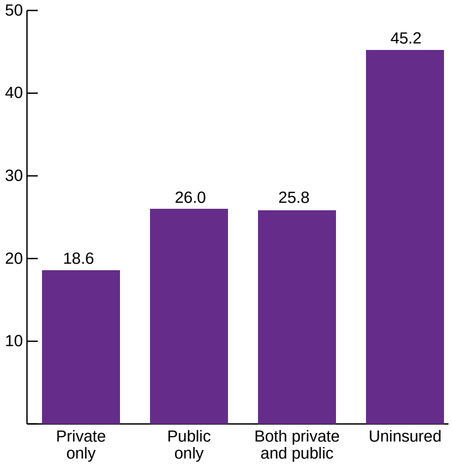
Of those who needed a referral, 23.4 percent reported having a problem receiving this referral. Reported problems obtaining referrals were most common among uninsured children: 45.2 percent of uninsured children who needed referrals had difficulty receiving them, compared to 26.0 percent of children with public insurance and 18.6 percent of children with private insurance.

Children whose conditions have a greater impact on their daily lives are also more likely to report problems obtaining referrals. Of children whose conditions consistently affect their daily activities, often a great deal, 30.6 percent reported problems getting referrals when needed, compared to 15.4 percent of children whose daily activities are never affected by their conditions.

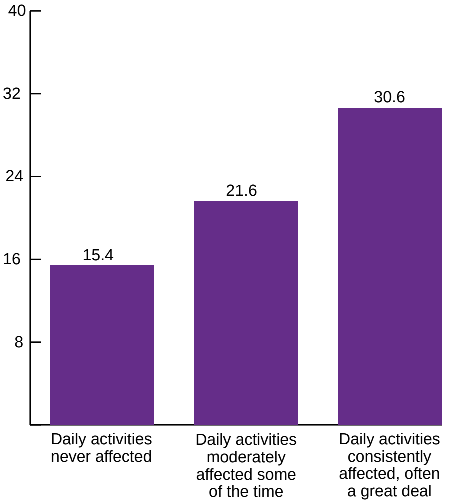
**CSHCN Needing Referrals Reporting Problems Obtaining Them**



**Problems Getting Referrals for Specialist Care or Services, Among Those Who Needed Referrals, by Insurance Type**



**Problems Getting Referrals for Specialist Care or Services, Among Those Who Needed Referrals, by Impact of Condition**



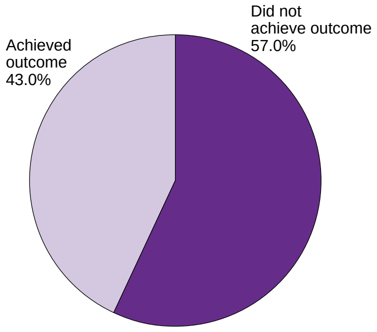
## *Core Outcome Summary*

Children who met the criteria for all of these indicators—presence of a usual source of care and a personal doctor or nurse, receipt of care coordination when needed, receipt of family-centered care, and access to specialty referrals—are considered to receive ongoing, comprehensive care within a medical home. Overall, the care of 43.0 percent of CSHCN met this standard.

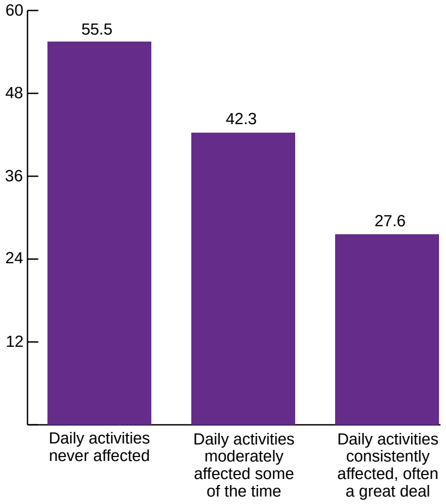
Children whose conditions consistently affect their functional abilities are less likely to receive their care from a medical home (27.6 percent) than children whose activities are moderately affected (42.3 percent) or never affected (55.5 percent). Children who are uninsured or who have public insurance are also less likely to achieve this outcome: of uninsured children, 24.2 percent receive care from a medical home, as do 34.0 percent of those with public insurance and 51.2 percent of those with private insurance.

Children in lower-income families are also less likely to receive care from a medical home. Of children with family incomes below the Federal Poverty Level (FPL), 30.9 percent met all of the criteria for the medical home, compared to 52.2 percent of children with family incomes of 400 percent of the FPL or more.

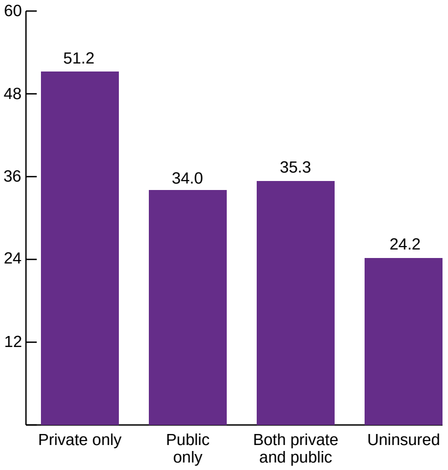
**CSHCN Who Receive Coordinated, Ongoing, Comprehensive Care within a Medical Home**



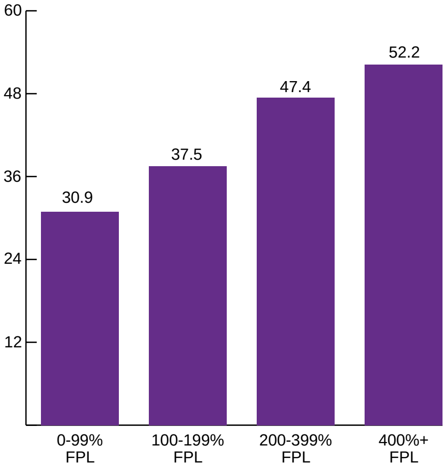
**Percent of CSHCN Who Receive Coordinated, Ongoing, Comprehensive Care within a Medical Home, by Impact of Condition**



**Percent of CSHCN Who Receive Coordinated, Ongoing, Comprehensive Care within a Medical Home, by Insurance Type**



**Percent of CSHCN Who Receive Coordinated, Ongoing, Comprehensive Care within a Medical Home, by Poverty Status**



## *Families of CSHCN have adequate public and/or private insurance to pay for needed services*

Health insurance, whether financed through the public or private sector, is essential for children to access needed care. Without health insurance, children are more likely to forgo necessary preventive care, and acute health care when children are sick can leave their families with overwhelming medical bills.

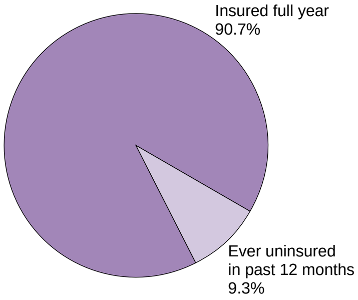
This section reviews the survey's findings on insurance coverage among CSHCN, including the proportion that have health insurance and the type of coverage (public or private) that they have. For children with insurance, the survey also assesses parents' perceptions of the adequacy of that coverage. To do this, the survey measured whether the plan offers benefits and services that meet the child's needs, whether the family considers any costs not covered by the plan to be reasonable, and whether the plan allows the child to see the providers that he or she needs.

The survey asked parents of CSHCN whether their child had insurance in the past 12 months and what kind of insurance they had. Health insurance was defined as private insurance provided through an employer or union or obtained directly from an insurance company; public insurance, such as Medicaid, the Children's Health Insurance Program (CHIP), military health care (TRICARE, CHAMPUS, or CHAMP-VA); or some other plan that pays for health services obtained from doctors, hospitals, or other health professionals.

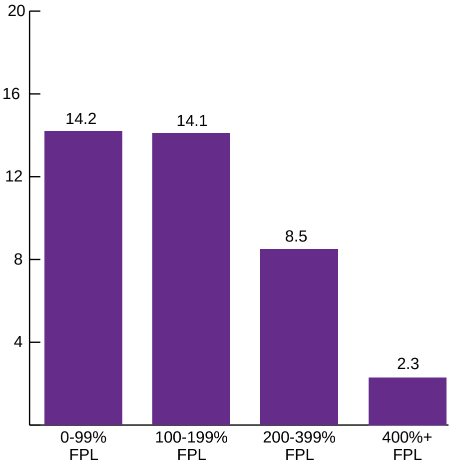
Overall, 90.7 percent of CSHCN were insured for all of the previous 12 months, while the remaining 9.3 percent were uninsured for all or some part of the year. The percentage of CSHCN without insurance varies by race/ethnicity. Hispanic children were the most likely to have been uninsured at some point in the past year (15.9 percent), and this percentage was even higher for those children whose primary language was Spanish (22.7 percent). Among non-Hispanic Black children, 10.0 percent were uninsured at some point during the year, as were 7.2 percent of non-Hispanic White children and 9.6 percent of children of other races.

Family income is also associated with the likelihood that children have consistent health insurance. Of children with family incomes below 200 percent of the Federal Poverty Level (FPL), over 14 percent were uninsured for some part of the year, compared to 8.5 percent of children with family incomes between 200 and 399 percent of the FPL and 2.3 percent of children with family incomes of 400 percent of poverty or more.

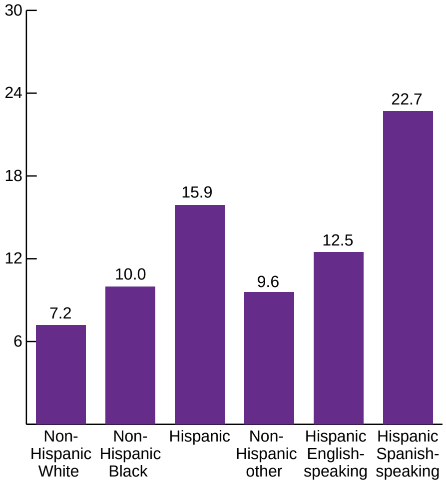
**Health Insurance Coverage for CSHCN in The Past 12 Months**



**Percent of CSCHN Who Were Uninsured for One or More Periods During the Past Year, by Poverty Status**



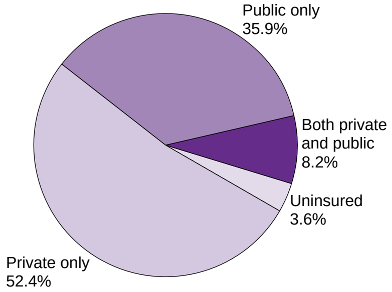
**Percent of CSCHN Who Were Uninsured for One or More Periods During the Past Year, by Race/Ethnicity and Primary Language**



## *Type of Health Insurance Coverage*

Parents of CSHCN were asked what type of insurance their child had at the time of the interview. Overall, approximately 96 percent of CSHCN had some type of insurance at the time of the survey: 52.4 percent had private insurance, which includes insurance provided through an employer or union or obtained directly from an insurance company; 35.9 percent had public coverage, such as Medicaid, the Children's Health Insurance Program (CHIP), or military health care (TRICARE, CHAMPUS, or CHAMP-VA); and 8.2 percent were reported to have both private and public insurance. Finally, 3.6 percent of CSHCN were uninsured at the time of the interview.

**Type of Insurance at the Time of the Survey**



## *Adequacy of Current Insurance Coverage*

The parents of CSHCN with health insurance were asked three questions about their children's coverage:

- Does the plan allow the child to see the health care providers that he/she needs?
- Does the plan offer benefits and cover services that meet their needs?
- Are the costs not covered by the plan reasonable?

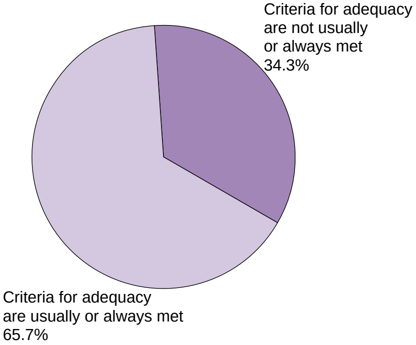
If parents answered "usually" or "always" to all three of these questions, then the child's coverage is considered to be adequate. All others are considered to have inadequate insurance coverage.

Nearly two-thirds (65.7 percent) of CSHCN were reported by their parents to have adequate insurance coverage. Of the three items that make up the adequacy standard, the one most likely to be met is the providers that are included in the plan; the parents of 89.5 percent of insured CSHCN report that their insurance usually or always allows them to see the providers they need. Similarly, the parents of 86.8 percent of CSHCN report that their insurance benefits usually or always meet their child's needs. However, the parents of only 71.3 percent report that the non-covered charges for their plan are reasonable.

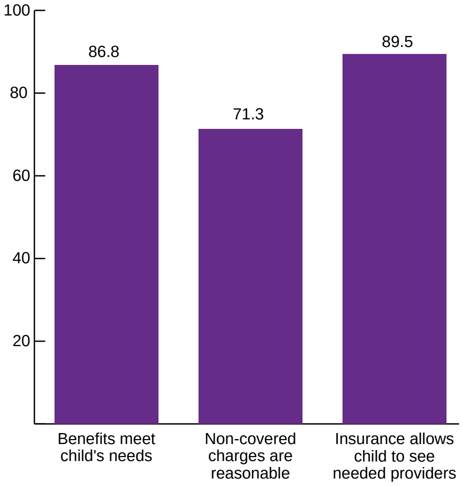
Children insured exclusively through public programs were the most likely to have coverage that is reported to meet all of the criteria for adequacy. Of CSHCN with only public insurance, 69.4 percent were reported to have adequate insurance, compared to 64.3 percent of those with only private insurance and 64.1 percent of those with both public and private insurance.

Children whose conditions have a greater impact on their daily lives are less likely to have insurance that meets their needs. Of CSHCN whose daily activities are consistently affected by their conditions, 58.2 percent were reported to have adequate insurance, compared to 73.8 percent of children whose daily activities are never affected by their conditions.

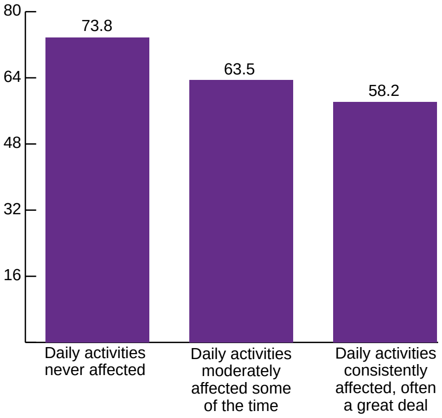
**Currently Insured CSHCN with Adequate Insurance**



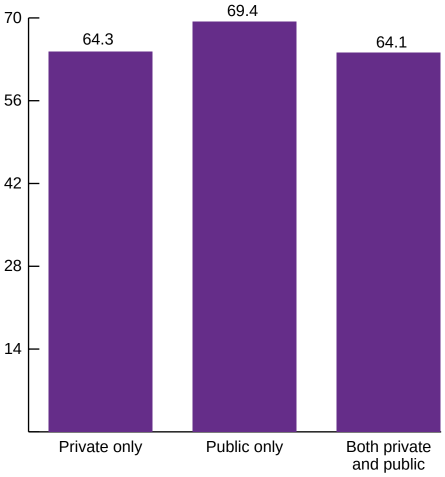
**Percent of Currently Insured CSHCN Whose Insurance Usually or Always Meets Each Component of Insurance Adequacy**



**Percent of Currently Insured CSHCN with Adequate Insurance, by Impact of Condition**



**Percent of Currently Insured CSHCN with Adequate Insurance, by Insurance Type**



## Core Outcome Summary

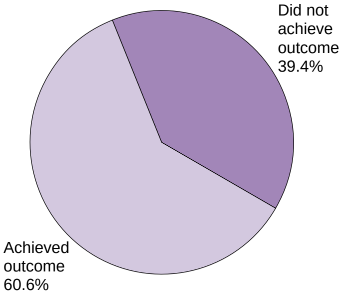
CSHCN were considered to have met the outcome goal for health insurance if they were consistently insured for the past year, and if that insurance met all the standards for adequacy. This outcome was achieved for 60.6 percent of CSHCN.

Among racial/ethnic groups, non-Hispanic White CSHCN were the most likely to meet this standard (62.9 percent), and Hispanic CSHCN were the least likely (53.7 percent). Among Hispanics, 56.4 percent of those who primarily speak English at home achieved this outcome, compared to 49.2 percent of those who spoke Spanish at home.

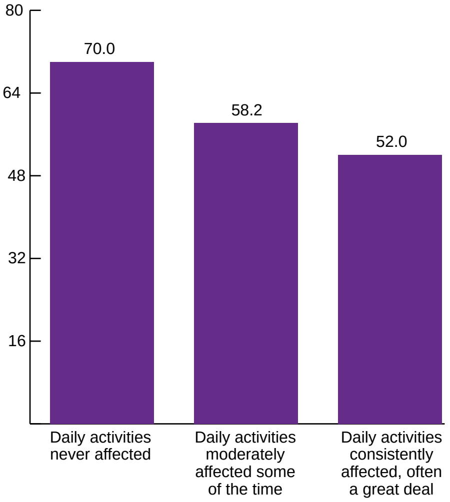
Children whose conditions have a greater impact on their daily lives are also less likely to achieve this outcome. Of CSHCN whose conditions consistently affect their activities, 52.0 percent were adequately insured for the full year, compared to 70.0 percent of those whose conditions never affect their activities.

Finally, the higher a child's family income, the greater the likelihood that they will achieve this outcome. Of children with family incomes below the Federal Poverty Level (FPL), 57.8 percent met the standard, compared to 67.0 percent of those with family incomes of 400 percent of the FPL or more.

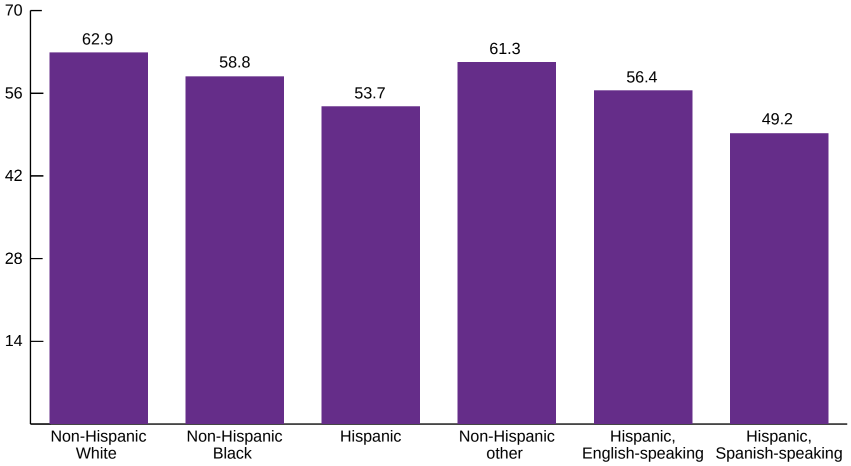
**CSHCN with Consistent, Adequate Insurance to Pay for the Services They Need**



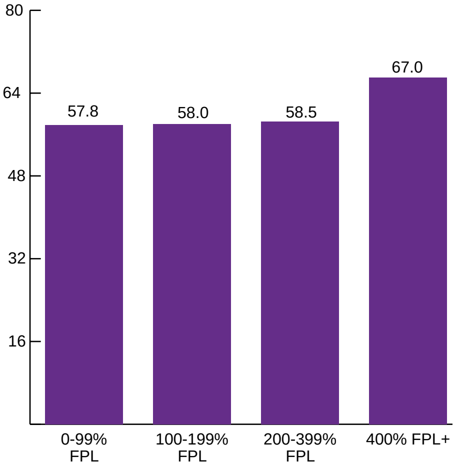
**Families of CSHCN Have Consistent Adequate Public and/or Private Insurance to Pay for the Services They Need, by Impact of Condition**



**Families of CSHCN Have Consistent Adequate Public and/or Private Insurance to Pay for the Services They Need, by Race/Ethnicity and Primary Language**



**Families of CSHCN Have Consistent Adequate Public and/or Private Insurance to Pay for the Services They Need, by Poverty Status**



## *Children are screened early and continuously for special health care needs*

In public health, screening often refers to a population-based intervention to detect a particular condition or disease. However, as used in the context of this goal, screening is much more comprehensive and includes ongoing monitoring and assessment of children and youth to promote health and well-being through family-centered care practices. Seen this way, screening has two major goals. First, it is critical to identify, as early as possible, children in the general population who have special health care needs so that they and their families can receive appropriate services to reduce long term consequences and complications. Some needs may be identified in infancy, or during the perinatal period, while others may emerge later in childhood and adolescence. Second, and equally important, children and youth with special health care needs require ongoing assessments to identify newly emerging issues including developmental/behavioral issues, oral health, and psychosocial issues, and to prevent secondary conditions that may interfere with development and well-being. Ongoing assessment should also focus on identifying the unique strengths of each child and family.

For this outcome, an estimate was arrived at using two survey questions: whether or not CSHCN received routine preventive medical care in the past year and whether they received routine preventive dental care during the past year. In addition, this section includes data on developmental screening for children aged 1-5, another important source of information on children's developmental needs and challenges. This indicator, however, is not incorporated into the Core Outcome.

## *Preventive Health Visits*

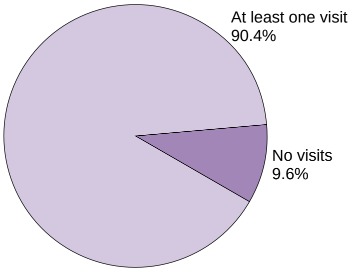
Like all children, CSHCN require regular preventive health care. The Bright Futures guidelines for health supervision of infants, children, and adolescents recommend that children visit a physician six times during the first year, three times in the second year, and annually thereafter for preventive health care visits.[5] An annual preventive health care visit provides an opportunity to monitor a child's growth and development, to assess his or her behavior, to provide appropriate immunizations, to discuss important issues regarding nutrition and prevention of injury and violence, and to answer parents' questions about their children's health and care.

The survey asked parents if their children received a preventive medical visit within the past year. The survey did not directly evaluate the number of visits each child received and whether children's care met the Bright Futures recommendations.

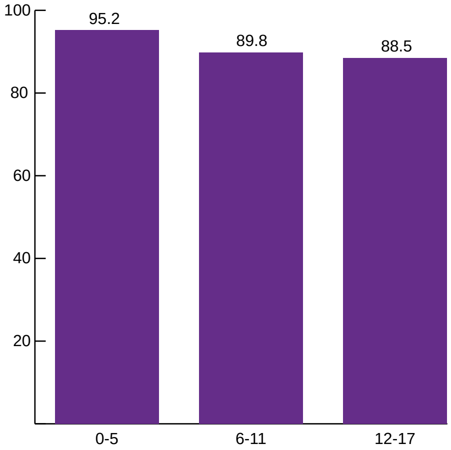
Overall, the parents of 90.4 percent of CSHCN reported that their children received at least one preventive medical visit in the past year. This percentage was slightly higher among the youngest children (aged 0-5); 95.2 percent of these children received at least one well-child visit, compared to 88.5 percent of adolescents aged 12-17.

Among children with any type of insurance coverage, approximately 91 percent received at least one preventive medical visit, while only 70.3 percent of uninsured children had a well-child checkup.

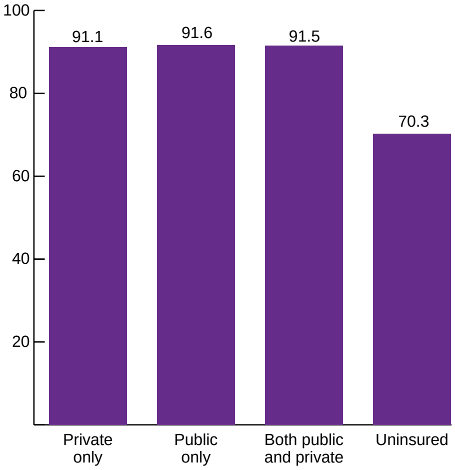
**Receipt of an Annual Preventive Medical Visit Among CSHCN**



**Receipt of an Annual Preventive Medical Visit, by Age**



**Receipt of an Annual Preventive Medical Visit, by Insurance**



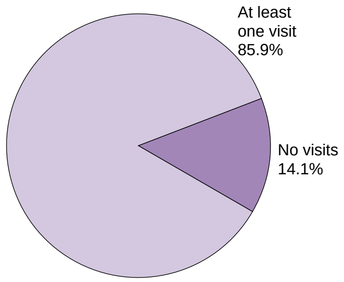
## *Preventive Dental Visits*

In addition to an annual medical visit, Bright Futures also recommends that all children see a dentist every six months beginning at age 1 or when the first tooth appears.[5] This is particularly critical for CSHCN, who are at high risk for oral health problems.

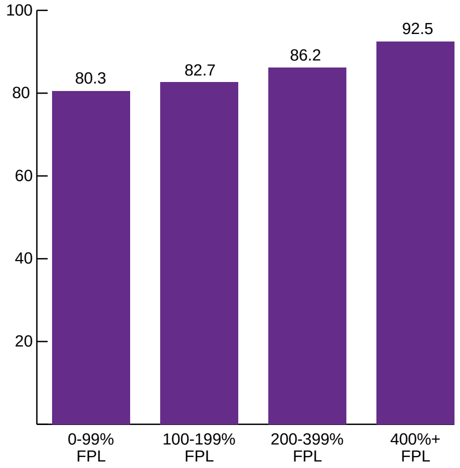
As with preventive medical care, the survey asked whether children aged 1-17 had received a preventive dental visit, such as a checkup or a cleaning, within the past year. Overall, the parents of 85.9 percent of CSHCN reported that their children received a preventive dental visit.

Children with higher family incomes were the most likely to receive an annual preventive dental visit; 92.5 percent of CSHCN with family incomes of 400 percent of the Federal Poverty Level (FPL) or more did so, compared to 80.3 percent of children with family incomes below the FPL.

**Receipt of an Annual Preventive Dental Visit Among CSHCN**



**Receipt of an Annual Preventive Dental Visit, by Poverty Status**



## *Core Outcome Summary*

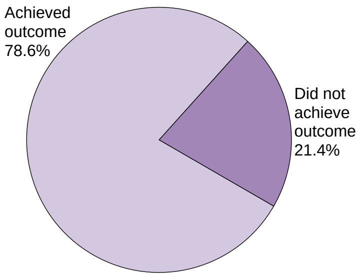
Children were considered to have met the goal for early and continuous screening if they received both an annual preventive medical visit and an annual preventive dental visit. Overall, 78.6 percent of CSHCN achieved this outcome; this percentage ranged from 64.8 percent of children aged 0-5 to 83.8 percent of CSHCN aged 6-11.

Little variation is evident in this outcome by race and ethnicity, although non-Hispanic White children are slightly more likely to achieve the objective than Hispanic children (79.6 percent versus 74.9 percent). Among Hispanics, however, those who primarily speak English at home are much more likely than Spanish speakers to achieve the objective (80.5 percent versus 64.4 percent).

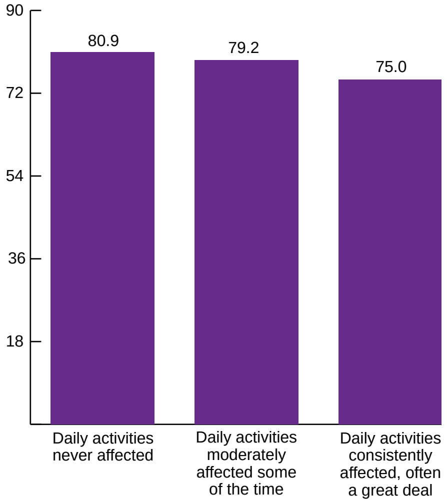
Children whose conditions consistently affect their activities are slightly less likely than children whose conditions have less of an impact to receive both preventive medical and dental care annually. Of children whose daily activities are never affected by their conditions, 80.9 percent achieved the objective, compared to 75.0 percent of those whose activities are consistently affected.

Children with higher family incomes were also more likely to achieve the objective for regular screening. Of children with family incomes of 400 percent of the Federal Poverty Level (FPL) or more, 85.8 percent received annual preventive medical and dental care, as did 78.6 percent of children with family incomes between 200 and 399 percent of the FPL. Of children with family incomes below the FPL, 73.2 percent achieved the objective.

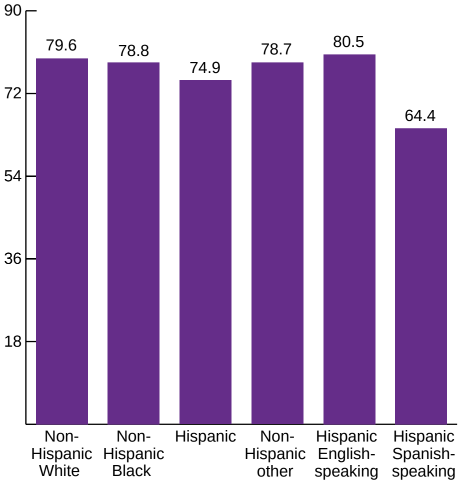
**CSHCN Who Are Screened Early and Continuously for Special Needs**



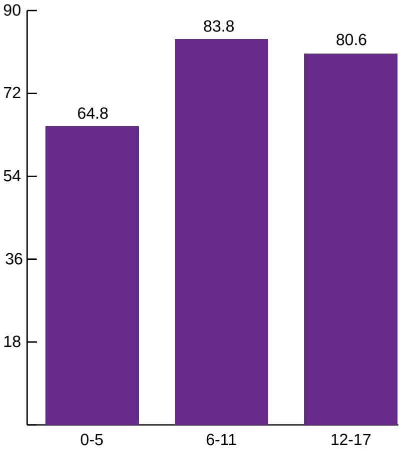
**Percent of CSHCN Who Are Screened Early and Continuously for Special Health Care Needs, by Impact of Condition**



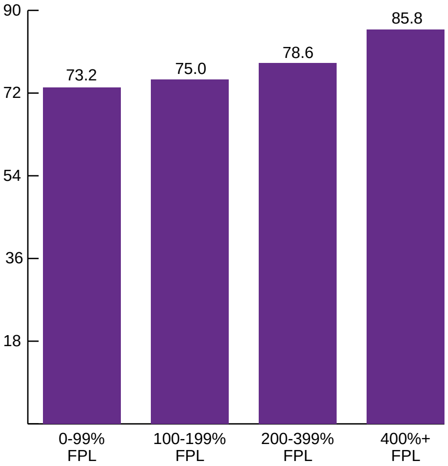
**Percent of CSHCN Who Are Screened Early and Continuously for Special Health Care Needs, by Race/Ethnicity and Primary Language**



**Percent of Children Who Are Screened Early and Continuously for Special Health Care Needs, by Age**



**Percent of CSHCN Who Are Screened Early and Continuously for Special Health Care Needs, by Poverty Status**



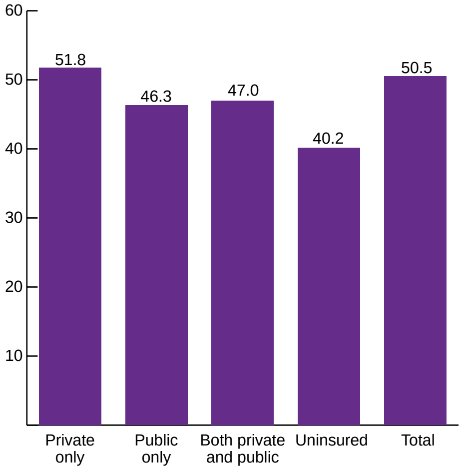
## Related Measure: Developmental Screening

The use of standard tools to assess young children's development is an important part of children's primary health care. The Bright Futures Guidelines for Health Supervision of Infants, Children, and Adolescents, supported by the American Academy of Pediatrics and the Maternal and Child Health Bureau, recommends routine screening by pediatric health care providers for developmental and behavioral problems using standardized screening tools.[5]

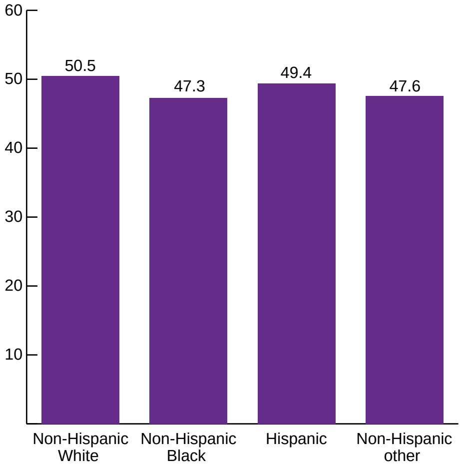
Despite this recommendation, only half (50.5 percent) of CSHCN aged 1-5 were reported to have received such a screening during a preventive health visit in the past 12 months. This percentage was highest among children with private insurance, of whom 51.8 percent were reported to have received a developmental screening, and lowest among uninsured CSHCN, of whom 40.2 percent were screened.

The likelihood of receiving a standard developmental screen varies slightly by race and ethnicity, from 47.3 percent of non-Hispanic Black children to 50.5 percent of non-Hispanic White children.

**Percent of CSHCN Aged 1-5 Years Who Were Screened for Developmental, Behavioral or Social Delays Using a Parent-Reported Standardized Developmental/Behavioral Screening Tool During a Health Visit in the Past 12 Months, by Insurance Type**



**Percent of CSHCN Aged 1-5 Years Who Were Screened for Developmental, Behavioral or Social Delays Using a Parent-Reported Standardized Developmental/Behavioral Screening Tool During a Health Visit in the Past 12 Months, by Race/Ethnicity**



## *Community-based services are organized so families can use them easily*

A community-based system of services is an infrastructure that operates across service sectors. It facilitates the integration of services in several dimensions—including organization, delivery, and financing. The development of community-based systems of services is a response to the complexity and fragmentation of services for children with special health care needs and their families. Multiple service programs—each with its own funding streams, eligibility requirements, policies, procedures, and service sites—serve CSHCN. It is clear that communities and their resources affect the way families of children with special health needs find and use services. Therefore, the health of communities themselves can have a positive effect on the growth and development of children with special health care needs. There now exist a number of initiatives to develop community-based systems of services and a number of related community development initiatives in communities throughout the nation. The public sector has furnished much of the impetus for such initiatives, but the private sector, especially through the efforts of several national foundations, has increasingly become active in instituting such initiatives.

To evaluate this outcome, the 2009-2010 survey used a series of questions about potential barriers to access to services for CSHCN, and whether or not parents were often frustrated in their efforts to obtain services for their children. It should be noted that the results for this outcome cannot be compared to either of the previous rounds of the survey, as the set of questions used to evaluate the outcome have changed completely.

In addition to the questions that are directly used to assess the achievement of the outcome goal, this section also presents the findings of the survey on the specific services that CSHCN and their families need, and whether or not they received all of the services they needed.

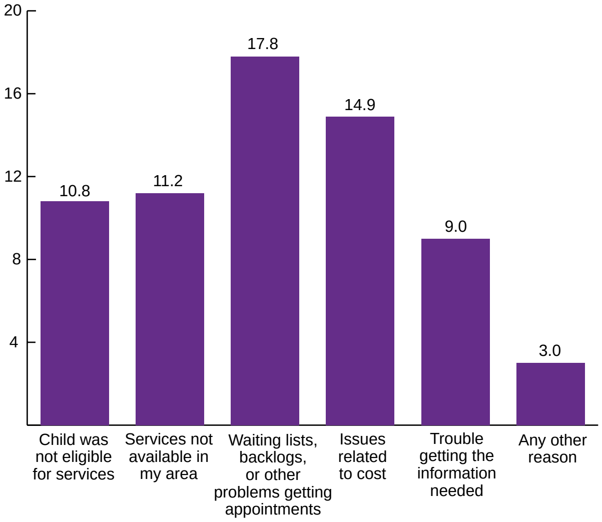
## *Difficulties Receiving Services*

Parents of CSHCN were asked whether or not a list of potential difficulties had impeded their efforts to obtain services for their children. Parents were asked about each of these reasons individually, so each child may experience more than one of these potential barriers to services.

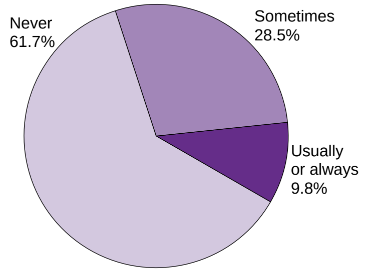
The reason most frequently reported for unmet need for services is waiting lists, backlogs, or other problems getting appointments, which was reported to be a problem for 17.8 percent of CSHCN. For 14.9 percent of CSHCN, issues related to the cost of services caused difficulty in obtaining services. For 11.2 percent of CSHCN, the fact that services were not available in their area presented a barrier, and for 10.8 percent, the child was not eligible for services that he or she needed.

Overall, the parents of 38.3 percent of children reported that they were sometimes, usually, or always frustrated in their efforts to obtain services for their children. This frustration is felt most often on behalf of uninsured children; the parents of 26.8 percent of uninsured CSHCN reported that they usually or always experienced this frustration, compared to 6.1 percent of privately insured children.

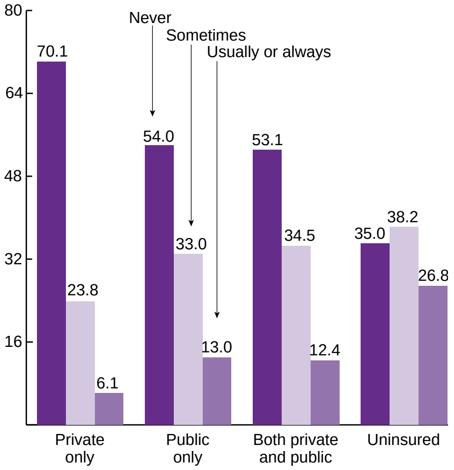
**Reasons for Difficulties or Delays Getting Services**



**CSHCN Who Are Frustrated in Their Efforts to Obtain Services**



**Frequency of Frustration in Efforts to Obtain Services for CSHCN, by Insurance Type**



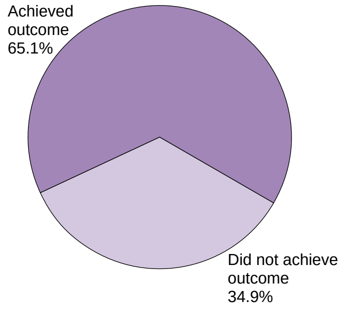
## Core Outcome Summary

Services were considered to be organized for easy use by families if parents did not report any of the barriers to care listed on the previous page, and if they did not report that they were usually or always frustrated in their efforts to obtain services for their children. Overall, 65.1 percent of CSHCN achieved this outcome. Again, this finding cannot be compared to those reported in previous rounds of the survey.

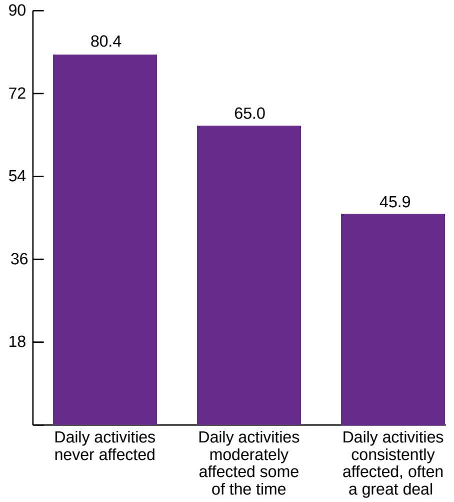
Children whose conditions never affect their daily activities are the most likely to report that services are organized for easy use. Of CSHCN whose conditions never affect their activities, 80.4 percent met this objective, compared to 45.9 percent of CSHCN whose conditions consistently affect their daily lives.

Uninsured children were particularly unlikely to report that services are organized for easy use, with only 30.5 percent achieving this outcome. Of children with private insurance 71.8 percent achieved the outcome, and 59.9 percent of those with public insurance did so.

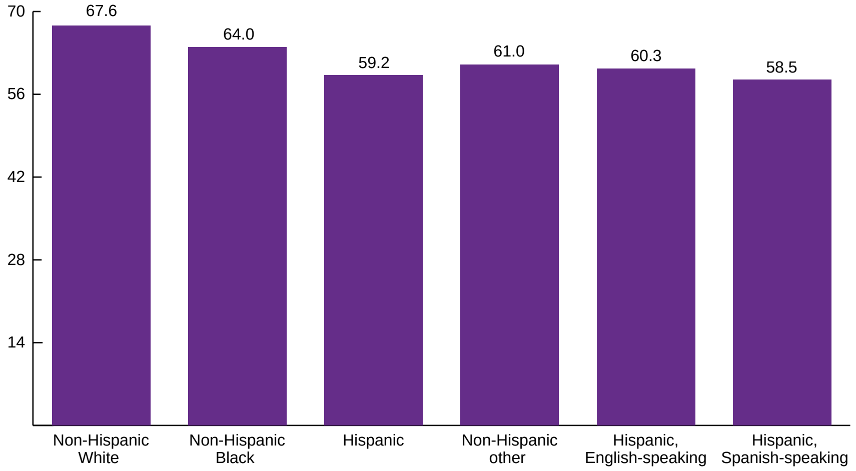
**CSHCN for Whom Community-Based Services Are Organized So That Families Can Use Them Easily**



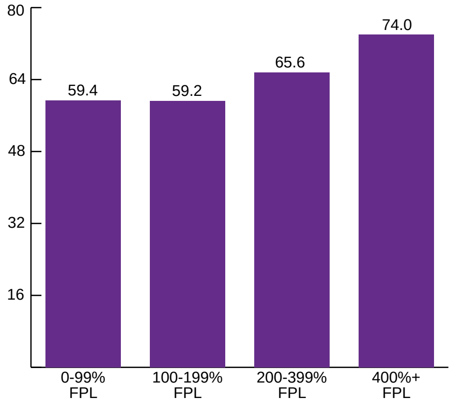
**Community-Based Services Are Organized So That Families Can Use Them Easily, by Impact of Condition**



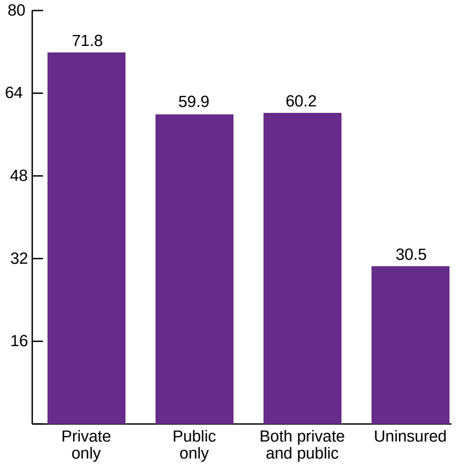
**Community-Based Services Are Organized So That Families Can Use Them Easily, by Race/Ethnicity and Primary Language**



**Community-Based Services Are Organized So That Families Can Use Them Easily, by Poverty Status**



**Community-Based Services Are Organized So That Families Can Use Them Easily, by Insurance Type**



## *Related Measure: Specific Health Care Needs*

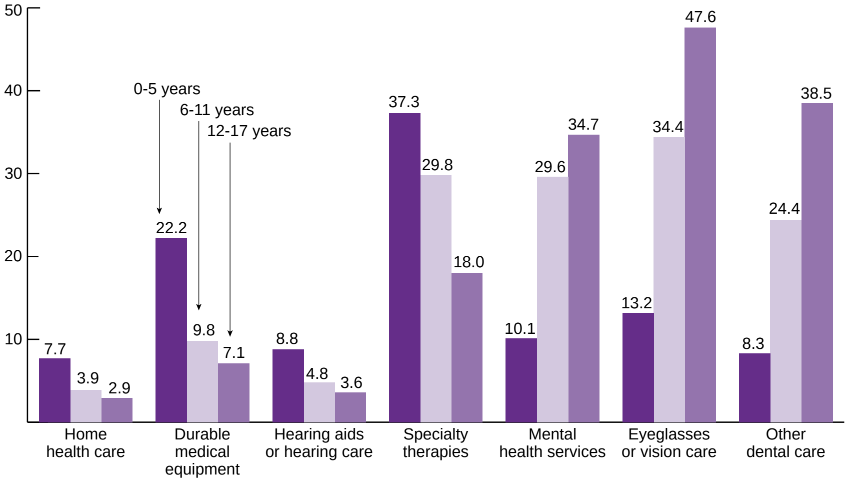
Children with special health care needs require a broad range of services, from primary and specialty medical care to prescription medications, medical equipment and therapies. In addition, the families of CSHCN may need additional support services, such as respite care, family counseling, or genetic counseling. Parents of CSHCN were asked if their children needed any of a range of medical services at any time in the past year.

The need most often cited for CSHCN is prescription medication: 86.0 percent of these children are reported to need prescription drugs. Just under half (47.5 percent) of CSHCN needed the care of medical specialists, such as cardiologists or pulmonologists. Other services needed by a smaller proportion of CSHCN include eyeglasses or vision care (needed by 35.3 percent of CSHCN), mental health care or counseling (27.6 percent), acute dental care, including orthodontia (26.7 percent), and physical, occupational, or speech therapy (26.6 percent).

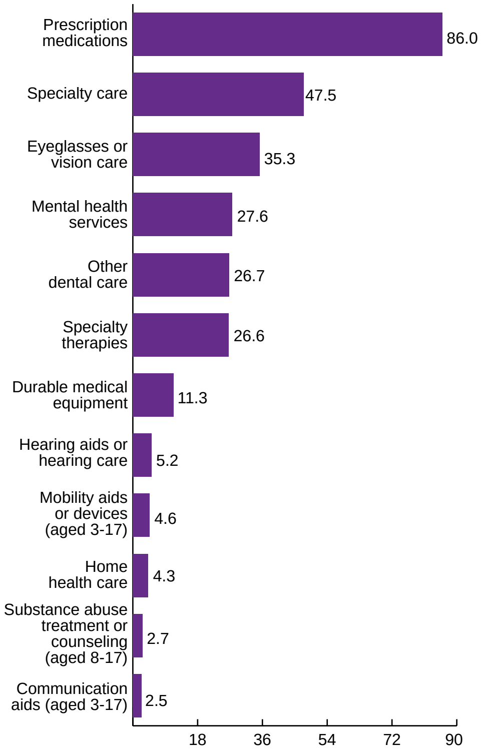
Some services that are needed relatively infrequently among the population of CSHCN as a whole are more commonly required by children whose conditions have a greater impact on their daily lives. Of CSHCN whose conditions consistently affect their activities, one-third require care from specialists, more than half need physical, occupational, or speech therapy, and 42.8 percent need mental health services. These services are less often needed by children whose conditions have a lesser impact on their daily lives.

Other needs vary greatly by age. Preschool-aged children (from birth through age 5) are much more likely than older children to need home health care (7.7 percent, compared to 3.9 percent of school-aged children and 2.9 percent of adolescents), durable medical equipment (22.2 percent, compared to 9.8 and 7.1 percent), and specialty therapies (37.3 percent, compared to 29.8 and 18.0 percent). Conversely, adolescents (those aged 12-17 years) are more likely to need mental health services (34.7 percent, compared to 10.1 percent of preschoolers), eyeglasses or vision care (47.6 percent, compared to 13.2 percent), and non-preventive dental care, including orthodontia (38.5 percent, compared to 8.3 percent of the youngest children).

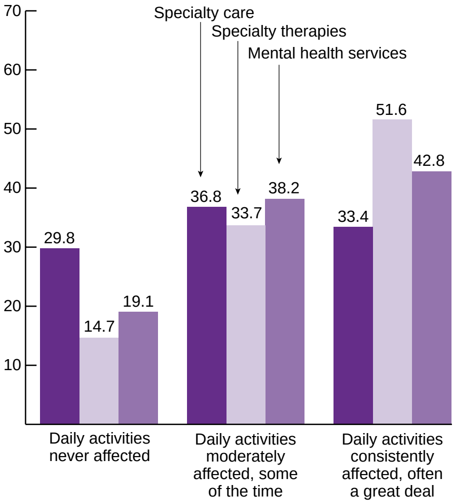
**Percent of CSHCN Needing Specific Services, by Age**



**Percent of CSHCN Needing Specific Services**



**Percent of CSHCN Needing Specific Services, by Impact of Condition**

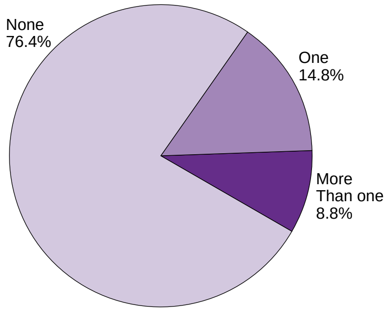


## *Related Measure: Unmet Need for Services*

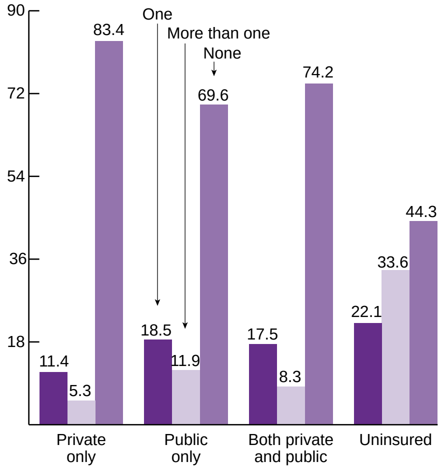
For each service that a child needed, parents were asked if their child received all of the care that he or she needed. Overall, nearly one quarter of CSHCN (23.6 percent) did not receive at least one service that they needed, and 8.8 percent did not receive more than one needed service. The service most commonly reported as needed but not received was mental health care or counseling, which was reported as needed but not received by 5.6 percent of CSHCN. Other common unmet needs were for dental care (5.4 percent), specialty therapies (4.7 percent), and specialty medical care (4.3 percent).

Low-income and uninsured children are the most likely not to receive all of the services they need. Of children in poverty, nearly one-third (33.1 percent) had at least one unmet need among the 14 services listed, compared to 12.3 percent of children with family incomes of 400 percent of poverty or more. Likewise, over half (55.7 percent) of uninsured children had at least one unmet need, compared to 16.7 percent of CSHCN with private insurance.

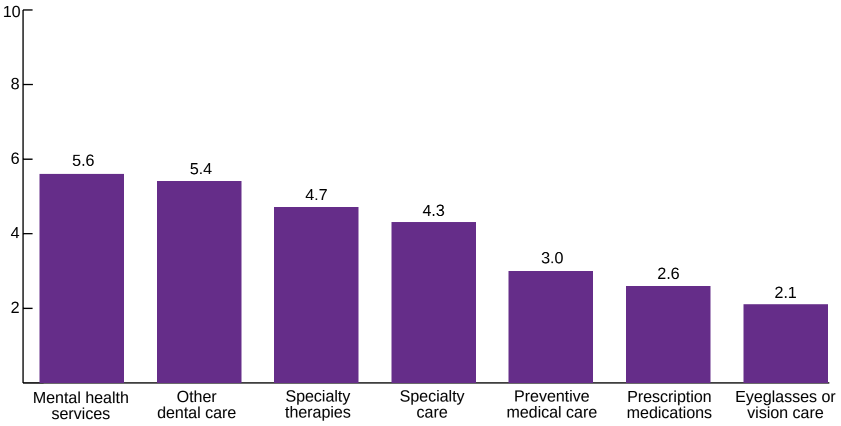
**CSHCN with One or More Unmet Needs**



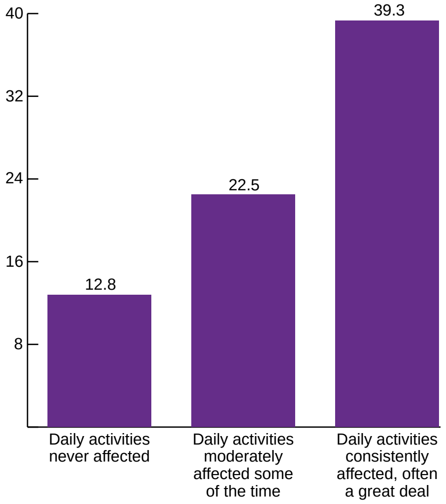
**Percent of CSHCN with One or More Reported Unmet Service Needs (of 14 Services Listed), by Insurance Type**



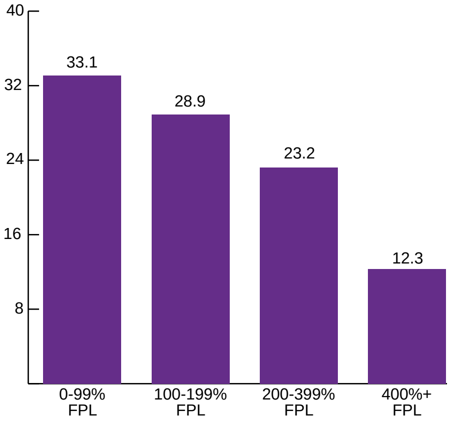
**Percent of CSHCN with Unmet Need for Specific Services**



**Percent of CSHCN with One or More Reported Unmet Service Needs (of 14 Services Listed), by Impact of Condition**



**Percent of CSHCN with One or More Reported Unmet Service Needs (of 14 Services Listed), by Poverty Status**



## Related Measure: Family Support Services

In addition to their children's needs, families of CSHCN may also benefit from services that help them to cope with the challenges associated with their children's conditions. These family support services include family counseling (mental health care for family members), genetic counseling (for advice on inherited conditions related to the child), and respite care (having someone else care for the child so that parents or other family members can take a break).

Overall, the parents of 19.6 percent of CSHCN reported needing at least one of these family support services. The service most often needed was family counseling, needed by the families of 11.9 percent of CSHCN, followed by respite care (6.7 percent) and genetic counseling (6.5 percent).

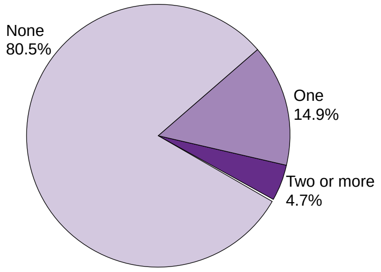
## Related Measure: Unmet Need for Family Support Services

The parents of 7.2 percent of all CSHCN report that they did not receive at least one family support service that they needed. The service most commonly needed but not received was family counseling services, which was needed but not received by the families of 3.7 percent of CSHCN, followed by respite care (3.3 percent) and genetic counseling (1.9 percent). Thus, half of children whose families reported a need for respite care did not receive it.

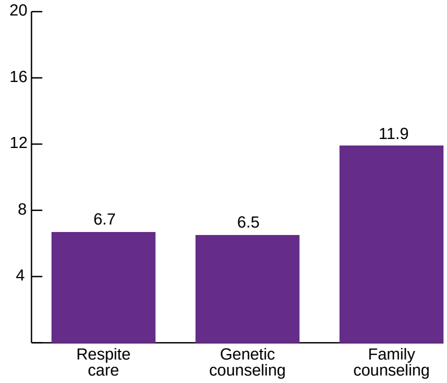
While these overall proportions are small, families of low-income and uninsured CSHCN were most likely to report unmet need for family support services. Of uninsured children, the families of 18.1 percent did not receive at least one support service that they needed, as did the families of 8.9 percent of children in poverty.

In addition, the families of children whose conditions have a greater impact on their daily lives are more likely to report unmet need for family support services. Of children whose daily activities are consistently affected, the families of 18.1 percent did not receive all of the family support services they needed.

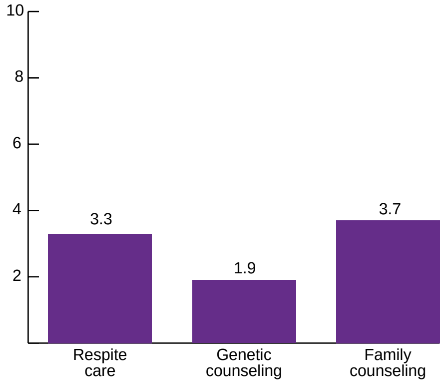
**Need for Family Support Services Among CSHCN**



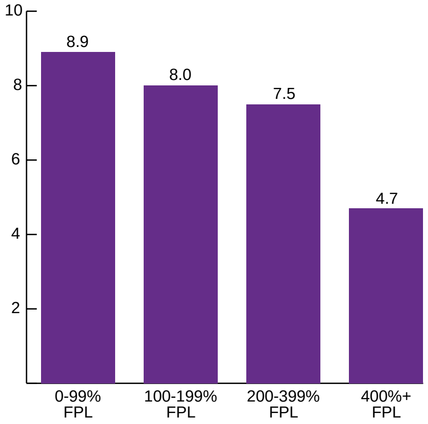
**Percent of CSHCN Who Needed Family Support Services**



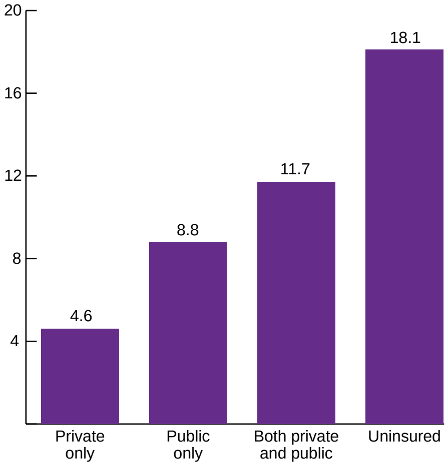
**Percent of CSHCN with Unmet Need for Specific Family Support Services**



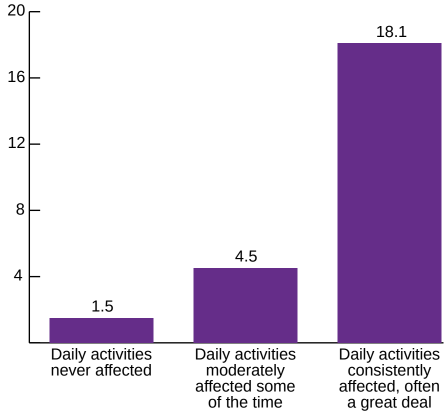
**CSHCN with One or More Reported Unmet Need for Family Support Services, by Poverty Status**



**Unmet Need for at Least One Family Support Service Among CSHCN, by Insurance Type**



**CSHCN with One or More Reported Unmet Need for Family Support Services, by Impact of Condition**



## *Youth with special health care needs receive the services necessary to make transitions to adult health care*

While rapid advances in medical science have enabled more than 90 percent of children born with special needs to reach adulthood, youth with special health care needs are much less likely than their non-disabled peers to finish high school, pursue post-secondary education, get jobs, or live independently. Few coordinated services have been available to assist them in their transition to adult-oriented care. Transition planning must begin early in order to move children and families along in a developmentally appropriate fashion. One of the greatest challenges in planning is how to make a successful transition from the pediatric to the adult model system of care. Health care professionals, on both the pediatric and adult sides, may lack the training, support, and opportunities they need to promote the development of youth with special health care needs as partners in health care decision-making. Some adult health care providers may not be prepared to treat patients with complex medical conditions that begin in childhood. The challenge remains to improve the system that serves youth with special health care needs while simultaneously preparing youth and their families with the knowledge and skills necessary to promote self-determination, wellness, and successful navigation of the adult service system.

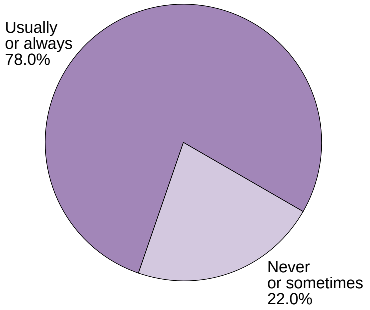
The standard for transition outcome was evaluated for CSHCN aged 12 to 17 using two questions: whether a child's doctors usually or always encourage adolescents to take increasing responsibility for their care, and whether doctors had provided anticipatory guidance for the transition to adult health care.

### *Taking Responsibility for Health Care Needs*

As adolescents approach adulthood, they take on increasing responsibility for their health and health care. For youth with special health care needs, this transition is especially important, as their medical needs may be complex and they will eventually need to manage their medications and other aspects of their health themselves.

The survey asked parents of CSHCN aged 12-17 how often their children's health care providers encourage their children to take responsibility for their health care needs, including taking medication, understanding their diagnosis, or following medical advice. The parents of 78.0 percent of these children reported that their doctors usually or always did this.

**CSHCN Aged 12-17 Whose Providers Discussed Their Changing Health Needs as They Approach Adulthood**

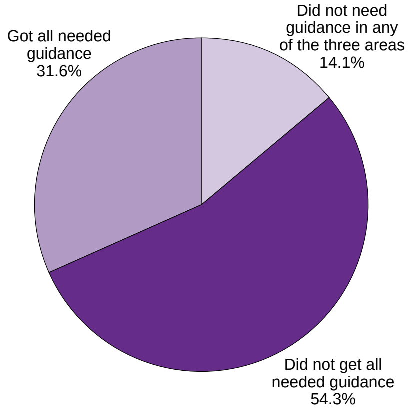


## Provision of Anticipatory Guidance

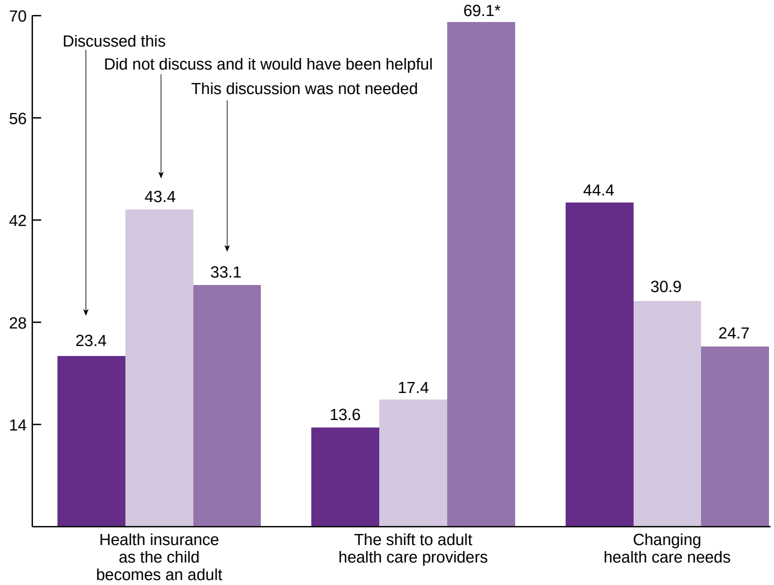
To ease the transition to adult health care, providers can offer guidance to adolescents and their families about various aspects of their care. The survey asked parents of youth with special health care needs whether their children's providers had discussed health insurance; the shift to adult health care providers, if needed; and the child's changing health care needs as he or she approaches adulthood. Overall, the parents of 31.6 percent of youth with special health care needs reported that they received all the guidance they needed in these three areas, while an additional 14.1 percent reported that they did not need any anticipatory guidance. The parents of over half of youth with special health care needs reported that they did not get all the anticipatory guidance they needed.

Parents were most likely to report that their children's providers had discussed their children's changing health care needs; the parents of 44.4 percent of CSHCN did so. The shift to adult health care providers was much less common, reported by the parents of only 13.6 percent of CSHCN, but the majority reported that this discussion was not needed. (For just over one-third of children in this age group, parents reported that their providers treated both adults and children, so a discussion of the transition to adult providers was not necessary.) The parents of 23.4 percent of youth with special health care needs reported that their children's providers discussed health insurance.

**Receipt of Anticipatory Guidance about Transition by CSHCN Aged 12-17**



**Percent of CSHCN Aged 12-17 Whose Providers Offered Anticipatory Guidance about Transition**



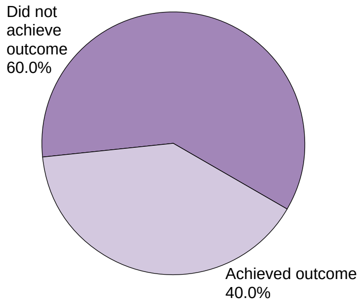
*Includes those who reported that their providers treat both adults and children.

## Core Outcome Summary

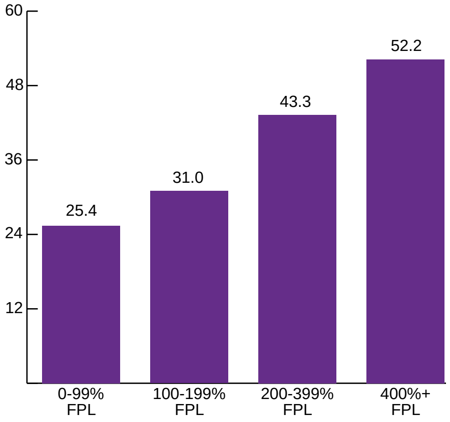
Youth with special health care needs were considered to have achieved the outcome for making effective transitions to adult life if their parents reported that they received anticipatory guidance in all three areas and their providers usually or always encouraged them to take responsibility for their health. This standard was met for 40.0 percent of youth aged 12-17 years.

Adolescents whose conditions consistently affect their daily lives were half as likely as those whose conditions never affect their daily activities to achieve this objective (25.5 versus 52.0 percent). Children living in poverty were also half as likely as those in the highest income bracket to receive transition services (25.4 versus 52.2 percent).

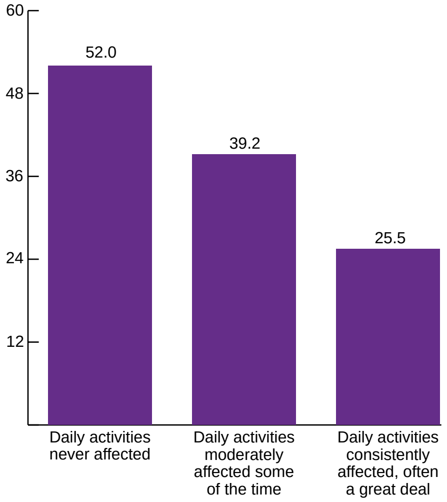
**Youth with Special Health Care Needs Who Receive the Services Necessary to Make the Transition to Adult Health Care (CSHCN Aged 12-17)**



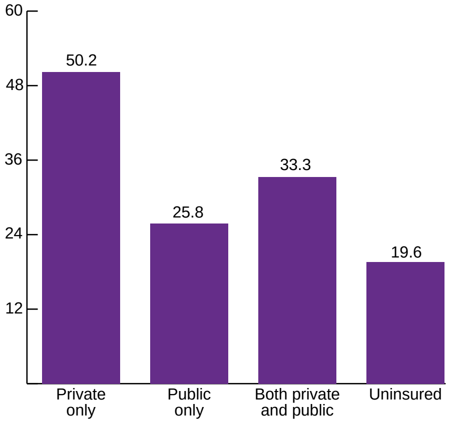
**Percent of Youth with Special Health Care Needs Who Receive the Services Necessary to Make Transitions to Adult Health Care (CSHCN Aged 12-17), by Poverty Status**



**Percent of Youth with Special Health Care Needs Who Receive the Services Necessary to Make Transitions to Adult Health Care (CSHCN Aged 12-17), by Impact of Condition**



**Percent of Youth with Special Health Care Needs Who Receive the Services Necessary to Make Transitions to Adult Health (CSHCN Aged 12-17), by Insurance Type**

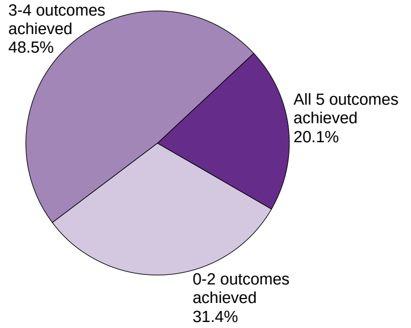


## *Overall Quality of the System of Services*

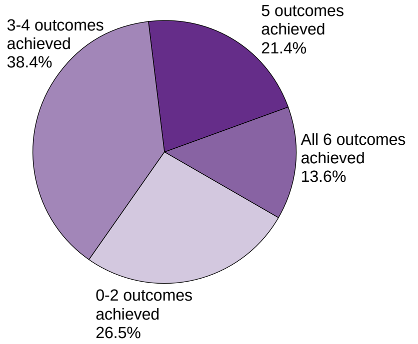
To further evaluate the system of care serving CSHCN, the core outcomes were combined into a single indicator of “system-ness”. A child was considered to be served by a well-functioning “service system,” as described in the Healthy People objective, if his or her care met all relevant criteria for his or her age. For children from birth through age 11, the first 5 outcomes were included, and all 6 outcomes were counted for children from age 12 through 17.

Among children aged 11 and under, 20.1 percent were served by a well-functioning system of care according to these standards. For children aged 12 to 17, 13.6 percent had care that met all 6 criteria. For children whose conditions have a greater impact on their daily lives, these outcomes were much more difficult to achieve. Among 0- to 11-year-olds whose conditions consistently affect their activities, only 10.5 percent are served by systems of care that meet all 5 criteria; among 12- to 17-year-olds, only 6.0 percent met all 6. Among children whose conditions never affect their activities, a greater percentage were served by a system that met all of the outcomes (29.6 percent of children aged 0-11 and 22.1 percent of those aged 12-17).

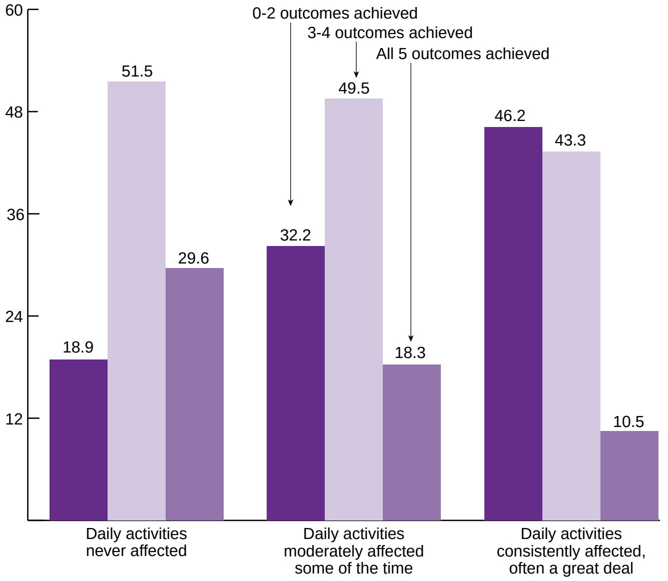
**CSHCN Aged 0-11 Who Are Served by Systems of Care That Met One or More Core Outcomes**



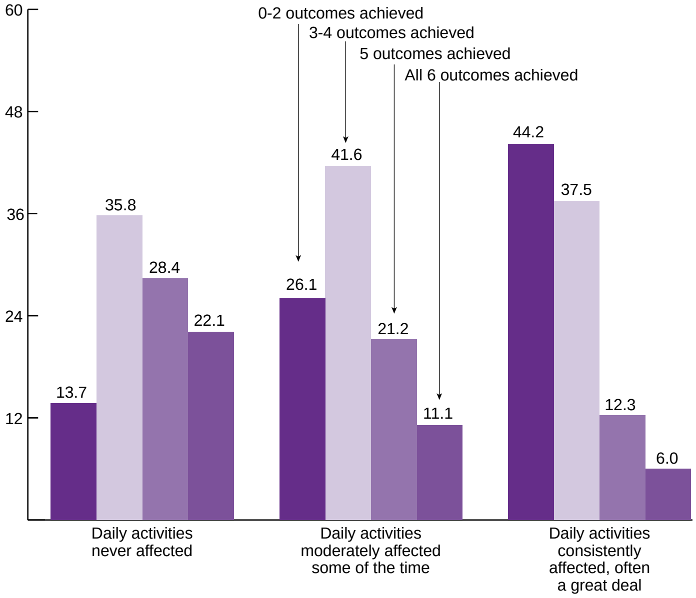
**CSHCN Aged 12-17 Who Are Served by Systems of Care That Met One or More Core Outcomes**



**Percent of CSHCN Aged 0-11 Who Are Served by Systems of Care That Met One or More Core Outcomes, by Impact of Condition**



**Percent of CSHCN Aged 12-17 Who Are Served by Systems of Care That Met One or More Core Outcomes, by Impact of Condition**



## Impact on Families

Having a child with special health care needs can affect a family's finances, employment status, and mental health. The demands on families may require that parents cut down their work hours or give up a job, at the same time that they face burdensome out-of-pocket health care costs.

This section describes the impact that children with special health care needs have on their families. One way to measure this impact is in dollars, as families often have substantial out-of-pocket expenses for their children's health care that are not covered by insurance. Parents were also asked whether their children's conditions created a financial burden, a qualitative measure of the economic impact of having a child with special health care needs.

Another measure is the time spent by family members providing care directly or arranging for and coordinating their child's care. The third indicator presented in this section is the number of hours parents spend per week on these tasks.

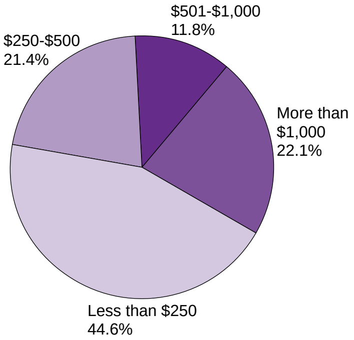
Finally, parents were asked whether their children's needs had required them to cut down on work or stop working altogether to care for their child, or whether they had avoided changing jobs to preserve their child's health insurance.

## *Out-of-Pocket Costs*

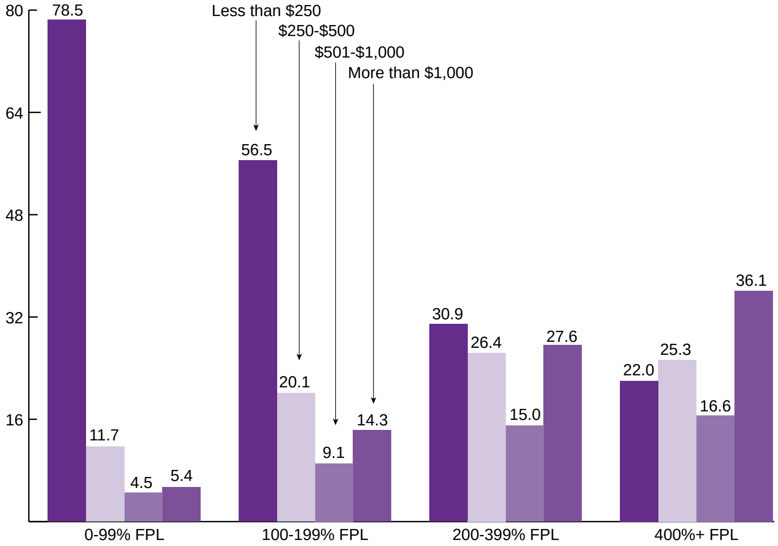
Families are often required to pay for health care services not covered or inadequately covered by their insurance plans. These services may include therapies, home health care, prescription drugs, mental health care, medical equipment, and dental services. Families of over half of children with special health care needs reported spending $250 or more on health care in the previous year for the care of their child with special health care needs. The families of 11.8 percent of CSHCN spent between $501 and $1,000, and the families of 22.1 percent of children spent more than $1,000.

Children in low-income families are less likely to have high levels of expenditures than are children from families with higher incomes. This could be because children in low-income families are more likely to be covered by Medicaid and SCHIP, which limit the co-pays charged to families. In addition, these data only include the expenses that families actually paid; low-income families may be more likely to have unpaid bills that are not reported here. Alternatively, low-income families may be more likely to delay or forgo care if they feel they cannot afford the out-of-pocket costs.

**Annual Out-of-Pocket Expenditures for CSHCN**



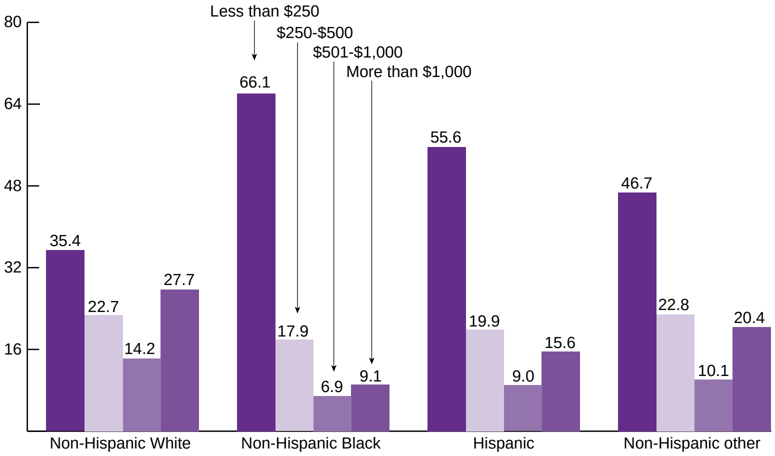
**Annual Out-of-Pocket Expenses for Care of CSHCN, by Poverty Status**



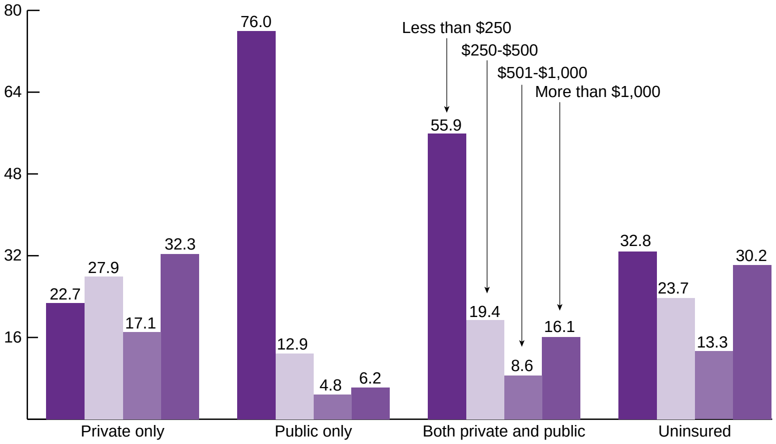
The families of non-Hispanic White children are the most likely to pay more than $1000 in health care expenses; 27.7 percent did so, compared to the families of 15.6 percent of Hispanic children and 9.1 percent of non-Hispanic Black children. Non-Hispanic White children are also the least likely to have families that pay less than $250 per year. This may be related to the insurance status of non-Hispanic White children.

The level of out-of-pocket costs borne by families of CSHCN also varies by their children's insurance status. Thirty percent of uninsured children's families pay more than $1000 annually, compared to 32.3 percent of those with private coverage and 6.2 percent of those with public insurance. Similarly, 76.0 percent of children with public coverage live in families that pay less than $250 per year out of pocket for their child's health care, compared to 22.7 percent of those with private insurance and 32.8 percent of uninsured children. This may be due to the limits on copayments within public insurance programs, or because publicly-insured and uninsured families are not able to pay bills they receive.

**Annual Out-of-Pocket Expenses for Care of CSHCN, by Race/Ethnicity**



**Annual Out-of-Pocket Expenses for Care of CSHCN, by Insurance Type**



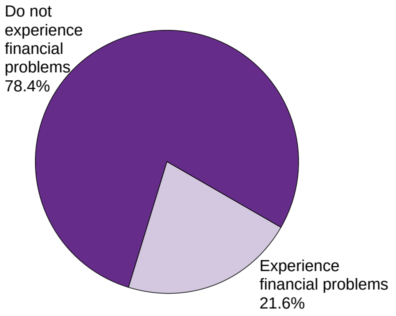
## *Financial Problems*

To further assess the financial impact of a child's condition on his or her family, the survey asked whether their child's condition or need had caused a financial problem for the family. It was reported that 21.6 percent of CSHCN have conditions that create financial problems for their families. Even though children from low-income families have lower out-of-pocket costs, these children are more likely as children from higher-income families to have conditions that result in self-reported financial problems (23.1 compared to 14.9 percent).

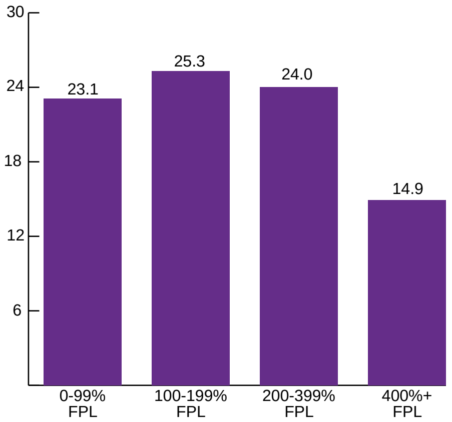
The financial burden appears to be greatest for the families of CSHCN who are uninsured. Nearly half (47.6 percent) of uninsured CSHCN live in families that reported a financial problem, compared to 21.0 percent of those with public coverage and 19.0 percent of those with private insurance.

Families of children whose conditions affect their abilities usually, always, or a great deal are also the most likely to report experiencing financial problems. More than one-third (38.5 percent) of children whose conditions usually or always affect their abilities live in families who report experiencing financial problems, compared to only 9.4 percent of children whose conditions never affect their abilities.

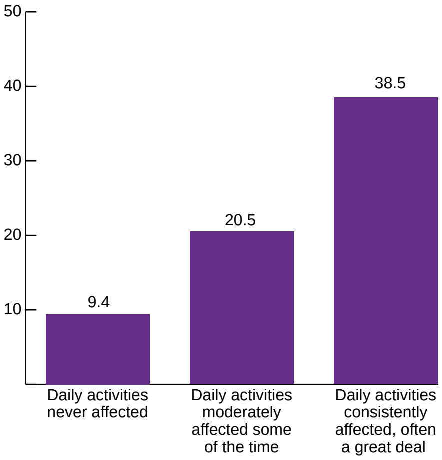
**CSHCN Whose Families Experience Financial Problems Due to Child's Condition**



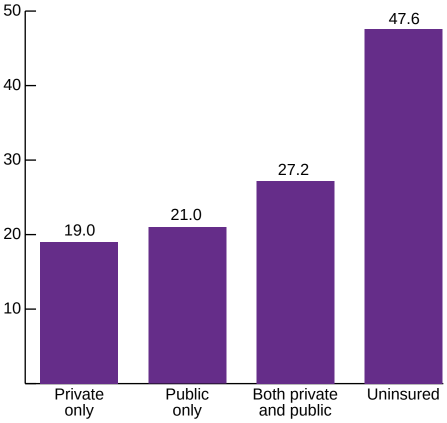
**Percent of CSHCN Whose Health Conditions Cause Financial Problems for the Family, by Poverty Status**



**Percent of CSHCN Whose Health Conditions Cause Financial Problems for the Family, by Impact of Condition**



**Percent of CSHCN Whose Health Conditions Cause Financial Problems for the Family, by Insurance Type**



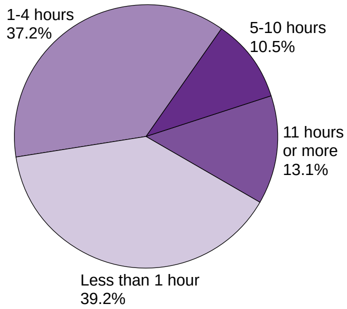
## Time Spent Providing Care

Another way a child's special health care needs can affect the family is in the time parents and other family members devote to providing and coordinating their care. Many families participate in providing health care to their children through such tasks as administering medications and therapies, maintaining equipment, and providing transportation to appointments. Families also spend time arranging or coordinating care for their children by making appointments, making sure that care providers are exchanging information, and following up on their child's health care needs. While the families of 39.2 percent of CSHCN spend less than an hour a week on these activities, the families of 37.2 percent devote 1 to 4 hours a week to these tasks, and the families of 13.1 percent spend 11 hours a week or more.

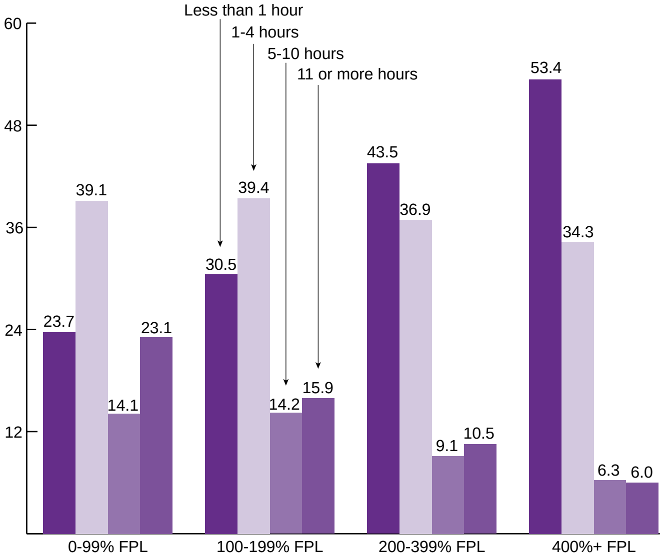
The self-reported time burden is greatest on low-income families. The families of over 20 percent of poor children spend at least 11 hours per week providing, arranging, or coordinating their children's care, compared to the families of 6.0 percent of children with family incomes of 400 percent of the poverty level or more.

The greater the impact of a child's condition on his or her functional ability, the more time the family spends on the child's care. The families of 29.3 percent of children whose activities are consistent affected by their conditions spend 11 hours or more providing, arranging, or coordinating their care, compared to the families of only 3.9 percent of children whose daily activities are never affected by their conditions.

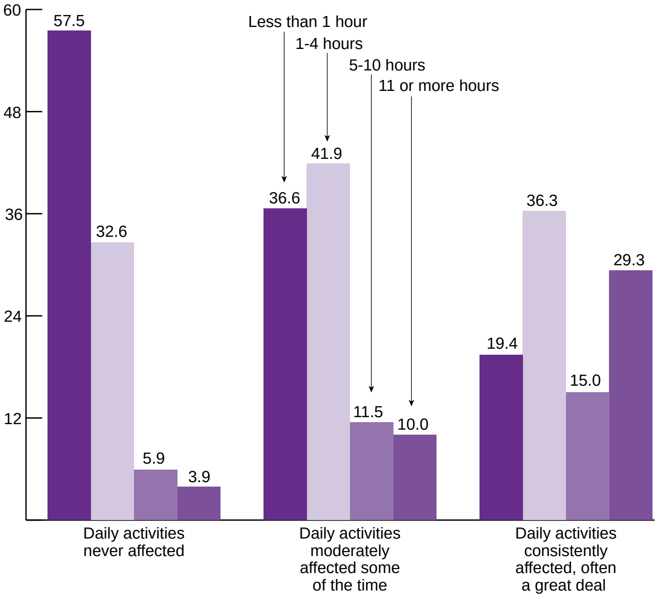
**Time Spent Providing, Arranging, or Coordinating Health Care for CSHCN, Per Week**



**Hours Per Week Spent by Families of CSHCN Providing and/or Coordinating Care, by Poverty Status**



**Hours Per Week Spent by Families of CSHCN Providing and/or Coordinating Care, by Impact of Condition**



## *Impact on Employment*

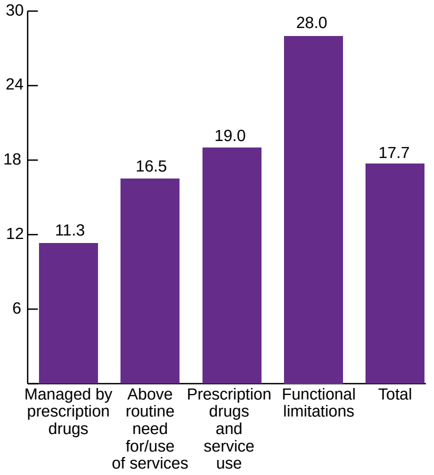
The complexity of a child's special needs and the parents' need to devote time to the child's care sometimes requires that parents cut back on the number of hours they work or stop working completely to care for their child. Other families may keep a job in order to preserve their child's health insurance.

Overall, the parents of one-quarter of CSHCN report having to stop work or cut back on their hours at work, or both, because of their children's needs. This percentage was much higher among children whose conditions had a greater impact on their activities; of those whose conditions consistently affect their daily lives, the parents of nearly half cut back their hours or stopped working, compared to 8.9 percent of those whose activities are never affected by their conditions.

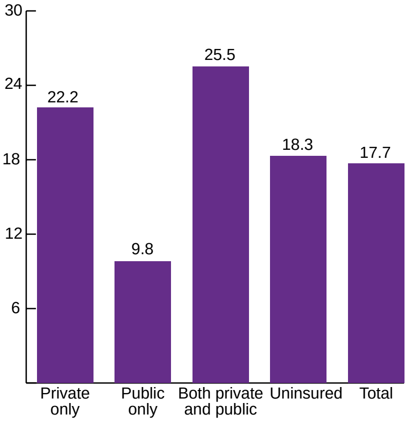
Of course, giving up a job is likely to reduce a family's income. Therefore, it is not surprising that children in lower-income families are more likely to have parents who have given up their jobs: one-third of CSHCN in poverty and nearly 30 percent of those with family incomes between 100 and 199 percent of poverty have parents who reported that they cut back on work or stopped working to care for their children, compared to 18.0 percent of children with family incomes of 400 percent of poverty or more.

Parents of CSHCN may also stay in a job longer than they would like because the job provides needed health insurance for the child. Overall, the parents of 17.7 percent of CSHCN reported that they avoided changing jobs because of concerns about maintaining their child's health insurance.

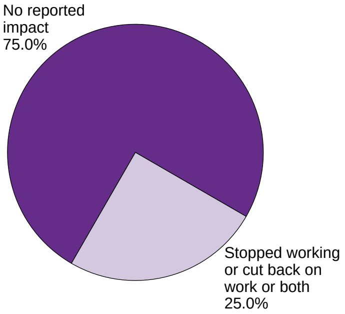
**Percent of CSHCN Whose Family Members Avoided Changing Jobs Because of Concerns about Maintaining the Child's Health Insurance, by Type of Special Health Care Need**



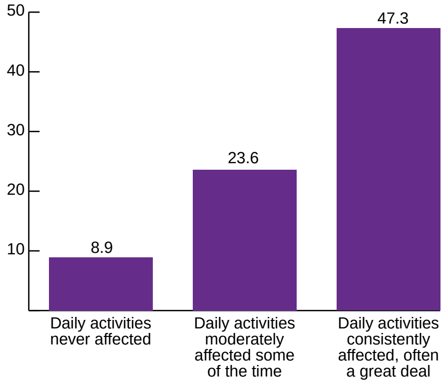
**Percent of CSHCN Whose Family Membe Avoided Changing Jobs Because of Concerns about Maintaining the Child's Health Insurance, by Insurance Type**



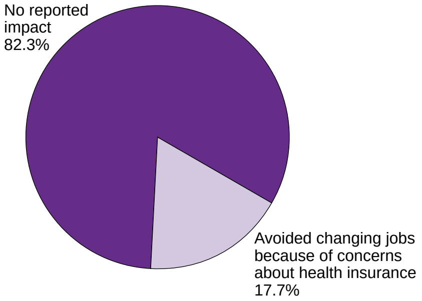
**Impact of Child's Conditions on Parents' Employment**



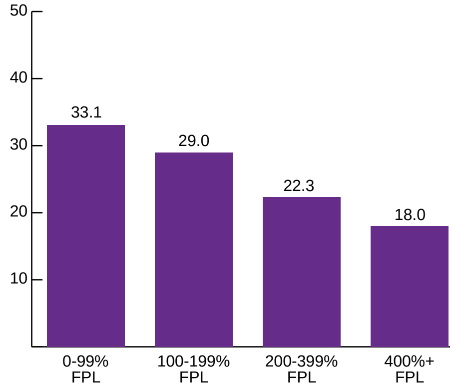
**CSHCN Whose Health Conditions Cause Family Members to Cut Back or Stop Working, by Impact of Condition**



**Impact of Conditions on Parents' Job Mobility**



**Percent of CSHCN Whose Health Conditions Cause Family Members to Cut Back or Stop Working, by Poverty Status**



## State Data Pages

The National Survey of Children with Special Health Care Needs provides information on CSHCN in the 50 States and the District of Columbia. This section presents the survey's findings for each state and D.C., including indicators of the prevalence of special needs among children; the percentage of CSHCN whose care meets each of the MCHB's six Core System Outcomes and their components; and indicators of the impact of the care of CSHCN on their families.

The indicators of prevalence show the parent-reported percentage of children who have special health care needs by age, sex, income level in relation to the Federal poverty guidelines, and race and ethnicity. For most States, however, prevalence is shown only among non-Hispanic White, non-Hispanic Black, and Hispanic children. For smaller racial/ethnic groups, data have been suppressed in most States to protect the confidentiality of the respondents. The exceptions are States with significant populations of Asian Americans, Native American/Alaska Natives, or Native Hawaiians or other Pacific Islanders.

The Core Outcomes and their components, as well as the indicators of family impact, are shown for each jurisdiction in comparison with the national statistics presented earlier in this book.

# Alabama

**Estimated number of CSHCN: 200,367**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **17.8** | 15.1 |
| **Age** | | |
| 0–5 years | **13.2** | 9.3 |
| 6–11 years | **20.7** | 17.7 |
| 12–17 years | **19.5** | 18.4 |
| **Sex** | | |
| Male | **20.3** | 17.4 |
| Female | **15.2** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **17.8** | 16.0 |
| 100–199% FPL | **21.7** | 15.4 |
| 200–399% FPL | **17.8** | 14.5 |
| 400% FPL or more | **15.4** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **18.1** | 16.2 |
| White | **17.1** | 16.3 |
| Black | **20.6** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **13.1** | 11.2 |
| Spanish language household | * | 8.2 |
| English language household | **25.9** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **22.7** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **15.2** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **74.0** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **50.7** | 43.0 |
| CSHCN with a usual source of care when sick | **93.8** | 90.5 |
| CSHCN with a personal doctor or nurse | **90.4** | 93.1 |
| CSHCN who receive family-centered care | **65.8** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **64.7** | 60.6 |
| CSHCN with insurance for the entire past year | **91.8** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **69.9** | 65.7 |
| Children are screened early and continuously for special health care needs | **75.8** | 78.6 |
| Community-based services are organized so families can use them easily | **73.5** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **74.5** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **93.0** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **34.8** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **15.2** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **19.0** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **15.1** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **21.4** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **13.5** | 17.7 |

# Alaska

**Estimated number of CSHCN: 19,916**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **10.9** | 15.1 |
| **Age** | | |
| 0–5 years | **5.0** | 9.3 |
| 6–11 years | **12.9** | 17.7 |
| 12–17 years | **14.6** | 18.4 |
| **Sex** | | |
| Male | **12.7** | 17.4 |
| Female | **8.8** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **10.9** | 16.0 |
| 100–199% FPL | **9.1** | 15.4 |
| 200–399% FPL | **10.4** | 14.5 |
| 400% FPL or more | **11.5** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **11.0** | 16.2 |
| White | **11.9** | 16.3 |
| Black | **12.0** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | **7.4** | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **9.4** | 11.2 |
| Spanish language household | * | 8.2 |
| English language household | **10.9** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **25.9** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **17.9** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **66.8** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **42.8** | 43.0 |
| CSHCN with a usual source of care when sick | **89.5** | 90.5 |
| CSHCN with a personal doctor or nurse | **93.2** | 93.1 |
| CSHCN who receive family-centered care | **62.4** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **56.7** | 60.6 |
| CSHCN with insurance for the entire past year | **89.5** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **61.3** | 65.7 |
| Children are screened early and continuously for special health care needs | **75.3** | 78.6 |
| Community-based services are organized so families can use them easily | **55.2** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **55.5** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **88.4** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **45.0** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **26.7** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **23.6** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **12.0** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **27.3** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **24.7** | 17.7 |

# Arizona

**Estimated number of CSHCN: 241,067**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **13.9** | 15.1 |
| **Age** | | |
| 0–5 years | **7.6** | 9.3 |
| 6–11 years | **17.6** | 17.7 |
| 12–17 years | **17.4** | 18.4 |
| **Sex** | | |
| Male | **16.1** | 17.4 |
| Female | **11.8** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **13.9** | 16.0 |
| 100–199% FPL | **13.0** | 15.4 |
| 200–399% FPL | **14.2** | 14.5 |
| 400% FPL or more | **14.2** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **16.1** | 16.2 |
| White | **15.9** | 16.3 |
| Black | **25.3** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | **13.0** | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **11.0** | 11.2 |
| Spanish language household | **7.9** | 8.2 |
| English language household | **13.6** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **30.1** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **18.8** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **66.2** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **36.1** | 43.0 |
| CSHCN with a usual source of care when sick | **85.3** | 90.5 |
| CSHCN with a personal doctor or nurse | **92.4** | 93.1 |
| CSHCN who receive family-centered care | **61.3** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **52.9** | 60.6 |
| CSHCN with insurance for the entire past year | **85.8** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **60.8** | 65.7 |
| Children are screened early and continuously for special health care needs | **78.7** | 78.6 |
| Community-based services are organized so families can use them easily | **59.7** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **60.9** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **86.8** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **35.6** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **24.8** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **24.3** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **12.6** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **26.4** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **18.6** | 17.7 |

# Arkansas

**Estimated number of CSHCN: 139,580**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **19.8** | 15.1 |
| **Age** | | |
| 0–5 years | **12.3** | 9.3 |
| 6–11 years | **27.1** | 17.7 |
| 12–17 years | **20.3** | 18.4 |
| **Sex** | | |
| Male | **21.3** | 17.4 |
| Female | **18.2** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **19.8** | 16.0 |
| 100–199% FPL | **26.3** | 15.4 |
| 200–399% FPL | **18.3** | 14.5 |
| 400% FPL or more | **17.5** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **20.5** | 16.2 |
| White | **18.6** | 16.3 |
| Black | **25.6** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **13.6** | 11.2 |
| Spanish language household | **8.9** | 8.2 |
| English language household | **22.3** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **32.5** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **17.9** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **67.8** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **43.9** | 43.0 |
| CSHCN with a usual source of care when sick | **88.9** | 90.5 |
| CSHCN with a personal doctor or nurse | **89.6** | 93.1 |
| CSHCN who receive family-centered care | **61.3** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **59.1** | 60.6 |
| CSHCN with insurance for the entire past year | **91.8** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **63.7** | 65.7 |
| Children are screened early and continuously for special health care needs | **71.5** | 78.6 |
| Community-based services are organized so families can use them easily | **59.1** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **61.5** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **86.6** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **32.4** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **16.9** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **21.2** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **15.8** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **25.5** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **16.0** | 17.7 |

# California

**Estimated number of CSHCN: 997,157**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **10.6** | 15.1 |
| **Age** | | |
| 0–5 years | **6.4** | 9.3 |
| 6–11 years | **12.5** | 17.7 |
| 12–17 years | **13.1** | 18.4 |
| **Sex** | | |
| Male | **12.9** | 17.4 |
| Female | **8.2** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **10.6** | 16.0 |
| 100–199% FPL | **8.5** | 15.4 |
| 200–399% FPL | **8.4** | 14.5 |
| 400% FPL or more | **12.3** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **12.1** | 16.2 |
| White | **12.8** | 16.3 |
| Black | **15.7** | 17.5 |
| Asian | **6.7** | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **9.1** | 11.2 |
| Spanish language household | **7.5** | 8.2 |
| English language household | **10.8** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **29.2** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **12.5** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **61.8** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **38.3** | 43.0 |
| CSHCN with a usual source of care when sick | **90.5** | 90.5 |
| CSHCN with a personal doctor or nurse | **94.1** | 93.1 |
| CSHCN who receive family-centered care | **61.2** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **59.1** | 60.6 |
| CSHCN with insurance for the entire past year | **91.7** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **62.8** | 65.7 |
| Children are screened early and continuously for special health care needs | **77.5** | 78.6 |
| Community-based services are organized so families can use them easily | **64.8** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **65.5** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **88.0** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **37.4** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **21.8** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **24.2** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **16.3** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **29.4** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **22.0** | 17.7 |

# Colorado

**Estimated number of CSHCN: 167,524**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **13.7** | 15.1 |
| **Age** | | |
| 0–5 years | **7.3** | 9.3 |
| 6–11 years | **16.1** | 17.7 |
| 12–17 years | **18.3** | 18.4 |
| **Sex** | | |
| Male | **14.9** | 17.4 |
| Female | **12.5** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **13.7** | 16.0 |
| 100–199% FPL | **12.0** | 15.4 |
| 200–399% FPL | **11.4** | 14.5 |
| 400% FPL or more | **15.2** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **15.1** | 16.2 |
| White | **14.8** | 16.3 |
| Black | **14.7** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **10.3** | 11.2 |
| Spanish language household | **7.1** | 8.2 |
| English language household | **12.8** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **26.1** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **17.7** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **66.5** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **43.7** | 43.0 |
| CSHCN with a usual source of care when sick | **89.6** | 90.5 |
| CSHCN with a personal doctor or nurse | **91.4** | 93.1 |
| CSHCN who receive family-centered care | **66.5** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **49.9** | 60.6 |
| CSHCN with insurance for the entire past year | **89.4** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **55.2** | 65.7 |
| Children are screened early and continuously for special health care needs | **81.7** | 78.6 |
| Community-based services are organized so families can use them easily | **60.1** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **61.1** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **87.9** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **42.1** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **30.3** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **29.2** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **11.0** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **25.9** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **22.4** | 17.7 |

# Connecticut

**Estimated number of CSHCN: 139,453**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **17.3** | 15.1 |
| **Age** | | |
| 0–5 years | **9.9** | 9.3 |
| 6–11 years | **17.9** | 17.7 |
| 12–17 years | **23.1** | 18.4 |
| **Sex** | | |
| Male | **20.8** | 17.4 |
| Female | **13.7** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **17.3** | 16.0 |
| 100–199% FPL | **21.1** | 15.4 |
| 200–399% FPL | **16.1** | 14.5 |
| 400% FPL or more | **16.8** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **17.4** | 16.2 |
| White | **18.0** | 16.3 |
| Black | **15.4** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **16.8** | 11.2 |
| Spanish language household | **11.4** | 8.2 |
| English language household | **20.6** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **29.0** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **16.4** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **70.4** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **46.0** | 43.0 |
| CSHCN with a usual source of care when sick | **94.0** | 90.5 |
| CSHCN with a personal doctor or nurse | **94.6** | 93.1 |
| CSHCN who receive family-centered care | **67.4** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **59.6** | 60.6 |
| CSHCN with insurance for the entire past year | **95.1** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **61.5** | 65.7 |
| Children are screened early and continuously for special health care needs | **87.1** | 78.6 |
| Community-based services are organized so families can use them easily | **66.8** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **66.9** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **88.6** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **46.0** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **24.6** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **18.8** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **9.9** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **24.9** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **21.2** | 17.7 |

# Delaware

**Estimated number of CSHCN: 36,143**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **17.5** | 15.1 |
| **Age** | | |
| 0–5 years | **10.6** | 9.3 |
| 6–11 years | **19.3** | 17.7 |
| 12–17 years | **22.6** | 18.4 |
| **Sex** | | |
| Male | **20.9** | 17.4 |
| Female | **13.9** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **17.5** | 16.0 |
| 100–199% FPL | **15.2** | 15.4 |
| 200–399% FPL | **19.5** | 14.5 |
| 400% FPL or more | **16.7** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **18.4** | 16.2 |
| White | **18.5** | 16.3 |
| Black | **19.4** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **10.8** | 11.2 |
| Spanish language household | **4.9** | 8.2 |
| English language household | **17.4** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **20.1** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **14.7** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **72.0** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **41.4** | 43.0 |
| CSHCN with a usual source of care when sick | **93.0** | 90.5 |
| CSHCN with a personal doctor or nurse | **91.8** | 93.1 |
| CSHCN who receive family-centered care | **64.2** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **69.9** | 60.6 |
| CSHCN with insurance for the entire past year | **92.1** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **74.5** | 65.7 |
| Children are screened early and continuously for special health care needs | **84.6** | 78.6 |
| Community-based services are organized so families can use them easily | **69.0** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **70.4** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **92.4** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **38.4** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **22.6** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **19.1** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **13.0** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **21.6** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **16.1** | 17.7 |

# District of Columbia

**Estimated number of CSHCN: 18,819**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **16.6** | 15.1 |
| **Age** | | |
| 0–5 years | **10.8** | 9.3 |
| 6–11 years | **17.7** | 17.7 |
| 12–17 years | **22.1** | 18.4 |
| **Sex** | | |
| Male | **19.4** | 17.4 |
| Female | **13.7** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **16.6** | 16.0 |
| 100–199% FPL | **18.3** | 15.4 |
| 200–399% FPL | **17.1** | 14.5 |
| 400% FPL or more | **16.9** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **17.4** | 16.2 |
| White | **15.7** | 16.3 |
| Black | **18.1** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **10.6** | 11.2 |
| Spanish language household | **8.5** | 8.2 |
| English language household | **14.1** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

***Estimate suppressed as it does not meet the standard for reliability or precision.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **21.9** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **11.0** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **67.3** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **34.2** | 43.0 |
| CSHCN with a usual source of care when sick | **90.4** | 90.5 |
| CSHCN with a personal doctor or nurse | **88.4** | 93.1 |
| CSHCN who receive family-centered care | **58.9** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **65.8** | 60.6 |
| CSHCN with insurance for the entire past year | **95.2** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **68.8** | 65.7 |
| Children are screened early and continuously for special health care needs | **88.2** | 78.6 |
| Community-based services are organized so families can use them easily | **65.5** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **66.8** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **88.9** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **33.8** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **17.9** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **15.1** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **11.7** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **24.6** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **14.2** | 17.7 |

# Florida

**Estimated number of CSHCN: 606,215**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **15.0** | 15.1 |
| **Age** | | |
| 0–5 years | **9.3** | 9.3 |
| 6–11 years | **16.9** | 17.7 |
| 12–17 years | **18.8** | 18.4 |
| **Sex** | | |
| Male | **16.3** | 17.4 |
| Female | **13.5** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **15.0** | 16.0 |
| 100–199% FPL | **16.1** | 15.4 |
| 200–399% FPL | **16.0** | 14.5 |
| 400% FPL or more | **14.3** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **15.8** | 16.2 |
| White | **16.2** | 16.3 |
| Black | **14.5** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **12.7** | 11.2 |
| Spanish language household | **11.0** | 8.2 |
| English language household | **14.3** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **29.6** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **15.2** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **68.2** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **36.2** | 43.0 |
| CSHCN with a usual source of care when sick | **89.1** | 90.5 |
| CSHCN with a personal doctor or nurse | **91.4** | 93.1 |
| CSHCN who receive family-centered care | **56.7** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **56.5** | 60.6 |
| CSHCN with insurance for the entire past year | **85.4** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **64.3** | 65.7 |
| Children are screened early and continuously for special health care needs | **71.4** | 78.6 |
| Community-based services are organized so families can use them easily | **63.2** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **64.5** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **86.6** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **37.0** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **24.3** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **26.0** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **12.4** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **27.5** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **18.2** | 17.7 |

# Georgia

**Estimated number of CSHCN: 411,526**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **16.0** | 15.1 |
| **Age** | | |
| 0–5 years | **11.5** | 9.3 |
| 6–11 years | **18.1** | 17.7 |
| 12–17 years | **18.5** | 18.4 |
| **Sex** | | |
| Male | **17.8** | 17.4 |
| Female | **14.1** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **16.0** | 16.0 |
| 100–199% FPL | **17.4** | 15.4 |
| 200–399% FPL | **15.4** | 14.5 |
| 400% FPL or more | **14.9** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **17.1** | 16.2 |
| White | **17.5** | 16.3 |
| Black | **17.8** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **7.9** | 11.2 |
| Spanish language household | **4.9** | 8.2 |
| English language household | **12.2** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **23.7** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **13.2** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **67.6** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **45.7** | 43.0 |
| CSHCN with a usual source of care when sick | **90.9** | 90.5 |
| CSHCN with a personal doctor or nurse | **91.0** | 93.1 |
| CSHCN who receive family-centered care | **65.3** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **62.2** | 60.6 |
| CSHCN with insurance for the entire past year | **88.4** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **69.0** | 65.7 |
| Children are screened early and continuously for special health care needs | **78.0** | 78.6 |
| Community-based services are organized so families can use them easily | **69.5** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **69.6** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **92.0** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **33.9** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **19.4** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **22.4** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **11.1** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **21.1** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **16.0** | 17.7 |

# Hawaii

**Estimated number of CSHCN: 35,022**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **12.3** | 15.1 |
| **Age** | | |
| 0–5 years | **8.1** | 9.3 |
| 6–11 years | **14.2** | 17.7 |
| 12–17 years | **15.0** | 18.4 |
| **Sex** | | |
| Male | **14.3** | 17.4 |
| Female | **10.0** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **12.3** | 16.0 |
| 100–199% FPL | **11.0** | 15.4 |
| 200–399% FPL | **13.3** | 14.5 |
| 400% FPL or more | **12.0** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **11.9** | 16.2 |
| White | **12.6** | 16.3 |
| Black | **17.3** | 17.5 |
| Asian | **9.0** | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | **13.0** | 12.3 |
| Multiple races | **11.5** | 17.9 |
| Hispanic | **14.3** | 11.2 |
| Spanish language household | * | 8.2 |
| English language household | **15.2** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **24.0** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **14.0** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **77.7** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **45.4** | 43.0 |
| CSHCN with a usual source of care when sick | **91.7** | 90.5 |
| CSHCN with a personal doctor or nurse | **93.8** | 93.1 |
| CSHCN who receive family-centered care | **66.8** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **72.6** | 60.6 |
| CSHCN with insurance for the entire past year | **94.7** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **74.1** | 65.7 |
| Children are screened early and continuously for special health care needs | **81.1** | 78.6 |
| Community-based services are organized so families can use them easily | **71.5** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **72.9** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **90.1** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **37.3** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **15.5** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **14.0** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **11.3** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **23.6** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **15.5** | 17.7 |

# Idaho

**Estimated number of CSHCN: 53,280**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **12.7** | 15.1 |
| **Age** | | |
| 0–5 years | **7.2** | 9.3 |
| 6–11 years | **13.7** | 17.7 |
| 12–17 years | **17.9** | 18.4 |
| **Sex** | | |
| Male | **14.9** | 17.4 |
| Female | **10.5** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **12.7** | 16.0 |
| 100–199% FPL | **14.2** | 15.4 |
| 200–399% FPL | **12.3** | 14.5 |
| 400% FPL or more | **12.4** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **13.5** | 16.2 |
| White | **13.3** | 16.3 |
| Black | ** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **9.1** | 11.2 |
| Spanish language household | **4.7** | 8.2 |
| English language household | **13.8** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

***Estimate suppressed as it does not meet the standard for reliability or precision.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **29.2** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **18.6** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **72.4** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **42.9** | 43.0 |
| CSHCN with a usual source of care when sick | **88.0** | 90.5 |
| CSHCN with a personal doctor or nurse | **91.2** | 93.1 |
| CSHCN who receive family-centered care | **61.6** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **55.2** | 60.6 |
| CSHCN with insurance for the entire past year | **87.1** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **62.5** | 65.7 |
| Children are screened early and continuously for special health care needs | **72.1** | 78.6 |
| Community-based services are organized so families can use them easily | **64.6** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **64.9** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **92.2** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **46.6** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **23.6** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **22.2** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **14.0** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **24.7** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **17.4** | 17.7 |

# Illinois

**Estimated number of CSHCN: 452,574**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **14.3** | 15.1 |
| **Age** | | |
| 0–5 years | **9.2** | 9.3 |
| 6–11 years | **16.3** | 17.7 |
| 12–17 years | **17.4** | 18.4 |
| **Sex** | | |
| Male | **16.2** | 17.4 |
| Female | **12.3** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **14.3** | 16.0 |
| 100–199% FPL | **13.6** | 15.4 |
| 200–399% FPL | **15.9** | 14.5 |
| 400% FPL or more | **14.1** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **15.1** | 16.2 |
| White | **15.1** | 16.3 |
| Black | **16.5** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **11.7** | 11.2 |
| Spanish language household | **8.1** | 8.2 |
| English language household | **17.1** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **27.3** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **16.3** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **71.1** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **44.5** | 43.0 |
| CSHCN with a usual source of care when sick | **85.9** | 90.5 |
| CSHCN with a personal doctor or nurse | **91.4** | 93.1 |
| CSHCN who receive family-centered care | **66.8** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **62.2** | 60.6 |
| CSHCN with insurance for the entire past year | **96.8** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **63.8** | 65.7 |
| Children are screened early and continuously for special health care needs | **81.3** | 78.6 |
| Community-based services are organized so families can use them easily | **64.6** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **66.1** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **89.4** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **45.3** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **22.6** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **20.6** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **10.7** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **23.7** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **16.4** | 17.7 |

# Indiana

**Estimated number of CSHCN: 268,717**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **17.0** | 15.1 |
| **Age** | | |
| 0–5 years | **11.4** | 9.3 |
| 6–11 years | **18.8** | 17.7 |
| 12–17 years | **20.8** | 18.4 |
| **Sex** | | |
| Male | **19.4** | 17.4 |
| Female | **14.5** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **17.0** | 16.0 |
| 100–199% FPL | **19.1** | 15.4 |
| 200–399% FPL | **16.0** | 14.5 |
| 400% FPL or more | **16.3** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **17.5** | 16.2 |
| White | **17.3** | 16.3 |
| Black | **19.0** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **10.8** | 11.2 |
| Spanish language household | **5.7** | 8.2 |
| English language household | **15.5** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **28.2** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **11.9** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **72.6** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **48.5** | 43.0 |
| CSHCN with a usual source of care when sick | **90.9** | 90.5 |
| CSHCN with a personal doctor or nurse | **93.9** | 93.1 |
| CSHCN who receive family-centered care | **69.6** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **58.6** | 60.6 |
| CSHCN with insurance for the entire past year | **90.5** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **64.7** | 65.7 |
| Children are screened early and continuously for special health care needs | **79.1** | 78.6 |
| Community-based services are organized so families can use them easily | **65.9** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **66.8** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **88.9** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **43.7** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **23.5** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **25.0** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **12.5** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **24.9** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **20.0** | 17.7 |

# Iowa

**Estimated number of CSHCN: 105,815**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **15.0** | 15.1 |
| **Age** | | |
| 0–5 years | **8.5** | 9.3 |
| 6–11 years | **17.2** | 17.7 |
| 12–17 years | **19.0** | 18.4 |
| **Sex** | | |
| Male | **17.5** | 17.4 |
| Female | **12.3** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **15.0** | 16.0 |
| 100–199% FPL | **21.4** | 15.4 |
| 200–399% FPL | **16.5** | 14.5 |
| 400% FPL or more | **12.8** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **15.3** | 16.2 |
| White | **14.7** | 16.3 |
| Black | **21.5** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **10.9** | 11.2 |
| Spanish language household | * | 8.2 |
| English language household | **19.0** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **24.7** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **12.3** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **75.8** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **47.0** | 43.0 |
| CSHCN with a usual source of care when sick | **92.7** | 90.5 |
| CSHCN with a personal doctor or nurse | **93.3** | 93.1 |
| CSHCN who receive family-centered care | **67.6** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **64.6** | 60.6 |
| CSHCN with insurance for the entire past year | **92.3** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **68.7** | 65.7 |
| Children are screened early and continuously for special health care needs | **81.1** | 78.6 |
| Community-based services are organized so families can use them easily | **68.0** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **68.1** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **94.1** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **45.0** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **24.3** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **20.6** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **10.9** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **17.6** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **16.0** | 17.7 |

# Kansas

**Estimated number of CSHCN: 120,822**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **17.3** | 15.1 |
| **Age** | | |
| 0–5 years | **9.9** | 9.3 |
| 6–11 years | **19.2** | 17.7 |
| 12–17 years | **23.1** | 18.4 |
| **Sex** | | |
| Male | **19.9** | 17.4 |
| Female | **14.6** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **17.3** | 16.0 |
| 100–199% FPL | **20.0** | 15.4 |
| 200–399% FPL | **16.3** | 14.5 |
| 400% FPL or more | **16.7** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **18.0** | 16.2 |
| White | **17.6** | 16.3 |
| Black | **22.5** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **12.8** | 11.2 |
| Spanish language household | **8.2** | 8.2 |
| English language household | **18.2** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **24.0** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **13.5** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **72.6** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **49.4** | 43.0 |
| CSHCN with a usual source of care when sick | **91.9** | 90.5 |
| CSHCN with a personal doctor or nurse | **93.0** | 93.1 |
| CSHCN who receive family-centered care | **69.8** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **60.0** | 60.6 |
| CSHCN with insurance for the entire past year | **89.3** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **67.3** | 65.7 |
| Children are screened early and continuously for special health care needs | **82.9** | 78.6 |
| Community-based services are organized so families can use them easily | **66.8** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **66.9** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **90.4** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **52.7** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **29.0** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **26.3** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **10.8** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **23.0** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **19.8** | 17.7 |

# Kentucky

**Estimated number of CSHCN: 197,916** **All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **19.5** | 15.1 |
| **Age** | | |
| 0–5 years | **11.5** | 9.3 |
| 6–11 years | **24.0** | 17.7 |
| 12–17 years | **23.1** | 18.4 |
| **Sex** | | |
| Male | **23.1** | 17.4 |
| Female | **15.8** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **19.5** | 16.0 |
| 100–199% FPL | **26.3** | 15.4 |
| 200–399% FPL | **19.9** | 14.5 |
| 400% FPL or more | **14.4** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **19.6** | 16.2 |
| White | **18.5** | 16.3 |
| Black | **18.2** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **17.8** | 11.2 |
| Spanish language household | * | 8.2 |
| English language household | **21.5** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **30.1** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **14.7** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **73.6** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **50.2** | 43.0 |
| CSHCN with a usual source of care when sick | **93.6** | 90.5 |
| CSHCN with a personal doctor or nurse | **94.4** | 93.1 |
| CSHCN who receive family-centered care | **67.5** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **66.8** | 60.6 |
| CSHCN with insurance for the entire past year | **90.9** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **71.0** | 65.7 |
| Children are screened early and continuously for special health care needs | **79.7** | 78.6 |
| Community-based services are organized so families can use them easily | **63.8** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **65.4** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **87.9** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **37.1** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **16.8** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **21.0** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **13.7** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **23.4** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **17.0** | 17.7 |

# Louisiana

**Estimated number of CSHCN: 207,840**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **18.6** | 15.1 |
| **Age** | | |
| 0–5 years | **11.2** | 9.3 |
| 6–11 years | **22.2** | 17.7 |
| 12–17 years | **22.5** | 18.4 |
| **Sex** | | |
| Male | **21.4** | 17.4 |
| Female | **15.6** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **18.6** | 16.0 |
| 100–199% FPL | **21.0** | 15.4 |
| 200–399% FPL | **20.1** | 14.5 |
| 400% FPL or more | **17.3** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **18.7** | 16.2 |
| White | **18.3** | 16.3 |
| Black | **19.9** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **15.4** | 11.2 |
| Spanish language household | * | 8.2 |
| English language household | **20.4** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **30.6** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **17.3** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **67.1** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **40.4** | 43.0 |
| CSHCN with a usual source of care when sick | **89.2** | 90.5 |
| CSHCN with a personal doctor or nurse | **91.4** | 93.1 |
| CSHCN who receive family-centered care | **60.7** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **63.4** | 60.6 |
| CSHCN with insurance for the entire past year | **92.3** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **67.8** | 65.7 |
| Children are screened early and continuously for special health care needs | **76.7** | 78.6 |
| Community-based services are organized so families can use them easily | **65.5** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **66.9** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **87.6** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **32.9** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **21.0** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **23.4** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **19.2** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **28.7** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **18.6** | 17.7 |

# Maine

**Estimated number of CSHCN: 53,122**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **19.4** | 15.1 |
| **Age** | | |
| 0–5 years | **12.7** | 9.3 |
| 6–11 years | **21.9** | 17.7 |
| 12–17 years | **23.2** | 18.4 |
| **Sex** | | |
| Male | **21.8** | 17.4 |
| Female | **17.2** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **19.4** | 16.0 |
| 100–199% FPL | **29.7** | 15.4 |
| 200–399% FPL | **23.1** | 14.5 |
| 400% FPL or more | **14.7** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **19.3** | 16.2 |
| White | **19.0** | 16.3 |
| Black | **23.8** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **25.1** | 11.2 |
| Spanish language household | * | 8.2 |
| English language household | **25.1** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **26.7** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **15.0** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **74.5** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **47.5** | 43.0 |
| CSHCN with a usual source of care when sick | **92.2** | 90.5 |
| CSHCN with a personal doctor or nurse | **93.6** | 93.1 |
| CSHCN who receive family-centered care | **72.3** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **70.2** | 60.6 |
| CSHCN with insurance for the entire past year | **95.1** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **73.8** | 65.7 |
| Children are screened early and continuously for special health care needs | **83.4** | 78.6 |
| Community-based services are organized so families can use them easily | **63.7** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **64.7** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **89.9** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **43.1** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **17.4** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **18.6** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **13.4** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **23.9** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **16.3** | 17.7 |

# Maryland

**Estimated number of CSHCN: 211,442**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **15.7** | 15.1 |
| **Age** | | |
| 0–5 years | **9.2** | 9.3 |
| 6–11 years | **18.1** | 17.7 |
| 12–17 years | **19.7** | 18.4 |
| **Sex** | | |
| Male | **18.2** | 17.4 |
| Female | **13.1** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **15.7** | 16.0 |
| 100–199% FPL | **18.6** | 15.4 |
| 200–399% FPL | **16.5** | 14.5 |
| 400% FPL or more | **15.0** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **16.2** | 16.2 |
| White | **17.6** | 16.3 |
| Black | **14.7** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **11.2** | 11.2 |
| Spanish language household | **5.6** | 8.2 |
| English language household | **17.5** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **22.8** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **13.1** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **69.3** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **44.2** | 43.0 |
| CSHCN with a usual source of care when sick | **92.3** | 90.5 |
| CSHCN with a personal doctor or nurse | **93.8** | 93.1 |
| CSHCN who receive family-centered care | **67.1** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **61.3** | 60.6 |
| CSHCN with insurance for the entire past year | **92.4** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **65.3** | 65.7 |
| Children are screened early and continuously for special health care needs | **81.2** | 78.6 |
| Community-based services are organized so families can use them easily | **65.1** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **65.8** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **91.1** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **36.8** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **22.3** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **18.3** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **9.0** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **22.2** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **17.0** | 17.7 |

# Massachusetts

**Estimated number of CSHCN: 261,475**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **18.3** | 15.1 |
| **Age** | | |
| 0–5 years | **9.8** | 9.3 |
| 6–11 years | **21.4** | 17.7 |
| 12–17 years | **23.3** | 18.4 |
| **Sex** | | |
| Male | **21.1** | 17.4 |
| Female | **15.3** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **18.3** | 16.0 |
| 100–199% FPL | **21.7** | 15.4 |
| 200–399% FPL | **19.6** | 14.5 |
| 400% FPL or more | **17.3** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **18.2** | 16.2 |
| White | **18.8** | 16.3 |
| Black | **16.1** | 17.5 |
| Asian | **9.7** | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **18.9** | 11.2 |
| Spanish language household | **14.6** | 8.2 |
| English language household | **22.7** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **25.2** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **15.7** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **74.1** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **47.1** | 43.0 |
| CSHCN with a usual source of care when sick | **91.7** | 90.5 |
| CSHCN with a personal doctor or nurse | **96.6** | 93.1 |
| CSHCN who receive family-centered care | **71.5** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **62.2** | 60.6 |
| CSHCN with insurance for the entire past year | **94.4** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **66.4** | 65.7 |
| Children are screened early and continuously for special health care needs | **89.1** | 78.6 |
| Community-based services are organized so families can use them easily | **68.2** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **68.8** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **92.1** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **46.6** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **25.7** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **19.1** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **11.5** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **27.5** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **16.1** | 17.7 |

# Michigan

**Estimated number of CSHCN: 430,222**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **18.4** | 15.1 |
| **Age** | | |
| 0–5 years | **9.7** | 9.3 |
| 6–11 years | **22.8** | 17.7 |
| 12–17 years | **21.9** | 18.4 |
| **Sex** | | |
| Male | **21.7** | 17.4 |
| Female | **14.9** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **18.4** | 16.0 |
| 100–199% FPL | **21.1** | 15.4 |
| 200–399% FPL | **20.3** | 14.5 |
| 400% FPL or more | **15.9** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **18.6** | 16.2 |
| White | **18.0** | 16.3 |
| Black | **20.8** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **15.5** | 11.2 |
| Spanish language household | * | 8.2 |
| English language household | **12.4** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **25.0** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **15.1** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **74.5** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **43.7** | 43.0 |
| CSHCN with a usual source of care when sick | **91.6** | 90.5 |
| CSHCN with a personal doctor or nurse | **93.5** | 93.1 |
| CSHCN who receive family-centered care | **66.0** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **59.9** | 60.6 |
| CSHCN with insurance for the entire past year | **90.6** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **65.1** | 65.7 |
| Children are screened early and continuously for special health care needs | **79.3** | 78.6 |
| Community-based services are organized so families can use them easily | **71.7** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **71.9** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **94.1** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **41.2** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **19.0** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **18.2** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **11.0** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **23.3** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **15.5** | 17.7 |

# Minnesota

**Estimated number of CSHCN: 179,162**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **14.3** | 15.1 |
| **Age** | | |
| 0–5 years | **7.8** | 9.3 |
| 6–11 years | **16.0** | 17.7 |
| 12–17 years | **19.3** | 18.4 |
| **Sex** | | |
| Male | **16.8** | 17.4 |
| Female | **11.7** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **14.3** | 16.0 |
| 100–199% FPL | **18.1** | 15.4 |
| 200–399% FPL | **13.8** | 14.5 |
| 400% FPL or more | **14.0** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **14.3** | 16.2 |
| White | **14.2** | 16.3 |
| Black | **16.0** | 17.5 |
| Asian | **7.9** | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **13.4** | 11.2 |
| Spanish language household | * | 8.2 |
| English language household | **23.7** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **19.1** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **10.8** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **76.3** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **48.0** | 43.0 |
| CSHCN with a usual source of care when sick | **90.7** | 90.5 |
| CSHCN with a personal doctor or nurse | **92.0** | 93.1 |
| CSHCN who receive family-centered care | **70.9** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **62.5** | 60.6 |
| CSHCN with insurance for the entire past year | **89.4** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **67.3** | 65.7 |
| Children are screened early and continuously for special health care needs | **75.0** | 78.6 |
| Community-based services are organized so families can use them easily | **69.5** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **69.6** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **93.6** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **47.1** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **30.1** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **23.1** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **11.4** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **23.6** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **22.1** | 17.7 |

# Mississippi

**Estimated number of CSHCN: 124,905**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **16.4** | 15.1 |
| **Age** | | |
| 0–5 years | **10.6** | 9.3 |
| 6–11 years | **19.5** | 17.7 |
| 12–17 years | **19.2** | 18.4 |
| **Sex** | | |
| Male | **18.8** | 17.4 |
| Female | **13.8** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **16.4** | 16.0 |
| 100–199% FPL | **20.2** | 15.4 |
| 200–399% FPL | **17.5** | 14.5 |
| 400% FPL or more | **12.7** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **16.5** | 16.2 |
| White | **14.6** | 16.3 |
| Black | **18.3** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **11.8** | 11.2 |
| Spanish language household | * | 8.2 |
| English language household | **18.6** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **28.4** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **16.1** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **68.7** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **36.8** | 43.0 |
| CSHCN with a usual source of care when sick | **87.5** | 90.5 |
| CSHCN with a personal doctor or nurse | **92.0** | 93.1 |
| CSHCN who receive family-centered care | **55.8** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **57.4** | 60.6 |
| CSHCN with insurance for the entire past year | **87.3** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **64.2** | 65.7 |
| Children are screened early and continuously for special health care needs | **74.1** | 78.6 |
| Community-based services are organized so families can use them easily | **65.4** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **66.6** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **90.2** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **38.5** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **14.6** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **21.0** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **19.5** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **21.9** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **11.0** | 17.7 |

# Missouri

**Estimated number of CSHCN: 252,734**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **17.7** | 15.1 |
| **Age** | | |
| 0–5 years | **11.4** | 9.3 |
| 6–11 years | **21.9** | 17.7 |
| 12–17 years | **20.0** | 18.4 |
| **Sex** | | |
| Male | **19.9** | 17.4 |
| Female | **15.5** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **17.7** | 16.0 |
| 100–199% FPL | **18.9** | 15.4 |
| 200–399% FPL | **20.7** | 14.5 |
| 400% FPL or more | **15.3** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **18.0** | 16.2 |
| White | **17.7** | 16.3 |
| Black | **19.9** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **13.4** | 11.2 |
| Spanish language household | * | 8.2 |
| English language household | **22.2** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **27.9** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **15.7** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **72.5** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **44.9** | 43.0 |
| CSHCN with a usual source of care when sick | **87.9** | 90.5 |
| CSHCN with a personal doctor or nurse | **92.9** | 93.1 |
| CSHCN who receive family-centered care | **66.1** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **62.7** | 60.6 |
| CSHCN with insurance for the entire past year | **92.1** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **67.4** | 65.7 |
| Children are screened early and continuously for special health care needs | **73.7** | 78.6 |
| Community-based services are organized so families can use them easily | **65.5** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **65.2** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **90.1** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **40.3** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **20.7** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **19.7** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **14.0** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **22.9** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **13.8** | 17.7 |

# Montana

**Estimated number of CSHCN: 30,571**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **14.0** | 15.1 |
| **Age** | | |
| 0–5 years | **7.6** | 9.3 |
| 6–11 years | **15.9** | 17.7 |
| 12–17 years | **18.2** | 18.4 |
| **Sex** | | |
| Male | **16.0** | 17.4 |
| Female | **11.9** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **14.0** | 16.0 |
| 100–199% FPL | **16.1** | 15.4 |
| 200–399% FPL | **15.8** | 14.5 |
| 400% FPL or more | **12.3** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **13.9** | 16.2 |
| White | **13.6** | 16.3 |
| Black | **29.3** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | **13.9** | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **16.3** | 11.2 |
| Spanish language household | * | 8.2 |
| English language household | **17.3** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **30.6** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **22.3** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **72.9** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **39.1** | 43.0 |
| CSHCN with a usual source of care when sick | **89.5** | 90.5 |
| CSHCN with a personal doctor or nurse | **86.6** | 93.1 |
| CSHCN who receive family-centered care | **64.3** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **53.3** | 60.6 |
| CSHCN with insurance for the entire past year | **83.9** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **62.6** | 65.7 |
| Children are screened early and continuously for special health care needs | **70.6** | 78.6 |
| Community-based services are organized so families can use them easily | **54.3** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **55.0** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **81.5** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **48.6** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **31.3** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **29.8** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **13.2** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **23.1** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **20.4** | 17.7 |

# Nebraska

**Estimated number of CSHCN: 61,071**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **13.7** | 15.1 |
| **Age** | | |
| 0–5 years | **6.5** | 9.3 |
| 6–11 years | **16.9** | 17.7 |
| 12–17 years | **18.5** | 18.4 |
| **Sex** | | |
| Male | **15.9** | 17.4 |
| Female | **11.4** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **13.7** | 16.0 |
| 100–199% FPL | **14.1** | 15.4 |
| 200–399% FPL | **14.9** | 14.5 |
| 400% FPL or more | **12.8** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **14.3** | 16.2 |
| White | **14.4** | 16.3 |
| Black | **14.0** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **9.9** | 11.2 |
| Spanish language household | **4.1** | 8.2 |
| English language household | **16.4** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **19.8** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **15.9** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **75.6** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **48.2** | 43.0 |
| CSHCN with a usual source of care when sick | **91.0** | 90.5 |
| CSHCN with a personal doctor or nurse | **94.0** | 93.1 |
| CSHCN who receive family-centered care | **67.9** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **59.7** | 60.6 |
| CSHCN with insurance for the entire past year | **91.0** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **64.9** | 65.7 |
| Children are screened early and continuously for special health care needs | **75.0** | 78.6 |
| Community-based services are organized so families can use them easily | **70.7** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **71.5** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **92.8** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **47.6** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **27.2** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **22.6** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **8.9** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **17.8** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **17.2** | 17.7 |

# Nevada

**Estimated number of CSHCN: 82,108**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **12.0** | 15.1 |
| **Age** | | |
| 0–5 years | **6.9** | 9.3 |
| 6–11 years | **13.6** | 17.7 |
| 12–17 years | **16.1** | 18.4 |
| **Sex** | | |
| Male | **14.2** | 17.4 |
| Female | **9.8** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **12.0** | 16.0 |
| 100–199% FPL | **9.4** | 15.4 |
| 200–399% FPL | **13.5** | 14.5 |
| 400% FPL or more | **13.2** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **14.5** | 16.2 |
| White | **15.7** | 16.3 |
| Black | **13.1** | 17.5 |
| Asian | **6.3** | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **8.3** | 11.2 |
| Spanish language household | **6.2** | 8.2 |
| English language household | **11.2** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **29.3** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **15.9** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **64.0** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **36.8** | 43.0 |
| CSHCN with a usual source of care when sick | **89.0** | 90.5 |
| CSHCN with a personal doctor or nurse | **88.3** | 93.1 |
| CSHCN who receive family-centered care | **57.7** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **55.2** | 60.6 |
| CSHCN with insurance for the entire past year | **84.0** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **61.9** | 65.7 |
| Children are screened early and continuously for special health care needs | **69.7** | 78.6 |
| Community-based services are organized so families can use them easily | **57.2** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **57.1** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **88.0** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **31.7** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **26.5** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **25.4** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **15.3** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **28.3** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **21.1** | 17.7 |

# New Hampshire

**Estimated number of CSHCN: 54,569**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **19.0** | 15.1 |
| **Age** | | |
| 0–5 years | **11.8** | 9.3 |
| 6–11 years | **18.6** | 17.7 |
| 12–17 years | **25.3** | 18.4 |
| **Sex** | | |
| Male | **22.0** | 17.4 |
| Female | **16.0** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **19.0** | 16.0 |
| 100–199% FPL | **24.2** | 15.4 |
| 200–399% FPL | **23.6** | 14.5 |
| 400% FPL or more | **17.8** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **19.0** | 16.2 |
| White | **18.6** | 16.3 |
| Black | ** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **18.5** | 11.2 |
| Spanish language household | * | 8.2 |
| English language household | **20.7** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

***Estimate suppressed as it does not meet the standard for reliability or precision.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **21.5** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **15.5** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **74.9** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **49.4** | 43.0 |
| CSHCN with a usual source of care when sick | **93.7** | 90.5 |
| CSHCN with a personal doctor or nurse | **96.1** | 93.1 |
| CSHCN who receive family-centered care | **70.1** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **66.2** | 60.6 |
| CSHCN with insurance for the entire past year | **93.2** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **71.1** | 65.7 |
| Children are screened early and continuously for special health care needs | **87.4** | 78.6 |
| Community-based services are organized so families can use them easily | **67.0** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **67.8** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **92.3** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **49.0** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **23.6** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **19.6** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **9.3** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **23.0** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **19.8** | 17.7 |

# New Jersey

**Estimated number of CSHCN: 294,346** **All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **14.4** | 15.1 |
| **Age** | | |
| 0–5 years | **9.6** | 9.3 |
| 6–11 years | **15.8** | 17.7 |
| 12–17 years | **17.6** | 18.4 |
| **Sex** | | |
| Male | **17.4** | 17.4 |
| Female | **11.4** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **14.4** | 16.0 |
| 100–199% FPL | **15.0** | 15.4 |
| 200–399% FPL | **14.1** | 14.5 |
| 400% FPL or more | **14.8** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **14.7** | 16.2 |
| White | **15.3** | 16.3 |
| Black | **15.9** | 17.5 |
| Asian | **7.9** | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **13.4** | 11.2 |
| Spanish language household | **8.0** | 8.2 |
| English language household | **18.6** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **24.5** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **16.1** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **69.2** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **38.3** | 43.0 |
| CSHCN with a usual source of care when sick | **89.7** | 90.5 |
| CSHCN with a personal doctor or nurse | **93.4** | 93.1 |
| CSHCN who receive family-centered care | **64.5** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **54.9** | 60.6 |
| CSHCN with insurance for the entire past year | **93.2** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **58.3** | 65.7 |
| Children are screened early and continuously for special health care needs | **83.8** | 78.6 |
| Community-based services are organized so families can use them easily | **62.3** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **63.0** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **92.6** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **41.8** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **29.8** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **20.3** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **11.3** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **24.6** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **23.0** | 17.7 |

# New Mexico

**Estimated number of CSHCN: 70,725**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **13.8** | 15.1 |
| **Age** | | |
| 0–5 years | **8.6** | 9.3 |
| 6–11 years | **15.3** | 17.7 |
| 12–17 years | **17.9** | 18.4 |
| **Sex** | | |
| Male | **15.9** | 17.4 |
| Female | **11.7** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **13.8** | 16.0 |
| 100–199% FPL | **14.1** | 15.4 |
| 200–399% FPL | **13.9** | 14.5 |
| 400% FPL or more | **12.4** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **15.1** | 16.2 |
| White | **17.1** | 16.3 |
| Black | ** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | **9.9** | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **12.7** | 11.2 |
| Spanish language household | **8.5** | 8.2 |
| English language household | **14.7** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

***Estimate suppressed as it does not meet the standard for reliability or precision.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **26.8** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **17.5** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **67.9** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **34.9** | 43.0 |
| CSHCN with a usual source of care when sick | **89.6** | 90.5 |
| CSHCN with a personal doctor or nurse | **90.3** | 93.1 |
| CSHCN who receive family-centered care | **60.0** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **60.6** | 60.6 |
| CSHCN with insurance for the entire past year | **90.0** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **65.9** | 65.7 |
| Children are screened early and continuously for special health care needs | **77.0** | 78.6 |
| Community-based services are organized so families can use them easily | **55.5** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **55.7** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **89.6** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **35.7** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **18.0** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **23.2** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **14.7** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **28.7** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **18.5** | 17.7 |

# New York

**Estimated number of CSHCN: 660,565**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **15.0** | 15.1 |
| **Age** | | |
| 0–5 years | **9.5** | 9.3 |
| 6–11 years | **17.8** | 17.7 |
| 12–17 years | **17.5** | 18.4 |
| **Sex** | | |
| Male | **17.4** | 17.4 |
| Female | **12.4** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **15.0** | 16.0 |
| 100–199% FPL | **17.4** | 15.4 |
| 200–399% FPL | **15.3** | 14.5 |
| 400% FPL or more | **12.9** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **15.3** | 16.2 |
| White | **16.2** | 16.3 |
| Black | **15.6** | 17.5 |
| Asian | **6.5** | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **13.9** | 11.2 |
| Spanish language household | **8.9** | 8.2 |
| English language household | **18.3** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **28.1** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **17.0** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **64.4** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **38.4** | 43.0 |
| CSHCN with a usual source of care when sick | **92.0** | 90.5 |
| CSHCN with a personal doctor or nurse | **94.7** | 93.1 |
| CSHCN who receive family-centered care | **56.9** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **56.8** | 60.6 |
| CSHCN with insurance for the entire past year | **91.7** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **62.0** | 65.7 |
| Children are screened early and continuously for special health care needs | **82.8** | 78.6 |
| Community-based services are organized so families can use them easily | **65.6** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **66.7** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **89.5** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **39.7** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **18.0** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **17.6** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **14.4** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **26.7** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **13.6** | 17.7 |

# North Carolina

**Estimated number of CSHCN: 389,439**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **17.2** | 15.1 |
| **Age** | | |
| 0–5 years | **10.5** | 9.3 |
| 6–11 years | **20.5** | 17.7 |
| 12–17 years | **20.8** | 18.4 |
| **Sex** | | |
| Male | **20.8** | 17.4 |
| Female | **13.5** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **17.2** | 16.0 |
| 100–199% FPL | **17.1** | 15.4 |
| 200–399% FPL | **20.4** | 14.5 |
| 400% FPL or more | **15.2** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **18.0** | 16.2 |
| White | **18.4** | 16.3 |
| Black | **17.8** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **11.5** | 11.2 |
| Spanish language household | **7.6** | 8.2 |
| English language household | **18.7** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **24.6** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **14.9** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **74.6** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **45.1** | 43.0 |
| CSHCN with a usual source of care when sick | **92.6** | 90.5 |
| CSHCN with a personal doctor or nurse | **91.2** | 93.1 |
| CSHCN who receive family-centered care | **66.6** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **58.47** | 60.6 |
| CSHCN with insurance for the entire past year | **90.4** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **63.7** | 65.7 |
| Children are screened early and continuously for special health care needs | **78.7** | 78.6 |
| Community-based services are organized so families can use them easily | **70.3** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **71.1** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **92.1** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **43.7** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **19.1** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **22.5** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **13.0** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **22.6** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **13.9** | 17.7 |

# North Dakota

**Estimated number of CSHCN: 19,748**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **13.9** | 15.1 |
| **Age** | | |
| 0–5 years | **7.5** | 9.3 |
| 6–11 years | **15.6** | 17.7 |
| 12–17 years | **19.0** | 18.4 |
| **Sex** | | |
| Male | **17.0** | 17.4 |
| Female | **10.8** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **13.9** | 16.0 |
| 100–199% FPL | **18.8** | 15.4 |
| 200–399% FPL | **16.9** | 14.5 |
| 400% FPL or more | **12.3** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **13.9** | 16.2 |
| White | **13.7** | 16.3 |
| Black | ** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | **13.8** | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **14.8** | 11.2 |
| Spanish language household | * | 8.2 |
| English language household | **15.7** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

***Estimate suppressed as it does not meet the standard for reliability or precision.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **22.5** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **10.9** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **75.0** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **47.8** | 43.0 |
| CSHCN with a usual source of care when sick | **88.0** | 90.5 |
| CSHCN with a personal doctor or nurse | **95.5** | 93.1 |
| CSHCN who receive family-centered care | **68.5** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **60.1** | 60.6 |
| CSHCN with insurance for the entire past year | **92.7** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **64.2** | 65.7 |
| Children are screened early and continuously for special health care needs | **66.8** | 78.6 |
| Community-based services are organized so families can use them easily | **67.9** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **67.6** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **93.0** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **46.5** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **26.7** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **22.2** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **10.1** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **21.6** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **17.9** | 17.7 |

# Ohio

**Estimated number of CSHCN: 483,467**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **17.8** | 15.1 |
| **Age** | | |
| 0–5 years | **12.1** | 9.3 |
| 6–11 years | **19.9** | 17.7 |
| 12–17 years | **21.2** | 18.4 |
| **Sex** | | |
| Male | **20.6** | 17.4 |
| Female | **15.1** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **17.8** | 16.0 |
| 100–199% FPL | **23.0** | 15.4 |
| 200–399% FPL | **19.9** | 14.5 |
| 400% FPL or more | **15.1** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **17.8** | 16.2 |
| White | **17.0** | 16.3 |
| Black | **20.3** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **19.3** | 11.2 |
| Spanish language household | * | 8.2 |
| English language household | **21.4** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **30.7** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **17.6** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **73.7** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **46.4** | 43.0 |
| CSHCN with a usual source of care when sick | **91.6** | 90.5 |
| CSHCN with a personal doctor or nurse | **94.8** | 93.1 |
| CSHCN who receive family-centered care | **70.7** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **64.8** | 60.6 |
| CSHCN with insurance for the entire past year | **92.8** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **68.4** | 65.7 |
| Children are screened early and continuously for special health care needs | **77.2** | 78.6 |
| Community-based services are organized so families can use them easily | **65.2** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **65.6** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **90.6** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **35.6** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **20.2** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **18.3** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **15.2** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **24.5** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **19.7** | 17.7 |

# Oklahoma

**Estimated number of CSHCN: 161,799**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **17.6** | 15.1 |
| **Age** | | |
| 0–5 years | **10.9** | 9.3 |
| 6–11 years | **20.8** | 17.7 |
| 12–17 years | **21.7** | 18.4 |
| **Sex** | | |
| Male | **20.4** | 17.4 |
| Female | **14.8** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **17.6** | 16.0 |
| 100–199% FPL | **19.6** | 15.4 |
| 200–399% FPL | **16.5** | 14.5 |
| 400% FPL or more | **16.9** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **18.6** | 16.2 |
| White | **17.9** | 16.3 |
| Black | **19.9** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | **18.8** | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **11.1** | 11.2 |
| Spanish language household | **6.7** | 8.2 |
| English language household | **16.1** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **24.0** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **16.4** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **69.9** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **46.1** | 43.0 |
| CSHCN with a usual source of care when sick | **91.3** | 90.5 |
| CSHCN with a personal doctor or nurse | **89.4** | 93.1 |
| CSHCN who receive family-centered care | **66.8** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **59.3** | 60.6 |
| CSHCN with insurance for the entire past year | **89.5** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **66.2** | 65.7 |
| Children are screened early and continuously for special health care needs | **73.2** | 78.6 |
| Community-based services are organized so families can use them easily | **65.7** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **65.5** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **92.9** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **40.5** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **21.9** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **22.2** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **11.7** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **21.0** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **15.3** | 17.7 |

# Oregon

**Estimated number of CSHCN: 119,187** **All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **13.7** | 15.1 |
| **Age** | | |
| 0–5 years | **8.4** | 9.3 |
| 6–11 years | **14.9** | 17.7 |
| 12–17 years | **17.6** | 18.4 |
| **Sex** | | |
| Male | **15.9** | 17.4 |
| Female | **11.4** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **13.7** | 16.0 |
| 100–199% FPL | **12.7** | 15.4 |
| 200–399% FPL | **14.8** | 14.5 |
| 400% FPL or more | **13.8** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **14.6** | 16.2 |
| White | **14.6** | 16.3 |
| Black | ** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **10.0** | 11.2 |
| Spanish language household | **6.5** | 8.2 |
| English language household | **14.2** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

***Estimate suppressed as it does not meet the standard for reliability or precision.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **29.3** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **17.8** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **69.8** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **41.1** | 43.0 |
| CSHCN with a usual source of care when sick | **93.0** | 90.5 |
| CSHCN with a personal doctor or nurse | **92.2** | 93.1 |
| CSHCN who receive family-centered care | **65.0** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **55.8** | 60.6 |
| CSHCN with insurance for the entire past year | **88.4** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **61.4** | 65.7 |
| Children are screened early and continuously for special health care needs | **71.1** | 78.6 |
| Community-based services are organized so families can use them easily | **63.4** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **63.9** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **91.6** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **35.6** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **24.7** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **22.7** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **10.0** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **26.5** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **19.3** | 17.7 |

# Pennsylvania

**Estimated number of CSHCN: 469,906**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **17.0** | 15.1 |
| **Age** | | |
| 0–5 years | **8.9** | 9.3 |
| 6–11 years | **20.7** | 17.7 |
| 12–17 years | **20.9** | 18.4 |
| **Sex** | | |
| Male | **19.4** | 17.4 |
| Female | **14.5** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **17.0** | 16.0 |
| 100–199% FPL | **20.3** | 15.4 |
| 200–399% FPL | **17.7** | 14.5 |
| 400% FPL or more | **15.6** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **16.7** | 16.2 |
| White | **17.1** | 16.3 |
| Black | **15.9** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **20.4** | 11.2 |
| Spanish language household | **18.4** | 8.2 |
| English language household | **21.8** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **25.0** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **17.2** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **73.1** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **48.0** | 43.0 |
| CSHCN with a usual source of care when sick | **92.7** | 90.5 |
| CSHCN with a personal doctor or nurse | **95.1** | 93.1 |
| CSHCN who receive family-centered care | **67.5** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **69.0** | 60.6 |
| CSHCN with insurance for the entire past year | **93.2** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **73.5** | 65.7 |
| Children are screened early and continuously for special health care needs | **86.2** | 78.6 |
| Community-based services are organized so families can use them easily | **69.4** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **70.1** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **92.3** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **40.0** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **16.9** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **16.5** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **11.8** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **23.7** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **16.2** | 17.7 |

# Rhode Island

**Estimated number of CSHCN: 39,170**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **17.3** | 15.1 |
| **Age** | | |
| 0–5 years | **10.1** | 9.3 |
| 6–11 years | **20.1** | 17.7 |
| 12–17 years | **21.1** | 18.4 |
| **Sex** | | |
| Male | **19.8** | 17.4 |
| Female | **14.6** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **17.3** | 16.0 |
| 100–199% FPL | **22.8** | 15.4 |
| 200–399% FPL | **17.6** | 14.5 |
| 400% FPL or more | **17.0** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **17.6** | 16.2 |
| White | **17.8** | 16.3 |
| Black | **13.9** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **15.9** | 11.2 |
| Spanish language household | **12.9** | 8.2 |
| English language household | **20.0** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **26.1** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **15.1** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **75.5** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **44.0** | 43.0 |
| CSHCN with a usual source of care when sick | **91.9** | 90.5 |
| CSHCN with a personal doctor or nurse | **93.4** | 93.1 |
| CSHCN who receive family-centered care | **65.9** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **65.0** | 60.6 |
| CSHCN with insurance for the entire past year | **93.3** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **68.7** | 65.7 |
| Children are screened early and continuously for special health care needs | **87.7** | 78.6 |
| Community-based services are organized so families can use them easily | **71.2** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **71.5** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **91.6** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **43.7** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **16.8** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **14.7** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **11.3** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **25.6** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **15.0** | 17.7 |

# South Carolina

**Estimated number of CSHCN: 177,157**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **16.5** | 15.1 |
| **Age** | | |
| 0–5 years | **10.4** | 9.3 |
| 6–11 years | **18.4** | 17.7 |
| 12–17 years | **20.9** | 18.4 |
| **Sex** | | |
| Male | **18.2** | 17.4 |
| Female | **14.8** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **16.5** | 16.0 |
| 100–199% FPL | **17.8** | 15.4 |
| 200–399% FPL | **18.7** | 14.5 |
| 400% FPL or more | **14.5** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **17.2** | 16.2 |
| White | **17.5** | 16.3 |
| Black | **16.2** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **7.5** | 11.2 |
| Spanish language household | * | 8.2 |
| English language household | **12.7** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **27.4** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **14.1** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **73.6** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **45.3** | 43.0 |
| CSHCN with a usual source of care when sick | **91.5** | 90.5 |
| CSHCN with a personal doctor or nurse | **92.1** | 93.1 |
| CSHCN who receive family-centered care | **64.6** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **54.1** | 60.6 |
| CSHCN with insurance for the entire past year | **86.6** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **61.3** | 65.7 |
| Children are screened early and continuously for special health care needs | **79.9** | 78.6 |
| Community-based services are organized so families can use them easily | **63.9** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **64.0** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **89.6** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **41.0** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **20.7** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **22.4** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **12.2** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **24.7** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **17.0** | 17.7 |

# South Dakota

**Estimated number of CSHCN: 24,415**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **12.5** | 15.1 |
| **Age** | | |
| 0–5 years | **6.9** | 9.3 |
| 6–11 years | **14.5** | 17.7 |
| 12–17 years | **16.6** | 18.4 |
| **Sex** | | |
| Male | **14.5** | 17.4 |
| Female | **10.5** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **12.5** | 16.0 |
| 100–199% FPL | **16.1** | 15.4 |
| 200–399% FPL | **15.4** | 14.5 |
| 400% FPL or more | **9.4** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **12.5** | 16.2 |
| White | **12.6** | 16.3 |
| Black | ** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | **10.6** | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **11.9** | 11.2 |
| Spanish language household | * | 8.2 |
| English language household | **11.2** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

***Estimate suppressed as it does not meet the standard for reliability or precision.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **30.3** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **19.0** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **69.7** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **42.2** | 43.0 |
| CSHCN with a usual source of care when sick | **88.5** | 90.5 |
| CSHCN with a personal doctor or nurse | **95.1** | 93.1 |
| CSHCN who receive family-centered care | **61.7** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **62.0** | 60.6 |
| CSHCN with insurance for the entire past year | **92.9** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **65.4** | 65.7 |
| Children are screened early and continuously for special health care needs | **64.9** | 78.6 |
| Community-based services are organized so families can use them easily | **64.9** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **65.5** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **90.7** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **48.3** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **25.9** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **27.3** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **14.2** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **26.2** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **18.1** | 17.7 |

# Tennessee

**Estimated number of CSHCN: 255,692**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **17.2** | 15.1 |
| **Age** | | |
| 0–5 years | **10.7** | 9.3 |
| 6–11 years | **20.8** | 17.7 |
| 12–17 years | **20.3** | 18.4 |
| **Sex** | | |
| Male | **20.0** | 17.4 |
| Female | **14.3** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **17.2** | 16.0 |
| 100–199% FPL | **20.6** | 15.4 |
| 200–399% FPL | **17.9** | 14.5 |
| 400% FPL or more | **14.7** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **17.4** | 16.2 |
| White | **16.8** | 16.3 |
| Black | **18.2** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **14.4** | 11.2 |
| Spanish language household | **8.7** | 8.2 |
| English language household | **22.1** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **28.0** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **14.8** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **72.3** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **45.9** | 43.0 |
| CSHCN with a usual source of care when sick | **88.9** | 90.5 |
| CSHCN with a personal doctor or nurse | **90.9** | 93.1 |
| CSHCN who receive family-centered care | **67.5** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **70.4** | 60.6 |
| CSHCN with insurance for the entire past year | **94.9** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **74.1** | 65.7 |
| Children are screened early and continuously for special health care needs | **79.1** | 78.6 |
| Community-based services are organized so families can use them easily | **71.5** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **72.6** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **92.6** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **41.8** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **22.0** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **20.1** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **16.4** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **22.9** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **15.9** | 17.7 |

# Texas

**Estimated number of CSHCN: 919,876**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **13.4** | 15.1 |
| **Age** | | |
| 0–5 years | **9.4** | 9.3 |
| 6–11 years | **16.9** | 17.7 |
| 12–17 years | **14.2** | 18.4 |
| **Sex** | | |
| Male | **15.3** | 17.4 |
| Female | **11.4** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **13.4** | 16.0 |
| 100–199% FPL | **11.5** | 15.4 |
| 200–399% FPL | **14.3** | 14.5 |
| 400% FPL or more | **13.4** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **15.7** | 16.2 |
| White | **16.2** | 16.3 |
| Black | **17.9** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **10.7** | 11.2 |
| Spanish language household | **7.4** | 8.2 |
| English language household | **14.1** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **27.2** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **15.5** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **70.3** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **40.1** | 43.0 |
| CSHCN with a usual source of care when sick | **88.4** | 90.5 |
| CSHCN with a personal doctor or nurse | **94.4** | 93.1 |
| CSHCN who receive family-centered care | **62.2** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **57.9** | 60.6 |
| CSHCN with insurance for the entire past year | **84.4** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **66.0** | 65.7 |
| Children are screened early and continuously for special health care needs | **76.8** | 78.6 |
| Community-based services are organized so families can use them easily | **56.6** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **58.0** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **88.8** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **35.4** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **23.9** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **24.2** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **14.8** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **27.1** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **17.2** | 17.7 |

# Utah

**Estimated number of CSHCN: 112,278**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **13.0** | 15.1 |
| **Age** | | |
| 0–5 years | **7.9** | 9.3 |
| 6–11 years | **14.5** | 17.7 |
| 12–17 years | **17.6** | 18.4 |
| **Sex** | | |
| Male | **14.2** | 17.4 |
| Female | **11.7** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **13.0** | 16.0 |
| 100–199% FPL | **13.0** | 15.4 |
| 200–399% FPL | **12.9** | 14.5 |
| 400% FPL or more | **12.1** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **13.1** | 16.2 |
| White | **12.7** | 16.3 |
| Black | **25.8** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **12.1** | 11.2 |
| Spanish language household | **6.0** | 8.2 |
| English language household | **17.9** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **28.8** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **17.3** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **71.5** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **46.2** | 43.0 |
| CSHCN with a usual source of care when sick | **89.5** | 90.5 |
| CSHCN with a personal doctor or nurse | **94.3** | 93.1 |
| CSHCN who receive family-centered care | **68.7** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **55.9** | 60.6 |
| CSHCN with insurance for the entire past year | **87.0** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **62.3** | 65.7 |
| Children are screened early and continuously for special health care needs | **68.6** | 78.6 |
| Community-based services are organized so families can use them easily | **62.2** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **63.5** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **90.4** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **49.3** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **34.3** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **28.3** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **14.3** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **25.5** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **27.1** | 17.7 |

# Vermont

**Estimated number of CSHCN: 21,790**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **17.1** | 15.1 |
| **Age** | | |
| 0–5 years | **9.3** | 9.3 |
| 6–11 years | **19.4** | 17.7 |
| 12–17 years | **21.3** | 18.4 |
| **Sex** | | |
| Male | **19.6** | 17.4 |
| Female | **14.7** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **17.1** | 16.0 |
| 100–199% FPL | **27.5** | 15.4 |
| 200–399% FPL | **21.0** | 14.5 |
| 400% FPL or more | **15.1** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **17.0** | 16.2 |
| White | **16.6** | 16.3 |
| Black | **34.2** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **21.5** | 11.2 |
| Spanish language household | * | 8.2 |
| English language household | **22.9** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **27.8** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **13.0** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **75.4** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **44.3** | 43.0 |
| CSHCN with a usual source of care when sick | **89.8** | 90.5 |
| CSHCN with a personal doctor or nurse | **94.9** | 93.1 |
| CSHCN who receive family-centered care | **68.0** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **68.9** | 60.6 |
| CSHCN with insurance for the entire past year | **94.0** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **72.4** | 65.7 |
| Children are screened early and continuously for special health care needs | **86.8** | 78.6 |
| Community-based services are organized so families can use them easily | **70.3** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **70.3** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **92.3** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **51.8** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **20.2** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **17.3** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **10.2** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **27.0** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **15.5** | 17.7 |

# Virginia

**Estimated number of CSHCN: 296,668**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **16.1** | 15.1 |
| **Age** | | |
| 0–5 years | **10.5** | 9.3 |
| 6–11 years | **17.5** | 17.7 |
| 12–17 years | **20.5** | 18.4 |
| **Sex** | | |
| Male | **18.2** | 17.4 |
| Female | **14.0** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **16.1** | 16.0 |
| 100–199% FPL | **22.0** | 15.4 |
| 200–399% FPL | **16.2** | 14.5 |
| 400% FPL or more | **14.8** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **16.7** | 16.2 |
| White | **16.7** | 16.3 |
| Black | **18.3** | 17.5 |
| Asian | **10.5** | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **11.0** | 11.2 |
| Spanish language household | **7.8** | 8.2 |
| English language household | **14.5** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **26.8** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **18.2** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **77.1** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **42.4** | 43.0 |
| CSHCN with a usual source of care when sick | **93.4** | 90.5 |
| CSHCN with a personal doctor or nurse | **93.7** | 93.1 |
| CSHCN who receive family-centered care | **65.7** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **65.2** | 60.6 |
| CSHCN with insurance for the entire past year | **94.3** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **68.9** | 65.7 |
| Children are screened early and continuously for special health care needs | **76.7** | 78.6 |
| Community-based services are organized so families can use them easily | **67.0** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **67.5** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **92.3** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **44.9** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **23.2** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **19.5** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **11.0** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **22.7** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **18.6** | 17.7 |

# Washington

**Estimated number of CSHCN: 235,920**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **15.0** | 15.1 |
| **Age** | | |
| 0–5 years | **8.1** | 9.3 |
| 6–11 years | **17.6** | 17.7 |
| 12–17 years | **19.5** | 18.4 |
| **Sex** | | |
| Male | **16.9** | 17.4 |
| Female | **13.2** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **15.0** | 16.0 |
| 100–199% FPL | **15.6** | 15.4 |
| 200–399% FPL | **14.9** | 14.5 |
| 400% FPL or more | **14.8** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **16.0** | 16.2 |
| White | **16.2** | 16.3 |
| Black | **14.2** | 17.5 |
| Asian | **15.0** | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **10.7** | 11.2 |
| Spanish language household | **7.4** | 8.2 |
| English language household | **15.5** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **27.6** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **16.5** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **72.8** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **45.5** | 43.0 |
| CSHCN with a usual source of care when sick | **91.8** | 90.5 |
| CSHCN with a personal doctor or nurse | **92.8** | 93.1 |
| CSHCN who receive family-centered care | **69.8** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **65.0** | 60.6 |
| CSHCN with insurance for the entire past year | **93.7** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **68.2** | 65.7 |
| Children are screened early and continuously for special health care needs | **80.7** | 78.6 |
| Community-based services are organized so families can use them easily | **62.6** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **64.4** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **91.2** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **41.7** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **25.5** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **21.3** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **9.4** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **24.7** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **19.7** | 17.7 |

# West Virginia

**Estimated number of CSHCN: 70,609**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **18.5** | 15.1 |
| **Age** | | |
| 0–5 years | **11.1** | 9.3 |
| 6–11 years | **23.1** | 17.7 |
| 12–17 years | **21.3** | 18.4 |
| **Sex** | | |
| Male | **21.0** | 17.4 |
| Female | **15.9** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **18.5** | 16.0 |
| 100–199% FPL | **25.1** | 15.4 |
| 200–399% FPL | **20.0** | 14.5 |
| 400% FPL or more | **15.0** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **18.5** | 16.2 |
| White | **18.1** | 16.3 |
| Black | **21.5** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **18.1** | 11.2 |
| Spanish language household | * | 8.2 |
| English language household | **19.5** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **28.0** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **23.5** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **72.0** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **46.7** | 43.0 |
| CSHCN with a usual source of care when sick | **93.3** | 90.5 |
| CSHCN with a personal doctor or nurse | **91.8** | 93.1 |
| CSHCN who receive family-centered care | **68.5** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **62.0** | 60.6 |
| CSHCN with insurance for the entire past year | **91.0** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **67.4** | 65.7 |
| Children are screened early and continuously for special health care needs | **82.4** | 78.6 |
| Community-based services are organized so families can use them easily | **66.6** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **66.6** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **91.1** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **41.6** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **16.8** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **22.0** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **15.4** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **22.3** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **14.5** | 17.7 |

# Wisconsin

**Estimated number of CSHCN: 201,529**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **15.5** | 15.1 |
| **Age** | | |
| 0–5 years | **7.1** | 9.3 |
| 6–11 years | **17.7** | 17.7 |
| 12–17 years | **21.3** | 18.4 |
| **Sex** | | |
| Male | **17.9** | 17.4 |
| Female | **12.9** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **15.5** | 16.0 |
| 100–199% FPL | **16.6** | 15.4 |
| 200–399% FPL | **15.3** | 14.5 |
| 400% FPL or more | **15.6** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **15.8** | 16.2 |
| White | **15.5** | 16.3 |
| Black | **21.2** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **12.5** | 11.2 |
| Spanish language household | **8.5** | 8.2 |
| English language household | **16.4** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **26.6** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **16.5** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **74.4** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **44.1** | 43.0 |
| CSHCN with a usual source of care when sick | **88.8** | 90.5 |
| CSHCN with a personal doctor or nurse | **96.4** | 93.1 |
| CSHCN who receive family-centered care | **67.1** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **65.1** | 60.6 |
| CSHCN with insurance for the entire past year | **94.6** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **68.3** | 65.7 |
| Children are screened early and continuously for special health care needs | **76.9** | 78.6 |
| Community-based services are organized so families can use them easily | **64.6** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **65.7** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **90.8** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **44.4** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **24.4** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **18.4** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **11.0** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **24.5** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **17.7** | 17.7 |

# Wyoming

**Estimated number of CSHCN: 18,194**

**All statistics are based on parental reports**

| Prevalence of CSHCN | State % | National % |
|---|---|---|
| Percent of children who have special health care needs | **14.1** | 15.1 |
| **Age** | | |
| 0–5 years | **7.8** | 9.3 |
| 6–11 years | **16.4** | 17.7 |
| 12–17 years | **19.4** | 18.4 |
| **Sex** | | |
| Male | **16.9** | 17.4 |
| Female | **10.9** | 12.7 |
| **Poverty Level** | | |
| 0–99% FPL | **14.1** | 16.0 |
| 100–199% FPL | **15.0** | 15.4 |
| 200–399% FPL | **17.9** | 14.5 |
| 400% FPL or more | **12.8** | 14.7 |
| **Hispanic Origin and Race** | | |
| Non-Hispanic | **14.6** | 16.2 |
| White | **14.1** | 16.3 |
| Black | ** | 17.5 |
| Asian | * | 8.0 |
| American Indian/ Alaska Native | * | 13.5 |
| Native Hawaiian/ Pacific Islander | * | 12.3 |
| Multiple races | * | 17.9 |
| Hispanic | **10.7** | 11.2 |
| Spanish language household | * | 8.2 |
| English language household | **13.9** | 14.4 |

**Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.*

***Estimate suppressed as it does not meet the standard for reliability or precision.*

| Indicator | State % | National % |
|---|---|---|
| **Child Health** | | |
| CSHCN whose conditions consistently affect their activities, often a great deal | **28.5** | 27.1 |
| CSHCN with 11 or more days of school absences due to illness | **16.7** | 15.5 |
| **Core System Outcomes** | | |
| CSHCN whose families partner in decision making regarding their child's health | **70.0** | 70.3 |
| CSHCN receive coordinated, ongoing, comprehensive care within a medical home | **44.6** | 43.0 |
| CSHCN with a usual source of care when sick | **90.0** | 90.5 |
| CSHCN with a personal doctor or nurse | **88.8** | 93.1 |
| CSHCN who receive family-centered care | **67.7** | 64.6 |
| Families of CSHCN have adequate private and/or public insurance to pay for the needed services | **58.2** | 60.6 |
| CSHCN with insurance for the entire past year | **88.2** | 90.7 |
| Currently insured CSHCN whose insurance is adequate | **66.1** | 65.7 |
| Children are screened early and continuously for special health care needs | **72.6** | 78.6 |
| Community-based services are organized so families can use them easily | **63.9** | 65.1 |
| CSHCN whose families had no difficulties or delays receiving services | **64.2** | 65.9 |
| CSHCN whose families are sometimes or never frustrated in obtaining services | **90.8** | 90.2 |
| Youth with special health care needs receive the services necessary to make transitions to adult health care | **47.4** | 40.0 |
| **Impact on the Family** | | |
| CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child | **31.0** | 22.1 |
| CSHCN whose conditions cause financial problems for the family | **23.3** | 21.6 |
| CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care | **14.8** | 13.1 |
| CSHCN whose conditions cause family members to cut back or stop working | **21.8** | 25.0 |
| CSHCN whose parents avoided changing jobs to maintain their child's health insurance | **17.6** | 17.7 |

# Technical Appendix

## Survey Methods

The National Survey of Children with Special Health Care Needs (NS-CSHCN) was fielded using the State and Local Area Integrated Telephone Survey (SLAITS) mechanism. SLAITS is conducted by the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention (CDC). It uses the same large-scale random-digit-dial sampling frame as the CDC's National Immunization Survey.[6]

Over 7 million telephone numbers were randomly generated for inclusion in the NS-CSHCN. Separate random-digit-dial samples were generated for landline and cell-phone numbers. After eliminating numbers that were determined to be nonresidential or nonworking, the remaining numbers were called to identify households with children under 18 years of age. In addition, when cell phones were called, respondents were considered eligible only if they reported that they did not have a landline telephone or if they said they were unlikely to be reached through a landline. When households with children were identified, all children in the household were screened for special health care needs.

In households where two or more children were identified as having special needs, one child was randomly sampled to be the subject of the detailed interview.

The goal was to complete approximately 750 interviews regarding a sampled child with special health care needs in each of the 50 States and the District of Columbia. The number of households screened in each State in order to identify these 750 CSHCN varied depending on the prevalence of CSHCN in each State.

## Questionnaire

CSHCN were identified using the CSHCN Screener, which consists of five questions concerning common health care consequences of a chronic condition experienced by CSHCN. The questionnaire for sampled CSHCN included sections regarding health and functional status, access to care, care coordination, satisfaction with care, health insurance coverage, adequacy of health care coverage, impact of the child's special needs on the family, and demographic information about the child, respondent, and household.

The questionnaire was translated into Spanish, Mandarin, Cantonese, Vietnamese, and Korean. Overall, 1,048 special-needs interviews were conducted in Spanish and 25 were conducted in the four Asian languages.

The respondent was the parent or guardian in the household who was knowledgeable about the health and health care of the children under 18 years of age. For 75 percent of the children, the respondent was the mother. Respondents for the remaining children were fathers (17 percent), grandparents (6 percent), or other relatives or guardians (2 percent).

## Data Collection

Data collection began on July 7, 2009 and ended on March 2, 2011, with interviews conducted from telephone centers in Chicago, Illinois, and Las Vegas, Nevada. A computer-assisted telephone interviewing system was used to collect the data. From 196,159 households with children, 372,698 children were screened for special health care needs and 40,242 interviews were completed regarding CSHCN. Of the total number of completed interviews, 2,991 were conducted within the cell-phone sample.

The special-needs interview completion rate, which is the proportion of interviews completed after a child with special needs was selected in the household, was 83.6 percent for the landline sample, 76.6 percent for the cell-phone sample, and 80.8 percent for the combined sample. Combined interview completion rates ranged from 73.9 percent in Hawaii to 86.2 percent in Vermont. The national weighted response rate, which includes the cooperation rate as well as the resolution rate (the proportion of telephone numbers identified as residential or nonresidential) and the screening completion rates (the proportion of households successfully screened for children and for CSHCN), was 43.7 percent for the landline sample, 15.2 percent for the cell-phone sample, and 25.5 percent overall.

## Data Analysis

For producing the population-based estimates in this report, the data records for each screening interview and for each special needs interview were assigned a sampling weight. These weights are based on the probability of selection of each household telephone number within each State, with adjustments that compensate for households that have multiple telephone numbers, for households without telephones, and for nonresponse.

With data from the U.S. Bureau of the Census, the weights were also adjusted by age, sex, race, ethnicity, income, highest level of education among adults in the household, and household size to provide a dataset that was more representative of each State's population of children less than 18 years of age. Analyses were conducted using statistical software that accounts for the weights and the complex survey design. Responses of "don't know" and "refuse to answer" were counted as missing data.

## Accuracy of the Results

The data from the NS-CSHCN are subject to the usual variability associated with sample surveys. Small differences between survey estimates may be due to random survey error and not to true differences among children or across States.

The precision of the survey estimates is based on the sample size and the measure of interest. Estimates at the national level will be more precise than estimates at the State level. Estimates of the prevalence of special health care needs among all children will be more precise than estimates of the health and health care of CSHCN. The margin of error for the national prevalence estimate is 0.2 percentage points. For national estimates of the health and health care for all CSHCN, the maximum margin of error is 1.4 percentage points. For State prevalence estimates, the maximum margin of error is 2.1 percentage points. For the State indicators, the maximum margin of error is 11.8 percentage points, though half of the State indicators have a margin of error less than 7.3 percentage points.

## Availability of the Data

Except for data suppressed to protect the confidentiality of the survey subjects, all data collected in the National Survey of CSHCN are available to the public on the NCHS and MCHB Web sites.

For children in racial groups that do not represent at least 5 percent of the population in a State, the child's race was coded as "other."

In other cases, information on the child's race is included in the data set but not reported in this chartbook. Because the number of interviewed children in a racial group was small, the relative standard error of the estimate was greater than 30 percent. Estimates with relative standard errors greater than 30 percent are not considered reliable or precise. Data documentation and additional details on the methodology are also available on-line.

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