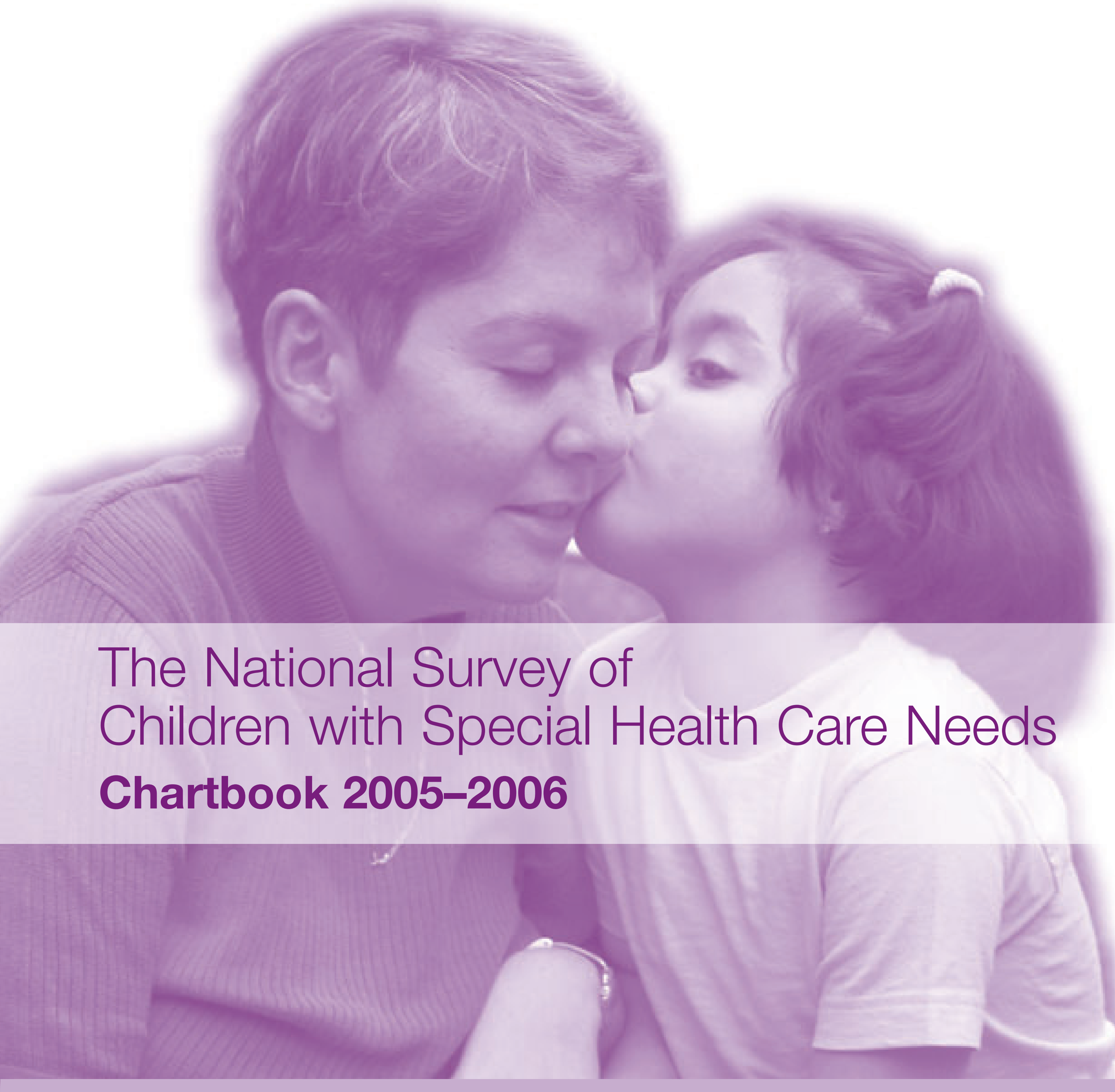

The National Survey of Children with Special Health Care Needs

Chartbook 2005–2006

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

The National Survey of Children with Special Health Care Needs

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

DEPARTMENT OF HEALTH & HUMAN SERVICES

Health Resources and Services
Administration

Rockville MD 20857

Dear Colleague:

The Health Resources and Services Administration is pleased to present this chartbook highlighting the major findings of *The 2005–2006 National Survey of Children with Special Health Care Needs*. This represents the second time the survey has been administered, providing updated information on the prevalence of special health care needs among children, both nationally and within each State, and on access to and satisfaction with health care among children with special health care needs (CSHCN) and their families.

The survey continues to produce encouraging findings. A total of 10.2 million children, or 13.9 percent of the Nation's children, have special health care needs. Of these children, 38 percent are never affected in their daily activities by their conditions, as reported by their parents. This finding, which is consistent with the results of the 2001 survey, may reflect their access to the services that CSHCN and their families need: 84 percent of CSHCN are reported to receive all of the services they need, and the parents of 95 percent report receiving all of the family support services they require.

The 2005–2006 survey also provides information about the six Core Outcomes used to measure progress toward the Healthy People 2010 objective to increase the proportion of States that have service systems for CSHCN. This analysis shows that while the care received by a majority of CSHCN reflects most of the core outcomes, work remains to be done to assure that all CSHCN receive comprehensive care through a medical home, and that youth with special health care needs receive the services necessary to make transitions to adult life and health care.

We at HRSA hope that these findings continue to be useful to you in your efforts to monitor and improve systems of care for CSHCN.

Sincerely,

Elizabeth M. Duke

Elizabeth M. Duke
Administrator

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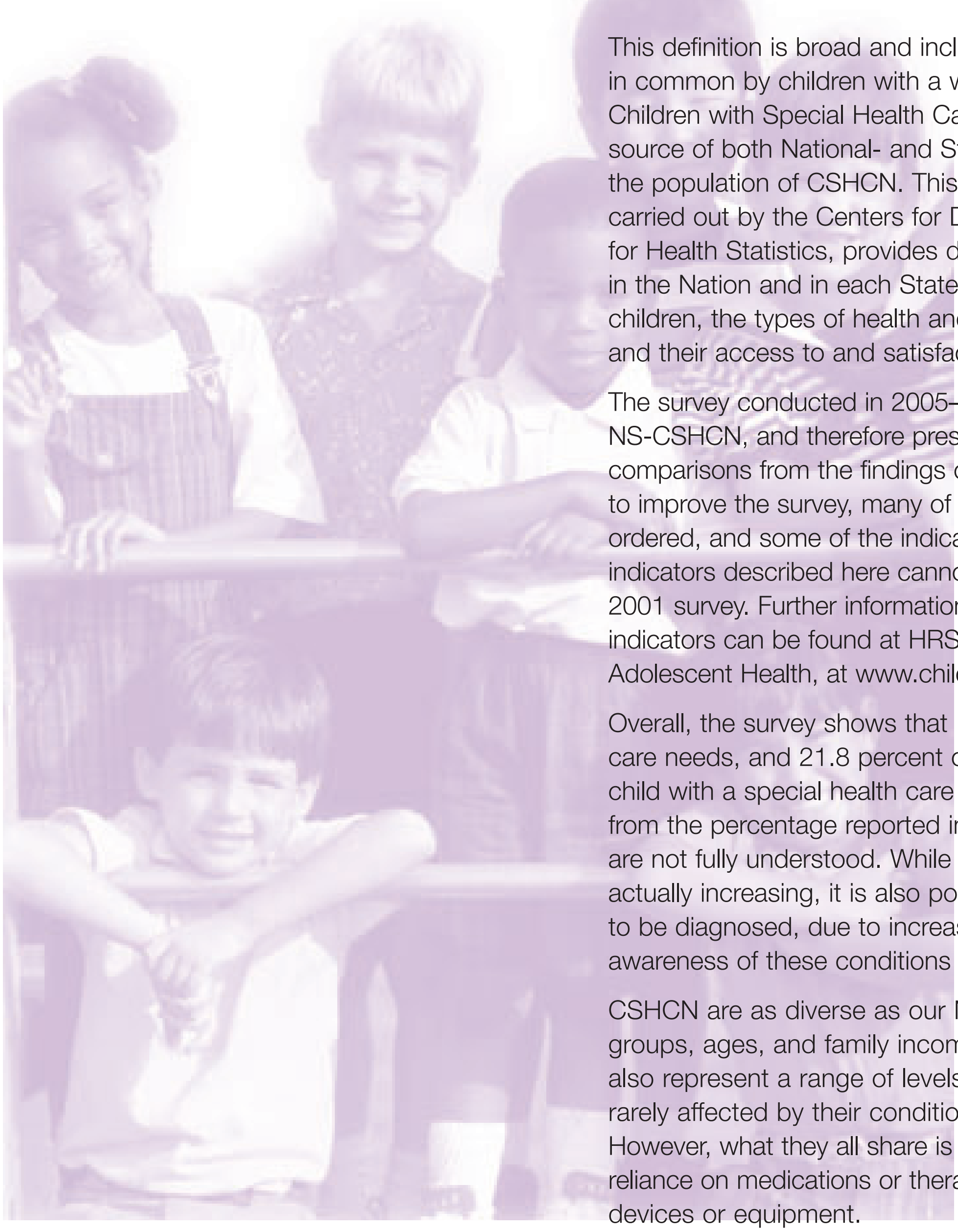
Introduction

Children with special health care needs (CSHCN) are defined by the Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) 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 diagnoses. 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 HRSA's MCHB and carried out by the Centers for Disease Control and Prevention's National Center for Health Statistics, 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 satisfaction with the care they receive.

The survey conducted in 2005–2006 represents the second round of the NS-CSHCN, and therefore presents an opportunity, in some cases, to make comparisons from the findings of the original 2001 survey. However, in an effort to improve the survey, many of the survey's questions were revised or re-ordered, and some of the indicators have been re-defined, so some of the indicators described here cannot be compared directly with the findings of the 2001 survey. Further information about the changes in the survey and the indicators can be found at HRSA's MCHB Data Resource Center for Child and Adolescent Health, at www.childhealthdata.org.

Overall, the survey shows that 13.9 percent of U.S. children have special health care needs, and 21.8 percent of households with children include at least one child with a special health care need. These rates represent a modest increase from the percentage reported in 2001; however, the reasons for this increase are not fully understood. While it is possible that the number of CSHCN is actually increasing, it is also 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.

CSHCN 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 is the consequences of their conditions, such as reliance on medications or therapies, special educational services, or assistive devices or equipment.

Another common characteristic of CSHCN is their need for access to a wide range of medical and support services to maintain their physical health, mental and emotional health, and development. The survey documents the breadth and extent of these needs, including prescription medications (needed by 86 percent of CSHCN), specialty medical care (52 percent), vision care (33 percent), mental health care (25 percent), specialized therapies (23 percent), and medical equipment (11 percent). Most CSHCN receive the services they need. However, 16 percent report at least one unmet need for services; the most commonly mentioned is preventive dental care.

Families of CSHCN often require support as well in coping with the consequences of their children's conditions. Overall, 4.5 percent of families report a need for respite care, 5.7 percent for genetic counseling, and 12 percent need family counseling to help deal with the stresses involved in having a CSHCN. Again, while most families receive the services they need, the parents of 5 percent of CSHCN report at least one unmet support service need.

A variety of factors influence children's access to needed health and support services. One is the availability and adequacy of health insurance coverage. CSHCN are more likely than the population of children as a whole to have insurance; at the time of the survey, only 3.5 percent of CSHCN were uninsured, and 8.8 percent were uninsured at some time over the previous 12 months. However, one-third of insured respondents report that this insurance is not always adequate to meet their children's needs, either because the benefits do not meet their needs, the charges are not reasonable, or they do not have access to the providers they need.

Another indicator of access to care is the presence of a usual source of care that families can turn to when their child is sick, as well as a personal doctor or nurse who knows the child and his or her particular needs. Again, while most CSHCN have a usual source of sick care and a personal doctor or nurse, some do not: 5.7 percent of CSHCN have no regular source of care when they are sick or they rely on an emergency department, and 6.5 percent do not have a personal doctor or nurse.

In addition to being accessible, care for CSHCN must also be family-centered; that is, health care providers must respect the family as the constant in the child's life and family members as the child's primary caretakers. To ensure that care is family-centered, providers must spend enough time with the family; ensure that they have the information they need; listen to the family's concerns; be sensitive to the family's values and customs; and make the parents feel like partners in their children's care. Again, while a majority of families report that their children's care meets all of these criteria, one-third report that it does not.

Another important set of indicators reflects the impact of a CSHCN on the family's time, finances, and employment status. The financial impact of the care of CSHCN can be substantial: the families of nearly one-third of CSHCN report that they spend more than $500 per year on their child's health care. Moreover, the parents of 18 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 cut their work hours to care for their children, as 24 percent of families report that they do.

The final set of indicators presented here includes HRSA'S MCHB six Core Outcomes. These are measures that are used to monitor our progress toward the goal of a comprehensive, family-centered, community-based, coordinated system of care for CSHCN, and the outcomes can be monitored through the questions asked in the NS-CSHCN. This analysis has found that, among children from birth through age 11 (for whom five of the six outcomes apply), 20 percent receive care that meets all five criteria, and for adolescents aged 12–17, for whom all six outcomes are relevant, only 14 percent receive care that meets all six standards.

Taken together, the indicators presented here paint a picture of a system of care for CSHCN that meets the needs of many children and their families. However, much 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. 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; however, the full set of findings for each indicator are available at HRSA's MCHB Data Resource Center for Child and Adolescent Health at 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. Finally, this chartbook concludes with a technical description of the survey methodology.

Prevalence of CSHCN

The U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), 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."[1]

This definition is broad and inclusive, incorporating children and youth with a wide range of conditions and risk factors, and identifies children based on the consequences they experience due to an ongoing health 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 place children at increased risk for special health care needs, the population of children "at increased risk" for chronic conditions has been excluded from this report.

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.

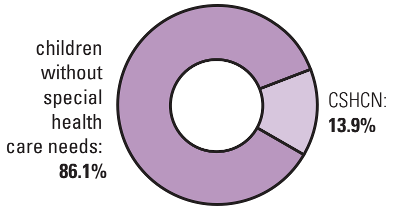
Prevalence of CSHCN: Individuals and Households

One purpose of the NS-CSHCN was to estimate the prevalence of CSHCN in the population nationally and in each State. CSHCN were identified by asking parents if their child used more medical care, mental health services, or educational services than is usual for most children of the same age; if the child used specialized therapies, mental health counseling, or prescription medications; and/or if the child was limited or prevented in any way in his or her ability to do things that most children of the same age can do because of a medical, behavioral, or other health condition that is expected to last at least one year. 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]

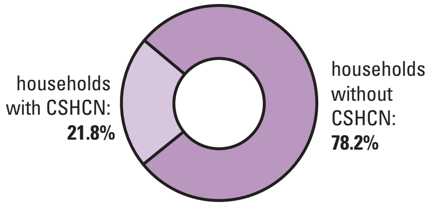
Based on the series of screening questions, 13.9 percent of children under 18 years of age in the United States, or approximately 10.2 million children, are estimated to have special health care needs. Overall, 21.8 percent of U.S. households with children have at least one child with special health care needs.

Each of these figures represents an increase since the last survey in 2001: at that time, 12.8 percent of children were estimated to have special health care needs, and 20.0 percent of households with children had a child with special health care needs. A variety of factors may have contributed to this increase, including increased access to diagnostic services, better recognition of children's conditions on the part of parents and physicians, or a true increase in the prevalence of chronic conditions in the population. More information on this issue can be found at HRSA's MCHB Data Resource Center for Child and Adolescent Health (www.childhealthdata.org).

Prevalence of CSHCN: Individuals



Prevalence of CSHCN: Households*



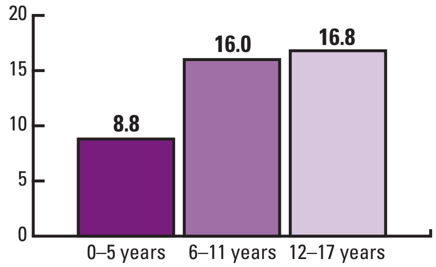
*Includes only households with children.

Prevalence of CSHCN: Age and Sex

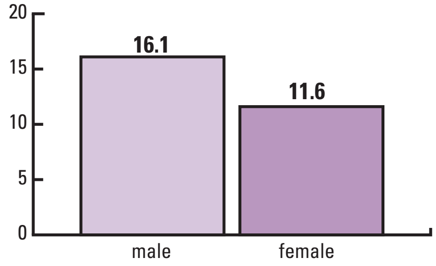
The prevalence of special health care needs within the child population increases with age. Preschool children (from birth through 5 years of age) have the lowest prevalence of special health care needs (8.8 percent), followed by children aged 6–11 years (16.0 percent). Children in the oldest age group (12–17 years) have the highest prevalence of special health care needs (16.8 percent). The higher prevalence among older children is likely 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: 16.1 percent of boys are estimated to have special health care needs compared to 11.6 percent of girls.

Prevalence of CSHCN: Age



Prevalence of CSHCN: Sex



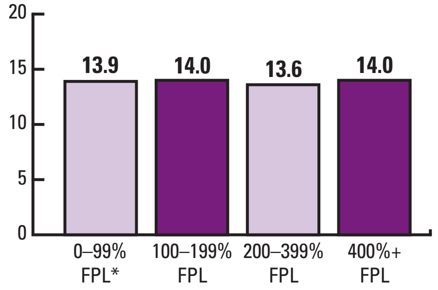
Prevalence of CSHCN: Family Income, Race/Ethnicity, and Primary Language

The prevalence of special health care needs among the child population does not vary significantly by income group: prevalence rates in each income group are approximately 14 percent. Poverty guidelines are determined by a combination of family income and family size: in 2005, the Federal poverty guideline (100 percent of poverty) was $19,350 for a family of four.

The prevalence of special health care needs varies by the race/ethnicity of the child. The prevalence of special health care needs is highest among multiracial children (18.0 percent), followed by non-Hispanic White (15.5 percent), non-Hispanic Black (15.0 percent), American Indian/Alaska Native (14.5 percent) and Native Hawaiian/Pacific Islander children (11.5 percent). The prevalence of special health care needs is lowest among Hispanic children (8.3 percent) and Asian children (6.3 percent).

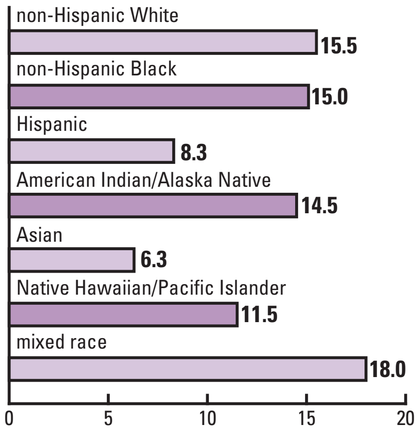
Among Hispanics, the prevalence of special health care needs among children varies substantially depending on whether English or Spanish is the primary language spoken at home. Among Spanish speakers, 4.6 percent of children are reported to have special health care needs, but the prevalence among English-speaking Hispanics more closely resembles that of the population as a whole (13.0 percent). These findings are consistent with other studies of the prevalence of health conditions among Hispanic children.[3,4,5]

Prevalence of CSHCN: Family Income

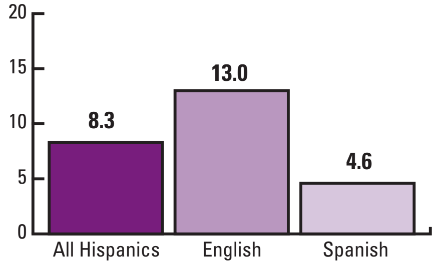


*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as $19,350 for a family of four.

Prevalence of CSHCN: Race/Ethnicity



Prevalence of CSHCN Among Hispanics: Primary Language



Health and Functional Status of CSHCN

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.

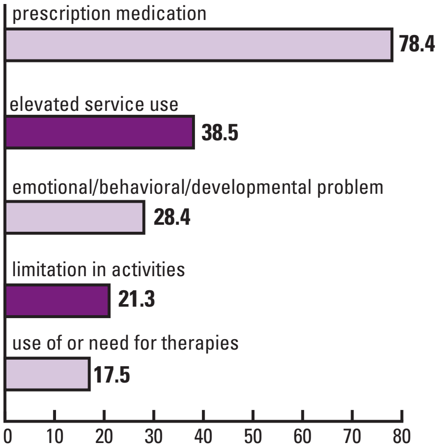
Types of special health care needs are described in three ways. First, we discuss the consequences of children's conditions: that is, the types of services or treatments that children require or the effect of the condition on the child's functional abilities. Next, we group these functional impacts into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

In addition, this section also 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.

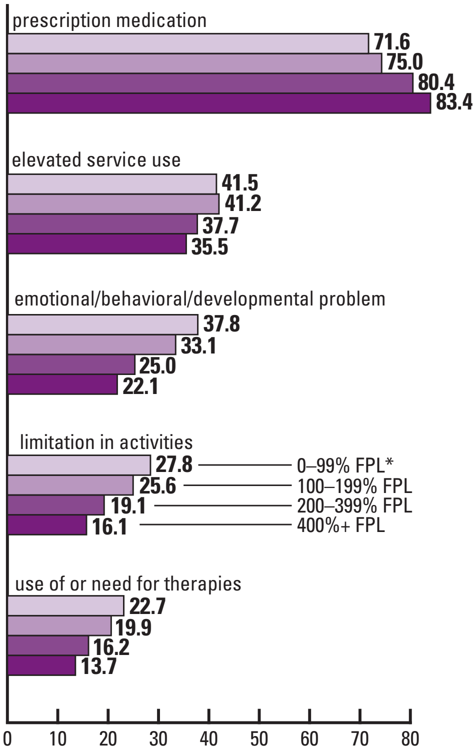
The survey also measured one specific aspect that is important to all children of school age: the number of school days missed due to both chronic and acute conditions during the year.

Consequences of Special Needs

Proportion of CSHCN Experiencing Each Consequence of Special Needs



Type of Special Health Care Need: Family Income



*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as $19,350 for a family of four.

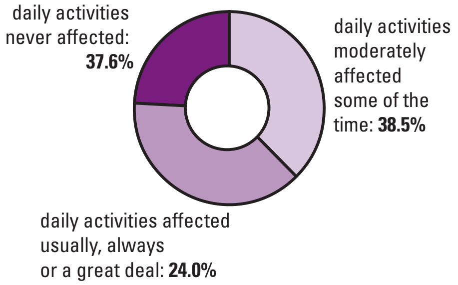
The screening questions used in the survey to identify CSHCN included five major components. In addition to the existence of a condition that has lasted or is expected to last at least 1 year, the respondent must report that the condition had at least one of the following consequences for the child:

- 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, developmental, or behavioral problem that requires treatment or counseling;
- A limitation in the child's ability to do the things most children of the same age do;
- The use of or need for special therapy, such as physical, occupational, or speech therapy.

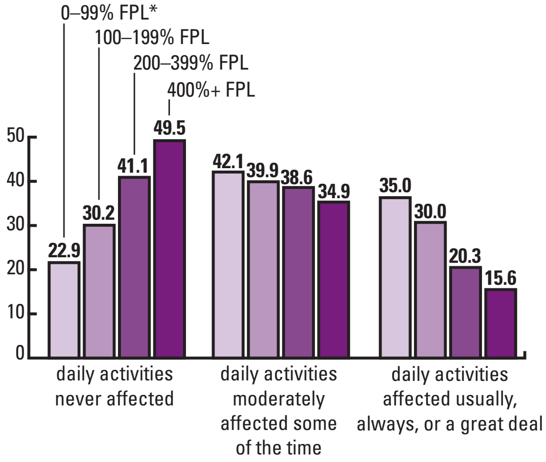
Of these five qualifying criteria, the need for prescription medication is by far the most common, reported for more than three-fourths of CSHCN. The next most frequently reported consequence is the use of or need for extra medical, mental health, or educational services (39 percent of CSHCN), followed by the use of or need for emotional, behavioral, or developmental problems (28 percent), limitation in activities (21 percent), and the use of specialized therapies (18 percent). The percentages do not add to 100 because each child may experience more than one consequence of his or her condition(s).

The proportion of CSHCN experiencing each consequence varies across income levels. While the need for prescription medication is the most common consequence among all income groups, the percentage of CSHCN who currently need or use prescription drugs ranges from 72 percent of CSHCN with family incomes below the poverty level to 83 percent of CSHCN with family incomes of 400 percent of poverty or more. Among CSHCN living in poverty, the parents of 38 percent report an emotional, behavioral, or developmental problem, compared to 22 percent of CSHCN in the highest-income families. The prevalence of limitations in activities also varies by income: the parents of 28 percent of poor children report this consequence, compared to 16 percent of children in high-income families.

Impact of Child's Condition on Functional Ability

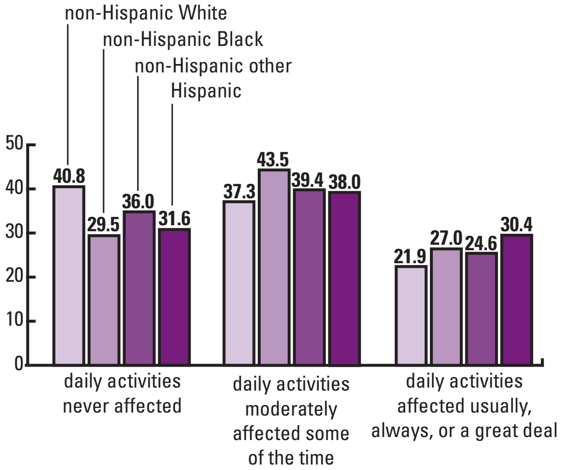


Impact of Child's Condition: Family Income



*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as $19,350 for a family of four.

Impact of Child's Condition: Race/Ethnicity



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, 38 percent of CSHCN are never affected in their ability to do things other children do. This may be attributable to the nature of their health condition or to the treatment they receive to manage their conditions. Another 39 percent are moderately affected some of the time. Nearly one quarter (24 percent) are affected usually, always, or a great deal by their conditions.

The percentage of children who are affected by their conditions usually, always, or a great deal is more than twice as high among children in low-income families as among those in families in the highest income group. Overall, 35 percent of children in poverty are affected usually, always, or a great deal, compared to 16 percent of children in families with incomes of 400 percent of poverty or more.

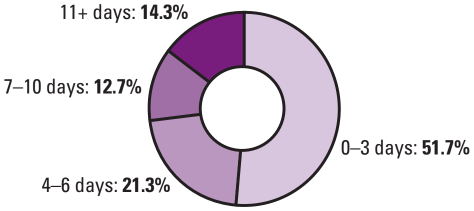
The impact of children's conditions also varies across racial/ethnic groups. Non-Hispanic White children are the most likely to report never being affected by their conditions, and the least likely to be affected usually, always or a great deal. Despite the fact that Hispanic children are less likely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

Missed School Days

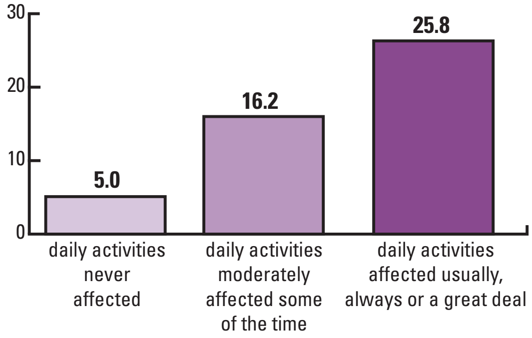
The number of days of school a child misses during the year is another measure of the impact of a child's condition on his or her ability to function as other children do. In general, the average child misses 3 days of school due to acute conditions.[6] In comparison, among school-aged CSHCN, the average is 7 school days (due to both chronic and acute conditions). However, this average is affected by a relatively small group of children who miss many school days: approximately 14 percent of CSHCN miss 11 or more school days, while just over half miss 3 or fewer days.

Children whose conditions have a greater impact on their activities were more likely to miss 11 or more days of school than children whose conditions have a lesser impact. More than one quarter of children whose conditions affect their activities usually, always, or a great deal missed at least 11 school days, compared to 5 percent of children whose daily activities are never affected by their conditions.

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



Percent of CSHCN Who Missed 11 or More Days of School Due to Illness: Impact of Condition on Child's Functional Ability



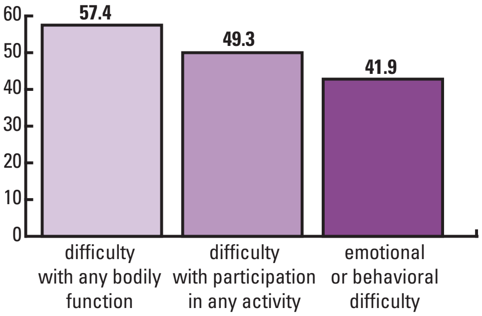
Functional Difficulties

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 57 percent of CSHCN report that their child has difficulty with at least one bodily function (such as eating, dressing, or bathing), and half report that their child has difficulty with participation in activities (such as walking or running). Finally, 42 percent report emotional or behavioral difficulties. A child can have difficulties in more than one area.

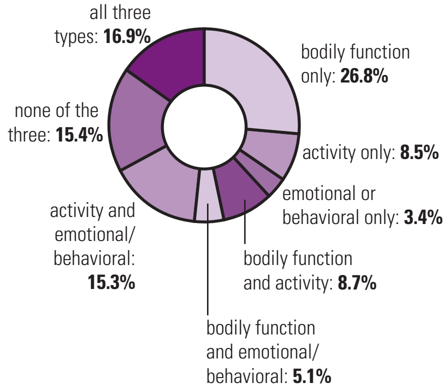
Another way of looking at functional impact is to create mutually exclusive categories (in which each child falls into only one group). Of these categories, the largest is that of children who have difficulty with their bodily functions only, representing 27 percent of CSHCN. The next largest group is children who are reported to have all three kinds of difficulties (17 percent), followed by those who have difficulty with participation in activities and an emotional or behavioral difficulty (approximately 15 percent of CSHCN). Only 3.4 percent of CSHCN are reported to have emotional or behavioral difficulties without any additional difficulties with bodily functions or participation in activities.

It should be noted that 15 percent of CSHCN are reported as not having any of these types of difficulties as a result of their conditions. In 90 percent of these cases, this is attributable to the treatments and therapies that keep their conditions well-managed.

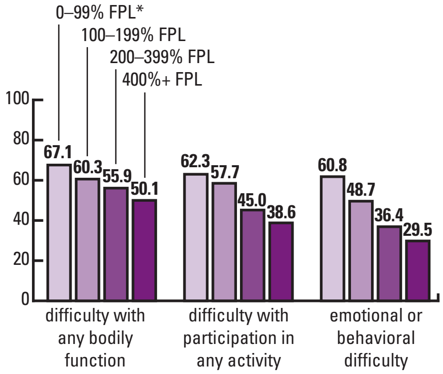
Types of Functional Difficulties Among CSHCN



Distribution of Functional Difficulties Among CSHCN

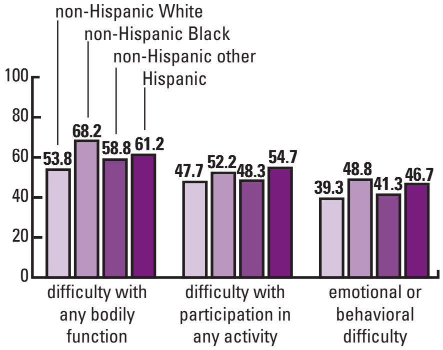


Percent of CSHCN with Each Type of Functional Difficulty: Family Income



*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as $19,350 for a family of four.

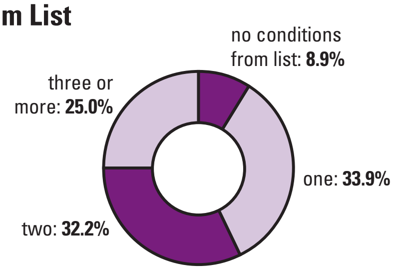
Percent of CSHCN with Each Type of Functional Difficulty: Race/Ethnicity



Children with lower family incomes were more likely to be reported to have each kind of functional difficulty than children with higher family incomes. The difference was most pronounced for emotional or behavioral difficulties: 61 percent of CSHCN in poverty were reported to have difficulties in this area, compared to 30 percent of CSHCN with family incomes of 400 percent of poverty or more.

Non-Hispanic Black and Hispanic children were also more likely than non-Hispanic White and non-Hispanic children of other races to have each type of functional difficulty. Difficulties with bodily functions were most commonly reported among children of all racial and ethnic groups, but the percentage of children who were reported to have these difficulties ranged from 54 percent of non-Hispanic White children to 68 percent of non-Hispanic Black children. There was also a substantial racial/ethnic disparity in the percentage of children reported to have emotional or behavioral difficulties; the proportion ranged from 39 percent of non-Hispanic White children to 49 percent of non-Hispanic Black children.

Number of Conditions Reported From List



Percent of CSHCN with Selected Conditions	
Allergies	53.0%
Asthma	38.8%
Attention deficit disorder/attention deficit hyperactivity disorder	29.8%
Depression, anxiety, or other emotional problems	21.1%
Migraine or frequent headaches	15.1%
Mental retardation	11.4%
Autism or autism spectrum disorder	5.4%
Joint problems	4.3%
Seizure disorder	3.5%
Heart problems	3.5%
Blood problems	2.3%
Cerebral palsy	1.9%
Diabetes	1.6%
Down syndrome	1.0%
Muscular dystrophy	0.3%
Cystic fibrosis	0.3%

Health Conditions

The survey asked parents of CSHCN whether their children had any of a list of 16 conditions. This list did not, of course, include all possible conditions that CSHCN might have. In addition, parents could report that their children had more than one condition, so any given condition listed may or may not be the cause of the child's special health care needs.

Overall, 91 percent of CSHCN were reported to have at least one condition on the list. One in three CSHCN have any two conditions on the list (32 percent) and one in four have three or more conditions (25 percent). Allergies, reported by parents of 53 percent of CSHCN, are the health condition most commonly reported by parents of CSHCN. Other commonly reported conditions are asthma (39 percent), attention deficit disorder (30 percent), and emotional problems (21 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 of children as a whole.

Health Insurance Coverage

Health insurance, whether financed through the public or private sector, is essential for children to access needed care. Without health insurance, children are less likely to receive 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.

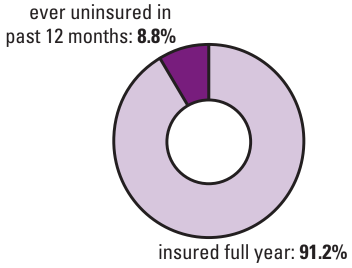
Finally, this section assesses the use of other programs and services, such as special education and early intervention services, that help CSHCN meet their medical and education needs.

Health Insurance Coverage during the Past 12 Months

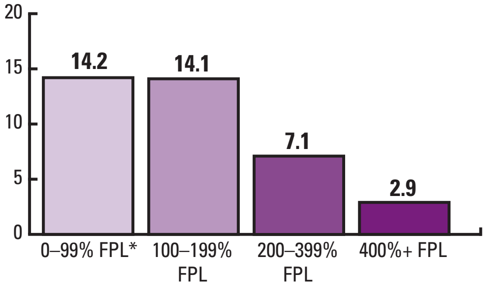
The survey asked parents of CSHCN whether their child had insurance in the past 12 months and what kind of insurance they had. Health insurance was defined as private insurance provided through an employer or union or obtained directly from an insurance company; public insurance, such as Medicaid, the State Children's Health Insurance Program (SCHIP), 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, 91 percent of CSHCN were reported to have been insured for all of the previous 12 months, while the remaining 9 percent were uninsured for all or some part of the year. This represents an increase in insured CSHCN since the last survey in 2001: at that time, nearly 12 percent of CSHCN were reported to have been uninsured at some point during the previous year. This decrease in the percentage of CSHCN who were uninsured was accompanied by an increase in the percentage with public insurance.

Health Insurance Coverage for CSHCN in the Past 12 Months

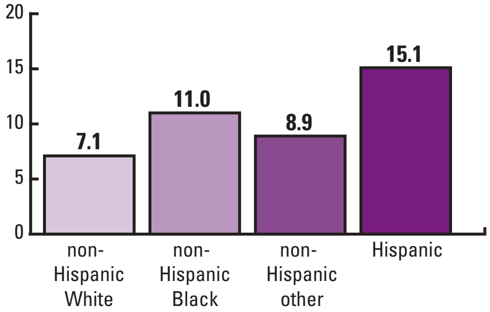


Percent of CSHCN Ever Uninsured in the Past 12 Months: Family Income



*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as $19,350 for a family of four.

Percent of CSHCN Ever Uninsured in the Past 12 Months: Race/Ethnicity



Health insurance coverage among CSHCN varies by income level. CSHCN with family incomes below 100 percent of poverty and CSHCN with family incomes between 100 and 199 percent of poverty are the most likely to have been uninsured at some point during the past year (14 percent of each group). Children with higher family incomes are much less likely to be without insurance: 7.1 percent of CSHCN with family incomes between 200 and 399 percent of poverty were uninsured at some point during the past year, while the same was true of only 2.9 percent of CSHCN with family incomes of 400 percent of poverty or greater.

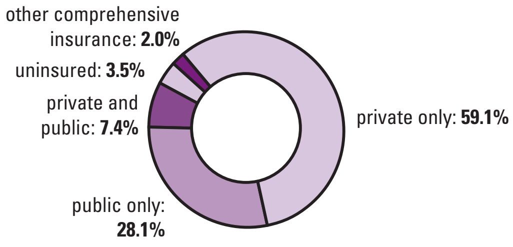
Health insurance coverage among CSHCN also varies by race/ethnicity. Hispanic children were the most likely to have been uninsured at some point during the past year (15 percent), followed by non-Hispanic Black children (11 percent). Non-Hispanic White CSHCN were the least likely to have been uninsured at some point during the year (7 percent). Although uninsured rates declined within each racial/ethnic group since the last survey in 2001, the most notable drop is for Hispanic CSHCN (from 19 to 15 percent).

Type of Health Insurance Coverage

Parents of CSHCN were asked what type of insurance their child had at the time of the interview. Overall, almost 97 percent of CSHCN were reported to have some type of insurance at the time of the interview: 59 percent had private insurance, which includes insurance provided through an employer or union or obtained directly from an insurance company, and 28 percent had public insurance, such as Medicaid, the State Children's Health Insurance Program (SCHIP), military health care (TRICARE, CHAMPUS, or CHAMP-VA). A small percentage (2.0 percent) had another form of comprehensive insurance. Another 7.4 percent of CSHCN had both private and public insurance, and 3.5 percent were uninsured at the time of the interview.

Compared to 2001, a smaller percentage of CSHCN were reported to have private coverage (65 percent in 2001 compared to 59 percent in 2005–2006), and a higher percentage were reported to have public coverage (22 percent in 2001 versus 28 percent in 2005–2006).

Type of Current Insurance Coverage for CSHCN



Adequacy of Current Insurance Coverage

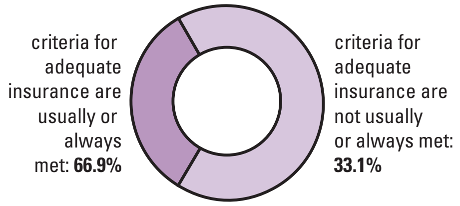
The parents of CSHCN with health insurance were asked three questions about their children's coverage:

- 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?

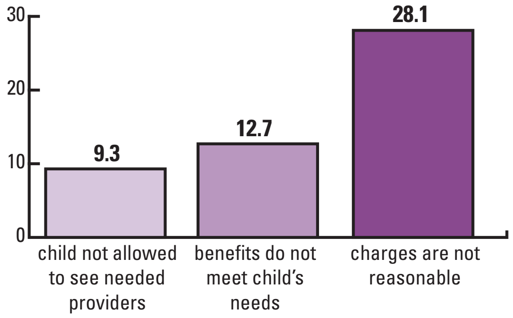
If parents answered "usually" or "always" for all three of these questions, then the child's coverage is considered to be adequate. All others are considered to have inadequate insurance coverage.

Overall, one-third of CSHCN were reported by their parents to have inadequate insurance coverage. Nine percent of CSHCN were reported to have coverage where the child was not allowed to see needed providers, almost 13 percent were reported to have a plan where the benefits do not meet the child's needs, and 28 percent were reported to have a plan with charges that are unreasonable. These figures are not mutually exclusive and the parents of some CSHCN may have reported more than one of these problems with their child's coverage.

Percent of Insured CSHCN with Inadequate Insurance

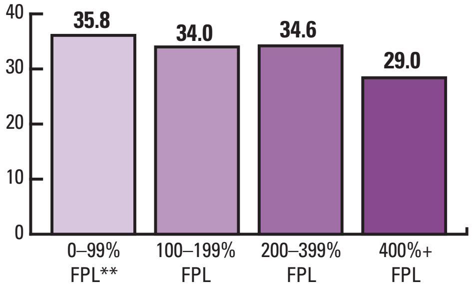


Percent of CSHCN Whose Insurance Does Not Meet Each Criterion for Adequacy*



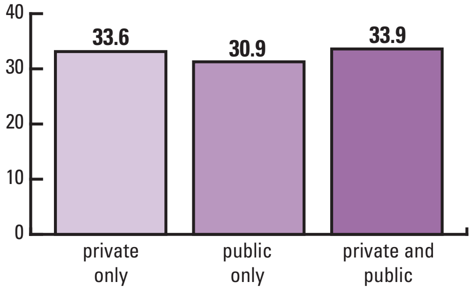
*The criterion is not usually or always met.

Percent of Insured CSHCN with Inadequate Insurance:* Family Income



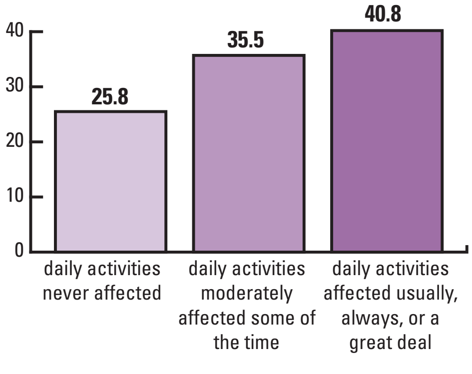
*One or more criteria are not always or usually met: adequate benefits, access to needed providers, and reasonable charges. **Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as $19,350 for a family of four.

Percent of Insured CSHCN with Inadequate Insurance:* Insurance Type



*One or more criteria are not always or usually met: adequate benefits, access to needed providers, and reasonable charges.

Percent of Insured CSHCN with Inadequate Insurance:* Impact of Child's Condition on Functional Ability



*One or more criteria are not always or usually met: adequate benefits, access to needed providers, and reasonable charges.

Adequacy of insurance coverage among CSHCN varies by family income. CSHCN with family incomes below 100 percent of the poverty level are most likely to be reported to have inadequate insurance coverage (36 percent), while the parents of CSHCN with family incomes of 400 percent of poverty or more are least likely to report that their children have inadequate insurance (29 percent).

The perceived adequacy of insurance coverage also varies by type of insurance. Children with public insurance alone are less likely to be reported to have inadequate coverage (31 percent) than children with private insurance alone or in combination with public coverage (34 percent).

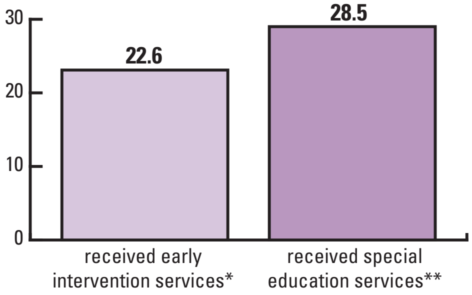
Perceived adequacy of insurance coverage among CSHCN also varies noticeably by the impact of the child's condition. Children who are reported by parents to have a condition that never affects their abilities are the least likely to have inadequate insurance (26 percent), followed by children who are sometimes affected by their condition (36 percent). Children who are affected usually, always, or a great deal by their condition are the most likely to have inadequate insurance; 41 percent of these children are reported to have a plan that does not usually or always meet all of their needs.

Program Participation

In addition to health insurance, a number of public programs are available to provide essential services and supports to eligible CSHCN. One program, the Infants and Toddlers with Disabilities Program funded through the Individuals with Disabilities Education Act (IDEA), commonly known as Early Intervention Services, provides specialized therapies to children under age 3 with developmental delays. These services include counseling, nutrition, occupational and physical therapy, service coordination, speech-language therapy, and transportation, among others. Overall, 23 percent of CSHCN under age 3 received these types of services.

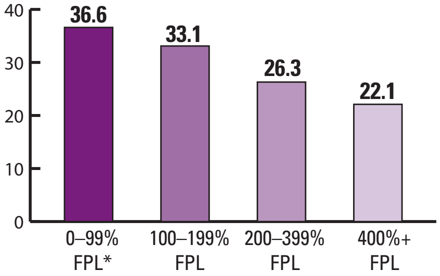
Special education programs provide educational and education-related health care services to children aged 3 years and older. Of CSHCN in this age group, 29 percent received these services. This proportion varies greatly by family income; nearly 37 percent of CSHCN in poverty receive services compared to 22 percent of children with family incomes of 400 percent of poverty or more.

Receipt of Early Intervention and Special Education Services: CSHCN



*Among CSHCN under age 3.
**Among CSHCN 3 years of age and older.

Percent of CSHCN Aged 3 and Older Participating in Special Education: Family Income



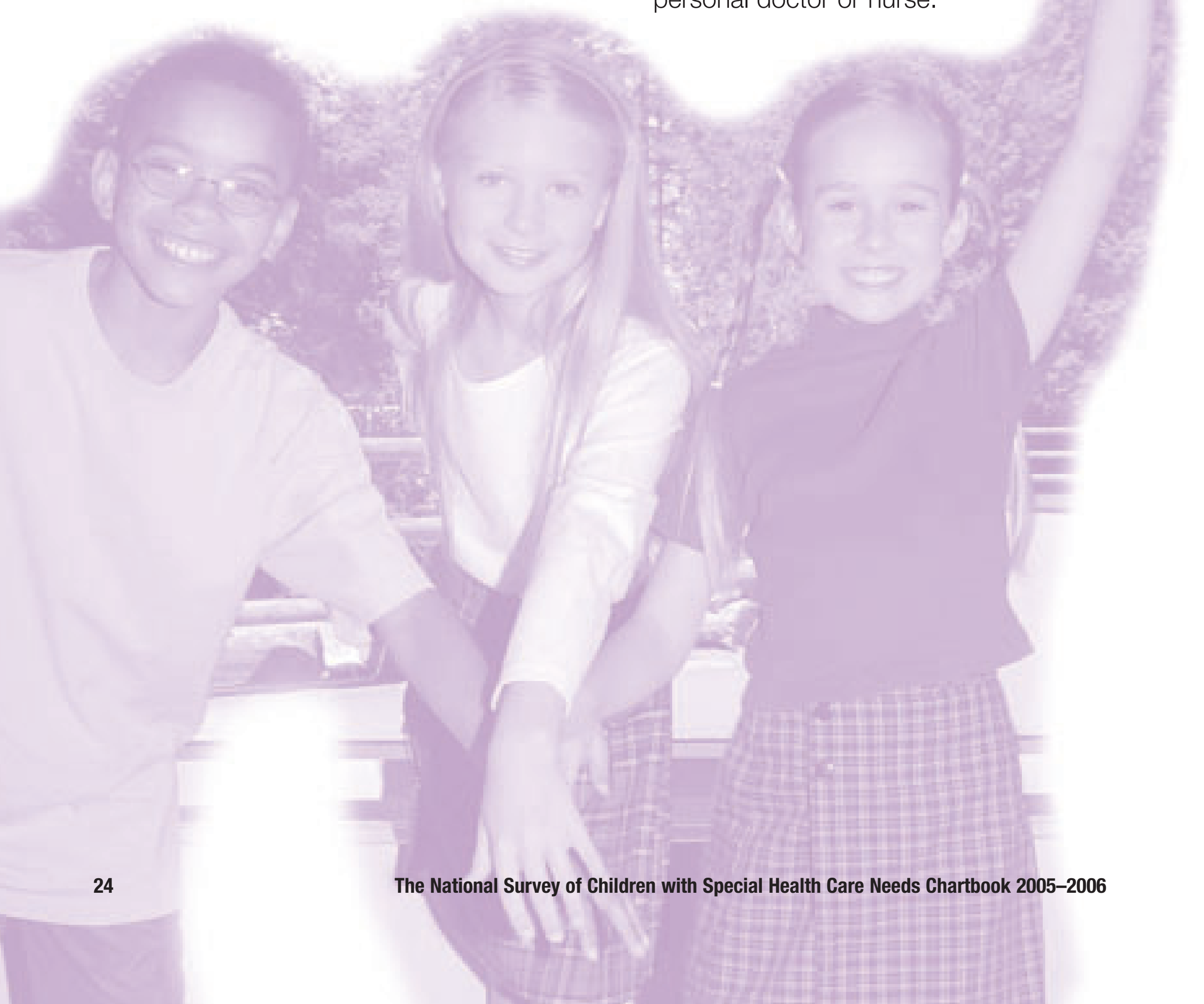
*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as $19,350 for a family of four.

Health Care Needs and Access to Care

CSHCN 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.

This section describes the percentage of CSHCN who need each of a variety of medical and ancillary services, and the percent whose families need each type of support service. In addition, this section presents the percent whose parents report that their children needed the service during the past year but did not receive it.

Other indicators used to assess access to care are described here as well, including the percent of CSHCN who had difficulty receiving referrals for specialty care when needed. In addition, this section includes indicators that describe access to a usual source of care when the child is sick, an important element of primary care for children. These indicators include the percent of CSHCN who have a place that they usually go when they are sick and whether they have a personal doctor or nurse.



Specific Health Care Needs

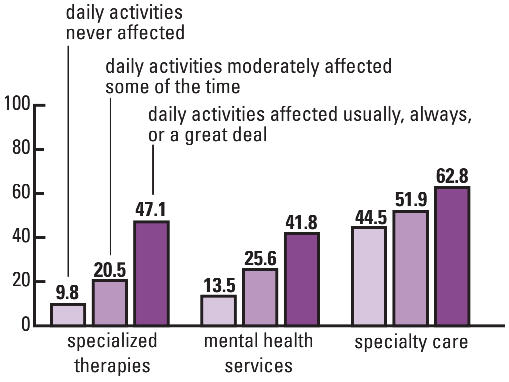
Percent of CSHCN Needing Specific Health Services	
Prescription drugs	**86.4%**
Preventive dental care	**81.1%**
Routine preventive care	**77.9%**
Specialty care	**51.8%**
Eyeglasses/vision care	**33.3%**
Mental health care	**25.0%**
Other dental care	**24.2%**
Physical, occupational, or speech therapy	**22.8%**
Disposable medical supplies	**18.6%**
Durable medical equipment	**11.4%**
Hearing aids/hearing care	**4.7%**
Home health care	**4.5%**
Mobility aids/devices	**4.4%**
Substance abuse treatment	**2.8%**
Communication aids/devices	**2.2%**

Like all children, those with special health care needs require preventive health care and dental services and acute care when they are sick. In addition, CSHCN need a variety of other services to manage their conditions, maintain their abilities, and promote their development. To assess the prevalence of need for specific services, parents were asked whether there was a time in the past year when their children needed any of the services listed in the table to the left.

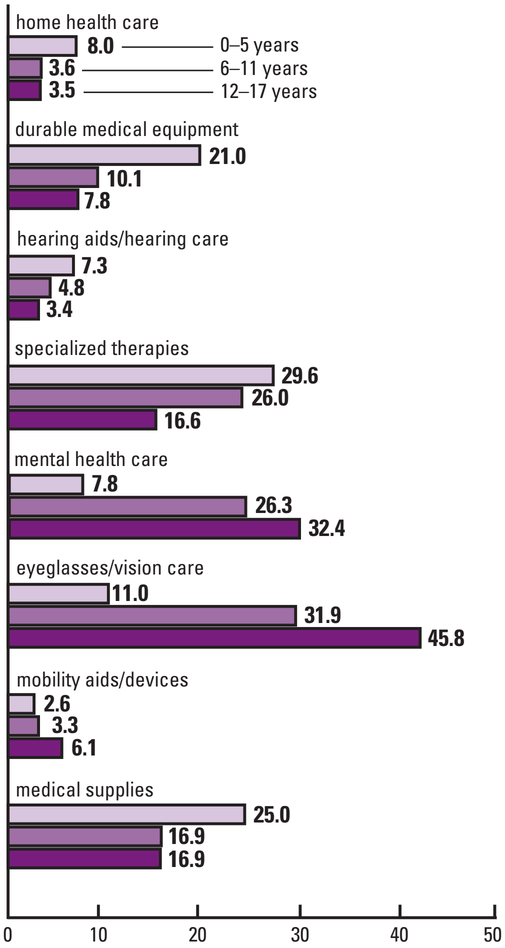
The need most often cited for CSHCN is prescription medication: 86 percent of these children are reported to need prescription drugs. The parents of most CSHCN also recognize their children’s need for preventive dental care (81 percent) and routine preventive medical services (78 percent). Just over half of CSHCN need the care of medical specialists, such as cardiologists or pulmonologists. Other services needed by a smaller proportion of children include eyeglasses or vision care (needed by 33 percent of CSHCN), mental health care (25 percent), dental care other than preventive care (24 percent), and physical, occupational, or speech therapy (23 percent).

Some of the services that are reported infrequently among the population of CSHCN as a whole are much more commonly needed by children whose conditions have a greater impact on their daily lives. Of those children whose conditions affect them usually, always, or a great deal, 47 percent needed specialized therapies such as physical, occupational, or speech therapy, 42 percent needed mental health services, and 63 percent needed specialty medical care.

Percent of CSHCN Needing Specific Health Services: Impact of Child’s Condition on Functional Ability



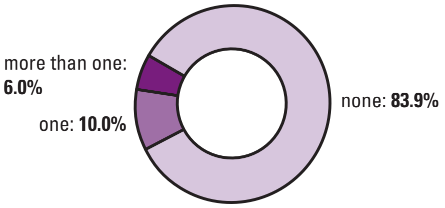
Specific Health Services Needed: Age



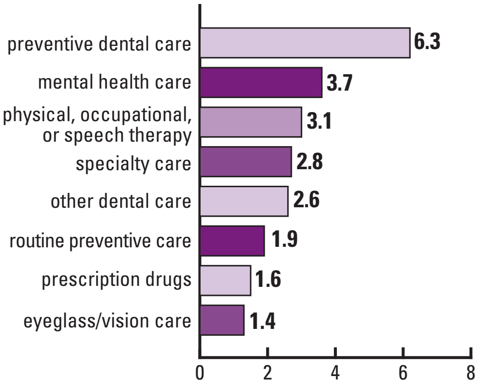
Other needs vary greatly by age. Preschool-aged children (aged 5 years and under) are much more likely than older children to need home health care (8.0 percent, compared to 3.6 percent of school-aged children and adolescents), durable medical equipment (21 percent, compared to 7.8 percent of adolescents), and hearing aids (7.3 percent, compared to 3.4 percent of adolescents). In addition, the need for specialized therapies declines with age: nearly 30 percent of children aged 5 years and under needed these services, compared to 26 percent of children aged 6–11 years and 17 percent of adolescents aged 12–17 years.

Conversely, adolescents (aged 12–17 years) are more likely to need mental health care (32 percent, compared to 7.8 percent of preschoolers), eyeglasses or vision care (46 percent, compared to 11 percent of preschoolers), and mobility aids (6.1 percent, compared to 2.6 percent of preschoolers).

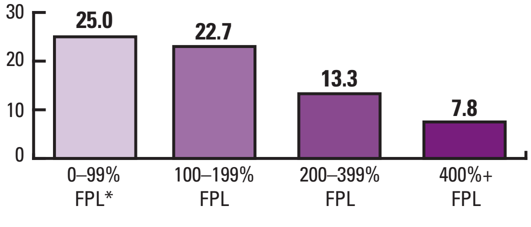
Percent of CSHCN with One or More Reported Health Services Needed but Not Received



Percent of CSHCN with Reported Health Services Needed but Not Received

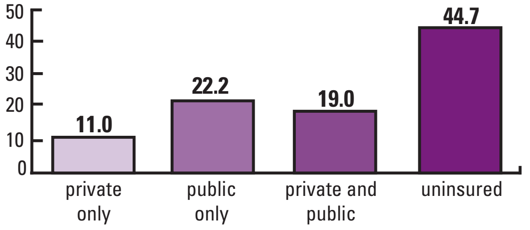


Percent of CSHCN with at Least One Needed Service Not Received: Family Income



*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as $19,350 for a family of four.

Percent of CSHCN with at Least One Needed Service Not Received: Insurance Type



Services Needed but Not Received

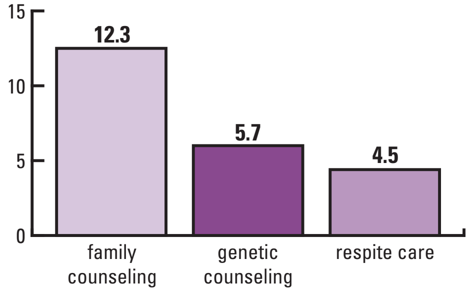
For each service, families were asked if their child received all of the care that he or she needed. Children may not receive services they need for various reasons, including financial barriers, lack of access to providers, and competing demands on families' time.

Overall, 16 percent of CSHCN were reported to need at least one health care service that they did not receive in the past year, and 6 percent needed more than one service that they did not receive. The service most commonly reported as needed but not received was preventive dental care: 6.3 percent of CSHCN overall needed but did not receive preventive dental care. Other relatively common services needed but not received were mental health care (3.7 percent), therapies (3.1 percent), specialty care (2.8 percent), and other dental care (2.6 percent).

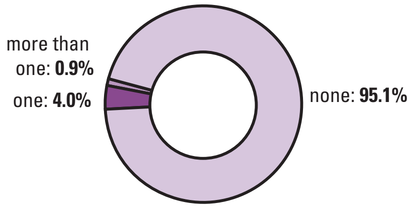
Low-income and uninsured children are the most likely not to receive the services they need. For example, children in poverty are three times as likely as children with family incomes of 400 percent of poverty or more not to receive at least one service they need (25 percent versus 7.8 percent).

Uninsured children are also more likely not to receive all the services they need. Of uninsured children, 45 percent were reported to have at least one service needed but not received, compared to 22 percent of children with public insurance, 19 percent of children with both public and private insurance, and 11 percent of privately-insured children.

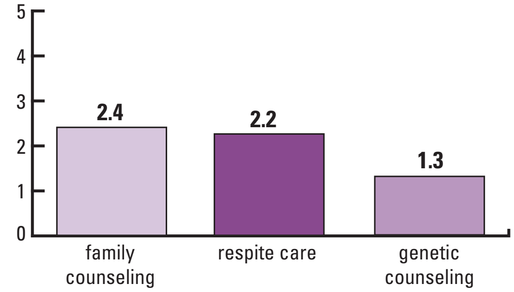
Percent of CSHCN Whose Families Need Support Services



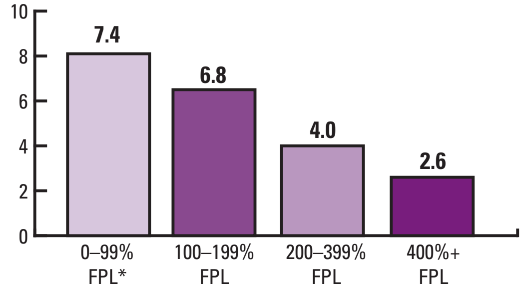
Percent of CSHCN with Needed Family Support Services Not Received



Percent of CSHCN with Needed Family Support Services Not Received



Percent of CSHCN with Needed Family Support Services Not Received: Insurance Type



*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as $19,350 for a family of four.

Need for Family Support Services

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

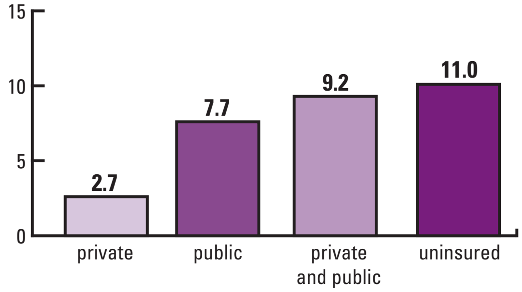
Overall, family counseling is the support service most commonly needed by families of CSHCN, with the families of 12 percent needing this service. Nearly six percent reported needing genetic counseling, and 4.5 percent needed respite care.

Family Support Services Needed but Not Received

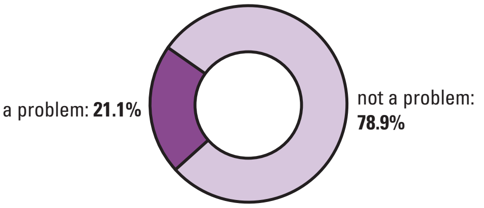
The parents of a total of 4.9 percent of CSHCN reported needing but not receiving family support services. The most common of these is family counseling, needed but not received by the families of 2.4 percent of CSHCN, closely followed by respite care, needed but not received by the families of 2.2 percent. The families of 1.3 percent of CSHCN reported needing but not receiving genetic counseling services.

While these overall proportions are small, families of low-income and uninsured children were most likely to report needing but not receiving family support services. Of CSHCN living in poverty, 7.4 percent reported needing but not receiving at least one family support service, compared to 2.6 percent of children with family incomes of 400 percent of poverty or more.

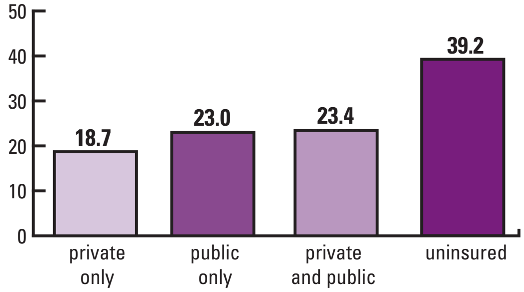
Percent of CSHCN with Reported Family Support Services Needed but Not Received: Insurance Type



Percent of CSHCN Needing Referrals Reporting Problems Obtaining Them



Percent of CSHCN Needing Referrals Reporting Problems Receiving Them: Insurance Type



Similarly, families of uninsured children are more likely to report that they needed but did not receive family support services. The families of 11 percent of uninsured children did not receive needed family support services, compared to 7.7 percent of children with public insurance and 2.7 percent of privately-insured children.

Difficulty Receiving Referrals

As discussed earlier, just over half of CSHCN need care from specialists, which may require referrals from a primary care provider. Parents who reported that their children needed a referral in order to see another doctor or receive services—33 percent of CSHCN—were asked how much of a problem it was over the past 12 months to get such a referral for their children.

Of those who needed a referral, 21 percent reported having a problem receiving this referral. Reported problems obtaining referrals were most common among uninsured children: 39 percent of uninsured children who needed referrals had difficulty receiving them, compared to 23 percent of CSHCN with public insurance and CSHCN with both private and public insurance, and 19 percent of children with private insurance.

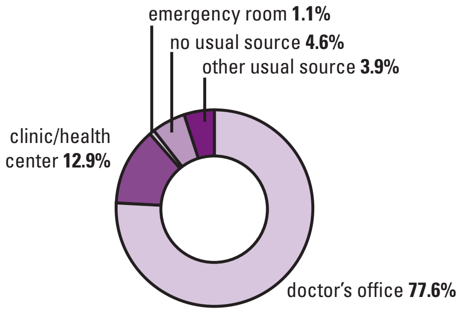
Usual Source of Care When Sick

Another measure of access to appropriate care is whether children have an identified place to go when they are sick. The survey asked 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.

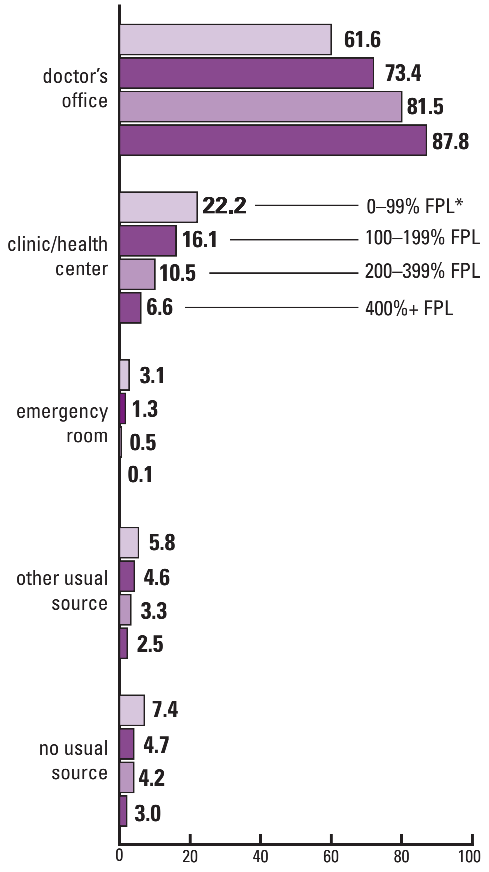
Overall, 94 percent of CSHCN have a usual source of sick care. In the vast majority of cases (78 percent) this is a private doctor's office; for 13 percent of children, it is a clinic or health center; and for 3.9 percent it is another setting. The parents of just 4.6 percent of CSHCN report that their children have no usual source of sick care and an additional 1.1 percent rely on an emergency room.

Children in low-income families are considerably more likely than children in higher-income families to lack a usual source of sick care. Of children with family incomes below the poverty level, 7.4 percent had no usual place to go when they were sick, compared to 3.0 percent of children with family incomes of 400 percent of poverty or more. Children in low-income families are also more likely to use clinics or health centers as their usual source of care (22 percent, compared to 6.6 percent of higher-income children), and less likely to report that they go to a doctor's office when they are sick (62 percent compared to 88 percent).

Usual Source of Sick Care Among CSHCN



Usual Source of Sick Care: Family Income



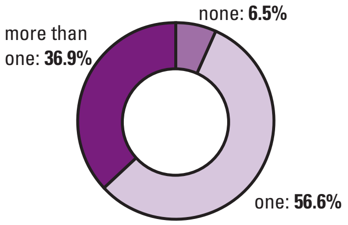
*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as $19,350 for a family of four.

Personal Doctor or Nurse

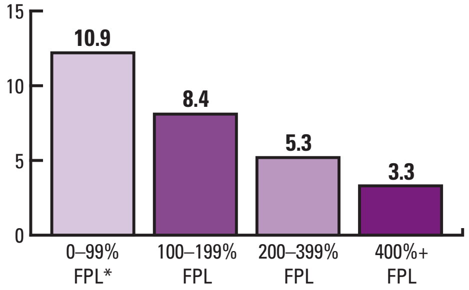
The survey also asked whether children have one or more personal doctors or nurses, defined as the health care provider or providers who know the child best. Because the health conditions and risks faced by CSHCN can be complex, having such a consistent source of care can be especially important.

Overall, 94 percent of CSHCN are reported to have at least one personal doctor or nurse and 6.5 percent do not have any. The proportion of children who lack a personal health care provider is highest among children in low-income families, of whom 11 percent do not have such a provider. Among children with family incomes of 400 percent of poverty or more, 3.3 percent lack a personal doctor or nurse.

Percent of CSHCN with a Personal Doctor or Nurse



Percent of CSHCN Without a Personal Doctor or Nurse: Family Income



*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as $19,350 for a family of four.

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.”[7] While care coordination plays an important role in the care received by CSHCN, not all families who need this coordination receive it. To measure the proportion of CSHCN receiving care coordination, the survey asked parents about their satisfaction with the communication among the child’s doctors and between the child’s doctor and other providers, and about how often care coordination was available, if needed.

This section describes the proportion of children who are receiving needed care coordination.

Receipt of Coordinated Care

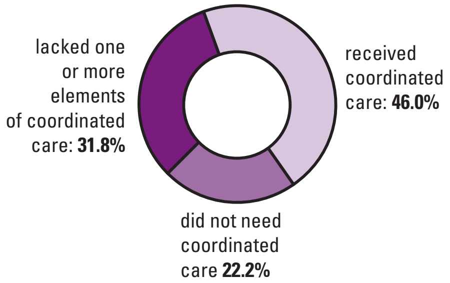
The survey asked several questions to determine whether CSHCN were receiving coordinated care:

- How satisfied are you with the communication among your child's doctors and other health care providers, if needed?
- How satisfied are you with communication between your child's health care providers and his/her school, early intervention program, child care providers, or vocational education or rehabilitation program, if needed?
- How often do you get as much help as you want with arranging or coordinating care, if needed?

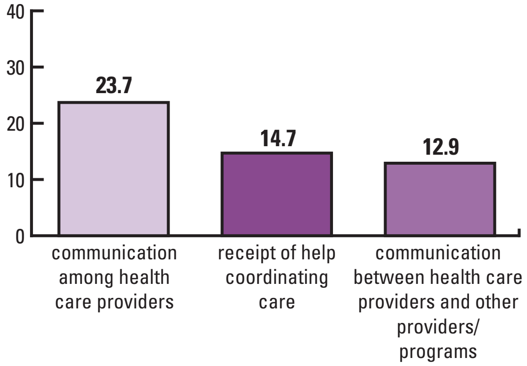
For a child to qualify as receiving coordinated care, the parent had to report usually receiving help when needed and being "very satisfied" with communication among providers (when needed) and communication between providers and other programs (when needed). Overall, 46 percent of CSHCN received coordinated care by this definition.

Of the three individual elements of care coordination, the one that was least often met was communication among health care providers: the parents of 24 percent of CSHCN reported not being very satisfied. The parents of 15 percent of CSHCN reported that they did not usually receive help when needed, while the parents of 13 percent of CSHCN reported that they were not very satisfied with communication between health care providers and other programs.

Receipt of Coordinated Care: CSHCN



Percent of CSHCN Whose Care Did Not Meet Individual Care Coordination Components*

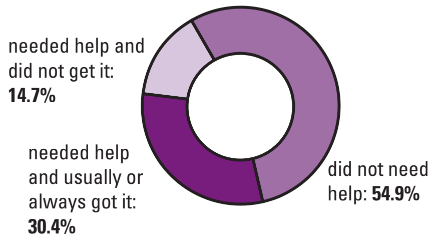


*Parents reported they were not "very satisfied" with communications components (when such communication was needed) or did not usually get help when needed.

Need for Care Coordination

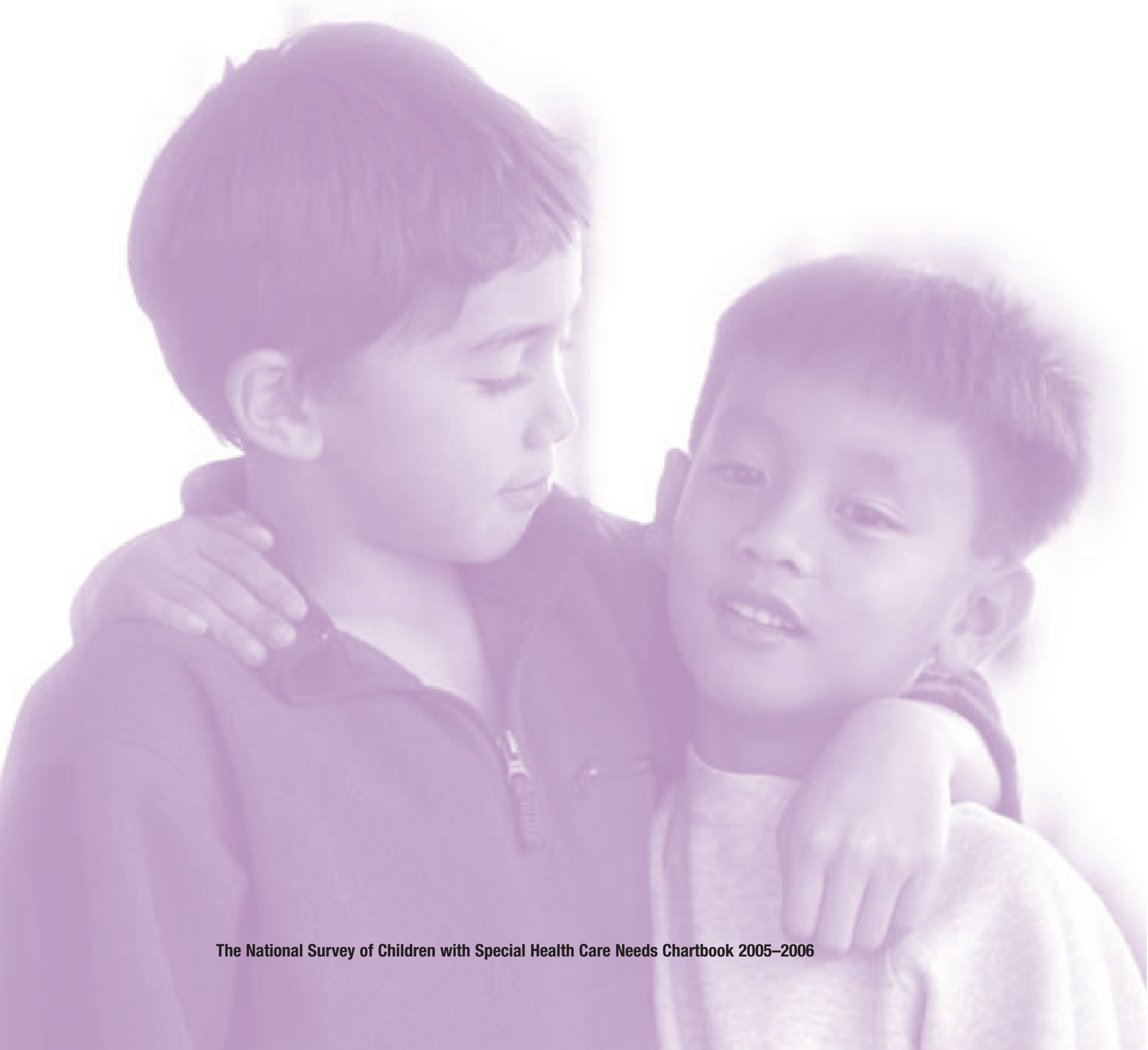
Some families who need help with coordination of their children's care have difficulty obtaining access to care coordination services. Overall, the parents of 55 percent of CSHCN did not report that they needed help with care coordination, either because their children only saw one provider or because the parents coordinated their care themselves. The parents of 30 percent reported that they needed help and usually received it. The parents of the remaining 15 percent reported that they needed help and did not receive it.

Need for and Receipt of Help Arranging or Coordinating Care



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 child, 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. In addition, for families who needed an interpreter to help them speak to the child's doctors, the survey asked how often they were able to get this service.



Receipt of Family-Centered Care

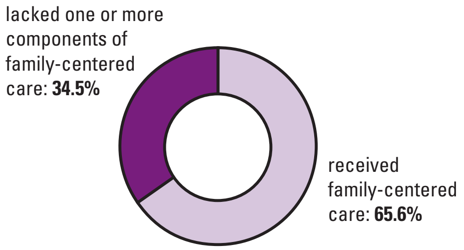
The survey asked several questions to determine whether CSHCN were receiving family-centered care:

- How often did your child's doctors and other health care providers spend enough time with him/her?
- How often did you get the specific information you needed from your child's doctors and other health care providers?
- How often did your child's doctors or other health care providers help you feel like a partner in his/her care?
- When your child is seen by doctors or other health care providers, how often are they sensitive to your family's values and customs?
- How often did your child's doctors and other health care providers listen carefully to you?
- How often were you able to get someone other than a family member to help you speak with your child's doctors or other health care providers when an interpreter was needed?

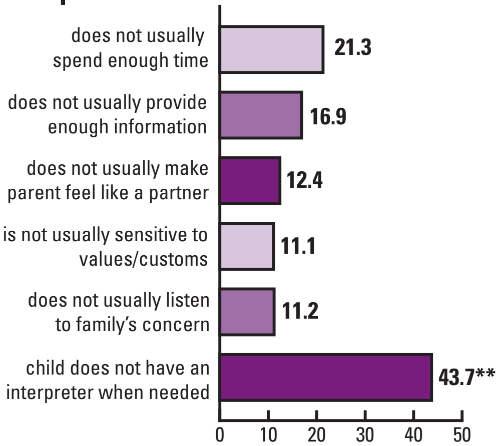
For a child's care to qualify as family-centered, the parent needed to answer "usually or always" to each of the above elements. (If the child did not need interpreter services, that component was excluded.) Overall, 35 percent of CSHCN received care that lacked one or more of the essential components of family-centered care.

Among the general population of CSHCN, the most commonly lacking component of family-centered care was the doctor usually or always spending enough time with the child: the parents of 21 percent of CSHCN reported that their child's care did not meet this criterion. The parents of 17 percent of CSHCN reported that their doctor did not usually or always provide enough information, and the parents of 12 percent reported that the doctor did not usually or always make the parent feel like a partner. Among children who needed interpreter services, 44 percent did not usually or always get the services they needed.

Receipt of Family-Centered Care: CSHCN

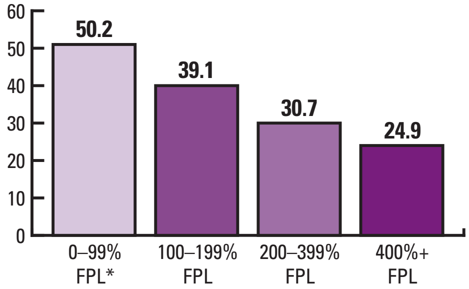


Percent of CSHCN Who Did Not Receive Family-Centered Care: Individual Component*



*Parents reported that care did not "usually or always" meet this criterion.
**Among children who needed interpreter services.

Percent of CSHCN Lacking One or More Components of Family-Centered Care: Family Income

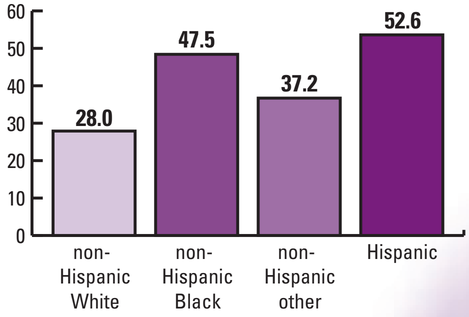


*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as $19,350 for a family of four.

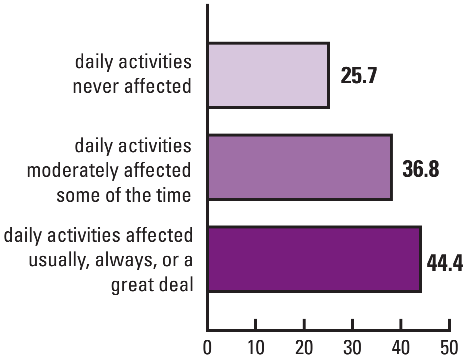
Receipt of family-centered care varies by family income, with those in the lower income groups being more likely to receive care that is not considered family-centered. Of CSHCN with family incomes below 100 percent of the poverty level, 50 percent did not receive family-centered care, according to their parents, followed by children with family incomes between 100 and 199 percent of poverty (39 percent). Children with family incomes of 400 percent of the poverty level or higher were most likely to receive family-centered care.

Race/ethnicity is also a factor in children's receipt of family-centered care: Hispanic children were the most likely to receive care that was lacking one or more components of family-centered care, according to their parents (53 percent), followed by the parents of non-Hispanic Black children (48 percent). Non-Hispanic White children were the most likely to receive family-centered care, based on their parents' reports.

Percent of CSHCN Lacking One or More Components of Family-Centered Care: Race/Ethnicity



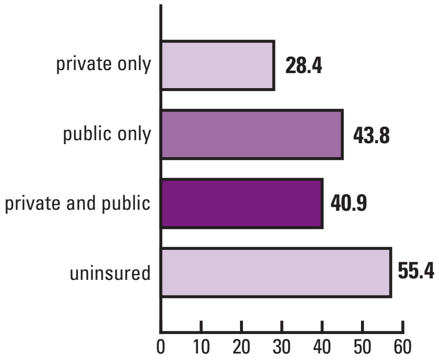
Percent of CSHCN Lacking One or More Components of Family-Centered Care: Impact of Child's Condition on Functional Ability



Receipt of family-centered care varies based on the impact of the child's condition on his or her abilities. Among children whose daily activities are never affected by their conditions, 26 percent received care that was not family-centered, compared to 37 percent of those who are sometimes affected by their condition. Children who are usually/always affected or are affected a great deal are most likely to receive care that is not family-centered (44 percent).

Insurance type also appears to have an impact on receipt of family-centered care. Children who are uninsured are the most likely to receive care that is not family-centered (55 percent), followed by children with only public insurance (44 percent). Children with only private insurance are the most likely to receive family-centered care.

Percent of CSHCN Lacking One or More Components of Family-Centered Care: Insurance Type



Impact on Families

Having a CSHCN 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 CSHCN 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, another measure of the economic impact of having a CSHCN.

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.

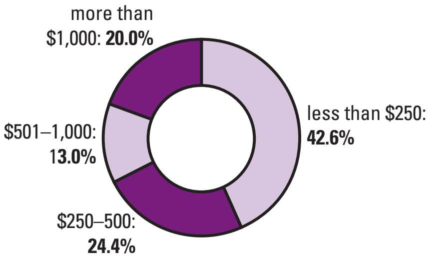
Finally, parents were asked whether their children's needs had required them to cut down on work or stop working altogether to care for their child—requiring both the parent's time as well as a financial sacrifice.

Out-of-Pocket Expenditures

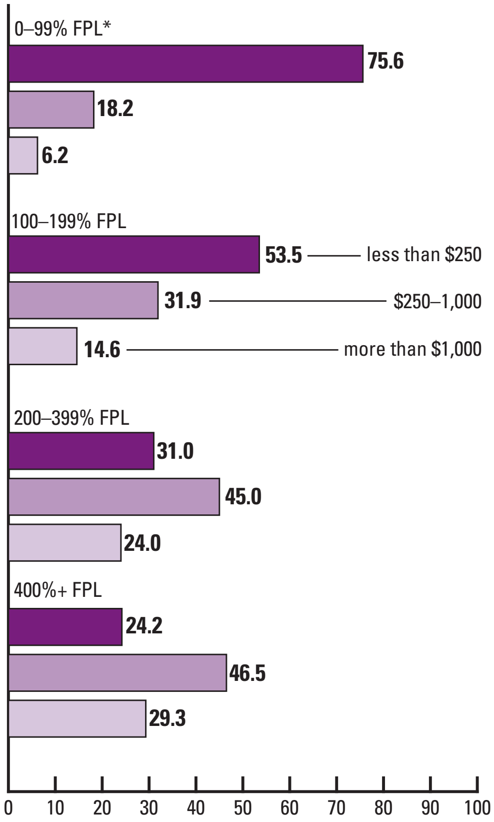
Families are often required to pay out of their pockets for health care services not fully covered by their insurance plans. These services may include therapies, home health care, prescription drugs, mental health care, medical equipment, and dental services. Families of over half of CSHCN reported spending $250 or more on health care in the previous year for the care of their CSHCN. The families of 13 percent of CSHCN spent between $501 and $1,000, and the families of 20 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: the families of only 6.2 percent of children in poverty paid more than $1,000 out of pocket for their children's care, compared to the families of 29 percent of CSHCN with incomes of 400 percent of poverty level or more. This could be because children in low-income families are more likely to be covered by Medicaid and State Children's Health Insurance Program (SCHIP), which limit the copays 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 Care of CSHCN

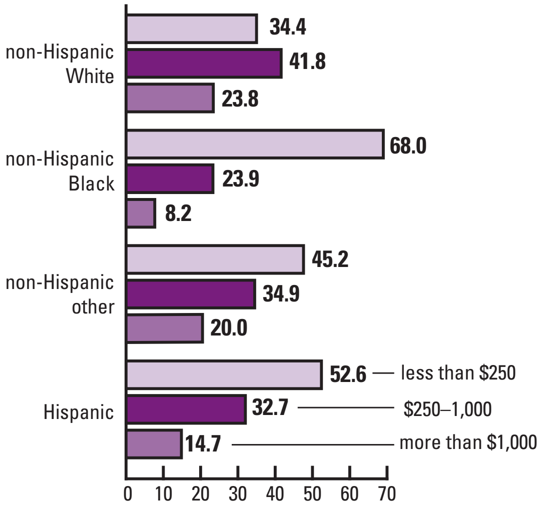


Annual Out-of-Pocket Expenditures for Care of CSHCN: Family Income



*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as $19,350 for a family of four.

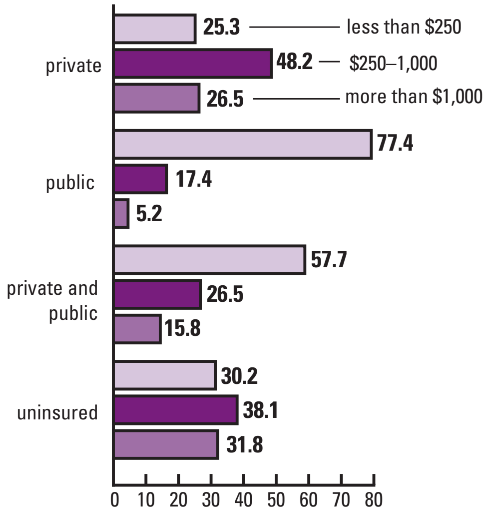
Annual Out-of-Pocket Expenditures for CSHCN: Race/Ethnicity



The families of non-Hispanic White children are the most likely to pay more than $1,000 in health care expenses; 24 percent did so, compared to the families of 15 percent of Hispanic children and 8 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-two percent of uninsured children's families pay more than $1,000 annually, compared to 27 percent of those with only private coverage and 5 percent of those with only public insurance. Similarly, 77 percent of children with only public coverage live in families that pay less than $250 per year out of pocket for their child's health care, compared to 25 percent of those with only private insurance and 30 percent of uninsured children. This may be due to the limits on copayments within public insurance programs, because publicly-insured and uninsured families are not able to pay bills they receive, or because these families do not seek care if they cannot pay the required copayments.

Annual Out-of-Pocket Expenditures for CSHCN: Insurance Type



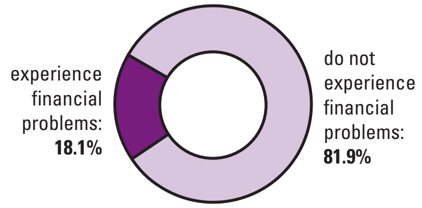
Financial Burden

To further assess the financial impact of a child's condition on his or her family, the survey asked whether the child's condition had caused a financial problem. It was reported that over 18 percent of CSHCN have conditions that create financial problems for their families.

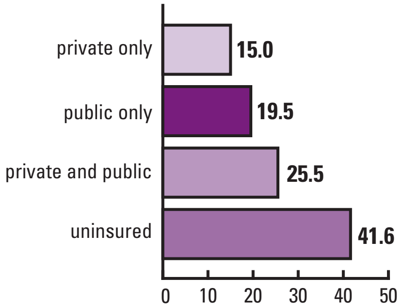
The financial burden appears to be greatest for the families of CSHCN who are uninsured. Nearly 42 percent of uninsured CSHCN live in families that reported a financial problem, compared to 20 percent of those with only public coverage and 15 percent of those with only private insurance.

Families of children whose conditions affect their abilities usually, always, or a great deal are also the most likely to report experiencing financial problems. One-third of children whose conditions usually or always affect their abilities live in families who report experiencing financial problems, compared to only 7.5 percent of children whose conditions never affect their abilities.

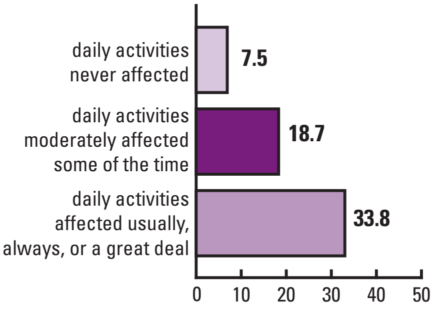
Percent of CSHCN Whose Families Experience Financial Problems Due to Child's Condition



Percent of CSHCN Whose Families Experience Financial Problems : Insurance Type



Percent of CSHCN Whose Families Experience Financial Problems: Impact of Child's Condition on Functional Ability



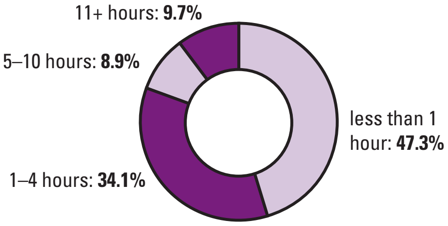
Time Spent Providing Care

Many families devote substantial amounts of time to their children's health care. They may 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 47 percent of CSHCN spend less than an hour a week on these activities, the families of 34 percent devote 1 to 4 hours a week to these tasks, and the families of 10 percent spend 11 hours a week or more.

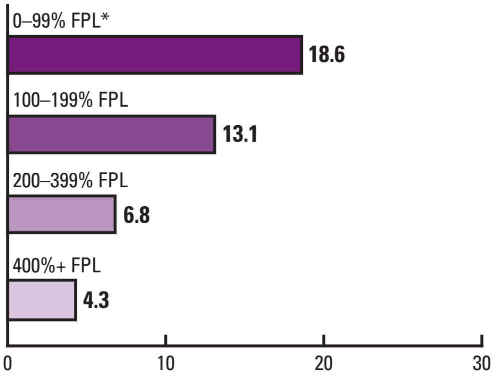
The self-reported time burden is greatest on low-income families. The families of nearly 19 percent of poor children spend at least 11 hours per week providing, arranging, or coordinating their children's health care, compared to the families of 4.3 percent of children with family incomes of 400 percent 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 24 percent of children whose activities are affected usually, always, or a great deal by their conditions spend 11 hours or more providing, arranging, or coordinating their care, compared to the families of only 3.2 percent of children whose daily activities are never affected by their conditions.

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

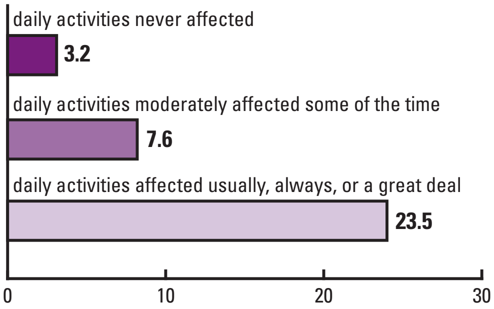


Percent of CSHCN Whose Families Spend 11 Hours or More Per Week Providing, Arranging, or Coordinating Care: Family Income



*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as $19,350 for a family of four.

Percent of CSHCN Whose Families Spend 11 Hours or More Per Week Providing, Arranging, or Coordinating Care: Impact of Child's Condition on Functional Ability



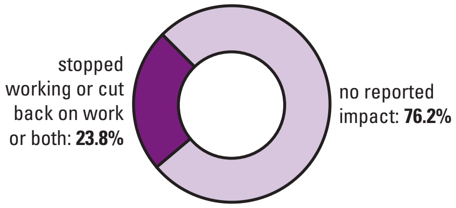
Impact on Employment

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. Overall, the parents of nearly 24 percent of CSHCN report having to stop work or cut back on their hours at work, or both, because of their children's needs.

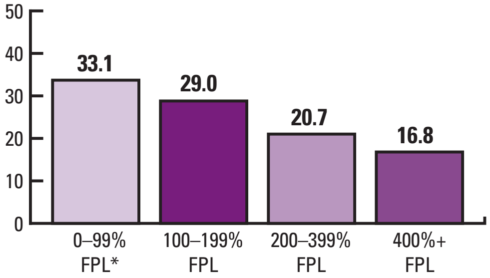
Of course, giving up a job is likely to reduce a family's income. Therefore, it is not surprising that children in lower-income families are more likely to have parents who have sacrificed work hours: one-third of CSHCN in poverty and 29 percent of those with family incomes between 100 and 199 percent of poverty have parents who reported that they cut back on work or stopped working to care for their children, compared to 17 percent of children with family incomes of 400 percent of poverty or more.

A change in employment status is also more apt to occur in families who have a child who is more severely affected by his or her condition. The parents of 47 percent of children whose activities are affected usually, always, or a great deal by their conditions report cutting back on work or stopping work completely to care for their children, compared to 9.1 percent of children whose daily activities are never affected by their conditions.

Impact of Child's Condition on Parent's Employment

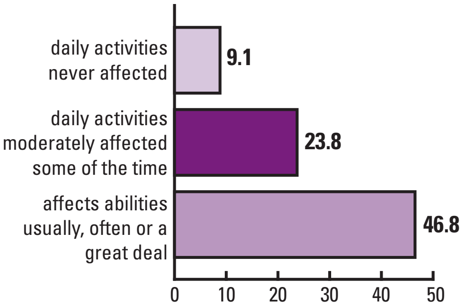


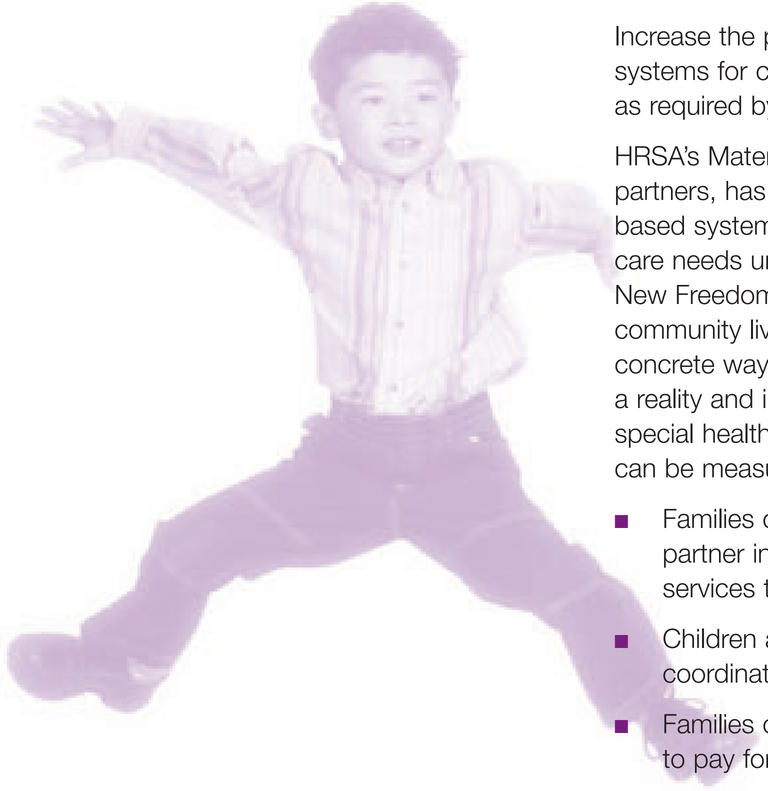
Percent of CSHCN Whose Parents Cut Back on Work or Stopped Working to Care for the Child: Family Income



*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as $19,350 for a family of four.

Percent of CSHCN Whose Parents Cut Back on Work or Stopped Working to Care for the Child: Impact of Child's Condition on Child's Functional Ability





Core Outcomes: Key Measures of Performance

Since 1989, the goal of the State Title V programs for CSHCN has been to provide and promote family-centered, community-based, coordinated care for CSHCN and to facilitate the development of community-based systems of services for such children and their families. A long-term national goal was articulated in Healthy People 2000: National Health Promotion and Disease Prevention Objectives (also included in the 2010 edition) 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.

HRSA's Maternal and Child Health Bureau (MCHB), together with its partners, has identified six core outcomes to promote the community-based system of services mandated for all children with special health care needs under Title V, Healthy People 2010, and the President's New Freedom Initiative (NFI) designed to break down barriers to community living for people with disabilities. 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 and youth with special health care needs partner in decision making at all levels and are satisfied with the services they receive;
- Children and youth with special health care needs receive coordinated ongoing comprehensive care within a medical home;
- Families of CSHCN have adequate private and/or public insurance to pay for the services they need;
- Children are screened early and continuously for special health care needs;
- Community-based services for children and youth with special health care needs are organized so families can use them easily;
- Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

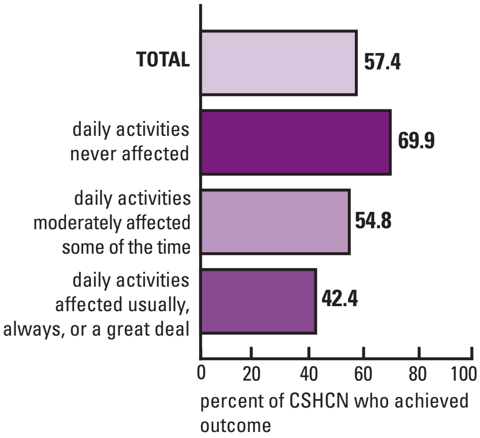
Families of CSHCN partner in decision-making at all levels and are satisfied with the services they receive.

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 professionals 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 decision-making as they mature.

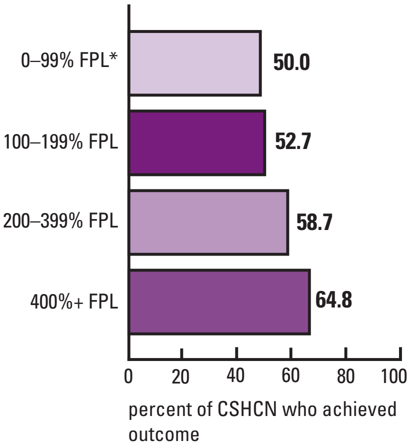
This outcome was evaluated using two questions from the NS-CSHCN: whether the doctor makes the parent feel like a partner in the child's care, and the parent's level of satisfaction with the child's health services. Children whose parents reported that they usually or always feel like a partner and that they are very satisfied with care were considered to meet the overall criterion. This outcome was achieved by 57.4 percent of CSHCN.

The greater the impact of the child's condition on his or her functional ability, the less likely he or she is to have care that meets this criterion: 42 percent of children who are consistently or greatly affected by their conditions achieved this outcome, compared to 70 percent of children whose daily activities are never affected. Children in higher-income families were also more likely to receive family-centered care: nearly two-thirds of children with family incomes of 400 percent of poverty or more achieved this outcome, compared to 50 percent of children in poverty.

CSHCN Whose Families Partner in Decision-Making at All Levels and Are Satisfied with the Services They Receive: Impact of Condition on Functional Ability



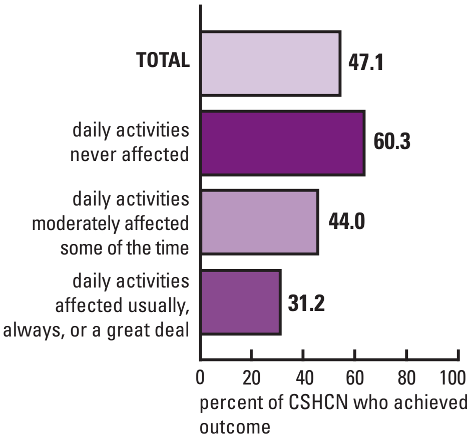
CSHCN Whose Families Partner in Decision-Making at All Levels and Are Satisfied with the Services They Receive: Family Income



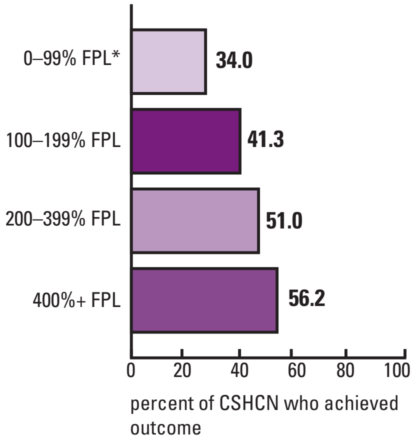
*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as $19,350 for a family of four.

CSHCN receive coordinated, ongoing, comprehensive care within a medical home.

CSHCN Who Receive Coordinated, Ongoing, Comprehensive Care Within a Medical Home: Impact of Condition on Functional Ability



CSHCN Who Receive Coordinated, Ongoing, Comprehensive Care Within a Medical Home: Family Income



*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as $19,350 for a family of four.

Simply put, a medical home means a source of ongoing, comprehensive, coordinated, family-centered care in the child's community. Child health care professionals and families agree that medical homes provide important and unique 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 patient and family counseling 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, it must be supported to provide care coordination services so that each family and all the 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 formulate a clear articulation of each other's role is a key component of the medical home concept.

Equally key is the partnership between the primary care professional and the broad range of other community providers and programs serving CSHCN and their families. The medical home concept includes a responsibility for primary care professionals to become knowledgeable about all the community services and organizations families can access.

This outcome 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 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; whether the parent feels like a partner in the child's care; and whether the family receives interpretation services when needed. All of these criteria were met by 47.1 percent of CSHCN.

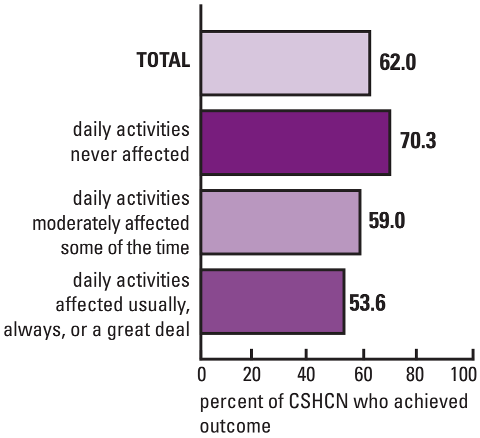
Children whose conditions affected their functional ability usually, always, or a great deal were less likely to receive care through a medical home (31 percent, compared to 60 percent of children whose activities were never affected by their conditions). Children in higher-income families were also more likely to have medical homes: 56 percent of children with family incomes of 400 percent of poverty or more achieved this outcome, compared to 34 percent of children in poverty.

Families of CSHCN have adequate private and/or public insurance to pay for the services they need.

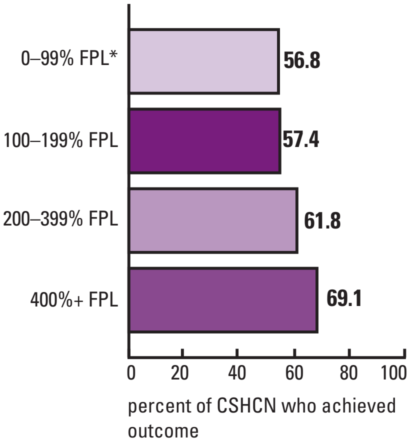
Health insurance coverage plays a critical role in ensuring access to family-centered care for CSHCN. For children, gaps in health care financing may mean that health care is delayed or that services are not delivered. Uninsured and underinsured children are less likely to receive care in a medical home that addresses their comprehensive needs. The availability of private or public insurance is strongly associated with the ability to obtain community-based services such as medical care, dental care, mental health services, medical equipment, supplies and prescriptions. Although Medicaid and the State Children's Health Insurance Program (SCHIP) have made a significant contribution to decreasing the number of uninsured children, the problem of underinsurance persists.

Adequacy of insurance was assessed using three questions: whether or not health insurance benefits met the child's needs, whether non-covered charges were reasonable, and whether the plan allows the child to see the providers he or she needs. In addition, children without any insurance at the time of the survey or at any time in the past year were considered not to have adequate insurance. Overall, this outcome was achieved by 62.0 percent of CSHCN. The likelihood of achieving this outcome varied somewhat by the impact of the child's condition on his or her functional ability (from 54 percent of children who were affected usually, always, or a great deal to 70 percent of children who were never affected) and by family income (from 57 percent of children in poverty to 69 percent of children with family incomes of 400 percent of poverty or more).

CSHCN Whose Families Have Adequate Private and/or Public Insurance to Pay for the Services They Need: Impact of Condition on Functional Ability



CSHCN Whose Families Have Adequate Private and/or Public Insurance to Pay for the Services They Need: Family Income



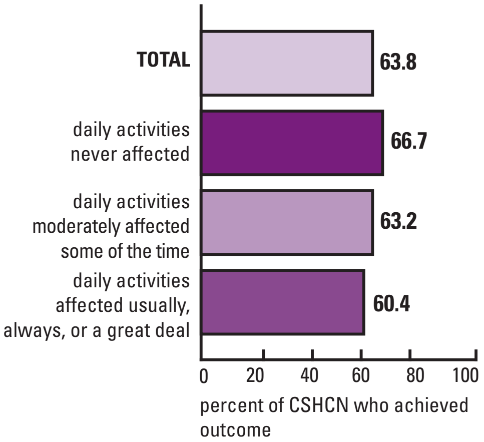
*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as $19,350 for a family of four.

Children are screened early and continuously for special health care needs.

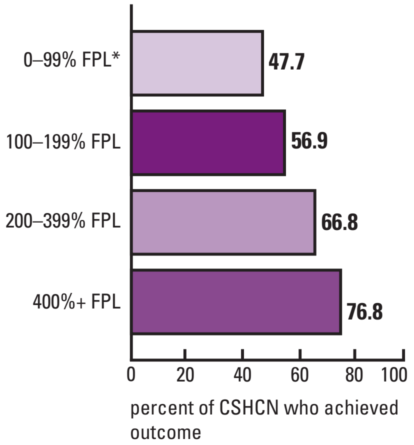
In public health, screening often refers to a population-based intervention to detect a particular condition or disease. However, as used in the context of this goal, screening is much more comprehensive and includes ongoing monitoring and assessment of children and youth to promote health and well-being 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.

Only the second component of screening—ongoing assessments for CSHCN—was measured in the NS-CSHCN. An estimate for this outcome 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. Overall, this outcome was successfully achieved for 63.8 percent of CSHCN. Children's likelihood of achieving this outcome did not vary substantially based on the impact of the condition on the child's functional ability. However, children with higher family incomes were significantly more likely to be screened regularly: 77 percent of children with family incomes of 400 percent of the poverty level achieved this outcome, compared to 48 percent of children with family incomes below the poverty level.

CSHCN Who Are Screened Early and Continuously for Special Health Care Needs: Impact of Condition on Functional Ability



CSHCN Who Are Screened Early and Continuously for Special Health Care Needs: Family Income



*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as $19,350 for a family of four.

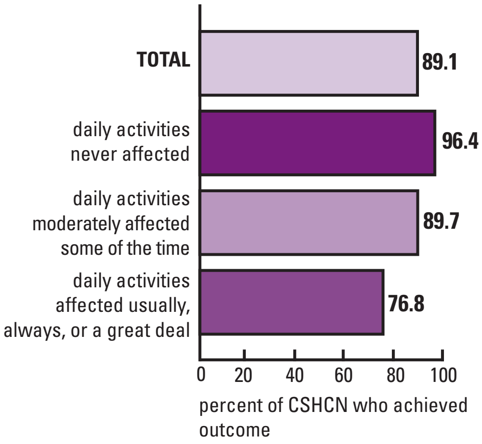
Community-based services for CSHCN are organized so families can use them easily.

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 CSHCN. 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.

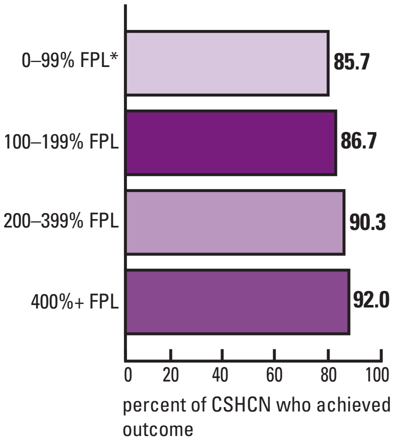
This outcome was assessed using a single question asking parents whether they had had difficulties trying to use the range of services their children had needed over the past year. This outcome was achieved by 89.1 percent of CSHCN.

Three-quarters of children whose conditions affected their daily activities usually, always, or a great deal achieved this objective, compared to nearly all (96 percent) children whose activities were never affected. In addition, 92 percent of children in the highest income bracket achieved the objective, compared to 86 percent of children in poverty.

CSHCN Whose Services Are Organized So Families Can Use Them Easily: Impact of Condition on Functional Ability



CSHCN Whose Services Are Organized So Families Can Use Them Easily: Family Income



*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as $19,350 for a family of four.

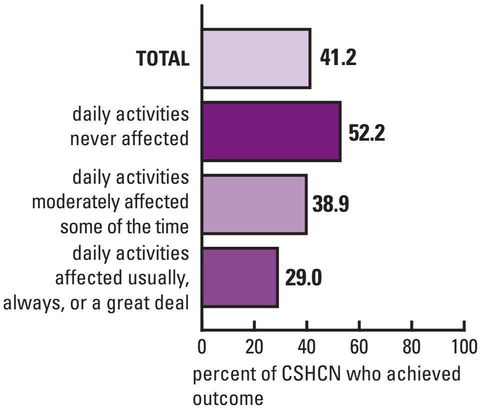
Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

While rapid advances in medical science have enabled nearly all 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 transitions from school to work, home to independent living, and child and family-focused care to adult-oriented care. Transition planning must begin early in order to move children and families along in a developmental fashion. One of the greatest challenges in planning is how to make a successful transition from the pediatric to adult health care system for youth with special health care needs. 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 and policy formulation. 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.

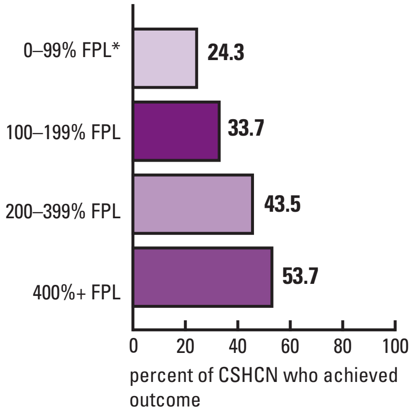
This outcome was evaluated for CSHCN 12–17 years of age using several questions: whether doctors had discussed the shift to adult providers, whether doctors had discussed the child's changing needs as he or she approached adulthood, whether anyone had discussed insurance coverage in adulthood, and whether the child was usually or always encouraged to take responsibility for his or her health. This outcome was achieved for 41.2 percent of adolescents.

Adolescents whose conditions affected their activities usually, always, or a great deal were considerably less likely to achieve this objective than those whose daily activities were never affected (30 percent versus 52 percent). Children living in poverty were only half as likely as high-income children to receive adequate transition services (24 percent versus 54 percent).

Youth with Special Health Care Needs Who Receive the Services Necessary to Make Transitions to All Aspects of Adult Life, Including Adult Health Care, Work, and Independence: Impact of Condition on Functional Ability

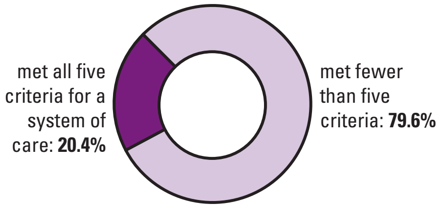


Youth with Special Health Care Needs Who Receive the Services Necessary to Make Transitions to All Aspects of Adult Life, Including Adult Health Care, Work, and Independence: Family Income

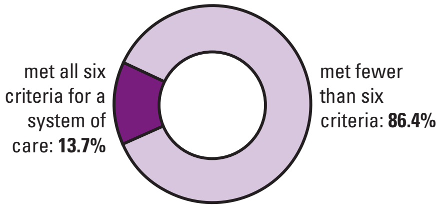


*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as $19,350 for a family of four.

Percent of CSHCN Aged 0–11 Years Served by a System of Care



Percent of CSHCN Aged 12–17 Years Served by a System of Care



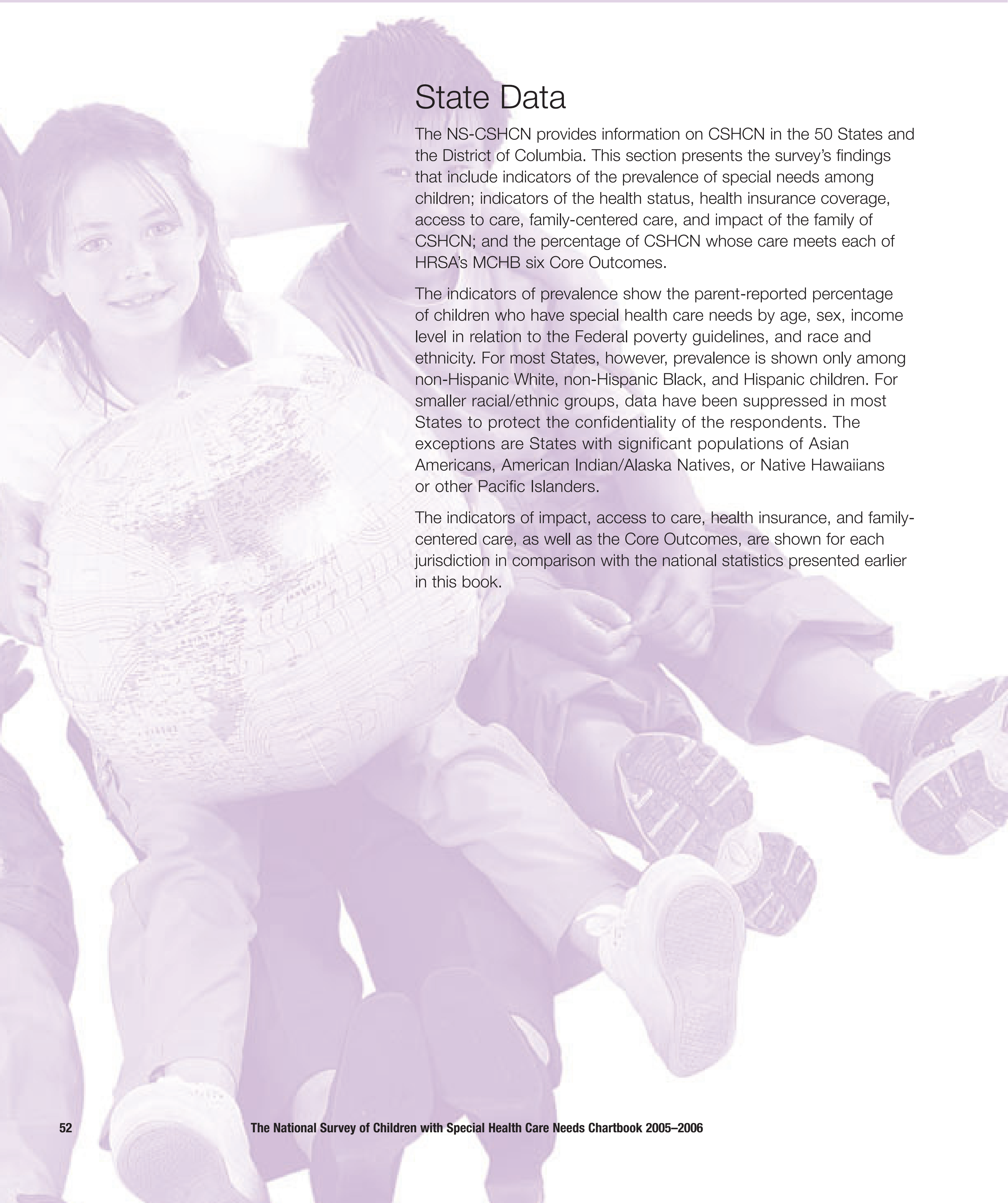
Overall Quality of the System of Care

HRSA's MCHB uses six critical indicators to measure the quality of a system of care for CSHCN:

- Families of children and youth with special health care needs partner in decision making at all levels and are satisfied with the services they receive;
- Children and youth with special health care needs receive coordinated ongoing comprehensive care within a medical home;
- Families of CSHCN have adequate private and/or public insurance to pay for the services they need;
- Children are screened early and continuously for special health care needs;
- Community-based services for children and youth with special health care needs are organized so families can use them easily;
- Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

Together, these six Core Outcomes can be used to measure progress toward the Healthy People 2010 objective to increase the proportion of States and territories that have service systems for children with or at risk for chronic and disabling conditions. In this analysis, a child was considered to be served by a "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 years, the first five outcomes were included, and all six outcomes were counted for children from age 12 through 17 years.

Among children aged 11 years and under, 20.4 percent were served by a system of care according to these standards. For children aged 12–17 years, 13.7 percent had care that met all six criteria.



State Data

The NS-CSHCN provides information on CSHCN in the 50 States and the District of Columbia. This section presents the survey's findings that include indicators of the prevalence of special needs among children; indicators of the health status, health insurance coverage, access to care, family-centered care, and impact of the family of CSHCN; and the percentage of CSHCN whose care meets each of HRSA's MCHB six Core Outcomes.

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, American Indian/Alaska Natives, or Native Hawaiians or other Pacific Islanders.

The indicators of impact, access to care, health insurance, and family-centered care, as well as the Core Outcomes, are shown for each jurisdiction in comparison with the national statistics presented earlier in this book.

Alabama

Estimated number of CSHCN: 187,263

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**17.1**	13.9
Age		
Age 0–5 years	**12.3**	8.8
Age 6–11 years	**20.8**	16.0
Age 12–17 years	**18.1**	16.8
Sex		
Male	**20.1**	16.1
Female	**14.1**	11.6
Poverty Level		
0–99% FPL	**21.3**	13.9
100–199% FPL	**16.7**	14.0
200–399% FPL	**14.7**	13.6
400% FPL or more	**16.0**	14.0
Hispanic Origin and Race		
Non-Hispanic	**17.0**	15.0
White	**17.4**	15.5
Black	**16.5**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**16.6**	17.9
Hispanic	**7.6**	8.3
Spanish language household	**	4.6
English language household	**14.2**	13.1

* 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 affect their activities usually, always, or a great deal	**21.3**	24.0
CSHCN with 11 or more days of school absences due to illness	**15.1**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**7.8**	8.8
CSHCN without insurance at time of survey	**1.8**	3.5
Currently insured CSHCN whose insurance is inadequate	**30.5**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**12.5**	16.1
CSHCN with any unmet need for family support services	**3.1**	4.9
CSHCN needing a referral who have difficulty getting it	**14.7**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**6.5**	5.7
CSHCN without any personal doctor or nurse	**5.8**	6.5
Family-Centered Care		
CSHCN without family-centered care	**32.0**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**17.9**	20.0
CSHCN whose conditions cause financial problems for the family	**15.5**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**14.0**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**22.5**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**59.9**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**50.0**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**65.0**	62.0
CSHCN who are screened early and continuously for special health care needs	**62.3**	63.8
CSHCN whose services are organized in ways that families can use them easily	**91.7**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**38.3**	41.2

Alaska

Estimated number of CSHCN: 22,406

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**11.9**	13.9
Age		
Age 0–5 years	**7.6**	8.8
Age 6–11 years	**13.2**	16.0
Age 12–17 years	**14.6**	16.8
Sex		
Male	**12.8**	16.1
Female	**10.9**	11.6
Poverty Level		
0–99% FPL	**12.4**	13.9
100–199% FPL	**11.3**	14.0
200–399% FPL	**12.0**	13.6
400% FPL or more	**12.0**	14.0
Hispanic Origin and Race		
Non-Hispanic	**11.9**	15.0
White	**13.0**	15.5
Black	**12.3**	15.0
Asian	*	6.3
American Indian/ Alaska Native	**7.8**	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**14.1**	17.9
Hispanic	**10.5**	8.3
Spanish language household	**	4.6
English language household	**11.8**	13.1

* 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 affect their activities usually, always, or a great deal	**28.2**	24.0
CSHCN with 11 or more days of school absences due to illness	**16.1**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**7.6**	8.8
CSHCN without insurance at time of survey	**3.6**	3.5
Currently insured CSHCN whose insurance is inadequate	**33.2**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**21.5**	16.1
CSHCN with any unmet need for family support services	**8.6**	4.9
CSHCN needing a referral who have difficulty getting it	**20.3**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**7.1**	5.7
CSHCN without any personal doctor or nurse	**9.8**	6.5
Family-Centered Care		
CSHCN without family-centered care	**36.8**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**23.1**	20.0
CSHCN whose conditions cause financial problems for the family	**18.4**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**10.5**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**25.9**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**51.8**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**39.3**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**62.2**	62.0
CSHCN who are screened early and continuously for special health care needs	**62.0**	63.8
CSHCN whose services are organized in ways that families can use them easily	**85.1**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**42.2**	41.2

Arizona

Estimated number of CSHCN: 201,608

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**12.5**	13.9
Age		
Age 0–5 years	**7.9**	8.8
Age 6–11 years	**14.0**	16.0
Age 12–17 years	**15.8**	16.8
Sex		
Male	**14.0**	16.1
Female	**10.9**	11.6
Poverty Level		
0–99% FPL	**9.9**	13.9
100–199% FPL	**13.0**	14.0
200–399% FPL	**13.1**	13.6
400% FPL or more	**13.9**	14.0
Hispanic Origin and Race		
Non-Hispanic	**15.2**	15.0
White	**15.8**	15.5
Black	**24.8**	15.0
Asian	*****	6.3
American Indian/ Alaska Native	**5.3**	14.5
Native Hawaiian/ Pacific Islander	*****	11.5
Multiple races	**15.1**	17.9
Hispanic	**8.4**	8.3
Spanish language household	**4.3**	4.6
English language household	**14.4**	13.1

* 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 affect their activities usually, always, or a great deal	**25.3**	24.0
CSHCN with 11 or more days of school absences due to illness	**17.3**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**11.6**	8.8
CSHCN without insurance at time of survey	**5.1**	3.5
Currently insured CSHCN whose insurance is inadequate	**35.3**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**21.6**	16.1
CSHCN with any unmet need for family support services	**4.8**	4.9
CSHCN needing a referral who have difficulty getting it	**29.7**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**7.4**	5.7
CSHCN without any personal doctor or nurse	**8.7**	6.5
Family-Centered Care		
CSHCN without family-centered care	**37.7**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**22.2**	20.0
CSHCN whose conditions cause financial problems for the family	**20.2**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**11.3**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**23.1**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**53.6**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**40.4**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**58.1**	62.0
CSHCN who are screened early and continuously for special health care needs	**61.1**	63.8
CSHCN whose services are organized in ways that families can use them easily	**86.5**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**39.4**	41.2

Arkansas

Estimated number of CSHCN: 120,087

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**17.7**	13.9
Age		
Age 0–5 years	**11.9**	8.8
Age 6–11 years	**20.5**	16.0
Age 12–17 years	**20.5**	16.8
Sex		
Male	**20.3**	16.1
Female	**15.0**	11.6
Poverty Level		
0–99% FPL	**21.6**	13.9
100–199% FPL	**17.8**	14.0
200–399% FPL	**15.8**	13.6
400% FPL or more	**15.7**	14.0
Hispanic Origin and Race		
Non-Hispanic	**17.7**	15.0
White	**18.0**	15.5
Black	**17.4**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**21.4**	17.9
Hispanic	**11.7**	8.3
Spanish language household	**	4.6
English language household	**21.5**	13.1

* 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 affect their activities usually, always, or a great deal	**28.6**	24.0
CSHCN with 11 or more days of school absences due to illness	**17.4**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**7.5**	8.8
CSHCN without insurance at time of survey	**1.9**	3.5
Currently insured CSHCN whose insurance is inadequate	**30.8**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**16.6**	16.1
CSHCN with any unmet need for family support services	**4.7**	4.9
CSHCN needing a referral who have difficulty getting it	**15.1**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**5.5**	5.7
CSHCN without any personal doctor or nurse	**8.9**	6.5
Family-Centered Care		
CSHCN without family-centered care	**33.1**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**16.2**	20.0
CSHCN whose conditions cause financial problems for the family	**20.5**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**12.3**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**20.7**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**61.7**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**50.2**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**65.3**	62.0
CSHCN who are screened early and continuously for special health care needs	**50.3**	63.8
CSHCN whose services are organized in ways that families can use them easily	**89.3**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**33.1**	41.2

California

Estimated number of CSHCN: 964,167

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**9.9**	13.9
Age		
Age 0–5 years	**5.6**	8.8
Age 6–11 years	**11.7**	16.0
Age 12–17 years	**12.4**	16.8
Sex		
Male	**11.7**	16.1
Female	**8.1**	11.6
Poverty Level		
0–99% FPL	**6.9**	13.9
100–199% FPL	**9.8**	14.0
200–399% FPL	**10.9**	13.6
400% FPL or more	**11.4**	14.0
Hispanic Origin and Race		
Non-Hispanic	**12.7**	15.0
White	**13.9**	15.5
Black	**15.1**	15.0
Asian	**5.2**	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**17.1**	17.9
Hispanic	**6.2**	8.3
Spanish language household	**3.7**	4.6
English language household	**10.1**	13.1

* 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 affect their activities usually, always, or a great deal	**23.7**	24.0
CSHCN with 11 or more days of school absences due to illness	**15.4**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**8.0**	8.8
CSHCN without insurance at time of survey	**3.1**	3.5
Currently insured CSHCN whose insurance is inadequate	**35.5**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**17.5**	16.1
CSHCN with any unmet need for family support services	**5.4**	4.9
CSHCN needing a referral who have difficulty getting it	**27.6**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**7.4**	5.7
CSHCN without any personal doctor or nurse	**6.8**	6.5
Family-Centered Care		
CSHCN without family-centered care	**40.7**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**17.9**	20.0
CSHCN whose conditions cause financial problems for the family	**15.5**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**9.2**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**23.7**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**46.6**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**42.2**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**59.6**	62.0
CSHCN who are screened early and continuously for special health care needs	**62.7**	63.8
CSHCN whose services are organized in ways that families can use them easily	**85.3**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**37.1**	41.2

Colorado

Estimated number of CSHCN: 149,000

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**12.5**	13.9
Age		
Age 0–5 years	**8.4**	8.8
Age 6–11 years	**13.0**	16.0
Age 12–17 years	**16.1**	16.8
Sex		
Male	**14.6**	16.1
Female	**10.4**	11.6
Poverty Level		
0–99% FPL	**9.6**	13.9
100–199% FPL	**12.1**	14.0
200–399% FPL	**13.1**	13.6
400% FPL or more	**13.4**	14.0
Hispanic Origin and Race		
Non-Hispanic	**13.7**	15.0
White	**13.4**	15.5
Black	**15.6**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**21.3**	17.9
Hispanic	**8.9**	8.3
Spanish language household	**2.9**	4.6
English language household	**13.7**	13.1

* 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 affect their activities usually, always, or a great deal	**23.4**	24.0
CSHCN with 11 or more days of school absences due to illness	**14.3**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**12.7**	8.8
CSHCN without insurance at time of survey	**5.4**	3.5
Currently insured CSHCN whose insurance is inadequate	**34.6**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**20.0**	16.1
CSHCN with any unmet need for family support services	**5.0**	4.9
CSHCN needing a referral who have difficulty getting it	**24.9**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**6.5**	5.7
CSHCN without any personal doctor or nurse	**6.5**	6.5
Family-Centered Care		
CSHCN without family-centered care	**32.6**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**27.7**	20.0
CSHCN whose conditions cause financial problems for the family	**23.9**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**8.4**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**20.6**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**59.1**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**48.2**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**59.1**	62.0
CSHCN who are screened early and continuously for special health care needs	**65.5**	63.8
CSHCN whose services are organized in ways that families can use them easily	**87.8**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**47.0**	41.2

Connecticut

Estimated number of CSHCN: 133,073

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**16.0**	13.9
Age		
Age 0–5 years	**10.7**	8.8
Age 6–11 years	**18.3**	16.0
Age 12–17 years	**18.4**	16.8
Sex		
Male	**18.3**	16.1
Female	**13.6**	11.6
Poverty Level		
0–99% FPL	**19.5**	13.9
100–199% FPL	**16.0**	14.0
200–399% FPL	**14.9**	13.6
400% FPL or more	**15.8**	14.0
Hispanic Origin and Race		
Non-Hispanic	**15.7**	15.0
White	**16.0**	15.5
Black	**14.6**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**22.4**	17.9
Hispanic	**16.9**	8.3
Spanish language household	**13.2**	4.6
English language household	**20.3**	13.1

* 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 affect their activities usually, always, or a great deal	**18.7**	24.0
CSHCN with 11 or more days of school absences due to illness	**13.2**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**6.2**	8.8
CSHCN without insurance at time of survey	**2.2**	3.5
Currently insured CSHCN whose insurance is inadequate	**34.4**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**12.0**	16.1
CSHCN with any unmet need for family support services	**6.0**	4.9
CSHCN needing a referral who have difficulty getting it	**24.0**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**4.2**	5.7
CSHCN without any personal doctor or nurse	**3.9**	6.5
Family-Centered Care		
CSHCN without family-centered care	**33.4**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**22.1**	20.0
CSHCN whose conditions cause financial problems for the family	**15.7**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**7.6**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**21.9**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**57.8**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**48.5**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**61.7**	62.0
CSHCN who are screened early and continuously for special health care needs	**70.6**	63.8
CSHCN whose services are organized in ways that families can use them easily	**89.4**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**43.4**	41.2

Delaware

Estimated number of CSHCN: 34,522

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	17.5	13.9
Age		
Age 0–5 years	10.4	8.8
Age 6–11 years	21.8	16.0
Age 12–17 years	20.5	16.8
Sex		
Male	21.5	16.1
Female	13.4	11.6
Poverty Level		
0–99% FPL	17.5	13.9
100–199% FPL	16.5	14.0
200–399% FPL	18.1	13.6
400% FPL or more	17.4	14.0
Hispanic Origin and Race		
Non-Hispanic	18.1	15.0
White	19.7	15.5
Black	16.0	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	17.0	17.9
Hispanic	9.2	8.3
Spanish language household	**	4.6
English language household	20.4	13.1

* 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 affect their activities usually, always, or a great deal	20.4	24.0
CSHCN with 11 or more days of school absences due to illness	12.3	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	8.7	8.8
CSHCN without insurance at time of survey	2.2	3.5
Currently insured CSHCN whose insurance is inadequate	32.2	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	14.2	16.1
CSHCN with any unmet need for family support services	3.8	4.9
CSHCN needing a referral who have difficulty getting it	24.4	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	4.5	5.7
CSHCN without any personal doctor or nurse	3.5	6.5
Family-Centered Care		
CSHCN without family-centered care	29.7	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	17.4	20.0
CSHCN whose conditions cause financial problems for the family	17.4	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	8.4	9.7
CSHCN whose conditions cause family members to cut back or stop working	21.2	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	61.1	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	48.1	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	63.2	62.0
CSHCN who are screened early and continuously for special health care needs	67.2	63.8
CSHCN whose services are organized in ways that families can use them easily	88.1	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	42.4	41.2

District of Columbia

Estimated number of CSHCN: 16,369

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	14.7	13.9
Age		
Age 0–5 years	10.2	8.8
Age 6–11 years	18.6	16.0
Age 12–17 years	16.7	16.8
Sex		
Male	17.2	16.1
Female	12.2	11.6
Poverty Level		
0–99% FPL	17.2	13.9
100–199% FPL	12.5	14.0
200–399% FPL	14.1	13.6
400% FPL or more	13.7	14.0
Hispanic Origin and Race		
Non-Hispanic	15.4	15.0
White	13.4	15.5
Black	15.9	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	18.0	17.9
Hispanic	7.2	8.3
Spanish language household	4.7	4.6
English language household	14.3	13.1

* 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 affect their activities usually, always, or a great deal	20.9	24.0
CSHCN with 11 or more days of school absences due to illness	16.7	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	5.0	8.8
CSHCN without insurance at time of survey	1.9	3.5
Currently insured CSHCN whose insurance is inadequate	34.7	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	18.0	16.1
CSHCN with any unmet need for family support services	7.2	4.9
CSHCN needing a referral who have difficulty getting it	25.2	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	8.5	5.7
CSHCN without any personal doctor or nurse	9.6	6.5
Family-Centered Care		
CSHCN without family-centered care	43.8	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	14.7	20.0
CSHCN whose conditions cause financial problems for the family	14.8	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	12.7	9.7
CSHCN whose conditions cause family members to cut back or stop working	25.6	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	53.1	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	36.9	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	62.7	62.0
CSHCN who are screened early and continuously for special health care needs	62.8	63.8
CSHCN whose services are organized in ways that families can use them easily	88.8	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	24.0	41.2

Florida

Estimated number of CSHCN: 551,263

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**13.4**	13.9
Age		
Age 0–5 years	**9.3**	8.8
Age 6–11 years	**15.2**	16.0
Age 12–17 years	**15.7**	16.8
Sex		
Male	**15.9**	16.1
Female	**10.9**	11.6
Poverty Level		
0–99% FPL	**12.9**	13.9
100–199% FPL	**16.3**	14.0
200–399% FPL	**12.2**	13.6
400% FPL or more	**12.6**	14.0
Hispanic Origin and Race		
Non-Hispanic	**14.4**	15.0
White	**15.6**	15.5
Black	**11.9**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**14.9**	17.9
Hispanic	**9.4**	8.3
Spanish language household	**7.4**	4.6
English language household	**11.9**	13.1

* 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 affect their activities usually, always, or a great deal	**28.0**	24.0
CSHCN with 11 or more days of school absences due to illness	**15.4**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**12.2**	8.8
CSHCN without insurance at time of survey	**4.9**	3.5
Currently insured CSHCN whose insurance is inadequate	**35.8**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**21.8**	16.1
CSHCN with any unmet need for family support services	**6.0**	4.9
CSHCN needing a referral who have difficulty getting it	**26.9**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**6.0**	5.7
CSHCN without any personal doctor or nurse	**8.4**	6.5
Family-Centered Care		
CSHCN without family-centered care	**38.3**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**23.9**	20.0
CSHCN whose conditions cause financial problems for the family	**21.9**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**10.0**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**30.1**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**50.2**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**41.9**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**58.0**	62.0
CSHCN who are screened early and continuously for special health care needs	**59.8**	63.8
CSHCN whose services are organized in ways that families can use them easily	**85.9**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**33.8**	41.2

Georgia

Estimated number of CSHCN: 334,420

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**14.0**	13.9
Age		
Age 0–5 years	**10.0**	8.8
Age 6–11 years	**16.4**	16.0
Age 12–17 years	**15.9**	16.8
Sex		
Male	**16.5**	16.1
Female	**11.3**	11.6
Poverty Level		
0–99% FPL	**14.8**	13.9
100–199% FPL	**15.3**	14.0
200–399% FPL	**12.8**	13.6
400% FPL or more	**13.3**	14.0
Hispanic Origin and Race		
Non-Hispanic	**14.4**	15.0
White	**15.4**	15.5
Black	**13.4**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**15.2**	17.9
Hispanic	**8.0**	8.3
Spanish language household	**5.3**	4.6
English language household	**16.4**	13.1

* 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 affect their activities usually, always, or a great deal	**26.1**	24.0
CSHCN with 11 or more days of school absences due to illness	**10.4**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**10.4**	8.8
CSHCN without insurance at time of survey	**4.7**	3.5
Currently insured CSHCN whose insurance is inadequate	**32.6**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**18.2**	16.1
CSHCN with any unmet need for family support services	**5.7**	4.9
CSHCN needing a referral who have difficulty getting it	**17.4**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**5.9**	5.7
CSHCN without any personal doctor or nurse	**8.9**	6.5
Family-Centered Care		
CSHCN without family-centered care	**35.0**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**18.8**	20.0
CSHCN whose conditions cause financial problems for the family	**17.1**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**9.9**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**23.8**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**54.0**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**47.3**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**61.2**	62.0
CSHCN who are screened early and continuously for special health care needs	**65.3**	63.8
CSHCN whose services are organized in ways that families can use them easily	**91.0**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**37.0**	41.2

Hawaii

Estimated number of CSHCN: 36,066 | **All statistics are based on parental reports**

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**12.0**	13.9
Age		
Age 0–5 years	**8.3**	8.8
Age 6–11 years	**14.2**	16.0
Age 12–17 years	**13.8**	16.8
Sex		
Male	**14.0**	16.1
Female	**9.9**	11.6
Poverty Level		
0–99% FPL	**13.8**	13.9
100–199% FPL	**11.7**	14.0
200–399% FPL	**11.9**	13.6
400% FPL or more	**11.5**	14.0
Hispanic Origin and Race		
Non-Hispanic	**11.4**	15.0
White	**13.1**	15.5
Black	**9.6**	15.0
Asian	**8.9**	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	**11.2**	11.5
Multiple races	**12.9**	17.9
Hispanic	**15.5**	8.3
Spanish language household	**	4.6
English language household	**16.7**	13.1

* 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 affect their activities usually, always, or a great deal	**23.5**	24.0
CSHCN with 11 or more days of school absences due to illness	**12.8**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**3.3**	8.8
CSHCN without insurance at time of survey	**0.9**	3.5
Currently insured CSHCN whose insurance is inadequate	**24.3**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**13.3**	16.1
CSHCN with any unmet need for family support services	**5.6**	4.9
CSHCN needing a referral who have difficulty getting it	**21.4**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**6.8**	5.7
CSHCN without any personal doctor or nurse	**6.0**	6.5
Family-Centered Care		
CSHCN without family-centered care	**36.1**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**11.1**	20.0
CSHCN whose conditions cause financial problems for the family	**11.0**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**11.3**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**22.1**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**59.3**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**45.2**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**73.5**	62.0
CSHCN who are screened early and continuously for special health care needs	**69.7**	63.8
CSHCN whose services are organized in ways that families can use them easily	**88.8**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**39.4**	41.2

Idaho

Estimated number of CSHCN: 43,306

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**11.4**	13.9
Age		
Age 0–5 years	**7.1**	8.8
Age 6–11 years	**12.8**	16.0
Age 12–17 years	**14.3**	16.8
Sex		
Male	**12.9**	16.1
Female	**9.9**	11.6
Poverty Level		
0–99% FPL	**12.0**	13.9
100–199% FPL	**12.3**	14.0
200–399% FPL	**10.5**	13.6
400% FPL or more	**11.2**	14.0
Hispanic Origin and Race		
Non-Hispanic	**11.9**	15.0
White	**11.8**	15.5
Black	**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**18.7**	17.9
Hispanic	**7.3**	8.3
Spanish language household	**3.3**	4.6
English language household	**12.3**	13.1

* 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 affect their activities usually, always, or a great deal	**25.9**	24.0
CSHCN with 11 or more days of school absences due to illness	**15.3**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**11.1**	8.8
CSHCN without insurance at time of survey	**6.3**	3.5
Currently insured CSHCN whose insurance is inadequate	**36.7**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**17.8**	16.1
CSHCN with any unmet need for family support services	**6.4**	4.9
CSHCN needing a referral who have difficulty getting it	**22.1**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**4.8**	5.7
CSHCN without any personal doctor or nurse	**5.3**	6.5
Family-Centered Care		
CSHCN without family-centered care	**33.0**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**25.4**	20.0
CSHCN whose conditions cause financial problems for the family	**19.5**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**8.6**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**24.7**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**52.7**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**47.7**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**56.9**	62.0
CSHCN who are screened early and continuously for special health care needs	**57.2**	63.8
CSHCN whose services are organized in ways that families can use them easily	**86.0**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**45.8**	41.2

Illinois

Estimated number of CSHCN: 451,776

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**13.9**	13.9
Age		
Age 0–5 years	**9.4**	8.8
Age 6–11 years	**16.2**	16.0
Age 12–17 years	**16.3**	16.8
Sex		
Male	**16.1**	16.1
Female	**11.8**	11.6
Poverty Level		
0–99% FPL	**13.3**	13.9
100–199% FPL	**14.2**	14.0
200–399% FPL	**14.0**	13.6
400% FPL or more	**14.0**	14.0
Hispanic Origin and Race		
Non-Hispanic	**15.1**	15.0
White	**16.0**	15.5
Black	**14.1**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**14.5**	17.9
Hispanic	**7.5**	8.3
Spanish language household	**5.9**	4.6
English language household	**10.4**	13.1

* 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 affect their activities usually, always, or a great deal	**23.4**	24.0
CSHCN with 11 or more days of school absences due to illness	**12.9**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**7.4**	8.8
CSHCN without insurance at time of survey	**3.7**	3.5
Currently insured CSHCN whose insurance is inadequate	**37.8**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**13.0**	16.1
CSHCN with any unmet need for family support services	**4.4**	4.9
CSHCN needing a referral who have difficulty getting it	**16.7**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**4.9**	5.7
CSHCN without any personal doctor or nurse	**7.0**	6.5
Family-Centered Care		
CSHCN without family-centered care	**36.2**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**23.4**	20.0
CSHCN whose conditions cause financial problems for the family	**17.9**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**8.5**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**21.7**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**60.3**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**45.1**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**59.3**	62.0
CSHCN who are screened early and continuously for special health care needs	**62.7**	63.8
CSHCN whose services are organized in ways that families can use them easily	**89.8**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**44.2**	41.2

Indiana

Estimated number of CSHCN: 266,494

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**16.6**	13.9
Age		
Age 0–5 years	**10.6**	8.8
Age 6–11 years	**19.2**	16.0
Age 12–17 years	**19.9**	16.8
Sex		
Male	**18.7**	16.1
Female	**14.5**	11.6
Poverty Level		
0–99% FPL	**20.4**	13.9
100–199% FPL	**15.8**	14.0
200–399% FPL	**15.5**	13.6
400% FPL or more	**16.2**	14.0
Hispanic Origin and Race		
Non-Hispanic	**17.0**	15.0
White	**17.2**	15.5
Black	**14.5**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**17.7**	17.9
Hispanic	**8.9**	8.3
Spanish language household	**	4.6
English language household	**15.3**	13.1

* 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 affect their activities usually, always, or a great deal	**23.8**	24.0
CSHCN with 11 or more days of school absences due to illness	**10.7**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**9.2**	8.8
CSHCN without insurance at time of survey	**4.2**	3.5
Currently insured CSHCN whose insurance is inadequate	**32.7**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**16.7**	16.1
CSHCN with any unmet need for family support services	**2.7**	4.9
CSHCN needing a referral who have difficulty getting it	**20.0**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**5.7**	5.7
CSHCN without any personal doctor or nurse	**5.9**	6.5
Family-Centered Care		
CSHCN without family-centered care	**29.7**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**20.1**	20.0
CSHCN whose conditions cause financial problems for the family	**21.1**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**9.4**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**24.3**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**59.3**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**54.6**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**61.8**	62.0
CSHCN who are screened early and continuously for special health care needs	**63.1**	63.8
CSHCN whose services are organized in ways that families can use them easily	**94.3**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**41.1**	41.2

Iowa

Estimated number of CSHCN: 95,094

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**14.2**	13.9
Age		
Age 0–5 years	**8.5**	8.8
Age 6–11 years	**16.2**	16.0
Age 12–17 years	**17.6**	16.8
Sex		
Male	**16.0**	16.1
Female	**12.3**	11.6
Poverty Level		
0–99% FPL	**15.1**	13.9
100–199% FPL	**15.7**	14.0
200–399% FPL	**14.1**	13.6
400% FPL or more	**12.6**	14.0
Hispanic Origin and Race		
Non-Hispanic	**14.4**	15.0
White	**14.0**	15.5
Black	**20.9**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**24.1**	17.9
Hispanic	**8.2**	8.3
Spanish language household	**	4.6
English language household	**21.3**	13.1

* 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 affect their activities usually, always, or a great deal	**18.4**	24.0
CSHCN with 11 or more days of school absences due to illness	**11.4**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**5.6**	8.8
CSHCN without insurance at time of survey	**1.2**	3.5
Currently insured CSHCN whose insurance is inadequate	**28.2**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**10.7**	16.1
CSHCN with any unmet need for family support services	**3.2**	4.9
CSHCN needing a referral who have difficulty getting it	**12.7**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**3.6**	5.7
CSHCN without any personal doctor or nurse	**3.9**	6.5
Family-Centered Care		
CSHCN without family-centered care	**25.3**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**21.7**	20.0
CSHCN whose conditions cause financial problems for the family	**19.3**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**6.2**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**17.0**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**64.7**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**57.4**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**68.6**	62.0
CSHCN who are screened early and continuously for special health care needs	**65.6**	63.8
CSHCN whose services are organized in ways that families can use them easily	**92.9**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**47.3**	41.2

Kansas

Estimated number of CSHCN: 108,024

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**16.0**	13.9
Age		
Age 0–5 years	**10.3**	8.8
Age 6–11 years	**17.3**	16.0
Age 12–17 years	**20.4**	16.8
Sex		
Male	**18.7**	16.1
Female	**13.2**	11.6
Poverty Level		
0–99% FPL	**17.7**	13.9
100–199% FPL	**15.1**	14.0
200–399% FPL	**15.4**	13.6
400% FPL or more	**16.6**	14.0
Hispanic Origin and Race		
Non-Hispanic	**16.4**	15.0
White	**16.3**	15.5
Black	**18.7**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**24.6**	17.9
Hispanic	**9.9**	8.3
Spanish language household	**4.2**	4.6
English language household	**16.3**	13.1

* 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 affect their activities usually, always, or a great deal	**21.2**	24.0
CSHCN with 11 or more days of school absences due to illness	**11.8**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**9.3**	8.8
CSHCN without insurance at time of survey	**3.1**	3.5
Currently insured CSHCN whose insurance is inadequate	**30.3**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**12.0**	16.1
CSHCN with any unmet need for family support services	**3.2**	4.9
CSHCN needing a referral who have difficulty getting it	**11.4**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**5.6**	5.7
CSHCN without any personal doctor or nurse	**4.5**	6.5
Family-Centered Care		
CSHCN without family-centered care	**30.5**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**21.9**	20.0
CSHCN whose conditions cause financial problems for the family	**21.4**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**8.0**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**20.1**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**65.6**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**55.3**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**62.9**	62.0
CSHCN who are screened early and continuously for special health care needs	**68.5**	63.8
CSHCN whose services are organized in ways that families can use them easily	**92.5**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**50.3**	41.2

Kentucky

Estimated number of CSHCN: 181202 **All statistics are based on parental reports**

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	18.5	13.9
Age		
Age 0–5 years	13.0	8.8
Age 6–11 years	21.7	16.0
Age 12–17 years	20.8	16.8
Sex		
Male	20.5	16.1
Female	16.4	11.6
Poverty Level		
0–99% FPL	25.7	13.9
100–199% FPL	16.9	14.0
200–399% FPL	16.0	13.6
400% FPL or more	16.5	14.0
Hispanic Origin and Race		
Non-Hispanic	18.4	15.0
White	18.3	15.5
Black	20.3	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	20.0	17.9
Hispanic	12.2	8.3
Spanish language household	**	4.6
English language household	17.5	13.1

* 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 affect their activities usually, always, or a great deal	24.9	24.0
CSHCN with 11 or more days of school absences due to illness	16.5	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	6.0	8.8
CSHCN without insurance at time of survey	2.4	3.5
Currently insured CSHCN whose insurance is inadequate	31.9	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	12.9	16.1
CSHCN with any unmet need for family support services	4.6	4.9
CSHCN needing a referral who have difficulty getting it	15.9	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	5.0	5.7
CSHCN without any personal doctor or nurse	6.4	6.5
Family-Centered Care		
CSHCN without family-centered care	35.7	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	15.6	20.0
CSHCN whose conditions cause financial problems for the family	19.0	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	14.5	9.7
CSHCN whose conditions cause family members to cut back or stop working	21.8	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	58.6	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	47.3	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	64.7	62.0
CSHCN who are screened early and continuously for special health care needs	57.4	63.8
CSHCN whose services are organized in ways that families can use them easily	91.4	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	42.8	41.2

Louisiana

Estimated number of CSHCN: 162,116

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**14.8**	13.9
Age		
Age 0–5 years	**10.4**	8.8
Age 6–11 years	**17.4**	16.0
Age 12–17 years	**16.5**	16.8
Sex		
Male	**17.3**	16.1
Female	**12.1**	11.6
Poverty Level		
0–99% FPL	**16.8**	13.9
100–199% FPL	**13.5**	14.0
200–399% FPL	**13.9**	13.6
400% FPL or more	**15.2**	14.0
Hispanic Origin and Race		
Non-Hispanic	**14.5**	15.0
White	**15.8**	15.5
Black	**12.8**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**23.7**	17.9
Hispanic	**14.1**	8.3
Spanish language household	**	4.6
English language household	**16.9**	13.1

* 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 affect their activities usually, always, or a great deal	**24.6**	24.0
CSHCN with 11 or more days of school absences due to illness	**18.8**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**8.3**	8.8
CSHCN without insurance at time of survey	**5.1**	3.5
Currently insured CSHCN whose insurance is inadequate	**28.2**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**12.2**	16.1
CSHCN with any unmet need for family support services	**4.0**	4.9
CSHCN needing a referral who have difficulty getting it	**15.8**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**8.8**	5.7
CSHCN without any personal doctor or nurse	**6.1**	6.5
Family-Centered Care		
CSHCN without family-centered care	**34.7**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**19.8**	20.0
CSHCN whose conditions cause financial problems for the family	**19.8**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**12.1**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**25.3**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**62.2**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**49.6**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**65.5**	62.0
CSHCN who are screened early and continuously for special health care needs	**54.3**	63.8
CSHCN whose services are organized in ways that families can use them easily	**89.3**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**41.0**	41.2

Maine

Estimated number of CSHCN: 48,891

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	17.7	13.9
Age		
Age 0–5 years	9.5	8.8
Age 6–11 years	19.8	16.0
Age 12–17 years	22.1	16.8
Sex		
Male	20.9	16.1
Female	14.3	11.6
Poverty Level		
0–99% FPL	27.5	13.9
100–199% FPL	19.5	14.0
200–399% FPL	15.1	13.6
400% FPL or more	15.3	14.0
Hispanic Origin and Race		
Non-Hispanic	17.4	15.0
White	17.4	15.5
Black	**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	23.9	17.9
Hispanic	19.3	8.3
Spanish language household	†	4.6
English language household	21.0	13.1

* 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.

† No CSHCN were identified among predominantly Spanish-speaking Hispanics in the survey sample.

Indicator	State %	National %
Child Health		
CSHCN whose conditions affect their activities usually, always, or a great deal	26.3	24.0
CSHCN with 11 or more days of school absences due to illness	14.2	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	7.0	8.8
CSHCN without insurance at time of survey	2.5	3.5
Currently insured CSHCN whose insurance is inadequate	25.4	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	15.2	16.1
CSHCN with any unmet need for family support services	5.4	4.9
CSHCN needing a referral who have difficulty getting it	15.5	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	4.3	5.7
CSHCN without any personal doctor or nurse	3.0	6.5
Family-Centered Care		
CSHCN without family-centered care	28.5	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	17.2	20.0
CSHCN whose conditions cause financial problems for the family	19.3	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	9.2	9.7
CSHCN whose conditions cause family members to cut back or stop working	24.6	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	60.7	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	51.7	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	70.0	62.0
CSHCN who are screened early and continuously for special health care needs	70.1	63.8
CSHCN whose services are organized in ways that families can use them easily	87.6	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	49.0	41.2

Maryland

Estimated number of CSHCN: 216,984

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**15.5**	13.9
Age		
Age 0–5 years	**9.5**	8.8
Age 6–11 years	**17.9**	16.0
Age 12–17 years	**18.6**	16.8
Sex		
Male	**18.4**	16.1
Female	**12.4**	11.6
Poverty Level		
0–99% FPL	**17.8**	13.9
100–199% FPL	**13.2**	14.0
200–399% FPL	**14.5**	13.6
400% FPL or more	**16.3**	14.0
Hispanic Origin and Race		
Non-Hispanic	**15.7**	15.0
White	**17.4**	15.5
Black	**14.3**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**17.2**	17.9
Hispanic	**9.8**	8.3
Spanish language household	**5.4**	4.6
English language household	**18.8**	13.1

* 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 affect their activities usually, always, or a great deal	**24.1**	24.0
CSHCN with 11 or more days of school absences due to illness	**13.7**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**6.3**	8.8
CSHCN without insurance at time of survey	**3.0**	3.5
Currently insured CSHCN whose insurance is inadequate	**30.8**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**16.5**	16.1
CSHCN with any unmet need for family support services	**4.6**	4.9
CSHCN needing a referral who have difficulty getting it	**20.9**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**5.6**	5.7
CSHCN without any personal doctor or nurse	**4.2**	6.5
Family-Centered Care		
CSHCN without family-centered care	**37.7**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**23.5**	20.0
CSHCN whose conditions cause financial problems for the family	**17.5**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**8.1**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**25.8**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**54.8**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**45.6**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**65.5**	62.0
CSHCN who are screened early and continuously for special health care needs	**65.7**	63.8
CSHCN whose services are organized in ways that families can use them easily	**89.3**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**37.5**	41.2

Massachusetts

Estimated number of CSHCN: 237,838

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**16.4**	13.9
Age		
Age 0–5 years	**10.2**	8.8
Age 6–11 years	**17.9**	16.0
Age 12–17 years	**20.6**	16.8
Sex		
Male	**19.6**	16.1
Female	**13.0**	11.6
Poverty Level		
0–99% FPL	**19.9**	13.9
100–199% FPL	**17.6**	14.0
200–399% FPL	**14.8**	13.6
400% FPL or more	**16.2**	14.0
Hispanic Origin and Race		
Non-Hispanic	**16.5**	15.0
White	**17.2**	15.5
Black	**14.6**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**24.4**	17.9
Hispanic	**14.0**	8.3
Spanish language household	**10.8**	4.6
English language household	**16.7**	13.1

* 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 affect their activities usually, always, or a great deal	**23.7**	24.0
CSHCN with 11 or more days of school absences due to illness	**14.9**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**5.2**	8.8
CSHCN without insurance at time of survey	**1.2**	3.5
Currently insured CSHCN whose insurance is inadequate	**32.7**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**11.1**	16.1
CSHCN with any unmet need for family support services	**5.2**	4.9
CSHCN needing a referral who have difficulty getting it	**13.9**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**4.8**	5.7
CSHCN without any personal doctor or nurse	**3.6**	6.5
Family-Centered Care		
CSHCN without family-centered care	**31.2**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**20.4**	20.0
CSHCN whose conditions cause financial problems for the family	**15.0**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**8.0**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**24.7**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**57.1**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**45.7**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**63.1**	62.0
CSHCN who are screened early and continuously for special health care needs	**75.8**	63.8
CSHCN whose services are organized in ways that families can use them easily	**87.6**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**46.6**	41.2

Michigan

Estimated number of CSHCN: 387,008

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**15.4**	13.9
Age		
Age 0–5 years	**9.7**	8.8
Age 6–11 years	**16.4**	16.0
Age 12–17 years	**19.5**	16.8
Sex		
Male	**18.5**	16.1
Female	**12.3**	11.6
Poverty Level		
0–99% FPL	**19.1**	13.9
100–199% FPL	**13.8**	14.0
200–399% FPL	**14.5**	13.6
400% FPL or more	**15.6**	14.0
Hispanic Origin and Race		
Non-Hispanic	**15.3**	15.0
White	**15.4**	15.5
Black	**15.6**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**19.7**	17.9
Hispanic	**12.7**	8.3
Spanish language household	**	4.6
English language household	**16.8**	13.1

* 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 affect their activities usually, always, or a great deal	**24.7**	24.0
CSHCN with 11 or more days of school absences due to illness	**14.2**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**6.7**	8.8
CSHCN without insurance at time of survey	**2.7**	3.5
Currently insured CSHCN whose insurance is inadequate	**35.7**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**16.6**	16.1
CSHCN with any unmet need for family support services	**5.7**	4.9
CSHCN needing a referral who have difficulty getting it	**22.9**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**5.6**	5.7
CSHCN without any personal doctor or nurse	**8.6**	6.5
Family-Centered Care		
CSHCN without family-centered care	**35.3**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**19.7**	20.0
CSHCN whose conditions cause financial problems for the family	**16.1**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**11.0**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**25.6**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**56.4**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**46.0**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**60.8**	62.0
CSHCN who are screened early and continuously for special health care needs	**68.8**	63.8
CSHCN whose services are organized in ways that families can use them easily	**90.9**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**40.8**	41.2

Minnesota

Estimated number of CSHCN: 177,668

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**14.4**	13.9
Age		
Age 0–5 years	**8.7**	8.8
Age 6–11 years	**15.6**	16.0
Age 12–17 years	**18.7**	16.8
Sex		
Male	**17.3**	16.1
Female	**11.4**	11.6
Poverty Level		
0–99% FPL	**13.3**	13.9
100–199% FPL	**15.3**	14.0
200–399% FPL	**13.4**	13.6
400% FPL or more	**15.2**	14.0
Hispanic Origin and Race		
Non-Hispanic	**14.5**	15.0
White	**14.4**	15.5
Black	**19.5**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**14.3**	17.9
Hispanic	**8.3**	8.3
Spanish language household	**	4.6
English language household	**15.5**	13.1

* 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 affect their activities usually, always, or a great deal	**19.8**	24.0
CSHCN with 11 or more days of school absences due to illness	**10.1**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**7.0**	8.8
CSHCN without insurance at time of survey	**2.6**	3.5
Currently insured CSHCN whose insurance is inadequate	**30.0**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**12.9**	16.1
CSHCN with any unmet need for family support services	**3.7**	4.9
CSHCN needing a referral who have difficulty getting it	**18.9**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**4.8**	5.7
CSHCN without any personal doctor or nurse	**4.6**	6.5
Family-Centered Care		
CSHCN without family-centered care	**29.2**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**23.8**	20.0
CSHCN whose conditions cause financial problems for the family	**18.3**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**7.2**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**21.1**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**60.3**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**51.8**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**66.3**	62.0
CSHCN who are screened early and continuously for special health care needs	**64.9**	63.8
CSHCN whose services are organized in ways that families can use them easily	**90.7**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**52.9**	41.2

Mississippi

Estimated number of CSHCN: 111,852

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**15.0**	13.9
Age		
Age 0–5 years	**12.1**	8.8
Age 6–11 years	**17.4**	16.0
Age 12–17 years	**15.8**	16.8
Sex		
Male	**17.0**	16.1
Female	**13.0**	11.6
Poverty Level		
0–99% FPL	**17.2**	13.9
100–199% FPL	**14.5**	14.0
200–399% FPL	**13.5**	13.6
400% FPL or more	**14.5**	14.0
Hispanic Origin and Race		
Non-Hispanic	**14.9**	15.0
White	**15.7**	15.5
Black	**13.9**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**23.7**	17.9
Hispanic	**11.0**	8.3
Spanish language household	**	4.6
English language household	**16.4**	13.1

* 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 affect their activities usually, always, or a great deal	**24.2**	24.0
CSHCN with 11 or more days of school absences due to illness	**17.1**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**11.9**	8.8
CSHCN without insurance at time of survey	**4.2**	3.5
Currently insured CSHCN whose insurance is inadequate	**34.7**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**16.7**	16.1
CSHCN with any unmet need for family support services	**2.9**	4.9
CSHCN needing a referral who have difficulty getting it	**18.8**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**6.2**	5.7
CSHCN without any personal doctor or nurse	**8.7**	6.5
Family-Centered Care		
CSHCN without family-centered care	**38.4**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**16.5**	20.0
CSHCN whose conditions cause financial problems for the family	**19.4**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**14.0**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**23.1**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**60.4**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**45.0**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**58.8**	62.0
CSHCN who are screened early and continuously for special health care needs	**51.4**	63.8
CSHCN whose services are organized in ways that families can use them easily	**90.9**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**30.9**	41.2

Missouri

Estimated number of CSHCN: 223,070

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**16.2**	13.9
Age		
Age 0–5 years	**9.0**	8.8
Age 6–11 years	**19.5**	16.0
Age 12–17 years	**19.8**	16.8
Sex		
Male	**19.3**	16.1
Female	**12.9**	11.6
Poverty Level		
0–99% FPL	**18.3**	13.9
100–199% FPL	**16.4**	14.0
200–399% FPL	**14.5**	13.6
400% FPL or more	**16.7**	14.0
Hispanic Origin and Race		
Non-Hispanic	**16.2**	15.0
White	**15.6**	15.5
Black	**17.8**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**22.4**	17.9
Hispanic	**12.6**	8.3
Spanish language household	**	4.6
English language household	**18.7**	13.1

* 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 affect their activities usually, always, or a great deal	**19.5**	24.0
CSHCN with 11 or more days of school absences due to illness	**12.8**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**6.3**	8.8
CSHCN without insurance at time of survey	**3.1**	3.5
Currently insured CSHCN whose insurance is inadequate	**31.0**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**14.6**	16.1
CSHCN with any unmet need for family support services	**3.1**	4.9
CSHCN needing a referral who have difficulty getting it	**14.3**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**7.9**	5.7
CSHCN without any personal doctor or nurse	**5.6**	6.5
Family-Centered Care		
CSHCN without family-centered care	**27.8**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**19.4**	20.0
CSHCN whose conditions cause financial problems for the family	**15.6**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**9.0**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**19.5**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**64.1**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**51.8**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**64.8**	62.0
CSHCN who are screened early and continuously for special health care needs	**62.1**	63.8
CSHCN whose services are organized in ways that families can use them easily	**90.1**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**54.4**	41.2

Montana

Estimated number of CSHCN: 27,853

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	13.6	13.9
Age		
Age 0–5 years	7.9	8.8
Age 6–11 years	13.9	16.0
Age 12–17 years	18.1	16.8
Sex		
Male	15.9	16.1
Female	11.3	11.6
Poverty Level		
0–99% FPL	18.0	13.9
100–199% FPL	12.8	14.0
200–399% FPL	12.5	13.6
400% FPL or more	12.2	14.0
Hispanic Origin and Race		
Non-Hispanic	13.4	15.0
White	13.4	15.5
Black	**	15.0
Asian	*	6.3
American Indian/ Alaska Native	11.2	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	15.2	17.9
Hispanic	14.0	8.3
Spanish language household	†	4.6
English language household	14.4	13.1

* 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.

† No CSHCN were identified among predominantly Spanish-speaking Hispanics in the survey sample.

Indicator	State %	National %
Child Health		
CSHCN whose conditions affect their activities usually, always, or a great deal	28.7	24.0
CSHCN with 11 or more days of school absences due to illness	18.7	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	17.4	8.8
CSHCN without insurance at time of survey	10.4	3.5
Currently insured CSHCN whose insurance is inadequate	33.5	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	21.8	16.1
CSHCN with any unmet need for family support services	7.6	4.9
CSHCN needing a referral who have difficulty getting it	23.4	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	7.4	5.7
CSHCN without any personal doctor or nurse	9.5	6.5
Family-Centered Care		
CSHCN without family-centered care	37.7	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	26.2	20.0
CSHCN whose conditions cause financial problems for the family	25.3	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	12.3	9.7
CSHCN whose conditions cause family members to cut back or stop working	22.0	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	56.5	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	45.9	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	55.2	62.0
CSHCN who are screened early and continuously for special health care needs	55.7	63.8
CSHCN whose services are organized in ways that families can use them easily	88.6	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	46.2	41.2

Nebraska

Estimated number of CSHCN: 62,759

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**14.6**	13.9
Age		
Age 0–5 years	**8.6**	8.8
Age 6–11 years	**17.4**	16.0
Age 12–17 years	**18.0**	16.8
Sex		
Male	**16.0**	16.1
Female	**13.1**	11.6
Poverty Level		
0–99% FPL	**13.8**	13.9
100–199% FPL	**14.6**	14.0
200–399% FPL	**14.5**	13.6
400% FPL or more	**15.0**	14.0
Hispanic Origin and Race		
Non-Hispanic	**15.5**	15.0
White	**15.3**	15.5
Black	**15.0**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**20.4**	17.9
Hispanic	**7.2**	8.3
Spanish language household	**	4.6
English language household	**12.1**	13.1

* 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 affect their activities usually, always, or a great deal	**19.8**	24.0
CSHCN with 11 or more days of school absences due to illness	**11.6**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**6.4**	8.8
CSHCN without insurance at time of survey	**3.1**	3.5
Currently insured CSHCN whose insurance is inadequate	**30.2**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**10.4**	16.1
CSHCN with any unmet need for family support services	**4.0**	4.9
CSHCN needing a referral who have difficulty getting it	**20.4**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**3.5**	5.7
CSHCN without any personal doctor or nurse	**4.9**	6.5
Family-Centered Care		
CSHCN without family-centered care	**28.0**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**24.6**	20.0
CSHCN whose conditions cause financial problems for the family	**18.7**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**8.6**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**17.2**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**65.7**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**54.2**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**65.9**	62.0
CSHCN who are screened early and continuously for special health care needs	**63.1**	63.8
CSHCN whose services are organized in ways that families can use them easily	**91.9**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**54.4**	41.2

Nevada

Estimated number of CSHCN: 65,900

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**10.4**	13.9
Age		
Age 0–5 years	**6.7**	8.8
Age 6–11 years	**11.1**	16.0
Age 12–17 years	**13.4**	16.8
Sex		
Male	**11.8**	16.1
Female	**8.9**	11.6
Poverty Level		
0–99% FPL	**8.6**	13.9
100–199% FPL	**10.7**	14.0
200–399% FPL	**10.7**	13.6
400% FPL or more	**10.9**	14.0
Hispanic Origin and Race		
Non-Hispanic	**12.1**	15.0
White	**12.5**	15.5
Black	**14.5**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**10.8**	17.9
Hispanic	**5.7**	8.3
Spanish language household	**3.5**	4.6
English language household	**10.3**	13.1

* 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 affect their activities usually, always, or a great deal	**28.5**	24.0
CSHCN with 11 or more days of school absences due to illness	**17.4**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**17.8**	8.8
CSHCN without insurance at time of survey	**10.2**	3.5
Currently insured CSHCN whose insurance is inadequate	**37.0**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**23.0**	16.1
CSHCN with any unmet need for family support services	**6.9**	4.9
CSHCN needing a referral who have difficulty getting it	**27.5**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**7.0**	5.7
CSHCN without any personal doctor or nurse	**7.5**	6.5
Family-Centered Care		
CSHCN without family-centered care	**40.6**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**23.7**	20.0
CSHCN whose conditions cause financial problems for the family	**23.2**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**11.7**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**27.2**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**47.5**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**41.2**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**53.5**	62.0
CSHCN who are screened early and continuously for special health care needs	**56.3**	63.8
CSHCN whose services are organized in ways that families can use them easily	**82.6**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**41.7**	41.2

New Hampshire

Estimated number of CSHCN: 50,365

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**16.6**	13.9
Age		
Age 0–5 years	**9.6**	8.8
Age 6–11 years	**18.5**	16.0
Age 12–17 years	**20.3**	16.8
Sex		
Male	**19.8**	16.1
Female	**13.1**	11.6
Poverty Level		
0–99% FPL	**22.4**	13.9
100–199% FPL	**19.2**	14.0
200–399% FPL	**16.2**	13.6
400% FPL or more	**14.9**	14.0
Hispanic Origin and Race		
Non-Hispanic	**16.4**	15.0
White	**16.3**	15.5
Black	**23.1**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**20.1**	17.9
Hispanic	**18.4**	8.3
Spanish language household	**	4.6
English language household	**25.5**	13.1

* 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 affect their activities usually, always, or a great deal	**21.9**	24.0
CSHCN with 11 or more days of school absences due to illness	**12.6**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**7.0**	8.8
CSHCN without insurance at time of survey	**2.3**	3.5
Currently insured CSHCN whose insurance is inadequate	**28.1**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**14.0**	16.1
CSHCN with any unmet need for family support services	**5.0**	4.9
CSHCN needing a referral who have difficulty getting it	**16.0**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**3.6**	5.7
CSHCN without any personal doctor or nurse	**4.4**	6.5
Family-Centered Care		
CSHCN without family-centered care	**30.0**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**18.8**	20.0
CSHCN whose conditions cause financial problems for the family	**18.6**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**6.1**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**25.5**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**60.0**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**49.6**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**67.3**	62.0
CSHCN who are screened early and continuously for special health care needs	**79.9**	63.8
CSHCN whose services are organized in ways that families can use them easily	**85.8**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**51.6**	41.2

New Jersey

Estimated number of CSHCN: 286,826

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**13.3**	13.9
Age		
Age 0–5 years	**8.1**	8.8
Age 6–11 years	**15.3**	16.0
Age 12–17 years	**16.1**	16.8
Sex		
Male	**15.9**	16.1
Female	**10.7**	11.6
Poverty Level		
0–99% FPL	**13.7**	13.9
100–199% FPL	**12.2**	14.0
200–399% FPL	**12.9**	13.6
400% FPL or more	**13.8**	14.0
Hispanic Origin and Race		
Non-Hispanic	**13.8**	15.0
White	**14.6**	15.5
Black	**13.7**	15.0
Asian	**7.7**	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**14.7**	17.9
Hispanic	**10.5**	8.3
Spanish language household	**5.0**	4.6
English language household	**16.4**	13.1

* 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 affect their activities usually, always, or a great deal	**25.0**	24.0
CSHCN with 11 or more days of school absences due to illness	**11.7**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**8.7**	8.8
CSHCN without insurance at time of survey	**3.3**	3.5
Currently insured CSHCN whose insurance is inadequate	**36.6**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**16.1**	16.1
CSHCN with any unmet need for family support services	**4.6**	4.9
CSHCN needing a referral who have difficulty getting it	**22.2**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**5.2**	5.7
CSHCN without any personal doctor or nurse	**4.7**	6.5
Family-Centered Care		
CSHCN without family-centered care	**39.1**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**25.7**	20.0
CSHCN whose conditions cause financial problems for the family	**17.4**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**12.5**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**25.5**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**55.4**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**40.8**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**59.9**	62.0
CSHCN who are screened early and continuously for special health care needs	**71.7**	63.8
CSHCN whose services are organized in ways that families can use them easily	**88.0**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**37.9**	41.2

New Mexico

Estimated number of CSHCN: 59,535

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**12.1**	13.9
Age		
Age 0–5 years	**7.3**	8.8
Age 6–11 years	**14.4**	16.0
Age 12–17 years	**14.4**	16.8
Sex		
Male	**13.6**	16.1
Female	**10.7**	11.6
Poverty Level		
0–99% FPL	**10.6**	13.9
100–199% FPL	**11.6**	14.0
200–399% FPL	**13.4**	13.6
400% FPL or more	**13.2**	14.0
Hispanic Origin and Race		
Non-Hispanic	**13.6**	15.0
White	**15.2**	15.5
Black	**13.3**	15.0
Asian	*****	6.3
American Indian/ Alaska Native	**9.2**	14.5
Native Hawaiian/ Pacific Islander	*****	11.5
Multiple races	**17.5**	17.9
Hispanic	**10.7**	8.3
Spanish language household	**4.6**	4.6
English language household	**13.6**	13.1

* 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 affect their activities usually, always, or a great deal	**25.8**	24.0
CSHCN with 11 or more days of school absences due to illness	**17.3**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**14.0**	8.8
CSHCN without insurance at time of survey	**5.5**	3.5
Currently insured CSHCN whose insurance is inadequate	**35.7**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**21.4**	16.1
CSHCN with any unmet need for family support services	**6.9**	4.9
CSHCN needing a referral who have difficulty getting it	**25.9**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**4.7**	5.7
CSHCN without any personal doctor or nurse	**7.5**	6.5
Family-Centered Care		
CSHCN without family-centered care	**38.5**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**19.9**	20.0
CSHCN whose conditions cause financial problems for the family	**20.4**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**13.0**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**25.1**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**53.2**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**41.6**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**56.6**	62.0
CSHCN who are screened early and continuously for special health care needs	**64.1**	63.8
CSHCN whose services are organized in ways that families can use them easily	**85.7**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**33.7**	41.2

New York

Estimated number of CSHCN: 572,503

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	12.7	13.9
Age		
Age 0–5 years	8.5	8.8
Age 6–11 years	14.1	16.0
Age 12–17 years	15.3	16.8
Sex		
Male	14.6	16.1
Female	10.7	11.6
Poverty Level		
0–99% FPL	12.6	13.9
100–199% FPL	13.0	14.0
200–399% FPL	13.9	13.6
400% FPL or more	11.3	14.0
Hispanic Origin and Race		
Non-Hispanic	13.5	15.0
White	13.9	15.5
Black	15.3	15.0
Asian	2.8	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	18.5	17.9
Hispanic	9.0	8.3
Spanish language household	5.8	4.6
English language household	12.6	13.1

* 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 affect their activities usually, always, or a great deal	23.7	24.0
CSHCN with 11 or more days of school absences due to illness	14.8	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	7.4	8.8
CSHCN without insurance at time of survey	2.0	3.5
Currently insured CSHCN whose insurance is inadequate	34.7	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	13.5	16.1
CSHCN with any unmet need for family support services	4.0	4.9
CSHCN needing a referral who have difficulty getting it	22.7	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	6.3	5.7
CSHCN without any personal doctor or nurse	5.2	6.5
Family-Centered Care		
CSHCN without family-centered care	33.4	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	16.8	20.0
CSHCN whose conditions cause financial problems for the family	17.8	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	8.6	9.7
CSHCN whose conditions cause family members to cut back or stop working	25.7	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	59.0	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	45.2	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	62.1	62.0
CSHCN who are screened early and continuously for special health care needs	67.7	63.8
CSHCN whose services are organized in ways that families can use them easily	90.6	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	38.4	41.2

North Carolina

Estimated number of CSHCN: 333,895

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	15.4	13.9
Age		
Age 0–5 years	10.1	8.8
Age 6–11 years	17.7	16.0
Age 12–17 years	18.4	16.8
Sex		
Male	18.1	16.1
Female	12.7	11.6
Poverty Level		
0–99% FPL	14.7	13.9
100–199% FPL	17.2	14.0
200–399% FPL	14.8	13.6
400% FPL or more	15.3	14.0
Hispanic Origin and Race		
Non-Hispanic	16.1	15.0
White	17.0	15.5
Black	14.1	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	22.8	17.9
Hispanic	6.4	8.3
Spanish language household	3.5	4.6
English language household	13.6	13.1

* 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 affect their activities usually, always, or a great deal	21.3	24.0
CSHCN with 11 or more days of school absences due to illness	13.4	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	7.1	8.8
CSHCN without insurance at time of survey	2.4	3.5
Currently insured CSHCN whose insurance is inadequate	30.8	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	14.9	16.1
CSHCN with any unmet need for family support services	4.1	4.9
CSHCN needing a referral who have difficulty getting it	13.3	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	5.8	5.7
CSHCN without any personal doctor or nurse	7.5	6.5
Family-Centered Care		
CSHCN without family-centered care	35.7	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	18.0	20.0
CSHCN whose conditions cause financial problems for the family	18.3	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	9.6	9.7
CSHCN whose conditions cause family members to cut back or stop working	22.2	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	58.3	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	46.5	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	63.7	62.0
CSHCN who are screened early and continuously for special health care needs	65.0	63.8
CSHCN whose services are organized in ways that families can use them easily	89.3	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	39.9	41.2

North Dakota

Estimated number of CSHCN: 16,541

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**12.2**	13.9
Age		
Age 0–5 years	**6.4**	8.8
Age 6–11 years	**14.6**	16.0
Age 12–17 years	**15.4**	16.8
Sex		
Male	**14.1**	16.1
Female	**10.3**	11.6
Poverty Level		
0–99% FPL	**14.4**	13.9
100–199% FPL	**13.1**	14.0
200–399% FPL	**10.8**	13.6
400% FPL or more	**12.8**	14.0
Hispanic Origin and Race		
Non-Hispanic	**12.1**	15.0
White	**12.2**	15.5
Black	**	15.0
Asian	*	6.3
American Indian/ Alaska Native	**12.1**	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**12.8**	17.9
Hispanic	**11.4**	8.3
Spanish language household	**	4.6
English language household	**12.6**	13.1

* 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 affect their activities usually, always, or a great deal	**20.4**	24.0
CSHCN with 11 or more days of school absences due to illness	**12.8**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**9.6**	8.8
CSHCN without insurance at time of survey	**5.3**	3.5
Currently insured CSHCN whose insurance is inadequate	**26.1**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**10.9**	16.1
CSHCN with any unmet need for family support services	**3.5**	4.9
CSHCN needing a referral who have difficulty getting it	**15.6**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**6.3**	5.7
CSHCN without any personal doctor or nurse	**7.3**	6.5
Family-Centered Care		
CSHCN without family-centered care	**30.9**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**21.9**	20.0
CSHCN whose conditions cause financial problems for the family	**18.5**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**9.1**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**18.1**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**63.0**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**51.2**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**67.9**	62.0
CSHCN who are screened early and continuously for special health care needs	**57.5**	63.8
CSHCN whose services are organized in ways that families can use them easily	**92.3**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**51.2**	41.2

Ohio

Estimated number of CSHCN: 445,205 | **All statistics are based on parental reports**

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**16.2**	13.9
Age		
Age 0–5 years	**9.7**	8.8
Age 6–11 years	**19.6**	16.0
Age 12–17 years	**19.0**	16.8
Sex		
Male	**18.4**	16.1
Female	**13.7**	11.6
Poverty Level		
0–99% FPL	**19.0**	13.9
100–199% FPL	**17.6**	14.0
200–399% FPL	**14.4**	13.6
400% FPL or more	**15.7**	14.0
Hispanic Origin and Race		
Non-Hispanic	**16.1**	15.0
White	**15.4**	15.5
Black	**20.1**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**17.0**	17.9
Hispanic	**14.9**	8.3
Spanish language household	**	4.6
English language household	**18.1**	13.1

* 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 affect their activities usually, always, or a great deal	**25.2**	24.0
CSHCN with 11 or more days of school absences due to illness	**15.4**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**7.1**	8.8
CSHCN without insurance at time of survey	**2.1**	3.5
Currently insured CSHCN whose insurance is inadequate	**32.0**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**14.2**	16.1
CSHCN with any unmet need for family support services	**4.6**	4.9
CSHCN needing a referral who have difficulty getting it	**13.8**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**5.2**	5.7
CSHCN without any personal doctor or nurse	**5.4**	6.5
Family-Centered Care		
CSHCN without family-centered care	**27.5**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**16.6**	20.0
CSHCN whose conditions cause financial problems for the family	**16.0**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**10.0**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**23.4**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**65.4**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**55.6**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**64.6**	62.0
CSHCN who are screened early and continuously for special health care needs	**65.1**	63.8
CSHCN whose services are organized in ways that families can use them easily	**92.2**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**48.5**	41.2

Oklahoma

Estimated number of CSHCN: 141,129

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**16.5**	13.9
Age		
Age 0–5 years	**11.2**	8.8
Age 6–11 years	**19.5**	16.0
Age 12–17 years	**19.1**	16.8
Sex		
Male	**18.9**	16.1
Female	**14.1**	11.6
Poverty Level		
0–99% FPL	**18.3**	13.9
100–199% FPL	**17.0**	14.0
200–399% FPL	**15.3**	13.6
400% FPL or more	**16.3**	14.0
Hispanic Origin and Race		
Non-Hispanic	**16.9**	15.0
White	**16.0**	15.5
Black	**17.8**	15.0
Asian	*	6.3
American Indian/ Alaska Native	**19.4**	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**23.3**	17.9
Hispanic	**9.3**	8.3
Spanish language household	**	4.6
English language household	**16.1**	13.1

* 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 affect their activities usually, always, or a great deal	**26.4**	24.0
CSHCN with 11 or more days of school absences due to illness	**14.3**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**12.3**	8.8
CSHCN without insurance at time of survey	**4.9**	3.5
Currently insured CSHCN whose insurance is inadequate	**31.5**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**18.5**	16.1
CSHCN with any unmet need for family support services	**5.5**	4.9
CSHCN needing a referral who have difficulty getting it	**19.8**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**5.1**	5.7
CSHCN without any personal doctor or nurse	**8.0**	6.5
Family-Centered Care		
CSHCN without family-centered care	**32.8**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**19.9**	20.0
CSHCN whose conditions cause financial problems for the family	**19.8**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**9.0**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**18.9**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**56.9**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**49.7**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**61.6**	62.0
CSHCN who are screened early and continuously for special health care needs	**61.4**	63.8
CSHCN whose services are organized in ways that families can use them easily	**90.3**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**43.7**	41.2

Oregon

Estimated number of CSHCN: 116,988

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**13.7**	13.9
Age		
Age 0–5 years	**8.6**	8.8
Age 6–11 years	**14.7**	16.0
Age 12–17 years	**17.3**	16.8
Sex		
Male	**14.8**	16.1
Female	**12.4**	11.6
Poverty Level		
0–99% FPL	**12.6**	13.9
100–199% FPL	**15.6**	14.0
200–399% FPL	**12.9**	13.6
400% FPL or more	**13.6**	14.0
Hispanic Origin and Race		
Non-Hispanic	**14.4**	15.0
White	**14.5**	15.5
Black	**14.8**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**18.1**	17.9
Hispanic	**8.7**	8.3
Spanish language household	**5.5**	4.6
English language household	**12.9**	13.1

* 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 affect their activities usually, always, or a great deal	**30.3**	24.0
CSHCN with 11 or more days of school absences due to illness	**18.8**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**11.2**	8.8
CSHCN without insurance at time of survey	**5.7**	3.5
Currently insured CSHCN whose insurance is inadequate	**31.3**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**21.7**	16.1
CSHCN with any unmet need for family support services	**6.3**	4.9
CSHCN needing a referral who have difficulty getting it	**23.5**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**6.0**	5.7
CSHCN without any personal doctor or nurse	**7.1**	6.5
Family-Centered Care		
CSHCN without family-centered care	**31.1**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**20.0**	20.0
CSHCN whose conditions cause financial problems for the family	**18.1**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**8.7**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**29.2**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**55.5**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**47.4**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**61.5**	62.0
CSHCN who are screened early and continuously for special health care needs	**60.0**	63.8
CSHCN whose services are organized in ways that families can use them easily	**88.3**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**43.7**	41.2

Pennsylvania

Estimated number of CSHCN: 430,640

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**15.4**	13.9
Age		
Age 0–5 years	**8.8**	8.8
Age 6–11 years	**17.2**	16.0
Age 12–17 years	**19.4**	16.8
Sex		
Male	**17.8**	16.1
Female	**12.8**	11.6
Poverty Level		
0–99% FPL	**17.5**	13.9
100–199% FPL	**17.2**	14.0
200–399% FPL	**14.1**	13.6
400% FPL or more	**14.1**	14.0
Hispanic Origin and Race		
Non-Hispanic	**15.1**	15.0
White	**14.8**	15.5
Black	**18.1**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**15.7**	17.9
Hispanic	**13.6**	8.3
Spanish language household	**6.9**	4.6
English language household	**17.2**	13.1

* 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 affect their activities usually, always, or a great deal	**25.0**	24.0
CSHCN with 11 or more days of school absences due to illness	**15.2**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**7.6**	8.8
CSHCN without insurance at time of survey	**2.0**	3.5
Currently insured CSHCN whose insurance is inadequate	**30.1**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**16.1**	16.1
CSHCN with any unmet need for family support services	**4.8**	4.9
CSHCN needing a referral who have difficulty getting it	**28.0**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**4.5**	5.7
CSHCN without any personal doctor or nurse	**5.6**	6.5
Family-Centered Care		
CSHCN without family-centered care	**33.6**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**16.8**	20.0
CSHCN whose conditions cause financial problems for the family	**18.2**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**11.0**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**24.4**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**60.6**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**45.8**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**66.2**	62.0
CSHCN who are screened early and continuously for special health care needs	**69.7**	63.8
CSHCN whose services are organized in ways that families can use them easily	**89.5**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**46.0**	41.2

Rhode Island

Estimated number of CSHCN: 41,783

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**17.2**	13.9
Age		
Age 0–5 years	**10.1**	8.8
Age 6–11 years	**19.9**	16.0
Age 12–17 years	**20.7**	16.8
Sex		
Male	**20.8**	16.1
Female	**13.5**	11.6
Poverty Level		
0–99% FPL	**19.9**	13.9
100–199% FPL	**21.0**	14.0
200–399% FPL	**15.8**	13.6
400% FPL or more	**14.8**	14.0
Hispanic Origin and Race		
Non-Hispanic	**17.7**	15.0
White	**18.3**	15.5
Black	**14.6**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**23.2**	17.9
Hispanic	**12.4**	8.3
Spanish language household	**8.2**	4.6
English language household	**21.0**	13.1

* 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 affect their activities usually, always, or a great deal	**21.3**	24.0
CSHCN with 11 or more days of school absences due to illness	**14.9**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**6.2**	8.8
CSHCN without insurance at time of survey	**1.4**	3.5
Currently insured CSHCN whose insurance is inadequate	**26.8**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**12.6**	16.1
CSHCN with any unmet need for family support services	**4.3**	4.9
CSHCN needing a referral who have difficulty getting it	**10.2**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**4.7**	5.7
CSHCN without any personal doctor or nurse	**2.3**	6.5
Family-Centered Care		
CSHCN without family-centered care	**30.1**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**12.6**	20.0
CSHCN whose conditions cause financial problems for the family	**14.0**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**9.6**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**23.0**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**61.4**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**50.9**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**68.2**	62.0
CSHCN who are screened early and continuously for special health care needs	**74.2**	63.8
CSHCN whose services are organized in ways that families can use them easily	**87.6**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**37.6**	41.2

South Carolina

Estimated number of CSHCN: 157,802

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**15.2**	13.9
Age		
Age 0–5 years	**10.2**	8.8
Age 6–11 years	**18.6**	16.0
Age 12–17 years	**16.7**	16.8
Sex		
Male	**18.6**	16.1
Female	**11.9**	11.6
Poverty Level		
0–99% FPL	**17.4**	13.9
100–199% FPL	**16.0**	14.0
200–399% FPL	**14.0**	13.6
400% FPL or more	**14.3**	14.0
Hispanic Origin and Race		
Non-Hispanic	**15.3**	15.0
White	**16.0**	15.5
Black	**14.0**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**17.9**	17.9
Hispanic	**6.7**	8.3
Spanish language household	**	4.6
English language household	**14.3**	13.1

* 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 affect their activities usually, always, or a great deal	**20.7**	24.0
CSHCN with 11 or more days of school absences due to illness	**14.2**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**9.1**	8.8
CSHCN without insurance at time of survey	**5.2**	3.5
Currently insured CSHCN whose insurance is inadequate	**33.0**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**14.1**	16.1
CSHCN with any unmet need for family support services	**5.7**	4.9
CSHCN needing a referral who have difficulty getting it	**14.5**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**5.4**	5.7
CSHCN without any personal doctor or nurse	**4.8**	6.5
Family-Centered Care		
CSHCN without family-centered care	**30.7**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**18.2**	20.0
CSHCN whose conditions cause financial problems for the family	**20.5**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**10.9**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**21.8**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**60.4**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**53.1**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**61.2**	62.0
CSHCN who are screened early and continuously for special health care needs	**60.0**	63.8
CSHCN whose services are organized in ways that families can use them easily	**91.7**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**37.2**	41.2

South Dakota

Estimated number of CSHCN: 23,644

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**12.6**	13.9
Age		
Age 0–5 years	**8.3**	8.8
Age 6–11 years	**14.6**	16.0
Age 12–17 years	**15.1**	16.8
Sex		
Male	**13.8**	16.1
Female	**11.4**	11.6
Poverty Level		
0–99% FPL	**13.3**	13.9
100–199% FPL	**12.4**	14.0
200–399% FPL	**12.4**	13.6
400% FPL or more	**12.7**	14.0
Hispanic Origin and Race		
Non-Hispanic	**12.6**	15.0
White	**12.8**	15.5
Black	**	15.0
Asian	*	6.3
American Indian/ Alaska Native	**11.5**	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**15.6**	17.9
Hispanic	**8.9**	8.3
Spanish language household	**	4.6
English language household	**11.5**	13.1

* 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 affect their activities usually, always, or a great deal	**22.8**	24.0
CSHCN with 11 or more days of school absences due to illness	**13.3**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**6.6**	8.8
CSHCN without insurance at time of survey	**3.3**	3.5
Currently insured CSHCN whose insurance is inadequate	**29.7**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**11.6**	16.1
CSHCN with any unmet need for family support services	**4.9**	4.9
CSHCN needing a referral who have difficulty getting it	**16.6**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**4.4**	5.7
CSHCN without any personal doctor or nurse	**3.9**	6.5
Family-Centered Care		
CSHCN without family-centered care	**30.2**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**23.9**	20.0
CSHCN whose conditions cause financial problems for the family	**19.9**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**8.8**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**21.0**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**63.4**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**53.8**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**66.6**	62.0
CSHCN who are screened early and continuously for special health care needs	**56.3**	63.8
CSHCN whose services are organized in ways that families can use them easily	**90.4**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**50.6**	41.2

Tennessee

Estimated number of CSHCN: 229,744

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**16.4**	13.9
Age		
Age 0–5 years	**11.9**	8.8
Age 6–11 years	**18.5**	16.0
Age 12–17 years	**18.9**	16.8
Sex		
Male	**18.1**	16.1
Female	**14.7**	11.6
Poverty Level		
0–99% FPL	**20.4**	13.9
100–199% FPL	**15.3**	14.0
200–399% FPL	**14.2**	13.6
400% FPL or more	**17.3**	14.0
Hispanic Origin and Race		
Non-Hispanic	**16.5**	15.0
White	**16.8**	15.5
Black	**14.5**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**21.9**	17.9
Hispanic	**10.9**	8.3
Spanish language household	**	4.6
English language household	**19.5**	13.1

* 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 affect their activities usually, always, or a great deal	**22.8**	24.0
CSHCN with 11 or more days of school absences due to illness	**14.3**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**6.9**	8.8
CSHCN without insurance at time of survey	**3.2**	3.5
Currently insured CSHCN whose insurance is inadequate	**28.3**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**14.2**	16.1
CSHCN with any unmet need for family support services	**3.0**	4.9
CSHCN needing a referral who have difficulty getting it	**15.3**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**5.0**	5.7
CSHCN without any personal doctor or nurse	**6.4**	6.5
Family-Centered Care		
CSHCN without family-centered care	**30.7**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**22.6**	20.0
CSHCN whose conditions cause financial problems for the family	**17.9**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**11.1**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**22.8**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**60.7**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**52.7**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**67.7**	62.0
CSHCN who are screened early and continuously for special health care needs	**59.8**	63.8
CSHCN whose services are organized in ways that families can use them easily	**91.8**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**39.6**	41.2

Texas

Estimated number of CSHCN: 806,746

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**12.6**	13.9
Age		
Age 0–5 years	**8.3**	8.8
Age 6–11 years	**14.7**	16.0
Age 12–17 years	**15.1**	16.8
Sex		
Male	**14.7**	16.1
Female	**10.5**	11.6
Poverty Level		
0–99% FPL	**9.6**	13.9
100–199% FPL	**11.5**	14.0
200–399% FPL	**14.0**	13.6
400% FPL or more	**15.4**	14.0
Hispanic Origin and Race		
Non-Hispanic	**15.6**	15.0
White	**16.6**	15.5
Black	**14.0**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**17.4**	17.9
Hispanic	**8.6**	8.3
Spanish language household	**4.6**	4.6
English language household	**13.9**	13.1

* 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 affect their activities usually, always, or a great deal	**22.8**	24.0
CSHCN with 11 or more days of school absences due to illness	**12.9**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**14.9**	8.8
CSHCN without insurance at time of survey	**6.7**	3.5
Currently insured CSHCN whose insurance is inadequate	**33.7**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**17.6**	16.1
CSHCN with any unmet need for family support services	**4.6**	4.9
CSHCN needing a referral who have difficulty getting it	**25.4**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**4.8**	5.7
CSHCN without any personal doctor or nurse	**8.5**	6.5
Family-Centered Care		
CSHCN without family-centered care	**37.8**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**19.5**	20.0
CSHCN whose conditions cause financial problems for the family	**18.8**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**9.4**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**25.3**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**57.9**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**46.3**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**58.2**	62.0
CSHCN who are screened early and continuously for special health care needs	**58.6**	63.8
CSHCN whose services are organized in ways that families can use them easily	**88.2**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**37.1**	41.2

Utah

Estimated number of CSHCN: 82,502

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**11.0**	13.9
Age		
Age 0–5 years	**6.0**	8.8
Age 6–11 years	**12.2**	16.0
Age 12–17 years	**16.0**	16.8
Sex		
Male	**12.5**	16.1
Female	**9.4**	11.6
Poverty Level		
0–99% FPL	**9.0**	13.9
100–199% FPL	**10.7**	14.0
200–399% FPL	**11.0**	13.6
400% FPL or more	**12.3**	14.0
Hispanic Origin and Race		
Non-Hispanic	**11.4**	15.0
White	**11.5**	15.5
Black	**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**10.6**	17.9
Hispanic	**6.8**	8.3
Spanish language household	**2.6**	4.6
English language household	**12.3**	13.1

* 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 affect their activities usually, always, or a great deal	**28.1**	24.0
CSHCN with 11 or more days of school absences due to illness	**16.4**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**11.4**	8.8
CSHCN without insurance at time of survey	**4.2**	3.5
Currently insured CSHCN whose insurance is inadequate	**34.1**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**20.2**	16.1
CSHCN with any unmet need for family support services	**8.4**	4.9
CSHCN needing a referral who have difficulty getting it	**19.0**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**4.0**	5.7
CSHCN without any personal doctor or nurse	**5.0**	6.5
Family-Centered Care		
CSHCN without family-centered care	**31.4**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**26.4**	20.0
CSHCN whose conditions cause financial problems for the family	**22.1**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**7.8**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**19.9**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**55.1**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**52.3**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**59.5**	62.0
CSHCN who are screened early and continuously for special health care needs	**62.1**	63.8
CSHCN whose services are organized in ways that families can use them easily	**86.2**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**42.5**	41.2

Vermont

Estimated number of CSHCN: 19,937

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**15.0**	13.9
Age		
Age 0–5 years	**7.6**	8.8
Age 6–11 years	**16.7**	16.0
Age 12–17 years	**19.1**	16.8
Sex		
Male	**17.2**	16.1
Female	**12.6**	11.6
Poverty Level		
0–99% FPL	**23.8**	13.9
100–199% FPL	**18.3**	14.0
200–399% FPL	**13.0**	13.6
400% FPL or more	**13.1**	14.0
Hispanic Origin and Race		
Non-Hispanic	**14.8**	15.0
White	**14.5**	15.5
Black	**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**21.3**	17.9
Hispanic	**21.1**	8.3
Spanish language household	†	4.6
English language household	**22.7**	13.1

* 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.

† No CSHCN were identified among predominantly Spanish-speaking Hispanics in the survey sample.

Indicator	State %	National %
Child Health		
CSHCN whose conditions affect their activities usually, always, or a great deal	**21.7**	24.0
CSHCN with 11 or more days of school absences due to illness	**12.3**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**6.6**	8.8
CSHCN without insurance at time of survey	**2.1**	3.5
Currently insured CSHCN whose insurance is inadequate	**25.8**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**12.9**	16.1
CSHCN with any unmet need for family support services	**6.3**	4.9
CSHCN needing a referral who have difficulty getting it	**17.3**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**4.5**	5.7
CSHCN without any personal doctor or nurse	**3.0**	6.5
Family-Centered Care		
CSHCN without family-centered care	**27.8**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**16.3**	20.0
CSHCN whose conditions cause financial problems for the family	**15.2**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**8.2**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**22.5**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**59.8**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**51.6**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**69.4**	62.0
CSHCN who are screened early and continuously for special health care needs	**74.4**	63.8
CSHCN whose services are organized in ways that families can use them easily	**89.3**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**52.0**	41.2

Virginia

Estimated number of CSHCN: 289,176

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**15.8**	13.9
Age		
Age 0–5 years	**8.4**	8.8
Age 6–11 years	**20.1**	16.0
Age 12–17 years	**19.1**	16.8
Sex		
Male	**18.3**	16.1
Female	**13.3**	11.6
Poverty Level		
0–99% FPL	**22.0**	13.9
100–199% FPL	**14.3**	14.0
200–399% FPL	**14.1**	13.6
400% FPL or more	**15.9**	14.0
Hispanic Origin and Race		
Non-Hispanic	**16.4**	15.0
White	**17.1**	15.5
Black	**17.3**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**16.5**	17.9
Hispanic	**6.0**	8.3
Spanish language household	**	4.6
English language household	**14.0**	13.1

* 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 affect their activities usually, always, or a great deal	**22.1**	24.0
CSHCN with 11 or more days of school absences due to illness	**14.4**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**7.6**	8.8
CSHCN without insurance at time of survey	**2.0**	3.5
Currently insured CSHCN whose insurance is inadequate	**31.7**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**13.1**	16.1
CSHCN with any unmet need for family support services	**6.0**	4.9
CSHCN needing a referral who have difficulty getting it	**20.8**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**5.4**	5.7
CSHCN without any personal doctor or nurse	**6.6**	6.5
Family-Centered Care		
CSHCN without family-centered care	**34.6**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**22.7**	20.0
CSHCN whose conditions cause financial problems for the family	**17.4**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**8.1**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**24.9**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**59.8**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**43.9**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**63.7**	62.0
CSHCN who are screened early and continuously for special health care needs	**64.5**	63.8
CSHCN whose services are organized in ways that families can use them easily	**89.6**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**37.8**	41.2

Washington

Estimated number of CSHCN: 214,583

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**14.4**	13.9
Age		
Age 0–5 years	**8.1**	8.8
Age 6–11 years	**16.0**	16.0
Age 12–17 years	**18.5**	16.8
Sex		
Male	**16.3**	16.1
Female	**12.4**	11.6
Poverty Level		
0–99% FPL	**14.1**	13.9
100–199% FPL	**17.6**	14.0
200–399% FPL	**13.7**	13.6
400% FPL or more	**13.1**	14.0
Hispanic Origin and Race		
Non-Hispanic	**15.0**	15.0
White	**14.8**	15.5
Black	**21.4**	15.0
Asian	**6.7**	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**20.0**	17.9
Hispanic	**7.8**	8.3
Spanish language household	**4.4**	4.6
English language household	**12.3**	13.1

* 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 affect their activities usually, always, or a great deal	**26.6**	24.0
CSHCN with 11 or more days of school absences due to illness	**18.4**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**8.3**	8.8
CSHCN without insurance at time of survey	**3.2**	3.5
Currently insured CSHCN whose insurance is inadequate	**29.3**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**21.5**	16.1
CSHCN with any unmet need for family support services	**7.6**	4.9
CSHCN needing a referral who have difficulty getting it	**24.6**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**4.0**	5.7
CSHCN without any personal doctor or nurse	**6.3**	6.5
Family-Centered Care		
CSHCN without family-centered care	**31.7**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**18.6**	20.0
CSHCN whose conditions cause financial problems for the family	**19.1**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**6.3**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**22.7**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**55.7**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**48.3**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**65.3**	62.0
CSHCN who are screened early and continuously for special health care needs	**68.5**	63.8
CSHCN whose services are organized in ways that families can use them easily	**85.4**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**47.3**	41.2

West Virginia

Estimated number of CSHCN: 69,567

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**18.3**	13.9
Age		
Age 0–5 years	**11.4**	8.8
Age 6–11 years	**20.5**	16.0
Age 12–17 years	**22.1**	16.8
Sex		
Male	**20.4**	16.1
Female	**16.0**	11.6
Poverty Level		
0–99% FPL	**23.6**	13.9
100–199% FPL	**19.4**	14.0
200–399% FPL	**15.6**	13.6
400% FPL or more	**14.9**	14.0
Hispanic Origin and Race		
Non-Hispanic	**18.1**	15.0
White	**17.9**	15.5
Black	**14.2**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**30.2**	17.9
Hispanic	**19.6**	8.3
Spanish language household	**	4.6
English language household	**20.2**	13.1

* 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 affect their activities usually, always, or a great deal	**26.9**	24.0
CSHCN with 11 or more days of school absences due to illness	**22.3**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**6.8**	8.8
CSHCN without insurance at time of survey	**1.9**	3.5
Currently insured CSHCN whose insurance is inadequate	**31.7**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**14.0**	16.1
CSHCN with any unmet need for family support services	**4.5**	4.9
CSHCN needing a referral who have difficulty getting it	**19.7**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**5.4**	5.7
CSHCN without any personal doctor or nurse	**3.5**	6.5
Family-Centered Care		
CSHCN without family-centered care	**31.6**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**18.0**	20.0
CSHCN whose conditions cause financial problems for the family	**18.2**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**14.3**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**21.1**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**59.2**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**50.5**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**64.2**	62.0
CSHCN who are screened early and continuously for special health care needs	**64.6**	63.8
CSHCN whose services are organized in ways that families can use them easily	**89.7**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**41.3**	41.2

Wisconsin

Estimated number of CSHCN: 197,791

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**15.3**	13.9
Age		
Age 0–5 years	**9.5**	8.8
Age 6–11 years	**17.5**	16.0
Age 12–17 years	**18.3**	16.8
Sex		
Male	**17.6**	16.1
Female	**12.9**	11.6
Poverty Level		
0–99% FPL	**17.7**	13.9
100–199% FPL	**14.8**	14.0
200–399% FPL	**14.7**	13.6
400% FPL or more	**15.0**	14.0
Hispanic Origin and Race		
Non-Hispanic	**15.6**	15.0
White	**15.1**	15.5
Black	**19.0**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**18.1**	17.9
Hispanic	**10.0**	8.3
Spanish language household	**	4.6
English language household	**16.9**	13.1

* 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 affect their activities usually, always, or a great deal	**23.2**	24.0
CSHCN with 11 or more days of school absences due to illness	**11.4**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**6.4**	8.8
CSHCN without insurance at time of survey	**1.6**	3.5
Currently insured CSHCN whose insurance is inadequate	**34.4**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**15.5**	16.1
CSHCN with any unmet need for family support services	**5.9**	4.9
CSHCN needing a referral who have difficulty getting it	**15.1**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**5.1**	5.7
CSHCN without any personal doctor or nurse	**5.2**	6.5
Family-Centered Care		
CSHCN without family-centered care	**28.8**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**20.2**	20.0
CSHCN whose conditions cause financial problems for the family	**17.2**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**9.6**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**21.7**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**65.3**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**54.6**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**63.0**	62.0
CSHCN who are screened early and continuously for special health care needs	**62.0**	63.8
CSHCN whose services are organized in ways that families can use them easily	**90.0**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**44.5**	41.2

Wyoming

Estimated number of CSHCN: 16,456

All statistics are based on parental reports

Prevalence of CSHCN	State %	National %
Percent of children who have special health care needs	**14.5**	13.9
Age		
Age 0–5 years	**8.6**	8.8
Age 6–11 years	**17.6**	16.0
Age 12–17 years	**17.0**	16.8
Sex		
Male	**16.6**	16.1
Female	**12.2**	11.6
Poverty Level		
0–99% FPL	**20.9**	13.9
100–199% FPL	**13.8**	14.0
200–399% FPL	**13.9**	13.6
400% FPL or more	**12.9**	14.0
Hispanic Origin and Race		
Non-Hispanic	**14.5**	15.0
White	**14.4**	15.5
Black	**	15.0
Asian	*	6.3
American Indian/ Alaska Native	*	14.5
Native Hawaiian/ Pacific Islander	*	11.5
Multiple races	**20.8**	17.9
Hispanic	**12.6**	8.3
Spanish language household	**	4.6
English language household	**15.2**	13.1

* 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 affect their activities usually, always, or a great deal	**23.7**	24.0
CSHCN with 11 or more days of school absences due to illness	**18.0**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	**8.8**	8.8
CSHCN without insurance at time of survey	**3.6**	3.5
Currently insured CSHCN whose insurance is inadequate	**34.9**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**15.7**	16.1
CSHCN with any unmet need for family support services	**4.1**	4.9
CSHCN needing a referral who have difficulty getting it	**19.2**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**5.1**	5.7
CSHCN without any personal doctor or nurse	**6.7**	6.5
Family-Centered Care		
CSHCN without family-centered care	**32.8**	34.5
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**29.2**	20.0
CSHCN whose conditions cause financial problems for the family	**21.3**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	**12.0**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**22.8**	23.8

Core Outcomes (Percent of CSHCN achieving outcome)	State %	National %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**57.5**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**49.1**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**60.0**	62.0
CSHCN who are screened early and continuously for special health care needs	**63.4**	63.8
CSHCN whose services are organized in ways that families can use them easily	**88.8**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**47.0**	41.2

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.[8]

Over 4 million telephone numbers were randomly generated for inclusion in the NS-CSHCN. After eliminating numbers that were determined to be non-residential, nonworking, or assigned to cell phones, the remaining numbers were called to identify households with children under 18 years of age. 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.

Estimates for Louisiana are based on interviews conducted in 2006 only; interviews conducted before the August and September 2005 hurricanes are not included.

Questionnaire

CSHCN were identified using the CSHCN Screener, which consists of five questions concerning common health care consequences 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, 944 special-needs interviews were conducted in Spanish and 21 were conducted in the four Asian languages.

The respondent was the parent or guardian in the household who was most knowledgeable about the health and health care of the children under 18 years of age. For 78 percent of the children, the respondent was the mother. Respondents for the remaining children were fathers (16 percent) or other relatives or guardians (6 percent).

Data Collection

Data collection began on April 5, 2005 and ended on February 5, 2007, with interviews conducted from telephone centers in Chicago, Illinois; Downers Grove, Illinois; and Las Vegas, Nevada. A computer-assisted telephone interviewing system was used to collect the data. From 192,083 households with children, 364,481 children were screened for special health care needs and 40,465 interviews were completed regarding CSHCN. 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 96.2 percent. 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 56.1 percent. Overall response rates ranged from 49.3 percent in New Jersey to 68.3 percent in North Dakota.

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. Census Bureau, 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 1.3 percentage points. For State prevalence estimates, the maximum margin of error is 1.3 percentage points. For the State indicators, the maximum margin of error is 7.4 percentage points, though most of the State indicators have a margin of error less than 4 percentage points.

Availability of the Data

Except for data suppressed to protect the confidentiality of the survey subjects, all data collected in the NS-CSHCN are available to the public on the NCHS and HRSA's Maternal and Child Health Bureau 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 online.

Endnotes

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