

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).

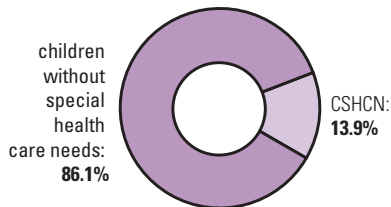
One of the major goals of the NS-CSHCN is to determine the proportion of children (from birth through 17 years of age), nationally and in each State, who meet this definition. However, because of the difficulty of including the range of factors that might place children at increased risk for special 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.

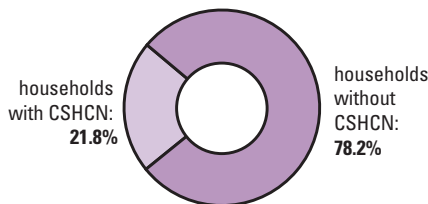


Prevalence of CSHCN: Individuals and Households

Prevalence of CSHCN: Individuals



Prevalence of CSHCN: Households*

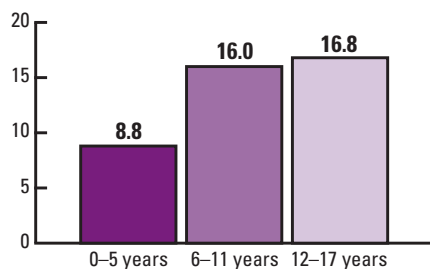


*Includes only households with children.

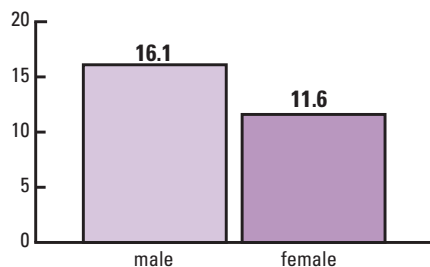
One purpose of the NS-CSHCN was to estimate the prevalence of CSHCN in the population nationally and in each State. CSHCN were identified by asking parents if their child used more medical care, mental health services, or educational services than is usual for most children of the same age; if the child 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.

Prevalence of CSHCN: Age



Prevalence of CSHCN: Sex



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).

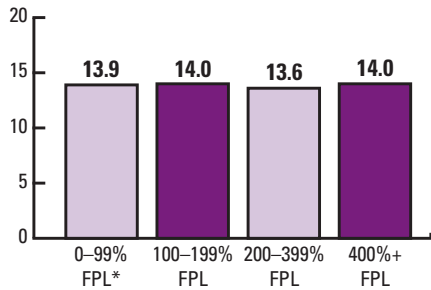
Prevalence of CSHCN: Age and Sex

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: Family Income, Race/Ethnicity, and Primary Language

Prevalence of CSHCN: Family Income

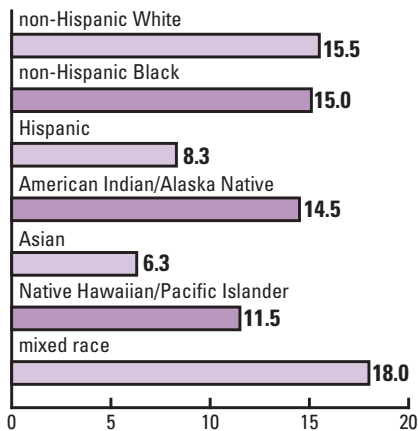


*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as \$19,350 for a family of four.

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.

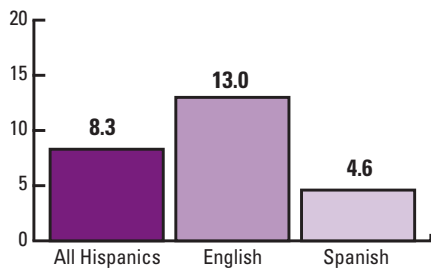
The prevalence of special health care needs varies by the race/ethnicity of the child. The prevalence of special health care needs is highest among multiracial children (18.0 percent), followed by non-Hispanic White (15.5 percent), non-Hispanic Black (15.0 percent), American Indian/Alaska Native (14.5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

Prevalence of CSHCN: Race/Ethnicity



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 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.

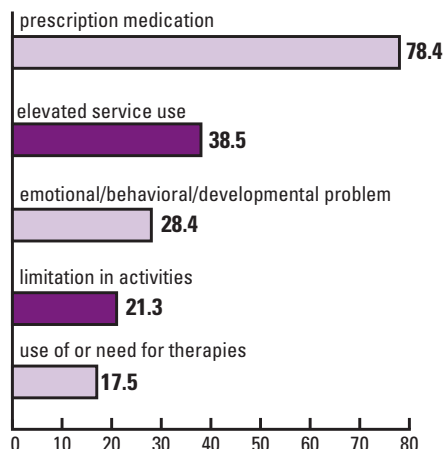
Types of special health care needs are described in three ways. First, we discuss the consequences of children's conditions: that is, the types of services or treatments that children require or the effect of the condition on the child's functional abilities. Next, we group these functional impacts into 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.

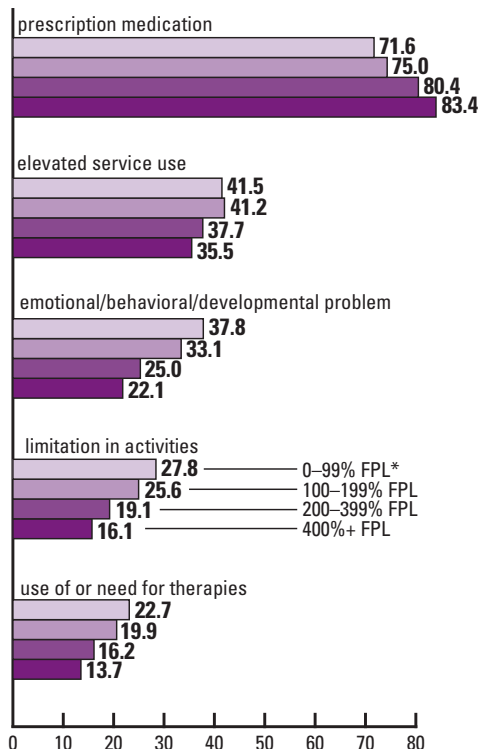
The survey also measured one specific aspect that is important to all children of school age: the number of school days missed due to both chronic and acute conditions during the year.



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.

Consequences of Special Needs

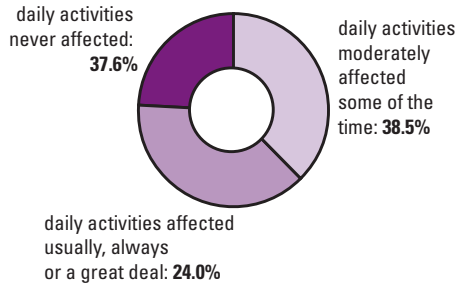
The screening questions used in the survey to identify CSHCN included five major components. In addition to the existence of a condition that has lasted or is expected to last at least 1 year, the respondent must report that the condition had at least one of the following consequences for the child:

- 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 on the Child

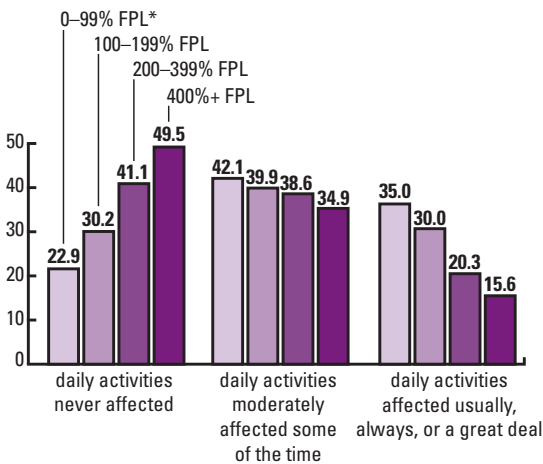
The survey measured the impact of the child's special need through two questions:

- 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.

Impact of Child's Condition: Family Income

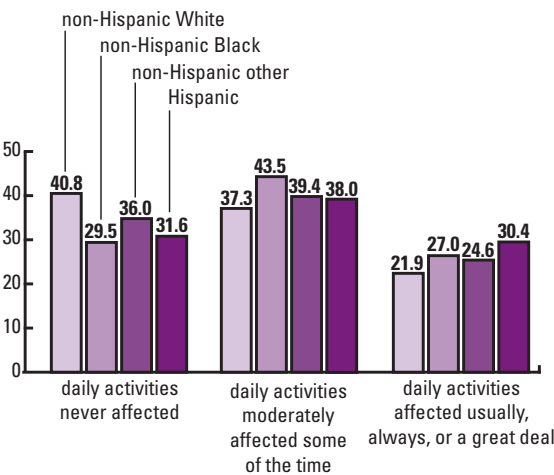


*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as \$19,350 for a family of four.

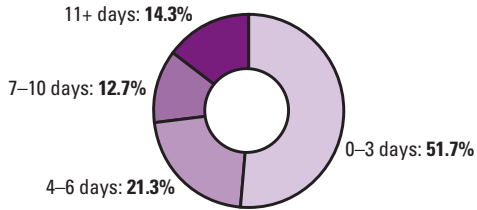
The percentage of children who are affected by their conditions usually, always, or a great deal is more than twice as high among children in low-income families as among those in families in the highest income group. Overall, 35 percent of children in poverty are affected usually, always, or a great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

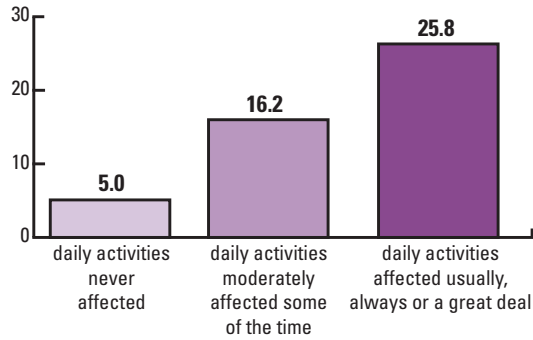
Impact of Child's Condition: Race/Ethnicity



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

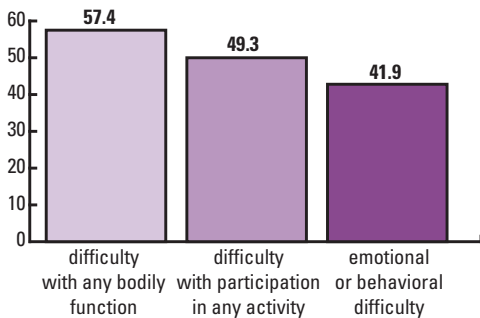


Missed School Days

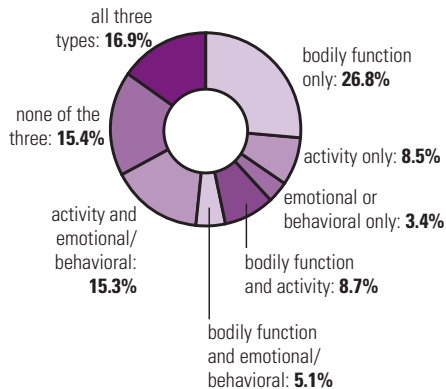
The number of days of school a child misses during the year is another measure of the impact of a child’s condition on his or her ability to function as other children do. In general, the average child misses 3 days of school due to acute conditions.⁶ In comparison, among school-aged CSHCN, the average 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.

Types of Functional Difficulties Among CSHCN



Distribution of Functional Difficulties Among CSHCN



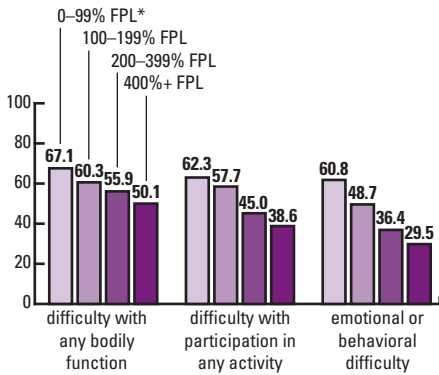
Functional Difficulties

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.

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

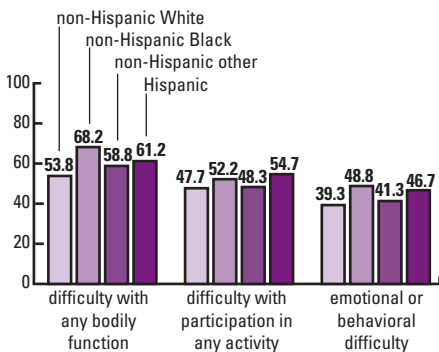


*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as \$19,350 for a family of four.

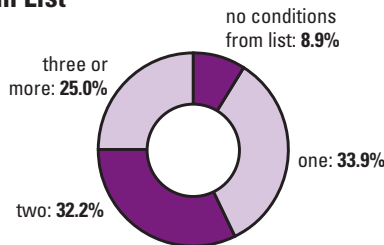
Children with lower family incomes were more likely to be reported to have each kind of functional difficulty than children with higher family incomes. The difference was most pronounced for emotional or behavioral difficulties: 61 percent of CSHCN in poverty were reported to have difficulties in this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

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



Number of Conditions Reported From List



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.

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 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.

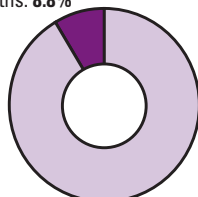
For children with insurance, the survey also assesses parents’ perceptions of the adequacy of that coverage. To do this, the survey measured whether the plan offers benefits and services that meet the child’s needs, whether the family considers any costs not covered by the plan to be reasonable, and 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

Health Insurance Coverage for CSHCN in the Past 12 Months

ever uninsured in past 12 months: **8.8%**

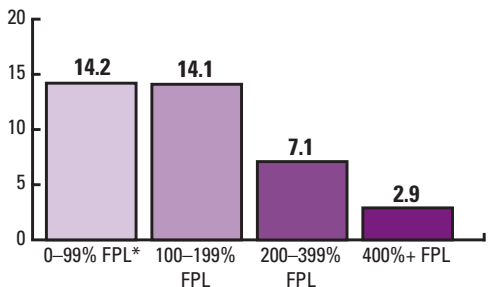


insured full year: **91.2%**

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.

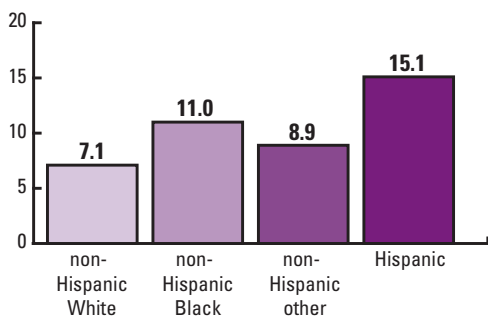
Percent of CSHCN Ever Uninsured in the Past 12 Months: Family Income



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

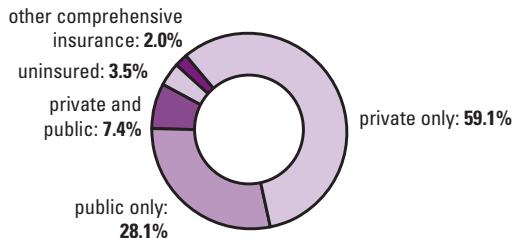
Health insurance coverage among CSHCN varies by income level. CSHCN with family incomes below 100 percent of poverty and CSHCN with family incomes between 100 and 199 percent of poverty are the most likely to have been uninsured at some point during the past year (14 percent of each group). Children 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.

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



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 Current Insurance Coverage for CSHCN

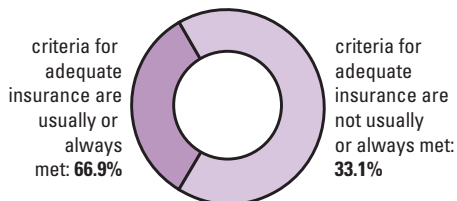


Type of Health Insurance Coverage

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).

Percent of Insured CSHCN with Inadequate Insurance



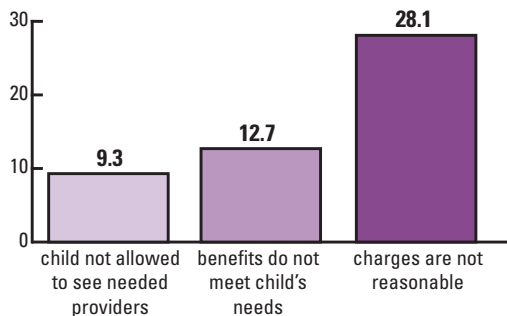
Adequacy of Current Insurance Coverage

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.

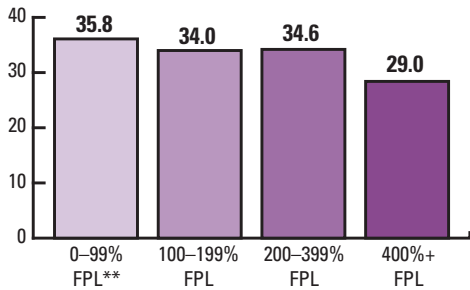
Percent of CSHCN Whose Insurance Does Not Meet Each Criterion for Adequacy*



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.

*The criterion is not usually or always met.

Percent of Insured CSHCN with Inadequate Insurance:* Family Income

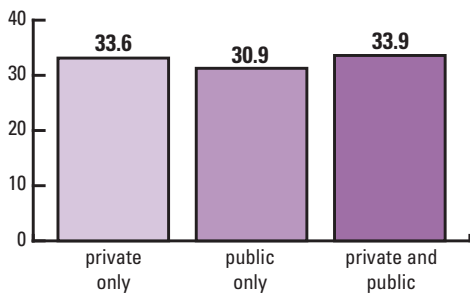


*One or more criteria are not always or usually met: adequate benefits, access to needed providers, and reasonable charges. **Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as \$19,350 for a family of four.

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).

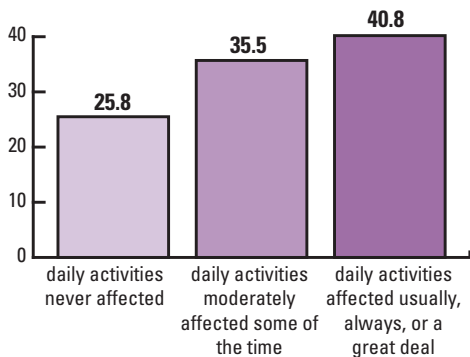
Percent of Insured CSHCN with Inadequate Insurance:* Insurance Type



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

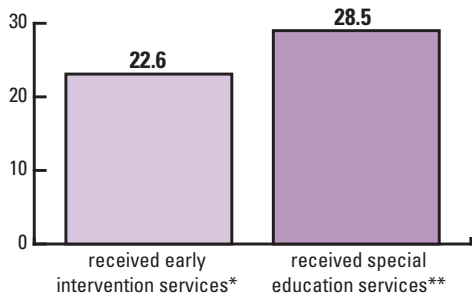
Perceived adequacy of insurance coverage among CSHCN also varies noticeably by the impact of the child's condition. Children who are reported by parents to have a condition that never affects their abilities are the least likely to have inadequate insurance (26 percent), followed by children who are 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.

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.

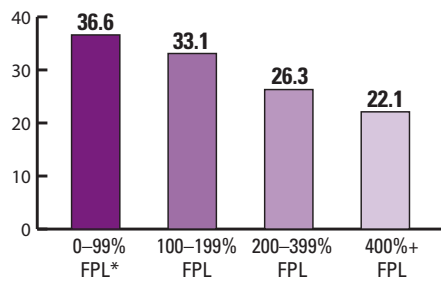
Receipt of Early Intervention and Special Education Services: CSHCN



*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.

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.

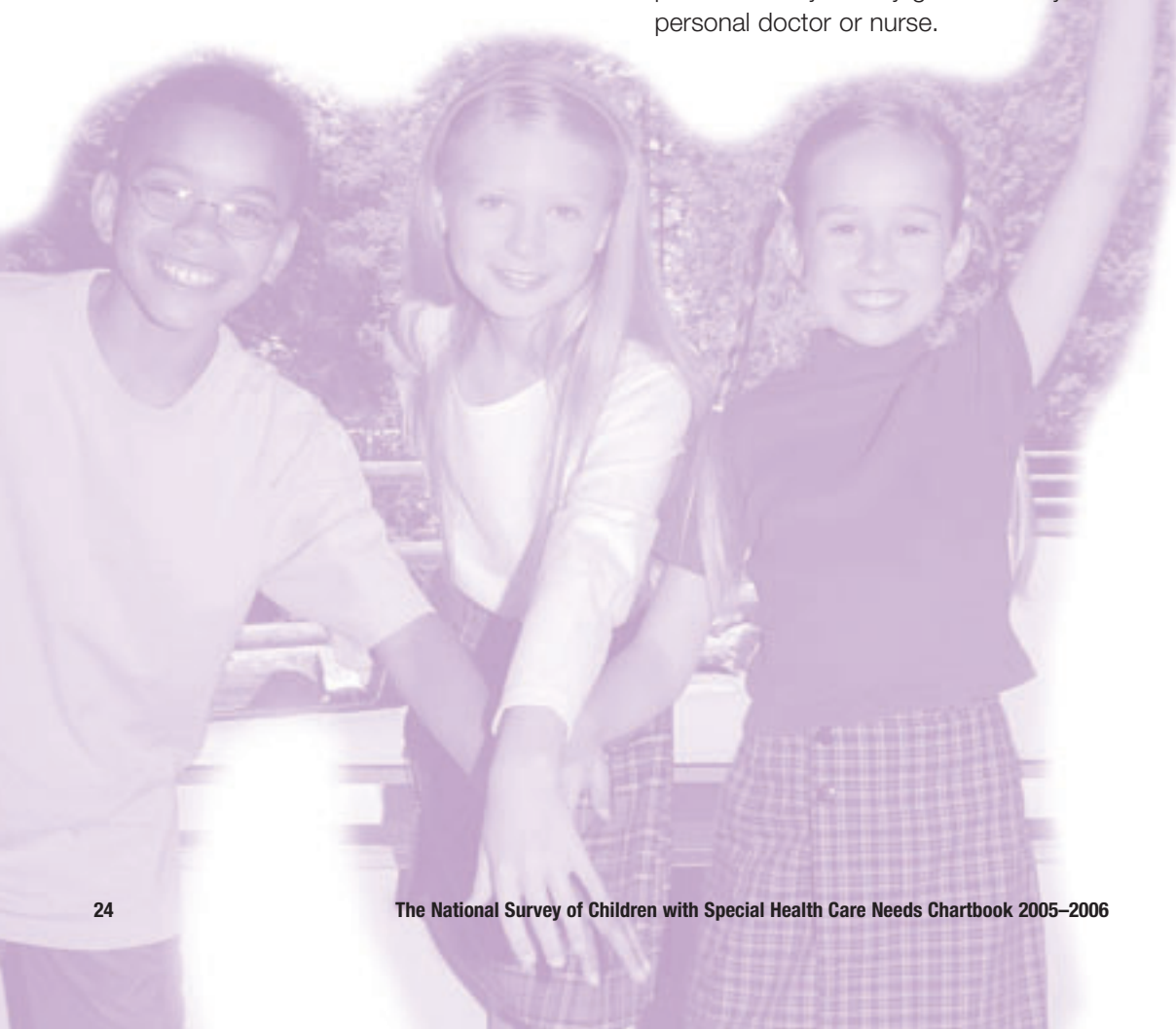
Special education programs provide educational and education-related health care services to children aged 3 years and older. Of CSHCN in this age group, 29 percent received these services. This proportion varies greatly by family income; nearly 37 percent of CSHCN in poverty receive services compared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

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.



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%

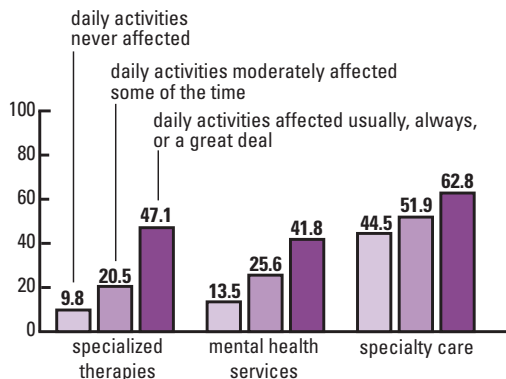
Specific Health Care Needs

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.

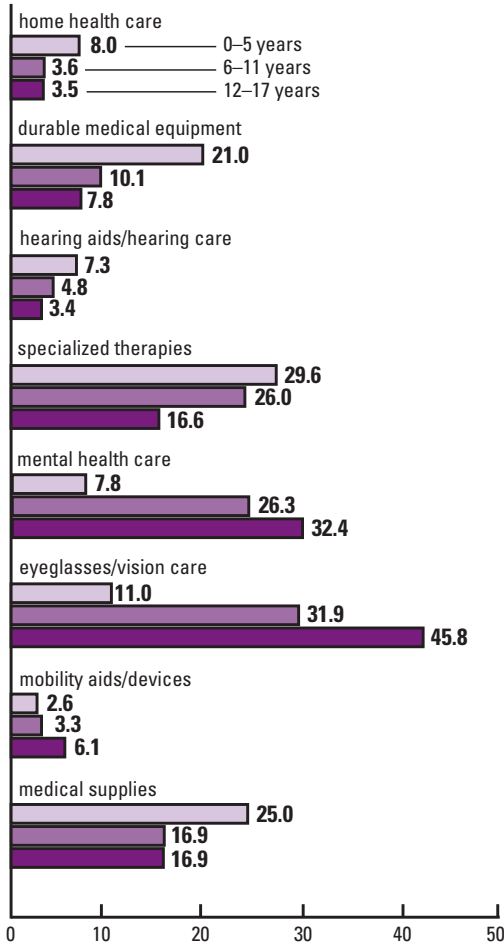
The need most often cited for CSHCN is prescription medication: 86 percent of these children are reported to need prescription drugs. The parents of most CSHCN also recognize their children's need for preventive dental care (81 percent) and routine preventive medical services (78 percent). Just over 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

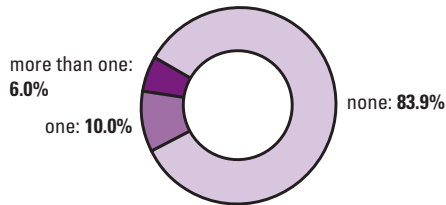


Other needs vary greatly by age. Preschool-aged children (aged 5 years and under) are much more likely than older children to need home health care (8.0 percent, compared to 3.6 percent of school-aged children and adolescents), durable medical equipment (21 percent, compared to 7.8 percent of adolescents), 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.

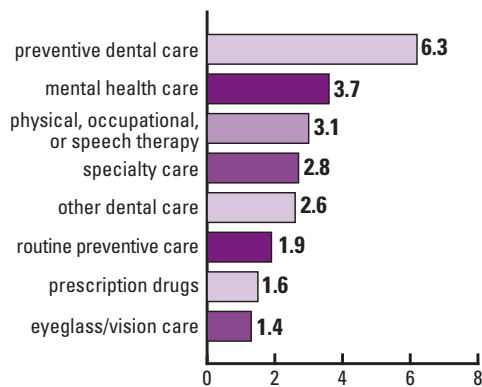
Conversely, adolescents (aged 12–17 years) are more likely to need mental health care (32 percent, compared to 7.8 percent of preschoolers), eyeglasses or vision care (46 percent, compared to 11 percent of preschoolers), and mobility aids (6.1 percent, compared to 2.6 percent of preschoolers).



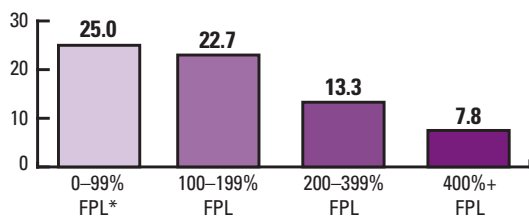
Percent of CSHCN with One or More Reported Health Services Needed but Not Received



Percent of CSHCN with Reported Health Services Needed but Not Received

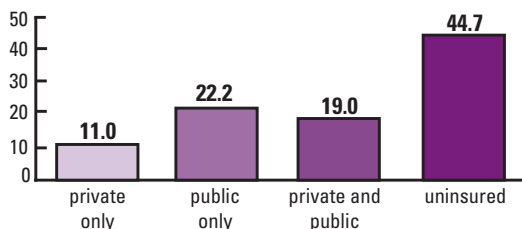


Percent of CSHCN with at Least One Needed Service Not Received: Family Income



*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

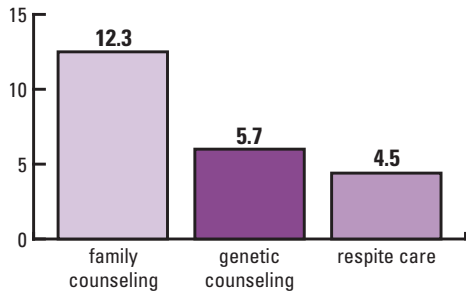
For each service, families were asked if their child received all of the care that he or she needed. Children may not receive services they need for various reasons, including financial barriers, lack of access to providers, and competing demands on families' time.

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).

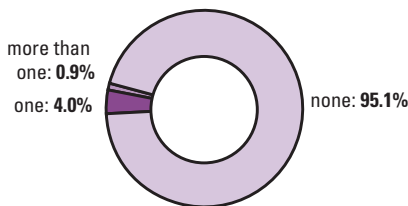
Low-income and uninsured children are the most likely not to receive the services they need. For example, children in poverty are three times as likely as children with family incomes of 400 percent of poverty or more not to receive at least one service they need (25 percent versus 7.8 percent).

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.

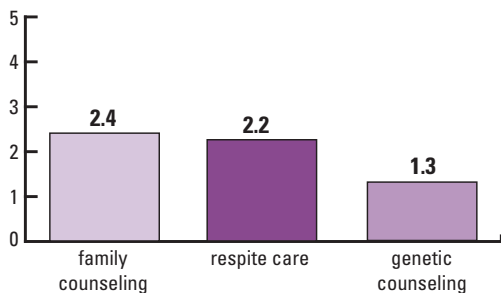
Percent of CSHCN Whose Families Need Support Services



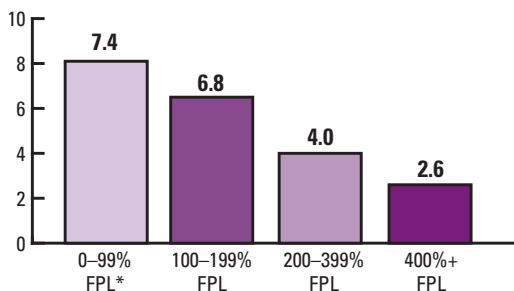
Percent of CSHCN with Needed Family Support Services Not Received



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).

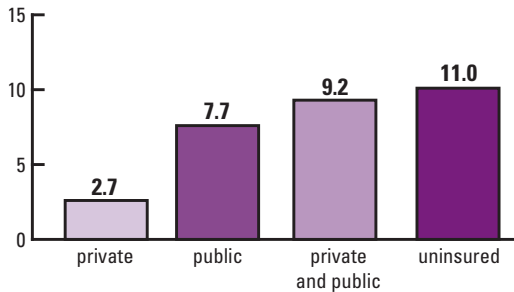
Overall, family counseling is the support service most commonly needed by families of CSHCN, with the families of 12 percent needing this service. Nearly six percent reported needing genetic counseling, and 4.5 percent needed respite care.

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

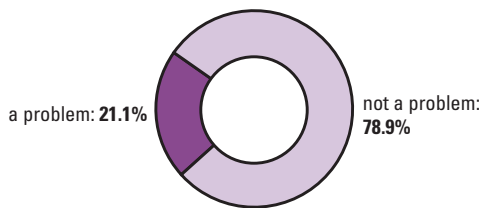


Similarly, families of uninsured children are more likely to report that they needed but did not receive family support services. The families of 11 percent of uninsured children did not receive needed family support services, compared to 7.7 percent of children with public insurance and 2.7 percent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

Difficulty Receiving Referrals

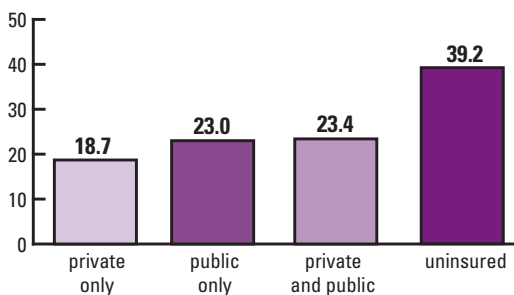
As discussed earlier, just over half of CSHCN need care from specialists, which may require referrals from a primary care provider. Parents who reported that their children needed a referral in order to see another doctor or receive services—33 percent of CSHCN—were asked how much of a problem it was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

Percent of CSHCN Needing Referrals Reporting Problems Obtaining Them

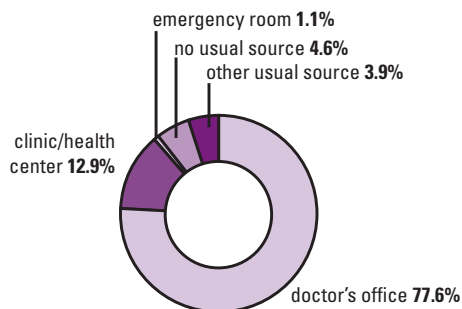


Of those who needed a referral, 21 percent reported having a problem receiving this referral. Reported problems obtaining referrals were most common among uninsured children: 39 percent of uninsured children who needed referrals had difficulty receiving them, compared to 23 percent of CSHCN with public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

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



Usual Source of Sick Care Among CSHCN

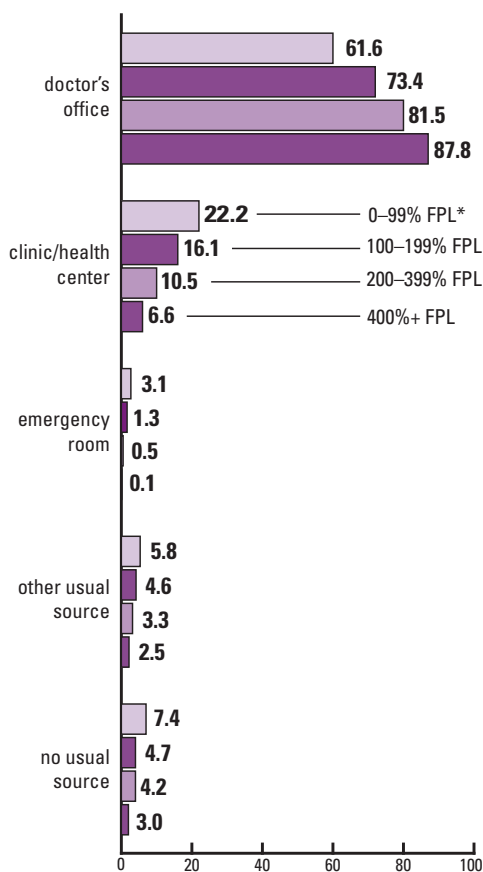


Usual Source of Care When Sick

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.

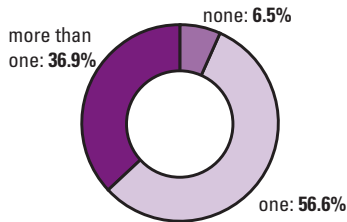
Usual Source of Sick Care: Family Income



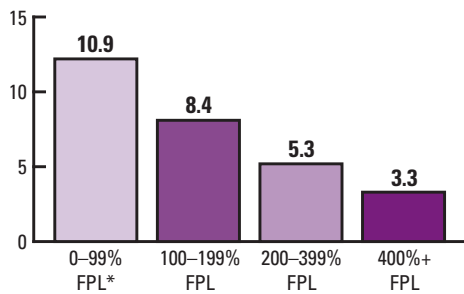
Children in low-income families are considerably more likely than children in higher-income families to lack a usual source of sick care. Of children with family incomes below the poverty level, 7.4 percent had no usual place to go when they were sick, compared to 3.0 percent of children with family 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).

*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 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.

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.



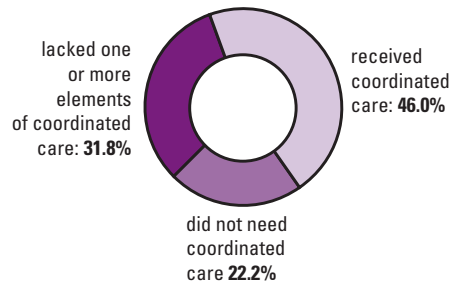
Care Coordination

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.

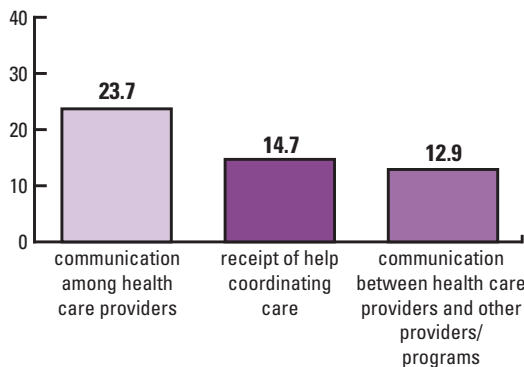
This section describes the proportion of children who are receiving needed care coordination.



Receipt of Coordinated Care: CSHCN

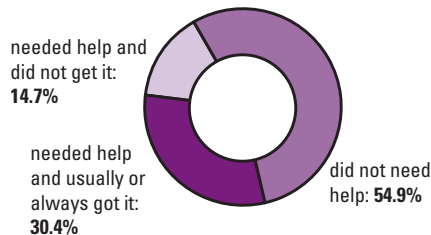


Percent of CSHCN Whose Care Did Not Meet Individual Care Coordination Components*



*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 and Receipt of Help Arranging or Coordinating Care



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.

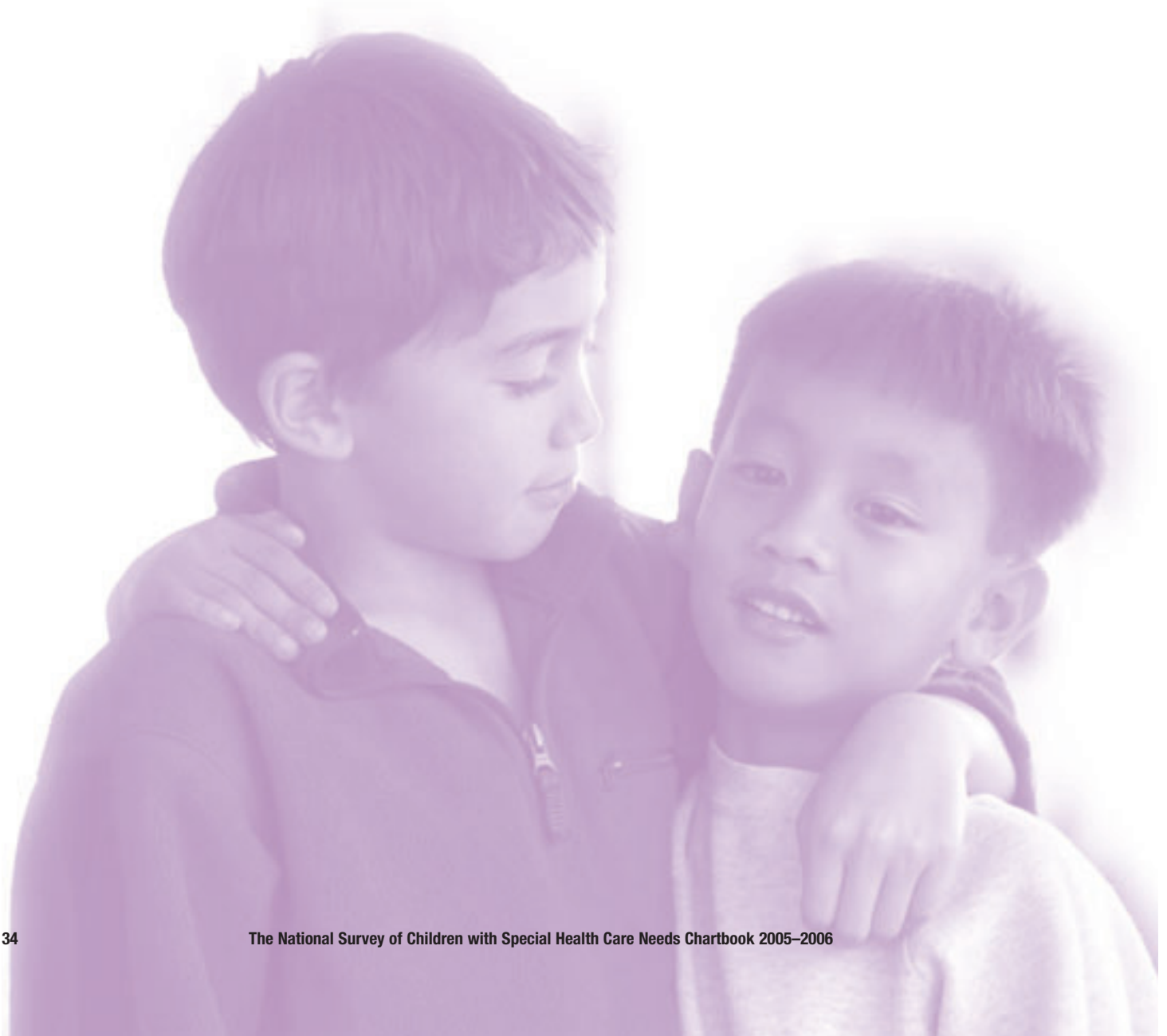
Of the three individual elements of care coordination, the one that was least often met was communication among health care providers: the parents of 24 percent of CSHCN reported not being very satisfied. The parents of 15 percent of CSHCN reported that they did not usually receive help when needed,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

Need for Care Coordination

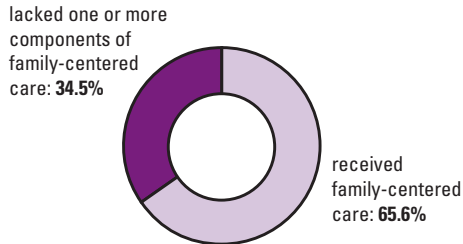
Some families who need help with coordination of their children’s care have difficulty obtaining access to care coordination services. Overall, the parents of 55 percent of CSHCN did not report that they needed help with care coordination, either because their children only saw one provider or because 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.

Family-Centered Care

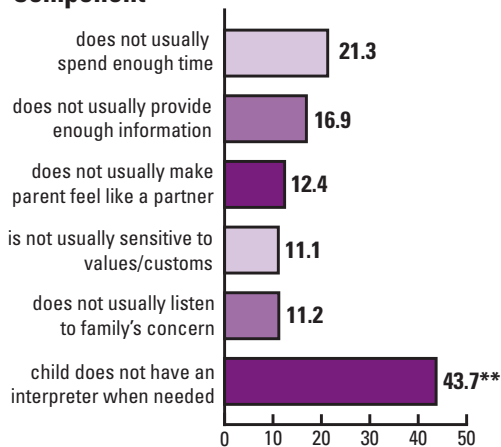
Family-centered care is an approach to the planning, delivery, and evaluation of health care whose cornerstone is active participation between families and professionals. Family-centered care helps support the family's relationship with the child's health care providers and recognizes the importance 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: 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.

Receipt of Family-Centered Care

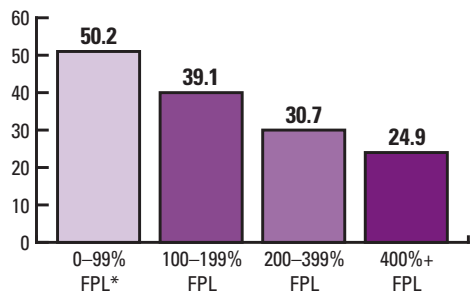
The survey asked several questions to determine whether CSHCN were receiving family-centered care:

- 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.

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

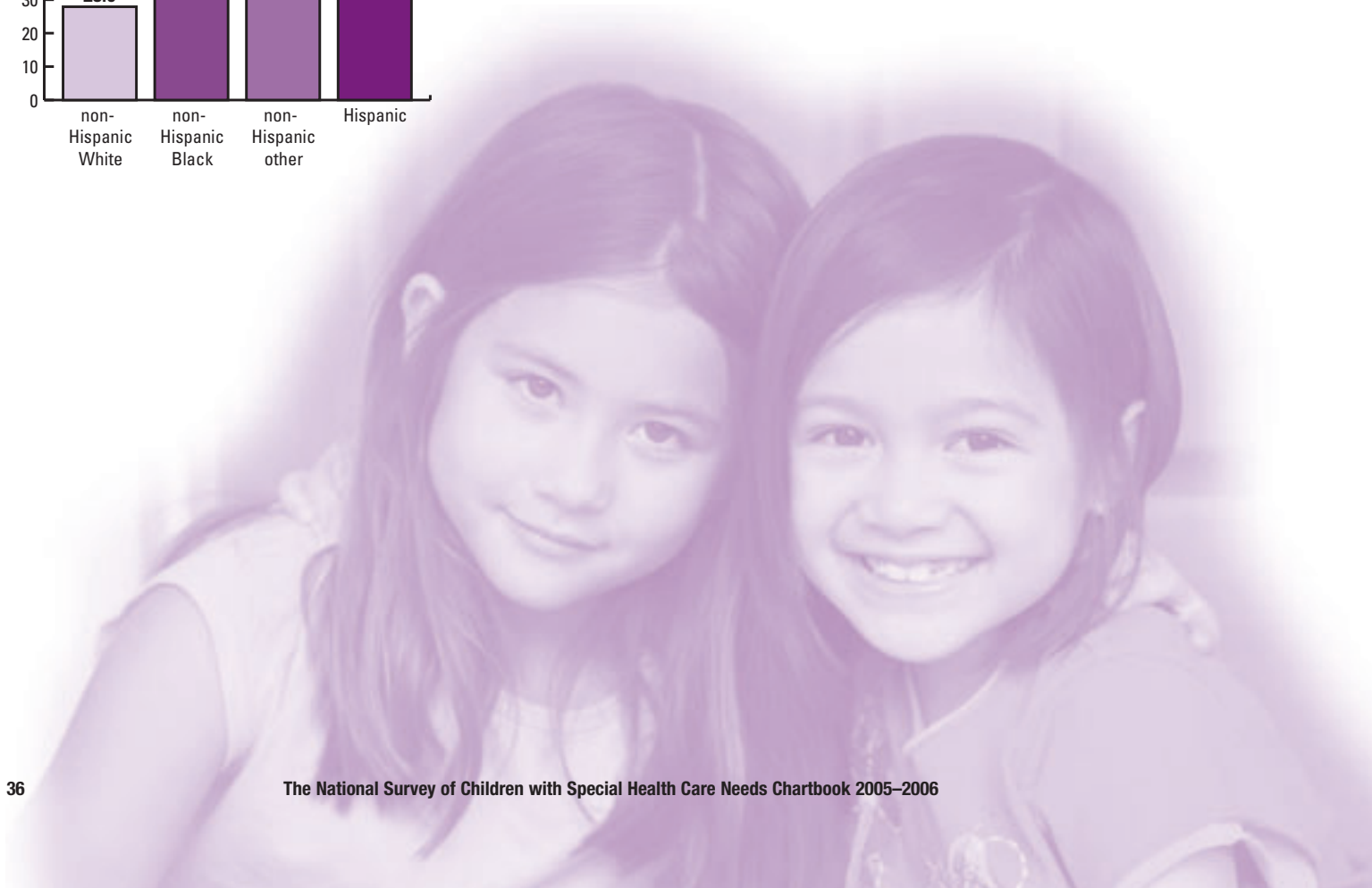
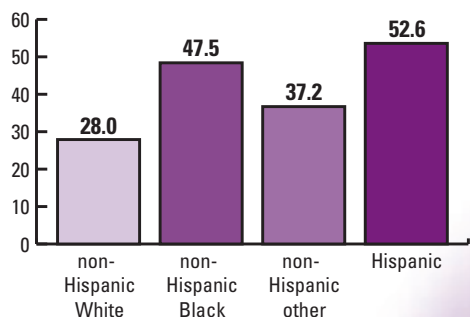


*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as \$19,350 for a family of four.

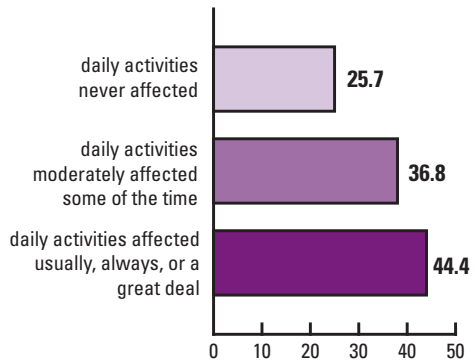
Receipt of family-centered care varies by family income, with those in the lower income groups being more likely to receive care that is not considered family-centered. Of CSHCN with family incomes below 100 percent of the poverty level, 50 percent did not receive family-centered care, according to their 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



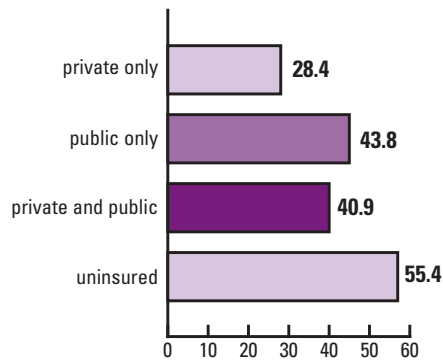
Percent of CSHCN Lacking One or More Components of Family-Centered Care: Impact of Child's Condition on Functional Ability



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



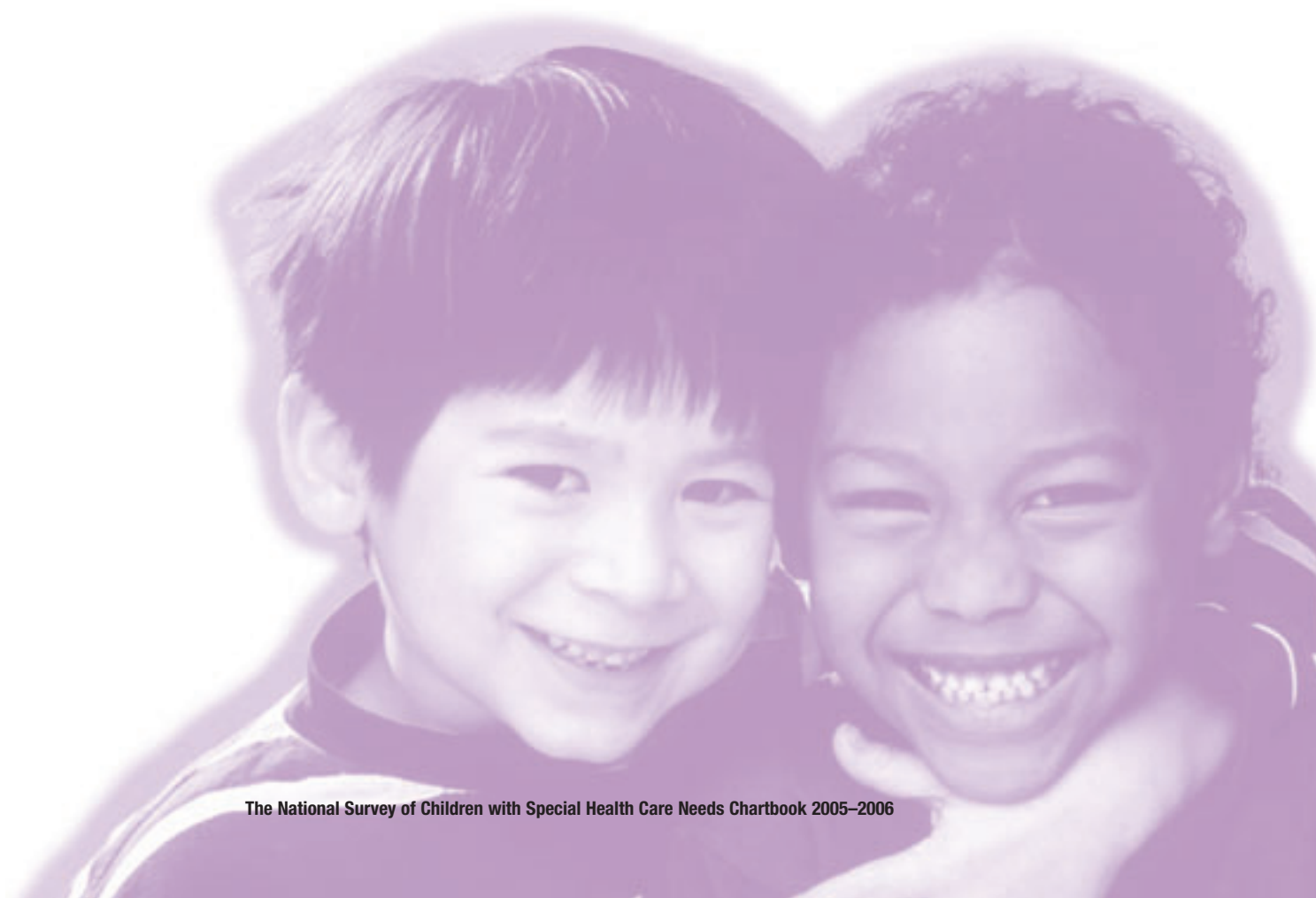
Impact on Families

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.

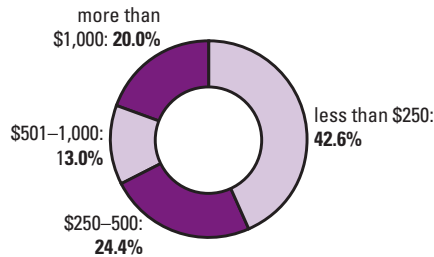
This section describes the impact that CSHCN have on their families. One way to measure this impact is in dollars, as families often have substantial out-of-pocket expenses for their children's health care that are not covered by insurance. Parents were also asked whether their children's conditions 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.

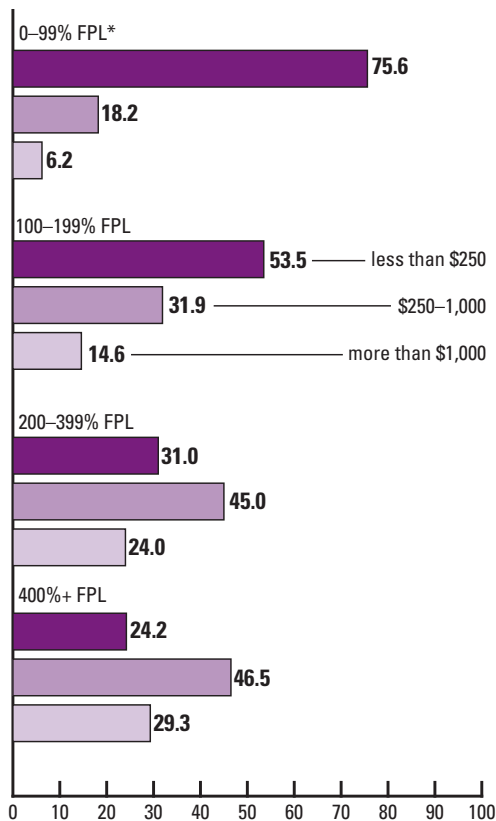
Finally, parents were asked whether their children's needs had required them to cut down on work or stop working altogether to care for their child—requiring both the parent's time as well as a financial sacrifice.



Annual Out-of-Pocket Expenditures for Care of CSHCN



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



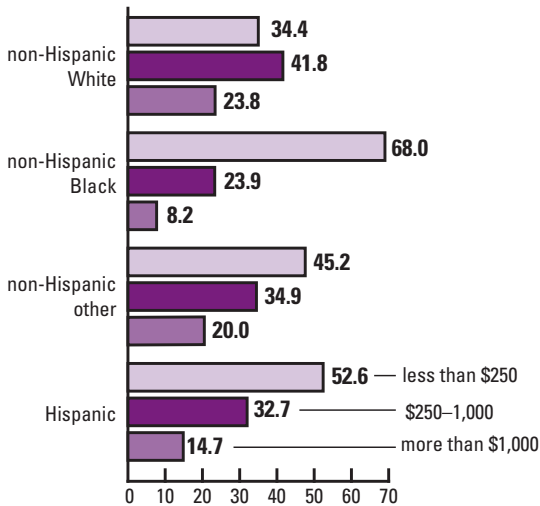
*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as \$19,350 for a family of four.

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.

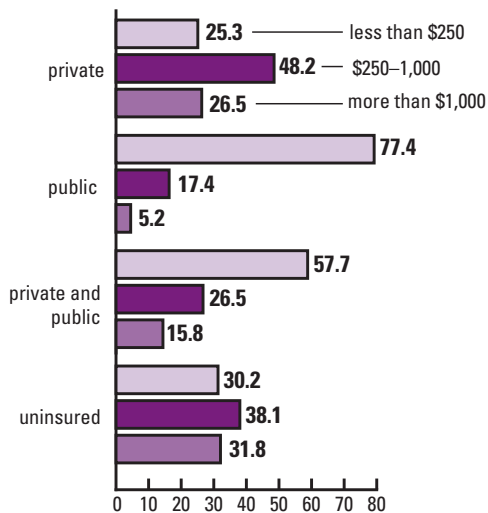
Annual Out-of-Pocket Expenditures for CSHCN: Race/Ethnicity



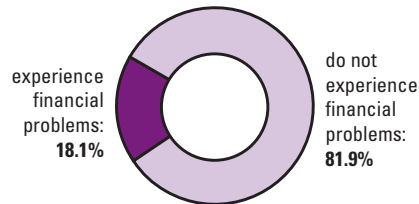
The families of non-Hispanic White children are the most likely to pay more than \$1,000 in health care expenses; 24 percent did so, compared to the families of 15 percent of Hispanic children and 8 percent of non-Hispanic Black children. Non-Hispanic White children are also the least likely to have 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.

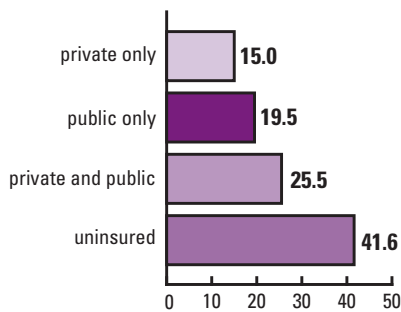
Annual Out-of-Pocket Expenditures for CSHCN: Insurance Type



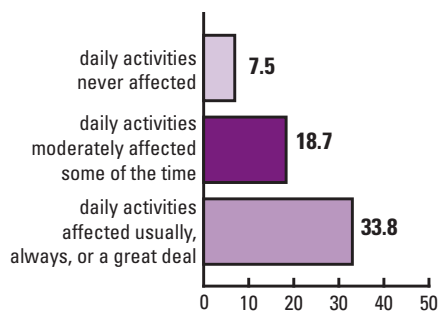
Percent of CSHCN Whose Families Experience Financial Problems Due to Child's Condition



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



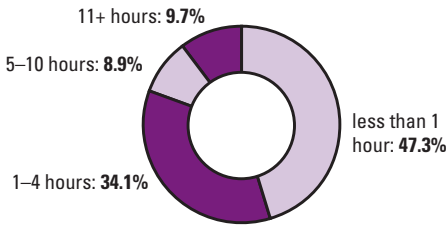
Financial Burden

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.

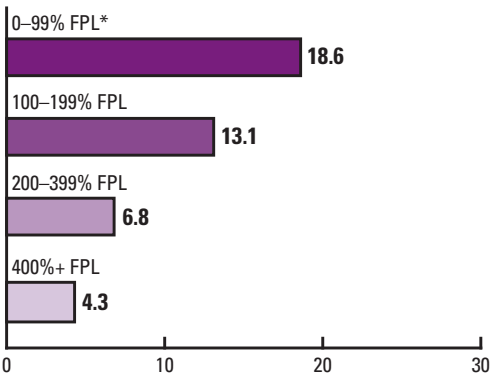
The financial burden appears to be greatest for the families of CSHCN who are uninsured. Nearly 42 percent of uninsured CSHCN live in families that reported a financial problem, compared to 20 percent of those with only public coverage and 15 percent of those with only private insurance.

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.

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

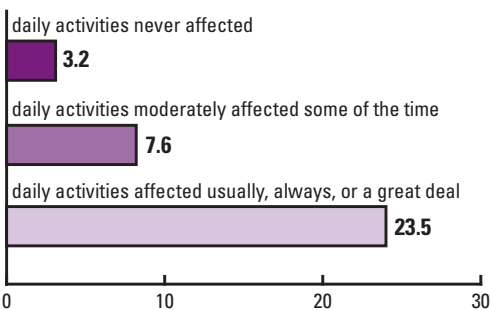


Percent of CSHCN Whose Families Spend 11 Hours or More Per Week Providing, Arranging, or Coordinating Care: Family Income



*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



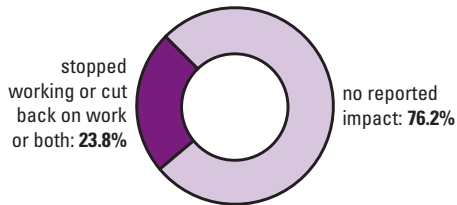
Time Spent Providing Care

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.

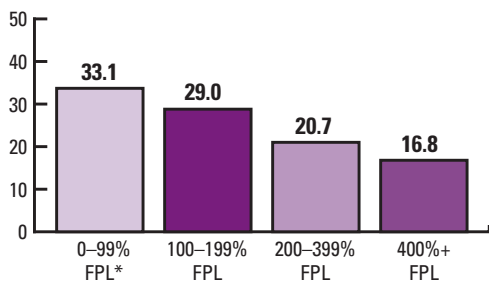
The self-reported time burden is greatest on low-income families. The families of nearly 19 percent of poor children spend at least 11 hours per week providing, arranging, or coordinating their children's health care, compared to the families of 4.3 percent of children with family incomes of 400 percent 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.

Impact of Child's Condition on Parent's Employment

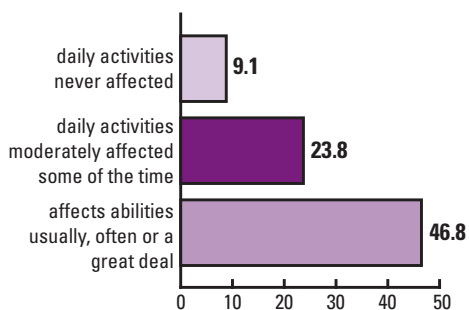


Percent of CSHCN Whose Parents Cut Back on Work or Stopped Working to Care for the Child: Family Income



*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



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.