

### Impact on Families

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

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

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

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

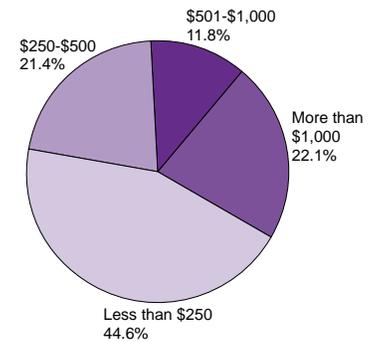


## Out-of-Pocket Costs

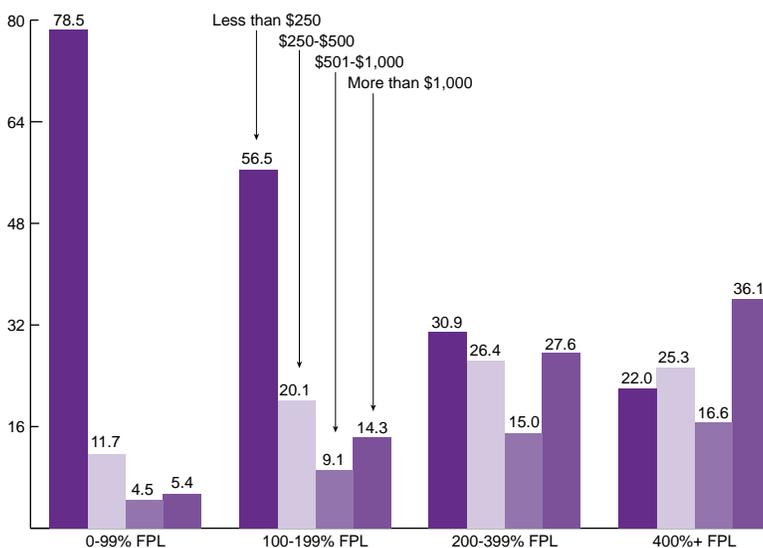
Families are often required to pay for health care services not covered or inadequately covered by their insurance plans. These services may include therapies, home health care, prescription drugs, mental health care, medical equipment, and dental services. Families of over half of children with special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

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

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



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

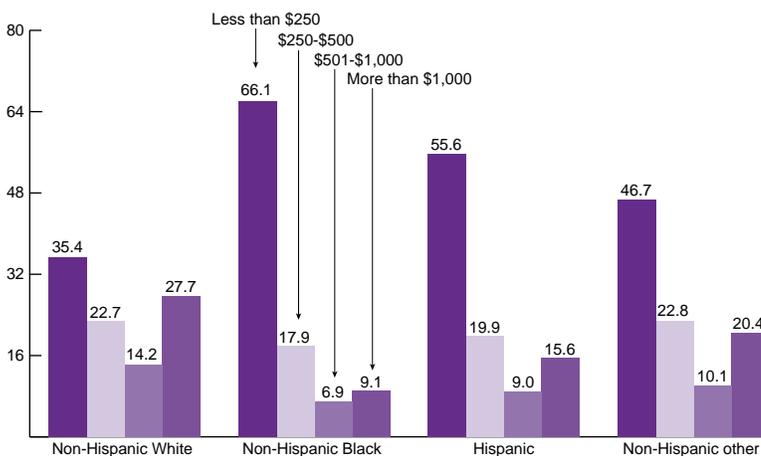


## Impact on Families

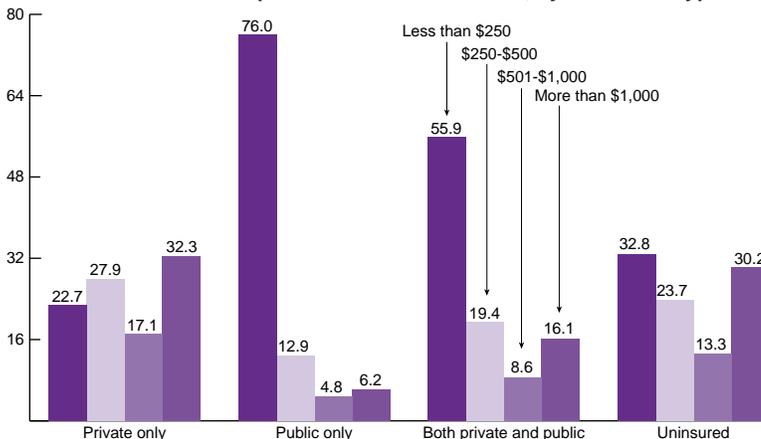
The families of non-Hispanic White children are the most likely to pay more than \$1000 in health care expenses; 27.7 percent did so, compared to the families of 15.6 percent of Hispanic children and 9.1 percent of non-Hispanic Black children. Non-Hispanic White children are also the least likely to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

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

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



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



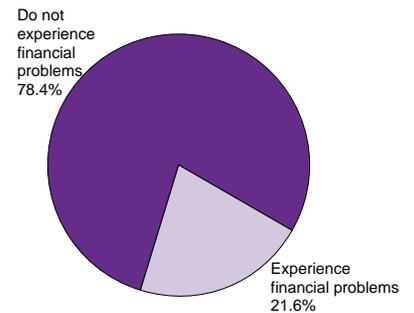
## Financial Problems

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

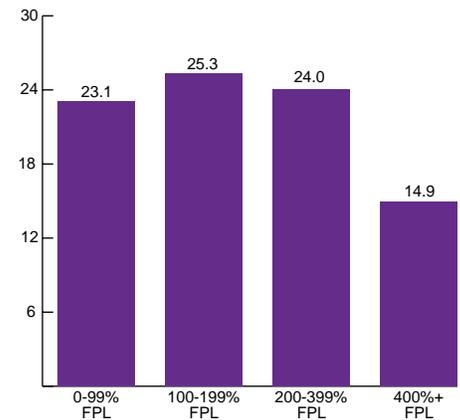
The financial burden appears to be greatest for the families of CSHCN who are uninsured. Nearly half (47.6 percent) of uninsured CSHCN live in families that reported a financial problem, compared to 21.0 percent of those with public coverage and 19.0 percent of those with private insurance.

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

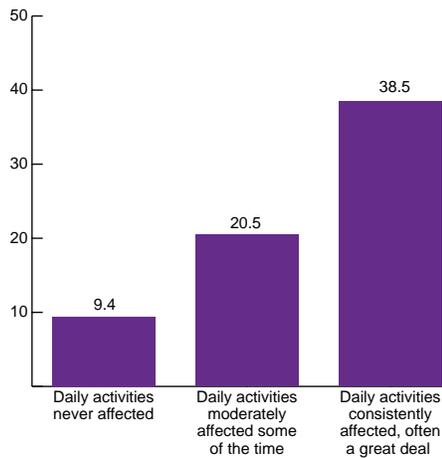
**CSHCN Whose Families Experience Financial Problems Due to Child's Condition**



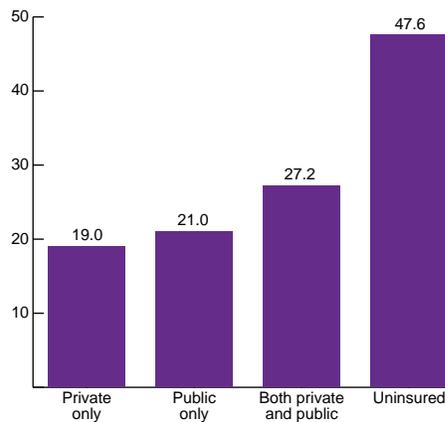
**Percent of CSHCN Whose Health Conditions Cause Financial Problems for the Family, by Poverty Status**



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



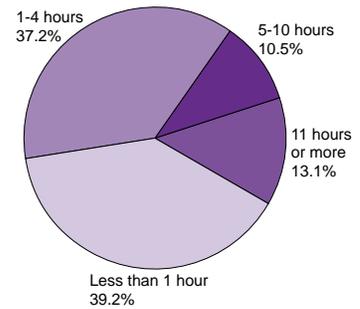
**Percent of CSHCN Whose Health Conditions Cause Financial Problems for the Family, by Insurance Type**



*Time Spent Providing Care*

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

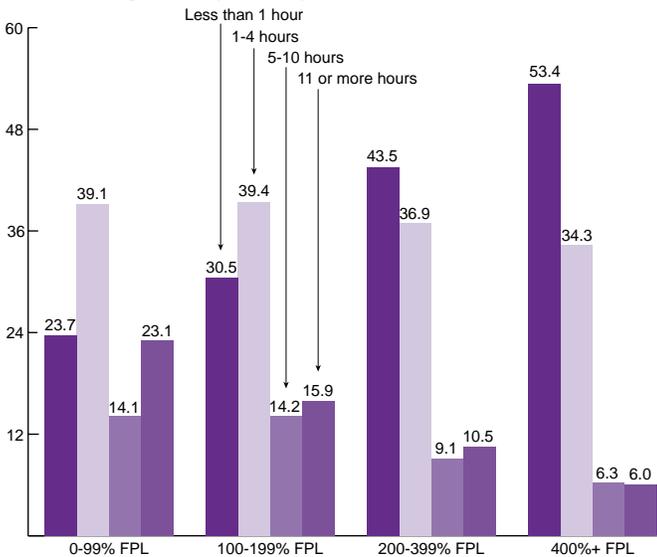
**Time Spent Providing, Arranging, or Coordinating Health Care for CSHCN, Per Week**



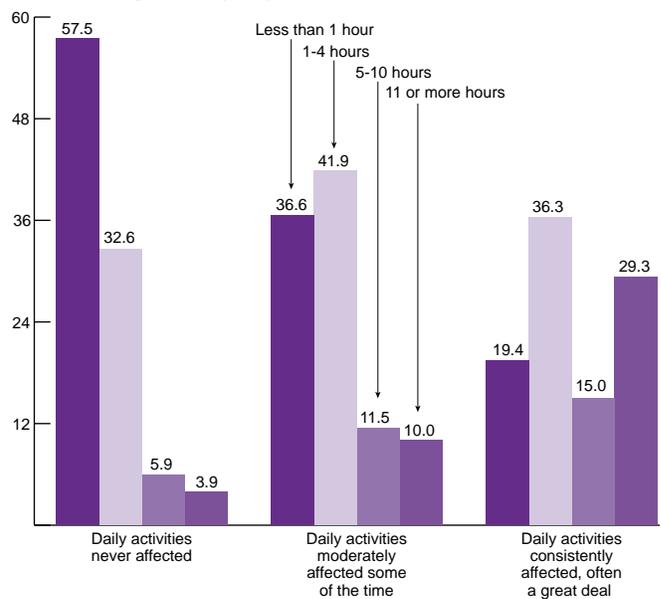
The self-reported time burden is greatest on low-income families. The families of over 20 percent of poor children spend at least 11 hours per week providing, arranging, or coordinating their children’s care, compared to the families of 6.0 percent of children with family incomes of 400 percent of the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

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

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



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



## Impact on Employment

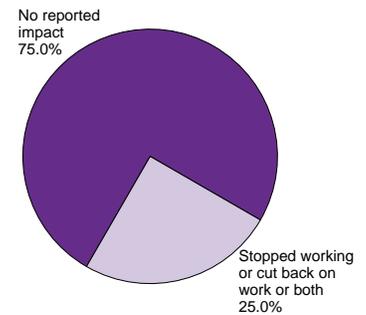
The complexity of a child's special needs and the parents' need to devote time to the child's care sometimes requires that parents cut back on the number of hours they work or stop working completely to care for their child. Other families may keep a job in order to preserve their child's health insurance.

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

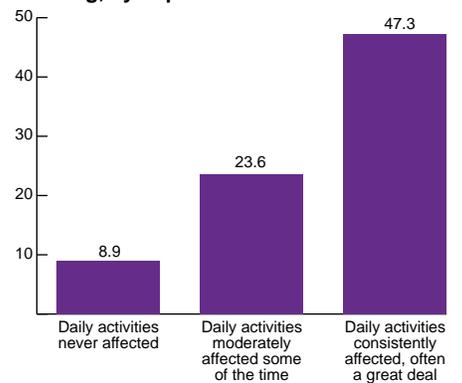
Of course, giving up a job is likely to reduce a family's income. Therefore, it is not surprising that children in lower-income families are more likely to have parents who have given up their jobs: one-third of CSHCN in poverty and nearly 30 percent of those with family incomes between 100 and 199 percent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

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

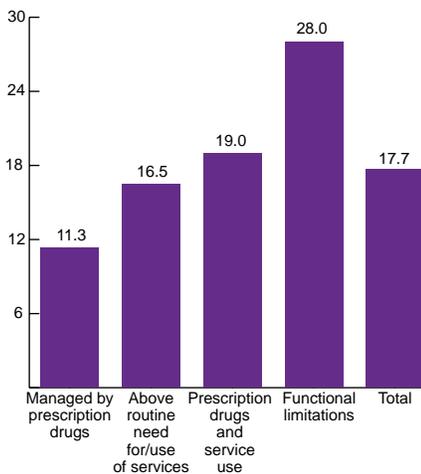
### Impact of Child's Conditions on Parents' Employment



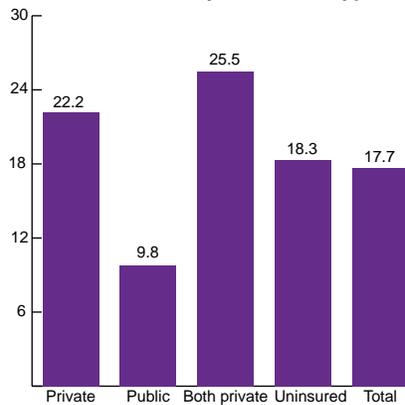
### CSHCN Whose Health Conditions Cause Family Members to Cut Back or Stop Working, by Impact of Condition



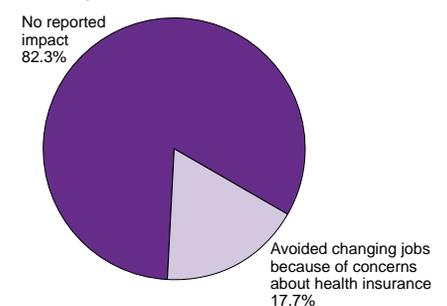
### Percent of CSHCN Whose Family Members Avoided Changing Jobs Because of Concerns about Maintaining the Child's Health Insurance, by Type of Special Health Care Need



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



### Impact of Conditions on Parents' Job Mobility



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

