

A photograph of a woman with short dark hair kissing a young girl on the cheek. The woman is wearing a dark sweater and a necklace. The girl is wearing a light-colored t-shirt. The image is overlaid with a semi-transparent purple rectangle containing the title text.

# 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**





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





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,

A handwritten signature in black ink, reading "Elizabeth M. Duke", is positioned above the typed name and title.

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.”***

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](http://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](http://www.childhealthdata.org).

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