

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

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

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

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

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

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

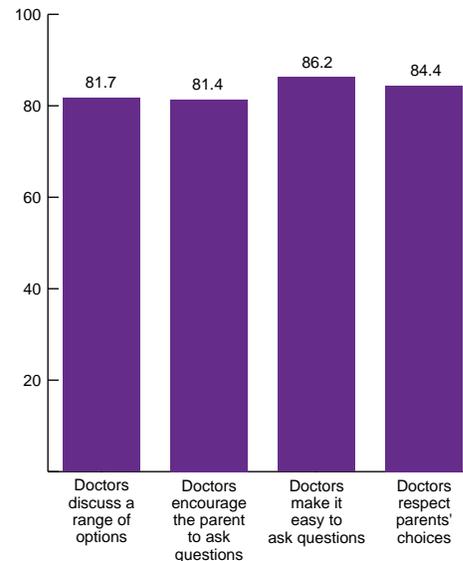
The following sections describe the Nation's progress on each of these indicators, presenting first the individual indicators that make up the outcome measure, followed by any related indicators that are not part of the overall measure. Finally, we discuss the proportion of CSHCN whose care meets each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

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

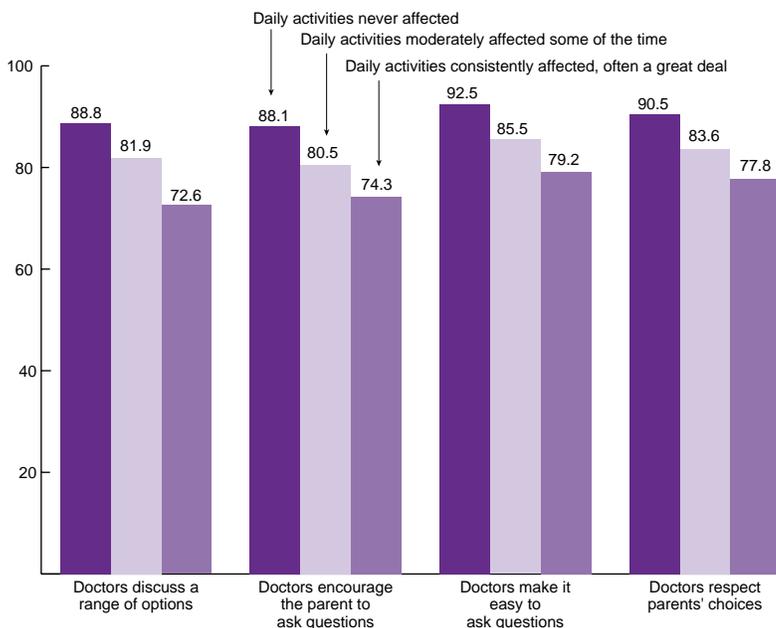
Family-centered care is based on the recognition that children live within the context of families, which may include biological, foster, and adoptive parents, step-parents, grandparents, other family caregivers, and siblings. Family-centered care is a process to ensure that the organization and delivery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

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

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



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

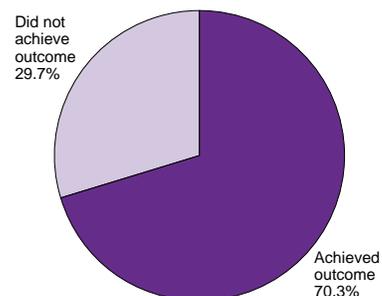


## Core Outcome Summary

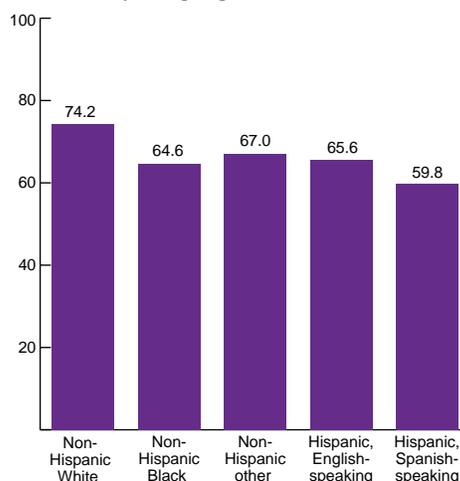
A child was determined to meet the standard for family partnership if their parents answered “usually or always” to all four questions. Overall, 70.3 percent of CSHCN met this standard. This percentage is highest among non-Hispanic White CSHCN (74.2 percent) and lowest among Hispanic CSHCN who primarily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

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

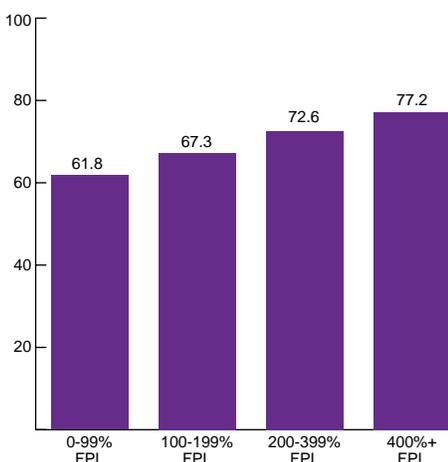
**CSHCN Whose Families Are Partners in Decision-Making Regarding the Child’s Health**



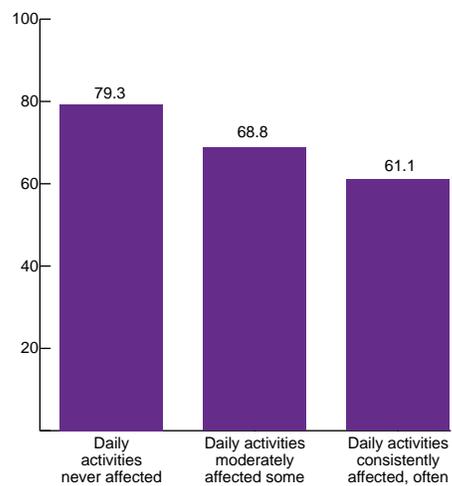
**Percent of CSHCN Whose Families Are Partners in Shared Decision-Making for Child’s Optimal Health, by Race/Ethnicity and Primary Language**



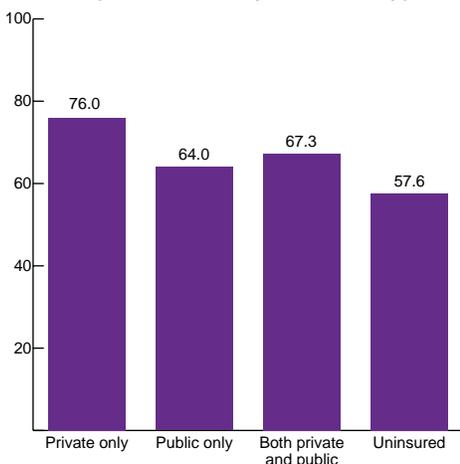
**Percent of CSHCN Whose Families Are Partners in Shared Decision-Making for Child’s Optimal Health, by Poverty Status**



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



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



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

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

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

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

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

## Usual Source of Care

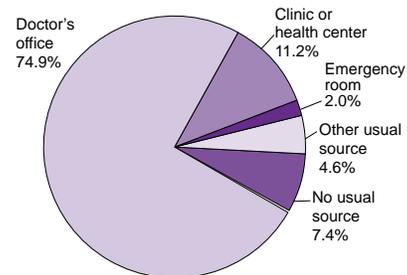
A basic element of a medical home is a regular place that children can go—whether it be a doctor’s office, clinic, or health center—when they are sick. The survey asked parents whether there is a place, and what kind of place, the family usually goes when the child is sick or when the family needs advice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

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

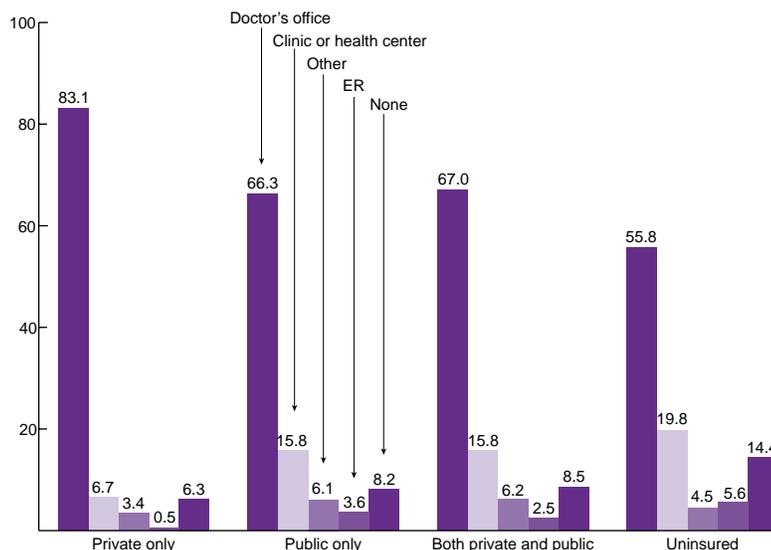
Children with private insurance are more likely than those with public insurance, who in turn are more likely than uninsured children, to have a usual source of care. Of CSHCN with private insurance, 83.1 percent go to a doctor’s office and 6.7 percent a clinic or health center, while 6.3 percent are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

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

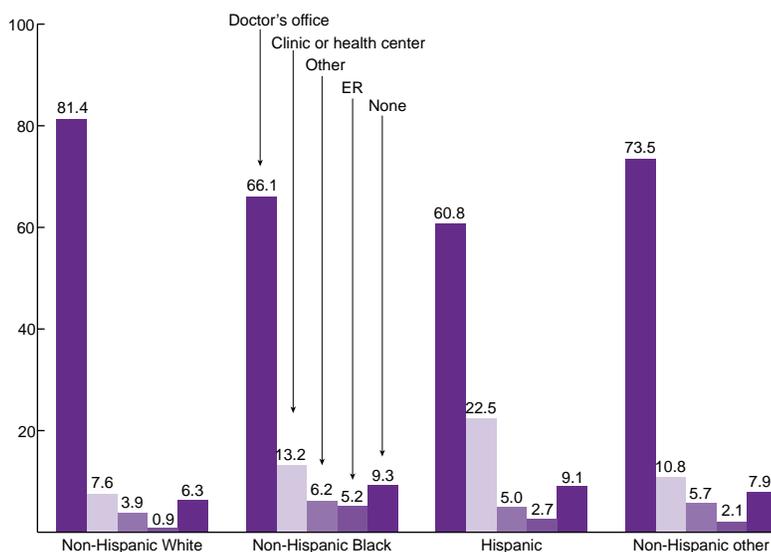
**Usual Source of Sick Care Among CSHCN**



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



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

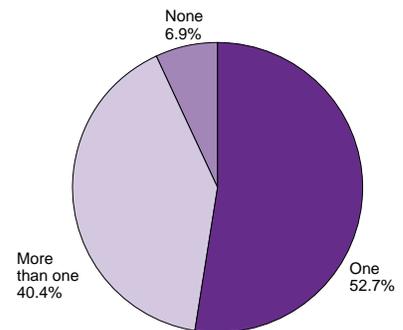


## Personal Doctor or Nurse

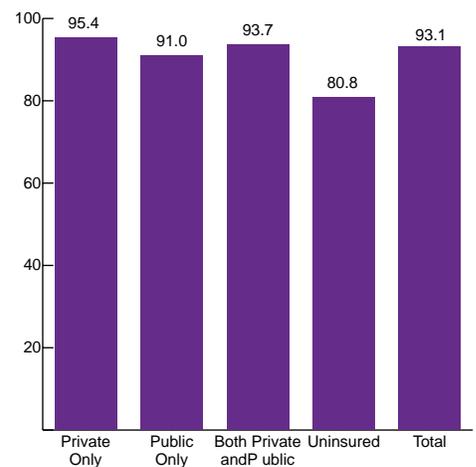
Another essential element of the medical home is having one or more personal doctors or nurses, defined as the health care provider(s) who know the child best. Because the health conditions and risks faced by CSHCN can be complex, having a consistent source of care can be especially important.

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

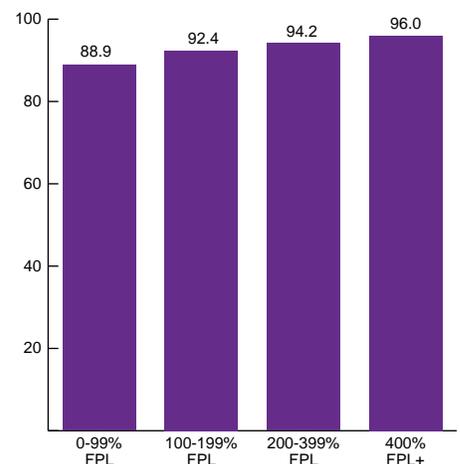
**CSHCN with a Personal Doctor or Nurse**



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



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



## Care Coordination

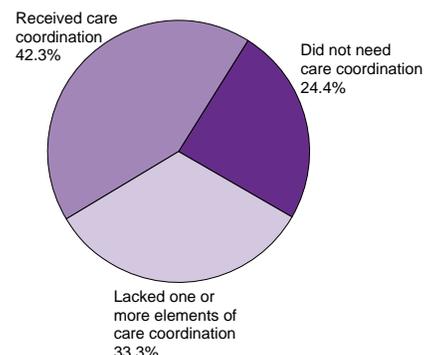
Care coordination has been defined as “a process that links CSHCN to services and resources in a coordinated effort to maximize the potential of children and provide them with optimal health care.”<sup>4</sup> The survey addressed the issue of care coordination in two ways. To measure the proportion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

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

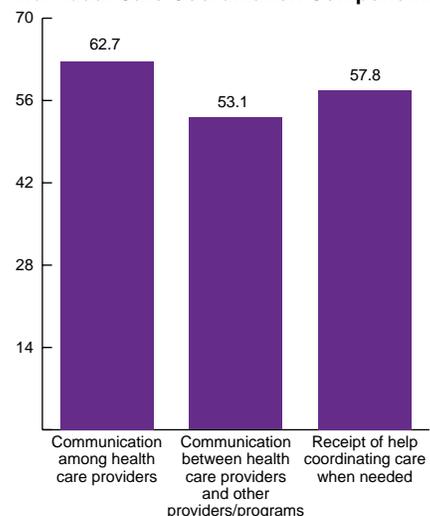
For a child to qualify as receiving coordinated care, the parent had to report that they usually received help when needed, and that they were “very satisfied” with communication among providers (when needed) and communication between providers and other programs (when needed). Overall, 42.3 percent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

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

**Receipt of Coordinated Care Among CSHCN**

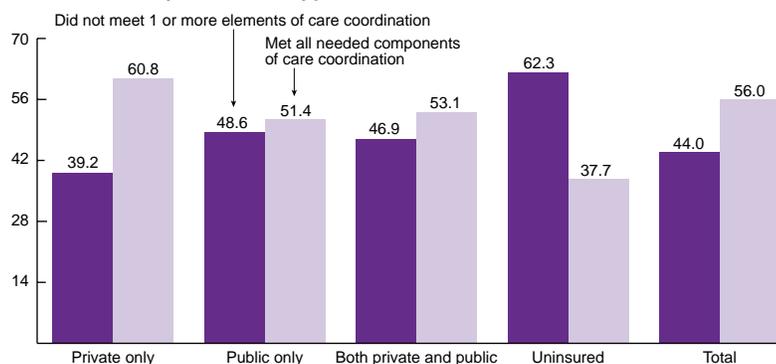


**Percent of CSHCN Whose Care Met Individual Care Coordination Components\***



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

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



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

**Family-Centered Care**

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

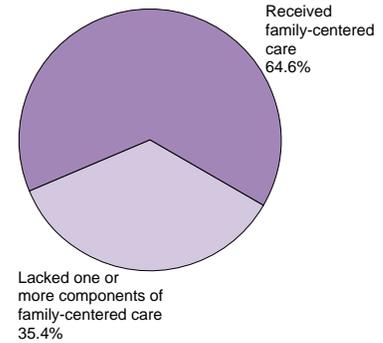
For a child’s care to qualify as family-centered, the parent needed to answer “usually or always” to each of the above elements. Overall, 64.6 percent of CSHCN received care that met all of the components of family-centered care.

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

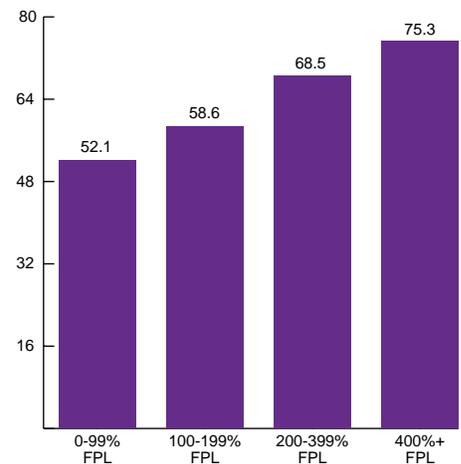
Children’s receipt of family-centered care varies by family income, with those in the lower income categories being less likely to receive care that meets all criteria for family-centeredness. Of CSHCN with family incomes below the Federal Poverty Level (FPL), 52.1 percent received family-centered care,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

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

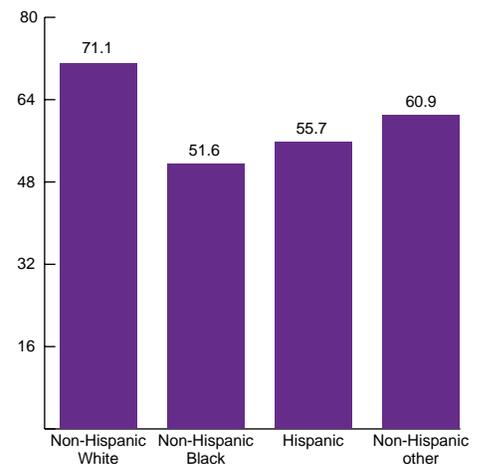
**Receipt of Family-Centered Care Among CSHCN**



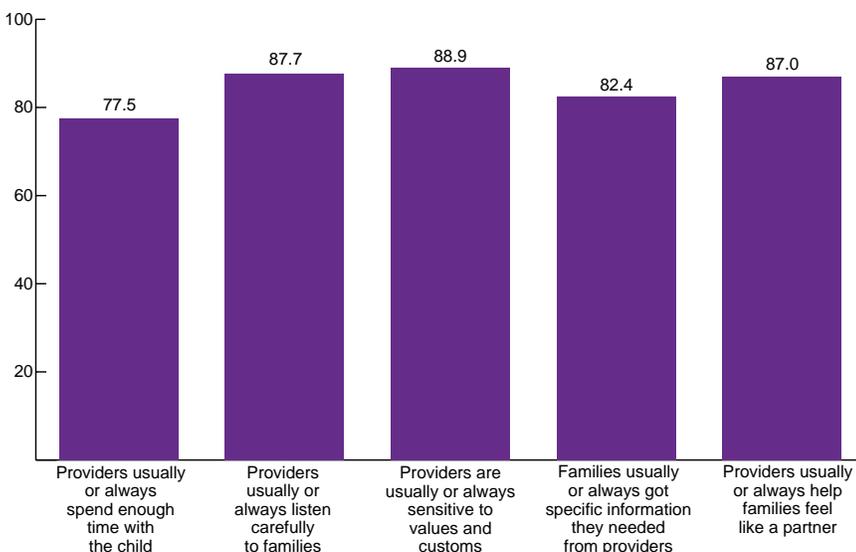
**Receipt of Family-Centered Care, by Poverty Status**



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



**Components of Family-Centered Care**



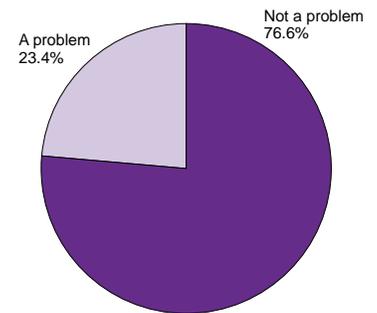
## Getting Needed Referrals

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

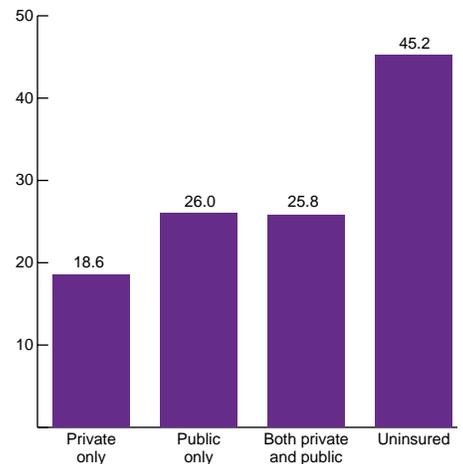
Of those who needed a referral, 23.4 percent reported having a problem receiving this referral. Reported problems obtaining referrals were most common among uninsured children: 45.2 percent of uninsured children who needed referrals had difficulty receiving them, compared to 26.0 percent of children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

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

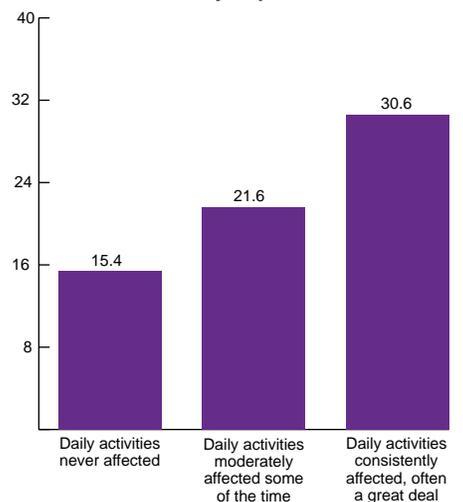
**CSHCN Needing Referrals Reporting Problems Obtaining Them**



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



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



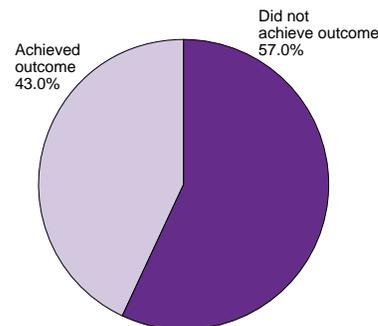
## Core Outcome Summary

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

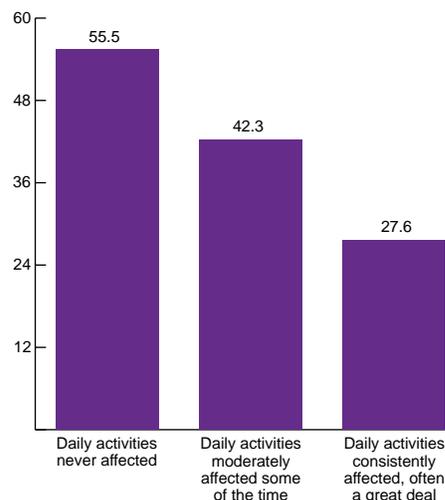
Children whose conditions consistently affect their functional abilities are less likely to receive their care from a medical home (27.6 percent) than children whose activities are moderately affected (42.3 percent) or never affected (55.5 percent). Children who are uninsured or who have public insurance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

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

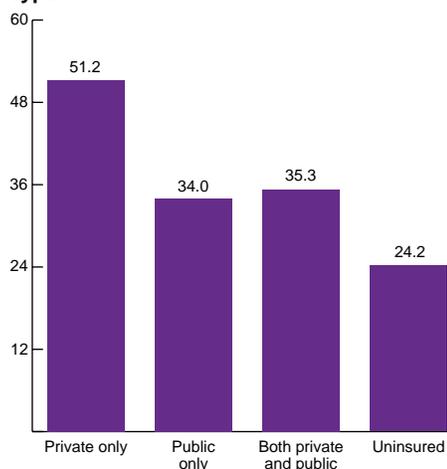
**CSHCN Who Receive Coordinated, Ongoing, Comprehensive Care within a Medical Home**



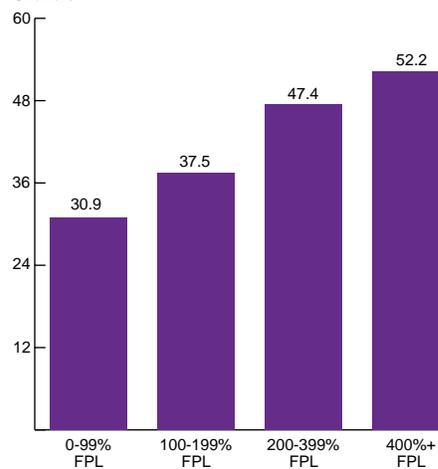
**Percent of CSHCN Who Receive Coordinated, Ongoing, Comprehensive Care within a Medical Home, by Impact of Condition**



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



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



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

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

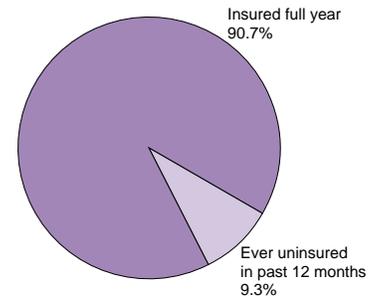
This section reviews the survey’s findings on insurance coverage among CSHCN, including the proportion that have health insurance and the type of coverage (public or private) that they have. For children with insurance, the survey also assesses parents’ perceptions of the adequacy of that coverage. To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

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

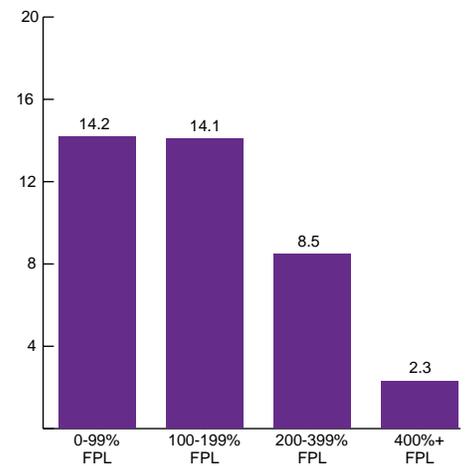
Overall, 90.7 percent of CSHCN were insured for all of the previous 12 months, while the remaining 9.3 percent were uninsured for all or some part of the year. The percentage of CSHCN without insurance varies by race/ethnicity. Hispanic children were the most likely to have been uninsured at some point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

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

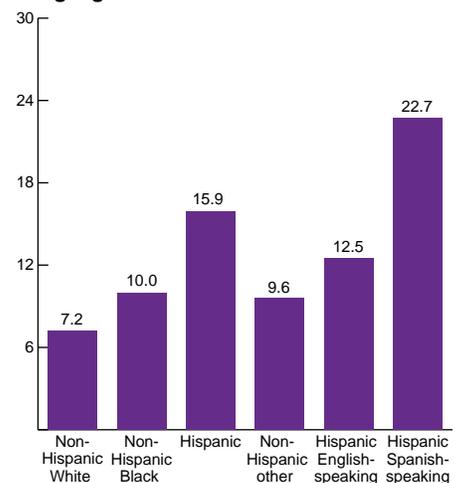
**Health Insurance Coverage for CSHCN in The Past 12 Months**



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



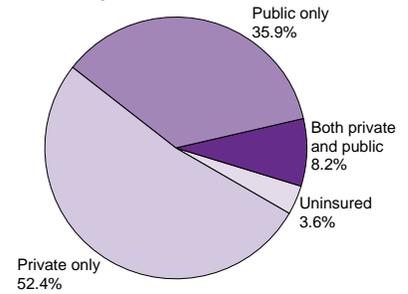
**Percent of CSHCN Who Were Uninsured for One or More Periods During the Past Year, by Race/Ethnicity and Primary Language**



## Type of Health Insurance Coverage

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

Type of Insurance at the Time of the Survey



## Adequacy of Current Insurance Coverage

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

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

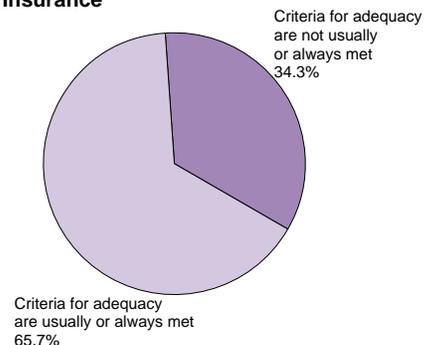
If parents answered “usually” or “always” to all three of these questions, then the child’s coverage is considered to be adequate. All others are considered to have inadequate insurance coverage.

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

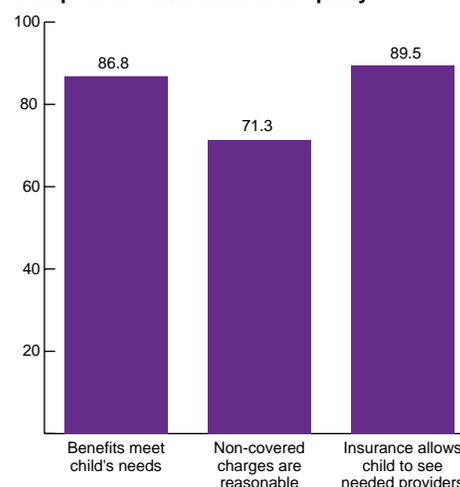
Children insured exclusively through public programs were the most likely to have coverage that is reported to meet all of the criteria for adequacy. Of CSHCN with only public insurance, 69.4 percent were reported to have adequate insurance, compared to 64.3 percent of those with only private insurance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

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

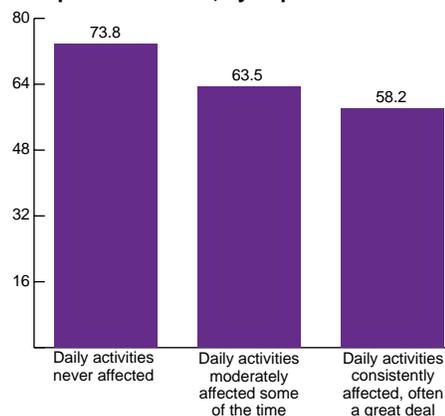
**Currently Insured CSHCN with Adequate Insurance**



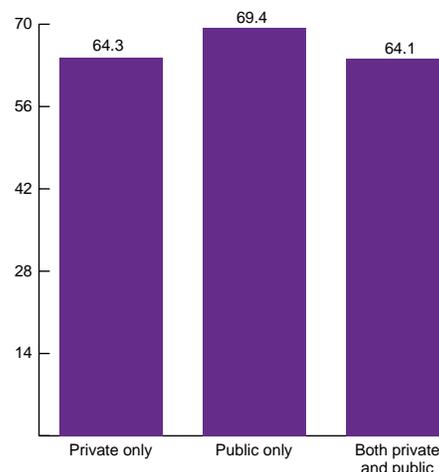
**Percent of Currently Insured CSHCN Whose Insurance Usually or Always Meets Each Component of Insurance Adequacy**



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



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



**Core Outcome Summary**

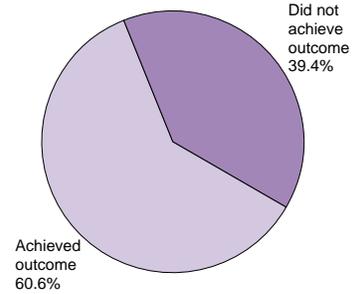
CSHCN were considered to have met the outcome goal for health insurance if they were consistently insured for the past year, and if that insurance met all the standards for adequacy. This outcome was achieved for 60.6 percent of CSHCN.

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

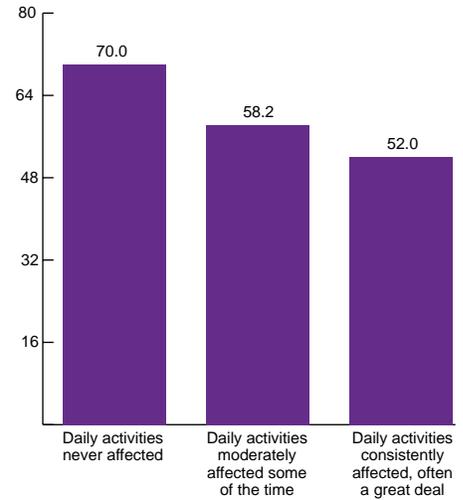
Children whose conditions have a greater impact on their daily lives are also less likely to achieve this outcome. Of CSHCN whose conditions consistently affect their activities, 52.0 percent were adequately insured for the full year, compared to 70.0 percent of those whose conditions never affect their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

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

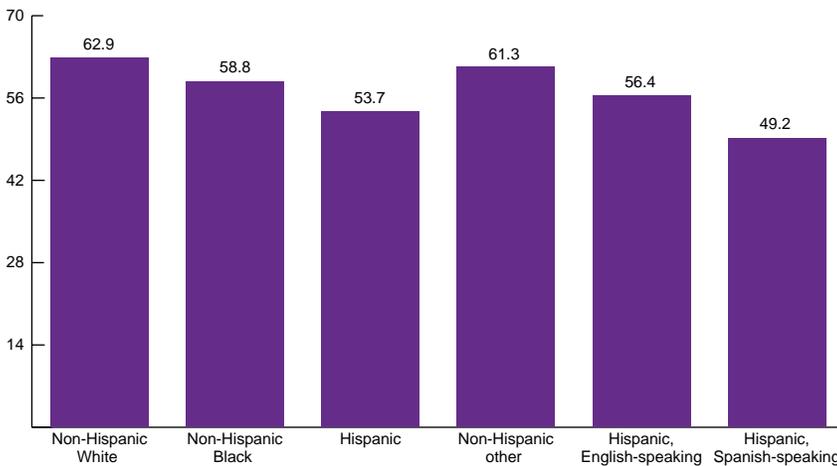
**CSHCN with Consistent, Adequate Insurance to Pay for the Services They Need**



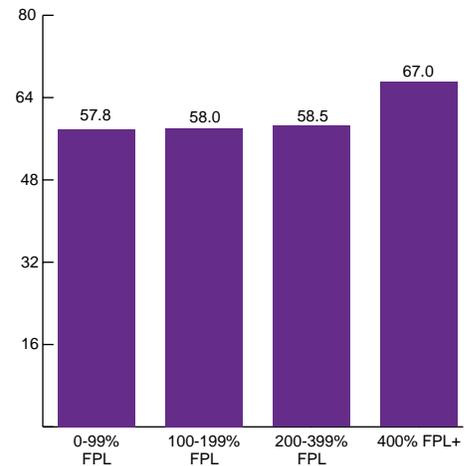
**Families of CSHCN Have Consistent Adequate Public and/or Private Insurance to Pay for the Services They Need, by Impact of Condition**



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



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



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

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

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

**Preventive Health Visits**

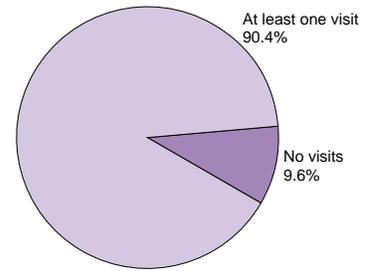
Like all children, CSHCN require regular preventive health care. The Bright Futures guidelines for health supervision of infants, children, and adolescents recommend that children visit a physician six times during the first year, three times in the second year, and annually thereafter for preventive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

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

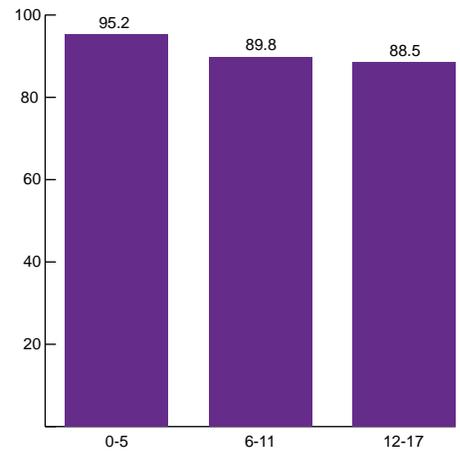
Overall, the parents of 90.4 percent of CSHCN reported that their children received at least one preventive medical visit in the past year. This percentage was slightly higher among the youngest children (aged 0-5); 95.2 percent of these children received at least one well-child visit, compared to 88.5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

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

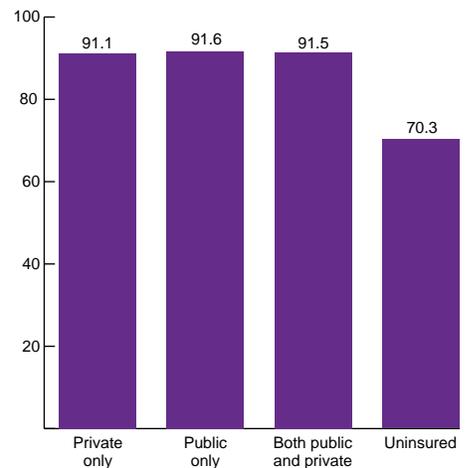
**Receipt of an Annual Preventive Medical Visit Among CSHCN**



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



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



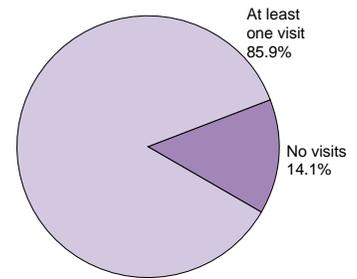
## Preventive Dental Visits

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

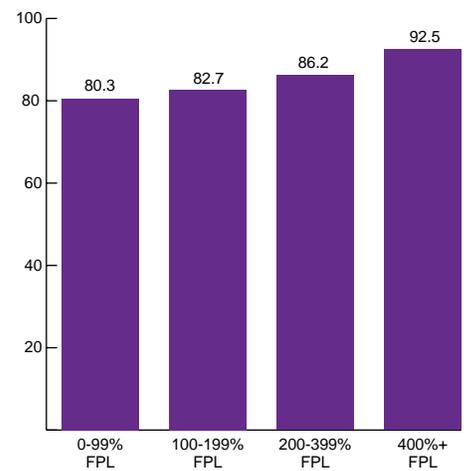
As with preventive medical care, the survey asked whether children aged 1-17 had received a preventive dental visit, such as a checkup or a cleaning, within the past year. Overall, the parents of 85.9 percent of CSHCN reported that their children received a preventive dental visit.

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

Receipt of an Annual Preventive Dental Visit Among CSHCN



Receipt of an Annual Preventive Dental Visit, by Poverty Status



**Core Outcome Summary**

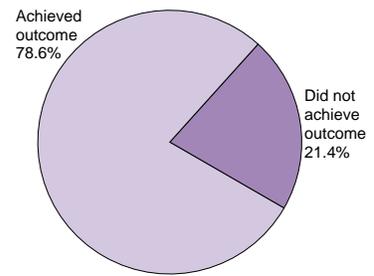
Children were considered to have met the goal for early and continuous screening if they received both an annual preventive medical visit and an annual preventive dental visit. Overall, 78.6 percent of CSHCN achieved this outcome; this percentage ranged from 64.8 percent of children aged 0-5 to 83.8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

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

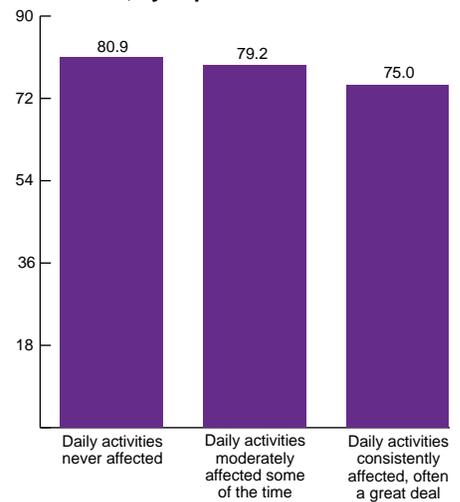
Children whose conditions consistently affect their activities are slightly less likely than children whose conditions have less of an impact to receive both preventive medical and dental care annually. Of children whose daily activities are never affected by their conditions, 80.9 percent achieved the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

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

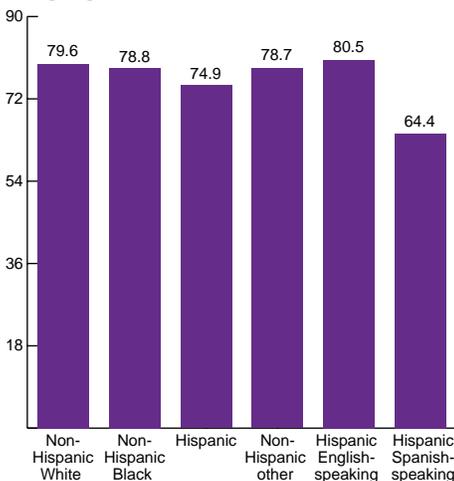
**CSHCN Who Are Screened Early and Continuously for Special Needs**



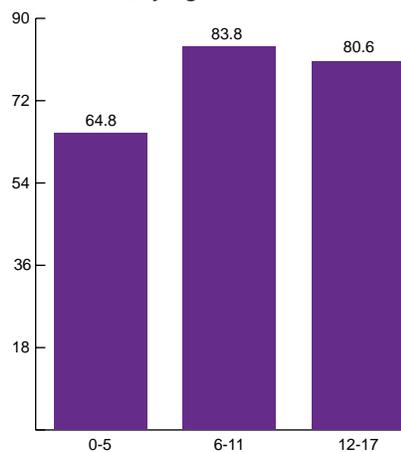
**Percent of CSHCN Who Are Screened Early and Continuously for Special Health Care Needs, by Impact of Condition**



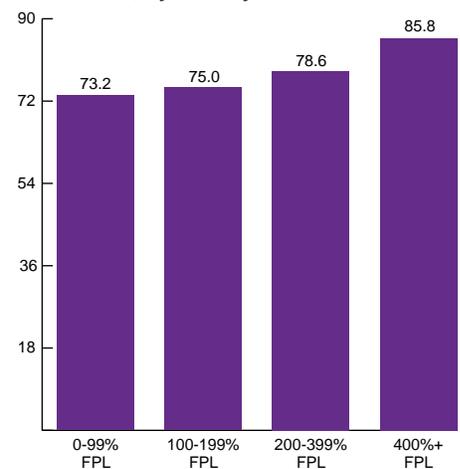
**Percent of CSHCN Who Are Screened Early and Continuously for Special Health Care Needs, by Race/Ethnicity and Primary Language**



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



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



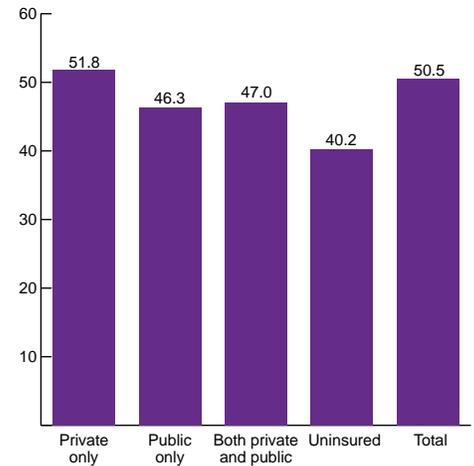
*Related Measure: Developmental Screening*

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

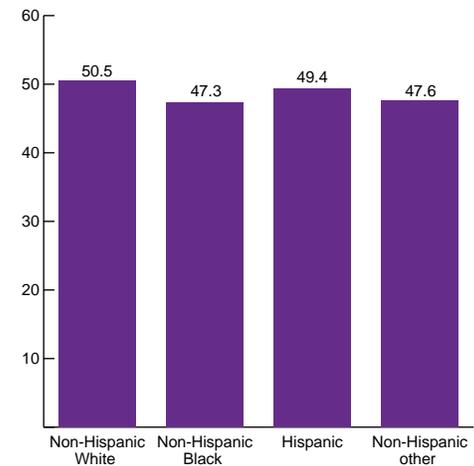
Despite this recommendation, only half (50.5 percent) of CSHCN aged 1-5 were reported to have received such a screening during a preventive health visit in the past 12 months. This percentage was highest among children with private insurance, of whom 51.8 percent were reported to have received a developmental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

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

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



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



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

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

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

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

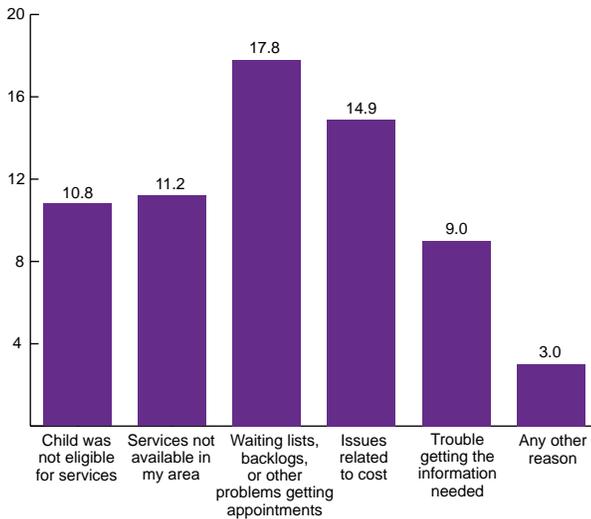
## Difficulties Receiving Services

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

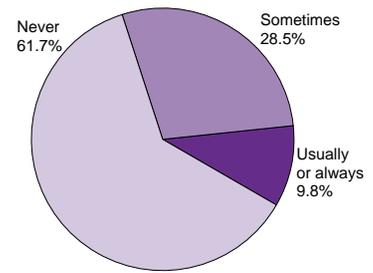
The reason most frequently reported for unmet need for services is waiting lists, backlogs, or other problems getting appointments, which was reported to be a problem for 17.8 percent of CSHCN. For 14.9 percent of CSHCN, issues related to the cost of services caused difficulty in obtaining services.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

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

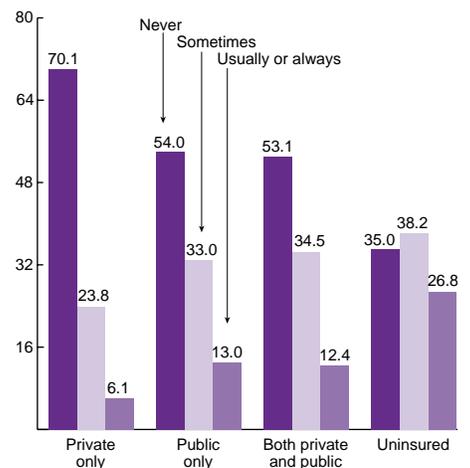
**Reasons for Difficulties or Delays Getting Services**



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



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



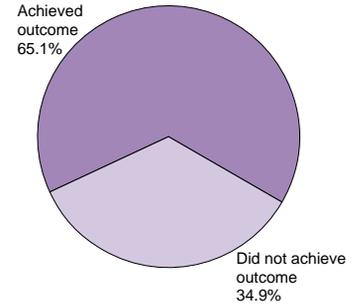
**Core Outcome Summary**

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

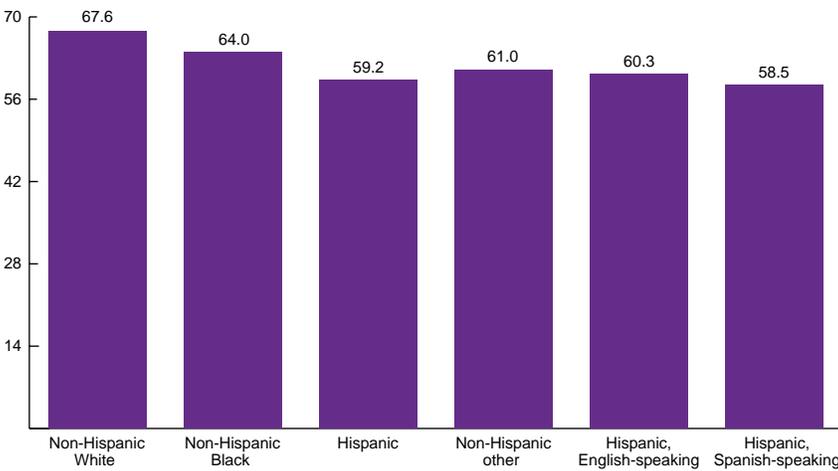
Children whose conditions never affect their daily activities are the most likely to report that services are organized for easy use. Of CSHCN whose conditions never affect their activities, 80.4 percent met this objective, compared to 45.9 percent of CSHCN whose conditions consistently affect their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

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

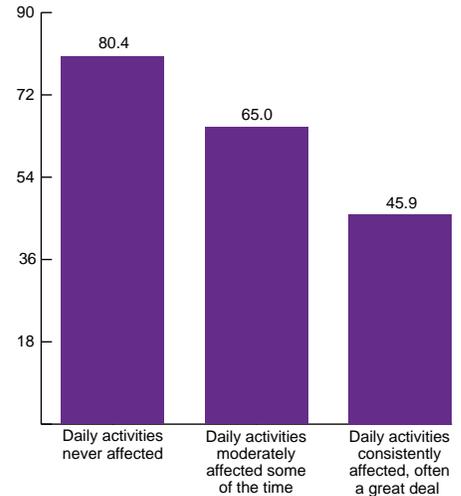
**CSHCN for Whom Community-Based Services Are Organized So That Families Can Use Them Easily**



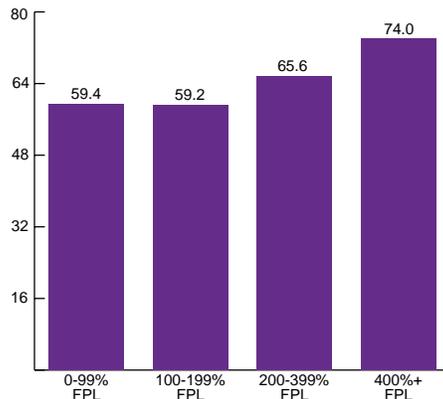
**Community-Based Services Are Organized So That Families Can Use Them Easily, by Race/Ethnicity and Primary Language**



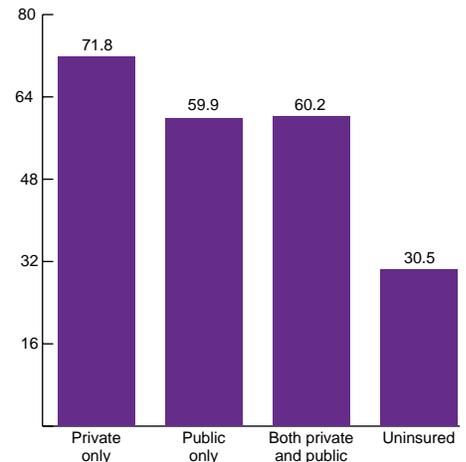
**Community-Based Services Are Organized So That Families Can Use Them Easily, by Impact of Condition**



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



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



## Related Measure: Specific Health Care Needs

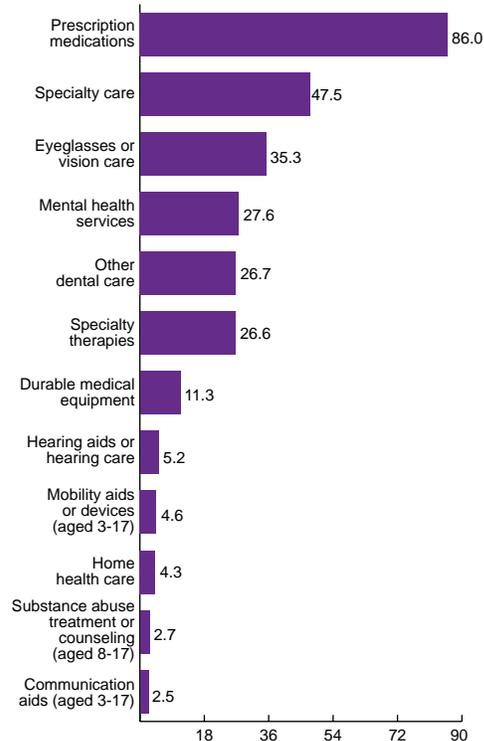
Children with special health care needs require a broad range of services, from primary and specialty medical care to prescription medications, medical equipment and therapies. In addition, the families of CSHCN may need additional support services, such as respite care, family counseling, or genetic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

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

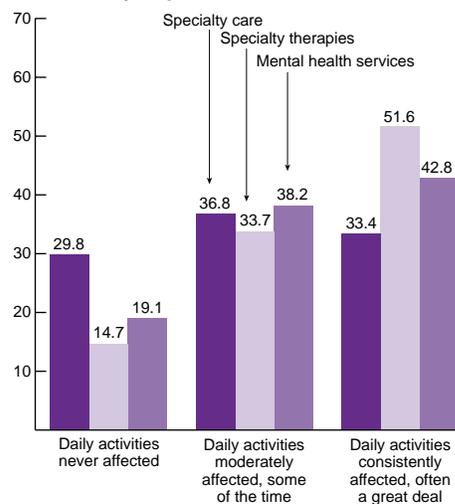
Some services that are needed relatively infrequently among the population of CSHCN as a whole are more commonly required by children whose conditions have a greater impact on their daily lives. Of CSHCN whose conditions consistently affect their activities, one-third require care from specialists, more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

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

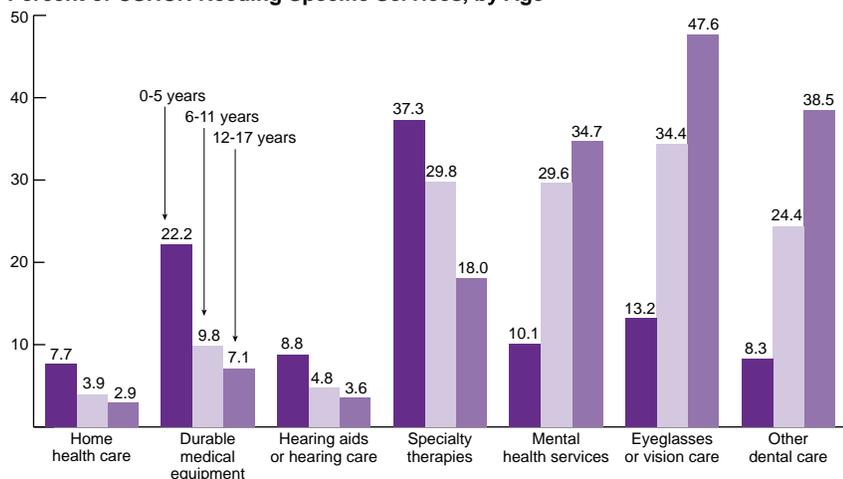
**Percent of CSHCN Needing Specific Services**



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



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

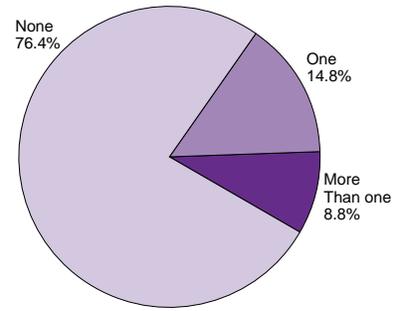


**Related Measure: Unmet Need for Services**

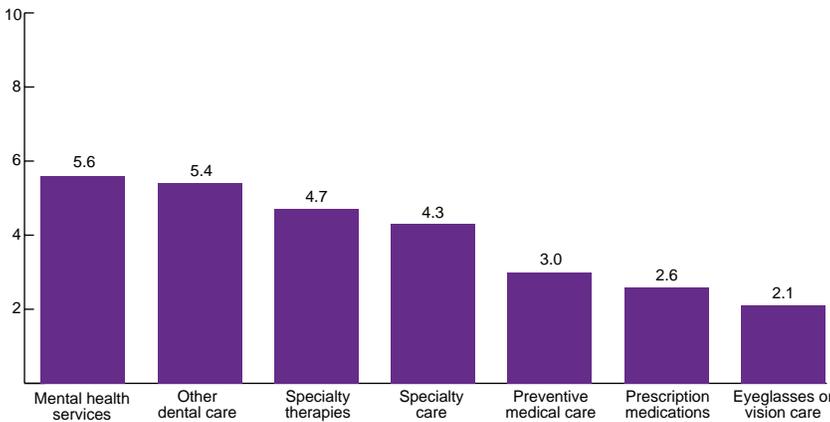
For each service that a child needed, parents were asked if their child received all of the care that he or she needed. Overall, nearly one quarter of CSHCN (23.6 percent) did not receive at least one service that they needed, and 8.8 percent did not receive more than one needed service. The service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

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

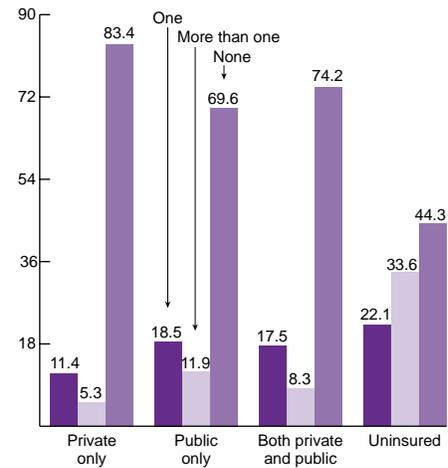
**CSHCN with One or More Unmet Needs**



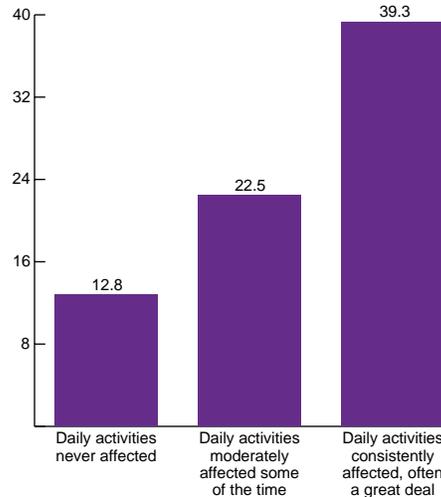
**Percent of CSHCN with Unmet Need for Specific Services**



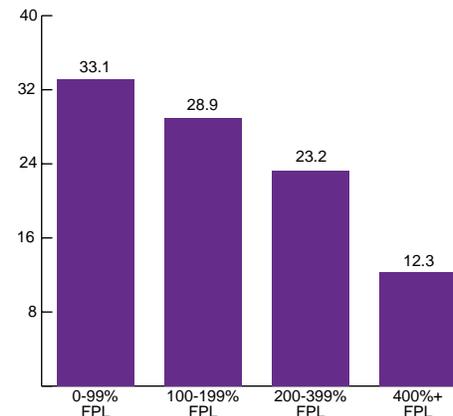
**Percent of CSHCN with One or More Reported Unmet Service Needs (of 14 Services Listed), by Insurance Type**



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



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

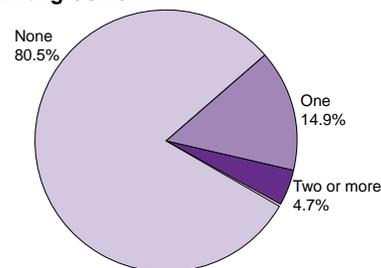


### Related Measure: Family Support Services

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

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

Need for Family Support Services Among CSHCN



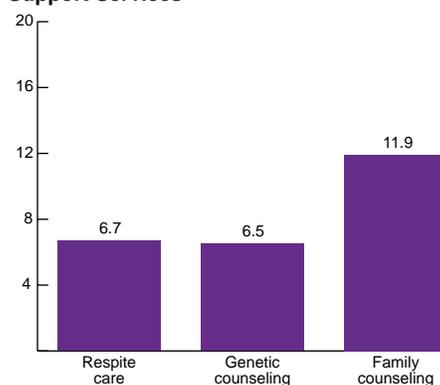
### Related Measure: Unmet Need for Family Support Services

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

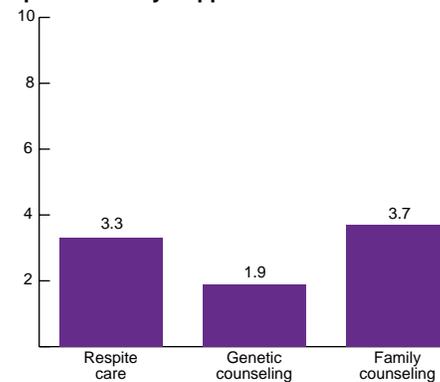
While these overall proportions are small, families of low-income and uninsured CSHCN were most likely to report unmet need for family support services. Of uninsured children, the families of 18.1 percent did not receive at least one support service that they needed, as did the families of 8.9 percent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

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

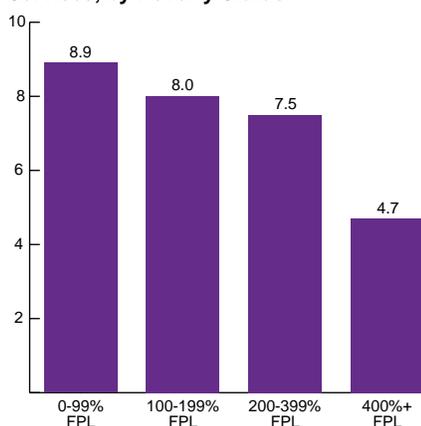
Percent of CSHCN Who Needed Family Support Services



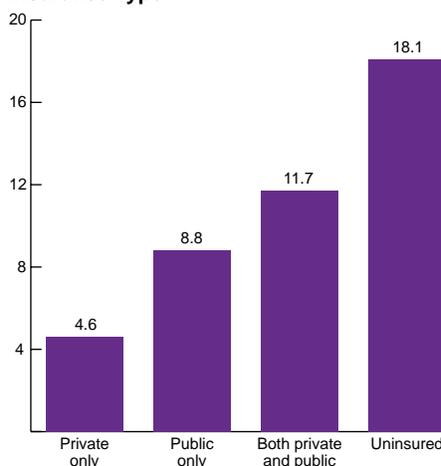
Percent of CSHCN with Unmet Need for Specific Family Support Services



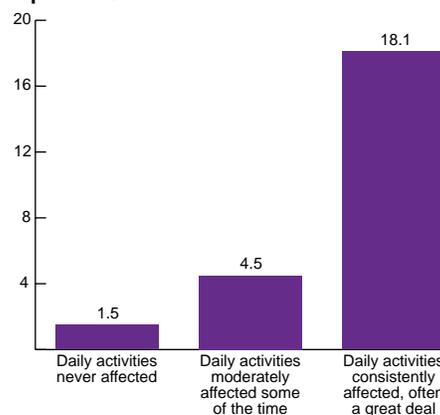
CSHCN with One or More Reported Unmet Need for Family Support Services, by Poverty Status



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



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



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

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

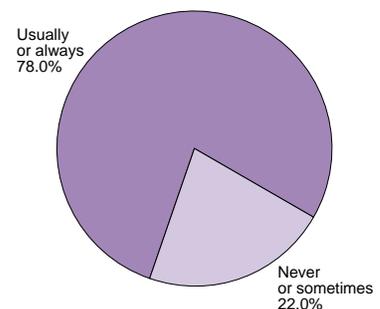
The standard for transition outcome was evaluated for CSHCN aged 12 to 17 using two questions: whether a child's doctors usually or always encourage adolescents to take increasing responsibility for their care, and whether doctors had provided anticipatory guidance for the transition to adult health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

### ***Taking Responsibility for Health Care Needs***

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

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

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

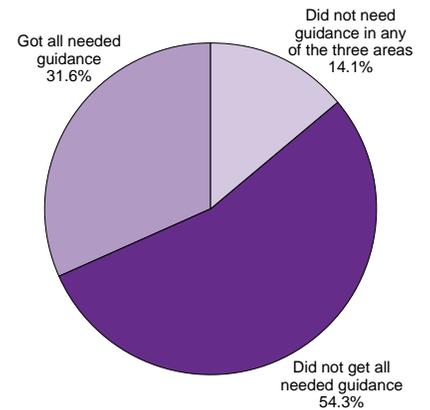


**Provision of Anticipatory Guidance**

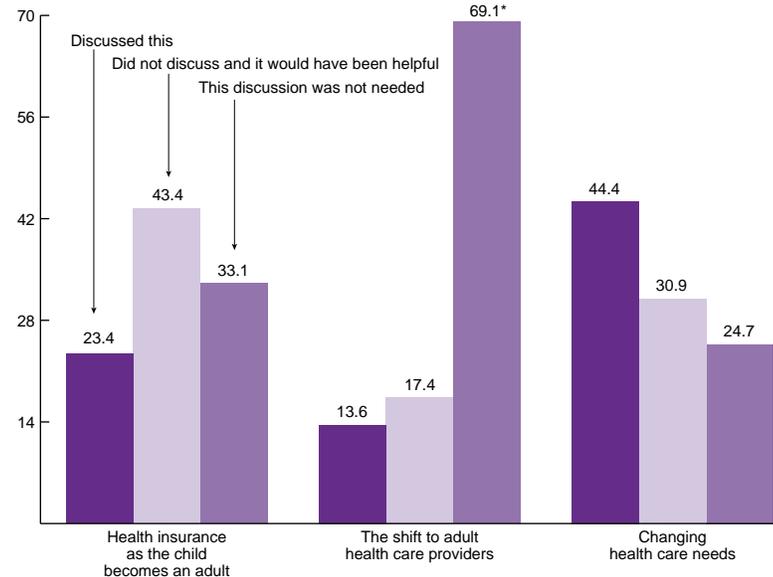
To ease the transition to adult health care, providers can offer guidance to adolescents and their families about various aspects of their care. The survey asked parents of youth with special health care needs whether their children’s providers had discussed health insurance; the shift to adult health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

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

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



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



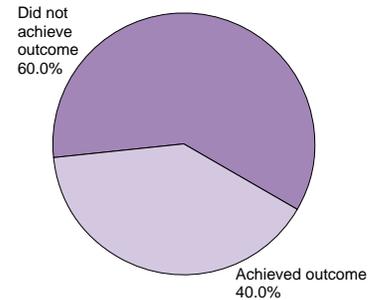
\*Includes those who reported that their providers treat both adults and children.

**Core Outcome Summary**

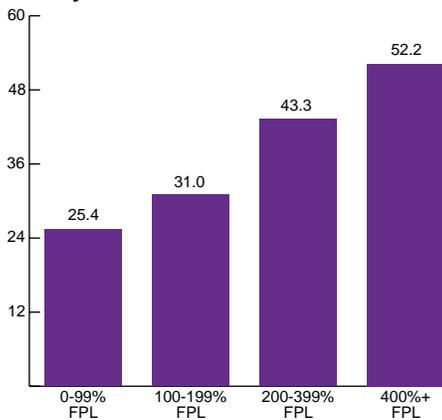
Youth with special health care needs were considered to have achieved the outcome for making effective transitions to adult life if their parents reported that they received anticipatory guidance in all three areas and their providers usually or always encouraged them to take responsibility for their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

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

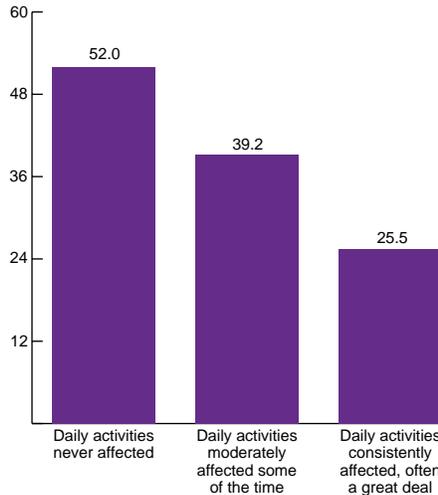
**Youth with Special Health Care Needs Who Receive the Services Necessary to Make the Transition to Adult Health Care (CSHCN Aged 12-17)**



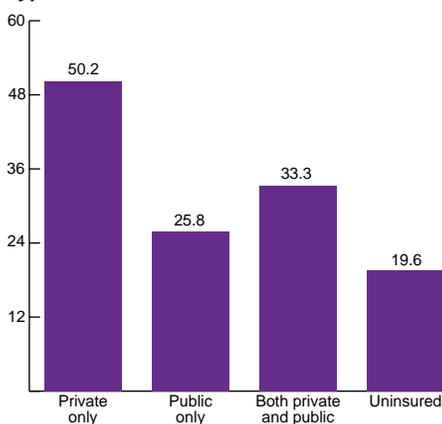
**Percent of Youth with Special Health Care Needs Who Receive the Services Necessary to Make Transitions to Adult Health Care (CSHCN Aged 12-17), by Poverty Status**



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



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

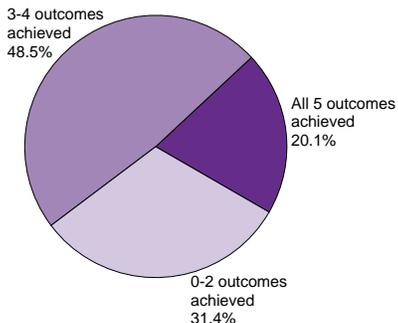


### Overall Quality of the System of Services

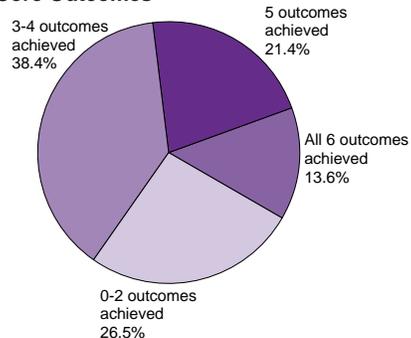
To further evaluate the system of care serving CSHCN, the core outcomes were combined into a single indicator of “system-ness”. A child was considered to be served by a well-functioning “service system,” as described in the Healthy People objective, if his or her care met all relevant criteria for his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

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

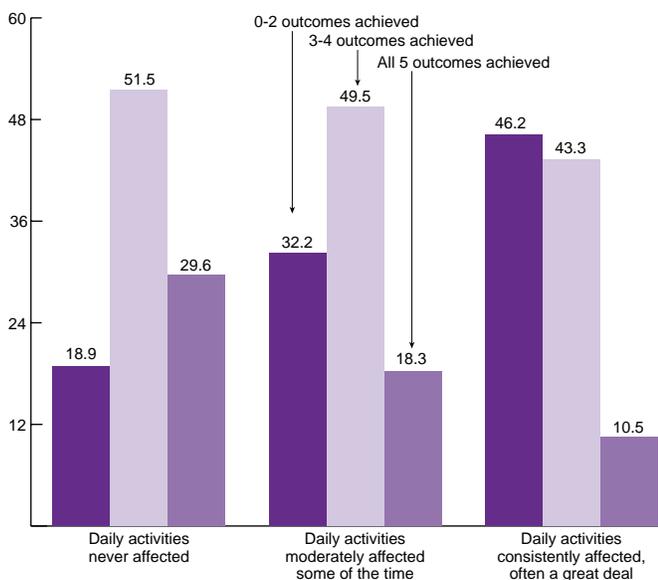
**CSHCN Aged 0-11 Who Are Served by Systems of Care That Met One or More Core Outcomes**



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



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



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

