

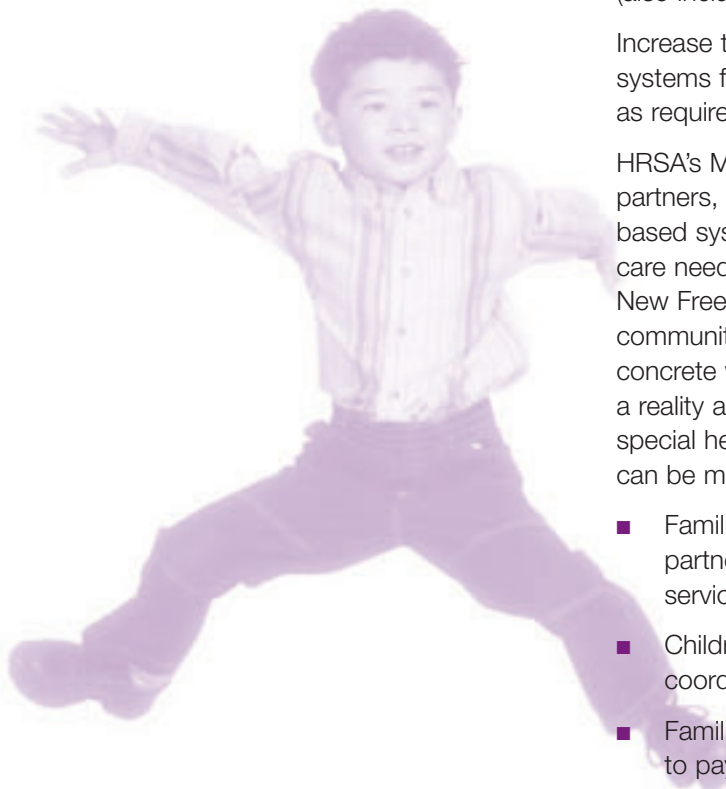
## Core Outcomes: Key Measures of Performance

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

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

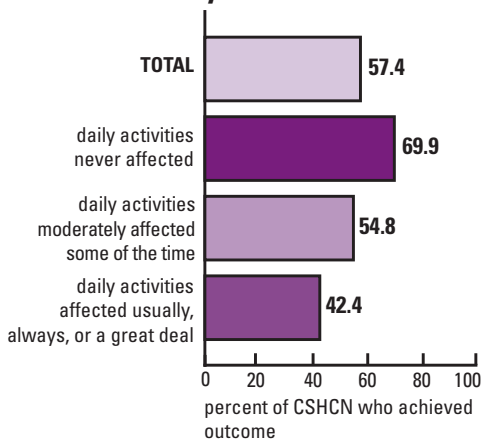
HRSA's Maternal and Child Health Bureau (MCHB), together with its partners, has identified six core outcomes to promote the community-based system of services mandated for all children with special health care needs under Title V, Healthy People 2010, and the President's New Freedom Initiative (NFI) designed to break down barriers to community living for people with disabilities. These outcomes give us a concrete way to measure our progress in making family-centered care a reality and in putting in place the kind of systems all children with special health care needs deserve. Progress toward the overall goal can be measured using these six critical indicators:

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

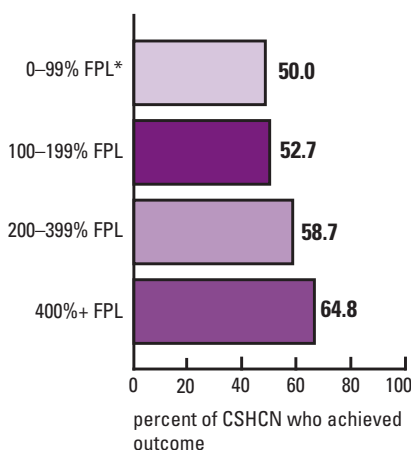


## Families of CSHCN partner in decision-making at all levels and are satisfied with the services they receive.

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



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



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

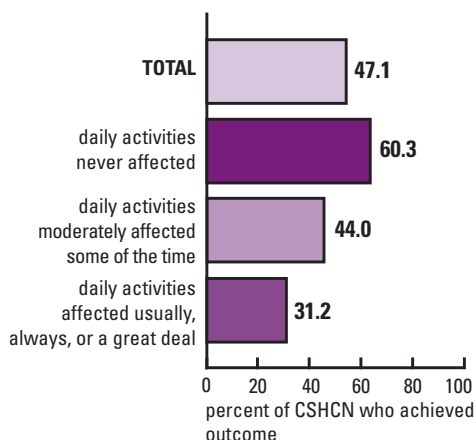
Family-centered care is based on the recognition that children live within the context of families—which may include biological, foster, and adoptive parents, step-parents, grandparents, other family caregivers, and siblings. Family-centered care is a process to ensure that the organization and delivery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

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

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

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

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



Simply put, a medical home means a source of ongoing, comprehensive, coordinated, family-centered care in the child's community. Child health care professionals and families agree that medical homes provide important and unique benefits to children and youth with special health care needs.

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

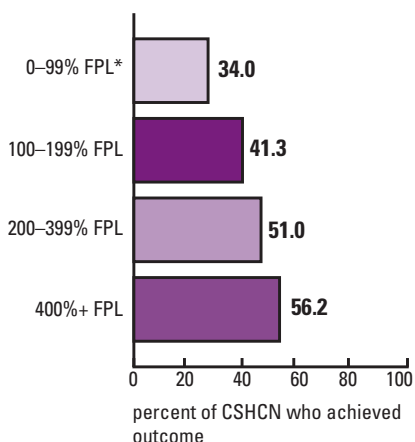
Collaboration between the primary, specialty, and subspecialty providers to establish shared management plans in partnership with the child and family and to formulate a clear articulation of each other's role is a key component of the medical home concept.

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

This outcome was evaluated using a series of questions from the NS-CSHCN: whether the child has a personal doctor or nurse; whether he or she has a usual source of sick and well-child care; whether the child has had problems obtaining needed referrals; whether the family is satisfied with doctors' communication with each other and the child's school and other systems; whether the family gets help coordinating the child's care if needed; whether the doctor spends enough time with the child; whether the doctor listens carefully to the parent; whether the doctor is sensitive to the family's customs; whether the doctor provides the family with enough information; whether the parent feels like a partner in the child's care; and whether the family receives interpretation services when needed. All of these criteria were met by 47.1 percent of CSHCN.

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

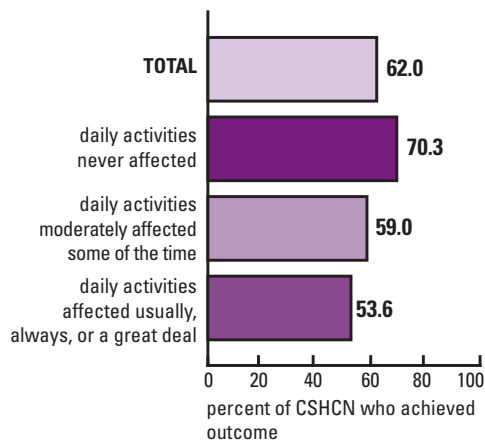
### CSHCN Who Receive Coordinated, Ongoing, Comprehensive Care Within a Medical Home: Family Income



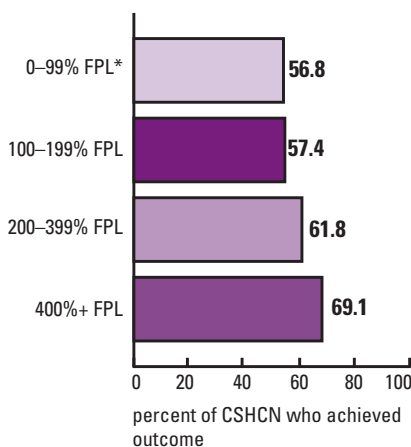
\*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as \$19,350 for a family of four.

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

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



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



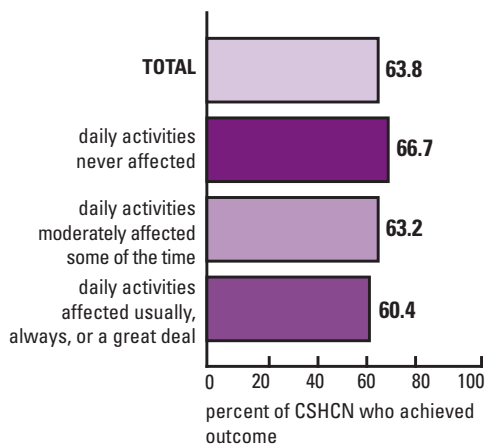
\*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as \$19,350 for a family of four.

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

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

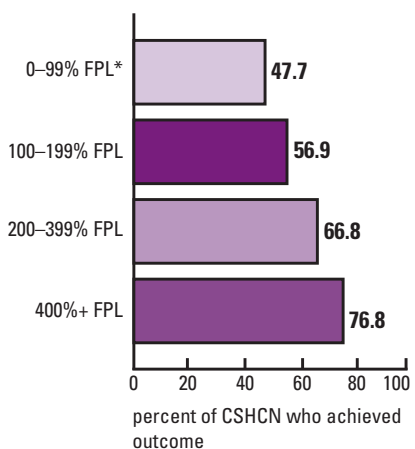
## Children are screened early and continuously for special health care needs.

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



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.

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

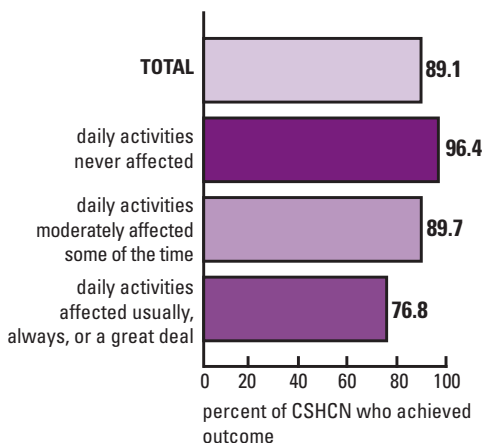


Only the second component of screening—ongoing assessments for CSHCN—was measured in the NS-CSHCN. An estimate for this outcome was arrived at using two survey questions: whether or not CSHCN received routine preventive medical care in the past year and whether they received routine preventive dental care during the past year. Overall, this outcome was successfully achieved for 63.8 percent of CSHCN. Children’s likelihood of achieving this outcome did not vary substantially based on the impact of the condition on the child’s functional ability. However, children with higher family incomes were significantly more likely to be screened regularly: 77 percent of children with family incomes of 400 percent of the poverty level achieved this outcome, compared to 48 percent of children with family incomes below the poverty level.

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

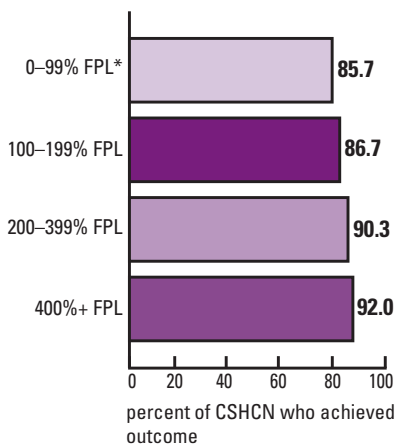
## Community-based services for CSHCN are organized so families can use them easily.

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



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

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



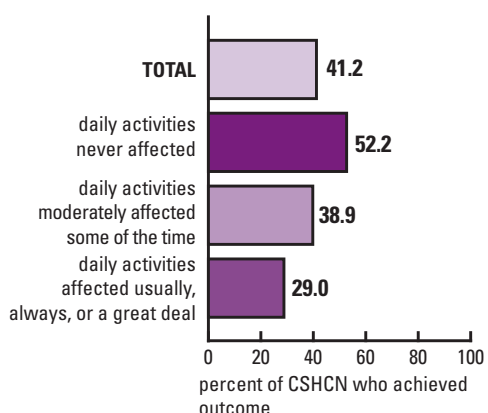
This outcome was assessed using a single question asking parents whether they had had difficulties trying to use the range of services their children had needed over the past year. This outcome was achieved by 89.1 percent of CSHCN.

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

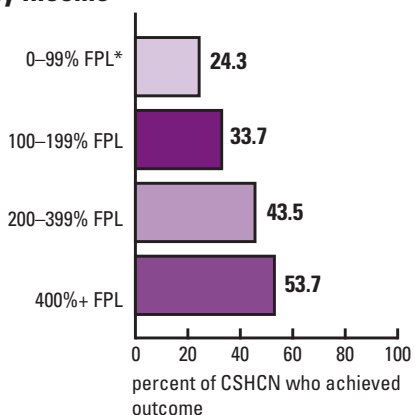
\*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as \$19,350 for a family of four.

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

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



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



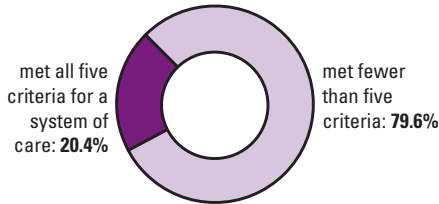
\*Federal Poverty Level. In 2005, the HHS poverty guidelines defined 100 percent of poverty as \$19,350 for a family of four.

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

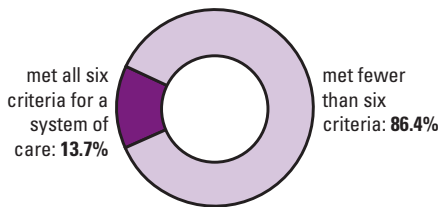
This outcome was evaluated for CSHCN 12-17 years of age using several questions: whether doctors had discussed the shift to adult providers, whether doctors had discussed the child's changing needs as he or she approached adulthood, whether anyone had discussed insurance coverage in adulthood, and whether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

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

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



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



**Overall Quality of the System of Care**

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

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

Together, these six Core Outcomes can be used to measure progress toward the Healthy People 2010 objective to increase the proportion of States and territories that have service systems for children with or at risk for chronic and disabling conditions. In this analysis, a child was considered to be served by a “service system,” as described in the Healthy People objective, if his or her care met all relevant criteria for his or her age. For children from birth through age 11 years, the first five outcomes were included, and all six outcomes were counted for children from age 12 through 17 years.

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