

Who Are Children with Special Health Care Needs?

Definition of Children with Special Health Care Needs

The federal Maternal and Child Health Bureau defines children with special health care needs (CSHCN) as:

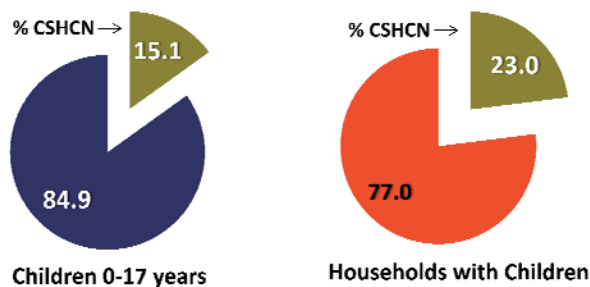
“those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally”¹

This definition is used to guide the development of family-centered, coordinated systems of care for children and families for children with special needs served by the state Title V block grants administered by the Maternal and Child Health Bureau.

The National Survey of CSHCN (NS-CSHCN) and the National Survey of Children’s Health (NSCH) – two child health surveys – use a validated, non-condition specific, consequences-based screening tool to identify children meeting the Maternal and Child Health definition of CSHCN, with the exception that the “at risk” component is not included, so as to focus on current CSHCN.^{2,3}

Prevalence Profile: 2009/10 NS-CSHCN

Source: 2009-2010 NS-CSHCN; www.childhealthdata.org



According to the 2009/10 National Survey of Children with Special Health Care Needs:

- Approximately 11.2 million children ages 0–17 years in the United States (15.1%) have special health care needs.
- Prevalence of CSHCN ranges from 10.6% to 19.8% across the 50 states and the District of Columbia.
- Over 1 in 5 households with children in the United States have at least one child with special health care needs. This translates into almost 9 million households nationally.
- About 60% of CSHCN experience more complex service needs that go beyond a primary need for prescription medications to manage their health condition.
- Compared to children not meeting CSHCN criteria (non-CSHCN), CSHCN are more likely to be male (58.9% vs. 49.7%) and older 12–17 years (40.9% vs. 32.2%)

Health Issues and Functional Difficulties CSHCN Experience:

All CSHCN experience at least one type of ongoing health condition that results in an above routine need for health and related services. Across the list of 20 specific health issues asked about in the 2009/10 NS-CSHCN, 87.7% of CSHCN were reported to experience at least one, 57.1% experienced two or more and 29.1% of CSHCN were reported to experience three or more from the limited list. Of the 20 health issues asked about, CSHCN most commonly were reported to experience asthma and/or allergies (59.4%). Nearly 50% of these children (46.6%) also experienced at least one other health issue from the list of 20 asked about.

Health Issue Asked About*	% Among CSHCN	Health Issue Asked About	% Among CSHCN
ADD/ADHD	30.2	Headaches	9.8
Depression	10.3	Head Injury	1.4
Anxiety	17.1	Heart Problem	3.0
Behavioral problems	13.5	Blood Problems	1.5
Autism, ASD	7.9	Cystic Fibrosis	0.3
Developmental Delay	17.6	Cerebral Palsy	1.6
Intellectual Disability	5.8	Muscular Dystrophy	0.3
Asthma	35.3	Down Syndrome	1.1
Diabetes	1.7	Arthritis	2.9
Epilepsy	3.1	Allergies	48.6

*Condition prevalence in 2009/10 was asked using two questions: prevalence of conditions ever or currently. Only current prevalence is reported here.

Functional difficulties impact the day-to-day life of CSHCN. Among 14 difficulties asked about, 91.2% of CSHCN experienced at least one, 72% experienced two or more and 45.6% of CSHCN experienced 4 or more. We cannot assess whether functional difficulties experienced are specifically due to the health issues asked about in the NS-CSHCN. However, results indicate nearly all CSHCN experience functional difficulties regardless of the type or severity of specific health issues or diagnoses they have. Over 92% of the 59.4% of CSHCN reported to experience asthma and/or allergies were also reported to experience one or more functional difficulties, with 43.2% experiencing 4 or more.

Functional Difficulty Experienced	% CSHCN
Breathing or other respiratory problems	46.5
Swallowing, digesting food, or metabolism	19.1
Blood Circulation	6.1
Repeated or chronic physical pain, including headaches	29.0
Seeing even when wearing glasses or contact lenses	15.6
Hearing even when using a hearing aid/other device	6.3
Taking care of self, such as eating, dressing, bathing	19.8
Coordination or moving around	19.6
Using his/her hands	16.1
Learning, understanding or paying attention	51.1
Speaking, communicating, or being understood	32.9
Feeling anxious or depressed	42.9
Behavior problems	41.4
Making and keeping friends	32.4

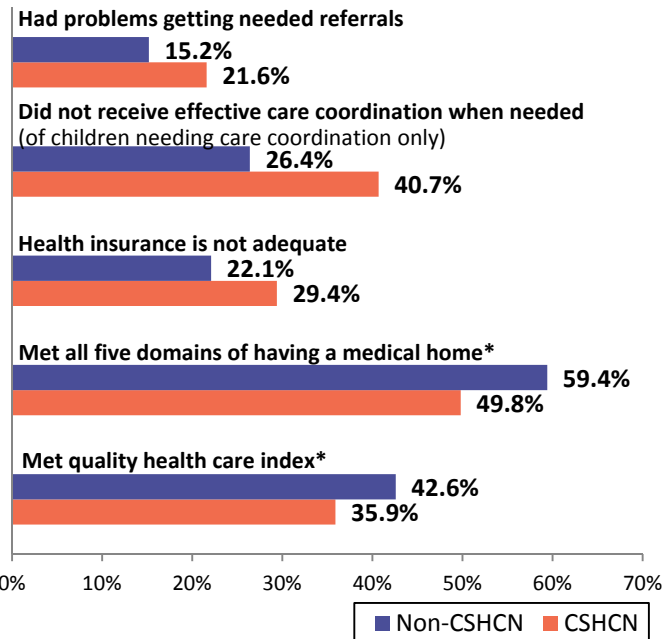
1 McPherson M, Arango P, Fox H, et al. “A new definition of children with special health care needs”, *Pediatrics*, 1998; 102: 137-140.

2 Bethell, CD, Read, D, Stein, R., Blumberg, S, Newacheck, P., *Identifying Children with Special Health Care Needs: Development and Evaluation of a Short Screening Tool. Ambulatory Pediatrics*. 2002

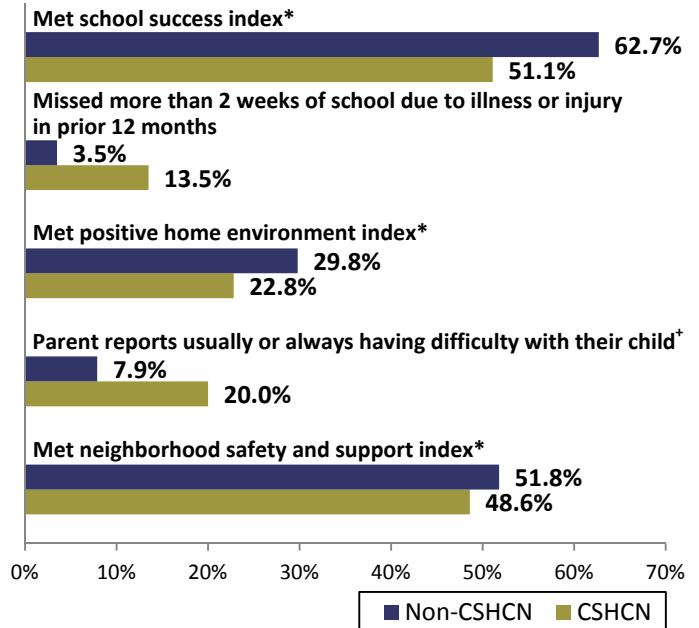
3 Bethell, CD, Read, D, Blumberg, SJ, Newacheck, P. *What is the Rate of Children with Special Health Care Needs: Towards an Understanding of Variations in Prevalence and Methods across Three National Surveys. MCH Journal*. July 2007

4 Newacheck, PW & Kim, SE. *A national profile of health care utilization and expenditures for children with special health care needs. Archives of Pediatrics and Adolescent Medicine*. 2005;159:10-17.

2007 National Survey of Children's Health: Measures of Health Care Access and Quality for CSHCN and Non-CSHCN



2007 National Survey of Children's Health: Home and School Profile for CSHCN and Non-CSHCN



***Medical home:** (1) Have a personal doctor or nurse, (2) have a usual source for sick care, (3) receive family-centered care, (4) have no problems getting needed referrals and (5) receive effective care coordination when needed

Quality health care index: have a medical home, adequate insurance and at least one preventive medical visit in the prior 12 months

School success index: child usually or always is engaged in school, participates in extracurricular activities and usually/always feels safe at school (age 6-17)

Positive home environment index: watches 2 or fewer hours of TV per day (age 0-17) and does not have a TV in bedroom (age 6-17), no one in household smokes, usually/always does required homework (age 6-17), parent has met most or all of child's friends (age 6-17), child is read or sung to every day (age 0-5), child was ever breastfed (age 0-5) and family eats meals together 4 or more days/week

Neighborhood safety and support index: Children live in a supportive community and safe neighborhood with 3 or more neighborhood amenities (age 0-17) and attend a safe school (age 6-17)

+Usually or always feels at least one of the following three ways: (1) that child is much harder to care for than other children; (2) bothered a lot by their child's behavior; (3) angry with their child

Identifying CSHCN

CSHCN are identified in the NS-CSHCN and the NSCH using the CSHCN Screener[©] – a five item, parent-reported tool designed to reflect the federal Maternal and Child Health Bureau's consequences-based definition of children with special health care needs.^{3,4}

- The CSHCN Screener[©] operationalizes the MCHB definition of CSHCN by focusing on the health consequences a child experiences as a result of having an on-going health condition rather than on the presence of a specific diagnosis or type of disability.
- The screener assesses children's health care needs status by using questions that ask about need or use of services, prescription medications, specialized therapies, and having functional difficulties due to an ongoing condition.
- The non-condition specific approach used by the CSHCN Screener[©] identifies children across the range and diversity of childhood chronic conditions and special needs, allowing a more comprehensive assessment of health needs and health care system performance.

Developed by The Child & Adolescent Health Measurement Initiative (CAHMI at www.cahmi.org); National Data Resource Center for Child and Adolescent Health; Oregon Health & Science University, School of Medicine, Department of Pediatrics

Visit the Data Resource Center
to learn more about CSHCN in your state



www.childhealthdata.org