

# Who are Children with Special Health Care Needs?

## Definition

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”<sup>1</sup>*

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.

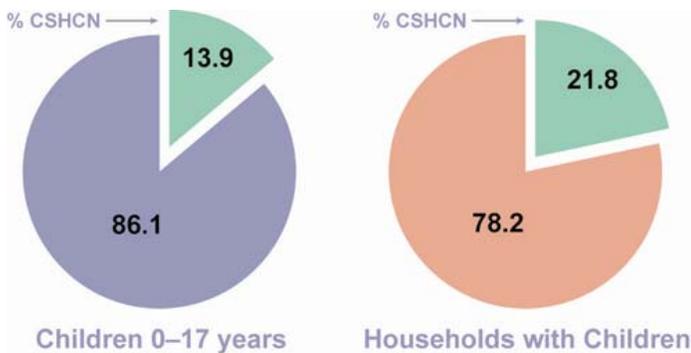
The National Survey of CSHCN (NS-CSHCN) and the National Survey of Children’s Health (NSCH) – two child health prevalence surveys – use a validated non-condition specific, consequences based screening tool to identify children meeting the Maternal and Child Health definition of CSHCN with the exception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

## Demographic Profile

- Compared to children not meeting CSHCN criteria (non-CSHCN), CSHCN are more likely to be male (59% vs. 50%) and older, 12–17 years (42% vs. 33%).
- CSHCN and non-CSHCN are equally likely to live in low income families.
- While estimated by the NS-CSHCN to be about 14% of the child population, CSHCN account for 40% or more of medical expenditures for children overall.<sup>4</sup>

## Prevalence Profile

Source: 2005-2006 National Survey of Children with Special Health Care Needs



## According to the 2005-2006 National Survey of Children with Special Health Care Needs:

- Approximately 10.2 million children ages 0–17 years in the United States (13.9%) have special health care needs.
- Prevalence of CSHCN ranges from 10% to 18.5% across the 50 states and the District of Columbia.
- 1 in 5 households with children in the United States have at least one child with special health care needs. This translates into over 8.8 million households nationally.

## Health Status Profile

91% of CSHCN have 1 or more conditions on the list of sixteen shown below and 25% of CSHCN have 3 or more of these conditions

CONDITIONS % OF CSHCN	% of CSHCN
Allergies	53%
Asthma	38%
ADD/ADHD	30%
Depression, anxiety, or emotional problems	21%
Migraine/frequent headaches	15%
Mental Retardation	11%
Autism or autism spectrum disorder	5%
Joint problems	4%
Seizure disorder	4%
Heart Problems	4%
Blood problems	2%
Diabetes	2%
Cerebral Palsy	2%
Down Syndrome	1%
Muscular dystrophy	0.3%
Cystic fibrosis	0.3%

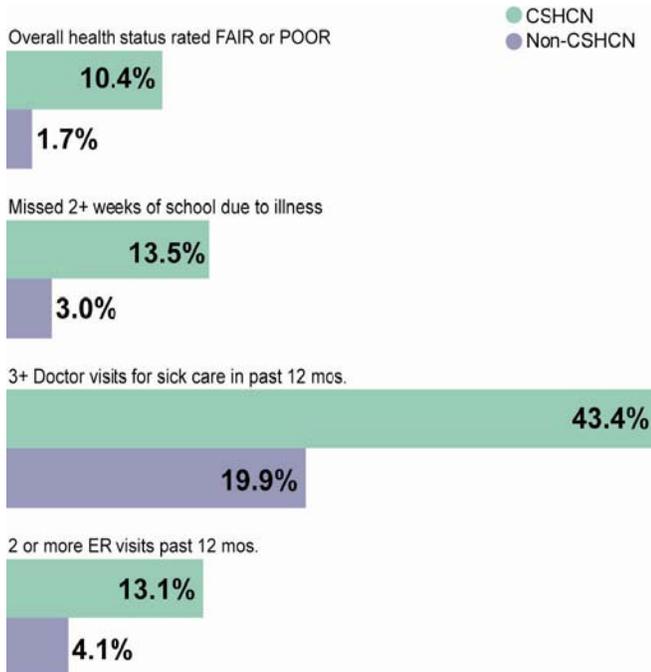
85% of CSHCN experience 1 or more of the following functional difficulties and 28% of CSHCN have 4 or more of the difficulties listed

FUNCTIONAL DIFFICULTIES % OF CSHCN	% of CSHCN
Respiratory problems	43%
Learning, understanding, or paying attention (ages 2–17 yrs old)	41%
Feeling anxious or depressed	29%
Behavior problems	28%
Speaking, communicating or being understood	23%
Making & keeping friends (ages 3–17 yrs old)	20%
Chronic pain	18%
Gross motor	14%
Self care (ages 3-17 yrs old)	12%
Fine motor	11%
Swallowing, digesting food, or metabolism	10%
Difficulty seeing even with glasses	4%
Blood circulation	2%
Uses a hearing aid	1%

Source, both tables: 2005-2006 National Survey of Children with Special Health Care Needs

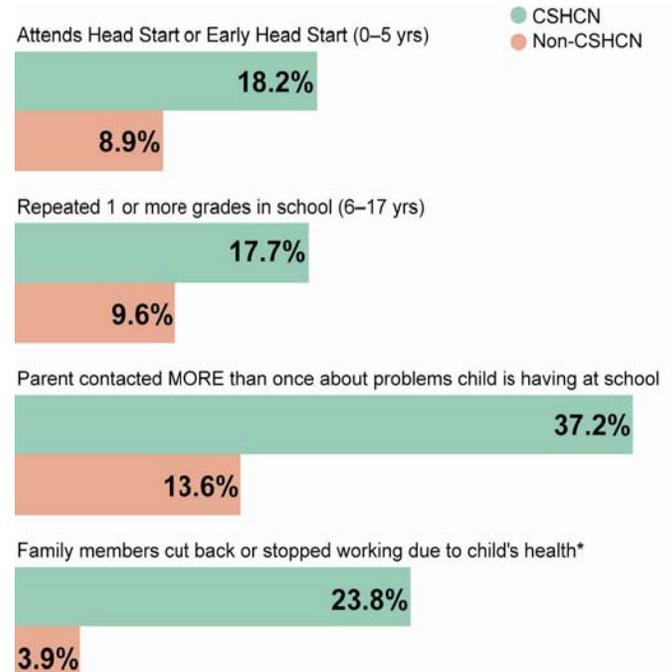
## Comparing CSHCN to Those without Special Health Care Needs

### Health Status and Utilization



Source: 2003 National Survey of Children's health, [www.nschdata.org](http://www.nschdata.org)

### Profile School and Home Profile



Source: 2003 National Survey of Children's health, [www.nschdata.org](http://www.nschdata.org)

\* Source: 2005-2006 National Survey of Children with Special health Care Needs

## Identifying CSHCN

CSHCN are identified in the NS-CSHCN and the NSCH using the CSHCN Screener<sup>®</sup> – 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.<sup>3,4</sup>

- The CSHCN Screener<sup>®</sup> 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<sup>®</sup> 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](http://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](http://www.childhealthdata.org)

## References

- 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.