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.”

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.

Prevalence Profile: 2011/12 NSCH & 2009/10 NS-CSHCN

According to the 2011/12 National Survey of Children with Special Health Care Needs:

- Approximately 14.6 million children ages 0–17 years in the United States (19.8%) have special health care needs.
- Prevalence of CSHCN ranges from 14.4% to 26.4% across the 50 states and the District of Columbia.
- About 65% 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 (58.1% vs. 49.4%) and older 12–17 years (43.2% vs. 31.8%).

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 18 specific health issues asked about in the 2011/12 NSCH, 78.4% of CSHCN were reported to experience at least one, 41.1% experienced two or more from the limited list. Of the 18 health issues asked about, CSHCN most commonly were reported to experience ADD/ADHD (32.2%). Over 70% of these children (71.8%) also experienced at least one other health issue from the list of 18 asked about.

<table>
<thead>
<tr>
<th>Health Issue Asked About*</th>
<th>% Among CSHCN</th>
<th>Health Issue Asked About</th>
<th>% Among CSHCN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning Disability</td>
<td>27.2</td>
<td>Speech Problems</td>
<td>15.6</td>
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<tr>
<td>ADD/ADHD</td>
<td>32.2</td>
<td>Tourette Syndrome</td>
<td>0.2</td>
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<tr>
<td>Depression</td>
<td>8.5</td>
<td>Asthma</td>
<td>30.2</td>
</tr>
<tr>
<td>Anxiety Problems</td>
<td>13.4</td>
<td>Diabetes</td>
<td>1.4</td>
</tr>
<tr>
<td>Autism, Asperger’s, ASD</td>
<td>8.0</td>
<td>Epilepsy</td>
<td>3.1</td>
</tr>
<tr>
<td>Behavioral Problems</td>
<td>13.6</td>
<td>Hearing Problems</td>
<td>4.2</td>
</tr>
<tr>
<td>Developmental Delay</td>
<td>14.7</td>
<td>Vision Problems</td>
<td>3.2</td>
</tr>
<tr>
<td>Intellectual Disability</td>
<td>4.8</td>
<td>Bone, Joint or Muscle Problems</td>
<td>7.7</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>1.0</td>
<td>Brain Injury</td>
<td>1.1</td>
</tr>
</tbody>
</table>

*Condition prevalence in 2011/12 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 in the 2009/10 NS-CSHCN, 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


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