Exploring Health Conditions in the 2009/10 NS-CSHCN

All children included in the 2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN) are children with special health care needs (CSHCN) and therefore have at least one ongoing health condition or problem. The CSHCN Screener used in the survey is a non-condition-specific, consequences-based screening tool used to identify CSHCN. To qualify as CSHCN on the Screener, a child must experience at least one of the following 5 consequences:

1. Need or use of prescription medication
2. Above routine use of medical care, mental health or educational services
3. Being limited or prevented in his or her ability to do the things most children the same age can do
4. Use of specialized therapies (physical, speech, occupational)
5. An emotional, developmental or behavioral problem for which child needs treatment or counseling and that has lasted or is expected to last 12 months or more

A non-condition specific approach is vital for identifying CSHCN. This is because diagnoses among children are unreliable, as children are developing and many health issues are emergent or temporary. Not only are misdiagnoses common, but even a correct diagnosis does not provide the complete picture. Two children with the same diagnosis may have vastly different functioning, health needs and outcomes depending upon their comorbid conditions, health issues or functional difficulties. Thus, a non-condition-specific approach is the most robust, accurate and useful way to identify CSHCN.

The 2009/10 National Survey of Children with Special Health Care Needs asks about the prevalence of 20 specific health conditions. The conditions asked about are those that are common and/or important for research or policy objectives. They do not represent all conditions potentially experienced by CSHCN. Therefore, given that an exhaustive list of conditions is not included in the national survey, this condition data likely underestimates the total number of conditions CSHCN may have.

Comorbidity of Health Conditions

As shown in the table below, the majority of CSHCN currently with any one of the 20 specific health conditions also had at least one other condition asked about. This illustrates the interconnected and co-morbid nature of health conditions among CSHCN. Keep in mind that not all conditions experienced by CSHCN are asked about in the survey.

<table>
<thead>
<tr>
<th>Current health condition* (prevalence among CSHCN)</th>
<th>% of CSHCN with condition listed who also have at least 1 other condition asked about in survey</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual Disability or Mental Retardation (5.8%)</td>
<td>99.4%</td>
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<tr>
<td>Head Injury, Concussion or Traumatic Brain Injury (1.4%)</td>
<td>97.3%</td>
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<tr>
<td>Behavioral or Conduct Problems (13.5%)</td>
<td>96.5%</td>
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<tr>
<td>Depression (10.3%)</td>
<td>96.5%</td>
</tr>
<tr>
<td>Anxiety Problems (17.1%)</td>
<td>95.3%</td>
</tr>
<tr>
<td>Autism Spectrum Disorder (7.9%)</td>
<td>93.2%</td>
</tr>
<tr>
<td>Cerebral Palsy (1.6%)</td>
<td>92.6%</td>
</tr>
<tr>
<td>Migraines or Frequent Headaches (9.8%)</td>
<td>92.5%</td>
</tr>
<tr>
<td>Developmental Delay (17.6%)</td>
<td>92.3%</td>
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<tr>
<td>Down Syndrome (1.1%)</td>
<td>89.6%</td>
</tr>
<tr>
<td>Epilepsy or Seizure (3.1%)</td>
<td>87.0%</td>
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<tr>
<td>Arthritis or Other Joint Problems (2.9%)</td>
<td>86.9%</td>
</tr>
<tr>
<td>Muscular Dystrophy (0.3%)</td>
<td>85.5%</td>
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<tr>
<td>Blood Problems (1.5%)</td>
<td>82.4%</td>
</tr>
<tr>
<td>Asthma (35.3%)</td>
<td>80.0%</td>
</tr>
<tr>
<td>Heart Problem (3.0%)</td>
<td>79.6%</td>
</tr>
<tr>
<td>Allergies (48.6%)</td>
<td>79.1%</td>
</tr>
<tr>
<td>ADD/ADHD (30.2%)</td>
<td>77.4%</td>
</tr>
<tr>
<td>Cystic Fibrosis (0.3%)</td>
<td>76.2%</td>
</tr>
<tr>
<td>Diabetes (1.7%)</td>
<td>52.7%</td>
</tr>
</tbody>
</table>

*Condition prevalence in 2009/10 was asked with two items: “ever told” and “is condition current”. Only current prevalence is included here.
**Impact of Conditions on CSHCN and their Families**

<table>
<thead>
<tr>
<th>Condition Description</th>
<th>Percentage</th>
<th>No conditions from list</th>
<th>1 condition from list</th>
<th>2 conditions from list</th>
<th>3 conditions from list</th>
<th>4 or more conditions from list</th>
</tr>
</thead>
<tbody>
<tr>
<td>CSHCN with one or more unmet need(s) for health care services</td>
<td>42.5%</td>
<td>21.5%</td>
<td>16.4%</td>
<td>18.8%</td>
<td>29.3%</td>
<td></td>
</tr>
<tr>
<td>CSHCN whose daily activities are consistently affected, often a great deal</td>
<td>61.6%</td>
<td>17.5%</td>
<td>14.5%</td>
<td>19.9%</td>
<td>37.4%</td>
<td></td>
</tr>
<tr>
<td>CSHCN whose health conditions caused a family member to cut back and/or stop working</td>
<td>50.5%</td>
<td>16.1%</td>
<td>14.9%</td>
<td>20.9%</td>
<td>33.8%</td>
<td></td>
</tr>
</tbody>
</table>

**MCHB Core Outcomes on Systems of Care for CSHCN**

Nationally only 17.6% of CSHCN meet all six age-appropriate Maternal and Child Health Bureau (MCHB) Core Outcomes. However, the more conditions experienced by CSHCN, the less likely they are to meet all criteria. Among CSHCN reporting only 1 of the 20 conditions, 22.8% meet all age appropriate criteria, whereas only 8.1% of CSHCN with 4 or more conditions do so.

**Who are CSHCN who report none of the 20 conditions asked about in the survey?**

Among the 12.3% of CSHCN currently without any of the 20 conditions asked about:

- 18.1% had an emotional, behavioral, or developmental problem for which treatment or counseling was needed
- Nearly 3 in 10 (27.6%) did not receive early and continuous screening for special health care needs
- 76.6% reported 1 or more functional difficulty*

Compared to CSHCN with 1 or more of the conditions asked about, the 12.3% of CSHCN with none of the conditions asked about are:

- More likely to be under 6 years old (37.7% vs. 18.4%)
- More likely to qualify as CSHCN on service use criteria only [and not on functional limitations or prescription medication use] (36.6% vs. 12.9%)
- Less likely to have functional limitations* (13.4% vs. 24.9%)
- Nearly as likely to report $1,000 or more in out-of-pocket medical expenses in prior year (18.7% vs. 22.6%)