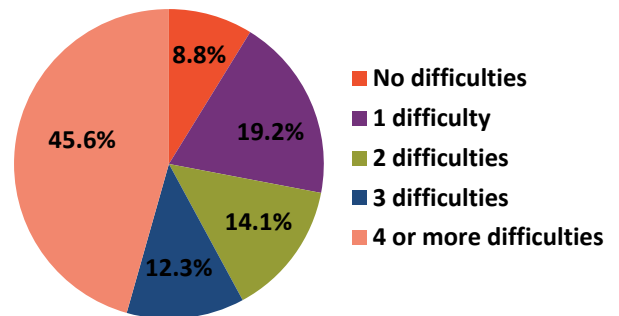


Exploring Functional Difficulties in the 2009/10 NS-CSHCN

Functional difficulties can impact the day-to-day life of children with special health care needs (CSHCN). Functional difficulties include difficulties with bodily functions, emotional or behavioral issues, and/or difficulties with participation or daily activities. In the 2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN), parents were asked whether their child experienced a lot, a little or no difficulty with each of 14 specific difficulties. Among the 14 difficulties asked about, 91.2% of CSHCN experienced at least 1 and 45.6% of CSHCN experienced 4 or more.

The 8.8% of CSHCN who did not experience any functional difficulties on the list were asked why the child did not have any difficulties. Over 90% reported that this was due to the child's health problems being treated and under control. While these CSHCN do not report functional difficulties, like all CSHCN, they experience at least one ongoing health condition resulting in an above routine need for health and related services.

Number of Functional Difficulties Experienced among CSHCN



Specific Functional Difficulties

Functional Difficulty Experienced	% of CSHCN
Learning, understanding or paying attention	51.1
Breathing or other respiratory problems	46.5
Feeling anxious or depressed	43.0
Behavior problems	41.4
Speaking, communicating, or being understood	32.9
Making and keeping friends	32.3
Repeated or chronic physical pain, including headaches	28.9
Taking care of self, such as eating, dressing, bathing	19.8
Coordination or moving around	19.6
Swallowing, digesting food, or metabolism	19.2
Using his/her hands	16.0
Seeing even when wearing glasses or contact lenses	15.6
Hearing even when using a hearing aid/other device	6.3
Blood Circulation	6.1

Learning, understanding or paying attention is the most common functional difficulty reported, affecting over half of CSHCN. However, this difficulty rarely occurs in isolation. Over 75% of CSHCN who experience difficulty learning, understanding or paying attention also experience 3 or more other difficulties. This exemplifies the interconnected and co-morbid nature of functional difficulties.

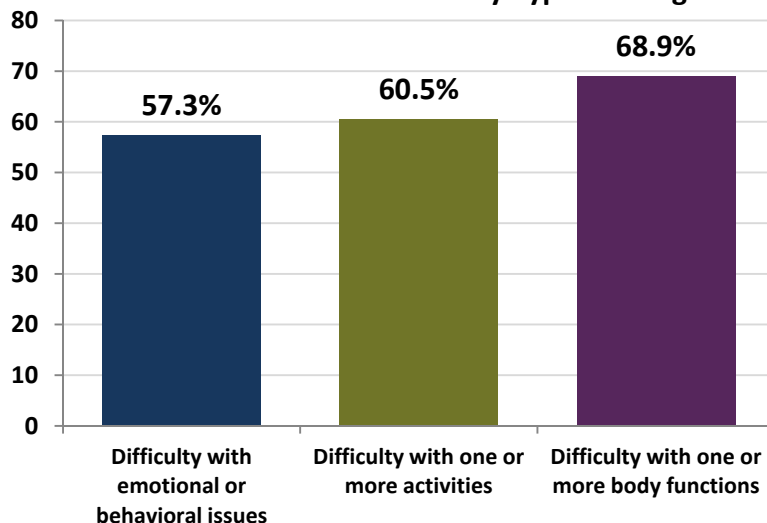
Nearly all (99.3%) CSHCN with emotional, behavioral or developmental problems have one or more functional difficulties. Meanwhile, CSHCN with less complex service needs are the least likely to report at least one difficulty (83.0%).

Functional difficulties can be categorized into three types: emotional/behavioral, activity-based, and bodily functions. Over half of CSHCN experience at least 1 type of functional difficulty from the 3 domains (63.7%), further demonstrating the complexity of CSHCN needs.

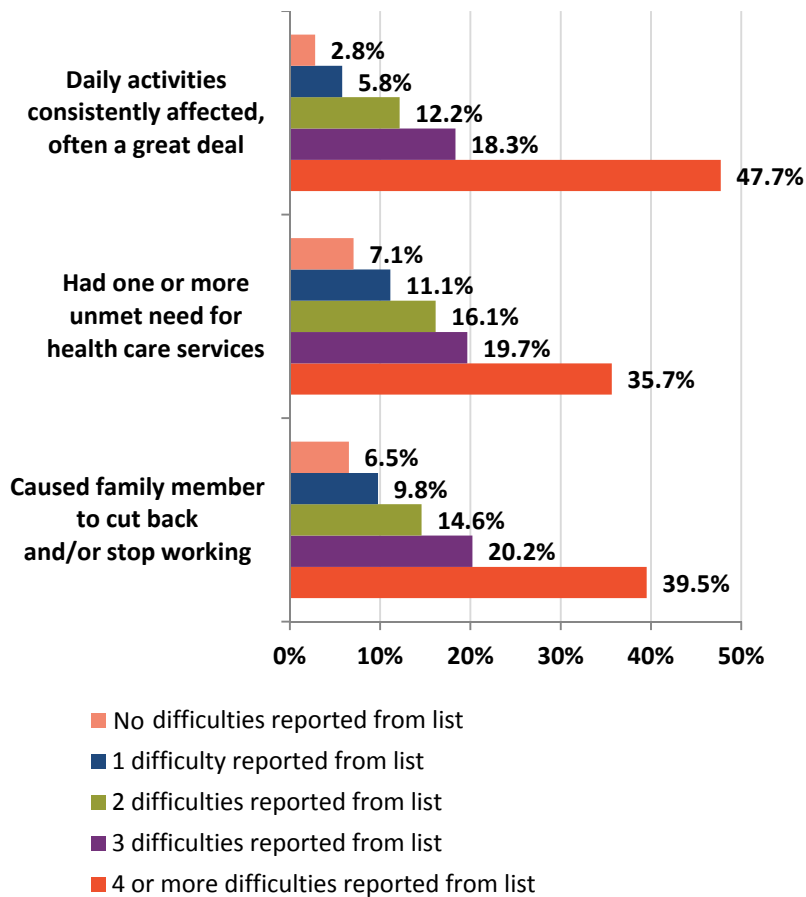
Functional difficulties vs. functional limitations:

The functional limitation Screener criterion asks if the child is limited or prevented in any way in [his/her] ability to do the things most children the same age can do because of an ongoing medical, behavioral or other health condition. This is very high-bar. Many CSHCN experience at least 1 of 14 functional difficulties but are not globally limited or prevented from doing things as specified in the functional limitations Screener criterion.

Prevalence of Functional Difficulty Types among CSHCN



Impact of Functional Difficulties on CSHCN and their Families



Compared to CSHCN with 3 or fewer functional difficulties, CSHCN with at least 4 functional difficulties are more likely to:

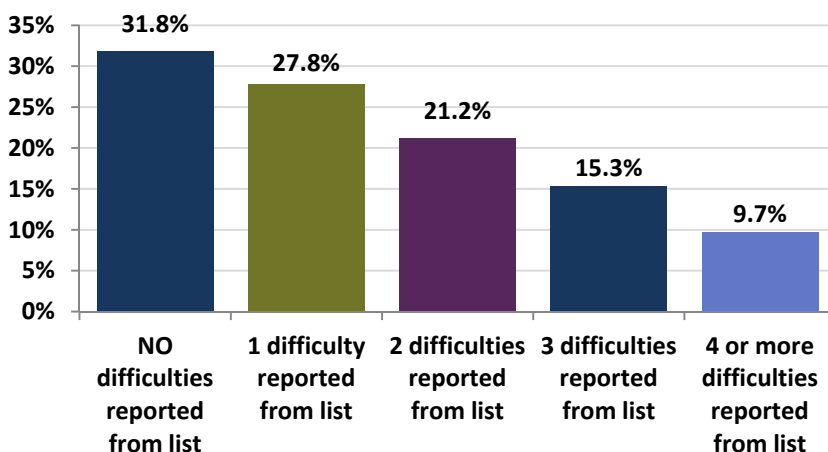
- ❖ Have their daily activities consistently affected, often a great deal (47.7% vs. 9.8%)
- ❖ Miss more than 2 weeks of school due to illness or injury in a year (22.6% vs. 9.2%)
- ❖ Have one or more unmet need for health care services (35.7% vs. 13.7%)
- ❖ Have health conditions that caused financial problems for their family (33.2% vs. 11.8%)
- ❖ Have family members who cut back and/or stop working because of child's health conditions (39.5% vs. 12.9%)

CSHCN with 4 or more functional difficulties represent 45.6% of the CSHCN population and are the most affected in their daily living and have the greatest impact on their families and the health care system. CSHCN with four or more functional difficulties represent over 5 million CSHCN nationwide.

MCHB Core Outcomes: Systems of Care

The more functional difficulties experienced by CSHCN, the less likely they are to achieve all six Maternal and Child Health Bureau (MCHB) Core Outcomes. CSHCN with four or more functional difficulties are almost half as likely to receive care within a medical home and to receive transition to adult services compared to CSHCN with no difficulties or only one difficulty reported from the list.

CSHCN Who Met All Age-Appropriate MCHB Core Outcomes



For more information on CSHCN, please visit the Data Resource Center (DRC) for Child and Adolescent Health at www.childhealthdata.org.

