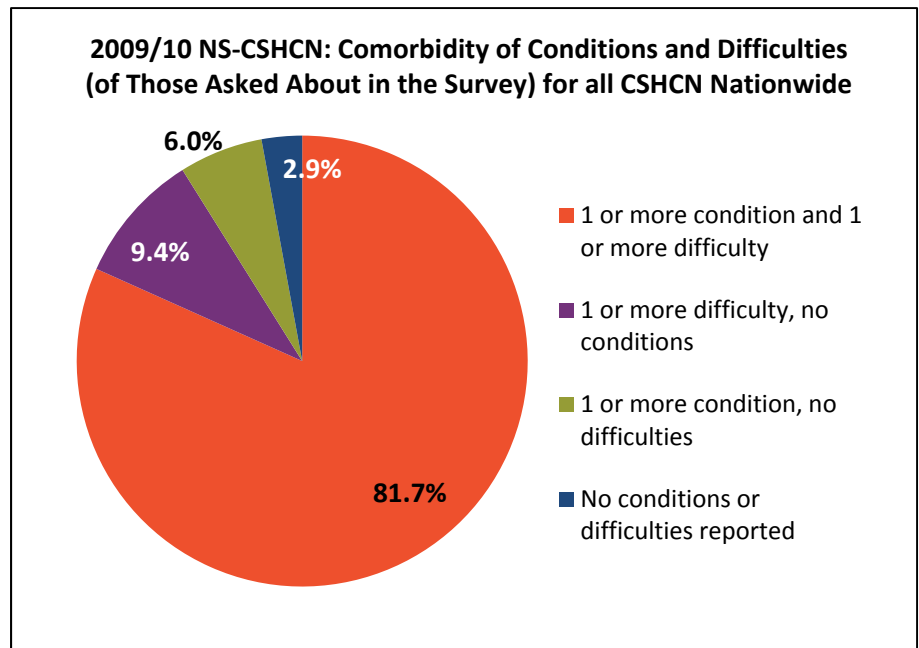


2009/10 National Survey of Children with Special Health Care Needs: Comorbidity of Conditions & Difficulties among CSHCN

All CSHCN experience at least one type of ongoing health condition that results in an above routine need for health and related services. The 2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN) assessed prevalence of 20 specific chronic health conditions and 14 functional difficulties. An estimated 87.7% of CSHCN nationwide have at least one of the 20 conditions asked about and 91.2% of CSHCN nationwide experience at least one of the 14 difficulties asked about.

The survey does not have open-ended questions asking if the child experiences any conditions or difficulties not included in the survey. The lists of conditions and difficulties are not comprehensive, but rather represent common conditions and difficulties and those deemed important for research or policy objectives. Therefore, while the estimates from the survey are accurate, they underestimate the total number of conditions and difficulties CSHCN have.



Even when considering only the items asked about in the survey, **the majority of CSHCN (81.7%) have 1 or more condition and at least 1 difficulty**, which represents an estimated 9.08 million CSHCN nationwide.

Who are CSHCN reporting none of the conditions or difficulties asked about in the survey?

- ❖ They may have a condition or conditions that are not yet diagnosed or asked about in the survey (*remember, all CSHCN have at least one ongoing health condition, as identified by the CSHCN Screener*)
 - Children are still developing and many conditions cannot be diagnosed until a certain age - CSHCN age 0-5 years are more likely to report difficulties but no conditions compared to CSHCN 6 years and older (17.2% versus 7.4%)
- ❖ Among CSHCN reporting none of the 14 difficulties (8.9% of CSHCN), 91.3% reported that their conditions were under control due to treatment and/or medication, 6.2% reported that their conditions were not function-related and 2.5% (n=102) reported another reason
 - These values were nearly identical for CSHCN reporting no difficulties and no conditions (2.9% of CSHCN) and CSHCN reporting 1 or more of the conditions but no difficulties (6.0% of CSHCN)
- ❖ Among CSHCN reporting no conditions and no difficulties, 65.7% qualified as CSHCN by the prescription medication Screener criterion only
 - CSHCN who qualify on only this criterion are less likely to report impact on their daily life, impact on the family, or have unmet needs for care
 - For comparison, 39.3% of all CSHCN qualify on only this criterion

Are CSHCN with certain conditions more likely to experience difficulties?

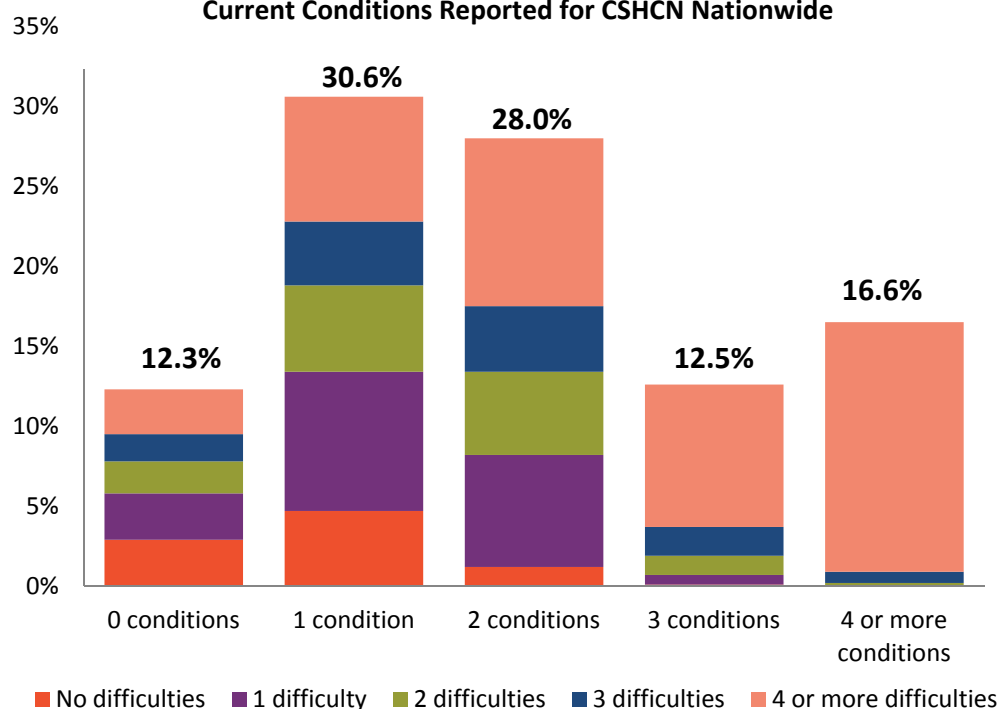
The table to the right shows the mean number of difficulties (of the 14 asked about in the survey) experienced by CSHCN reporting each of the 20 conditions asked about in the survey. The prevalence of each condition is shown in parentheses. Note that comorbidity of different conditions is common and therefore CSHCN with each condition listed are likely to have at least one of the other conditions as well. For example, 80.0% of CSHCN with current asthma also have one or more of the other conditions asked about.

CSHCN with Cerebral Palsy reported the greatest number of difficulties; however, they represent less than 2% of CSHCN. This highlights that a variety of factors relating to the number, comorbidity and prevalence of conditions and difficulties are important to consider for policy and program development.

Health Issue Asked About* (prevalence among CSHCN)	Mean # of Difficulties – A Little or A Lot	Mean # of Difficulties – A Lot Only	Mean # of Body Difficulties	Mean # of Activity Difficulties	Mean # of Emotional Difficulties
Cerebral Palsy (1.6%)	7.7	4.4	2.1	4.1	1.4
Intellectual Disability (5.8%)	7.6	4.0	1.8	3.9	1.9
Head Injury (1.4%)	7.3	3.8	2.2	3.4	1.7
Autism, ASD (7.9%)	6.9	3.3	1.2	3.5	2.2
Developmental Delay (17.6%)	6.9	3.2	1.6	3.4	1.9
Muscular Dystrophy (0.3%)	6.8	3.9	2.2	3.6	1.0
Down Syndrome (1.1%)	6.8	2.8	1.9	3.8	1.1
Epilepsy (3.1%)	6.4	3.3	1.9	3.1	1.4
Behavioral problems (13.5%)	6.4	3.0	1.4	2.4	2.5
Depression (10.3%)	6.3	2.9	1.7	2.1	2.5
Arthritis (2.9%)	6.3	2.7	2.5	2.3	1.5
Anxiety (17.1%)	6.1	2.7	1.5	2.2	2.3
Headaches (9.8%)	5.5	2.2	2.3	1.6	1.6
Heart Problem (3.0%)	5.1	2.0	2.1	1.9	1.1
ADD/ADHD (30.2%)	4.9	1.8	1.1	2.0	1.8
Blood Problems (1.5%)	4.9	1.8	2.2	1.6	1.1
Cystic Fibrosis (0.3%)	4.1	1.9	2.4	0.9	0.8
Allergies (48.6%)	3.8	1.2	1.5	1.2	1.1
Asthma (35.3%)	3.6	1.1	1.7	1.0	0.9
Diabetes (1.7%)	3.3	0.9	1.4	0.9	0.9

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

2009/10 NS-CSHCN: Number of Difficulties Experienced by Number of Current Conditions Reported for CSHCN Nationwide

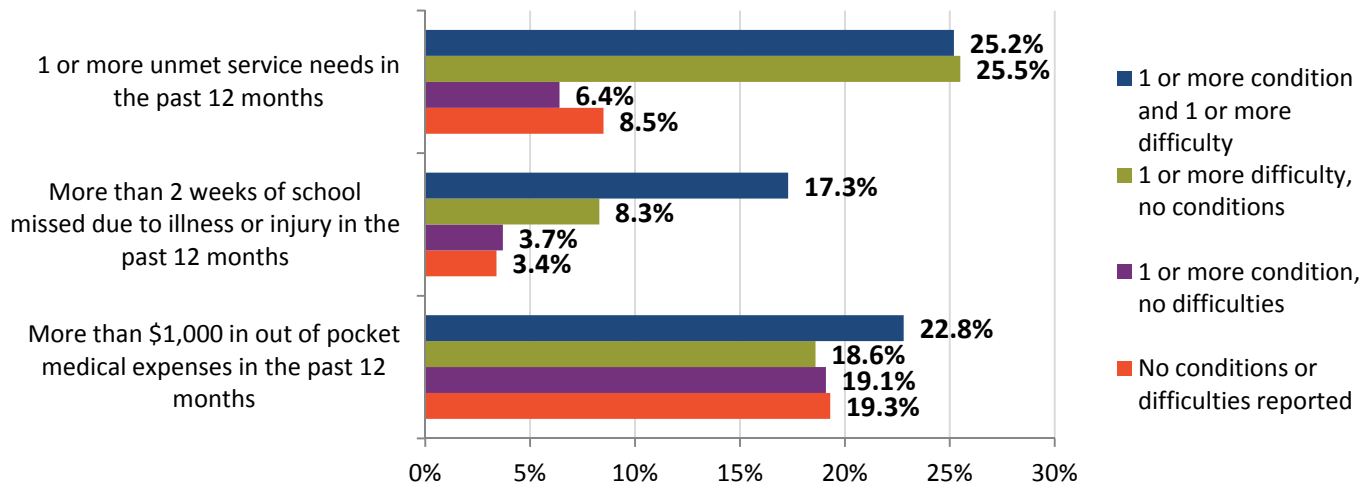


Note: the above chart is based upon the 14 difficulties (either a little or a lot) and the 20 health conditions asked about in the survey

CSHCN reporting more conditions also experience a greater number of difficulties. The graph to the left shows the number of difficulties by the number of conditions reported for CSHCN.

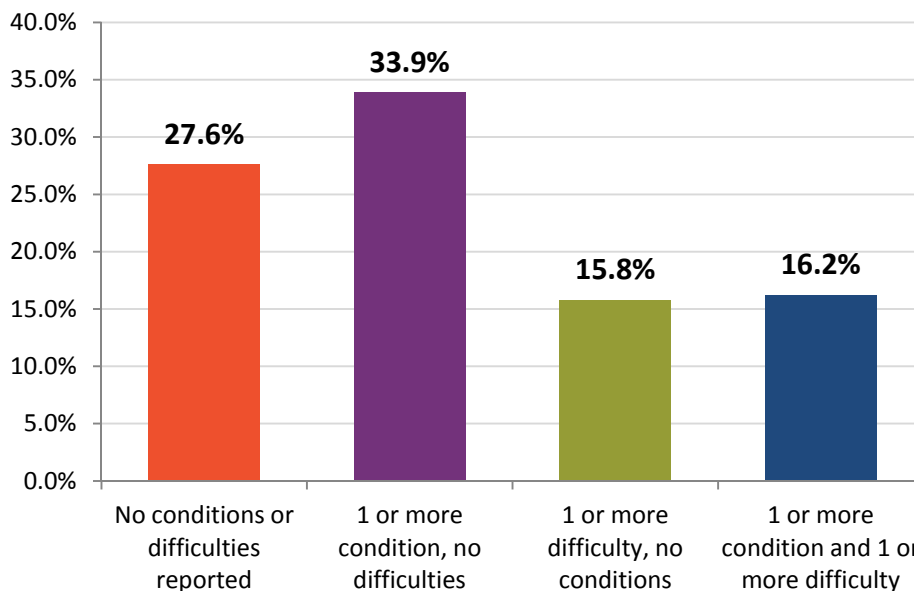
Comorbidity of conditions is common among CSHCN (57.1% of CSHCN report 2 or more conditions from the list asked about), as is comorbidity of conditions and difficulties. As the number of reported conditions increases, so does the number of reported difficulties. The graph shows that nearly all of the 16.6% of CSHCN who reported 4 or more conditions also experience 4 or more difficulties.

2009/10 NS-CSHCN: Unmet Needs, Missed School and Medical Expenses for CSHCN by Presence of the Difficulties and/or Current Conditions Asked About in the Survey



- ❖ CSHCN reporting difficulties are more likely to have unmet service needs than CSHCN not reporting difficulties, regardless of whether they also reported 1 or more condition. *This may indicate that CSHCN with no unmet service needs are more likely to have their conditions well managed and fewer functional difficulties.*
- ❖ CSHCN reporting both conditions and difficulties are more likely to miss 2 or more weeks of school per year than other CSHCN.
- ❖ About 1 in 5 CSHCN report more than \$1,000 in out of pocket medical expenses in the past year regardless of whether s/he reported conditions only, difficulties only, neither or both.

2009/10 NS-CSHCN: Percent of CSHCN Meeting all Age-Appropriate MCHB Core Outcomes by Presence of Conditions and/or Difficulties



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

CSHCN with difficulties are less likely to meet all age-appropriate MCHB Core Outcomes than CSHCN without difficulties, regardless of whether they report having one of the conditions asked about in the survey.