

Children with Special Health Care Needs

NSCH Data Brief | July 2020

ABOUT THE NSCH _

The National Survey of Children's Health (NSCH), funded and directed by the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB), provides information on the health and wellbeing of children ages 0-17 years in the United States. The NSCH is the largest national and state-level survey on the health and health care needs of children, their families, and their communities.

The NSCH contains the Children with Special Health Care Needs (CSHCN) Screener® to support the collection of detailed national and state-level estimates of the prevalence and impact of special health care needs among children ages 0-17 years and their families.

DEFINING CHILDREN WITH SPECIAL HEALTH CARE NEEDS _____

HRSA MCHB defines children and youth 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."

2018 DATA RELEASE

New data from the 2018 NSCH are now available. To access these data and supporting materials, please visit <u>HRSA MCHB</u> or the U.S. Census Bureau.

The National Survey of Children's Health (NSCH) is a key source of state and national data for children with special health care needs (CSHCN). The NSCH uses a validated screening tool to identify CSHCN and includes questions about the health and health care needs of this important subpopulation of children.

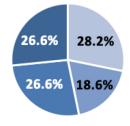
The NSCH identifies special health care needs based on the health consequences a child experiences due to an ongoing health condition, regardless of diagnosis. These are categorized as: 1) need or use of prescription medications, 2) need or use of services, 3) need or use of specialized therapies, 4) functional difficulties, and 5) emotional, developmental, or behavioral problems for which treatment or counseling is needed. This approach allows the NSCH to identify CSHCN across the range and diversity of health care conditions, disabilities, and special needs.

2017-2018 DATA SNAPSHOT OF CSHCN

Prevalence, Limitations, and Health Conditions

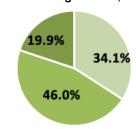
- In 2017-2018, approximately 13.6 million children in the U.S. (18.5%) had a special health care need. One in four households (24.8%) in the U.S. had one or more CSHCN.
- CSHCN are a diverse group exhibiting a range of needs and severity. In 2017-2018, one in four CSHCN (26.6%) had functional limitations. In addition, one in five (19.9%) were consistently and/or significantly impacted by their health condition(s), and nearly half (46.0%) were sometimes/moderately impacted by their health condition(s).

Type of Special Health Care Need among CSHCN, 2017-2018



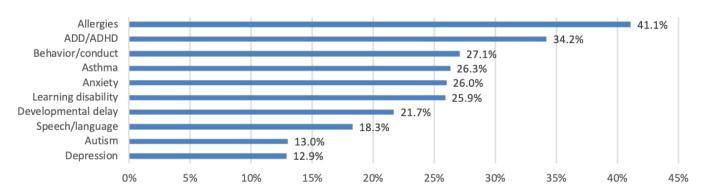
- Prescription medications ONLY
- Elevated service use/need ONLY
- Medication AND services
- Functional limitations

Frequency/Degree of Activity Limitations among CSHCN, 2017-2018



- Never impacted
- Sometimes/moderately impacted
- Consistently/significantly impacted
- of over 20 conditions in the NSCH, allergies, ADD/ADHD, and behavior/conduct were the most frequently reported for CSHCN. Mental, behavioral, and developmental conditions were more prevalent among CSHCN than children without special health care needs (non-CSHCN). For example, the rates of anxiety and depression among CSHCN were 9 and 16 times greater than among non-CSHCN (26.0% vs. 2.7% and 12.9% vs. 0.8%, respectively).

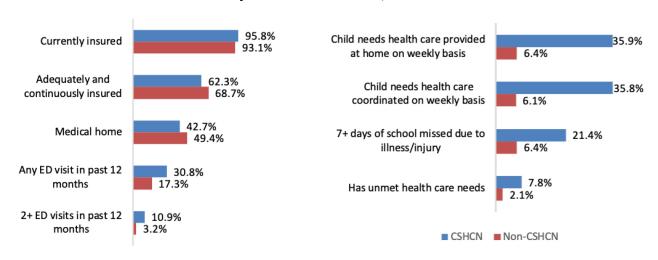
Prevalence of Health Conditions among CSHCN, 2017-2018



Key Indicators for CSHCN in 2017-2018:

- While nearly all CSHCN (95.8%) were insured at the time of the survey, only 62.3% were reported to be adequately and continuously insured throughout the year, including coverage for needed providers and services and reasonable costs.
- Less than half of CSHCN (42.7%) had a medical home. The medical home is a model of primary health care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective.
- Rates of emergency department (ED) use were nearly 2-3 times higher among CSHCN compared to non-CSHCN. Nearly one in three CSHCN (30.8%) had at least one past-year ED visit, and 10.9% had two or more visits.
- One in three CSHCN needed health care provided at home and/or health care coordinated on a weekly basis. Among those that needed home care or health care coordination, over one in four (28.4%) had family members who spent five or more hours a week providing home care and 9.7% who spent five or more hours a week arranging health care.
- Approximately one in five CSHCN (21.4%) missed seven or more days of school in the past year due to illness or injury, and 7.8% had unmet health care needs, compared to 6.4% and 2.1% of non-CSHCN, respectively.

Key Indicators for CSHCN, 2017-2018



EFFECTIVE SYSTEMS OF CARE FOR CSHCN

HRSA MCHB, together with its partners, has identified six components for an effective system of care for CSHCN: 1) children are screened early and continuously for special health care needs, 2) families of CSHCN are partners in decision-making, 3) community-based services are organized so families can use them easily, 4) CSHCN receive care in a medical home, 5) there is adequate insurance and funding to cover services, and 6) CSHCN receive services necessary to make transitions to adult health care. In 2017-2018, only 13.9% of CHSCN received all six components of a well-functioning system of care.

More information on systems of care for CSHCN, the six components, and how HRSA MCHB is working to achieve effective systems of care for all CSHCN.

NSCH DATA COLLECTION

HRSA MCHB works with the U.S. Census Bureau to conduct the survey and produce a final data set for public use.

- How often is the NSCH conducted? The NSCH is conducted annually.
- How are the data collected? Survey participants complete either web-based or self-administered paper-and-pencil questionnaires.
- Who completes the survey? The NSCH is conducted as a household survey, and the respondent is a parent or guardian with knowledge of the sampled child.
- How many households participate in the NSCH? One child per household is selected to be the subject of the detailed age-specific questionnaire. In 2018, parents completed age-specific questionnaires for 30,530 children. These data can be combined with an additional 21,599 children from 2017, representing a combined total of 52,129 children in 2017-2018.



For more information visit HRSA's Maternal and Child Health Bureau.