

Children and Youth with Special Health Care Needs

NSCH Data Brief | June 2022

ABOUT THE NSCH

The Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB) funds and directs the National Survey of Children's Health (NSCH), which the U.S. Census Bureau conducts.

The NSCH is the largest national- and state-level survey on the health and health care needs of children ages 0-17, their families, and their communities.

It is an annual household survey completed by a parent or guardian, either by web or paper and pencil.

Combining multiple years of data enables more reliable estimates, especially for smaller subpopulations. In 2019-2020, parents completed questionnaires for 72,210 children of whom 17,065 had a special health care need.

All estimates presented in this brief are weighted to represent the population of U.S. children living in households.

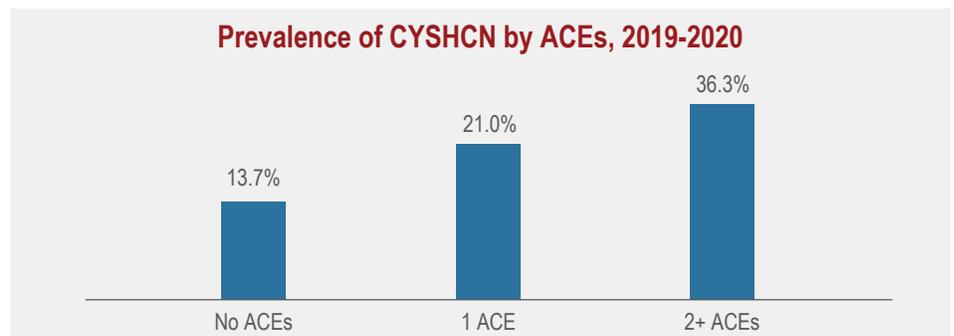
[Access NSCH Data](#)

The Maternal and Child Health Bureau (MCHB) has a core responsibility to monitor and improve services for children and youth with special health care needs (CYSHCN)—defined 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.¹ The National Survey of Children's Health (NSCH) identifies CYSHCN through a validated 5-item screener that asks parents/caregivers if their child has any of the following service needs or limitations due to a health condition that has lasted or is expected to last 12 months or longer:

- ✓ Need or use of prescription medication(s)
- ✓ Elevated need or use of medical care, mental health, or education services
- ✓ Functional limitation(s) (that limit daily activity)
- ✓ Need or use of special therapies (e.g. physical, occupation, or speech therapy)
- ✓ Emotional, developmental, or behavioral problem for which treatment or counseling is needed

Prevalence of Special Health Care Needs

- In 2019-2020, nearly 1 in 5 children (19.4%) in the United States had a special health care need, representing 14.1 million children. More than 1 in 4 households with children (28.6%) had at least one CYSHCN.
- Special health care needs were slightly more common among [non-Hispanic Black children](#) (23.3%) and [children living in poverty](#) (22.8%).
- More than 1 in 3 children with multiple adverse childhood experiences known as ACEs (36.3%) had a special health care need. ACEs are potentially traumatic childhood events, such as economic hardship, parental death or incarceration, witnessing domestic violence, or living with anyone struggling with mental illness. Research shows ACEs have a strong relationship with poor health outcomes.²



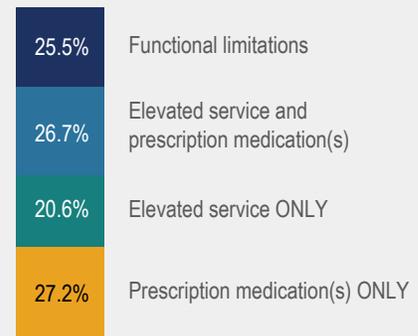
¹ A New Definition of Children With Special Health Care Needs

² CDC: Adverse Childhood Experiences

Type of Special Health Care Needs

- CYSHCN are a diverse group who may experience varying degrees of health care needs and functional limitations.
- In 2019-2020, one in four CYSHCN (25.5%) experienced functional limitations either alone or in combination with some other health care need.
- Nearly half (47.3%) of CYSHCN required elevated services without a functional limitation. Over a quarter also needed prescription medications (26.7%) and 20.6% did not.
- More than a quarter (27.2%) of CYSHCN only required a prescription medication and did not have functional limitations or use extra services.

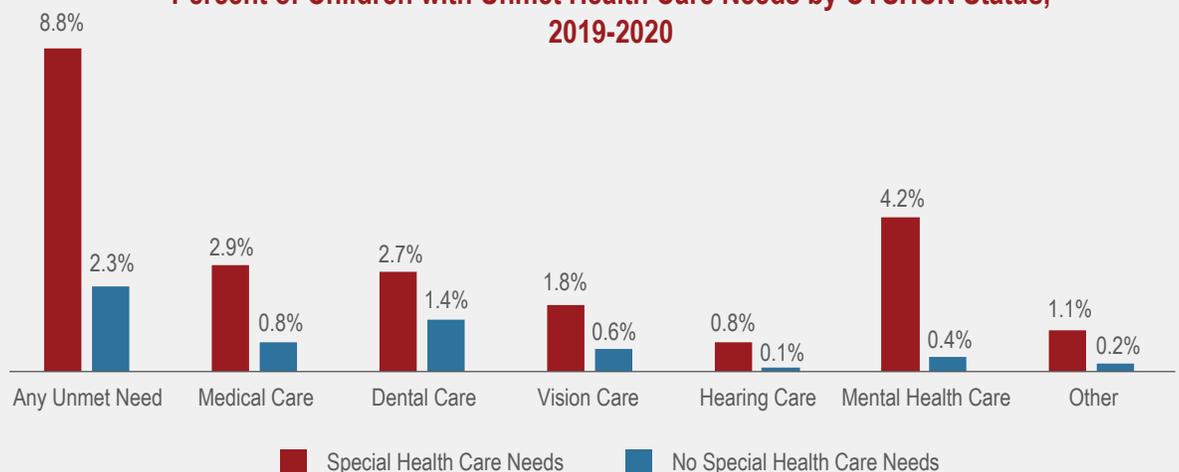
Type of Special Health Care Needs among CYSHCN, 2019-2020



Unmet Health Care Needs

- CYSHCN are more likely than non-CYSHCN to experience unmet health care needs, defined as needing but being unable to receive health care for any reason.
- In 2019-2020, CYSHCN were nearly four times as likely to have unmet health care needs in the past year compared to non-CYSHCN (8.8% v. 2.3%). CYSHCN were also more likely than non-CYSHCN to have unmet needs across every type of care (medical, dental, vision, hearing, mental, and other) with the widest gap for mental health care (4.2% v. 0.4%).
- Among CYSHCN who experienced an unmet health need, the most commonly reported reasons were related to cost (48.9%) and appointment availability (53.9%).

Percent of Children with Unmet Health Care Needs by CYSHCN Status, 2019-2020

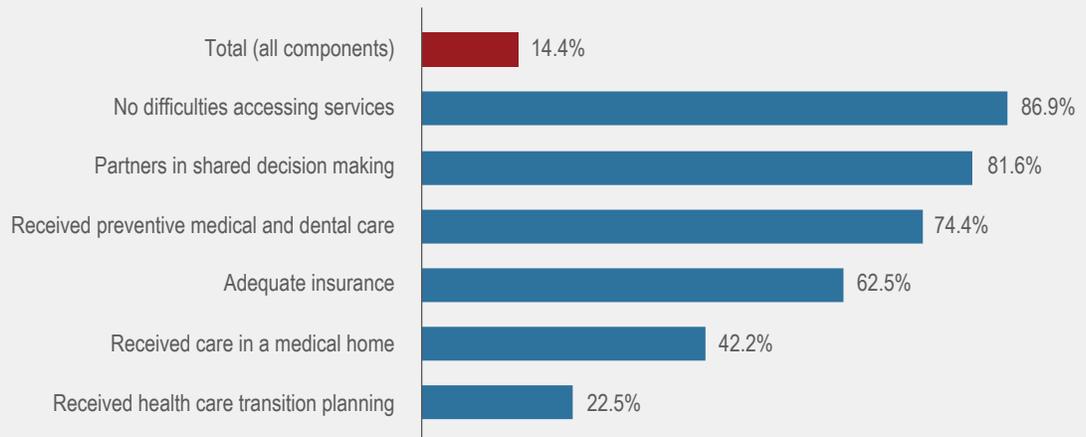


Effective Systems of Care for CYSHCN

HRSA MCHB, together with its partners, has identified six foundational components for an effective system of care for CYSHCN: 1) children are screened early and continuously for special health care needs (captured by receipt of preventive medical and dental care), 2) families of CYSHCN are partners in decision-making, 3) community-based services are organized so families can use them easily (captured by no difficulties accessing services), 4) CYSHCN receive care in a medical home, 5) there is adequate insurance and funding to cover services, and 6) CYSHCN receive services necessary to make transitions to adult health care.

- In 2019-2020, only 14.4% of CYSHCN received all six components of a well-functioning system of care.
- While over 80% of CYSHCN and their families did not have difficulties accessing services (86.9%) and were partners in decision-making (81.6%), less than two-thirds had adequate insurance to cover needed services (62.5%), less than half (42.2%) received care in a medical home, and less than a quarter of CYSHCN ages 12-17 years received adult health care transition planning (22.5%).

Percent of CYSHCN Meeting Components of Well-Functioning System of Care, 2019-2020



In 2022, HRSA MCHB released a *Blueprint for Change: A National Framework for a System of Services for Children and Youth with Special Health Care Needs*, which builds on the foundation of the six core outcomes with a lens of equity, quality of life, access to services, and financing of services. Please visit the [MCHB CYSHCN Focus Area webpage](#) to access the *Blueprint for Change* and HRSA MCHB's investments in effective systems of care for all CYSHCN.