

3 POLICY PRIORITIES for States to Support Equitable Systems of Care for Children and Youth with Special Health Care Needs



NATIONAL ACADEMY
FOR STATE HEALTH POLICY



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Children's Health

Despite having greater needs for health care and specialty services, children and youth with special health care needs (CYSHCN) continue to face challenges accessing high-quality health care.

Snapshot of CYSHCN in the U.S.:



1 in 5

1 in 5 children (over 15 million) have a special health care need.



44.6%

Nearly half of all CYSHCN families report frustration with accessing the services they need.



~13%

Only 13% of CYSHCN receive care in a well-functioning system.

Many families experience significant burdens and challenges in caring for CYSHCN, including high costs, inadequate availability of specialty care services, challenges accessing or using health coverage, and fragmented and uncoordinated systems.

CYSHCN who are Black or Latinx are at particular risk of receiving infrequent, low-quality care. American Indian and Alaska Native CYSHCN are less likely to be able to access specialty treatment or receive culturally appropriate services.

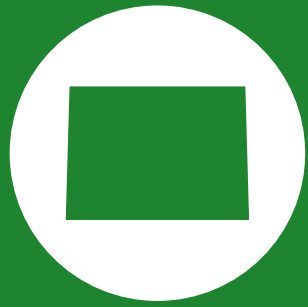
States are adopting approaches across 3 policy areas to support and improve equitable systems of care for CYSHCN.

Priority #1: Supports for Family Caregivers

Caregivers of CYSHCN experience significant challenges and burdens, including:

- Mental health conditions
- Missed earnings and financial hardships
- Unmet health and social needs

States are implementing strategies to provide supports for family caregivers of CYSHCN, with particular focus on ensuring access for caregivers who speak languages other than English.



Paid Family Caregiving

Colorado allows family members of Medicaid-enrolled CYSHCN to become licensed as certified nursing aides and receive payment for providing medical care to their children. The certification process includes a nurse aide training program and a two-part exam.

State agencies are exploring opportunities to administer the exam in multiple languages to improve access for families whose primary language is not English.



Trainings and Peer Supports for Caregivers

Oregon's Title V CYSHCN program partners with the Oregon Family-to-Family Health Information Center to support Spanish-speaking family caregivers through trainings, listening sessions, toolkits, and a phone support hotline.

Additionally, collaborations with community partners provide culturally competent and accessible support for families of CYSHCN from Latin American and African refugee and immigrant populations.

Priority #2: Improving Access to Providers and Specialists

Families of CYSHCN living in rural areas often experience limited provider availability in their communities, requiring long-distance travel to obtain care.

States are prioritizing strategies such as expanded transportation benefits, telehealth services, and provider supports to help families that face obstacles to accessing care.



Transportation

Virginia offers services to rural areas of the state through a collaboration between the University of Virginia health system and the state health department.

To minimize drive time for families, staff travel to Southwest Virginia to provide clinical services to CYSHCN who require specialty care, such as genetics, neurology, orthopedic, and neurodevelopment services.



Telehealth

Michigan's Children's Special Health Care Services Division within the Department of Health and Human Services collaborates with key partners to lead the Michigan Pediatric Epilepsy Project, a statewide initiative to improve health outcomes for children and youth with epilepsy, especially in rural and underserved communities.

Primary and specialty providers participate in the Statewide Quality Improvement Network to expand the use of telehealth and telemedicine for specialty care.



Provider and Workforce Supports

Ohio's Department of Mental Health and Addiction Services expanded access to peer supports by adding youth and family peer credentials for individuals with lived experience to serve families with similar needs.

Certified Youth Peer Supporters specialize in youth and young adult needs, helping them navigate recovery from mental illness and substance use disorder.

Priority #3: Data Collection, Sharing, Use, and Quality Assurance

As states focus on improving quality of care for CYSHCN, they require robust, equitable data to establish quality measures.

States are prioritizing innovative data collection and sharing practices, risk assessments, and cross-sector quality initiatives to support informed policy and programmatic decisions that improve high-quality care for the CYSHCN population.



Demographic Data Collection and Use

Hawaii's Title V CYSHCN program partners with the University of Hawaii Center on Disabilities Studies to conduct ongoing culturally competent needs assessments of the CYSHCN population.

The state provides surveys in multiple languages, conducts community-based focus groups, and encourages participation among underrepresented populations to support equity and inclusion.



Risk and Needs Assessments

The **Pennsylvania** Department of Health supports the Community to Home Program, which engages community health workers (CHWs) to assess the needs of newly diagnosed CYSHCN who live in rural settings, particularly those from racial and ethnic minority groups.

CHWs conduct assessments through in-home visits with CYSHCN families to determine their needs and develop a care management plan and referral to services.



Medicaid Quality Initiatives

California requires Medicaid managed care plans to create a standardized protocol for assessing the health and social needs of CYSHCN to monitor and improve their quality of care.

The state maintains dashboards with demographic and performance data on specific populations of Medicaid-enrolled youth, including those with complex medical conditions, those receiving specialty mental health services, and those in foster care.

Read about more state examples and policy considerations to support equitable systems of care for CYSHCN in our brief:



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