

# **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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Foundation

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Children's Health

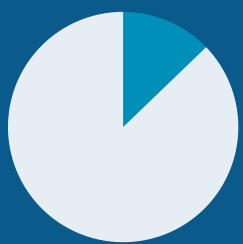
Children and youth with special health care needs (CYSHCN) require services beyond those needed by children generally — yet they often face difficulties accessing high-quality health care.

## CYSHCN BY THE NUMBERS:



**15 MILLION**

CYSHCN in the U.S.



**12.8%**

Percentage of CYSHCN who receive care in a well-functioning system



**44.6%**

Percentage of families with CYSHCN who report frustrations accessing services

Key barriers to care for CYSHCN include:

- Fragmented and uncoordinated systems
- Inadequate availability of services and specialists
- Difficulties accessing or using health coverage
- High costs

Many of these challenges are compounded for certain populations, including youth with more complex conditions; CYSHCN who are Black, Latinx, or American Indian and Alaska Native; families with low incomes; and families who live in rural areas.

**Here are three policy areas states are prioritizing to address barriers and support equitable systems of care for CYSHCN**



# **Priority #1: Supports for Family Caregivers**

Family caregivers provide an estimated 1.5 billion hours of health services to CYSHCN each year, with an average of 29.7 hours per family each week.

But caregivers of CYSHCN often report unmet health and social needs, financial burdens, and mental conditions related to stress and isolation.

States are prioritizing strategies to support family caregivers of CYSHCN, with a focus on underserved communities who are most likely to rely on family members for caregiving.



## **Paid Family Caregiving**

In April 2023, **North Dakota** passed a law to establish a family caregiver service pilot project, which will expand payments to legally responsible caregivers of individuals who require extraordinary care and qualify to receive home and community-based services through the state's 1915(c) waivers.

The law also created an advisory council to support the pilot and provide feedback to the state's Department of Health and Human Services.



## **Trainings and Peer Supports for Caregivers**

**Oklahoma's** Family Support 360° Center provides training, family and peer supports, and navigational assistance for Medicaid-eligible families of CYSHCN, with a focus on serving families from Hispanic and Black Communities.

The center, which is funded through the state's Title V CYSHCN Program, has partnered with a state family network and community medical provider to conduct caregiver trainings on mental health supports for children with autism, ADHD, and related conditions.

## **Priority #2: Improving Access to Providers and Specialists**

Families of CYSHCN often face obstacles in obtaining quality care or getting the specialized services they need. Accessing care can be even more challenging for families of CYSHCN with low incomes or living in rural communities.

States are implementing strategies that support access to providers and specialized care for CYSHCN.





## Transportation

**Texas** Medicaid requires contracted managed care organizations that deliver transportation services to provide physical assistance to members who need to use wheelchair lifts or ramps. Drivers must also assist with placing mobility aids in the vehicle and folding wheelchairs.

These efforts can help ensure adequate access for Medicaid beneficiaries, including CYSHCN, who have unique transportation needs.



## Telehealth

**South Carolina's Title V CYSHCN** program partners with the Telehealth Alliance of South Carolina to create a provider network offering telehealth services to ensure equitable access to care.

This partnership supports expanded access to telehealth for CYSHCN, helping to make specialty services more accessible in rural areas and more affordable for families with low incomes.



## **Provider and Workforce Supports**

**Washington** sponsors the Medical Home Partnerships Project to support providers who serve youth with co-occurring behavioral health and intellectual and developmental disability (IDD) needs, including CYSHCN.

The state also partners with the University of Washington to operate Project ECHO, which provides telehealth training and virtual support to clinicians and the community serving individuals with IDD.

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

The availability of robust, adequate, and equitable data is crucial for states to identify and address barriers that limit or reduce access to high-quality and coordinated care for CYSHCN and their families.

By using sound data equity principles, investing in robust data collection, and sharing data across systems, states are ensuring that they have the information necessary to understand the needs of CYSHCN, design effective programs, and invest in policy solutions that improve care delivery.



## Demographic Data Collection and Use

The **Ohio** Department of Health's Bureau of Maternal, Child, and Family Health publicly shares 69 public health data sets through the DataOhio Portal and InnovateOhio Platform.

The platforms include data on diagnosed birth defects and congenital anomalies across the state, including breakdowns by race and ethnicity, to identify risk factors, target prevention strategies, and inform referral practices.



## **Risk and Needs Assessments**

The **Arizona** Department of Health Services' Office of Newborn Screening partners with the state's Title V CYSHCN program to promote access to screenings that detect hearing conditions for newborns.

The state's CYSHCN program also lends hearing screening equipment to early-learning facilities, home visitors, community health workers, and schools, with a focus on rural and high-volume urban settings.



## **Medicaid Quality Initiatives**

**Utah** Medicaid's Healthy Outcomes Medical Excellence (HOME) is a managed care program designed to meet the behavioral and physical health care needs of CYSHCN who are dually diagnosed with a developmental disability and a mental illness.

HOME coordinates primary and specialty care, mental health care, and other needed services. The program also reports performance measures for the state's managed care quality strategy and supports a performance improvement project.

Learn more about state  
policy considerations to  
support equitable systems  
of care for CYSHCN:



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