

Children and Youth with Special Health Care Needs NETWORK NEWSLETTER

News, policy updates, resources, events, and advocacy opportunities

Dear Readers,

The recent passage of federal legislation significantly reducing Medicaid funding underscores the importance of the work of our grantees, partners, colleagues, and family advocates. We remain committed to improving care for children and youth with special health care needs. Together with our partners, we will continue working to ensure that children and families have access to equitable, efficient systems that deliver high-quality, coordinated, family-centered care.

We are deeply grateful for your continued partnership and shared dedication to this mission.

—Children and Youth with Special Health Care Needs Program Team

NATIONAL POLICY

New Federal Budget Law Could Affect Many CYSHCN, Families

The much-contested budget bill that the President signed on July 4 includes provisions that will reduce funding for Medicaid, which provides health care and supports for almost half of CYSHCN. A blog and video series from PolicyLab at Children's Hospital of Philadelphia explores the role Medicaid plays in the health of children, families, and communities. Several posts specifically dive into how Medicaid serves CYSHCN, homing in on topics such as how privately insured children also rely on Medicaid, Medicaid's lifelong benefit for those with medical complexity, and the many ways Medicaid provides support for the health and well-being of children and youth with disabilities.

[See the series](#)

Related: [The One Big, Beautiful Bill Act Will Mean Big Budget Hits for Families](#) – from Georgetown Center for Children and Families.

Also see: [\\$1 Trillion in Cuts to Medicaid Threatens Disability Services](#) – from *Disability Scoop*.

Webinar: Changes to Medicaid in the Budget Reconciliation Law

State Health & Value Strategies (SHVS) will host a webinar to review the Medicaid provisions included in the new budget reconciliation law. SVHS experts will discuss timelines for implementation of these provisions and specific considerations for states. This webinar is not specific to pediatrics.

DATE/TIME: Thursday, July 24 | 12:00-1:00pm PT

[Register](#)

Webinar: Budget Reconciliation Medicaid and Marketplace Provisions

Georgetown University Center for Children and Families and Center on Health Insurance Reforms will host a joint webinar about the Medicaid and Marketplace provisions of the new budget reconciliation law.

DATE/TIME: Monday, July 28 | 10:30-11:30am PT

[Register](#)

RESOURCES

KidsData Series Offers Comprehensive Picture of CYSHCN, Families

More than 15 million children nationwide have special health care needs. When this definition is expanded to include those with a diagnosed health condition and at least one functional difficulty, the numbers jump to nearly 19 million nationally. Foundation grantee KidsData recently published the final installment of its five-part series that uses comprehensive data to understand who California CYSHCN and their families are, their strengths, and the challenges they face. Data are available on [how health conditions affect children and families](#), [quality of care](#), [access to services](#), [demographic and health characteristics](#), and [family-centered care](#).

[See all data and related information](#)

CHILDREN WITH MEDICAL COMPLEXITY (CMC)

Support Growing for Training, Reimbursing Family Members to Provide Home Health Care

A small but growing number of state Medicaid programs are adopting the Family Certified Nursing Assistant (CNA) model, which trains and reimburses family members to provide home care for CMC that would otherwise be provided by a nurse or a non-family nursing assistant. A paper from Manatt, developed in partnership with our Foundation, provides policy tools for legislators and Medicaid officials to implement the Family CNA model in their own states.

[Subscribe](#) to our email list.

Read the paper

Podcast: Practice-Changing Research in Complex Care

A number of speakers at the recent meeting of the Pediatric Academic Societies presented posters and oral abstracts related to the care of CMC. In a *Complex Care Journal* podcast, researchers describe the implications of their study findings, key takeaways for patients and families, and future priority research areas for the complex care community.

Listen to the podcast

Complex Medical Conditions among Teens, Young Adults in Medicaid: National, State Estimates

As reported in the *Journal of Adolescent Health*, researchers at the University of Chicago measured the prevalence of individuals with medical complexity ages 15-25 enrolled in Medicaid, both nationally and within each state. Given that transition from pediatric to adult care is fraught with disruptions in care and support, the results of the study can help policymakers better understand the landscape of health insurance coverage for transitional age youth and develop policy solutions that support those with medical complexity.

Read the article

HEALTH EQUITY

Study: Disability-Based Discrimination Leads Some CYSHCN to Forgo Health Care

Disability-based discrimination in health care settings can hurt patients by limiting access to care, leading to changes in health care use patterns. A recent article in *Pediatrics* highlights a study that examined disability-based discrimination in a nationally representative cohort of CYSHCN and assessed the association with health care use. The authors found that about 10 percent of CYSHCN families reported facing disability-based discrimination, which resulted in twice the likelihood of skipping necessary health care. The authors suggest that clinicians need better education on how to understand and accommodate the needs of families with CYSHCN.

View the video abstract

Also see this plain language publication: [Why Children with Disabilities Are Skipping Vital Medical Visits](#).

An Experiment in Empowering Community Health Care Workers

Care workers play a crucial role in caring for children, parents, and communities, but they often work outside of health care systems. In 2020, Children's Hospital Los Angeles' engaged *promotoras*—individuals who liaise between providers and communities — to

[Subscribe](#) to our email list.

Stanford Social Innovation Review describes the program's results, and explains how a multi-agency partnership developed four principles that can help organizations design their own assessment tools to support the equitable inclusion of care workers and other marginalized workforces.

[Read the article](#)

Report: Power in Disability Solidarity

The Disability & Philanthropy Forum released a report filled with insights and stories on how foundations can amplify the leadership of people with disability expertise and foster a culture of inclusion.

[Read the report](#)

DENTAL CARE

Experts, Families Weigh in on Oral Health Needs, Experiences of CYSHCN

With support from our foundation, NORC at the University of Chicago conducted a comprehensive national study to better understand the oral health needs and dental care experiences of CYSHCN, and compared these experiences to those of children without special health care needs. The researchers spotlighted the unique experiences of key subgroups, such as children with medical complexity and children with intellectual and developmental disabilities. NORC also convened a virtual panel of experts to identify potential policy solutions, and conducted focus groups with parents of CYSHCN from around the country.

[Read the data brief and view related resources](#)

SPECIAL EDUCATION

US Supreme Court: No Higher Standard for Disability Discrimination Claims in Schools

The U.S. Supreme Court unanimously ruled in June that claims of disability discrimination at schools should not be held to a higher standard than those originating from other settings. In *A.J.T. v. Osseo Area Schools*, the justices weighed whether students with disabilities must demonstrate that schools acted wrongfully in order to claim that their rights had been violated.

[Read about the court's decision](#)

Podcast: Department of Education Cuts Impact Schools and Students

[Subscribe](#) to our email list.

Department to be disbanded. The Department of Education plays a crucial role in ensuring that students with disabilities receive the services they need. Listen to NPR's podcast on what this ruling could mean for students and schools across the nation.

[Listen to the podcast](#)

EVENTS

Disability Pride Month

July is Disability Pride Month. Disability rights advocacy organization, The Arc, describes the history and purpose of the month and how best to celebrate.

[Learn about Disability Pride Month](#)

WE WANT TO HEAR FROM YOU

Let us know what's happening with your organization or program. Send news and updates to info@lpfch.org. Thank you!

To see past issues, visit our [Newsletter Archive](#). If you were forwarded this newsletter and would like to receive it monthly, click the subscribe button below.

[Subscribe to CYSHCN News](#)

[Manage](#) your preferences | [Opt Out](#) using TrueRemove™
Got this as a forward? [Sign up](#) to receive our future emails.
View this email [online](#).

400 Hamilton Ave, Suite 340 | Palo Alto, CA 94301 US

This email was sent to .
To continue receiving our emails, add us to your address book.

[Subscribe](#) to our email list.