

Children and Youth with Special Health Care Needs NETWORK NEWSLETTER

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



Note from the editor: We've heard from a few readers that recent issues of the newsletter have ended up in their spam filters. We're working on that on our end, but you can also help by adding kristen.rogers@lpfch.org and info@lpfch.org to your safe senders list.

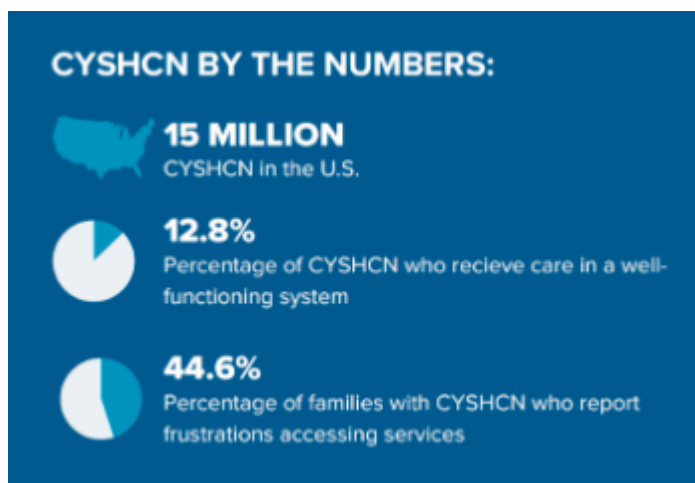
In this month's issue, we've included many upcoming events, so have your calendars ready! You can also find more CYSHCN-related events by scrolling to the bottom of our program's [new home page](#).

Warmly,
Kristen Holmstrand Rogers

HEALTH EQUITY

New Resource Highlights States' Approaches to Addressing Barriers to Care for CYSHCN

How are states advancing equitable systems of care for CYSHCN? A brief from the National Academy for State Health Policy (NASHP) highlights states' approaches in areas such as paid family caregiving, non-emergency medical transportation, telehealth, data collection, Medicaid quality initiatives, and more.



Also from NASHP is a [visual summary of the brief](#) and an [updated online, interactive map](#) of states' use of the National Standards for Systems of Care for CYSHCN and the National Care Coordination Standards. This research and product development were supported by our Foundation.

Access these resources via LPFCH.org

Related resource:

- [Medicaid and CHIP Reimbursement Models for Language Services: 2024 Update](#) (National Health Law Program, 3/19/24)

TRANSITION TO ADULT CARE



Aging Out of Public Program Services: Barriers, Inequities, and Recommendations

Got Transition, a program of the National Alliance to Advance Adolescent Health, will host an hour-long webinar highlighting findings from a study that examined the challenges that youth with disabilities (especially Black youth) and their families face as they move into adulthood. Learn about issues with Medicaid, the Children's Health Insurance Program, Supplemental Security Income, and Title V, as well as policy and program recommendations. Plus, hear from a self-advocate about his experiences with aging out. This work was supported by our Foundation.

DATE/TIME: Tuesday, May 22, 2024 | 10-11 am PT

Register for "Aging Out" webinar

Related resources:

- [The Goal Setting Challenge App: Impact on Transition Goal Attainment Outcomes of Students with Disabilities](#) (*Career Development and Transition for Exceptional Individuals*, February 2024)
- [Improving Health Care Transitions for Children and Youth With Special Health Care Needs](#) (LPFCH.org, November 2021)

PALLIATIVE CARE

See How Five Families Balance Care and Comfort in Pediatric Palliative Care

A National Geographic photo essay profiles several families served by the pediatric palliative care team at the University of Pittsburgh Medical Center - Children's Hospital of Pittsburgh and raises awareness about children with medical complexities, their families, and those who care for them.

[View the photo essay at NationalGeographic.com](#)

2024 Pediatric Palliative Care (PPC) Webinar Series

TOPIC: Chronic Home Ventilation: Helping Families Make Decisions

DATE/TIME: Tuesday, May 21, 2024 | 12-1 pm PT

SPEAKER: Renee D. Boss, MD, MHS

[Register for PPC webinars](#)

CHILDREN WITH MEDICAL COMPLEXITY (CMC)

Next Week: Transforming Care for Children with Complex Medical Needs: Insights from HRSA-funded Demonstration Sites

In this webinar from AcademyHealth, learn about the Enhancing Systems of Care for CMC initiative and other efforts to make accessing care from multiple providers easier for families. Hear from parents and providers about their lived experiences. (NOTE: A free AcademyHealth account is required to register for the webinar.)

DATE/TIME: Tuesday, April 23, 2024 | 9-10:30 am PT

[Learn more and register](#)

CALIFORNIA-SPECIFIC RESOURCES

Next Week: Family Voices of California 2024 Virtual Health Summit

This free, annual virtual summit provides a forum for families, youth, providers, policymakers, advocates, state agencies, insurers, and other stakeholders to learn about key issues affecting CYSHCN in California. Our Foundation is a sponsor of the event.

DATES/TIMES:

- Wednesday, April 24, 2024 | 9 am-2 pm PT
- Thursday, April 25, 2024 | 9 am-2 pm PT

[Learn more and register](#)

Related resources:

- [Who Are California's Children With Special Health Care Needs?](#) (KidsData News, 3/28/24)
- [Medi-Cal Hopes to Deliver Better Care to Kids: Will It Work?](#) (Children Now, 3/25/24)
- [Slides available from April 2024 California Children's Services Advisory Group Stakeholder Meeting.\(PDF\)](#) (CA Department of Health Care Services, 4/10/24)
- [ALL IN to #KeepKidsCovered Community Outreach Toolkit](#) (The Children's Partnership)

NATIONAL POLICY

- [Some States Consider Slashing Payments to Parents Who Care for Disabled Kids](#) (*Marketplace*, 4/1/24)
- [Webinar slides & recording available for "Unwinding: Where Do We Go from Here?"](#) (Georgetown Center for Children and Families, 4/15/24)
- [Most Disability Programs See Flat Funding in Federal Budget](#) (*Disability Scoop*, 3/18/24)

PHE UNWINDING

- [Webinar slides & recording available for "CMS Final Rule on Medicaid and CHIP Eligibility, Enrollment, and Renewal"](#) (State Health and Value Strategies, 4/11/24)
- [New Rule Simplifies Medicaid Enrollment and Aims to Help Eligible People Stay Enrolled](#) (National Health Law Program, 3/27/24)

- [Biden Administration Adds Protections to Keep Children Covered in CHIP](#) (Say Ahhh!, 3/27/24)

WE WANT TO HEAR FROM YOU

Let us know what's happening with your organization or program. Send your news and updates to Kristen Rogers, Assistant Communications Director, Programs & Partnerships, at 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.

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