

Children and Youth with Special Health Care Needs NETWORK NEWSLETTER

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



Follow us on LinkedIn

Our Program for CYSHCN has launched a new LinkedIn page, and we'd love for you to follow us. We'll be sharing **timely events and news stories** that might not be shared in our newsletter, commentary and thought pieces from our program officers and other experts in the field, some behind-the-scenes stories with our program team, and more. [Please join us!](#)

HEALTH EQUITY

Three Policy Priorities for States to Support Equitable Systems of Care for CYSHCN

Learn about three policies states are prioritizing to support equitable systems of care for CYSHCN and what that looks like in practice. This new visual summary of recent research, designed for sharing on social media, highlights specific examples of states' work, such as improving access to health care providers by offering transportation services (Virginia) and expanding telehealth (Michigan).

[Access the new visual summary](#)

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.

FAMILY ENGAGEMENT

How Children's Hospitals Can Best Support Patient and Family Advisors and Diversity, Equity, and Inclusion Efforts

A [new article in *Pediatrics*](#) explores patient and family advisor (PFA) perspectives on recruiting, preparing, and supporting PFAs from groups at greater risk of health inequities. The article also looks at PFAs' recommendations for developing meaningful partnerships with patient and family advisory councils (PFACs) to strengthen hospital diversity, equity, and inclusion efforts. Among the emerging themes from the study, PFAs noted that efforts to increase PFAC diversity must be accompanied by work to develop inclusive environments, and that diversity efforts require meaningful engagement from children's hospitals. This research was funded by our Foundation.

[Read the article](#)

Children's Hospitals Wanted for Learning Collaborative Focused on PFAC Diversity, Equity, and Inclusion

The Institute for Patient and Family-Centered Care is seeking up to 15 children's hospitals to join a new PFAC Diversity, Equity, and Inclusion (DEI) Learning Community. Participating hospitals will have access to a framework for advancing PFAC DEI, along with guidance, tools, and technical assistance. **Applications are due by October 1, 2024.** This work is funded by our Foundation.

- [Download PDF of FAQs](#) (includes eligibility information and selection criteria)
- [Submit an application](#)

Reminder: Share Your Family's Story by October 1

Do you have a story about your experiences interacting with the health care system for your child with disability or medical complexity?

The University of Wisconsin-Madison and the Bluebird Way Foundation are developing a series of Family-Led Academic Grand (FLAG) Rounds focused on addressing ableism in pediatrics. FLAG Rounds flip the traditional model of Grand Rounds by having families with lived experience, rather than clinicians, educate medical students and residents.

Families whose stories are selected will receive mentoring to further develop and present their stories in one of five virtual FLAG Rounds sessions. Sessions begin in January 2025.

[Learn more & submit your story](#)

CHILDREN WITH MEDICAL COMPLEXITY (CMC)

CMC Virtual Café: Health Equity and Anti-Ableism Through Family Partnership

Session five of six in the [Future of Care for Children with Medical Complexity Virtual Café Series](#) will focus on the pressing need to address bias in systems of care and move from a medical to social model of care. Discussants will share ways families' lived expertise is essential to humanizing systems. Participants will also learn about strategies and resources for effectively partnering with families to make real progress in health equity and anti-ableism. This work is funded by our Foundation.

DATE/TIME: **Wednesday, October 30 | 1 - 2 pm PT**

DISCUSSANTS:

Nikki Montgomery of Family Voices and mother of a child with medical complexity
Dr. Michelle J. White of Duke University School of Medicine

[Register for the virtual café](#)



Missed previous sessions? Access recordings, presentations, and summary resources (like the [graphic summary from Café #1](#) above):

- [Virtual Café #4: Family-Driven Approach to Understand Family Well-being and Its Facilitators](#)
- [Virtual Café #3: Meaningful Policy Opportunities That Matter to Families](#)
- [Virtual Café #2: Humanism in Clinical Care to Meet Whole Child/Family Needs](#)
- [Virtual Café #1: Where We Are Now and Where We Need to Go](#)

Don't Miss the 2024 Pediatric Complex Care Lifetime Achievement Awards Presentation

CYSHCNet invites you to join via Zoom as they present the 2024 Pediatric Complex Care Lifetime Achievement Awards to [Nora Wells and Dr. John Gordon](#). The Awards honor individuals who have made lifelong, exceptional, long-lasting contributions to helping children with medical complexity.

DATE/TIME: **Thursday, September 26 | 11:30 am - 12:30 pm PT**

[Register for the awards presentation](#)



Putting Care at the Center 2024: From Partnerships to Ecosystems of Care

Co-hosted by the Camden Coalition's National Center for Complex Health and Social Needs and UPMC Health Plan, [Putting Care at the Center 2024](#) is a dedicated venue for members of the complex care field to learn, network, and create a shared agenda for improving care for people with complex medical needs. Our Foundation is a sponsor of this event. Visit our booth at the conference Beehive to learn about our [Program for Children and Youth with Special Health Care Needs](#).

DATES: **Wednesday, October 16 - Friday, October 18**

LOCATION: Wyndham Grand Pittsburgh Downtown, Pittsburgh, PA

[Subscribe](#) to our email list.

TRANSITION

Recording Available for Transition from Pediatric to Adult Healthcare Webinar



See also:

- [AMCHP Awarded \\$3.4M to Form National Coordinating Center on Transition](#) (Association of Maternal & Child Health Programs, 9/4/24)

PHE UNWINDING

Webinar: Medicaid Eligibility and Enrollment Post-Unwinding

In the final session of National Health Law Program's Hot Topics in Health Law & Policy webinar series, advocates will dive into the current landscape of Medicaid eligibility, enrollment, and renewals. They will discuss lessons learned from the Medicaid continuous coverage unwinding, and implementation of the final eligibility and enrollment rule. They will also address current state emergency Medicaid policies and practices. Fee: \$35 for those seeking Continuing Legal Education credits; free for all others.

DATE/TIME: **Thursday, October 1 | 11 am - 12 pm PT**

[Register for the webinar](#)

See also:

- [State Momentum, New Tools, Implementation Questions on Multi-Year Continuous Eligibility](#) (Say Ahhh! blog, 9/12/24)
- [Guidelines for Achieving Compliance with Medicaid and CHIP Eligibility Renewal Timeliness Requirements Following the Medicaid and CHIP Unwinding Period](#) (PDF) (Center for Medicaid & CHIP Services, 8/29/24)

NATIONAL POLICY

- [Nearly 1 Million More Children Were in Poverty in 2023 Than 2022, Despite Economic Growth](#) (Child Trends, 9/10/24)
- [Feds Urge Guardrails to Protect Access to Medicaid Community-Based Services](#) (Disability Scoop, 9/9/24)

CALIFORNIA POLICY

Next California Children's Services (CCS) Advisory Group Stakeholder Meeting

The next CCS Advisory Group Stakeholder meeting will be held on October 9. The meeting is open to the public and can be attended virtually or in person in Sacramento.

DATE/TIME: **Wednesday, October 9 | 1-4 pm PT**

[Learn more](#)

Perspectives on California Ballot Measure Proposition 35

A measure on the California November ballot would permanently secure funds for the Medi-Cal program and block lawmakers from using it for other government services. ([See the CA Voter Guide for more information.](#)) Those funds, generated by a state tax on managed care organizations, are intended to increase reimbursement rates to health care providers who care for Medi-Cal patients and help reduce the current shortage of providers who accept Medi-Cal. CalMatters has published two perspectives on the issue:

- [California's Medi-Cal Ballot Measure Creates Winners and Losers. My Daughter Would Lose](#) (CalMatters, 8/28/24)
- [Medi-Cal Needs Reliable Funding. This California Ballot Measure Could Make It Happen](#) (CalMatters, 8/28/24)

See also:

- [DHCS Releases Referral Standards to Help Streamline Access to Enhanced Care Management](#) (PDF) (Department of Health Care Services, August 2024)
- [Nearly \\$1 Billion in Funds Left Unspent by Centers for Disabled Californians](#) (*LA Times*, 8/20/24)



REMINDER: TAKE OUR READER SURVEY BY SEPTEMBER 30

Thank you to everyone who has already completed our survey about this newsletter! If you haven't taken it yet, **we'd still love to get your feedback**. It takes less than 4 minutes to finish and, at the end, you can enter a raffle for a \$100 Amazon gift card.

[Go to the survey](#)

WE WANT TO HEAR FROM YOU

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

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