

Children and Youth with Special Health Care Needs NETWORK NEWSLETTER

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

FAMILY ENGAGEMENT

Call for Family Stories



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 Family-Led Academic Grand (FLAG) Rounds focused on addressing ableism in pediatrics. FLAG Rounds flip the traditional model of Grand Rounds by adopting families with lived experience, rather than clinicians, as educators.

Join this groundbreaking work by [sharing your story](#). Families whose stories are selected will receive mentoring to further develop and present their story in a virtual FLAG Rounds session.

Story submission form and requirements:

<https://bit.ly/FLAGroundsStories>

If you have questions:

[Informational Webinar](#) - Thursday, Aug. 22 | 12-1 pm PT

If you need help selecting or writing your story (register for one only):

[Choosing Your Story: Narrative Medicine Workshop](#) - Tuesday, Aug. 27 | 4:30-5:30 pm PT

[Writing Your Story Workshop](#) - Friday, Sept. 6 | 10-11 am PT

CHILDREN WITH MEDICAL COMPLEXITY (CMC)

CMC Virtual Café—Family-Driven Approach to Understand Family Well-Being and Its Facilitators

During session four of six in the [Future of Care for Children with Medical Complexity Virtual Café Series](#), Drs. Jay Berry and Katie Huth of Boston Children’s Hospital, and Meg Comeau of the Center for Innovation in Social Work & Health at Boston University, will discuss the current state of research priorities for CMC, including family-driven measurement. Participants will then explore research opportunities for advancing policy and practice. This work is funded by our Foundation.

DATE/TIME: **Wednesday, August 21 | 11 am - 12 pm PT**

[Register for the virtual café](#)

Missed previous sessions? Access the recordings and presentations:

- [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](#)

Webinar: Care Mapping for the Child with Medical Complexity

Hosted by the Pediatric Palliative Care Coalition, this interactive conversation will explore the concept of care mapping and how it can help families and caregivers of children with medical complexity navigate and access the wide variety of services and systems they need.

DATE/TIME: **Wednesday, August 28 | 9-10 am PT**

[Register for the webinar](#)

CYSHCNet Announces Recipients of the 2024 Pediatric Complex Care Lifetime Achievement Award

Congratulations to Nora Wells and Dr. John Gordon, the 2024 winners of the Pediatric Complex Care Lifetime Achievement Award, which honors individuals who have made exceptional contributions to help children with medical complexity in many areas, including clinical care delivery, advocacy, policy, administration, research, and education/training. The award also honors lived experience incorporated into any of these areas. [Learn about the winners](#) and [join CYSHCNet for the award presentation webinar](#) next month.

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

[Register for the awards presentation](#)

TRANSITION

Webinar: Transition from Pediatric to Adult Health Care—Patient Safety and Health Quality Gaps

The transition from pediatric to adult health care can be challenging, especially for CYSHCN. Difficulties transitioning can impact a young adult’s safety and the quality of care they receive. Join the National Quality Forum for a webinar that explores these issues with insights from both experts and families, including Dr. Patience White, Co-Project Director of Got Transition and Senior Medical Director of the National Alliance to Advance Adolescent Health.

CALIFORNIA POLICY

Few CSHCN in California Receive Health Care That Meets Minimum Federal Quality Standards

A fourth installment in KidsData's series on children with special health care needs (CSHCN) looks at the quality of care that children receive in California. Data from the National Survey of Children's Health showed that, in 2022, fewer than 1 in 13 CSHCN received care in a system meeting minimum federal quality-of-care standards. This [blog post](#) explores how many California children receive care within a medical home, the percentage of families receiving care coordination services, and the number of CSHCN with adequate health insurance coverage. Also provided are several policy recommendations for promoting equitable access to care for CSHCN and their families.

[Read the blog post](#)

92% of children with special health care needs in California did **not** receive care in a **well-functioning system.**

KidsData.org

What Health4All Means for California's Kids: A Conversation with Ricardo Lara, California Insurance Commissioner

Join The Children's Partnership (TCP) for this online event featuring a screening of a new documentary short on the history of [Health4All](#) in California. The screening will be followed by a fireside chat between Ricardo Lara, current California insurance commissioner, and Mayra E. Alvarez, TCP President, on the decades of work required to enact this important legislation.

DATE/TIME: **Thursday, August 29 | 1-2 pm PT**

[Register for the event](#)

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

The next CCS Advisory Group Stakeholder meeting will be 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](#)

NATIONAL POLICY

[Subscribe](#) to our email list.

Generating Policy Solutions to Protect Children with Complex Health Care Needs During Emergencies

The [newest episode](#) of the Maternal and Child Health (MCH) Bridges podcast focuses on policy changes that protect children with medical complexity from the impact of natural disasters and other emergencies. Hear from family advocates and staff from state agencies in Illinois who successfully partnered to amend policy and purchase back-up power generators for families.



[Listen to the podcast](#)

More policy resources:

- [Providing Multi-Year Continuous Enrollment to Medicaid and CHIP Populations: State Toolkit](#) (State Health and Value Strategies, 7/26/24)
- [Transparency in Medicaid Managed Care: CMS Posts the Managed Care Program Annual Reports](#) (*Say Ahhh!* blog, 7/25/24)

COMMUNITY ENGAGEMENT

- [A Roadmap for Effective Community Engagement in Healthcare](#) (Initiating National Strategies for Partnership, Inclusion, and Real Engagement, Camden Coalition, 7/9/24)

PHE UNWINDING

- [GAO Releases Report on Federal Oversight and the Unwinding](#) (*Say Ahhh!* blog, 8/8/24)
- [Racial Disparities Persist During the Unwinding of the Medicaid Continuous Coverage Requirement](#) (National Health Law Program, 8/7/24)

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!

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