

Children and Youth with Special Health Care Needs NETWORK NEWSLETTER

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

Dear Readers:

We remain unwavering in our commitment to improving health care systems for children and youth with special health care needs (CYSHCN) and their families, regardless of changes in the national or local landscape of children's health. Our dedication to collaboration with our grantees and partners will continue, ensuring that CYSHCN have access to the services and supports they need—no matter where they live, what financial means they have, or with which communities they identify. We are deeply grateful for your ongoing partnership and shared commitment to this vital mission.

—Children and Youth with Special Health Care Needs Program Team

CHILDREN WITH MEDICAL COMPLEXITY (CMC)

CMC Virtual Café: Sustainability and Strategic Partnerships

Don't miss the last session in the [Future of Care for Children with Medical Complexity Virtual Café Series](#), which will focus on a strategic yet practical perspective for advancing sustainable care coordination. This work is supported by our Foundation.

DATE/TIME: **Wednesday, December 4 | 1-2 pm PT**

DISCUSSANTS:

Richard C. Antonelli, MD, MS, FAAP, Boston Children's Hospital

Jeffrey S. Schiff, MD, MBA, FAAP, AcademyHealth

Meg Comeau, MHA, Center for Innovation in Social Work & Health, Boston University

[Register for the final virtual café](#)

Missed previous sessions? [Access recordings, presentations, and other resources from all the virtual cafés on our Foundation's website.](#)

FAMILY ENGAGEMENT

[Subscribe](#) to our email list.

Webinar—Supporting Family Partners on their Engagement Journey: Early Lessons from the Enhancing Systems of Care for Children with Medical Complexity Initiative

Join this webinar from AcademyHealth to learn about collaboration with family partners at two HRSA-funded Demonstration Sites that are exploring strategies to engage caregivers effectively and meaningfully. Parent partners will discuss what drives their involvement and how they are working to improve care models for children with medical complexity to create sustainable change.

Note: The webinar is free and open to the public, but you must first create or log into an AcademyHealth account to register.

DATE/TIME: **Thursday, December 5 | 9-10 am PT**

[Learn more and register](#)



Plan Ahead for 2025: Register to Attend Virtual Family-Led Academic Grand Rounds Sessions

Family-Led Academic Grand (FLAG) Rounds flip the traditional grand rounds model by embracing families and youth as primary medical educators. With a focus on ableism in pediatric health care and its impact on children with disabilities and/or medical complexity and their families, this series of virtual FLAG Rounds will be led by individuals with lived experience who have been mentored by the University of Wisconsin and the Bluebird Way Foundation. This work is supported by our Foundation.

The sessions are open to anyone, including medical students, residents, doctors, nurses, social workers, and families. Continuing Education Units are available.

2025 DATES: **January 16, March 13, May 29, September 25, December 4**

TIME: **All sessions are from 10-11 am PT**

[Learn more and register](#)

HEALTH EQUITY

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Free Online Course About Language Access in Health Care

To improve language access in the health care system for families of CYSHCN, Family Voices has developed a free online course called "My Language, My Care." The course covers language access rights, how to advocate for high-quality services, and how to get the most from language access services in the health care setting. The course is available in English, Spanish, Chinese, and American Sign Language.

[Access the course](#)

CALIFORNIA POLICY

More California Kids with Disabilities Are Enrolled in a New Health Program, But Is It Helping?

California Health Report looks at how the rollout of a new Medi-Cal benefit called Enhanced Care Management (ECM) is going in California, including what the experience has been like for some families of CYSHCN. The program is designed to identify and close gaps in needed services, and ensure coordination across medical care, behavioral health, and social service delivery systems. So far, the results of the program have been mixed. Senior Reporter Claudia Boyd-Barrett speaks with health department officials, state children's advocacy organizations, providers, and families to examine the issue. This work is supported by our Foundation.

[Read the article](#)

Next California Children's Services (CCS) Advisory Group Stakeholder Meeting on January 8, 2025

Check the Department of Health Care Services' [CCS Advisory Group website](#) for the agenda and the 2025 meeting schedule. All meetings are open to the public and are held virtually and in person.

[Learn more](#)

PALLIATIVE CARE

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2025 Pediatric Palliative Care Webinar Series Begins with Session on Motivational Interviewing

The Pediatric Palliative Care Coalition (PPCC) has released its calendar of webinars for 2025. The first webinar—Transforming Communication with Motivational Interviewing: A Primer for Pediatric Palliative Care Clinicians—will provide an overview of the philosophy and principles of motivational interviewing and how they can be applied to daily pediatric palliative care clinical practice.

Note: Registration for the 2025 series opens on December 1.

DATE/TIME: **Wednesday, January 15 | 12-1 pm PT**

PRESENTER: **Rachel Kentor, PhD**, Baylor College of Medicine

[Learn more](#)

Resource:

- [PPCC Self-Advocacy Toolkit: A Guide for Parents, Caregivers, Children and Adolescents](#) (PPCC, November 2024)

TRANSITION TO ADULT CARE

Webinar: My Child with Medical Complexity Is Turning 18, Now What?

In this Firefly Chat, presenter Jennifer Shuckrow will share her family's experience with the guardianship application process and transitioning out of pediatric care for her child with medical complexity. The webinar will help families identify decisions to be made and potential challenges, as well as provide sources of support and resources to aid them through the process.

DATE/TIME: **Wednesday, December 11 | 9-10 am PT**

[Register for the webinar](#)

NEWS

- [How Health Care Could Change Under the New Trump Administration](#) (NPR, 11/6/24)
 - [A Proclamation on National Family Caregivers Month, 2024](#) (The White House, October 31, 2024)
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