

Children and Youth with Special Health Care Needs NETWORK NEWSLETTER

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

FROM OUR FOUNDATION



Looking for news and updates in between newsletters? Be sure to [follow us on LinkedIn](#).

Health Equity and Family Engagement at Forefront of New Grants Awarded by Our Foundation

We are thrilled to announce the latest grants awarded through the Foundation's CYSHCN grantmaking and advocacy program. The work funded by these four grants will focus on:

- Supporting and empowering Black caregivers of children with medical complexity
- Advocating for policies to address inequities in services provided for children with disabilities in California
- Strengthening organizational infrastructure and building capacity for CYSHCN family engagement work at the national level
- Expanding and diversifying hospital and clinic sites for a statewide study of self-management support in pediatric care for CYSHCN in California

[Learn more about the new grants](#)

Investing in Inclusion: How Health Philanthropy Can Prioritize the Needs and Perspectives of Individuals with Disabilities

Disability-related grants represent just 2% of all philanthropic giving. To help change that, our team co-wrote a blog post with Ryan Easterly, Executive Director of the WITH Foundation, for Grantmakers In Health's *Views from the Field*. The piece provides guidance for how other foundations can promote disability inclusion and highlights The National Alliance to Advance Adolescent Health's recent research on the pediatric to adult health care transition as an example of disability-inclusive work that authentically engages individuals with lived experience.

[Read the blog post](#)

FAMILY-CENTERED CARE

Report: Development of a Survey Instrument for Caregivers of Children and Youth with Special Health Care Needs to Assess Self-Management Support

The Assessing Family Friendly Care in Realizing Self-Management (AFFIRM) study team piloted a survey to understand how families receive self-management support (SMS) from their medical care team. This report outlines the key lessons learned on survey content, structure, and research methodology, which have been applied to the [2024-2025 AFFIRM California survey](#). These lessons will also help clinicians, policymakers, and funders focus on the development of SMS resources and processes that are most valuable to families of CYSHCN. This work is supported by our Foundation.

[Download the report](#)

Pediatric Subspecialist Referrals to Peer Support for Families

Families of children with special health care needs (CSHCN) often reference the benefits of peer support—social, emotional, and informational support provided by other families with similarly affected children. Pediatric subspecialists play a key role in educating families, but little is known about the degree to which subspecialty practices refer families to peer support. This article published in the *Maternal and Child Health Journal* reports on a statewide study of California subspecialists that examined opinions on and referral practices for peer support. The authors also offer recommendations for increasing families' access to peer support. This work is supported by our Foundation.

[Read the full article](#)



Family-Led Academic Grand (FLAG) Rounds Begin: First Session - "Whose Expectation Is it Anyway? Access, Care, and Humanization"

FLAG Rounds train and empower families of children with complex medical conditions to share their stories and experiences of ableism in the pediatric health care system with medical students and residents. The goal of FLAG Rounds is to facilitate change and foster partnership in the care of CYSHCN.

The first of five virtual FLAG Rounds sessions, “Whose Expectation is it Anyway? Access, Care, and Humanization,” will be held on January 16, 2025. All are invited to register. FLAG Rounds are accredited and approved to offer continuing education credits. This work is supported by our Foundation.

DATE/TIME: **Thursday, January 16 | 10-11 am PT**

MORE 2025 DATES: March 13, May 29, September 25, December 4 (all from 10-11 am PT)

[Learn more and register](#)

NATIONAL POLICY

Webinar Recording: Federal Medicaid Cuts & What’s at Stake for State Budgets and Families

Potential restructuring of Medicaid and federal funding cuts in 2025 could have serious impacts for CYSHCN and their families. This webinar, held by the new Child Medicaid Policy Institute at the Georgetown University Center for Children and Families, explained the fundamentals of the Medicaid program, its importance for children, families, and other low-income individuals, and how states will have to adjust to changes to the program at the federal level.

[Watch the recording](#)

See also:

- [Medicaid Defense – Resources and Analysis](#) (National Health Law Program, December 2024)
- [Opinion: Medicaid and a Second Trump Administration](#) (*Milbank Quarterly*, 12/9/24)
- [Nine States Poised to End Coverage for Millions If Trump Cuts Medicaid Funding](#) (*KFF Health News*, 12/4/24)
- [The Role of Continuing Disability Reviews in Child Supplemental Security Income Program Participation Patterns](#) (*Social Security Bulletin*, November 2024)

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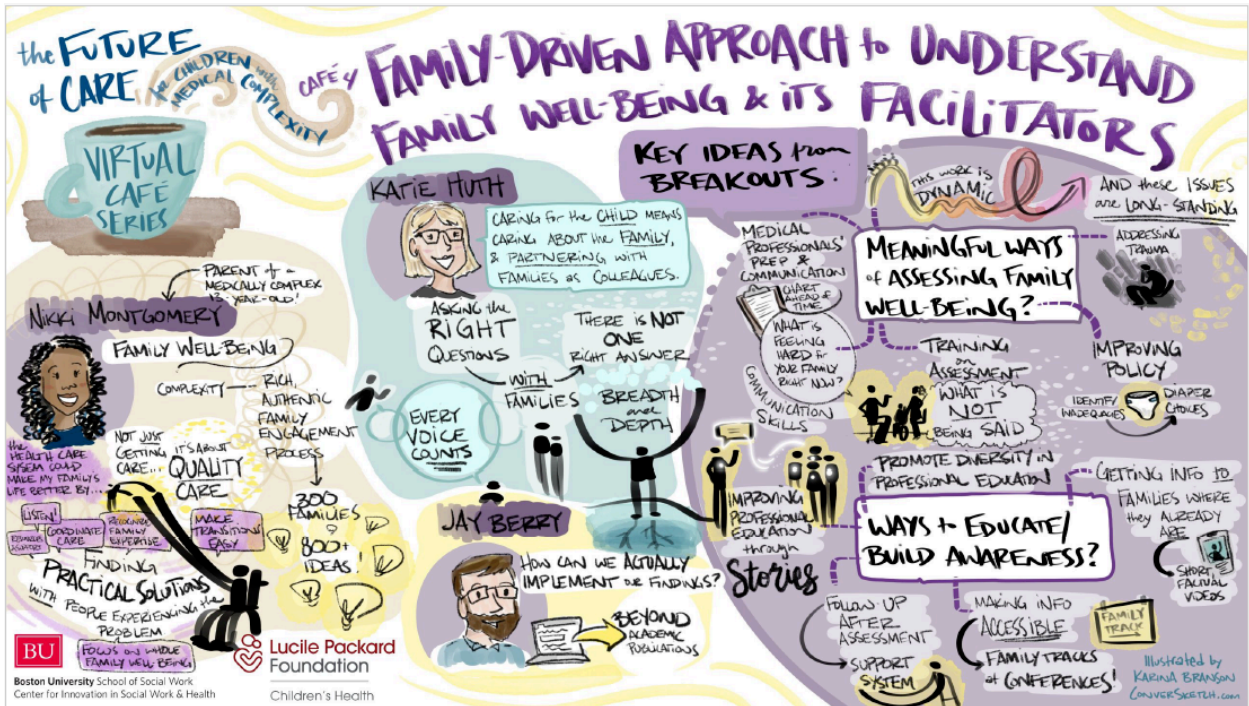
RESEARCH

Call for Abstracts: AcademyHealth's 2025 Annual Research Meeting

Abstract submissions are open for AcademyHealth's [2025 Annual Research Meeting](#), which will be held June 7-10, 2025, in Minneapolis, MN. This year's meeting is organized around 21 themes, including: Individuals Living with Disability or Other Complex Conditions, Medicaid Coverage and Access, Patient-Centered, -Partnered, or -Led Research, and more. **Abstract submissions are due by Wednesday, January 8, 2025, at 2 pm PT.**

[Learn more](#)

CHILDREN WITH MEDICAL COMPLEXITY (CMC)



Recordings from All CMC Virtual Cafés Now Available

Visit our website to find video recordings, slides, and other resources from all of the 2024 Future of Care for Children with Medical Complexity Virtual Cafés, including the graphic drawing from Café #4 pictured above. Each café page has links to all the other café recaps and resources. This work was supported by our Foundation.

[Access all café series resources](#)

PALLIATIVE CARE

Transforming Communication with Motivational Interviewing: A Primer

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The first Pediatric Palliative Care Coalition webinar of 2025 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: There is a registration fee of \$40 for individuals; group rates are also available.*

DATE/TIME: **Thursday, January 16 | 12-1 pm PT**

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

[Learn more](#)

CALIFORNIA POLICY

How Rural Communities Can Fill Care Gaps for Children with Disabilities

Amidst a nationwide shortage of pediatric subspecialists, families of CYSHCN in rural areas are often forced to travel long distances or even move to get the care they need. To shine a light on this issue, *California Health Report* shares the experiences of two families living in California's remote Eastern Sierra and explores some factors behind the pediatric subspecialist shortage. The story also features recommendations from parents and physicians to help ease the burden on families. This work is supported by our Foundation.

[Read the article](#)

See also:

- [Accessing Pediatric Subspecialty Care in California](#) (LPFCH.org)
- [How Potential Medicaid Cuts Could Play Out in California](#) (*KFF Health News*, 12/5/24)

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

See the Department of Health Care Services' [CCS Advisory Group website](#) for the meeting WebEx details. The agenda will be available prior to the meeting. All meetings are open to the public and are held virtually and in person (1700 K Street, Sacramento, CA 95811).

DATE/TIME: **Wednesday, January 8 | 1-4 pm PT**

[Learn more](#)

NEWS & RESOURCES

- [New Federal Rule Seeks to Improve Airline Travel for People with Disabilities](#) (*CBS News*, 12/16/24)
- [Study: Improving Pediatric Emergency Care Could Save More than 2,100 Children's Lives](#)

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- [Annual Family and Community Issue: The Story Behind the Smile](#) (*Exceptional Parent Magazine*, December 2024)

WE WANT TO HEAR FROM YOU

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

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