

Children and Youth with Special Health Care Needs NETWORK NEWSLETTER

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



FOUNDATION NEWS

Seven New Grants Awarded to Propel Systems and Policy Change for Children and Youth with Special Health Care Needs

Our Foundation is thrilled to announce the newest cohort of researchers and organizations receiving grants through our Program for Children and Youth with Special Health Care Needs (CYSHCN). The seven grants will fund groundbreaking research necessary for driving health care systems and policy change, as well as support growth for programs that are on the forefront of CYSHCN advocacy and family engagement.

The projects funded by these grants will examine ableism in pediatric health care, evaluate policies and programs related to home modifications for children with disabilities, investigate the transition from pediatric to adult health care, explore family-led medical education, and address other critical topics.

[Read the full announcement](#)

PEER SUPPORT

A Survey of Caregivers of Children and Youth with Special Health Care Needs: Family Perspectives on Peer Support

Caregivers, who often work tirelessly to coordinate care for CYSHCN, may benefit from informational and emotional support from other caregivers, also known as peer support. Through a short survey, researchers gathered information about California-based caregivers' experiences in accessing pediatric subspecialty care for CYSHCN and receiving

peer support. [This report](#) highlights the results of the survey related to peer support, including how caregivers were referred to peer support, how they received it, and what positive and negative effects they reported. This work was supported by our Foundation.

[See the survey results](#)

Nearly 70% of caregivers reported that they felt **more confident in caring for their child** due to peer support.

from A Survey of Caregivers of Children and Youth with Special Health Care Needs

HOME- AND COMMUNITY-BASED CARE

Expanding Access to Home-Based Behavioral Health Services for Children in Foster Care

Children in foster care in the United States are designated as CYSHCN by the American Academy of Pediatrics. These children often require behavioral health services due to their high rates of previous trauma and abuse. Unfortunately, many children in foster care needing behavioral health treatment end up in hospitals and psychiatric institutions, even when not medically necessary. [This article](#) presents recommendations for guiding policy and systems change to increase availability of home-based behavioral health services for children. This work was supported by our Foundation.

[Read the article](#)

TRANSITION TO ADULT CARE

New Resources on Young Adults with Disabilities Aging Out of Public Programs

The transition from pediatric to adult health care for youth with disabilities is getting some much-needed attention. The American Academy of Pediatrics released [a new policy statement](#) at the end of May. And, with support from our Foundation and the WITH Foundation, the National Alliance to Advance Adolescent Health has released a set of five publications focused on what happens when young adults with disabilities age out of childhood eligibility for health care programs like Medicaid and the Children's Health Insurance Program. These new resources help fill the gap in our understanding of the aging out experience, particularly for Black young adults, and recommend strategies to reduce disruptions and inequities in care.

Access the new resources:

- [A National Report: Youth and Young Adults with Disabilities Aging Out of Medicaid, CHIP, SSI, and Title V Programs – Barriers, Inequities, and Recommendations](#)
- [Policy Brief: Recommendations to Assist Youth and Young Adults with Disabilities Aging Out of Medicaid & CHIP](#)

- [Policy Brief: Recommendations to Assist Youth and Young Adults with Disabilities Aging Out of SSI](#)
- [Policy Brief: Recommendations to Assist Youth and Young Adults with Special Health Care Needs Aging Out of Title V](#)
- [A Five-State Case Study: Black Youth and Young Adults with Disabilities Aging Out of Medicaid, CHIP, SSI, and Title V Programs](#)

See also:

- [Barriers and Facilitators to Transition from Pediatric to Adult Healthcare for Immigrant Youth with Chronic Health Conditions](#) (*Journal of Pediatric Nursing*, 5/17/24)

CHILDREN WITH MEDICAL COMPLEXITY (CMC)

Virtual Café: Policy Opportunities

During session three of six in the [Future of Care for Children with Medical Complexity Virtual Café Series](#), Aimee Ossman, MPA, of the Children’s Hospital Association and Lisa Kirsch, MPAff, of Dell Medical School will share thoughts about the current policy landscape for CMC. Then, through facilitated breakout discussions, participants will explore opportunities for policy changes at the local, state, and national levels. This work is funded by our Foundation.

DATE/TIME: **Wednesday, July 24 | 12-1 pm PT**

[Register for the Virtual Café](#)

Related resources:

- [The Clinical Definition of Children with Medical Complexity: A Modified Delphi Study](#) (*Pediatrics*, 5/28/24)

FAMILY ENGAGEMENT

Advocating for Health Successes: Filling Gaps with Patient-Family Engagement

[This episode](#) of the *Charting Pediatrics* podcast from Children’s Hospital Colorado features Hala Durrah, a consultant and advocate for patient-family engagement and mother of a child who has undergone two liver transplants and a bone marrow transplant. Hala talks about her work in patient- and family-centered care, as well as the Accelerating Child Health Transformation initiative, which aims to accelerate the adoption of family-centered pediatric practices.



[Listen to the podcast episode](#)

CALIFORNIA POLICY

- [FAQs About the Transition from Pediatric to Adult Health Care](#) (PDF) (California Children's Services, June 2024)
- [Spotlight on Children with Special Needs \(Part 3\): A Look at Access to Care](#) (*KidsData News*, 5/23/24)
- [Analysis: California Has the Best Programs for Kids with Complex Health Needs, But We Can Do Even Better](#) (*California Health Report*, 5/16/24)

Next California Children's Services Advisory Group Stakeholder Meeting

The meeting is held virtually and in person and is open to the public. The July meeting agenda is available on the [Advisory Group page](#).

DATE/TIME: **Wednesday, July 10 | 1-4 pm PT**

[Learn more](#)

SUBSPECIALTY CARE

- [Loan Repayment Available for Pediatric Specialty, Child and Adolescent Mental Health Providers](#); Application deadline 7/9/24 (Health Resources & Services Administration)

PALLIATIVE CARE

- [Hawaii Is First State to Provide Palliative Care Coverage Through Medicaid](#) (Office of the Governor, 6/3/24)
- [Dispelling 5 Myths About Palliative Care](#) (*Packard Children's News*, Spring 2024)

PHE UNWINDING

- [How Families' Medicaid Unwinding Experience Can Help Us Advance Health Equity](#) (*Say Ahhh!* blog, 6/3/24)
- [Introduction to Medicaid and CHIP Outreach Snapshot Blog Series](#) (Georgetown Center for Children and Families, 5/31/24)

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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