Lucile Packard Foundation
Children's Health

October 15, 2026

Children and Youth with Special Health Care Needs
NETWORK NEWSLETTER

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

FROM OUR FOUNDATION

National Survey Highlights Unmet Need for Medical Equipment and Devices

The second data brief in a series about the health care experiences of children and youth with special health care needs (CYSHCN) reveals that nearly half (48%) of those who needed medical equipment or devices experienced at least one barrier to obtaining them. The brief, *Unmet Need for Medical Equipment and Devices*, shares that the most common barrier was the inability to obtain a referral. Learn more about the findings from a national survey our Foundation commissioned, conducted by NORC at the University of Chicago.

Read the data brief

Learn more about the survey findings

Webinar Series Sheds Light on Home Modifications for Children with Disabilities

Our Foundation hosted a two-part webinar series on home modifications, introducing Foundation-funded research on the national landscape of programs and policies that support home accessibility for children with disabilities and their families. Recordings and slides are now available for both webinars: the first provides an overview of home modifications and why they matter; the second demystifies resources available in the U.S. and provides recommendations for how families can access them.

See webinar #1: Essential Yet Out of Reach

See webinar #2: The Best Kept Secret

Family Voices Announces Leadership Transition

Dr. Allysa Ware is stepping down from her role as Executive Director of Family Voices at the end of October. The Foundation would like to recognize her national leadership, contributions to the field of family engagement, and partnership across many Foundation-funded projects.

Read about the leadership transition

NATIONAL POLICY AND RESOURCES

Young Adults at Risk of Losing Medicaid

A new analysis by the Urban Institute found that up to 2.3 million young adults ages 19 to 24 could lose Medicaid coverage due to H.R. 1's work reporting requirements and the paperwork burden of more frequent re-determinations. This is particularly important for young adults with complex health needs.

Read the report

Also see in *Marketplace*: More than 2 million young adults could lose Medicaid soon

TRANSITION TO ADULT CARE

Ethics and Equity Implications of AI Use Among Young Adults with Chronic Conditions

Generation Patient led a roundtable discussion on AI use in health care at the seventh in a series of roundtables focused on young adults with chronic conditions, supported by our Foundation. Proceedings, co-authored by young adults with chronic conditions, were published in *Frontiers in Digital Health* and recommend that AI developers work collaboratively with users and health equity experts to build safer and more equitable AI tools.

Read the article

Watch the Roundtable on AI

CALIFORNIA POLICY AND RESOURCES

California Disability Community Town Halls Gather Advocates

Our Foundation sponsored the first-ever California Disability Community Town Hall series, which took place last week in Berkeley and Los Angeles, hosted by the Disability and Philanthropy Forum.

Read more and follow us on LinkedIn

Keeping Care at Home Webinar Series

Family Voices of California is hosting a three-part virtual webinar series for families of CYSHCN, led by parent advocate Jenny McLelland. The series, *Keeping Care at Home*, will break down the laws, programs, and funding that support care at home — including Section 504 of the Rehabilitation Act, the Olmstead Act, Early and Periodic Screening,

Diagnostic, and Treatment (EPSDT), Home- and Community-Based Services (HCBS) waivers, In-Home Supportive Services (IHSS), regional centers, and current federal policy changes and legal challenges.

DATES/TIMES: November 2, 9 & 16 | 6-7:30 PM PT

Register and learn more

Understanding Public Charge 2026: Webinar Recording Available

The Children's Partnership hosted a webinar breaking down what the new public charge rule means for California advocates, providers, and families – what it is, what has changed, what remains the same, what advocates need to do now, and what resources are available.

Access the webinar recording in English

Acceda a la grabación del seminario web en español

Access the slides

FAMILY ENGAGEMENT

Webinar Series: The Science and Practice of Family Engagement

The final webinar in Family Voices' fall series will include an overview of the Family Engagement in Systems Assessment Tool (FESAT) and introduce newly developed FESAT resources. The presenter will share how organizations can use these tools to support reflection across four key domains of engagement (commitment, transparency, representation, and impact) and how these domains translate into actionable practices in systems of care transformation efforts. Our Foundation supported the development and implementation of the FESAT.

DATE/TIME: November 4 | 11 AM PT/2 PM ET

Register and see past webinar recordings

Julie Beckett Policy Academy Applications Open

Family Voices launched the Julie Beckett Policy Academy to train the next generation of family and youth advocates. The program seeks applicants who have experience advocating at the state level and are looking to move to national policy advocacy. Applications are due **November 20**.

Learn more and apply

Metrics for Peer Mentor Programs

The Parent Mentor Learning Center at Lucile Packard Children's Hospital Stanford provides information, resources, and strategies for pediatric health care settings looking to launch or enhance a peer mentor program. Join the center's webinar to learn more about the importance of metrics for peer mentor programs and innovative approaches to data collection.

DATE/TIME: October 29 | 10 AM PT/1 PM ET

Learn more and register

CHILDREN WITH MEDICAL COMPLEXITY (CMC)

North Carolina Program Provides Integrated Care for Youth with Chronic and Complex Conditions

A new brief from the National Academy for State Health Policy explores North Carolina's approach to a specialized Medicaid managed care program for individuals with serious mental illness, disabilities, traumatic brain injuries, and co-occurring conditions.

Read the brief

Patient Safety for Children Receiving Home Health Care

An article in *JAMA Network Open* explores systems-level approaches to addressing patient safety in pediatric home health care for children with medical complexity.

Read the article

IN THE NEWS

My Daughter Belongs at Home, Not in an Institution. (*Other Words*, 9/16/26)

CONFERENCES

Annual Chronic Illness and Disability Conference: Transition from Pediatric to Adult-Based Care

The Baylor College of Medicine is holding its annual conference focused on pediatric to adult health care transition, both in-person in Houston, Texas and virtually via live stream. Registration is open through **October 19.**

DATES: October 22-23

Register and learn more

WE WANT TO HEAR FROM YOU

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

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