

Children and Youth with Special Health Care Needs NETWORK NEWSLETTER

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

FROM OUR FOUNDATION

The Best Kept Secret: Programs and Policies Across States to Support Accessible Homes for Children with Disabilities

Join our Foundation for *The Best Kept Secret: Programs and Policies Across States to Support Accessible Homes for Children with Disabilities*, the second in a two-part webinar series on home accessibility for children with disabilities and complex health needs. The series shares findings from a landscape analysis that included over 60 key informant interviews across 10 states to elucidate programs and policies that support accessible housing for children and their families.

The first webinar focused on why home modifications matter and the barriers families face in accessing them. This second webinar will highlight programs, policies, and resources that exist to help families make their homes more accessible and explore why home modification supports are often difficult to find and use.

DATE/TIME: September 29 | 11 AM PT/2 PM ET

[Register for the webinar](#)

[Access the first webinar recording and slides](#)

NATIONAL POLICY AND RESOURCES

Leading with Lived Experience: Lessons from Medicaid Leaders

The Center for Health Care Strategies recently aired a podcast exploring how leaders in Pennsylvania, Idaho, and Oregon drew on their personal experiences with health care to expand access, make services easier to navigate, and keep people at the center of policy and programmatic decisions.

[Listen to the podcast](#)

Cutting Medicaid for Children: A Bet Against the Future

Medicaid, the largest public health insurance program in the U.S., provides coverage to 85 million people, including more than 40 million children. A new Viewpoint in *JAMA* asserts that although H.R. 1 policy changes are focused on adults, the magnitude of the cuts will have significant implications for children's health.

[Read the article](#)

Advocates Raise Concern about Section 1115 Medicaid Waiver Guidance

A new blog from the Georgetown Center for Children and Families analyzes guidance issued by the Centers for Medicare and Medicaid Services in June to implement Section 1115, which was added to the Social Security Act by H.R. 1. The blog explores budgetary complexities and implications of the guidance for states.

[Read the blog](#)

CALIFORNIA POLICY AND RESOURCES

California Disability Community Town Halls

The Disability & Philanthropy Forum is gathering funders, policy makers, and disability movement leaders for the first-ever series of California Disability Community Town Halls. Our Foundation is sponsoring these virtual and in-person events, designed to amplify the perspectives of frontline activists and advocates. The town halls will cover issues including Medi-Cal, housing, economic mobility, and long-term care.

DATE/TIME: October 6 in Berkeley | 1-4 PM PT

DATE/TIME: October 8 in Los Angeles | 1-4 PM PT

[Register here](#)

Webinar on Navigating Due Process Rights in the California Children's Services Program

The National Health Law Program and Disability Rights California are hosting a webinar on due process rights in the California Children's Services (CCS) Program. CCS, a state program for children and youth with special health care needs, is complex to navigate as rules depend on how the beneficiary gets CCS services and vary by county. This webinar will provide guidance and best practices on filing grievances and appeals, and discuss tools to help beneficiaries receive care through the CCS program.

DATE/TIME: September 11 | 9:30 AM PT

[Register for the webinar](#)

Medi-Cal Children's Health Advisory Panel to Meet

The Medi-Cal Children's Health Advisory Panel (MCHAP), convened by the California Department of Health Care Services, has its next public meeting is September 10. Public comments can be submitted to MCHAP@dhcs.ca.gov prior to the meeting.

DATE/TIME: September 10 | 10 AM–2 PM PT

[Learn more and comment](#)

HOME HEALTH

Complex Needs, Complex Costs: New Study Assesses Medicaid Payments in South Carolina

A new study published in *Academic Pediatrics* analyzes Medicaid payments for a subset of home- and community-based services (HCBS) for children with medical complexity. From a sample of over 21,000 children, the authors found that a small cohort enrolled in South Carolina's Medically Complex Children's waiver program accounts for a high concentration of Medicaid payments, reflecting the resource-intensive nature of hospital-level care delivered at home.

[Read the article](#)

FAMILY ENGAGEMENT

Family Voices' Free Family and Youth Leadership Certificate Programs

Applications are open, and **due August 24**, for Family Voices' free online leadership certificate programs for youth and families who want to transform health care. The programs are designed for children and youth with special health care needs (CYSHCN) and/or disabilities, family members of CYSHCN, and organizational teams looking to strengthen youth and family engagement. Participants will develop new leadership skills and be equipped to expand their impact on national policy and help create sustainable family engagement initiatives.

[Learn more and apply](#)

New PFAC Webinar Series: Building Authentic Partnerships with Patients and Families

Building truly representative and welcoming Patient and Family Advisory Councils (PFACs) requires continuous learning. To support this journey, the Institute for Patient- and Family-Centered Care (IPFCC) is launching a 6-part webinar series, supported by our Foundation. Expanding on the practical guidance in IPFCC's [Reflecting Our Community](#) toolkit, this series offers health care leaders, staff, and advisors actionable strategies to build authentic partnerships with patients and families. The monthly webinars start October 13 and run through April 2027.

DATE/TIME OF FIRST WEBINAR: October 13 | 10 AM PT/1 PM ET

[Register for the webinar series](#)

Parent Mentor Learning Center Webinar

The Parent Mentor Learning Center (PMLC) at Lucile Packard Children's Hospital is hosting a webinar to introduce the PMLC's goals and activities, present findings from a recent survey of pediatric peer mentor programs across the US and Canada, and share opportunities to get involved in their work.

DATE/TIME: September 24 | 10 AM PT/1 PM ET

[Register for the webinar](#)

CHILDREN WITH MEDICAL COMPLEXITY (CMC)

Caregiver Perspectives on Preventing Future Hospitalization for CMC

CMC are hospitalized frequently, and caregivers play a critical role in mitigating hospitalization risk. A national multi-site study published in *Hospital Pediatrics* examined the association between caregiver self-efficacy and the perception of future hospitalization preventability. The authors found that most caregivers of CMC believe hospitalizations can be prevented, and that higher self-efficacy in managing acute illness is strongly linked to this belief.

[Read the article](#)

TRANSITION TO ADULT CARE

New Proceedings on Young Adults with Chronic Conditions in Clinical Trials

Generation Patient has published the proceedings from the 6th roundtable in a series, supported by our Foundation, focused on young adults with chronic conditions. During this roundtable, young adult patients and clinicians discussed how clinical trials often do not adequately address the needs of those aged 18—35, despite the increasing prevalence of chronic conditions among this population. Co-authored by young adults and published in *Open Access Journal of Clinical Trials*, the proceedings include a call for the disaggregation of data to better highlight ages of clinical trial participants and more support for efforts to create a nationally agreed-upon definition of “young adult.”

[Read the proceedings](#)

IN THE NEWS

[A Mother Has Spent Years Caring for Her Special-Needs Child. The Toll Quietly Grew.](#) (*The Washington Post*, 8/16/26)

[People With Disabilities Say Medicaid's Limits on Income Stifle Career Advancement.](#) (*KFF Health News*, 8/13/26)

[The U.S. Relies on Family Caregivers. Millions of Them Are Kids.](#) (*The New York Times*, 8/5/26)

CONFERENCES AND EVENTS

Putting Care at the Center 2026

Putting Care at the Center 2026 is a national conference for health and social care providers, policymakers, consumer advocates, program leaders, payers, and researchers working to improve care for people with complex needs. The conference, taking place in Oakland, CA, is co-hosted by the Camden Coalition's National Center for Complex Health and Social Needs and Kaiser Permanente, with sponsorship from our Foundation. Foundation grantees will be in attendance: [Family Voices of California](#) will lead a workshop, and [Generation Patient](#) will present a Beehive exhibit.

DATES: October 14-16

[Registration and information](#)

Home for Every Child Summit: Inaugural Gathering for Pediatric Palliative Care

The National Center for Pediatric Palliative Care Homes is inviting healthcare leaders, families, policymakers, researchers, and community innovators to come together for the first national gathering dedicated to ensuring every child has access to compassionate, community-based care and support. Registration is free, and the event is virtual.

DATE/TIME: September 24 | 9 AM-Noon PT/Noon-3 PM ET

[Registration and information](#)

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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