

Children and Youth with Special Health Care Needs **NETWORK NEWSLETTER**

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

FROM OUR FOUNDATION

National Survey Reveals Health Care Experiences of CYSHCN

Data on access to care for children and youth with special health care needs (CYSHCN) is limited. Our Foundation contracted with NORC at the University of Chicago to conduct a national survey of parents of CYSHCN to better understand the challenges they face.

NORC has published a series of data briefs resulting from this research. The first brief, *Unmet Need for Home Health Care*, highlights that almost 40% of CYSHCN were not able to access all of the home health care they needed.

[Read the data brief on Home Health](#)

[Learn more about the survey and findings](#)

Upcoming Webinar Explores State-level Support for Accessible Homes for Children with Disabilities

Don't miss it: 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.

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

[Register for the webinar](#)

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

New Grant to Advance Children's Access to Medicaid's EPSDT Benefit

Our Foundation has awarded a grant to the National Health Law Program (NHeLP) to advance understanding and implementation of Medicaid's Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit. NHeLP and its partners will develop practical resources to help pediatricians, advocates, and families better understand EPSDT and strengthen children's access to critical health services.

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NATIONAL POLICY AND RESOURCES

State of Children's Health Dashboard

The Children's Hospital Association released updates to its State of Children's Health Dashboard, designed to improve understanding of children's health issues by state and congressional districts. The dashboard includes statistics about health insurance coverage, mental health/well-being, and access to preventive care.

[See the dashboard](#)

Innovative Approach to Medicaid and Title V Partnership

The Center for Health Care Strategies published a brief, *Maximizing Impact for Maternal and Child Health: Alignment between Medicaid and Title V Programs Framework*, which introduces a practical six-step approach to help states move from siloed efforts to coordinated action.

[Read the brief](#)

H.R. 1 Readiness Tracker Highlights that Strain is Building

The Georgetown Center for Children and Families' H.R. 1 Tracker highlights impacts of the legislation on the health care system. Data from the tracker indicates that strain on eligibility systems is building as work reporting requirement implementation looms. The Center is monitoring several key Medicaid and the Children's Health Insurance Program (CHIP) performance indicators, which indicate that renewals and applications are taking longer to process.

[See the tracker](#)

Guide for Title V CYSHCN Teams Navigating Change

The American Academy of Pediatrics' National Center for a System of Services for CYSHCN released a new *Resource Guide for Implementing Complex System Change in Title V CYSHCN Programs*. Developed in collaboration with the National Maternal and Child Health Workforce Development Center, the guide is designed to help Title V CYSHCN teams plan, implement, and track system-level changes.

[See the Resource Guide](#)

TRANSITION TO ADULT CARE

Recommendations to Congress on Transition to Adult Medicaid Coverage

Got Transition and our Foundation are co-hosting a webinar, *Improving Continuity of Care for CYSHCN in Transition to Adult Medicaid Coverage*.

[Subscribe](#) to our email list.

Commission's (MACPAC) June 2026 [Report to Congress](#) will present findings and recommendations.

DATE/TIME: October 7 | 9 AM PT/Noon ET

[Register for the webinar](#)

CALIFORNIA POLICY AND RESOURCES

Survey Seeks Family Experiences with Specialty and Dental Care

Family Voices of California is conducting a survey of California parents and caregivers of CYSHCN to gather information on experiences accessing pediatric specialty care and dental care.

[Take the survey](#)

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 such as 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](#)

FAMILY ENGAGEMENT

Webinar Series Focuses on Meaningful Family Partnership

Family Voices is hosting a three-part webinar series entitled *The Science and Practice of Family Engagement: Building the Foundation for Meaningful Family Partnership in Systems Transformation*. The first webinar this month, *Building More Responsive Systems*, will explore the science and principles behind authentic family engagement and highlight how partnerships among families, youth, service providers and other partners can transform programs and systems.

DATE/TIME: September 30 | 11 AM PT/2 PM ET

[Register and learn about the series](#)

A New Model for Parent Mentor Programs

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The Parent Mentor Learning Center (PMLC) at Lucile Packard Children's Hospital Stanford 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.

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

[Register for the webinar](#)

CHILDREN WITH MEDICAL COMPLEXITY (CMC)

Benefits of a Medical Home for CMC

A new study published in *Academic Pediatrics* gathers perspectives of families of children with medical complexity on the value of clinics that adhere to medical home principles. The study found that receiving care in a medical home helped reduce the mental load of caregiving for the families in the study.

[Read the article](#)

IN THE NEWS

[Analysis: Rights for People With Disabilities Are Under Attack, But California Can Protect Them](#) (*California Health Report*, 8/17/26)

[School Voucher Programs Don't Offer Much Choice to Kids with Disabilities](#) (*ProPublica*, 9/11/26)

CONFERENCES AND EVENTS

Putting Care at the Center 2026

Putting Care at the Center 2026 is a national conference focused on improving care for people with complex needs. Foundation grantees [Family Voices of California](#) will lead a workshop and [Generation Patient](#) will present a Beehive exhibit. The conference is co-hosted by the Camden Coalition's National Center for Complex Health and Social Needs and Kaiser Permanente, with sponsorship from our Foundation.

DATES: October 14-16 in Oakland

[Registration and information](#)

Home for Every Child Summit

The National Center for Pediatric Palliative Care Homes is hosting its first national

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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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