

Children and Youth with Special Health Care Needs NETWORK NEWSLETTER

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

FROM THE FOUNDATION

CYSHCN National Advisory Board's New Webpage and Member Application

The American Academy of Pediatrics, in partnership with our Foundation, has launched a new webpage for the multidisciplinary Children and Youth with Special Health Care Needs (CYSHCN) National Advisory Board (NAB). Created to coordinate and strengthen the system of services for this population, the NAB brings together experts representing sectors that support and provide services to CYSHCN and their families, young adults, and those with lived experience. The NAB is seeking additional members and the application is now available. Applications will be reviewed on a rolling basis.

[See the NAB webpage and find the member application](#)

Co-learning and Collaborating at AMCHP 2026

Team members from our Foundation's Program for CYSHCN participated in the annual conference of the Association of Maternal & Child Health Programs (AMCHP) last week in Washington, D.C. Sessions provided valuable opportunities to learn together and engage with partners from across the country, yielding new ideas for improving access to care and building and maintaining partnerships.

Follow us on LinkedIn to see more about our time at AMCHP 2026:

- [Co-learning and collaborating with representatives of Title V CYSHCN programs, family partners, and grantees](#)
- [Panel session on "From Conversations to Action: Advancing Humanistic Care at the Systems Level"](#)

[Follow us on LinkedIn](#)

NATIONAL POLICY AND RESOURCES

Medicaid and CHIP Payment and Access Commission (MACPAC) March Report

In its recently released report to Congress, MACPAC offers payment policy recommendations that aim to address workforce shortages in home- and community-based services (HCBS), a Medicaid-funded program that allows CYSHCN to live at home and receive care in community settings rather than institutions. The report also analyzes behavioral health in Medicaid and the Children’s Health Insurance Program (CHIP), the role of Medicaid in supporting justice-involved youth, and access to care for children in foster care.

[Read the report](#)

State Perspectives on Potential Reductions in Medicaid Disability Services

To better understand the range of potential service disruptions for the nation’s roughly 15 million Medicaid beneficiaries with disabilities—and to identify opportunities to support state Medicaid agencies and key stakeholders in addressing potential funding cuts for this population—the Center for Health Care Strategies (CHCS) surveyed Medicaid leaders across 14 Western U.S. states. The survey results provide insights into how states are preparing for potential funding reductions to disability services and where they anticipate the greatest challenges.

[See the results](#)

Also see from KFF:

- [5 Key Facts About Children with Special Health Care Needs and Medicaid](#)
- [5 Key Facts About Medicaid Coverage for People with Disabilities](#)

FAMILY ENGAGEMENT

Family Voices Leadership Conference Next Month

Family Voices Leadership Conference is the premier national gathering for family leaders and family engagement professionals to learn, network, and build their skills to support family engagement in systems of care. This year’s conference will be offered as a virtual experience in English and Spanish to support attendance across the country.

La conferencia virtual está disponible en inglés y español.

DATES/TIMES: April 15-16 | 12 pm-6 pm ET

Preconference: April 13-14 | 9 am-5 pm ET

[Register and learn more](#)

NICU Family Advisory Council Toolkit

The California Perinatal Quality Care Collaborative (CPQCC) created a toolkit to help Neonatal Intensive Care Unit (NICU) staff and families build and sustain Family Advisory Councils (FACs) within their local hospitals. The toolkit, supported by our Foundation, includes actionable strategies to create a successful NICU FAC or to improve an existing one.

CHILDREN WITH MEDICAL COMPLEXITY (CMC)

[Addressing the 'Unseen and Undervalued' Administrative Work of Families with CMC](#)

The high-intensity coordinated care required for CMC includes a substantial administrative workload borne by parents and caregivers. A new commentary in *Pediatrics & Child Health* illustrates the immense scope of caregiver administrative labor for CMC and underscores the disproportionate impact on those facing structural inequalities. The authors also offer a call to action across research, clinical practice, health systems, and policy. Subscription required for full article access.

[Read the abstract](#)

[Families Comment on Medical Device Design Flaws for CMC at Home](#)

CMC are a growing population whose multisystem conditions often require reliance on in-home medical devices. A newly released synthesis of interviews with English- and Spanish-speaking parents of CMC outlines multiple issues that families face while operating in-home medical devices, raising concerns about safety risks and negative impacts on the health of CMC. The authors suggest that future work incorporate user input into tailoring both medical product design and insurance coverage.

[Read the article and watch a video abstract](#)

[Complex Care Journal Club Podcast Series](#)

The Complex Care Journal Club Podcast is a monthly series hosted by pediatricians who care for CMC. Run by *OPENPediatrics*, the podcast discusses emerging evidence in complex care with authors of recently published research and explores implications for clinical practice for the interprofessional care team. Clinicians, advocates, researchers, and patients and families are encouraged to engage and provide feedback.

[Listen to the podcast series](#)

TRANSITION TO ADULT CARE

[Town Hall on Young Adults with Chronic Conditions Leading Systems Change](#)

Following a [series of roundtable discussions](#) over the past year, which explored the most pressing systemic challenges facing young adults with chronic and rare conditions, Generation Patient will host a virtual town hall to walk through the roundtable model of multidisciplinary collaboration, share the key themes that emerged, and discuss the process of young adult patients leading authorship for peer-reviewed publications. The roundtable series and this town hall are supported by our Foundation.

DATE/TIME: April 23 | 12:00 pm - 1:00 pm ET

[Register for the virtual town hall](#)

[Learn more about the roundtable series](#)

Adult-size Changing Tables to be Required at Major Airports; Feedback Requested

Many airports will soon be required by the 2024 Federal Aviation Administration Reauthorization Act to provide changing tables for individuals with disabilities. Federal officials are looking for input on how to implement the new mandate. The U.S. Access Board is [accepting feedback](#) on the development of technical standards for the new universal changing stations through **April 20**. Learn more in *Disability Scoop* (limited number of free articles available without subscription).

[Read the Disability Scoop article](#)

[Go to the feedback form](#)

CALIFORNIA POLICY AND RESOURCES

Family Voices of California Summit Next Week

Registration is still open for virtual participation in the Family Voices of California's 2026 Hybrid Health Summit: *Navigating Health for California's Kids*. The summit, sponsored by our Foundation, brings together a range of stakeholders—from parents to policymakers—to explore critical topics and policies shaping services for CYSHCN. All sessions will be available online via Zoom.

DATE/TIME: March 23 | 9 am-4 pm PT

[Register here](#)

Help Identify Data Gaps Impacting Child Health and Well-Being

KidsData is seeking feedback from families, researchers, policymakers, and others on where current health and well-being data may be lacking for CYSHCN and other key populations—and how the site's current data offerings could better align with users' needs through more detailed, disaggregated information about specific demographic groups. Complete KidsData's short questionnaire by **March 24**.

[Go to the questionnaire](#)

If you prefer to have a conversation, email KidsData@prb.org.

Survey Seeks Parent and Caregiver Input on California Children's Services Program

The National Health Law Program (NHeLP) California Children's Services (CCS) Family Engagement Survey seeks to better understand family and caregiver experience with accessing services for their children through the CCS program. This data will be used to inform NHeLP's policy work and advocacy to improve the CCS program. The survey can be completed in English

or Spanish and is open through **April 30**. NHeLP will raffle three \$50 gift cards to all participants.

[Go to the survey in English](#)

[Ir a la encuesta en español](#)

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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