

Children and Youth with Special Health Care Needs NETWORK NEWSLETTER

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

FOUNDATION NEWS

2025 Foundation Highlights

Here are highlights from our grant-funded work and partnerships in 2025.

National:

- **Moving the Needle on Ableism Research:** The [DIVERSE Collective](#) at the University of Pittsburgh advanced the field's understanding of issues facing children with disabilities through two publications:
 - [Health Care Cost Concerns and Hardships for Families of Children with Disabilities](#)
 - [Measuring Childhood Disability Using the National Health Interview Survey](#)
- **Flipping the Script with Family Partners:** Family-Led Academic Grand (FLAG) Rounds, an educational webinar series hosted by the University of Wisconsin–Madison and The Bluebird Way Foundation, was led and presented by families—flipping the traditional Grand Rounds model and positioning families as medical educators who share their experiences of ableism with medical students and residents to heighten awareness about this issue. [See all five session recordings.](#)
- **Investigating Gaps in the Transition from Adolescent to Young Adult Care:** An article in the *American Journal of Preventive Medicine*, authored by colleagues at Got Transition of the National Alliance to Advance Adolescent Health, described the gaps in the transition to adult health care that may lead to missed opportunities for health promotion, intervention, and care management. [See the article.](#)
- **Identifying State Priorities and Solutions for CYSHCN:** The National Academy for State Health Policy (NASHP) published a brief summarizing states' priorities and approaches for this population, including systems integration, access to specialty care, and family caregiver supports, and provided examples of initiatives led by states. [See the brief.](#)

California:

- **Understanding Peer Support:** In partnership with Mathematica, our Foundation supported a qualitative study on referrals to peer support for families in pediatric subspecialty practices, which was published in the *Maternal and Child Health Journal*. [Read the article.](#)
- **Assessing Implementation Challenges and Opportunities for Enhanced Care Management:** In partnership with the California Health Care Foundation and Goodwin Simon Strategic Research, we supported a survey of staff who implement CalAIM (California Advancing and Innovating Medi-Cal) on challenges and opportunities for

enhanced care management for families in the California Children's Services population of focus. [Read the issue brief.](#)

HOME HEALTH CARE

Home Health Care Experts Emphasize Need for Advocacy

Our Foundation recently hosted a panel focused on challenges accessing home health care for children with complex health needs. Pediatrician, researcher, and parent perspectives offered insights into common barriers families face in the home setting and the complex systems they must navigate to obtain needed medical equipment, home modifications, and care for their children. The panelists emphasized the importance of engaging in advocacy that combines policy-driven solutions with lived experience as a strategy for systems-level change. The film [Feels Like Home](#) informed the discussion, shedding light on the challenges families face in modifying their homes to care for children with complex health needs.

[Read more about the panel on LinkedIn](#)

[Learn about our grant supporting home modification policy research](#)

Panelists pictured (left to right): Moderator Rebecca Cormack, Program Associate at the Foundation; Crystal Thomas, Parent Navigation Program Lead at Children's National Hospital, Dr. Rebecca Seltzer; Associate Professor of Pediatrics at Johns Hopkins School of Medicine; and Dr. Ryan Padrez, Clinical Associate Professor of Pediatrics at Stanford University's Division of General Pediatrics.



NATIONAL POLICY AND RESOURCES

Data Brief: National Survey of Children's Health

A newly issued data brief from the Maternal and Child Health Bureau provides 2022–2023 updates on the experiences of CYSHCN from the National Survey of Children's Health. The brief features data on the prevalence of special health care needs, child and caregiver well-being, family impacts, and health care access and quality.

[Read the brief](#)

Assessing and Expanding the Capacity of the Pediatric Health Care Workforce

The population of children and youth with chronic and complex needs in the U.S. continues to rise, and states are simultaneously experiencing a reduced health care workforce in many areas. A new brief, produced by the National Academy for State Health Policy with support from our Foundation, explores how states are addressing health care workforce challenges, including in pediatric primary and subspecialty care.

[Read the brief](#)

JAMA Health Forum on Variability in Insurance Adequacy for CSHCN Covered by Medicaid

A Research Letter in *JAMA Health Forum* investigated inadequate health insurance coverage among children with special health care needs (CSHCN). Medicaid is the primary insurer for nearly half of CSHCN, however there is substantial variability in the quality and continuity of coverage across states. Quantifying state-to-state variation and predictors of Medicaid insurance continuity and adequacy among CSHCN can inform states considering changes to their Medicaid programs.

[Read the article](#)

CALIFORNIA POLICY AND RESOURCES

2026 California Children's Report Card

Children Now released the 2026 California Children's Report Card grading the state on its performance in supporting better outcomes for children from the prenatal period through age 26 and offering recommendations to California's leaders on how to help children thrive. It includes data on the needs of and investments in CYSHCN.

[See the Children's Report Card](#)

Recap: California Children's Services Advisory Group Meeting

At its January 21 meeting, the California Children's Services (CCS) Advisory Group reviewed 2025 accomplishments and outlined 2026 priorities. Topics included improving the transition-to-adulthood experience, streamlining and expanding CCS provider paneling, examining Whole Child Model enrollment, redesigning quality metrics, and sharing the Department of Health Care Services' new Enhanced Care Management Technical Assistance Resource. DHCS also provided

updates on Medi-Cal Rx Pediatric Pharmacy Benefits and the potential impact of freezing new Medi-Cal enrollments for CCS members ages 19 and 20 with unsatisfactory immigration status. Meeting materials will be posted online; the next meeting is April 15.

[Learn more about the CCS Advisory Group](#)

CHILDREN WITH MEDICAL COMPLEXITY (CMC)

New Framework to Advance Humanistic Care for CMC

The ROOTED IN HUMANITY Urgent Action Framework, created by the Boston University Center for Innovation in Social Work and Health and supported by our Foundation, empowers changemakers to reshape systems of care in practical ways that matter to CMC, families, and clinicians. The framework was co-developed by family partners and clinician faculty using learnings from [The Future of Care for CMC Virtual Café Series](#) and shares actionable strategies, tools, and stories.

[Learn more](#)

FAMILY ENGAGEMENT

Tip Sheet: Ensuring Trauma-Informed Engagement

Family Voices published a tip sheet to ensure that trauma-informed principles are applied in advisory and system-level engagement with families of CYSHCN. Guidance includes the use of the Family Engagement in Systems Assessment Tools (FESAT), a body of work that the Foundation has long supported to promote meaningful family-professional partnerships.

[See the tip sheet](#)

BEHAVIORAL HEALTH

How State Medicaid Policies Shape Access to Behavioral Health Care

Medicaid is the primary payer for behavioral health services for children and youth, yet access to and coverage of behavioral health resources vary by state. To understand these variations, the National Academy for State Health Policy analyzed Medicaid behavioral health therapy coverage in all 50 states and D.C. A new brief highlights key findings on diagnostic criteria, billing approaches, and limits that affect children and youth's access to behavioral health therapies.

[Read the brief](#)

CONFERENCES AND EVENTS

NHeLP's 2026 Health Advocates Conference: Early-Bird Pricing Ends January 31

Registration is open for the National Health Law Program's 2026 Health Advocates Conference. The online gathering brings together leading health advocates, attorneys, and policymakers to address health care issues affecting low-income and underserved communities. Early-bird pricing is available through **January 31**.

CONFERENCE DATES: March 3-5

[Registration and details](#)

AMCHP Annual Conference: Early-Bird Pricing Ends January 23

The Association of Maternal and Child Health Programs Annual Conference, in Washington, D.C., is one of the largest gatherings of maternal and child health professionals in the United States. Early-bird pricing is available through tomorrow, **January 23**.

CONFERENCE DATES: March 7-10

[Registration and details](#)

Call for Proposals: Putting Care at the Center 2026

The Camden Coalition is accepting applications to present a workshop at *Putting Care at the Center 2026*, to be held in Oakland, CA. Applications are due by **March 4**. Complex care and complex health and social needs are at the core of the conference.

CONFERENCE DATES: October 14-16

[Learn more to apply](#)

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