

Children and Youth with Special Health Care Needs NETWORK NEWSLETTER

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

Dear Readers:

We wish you a joyful holiday season and a happy, healthful new year! Please note that our January newsletter will come out January 22, 2026, due to the holidays.

FOUNDATION NEWS

New Grant to Address Barriers to Health Care for CYSHCN, Support Advocacy

In this time of historic cuts to Medicaid, and related significant policy changes, advocacy is needed to safeguard access to systems and services for CYSHCN. Our Foundation has awarded a new grant to the National Health Law Program to continue its work to advocate for CYSHCN and prioritize health care coverage for this population, to ensure that families' voices and legal rights remain central to policy decisions.

[Read about the grant](#)

FAMILY ENGAGEMENT

Interactive Webinar: Community Reflection and a Toolkit for Strengthening Hospital Patient and Family Advisory Councils

The Institute for Patient- and Family-Centered Care (IPFCC) will host an informal conversation to highlight the collective effort of two learning communities made up of 26 children's hospitals across North America working to embed community representation and health equity into Patient and Family Advisory Councils. The IPFCC team will introduce a toolkit used to guide the efforts of the learning communities and share ways to take action to ensure every community voice is heard. This work was supported by our Foundation.

DATE/TIME: January 20, 2026 | 12 – 1 pm ET/ 9 – 10 am PT

[Register here](#)

How Disability Identification Shapes the Lives of Children and Families

A recent article in *JAMA Pediatrics* discussed the limitations of tools used to measure childhood disability. In response, Cara Coleman, a Foundation grantee through the Bluebird Way Foundation, has written a commentary featuring parents' perspectives on how the complexity of measuring their child's disability affected the child's life, education, resources, services, and more. Coleman, a nationally recognized family partner and advocate, calls for more attention to the far-reaching effects on children and families of how disability is measured. The *JAMA Pediatrics* article was published by Foundation grantee the DIVERSE Collective.

[Read the commentary](#)

[See the *JAMA Pediatrics* article](#)

In Final FLAG Rounds, Families Discuss Being Dismissed by Clinicians

During the fifth and final session of Family-Led Academic Grand (FLAG) Rounds, family members serving as faculty told stories of being dismissed while seeking health care for their children with disabilities. The family faculty discussed strategies for enhancing professionalism and communication, and reflected on the importance of partnering with clinicians despite experiencing ableism in the health care setting. FLAG Rounds is a national, quarterly educational series led and presented by families. The FLAG Rounds series was supported by our Foundation.

[Watch the recording](#)

[See the full series of recordings](#)

CHILDREN WITH MEDICAL COMPLEXITY (CMC)

Families of CMC Seek Broader Definitions of Family Well-Being

Family well-being (FWB) is generally described as occurring when all family members are safe, healthy, and have chances for educational advancement and economic mobility. A new Perspectives article in *Pediatrics* suggests that families of children with complex conditions question the validity of standard definitions, calling them too narrow and not reflective of many families' experiences. The authors propose a framework for defining and improving FWB, informed by crowdsourced views of families of children with medical complexity. They call for a broader definition of FWB to capture what matters to families, and to encourage changes to clinical care, education, and policy that are informed by family insights. This work was supported by our Foundation.

[Read the article](#)

Also see the American Academy of Pediatrics Journals Blog: [Family Connections with Pediatrics - Family Well-Being: What Matters Most to Families of Children With Medical Complexity?](#)

Call for Nominations: Complex Care Lifetime Achievement Award

The Systems and Policy Research Network for CYSHCN and Their Families is now accepting

applications for the 2026 Pediatric Complex Care Achievement Awards. The Lifetime Achievement and Mid-Career awards celebrate individuals who dedicate their lives to improving the lives of children with medical complexity through exceptional and lasting contributions, including lived experience, clinical care delivery, advocacy, policy, administration, research, and education/training. Application materials are due by **January 15, 2026**.

[Learn more and make a nomination](#)

NATIONAL POLICY AND RESOURCES

How Title V CYSHCN Programs Can Advance the System of Services

Title V programs around the country strive to improve the system of services for CYSHCN through a variety of initiatives. The National Center for a System of Services for CYSHCN has published a “From the Field” section of its website highlighting some of these innovative programs that address emerging policy issues, priority needs, and cross-sector partnerships. These real-world examples can assist states or jurisdictions in their own program development.

[See From the Field Vignettes](#)

Comment Period Open on Proposed Changes to the National Survey of Children's Health

The National Survey of Children's Health (NSCH) is designed to produce data on the physical and emotional health of children under 18 years of age who live in the United States. It provides specific data on CYSHCN. Public comment on proposed revisions to the survey must be received by **February 3, 2026**.

[Read more and submit comments](#)

Also see to [learn more about the NSCH](#).

CALIFORNIA POLICY AND RESOURCES

'Future of Medi-Cal Commission' to Create 10-Year Modernization Roadmap

A recently launched Future of Medi-Cal Commission brings together health care leaders from across California to develop a 10-year vision and roadmap to modernize and protect Medi-Cal, which provides vital health coverage and services for half of all CYSHCN in the state. The Commission will culminate in a set of concrete recommendations in early 2027.

[Learn more](#)

SPECIAL EDUCATION

- California Students with Disabilities Face 'Terrifying' Special Ed Cuts after Trump Changes: [Read the Cal Matters article](#)

- Ed Department Recalls Staffers Who Handle Complaints from Students with Disabilities:
[Read the Disability Scoop article](#) (Registration required)

TRANSITION TO ADULT CARE

Exploring Peer Support Needs, Experiences of Young Adults with Chronic Conditions

A study from Foundation grantee Generation Patient and Boston Children's Hospital surveyed young adults with chronic conditions to address a lack of understanding about how this population views peer support and virtual peer-support programming. The results, published in *Health Care Transitions*, found that across different chronic conditions peer support was seen as an unmet need, and that greater availability of virtual peer support programs may help improve the psychosocial well-being of young adults with chronic conditions.

[Read the article](#)

EVENTS

Early Bird Registration for the 2026 AMCHP Annual Conference

The Association of Maternal and Child Health Programs (AMCHP) Annual Conference, March 7-10, 2026, in Washington, D.C., is one of the largest gatherings of maternal and child health (MCH) professionals in the United States. The conference aims to highlight MCH programs' impact at all levels and to provide participants with tools and resources to develop, enhance, and sustain vital programs and services, including those for CYSHCN. Early bird pricing is available through **January 23, 2026**.

[Registration and details](#)

Family Voices 2026 Leadership Conference Scheduled

Family Voices National will host its 2026 Virtual Leadership Conference on April 13-16, 2026. The gathering is the nation's premier conference for family leaders and family engagement professionals to learn, network, and build their skills to support family engagement in systems of care. Title V CYSHCN program staff are encouraged to attend the conference to learn more about enhancing family engagement at the systems level.

[Registration and details](#)

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