

Children and Youth with Special Health Care Needs NETWORK NEWSLETTER

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

NATIONAL POLICY

Judge Blocks Layoffs at Department of Education While Services for Students with Disabilities Remain at Risk

The U.S. Department of Education, including the Office of Special Education Programs (OSEP), has been a target for significant layoffs over the past week as part of the government shutdown. A federal judge temporarily stopped plans to gut OSEP, but advocates say that the future of services for students with disabilities remains uncertain. OSEP is responsible for safeguarding the educational rights of children and youth with disabilities, providing guidance to families, and monitoring states to ensure compliance with the landmark Individuals with Disabilities Education Act (IDEA).

[Read Disability Scoop's coverage](#)

Webinar: Impact of H.R.1 on People with Disabilities

As part of its webinar series, "*What We Know and What Happens Next: OBBBA and its Impact on Health Care Coverage*," the National Health Law Program is helping advocates prepare for the provisions of H.R.1 by providing legal and policy analysis on key topics. An upcoming webinar will focus on H.R.1's impact on people with disabilities, including home- and community-based services, higher out-of-pocket costs, and changes to home equity limits for long-term care.

DATE/TIME: Thursday, October 23 | 11am PT/2pm ET

[Register](#)

What 'Federal Funding Cuts' Really Mean for Health Systems

Becker's Hospital Review published a broad overview of what the passage of H.R.1 means for hospitals and health systems. The article covers the impact in the near and longer term on Medicaid reductions, expiring Affordable Care Act subsidies, Medicare Advantage pressures, drug pricing programs, and National Institutes of Health research funding.

[Read the article](#)

Updated Congressional District Health Dashboard

The Department of Population Health at NYU Grossman School of Medicine released an update to the Congressional District Health Dashboard. The goal of the dashboard is to provide policymakers and community members with an array of actionable, nonpartisan data at the congressional district level. The latest update includes Medicaid enrollment data across all 50 states.

[View the dashboard](#)

Rural Health Transformation Application Process Open

The Centers for Medicare and Medicaid Services released the application for the new [Rural Health Transformation \(RHT\) Program](#), due **November 5**. This program provides states with the opportunity to improve health care access, quality, and outcomes in rural communities. Title V CYSHCN programs can be important partners in preparing and submitting applications, including providing insights on the needs of CYSHCN in rural/frontier communities, offering public comment, and connecting state agencies to lived experience partners.

[Learn more about the program](#)

CHILDREN WITH MEDICAL COMPLEXITY (CMC)

Family-Led Academic Grand (FLAG) Rounds Session Four Recording Available

During the fourth session of FLAG Rounds, family members serving as faculty shared stories of caring for their children with disabilities, highlighting the delicate balance between providing care and the risk of care being forgone. FLAG Rounds is a national, quarterly educational series led and presented by families that flips the traditional Grand Rounds model and positions families as medical educators who share their experiences of ableism with medical students and residents.

[Watch the recording](#)

FAMILY CAREGIVING

New Communications Toolkit to Reach Family Caregivers

The National Academy for State Health Policy developed a toolkit designed as a practical resource for state agencies, community partners, nonprofits, and advocates – anyone who supports family caregivers. It contains ready-to-use templates, sample messaging, and materials to raise awareness, connect caregivers to services, and strengthen public understanding of the caregiver role. This toolkit applies to a range of caregivers, such as those caring for spouses, aging parents, and children.

[See the toolkit](#)

HEALTH CARE TRANSITION

Reframing Health Care Transition: Systems, Relationships, and Independence in Adolescent-to-Adult Care

Foundation grantee Generation Patient recently hosted a roundtable convening of patients, health care providers, and researchers to discuss the transition from pediatric to adult care. In the proceedings, published in *Health Care Transitions*, the authors address barriers identified within clinical settings and at the systems level that hinder health care transition. They also provide recommendations to strengthen this transition.

[Read the Roundtable proceedings](#)

[See the Roundtable series](#)

CALIFORNIA POLICY & RESOURCES

Survey on Experiences With California Children's Services Program

The National Health Law Program (NHeLP) seeks input from English- and Spanish-speaking parents and caregivers of children who are enrolled in the California Children's Services (CCS) Program. The survey findings will be used to inform NHeLP's work to improve the CCS Program. The survey takes about 15 minutes to complete and responses are anonymous. Participants will have the chance to win one of three \$50 gift cards by entering a raffle after completing the survey. Please submit the survey by **November 16**.

[Take the survey in English](#)

[Take the survey in Spanish](#)

California Acts to Protect Access to Preventive Services

Governor Gavin Newsom recently signed into law [AB 144](#), a budget bill that seeks to protect access to health care services for Californians, including preventive screenings and vaccinations. The bill includes two important provisions that counter efforts by the U.S. Department of Health and Human Services to dismantle the preventive services framework.

Also see: [California Takes Bold Action to Protect Access to Preventive Services](#), from National Health Law Program.

Recap: California Children's Services Advisory Group Meeting

At its October 15 meeting, the CCS Advisory Group discussed progress on the CCS priorities for 2025, including transition to adulthood, the Whole Child Model Expansion, Enhanced Care Management, referral and enrollment analysis, and other topics. The Department of Health Care Services also provided updates on pharmacy benefits and program guidance documents. The agenda and presentation slides can be found on the Advisory Group's [website](#). The next meeting is scheduled for January 21, 2026.

[Learn more](#)

How California Families Are Confronting Medicaid Cuts

California families are bracing for forthcoming cuts to Medicaid and food and nutrition programs. Many are already feeling the impacts, while public and private health care providers are preparing for federal funding cuts. The *Los Angeles Times* shares the experiences of individuals and families in California, including the family of a child with cerebral palsy, as well as how officials are responding.

[Read the article](#)

RESOURCES

***JAMA Pediatrics* Article on Measuring Disability Now Available**

The full article, “Measuring Childhood Disability Using the National Health Interview Survey,” is now available in *JAMA Pediatrics*. Led by Foundation grantee the [DIVERSE Collective](#), this first-of-its-kind study reveals that childhood disability prevalence estimates varied between 11% and 23%, depending on the disability identification strategy used.

[Learn more and access the article](#)

KFF Releases Health Policy 101 Updated Chapters

KFF has published updated chapters for its 2025 *Health Policy 101*, an online resource for faculty and students interested in health policy. It includes chapters on the Affordable Care Act, Medicare, Medicaid, Health Care Costs and Affordability, and Race, Inequality, and Health – among other topics.

[See the resource](#)

EVENTS



Our Foundation Staff Attending Putting Care at the Center 2025 This Week

Our Foundation is a sponsor of *Putting Care at the Center 2025*, "Complex Care: Meeting the Moment," a conference hosted by the Camden Coalition's National Center for Complex Health and Social Needs. Attendees can connect with Foundation Program Associates at our table at the conference Beehive.

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