Lucile Packard Foundation
Children's Health

May 21, 2026

Children and Youth with Special Health Care Needs
NETWORK NEWSLETTER

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

NATIONAL POLICY AND RESOURCES

Analyzing the Troubling Decline in Child Medicaid and CHIP Enrollment

A new blog from the Georgetown University Center for Children and Families highlights a concerning decrease in child enrollment in Medicaid and the Children's Health Insurance Program (CHIP). Between January 2025 and January 2026, child enrollment dropped by 1.5 million, and this trend is expected to continue. The blog explores the potential reasons for and significance of the decreases and notes the potential impact that work reporting requirements and other provisions of H.R. 1 could have on future children's coverage.

Read the blog

Also see: Families Caring for Disabled Relatives Face Unthinkable Choices as Medicaid Cuts Loom

---

Tip Sheet on Medical Frailty Exemptions to Federal Medicaid Work Requirements

With federal Medicaid work requirements taking effect next year, states are preparing for a significant shift in how members, including young adults with special health care needs, qualify for and maintain coverage. A new tip sheet on medical frailty from the Center for Health Care Strategies provides practical strategies to help states prepare.

See the tip sheet

Also see:

- Explainer from the American Association of People with Disabilities on New Medicaid Work Reporting Requirements
- Recommendations for Mitigating Harms to People with Disabilities, Older Adults, and Caregivers from Medicaid Work Requirements from the National Health Law Program

---

New in JAMA: Mapping Meaningful Populations of CYSHCN

A new publication in *JAMA Health Forum* explores distinct, policy-relevant subpopulations within the large and heterogeneous population of CYSHCN. Analyzing data from the National Survey of Children's Health, researchers identified four specific subpopulations of CYSHCN and recommend consideration of policies and programs tailored to the unique needs of these subpopulations.

Read the article

CALIFORNIA POLICY AND RESOURCES

CA Bills Aim to Protect Medi-Cal Recipients from Federal Cuts

Health care advocates spoke at the State Assembly in Sacramento last week in support of a series of bills designed to keep people enrolled in Medi-Cal. "Medi-Cal is not an abstract policy," said Nancy Netherland of Family Voices of California. "It's therapies, medications, and wraparound services that allow children with complex health care needs to remain safely at home and in their communities." The bills discussed aim to streamline Medi-Cal eligibility determinations to reduce the administrative burden, cap cost-sharing, and expand outreach to those impacted by federal changes.

Learn more

California Endowment Webinar on the May Revise, H.R. 1, and California's Safety Net

As California lawmakers weigh the governor's May Budget Revise ahead of the June 15 budget deadline, federal H.R. 1 changes are reshaping the choices ahead — with major implications for health and nutrition programs that families across the state rely on, including families of CYSHCN. The California Endowment's *Policy Perspectives* series is hosting a webinar exploring how these federal and state decisions intersect, what's putting coverage at risk, and what the ripple effects mean for communities across California.

DATE/TIME: June 3 | 10-11:15 AM PT

Register

FAMILY ENGAGEMENT

Take Survey of Peer Support in Pediatric Health Care Settings

The Parent Mentor Learning Center (PMLC), housed at Lucile Packard Children’s Hospital Stanford, is recruiting peer mentor program volunteers, staff, and leadership across the country to complete a survey on the current state of peer mentor programs in pediatric health care settings. The survey asks about the structure, characteristics, practices, and processes of peer mentor programs and aims to gauge respondents' interest in developing and improving these programs. Survey results will guide future PMLC activities and will be shared on the PMLC website. This work is supported by our Foundation.

Take the survey

CHILDREN WITH MEDICAL COMPLEXITY (CMC)

Systems and Policy Research Network Offers Module on Family Well-Being

Family well-being (FWB) is a paramount outcome for all families caring for children with medical complexity (CMC). Emerging evidence suggests that families of CMC question the validity of existing FWB definitions and measures, identifying them as too narrow, biased toward viewing CMC as a "burden", and not reflective of the range of family experiences. The Systems and Policy Research (SPR) Network's new module explores what determines FWB, according to families raising CMC across the United States. The module is built for the range of stakeholders that impact FWB: caregivers, clinicians, policymakers, educators, and researchers.

See the module

2026 Pediatric Complex Care Achievement Awards

The SPR Network has announced the 2026 Pediatric Complex Care Achievement Awards, which celebrate individuals who dedicate their lives to serving children with medical complexity.

- **Lifetime Achievement Awards:** Carolyn Allshouse and Lauren Agoratus
- **Mid-Career Achievement Award:** Dr. Eyal Cohen

Learn more about their work and contributions

Foundation Grantee Recognized for Study on Black Caregivers of CMC

Ashley Nmoh, a member of a research team at Duke University School of Medicine, recently received the *Trainee Research Abstract Award for Students* at the Pediatric Academic Societies Meeting in Boston. The work Ashley presented, *"Centering Black Voices: How Discrimination Shapes Care-Seeking and Communication for Black Caregivers of Children with Medical Complexity,"* is supported by a grant from our Foundation.

See more on LinkedIn

Read about the grant

FOSTER YOUTH

Study Assesses Experiences of CYSHCN in Foster Care

More than 1 in 4 children and youth in foster care have a special health care need (SHCN), and children with special needs enter foster care at higher rates than their peers, according to a recent report from Child Trends. Once in foster care, this population has different experiences than those without SHCN, including longer stays in foster care, multiple placements, and exiting foster care permanently at lower rates. In addition, research shows that children and youth in foster care often lack access to appropriate health care, both before and during their placement.

Read the report

TRANSITION TO ADULT CARE

Ageism, Ableism, and Other Biases in Health Care: The Impact on Young Adult Patients

Generation Patient's Roundtable series on Young Adults with Chronic Medical Conditions, funded by our Foundation, explores the most pressing systems-level challenges impacting young adults living with chronic and rare conditions. Co-authored by young adults with chronic conditions and members of the project team, proceedings from the third Roundtable, published in *Health Care Transitions,* examine dismissal, and ableist and ageist biases toward young adult patients, highlighting both patient and provider perspectives on their consequences. The proceedings also address misconceptions of young adults with chronic illness and the power imbalance that can sometimes exist between providers and young adult patients.

Read the proceedings

Webinar Recording: Advancing Systems Change for Young Adults with Chronic Conditions

As part of Generation Patient's Roundtable series, described above, presenters in the eighth virtual Roundtable outlined the process of multidisciplinary collaboration, shared key themes that emerged from the Roundtable series, and discussed the process of young adult patients leading authorship for peer-reviewed publications.

Watch the recording

See the full Roundtable Series

CONFERENCES AND EVENTS

National Academy for State Health Policy Annual Conference Registration Open

Registration is open for the National Academy for State Health Policy's 2026 Annual Conference, September 28–30, in New York City. Join more than 1,000 health policy leaders from all 50 states and Washington, D.C., for three days of forward-looking discussion, practical learning, and cross-sector collaboration with the theme *Health Policy State of Mind,* including sessions on children's health and home and community-based services.

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!

To see past issues, visit our Newsletter Archive. If you were forwarded this newsletter and would like to receive it monthly, click the subscribe button below.

Subscribe to CYSHCN News

Follow us on LinkedIn