

## Children and Youth with Special Health Care Needs NETWORK NEWSLETTER

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

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### FROM OUR FOUNDATION

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#### **New Grants Focus on Ableism Research and Protecting Access to Care**

The Foundation has awarded two new grants this fall encompassing the following work:

The University of Utah will lead a three-year research project with the University of Pittsburgh and the University of Wisconsin-Madison to create a first-of-its-kind, reliable measurement tool of ableism in pediatric health care. Once developed and tested, this tool will be publicly available and enable future efforts to understand and address ableism.

The National Academy for State Health Policy (NASHP) will create a State Health Policy Center to provide critical support services and a virtual learning community for state health officials at a time of unprecedented funding cuts to Medicaid and other public health programs. State health officials across the country will have access to expert consulting including policy analysis, guidance, and facilitated peer learning.

[Learn more about our new grants](#)

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### NATIONAL HEALTH CARE POLICY

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#### **H.R.1 Implementation Roadmap: A Tool to Support States**

After the passage of the budget reconciliation legislation (H.R.1) in July, sweeping changes to Medicaid and the Affordable Care Act Marketplace programs are projected. Manatt Health has created an Excel tool to provide an integrated view of implementation dates for Medicaid, the Children's Health Insurance Program, Marketplace, and Medicare provisions in H.R.1. This tool is intended to support states in planning for timely implementation of reconciliation-driven health policy changes, and effectively communicating potential impacts to communities and key stakeholders.

[See the roadmap](#)

## How Medicaid Strengthens Pediatric Screenings Through School-Based Health Care

For children who face challenges accessing health care, school may be the most consistent — or only — place where they can receive essential health services. The Center for Health Care Strategies' blog shared five key strategies for states to strengthen pediatric screenings in school-based environments.

[Read the blog](#)

## **CHILDREN WITH MEDICAL COMPLEXITY (CMC)**

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## ***JAMA Pediatrics*: Measuring Childhood Disability Using the National Health Interview Survey**

A first-of-its-kind study published this month in *JAMA Pediatrics* provides prevalence data for four strategies to identify children with disabilities, using questions from the 2019-2022 National Health Interview Survey (NHIS). The research team, led by Foundation grantee the DIVERSE Collective, determined that prevalence estimates varied between 11% and 23% depending on which disability identification strategy was used. Results also revealed differences in prevalence of disability based on gender, race and ethnicity, and poverty level. The authors conclude that since there is limited overlap in prevalence estimates across strategies, caution is recommended when interpreting results based on a single identification strategy. The full article will be available via open access in October.

[Read the abstract](#)

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## **CYSHCNet Has New Name and Website**

The Children and Youth with Special Health Care Needs National Research Network (CYSHCNet) has reintroduced itself with a new name and identity, the Systems & Policy Research Network (SPR Network). The renamed network is focused on conducting research, improving systems of care, and developing policy with families at the center.

[Learn more about the SPR Network](#)

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## **Family-Led Academic Grand (FLAG) Rounds Series Continues**

The fourth session of FLAG Rounds, “Walking the Line: Giving Care/Forgone Care (and Everything in Between)” is part of a national, quarterly educational series. FLAG Rounds flip the traditional grand rounds model and embrace family as educators. Family Faculty present an aspect of their “case” as a story and then offer strategies to develop knowledge, skills, and abilities to perform, or partner in, the essential activities of care of children with disabilities and/or medical complexity. The Rounds are approved for continuing education credits.

**DATE/TIME:** Thursday, September 25 | 10-11am PT/1-2pm ET

[Register](#)

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## **CALIFORNIA POLICY & RESOURCES**

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### **More Accessible Medi-Cal Website**

California’s Department of Health Care Services launched a new website to help Medi-Cal members and potential new members find information. The website is accessible and mobile-friendly: pages are written in clear, plain language and are supported in multiple languages.

[View the new site](#)

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## **Fact Sheet Series from NHeLP on How H.R.1 Will Impact CA Budget**

The National Health Law Program (NHeLP) has developed a fact sheet series to provide an overview of the key changes to Medi-Cal and Covered California under both the H.R.1 and the FY2025-26 California budget bills. The series covers cost-sharing, work requirements, eligibility, enrollment, affordability, and more, with later installments on the way.

[See the fact sheets](#)

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## **HIPAA & FERPA Toolkit and Fall Webinars**

California Health and Human Services Children and Youth Behavioral Health Initiative (CYBHI) released a toolkit and webinar series on how HIPAA (Health Insurance Portability and Accountability Act) and FERPA (Family Educational Rights and Privacy Act) apply in different school-behavioral health partnerships. The toolkit identifies when and how information can be shared and provides real-world scenarios and tools for common challenges. An accompanying webinar series will be held in September, October, and November.

[Access the toolkit and register for the webinars](#)

## **FAMILY CAREGIVING**

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## Family Caregivers Under Increasing Strain

The number of family members providing care for people with complex medical conditions or disabilities is on the rise, according to a new report from the National Alliance for Caregiving. This *Disability Scoop* article notes that family caregivers are coping with poor health, financial strain, and isolation. *Requires login.*

[Read the article](#)

**Also see:** [More Americans Are Family Caregivers; States Struggle to Help Them, Report Finds.](#) From *Stateline*.

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## Perspectives of Spanish-speaking Caregivers on Pediatric Patient Portal Use

A recent study, supported by the Foundation and published in *Applied Clinical Informatics*, looked at how Spanish-speaking caregivers, particularly caregivers of children with chronic conditions, use patient portals. Through interviews with caregivers, the research team from Stanford University School of Medicine identified perceived benefits of patient portals, facilitators that improved use, and barriers that negatively affected use. The authors conclude that while patient portals are beneficial for managing a child's health care, language barriers and differences in digital and health literacy are significant challenges. The authors also highlight the need for health systems to provide language concordance and consider innovative solutions to advance equitable healthcare access.

[Read the article](#)

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## HEALTH CARE TRANSITIONS

### Gaps in Care Among Adolescents and Young Adults

As adolescents and young adults transition into adulthood, they are confronted with many challenges. An article in the *American Journal of Preventive Medicine* describes a study of gaps in care that may lead to missed opportunities for health promotion and maintenance, early intervention, and acute and chronic care management. Results revealed that more than 1 in 4 young adults experienced a care gap of 1 or more years and that sociodemographic factors were associated with care gaps. The authors conclude that stakeholders should prioritize supporting adolescents and young adults with, and at risk for, lapses in coverage and care. The Foundation supported this study.

[Read the article](#)

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### Disparities in Health Care Transition Preparation Among US Youth

The National Alliance to Advance Adolescent Health, in partnership with Family Voices and the Maternal and Child Health Bureau, has published a new article in *Pediatrics* that examines individual, family, and health system characteristics to determine which are

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receive guidance on health care transition and offers clinical and system-level approaches to help health care providers better prepare youth for this critical shift.

[Read the article](#)

## EVENTS

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### Putting Care at the Center 2025 - Complex Care: Meeting the Moment

[Putting Care at the Center 2025](#) is a national conference for health and social care providers, policymakers, consumer advocates, program leaders, payers, and researchers working to improve care for people with complex health and social needs. The conference is co-hosted by the Camden Coalition's National Center for Complex Health and Social Needs and CareOregon. Workshop sessions include a focus on children, youth, and families with complex needs. The Foundation is a conference sponsor.

**DATES:** October 15-17, 2025

[Register](#)

## WE WANT TO HEAR FROM YOU

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