

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

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

### **NATIONAL POLICY AND RESOURCES**

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#### **Monitoring Risks for Child and Family Health**

A blog from the Georgetown University Center for Children and Families outlines impending threats to child and family health in 2026 and describes issues the Center is monitoring amid significant changes in the policy landscape. This includes the passage of H.R. 1, also known as the One Big Beautiful Bill Act, which contains major cuts to Medicaid, the program that funds medical care for nearly half of CYSHCN.

[Read the blog](#)

#### **Weekly Advice for Safeguarding Medicaid**

The National Health Law Program has launched *Timely Tips to Safeguard Medicaid*, a weekly series to help advocates navigate Medicaid issues as federal and state agencies move quickly to implement sweeping policy changes stemming from H.R. 1.

[See the weekly tips](#)

#### **KFF Poll: Waning Confidence in CDC, Concerns About Vaccine Changes**

A new poll from KFF, part of its Health Information and Trust Initiative, found that trust and confidence in the Centers for Disease Control and Prevention remains at a low point after changes to recommended childhood vaccines, and that a majority of those surveyed are concerned that the changes will be detrimental to children's health. Immunizations help safeguard those who cannot be vaccinated and are especially important for CYSHCN.

[See the poll results](#)

### **FAMILY ENGAGEMENT**

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#### **Toolkit for Strengthening Hospital Patient and Family Advisory Councils**

Health care organizations that partner with patient and family advisors (PFAs) who represent the communities they serve can deliver more culturally responsive and effective care. However, [prior research](#) shows significant gaps in PFA representation. With a grant from our Foundation, the Institute for Patient- and Family-Centered Care created the *Reflecting Our Community Toolkit* to help hospitals strengthen and sustain diverse Patient and Family Advisory Councils (PFACs) as a means to advance health equity.

[Explore the toolkit](#)

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## Family Voices Leadership Conference

Family Voices' annual conference is the premier national gathering for family leaders and family engagement professionals to learn, network, and build their skills to support family engagement in systems of care. This year's conference, in April, will be offered as a virtual experience in English and Spanish to support attendance across the country. Early bird discount available through **February 27**.

**DATES/TIMES:** April 15-16 | 12 pm-6 pm ET

**Preconference:** April 13-14 | 9 am-5 pm ET

[Register and learn more](#)

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## Next Month: Family Voices of California Hybrid Health Summit

Registration is open for the Family Voices of California's 2026 Hybrid Health Summit: *Navigating Health for California's Kids*. The Summit brings together a range of stakeholders from parents to policymakers to explore critical topics and policies shaping services for CYSHCN. In-person seats are limited at the Sacramento conference venue. All sessions will be available online via Zoom.

**DATE/TIME:** March 23 | 9 am-4 pm PT

[Registration information](#)

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## Bilingual Family Voices of California Virtual Project Leadership Training

Family Voices of California's next Project Leadership cohort begins April 8 with online training in English and Spanish. Project Leadership is an eight-week training that helps families of CYSHCN build confidence and skills to advocate for children and the community, understand how health care systems work, and use lived experience to create meaningful systems-level change. This program, for families living in California, is ideal for parents and caregivers who are new to advocacy—or those looking for a refresher and renewed momentum. The Spanish-speaking cohort has closed registration; however, contact information is available at the link below.

**START DATE:** April 8

**WEEKLY TIMES:** Wednesdays | 6-8 pm PT

[Register for the English-speaking cohort](#)

## HEALTH EQUITY

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### Understanding Language Barriers for Caregivers' Use of Patient Portals

Patients and caregivers widely use patient portals to access medical records, yet significant disparities persist in portal usage among patients who speak languages other than English. A study published in *JAMIA Open* examined how Spanish-speaking caregivers of children with chronic conditions navigate language barriers in patient portals and gathered their perspectives on improving translation. Led by researchers at the Stanford School of Medicine, this work was supported by a grant from our Foundation.

[Read the article](#)

## CHILDREN WITH MEDICAL COMPLEXITY (CMC)

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### Medical Disenrollment Among Young Adults With and Without Complex Medical Conditions

Eligibility for health insurance shifts as children transition to adulthood, creating risk of coverage loss and disruption. For youth with complex health needs, this instability can be especially harmful. A new *JAMA Pediatrics* article highlights a study led by the University of Chicago, supported by a grant from our Foundation, which examined Medicaid disenrollment around age 19 for individuals with and without complex medical conditions across 46 states and Washington, D.C. The findings underscore critical gaps in Medicaid coverage during the transition to adulthood and highlight variation by state and by condition.

[Read the article](#)

Also see [a summary of the study from the University of Chicago](#).

## MENTAL AND BEHAVIORAL HEALTH

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### The Role of Certified Community Behavioral Health Clinics in Improving Outcomes for Children and Families

A new brief from the Center for Health Care Strategies outlines how Certified Community Behavioral Health Clinics can support children's behavioral health services within a System of Care (SOC) framework and provides recommendations for policymakers and community providers on aligning criteria with SOC values and principles. States and jurisdictions can utilize this information to strengthen systems that support child and family well-being, quality of life, and access to services for CYSHCN.

[Read the brief](#)

## TRANSITION TO ADULT CARE

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### Coming in May: Pediatric to Adult Health Care Transition Summit

Registration is open for the 2026 Gillette Children's Pediatric to Adult Health Care Transitions Summit, a hybrid event held in Saint Paul, MN and online. Hosted by Got Transition and the Minnesota Department of Health, the theme is *Connection: Humanizing the Health Care Transition from Pediatric to Adult Serving Systems*. The summit is free for family caregivers with a fee for other attendees.

**DATE:** May 18 | 9 am-4 pm CDT

[Registration and more information](#)

## PALLIATIVE CARE

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### A National Policy Framework for Supporting Pediatric Palliative Care Homes

The National Center for Pediatric Palliative Care Homes released a new National Policy Framework to help policymakers better understand the structural, licensing, and reimbursement pathways needed to support Pediatric Palliative Care Centers nationwide. The framework outlines an actionable pathway to ensure that children with life-limiting and life-threatening conditions can access medically necessary pediatric palliative care respite in their communities.

[See the framework](#)

Also see a [supplemental technical report](#).

## CALIFORNIA POLICY AND RESOURCES

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### Help Identify Data Gaps Impacting Children and Families

KidsData is seeking feedback from families, researchers, policymakers and others on where current health and well-being data overlook CYSHCN and other key populations—and how more detailed, disaggregated information could better reflect children's diverse experiences across California. Participants may complete a short online questionnaire or have a brief conversation with KidsData during February and March. **To receive information about how to participate, email [KidsData@prb.org](mailto:KidsData@prb.org).**

[Learn more about KidsData](#)

### New DHCS Web Pages Address Impact of Federal Policy on Medi-Cal

The Department of Health Care Services has launched a set of web pages to help counties, health plans, providers, and community partners track federal actions that affect Medi-Cal, including H.R. 1. The site covers Medi-Cal eligibility, benefits, behavioral health, Section 1115 waivers, and more, and describes how California plans to implement the required changes with minimal disruption.

[Visit the website](#)

## WE WANT TO HEAR FROM YOU

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