

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

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

NATIONAL POLICY

Webinar: Medicaid in Motion - Navigating Post-Election Policy Changes and Opportunities

During the upcoming budget reconciliation process, significant changes to Medicaid are possible, creating both risks and opportunities for Medicaid stakeholders. In this webinar, experts from Health Management Associates will discuss the latest developments in Medicaid financing and policy, and explain how options Congress and the Administration are considering may affect Medicaid.

DATE/TIME: Wednesday, February 26 | 9-10 am PT

[Learn more and register](#)

Webinar: How Medicaid Supports Parents in Crisis, Children in or Aging Out of Foster Care, Relative Caregivers, and Adoptive Families

Medicaid provides health care to 99 percent of children in foster care and is a lifeline to youth who have aged out of foster care up to age 26. It also helps prevent unnecessary foster care by providing parents with mental health and substance use treatment so families can remain safely together. Learn more at this webinar and also see a [new brief](#) on this topic from the Georgetown Center for Children and Families.

DATE/TIME: Tuesday, March 4 | 12-2 pm PT

[Register](#)

Tracking Proposed Policy Changes That Could Affect CYSHCN

Many national policy proposals have been floated that could disrupt programs for CYSHCN and their families, including Medicaid and the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit. Nothing definitive has emerged yet. These [links](#) offer some background information

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[Why Medicaid Is Important: EPSDT and Services for Children and Youth with Disabilities](#) – National Health Law Program

Related: The fifth edition of the [Advocate's Guide to the Medicaid Program](#) is now available from the National Health Law Program. The guide is updated with the major developments in Medicaid law through April 2024.

VIEWPOINT

The Power of Storytelling and Why It Matters Now More Than Ever

In a recent *California Health Report* article, Jennifer McLelland, disability rights columnist, makes the case for the urgent need to harness the power of storytelling to advocate for the protection of Medicaid in the face of threatened cuts. McLelland describes how she began telling her story as a parent of a child with medical complexity to help legislators understand that her son and other medically complex children depend on Medicaid to access the lifesaving care they need. *California Health Report* is supported by our Foundation.

[Read the article](#)

CHILDREN WITH MEDICAL COMPLEXITY

Family-Led Academic Grand Rounds Flip the Model

Family-Led Academic Grand (FLAG) Rounds train and empower families of children with complex medical conditions (CMC) to share their experiences of ableism in the pediatric health care system with medical students and residents. At the rounds, a family member with lived experience presents the child's "case" and offers strategies for attendees to develop knowledge and skills for partnering with families in the care of CMC. FLAG Rounds is a collaboration with the University of Wisconsin Center for Excellence in Developmental Disabilities, its Department of Pediatrics, and the Bluebird Way, with support from our Foundation. FLAG Rounds are approved to offer continuing education credits.

Watch the recording of the first session: [Whose Expectation Is It Anyway? Access, Care, and Humanization.](#)

Register for the [March 13 no-cost FLAG Rounds](#) and three upcoming Rounds.

FAMILY ENGAGEMENT

Referrals to Peer Support for Families in Pediatric Subspecialty Practices: A Qualitative Study

Peer support provided by families of CYSHCN to other families with similarly affected children can help ease families' stress and anxiety and improve their understanding of their child's diagnosis and treatment. A [2022 survey](#) of California pediatric subspecialists

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survey, Mathematica, with support from our Foundation, conducted a follow-up study, the results of which have been published in the *Maternal and Child Health Journal*, to understand how referrals for peer support occur. The researchers also identified factors that may facilitate or impede the referral process.

[Read about the new findings](#)

HOME- AND COMMUNITY-BASED SERVICES

Research: Home Health Care for Children with Disability, Medical Complexity

Home health care is crucial for the health of children with disability and medical complexity, and their ability to function in home, school, and community settings, yet in-depth research on the topic is lacking. A new article in *Pediatrics* provides an overview of the literature on pediatric home health care and proposes an actionable agenda for addressing gaps in information. The authors suggest that pediatricians should partner with patients and family caregiving experts to advance knowledge. They also recommend that all efforts have the goal of ensuring equitable outcomes for every child and family.

[Read the article](#)

Report: Co-Creating a Financially Sustainable Future for Caregivers

Caregivers, both paid and unpaid, play a critical role in the lives of CYSHCN and their families, but they often are excluded from the creation and implementation of policies that affect them. In 2022, Health Leads established the National Caregiver Coalition, composed of family caregivers, care workers, care receivers, and organizational partners. In a new report, the Coalition describes its process to identify key insights and develop recommendations to create caregiver-driven solutions to care worker financial sustainability. Though the Coalition is not solely focused on CYSHCN, the information may be of interest.

[Read the report](#)

PALLIATIVE CARE

Literature Review: Racism in Pediatric Serious Illness and Palliative Care

In a new study published in the *Journal of Pain and Symptom Management*, researchers assess the extent to which the experiences of Black and Native American families have been captured in existing literature on serious illness and palliative care. The authors document a general lack of discussion about how racism impacts the experiences of these families, and suggest that their findings reveal a potential area for growth within pediatric palliative care, research, and policies.

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[Read the article](#)

CALIFORNIA CHILDREN'S SERVICES

CCS Due Process Toolkit Helps Families Navigate Complex Appeals Process

An *Alianza News* story highlights a mother's experience with the confusing and time-consuming appeals process for California Children's Services (CCS) after her daughter was denied vital nursing care. The author notes that many families caring for CYSHCN have encountered such challenges and have been forced to pay out-of-pocket for the services their children urgently need. As described in the story, the [National Health Law Program's CCS Due Process Toolkit](#) (available in English and en Español) was created to address these issues and provides accessible information to help families understand their rights and options in the appeals process. This story is available in English or en Español and was produced in collaboration with Foundation grantee *California Health Report*.

[Read the story](#)

EVENTOS EN ESPAÑOL

Congreso Familiar: Sessions on Regional Centers, IHSS, and More

Congreso Familiar is a collaboration of parents, professionals, and community agencies dedicated to promoting education and leadership skills in Spanish-speaking families who have members with disabilities. In the coming weeks, Congreso Familiar will present sessions on Regional Centers, In-Home Supportive Services, and other topics.

[Register in English or en Español](#)

[See additional material on the Congreso YouTube channel](#)

LINKEDIN

Advocates Tell Their Stories

At a recent Foundation-hosted event, experts in legal, policy, administrative, and family advocacy discussed how they became systems-level advocates for CYSHCN and highlighted the top health care issues they currently are addressing. [Read about their conversation](#) on our LinkedIn page and follow us for news and updates between newsletters.



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