

California Advocacy Network for Children with Special Health Care Needs

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

Children with Medical Complexity

Improving Access to In-Home Nursing Services for Children with Medical Complexity

In states across the country, many Medicaid-enrolled children with medical complexity are not receiving the in-home nursing care they require, according to the National Health Law Program (NHeLP). Along with other advocacy organizations, NHeLP reached a settlement in Missouri in a case they filed arguing that the Medicaid Act and the Americans with Disabilities Act require the Missouri Medicaid agency to take steps to ensure that approved in-home nursing services are available. The settlement could be informative to advocates and policymakers in other states. [Read more.](#)

In Brief

- [Key Themes in Complex Care Emerge from Putting Care at the Center 2022 Conference](#) – A blog post from the National Center for Complex Health and Social Needs highlights ideas to improve complex care delivery.

Family Caregiving

Public Comment Sought on 2022 National Strategy to Support Family Caregivers

The federal Administration for Community Living has released its 2022 national strategy, which recommends actions that can be taken to ensure that family caregivers have the resources they need to maintain their own health, well-being, and financial security while providing crucial support for others. A 60-day comment period began on October 1, and the strategy will be updated in response to comments. [Read the report and offer comment.](#)

COVID-19 Information

Webinar: Medicaid and CHIP Continuous Enrollment Unwinding: What to Know and How to Prepare

Date Wednesday, October 26
Time 9 to 10 a.m. Pacific Time
Sponsor Centers for Medicare and Medicaid Services
Details This monthly webinar series addresses topics related to the Medicaid and CHIP continuous enrollment unwinding. [Learn more and register.](#)

Working with Community-Based Organizations and Individuals to Support Continuity of Coverage

In the second of this series of issue briefs regarding children who potentially could lose Medicaid coverage when the Public Health Emergency ends, the authors offer recommendations on how to partner with community-based organizations, family-led organizations, and individuals with lived experience to help support efforts to ensure continuity of coverage. The briefs were produced by Manatt, in partnership with Family Voices, with support from our Foundation. [Read the brief.](#)

Pediatric Palliative Care

Webinar: A Collaborative Approach to Addressing Trauma and Building Resilience in Palliative Care Providers

Date Tuesday, October 18
Time 12 to 1 p.m. Pacific Time
Sponsors Pennsylvania's Pediatric Palliative Care Coalition, Greater Illinois Pediatric Palliative Care Coalition, Children's Hospice & Palliative Care Coalition of California, and the CSU Shiley Haynes Institute for Palliative Care
Details Speakers will discuss the importance of adopting a trauma lens for palliative care health professionals and educators. [Read more and register.](#) Fee.

Intellectual/Developmental Disabilities

National Plan for Developmental Disabilities Released

The strategic plan that will guide the work of the National Center on Birth Defects and Developmental Disabilities (NCBDDD) through 2026 is now available. NCBDDD, a program of the Centers for Disease Control and Prevention, focuses on advancing health for the nation's most vulnerable populations, including children with developmental disabilities. [Read about the plan's four focus areas.](#)

The Arc Annual Convention: Final Week for Discounted Registration

Early-bird registration is available through **October 12** for The Arc's National Convention, scheduled for November 10-12 in Denver. [See the tentative schedule and register.](#)

California Children's Services

CCS Advisory Group to Meet

Date Wednesday, October 12
Time 1 to 4 p.m. Pacific Time
Details The agenda, slides, and login information will be posted on the group [website](#).

California Policy

Little Hoover Commission to Hold Hearings on Regional Center Service Disparities

Date Thursday, October 13
Time 12 to 2:30 p.m. Pacific Time
Location Virtual
Details Recent research highlights ongoing challenges around disparities in the availability and quality of services across racial and ethnic groups receiving services from California's regional center system. The Little Hoover Commission, an independent state oversight agency, is conducting a study on the extent of current disparities and considering how the state can make improvements. The upcoming hearing will include 30 minutes for public comment. [Read more and register.](#)

Department of Health Care Services Stakeholder Advisory Committee to Meet

Date Thursday, October 20
Time 9:30 a.m. to 1:30 p.m. Pacific Time
Location Virtual or in-person
Details The committee provides the Department with input on the ongoing [California Advancing and Innovating Medi-Cal \(CalAIM\)](#) implementation efforts and other goals. Details will be posted on the [website](#).

Events

Conference Session to Highlight Home Health Care Services for CYSHCN in Foster Care

Date Monday, October 10
Time 3:20 – 4 p.m. Pacific Time
Sponsor American Academy of Pediatrics
Details Half of children entering foster care have chronic medical conditions. The American Academy of Pediatrics (AAP) classifies all children in foster care as children with special health care needs. At the upcoming AAP National Conference, researchers will discuss initial findings in a presentation on "The Use and Impact of Home Health Care Services for Children in Foster Care." Based on research funded by our Foundation, their work will be shared during the Oral Abstracts session of the Council on Foster Care, Adoption, and Kinship Care Program. [Read more and register for the conference.](#) Fee.

National Policy

National Survey of Children's Health Data Released on Child Health Day

The newest dataset from the National Survey of Children's Health was released on October 3, Child Health Day. The survey covers multiple, intersecting aspects of children's lives—including physical and mental health, access to quality health care, and the child's family, neighborhood, school, and social context. The survey is funded and directed by the federal Maternal and Child Health Bureau. The combined 2020-2021 dataset includes data from 93,669 children ages 0-17 years. [Read more.](#)

In Brief

- [Long-Awaited Rule on Mandatory Reporting of Child Core Set Quality Measures Proposed](#) – from Georgetown Center for Children and Families

Special Education

- [Office of Special Education: Fast Facts – Educational Environments of School Aged Children with Disabilities](#) – from Individuals with Disabilities Education Act

Resources

- [Children and Youth with Special Healthcare Needs in Emergencies](#) – from the Centers for Disease Control and Prevention

In the News

- [Oregon Is Guaranteeing Kids Won't Get Kicked off Medicaid Until at Least Age 6](#)
Washington Post, 9/29/22
- [Senators Demand Answers on Web Accessibility](#)
Disability Scoop, 9/27/22
- [COVID-19 Was Leading Killer of People With Developmental Disabilities](#)
Disability Scoop, 9/26/22

We'd like to hear from you

Let us know what's happening with your organization or family. Email newsletter assistant editor Hannah Au at Hannah.Au@pfch.org with your news or updates. Or contact newsletter editor: Eileen Walsh at Eileen.Walsh@pfch.org.

[Join the Network](#)

To see past issues, visit the [Network Newsletter Archive](#).

The California Advocacy Network for Children with Special Health Care Needs is a collaborative organized by the Lucile Packard Foundation for Children's Health. Through grantmaking, advocacy, and communications, the Foundation promotes a system of care that improves the lives of children with special health care needs and their families.

