

California Advocacy Network

for Children with Special Health Care Needs

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

Network News

New Foundation Grant Promotes Family Engagement in Neonatal Intensive Care Units

Strengthening and diversifying family representation in care is the goal of a new Foundation grant that will support creation of a statewide Family Advisory Council for neonatal intensive care units (NICUs) across California. The grant, to the California Perinatal Quality Care Collaborative, also will support planning for development of Family Advisory Councils in NICUs around the state. The Collaborative, housed at the Stanford University School of Medicine, works to improve the quality and equity of health care delivery for these vulnerable NICU infants and their families. [Read more.](#)

Related: The [California Perinatal Quality Care Collaborative](#) (CPQCC) seeks diverse family members to join the proposed statewide NICU Family Advisory Council. CPQCC is offering a stipend to family members who join the council for two years. Read more and [apply](#) by **December 9**.

A New Look for National Research Network

The Children and Youth with Special Health Care Needs National Research Network (CYSHCNNet) has refreshed the look of its website and updated its home page to make its work accessible to people outside of academic medicine. Visit the [new site](#).

Children with Medical Complexity

Article: A Perspective on Cost Effectiveness in Pediatric Comprehensive Complex Care Service Models

As comprehensive service delivery models are being developed to improve care for children with medical complexity, financially supporting and sustaining the necessary additional resources that their care requires is an almost universal problem. A recent article in the *Complex Care Journal* presents evidence on the cost effectiveness of these models and describes the unique challenges in cost effectiveness evaluations for this population. The article also points to Medicaid policy opportunities that provide financial support for a developmental period, whether focused on model development or systems building expansion. [Read the article.](#)

Opportunity to Share Complex Care Work

The National Center for Complex Health and Social Needs is accepting proposals to present a webinar at one of its monthly free virtual learning events. The webinars will feature subject matter experts covering a range of topics relevant to the field of complex care. Priority will be given to proposals that include a community member/consumer of complex care as a primary presenter and content expert. Proposals are due **January 18, 2023**. [Read more and apply.](#)

In Brief

- [The Paramedic Will See You Now: Expanding Access to Community-Based Care for People with Complex Needs](#)

Public Health Emergency Unwinding

Webinar: Medicaid And CHIP Continuous Enrollment Unwinding: What To Know And How To Prepare

Date Wednesday, December 7

Time 9 to 10 a.m. Pacific Time

Sponsor Centers for Medicare & Medicaid Services, Department of Health and Human Services

Details Part of a webinar series covering different topics related to Medicaid and CHIP Continuous Enrollment Unwinding. [Read more and register.](#)

Systems and Standards

Webinar Reminder: Health Systems Strategies that Prioritize Children with Health Complexity

Date Wednesday, December 7

Time 10 to 11 a.m. Pacific Time

Sponsors Oregon Pediatric Improvement Partnership and Lucile Packard Foundation for Children's Health

Details An engaging discussion about a recently released brief, [Health Systems Strategies to Ensure a Focus on Children with Health Complexity](#). Presenters will share actionable strategies and models that can be used to improve services and supports for families. Audience Q&A is highly encouraged. [Read more and register.](#)

Health Equity

Navigating Bias in Health Care Delivery: Tools to Foster Patient-Provider Trust

Building patient-provider trust by addressing providers' biases — both conscious and unconscious — is critical to achieving high quality, patient-centered care and better supporting patients of color. Two tools from the Center for Health Care Strategies aim to help foster trust between patients and providers:

- [Words Matter: Strategies to Reduce Bias in Electronic Health Records](#)
- [Building Patient-Provider Trust to Help Patients Navigate a Biased System](#)

Family Engagement

- [Promoting Family Engagement and Early Identification of Developmental Delays: The Role of Act Early Ambassadors](#) - from Zero to Three
- [Yes, You Do Need to Plan - Exceptional Parent Annual Financial Planning Issue](#)

Special Education

Webinar: The Intersection of Future Planning and Special Education Transition Planning

Date Wednesday, December 7

Time 11 a.m. to 12:15 p.m. Pacific Time

Sponsor The Arc

Details Attendees will learn about how special education transition planning fits into the broader idea of future planning. They will gain insight into approaches for effective transition planning for students with Individualized Education Programs, as well as considerations for families, educators, and support professionals as they collaborate with the student during the transition planning process. [Read more and register.](#)

In Brief

- [When Your Disability Gets You Sent Home from School – Students with Special Needs Are Often Met with Off-the-Books Suspensions](#) - from Hechinger Report

Intellectual and Developmental Disabilities

Hearing on California's Developmental Disabilities System

Date Thursday, December 8

Time 12 to 2 p.m. Pacific Time

Location Virtual

Sponsor Little Hoover Commission

Details The commission is assessing the extent of current disparities in service access, and identifying the underlying causes of these disparities and the current state efforts to address them. The public may join online or by phone. [Read more and register.](#)

California Policy

CalAIM Enhanced Care Management for Children Is Topic for Joint Advisory Group Meeting

Date Monday, December 5

Time 10 to 11:30 a.m. Pacific Time

Sponsor Department of Health Care Services

Details A joint meeting of the Population Health Management Advisory Group and members of the Children and Youth Advisory Group will include a panel discussion on implementing [Enhanced Care Management](#) for children, youth, and maternal populations of focus. [Advance registration](#) is required.

Webinar: Medi-Cal Services Guide Updates: Managed Long Term Services and Supports

Date Thursday, December 8

Time 10 to 11 a.m. Pacific Time

Sponsor National Health Law Program

Details The National Health Law Program will provide an overview of Managed Long Term Services and Supports services provided through Medi-Cal. The information will assist advocates with an improved understanding of these covered benefits, along with developments under CalAIM. [Read more and register.](#)

Events

Register for Association of Maternal and Child Health Programs Conference

[Early registration](#) for the 2023 AMCHP Annual Conference now is open. Register to attend in person or virtually by **March 8, 2023**.

In the News

- [Controversial and Often Used Practices Cause Harm, Even Death, Among Students with Disabilities](#) *Disability Scoop, 11/29/22*
- [Disney Adds Dolls in Wheelchairs to 'It's A Small World'](#) *Disability Scoop, 11/15/22*
- [States Leading the Way on Connecting All Children with Health Coverage – Will Congress Follow?](#) *Georgetown Center for Children and Families, 11/15/22*
- [Students With Disabilities Innovate Ways to Use Spaces, Products Not Designed for Them](#) *PBS, 10/26/22*

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@lpfch.org with your news or updates. Or contact newsletter editor: Eileen Walsh at Eileen.Walsh@lpfch.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.

