

California Advocacy Network for Children with Special Health Care Needs

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

Network News

New Foundation Grants Focus on Equitable Care

Five newly awarded grants from our Foundation aim to bring renewed attention to health care inequities for children with special health care needs, and enhance diversity, equity, and inclusion efforts in the health care system. The grants cover equity issues in four areas: marginalized CSHCN populations, transition, state equity initiatives, and family engagement in children's hospitals. [Read about the grants.](#)

National Policy

Call to Action: A National Roadmap to Rethink Care

A vision for a transformed system of care for CYSHCN is outlined in a seven-article supplement to *Pediatrics* just released by the federal Maternal and Child Health Bureau. The *Blueprint for Change: A National Framework for a System of Services for Children and Youth with Special Health Care Needs* describes a system that will enable CYSHCN to enjoy a full life, from childhood through adulthood; thrive in systems that support their families, their social, health, and emotional needs; and ensure dignity, autonomy, independence, and active participation in their community. The goal of the *Blueprint* is to promote shared understanding and action for real change to the system of care. [Read more and learn how to get involved.](#)

Health Care Finance

Webinar: A Research Agenda for Improving Health Care Financing for CYSHCN

Date Wednesday, June 22
Time 10 to 11 a.m. Pacific Time
Sponsors CYSHCN National Research Network (CYSHCNNet), University of Colorado Denver, and Lucile Packard Foundation for Children's Health
Details Over the past three years, family leaders and researchers from across the country partnered to develop a national research agenda focused on improving the health care system for CYSHCN. The team produced eight articles that were published in *Academic Pediatrics* with support from our Foundation. In this webinar, some of the authors will discuss the findings and recommendations from their article, [Moving from Spending to Investment: A Research Agenda for Improving Health Care Financing for Children and Youth With Special Health Care Needs](#).
[Read about the speakers and register.](#)

Resource

Webinar: Catalyst Center Offers Primer on Medicaid

Date Tuesday, June 14
Time 12 to 1 p.m. Pacific Time
Sponsor Catalyst Center
Details Medicaid is the single largest source of health coverage for CYSHCN. This webinar will present foundational knowledge about Medicaid for Title V staff and also the general public. Catalyst Center staff will explain the basics of Medicaid, including the eligibility pathways to Medicaid coverage for children and the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) program, a benefit unique to Medicaid that is crucial for access to care for CYSHCN. [Register.](#)

Children with Medical Complexity

Awards Will Support Investigators New to CYSHCN Field

Applications are open for the [CYSHCN National Research Network](#) Emerging Investigator Guided Research Training Program. Three investigators will receive up to \$15,000 each for a one-year research project that addresses an important area of concern for the health or health care of children or youth with special health care needs and their families. [Read more about current investigator projects and apply](#) by July 8.

Webinar: Understanding the Lived Experience of Siblings of Children with Significant Neurological Impairment

Date Thursday, June 23
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 results of a qualitative study of sibling/parent dyads to better understand the lived experience of being a sibling to a child with significant neurological impairment. Key findings will be highlighted, as well as takeaways for providers regarding how best to meet the needs of these siblings. Fee. [Register.](#)

Webinar: Traveling with a Medically Complex Child

Date Wednesday, June 15
Time 5 to 6 p.m. Pacific Time
Sponsor Courageous Parents Network
Details A panel of parents will offer tips and tricks to create a memorable family experience. [Read more and register.](#)

Transition to Adult Care

Reminder: Roundtable – Pediatric to Adult Healthcare Transition for Children with Complex Medical Needs

Date Tuesday, June 14
Time 11 a.m. to 2 p.m. Pacific Time
Sponsor Chloe Barnes Advisory Council on Rare Diseases
Details [Read more and register.](#)

Home- and Community-Based Care

Funding Opportunity: Non-medical Assistance to Family Caregivers

Community Care Corps has released a request for proposals for innovative local models in which volunteers provide non-medical assistance to family caregivers, older adults, or adults with disabilities in order to maintain their independence. Applications are due **July 8**. [Read more and apply.](#)

In Brief

- [Video: How Julie Beckett Improved Life for Millions of CYSHCN Families](#) – from Family Voices

COVID-19 Information

Supporting Children with Disabilities: Lessons from the Pandemic

Date June 13-15
Time 9 a.m. to 12:30 p.m. Pacific Time
Sponsors Board on Children, Youth, and Families within the National Academies of Sciences, Engineering, and Medicine; U.S. Health Resources and Services Administration
Details A three-day virtual workshop that will include panels focused on a breadth of topics related to promising approaches and strategies employed during the pandemic to address challenges faced by children. [Read more and register.](#)

Telehealth

Webinar: Navigating the Virtual Care Explosion: Mapping the Shifting Policy, Payment and Strategy Landscape

Date Wednesday, June 22
Time 12 to 1 p.m. Pacific Time
Sponsor Manatt Health
Details Experts will discuss how virtual care is remapping the health care landscape. [Register.](#)

California Policy

Enhanced Care Management Webinar Series

California Advancing and Innovating Medi-Cal (CalAIM) is a program that is bringing major changes to Medi-Cal, which is a source of health coverage for many CYSHCN. A series of webinars offers updates and training for advocates.

Title **Enhanced Care Management in Rural California**
Date Tuesday, June 14
Time 11:30 a.m. to 1 p.m. Pacific Time
Sponsor Department of Health Care Services
Details [Register.](#)

Title **Enhanced Care Management & Community Supports Intersection**
Date Tuesday, June 21
Time 10 to 11:30 a.m. Pacific Time
Sponsor Department of Health Care Services
Details [Register.](#)

Related: [Launching CalAIM: 10 Observations About Enhanced Care Management and Community Supports So Far](#) – from Center for Health Care Strategies

Did You Know?

Five-Year Estimates Available for Title V National Outcome and Performance Measures

The Data Resource Center for Child and Adolescent Health has released the five-year estimates from the National Survey of Children's Health (NSCH). State, regional, and national estimates for Title V Block Grant National Outcome and Performance Measures are accessible at [Interactive Data Query](#). This five-year dataset provides sufficient sample sizes to allow for important subgroup analyses across state and child populations.

In the News

- [Overcoming Obstacles and Defying the Odds, Whittier Student Graduates High School](#)
Los Angeles Times, 6/3/22
- [Feds Push Forward with New Medicaid Waiver Rule](#)
Disability Scoop, 6/1/22
- [Analysis: The Formula Shortage Is Also a Disability Rights Issue](#)
California Health Report, 5/30/22

We'd like to hear from you

Let us know what's happening with your organization or family. Email newsletter assistant editor Ali Rivera at Ali.Rivera@pfch.org with your news or updates. Or contact news 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.

