

California Advocacy Network for Children with Special Health Care Needs

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

Transition to Adult Care

Webinar: Designing Value-Based Payment Innovations for Pediatric-to-Adult Transitional Care

Date Wednesday, January 26
Time 10 to 11 a.m. Pacific Time
Sponsor National Alliance to Advance Adolescent Health
Details The webinar will cover a step-by-step approach to designing value-based payment (VBP) innovations for pediatric-to-adult transitional care. VBP links provider payments to performance. Senior officials from two large Medicaid Managed Care Organizations will discuss their experiences with designing a transition VBP pilot. This work was supported by our Foundation. [Read more and register.](#)

Children with Medical Complexity

Health Affairs Virtual Briefing: Caring for Those with Complex Needs

Date Friday, January 28
Time 10 to 11:30 a.m. Pacific Time
Sponsor Health Affairs
Details For the past year, *Health Affairs* has published a series of articles about caring for people with complex health and social needs. This virtual forum, hosted by *Health Affairs* Editor-in-Chief Alan Weil, will highlight key findings from this work and examine the many pathways to improved care and responsive policymaking. [Read more and register.](#)

Network News

Reminder: Deadline Approaching for Letters of Inquiry

Letters of Inquiry (LOI) for the Foundation's next grant cycle are due **February 11**. Potential applicants should carefully review our program goals, priorities, and restrictions before submitting an LOI. [Read about the application process.](#)

Family Engagement

Updated: Guidelines for Compensating Families as Research Partners

Standards of Compensation for Youth, Family, and Patient Partners is a free resource that offers guidance to help researchers and their family partners understand the levels of support, compensation, and reimbursement families should receive as research participants. Developed by the Children and Youth with Special Health Care Needs National Research Network and Family Voices, the guide offers a version for investigators and a version for research partners, available in English and now also in Español. [Read the guide.](#)

How Patient and Family Advisory Councils Can Succeed in Children's Hospitals

A recent study from the Institute for Patient- and Family-Centered Care explored the prevalence and characteristics of patient and family advisory councils in US children's hospitals. The report analyzes the factors that contribute to councils' success, and offers practical guidance about strengthening partnerships with families and patients. The study was supported by our Foundation. [Read the report and watch a related webinar.](#)

California Children's Services

CCS Advisory Group to Meet

Date Tuesday, January 25
Time 1 to 4 p.m. Pacific Time
Details Find the agenda and meeting details on the group [website](#).

Mental and Behavioral Health

Webinar: Assessing Readiness to Effectively Support Emotional Health of Patients with Chronic Conditions

Date Wednesday, February 2
Time 11 a.m. to 12 p.m. Pacific Time
Sponsor Children's Hospital Association and American Board of Pediatrics
Details The American Board of Pediatrics has developed tools and resources for pediatricians and subspecialists to support the emotional health and resilience of patients with chronic conditions and their families. Guided by a readiness checklist, the webinar will help clinicians understand what steps and resources will prepare them to initiate efforts to support a patient's emotional health. [Read more and register.](#)

Telehealth

- [Telehealth Tip Sheet](#) (PDF) – How families and children can prepare for their video or phone appointments – from the Child Neurology Foundation

Resources

- *Exceptional Parent Magazine* January Issue – [EP Guide 2022: Navigating Special Needs Resources](#)

Health Equity

Promoting Access to Equitable Care for Black/African American CSHCN

A logic model developed by the National Resource Center for Patient/Family-Centered Medical Home suggests how to increase the number of African American and Black CSHCN and their families who have access to services/supports and receive equitable, culturally competent, and family-centered care from their pediatrician, health care team, and system of care. [See the logic model](#) (PDF).

Also see: [What It Takes to Get Support for a Black Boy with Special Needs](#) – A mother's story in *TIME*

COVID-19 Information

- [COVID-19 Resources for Families](#) – from Parents Helping Parents, an organization devoted to supporting and educating families of children and youth with special needs.
- The federal website to [order free COVID-19 tests](#) is up and running.

California Policy

State Assesses How Families, Youth Are Engaged in Advising Key Agencies

In partnership with Children Now and our Foundation, Assembly Majority Leader Eloise Gómez Reyes asked the California Legislative Analyst's Office (LAO) to conduct research on how and whether child-serving state departments and agencies work to ensure meaningful youth and family engagement in their advisory bodies. The LAO found varying levels of engagement across agencies, and offered a series of issues to be considered that could help ensure meaningful participation by youth and families, including monetary support. [Read the report.](#)

Electronic Visit Verification Stakeholder Meeting

Date Friday, January 21
Time 2 to 3 p.m. Pacific Time
Location Via webinar. [Register for the webinar](#) in advance.
Details Stakeholder meetings provide the opportunity to discuss the state's approach to electronic visit verification, the steps providers will need to take, and the training that will be offered. [Read more.](#)

National Policy

- [The New Year Brings New Protection Against Surprise Medical Bills: What Consumers Need to Know](#) – from the Georgetown University Center on Health Insurance Reforms

Events

AMCHP Extends Conference Registration Deadline

The Association of Maternal & Child Health Programs has changed the early-bird registration deadline for its 2022 Annual Conference to **January 28**. [Read more and register.](#)

In the News

- [An Airline Broke an Activist's Wheelchair. Her Death Months Later Amplified Calls for Change.](#)
Disability Scoop, 1/18/22
- [CDC Director Apologizes to Disability Advocates for 'Hurtful' Comments](#)
Disability Scoop, 1/18/22
- [Doctors Know Little About Their Obligations to People with Disabilities, Study Finds](#)
Disability Scoop, 1/11/22
- [A Teacher Hoped to Connect with Students with Disabilities. She Found a Way through Music.](#)
Washington Post, 1/9/22

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 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.

