

California Advocacy Network for Children with Special Health Care Needs

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

Editor's Note: Our Foundation is redesigning its [website](#), and we are asking Newsletter readers to complete a brief survey on how the website could better serve our stakeholders. The questions should take fewer than 10 minutes to complete, and responses will be anonymous. Please respond by **October 24**. Thank you for your assistance. [Please click here to begin the survey](#).

Family Engagement

Case Studies Highlight Ways to Use the *Family Engagement in Systems Assessment Tool*

In 2019, Family Voices released the *Family Engagement in Systems Assessment Tool* (FESAT), a suite of tools and resources that child- and family-oriented organizations can use to plan, assess, and improve family engagement in policy, practice, quality improvement projects, and other systems-level activities. A new report, produced with support from our Foundation, profiles three organizations that used the FESAT in different ways to ensure meaningful family engagement in systems change. [Read about their experiences](#).

COVID-19 Information

Maintaining Pediatric Telehealth Access after the Public Health Emergency Ends

The federal government has officially extended the Public Health Emergency (PHE) to January 2023, but states continue to plan for its eventual end. This issue brief, last in a three-part series on improving access to coverage when the PHE ends, outlines state policy flexibilities that improved access to pediatric telehealth services, and highlights opportunities for permanent state policy expansions to maintain these services within Medicaid. The briefs were produced by Manatt, in partnership with Family Voices, with support from our Foundation. [Read this brief and see all three](#).

Related: [50-State Unwinding Tracker](#) – from Georgetown Center for Children and Families

Children with Medical Complexity

Viewpoint: Looking Ahead at Caring for Children with Medical Complexity

A pediatrician who attended the *National Convening on the Future of Care for Children with Medical Complexity* discusses the accomplishments of the [Collaborative Improvement and Innovation Network to Advance Care for Children with Medical Complexity](#). She reflects on how clinical teams and families are working together to identify barriers to care and propose solutions. [Read her blog](#).

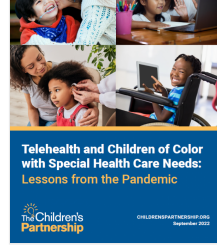
Home- and Community-Based Services

Webinar: Innovating Digitally Enabled Home-Based Care

Date Tuesday, November 1
Time 10 to 11 a.m. Pacific Time
Sponsor Manatt Health
Details A panel discussion on innovations in digitally enabled home-based care models for people who use long-term services and supports (LTSS). Speakers will examine the population, payer, and delivery system trends driving the growth in “care at home” models—and discuss the opportunities and barriers for LTSS-focused digital health and other technology solutions that support independent living. [Read more and register](#).

Telehealth/Health Equity

How Telehealth Can Make Care More Equitable



The recording from the webinar [Telehealth and Children of Color with Special Health Care Needs - Lessons from the Pandemic](#) is now available, along with the related [report](#) on which the webinar was based. Produced by The Children's Partnership with support from our Foundation, the report analyzes the role telehealth played in keeping children of color with special health care needs connected to care during the pandemic, and provides family-centered recommendations to make California's health care system and the use of telehealth more equitable.

California Children's Services

Whole Child Model, Cal-AIM Work Highlighted

The CCS Advisory Group heard and discussed updates on multiple programs at its October 12 meeting, including UCSF's submission of the final report on its evaluation of the Whole Child Model. Advisory Group members also considered the progress of the California Advancing and Innovating Medi-Cal (Cal-AIM) County Monitoring and Oversight Workgroup; the transition of the Children's Health and Disability Prevention Program; the status of the Electronic Visit Verification program; the proposed Enhanced Care Management program and CCS case management; and other CCS program updates. Details on each topic are available on the meeting's [slide presentation](#).

Intellectual and Developmental Disabilities

Hearings on Regional Center Disparities to Continue

A [recording](#) of the first segment of the Little Hoover Commission's Hearing on California's Developmental Disabilities System is available. The Commission, an independent state oversight agency, is conducting a study on the extent of current service disparities and considering how the state can make improvements. An [Advisory Committee Roundtable](#) is scheduled for **October 27**, and a [second hearing](#) is set for **November 10**. Public comment will be accepted at both.

In Brief

- [Talking to Patients Who Have Intellectual and Developmental Disabilities about COVID-19](#) – from the Centers for Disease Control and Prevention
- [Lawmakers Drop Plan to Ban Electric Shock Devices for Those with IDD](#)
Disability Scoop, 9/28/22

Call for Proposals

Maternal and Child Health Conference Offers Opportunities to Present CYSHCN Work

“Equity and Access for Children and Youth with Special Health Care Needs” is one of the tracks for the 2023 Annual Conference of the Association of Maternal and Child Health Programs, scheduled for May 6-9 in New Orleans and virtually. Proposals to present a conference session or a poster are now being accepted, with a preference for work that addresses the theme *Cultivating Diverse Leaders in Maternal and Child Health*. The proposal deadline is **November 22**. [Read more](#).

Pediatric Palliative Care

Building a Coalition for Pediatric Palliative Care

The Children's Hospice and Palliative Care Coalition of California (CHPCC) is working to rebuild a sustainable, effective coalition for the future of pediatric palliative care in the state. Interested stakeholders are invited to participate in a roundtable discussion on [November 9](#) or [November 10](#). Advance registration is required.

California Policy

Webinar: Maintaining Coverage for California's Most Vulnerable - Unwinding of the Public Health Emergency

Date Tuesday, October 25
Time 1 to 3 p.m. Pacific Time
Sponsor Insure the Uninsured Project
Details Speakers will provide updates on how the state and counties are preparing for changes to Medi-Cal coverage and retention as the program returns to pre-pandemic eligibility, and how to prepare for challenges. [Read more and register](#).

Resources

- [County Disability and Natural Disasters Maps](#) – from Mathematica
- [More than 535,000 Medi-Cal Enrollees Are No Longer Required to Pay Premiums](#) – from Children Now

In the News

- [Disney Expands Costume Options for Children with Disabilities](#)
Disability Scoop, 10/18/22
- [Ed Department Warns States Not to Waive Requirements for Special Education Teachers](#)
Disability Scoop, 10/17/22
- [As Hospitals Close Children's Units, Where Does That Leave Lachlan?](#)
New York Times, 10/11/22
- [Supreme Court Case Could Sharply Limit Disability Rights](#)
Disability Scoop, 10/10/22

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.

