

California Advocacy Network for Children with Special Health Care Needs

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

Network News

New Grants: Learning to Care for Children with Complexity, Engaging Diverse Families in Policymaking

A grant recently awarded by our Foundation will support a series of seminars to allow care providers and families to share their knowledge on how to care for children with medical complexity. A second grant will continue funding for Project Leadership, a program that offers training for families of children with special health care needs to become meaningfully involved in policymaking, with a special emphasis on engaging diverse families. [Read about the grants.](#)

Letters of Inquiry for Foundation Grants Due Next Month

The deadline for Letters of Inquiry (LOI) for the Foundation's next grant cycle is **July 23**. We fund programs and projects that will contribute to improving systems of care for children with special health care needs and their families. We strongly recommend that potential applicants carefully review our program goals, priorities, and restrictions before submitting an LOI. [Read about the application process.](#)

COVID-19 Information

Webinar: COVID-19 Telehealth Policies Affecting CYSHCN: What to Keep, Modify, or Discard?

Date Tuesday, July 6

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

Sponsors Health Management Associates and the Lucile Packard Foundation for Children's Health

Details This webinar is based on the new report, [COVID-19 Policy Flexibilities Affecting Children and Youth with Special Health Care Needs](#). Speakers will discuss their experiences with how COVID-driven telehealth flexibilities have affected CYSHCN, families, providers, and health systems. They will reflect on what is important to retain and how to apply lessons learned moving forward. [Read more and register.](#)

Related: [Medicaid Options for States During COVID-19: Considerations for Maternal and Child Health](#) (PDF) – from the Association of Maternal and Child Health Programs and the Georgia Health Policy Center

Story: Some Kids in Long-Term Care Facilities Didn't See Parents for More Than a Year

Throughout the pandemic, medically fragile children in California's pediatric long-term care facilities and their parents have endured drastic limits on their ability to see and interact with each other, sometimes for as long as a year.

According to a story in the California Health Report, which receives support from our Foundation, families fear that the separation may have caused long-term harm to their children – developmentally, socially, mentally, and educationally – and hindered parents' ability to effectively monitor their children's care. [Read the story.](#)

Archived Webinar: Medicaid Forward



The [recording](#) of *Medicaid Forward: Opportunities to Transform Children's Healthcare Delivery* is now available from the National Association of Medicaid Directors.

Family Engagement

Webinar – In the Room: Being the Dad

Date Tuesday, June 29

Time 5 to 6 p.m. Pacific Time

Sponsor Courageous Parents Network

Details A panel of fathers of children with serious illness will discuss their experiences, along with a clinical psychologist. [Read more and register.](#)

Children with Medical Complexity

Assessing the Impact of Complex Care Models: Opportunities to Fill in the Gaps

Through an initiative called [Advancing Integrated Models](#) (AIM), eight pilot sites are implementing approaches that seek to improve integrated, person-centered care models for adults and children with complex health and social needs. A new issue brief from the Center for Health Care Strategies discusses a set of patient- and staff-reported quality measures for the AIM pilot sites. These measures can supplement traditional utilization, outcomes, and cost measures and support programs interested in expanding their capacity to evaluate care delivery innovations. [Read the issue brief.](#)

Home Health Care

Caregiver Summit



The [session recordings](#) from the National Caregiver Summit 2021 are now available.

Health Equity

Webinar: Strategies for an Expanded Pediatric Care Team

Date Tuesday, June 29

Time 1 to 2 p.m. Pacific Time

Sponsors Manatt Health and the Center for the Study of Social Policy

Details The COVID-19 pandemic has highlighted the long-standing need for a more comprehensive, advanced, and equitable child health system equipped to deliver whole-child, family-based care. Speakers will share innovative strategies that stakeholders can put into action to better support the whole child and promote health equity. [Read more and register.](#)

California Policy

- **Self Determination: An Exciting Alternative to Regional Center Services** is a webinar recording from Family Voices of California that updates information about a [state policy](#) designed to provide consumers and their families with more control and responsibility in choosing services and supports to help them meet objectives in their Individual Program Plan. [Listen to the recording.](#)

Resources

- AMCHP has redesigned its [Innovation Hub](#) (formerly known as Innovation Station), an online platform that provides resources and tools to explore, build, and share effective practices grounded in evidence that improve the health and well-being of maternal and child health populations, including children with special health care needs. See a [video](#).

In the News

- [Disability Groups Call Supreme Court Ruling on Affordable Care Act a Victory](#)
Disability Scoop, 6/21/21
- [After Months of Special Education Turmoil, Families Say Schools Owe Them](#)
NPR, 6/16/21
- [A Utah Student with Down Syndrome Was Left Out of a Photo of Her School's Cheerleading Squad](#)
The Salt Lake Tribune, 6/16/21

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@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.

