

California Advocacy Network for Children with Special Health Care Needs

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

Editor's note: The Newsletter will return on January 6, 2022. Best wishes to all for the coming year.

Network News

Foundation Accepting Letters of Inquiry for Grants

The deadline for Letters of Inquiry (LOI) for the Foundation's next grant cycle is **February 11, 2022**. 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.](#)

Family Engagement

Conversations with Families

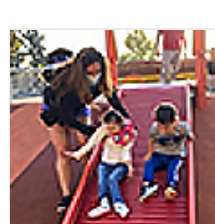


In the fifth session of this 10-part pediatric complex care series, clinicians and parents will discuss shared decision making. The series is funded by our Foundation.

Shared Decision Making
Thursday, January 13, 2022
10 to 11 a.m. Pacific Time
[Read more and register.](#)

See the recording from the fourth seminar: [Behavior/Child Mental Health](#).

Parent Leadership Training Helps Bring a Dream to Life



Mia Vasquez, born with a severe form of cerebral palsy, was not expected to live past her first birthday. As she grew to her current age of 12, Mia's parents were frustrated in their attempts to find a local outdoor playground with accessible structures that could accommodate their daughter's love of playing outside.

Through [Project Leadership](#), the Family Voices of California's advocacy training program that is supported by our Foundation, Mia's parents learned how to rally community support and raise funds. Now, Mia's Dream Come True, an all-abilities playground, is open close to her home in Hayward, California. [Read Mia's story.](#)

Children with Medical Complexity

Reminder: Opportunity to Present Webinars on Complex Care

Proposals are due **January 13, 2022**, to present one-hour webinars at the monthly virtual learning sessions of the National Center for Complex Health and Social Needs. [Learn more.](#)

Listen to an earlier webinar: [Building a System of Care for Children with Complex Medical and Social Needs](#)

Perspectives on Using Telehealth to Improve Complex Care

A collection of peer-reviewed research, case studies, tools, and on-the-ground perspectives provides recent evidence regarding telehealth-delivered interventions for people with complex needs, and practical strategies to support their effective implementation. The collection was compiled by The Playbook, an online resource center that offers up-to-date knowledge about promising approaches to improving complex care. Not pediatric specific. [See the collection.](#)

COVID-19 Information

Supporting Providers in Caring for Children with Medical Complexity During COVID-19

With the goal of building capacity for providers and interprofessional teams to care for children with medical complexity and their families during the pandemic, the American Academy of Pediatrics and the Collaborative Improvement and Innovation Network to Advance Care for Children with Medical Complexity developed the Extension for Community Healthcare Outcomes (ECHO) project, an evidence-based collaborative model of medical education and peer mentoring. ECHO has released the first in a series of infographics that share lessons learned through the project. See the first [infographic](#) and listen to a series of ECHO [webinars](#) on COVID-19 and children with medical complexity.

Viewpoint: The Vaccine Is a Health Equity Issue for Kids Like My Son

In her column for the *California Health Report*, the mother of a ventilator-dependent son discusses the emotional and practical impact of the pandemic on her family, particularly in a community with low vaccination rates. [Read her commentary.](#)

California Children's Services

Applications Open for CalAIM Workgroup

The Department of Health Care Services is accepting applications for participation in a new CCS "CalAIM Enhancing County Oversight and Monitoring Workgroup." Workgroup members will help the Department establish, implement, and evaluate statewide performance, quality, and reporting standards for county administration of the CCS program. Interested stakeholders are encouraged to complete this [survey](#) by **December 22**. To learn more about the workgroup write to CountyOversightandMonitoring@dhcs.ca.gov.

Conference Session Addresses CCS Transition



A new recording, *CCS Youth Aging Out: Successful Transition Strategies*, has been added to the recap of the conference, CCS Best Practices: Shifting the Paradigm for a Post-COVID World. [Listen to all three conference recordings.](#)

California Policy

Latinx Family Group Files Suit Against Harbor Regional Center

Disability Rights California has announced that Padres Buscando el Cambio, a group of Latinx families, has initiated litigation against Harbor Regional Center and California's Department of Developmental Services. The families seek to ensure that the regional center provides Latinx families with full and equal access to state-funded services. [Read more.](#)

Also see: [Confronting Inequities in California's Funding of Services for Children with Developmental Disabilities: A Sobering View of Our Current Standpoint](#)

In Brief

- The new Medi-Cal Rx program goes live on January 1, 2022. The state is transitioning Medi-Cal pharmacy services from managed care to the fee-for-service delivery system. [Learn more.](#)

Resources

- Centering Disability in Technology Policy – A report highlighting [how technology can discriminate against disabled people](#) and what advocacy groups, regulators, and funders can do to make changes – from the American Association of People with Disabilities and the Center for Technology and Democracy
- The Association of Maternal & Child Health Programs has launched a podcast, MCH Bridges, which is designed to help listeners create new connections to maternal and child health leaders, organizations, and ideas, and to inspire and guide listeners toward actions that will improve the systems that affect maternal and child health populations. [Read more.](#)

In the News

- [Court Won't Reconsider FDA Ban on Shock Devices for Those with Disabilities](#)
Disability Scoop, 12/10/21
- [Home Care Workers Are Far More Likely to Have Poor Mental Health, New Study Shows](#)
Modern Healthcare, 12/9/21
- [1 in 3 U.S. Children Lack Adequate Health Insurance](#)
U.S. News & World Report, 12/7/21
- [Feds Look to Address Disability Discrimination in Organ Transplants](#)
Disability Scoop, 12/6/21
- [After Last Year's Learning Loss, We Need a Plan for Students with Disabilities](#)
The Hill, 12/2/21

We'd like to hear from you

Let us know what's happening with your organization or family. Email newsletter assistant editor [Ali Rivera](mailto:Ali.Rivera@lpfch.org) at Ali.Rivera@lpfch.org with your news or updates. Or contact newsletter editor: Eileen Walsh at Eileen.Walsh@lpfch.org.

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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.

