

California Advocacy Network

for Children with Special Health Care Needs

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

Network News

Letters of Inquiry for Foundation Grants Due in July

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.](#)

Children with Medical Complexity

Complex Care Issues Highlighted at Pediatric Academic Societies Meeting

Two of our Foundation's grantees presented poster sessions on topics related to children with medical complexity at the recent Pediatric Academic Societies virtual conference:

Jennifer Baird addressed [Stakeholder Perspectives on Telemedicine and Pediatric Home-Based Palliative Care](#).

Carolyn Foster presented [PediHome: Development of a Family-Reported Measure of Pediatric Home Healthcare Quality](#).

Apply to Be a Consumer Scholar in the Field of Medical Complexity

The National Center for Complex Health and Social Needs is seeking applications for its National Consumer Scholars program. Applicants must be individuals, or their caregivers, with lived experience of complex health and social needs who are willing to share their insights on how to improve care and services. The deadline to apply is **June 11**. [Read more.](#)

Telehealth

Webinar: The Lifeline Program and Telehealth

Date Thursday, May 20

Time 12 to 1 p.m. Pacific Time

Sponsor Family Voices

Details Lifeline is a federal program that offers a monthly benefit towards phone or internet services for eligible subscribers. Speakers will discuss the program, application process, COVID-19 relief expansion, and resources available for families. [Register.](#)

Caregiving

Viewpoint: As a Parent of a Medically Fragile Child, How I've Learned to Stay Calm in a Crisis



Parents of children with medically complex disabilities often are expected to provide the same level of care as intensive care units, says disability rights advocate Jennifer McLelland. A mother of a child with medical complexity and former police officer, she offers advice on how not to panic during a child's medical emergency and be able to respond appropriately. This is the first of a quarterly column from *California Health Report*, with support from our Foundation, on being the parent of a medically fragile child. [Read more.](#)

Webinar: Paying Family Caregivers through Medicaid Consumer-Directed Programs – State Opportunities and Innovations

Date Friday, May 21

Time 12 to 1 p.m. Pacific Time

Sponsor National Academy for State Health Policy

Details States can use consumer-directed programs to support Medicaid enrollees who receive care from family members or individuals they prefer. This webinar will feature highlights from a new study that explores state approaches to payment of family caregivers within Medicaid consumer direction programs. [Register.](#)

Caregivers Summit Coming Up Soon

Caregivers, both paid and unpaid, are crucial to maintaining the health care system, yet their work is not adequately recognized or compensated. The free, virtual National Caregiver Summit on May 25 will offer the opportunity for caregivers, advocates, and thought leaders to identify and support solutions to issues that affect all caregivers. The summit is sponsored by Health Leads and the Stanford Clinical Excellence Research Center, with support from our Foundation. [Read more and register.](#)

Family Engagement

Early Registration Extended for Family Voices Leadership Conference

Reduced rates for individual registration are available through **May 24** for the virtual conference scheduled for June, *Families as Partners Shaping the Future in Times of Crisis*. [See the schedule and details.](#)

Equity

Conversation: Research-Informed Practices to Improve Outcomes for Black Students with Disabilities

Date Tuesday, May 18

Time 12:30 to 2 p.m. Pacific Time

Sponsor WestEd's National Center for Systemic Improvement

Details This conversation is part of a virtual series with experts focusing on questions related to the intersection of race and disability in special education, and in education more broadly, to explore ways that systems can actively improve conditions and outcomes for Black students. [Read more and register.](#)

Families Discuss Need for Equitable Regional Center Services for Latinx Children

In 2020, Public Counsel released a [report](#) citing inequities in funding of services for children of color with developmental disabilities served by California's regional centers. Two new articles report on the current situation.

- [For Spanish-Speaking Families, an Uphill Battle for Special Needs Services](#)
Disability Scoop, 5/4/21
- [How to Better Serve Latinx Children with Special Needs: A Conversation with Parents Helping Parents](#)
California Health Report, 5/3/21

California Children's Services

Whole Child Model: Requiring Medical Documentation from Health Plans

Medi-Cal managed care organizations now deliver services to California Children's Services (CCS) clients in 21 counties, under a program called the Whole Child Model (WCM). The [Children's Regional Integrated Service System](#) has closely monitored the implementation of the WCM and has developed a series of issue papers identifying potential strategies to address issues and concerns.

The last of five papers we are featuring notes that some WCM managed care plans are not providing the current medical reports that CCS staff need in order to conduct timely and annual medical eligibility determinations. The paper recommends that the Department of Health Care Services clarify that it is the responsibility of WCM plans to provide the necessary medical documentation, and offer WCM plans guidance for appropriate referrals, including a standardized form or template. [Read more and see the earlier papers.](#)

COVID-19 Information

Find additional information and resources on our [COVID-19 web page](#).

- COVID-19 has exacerbated an already troublesome downward trend in children's mental well-being. In response, the [Children's Hospital Association](#) and the [American Academy of Pediatrics](#) have launched an [awareness campaign](#) to highlight the escalating crisis and promote ideas of what government can do to ensure that families have access to services.
- [Disability Scoop](#) reports on how [Mock Clinic Helps Those with Special Needs Prepare for COVID-19 Vaccine](#).

Transition to Adult Care

Telehealth Toolkit Provides Guidance for Joint Pediatric/Adult Transition Visit

For readers who have not been able to access this guide, which was noted in the last newsletter, please go to [GotTransition.org](#) and search for *Telehealth Toolkit for a Joint Visit with Pediatric and Adult Health Care Clinicians and Transferring Young Adults*.

In the News

- [Schools Are Sending Kids to Virtual Classes as Punishment. Advocates Say That Could Violate Their Rights.](#)
NBC News, 5/4/21
- [How Biden's Families Plan Impacts People with Disabilities](#)
Disability Scoop, 4/30/21

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.

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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.

