

California Advocacy Network for Children with Special Health Care Needs

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

Network News

Final Reminder: Letters of Inquiry Due

July 23 is the deadline to submit a preliminary letter to apply for a grant from our Foundation. Applicants should carefully review the program goals, priorities, and restrictions before submitting a letter. [Read about the application process.](#)

Children with Medical Complexity

Research: Parents of Kids with Complex Conditions Need Mental Health Support

A new study that assessed parent-reported data from the National Survey of Children's Health found that parents of children with medical complexity are more likely than other parents to report fair or poor mental health. These parents are also more likely to state that they do not know where to find community help, but they indicate that they receive emotional support from health care providers and advocacy groups. Read [A National Mental Health Profile of Parents of Children with Medical Complexity](#) in *Pediatrics*.

Family Engagement

Webinar: How Medicaid Agencies Can Engage with Families, Youth

Date Tuesday, July 27
Time 10 to 11 a.m. Pacific Time
Sponsor Center for Health Care Strategies
Details Meaningful partnerships with enrollees can help Medicaid agencies better serve youth and families, including those with special health care needs. The Center for Health Care Strategies (CHCS), with support from our Foundation, conducted a survey to understand engagement strategies Medicaid agencies are using across the country. CHCS also interviewed family-led CSHCN-focused organizations and Medicaid leadership. This webinar will examine their findings and provide recommendations. [Read more and register.](#)

Case Study: A Unique Model of Care for Children with Intellectual/Developmental Disabilities

Many primary care providers lack the time, experience, and resources necessary to provide high-quality care for children with intellectual and developmental disabilities (I/DD), and they may not practice in settings that integrate the extensive social and behavioral health services these children require. To address these challenges, the Achievable Foundation, founded by parents, developed a federally qualified health center in Los Angeles that, uniquely, is physically co-located with its local Regional Center for Developmental Disabilities. A new case study, supported by our Foundation, documents the challenges and successes of the process and offers advice on how others might collaborate to improve health care for individuals with I/DD. [Read the case study.](#)

California Children's Services

CCS Advisory Group to Meet

Date Wednesday, July 14
Time 11 a.m. to 3 p.m. Pacific Time
Details Find the agenda and meeting details on the group [website](#).

Pediatric Palliative Care

Webinar: Pediatric Concurrent Care – Research Updates

Date Tuesday, July 20
Time 12 to 1 p.m. Pacific Time
Sponsors Pennsylvania's Pediatric Palliative Care Coalition, Greater Illinois Pediatric Palliative Care Coalition, Children's Hospice & Palliative Care Coalition of California, Jacob's Heart Children's Cancer Support Services, and the CSU Shiley Institute for Palliative Care
Details Until the Patient Protection and Affordable Care Act (ACA) was enacted there were two care choices for children given six months to live: continue treatment or cease treatment and enter hospice. The ACA added a third choice by mandating that concurrent care be offered to Medicaid and Children's Health Insurance Program (CHIP) patients. However, there is limited evidence about the impact of this end-of-life care delivery model on patient and family outcomes. Speakers will review the latest developments. [Read more and register.](#)

COVID-19 Information

Applying Family-Centered Care to Food Insecurity During COVID-19

In response to the pandemic, the Department of Family-Centered Care at Lucile Packard Children's Hospital Stanford launched a Family Food Support Program, with support from our Foundation. The program aimed to provide immediate resources to address acute food insecurity in clinical settings, establish pathways of distribution to provide caregivers with multiple points of access to resources, and partner with community organizations to support families outside the clinical setting. The program's first year and its outcome are highlighted in an article in *Pediatric Nursing*. [Read more.](#)

Viewpoint

Opinion: If Restaurants Can Build a Sidewalk Shed, They Can Accommodate Disabled Diners

The author contends that many restaurants have long ignored the Americans with Disabilities Act (ADA) requirements that restaurants have a barrier-free environment, including door entrance widths and ramps, table heights, accessible bathrooms, and accommodations for the visually impaired. She argues that if restaurant owners could learn to navigate COVID laws, they can now learn to navigate ADA guidelines, which broaden opportunities for individuals who need accommodations. [Read more.](#)

Health Equity

Webinar: Medi-Cal Mental Health Services – An Unfulfilled Promise for Mild to Moderate Consumers

Date Tuesday, July 27
Time 11 a.m. to 12 p.m. Pacific Time
Sponsor California Pan-Ethnic Health Network
Details The mental health benefit for Medi-Cal consumers with mild to moderate mental health concerns has been severely underutilized by communities of color and limited English proficient consumers. Speakers will discuss systemic barriers to care, make recommendations for change, and identify opportunities for advocacy. [Read more and register.](#)

In the News

- [When It Comes to People Like My Daughter, One Size Does Not Fit All](#)
NY Times, 7/4/21
- [Special Education Sees 'Historic' Boost in New Funding](#)
EdSource, 7/2/21
- [ESPN to Honor Athlete with Down Syndrome](#)
Disability Scoop, 6/29/21

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@pfch.org with your news or updates. Or contact newsletter editor: Eileen Walsh at Eileen.Walsh@pfch.org.

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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.

