

California Advocacy Network

for Children with Special Health Care Needs

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

Network News

Deadline Approaching for Letters of Inquiry

Letters of Inquiry for funding from the Lucile Packard Foundation for Children's Health will be accepted until **Wednesday, July 10**. Read [detailed information](#) about the funding criteria. Please submit only a Letter of Inquiry, not a full proposal.

California Policy

Update: Stark Funding Inequities Persist for Children Served by Regional Centers

Despite recent increased attention to addressing funding inequities within California's system of services for children with developmental disabilities, a new report by Public Counsel finds continuing disparities in regional center funding between White and Hispanic clientele and between English-speaking and Spanish-speaking clientele. New data confirm a long-term trend of inequalities that have dogged the system for more than 25 years. The study was funded by the Lucile Packard Foundation for Children's Health. [Read more](#).

Advocacy Opportunity

- **Medi-Cal Rate Cuts – Call to Action:** Medi-Cal is planning to lower fee-for-service rates for certain durable medical equipment items. Family Voices of California is urging stakeholders to fill out a [form](#) opposing the cuts to send to legislators.

Also See: [Threading the Labyrinth: Why Children in California with Special Health Care Needs Endure Delays in Securing the Medical Equipment and Supplies They Need](#)

Electronic Visit Verification (EVV) Phase II Meeting

Date Monday, June 17
Time 1 p.m. to 3 p.m. Pacific Time
Location 1700 K Street, Sacramento – First Floor Conference Room
Sponsors California Departments of Health Care Services, Social Services, Developmental Services, Public Health, and Aging
Dial-In (800) 593-0582; Passcode: 6023673

Details The meeting agenda and materials will be posted on the EVV [website](#). EVV is a system that electronically verifies that in-home service visits occurred. The federal government requires that all states implement EVV for Medicaid-funded personal care services.

Funding Opportunity

Applicants Sought for CSHCN Research Projects

The Children and Youth with Special Health Care Needs National Research Network (CYSHCN) is seeking applications for its Emerging Investigator Guided Research Program. CYSHCN is an interdisciplinary network focused on supporting, optimizing, and centralizing research on health systems that support CYSHCN and their families. Applications are accepted from investigators based at CYSHCN member institutions in any discipline. [See details about the projects, eligibility, and application process](#). A [webinar](#) is scheduled for **June 10** to assist applicants. No registration required. For questions, contact Charlene Shelton at Charlene.Shelton@UCDenver.edu or (303) 724-4359.

Social Determinants of Health

Viewpoint: Shared Lessons from Pediatrics and Adult Health Care

Adult and pediatric providers share many of the same challenges when helping their patients manage chronic conditions. One strategy that both are employing is paying more attention to families, social networks, and the social determinants of health. A recent commentary co-authored by the National Center for Complex Health and Social Needs and the Lucile Packard Foundation for Children's Health provides examples of lessons that adult health care can learn from pediatrics and vice versa. [Read more](#).

Children with Medical Complexity

How 10 Hospitals Redefined Care for Medically Complex Children

Ten children's hospitals across the country spent three years testing change concepts to improve care, avoid unnecessary visits, and reduce health care spending. A four-part webinar series highlights their success stories in transforming care for children with complex conditions. Their work was part of the Coordinating All Resources Effectively (CARE) Award. [Read more and view the webinars](#).

Transition to Adult Care

In Brief

- [Preparing for the Transition from Pediatric to Adult Health Care: Parent Guide](#) (PDF) – from Got Transition

National Policy

Bills to Watch

- [HR 2822 Family-to-Family Reauthorization Act of 2019](#) – Would extend funding for Family-to-Family Health Information Centers for five more years. Families staff the centers, which provide guidance and support to families of children with special health care needs.
- [S 651 / HR 1814 The ABLE Age Adjustment Act](#) – Would increase the threshold from age 26 to 46 for tax-favored ABLE (Achieving a Better Life Experience) accounts. ABLE accounts help individuals with disabilities save for and pay for disability-related expenses.

Webinar

Ensuring Psychosocial Wellness in School and the Community for the Seriously Ill Child

Date Thursday, June 20
Time 12 p.m. to 1 p.m. Pacific Time
Sponsors Children's Hospice and Palliative Care Coalition, Pennsylvania's Pediatric Palliative Care Coalition, and Greater Illinois Pediatric Palliative Care Coalition
Details This webinar will focus on specific ways to help children continue to succeed in school, activities, and the community despite a serious illness. Strategies for collaboration with school administrators, teachers, coaches, activity directors, clergy, and others will be highlighted. Fee: [Read more and register](#).

Resources

- [Guidance Updated for Sedation in Pediatric Dental Patients](#) – from the American Academy of Pediatrics and the American Academy of Pediatric Dentistry

- *Complex Child* June Issue: [Preemies and the NICU](#)

Did You Know?

Mental Health Issues Account for Largest Percentage of Hospitalizations Among Youth

The highest percentage of [hospitalizations](#) in 2017 among California youth ages 0-17 was for mental health reasons. Mental diseases and disorders accounted for 14% of hospitalizations, almost twice the rate due to asthma/bronchitis. The rate of hospitalization due to mental health issues has been on the rise since 2008, according to kidsdata.org.

In the News

- [People with Special Needs, Police Cadets Connect Through Art](#)
NBC Los Angeles, 6/2/19
- [A Final Comfort: Palliative Transport Brings Dying Children Home](#)
Kaiser Health News, 5/28/19
- [California Governor and Lawmakers at Odds over New Special Education Funding](#)
EdSource, 5/28/19
- [Health Tax Splits California Amid Need for Trump's Approval](#)
NY Times, 5/24/19
- [Children with Cancer Wait an Average of 6.5 Years Longer Than Adults to Access New Drugs](#)
Youth Health Magazine, 5/22/19

We'd like to hear from you

Let us know what's happening with your organization or family. Email newsletter editor Eileen Walsh at Eileen.Walsh@lpfch.org with your news or updates.

