

California Advocacy Network

for Children with Special Health Care Needs

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

Children with Medical Complexity

Medicaid Waivers: Home and Community-Based Care Coverage Varies Widely by State

Much of the care for children with medical complexity (CMC) is delivered in home and community-based settings and covered by Medicaid waivers. Little is known about the economic impact or effectiveness of waivers because their components and coverage have not been well defined. A new study, published in *Health Affairs* and funded by our Foundation, analyzes the scope of coverage offered by the waivers and evaluates how states are using waivers to provide care for CMC. The researchers found great variability among states in services offered, which may have an impact on child and family outcomes. [Read the abstract](#) or see the full article with a subscription.

National Policy

Webinar: Keeping Medicaid's Promise for Children with Special Health Care Needs

How can state Medicaid agencies, families, advocates, providers, and other stakeholders partner to improve access to services for Medicaid-enrolled children with special health care needs (CSHCN)? Although federal Medicaid law requires providing all children under age 21 with comprehensive pediatric health care services, almost a fifth of families of CSHCN report at least one unmet need and that number increases to 44% for children who are medically complex. Based on a soon-to-be-released issue brief, this webinar will feature a suite of actions that states can implement to ensure that CSHCN receive optimal care.

Date Wednesday, October 2
Time 12 to 1:30 p.m. Pacific Time
Sponsors Manatt Health, Robert Wood Johnson Foundation, Lucile Packard Foundation for Children's Health
Details CLE available. [Read more and register.](#)

Policy Allowing Seriously Ill Immigrants to Remain in US for Treatment in Jeopardy

Advocates are [fiercely opposing](#) an abrupt action on August 7 by the United States Citizenship and Immigration Services that eliminated a "deferred action" program allowing immigrants to avoid deportation while they or their relatives undergo lifesaving medical treatment. Reacting to sharp criticism, the administration announced on September 2 that it would [reconsider its decision](#). At present the future of the program is unclear, potentially placing seriously ill children in jeopardy. [Read more.](#)

Network News

Foundation Grants Help Improve System of Care, Survey Finds

To ensure that our investments are meeting the goal of improving the system of care for CSHCN, the Lucile Packard Foundation for Children's Health recently contracted with Public Health Institute (PHI) to conduct an independent survey of current and former grantees. PHI concluded that our Foundation funding is having a significant impact, both nationally and in California, most notably by enhancing the body of knowledge about the system of care and influencing public policy. The report also recommends an increased focus on direct advocacy. [Read the report](#) (PDF).

California Children's Services

How the Whole Child Model Will Be Evaluated

Under Senate Bill 586 the Department of Health Care Services (DHCS) is required to contract for an evaluation of the Whole Child Model (WCM), which transfers children from CCS coverage to Medi-Cal managed care plans. The evaluation must assess the performance of the health plans as compared to the performance of the CCS program prior to the implementation of the WCM in the counties where it is now under way. The evaluation must cover access to care, service use, quality and coordination of care for patients, and more. DHCS has contracted with the University of California, San Francisco, to conduct the evaluation. [Read a project summary and the scope of work](#) (PDF).

Family Engagement

Deadline Extended for Family Survey: Improving California Programs for CSHCN

The Family Health Outcomes Project at the University of California, San Francisco, and the California Department of Health Care Services are seeking families' opinions on how well CSHCN are being served in the state. Families may take the anonymous survey in [English](#) or [Español](#).

Quality Standards

- [Dental Students Will Soon Be Trained to Care for Those with Special Needs](#) – from Disability Scoop

Pediatric Palliative Care

Webinar: Pain Management for Children with Serious Illness in the Context of the Opioid Epidemic

Date Thursday, September 19
Time 12 to 1 p.m. Pacific Time
Sponsors Children's Hospice and Palliative Care Coalition, a division of Coalition for Compassionate Care of California, Pennsylvania's Pediatric Palliative Care Coalition, and Greater Illinois Pediatric Palliative Care Coalition
Details Fee. Complimentary registration is available for parents. [Register.](#)

Conference Presentation Opportunity in Palliative Care

The Coalition for Compassionate Care of California and Children's Hospice & Palliative Care Coalition invite members and professionals in pediatric palliative medicine and advance care planning to submit breakout session proposals for their 12th Annual Summit, which is scheduled for May 5-6, 2020, in Sacramento. Deadline for submissions is **September 30**. [See details.](#)

Call for Proposals

AMCHP Accepting Submissions for Annual Conference Presentations; CSHCN Track Included

The Association of Maternal & Child Health Programs (AMCHP) is seeking proposals for poster and session presentations at its 2020 Annual Conference, to be held March 21-24 in Crystal City, VA. The theme is *The Power of Connections: Building Equity for Healthy Generations*. A track is dedicated to children with special health care needs. Directors of state programs, federal officials, advocates, family leaders, researchers, and health care providers attend the conference. The submission deadline is **October 4**. [Find details.](#)

Webinar

Medicare-for-All? Public Option? What Does It All Mean for Low-Income Individuals?

Date Thursday, September 12
Time 10 to 11 a.m. Pacific Time
Sponsor National Health Law Program (NHeLP)
Details In preparation for the 2020 election, NHeLP has created a set of [guideposts and principles](#) and a [blog](#) to help advocates navigate and better understand the impact of the various "universal health care" proposals. In this webinar experts will discuss these proposals and what they would mean for individuals on Medicaid. [Register here.](#)

In the News

- [A Young Woman, a Wheelchair and the Fight to Take Her Place at Stanford](#)
Kaiser Health News, 9/4/19
- [On the Job, 24 Hours a Day, 27 Days a Month](#) (Home Health Care Workers)
NY Times, 9/2/19
- [Target Offering Costumes for Kids with Special Needs](#)
Disability Scoop, 8/27/19

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.

