

California Advocacy Network

for Children with Special Health Care Needs

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

Family Engagement

Project Leadership: A Growing Network of Family Advocates



Families of CSHCN are the experts on their children's health care and on how systems and services could function more effectively to meet their needs. However, many family members lack the skills, confidence, and support to pursue advocacy and leadership roles in systems change. That's beginning to change in California. [Read more.](#)

Also See: [A Framework for Assessing Family Engagement in Systems Change](#) – from Family Voices

A Conversation on Meaningful Family Engagement, from Clinical Care to Health Policy

Date Wednesday, June 6

Time 10 a.m. to 11 a.m. Pacific Time

Sponsor The Lucile Packard Foundation for Children's Health

Details Engaging with families is vital to transforming the health care system and improving quality of life for children with complex conditions. Join the lead author and other experts for a lively discussion of the recently published article, [Families of Children with Medical Complexity: A View from the Front Lines](#). The speakers will lead a conversation about how to meaningfully involve families at all levels of health care systems, and engage them as partners in designing better policies. Second in a series of conversations with authors of the *Pediatrics* supplement: Building Systems that Work for Children with Complex Health Care Needs. [Read more and register.](#)

Information from Webinar on CCS Transition, Whole-Child Model

On May 18 the Department of Health Care Services presented a webinar on the upcoming transfer of some CCS clients to Medi-Cal managed care. [Slides](#) (PDF) from the presentation are now available. Find [information](#) about the Whole-Child Model.

Also See: [Medical Therapy Program \(MTP\) Service Interface with the Whole-Child Model](#) (PDF) – newly posted guidelines from the Department of Health Care Services

Why the Delays in Children Receiving Needed Durable Medical Equipment and Supplies?



Editor's note: Given the strong interest in this report, published in the May 10 newsletter, we are repeating it. Families and health care providers frequently report lengthy delays in obtaining essential supplies and equipment for children with special needs, sometimes with severe consequences for the child's health and development. A new report outlines the multiple administrative obstacles that contribute to these delays, and offers recommendations on how to address them. [Read](#) the full report and a fact sheet outlining its recommendations.

Also See: [Special Needs Children Often Left Waiting for Medical Equipment, Report Says](#)

Research

Study: How Pediatricians View Caring for Children with Special Health Care Needs

A large proportion of California children with special health care needs are cared for by primary care pediatricians, who face numerous challenges in providing appropriate services. A new study, published in the Maternal and Child Health Journal, assesses who is providing medical care to CSHCN in California, how providers differ in the types of patients and conditions they treat, and the level of pediatricians' access to subspecialty and practice resources. The authors discuss factors that might improve pediatricians' capacity for caring for CSHCN. Funding was provided by the Lucile Packard Foundation for Children's Health. [Read the study](#).

Also See: [Survey: Quantifying Pediatricians' Views on Caring for Children with Special Health Care Needs](#)

In Brief

- [How Do Medicaid/CHIP Children with Special Health Care Needs Differ from Those with Private Insurance?](#) – from Kaiser Family Foundation

Mental and Behavioral Health

Addressing Children's Mental Health Needs

May is Mental Health Awareness Month, a time to note that many children with special health care needs also require mental health services. Yet a 2017 survey of families and care providers by the National Health Law Program identified mental health treatment as one of the most difficult services for CSHCN to obtain. Similarly, respondents in a 2015 survey of pediatricians who care for CSHCN described great difficulty in making successful referrals for pediatric psychiatry and psychology services. The California Legislature has proposed several bills that address children's mental health. [Two current bills are worth noting.](#)

Also See: [Access to Mental Health Services for Children with Special Health Care Needs in California](#)

Resources

- [Turning Wheelchairs into Dreams](#) – costumes transform the chair and shift focus to the child – from Abilities.com
- [Center on Technology and Disability](#) – free resources on assistive and instructional technology, including webinars, articles, training materials, and more
- *Complex Child* May issue: [Respiratory](#)
- *Exceptional Parent Magazine* May issue – [Mobility](#)

California Policy

Voter Guide for Promoting Children's Health and Well-Being

As voters prepare to head to the polls on June 5, The Children's Partnership and the Children's Defense Fund-California have published *Building California's Future - A Voter Guide to Championing Policies that Improve the Lives of California's Children*. The guide lists facts about the state's children and poses potential questions for candidates. The guide does not endorse or oppose any candidate or party. [Read more](#).

In Brief

- [State Policymakers Could Be on the Verge of Boosting Basic Support for Low-Income Seniors and People With Disabilities](#) – from the California Budget and Policy Center

National Policy

In Brief

- [GAO Gives Green Light for CHIP Cuts](#) – from Public News Service
- [Potential Effects of Public Charge Changes on Health Coverage for Citizen Children](#) – from Kaiser Family Foundation
- [Step Guide to Updating States' Essential Health Benefits Benchmark Plans](#) – from National Health Law Program

Webinars

Cultural Perspectives on Self-Care in Leadership

Date Wednesday, May 30
Time 3 p.m. to 3:30 p.m. Pacific Time
Sponsor Family Voices National Center for Family Professional Partnerships
Details Part of a series for youth self-advocates. [Read more and register](#) (PDF).

Got Transition Webinar Series – Integration into Adult Care

Date Thursday, May 31
Time 12 p.m. to 1 p.m. Pacific Time

Sponsor Got Transition

Details Fourth in a series on health care transition featuring examples of best practices among state Title V agencies, tools and resources, and problem-solving strategies. [Read more and register.](#)

Developmental Screenings in Medicaid and CHIP: Federal Progress, State Opportunities

Date Thursday, May 31

Time 12 p.m. Pacific Time

Sponsor Georgetown Center for Children and Families

Details Will provide an overview of developmental screening in Medicaid and CHIP, federal efforts to improve state-level measurement as part of the [Child Core Set](#), and steps state stakeholders can take to improve developmental screening and follow-up services and supports in Medicaid and CHIP. [Register.](#)

Events

Who's Caring for the Children? A Pediatric Palliative Care Training – Communicating Difficult News with Clarity and Compassion

Date Friday, June 1

Time 8:30 a.m. to 4:30 p.m. Pacific Time

Location Jacob's Heart Children's Cancer Support Services
680 West Beach Street, Watsonville, CA

Sponsor Stanford Children's Health and six others

Details An interagency and interdisciplinary training for physicians, nurses, social workers, chaplains, administrators, and others caring for children with life-threatening conditions and families bereaved by the loss of a child. Fee. Six hours of CME from the American Academy of Family Physicians; five hours approved by the California Board of Registered Nursing. [Read more and register.](#)

Did You Know?

News Site Focuses on Child Health

California Health Report is a non-partisan, editorially independent news site that covers health and health policy throughout California. Two recently published articles highlighted concerns about long delays in providing durable medical equipment to children with special needs, and the lack of access to doctors for children covered by Medi-Cal. The site is supported by the Lucile Packard Foundation for Children's Health and grants from other foundations. [Read more and subscribe to their newsletter](#) to keep up to date with child health news.

In the News

- [Pros, Cons of Online Learning for Students with Disabilities](#)
U.S. News & World Report, 5/18/18
- [Caregiver Shortage Forcing Young People with Disabilities into Institutions](#)
Disability Scoop, 5/9/18
- [CDC: Primary Care Physicians Need to Conduct More Pediatric Developmental Screenings](#)
Healio, 5/8/18
- [Designing "Adaptive Clothing" for Those with Special Needs](#)
Smithsonian.com, 5/8/18

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.

This email was sent by:
Lucile Packard Foundation for Children's Health
400 Hamilton Ave, Suite 340 Palo Alto, CA, 94301,
USA

