

California Advocacy Network

for Children with Special Health Care Needs

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

Children with Medical Complexity

Webinar: Maximizing System-Level Data to Address Medical and Social Complexity in Children

Date Tuesday, April 2
Time 11 a.m. to 12 p.m. Pacific Time
Sponsors Oregon Pediatric Improvement Partnership (OPIP) and Oregon Health Authority
Details Second in a two-part series. An innovative methodology that uses system-level data to identify children with health complexity, based on both medical and social complexity, is transforming care for these children in Oregon. Learn how the state's standardized approach has helped inform priority areas, potential policy improvements, investments, and partnerships in support of children with health complexity. [Register and find suggested reading](#) to prepare for the webinar. Also see information about [Part 1](#) of the series.

Network News

From the Foundation: Current Issues Facing CSHCN and Their Families

In a recent webinar for California state and county stakeholders, staff members from the Lucile Packard Foundation for Children's Health presented an overview of topics that are a priority in the field of special health care needs, noting crucial but missing services for CSHCN and their families. The speakers also suggested issues that can be addressed by public agencies, and identified resources to help guide programs and policies. The Foundation's work in three key areas – system standards, care coordination, and family engagement – was highlighted. [See the slides and resource sheet](#).

Family Engagement and Support

Opportunities for States to Support Family Caregivers

The Center for Health Care Strategies recently convened a meeting of six states that are seeking to advance state-based strategies to support family caregivers. Participants identified five priority areas for an aging population that have equal applicability for CSHCN and their families. [Read more](#).

California Children's Services

CCS Transition to Adulthood Workgroup to Meet

The next meeting of the California Children's Services (CCS) Transition to Adulthood Workgroup is scheduled for March 27. Call-in and registration information is available on the CCS Advisory Group [website](#). The agenda and meeting materials are scheduled to be posted prior to the meeting.

Telemedicine

Webinar: Using Telemedicine for Pediatric Behavioral Health Services

Date Thursday, March 28
Time 11 a.m. to 12 p.m. Pacific Time
Sponsor Children's Hospital Association
Details Long travel times, unfamiliar clinical settings, and a lack of providers are barriers to mental health care for children in rural communities. Omaha's Children's Hospital & Medical Center is partnering with primary care clinics throughout Nebraska to provide telepsychiatry to youth. Speakers will discuss telepsychiatry development steps, identify reimbursement solutions, and describe keys to program maintenance. [Register](#).

Special Education

- [Trump Administration Ordered to Reinstate Special Ed Rule](#) – Judge rules that US Department of Education cannot delay implementation of a regulation aimed at preventing certain students from being wrongly placed in special education.

California Policy

Webinar: Proposal for Value-Based Payment Program through Medi-Cal Managed Care Plans

Date Tuesday, March 19
Time 11 a.m. to 12 p.m. Pacific Time
Sponsor Department of Health Care Services
Details The Value-Based Payment Program would provide incentive payments to providers for meeting specific measures aimed at improving care for certain high-cost or high-need populations, including those with chronic disease. [Read more](#), including information on how to comment. Register [here](#).

Bill to Watch

- [AB 236](#) – This bill revises and recasts requirements for Family Empowerment Centers on Disability in 32 regions throughout California. The centers provide training and services to children and young adults with disabilities and their families.

In Brief

- [Clocking In: The Caregivers Who Step in to Care for California's Most Fragile Kids](#) – An article highlighting Angels in Waiting, a nonprofit made up of nurses who care for medically fragile babies and children in foster care in California. The piece draws attention to the need for better options to provide skilled care in homes for these vulnerable children, to avoid placing them in institutions.

Resources

- The Catalyst Center has published three new one-page infographics regarding health care financing and coverage for CYSHCN. The new topics in the series include:
 - [Family Engagement and CYSHCN](#)
 - [Pathways to Medicaid Coverage for CYSHCN](#)
 - [EPSDT and CYSHCN](#)
- [What Parents Need to Know About Genetic Testing](#) – Pediatricians may recommend a genetics consult or genetic testing for a child for various reasons. This article from *JAMA Pediatrics* offers information to help families decide whether to proceed.
- *Complex Child* March issue: [Neurological Conditions](#)

Child Health Advocacy

Two New Organizations Target Child Health and Well-Being Nationwide

- [Leading for Kids](#) – This nonprofit seeks to improve child health and well-being by launching a movement to inspire individuals and decision-makers to create a society that more deeply values children. Its founder and CEO is David Alexander, MD, former CEO and President of the Lucile Packard Foundation for Children's Health.
- [Accelerating Policymaker Accountability for US Kids' Well-Being: Charting the Course & A Call to Action](#) (PDF) – A new report from the founders of The Children's Partnership describes kidsimpact, their recently launched venture aimed at developing and promoting strategies to support and strengthen the child advocacy field.

Webinar

Building Resilience in Children and Caregivers Facing Serious Pediatric Illness

Date Tuesday, March 19
Time 12 p.m. to 1 p.m. Pacific Time
Sponsors Coalition for Compassionate Care of California, Pennsylvania's Pediatric Palliative Care Coalition and Greater Illinois Pediatric Palliative Care Coalition
Details Learn ways to help children, teens, and young adults – and their parents – become more resilient in the face of serious health problems. The goal is to equip patients and families with skills that improve their outcomes and help them lead happier, more fulfilling lives. Fee: [Register](#).

Event

March Is National Developmental Disabilities Awareness Month

Find [resources](#) for a social media campaign that highlights the many ways in which people with and without disabilities come together to form strong, diverse communities.

In the News

- [Opinion: Could the Fallout from the Admissions Scandal Hurt Kids with Disabilities?](#)
Washington Post, 3/14/19
- [The Shrinking Number of Special Ed Teachers Adds to Schools' Pressures](#)
PBS, 2/28/19
- [There Is a Better Way to Teach Students with Learning Disabilities](#)
Time, 2/28/19
- [Opinion: Parents, It's Okay to Label Kids with Special Needs. It May Even Be Good for Them.](#)
Washington Post, 2/25/19

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.

