

California Advocacy Network for Children with Special Health Care Needs

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

Caregiving

Webinar: Understanding the Emotional Well-Being of Family Caregivers of Children with Medical Complexity

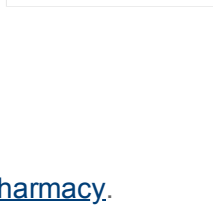
Date Tuesday, April 19
Time 12 p.m. Pacific Time
Sponsors Pennsylvania's Pediatric Palliative Care Coalition, Greater Illinois Pediatric Palliative Care Coalition, Children's Hospice & Palliative Care Coalition of California, and the CSU Shiley Haynes Institute for Palliative Care
Details Caring for a child with medical complexity can affect the emotional health of the caregivers, but the effects are not widely known. The speaker will review the existing literature, the team's current research, and plans for next steps to improve the health and well-being of the critical caregiver population. Fee. [Read more and register.](#)

Shining Light on the 'Invisible' Health Care System: Understanding Caregiving and Caregivers

Family caregivers deliver an estimated 1.5 billion hours of health care annually to their children at home. Yet this aspect of the health care system is largely "invisible." In a paper titled *Understanding Caregiving and Caregivers: Supporting Children and Youth With Special Health Care Needs at Home*, researchers from [CYSHCN](#) outline research priorities centered on partnerships with diverse families. The aim is to develop an evidence base relevant to family caregivers and the unique needs of their children. [Read more](#) and [see a related webinar](#).

Children with Medical Complexity

Webinar Reminder: Conversations with Families – Sleep Issues



Thursday, April 14
10 to 11 a.m. Pacific Time
[Read more and register.](#)

See the recording from the seventh seminar: [Polypharmacy](#).

California Children's Services

CCS Advisory Group to Meet

Date Wednesday, April 13
Time 1 to 4 p.m. Pacific Time
Dial-In 1-415-655-0001; [Join via WebEx](#)
Details See details on the [website](#).

California Policy

Viewpoint: Why California Needs an Oversight Office for Durable Medical Equipment

A *California Health Report* columnist who is the mother of a child with special health care needs writes that the state's system of supplying medical equipment is already complicated, and the pandemic has exacerbated supply shortages, putting children's lives at risk. She calls for an oversight office. [Read her opinion piece.](#)

Also see: [Helping Families Obtain Durable Medical Equipment and Supplies through the California Children's Services Program](#)

Family Engagement

Webinar: AMCHP's Family Delegate Guide

Date Wednesday, April 13
Time 11 a.m. to 12 p.m. Pacific Time
Sponsor The Family Leadership, Education, Advocacy, and Development (LEAD) Committee of the Association of Maternal and Child Health Programs (AMCHP)
Details The webinar will focus on AMCHP's [Family Delegate Guide](#) (PDF) and partnerships between Title V programs and family delegates/family leaders. Complete a [registration form](#) by **April 8** to receive information on participation.

Developmental Disabilities

Webinar: Optimizing Outcomes for Patients with Chronic Illnesses and Disabilities

Date Tuesday, April 12
Time 11 a.m. to 12 p.m. Pacific Time
Sponsor Camden Coalition of Health Care Providers
Details Discussion will focus on bringing awareness to the challenges faced by patients with disabilities and chronic illnesses and their caregivers, and the importance of better understanding their needs. Not pediatric specific. [Read more and register.](#)

In Brief

- [Health Needs and Use of Services among Children with Developmental Disabilities](#) – an update from the Centers for Disease Control and Prevention

Health Equity

Commentary: The Need for Disability Documentation in the Electronic Health Record

In a blog in *Health Affairs Forefront*, a medical student makes the case that robust use of the electronic health record could improve quality of care for patients with disabilities by enhancing caregivers' documentation of their conditions and their needs for accommodations. [Read the blog.](#)

Disability and Reproductive Health: It's Time to Talk about It

The March newsletter of the Association of Maternal and Child Health Programs devotes several articles to the intersection of reproductive health and disability justice. [Read the articles.](#)

COVID-19 Information

- [Medicaid and CHIP Eligibility and Enrollment Policies as of January 2022: Findings from a 50-State Survey](#) – from the Georgetown Center for Children and Families

Telehealth

Promoting High-Value Care through Telehealth

As telemedicine becomes increasingly prevalent, providers and payers, including those implementing value-based payment approaches, may need to consider how best to provide telehealth services that encourage high-quality and cost-efficient care. A Better Care Playbook interview with a Harvard Medical School professor offers some thoughts. [Read the Q&A.](#)

National Policy

Webinar: Meeting Health-Related Social Needs through Medicaid: A New Opportunity for States

Date Wednesday, April 6
Time 9:30 to 10:30 a.m. Pacific Time
Sponsors Manatt Health, Commonwealth Fund
Details In recent years, states have sought to leverage Medicaid to address social drivers of health, relying primarily on waivers for financing. The Centers for Medicare & Medicaid Services approved California's recent Medicaid proposal to establish a new framework for states to embed health-related services into their Medicaid programs through "in lieu of" services regulatory authority. In this webinar, speakers will discuss California's experience and what other states can learn as they seek to implement their own "in lieu of" services. Not pediatric specific. [Read more and register.](#)

In Brief

- [Fact Sheet: Early and Periodic Screening, Diagnostic and Treatment \(EPSDT\), Litigation Trends and Docket](#) – from the National Health Law Program
- [Justice Department Issues Web Accessibility Guidance under the Americans with Disabilities Act.](#)

Events

Conferencia: Prevención del Abuso Sexual

Fecha Sábado, 2 de abril
Hora 10 a.m. a 12 p.m. Hora del Pacífico
Patrocinador Congreso Familiar
Detalles Congreso Familiar es una conferencia dedicada a promover la educación y el liderazgo en familias latinas que tienen hijos o familiares con discapacidades. En este evento virtual, aprenda estrategias para proteger a los niños del abuso sexual sin asustarlos, sin destruir su confianza ni explicar el abuso sexual. [Regístrate.](#)

In Brief

- The last chance for early-bird registration for the [AMCHP 2022 Annual Conference](#) is **April 1** at 11:59 p.m. Eastern Time. Fee.

In the News

- [CDC, WHO Criticized for Perpetuating Down Syndrome 'Misinformation'](#)
Disability Scoop, 3/22/22
- [Congress Boosts Funding for Special Ed, Disability Programs](#)
Disability Scoop, 3/17/22

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.

[Join the Network](#)

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.

