

Children and Youth with Special Health Care Needs

Network Newsletter

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

HOME- AND COMMUNITY-BASED CARE

Webinar: Addressing the Crisis in Pediatric Home Health Care

- DATE** Wednesday, March 8
- TIME** 10 to 11 a.m. Pacific Time
- SPONSOR** Lucile Packard Foundation for Children's Health
- DETAILS** Children with medical complexity require a substantial amount of medical care and activities-of-daily-living support to live at home. However, due to a shrinking pool of available home health care workers and narrow state eligibility requirements for services, most of their care is increasingly delivered by families without pay. In response, the option to pay family caregivers for their children's medical labor is gaining national traction. This webinar will provide a brief overview of laws that govern care for this population and then spotlight specific models of paid family caregiving and how they have been expanded recently in several states. [Read more and register.](#)
- Two related fact sheets, available in English and Español, provide additional information about how the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) Medicaid benefit might assist with payment.
- [What Is EPSDT?](#)
 - [Children's Home Health and EPDST](#)

Related: [Biden Renews Calls to Invest in Services for People with Disabilities](#) and [Senate Bill 100](#), which would expand access to home and community-based services while increasing pay and improving benefits for caregivers.

FAMILY ENGAGEMENT

Measuring Parents' Confidence in Caring for CYSHCN

Confidence in completing a task, known as self-efficacy, is important for families managing a child's chronic health condition. Knowing parents' level of self-efficacy may be valuable for professional caregivers. A new open-access paper, published in the *Journal of Patient-Reported Outcomes*, describes the development of a patient-reported outcomes measure designed to assess self-efficacy of parents managing their child's conditions. The authors note that the measure was found to be both acceptable and understandable to English and Spanish speakers, and may be useful to identify parents in need of additional supports at hospital discharge or at the time of a new diagnosis. [Read the paper.](#)

Reminder

There is still time to register for the [Family Voices of California Health Summit](#).

PUBLIC HEALTH EMERGENCY UNWINDING UPDATES

High Stakes for Children When Medicaid Continuous Coverage Protection Expires

A webinar and a new report from the Georgetown Center for Children and Families discuss the implications for children of the ending of Medicaid continuous coverage protection, and suggest steps states can take to mitigate coverage loss. [View the webinar and read the report](#), *Child Uninsured Rate Could Rise Sharply If States Don't Proceed with Caution*, which covers all 50 states.

Additional PHE Unwinding Resources

- [What Does the End of COVID Emergency Declarations Mean for Medicaid/CHIP?](#) - from Georgetown Center for Children and Families
- [Important Consumer Protection for People Losing Medicaid/CHIP](#) - from the Centers for Medicare and Medicaid Services
- [Renew Your Medicaid or CHIP Coverage](#) - from Medicaid.gov
- [Keep Yourself and Your Family Covered](#) - from the California Department of Health Care Services

HEALTH EQUITY

Opportunities to Advance Health Equity for Seniors and People with Disabilities in California and Beyond

California is implementing [CalAIM](#), a strategy to improve and align care for all Medi-Cal (Medicaid) enrollees. A "policy cheat sheet" from the Center for Health Care Strategies explores several CalAIM initiatives that specifically affect seniors and people with disabilities, and the opportunities they present to address health equity for these populations. The authors suggest that lessons from California can help inform other states seeking to improve care and address health equity for these groups. [Read more.](#)

PEDIATRIC PALLIATIVE CARE

Webinar: Compassion, Connection and Creativity - Utilizing Music Therapy to Navigate Caregiver Guilt in Pediatric Palliative Care

- DATE** Tuesday, February 21
- TIME** 12 to 1 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** The speaker will highlight the role of music therapy to support caregiver coping and will discuss how music therapists can provide meaningful opportunities for connection and beauty. She also will discuss the ways in which concepts from this presentation can be integrated into clinical work by interdisciplinary providers, and she will describe techniques that can be used in the home setting. [Read more and register.](#) Fee.

SPECIAL EDUCATION

Article: How Educators Secretly Remove Students with Disabilities from School

A front-page article in *The New York Times* explores the impact on children and families of a practice known as "informal removal," which some schools use to keep certain students with disabilities out of class. The removals — which can include repeated dismissals in the middle of the day or shortening students' education to a few hours a week — are often in violation of federal civil rights protections for those with disabilities, the article says. [Read more.](#)

In Brief

- [Ed Department Urges Schools to Limit Suspensions of Students with Disabilities](#) - from *Disability Scoop*
- [There's a New Pathway to Special Education for up to 300,000 California Children](#) - from *California Health Report*

CALIFORNIA CHILDREN'S SERVICES

Senate Bill Aims to Modernize CCS

Adjusting reimbursement rates for care providers, enhancing financial assistance for families, and addressing further expansion of the Whole Child Model are among the many components of a just-introduced California Children's Services Modernization Senate Bill ([SB424](#)). Designed to improve children's quality of, and access to, health care, the bill also will update financial eligibility for the program, and cover high-cost specialty drugs at the same rate regardless of whether the drug is provided on an in-patient or out-patient basis, among other provisions. Read [a fact sheet](#) from the Children's Specialty Care Coalition and the California Children's Hospital Association.

RESOURCES

- *Exceptional Parent Magazine* [Annual Healthcare Issue](#)
- The Centers for Disease Control and Prevention offers [photo and video examples of important developmental milestones](#) and a milestone checklist that families can use to track a child's progress.

IN THE NEWS

- [States Scramble to Replace Ripped-Off SNAP Benefits](#)
Disability Scoop, 2/14/23
- [Children's Books Honored for Disability Representation](#)
Disability Scoop, 2/3/23
- [The Funding Cliff for Student Mental Health](#)
AXIOS, 2/2/23

WE'D LIKE TO HEAR FROM YOU

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

[Join The Network](#)

To see past issues, visit the [Network Newsletter Archive](#).