

Children and Youth with Special Health Care Needs

Network Newsletter

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

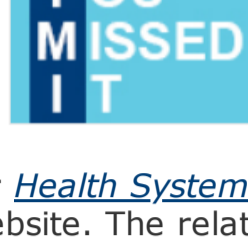
Editor's Note -- This issue of the Newsletter features a new masthead, some formatting modifications, and the new logo of the Lucile Packard Foundation for Children's Health. The logo pays tribute to Lucile Packard's lifelong commitment to children's health, and the color palette honors our relationship with Stanford Medicine and Lucile Packard Children's Hospital Stanford. The portrayal of a parent and child embracing is a reminder that families are at the heart of our Foundation's work.

CHILDREN WITH MEDICAL COMPLEXITY

Now Available for Use: PediHome – A Family-Reported Measure of Pediatric Home Healthcare Quality

PediHome is a content-valid family-reported survey measure of home healthcare quality for children with medical complexity that can be used to evaluate family caregivers' perspectives on to what degree their child is receiving accessible, high-quality home healthcare. The freely available survey, whose development was funded by our Foundation, can be used for care delivery evaluation, research, quality improvement, and identifying deficits in care to improve training. The survey is available in several formats, including REDcap, Qualtrics, and paper versions, in English and Spanish.

[Read more](#)



The slides and recording of the webinar [Health Systems Strategies that Prioritize Children with Health Complexity](#) are posted to our website. The related [report](#) also is available.

In Brief

- [Obesity in Children with Medical Complexity](#) – from *Contemporary Pediatrics*

COVID-19 UPDATES

Maintaining Children's Health Coverage as New Law Brings Changes

A new federal law, the Consolidated Appropriations Act 2023, has wide-ranging and important effects on policies relating to CYSHCN, including Medicaid and the Children's Health Insurance Program. A [blog](#) from the Georgetown Center for Children and Families explains key provisions, including the date for the ending of the Medicaid continuous coverage requirement and the phasing out of the flexible Public Health Emergency policies. [Information](#) is available to help organizations and families take the steps necessary to maintain children's health insurance after the continuous coverage requirement ends. Also, the Centers for Medicare & Medicaid Services is offering a series of webinars, beginning January 25, on [Medicaid and CHIP Continuous Enrollment Unwinding: What to Know and How to Prepare](#).

Related: California has established a [Coverage Ambassador Program](#) to develop trusted messengers from diverse organizations to inform beneficiaries, in culturally and linguistically appropriate ways, about how to maintain coverage.

INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Caregiver Survey: Family and Individual Needs for Disability Supports

The Arc and the University of Minnesota are conducting a national survey of family members or unrelated caregivers, such as a friend or neighbor, who provide primary and frequent support to a person with an intellectual or developmental disability. The goal is to identify the most pressing needs.

[Read more](#)

TRANSITION TO ADULTHOOD

Webinar: Pursuing a Secure Economic Future for Youth with Disabilities

DATE	Wednesday, January 25
TIME	9 to 10:30 a.m. Pacific Time
SPONSOR	Mathematica Center for Studying Disability Policy
DETAILS	Speakers will discuss <i>Pursuing a Secure Economic Future for Youth with Disabilities – Lessons from the Promoting Readiness of Minors in Supplemental Security Income</i> , a report on a five-year federal demonstration project. They will explain how those findings may assist states and service providers seeking to improve the long-term economic well-being of youth with disabilities.

[Read more and register](#)

HOME- AND COMMUNITY-BASED CARE

Roundtable: Strengthening the Home- and Community-based Ecosystem

DATE	Thursday, January 26
TIME	9 am to 12 p.m. Pacific Time
SPONSOR	National Council on Disability
DETAILS	This two-part policy roundtable will focus on strengthening the home- and community-based ecosystem, with emphasis on the direct care workforce and affordable, accessible housing.

[Read more and register](#)

Related: [To Attract In-Home Caregivers, State Offers Paid Training — and Self-Care](#) – from *Disability Scoop*

HEALTH EQUITY

Conference to Focus on Developing Diverse Leaders in Maternal, Child Health

Early registration for the 2023 Association of Maternal and Child Health Programs is available until **March 8**. The theme is *Cultivating Diverse Leaders in Maternal and Child Health* for the May 6-9 event in New Orleans, which also may be attended virtually.

[Read more and register](#)

In Brief

- [Promoting Health Equity and Combating Racism Through Health Policy](#) – from The Commonwealth Fund
- [The Path Forward: Improving Data to Advance Health Equity Solutions](#) – from the Centers for Medicare & Medicaid Services

CALIFORNIA POLICY

Updated: Advocate's Guide to Medi-Cal Services Highlights CalAIM, Telehealth Changes

The National Health Law Program has updated its 2020 guide for Medi-Cal advocates. The guide explains policy changes related to the California Advancing and Innovating Medi-Cal (CalAIM) initiative, including a chapter on Case Management and Community-Support Services, which provides information on new services that have become widely available. There is also a new addendum summarizing Medi-Cal's telehealth policy in light of changes adopted during the COVID-19 pandemic.

[Read more](#)

NATIONAL POLICY

- [Public Charge Final Rule Took Effect December 23, 2022](#)

SPECIAL EDUCATION

Seminarios Web: Educación Especial

En esta serie de 4 presentaciones hablaremos sobre la educación especial y como propugnar por sus hijos en el sistema educativo. Los primeros dos eventos:

FECHA	Sábado, 21 de enero
HORA	10 a.m. – 12 p.m., Tiempo del Pacífico
PATROCINADOR	Congreso Familiar
DETALLES	En momentos de crisis todos necesitamos ayuda. Como padres podemos prevenir una crisis en los servicios de educación especial provocada por la diferencia de opiniones en el equipo de Programa Educativo Individualizado (IEP).
FECHA	Sábado, 28 de enero
HORA	10 a.m. – 12 p.m., Tiempo del Pacífico
PATROCINADOR	Congreso Familiar
DETALLES	Cómo hacer posibles los servicios educativos para niños y jóvenes con discapacidades por medio de un Programa Educativo Individualizado (IEP).

[Leer más y registrarse](#)

In Brief

- [Supreme Court Case Could Change How Special Ed Disputes Are Handled](#) - from *Disability Scoop*
- [Congress Approves Boost to Special Ed Disability Programs](#) - from *Disability Scoop*

RESOURCES

- *Exceptional Parent* January issue offers a [Guide to Navigating Special Needs Resources](#).

IN THE NEWS

- [Advocates Sue the State of Iowa over Failure to Provide Mental Health Care for Medicaid-Eligible Children](#)
National Health Law Program, 1/6/23
- [Walmart Accused of Wrongfully Firing Greeter with IDD](#)
Disability Scoop, 1/6/23

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.

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