

Children and Youth with Special Health Care Needs

Network Newsletter

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

HOME- AND COMMUNITY-BASED CARE

Access and Quality of Pediatric Home Health Care: A Systematic Review

The number of children with medical complexity who require extensive medical care at home is rising, but the literature evaluating pediatric home health care has not been well summarized. In an article based on research funded by our Foundation, the authors systematically review the evidence base of pediatric home health care to understand what is currently known about access and quality of care. [Read the article.](#)

In the Media

- [The Quiet Rage of Caregivers](#) – from the *New York Times*
- [Disability Providers Warn Overtime Pay Rule Could Jeopardize Services](#) – from *Disability Scoop*
- [Californians Who Need Help Paying for Round-the-Clock Home Care Are Stuck on a State Waitlist](#) – from the *Los Angeles Times*
- [Analysis: California Is Rationing Care for People with Disabilities. It's Indefensible, But Here's a Solution](#) – from the *California Health Report*

CHILDREN WITH MEDICAL COMPLEXITY

Reminder: Take a Survey to Help Improve Family Well-Being

Researchers at the [CYSHCNet](#) are asking families of children, youth, or young adults with complex health issues to complete a 15-minute survey on what their day-to-day life is like and what the health care system can do to improve family well-being. [Take the survey in English or Español](#) through **December 31**.

HEALTH EQUITY



Opinion: A Step in the Right Direction to End Disability Discrimination in Health Care

The federal government has issued a proposed rule to enhance Section 504, the landmark 1973 national law that protects qualified individuals from discrimination based on their disability. In an American Academy of Pediatrics blog, Dr. Amy Houtrow, a member of the National Center for a System of Services for CYSHCN Steering Committee and an author of [Health Equity for CYSHCN: A Vision for the Future](#), discusses the importance of the proposed rule in advancing equity for children with disabilities and shares patient and family stories from her own experiences. [Read the blog](#).

Related: [Comments on Section 504 Proposed Rules](#) – from the National Health Law Program

FAMILY ENGAGEMENT



The slides and recording from the webinar [Do Patient and Family Advisory Councils Make a Difference? Measuring Their Impact](#) now are available.

Also see: [Strengthening the Diversity and Role of Patient and Family Advisory Councils: Opportunities for Action](#)

In Brief

- [How One Bay Area Organization Is Helping Asian American Families Find Support](#) – from the *California Health Report*

NATIONAL POLICY

Time to Sign Up for Health Insurance

Enrollment is open for health insurance coverage through the Affordable Care Act marketplace, which offers a range of plans and prices for those who qualify. The deadline is **December 15** in most states, but it is important to check local rules. [Read more](#).

In Brief

- [Congress Urged to Update SSI Asset Limits](#) - from *Disability Scoop*

TELEHEALTH

Webinar: State Telehealth Policy Trends - 2023 Year in Review

DATE

Tuesday, December 5

TIME

9 to 10 a.m. Pacific Time

SPONSORS

American Medical Association and Manatt

DETAILS

In the wake of COVID-19 temporary policies, many states continue to enact permanent changes to telehealth laws that affect how physicians and other providers can deliver care remotely. Speakers will provide a year-end snapshot of key telehealth policy trends, including a summary of 2023 legislative activity with specific state examples. [Read more and register.](#)

HEALTH CARE FINANCING

Strategies to Finance Services for CYSHCN

Many Title V and Medicaid programs use funds from their own programs or leverage other funding to reduce the number of CYSHCN without health insurance, and to close benefit gaps, pay for additional services, and build the capacity of the system of care. A report from the Catalyst Center provides examples of strategies for improving and financing care for CYSHCN that were collected through interviews with CYSHCN program directors and family-to-family organization leaders. [Read more.](#)

PUBLIC HEALTH EMERGENCY UNWINDING



Public Health Emergency Unwinding

- [Issue Spotting Common Policy and Operational Barriers to Ex Parte Renewals: State Assessment Tool](#) – from Manatt
- The slides from the National Health Law Program webinar [Medi-Cal Renewals Are Back – Tips for Keeping Coverage](#) now are available.

Webinar: Medicaid and CHIP Renewals - What to Know and How to Prepare, A Partner Education Monthly Series

DATE

Wednesday, December 6

TIME

9 to 10 a.m. Pacific Time

SPONSOR

Centers for Medicare & Medicaid Services

DETAILS

This monthly webinar series provides stakeholders with information to prepare for Medicaid and CHIP renewals. [Read more and register.](#)

INTELLECTUAL/DEVELOPMENTAL DISABILITIES

Webinar: Healthcare Transition - Options for Providing Decision-Making Support for Youth with I/DD

DATE

Wednesday, December 6

TIME

1 to 2:15 p.m. Pacific Time

SPONSORS

Center on YouthVoice YouthChoice, University of Massachusetts, Boston

DETAILS

The fourth session in a four-part series for parents on supporting youth and young adults with I/DD with decision-making. Featured speakers will share their expertise and/or lived experience in alternatives to guardianship and supported decision making. [Read more and register.](#)

Emerging Advocates Student Group Meeting

DATE

Monday, December 11

TIME

Think College and Association of University Centers on Disabilities

Students with disabilities from different colleges discuss being a college student, disability rights, and other relevant topics. [Read more and register.](#)

In Brief

- The National Association of Councils on Developmental Disabilities, the National Disability Rights Network, and the Association of University Centers on Disabilities issued a statement honoring the [60th Anniversary of the Developmental Disabilities Assistance and Bill of Rights Act.](#)

CALIFORNIA POLICY

Spotlight: Enhanced Care Management for Children and Youth

In an extensive fact sheet, the Department of Health Care Services explains the intent of the Enhanced Care Management benefit (ECM) for children and youth with complex needs, and offers operational guidance, vignettes showing how ECM can work, and resources for assessing organizations' capacity to contract with managed care plans as an ECM provider. [Read the fact sheet \(PDF\).](#)

YOUTH SCHOLARSHIP OPPORTUNITY

Nominations are open for the [Ryan Colburn Scholarship Award \(PDF\)](#) that allows a youth-with-disabilities leader to attend the Association of Maternal and Child Health Programs Annual Conference, to be held in a hybrid format from April 13-16, 2024, in Oakland. A webinar on **December 7** will provide details on how to submit nominations, which are due by **January 12, 2024.** [Read about the webinar and all the available awards.](#)

IN THE NEWS

- [More States Strive To Make Parks, Trails Accessible](#)
Disability Scoop, 11/17/23
- [Report Finds Disabilities 'Severely Underrepresented' On TV](#)
Disability Scoop, 11/14/23
- [How the Rollettes Dance Team Created a Sisterhood for People with Disabilities](#)
New York Times, 11/9/23

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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