

Children and Youth with Special Health Care Needs NETWORK NEWSLETTER

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



NATIONAL POLICY

Providing Equitable Medical Care for Children at Home: Federal Law and State Policy

Pediatric home health care services are provided through state government programs that attempt to fulfill federal policy requirements, but nationwide access to such care is not yet a reality for many children with disabilities and their families. This [issue brief](#) identifies inconsistencies within the federal laws and provides recommendations for how states can provide accessible, high-quality pediatric home health care. This work was supported by our Foundation.

[Read the issue brief](#)

New Companion Articles Reevaluate the Calculation of CYSHCN Using National Survey of Children's Health

A [new article](#) in *Pediatrics* examines whether there are children who may not be classified as CYSHCN through the Children with Special Health Care Needs Screener, yet experience similar health impacts and needs to CYSHCN. A key finding is that approximately 7% of children with reported health conditions and functional difficulties did not meet the CYSHCN criteria even though their needs closely resemble those of CYSHCN. The study also revealed sociodemographic disparities in groups of children who were not identified as CYSHCN using the screener. A [companion piece](#) explores how the expanded calculation of CYSHCN may affect policy and research related to children's health.

Webinar: Section 504 Final Rule—Protections Against Disability Discrimination in Health Care Programs

The U.S. Department of Health and Human Services recently released [updates to Section 504 of the Rehabilitation Act](#). The final rule strengthens protections against disability discrimination in health care programs and activities that receive federal financial assistance, including in the areas of medical treatment decision-making and providing services in the most integrated setting. In this [webinar](#), National Health Law Program staff will provide an overview of the updated regulations and how they will impact people with disabilities.

DATE/TIME: **Wednesday, May 23** | 12 pm PT

[Register for the Section 504 webinar](#)

TRANSITION TO ADULT CARE



Webinar Reminder: Aging Out of Public Program Services—Barriers, Inequities, and Recommendations

Next week, Got Transition, a program of the National Alliance to Advance Adolescent Health, will host a [webinar](#) highlighting findings from a study that examined the challenges that youth with disabilities (especially Black youth) and their families face as they move into adulthood. Learn about issues with Medicaid, the Children's Health Insurance Program, Supplemental Security Income, and Title V, as well as policy/program recommendations and the experiences of a self-advocate. This work was supported by our Foundation.

DATE/TIME: **Tuesday, May 22** | 10-11 am PT

[Register for the "Aging Out" webinar](#)

PALLIATIVE CARE

2024 Pediatric Palliative Care (PPC) Webinar Series

Chronic Home Ventilation: Helping Families Make Decisions

DATE/TIME: **Tuesday, May 21** | 12-1 pm PT

Pediatric to Adult Health Transition for Adolescents with Medical Complexity: The Role of Family and Social Determinants of Health

DATE/TIME: **Thursday, June 20** | 12-1 pm PT

[Learn more and register for all PPC Webinars](#)

Related resource:

- [National Hospice and Palliative Care Organization \(NHPCO\) Pediatric e-Journal: The Anniversary Issue](#) (PDF) (NHPCO, May 2024)

CHILDREN WITH MEDICAL COMPLEXITY (CMC)

Virtual Café: Humanism in Clinical Care to Meet Whole Child/Family Needs

During session two of six in the [Future of Care for Children with Medical Complexity Virtual Café Series](#), discussants Dennis Kuo, MD, MHS; Bethlyn Houlihan, MSW, MPH; and Meg Comeau, MHA, will share what matters most to families of CMC and present strategies to improve care delivery and mitigate systems-level bias. The program will then open to facilitated discussion exploring how to reinvigorate human-driven approaches to meet whole child/family needs in systems of care.

DATE/TIME: **Wednesday, May 29 | 1-2 pm PT**

[Register for the Virtual Café](#)

HOME- AND COMMUNITY-BASED CARE

Webinar: Centers for Medicare & Medicaid Services (CMS) Final Rules, Part 3: Home and Community-Based Services

Join State Health and Value Strategies for the [final webinar](#) in its series on the CMS final rules. In this session, experts from Manatt Health will provide a detailed overview of provisions in the "Access Rule" ([see CMS fact sheet](#)) that aim to enhance access to home and community-based services, standardize quality measures and reporting requirements, and help address shortages in the direct care workforce.

DATE/TIME: **Thursday, June 6 | 11:30-12:30 pm PT**

[Register for the webinar](#)

FAMILY CAREGIVING

Webinar: Family Caregivers as a Health Care Workforce—Innovations and Investment Across Policy and Business

Join Manatt for a [webinar and interactive discussion](#) on efforts from federal and state governments, businesses, investors, and long-term care advocates to unlock the potential of, and better support for, family caregivers.

DATE/TIME: **Wednesday, June 5 | 10-11 am PT**

[Register for the webinar](#)

DURABLE MEDICAL EQUIPMENT

Ventilator Recalls Leave Few Options for Kids with Breathing Conditions. Here's What Would Help.

California Health Report explores the impact of a recall of Philips Respironics ventilators on CYSHCN and offers advice for concerned families. Through interviews with doctors, children's advocates, and families, [the article](#) shares requests for changes at the federal level to better track the health of patients exposed to the recalled ventilators, provide physicians with more information on how to assess patients for potential problems caused by the devices, and provide stronger oversight of medical devices in general.

RELATED NEWS

- [Child Medicaid Disenrollment Data Shows Wide Variation in State Performance as Continuous Coverage Pandemic Protections Lifted](#) (Georgetown University Center for Children and Families, 5/2/24)
- [16,000 People with Disabilities Are in State-Operated Institutions. This Is How Experts Say Health Care Should Change.](#) (CBS News, 4/30/24)
- [Can California Kids Get Specialty Care Sooner?](#) (YES! Magazine & California Health Report, 4/26/24)

WE WANT TO HEAR FROM YOU

Let us know what's happening with your organization or program. Send your news and updates to Kristen Rogers, Assistant Communications Director, Programs & Partnerships, at info@lpfch.org. Thank you!

To see past issues, visit our [Newsletter Archive](#). If you were forwarded this newsletter and would like to receive it monthly, click the subscribe button below.

Subscribe to CYSHCN News

[Manage](#) your preferences | [Opt Out](#) using TrueRemove™
Got this as a forward? [Sign up](#) to receive our future emails.
View this email [online](#).

400 Hamilton Ave, Suite 340 | Palo Alto, CA 94301 US

This email was sent to kristen.rogers@lpfch.org.
To continue receiving our emails, add us to your address book.