

## California Advocacy Network

for Children with Special Health Care Needs

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

### Children with Medical Complexity

#### Researchers Develop a Family-Reported Measure of Pediatric Home Health Care Quality

No validated tools currently exist to measure the quality of pediatric home health care. New research published in *Academic Pediatrics* outlines the development and testing of PediHome, a content-valid family-reported survey measure of home health care quality for children with medical complexity. PediHome, developed with support from our Foundation, can identify deficits in timely access to care, overall home health care quality, and specific aspects of care such as confidence in nursing care provided. [Read the journal article.](#)

#### Webinar: Health Systems Strategies that Prioritize Children with Health Complexity

**Date** Wednesday, December 7

**Time** 10 to 11 a.m. Pacific Time

**Sponsors** Oregon Pediatric Improvement Partnership and Lucile Packard Foundation for Children's Health

**Details** Health complexity is a concept that considers both medical and social complexity in a child's life. Webinar speakers will discuss the Oregon Pediatric Improvement Partnership's work to identify children with health complexity and provide actionable strategies and models to use this information to improve services. The work, which was supported by our Foundation, aligns with efforts to address health disparities. Read the related [issue brief](#) about health complexity and [register](#) for the webinar.

### Family Engagement

#### Promoting Diversity, Equity in Patient and Family Advisory Councils

Patient and family advisory councils (PFACs) advance patient- and family-centered care within children's hospitals but may not reflect the diversity of the communities they serve. Researchers assessed PFACs among children's hospitals across the country, and explored barriers, drivers, and enablers of recruitment, retention, and engagement of patient and family advisors with diverse perspectives and backgrounds. Their research, supported by our Foundation, and their report published in the *Patient Experience Journal* may assist in promoting inclusion within PFACs across hospital systems. [Read the report.](#)

### Systems and Standards

#### National Academies: Supporting Children with Disabilities – Lessons from the Pandemic

During the pandemic, children with disabilities suffered disproportionately compared to those without disabilities. The National Academies of Sciences, Engineering, and Medicine hosted a workshop with families, providers, and policymakers to identify post-pandemic practices that could improve the system of care for children with disabilities and improve access to services for underserved and marginalized populations. An accompanying interactive resource guide highlights those innovative practices in education, health care, state and federal policy, home care settings, and more. [Read the proceedings](#) and [explore the interactive resource guide.](#)

### Health Equity

#### Health Affairs Addresses Disability and Health, Racism in Pediatrics

*Health Affairs* devoted its October issue to disability and health, including many open-access articles relevant to the CYSHCN population. [Read the issue.](#) In the November issue, a clinical professor of pediatrics urges the field to address the issue of racism in pediatric care. [Read his essay.](#)

### Pediatric Palliative Care

#### Helping Children Grieve

Many losses and events can cause grief for children. November 17 has been designated as [Children's Grief Awareness Day](#). The November issue of the Pediatric Palliative Care Coalition's newsletter is dedicated to children and grief, and offers a variety of resources for helping children cope. [Read more.](#)

### Intellectual and Developmental Disabilities

#### Stories Explore the Lives of Individuals with Intellectual Disabilities

The Arc has launched a story hub to offer insight into the unique challenges that people with disabilities face, as well as their dreams and goals. The stories aim to help expand understanding of what's possible for people with intellectual disabilities in school, jobs, love, and life. [Read their stories.](#)

### In Brief

- A recording of the Little Hoover Commission's second Hearing on California's Developmental Disabilities System now is [available](#). Also available [en español](#).

### National Policy

- Open enrollment for health plan coverage through the Health Insurance Marketplace is available now. [Find details and deadline information.](#)
- [Medicaid Appears Likely to Survive Its Latest Encounter with the Supreme Court](#) – from Vox, 11/8/22

### California Policy

#### Applicants Sought to Manage a New Medi-Cal Consumer Advisory Committee

The Department of Health Care Services (DHCS) is creating a Medi-Cal Consumer Advisory Committee to ensure that Medi-Cal enrollees, many of whom are from historically marginalized communities across California, have an active voice in shaping DHCS programs. The California Health Care Foundation and our Foundation, in partnership with DHCS, have issued a request for proposals to manage and facilitate the Committee. The work would include project management, member recruitment, meeting planning and facilitation, preparing and supporting members, and measuring impact. [Read more](#) and apply by **November 22**.

#### Webinar: Demand for Aging and Disability Services Is Increasing in California: Can We Meet the Need?

**Date** Wednesday, November 30

**Time** 12 to 1 p.m. Pacific Time

**Sponsor** UCLA Center for Health Policy Research

**Details** Many Medi-Cal beneficiaries need help with personal and household care to stay in their homes, but the proportion of this group receiving help from non-family caregivers is a small fraction of those eligible. Speakers will discuss use of two major Medi-Cal long-term supports and services programs. Not pediatric-focused, but relevant. [Read more and register.](#)

*Related:* [California's In-Home Supportive Services \(IHSS\) Program](#) and [New Medi-Cal Benefit Will Address Longstanding Reimbursement Inconsistency for Community Health Workers, Expert Says](#)

### In the News

- [Judge Rejects Walmart's Request for New Trial After Firing of Employee With Down Syndrome](#)  
*CNBC, 11/9/22*
- [All-Terrain Wheelchairs Arrive at U.S. Parks: 'This Is Life-Changing'](#)  
*The Washington Post, 11/8/22*
- [NHL Team Yanks Contract of a Player Who Bullied a Black Classmate with Disabilities](#)  
*NPR, 11/7/22*
- [Lois Curtis, Who Won a Landmark Civil Rights Case for People With Disabilities, Died](#)  
*NPR, 11/5/22*
- [Not All Schools Use Restraint or Seclusion. Here's a Look at Some Alternatives](#)  
*Disability Scoop, 11/4/22*
- ['Crisis Mode' for Children's Hospitals Amid RSV Surge](#)  
*Modern Healthcare, 11/4/22*
- [Oakland Director Turns Camera Around on Disability with Documentary 'I Didn't See You There'](#)  
*Datebook, 11/3/22*
- [Feds Raise Red Flags About Delayed Special Ed Evaluations, Other IDEA Violations](#)  
*Disability Scoop, 11/3/22*

#### 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](mailto:Hannah.Au@lpfch.org) with your news or updates. Or contact newsletter editor: Eileen Walsh at [Eileen.Walsh@lpfch.org](mailto:Eileen.Walsh@lpfch.org).

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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.

