

## Children and Youth with Special Health Care Needs **NETWORK NEWSLETTER**

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



### **FAMILY ENGAGEMENT**

---

#### **Diversity, Equity, and Inclusion in Patient and Family Advisory Councils—Advancing Best Practice in Children's Hospitals**

A new article in the *Journal of Pediatric Health Care* from the Institute for Patient- and Family-Centered Care and Cincinnati Children's Hospital Medical Center discusses best practices for supporting diverse membership in children's hospital patient and family advisory councils. The article also addresses ways to involve patient and family advisors in hospital-wide diversity, equity, and inclusion projects and initiatives. This work was supported by our Foundation.

Learn more at [LPFCH.org](https://LPFCH.org)

#### *Related news:*

- [How to Authentically Engage Families: Spotlight on Debbi Harris, Vice President of the Board, The Arc](#) (The Arc blog, 1/25/24)

### Fact Sheet: Know Your Appeal Rights for the California Children's Services (CCS) Program

This fact sheet from the National Health Law Program is designed to inform families about the steps they can take to appeal decisions about their child's CCS benefits when they experience delays, denials, reductions, discontinuances, or other changes. Also available in Spanish and Chinese. This work was supported by our Foundation.

[View the fact sheet at LPFCH.org](#)

#### *Related resources:*

- [Helping Families Obtain Durable Medical Equipment and Supplies Through the CCS Program](#)
- [Proceedings from the National Forum on Care Coordination for CYSHCN](#)

## EVENTS

---

### The Future of Care for Children with Medical Complexity (CMC) Virtual Café Series

Connect with and learn from others around the country on topics that matter most to CMC and their families. This café-style series will include short presentations by nationally recognized experts in the care of CMC, including families, with a primary focus on facilitated discussion aimed at advancing policy, clinical practice, research, and medical education.

#### **Virtual Café #1: Where We Are Now & Where We Need to Go**

**DATE/TIME:** Wednesday, March 27, 2024 | 12-1 pm PT (3-4 pm ET)

**DISCUSSANTS:** Meg Comeau, MHA; Cara Coleman, MPH, JD; and Bethlyn Houlihan, MSW, MPH

[Register for Café #1](#)

---

#### **Virtual Cafe #2: Humanism in Clinical Care to Meet Whole Child/Family Needs**

**DATE/TIME:** Wednesday, May 29, 2024 | 1-2 pm PT (4-5 pm ET)

**DISCUSSANTS:** Dennis Kuo, MD, MHS; Bethlyn Houlihan, MSW, MPH; and Cara Coleman, MPH, JD

[Register for Café #2](#)

---



## National Caregiver Summit

Join Health Leads for a free, half-day, virtual event that brings together caregivers, care receivers, and allied partners to set new priorities for action and examine caregiver financial well-being and sustainability. Designed by caregivers, for caregivers, this event enables attendees to build community, collaborate on advocacy, rejuvenate, and share strategies and tools. This event is sponsored by our Foundation.

**DATE/TIME:** Thursday, May 2, 2024 | 8 am-2 pm PT (11 am-5 pm ET)

[Learn more and register](#)

## HOME- AND COMMUNITY-BASED CARE

---

### Centers for Medicare & Medicaid Services Releases Report to Congress: Best Practices in the Money Follows the Person (MFP) Demonstration

The MFP Demonstration, first authorized by Congress in the Deficit Reduction Act of 2005, has provided nearly \$6 billion to 43 states and the District of Columbia to improve access to home- and community-based services for Medicaid-eligible individuals who need long-term services and supports. This report identifies effective strategies for implementing the program's key components and features case studies of distinctive state approaches.

[Learn more at Mathematica.org](#)

#### *Related news:*

- [A Hospital Is Suing to Move a Quadriplegic 18-year-old to a Nursing Home. She Says No.](#) (NPR, 2/22/24)
- [States Offer Services for Disabled Kids, Then Make Their Families Wait 10 Years for Them](#) (AP News, 2/28/24)
- [Feds Take Steps to Shore Up Disability Caregiver Workforce](#) (Disability Scoop, 2/29/24)

FAMILY VOICES  
of California  
**2024**  
Virtual  
HEALTH SUMMIT

Wed, April 24 &  
Thurs, April 25  
9:00am - 2:00pm

Sharing knowledge  
and improving access  
for children and youth  
with special health  
care needs



## Family Voices of California 2024 Virtual Health Summit

This free, annual virtual summit provides a forum for families, youth, providers, policymakers, advocates, state agencies, insurers, and other stakeholders to learn about key issues affecting CYSHCN in California.

### DATES/TIMES:

- Wednesday, April 24, 2024 | 9 am-2 pm PT
- Thursday, April 25, 2024 | 9 am-2 pm PT

[Learn more and register](#)

## California Children's Services Advisory Group Stakeholder Meeting

The next quarterly meeting of the CCS Advisory Group will include department and program updates, a recap of the January 2024 meeting, a Whole Child Model update, time for public comment, and more. Members of the public can attend virtually or in person.

**DATE/TIME:** Wednesday, April 10, 2024 | 1-4 pm PT

[Learn more](#)

### *California policy news:*

- [How to Make it Easier for Kids with Disabilities to Get Care](#) (*California Health Report*, 3/15/24)
- [New Eligibility Rules Are a Financial Salve for Nearly 2 Million on Medi-Cal](#) (*KFF Health News*, 2/15/24)
- [California Advancing and Innovating Medi-Cal Enhanced Care Management Policy Guide \(PDF\)](#). (California Department of Health Care Services, updated Feb. 2024)
- [Hours on Hold, Limited Appointments: Why California Babies Aren't Going to the Doctor](#) (*LA Times*, 2/26/24)

## 'She's Taught Me So Much About What Real Courage Is:' A Window into the Life of a Family Caring for a Child with Intensive Medical Needs

*California Health Report's* Claudia Boyd-Barrett brings to life the joys and challenges of caring for a three-year-old girl with special health care needs in this honest portrait of the Hernandez family from Los Angeles, CA. The story shines a light on the struggles that many families with CYSHCN face in getting health insurance, applying for state programs, and accessing benefits for home care, while giving a glimpse into what daily family routines are like for young Claire, her older brother, and her parents.

Read full story at [CalHealthReport.org](https://CalHealthReport.org)

### ***DID YOU KNOW?***

Families of children with disabilities are **3x more likely** to experience job disruptions because of issues with child care.

### **Tell Congress: Invest in Child Care for Children with Disabilities**

Between limited access to providers and the high costs of care, families in the United States are facing a child care crisis. But, families of children with disabilities face even greater obstacles to finding care because many programs and providers don't have the necessary training or are reluctant to care for children with disabilities. Advocates recommend contacting your legislators to inform them of the particular challenges that families of children with disabilities face.

Learn more at [TheArc.org](https://TheArc.org)

#### *Related resources:*

- [Annual Vision, Hearing and Speech Issue](#) (*EP Magazine*, March 2024)
- [Big Feelings: Parents and Caregivers Need More Help to Support Children Under 5](#) (Children Now, Feb. 2024)



## Medicaid Redetermination: Stories from Families to Inspire Action

A new episode of the *MCH Bridges* podcast examines the lived experiences of families who have lost their Medicaid coverage due to the public health emergency unwinding process. Hear real stories from families and gain insight from advocates on how maternal and child health professionals can provide support.

[Listen to the podcast episode](#)

### *Related resources:*

- [Medicaid Continuous Coverage Unwinding: Messaging and Outreach Resources](#) (National Health Law Program, 2/12/24)
- [As Medicaid Shrinks, Clinics for the Poor Are Trying to Survive](#) (*New York Times*, 2/24/2024)

## HEALTH EQUITY

---

- [How to Get Medical and Education Services When You Don't Speak English](#) (*California Health Report*, 2/12/24)
- [Understanding Latino Children and Families' Well-being Requires Data Disaggregated by Birth Within or Outside the United States](#) (National Research Center on Hispanic Children & Families, 2/15/24)

## TELEHEALTH

---

- [Updated State Medicaid & Children's Health Insurance Program Telehealth Toolkit](#) (Medicaid.gov)

## 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](mailto: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.*