

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

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



### ACCESS TO CARE

#### Accessing Pediatric Subspecialty Care in California

Accessing pediatric subspecialty care is a growing concern for families of children and youth with special health care needs (CYSHCN) nationwide. Our Foundation has supported research to better understand workforce challenges, current wait and travel times for patients, and the effects of delays on children and their families in California. The results from this body of work—including a new fact sheet on [Travel Time and Family Preferences for In-Person Care](#)—are now available as one compiled resource.

[See the resource](#)

More than 25% of families  
reported having to travel **over**  
**an hour each way** for  
appointments with subspecialists.

*from Travel Time and Family Preferences for In-Person Care*

See also:

- [Viewpoint: Where Are All the Pediatricians?](#) (*Journal of the American Medical Association*, 7/3/24; requires free login to view full text)
- [Opinion: Why Doctors Aren't Going Into Pediatrics](#) (*The New York Times*, 7/1/24; requires free login)

## CHILDREN WITH MEDICAL COMPLEXITY (CMC)

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### Upholding Human Dignity for Children with Medical Complexity and Their Families

In this *Complex Care Journal Club* [podcast episode](#), Bethlyn Vergo Houlihan and Meg Comeau of the Center for Innovation in Social Work & Health at Boston University discuss what families of CMC say they need to ensure quality of life and family well-being. Be sure to also read the related [Pediatrics article](#) from January 2024.



[Listen to the podcast episode](#)

### Reminder: CMC Virtual Café—Meaningful Policy Opportunities That Matter to Families

During session three of six in the [Future of Care for Children with Medical Complexity Virtual Café Series](#), Lisa Kirsch of Dell Medical School and Meg Comeau of the Center for Innovation in Social Work & Health at Boston University will discuss the current policy landscape for CMC. Then, participants will join facilitated breakout groups to explore opportunities for policy changes at the local, state, and national levels. This work is funded by our Foundation.

DATE/TIME: **Wednesday, July 24 | 12-1 pm PT**

[Register for the Virtual Café](#)

## FAMILY ENGAGEMENT

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### Webinar: How to Establish and Sustain Effective Patient and Family Advisory Councils

Next week, the Institute for Patient- and Family-Centered Care will host a webinar to share and discuss practice-based strategies for Patient and Family Advisory Councils (PFACs). These practices are designed to help ensure that the work of PFACs is meaningful and leads to improvement and change.

DATE/TIME: **Wednesday, July 24 | 9-10 am PT**

[Register for the webinar](#)

## EVENTS

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### Association of Maternal & Child Health Programs (AMCHP) Annual Conference 2025: Call for Proposals Opens August 1

Mark your calendar for next year's AMCHP Annual Conference, taking place in Washington, DC, from **March 15-18, 2025**. [Proposals for workshops, posters, skills sessions, and roundtables can be submitted beginning on August 1](#). [Subscribe to AMCHP's newsletter](#) to receive the latest updates or visit the [Annual Conference website](#) for more information.

## HEALTH EQUITY

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### Lurie Children's Launches Peer-Reviewed Journal on Health Advocacy

[The Journal of Health Advocacy](#) is a new peer-reviewed, online, open access publication that shares information about successful health advocacy practices to help practitioners, researchers, policymakers, community members, families, and youth take effective action toward systems change. Launched by the Ann & Robert H. Lurie Children's Hospital in May, the journal publishes health advocacy research, scholarship, and perspectives in a variety of article types and media formats. Learn how to submit content for publication on the journal's [For Authors page](#).

[Read the announcement](#)

## NATIONAL POLICY

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### How Medicaid Can Better Support Families of Children with Special Health Care Needs

In [this episode](#) of the *Medicaid Leadership Exchange* podcast, Medicaid leaders and a parent advocate from the state of Ohio discuss the importance of partnering across silos and opening lines of communication between agencies and families. They also talk about their state's managed care program for youth with complex behavioral health and multisystem needs.



[Listen to the podcast episode](#)

## CALIFORNIA POLICY

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### Analysis: You Can't Surf With a Ventilator. The Problems With AI in Health Care, and Some Solutions.

Can artificial intelligence (AI) help families get medical information or connect with services? Will AI make our health care system more equitable? *California Health Report* put three chatbots to the test to explore these questions and to examine the accuracy of information related to CYSHCN and their medical care.

[Read the article](#)

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### California Children's Services Advisory Group Stakeholder Meetings

At its July 10th meeting, the CCS Advisory Group discussed recruitment to Medi-Cal Managed Care Plan advisory committees, monitoring of Kaiser Whole Child Model transition, Whole Child Model Managed Care Plan readiness, Enhanced Care Management referrals and authorizations, CCS Monitoring and Oversight Program implementation, and updates on the Child Health and Disability Prevention Program transition, among other topics. See [agenda and slide presentation](#) for additional information. Save the date for the next meeting on October 9, which will be held virtually and in person and is open to the public.

DATE/TIME: **Wednesday, October 9 | 1-4 pm PT**

[Learn more](#)

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- [National Health Law Program Launches New Listserv to Help Foster Youth Access Health Care in California](#) (National Health Law Program, 6/25/24)

## **PHE UNWINDING**

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- [California Revisited: Where the Golden State Stands After the Unwinding](#) (National Health Law Program blog, 7/9/24)
- [The Unwinding: It's Not Over Until It's Over](#) (*Say Ahhh!* blog, 6/24/24)
- [COVID-19 Public Health Emergency \(PHE\) Unwinding Resources](#) (LPFCH.org, 6/13/24)

## **WE WANT TO HEAR FROM YOU**

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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.

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