

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

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



### **Dear Readers:**

Beginning today, the newsletter will be edited by Kristen Rogers, the Foundation's new assistant director of communications, and will transition to a monthly publication. We launched the newsletter in January 2013 with 100 subscribers in California. Today our mailing list includes 9,000 individuals all around the country, and even some international subscribers. It has been a privilege to serve as editor since the beginning, and I thank you for your faithful readership, your helpful comments, and the valuable information so many of you have provided for us to share in support of our joint efforts to create a better system of care for CYSHCN and their families.

***—Eileen Walsh, Founding Editor***

### **New Foundation Website Coming in February!**

Next month, we'll be launching a brand new website for the Lucile Packard Foundation for Children's Health at [www.lpfch.org](http://www.lpfch.org). You'll still find our library of CYSHCN publications and resources, information about grants, and

previous issues of this newsletter. You'll also learn about our Foundation's work to support the Lucile Packard Children's Hospital Stanford and the maternal and child health programs at the Stanford School of Medicine.

## CHILDREN WITH MEDICAL COMPLEXITY

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### New Supplement to *Pediatrics* Focuses on the Collaborative Improvement and Innovation Network for Children with Medical Complexity (CMC CoIN)



Find out how the CMC CoIN is inspiring broader family partnership in systems change work and innovations in care delivery to benefit children with medical complexity, their families, and the health and social service systems that support them. This supplement to *Pediatrics* includes an introduction to the project and six in-depth articles about what has been learned through its work. Available for free viewing/download.

[View the supplement](#)

#### *Coming in March*

Stay tuned for a related series of virtual conversations aimed at bringing a wider array of voices and experiences to the growing call for improving quality of life and well-being for children with medical complexity and their families. We'll share the schedule, speakers, and registration details in an upcoming newsletter.

## FEATURED EVENT

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### BRIEFING: Pediatric Subspecialty Physician Workforce—A Growing Crisis



Join the Children's Specialty Care Coalition for a virtual legislative briefing on a recent report from the National Academies of Sciences, Engineering, and Medicine titled, [\*The Future Pediatric Subspecialty Physician Workforce: Meeting the Needs of Infants, Children, and Adolescents\*](#). Learn about the report's key findings and policy recommendations, hear from the reactor panel to understand the challenges of physician recruitment and retention in California and to gain insight into families' experiences accessing care, and find out what policymakers can do to drive change.

**DATE:** Wednesday, February 14

**TIME:** 12 to 1 pm PT

## KEYNOTE SPEAKERS:

- Assemblymember Akilah Weber, MD, Chair, Budget Subcommittee #1 on Health and Human Services
- Sherin Devaskar, MD, Member Representative, Children's Specialty Care Coalition; Past President, Association of Medical School Pediatric Department Chairs; Member, National Academy of Medicine

[Learn more and register](#)

### *Related Resource:*

- [Fact Sheet: California's Children Need Access to Pediatric Subspecialists](#)

## MORE EVENTS

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- Early registration is open for **AMCHP 2024: Partnering with Purpose** until **February 12**. The annual conference of the Association of Maternal and Child Health Programs will take place April 13-16, 2024, in Oakland, CA. [Get full details & registration information](#).
- [Apply to present a workshop](#) at **Putting Care at the Center 2024**. This annual conference of the Camden Coalition's National Center for Complex Health and Social Needs is happening October 16-18, 2024, in Pittsburgh, PA. Workshop proposals will be accepted until **March 4**.

## HOME- AND COMMUNITY-BASED CARE

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### Medicaid Home and Community-Based Services Program Gets \$37 Billion Boost

In 2021, Congress approved a temporary funding increase for Medicaid home and community-based services as part of the American Rescue Plan. The White House recently announced that the package, originally intended to provide \$12.7 billion to states, has actually distributed nearly three times that amount, reaching \$37 billion. Most of the funds have been allocated to retain, expand, and train direct care providers in the midst of a workforce shortage. States now have until March 31, 2025, to use the funds, but there is legislation in progress to extend the investment for longer-term success.

[Read full story at Disability Scoop](#)

## FAMILY ENGAGEMENT

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## Complex Care Journal Club Podcast Talks Family Representation and Coverage of Complex Care with *Pediatrics* Editors



Have you listened to the Complex Care Journal Club podcast? In the episode titled, "Collective Voice: A Conversation about Complex Care and Disability in the Journal *Pediatrics*," guests Lewis First, MD, editor-in-chief of *Pediatrics*, and Cara Coleman, associate editor for family partnerships for *Pediatrics*, discuss how the journal helps share emerging practices in complex care and disability. They talk about the Family Partnerships column, the journal's inclusive decision-making process for what submissions are published, and how clinicians and families can participate.

Listen to the episode on [YouTube](#), [Apple](#), [Google](#), [Soundcloud](#), or [Spotify](#).

### *Resources for Families:*

- [How Families of Children with Disabilities Can Find Support](#) (*EP Magazine*, Jan. 2024)
- [The National Alliance for Children's Grief](#)
- [Winter Issue of Family Voices \*En Español Magazine\*](#)

## **PUBLIC HEALTH EMERGENCY UNWINDING**

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### **Child Medicaid Enrollment Decline Reaches 3 Million: How Many Kids Are Moving to the Children's Health Insurance Program (CHIP)?**

As the US reaches the halfway point of the Medicaid unwinding process, recent data shows that more than 3 million children have been disenrolled from the program. Researchers had initially estimated that the majority of children affected would move to CHIP, but CHIP enrollment increases account for less than 10% of the children disenrolled from Medicaid, raising concerns about gaps in coverage. Some states are taking additional steps to protect children, such as eliminating premiums or extending current 12-month continuous eligibility requirements and moving toward a system of continuous coverage for children ages 0-6.

Read more at "Say Ahhh!" blog

### *More PHE Unwinding news:*

- [Biden Administration Warns 9 Governors About Medicaid Losses Among Children](#) (*The New York Times*, 12/18/23)

## **POLICY**

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- [A Quick Guide to Choosing Federal Medicaid Authorities to Address Health-Related Social Needs](#) (Mathematica, 1/11/24)
- [Respite Care: State Policy Resource Guide](#) (National Academy for State Health Policy)
- [Policy Statement on Inclusion of Children with Disabilities in Early Childhood Programs](#) (ACF Office of Early Childhood Development)
- [Explainer: Proposed Changes to the Essential Health Benefits Standard in the 2025 Notice of Benefits and Payment Parameters](#) (National Health Law Program, 12/4/23)

## DATA

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### Estimates from the 2022 National Survey of Children's Health Now Available

The [Data Resource Center for Child and Adolescent Health](#) announced that the 2022 National Survey of Children's Health (NSCH) Child and Family Health Measures estimates are now available through its Interactive Data Query tool. Use the tool to access national, state, and regional data on more than 350 measures.

Access the data at [childhealthdata.org](https://childhealthdata.org)

## CALIFORNIA POLICY

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### Facing Budget Shortfall, California Governor Newsom Proposes Changes to Recently Approved Managed Care Organization (MCO) Tax

Federal approval of the MCO tax in December would enable the Department of Health Care Services to begin implementing targeted provider rate increases and new health care system investments to advance access, quality, and equity in care and services for millions of Californians using Medi-Cal. But with a \$38 billion shortfall, the Governor now hopes to get support early in the legislative session for an amendment to increase the tax, which would generate an additional \$1.5 billion, pending federal approval. Under this plan, the Governor's budget would set aside \$12.9 billion to support the Medi-Cal program and \$8 billion for provider rate increases and investments.

Read full story at [manatt.com](https://www.manatt.com)

## FELLOWSHIP OPPORTUNITY

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### HHS Pediatric Mental Health Care Access Program Research Fellowship

The Maternal and Child Health Bureau's Division of Maternal and Child Health Workforce Development is recruiting for an Oak Ridge Institute for Science and Education (ORISE) Fellow to provide research, analytic, and evaluative support for the Pediatric Mental Health Care Access Program. Deadline for applications is **February 19**.

[Learn more](#)

## MORE NEWS

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- [The Daunting Child Care Challenges For Kids With Disabilities](#)  
*Disability Scoop, 1/16/24*
- [Georgia Children's Hospitals Get Pediatrics Workforce Grant, Over \\$700K in Total Funding](#)  
*WABE, 12/20/23*
- [Adults With IDD Face Significant Hurdles at the Doctor, Study Finds](#)  
*Disability Scoop, 12/15/23*



## 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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