



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

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

Dear Readers:

We remain committed to keeping you informed as we monitor developments in federal funding cuts to Medicaid and other public health programs. In this issue, you will find updates and resources describing how these changes may affect CYSHCN and their families.

Please see the *Medicaid and Other National Policies* section below for recent articles and resources. If you have suggestions or resources to share with our readers, please email us at [info@lpfch.org](mailto:info@lpfch.org)—we'd love to hear from you!

We know these are challenging times for CYSHCN and their families. Together, we can stay informed and advocate effectively.

- Children and Youth with Special Health Care Needs Program Team

### **MEDICAID AND OTHER NATIONAL POLICIES**

#### **Webinar and Report: Possible Medicaid, CHIP Cuts in New Budget Law Explained**

In a webinar based on their recent report, experts from the Georgetown University Center for Children and Families and the Center on Health Insurance Reforms outlined the Medicaid, CHIP, and Affordable Care Act Marketplace cuts in the new budget reconciliation law.

[Watch the recording](#)

[Read the report](#)

#### **New CHIP Protections in Effect Despite Congressional Efforts to**

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An extensive analysis from the Georgetown University Center for Children and Families explains the complex process that currently guarantees protection for children covered under the Children’s Health Insurance Program (CHIP), and discusses whether the Centers for Medicare & Medicaid Services will ensure that all states enforce the rules going forward.

[Read the analysis](#)

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***Additional information:***

- [Webinar Series on the Impact of New Budget Law](#) – from the National Health Law Program.
- [The Big Beautiful Act Is Law. Now What?](#) – from Family Voices.
- [Medicaid Changes Will Hurt Family Caregivers, Experts Warn](#) – from *The Hill*.
- [Medicaid Cuts Could Cost Kids Coverage that Aids Learning](#) – from The 74.
- [How Medicaid Cuts Could Impact School Services](#) – from *Disability Scoop*. Requires login.
- [Millions of Californians May Lose Health Coverage Because of New Medicaid Work Requirements](#) – from the *Los Angeles Times*.

## **CHILDREN WITH MEDICAL COMPLEXITY (CMC)**

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### **How Pediatricians Can Support CMC and Their Communication Needs**

The American Academy of Pediatrics recently published a report describing the critical role that pediatricians, especially pediatric specialists, play in ensuring that children with complex communication needs gain access to augmentative and alternative communication technology. The authors offer recommendations that physicians can implement to support CMC and their communication needs.

[Read the report](#)

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### **Series Continues of Family-Led Academic Grand (FLAG) Rounds**

The fourth session of FLAG Rounds, “Walking the Line: Giving Care/Forgone Care (and everything in between)” will take place via Zoom. Family members serving as faculty will share stories of caring for their children with disabilities, highlighting the delicate balance between providing care and the risk of care being forgone. FLAG Rounds train and empower families of children with complex medical conditions to share their experiences of ableism with medical students and residents. The Rounds are approved for continuing education credits.

**DATE/TIME:** Thursday, September 25 | 10-11am PT/1-2pm ET

[Register](#)

[See previous sessions and more information](#)

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## Opinion: A Broken System Forces Families to Cope with Complex Durable Medical Equipment

An opinion piece in *STAT* by a medical device designer discusses how families whose children require the use of durable medical equipment often struggle to obtain, operate, and repair the equipment that is essential to their child's survival. The author suggests initial steps that can be taken to reform the broken system.

[Read the opinion piece](#)

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## Watch Academy Health's recorded webinar from June 23: Enhancing Systems of Care for CMC - Environmental Scan Findings and Key Learnings

[Watch recorded webinar](#)

## SPECIAL EDUCATION

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### Most States Failing to Meet Special Education Requirements

*Disability Scoop* reports that only 19 states meet the full requirements for serving children with disabilities ages 3-21, according to a recent report from the US Department of Education. If states do not achieve the “meets requirements” status for two or more years, the Education Department must take enforcement action, which can include requiring the state to access technical assistance or directing funds to the areas deemed inadequate. *Requires login.*

[See the full report](#)

Also see: [How the Education Department Helps Students with Disabilities Get an Education](#) – from NPR.

## MENTAL AND BEHAVIORAL HEALTH

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### Recordings Available: Roundtable on Young Adults with Chronic Medical Conditions

Generation Patient is a non-profit organization created by and for young adult patients focused on peer support, research, health policy, and leadership programming. With support from our Foundation, Generation Patient created the *Roundtable on Young Adults with Chronic Medical Conditions* to explore the most pressing systems-level challenges affecting young adults living with chronic and rare conditions. The recordings from sessions three and four now are available.

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## RESOURCES

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### Program for Children and Youth with Special Health Care Needs

Grantmaking, thought leadership, and advocacy to make our health care system work better for CYSHCN and their families.

### Join Our LinkedIn Community

Stay connected with a growing network of professionals, advocates, family leaders, and organizations committed to improving systems of care for CYSHCN and their families. Our LinkedIn page is your go-to source for timely updates between newsletter issues. [Follow us](#) to stay informed and engaged with the issues that matter most to CYSHCN, their families, and the field.

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### Children Now's Playbook for Supporting Caregiver Advocates

Caregivers of CYSHCN provide essential expertise to help shape policies that affect their children's lives; however, they often lack the support needed to advocate in the policy space. Supporting caregiver engagement in children's health policymaking can lead to policies designed by and for families, strengthen trust between families and government, and improve family well-being. Children Now's *Playbook for Engaging, Supporting, & Sustaining Caregiver Advocates* offers guidance to state agencies, health plans, and organizations on building respectful, accessible, and equitable spaces for caregivers to meaningfully partake in policymaking.

Read the Playbook

## EVENTS

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### Register: National Academy for State Health Policy (NASHP) Annual Conference

State leaders from all 50 states and Washington, DC, will gather next month in San Diego for "Riding the Waves of State Health Policy," NASHP's annual conference. The meeting will bring attention to issues facing state health policymakers and highlight innovative solutions from leading experts. Sessions focused on CYSHCN include:

- Strengthening Access to Interventions for Youth with Complex Behavioral Health Needs
- Charting the Course for Caregiving and Home- and Community-Based Services
- Tides of Change: Strengthening Pediatric Systems of Care for Children with Chronic and Complex Needs

**DATES:** September 8-10

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Register

## WE WANT TO HEAR FROM YOU

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Let us know what's happening with your organization or program. Send news and updates to [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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