

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

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

*Editor's note: The Foundation will be closed on June 19 in observance of Juneteenth. The June issue of the CYSHCN Newsletter will be released on Wednesday, June 18.*

### NATIONAL POLICY

#### Medicaid Under Threat: Resources for Advocates

Medicaid provides comprehensive health coverage to more than four in 10 CYSHCN in the U.S. Proposals moving ahead in Congress to significantly reduce Medicaid spending could have serious implications for CYSHCN and their families, including increased difficulty for these children to access the care and supports they need. Organizations nationwide are using data and information to make the case for maintaining coverage. Some resources:

- On May 6, Manatt Health and our Foundation hosted a national webinar on the effects that the Congressional proposals could have on children. Manatt experts outlined findings from their report, *No Place to Hide: Children Will Be Hurt by Medicaid Cuts*. Manatt's model estimates how the Congressional proposals being considered would affect federal and state Medicaid spending, children's access and care, and, where applicable, estimated children's coverage.

**[Access the report, webinar recording, and slides](#)**

- KFF created a brief featuring five key facts about CYSHCN and Medicaid and an exploration of how Medicaid provides coverage for these children and their families. The brief includes how coverage varies by state, and an explanation of how Medicaid's [Early and Periodic Screening, Diagnostic, and Treatment \(EPSDT\)](#) program supports families of CYSHCN.

**[Read the brief](#)**

**[Related: Webinar - Proposed Medicaid Funding Cuts and the Harms They Pose](#)**

The proposed Medicaid cuts threaten critical services that support everyday life for people with disabilities. Though this webinar is not specifically focused on children, speakers will discuss what is at stake for people with disabilities and how to take action. This webinar is organized by the Center for Innovation in Social Work & Health at the Boston University School of Social Work.

**DATE/TIME:** Wednesday, May 21 | 12:00-1:00pm PT

[Register](#)

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## **State Medicaid Non-Emergency Medical Transportation Contracts: Key Provisions, Standards, and Considerations**

Federal statute requires states to provide non-emergency medical transportation (NEMT) to Medicaid beneficiaries who have no other means of getting to medically necessary health care appointments. States have flexibility in the design and operation of their NEMT program, and services vary widely. Health Management Associates developed a report and toolkit after examining NEMT-related requests for proposals and contracts for five states, and interviewing state Medicaid officials and other stakeholders about NEMT standards, challenges, and successes.

[View the toolkit](#)

## **MEDICAL AND DENTAL CARE**

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## Webinar: Improving Access to Dental Care for CYSHCN

In an upcoming webinar, NORC at the University of Chicago will share key findings from a Foundation-funded project that examined the oral health needs and dental care experiences of CYSHCN and their families. The researchers identified potential policy solutions to improve access to high-quality dental care.

**DATE/TIME:** Tuesday, June 10 | 10:00-11:00am PT

[Register](#)

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## Health Care Cost Hardships Doubled for Families of Children with Disabilities

A study regarding financial concerns published in *JAMA Network Open* revealed that families of children with disabilities were almost twice as likely to experience any of the financial hardships evaluated than families without a child with disabilities. The authors call for structuring health insurance policies to ensure that children with disabilities have their medical care covered in a way that does not financially burden their families. The article underscores that proposed federal Medicaid cuts would likely increase the financial distress experienced by families.

[Read the article](#)

## TRANSITION TO ADULT CARE

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### Exploring Challenges for Young Adults with Chronic Medical Conditions

Generation Patient's *Roundtable on Young Adults with Chronic Medical Conditions*, funded by our Foundation, gathers a multi-stakeholder learning community of young adult patients, health care professionals, caregivers, and researchers to explore systemic challenges that affect young adults living with chronic conditions. The first roundtable focused on transition to adult care. Participants discussed the challenges young adults face during this stage of their health care journey.

[Watch the recording of the first roundtable](#)

## CHILDREN WITH MEDICAL COMPLEXITY

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

In the third session of five FLAG Rounds, “The Compass We Carry,” family faculty will tell stories that involve diagnostic overshadowing, end-of-life decision making, and defining dignity. 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.

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[Subscribe](#) to our email list.

[Watch the recordings](#) of the first and second sessions, and [refer to this guide](#) to make the most out of FLAG Rounds recordings.

[Register](#) for the May 29 no-cost FLAG rounds and more upcoming rounds.

## SYSTEMS OF CARE

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### How States Are Improving Systems to Serve Children and Youth with Chronic and Complex Needs

Fragmented systems and limited availability of services result in children and youth with chronic and complex needs often being unable to access the specialized care they require. To improve systems of care for this population, states are implementing a range of policies and utilizing various strategies, such as legislation and programmatic changes, across Medicaid and other programs. This brief, produced by the National Academy for State Health Policy and supported by our Foundation, summarizes states' priorities and approaches for this population, and provides specific examples of state-led initiatives.

[Read the brief](#)

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### Viewpoint: States Should Stay the Course on Medicaid 1115 Demonstration Implementation

Medicaid Section 1115 waivers provide state programs with critical flexibility to experiment with innovative approaches to address unique coverage, benefit, and access needs of their populations, including CYSHCN. Most states utilize waivers and some states have several. The Trump Administration has signaled potential changes to the program as part of its Medicaid restructuring. An article from the *80 Million* discusses the possible implications for states, and urges states to continue advocating for waivers and implementing programs that already have been approved.

[Read the article](#)

## FAMILY ENGAGEMENT

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### Family Voices FESAT survey

Family Voices' [Family Engagement in Systems Assessment Tools \(FESAT\)](#) are widely used across the maternal and child health field to evaluate how well systems engage families in improvement efforts. As Family Voices works to refine the FESAT, they want to hear from those who have used it about what worked well, what could be better, and how it supported their work. Users' insights are critical in shaping future FESAT training, tools, and implementation. The survey close date is **May 23**.

[Take the survey](#)

## CALIFORNIA POLICY

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### **TODAY: California Medi-Cal Defense Webinar: Assessing the Impact of Federal Medicaid Cuts for Children and Youth in California**

Medi-Cal covers nearly half of all CYSHCN. Major federal Medicaid funding reductions and coverage proposals, if enacted, will inevitably put Californian children's health and well-being at risk. Join Manatt Health and our Foundation for a webinar on the effects the Congressional proposals could have on Californian children's coverage and access to health care services.

**DATE/TIME:** TODAY, Thursday, May 15 | 12:00-1:00pm PT

Presentation slides will be available on our website after the webinar.

[Register](#)

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### **Perspectives on Providing Enhanced Care Management for Children and Youth in California**

Enhanced Care Management (ECM) is a Medi-Cal benefit designed to better support children and youth with complex clinical and non-clinical needs who require care across multiple delivery systems. Our Foundation, in partnership with the California Health Care Foundation, supported a survey of more than 900 ECM "implementers" to examine the challenges and opportunities of contracting to provide ECM services to children and youth, with particular focus on those serving children enrolled in California Children's Services. Despite challenges with implementation of, and payment for, ECM services, most providers reported optimism that the program has potential and could meet many patient/family needs through improved coordination.

[Read the issue brief](#)

## RESOURCES

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### **Family Voices Language Access Courses for Families and Community Health Workers**

To increase the quality and use of language access services for families of CYSHCN, Family Voices has created My Language, My Care, two free online courses about language services in health systems. The courses, tailored to families and community health workers, provide information about patients' rights to language services and ways to improve the quality of these services. The family course is available in English, American Sign Language, Chinese, and Spanish. The community health worker training course is available only in English.

[Access the courses](#)

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## Exceptional Parent Magazine: Annual Mobility Issue

This issue of *Exceptional Parent Magazine* turns readers' attention to the millions of Americans who live with mobility limitations. The issue discusses the challenges they face and how to help create a more accommodating and equitable society.

[Read the issue](#)

## 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!

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