

## **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.*

### **NATIONAL POLICY**

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#### **Senate Weighs Changes to Bill That Would Slash Medicaid; Report Shows Potential Impact**

The House has passed the bill that includes major cuts to Medicaid that could affect many CYSHCN and their families, but the Senate continues to negotiate, with some Senators calling for even deeper reductions. *No Place to Hide: Children Will Be Hurt by Medicaid Cuts*, a recent report with an accompanying webinar from Manatt and our Foundation, estimates how the Congressional proposals 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](#)**

Also see: [Medicaid and CHIP Cuts in the House-Passed Reconciliation Bill Explained](#) – from the Georgetown Center for Children and Families

#### **Share Your Story with Lawmakers about the Value of Medicaid**

Families know best how Medicaid services help them and their children with disabilities. The University of Southern California Center for Excellence in Developmental Disabilities at Children's Hospital Los Angeles is seeking family stories to help lawmakers understand what could happen if services change or are eliminated.

**[Learn more and submit a story](#)**

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

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#### **Creating Workable Medicaid Policies for CMC: Environmental Scan, Upcoming Webinar**

Results have just been released from an environmental scan that was conducted to support Medicaid policymakers in improving care for CMC and their families. The goal of the research,

led by [Academy Health's Enhancing Systems of Care for CMC Coordinating Center](#), was to highlight challenges and opportunities in translating the concepts of CMC and family-centered health homes into practical, workable Medicaid policies. The scan also examined where current measurement tools may not fully capture the important features and outcomes of quality care for CMC. Academy Health will host a webinar on the findings. To register for the webinar, create a free Academy Health account.

**DATE/TIME:** Monday, June 23 | 11am-12pm PT

[Read about the scan](#)

[Register for the webinar](#)

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## Putting Care at the Center Conference to Feature Focus on CMC

Children, youth, and families with complex health and social needs are the topic of one of the workshop tracks scheduled for the "Putting Care at the Center" conference to be held in October in Portland, Oregon. The tracks are designed to offer participants the opportunity to explore topics in a more intentional and connected way. Through a focus on community-driven and family-centered strategies, these workshops will explore innovative models that improve outcomes, promote equity, and strengthen systems of care. Early-bird registration is available now through **July 30**.

**DATES:** October 15-17, 2025

[Read more and register](#)

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## Grand Rounds: Insights from a Pediatrician Who Is Parent of a Child with Complex Needs

In a recent lecture at Stanford Pediatrics Grand Rounds, Tasha Faruqi, DO, a pediatrician at Cincinnati Children's Hospital and parent of a child with medical complexity, discussed family experiences of living with and caring for a child with complex medical needs. She noted the financial and emotional burdens this can place on families and siblings, and outlined difficulties in navigating complex care systems. Faruqi encouraged her physician colleagues to challenge their perceptions of patients with complex needs.

[Watch the recording](#)

[View past Grand Rounds recordings](#)

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## HEALTH CARE TRANSITION

### Report to Congress Targets Better CYSHCN Transition to Adult Care; Webinar to Highlight Recommendations

In a June report to Congress, the Medicaid and CHIP Payment and Access Commission (MACPAC) offers recommendations for improving transition from pediatric to adult care for CYSHCN covered by Medicaid. The report notes the challenges experienced by CYSHCN during transition, the absence of a requirement for states to document their transition strategy, the dearth of data on this population, and the limited coordination between state Medicaid and

Title V agencies. The MACPAC's recommendations would require states to develop and implement a strategy for transitions for CYSHCN and address these challenges. This report was informed by the work of the National Alliance to Advance Adolescent Health, a partner of our Foundation. Got Transition and our Foundation will host a webinar with MACPAC staff to discuss the recommendations.

**DATE/TIME:** Friday, July 11 | 9-10am PT

[Read about the recommendations](#)

[Register for the webinar](#)

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## Moving to Adult Health Care: A Six-Part Toolkit

[The Center for Transition to Adult Health Care for Youth with Disabilities](#), led by Family Voices, has developed six new toolkits in partnership with youth with developmental disabilities. The Moving to Adult Health Care toolkits help youth take the lead in health care visits, manage their health needs, know their legal rights, and make plans for moving to adult care. Each kit includes a side-by-side guide that youth and young adults can use in partnership with a health care supporter, an accessible EZ Reader, and tools or worksheets to help youth put information into action.

[Access the toolkits](#)

## MENTAL AND BEHAVIORAL HEALTH

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### New Peer Support Toolkit for Young Adults with Mental Health Needs

Patient-led peer support is an effective tool to help address the mental health needs of young adults with chronic conditions. Generation Patient, a non-profit organization created by and for young adult patients focused on peer support, research, health policy, and leadership programming, has created a Peer Support Toolkit that offers processes and recommendations for creating, facilitating, and sustaining community-led peer-support groups.

[See the toolkit](#)

## FAMILY ENGAGEMENT

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### Family-Led Academic Grand Rounds Series Continues in September; Recordings Available

Family-Led Academic Grand (FLAG) Rounds train and empower families of children with complex medical conditions to share their experiences with medical students and residents. The recording and slides from *The Compass We Carry*, the third session of five, are now available, along with recordings from two previous FLAG Rounds. FLAG Rounds, which are supported by our Foundation, are approved to offer continuing education credits.

**Register** for the [September 25 no-cost FLAG Rounds](#) and one more upcoming Round.

[View the recordings](#)

## SYSTEMS OF CARE

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### Report Examines How States Utilize Vital Community Health Workers

Community health workers (CHWs) are trusted members of communities who serve as intermediaries between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery. As state, federal, and local partners increasingly recognize the value of the CHW role, the National Academy for State Health Policy offers a state-by-state comparison of CHW models, including state definitions, certification and training, Medicaid reimbursement, other funding mechanisms, key partnerships, and state legislation.

[Read the report](#)

## TELEHEALTH

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### How States Use Telehealth to Support Children with Chronic and Complex Needs

Telehealth is an important tool for improving access to care for children with chronic and complex needs. Evidence shows that the addition of telehealth-based services to comprehensive care can reduce adverse outcomes and health care costs for these children and their families. A brief from the National Academy for State Health Policy highlights state innovations and considerations for delivering care via telehealth. The authors describe the use of telehealth approaches to support primary care providers, address pediatric specialty care workforce shortages, and strengthen access to behavioral and mental health services. This work was supported by our Foundation.

[Read the brief](#)

## HOME- AND COMMUNITY-BASED SERVICES

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### Early Registration: Home- and Community-Based Services Conference

The annual Home and Community-Based Services (HBCS) Conference will be held August 24-28 in Baltimore, with an additional virtual conference to be held September 17-18. This conference brings together state, federal, and local policymakers as well as leaders who administer, manage, and deliver waiver and other HCBS programs to share practices and policies that improve state systems delivering long-term services and supports for all ages and abilities. Early bird registration closes on **June 30**.

**DATES (in-person):** August 24-28, 2025

**DATES (virtual):** September 17-18, 2025

[Learn more and register](#)

## CALIFORNIA POLICY

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### Viewpoint: Potential Impact of Tariffs on Medically Fragile Children

As the federal government imposes and retracts international tariffs, one mother worries about her son's specialized medical equipment and supplies, which contain parts produced in countries all around the world. In a *California Health Report* opinion piece, the author discusses equipment sources, rising prices, and her fears of being unable to obtain the supplies her son needs to survive. She suggests that families inventory their supplies and review their vendors, and offers possible ways to address the issue.

[Read the article](#)

## Webinar Recording: Impact of Proposed Federal Cuts on California's Children

Manatt Health and our Foundation recently hosted a webinar on the potential effects that Congressional Medicaid proposals could have on Californian children's coverage and access to health care services.

[Access the webinar recording and slides](#)

## EVENTS

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

Join hundreds of state leaders at "Riding the Waves of State Health Policy," NASHP's annual conference in San Diego. The conference 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, 2025

[Learn more and register](#)

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