

# Children and Youth with Special Health Care Needs

## Network Newsletter

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

**Editor's Note** -- During the summer, the Newsletter will publish monthly rather than every two weeks. We will keep in touch via email about specific items if the need arises. Our next issue is scheduled for August 17.

### NATIONAL POLICY

#### Federal Funding to Create a National Center for A System of Services for CYSHCN

The American Academy of Pediatrics has received funding from the federal Maternal and Child Health Bureau (MCHB) to lead a five-year collaborative aimed at providing better services and care for children and youth with special health care needs (CYSHCN) and their families. The collaborative, which includes Boston University, Family Voices, and The National Alliance to Advance Adolescent Health, will support implementation of the MCHB [Blueprint for Change](#), a national framework for a system of services for CYSHCN that would enable them to live and thrive in their communities from childhood through adulthood. [Read more](#).

#### **Related: Town Hall on New National Center**

**DATE** Thursday, July 27

**TIME** 9 to 10 a.m. Pacific Time

**LOCATION** Virtual

**DETAILS** The town hall will provide an overview of the Blueprint for Change, featuring its authors, and will highlight the new National Center's goals and objectives. [Read more and register](#).

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#### Federal Agencies: How to Engage People with Disabilities in Policies, Programs, and Evaluations

**DATE** Tuesday, July 18

**TIME** 9 to 10 a.m. Pacific Time

**LOCATION** Virtual

**SPONSOR** Mathematica's Center for Studying Disability Policy

**DETAILS** A roundtable discussion about federal agencies' successes, challenges, and lessons learned as they work to incorporate lived experience and equitable research practices into their programs and policies. [Read more and register.](#)

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### **In Brief**

- [Affordable Care Act Preventive Services Under Threat in Braidwood vs. Becerra](#) – from National Health Law Program
- [Biden Administration Plans Crackdown on Disability Rights Violations](#) – from *Disability Scoop*

## **CHILDREN WITH MEDICAL COMPLEXITY**

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### **Article: Perceived Disability-Based Discrimination in Health Care for Children with Medical Complexity**

Little is known regarding disability-based discrimination in health care for children with medical complexity and disability, yet an understanding of this topic is needed to drive change and improve care. An open-access article in *Pediatrics* discusses the results of a study whose objective was to qualitatively describe the perspectives and experiences of family caregivers of children with medical complexity regarding disability-based discrimination in health care. [Read the study results.](#)

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### **CYSHCN Research Group Seeks Advisory Committee Applicants**

**August 10** is the deadline to apply to participate in the Advisory Committee for [CYSHCNet](#), a national group of researchers who work to improve the health care system for CYSHCN and their families. Applications are accepted from CYSHCN and anyone who supports them. [Read more and apply.](#)

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### **In Brief**

- [Early-Bird Registration for \*Putting Care at the Center 2023\* extended through \*\*July 18.\*\*](#)

## **HOME- AND COMMUNITY-BASED CARE**

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### **Webinar: Delivering Care at Home - Challenges and Approaches to Success**

**DATE** Tuesday, July 25

**TIME** 11:30 a.m. to 12:30 p.m. Pacific Time

**SPONSORS** Manatt

**DETAILS** The second segment of a webinar series aimed at learning to navigate the complicated care-at-home landscape. A panel of health care leaders will discuss real-life examples of how to work effectively across the ecosystem of health care providers, payers, and non-billing service providers. [Read more and register.](#)

*Also see:* Part one of the series, [Care at Home 101: Understanding Why It's Important, Services Provided and How It's Paid For](#)

### **Related:**

- Explainer: [Health Home Services for Medicaid-Enrolled Children with Medically Complex Conditions](#) – from the Catalyst Center
- [Why Children Are Stranded in the Hospital and How to Get Them Out](#) – from University of Pennsylvania's Leonard Davis Institute of Health Economics

## **FAMILY ENGAGEMENT**

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### **New Online Magazine - Family Voices En Español**

In collaboration with the Family Voices Hispanic Affinity Group, Family Voices has launched a virtual magazine to provide an opportunity to share content, articles, stories and resources from Hispanic/Latino families and family leaders. The new publication covers a range of topics, from mental health to featured leaders to recipes. Read it [en Español](#) or [in English](#).

## **HEALTH CARE FINANCING**

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### **Report: Strategies to Finance Services for CYSHCN**

Many Title V and Medicaid programs use funds from their own programs or leverage other funding to reduce the number of CYSHCN without health insurance, close benefit gaps, pay for additional services, and build the capacity of the system of care. A report from the Catalyst Center provides examples of strategies for improving and financing care for CYSHCN that were collected through interviews with CYSHCN Program Directors and Family-to-Family organization leaders. [Read more.](#)

## **PEDIATRIC PALLIATIVE CARE**

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### **Webinar: Whole Person Care - Looking at the Child Behind the Medical Complexity**

**DATE** Tuesday, August 15

**TIME** 12 to 1 p.m. Pacific Time

**SPONSORS** Pediatric Palliative Care Coalition

**DETAILS** This webinar will illustrate the importance of seeing a child with medical complexity beyond their medical condition, and how this viewpoint can advance more equitable and inclusive care for all patients and their families. [Read more and register](#). Fee.

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## In Brief

- [For Medically Fragile Kids, Access to Palliative Care Depends on Family Resources](#) – from *California Health Report*

## PUBLIC HEALTH EMERGENCY UNWINDING

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Public  
Health  
Emergency  
Unwinding

## Feds Ask States and Stakeholders to Help Prevent Coverage Loss

Amid increasing concerns that eligible children and others are losing Medicaid and Children's Health Insurance Program coverage due to procedural disenrollments, the Centers for Medicare and Medicaid Services (CMS) is urging states to adopt additional flexibilities to minimize the number of enrollees losing coverage inappropriately. CMS issued a list of State Strategies to Minimize Terminations for Procedural Reasons and a call-to-action for community partners. [Read more](#) from the Georgetown Center for Children and Families.

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## Webinar on Medi-Cal Renewals

**DATE** Wednesday, July 19

**TIME** 12 to 1 p.m. Pacific Time

**LOCATION** Virtual

**SPONSORS** Children's Partnership and the National Health Law Program

**DETAILS** A feedback loop to identify and help address issues and concerns with the Medi-Cal renewal process in California. [Read more and register](#).

## CALIFORNIA CHILDREN'S SERVICES

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## CCS Advisory Group Meets

Topics at the July 12 CCS Advisory Group meeting included updates on the CCS Monitoring and Oversight Program and the Child Health and Disability Prevention Program transition plan; an overview of the Hearing Aid Coverage for Children Program; discussion of the Whole Child Model expansion as outlined in [SB/AB 118](#) and Kaiser Permanente’s Whole Child Model readiness for expansion; and significant changes to the upcoming Title V CYSHCN Needs Assessment. The presentation slides with details will be posted on the Advisory Group [website](#). A meeting summary and slides from the April 12 meeting now are available on the site.

## CALIFORNIA POLICY

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### In Brief

- [State Budget Provides Largest-Ever Medi-Cal Rate Increase](#) – from the California Medical Association
- [Kids in Medi-Cal to Get New Care Coordination Help](#) – from Children Now. Discusses new Enhanced Care Management benefit.
- [Your Child’s Medi-Cal Managed Care Plan Is Responsible for Providing More than Just Health Care Services \(PDF\)](#) – from Children Now

## RESOURCES

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- [Essential Elements for Developmental and Behavioral/Social/Emotional Screening Using Bright Futures in Title V Programs](#) – from the Association of Maternal and Child Health Programs
- [Traveling with a Medically Complex Kid](#) – from the Child Neurology Foundation

## EVENTS

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### Celebrating the Americans with Disabilities Act

**DATE** Wednesday, July 26

**TIME** 2:30 to 4:30 p.m. Pacific Time

**LOCATION** Washington, DC; free live streaming

**SPONSOR** American Association of People with Disabilities

**DETAILS** In celebration of the 33rd anniversary of the signing of the Americans with Disabilities Act, speakers will reflect on the progress of the disability rights movement and highlight the work ahead to ensure equal opportunity for all disabled Americans. [Read more and register.](#)

## IN THE NEWS

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- [Adult-Size Changing Tables Poised to Become More Available](#)  
*Disability Scoop, 6/28/23*
- [Forget The Birds And Bees. Sex Ed Series Preps Young Adults with Disabilities for Life, Dating](#)  
*Disability Scoop, 6/27/23*
- [Medicaid Aims to Better Serve Adults with IDD, Aging Caregivers](#)  
*Disability Scoop, 6/22/23*
- [Accessible Nature: A Trail Guide for Disabled Hikers](#)  
*New York Times, 6/19/23*
- [Why the Number of Kids Enrolled in a Federal Benefit Program Has Dropped Dramatically](#)  
*NPR, 6/19/23*
- [Booting 18-Year-Olds from Disability Rolls Has Lifelong Consequences](#)  
*Mother Jones, 6/23*
- [As Medicaid Cutoffs Surpass 1 Million, Worries Grow Over Impact on People with Disabilities](#)  
*Disability Scoop, 6/15/23*

#### **WE'D LIKE TO HEAR FROM YOU**

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Let us know what's happening with your organization or family. Email newsletter assistant editor Hannah Au at [Hannah.Au@lpfch.org](mailto:Hannah.Au@lpfch.org) with your news or updates. Or contact newsletter editor: Eileen Walsh at [Eileen.Walsh@lpfch.org](mailto:Eileen.Walsh@lpfch.org).

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