

California Advocacy Network for Children with Special Health Care Needs

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

Editor's Note: The next edition of the Newsletter will be published on August 12.

COVID-19 Information

Medicaid Options for States During COVID-19: Considerations for CYSHCN

A new fact sheet summarizes the implications for children and youth with special health care needs of critical Medicaid policy modifications that states implemented rapidly in response to the COVID-19 crisis. The document, second in a series from the Association of Maternal and Child Health Programs and the Georgia Health Policy Center, may help inform state decisions regarding which adaptations should become permanent. [Read the fact sheet](#) (PDF).

Medicaid During and 'After' the Pandemic: Changes that Should Become Permanent

The National Health Law Program also weighs in on which temporary pandemic changes should be made permanent in order to fight COVID-19 in the short term, improve access to health care in the long term, and address new and ongoing disparities in health equity. [Read the paper](#).

In Brief

- [American Academy of Pediatrics Urges In-person Learning, Masking in Updated Guidance on Safe Schools](#) – from AAP News

Family Engagement

Shared Struggles – Stories from Parents and Pediatricians Caring for Children with Serious Illnesses

A new book offers glimpses into how parents of children with complex needs and physicians think, feel, and interact. Sections include stories contributed by parents from across the United States and by pediatricians practicing at children's hospitals throughout the country. The goal is to improve communication, minimize conflicts, and foster trust and compassion among physicians, patients, and families. [Read more](#).

Webinar Reminder – How Medicaid Agencies Can Engage with Families, Youth

Date Tuesday, July 27
Time 10 to 11 a.m. Pacific Time
Sponsor Center for Health Care Strategies
Details Meaningful partnerships with enrollees can help Medicaid agencies better serve youth and families, including those with special health care needs. The Center for Health Care Strategies, with support from our Foundation, conducted a survey to understand engagement strategies Medicaid agencies are using across the country. Speakers will discuss the findings and recommendations. [Read more and register](#).

Children with Medical Complexity

How to Talk About Complex Care

The [Complex Care Field Coordinating Committee](#), which works to coordinate and align complex care activities across the field, is asking complex care practitioners, including those who serve children, to complete a survey designed to help develop messaging that will more effectively articulate complex care work and its value to a diverse range of audiences. [Read more and take the survey](#).

Early Bird Savings for 'Putting Care at the Center' Conference

August 1 is the deadline for early registration for the national conference that focuses on complex care, scheduled virtually for October 20-22 and sponsored in part by our Foundation. [Read more and register](#).

California Children's Services

CCS Advisory Group Reviews Monitoring of Whole Child Model

At its July 14 meeting the CCS Advisory Group discussed updated guidance on Medical Therapy Units, including in-person services; the charter and membership criteria of the Advisory Group itself; CCS dashboard data; and monitoring of the Whole Child Model, among other issues. [See the agenda and PowerPoint presentation](#).

California Policy

Department of Health Care Services Stakeholder Advisory Committee to Meet

Date Thursday, July 29
Time 9:30 a.m. to 12:30 p.m. Pacific Time
Details The [agenda](#) includes discussion of the [Home and Community Based Services Spending Plan](#). To view materials and make comments, [register in advance](#).

Viewpoint: Care for Children with Disabilities Is Infrastructure, too. Let's Invest in It.

The mother of a child with a chronic complex condition argues that programs that make day-to-day life manageable for families, such as Home and Community Based Services, should be considered part of a state's infrastructure. She notes that the lack of investment in such programs is shortsighted and expensive, as out-of-home care is much more costly for the government. [Read her essay](#) in the *California Health Report*, which receives support from our Foundation.

Pediatric Palliative Care

Webinar – Let's Talk About Masks

Date Wednesday, August 4
Time 9 to 10 a.m. Pacific Time
Sponsor Pediatric Palliative Care Coalition
Details The use of masks is nothing new for many families of children with medical complexity. In this webinar, a care provider and a family caregiver will explore the difficulties of communicating with masks, the obstacles that arise during in-person conversation, and potential solutions. [Read more and register](#).

National Policy

Affordable Care Act Special Enrollment Period Ending

A special opportunity to enroll in the Affordable Care Act insurance program is available through **August 15**. Some individuals who previously were not eligible for coverage now may qualify. [Find out how to enroll](#).

Webinar – Navigating the No Surprises Act: Your Guide to Requirements, Challenges, and Compliance

Date Monday, August 2
Time 10 to 11 a.m. Pacific Time
Sponsor Manatt
Details The No Surprises Act is intended to protect patients from surprise medical bills. This webinar will help care providers and health plans prepare to navigate the complexities of the Act. [Read more and register](#).

Bills to Watch

- [S.2210, the Better Care Better Jobs Act](#), is a broad-based bill that includes major investment in Medicaid Home and Community based Services (HCBS), including enhanced compensation for workers. This issue, which affects many families of CYSHCN, also is being considered in the ongoing federal budget negotiations. [Read more about the proposal](#).
- [S.1670, the Credit for Caring Act](#), would provide a non-refundable federal tax credit of up to \$5,000 to eligible family caregivers to help address the financial challenges of providing care while remaining in the workforce.

Telehealth

Archived Webinar



The [presentation slides and a recording](#) of the webinar *COVID-19 Telehealth Policies Affecting CYSHCN: What to Keep, Modify, or Discard?* are now available.

Special Education

- [Education Department to Release Extra IDEA Funds, New Guidance](#) – from Disability Scoop

Resources

- [Promoting Healthy Sexuality for Children and Adolescents with Disabilities](#) – from the American Academy of Pediatrics
- *Exceptional Parent Magazine* July Issue – [Accessible Homes](#)

In the News

- [JCPenney Unveils Clothing Aimed at Kids with Disabilities](#)
Disability Scoops, 7/15/21
- [Court Throws Out FDA Ban on Shock Devices for Those with Developmental Disabilities](#)
Disability Scoop, 7/12/21
- [The Democratic Plan to Smash Poverty for Seniors and People with Disabilities](#)
Vox, 7/9/21
- [G.O.P. Bills Rattle Disabled Voters: 'We Don't Have a Voice Anymore'](#)
NY Times, 6/14/21

We'd like to hear from you

Let us know what's happening with your organization or family. Email newsletter assistant editor Ali Rivera at Ali.Rivera@lpfch.org with your news or updates. Or contact newsletter editor: Eileen Walsh at Eileen.Walsh@lpfch.org.

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The California Advocacy Network for Children with Special Health Care Needs is a collaborative organized by the Lucile Packard Foundation for Children's Health. Through grantmaking, advocacy, and communications, the Foundation promotes a system of care that improves the lives of children with special health care needs and their families.

