

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 July 13.

NETWORK NEWS

Foundation Grants Address Health Equity, Impact of Public Health Emergency Ending

Four new grants from our Foundation focus on advancing health equity for children and youth with special health care needs (CYSHCN), while five additional grants are designed to educate and support families of CYSHCN – along with health system administrators, community health workers, legal advocates, and providers – to prevent lapses in health coverage as the Public Health Emergency ends. [Read about the grants.](#)

HOME- AND COMMUNITY-BASED SERVICES

Webinar Series Part 1: Care at Home 101 - Understanding Why It's Important, Services Provided, and How It's Paid For

DATE	Wednesday, June 21
TIME	10 to 11 a.m. Pacific Time
SPONSOR	Manatt
DETAILS	A detailed primer on the care-at-home issues that senior health care leaders have identified as most challenging. Read more and register.

State Offers Incentive Payments for HCBS Direct Care Workers

California's Department of Health Care Services is offering an opportunity for organizations to

apply for a \$500 one-time incentive payment for employees who are direct care providers of Medi-Cal Home and Community-Based Services (HCBS) and meet certain criteria. The application will close on **July 10**. [See eligibility requirements and application](#).

NATIONAL POLICY

Webinar: Proposed Rules on Medicaid Payments, Access, and Quality - Implications for Health Care Stakeholders

DATE Tuesday, June 20

TIME 10 to 11 a.m. Pacific Time

SPONSORS Manatt

DETAILS The Centers for Medicare & Medicaid Services (CMS) recently released two proposed rules that would reshape the federal regulatory landscape for Medicaid and the Children's Health Insurance Program. Speakers will review some of the key proposals and discuss the implications for stakeholders, including Medicaid and CHIP beneficiaries, health care providers, state Medicaid agencies, and Medicaid managed care plans. [Read more and register](#).

PEDIATRIC PALLIATIVE CARE

Webinar: When Parents Want Aggressive Treatment for Their Dying Child – How Do I Respond and Where Do I Turn?

DATE Tuesday, June 20

TIME 12 to 1 p.m. Pacific Time

SPONSORS Pediatric Palliative Care Coalition

DETAILS This webinar will provide tools for analysis and resolution of critical situations when parents request treatment that may not help, and potentially may harm, their child. [Read more and register](#). Fee.

Event: Shared Decision-Making – What Does This Actually Mean and What Does It Look Like?

DATE Tuesday, June 20

TIME 5 to 6 p.m. Pacific Time

SPONSOR Courageous Parents Network

LOCATION Virtual

DETAILS What happens when clinicians and parents/caregivers aren't on the same page for treating a seriously ill child? This session will explore the dimensions of shared decision-making and give participants a framework for considering the variables, including medical facts, personal values, personal preferences, and risk tolerance. [Read more and register.](#)

HEALTH EQUITY

Issue Briefs: Digital Equity and Health Care

Health care became increasingly reliant on technology during the pandemic, and as that trend continues the inequity in access becomes more apparent. Two new issue briefs address possible solutions for communities that historically have lacked access.

- [Addressing Digital Equity for Equitable, Accessible Health Care](#) – from the Insure the Uninsured Project. Highlights the roles health care stakeholders can take in closing the digital divide, the state and federal regulation of broadband, and where and how to meaningfully engage in efforts to advance digital equity at the state and local levels.
- [Digital Equity – A Key to Children's Health and Racial Justice](#) – from The Children's Partnership. Serves as a resource for advocacy to advance digital equity in order to address the disparate impact of the digital divide on BIPOC (Black, Indigenous, People of Color) children.

In Brief

- [U.S. Access Board Seeks Public Comment on Final Specification for Low Transfer Surface Height of Medical Diagnostic Equipment](#) – Comments are due by **July 24**.

INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Report: Advancing a Roadmap for Health and Equity Data for Persons with Intellectual and Developmental Disabilities

Noting the ongoing serious data gaps about the health of people with intellectual and developmental disabilities (I/DD), a newly released report from the Administration for Community Living proposes a path that would lead to a robust health monitoring system for people with I/DD in the U.S. The monitoring system would be used to inform policies, programs, and projections. The report summarizes the proceedings of a summit held in November 2022. [Read more \(PDF\).](#)

In Brief

- [People with Down Syndrome Are Living Longer, but the Health System Still Treats Many as Kids](#) - from *Disability Scoop*
- [HR 3380](#) proposes to designate people with Intellectual and Developmental Disabilities as a Medically Underserved Population, a group that has a shortage of personal health services.

PUBLIC HEALTH EMERGENCY UNWINDING

California Medi-Cal Renewal Feedback Loop

DATE Wednesday, June 21

TIME 12 to 1 p.m. Pacific Time

LOCATION Virtual

DETAILS Hosted jointly by the National Health Law Program and The Children's Partnership, this series of sessions will assist organizations, advocates, and families to identify and help resolve issues and concerns with the Medi-Cal renewal process. Three additional sessions are scheduled through September. Interpretation available. [Read more and register.](#)



Public
Health
Emergency
Unwinding

In Brief

Note: See more resources on our regularly updated [Public Health Emergency Unwinding page](#).

- [More Outreach to Families Needed During the Unwinding; Some States Are Stepping Up Their Game](#) – from Georgetown Center for Children and Families
- [As Medicaid Purge Begins, 'Staggering Numbers' of Americans Lose Coverage](#) – from Kaiser Family Foundation
- [How to Keep Your Family's Medi-Cal Benefits](#) - from *California Health Report*

CALIFORNIA CHILDREN'S SERVICES

CCS Advisory Group to Meet

DATE Wednesday, July 12

TIME 1 to 4 p.m. Pacific Time

DETAILS The agenda and login information will be posted on the group [website](#).

CALIFORNIA POLICY

Virtual Event to Focus on Launch of Enhanced Care Management for Children and Youth

DATE Friday, June 23

TIME 1 to 2:30 p.m. Pacific Time

SPONSOR Department of Health Care Services

DETAILS In advance of the July 1 start of Enhanced Care Management for Children and Youth Populations of Focus, DHCS leaders will be joined by a panel of providers, community-based organizations, and managed care plans to discuss the program and respond to questions. [Advance registration required](#).

SPECIAL EDUCATION

- [It's Here! An Introduction to the Much-Anticipated Updated School-Based Medicaid Services and Administrative Claiming Guide](#) – from Georgetown Center for Children and Families

RESOURCES

- [Summer Fun and Travel Issue](#) - from Exceptional Parent Magazine
- [Care Coordination Resources for Families and Physicians](#) – from the Child Neurology Foundation

IN THE NEWS

- [Google Displaying Accessibility Information More Prominently](#)
Disability Scoop, 5/26/23

WE'D LIKE TO HEAR FROM YOU

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

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