

Children and Youth with Special Health Care Needs

Network Newsletter

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

Editor's Note -- Happy Thanksgiving to all. The next newsletter is scheduled for November 30.

CHILDREN WITH MEDICAL COMPLEXITY

Take a Survey: Help Improve Well-Being of Families Who Care for Children with Health Complexity

Parents, guardians, siblings, or other family caregivers of a child with complex health issues are invited to complete a short survey to help researchers better understand how to improve family well-being. The study, funded by our Foundation, is being conducted by a team of family leaders, clinicians, and researchers from the CYSHCN National Research Network. The team seeks to document what day-to-day life is like for families, with the goal of developing recommendations on how the health care system can improve family well-being. [Take the survey in English or Español.](#)

Report: The Future Pediatric Subspecialty Physician Workforce

Pediatric subspecialists are critical to ensuring quality care and conducting research to improve prevention, diagnosis, and treatment, but there are substantial disincentives to pursuing a career as a pediatric subspecialist. A report from the National Academies of Sciences, Engineering, and Medicine recommends strategies and actions to ensure an adequate pediatric subspecialty physician workforce to support broad access to subspecialty care and a robust research portfolio. [See the recommendations.](#)

Also see: [Access to Pediatric Specialty Care in California: Results of the Children's Specialty Care Coalition 2022 Member Survey.](#)

HOME- AND COMMUNITY-BASED CARE

Innovative Approach: Asking Caregivers to Tell Their Stories

As part of its effort to ensure that caregivers have the resources they and their families need to be healthy, as well as a voice in the policies and practices that affect them, Health Leads is

using an innovative approach to gathering data. They are asking caregivers to use an online tool to share a story of what works for them and what would make their experience better. Health Leads then will follow up with a few questions. The tool is anonymous. Read about the [tool](#) and see a [video](#) on how it works.

In Brief

- Bill to Watch: [SB 3118](#). A bill to provide for an emergency increase in federal funding to state Medicaid programs for expenditures on home- and community-based services.
- [As 2024 Nears, Advocates Push for Caregiving as Campaign Issue](#) – from *Disability Scoop*

FAMILY ENGAGEMENT

INSPIRE: A National Strategy to Advance Community Partnerships in Health Care

[Initiating National Strategies for Partnership, Inclusion, and Real Engagement](#) (INSPIRE) is a newly launched national partnership that seeks to codify best practices for effective and mutually beneficial community engagement to improve health care. The founding organizations plan to create tools, resources, and learning and coaching models that will meet the varied needs of health care stakeholders and people with lived experience to advance meaningful partnerships in their communities. [Read more](#).

Also see: [Are We Speaking the Same Language? Defining What We Mean by “Community Engagement”](#) – from the INSPIRE project

PEDIATRIC PALLIATIVE CARE

Webinar: What is Structural Competency? How Inequality Makes Us Sick.

DATE

Thursday, November 16

TIME

12 to 1 p.m. Pacific Time

SPONSOR

Pediatric Palliative Care Coalition

DETAILS

Structural competency is the capacity for health professionals to recognize and respond to health and illness as the downstream effects of broad social, political, and economic structures. Speakers will discuss these concepts through a pediatric palliative care case and examine how structures affect the practice of health care. [Read more and register](#). Fee.

In Brief

- Booklet: [Building Communities Full of Joy and Care for Medically Fragile Children](#) (PDF) – from National Center for Pediatric Palliative Care Homes and Children’s Respite Homes of America

TELEHEALTH

Webinar: Tele-Transformation in North Carolina - Telehealth Policy Lessons Learned During COVID-19 and Beyond

DATE

Monday, November 13

TIME

12 to 1 p.m. Pacific Time

SPONSOR

Manatt

DETAILS

Manatt Health staff and leadership from the North Carolina Department of Health and Human Services will describe the state’s innovative approach to telehealth policymaking, which could serve as a model for other states and stakeholders. [Register](#).

PUBLIC HEALTH EMERGENCY UNWINDING



Public Health Emergency Unwinding

- [‘Worse Than People Can Imagine’: Medicaid ‘Unwinding’ Breeds Chaos in States](#) - from *KFF Health News*
- [What’s New for 2024 Marketplace Enrollment?](#) – from Georgetown Center for Children and Families. Includes information about special enrollment opportunities tied to the Medicaid unwinding.
- [Medicaid Enrollment Is Down by Five Million Including Two Million Children](#) - from Georgetown Center for Children and Families
- [Eliminating CHIP Premiums Could Help with Child Transitions from Medicaid to CHIP](#) – from Georgetown Center for Children and Families

Webinar: Keep Your Community Covered - Schools and Families

DATE

Thursday, November 16

TIME

2 to 3 p.m. Pacific Time

SPONSOR

California Department of Health Care Services

DETAILS

The webinar will provide school partners with information to assist students and their families with renewing Medi-Cal coverage. [Advance registration required.](#)

Webinar: California Medi-Cal Renewal Feedback Loop

DATE

Wednesday, November 15

TIME

12 to 1 p.m. Pacific Time

SPONSORS

The Children's Partnership, National Health Law Program

DETAILS

Experts provide updates on Medi-Cal renewals and host a discussion to identify and help address concerns with the unwinding process. [Read more and register.](#)

CALIFORNIA CHILDREN'S SERVICES

CCS Advisory Group Meeting Review

The [summary](#) from the October 11 Advisory Group meeting now is available on the group's web page.

CCS Redesign: Subcommittee on Performance Measure Quality to Meet

DATE

Wednesday, November 29

TIME

1 to 5 p.m. Pacific Time

SPONSOR

The subcommittee is charged with developing a comparison analysis with clinical and non-clinical measures by which CCS Whole Child Model and Classic counties will be evaluated. Find meeting details on the subcommittee [website](#).

RESOURCES

- [Financial Planning: Discussing Future Needs](#) - from Exceptional Parent Magazine

EVENTOS

Congreso Familiar to Host Informational Events

In the coming weeks, Congreso Familiar, a conference dedicated to promoting education and leadership skills in Spanish-speaking families who have members with disabilities, will present sessions on how to deal with bullying, the services of the Department of Rehabilitation, and CalABLE. [Read more and register](#) in Español or English.

IN THE NEWS

- [Justice Department Warns Sheltered Workshops May Violate ADA](#)
Disability Scoop, 11/2/23
- [Museum Makes Major Acquisition of Works by Artists with IDD](#)
Disability Scoop, 10/27/23
- [Senators Seek Emergency Funding to Ensure Access to Disability Services](#)
New York Times, 10/26/23

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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