

Children and Youth with Special Health Care Needs

Network Newsletter

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

NETWORK NEWS

New: Consensus Standards to Promote Continuity of Care in Pediatric Intensive Care Units

Children who require extended stays in Pediatric Intensive Care Units (PICUs) have higher rates of medical errors, morbidity, and mortality than other patients, and their prolonged hospitalizations cause obstacles and stress for patients, families, providers, and institutions. To date there have been no agreed-upon standard practices to ensure continuity of care for long-stay patients, and existing strategies are underutilized and understudied. With funding from our Foundation, Columbia University Medical Center and Riley Hospital for Children at Indiana University convened a multidisciplinary working group of professional and family stakeholders who developed PICU Continuity Consensus standards that offer practical guidance and have been endorsed by the Society of Critical Care Medicine (SCCM). [Read more.](#)

MENTAL/BEHAVIORAL HEALTH

Webinar: Leveraging Medicaid to Support Children and Youth Living with Complex Behavioral Needs

DATE	Wednesday, November 8
TIME	10 to 11 a.m. Pacific Time
SPONSOR	Manatt
DETAILS	An interactive panel, including state officials, youth advocates with lived experience, and leading clinicians, will discuss actionable strategies to respond effectively to the crisis in youth mental and behavioral health that has been exacerbated by the pandemic. Read more and register.

PEDIATRIC PALLIATIVE CARE

Webinar: Realign-Respond-Repair: Responding to Discrimination with your

Interdisciplinary Team

- DATE** Tuesday, October 17
- TIME** 12 to 1 p.m. Pacific Time
- SPONSOR** Pediatric Palliative Care Coalition
- DETAILS** Interdisciplinary medical teams experience discrimination from patients every day. Care providers will learn about an innovative communication tool for responding to discrimination in real time in the clinical setting, while aligning with patients around care and supporting teammates. [Read more and register](#). Fee.
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In Brief

- [Education and Training Resources for Adult Palliative and Hospice Care Providers and Programs Who Are Called Upon to Care for a Child and Family](#) - from the National Hospice and Palliative Care Organization

PUBLIC HEALTH EMERGENCY UNWINDING



Public Health Emergency Unwinding

- [Unwinding Data Recap: What Do We Know So Far?](#) – from Georgetown Center for Children and Families
- [Medicaid Continuous Coverage Unwinding: Messaging and Outreach Resources](#) - from National Health Law Program
- [New Resource Helps Pediatricians Inform Families on How to Keep Eligible Children Enrolled in Medicaid](#) – from Georgetown Center for Children and Families
- [Take a Survey on Medi-Cal Renewal](#) - from Family Voices and The Children's Partnership

Webinar: California Medi-Cal Renewal Feedback Loop

- DATE** Wednesday, October 18
- TIME** 12 to 1 p.m. Pacific Time
- SPONSORS** The Children's Partnership (TCP), National Health Law Program (NHeLP)
- DETAILS** Experts lead a discussion to identify and help address issues and concerns with the renewal process. [Read more and register](#).

Webinar: Medi-Cal Renewals Are Back – Tips for Keeping Coverage

DATE Wednesday, October 25

TIME 10 to 11 a.m. Pacific Time

SPONSORS Western Center on Law & Poverty, National Health Law Program (NHeLP)

DETAILS Speakers will provide a brief refresher on the unwinding process, new renewal tips and flexibilities, current renewal activities and updates, and a call to action to improve the unwinding process in California. [Read more and register.](#)

FAMILY ENGAGEMENT

CAHMI: A History of Promoting Family Involvement in System Change

Since 1996, the national Child and Adolescent Health Measurement Initiative (CAHMI) has worked to put families at the center of defining, measuring, and using health care performance information to drive improved services and outcomes, including a focus on CYSHCN. A new article in the *Maternal and Child Health Journal* highlights CAHMI's history in shaping the field of maternal and child health, and offers six ideas for enhancing the field going forward. [Read the article.](#)

In Brief

- [Four Tips for Including and Engaging Family Partners in Your Work](#) – from the National Institute for Children's Health Quality

HEALTH EQUITY



The [recording](#) and [slides](#) from the Institute for Patient- and Family-Centered Care webinar, More Than Checking A Box: Strengthening DEI In Children's Hospital PFACs (Patient Family Advisory Councils), now are available.

- [Viewpoint: It's Time to Rethink the Americans with Disabilities Act](#) – An attorney with disabilities discusses how to encourage compliance with the Americans with Disabilities Act without burdening members of the disability community with the need to sue non-compliant businesses.

Related: [Supreme Court to Weigh ADA Protections](#) - from *Disability Scoop*

HOME- AND COMMUNITY-BASED CARE



The recording of [The Unforgotten Families Webinar: What's Next? Legislative Updates for Family Certified Nursing Assistant Model](#) now is available.

INTELLECTUAL/DEVELOPMENTAL DISABILITIES

‘Think College’ Helps Families Weigh Higher Education Options

An organization dedicated to developing and improving research and practice in inclusive higher education for students with intellectual disability, Think College offers resources for families and prospective students. [Read more.](#)

In Brief

- [Feds Back Effort to Train Doctors on Developmental Disabilities](#) - from *Disability Scoop*

CALIFORNIA CHILDREN'S SERVICES

CCS Advisory Group Covers Range of Topics

At its October 11 meeting the CCS Advisory Group discussed Whole Child Model readiness, monitoring of CCS performance, the Enhanced Care Management program, and the transition of the Child Health and Disability Prevention Program, among other topics. [See the agenda and slide presentation.](#)

Kaiser Care to Become Available in Some Whole Child Model Counties

As a result of legislation passed in 2022, CCS clients in eight Whole Child Model counties may be enrolled in Kaiser Permanente for services beginning January 1. For details, [read the letter \(PDF\)](#) from the Department of Health Care Services.

CALIFORNIA POLICY

Department of Health Care Services Stakeholder and Behavioral Health Stakeholder Advisory Committees to Meet Jointly

- DATE** Thursday, October 19
- TIME** 9:30 a.m. to 3:30 p.m. Pacific Time
- LOCATION** The California Endowment, 1414 K Street, Sacramento, or attend virtually.
- DETAILS** More information available on the [SAC](#) and [BH-SAC](#) webpages. Advance registration required.

Two articles from the *California Health Report* Address Issues of Concern to Families of CYSHCN:

- [How Families of Children with Disabilities Can Find Support](#)
- [Analysis: Overwhelmed With Medical Bills? It Helps to Think Like a Detective](#)

RESOURCES

- [Employment and Transition](#) - from Exceptional Parent Magazine

IN THE NEWS

- [Feds Aim to Ease Shortage of Special Educators](#)
Disability Scoop, 10/10/23
- [Labor Department Scrutinizing Subminimum Wage Employment](#)
Disability Scoop, 10/2/23

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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