

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 June 15.

FAMILY CAREGIVING

Paying Family Medical Caregivers for Children's Home Health Care: A Colorado Model

To address the shortage of home health care workers for children with complex medical needs, some states allow trained family members to be paid for providing medical care. A new study published in the *Journal of Pediatrics* compared aspects of paid certified nursing assistant care from a family member to care provided by a traditional non-family member. The researchers sought to understand whether the family model provides care comparable to non-related care, and whether the model could be replicated in other settings. They suggest that the model may help address workforce shortages while also providing income to family caregivers. [Read the study.](#)

Also see: [Webinar - Paid Family Caregiving for Children with Medical Complexity and Disabilities](#)

Federal Grant Opportunity Aims to Support Family Caregivers

The Administration for Community Living has announced that it has earmarked \$20 million for a [grant opportunity](#) to fund up to five new cooperative agreements to eligible entities to work at the national level to further advance the development of state, community and tribal family caregiver support programs. Each project will receive up to \$1.1 million annually for four years to develop, test, and disseminate new approaches to supporting family caregivers. Applications are due by **June 26**. [Read about how to apply.](#)

TRANSITION TO ADULTHOOD

Tracking How States Are Implementing the Six Core Elements of Health Care Transition

A new report from Got Transition examines how state Title V care coordination programs have made improvements in their use of evidence-informed Health Care Transition strategies over the past five years. The report notes substantial progress as well as room for improvement, and offers a number of recommendations. [Read the report \(PDF\).](#)

Related Webinar: What Does Health Care Transition Look Like in Your State?

DATE	Thursday, June 8
TIME	10 to 11 a.m. Pacific Time
SPONSOR	Got Transition
DETAILS	The webinar will highlight five years of state data trends, and walk through strategies to improve Health Care Transition. It will include a discussion of Michigan's Children's Special Health Care Services and its innovative efforts to measure Health Care Transition performance among local health departments. Register.

CHILDREN WITH MEDICAL COMPLEXITY

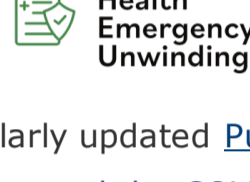
Register for Putting Care at the Center Conference; Apply to Present Work

Applications are due **June 15** to present complex care work during a Beehive Session at *Putting Care at the Center*, the annual national gathering of individuals who work to improve care for people with complex health and social needs. Early-bird registration is available until **July 2** for the conference, which is scheduled from November 1-3 in Boston. [Read more.](#)

HOME- AND COMMUNITY-BASED SERVICES

- Reminder: Register for the June 1 webinar [Proposed Rules to Enhance Access and Quality for Medicaid HCBS and Strengthen the HCBS Workforce](#) - from Manatt. Also see Manatt summary, [CMS Proposes Significant Medicaid Policy Changes for Access Monitoring, Managed Care, and HCBS](#)

PUBLIC HEALTH EMERGENCY UNWINDING

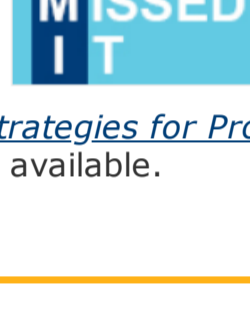


Note: See more resources on our regularly updated [Public Health Emergency Unwinding page](#).

- [Telehealth Flexibilities and Resources and the COVID-19 Public Health Emergency](#) - from the US Department of Health and Human Services
- [Fact Sheet: End of the COVID-19 Public Health Emergency](#) - from the US Department of Health and Human Services
- [A Closer Look at Medicaid Call Center Options as the Unwinding Kicks into High Gear](#) - from Georgetown Center for Children and Families

SOCIAL DETERMINANTS OF HEALTH

Webinar Recording Now Available



The recording of the Manatt webinar, [Strategies for Providing Whole Child Care: A Blueprint for Meeting Children's Social Needs](#), is now available.

HEALTH EQUITY

Voices for Change Conference Coming Up

DATE	Thursday, June 22
TIME	10 a.m. to 5 p.m. Pacific Time
LOCATION	The California Endowment, 1000 Alameda St, Los Angeles
SPONSOR	California Pan-Ethnic Health Network
DETAILS	Policymakers, elected officials, non-profits, and community organizations meet to share their thoughts and expertise on a wide variety of health equity policy areas. Our Foundation is a sponsor of the conference, which includes a session on <i>Leveraging Community Health Workers/Promotoras, and Representatives, Doulas, Peer Support Specialists and Navigators as an Anti-Racist Strategy to Advance Health Equity.</i> Read more and register. Fee.

PEDIATRIC PALLIATIVE CARE

Firefly Chat: Honoring Our Children - Initiating Conversations About Funeral Planning and Memorialization

DATE	Wednesday, June 7
TIME	9 to 10 a.m. Pacific Time
SPONSORS	Pediatric Palliative Care Coalition
DETAILS	Panelists will discuss how to have productive conversations about the complicated, and often difficult to initiate, topic of making arrangements at the end of a child's life, something that is approached differently by every family and caregiver. Read more and register.

SPECIAL EDUCATION

- [Senate Confirms New Special Education Chief](#)

FAMILY ENGAGEMENT

Highlights from the Family Voices of California Health Summit

Family Voices of California has assembled materials that summarize the topics and speakers from its Health Summit that was held in early March. On the Summit home page, see an overview of the addresses, panels, and breakout sessions, and a highlights report that lists all the summit videos. [Read more.](#)

CALIFORNIA CHILDREN'S SERVICES

Survey: Families' Thoughts on How to Improve CCS Appeals Process

In 2022, the National Health Law Program, in partnership with Family Voices of California, conducted a survey of English- and Spanish-speaking parents and caregivers of CCS beneficiaries, focusing specifically on CCS notices, hearings and appeals, with the goal of developing recommendations to improve the appeals process. A new blog summarizes the results and the recommendations from the survey, which was supported by our Foundation. [Read more.](#)

CALIFORNIA REGIONAL CENTERS

Bill Proposes Increased Oversight of Regional Center Services

Assembly Bill 1147, the Disability Equity and Accountability Act of 2023, would require an evaluation of regional center performance by the Department of Developmental Services that would be implemented using a common set of performance measures in seven domains. The bill also would require the Department to establish standards for the performance measures, and to develop, in consultation with stakeholders, a uniform process to be used by regional centers to develop corrective action plans when standards are not met. [Read more.](#)

CALIFORNIA POLICY

Viewpoint: Day Cares for Medically Fragile Children Are Closing. Here's How to Save Them

Children who need medically intensive care cannot attend traditional day care programs, and California has an option for these children called Pediatric Day Health and Respite Care facilities. A column in the *California Health Report* notes that Medi-Cal rates for these programs have not kept pace with their costs, meaning that many are in danger of closing. The author notes that these day care programs often help families keep their children at home, rather than in hospitals or residential facilities, and she calls for the state to increase their rates in the 2023 budget. [Read more.](#)

EVENTO

Seminario Web: Programa de Servicios de Apoyo en el Hogar (IHSS) - Cómo prepararse para las evaluaciones y reevaluaciones

FECHA	Sábado, 10 de Junio
HORA	10 a.m. to 12 p.m., Tiempo del Pacifico
PATROCINADOR	Congreso Familiar
DETALLES	En esta presentación se demostrará: cómo comprender las evaluaciones obligatorias del IHSS; aprender a abogar por el cliente; cómo realizar una autoevaluación; empoderamiento para representarse a sí mismo; y obtener las herramientas para comprender cómo se asignan las horas a los clientes. Leer más y registrarse.

RESOURCES

Two books of potential interest:

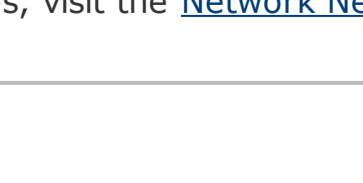
- [Born Extraordinary: Empowering Children with Differences and Disabilities](#)
- [Demystifying Disability: What to Know, What to Say, and How to Be an Ally](#)

IN THE NEWS

- [Apple Rolls Out Accessibility Features Aimed at Users with Developmental Disabilities Disability Scoop, 5/17/23](#)

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.



To see past issues, visit the [Network Newsletter Archive](#).