

Children and Youth with Special Health Care Needs

Network Newsletter

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

Editor's Note -- Happy holidays and a healthful new year to all. The next newsletter is scheduled for January 18, 2024.

NETWORK NEWS

New Grants Focus on Dental Care, Medical Device Training for Non-English Speakers, Diversity of Hospital Advisory Councils

Grants recently awarded by our Foundation aim to address health care inequities for CYSHCN in three significant areas. A first-ever comprehensive, national study of the oral health needs of CYSHCN will document disparities that exist in their access to dental care. The second grant will identify barriers to providing education in languages other than English on the use of life-saving medical devices, and will assess whether caregivers feel prepared to use these devices. The third grant will build on previous work to assist hospitals in ensuring that the membership of Patient and Family Advisory Councils reflects the diversity of patient populations. [Read about the grants.](#)

TRANSITION TO ADULT LIFE

New Tool Helps Youth, Families, Providers Navigate Health Care Transition

Empowering young people and their families to take the lead in health care transition is the goal of a new website from the national Center for Transition to Adult Health Care for Youth with Disabilities. The site, developed for and by youth with intellectual and developmental disabilities, includes tools and resources for youth and their families, along with resources for health care professionals. Family Voices leads the project, in partnership with Got Transition and other organizations. [See the new site.](#)

Also see: [Transition for Young Adults with Disabilities Is Complicated, But Some Steps Can Help](#)
- from *Disability Scoop*

HOME- AND COMMUNITY-BASED SERVICES

Paying Family Caregivers: State Options, Limitations, and Policy Considerations

Despite the growing popularity of paying family members to provide care, many states are reluctant to authorize payment, citing a variety of reasons. A new issue brief from the National Health Law Program summarizes the various considerations that states must address to expand policy options for compensating family members. [Read the issue brief.](#)

Hearing Coming Up in Lawsuit Over State's Failure to Provide In-Home Services for Children with Complex Medical Needs

In a case originally filed 10 years ago against the state of Florida, a district court concluded in July that the state's failure to provide required in-home services contributes to unnecessary institutionalization of children with complex medical needs, and places many other children at serious risk of being unable to remain in their homes. The state was ordered to implement policy modifications, but immediately appealed. An issue brief from the National Health Law Program explains the case history and the implications of an upcoming January hearing on the appeal in the Eleventh Circuit Court. [Read the issue brief.](#)

FAMILY ENGAGEMENT

Family Voices Calls for Proposals for National Convening

Family Engagement: The Catalyst for Change will be the theme when representatives from Family-to-Family Health Information Centers and Family Voices Affiliate Organizations from across the country gather virtually May 7-9, 2024. Organizers are soliciting proposals for workshops based on the principles of the [Blueprint for Change](#), the national framework for a system of services for children and youth with special health care needs. Proposals are due **January 19, 2024**. [Read more.](#)

Engaging Community Members: A Guide to Equitable Compensation

As demand for partnerships with stakeholders grows among health care agencies and organizations, the Center for Health Care Strategies notes that compensation is essential for sustaining these relationships, and offers guidance to develop appropriate compensation practices for community members. [Read more.](#)

Also see: [Standards of Compensation for Youth, Family, & Patient Research Partners](#) - from the CYSHCN Research Network

NATIONAL POLICY

Advocates Urge Opposition to Proposed Changes to Census Bureau Definition of Disability

A proposal from the U.S. Census Bureau to [change the questions about disability](#) in the American Community Survey could result in a dramatic drop in the number of individuals defined as disabled, potentially reducing funding for services and affecting civil rights

enforcement. Advocates are urging stakeholders to [read the proposed changes and leave a comment](#) for the Census Bureau by **December 19**.

In Brief

- A new [Medicaid Transportation Coverage Guide](#) highlights existing policies and includes new policies to address issues such as extended wait times and long-distance trips. It also addresses coverage of transportation for non-Medicaid eligible parents, family members, or other caregivers when required to participate in a Medicaid eligible child's care.
- [Supreme Court Throws Out Closely Watched Americans with Disabilities Case](#) - from *Disability Scoop*
- Reminder: [Health Insurance Deadlines Approaching](#)

PEDIATRIC PALLIATIVE CARE

2024 Pediatric Palliative Care Webinar Series Announced

Registration is open for the 10-webinar series on pediatric palliative care that begins January 16, 2024, with a session on *Embracing Uncertainty: The Role of Narrative in Decision-Making for Children with Medical Complexity*. [See the full schedule and registration information](#). Fee.

HEALTH EQUITY

- [Disability Studies Programs Popping Up At More Universities](#) - from *Disability Scoop* via *Los Angeles Times*
- [For Families with Limited English Proficiency, IEP Meetings Often Lost in Translation](#) - from *Disability Scoop*
- [Improving Health Equity by Eliminating Biased and Stigmatizing Language in Medical Notes](#) - from Better Care Playbook

PUBLIC HEALTH EMERGENCY UNWINDING



Public
Health
Emergency
Unwinding

- [How States Can Reduce Coverage Loss Among Children During The Medicaid Unwinding](#) - from *Health Affairs*
- [Unwinding Call Center Data Shows Ongoing Problems](#) - from National Health Law Program

- [CMS Releases New Unwinding-Related Renewal Resources for Health Care Settings](#) - from Georgetown Center for Children and Families
- [What States Are Doing to Keep People Covered as Medicaid Continuous Enrollment Unwinds](#) - from The Commonwealth Fund

RESOURCES

- [Family & Community](#) - from Exceptional Parent Magazine

INTELLECTUAL/DEVELOPMENTAL DISABILITIES

- [Annual Report: Family and Individual Needs for Disability Supports \(PDF\)](#) – from The Arc and the Institute on Community Integration, University of Minnesota

CALIFORNIA CHILDREN'S SERVICES

CCS Advisory Group to Meet

DATE

Wednesday, January 10

TIME

1 to 4 p.m. Pacific Time

SPONSOR

Department of Health Care Services

LOCATION

1700 K Street, Sacramento, CA 95811 or Virtual

DETAILS

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

EVENTS

Congreso Familiar to Host December 16 Event on IEP Basics

Congreso Familiar is a conference dedicated to promoting leadership skills and education for Spanish-speaking families who have children with disabilities. A virtual event from 10 a.m. to noon on December 16 will provide basic information on the Individualized Education Program. [Read more and register](#) in Español or English.

IN THE NEWS

- [After Tackling 'R-Word,' Disability Group Seeks to Erase Stigma Associated with 'Special' Disability Scoop, 12/11/23](#)
- [Feature Film About Accessible Theme Park Gets Green Light Disability Scoop, 12/1/23](#)

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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