

Children and Youth with Special Health Care Needs Network Newsletter

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

TRANSITION TO ADULT CARE

Webinar: New Recommendations to Strengthen the Adult Primary Care Workforce for Young Adults with Medical Complexity

- DATE** Tuesday, September 26
- TIME** 12 to 1 p.m. Pacific Time
- LOCATION** Virtual
- SPONSOR** Camden Coalition
- DETAILS** Adult primary care physicians often lack the services and infrastructure necessary to care effectively for young adults with medical complexity. This webinar will address 10 recommendations that were developed by a national advisory committee with the goal of strengthening primary care workforce capacity and service delivery to smooth the transition to adult care. [Read more and register.](#)

HOME- AND COMMUNITY-BASED SERVICES

Webinar: What's Next? Legislative Updates for Family Certified Nursing Assistants

- DATE** Wednesday, September 20
- TIME** 11 a.m. to 12 p.m. Pacific Time
- LOCATION** Virtual
- SPONSOR** The Unforgotten Families
- DETAILS** [The Unforgotten Families](#) supports efforts to scale, strengthen, and sustain community-based home care providers that support children with life-limiting conditions and their families. This webinar will address the organization's work to bring the Family Certified Nursing Assistant model to more families in more states nationwide. [Register.](#)

In Brief

- [States Chart Path Forward on Paying Parents as Caregivers](#) – from *Disability Scoop*

NETWORK NEWS

New Program: Apply to Learn about CYSHCN Research

Individuals who are interested in learning more about health systems research that supports CYSHCN, their families, and providers may apply to participate in the *Pathways Research Program* conducted by the [CYSHCN National Research Network](#). The program comprises four one-hour Zoom meetings over the course of a year. Research experience is not required and there is no cost for the program. Students and trainees in health and health-related professions may apply, and individuals from historically underrepresented groups are especially encouraged to participate. [Read more and apply.](#)

PEDIATRIC PALLIATIVE CARE

Webinar: State Palliative Care Policies and Emerging Innovations

DATE	Monday, September 18
TIME	12:30 to 1:30 p.m. Pacific Time
SPONSOR	National Academy for State Health Policy
DETAILS	This webinar will highlight recent state policies that expand access to palliative care, and key takeaways from a new Center to Advance Palliative Care report that spotlights home-based palliative care. A Hawaii state official will outline developments and advancements to establish a Medicaid state plan benefit for community-based palliative care. Read more and register.

Launch Event: Unite for Medically Fragile Children

DATE	Thursday, September 21
TIME	10 to 11 a.m. Pacific Time
LOCATION	Virtual
SPONSOR	National Center for Pediatric Palliative Care Homes
DETAILS	A range of speakers will address thought leaders, advocates, and families interested in improving the lives of medically fragile children and their families by building community-based palliative care provider capacity in the U.S. Read more and register.

Webinar: Blending the Art & Science of Child Life to Foster Choice, Connection, and Agency in Pediatric Patients

- DATE** Thursday, September 21
- TIME** 12 to 1 p.m. Pacific Time
- SPONSOR** Pediatric Palliative Care Coalition
- DETAILS** The presentation will provide professionals with education and tools on how to involve children in decision making commensurate with their development, medical knowledge, and interest in participating in their medical treatment. [Read more and register](#). Fee.

SYSTEMS OF CARE



Town Hall: The Blueprint for Change

The slides and recording of a town hall that provided an overview of the [Blueprint for Change: Guiding Principles for a System of Services for CYSHCN and Their Families](#) now are available. Participants also discussed the goals and plans of the new National Center for Systems of Services for Children and Youth with Special Health Care Needs, which hosted the town hall.

FAMILY ENGAGEMENT

Webinar: More Than Checking a Box - Strengthening DEI in Children's Hospital Patient and Family Advisory Councils

- DATE** Wednesday, September 27
- TIME** 11 a.m. to 12:30 p.m. Pacific Time
- SPONSOR** Institute for Patient- and Family-Centered Care
- DETAILS** An overview of a new resource called *Strengthening the Diversity and Role of Patient and Family Advisory Councils: Opportunities for Action*. Attendees will hear from a panel of individuals working to improve Diversity, Equity, and Inclusion and partnership with patients and families, learn about best practices, and participate in an interactive Q&A session. The work was funded by our Foundation. [Read more and register](#).
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Webinar: Supportive Decision-Making

- DATE** Thursday, September 14
- TIME** 10 a.m. to 12 p.m. Pacific Time
- SPONSOR** Family Voices of California, UC Davis, UCLA, Disability Rights California
- DETAILS** Supportive decision-making is an alternative to guardianship in which individuals with disabilities make their own decisions with the support of a trusted network. Panelists will discuss best practices and participate in a Q&A. [Read more and register.](#)

PUBLIC HEALTH EMERGENCY UNWINDING



Public Health Emergency Unwinding

- [Breaking News: CMS Reveals States Are Incorrectly Processing Ex Parte Renewals; Kids Are Most at Risk](#) – from Georgetown Center for Children and Families
- [Medicaid and CHIP Renewals: What to Know and How to Prepare](#) – A monthly education series from the Centers for Medicare & Medicaid Services. Next webinar is September 27.
- [Medicaid's Role in Rural Areas Has Grown: Families Have Much at Stake in the Unwinding](#) – from the Georgetown Center for Children and Families
- With support from our Foundation, The Children's Partnership has developed [educational videos in five languages](#) to provide families with information about renewing their Medi-Cal coverage, and a [community outreach toolkit](#) to help schools, child care providers, and other child advocates inform families about the Medi-Cal renewal process.

PHE In the News:

- [Two Families Sue Florida for Being Kicked Off Medicaid in 'Unwinding' Process](#) – from NPR
- [Many Children May Have Lost Medicaid Coverage Because of State Errors](#) – from *The New York Times*
- [Opinion: Paperwork Mistakes Should Not End a Child's Health Coverage](#) – from the *Washington Post*

INTELLECTUAL/DEVELOPMENTAL DISABILITIES

Registration Open for The Arc National Convention

Discounted registration ends **September 22** for The Arc's National Convention to be held November 6-8 in New Orleans. [Read more and register](#).

In Brief

- [Financing the Future – A Free Tool to Help with Financial Planning for Individuals with Intellectual/Developmental Disabilities](#) – from The Arc

SPECIAL EDUCATION

- [Students Could Get Millions More in Medicaid Healthcare Dollars. Why Aren't They?](#) – NPR, 8/24/2023
- [Education Department Tells States to Step Up IDEA Compliance](#) - *Disability Scoop*, 7/25/23
- [Equity in IDEA: Why Racial Disparities Are Increasing in Special Ed Programs](#) – from Deep Dive

CALIFORNIA CHILDREN'S SERVICES

Posted: Summary of the July Advisory Group Meeting

The [meeting summary](#) from the July 12 CCS Advisory Group meeting is now available on the group's website, along with the previously posted slide presentation.

CALIFORNIA POLICY

Webinars: Hearing Aid Coverage for Children - Information for Families, Providers

A September 12 webinar will provide guidance to families and communities about applying for hearing aid coverage under a state program. A September 14 webinar will offer information to providers to help patients and families enroll and maximize their benefits. Sponsored by the Department of Health Care Services, both require advance registration. [Find details and register](#).

EVENTS

Summit to Focus on Rare Diseases

The 2023 RARE Advocacy Summit, one of the world's largest gatherings of rare disease patients, caregivers, advocates, health care professionals, researchers, partners, and allies will take place September 19-21 in San Diego. Sponsored by Global Genes, the summit provides an opportunity to connect with others in the rare disease community and find opportunities for future collaboration. [Read more and register](#). Fee.

RESOURCES

- [The National Resource Center for Patient/Family-Centered Medical Home Ends Operation, but Resources Remain Available](#)
- [Preparing for Disaster for People with Disabilities and Other Special Needs](#) (PDF) – from FEMA and the American Red Cross

IN THE NEWS

- [Be Wary of Offering 'Help,' and Other Ways to Support Families with Disabilities](#)
CNN, 8/29/23
- [Meet the Man Who Stands on Corners, Tirelessly Advocating for Disability Rights](#)
Disability Scoop, 8/22/23
- [Walmart Spotighting Products for People with Disabilities](#)
Disability Scoop, 8/21/23
- [The Ones We Sent Away](#)
The Atlantic, 8/7/23

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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