

# Children and Youth with Special Health Care Needs

## Network Newsletter

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

### FAMILY ENGAGEMENT

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#### **Weaving Lived Experience into Health Services Research**

A new handbook from the Children and Youth with Special Health Care Needs National Research Network (CYSHCNNet) aims to assist researchers in collaborating with people with lived experience to make research studies more relevant and meaningful. The handbook, produced with support from our Foundation, provides guidance to ensure that researchers, families, and patients work collaboratively on research studies in which all participants' input is valued. This "how-to" guide covers topics such as power dynamics in research partnerships, recruitment and retention of participants, family-driven research and design, ethics, evaluation, and much more. [Read the handbook.](#)

### HOME- AND COMMUNITY-BASED CARE

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#### **Fact Sheet: Medicaid Paid Family Caregiving for Children**

Most home health care for children with medical complexity is delivered by families who are not compensated for providing care, but the option to pay family caregivers is gaining national traction. Our Foundation recently sponsored a [Paid Family Caregiving webinar](#) that explored potential policy solutions to address this issue. While state laws, policies, and regulations vary greatly, a new fact sheet produced as a follow-up to the webinar offers basic information about available policy options, examples of legislation and payment options in various states, opportunities for advocacy, resources, and answers to frequently asked questions. [Read the fact sheet.](#)

#### **Related:**

- [Illinois Nursing Shortage Keeps Boy in Hospital for His 1st Birthday Unnecessarily](#) – Features commentary from Foundation grantee Carolyn Foster, MD, on training family members to be paid caregivers – CBS News, 6/12/23

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**Federal Judge: Keeping Children with Complex Conditions in Institutions Violates the**

## Americans with Disabilities Act

In a ruling that could have nationwide implications, a federal judge in Florida ruled that the state's failure to provide adequate care to children with complex medical needs in their communities has forced families to "warehouse" their fragile children in institutions. The state is violating the Americans with Disabilities Act by failing to provide Medicaid payment for private nursing care that could allow children to live in home settings, he ruled. The state is appealing the decision. [Read the decision](#).

Also see: [Florida Kept Disabled Kids in Institutions. A Judge Is Sending Them Home](#) – *Washington Post*, 7/19/23

### **Viewpoint: Doctors Told Me My Son Would Be Better Cared for in an Institution. They Were Wrong**

The mother of a technology-dependent child with medical complexity recounts her family's intense struggle to overcome barriers to caring for their son at home after he spent most of his first year of life in an institution. [Read her story](#) in the *California Health Report*, which receives funding from our Foundation.

## CHILDREN WITH MEDICAL COMPLEXITY

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### **Children's Hospital Builds an Ecosystem of Care to Improve Mental Health of Children with Complex Needs**

In 2021, the National Center for Complex Health and Social Needs launched a nationwide [Ecosystems Learning Collaborative](#) to help care teams learn how to rapidly expand and sustain cross-sector partnerships to address the needs of individuals with complex health and social needs. A recently published case study recounts how Rady's Children's Hospital in San Diego built an ecosystem that expanded its network of social and behavioral health providers. The study describes the project's challenges, and offers advice for others looking to build an ecosystem. [Read the case study](#).

## INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

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### **Centers Around the Country Receive Funding to Address Issues in Developmental Disabilities**

Seventeen [University Centers for Excellence in Developmental Disabilities Education, Research, and Service](#) (UCEDDs) have been awarded federal funding for a new five-year cycle to address issues, find solutions, and conduct research to advance the needs of individuals with developmental disabilities and their families. UCEDDs are interdisciplinary education, research, and public service units of universities, or public or nonprofit entities associated with universities. [Read more](#).

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### **In Brief**

- [CDC Finds 'Significant Increase' in Kids with Developmental Disabilities](#) - *Disability Scoop*, 7/17/23

- Study: [Remote Supports for People with Intellectual/Developmental Disabilities in Home- and Community-Based Services](#) - from The Council on Quality in Leadership

## CALIFORNIA CHILDREN'S SERVICES

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### CCS Advisory Group Meeting Materials Available

The slides from the July 12 CCS Advisory Group meeting now are posted on the group's web page. The slides provide details about the breadth of topics covered, including updates on the CCS Monitoring and Oversight Program and the Child Health and Disability Prevention Program transition plan; an overview of the Hearing Aid Coverage for Children Program; discussion of the Whole Child Model expansion as outlined in [SB/AB 118](#), and Kaiser Permanente's Whole Child Model readiness for expansion; and significant changes to the upcoming Title V CYSHCN Needs Assessment. [See the slides.](#)

## NATIONAL POLICY

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- [Justice Department Advances Proposed Rule to Strengthen Web and Mobile App Access for People with Disabilities](#) – from US Department of Justice

## PUBLIC HEALTH EMERGENCY UNWINDING

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### Public Health Emergency Unwinding

- [Unwinding Continuous Coverage](#) - from the Georgetown Center for Children and Families. Provides extensive and updated information about the unwinding from around the country, including resources, tips, and data.
- [Renewal Tips of the Day: March -June 2023](#) – from the National Health Law Program. New document brings together all the Medicaid Renewal Tips of the Day on one site and organizes them by subject.
- [Feds Extend Lifeline to Disability Service Providers](#) - *Disability Scoop*, 8/4/23
- ["Scared Out of My Mind": A Family Scrambles after Their Disabled 3-year-old Loses Medicaid](#) - *Texas Tribune*, 7/28/2023

## HEALTH EQUITY

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The recording and materials from the webinar [Strategies for Providing Whole Child Care: A Blueprint for Meeting Children’s Social Needs](#) are available from Manatt. Speakers discussed new ways to address the health-related social needs of children.

### **In Brief**

- [Health and Human Services Releases Report to Increase Language Access for Persons with Limited English Proficiency](#)
- [Michigan's Largest Children's Hospitals Team Up to Study Pediatric Care Inequity](#) - *The Detroit News*, 7/13/23

## **TRANSITION TO ADULTHOOD**

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### **Building Better Interventions for Youth with Disabilities**

A fragmented and complex system of supports continues to make it difficult for youth with disabilities to get the services that can help them the most. Mathematica has created a website that examines research on transition and offers ideas that could be explored to develop solutions for more successful transitions. [Read more](#).

## **PEDIATRIC PALLIATIVE CARE**

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- [Pediatric E-Journal Provides Education and Training Resources for Pediatric Palliative and Hospice Care Providers and Programs](#)– from the National Hospice and Palliative Care Organization

## **EVENTS**

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### **Congreso Familiar to Host Informational Events Regarding Regional Center Services**

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 two sessions on social and recreational services for Regional Center clients, and another session on changes to the Regional Center appeals process. [Read more and register](#) in Español or English.

## **RESOURCES**

- [Become a Disability A.L.L.Y. – Information for Health Care Providers](#)– from the Centers for Disease Control and Prevention
- [Back to School Issue](#) - Exceptional Parent Magazine

## IN THE NEWS

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- [Airlines Face Mandate to Improve Planes for Passengers with Disabilities](#)  
*Disability Scoop, 7/31/23*

## WE'D LIKE TO HEAR FROM YOU

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Let us know what's happening with your organization or family. Email newsletter assistant editor Hannah Au at [Hannah.Au@lpfch.org](mailto:Hannah.Au@lpfch.org) with your news or updates. Or contact newsletter editor: Eileen Walsh at [Eileen.Walsh@lpfch.org](mailto:Eileen.Walsh@lpfch.org).

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