

## California Advocacy Network for Children with Special Health Care Needs

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

**Editor's Note** -- National, state, and local policies affect the health and well-being of children and youth with special health care needs and their families. Exercise your power to influence those policies. **Vote by November 8.**

### Care Coordination

#### National Forum Tackles Care Coordination Workforce, Integrated Care

Building on the previously released [National Care Coordination Standards for Children and Youth with Special Health Care Needs](#), the National Academy for State Health Policy, with support from our Foundation, convened a national forum of experts representing state and federal health agencies, families of CYSHCN, providers, and health plans to discuss strategies and opportunities to improve care coordination for CYSHCN. The forum focused on integrated care and the care coordination workforce. [Read the proceedings](#).

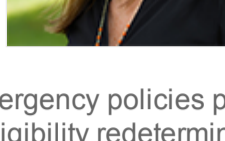
### Grant Opportunity - Systems and Standards

#### Advancing the System of Services for CYSHCN

The Health Resources and Services Administration's Maternal and Child Health Bureau has opened applications for a grant to improve services by supporting implementation of the [Blueprint for Change: Guiding Principles for a System of Services for Children and Youth with Special Health Care Needs](#) under the National Center for a System of Services for CYSHCN. The *Blueprint* addresses four key areas: health equity; CYSHCN and family well-being and quality of life; access to services; and financing of services. Any domestic public or private entity is eligible to apply. Applications are due by **January 26, 2023**. [Read more](#).

### Public Health Emergency Unwinding

#### A Parent/Advocate's View: Supporting CYSHCN Families after the Public Health Emergency Ends



The winding down of COVID-19 Public Health Emergency policies presents a challenge for many CYSHCN families whose children will need to undergo a Medicaid eligibility redetermination. Family Voices and Manatt Health, with support from our Foundation, developed three policy briefs with recommendations on how to minimize insurance coverage losses during the unwinding. Cara Coleman, director of public policy and advocacy at Family Voices, shares her perspective on the challenges ahead and discusses how to use the briefs to advocate for CYSHCN and their families. [Read her viewpoint and the three briefs](#).

*Related:* [Supporting Children & Families Enrolled in Medicaid as the COVID-19 PHE Conclusion & Unwinding Nears](#) – from Manatt

### Home- and Community-Based Care

#### Feds Launch National Center to Strengthen the Direct Care Workforce

The Administration for Community Living has awarded a five-year grant to establish a national center to expand and strengthen the direct care workforce across the country. The initiative will provide technical assistance to states and service providers, and facilitate collaboration with stakeholders to improve recruitment, retention, training, and professional development of direct care workers, who help individuals with disabilities remain in their own homes. [Read more](#).

#### In Brief

- [Disability Service Provider Crisis Worsening, Survey Finds](#) - from Disability Scoop, 10/21/22

### Pediatric Palliative Care

#### Webinar: Palliative Care - A Cloak of Comfort in Sickle Cell Disease

**Date** Thursday, November 17  
**Time** 12 to 1 p.m. Pacific Time  
**Details** Details: Speakers will discuss strategies, barriers, and goals for a broader implementation of palliative care for those living with sickle cell disease. Fee. [Read more and register](#).

#### In Brief

- [How a Bereaved Mom Is Helping Researchers Improve Palliative Care](#)

### National Policy

#### In Brief

- [Medicaid's Transportation Benefit and Children and Youth with Special Health Care Needs](#) - from National Academy for State Health Policy
- [More Families Will Spend Less on Health Care Premiums Thanks to a Fix for the "Family Glitch"](#) - from Center on Budget and Policy Priorities

### California Children's Services

#### Helping Families Navigate the Whole Child Model

Under a program called the Whole Child Model, California has transferred many children with complex medical needs from the California Children's Services program into managed care organizations. The Orange County Care Coordination Collaborative for Kids, a multi-agency, cross-sector collaborative, examined the strengths, challenges, and barriers that emerged during the transition in Orange County, and developed a guide to assist parents and caregivers to navigate the complexities of the Whole Child Model. The work, which may be of assistance to other Whole Child Model counties, was funded by our Foundation. Read the report, [Working Together for System Improvement](#), and the [guide](#) in three languages.

### Family Engagement

#### Webinar: How Families of CYSHCN Are Coping in the "New Normal"

**Date** Tuesday, November 15  
**Time** 10 to 11 a.m. Pacific Time  
**Sponsor** KidsData at PRB  
**Details** Families of CYSHCN have faced significant challenges over the course of the pandemic. In California, their experiences — from caregiver stress to concerns about emotional and mental health — were captured in four surveys from 2020 to 2022. Speakers will highlight key data findings, demonstrate how to access the data, share their lived experiences, and suggest opportunities for change. [Read more and register](#).

### Special Education

- [Supreme Court to Weigh In on Special Ed Disputes](#) – from Disability Scoop, 10/27/22

### Intellectual and Developmental Disabilities

#### Regional Center Disparities

Part Two of the Little Hoover Commission's *Hearing on the Developmental Disabilities System* is scheduled for noon on Thursday, November 10. Public comment will be accepted. [Read more](#).

The recording of the October 27 *Advisory Committee Roundtable on California's Developmental Disabilities System* is now [available](#).

#### In Brief

- [In California, Spending on Adults With Disabilities Differs by 'Race and Place'](#) - from LA Times, 10/27/22

### California Policy

- [New Law on Conservatorship & Supported Decision-Making – What You Should Know](#) – from The Arc California

### In the News

- [Lucy Has a Rare Disease. Two Doctors Are Leading the Desperate Hunt for a Cure: Her Parents.](#) *SF Chronicle*, 11/3/22
- [While Respiratory Viruses Surge, Shortage of Pediatric Hospital Beds Delays Care for Some Kids](#) *CNN*, 10/25/22
- [An Autistic Teen Needed Mental Health Help. He Spent Weeks in an ER Instead.](#) *Center for Health Journalism*, 10/24/22
- [These Doctors Admit They Don't Want Patients with Disabilities](#) *New York Times*, 10/19/22
- [Finding Dental Care for Those with IDD Can Be Difficult. A Dentist Wants to Change That.](#) *Disability Scoop*, 10/19/22
- [Listen Up: You Can Now Buy Hearing Aids without a Prescription](#) *Washington Post*, 10/16/22

#### 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](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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The California Advocacy Network for Children with Special Health Care Needs is a collaborative organized by the Lucile Packard Foundation for Children's Health. Through grantmaking, advocacy, and communications, the Foundation promotes a system of care that improves the lives of children with special health care needs and their families.

