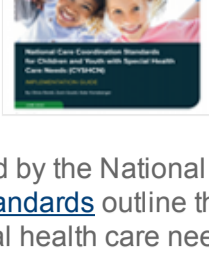


California Advocacy Network for Children with Special Health Care Needs

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

Care Coordination

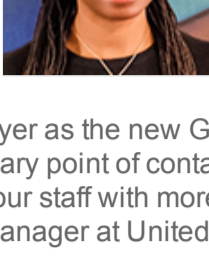
Care Coordination Standards for CYSHCN: An Implementation Guide



National standards for care coordination, developed by the National Academy for State Health Policy with support from our Foundation, were released in late 2020. The [standards](#) outline the core system-level components of high-quality care coordination for children and youth with special health care needs (CYSHCN), organized by six domains. Now, a new guide provides tools and resources that can be used to implement the standards, which are designed to help state health officials and other stakeholders develop and strengthen care coordination systems. [Read the guide.](#)

Network News

New Grants Manager Joins Foundation



Our Foundation is pleased to welcome Sheba Sawyer as the new Grants Manager for the Program for Children with Special Health Care Needs. Sheba will be the primary point of contact for grantseekers and grantees, managing applications, deliverables, and budgets. She joins our staff with more than ten years of experience as a grants manager and grant writer. Most recently Sheba was grants manager at United Way of Northern California. Find [information](#) about the Foundation's grantmaking program.

Home- and Community-Based Care

Report: All States Must Set Higher Wage Benchmarks for Home Health Care Workers

Home health care workers, who are vital to allowing many CYSHCN to remain at home with their families, are paid extremely low wages in every state, according to a new report from the Economic Policy Institute. The report outlines how state and federal officials could help establish a living wage for these essential workers, who primarily are women, people of color, and immigrants. The report also estimates how much they should be paid in each state to be appropriately compensated. [Read the report.](#)

Feds Give States Extra Time to Spend Home- and Community-Based Services Funds

The American Rescue Plan provided temporary funding opportunities for state Medicaid programs to enhance, expand, and strengthen home- and community-based services for individuals covered by Medicaid. States now have through March 31, 2025, to use those funds. [Read more](#) in an essay from the Georgetown Center for Children and Families.

Children with Medical Complexity

Share Complex Care Stories at *Putting Care at the Center* Conference

Individuals who work in complex care are invited to apply to share stories that relate to the theme of "in community we flourish" at the upcoming conference for the complex care field. Applications are due by **July 18**. [See the guidelines and apply.](#)

Family Engagement

Register for National Family Leadership Conference

Moving Forward: Embracing Change and Transformation is the theme for the National Family Leadership Conference scheduled for October 18-20 in Washington, DC. The conference is sponsored by Family Voices, the Center for Parent Information and Resources at the Statewide Parent Advocacy Network, and the Regional Parent Technical Assistance Centers. It will bring together family and youth leaders, representatives from Parent Centers, Family-to-Family Health Information Centers, Family Voices Affiliate Organizations, and other professional partners and stakeholders from across the country. [Register](#) for in-person or virtual attendance.

COVID-19 Information

Families Should Check Children's Health Coverage as COVID-19 Policies Change

As pandemic-based Public Health Emergency policies wind down, some individuals with Medicaid or Children's Health Insurance Program (CHIP) coverage may be disenrolled. Families should take steps to ensure that their children's coverage does not change. Several resources are available for families and organizations that assist families:

Title	Webinars: Medicaid and CHIP Continuous Enrollment Unwinding – What to Know and How to Prepare
Dates	July 27 – December 7
Time	9 to 10 a.m. Pacific Time
Sponsor	Centers for Medicare & Medicaid Services
Details	This monthly webinar series will provide stakeholders with information to prepare for the Medicaid and CHIP continuous enrollment unwinding. Read more and register.

Also see:

- [Renew Your Medicaid or CHIP Coverage](#) – from Medicaid.gov
- [Medicaid and CHIP Continuous Enrollment Unwinding: A Communications Toolkit](#) (PDF) – from Centers for Medicare and Medicaid Services

Pediatric Palliative Care

Webinar: Creating Legacy – Developing End of Life Protocols Following the Death of a Child

Date	Tuesday, July 19
Time	12 p.m. Pacific Time
Sponsors	Pennsylvania's Pediatric Palliative Care Coalition, Greater Illinois Pediatric Palliative Care Coalition, Children's Hospice & Palliative Care Coalition of California, and the CSU Shiley Haynes Institute for Palliative Care
Details	Speakers will discuss end of life protocols through the lens of creating legacy with the goal to integrate medical practicalities with the wishes, hopes, and beliefs of the child and family. Read more and register.

Telehealth

Webinar: Post-Public Health Emergency State Telehealth Policy Trends – What Does the Permanent Policy Landscape Look Like?

Date	Wednesday, July 13
Time	10 to 11 a.m. Pacific Time
Sponsors	Manatt Health, American Medical Association
Details	A discussion of how a long-term perspective is driving state policymaking for the use, coverage, and payment of telehealth in the future. Read more and register.

California Children's Services

Access to CCS Services: Fact Sheets Updated in Three Languages

During the COVID-19 Public Health Emergency, the Department of Health Care Services put in place temporary flexibilities for both Medi-Cal and CCS. The National Health Law Program and Family Voices of California, with funding from our Foundation, created a fact sheet explaining how to obtain CCS services as these flexibilities evolve. The [fact sheet](#) is now updated [en Español](#) (PDF) and [中文](#) (PDF).

Reminder: CCS Advisory Group to Meet

Date	Wednesday, July 13
Time	1 to 4 p.m. Pacific Time
Dial-In	1-415-655-0001; Passcode: 25931967613
Details	Meeting materials will be available on the Department of Health Care Services website .

Health Equity

Disabled and Healthy – Committing to Health Equity for All, Including People with Disability

In a blog posted by Mathematica, two individuals with disabilities express their concern that new equity-focused work largely overlooks and excludes people with disabilities. The authors explain why disabled individuals must be included in advocacy for health equity, and suggest several concrete actions that organizations could take to ensure this population is included in the research and policymaking process. [Read their post.](#)

In the News

- [How a Nationwide Extreme Formula Shortage Is Causing California Kids with Special Needs to Suffer](#)
San Francisco Chronicle, 7/5/22
- [Across US, Special Education Enrollment on the Rise](#)
Disability Scoop, 6/24/22

We'd like to hear from you

Let us know what's happening with your organization or family. Email newsletter assistant editor Ali Rivera at Ali.Rivera@pfch.org with your news or updates. Or contact newsletter editor: Eileen Walsh at Eileen.Walsh@pfch.org.

[Join the Network](#)

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

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.

