

California Advocacy Network

for Children with Special Health Care Needs

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

Care Coordination

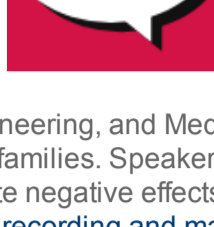
Two Avenues for Implementing High-Quality Care Coordination: Quality Measurement, Medicaid Financing

Building on previously released [National Care Coordination Standards for CYSHCN](#) and an [implementation guide](#) for using those standards, the National Academy for State Health Policy, with support from our Foundation, has released two issue briefs highlighting resources that can be used to implement high-quality care coordination:

- [Aligning Quality Measures with the National Care Coordination Standards for Children and Youth with Special Health Care Needs](#) describes key considerations and challenges in care coordination quality measurement and identifies sample metrics that could be leveraged to evaluate the quality of care coordination systems.
- [Medicaid Financing of Care Coordination Services for Children and Youth with Special Health Care Needs](#) notes that there are various methods that states can use to finance care coordination services, and highlights financing approaches across Medicaid programs in five states: California, Florida, Georgia, Texas, and Wisconsin.

COVID-19 Information

Supporting Children with Disabilities: Lessons from the Pandemic



In June, the National Academies of Sciences, Engineering, and Medicine sponsored a workshop assessing the impact of COVID-19 on children with disabilities and their families. Speakers described promising approaches and innovative strategies employed during the pandemic to mitigate negative effects, and discussed policies and practices that might be sustained or implemented going forward. [See a recording and materials from the three-day workshop.](#)

In Brief

- [States Should Take Advantage of Enhanced CHIP Funding to Keep Kids Connected to Coverage](#) – from Georgetown Center for Children and Families
- [COVID-19 Public Health Emergency Extended in the US](#) – from CNN

Transition to Adult Life

Videos Cover a Multitude of Transition Topics

The SPAN Parent Advocacy Network has compiled 39 videos that address transition topics, including higher education, employment, COVID-19, independent living, sexuality, guardianship, and more. The videos are aimed at youth/young adults with disabilities and their families, but also include "train the trainers" titles for use by professionals who work to support youth and families. [View the collection.](#)

Family Engagement

Funding Opportunity: Building an Evidence Base for Effective Family Engagement in Research

The Patient-Centered Outcomes Research Institute (PCORI) is accepting applications for research that builds an evidence base to support meaningful involvement and partnership of patients and other stakeholders throughout the research process—from planning to conducting the study, to ultimately disseminating study results. [Find details and applicant resources.](#) Proposals due **November 15.**

Caregiving

Making the Invisible Visible: State Strategies for Identifying and Reaching Family Caregivers

Many states seek to better support the critical paid and unpaid family caregiver workforce, but lack effective ways to identify the number, diversity, and unique needs of caregivers in their state. This brief outlines practical strategies some states have used to identify and reach family caregivers. Although focused on the aging population, the recommendations are relevant for CYSHCN caregivers as well. [Read the brief](#) from the Center for Health Care Strategies.

Health Care Financing

Archived Webinar: Research Agenda for Improving Health Care Financing



The [recording and slides](#) are now available for *A Conversation on Moving from Spending to Investment: A Research Agenda for Improving Health Care Financing for Children and Youth with Special Health Care Needs.*

Medical Complexity

Webinar: Healthcare on Wheels – How Mobile Clinics Meet the Complex Health and Social Needs of Patients

Date Tuesday, July 26
Time 12 to 1 p.m. Pacific Time
Sponsor National Center for Complex Health and Social Needs
Details During the pandemic, mobile clinics have become a key resource in some areas for addressing the complex health and social needs of patients. Speakers will discuss the role of these clinics, and how health care leaders can make the case that mobile clinics are both good for community health and good for business. Not pediatric specific. [Read more and register.](#)

National Policy

Celebrating Disability Rights

On July 26, organizations across the country will celebrate the 32nd anniversary of the Americans with Disabilities Act (ADA), which guarantees comprehensive civil rights protections to individuals with disabilities in the areas of employment, state and local government services, public accommodations, transportation, and telecommunication. [Read what the ADA guarantees](#) (PDF) and see suggestions for [celebration.](#)

California Children's Services

CCS Advisory Group Meeting Materials Available

Updates on the CCS and the Electronic Visit Verification programs were among multiple topics reviewed by the CCS Advisory Group at its July 13 meeting. Find details on the [slides on the Group website.](#)

Resource

Easing the End-of-Life Process: Guidance from the American Academy of Pediatrics

To lessen the stress for families, pediatricians, and other pediatric caregivers, the American Academy of Pediatrics has issued a new clinical report that reviews essential elements of care for the final hours, days, and weeks in the lives of children and adolescents with serious illness. The elements include establishing end-of-life care goals, anticipatory counseling about the dying process, and engagement with palliative and hospice resources. This report also outlines postmortem tasks for the pediatric team. [Read the report.](#)

Leadership Opportunity

Become an Ambassador for *Learn the Signs. Act Early.*

The deadline is **July 29** to apply to work with the *Learn the Signs. Act Early.* program sponsored by the Centers for Disease Control and Prevention's National Center on Birth Defects and Developmental Disabilities and the Association of University Centers on Disabilities. Ambassadors work to improve early childhood programs, systems, and outcomes related to early identification of young children with developmental delays and disabilities so that they and their families can get the help they need. [Read more and apply.](#)

In the News

- [New 988 Hotline May Help Those with IDD in Crisis](#)
Disability Scoop, 7/15/22
- [How a Nationwide Formula Shortage Is Causing Medically Fragile Kids to Suffer](#)
Disability Scoop, 7/12/22
- [In First, Feds Issue 'Bill Of Rights' for Airline Passengers with Disabilities](#)
Disability Scoop, 7/11/22
- [Disability Often Intersects with Domestic Violence. Here's How to Better Help Survivors](#)
California Health Report, 7/7/22
- [New Study: Black, Special Ed Students Punished at Greater Rate Through Pandemic](#)
The 74, 7/7/22

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@lpfch.org with your news or updates. Or contact newsletter editor: Eileen Walsh at Eileen.Walsh@lpfch.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.

