

California Advocacy Network

for Children with Special Health Care Needs

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

Caregiving

Webinar and Article: A Family-Centered Research Agenda for Supporting Caregivers of CYSHCN

Date Tuesday, February 15
Time 10 to 11 a.m. Pacific Time
Sponsors CYSHCN National Research Network, Lucile Packard Foundation for Children's Health
Details Family leaders and researchers from across the country have partnered to develop a national research agenda focused on improving the health care system for children and youth with special health care needs. [Understanding Caregiving and Caregivers: Supporting CYSHCN at Home](#) is the second in a resulting eight-part series of articles to be published as a supplement to *Academic Pediatrics*. In the webinar, the authors will discuss the integral role of family caregiving in the health care system, describe their study's findings, and reflect on the implications of their recommendations. [Read the article and register for the webinar.](#)

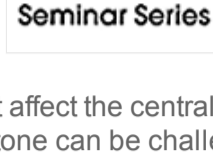
Related: View the recording from the first webinar: [A Family-Centered Research Agenda for Improving Health Care Transitions for Children with Special Health Care Needs](#).

What Works for Supporting Family Caregivers

The Better Care Playbook for People with Complex Needs has developed a collection of peer-reviewed research, case studies, tools, and on-the-ground perspectives that explore the evidence behind care models that support family caregivers. [See the collection.](#)

Children with Medical Complexity

Conversations with Families: Disorders of Muscle Tone



Complex medical conditions, particularly those that affect the central nervous system, can cause a child's muscles to become flaccid or rigid. These issues with muscle tone can be challenging for families and providers to manage. In this sixth complex care seminar, speakers will discuss current treatment options and opportunities for research. The series is funded by our Foundation.

Disorders of Tone
Thursday, February 10
10 to 11 a.m. Pacific Time

[Read more and register.](#)

View the recording from the fifth seminar: [Shared Decision Making](#).

Archived Webinar



- [Working with Medically Complex Children in Foster Care and Their Caregivers](#) – from the National Center for Complex Health and Social Needs

Transition to Adult Care

New Publication Offers Guidance for Expanding Value-Based Payment for Pediatric-to-Adult Care Transition

A newly released publication and related webinar can assist state Medicaid agencies, commercial insurers, health plans, and pediatric and adult health systems to expand their value-based payment (VBP) efforts around pediatric-to-adult health care transition. [A Guide for Designing a Value-Based Payment Initiative for Pediatric-to-Adult Transitional Care](#), developed by the National Alliance to Advance Adolescent Health with support from our Foundation, offers a step-by-step approach to designing a VBP initiative. [See the webinar.](#)

“We Advocate and Advocate until We Break” – A Personal Transition Story

In the first issue of a newsletter from the [CYSHCN National Research Network](#), an adult who has lived with a rare disease recounts her harrowing transition experiences and urges stakeholders to listen to those who have coped with transition. The author suggests a list of questions for researchers focusing on transitions of care, and emphasizes the importance of engaging providers of adult care in transition conversations. [Read her perspective](#) (PDF).

Family Engagement

The Primary Care Pediatrician: Quarterback of Your Child's Care Team?

Date Thursday, February 17
Time 11 a.m. to 12 p.m. Pacific Time
Sponsor Courageous Parents Network
Details For families of CSHCN, a relationship with a primary care provider can have a long-term impact on the family feeling supported, understood, prepared, and empowered. In this live, virtual conversation, several parents of medically complex children join their child's primary care pediatricians to talk about optimizing the care partnership. [Read more and register.](#)

In Brief

- All of the sessions from the [Family Voices of California Health Summit](#) now are available online.

Pediatric Palliative Care

Firefly Chat: The Challenges of Organizing Medical Data

Date Tuesday, February 15
Time 9 to 10 a.m. Pacific Time
Sponsor Pediatric Palliative Care Coalition
Details A provider and a caregiver will discuss their challenges and successes in trying to improve organization of medical data for their child and/or patients with complex conditions. Speakers will highlight two tools that the Pediatric Palliative Care Coalition has created to support families. [Read more and register.](#)

California Children's Services

CCS Advisory Group Reviews Plans, Priorities for 2022

At its January 25 meeting, the CCS Advisory Group considered CCS program planning and possible priorities for the coming year, and discussed how the CalAIM initiative may transform the Medi-Cal and CCS programs. The meeting [slides](#) (PDF) provide details about these topics and several others on the agenda, including the new Medi-Cal pharmacy plan. Also, as requested by the group, the Department of Health Care Services now will provide public summaries of each Advisory Group meeting. See the details of the [October 2021 meeting](#) (PDF).

New: CCS County Monitoring Workgroup

The first meeting of a newly formed CCS County Monitoring Workgroup was held on January 31. The workgroup's mission is to "develop, implement, and evaluate consistent standards for quality and access to care for beneficiaries enrolled in the CCS program throughout the state of California." See the [slides from the meeting](#), which explain the group's goals and the topics to be addressed at the group's monthly meetings.

Resource

- [Developmental Concern? Next Steps for Families and Caregivers](#) (PDF) is a family-friendly referral guide available from the American Academy of Pediatrics.

California Policy

Department of Health Care Services Stakeholder Advisory Committee to Meet

Date Thursday, February 17
Time 9:30 a.m. to 1:30 p.m. Pacific Time
Details [See meeting information and the agenda.](#)

COVID-19 Information

- [Supreme Court Ruling Means Fewer Disability Providers Face Vaccine Mandate](#) – from Disability Scoop
- [More Kids in the Hospital with COVID Renew Fears for Medically Fragile Children](#) – from Disability Scoop

Event

- [AMCHP 2022 Annual Conference Is Rescheduled to May 24-26 in an All-Virtual Format.](#)

In the News

- [Schools Use Off-Book Suspensions to Push Out Students in Special Ed, Report Finds](#)
Disability Scoop, 1/27/22
- [Latinx Families Ask for Equal Services for Their Children with Disabilities](#)
California Health Report, 1/27/22

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.

