

California Advocacy Network for Children with Special Health Care Needs

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

Transition to Adult Care

Webinar: A Family-Centered Research Agenda for Improving Health Care Transitions

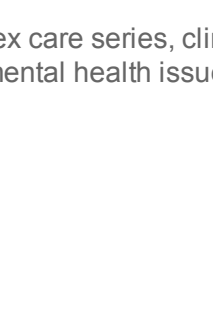
Date Tuesday, December 7
Time 10 to 11 a.m. Pacific Time
Sponsors CYSHCN Research Network, University of Colorado Denver, and Lucile Packard Foundation for Children's Health
Details Over the past three years, researchers and family leaders from across the country have partnered to develop a national research agenda focused on improving the health care system for children and youth with special health care needs (CYSHCN). A newly published article, [Improving Health Care Transitions for Children and Youth with Special Health Care Needs](#), is first in an eight-part series to be published as a supplement to *Academic Pediatrics*. In this webinar, the authors will discuss the health care transition process for CYSHCN, describe their study's findings, and reflect on the implications of their recommendations. [Register](#).

In Brief

- [Healthcare Access and Utilization for Young Adults with Disability: U.S., 2014 – 2018](#) – An abstract from the Journal of Adolescent Health

Children with Medical Complexity

Conversations with Families: Behavior/Child Mental Health



In the fourth session of this 10-part pediatric complex care series, clinicians and parents will discuss how care providers can support families in managing behavioral and mental health issues in children with medical complexity. The series is funded by our Foundation.

Behavior/Child Mental Health
Thursday, December 9
10 to 11 a.m. Pacific Time
[Read more and register](#).

See the recording from the third seminar: [Feeding Intolerance](#).

Call for Proposals to Present Webinars on Complex Care

The National Center for Complex Health and Social Needs is accepting proposals to present one-hour webinars at its monthly virtual learning sessions. Presenters share their lived experience and their work in the field of complex care. Proposals are due **January 13, 2022**. [Learn more](#).

Family Engagement

Webinar: Strengthening Patient and Family Advisory Councils in Children's Hospitals

Date Tuesday, December 14
Time 9 to 10 a.m. Pacific Time
Sponsor Institute for Patient- and Family-Centered Care (IPFCC)
Details Based on a recent national study, speakers will discuss the prevalence and characteristics of Patient and Family Advisory Councils (PFACs) in children's hospitals, and how PFACs adapted during the pandemic. They will share guidance about strengthening partnerships with patients and families. The study was conducted by IPFCC in collaboration with Cincinnati Children's Hospital Medical Center, with support from our Foundation. [Read more and register](#).

System of Care

Organizing Care Systems for People with Intellectual and Developmental Disabilities: A Workshop Series

Dates December 8, 10, and 14
Time 10 a.m. to 1 p.m. Pacific Time
Sponsor National Academies of Sciences, Engineering, and Medicine
Details This workshop series will explore the challenges and opportunities for creating an optimal care system for individuals with intellectual and developmental disabilities. The workshop, sponsored in part by our Foundation, will consider questions related to models of care, workforce, and financing and payment for care. [Learn more and register for each workshop](#).

Mental and Behavioral Health

Webinar: Supporting Emotional Health – 'Tell Me, How Are You Doing?'

Date Wednesday, December 1
Time 11 a.m. to 12 p.m. Pacific Time
Sponsor Children's Hospital Association
Details The emotional toll of pediatric chronic conditions affects adherence to treatment, health outcomes, costs, and families' lives. This webinar will introduce findings about these effects and provide a concrete way for health care providers to begin addressing them. [Read more and register](#).

Caregiving

Webinar: Who Is Caring? How Are They Faring? A Look at Family and Friend Caregivers in California

Date Wednesday, December 1
Time 12 to 1 p.m. Pacific Time
Sponsor UCLA Center for Health Policy Research
Details In addition to outlining the financial, physical, mental, and emotional factors associated with caregiving, UCLA researchers will discuss some of California's policies that support caregivers, and will propose recommendations that policymakers can use to improve conditions for family caregivers in California and beyond. [Read more and register](#).

Health Equity

Toolkit Introduction: Family Voices United to End Racism Against CYSHCN and Families (FamU)

Date Tuesday, November 30
Time 12 to 1 p.m. Pacific Time
Sponsors Families United, including Family Voices, PATH, The Parents' Place of Maryland, and Family Resource Center South Atlantic
Details This call will introduce an antiracism toolkit in the form of a website and other materials and resources that the Families United project has assembled to be used by affiliates, states, community-based organizations, and other CYSHCN allies. [Read more and register](#).

National Policy

'Public Charge' Immigration Regulations Under Review

The National Health Law Program has sent comment to the Department of Homeland Security following its publication of an "advance notice of proposed rulemaking" regarding the public charge rule. Public charge regulations may be cited to deny admission to the United States to individuals who would be dependent on certain public services. [Read the commentary](#).

California Policy

Information Available on New Medi-Cal Pharmacy Plan

Outreach and education activities have begun for the new Medi-Cal Rx program that is scheduled to launch on January 1, 2022. The program requires transition of all Medi-Cal pharmacy services from managed care to fee-for-service. For more information see the transition [website](#).

Also see: [Introducing the Medi-Cal Rx Education & Outreach Team](#) (PDF).

California Children's Services

Conference Recap: Considering CCS Best Practices in a Post-COVID World

Materials and PowerPoint presentations from a recent conference looking at CCS in a post-COVID world are now available. Topics covered by speakers from around the state included racism, adversity, and child health; lessons learned from COVID-19; state quality and equity initiatives for CCS; an update on evaluation of the Whole Child Model (WCM); real-life experiences with the WCM; and an update on the new California Advancing and Innovating Medi-Cal (CalAIM) initiative in relation to CCS. [See the materials](#).

COVID-19 Information

- [Federal Judge Overrules Texas Ban on Mask Mandates in Schools](#)
The Washington Post, 11/10/21
- [What COVID-19 Vaccine Mandates Mean for People with IDD](#)
Disability Scoop, 11/8/21
- [With Masks Optional at Some Schools, Students with Disabilities Feel Cast Aside](#)
Disability Scoop, 11/3/21

Resources

- The American Academy of Pediatrics Early Hearing Detection and Intervention program has developed an introductory Frequently Asked Questions [resource for pediatricians serving families with children who are deaf or hard of hearing](#). It provides linkages and connections to important resources in states, critical components of working with families, and tips and strategies for billing and coding.
- *Ready*, a national public service campaign that assists people in [preparing for and responding to emergencies](#), provides specific information for people with disabilities. Also available as [Listo](#), en Español.

In the News

- [CVS Drops Supreme Court Case over Disability Community Concerns](#)
Disability Scoop, 11/12/21

We'd like to hear from you

Let us know what's happening in your community or family. Email newsletter 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.

