

California Advocacy Network

for Children with Special Health Care Needs

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

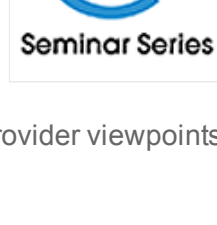
Care Coordination

Webinar: Meeting the Care Needs of CYSHCN and Their Families: Implementation of Equitable Care Coordination

Date Thursday, April 28
Time 9:30 to 10:30 a.m. Pacific Time
Sponsors National Resource Center for Patient/Family-Centered Medical Home in partnership with the National Center for Care Coordination Technical Assistance, Family Voices of Wisconsin, and Wisconsin Title V
Details This webinar will focus on the role of care coordination in supporting equitable care for CYSHCN and their families. Speakers from Wisconsin will discuss strategies used to build a sustainable care coordination system for CYSHCN in their state. National speakers will highlight care coordination tools and resources for implementation at the clinical, community, and systems levels. [Read more and register.](#)

Children with Medical Complexity

Save the Date: Pediatric Complex Care Seminar – Aspiration



This 10-part series features both family and care provider viewpoints.

Thursday, May 12
10 to 11 a.m. Pacific Time
[Register.](#)

Documenting the Impact of Complex Care Work

A key aspect of making the case for complex care is choosing the right measures to demonstrate a program's impact. A team from the National Center for Complex Health and Social Needs interviewed leaders of successful complex care programs to develop a comprehensive set of measures for the field. The measures expand the definition of return on investment while keeping a foundation in traditional measures such as cost and utilization. Not pediatric specific. [Read more.](#)

In Brief

- Reminder: Apply by **April 15** to [present your complex care work](#) at the Putting Care at the Center conference.

Transition to Adult Care

Webinar: Launching Students from School-Based Health Centers into Adult Health Care

Date Tuesday, April 26
Time 12 to 1:15 p.m. Pacific Time
Sponsors Got Transition and the School-Based Health Alliance
Details The webinar sponsors have developed the *Got Transition in School-Based Health Centers Playbook*, aimed at improving transition through evidence-based strategies. Panelists will discuss the numerous resources available for starting a school-based transition program and answer questions about getting started. [Read more and register.](#)

Pediatric Palliative Care

When to Discuss Pediatric Palliative Care or Hospice Care

A 'Caring Conversations' toolkit from the Pediatric Palliative Care Coalition offers a series of questions for caregivers and families to consider in deciding if it is time to start a conversation about hospice or palliative care for a child with serious illness. [Read more.](#)

Developmental Disabilities

Developmental Disabilities Public Policy Conference

Date April 26-28
Sponsors The Arc California, Easterseals, United Cerebral Palsy
Details This virtual conference is designed to inspire, educate, and empower attendees to become advocates for Californians with intellectual and developmental disabilities. Fee. Registration scholarships available for families. [Read more and register.](#) [Leer más y registrarse.](#)

In Brief

- [Emergency Preparedness Toolkit for Young Adults with Intellectual and Developmental Disabilities and Their Primary Care Team](#) – from the National Alliance to Advance Adolescent Health
- [What Happens After High School? A Review of Independent Living Practices to Support Youth with Disabilities Transitioning to Adult Life](#) – from the Journal of Vocational Rehabilitation

California Children's Services

CCS Advisory Group Covers Extensive Agenda

Post-COVID telehealth services, Medical Treatment Units, the new Medi-Cal prescription program, and monitoring the CCS compliance program were among the topics considered by the CCS Advisory Group at its April 13 meeting. The group also reviewed proposed 2022-23 priorities for the Department of Health Care Services, plans for child and youth behavioral services, and the state's wide-ranging proposals for improving health for children and families. Find more information on each topic on the presentation slides on the group's [website](#).

Family Engagement

It's Beautiful to Be Heard: Study Analyzes Extent of Family Engagement in Policymaking

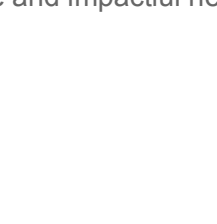
The knowledge and experience of families are often underutilized in policymaking for children with special needs. A recently released report from the California Legislative Analyst's office assesses the extent of family involvement in four state departments that provide vital services to children. The report provides recommendations for the Legislature that could maximize input from youth and families. A parent who serves on the state's Medi-Cal Children's Health Advisory Panel provides commentary on the report's findings and recommendations. [Read more.](#)

Family Leadership Conference: Deadline for Workshop Proposals Extended

Family Leadership Conference organizers are seeking proposals for workshops that will build capacity for attendees to reach and serve diverse families, youth, and professionals to improve systems that serve families and operate effective family-serving organizations. The deadline has been extended to **April 22**. [Read more and apply.](#)

Health Equity

Webinar: Advancing Health Equity – The Roles of Health Plans



A Manatt Health-sponsored webinar featured a panel of speakers from major private and public health plans sharing lessons learned and guidance for building effective and impactful health equity programs. Not pediatric specific. [View the materials.](#)

Did You Know?

Child and Family Health Measures Available

The Child and Family Health Measures from the 2020 National Survey of Children's Health have been released by the Data Resource Center for Child and Adolescent Health. The 2020 survey includes data from 42,777 children ages 0-17 years. [Find the data.](#)

In the News

- [For People with Down Syndrome, a Longer Life, but under a Cloud](#)
The Washington Post, 4/7/22
- [Biden Administration Expanding Program That Helps People Leave Institutions](#)
Disability Scoop, 4/7/22
- [Feds Seek to Improve Airline Accessibility.](#)
Disability Scoop, 4/4/22
- ['Sesame Street' Welcomes New Muppet with Disability](#)
Disability Scoop, 4/1/22
- [Biden Budget Calls for Increase in Special Education Spending](#)
Disability Scoop, 3/31/22
- [Cardona Urges Schools to Consider Students with Disabilities When Lifting COVID-19 Mandates](#)
US News & World Report, 3/24/22

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@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.

