

California Advocacy Network

for Children with Special Health Care Needs

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

Children with Medical Complexity

Improving Care Coordination for Children with Medical Complexity: Exploring Medicaid Health Home State Options

States are increasingly interested in care coordination as a strategy for improving systems of care for children with medical complexity (CMC) and their families. The Section 2703 Medicaid Health Home State Option and the new Advancing Care for Exceptional (ACE) Kids Act Health Home State Option present opportunities to enhance and expand care coordination for CMC in Medicaid. A new issue brief compares the two approaches and presents key considerations for states as they explore implementing health home options. [Read the brief.](#)

Telehealth for Families

Curriculum: The Nuts and Bolts of Telemedicine for Families

The use of telehealth has exploded during the pandemic, but many families remain unclear on what telemedicine is, what it requires, how to do it, and what different providers offer. Family Voices offers a curriculum of four webinars that explains the basics, along with other information about overcoming barriers to telehealth and how to ensure family-centered appointments. [The curriculum is available in English](#) and [Español](#).

Telehealth Survey: Family Voices of California

As part of a new telehealth project, Family Voices of California is asking families to complete a short survey that will provide feedback on problems they may be encountering in getting services for their children via telehealth. Responses will help identify resources families need to use telehealth. Take the survey in [English](#) or [Español](#) by **April 25**.

Webinar: CARES Act Telehealth Project: Materials for Youth, by Youth

Date Tuesday, April 20

Time 1 to 2 p.m. Pacific Time

Sponsors Family Voices, Connecticut Kids as Self Advocates (KASA), and Youth as Self Advocates (YASA)

Details Family Voices is launching youth-facing tools on the topic of telehealth. Young people will discuss their collaboration in creating videos and social stories using virtual platforms. These tools will be available to download from the Family Voices Telehealth [page](#). [Read more and register.](#)

COVID-19 Information

New Report Analyzes COVID-19 Risk Factors, Vaccine Priority for Children with Special Health Care Needs

In [Prevalence of Risk Factors for Severe COVID-19 Disease: Implications for Children and Youth with Special Health Care Needs](#), researchers from [Boston Children's Hospital](#) and the [Children and Youth with Special Health Care Needs National Research Network](#), with support from our Foundation, report on the at-risk health conditions for CYSHCN. The paper covers how the conditions are being used to prioritize vaccine distribution, how to identify the conditions using health care claims, and how estimating the prevalence of these conditions can help ensure that children and youth receive the care they need during the pandemic.

Webinar: Data on Family Experiences During COVID-19

Date Thursday, April 29

Time 1 to 2:30 p.m. Pacific Time

Sponsor Essentials for Childhood

Details Speakers will discuss national and California findings from a questionnaire, supported by our Foundation, that reports on a range of content areas to help document the impact of the pandemic on children and families, including those with special health care needs. [Register.](#)

Find additional information and resources on our [COVID-19 web page](#).

- [Feds Ramping Up Vaccine Access for People with Disabilities](#). Disability Scoop reports.
- [Get Out the Vaccine](#) is a website from the [National Association of Councils on Developmental Disabilities](#) that provides information to help people with disabilities and their families make decisions about being vaccinated for COVID-19.

Pediatric Palliative Care

Webinar: Big Pharma, Little People

Date Tuesday, April 20

Time 12 to 1 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, Jacob's Heart Children's Cancer Support Services, and the CSU Shiley Institute for Palliative Care

Details Children with life-limiting conditions have complex, frequently changing medication regimens that can be difficult for families to understand. This session will walk through three complicated pediatric cases, focusing on interdisciplinary communication strategies to ensure effective and accurate discussions with patients and families regarding medication plans. [Register.](#)

In Brief

- April 16 is designated as National Health Care Decisions Day. The Pediatric Palliative Care Coalition offers resources for how families can consider [Advance Care Planning for Pediatric Patients](#).

California Children's Services

CCS Advisory Group to Meet

Date Thursday, April 22

Time 11 a.m. to 3 p.m. Pacific Time

Location [Via WebEx](#)

Dial-In 1(415) 655-0001; Passcode: 1458783379

Details Agenda and materials will be posted on the [website](#).

Maintenance and Transportation for CCS Clients in Medi-Cal Managed Care

Medi-Cal managed care organizations now deliver services to California Children's Services clients in 21 counties, under a program called the Whole Child Model (WCM). The [Children's Regional Integrated Service System](#) (CRISS) has developed a series of papers identifying potential strategies to address issues and concerns. We are featuring one in each of the next several newsletters.

The third paper, which covers maintenance and transportation (M&T), notes that some families/clients requesting travel assistance are not getting the same level of service that they received prior to the WCM, which could be affecting children's access to care. The paper recommends that in WCM counties M&T should be included in case management in the same way it is in traditional CCS counties. The paper also includes several other key recommendations. [Read more and see previously published papers.](#)

National Policy

Reminder: Comment on Draft Bill Requiring Medicaid Coverage of Home and Community-Based Services

The Senate is accepting comment until **April 26** on a discussion draft of the Home and Community-Based Services Access Act, which would [require the Medicaid program to cover home and community-based services](#) (PDF). Comments should be sent to HCBScomments@aging.senate.gov. Read a related [commentary](#) from the National Health Law Program.

Related: [What's in Biden's \\$400 Billion Plan to Support Families' Long-Term Health Needs](#)

In Brief

- [Families with Sick Kids on Medicaid Seek Easier Access to Out-of-State Hospitals](#) – from NPR
- [Biden Budget Includes 'First Step Toward Fully Funding IDEA'](#) – from Disability Scoop

California Policy

Webinar: Fair Housing and Tenancy Rights for People with Disabilities During the COVID-19 Pandemic

Date Wednesday, April 21

Time 12 to 1 p.m. Pacific Time

Sponsor Family Voices of California

Details An attorney from Mental Health Advocacy Services will cover a breadth of questions. Translation available in Español and Cantonese. [Read more and register.](#)

Department of Health Care Services Stakeholder Advisory Committee to Meet

Date Thursday, April 29

Time 1:30 to 4:30 p.m. Pacific Time

Details Register for the [webinar](#), and find the agenda and call-in information on the [website](#).

In the News

- [Why Native American Children Have Higher Rates of Disability](#)
ABC News, 4/5/21

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.

