

California Advocacy Network for Children with Special Health Care Needs

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

Caregiving

Save the Date: National Caregiver Summit

Paid and unpaid caregivers have been the backbone of the health care system for CSHCN for many years, yet their work is not adequately recognized or compensated. A National Caregiver Summit on May 25 will offer the opportunity for caregivers, advocates, and thought leaders to work with others to identify and support solutions to issues that affect all caregivers – family members, home health workers, community health workers, etc. The summit is sponsored by Health Leads and the Stanford Clinical Excellence Research Center, with support from our Foundation. To receive updates and register for this event, [join the mailing list](#).

Medical Complexity

Viewpoint: The Impact of Racism and Ableism on Families of CSHCN

In a powerful essay in the *Complex Care Journal* an African American parent of a child born with a host of special health care needs expresses her concerns about implicit bias in the U.S. maternal and infant health care system. She discusses difficult questions about the intersection of health care, ableism, and racism, and explains how unrelenting stress and discrimination can affect countless families who do not have adequate support. [Read the commentary](#).

California Children's Services

Monitoring Case Management/Authorizations for CCS Clients in Managed Care

Medi-Cal managed care organizations now are responsible for California Children's Services activities in 21 counties, under a program called the Whole Child Model (WCM) that began in 2018. With support from our Foundation, the [Children's Regional Integrated Service System](#) (CRISS) has closely monitored the implementation of the WCM and has developed a series of issue papers identifying potential strategies to address concerns. We will feature one paper in each of the next several newsletters. The first paper highlights the current case management/authorizations process under WCM, and recommends that WCM plan contracts be revised to include adherence to a standardized definition of CCS case management. [Read the issue paper](#).

National Policy

Comment Sought: Draft Bill Requires 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 HCBScments@aging.senate.gov. Read a related [commentary](#) from the National Health Law Program.

In Brief

- [The American Rescue Plan: Major Relief for People with Disabilities](#) – from National Health Law Program
- [Biden Administration Actions on Public Charge Rules Help Restore Hope for Immigrant Families](#) – from Georgetown University Center for Children & Families
- [Helping Children Live to the Fullest by Understanding Developmental Disabilities](#) – Annual Report from the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention

California Policy

State Auditor Finds Widespread Flaws in In-Home Supportive Services Program

An auditor's report recently sent to the Governor and legislative leaders documents a number of weaknesses in California's In-Home Supportive Services Program, including findings that tens of thousands of recipients fail to receive needed services each month, and that no county pays caregivers a living wage. Read the [audit report](#).

Network News

Case Study: Partnering to Create Transportation Options for Families of CSHCN

An alarming lack of transportation to specialty care for children in California's San Joaquin Valley sparked a collaboration that illustrates how connecting committed partners and forging new relationships can effect systems change. The San Joaquin County Community Care Coordination Collaborative, part of our Foundation's [California Community Care Coordination Collaborative](#), united representatives from a wide range of children's services agencies to work with the local regional transit district to launch a service to provide non-emergency medical transportation to children's hospitals in other counties. [Read about the collaboration](#).

COVID-19 Information

Webinar: Ensuring Free and Appropriate Education During COVID-19

Date	Thursday, March 25
Time	11 a.m. Pacific Time
Sponsor	The Arc
Details	Practical tips that families can use will be highlighted in this webinar, which will explore some of the common hurdles for students with disabilities in distance learning/hybrid models during the pandemic. Read more and register .

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

- In late February the **Centers for Disease Control and Prevention** updated its COVID-19 information on [people with certain medical conditions](#), including a section on children with underlying conditions.
- **Stanford Medicine's Department of Pediatrics** is offering a monthly seminar series, [COVID-19 in Children](#), available on YouTube.
- Effective **March 15**, California has [opened COVID-19 vaccines to people ages 16 to 64 with disabilities or qualifying health conditions](#) that put them at greater risk of severe illness or death if they become infected, according to the **Department of Public Health**.
- The **New York Times** notes [How America's Vaccine System Makes People with Health Problems Fight for a Place in Line](#).
- The **Centers for Medicare and Medicaid Services** has released a [State Medicaid & CHIP Telehealth Toolkit: Policy Considerations for States Expanding Use of Telehealth – COVID-19 Version](#) (PDF), which aggregates information and highlights questions that states may ask when establishing new telehealth policies, including telehealth policies for pediatrics.
- **The Arc** has published [New COVID-19 Response Legislation Finally Recognizes Urgent Needs of People with Disabilities](#), including discussion of funding to strengthen and expand access to Medicaid home and community based services.

Events

Registration Open for AMCHP Annual Conference

Date	May 24-27
Location	Virtual
Sponsor	Association of Maternal and Child Health Programs
Details	This year's theme is <i>Global Meets Local: A Global Approach for Local Outcomes</i> . Early registration is available until March 26 . Read more and register . Fee.

Spring into Action: Virtual Career and Internship Fair

Date	Thursday, April 1
Time	11 a.m. to 2 p.m. Pacific Time
Sponsor	American Association of People with Disabilities
Details	High school and college students with disabilities will have the opportunity to connect with representatives of businesses that are committed to a more inclusive workforce. Presentations will be followed by a question-and-answer session. Read more .

Disability Policy Seminar

Date	April 19-22
Location	Virtual
Sponsors	The Arc and seven other national disability organizations
Details	Advocates, self-advocates, experts, and professionals will learn about key issues that affect them, and will meet with their members of Congress. Learn more and register . Fee.

Resources

- [Free Bilingual Texting Service Helps Parents Worried About Their Child's Speech and Language Development](#) – from PRWeb
- *Exceptional Parent Magazine* March Issue – [Schools, Camps and Residences](#)

In the News

- [Some Children's Hospitals See a Surge in Rare COVID-19 Complication MIS-C](#)
CNN, 3/6/21
- [Children's Hospitals Grapple with Young Covid 'Long Haulers'](#)
Kaiser Health News, 3/3/21

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.



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