

California Advocacy Network for Children with Special Health Care Needs

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

Network News

Last Call: Letters of Inquiry Due

The deadline for Letters of Inquiry (LOI) for our Foundation's next grant cycle is **February 15**. Potential applicants should carefully review our program goals, priorities, and restrictions before submitting an LOI. [Read about the application process.](#)

Family Caregiving

Report: State Approaches to Reimbursing Family Caregivers of CYSHCN through Medicaid

Some state Medicaid agencies have developed unique approaches to finance family caregivers who provide home health services to children and youth with special health care needs. A new report from the National Academy for State Health Policy explores how states have used a variety of waiver authorities to promote reimbursement of caregivers. [Read the report.](#)

Supporting Family Caregivers Providing Complex Care

The Home Alone Alliance is an initiative that helps medical providers and family caregivers improve the quality of home care for individuals with complex needs. Its website offers publications and webinars on key caregiving topics, along with a Family Caregiving How-To Video Series covering issues such as special diets, operating medical equipment, and incontinence. Although this resource was created by the AARP Public Policy Institute with seniors in mind, much of the information could be of interest to those providing care for younger individuals. [Read more and find the resources.](#)

Pediatric Palliative Care

Webinar: Together in the Sandbox – Palliative Care and Complex Care Partnerships in the Medical Neighborhood

Date Tuesday, February 16
Time 12 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 Speakers will review the current state of pediatric palliative/hospice care, including the overlap between palliative and complex care principles. They will explore the medical neighborhood as a common ground to offer seamless, integrated care across the continuum for children with serious illness, incorporating palliative/hospice principles as well as primary care. [Read more and register.](#) CE credit for nurses and social workers. Fee.

California Children's Services

CCS Advisory Group Considers Range of Topics

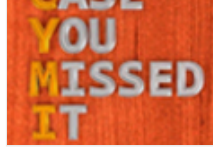
Three health plan representatives provided updates on how the Whole Child Model is progressing in their counties at the CCS Advisory Group meeting on January 27. The Advisory Group members also discussed reported decreases in referrals to CCS in Whole Child Model counties, and the changes in Medi-Cal pharmacy services scheduled to begin April 1. They reviewed a number of CCS policy updates, including COVID-19 guidance, and heard a brief update on the ongoing evaluation of the Whole Child Model being conducted by UCSF. See the [agenda and the slides](#) from the meeting on the group website.

COVID-19 and CCS Services Fact Sheet Now Available in Español and Chinese (中文)

A fact sheet created by the National Health Law Program and Family Voices of California, with support from our Foundation, answers key questions about [Access to Care Through California Children's Services During COVID-19](#). The fact sheet now is available in Español and Chinese (中文).

Social Determinants of Health

Webinars: Making Connections – The Critical Role of Family-Centered Care in Addressing Social Determinants of Health for CYSHCN



This two-part webinar series highlighted information about the impact of social determinants of health on CYSHCN and their families, including implementation strategies for state programs. Presented by the National Resource Center for Patient/Family-Centered Medical Home, in partnership with Bright Futures National Center and the Screening Technical Assistance and Resource Center of the American Academy of Pediatrics. [Listen to the webinars.](#)

Caring for the Whole Child: A New Way to Finance Initiatives to Improve Children's Health

According to an issue brief from Manatt Health, children have been left behind in investments in improving the social determinants of health (SDOH), defined as the structural conditions in which people are born, grow, live, work, and age. The authors propose a pathway to ensure that children and their families benefit from SDOH investments, and review options for designing and implementing a Children's Health and Wellness Fund to address a range of child health issues. [Read the brief.](#)

Health Equity

NICHQ to Develop Framework to Improve Equity in Health Systems

The National Institute for Children's Health Quality (NICHQ) has announced the launch of a two-year initiative to develop an Equity Systems Continuum framework for health care systems, using a maternal and child health lens. In addition to the framework, NICHQ will develop an Equity Systems Auditing Tool for organizations to examine longstanding policies and practices that contribute to systemic racism and other forms of oppression. [Read more.](#)

Conference Reminder: Voices for Change – Revolutionizing Health Equity

Date February 9 – 11
Time 10 a.m. to 1 p.m. Pacific Time
Sponsor California Pan-Ethnic Health Network
Details [Read about this virtual conference and register.](#) Fee (waivers available).

Did You Know?

Updated CSHCN Data Available; Blog Considers How to Ease the Family Experience



Kidsdata has released updated data on children with special health care needs that describe their characteristics, access to services, level of insurance coverage, and quality of care. The data are for California, with some national comparisons available. [See the data.](#)

The data also describe the impact of having a special health care need on children and their families. An accompanying blog post by Allison Gray, senior program officer at our Foundation, discusses how a more family-centered and coordinated system of health care could ease the family experience. [Read the blog post.](#)

COVID-19 Resources

Our COVID-19 [web page](#) offers additional information and resources.

- Writing in the **Disability and Health Journal**, three physicians make the case for [The Importance of Seasonal Influenza Vaccination for People with Disabilities During the COVID-19 Pandemic](#).
- The **California Department of Health Care Services** has issued [Guidance Related to Non-Discrimination in Medical Treatment for COVID-19](#) (PDF), a reminder that under federal and state policies providers are prohibited from illegally discriminating against Medi-Cal members, including in determining how to allocate scarce resources for the treatment of COVID-19.

National Policy

- **Biden Administration Announces It Will Reopen Federal Marketplace Enrollment** – from the Georgetown Center for Children and Families. Enrollment will be permitted between February 15 and May 15.
- **Pandemic Could Hurt Home-Based Care for Kids with 24/7 Needs** – from The Pew Charitable Trusts

California Policy

Department of Health Care Services Stakeholder Advisory Committee to Meet

Date Thursday, February 11
Time 9:30 a.m. to 12:30 p.m. Pacific Time
Details [Register in advance](#) and [find the meeting agenda and details.](#)

Special Education



[Webinar: Elevating the Need for Health-Education Coordination: Bridging Together Title V and IDEA to Best Support Children with Disabilities](#) – from the Association of Maternal and Child Health Programs and Child Trends

In the News

- [Mental Health Issues Affect 3 in 4 Kids with Autism](#)
Disability Scoop, 1/26/21
- [Parents with Disabilities Face Extra Hurdles with Kids' Remote Schooling](#)
NPR, 1/23/21
- [HHS Civil Rights Office Tackles Health Care Discrimination of People with Disabilities](#)
NPR, 1/15/21
- [People with Disabilities Desperately Need the Vaccine. But States Disagree on When They'll Get It.](#)
Washington Post, 1/13/21

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@jpfch.org with your news or updates. Or contact newsletter editor: Eileen Walsh at Eileen.Walsh@jpfch.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.

