



January 6, 2022

California Advocacy Network for Children with Special Health Care Needs

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

Family Engagement

Large Study Assesses How Caring for Children with Serious Conditions Affects Health of Parents, Siblings

Family members of children with a serious pediatric illness may have increased physical and mental health care needs, a newly published study in *JAMA Network* suggests. Researchers found higher rates of health care encounters, physical and mental health diagnoses, and physical and mental health medication prescriptions among parents and siblings of children with life-threatening conditions, compared with a control group. The authors conclude that interventions to safeguard the mental and physical well-being of parents and siblings appear to be warranted. [Read the article](#).

Upcoming Webinar Reminder



Pediatric Complex Care Seminar: Shared Decision Making
Thursday, January 13
10 to 11 a.m. Pacific Time
SickKids Learning Institute

The fifth webinar in the *Collaborative Conversations with Families to Advance the Clinical Care of Children with Medical Complexities and Disabilities* (C6 Series). [Read more and register](#).

Network News

A Look Back at 2021: Children with Complex Issues, Transition to Adult Care, Telehealth Policies, and More

View some of the publications or webinars you may have missed this past year, or refresh your knowledge with a second look. Remember to scroll down each web page to watch the recording. Find additional 2021 publications [here](#).

The first four sessions of a 10-part seminar series, *Collaborative Conversations with Families to Advance the Clinical Care of Children with Medical Complexities and Disabilities*, covered knowledge gaps, irritability and pain, feeding issues, and behavioral/mental health. SickKids Learning Institute. [See the links for all four sessions](#).



- Webinar and Report: [A Family-Centered Research Agenda for Improving Health Care Transitions for Children with Special Health Care Needs](#) – Children and Youth with Special Health Care Needs Research Network (CYSHCN).
- Issue Brief: [Helping Families Obtain Durable Medical Equipment and Supplies Through the California Children's Services \(CCS\) Program – Updated](#) – National Health Law Program (NHeLP)
- Webinar and Report: [Engaging Youth with Special Health Care Needs and Families of Children with Special Health Care Needs: Recommendations for Medicaid Agencies](#) – Center for Health Care Strategies (CHCS)
- Webinar and Report: [COVID-19 Telehealth Policies Affecting CYSHCN: What to Keep, Modify, or Discard?](#) – Health Management Associates (HMA).
- Webinar: [CARE PATH for Kids: A Family-Centered Approach to Shared Plans of Care for Children with Special Health Care Needs](#) – Child and Adolescent Health Measurement Initiative (CAHMI)

Pediatric Palliative Care

Webinar: Discharge from Hospital to Home – The CAITLYNN Project, A Model of Excellence

Date Thursday, January 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, and CSU Shiley Haynes Institute for Palliative Care
Details Speakers will discuss gaps in the traditional discharge process, and highlight the CAITLYNN Project, which uses family experiences to address the increased care requirements and safety concerns associated with the child's transition from hospital to home. [Read more and register](#).

Systems of Care

Intellectual/Developmental Disabilities Workshops



Recordings from the three workshops on *Optimizing Care Systems for People with Intellectual and Developmental Disabilities*, sponsored by the National Academies of Sciences, Engineering and Medicine, are now available. Watch the recordings for [Workshop 1](#), [Workshop 2](#), and [Workshop 3](#).

Children with Medical Complexity

Last Call for Complex Care Webinar Proposals

Proposals are due **January 13** to present hour webinars on innovative complex care work at the National Center for Complex Health and Social Needs' monthly virtual learning sessions. [Learn more](#).

Resources

- The Catalyst Center and the National Academy for State Health Policy partnered in 2021 to develop [three issue briefs that highlight opportunities for Title V and Medicaid to collaborate to improve systems of care for CYSHCN](#). The briefs cover equity, Medicaid Managed Care collaborations, and health homes options for states.

National Policy

Deadline Approaching for Health Care Insurance Enrollment

Fact sheets in [English](#) (PDF) and [Español](#) (PDF) that explain how families can obtain health care coverage are available from the Association of Maternal and Child Health Programs. **January 15** is the last day to enroll, though some states have different deadlines.

California Policy

Plan to Transform Medi-Cal Receives Federal Approval

The Centers for Medicare & Medicaid Services has approved the California and Innovating Medi-Cal (CalAIM) proposal that is designed to make Medi-Cal more equitable, coordinated, and person-centered, the Department of Health Care Services has announced. Medi-Cal is a vital resource for many children with special health care needs and their families. [Read more](#) (PDF).

Events

Register Early and Save for AMCHP National Conference

Sessions on children with special health care needs will be presented at the 2022 conference of the Association of Maternal and Child Health Programs, scheduled for March 5-8 in Washington, DC, and also available virtually. Early bird registration ends **January 14** for the conference, whose theme is *Reflecting on our Past, Shaping our Future*. Fee. [Read more and register](#).

In the News

- [For Parents of Kids with Special Needs, Mask Mandates Can Be Difficult to Navigate](#)
Disability Scoop, 1/4/22

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.

