

California Advocacy Network

for Children with Special Health Care Needs

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

Children with Medical Complexity

Parent Perspectives in Shared Decision-Making for Children with Medical Complexity

Shared decision-making may improve outcomes for children with medical complexity (CMC), but little is known about how to improve this process for CMC and their families. A new study published in *Academic Pediatrics* examines parent perspectives regarding shared decision-making and identifies opportunities for improvement. [Read the abstract.](#)

Registration Open for Virtual *Putting Care at the Center* Conference

Putting Care at the Center, the annual meeting that brings people together to learn, network, and create a shared agenda for improving care for individuals with complex needs, is scheduled online for October 27-28. Early bird registration is available through **September 15**. Read more about the [agenda](#), which will include discussions about major events of 2020.

COVID-19 Information

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

Webinar: Ensuring Children's Access to Care Through Medicaid During COVID-19

Date Monday, August 10
Time 1 to 2 p.m. Pacific Time
Sponsors Manatt Health, the American Academy of Pediatrics, Family Voices, and the Georgetown University Center for Children and Families, with funding from the Robert Wood Johnson Foundation, the Lucile Packard Foundation for Children's Health, the David and Lucile Packard Foundation, and the Annie E. Casey Foundation.
Details Speakers will discuss how states can leverage telehealth policies and implement eligibility and enrollment strategies to protect children's access to Medicaid during the pandemic. [Read more and register.](#)

- ["When Should My Child Go Back to School?"](#) is the topic discussed by a school nurse and a child neurologist in an educational series sponsored by the **Child Neurology Foundation** and the **American Academy of Pediatrics**. Additional topics relevant to CSHCN are covered.
- A [COVID-19 Preparedness Tool for Families and Caregivers](#), developed by the **Stanford Health Literacy Lab** in collaboration with families and providers, helps families of CSHCN prepare for the pandemic in a variety of settings. The user-friendly tool, also available in [Spanish](#), provides tips for home, health care settings, schools, and work, and also offers advice for coping with family stress. For information about adapting the tool for organizational use, e-mail mcjsmith@stanford.edu.
- [Coronavirus: Caring for Kids with Special Health Needs](#), an article and recording from **KidsHealth at the Nemours Foundation**, answers COVID-19 health questions specific to CSHCN.
- Many families are struggling to piece together continuity of care for their children with special health care needs during the pandemic. [Easing the Financial Burden on Family Caregivers: Translating 1915\(c\) Appendix K](#), an article from the **Center for Health Care Strategies**, discusses options for states to assist families, including paid family caregiving.
- [The Pandemic's Toll on Children with Special Needs and Their Parents](#) – from the *New York Times*, July 27, 2020.

Family Engagement

Commentary: Benefits and Risks of Visitor Restrictions for Hospitalized Children During the COVID-19 Pandemic

During the pandemic, many children's hospitals have strict visitor policies that may prohibit both parents from visiting a child at the same time, or restrict other family members from visiting at all. An article from *Pediatrics* discusses ethical dilemmas caused by such restrictions, and possible cases for making exceptions to the rules for children with severe medical issues. [Read more.](#)

Distance Learning and CSHCN: Family Voices of California Seeks Information

Family Voices of California (FVCA) is fielding a survey to learn about the challenges that families of CSHCN are facing regarding their children's education and school services during the pandemic. Families are asked to share their experiences over the past months and how they see their experiences changing in the fall semester and beyond. FVCA plans to use the responses to design a session on meeting families' educational needs as part of its fall virtual Health Summit. Take the survey in [English](#) or [Español](#).

Telehealth

- [Telehealth and Disabilities: Challenges and Opportunities for Care](#) – A policy brief from the National Health Law Program considers the benefits and limitations of telehealth for individuals with disabilities covered by Medicaid.

CSHCN and Equity

Webinar: Measuring Health Equity

Date Thursday, August 13
Time 11 a.m. to 12 p.m. Pacific Time
Sponsor Children's Hospital Association
Details Children's Hospital of Minnesota developed a dashboard to track and display inequities in patient care. Speakers will discuss using these types of data to develop quality improvement initiatives to address structural racism. [Read more and register.](#)

Advocacy

Action Needed on Senate's COVID-19 Relief Bill

The US Senate continues to debate the COVID-19 [HEALS ACT](#), and advocates urge immediate stakeholder action to ensure inclusion of provisions that support the disability community:

- [Senate COVID-19 Relief Proposal Overlooks Disability Community, Advocates Say](#)
- [The Arc: Tell Congress to Include the Disability Community in COVID-19 Relief Bills](#)

The ADA at 30: Beyond the Law's Promise

A series from the *New York Times* explores how the Americans with Disabilities Act has shaped modern life for people with disabilities in the 30 years since it was passed. [Read more.](#)

Special Education

- [Majority of States Failing to Meet Obligations under IDEA](#) – from Disability Scoop, July 6, 2020.
- [Overview of Special Education in California](#) (PDF) – from the Legislative Analyst's Office. A look at how California organizes, delivers, and funds special education.

In the News

- [The COVID-19 Downturn Triggers Jump in Medicaid Enrollment](#)
Kaiser Health News, 7/28/20
- [A Boy with Muscular Dystrophy Was Headed for a Wheelchair. Then Gene Therapy Arrived](#)
NPR, 7/27/20
- [Families of Children with Special Needs Are Suing in Several States. Here's Why.](#)
NPR, 7/23/20

We'd like to hear from you

Let us know what's happening with your organization or family. Email newsletter editor Eileen Walsh at Eileen.Walsh@lpfch.org with your news or updates.

