

California Advocacy Network

for Children with Special Health Care Needs

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

Dear Readers,

We hope you and your families are doing well. Please check our [web page](#) regularly for the latest resources and information about COVID-19 and children with special health care needs and their families.

Though we are trying to keep current, some of the events listed in this issue may have changed. Please check the links.

COVID-19 Resources

Here is some new information that was not included in our [special COVID-19 edition](#) on March 27.

- [COVID-19 Resources for People with Disabilities, Families, and Service Providers](#) – from The Arc. Includes latest national guidance, “plain language” materials on COVID-19, and avenues to advocate in Congress to ensure that individuals with disabilities are included in legislation.
- [Wide Open School](#) – New website from Common Sense Media offers families and educators resources on how to support students with disabilities during remote learning.
- [Archived Webinar – A Rare Response: Addressing the COVID-19 Pandemic](#) – from the National Organization for Rare Disorders. Experts offer guidance on living with a rare disease and maintaining physical and mental health in the time of COVID-19. Appropriate for patients, caregivers, and advocates.
- [Bill to Watch: SB 3544](#) – A bill to assist older Americans and people with disabilities affected by COVID-19. Introduced March 19 and referred to the Committee on Finance.
- [Webinar: Child and Family Health and COVID-19](#) – Hosted by the Georgetown University Center for Families and Children on Tuesday, April 7 at 10 a.m. Pacific Time. It will provide an overview of how the latest federal legislation affects Medicaid and CHIP financing and operations, as well as policy options state officials can consider to ensure coverage for children and families.
- [A Fact Sheet from the National Health Law Program](#) discusses options that states have under Medicaid to improve access to services for people with disabilities living at home during the COVID-19 crisis. Possibilities include lifting budget and service limitations, adding services, changing provider qualifications, raising provider rates, and more.

Both the [federal government](#) (PDF) and the [State of California](#) (PDF) have issued reminders that individuals with disabilities must not be denied care during medical emergencies based on the presence of a disability.

Related Call Friday, April 3: Disability Rights and Medical Rationing, 9 to 10:30 a.m. Pacific Time, sponsored by the American Association of People with Disabilities. Speakers, including a professor of pediatrics, will address the rights of individuals with disabilities in the health care setting and the legal obligations of providers to administer needed care to people with disabilities under federal law.

Children with Medical Complexity

Webinar: Helping Students Learn to Work Collaboratively on Complex Needs

Date Wednesday, April 8

Time 11 a.m. to 12 p.m. Pacific Time

Sponsor National Center for Complex Health and Social Needs

Details Applications are open for the Interprofessional Student Hotspotting Learning Collaborative, which trains interdisciplinary teams of students to work collaboratively on complex medical and social needs, using a patient-centered approach. This webinar will provide a program overview. **The application deadline is May 1.** [Read more.](#)

In Brief

- [Using Videoconferencing for Hospital Discharge for Children with Complexity](#) – Abstract of a pilot study designed to evaluate the implementation of a discharge videoconference that includes the patient, caregiver, primary care provider (PCP), hospitalist physician, and case manager.

California Children's Services

CCS Advisory Group to Meet

Date Wednesday, April 15

Time 10 a.m. – TBD

Location Group will not meet in person.

Dial-In (888) 989-6488; Passcode: 1945234

Details Details may be posted on the group's [website](#).

Social Determinants of Health

New: Identification and Screening of Social Determinants of Health among CSHCN in Medicaid

This fact sheet highlights how state Medicaid agencies are working to incorporate social determinants of health screenings into their programs to improve health outcomes for CSHCN. The fact sheet, developed by the National Resource Center for Patient/Family-Centered Medical Home in partnership with the National Academy for State Health Policy, notes opportunities for collaboration and partnership among Medicaid, Title V Maternal and Child Health/CSHCN programs, and pediatricians. [Read more](#) (PDF).

National Policy

Why the Census Matters to CSHCN

The 2020 Census is under way, and work will proceed despite COVID-19. [Responses](#) are being accepted online, by phone, or by mail. The Census determines how much federal money flows into states for public programs, such as Medicaid, education, hospitals, and many others that serve individuals with special needs and their families. The Census also determines how many members a state will have in the House of Representatives. Read more from AMCHP about how the Census works and why it matters for CSHCN in [English](#) (PDF) and [Español](#) (PDF).

In Brief

- The Food and Drug Administration (FDA) has issued a ban on electrical stimulation devices for self-injurious or aggressive behavior, effective April 6. [Read more.](#)

California Policy

- [Coronavirus Stretches California's Special Education System to the Brink](#) – from Cal Matters. Explores how families and schools are struggling to implement remote teaching, which is at odds with how students in special education usually learn.
- [California's Paid Family Leave Program Is Out of Reach for Workers with Very Low Wages](#) – from the California Budget and Policy Center. A fact sheet of possible relevance during the COVID-19 outbreak.

Events

Developmental Disabilities Conference Postponed

The 2020 Developmental Disabilities Public Policy Conference, scheduled for April 27-28 in Sacramento, has been postponed, and a new date has not been set. The conference is sponsored by The Arc and United Cerebral Palsy of California Collaboration. [Read more.](#)

School-Based Health Conference Delayed

A Shared Vision for Healthy Students, the 2020 California School-Based Health Conference currently scheduled for May 14-15, is postponed, possibly until the fall. [Read more.](#)

In the News

- [Parents and Schools are Struggling to Care for Kids with Special Needs](#)
NY Times, 3/31/20

- [FDA Warns About EpiPen Malfunctions](#)
Pittsburgh Post-Gazette, 3/24/20

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.

