

California Advocacy Network

for Children with Special Health Care Needs

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

Dear Readers,

We hope that you and your families are doing well during this crisis. The newsletter continues to highlight newer COVID-19 resources specific to children with special needs and their families, but please also see our COVID-19 [web page](#).

COVID-19 Resources

- A three-part online COVID-19 series from **Family Voices** covers [self-care for family caregivers](#), [telehealth](#), and [parenting during quarantine](#), in English and Español.
- Advice on health care and education for families with CSHCN are highlighted in a special COVID-19 edition of [Complex Child](#).
- [Tips and resources](#) for CSHCN and their families are offered by the **California Department of Public Health**.
- Telehealth has become increasingly important during the pandemic. The **Center for Connected Health Policy** provides up-to-date information on how the [federal government and each state](#) are adjusting their policies to address the need to make services more available.
- Home and community-based services (HCBS), which help people with disabilities stay in their homes, are always under pressure, but now more than ever. The **National Health Law Program** outlines [options that states have](#) to modify their policies to ensure that HCBS participants have access to providers and flexibility in services.
- Many states are modifying Medicaid policies and programs so individuals and their families can continue to access critical services during the COVID-19 crisis. The **National Academy for State Health Policy** has created an update on [State Medicaid Strategies to Maintain Access to Care for Children with Special Health Needs During the Pandemic](#).

Advocacy Opportunities

Families Fear Waivers of Federal Special Education Law During COVID-19

Advocates are urging families to contact their [Congressional representatives](#) to oppose any waivers to parts of the federal law that protect students with disabilities. The new coronavirus relief package allows the Secretary of Education to seek Congressional approval to implement some waivers during the pandemic. Read [DeVos Weighs Waivers for Special Education, Parents Are Worried](#), and [Disability Rights Groups, School Administrators Spar over Possible Changes to Special Education Laws](#).

Including the Disability Community in COVID-19 Relief Bills

A number of advocacy organizations are encouraging stakeholders to send emails to Congress noting that the current relief bills do not adequately address the needs of people with disabilities, who often are medically vulnerable. Find a [sample email](#) from The Arc and your representatives' names.

Family Engagement

Family Voices to Present Virtual Series on Leadership in Family and Professional Partnerships

The Leadership in Family and Professional Partnerships convening from Family Voices brings together family leaders, Title V professionals, and other stakeholders to discuss successful strategies and best practices on how to improve engagement of families, particularly those from medically underserved populations. The sessions also cover emergency responsiveness in times of crisis; organizational development; assessment of family engagement; and more. In place of an in-person convening, eight online Zoom sessions are scheduled from April 21 to May 19. [Read more and register](#).

California Children's Services

CCS Advisory Group Discusses State Policy Adjustments in Response to COVID-19

Families, service providers, state and county officials, and other stakeholders participated in a wide-ranging discussion of the state's modifications to policies in response to COVID-19 at the April 15 CCS Advisory Group meeting. Acknowledging the extreme stress the pandemic places on CSHCN families and care providers alike, members raised questions related to access to, and payment for, telehealth services, durable medical equipment and supplies, medical care, Medical Therapy Units, and other critical services. Department of Health Care Services staff said that a guidance document will be published soon, reflecting the modifications in federal and state policies designed to expedite care for CCS clients.

The advisory group also discussed the potential impact on CCS clients of the state's plan to move all Medi-Cal pharmacy services from managed care to fee for service by January 1, 2021. Members suggested that the state consider delaying the Medi-Cal Rx transition in light of the current crisis, and form a workgroup of Advisory Group members to address CCS-related issues. See the meeting agenda and slides on the Advisory Group [website](#).

Transition to Adulthood Workgroup to Meet

Date Wednesday, April 29
Time 1 to 2 p.m. Pacific Time
Location The meeting will be conducted by webinar.
Dial-In (888) 924-9621; Passcode: 8500518
Details **Subject to change.** See details on the [website](#) closer to the date. For information email CCSRedesign@dhs.ca.gov.

Children with Medical Complexity

Putting Care at the Center 2020 Offers Worry-Free Registration

Putting Care at the Center 2020, the annual conference of the National Center for Complex Health and Social Needs, is still planned for October 28-30 in Philadelphia. The conference provides an opportunity for innovators and advocates for health care delivery reform to create a shared agenda for the emerging field of complex care. Pediatrics is expected to be included. The sponsors are extending the early-bird registration deadline to June 30 and offering registration that may be canceled with a full refund until September 28. Proposals for presentations may be submitted until May 6. [Read more](#).

Pediatric Palliative Care

Pediatric Palliative Care and COVID-19 Town Hall Meeting

Date Tuesday, April 21
Time 12 to 1 p.m. Pacific Time
Sponsors Jacob's Heart Children's Cancer Support Services, Pennsylvania's Pediatric Palliative Care Coalition, Greater Illinois Pediatric Palliative Care Coalition, Stanford Medical School, and the California State University Shiley Institute for Palliative Care
Details A moderated interactive discussion of issues related to COVID-19 and pediatric palliative care. [Read about the speakers](#) and [register](#).

California Policy

Medi-Cal, Regional Center Policies During the Pandemic

California's Department of Health Care Services is modifying a number of eligibility and payment policies in an effort to streamline response to COVID-19 for Medi-Cal recipients. Topics covered include telehealth, home and community-based services, prior authorization, behavioral health, and more that may be of interest to families of CSHCN. Find [links](#) with information about each topic.

The Department of Developmental Services, which oversees Regional Centers, also has created a [web page](#) to inform providers and families about flexibility in policies during the pandemic.

Medi-Cal Children's Health Advisory Panel to Meet

Date Friday, April 24
Time 10 a.m. to 1 p.m. Pacific Time
Location The meeting will be conducted by webinar. [Register](#).
Details The panel is a 15-member independent statewide advisory body that advises the Department of Health Care Services on matters relevant to children enrolled in Medi-Cal. See the meeting agenda and other materials on the [website](#).

Scholarship Opportunity

Awards Available for Students Interested in Media, Entertainment

The American Association of People with Disabilities is accepting applications for eight NBC Universal Tony Coelho Media Scholarships for the fall semester of 2020. The scholarship is available to undergraduate and graduate students with disabilities who are pursuing an interest in the media, entertainment, or communications fields. High school seniors also may apply. **Applications are due May 21.** [Read more](#).

In the News

- [Caregivers May Be Eligible for Paid Leave Under COVID-19 Relief Law](#)
Disability Scoop, 4/6/20
- [Coronavirus Ravages Services for People with Disabilities, Leaving Many at Risk](#)
CalMatters, 4/5/20
- [With Schools Closed, Kids with Disabilities Are More Vulnerable Than Ever](#)
NPR, 3/27/20

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.

