

May 14, 2020

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 safe and doing well. COVID-19 information is available throughout the various Newsletter sections, and more resources are posted on our [COVID-19 Resources Page](#).

Network News

Foundation Emergency Grants Respond to COVID-19

Our Foundation has awarded five emergency grants totaling \$230,000 to help mitigate the impact of COVID-19 on children with special health care needs and their families. The grants aim to address immediate basic needs for local families, and to encourage national system and policy adjustments to ensure that CSHCN receive the care they need during the pandemic and beyond. [Read about the grants](#).

Reminder: Letters of Inquiry Accepted for Non-Emergency Grants

Letters of Inquiry (LOI) for the Foundation's next grant cycle will be accepted until **Thursday, June 11**. Before applying, read about our program goals, priorities, restrictions, and [application process](#).

Family Engagement

Family Voices Awarded Grant to Boost Telehealth for CSHCN During COVID-19

On April 30, the federal government awarded \$20 million to increase telehealth access and infrastructure for providers and families to help prevent and respond to COVID-19. As part of that grant Family Voices will receive \$1 million to increase capability, capacity, and access to telehealth for families of children and youth with special health care needs. The American Academy of Pediatrics and the Association of Maternal and Child Health Programs also received grants. Read about [all the grants](#) and the [Family Voices grant](#) specifically.

COVID-19

- [Which Kids Get Sickest from COVID-19? The 'Medically Complex,' Study Finds](#) – from **NBC News**, based on a study published in [JAMA Pediatrics](#), May 11, 2020
- [Schools and Child Care Programs During COVID-19: Plan, Prepare, and Respond](#) – from the **Centers for Disease Control and Prevention**
- [Opportunities for Health Insurance Coverage During COVID-19 Pandemic](#) – from **Healthcare.gov**
- [The Latest on "Public Charge" and COVID-19](#) – from **Protecting Immigrant Families**
- [Broadening Medicare's Accelerated and Advance Payment Program to Save Health Care Providers That Serve Our Most Vulnerable Populations](#) – from **The Commonwealth Fund**, May 13, 2020
- [Disability Nondiscrimination in Health Care and Community Life During the COVID-19 Pandemic](#) (PDF) – from **Disability Rights Education and Defense Fund**

Viewpoint

Children's Hospitals Are Losing \$1 Million a Day

Mark Wietcha, president and CEO of the Children's Hospital Association, discusses the fiscal impact of COVID-19 on children's hospitals, which provide essential services for children with medical complexity. He suggests that the federal CARES Act does not offer an adequate response. [Read his viewpoint](#).

Children with Medical Complexity

Invitation: Share Your Successes on the Playbook

The Better Care Playbook, which provides users with the best available knowledge about promising approaches to improving care for people with complex needs, is made possible by seven leading health care foundations, and led by the Center for Health Care Strategies. Currently the Playbook is accepting submissions about promising resources from stakeholders. Although focused primarily on adults, the Playbook also includes pediatric information. [Read about how to submit your best practice ideas](#) for distribution.

In Brief

- [Putting Care at the Center 2020 Conference Postponed to 2021](#)
- [Addressing Complex Care Needs Amid COVID-19](#) – Better Care Playbook, updated May 14, 2020

Advocacy

A Call to Include People with Disabilities in COVID-19 Relief Bills

The Arc and other advocacy organizations are urging stakeholders to be in touch with their federal legislators to ensure that individuals with special needs are included in the COVID-19 bill that is currently pending. [Read more](#).

California Policy

Department of Health Care Services Stakeholder Advisory Committee and Behavioral Health Stakeholder Advisory Committee to Meet Jointly

Date Wednesday, May 27
Time 9 a.m. to 12:30 p.m. Pacific Time
Location By webinar. [Register](#).
Dial-In (415) 655-0001; Passcode: 926758433
Details The agenda and other materials are available on the [website](#).

Support Person Now Permitted in California Health Facilities

A new [directive](#) from the Department of Public Health clarifies that California health facilities may permit a support person to accompany a patient for whom a support person has been determined to be essential to the care of the patient, including pediatric patients, patients with physical, intellectual, and/or developmental disabilities and patients with cognitive impairments.

In Brief

- [California Has a New Web 'Portal' to Help Essential Workers Find Child Care](#) – from EdSource, April 30, 2020
- [Department of Health Care Services Highlights Policy Responses to COVID-19](#)

Webinar

COVID-19 Family Forum

Date Friday, May 29
Time 11 a.m. Pacific Time
Sponsor AMCHP Family and Youth Leadership Committee
Details A discussion on the impacts of COVID-19. [Register](#).

Special Education

- [The Challenge of Distance Learning for Parents of Children with Special Needs](#)
PBS/KQED, 4/30/20

In the News

- [In-Home Nurses Caring for Youth with Special Needs During COVID-19 Pandemic](#)
KSTP, updated 5/1/20
- [Target Expands Adaptive Clothing and Products for People with Special Needs](#)
Disability Scoop, 4/22/20

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.

