

March 19, 2020

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 remaining healthy in this difficult time. As you know, efforts to contain the coronavirus (COVID-19) have led to the cancellation or postponement of many events. Though we are trying to stay current, some information in this abbreviated issue may be out of date, as developments are moving quickly. The Foundation office is closed, but staff members are working remotely and our operations continue. Thank you.

Network News

Home Health Care Policies Are Target of New Grant

Creating better national policies to improve home health care for children with medical complexity is the focus of a grant recently awarded to the Ann & Robert H. Lurie Children's Hospital of Chicago by our Foundation. The project, to be co-led by Family Voices, aims to generate high-quality evidence regarding how state-level policies affect access to pediatric home health services. This evidence will form the basis for developing a more coherent, accessible system of home health care for children nationally. [Read more.](#)

COVID-19

In-Home Virtual Care for Children with Complex Conditions During Social Distancing

Representatives from four complex care programs around the country have recorded discussions about how they are providing tele-health services for children with medical complexity during the COVID-19 outbreak. Some of the programs are well-established, while others are just ramping up in response to the virus. The programs represented are Mercy Hospital in St. Louis, University of Texas in Houston, Children's National in Washington, DC, and Baystate Hospital in Massachusetts. [Listen.](#)

COVID-19 Resources

The following sites offer information related to children or specifically to children with special health care needs or disabilities. Many links are regularly updated.

- [Coronavirus Information and Resources](#) – from Family Voices. Advice about what families of children with special health care needs can do, and links to reliable resources.
- [Coronavirus Disease 2019 \(COVID-19\) Information for Children's Health Advocates](#) – from the National Institute for Children's Health Quality (NICHQ). A summary of key information related to children's health, and links to additional references.
- [Ensuring People Have Access to Prescription Drugs During the COVID-19 Pandemic](#) – from the National Health Law Program (NHeLP). Information about rules that apply under various programs, including Medicaid and private health plans.
- [Coronavirus Resources for Advocates](#) – from NHeLP. A range of resources, including information about various government policies, including Medicaid and the Children's Health Insurance Program.
- [Questions and Answers on Providing Services to Children with Disabilities During the Coronavirus Disease 2019 Outbreak \(March 2020\)](#) – from Individuals with Disabilities Education Act (IDEA). Information about special education.

Advocacy Opportunity

Coronavirus Relief Bill: Tell Congress to Include People with Disabilities

The Arc, the Center for Public Representation and other advocacy organizations have noted that the coronavirus relief bills passed by Congress do not do enough to support individuals with disabilities and their families. A third bill is pending, and members of Congress need to hear from their constituents. [Read more](#) about how to make your voice heard now.

Also See: [Coronavirus Relief Bill: Tell Congress to Include People with Disabilities](#)

Family Engagement

Project Leadership: A Family Success Story



Just under a year ago we featured an [article](#) about a family's drive to create Mia's Dream Come True Playground, a fully accessible park space to be constructed near their home in Hayward, California. Parents Daniel Vasquez and Emelyn Lacayo, both graduates of Family Voices of California's [Project Leadership](#) training program, mobilized community support and funding, and now are planning for a grand opening celebration in April or May.

In the News

- [Is Online School Illegal? With Schools Closing from Coronavirus, Special Education Concerns Give Districts Pause](#)
USA Today, 3/19/20
- [Home Healthcare Looks to Step in to Care for COVID-19 Patients](#)
Modern Healthcare, 3/18/20
- [Coronavirus Disrupts Services, Heightens Risk for Medically Fragile Children](#)
CaliforniaHealthReport.org, 3/17/20
- [Coronavirus Brings Added Worries for People with Disabilities](#)
Disability Scoop, 3/17/20

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.

