

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 Though we are trying to stay current, some information in this abbreviated issue may be out of date, as developments are moving quickly.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

Creating better national policies to improve home health care for children with medical complexity is the focus of a

Home Health Care Policies Are Target of New Grant

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.

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

COVID-19

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

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

The following sites offer information related to children or specifically to children with special health care needs or

- 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
- 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.

Health Law Program (NHeLP). Information about rules that apply under various programs, including Medicaid

2019 Outbreak (March 2020) - from Individuals with Disabilities Education Act (IDEA). Information about special education.

• Questions and Answers on Providing Services to Children with Disabilities During the Coronavirus Disease

Advocacy Opportunity

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.

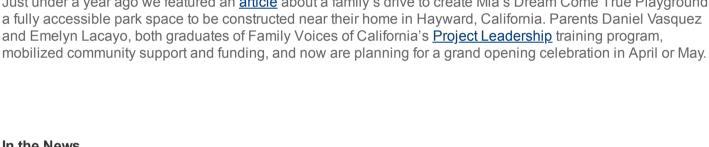
Also See: Coronavirus Relief Bill: Tell Congress to Include People with Disabilities

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,



• <u>Is Online School Illegal? With Schools Closing from Coronavirus, Special Education Concerns Give Districts</u> **Pause**

• Coronavirus Disrupts Services, Heightens Risk for Medically Fragile Children CaliforniaHealthReport.org, 3/17/20

In the News

USA Today, 3/19/20

Modern Healthcare, 3/18/20

We'd like to hear from you

- Disability Scoop, 3/17/20
- Let us know what's happening with your organization or family. Email newsletter editor Eileen Walsh at <u>Eileen.Walsh@lpfch.org</u> with your news or updates.

Home Healthcare Looks to Step in to Care for COVID-19 Patients

Coronavirus Brings Added Worries for People with Disabilities



