

California Advocacy Network

for Children with Special Health Care Needs

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

Network News

Our Foundation Accepting Grant Inquiries

Letters of Inquiry (LOI) for the Foundation's next grant cycle will be accepted until **October 1**. We fund programs and projects that contribute to improving systems of care for children with special health care needs and their families. We strongly recommend that potential applicants carefully review our program goals, priorities, and restrictions before submitting an LOI. [Read about the application process.](#)

Webinar: Improving Hospital Discharge Care for Children with Special Health Care Needs through a Nurse-led Learning Collaborative

Date Tuesday, September 22
Time 10 to 11 a.m. Pacific Time
Sponsor Lucile Packard Foundation for Children's Health
Details When a child with special health care needs is discharged from the hospital, appropriate resources and support are essential for care at home and to prevent complications or readmission. In this webinar, speakers from the [California-based Nurse-led Discharge Learning Collaborative](#), which is sponsored by our Foundation, will describe two newly developed discharge practices, and discuss how these innovations can be integrated into existing hospital practices. [Read more and register.](#)

Telehealth

New Article: Ensuring Children's Access to Care Using Telehealth in Medicaid During COVID-19

In response to COVID-19, pediatric providers are rapidly scaling up their telehealth capabilities to ensure that children continue to receive needed care. State Medicaid programs have a wide range of policy levers available to increase or restrict access to telehealth services. A new article from Manatt summarizes a recent webinar that highlighted those policy levers and the pediatric telehealth services that are of particular relevance for children with special health care needs. [Read the article and find a link to the webinar](#), which was co-sponsored by Family Voices, among others.

COVID-19 Information

Our [COVID-19 web page](#) offers more information and resources.

- [Considerations for Young Children and Those with Special Needs as COVID-19 Continues](#) – In this article from *JAMA Pediatrics*, physicians offer strategies that families can use to help children adjust to new routines and express their emotions.
- Four parents of CSHCN discuss [their various perspectives on preparing to go back to school](#) and how they came to their decisions, in this conversation from the [Child Neurology Foundation](#).
- [Back to School: How Can Schools Safely Social Distance, Particularly for Students with Special Services and Full-Time Aides?](#) – Tips for going back to school safely are provided by the [Child Neurology Foundation](#).
- [Why the Coronavirus More Often Strikes Children of Color](#) – *New York Times*, 9/1/20
- [Pandemic Hitting Families of Those with Disabilities Harder](#) – *Disability Scoop*, 8/28/20

CSHCN and Equity

Children with Disabilities and Organ Transplants

Children with intellectual and developmental disabilities often have been excluded as potential recipients of organ transplants. A 2020 policy statement from the American Academy of Pediatrics offers recommendations on how to address this ongoing inequity. [Read the statement.](#)

In Brief

- [Black Children Wait Longer for Autism Diagnosis](#) – from *Disability Scoop*, 8/25/20
- [Black, Disabled, and Uncounted](#) – from the *National Health Law Program*, 8/7/2020

Transition to Adult Care

A Second Look: Updated Information to Ease Transition



Got Transition, the federally funded national resource on health care transition, has updated its Six Core Elements of Health Care Transition, including step-by-step implementation guides, and has posted new tools and resources on a revamped website. The new information, available in English and Español, can be used by clinicians, youth, and caregivers to assist young people as they move from pediatric to adult care. [Read more](#) (PDF).

Also See: [Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home](#) – This updated clinical report from the American Academy of Pediatrics, published in *Pediatrics*, includes a section on children with special health care needs and disabilities.

California Children's Services

Durable Medical Equipment Under the Whole Child Model

Family Voices of California maintains a web page of resources for families whose children have been moved into Medi-Cal managed care health plans under the Whole Child Model (WCM). [Fact sheets about durable medical equipment](#) under each of the five WCM health plans are available.

Webinar: How States Are Rethinking Medicaid Managed Care Performance Management

Date Tuesday, September 8
Time 11 to 11:30 a.m. Pacific Time
Sponsor Health Management Associates
Details Many CSHCN, including California children previously covered by CCS, are insured under Medicaid managed care plans. State Medicaid agencies are exploring new approaches to managing the performance of these plans, emphasizing tailored quality measures, new incentive models, improved technology, and revised contract requirements. Experts will outline some of the best practices being utilized as states fundamentally rethink their approach to performance management. [Register.](#)

Advocacy

Update: Bill to Include Family Caregivers Under Unemployment Benefits Goes to California Governor

California law does not permit parents and certain other family caregivers employed by the state's In-Home Supportive Services program to pay unemployment taxes and receive benefits when the need for caretaking ends. Non-family caregivers are eligible for these benefits. A mother of a child with complex needs who cared for her son until his death has championed passage of [Assembly Bill 1993](#), which would extend coverage to all family caregivers. The bill has passed both the Assembly and the Senate, and now is on the Governor's desk. See [Bill Would Reverse 'Discriminatory' Policy That Mostly Impacts Women of Color](#).

California Policy

Webinar: Children's Services Under Medi-Cal

Date Thursday, September 17
Time 2 p.m. Pacific Time
Sponsor National Health Law Program
Details Speakers will provide an overview of the children's services provided through Medi-Cal. Advocates will have an improved understanding of these covered benefits and the role that Medi-Cal plays in improving the health and well-being of low-income individuals and families in California. Many CSHCN are covered under Medi-Cal. [Register.](#)

See California's Ongoing COVID-19 Updates on Policies Affecting CSHCN

California's [Department of Health Care Services](#), [Department of Developmental Disabilities](#), and [Department of Public Health](#) continually update their COVID-19 pages with information that may be of use to policymakers, families, and providers.

National Policy

- [Ending Census Early Could Impact Disability Programs for Years](#)
Disability Scoop, 8/31/2020

Webinar

Preventing Suicide through Empowerment of Youth with Disabilities

Date Thursday, September 17
Time 11 a.m. Pacific Time
Sponsor University of Kentucky College of Social Work
Details According to the Centers for Disease Control and Prevention, youth suicide rates have increased 56% since 2007. Reports also show that youth with disabilities are four times more likely to have suicidal ideation than their nondisabled peers. The University of Kentucky has developed a curriculum to give young people the tools to navigate any ableism and stigma they may experience. Speakers will discuss the curriculum and other work regarding medical discrimination. CEU available. [Register.](#)

Special Education

- [How to Protect Your Family's Privacy During Remote Learning](#)
NY Times, 8/21/20
- [K-12 EDUCATION: School Districts Need Better Information to Help Improve Access for People with Disabilities](#) (PDF) – A report from the US Government Accountability Office, June 2020

In the News

- [California OKs School Return for Kids with Special Needs](#)
CBS, 8/25/20
- [COVID-19 May Shut Many Disability Programs For Good](#)
Disability Scoop, 8/24/20
- [Coronavirus: Lack of Nurses Another Worry for California Schools](#)
Mercury News, 8/24/2020
- [Kids with Special Needs Struggling to Receive Good Care During Pandemic](#)
U.S. News & World Report, 8/19/20

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.

