

May 28, 2020

California Advocacy Network

for Children with Special Health Care Needs

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

Dear Readers,

We hope you all are doing well. You will find COVID-19 information throughout the newsletter, and also on our COVID-19 [web page](#).

Network News

Final Reminder: Deadline for Letters of Inquiry

Letters of Inquiry 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

Webinar Series – Making Connections: The Critical Role of Family-Centered Care in Addressing Social Determinants of Health for CSHCN

Dates June 18 and 23

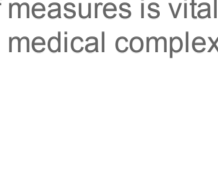
Time 8 to 9 a.m. Pacific Time

Sponsors National Resource Center for Patient/Family-Centered Medical Home, in partnership with Bright Futures National Center and the Screening Technical Assistance and Resource (STAR) Center.

Details This series will discuss the impact of social determinants of health on children and youth with special health care needs and their families. [Read more and register](#).

Children with Medical Complexity

Measuring Complexity: Moving Toward Standardized Quality Measures for the Field of Complex Care



A new report from the Institute for Healthcare Improvement, commissioned by the National Center for Complex Health and Social Needs, examines the current state of quality measurement in the complex care field and provides eight recommendations for how the field can move standardized quality measurement forward. An accompanying [brief](#) and [blog post](#) outline why developing a standard set of measures is vital to strengthening the field. Although focused on adults, the report includes mention of children with medical complexity as a patient group. [Read the report](#) (PDF).

In Brief

- [Reopening of Comment Period: Coordinating Care from Out-of-State Providers for Medicaid-Eligible Children with Medically Complex Conditions](#) – The Centers for Medicare and Medicaid Services will accept comments until June 3.

COVID-19 Information

- **COVID-19 Severity High in Children.** Researchers at **Children's National Hospital** in Washington, D.C., report a significant number of children and young adults requiring hospitalization and critical care – contrary to published and anecdotal reports from elsewhere around the country and the world. [Read more](#).
- **How the COVID-19 Pandemic Impacts Kids with Special Healthcare Needs.** On a podcast from RadioMD, which features experts from the **American Academy of Pediatrics**, a pediatrician who focuses on CSHCN discusses ideas for how families can cope with the pandemic, especially when the supports provided by schools are unavailable. [Listen to the podcast](#).
- **Managing Home Healthcare and Access to Medical Supplies During COVID-19.** A video from the **Child Neurology Foundation** features the father of a young adult who requires 24-hour care interviewing a home health provider about how care is changing. [See the video](#).
- Asian American, Native Hawaiian and Pacific Islander communities use a diversity of languages. The **Asian and Pacific Islander American Health Forum** has launched a crowd-sourcing project to collect COVID-19 resources in a broad range of these languages. [Read more and submit ideas](#).
- **Respecting Disability Rights – Toward Improved Crisis Standards of Care.** A perspective piece published in the **New England Journal of Medicine** assesses complaints about discrimination against people with disabilities during COVID-19, and suggests six guideposts that states and hospitals should follow to respect disability rights. [Read the perspective](#).
- Many aspects of Medicaid are evolving during the pandemic. The **Center for Health Care Strategies** has produced fact sheets to clarify the impact of COVID-19 on Medicaid policies. [See the series](#).

Viewpoint

Opinion: In Covid-19 Crisis, Philanthropy's Attention Must Focus on People with Disabilities

Rich Besser, president of the Robert Wood Johnson Foundation, and Darren Walker, president of the Ford Foundation, urge fellow foundations to work with and for individuals with disabilities and their families to uphold their civil rights and ensure equal access to health care, resources, and support during the pandemic. The authors suggest making disability rights and inclusion part of foundations' COVID-19 response, including in advocacy, grants, and working within their own organizations. [Read more](#).

Also See: [LPFCH: Supporting CSHCN During COVID-19](#)

Advocacy Opportunity

One-click Option: Include the Disability Community in COVID-19 Relief Bills

As federal and state legislation related to COVID-19 rapidly moves forward, this website offers the chance to tell lawmakers that they must make a commitment to protecting the safety and health of individuals with special needs and disabilities in the coming months. The email covers home- and community-based services, paid leave for all caregivers, and other significant issues. [See the site](#).

Related: [H.R. 6800](#) – The Health and Economic Recovery Omnibus Emergency Solutions Act (HEROES Act), which was passed by the House, awaits consideration in the Senate, where it is expected to be controversial.

Pediatric Palliative Care

Archived Webinar: Provider Grief and Moral Distress

A link to the May 6 webinar, *Trudging through COVID-19: Coping with Provider Grief & Moral Distress*, is now available. The password is 7S#A4k&2. [Listen](#).

California Children's Services

Members Appointed to CCS Advisory Group

The Department of Health Care Services has announced five members who will serve on the California Children's Services Advisory Group for the term of July 2020 to July 2021. As required by Senate Bill 586, these individuals are members of their local County Organized Health Systems Family Advisory Committees. They are Jenni Basch, CenCal Health; Lianna Chen, Health Plan of San Mateo; Samantha Williams Coburn, Partnership Health Plan; Kristen Rogers, CalOptima; and Susan Skotzke, Central California Alliance for Health.

California Policy

Webinar: Health Care Coverage Options During COVID-19

Date Thursday, June 4

Time 2 to 3 p.m. Pacific Time

Sponsor Insure the Uninsured Project (ITUP)

Details Attendees will learn what steps the state and federal government have taken to address the impact of the COVID-19 pandemic on the uninsured and underinsured, and engage in a question and answer session with the ITUP Executive Director. [Read more and register](#).

In Brief

- [Department of Developmental Services Offers Information on COVID-19, Regional Centers](#)
- [Department of Health Care Services Provides Updates on Numerous Policy Adjustments](#)

Special Education

- [Education Needs to Address Significant Quality Issues with its Restraint and Seclusion Data](#)

Resources

Offer Your Views on the Data Resource Center

The [Data Resource Center for Child and Adolescent Health](#), which supports use of data from the National Survey of Children's Health (NSCH) to improve child, youth, family, and community health and well-being, is asking users to complete a short survey. The website provides an interactive data query with point and click data from the NSCH as well as survey resources, downloadable data sets and codebooks, and comparison tables and maps. [Take the survey](#).

In Brief

- *Exceptional Parent Magazine* May Issue – [Special Coverage COVID-19](#)

In the News

- [A Switch to Medicaid Managed Care Worries Some Illinois Foster Families](#)
NPR Shots, 5/20/20
- [A Special Education Teacher Explains Why Virtual Learning Is So Hard on Her Students](#)
Vox, 5/15/20
- [Opinion: Until My Disabled Son's Needs Are Met, Can I Get a Genius Award?](#)
NY Times, 5/14/20
- [Disability Service Providers Struggling to Stay Afloat Amid COVID-19](#)
Disability Scoop, 5/4/20
- [Disability Representation in Family Films Hits Historic High](#)
Disability Scoop, 4/17/20

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.

