



June 11, 2020

## California Advocacy Network

for Children with Special Health Care Needs

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

Dear Readers,

The appalling deaths of black men and women and the ensuing protests have cast renewed light on our country's longstanding and deeply embedded racial inequities. In response, our Foundation is developing a plan of action for its programs, including our Program for Children with Special Health Care Needs. We will send an update in the coming weeks, and we welcome your thoughts and suggestions. Please send your ideas to [info@lpfch.org](mailto:info@lpfch.org).

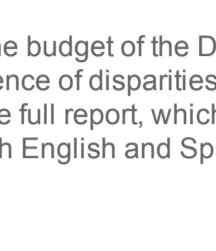
### Network News

#### How National Standards Are Being Used to Improve Systems of Care for CSHCN

New fact sheets from the National Academy for State Health Policy highlight the five most-utilized domains from the [National Standards for Systems of Care for Children and Youth with Special Health Care Needs](#). The Standards define the core components of a comprehensive, coordinated, and family-centered system. The most-used domains are identification and assessment, access to care, transition to adult care, medical home, and community-based services and supports. The one-page fact sheets include examples of states' implementation of the Standards. Read the [fact sheets](#).

Related: [Toolkit: National Standards for Children and Youth with Special Health Care Needs](#)

#### Report: Longstanding Inequities in Access to Regional Center Services Worsening for Children of Color



Even as the state is proposing millions in cuts to the budget of the Department of Developmental Services, a new report from Public Counsel documents the persistence of disparities in services and supports among ethnic and racial groups served by the 21 regional centers. [Read](#) the full report, which was funded by our Foundation. A press release and fact sheet are available at the same link in both English and Spanish.

### Advocacy Opportunity

#### June 12 Is Deadline for Opposing California Budget Cuts for Disability Services

California's proposed budget includes major cuts to a broad range of services that support individuals with special needs and their families, including the developmental disabilities system that oversees regional centers. Cuts are being debated now and a final budget will be sent to the Governor on June 15. Family Voices of California, The Arc and other organizations offer [information](#) on how to urge support for an alternative budget proposed by legislators. Comments should be sent by **Friday, June 12**.

### COVID-19 Information

#### Webinar: Patient- and Family-Centered Care and Pediatric Partnerships During COVID-19 – Focusing on the Most Vulnerable Children

**Date** Thursday, June 25  
**Time** 9 to 10 a.m. Pacific Time  
**Sponsor** Institute for Patient- and Family-Centered Care  
**Details** Speakers will discuss how to ensure that children with special health care needs, the biggest "consumers" of pediatric health care, receive the care that they need in the time of the pandemic. [Register](#).

Please see additional information on our [COVID-19 web page](#).

- [Ways to Support Siblings through COVID-19](#) – A video from the **Child Neurology Foundation** features parents of CSHCN and psychologists.
- **Bills to Watch:**  
SB 3878 – [Protecting Family Caregivers from Discrimination Act](#). This bill would prohibit employers from discriminating against employees for being family caregivers.  
  
HR 6800 – [The Health and Economic Recovery Omnibus Emergency Solutions Act \(HEROES Act\)](#), which was passed by the House, awaits consideration in the Senate.
- The **Centers for Disease Control and Prevention** has published [guidance for direct service providers](#), including personal care attendants, direct support professionals, paraprofessionals, therapists, and others.
- [Stemming the Risk of Disability Bias During the COVID-19 Pandemic](#) – In an interview with the **Center for Health Care Strategies**, a Harvard professor of medicine who has multiple sclerosis explores treatment bias that people with disabilities may face in the current environment, and discusses opportunities to reduce potential discrimination.

### Children with Medical Complexity

#### Telehealth Reduces Hospitalizations for Medically Complex Pediatric Patients

"vKids at Home," a virtual care program for pediatric patients with medical complexity, improved patient and family quality of life and reduced unnecessary emergency department visits and hospitalizations in its first year, according to newly released research. The program uses a physician-led virtual clinical team and home monitoring technology to manage medically complex ambulatory pediatric patients. [Read more](#).

#### Comment Sought on Core Competencies for Providing Complex Care

The practice of complex care requires significantly different knowledge, skills, and attitudes from traditional practice. Since 2019, an expert working group has been developing a set of core competencies for providers across disciplines who care for people with complex health and social needs. A draft is available for review now and the working group is soliciting comments. Although the focus is on adults, the topics are relevant to children with complexity and their families. [Review the draft and submit comments](#) by **June 18**.

#### Related Webinar: The Complex Care Core Competencies Draft – An Opportunity for Feedback

**Date** Friday, June 12  
**Time** 10 to 11 a.m. Pacific Time  
**Sponsors** National Center for Complex Health and Social Needs, Camden Coalition  
**Details** Learn about how the core competencies were developed, discuss the draft, and provide feedback. [Register](#).

### Resources

#### Webinar: Emergency Planning – Preparing for the Unexpected

**Date** Thursday, June 18  
**Time** 11 a.m. to 12:15 p.m. Pacific Time  
**Sponsor** The Arc  
**Details** The speaker will provide tips and strategies that people with disabilities, families, and disability professionals can use to help plan for when disasters strike. Many of the tips will be applicable to the current COVID-19 pandemic. [Read more and register](#).

### Family Engagement

#### Reminder: Webinar Series on Social Determinants of Health and 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](#).

### In Memoriam

#### Lifelong Children's Advocate Richard Behrman, MD



Many of our readers may have been acquainted with the work of Richard Behrman, MD, a nationally recognized champion of the health and well-being of children, including children with special health care needs. In addition to his distinguished and influential career in academic medicine at institutions around the country, Dr. Behrman was instrumental in developing the work of our Foundation, the David and Lucile Packard Foundation, and Lucile Packard Children's Hospital Stanford. Read an [appreciation](#) and his [full obituary](#).

### California Policy

- [Opinion: Why New Telehealth Benefits Must Be Extended Beyond the COVID-19 Crisis](#) – San Francisco Chronicle, May 21

### In the News

- [People with Developmental Disabilities More Likely to Die from COVID-19](#)  
*Disability Scoop, 6/8/20*
- [Coronavirus Pandemic Showed Importance of Digital Access for People with Disabilities](#)  
*San Francisco Chronicle, 5/21/20*

#### 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](mailto:Eileen.Walsh@lpfch.org) with your news or updates.

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To see past issues, visit the [Network Newsletter Archive](#).

The California Advocacy Network for Children with Special Health Care Needs is a collaborative organized by the Lucile Packard Foundation for Children's Health. Through grantmaking, advocacy, and communications, the Foundation promotes a system of care that improves the lives of children with special health care needs and their families.



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