

July 9, 2020

## California Advocacy Network

for Children with Special Health Care Needs

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

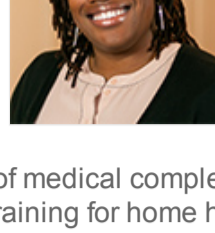
### Transition to Adult Care

#### A Fresh Look for the Core Elements of 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 also has posted new tools and resources on its revamped website. The new information, available in English and Spanish, can be used by clinicians, youth, and caregivers to assist young people as they move from pediatric to adult care. [See the new website.](#)

### Advocacy

#### A Mother's Perspective: How People with Complex Health and Social Needs Can Become Advocates for Change



Inspired by her daughter, who was born with a host of medical complexities, Mia Matthews embarked on a journey to advocate for continuing education and specialized training for home health nurses who care for people with complex medical conditions. In an article for the National Center for Complex Health and Social Needs, Ms. Matthews, president and executive director of the CHANs Promise Foundation, recounts her story and suggests multiple ways consumers can become advocates. [Read more.](#)

#### In Brief

- [National Disability Voter Registration Week Is July 13-17](#) – A guide to increasing the political power of people with disabilities, including through voter registration.

### Children with Medical Complexity

#### New Journal Highlights Work to Advance Pediatric Complex Care

The first edition of the Complex Care Journal, an open-access publication that aims to advance care for children with medical complexity, is now available. This self-published, peer-reviewed, practice-oriented journal offers a wide range of content, including reports on promising programs from around the country. The editors will accept submissions. Read the [first edition](#) (PDF).

#### In Brief

- [Study: Housing Intervention for Medically Complex Families Is Associated with Improved Family Health](#)

### Family Engagement

#### 'It Will Consume Your Life': 4 Families Take on Rare Diseases

A *New York Times* [article](#) chronicles how four families, confronted by rare illnesses that most scientists overlook, had to work out their own approaches to find treatments.

### CSHCN and Equity

- [Maternal and Child Health Inequities Emerge Even Before Birth](#) – An issue brief from Child Trends, July 1, 2020.
- [Racial Inequality and Injustice and the Health of America's Children](#) – A perspective from Scott D. Bems, CEO of the National Institute for Children's Health Quality, June 2020.

### California Children's Services

#### CCS Advisory Group: Whole Child Model, Telehealth, Prescription Drugs

Several key topics were the subject of wide-ranging discussion at the CCS Advisory Group meeting on July 8. Program and payment flexibilities allowed under COVID-19, particularly telehealth services, were noted, along with an extended explanation of the upcoming [changes to prescription medications](#) under Medi-Cal. The group discussed updates to the CCS program, including the Whole Child Model and the Medical Therapy Program, as well as issues that have arisen. Members also urged the state to begin post-COVID-19 planning now. The [slide presentation](#) provides some details, particularly on the planned prescription drug changes. For more information, write to [CCSRedesign@dhcs.ca.gov](mailto:CCSRedesign@dhcs.ca.gov).

#### Department of Health Care Services Stakeholder Advisory Committee to Meet

**Date** Thursday, July 16  
**Time** 9:30 a.m. to 12:30 p.m. Pacific Time  
**Location** [Register for the WebEx Meeting](#)  
**Dial-In** 1 (415) 655-0001; Passcode: 1456989997  
**Details** Agenda is posted on the committee [website](#).

### COVID-19 Information

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

- Webinar: [CDC COVID-19 Partner Update: Considerations on Keeping Students Safe as K-12 and Institutes of Higher Education Gear Up for Fall](#) – Monday, July 13, 12 p.m. Pacific Time, sponsored by the **Centers for Disease Control and Prevention**.
- [The Impact of Lost Therapy Services During COVID-19 and What Parents Can Do in the Interim](#) – In a video from the **Child Neurology Foundation** an educational consultant who also is a special education advocate discusses setting expectations about maintaining ground during the pandemic; how parents can prioritize which skills to focus on; and ways parents can work with their current therapists to integrate therapy into daily life.
- [Supporting Family Caregivers in the Time of COVID-19: State Strategies](#) – A blog from the **Center for Health Care Strategies** discusses the strains on family caregivers and strategies states could employ to better support them.

### Special Education

#### Bill to Watch

[SB 4112: Child Care and Education Relief Act](#) – Includes funding for the Individuals with Disabilities Education Act (IDEA), and contains other requirements regarding students with disabilities and Individualized Education Programs (IEP) during COVID-19.

### California Policy

- [Medi-Cal Payment for Telehealth and Virtual/Telephonic Communications Relative to the 2019-Novel Coronavirus](#) (PDF) – Information from the Department of Health Care Services updating the April 30, 2020, guidance.

### Webinar

#### What are Respite Services?

**Date** Wednesday, July 15  
**Time** 10:30 a.m. to 12 p.m. Pacific Time (Spanish)  
6 to 7:30 p.m. Pacific Time (English and Cantonese)  
**Sponsors** Support for Families of Children with Disabilities and Disability Rights California  
**Details** This webinar will discuss the most common questions about respite services and other family supports for children and adults with developmental disabilities who live at home. Register for the webinar in [English and Cantonese](#) or in [Spanish](#).

### Event

#### AMCHP Annual Conference Coming Up

The Association of Maternal and Child Health Programs (AMCHP) will hold its 2020 conference virtually from August 4-6, with the theme "Power of Connections: Building Equity for Healthy Generations." Fee. [Read more and register.](#)

### In the News

- [U.S. Pediatricians Call for In-Person School This Fall](#)  
*NPR, 6/29/20*
- [As the Country Opens Up, Children with Disabilities Are Getting Left Behind](#)  
*NY Times, 6/10/20*

#### 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.

