

## California Advocacy Network for Children with Special Health Care Needs

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

### Children with Medical Complexity

#### Webinar Series to Focus on Advancing Clinical Care of Children with Medical Complexities and Disabilities



Next month will see the launch of a 10-part seminar series, *Collaborative Conversations with Families to Advance the Clinical Care of Children with Medical Complexities and Disabilities (C6)*, which will highlight key clinical research questions for the care of these children. Each session will include a panel of national experts, both clinical and caregiver. The series, funded by our Foundation, is led by complex care pediatricians Dr. Eyal Cohen and Dr. Catherine Diskin from the Hospital for Sick Children (SickKids) in Toronto, Dr. Rishi Agrawal from Lurie Children's Hospital of Chicago, and Family Voices representatives Nora Wells, Cara Coleman, and Kate Robinson. CME credit available. The first session will provide an overview of topics to be covered:

##### Knowledge Gaps in the Care of Children with Medical Complexity and Neurodisability

Thursday, September 9  
10 to 11 a.m. Pacific Time

[Read more and register.](#)

#### Webinar: Rethinking Complex Care Measurement: Using Patient- and Staff-Reported Measures

**Date** Tuesday, August 31

**Time** 9 to 10:15 a.m. Pacific Time

**Sponsors** Center for Health Care Strategies (CHCS) and the Camden Coalition of Healthcare Providers' National Center for Complex Health & Social Needs

**Details** Speakers will discuss their first-hand experiences and reflections regarding recent innovations in complex care measurement, and will describe a recently developed quality measures library. [Read more and register.](#)

### California Children's Services

#### For Advocates: Helping Families Obtain Durable Medical Equipment and Supplies through CCS

An updated issue brief from the National Health Law Program, supported by our Foundation, provides a description of current CCS policies regarding durable medical equipment (DME) and supplies. The brief offers a series of advocacy tips for navigating the complex DME request process, including consumers' rights and the appeal process. [Read more.](#)

### Telehealth



The Q&A from the recent webinar *COVID-19 Telehealth Policies Affecting CYSHCN: What to Keep, Modify, or Discard?* is now available. Speakers address questions about family-centered care, pediatric patient care, and the future of telehealth. [Read the Q&A](#) (see under Downloads).

### Health Equity

#### Webinar: How Health Care Payers Can Advance Equity by Addressing Social Determinants of Health

**Date** Wednesday, September 15

**Time** 11 a.m. to 12:30 p.m. Pacific Time

**Sponsor** Mathematica

**Details** A number of payers have been at the forefront of the difficult work of designing and deploying policies that encourage health care providers to help address health-related social needs. Speakers will highlight ways that payers can change how they pay for health care to advance health equity, the roadblocks to doing so, and lessons learned from early efforts. [Read more and register.](#)

### In Brief

- [Black Students and Students with Disabilities Remain More Likely to Experience Suspension](#) – from Child Trends

### California Policy

#### Medi-Cal Children's Health Advisory Panel to Meet

**Date** Thursday, September 9

**Time** 9:30 a.m. to 1 p.m. Pacific Time

**Details** The agenda and registration link will be posted on the panel [website](#). [Advance registration required](#) to see meeting materials or comment.

### COVID-19 Information

#### Viewpoint: School Mask Policies and Children with Disabilities

In a column in the *California Health Report*, the mother of a 10-year-old makes her case for requiring masks in the classroom. Her son has severe disabilities that put him at high risk for respiratory infections, and the local school board allows parents to exempt their children from wearing masks or face shields in the classroom by filling out a form. [Read her opinion piece.](#)

*Related:* [California's Battle over Schools and COVID Shifts to Masks in Class this Fall](#) – from The Mercury News

### Resources

- [State Definitions of Medical Necessity Under the Medicaid EPSDT Benefit](#) – from the Catalyst Center. State Medicaid programs are required to provide Medicaid enrollees under age 21 with comprehensive and preventive health care services through the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit. With Catalyst Center support, the National Academy for State Health Policy conducted a 50-state scan of medical necessity definitions used by state Medicaid programs for their EPSDT benefit. This resource presents definitions from all 50 states and the District of Columbia.
- *Exceptional Parent Magazine* August Issue – [Healthcare](#)

### Events

#### The Arc's National Convention Set for New Orleans

Advocates, professionals, and individuals with intellectual and developmental disabilities and their families will gather for The Arc's National Convention, scheduled for September 27-29 in New Orleans. Topics to be addressed include employment, education, advocacy, housing, criminal justice, and more. [Read more and register](#) by **August 27** for the best rate.

### In the News

- [Opinion: Children with Disabilities Need Sex Ed Too](#)  
*NY Times*, 8/24/21
- [Disney Making Changes to Disability Access at Theme Parks](#)  
*Disability Scoop*, 8/24/21
- [Parents of High-Risk Students Face Tough Decisions Amid Delta Surge](#)  
*Disability Scoop*, 8/16/21

#### We'd like to hear from you

Let us know what's happening with your organization or family. Email newsletter assistant editor Ali Rivera at [Ali.Rivera@lpfch.org](mailto:Ali.Rivera@lpfch.org) with your news or updates. Or contact newsletter editor: Eileen Walsh at [Eileen.Walsh@lpfch.org](mailto:Eileen.Walsh@lpfch.org).

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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.

