

## California Advocacy Network

for Children with Special Health Care Needs

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

### COVID-19 Information

#### Webinar: COVID-19 Behavioral Health Policies Affecting CYSHCN: What to Keep, Modify, or Discard?

**Date** Wednesday, November 10  
**Time** 10 to 11 a.m. Pacific Time  
**Sponsors** Lucile Packard Foundation for Children's Health  
**Details** This webinar is based on the new report from Health Management Associates, [COVID-19 Policy Flexibilities Affecting Children and Youth with Special Health Care Needs](#). Speakers will discuss the regulatory flexibilities that had a positive impact on the behavioral health of CYSHCN, reflect on the unique stressors and behavioral health needs of this population, and highlight policy recommendations to address those needs. [Read more and register.](#)

*Related:* [Investments in Behavioral Health Service Systems: Top Three Emerging Themes from State Home and Community-Based Services Spending Plans](#) – from the National Academy for State Health Policy

### Transition to Adult Care

#### Feds Fund National Health Care Transition Resource Center

Family Voices has received a new federal five-year funding award to support development of a National Health Care Transition Resource Center for youth with intellectual and developmental disabilities. The center will serve youth ages 12-26, their families, and professionals who care for them, in collaboration with Got Transition and the SPAN Parent Advocacy Network. [Read about the award.](#)

#### Webinar: Improving Health Care Transition

**Date** Tuesday, October 26  
**Time** 1 to 2 p.m. Pacific Time  
**Sponsors** Family Voices, Got Transition, CT Kids As Self Advocates (CT KASA)  
**Details** This webinar will highlight a video and story to help youth with special health care needs and their families learn how to use a virtual meet-and-greet appointment to ease the transition to an adult health care provider. [Read more and register.](#)

### Children with Medical Complexity

#### Grand Rounds: Care Coordination for Children with Medical Complexity

**Date** Friday, October 22  
**Time** 8 to 9 a.m. Pacific Time  
**Sponsor** Stanford School of Medicine  
**Details** Dr. Jean Chia will describe the particular need for intensive care coordination for children with medical complexity (CMC) and their families. [Read more.](#)

#### Feeding Issues Are Topic for Third Seminar in Collaborative Conversations with Families Series



The third session of the 10-part seminar series will discuss recognizing the causes of feeding intolerance in medically complex children and the treatment options currently available for feeding intolerance. Each session of the series, which is funded by our Foundation, includes a panel of national experts, both clinical and caregiver.

**Feeding Intolerance**  
Thursday, November 11  
10 to 11 a.m. Pacific Time  
[Read more and register.](#)

See the recording from the second seminar [Pediatric Complex Care Seminar Session 2: Irritability and Pain.](#)

#### Archived Webinar



The [recording](#) from the September 15 webinar *Building a System of Care for Children with Complex Medical and Social Needs* is now available.

### Mental and Behavioral Health

#### Striving to Meet the Mental Health Needs of Children with Medical Issues

Focusing on one family's complex story, an article from *California Health Report*, which is funded in part by our Foundation, highlights the Mastering Each New Direction (MEND) program at Loma Linda University's Behavioral Medicine Center in Southern California. MEND is one of the few programs that provides mental health treatment specifically for children with chronic medical conditions and their families. MEND staff now are training other providers on how to run similar programs. [Read about the program.](#)

### Telehealth

#### Training Providers on Using Telehealth with CYSHCN

The American Academy of Pediatrics has developed online training resources to help pediatricians and other physicians review telehealth-related topics with staff and other team members to enhance care of CYSHCN. *Promoting Family Centered Care for CYSHCN through Telehealth* and *Using Telehealth to Support Interdisciplinary Care Delivery for CYSHCN Within the Medical Home* are topics for two of the available trainings. [See the training materials.](#)

#### In Brief

- [Executive Summary: Tracking Telehealth Changes State-by-State in Response to COVID-19 – October 2021](#) – from Manatt Health

### Health Equity

#### Research Priorities to Advance Disability Equity

Individuals with disabilities experience significant disparities in the receipt of equitable health care, and experts say that more research is needed. The Disability Equity Collaborative, with funding from the Patient-Centered Outcomes Research Institute (PCORI), has published a paper, *Patient Centered Outcomes Research Priorities to Advance Disability Equity*, that identifies 14 priorities in this area. [Read more.](#)

### California Children's Services

#### Two Upcoming Event Reminders:

- See the [agenda](#) (PDF) for the CCS Advisory Group meeting on October 27 at 11 a.m. Pacific Time
- [Register](#) (PDF) for the October 28-29 conference, CCS Best Practices 2021

### Events

- [Register](#) by **October 25** to request simultaneous translation in Spanish or Mandarin for the virtual Family Voices of California Health Summit 2021.

### Pediatric Palliative Care

#### Raising a Medically Complex Child

The Children's Palliative Care Coalition of Michigan is presenting an online conference on November 5 regarding the challenges of raising a child with medical complexity. Although Michigan-based, the topics have broad applicability for understanding and assisting families. CME and CE credits available. Fee. [Read more and register.](#)

#### West Coast Pediatric Palliative Care Summit Postponed

In order to hold the summit in person, the dates have been changed to March 28 and 29, 2022. [Read more about the summit.](#)

### California Policy

- [California Vaccine Mandate Extends to Aides for People with Disabilities](#) – from California Healthline

### In the News

- [CDC: People with Disabilities Want COVID-19 Vaccines, but Struggle to Get Them](#)  
*Disability Scoop, 10/11/21*
- [Students in Special Ed at High Risk of COVID-19 See Few School Options](#)  
*Disability Scoop, 10/8/21*
- [For Kids with Complex Needs, In-Home Care Tough to Find](#)  
*Disability Scoop, 10/6/21*

#### 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@pfch.org](mailto:Ali.Rivera@pfch.org) with your news or updates. Or contact newsletter editor: Eileen Walsh at [Eileen.Walsh@pfch.org](mailto:Eileen.Walsh@pfch.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.

