

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

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

### Family Engagement

#### Sibling Support Toolkit

Siblings of children with medical complexities have unique roles that can fluctuate as family situations change. The Pediatric Palliative Care Coalition and the Courageous Parents Network have developed a toolkit of resources to help parents, caregivers, and medical professionals provide support to siblings. [See the toolkit.](#)

#### Register: Family Voices of California Health Summit

Family Voices of California's Health Summit is an annual convening of families, youth, advocates, state and local agencies, and legislators and staff. This year's virtual summit, sponsored in part by our Foundation, is scheduled for November 3-4. [Read more and register.](#)

### Transition to Adult Care

#### 22nd Annual Chronic Illness and Disability Conference: Transition from Pediatric to Adult-Based Care

Baylor School of Medicine and Texas Children's Hospital present this conference, which will feature lectures, breakout sessions, and question-and-answer sessions addressing health care transition issues. The virtual conference, scheduled for October 28-29, is designed for care providers as well as youth and their families or guardians. Approved for CME credit. Fee. [Read more and register.](#)

Related: [13th Annual Health Care Transition Research Consortium Symposium – Virtual, October 27](#)

### In Brief

- [Youth with Disabilities Experience Better Outcomes as They Become Adults](#) – from Mathematica
- [Video: What Is Health Care Transition?](#) – from Got Transition

### Telehealth

#### From the American Academy of Pediatrics: Telehealth Resources Specific to CSHCN

The American Academy of Pediatrics is offering a six-part course to educate pediatric health care professionals on how to increase their team capacity in providing preventive, acute, and chronic care via telehealth for children and adolescents. Three of the six modules are specifically focused on enhancing telehealth care for children and youth with special health care needs. The free, online course is open to the public. [Read about the PediaLink Course: Providing Telehealth and Distant Care Services in Pediatrics.](#)

### Children with Medical Complexity

#### A Shift in Perspective: A Critical Care Physician Becomes Mother of a Child with Complex Needs

In a new book, *Catastrophic Rupture: A Memoir of Healing*, a Wisconsin physician who cares for children with severe disabilities recounts her journey learning to parent her own daughter who experienced neurologic impairment after a complicated birth. As she shifts from a medical to a mother's perspective, K. Jane Lee, MD, "finds that everything she had learned about disability and personhood as a physician and ethicist was no help as a parent." [Read her memoir.](#)

#### Reminder: Upcoming Events



The second session of the 10-part seminar series, *Collaborative Conversations with Families to Advance the Clinical Care of Children with Medical Complexities and Disabilities*.

**Irritability and Pain**  
Thursday, October 14  
10 to 11 a.m. Pacific Time  
[Read more and register.](#)



National Conference: **Putting Care at the Center 2021** – October 20-22 online, hosted by the National Center for Complex Health and Social Needs. [Read more and register.](#)

### COVID-19 Information

#### A Physician's View of the Impact of COVID-19 on CSHCN

In an interview with public radio, the medical director for the pediatric palliative care program at Valley Children's Hospital in Central California discusses how COVID-19, including the Delta variant, has been affecting children's health and well-being. Although locally focused, his comments have wider applicability. [Listen to the broadcast.](#)

### In Brief

- [Ed Department Issues Guidance on IEPs During Pandemic](#) – from Disability Scoop

### Pediatric Palliative Care

#### Webinar: Bereaved Parents' Views on End-of-Life Care

**Date** Tuesday, October 19  
**Time** 12 to 1 p.m. Pacific Time  
**Sponsors** Pennsylvania's Pediatric Palliative Care Coalition, Greater Illinois Pediatric Palliative Care Coalition, Children's Hospice & Palliative Care Coalition of California, Jacob's Heart Children's Cancer Support Services, and the CSU Shiley Institute for Palliative Care  
**Details** Despite an increase in specialized pediatric palliative care programs, there remain inadequacies in end-of-life care for children. This presentation will review the perspectives of 28 Spanish- and English-speaking bereaved parents who detailed qualitative experiences about their children's end-of-life care. Fee. [Read more.](#)  
*Related: Firefly Chat: Grief and the Holidays*, Wednesday, October 20, 9-10 a.m. Pacific Time. Free but [registration required.](#)

### California Children's Services

#### CCS Advisory Committee to Meet

**Date** Wednesday, October 27  
**Time** 11 a.m. to 3 p.m. Pacific Time  
**Details** Call-in and agenda details will be posted on the group's [website](#).

#### Conference: CCS Best Practices – Shifting the Paradigm for a Post-COVID World

Registration is now available for this free virtual conference presented October 28-29 by the Children's Regional Integrated Service System (CRISS). The conference, sponsored in part by our Foundation, will provide information on successful and feasible strategies for improving care delivery for children and youth with complex medical conditions in the California Children's Services (CCS) program, and will update attendees on important issues facing CCS. [Read more and register.](#)

### California Policy

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

**Date** Thursday, October 21  
**Time** 1:30 to 4:30 p.m. Pacific Time  
**Details** See the [agenda and call-in information](#) (PDF). [Advanced registration required](#) to see meeting materials or comment.

#### Regional Center COVID Policy Modifications Extended

Pandemic-driven waivers, modifications, or directives affecting a wide range of regional center services have been extended an additional 30 days from the current date of expiration, according to a memo from the Department of Developmental Services. [Read the memo](#) (PDF).

### National Policy

#### Mini-brief: Strengthening Title V – Medicaid Managed Care Collaborations

Forty-seven states use some form of managed care to serve children and youth with special health care needs (CYSHCN) enrolled in Medicaid. State Title V programs may serve these same children. By working collaboratively, Medicaid agencies, Medicaid managed care organizations, and state Title V programs can expand their individual capacities to strengthen the system of services. The Catalyst Center and the National Academy for State Health Policy describe how such partnerships can contribute to a reduction in duplication of services, enhanced care coordination efforts, and the development of cross-agency programmatic supports to meet the needs of Medicaid-enrolled CYSHCN and their families. [Read more.](#)

### In the News

- [For Children with Disabilities, Climate Change Brings Multiple Threats](#)  
*California Health Report, 9/29/21*
- [Low Wages and Pandemic Gut Staffing Support for Those with Disabilities](#)  
*Disability Scoop, 9/28/21*
- [People with JDD, DSPs May Qualify for COVID-19 Vaccine Boosters](#)  
*Disability Scoop, 9/27/21*
- [When San Diego County Schools Report Their Students to Police, Minorities and Kids with Disabilities Are Most Impacted](#)  
*CBS News, 9/27/21*
- [California's Reboot of Troubled Medi-Cal Puts Pressure on Health Plans](#)  
*Kaiser Health News, 9/21/21*

#### 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).

[Join the Network](#)

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.

