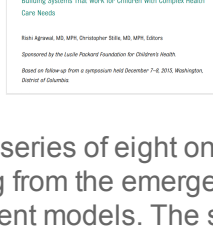


## California Advocacy Network for Children with Special Health Care Needs

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

### Children with Medical Complexity

#### A Review: Building Systems that Work for Children with Medical Complexity and Their Families



Just over a year ago, the Foundation launched our series of eight online conversations about children with medical complexity. Expert speakers covered topics ranging from the emergence and definition of pediatric complex care to meaningful family engagement and potential payment models. The series grew out of a March 2018 supplement in [Pediatrics](#) that in turn was based on a [symposium](#) on pediatric complexity that we co-sponsored with the Institute of Medicine in December 2015 in Washington, DC. Now, the information from all of these activities has been consolidated on a [new web page](#).

#### Webinar: Serving Medicaid Beneficiaries Who Need Long-Term Services and Supports: Better Outcomes at Lower Costs

**Date** Wednesday, June 5  
**Time** 9 a.m. to 10:30 a.m. Pacific Time  
**Sponsor** Mathematica  
**Details** Home and community-based services (HCBS) are designed to allow individuals with complex disabilities to live at home, and to reduce the use of expensive institutional care. However, the system still faces challenges. This webinar is a discussion of the needs of people whose HCBS are the most costly, and strategies for serving them in a cost-efficient way. [Read more and register](#).

### California Children's Services

#### Senate Budget Subcommittee Explores Whole Child Model Issues

The Senate Budget Subcommittee #3 for Health and Human Services convened on May 9 to discuss the implementation of the Whole Child Model with an informational panel of stakeholders representing the Department of Health Care Services, Health Plan of San Mateo, Family Voices of California, Children's Specialty Care Coalition, and California Children's Hospital Association. The subcommittee raised questions about appropriate case management, sufficient transportation to medical appointments, Medi-Cal eligibility, and evaluation of the transition of children from CCS to Medi-Cal managed care. [Watch the session](#) (recording starts at 5:05) and see the [agenda](#) (PDF).

#### Assistance Available with CCS Transition

Family Voices of California offers advice and assistance for families involved in the transition of their children from CCS coverage to Medi-Cal managed care. Call Ali Barclay at 888-387-0393 (toll free) or write [abarclay@familyvoicesofca.org](mailto:abarclay@familyvoicesofca.org). Fact sheets about the Whole Child Model transition are available in English and Spanish. [See more](#).

#### CCS Transition to Adulthood Workgroup to Meet

The CCS Transition to Adulthood Workgroup is scheduled to meet on Wednesday, May 29. See the agenda and call-in information on the CCS Advisory Group [website](#).

### Research

#### Study: Life Satisfaction for Children with Chronic Illness

Results from a survey of parents/caretakers suggest that children with chronic illness may have lower general health but similar life satisfaction compared with those who don't have chronic illness. The findings, published in *Pediatrics*, offer an opportunity to broaden the perspective of health beyond the absence of disease to one that considers the quality of life of children. [Read more](#).

### Webinar

#### Helpful Approaches to Navigating Sensory Sensitivities in the Community

**Date** Wednesday, June 5  
**Time** 9 a.m. to 10 a.m. Pacific Time  
**Sponsor** Vermont Family Network  
**Details** Learn about considerations and approaches that can be helpful when introducing or re-introducing a child with sensory sensitivity to a setting outside of their routine. Specialists from the University of Vermont Children's Hospital will share some successful strategies on how to help children and families process these experiences in a way that is meaningful. [Register](#).

### Resources

- *Complex Child* May Issue: [Annual Respiratory Edition](#)
- *Exceptional Parent Magazine* May Issue: [Imagining the Possibilities](#)

### Special Education

#### In Brief

- [Report: Protecting Students' Civil Rights – The Federal Role in School Discipline](#) (PDF) – from the Learning Policy Institute
- [Trump Administration to Appeal Special Ed Ruling](#) – from Disability Scoop. The US Department of Education seeks to delay implementation of the "Equity in IDEA" regulations. IDEA is the Individuals with Disabilities Education Act.

### California Policy

#### Bill to Watch

- [SB 428](#) – Would require the State Department of Education to identify an evidence-based training program for local educational agencies to use in training classified and certificated school employees in direct contact with pupils on youth mental health first aid. It passed with a unanimous vote from the California State Senate on May 21 and is now with the California State Assembly.

*Also See:* [Mental Health First-Aid Training Could Have Saved My Daughter's Life](#)

### Event

#### Community Care for High-Need Patients

**Date** Tuesday, June 4  
**Time** 6 a.m. to 9:30 a.m. Pacific Time  
**Location** Conrad Hotel, Washington, DC  
**Sponsor** Health Affairs  
**Details** There is a growing need for a large and diverse workforce to enable people with disabilities to live in their homes and communities. The June 2019 special issue of *Health Affairs* is devoted to understanding how to recruit, train and deploy the necessary clinical and non-clinical workforce and fully integrate family caregivers into care processes. Authors including Carolyn Foster, a current grantee of the Lucile Packard Foundation for Children's Health, will present their work during this live webcast. [Read more and register for the live webcast](#).

### Funding Opportunity

#### Testing Models of Care Integration for Children

The federally funded Integrated Care for Kids (InCK) Model provides funding opportunities to states and local organizations to test whether payment supporting integrated service delivery across behavioral health, physical health, and other child services reduces Medicaid and Children's Health Insurance Program (CHIP) expenditures and improves the quality of care for covered children. The InCK Model will assist states and local communities in addressing priority health concerns for children and will support awardees in developing state-specific pediatric alternative payment models (APMs). **Applications are due June 10**. [Read more](#).

*Also See:* [InCK Marks Resource Network](#) sponsored by the Help Me Grow National Center, which offers guidance to leverage this funding opportunity.

### Scholarship Opportunity

#### Media Scholarships Available for College Students

College students with disabilities who are pursuing a career in media, communications, or entertainment may apply for the NBCUniversal Tony Coelho Media Scholarship, which provides funding to help cover the cost of their education. [Read more and apply by June 6](#).

### In the News

- [Lawsuit Challenges Use of Restraint, Seclusion in California Special Education School](#)  
*EdSource, 5/20/19*
- [Trump's Talk on Preexisting Conditions Doesn't Match His Administration's Actions](#)  
*Kaiser Health News, 5/16/19*
- [Where Should a Child Die? Hospice Homes Help Families with the Unimaginable](#)  
*NY Times, 5/15/19*
- [The Chair of Change: Daniel Fights for a Suitable Park for His Little Disabled Daughter](#)  
*Univision, 5/4/19*
- [A Machine Learning Device, Meant to Monitor the Chronically Ill, Moves into Homes](#)  
*STAT, 4/24/19*

#### 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.

