

January 31, 2019

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

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

### Care Coordination

#### Federal Awards Boost Technology-Based Solutions for Care Coordination



Seven organizations around the country have won awards in the Care Coordination for Children with Special Health Care Needs (CSHCN) Challenge sponsored by the Maternal and Child Health Bureau. The winners proposed technology-based solutions designed to help families of CSHCN coordinate care for their children. Awardees next will develop prototypes and begin small-scale testing. [See the winners.](#)

### Family Engagement

#### Registration Open for Family Voices of California Annual Health Summit, Legislative Day

The 17th Annual Health Summit and Legislative Day is scheduled for March 10-12 in Sacramento. Families, youth, care providers, policymakers, advocates, state agencies, insurers, and other stakeholders gather to identify and address the health challenges facing CSHCN and their families. Free for families. Slots fill quickly. Read more and [register](#).

#### Webinar Follow-up: Assessing Family Engagement

The [recording and slides](#) are available from our recent webinar "A New Approach to Assessing Family Engagement in Health Care Systems." Links to related information also are included.

### California Children's Services

#### Members Appointed to CCS Transition Workgroup

The Department of Health Care Services has released the [names of members](#) (PDF) of the Transition to Adulthood Workgroup. The group met for the first time on January 30. See the meeting [agenda and slides](#). Also see the [2019 member list](#) (PDF) for the CCS Redesign Advisory Group.

#### Fact Sheets in English, Spanish Explain Whole Child Model Phase II

The second phase of the CCS Whole Child Model, which transfers children into Medi-Cal Managed Care, is under way in Del Norte, Humboldt, Lake, Lassen, Marin, Mendocino, Modoc, Napa, Shasta, Siskiyou, Solano, Sonoma, Trinity, and Yolo counties. Family Voices of California has developed fact sheets to assist families in understanding and navigating the changes. [Read the fact sheets](#)

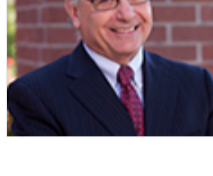
### Quality Standards/System Improvement

#### New Resources Added to the National Standards Toolkit

The National Academy of State Health Policy and the Association of Maternal & Child Health Programs have added new resources to the National Standards for Children and Youth with Special Health Care Needs Toolkit. The resources were developed to help states design, strengthen and improve health care systems serving CYSHCN and enable stakeholders to use the standards in quality measurement efforts and Medicaid managed care program design. The resources include e-learning modules, case studies, and tip sheets. [Read more.](#)

### Viewpoint

#### The Future of Pediatrics: Redefining "Chronic Care"



The term "chronic care" describes an approach that is usually limited to patients with chronic medical conditions. In a new issue brief, Edward Schor, MD, proposes a definition of chronic care and discusses how it should be the care model used not only for children with special health care needs but also should be the approach used for well-child care for all children. Both are intended to promote health throughout the life course. [Read more.](#)

### Children with Medical Complexity

- [Three Ways Hospitals are Transforming the Delivery System for Children with Complex Medical Conditions](#) – Features results from the Coordinating All Resources Effectively (CARE) Award program, a three-year project that aimed to transform care delivery and payment for children with medical complexity enrolled in Medicaid. [Read more about CARE.](#)
- [Educating Providers on Delivering the Best Care to Children with Complex Medical Conditions](#) – An educational program affiliated with Lurie Children's Hospital exposes community providers and medical students to a variety of situations they could encounter while providing care to children with complex medical conditions.

### Special Education

- [U.S. Department of Education Announces Initiative to Address the Inappropriate Use of Restraint and Seclusion to Protect Children with Disabilities. Ensure Compliance with Federal Laws](#)

### National Policy

#### Bill to Watch

- [HR 259](#) – The president has signed this bill to extend the [Money Follows the Person](#) program for three months, until September 30. The program helps people transition from institutional to community-based care.

### California Policy

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

**Date** Wednesday, February 13  
**Time** 10 a.m. to 2:30 p.m. Pacific Time  
**Location** The California Endowment  
1414 K St, Sacramento – First Floor Conference Room  
**Dial-In** (888) 606-5935; Passcode: 9283547  
**Details** The agenda and meeting materials are available on the [website](#).

#### Webinar: Department of Managed Health Care/Help Center 101

**Date** Wednesday, February 27  
**Time** 12 p.m. to 1 p.m. Pacific Time  
**Sponsor** Family Voices of California  
**Details** For individuals having problems with their health plans, this webinar will explain how problems are resolved. Topics include denied treatment services, cancellations of health coverage, complaints about a doctor or plan, and more. [Register.](#)

### Resources

#### Updated CDC Milestone Tracker for Ages 0-5 Available in English, Spanish

The Centers for Disease Control and Prevention's Milestone Tracker – a free app for easily tracking a child's early development – has been updated, and now is available in English and Spanish. The app adds to the suite of free, family-friendly materials from *Learn the Signs. Act Early.* [Download the free app.](#)

### Webinars

#### New Evidence of the Affordable Care Act's Effect on People with Disabilities

**Date** Thursday, February 7  
**Time** 9 a.m. to 10:30 a.m. Pacific Time  
**Sponsor** A Mathematica webinar presented by the Center for Studying Disability Policy  
**Details** This webinar will discuss new information about how policy changes from the 2010 Affordable Care Act affect individuals with disabilities, including removing limits on preexisting conditions, extending parent's health insurance coverage of young adults until the age of 26, and more. [Register.](#)

#### Promising Practices in Managed Long-Term Services and Supports: Network Adequacy and Accessibility

**Date** Friday, February 15  
**Time** 11 a.m. to 12:30 p.m. Pacific Time  
**Sponsor** Community Living Policy Center  
**Details** This webinar will highlight recent research on Managed Long-Term Services and Supports. Topics will include promising practices and options for states to measure network adequacy of Home and Community Based Services. [Register.](#)

### In the News

- [These Moms Are Building a Forever Home for Their Adult Autistic Children](#)  
*Washington Post, 1/29/19*
- [Dems Hit GOP on Pre-Existing Conditions at Panel's First Policy Hearing](#)  
*The Hill, 1/29/19*
- [Kids with Disabilities Can Be at Risk of Bullying by Adults](#)  
*WBUR, 1/29/19*
- [Ohio Dad Builds Wheelchair-Accessible Igloo for His Kids with Disabilities](#)  
*CBS News, 1/16/19*
- [A Legacy of Mistreatment for San Francisco's Black Special Ed Students](#)  
*KALW, 1/15/19*

#### 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.

