

## California Advocacy Network

for Children with Special Health Care Needs

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

### Children with Medical Complexity

#### Webinar: Identifying and Serving Children with Health Complexity – Spotlight on “Pediatric Care Together”

**Date** Thursday, March 14  
**Time** 10:30 a.m. to 11:30 a.m. Pacific Time  
**Sponsors** Oregon Pediatric Improvement Partnership (OPIP) and Kaiser Permanente Northwest

**Details** Health systems play an important role in addressing the unique medical and social factors that affect the health and health care of children with medical complexity (CMC). Speakers from OPIP and Kaiser will discuss their joint effort to use system- and practice-level data to better identify and serve CMC. [Read more and register](#). Also see a [publication](#) describing the work in detail.

#### In Brief

- [Partnering with Patient Families to Better Care for Children with Medical Complexity](#) – An article from the Children’s Hospital Association discusses how two children’s hospitals are moving to ensure that families are full participants in the care of their children with medical complexity.

### Network News

#### Foundation Funding Opportunity: Letters of Inquiry Due

Brief Letters of Inquiry (LOI) for funding from the Lucile Packard Foundation for Children’s Health may be submitted until Monday, March 4. Please read the [funding criteria](#) carefully before submitting an LOI. Do not submit a full proposal unless requested.

### California Children’s Services

#### CCS Transition to Adulthood, NICU Workgroups Meet

The CCS Transition to Adulthood Workgroup met February 27 in Sacramento. See the [agenda and slide presentation](#) and the member list on the CCS Advisory Group website. The next meeting is scheduled for March 27. The Neonatal Intensive Care Unit (NICU) Workgroup began meeting in February. Those meetings are not open to the public, but results from the workgroup will be shared at future CCS Advisory Group meetings. The next Advisory Group meeting is scheduled for April 10.

#### Viewpoint

- [Why the Battle to Bring Back School Nurses Is Such Big Deal for Health and Academics](#) – This article, by pediatrician ChrisAnna Mink, takes particular note of how the lack of school nurses affects children with special health care needs and their families.

Also See: [The ‘Hidden Health Care System’ in California Schools and Children with Special Health Care Needs](#)

### Transition to Adult Care

- [2019 Coding and Reimbursement Tip Sheet for Transition from Pediatric to Adult Health Care](#) (PDF) – An updated resource from Got Transition and the American Academy of Pediatrics to support the delivery of recommended transition services in pediatric and adult care settings.

### Family Engagement

#### National Family Voices’ Tool to Enhance Family Engagement Will Be Focus of Panel at AMCHP Annual Conference

Family engagement is becoming an important aspect of work in both the public and private sectors. Panelists will discuss Family Voices’ upcoming *Family Engagement in Systems Assessment Tool* in a workshop at the Association of Maternal and Child Health Programs (AMCHP) [Annual Conference](#) on March 11. Release of the tool is expected this summer.

#### Register for National Family Voices 2019 Leadership Conference

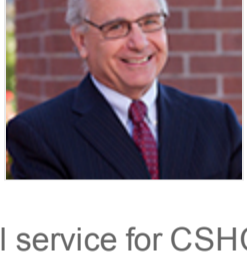
Registration opens tomorrow, March 1, for “Families as Partners Shaping Systems Change,” this year’s national Family Voices Leadership Conference, scheduled for May 8-10 in Washington, DC. Attendees will explore ways to improve supports to families, learn new strategies for managing nonprofits, and increase capacity for families to partner in systems change. [Read more](#).

#### In Brief

- [Family Navigation Story Wall](#) – Family navigators help guide families of CSHCN through the complexities of the health care system to improve their access to care. On this website, family navigators tell their first-person stories about how they became navigators and discuss the challenges, benefits, and rewards of their role.

### Care Coordination

#### Worth Another Look: Ten Essential Characteristics of Care Coordination



Care coordination is a critical service for CSHCN and their families, but there are multiple definitions, expectations, and approaches to its provision. As a starting point for discussion to advance care coordination provision and measurement, Edward Schor, MD, senior vice president at the Lucile Packard Foundation for Children’s Health, proposes 10 principles, drawn from a review of key indicators of the quality of care coordination. [Read more](#). The [original article](#) was featured in *JAMA Pediatrics* (subscription required).

Also See: [Pediatric Care Coordination](#)

### Resources

- [Prolonged Grieving: 20 Ways to Cope When Life Is Relentless](#) – from the Center for Family Involvement. Stories and information for families and individuals in the disability community.
- *Exceptional Parent Magazine* February issue – [Diet and Nutrition](#)

### National Policy

- [House Hearings Shed Light on a Key Policy Priority: Protecting People with Pre-Existing Conditions](#) – A blog from the Georgetown Center on Health Insurance Reforms

### California Policy

#### Assembly Subcommittee to Consider Rate Increase for Care Providers

On March 6 a California Assembly Budget Subcommittee will discuss issues affecting people with disabilities, including a request for a minimum 8 percent across-the-board rate increase for providers to stabilize services for people with intellectual and developmental disabilities. Assemblymembers Chris Holden and Jim Frazier have submitted a [letter](#) (PDF) to the Senate and Assembly committees documenting the need. The hearing is scheduled for 2:30 p.m. in Room 437 at the Capitol.

### Webinars

#### How We Are Leading: Voices from Alumni (Cultural Diversity)

**Date** Thursday, March 14  
**Time** 11 a.m. to 12:30 p.m. Pacific Time  
**Sponsor** Leadership Institute for Cultural Diversity and Cultural and Linguistic Competence at Georgetown University

**Details** The Leadership Institute is a catalyst for change in networks supporting individuals with [intellectual and developmental disabilities](#). This webinar is first in a series to discuss challenges and opportunities associated with leading cultural diversity and cultural and linguistic competence within developmental disability agencies. [Register](#).

#### Archived Webinar

- [Building Partnerships and Educating Families and Professionals about Supported Decision-Making](#) – Recording and slides from a recent Family Voices webinar.

### Events

#### 2019 Developmental Disabilities Public Policy Conference

**Date** March 18 to 20  
**Location** Holiday Inn Sacramento  
300 J St, Sacramento

**Sponsors** The Arc and United Cerebral Palsy  
**Details** Attendees will explore the theme “Intersections – Where Disability & Life Meet.” People with intellectual and developmental disabilities experience many intersections throughout their lives when critical choices must be made. This conference will explore those intersections and the implications for public policy. [Register](#).

#### Early Bird Registration Deadline: California School-Based Health Conference

“Advancing Wellness and Best Practices for the Future” is the theme of the California School-Based Health Conference scheduled for May 9-10 in Redondo Beach. Fee. Last day for early bird registration is **today, February 28**. [Read more and register](#).

### In the News

- [For Parents of Ill Children, a Growing Recognition of PTSD](#)  
*Wall Street Journal*, 2/19/19 (Membership required)
- [Half of U.S. Children with Mental Health Disorders Are Not Treated](#)  
*Michigan Medicine MHealth Lab*, 2/18/19
- [Parents, Teachers Agree Inclusion Works for Students with Disabilities, but More Resources are Needed](#)  
*Fox 40*, 2/13/19
- [Improving Oral Health Outcomes for Children with Special Needs](#)  
*Dentistry Today*, 2/11/19

#### 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.

