

California Advocacy Network

for Children with Special Health Care Needs

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

Children with Medical Complexity

Documenting the Cost of Care Coordination for CMC

Children with medical complexity (CMC) often have multiple social, developmental, behavioral, educational, and financial needs, and coordinating their care is a major challenge. A new commentary in *Pediatrics* discusses one complex care program's study of time spent on non-billable care coordination activities for 208 CMC over two years. The research is important in that it documents the true costs of care coordination for CMC at a time when payers, providers and systems seek alternative payment models to support non-face-to-face care. [Read the commentary.](#)

Rising Readmission Rates for CMC

While pediatric hospital admissions in the US declined between 2010 and 2016, readmission rates increased, especially for children with complex medical conditions, according to a newly released study. The findings, from Boston Children's Hospital and Harvard Medical School, highlight the need for more research on medical homes, care coordination, and chronic condition management for CMC. [Read more](#) and see the [abstract](#).

Transition to Adulthood

Chronic Care Management: Not Just for Adults

Though most commonly associated with adults, chronic care management is becoming increasingly important in pediatric practices. As the number of children with complex chronic conditions grows, so too does the need for smooth transition to adult care. A new analysis compares data from a survey of primary care pediatricians and adult internists who care for patients with multiple chronic conditions. Understanding their similarities and differences may be useful in identifying ways to improve chronic care and in preparing for transition. Responses from both types of practices suggested substantial room for improvement. [Read the issue brief.](#)

Challenges for Hispanic Youth Transitioning to Work

The transition from school to work can be challenging for many young adults with disabilities and their families, but those from Hispanic communities may face additional difficulties. A new study reports on caregivers' views. [Read more.](#)

California Children's Services

NICU Eligibility Workgroup Selected; Transition Workgroup to Meet

The California Department of Health Care Services has published the [member list](#) (PDF) of the Neonatal Intensive Care Unit (NICU) Medical Eligibility Workgroup. The group will consider alternate CCS NICU eligibility methodologies. The Department's Transition to Adulthood Work Group is scheduled to hold its second meeting on Wednesday, February 27. Check the [website](#) for call-in information.

Special Education

The Role of Pediatricians in Special Education

Jennifer Poon, a developmental-behavioral pediatrician, discusses how pediatricians can assist in advocating for children's developmental and behavioral needs in schools. This article from the American Academy of Pediatrics reviews key components of the Individuals with Disabilities Education Act (IDEA) and explains children's educational rights. [Read more.](#)

Family Engagement

Save the Date: National Family Voices 2019 Leadership Conference

"Families as Partners Shaping Systems Change" is the theme for this year's 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.](#)

Q & A on Assessing Family Engagement in Systems Change



Time ran out on our January 23 webinar on family engagement in health care systems change, so many audience questions were left unanswered by the speakers. See the [answers](#) to the questions and view the original [issue brief](#), and the [recording and presentation slides](#).

Reminder: Register 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. Free for families. See the [agenda](#) (PDF) and [register](#).

National Policy

ACE Kids Act Revived in Senate

The Advancing Care for Exceptional Kids Act (ACE Kids Act) has been introduced again in the US Senate. [S.317](#) would allow states to provide coordinated care for children with complex medical conditions through a health home, including across state lines. The prior ACE Kids Act was approved by the House last session but did not move forward. Advocates are seeking support for this new version. [Read more.](#)

In Brief

- [Democrats Unite to Begin Push to Protect Pre-Existing Condition Coverage](#) – from New York Times

Resources

- [The EDge Newsletter](#) – A publication of the California Department of Education, Special Education Division. Connects parents, policymakers, and educators with special education resources.
- *Complex Child* February issue: [Annual Feeding Tube and GI Edition](#)
- *Exceptional Parent Magazine* January issue – [2019 EP Guide: Navigating Special Needs Resources](#)

Webinars

Don't You Forget About Me: Caring for Siblings

Date Thursday, February 21
Time 12 p.m. to 1 p.m. Pacific Time
Sponsors Pennsylvania's Pediatric Palliative Care Coalition, Greater Illinois Pediatric Palliative Care Coalition
Details This webinar will highlight the experiences of siblings of chronically or terminally ill children and will examine evidence-based interventions to create an effective framework of support for siblings. Fee. Complimentary registration is available for parents. [Register.](#)

Building Partnerships and Educating Families and Professionals About Supported Decision-Making

Date Thursday, February 21
Time 12 p.m. to 1:15 p.m. Pacific Time
Sponsors Family Voices and Quality Trust's National Resource Center for Supported Decision-Making
Details Hear how three Family-to-Family Health Information Centers are helping to educate families, health care providers, legal professionals, and others about Supported Decision-Making as an alternative option to guardianship for transition age youth. [Register.](#)

Starting and Sustaining a Youth Advisory Board, Part 1: Youth Voice

Date Wednesday, February 27
Time 9 a.m. to 10 a.m. Pacific Time
Sponsor Family Voices
Details First in a series to inform organizations that seek to develop a youth advisory board. [Register.](#)

Strategies for Funding an ABLE Account

Date Thursday, February 28
Time 11 a.m. to 12 p.m. Pacific Time
Sponsor National Disability Institute
Details A review of basic rules for funding an ABLE account, which is a tax-advantaged savings account for individuals with disabilities and their families. The webinar will cover strategies that could be used to ensure that contributions are easy to make, occur automatically when possible, and are available to the ABLE account owner. [Register.](#)

Events

Disability Policy Seminar

Date April 8 to 10
Location Washington, DC
Sponsors The Arc, the American Association on Intellectual and Developmental Disabilities, the Association of University Centers on Disabilities, the National Association of Councils on Developmental Disabilities, Self-Advocates Becoming Empowered, and United Cerebral Palsy
Details This event cultivates champions from Capitol Hill and advances the grassroots movement for people with intellectual and developmental disabilities. Two days of information and discussion, and a third day of speaking directly to legislative representatives. Fee. Late registration fee after **March 1**. [Register.](#)

In the News

- [Barbie Introduces Dolls with Wheelchairs and Prosthetic Limbs](#)
CNN, 2/12/19
- [New Emoji Include People with Disabilities](#)
Disability Scoop, 2/6/19
- [These Military Families Say Public Schools Aren't Supporting Their Special-Needs Kids](#)
PBS NewsHour, 1/29/19
- [Opinion: My Special Needs Students Needed Their Teachers in the Classroom – Not on the Picket Line](#)
USA Today, 1/29/19

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 with your news or updates.

