

# California Advocacy Network

## for Children with Special Health Care Needs

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

### Children with Medical Complexity

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## Building Systems That Work for Children with Complex Health Care Needs: Next Steps

The current health care system is extremely challenging for children with complex, chronic conditions and their families. In 2015, the Lucile Packard Foundation for Children's Health sponsored a national symposium in Washington, DC, [Designing Systems That Work for Children with Complex Health Care Needs](#), which brought attention to the systemic issues that affect the health and well-being of these children. Building on the symposium, the Foundation has sponsored a just-released supplement to *Pediatrics* that features eight articles from leading health care providers, family representatives, advocates, policymakers, and researchers. Addressing topics that include families' viewpoints, models of care delivery, evolving state and national policies, and more, the authors aim to clarify some of the systemic challenges for children with medical complexity and point the way toward their resolution. [Read the Supplement articles.](#)

### California Children's Services

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## Planning Continues for Transition to Whole-Child Model

As the Whole-Child Model transition of some CCS children into Medi-Cal managed care moves forward, two new documents have been made available by the Department of Health Care Services that may be of interest to stakeholders:

- [Final draft of the 90-day Notice letter that will be sent to families whose child is transitioning \(PDF\)](#)

- [The slides from the February 28 meeting of the CCS Performance Measures Quality Subcommittee](#) (PDF)

**Also See:** [How Can We Tell Whether Medicaid MCOs Are Doing a Good Job for Kids?](#)  
– from Georgetown Center for Children and Families

## Network News

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### Offer Your Opinion – Maybe You'll Win a Gift Card

Recently you received an email asking you to participate in our survey about this newsletter's content, length, and frequency. Please fill out the five-minute survey so we can better tailor topics to meet your needs. Then enter to win a \$50 Amazon gift card. [Take the survey.](#)

## Family Engagement

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### From Family Voices – Promising Practices in Partnering with Diverse Families

Family-identified practices that effectively support families from underserved racial, ethnic, and rural communities are the subject of issue briefs from the Promising Practices initiative at the National Center for Family Professional Partnerships. The briefs offer information that organizations can incorporate in their work to become more culturally competent and better able to reach and serve families from diverse backgrounds. [Read more.](#)

### Trainings to Build Partnership Skills

Two upcoming trainings will help family leaders and professionals in Maternal and Child Health Bureau Regions 9 and 10 build skills to work collaboratively. Both trainings will be held at Support for Families of Children with Disabilities in San Francisco. They are sponsored by Family Voices National Center for Family/Professional Partnerships and the Statewide Parent Advocacy Network. There is a lunch fee for each training. [Read more and register.](#)

## Serving on Groups

**Date**      Wednesday, March 21  
**Time**      9 a.m. to 5 p.m. Pacific Time

**Details** A workshop targeted to family-led organizations that build leadership skills of families who want to serve on a decision-making group.

### Leading by Convening

**Date** Thursday, March 22

**Time** 8:30 a.m. to 4 p.m. Pacific Time

**Details** An interactive workshop targeted to leaders of groups such as Title V directors or their designees.

### Research

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## Pediatric Long-Term Care Program Prepares Patients and Families for Home

Blythedale Children's Hospital in New York last year opened a long-term care pavilion to address the specialized needs of children who require extended medical care and rehabilitation. The goal is "take the 'long' out of long-term care" and reunite children with families who are prepared to care for them. [Read about the program's results.](#)

### National Policy

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## Bill to Watch

[Senate Bill 2227](#), known as the EMPOWER Care Act, seeks renewed funding for the Medicaid "Money Follows the Person" program that helps individuals with disabilities move out of institutions into their own homes. Funding is running out for the program, which was established in 2005. [Read more.](#)

### Special Education

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## Study: Youth in Special Education and Their Preparation for Life after High School

A large-scale study by Mathematica Policy Research found that over the past decade, high school youth participating in special education became more engaged in school and increased their use

of school supports. At the same time, these youth are less likely than in the past to take some key steps to prepare for their transition to adult life. [Read more](#).

## Viewpoint

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- [Why Black Disability History Matters during Black History Month](#) – from Ramp Your Voice!

## Resources

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- [Understood](#) – personalized resources, free daily access to experts, practical tips, and more for learning and attention issues.
- *Exceptional Parent Magazine* February issue – [Diet & Nutrition](#).
- [National Center for Complex Health and Social Needs](#) – Helping Communities Improve Care for People with Complex Health and Social Needs

## Did You Know?

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### New Data on Children with Special Needs in CA

Kidsdata has updated information on children with special health care needs. [Find the latest data](#) on children with major disabilities by legislative district and by county, city, and school district. Also available are data on special education enrollment by disability and race/ethnicity, the number of active California Children's Services (CCS) enrollees by age group, and insured/uninsured children.

## Webinars

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# Pediatric Palliative Care Series: Kids Need Care Too! Developing Collaborations, Competencies and Confidence to Care for Kids

**Date** Tuesday, March 20

**Time** 12 p.m. to 1 p.m. Pacific Time

**Sponsor** Coalition for Compassionate Care of California

**Details** Fee; 1 CEU available for nurses and social workers. Communities across the country are facing a shortage of pediatric nurses and social workers needed to adequately address the needs of children for hospice and palliative care services. This webinar will provide practical and evidence-based information and resources on how agencies and their staff can increase competencies and confidence in providing pediatric palliative care. [Register](#).

## In the News

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- [What Life Is Like for Kids with Rare Genetic Conditions](#)  
*Today's Parent, 2/28/18*
- [Trump Directive Spurs Proposal to Delay IDEA Rule](#)  
*Disability Scoop, 2/27/18*
- [California Special Needs Students Would Be Allowed to Use Medical Marijuana in School Under New Legislation](#)  
*LA Times, 2/15/18*
- [Trump's 2019 Budget: What He Cuts, How Much He Cuts, and Why It Matters](#)  
*Vox, 2/12/18*

### We'd like to hear from you

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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.

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