

California Advocacy Network

for Children with Special Health Care Needs

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

Children with Medical Complexity

Coming Up: A Conversation on Protecting the Rights of Children with Medical Complexity in an Era of Spending Reduction

The sixth in our series on [Building Systems that Work for Children with Complex Health Care Needs](#), this conversation will focus on how medical-legal partnerships and other forms of advocacy can protect children's rights to receive appropriate and timely services. Jane Perkins, JD, MPH, legal director of the National Health Law Program, and other experts will discuss the *Pediatrics* article [Protecting Rights of Children with Medical Complexity in an Era of Spending Reduction](#).

Date Thursday, September 20
Time 11 a.m. to 12 p.m. Pacific Time
Sponsor The Lucile Packard Foundation for Children's Health
Details [Register](#).

California Children's Services

Event: Raising the Bar – California Children's Services and Continuous Quality Improvement

Date Thursday, October 4
Time 8 a.m. to 4:30 p.m. Pacific Time
Location The California Endowment
2000 Franklin Street, Oakland

Sponsors Children's Regional Integrated Service System (CRISS), CCS Executive Committee, Family Voices of California, and the Children's Specialty Care Coalition

Details This conference will provide information on successful and feasible strategies for improving local care delivery for children and youth with complex medical conditions in the CCS program. Details and registration material will be available soon.

Viewpoint: Experimental State Health Program May Hurt Medically Fragile Children, Including Me



A first-person account from CCS client JC Aguirre III about the challenges involved with transferring CCS children to Medi-Cal managed care under the [Whole-Child Model](#). Published in the California Health Report on September 4. Read his [opinion piece](#).

Family Engagement

A Mother's Quest to Empower Parents

A New Jersey mother first advocated for her medically compromised son in his early childhood years, then went on to a career helping other parents as they navigate confusing systems and pursue the medical care and other services their children need. [Read her story](#) and learn how New Jersey strives to empower parents.

Also see: [How to Advocate](#) – A short video featuring personal testimonials – from The Arc

Care Coordination

Expanding Care Coordination to Promote Children's Health, Development and Well-Being

The Connecticut Children's Center for Care Coordination uses cross-sector care coordination to support families during times of crisis, connect them to services across sectors, and empower them to ensure their children reach their fullest developmental potential. The center serves children with special health care needs, but also those whose development may be affected by

social determinants such as poverty. [Read about](#) how the center transformed its delivery of care coordination by implementing a family-centered approach to health and well-being.

Funding Opportunity

Challenge: Care Coordination for CSHCN

The federal Maternal and Child Health Bureau is sponsoring a competition to support the development and testing of low-cost, scalable technological innovations to meet the information needs of families and case managers involved with care coordination for children with special health care needs. The deadline for submitting a Phase 1 application is **October 30**. [Find out more](#).

Also See: [Realizing the Promise of Telehealth for Children with Special Health Care Needs](#)

California Policy

- [California Lawmakers Pass Limits on Restraint and Seclusion in Schools](#) – from EdSource

National Policy

- [Lawsuit Threatens Affordable Care Act Preexisting Condition Protections but Impact Will Depend on Where You Live](#) – from The Commonwealth Fund
- [Kavanaugh Won't Say If He'll Uphold Obamacare Preexisting Conditions Protections](#) – from Huff Post

Transition to Adult Care

Webinar: Transitioning Adolescents into Adult Care

Date Tuesday, September 25

- Time** 12 p.m. to 1 p.m. Pacific Time
- Sponsor** Coalition for Compassionate Care of California, Pennsylvania's Pediatric Palliative Care Coalition, and Greater Illinois Pediatric Palliative Care Coalition
- Details** An introduction to health care transition to adult care. Speaker is Parag Shah, MD, MPH, Medical Director, Chronic Illness Transition Program at the Ann & Robert H. Lurie Children's Hospital of Chicago. Fee. CEU available. [Register](#).

In Brief

- [Navigating the Transition from High School to College for Students with Disabilities](#) (PDF) – from the California Employment Consortium for Youth (CECY)

Special Education

- [Federal Appeals Court Rules in Favor of Mainstreaming](#) – from Disability Scoop
- [Study: Minorities Labeled Learning Disabled Because of Social Inequalities](#) – from U.S. News & World Report

Resources

- [Respite Care Notebook](#) – A tool that families can use to guide respite care providers in caring for a child with special health care needs – from the Child Neurology Foundation
- *Complex Child* September issue: [Care at Home](#)

Event

Association of University Centers on Disabilities Conference

- Date** November 14-19
- Location** Washington, DC
- Details** Registration is now open for the conference, whose theme is *We ALL Belong Here! Achieving Inclusive Communities*. Fee. [Read more and register](#).

In the News

- [Insulin's High Cost Leads to Lethal Rationing](#)
NPR, 9/1/18
- [The Extra Layer of Back-To-School Anxiety When Your Child Has Special Needs](#)
Washington Post, 8/31/18
- [ADHD Diagnoses May Be Rising in U.S.](#)
Reuters, 8/31/18
- [Online Education Is a Disability Rights Issue](#)
Inside Higher Ed, 8/29/18

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.

This email was sent by:
Lucile Packard Foundation for Children's Health
400 Hamilton Ave, Suite 340 Palo Alto, CA, 94301,
USA

