

California Advocacy Network

for Children with Special Health Care Needs

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

Family Engagement

Webinar: A New Approach to Assessing Family Engagement in Health Care Systems

Date Wednesday, January 23
Time 10 a.m. to 11 a.m. Pacific Time
Sponsor Lucile Packard Foundation for Children's Health
Details Health care providers, payers, and systems serving CSHCN increasingly focus on family engagement as a strategy to improve health care delivery, enhance consumer and provider satisfaction, and reduce costs. Assessing how well an organization or agency is engaging families is a critical step in achieving these goals. A 2018 issue brief from Family Voices, [A Framework for Assessing Family Engagement in Systems Change](#), proposes four domains of family engagement. This webinar will explore the framework, share models of success, and discuss common barriers to incorporating meaningful family engagement in systems-level initiatives. [Register](#).

Parent Survey: Most Valuable Components of a Medical Home

Providing care in a pediatric medical home results in improved health outcomes for children, increased satisfaction for families, and decreased cost of care. According to the American Academy of Pediatrics, a medical home should be accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective. A new issue brief from the Lucile Packard Foundation for Children's Health reports on a statewide survey of parents in California who responded to questions about which of these medical home components they most value, and how satisfied they are with the care their child receives. [Read the issue brief](#).

Also See: [Access to the Medical Home Among Children with and without Special Health Care Needs](#) – A video abstract of a study published in *Pediatrics*.

Children with Medical Complexity

Webinar: Introducing the Blueprint for Complex Care: Opportunities to Advance the Field

Date Tuesday, January 22
Time 11 a.m. to 12 p.m. Pacific Time
Sponsor National Center for Complex Health and Social Needs
Details Presenters will outline the goals of the [Blueprint for Complex Care](#), discuss how it was developed, and outline recommendations for building the field. Two experts will provide ground-level perspectives on the *Blueprint's* recommendations. [Read more and register](#).

Also See: [Highlights](#) from the third annual "Putting Care at the Center" conference, including a panel on the *Blueprint*.

In Brief

- [Transforming Care Delivery and Payment for Children with Medical Complexity](#) – A guest post in *Health Affairs* by Mark Wietecha, President and CEO of the Children's Hospital Association.
- [Complex Care Management Resources](#) – A website from the Oregon Pediatric Improvement Partnership that highlights useful information from across the country.

Quality Standards/System Improvement

Online Toolkit Available for Using the National Standards for Systems of Care for CYSHCN

The National Standards for Systems of Care for Children and Youth with Special Health Care Needs (CYSHCN) define a comprehensive, coordinated and family-centered system of care for CYSHCN, who make up 20 percent of US children. A toolkit provides links to critical tools, fact sheets and resources that states can use to design, strengthen and improve health care systems serving CYSHCN and their families. See the [toolkit](#).

Network News

A Look Back at 2018



Children with medical complexity (CMC) were the focus of much of the work of the Lucile Packard Foundation for Children's Health in 2018, including a sponsored *Pediatrics* supplement and a series of eight webinars on topics related to CMC. Family engagement in shaping systems of care also received increasing attention, and a major report examined why there are long delays in securing needed medical equipment and supplies for children with special health care needs. Take a look to see what you may have missed.

Fact Sheet

- [Five Top Tips for Engaging Families in Advisory Roles: Advice from a Family Leader](#)

Issue Briefs

- [A Better Way: Team Care for Children with Special Health Care Needs](#)
- [A Framework for Assessing Family Engagement in Systems Change](#)
- [How California Children's Services Programs in the 21 Whole-Child Model Counties Engage with Families](#)
- [Improving Chronic Care for Children in California: Learning from Medicare](#)

Reports

- [Achieving Care Integration for Children with Medical Complexity: The Human-Centered Design Approach to Care Coordination](#)
- [The National Standards for CYSHCN: A Compendium of National Data and Quality Measure Sets](#)
- [Recommendations for Value-Based Transition Payment for Pediatric and Adult Health Care Systems](#)
- [A State Multi-Sector Framework for Supporting Children and Youth with Special Health Care Needs](#)
- [Threading the Labyrinth: Why Children in California with Special Health Care Needs Endure Delays in Securing the Medical Equipment and Supplies They Need](#)
- [Aligning Services with Needs: Characterizing the Pyramid of Complexity Tiering for Children with Chronic and Complex Conditions](#)
- [How Interagency, Cross-Sector Collaboration Can Improve Care for CSHCN: Lessons from Six State Initiatives](#)

Supplement/Webinars

- [Pediatrics Supplement, "Building Systems that Work for Children with Complex Health Care Needs"](#)
- [Building Systems that Work for Children with Complex Health Care Needs](#) – A series of eight webinars based on the *Pediatrics* supplement.

Newsletters

- [Archived Network Newsletters](#)

California Children's Services

CCS Advisory Group to Meet

Date Wednesday, January 9
Time 10 a.m. – TBD Pacific Time
Location 1700 K St, Sacramento – First Floor Conference Room
Dial-In (888) 989-6488; Passcode: 1945234
Details Assistive services are available for those who require them. See the [website](#) for details and the meeting agenda and materials.

Resources

From a Mother/Physician: Tips for Doctors Who Care for Patients with Disabilities

Cori Poffenberger, MD, is a physician in the Stanford Department of Emergency Medicine with three children under age 6. Though she is a second-generation clinician, neither she nor her father, a retired general surgeon, received instruction in medical school on how to treat patients with disabilities. She has made it a personal mission to transform how physicians approach inclusion and accessibility, and she recently shared her [tips for physicians](#) in *Stanford Scope*.

Also See: [What This Doctor Realized When His Son Was Diagnosed with Cancer](#)

In Brief

- [Exceptional Parent Magazine](#) December issue – [Holiday Edition: Family and Community](#)

National Policy

Bill to Watch: ACE Kids Act Pending in Senate

The House has passed and the Senate now is considering [HR 7217](#), the Improving Medicaid Programs and Opportunities for Eligible Beneficiaries Act (IMPROVE Act). The bill includes a revised version of the Advancing Care for Exceptional Kids Act (ACE Kids Act) that would allow a state Medicaid program or child health plan to provide coordinated care in health homes for children with complex medical conditions, even allowing enrollment across state lines. HR 7217 also includes a three-month extension of the "Money Follows the Person" program, which helps people transition from institutional to community-based care.

In Brief

- [Update on Early and Periodic Screening, Diagnostic and Treatment \(EPSDT\) Litigation Trends](#) – from National Health Law Program (NHLP)

Webinar

Who's on Your Team? Connecting Your Goals with Great People

Date Tuesday, January 15
Time 10 a.m. to 11 a.m. Pacific Time
Sponsor University of New Hampshire Institute on Disability
Details A webinar for students with and without disabilities, from eighth grade through college, and the people who work with them. Students will identify the people they need to help them reach their long-term goals, and will develop an action plan to help them put together a team of supportive people. (closed captioned) [Read more and register](#).

In the News

- [Super Caring Parents – Exhibit at Sutter County Library Highlights the Caregivers of Children with Special Needs](#)
Appeal Democrat, 12/27/18
- [How to Plan Your Retirement When You Have Children with Special Needs](#)
Market Watch, 12/12/18
- [Who Cares for Volunteer Caregivers When They Get Sick?](#)
Washington Post, 12/11/18
- [Drugmaker to Sell Cheaper Generic Rival to EpiPen Injectors](#)
Modern Healthcare, 12/7/18
- [What Is a Pediatric Palliative Care Team? Your Partner in Hope.](#)
U.S. News & World Report, 12/4/18
- [Dancing Doctor Brings Joy to Seriously Ill Children](#)
You Tube, 9/12/18

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@jpcf.org with your news or updates.

