

California Advocacy Network

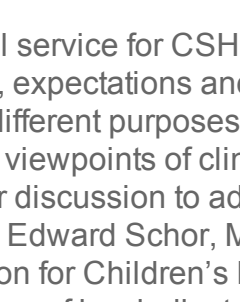
for Children with Special Health Care Needs

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

Note – The next Newsletter is scheduled for publication on January 3, 2019. Our best wishes for a peaceful holiday.

Care Coordination

Ten Essential Principles for Effective Care Coordination



Care coordination is a critical service for CSHCN and their families, but there are multiple definitions, expectations and approaches to its provision. These variations reflect the different purposes for which care coordination is intended, and the differing viewpoints of clinicians, consumers and payers. 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](#) appears in *JAMA Pediatrics* (subscription required).

California Children's Services

Whole Child Model Transition Coming in January; Family Voices Helpline Available

The Department of Health Care Services (DHCS) is preparing to implement the transition of children from CCS to Medi-Cal Managed Care on January 1 in counties served by Partnership HealthPlan. The counties are Del Norte, Humboldt, Lake, Lassen, Marin, Mendocino, Modoc, Napa, Siskiyou, Shasta, Solano, Sonoma, Trinity, and Yolo. Details are available on the DHCS [website](#). Family Voices of California is working with the Department to offer support for families who are navigating their child's move. Families who need information or assistance may email Ali Barclay at abarclay@familyvoicesofca.org or call the free helpline at (888) 387-0393. [Read more](#).

Also See: A [provider notice](#) (PDF) for CCS Panelled Providers outlining information about program eligibility, service authorization requests, continuity of care, claims submission, and more.

CCS Advisory Group to Meet

Date Wednesday, January 9
Time 10 a.m. – TBD
Location 1700 K St, Sacramento – First Floor Conference Room
Dial-In (888) 989-6488; Passcode: 1945234

For those unable to attend the meeting, comments may be submitted to CCSRedesign@dhs.ca.gov by **Wednesday, January 2, 2019**. All submitted comments will be read during the public comment portion of the meeting. Assistive services are available for those who require them. See the [website](#) for details and the meeting agenda and materials.

Family Engagement

Call for Presentations: National Family Voices Leadership Conference

Families as Partners Shaping Systems Change is the theme of the 2019 Family Voices Leadership Conference, which will bring together family and youth leaders, family members, professional partners, and other stakeholders from across the country in May in Washington, DC. Attendees will share resources and expertise, explore ways to improve supports to families, learn new strategies for managing nonprofits, and increase capacity for families to partner in systems change. Family Voices is seeking [proposals for presentations](#), which are due **January 15, 2019**. Contact Beth Dworetzky at bdworetzky@familyvoices.org with questions.

Children with Medical Complexity

CARE Award Webinar: Family Partners for Better Care

Date Tuesday, December 18
Time 11:30 a.m. to 1 p.m. Pacific Time
Sponsor Children's Hospital Association
Details This webinar, the last in a four-part [series](#) on improving care for children with medical complexity, will focus on how families are essential partners in providing better care for their children. Children's National Health System will discuss development of a parent navigator model and use of telehealth for virtual home visits. Children's Hospital Colorado will explore understanding the care needed and integrating social risk assessment into family profiles. [Read more and register](#).

See [related papers](#): *Invoking the Power of Family Partnerships* and *10 Vital Actions for Effective Family Partnerships*.

Blueprint for Complex Care Released

Blueprint for Complex Care, a guide that assesses the current strengths and weaknesses of the complex care field and presents actionable recommendations, has been released by the National Center for Health and Social Needs, the Center for Health Care Strategies, and the Institute for Healthcare Improvement. Though focused on adults, it has applicability for children with medical complexity. [Read the blueprint](#).

In Brief

- [Delays in Discharge of Children with Complex Health Care Needs: What Causes Them and How Bad Are They?](#) – Results of a study, published in *Pediatrics*, of 185 children discharged from four children's hospitals in Minnesota. Lack of availability of home care nursing was identified as a major reason for long delays in discharge.

Also See: [Improving Pediatric Hospital Discharge Care for Children and Families](#)

Quality Standards/System Improvement

Archived Webinar: The Systems of Care that Serve Children and Youth with Special Health Care Needs

Children with special health care needs have exceptional and often long-term health, educational, developmental, and social service needs, which are extensive and expensive to deliver. This webinar examines the programs, practices and systems that have evolved to meet the needs of these children and their families. It was sponsored by the Children's Hospital Los Angeles and the University of Southern California. [Recording and slides are now available](#). (Please note: There are several minutes of silence at the beginning. Skip to 15:47 for the start of the webinar.)

In Brief

- [Strengthening Health Care Delivery Systems for Children with Special Health Care Needs and the Role of Quality Measurement](#) – Archived webinar from November 28, sponsored by National Academy for State Health Policy (NASHP)

Viewpoint

Health Care in America: Listening to People with Serious Illness

Individuals with serious or chronic illnesses in the United States benefit from many advanced treatments and services, but those services can come with physical, emotional and financial burdens for both the patient and the caregivers. Some of these burdens result from the choices made by policymakers, practitioners, payers, and others. The New York Times, the Commonwealth Fund, and the Harvard T.S. Chan School of Public Health recently surveyed nearly 1,500 Americans with serious illness and the friends or family members caring for them with the goal of understanding whether the health care system is doing all it can, not just to treat illness but to help people cope with illness. See [Healthcare in America: The Experience of People with Serious Illness](#) and [Being Seriously Ill in America Today](#) (PDF), and the archived webinar [Being Seriously Ill in the US: Financial and Healthcare Impacts](#).

National Policy

Last Call for Health Insurance Sign-up

Open enrollment for 2019 health insurance through the Affordable Care Act ends December 15 in most states (January 15 in [California](#)). Check your local information at healthcare.gov.

Bill to Watch

- [House Passes ACE Kids Act Aimed at Improving Care Coordination](#) (HR 7217) – The House passed 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. The legislation is designed to simplify care coordination for families and save states money. 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. Advocacy groups are encouraging stakeholders to [urge their Senators](#) to take up the legislation immediately.

Resources

- *Complex Child* December issue: [Sensory and Behavioral Issues](#)
- [Respite Care Notebook](#) – As the holidays approach, a reminder about this family resource.
- [Providing People with Disabilities Greater Financial Security](#) (PDF) – A fact sheet about CalABLE, the California program that allows people with disabilities to establish a tax-advantaged savings account and save up to \$15,000 per year and up to \$100,000 in total without losing vital public benefits. ABLE Accounts are available [nationally](#).

Webinars

Communicating Your Organization's Commitment to Disability Inclusion

Date Thursday, December 20
Time 10 a.m. to 11 a.m. Pacific Time
Sponsor Employer Assistance and Resource Network on Disability Inclusion
Details Speakers will explore strategies organizations can use to effectively communicate a commitment to disability inclusion, both externally and internally. Aimed at anyone involved in an organization's internal or external communications, including human resources, diversity and inclusion, and corporate communications professionals. [Register](#).

In the News

- [Daughter's Diagnosis Inspires Mom to Create Health Matchmaking Service](#)
Healthline, 12/5/18
- [Ed Department Reopening Hundreds of Disability-Related Complaints](#)
Disability Scoop, 12/3/18
- [Medical Detectives: The Last Hope for Families Coping with Rare Diseases](#)
KQED, 12/3/18
- [To Find Jobs for Those with Intellectual Disabilities, Parents Get Creative](#)
Disability Scoop, 11/30/18
- [Caring for Children with Severe Disabilities Financially Devastates Tennessee Families](#)
Tennessean, 11/26/18

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.

