

California Advocacy Network

for Children with Special Health Care Needs

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

Care Coordination

Under Development: National Care Coordination Standards for Children with Special Health Care Needs

The benefits of providing care coordination to children with special health care needs and their families are well recognized, yet the availability and quality of care coordination services vary widely across the country. The National Academy for State Health Policy (NASHP), with funding from our Foundation and in collaboration with a broad-based National Care Coordination Standards Work Group, is developing voluntary standards designed to help states create high-quality care coordination programs. [Read more.](#)

Children with Medical Complexity

National Complex Care Conference Includes Pediatrics; Early Bird Registration Ends Soon

It Takes an Ecosystem: Complex Care Across the Community is the theme of Putting Care at the Center 2019, a conference hosted by the National Center for Complex Health and Social Needs and Regional One Health. While most attention to complex care has focused on adults, many aspects of identification, management, and financing also apply to children. Colleen Reuland, director of the [Oregon Pediatric Improvement Partnership](#) and a Foundation grantee, will speak at a workshop that explores trends in pediatric assessments, care planning, and quality measurement and their relevance to adult health. Early bird registration is available until **August 31** for the conference, scheduled for November 13-15 in Memphis. Fee. [Read more and register.](#)

In Brief

- [Re-envisioning Care for People with Involved Disabilities](#) – Four videos from [The Better Care Playbook](#) focus on the independent living model for adults but contain relevant information for children and youth.

Family Engagement

Federal Family Caregiving Advisory Council to Hold Inaugural Meeting

A federal law passed in 2018 requires the Department of Health and Human Services to develop a national strategy to support family caregivers. As part of implementing the strategy, the law also requires establishment of a Family Caregiving Advisory Council to make recommendations on effective caregiving models and ways to improve coordination across federal programs. The first public meeting of the RAISE (Recognize, Assist, Include, Support, and Engage) Family Caregiving Advisory Council is scheduled for August 28-29 in Washington, DC. The meeting also will be [live streamed](#) for those unable to attend. [Find details about the Council and the meeting.](#)

California Children's Services

New Contact for Whole Child Model Assistance at Family Voices of California

Family Voices of California provides fact sheets, webinar slides, and other information to help families navigate the transition from CCS coverage to Medi-Cal managed care. See the [website](#), call the free helpline at (888) 387-0393, or write to Jacqui Knudsen at jknudsen@familyvoicesofca.org.

Pediatric Palliative Care

- [Pediatric Palliative Care Focusing on Helping Patients Live Best Life](#) – An article from the American Academy of Pediatrics discusses how palliative care is shifting from preparing for end of life to helping patients live well with chronic illness.

National Policy

Proposed 'Public Charge' Rule Draws Strong Opposition

The federal government has finalized proposed changes to its definition of "public charge," with a scheduled implementation date of October 15. The new rule greatly expands the government's ability to label legal immigrants who are not yet citizens as financially dependent on the government. The changes have major implications for families and for immigration. Child and family advocates overwhelmingly oppose the proposed rule, and some states already have filed legal challenges. [Read more.](#)

Also See:

- [The New 'Public Charge' Rule Affecting Immigrants Has Major Implications for Medicaid and Entire Communities](#) – from The Commonwealth Fund
- [As Families Drop Health Benefits Over 'Public Charge' Rule, Clinics Scramble to Respond](#) – from California Health Report

California Policy

Opportunity to Serve on Medi-Cal Children's Health Advisory Panel

The Department of Health Care Services (DHCS) is accepting applications to fill a vacancy on the [Medi-Cal Children's Health Advisory Panel](#) (MCHAP). Individuals may apply if they are a parent, foster parent, relative caregiver, or legal guardian of a Medi-Cal enrollee who is 21 or younger. MCHAP advises DHCS on policy and operational issues that affect children in Medi-Cal, including children with special health care needs. Interested applicants should submit their [Statement of Interest](#) (PDF) and resume to MCHAP@dhcs.ca.gov by **September 6**.

Applicants Sought for Developmental Services Task Force

September 3 is the deadline to apply to serve on the Developmental Services Task Force, whose goal is to strengthen community services for people with developmental disabilities. Individuals also may serve on workgroups that focus on issues such as service access and equity and system and fiscal reform. [Read more and apply.](#) (PDF).

Bill to Watch

- [AB 744 Health Care Coverage: Telehealth](#) – This bill would require health plans to reimburse telehealth services at the same rate and to the same extent that they reimburse for in-person diagnosis, consultation, or treatment. Bill is currently in committee process.

Special Education

- [How to Leverage Mainstream Technology to Boost Special Education](#) – from EdTech

Resources

- [Addressing the Needs of People with Disabilities in Public Health Emergencies](#) – Webinar slides from the Centers for Disease Control and Prevention address how community leaders, community members, emergency response workers, and caretakers can plan ahead to lessen the harm for people with disabilities in emergencies.
- *Exceptional Parent Magazine* August Issue – [Healthcare](#)

Webinar

Highlighting Advocacy Tools to Share with Your Community

Date Tuesday, August 27
Time 12 to 1 p.m. Pacific Time
Sponsors National Genetics Education and Family Support Center (Family Center) and Genetic Alliance
Details Finding details about genetic services and related health care resources can be difficult and overwhelming, often leading to a delay in getting the information that is needed. This discussion will highlight educational resources and the ways that patients, providers, families, and caregivers utilize these tools. [Register.](#)

In the News

- [IEP Meetings Warrant Time Off from Work, Labor Department Says](#)
Disability Scoop, 8/16/19
- [Agency Did Not Conduct Required Oversight of Program for Those with Disabilities](#)
Washington Post, 8/13/19
- [At This Summer Camp, Struggling with a Disability Is the Point](#)
Kaiser Health News, 8/13/19
- [US Military Families Face Challenges Getting Healthcare for Kids](#)
Reuters, 8/5/19
- [Opinion: A Quiet Healthcare Crisis in Dentistry](#)
Washington Examiner, 8/5/19
- [For People with Disabilities, Finding Clothing That Is Stylish and Meets Their Needs Is Getting Easier](#)
Washington Post, 8/3/19

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.

