

California Advocacy Network

for Children with Special Health Care Needs

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

Caregiving

Family Caregiving Advisory Council to Meet

The federal Family Caregiving Advisory Council, established by the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act, is charged with providing recommendations to the Secretary of Health and Human Services on effective models of both family caregiving and support to family caregivers, as well as improving coordination across federal government programs. The Council will hold a webinar on February 11 and 12. [Find details](#) (right column).

Related: February 7 is the last day to [submit feedback](#) to the Council about family caregiving challenges.

Webinar: Family Caregiving Policies and Innovations

Date Thursday, February 20
Time 11 a.m. Pacific Time
Sponsor NASHP's RAISE Family Caregiver Resource and Dissemination Center
Details Family caregivers are critical to helping children with complex needs stay in their homes and communities. This webinar will cover state and federal policies and initiatives to support family caregivers. It also will provide an overview of the RAISE Family Caregivers Act, and will feature state leaders from Tennessee and Washington who will share their policies and innovations to support family caregivers. [Read more and register](#).

Viewpoint

A Roadmap to Emotional Health for Children with Chronic Pediatric Conditions and Their Families

A new article in *Pediatrics* tracks the development of a Roadmap initiative funded by the American Board of Pediatrics to increase the resilience and emotional health of children with chronic conditions and their families. The authors – a parent and health providers – note that many of these families navigate a host of extremely challenging issues that often cause anxiety, depression and stress, yet many clinicians are not comfortable asking pediatric patients and their caregivers about their mental health. The Roadmap is a joint effort with families to address these issues. [Read the article](#) and learn about available resources.

Children with Medical Complexity

Call for Proposals: Pediatric Complex Care Association's Annual Conference

The Pediatric Complex Care Association has issued a call for proposals for its annual educational conference scheduled for October 14-16 in San Antonio, Texas. The deadline for submission is **February 25**. [Read more and apply](#).

Family Engagement

Webinar: Regional Centers – Self-Determination

Date Wednesday, February 19
Time 12 to 1 p.m. Pacific Time
Sponsor Family Voices of California
Details Regional Center clients soon will have the option to switch to "Self-Determination." Currently, Regional Center client plans are written and fulfilled by caseworkers. Under Self-Determination, clients are given their own budgets to pay whomever they wish for whichever sets of supports they feel are required. [Read more and register](#).

Care Coordination

Insure the Uninsured Conference to Feature Session on Children

Coordinating care and services for children is among the items to be addressed at *Taking Bold Steps in Uncertain Times*, the annual conference of the Insure the Uninsured Project, scheduled for February 24-25. Speakers will include representatives from the California Children's Hospital Association and the National Health Law Program. [Read more](#).

California Children's Services

New Chief for Department of Health Care Services

Bradley P. Gilbert, MD, MPP, has been appointed director of the Department of Health Care Services, which oversees California Children's Services and Medi-Cal, both of which provide important services for children with complex, chronic conditions. [Read about Dr. Gilbert](#).

In Brief

- [Children Who Need Wheelchairs and Other Medical Equipment Often Wait Months or Years Because of Byzantine State System](#) – from the California Health Report

Also See: [Helping Families Obtain Durable Medical Equipment and Supplies through the California Children's Services Program](#)

National Policy

A Lawsuit over Early and Periodic Screening, Diagnostic, and Treatment Program

The National Health Law Program (NHeLP) has filed an amicus brief in a Massachusetts lawsuit related to the question of whether Medicaid's Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) program requires timely treatment after screening and diagnosis. The American Academy of Pediatrics, the National Center for Youth Law, and other advocacy groups joined in the brief. [Read more](#).

Leading Children's Health Groups Oppose Medicaid Changes

The American Academy of Pediatrics and other leaders in children's health have banded together to push back against recently announced guidance from the Centers for Medicare and Medicaid Services. The changes would fundamentally alter how Medicaid is financed by capping federal funding and offering states the option to use block grants and per capita caps for low-income adult populations. In a joint statement the organizations note that when parents lose coverage, their children are more likely to lose coverage as well, putting their health at risk. Medicaid is a fundamental service for CSHCN and their families. [Read the statement](#).

In Brief

- [Social Security Administration Launches a Stealth Assault on Medicaid Coverage for Children and Parents with Disabilities](#) – from Georgetown Center for Children and Families

- [Public Charge Update: What Advocates Need to Know Now](#) – from Protecting Immigrant Families, as of February 5.

Pediatric Palliative Care

Webinar: Burnout – Can Compassion Fatigue?

Date Tuesday, February 18
Time 12 to 3 p.m. Pacific Time
Sponsor Stanford Medicine
Details Using emerging research from nurses who volunteer at a camp for children with cancer, this session will guide participants in discovering ways to alleviate moral distress. It will examine whether it is compassion that fatigues medical professionals when they are on the brink of burnout, leaving them to ponder the question, "If everyone is burning out, who will care for the children?" CME available. Fee. [Register](#).

Resources

- *Complex Child* February Issue: [Annual Feeding Tube and GI Edition](#)
- [Children and Youth with Special Healthcare Needs in Emergencies](#) and [en Español](#) – from the Centers for Disease Control and Prevention

Webinars/Podcasts

ABLE, the IRS and Tax Advantages – What You Need to Know

Date Thursday, February 13
Time 11 a.m. Pacific Time
Sponsor ABLE National Resource Center
Details ABLE is a program to allow tax-advantaged accounts for individuals with disabilities. This webinar will explain how to maximize your ABLE savings, qualify for tax credits, which may result in tax savings, and access free tax preparation services. [Read more and register](#).

From Awareness to Action: Strategies for Combating Racism in Health Systems

Date Thursday, February 13
Time 12 to 1 p.m. Pacific Time
Sponsor National Institute for Children's Health Quality
Details This webinar addresses the stark racial disparities in health outcomes for moms and babies and the disturbing differences in care that families of color have received. Speakers will focus on providing strategies and guidance that individuals can use to identify and address racism and racial bias. [Read more and register](#).

In the News

- [Families Struggle to Find Child Care for Kids with Special Needs](#)
Disability Scoop, 2/4/20

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@pfch.org with your news or updates.

