

California Advocacy Network for Children with Special Health Care Needs

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

Family Engagement

Family Voices: New Tool to Assess Family Engagement

Family participation is essential for creating the policies and programs that shape the services children and families receive. Family Voices, with support from our Foundation, has created the Family Engagement in Systems Assessment Tool (FESAT) and Family Engagement in Systems (FES) Toolkit. Organizations can use the tool and toolkit to assess how well they engage families, improve family engagement over time, and guide the design of systems-level activities to ensure family engagement. [Read more, listen to an introductory webinar, and access the tools.](#)

Caregiving

Webinar: Genuine Resilience is Closer (and Easier) Than You May Think

Date Wednesday, January 29

Time 11 a.m. to 12 p.m. Pacific Time

Sponsor Family Caregiver Alliance

Details Resilience – the ability to rebound from difficult or traumatic experiences – is key to well-being. In the context of family caregiving, developing emotional skills for coping with stress is essential for long-term sustainability and quality care. This webinar will introduce ideas for coping with stress and provide simple practices caregivers can use to build resilience. [Read more and register.](#)

Final Weeks: Feds Seek Information about Family Caregiving Challenges

The national Recognize, Assist, Include, Support and Engage Family Caregivers Act (the [RAISE Act](#)) became law in January 2018. To help shape policy recommendations, the Department of Health and Human Services is asking individuals and organizations to submit information on the challenges faced by caregivers. Send your thoughts on this [form](#) by **February 7**.

Viewpoint

- [No, I'm Not an Amazing Mom Just Because My Child Has Special Needs](#) – The mother of a child with a rare neurological disorder reflects on her life and what she would appreciate from family and friends. From the *Washington Post*.

Network News

Reminder: Deadline Approaching for Grant Inquiries

Letters of Inquiry (LOI) for the Foundation's next grant cycle must be submitted by **February 12**. Potential applicants should carefully review our program goals, priorities, and restrictions before submitting an LOI. [See how to apply.](#)

California Children's Services

CCS Advisory Group Considers Range of Issues

An update on the Whole Child Model, along with discussions of the new Medi-Cal prescription process and the state's long-term plan for improving Medi-Cal, were on the agenda for the CCS Advisory Group meeting on January 15. See the group's updated [website](#) for the agenda and slides, along with a draft Whole Child Model Performance Dashboard. In response to a longstanding request for meeting minutes, the Department of Health Care Services has indicated that in the future it will provide reports after each Group meeting outlining the Department's promised commitments/actions. Contact CCSRedesign@dhcs.ca.gov with questions.

National Policy

Families Urged to Comment on Social Security's Proposal for More Frequent Documentation of Disability

The Social Security Administration (SSA) has [proposed a process](#) called Continuing Disability Reviews that could increase the frequency with which adults and children must prove that they have a disability. SSA is accepting comments on this proposal until **January 31**. The Arc urges families to [send in comments](#) on what they say can be an extremely complicated process for families.

In Brief

- [Supreme Court Refuses to Fast-track a Challenge to the Affordable Care Act](#)
SF Gate, 1/21/20
- [Trump Asks Supreme Court to Allow Public Charge Rule to Go Into Effect](#)
CNN, 1/13/20

Children with Medical Complexity

Feds Seek Comment on Coordinating Care from Out-of-State Providers for Children with Complex Conditions

The Centers for Medicare & Medicaid Services (CMS) is requesting public comment on coordinating care from out-of-state providers for children with medically complex conditions. Responses will inform efforts to craft guidance to state Medicaid directors. Specifically, CMS wants children and their families, states, providers (including children's hospitals and pediatricians), managed care plans, children's health groups, family and beneficiary advocates, and other stakeholders to give their perspectives. Comments are due by **March 23**. [Read more.](#)

Special Education

Why the Feds Still Fall Short on Special Education Funding

Education Week traces the history of the underfunding of the federal Individuals with Disabilities Education Act (IDEA), and notes that it may become an issue in the presidential campaign. [Read more.](#)

Also See: [HR 1878](#), the IDEA Full Funding Act, introduced in March 2019, and [Congress Hands Special Ed Hefty Funding Boost](#).

Pediatric Palliative Care

Posters Invited for Palliative Care Annual Summit

Health professionals interested in palliative care are invited to submit poster presentation proposals for the 2020 Summit of the Coalition for Compassionate Care of California, scheduled for May 5-6. The Coalition is a statewide collaboration of health care providers, consumers, government agencies, and others working to improve palliative and end-of-life care, including pediatric care. Proposals are due **January 31**. [Find details.](#)

Did You Know?

Data Sets and Codebooks Available for National Survey of Children's Health

The Data Resource Center has released the combined 2017-2018 National Survey of Children's Health [data sets](#) and [codebooks](#) through childhealthdata.org. The multi-year data set includes data from 52,129 children ages 0-17 years. Increased sampling over multiple years allows for more reliable national and state-level estimates, particularly for measures that are restricted to certain age ranges or subgroups, including children with special health care needs.

Webinar

Social Determinants of Health: Technology and Workforce Approaches

Date Monday, January 27

Time 10 to 11:30 a.m. Pacific Time

Sponsor National Institute for Health Care Management Foundation

Details Recognizing that addressing unmet social needs can have an outsized impact in improving health, leaders are leveraging technology and nonmedical professionals to address these issues. The webinar will explore current initiatives and innovations. Not CSHCN specific, but of possible interest. [Read more and register.](#)

In the News

- [FDA Misses Deadline to Ban Devices Used to Shock Those with Special Needs](#)
Disability Scoop, 1/20/20
- [Why People with Disabilities Deserve Better Than the 'Checkbox' Approach](#)
Center for Health Journalism, 1/10/20
- [Kids with Disabilities Have a Right to Outdoor Field Trips](#)
Sierra Health Club, 11/30/19

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.

