

California Advocacy Network

for Children with Special Health Care Needs

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

Family Engagement

From Family Voices: Tool Measures Level of Family Engagement, Offers Ideas for Enhancement

Though there is much agreement on the value of family involvement at the systems level of health care – where policies, programs, and services are created or changed – it is still rare for families to have more than a token amount of power and influence. A new issue brief from Family Voices provides a framework, featuring four domains and specific criteria, that organizations can use to measure and improve the level of family engagement in their work. [Read the Issue Brief](#).

California Children's Services

CCS Advisory Group Addresses Specialty Care, Other Whole-Child Transition Issues

On April 4, members of the CCS Advisory Group questioned state representatives on a range of subjects related to the upcoming transfer of some CCS children into Medi-Cal managed care, including the availability of pediatric specialty care in the selected counties, the future of coverage after the first year of transition, and family engagement with the plans. CalOptima, one of the managed care plans, made a presentation on how it is addressing stakeholder engagement. See the [agenda and slides](#) from the meeting. The state also has sent and posted the [90-Day Notice](#) (PDF) to families that explains how the transition will work and answers frequently asked questions.

Also See Related Opinion: [A CCS Client Says His County Health Plan Is Not Ready for the Whole Child Model](#) (PDF). The author is a 15-year-old student who has spoken at several

Sacramento hearings over the last two-and-a-half years in support of children who are clients of the California Children's Services Program.

Transition to Adult Care

Webinar: Transfer to Adult Care

Date Thursday, April 26
Time 12 p.m. to 1 p.m. Pacific Time
Sponsor Got Transition/Center for Health Care Transition Improvement
Details The third in a [five-part series](#), this webinar will feature examples of best practices among state Title V agencies, along with tools, resources, and problem-solving strategies. [Register](#).

Research

Children's Hospitals Explore Screening for Social Determinants of Health

Social determinants – such as food insecurity, homelessness, and lack of access to care – have a substantial effect on children's health and on outcomes for hospitalized children. The Children's Hospital Association has begun a process to define ways to implement screening of patients for social determinants and to find community resources to address them. [Read more](#).

California Policy

Medi-Cal Children's Health Advisory Panel to Meet

Date Thursday, April 19
Time 10 a.m. to 2 p.m. Pacific Time
Location 1414 K St, Sacramento – The California Endowment, 1st Floor Conference Room
Dial In 888-947-8923; Passcode 2475546
Details Agenda and meeting materials are posted on the panel [website](#). MCHAP is a 15-member independent statewide advisory body that advises DHCS on matters relevant to children enrolled in Medi-Cal.

Comments Sought on CSHCN Title V Funding

Every year the state completes a report and an application for funding through the federal Title V Maternal and Child Health Services Block Grant Program. One of the report sections covers goals for children with special health care needs. The [draft report](#) (PDF) is now available, and comments should be sent to CaliforniaTitleV@cdph.ca.gov by Friday, April 20.

State Responds to Break-in at Department of Developmental Services

On February 11 a break-in occurred at the Department of Developmental Services legal and audits office building in Sacramento. The Department has issued a [notice](#) explaining what happened and what consumers can do.

Resources

- [Seven Things Parents of Kids with Special Needs Hate, and Seven Ways to Be Supportive](#) – from the *Washington Post*
- [Center on Technology and Disability](#) – Free resources to increase the capacity of families and providers to advocate for, acquire, and implement assistive and instructional technology tools to improve children's quality of life.
- *Complex Child* April issue: [Spirituality](#)

Webinars

Pediatric Webinar Series: Perinatal Palliative Care

Date	Tuesday, April 17
Time	12 p.m. to 1 p.m. Pacific Time
Sponsor	Coalition for Compassionate Care of California
Details	Fee; 1 CEU available for nurses and social workers. This webinar will describe the challenges that have resulted from the ever-improving ability to diagnose problems in utero. Specifically, how to apply the principles of palliative care to effectively support a woman who learns her unborn child has a life-limiting condition. Register .

Measure What Matters: Advancing Multidisciplinary Care Coordination in Primary and Subspecialty Care Settings

- Date** Thursday, May 10
- Time** 9 a.m. to 9:45 a.m. Pacific Time
- Sponsor** National Center for Medical Home Implementation and the National Center for Care Coordination Technical Assistance
- Details** The first in a two-part series, this webinar will present real-world experiences from diverse health care providers with the common goal of capturing the value of care coordination using the [Care Coordination Measurement Tool](#) and its accompanying adaptation guide. [Read more and register.](#)

Employment Opportunity

The federal Health Resources and Services Administration (HRSA) seeks applicants for the position of Associate Administrator for the Maternal and Child Health Bureau. Apply by April 25. [Read details.](#)

Funding Opportunity

The American Association of People with Disabilities (AAPD) is offering eight NBCUniversal Tony Coelho Media Scholarships for the fall semester of 2018. The scholarships are available to undergraduates, graduate students, and high school seniors with disabilities who are pursuing an interest in the media, entertainment, or communications fields. Each recipient will receive \$5,625 to help cover the cost of education. [Read more.](#)

Event

2018 California School-Based Health Conference

- Date** May 17 to 18
- Location** Sheraton Grand Hotel, Sacramento, CA

Details Learn, grow, and connect with providers, educators, advocates, and other leaders in the school-based health care movement across the state. The conference will feature workshops for all levels of experience and engagement. [Read more and register.](#)

In the News

- [Federal Watchdog: Students with Disabilities More Frequently Disciplined](#)
Disability Scoop, 4/9/18
- [Justice Department Sued Over Rescinded Disability Guidance](#)
Disability Scoop, 4/6/18
- [Creative Growth's Special Needs Clients Seize the Limelight at Fashion Show](#)
SF Chronicle, 4/6/18
- [Twitter Adds Disability to Abuse Reporting Options](#)
Disability Scoop, 4/3/18
- [Addy & Uno: Musical Starring Characters with Disabilities Spreads Message of Kindness](#)
ABC, 4/1/18
- [Families Moving Across the Country to Help Their Kids with Disabilities](#)
Disability Scoop, 3/29/18

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.

This email was sent by:
Lucile Packard Foundation for Children's Health
400 Hamilton Ave, Suite 340 Palo Alto, CA, 94301,
USA

