

## California Advocacy Network for Children with Special Health Care Needs

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

### Children with Medical Complexity

#### Addressing the Home Health Care Crisis

Home health care is critical to many families of children with special health care needs, but the field is sorely in need of attention, according to experts who spoke at a Foundation webinar on October 23. The panelists noted that children frequently remain in the hospital long after they are ready for discharge because of a lack of home health care providers with pediatric expertise. The speakers discussed other issues that must be addressed, including pay discrepancies, lack of quality measures, need for pediatric training programs, and the focus on adult over pediatric home health care. They also outlined potential solutions. [Listen to the webinar and view the slides.](#)

#### In Brief

- See the [second-year annual report](#) (PDF) from [CYSHCNet](#), a federally funded national network designed to lead, promote, and coordinate research activities across the country to improve systems of care for children and youth with special health care needs and their families.

### Care Coordination

#### Webinar: Applications of Network Science to Strengthen Systems of Care for Children and Families

**Date** Monday, November 4  
**Time** 10 to 11 a.m. Pacific Time  
**Sponsor** Federal Maternal and Child Health Bureau  
**Details** Navigating complex systems of care is a struggle for children and youth with special health care needs and their families. Current approaches to improve the process overlook families' personal and community assets. A network science approach can demonstrate how to develop person-centered care navigation, coordination, and referrals for families in health care and community-based settings. [Read more and register.](#)

### Family Engagement

#### Project Leadership: Training of Trainers Workshop Offered by Family Voices of California

[Project Leadership](#) is a Foundation-supported advocacy and leadership training program designed to increase the number of family members of children with special health care needs/disabilities who are prepared and supported to become advocates for health care policy and service improvements. Staff and leaders of organizations serving families of CSHCN are invited to apply to attend a free workshop that will provide education on how to successfully implement Project Leadership training in their communities. For questions contact Elaine Linn at [elinn@familyvoicesofca.org](mailto:elinn@familyvoicesofca.org). Applications are due by **November 15**. [Read more and apply.](#)

#### Recording Available for Family-Professional Partnership Webinar



National Family Voices presented an October 10 webinar on *The Leadership in Family and Professional Partnerships Program: What It Is and How You Can Benefit*. The [recording and slides](#) now are available.

### Quality Standards

#### How States Use the National Standards to Improve Health Systems for CYSHCN

The [National Standards](#) for Children and Youth with Special Health Care Needs are used by many state health policy leaders to inform, structure, and improve quality systems of care and ultimately health outcomes for CYSHCN. New [charts and map](#) from the National Academy for State Health Policy (NASHP) highlight how states have integrated the Standards into their state Medicaid programs and state Title V Maternal and Child Health Services Block Grant Programs. Development and dissemination of the Standards is supported by our Foundation.

### Network News

#### Apply for a Foundation Grant: Letters of Inquiry Due

Our Foundation funds programs and projects that will contribute to improving systems of care for children with special health care needs and their families. We are accepting Letters of Inquiry (LOI) until Friday, **November 8**. We strongly recommend that potential applicants carefully review our program goals, priorities, and restrictions before submitting an LOI. [Read how to apply.](#)

### California Children's Services

#### Families Invited to Discuss Their Experiences Receiving Services under the Whole Child Model

Researchers at the University of California, San Francisco, will be conducting an evaluation of the Whole Child Model, the state program that moved CCS-covered children in some counties into Medi-Cal Managed Care plans. The researchers seek to interview parents or guardians about their experiences in getting care for their child through the Whole Child Model program. Interviews will last about an hour, can be in English or Spanish, will be conducted by phone, and will be confidential. Participants will receive a \$50 gift card to Safeway or Target. To find out if you are eligible, call the UCSF research team at 415-476-0483 or email them at [WholeChildEvaluation@ucsf.edu](mailto:WholeChildEvaluation@ucsf.edu). Read more in [English](#) (PDF) and [Español](#) (PDF).

Related: [Study Shows Lagging Quality Improvement in Medi-Cal Managed Care](#)

#### Obtaining Durable Medical Equipment: New Guidance for Navigating the CCS Program

Attorneys from the National Health Law Program (NHelp) have published an advocates' guide to help families obtain the durable medical equipment and supplies to which they are entitled. NHelp attorneys also discussed the guide and answered questions on a recent webinar. The work was funded by our Foundation. [Read the issue brief](#) (PDF) and [listen to the webinar recording](#) (registration required).

### Pediatric Palliative Care

#### In Brief

- [States Chart a Policy Path to Improve Palliative Care Services across the Care Continuum](#)  
*Health Affairs Blog, 8/13/19*

### California Policy

#### Medi-Cal for All Young Adults: A Webinar for and by Community Advocates

**Date** Tuesday, November 5  
**Time** 1 to 2 p.m. Pacific Time  
**Sponsors** The Children's Movement and multiple advocacy organizations  
**Details** Beginning January 1, 2020, a new law will allow young adults, up to age 26 and regardless of immigration status, to enroll in full-scope Medi-Cal. This webinar will provide information on program implementation, tips on working with immigrant communities, and more. [Register.](#)

### National Policy

#### In Brief

- [Can States Fill the Gap if the Federal Government Overturns Preexisting-Condition Protections?](#) – from The Commonwealth Fund
- [States Lead on Surprise Medical Billing Protections, Congress Poised to Follow](#) – from the National Academy for State Health Policy

### Telehealth

#### Webinar: Expanding Access to School Behavioral Services via Telehealth

**Date** Thursday, November 14  
**Time** 11 a.m. to 12 p.m. Pacific Time  
**Details** This webinar will provide an overview of how school telehealth programs are being utilized to provide behavioral health services, and provide an in-depth look at different models for delivering behavioral health services via school telehealth programs. [Register.](#)

#### Tips and Guidance for Developing Telehealth Programs

The Association of Maternal & Child Health Programs (AMCHP) has released a fact sheet that offers advice for public health professionals considering implementation of telehealth programs for child populations. Topics include selecting a provider, modalities, reimbursement, HIPAA compliance, and more. [Read the tip sheet](#) (PDF).

### Resources

- *Exceptional Parent Magazine* October Issue – [Employment & Transition](#)

### Special Education

#### In Brief

- [Schools Must Protect Students with Disabilities from Sexual Harassment](#) – from Parent.com
- [Trump Administration Drops Appeal of Special Ed Suit](#) (regarding Equity in IDEA regulations) – from Disability Scoop

#### Did You Know?

#### New Data Sets Available from National Survey of Children's Health

The Data Resource Center for Child and Adolescent Health has released the National Performance Measures and National Outcome Measures data findings from the combined 2017-2018 National Survey of Children's Health. All data are available through the interactive data query on [childhealthdata.org](http://childhealthdata.org). The combined 2017-2018 NSCH is the second multi-year data set since the redesign of the survey in 2016 and includes data from 52,129 children ages 0-17 years.

### In the News

- [What a Stanford Children's Health Doctor Has Learned from Her Child with Down Syndrome](#)  
*Healthier, Happy Lives Blog, 10/28/19*
- [PG&E May Pay \\$5 Million for Batteries, Hotel Vouchers for People with Disabilities](#) (related to recent wildfires)  
*SF Chronicle, 10/24/19*
- [Viewers Want More People with Disabilities on Screen, Study Shows](#)  
*Disability Scoop, 10/15/19*

#### 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@pfch.org](mailto:Eileen.Walsh@pfch.org) with your news or updates.

