

California Advocacy Network

for Children with Special Health Care Needs

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

Children with Medical Complexity

Join a Conversation on Supporting Self-Management

While self-management support has been a core component of adult chronic care for decades, its importance in the care of children with chronic and complex conditions is just being recognized. Join a discussion on the article, [Supporting Self-Management in Children and Adolescents with Complex Chronic Conditions](#). Lead author Amy Houtrow, MD, PhD, MPH, and other experts will share their background and experience with pediatric self-management and discuss how health systems could better support self-management by children and their families. [Read more and register](#).

Date Wednesday, August 22
Time 10 a.m. to 11 a.m. Pacific Time
Sponsor The Lucile Packard Foundation for Children's Health

Q&A from a Conversation on Models of Care Delivery

Read the [responses](#) to questions that were submitted during the June 28 "Conversation on Models of Care Delivery for Children with Medical Complexity," a webinar in our series, *Building Systems that Work for Children with Complex Health Care Needs*.

Webinar: Approaches to Extending Complex Care Models into the Community – Emerging Evidence

Date Thursday, August 16
Time 9:30 a.m. to 11 a.m. Pacific Time
Sponsor Center for Health Care Strategies

Details Speakers will discuss their experiences building effective care models to address social determinants of health, developing tools to support community-based care team members, and designing a business case for sustaining complex care models. Not pediatric specific, but perhaps of interest. [Read more and register.](#)

California Children's Services

Save the Dates

Raising the Bar: California Children's Services & Continuous Quality Improvement

Date Thursday, October 4
Time 8 a.m. to 4:30 p.m. Pacific Time
Location The California Endowment
2000 Franklin Street, Oakland
Sponsor Children's Regional Integrated Service System (CRISS), CCS Executive Committee and Family Voices of California
Details This conference will provide information on successful and feasible strategies for improving local care delivery for children and youth with complex medical conditions in the CCS program. Details to come.

Whole Child Model Overview Webinar for Phase II Implementation

Date Thursday, October 18
Time 1 p.m. to 2:30 p.m. Pacific Time
Sponsor The Department of Health Care Services
Details Speakers will provide a summary of the Whole Child Model (WCM) Program. Phase II currently is scheduled for implementation on January 1, 2019. Details will be posted on the WCM [website](#).

Family Engagement

Two Films about Families

- [Far from the Tree](#) – based on the [book](#) by Andrew Solomon about what it means to be a family and dealing with "differences."
- [Intelligent Lives](#) – actor Chris Cooper's family story about cerebral palsy and reframing intellectual disabilities.

Care Coordination

California Care Coordination Assessment Project

The Department of Health Care Services has convened an advisory committee to conduct a systemic review of care coordination across the Medi-Cal delivery system. The committee will draft recommendations for policy changes. Meetings are open to the public. [Read more](#) and see the list of committee members. Next meeting:

Date Wednesday, August 22
Time 10 a.m. to 3 p.m. Pacific Time
Location The California Endowment
 1414 K Street, Sacramento – First Floor, Suite 100

Also See: [Care Coordination for California's Children and Youth with Special Needs](#)

In Brief

- [Physician's Role in Coordinating Care of Hospitalized Children](#) – from the American Academy of Pediatrics

National Policy

Bill to Watch

[HR 6560](#) – The Children's Program of All-Inclusive Coordinated Care (ChiPACC) would require provision of a full range of medical services to families with children who have life-limiting illnesses and who qualify for Medicaid. Currently there are gaps in Medicaid coverage for hospice and palliative services. Introduced July 26.

Research

Overcoming Payment Challenges to Realize the Promise of Telehealth

Inconsistent public and private insurance coverage and other challenges have hindered implementation of telehealth, one of the most promising tools to enhance access to care for children and youth with complex conditions. The National Academy for State Health Policy's (NASHP) Patient-Centered Outcomes Research Workgroup explored how telehealth services can be effectively deployed, and outlines what new state policies and funding are needed to implement it. [Read more.](#)

Archived Webinar

- [Individuals with Disabilities & Families of Children with Special Health Care Needs, Pre/Post Disaster](#) – Discusses the importance of emergency preparedness; how families with CSHCN can prepare for various types of disasters; and some practices that may be implemented post disaster to mitigate trauma to the family.

Also See: [Many U.S. Schools Still Not Fully Prepared for Disasters](#) – Includes information about children with special needs.

Resources

- [Serious Game Helps Teens Dealing with Chronic Illness Foster Self-Inquiry](#)
- *Complex Child* August issue: [Rare and Interesting Conditions, Part II](#)
- *Exceptional Parent Magazine* July issue – [Pet Space Design + Animal Therapy](#)

Events

Proposals Sought for Sessions at AMCHP 2019 Annual Conference

The Association of Maternal & Child Health Programs (AMCHP) has issued a call for proposals (workshop, skills-building session, or poster), including topics related to children and youth with special health care needs. The annual conference is scheduled for March 9-12 in San Antonio, Texas. **The proposal deadline is September 21.** [Read more.](#)

Did you Know?

New on kidsdata.org: [Access to Services for Children with Special Health Care Needs](#)

Funding Opportunity

Healthy Tomorrow Grants Available

Applications for funding are being accepted for the Healthy Tomorrows Partnership for Children Program, a cooperative agreement between the federal Maternal and Child Health Bureau and the American Academy of Pediatrics. Federal grants of up to \$50,000 per year for up to five years are awarded to support community-based child health projects that increase access to health services. Funds support projects that provide clinical or public health services, and do not support research. **Applications are due October 1.** [Read more and apply.](#)

Employment Opportunity

- Family Voices of California seeks [Family Engagement Manager](#)

In the News

- [Temple Institute Uses Technology to Help Disabled Young People Live More Independently](#)
Radio.com, 8/6/18
- [Healthy Kids with Sick Sibling May Hide Emotions](#)
Reuters, 7/26/18
- [Students Seeking Equal Access to Education May Find Federal Help Harder to Come By](#)
NPR, 7/25/18

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.

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