

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

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

### Children with Medical Complexity

#### Collaborative Conversations with Families – Seminar 2: Irritability and Pain



Learning objectives for this second session of the 10-part seminar series, *Collaborative Conversations with Families to Advance the Clinical Care of Children with Medical Complexities and Disabilities* (C6), are to identify differences between acute and chronic pain management; demonstrate language strategies with parents when introducing and managing chronic pain; and develop care plans for breakthrough symptoms. Each session of the series, which is funded by our Foundation, includes a panel of national experts, both clinical and caregiver.

**Irritability and Pain**  
Thursday, October 14  
10 to 11 a.m. Pacific Time  
[Read more and register.](#)

See the recording and slides from the first seminar [Knowledge Gaps in the Care of Children with Medical Complexity and Neurodisability](#).

#### Telemedicine for Children with Medical Complexity: A Randomized Clinical Trial

A study published in *Pediatrics* compares comprehensive care that included telemedicine with comprehensive care alone, when caring for medically complex children. The authors conclude that telemedicine likely reduced days of care in a medical setting, serious illnesses, other adverse outcomes, and health care costs for this population of children. [Read more.](#)

#### National Conference on Complex Care Set for October

Registration is available for *Putting Care at the Center*, the national complex care conference scheduled virtually for October 20-22. Speakers will discuss innovative models, tools, and partnerships that complex care programs and practitioners across the country are creating to meet their participants' needs. Sponsored in part by our Foundation, the conference, which focuses primarily on adults, will include some pediatric sessions, including one that features Family Voices' Family Engagement in Systems Assessment Tool. Fee. [Read more and register.](#)

### Family Engagement

#### Supporting Family Engagement in Title V Programs

Federal Title V funds support many programs of importance to children and youth with special health care needs, and family engagement in these programs is essential. The Association of Maternal and Child Health Programs (AMCHP) has developed a statement titled *Family Engagement & Partnerships – Guiding Principles and Values*. AMCHP also has released *AMCHP Family Delegate: A Guide for Family Leaders and Title V Programs*. [Read more about family engagement.](#)

### California Children's Services

#### Upcoming Conference: California Children's Services Best Practices – Shifting the Paradigm for a Post-Covid World

Save the date for this free virtual conference presented by the Children's Regional Integrated Service System (CRISS), which works to create a regional seamless system of care for the CCS children in a 28-county region in Northern California. The conference, sponsored in part by our Foundation, is scheduled for Thursday, October 28, from 1 to 4:30 p.m., and Friday, October 29, from 9 a.m. to 12 p.m. Pacific Time. [See more](#) (PDF).

### COVID-19 Information

#### The Impact of the Pandemic on Households with CYSHCN

COVID-19 has resulted in increased isolation, reduced access to social support, and limited access to resources for many families. To understand the impact of these factors, the American Academy of Pediatrics collaborated with other agencies to conduct a [Family Snapshot Survey](#) that asked about how families' financial, educational, and relational lives have changed during the pandemic. A new report highlights responses from families of children and youth with special health care needs. [Read the report.](#)

#### In Brief

- [For Parents of Disabled Children, School Mask Wars Are Particularly Wrenching](#) – from *NY Times*

### Palliative Care

#### Reframing Hope: West Coast Pediatric Palliative Care Summit

This two-day summit, hosted by George Mark Children's House, is designed for a multidisciplinary audience to highlight skills specific for providers who are interested in learning more about pediatric palliative care practice, techniques, and teamwork. There are options to attend in person or to receive a post-event recording. Continuing education units are available through Stanford for the summit, which is sponsored in part by our Foundation. Fee. [Read more and register.](#)

### National Policy

#### Advocates: Legislation Would Bolster Home- and Community-based Services

Congress continues to consider the [Better Care Better Jobs Act](#), which includes major investments in home- and community-based services (HCBS) and closes a Medicaid coverage gap. These programs allow people with disabilities to remain at home and in their communities. The National Health Law Program (NHeLP) is urging Congressional leaders to invest the resources necessary to meaningfully increase these services. [Read the NHeLP letter to Congress.](#)

### California Policy

#### New Director Appointed to Lead Department of Health Care Services

Michelle Baass, who has been the California Health and Human Services Agency Undersecretary since 2018, has been appointed director of the California Department of Health Care Services (DHCS), effective September 15. DHCS oversees the California Children's Services Program, Medi-Cal, and other agencies of vital importance to children with special health care needs and their families. The position requires Senate confirmation. [Read more.](#)

### Health Equity

#### Archived Webinar



The [recording](#) is now available for the webinar *The Vital Role of Health Care Payers in Addressing Social Determinants of Health to Advance Equity*.

### Resources

- [How to Prepare for a Disaster if You Live with a Disability](#) – from Disability Scoop

### Events

#### Call for Proposals: AMCHP National Conference

The Association of Maternal and Child Health Programs (AMCHP) annual conference is scheduled for March 5-8, 2022, with the theme *Reflecting on our Past, Shaping our Future*. Proposals for presentations or poster sessions at this in-person/virtual event are due **November 9**. [Read about the submission process](#) (PDF).

### Internship Opportunity

#### Applications Open for Summer Program

The American Association of People with Disabilities offers summer internship opportunities in Washington, DC, for college and post-grad students with disabilities. In 2022 a virtual option is available. [Read more and apply](#) by **October 20**.

### In the News

- [Parents Want More Financial Counseling About Kids' Hospitalization Costs, Study Finds](#)  
*Stanford University School of Medicine, 9/21/21*
- [FDA Wants Court to Reconsider Ban on Shock Devices for Those with IDD](#)  
*Disability Scoop, 9/21/21*
- [Parents of Students with Disabilities Try to Make Up for Lost Year](#)  
*NY Times, 9/17/21*
- [Disability Service Providers Shuttering in Many States](#)  
*Disability Scoop, 9/10/21*
- [Pandemic Leaves Families of Children in Special Ed Feeling Left Behind](#)  
*Disability Scoop, 9/9/21*
- [Education Department Will Erase \\$5.8 Billion in Loans for Borrowers with Disabilities](#)  
*NPR, 8/19/21*

#### We'd like to hear from you

Let us know what's happening with your organization or family. Email newsletter assistant editor Ali Rivera at [Ali.Rivera@pfch.org](mailto:Ali.Rivera@pfch.org) with your news or updates. Or contact newsletter editor: Eileen Walsh at [Eileen.Walsh@pfch.org](mailto:Eileen.Walsh@pfch.org).

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The California Advocacy Network for Children with Special Health Care Needs is a collaborative organized by the Lucile Packard Foundation for Children's Health. Through grantmaking, advocacy, and communications, the Foundation promotes a system of care that improves the lives of children with special health care needs and their families.

