

## California Advocacy Network

### for Children with Special Health Care Needs

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

#### Network News

### Three Foundation Grants Awarded

Identifying ways to pay for transition from pediatric to adult care, using data to identify children with complex medical and social needs, and addressing pervasive racial and ethnic inequity in funding services for children with developmental disabilities are the focus of three grants recently approved by the board of directors of the Lucile Packard Foundation for Children's Health. Each of the grants builds on prior foundation funding. Recipients are the National Alliance to Advance Adolescent Health, the Oregon Pediatric Improvement Partnership/Oregon Health Sciences University, and Public Counsel. [Read more.](#)

#### Webinar

### Mental Health Policy Briefing: Raising the Priority of California Children with Special Health Care Needs

<b>Date</b>	Wednesday, May 8
<b>Time</b>	2 to 2:30 p.m. Pacific Time
<b>Sponsors</b>	National Health Law Program and the Lucile Packard Foundation for Children's Health
<b>Details</b>	This online briefing will provide an overview of the mental health services to which California CSHCN are entitled, highlight current state policy priorities, and outline ways to engage in advocacy efforts. Speakers will be available for questions after the 30-minute briefing. <a href="#">Register.</a>

#### Children with Medical Complexity

#### In Brief

- [Three Ways Hospitals Are Transforming the Delivery System for Children with Complex Medical Conditions](#) – A look at how the federal Coordinating All Resources Effectively (CARE) Award helped children's hospitals achieve true transformation in how they provide care for children with complex, chronic conditions.

#### Telehealth

### Pilot Program Tests Pediatric Tele-Physiatry

A pilot program in Northern California explores the use of telehealth to bring subspecialty services to rural and underserved communities. The program provides physical therapy, occupational therapy, and other services to children with neurological or musculoskeletal disorders at designated school-based Medical Therapy Units (MTU) run by the California Children's Services program. [Read more](#) about the pilot program.

#### In Brief

- [Telehealth Reimbursement Guide for California](#) – A publication to assist telehealth providers in obtaining information on reimbursement for provision of clinical services from a distance. Published November 2018. From the California Telehealth Resource Center.

#### Family Engagement and Support

### Viewpoint: My Child Is Sick; Don't Call Her a 'Consumer'

The mother of a chronically ill child describes her family's harrowing health care journey and explains why the terminology and goals of consumerism that are appropriate in many industries should not apply to health care. The author also is a patient and family engagement consultant and advocate. *Health Affairs* Podcast, March 4, 2019. [Listen to her story.](#)

#### California Policy

#### In Brief

- [Federal Judge Preliminarily Approves Class Action Settlement over California's Failure to Arrange Medi-Cal In-Home Nursing Care for Children](#) – News from the National Health Law Program, April 9. The ruling affects more than 4,000 children with complex medical needs. The suit claims that the state failed to fulfill its commitment to provide these children with sufficient Medi-Cal in-home nursing services to keep them safely at home.

#### Bills to Watch

- [AB 898](#) – Would require the California Health and Human Services Agency to convene a Children's Behavioral Health Action Team to maximize the Medi-Cal program's investment in the social, emotional, and developmental health and well-being of child beneficiaries in California.

- [AB 763](#) – Would require the Department of Health Care Services to convene a stakeholder work group to streamline and standardize the paperwork that pediatric specialty mental health providers must complete when serving children in the Medi-Cal program. Advocates say that this paperwork can take up 40-50% of a provider's time.

#### National Policy

### ACE Kids Act Now Law; Funding Extended for Money Follows the Person

The President has signed [H.R. 1839](#) which includes the Advancing Care for Exceptional Kids Act ([ACE Kids Act](#)), that allows state Medicaid programs or health care plans to provide coordinated care in health homes for children with complex medical conditions, even allowing enrollment across state lines. The new law also allocates funds for another extension of [Money Follows the Person](#), a program designed to help individuals with disabilities transition from nursing homes and other institutions to home.

#### Special Education

- [Education Department Accused of Dragging Its Feet on IDEA Rule](#)

#### Resources

- *Complex Child* April Issue: [Challenges of Caregiving](#)
- *Exceptional Parent Magazine* April Issue – [Autism Awareness](#)

#### In the News

- [Neighborhood Under Construction for Those with Special Needs](#)  
*Disability Scoop*, 4/18/19
- [How One Mother's Battle Is Changing Police Training on Disabilities](#)  
*NPR*, 4/13/19
- [Real Equity Means Including People with Disabilities in Philanthropy](#)  
*The Chronicle of Philanthropy*, 4/2/19

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

