

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

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

### Mental Health

#### Mental Health and Children with Special Needs



The recording and slides from the May 8 webinar, "Mental Health Policy Briefing: Raising the Priority of California Children with Special Health Care Needs," are now available. Experts from the National Health Law Program provided an overview of the mental health services to which CSHCN are entitled, highlighted current state policy priorities, and shared ways to engage in advocacy efforts. [Access the recording.](#)

Also See:

- [The Long and Winding Road to Mental Health Care for Your Kid](#) – from California Healthline
- [Access to Mental Health Services for Children with Special Health Care Needs in California](#)

### Children with Medical Complexity

#### Webinar: Addressing Medication Complexity

**Date** Wednesday, May 22  
**Time** 10:30 to 11:30 a.m. Pacific Time  
**Sponsor** Center for Health Care Strategies  
**Details** Complicated drug regimens can be confusing or even dangerous for individuals with complex needs. Speakers will discuss two innovative programs aimed at helping guide patients with multiple and complex prescriptions and their caregivers. [Read more and register.](#)

### Family Engagement and Support

#### Viewpoint: Not Just Along for the Ride – Families Are the Engine That Drives Pediatric Home Health Care

The mother of a child with multiple complex needs writes that families must be supported, valued, and respected as equal partners in care because the pediatric home health care system cannot exist without them. Families, she writes, are not passive observers in the system; they are specialists in medical care, advocacy, and public health, uniquely qualified through their lived experience of providing care across multiple systems. *Health Affairs* Blog, April 18, 2019. [Read her story.](#)

#### Take a Family Survey: Improving California Programs for CSHCN

What are the needs of California children with special health care needs (CSHCN) and how well are those needs being met? A new survey provides California families an opportunity to offer their views. The survey is sponsored by the Family Health Outcomes Project at UC-San Francisco and the California Department of Health Care Services. The sponsors say that the information from the survey will be used to help improve California Children's Services and other programs for CSHCN. Take the survey in [English](#) or [Español](#).

### Research

#### Study: 'Concerning' Disparities Found in End-of-Life Care for Children with Complex Conditions

Neighborhood income and race/ethnicity are tied to the intensity of end-of-life care provided to children with complex chronic conditions, according to a study published in *Pediatrics*. A review found that children from lower-income neighborhoods received more medically intensive procedures at the end of life and were more likely to be hospitalized at the time of death than those from wealthier neighborhoods. The data may indicate that disadvantaged children have less access to quality end-of-life services such as hospice and palliative care, the researchers said. [Read more.](#) (Free registration required.)

### California Children's Services

#### Transition to Adulthood Workgroup

The next meeting of the California Children's Services workgroup on transition will be held May 29. The April 24 meeting was canceled. Information is available on the CCS Advisory Group [website](#).

### California Policy

#### Advocacy Opportunities

- **Developmental Disabilities System Funding:** The Arc of California is urging stakeholders to write to their state legislators and/or sign a petition to Governor Newsom seeking support for an 8 percent statewide rate increase for service providers for individuals with developmental or intellectual disabilities. The funding, proposed in the 2019-20 budget, would help stabilize California's developmental disabilities system, which has been subject to budget cuts since 2008. [Read more and sign the petition.](#)
- **Behavioral Health Action Team:** The California Children's Trust is seeking letters of support by **Friday, May 10**, for [AB 898](#), which 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. Letters should be sent to the Assembly Appropriations Committee. [Download a template.](#)

#### Department of Health Care Services Stakeholder Advisory Committee to Meet

**Date** Thursday, May 23  
**Time** 10 a.m. to 3 p.m. Pacific Time  
**Location** The California Endowment  
1414 K Street, Sacramento – First Floor Conference Room  
**Details** The agenda includes an item on Strengthening Oversight for Managed Care Plans. Full agenda is available on the [website](#).

### Resources

#### Safety, Emergency Tips

Several organizations offer advice on keeping children with physical, developmental, or behavioral conditions safe.

- [Traveling Safely: Guidance for Transportation of Children with Special Needs](#) – A Policy Statement from the American Academy of Pediatrics.
- An [Emergency Information Card](#) (PDF) that patients or caregivers can download and customize with information about the cardholder's disability. From the federal Administration for Community Living.
- [State emergency-preparedness tools and resources](#) for individuals with disabilities and their caretakers, along with information for first responders, emergency managers, and community-based organizations. From the Centers for Disease Control and Prevention.

### Webinar

#### Maximizing ABLE Accounts: Presented by the National STABLE Account Plan

**Date** Wednesday, May 22  
**Time** 11 a.m. to 12:15 p.m. Pacific Time  
**Sponsor** ABLE National Resource Center  
**Details** This webinar will provide program specific details, general guidance, and best practices on how to maximize your ABLE account, which is a tax-advantaged savings account for individuals with disabilities. This webinar is intended for those who already have a basic understanding of ABLE. [Read more and register.](#)

### In the News

- [Saving the Teeth of Patients with Special Needs](#)  
*NY Times, 5/2/19*
- [Court Settlement to Help Low-Income Children with Complex Medical Needs](#)  
*CaliforniaHealthReport.org, 4/24/19*
- [Remote Monitoring Offering Adults with Disabilities More Independence](#)  
*Disability Scoop, 4/24/19*
- [Dental Care Is Tough to Find for People with Autism, Other Developmental Disorders](#)  
*Washington Post, 4/22/19*
- [Inspired by Their Sons, Two Moms Create an App to Connect Parents Raising Special-Needs Kids](#)  
*People, 4/19/19*

#### 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.

