

## California Advocacy Network

for Children with Special Health Care Needs

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

### Network News

#### Foundation Grants Awarded

Six new grants from our Foundation will support work to improve the health care systems that serve children with special health care needs and their families. Grantees will use funds to study family advisory councils on a national level, develop a national CSHCN research agenda, enhance hospital discharge policies, improve access to durable medical equipment, and monitor California's Whole Child Model implementation. [Read about the grants.](#)

### Quality Standards/System Change

#### Case Study: An Innovative Approach to System Change

Given the complexity of the health care systems for CSHCN and their families, novel strategies are needed to build programs that lead to meaningful improvements. Innovation Station, a resource from the Association of Maternal and Child Health Programs (AMCHP), offers a detailed example of how North Carolina has worked over the past decade to examine its community system of care for CSHCN, identify sustainable changes and best practices, and coordinate the implementation of those practices with agencies, providers, and families. Read about the [Innovative Approaches Systems Change Model](#) (PDF), which has increased family engagement and bolstered community capacity for creating change.

#### In Brief

- [National Network for Advancing Systems of Services for Children and Youth with Special Health Care Needs – Year 1 Accomplishments](#) (PDF) – from the Catalyst Center, Got Transition, and the National Resource Center for Patient/Family-Centered Medical Home. The Network focuses on improving three core health system components: access to the patient/family-centered medical home, transition into adult health care systems, and adoption of health care financing models that improve care and outcomes while achieving cost savings.

### Family Engagement

#### Webinar Reminder: Building a Transformative Partnership with Families and Clinicians

**Date** Wednesday, December 11  
**Time** 10:30 to 11:30 a.m. Pacific Time  
**Sponsor** Lucile Packard Foundation for Children's Health  
**Details** Learn about two statewide projects – [a parent leadership training program](#) and [a hospital learning collaborative](#) – and their efforts to integrate families as equal partners in addressing system issues. [Read about the speakers](#) and [register](#).

### Children with Medical Complexity

#### In Brief

- [Few Home Nurses Available to Care for Children with Complex Medical Needs](#)
- [Abstract: Unmet Respite Needs of Children with Medical Technology Dependence](#)

### California Children's Services

#### CCS Transition to Adulthood Workgroup Meeting

**Date** Wednesday, December 18  
**Time** To be announced  
**Dial-In** To be announced  
**Details** The [workgroup](#) was formed to address three questions: at what age should transition activities begin; what transition activities should be required; and for what population of children. For call-in information write to [csredesign@dhcs.ca.gov](mailto:csredesign@dhcs.ca.gov).

### Resources

- [Courageous Parents Network](#) – Parent-created information available in English and Español for families of children with serious illness and complex conditions.
- *Complex Child* December Issue: [Orthopedic Issues](#)

### Viewpoint

#### Opinion: Join the Movement to Elect Kid-Friendly Leaders – Here's How

Wendy Lazarus and Laurie Lipper, longtime advocates for children and co-founders of kidsimpact, write that the upcoming elections offer a vital opportunity to hold elected leaders accountable for the health and well-being of the country's children, now and into the future. They suggest [steps to take](#).

### Mental and Behavioral Health

#### In Brief

- [Four Ways to Improve Pediatric Mental Health Care in the Emergency Department](#) – from the Children's Hospital Association and Seattle Children's Hospital

### California Policy

#### Developmental Services Task Force to Meet

**Date** Monday, December 9  
**Time** 10 a.m. to 4 p.m. Pacific Time  
**Location** Alta California Regional Center  
2441 Harvard Street, Sacramento  
**Dial-In** 1 (877) 692-8957; Passcode: 2126099  
**Details** The task force is an advisory group to the Department of Developmental Services. Members provide guidance on the delivery of services to Californians who have intellectual and developmental disabilities. Membership of the task force recently was greatly expanded. See a [list](#) (PDF) as of November 22. [Read more](#) about the task force and see the December 9 [agenda](#) (PDF).

#### State Proposing Major Modifications to Medi-Cal

The Department of Health Care Services has launched *California Advancing and Innovating Medi-Cal* (CalAIM), a multi-year initiative with a stated goal "to improve the quality of life and health outcomes" of Californians by "implementing broad delivery system, program and payment reform across the Medi-Cal program." The Department will conduct stakeholder engagement through 2019 and 2020 for this wide-ranging proposal. Many of the state's children with special health care needs rely on Medi-Cal coverage. [Learn more](#) and find out how to become involved.

### Webinars/Podcasts

#### Mental Health and Self-Care for Caregivers

**Date** Thursday, December 12  
**Time** 11 a.m. to 12 p.m. Pacific Time  
**Sponsor** Christopher and Dana Reeve Foundation  
**Details** Second in a three-part series on self-care, managing anxiety, and mental health. This session will consider aspects of good mental health and explore ways that behavioral patterns people learned growing up influence self-care success. The presenter will discuss techniques to shift these patterns and encourage healthier habits. [Register](#).

#### Building Capacity: Using the Touchpoints Approach for Productive Conversations with Parents About Their Children's Development

**Date** Tuesday, December 17  
**Time** 11 a.m. to 12 p.m. Pacific Time  
**Sponsor** Help Me Grow National Center  
**Details** This webinar will provide an introduction to Brazelton Touchpoints, an evidence-based approach for building strong family-child relationships from before birth through the earliest years. Learn about the Touchpoints approach to having productive conversations with parents about developmental surveillance and screening. [Register](#).

### Did You Know?

#### Find State Data on CSHCN

The Catalyst Center produces the [State Data Chartbook](#), a regularly updated, selective list of health indicators related to CSHCN for all 50 states as well as Puerto Rico and the District of Columbia. The book provides data on demographics, economics, child health services, insurance availability, and factors affecting coverage for CSHCN. The information can be compared state-by-state or against the national average.

### Events

#### Early Bird Registration Available for AMCHP Annual Conference

*The Power of Connections: Building Equity for Healthy Generations* is the theme for the annual conference of the Association of Maternal and Child Health Programs, scheduled for March 21-24 in Crystal City, Virginia. [Register](#) by **February 21** to receive a discounted rate.

### In the News

- [Student Loan Borrowers with Disabilities Aren't Getting Help They Were Promised](#)  
*NPR, 12/4/19*
- [New Data Updates the Economic Value of Family Caregiving](#)  
*Association of Health Care Journalists, 11/15/19*
- [School Becomes Model for How Peer Groups Can Help Students in Special Ed](#)  
*Disability Scoop, 11/5/19*

#### 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.

