

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

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

### Family Engagement

#### Webinar: Stories from the Field – 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** Family-professional partnerships help ensure that health care programs and policies are appropriate and well-utilized. While including parents as equal members of their child's care team is an accepted standard for pediatric care, the core principles of family engagement have not been widely adopted as drivers of health care systems improvement. 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](#).

#### Center Provides Resources for Family Caregivers

Millions of family caregivers across the country provide critical yet unpaid services. To better support them, Congress passed the Recognize, Assist, Include, Support, and Engage Family Caregivers (RAISE) Act in 2018. One outcome is that the National Academy of State Health Policy (NASHP) has established the RAISE Act Family Caregiver Resource and Dissemination Center, designed to be a focal point for resources, technical assistance, and policy analysis for states and stakeholders interested in family caregiver issues. [Read about the Center's plans](#).

#### Long-Term Care: Where Are We and What's Next?

**Date** Monday, November 18  
**Time** 10:30 to 11:45 a.m. Pacific Time  
**Sponsors** Alliance for Health Policy and National Institute for Health Care Management Foundation, in collaboration with the Association of Health Care Journalists  
**Details** Currently the US has no comprehensive long-term care system for people with disabilities. Panelists on this webinar will discuss the current landscape and potential solutions to relieve the financial and emotional strain on family caregivers. [Register](#).

#### Call for Abstracts: Patient- and Family-Centered Care Conference

The theme of the 9th International Conference on Patient- and Family-Centered Care is "Partnerships for Quality, Safety, and Equity." The conference will showcase exemplary programs dedicated to collaboration among health care professionals, patients, and families to address the challenges in the complex US health care system. The organizers are calling for abstracts for a range of presentation types and topics. The submission deadline is **December 4**. [Find all details](#) (PDF).

### Children with Medical Complexity

#### Community-Based Care: How Medicaid Waivers Vary Across States

Care delivered in home and community-based settings (HCBS) is a critical part of treatment for many children with medical complexity (CMC) who rely on such care to keep them in their homes. Many states cover this care through Medicaid waivers that allow states to waive certain Medicaid income eligibility criteria and definitions. A recent study, funded by our Foundation, analyzes the scope of coverage offered under these waivers and evaluates how states are using them to provide care for CMC. The researchers found great variability among states in services, which can affect child and family outcomes. The authors recommend some changes in age and diagnostic eligibility. [Read more](#) (PDF).

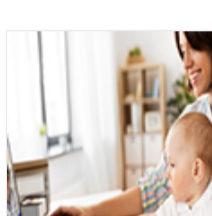
#### Cross-Sector Partnerships for Complex Populations



The recording of the webinar "What Matters Most in Driving Cross-Sector Partnerships for Complex Populations" is now available [online](#).

### Telehealth

#### Integrating Telehealth into Care for Children



California updated its telehealth policies in the state's Medi-Cal provider manual in August. An analysis of the changes by The Children's Partnership concludes that the update contains some promising developments, but the new policies also create barriers that severely restrict the ways in which children, especially children enrolled in Medi-Cal managed care plans, can benefit from telehealth. The issue brief, funded by our Foundation, provides recommendations about how to ensure that telehealth is integrated into the state's health care and support systems for children. Read the [issue brief](#) (PDF).

### California Children's Services

#### CCS Transition to Adulthood Workgroup to Meet

**Date** Wednesday, November 20  
**Time** 1 to 2:30 p.m. Pacific Time  
**Dial-In** (888) 324-9621; Passcode: 8500518  
**Details** The workgroup was formed this year to address three questions: at what age should transition activities begin; what transition activities should be required; and for what population of children? See this meeting's [agenda](#) (PDF) and [past meeting materials](#).

### National Policy

#### In Brief

- [Federal Study Finds Nation's Assisted Suicide Laws Rife with Dangers to People with Disabilities](#) – from National Council on Disability
- The federal government has revised its [Benefit Finder](#), a tool to make it easier to find information on government benefits and eligibility requirements.

#### Bills to Watch

- [H.R. 2781 Educating Medical Professionals and Optimizing Workforce Efficiency and Readiness for Health Act of 2019](#) – Passed House on October 28. In addition to other elements, contains a section to invest in future of pediatric health care workforce, including subspecialists.
- [H.R. 647 Palliative Care and Hospice Education and Training Act](#) – Passed House on October 28. Would expand hospice and palliative care by increasing education, training, and research; and creating education centers.

### Special Education

- [California Legislative Analyst Publishes Overview of Special Education Services](#) (PDF)

### Resources

- *Exceptional Parent Magazine* November Issue – [Financial Planning](#)
- *Complex Child* November Issue: [Coping Strategies](#)

### Webinars/Podcasts

#### Gaining Ground: The Primary Care Pediatrician's Role in Public Health Systems of Care for CYSHCN

This three-part podcast series from the National Resource Center for Patient/Family-Centered Medical Home provides an overview of the history and functions of the Title V Maternal and Child Health/CYSHCN program, and highlights opportunities for partnerships between Title V programs and primary care physicians and families. Tools and resources are available. [Read more](#).

### In the News

- [Rethinking Tiny Tim: Should a Disabled Actor Play the Role?](#)  
*NY Times*, 11/13/19
- [Despite Gains, the Emotional Lives of Children Often Forgotten by Our Medical System](#)  
*Center for Health Journalism*, 11/11/19
- [Online Matching Service Pairs Adult Roommates with Developmental Disabilities](#)  
*Disability Scoop*, 11/11/19
- [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.

