

## California Advocacy Network

### for Children with Special Health Care Needs

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

#### Network News

### New Grants Support Family Engagement, Palliative Care, Developmental Disabilities Care

Increasing family influence on policies and programs that affect children with special health care needs and their families is the focus of two new grants from the Foundation. Two additional awards support improving home-based pediatric palliative care and enhancing integrated care for individuals with developmental disabilities. The Foundation also has contracted for an external evaluation of its National Standards for Systems of Care initiative. [Read more.](#)

#### Family Engagement

### Webinar: Building Family Leadership and Voice

**Date** Friday, July 12  
**Time** 11 a.m. to 12:30 p.m. Pacific Time  
**Sponsor** Substance Abuse and Mental Health Services Administration  
**Details** This webinar will include strategies that provider agencies and system of care leaders can use for increasing genuine family engagement and for strengthening partnerships with family-run organizations. Presenters will highlight successful efforts of organizations working in rural and frontier areas. [Read more and register.](#)

#### In Brief

[A 21st Century Job Description for Family Caregiving](#) – Blog from the June 14 *Health Affairs* addresses the outdated assumptions about what family caregivers actually do, and proposes a new look at this role and the policies designed to support caregivers.

*Also See:* [In Support of Family Caregivers: A Snapshot of Five States](#) (PDF) – from Milbank Memorial Fund and The John A. Hartford Foundation. This report focuses on aging, but is relevant to all family caregivers.

#### California Children's Services

### CCS Advisory Group to Meet

**Date** Wednesday, July 24  
**Time** 10 a.m. – TBD Pacific Time  
**Location** 1700 K Street, Sacramento – First Floor Conference Room  
**Dial-In** (888) 989-6488; Passcode: 1945234  
**Details** The Advisory Group provides feedback to the Department of Health Care Services on delivery of care to CCS-enrolled children and their families, and monitors implementation of the Whole Child Model, in which children are transferred from CCS coverage to a Medi-Cal managed care plan. Read more on the [website](#).

### Workshops on the Whole Child Model

"The Whole Child Model: Changes to California Children's Services" is the subject of workshops for professionals and families scheduled around the state at the end of July, co-sponsored by Family Voices of California. [Find details.](#)

#### Children with Medical Complexity

### A Step-by-Step Guide to Building a Complex Care Coordination Program in a Small Setting

This report from *Clinical Pediatrics* describes a care support project that delivered shared plans of care to providers and families of children with medical complexity. The program was built around carefully constructed care support teams in which each member had clearly defined roles and responsibilities. The project allowed patients to remain in their local medical homes. [Read the abstract.](#)

#### In Brief

- [Opportunities to Advance Complex Care in Rural and Frontier Areas](#) – from the Center for Health Care Strategies

#### Research

### How Do CSHCN Insured by Medicaid/CHIP Differ from Those with Private Insurance?

This Kaiser Family Foundation issue brief compares key characteristics of CSHCN insured by Medicaid/CHIP with those who have both public and private insurance, private insurance only, and those who are uninsured. [Read the brief.](#)

#### Special Education

#### In Brief

- [How Some Schools Restrain or Seclude Students: A Look at a Controversial Practice](#)  
Restraints are used most often on children with disabilities. *NPR*, 6/15/19
- [Schools' Racial Makeup Can Sway Disability Diagnoses](#)  
*Education Week*, 6/11/19
- [Alarming Absences in Rural Schools; Big Fight over New Money for Special Ed](#)  
Discussion of California's special education funding starts at 3:48 in the podcast. *EdSource*, 6/1/19

#### California Policy

### Advocacy Opportunity

- [AB 898 Early and Periodic Screening, Diagnostic, and Treatment Services: Behavioral Health](#) – This bill, which would create the Children's Behavioral Health Action Team to increase children's access to critical behavioral health services, continues to move through the Legislature. Advocates are seeking [support letters](#) that should be submitted through the California Legislature [Position Letter Portal](#).

#### National Policy

- [President Signs Law Improving Disaster Planning for Those with Disabilities](#)  
*Disability Scoop*, 6/26/19  
*Also See:* Slide deck from a webinar on "[Addressing the Needs of People with Disabilities in Public Health Emergencies](#)" (PDF). Offers planning advice for individuals, caregivers, and communities.

#### Resources

- *Complex Child* July Issue: [Special Education](#)
- [Social Media Toolkit](#) (PDF) – A guide for Family Resource Centers and other family-strengthening organizations. From the California Family Resource Association.

#### Webinars

### Public Charge 101

**Date** Tuesday, July 16  
**Time** 10 to 11 a.m. Pacific Time  
**Sponsor** Protecting Immigrant Families  
**Details** "Public charge" is a term used in immigration law to refer to a person who is primarily dependent on the government for support. The Trump Administration has proposed changes to the public charge rule. Speakers will describe public charge policy today, discuss how and when it may change, and explain what individuals who work with immigrant families need to know. [Register.](#)

### Care of Adolescents and Young Adults with Life-Threatening Illness

**Date** Thursday, July 18  
**Time** 12 p.m. Pacific Time  
**Sponsors** Children's Hospice and Palliative Care Coalition (a division of Coalition for Compassionate Care of California), Pennsylvania's Pediatric Palliative Care Coalition and Greater Illinois Pediatric Palliative Care Coalition  
**Details** Jennifer Mack, MD, MPH, from Boston Children's Hospital/Dana Farber Cancer Institute, will discuss her experiences working with adolescents and young adults with life-threatening illnesses, including their end-of-life care experiences and their needs for communication and engagement in decision-making. Fee. Complimentary registration for parents. CEU available for nurses and social workers. [Read more and register.](#)

### Cross-Sector Collaborations in Pediatrics

**Date** Thursday, July 18  
**Time** 11 a.m. to 12 p.m. Pacific Time  
**Sponsor** Child Health and Development Institute of Connecticut  
**Details** A report published in February, [Transforming Pediatrics to Support Population Health: Recommendations for Practice Changes and How to Pay for Them](#), makes the case for redesigning pediatric primary care to play a broader role in the health and well-being of families and children, and outlines the principles to guide payment reform to support new services. This second of three webinars based on the report's recommendations focuses on initiatives that harness the power of collaborations across other sectors. [Read more and register.](#)

#### In the News

- [A Boy Who Had Spinal Surgery in the Womb Stands on His Own Two Feet](#)  
*NY Times*, 6/24/19
- [CBS Pledges to Make Casting More Inclusive](#)  
*Disability Scoop*, 6/24/19
- [How an App Is Helping Screen More Kids for Developmental Delays](#)  
*Disability Scoop*, 6/21/19
- [Margin for Error 'Almost Zero' in Testing Pediatric Devices](#)  
*MedTechDive*, 6/14/19

#### 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.

