

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

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

### Care Coordination

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## Report, Webinar Shine Spotlight on "Risk Tiering" for Care of CSHCN



Health care systems are increasingly using a process known as "risk tiering" to group patients with similar degrees of need for health care and care coordination services. Families and care providers of children with chronic and complex conditions should understand risk tiering, as it may affect access to services these children need. A new report outlines how tiering currently is being used, and makes recommendations for policy and research. [Read the report](#) and attend a webinar:

- Date** Wednesday, February 28
- Time** 11 a.m. to 12 p.m. Pacific Time; 2 p.m. to 3 p.m. Eastern Time
- Sponsors** Lucile Packard Foundation for Children's Health, Family Voices, and the Catalyst Center
- Details** Speakers will be report authors Christopher Stille, MD, MPH, professor of pediatrics and section head of General Academic Pediatrics at the University of Colorado School of Medicine and Children's Hospital Colorado; Nora Wells, MEd, executive director of Family Voices; James Perrin, MD, professor of pediatrics at Harvard Medical School and former director of the Division of General Pediatrics at MassGeneral Hospital for Children. [Register](#).

### Transition to Adult Care

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## Have a Transition Story? Researchers at Harvard, Boston Children's Would Like to Hear It

The Transition Readiness and Self-Efficacy Study at Boston Children's Hospital and Harvard Medical School is recruiting participants for a research study on transition from pediatric to adult health care. The researchers plan to investigate medical and non-medical needs during transition and establish patient preferences for models of transition care. They are asking for input from youth and young adults (ages 15-30) with chronic medical conditions, and their parents. Participants will receive up to \$120 in Amazon gift cards. [Find more information.](#)

### Family Engagement

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## New Foundation Program Officer to Focus on Family Engagement



Allison Gray has joined the Lucile Packard Foundation for Children's Health to spearhead its efforts to empower families to be advocates and to oversee its investments that support family engagement. She has been a leader in the field for many years, serving as project manager for Family Voices of California Project Leadership, a parent advocacy training program. In an interview, she discusses her thoughts on the importance of family engagement and the exciting work ahead. [Read the Q&A.](#)

## What Parents Want Docs to Know

Three parents of children with special health care needs have published an article in *JAMA Network Open* listing 10 things parents would like their child's physicians to understand. Their article was based on survey research conducted at Franciscan Children's in Brighton, Massachusetts, which quantified the health care obstacles parents routinely encounter in the course of their children's medical care. [Read the parents' list.](#)

*JAMA Network Open*, part of the Journal of the American Medical Association network of journals, is an open access site that publishes original research and commentary. [Submissions are welcome.](#)

### Quality Standards

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## Applications Sought for Participants in Nurse-Led Learning Collaborative that Aims to Improve Hospital Discharge, Care Transition

Children's hospitals or hospital-based teams are invited to apply to participate in a nurse-led learning collaborative to improve hospital discharge and care transitions for CSHCN. The California Nurse-Led Learning Collaborative (CANDLE) will engage interprofessional teams from children's hospitals across California to catalyze systems-level changes in discharge care delivery. The project will be led by the Institute for Nursing and Interprofessional Research at Children's Hospital Los Angeles, with funding from the Lucile Packard Foundation for Children's Health. The application deadline is **February 23**. [Read more](#).

*Also See:* [Improving Pediatric Hospital Discharge Care for Children and Families](#)

### National Policy

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## Bill Passed to Allow Businesses to Delay Accessibility

Disability advocates strongly opposed [HR 620](#), which passed a House vote today. The bill allows long delays by businesses not in compliance with laws requiring accessible services for persons with disabilities. The bill says that individuals must provide written notice about a barrier to a business, which is allowed 60 days to respond and then another 120 days to demonstrate substantial progress in removing the barrier. The bill now moves to the Senate, where advocates will continue to oppose it. [Read more](#).

## Flu Vaccine Urged for At-Risk Groups

Complications from the flu are more likely to affect children with neurological and neurodevelopmental disorders. The Centers for Disease Control and Prevention recommends that everyone older than six months get vaccinated, and says it's not too late. [Read more](#).

### In Brief

- [Congress Just Funded CHIP for a Full Decade](#)

### Resources

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- Three authors have been honored by the American Library Association with [2018 Schneider Family Book Awards](#). The awards recognize authors or illustrators for an artistic expression of the disability experience for child and adolescent audiences.
- [Complex Child](#) Annual Feeding Tube and GI Edition
- *Exceptional Parent Magazine* January issue – [Navigating Special Needs Resources](#).

## Webinars

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# Innovations in Medicaid Managed Long-Term Services and Supports: How Health Plans are Providing Support to Family Caregivers

**Date** Wednesday, February 28

**Time** 10 a.m. to 11 a.m. Pacific Time

**Sponsor** Health Management Associates and the AARP Public Policy Institute

**Details** Health plans are increasingly recognizing and supporting family caregivers for individuals with long-term services and supports (LTSS) needs. This webinar will discuss a new report on Emerging Innovations in Managed LTSS for Family Caregivers, and will also feature real-world experiences. [Register](#).

## In the News

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- [School District Ordered to Reimburse Family for Private Placement](#)  
*Disability Scoop, 2/13/18*
- [Caring for Siblings of Sick or Disabled Children](#)  
*NY Times, 2/12/18*
- [Innovative Product Helps Kids with Special Needs Learn to Skate](#)  
*Autism Parenting, 2/12/18*
- [Court Rules Against Teen with Cerebral Palsy](#)  
*Chicago Tribune, 2/7/18*
- [The Next Gerber Baby Will Be This Adorable Boy with Down Syndrome](#)  
*Salon, 2/7/18*

- [We Must Stop the Rampant Criminalization of Youth with Disabilities](#)  
*Juvenile Justice, 2/5/18*
- [Creating a Community for People with Developmental Disabilities](#)  
*NPR, 2/4/18*
- [Report: Colleges Failing to Protect Students with Disabilities](#)  
*Disability Scoop, 1/30/18*

### **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.

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