

June 20, 2019

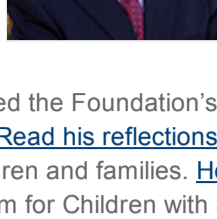
## California Advocacy Network for Children with Special Health Care Needs

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

**Note – The Newsletter will not publish on July 4. Our best wishes for an enjoyable holiday.**

### Network News

#### Changing of the Guard: Dr. Ed Schor to Retire from the Foundation

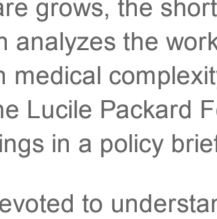


Edward Schor, MD, who for the past eight years has led the Foundation's work to improve the system of care for children with special health care needs (CSHCN), will retire July 2. [Read his reflections](#) on the Foundation's progress and how best to continue efforts to create a system that works for children and families. [Holly Henry](#), PhD, currently the Foundation's Research Program Manager, will become Director of the Program for Children with Special Health Care Needs.

Reminder: [Letters of Inquiry](#) for grants from the Lucile Packard Foundation for Children's Health are due **July 10**.

### Children with Medical Complexity

#### Pediatric Home Health Care: Workforce Gaps, Policy, Future Directions

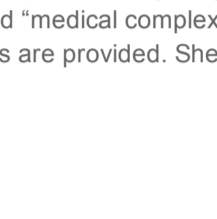


As the number of children who require home health care grows, the shortage of available providers with pediatric training is becoming ever more critical. Newly published research analyzes the workforce gaps, payment models, and policy challenges unique to home health care for children and youth with medical complexity, and the authors propose a range of potential solutions. Funding for the study was provided by the Lucile Packard Foundation for Children's Health. [Read the article](#). Lead author Carolyn Foster, MD, MSHS, presented the findings in a policy briefing that is available via a [webcast](#).

The article is part of a [special issue of Health Affairs](#) devoted to understanding how to recruit, train, and deploy the necessary clinical and non-clinical workforce and fully integrate family caregivers into care processes.

### Family Engagement

#### Viewpoint: 'Family Burden' and 'Medical Complexity': Wrestling with Meaning, Impact of Common Terminology



Meg Comeau, a long-time CSHCN professional and the parent of a young adult with a complex genetic syndrome, suggests that commonly used terms such as "family burden" and "medical complexity" are viewed differently by parents and professionals, with consequent impact on how services are provided. She proposes reconciling those views, with the goal of creating a better system of care. [Read her article](#).

### California Children's Services

#### CCS Transition to Adulthood Workgroup to Meet

The CCS Transition to Adulthood Workgroup is scheduled to meet on Wednesday, June 26. The agenda and call-in information will be posted on the CCS Advisory Group [website](#).

#### July 1: Whole Child Model Transition in Orange County

The transition of CCS-enrolled children into coverage by CalOptima in Orange County is scheduled for July 1. For more information, visit the Department of Health Care Services [website](#). Families who would like assistance or information also may contact Ali Barclay at Family Voices of California: [abarclay@familyvoicesofca.org](mailto:abarclay@familyvoicesofca.org) or (toll free) (888) 387-0393.

Also See: [How Well Are Medicaid Plans Taking Care of Kids? It's a Frustrating Black Box](#) – from the Center for Health Journalism

### Research

#### Medicaid's Role for CSHCN: A Look at Eligibility, Services, and Spending in Every State

Almost half of US children with special health care needs receive their medical coverage through Medicaid and the Children's Health Insurance Program. In light of pending proposals to cap federal Medicaid funding, the Kaiser Family Foundation analyzed data on the role that Medicaid plays for CSHCN in each state. The study describes eligibility, covered services, and program spending. [Read the study results](#).

#### Chronic Physical Conditions Linked to Mental Health Issues

Young people with chronic physical conditions may be at greater risk for developing chronic mental health conditions, according to a study published in *Pediatrics*. The authors suggest that limitations on the ability to engage in developmentally appropriate activities may be a contributing factor. They highlight the need for care providers to monitor the mental health of youth with chronic physical limitations. [Read the abstract](#).

### Resource

- *Exceptional Parent Magazine* June Issue – [Summer Fun](#)

#### If You Like What You're Reading ...

We hope that you will share the Newsletter with others who are interested in promoting better systems of care for children with special health care needs and their families. Currently, we mail every two weeks to more than 6,000 individuals nationwide. Please help build the Network by forwarding this edition to colleagues and encouraging them to [subscribe](#) to the Newsletter.

### California Policy

#### Department of Health Care Services Stakeholder Advisory Committee Meeting

**Date** Wednesday, July 10  
**Time** 9 a.m. to 12:30 p.m. Pacific Time  
**Location** The California Endowment  
1414 K Street, Sacramento – First Floor Conference Room  
**Dial-In** (888) 606-5935; Passcode: 9283547  
**Details** The committee provides feedback on health care policy issues affecting the Department of Health Care Services. View materials on the Department's [website](#).

#### Medi-Cal Children's Health Advisory Panel Meeting

**Date** Thursday, July 11  
**Time** 10 a.m. to 2 p.m. Pacific Time  
**Location** The California Endowment  
1414 K Street, Sacramento – First Floor Conference Room  
**Details** The agenda and materials will be posted on the Department of Health Care Services (DHCS) [website](#). The MCHAP is a 15-member independent statewide advisory body that advises DHCS on matters relevant to children enrolled in Medi-Cal.

#### Bill to Watch

- [AB 899](#) **Early and Periodic Screening, Diagnostic, and Treatment Services: Behavioral Health** – This bill would create the Children's Behavioral Health Action Team to increase children's access to critical behavioral health services. The Team would develop strategies to maximize federal, state, and local funding; address gaps in access to behavioral health supports for children; and identify alternative contracting and payment arrangements that improve access to coordinated and integrated care. Currently in committee.

### National Policy

#### Bill to Watch

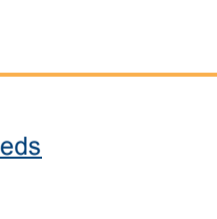
- [S 1443](#) and [HR 2730](#) – The **Credit for Caring Act** would allow certain tax credits for eligible caregivers. Currently in committee.

### Media Representation

Several recent articles have focused on portrayals of individuals with special needs in popular culture.

- [Improving Disability Representation, Both On-Screen and Off](#)
- [Movie Starring Actor with Down Syndrome Coming to Theaters](#)
- [One Tony Award Made History – but It Also Exposes a Persistent Problem](#)
- [With Muppet on the Spectrum, 'Sesame Street' Makes Impact](#)

### Funding Opportunity



The [deadline for applying](#) to the Emerging Investigator Guided Research Program at the Children and Youth with Special Health Care Needs National Research Network (CYSHCN) is **July 5**.

### In the News

- [Kohl's Rolls out Clothing for Kids with Special Needs](#)  
*Disability Scoop, 6/17/19*
- [Pension Relief, Special Education Funding Highlight Gov. Newsom's Budget](#)  
*EdSource, 6/14/19*
- [Push to Require Disability Training for Doctors Meets Resistance](#)  
*Disability Scoop, 6/13/19*
- [Report Alleges 'School to Guardianship Pipeline'](#)  
*Disability Scoop, 6/11/19*
- [Couple Transforms Children with Special Needs into Superheroes with Free Photo Shoots](#)  
*Inside Edition, 6/10/19*
- [Desperation and Broken Trust When Schools Restrain Students or Lock Them in Rooms](#)  
*NPR, 6/5/19*

#### 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.

