

March 4, 2021

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

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

### Quality Standards

#### Supporting States to Improve Care for Children with Special Health Care Needs During COVID-19

COVID-19 has altered many state programs that serve children with special health care needs (CSHCN), a group that has been severely affected by the pandemic, particularly CSHCN of color. A new blog post in *Health Affairs* discusses how states might protect and expand care for CSHCN and their families in the long term by permanently adopting COVID-related policy changes in areas such as telehealth, reimbursement of family caregivers, flexibility in Medicaid prior authorization policies, and others. The post, written by NASHP staff with support from our Foundation, also highlights how the [National Standards for Systems of Care](#) can be leveraged to maintain care for CSHCN. [Read more](#). (Free registration may be required.)

### Family Caregiving

#### Family Caregiving Advisory Council Developing Report to Congress

Improving family caregiving and supporting caregivers is the goal of the federally mandated Recognize, Assist, Include, Support and Engage ([RAISE](#)) Family Caregiving Advisory Council, which provides recommendations to the Secretary of Health and Human Services. At its January 19 meeting the Council heard various reports and discussed the process for reviewing its upcoming Report to Congress. [See a meeting summary and the recording and slide presentation](#).

*Related: [In Their Own Words: Family Caregivers Priorities and Recommendations](#) (PDF)* – In a new report, family caregivers and organizations that work with and serve them describe their concerns and offer recommendations to the Administration for Community Living, which is implementing the requirements of the RAISE Family Caregivers Act.

#### Opinion: 50 Million Americans Are Unpaid Caregivers. We Need Help.

In a *New York Times* piece, the author, a family caregiver with a forthcoming book on caregiving, discusses the needs of the millions of caregivers with little or no support in managing the medical, financial, logistical, and emotional challenges of providing care for loved ones. [Read more](#).

### Children with Medical Complexity

#### Looking Ahead at Complex Care

Two publications highlight recent developments in the growing field of complex care, and discuss prospects for future strategies and improvements. Not pediatric specific:

- [Envisioning the Future of Complex Care](#) – from *Health Affairs*
- [The State of the Field of Complex Care 2021: A Message from the Complex Care Field Coordinating Committee](#) – from the National Center for Complex Health and Social Needs

### COVID-19 Information

Our COVID-19 [web page](#) offers additional information and resources.

- [Ensuring the Success of Students with Disabilities Through the Pandemic](#), from **WestEd**, provides guidance for administrators at both the school and district level who are responsible for managing distance learning for students with disabilities.
- [Promising Practices to Accelerate Learning for Students with Disabilities During COVID-19 and Beyond](#) (PDF), from the **National Center for Learning Disabilities**, suggests approaches to remediate academic losses caused by the pandemic.
- [VaccineFinder](#), a free online tool launched by **Boston Children's Hospital** and the **Centers for Disease Control and Prevention**, allows users around the country to look for local sites that have the vaccine stocked. Limited information available for some areas.

### Pediatric Palliative Care

#### Using POLST/MOLST to Engage in Meaningful Conversations in Pediatric Palliative Care

**Date** Tuesday, March 16  
**Time** 12 p.m. Pacific Time  
**Sponsors** Pennsylvania's Pediatric Palliative Care Coalition, Greater Illinois Pediatric Palliative Care Coalition, Children's Hospice & Palliative Care Coalition of California, Jacob's Heart Children's Cancer Support Services, and the CSU Shiley Institute for Palliative Care  
**Details** The webinar will offer an overview of using POLST/MOLST (Physician Orders for Life-Sustaining Treatment and Medical Orders for Life-Sustaining Treatment) in pediatric care. The presenters will focus on how a POLST can be used as a tool to speak with parents about goals of care and what different states are doing with POLST, across different settings of care. Fee. [Register](#).

### Mental and Behavior Health

#### Strengthening Children's Social and Emotional Health



An analysis from Manatt Health identified innovative strategies and options for California to leverage Medi-Cal, the state's Medicaid program, for creating an equitable and advanced health care system. A February 4 webinar presented key findings from that analysis, highlighting [best practices that all states can adapt](#) to advance and promote children's social and emotional health and leverage Medicaid resources. (Click the box that says View and Download to see materials from the webinar.)

### National Policy

#### Upcoming: Georgetown Medicaid Learning Lab Webinar

The next webinar from the [Medicaid Learning Lab](#) at the Georgetown University Center for Children and Families is scheduled for March 18. This free monthly webinar series aims to help participants better understand the roles that Medicaid and CHIP play in providing health coverage to children, pregnant women, and families. Past sessions are available on the site. [Register for the series](#).

#### In Brief

- [Public Charge: What Advocates Need to Know](#) – A February 2 update from Protecting Immigrant Families

### California Policy

#### Medi-Cal Children's Health Advisory Panel to Meet

**Date** Tuesday, March 16  
**Time** 9:30 a.m. to 1 p.m. Pacific Time  
**Details** The 15-member panel advises the Department of Health Care Services on policy and operational issues that affect children in Medi-Cal. See the [agenda](#) on the panel website. [Advance registration](#) required to view materials or comment.

#### In Brief

- The Department of Developmental Services has notified Regional Center directors that it is temporarily extending the terms of waivers, modifications, and directives issued in response to COVID-19. [Read the notification](#).

### Resources

- The Arc is offering [six free resources en Español](#) to assist individuals with intellectual and developmental disabilities (IDD) and their families. The resources cover myths about guardianship, resources to consider when creating a financial plan, when to use a Special Needs Trust or ABLE account, assistance in helping people with IDD make decisions, and more. Also available in English.
- [A Parent's Guide to Self-Care – Myths and Tips from the Courageous Parents Network](#) (PDF)

### Health Equity

#### Webinar: Working with Culturally or Linguistically Diverse Families in Early Intervention and Early Childhood Special Education

**Date** Friday, March 19  
**Time** 7 to 9 a.m. Pacific Time – recording will be available  
**Location** Virtual  
**Sponsor** PACER Center  
**Details** Participants will learn strategies to enhance communication between families and school staff during Individualized Family Service Plan (IFSP) and Individualized Education Program (IEP) meetings for children ages birth to five. [Register](#).

#### In Brief

- Toolkit: [Equity for People Living with a Rare Disease](#) (PDF)
- Request for Social Determinants of Health and Health Care: Organizations or partnerships that address health inequities and special determinants of health are invited to submit proposals to serve as a featured speaker or lead a breakout session describing their work. Submission deadline is **March 15**. [Read more](#).

### Advocacy

#### Developmental Disabilities Public Policy Conference

**Date** March 15-18  
**Location** Virtual  
**Sponsors** The Arc California and United Cerebral Palsy California Collaboration  
**Details** Speakers aim to inspire, educate, and empower attendees to become advocates for Californians with intellectual and developmental disabilities. [Register](#). Fee.

### In the News

- [Parents Desperate to Get Their Disabled Kids Vaccinated Face Big Hurdle: CDC Guidelines](#)  
*NBC News, 2/26/21*
- [How the Pandemic Is Impacting Children's Health and Pediatric Hospitals](#)  
*U.S. News & World Report, 2/26/21*
- [When Does COVID-19 Become a Disability? 'Long-Haulers' Push for Answers and Benefits](#)  
*NPR, 2/22/21*
- [It's Time to Stop Even Casually Misusing Disability Words](#)  
*Forbes, 2/20/21*

#### We'd like to hear from you

Let us know what's happening with your organization or family. Email newsletter assistant editor Ali Rivera at [Ali.Rivera@pfch.org](mailto:Ali.Rivera@pfch.org) with your news or updates. Or contact newsletter editor: Eileen Walsh at [Eileen.Walsh@pfch.org](mailto:Eileen.Walsh@pfch.org).

[Join the Network](#)

To see past issues, visit the [Network Newsletter Archive](#).

The California Advocacy Network for Children with Special Health Care Needs is a collaborative organization by the Lucile Packard Foundation for Children's Health. Through grantmaking, advocacy, and communications, the Foundation promotes a system of care that improves the lives of children with special health care needs and their families.



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