

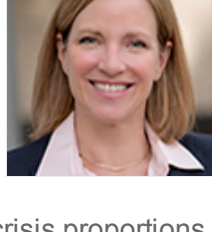
March 5, 2020

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

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

### Mental and Behavioral Health

#### A Blueprint for Improving Mental, Behavioral Health Care Services for Children



Mental and behavioral health issues are reaching crisis proportions among California's children, including those with complex medical needs, yet the state lacks a coherent system of care. The California Children's Hospital Association (CCHA) has released a report documenting the roadblocks to quality care and offering recommendations for action. CCHA President & CEO Ann-Louise Kuhns discusses the report in a [Question and Answer](#) with our staff. See the [full report](#) and an infographic [fact sheet](#) (PDF).

Also see a national perspective on this issue: [Children's Hospitals Enter 2020 with Renewed Focus on Priorities](#)

### Family Engagement

#### How to Achieve Authentic Family Partnership

In an essay for the National Institute for Children's Health Quality (NICHQ), board member Cara Coleman, JD, MPH, reflects on the lack of true family partnership during her 11 years of seeking care for her daughter, who required comprehensive in-home medical care. As a program manager for Family Voices and a Foundation grantee, she now is committed to helping health care providers and professionals engage in authentic family partnership, both at the individual and systems level. [Read her essay](#).

Also See: [Five Strategies for Building Diversity in a Patient Family Advisory Council](#) – from the National Institute for Children's Health Quality

#### Presentations Sought for Patient Family Centered Care Conference

The 10th Annual Patient Family Centered Care Conference is accepting proposals for presentation of work that highlights the value of engagement of patients and family caregivers in health care. The deadline is **March 23**. Find [details](#) (PDF) about the conference and the application process.

### Children with Medical Complexity

#### Lawsuit Filed to Improve Medicaid In-Home Services for Children with Complex Medical Needs

Nine children with complex medical needs and their families have filed a lawsuit in Missouri to compel the state to ensure coverage of the in-home nursing care that it has found the children need. The services are required under the Medicaid Act and the Americans with Disabilities Act, but are not being provided. The children are represented by the National Health Law Program and Legal Services of Eastern Missouri. [Read more](#).

#### In Brief

- [Piloting Voice Technology to Improve Care and Independence for People with Complex Needs](#) – from the Center for Health Care Strategies
- **March 6** is the new deadline to apply to host a [complex care regional convening](#) in your community.

#### Transition to Adult Care

- [Healthcare Transition: A Free Online Course for Patients and Families](#) – The course helps identify youth readiness for transition, suggests best practices, and describes measurable outcomes.

### Research

- Hospital Discharge: [Through a More Efficient Discharge System, Cincinnati Children's Reduced Costs to Families and Insurers, and Improved the Overall Patient Experience](#)
- [International Survey: Primary Care Physicians in US Struggle More to Coordinate Care and Communicate with Other Providers but Offer Patients More Health IT Tools](#) – from The Commonwealth Fund

### Advocacy Opportunity

#### Advocates Seek Support for Funding of Respite Care

Federal grants for the Lifespan Respite Care Program (LRCP) provide direct planned and emergency respite services to family caregivers, ensure that services are person and family-centered, and make respite more available and affordable to underserved families. Two members of Congress are seeking sign-ons from other members to a letter asking Congressional appropriators to fund the LRCP at \$10 million in FY 2021. Stakeholders are urging constituents to call their representatives to ask them to sign the letter. The deadline is **March 9**. [Read more](#) (PDF).

Also See: [S. 995 Lifespan Respite Care Reauthorization Act of 2019](#)

### National Policy

#### Public Charge Rule Now in Effect

The "public charge" rule, which greatly expands the government's ability to label certain immigrants as dependent on government benefits, became active again on February 24, even as litigation is pending. The rule, strongly opposed by child and family advocates, has major implications for families and for immigration. There are many exceptions to the public charge rule. Families can find details in [English](#) (PDF) and [Español](#) (PDF).

#### In Brief

- [What Do Older Adults and People with Disabilities Need to Know about Coronavirus Disease 2019 \(COVID-19\)?](#) – from the Administration for Community Living, US Department of Health and Human Services

### Palliative Care

#### Webinar: Spirituality in Children and Families Facing Serious Illness

**Date** Thursday, March 12  
**Time** 12 to 1 p.m. Pacific Time  
**Sponsor** Stanford Center for Continuing Medical Education  
**Details** This session will describe the spiritual needs of children and their families as they face serious illness and the end of life, and help clinicians recognize their role in their patients' spiritual care. Fee. CME available. [Read more and register](#).

Also See: *Complex Child* March Issue: [Palliative Care and Death](#)

### Special Education

- [School Lockdown Drills Pose Particular Challenges \(and Risks\) for Students with Disabilities](#) – from Child Trends

### Webinar

#### CalABLE Spotlight

**Date** Thursday, March 12  
**Time** 11 a.m. Pacific Time  
**Sponsor** ABLE National Resource Center  
**Details** State ABLE programs that are a part of multi-state collaborations will provide general guidance and best practices in a series of "ABLE Program Spotlight" webinars. This webinar will highlight CalABLE, the California program that allows people with disabilities to establish a tax-advantaged savings account without losing public benefits. [Read more and register](#).

### In the News

- [My Coronavirus Prep Includes Protecting My Disabled Child](#)  
*Washington Post*, 3/4/20
- [A Third of Pediatricians Still Don't Do Developmental Screenings](#)  
*Disability Scoop*, 3/2/20
- [Who's Caring for Family Caregivers? 1 in 5 Says Health Is Poor](#)  
*U.S. News & World Report*, 2/20/20

#### 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.

