

## California Advocacy Network

for Children with Special Health Care Needs

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

Dear Readers: Our next newsletter is scheduled for January 7, 2021. We wish you and your families a healthy and happy new year.

### Research

#### Children and Youth with Special Health Care Needs in Foster Care

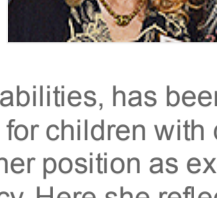
A new issue brief from Child Trends examines the prevalence of children and youth with special health care needs in the foster care system. CYSHCN comprise about 24 percent of the foster care population. The brief provides an overview of the literature on CYSHCN and their experiences in foster care, an explanation of the study findings, and a brief discussion of practice and policy implications. [Read the brief.](#)

### Family Engagement

#### Proposals Sought for Family Voices Leadership Conference

*Families as Partners Shaping the Future in Times of Crisis* is the theme for the Family Voices virtual leadership conference, scheduled to begin on June 8. Family Voices is seeking proposals for one-hour webinars, particularly on the topics of health equity, supporting families during the pandemic, telehealth, family and youth engagement, organizational development, communication strategies, and impacting policies. Proposals are due **January 27, 2021**. [Read more and apply.](#)

#### Q&A: A Lifetime of Advocating for Families



Juno Duenas, parent of a daughter with severe disabilities, has been a tenacious and passionate leader for more than 30 years in advocating for better care and services for children with disabilities and their families, in California and nationally. As of December 18, she will retire from her position as executive director of [Support for Families of Children with Disabilities](#), a parent-run San Francisco agency. Here she reflects on her decades of championing the family perspective, and what lies ahead for her. [Read the Q&A.](#)

### Network News

#### Banding Together to Change the System: A Case Study on Incontinence Care

Some individuals may require lifelong use of diapers and incontinence supplies due to their conditions. Requirements for constant prescription renewal cause challenges and frustrations for them and their families. California's Orange County Care Coordination Collaborative for Kids, part of the [California Community Care Coordination Collaborative](#), organized a cross-sector collaboration that led to implementation of an authorization process that flags cases of children who have lifelong incontinence so that they receive diapers until they age out of the California Children's Services program at 21. [Read about the collaboration.](#)

### Transition to Adult Care

#### Webinar: Creating an Evidence-Driven Process for Preparing Youth, Families for Transition to Adult Care

**Date** Friday, December 18

**Time** 11:30 a.m. Pacific Time

**Sponsor** National Council for Behavioral Health

**Details** Having a structured process for transition to adult care is associated with improvements in health and well-being, self-care skill-building, satisfaction, use of care in adult systems, and reductions in hospital use. This session will introduce the [Six Core Elements](#) of health care transition, and will discuss an innovative health care transition approach for adaptation in a variety of care settings. It also will make available existing tools and resources and address current implementation challenges facing providers. [Read more and register.](#)

### Telehealth

#### Take the Family Voices Telehealth Readiness Quiz

As health care providers ramp up the use of telemedicine, Family Voices is interested in improving families' access to and use of telehealth. Families are asked to complete a survey describing their access to telehealth, and their confidence in and concerns about virtual services. Take the anonymous [survey](#).

### COVID-19 Information

See our [COVID-19 web page](#) for additional resources and information.

- A recording of the webinar, [Supporting Children and Youth with Special Health Care Needs During COVID-19](#), from [State Health & Value Strategies](#), is available.
- [Telehealth and COVID-19](#) is a fact sheet from the [Insure the Uninsured Project](#) about the telehealth policies put into place during the pandemic and considerations for the post-pandemic environment.
- A recording of the webinar, [Pediatric Telehealth Strategies During and Post \(?\) the COVID-19 Pandemic](#), from the [National Institute for Children's Health Quality](#), is available.

### National Policy

#### In Brief

- [New Centers for Medicare and Medicaid \(CMS\) Rule Would Weaken Families First Continuous Coverage Protection in Medicaid](#) – from the Georgetown Center for Children and Families
- [Now on Demand: Mitigating Coverage Loss When Medicaid Continuous Coverage Requirements Expire](#) – See materials from a webinar from Manatt Health, the American Academy of Pediatrics, Family Voices, and the Georgetown University Center for Children and Families

### California Policy

#### In Brief

- The California Department of Health Care Services has decided to extend the full implementation of the [changes to Medi-Cal prescription policy](#) until April 1, 2021.
- [California Policy Needs During COVID and Beyond: Telehealth](#) – An issue brief from the National Health Law Program discusses which telehealth policy flexibilities should or should not remain after the pandemic, and what other policy changes are needed.

### Events

#### Deadline Extended for Proposals to Present at AMCHP Conference

The 2021 conference of the Association of Maternal and Child Health Programs, with the theme *Global Meets Local: A Global Approach for Local Outcomes*, is scheduled for May 23-25 in New Orleans. Proposals for workshops, skills-building sessions, or posters must be submitted by **December 30**. [Read more and apply.](#) Registration is now open for the conference, which may be an in-person/virtual hybrid depending on current circumstances. Payment is not required at time of registration. [Register.](#)

### Special Education

- [Characteristics of Preschool Special Education Services and Educators](#) – Mathematica assembled a comprehensive nationwide study on services for children ages 3 to 5 with disabilities.

### Resources

- [Complex Child](#) – Includes [new articles on COVID-19](#)
- [Exceptional Parent Magazine](#) December Issue – [Family, Community and the Holidays](#)
- [Create a Financial Plan Using Free Resources from The Arc](#)

### Did You Know?

#### Kidsdata.org to Move to New Home

Our Foundation has selected PRB to be the new home for [kidsdata.org](#), our program that provides data on the health and well-being of California's children, often with national comparisons. [Read more.](#)

### In the News

- [New Program Aims to Train Doctors on Developmental Disabilities](#)  
*Disability Scoop, 12/11/20*
- [COVID-19 Vaccine Should Go to Those with Developmental Disabilities First, Advocates Say](#)  
*Disability Scoop, 12/7/20*
- [COVID-19: Pandemic Has Hit Special Needs Kids Hard, Advocate's Report Says](#)  
*Vancouver Sun, 12/4/20*
- [Feds Reach 'Landmark Agreement' on Rights of Parents with Disabilities](#)  
*Disability Scoop, 12/1/20*

#### 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.

[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 organized 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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