

California Advocacy Network for Children with Special Health Care Needs

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

Editor's note: We wish you all a healthful and happy new year. The Newsletter will resume publication on January 5, 2023.

Network News

Foundation Increases Access to Journal Articles

Access to scholarly research is vital to creating effective and equitable systems of care for CYSHCN, yet family members and non-profit staff, who are essential to system improvement, often do not have access to key articles. Our Foundation recently reviewed all journal articles produced with our grant funding to ensure that these articles are freely available on our website. Going forward, we are committed to making the work we support accessible to all. See the newly accessible articles:

- [A Healthy Life for a Child with Medical Complexity: 10 Domains for Conceptualizing Health](#) (*Pediatrics*, September 2018)
- [Experts' Perspectives toward a Population Health Approach for Children with Medical Complexity](#) (*Academic Pediatrics*, August 2017)
- [Validation of a Parent-Reported Experience Measure of Integrated Care](#) (*Pediatrics*, December 2016)
- [The Medical Home and Hospital Readmissions](#) (*Pediatrics*, December 2015)
- [Supporting Self-Management of Chronic Health Problems](#) (*Pediatrics*, May 2015)
- [Reshaping Pediatric Practice](#) (*Pediatrics*, February 2013)

Public Health Emergency Unwinding

Website Provides Ongoing Information on Unwinding

The COVID-19 Public Health Emergency likely will be extended until April 2023, but early preparation is essential to ensure that children do not lose health coverage. The Georgetown Center for Children and Families maintains an "unwinding resources" web page that offers a breadth of information for policymakers, care providers, and families to assist in planning and preparation. [Read more.](#)

Pediatric Palliative Care

Parents Are Focus of First Webinar in 2023 Series

Registration is open for the 2023 Pediatric Palliative Care Webinar Series, which begins on January 19 with a session focused on parents of children with medical complexity. The series was created by the Pennsylvania Pediatric Palliative Care Coalition, Greater Illinois Pediatric Palliative Care Coalition, Children's Hospice & Palliative Care Coalition of California, and the CSU Shiley Haynes Institute for Palliative Care. [Read about the series and the upcoming topics.](#) Fee.

Home- and Community-Based Care



The recording of the webinar [Innovating Digitally Enabled Home-Based Care: Promoting Longer, Healthier Living](#) now is available.

In Brief

- [Labor Department Crackdown on Caregiver Industry Uncovers Widespread Violations](#) - from *Disability Scoop*, 12/1/22

Special Education

Ed Department Wants Expedited Evaluations for Students with Disabilities Who Move

The U.S. Department of Education has issued guidance that outlines steps schools should be taking to ease the transition for "highly mobile children" in accessing special education services. The category incorporates a range of children, including those from military families, migrants, and homeless and foster children. [Read more.](#)

In Brief

- [Forty-seven Years Later, Are We Delivering on the Promise of the Individuals with Disabilities Education Act?](#) - from US Department of Education, Office of Special Education and Rehabilitative Services

California Children's Services

Take a Survey Regarding CCS Services

CCS beneficiaries and their families are invited to complete a survey created by the National Health Law Program (NHeLP) to learn about family experiences with the CCS program. Questions about service denials and the CCS appeal process are included in the survey, whose results will inform recommendations to the Department of Health Care Services, which oversees the CCS program. NHeLP also is interested in connecting with families who would like to further discuss their experiences with the program. Take the survey in [English](#) or [en español](#) by **December 31**.

Intellectual and Developmental Disabilities



A recording of the Little Hoover Commission's third Hearing on California's Developmental Disabilities System now is available in [English](#) and [en español](#).

In Brief

- ['Impending Intergenerational Crisis': Americans with IDD Lack Long-Term Care Plans](#) - from *Disability Scoop*, 12/7/22

National Policy

- [Analysis: 30 Years After the Americans with Disabilities Act, There's Still Work to Be Done](#) - from *California Health Report*, 12/2/22

California Policy

State Outlines Planned Improvements to Medi-Cal for Children, Families

The Department of Health Care Services has released a set of slides that describe the numerous programs and initiatives designed to improve the Medi-Cal program, on which many CYSHCN depend for health care coverage. The slides cover the California Advancing and Innovating Medi-Cal (CalAIM) initiative, improvements to Medi-Cal eligibility policy, new physical and behavioral health policies and benefits, and the Children and Youth Behavioral Health Initiative. [See the slides.](#)

Related: [California Wants to Protect Kids Against Losing Medicaid Coverage](#) - from *San Francisco Chronicle*, 11/11/22

In the News

- *Exceptional Parent Magazine* - [The Holidays - Family and Community](#)
- [Google Enhances Accessibility Information](#) *Disability Scoop*, 12/8/22

We'd like to hear from you

Let us know what's happening with your organization or family. Email newsletter assistant editor Hannah Au at Hannah.Au@pfch.org with your news or updates. Or contact newsletter editor: Eileen Walsh at 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 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.

