

## Children and Youth with Special Health Care Needs

### Network Newsletter

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

#### TRANSITION TO ADULT CARE

##### A Framework to Guide Development of New Quality Measures of Transition to Adult Care

Few youth and young adults with chronic conditions receive critically necessary guidance as they transition from pediatric to adult care, an issue compounded by the lack of quality measures. A new open-access article in the *Journal of Adolescent Health* provides a comprehensive framework for health care transition that identifies gaps and proposes measures to help improve the process. The research, from the National Alliance to Advance Adolescent Health, was supported by our Foundation. [Read the article.](#)

#### HOME- AND COMMUNITY-BASED CARE

##### Still Time to Register: Paid Family Caregiving Webinar

<b>DATE</b>	Wednesday, March 8
<b>TIME</b>	10 to 11 a.m. Pacific Time
<b>SPONSOR</b>	Lucile Packard Foundation for Children's Health
<b>DETAILS</b>	This webinar will provide a brief overview of laws that govern paying family members to care for children with medical complexity, and then spotlight specific models of paid family caregiving and how they have been expanded recently in several states. <a href="#">Read more and register.</a>

Related: [Paying Family Medical Caregivers for Children's Home Healthcare in Colorado: A Working Medicaid Model](#) – from *The Journal of Pediatrics*

##### Article: Nursing Shortage Puts Medically Fragile Children at Risk, Spurs Calls for Change

Several parents detail their often-futile searches for nurses to help care for their medically fragile children at home, and the enormous stress it puts on their families. Ideas for mitigating the nursing shortage, a longstanding issue that has been exacerbated by the COVID-19 pandemic, also are outlined in this article from the *California Health Report*. [Read more.](#)

#### CHILDREN WITH MEDICAL COMPLEXITY

##### In Conversation: The Role of Academic Medicine in Helping Families

In a blog post, *Lessons in Humility: Building a Foundation for a Regional Network of Complex Care*, two academic CYSHCN researchers discuss how a common interest in the "pain points" of the system of care for children with complex needs brought together North Carolina families, parents, state agencies, clinicians, researchers, and community agencies. Their meetings evolved into a coalition in which members collaborate on projects informed by lived experience. The authors suggest that all states have the potential to develop such a broad partnership, and discuss how including multiple viewpoints can enhance the relevance and value of academic research. [Read more.](#)

##### Opportunity to Present Complex Care Work at National Conference

The Camden Coalition's National Center for Complex Health and Social Needs is seeking proposals for workshop and beehive presentations for its annual [Putting Care at the Center](#) conference, set for November 1-3 in Boston. Complex care leaders, practitioners, students, researchers, advocates, and others wishing to share resources and tools, innovative programs/partnerships, and research findings may apply. Workshop proposals are due **March 13**, and beehives are due **June 15**. [Read more and apply.](#)

#### PEDIATRIC PALLIATIVE CARE

##### Common Problem - Uncommon Solution: Managing Pediatric Pain with Methadone

<b>DATE</b>	Thursday, March 16
<b>TIME</b>	12 to 1 p.m. Pacific Time
<b>SPONSORS</b>	Pennsylvania's 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
<b>DETAILS</b>	Methadone, when dosed appropriately, may improve pain control for children even when other opioids have been insufficient. Providers are often hesitant to prescribe methadone for children due to somewhat complex pharmacology. Attendees will increase confidence and understanding of when to initiate, monitor, and care for children on methadone safely and effectively. <a href="#">Read more and register.</a> Fee.

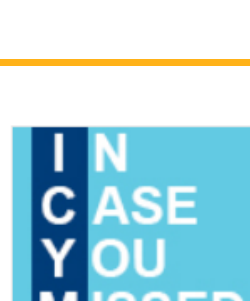
#### PUBLIC HEALTH EMERGENCY UNWINDING

##### Resources Highlight Issues Related to Upcoming Insurance Changes

Organizations around the country are offering extensive information and guidance to ensure that CYSHCN retain health care coverage as the Public Health Emergency and the Medicaid Continuous Coverage protection come to an end. Some sites provide compilations that cover multiple topics, including advice for advocates:

- [Public Health Emergency and Continuous Coverage Unwinding Resources](#) – from the National Health Law Program
- [Unwinding Resources](#) – from the Georgetown Center for Children and Families
- [Fact Sheet: COVID-19 Public Health Emergency Transition Roadmap](#) - from the US Department of Health and Human Services
- [Public Health Emergency Unwinding Resources](#) – from the Kaiser Family Foundation

#### HEALTH EQUITY



The slides and recording of the webinar, [Supporting Providers of Color in the Pediatric Workforce: Practices to Diversify the Workforce and Improve Retention](#) now are available.

#### CALIFORNIA POLICY

##### Fact Sheet: Tracking Upcoming Changes to Medi-Cal Services

Over the next two years, California is making major changes to the delivery of Medi-Cal services, which cover many CYSHCN. The National Health Law Program has issued a fact sheet that outlines some of these upcoming changes and discusses consumer protections that are designed to ensure that beneficiaries maintain access to needed care. [Read the fact sheet.](#)

Related: [California to Launch Statewide Medi-Cal Population Health Management Program](#)

##### New: State Launches a Medi-Cal Member Advisory Committee

The Department of Health Care Services has created an advisory committee that offers the opportunity for Medi-Cal members to directly provide input to the Department's director and leadership staff. The Committee will be composed entirely of Medi-Cal members and family caregivers with direct experience with the program. Many CYSHCN receive their health insurance through Medi-Cal. To protect the privacy of the Medi-Cal members the meetings will not be open to the public. The Department will post meeting summaries online and will report key findings. Operational support of the Committee is funded by the California Health Care Foundation and our Foundation. [Read more.](#)

#### EVENTS

##### CYSHCN, Family Leadership on Agenda for AMCHP Conference

Family leadership and equity and access for CYSHCN are among the subjects to be addressed at the Association of Maternal & Child Health Program's 2023 Annual Conference, scheduled May 6-9 in New Orleans and virtually. See the [full list](#) of conference workshops, skill-building sessions and roundtables.

##### Congreso Familiar: Dos Seminarios Web

Congreso Familiar es una conferencia dedicada a promover educación y liderazgo en familias Latinas que tienen niños o miembros de familia con discapacidades. Próximas presentaciones: Oportunidades de Inmigración para Padres con Niños con Necesidades Especiales (March 4), y Aprenda donde obtener servicios legales para su ser querido (March 11).

[Leer más y registrarse.](#)

#### RESOURCES

- [Traveling with a Child with Medical Complexity](#) – Tips from the Courageous Parents Network in English and Español
- [Darby's Legacy: Best Practices When Serving Families with Infants and Toddlers Who Are Medically Fragile](#) – from California Early Start

#### IN THE NEWS

- [New Lego Sets Feature Characters with a Range of Disabilities](#)  
*Disability Scoop*, 2/24/23
- [Ed Department: Graduation Rate for Students with Disabilities on the Rise](#)  
*Disability Scoop*, 2/23/23
- [Social Security Proposes Change to SSI Benefits](#)  
*Disability Scoop*, 2/21/23
- [My Child is in an Impossible Place, and I Am There with Her](#)  
*New York Times*, 2/17/23

#### 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@jpfch.org](mailto:Hannah.Au@jpfch.org) with your news or updates. Or contact newsletter editor: Eileen Walsh at [Eileen.Walsh@jpfch.org](mailto:Eileen.Walsh@jpfch.org).

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