

August 4, 2022

California Advocacy Network for Children with Special Health Care Needs

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

Editor's Note: The newsletter will be on a break until after Labor Day, with our next issue scheduled for September 8. In the meantime, we will send emails about issues or events as necessary.

System Improvement

National CYSHCN Research Network Funding Extended

The CYSHCN Research Network (CYSHCNNet) is a group of child systems researchers, families and youth, clinician partners, national organizations, and others focused on improving health systems for CYSHCN. Founded in 2017, the research network, which has 13 sites across the country and serves all 50 states, now has received funding for an additional five years from the federal Maternal and Child Health Bureau. [Read about the extensive work of CYSHCNNet.](#)

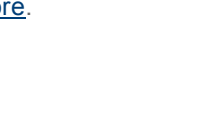
Family Engagement

Pediatrics Journal Connects Research Findings with Families' Real-Life Needs

"Family Connections with *Pediatrics*" is a series of family-written blogs, each of which summarizes a research article in *Pediatrics* and explains what the findings may mean for families' real-life situations. Each post suggests ways that families and health care professionals can work together for the health and well-being of children and families. [Read an introduction to the series](#) and [all the blog posts](#).

Health Equity

Helping Health Care Providers Avoid Miscommunication with Spanish-speaking Families



As a parent mentor at Lucile Packard Children's Hospital Stanford, Marsha Perez provides bilingual support for Spanish-speaking families in the hospital's care coordination program for children with medical complexity. In an interview, she describes cultural and language issues that may go unrecognized in medical situations, and offers strategies for how caregivers might enhance their communication with Spanish-speaking families. [Read more.](#)

Developmental Disabilities

A Conversation about Regional Center Inequities

Public Counsel, with support from our Foundation, had produced a [series of reports](#) over the past several years documenting ethnic and racial inequities in services provided to children at California's regional centers. In a short video, Dr. Ryan Padrez, pediatrician at Stanford Children's Health, and Brian Capra, the senior staff attorney at Public Counsel who conducted the research, discuss the reports' findings, advocacy efforts, and possibilities for improving the system. [Watch the video.](#)

Webinar: Strategies for Improving Care Coordination for Individuals with Intellectual/Developmental Disabilities

Date Tuesday, August 9
Time 11 a.m. to 12:30 p.m. Pacific Time
Sponsor Resources for Integrated Care
Details Speakers will discuss strategies for providing coordinated care for individuals with intellectual and developmental disabilities, including person-centered medical assessment considerations, risk stratification strategies to drive interventions, and family or caregiver support, education, and outreach. Not pediatric specific. CEC credit available. [Learn more and register.](#)

Home- and Community- Based Services

Policy Brief: State Approaches to Expanded Federal Investment in Home- and Community-Based Services

Children with special health care needs receive attention in a new report from the National Academy for State Health Policy about how states are using expanded federal funding for Medicaid home- and community-based services (HCBS). All 50 states have received approval from the Centers for Medicare and Medicaid Services to claim the enhanced Medicaid HCBS Federal Medical Assistance Percentage and begin to implement proposals. [Read the policy brief.](#)

Palliative Care

Webinar: Conversations Matter – Pediatric Advance Care Planning and Shared Decision Making with Adolescents

Date Thursday, August 18
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, and the CSU Shiley Haynes Institute for Palliative Care
Details This presentation will describe how to conduct pediatric advance care planning safely, the best timing from the adolescent patient's perspective, and outcomes from select randomized clinical trials. [Read more and register.](#)

Medical Complexity

Reminder: Putting Care at the Center 2022 Conference

Dates September 21-23
Location Sacramento, CA
Sponsor Camden Coalition
Details *Values and Value in Complex Care* is the theme for this year's Putting Care at the Center national conference on complex care. Our Foundation is a conference sponsor, and the agenda includes sessions on supporting family leaders and addressing how to care for children with medical complexity. [Read more and register by September 19.](#)

Health Care Finance

Recent Publications Highlight Funding Issues

The Catalyst Center has assembled a "summer reading list" that features its most recent resources and some of its most popular reports on a range of topics, including care coordination, Medicaid Managed Care, and family financial hardship. [See the links.](#)

National Policy

- [Bipartisan Safer Communities Act Provision Directs CMS to Review State EPSDT Implementation, including in Managed Care](#) – from the Georgetown Center for Children and Families
- [Federal Disability Employment Program Bans Subminimum Wage](#) – from Disability Scoop

Special Education

Advice on Returning to School in "New Normal" Times

The Child Neurology Foundation and the American Academy of Pediatrics have joined forces with medical and educational experts to create a [Back to School Educational Series](#) that addresses issues such as when a child should return to school, medications in school, and holding an IEP in the "new normal" COVID-19 era. The series also includes a list of additional resources to inform decision-making for families of children with special needs.

Telehealth

Archived Webinar: Virtual Care



The [recording and slides](#) from the webinar, *Navigating the Virtual Care Explosion: Mapping the Shifting Policy, Payment and Strategy Landscapes*, are now available.

Eventos

Serie Virtual: La Toma de Decisiones con Apoyo

Fechas Los Jueves: 18 de Agosto, 25 de Agosto, 1 de Septiembre
Hora 5 a 7 p.m. Hora del Pacífico
Patrocinador Congreso Familiar
Detalles Congreso Familiar es una conferencia dedicada a promover la educación y el liderazgo en familias Latinas que tienen hijos o familiares con discapacidades. En esta serie de tres presentaciones, aprenderá más sobre sus opciones para continuar a apoyando a su ser querido después de que cumpla 18 años a través del nuevo proceso de la toma de decisiones con apoyo. [Aprende más y regístrate.](#)

Resources

- Noting that legislators are at home in their districts in August, The Arc has created an [August Recess Toolkit](#) that offers resources, tools, and tips for educating members of Congress about key issues affecting individuals with special needs and their families.
- The National Suicide Prevention Lifeline has changed from a 10-digit number to 988, an easy-to-remember number for free and confidential emotional support, 24 hours a day, 7 days a week, for people in suicidal crisis or emotional distress. [Read more.](#)

In the News

- [New Push Underway to Train Doctors, Dentists on Developmental Disabilities](#)
Disability Scoop, 7/29/22
- [PBS Documentary Explores Shortcomings of Disability Support System](#)
Disability Scoop, 7/26/22
- [Study Shows Disability Representation Onscreen Is Increasing, but Still Falls Short](#)
NY Times, 7/26/22
- [Parents Become Drug Developers to Save Their Children's Lives](#)
Kaiser Health News, 7/21/22
- [Biden Administration Warns Schools about Disciplining Students with Disabilities](#)
Disability Scoop, 7/20/22

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@lpfch.org with your news or updates. Or contact newsletter editor: Eileen Walsh at Eileen.Walsh@lpfch.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.

