

California Advocacy Network

for Children with Special Health Care Needs

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

Family Engagement

CYSHCNet Develops Standards of Compensation for Family Partners in Research

The knowledge and experience of families and youth is invaluable to research about children with special health care needs (CSHCN), but family contributions have not been consistently recognized or compensated. CYSHCNet, a national research network founded in 2017, has developed [a standard of compensation for youth and family partners](#) (PDF) who participate on a research team, noting possible roles and responsibilities, as well as the type of support and compensation family members might expect. CYSHCNet also has created a companion piece, [a standard of compensation for research teams](#) (PDF) on how researchers can identify, orient, support, and compensate family and youth partners. [Read more about CYSHCNet.](#)

Children with Medical Complexity

Study: Hospital Readmission of Adolescents and Young Adults with Complex Chronic Disease

Adolescents and young adults with complex conditions are a growing population who often require hospitalization for acute health problems as they grow into adulthood. A new study finds that they also may be at increased risk of readmission as they assume more responsibility for self-management of their condition and transfer from pediatric to adult care. The authors suggest that increased attention to the hospital discharge process and self-management is necessary. [Read the study](#) in *JAMA Network*.

California Children's Services

CCS Stakeholder Advisory Group to Meet

Date Wednesday, October 9
Time 10 a.m. – TBD Pacific Time
Location 1700 K Street, Sacramento – First Floor Conference Room
Dial-In (888) 989-6488; Passcode: 1945234
Details The Advisory Group provides feedback to the Department of Health Care Services on delivery of care to CCS-enrolled children and their families, and monitors implementation of the Whole Child Model. The Advisory Group [website](#) is still being updated, so the agenda may not be available online.

Department of Health Care Services Director Jennifer Kent Resigns

Jennifer Kent, director of the Department of Health Care Services (DHCS) since February 2015, has submitted her resignation, effective at the end of September. DHCS oversees [California Children's Services](#) and [Medi-Cal](#), both of which are extremely important to CSHCN and their families.

Viewpoint

Rare Diseases Deserve Our Attention: A Personal and Professional Story

As president and CEO of the National Institute for Children's Health Quality (NICHQ), pediatrician Scott Berns understands the challenges facing children and families living with rare diseases. But he also understands as a father who lost his only child to one of the world's rarest diseases. [Read his story](#) and his thoughts on why an increased sense of national urgency is imperative to address rare diseases, which affect nearly one in 10 individuals.

Transition to Adult Care

In Brief

- [Ed Department Wants Input on Improving Transition Services](#) – from Disability Scoop
- [State Internship Program for CYSHCN Pays Dividends](#) – from the Association of Maternal & Child Health Programs

Pediatric Palliative Care

It's About the Journey: Pediatric Palliative Care West Coast Summit

Date October 28-29
Location Oakland, CA
Sponsor George Mark Children's House
Details A gathering of health care professionals and providers from a variety of disciplines to discuss issues such as integrative care, symptom management, self-care, communication, and other topics related to the care of fragile children with complex medical conditions. Fee. Early bird registration ends **September 30**. CME and CEU available. [Read more and register.](#)

Quality Standards

Using the National Standards as a Key Resource to Support the CSHCN Workforce

A high turnover rate among employees in Title V programs that serve children and youth with special health care needs is a challenge for states. The Association of Maternal & Child Health Programs (AMCHP) suggests that the [National Standards for Systems of Care for CYSHCN](#) may be a helpful tool for developing leadership and workforce capacity. A new report highlights examples of how three states use the standards to improve their workforce capacity. [Read more.](#)

National Policy

Webinar: Keeping Medicaid's Promise for Children with Special Health Care Needs

Date Wednesday, October 2
Time 12 p.m. to 1:30 p.m. Pacific Time
Sponsors Manatt Health, Robert Wood Johnson Foundation, Lucile Packard Foundation for Children's Health
Details A discussion about how state Medicaid agencies, families, advocates, providers, and other stakeholders can partner to improve access to services for Medicaid-enrolled CSHCN. This webinar will feature a suite of actions that states can implement. CLE available. [Read more and register.](#)

Legislation, Lawsuits Seek to Block Proposed Changes to 'Public Charge'

The federal government's proposed changes to its definition of "public charge" are scheduled to go into effect on October 15. The proposal greatly expands the government's ability to label legal immigrants who are not yet citizens as financially dependent on the government. The changes have major implications for families. Twenty states have filed suits to block implementation, and most recently a Senate bill was introduced on September 17. [Read more](#) and see [Frequently Asked Questions](#).

Research

Assistive Technology Helps Kids Connect with the World

Many children are unable to communicate because of loss of speech or movement. In *Children's Hospitals Today*, Larry Levine, president and CEO of Blythedale Children's Hospital in Valhalla, New York, describes how assistive technology can improve the functional capacities of children at home and in school and help them find a way to "speak" and connect with their families and the world. [Read more.](#)

Resources

- [In Case of Emergency, CYSHCN Parents Now Have a Plan](#) – from the Association of Maternal & Child Health Programs
- *Exceptional Parent Magazine* September Issue – [Back to School](#)
- *Complex Child* September Issue: [Accessibility](#).

Event

Coming Up: The Arc's National Convention

Date October 11-14
Location Washington, DC
Sponsor The Arc
Details Registration is open for The Arc's 2019 National Convention in Washington, DC. Individuals with intellectual or developmental disabilities, family members, and professionals attend and discuss how to navigate and work to improve employment, education, housing, technology, criminal justice, and more. Fee. [Read more and register.](#)

In the News

- [Disability Portrayals in Hollywood Films Plummet](#)
Disability Scoop, 9/12/19
- [In a Tight Labor Market, a Disability May Not Be a Barrier](#)
NY Times, 9/5/19
- ['Just Ask' Says Sonia Sotomayor. She Knows What It's Like to Feel Different](#)
NPR Shots, 9/1/19

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 with your news or updates.

