

California Advocacy Network for Children with Special Health Care Needs

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

Network News

Developing a Family-Centered National Research Agenda for CYSHCN: *Academic Pediatrics* Supplement



With the goal of narrowing the gaps between how health systems currently work and how they could work better for CYSHCN and their families, a national group of researchers and family leaders has created a family-centered national research agenda. Their findings are available in a just-published supplement to *Academic Pediatrics* that includes seven papers that explain each of the research agenda's priority topics, such as transition, telemedicine, and financing, plus an executive summary. In addition to implications for researchers, the agenda and research gaps reported are intended to influence policy and research funding decisions. The work was led by the [CYSHCN](#), with support from our Foundation. Read the [supplement](#).

Children with Medical Complexity

Webinar Reminder: Conversations with Families – Poly-pharmacy



Thursday, March 10
10 to 11 a.m. Pacific Time
[Read more and register.](#)

See the recording from the sixth seminar: [Disorders of Tone](#)

Webinar: Talking About Complex Care – Resources for Clear and Effective Messaging

Date Wednesday, March 16
Time 11 a.m. to 12 p.m. Pacific Time
Sponsors Center for Health Care Strategies and the National Center for Complex Health and Social Needs
Details This webinar will explore approaches to building support for complex care programs by clearly communicating to key audiences. It will orient attendees to the newly released guide, [Talking About Complex Care: A Guide for Clear and Effective Communications](#). Not pediatric specific. [Read more and register.](#)

Pediatric Palliative Care

Coming Up: West Coast Pediatric Palliative Care Summit

"Reframing Hope" is the theme for a two-day summit that will cover a breadth of topics related to pediatric palliative care. Hosted by George Mark Children's House, and sponsored in part by our Foundation, the summit is scheduled for March 28-29 in San Jose, California. Fee. CEU/CME credits available. [Read more and register.](#)

Webinar: Minute to Minute Mindfulness – Self-care Strategies for Busy Lives

Date Tuesday, March 15
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 Stress is an inevitable part of life, especially for those who are caregivers. A palliative care physician and a mindfulness teacher will discuss practical tools for managing stress and strategies for fitting these tools into busy lives. [Read more and register.](#)

Family Engagement

Graphic Recording Highlights Family Partnership Tools

A graphic recording from the Collaborative Improvement and Innovation Network to Advance Care for Children with Medical Complexity (CoIN) illustrates tools and approaches that can facilitate effective family partnership for quality improvement and innovation in clinical systems of care. Interdisciplinary teams can use the poster as a guidepost to foster progress in integrating family leaders as equal partners on the team. Read more about the work of the [CoIN](#) and [see the graphic](#) (PDF).

Webinar: Medi-Cal Rx and the Impact on CYSHCN

Date Wednesday, March 23
Time 12 p.m. Pacific Time
Sponsor Family Voices of California
Details This webinar will assist families of children and youth with special health care needs/disabilities who rely on medication provided through the recently revised Medi-Cal program, as well as the professionals who care for this population. [Read more and register.](#)

Health Equity

National Blueprint Targets Health Equity for People with Disabilities

In an effort to overcome decades of health disparities for people with disabilities, the National Council on Disability (NCD) has created a Health Equity Framework for policymakers that calls for an all-of-government approach to longstanding medical discrimination. The framework provides a roadmap for fixing systemic barriers within the health care system that impede the health of individuals with disabilities. NCD is an independent federal agency charged with advising the President, Congress, and other federal agencies regarding policies, programs, practices, and procedures that affect people with disabilities. [Read more about the framework.](#)

COVID-19 Information

- [The Department of Health and Human Services Issues New Guidance for Health Care Providers on Civil Rights Protections for People with Disabilities](#)
- [Biden Administration Announces New Actions to Address the Needs of People with Disabilities and Older Adults in Response to and Recovery from COVID-19](#)
- [Unwinding the Maintenance of Effort Requirement at the end of the Public Health Emergency: The Role of Title V Programs](#) – from the Catalyst Center

National Policy

Court Case Raises Challenges Regarding Disability Rights

A lawsuit brought by blind students against the Los Angeles Community College District could have far-reaching implications for the rights of individuals with disabilities. The Americans with Disabilities Act and Section 504 of the Rehabilitation Act protect disabled people from discrimination that is intentional. *Payan v. Los Angeles Community College District*, which potentially could go to the Supreme Court, hinges on whether these laws cover "unintentional discrimination." [Read more.](#)

Also see: [Ed Department Prods Schools on Compensatory Services for Students with Disabilities](#)

In Brief

- [Centers for Medicare and Medicaid Services Solicits Input on Potential Medicaid and CHIP Reforms Around Eligibility, Enrollment and Access](#)
- [What Can States Do to Reduce Risk of Children Unfairly Losing Health Insurance](#) – from the Georgetown Center for Children and Families

Resource

- The Creative Expressions Toolkit, produced by the Pediatric Palliative Care Coalition, is a resource that caregivers and families can use to provide children with fun activities in art, music, and play, at home, on trips, or in the hospital. The activities also promote movement, self-expression, and fine motor skills. [Learn more.](#)

Did You Know?

National Survey of Children's Health Data Released

The Data Resource for Child and Adolescent Health has posted the combined 2019-2020 National Survey of Children's Health (NSCH) datasets and codebooks, available through [childhealthdata.org](#). They include data from 72,210 children ages 0-17 years, including specific information on CSHCN.

In the News

- [Parents Struggle to Get Home Nurses for Kids Who Are Medically Fragile](#)
Disability Scoop, 2/23/22
- [Millions of Children Could Lose Medicaid Coverage Once the Public Health Emergency Ends](#)
CNN, 2/17/22

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

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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.

