

California Advocacy Network for Children with Special Health Care Needs

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

Network News

Year in Review: A Refresher on Key Issues

In work supported by our Foundation in 2022 a 10-part webinar series brought together clinicians and families to discuss a series of significant research questions related to children with medical complexity; two issue briefs highlighted resources that can be used to implement high-quality care coordination; and a journal article examined the intersection of diversity, equity, and inclusion in pediatric patient and family advisory councils. As the new year begins, read about some of the publications and webinars you may have missed, or refresh your knowledge with a second look. Find all 2022 publications [here](#).



- [Collaborative Conversations with Families to Advance the Clinical Care of Children with Medical Complexities \(CMC\) and Disabilities](#) (recap video) or see [individual topic recordings](#)
- [Aligning Quality Measures with the National Care Coordination Standards for Children and Youth with Special Health Care Needs](#)
- [Medicaid Financing of Care Coordination Services for Children and Youth with Special Health Care Needs](#)
- [The Intersection of Diversity, Equity, and Inclusion with Pediatric Patient and Family Advisory Councils](#)
- [Strategies to Ensure Continuous Coverage for Children at the End of the COVID-19 Public Health Emergency](#)
- [PediHome: Development of a Family-Reported Measure of Pediatric Home Healthcare Quality](#)
- [A National Health Systems Research Agenda for Children and Youth with Special Health Care Needs: Supplement to Academic Pediatrics](#)
- [A Guide for Designing a Value-Based Payment Initiative for Pediatric-to-Adult Transitional Care](#)

Family Engagement

Using the Family Engagement in Systems Assessment Tool: A Real World Example



As the Maternal and Child Health Coordinator for Alabama's Title V program serving children and youth with special health care needs, Stacey Neumann is leading efforts to strengthen family partnerships throughout the state's service districts. In collaboration with the State Parent Consultant, she implemented the Family Voices Family Engagement in Systems Assessment Tool (FESAT), developed with support from our Foundation. In an interview, she describes the experience of applying this approach and offers recommendations for use. Read the [Q&A](#) and [the FESAT Case Studies](#).

Family Voices Project: Promoting Equitable Access to Language Services for Families of CYSHCN

Family Voices and the American Academy of Pediatrics are joining forces in a federally funded project designed to improve the quality and use of language access services in health care settings for families who speak a language other than English. Families with lived experience will assist in developing educational tools and strategies for families, community health workers, and health care providers to improve the way they use language-access services. [Read more and see a video about the project in English and en español.](#)

Children with Medical Complexity

American Academy of Pediatrics Offers Support for Providers Who Serve CYSHCN

An Academy website provides guidance and resources to assist pediatricians and health care teams caring for children with medical complexity, and outlines ways to build successful partnerships with families and caregivers. [Read more.](#)

Reminder: Last Call for Proposals to Present Complex Care Work

January 18 is the deadline to apply to present a webinar on your complex care work in the series offered by the National Center for Complex Health and Social Needs. [Read more.](#)

Pediatric Palliative Care

Webinar: Parents of Children with Complex Medical Needs - Toward an Integrated Behavioral Health Approach

Date Thursday, January 19
Time 12 to 1 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 Speakers will highlight the growing population of parents as long-term caregivers who experience significant psychological distress and trauma; offer guidance to all providers about how to recognize and treat this population; and describe leadership experiences within the hospital setting to improve care for children and their families. [Register](#). Fee.

Health Equity

Webinar: Supporting Providers of Color in the Pediatric Workforce

Date Thursday, January 19
Time 9 to 10:30 a.m. Pacific Time
Sponsor Center for Health Care Strategies
Details This webinar will explore opportunities to recruit and support a pediatric workforce that is more racially and ethnically diverse and better reflects the communities served. It also will discuss anti-racist training opportunities for pediatric staff and residents to more effectively serve children most affected by structural racism. [Learn more and register.](#)

In Brief

- [Ignored, Punished, and Underserved: Understanding and Addressing Disparities in Education Experiences and Outcomes for Black Children with Disabilities](#) – from Bellwether and Easter Seals

Special Education

In Brief

- [The US Regulates How Hospitals Can Use Restraint and Seclusion. Why Not Schools?](#) – from *Disability Scoop*
- [Eye to Eye](#) seeks to improve the educational experience and outcomes of every student who learns differently, while engaging them and their allies in the movement for a more equitable and inclusive society.

California Children's Services

CCS Advisory Group to Meet

Date Wednesday, January 11
Time 1 to 4 p.m. Pacific Time
Details [See agenda and log-in information.](#)

National Policy

- [Medicaid Unwinding Will Begin in April but There's Good News in Congressional Funding Agreement](#) – from Georgetown Center for Children and Families

California Policy

State to Hold Medi-Cal Health Care Plans Accountable

The Department of Health Care Services has announced that it will impose financial sanctions on the state's Medi-Cal Managed Care Plans (MCPs) if they do not meet minimum performance measures, including some quality metrics of children's health. [Read more](#) (PDF).

Related: [Medicaid Managed Care: Quality Performance, Sanctions, and Transparency in California](#) – from Georgetown Center for Children and Families

Resources

- [Birth Defects and Infant Disorders Resources](#) (PDF) A list of resources from the American Academy of Pediatrics educates individuals, parents, and families by providing information needed to seek proper care. Health care clinicians also can learn more about how to deliver the best care for patients across all stages of life.
- [Parent to Parent USA](#) supports a national network of programs to ensure access to quality emotional support for families of individuals with disabilities and/or special health care needs.

In the News

- [Judy Woodruff on How Her Son with Disabilities Changed Her View of Health Care](#)
Washington Post, 12/29/22
- [Opinion: Why Are Schools Submitting Kids to This Barbaric Treatment?](#)
Washington Post, 12/22/22
- [Understanding Minority Youth with Disabilities Through Data and Personal Experience](#)
Mathematica, 12/14/22
- [Employment Helps Adults with Intellectual Disabilities See What They're Capable Of](#)
NPR, 12/5/22

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

