

California Advocacy Network

for Children with Special Health Care Needs

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

The Lucile Packard Foundation for Children's Health stands in solidarity with our Asian, Asian American, and Pacific Islander communities. Racial injustice is a health crisis. Recent attacks across the United States may leave parents struggling with how to launch or continue conversations about racism with their children. [Read about how to talk to your children about anti-Asian racism and violence.](#)

Network News

New Grants Support Providers, Caregivers

Four grants recently awarded by our Foundation will provide funding to create standards for continuity of care in pediatric intensive care units (PICUs), promote telehealth use, bolster self-management supports for families, and expand media coverage of children's issues. [Read about the grants.](#)

Webinar: CARE_PATH for Kids: A Family-Centered Approach to Shared Plans of Care

Date Thursday, April 15
Time 11 a.m. to 12 p.m. Pacific Time
Sponsors Child and Adolescent Health Measurement Initiative, with support from the Lucile Packard Foundation for Children's Health
Details Shared care planning for children with special health care needs must start with a comprehensive view of the child and family, and be anchored to their unique strengths and needs. This webinar will present the [CARE_PATH for Kids](#), a three-step, family-centered approach to the process of creating shared plans of care that complements existing models in the field. [Read more and register.](#)

Transition to Adult Care

A Family Toolkit: Pediatric-to-Adult Health Care Transition

A toolkit from Got Transition and its National Family Health Care Transition Advisory Group provides resources for youth and families to help youth assume more independence in taking care of their own health and using health services. Find information on whether a child is ready for transition, a transition timeline, questions to ask the doctor, and what turning 18 means for one's health, as well as links to webinars that discuss the toolkit and additional resources. [Read more.](#)

Mental and Behavioral Health

State Approaches to Improve Comprehensive School Mental Health Systems

The pandemic has reduced access to comprehensive mental health care for children and adolescents, many of whom receive their services through school. A new [report](#) from the National Academy for State Health Policy discusses recent federal actions to expand school mental health programs, and provides examples of how several states have introduced legislation to help schools enhance their mental health programs during and after the pandemic. The report also notes that the [National Standards for Systems of Care for CYSHCN](#), which were developed with support from our Foundation, are a resource that states can use to guide improvements to systems of care for children with special health care needs, including mental health systems.

Medical Complexity

- [Navigating the Challenges of Cross-Sector Partnerships to Meet the Needs of Older Adults and People with Disabilities](#) – A blog post from The Playbook: Better Care for People with Complex Needs.

California Children's Services

Families Sought to Complete Survey on CCS Services

The National Health Law Program (NHeLP) is soliciting feedback from families who have been served by the California Children's Services (CCS) program. NHeLP will use the information to identify gaps in CCS services and to inform its work to expand access to care. Responses will be confidential and are due by **April 11**. Take the survey in [English](#) or [Español](#).

Responsibility for NICU Care for CCS Clients in Medi-Cal Managed Care

Medi-Cal managed care organizations now deliver services to California Children's Services (CCS) clients in 21 counties, under a program called the Whole Child Model (WCM). The [Children's Regional Integrated Service System](#) has closely monitored the implementation of the WCM and has developed a series of issue papers identifying potential strategies to address issues and concerns. We are featuring one paper in each of the next several newsletters.

The second paper, on Neonatal Intensive Care Units (NICUs), recommends that the Department of Health Care Services (DHCS) require use of a standardized referral form by all WCM plans to notify CCS that NICU criteria have been met for a child, and to advise the appropriate CCS county of NICU eligibility. The paper also suggests that DHCS complete data analysis regarding the state of NICU referrals pre- and post-WCM and in comparison with traditional CCS counties. [See the first two papers.](#)

Pediatric Palliative Care

Stressed but Not Stressed Out: Practical Tools for Managing Stress

Date Wednesday, April 7
Time 9 to 10 a.m. Pacific Time
Sponsor Pediatric Palliative Care Coalition
Details Family members, caregivers, and medical professionals are invited to an interactive virtual discussion exploring issues facing the community caring for children with complex medical needs. Speakers will discuss practical tools for managing stress and strategies for fitting these tools into busy lives. [Read more and register.](#)

Health Equity

Promoting Equity in Advocating for Public Policies

Voices for Healthy Kids and the American Heart Association have published a [2021 Racial Equity in Public Policy Message Guide](#) (PDF), which offers advice for advocating with decision-makers to include racial equity in policymaking. [Learn more.](#)

COVID-19 Information

Find additional information and resources on our [COVID-19 web page](#).

- A [Child Neurology Foundation](#) video conversation about [PTSD During a Pandemic for Parents with Medically Fragile Children](#) features a mother of a child with multiple genetic mutations and a clinical psychologist who is an associate professor of pediatrics at Cincinnati Children's Hospital.
- [Special-Needs Children Still Seek Help After Year Afloat](#), according to an article in [CalMatters](#)
- The [Washington Post](#) reports on [Advocates to Education Department: Tell Schools to Focus Relief Funding on Students with Disabilities](#)

Resource

- [Developmental Screening Follow-up Practices and Policies](#) – Guidance and recommendations on follow-up practices when infants and toddlers demonstrate developmental concerns. From Zero to Three and the National Institute for Children's Health Quality.

Evento/Event

Congreso Familiar Virtual 2021

[Congreso Familiar](#) es una conferencia dedicada a promover la educación y el liderazgo en familias latinas que tienen hijos o familiares con discapacidades. Unase los próximos sábados a las 10 a.m. Pacífico para aprender sobre varias temas. Los presentadores hablaran sobre la inmigración en general, el Departamento de Rehabilitación, y el Programa de ABA (Análisis de Comportamiento Aplicado). [Ver el horario y registrarse.](#)

[Congreso Familiar](#) is a Spanish-language conference dedicated to promoting education and leadership in Latino families who have children or relatives with disabilities. On upcoming Saturdays at 10 a.m. Pacific Time presenters will discuss immigration in general, the Department of Rehabilitation, and the Applied Behavior Analysis (ABA) Program. [See the schedule and register.](#)

In the News

- [Waiting Lists May Be Eliminated for Disability Services Provided by Medicaid](#)
Disability Scoop, 3/22/21
- [The Costly, Painful, Lonely Burden of Care](#)
New York Times, 3/16/21
- [Parents Are DIYing Clothes for Their Kids Until Adaptive Brands Catch Up](#)
Romper, 3/14/21

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.

