

California Advocacy Network

for Children with Special Health Care Needs

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

CSHCN Families and Finance

Study: Children with Special Health Care Needs and Forgone Family Employment

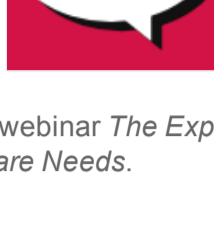
Researchers from Lurie Children's Hospital have published a study in *Pediatrics* which estimates that families lose an average of \$18,000 a year in wages when they must reduce work hours or leave a job to care for their child with special health care needs. The authors propose programs and policies to help address this lost income. [Read the abstract and see a video abstract](#)

Related: [Leaving Work to Care for Special Needs Child Takes Big Financial Toll](#)
– from U.S. News & World Report

Webinar: What Is a Pharmacy Benefit and How Does it Affect Families?

Date Tuesday, September 14
Time 11 a.m. to 12 p.m. Pacific Time
Sponsor Child Neurology Foundation
Details Topics will include a general overview of health insurance's pharmacy benefit component; common terms used by health insurance companies regarding pharmacy benefits; factors to consider when using a pharmacy benefit to fill prescriptions; and resources available that may help with medication costs. [Read more and register](#).

Archived Webinar



The [recording and slides](#) are now available for the webinar *The Expanded Child Tax Credit: Implications for Families Raising Children and Youth with Special Health Care Needs*.

Children with Medical Complexity

Webinar: Building a System of Care for Children with Complex Medical and Social Needs

Date Wednesday, September 15
Time 11 a.m. to 12 p.m. Pacific Time
Sponsors Camden Coalition and the National Center for Complex Health and Social Needs
Details Speakers from [Almost Home Kids](#) will describe a unique care delivery model through which they provide transitional and respite care for children with medical complexities, serving as a crucial bridge from hospital to home. The panelists also will describe the model's outcomes, including improved well-being of children and their families, financial benefits for hospitals and Medicaid, and addressing gaps in their community's system of care. [Read more and register](#).

Transition to Adult Care

Viewpoint: Growing Up Is Hard, Especially for People with Disabilities

In interviews with the *California Health Report*, young adults with serious disabilities and their families discuss the challenges of transitioning to adulthood – including lack of access to medical care, transportation, and socialization – that must be addressed to allow young people to live more independently. The interviewees suggest that officials need to foster more awareness about their requirements, and provide better information about how they can obtain the services they need. [Read more](#)

California Children's Services

Report: California's Whole Child Model – Lessons Learned from the Implementation of Family Advisory Committees



Medi-Cal managed care health plans serving children covered by the California Children's Services program (CCS) are required to create Family Advisory Committees (FACs) to ensure that the health plans engage with CCS families and caregivers. A new case study, funded by our Foundation, captures the lessons learned in the establishment and management of the FACs, and offers recommendations to help ensure that FACs are effective over time. [Read the report](#).

COVID-19 Information

Study: How Has the Pandemic Affected Students with Disabilities?

Researchers reviewed studies and convened panels to gauge the pandemic's effects on students' academic progress, its effects on their mental health and social-emotional well-being, and its impact on students with disabilities. [Read more](#).

In Brief

- [Education Department Weighs in on Special Education Requirements Amid Ongoing Pandemic](#) – from Disability Scoop
- [Back to School for Quirky Kids: Ease the Transition to In-person Learning](#) – from healthychildren.org
- [The U.S. Education Department Is Investigating Five States over Their Mask Mandate Bans](#) – from the *New York Times*
- [CDC Rolls Out New COVID-19 Resources for People with IDD](#) – from Disability Scoop

Palliative Care

Webinar: Beyond Words – Using Expressive and Integrative Therapies as Communication Tools

Date Thursday, September 23
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, Jacob's Heart Children's Cancer Support Services, and the CSU Shiley Institute for Palliative Care
Details In a medical setting, play and expressive therapies can be used to help children understand and process their illness and can even have a tangible effect on their physical symptoms and overall wellness. This course will introduce the broad range of expressive therapy options that can be used as a part of a child's medical care. Fee. [Read more and register](#).

In Brief

- Webinar: [Strengthening the Payer-Provider Relationship for Value-Based Success in Home- and Community-Based Palliative Care](#) – September 10, 9 to 10:30 a.m. Pacific Time, from the Better Care Playbook. Not pediatric specific.

Health Equity

Webinar: Engaging Families in Program and Policy Development to Advance Health Equity

Date Tuesday, September 14
Time 10 to 11:30 a.m. Pacific Time
Sponsor Center for Health Care Strategies
Details Speakers will explore best practices for authentically engaging with families in public services delivery to inform state and local programs, practices, and policy development. They will discuss insights from their work to elevate community voices. [Read more and register](#).

Archived Webinar



The [recording and slides](#) are now available for the webinar, *Transforming Child Health Care Through Anti-Racist, Family-Driven Approaches*.

National Policy

- [Medicaid Non-Emergency Transportation Benefit: Stakeholder Perspectives on Trends and Innovations](#) – from Health Management Associates

Events

[National Disability Voter Registration Week](#) is scheduled for September 13-20.

In the News

- [Parents of Children with Disabilities Join the Legal Battle Over Masks in Schools](#)
NPR, 9/7/21
- [Headed Away to School? Here's What Students with Health Issues Need to Know](#)
Kaiser Health News, 8/23/21

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.

