

California Advocacy Network

for Children with Special Health Care Needs

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

Health Care Finance

From Spending to Investing: Researching Health Care Financing for Children with Special Health Care Needs

Children with special health care needs make up 20 percent of the child population, yet they comprise half of all pediatric health care spending. In a paper titled *Moving from Spending to Investment: A Research Agenda for Improving Health Care Financing for Children and Youth with Special Health Care Needs*, researchers discuss high-priority research topics, including benefits, payment models, and quality measures, and provide recommendations for a research agenda that will help inform the evidence base for testing and improving health care payment reform. [Read the paper](#) in a supplement to *Academic Pediatrics* funded by our Foundation.

In Brief

- [The Role of Title V Programs in Increasing Access to School-Based Health Services: Opportunities for Bolstering Medicaid Reimbursement](#) – from the Catalyst Center
- [Reducing the burden of medical debt on households](#) (PDF) is the goal of a new federal Executive Order that instructs the Department of Health and Human Services to examine relevant policies and practices.

Funding Opportunity

Awards Support Investigators New to CYSHCN Field

Beginning May 1, the CYSHCN National Research Network will accept applications for its Emerging Investigator Guided Research Training Program. Three investigators will receive up to \$15,000 each for a one-year research project that addresses an important area of concern for the health or health care of children or youth with special health care needs and their families. [Read more and apply.](#)

Children with Medical Complexity

Conversations with Families: Aspiration



Many children with medical complexity experience respiratory complications. In this ninth seminar in the pediatric complex care series, family members and care providers will address common respiratory complications, management strategies in the home, and available treatment options. The series is funded by our Foundation.

Thursday, May 12
10 a.m. to 11 a.m. Pacific Time
[Read more and register.](#)

View the recording of the eighth seminar on [sleep issues](#).

Registration Open for *Putting Care at the Center 2022*

Early-bird registration is available until **June 10** for *Putting Care at the Center 2022*, an in-person event scheduled for September 21-23 in Sacramento, CA. The annual conference of the Camden Coalition's National Center for Complex Health and Social Needs offers an opportunity for the national complex care community to learn, network, and create a shared agenda. Consumers, providers, administrators, researchers, policymakers, caregivers, students, and more attend. Not pediatric specific. [Read more and register.](#)

Caregiving

Study Finds High Need for Health Services by Mothers of Chronically Ill Children

Mothers of children with chronic conditions use more health services, particularly psychotherapy, than other mothers, according to researchers at Stanford University and Denmark's Aarhus University. Their study also found that the long-term physical and psychological challenges of caregiving can take a toll on mothers' health and force them to leave the workforce. The authors suggest that a better understanding of these challenges could lead to interventions that protect these mothers' physical and mental health. [Read about the study.](#)

How Families Are Advocating for Children with Disabilities in Foster Care

Families often foster and adopt children with disabilities despite a number of challenges, which may include incomplete information about the child, inadequate medical supplies, or lack of coordination among the multiple agencies that serve these children. Now, some parents are taking action to fill the gaps in the system and press for better integration of care, according to an article in the *California Health Report*, whose work is funded in part by our Foundation. [Read the article.](#)

In Brief

- [When Your Child Has a Chronic Medical Illness: A Guide for the Parenting Journey](#) – from the Child Neurology Foundation
- [How Parenting Kids with Disabilities Affects Marriage](#) – from Disability Scoop

Pediatric Palliative Care

The Perinatal Palliative Care Birth Plan as an Advance Care Planning Tool

Date Tuesday, May 17
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 This webinar will highlight the perinatal palliative care birth plan and how it acts as an advance care planning tool for families facing complicated pregnancies. Fee. [Read more and register.](#)

Health Equity

Health and Human Services Reports on Equity Work

The federal Department of Health and Human Services has released an update of its Equity Action Plan, which is designed to address inequities and advance equity throughout the Department by assessing and changing policies, programs, and processes. The plan highlights actions taken to date and notes areas where work will be done. [Read the plan.](#)

California Children's Services

Updated: Access to CCS Services

During the COVID-19 Public Health Emergency, the Department of Health Care Services put in place temporary flexibilities for both Medi-Cal and CCS. The National Health Law Program and Family Voices of California, with funding from our Foundation, has updated a fact sheet explaining how to obtain CCS services as these flexibilities evolve. The [fact sheet](#) is also available in Español and 中文.

California Policy

Explaining Eligibility for Medi-Cal Mental Health Services for Children, Families

The National Health Law Program has developed two fact sheets regarding mental health:

- [New Criteria for Access to Medi-Cal Specialty Mental Health Services for Beneficiaries under Age 21](#)
- [Medi-Cal Family Therapy.](#)

Department of Health Care Services Stakeholder Advisory Committee to Meet

Date Thursday, May 12
Time 9:30 a.m. to 1:30 p.m. Pacific Time
Details In a new format, the committee will hold a joint meeting with the Behavioral Health Stakeholder Advisory Committee. [Register in advance](#) and find more details on the website.

Ambassadors Program to Help Medi-Cal Beneficiaries Retain Coverage as Emergency Regulations End

As the Public Health Emergency winds down, Medi-Cal Continuous Coverage regulations will end, and beneficiaries may be at risk of losing health insurance. The Department of Health Care Services has developed a Coverage Ambassadors communications program to assist diverse organizations in reaching beneficiaries in culturally and linguistically appropriate ways to help with redetermination of eligibility. Organizations can use a provided Medi-Cal Continuous Coverage Toolkit to educate their clients and help ensure their coverage. [Read more and see the toolkit.](#)

Comment Sought on Title V Funding Application

The California Department of Public Health is accepting comment until **May 13** on its draft 2022-23 application for Title V Block Grant funding. Title V federal funds support key programs for children and youth with special health care needs, among other populations. [Read more and comment.](#)

In the News

- [Students with Disabilities Have a Right to Qualified Teachers – But There's a Shortage](#)
NPR, 4/20/22
- [A Report on Violence against Kids with Disabilities Is Sobering – If Not Surprising](#)
NPR, 4/12/22

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@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.



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