

## California Advocacy Network for Children with Special Health Care Needs

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

### Telehealth

#### Free Course: Providing Telehealth Care for CSHCN

The American Academy of Pediatrics is offering a free, six-unit online course to support pediatric health care professionals in providing preventive, acute, and chronic telehealth and distant care services. Three of the six units, all of which can be taken at any time, are specifically focused on enhancing telehealth care for children and youth with special health care needs. [Read more and register.](#)

#### Telemedicine and Pediatric Home-based Palliative Care: Next Steps for Policy and Practice in California



Often misunderstood as end-of-life care, pediatric palliative care can improve quality of life for children with complex needs and their families. A Foundation-funded issue brief from Children's Hospital Los Angeles summarizes changes in pediatric palliative care policy in California and notes that the service is often underutilized, due in part to a lack of understanding by families and care providers alike. After surveying these stakeholders, the authors suggest that telemedicine is one promising tool to improve utilization. [Read more.](#)

### Children with Medical Complexity

#### Viewpoint: Stresses of Caregiving for Parents of Children with Medical Complexity

In an essay published in *Pediatrics*, the mother of a child with medical complexity (CMC), who is also a patient advocate for families of CMC, comments on research documenting the mental, emotional, and physical stress of caregiving. She poses questions that should be asked to create a system that better supports family caregivers. [Read her commentary.](#)

*Related: [How to Be a Caregiver](#)* – an article from the *New York Times* on six things to know about caregiving.

### Family Engagement

#### Report: How Medicaid Agencies Can Better Engage Families



Following up on its recent [webinar](#), the Center for Health Care Strategies has released a report summarizing findings from a nationwide survey about the range of family engagement strategies Medicaid agencies are using, including for families of CSHCN. The report, supported by our Foundation, highlights key findings and offers recommendations for strengthening engagement aimed at Medicaid agencies, youth with special health care needs, families of CSHCN, and funders. [Read the report.](#)

### Home- and Community-based Services

- [10 Ways the "Better Care Better Jobs Act" Helps Older People and People with Disabilities](#) – from the National Health Law Program. This pending federal legislation would make long-term investments in Medicaid-funded home- and community-based service (HCBS).

### National Policy

#### Webinar: Child Tax Credit to Aid Families

<b>Date</b>	Tuesday, August 24
<b>Time</b>	11 a.m. to 12 p.m. Pacific Time
<b>Sponsor</b>	Catalyst Center
<b>Details</b>	The recent Child Tax Credit (CTC) expansion is expected to improve the economic security of millions of families, including those raising children and youth with special health care needs. While many families will receive the expanded tax credit automatically, many of the most vulnerable families will need to take action to obtain the credit. Speakers will explain the expanded CTC and how Title V and family organizations might assist families in applying. <a href="#">Read more and register.</a>

### Transition to Adult Care



[Recordings Available from 2021 Transitions of Care Summit](#) – from the Child Neurology Foundation

### COVID-19 Information

#### Important Considerations for COVID-19 Vaccinations of Children with Developmental Disabilities

Children who have developmental disabilities often have medical conditions that contribute to higher risk for severe illness from COVID-19, and they also may have limited access to care. A report from the American Academy of Pediatrics describes strategies that health care providers can implement to tailor COVID-19 vaccination efforts for these children and their families. [Read more](#) (Download the PDF).

### Health Equity

#### Community Health Workers Advancing Child Health Equity

A series of issue briefs from The Children's Partnership explores the impact of racism on children's health and development. The latest brief focuses on the community health workforce as a community-led, anti-racist solution in health care delivery for children, including those with special health care needs. [Read the brief.](#)

### Resources

- [Getting a Neurologic Diagnosis for a Newborn – Managing Challenges and Finding a Path Forward](#) – A video from the Child Neurology Foundation

### Did You Know?

#### Spread the Word About Your Effective Programs

The Association of Maternal and Child Health Programs is currently accepting submissions to the [MCH Innovations Database](#). The database is a searchable repository of effective practices, programs, and strategies that are positively affecting Maternal and Child Health populations, including children with special health care needs.

### In the News

- [Children's Hospitals Are Swamped with COVID Patients – And It May Only Get Worse](#)  
*Politico*, 8/11/21
- [Families of High-Risk Children Despair Over Covid Resurgence](#)  
*NY Times*, 8/9/21
- [Special Education Funding Should Be More Streamlined, Report Finds](#)  
*EdSource*, 7/30/21
- [How Disabled Americans Are Pushing to Overhaul a Key Benefits Program](#)  
*NY Times*, 7/30/21
- [New Report Guides Pediatricians on Offering Sexual Education to Children with Disabilities](#)  
*Contemporary Pediatrics*, 7/29/21
- [Most States Struggling to Fulfill IDEA Requirements](#)  
*Disability Scoop*, 7/20/21
- [Jury Awards \\$125 Million After Walmart Fires Woman with Down Syndrome](#)  
*NY Times*, 7/18/21

#### 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](mailto:Ali.Rivera@lpfch.org) with your news or updates. Or contact newsletter editor: Eileen Walsh at [Eileen.Walsh@lpfch.org](mailto: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.

