Lucile Packard Foundation for Children's Health August 12, 2021

for Children with Special Health Care Needs *News*, policy updates, resources, events, and advocacy opportunities

California Advocacy Network

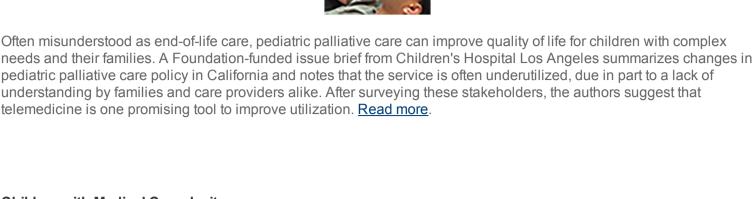
Telehealth

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.

Free Course: Providing Telehealth Care for CSHCN

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



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.

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

• 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

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

In Case

Important Considerations for COVID-19 Vaccinations of Children with Developmental

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

Family Engagement Report: How Medicaid Agencies Can Better Engage Families

funders. Read the report.

Home- and Community-based Services



11 a.m. to 12 p.m. Pacific Time

might assist families in applying. Read more and register.

home- and community-based service (HCBS).

Time

Details

Transition to Adult Care

Sponsor Catalyst Center

Missed I Recordings Available from 2021 Transitions of Care Summit – from the Child Neurology Foundation

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

Resources

Did You Know?

Disabilities

COVID-19 Information

health care delivery for children, including those with special health care needs. Read the brief.

Community Health Workers Advancing Child Health Equity

 Getting a Neurologic Diagnosis for a Newborn – Managing Challenges and Finding a Path Forward – A video from the Child Neurology Foundation

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

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

affecting Maternal and Child Health populations, including children with special health care needs.

In the News

EdSource, 7/30/21

NY Times, 7/30/21

NY Times, 7/18/21

We'd like to hear from you

Join the Network

Contemporary Pediatrics, 7/29/21

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

How Disabled Americans Are Pushing to Overhaul a Key Benefits Program

Children's Hospitals Are Swamped with COVID Patients – And It May Only Get Worse

New Report Guides Pediatricians on Offering Sexual Education to Children with Disabilities

Let us know what's happening with your organization or family. Email newsletter assistant editor Ali Rivera at

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

Spread the Word About Your Effective Programs

- Most States Struggling to Fulfill IDEA Requirements Disability Scoop, 7/20/21 Jury Awards \$125 Million After Walmart Fires Woman with Down Syndrome
- Ali.Rivera@lpfch.org with your news or updates. Or contact newsletter editor: Eileen Walsh at Eileen.Walsh@lpfch.org.

To see past issues, visit the Network Newsletter Archive.

health care needs and their families.





Subscribe to our email list.