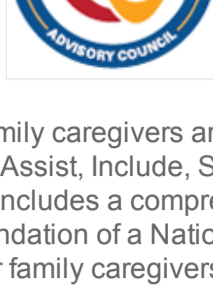


California Advocacy Network for Children with Special Health Care Needs

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

Caregiving

Report Highlights Crucial Steps for Improving Family Caregiving Policies



Twenty-six recommendations on how to support family caregivers are the keystone of a report recently presented to Congress. The report, the first from the Recognize, Assist, Include, Support, and Engage (RAISE) Act Family Advisory Council, is the culmination of a two-year effort that includes a comprehensive review of the current state of family caregiving. The recommendations will form the foundation of a National Family Caregiving Strategy that will include action steps to increase recognition and support for family caregivers. [Read the report.](#)

Proposed Federal Law Would Bolster Home- and Community-Based Services

The pending federal Build Back Better bill includes \$150 billion for Medicaid home- and community-based services, the largest investment in the program in 40 years. The funds would help reduce waiting lists for in-home care and improve pay for in-home care professionals, among other provisions. A vote may come soon. The Arc and other advocacy organizations are urging stakeholders to [contact their legislators](#) now. You also can read about the bill's other provisions and offer [comments](#) to the White House. [Read more.](#)

Health Care Financing

Issue Brief: CSHCN – Coverage, Affordability, and Access to Home- and Community-Based Services

Almost half of US CSHCN are covered by Medicaid/CHIP (the Children's Health Insurance Program). A new issue brief from the Kaiser Family Foundation describes key characteristics of CSHCN and explores insurance affordability and benefits for those covered by Medicaid/CHIP compared to those with private insurance only. The brief notes how the pandemic has increased the importance of home- and community-based services for CSHCN. [Read the brief.](#)

In Brief

- [Value-Based Payment to Support Children's Health and Wellness: Shifting the Focus from Short-Term to Life Course Impact](#) – A report from the Center for Health Care Strategies
- The Arc's Center for Future Planning has published four new videos on [financial planning for families](#). Each video covers why to consider using each resource, how they work, what they can pay for, and how to get started. The videos also are available [en Español](#).

Mental and Behavioral Health

Pediatricians, Child Psychiatrists Issue 'National Wake-up Call' Over Children's Mental Health

Noting that an already grim picture of children's mental health has been exacerbated by COVID-19, the American Academy of Pediatrics, the American Academy of Child and Adolescent Psychiatry, and the Children's Hospital Association issued a statement declaring a national state of emergency in children's mental health. They called on policymakers to take urgent action, and also launched a [Sound the Alarm for Kids website](#) for constituents to send comments. [Read their statement and recommendations.](#)

Upcoming Webinar Reminders

- [COVID-19 Behavioral Health Policies Affecting Children and Youth with Special Health Care Needs: What to Keep, Modify or Discard?](#)
Wednesday, November 10; 10 to 11 a.m. Pacific Time
[See related slides](#) (PDF) from an earlier presentation by Health Management Associates.
- [Pediatric Complex Care Seminar Session 3: Feeding Intolerance](#)
Thursday, November 11; 10 to 11 a.m. Pacific Time
Join the third webinar in the Collaborative Conversations with Families to Advance the Clinical Care of Children with Medical Complexities and Disabilities (C6) series.

Children with Medical Complexity

Webinar: Working with Medically Complex Children in Foster Care and Their Caregivers

Date Tuesday, November 9
Time 12 to 1 p.m. Pacific Time
Sponsor The National Center for Complex Health and Social Needs
Details Medically fragile foster children are an especially vulnerable population. This webinar will provide information on how to best serve these children and their caregivers to ensure the children's safety and well-being. Topics will include navigating the court system, advocating for quality of life, understanding caregiver needs, care coordination, and permanency planning. [Read more and register.](#)

Transition to Adult Care

Join Research for Improving Transition Outcomes

As part of an effort to support the development and implementation of evidence-based practices to assist transitioning youth and young adults with disabilities, the Center for Advanced Policy on Employment for Youth is leading a nationwide study of best practices in interagency collaboration and coordination among state agencies that serve transitioning youth. [Read more and take part in the research.](#)

COVID-19 Information

Webinar: Family Experiences During COVID-19 Pandemic

Date Thursday, November 18
Time 1 to 2 p.m. Pacific Time
Sponsor The Essentials for Childhood Initiative
Details A look at results from a [national survey](#) that measured the impact of the pandemic on family life, adverse childhood experiences, and positive childhood experiences. Speakers will provide an overview of the survey, key findings, and a demonstration on how to access the data on the KidsData website, among other topics. Data on CSHCN are included in the survey results. [Read more and register.](#)

Related: [Caregivers Express Concern About Children's Mental Health](#) – from KidsData

Health Equity

Webinar: Essential Health Benefits Benchmark Plans – Who Decides?

Date Tuesday, November 9
Time 1 to 2 p.m. Pacific Time
Sponsor National Health Law Program
Details State officials can address health disparities and close coverage gaps by updating their Essential Health Benefits (EHB) benchmark plans, which establish minimum coverage standards in each state. Attorneys will explain the EHB process and discuss how advocates can help implement best practices in their states' EHB benchmark selection process, and how updating EHBs can help address unmet health care needs. [Read more and register.](#)

California Children's Services

CCS Advisory Group Covers Packed Agenda

The transition to a [new pharmacy program](#) and the upcoming [Enhanced Care Management](#) program were the subject of wide-ranging discussion at the October 27 meeting of the CCS Advisory Group. Members also discussed Medical Therapy Units, data dashboards and quality measures for the Whole Child Model, and other topics. For extensive details, [see the agenda and the slides from the meeting.](#)

Pediatric Palliative Care

Webinar: Alternative Payment Strategies to Enhance Access to Pediatric Palliative Care

Date Tuesday, November 16
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 With the growing emphasis on value-based payments in health care, there is significant potential for enhanced access to pediatric palliative care (PPC) services. This presentation will highlight the challenges in accessing PPC services, share existing state models, and suggest a process for exploring policy and legislative opportunities to develop alternative payment strategies. [Read more and register.](#)

Special Education

Consensus Statement: Managing Chronic Conditions in Schools

The American Academy of Pediatrics, in collaboration with numerous health and education organizations, has released a statement on the core tenets of chronic condition management in schools. The goal is to improve health and academic outcomes for children by establishing a common framework that can be used by schools, physicians, and other partners to guide an integrated and equitable approach to chronic condition management. [Read the statement.](#)

In the News

- [The Child Tax Credit Was a Lifeline to My Special-Needs Sons. Congress Must Extend It.](#)
Time, 11/2/21
- [When a Wheelchair Becomes a Magical Chariot](#)
NY Times, 10/29/21
- [Day Care for Disabled Children Requires Better Funding, Parents and Experts Say](#)
NPR, 10/26/21
- [Disney Implementing Changes to Disability Access at Theme Parks](#)
Disability Scoop, 10/25/21

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.

