

California Advocacy Network

for Children with Special Health Care Needs

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

Home Health Care

Strategies for Providing Home Health Services to Children Enrolled in Medicaid

Home health services, which can help families avoid emergency department use, hospitalization, and institutional care for their children, are particularly valuable during the pandemic. A new report from the National Academy for State Health Policy explains how six states are employing strategies to support access to home health services for CSHCN, and offers insights that other states can use in their own systems to improve service delivery and reduce costs. [Read more.](#)

CSHCN and Equity

The Benefits of Screening for Social Determinants of Health

Screening for social determinants of health, which disproportionately affect children with special health care needs (CSHCN) and their families, is addressed in two new fact sheets developed by the National Resource Center for Patient/Family-Centered Medical Home, in partnership with the National Academy for State Health Policy. The fact sheets highlight replicable examples from states that are using social determinants screening data to support CSHCN at both the individual and population level.

Read:

- [Identification and Screening of Social Determinants of Health Among Children with Special Health Care Needs in Medicaid](#) (PDF)
- [Social Determinants of Health Referrals in Medicaid and the Role of Medicaid Managed Care Contracts](#) (PDF)

Our Foundation Joins Call for Governor to Declare Racism a Public Health Crisis in California

As a step toward addressing racial inequities in our work and community, our Foundation joined 161 other organizations and 447 individuals in signing a letter urging Governor Gavin Newsom to issue an Executive Order to declare racism a public health crisis in California. The letter, sent to the Governor on July 14, outlined several action steps the state could consider taking. [Read the letter](#) (PDF).

Children with Medical Complexity

Training Emergency Responders to Treat Medically Fragile Children

Many paramedics and other community emergency service providers are underprepared to respond to the unique needs of medically fragile children, who are twice as likely as their healthier peers to suffer a medical emergency requiring 911 services. Cardinal Glennon Children's Hospital in St. Louis developed a program to identify children who are at risk, provide education to the providers who manage children during an emergency, and share pertinent information with all who will be a part of the care team should an emergency arise. [Read more.](#)

Webinar – Charting a Path to Measurement: Next Steps in Standardizing Quality Measures for Complex Care

Date Thursday, July 30
Time 9:30 a.m. Pacific Time
Sponsor National Center for Complex Health and Social Needs
Details A discussion with the authors of a new report that assesses the current state of complex care measurement and recommends a path forward. Not pediatric specific. [Read more and register.](#)

COVID-19 Information

Our [COVID-19 web page](#) offers more information and resources.

- [Ensuring Support Services for Youth with Disabilities and Special Health Care Needs Amid COVID-19](#) – A Zoom conversation from PolicyLab at Children's Hospital of Philadelphia, featuring parents, educators, and physicians.
- [Pediatricians, Educators and Superintendents Urge a Safe Return to School this Fall](#) – The American Academy of Pediatrics (AAP), the American Federation of Teachers, National Education Association and The School Superintendents Association issued a [joint statement](#) on July 10 that calls on Congress and the Administration to provide the federal resources needed to ensure that students, teachers, and staff can return safely to school. The AAP also issued extensive [guidelines](#) for reopening.
- [Coping with Crayons: Kid-Friendly COVID-19 Information](#) – To help children understand the disruption in their lives, Children's Hospital of Richmond at Virginia Commonwealth University created a coloring book to provide COVID-19 information that children of all ages can easily digest and understand. An article from the Children's Hospital Association notes that the activity book, available online and in print, also can help parents gauge their children's feelings about the pandemic.
- In a [video](#) from the **Child Neurology Foundation**, a caregiver and a psychologist discuss the impact of isolation and stress on parents caring for medically fragile children during a pandemic.
- Webinar: [How Community Health Workers and Promotores Can Support Individuals with Complex Needs Amid COVID-19](#) – Wednesday, July 29, 10 to 11:15 a.m. Pacific Time, sponsored by the **Better Care Playbook** and the **Seven Foundation Collaborative**.

Family Engagement

Compensating Families for Participation in Research

How to compensate families for their contribution to research will be the subject of a poster session at the virtual [annual conference](#) of the Association of Maternal and Child Health Programs, scheduled for August 4-6. Speakers from our Foundation, CYSHCN National Research Network, and Family Voices will discuss "[A Standard of Compensation for Research Teams](#)," a guide for principal investigators that provides a step-by-step process to help plan and budget for engaging youth, patient, and family partners. A companion piece, "[A Standard of Compensation for Youth and Family Partners](#)," also is available.

National Policy

Still Time to Weigh in on Contentious Senate COVID-19 Bill

The Senate currently is grappling with the [COVID-19 relief bill](#), and advocates continue to urge constituents to contact their legislators. The bill contains a number of provisions potentially beneficial to children with special needs and their families. [Read more.](#)

Bill to Watch

- [HR 3935](#) – The Protecting Patients' Transportation to Care Act would amend the Medicaid statute to include non-emergency medical transportation in the list of mandatory Medicaid services. Introduced July 15.

Advocacy Opportunities

Celebrating Progress: Americans with Disabilities Act

Two upcoming webinars help mark the [30th anniversary](#) of the July 26, 1990, signing of the Americans with Disabilities Act, the groundbreaking legislation that prohibits discrimination against individuals with disabilities in all areas of public life, including jobs, schools, transportation, and all public and private places that are open to the general public.

Continuing the Fight: Ensuring the ADA Works for Everyone

Date Friday, July 24
Time 10 to 11 a.m. Pacific Time
Sponsors US Senator Patty Murray and Senator Bob Casey
Details [Register.](#)

Thirty Years After the Americans with Disabilities Act: Where Are We Now, and Where Are We Heading?

Date Wednesday, August 5
Time 11:30 a.m. to 12:45 p.m. Pacific Time
Sponsor Mathematica
Details [Register.](#)

In Brief

- [California School-Based Health Alliance Sets 2020 Virtual Advocacy Day](#) – August 5 will provide an opportunity to visit with legislators and their staff members to discuss the importance of school-based health.

Resource

- [Exceptional Parent Magazine July Issue – Accessible Homes](#)

Event

Virtual Summit Brings Together Teens, Young Adults with Chronic Conditions

The Health Advocacy Summit is a no-cost advocacy event for young people between ages 13 and 30 who are living with chronic and rare diseases. The summit is run entirely by young adults with chronic conditions, with the goal of connecting and empowering youth to ensure that they have resources and opportunities to thrive. The summit is scheduled for August 8. [Read more.](#)

In the News

- [Interruption Caused by COVID-19 Poses Challenges Beyond Classroom](#)
Disability Scoop, 7/17/20
- [Telemedicine Is Booming During the Pandemic. But It's Leaving People Behind.](#)
Washington Post, 7/9/20
- [Quadriplegic Man's Death from COVID-19 Spotlights Questions of Disability, Race and Family](#)
Washington Post, 7/5/20

We'd like to hear from you

Let us know what's happening with your organization or family. Email newsletter editor Eileen Walsh at Eileen.Walsh@lpfch.org with your news or updates.

