

California Advocacy Network

for Children with Special Health Care Needs

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

Children with Medical Complexity

Next Steps to Improving Home Health Care for Children with Medical Complexity

Many children with complex conditions rely on home-based care for daily health monitoring and care tasks. A shortage of adequately trained pediatric home health care providers means that this care often is provided by families. This questions and answers discussion, based on an [article](#) published in *Health Affairs* with support from our Foundation, addresses family needs for home health care, and suggests potential workforce and policy solutions. Perspectives are provided by a parent advocate, a home health care administrator, a pediatrician, and a state official. See the [Q&A](#) and the webinar recording and slides.

National Network's Annual Report Illustrates Progress toward Better Health Systems for CYSHCN

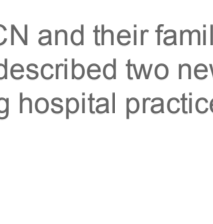
The Children and Youth with Special Health Care Needs National Research Network (CYSHCNNet) has released its 2019-20 annual report, highlighting its grants, research projects, publications, partners, data, and plans for the future. Founded in 2017, CYSHCNNet helps children and families by advancing knowledge and implementation of optimal health systems. [Read the report](#) (PDF).

Network News

The Local Angle: How County Coalitions Improved Systems of Care for CSHCN

Can small groups bring about change in local systems of care for children with special health care needs? Yes, they can, according to an independent evaluation of seven years of work by the California Community Care Coordination Collaborative (5Cs). Founded and funded by our Foundation, the 5Cs brought together working groups in 10 counties around the state to address local system challenges and learn from each other. Participating counties achieved successes in multiple areas, not least of which was bringing together – sometimes for the first time – agencies that serve overlapping populations of children. [Read about this work](#).

Archived Webinar: Innovations in Hospital Discharge



Hospital discharge can be a traumatic time for CSHCN and their families. In this webinar, speakers from the [California-based Nurse-led Discharge Learning Collaborative](#) described two newly developed discharge practices, and discussed how these innovations can be integrated into existing hospital practices. [Listen to the webinar](#).

California Children's Services

CCS Advisory Group to Meet

The next Advisory Group meeting is scheduled for Wednesday, October 7. Details about the time, agenda, and viewing options should be announced on the group's [website](#).

CCS Needs Assessment Notes Areas for Improvement

Every state is required to conduct a needs assessment every five years for programs funded under federal Title V. In California, this includes California Children's Services (CCS). In the state's newly released needs assessment, families generally reported satisfaction with CCS services, but the report also notes numerous areas that require improvement. These include assistance with care coordination, access to mental and behavioral health services, turnaround time for service authorizations, processes for transition to adult care, and involvement of CCS parents in program and policy decisions. [Read the report](#).

In Brief

Updated Medical Therapy guidance from the California Department of Health Care Services, as of September 17:

- [California Children's Services Medical Therapy Programs during COVID-19 – Step 2 Guidance](#) (PDF)
- [Access to Medical Therapy Units for Medically Necessary Therapy Services](#) (PDF)

COVID-19 Information

Please find additional resources and information on our [COVID-19 web page](#).

- A [policy brief](#) from the **Kaiser Family Foundation** examines how COVID-related school openings/closures, social distancing, loss of health coverage, and disruptions in medical care could negatively affect the health and well-being of children.
- [New Data Help Cut Through the Uncertainty of "Back to School" Amid COVID](#), a blog from **Mathematica**, describes recent work in Pennsylvania designed to provide a road map to help school and community leaders around the country create operating, quarantine, and closure strategies that might allow students to attend in person while minimizing the risk of outbreaks.

CSHCN and Equity

New Strategy for The Arc Emphasizes Inclusion and Equity

What does true inclusion and equity look like for people with intellectual and developmental disabilities? That is the question that The Arc pondered as it developed its new [Strategic Framework for the Future of The Arc](#), which will guide the organization's work across local, state, and national levels. An October 7 virtual [Town Hall discussion](#) for self-advocates, family members, caregivers, and service providers will provide highlights.

National Policy

Census Deadline Extended

The deadline for completing the US Census has been extended, though the final date has not yet been determined. It's important for individuals with special needs and their families to be counted to ensure adequate federal funding for the next decade for essential programs such as Medicaid. [See various ways to take the census](#).

Final Weeks to Register to Vote

[Rev Up the Vote](#), an organization that works to increase the number of voters interested in disability issues, notes that voting choices affect access to health care, education, transportation, and many other services important to children with special needs. The deadline to register to vote on November 3 is approaching. [Check the date for your state](#) and sign up to make your voice heard.

Events

Congreso Familiar Virtual 2020: El Impacto de Inmigración y COVID-19 en Niños Latinos con Discapacidades

[Congreso Familiar](#) es una conferencia dedicada a promover educación y liderazgo en familias Latinas que tienen niños o miembros de familia con discapacidades. Sintonice las sesiones virtuales restantes programadas para el 3 y 10 de octubre a las 10 a.m., hora del Pacífico. Los oradores hablarán sobre oportunidades de inmigración para padres con niños con necesidades especiales y cómo COVID-19 ha impactado a los estudiantes en educación especial. [Aprende más y regístrate](#) (PDF).

Proposals Sought for AMCHP Annual Conference 2021; CSHCN a Focus

A call for proposals is open for the 2021 conference of the Association of Maternal and Child Health Programs, currently scheduled as an in-person meeting in New Orleans on May 22-25. Children with special health care needs are the focus of one of the conference tracks. Submissions are due by **November 17**. [Read more](#).

Special Education

Webinar: Instructional Planning for School and Distance Learning for Students with Intellectual Disabilities

Date Thursday, October 8
Time 11 a.m. to 12 p.m. Pacific Time
Sponsor The Arc
Details To assist families as they grapple with multiple learning scenarios, this webinar will explain the 5C Process, which is used for identifying learning priorities for each student with intellectual disabilities and building continuity between their inclusive environments and instructional supports to provide meaningful instruction across their day. [Read more and register](#).

Resource

- *Exceptional Parent Magazine* September Issue – [Annual Education Issue](#)

Funding Opportunity

Awards Available for Emerging Leaders in Disability Community

Applications are open now for the American Association of People with Disabilities Paul G. Hearne Emerging Leaders Awards. The award recognizes individuals who exemplify leadership, advocacy, and dedication to the broader cross-disability community. [Read more and apply](#) by **October 28**. A webinar on Thursday, October 15, from 1-2 p.m. Pacific Time will help applicants to review information and ask questions. [Register for the webinar](#).

In the News

- [Children Missing Out on Developmental Services Because of Labyrinth System](#)
California Health Report, 9/29/20
- [Ginsburg Remembered for Impact on Disability Rights](#)
Disability Scoop, 9/22/20
- [Hollywood Continues to Overlook Disability Community, Report Shows](#)
Disability Scoop, 9/21/20
- [Closed Schools Have to Serve Some Special Education Students in Person, Experts Say](#)
San Diego Union-Tribune, 9/19/20

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.

