

California Advocacy Network for Children with Special Health Care Needs

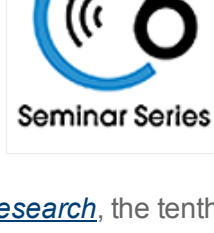
News, policy updates, resources, events, and advocacy opportunities

Systems and Standards

Research Agenda for Implementing Principles of Care

The range of services needed by CYSHCN crosses different health care settings as well as education and community-based services, often leading to fragmented and poor care. More research is needed on how to implement care across care settings, according to the [CYSHCN National Research Network](#) (CYSHCNNet). In a paper, *Research Agenda for Implementation of Principles of Care for Children and Youth with Special Health Care Needs*, CYSHCNNet researchers recommend additional studies to help families, practices, payers, and systems promote cross-system care through actionable and sustainable steps. [Read the article.](#)

Children with Medical Complexity



The recording of [Patient Engagement in Clinical Research](#), the tenth and final webinar in the series *Conversations with Families to Advance Clinical Care of Children with Medical Complexities and Disabilities* is now available, along with recordings of all the other webinars in the series.

In Brief

- Early-bird registration for [Putting Care at the Center 2022](#) has been extended through **June 24**.

Mental and Behavioral Health

Webinar: The Role of Medical Home in Behavioral and Mental Health for CYSHCN

Date Thursday, June 30
Time 10 to 11 a.m. Pacific Time
Sponsor National Resource Center for Patient/Family-Centered Medical Home
Details This is the second webinar in a series that examines the behavioral and mental health systems of care for CYSHCN and the role of the medical home within those systems. [Read more and register.](#)

Transition to Adult Care

Panel Responds to Follow-up Questions from Webinar on Transition



In a previous webinar, [A Family-Centered Research Agenda for Improving Health Care Transitions for Children with Special Health Care Needs](#), panel members highlighted the health care transition process for CYSHCN, described their research findings, and reflected on the implications of their recommendations. Now, they have responded in detail to attendee questions they were unable to answer within the time allotted. [Read the Q&A](#) (PDF).

In Brief

- [2022 Coding and Payment Tip Sheet for Transition from Pediatric to Adult Health Care](#) (PDF) – from Got Transition and the American Academy of Pediatrics

Health Equity

Live Virtual Education Course: Addressing Equity for Black CYSHCN

Date Tuesday, July 12
Time 7 to 9 a.m. Pacific Time
Sponsor National Resource Center for Patient/Family Centered Medical Home
Details The course will provide education and training to pediatricians and allied health professionals on how to implement an equitable, culturally responsive, and family-centered medical home for African American and Black CYSHCN. AMA PRA Category 1 Credit™ available. [Read more and register.](#)

Georgetown Center Virtual Conference on Child and Family Health Policy to Address Promoting Equity

Date Tuesday, July 12
Time 8 a.m. to 1 p.m. Pacific Time
Sponsor Georgetown Center for Children and Families
Details The theme for the keynote session of this one-day conference will be *How Can Medicaid and CHIP Promote Health Equity?* [Read more and register.](#)

California Children's Services

CCS Advisory Group to Meet

Date Wednesday, July 13
Time 1 to 4 p.m. Pacific Time
Dial-In 1-415-655-0001; Passcode: 25931967613
Details Meeting materials will be available on the Department of Health Care Services [website](#).

COVID-19 Information

- [American Academy of Pediatrics and Georgetown University Center for Children and Families Urge Public Health Emergency Extension to Protect Children from Losing Medicaid Health Coverage](#)

Resources

Assistance in Preparing for Disasters

Two toolkits can help families and providers prepare for disasters:

- [Be Ready: Tips for Families of Children and Youth with Special Health Care Needs](#) offers a suite of multi-language infographics and just-in-time ADA compliant videos.
- [Disaster and Families of Children with Disabilities: What Every Health Care Provider Needs to Know](#) offers a four-minute video, infographic, and provider teaching checklist.

Federal Program Helps Pay for Internet Service

Families in low-income households may be eligible for the Affordable Connectivity Program, operated by the Federal Communications Commission, which helps pay for internet service and connected devices such as laptops or tablets. [Read about eligibility and the application process.](#)

National Policy

Advocates Urge Support for Fixing “Family Glitch” in Health Insurance

Individuals who do not have access to health insurance through their jobs can receive assistance to buy coverage through the Affordable Care Act. But current rules only consider the cost of the insurance for the employee and don't take into account the cost of insurance for spouses, partners, dependents, or other family members. The Arc, the National Health Law Program, and other advocacy groups support proposed new rules that would fix this glitch. [Read more.](#)

California Policy

- [California Finally Pays for Summer Programs for Children with Disabilities, but Access Hurdles Remain](#) – from California Health Report
- The Department of Developmental Services has released a presentation about changes and updates to its appeal processes in [English](#) (PDF) and [Español](#) (PDF).
- [Department of Health Care Services Releases Medi-Cal COVID-19 Public Health Emergency Operational Unwinding Plan](#) (PDF)

In the News

- [Despite a First-Ever 'Right-to-Repair' Law, There's No Easy Fix for Wheelchair Users](#)
Disability Scoop, 6/17/22
- [House Approves Ban on Electric Shock Devices for Those with Developmental Disabilities](#)
Disability Scoop, 6/13/22
- [Hallmark to Air Movie Starring Actors with Down Syndrome](#)
Disability Scoop, 6/10/22

We'd like to hear from you

Let us know what's happening with your organization or family. Email newsletter editor Ali Rivera at Ali.Rivera@pfch.org with your news or updates. Or contact newsletter editor: Eileen Walsh at Eileen.Walsh@pfch.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 organization of 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.

