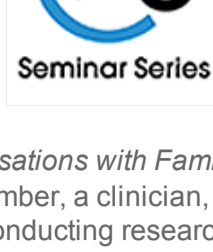


California Advocacy Network for Children with Special Health Care Needs

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

Children with Medical Complexity

Last Webinar in the Series: Patient Engagement in Clinical Research



In the tenth and final seminar in this series, *Conversations with Families to Advance Clinical Care of Children with Medical Complexities and Disabilities*, a family member, a clinician, and a policymaker will describe the value of partnership with patients and their families when conducting research; review challenges in patient and family engagement; and identify potential strategies for successful engagement. The C6 Seminar Series is funded by our Foundation and operated by the Hospital for Sick Children (SickKids) in partnership with Family Voices.

Thursday, June 2
10 to 11 a.m. Pacific Time
[Register](#).

See the recordings of the ninth webinar on [Aspiration](#) and all the webinars in the series.

Understanding the Impact of Social Determinants of Health on Medically Complex Children

Pediatricians have increased screening and interventions for social determinants of health (SDOH), but research specific to medically complex children and their families is lacking. Researchers at [CYSHCNet](#) examined which strategies best identify and mitigate the effects of negative SDOH on CYSHCN, and which outcomes are most meaningful to families receiving interventions. In an article in a supplement to *Academic Pediatrics*, supported by our Foundation, the researchers also make specific recommendations for future studies, including policy-level research that addresses the root causes of health inequities. [Read the article](#).

In Brief

- Early-bird registration for [Putting Care at the Center 2022](#) is available until **June 10**. The conference is scheduled for September 21-23 in Sacramento, CA. Scholarships available for some groups. Partial virtual option available. [Register](#).

Developmental Disabilities

New Report Documents Continuing Inequities in Regional Center Service Provision



An updated report by Public Counsel outlines persistent service funding disparities between racial and ethnic groups of children in California's regional center system. The report evaluates the outcomes of a disparity reduction program established by the state in 2016 and urges the state's legislative and executive administration leadership to take action on the identified recommendations for addressing the system's ongoing problems. [Read the report](#), which was supported by a grant from our Foundation.

Also see: [Racial Disparities Persist at California Regional Centers for Disabled Kids, Report Says](#) – from *Los Angeles Times*

Resources

Talking to Children about School Shootings

After the horrific mass shootings in Uvalde, Texas, and other cities, a psychiatrist and a psychologist from Stanford offer suggestions on how to talk to children and help them process these kinds of events. [Read the Q&A](#).

Also see: [Resources in Response to the Robb Elementary School Shooting](#) in both English and Español – from the University of Colorado Boulder and The National Child Traumatic Stress Network

Transition to Adult Care

Pilot Program Explores Transition Planning in Medicaid Managed Care Plans

To address the gaps in the transition of youth with complex health care needs from pediatric to adult care, a Medicaid managed care plan (MCP) in California has developed a pilot program for its highest-risk youth. The pilot addresses how and why MCPs should implement transition planning for YSHCN. Its model uses the [Got Transition Six Core Elements](#), modified for an MCP. Early findings are reported in an article in the *American Journal of Managed Care*. The authors suggest that the model could have value for transition planning for youth enrolled in MCPs across the country. [Read the article](#).

Network News

Tributes Pour in for Julie Beckett, Family Voices Co-Founder and National Champion for Care at Home

Julie Beckett, one of the founders of Family Voices and a tireless, passionate, and highly effective advocate for CYSHCN, died May 13 at her home in Cedar Rapids, Iowa. On behalf of her daughter, Katie, Julie lobbied all the way up to then-President Ronald Reagan to create a federal government program that allowed people with disabilities to use Medicaid dollars to get health care while living in the community rather than in institutions. The Katie Beckett Waiver, named in her daughter's honor, continues to have a nationwide impact. [Read more about Julie's life and legacy](#).

Also see: [Julie Beckett, Who Helped Disabled Children Live at Home, Dies at 72](#) – from *The New York Times*

Health Equity

American Academy of Pediatrics Calls for Elimination of Race-Based Medicine

In a new policy statement, the American Academy of Pediatrics makes the case for critical self-evaluation and fundamental changes in the practice of medicine to end long-standing inequities in health care. The statement includes a list of activities that the Academy intends to pursue. [Read more](#).

Special Education

- During the pandemic, many school board decisions affected children with special needs. See [a toolkit of resources and tips to help families advocate with school boards](#) – from the Center for Dignity in Healthcare for People with Disabilities
- [Ed Department Ramps Up Disability Related Compliance Reviews](#) – from Disability Scoop

National Policy

Advocacy Opportunity Regarding SSI Asset Limit

The asset limit in the Supplemental Security Income program, which serves many families of CYSHCN, has not been updated since 1989. The Arc urges stakeholders to ask their Senators to cosponsor the SSI Savings Penalty Elimination Act ([S.4102](#)), which would raise the limits. [Read more](#).

California Policy

Webinar Series to Provide Information on Changes to Medi-Cal under CalAIM Program

California Advancing and Innovating Medi-Cal (CalAIM) is a program that is bringing major changes to Medi-Cal, which is a source of health coverage for many CYSHCN. A series of webinars offers updates and training for advocates.

Title Enhanced Care Management: A New Vision for Whole Person Care
Date Thursday, June 2
Time 10 a.m. to 12 p.m. Pacific Time
Sponsor Department of Health Care Services
Details [Register](#).

Title CalAIM Changes to Medi-Cal Behavioral Health System
Date Thursday, June 9
Time 1 to 2 p.m. Pacific Time
Sponsor National Health Law Program
Details [Register](#).

Evento

Evento Virtual – El Seguro Social: Asegurando el Presente y el Futuro

Fecha Sábado, 4 de Junio
Hora 10 a.m. a 12 p.m. Hora del Pacífico
Patrocinador Congreso Familiar
Detalles Congreso Familiar es una conferencia dedicada a promover la educación y el liderazgo en familias Latinas que tienen hijos o familiares con discapacidades. Además de explicar las programas de incapacidad y otros servicios, en esta presentación se van a tener información general de Seguro Social y sobre cómo obtener su tarjeta. [Regístrese](#).

In the News

- [Businesses That Violate Disabled Citizens' Rights Must Pay Up, Should That Include Public Schools?](#)
San Francisco Chronicle, 5/24/22
- [Microsoft Unveils New Accessories for People with Disabilities](#)
Disability Scoop, 5/13/22
- [Two Behemoths Dominate the Motorized Wheelchair Industry, Disabled Customers Pay the Price.](#)
Mother Jones, 5/1/22
- [New Policy Opens the Door for States to Address Drivers of Health in Medicaid](#)
The Commonwealth Fund, 4/19/22

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@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 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.

