

## California Advocacy Network

### for Children with Special Health Care Needs

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

#### Research

##### Research Agenda Puts Focus on Supporting Families

Health systems are designed to support CYSHCN but often do not consider the impact of caregiving on the child's family. In response, the [CYSHCN National Research Network](#) has developed a national research agenda to prioritize key areas of insufficient understanding about the health and well-being of families of CYSHCN. Their findings and recommendations are outlined in an article, [Research on Family Health and Children and Youth with Special Health Care Needs](#), part of a supplement to *Academic Pediatrics* developed with funding from our Foundation.

#### Transition to Adult Care

##### Roundtable: Pediatric to Adult Healthcare Transition for Children with Complex Medical Needs

**Date** Tuesday, June 14  
**Time** 11 a.m. to 2 p.m. Pacific Time  
**Sponsors** Gillette Children's, Chloe Barnes Advisory Council on Rare Diseases, Minnesota Chapter American Academy of Pediatrics, Minnesota Department of Health  
**Details** This virtual discussion seeks to highlight the systemic barriers to the transition process for youth with medical complexity, and generate a pathway to solutions designed to break down these barriers. Though panelists are primarily from Minnesota health systems, government agencies, and public/private insurers, the discussion will have national applicability. CME available. [Read more and register.](#)

#### Family Engagement

##### Study: Lessons from How Children's Hospitals' Patient and Family Advisory Councils Coped During COVID-19

An article in the *Patient Experience Journal* highlights findings from a study of how Patient and Family Advisory Councils adapted operations during the pandemic, how patient and family advisors were engaged in the response to COVID-19, and how the pandemic intersected with Advisory Councils' diversity, equity, and inclusion efforts. The authors concluded that children's hospitals are well positioned to be leaders in the field. The research was supported by our Foundation. [Read more.](#)

#### Telehealth

##### Preserving Access to Telebehavioral Health Services After Public Health Emergency Ends

The high need for behavioral health services for children was exacerbated by the pandemic, and telehealth became an essential method for delivery of care. A severe shortage of providers persists as COVID-19 policies wind down. In a new article, Manatt Health describes how states are employing a variety of policy levers to maintain access to critical telebehavioral health services. [Read the article.](#)

#### Mental and Behavioral Health

##### Minimizing Anxiety and Emotional Trauma During Patient Visits

Clinical visits can be stressful when CSHCN have difficulty communicating or when providers do not have information about what triggers or soothes the patient. This sometimes can result in compromised care and unsuccessful procedures. Mercy Kids in St. Louis has created a program, Keys to Me, to minimize anxiety and potential emotional trauma. The program bridges the gap between parents and providers by encouraging early parent communication, a portal to update information directly into a child's medical record, and provider education. [Read more.](#)

#### In Brief

- The [Mental Health Hub](#) of the Child Neurology Foundation offers a range of resources to assist families of medically fragile children.

#### Children with Medical Complexity

##### Share Innovative Work on Complex Care with National Audience

The Better Care Playbook, a collaborative of seven leading health care foundations, welcomes content submissions from stakeholders in the field of complex care, with the goal of spreading best practices to the broader complex care community. [Read more and submit a practice.](#)

#### California Policy

##### Advocacy Opportunity: Save the Child Health and Disability Prevention Program

Family Voices of California has issued an alert asking stakeholders to urge their legislators to maintain the Child Health and Disability Prevention Program (CHDP), which is scheduled for elimination in the current budget proposal. CHDP ensures that children and youth covered by Medi-Cal are cared for by pediatricians and family medical clinicians who are trained, experienced, and knowledgeable about pediatric and adolescent care. The Department of Health Care Services says these provisions will be covered under the new CalAIM program. [Read more and take action before May 20.](#)

#### Special Education

- [Ed Department Cracks Down on Special Ed Failures During COVID-19](#) – from Disability Scoop
- [LAUSD Failed Students with Disabilities During Pandemic, Federal Investigation Finds](#) – from Los Angeles Times

#### Scholarship Opportunity

##### May 19 Deadline for Media Scholarship Opportunity

The American Association of People with Disabilities is accepting applications for the 2022 NBCUniversal Tony Coelho Media Scholarships, awarded to undergraduate and graduate students with disabilities who are pursuing careers in media, communications, or entertainment industries. [Read more and apply by May 19.](#)

#### COVID-19 Information

- [End to Public Health Emergency Could Have Consequences for People with Disabilities](#) – from Disability Scoop
- [Impact of the COVID-19 Pandemic on People with Disabilities: Research Findings](#) (PDF) – from the Administration for Community Living, a division of the US Department of Health and Human Services

#### National Policy

- [Building Capacity for Inclusion of People with Disabilities in Preparedness Planning and Response](#) – from the Centers for Disease Control and Prevention
- [Comments on Centers for Medicare and Medicaid Request for Information on Access to Coverage and Care in Medicaid & the Children's Health Insurance Program](#) – from the National Health Law Program (NHLP)

#### Funding Opportunity

##### Supporting Individuals with Co-occurring Developmental and Mental Health Disabilities

The Administration for Community Living is accepting applications under the Projects of National Significance program for one competitive, five-year cooperative agreement to establish a national, person-centered, culturally competent training center for building capacity in state and local service systems to support individuals with co-occurring intellectual and developmental disabilities and mental health disabilities. [Read more and apply by June 21.](#)

#### In the News

- [Lawsuit: State, Managed Care Organizations Not Providing Care to 'Most Vulnerable' Children](#)  
*NM Political Report, 5/3/22*
- [Practice Traffic Stops Help Prepare Those with IDD](#)  
*Disability Scoop, 5/3/22*
- [Pediatricians Get New Guidance on Caring for Kids with Down Syndrome](#)  
*Disability Scoop, 4/25/22*

#### 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@lpfch.org](mailto:Ali.Rivera@lpfch.org) with your news or updates. Or contact newsletter editor: Eileen Walsh at [Eileen.Walsh@lpfch.org](mailto:Eileen.Walsh@lpfch.org).

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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.

