

California Advocacy Network

for Children with Special Health Care Needs

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

Network News

New Grants Focus on Family Engagement and How Post-Pandemic Policy Changes May Affect Care for CSHCN

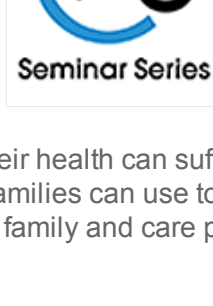
As the health care policy flexibilities that were instituted during the COVID-19 public health emergency begin to wind down, regulations are changing across the country and in states, potentially putting children's health at risk. Two new grants from our Foundation support efforts to understand and address the impact of these changes on children with special health care needs (CSHCN) and their families. A third grant promotes continued expansion of the assessment of family engagement in systems-level policy and decision making within CSHCN-serving health care entities. [Read about the grants.](#)

Related:

- [Millions of Vulnerable Americans Likely to Fall Off Medicaid Once the Federal Public Health Emergency Ends](#) – from *The Washington Post*
- The Centers for Medicare and Medicaid Services released guidance and tools for states and Medicaid stakeholders on [resuming routine operations when the Medicaid continuous coverage provision is lifted at the end of the public health emergency.](#)

Children with Medical Complexity

Conversations with Families: Sleep Issues



When a family or child cannot sleep comfortably, their health can suffer. This eighth seminar in the pediatric complex care series will offer strategies that clinicians and families can use to manage sleep issues for children with medical complexity. The series, which always features both family and care provider viewpoints, is funded by our Foundation.

Sleep
Thursday, April 14
10 to 11 a.m. Pacific Time
[Read more and register.](#)

Apply to Present at National Complex Care Conference

Presentation opportunities are open for *Putting Care at the Center 2022*, the annual conference for the field of complex care. Apply by **April 15** to present either a workshop session or in the interactive Beehive, and share complex care findings, models, lessons, and tools. The conference is scheduled for September 21-23 in Sacramento, CA. Participants will discuss how the value of complex care can be defined, measured, and demonstrated, beyond reductions in cost and utilization. [Read more and apply.](#)

Family Engagement

Call for Workshop Proposals: National Family Leadership Conference

Family Voices, along with other family leadership organizations, is seeking workshop proposals for a national leadership conference set for October 18-20 in Washington, DC, and online. Workshops should focus on learning that will build capacity for attendees to improve systems that serve families and operate effective family-serving organizations. [Read more and apply](#) by **April 1**.

Pediatric Palliative Care

California Pediatric Palliative Care Map Available

The Children's Hospice and Palliative Care Coalition of California, with support from our Foundation, has completed an environmental scan of pediatric palliative care services in the state in 2021, and made the data available on an interactive map. Designed as a resource for parents, caregivers, and providers, the map can be sorted by hospice or home health agencies, hospitals, and support organizations. It also can be searched by county. To add an organization or to learn more about the coalition, email chpcc20221@gmail.com. [View the map.](#)

In Brief

- [Educating the Public about Palliative Care](#) – An infographic from the National Academy for State Health Policy on what states can do to publicize palliative care. Not pediatric specific.

Transition

Webinar: Independent Living Services for Minority Youth with Disabilities – Strategies and Success

Date Tuesday, March 22
Time 12:30 to 1:30 p.m. Pacific Time
Sponsor Minority Youth and Centers for Independent Living
Details The webinar will focus on promising Centers for Independent Living (CIL) outreach, collaborations, and practice strategies to engage transition-age youth with disabilities from racial and ethnic minority backgrounds. CILs are community-based organizations whose goal is to empower people with disabilities, giving them more control over the decisions that affect their lives. [Read more and register.](#)

Caregiving

Archived Webinar: A Family-Centered Research Agenda for Supporting Caregivers



The [recording and slides](#) are now available for *A Family-Centered Research Agenda for Supporting Caregivers of Children with Special Health Care Needs*.

An Opportunity to Advise on Family Caregiving

The Family Caregiving Advisory Council, established under the Recognize, Assist, Include, Support, and Engage Family Caregivers Act (RAISE Act) of 2017, is seeking new members to provide advice and recommendations to the federal government on how to recognize and support family caregivers. [Read more and apply by April 11.](#)

COVID-19 Information

Mandates for masks are declining, but individuals with disabilities remain at risk. Two new articles discuss these concerns:

- [As Masks Come Off, Vulnerable Americans Feel Left Behind](#) – from Politico
- [Negotiating Masks in the Workplace: When the ADA Does and Does Not Apply](#) – from Petrie-Flom Center at Harvard Law School

National Policy

- [Following Protests, Case that Threatened Disability Rights Won't Go to Supreme Court](#) – An update on Payan vs. LA Community College District

California Policy

Evento Virtual: Disparidades en los Servicios que el Centro Regional Ofrece

Fecha Sábado 19 de marzo
Hora 5 to 7 p.m. hora del Pacifico
Patrocinador Congreso Familiar
Detalles Muchos clientes del Centro Regional y sus familias no utilizan todos los servicios disponibles para ellos. Esta conversación explicará en español lo que significa esta disparidad para las familias de niños con necesidades especiales de atención médica. [Aprende más.](#)

Employment Opportunities

Grants Manager: Lucile Packard Foundation for Children's Health

The Grants Manager is the key point of contact for Foundation grant applicants and recipients, responsible for managing the administration of all grants and contracts, including maintaining and improving the grants management database and grant application portal, communicating with grantees and internal stakeholders, monitoring all reporting, and processing documents and payments. [See the job posting.](#)

Director of Operations: Family Voices

National Family Voices is accepting applications for a Director of Operations to oversee a variety of operations and participate in strategic planning and internal initiatives. [See the job posting.](#)

Events

Reminder: [Disability Policy Seminar, March 28-30, in Washington, DC and virtual.](#)

In the News

- [Ed Department Issues Guidance on How IDEA Applies to Private Schools](#)
Disability Scoop, 3/10/22
- [Programs for People with Disabilities Still Not Seeing Federal Funds](#)
Disability Scoop, 3/9/22

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 with your news or updates. Or contact newsletter editor: Eileen Walsh at Eileen.Walsh@lpfch.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.

