

## California Advocacy Network for Children with Special Health Care Needs

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

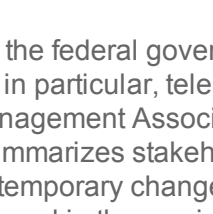
### Home Health Care

#### New York Times Calls Out Shortage of Home-Care Nurses for CYSHCN, Families

The front page headline in the *New York Times* tells the story: "To Keep Their Son Alive, They Sleep in Shifts. And Hope a Nurse Shows Up." The lengthy, illustrated piece documents the devastating effects on families of the pandemic-driven shortage of home-care nurses. The story features the [research](#) of pediatrician Carolyn Foster of Lurie Children's Hospital of Chicago, who, with support from our Foundation, surveyed parents of medically fragile children and found that half had lost home health care services during the pandemic, primarily for children with the most complex needs. Cara Coleman, director of public policy and advocacy at Family Voices, also is quoted. [Read the story.](#) (Registration may be required.)

### COVID-19 Impact on Child Health Policy

#### Report: COVID-19 Policy Flexibilities Affecting CYSHCN – What to Keep, Modify, or Discard?



To mitigate the impact of COVID-19 on health care, the federal government and many states created temporary policy flexibilities in areas such as eligibility, access, and, in particular, telehealth. Many of these changes broadened care options for CYSHCN. A new report from Health Management Associates, created with support from our Foundation, discusses the key flexibilities that were enacted, summarizes stakeholders' perspectives about their impact, makes recommendations about continuing or ceasing the temporary changes, and suggests new policies to best support CYSHCN. A webinar on the findings will be announced in the coming weeks. [Read the full report](#), a summary with the recommendations, and a California-specific report.

#### Medicaid Forward: Children's Health – Report, Webinar

**Date** Thursday, June 17  
**Time** 9 to 10 a.m. Pacific Time  
**Sponsor** National Association of Medicaid Directors  
**Details** Nearly half of all CYSHCN nationwide rely on Medicaid and the Children's Health Insurance Program (CHIP). After the pandemic, these two programs will be essential to children's resilience. The National Association of Medicaid Directors (NAMD) has published a report that provides specific, actionable steps that Medicaid and CHIP programs can take to improve the trajectory for children. The report includes a section on CSHCN. [Read the report.](#)

A related webinar will explain the new NAMD framework, *Medicaid Forward: Children's Health*, which lays out options Medicaid programs can consider to ensure that children and their caregivers are supported post-pandemic, and explores how Medicaid programs can build on pandemic-driven changes to transform health care delivery for children. [Register.](#)

#### In Brief

- [Medicaid and CHIP and the COVID Public Health Emergency](#) (PDF) – A preliminary Medicaid & CHIP Data Snapshot from the federal Centers for Medicare and Medicaid Services
- [Federal Disability Information and Access Line Offers Help with COVID-19 Vaccinations for People with Disabilities](#) – from the Administration for Community Living

### Pediatric Palliative Care

#### Webinar: Including and Supporting Siblings in Non-traditional, Multicultural Families

**Date** Tuesday, June 22  
**Time** 12 to 1 p.m. Pacific Time  
**Sponsors** Pennsylvania's Pediatric Palliative Care Coalition, Greater Illinois Pediatric Palliative Care Coalition, Children's Hospice & Palliative Care Coalition of California, Jacob's Heart Children's Cancer Support Services, and the CSU Shiley Institute for Palliative Care  
**Details** Participants will learn how to identify and address the needs of siblings in non-traditional and multicultural families, and will gain perspective on how to support them in home and clinical settings. [Read more and register.](#)

### Medical Complexity

#### Open Meeting: The Future of the National Center for Complex Health and Social Needs

**Date** Wednesday, June 23  
**Time** 10 to 11 a.m. Pacific Time  
**Sponsor** National Center for Complex Health and Social Needs  
**Details** As its five-year anniversary approaches, the National Center for Complex Health and Social Needs contracted with Mathematica to evaluate the value of its work to stakeholders. This event offers an opportunity for the complex care community to share thoughts on the needs and opportunities facing the field, and help envision the next phase of the National Center's work. Although much of the Center's work to date has focused on adults, some programs include children with medical complexity. Read about the [assessment](#) (PDF) and [register](#) for the conversation.

#### In Brief

- Reminder: [Apply by June 11 to Be a Consumer Scholar in the Field of Medical Complexity.](#)

### Health Equity

#### Webinar: Inverting the Burden: A Health Equity Strategy for Delivering Complex Care

**Date** Tuesday, June 22  
**Time** 10 to 11 a.m. Pacific Time  
**Sponsor** National Center for Complex Health and Social Needs  
**Details** "Inverting the burden" is an approach to achieving health equity by placing the burden of addressing racism and other inequities on institutions rather than individuals. This webinar will highlight an example focused on the Atlanta Regional Collaborative for Health Improvement (ARCHI), a multi-system health-housing collaborative of 100 partners. [Register.](#)

### Resources

#### Data to Help Advocate for Better Health Coverage for CYSHCN

The Catalyst Center's State Data Chartbook provides information on indicators of health coverage and health care financing for CYSHCN in every state and the District of Columbia and Puerto Rico. The book includes data covering demographics, economics, child health services, insurance availability, and factors impacting coverage of CYSHCN. The data can be used to advocate for improved coverage. [Read more.](#)

#### In Brief

- [Social Security Administration Update 2021: Benefits for Children with Disabilities](#) (PDF)

### Transition to Adult Care

- Reminder: [Transitions of Care Patient Advocacy Summit, June 15-24](#)

### California Policy

#### Medi-Cal Children's Health Advisory Panel to Meet

**Date** Thursday, June 24  
**Time** 9:30 a.m. to 1 p.m. Pacific Time  
**Location** Virtual; [Register in advance.](#)  
**Details** See more details on the [website.](#)

#### In Brief

- [State Health and Human Services Leaders Issue Joint Statement on Release of California's \\$5.2 Billion Medicaid Home and Community Based Services Spending Plan](#)

### Servicios para niños de California

#### Implementación del Modelo del Niño en su Totalidad de CCS

Las organizaciones de atención administrada de Medi-Cal ahora brindan servicios de California Children's Services (CCS) en 21 condados, bajo un programa llamado Modelo del Niño en su Totalidad (WCM). El Sistema de Servicio Integrado Regional para Niños (CRISS) ha monitoreado de cerca la implementación del WCM y ha desarrollado una serie de resúmenes temáticos que identifican estrategias potenciales para abordar problemas y preocupaciones. Los artículos cubren los siguientes temas: Coordinación de servicios/autorizaciones, Responsabilidad de los Servicios de la Unidad de Cuidados de Bebés de Alto Riesgo (NICU), Mantenimiento y transporte, Responsabilidad del programa de seguimiento de bebés de alto riesgo, Responsabilidad sobre la documentación médica para la redeterminación inicial y anual de CCS. Para aumentar la accesibilidad, los artículos se han traducido al español. [Lea los resúmenes temáticos en Español.](#)

### Did You Know?

The Data Resource Center for Child and Adolescent Health (DRC) has released the single-year 2019 National Survey of Children's Health (NSCH). This is the fourth data set since the survey redesign in 2016. Estimates are available on [childhealthdata.org.](#)

### In the News

- [State Will Pay \\$100K, Modify Disability Services Under Agreement with Feds](#)  
*Disability Scoop, 6/8/21*
- [Biden's Budget Includes Boost to Special Ed. Disability Services](#)  
*Disability Scoop, 6/2/21*
- [A Program Promised to Pay for Brain-Damaged Infants' Care. Then It Sent Families to Medicaid Instead](#)  
*ProPublica, 6/1/21*
- [Illinois Dramatically Limits Use of Seclusion and Face-Down Restraints in Schools](#)  
*ProPublica, 5/31/21*

#### 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).

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.

