

## Children and Youth with Special Health Care Needs

### Network Newsletter

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

#### SYSTEMS AND STANDARDS

##### Implementing the National Blueprint for Changing the System: The Role of Families

The [Blueprint for Change](#) is a national framework designed to address the concern that 85 percent of CYSHCN do not receive care through a well-functioning system of services. Two webinars from the Family LEAD Committee of the Association of Maternal and Child Health Programs explain the Blueprint and its goals, and discuss how families should be involved in moving the Blueprint work forward. Listen to [webinar 1](#) and [webinar 2](#).

#### HOME- AND COMMUNITY-BASED SERVICES

##### Executive Order Aims to Expand, Enhance Access to Care

In an action that may benefit many CYSHCN and their families, President Biden on April 18 issued a wide-ranging [executive order](#) that includes provisions to expand access to affordable, high-quality long-term care and provide support for care workers and family caregivers. [Read more](#).

##### Webinar: President's Committee for People with Intellectual Disabilities to Consider Home- and Community-Based Services

<b>DATE</b>	Monday, May 1
<b>TIME</b>	9 a.m. to 2 p.m. Pacific Time
<b>SPONSOR</b>	Administration for Community Living, US Department of Health and Human Services
<b>DETAILS</b>	The President's Committee for People with Intellectual Disabilities (PCPID) will discuss emerging issues related to home- and community-based services: direct support professionals, competitive integrated employment, community living, and federal support programs. This discussion will help develop a general framework for the preparation of the PCPID Report to the President. Public comment welcome. <a href="#">Read more</a> and <a href="#">register</a> .

#### FAMILY ENGAGEMENT

##### Apply to Be a National Consumer Scholar in Complex Care Program

Applications will be accepted until **May 31** for the Camden Coalition's National Consumer Scholars program. Scholars are individuals who have first-hand experience living with or caring for someone with complex health and social needs, experience with systems-level transformation, and leadership involvement with an organization that provides complex care or advocacy. Scholars take part in leadership development activities, and work alongside Camden Coalition staff to develop and inform the field of complex care. [Read more and apply](#) and [register for an information session](#) on **May 11** to learn more.

#### PEDIATRIC PALLIATIVE CARE

##### Webinar: Caring for a Child in the Community

<b>DATE</b>	Tuesday, May 16
<b>TIME</b>	12 to 1 p.m. Pacific Time
<b>SPONSOR</b>	Pennsylvania's Pediatric Palliative Care Coalition, Greater Illinois Pediatric Palliative Care Coalition, Children's Hospice & Palliative Care Coalition of California, and the CSU Shiley Haynes Institute for Palliative Care
<b>DETAILS</b>	Community-based hospice organizations are essential in providing home-based support to children and families facing life-limiting illness, especially those living in rural communities. This webinar will explore hospice best practices for communication and collaboration with a child's whole care team -- from hospital to community to home -- and how hospice organizations might leverage internal and community-based resources to support families. <a href="#">Read more and register</a> . Fee.

#### CHILDREN WITH MEDICAL COMPLEXITY

##### Opinion: Children Who Experience 'Health Complexity' Must Be a Primary Focus of Health Equity Efforts

"Health complexity" is a concept that combines and then quantifies the degree to which children have medical and/or social complexity. The Oregon Pediatric Improvement Partnership (OPIP), with support from our Foundation, developed a model of health complexity, along with recommendations for how to strategically use these data to begin eliminating health disparities. [In an opinion piece](#), OPIP researchers argue that focusing on health complexity is critical to achieving equity for children. [Read](#) how the health complexity model was developed.

#### PUBLIC HEALTH EMERGENCY UNWINDING

- [States Should Figure Out a Way to Share Renewal Month with Enrollees, Assisters, and Health Care Providers](#), from the Georgetown Center for Children and Families, outlines a variety of ways that states can share renewal month notifications with Medicaid enrollees and frontline organizations that serve them.
- [Oregon's Glide Path to a Basic Health Program Following the End of Medicaid Continuous Coverage](#) - from Manatt
- [Opinion: Medicaid and Dental Care - How to Protect Your Child's Coverage](#) - *Times of San Diego*
- [Here's What You Can Do if You Lose Medicaid Coverage](#) - CNN

#### NATIONAL POLICY

##### Medicaid Awareness Month Showcases Value, Concerns

As the country marks Medicaid Awareness Month in April, the executive director of the National Health Law Program warns that the program, essential to many CYSHCN and their families, may be threatened by various proposals being discussed in Congress. [Read her essay](#).

Also see:

- [A Medicaid and CHIP tutorial](#) from the Catalyst Center gives a broad overview of Medicaid and CHIP, the many different populations these programs serve, the changes they are undergoing as a result of health care reform, and some options to improve services for CYSHCN through communication and collaboration with Medicaid and CHIP staff.
- A [Protect Medicaid Funding Series](#) from the National Health Law Program includes fact sheets on child and adolescent health, disability rights, and health inequities.
- [Medicaid Coverage at Risk for People with Disabilities: How You Can Help](#) - from Georgetown Center for Children and Families

#### TRANSITION TO ADULTHOOD

##### Grants Available to Improve Transition to Employment

The U.S. Department of Education's Rehabilitation Services Administration has announced that \$224 million in grants is available for innovative demonstration projects that create systemic approaches to improving access to pre-employment transition services for children and youth with disabilities. State vocational rehabilitation agencies and state education agencies have until **June 5** to apply for the grants. [Read more](#).

#### HEALTH EQUITY

##### National Minority Health Month: Better Health Through Better Understanding

*Conversations in Equity* is a blog series from the Centers for Disease Control and Prevention devoted to increasing awareness of health inequities and promoting efforts to reduce health disparities and achieve health equity. This month's post addresses improving communications to help patients better understand and use information about their health. A lack of such "health literacy" is associated with worse health care and health outcomes, and research indicates that people with limited health literacy are more likely to identify themselves as members of racial or ethnic minority groups. [Read more](#).

#### CALIFORNIA POLICY

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

<b>DATE</b>	Thursday, May 4
<b>TIME</b>	10 a.m. to 2 p.m. Pacific Time
<b>SPONSOR</b>	Department of Health Care Services
<b>DETAILS</b>	Registration information and the meeting agenda are posted on the panel <a href="#">webpage</a> closer to the meeting date.

#### RESOURCES

##### Resources for Families, Clinicians on Birth Defects and Infant Disorders

Of the nearly four million infants born in the United States each year, approximately 3 percent have some type of birth defect. The American Academy of Pediatrics offers [resources \(PDF\)](#) that help families learn how to seek proper care, and that advise clinicians on how to deliver the best care for patients across all stages of life.

#### EVENTS

##### National Birth Defects Conference Scheduled

Registration is open for the National Birth Defects Prevention Network Conference, set for August 14-16 in Atlanta. Participants will learn about current advances and opportunities for birth defects surveillance, research, intervention, and prevention through sharing of best practices at state, local and national levels. Fee. [Learn more and register](#).

#### SCHOLARSHIP OPPORTUNITY

##### Program Supports Students Pursuing Media, Entertainment Careers

High school seniors, undergraduate, and graduate students with disabilities who are pursuing careers in media, communications, or entertainment industries may apply for the NBCUniversal Tony Coelho Media Scholarship. The program offers eight scholarships to be used by students enrolled in college in the fall semester of 2023. The application deadline is **May 22**. [Read more and apply](#).

#### IN THE NEWS

- [After a 4-month NICU Stay, I'm Not the Parent I Thought I Would Be](#) *NPR, 3/30/23*
- [Residency Program Aims to Ease Shortage of Special Education Teachers](#) *Disability Scoop, 4/14/23*

#### WE'D LIKE TO HEAR FROM YOU

Let us know what's happening with your organization or family. Email newsletter assistant editor Hannah Au at [Hannah.Au@lpfch.org](mailto:Hannah.Au@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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