

## Children and Youth with Special Health Care Needs

### Network Newsletter

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

#### PUBLIC HEALTH EMERGENCY UNWINDING

President Biden has announced his intention to end the Public Health Emergency (PHE) on May 11, which will affect many health care policies. The Georgetown Center for Children and Families provides multiple resources to understand and address the winding down of the emergency provisions and Medicaid continuous coverage protection. Review the Center's [unwinding webinar series](#), [50 state tracker](#), [resources](#) and [blog series](#). The National Health Law Program also has a list of [PHE unwinding and continuous coverage resources](#) to help maintain coverage.

*Related:* [Oregon Leads the Way for States to Provide Continuous Coverage in Medicaid](#) – from Manatt

#### CHILDREN WITH MEDICAL COMPLEXITY

**DATE** Thursday, February 23

**TIME** 11 a.m. to 12:15 p.m. Pacific Time

**SPONSOR** Center for Health Care Strategies

**DETAILS** A speaker will discuss a national movement to empower the voices of adolescents and young adults living with chronic conditions and ensure that they are given the opportunities and resources they need to thrive. This series focuses on expanding patient and family engagement to improve pediatric care. [Read more and register](#).

**DATE** Wednesday, February 8

**TIME** 9 to 10 a.m. Pacific Time

**SPONSOR** Pediatric Palliative Care Coalition

**DETAILS** Speakers will highlight the roles of a recreation therapist and a massage therapist who help to care for children with medical complexities in both the hospital and home setting. Discussion will include how to assess the needs of both verbal and non-verbal patients, and a parent caregiver familiar with these therapies will describe the experience. [Read more and register](#).

#### INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

In an open-access clinical report titled *The Hospitalized Adolescent*, the American Academy of Pediatrics devotes a major section to youth with varying degrees of intellectual/developmental disabilities and offers guidance for care providers. The authors note the potential emotional effects of hospitalization on these adolescents, the need for specific kinds of care, the importance of involving youth and families in care plans, and the significance of discharge planning and care coordination, among other topics. [Read the report](#).

Also see: [In First, Pediatricians Get Guidance On Hospitalized Teens with IDD](#) - from *Disability Scoop*

#### FAMILY ENGAGEMENT

**DATE** Wednesday, February 15

**TIME** 5 to 6 p.m. Pacific Time

**SPONSOR** Courageous Parent Network

**DETAILS** Partners caring for a child with a serious illness are confronted with unique challenges. Each person in the relationship may cope differently. A licensed psychologist will offer insights and considerations for coping together, and caregivers will discuss how they have managed. [Read more and register](#).

The Health Summit, scheduled virtually for March 6-7, brings together families, youth, providers, policymakers, advocates, state agencies, insurers, and other stakeholders to identify and address the health challenges for CYSHCN and their families. [Read more and register](#).

#### TRANSITION TO ADULTHOOD



The [slides and recording](#) of *Pursuing a Secure Economic Future for Youth with Disabilities—Lessons from PROMISE* are now available.

#### NATIONAL POLICY

**DATE** Thursday, February 9

**TIME** 11 a.m. to 12 p.m. Pacific Time

**SPONSOR** ABLE National Resource Center

**DETAILS** ABLE accounts are tax-advantaged savings accounts for individuals with disabilities and their families. Speakers will highlight tax filing tips that may result in significant tax savings and/or a refund that can be deposited directly into ABLE accounts. [Read more and register](#).

#### HOME AND COMMUNITY-BASED CARE

- [Lawmakers Revive Effort to Prop Up Disability Services](#) – from *Disability Scoop*
- [Addressing Wages of the Direct Care Workforce through Medicaid Policies](#) – from the National Governors Association

#### CALIFORNIA CHILDREN'S SERVICES

Title V legislation requires a statewide needs assessment every five years to examine needs and select priorities for maternal and child health program improvements. With support from our Foundation, the Family Health Outcomes Project at the University of California San Francisco conducted a case study to examine what was and was not accomplished following previous needs assessments of the CCS program. The author offers strategies and recommendations to ensure that progress is made on the priorities raised in future needs assessments, the next of which will begin in 2023. Read the [report](#) and see a related [webinar](#) that featured a stakeholder discussion of the report findings.

#### CALIFORNIA POLICY

**DATE** Thursday, February 16

**TIME** 9:30 a.m. to 3:30 p.m. Pacific Time

**DETAILS** The committee advises the Department's director on the behavioral health components of the Medi-Cal program as well as behavioral health policy issues more broadly.

Find details on the [website](#) and [register in advance for the Webex meeting](#).

In a *Cal Matters* opinion piece, the mother of two teenagers with complex medical needs discusses her search for behavioral health care, and calls for immediate resources and support for local behavioral health delivery systems. [Read more](#).

#### SPECIAL EDUCATION

- [Parents Seek Special Ed Services Lost to COVID](#) - from *Disability Scoop*
- [Ed Department Sees Sharp Rise in Disability Discrimination Complaints in Schools](#) - from *Disability Scoop*
- [More Schools Requiring Psych Clearances for Kids to Stay in Class](#) - from *Disability Scoop*

#### IN THE NEWS

- [Children's Mental Health Tops List of Parent Worries, Survey Finds](#)  
*CNN, 1/31/23*
- [McDonald's Fired Man Who Worked There 37 Years in Violation of ADA, Lawsuit Says](#)  
*Disability Scoop, 1/27/23*
- [Startup Creates Bionic Clothing to Help People with Cerebral Palsy](#)  
*Disability Scoop, 1/24/23*

#### 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).

[Join The Network](#)

To see past issues, visit the [Network Newsletter Archive](#).