

California Advocacy Network for Children with Special Health Care Needs

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

System Standards

Improving Systems by Implementing the National Standards of Care for CYSHCN

The National Standards define the core components of a comprehensive, coordinated, and family-centered system of care for children and youth with special health care needs. A new article in the *Maternal and Child Health Journal* takes an in-depth look at how Colorado and Florida redesigned their Medicaid managed care programs using the Standards, and offers a flexible framework that can be used by other states to improve their systems. The study was conducted by Issues Research with support from our Foundation. [Read *The Influence of National Standards on Medicaid Managed Care Programs: Implications for Children and Youth with Special Health Care Needs*](#).

Children with Medical Complexity

New Opportunity for States to Connect Children with Complex Conditions to Critical Services

Beginning October 1, states will have an opportunity to offer a new "health home" services benefit for Medicaid-eligible children with medically complex conditions. Under guidance issued by the Centers for Medicare and Medicaid Services, states have the option to file an application to provide access to a full range of pediatric specialty and subspecialty medical care, including services from out-of-state providers, as medically necessary. [Read more](#).

Webinar: A Patient-Centered Complex Care Research Agenda - Recommendations for Collective Action

Dates Thursday, September 15
Time 9 to 10:30 a.m. Pacific Time
Sponsor Center for Health Care Strategies
Details Experts note that much of the research on the effectiveness of complex care neglects the patient perspective. The Center for Health Care Strategies has developed a *Patient-Centered Complex Care Research Agenda*, scheduled for release next month. This webinar will highlight the agenda's recommendations and opportunities for adopting a person-centered approach to complex care research. [Read more and register](#).

Family Engagement

Schedule Set for October Family Leadership Conference

Registration is open for the 2022 Family Leadership Conference, a hybrid in-person/virtual event scheduled for October 18-20 in Washington, DC. In-person participation will be limited to family leaders, family organizations, and presenters. Fee. [Read more and register](#).



Related: Among the presentations at the Family Leadership Conference will be a session titled *Real Talk about Real Partnerships: What It Really Took for Family Leaders and Clinicians to Become Colleagues in the C6 Seminar Series*. In that [10-part series](#), family leaders and clinicians joined forces to discuss real-life experiences, clinical scenarios, and potential for research.

Health Equity

Course Considers Issues Affecting Care of Black CYSHCN

Data indicate that Black CYSHCN are less likely than their White counterparts to receive care through a medical home and within a well-functioning system, and that pediatricians require more training on the topic. *Addressing Equity for Black CYSHCN*, a free online PediaLink course, is now available through the National Resource Center for Patient/Family-Centered Medical Home. The two-hour asynchronous course examines factors that affect equitable health care, including medical home and systems of care. This activity is approved for AMA PRA Category 1 Credit™. [Read details and register](#).

In Brief

- [How Can Medicaid and CHIP Promote Health Equity?](#) -- Listen to the keynote speech from the Georgetown Center for Children and Families Annual Conference on Child Health Policy.

Pediatric Palliative Care

Webinar: Interprofessional Spiritual Care in Pediatric Palliative Care

Date Thursday, September 22
Time 12 to 1 p.m. Pacific Time
Sponsor 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
Details The presentation will discuss the importance of addressing spiritual health, particularly spiritual distress in the care of pediatric patients with serious illness, and strategies for integrating spiritual care in clinical practice. [Read more and register](#). Fee.

Firefly Chat: What Can Bereaved Siblings Teach Us

Date Tuesday, September 13
Time 9 to 10 a.m. Pacific Time
Sponsor 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
Details Siblings sometimes get "lost" during families' palliative care. This chat will include a bereaved sibling who will discuss how the death of his brother affected him and his family. Speakers will offer suggestions on language that can be helpful and harmful. [Read more and register](#).

Developmental Disabilities

The Arc Announces Annual Convention

Early-bird registration is available through **October 12** for The Arc's National Convention, scheduled for November 10-12 in Denver. Advocates, professionals, and people with intellectual and developmental disabilities and their families will discuss education, advocacy, housing, criminal justice, and more. Fee. [See the tentative schedule and register](#).

Special Education

Federal Guidance: Discipling Children with Disabilities at School

Noting that students with disabilities often face harsh and exclusionary disciplinary action at school, the federal Department of Education's Office for Civil Rights and Office of Special Education and Rehabilitative Services recently released resources that offer comprehensive guidance to help public elementary and secondary schools fulfill their responsibilities to meet the needs of students with disabilities and avoid the discriminatory use of student discipline. [See the guidance](#).

National Policy

In Brief

- [Proposed Eligibility Rule Simplifies Medicaid and CHIP Enrollment Process for Children](#) - from Georgetown Center for Children and Families
- [Congress Punts on Aid for Struggling Disability Services System](#) - from Disability Scoop
- [CMS Reminds States EPSDT Requirement Includes Behavioral Health, Offers Specific Strategies](#) - from Georgetown Center for Children and Families

California Policy

Medi-Cal Children's Health Advisory Panel to Meet

Date Thursday, September 15
Time 10 a.m. to 1 p.m. Pacific Time
Location 830 Stillwater Road, Sacramento or attend virtually
Details The panel is a 15-member independent statewide advisory body that advises the Department of Health Care Services on matters relevant to children enrolled in Medi-Cal. Meeting materials will be posted on the [website](#). Register in [advance](#) if attending virtually.

COVID-19 Information

Webinar: Medicaid and CHIP Continuous Enrollment Unwinding: What to Know and How to Prepare

Date September 28
Time 9 a.m. Pacific Time
Host Centers for Medicare and Medicaid Services
Details The Biden administration has not given notice of termination of the COVID-19 public health emergency (PHE), so the provisions likely will be [extended](#) to January 2023. In the meantime, a series of monthly webinars continues on topics related to the Medicaid and CHIP continuous enrollment unwinding. [Learn more and register](#).

Related: [An Estimated 3.8 Million Eligible Children Could Lose Medicaid Due to Administrative Churn During the Unwinding](#)

Resources

Submit Promising Practices, Programs for National Dissemination

The Association of Maternal and Child Health Programs Innovation Hub is currently accepting submissions to its [MCH Innovations Database](#), a searchable repository of "what's working" in the field that includes effective practices, programs, and strategies that positively affect maternal and child health populations, which include CYSHCN. Practices must be submitted by **September 30**. [Read more](#) or view a [short video](#).

In the News

- [Rule Change Could Improve Access to Dental Care for People with Disabilities](#)
Disability Scoop, 8/29/22
- [What Flying Is Like for Passengers Who Use Wheelchairs](#)
NY Times, 8/8/22
- [How to Talk About Disability Sensitively and Avoid Ableist Tropes](#)
NPR, 8/8/22
- [Penalties for Violating Rights of the Disabled Don't Apply to Public Schools, State Supreme Court Rules](#)
SF Chronicle, 8/4/22

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

