

Children and Youth with Special Health Care Needs NETWORK NEWSLETTER

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

For Medi-Cal members and providers affected by the fires in the Los Angeles area: The California Department of Health Care Services has an [Emergency and Disaster Assistance Questions & Answers page](#) to help you access care, fill prescriptions, secure transportation, and more.



Registration Open for 2025 AMCHP Annual Conference

Register now for the 2025 Association of Maternal & Child Health Programs (AMCHP) conference to take advantage of **early bird registration**, which **ends January 17**. This year's event for maternal and child health leaders, researchers, and advocates centers on the theme of "Partnering for Impact." See the conference website for the full schedule.

DATES: Saturday, March 15 - Tuesday, March 18

LOCATION: The Westin Washington, DC Downtown

[Learn more and register](#)

FAMILY ENGAGEMENT

New Leadership Webinar Series from the Institute for Patient- and Family-Centered Care

The series—entitled "The Art of the Possible"—will include conversations with leaders who have influenced health care and been champions of patient- and family-centered care. Learn who and what has shaped these leaders and hear about their greatest challenges, cautions, and advice for the future. *Note: There is a \$60 fee per webinar, with discounts available.*

FIRST SESSION THEME: Straight Talk: What Matters Most

DATE/TIME: Thursday, January 30 | 10-11 am PT

SPEAKER: Sherry Perkins, PhD, RN, FAAN, President, Luminus Health Anne Arundel Medical Center

[Learn more](#)

NATIONAL POLICY

Toolkit for States: The Role of Medicaid Continuous Enrollment in Improving Children's Health and Wellbeing

This toolkit from State Health & Value Strategies is designed to help states leverage continuous enrollment for Medicaid/Children's Health Insurance Program-eligible children and youth to promote access to care, ensure delivery of critical services, and monitor child health outcomes.

[Access the toolkit](#)

2025 Centers for Medicare & Medicaid Services (CMS) Health Equity Conference: Call for Proposals

CMS is accepting proposals for breakout session speakers and poster presenters for the 2025 CMS Health Equity Conference, which will take place April 23-24, 2025, in Bethesda, MD. Proposals should focus on the conference theme, "Building a Healthier America," and demonstrate a connection to a CMS program (e.g., Medicaid, CHIP). **The deadline for submissions is January 21 at 5 pm PT.**

[Learn more](#)

See also:

- [Why Medicaid Is Important: EPSDT and Services for Children and Youth with Disabilities](#) (National Health Law Program, 1/15/25)
- [Trump's Return Puts Medicaid on the Chopping Block](#) (*KFF Health News*, 1/13/25)
- [Medicaid and CHIP: Program Improvements and the Need to Protect Them](#) (*Health Affairs Forefront*, 1/13/25)

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- [House Republicans Actively Considering Deep and Damaging Cuts to Medicaid](#) (*Say Ahhh!* blog, 1/9/25)
- [Why Medicaid Cuts Could Be a ‘Crisis’ for People with Disabilities](#) (*STAT*, 1/6/25)

PALLIATIVE CARE

Three State Snapshots of Pediatric Palliative Care

This brief from the National Academy for State Health Policy looks at three states' approaches to providing pediatric palliative care. The brief highlights how programs in California, Massachusetts, and Vermont are leveraging Medicaid and Title V CYSHCN programs to pay for these services.

[Read the brief](#)

Webinar: Psychosocial Screening, Assessment and Intervention—The Role of the Pediatric Palliative Care (PPC) Social Worker

The next session in the 2025 PPC Webinar Series will focus on the role of integrated behavioral health on a PPC team and the implications for PPC social work practice. *Note: There is a registration fee of \$40 for individuals; group rates are also available.*

DATE/TIME: Tuesday, February 18 | 12-1 pm PT

DISCUSSANTS:

Esther Ammon, MSW, LCSW, APHSW-C
Stacy Remke, MSW, LICSW, APHSW-C
Akilah Burford, MSW
Allie Shukraft, MSW, MAT, APHSW-C
Erin Bonsall, Social Work Student

[Learn more](#)

Courageous Parents Network Seeking Next Cohort of Parent Champions

The Courageous Parents Network, which provides resources and tools for caregivers of children with serious medical conditions, is looking for four parents/caregivers for its Parent Champions program. The program brings palliative-informed, family perspectives to clinicians and patient organizations nationwide. Parent Champions are paid and trained to hone and present their stories.

[Learn more](#)

CALIFORNIA POLICY

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Why Does Medi-Cal and California Children's Services Matter to Your Family?

With cuts to Medicaid being considered at the federal level that may have significant impacts on state funding, Family Voices of California (FVCA) is encouraging families to share their Medi-Cal or California Children's Services stories with policymakers. Personal narratives help educate policymakers about the real-life impact of these programs and illustrate the importance of maintaining access to health care without cuts, caps, or limits on services for CYSHCN. To aid in this effort, FVCA has created an online form for collecting family stories.

Take action: share your story

If you prefer to share your story via video, send it to sbaysinger@familyvoicesofca.org. Videos should be 2-3 minutes long and in your preferred language.

California Children's Services (CCS) Due Process Toolkit: Now Available in Spanish

This National Health Law Program toolkit helps advocates, CCS beneficiaries, and families understand how to access care through the program and how to file grievances and appeals when children have been denied services. Included in the toolkit are applicable laws, regulations, policy guidance, flowcharts, advocacy tips, and an index of acronyms. Now available in English and Spanish versions. This work is supported by our Foundation.

Access the toolkit



What Is the Enhanced Care Management (ECM) Medi-Cal Benefit?

Children Now's ECM information webpage explains how the benefit works for children and

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providers, health plan representatives, and other community members the chance to share their feedback and stories about ECM. This work is supported by our Foundation.

[Learn more](#)

See also:

- [More California Kids with Disabilities Are Enrolled in a New Health Program, But Is It Helping?](#) (*California Health Report*, 11/7/24)
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California Children's Services (CCS) Advisory Group Meeting

At its January 8 meeting, the CCS Advisory Group welcomed new members, revisited 2024 program highlights, considered options for 2025 priorities, and discussed a range of topics including updates on the 2025 Whole Child Model Expansion, Medi-Cal Rx, and Enhanced Care Management (ECM). The Department of Health Care Services also shared new guidance on Closed-Loop Referral Implementation for ECM and Community Supports. Meeting agenda and instructions for requesting a copy of the presentation can be found on the Group's [website](#). The next meeting will be held virtually and in person on April 9, 2025.

[Learn more](#)

See also:

- [CCS Demographics and Enrollment Dashboard](#) (CA Department of Health Care Services)

NEWS

- [Already Battered Disability Providers Say More Cuts Could Be Coming](#) (*Disability Scoop*, 12/20/24; *free access to 2 articles/month*)

WE WANT TO HEAR FROM YOU

Let us know what's happening with your organization or program. Send news and updates to info@lpfch.org. Thank you!

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