

California Advocacy Network

for Children with Special Health Care Needs

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

California Children's Services

Helpline Available for Families in Transition from CCS to Medi-Cal Managed Care

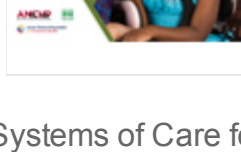
Family Voices of California is working with the Department of Health Care Services to offer support for CCS families who are navigating their child's move to Medi-Cal Managed Care under the Whole-Child Model. As a reminder, the 21 transitioning counties are Del Norte, Humboldt, Lake, Lassen, Marin, Mendocino, Merced, Modoc, Monterey, Napa, Orange, San Luis Obispo, San Mateo, Santa Barbara, Santa Cruz, Shasta, Siskiyou, Solano, Sonoma, Trinity, and Yolo. Families who need information or assistance may email Ali Barclay at abarclay@familyvoicesofca.org or call the free helpline at (888) 387-0393. [Read more.](#)

CCS Advisory Group to Meet on October 10

Date Wednesday, October 10
Time 10 a.m. – TBD Pacific Time
Location 1700 K Street, Sacramento – First Floor Conference Room
Dial-In (888) 989-6488; Passcode: 1945234 (listen only)
Details The Advisory Group members are CCS stakeholders who provide advice to the Department of Health Care Services on the transition to the Whole-Child Model. Public comment will be taken. The agenda and materials will be posted on the [website](#).

Quality Standards

New Toolkit Assists in Use of Quality Standards to Improve Systems of Care



The National Standards for Systems of Care for Children and Youth with Special Health Care Needs define the core components of a comprehensive, coordinated, and family-centered system of care. Since the standards were released in 2014, many government programs, health care systems, consumers, and others have used them as guideposts for system improvement. A new toolkit, developed by the National Academy for State Health Policy (NASHP) with support from the Lucile Packard Foundation for Children's Health, provides a portal to critical tools, fact sheets, and other resources that states can use to design, assess, and improve their systems. [Read more about the toolkit.](#)

Also See: [Standards for Systems of Care for Children and Youth with Special Health Care Needs, Version 2.0](#)

Children with Medical Complexity

Panelists Field Questions from Care Coordination Webinar



Panelists now have responded to unanswered questions from the July 26 online ["Conversation on Care Coordination for Children with Medical Complexity: Whose Care Is It, Anyway?"](#). Their responses touch on care coordination staffing, resources, communication, and more. The conversation was part of our series on children with medical complexity. [Read the Q&A.](#)

Family Engagement

'Journey Boards' Help Families Understand Complex Medical Information

In 2007 a team of diabetes nurses at Phoenix Children's Hospital developed a game-board concept – using squares on topics related to the child's condition – to initiate conversations between families and health care providers. The boards employed the "teach-back method" in which patients or family members state in their own words what they need to know about their health. The project was highly successful in increasing compliance, and the hospital has expanded the "Journey boards" to multiple diagnoses. Mobile app boards also are available. [Read more.](#)

California Policy

Advisory Committee to Meet on Care Coordination Assessment Project

Date Tuesday, September 25
Time 10 a.m. to 3 p.m. Pacific Time
Location The California Endowment
1414 K Street, Suite 100, Sacramento
Details The Department of Health Care Services is reviewing all aspects of care coordination across the Medi-Cal delivery system through its [Care Coordination Assessment Project](#). Those who cannot attend in person may submit comments to coordinatedcare@dhcs.ca.gov. Materials will be posted on the website.

Electronic Visit Verification Stakeholder Meeting

Date Tuesday, October 2
Time 1 p.m. to 3 p.m. Pacific Time
Location East End Complex, Auditorium
1500 Capitol Avenue, Sacramento
Details Electronic visit verification (EVV) is a telephone and computer-based system that electronically verifies that personal care and home health service visits occur. All states must implement EVV by January 2020. The stakeholder meeting agenda and materials will be posted on the [DHCS website](#) in advance of the meeting. For inquiries or to be added to the stakeholder interested parties e-mail list, write to EVV@dhcs.ca.gov.

National Policy

Bills to Watch

- [HR 3325](#) – The Advancing Care for Exceptional Kids Act (ACE) would establish a state Medicaid option to provide coordinated care through a medical home for children with complex medical conditions. Approved September 13 by the House Energy and Commerce Committee. [Read more.](#)
- [S 2227](#) – The EMPOWER Care Act would reauthorize the Medicaid "Money Follows the Person" program, which helps people transition from institutional to community-based care. Approved September 7 by the House Subcommittee on Health of the Committee on Energy and Commerce.

Viewpoint

[How Can We Prepare Our Kids with Special Needs for a School Crisis?](#) – An article from the Washington Post by a journalism professor who also is the mother of a son with autism.

Resources

Nurses Promote Palliative Care

The National Institute of Nursing Research has developed a Palliative Care Campaign to increase the use of palliative care for children and teens living with serious illnesses. Materials are available for patients and families as well as health care providers. [Read more.](#)

In Brief

- [Keeping Children with Disabilities Safe in Emergencies](#) – Advice from the Centers for Disease Control and Prevention.
- [Voting Resource: 2018 REV UP Campaign Issues Guide](#) – From the American Association of People with Disabilities, a comprehensive overview of the issues, legislation, and regulations that could have a significant impact on the disability community.
- *Exceptional Parent Magazine* September issue – [The Education Edition](#)

Webinars

Alternatives to Guardianship: Supported Decision Making

Date Tuesday, September 25
Time 9 a.m. to 10 a.m. Pacific Time
Sponsor The Parents' Place of Maryland
Details Morgan Whitlatch, legal director of Quality Trust for Individuals with Disabilities and lead project director of the National Resource Center for Supported Decision-Making, will discuss practical alternatives to guardianship. Supported decision-making is a way people can make their own decisions and stay in charge of their lives, while receiving any help they need. [Read more and register.](#)

ABLE Success in the Real World

Date Thursday, September 27
Time 11 a.m. to 12:30 p.m. Pacific Time
Sponsor National Disability Institute
Details Strategies and lessons learned from holders of ABLE accounts, which are tax-advantaged accounts that allow individuals with significant disabilities and their families to accrue savings that generally will not affect their benefits. [Learn more and register.](#)

Events

Deadline Extended for AMCHP Annual Conference Proposals

The Association of Maternal and Child Health Programs (AMCHP) has extended the deadline to [submit a proposal](#) (workshop, skills-building session, or poster) for its annual conference, to be held March 9-12 at the San Antonio Riverside Marriott. A track on children and youth with special health care needs is included on the agenda.

Fellowship Opportunity

The Robert Wood Johnson Health Policy Fellows program is accepting applications from outstanding mid-career health professionals, behavioral/social scientists, and others with an interest in health and health care. **The deadline is November 7.** [Read about how to apply.](#)

In the News

- [Republicans 'Duck and Cover' on Pre-Existing Conditions](#)
Politico, 9/19/18

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