

California Advocacy Network

for Children with Special Health Care Needs

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

Network News

AMCHP Announces a Focus on Children with Special Health Care Needs

Noting that 84 percent of children with special health care needs (CSHCN) do not receive care in a well-functioning system, the Association of Maternal and Child Health Programs (AMCHP) has announced that optimizing health for children and youth with special health care needs is a top priority for 2019-21. In "A Bridge for Action," its newly released [strategic plan](#) (PDF), AMCHP writes that for CSHCN it will support comprehensive, coordinated systems of care, create opportunities for families to be engaged in improving systems, and support the implementation of [National Standards for Systems of Care for CYSHCN](#).

California Children's Services

Case Management under the Whole Child Model

Children in 20 counties have been moved from CCS coverage to Medi-Cal managed care over the past year, under the [Whole Child Model](#). One issue that has arisen is how case management is defined and provided in Whole Child counties. The Children's Regional Integrated Service System ([CRISS](#)), in conjunction with local CCS programs throughout the state, has developed a definition of CCS case management and its critical components, including case finding, service authorizations, care coordination, transitions, quality assurance, and standards. CRISS has submitted this definition to the Department of Health Care Services with the expectation that case management under whole child health plans will include all CCS components, per [Senate Bill 586](#). See the [CRISS definition](#).

Transition to Adult Care

Toolkit Aims to Help States Boost Successful Transitions for Adolescents

Got Transition and the Association of Maternal and Child Health Programs (AMCHP) have created a toolkit that offers resources to help state Title V programs and public health professionals reach the goal of ensuring that adolescents with or without special health care needs receive the services necessary to make the transition to adult health care. [See the toolkit](#).

Care Coordination

Single Plan of Care Connects Children's Hospital and Community Partners to Enhance Care Coordination

An article from the Children's Hospital Association describes how one children's hospital connected primary and specialty care physicians, school nurses, and others for improved care coordination. Children's Hospital of Orange County, California, is nearly three years into its innovative plan that is designed to provide care coordination in the community beyond its high-risk hospital patients. [Read more](#).

Family Engagement

Educate Your Legislators During Congressional Recess

Members of Congress are at home in August, and Family Voices National and The Arc are urging families to make appointments to meet with their representatives and educate them about the needs of children and youth with special health care needs. To make messages more memorable, Family Voices suggests that families go in groups and bring their children (or photos of them). Find the local office numbers for Members of Congress at [contactingcongress.org](#). Check [Town Hall Project](#) to find local town halls and other public events where representative or senators will be present.

California Policy

Assembly Hearing: Overview of Early Childhood Intervention Services for Children with Special Needs

Date	Tuesday, August 13
Time	10 a.m. Pacific Time
Location	State Capitol, Sacramento – Room 126
Sponsor	Assembly Select Committee on Early Childhood Development
Details	Informational hearing about services and systems serving young children with special needs. Agenda is scheduled to include an overview of services, a report from the Assembly Blue Ribbon Commission on Early Care and Education, and a discussion of local approaches to early intervention and recommendations for system improvement. The hearing may be viewed on a live webcast . Public comment also may be sent to the select committee chair and members of the select committee before and after the hearing. See the announcement .

Pediatric Palliative Care

California Pediatric Palliative Care Collaborative Schedules Initial Call

An inaugural call for the newly formed California Pediatric Palliative Care Collaborative is scheduled for August 21 from 1 to 2 p.m. Pacific Time. The collaborative will serve as a forum for California stakeholders to share ideas, experiences, and research, and to discuss new ways to collaborate and move the field forward. Care providers, health plans, CCS county programs, and families all will be represented in the collaborative. To participate, fill out the required [pre-call survey](#) and you will receive call-in information. The topic of the inaugural call is home-based pediatric palliative care.

National Policy

- [HR 3253](#) – On August 6, the President signed this bill, which extends authorization for [Family-to-Family Health Information Centers](#) through 2024. The bill also adds funding for Money Follows the Person, which helps individuals avoid living in institutions, and includes other provisions affecting Medicaid.
- [S 995, HR 2035](#) – The House passed in July and the Senate now is considering this bill, which reauthorizes through 2024 the [Lifespan Respite Care Program](#), which helps build coordinated state lifespan respite systems to better assist family caregivers.

Special Education

- A newly released report from the federal Department of Education assesses how each state is [meeting requirements of the Individuals with Disabilities Education \(IDEA\) Act](#) (PDF) and how they might improve.
- [Beyond Suspensions: Examining School Discipline Policies and Connections to the School-to-Prison Pipeline for Students of Color with Disabilities](#) (PDF) – The report, from the United States Commission on Civil Rights, notes that students with disabilities and students of color are disproportionately subjected to suspension.

Mental and Behavioral Health

- New: [National School Mental Health Curriculum – Guidance and Best Practices for States, Districts and Schools](#) – from the Mental Health Technology Transfer Center Network and the National Center for School Mental Health.

Resources

- *Complex Child* August Issue: [Complex and Palliative Care](#)
- [The Times Magazine's 'Diagnosis' Column Is Now a Documentary Series](#) – A physician explores illnesses that elude diagnosis.

In the News

- [Grocery Chain Rolls Out Adaptive Shopping Carts](#)
Disability Scoop, 8/2/19
- [Racial Disparity in Care Starts with Youngest, Frailest Patients](#)
U.S. News & World Report, 7/29/19
- [Genetic Counselors of Color Tackle Racial, Ethnic Disparities in Health Care](#)
NPR, 7/27/19
- [Target Adapts Halloween Costumes for Special-Needs Kids](#)
Business Journals, 7/22/19

We'd like to hear from you

Let us know what's happening with your organization or family. Email newsletter editor Eileen Walsh at Eileen.Walsh@lpfch.org with your news or updates.

