

# California Advocacy Network

## for Children with Special Health Care Needs

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

**Note – The next Newsletter is scheduled for publication on July 12. Happy Fourth of July.**

### California Children's Services

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#### CCS Advisory Group to Meet

- Date** Wednesday, July 11  
**Time** 10 a.m. to 3 p.m. Pacific Time  
**Location** 1700 K Street, Sacramento – First Floor Conference Room  
**Dial-In** (888) 989-6488; Passcode (listen only): 1945234  
**Details** Agenda and materials will be posted on the [website](#).  
A presentation on delays in delivery of durable medical equipment is scheduled. See the report, [Threading the Labyrinth: Why Children in California with Special Health Care Needs Endure Delays in Securing the Medical Equipment and Supplies They Need](#).

*Also See:* [How States Can Improve Access to Care for Children Under the Medicaid Managed Care Rule](#) – from the National Academy for State Health Policy (NASHP). New federal rules that go into effect July 1 outline requirements for Medicaid provider networks.

### Family Engagement

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#### Two Views: The Mental Health Journey of a Mother and Daughter



When Magaly was 11, her mother, Olga, found suicide plans on her phone. Six years later, they continue to navigate the challenges of Magaly's diagnosis of depression and psychosis. Their journey touches upon the importance of early identification, access to care, the struggles for support, and the effects of stigma. Children with chronic and complex physical conditions often have mental and emotional issues that go unrecognized and untreated. [Read their stories.](#)

## Children with Medical Complexity

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### Join a June 28 Conversation on Models of Care Delivery for Children with Medical Complexity

Improvements in care delivery for children with medical complexity are becoming a major focus of national and local health care and policy initiatives. A number of new models have been developed, with promising examples of enhanced care coordination and family engagement. Join an upcoming conversation about the article, [Models of Care Delivery for Children with Medical Complexity](#), with the lead author and experts in the field. [Read more and register.](#)

## Research

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### How 16 States Advance Medical Homes for CSHCN

Medical homes can improve health outcomes for children with special health care needs while also reducing costs and easing family burden. A new report from the National Academy for State Health Policy (NASHP) highlights how 16 states used federal grant funds to expand and improve their medical homes and promote system integration. [Read the report.](#)

## California Policy

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### Article Explores Weaknesses in Early Start Program

A host of issues with California's Early Start program, which is designed to provide early intervention for young children with developmental delays, has prompted action at both the federal and state level. Regional Centers around the state are charged with administering the program, and families report variations among Regional Center practices, long delays, and sometimes a

complete lack of services. Read [That Early Help You Need for Your Child Doesn't Come Soon Enough](#).

## Advocates 'Outraged' at State Budget Provisions for Individuals with Disabilities

More than a dozen California organizations that serve individuals with developmental disabilities have sent a joint letter to Gov. Jerry Brown and members of the Legislature decrying the lack of support in the state's new budget for the addition of needed services or restoration of those previously cut, despite an anticipated budget surplus. [Read the letter](#) (PDF).

## Medi-Cal Children's Health Advisory Panel (MCHAP) to Meet

<b>Date</b>	Thursday, June 28
<b>Time</b>	10 a.m. to 2 p.m. Pacific Time
<b>Location</b>	The California Endowment 1414 K St, Sacramento – 1st Floor Conference Room
<b>Dial-In</b>	(888) 947-8923; Passcode: 2475546
<b>Details</b>	The MCHAP 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. See the meeting <a href="#">agenda</a> .

### National Policy

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## How Medicaid Protects Children with Special Health Care Needs

Half of U.S. children with special health care needs – around seven million – rely on the Medicaid/Children's Health Insurance Program (CHIP) to cover some or all of their medical care. As federal and state efforts to cut back on these programs continue, a new report from Families USA documents why the coverage they provide is so vital, and examines the impact cutbacks could have on these children and their families. [Read the report](#).

*Also See:* [Trump's \\$15B Cutbacks Bill Fails First Senate Test](#) – from Politico

### In Brief

- [Budget Proposal Would Allow States to Drop Medicaid Transportation Benefits Across the Entire Program](#) – from Health Affairs. The proposal would allow states to end the Medicaid non-emergency medical transportation benefit, which has been in place since 1966.
- [Experts: Protections on Pre-Existing Conditions at Risk](#) – from ABC News. The Justice Department no longer will defend the Affordable Care Act, which provides some protection for people with pre-existing conditions.

## Resources

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- A new video from the American Academy of Pediatrics highlights important [developmental surveillance](#) steps that pediatricians should take during each health supervision visit. It offers recommendations, tips, and resources available to pediatricians, clinicians, and families. The video notes that surveillance and screening are essential components in promoting the optimal development of children.
- *Exceptional Parent Magazine* June issue – [Summer Fun!](#)

## Webinars

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### Advantages of ABLE for Those Not Receiving Public Benefits

<b>Date</b>	Thursday, June 28
<b>Time</b>	11 a.m. to 12:30 p.m. Pacific Time
<b>Sponsor</b>	National Disability Institute
<b>Details</b>	ABLE accounts allow individuals with disabilities and their families to save money without jeopardizing their public benefits, but there also are advantages for those not using public benefits. <a href="#">Read more and register.</a>

### Palliative Care – Promoting Healthy and Resilient Teams

<b>Date</b>	Thursday, July 12
<b>Time</b>	12 p.m. to 1 p.m. Pacific Time
<b>Sponsor</b>	Coalition for Compassionate Care of California
<b>Details</b>	Fee. CEU included for nurses and social workers. <a href="#">Read more and register.</a>

## Employment Opportunities

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### Positions Available at Support for Families

Support for Families of Children with Disabilities seeks applicants for several positions, including Early Start Project Director, Family Engagement Manager, and Family Voices of California Outreach Education Project Manager. [See job descriptions and all open positions.](#)

### In the News

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- [10-Year-Old Girl with Down Syndrome Held at Border Detention Center, Mexico Says](#)  
*CNN, 6/20/18*
- [Students Dream Up Assistive Devices for Kids with Disabilities](#)  
*Disability Scoop, 6/6/18*
- [Bills Seek to Bolster Children's Mental Health](#)  
*CaliforniaHealthReport.org, 6/5/18*
- [DoD Offers Enhanced Support for Military Families with Special Needs](#)  
*Defense.gov, 6/4/18*

#### **We'd like to hear from you**

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

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