

California Advocacy Network

for Children with Special Health Care Needs

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

Network News

Foundation Awards Grants for Telehealth, News Coverage of Child Health

Expanding the use of telehealth services and increasing public attention to children's health are the goals of two grants recently awarded by the Lucile Packard Foundation for Children's Health. Recipients are The Children's Partnership and the California Health Report. [Read more.](#)

Grants to Focus on Transition to Adult Care, Access to Mental Health Services

The Foundation also awarded grants to two coalitions of the California Community Care Coordination Collaborative (5Cs) to improve coordination among agencies, service providers, and organizations that serve CSHCN and their families. Beginning in September, the [Orange County coalition](#) will address transition from pediatric to adult care, and the [San Joaquin County coalition](#) will address access to mental and behavioral health services. [Read more](#) about the 5Cs.

New President to Lead Foundation



Cynthia Brandt Stover will assume the role of president and chief executive officer of the Lucile Packard Foundation for Children's Health on September 4. Brandt Stover has been campaign director at the Smithsonian Institution since 2013, and previously held positions at Stanford University and Mills College. [Read more.](#)

CCS Advisory Group Hears Update on Transition

The first eleven days of the Whole-Child Model transition have gone fairly smoothly, according to reports made at the CCS Advisory Group meeting on July 11. The Advisory Group also heard a presentation on delays in children obtaining [durable medical equipment and supplies](#), and discussed topics that CCS might address in the future, including transition to adult care. See the meeting [agenda and slides](#), and other [background information](#) about the Whole-Child Model. Also see an updated [Frequently Asked Questions](#) (PDF) about the transition.

Also See:

- ["Pain & Profit:" How Not to Do Medicaid Managed Care](#) – from the Georgetown Center on Children and Families
- [How State Medicaid and Title V Partnerships Improve Care for Children with Special Health Care Needs in Medicaid Managed Care](#) – from the National Academy for State Health Policy (NASHP)
- Archived Webinar: [Supporting Children with Special Health Care Needs in Medicaid Managed Care](#) – from Manatt, Phelps & Phillips

Children with Medical Complexity

Webinar: Whose Care Is It, Anyway?

Children with medical complexity have multiple chronic conditions and require an array of medical and community-based services. Care coordination is increasingly seen as essential to addressing the fragmented care that these children and their families often encounter. Join a discussion on the article [Care Coordination for Children with Medical Complexity: Whose Care Is It, Anyway?](#). Lead author Dennis Kuo, MD, and other experts will review the article's key content and discuss why care coordination is vital to improving the system of care.

Date Thursday, July 26
Time 10 a.m. to 11 a.m. Pacific Time
Details [Register](#).

Also See: [A Conversation on Models of Care Delivery for Children with Medical Complexity](#), an earlier webinar in this series on Building Systems that Work for Children with Complex Health Care Needs

Funding Opportunity

Challenge: Care Coordination for CSHCN

The federal Maternal and Child Health Bureau is sponsoring a competition to support the development and testing of low-cost, scalable tech innovations to meet the information needs of families and case managers involved with care coordination for children with special health care needs. The challenge will launch in August. [Find out more.](#)

Family Engagement

Webinar: Collaborating with Non-Traditional Partners to Develop Diverse Family Leaders

Date Thursday, July 26

Time 10:30 a.m. to 11:30 a.m. Pacific Time

Sponsor National Center for Family-Professional Partnerships (a project of Family Voices)

Details Four family organizations will present their experiences collaborating with non-traditional partners to identify, recruit, train, and support family leaders representing the diversity of families in their states and communities. [Register.](#)

Caregiver Survey Documents Personal, Family, Economic Challenges

More than half of family caregivers in a recent survey reported that they had no plan for the future of their family member with disabilities, and two-thirds said that they had difficulty finding support staff to assist them with care. The results come from the 2017 Community Report of Family and Individual Needs for Disability Supports (FINDS), which surveyed 3,000+ family members nationwide who care for individuals with intellectual or other developmental disabilities. [Read more about the findings.](#)

California Policy

Department of Health Care Services Stakeholder Advisory Committee to Meet

Date Wednesday, July 18
Time 10 a.m. to 3 p.m. Pacific Time
Location The California Endowment
1414 K St, Sacramento – 1st Floor Conference Room
Dial-In (888) 606-5935; Passcode: 9283547
Details Public comment will be taken throughout the meeting. The agenda includes an update on the California Children's Services Whole-Child Model. The agenda and materials are posted on the [website](#). The webpage also includes a list of committee members, updated as of May.

Electronic Visit Verification (EVV) stakeholder meeting

Date Monday, July 23
Time 1 p.m. to 3 p.m. Pacific Time
Location California Department of Social Services
744 P St, Sacramento – OB 9, Room 205 (CDSS auditorium)
Details Check the [webpage](#) for call-in information and agenda.

National Policy

In Brief

- [Department of Education Delays Equity in IDEA Compliance Date by Two Years](#)

Resources

- [What Having a Child with Complex Medical Needs Has Taught Me About Getting Good Health Care](#) – from the Washington Post
- *Complex Child* July issue: [Recreation](#)
- [National Parent Center on Transition and Employment](#) – resources on assistive technology and tips for employment, postsecondary education, and independent living

Webinar

Early and Periodic Screening, Diagnostic and Treatment (EPSDT) Education for Providers and Advocates

Date Wednesday, July 18

Time 10 a.m. to 11:30 a.m. Pacific Time

Sponsor American Academy of Pediatrics and Georgetown Center for Children and Families

Details This webinar will identify EPSDT's history and structure, discuss the role of the federal government and states in the provision of this comprehensive benefit, and provide examples of services guaranteed to children covered by Medicaid. [Register](#).

In the News

- [Many Pediatricians Skip Developmental Screening, Study Finds](#)
Medscape, 7/10/18 (Free registration required)
- [Trump Administration Freezes Payments to Affordable Care Act Insurers with Sicker Patients](#)
Fortune, 7/8/18
- [Teaching Parents of Kids with Disabilities to Fight Back](#)
NPR, 6/29/18
- [ExceptionAlly Helps Parents Navigate the Special Needs Education Labyrinth](#)
Tech Crunch, 6/27/18
- [New York Woman Is Nation's First Lobbyist with Down Syndrome](#)
Disability Scoop, 6/26/18
- [States Aim to Halt Sexual Abuse of People with Intellectual Disabilities](#)
NPR, 6/25/18
- [Fearing Deportation, Immigrant Parents Are Opting Out of Health Benefits for Kids](#)
Kaiser Health News, 6/25/18

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.

This email was sent by:
Lucile Packard Foundation for Children's Health
400 Hamilton Ave, Suite 340 Palo Alto, CA, 94301,
USA

