

California Advocacy Network

for Children with Special Health Care Needs

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

Newsletter Survey Extended – Last Chance to Win

Respondents to our Network Newsletter survey have offered many interesting suggestions, so we are extending the deadline for another week to ensure that all readers have a chance to weigh in – and to enter to win an Amazon gift card. Your views matter. Average completion time is four minutes, so [please take the survey](#).

Network News

Foundation Grants Build on Prior Work to Create Better Systems of Care

Improving pediatric hospital discharge practices and easing the transition of youth with special needs to adult health care are the goals of two of four grants awarded recently by the Lucile Packard Foundation for Children's Health. Two other grants focus on better access to pediatric specialty care and more equitable purchase of services by California's Regional Centers. [Read about the grants](#).

Children with Medical Complexity

Status Complexicus? A Conversation about the Emergence of Pediatric Complex Care

Date Tuesday, April 10

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

Sponsor Lucile Packard Foundation for Children's Health

Register [Learn more and register](#)

Details On March 1, *Pediatrics* published a supplement that featured eight articles about the challenges of caring for children with medical complexity. The supplement was sponsored by the Lucile Packard Foundation for Children's Health as a follow-up to its 2015 national symposium, [Designing Systems That Work for Children with Complex Health Care Needs](#). This webinar is the first in a series featuring authors of each of the articles, along with discussants. The first conversation will cover the emergence of complex care as a focus area in pediatrics, and consider whether this new attention will lead to meaningful changes in systems of care and outcomes. [Read the related supplement article](#).

California Children's Services

CCS Advisory Group to Meet

Date Wednesday, April 4

Time 10 a.m. to 1:30 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 details will be posted on the Department of Health Care Services [website](#). Public comment will be accepted during the meeting.

Survey: Family Engagement Practices in the 21 CCS Whole-Child Model Counties

Quality and outcomes improve when families are engaged in their children's care, yet families are not consistently involved in the policy and programmatic planning that affects them. Last year, the Association of Maternal and Child Health Programs conducted a survey of California Children's Services (CCS) county administrators regarding their family engagement practices. A new issue brief analyzes the results from the 21 counties that are scheduled to move children from the current CCS program to Medi-Cal managed care. The brief suggests ways that families could be more meaningfully engaged with CCS programs and health plans. [Read the issue brief](#).

CCS Performance Measures Quality Subcommittee Meets

The agenda and slides from the March 28 webinar of the CCS Performance Measures Quality Subcommittee are now online, along with recommendations from stakeholders on each proposed measure. Subcommittee members discussed family participation measures. [Read more](#).

California Policy

Bill Addresses Quality Standards in Medi-Cal Managed Care Plans

On February 13, Assemblymember Arambula introduced [AB 2275](#), a bill to require that the Department of Health Care Services establish a quality assessment and performance improvement program for all Medi-Cal managed care plans. The bill contains several other provisions, including a process for public stakeholder involvement and annual reporting on results. The bill is currently being considered by the Assembly Committee on Health.

Telehealth

Children's Health in a Digital World: Opportunities and Challenges in Pediatric Telehealth

A briefing to educate policymakers about the potential of telehealth in providing accessible specialty care to California children was held February 27 in Sacramento. Sponsored by The Children's Partnership, the Children's Specialty Care Coalition, the California Children's Hospital Association, Family Voices of California, and the American Academy of Pediatrics-CA, the event included a focus on the importance of telehealth for children with special health care needs. [Read more](#) and find links to the recording, briefing slides, and a [seven-minute educational video](#).

Also see: [Realizing the Promise of Telehealth for Children with Special Health Care Needs](#)

Resources

- [Google Adds Wheelchair-Accessible Routes to Google Maps](#)
- *Exceptional Parent Magazine* March issue – [School and Camps](#)
- [What Do We Know About Developmental Screenings in Medicaid and CHIP?](#) – from Georgetown University Health Policy Institute
- [Early Identification and Intervention Systems in California: Bright Spots and Lessons Learned](#) – from Harder and Co, with support from the David and Lucile Packard Foundation

Webinars

Leadership Is a Journey: Knowing Yourself as a Change Agent Part 1

Date Wednesday, April 4

Time 3 p.m. to 3:30 p.m. Pacific Time

Sponsor Family Voices

Details The first in a series for youth self-advocates, this webinar will explore how personal reflection and self-assessment help increase understanding of personal leadership style. [Read more and register.](#)

Beyond Cost and Utilization: Rethinking Evaluation Strategies for Complex Care Programs

Date Monday, April 9

Time 11 a.m. to 12:30 p.m. Pacific Time

Sponsor Center for Health Care Strategies

Details As organizations and policymakers seek to enhance care management programs for low-income individuals with complex medical and social needs, it is critical to identify which models are effective. This webinar will review the merits and limitations of traditional evaluation approaches, new ways to evaluate these programs, and broader policy implications. [Read more and register.](#)

Event

Coalition for Compassionate Care of California Annual Palliative Care Summit

Date April 10 to 11

Location Wyndham Anaheim Garden Grove, Garden Grove, CA

Details The summit brings together patients, professionals, and policymakers interested in clinical research, quality, and policy as it pertains to palliative care. A pediatric track will feature breakout sessions with several of California's leading experts in pediatric palliative care. Professional continuing education credit will be available. Fee to attend. [Read more and register.](#)

In the News

- [Federal Report Calls for Alternatives to Guardianship](#)
Disability Scoop, 3/23/18
- [My Daughter's Disabled. Please Don't Look Away from Her](#)
LA Times, 3/22/18
- [Black and Latino Children are Often Overlooked When it Comes to Autism](#)
NPR, 3/19/18
- [The Trauma of Having a Newborn in the NICU](#)
The Atlantic, 3/19/18
- [Concerns Raised as Disability Panels Fail to Meet Under Trump](#)
Disability Scoop, 3/15/18
- [Trump's Immigration Policy Pushing Children into Foster Care](#)
Youth Today, 3/15/18
- [This Exciting New App Helps Special Needs Kids Speak Through Play](#)
Autism Parenting Magazine, 3/14/18
- [How Medicaid Became a Go-To Funder for Schools](#)
Disability Scoop, 3/14/18
- [Parents Play Big Role in Child's Chronic Pain](#)
Medpage Today, 3/6/18

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:
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