

# California Advocacy Network

## for Children with Special Health Care Needs

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

### National Policy

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## Major National Collaborative to Address Medical Home, Transition, Financing of Care for CSHCN

The American Academy of Pediatrics, Got Transition and the Catalyst Center have been awarded five years of funding through a Maternal and Child Health Bureau initiative, "Advancing Systems of Services for Children and Youth with Special Health Care Needs." The three organizations will establish a network of resource centers that focus on three core health system components: access to the patient/family-centered medical home, transition into adult health care systems, and adoption of health care financing models that improve care and outcomes while achieving cost savings. The centers will provide technical assistance, training, and education, and will work collaboratively. [Read more](#). Got Transition also [received funding](#) (PDF) to continue operation for five years.

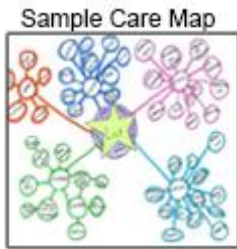
## Bill to Watch

[HR 6042](#) would delay implementation of the Electronic Visit Verification (EVV) requirement until 2020. The bill has passed the House and Senate and awaits presidential signature. Advocates have expressed privacy and other concerns about EVV, which requires electronic verification when an individual receives home health or personal care funded by Medicaid (Medi-Cal in California).

### Children with Medical Complexity

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## Thinking Through Care Coordination



A wide range of perspectives on how to deliver effective care coordination – the issue that families most often say they would like to see addressed – were highlighted in the latest webinar in the series on children with medical complexity hosted by the Lucile Packard Foundation for Children's Health. The July 26 conversation addressed definitions, information sharing, financing, family viewpoints, transition to adult care, and much more. The [recording and slides](#) of "A Conversation on Care Coordination for Children with Medical Complexity: Whose Care Is It, Anyway?" are now available. Also see previous webinars in the [series](#).

### California Children's Services

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## Media Attention for Problems in Obtaining Durable Medical Equipment and Supplies

The Washington Post, Kaiser Health News, California Healthline and other news outlets all have featured a story based on a recently published [report](#) about delays in providing medical equipment and supplies for children with complex conditions. Author Maryann O'Sullivan also presented the report's findings and recommendations to the CCS Advisory Group on [July 11](#). See the story in the [Post](#).

## CCS Performance Measures Quality Subcommittee Tackles Range of Topics

Care coordination, family participation, and transition to adult care were on the agenda for the July 25 meeting of the subcommittee that reviews the standards by which CCS performance is measured. See the [agenda and slide presentation](#).

## In Brief

Resource: [Advocates' Guide to Accessibility in Medicaid Managed Care Grievances and Appeals](#) – from the National Health Law Program, Disability Rights Education and Defense Fund, and Justice in Aging

### California Policy

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## Bill to Watch

[SB 1287 – Medi-Cal: Medically Necessary Services](#) contains provisions to help ensure that Medi-Cal beneficiaries under age 21 get access to medically necessary Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) services. [Read more](#) (PDF).

## In Brief

Resource: [Disability Vote California](#) – A nonpartisan website to engage and inform voters with disabilities and their families – from The Arc and Disability Rights California

## Viewpoint

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### The Case for Routine Screening for Maternal Depression



Child health professionals increasingly are being asked to include screening for adverse childhood experiences as part of routine preventive pediatric care. Screening and providing appropriate follow-up would be a huge challenge for most pediatric practices. In an article in *JAMA Pediatrics*, Edward Schor, MD, suggests that a good first step might be to incorporate routine screening for maternal depression, one of the most common risk factors for family psychosocial problems. Mothers of children with special health care needs are at higher risk for depression than mothers of typically developing children. [Read more](#) and see an [abstract](#) of the article.

## Network News

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### What Readers Say About the Newsletter



Earlier this year we asked our readers to complete a short survey about the Network Newsletter as it marks five years of publication. We are grateful to those who responded. As with our surveys in 2014 and 2016, your views were positive regarding the newsletter's content, format, length, and frequency. You also offered many useful suggestions. In a readership shift, nearly half of respondents came from outside of California. [Read](#)

[more about the survey results](#). (PS – The gift cards have been awarded, so if you didn't hear from us, you didn't win. Next time!)

## Resources

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- [When Bad News Isn't Necessarily Bad: Recognizing Provider Bias When Sharing Unexpected News](#) – from the American Academy of Pediatrics. Helping providers develop skills in presenting a family with a new, unexpected diagnosis.
- [Pediatric Starter Kit: Having the Conversation with Your Seriously Ill Child](#) – A free resource specifically designed to help parents who want guidance about "having the conversation" with their ill children. Available in Chinese, English and Spanish.
- [Where the Magic Happens: A Guide to Grassroots Organizing for Consumer-Driven Delivery Reform](#) (PDF) – from the Center for Consumer Engagement in Health Innovation.

## Events

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### Inscripción Congreso Familiar 2018

<b>Date</b>	Sábado, 4 de Agosto
<b>Time</b>	8:30 a.m. a las 4 p.m. Hora de la Pacífico
<b>Location</b>	Chabot College 25555 Hesperian Boulevard Hayward, CA
<b>Details</b>	Contáctenos al (925) 313-0999 ext. 111 o por e-mail: <a href="mailto:info@congresofamiliar.org">info@congresofamiliar.org</a> si tiene alguna pregunta.

Congreso Familiar es una conferencia gratuita en español para familias que tienen niños con discapacidades, sus amigos, y los profesionales que los apoyan. Los temas del taller incluyen el proceso del IEP, servicios del Centro Regional, alternativas a la tutela, inmigración, y muchos más. [Lea más e inscriba](#).

**In English:** Congreso Familiar is a free conference in Spanish for families who have children with disabilities, their friends, and the professionals who support them. [Read more and register](#). (Translate in web browser.)

## Educate. Advocate. Annual Back to School Conference and Resource Fair 2018

- Date** Saturday, August 18
- Time** 8 a.m. to 4 p.m. Pacific Time
- Location** Lions Center West – Brookside Room  
9161 Baseline Road  
Rancho Cucamonga, CA
- Details** Program specialists and legal experts share how to access Regional Center services and school district assistance. [Learn more.](#)

### Webinar

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## Innovations in Education for Youth Recipients of Supplemental Security Income (SSI)

- Date** Tuesday, July 31
- Time** 11 a.m. to 12 p.m. Pacific Time
- Sponsor** Office of Disability Employment Policy, U.S. Department of Labor
- Details** Part three of a five-part series on the transition to employment for youth receiving SSI, this webinar will highlight education interventions that engage students, families, and professionals and promote the seamless transition from school to work. [Register.](#)

### Fellowship Opportunity

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## Applicants Sought for Kennedy Leadership Fellowships

Two one-year fellowships will be awarded by the Joseph P. Kennedy Jr. Foundation to professionals, persons experiencing disability, or their family members who are currently working or volunteering in the field. The international fellowships are designed to prepare both early career and more seasoned leaders to assume leadership in the public policy arena. The application deadline is **September 15** at 2 p.m. Pacific Time. [Read more](#) (PDF).

## In the News

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- [The Best Way to Serve People with Special Needs: Live with Them](#)  
*Autism Parenting Magazine, 7/22/18*
- [Air Travel Is Often a Humiliating Nightmare for People with Disabilities](#)  
*Huff Post, 7/18/18*
- [No Drop in Adverse Events for Hospitalized Children](#)  
*MedPage Today, 7/15/18*
- [Changing Eligibility for Medicaid, CHIP Could Cost Families Billions](#)  
*Healio, 7/9/18*
- [Helping My Nonverbal Son Find His Voice](#)  
*NY Times, 7/6/18*
- [Measuring What Matters Most to People with Complex Needs](#)  
*Health Affairs, 6/26/18*

### 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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This email was sent by:  
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