

California Advocacy Network

for Children with Special Health Care Needs

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

Children with Medical Complexity

Developing Population Health Measures for Children with Medical Complexity

Children with medical complexity (CMC) account for about 40 percent of pediatric Medicaid spending, yet comprise only 3 percent of the pediatric population. The diversity of these children's conditions, and their variable severity, means that it has not been possible to reliably describe the overall health of the CMC population. A new study reports on efforts to identify a set of health domains that could be used to guide measurement of the health of this heterogeneous group.

[Learn more.](#)

Recording and Slides Available from the Conversation on Self-Management for Children with Complex Conditions



Experts led an online discussion about the *Pediatrics* article, [Supporting Self-Management in Children and Adolescents with Complex Chronic Conditions](#). The conversation was part of a [continuing series](#) on children with medical complexity. [Listen to the recording.](#)

Addressing Social Determinants of Health: Connecting People with Complex Needs to Community Resources

Date Monday, September 10

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

Sponsor Center for Health Care Strategies

Details Second in a two-part webinar series on expanding complex care programs to reach beyond the health system. Speakers will share strategies for addressing social determinants of health through screening approaches, innovative technologies that track social service referrals, and development of strong connections with community partners. Not pediatric specific but perhaps of interest. [Learn more and register.](#)

Family Engagement

Financial Hardship in Families Raising Children with Special Health Care Needs

A new [infographic](#) (PDF) from the Catalyst Center illustrates how inadequate insurance, both public and private, can cause financial strain for many CSHCN families.

Also See: [Nonmedical Expenses of Pediatric Hospitalizations Have Disproportionate Effects](#)

Viewpoint

A Better Way – Team Care for Pediatric Chronic Illness



Chronic illness in both children and adults is often accompanied by psychological, social, and financial challenges that can impede effective medical care if they are not addressed. Team-based health care is a key component of the Chronic Care Model, which has shown to be successful for adults with chronic conditions. As the number of children with such conditions grows, and payers seek innovative ways to increase efficiency and effectiveness, Dr. Edward Schor suggests that it may be time to invest in restructuring pediatric practice to promote team-based care. [Read more](#)

Telehealth

Roadmap for Action: Advancing the Adoption of Telehealth in Child Care Centers and Schools

Experts from 13 states and several key child health organizations joined forces to report on best practices, evidence-based outcomes, and keys to overcoming systemic barriers to the implementation of successful telehealth programs. Their findings potentially can be replicated in schools and child care settings across the country. See the [roadmap](#) produced by The Children's Partnership.

Also See: [Schools Partner with Children's Hospital for Telehealth Visits](#)

California Policy

Assembly Select Committee Explores Developmental Disability, Regional Center Issues

State officials and consumer representatives testified August 7 in Sacramento at the first meeting of a newly formed Assembly Select Committee designed to discuss policy issues and program challenges for individuals with intellectual and developmental disabilities. Speakers included the director of the Department of Developmental Services, representatives from the Legislative Analyst's Office, the chair of the State Council on Developmental Disabilities, the executive director of the Association of Regional Center Agencies, and multiple consumers who outlined a variety of pressing issues. The committee plans to hold hearings throughout the state. [Read more](#) and [watch the hearing](#) (recording starts at 20:52).

In Brief

[California Officials Show Little Interest in Providing Quality of Care Information for Medi-Cal Recipients](#) – from the USC Annenberg Center for Health Journalism

National Policy

Disability Groups Oppose Supreme Court Nominee

The Association of University Centers on Disabilities, The Arc, and the American Association of People with Disabilities are among a number of organizations asking their stakeholders to oppose the nomination of Judge Brett Kavanaugh to the US Supreme Court. His judicial opinions indicate that he would be a threat to the independence, health care, and well-being of people with

disabilities, according to statements released by these organizations. [Read more and see how to reach your Senator.](#)

In Brief

- The President has signed [HR 6042](#) which delays implementation of the Electronic Visit Verification (EVV) requirement until 2020. EVV mandates electronic verification when an individual receives home health or personal care funded by Medicaid (Medi-Cal in California).
- [Top Trump Health Official Vows to Help Protect Patients with Pre-Existing Conditions](#)
- [Rev Up Campaign](#) offers voter resources to increase the political power of people with disabilities while also engaging candidates and the media to recognize the disability community.

Resources

- [Receive Payment as a Caregiver: Cash and Counseling and Other Options](#) – from Paying for Senior Care
- [State Strategies to Incorporate Oral Health into Medicaid Payment and Delivery Models for People with Chronic Medical Conditions](#) – from the National Academy for State Health Policy
- *Exceptional Parent Magazine* August issue – [Special Olympics 50th Anniversary](#)
- [FDA Approves Generic EpiPen That May Be Cheaper](#) – from the New York Times

Special Education

Many States Lag in Implementing Individuals with Disabilities Education Act (IDEA)

Only 21 states met the full requirements for developing a plan to enact parts of the Individuals with Disabilities Education Act of the US Department of Education. [See how each state fared.](#)

In Brief

- As children go back to school, see an [Advocacy Toolkit](#) that provides talking points and a worksheet to ensure your child's rights under an Individualized Education Program (IEP) – from [Understood](#)

Events

Charting New Frontiers in Children's Health Policy & Practice Forum

Date Monday, October 22

Time 8:30 a.m. to 6 p.m.

Location National Museum of American Jewish History, Philadelphia

Sponsor Children's Hospital of Philadelphia PolicyLab

Details Registration is now open for this convening of regional and national leaders in child health policy to mark the 10th anniversary of PolicyLab. Speakers will outline emerging solutions that will move the dial on child, adolescent and family health and well-being over the next decade. **Early bird pricing ends September 9.** [Read more and register.](#)

In the News

- [Speech Professionals Denounce Controversial Communication Methods](#)
Disability Scoop, 8/15/18
- [Pompeo Ignores Plea from Diplomats with Children with Special Needs](#)
Foreign Policy, 8/14/18
- [California Allocates \\$1 Million to Improve Mental Health of Native American Youth](#)
CaliforniaHealthReport.org, 8/13/18
- [Looking Through 'Fresh Eyes' Could Be the Best Way to Solve Complex Medical Cases](#)
Children's Hospitals Today, 7/30/18

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.

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