

California Advocacy Network

for Children with Special Health Care Needs

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

Family Engagement

Pathways to Partnerships: Family-to-Family Health Information Centers

Whether it's facing the shock of a first diagnosis or responding to the many challenges along the way, parents of children with special health care needs often find that their most highly valued source of support is an experienced and knowledgeable parent who has navigated the same path. But where to find such a parent? Family-to-Family Health Information Centers may provide an answer. [Read about their services.](#)

California Children's Services

Raising the Bar: Conference on Improving CCS

Family-centered care, transition to adult care, private-duty nursing, innovations in care coordination, and updates on the Whole Child Model were among the wealth of topics covered at an October 4 conference sponsored by the Children's Regional Integrated Service System (CRISS), CCS Executive Committee, and Family Voices of California. The *Raising the Bar* conference, aimed at improving CCS services, was attended by families, care providers, CCS staff, funders and other stakeholders. [See the slide presentations and handouts.](#)

CCS Advisory Group Considers Whole Child Model Progress

At its October 10 meeting the CCS Advisory Group held an extended discussion of how children and families are faring under the Whole Child Model. Members also heard from Family Voices about its program to support families during the CCS transition to Medi-Cal managed care, which begins its second phase in January. Read more and find contact information for the Family Voices support program on the meeting [slides](#) (PDF). Questions about the transition also may be sent to Redesign@dchcs.gov.

Children with Medical Complexity

Congressional Briefing: Improving Care for Children with Complex Medical Needs

Factors that could improve the quality, affordability, and accessibility of care for children with complex medical needs were the topic of an October 5 briefing in Washington, DC, attended by Congressional staff, along with other national health policy stakeholders. The event was presented by the nonpartisan Alliance for Health Policy, with support from the Children's Hospital Association. [Read more and view the event recording.](#)

A Conversation on Ethical Considerations for a Fair and Effective Health Care System

A reminder that the next conversation in our series on [Building Systems that Work for Children with Complex Health Care Needs](#) will feature a discussion of the article [Ethical Framework for Risk Stratification and Mitigation Programs for Children with Medical Complexity](#).

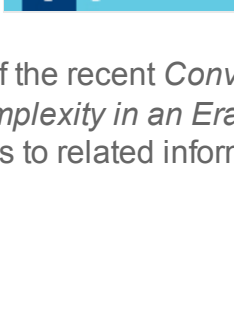
Date Wednesday, October 24

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

Sponsor Lucile Packard Foundation for Children's Health

Details [Register.](#)

Protecting the Rights of Children with Medical Complexity



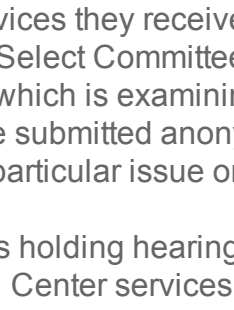
The slides and a recording of the recent *Conversation on Protecting Rights of Children with Medical Complexity in an Era of Spending Reduction*, now are [available](#), along with links to related information.

Transition to Adult Care

- [The Path to Independence: Mobile Apps to Support Transition-Age Youth](#) (PDF) – from the Pacer Center
- Got Transition has published [Health Care Transition in State Title V Programs: A Review of 2018 Block Grant Applications and Recommendations for 2020](#), which highlights examples of health care transition innovations from around the country, and offers detailed recommendations for states' upcoming Title V Action Plans.

California Policy

Survey and Hearings: Assembly Select Committee Seeks Views Regarding Regional Center Services



Clients and vendors of California's 21 Regional Centers are invited to complete a survey about services they receive or provide. The survey is sponsored by the Assembly Select Committee on Intellectual and Developmental Disabilities, which is examining how Regional Centers are operating. The survey can be submitted anonymously or respondents can request a response about a particular issue or concern. [Take the survey.](#)

The Select Committee also is holding hearings around the state asking stakeholders about Regional Center services. The next hearing is October 24 in Concord. See the [schedule](#) on the committee website.

Also See: An additional survey from the [Department of Developmental Services about Regional Centers](#)

Department of Health Care Services Advisory Committee to Meet

Date Thursday, October 25

Time 10 a.m. to 12 p.m. Pacific Time

Dial-In (888) 606-5935; Passcode: 9283547 (listen only)

Details Agenda and materials will be posted on the [website](#). Public comment will be taken at the end of the meeting.

National Policy

Numerous Groups Oppose "Public Charge" Rule that Affects Immigrants

More than [1,500 organizations](#) (PDF), including disability rights groups, physician organizations, and family advocacy groups are expressing strong opposition to the Trump Administration's proposed "public charge" rule, which could change how the use of public benefits may affect individuals' ability to enter the U.S. or adjust to legal permanent resident status. Comments may be sent to [Regulations.gov](#) through December 10.

Also See: [A New "Public Charge" Rule Affecting Immigrants Has Major Implications for Medicaid](#)

Resources

Project Focuses on Emotional, Mental Health for CSHCN and Families



Increasing awareness of the need to build resilience and support emotional health in children with special health care needs and their caregivers is the focus of a national project led by the American Board of Pediatrics. The Roadmap Project has developed a "change package" that can be used particularly by pediatric clinicians, but also by families, patients and other providers. [See the roadmap.](#)

Webinars

ABLE to Save – ABL Accounts, a New Savings Opportunity for Individuals with Disabilities

Date Tuesday, October 23

Time 4:30 p.m. to 6:30 p.m. Pacific Time

Sponsor PACER Center and ABL National Resource Center

Details [Learn](#) how the new Achieving a Better Life Experience (ABLE) Accounts allow families to save up to \$15,000 per year for their child with a disability without affecting their eligibility for Supplemental Security Insurance (SSI) or Medicaid.

EPSDT for Providers and Advocates: When to Engage the Legal Community

Date Wednesday, October 24

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

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

Details Third in a series designed to provide detailed information about Medicaid's Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit. This [webinar](#) will detail when and how providers and advocates can effectively leverage the legal system to help children access services when other avenues have not proven fruitful.

Kidsdata for Action on CSHCN

Date Wednesday, October 24

Time 12 p.m. to 1 p.m. Pacific Time

Sponsor Family Voices of California

Details Kidsdata, a program of the Lucile Packard Foundation for Children's Health, provides access to data about children in California on five topics focusing on children with special health care needs, including Characteristics, Access to Services, Insurance Coverage, Impact on Children and Families, and Quality of Care. [Learn more and register.](#)

Events

Association of University Centers on Disabilities Conference

Date November 11-14

Location Washington, DC

Details Registration is ongoing for the conference, whose theme is *We ALL Belong Here! Achieving Inclusive Communities*. Fee. [Read more and register.](#)

Breaking Barriers, Building Bridges, Third Annual Interagency Symposium

Date November 14-15

Location Sacramento

Details Agenda focuses on building collaborations so that all California children receive the services and supports necessary for them to succeed in school and society, nurtured by healthy families and strong communities. Fee. [Learn more and register.](#)

Call for Proposals

Building Partnerships in Palliative Care

Friday, October 26, is the deadline for breakout session proposals for the Annual Summit of the Coalition for Compassionate Care of California. Presentations should focus on cutting-edge strategies and programs for delivering and increasing access to palliative and hospice care for children, adolescents, and young adults. [Learn more.](#)

Employment Opportunity

Executive Director for Parent Organization

Parent to Parent USA, an organization that provides emotional and informational support for families of children who have special needs, seeks candidates for executive director. Part-time or full-time. Flexible location. Apply by November 15. [Read more](#) (PDF).

In the News

- [At 12, He Reads at a First-Grade Level: How New York Failed T.J.](#) *NY Times*, 10/5/18
- [Abandoning Restraint and Seclusion Has Unexpected Benefits, Study Finds](#) *Disability Scoop*, 10/3/18

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.

