

California Advocacy Network

for Children with Special Health Care Needs

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

Quality Standards

A Framework for Assessing How Well States Serve Children with Special Health Care Needs



The state in which a family lives can strongly influence whether a child with special health care needs (CSHCN) has access to quality health care and other needed services. Although federal programs are a major source of support for CSHCN and their families, state and local statutes and regulations often determine eligibility criteria and requirements for receiving care. A new report from Child Trends, funded by the Lucile Packard Foundation for Children's Health, offers a framework for state agencies and other stakeholders to assess and improve how a state provides care across health, education, justice, and other systems. [Read the report.](#)

California Children's Services

CCS Quality Measures Subcommittee Discusses Transition to Adult Care

Transition services were the focus of the May 30 meeting of the Performance Measures Quality Subcommittee, which advises the Department of Health Care Services on CCS operations. See a link to the [agenda and slides](#) on the CCS Advisory Group website.

Background on Upcoming CCS Transition to Medi-Cal Managed Care

The transition of some CCS children to Medi-Cal managed care is scheduled to begin July 1. Find information on the process and plans on the Department of Health Care Services [Whole-Child Model](#) and [CCS Advisory Group](#) websites. In October 2017, the Lucile Packard Foundation for Children's Health awarded a grant to CRISS (Children's Regional Integrated Service System) to monitor the transition. Their process is under way.

Family Engagement

Why Parents Don't Plan

Individuals with disabilities are living longer lives, but fewer than half of parents conduct future planning, according to research published in the Journal of Intellectual and Developmental Disabilities. The authors describe the barriers to planning that families identified in a survey, and discuss implications for policy, practice, and future research. [Read an abstract of the study.](#)

Children with Medical Complexity

Involving Families: A View from the Front Lines



Listen to the recording of the June 6 webinar, [A Conversation on Meaningful Family Engagement, from Clinical Care to Health Policy](#), sponsored by the Lucile Packard Foundation for Children's Health.

Related: See a [guest blog](#) regarding the article, *Families of Children With Medical Complexity: A View From the Front Lines*. The article, published in a *Pediatrics* [supplement](#), was written by a group of parents of children with medical complexity.

California Policy

Class Action Lawsuit Says California Fails to Arrange for Medi-Cal In-Home Nursing Care

On May 24, attorneys filed a federal class action lawsuit against the Department of Health Care Services on behalf of two children, claiming that California has failed to fulfill its commitment to provide them with sufficient Medi-Cal in-home nursing services. The suit says that the state lacks an effective system to arrange for approved nursing, placing the burden on families to recruit nurses and, if they are unsuccessful, provide the care themselves. [Read more](#).

Also See: [Not Enough Nurses? Parents Sue California Over Sick Kids' Lack of Access to At-Home Care](#) – from Capital Public Radio

State to Host Meeting on Proposed Changes to Palliative Care Program

Date Monday, June 11

Time 10 a.m. to 2 p.m. Pacific Time

Location 1331 Garden Highway, Sacramento – First Floor, NIC Main Room

Dial In (877) 929-7616; Passcode: 6918960

Details Since 2009 the Partners for Children Pediatric Palliative Care Waiver Program has offered support services at home and in the community for children with life-limiting or life-threatening medical conditions. The program operates under a Medicaid waiver that is expiring, and the state plans to move currently enrolled patients to another program. Advocates are concerned that the new program will exclude certain services and also limit eligible diagnoses for care. Stakeholders are urged to attend this upcoming meeting, or offer comments at CCSPPC@dhcs.ca.gov or 916-552-9105. [Read more](#) and see the meeting [agenda](#) (PDF).

Seeking Restoration of Regional Center Recreational Programs

Funding for camp and recreational activities was cut from Regional Center budgets in 2009 and has not been restored. Budget subcommittees are considering bringing back the funding, and advocates are urging stakeholders to voice their support immediately. [Read more](#).

Research

National Academies Study Notes Opportunities for Improving Programs and Services for Children with Disabilities

Despite their diversity in health conditions, children with special needs share many of the same requirements for programs and services. A new report from the National Academies of Sciences, Engineering, and Medicine emphasizes the need to coordinate those services across sectors and

focus on long-term goals that will help prepare children for adulthood. The report provides information about characteristics that contribute to effective programs, identifies gaps and limitations, and highlights opportunities to improve services. [Read the report.](#)

Care Coordination

Webinar Recording Available: [Measure What Matters: Advancing Multidisciplinary Care Coordination in Primary and Subspecialty Care Settings](#) – from the National Center for Medical Home Implementation and the National Center for Care Coordination Technical Assistance

National Policy

Children's Health May Be Affected by Proposed Change in "Public Charge" Rule

The Trump Administration is proposing a policy that, for the first time, would allow the federal government to take into account an immigrant family's use of Medicaid, CHIP, and other health benefits when determining if they might become a "public charge." Being a public charge affects decisions about green cards and permanent residency status. This change could affect the health care of millions of children in families with a noncitizen parent. [Read more.](#)

In Brief

- [The Importance of Medicaid for Children with Disabilities and Special Health Care Needs](#) – Policy brief from Digital Commons at the University of Maine
- [CHIP, CHIMPs and Trump's Budget-Rescission Request: A Guide to the Debate](#) – Analysis from the Washington Post

Webinars

Approach to Neurologic Symptom Management in Children at the End of Life

Date Thursday, June 21

Time 12 p.m. to 1 p.m. Pacific Time
Sponsor Coalition for Compassionate Care
Details Many children in hospice have neurologic symptoms at the end of life, whether their underlying disorder is primarily neurologic or a late complication of a medical issue. This webinar will review common causes and approaches to management of these symptoms. Fee. Social work, nursing, and chaplain continuing education credit available. [Read more and register.](#)

Estate Planning for Special Needs

Date Wednesday, June 27
Time 9 a.m. to 10:15 a.m. Pacific Time
Sponsor The Parent's Place of Maryland
Details Financial and tax planning aspects of special needs planning. [Read more and register.](#)

Got Transition Webinar Series - Youth, Young Adult, & Parent Engagement

Date Thursday, June 28
Time 12 p.m. to 1 p.m. Pacific Time
Sponsor Got Transition
Details Fifth in a series on health care transition featuring examples of best practices among state Title V agencies, tools and resources, and problem-solving strategies. [Read more and register.](#)

Resources

- [Special Superheroes](#) – a Facebook video on comic superheroes who all have a special need that is their superpower
- [Does My Child Have Physical Developmental Delays?](#) – An assessment tool for parents from the American Academy of Pediatrics that helps identify early signs of delay such as rolling over, sitting without support, or walking. [en Español](#)
- *Complex Child* June issue: [Rare and Interesting Conditions, Part 1](#)

Events

2018 National School-Based Health Care Convention

- Date** June 24 to 27
- Location** JW Marriott, Indianapolis, IN
- Sponsor** School-Based Health Alliance
- Details** Explore new ways health centers are serving their schools and their communities by promoting wellness and health equity. [Read more and register.](#)

In the News

- [Verma Unveils State Medicaid Scorecard but Refuses to Judge Efforts](#)
California Healthline, 6/5/18
- [Josh Greenfeld, Screenwriter Who Chronicled Son's Autism, Dies](#)
SF Chronicle, 6/1/18
- [Ed Department Sued Over Handling of Disability-Related Complaints](#)
Disability Scoop, 6/1/18
- [For Children in the Hospital, VR May Be the Cure for Anxiety](#)
Wall Street Journal, 5/28/18
- [Territories Can Apply for Special Needs Center Funding](#)
Pacific Daily News, 5/26/18
- [Parents of Students with Intellectual Disabilities Fight for Inclusion](#)
DiversityInc, 5/26/18

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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