

California Advocacy Network

for Children with Special Health Care Needs

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

Editor's note

Dear Reader – This month the Network Newsletter marks five years of publication. Every two years we have conducted a reader survey to help ensure that we are providing you with relevant information in a useful format. In February you will receive an email asking you to complete a survey, which should take about five minutes. Respondents may enter a drawing for a gift card. Thank you for helping us tailor content to your interests.

California Children's Services

CCS Advisory Group Considers Network Adequacy under Whole Child Model

Access to appropriate care under the Medi-Cal managed care plans that soon will cover some CCS children was a major topic of discussion at the CCS Advisory Group meeting on January 10. Group members also reviewed the timeline for transferring children to managed care, and heard updates on related topics, including rate setting. Details are available in the meeting's [PowerPoint presentation](#). The Department of Health Care Services also has released an updated list of the members of the [Advisory Group](#) as of January 2018. Members also have been appointed to a new [Performance Measure Quality Subcommittee](#), which will advise on plan performance measures and data collection. Find more information about the [CCS Advisory Group](#) and the [Whole-Child Model](#).

Viewpoint

Improving Chronic Care for Children: Learning from Medicare



As states continue the transition of children with chronic and complex health care needs into managed care plans, policymakers have an opportunity to improve services for these children by adopting policies proposed for Medicare, writes Edward Schor, MD, of the Lucile Packard Foundation for Children's Health. His new issue brief suggests that officials in California and others states should consider implementing proposals included in S.870, the [CHRONIC Act of 2017](#), related to home health care, tailored benefits, telehealth, and financial incentives for providers. [Read the issue brief.](#)

Network News

Understanding Title V Programs for Children with Special Health Care Needs

A learning module, "[History of Title V Children and Youth with Special Health Care Needs Programs](#)," has just been released by the Association of Maternal & Child Health Programs. This interactive module aims to inform Title V leaders, health professionals, students, and other stakeholders about the evolution of Title V CYSHCN programs and the policies and efforts that helped shape where those programs are today.

National Policy

Bill to Support Family Caregivers on President's Desk

A presidential signature is the final step needed to turn the [Recognize, Assist, Include, Support, and Engage \(RAISE\) Family Caregivers Act](#) into law. The act would establish a coordinated strategy to support the nation's 40 million family caregivers. An advisory body of stakeholders would develop recommendations on how the public and private sectors can support caregivers. Advocates might note that while the Act explicitly mentions veterans and the aged it makes no specific mention of family caregivers of children with special health care needs or of agencies, such as the Maternal and Child Health Bureau, which would represent them. [Read more.](#)

CHIP Funding Caught Up in Budget Negotiations

The Children's Health Insurance Program (CHIP) has become one of the bargaining issues as Congress attempts to reach a budget agreement to keep the government open after Friday. The situation is changing rapidly throughout the day. Inclusion of CHIP funding, and for how long, is not clear as of this writing. [Read more.](#)

Also See: [Parents Agonize over Their Kids' Health as Funding for Children's Insurance Program Remains in Doubt](#)

California Policy

Medi-Cal Children's Health Advisory Panel to Meet

- Date** Wednesday, January 31
Time 10 a.m. to 2 p.m. Pacific Time
Location 1414 K St, Sacramento – First Floor Conference Room
Dial In (888) 947-8923; Passcode: 2475546
Details MCHAP advises the Department of Health Care Services on policy and operational issues that affect children covered by Medi-Cal. [See the agenda and summary of last meeting.](#)

Research

NPR Series: "Hidden Epidemic of Sexual Assault" on People with Intellectual Disabilities

National Public Radio has produced *Abused and Betrayed*, a series based on a year-long investigation showing that people with intellectual disabilities – women and men – are the victims of sexual assaults at rates more than seven times those for people without disabilities. The rate is one of the highest of any group in America, yet is rarely talked about, the story says. [Listen to the series.](#)

Transition to Adult Care

Feds Seek Input on Transition Strategies

The Social Security Administration is asking for public input on strategies for improving the adult economic outcomes of youth ages 14 to 25 with disabilities who receive Supplemental Security Income (SSI). The agency is considering potential policy changes and future demonstration projects. Ideas are sought from states, community-based and other non-profit organizations, philanthropic organizations, researchers, and members of the public. Comments are due by February 2. [Read more.](#)

Resources

- [Disability Rights and Sexual Health](#) – People with disabilities have a right to be provided sexual and reproductive health resources in a format or manner that works for the individual. The Association of University Centers on Disabilities connects individuals interested in [this topic](#) and provides resources about disability and sexuality.

Webinars

Pediatric Webinar Series: Addressing the Spiritual Needs of Children

Date Tuesday, January 23
Time 12 p.m. to 1 p.m. Pacific Time
Sponsor Coalition for Compassionate Care and other sponsors
Details Fee; 1 CEU available for nurses and social workers. In times of illness and in health, the role of spirituality can be a crucial coping mechanism, even in young children. Children's spiritual development and needs will be discussed, both in terms of theology and practical application for integrating spiritual support for children into medical practice. [Register.](#)

Changes to ABLE in 2018

Date Thursday, January 25
Time 11 a.m. to 12:30 p.m. Pacific Time
Sponsor National Disability Institute

Details This webinar will summarize and explain new changes to the ABLE Act, which allows families to establish tax-advantaged savings accounts without losing benefits for their children with disabilities. [Register](#).

Oregon's Innovative Patient-Centered Primary Care Home Program

Date Tuesday, January 30

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

Details A discussion of the work of the Oregon Health Authority Patient-Centered Primary Care Home Program. The goals of the program are to develop strategies to identify and measure what a primary care home does, promote their development, and encourage consumers to seek care through recognized Patient-Centered Primary Care Homes. [Read more and register](#).

Archived Webinar

- [Paid Family and Medical Leave: The Disability Angle](#) – Explains how access to paid leave can promote economic security and stability for people with disabilities and their families. From The Arc and Georgetown Center on Poverty and Inequality.

Events

Family Voices CA Health Summit & Legislative Day

The Family Voices of California Health Summit & Legislative Day in February brings together families, youth, providers, policymakers, state agencies, and advocates who are eager to improve services and systems of care for children and youth with special health care needs. Hear from experts, build relationships with professionals, and learn how to address legislators to effectively implement change. [Register](#).

Temecula Valley Museum Exhibit



View the [stories](#) of 10 families living throughout California who provide care for their children with special needs every day and every night. On exhibit from January 21 to April 1. [Read more about the Family Stories project](#) and learn how to have the exhibit displayed in your community.

School-Based Health Conference

- Early-bird registration available through January 31 for the [2018 California School-Based Health Conference: Leading the Movement for a Healthy California](#)

Funding Opportunity

Seeking Small-Scale Pilots to Implement Principles of Patient-Centered Measurement

The American Institute for Research has developed five principles for making health care measurement patient-centered, meaning driven by patients' expressed preferences, needs, and values. Funding of up to \$197,000 is available for small-scale pilots that demonstrate ways to implement the five principles in real-world settings. Letters of intent are due by January 31. For details, see the program's [webpage](#).

In the News

- [Worried Parents: What's Wrong with My Child?](#)
The Sacramento Bee, 1/15/18
- [Texas Illegally Excluded Thousands from Special Education, Federal Officials Say](#)
NYTimes, 1/11/18
- [Mental Disorders Common in Kids with Chronic Physical Conditions](#)
Physician's Briefing, 1/9/18
- [Are Schools Doing Enough to Prepare Students for Life After Special Ed?](#)
Disability Scoop, 1/9/18
- [Guest Commentary: Invest in Pediatric Mental Healthcare to Avoid Adult Crises](#)
Modern Healthcare, 12/30/17 (free registration may be required)

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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