

California Advocacy Network

for Children with Special Health Care Needs

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

Research

National Network to Focus on Research to Strengthen Systems of Care for CSHCN

A recently established network will lead, promote, and coordinate research activities across the country to improve systems of care for children and youth with special health care needs and their families. Led by researchers at the University of Colorado School of Medicine, Children's Hospital Colorado, and Boston Children's Hospital, the federally funded, 11-site [CYSHCNet](#) aims to strengthen the base of evidence related to key components of a comprehensive, high-quality system of care. [Read more](#).

Care Coordination

Revised Pediatric Care Coordination Curriculum Released

The second edition of the [Pediatric Care Coordination Curriculum](#) (PDF) has been launched by the National Resource Center for Patient/Family-Centered Medical Home and the National Center for Care Coordination Technical Assistance. Grounded in American Academy of Pediatrics policy, the curriculum is designed to encourage communication and collaboration among traditional medical providers and non-medical providers to facilitate work across disciplines to assist families in achieving their goals for their children with special health care needs. Find more information [online](#), or contact medical_home@aap.org.

Also See: [Podcast: Multidisciplinary Care Coordination Training for Children with Medical Complexity: The Arizona Experience](#) – Features Richard Antonelli, MD, and Ashley Bach, MPH, discussing the curriculum.

California Children's Services

CCS Advisory Group Updates: Inter-County Transfers, Orange County Transition

An update on the recent shift of children into Medi-Cal managed care in Orange County and a detailed look at the process for transferring CCS clients between counties topped the agenda of the CCS Advisory Group meeting on July 24. See the [agenda](#) (PDF) and the [slide presentation](#) (PDF). The group's [website](#) is currently under revision.

CCS Transition to Adulthood Workgroup to Meet

The final meeting of the CCS Transition to Adulthood Workgroup is scheduled for Wednesday, July 31. Following this meeting, the workgroup will submit recommendations to the Department of Health Care Services that will be posted for public comment. Call-in information should be posted on the CCS Advisory Group [website](#), which is being updated.

Transition to Adult Care

Webinar Recording: Using ABLE Accounts to Support Youth from Transition to Independent Living

This webinar provides information for individuals with disabilities, their families, providers, and advocates on how establishing and using an ABLE account can provide options and choices to improve the life trajectory of transition age youth. ABLE accounts are tax-advantaged savings accounts that can be used to pay qualified disability expenses and are generally not considered in determining eligibility for federal means-tested programs. [See the webinar](#).

Also See: Webinar series [#ABLEtoSave Month: An Orientation on What You Need to Know about ABLE](#)

Children with Medical Complexity

From Siloed Systems to Ecosystem: The Evolution of the Camden Coalition's Complex Care Model

The New Jersey-based Camden Coalition of Health Care Providers has published the story of its 15-plus years developing a complex care model that is centered around both health *and* social complexity. The Camden Coalition created the [National Center for Complex Health and Social Needs](#) to search for solutions to bridge the gaps between medicine, behavioral health, public health, and social services to guarantee better health and well-being. Although currently focused primarily on adults, the work has relevance for children with complex conditions. [Read the four-part series](#).

Family Engagement

Seeking Personal Stories about Health Care Experiences

Family Voices National is working with the University of Pittsburgh to help promote StoryBooth, a research project designed to collect stories from patients and families about their experiences with health care. The goal is to improve health outcomes and the health system. The project would like to include some stories from [youth with special health care needs](#) (PDF), who are at least 18 years old. Stories are collected through phone interviews and then added to the project [website](#).

Special Education

In Brief

- [Survey Finds Teachers, Paraeducators Largely Unprepared for Students with IEPs](#)
Disability Scoop, 7/9/19
- [The New Racial Disparity in Special Education](#)
Phys.Org, 7/2/19

National Policy

Viewpoint: Block Granting or Capping Medicaid Would Affect Kids Health Care Coverage

Almost half of the nation's children with special health care needs rely on Medicaid and CHIP for medical coverage, according to the Kaiser Family Foundation. As officials consider large-scale changes to the health insurance system, a new report outlines potential threats to children's health if Medicaid is switched to block grants, thereby reducing federal funding to states. [Read more](#).

Bill to Watch

[HR 259](#) – The bill, which extends the Money Follows the Person (MFP) Demonstration Program, has become law. MFP encourages use of home and community-based services to enable individuals to live at home rather than in institutions.

Resources

- [Let's Talk: Protecting Immigrant Families](#) (PDF) – Updates and advice on a range of issues that affect immigrant children and their families – health care options, school safety, DACA, public charge. From the California School-Based Health Alliance and The Children's Partnership.
- *Exceptional Parent Magazine* July Issue – [Accessible Homes](#)

In the News

- [Disability-Focused TV Shows Nominated for Emmys](#)
Disability Scoop, 7/23/19
- [Surge in Voters with Disabilities May Influence 2020 Election](#)
Disability Scoop, 7/16/19

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.

