

California Advocacy Network for Children with Special Health Care Needs

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

Network News

Foundation Grants Target Systems Standards, Parent Empowerment, Durable Medical Equipment Delays

Eight grants, including two that support establishing national standards of care for children with special health care needs (CSHCN), recently were approved by the board of directors of the Lucile Packard Foundation for Children's Health. Three other grants seek to empower family members of CSHCN to advocate for their children, and another aims to improve access to durable medical equipment and supplies for these children. [Read about the grants.](#)

Letters of Inquiry for Funding Due; Grant Portal to Streamline Application Process

The next deadline for submitting a letter of inquiry for grant funding from the Lucile Packard Foundation for Children's Health is **December 5**. Please read the funding criteria thoroughly. Full proposals are accepted only upon invitation. Through a newly launched Grant Portal, applicants will be able to submit letters of inquiry online. Future grantees will be able to manage reports and deliverables in the Portal. [Learn more](#). Questions may be directed to the Grants Manager at Grants@lpfch.org.

Quality Standards

Tool Identifies Key Measures of Quality Care for Children with Special Health Care Needs

Quality measurement is a critical component of health programs that serve children and youth with special health care needs (CYSHCN). A new compendium of data and quality measures provides an easy-to-use reference tool for state officials and health plan administrators working to improve their CYSHCN programs. The measures align with the "National Standards for Systems of Care for Children and Youth with Special Health Care Needs." See the [compendium of quality measures](#) and a related [blog post](#).

Webinar: Strengthening Health Care Delivery Systems for CSHCN and the Role of Quality Measurement

Date Wednesday, November 28

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

Sponsor National Academy for State Health Policy (NASHP)

Details As more states serve CSHCN in Medicaid managed care, it is important to understand the unique needs of CSHCN and how program and policy changes affect their access to high quality care. This webinar will feature presenters from Delaware, Rhode Island, and Massachusetts, who participated in a NASHP learning collaborative focused on improving Medicaid managed care for CSHCN. The webinar also will feature an overview of resources that NASHP has recently developed to help states implement quality measurement and improvement efforts. [Learn more and register.](#)

Transition to Adult Care

Clinical Report: Supporting Health Care Transition

An updated clinical report published in the November issue of *Pediatrics* builds on the 2011 report, "Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home." The updated version provides more practice-based quality improvement guidance on key elements of transition: planning, transfer, and integration into adult care. [Read the report.](#)

Also See: [Few Teens with Chronic Health Problems Have Plans to Take Charge of Their Own Care](#) – Researchers found that only 17% of adolescents with special health care needs underwent transition planning for adult care. (May require free registration.)

Webinar: Creating a Vision for Adulthood

Date Thursday, November 29

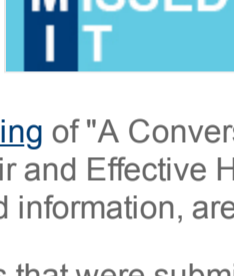
Time 9 a.m. to 10 a.m. Pacific Time

Sponsor Vermont Family Network

Details For parents of a young child, the transition to adulthood can seem like a distant bridge to cross. Arriving at that bridge can inspire anxiety, concern and trepidation, but those feelings can be minimized with early preparation and a plan for transition. A parent and her son will discuss how they, together with their family and team, designed his transition by focusing on the present while never losing sight of the bridge. [Register.](#)

Children with Medical Complexity

Follow-up on Series on Children with Medical Complexity



- The [slides and a recording](#) of "A Conversation on Ethical Considerations for a Fair and Effective Health Care System," including links to related information, are available.
- Responses to questions that were submitted during the September 20 "Conversation on Protecting Rights of Children with Medical Complexity in an Era of Spending Reduction" but not answered in the allotted time are posted. [Read the Q&A.](#)

Self-Management for Chronic Disease

Study: Theory-Based Health Behavior Interventions for Pediatric Chronic Disease Management

Health care professionals often use behavioral interventions to motivate patients and families to adopt better self-management behaviors for chronic disease. A new study in *JAMA Pediatrics*, funded by the Lucile Packard Foundation for Children's Health, examines previous research to assess whether such interventions actually have theoretical bases. The authors also sought to identify effective theory-based behavioral interventions and identify their common elements, with the goal of empowering those involved in the care of children and young adults with chronic conditions. [Read more.](#)

California Children's Services

Whole Child Model Transition Delayed in Orange County

The second phase of the transition of CCS children to Medi-Cal managed care in select counties is scheduled to be implemented on January 1, 2019. However, the transition in Orange County has been delayed until at least July 1, 2019, to allow more time to ensure that the health plan, CalOptima, is prepared to deliver the needed services. In the meantime, the county CCS redesign will continue to provide services. For questions or concerns, email CCSredesign@dohcs.ca.gov.

Family Engagement

How Hospitals Create Partnerships with the Families of Children with Complex Medical Conditions

Ten children's hospitals, along with the Children's Hospital Association, began work in 2015 on the Coordinating All Resources Effectively (CARE) Award, a three-year, federally funded study designed to transform care delivery and payment for children with medical complexity. A new article highlights the experiences of four families from around the country who benefited from CARE's focus on care coordination. [Read the article.](#)

Webinars

Early Childhood and Medicaid 101: The Tip of the Iceberg

Date Wednesday, November 28

Time 11:30 a.m. to 1 p.m. Pacific Time

Sponsor National Institute for Children's Health Quality (NICHQ)

Details Medicaid is a vital resource for ensuring that young children receive needed health care, especially in their early years. Panelists will discuss how Medicaid can be used to improve health in early childhood and address disparities. They will offer ideas about how families and community advocates can leverage Medicaid. The panel will engage in a Q&A workshop with some of the top policy experts in the field. [Learn more and register.](#)

Resources

- *Complex Child* November issue: [Colds, Flus, and Other Illnesses](#)

Events

2019 Patient and Family Centered Care Conference

Registration is open for the 9th Annual Patient and Family Centered Care Conference, scheduled for February 4, 2019, at the California Endowment Center in Los Angeles. The goal of the conference is to provide attendees with resources, tools and practical strategies for engaging patients and family members across all aspects of health care delivery. The conference will present examples of powerful outcomes achieved through partnerships in a variety of health care settings. [Read more and register](#) before **January 7** for an early bird discount. Reduced fee for patient family advisors.

Scholarship Opportunity

Chance for Youth Leaders to Attend AMCHP Annual Conference

The Association of Maternal & Child Health Programs has extended the deadline to apply for the [Ryan Colburn Scholarship Award](#) (PDF) to November 27. The award provides support for a youth leader with disabilities to attend the AMCHP Annual Conference in San Antonio March 9-12. [Read more.](#)

In the News

- [Principals a Vital Part of Special Education Success](#)
Education Dive, 11/2/18
- [Facility Would House Aging Parents Alongside Adult Kids with Disabilities](#)
Disability Scoop, 10/31/18

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.

