

California Advocacy Network for Children with Special Health Care Needs

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

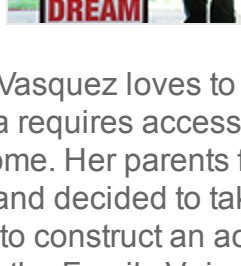
Quality Standards/System Improvement

New: National Network for Advancing Systems of Services

Three organizations are combining their resources and expertise to address the need for technical assistance to improve systems of services for children and youth with special health care needs. The National Resource Center for Patient/Family-Centered Medical Home at the American Academy of Pediatrics, the Catalyst Center at Boston University School of Social Work, and Got Transition at the National Alliance to Advance Adolescent Health will address medical home, insurance adequacy, and health care transition. The network was formed in collaboration with the federal Maternal and Child Health Bureau. [Read more](#) (PDF).

Family Engagement and Support

Parent Leaders Bring Their Daughter's Playground Dream to Life



Like most 10-year-olds, Mia Vasquez loves to spend the day at a playground. Unlike most, Mia requires accessible play structures, which are not available near her home. Her parents felt frustrated by the distances they had to drive, and decided to take on the challenge of persuading their home town to construct an accessible playground.

Through Project Leadership, the Family Voices of California's advocacy training program, they developed the skills to mobilize the community support and funding needed to make Mia's dream playground a reality. [Read about their journey.](#)

Children with Medical Complexity

Maximizing System-Level Data to Address Medical and Social Complexity in Children: Spotlight on Oregon



The recording and slides are available from this well-received April 2 webinar that described how an innovative methodology that uses system-level data to identify children with health complexity – based on both medical and social complexity – is transforming care for these children in Oregon. [Listen to the recording.](#)

California Children's Services

CCS Advisory Group Discusses Evaluation of the Whole Child Model, Telehealth, CalOptima

At its April 10 meeting the California Children's Services Advisory Group heard a report on how the Whole Child Model, which transfers CCS-enrolled children into Medi-Cal Managed Care, will be evaluated through a contract with the University of California, San Francisco. Staff from the Department of Health Care Services also reported on updates to telehealth policies in Medi-Cal, the progress of the Transition to Adulthood Workgroup, and other aspects of the Whole Child Model. CalOptima reported in depth on its Whole Child Model implementation plan. See the [agenda and slide presentations.](#)

New Members Added to CCS Advisory Group

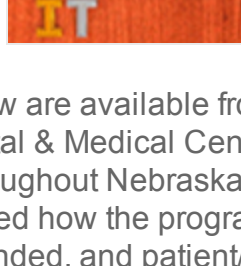
Two new representatives have joined the CCS Advisory Group. Both are members of their local County Organized Health Systems' Family Advisory Committees. Susan Skotzke represents the Central California Alliance for Health, and Kristin Rogers represents CalOptima. Family advisory committee members will serve on an annual basis. See the [member list](#) (PDF) as of March.

In Brief

- The Department of Health Care Services has announced that the delayed Phase III of the Whole Child Model program, which includes CalOptima in Orange County, will be implemented effective July 1.
- The CCS workgroup considering transition to adulthood for CCS clients met March 27. The agenda and some of the slide presentations are available on the CCS Advisory Group [website](#). The next meeting is scheduled for April 24.

Telemedicine

Archived Webinar: Using Telemedicine for Pediatric Behavioral Health Services

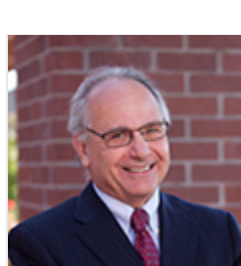


The recording and slides now are available from a March 28 webinar about how Children's Hospital & Medical Center in Omaha is partnering with primary care clinics throughout Nebraska to provide telepsychiatry to youth. The discussion covered how the program was developed and how it operates, how the work is funded, and patient/family and provider views of the services. [Listen to the webinar.](#)

Also See: [Realizing the Promise of Telehealth for Children with Special Health Care Needs](#)

Resources

An Almost Complete List of Services Used by Families and Children with Special Health Care Needs



It's probably next to impossible to compile a comprehensive list of services required by children with complex conditions and their families. However, a new fact sheet from Edward Schor, MD, offers groupings that may be useful in care mapping, care planning, creating resource databases, and developing referral systems. [Read the fact sheet.](#)

Critical Elements for Financing the System of Care for CYSHCN: An Infographic Series

The Catalyst Center has created an infographic series describing key focus areas in health care financing and coverage for children and youth with special health care needs. Each infographic offers a concise look at a complex issue from the perspective of children, their families, payers, policymakers, and providers. These one-pagers provide an easy way to share information about the system of care. [See the series.](#)

Also See: [The Care Coordination Conundrum and Children and Youth with Special Health Care Needs](#)

California Policy

- [The Arc of California 2019 Policy Conference](#) – See 11 videos of speakers, including Anne O'Leary, chief of staff to newly elected Governor Gavin Newsom. The Arc advocates for people with intellectual and developmental disabilities.

National Policy

ACE Kids Act Heading to President's Desk

The Senate has passed the Advancing Care for Exceptional Kids Act ([ACE Kids Act](#)), which would allow state Medicaid programs or health care plans to provide coordinated care in health homes for children with complex medical conditions, even allowing enrollment across state lines. The Act, which was supported by the Children's Hospital Association, is part of a package of Medicaid bills in [H.R. 1839](#), also passed the House of Representatives and now awaits presidential signature. [Read more.](#)

Transition

Using an ABLE Account to Support Youth from Transition to Independent Living

Date Thursday, April 25
Time 11 a.m. to 12 p.m. Pacific Time
Sponsor National Disability Institute
Details An ABLE account is a tax-advantaged savings account for individuals with disabilities and their families. This webinar will explain how establishing and using an ABLE account can provide options and choices to improve the life trajectory of transition age youth. [Register.](#)

Webinar

Advance Care Planning in Pediatrics

Date Tuesday, April 16
Time 12 p.m. to 1 p.m. Pacific Time
Sponsors Coalition for Compassionate Care of Pennsylvania, Children's Hospice Palliative Care Coalition, Pennsylvania's Pediatric Palliative Care Coalition and Greater Illinois Pediatric Palliative Care Coalition
Details Advance care planning can be complex, particularly in pediatrics. Speakers will discuss creative ways to engage patients and families in discussions to document goals of care and learn how to mitigate challenges. Fee. CEU available. [Register.](#)

In the News

- [Exhibit Focuses on the Super Parents: Caring for Children with Special Needs](#)
Independent News, 4/4/19
- [A Robotics Team Built a Toddler a Wheelchair. Now He's Chasing His Corgis Around](#)
NY Times, 4/3/19
- [Opinion: If Trump Ends Obamacare, Keeping My Daughter Alive Will Wipe Me Out](#)
Washington Post, 4/1/19
- [Flying Tips for Wheelchair Users, from Wheelchair Users](#)
NY Times, 3/8/19

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.

