

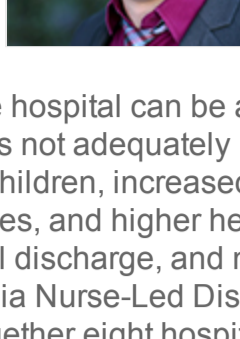
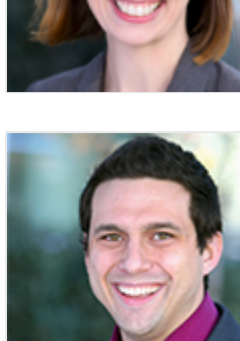
California Advocacy Network

for Children with Special Health Care Needs

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

Quality Standards/System Improvement

Nurses Leading the Charge to Improve Pediatric Hospital Discharge



Taking a child home from the hospital can be a frightening experience. Discharge planning that does not adequately prepare families can result in poorer health outcomes for children, increased chances of hospital readmission, stress on families, and higher health care costs. Nurses are on the front line of successful discharge, and now they are taking the lead in a new project, the California Nurse-Led Discharge Learning Collaborative, that brings together eight hospitals to create, test, and share innovative discharge planning initiatives. [Read about their work.](#)

Also see previous Foundation-supported work on hospital discharge:

- [Improving Pediatric Hospital Discharge Care for Children and Families](#)
- [Resources: The Road to Hospital Discharge Success for Children with Medical Complexity.](#)

California Children's Services

CCS Advisory Group to Meet

Date Wednesday, April 10
Time 10 a.m. – TBD Pacific Time
Location 1700 K Street, Sacramento – First Floor Conference Room
Details The call-in information, agenda and materials will be posted on the Advisory Group [website](#).

Family Engagement

Families Drive Better Outcomes in Children's Health

Two mothers of children with special health care needs became "parent partners" on projects at the National Institute for Children's Health Quality (NICHQ). This article highlights how their years-long efforts to elevate families' voices promoted improvements in family-centered pediatric care and care for children with epilepsy. [Read their stories.](#)

Family Voices Leadership Conference – Early Bird Registration Ending

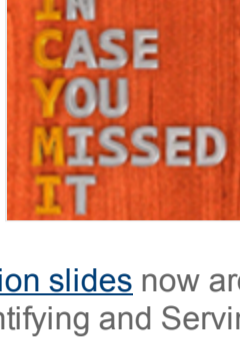
March 31 is the last day to take advantage of a reduced registration fee for the 2019 Family Voices Leadership Conference, scheduled for May 8-10 in Washington, DC. [Read more and register.](#)

Children with Medical Complexity

Medical, Social Complexity Webinar Series Continues

Date Tuesday, April 2
Time 11 a.m. to 12 p.m. Pacific Time
Sponsor Oregon Pediatric Improvement Partnership (OPIP) and Oregon Health Authority
Details Part 2 of the series will address "Maximizing System-Level Data to Address Health and Social Complexity in Children." [Register and find suggested reading](#) to prepare for the webinar.

Part 1: Recording and Slides Now Available



The [recording and presentation slides](#) now are available from the March 14 online conversation, "Identifying and Serving Children with Health Complexity."

In Brief

- [Quick Reference Guide to Promising Care Models for Patients with Complex Needs](#) – from The Commonwealth Fund.

Research

- [As Home Care Expands, Let's Make It Safer for Everyone](#) – from *Health Affairs*. Five principles for improving the safety of care in the home for individuals with health care needs and seniors, as well as their caretakers.

California Policy

"Keep the Promise" Rally in Sacramento for Intellectual/Developmental Disabilities Funding

Date Wednesday, April 3
Time 10 a.m. Pacific Time
Sponsor The Lanterman Coalition
Details A statewide rally, march, and legislative visits to encourage increased funding for systems serving individuals with intellectual/developmental disabilities. [Read more](#) (PDF).

Medi-Cal Children's Health Advisory Panel to Discuss Auditor's Report on Inadequate Preventive Services

Date Thursday, April 4
Time 10 a.m. to 2 p.m. Pacific Time
Location The California Endowment
1414 K Street, Sacramento – First Floor Conference Room
Dial-In (888) 947-8923; Passcode: 2475546
Details The agenda will include discussion of a newly released [State Auditor's report](#) that found an annual average of 2.4 million children enrolled in Medi-Cal do not receive all required preventive services under the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) program. The full meeting agenda is on the panel [website](#).

Bill to Watch

- [AB 236](#) – This bill revises requirements for establishing Family Empowerment Centers on Disability in 32 regions throughout California. The centers provide training and services to children and young adults with disabilities and their families.

National Policy

Bill to Watch

- The Advancing Care for Exceptional Kids Act ([ACE Kids Act](#)) would allow a state Medicaid program or child health plan to provide coordinated care in health homes for children with complex medical conditions, even allowing enrollment across state lines. It passed the House of Representatives on March 25, as part of a package of Medicaid bills, [H.R. 1839](#).

Resources

- *Exceptional Parent Magazine* March issue – [Schools and Camps](#)
- [American Association of People with Disabilities \(AAPD\) Career Center](#) – A source for people with disabilities to search for professional careers. The center attracts leading companies and universities searching for qualified and diverse candidates.

Webinars

Pursuing Health Equity: Start Where You Are – A Conversation About Individual Implicit Bias

Date Wednesday, April 10
Time 12 p.m. to 1 p.m. Pacific Time
Sponsor National Institute for Children's Health Quality
Details First in a series of webinars to support individuals who are pursuing equity for children within the health system. [Register.](#)

Improving Transition Outcomes for Youth SSI Recipients: Early Findings from the PROMISE Evaluation

Date Thursday, April 11
Time 9 a.m. to 10 a.m. Pacific Time
Sponsor Mathematica's Center for Studying Disability Policy
Details Speakers will discuss the landscape of transition services for youth with disabilities and the challenges that youth and families face in accessing those services. Findings from the PROMISE program, which seeks to help youth successfully transition to adulthood, will be presented. [Register.](#)

Events

Pediatrics Included in Palliative Care Summit

Breakouts and poster sessions on pediatric palliative care will be included on the agenda of the Palliative Care Summit, scheduled for April 8-9 in San Francisco. The conference is geared toward physicians, nurses, social workers, nursing home administrators, chaplains and others interested in clinical research, quality, and policy as it pertains to palliative care. Continuing education credits available. [See the agenda](#) and [register](#). Fee.

Disability Policy Seminar

Date April 8 to 10
Location Washington, DC
Sponsors The Arc, the American Association on Intellectual and Developmental Disabilities, the Association of University Centers on Disabilities, the National Association of Councils on Developmental Disabilities, Self-Advocates Becoming Empowered, and United Cerebral Palsy
Details This event cultivates champions on Capitol Hill and advances the grassroots movement for people with intellectual and developmental disabilities. Fee. [Read more and register.](#)

Did You Know?

Data Available from National Survey of Children's Health 2016-17

The combined 2016-2017 National Survey of Children's Health (NSCH) data sets and codebooks have been released by the Data Resource Center (DRC), in collaboration with the Health Resources and Services Administration's Maternal and Child Health Bureau. The combined 2016-2017 NSCH is the first multi-year data set acquired since the redesign of the NSCH in 2016. Data are available on more than 71,000 children ages 0-17. See the new information on [childhealthdata.org](#).

In the News

- [Betsy DeVos Grilled Again over Proposed Cuts to Special Olympics Funding](#)
Bloomberg, 3/28/19
- [Special Needs Kids Require Specialized Estate Planning](#)
Forbes, 3/27/19
- [Proposed CA State Bill Aims to Protect Special Needs Students After El Dorado Hills Death](#)
Sacramento Bee, 3/25/19
- [With \\$29 Million in Backing, MIT Launches Down Syndrome Center](#)
Disability Scoop, 3/21/19
- [Talking to Children About Terminal Illness](#)
NY Times, 3/18/19

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.

