

California Advocacy Network

for Children with Special Health Care Needs

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

Research

Reports Highlight Range of Issues Affecting Children with Special Needs and Their Families

- [Health System Research Priorities for Children and Youth With Special Health Care Needs](#) – from *Pediatrics*. This abstract and video report on a survey regarding stakeholder priorities for a CSHCN research agenda, as a first step toward developing an efficient and cohesive research blueprint for achieving effective health systems.
- [Children with Special Health Care Needs Face Challenges Accessing Information, Support, and Services](#) – from Child Trends. The authors note that while CSHCN face challenges to obtaining quality health care, access to services and resources has improved over the years.
- [The Child Care Crisis Disproportionately Affects Children with Disabilities](#) – from the Center for American Progress. This report examines families' child care experiences when they have children ages 0 to 5 with disabilities, and offers policy solutions that are critical to supporting these families.
- [Principles of Financing the Medical Home for Children](#) – from *Pediatrics*. The researchers suggest basic financing principles for providing effective, comprehensive pediatric care in a fiscally sustainable medical home.
- [Trends Over Time and Jurisdiction Variability in Supplemental Security Income and State Supplementary Payment Programs for Children with Disabilities](#) – from the *Journal of Public Health Management and Practice*. The authors note that understanding more about the way SSI and SSP reach children and work in combination with other federal and state income security programs may help identify policies and strategies that better support children with disabilities in low-income households.

Transition to Adult Care

Online Course Teaches Care Providers about Transition

An online course is available for professionals who assist youth in preparing to assume responsibility for managing their chronic conditions and making the transfer from a pediatric to an adult model of health care. The course is presented by Patience White, MD, co-director of Got Transition and professor of medicine and pediatrics at the George Washington University School of Medicine and Health Science. CME, CEU available. [Read more and enroll.](#)

REACH for Transition: Helping Youth/Young Adults Take Charge of Their Health Care

Date Tuesday, February 25
Time 9 to 10 a.m. Pacific Time
Sponsor SPAN Parent Advocacy Network
Details This workshop will discuss how young people can begin the transition process and become a partner with their medical providers. Not CSHCN-specific. [Read more and register.](#)

Call for Policy Proposals to Improve Transitions for Youth with Disabilities

Mathematica is seeking innovative ideas on how to help youth who receive Supplemental Security Income (SSI) improve their employment outcomes as they transition to adulthood. The program will provide support to selected experts to turn their ideas into full papers that will be published and shared with policymakers and other stakeholders. Applications are due February 27. [Read more.](#)

California Children's Services

Transition to Adulthood Workgroup Scheduled to Meet

Date Wednesday, February 26
Time 1 to 2:30 p.m. Pacific Time
Location 1515 K Street, Sacramento – Suite 400
Dial-In (888) 924-9621; Passcode: 8500518
Details Email CCSRRedesign@dhcs.ca.gov for webinar details. [See website.](#)

Children with Medical Complexity

Apply to Present Complex Care Work at the Putting Care at the Center 2020 Conference

Four different types of opportunities are available for sharing your work on complex care at the 2020 Putting Care at the Center conference, scheduled for October in Philadelphia. The theme is *Going the Distance: Teamwork and Resilience in Complex Care*, and applications are due **April 8**. Read about the opportunities and [how to apply](#).

Also See: **February 29** is the deadline for applying to host local complex care convenings. Read more and see the [Request for Proposals](#) (PDF).

Family Engagement

Webinar: Building Capacity Using Family-Centered Approaches

Date Wednesday, February 26
Time 12 p.m. Pacific Time
Sponsor National Center on Advancing Person-Centered Practices and Systems
Details This webinar, whose full title is *Building Capacity Using Family-Centered Approaches to Promote the Best Life for Young Children with Disabilities: An Innovative Family-to-Family Program*, will feature discussion of a program that has created novel approaches to family-centered planning, practices, and supports to build family participation. [Register.](#)

Family Voices Sacramento Summit to Include Youth Track

A separate program for youth and young adults with special health care needs and disabilities will be featured at the Family Voices of California Health Summit & Legislative Day, scheduled for March 15-17 in Sacramento. [Read more and register.](#)

Event

Parent-Professional Partnerships, Care Coordination on Agenda for AMCHP National Conference

The Power of Connections: Building Equity for Healthy Generations is the theme for the annual conference of the Association of Maternal and Child Health Programs (AMCHP), scheduled for March 21-24 in Crystal City, Virginia. The conference includes two skills-building sessions featuring parent-professional partnerships, and a session introducing the [Pediatric Care Coordination Curriculum, Second Edition](#) (PDF). Visit the poster session, *Compensating and Engaging Youth and Family Leaders as Research Partners*, to learn about our Foundation's new Family Engagement Policy. [Register](#) by **February 21** to receive a discounted conference rate.

Advocacy Opportunities

Rare Disease Day Emphasizes Action

Rare Disease Day is Saturday, February 29. The day highlights the fact that millions of people living with a rare disease face inequitable access to diagnosis, treatment, and care, and calls for action to raise awareness and seek equity. [Read more.](#)

Related: [Shortening the Diagnostic Odyssey](#) – the 2020 education initiative from the Child Neurology Foundation, and [S.3116](#) – Ending the Diagnostic Odyssey Act of 2019.

Advocates to Gather at Disability Policy Seminar

The Disability Policy Seminar is a three-day annual federal legislative conference in Washington, DC, co-sponsored by eight advocacy organizations. Participants meet for two days of training sessions on disability rights, followed by visits to Capitol Hill. This year's event is scheduled for March 23-25. [Read more and register.](#)

In Brief

- Comments due **March 2** on a Department of Transportation proposal to make airplane lavatories more accessible for passengers with disabilities. [Read more and comment.](#)

Resources

- [An Advocate's Guide to Medi-Cal Services](#) – from the National Health Law Program
- *Exceptional Parent Magazine* February Issue – [Diet and Nutrition](#)

In the News

- [Study: Rural Children Are More Likely to Have a Developmental Disability](#)
U.S. News & World Report, 2/19/20
- [A \\$4 Million NICU Bill: The Price of Prematurity](#)
NY Times, 2/11/20
- [Actor Zack Gottsagen First Person with Down Syndrome to Present at the Oscars](#)
The Mighty, 2/9/20
- [2020 Schneider Family Book Awards Recipients Named](#)
American Library Association News, 1/27/20
(Note: These awards honor an author or illustrator for the artistic expression of the disability experience for child and adolescent audiences.)

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.

