

Children and Youth with Special Health Care Needs

Network Newsletter

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

TRANSITION TO ADULT CARE

Helping Clinicians Make Transition Planning Part of Regular Care

[Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home](#), a joint clinical report from the American Academy of Family Physicians and the American College of Physicians, provides recommendations on how clinicians can establish a structured process to ensure a planned transition as part of routine care for adolescents and young adults, including those with chronic conditions. The report, first issued in 2011, has just been reaffirmed with new reference and data updates. Read the [updated report](#).

FAMILY ENGAGEMENT

Strengthening the Diversity and Role of Patient and Family Advisory Councils

Patient and Family Advisory Councils (PFACs) can improve hospital care by bringing consumer voices into the planning, delivery, and evaluation of care, but many hospitals lack diversity among PFAC members compared to their broader patient population. A new report from the Institute for Patient- and Family- Centered Care, produced with funding from our Foundation, highlights opportunities for action in six key areas to help hospitals strengthen the diversity of PFACs and enhance the role of Patient and Family Advisors in Diversity, Equity and Inclusion initiatives. [Read the report](#).

Nominate Excellent PICU Physicians for Hospital Research Study

Parents and guardians of children with medical complexity are invited to nominate pediatricians to participate in a research study on doctors who are especially effective in supporting families with children in the Pediatric Intensive Care Unit (PICU). To nominate a physician who truly valued your perspective on your child's care, complete this [survey](#). No personal information will be collected, and the hospital will not contact you. For more information, email The Hospital for Sick Children at Complexdecision.lab@sickkids.ca

‘Putting Care at the Center’ Conference Registration Open

Elevating Behavioral Health in Whole-Person Care is the theme for the Putting Care at the Center 2023 conference, an annual opportunity for the national complex care community to learn, network, and create a shared agenda for this growing field. The conference is scheduled November 1-3 in Boston. [Read more and register](#). Fee. Some discounts available.

In Brief

- [Staying Organized in the World of Medical Complexities](#) – Organizational tools and tips for families and caregivers from the Pediatric Palliative Care Coalition

HOME- AND COMMUNITY-BASED SERVICES

Webinar: Exploring Ways to Pay for In-Home Care

DATE	Thursday, October 12
TIME	10 to 11 a.m. Pacific Time
SPONSOR	American Society on Aging
DETAILS	Speakers will discuss the top six funding sources for in-home care. Although the focus is on seniors, some information may be of interest to families of CYSHCN. One Continuing Education credit available. Read more and register .

MENTAL AND BEHAVIORAL HEALTH

PBS: How Families Struggle to Find Mental Health Care for Youth

A segment of the PBS News Hour's series *Early Warnings: America's Youth Mental Health Crisis* reported on how the COVID-19 pandemic revealed the enormous strain on the mental health care system for youth. The broadcast recounts how parents whose children have complex mental and behavioral health needs had to take desperate measures to get their children treatment. [Listen](#).

HEALTH EQUITY

Funding Opportunity: Understanding and Mitigating Health Disparities Caused by Ableism

Encouraging research to understand the impact of ableism on health outcomes for people with disabilities is the goal of a funding opportunity announced by the federal Department of Health

and Human Services. Priorities include research on the underlying mechanisms by which ableism adversely influences the health of individuals with disabilities, and developing and/or testing interventions at a community or health systems level to mitigate adverse health effects of ableism. Applications are due **November 29**. [Read more](#).

In Brief

- [Feds Urged to Classify Disability as a Health Disparity](#) - from *Disability Scoop*

CALL FOR PROPOSALS

Present CYSHCN/Disabilities Work at AMCHP National Conference

Proposals will be accepted until **November 3** to present skills-building sessions, workshops, posters, or roundtables at the 2024 Association of Maternal and Child Health Programs (AMCHP) Annual Conference that will be held April 13-16 in Oakland, California. Children and Youth with Special Health Care Needs and Disabilities is one of the tracks for the conference, whose theme is *Partnering with Purpose*. AMCHP encourages those working in community organizations and tribal entities, family leaders, students, and early career professionals to share their completed (or in progress) work. [Read details](#).

NATIONAL POLICY

Comments Sought: Updates to Disability Discrimination Regulations

For the first time in 40 years the federal government is proposing a comprehensive update to Section 504 of the Rehabilitation Act of 1973, which prohibits disability discrimination by recipients of federal funding. The proposed rule clarifies some existing regulations and includes new requirements prohibiting discrimination in the areas of medical treatment, web, mobile, and kiosk accessibility, and requirements for accessible medical equipment, among other provisions. A 60-day comment period began on September 15. [Read more and comment](#).

Also see: [Biden Administration Proposes Rule to Curb Disability Discrimination in Health Care](#)

In Brief

- [Disability Groups Win Fight to Be Included in Health Equity Research](#) - from *The Washington Post*

PUBLIC HEALTH EMERGENCY UNWINDING



- [Looming Government Shutdown Could Undermine Federal Oversight of Medicaid Unwinding](#) - from Georgetown Center for Children and Families
- [Medicaid Eligibility Call Centers: Questions for Limited English Proficiency and Disability Access](#) – from National Health Law Program
- [Update on Medicaid Unwinding and Marketplace Enrollment](#) – from Georgetown Center for Children and Families
- [CMS Takes Swift Action to Require States to Address Medicaid Auto-Renewal Errors and Reinstate Children’s Coverage](#) - from Georgetown Center for Children and Families

EVENTS

Registration Open for Upcoming Association of University Centers on Disabilities Conference

Emerging Leaders: Shaping the Future is the theme for the annual conference of the Association of University Centers on Disabilities, scheduled for November 5-8 in Washington, DC. Registration is open for the conference, which draws experts from all across the disability field, individuals with disabilities, family members, students, and trainees to learn together. [Read more and register](#). Fee.

SPECIAL EDUCATION

- [Centers for Medicare and Medicaid Services Issues Guidance on Medicaid and CHIP Services in School-Based Settings](#) – An issue brief from Manatt
- [Major Flaws Identified with IDEA Complaint System](#) - from *Disability Scoop*
- [Ed Department Offers Up Nearly \\$199 Million to Improve Outcomes for Students with Disabilities](#)- from *Disability Scoop*

CALIFORNIA CHILDREN'S SERVICES

CCS Advisory Group to Meet

DATE Wednesday, October 11

TIME 1 to 4 p.m. Pacific Time

DETAILS The agenda and login information will be posted on the group [website](#).

CALIFORNIA POLICY

Enhanced Care Management: How Is It Working So Far?

On July 1, the Department of Health Care Services launched Enhanced Care Management for children and youth, a Medi-Cal benefit designed to assist families in coordinating care for their children with complex physical, behavioral, and social needs. A new article from *California Health Report* documents the slow start-up of the program, the low numbers of families being served, the lack of information for potential users, and the state's plans. [Read the article.](#)

CALIFORNIA REGIONAL CENTERS

California Spends \$14 Billion on People with Disabilities. Why Do Some Go without Help?

An article in the *Sacramento Bee* explores the impact on families of the well-documented racial and ethnic inequities in the provision of services by the state's Regional Centers for Developmental Disabilities. Families discuss long waits for services and the lack of transparency in how the system operates. The article includes links to resources that may assist families. Our Foundation supported some of the original research on this topic through grants to Public Counsel. [Read the article.](#)

RESOURCES

- [Annual Issue: Elderly Care](#) - from Exceptional Parent Magazine
- [The Disability Information and Access Line \(DIAL\)](#) helps individuals with disabilities get connected to information about local community resources that support independent living, including transportation, housing support, disability rights, and more. – from the Administration for Community Living

IN THE NEWS

- [This 6-year-old Is a Pioneer in the Quest to Treat a Deadly Brain Tumor](#)
The Washington Post, 9/28/23
- [Disability Advocates Fret as Government Shutdown Looms](#)
Disability Scoop, 9/22/23
- [Social Security, SSI Likely to See Increase as Lawmakers Eye Reforms](#)
Disability Scoop, 9/14/23
- [A New Device Could Help Students with Disabilities Navigate Technology](#)
EdTech, 8/22/23

WE'D LIKE TO HEAR FROM YOU

Let us know what's happening with your organization or family. Email newsletter assistant editor Hannah Au at Hannah.Au@lpfch.org with your news or updates. Or contact newsletter editor: Eileen Walsh at Eileen.Walsh@lpfch.org.

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