

Children and Youth with Special Health Care Needs

Network Newsletter

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

TRANSITION TO ADULTHOOD

Improving Primary Care to Support Young Adults Transitioning to Adult Care

When young adults with medical complexity age out of the pediatric system, they and their families consistently report difficulty in finding adult primary care providers (PCPs), which has a major impact on the quality of their lives. The National Alliance to Advance Adolescent Health/Got Transition and the George Washington University Fitzhugh Mullan Institute for Health Workforce Equity established a national *Advisory Committee on Strengthening the Adult Primary Care Workforce to Support Young Adults with Medical Complexity Transitioning to Adult Health Care*. The committee developed 10 recommendations to promote an increased supply and distribution of well-prepared adult PCPs to care for this transitioning population. [Read their report and recommendations \(PDF\)](#).

CHILDREN WITH MEDICAL COMPLEXITY

Webinar: Building Ecosystems of Care to Benefit Children with Medical Complexity

DATE	Monday, May 22
TIME	10 to 11 a.m. Pacific Time
SPONSOR	Camden Coalition's National Center for Complex Health and Social Needs
DETAILS	Children with complex health and social needs and their families interact with multiple systems of care. Communities across the country are building pediatric ecosystems of care to organize and encourage collaboration among these systems. This webinar will showcase two initiatives that are building these ecosystems. Speakers will describe their programs, the challenges they've faced, and the innovations they've developed. The webinar will also provide an overview of what the Camden Coalition and our Foundation are doing to build ecosystems around the country. Dr. Holly Henry, our CYSHCN program director, will be a featured speaker. Read more and register .

Reminder: Emerging Investigator Applications Due

June 5 is the deadline for applying to the CYSHCN Emerging Investigator Program. [Read more](#) and listen to an application assistance webinar.

HOME- AND COMMUNITY-BASED CARE

Proposed Federal Rule Would Improve Access to Home- and Community-Based Care

Two newly proposed rules from the Biden Administration contain a wealth of provisions that would make significant changes in access to care for Medicaid and Children's Health Insurance Program (CHIP) beneficiaries. One of the rules, [Ensuring Access to Medicaid Services](#), addresses the quality of home- and community-based care, including measures to improve employment for workers who provide home-based services. Comments are due by **July 3**. [Read more about the proposed rules](#).

Related Webinar: Proposed Rules to Enhance Access and Quality for Medicaid HCBS and Strengthen the HCBS Workforce

DATE	Thursday, June 1
TIME	10 to 11 a.m. Pacific Time
SPONSOR	Manatt
DETAILS	Speakers will review the key reforms proposed for Medicaid HCBS, including establishing requirements for rate transparency and payment adequacy, strengthening procedures regarding person-centered service plans, and standardizing state approaches for monitoring access to care, quality of care, critical safety incidents, and beneficiary grievances. Read more and register .

Report: Lagging Reimbursement for Home Nurses Means Children Stay in Hospital

Pediatric home health care is in crisis nationwide. A recent study commissioned by the California Association for Health Services at Home focuses on children with complex medical conditions in California who require specialized care in the home. According to the analysis, lagging Medi-Cal reimbursement rates result in a shortage of private duty nurses to care at home for children who are able to leave the hospital, ultimately increasing costs to the state. [Read the study findings \(PDF\)](#) and [read more](#) about the issue.

PUBLIC HEALTH EMERGENCY UNWINDING

Foundation Tracks Resources to Assist with Unwinding



The COVID-19 Public Health Emergency (PHE) ends today, May 11. Families nationwide are coping with the requirement to renew their children's Medicaid coverage, and many children risk losing coverage even if they are still eligible. For families of CYSHCN, any lapse in coverage could have devastating impacts. This is particularly concerning for children of color, many of whom are covered by Medicaid and also face additional barriers to accessing health care. Our Foundation has compiled a range of resources regarding the unwinding and its implications that will be updated regularly. [See the resources](#).

FAMILY ENGAGEMENT

Family Voices National Wins Major Grant

Family Voices has received a highly competitive five-year Family Engagement and Leadership in Systems of Care grant from the Maternal and Child Health Bureau. The funds will support national leadership on family engagement to support youth and family leaders, Maternal and Child Health programs, and other stakeholders that serve CYSHCN. Family Voices will continue its role as the technical assistance provider for the Family-to-Family Health Information Centers with a range of new goals. [Read more](#).

New Executive Director for Family Voices National



Allysya Ware, PhD, MSW, has been named the executive director of Family Voices, succeeding Nora Wells. Dr. Ware has served in many roles in the organization, most recently as interim executive director. She has extensive experience in strategic planning, family engagement, grant writing, human relations, and systems change, and is an advocate for family and community leadership in developing solutions and improving systems. [Read more](#).

PEDIATRIC PALLIATIVE CARE

Proposed California Bill Would Increase Access to Pediatric Palliative Care

California is considering [AB847](#), a bill that, among other key provisions, would extend eligibility to age 26 for pediatric palliative care services and concurrent treatment for an underlying illness for individuals who have been determined eligible for those services prior to age 21.

SYSTEMS AND SERVICES

Survey: Specialty Care for Children Declining in California

Findings from a 2022 survey indicate that access to specialty care for children and youth in California has worsened since 2019, when the survey last was conducted. The Children's Specialty Care Coalition, which represents 18 pediatric specialty medical groups in the state, surveyed its members on metrics related to access to care, including patient wait times and length of time for physician recruitment. The survey, which was conducted in collaboration with Practical Research Solutions and with funding from our Foundation, highlights concerns addressed in [Senate Bill 424](#), the California Children's Services (CCS) Modernization Act. [Read the full report](#) and [see a related infographic](#).

CALIFORNIA CHILDREN'S SERVICES

CCS Advisory Group Considers Whole Child Model Expansion, Enhanced Care Management, and More

At its April 12 meeting the CCS Advisory Group held extensive conversations about the potential expansion of the Whole Child to new counties; monitoring and oversight of the CCS program; transition to adulthood; the upcoming Enhanced Care Management program; and the conclusions reached in the recently released evaluation of the Whole Child Model. The meeting [slides](#) (PDF) contain detailed information on each topic.

Caution Urged on CCS Whole Child Model Expansion Plan

The Whole Child Model, currently implemented in 21 California counties, integrates children's specialty care services provided through CCS to 15 Medi-Cal managed care. The state is proposing to expand the Whole Child Model to into additional counties. A report from the Legislative Analyst's Office, which is the Legislature's nonpartisan fiscal and policy advisor, recommends that, given the complex policy considerations, the Legislature defer some or all of the proposed expansion and instead take a long-term, coordinated approach to changing and improving the CCS program. [Read the report](#).

RESOURCES

- [Behavior Management for Children with Various Neurologic Conditions](#) – from the Child Neurology Foundation
- EP Magazine annual [autism issue](#)

INTERNSHIP OPPORTUNITY

Paid Student Internships Available

Applications are open for the American Association of People with Disabilities Fall Internship Program. The fully virtual program places students and recent graduates with disabilities in paid internships that help them build leadership skills, explore career opportunities, and connect with the disability community. Applications are due **June 8**. A virtual information session will be held on **May 18**. [Read more](#).

IN THE NEWS

- [Attempts to Scam Medicaid Members Popping Up Nationwide as Unwinding Commences](#) *National Association of Medicaid Directors, 4/3/23*
- [Actor Is First with Down Syndrome to Star in Disney Film](#) *Disability Scoop, 4/25/23*
- [Disability Programs at Risk in Federal Budget Battle, Advocates Warn](#) *Disability Scoop, 4/28/23*

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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