

Children and Youth with Special Health Care Needs NETWORK NEWSLETTER

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

FROM THE FOUNDATION

New Grants Drive Systems Improvement for Children with Complex Health Needs

The Foundation has awarded four new grants both in response to the rapidly changing health care landscape and to continue core competencies development.

Three rapid response grants encompass the following work:

- Leveraging national data to inform policy priorities for children with medical complexity amid reductions in Medicaid funding - *Grantees: Boston Children's Hospital and the Children's Hospital Association*
- Tracking California and federal policy changes to protect programs and services for CYSHCN through the Children's Regional Integrated Service System (CRISS) - *Grantee: Lucile Packard Children's Hospital Stanford*
- Preserving and strengthening the California Children Services (CCS) Advisory Group - *Grantee: Children Now*

The fourth grant provides funding for a second phase of:

- Establishing core competencies for pediatric complex care fellowship training programs - *Grantees: Boston Children's Hospital, The Hospital for Sick Children (SickKids), and The Bluebird Way Foundation.*

[Learn more about the new grants](#)

NATIONAL POLICY AND RESOURCES

New Medicaid Work Requirements and Caregiver Exemptions Flowchart

The [National Center for a System of Services for CYSHCN](#)'s latest resource, *Medicaid Work Requirements and Caregiver Exemptions Flowchart*, is designed for Title V CYSHCN programs and family leadership organizations that are providing benefits counseling or working closely with state Medicaid programs as they navigate and respond to these upcoming changes.

[See the flowchart](#)

[Apply for the Emerging Investigators Guided Research Program 2026-2027](#)

Applications are open for the Systems & Policy Research Network Emerging Investigator Guided Research Program, which funds up to three projects each year dedicated to improving health systems for CYSHCN. Selected investigators receive up to \$15,000, one year of mentorship, and guidance in building meaningful family partnerships in research. Applicants from any US academic institution serving CYSHCN are eligible. The deadline to apply is **July 1**.

[Learn more and apply](#)

HOME HEALTH CARE

Webinar - Essential Yet Out of Reach: Home Accessibility for Children with Disabilities

The first of a two-part webinar series will introduce Foundation-funded research on the national landscape of programs and policies that support home accessibility for children with disabilities and their families. A panel of experts, including those with lived experience, will discuss common barriers to accessing these supports, the real-world impacts on children and families, and opportunities for action and advocacy. After this first webinar in May, watch for an announcement for the second webinar in the fall.

DATE/TIME: Thursday, May 21 | 10-11am PT/1-2pm ET

[Register for the webinar](#)

Understanding the Medical Home Model for Children with Complex Health Needs

The National Center for a System of Services for CYSHCN created a plain-language tip sheet to help families understand medical home. The tip sheet offers helpful explanations of what medical home is, its key features, and the importance of a medical home for CYSHCN, as well as additional information and resources.

[See the tip sheet](#)

FAMILY ENGAGEMENT

Survey of Peer Support in Pediatric Health Care Settings

The Parent Mentor Learning Center (PMLC), housed at Lucile Packard Children's Hospital Stanford, is recruiting peer mentor program volunteers, staff, and leadership to complete a survey on the current state of peer mentor programs in pediatric health care settings. The survey, supported by our Foundation, asks about the structure, characteristics, practices, and processes of peer mentor programs. Survey results will guide future PMLC activities and will be shared on the [PMLC website](#).

[Take the survey](#)

CHILDREN WITH MEDICAL COMPLEXITY (CMC)

State Use of Paraprofessional Providers for Children and Youth with Chronic and Complex Needs

Community-based paraprofessional providers can help states improve access to pediatric services and address workforce shortages for children with chronic and complex needs (CCCN). A new brief, produced by the National Academy for State Health Policy and supported by our Foundation, examines three states' cross-sector approaches to deploying paraprofessionals and identifies common strategies to help states expand this workforce to improve access to and quality of care for CCCN and their families.

[Read the brief](#)

Characterizing the Use of Home-based Behavioral Health Services Among Children in Foster Care

Children in foster care often require behavioral health services due to their high rates of mental health needs. Research funded by our Foundation analyzed mental health service utilization in 28 states among children with primary mental health diagnoses across three groups: foster care, disability, and low-income. The researchers found that home-based behavioral health service use was highest among children in foster care, and was associated with lower odds of hospitalization and emergency department visits as well as higher odds of school-based mental health services use. The study is published in *Children and Youth Services Review*.

[Read the article](#)

Scoping Review: Quality of Life Surveys Developed or Validated with CYSHCN

A scoping review recently published in *Quality of Life Research* examined survey measures of quality of life among CYSHCN. The researchers found that while surveys were developed and validated, few considered CYSHCN directly in the process, raising concerns about how accurately surveys address quality of life among CYSHCN. *Accessing the article requires login.*

[Read the article](#)

TRANSITION TO ADULT CARE

Town Hall Next Week on Young Adults with Chronic Conditions Leading Systems Change

Following a [series of roundtable discussions](#) over the past year, which explored the most pressing systemic challenges facing young adults with chronic and rare conditions, Generation Patient will host a virtual town hall to walk through the roundtable model of multidisciplinary collaboration, share the key themes that emerged, and discuss the process of young adult patients leading authorship for peer-reviewed publications. The roundtable series and this town hall are supported by our Foundation.

DATE/TIME: April 23 | 9-10am PT/12-1pm ET

[Register for the virtual town hall](#)

[Learn more about the roundtable series](#)

CALIFORNIA POLICY AND RESOURCES

Survey Seeks Parent and Caregiver Input on California Children's Services Program

A survey from the National Health Law Program (NHeLP) seeks to better understand family and caregiver experience with accessing services for their children through California Children's Services (CCS). The survey findings will be used to inform NHeLP's advocacy to improve the CCS program. The survey can be completed in English or Spanish and is open through **April 30**. All survey respondents have the option to participate in a raffle for three \$50 gift cards.

[Take the survey in English](#)

[Realice la encuesta en español](#)

CONFERENCES AND EVENTS

Pediatric Academic Societies Meeting 2026 | Grantee and Partner Sessions

From April 24-27, thousands of pediatric researchers, clinicians, and educators will convene in Boston for the Pediatric Academic Societies (PAS) Meeting. Several Foundation grantees and partners will lead sessions at PAS focused on health care for CYSHCN. We have shared session dates and titles of featured grantees and partners on our LinkedIn page.

[See our grantee and partner sessions on LinkedIn](#)

[Learn more about PAS 2026](#)

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