

Children and Youth with Special Health Care Needs NETWORK NEWSLETTER

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




PEDIATRIC SPECIALTY CARE

**New Fact Sheet Highlights Results of Caregiver Survey About
Accessing Pediatric Specialists**

Access to Care in California
The CYSHCN Family Experience

A total of 646 caregivers of children and youth with special health care needs (CYSHCN) across California were surveyed about new outpatient pediatric subspecialty visits in the last year to understand delays in care and their effects on families.



Wait Times for Pediatric Subspecialty Care

Families were asked how long they had to wait between referral to a subspecialist and the visit. Overall, 73% of families reported wait times that are longer than considered acceptable by the state. Overall, 19% of families reported wait times that are longer than considered acceptable by the state. Overall, 19% of families reported wait times that are longer than considered acceptable by the state.

Of concern, 23% of families experienced waits of more than 3 months for new appointments. For some subspecialties, wait times were even longer.


| Subspecialty | Wait Time | Percentage |
|---|----------------------|------------|
| All subspecialties* (n=642) | More than 3 months** | 23% |
| | 1-3 months | 51% |
| | 3 months | 26% |
| Developmental Behavioral Pediatrics (n=242) | More than 3 months** | 33% |
| | 1-3 months | 48% |
| | 3 months | 19% |
| Ear, Nose, and Throat (n=46) | More than 3 months** | 24% |
| | 1-3 months | 27% |
| | 3 months | 22% |
| Gastroenterology (n=25) | More than 3 months** | 36% |
| | 1-3 months | 40% |
| | 3 months | 24% |
| Neurology (n=42) | More than 3 months** | 27% |
| | 1-3 months | 52% |
| | 3 months | 21% |
| Ophthalmology (n=42) | More than 3 months** | 24% |
| | 1-3 months | 48% |
| | 3 months | 28% |
| Psychiatry (n=12) | More than 3 months** | 50% |
| | 1-3 months | 33% |
| | 3 months | 17% |

*In breaking down the wait times by open 10 subspecialties, some specialists included on the list cannot be used since they were too small to reliably estimate wait times. Number of people reporting on each subspecialty is noted as "n".

**The research indicates that wait times of more than 3 months indicate that patients have access to an appointment within 18 business days for non-urgent appointment needs and 3 business days for urgent care. Learn more at <https://www.aap.org/families/documents/families-access-to-specialty-care-report.pdf>

“[CYSHCN] waited 4 months to see a [developmental] specialist and during that time the gastroenterology fees were increased up and she hasn't gotten over a couple months since February.”

“Having to guess what might be causing [CYSHCN's] allergic reactions while we needed to see the allergist was stressful. Not knowing what we would do without an [CYSHCN] at the food is a severe reaction during the wait was also a huge concern. Until the appointment happened or plan for keeping my child safe and that was very unsettling.”



This fact sheet summarizes the results of a survey of nearly 650 caregivers of children and youth with special health care needs (CYSHCN) about their experiences trying to access pediatric specialty care in California. The voices of these caregivers provide crucial insight into the challenges they face and a fuller picture of:

- Wait times for pediatric specialty care
- Effects of delays in care for CYSHCN and their families
- Policy implications for California and beyond

[View the fact sheet](#)

Related resource:

- [Fact Sheet: California's Children Need Access to Pediatric Subspecialists - Provider perspectives on the issue](#)

SYSTEMS AND STANDARDS

Blueprint for Change Strategies: At-a-Glance Overview


The National Center for a System of Services for CYSHCN has published an easy-to-navigate list of the 40 strategies from the [Blueprint for Change: A National Framework for a System of Services for CYSHCN](#). The strategies are organized into four critical areas: health equity, family and child well-being and quality of life, access to services, and financing of services. The goal for implementing the strategies is to help transform our health care system into one that works for CYSHCN and their families.

[View strategies at AAP.org](#)

Related resource:

- [A National Health Systems Research Agenda for Children and Youth With Special Health Care Needs: Supplement to Academic Pediatrics](#)

FEATURED EVENT



AMCHP 2024

Full Schedule Now Available

The [full event schedule](#) is now available for the Association of Maternal & Child Health Program's 2024 annual conference. The event will be in a hybrid format again this year, and the **early bird registration deadline** has been extended to **February 26, 2024**. There are

several sessions and workshops focused on CYSHCN issues taking place throughout the conference, including: "Designing a Roadmap to Improve Coverage and Financing of Care for CYSHCN in Your State" and "Partnerships for Quality Improvement: The Impact of Statewide, Interdisciplinary Collaborative Partnerships for Improving Quality of and Access to Care for CYSHCN."

DATES: Friday, April 12 - Tuesday, April 16, 2024

LOCATION: Oakland Marriott City Center, Oakland, CA

[Register now](#)

PAST EVENT RECORDINGS

- [Medi-Cal Enhanced Care Management for Children and Youth](#) (National Health Law Program, 2/7/24)
- [The National Survey of Children's Health: New Data, Opportunities, and Directions](#) (Engaging Research Innovations and Challenges webinars, 12/5/23)



HOME- AND COMMUNITY-BASED CARE

Researchers Look at Durable Medical Equipment and Supplies Use in Children

Many children need durable medical equipment and supplies (DMES) for daily living. DMES can encompass a range of items, such as breathing and feeding equipment, but also more common aids like eyeglasses. A new study by a team from the [Children and Youth with Special Health Care Needs National Research Network \(CYSHCNet\)](#) aimed to address this knowledge gap by categorizing DMES. The team found that 1 in 6 children on Medicaid use DMES, and that the cost for the equipment represents almost 20% of all Medicaid spending for outpatient, community, and home health services. Findings also indicate, perhaps not surprisingly, that 61% of children with two or more complex chronic conditions use DMES.

[View the study at JAMA Network Open](#)

More news:

- [Caregiving Pressures Mount for Families of Those with IDD](#) (*Disability Scoop*, 1/22/2024)

PALLIATIVE CARE

Webinar: Palliative-Aware Anticipatory Guidance - NeuroJourney.org

This month's installment of the 2024 Pediatric Palliative Care Webinar Series explores the online tool [NeuroJourney.org](https://www.neurojourney.org), an educational resource for families and clinicians caring for children and youth with Severe Neurological Impairment. Intended as a roadmap for caregivers, the site blends guidance on the medical and psychosocial aspects of the disease trajectory with family-centered commentary.

SPEAKERS: Julie Hauer, MD & Jennifer Siedman, M.Ed

DATE/TIME: Tuesday, February 20, 2024 – 12:00 pm PT

[Register for webinar](#)

Palliative care news:

- **Register now** for the next event in the 2024 Pediatric Palliative Care Webinar Series on **Thursday, March 21, 2024:** [Navigating Facts and Values: Palliative Care in the Face of Significant Distress](#) - Speaker: Ian D. Wolfe, PhD, MA, RN, HEC-C
- [Incorporating Play for Children with Medical Complexity](#) (Pediatric Palliative Care Coalition Newsletter, Jan. 2024)

FAMILY ENGAGEMENT

Family-Centered Care Matters for CYSHCN, but Many Families Report Challenges with Providers

The Population Reference Bureau (PRB) has provided commentary on an analysis of [National Survey of Children's Health](#) data in which researchers from the University at Albany, SUNY, Penn State University, and SRI International examined disparities in receiving high-quality, family-centered care among families of CYSHCN in the United States. [The study](#) found that socioeconomic factors, rather than race or ethnicity, were the most consistent drivers of disparities in access to family-centered care. Recommendations for policymakers for addressing these disparities include adopting comprehensive, coordinated approaches to care to increase provider engagement, cultural responsiveness, and shared decision-making.

[Read commentary at PRB.org](#)

More news:

- [These Lessons Give Children with Chronic Illnesses a Chance to Be a Guitarist, Actor or Chef](#) (*California Health Report*, 2/5/24)
- [EP Annual Healthcare Issue: Parenting Takes a Village](#) (*EP Magazine*, Feb. 2024)
- [New Kind of Classroom for Sick Kids](#) (Reno KTVN 2 News, 1/17/24)

NATIONAL POLICY

New Research Suggests Children with Special Health Care Needs Are More Likely to Be Underinsured

Researchers at Children’s Hospital of Philadelphia’s PolicyLab studied the prevalence of underinsurance, or inadequate or inconsistent health coverage, among CYSHCN. Their results showed that, as children’s health care needs grow in complexity, they are more likely to be underinsured. The study also found that underinsurance is a problem particularly for middle-income households.

[View the study at JAMA Network Open](#)

More national policy news:

- [Census Bureau Halts Planned Changes to Disability Survey Questions](#) (KFF Health News, 2/7/24)
- [Insurance Doesn’t Always Cover Hearing Aids for Kids](#) (CBS News Healthwatch, 1/11/24)
- [Thousands of Children Potentially Eligible for Supplemental Security Income Aren’t Getting It: Medicaid Data Could Help Find Them](#) (Mathematica, 12/31/23)

CALIFORNIA POLICY

Join the Medi-Cal Unwinding Feedback Loop Monthly Meetings to Share Experiences and Concerns

If you work with California communities on Medi-Cal or assist individuals and families with Medi-Cal enrollment and renewals, you are invited to a series of virtual feedback loop meetings hosted by The Children’s Partnership and the National Health Law Program and supported in part by the Lucile Packard Foundation for Children’s Health. The goal of the monthly meetings is to identify and help address issues and concerns with the Medi-Cal renewal process.

DATES/TIMES: All meetings are at 12:00 pm PT.

- Wednesday, February 28, 2024
- Wednesday, March 27, 2024
- Wednesday, April 24, 2024
- Wednesday, May 22, 2024

[Register for Feedback Loop meetings](#)

More CA policy news:

- [California Holds Medi-Cal Plans Accountable for Ensuring Members Have Access to High-Quality, Equitable Care](#) (DHCS, 2/14/24)

- [Fact Sheet: Medi-Cal Enhanced Care Management for Children and Youth](#) (National Health Law Program, 1/29/24)
- [Blog Post: A Lifeline for Families of Children With Special Health Care Needs](#) (The Children's Partnership, 1/17/24)
- [The 2024 California Children's Report Card](#) (Children Now, 12/31/23)

WE WANT TO HEAR FROM YOU

Let us know what's happening with your organization or program. Send your news and updates to Kristen Rogers, Assistant Communications Director, Programs & Partnerships, at info@lpfch.org. Thank you!

To see past issues, visit our [Newsletter Archive](#). If you were forwarded this newsletter and would like to receive it monthly, click the subscribe button below.

Subscribe to CYSHCN News

[Manage](#) your preferences | [Opt Out](#) using TrueRemove™

Got this as a forward? [Sign up](#) to receive our future emails.

View this email [online](#).

400 Hamilton Ave, Suite 340 | Palo Alto, CA 94301 US

This email was sent to kristen.rogers@lpfch.org.

To continue receiving our emails, add us to your address book.