

Access to Care in California

The CYSHCN Family Experience

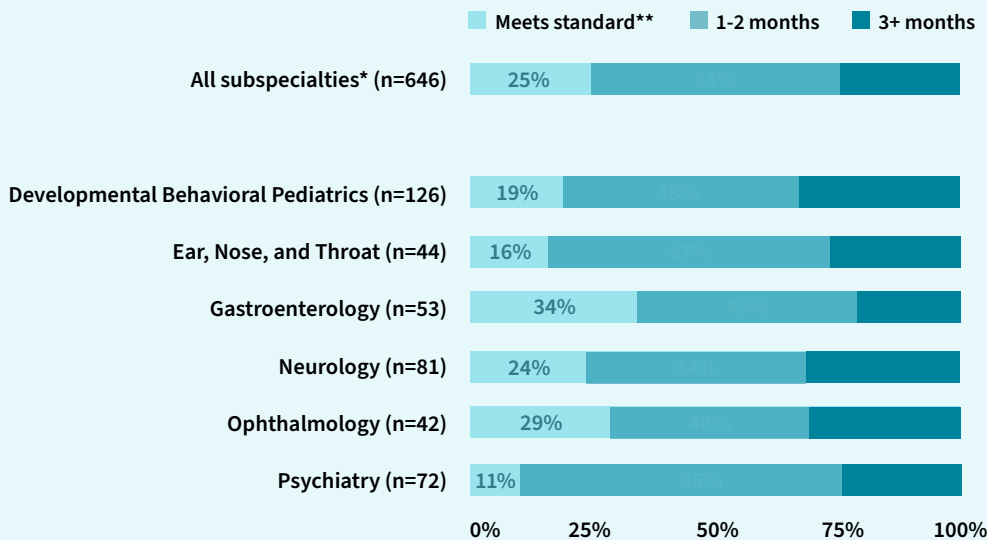


A total of **646 caregivers** of children and youth with special health care needs (CYSHCN) **across California were surveyed** about new outpatient pediatric subspecialty visits in the last year **to understand delays in care and their effects on families.**

Wait Times for Pediatric Subspecialty Care

Families were asked how long they had to wait between referral to a subspecialist and the visit. Overall, **75% of families reported wait times that are longer than considered acceptable by the state** (based on the Department of Health Care Services' Network Adequacy Standards [NAS]).

Of concern, **25% of families experienced waits of more than 3 months for new appointments.** For some subspecialties, wait times were even longer.



* In breaking down the wait times by specific subspecialties, some specialties included in the total estimate had sample sizes that were too small to reliably estimate wait times. Number of people reporting on each subspecialty is noted as "n=#".

** The Network Adequacy Standard (NAS) requires that California health plans ensure that patients have access to an appointment within 15 business days for non-urgent appointments and 3 business days for urgent ones. Learn more at <https://www.dhcs.ca.gov/formsandpubs/Documents/FinalRuleNAFinalProposal.pdf>

“ [Child] waited 8 months to see a [Gastroenterologist], and during that time her gastrostomy-tube feeds were messed up and she hasn't gained even a couple ounces since February.

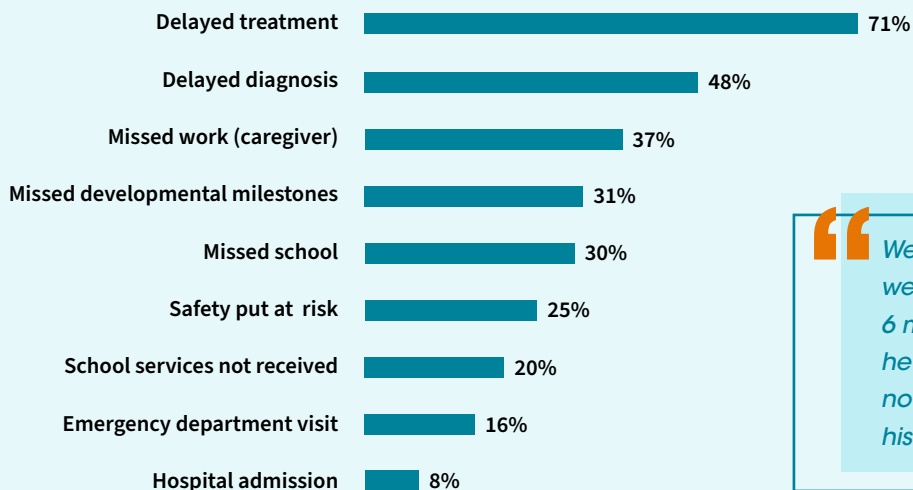
“ Having to guess what might be causing [child's name]'s allergic reactions while we waited to see the allergist was stressful. Not knowing what we would do without an EpiPen if he had a severe reaction during the wait was also a huge concern. ...Until the appointment I lacked a plan for keeping my child safe and that was very unsettling.



Effects of delays in care

In addition to delayed diagnosis and treatment, **not receiving care on time leads to missed work and school for many families.** In this study, one-quarter of caregivers also reported that not accessing a pediatric subspecialist on time **put their child's safety at risk.**

All responses reflect effects on the child, unless caregiver is specified (n=404)



Some families who have the means reported choosing to pay out of pocket for office visits and diagnostic evaluations to get more timely service. In addition, families are reporting **sizable expenses from emergency departments, home care supplies, and missed workdays** resulting from delays in care.



“ We still have referrals for appointments that we have been on the waiting list for over 6 months. If we didn't have to wait so long, maybe he would be eating, communicating or walking now. ...All of this could have lifelong effects on his development.

“ The impacts on the family have been very detrimental due to not having the right diagnosis and having to wait months [or] even a year to get [an] appointment and [the] right diagnosis. I have been laid off from work or fired due to the number of times that I have had to call in to handle a crisis with my child.

“ [We paid] \$300 for two ER visits that did not solve the situation.

“ We've had to pay around \$10k to see specialists faster than ones our insurance covered.

Policy Implications:

- Families of CYSHCN and chronic conditions in California are facing significant delays in access to pediatric subspecialty care.
- Timely access to care is essential, especially for kids with complex health care needs, who are facing harmful delays in treatment and diagnosis that may impact their development and results in missed school and work days.
- There are many possible drivers of delayed access to care. One is low Medi-Cal rates, which are the underpinning of reimbursement to support pediatric subspecialists. Reimbursement rates need to be sufficient to recruit and retain pediatric subspecialists.¹

About this survey:

Data are from a web-based survey of caregivers of children and youth with special health care needs conducted by the UCSF Center for Excellence in Primary Care and Practical Research Solutions in partnership with 17 Family Resource Centers across California from August to October 2023.

Of the children and youth represented in the survey, 76% were covered by Medi-Cal and 49% were 5 years old or younger. Participants were from Southern California (28%), the Central Valley (12%), the Central Coast (23%), and Northern California (37%). More on methods is available at <https://cepc.ucsf.edu/children-and-youth-special-healthcare-needs>. Support for this work was provided by the Lucile Packard Foundation for Children's Health. The views presented here are those of the author and do not reflect the views of the Foundation or its staff. Learn more at lpfch.org/CSHCN.

¹ National Academies of Sciences, Engineering, and Medicine. 2023. The Future Pediatric Subspecialty Physician Workforce: Meeting the Needs of Infants, Children, and Adolescents. Washington, DC: The National Academies Press. <https://doi.org/10.17226/27207>.