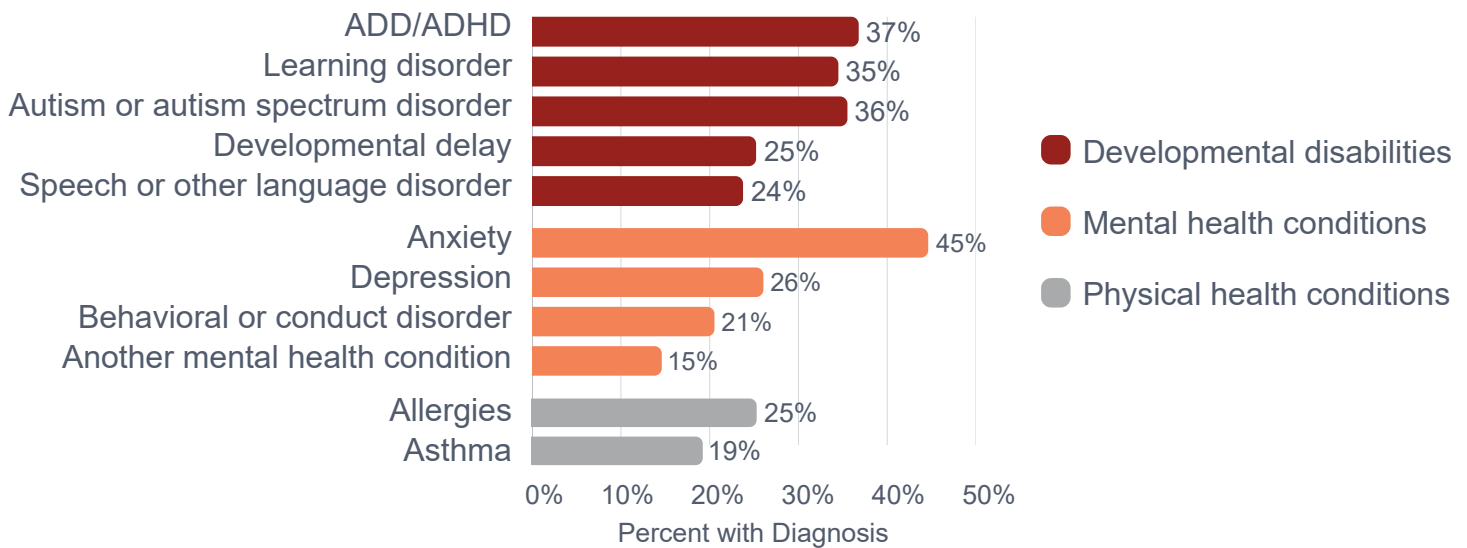


Unmet Need for Services Among Children with Complex Health Needs

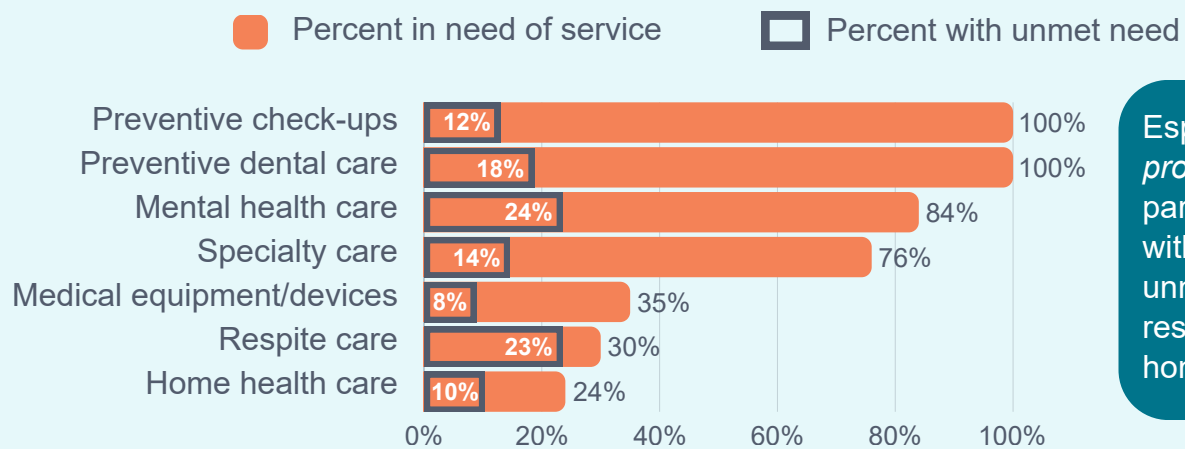


A 2025 national survey of parents showed that families of children with complex health needs (CHN)¹ faced extensive challenges while seeking a range of services and navigating the health care system.

Most Frequently Diagnosed Conditions Among Children with CHN²

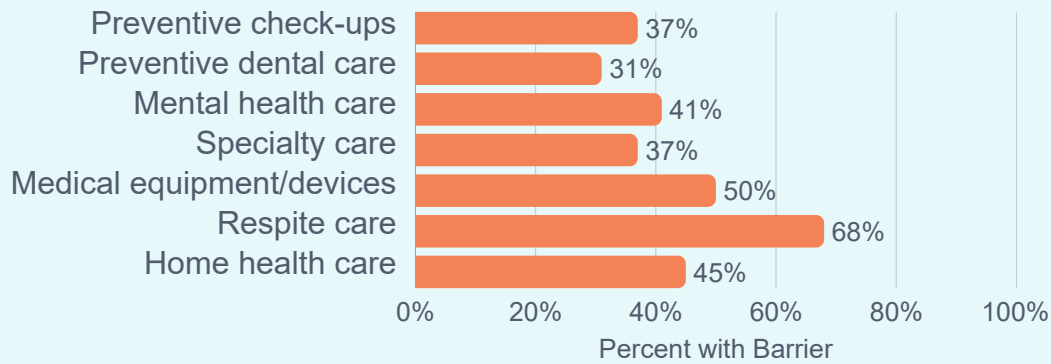


Percentage of Children with CHN who Have Unmet Health Care Needs³



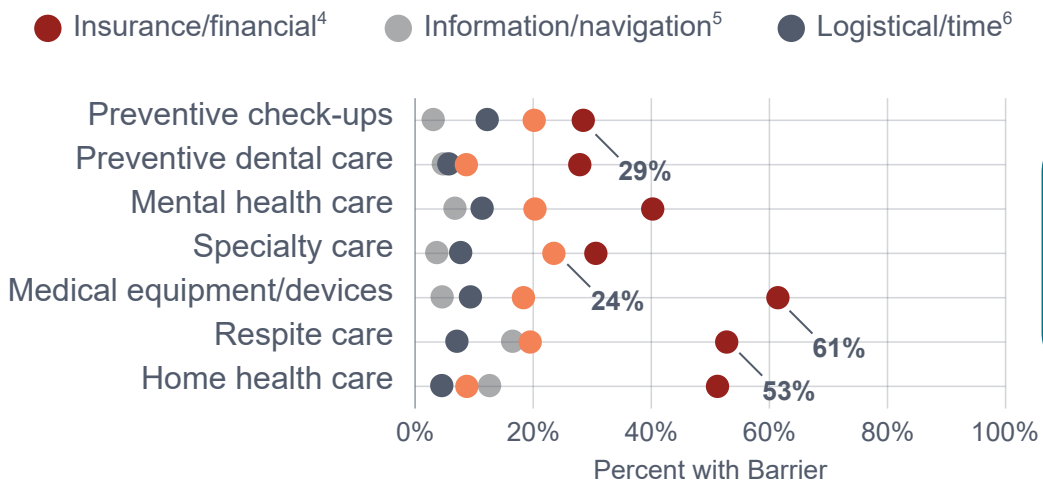
Especially *high proportions* of parents of children with CHN report unmet need for respite care and home health care.

Percentage of Children with CHN who Experienced One or More Barriers to Health Care Services in the Past 12 Months



More than two-thirds of parents of children with CHN who needed respite care experienced at least one barrier to receiving it.

Barriers to Health Care Services by Service Type



Challenges with insurance and cost were the most frequently reported barriers across all services.

“It’s a full-time job [to coordinate care for my child]. One full-time job with finding the insurance, finding the doctors, then getting him [to appointments] and making sure the meds are taken like they’re supposed to. And then you work a job, and then you come home, and you participate in the physical care. It’s three full-time jobs. It’s extremely stressful, and it’s physically demanding. And financially it’s – I can’t even speak on the financial part because I have no idea. I just funnel money to whoever sends me a bill, it seems like. Here, have it all.” - Parent Focus Group Participant

1. Children with complex health needs (CHN) were defined as those who screened positively on four or five of the criteria on the [Child and Adolescent Health Measurement Initiative’s screening instrument](#).
2. Frequencies are based on children with CHN in the sample.
3. Survey respondents were asked if, in the last 12 months, their child needed a given service (with the exception of preventive check-ups and dental care, which are recommended for all children). Respondents who reported that their child needed a service were then asked if “all”, “some”, or “none” of the needed service was received. We identified children with “unmet need” as those who received either “some” or “none” of the needed service.
4. Insurance/financial barriers included that their child’s insurance did not cover a service, they could not get a referral, they could not find a provider who accepted their child’s insurance, they had another problem with the insurance plan, or they had issues related to the cost of a needed service.
5. Information/navigation barriers meant they did not know where to go for their child to receive a service.
6. Logistical/time barriers included transportation barriers or responsibilities at home, school, or work that conflicted with appointments.
7. Service availability barriers included that the service was not available in their area or they experienced long wait times to get appointments.

About this study:

In January 2025, NORC at the University of Chicago conducted a national survey of 1,316 parents of children and youth with special health care needs (CYSHCN), aged 0 to 25. CYSHCN were identified using the [Child and Adolescent Health Measurement Initiative’s screening instrument](#). NORC conducted focus groups and interviews with survey respondents to learn more about their experiences with navigating the health care system for their children and caring for their children’s needs. Read more about the study and access all findings [here](#).

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: jpfch.org/CSHCN