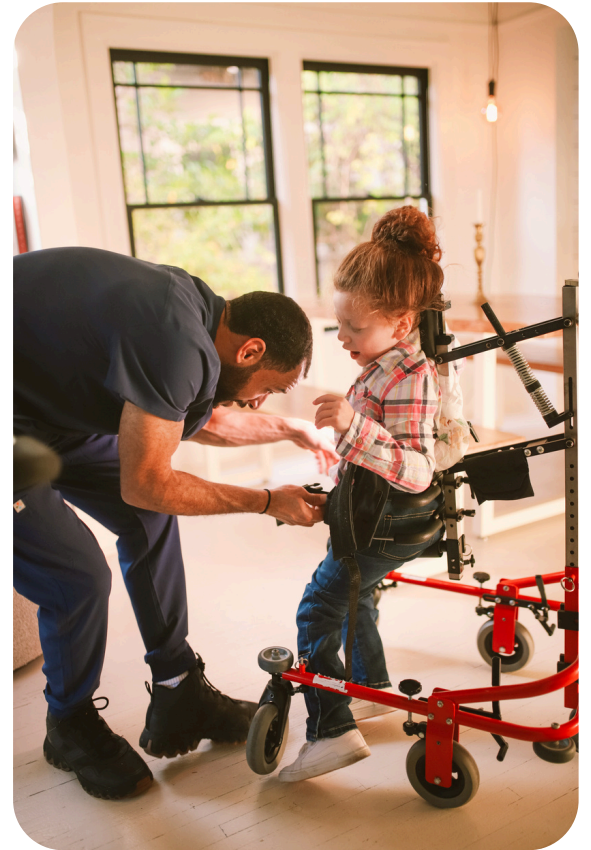


Unmet Need for Home Health Care

A 2025 national survey captured the home health care experiences of families of children and youth with special health care needs (CYSHCN),¹ including receipt of needed services, barriers to care, and impacts of forgone services.

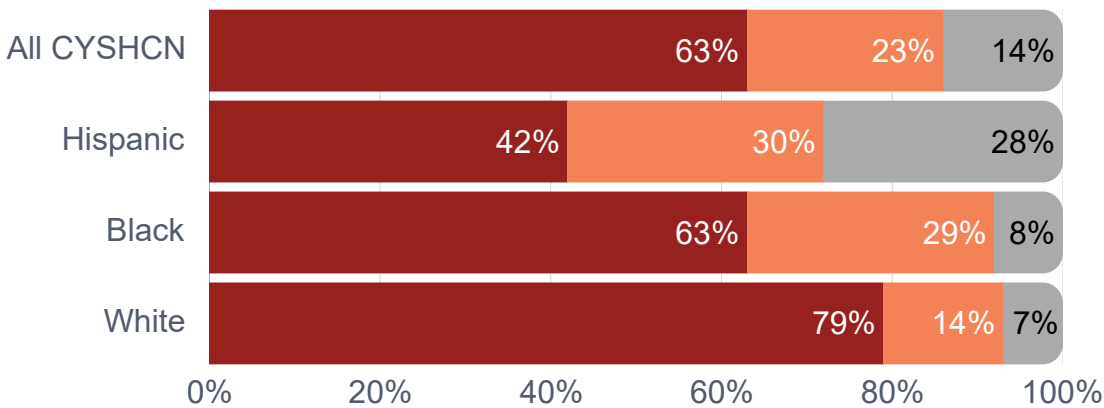


1 in 5 CYSHCN
needed home health care in the past 12 months



Percentage of CYSHCN Who Received All, Some, or None of the Home Health Care They Needed, by Race/Ethnicity

- Received all of the home health care needed
- Received some of the home health care needed
- Received none of the home health care needed



Hispanic CYSHCN had the highest level of unmet need² for home health care with 28% receiving none of the home health care needed.

Nearly 40% of CYSHCN did not receive all the home health care they needed.

Among CYSHCN who did not receive all the home health care they needed:



31% could not obtain a referral from a doctor or health plan

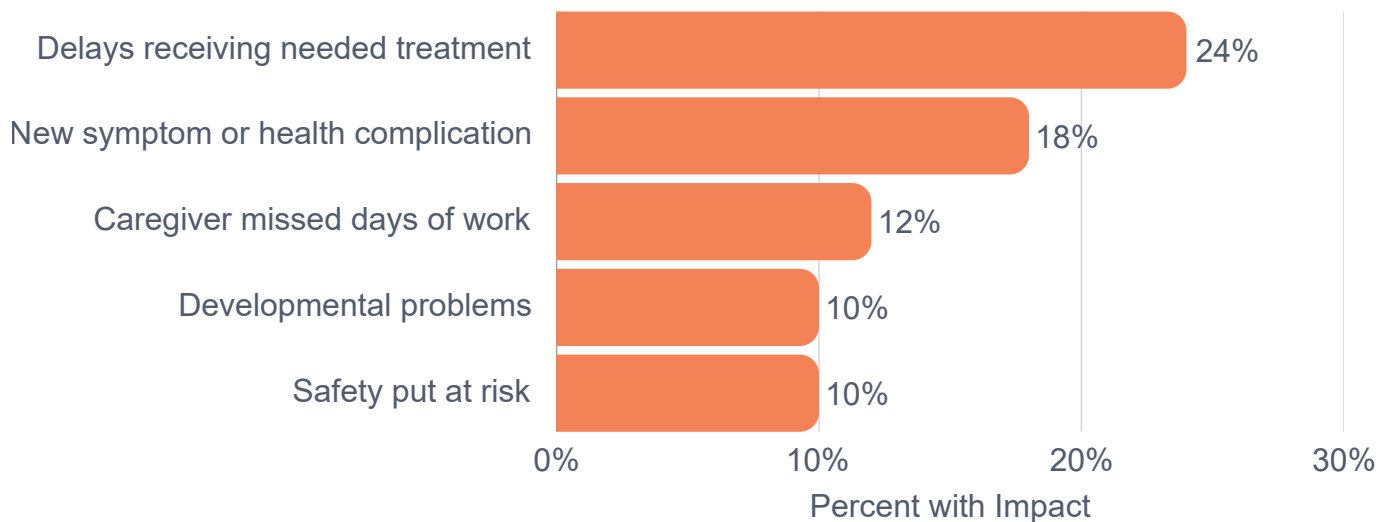


16% could not find a provider who accepted their insurance



16% encountered barriers due to the cost of the service

Impacts of Unmet Need for Home Health Care



“I actually had to quit my job just to be at home. [Leaving the workforce takes] a lot out of the household, and one income is bad when it's three people. We can't afford in-home health care services, and it's not provided by the insurance company ... It seems like you have no help.” - **Parent Focus Group Participant**

1. CYSHCN are defined by the Maternal and Child Health Bureau as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (McPherson et al., 1998).
2. 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.

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/CYSHCN