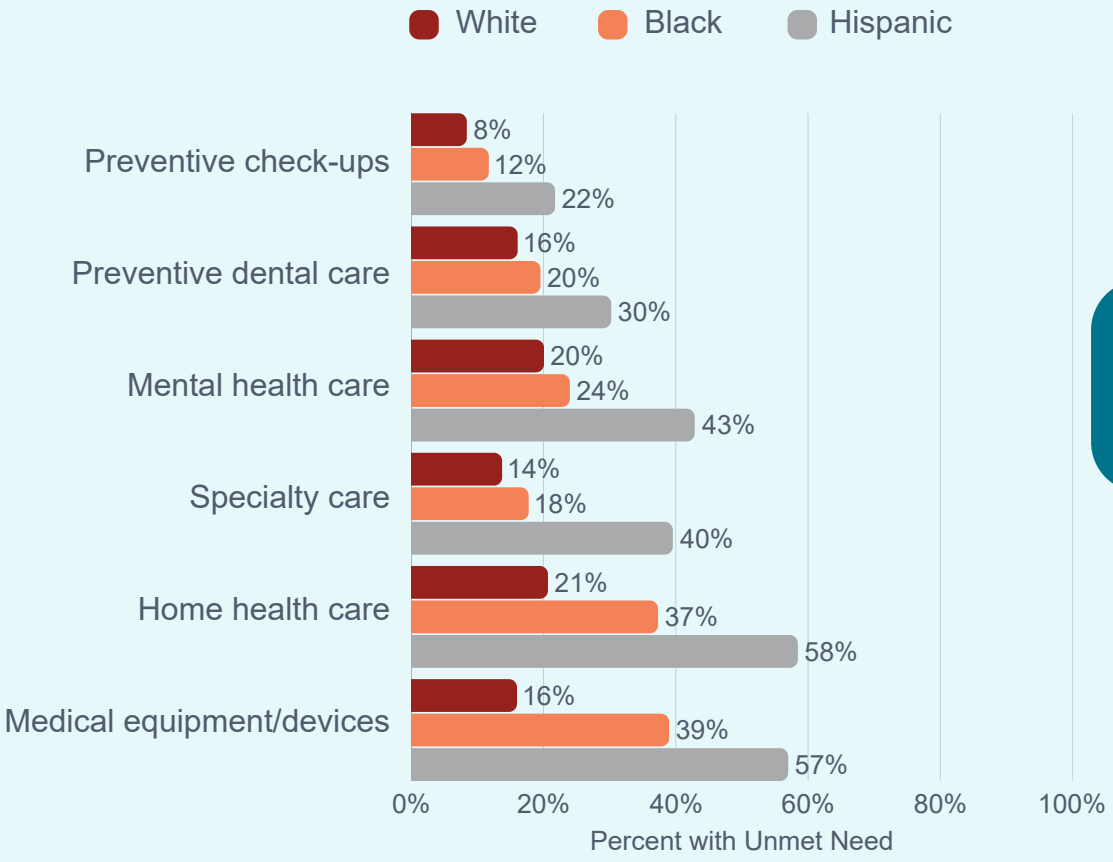
Racial and Ethnic Disparities in Receipt of Needed Services

A 2025 national survey of parents of children and youth with special health care needs (CYSHCN)[1] revealed racial and ethnic disparities in receipt of needed services, spanning preventive to specialty care.

Percentage of CYSHCN with Unmet Needs[2] for Health Care Services by Race/Ethnicity



Hispanic CYSHCN had the highest rates of unmet needs across all services.

Racial and ethnic disparities in receipt of needed services are greater for more specialized needs, such as home health care and medical equipment and devices.

Lucile Packard Foundation
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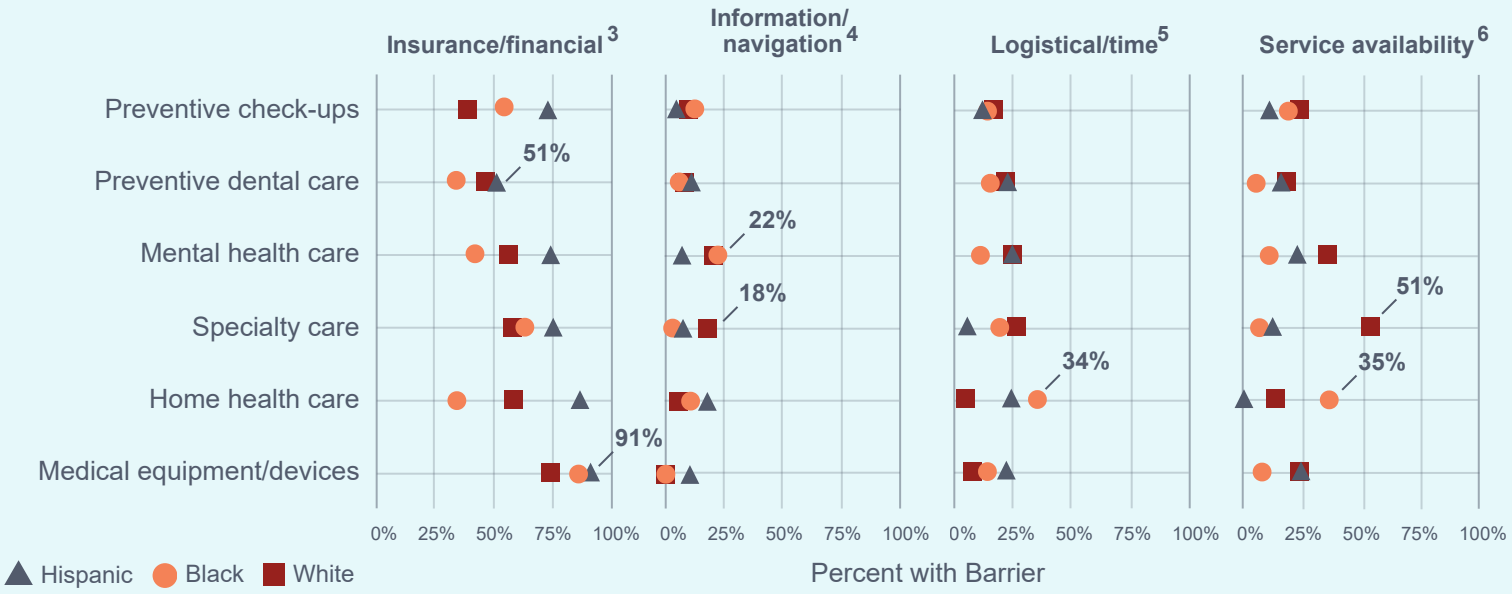
Barriers to Care by Service Type and Race/Ethnicity



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

Insurance and financial barriers were the most common obstacles across all racial and ethnic groups.

Seventy-five percent or more of White, Black, and Hispanic CYSHCN had insurance or financial barriers to obtaining **medical equipment or devices**.

Hispanic families experienced the highest rates of insurance and financial barriers across all service types (ranging from 51% to 91%).

> "Going to a specialist [is frustrating]. I never know what insurance is going to cover... I'll pay a copay, and we'll get some bill and it's more than the copay. So, then I have to call insurance, and argue [with them]." **- 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.
3. 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.
4. Information/navigation barriers meant they did not know where to go for their child to receive a service.
5. Logistical/time barriers included transportation barriers or responsibilities at home, school, or work that conflicted with appointments.
6. 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.

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