

Survey of Parents of Children and Youth with and without Special Health Care Needs



Lucile Packard Foundation for Children's Health (LPFCH)

September 2025

LPFCH commissioned a NORC survey of parents to analyze the experiences of children and youth with special health care needs and their families, focusing on barriers, care satisfaction, and helpful resources

About the survey

The survey, data collection, and analysis provided by NORC will inform the Foundation's strategic priorities, grant-making focus areas, and ongoing investments to ensure alignment with the needs and care experiences of Children and Youth with Special Health Care Needs (CYSHCN) and their families as well as disparities in these experiences compared to children and youth without special health care needs.

The survey investigated six primary domains:

- Experiences with Health Care Services
- Discrimination and Delayed/Mis-Diagnoses
- Experiences Traveling to Appointments/Wait Times
- Experiences with Peer Supports
- Pre-Transition Experiences
- Post-Transition Experiences

NORC leveraged the AmeriSpeak® panel to survey 4,464 individuals

Funded and operated by NORC at the University of Chicago, **AmeriSpeak®** is a probability-based panel designed to be representative of the US household population.

NORC analyzed the survey responses across a variety of different demographic subgroups, including race and ethnicity and age.



Sample Information

- **Total respondents:** 4,464
- **Population:** U.S. adults who have at least one child under the age of 26 and were familiar with their child's health and health care

Data Collection

- **Survey period:** January 10, 2025 - February 6, 2025
- **Median completion time:** 10 minutes
- **Modes:** Web (99%) and Phone (1%)
- **Language:** English (95%) and Spanish (5%)
- **Focus Groups:** 16 parents of children and youth with special health care needs

Survey participants and their children represented diverse demographic groups and characteristics of interest

Child Age		Child Gender Identity		Child Race/Ethnicity		Child Insurance Type	
0-5	24%	Female	47%	White	48%	Public only	30%
6-11	27%	Male	51%	Hispanic	21%	Private only	64%
12-15	20%	Transgender		Black	12%	Public & Private	2%
16-25	29%	Non-binary	1%	Other	19%	Uninsured	4%
		Gender Fluid				Other	1%

Survey participants and their children represented diverse demographic groups and characteristics of interest

Household Income	Metro Status	Region
<\$30K17%	Metro Area87%	Northeast16%
\$30K - <\$60K20%	Non-Metro Area13%	Midwest21%
\$60K - <\$100K22%		South39%
\$100K +41%		West24%

NORC also analyzed the survey data and stratified the results of all survey questions on the basis of medical complexity and insurance status.

Medical Complexity

Non-complex CYSHCN: children with scores ranging from 1-3 on the CAHMI screener.

Complex CYSHCN: children with scores ranging from 4-5 on the CAHMI screener.

Insurance Status

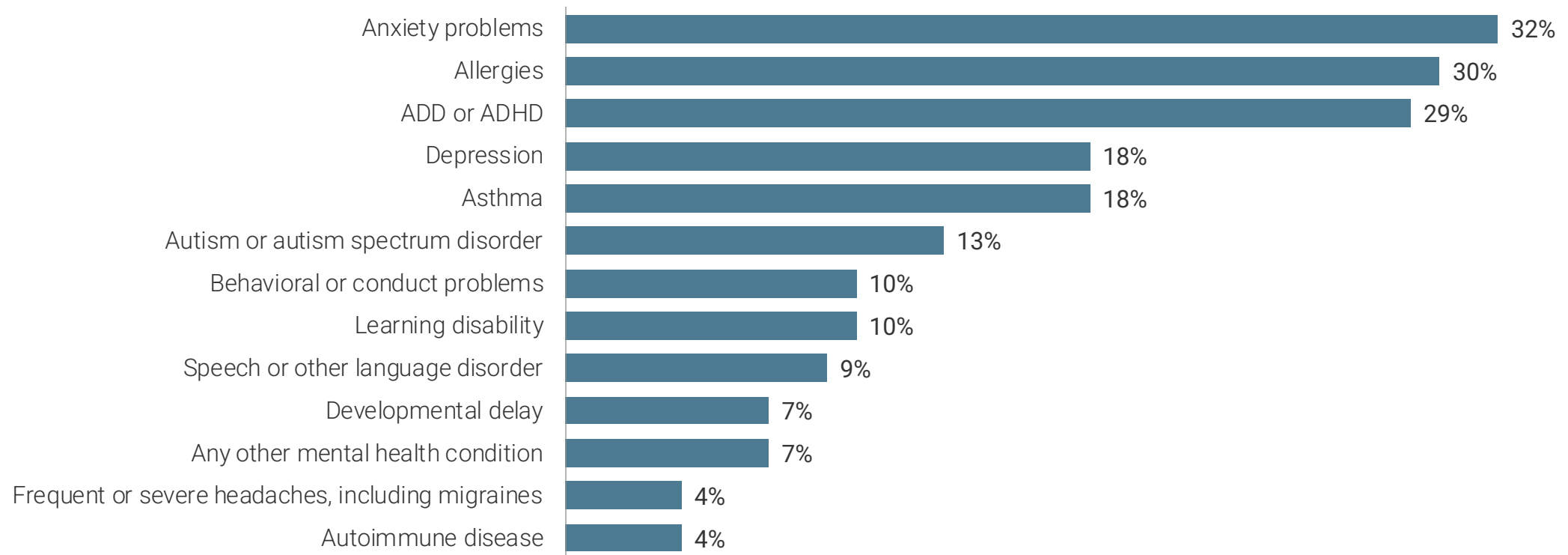
CYSHCN with private insurance: includes those with insurance through a current or former employer or union, insurance purchased directly from an insurance company, TRICARE or other military health care, and Indian Health Service.

CYSHCN with public insurance: includes those with Medicaid, Medical Assistance, or any kind of government assistance plan for those with low incomes or a disability.

* Neither of these groups includes individuals who have both insurance types, those who are uninsured, or those with other types of insurance.

Respondents with a child with special health care needs* reported a variety of different diagnoses for their children

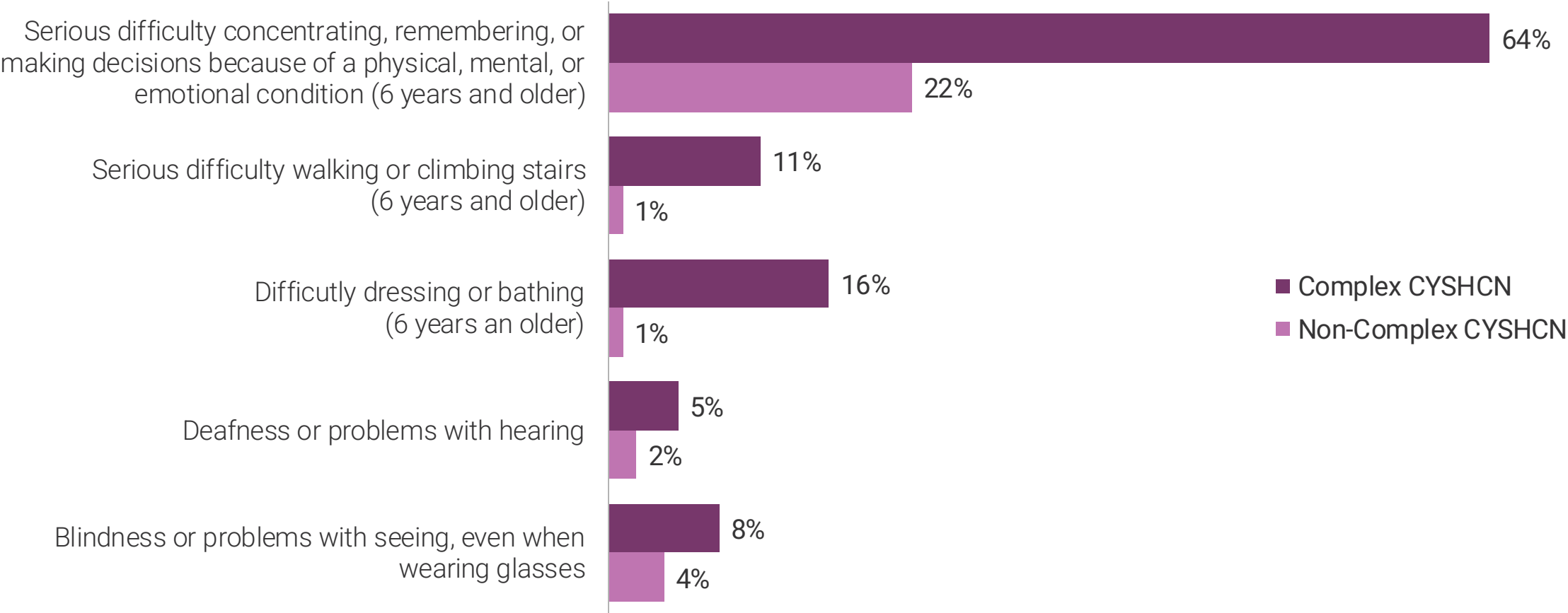
Parent-Reported Diagnosed Health Conditions Among CYSHCN



*Identified by use of the Child and Adolescent Health Measurement Initiative (CAHMI) Children with Special Health Care Needs (CSHCN) Screener
Q: Does your child currently have any of the following conditions that have been diagnosed by a doctor or other health care provider?

Complex CYSHCN were more likely than non-complex CYSHCN to have functional limitations.

Parent-Reported Functional Limitations Among CYSHCN with and without Complex Needs



Q: Does your child currently have any of the following conditions that have been diagnosed by a doctor or other health care provider?
All comparisons are statistically significant at p<0.05

Surveying parents of both CYSHCN and other children offered key insights into the health care experiences of CYSHCN and their families

Survey results revealed that CYSHCN:



Receive less of the care they need across different types of health care services



Face more barriers getting the care they need



Experience worse impacts from not receiving the care they need



These challenges are compounded for Black and Hispanic CYSHCN and their families

Experiences with Health Care

Respondents reported on their experiences with health care services, barriers to access, and the impact of those barriers

Health Care Services

- Preventive check-ups
- Preventive dental Care
- Mental health care/counseling
- Specialty care
- Home health care
- Medical equipment/devices
- Respite care

Access Barriers

- Insurance didn't cover service
- Lack of doctor referral
- No provider accepted child's insurance
- Child's health insurance issues
- Didn't know where to go for service
- Service not available locally
- Transportation problems
- Long wait time
- Cost issues
- Conflicting life responsibilities

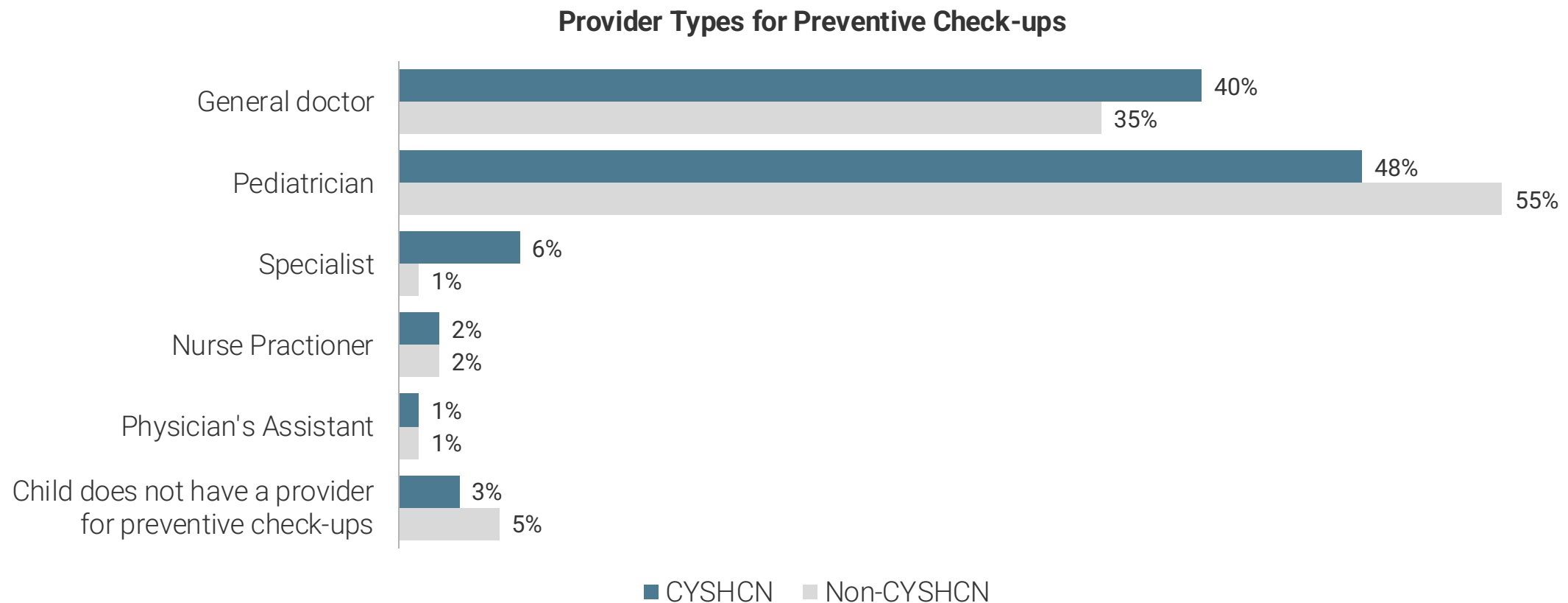
Impacts of Barriers

- Worsening symptoms
- Developmental issues
- New symptom/complication
- Delayed diagnosis
- Delayed treatment
- Missed school days
- Lack of needed services from school
- Safety at risk
- ER visit
- Overnight hospital stay
- Caregiver missed work

Preventive Care



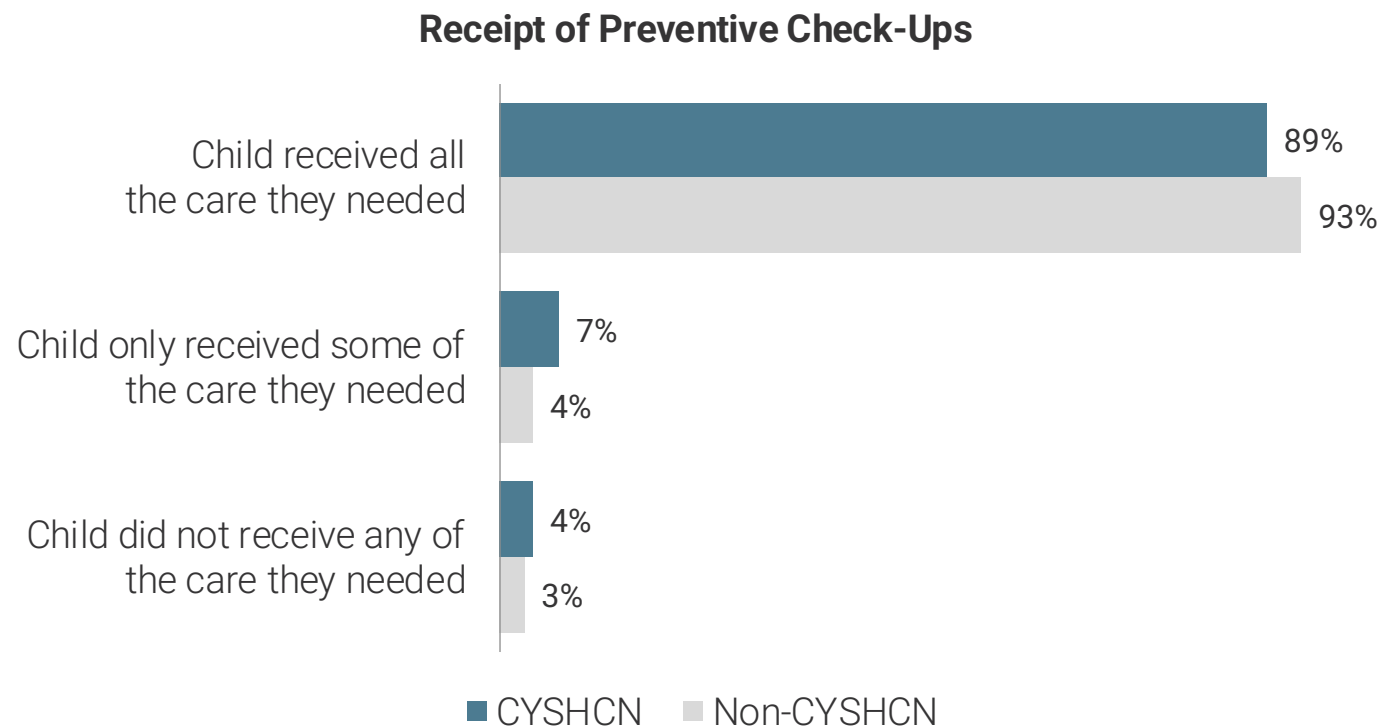
For children's preventive care, respondents used various provider types, with CYSHCN more often seeing specialists



Q: What kind of health care provider does your child usually see for preventive check-ups? A preventive check-up is an appointment when this child was not sick or injured, such as an annual or sports physical, or well-child visit.

All comparisons are statistically significant at $p < 0.05$

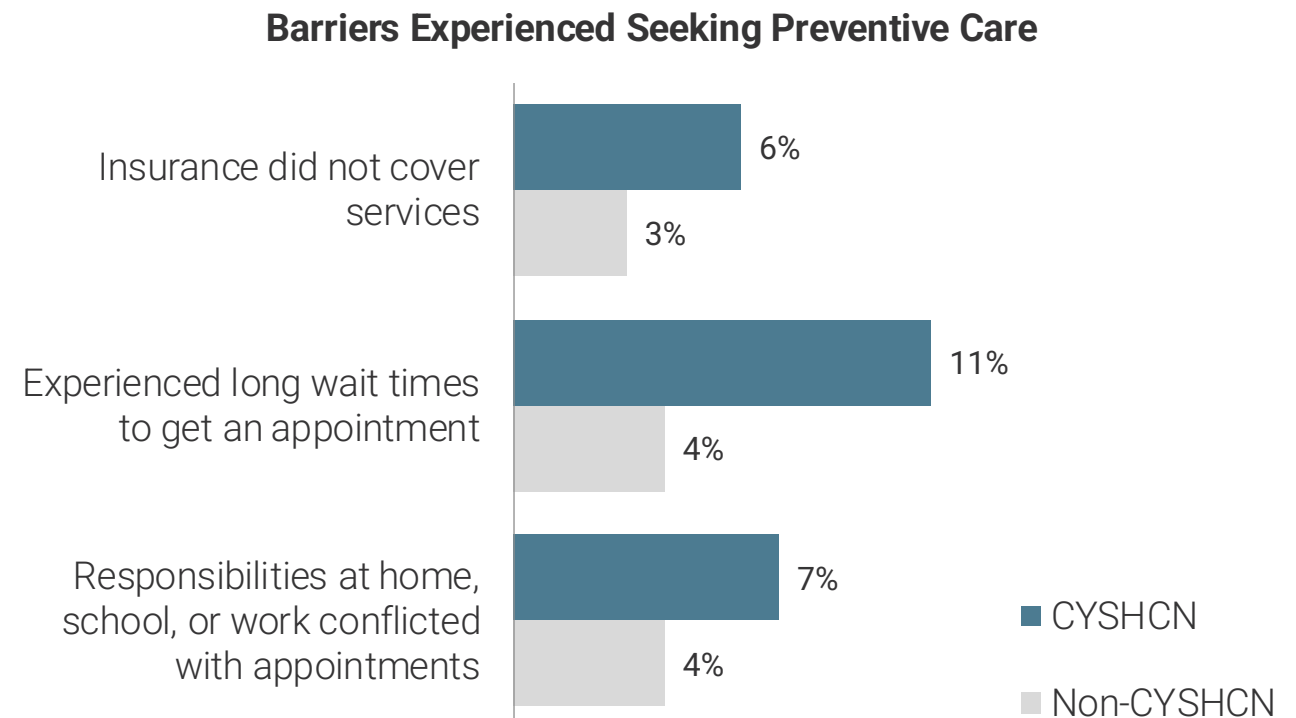
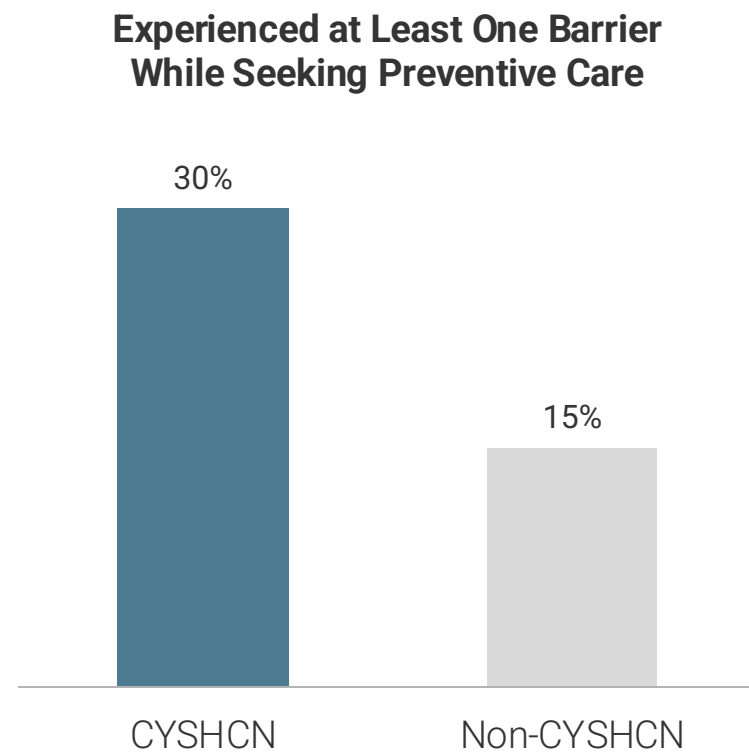
Compared to other children, CYSHCN were less likely to get the preventive care they needed



11% of CYSHCN did not receive all the preventive check-ups they needed.

Hispanic CYSHCN (21%) and Black CYSHCN (12%) were more likely than white CYSHCN (8%) to have unmet preventive care needs.

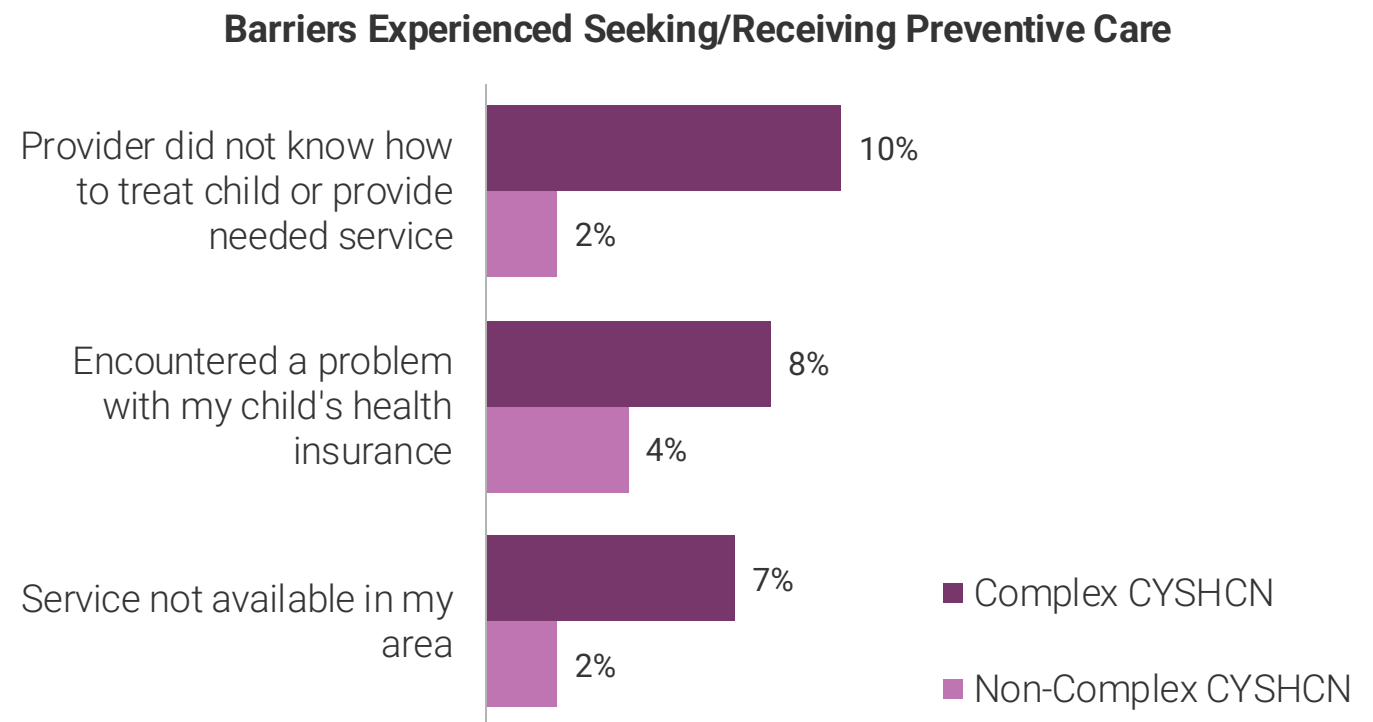
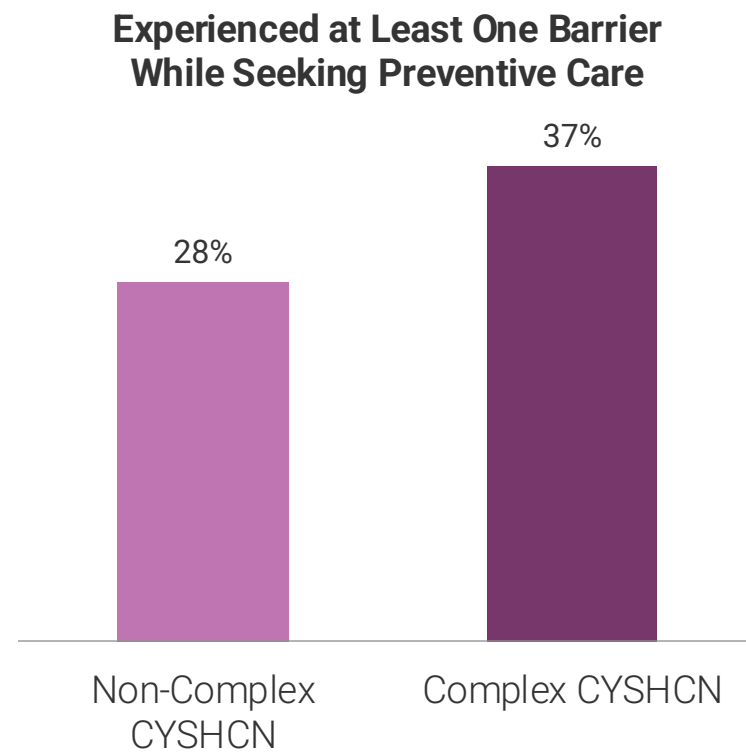
CYSHCN were twice as likely as other children to experience barriers to preventive check-ups, such as long waits and insurance challenges



Q: In seeking preventive check-ups for your child [during the past 12 months/since their birth], did you [or your child] experience any of the following challenges?

All comparisons are statistically significant at $p < 0.05$

Complex CYSHCN were more likely to experience barriers accessing preventive check-ups than non-complex CYSHCN. The most common barrier was having a provider who did not know how to treat the child.

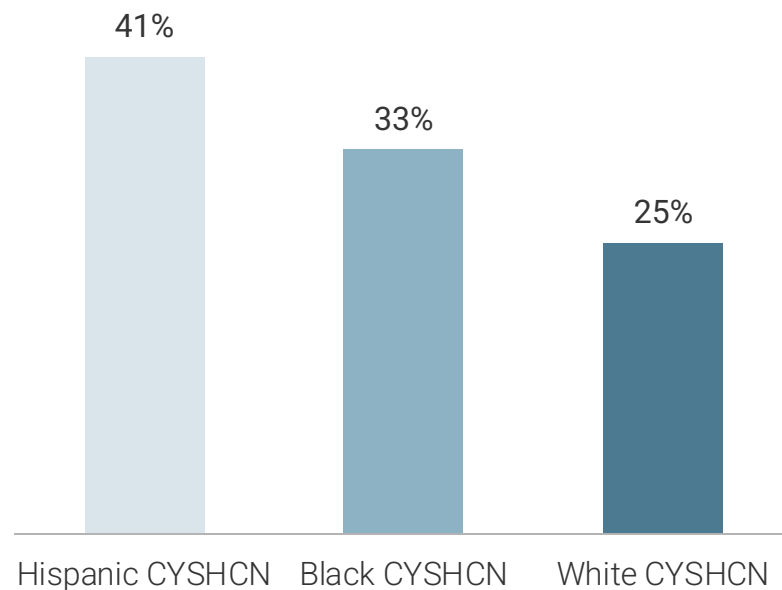


Q: In seeking preventive check-ups for your child [during the past 12 months/since their birth], did you [or your child] experience any of the following challenges?

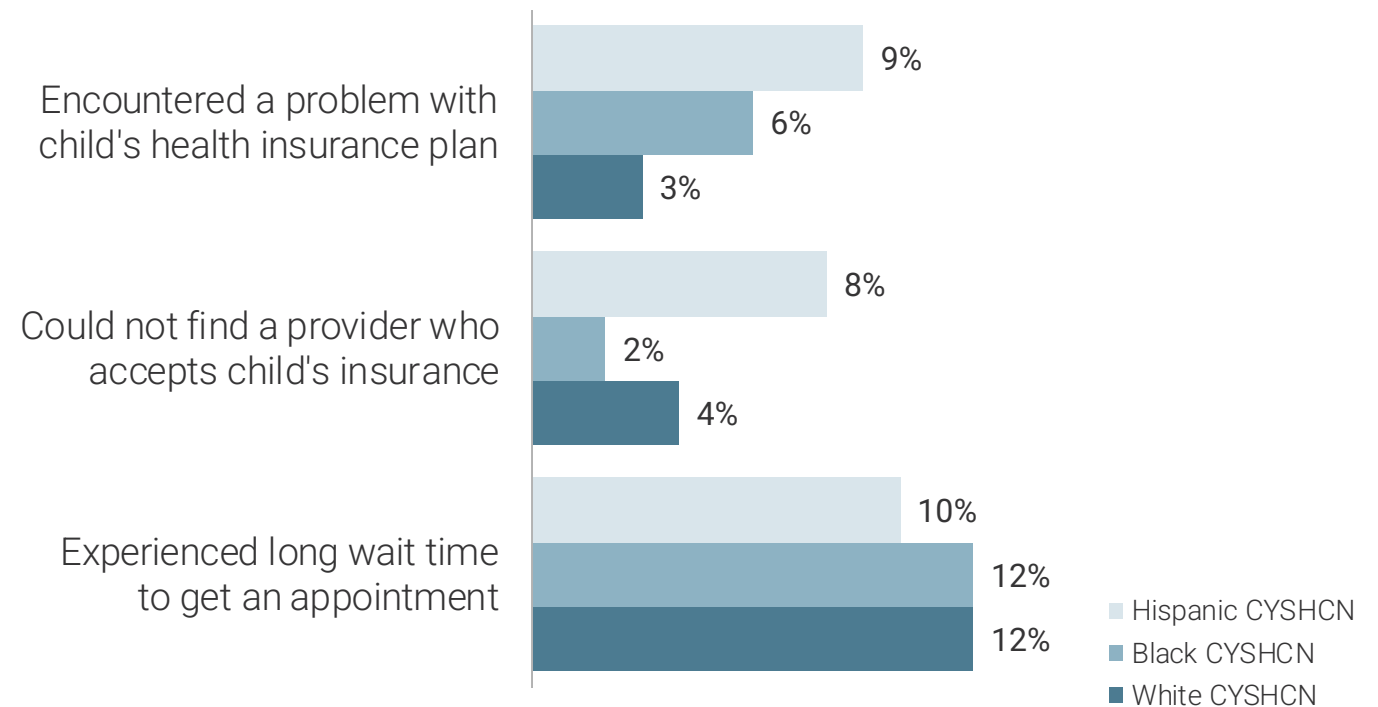
All comparisons are statistically significant at $p < 0.05$

Black and Hispanic CYSHCN faced more barriers to preventive check-ups than white CYSHCN, including finding providers who accept their insurance

Experienced at Least One Barrier While Seeking Preventive Care - Race/Ethnicity



Barriers Experienced Seeking Preventive Care -Race/Ethnicity

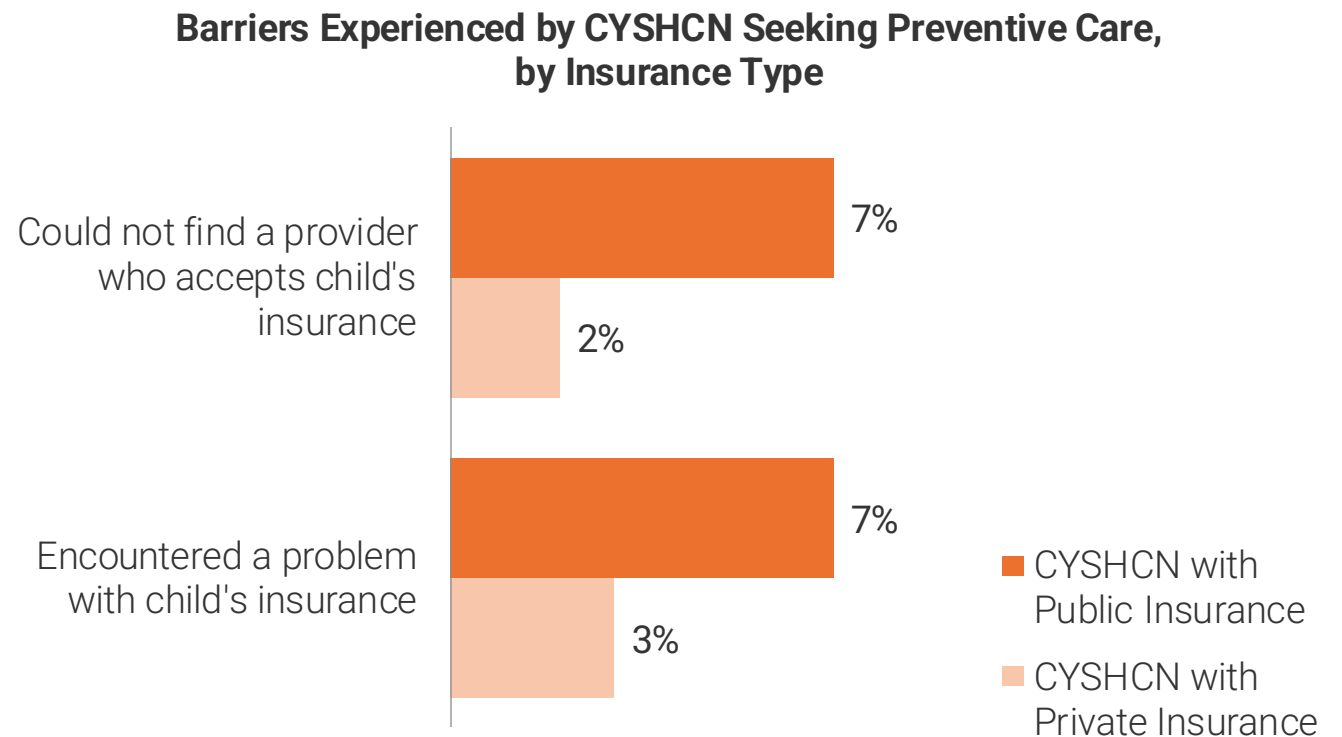


Q: In seeking preventive check-ups for your child [during the past 12 months/since their birth], did you [or your child] experience any of the following challenges?

All comparisons are statistically significant at $p < 0.05$

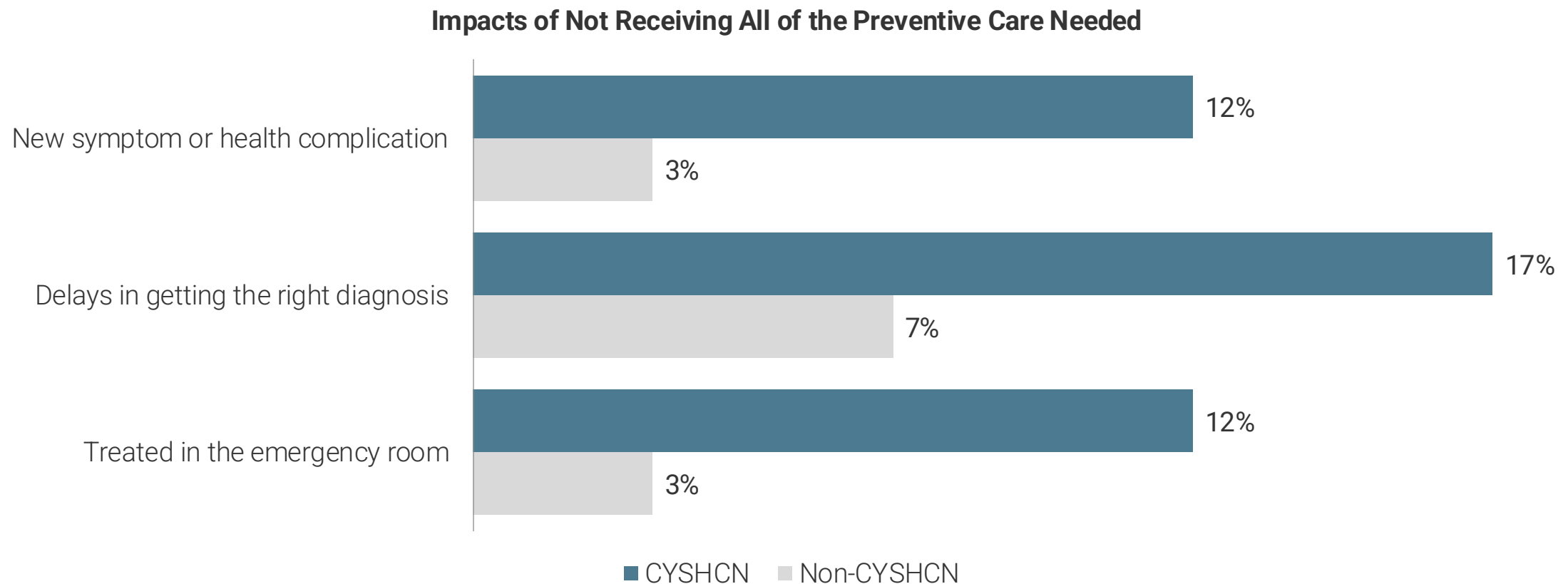
More CYSHCN with public insurance experienced barriers to accessing preventive care than CYSHCN with private insurance. These barriers included issues with insurance and wait times.

34% of CYSHCN with public insurance and **25% of CYSHCN with private insurance** experienced at least one barrier seeking preventive care



Q: In seeking preventive check-ups for your child [during the past 12 months/since their birth], did you [or your child] experience any of the following challenges?
All comparisons are statistically significant at $p < 0.05$

The impacts of not receiving preventive care were worse for CYSHCN than for other children



Q: In seeking preventive check-ups for your child [during the past 12 months/since their birth], did you [or your child] experience any of the following challenges?

All comparisons are statistically significant at $p < 0.05$



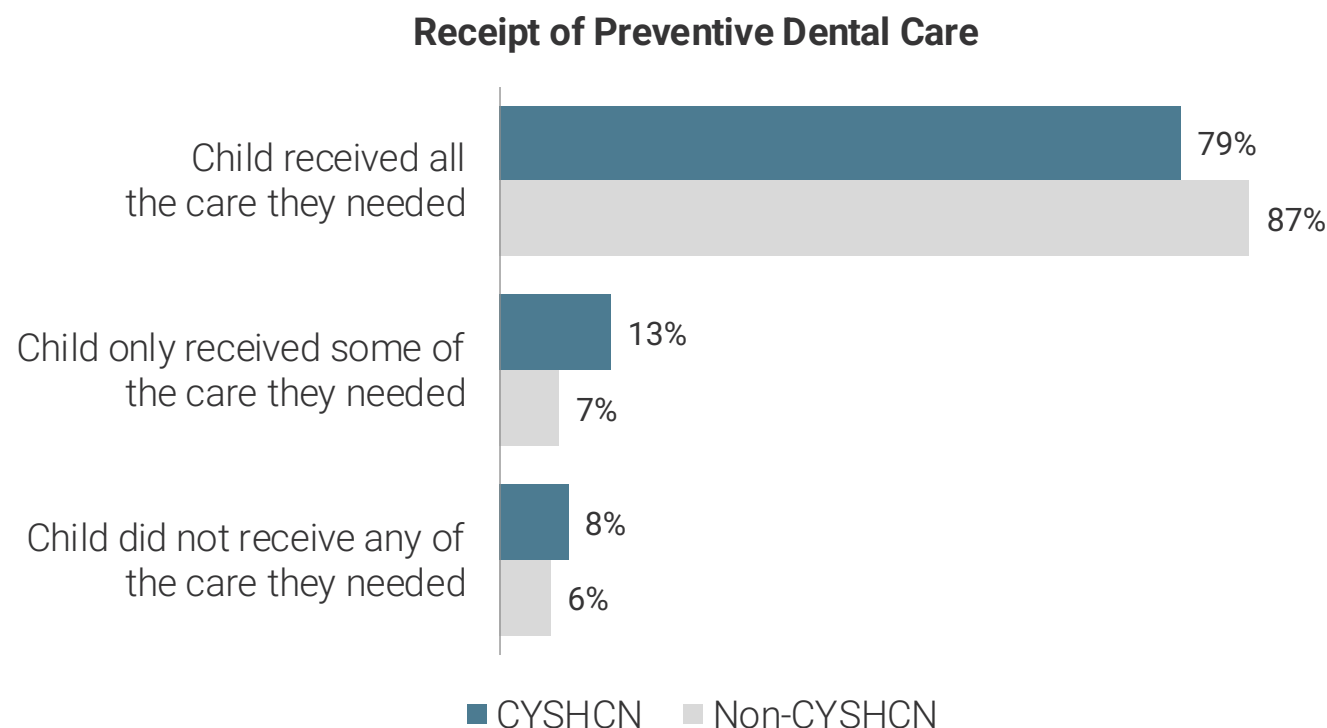
“It took us a while to find a good pediatrician. We had to bounce around until we found someone who's really good with kids with special needs. You're talking months to see the [next doctor]. And then you see them, and they might not be a good fit or they might not be giving you the answers you need. So, then you have to hit the reset button that takes them months to find someone else or find someone who's got a different specialty that you know [your child] might need.”

-- Father of a child with a developmental disability

Preventive Dental Care



CYSHCN were less likely than other children to receive all the preventive dental care they needed



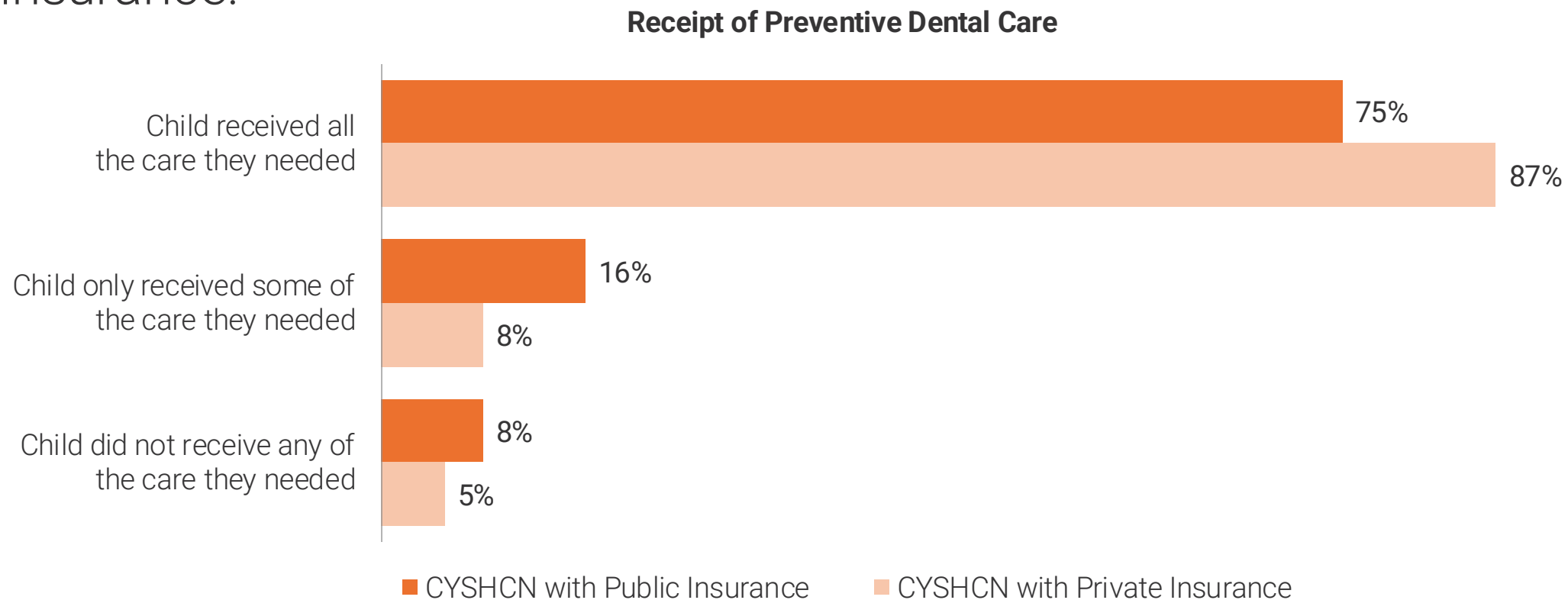
21% of CYSHCN did not receive all the preventive dental care they needed.

Hispanic CYSHCN (33%) and Black CYSHCN (21%) were more likely than white CYSHCN (17%) to have unmet preventive dental care needs.

Q: [During the past 12 months/Since their birth], did your child receive all the preventive dental care, such as check-ups and dental cleanings, that they needed? Preventive dental care includes regular check-ups and dental cleanings.

All comparisons are statistically significant at $p < 0.05$

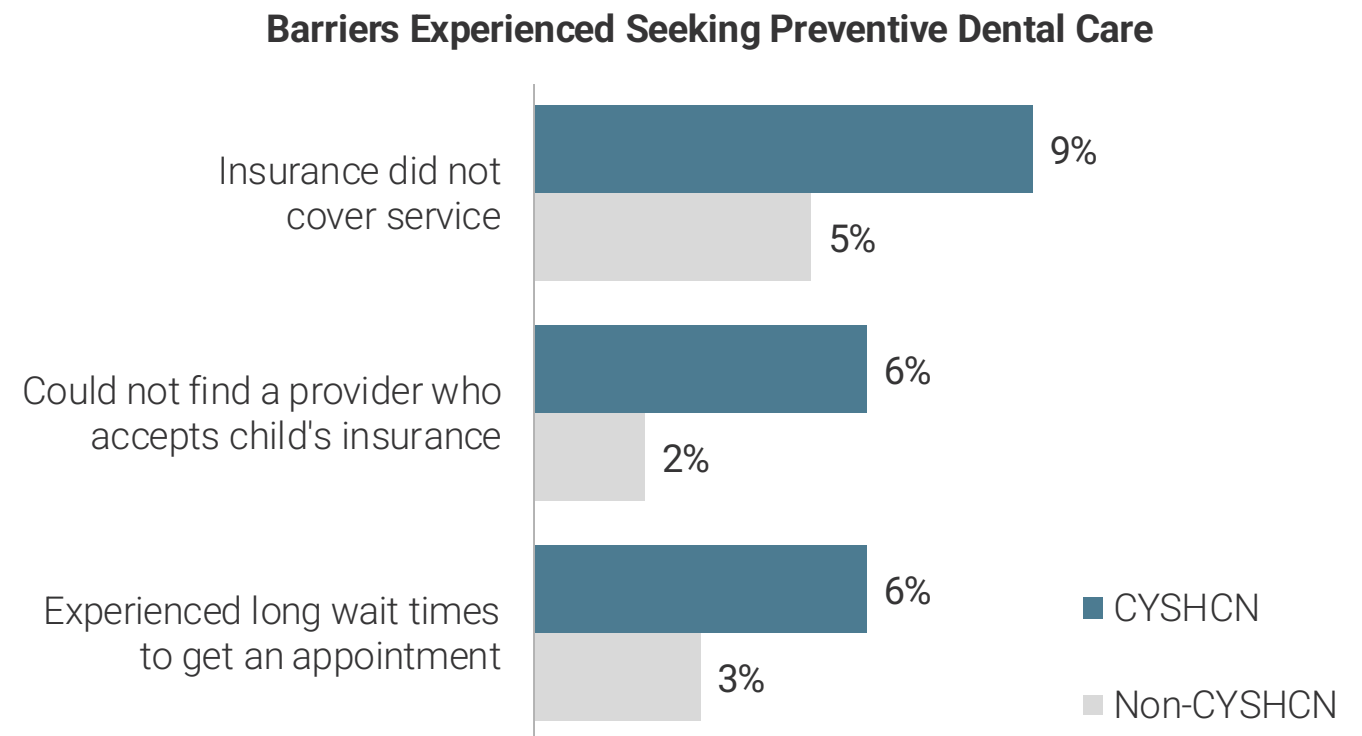
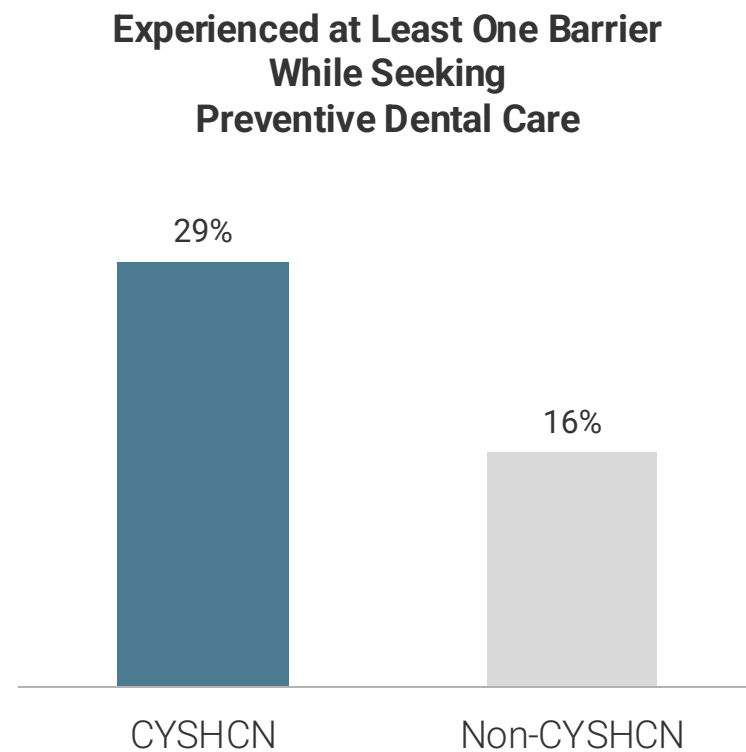
CYSHCN with public insurance were less likely to receive all of the preventive dental care they needed compared to CYSHCN with private insurance.



Q: [During the past 12 months/Since their birth], did your child receive all the preventive dental care, such as check-ups and dental cleanings, that they needed? Preventive dental care includes regular check-ups and dental cleanings.

Comparison is statistically significant at $p < 0.05$

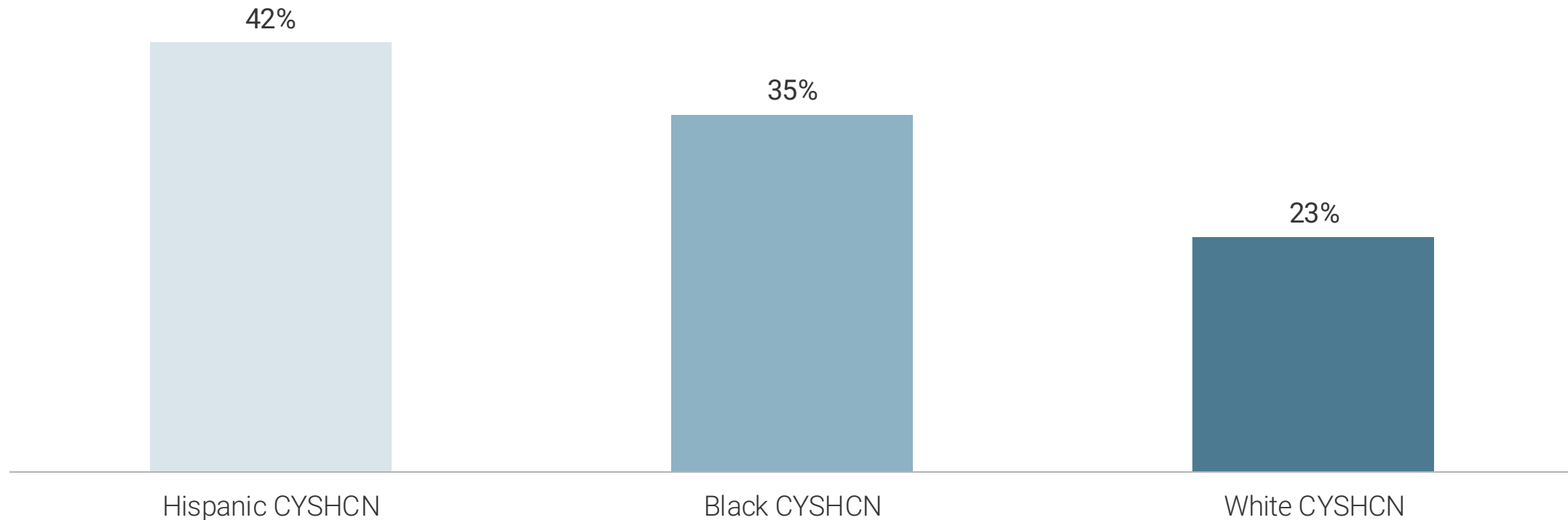
CYSHCN were about twice as likely as other children to face barriers like insurance coverage issues and long waits for preventive dental care



Q: In seeking preventive dental care for your child [during the past 12 months/since their birth], did you [or your child] experience any of the following challenges?
All comparisons are statistically significant at $p < 0.05$

Black and Hispanic CYSHCN were more likely than white CYSHCN to experience barriers to preventive dental care

Experienced at Least One Barrier While Seeking Preventive Dental Care – Race/Ethnicity



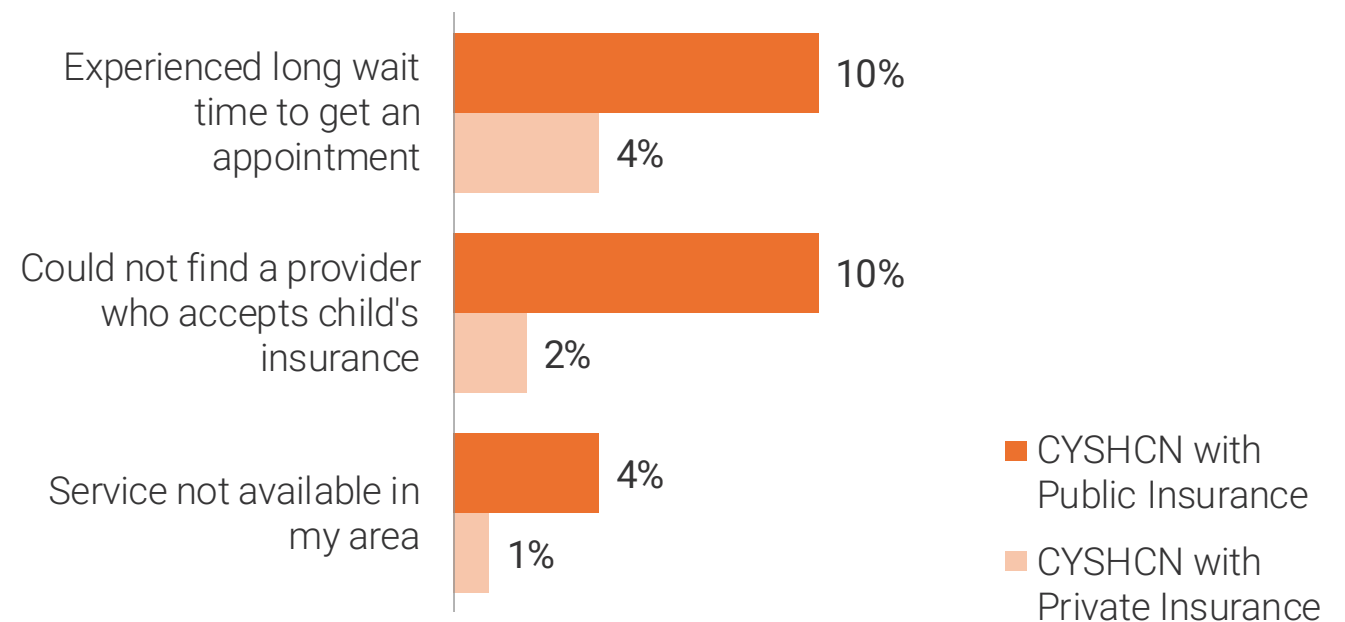
Q: In seeking preventive dental care for your child [during the past 12 months/since their birth], did you [or your child] experience any of the following challenges?

All comparisons are statistically significant at $p < 0.05$

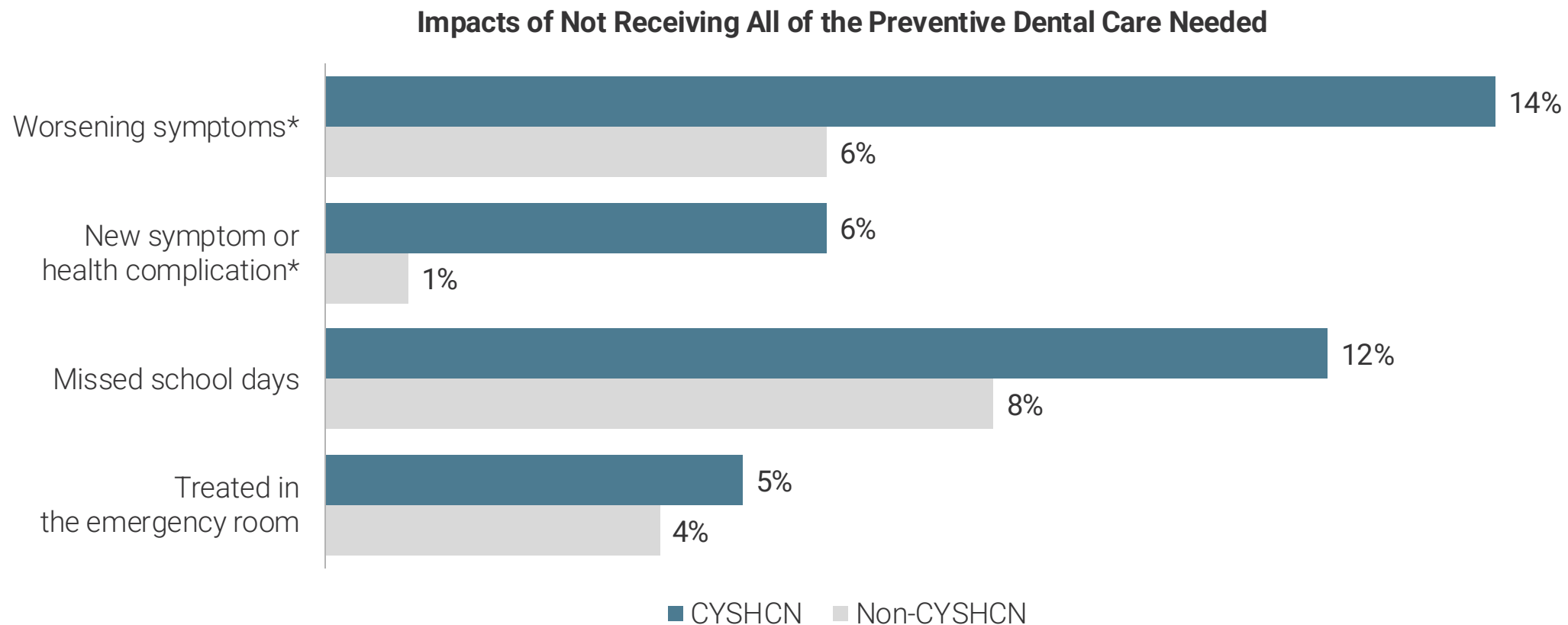
More CYSHCN with public insurance experienced barriers to preventive dental care than CYSHCN with private insurance. These barriers included wait times and finding a provider who accepts their insurance.

34% of CYSHCN with public insurance and **23% of CYSHCN with private insurance** experienced at least one barrier seeking preventive dental care

Barriers Experienced by CYSHCN Seeking Preventive Dental Care, by Insurance Type



The impacts of not receiving preventive dental care were worse for CYSHCN than for other children



Q: As a result of not receiving all the preventive dental care that they needed [during the past 12 months/since their birth], did your child experience any of the following?

*Statistically significant at $p < 0.05$



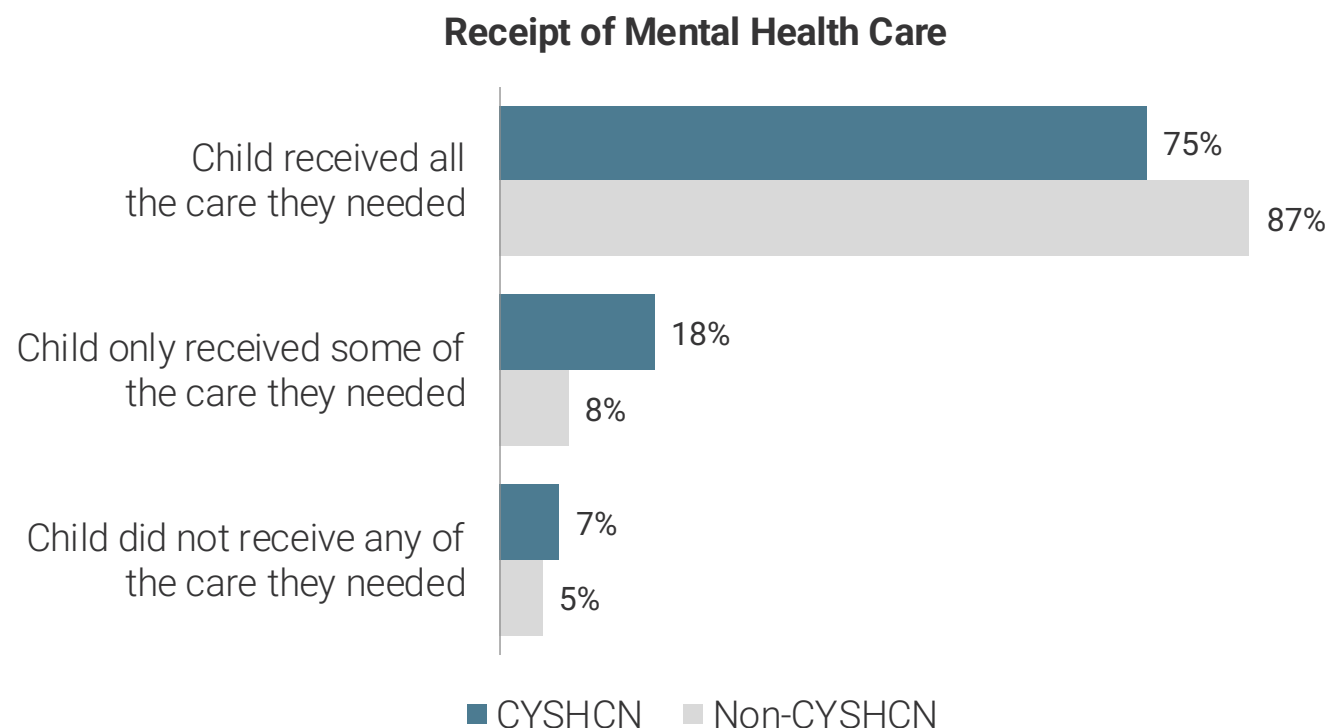
“It’s very hard to find dentistry for your child. There are very few dentists who have the skillset to deal with a special needs child. I found one...they’re very expensive. They do take health insurance, but a lot of insurances they don’t.”

-- Father of a child with a developmental disability

Mental Health Care and Counseling



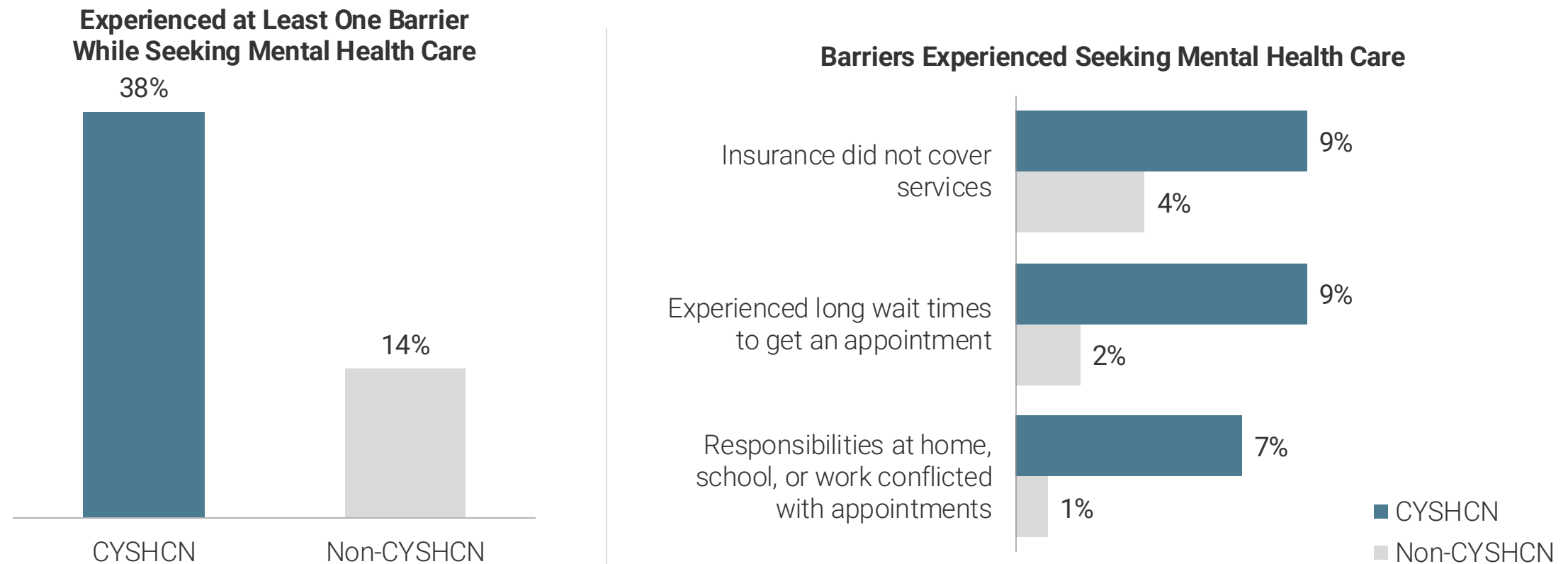
Among those needing mental health care, CYSHCN were less likely than other children to get the care they needed



25% of CYSHCN did not receive all the mental health care they needed.

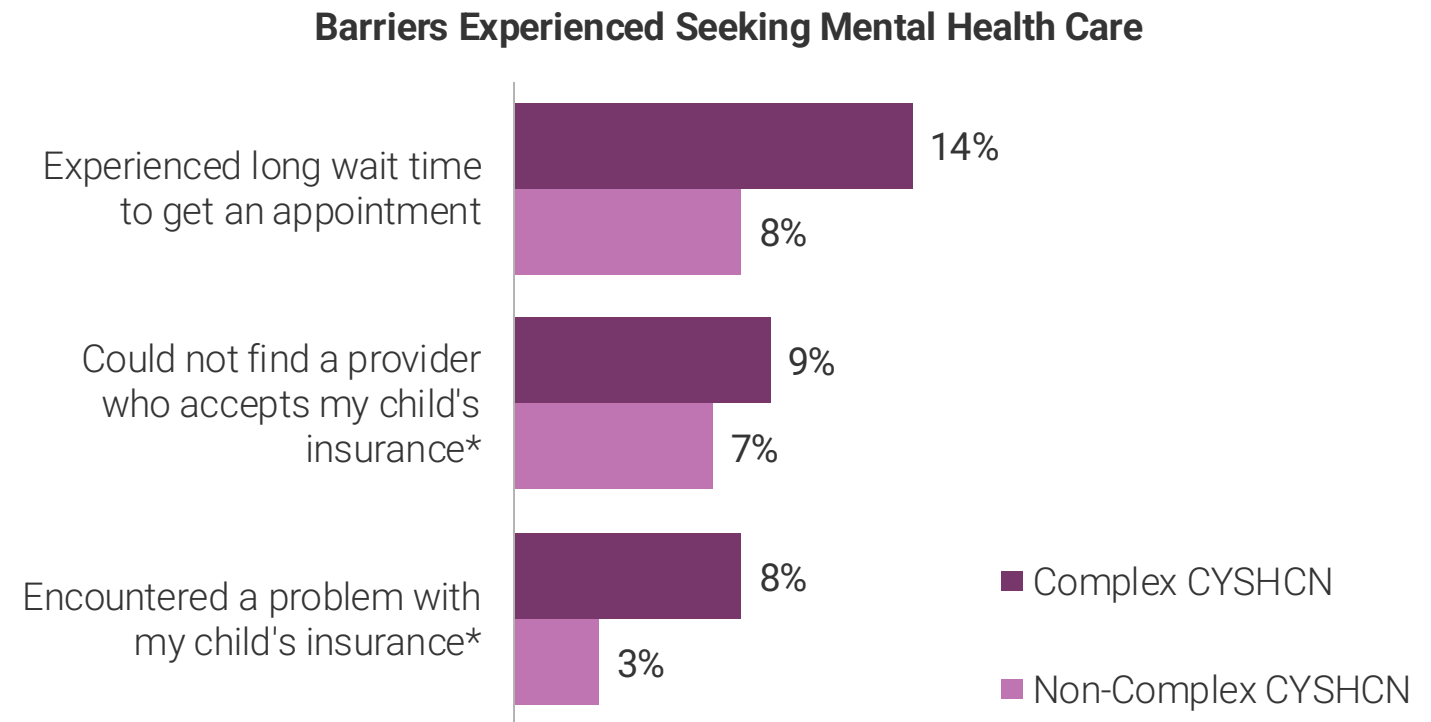
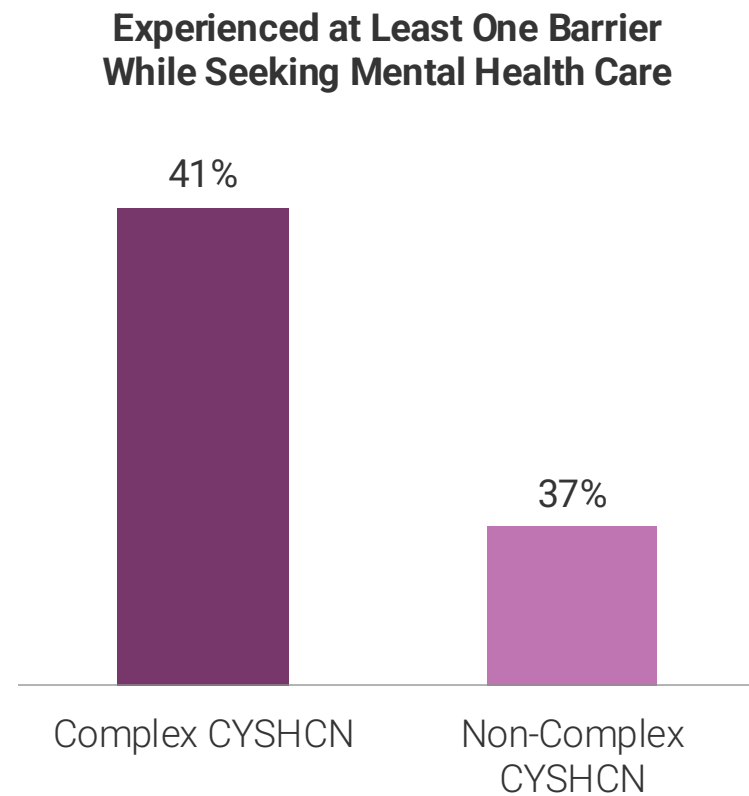
42% of Hispanic CYSHCN and 24% of Black CYSHCN did not receive all the mental health care or counseling they needed compared to 20% of white CYSHCN.

CYSHCN are more than twice as likely as other children to experience barriers to mental health care, such as insurance coverage issues



Q: In seeking mental health care or counseling for your child [during the past 12 months/since their birth], did you [or your child] experience any of the following challenges?
All comparisons are statistically significant at $p < 0.05$

CYSHCN with and without complex needs face barriers accessing mental health care at similar rates. Complex CYSHCN are more likely to experience problems with their insurance.

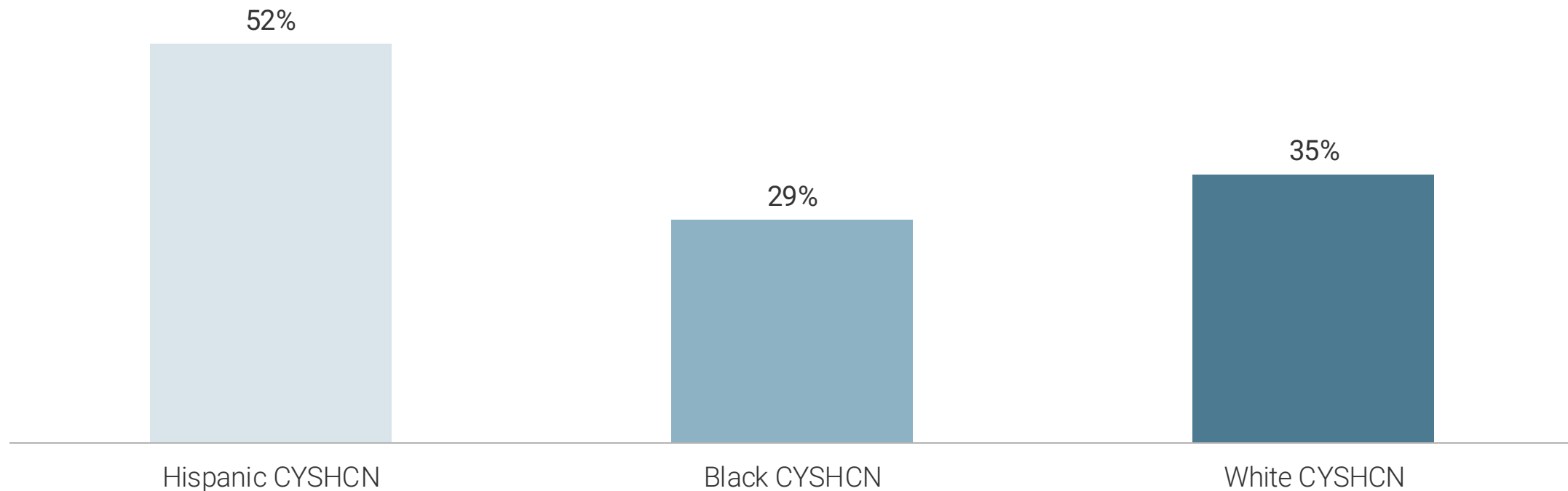


Q: In seeking mental health care or counseling for your child [during the past 12 months/since their birth], did you [or your child] experience any of the following challenges?

* NOT statistically significant at $p < 0.05$

Hispanic CYSHCN were more likely than white or Black CYSHCN to experience barriers to mental health care or counseling

Experienced at Least One Barrier While Seeking Mental Health Care or Counseling – Race/Ethnicity

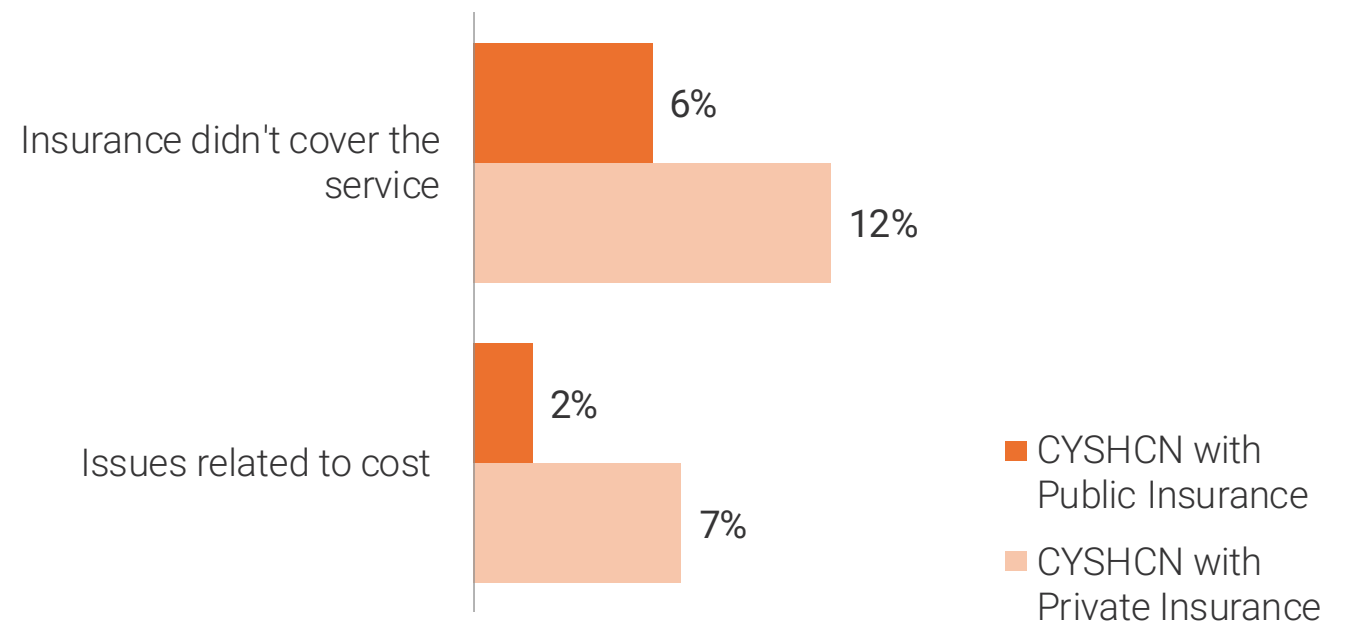


Q: In seeking mental health care or counseling for your child [during the past 12 months/since their birth], did you [or your child] experience any of the following challenges?
All comparisons are statistically significant at $p < 0.05$

Similar percentages of CYSHCN with public and private insurance experienced barriers to accessing mental health care but the types of barriers varied depending on insurance type.

33% of CYSHCN with public insurance and **39% of CYSHCN with private insurance** experienced at least one barrier seeking preventive mental health care*

Barriers Experienced by CYSHCN Seeking Mental Health Care, by Insurance Type**

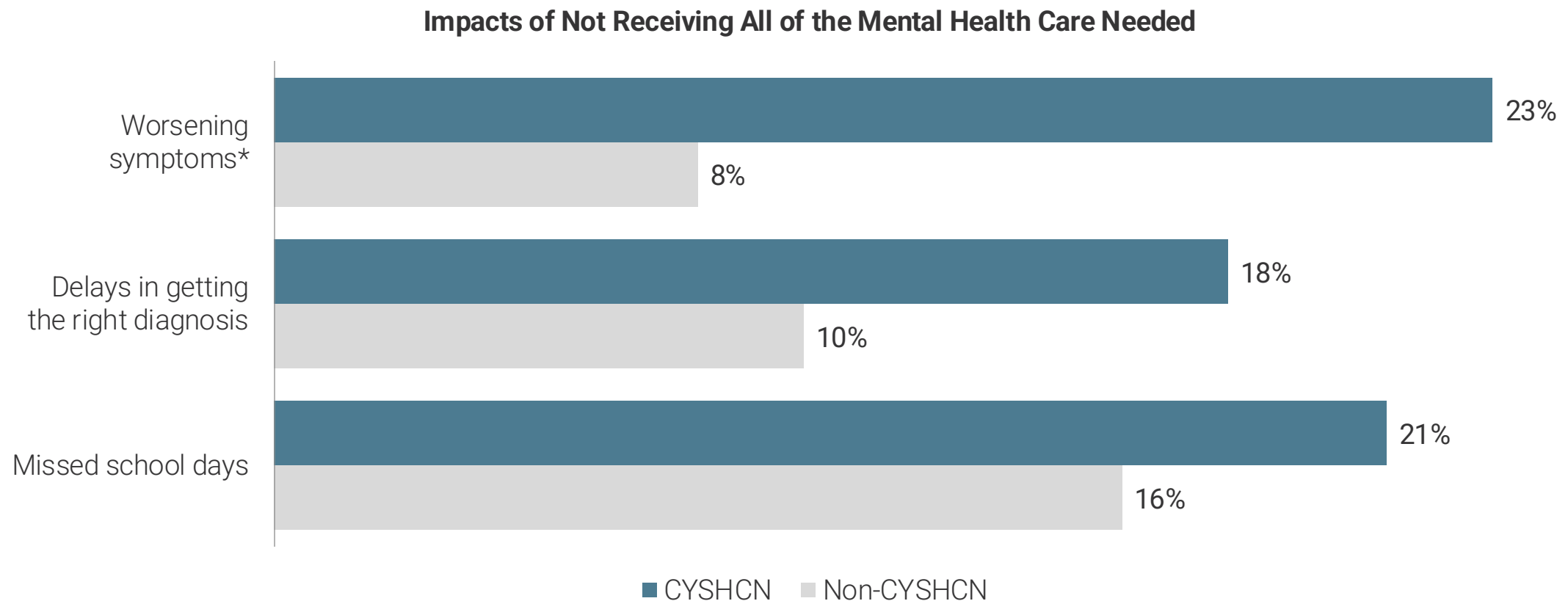


Q: In seeking preventive mental health care for your child [during the past 12 months/since their birth], did you [or your child] experience any of the following challenges?

* Not statistically significant at $p < 0.05$

** Statistically significant at $p < 0.05$

The impacts of not receiving mental health care were worse for CYSHCN than for other children



Q: As a result of not receiving all mental health care or counseling that they needed [during the past 12 months/since their birth], did your child experience any of the following?

*Statistically significant at $p < 0.05$



“You know when you're in a situation where your child is in [a mental health] crisis, it feels kind of like devastating because...you're worried about your child and you don't have access to the resources you need.”

-- Mother of child with mental health conditions



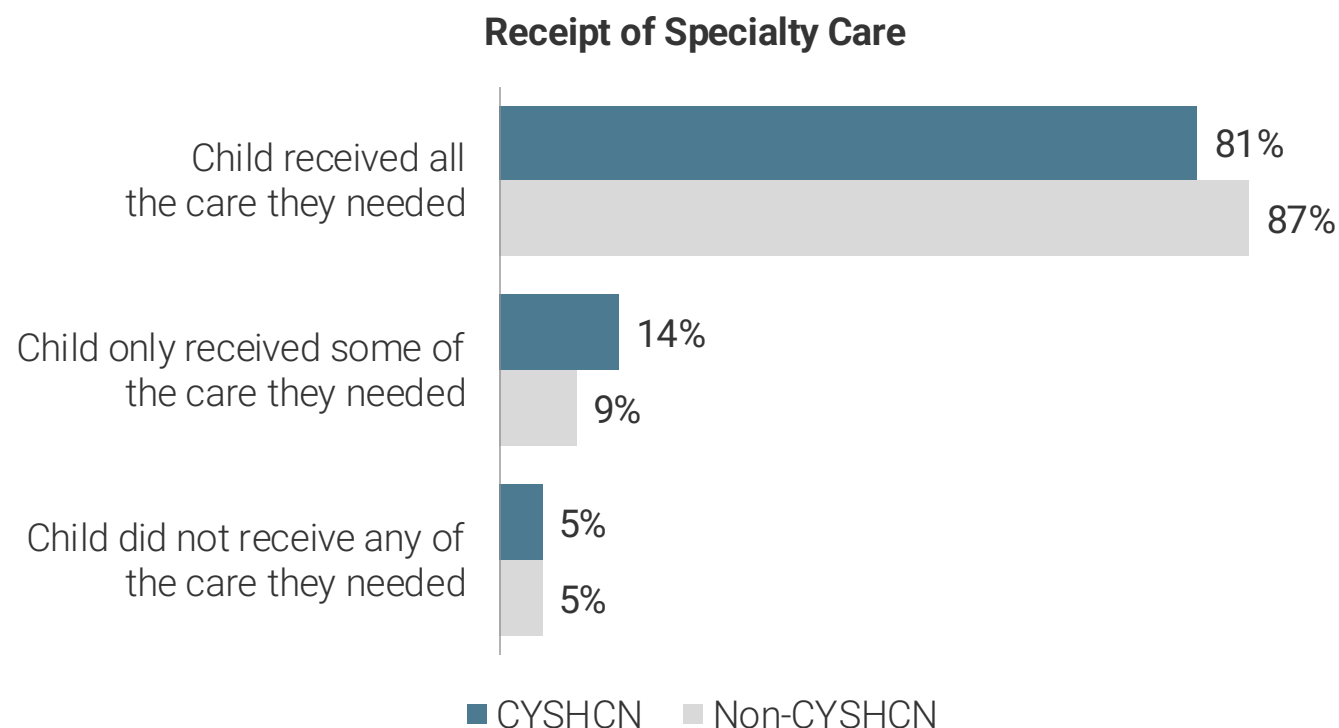
“To find her a mental health care provider, I went through about 23 people before, I was like, I don't know what to do. And then her school set me up with somebody who worked in cooperation with the school and that's the only reason she was able to get a health care provider for her mental health. That was the only way because every single person I went to, they were either telling me they didn't do adolescent psychiatry or that they didn't take our insurance”

-- Mother of child with mental health conditions

Specialty Care



Among those requiring specialty care, CYSHCN were less likely than other children to receive the care they needed



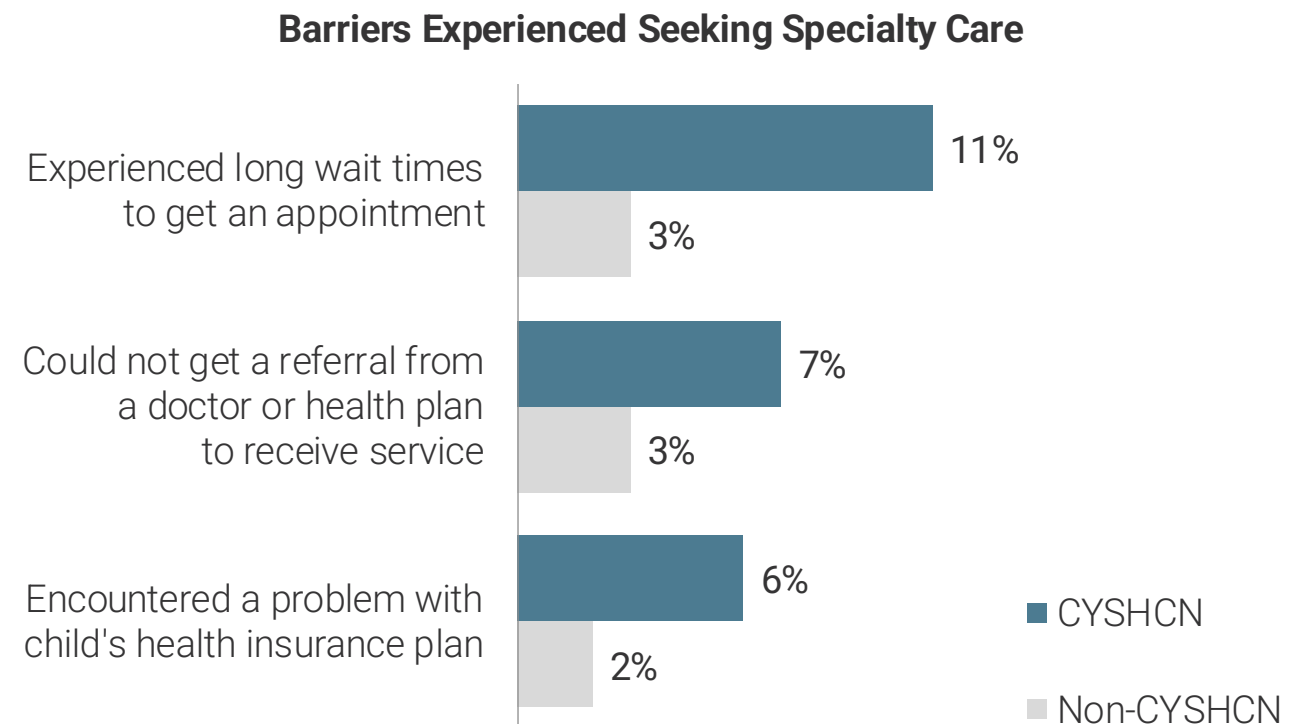
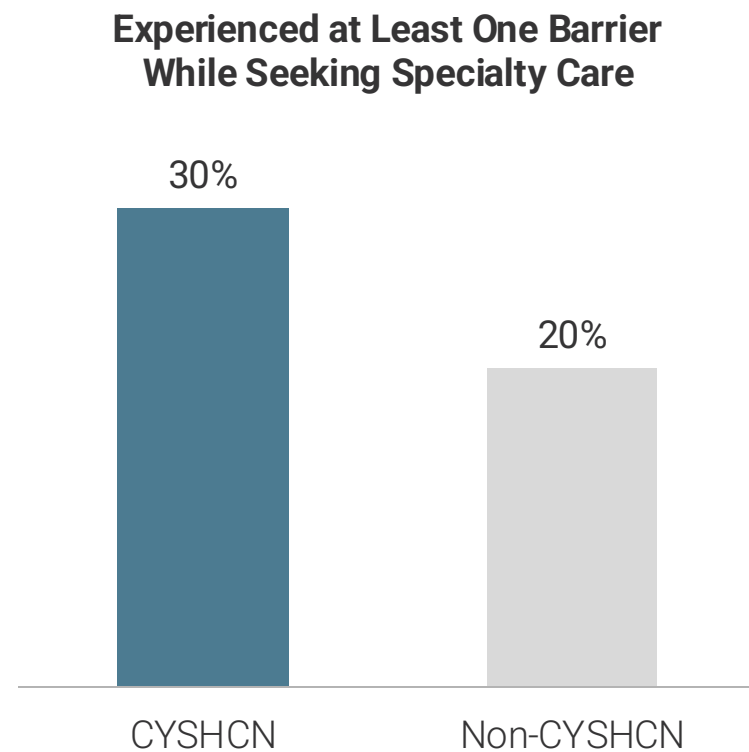
19% of CYSHCN did not receive all the specialty care they needed.

39% of Hispanic CYSHCN and **18% of Black CYSHCN** who needed specialty care did not receive all the care they needed compared to 14% of white CYSHCN.

Q: [During the past 12 months/Since their birth], did your child receive all the care from a specialty doctor that they needed? Specialty doctors include surgeons, heart doctors, allergy doctors, skin doctors, and others who specialize in one area of health care.

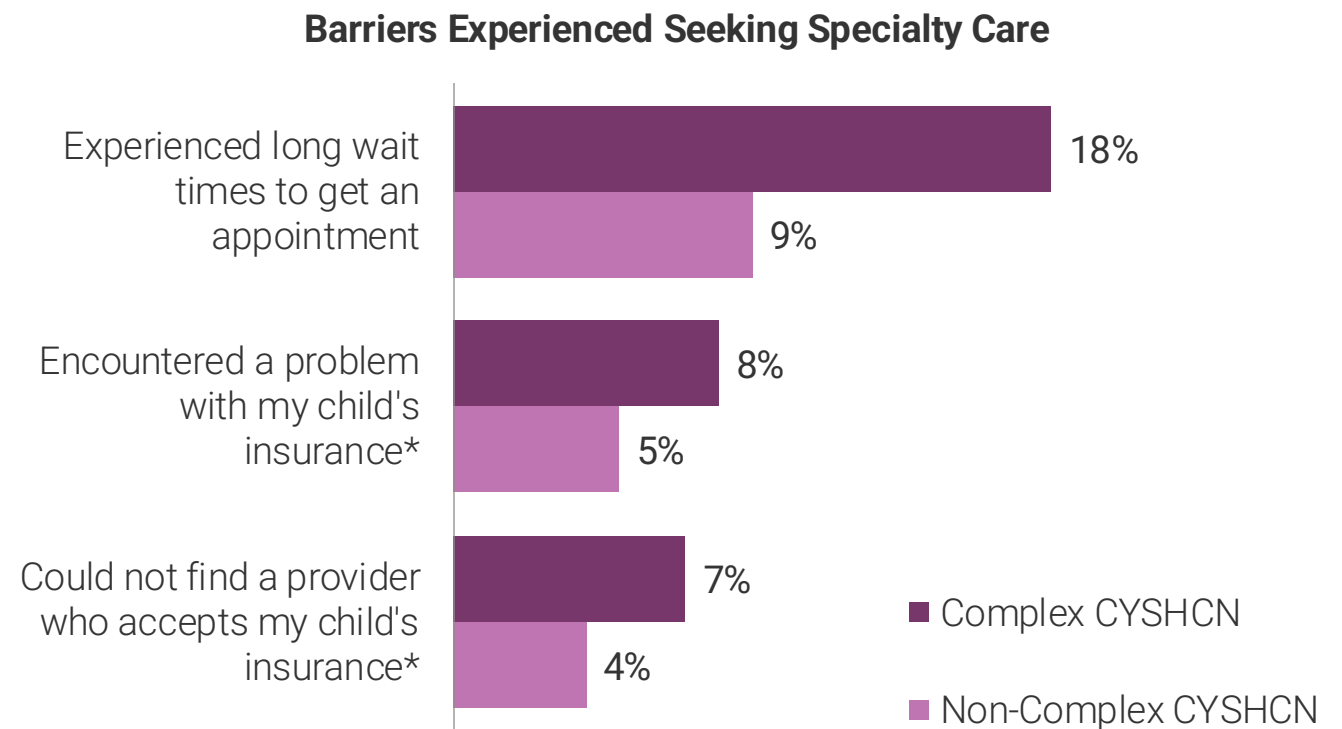
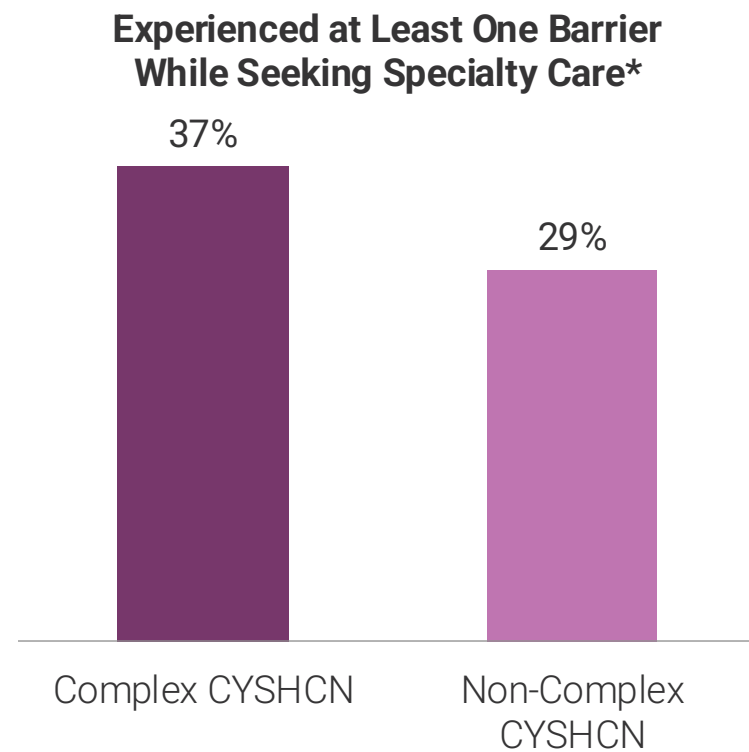
All comparisons are statistically significant at $p < 0.05$

CYSHCN were more likely to face barriers to specialty care, such as the inability to secure doctor or health plan referrals



Q: In seeking specialty care for your child [during the past 12 months/since their birth], did you [or your child] experience any of the following challenges?
All comparisons statistically significant at $p < 0.05$

CYSHCN with and without complex needs faced barriers to specialty care at similar rates, but complex CYSHCN were more likely to experience long wait times.



Q: In seeking specialty care for your child [during the past 12 months/since their birth], did you [or your child] experience any of the following challenges?

*Not statistically significant at $p < 0.05$

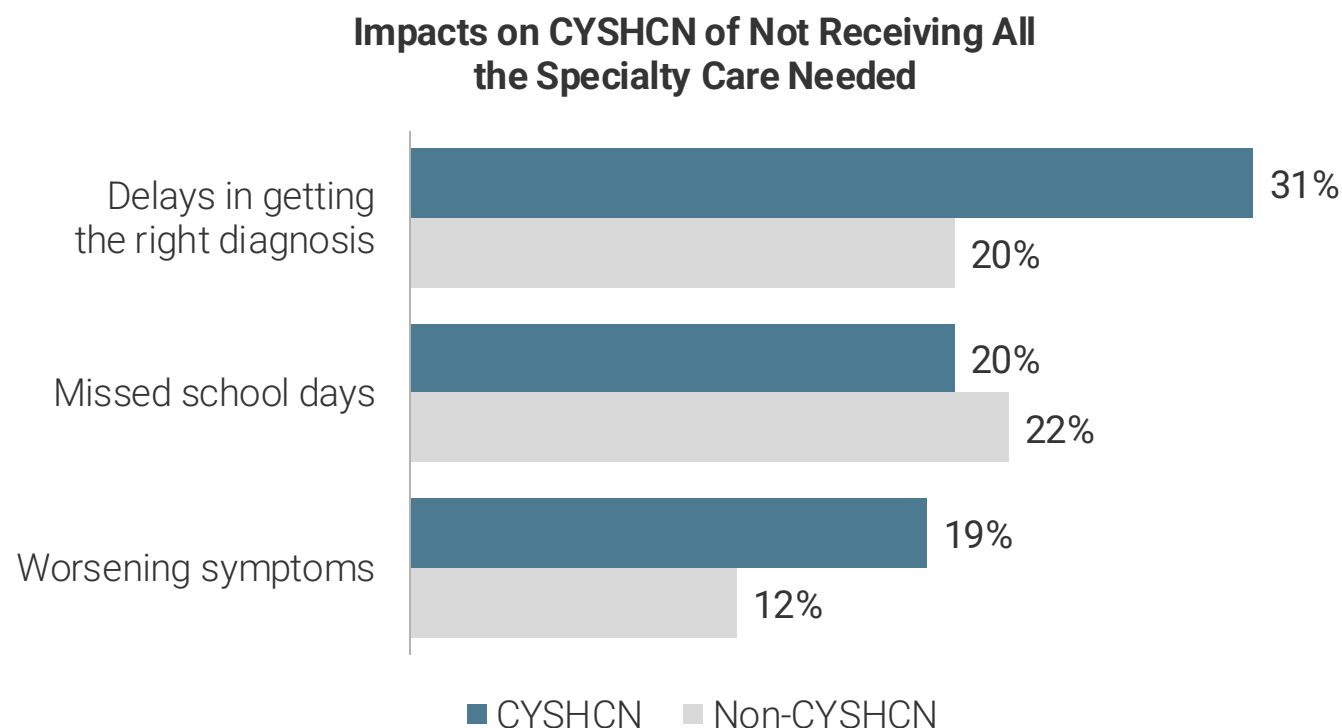


“It’s hard when you are trying to get your kid into specialists. If I pull [my child] out of school, school calls me and it's like, hey, you've pulled him out so many times. And I get it. But if they have one appointment, you take the appointment.

I mean it's definitely hard, and it’s not just the time it takes out of your day to get the kids to their appointments. So, the phone calls you have to make to get to the doctor, to follow up with the doctor, follow up with the nurse who took the notes to give to the doctor that the doctor never got. The call to the insurance to argue the payments or what they owe you. Sometimes you just pay the bill because it's either you pay the bill, or you stay on the phone for two hours trying to figure this out and get them to explain.”

-- Mother of a child with a developmental disability

CYSHCN and other children are profoundly impacted by not receiving the specialty care they need.



Hispanic CYSHCN (24%) were more likely than white CYSHCN (6%) and Black CYSHCN (4%) to develop a new symptom or health complication because of not receiving all the specialty care they needed.*

Parents of complex CYSHCN (28%) were more likely than parents of non-complex CYSHCN (8%) to miss day of work because of not receiving all the specialty care their child needed.*

Q: As a result of not receiving all the care from a specialty doctor they needed [during the past 12 months/since their birth], did your child experience any of the following?

* Statistically significant at $p < 0.05$



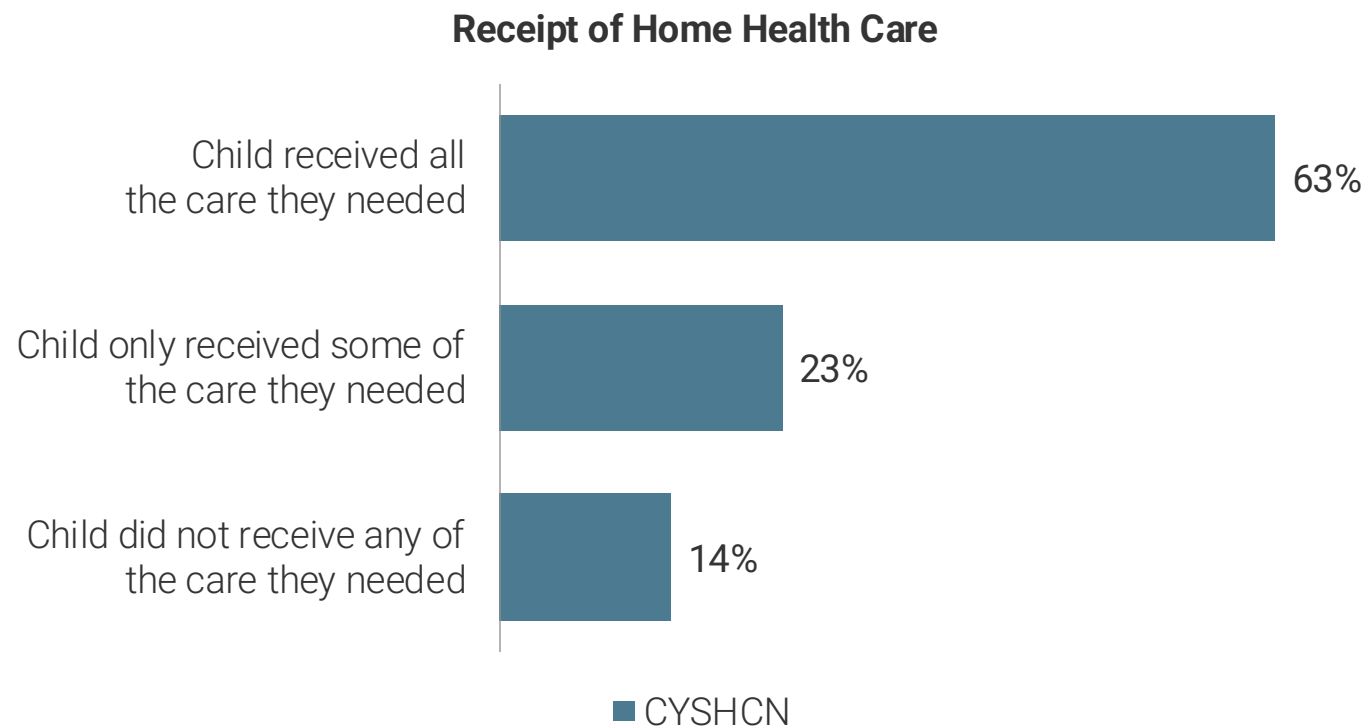
“It seems like it just takes forever just to get an appointment and get it approved [through insurance]. We had to go through I think like six specialists before we actually found somebody that could actually tell us what was going on. It's just heartbreaking, you know, that a child suffers like that. It's just frustrating.”

-- Father of child with a developmental disability

Home Health Care



Over one-third of CYSHCN needing home health care did not receive all needed services.



37% of CYSHCN did not receive all the home health care they needed.

42% of complex and **36% of non-complex CYSHCN** did not receive all the home health care they needed.

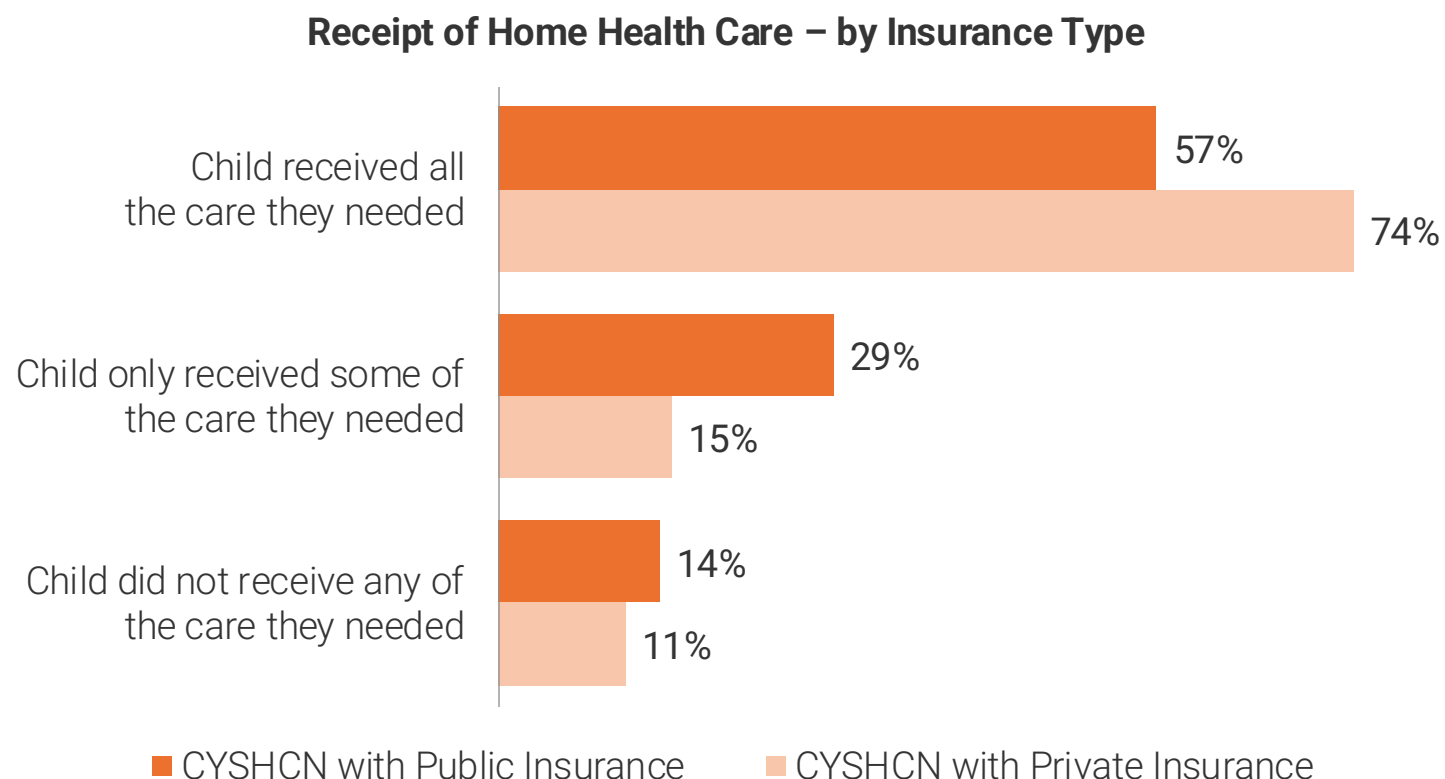
Hispanic CYSHCN (58%) and Black CYSHCN (37%) were more likely than white CYSHCN (21%) to not receive all the home health care they needed.

Q: [During the past 12 months/Since their birth], did your child receive all the home health care that they needed?

Home health care is routine care provided by a home nurse (also called a shift nurse or private duty nurse), a certified nursing assistant, or a home health aide (also called a home attendant, personal care aide, or caregiver assistant). These paid professionals are not family members and may help care for your child by giving medications, administering feedings, changing bandages, helping with medical equipment, and with activities of daily living such as dressing and bathing. These paid professionals may also provide care to your child at school and in community locations.

All comparisons are statistically significant at $p < 0.05$

CYSHCN with public insurance were less likely to receive all of the home health care they needed compared to CYSHCN with private health insurance.



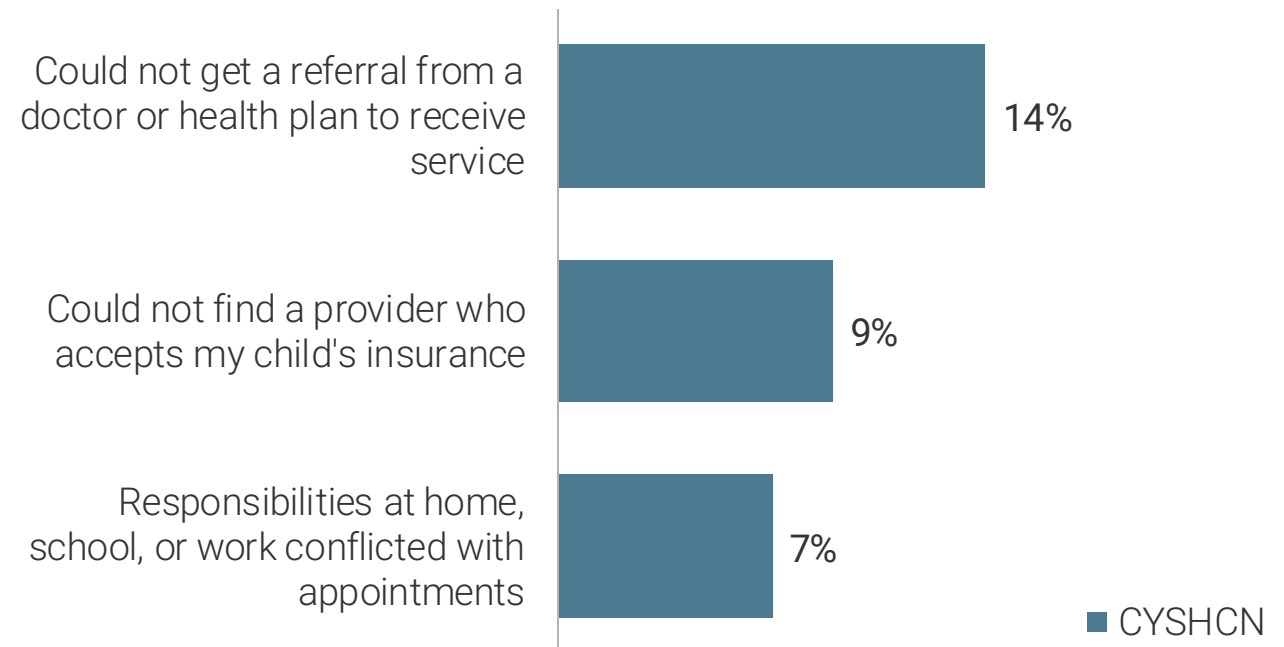
43% of CYSHCN with public insurance did not receive all of the home health care they needed

26% of CYSHCN with private insurance did not receive all of the home health care they needed

Four out of every ten CYSHCN encountered at least one barrier when seeking home health care, including issues obtaining referrals

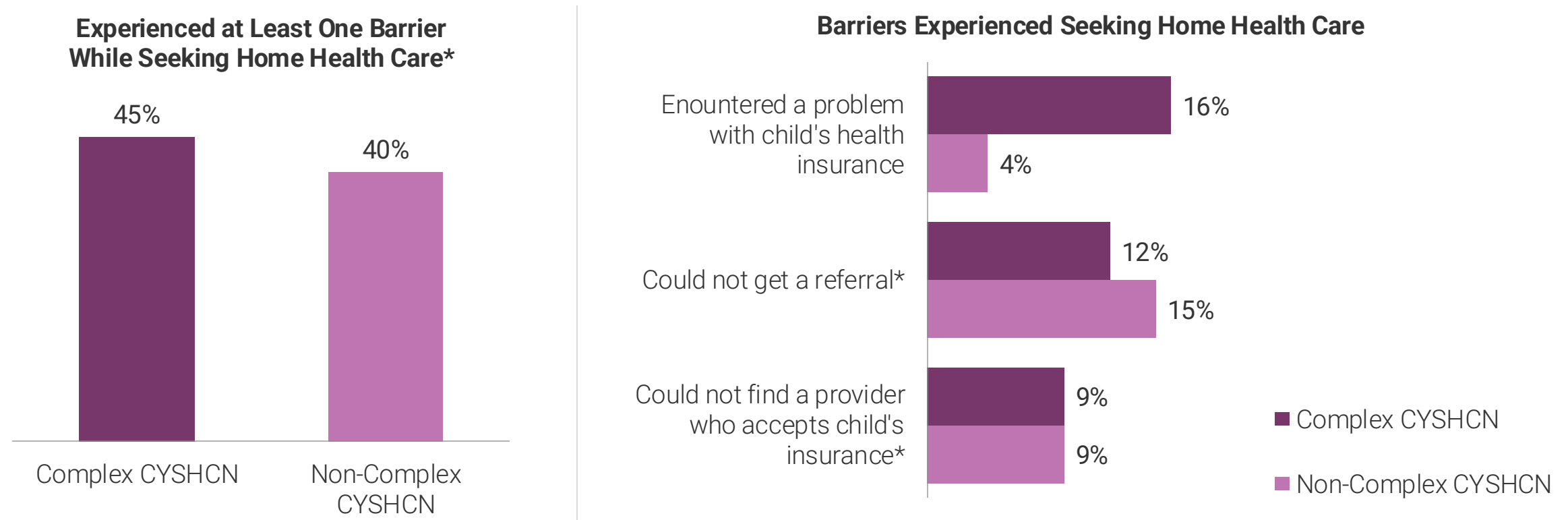
41% of CYSHCN who needed home health care experienced at least one barrier seeking the care

Barriers Experienced by CYSHCN Seeking Home Health Care



Q: In seeking home health care for your child [during the past 12 months/since their birth], did you [or your child] experience any of the following challenges?

CYSHCN with and without complex needs faced barriers to home health care at similarly high rates, but complex CYSHCN were more likely to encounter a problem with their insurance.

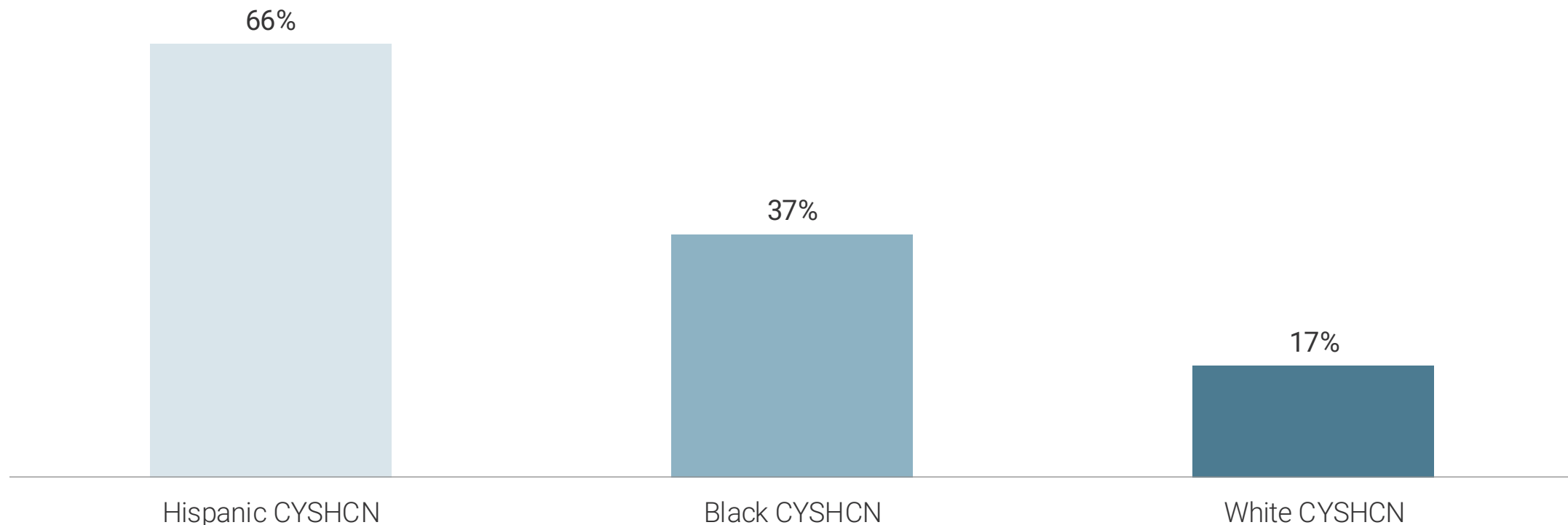


Q: In seeking home health care for your child [during the past 12 months/since their birth], did you [or your child] experience any of the following challenges?

*Not statistically significant at $p < 0.05$

Hispanic and Black CYSHCN were more likely than white CYSHCN to experience barriers seeking home health care

Experienced at Least One Barrier While Seeking Home Health Care – Race/Ethnicity



Q: In seeking home health care for your child [during the past 12 months/since their birth], did you [or your child] experience any of the following challenges?

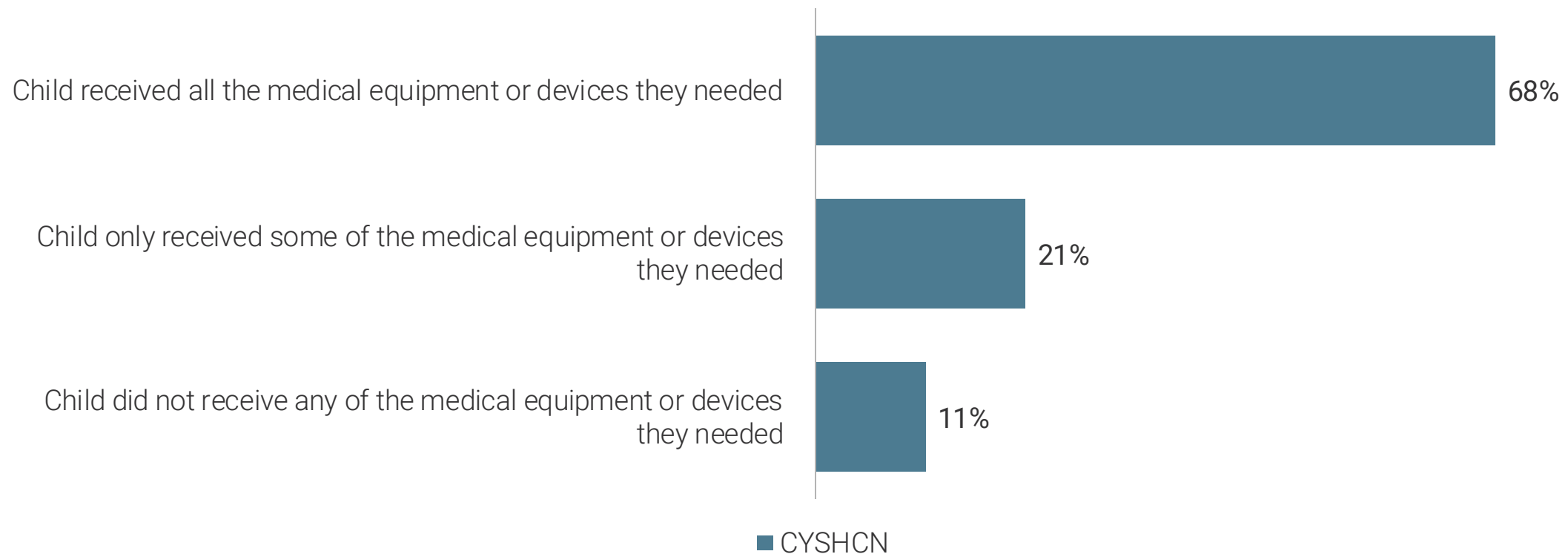
All comparisons are statistically significant at $p < 0.05$

Medical Equipment or Devices



Among CYSHCN who needed them, nearly one-third lacked some necessary medical equipment or devices

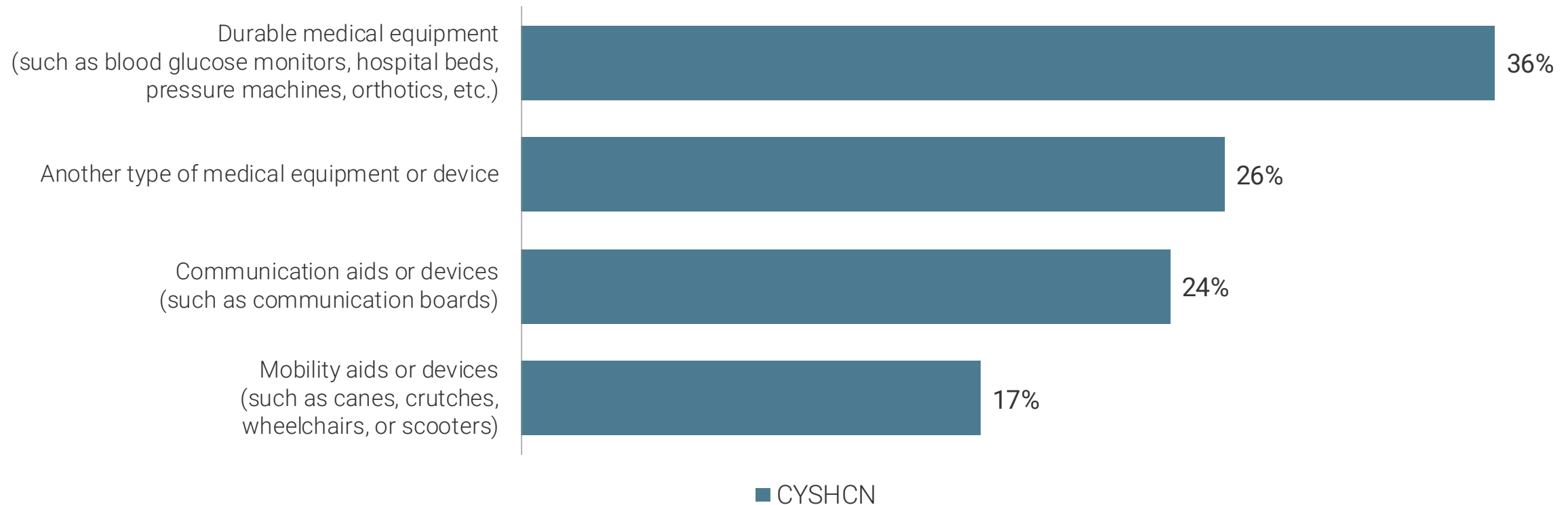
Receipt of Medical Equipment or Devices



Q: [During the past 12 months/Since their birth], did your child receive all the medical equipment or devices that they needed?

Parents reported that CYSHCN needed various types of medical equipment or devices, with durable medical equipment being the most common

Types of Medical Equipment or Device Needed by CSHCN

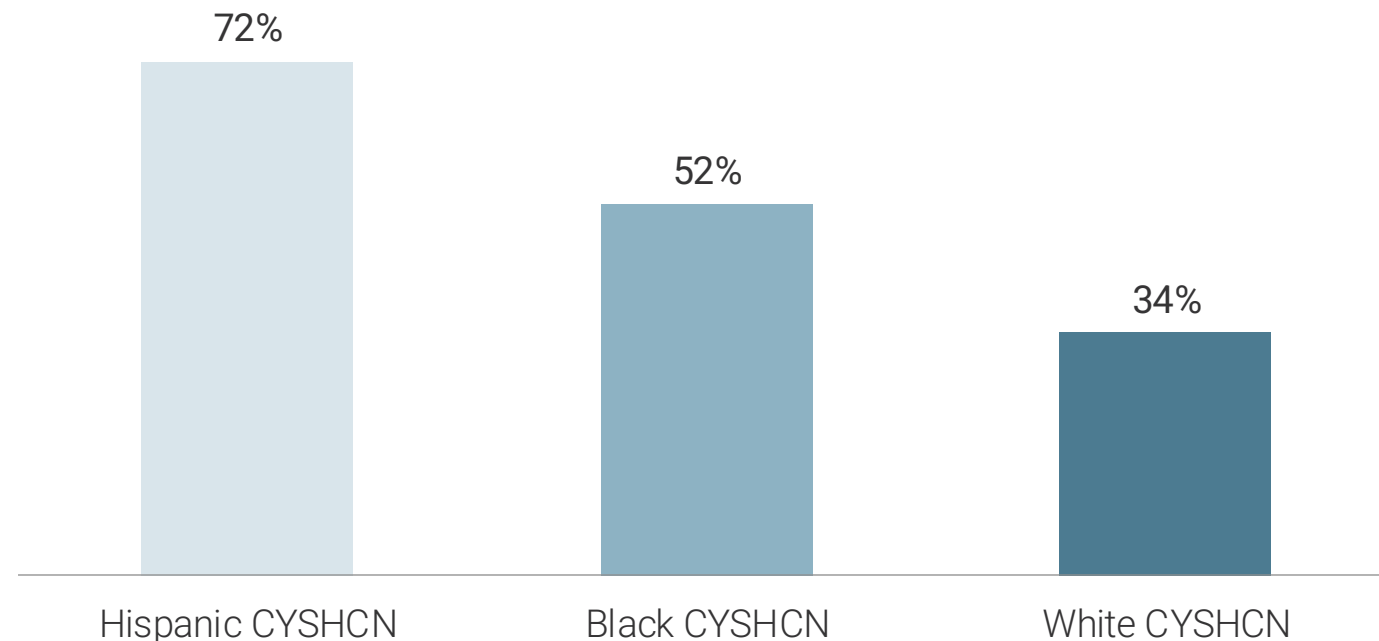


Q: What kind of medical equipment or device did your child need [during the past 12 months/since their birth]?

Almost half of CYSHCN experienced barriers when seeking medical equipment or devices and more Hispanic and Black CYSHCN experienced at least one barrier than white CYSHCN

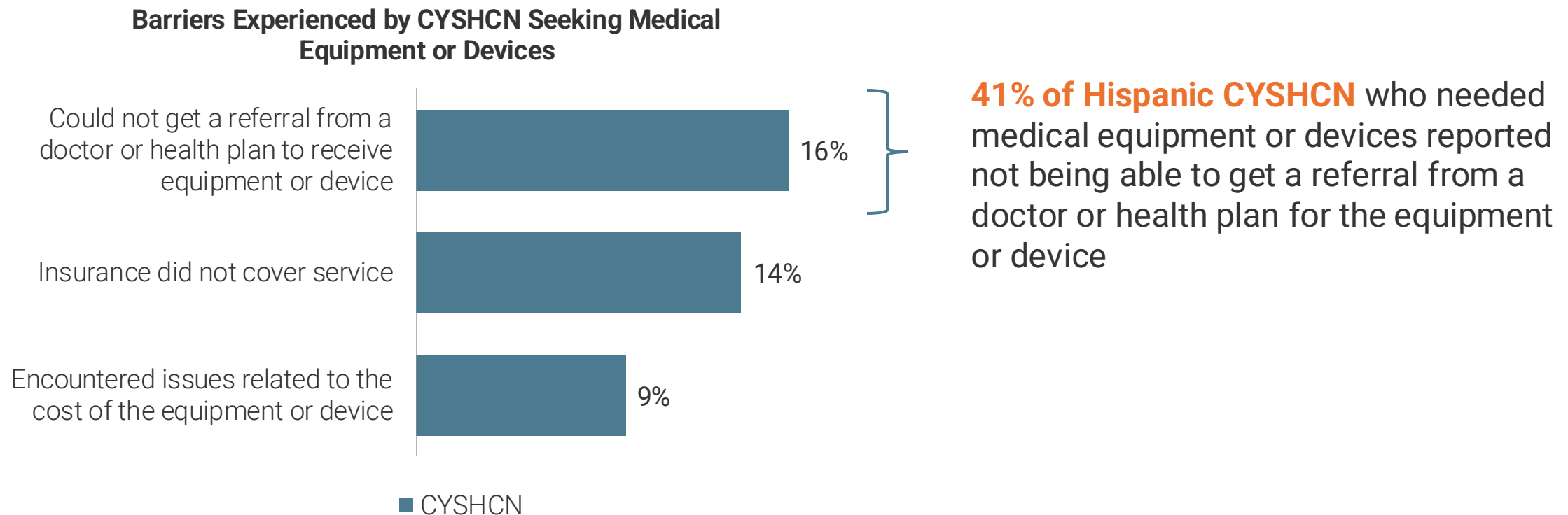
Experienced at Least One Barrier While Seeking Medical Equipment or Devices – Race/Ethnicity

48% of CYSHCN who needed medical equipment or devices experienced at least one barrier to access



Q: In seeking medical equipment or devices for your child [during the past 12 months/since their birth] did you [or your child] experience any of the following challenges?

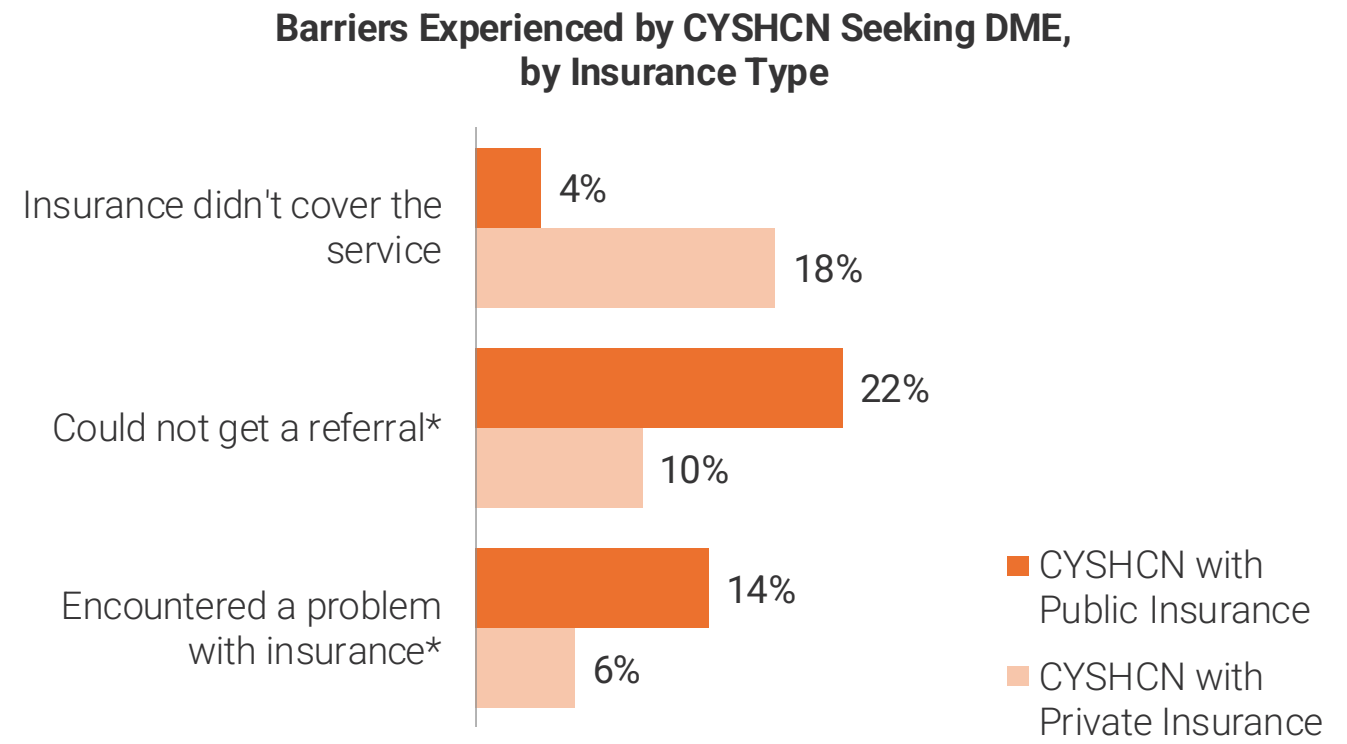
The most common barrier for CYSHCN seeking medical equipment or devices was not having a referral



Q: In seeking medical equipment or devices for your child [during the past 12 months/since their birth] did you [or your child] experience any of the following challenges?
All comparisons are statistically significant at $p < 0.05$

Similar percentages of CYSHCN with public and private insurance experienced barriers to accessing durable medical equipment or devices but the types of barriers varied depending on insurance source.

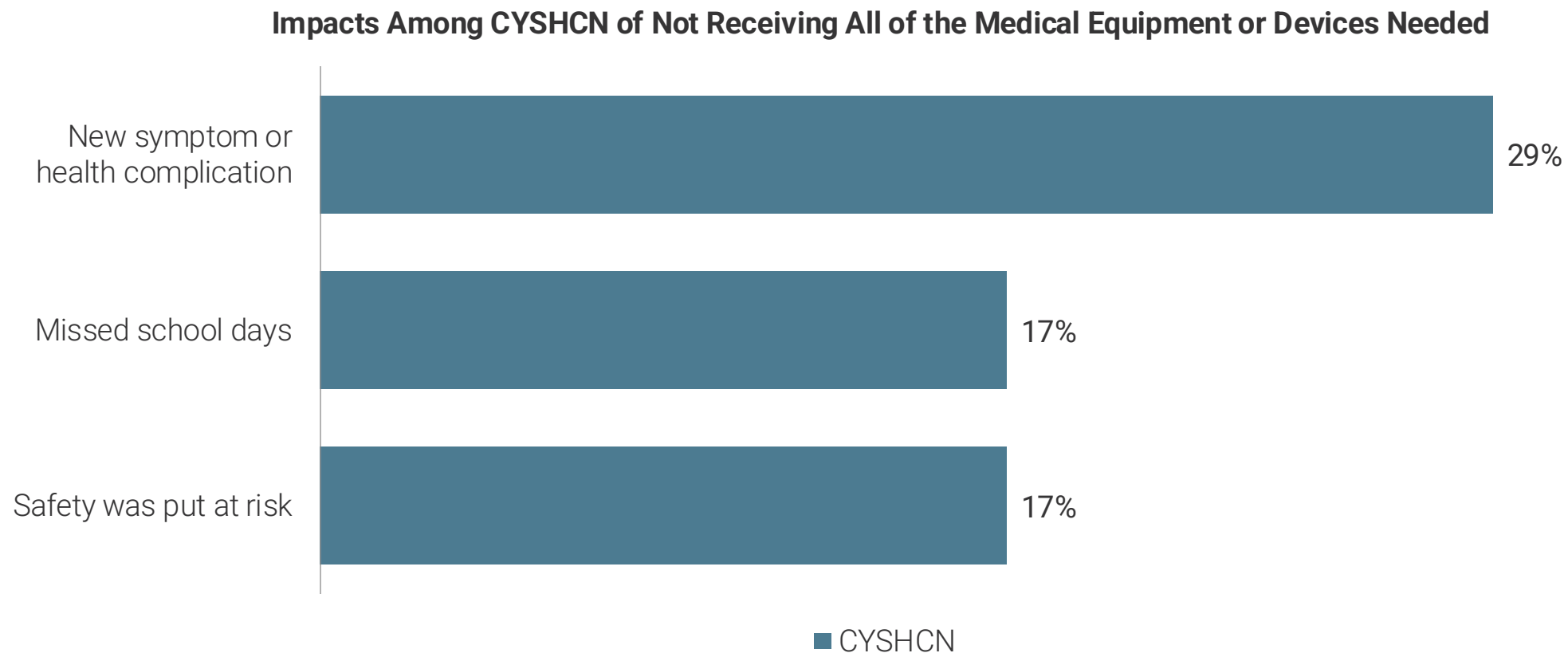
41% of CYSHCN with public insurance and **47% of CYSHCN with private insurance** experienced at least one barrier seeking durable medical equipment or devices*



Q: In seeking preventive medical equipment or devices for your child [during the past 12 months/since their birth], did you [or your child] experience any of the following challenges?

* Not statistically significant at $p < 0.05$

Nearly one-third of CYSHCN developed a new symptom or health complication from not getting all of the medical equipment they needed



Q: As a result of not receiving all the medical equipment or devices they needed [during the past 12 months/since their birth], did your child experience any of the following?



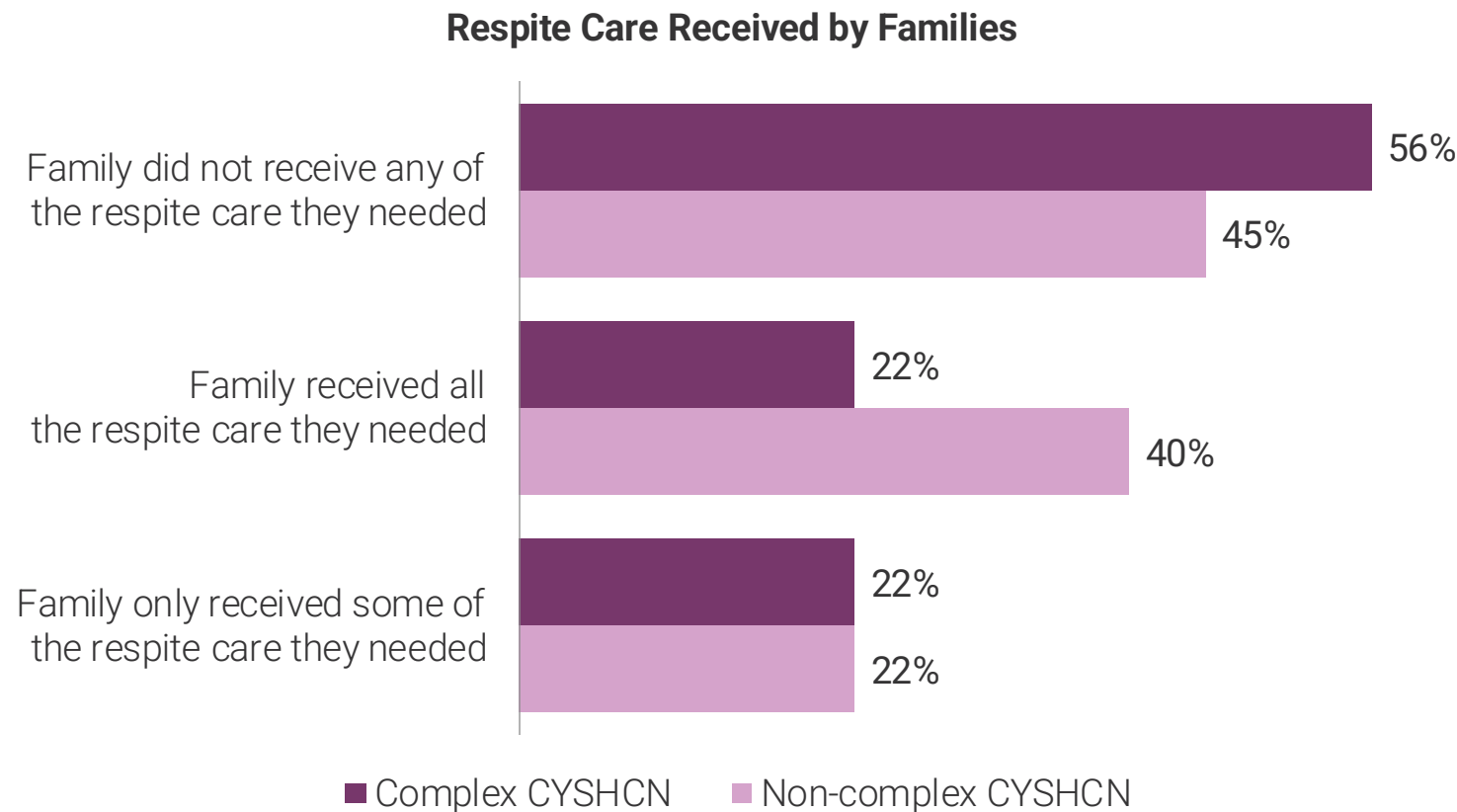
“The hardest thing for me is that my insurance doesn't offer certain things. My daughter needs an anti-seizure watch, and the insurance doesn't offer coverage on the watch and to get the watch in general, it's like \$500 or \$600. And then you have to have a prescription for it. And then you have to sign up for a service for it. The service itself is \$499 a year. The insurance doesn't cover any of it.”

- Mother of child with epilepsy and mental health conditions

Respite Care

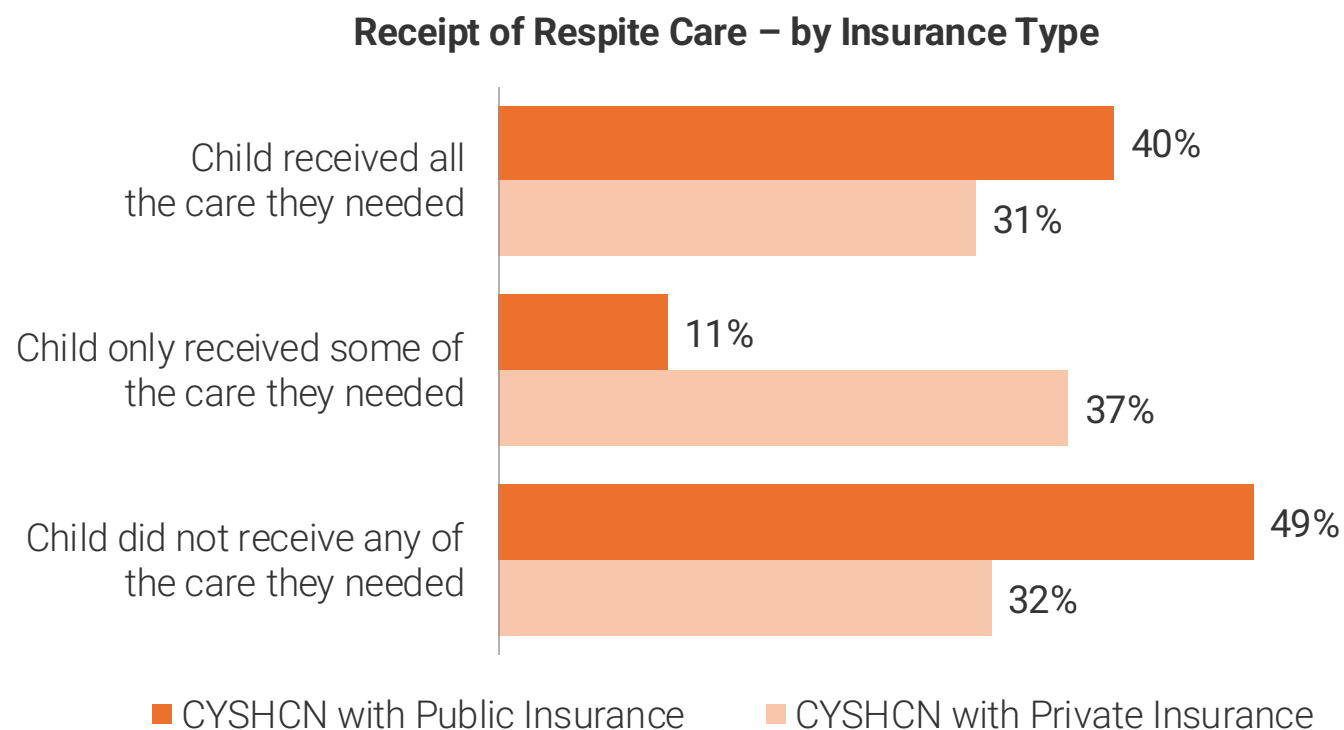


Two-thirds of parents of CYSHCN did not receive all the respite care they needed.



78% of parents of CYSHCN with complex needs did not receive all of the respite care they needed.

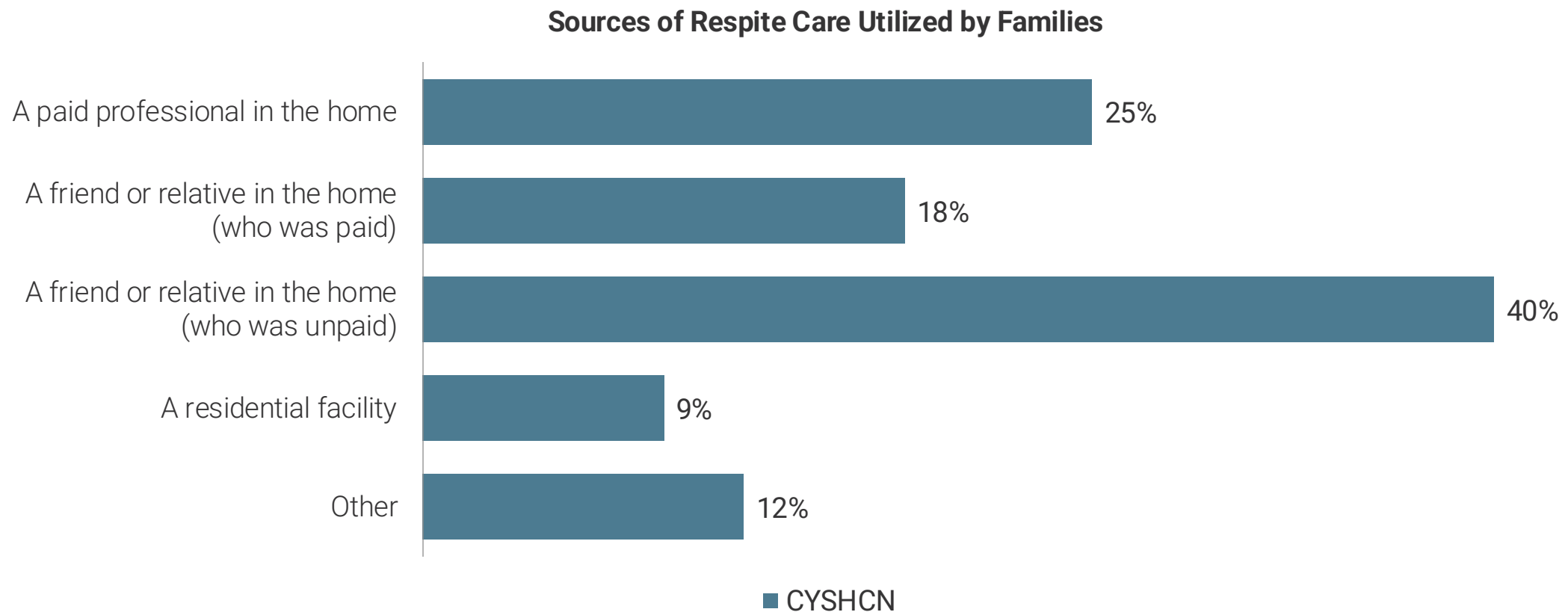
CYSHCN with private insurance were less likely to receive all of the respite care they needed compared to CYSHCN private health insurance.



60% of CYSHCN with public insurance did not receive all of the respite care they needed

69% of CYSHCN with private insurance did not receive all of the respite care they needed

Parents of CYSHCN reported using a variety of different types of respite care providers, with an unpaid friend or relative being the most common

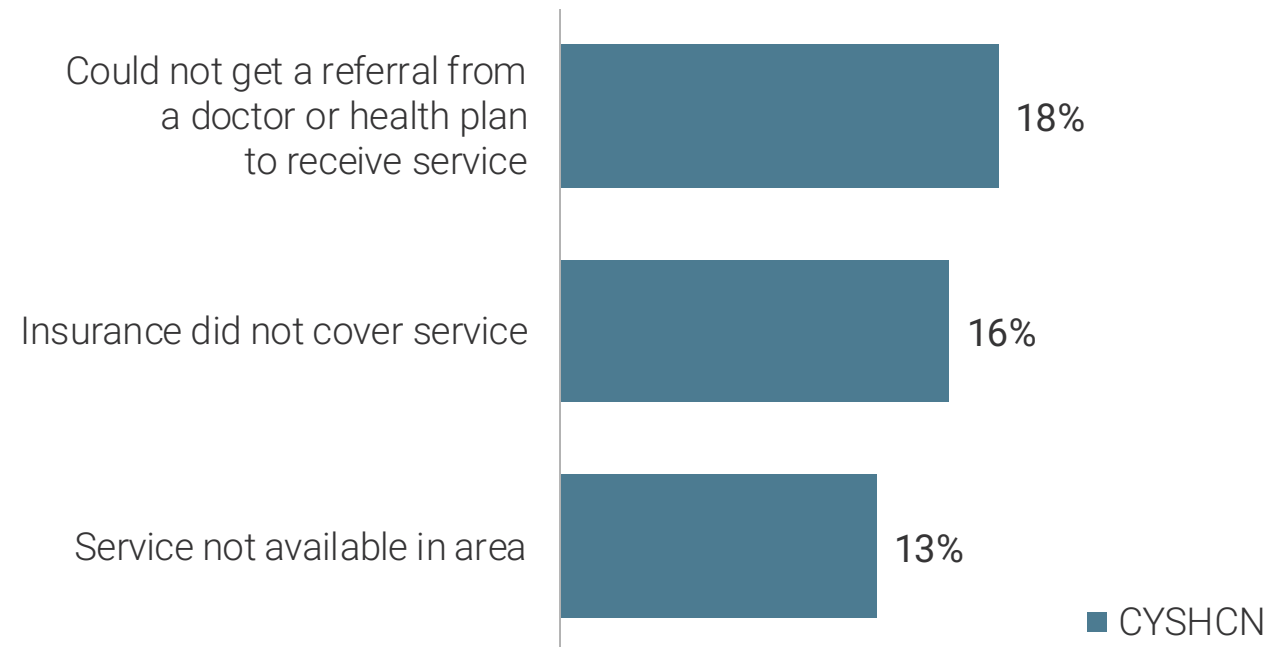


Q: Who provided the respite care [during the past 12 months/since their birth]?

Two-thirds of families of CYSHCN experienced barriers when trying to access respite care including insurance not covering the service

66% of families of CYSHCN
who needed respite care
experienced at least one
barrier seeking the service

Barriers Experienced While Seeking Respite Care

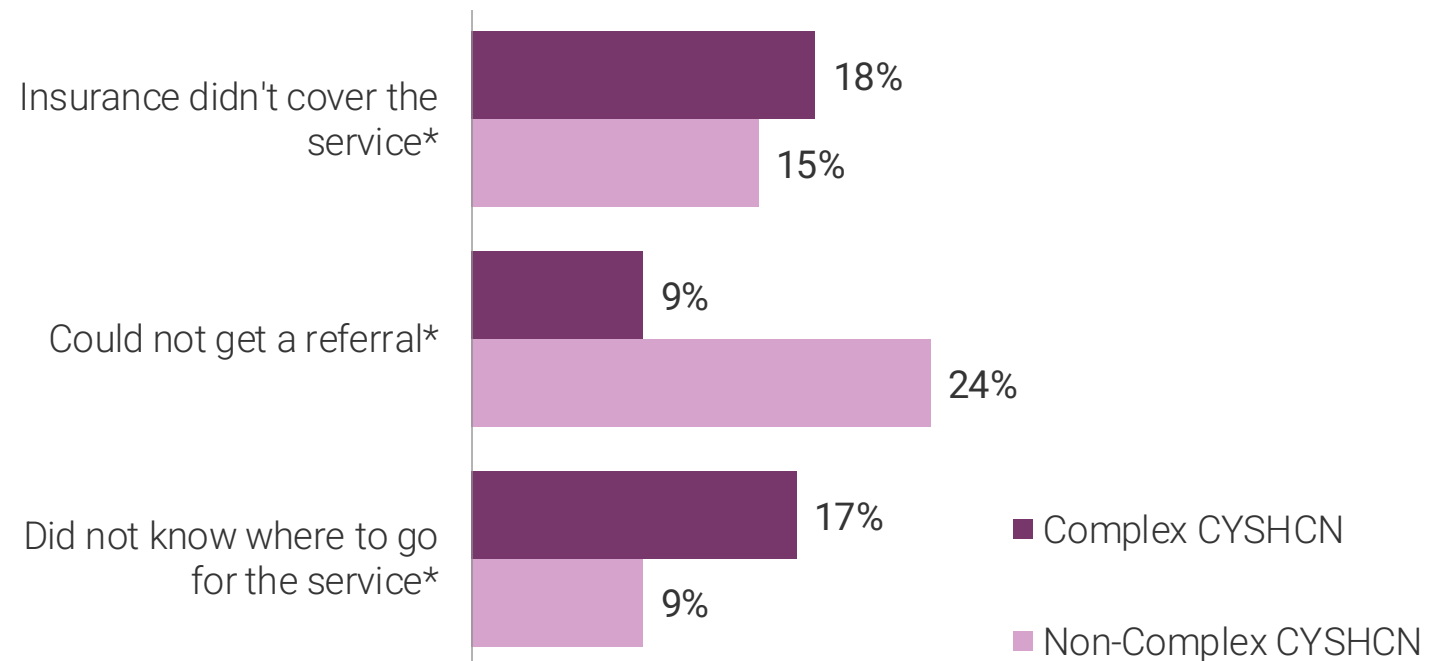


Q: In seeking respite care [during the past 12 months/since their birth] did you or your family experience any of the following challenges?

Similar percentages of parents of CYSHCN with and without complex needs experienced barriers to respite care.

68% of parents of complex CYSHCN and 64% of parents of non-complex CYSHCN experienced at least one barrier seeking respite care*

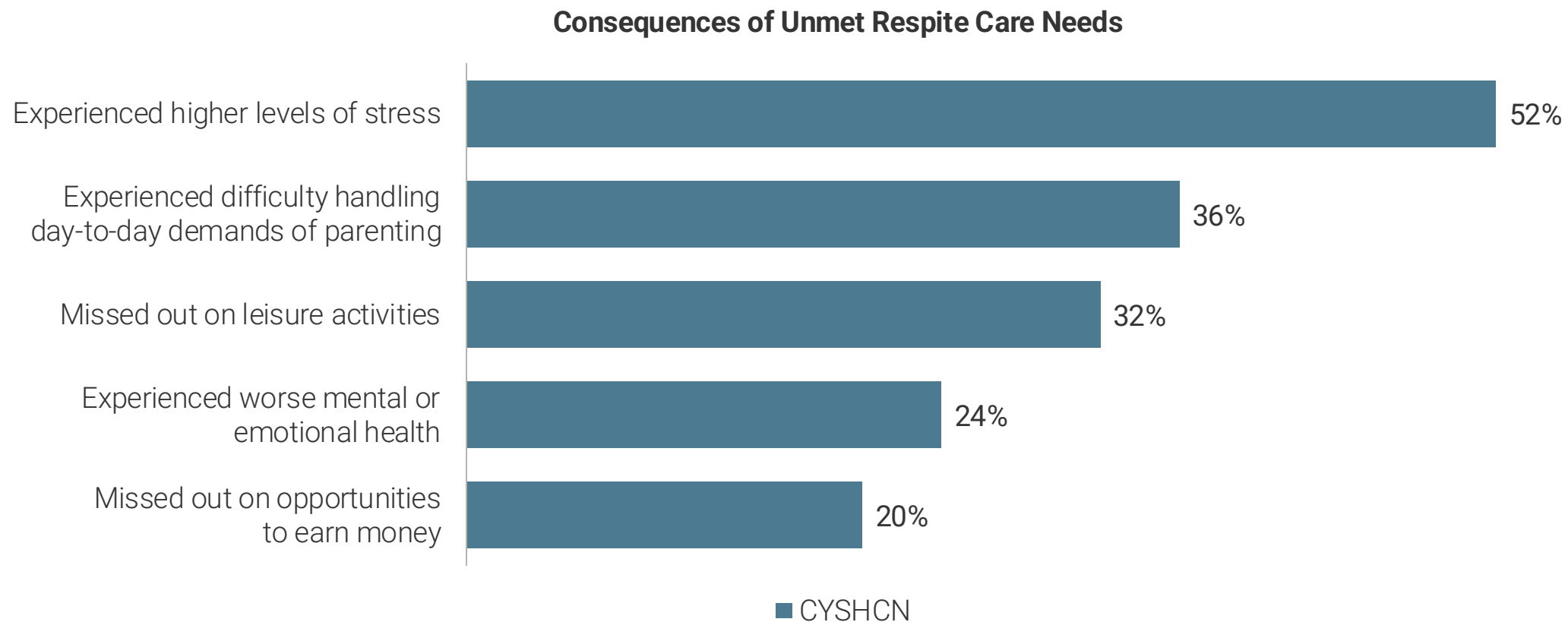
Barriers Experienced by CYSHCN Seeking Respite Care, by Insurance Type



Q: In seeking respite care for your child [during the past 12 months/since their birth], did you [or your child] experience any of the following challenges?

* Not statistically significant at $p < 0.05$

Parents of CYSHCN who didn't receive the respite care they needed were impacted in a variety of ways including higher levels of stress



Q: As a result of not receiving all the respite care you needed [during the past 12 months/since their birth], did you or your family experience any of the following?



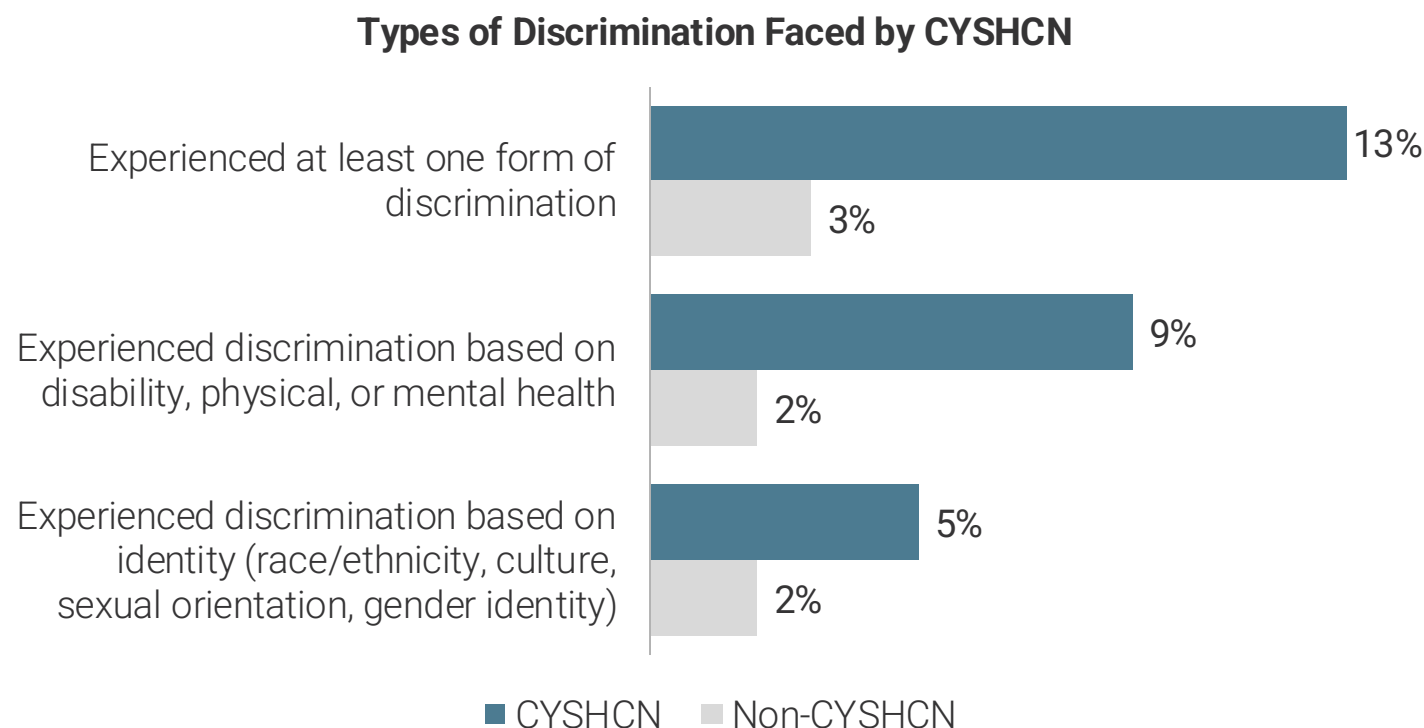
“It's extremely stressful. It's a full-time job. You have your full-time job to pay for this full-time job. One full-time job with finding the insurance, finding the doctors, then getting him here, getting him there, making sure the meds are taken like they're supposed to. And then you work a job and 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.”

- Mother of child with a developmental disability

Other Health Care Experiences



CYSHCN were more likely to experience various forms of discrimination *from a health care provider* than other children



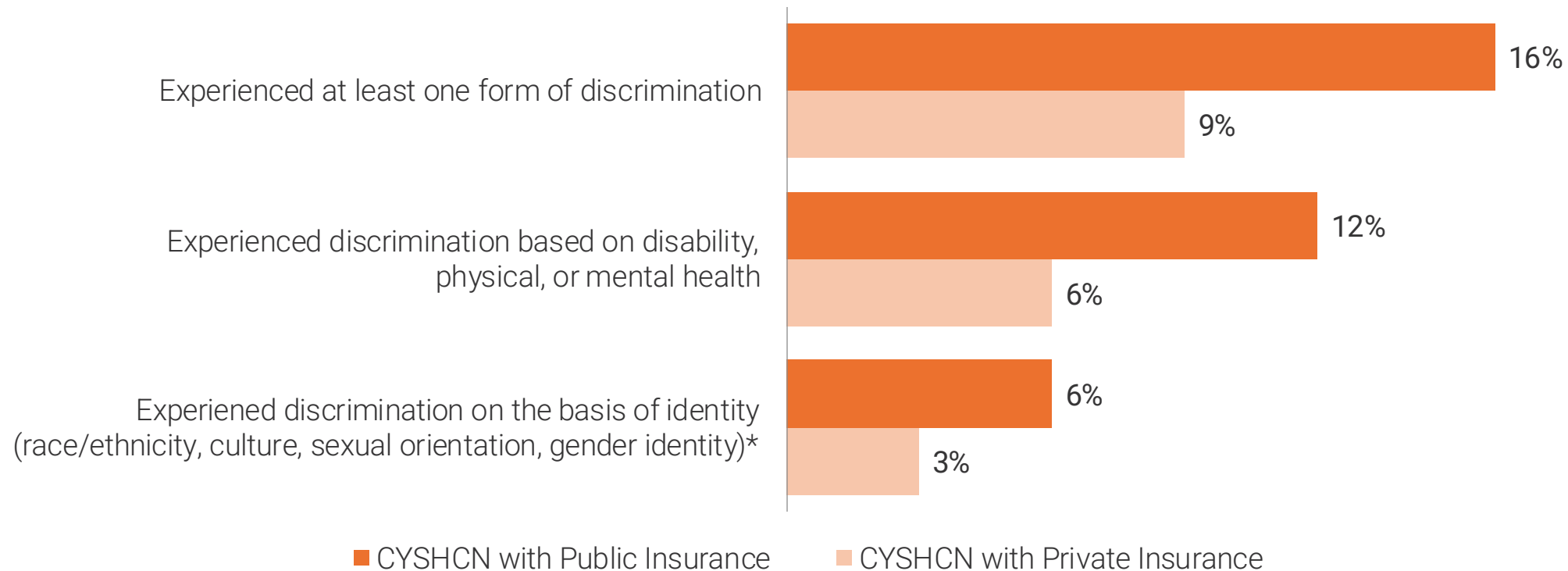
8% of Black and Hispanic parents of CYSHCN reported their children had experienced discrimination based on race or ethnicity.

20% of parents of children with ASD and 19% of parents of children with functional limitations reported their children had experienced discrimination based on disability, physical, or mental health.

Q: Have you ever felt your child was treated unfairly or inappropriately by a health care provider (such as a doctor or nurse) because of any of the following?

CYSHCN with public insurance face more discrimination than CYSHCN with private insurance.

Types of Discrimination Faced by CYSHCN – by Insurance Type

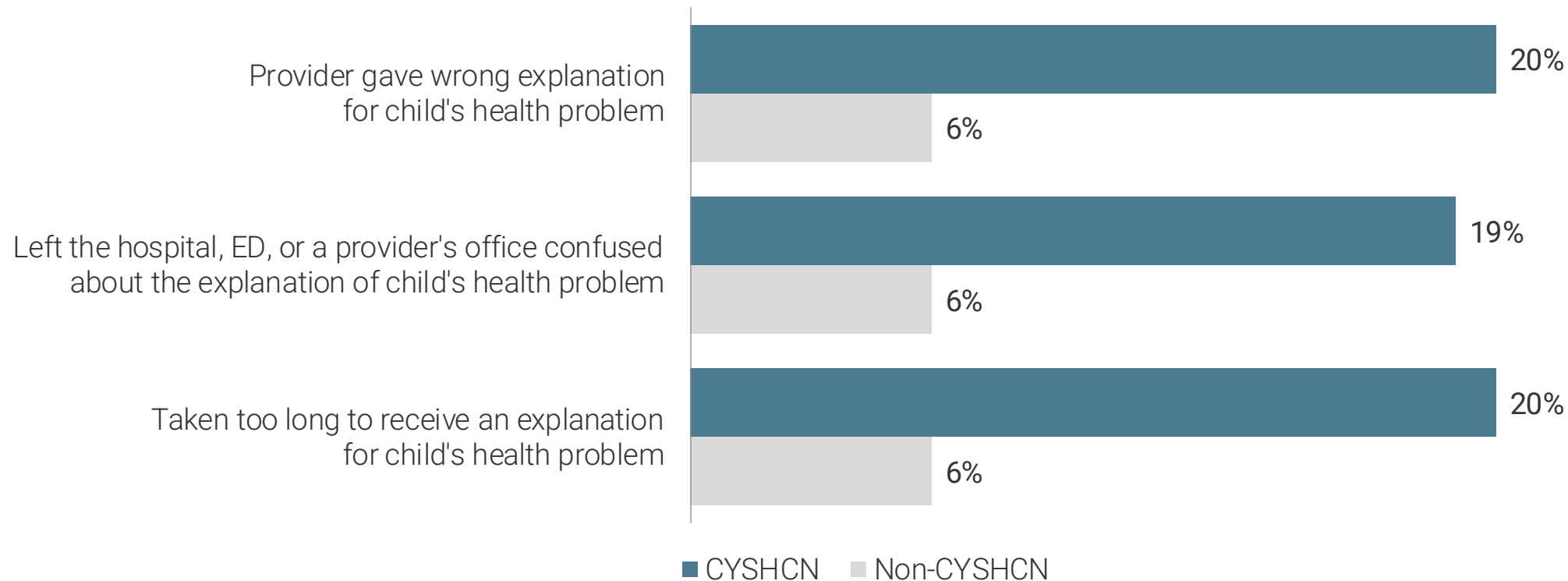


Q: Have you ever felt your child was treated unfairly or inappropriately by a health care provider (such as a doctor or nurse) because of any of the following?

* Not statistically significant at $p < 0.05$

CYSHCN were three times more likely to experience a diagnostic problem as compared to other children

Challenges Faced in Receiving and Understanding Explanations of Child's Health Problems



Q: [In the past 5 years / Since your child's birth], has a provider given you the wrong explanation for your child's health problem(s)?

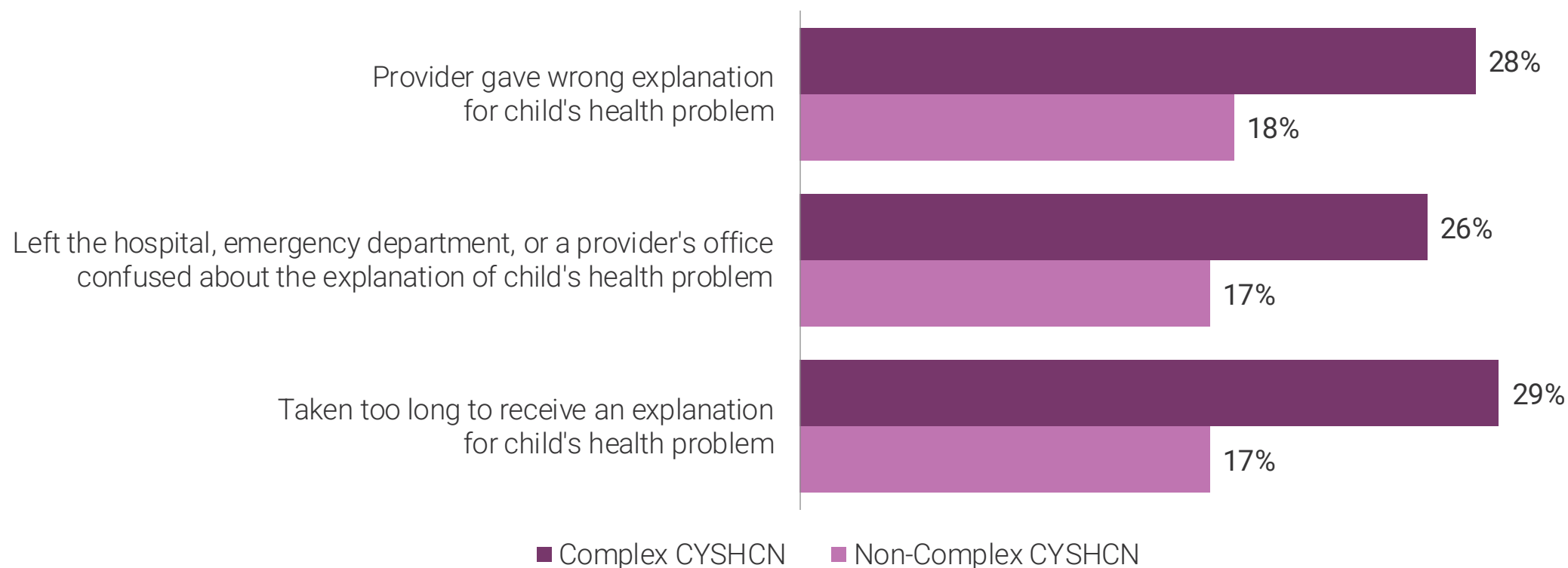
Q: [In the past 5 years / Since your child's birth], have you left the hospital, the emergency department, or a provider's office confused about the explanation of your child's health problem(s)?

Q: [In the past 5 years / Since your child's birth], has it taken too long to receive an explanation for your child's health problem(s)?

All comparisons are statistically significant at $p < 0.05$

Complex CYSHCN were more likely to experience a diagnostic problem compared to non-complex CYSHCN.

Challenges Faced in Receiving and Understanding Explanations of Child's Health Problems



Q: [In the past 5 years / Since your child's birth], has a provider given you the wrong explanation for your child's health problem(s)?

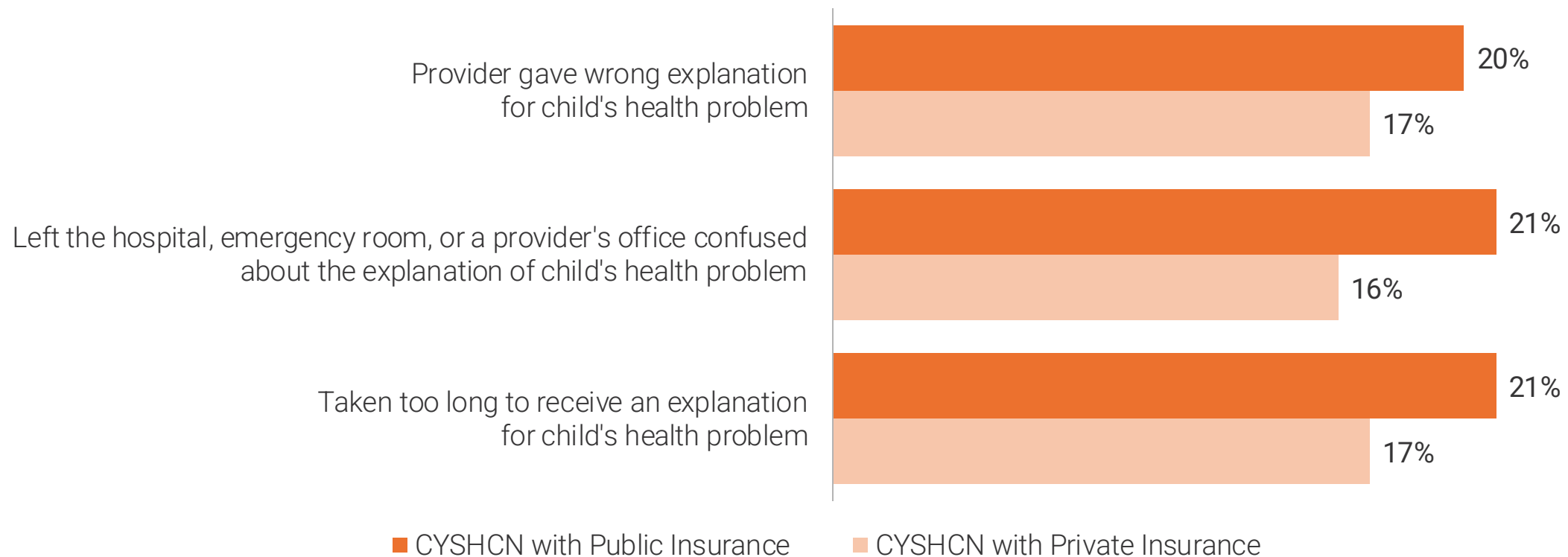
Q: [In the past 5 years / Since your child's birth], have you left the hospital, the emergency department, or a provider's office confused about the explanation of your child's health problem(s)?

Q: [In the past 5 years / Since your child's birth], has it taken too long to receive an explanation for your child's health problem(s)?

All comparisons are statistically significant at $p < 0.05$

CYSHCN with public and private insurance experienced diagnostic problems at similar rates.

Challenges Faced in Receiving and Understanding Explanations of Child's Health Problems



Q: [In the past 5 years / Since your child's birth], has a provider given you the wrong explanation for your child's health problem(s)?

Q: [In the past 5 years / Since your child's birth], have you left the hospital, the emergency department, or a provider's office confused about the explanation of your child's health problem(s)?

Q: [In the past 5 years / Since your child's birth], has it taken too long to receive an explanation for your child's health problem(s)?

All comparisons are NOT statistically significant at $p < 0.05$

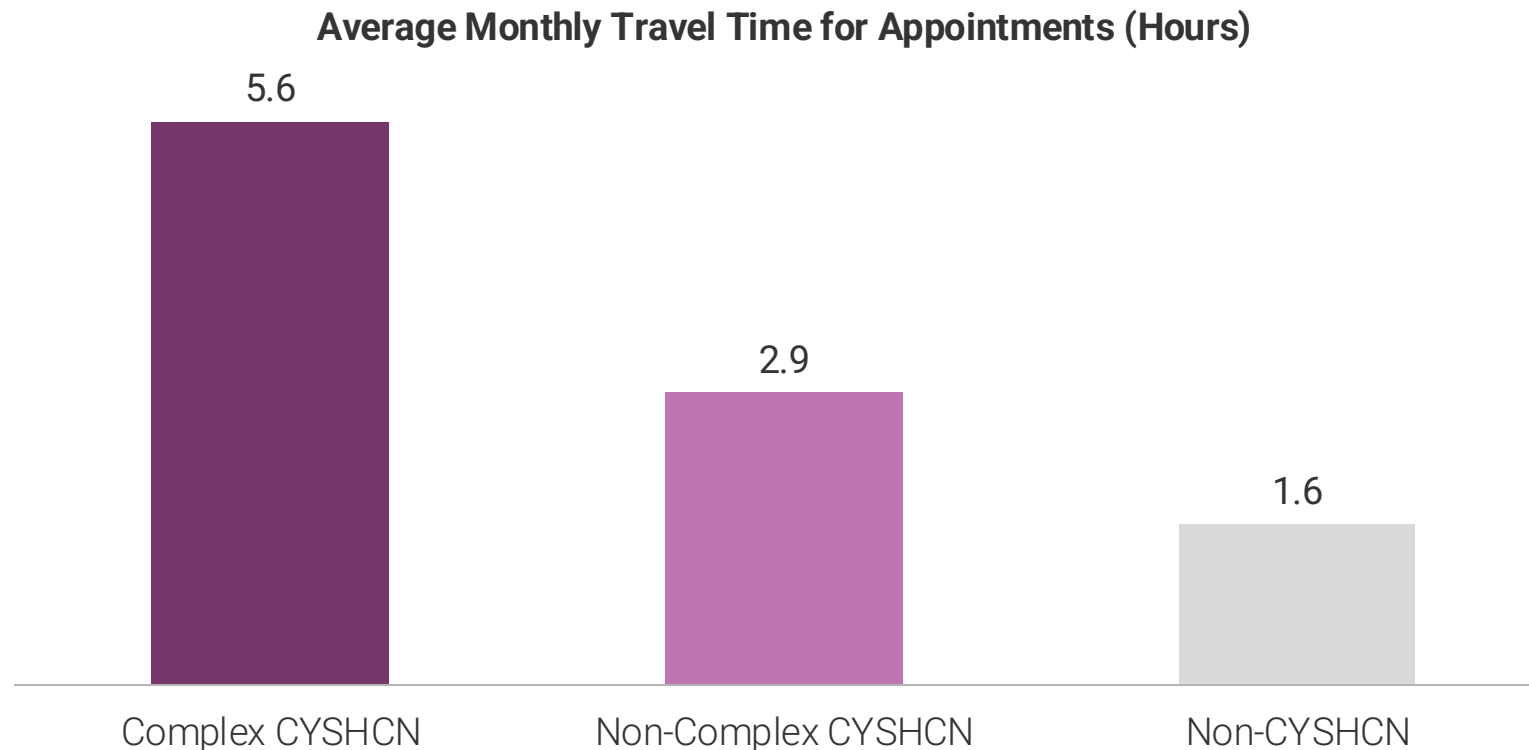


“I know when my daughter started having problems, I [noticed] she was having problems. But it wasn't getting ‘bad enough’ where [her doctors] believed me. Then she started losing weight. And they're like, ‘oh, she's just a *happy spitter*.’ And then they wanted to do all these invasive tests that are hard to do. And they're like, ‘oh, it's not this, it's not this, it's not this.’ But they wouldn't give me any answers. Yeah, it was really frustrating.

Once she started losing weight, they started taking it like a little more seriously. It was really annoying 'cause I knew that. She went through feeding therapy and all this because they didn't listen in the first place.”

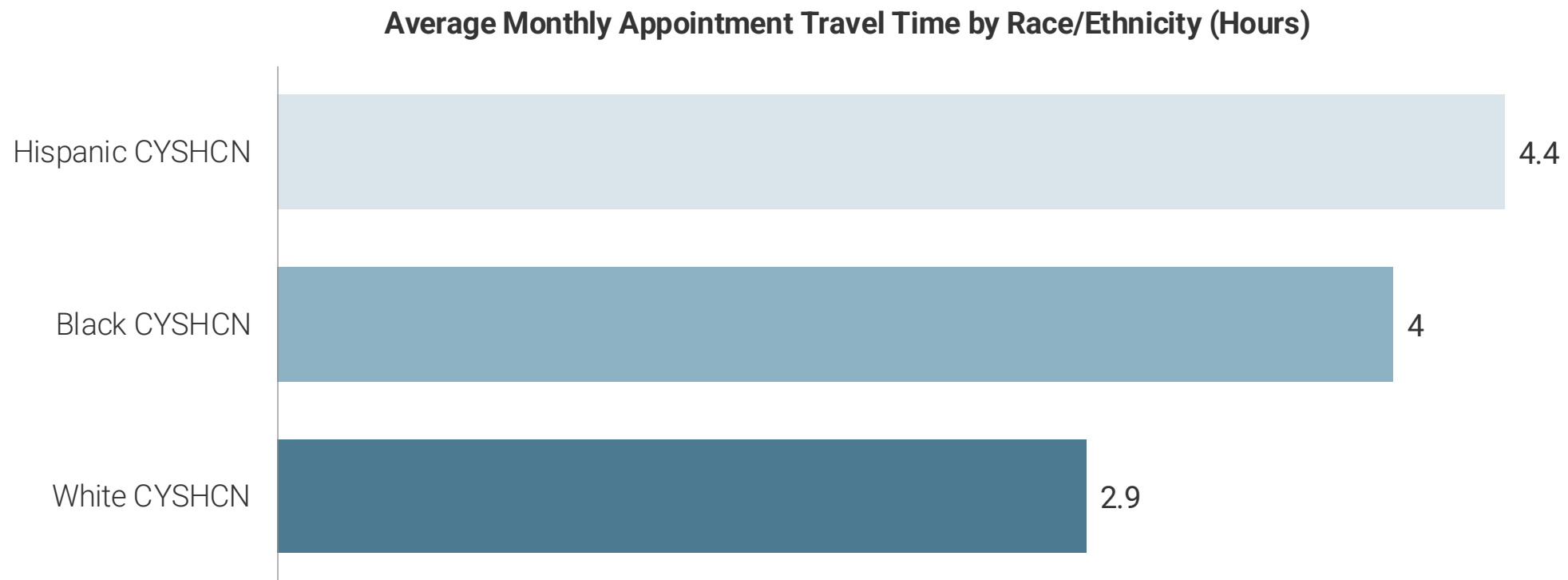
- *Mother of child with a developmental disability*

Parents of CYSHCN, particularly parents of complex CYSHCN, spend more time traveling to appointments than other parents.



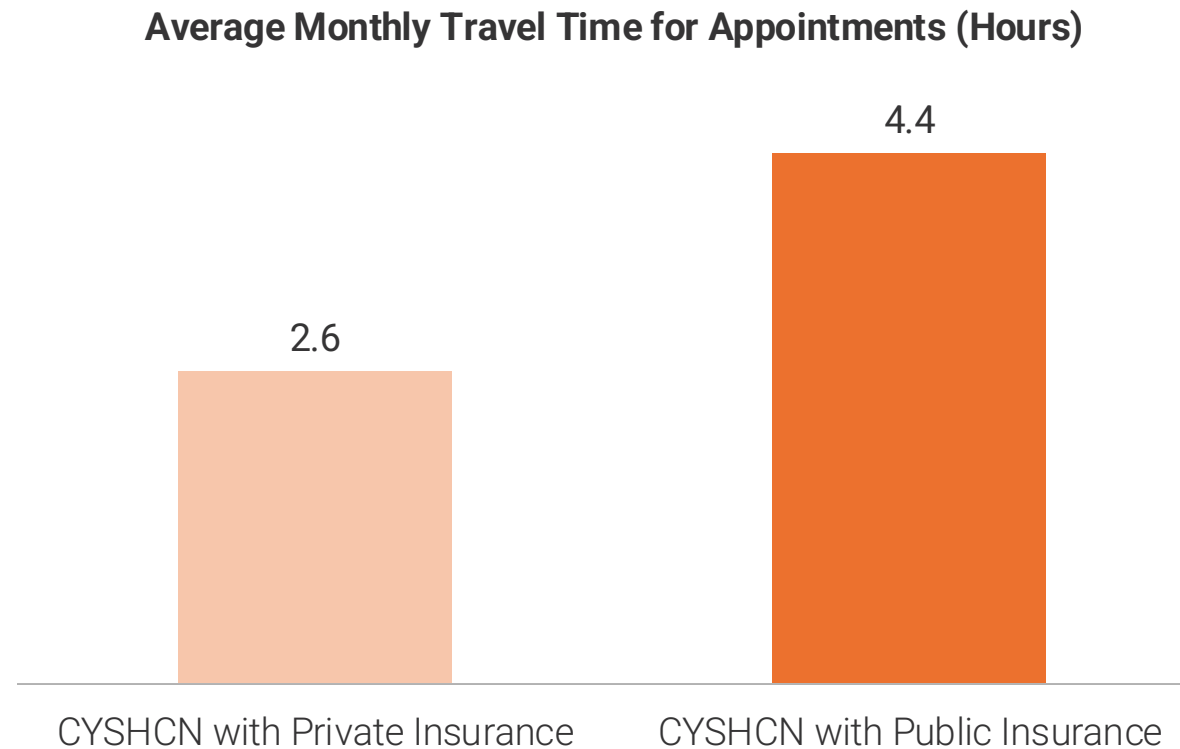
Q: How much time in a typical month do you spend traveling to take your child to all of their appointments?
All comparisons are statistically significant at $p < 0.05$

Black and Hispanic parents of CYSHCN have longer travel times than white parents.



Q: How much time in a typical month do you spend traveling to take your child to all of their appointments?
All comparisons are statistically significant at $p < 0.05$

CYSHCN with public insurance spent more time traveling to appointments in an average month than CYSHCN with private insurance.



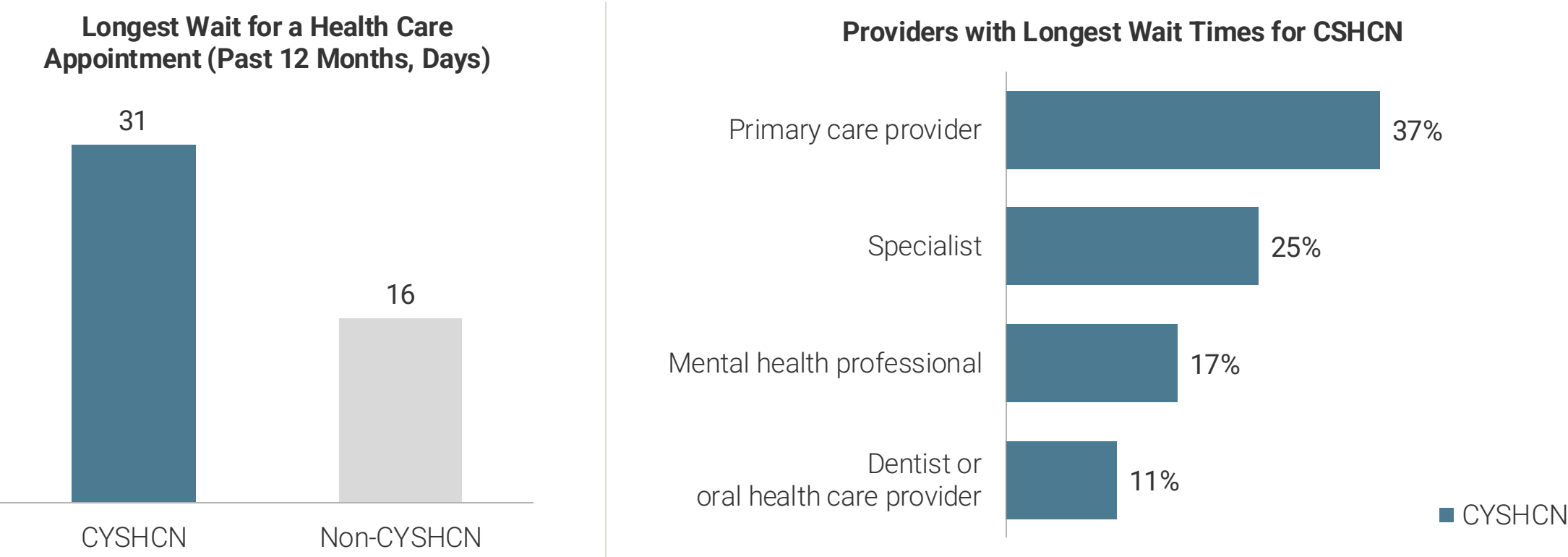
Q: How much time in a typical month do you spend traveling to take your child to all of their appointments?
All comparisons are statistically significant at $p < 0.05$



“The locations of the [doctors’ offices] are sometimes an hour away or maybe an hour and a half away, and then you go there just to be told that you have to see another specialist. They have to give you a recommendation for a specialist when they could have done that over the phone, you know? I spent the time and gas.”

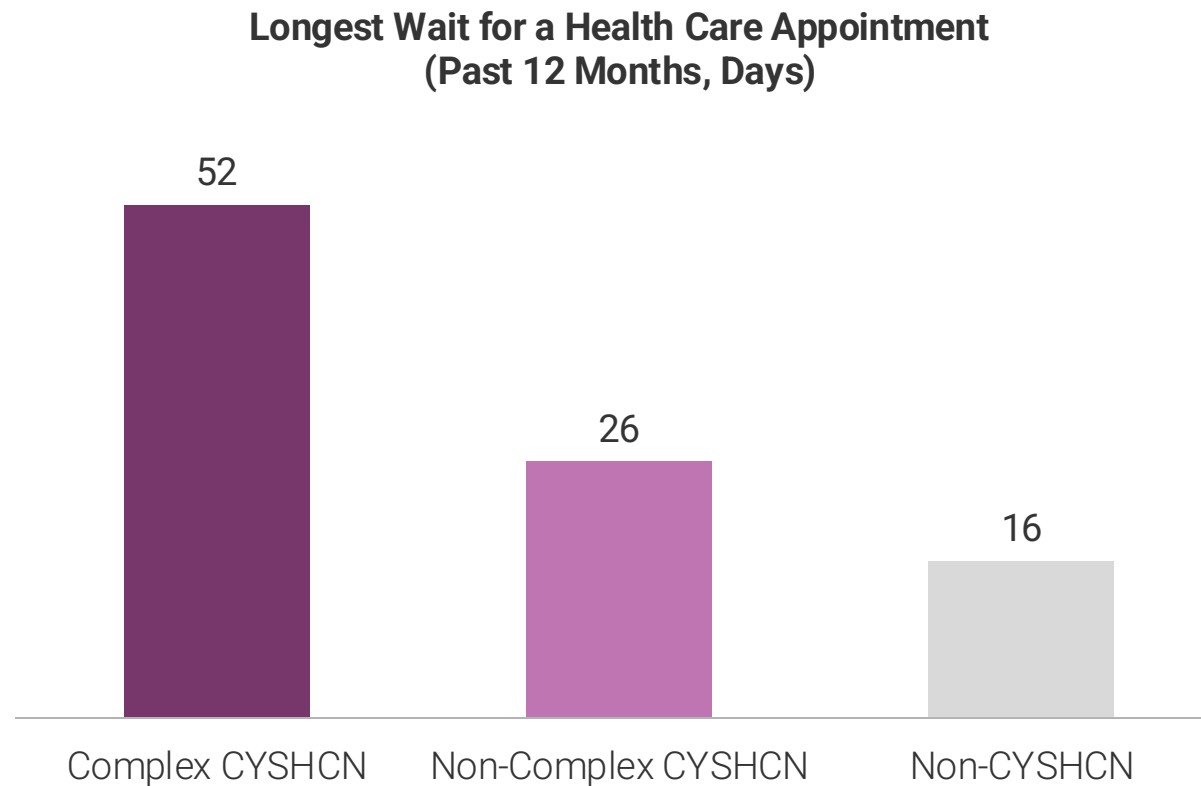
- Father of child with a developmental disability

CYSHCN also wait twice as long for appointments as other children



Q: [During the past 12 months/Since their birth], what was the longest you [or your child] had to wait for a health care appointment or service that your child needed?
Q: Thinking about the appointment that you [or your child] waited the longest for, what type of provider were they trying to see?
All comparisons are statistically significant at p<0.05

Complex CYSHCN wait more than three times as long for an appointment compared to non-complex CYSHCN.

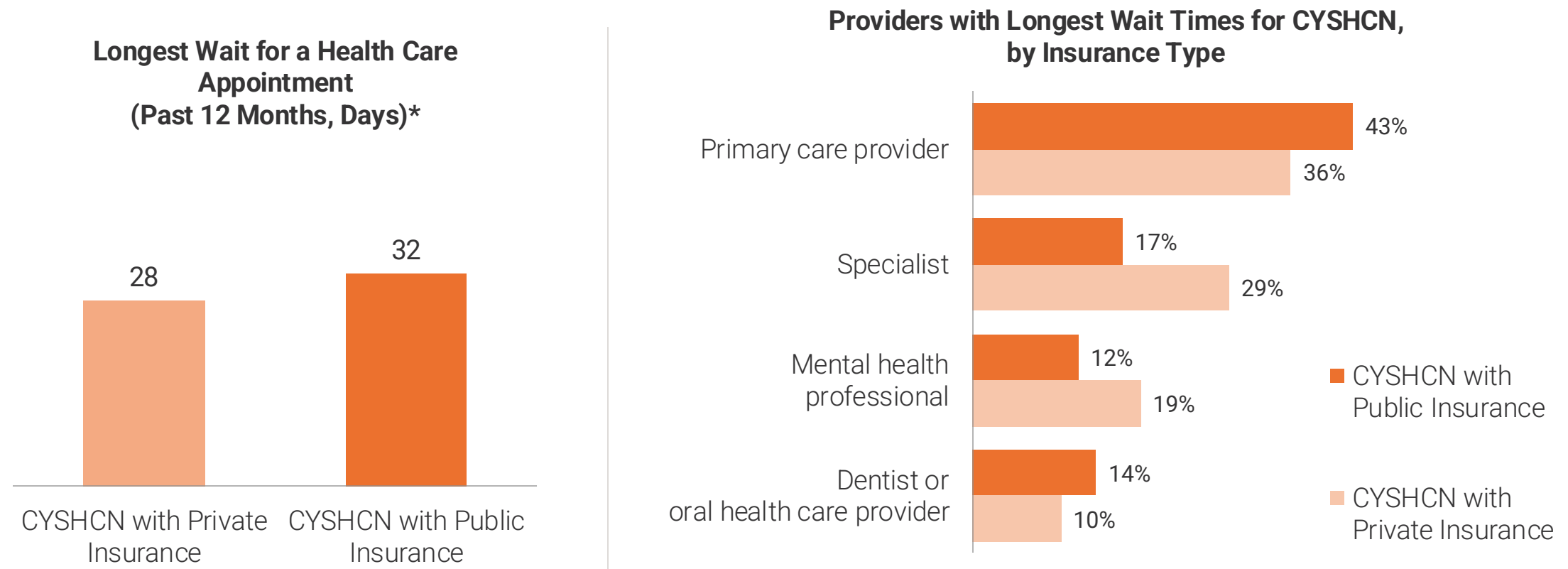


Q: [During the past 12 months/Since their birth], what was the longest you [or your child] had to wait for a health care appointment or service that your child needed?

Q: Thinking about the appointment that you [or your child] waited the longest for, what type of provider were they trying to see?

All comparisons are statistically significant at $p < 0.05$

CYSHCN with public and private insurance have similar “longest wait times” to see providers, but the type of provider they waited longest to see differs.



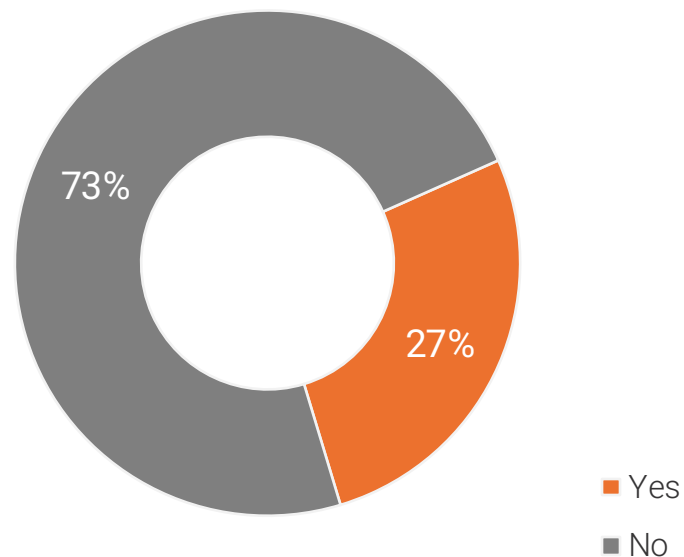
Q: [During the past 12 months/Since their birth], what was the longest you [or your child] had to wait for a health care appointment or service that your child needed?

Q: Thinking about the appointment that you [or your child] waited the longest for, what type of provider were they trying to see?

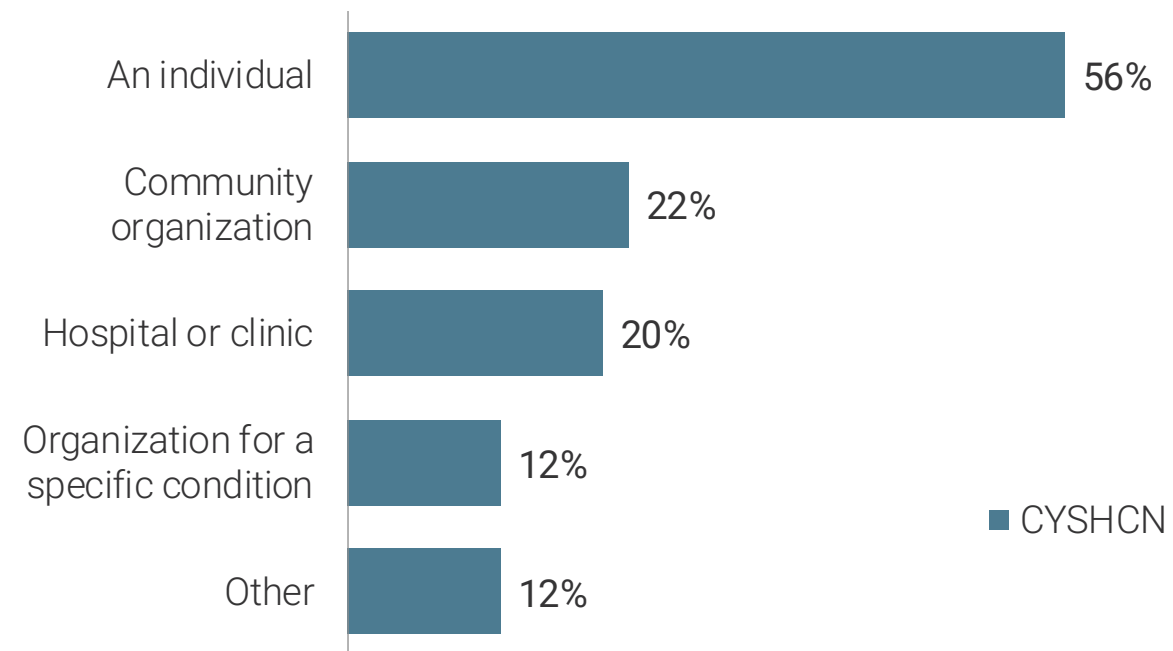
* NOT statistically significant at $p < 0.05$

Less than one-third of parents of CYSHCN report having gotten peer support related to their child's health, with most receiving it from an individual

Receipt of Peer Support among Parents of CYSHCN



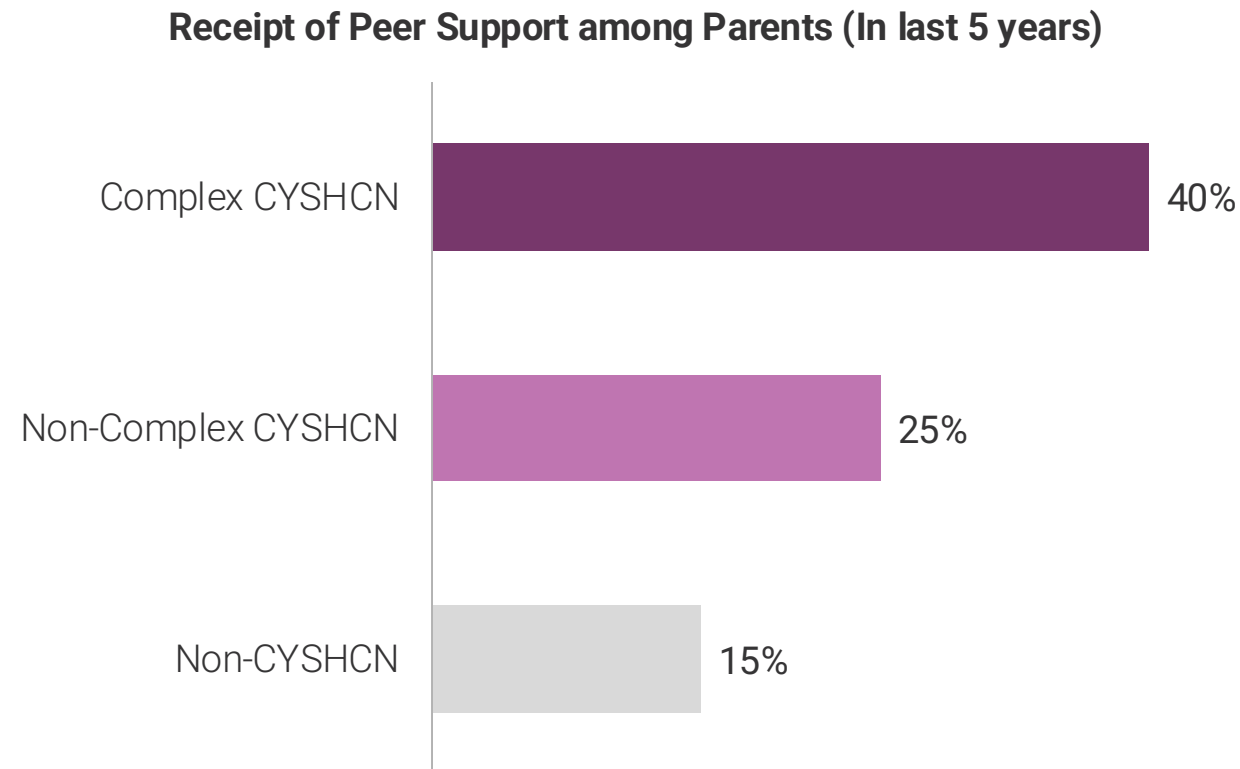
Sources of Peer Support among Parents of CSHCN



Q: [In the past 5 years / Since your child's birth], have you gotten peer support related to your child's health (that is, help and information from another parent or group of parents who have children with similar health experiences)?

Q: Who provided this peer support?

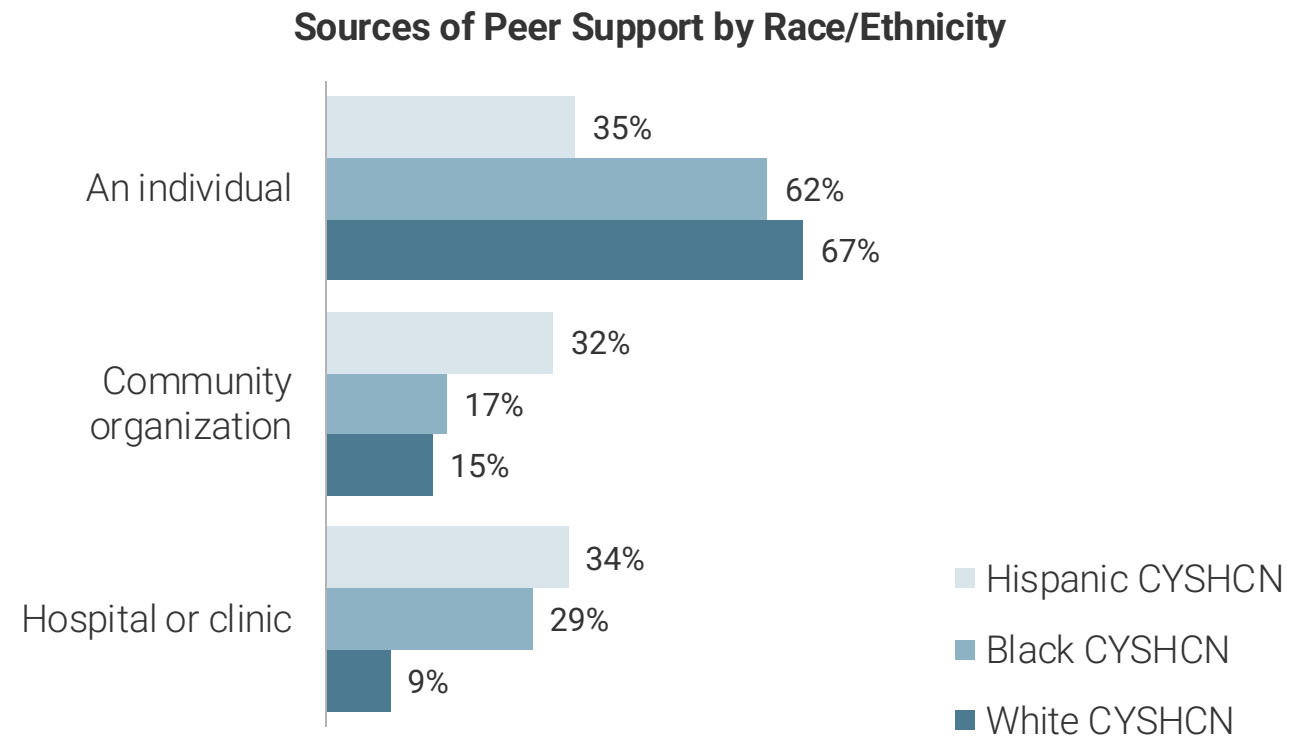
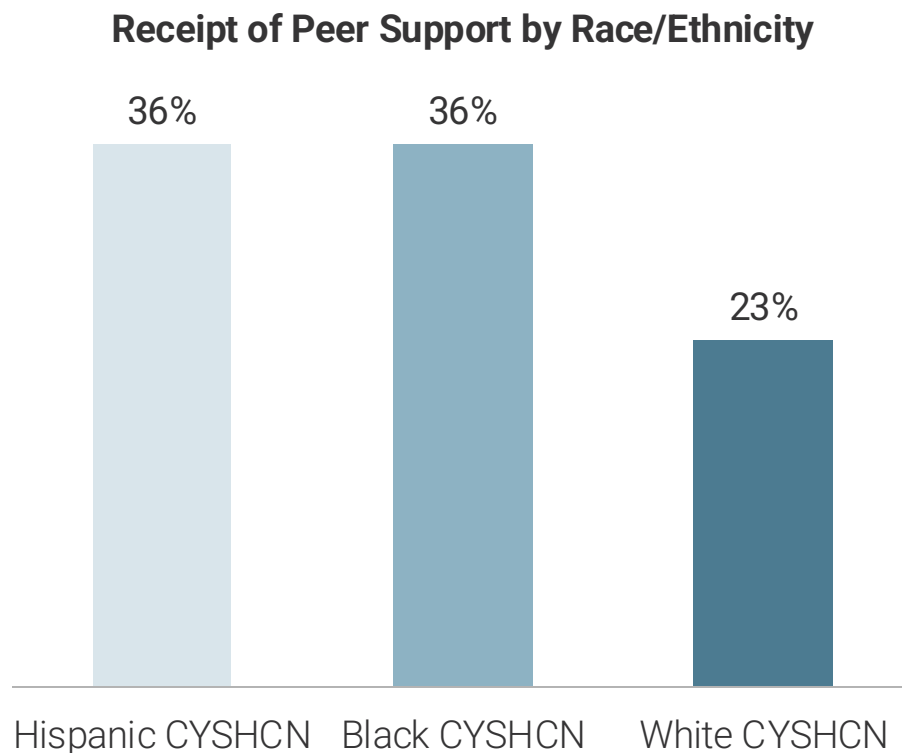
Parents of complex CYSHCN were more likely than parents of non-complex CYSHCN and non-CYSHCN to access peer supports.



Q: [In the past 5 years / Since your child's birth], have you gotten peer support related to your child's health (that is, help and information from another parent or group of parents who have children with similar health experiences)?

All comparisons are statistically significant at $p < 0.05$

Compared to white parents, Black and Hispanic parents of CYSHCN were more likely to receive peer support, and more often received it from institutional sources



Q: [In the past 5 years / Since your child's birth], have you gotten peer support related to your child's health (that is, help and information from another parent or group of parents who have children with similar health experiences)?

Q: Who provided this peer support?

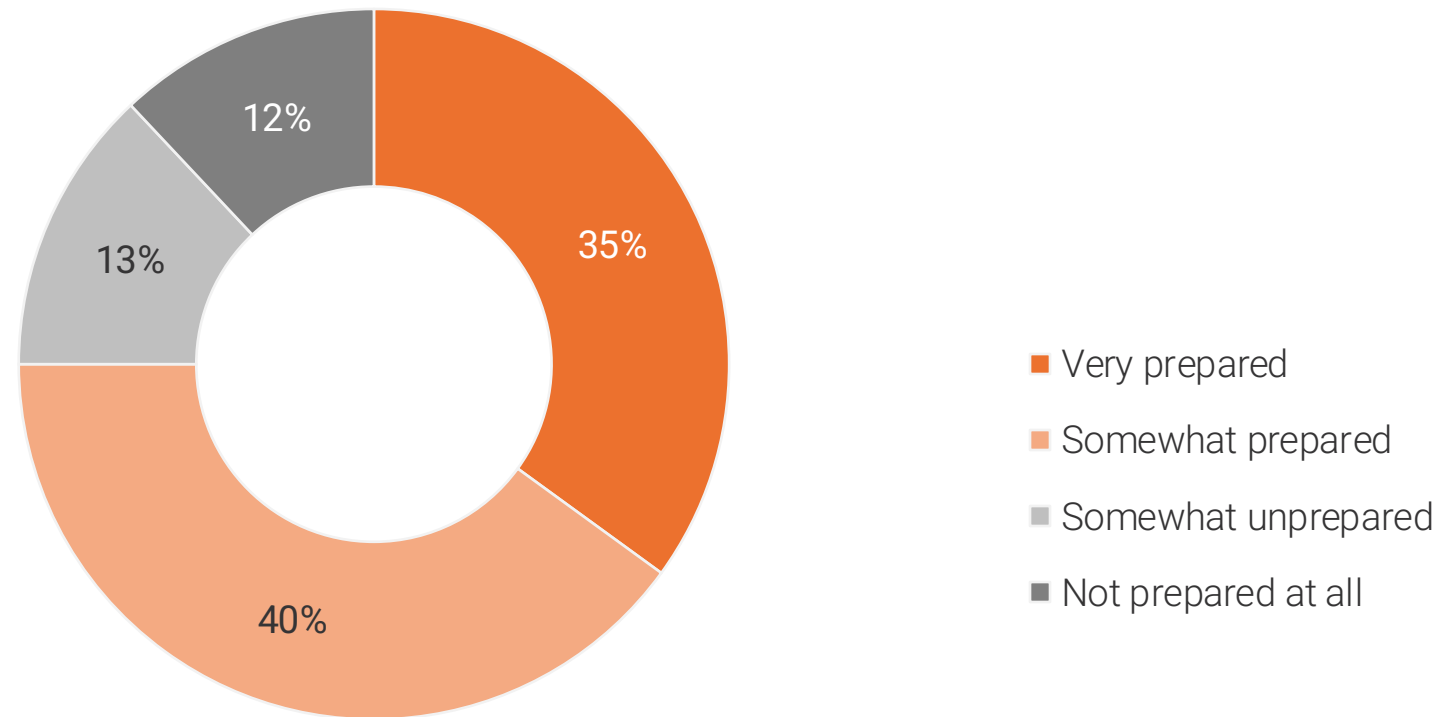
All comparisons are statistically significant at $p < 0.05$

Experiences with Transition from Pediatric to Adult Health Care



Most parents of CYSHCN aged 12-17 feel prepared for their child's transition to adult health care

Parent Perceived Preparedness for CYSHCN Transition to Adult Health Care Providers



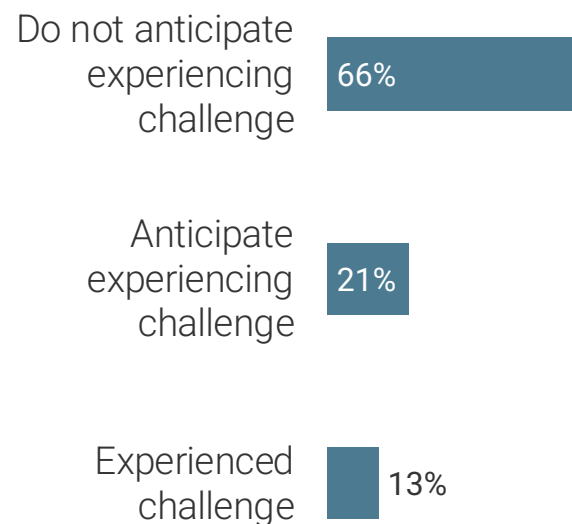
Q: How prepared do you feel for your child's transition from providers who see children to providers who see adults?

Parents of CYSHCN had varying levels of concern about challenges related to transitioning from pediatric to adult health care

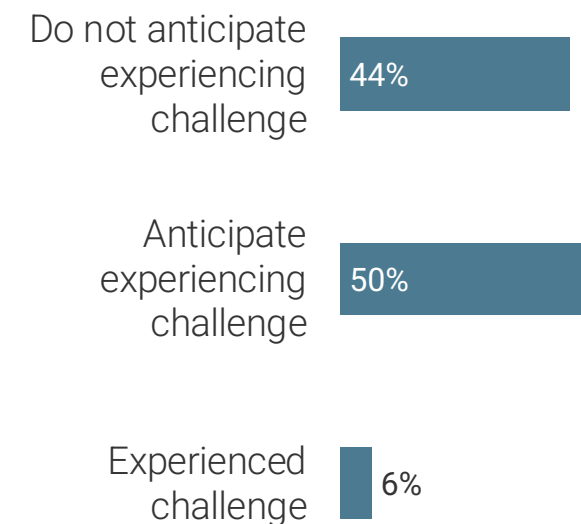
Finding an adult health care provider who understands child's medical condition(s)



Finding an adult health care provider who is nearby



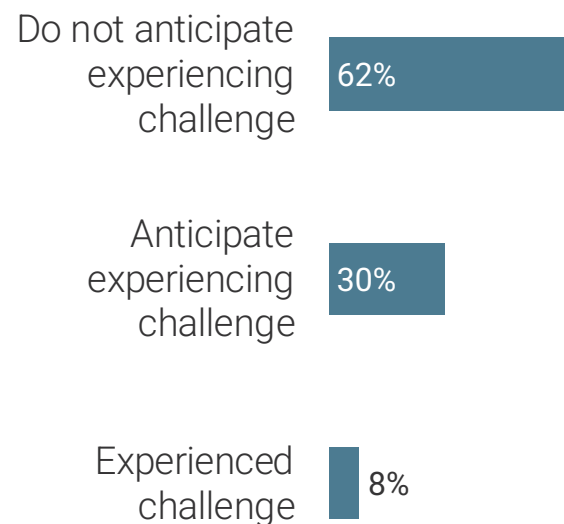
Child enrolling in or maintaining health care insurance as an adult



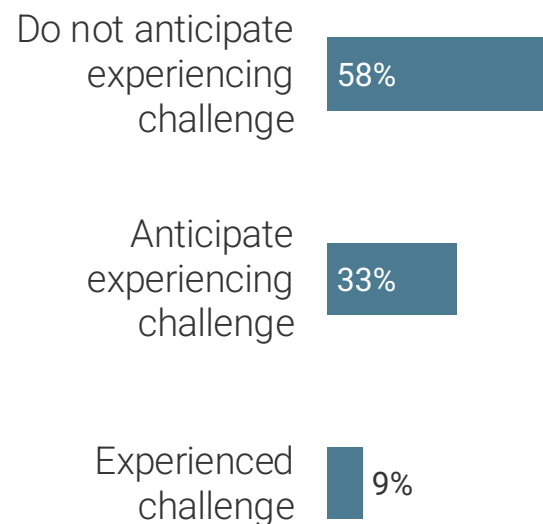
Q: Please indicate whether you have experienced or anticipate experiencing each challenge.

Parents of CYSHCN had varying levels of concern about challenges related to transitioning from pediatric to adult health care

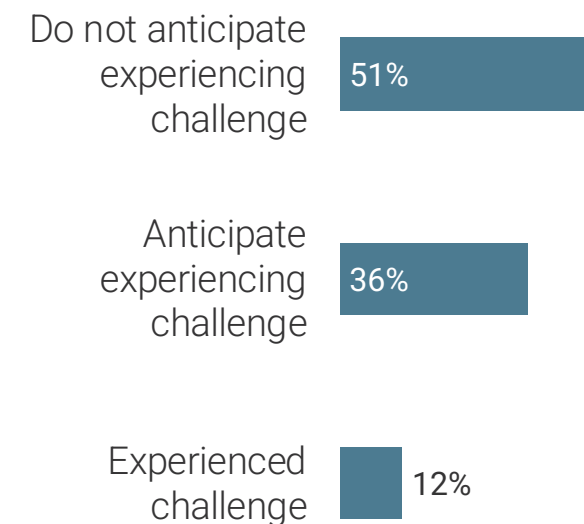
Finding an adult health care provider who takes child's insurance



Replacing the strong relationship child has or had with their pediatric providers, clinic, or health team



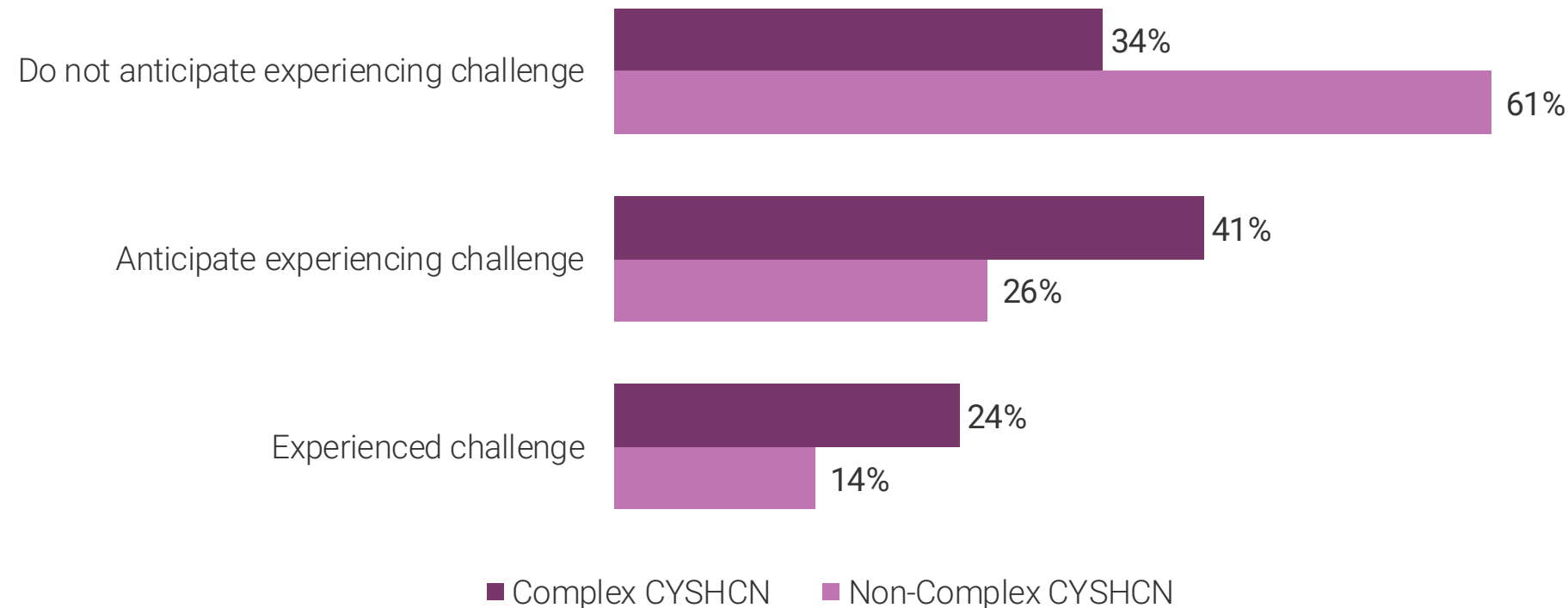
Child experiencing anxiety about receiving care from a different health care provider



Q: Please indicate whether you have experienced or anticipate experiencing each challenge.

Parents of complex CYSHCN were more concerned than parents of non-complex CYSHCN about finding an adult provider who understands their child's condition.

Finding an adult health care provider who understands child's medical condition(s)

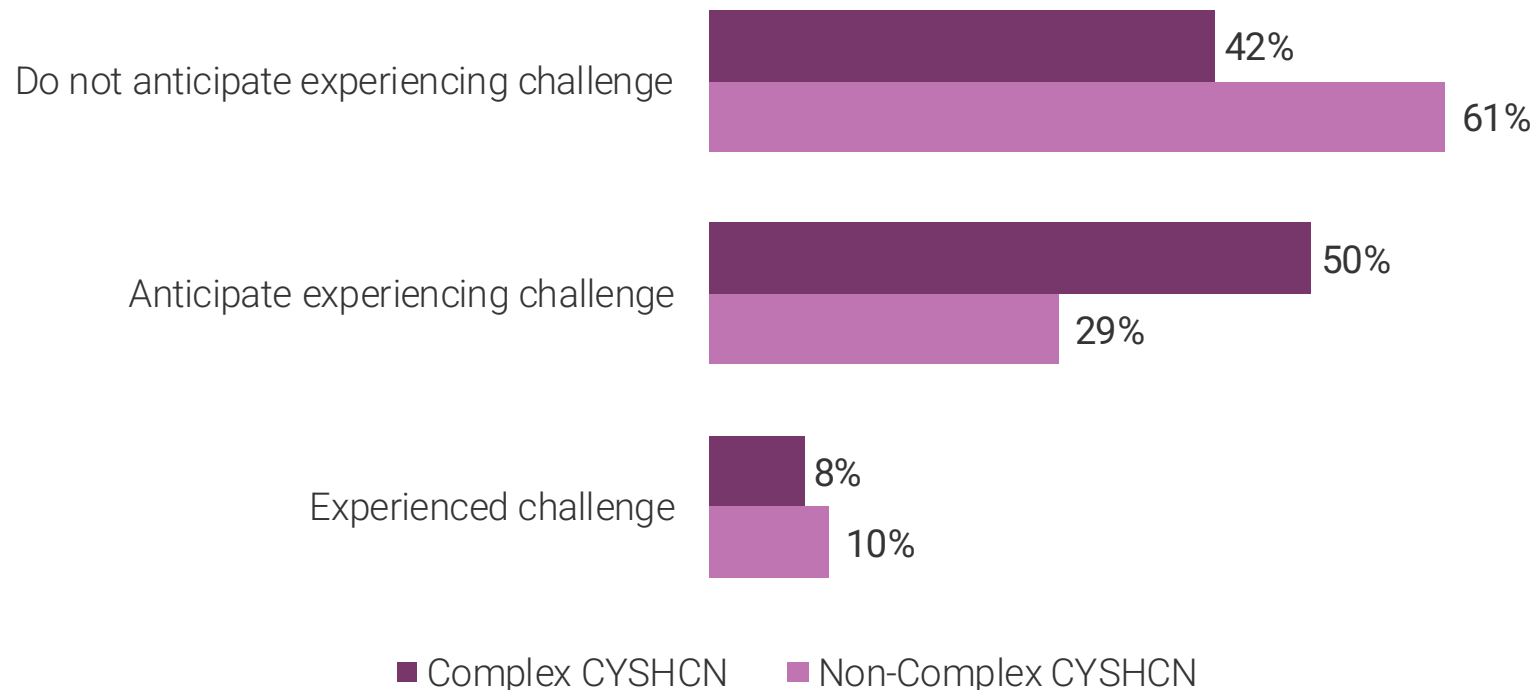


Q: Please indicate whether you have experienced or anticipate experiencing each challenge.

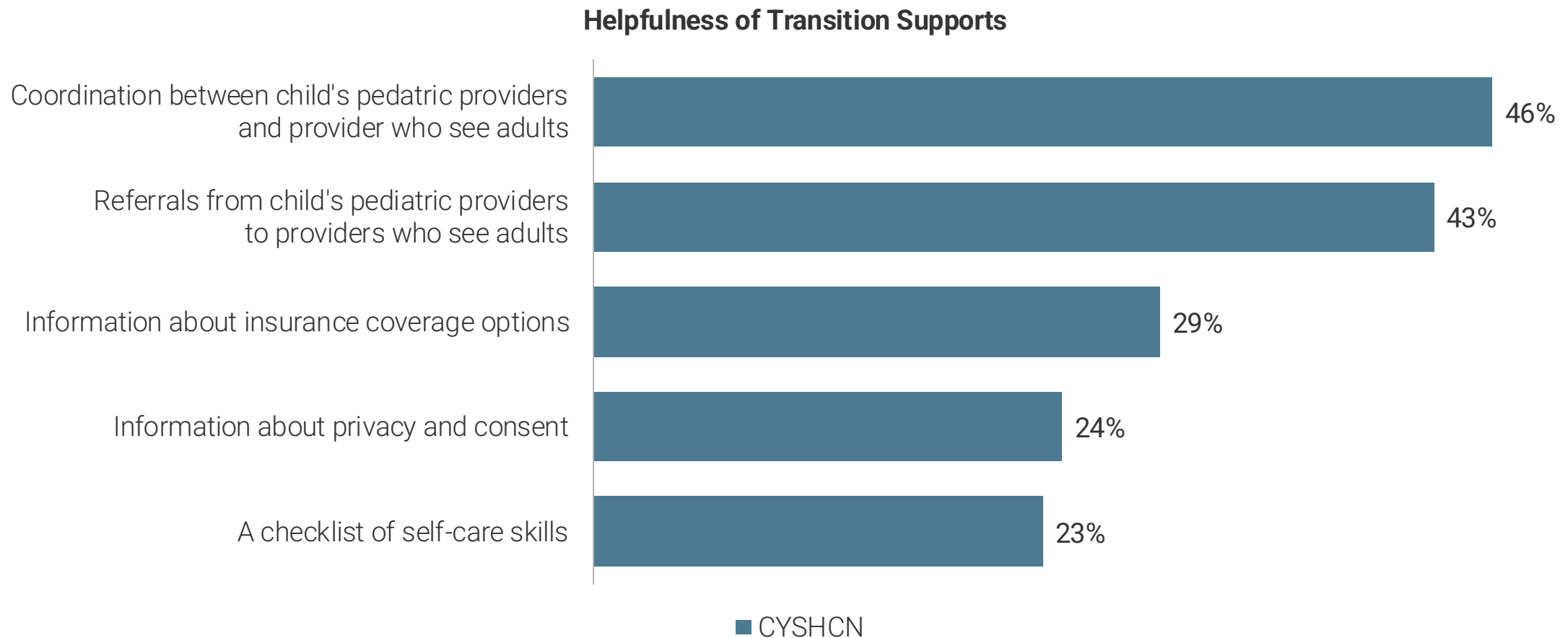
All comparisons are statistically significant at $p < 0.05$

Parents of complex CYSHCN were more concerned than parents of non-complex CYSHCN about replacing the strong relationship their child has with their pediatric providers.

Replacing the strong relationship child has or had with their pediatric providers, clinic, or health team



Parents of CYSHCN aged 12-17 find different types of transition support helpful



Q: What type of support(s) do you think are most helpful for transitioning your child from pediatric health care providers to adult health care providers?

According to parents of 18–25-year-olds with special health care needs, age 18 was the most common transition age to adult health care for their main provider

18.4

was the reported average age of transition for CYSHCN

12%

of CYSHCN over 18 are still seeing their pediatric provider

23%

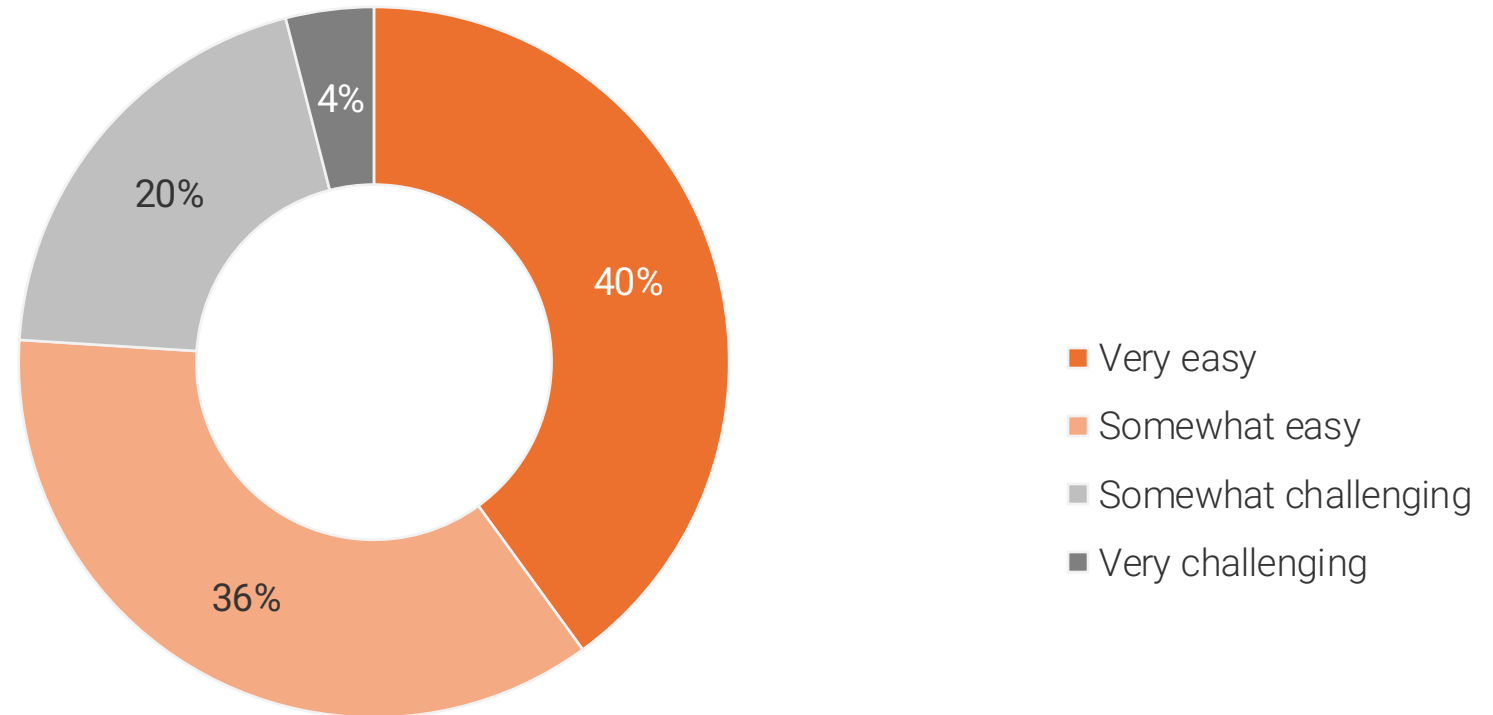
of CYSHCN over 18 did not need to transition because their provider sees children and adults

Q: At what age did your child transition from their main provider who sees children to one who sees adults?

Your child's main provider is the doctor, physician assistant, nurse, or other health care provider who knows the most about your child's health, and who is in charge of your child's overall care.

Most parents of CYSHCN over 18 reported the transition to adult health care for their child's main provider was easy

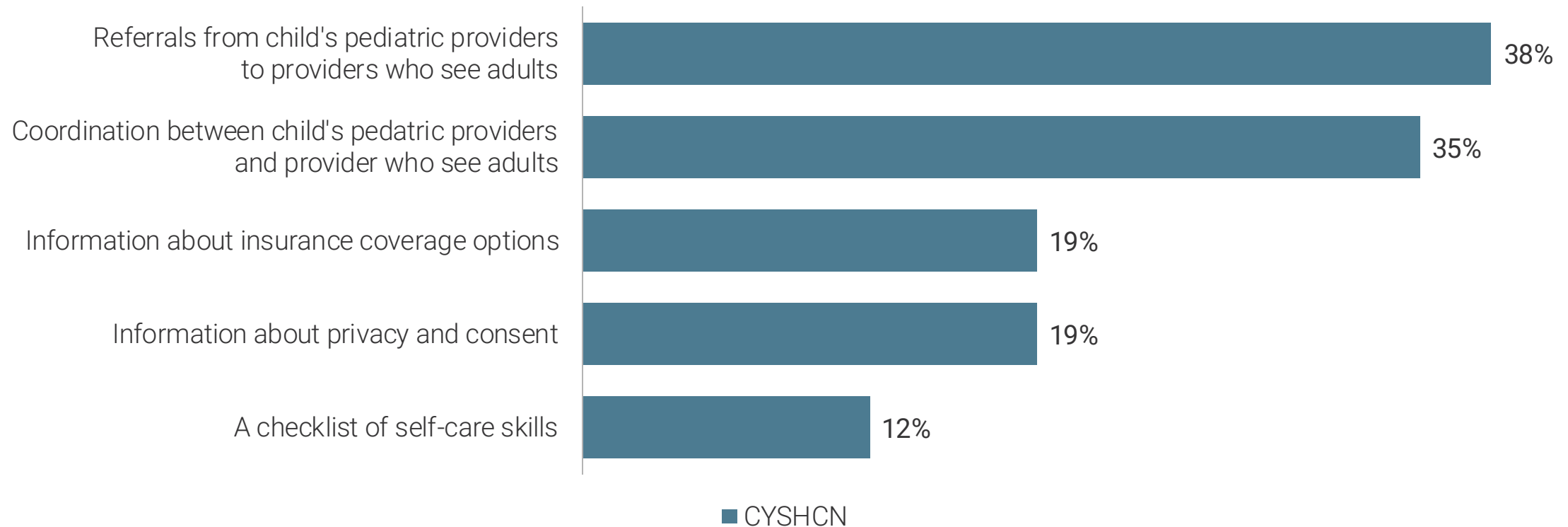
Reported Difficulty of CYSHCN's Transition to Adult Health Care



Q: How would you describe the process of transitioning from your child's main provider who sees children to one who sees adults?

Parents of CYSHCN aged 18-25 found different types of transition supports helpful

Helpfulness of Transition Supports for Parents of CYSHCN



Q: What type of support(s) do you think are most helpful for transitioning your child from pediatric health care providers to adult health care providers?



“When he turned 18, that's when things got so much harder. Because with getting his follow-ups, they're like ‘Oh well, he's 18 now. We're going to send an e-mail to him.’ And I'm like, that's going to get lost forever...They're like, ‘Whoa. We can't just give the records to you anymore, because he's 18.’ So, then it's a three-way conversation, and it has definitely become harder after he turned 18.”

- *Mother of child with a mental health condition*

Thank you.

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