

ADHD Assessment

Survey Results

Healthwatch Wirral

July 2024



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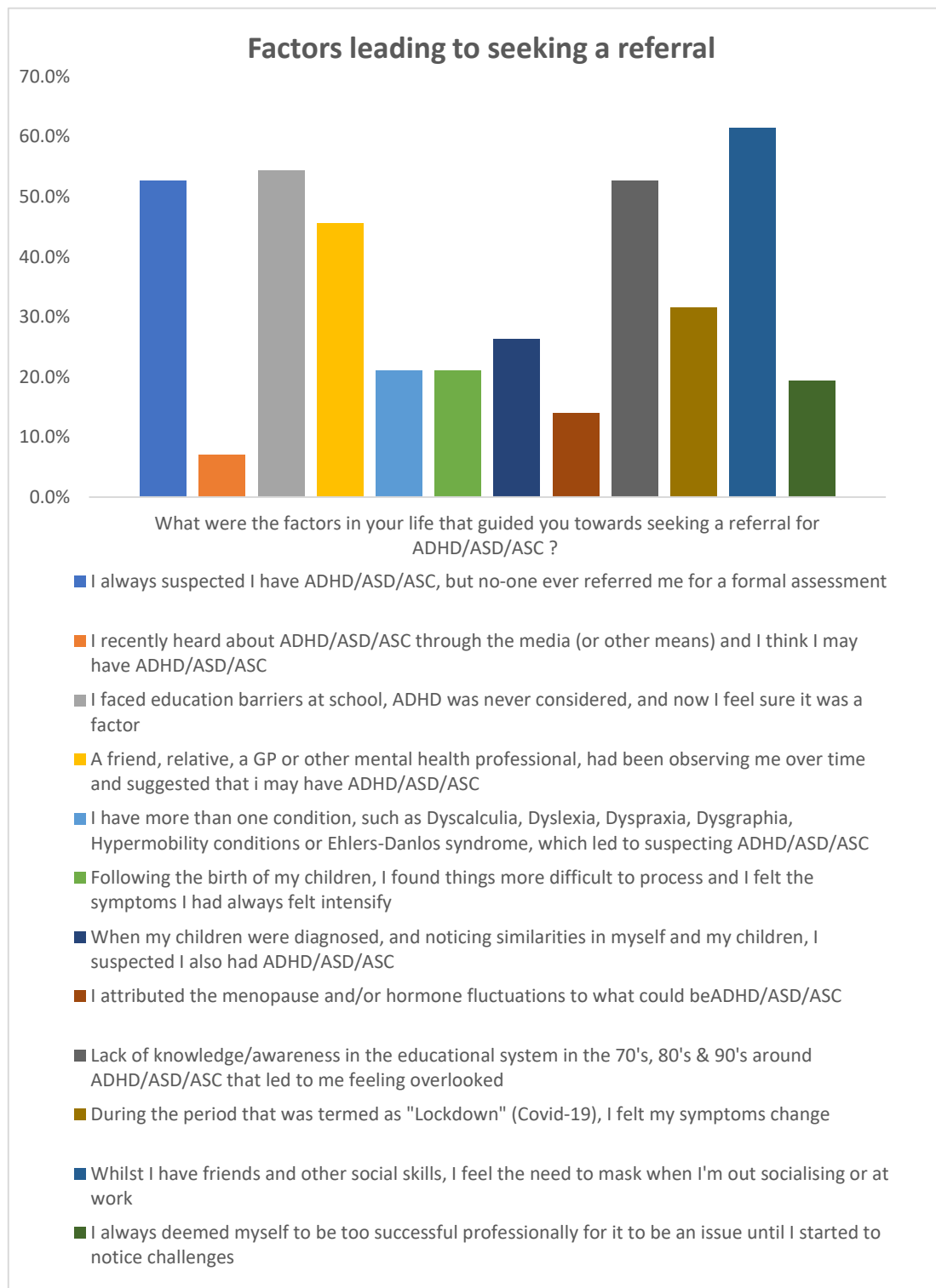
SUMMARY

Healthwatch Wirral conducted an online survey during May and June 2024 to gather public feedback from people who are waiting for an assessment for Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD) and Autistic Spectrum Condition (ASC) from services within the NHS. Key areas of the research included the process of seeking referrals, awareness of specific NHS pathways and agreements, waiting times and experiences with ADHD assessments.

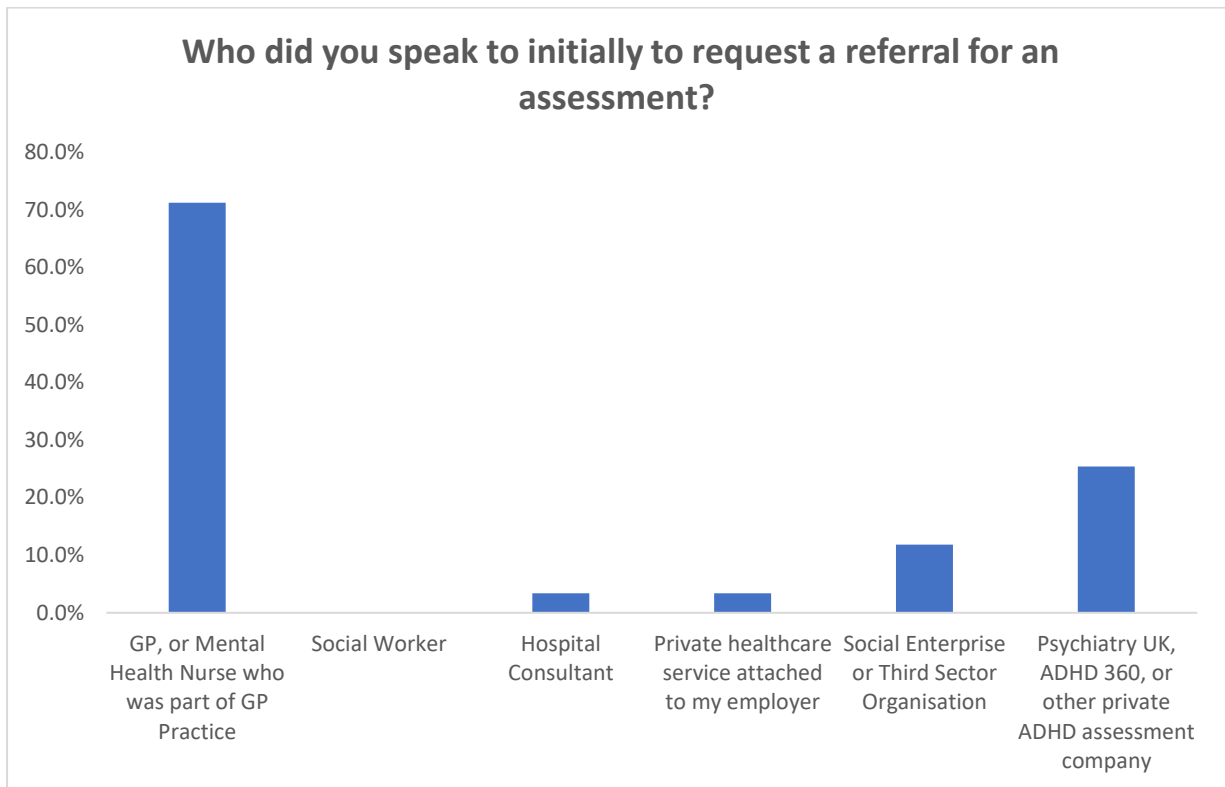
This report includes comments from service users, which highlight challenges in accessing ADHD/ASD/ASC assessments, including difficulties with referrals, long waiting times and a lack of support throughout the process. These insights reflect concerns about the availability and effectiveness of current services, particularly for women and children. This report also includes graphical representations of results.

Results of the Public Survey

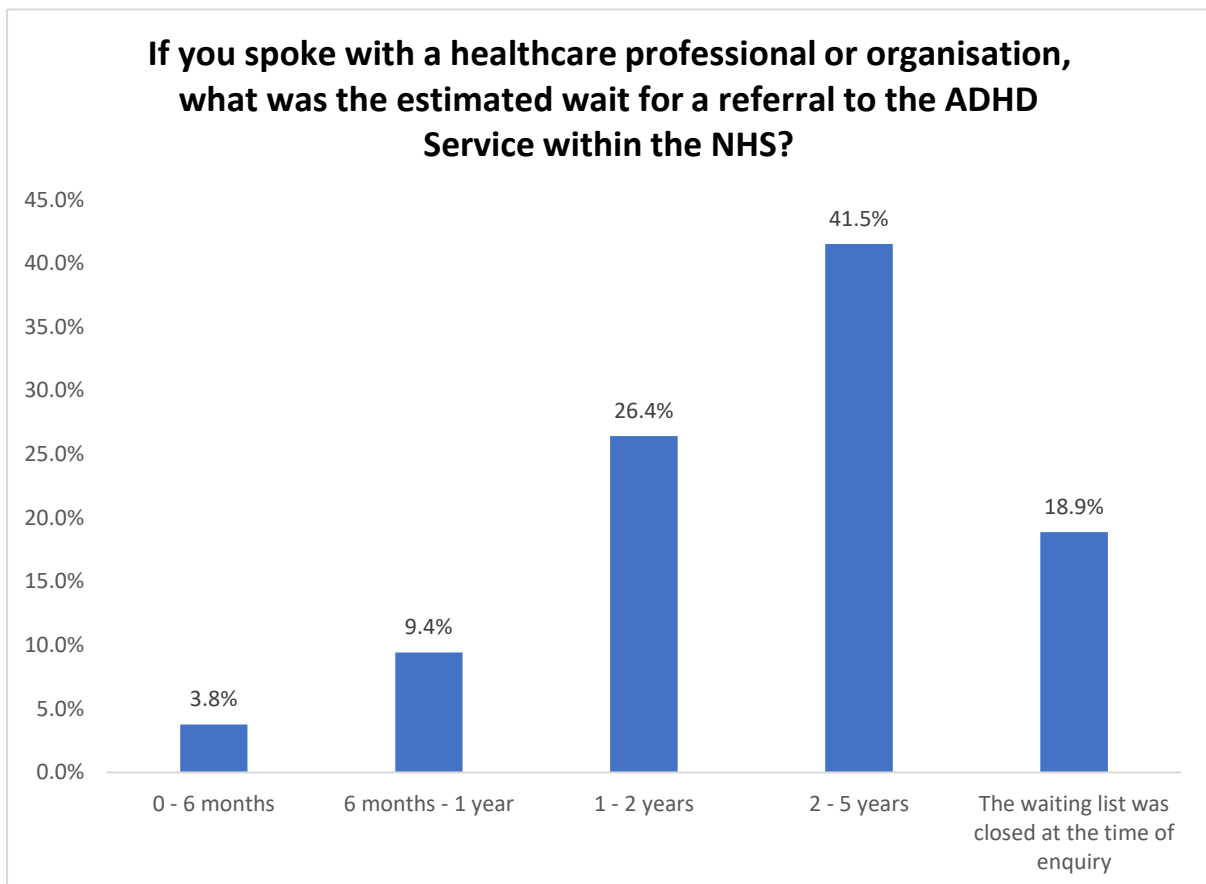
Quantitative Results



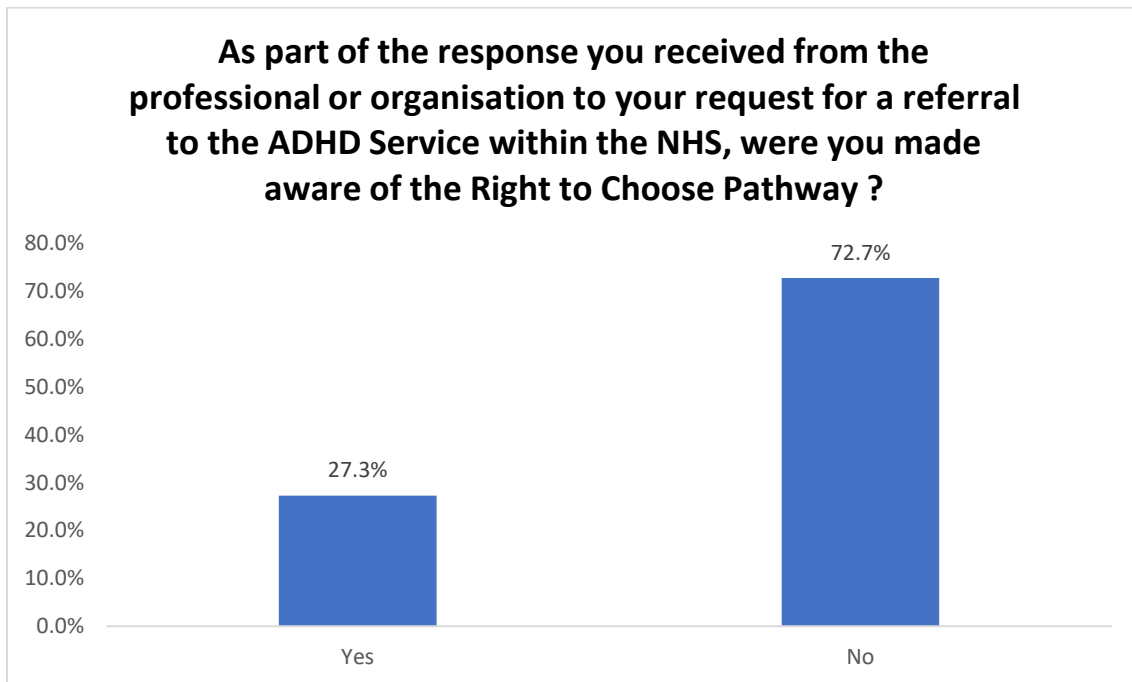
Who did you speak with:



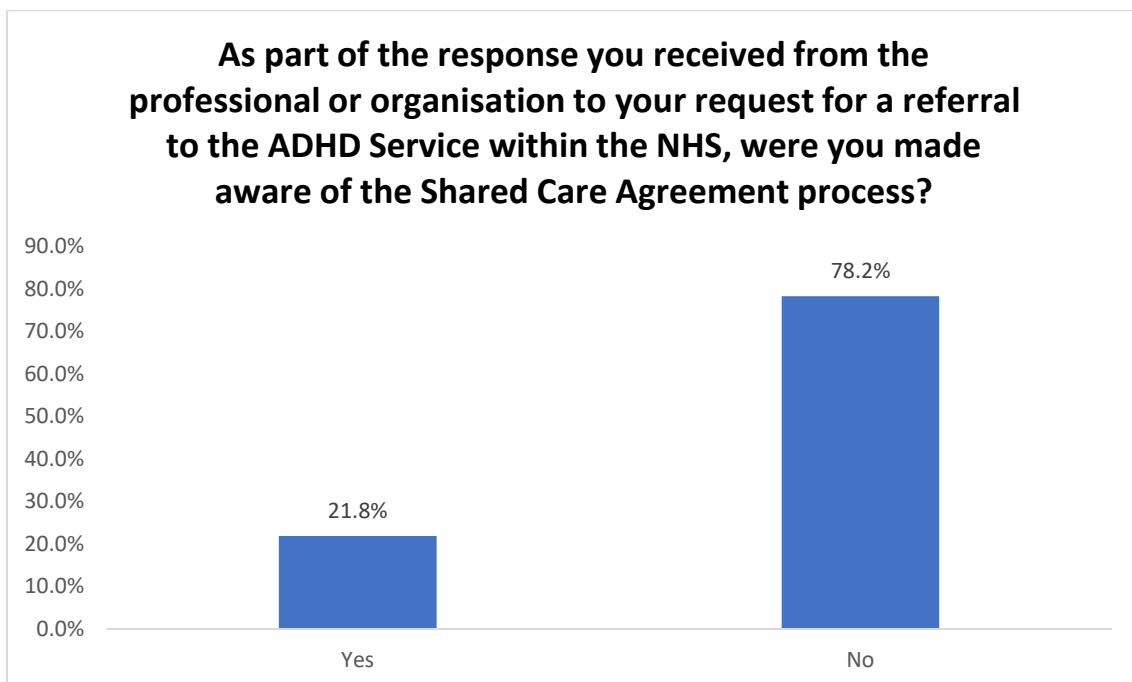
Estimated time for referral:



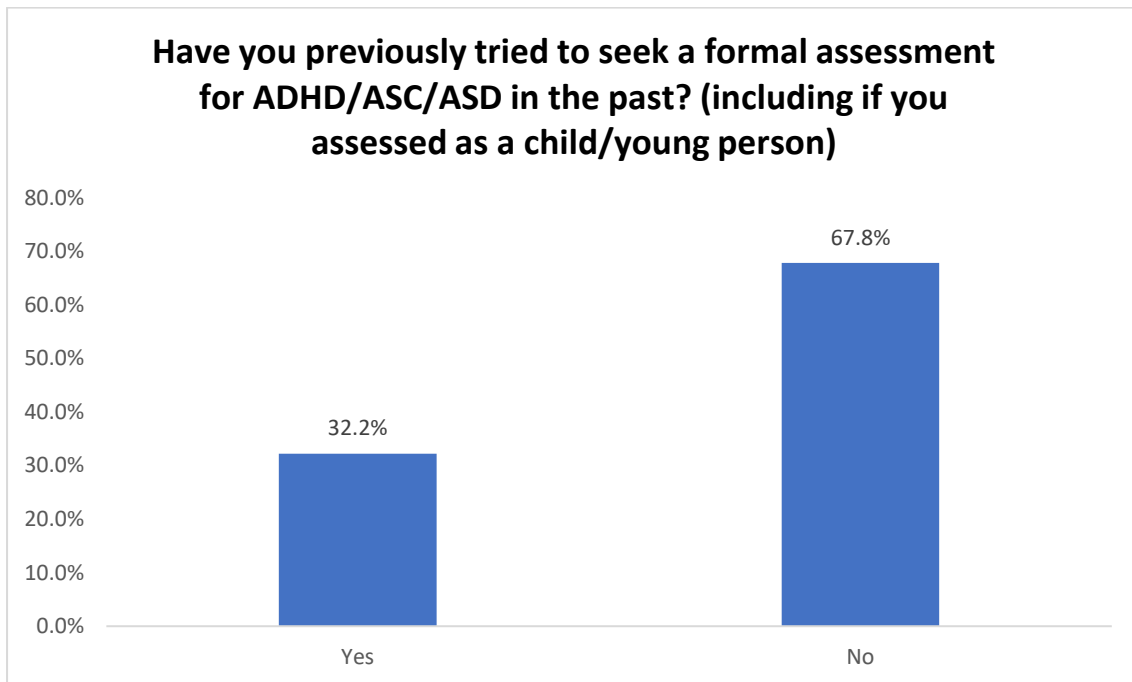
Right to Choose Pathway:



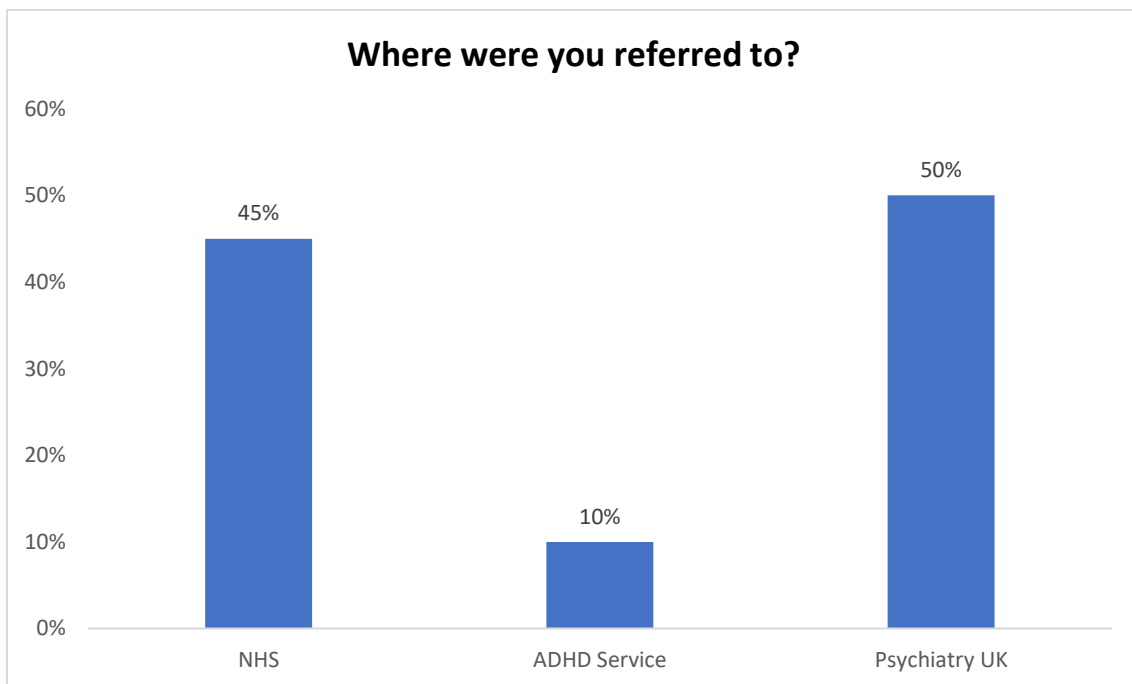
Shared Care Agreement:



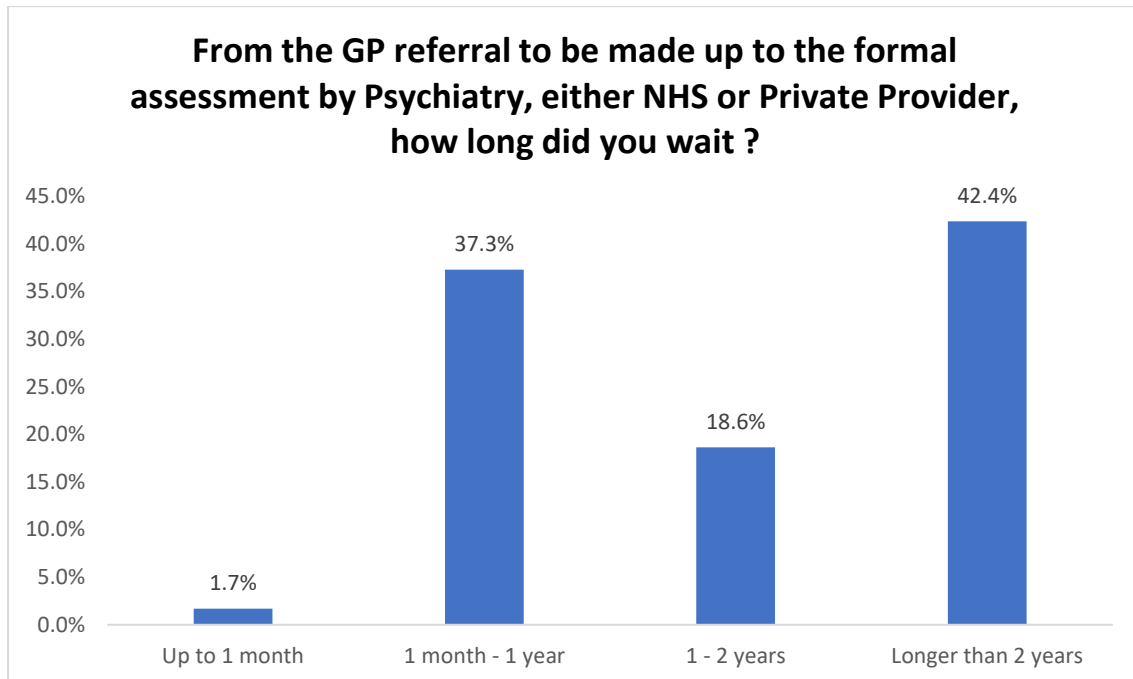
Previous Formal Assessment:



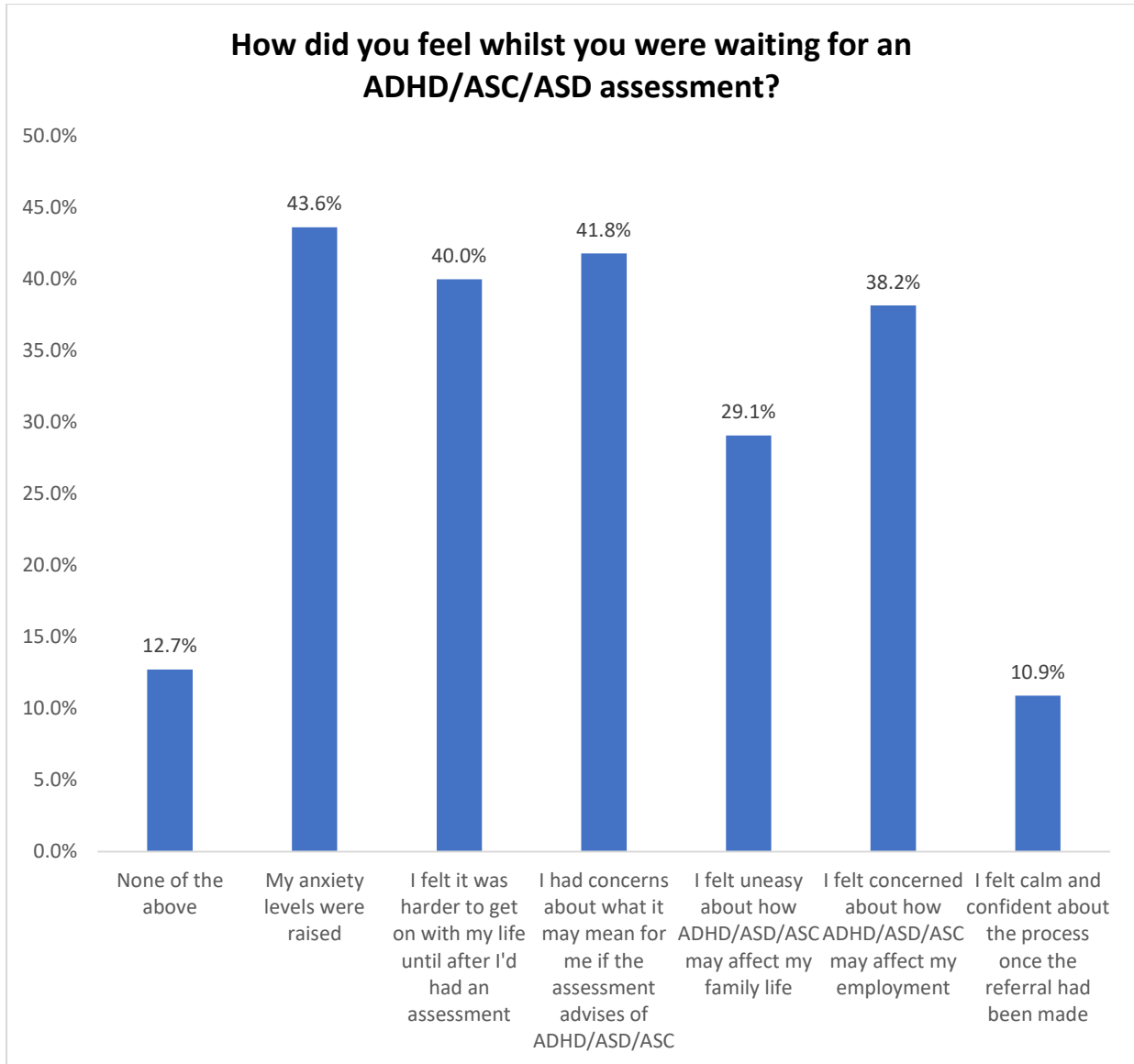
What service were you referred to:



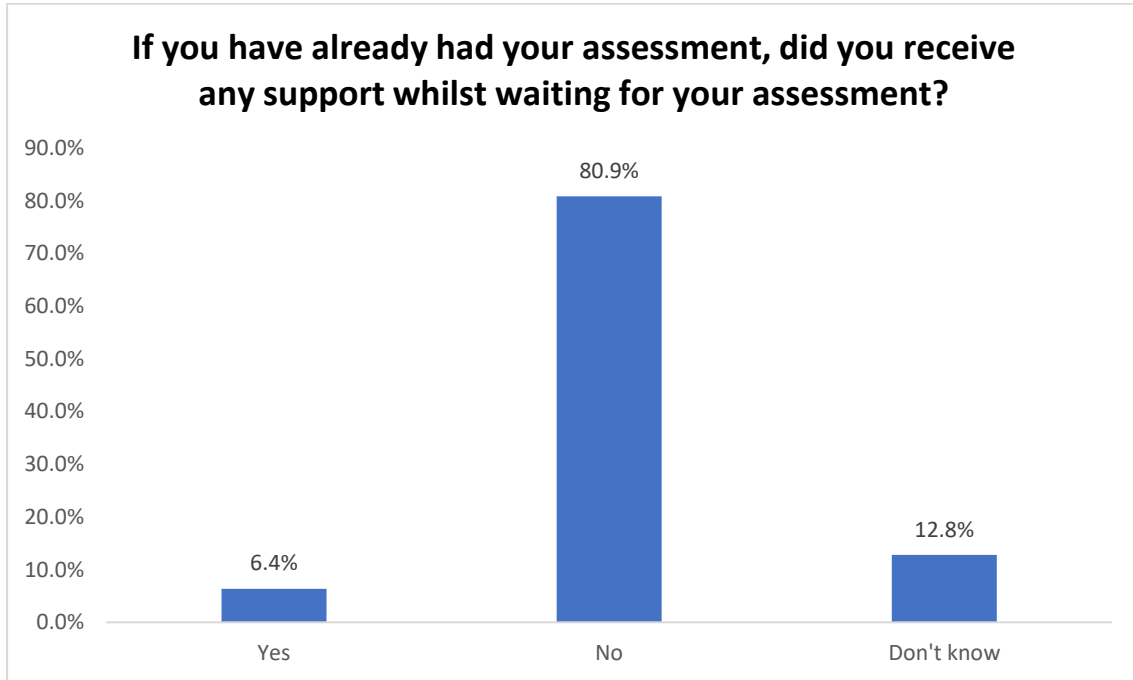
Waiting times:



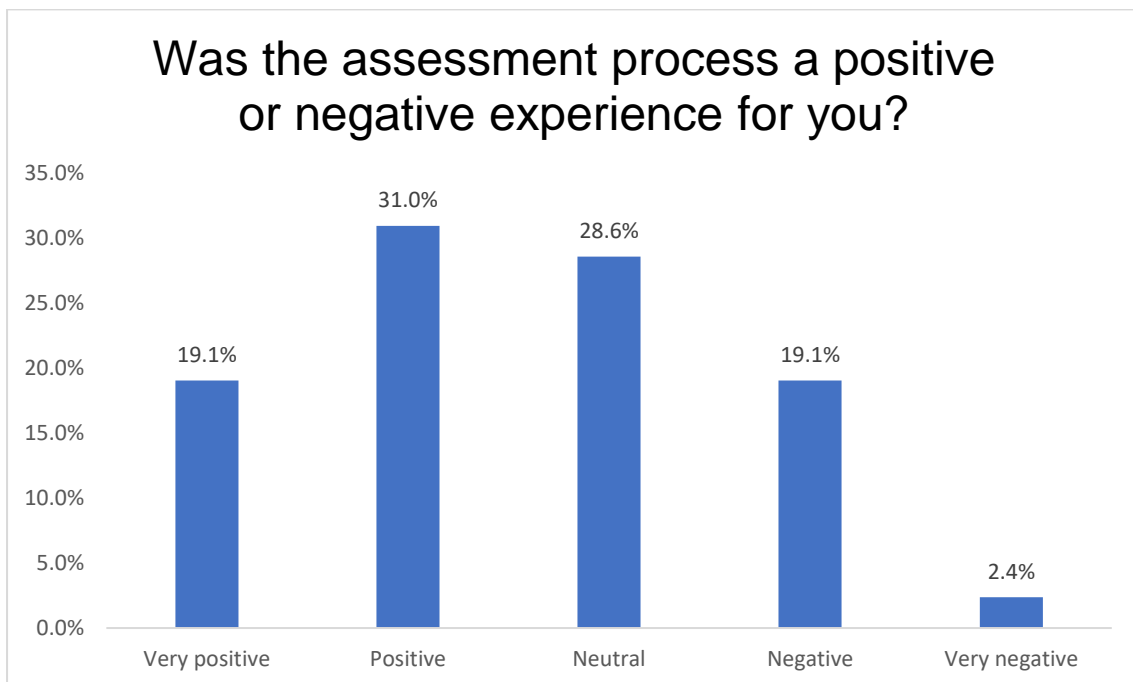
Managing waiting times:



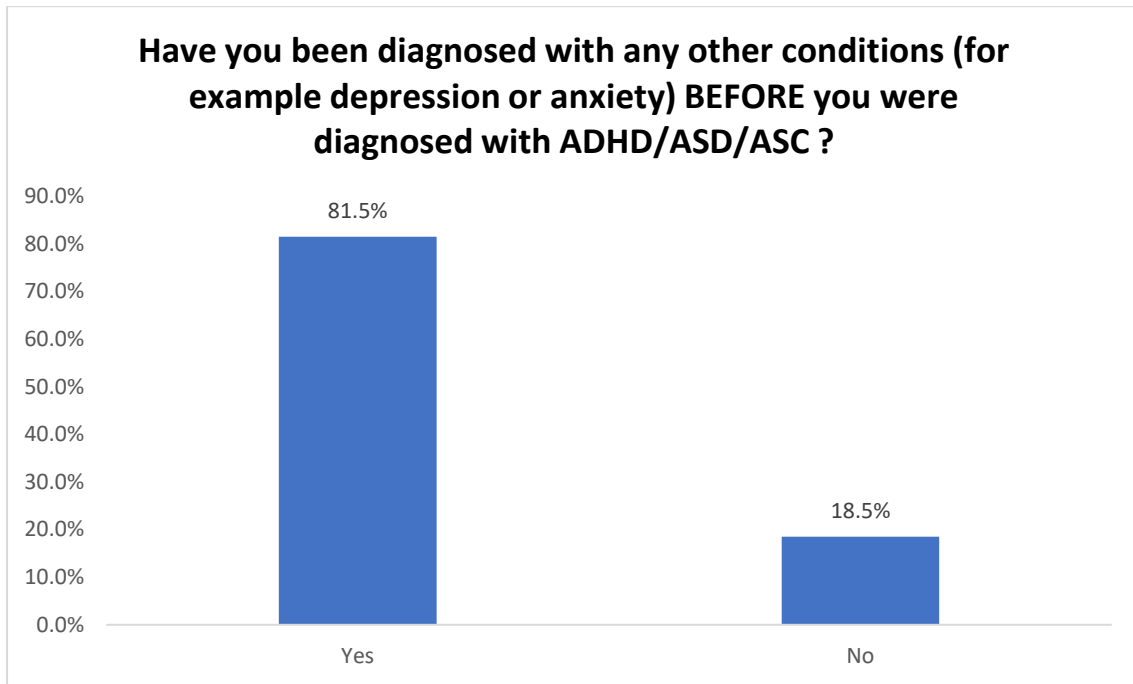
Support while waiting for assessment:



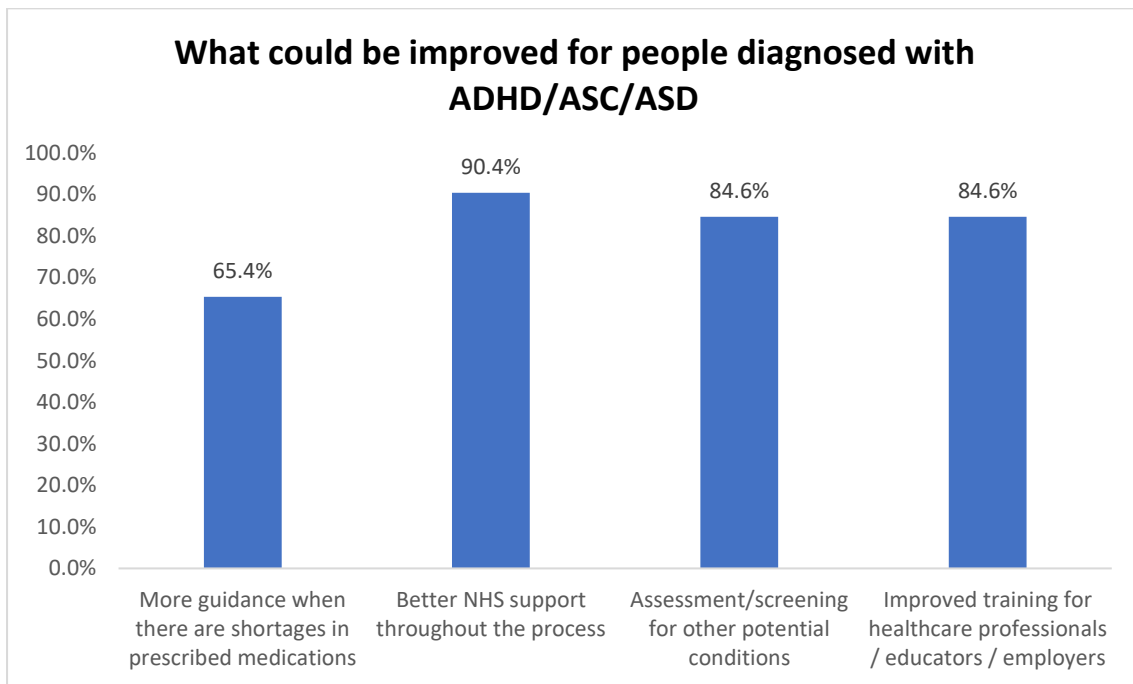
How was your experience with the assessment:



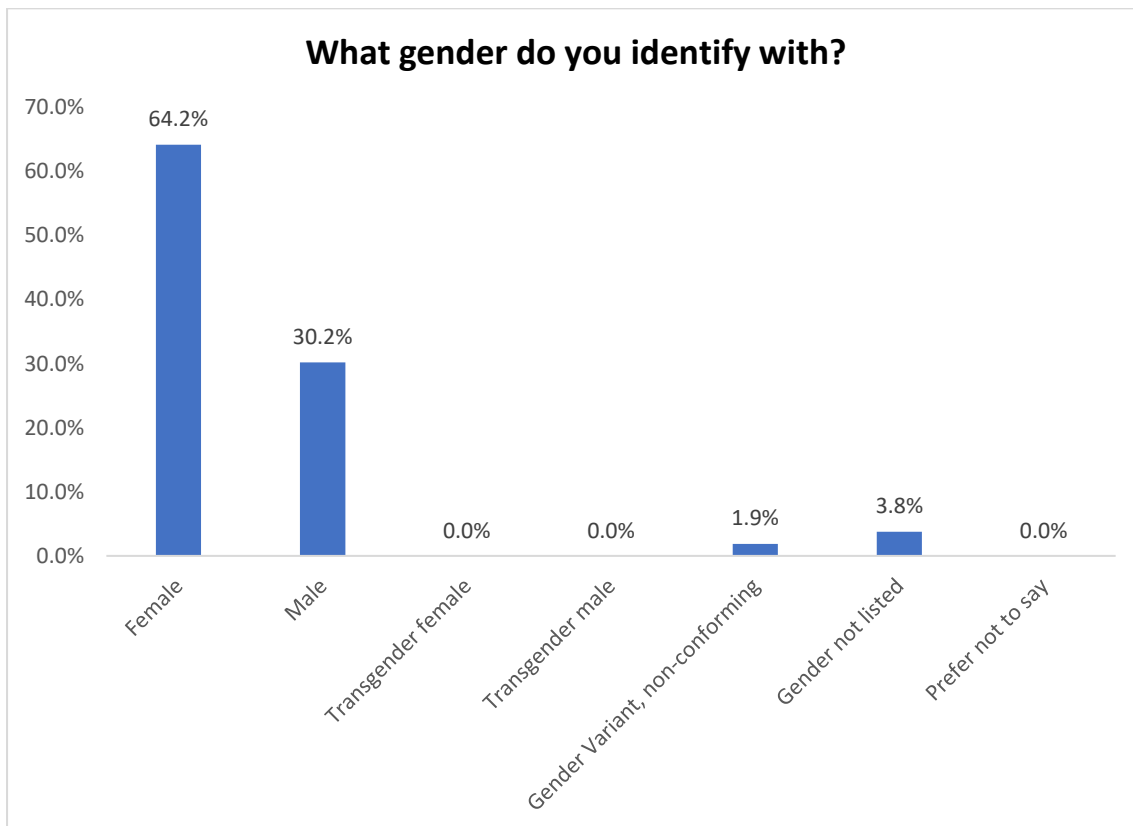
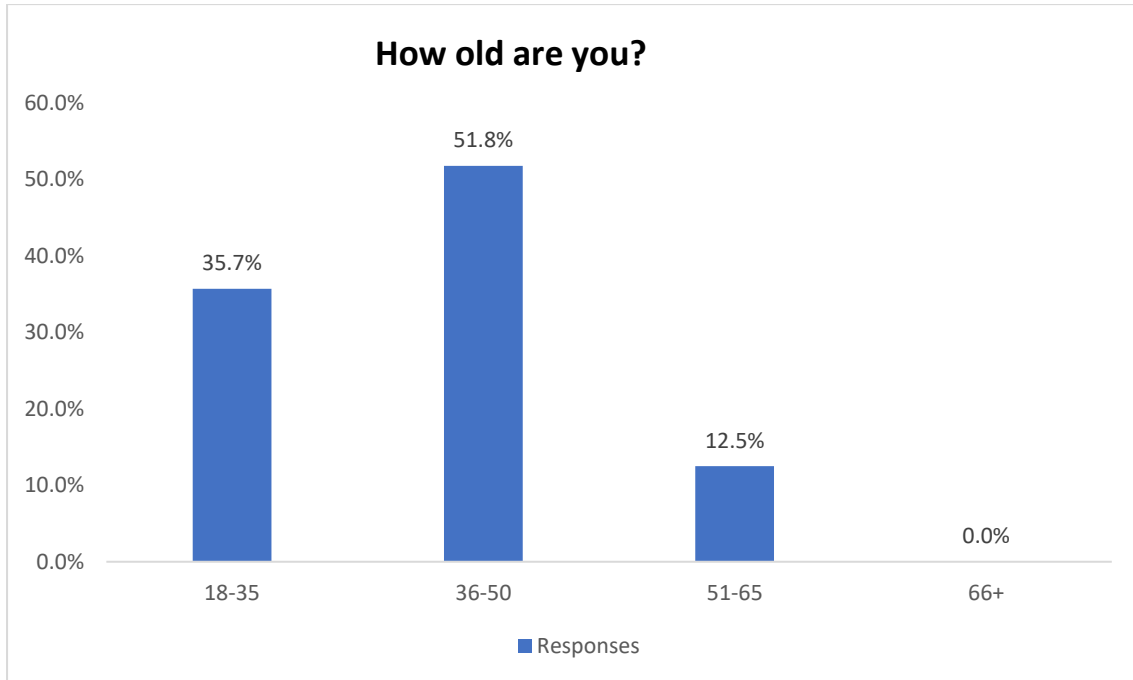
Any other conditions:



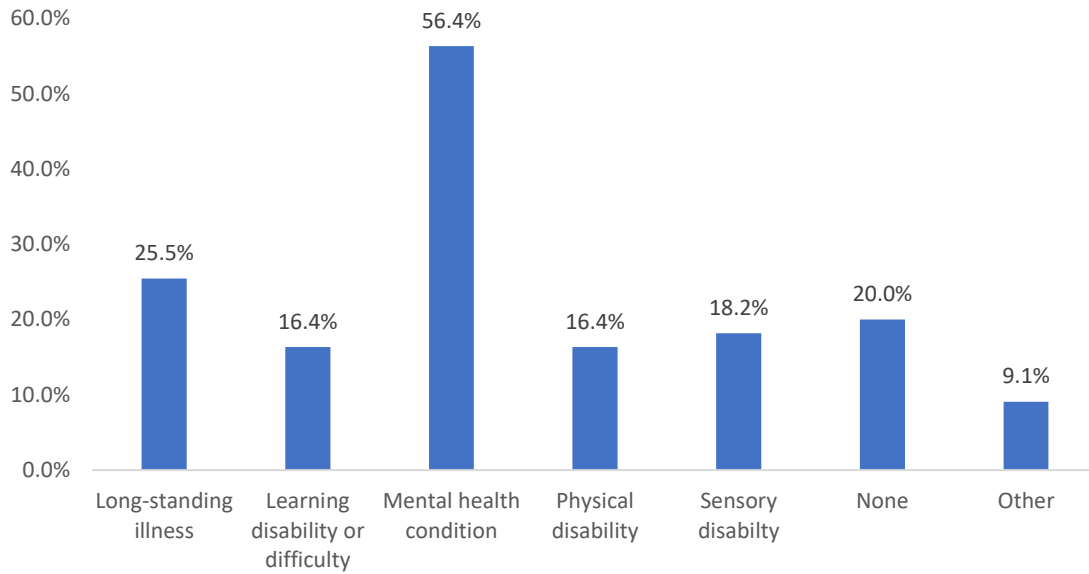
What could be improved:



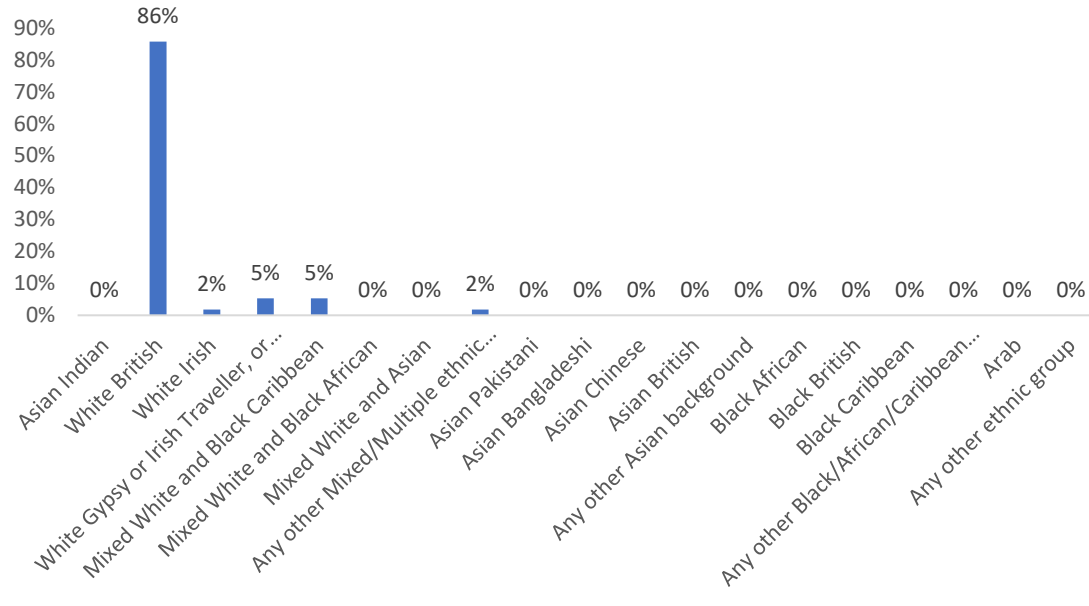
Demographics:

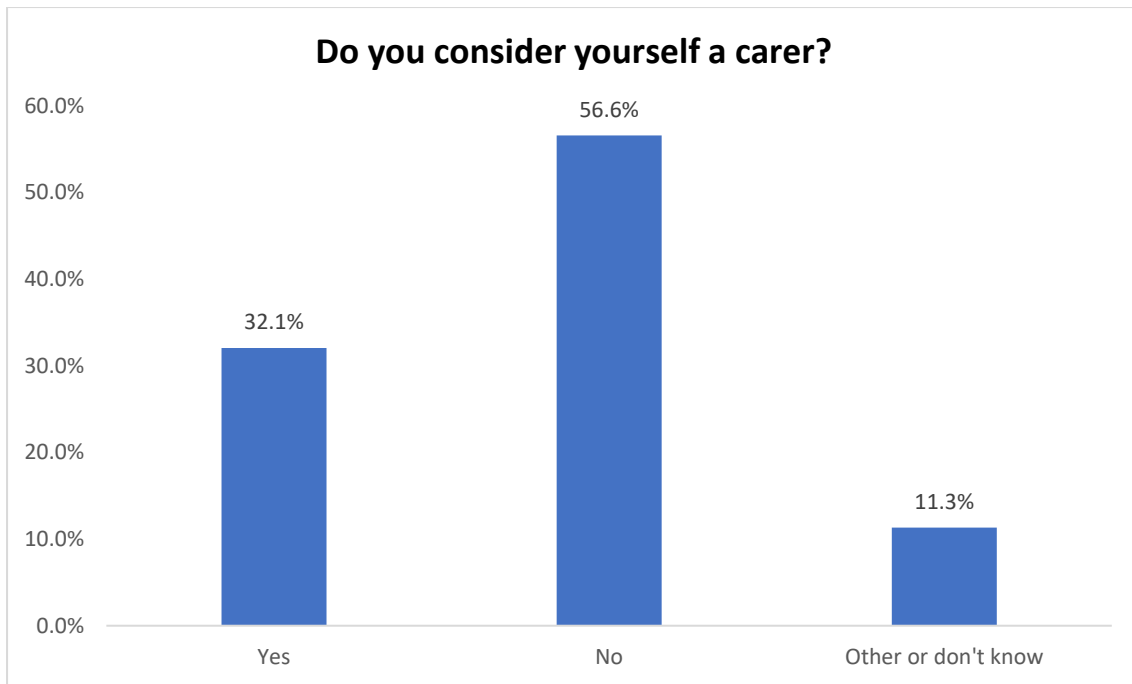


Do you consider yourself to have any of the following?



What is your race or ethnicity?





Lived Experience:

Please see Appendix I for the full report of comments made by service users.

‘My experience of requesting a referral for ADHD and ASC from the GP was unpleasant. He agreed to refer me for ADHD because it can be treated, but that they are no longer making ASC referrals because it is "behaviour" and can't be "treated". It was hard enough asking in the first place, but this has completely put me off requesting it again. I am also now 50 years old and am aware that the current waiting lists are several years. I also cannot afford a private assessment. For these reasons, I accept that a diagnosis is not accessible for me, and this adds to the feeling that myself, and so many women like me, continue to live without recognition, validation or support. My only reason for wanting an assessment is for my own self-knowledge and many years of suffering alone and in silence. So many women and girls will have been overlooked because it has been male-orientated, which has left girls, women and professionals trying to attribute difficulties and differences to other things. Poor mental health and low self-esteem is without a doubt a result of this. The inaccessibility of assessments for ADHD and ASC for older women in particular, is a continuation of a health inequality in my opinion’.

'More information and awareness of ADHD in girls so it can be diagnosed sooner to minimise the effect on mental health. More access to diagnosis with shorter waiting times especially for children struggling in schools. More ADHD/Autism support for both children and adults. More SEN support in schools, preferably more SEN school places for children that need it.'

'Whilst I have an assessment and diagnosis of Attention Deficit Disorder (ADD) in August 2023, I am still waiting for titration from Psychiatry UK, my GP has never followed up with me and Psychiatry UK do not respond. I feel that a local ADHD service would be much better. Other than Adult ADHD support group I feel I have been left without help.'

'There needs to be a suite of support offers, counselling, therapy, coaching, regular updates on the shortages AND WHAT TO DO WHEN THEY OCCUR, stop telling us what we know and help us.'

'No support in terms of managing condition, an OH appointment was cancelled because I was at work. Would have liked a reminder as I have ADHD. No support from Stein Centre with medication shortage; I was told to basically get on with it. GP was able to help and change my prescription and amend to what was available. Completely disgusted and let down by service specifically for ADHD (Stein Centre).'

'Just helping people know what to do and where to go. I have spoken to Healthwatch Wirral and they have given me information but this was only by accident when I met them at the Centre.'

'Without peer support and the support from services around Wirral that are offered for free and advising me to get help. I wouldn't be in the position I am in. Too many people are having to reach rock bottom and then require the most help before getting these options presented to them.'

CONCLUSION

This survey, conducted by Healthwatch Wirral provides, a snapshot with valuable insights into people's experiences with NHS ADHD Services. Gaps in awareness and support are highlighted, including a lack of support whilst waiting for assessment.

Feedback from service users emphasises the need for better access to diagnosis and better support systems, particularly for women and children. This report also highlights the need to acknowledge the gaps in current service provision and the need to enhance the experiences of those seeking ADHD and ASC support and assessments.

It is important that those who plan and commission services truly understand the experiences of people and the impact on them with a view to:

- provide the best service for people
- reduce firefighting and establish good preventative and sustainable support
- reduce pressure across the health and care system

ACKNOWLEDGEMENTS

Healthwatch Wirral would like to acknowledge and thank the organisations and individuals who gave their time and energy to this survey and report.

The project was co-produced with people who are personally affected, or who understand the frustrations and challenges in this area, and with those providing support and care at a time when it is most needed.

With special thanks to Matt Shepley of Sole Survivor and Adele Curley of Wirral ADHD Adults and the people they support and work with for their help with focus testing the survey questions ensuring their credibility and developing and sharing the survey.

July 2024.

APPENDIX I

Lived Experiences ADHD/ASC Diagnosis- Referral

Please use the space below for anything else you would like add, e.g. views, experiences, what matters to you, how things could be improved

- 1) *My experience of requesting a referral for ADHD and ASC from the GP was unpleasant. He agreed to refer me for ADHD because it can be treated, but that they are no longer making ASC referrals because it is "behaviour" and can't be "treated". It was hard enough asking in the first place, but this has completely put me off requesting it again. I am also now 50 years old and am aware that the current waiting lists are several years. I also cannot afford a private assessment. For these reasons, I accept that I diagnosis is not accessible for me, and this adds to the feeling that myself, and so many women like me, continue to live without recognition, validation or support. My only reason for wanting an assessment is for my own self-knowledge and many years of suffering alone and in silence. So many women and girls will have been overlooked because it has been male orientated, which have left girls and women and professionals trying to attribute difficulties and differences to other things. Poor mental health and low self-esteem is without a doubt a result of this. The inaccessibility of assessments for ADHD and ASC for older women in particular, is a continuation of a health inequality in my opinion.*

- 2) *Still early days for my own referral so can't comment on waits or outcomes.*

- 3) *No support in terms of managing condition , like at work and missed OH appointment and it was cancelled. Would of liked a reminder as ADHD No support from Stein centre with med shortage told to basically get on with it. GP was able to help and change my prescription and amend to what was available. Completely disgusted and let down by service specifically for ADHD (stein centre).*

- 4)** *I have been on the waiting list over 4 years now my doctor has signed me off with adhd but I feel need the treatment as my life is stagnating and I struggle a lot.*
- 5)** *Once diagnosed I am on a 7 month titration wait list. Knowing I have an untreated medical condition is far more stressful and distressing than dealing with symptoms before diagnosis .*
- 6)** *More information and awareness of Adhd in girls so it can be diagnosed sooner to minimise the effect on mental health. More access to diagnosis with less waiting times especially for children struggling in schools. More Adhd/Autism support for both children and adults. More SEN support in schools, preferably more sen school places for children that need it.*
- 7)** *Finding likeminded people within a community I belong.*
- 8)** *Whilst I have an assessment and diagnosis of ADHD in August 2023 I am still waiting for titration from psychiatry UK, my GP has never followed up with me and psychiatry UK do not respond. I feel that a local ADHD service would be much better. Other than Adult ADHD support group I feel I have been left without help.*
- 9)** *Just helping people know what to do and where to go . I have spoke to Healthwatch and they been given me info but this was only by accident when I met them at the centre.*
- 10)** *Compassion & communication. Peer support for people with adhd isn't good in my opinion. It can be toxic with people trying to one up manship you.*
- 11)** *I can only speak to private assessments as i was diagnosed with adhd & asd through private services, but had to be assessed twice for asd. I feel like the patient's*

experience should have more weight than the family members! mine did not want to admit anything was wrong for fear of seeming like a bad parent, and was in denial about also having the condition which i understand to be quite hereditary so that's probably a common situation, this caused them to downplay my difficulties. I dislike how assessments seem to be based upon how much of an inconvenience you are to others, rather than your personal experience. i found my first asd assessment quite infantilising, I think the adult assessment process needs work. My adhd assessment was very fast and i felt quite led into agreeing with simple statements that did apply to me but in a way that needed further explanation. there is no post-diagnostic support for adults which i think should not be the case.

12) *Negative media coverage about people being misdiagnosed and being “diagnosed by TikTok” comments were very harmful.*

13) *I wish the complaints process was more visible in the process and how to give more evidence to get a second opinion/ second chance. How masking can make you answer incorrectly and how not remembering something on the spot can actually be a symptom of the exact thing you’re trying to get a diagnosis for.*

14) *I have opted not to have medication for ADHD at present due to planning a child, but I am concerned about how long the wait will be when I am ready to try that.*

15) *It takes far too long and ‘the elbow doesn’t know what the hand is doing’!*

16) *There needs to be a suite of support offers, counselling, therapy, coaching, regular updates on the shortages AND WHAT TO DO WHEN THEY OCCUR, stop telling us what we know and help us.*

17) *Parents should be assessed when their children are diagnosed.*

18) *No one understands.*

19) *Looking at family diagnosis would've lead to an obvious connection.*

20) *Just updates along the way whilst in the waiting list. My referral went in over 2 years ago, I've no idea if it's been accepted and onto a waiting list, or if I've not 'qualified' to be seen. Who knows?*

21) *I have been in and out of prison and just seen as a trouble maker, I am not making excuses but I have just always struggled.*

22) *Because I know how overwhelmed the NHS is and am able to manage my symptoms I haven't spoken to a health professional. I am also scared that I won't be able to articulate my symptoms well enough.*

23) *I visited my GP as have had mental health issues since childhood and the GP suggested I have an ADHD assessment which was conducted through Psychiatry UK but paid for by the NHS. I had the ADHD assessment in 2023 which showed I had ADHD, however Psychiatry UK have said they are unable to treat me through their systems as they said I need close face to face monitoring due to other mental health issues. They said they would refer me back to the GP and then for the GP to refer me to my local psychiatry department. Eventually in 2024 the paperwork arrived so I visited my GP who was great, very understanding and did the referral for me there and then. [...] I received a letter from the Adult ADHD Service via Cheshire & Wirral Partnership saying that the ADHD service is closed to new assessments and the wait is longer than 2 years plus. I have rung them up and said I have already had the assessment with a positive diagnosis with written confirmation of the diagnosis as does my GP. They don't seem to understand this and that I don't need the*

assessment, I just need help to give me some kind of life as I am struggling big time with ADHD Avoidant/restrictive food intake disorder (ARFID) and ADHD Emotional Dysregulation. I don't know what to do anymore? I cannot wait another 2 years. Can/will another trust take me? [...] Can someone help me bypass the (CWP) ADHD assessment phase? I can't work, eat properly and other host of symptoms all because of this untreated ADHD.

24) *I feel that social media and societies views are a genuine concern. People are becoming very dismissive of ADHD and it's becoming a joke. Nobody seems to realise how truly debilitating it is and the impact it has. The grief associated with what could have been and the fear of letting people know and for you to be defined by the label negatively. It's a prison either way, if you have a diagnosis or not. Both situations are hard to manage without to correct support. There needs to be better education across all health services given the physical issues it can cause and challenges in accessing appointments and engaging with services.*

25) *I am waiting on a referral to speak to somebody with a view to being assessed for ADHD so couldn't answer all questions.*

26) *Without peer support and the support from services around Wirral that are offered for free and advising me to get help. I wouldn't be in the position I am in. Too many people are having to reach rock bottoms and require the most help before getting these options presented to them.*

27) *Validate those who work and function and provide better support alternative to medications. I was offered clubs and resources for a people with autism and complex learning difficulties or anti-social behaviour, I was not treated or supported like a professional adult who needed support.*

- 28)** *More communication about process and during process - found initial assessment form very stressful and distressing to fill out.*
- 29)** *After getting my diagnosis I felt significantly more depressed than usual, as it sort of made me become more aware of how I acted in social situations etc. I was exhausted all the time, anti-social etc, so I think the ability to unmask after receiving a diagnosis sounds ideal but it was somewhat detrimental to my mental health at the time.*
- 30)** *I was diagnosed aged 39 despite years of services as a child. As a female I feel my needs were dismissed and diminished as a young person as I wasn't typical textbook ADHD.*
- 31)** *I got a diagnosis of ASD and Adhd at age 16/17 and had absolutely no support after diagnosis. Referred to CAMHS due to sever self-harm, thoughts of suicide, eating disorders. Anxiety and panic attacks but no direct support for my ASD or ADHD.*