healthwatch
Liverpool

Healthwatch Liverpool ADHD report

January 2026

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Executive Summary

In recent years, awareness of attention deficit hyperactivity disorder (ADHD) in society has increased significantly, as has the number of people seeking help for the condition.

The impact of ADHD on people and their challenges in getting the right support led to NHS England commissioning the independent ADHD taskforce in March 2024.

Healthwatch England produced a report on Adult ADHD in May 2025. This was based on national polling and self-selecting surveys. We in Healthwatch Liverpool wanted to gather a local sample of data to supplement the national picture, to inform our local Neurodiversity Strategic Partnership Board and help shape local commissioning.

This report by Healthwatch Liverpool follows the structure and methodology of Healthwatch England's national work, but is based on local sampling.

We aim to help NHS decision makers understand the challenges and the improvements those seeking support want to see. These changes include quicker access to diagnosis and treatment, more support while they wait, and more non-medical help from NHS and other teams, including employers.

Key local findings

- **The impact of ADHD on people's lives can be profound.** Our findings on those diagnosed reveal significant negative effects on people's ability to concentrate at work or when studying (73%), mental wellbeing (74%), household management (73%), and relationships (59%). There are also impacts on those undiagnosed.
- **An ADHD diagnosis can change people's lives**, giving them a better understanding of themselves (91%), giving them new strategies to manage their ADHD traits (50%), helping them to concentrate at work or while studying (48%) and finding it easier to maintain relationships (50%).
- However, **people are experiencing long waits, pushing them to pay for private assessments**. This, in turn, creates a two-tier system based on the ability to pay for care. Over half (56%) of those waiting for an assessment who responded to our poll had been doing so for over a year.
- **There are hidden waits for ADHD referrals**. Along with long waits for assessment, people shared stories of referral delays and a reluctance to seek support due to long waits.
- **People want support while waiting for an ADHD assessment but most aren't getting any.** Half (50%) of people in our poll waiting for an ADHD assessment want support to manage their mental wellbeing, while three in five (60%) want a single point of contact. However, almost nine in ten (87%) people with an ADHD diagnosis said they received either no information or poor information whilst waiting for their assessment.
- **People with ADHD or suspected ADHD can be reluctant to speak to their employer about support**. Less than one in three (31%) of our respondents who were in work had done so. Reasons for not telling their employer included worrying about possible implications for their job and not thinking that changes would make a difference. However over half of people (55%) who had told their employer were offered at least one reasonable adjustment to support them.

- **Respondents who considered that they had both ADHD and autism reported a disjointed and drawn out process** and the weighty impact of both conditions on their lives.
- **A disadvantage of assessments mainly being done remotely by Right to Choose services is that there is no ability for these services to signpost people to local support** if needed. Many people were therefore unaware of local support options. They may have been able to develop coping and stabilising strategies sooner had they had access to this information.

Key Recommendations

The Healthwatch England report included the following recommendations. We have included some local recommendations after these.

Healthwatch England's national recommendations

There is a clear need for quicker access to NHS support for ADHD, as well as help from other sectors including employment. However, there are also challenges facing NHS teams, which are facing rising demand for a condition that is becoming more understood by the public.

To improve access, provide more consistent support to people waiting, and build capacity for specialist hospital teams to deliver more complex care, we have called on NHS decision-makers to:

1. **Move ADHD assessments to the community**. This includes providing NHS teams with the training and resources they need to deliver care closer to people's homes. This shift will require collaboration between NHS, social care, education, employment and criminal justice stakeholders.
2. **Review National Institute for Health and Care Excellence (NICE) ADHD guidance** to reflect this shift to more care delivered by general psychiatry and GP teams, as well as explore future prescribing of first-line medication from non-hospital settings.
3. **Provide better support to people waiting for ADHD assessments**, including keeping people updated with clear and accessible communication from the NHS.
4. **Collect and publish official data on ADHD assessment waiting times**, including demographic data, to understand and address health inequalities.
5. **Improve employers' support for those with ADHD** by raising awareness and proactive offers of reasonable adjustments and expanding support provided through the Access to Work scheme.

Healthwatch Liverpool's local recommendations

1. **Explore a coordinated pathway**. Consider a joined-up pathway for those needing both ADHD and autism assessments. This might include referrers and assessors being familiar with:
    a. Awareness of how the conditions may present when they co-exist.
    b. Suggesting screening for both if appropriate.
    c. Potential for combined or cordinated assessments in future.
    d. Advice, information and support provision which takes account of the complexity of living with both conditions.

2. **Local information about support**. Consideration be given to how people referred for an assessment can be more reliably signposted to sources of information and support while they wait.

   To support this Healthwatch Liverpool has developed an information page which referrers can point patients to. https://www.healthwatchliverpool.co.uk/advice-and-information/2025-09-12/what-can-i-do-while-waiting-adult-adhd-assessment

3. **Intersectionality: different barriers and experiences**

   Services should be:

   a. aware of the way ADHD can present with different groups and the barriers each has in receiving timely identification and appropriate support

   b. willing to tailor their approach accordingly.
   - The presentation among women and the interaction with female hormones
   - The strong correlation between neurodivergence and diverse sexual orientations and gender identities.
   - The potential for additional levels of stigma among people in minoritised communities

Introduction

ADHD is a neurodevelopmental condition, characterised by difficulties with concentration, energy levels, impulsiveness, or a person's ability to manage their time.

ADHD can be diagnosed in childhood or adulthood, and sometimes, traits can change as people get older. Because of the range of behaviours affected by ADHD, presentation can often look very different from one person to the next. ADHD symptoms often impact a person's mental wellbeing and/or have a detrimental effect on existing mental health issues.

There has been a massive rise in demand for assessment, diagnosis and support related to ADHD. Between 2000 and 2018, there was approximately a twenty-fold increase in ADHD diagnoses.

Additionally, between 2019/20 and 2022/23, there was a 51% increase in the number of patients prescribed medication for ADHD.

We have heard issues around ADHD delays and medication issuers this reflected in local feedback for many years, as have other local Healthwatch around the country. Healthwatch England have previously published some of the public's own stories of poor experiences. There is now a national ADHD taskforce which established eight priority areas.

1. Tackling stigma
2. Delivering more training for health and care professionals
3. More joined-up work between teams involved in delivering ADHD support
4. Better continuity of care
5. Earlier identification of ADHD
6. More support for people waiting for NHS diagnosis and treatment
7. Reduced waiting times
8. Easier access to support

Healthwatch England undertook its 2024-5 research to support the taskforce's work.

Healthwatch Liverpool is an active member of the Liverpool Neurodiversity Strategic Partnership and we wanted to get a get a clearer picture of how people in Liverpool were being affected and to support work being undertaken by Cheshire and Mersey Integrated Care Board (ICB) to review and redesign the ADHD assessment process.

In the coming chapters, we will share the scale of and stories behind long waits. We will conclude by making recommendations to decision-makers.

Key themes by chapter

Chapter 1 - How Common is ADHD? This looks at the difficulties of establishing prevalence of ADHD in adults in England.

Chapter 2 - How does having ADHD affect people's lives? This looks at the ways in which ADHD affects people's lives. We show that ADHD has a profound impact on people's ability to work and study, mental and physical health, relationships with loved ones and friends, ability to manage money and undertake household tasks, and personal interests.

Chapter 3 - Referrals and long waits for ADHD Assessments. This examines people's experience of referrals and waiting times for NHS ADHD assessments.

Chapter 4 - The support that people need. This outlines the type of support that people would benefit from whilst waiting for an ADHD assessment and people's experience of and barriers to receiving support at work.

Chapter 5 - The Benefits of diagnosis. This sets out the impact of having an ADHD diagnosis on major aspects of people's lives. We highlight that the major benefit is validation and self-understanding rather than the ability to receive ADHD medication.

Chapter 6 - Intersectionality and ADHD – This looks at the experiences of different groups of respondents, how they experience ADHD and the additional barriers they face.

Our conclusions and recommendations can be found on page 33.

What Healthwatch England did

Healthwatch England commissioned YouGov to run two rounds of polling about adults' experiences of ADHD.

- The first round was a nationally representative sample of 1,888 adults aged 18+ in England. Fieldwork was undertaken between 8 and 23 January 2025 and the survey was carried out online. The figures have been weighted and are representative of all English adults (aged 18+).
- The second round was conducted between 8 to 27 January 2025. The survey was conducted online. The total sample size was 2,579 adults with ADHD in England. This sample comprises:
    a. 363 people who have already been diagnosed with ADHD
    b. 336 people who were waiting for an ADHD assessment
    c. 109 people whose GP has refused to refer them for an ADHD assessment
    d. 808 people who haven't yet seen their GP for an ADHD assessment
    e. 963 people who don't want a formal ADHD diagnosis

The figures have been weighted and are representative of all English adults (aged 18+) with diagnosed and undiagnosed ADHD.

They also ran their own survey throughout January 2025 to gain complementary qualitative insight. The survey asked people with both diagnosed and possible ADHD to provide details of their experiences. The survey was self-selecting, meaning that they relied on people willing to complete the questions and could complete an online survey. They publicised this survey widely via social media. They had 1,161 completed responses in total.

What we did

Healthatch Liverpool were involved, alongside other stakeholders and people with lived experience in designing the national polling and survey questions. **We used the Healthwatch England survey design and issued it through our networks and our social media receiving 601 responses.**

Our respondents presented a similar range of experiences as seen in the national picture but some added nuances also emerged.

In this report we draw on our local responses and also in the data tables include the national information from the Healthwatch England polling for comparison. You can read the Healthwatch England report here https://www.healthwatch.co.uk/news/2025-05-28/adhd-diagnosis-life-changing-long-waits-nhs-need-urgent-action. We thank Healthwatch England for their work on this topic and draw heavily on their work here.

What the survey covered

In our survey we explored:

- The impact of ADHD on people’s lives
- The waiting time and support needs of people who’ve already been diagnosed with ADHD and the impact of a diagnosis on aspects of their lives
- The referral process, waiting times and support provided to people on the waiting list for an ADHD assessment
- The experiences of people who think they might have ADHD but their GP has refused to refer them for an assessment
- Why people who think they might have ADHD haven’t yet seen their GP to ask for a referral for an ADHD assessment
- Why people who think they have ADHD don’t want to have a formal ADHD assessment.
- People’s experiences of telling their employer that they have ADHD and receiving reasonable adjustments

1. How common is ADHD? - Why is establishing ADHD prevalence difficult?

External evidence on prevalence

NHS Digital publishes estimates on the number of people with ADHD in England, but there are no official statistics on the prevalence. Indeed, estimating prevalence is not straightforward.

One measure is prescribing rates for ADHD medication. Research has found that diagnosis and prescription rates for ADHD have increased significantly, with a 20-fold increase in ADHD diagnosis and a 50-fold increase in prescriptions between 2000 and 2018. Research quoted by the Nuffield Trust shows that there was a 51% increase in the number of patients prescribed medication for ADHD between 2019/20 and 2022/23 alone.

But this only tells part of the story. Only people who are diagnosed with ADHD can get ADHD medication. Data obtained via Freedom of Information (FOI) requests by the BBC in 2024 suggested that 196,000 people were on NHS waiting lists for an ADHD assessment across the UK.

FOI data can only be sourced from public services, and there are no official statistics on the number of people diagnosed in the private sector.

Recent research also shows that ADHD is considerably underdiagnosed in England amongst both children and adults. Using estimates of adult general population and ADHD prevalence data, the research estimates that only 15.6% of expected adult ADHD population is diagnosed.

The National Institute for Health and Care Excellence (NICE) estimates the prevalence in adults in the UK to be between 3-4%, with a male-to-female ratio of approximately 3:1. This equates to between 1.3 and 1.8 million adults.

A meta-analysis of studies across the world on the prevalence of ADHD in adults indicates that the prevalence in adults is 3.10%.

The findings

Healthwatch England polling and survey are based on people self-reporting that they have been diagnosed with ADHD or believe they have ADHD. As their research explores, some people may choose not to seek support. However, for others, a lack of support can have significant impacts on health, mental wellbeing, and ability to work.

These findings must be treated carefully. Not all people who believe they have ADHD will have it.

Taken in combination with external research and prevalence estimates , the work carried out by Healthwatch England adds to evidence that there may be significant numbers of people who are yet to be assessed or come forward for support. However, accurately establishing prevalence requires robust further investigation and access to NHS data.

The results of our local survey, which replicates the national survey, reinforce this picture.

How did people come to find or believe they had ADHD?

The Healthwatch England research estimates, combined with the other research outlined above, that ADHD prevalence could be rising alongside unmet need for support. This is unsurprising, given that ADHD in adults was only recognised by the NHS and NICE in 2008, so awareness will continue to rise.

To be referred for an ADHD assessment, NICE recommends that people must meet the diagnostic criteria listed in either the International Classification of Diseases (11th edition) (ICD-11) or the Diagnostic and Statistical Manual of Mental Disorders (fifth edition) (DSM-5).

DSM-5 was updated in 2013 to lower the threshold for diagnosis, meaning adults must meet five or more of the 18 criteria listed, which include nine for inattention and nine for hyperactivity or impulsivity. This, too, could lead to a rise in the prevalence of ADHD.

In the Healthwatch England second poll, they asked people what prompted them to think they had ADHD. These findings cover diagnosed and undiagnosed people. We replicated these findings, shown alongside national results in the table below.

How people came to realise they had or might have ADHD	Healthwatch Liverpool results	Healthwatch England results
Finding it hard to do things in daily life which others find easy	60%	58%
People I know talking about their ADHD	47%	50%
Someone else told me I might have it	43%	43%
By reading about it in the news, articles, books or watching online videos	36%	35%
I got into some kind of trouble	13%	17%
My working arrangements	8%	11%
Child went through the ADHD diagnosis process	20%	11%
Being at home during the Covid pandemic	5%	10%
Working from home during the Covid pandemic	4%	8%
Other	15%	11%
Don’t know	1%	3%

This shows that unmet need for support is a key driver of people came to realise they had or might have ADHD, with 60% of our respondents finding it hard to do things in their daily life, which others may find easy.

Discussion with other people is also a spur, including 47% who have discussed with others they know with ADHD, and 43% being told they may have ADHD.

Increased awareness, negative impacts, and changing habits during the pandemic all contribute to some people realising that they had or may have ADHD.

2. How does having ADHD affect people's lives?

This chapter examines how ADHD affects people's health, wellbeing, education, and personal lives.

As part of Healthwatch England's second national poll, they asked people to rate how ADHD impacted different parts of their lives. The results reveal significant negative effects on work performance, mental wellbeing, household management, and interpersonal relationships, with disparities across gender, age and socioeconomic backgrounds.

We replicated these findings locally. The table below shows that people without a diagnosis report more negative impacts across most areas of life.

	Healthwatch Liverpool results from self-selecting survey		**Healthwatch England results from national poll**	
Area of life affected	**Negative impact - diagnosed:**	**Negative impact - undiagnosed:**	**Negative impact - diagnosed:**	**Negative impact - undiagnosed:**
Concentration at work or when studying	73%	81%	63%	72%
Mental health and wellbeing	74%	81%	56%	67%
Carry out daily household tasks	73%	80%	57%	61%
Ability to socialise	59%	73%	46%	60%
Self-esteem	62%	81%	50%	59%
Ability to work	73%	81%	53%	50%
Relationships with partner, friends and family	59%	65%	44%	49%
Ability to budget and manage money	62%	66%	47%	46%
Ability to take part in hobbies and personal interests	46%	62%	40%	44%
Physical health	60%	61%	43%	41%

Impact on work and study

In this section, all figures refer to people who have been diagnosed as having ADHD unless otherwise stated.

Over seven in ten (73%) diagnosed respondents reported that their concentration at work or while studying was negatively impacted by their ADHD, and the same proportion indicated that their overall ability to work suffered due to ADHD. Women (75%) were more likely than men (71%) to report a negative impact on concentration.

A 2024 review of studies of people with ADHD highlighted poor educational and employment outcomes such as lower attainment, leaving education early and more frequent job changes.

In our own survey, both diagnosed and undiagnosed people described how their struggles with focus led to task avoidance, procrastination and difficulties maintaining productivity at work or study.

> **"I have held down a successful career. I struggled with deadlines, time management and concentration, but always worked to a high standard. It affected my self-esteem and confidence."** White British woman aged 50-65, (undiagnosed, awaiting assessment)

We heard about how these difficulties with concentration and focus, along with other ADHD-related challenges such as forgetfulness, could lead to inconsistent work performance. People talked about frequent job or course changes, career stagnation, or a sense of unfulfilled potential.

> **"I have been to university 5 times and don't have a degree, I am banned from studying with the Open University as I have not completed any courses and enrolled! If I had been diagnosed in my teens...would this be a different story??? I am very intelligent but cannot be bothered with finishing things without external forces"** Mixed/multiple ethnic groups woman aged 25-49, (diagnosed)

Mental health and self-esteem

Almost three quarters of our diagnosed respondents (75%) reported a negative impact on mental health and wellbeing. Women (77%) were more likely than men (71%) to report a negative impact on mental health.

When we looked at the undiagnosed group, we found the negative impact of their suspected ADHD on mental health was also higher at 84% compared to 74% for those diagnosed, possibly a result of the fact that those diagnosed generally have more access to support and medication.

In our survey, people described how low self-worth and self-esteem both contribute to and stem from these mental health struggles. This was a common issue: 62% of diagnosed people in the national polling reported a negative impact of ADHD on self-esteem, with women significantly more affected (67% of women compared to 53% of men).

Carrying out household tasks

Almost three quarters of our diagnosed respondents (73%) reported a negative impact of ADHD on their ability to carry out household tasks. This was most likely to affect women (75% compared to 71% of men), as well as people who were currently on the waiting list for an ADHD assessment (84%) or were yet to see their GP to get referred (81%).

People described wanting to do housework, shopping, gardening, household repairs and cooking, but not being able to get started or being distracted.

> **"My brain doesn't work like an allistic brain. People don't cry because they physically can't do the washing up because their brain is shouting at them."** White British woman aged 25-49, (undiagnosed, awaiting assessment)

Relationships and socialising

Over half (59%) of diagnosed respondents reported a negative impact on their ability to socialise.

Over half (59%) reported that ADHD had a negative impact on their ability to maintain relationships with their partner, friends and family. This aligns with findings from a recent review of ADHD research studies, which found that people with ADHD had increased difficulties with relationships and social interactions.

In our own survey, people described how executive function difficulties made it hard to keep in touch with friends and maintain relationships:

> **"I have to sacrifice personal relationships to be able to function as I am always exhausted by masking, but and get so overwhelmed by rejection sensitivity"** White British woman aged 50-65, (not seeking diagnosis)

> **"I struggle with relationships and friendships as I feel I have to have a mask up to start before I can let it drop with those I trust."** White British man aged 25-49, (diagnosed)

> **"I wish more people understood the emotional regulation side. It is far and above my most challenging (and definitely most embarrassing) symptom"** White British woman aged 25-49, (diagnosed)

Financial management

Research shows that people with ADHD have an impaired ability to make financial decisions.

62% of our respondents with a diagnosis reported negative impacts of ADHD on their ability to budget and manage their finances.

> **"I struggle to budget and manage finances and live constantly in my overdraft. I'm currently waiting on my meds to help and hopefully this helps"** White British man aged 25-49, (diagnosed)

Hobbies and personal interests

Research indicates that having a hobby is linked to good mental health and wellbeing. However, 46% of our diagnosed respondents reported a negative impact on their ability to spend time on hobbies and personal interests.

Hobbies require maintaining interest and concentration over time, which is a challenge for people with ADHD.

Physical health

Over half (60%) of our respondents with a diagnosis said that ADHD had a negative impact on their physical health. A review of studies on the effects of ADHD on people's lives found that there were a number of impacts on physical health, including quality of sleep, oral health, weight management, addiction and other health conditions.

In summary

ADHD has a far-reaching impact on various aspects of people's lives, often beyond what is commonly recognised or understood. Far from a simple deficit of attention, the harder-to-quantify impacts on self-esteem, health, and opportunity shape lives in ways that may be hidden from view but are, nonetheless, destructive.

Our findings suggest that people who have not yet been diagnosed are more likely to report challenges - particularly around concentration, mental health and socialising – compared to those who have received a diagnosis.

By better understanding these complex struggles in people's own words, we can design policy and support that improves quality of life.

The evidence from this chapter and throughout the report points to the importance of timely assessment, support, and treatment.

3. Referrals and long waits for ADHD assessments

In this chapter, we examine people's experiences of referrals and waiting times for NHS ADHD assessments. We also examine the experiences and concerns of people who believe they have ADHD but are neither diagnosed nor waiting for an assessment. These groups could benefit from improved referral processes and access to ADHD assessments.

How are people referred for assessment?

In England, adults needing an ADHD assessment must be referred by GPs to a mental health professional specialising in ADHD. This could be an NHS specialist or a private organisation providing NHS services under the Right to Choose. NICE guidance states that diagnosis should involve:

- a full clinical and psychosocial assessment of the person, including a discussion of behaviour and symptoms in the different aspects of the person's everyday life
- a full developmental and psychiatric history, and
- observer reports and assessment of the person's mental state.

Getting a referral for an ADHD assessment

For people who think they have ADHD, their GP must feel assured that the traits might constitute ADHD before a referral is given to join the waiting list for an assessment.

Our national poll and our own survey found that this process is not working well for many. This is perhaps unsurprising, considering research that GPs themselves find it difficult to identify ADHD.

Over one in ten of our survey respondents (11%) had been referred by their GP and were waiting for an assessment.

We found that:

- Almost half (48%) of people who were on the waiting list for an assessment had had one appointment with their GP before they were referred
- Over a quarter (28%) said it had taken more than one appointment.

Some people received a prompt referral which they appreciated:

> **"I have found the wait difficult, but I am grateful to the ANP [Advanced Nurse Practitioner] at my GP surgery who listened to my concerns and submitted my RTC [Right to Choose] referral the same day, although it was disappointing not to have a choice which provider I went with."** Woman, mixed Asian and White ethnicity aged 25-49, undiagnosed, awaiting assessment.

We also heard from people who said that they had had to have multiple visits to their GP to convince them to refer them for an ADHD assessment. This can have an emotional impact:

> **"Being told, you don't have it, by someone I've met once made me feel awful, self hatred. Loneliness. I was contemplating suicide."** White British man aged 25-49, undiagnosed, awaiting assessment.

In 2023, Healthwatch England highlighted the impact of this 'hidden wait' (the time spent waiting for a GP referral) across all referrals for specialist care. These waits go unreported but add to the overall waiting times for treatment. In that research, Healthwatch England found that people needed to see their GP multiple times before they got a referral. Their analysis of the 2023 data indicated that experiences of mental health referrals were worse for neurodivergent people, with one in five having to chase delays, compared with just 5% for all respondents.

The need to convince a GP to refer for an ADHD assessment was also cited as a problem by people who believed they had ADHD but hadn't been diagnosed or were waiting for a diagnosis.

Only 3% of our respondents reported that their GP had refused to refer them for an ADHD assessment. Those that did cited the following reasons for the refusal:

Perceived reason for not referring	**% of people giving this as a reason**
The GP didn't want to refer me because of long waiting lists	41%
The GP didn't listen to me	35%
My ADHD symptoms/traits weren't considered serious enough	29%
Other	29%
The appointment was too rushed	24%
The GP didn't consider all my symptoms/traits	24%
I find it difficult to express myself	12%
My GP refused to refer me without giving a reason	12%

I had a telephone appointment with my GP and I feel uncomfortable talking to people over the phone	6%
I was recommended a private assessment	6%
The ADHD diagnostic criteria used by GP didn't reflect my experience of ADHD	6%

Some people whose GP did refer them found this took some persistence.

> **"I am at breaking point in many areas of my life. Not helped by dr surgery not processing my referral and repeatedly told me it was in referral when it wasn't. Also had supporting letters about need for diagnosis from therapist."** White British woman aged 25-49, (undiagnosed, awaiting assessment)

37% of our survey respondents said that they believed that they had ADHD but hadn't yet been to see their GP about it. Their reasons were varied.

Reason for not going to the GP yet for a referral	**% of people giving this as a reason**
I've only recently realised I might have ADHD	39%
I'm worried that I might not be able to express myself well enough at the appointment	39%
I'm worried that my GP won't refer me for an ADHD assessment	28%
My ADHD traits mean it's difficult for me to book or attend a GP appointment	18%
In the past, I've had to wait a long time for a GP appointment when I needed one	11%
Other	10%
Don't know/prefer not to say	8%
The ADHD diagnostic criteria used by GP or at diagnosis doesn't reflect my experience of ADHD	6%

18% of our survey respondents said that they believed that they had ADHD but weren't seeking a formal diagnosis.

Reason for not seeking a formal ADHD diagnosis	**% of people giving this as a reason**
I believe I have ADHD and do not need a formal diagnosis – I am happy to self-diagnose at this stage	50%
I haven't pursued a diagnosis because I am worried a diagnosis may negatively impact me	28%
I can't afford to pay for a private ADHD diagnosis	24%
I am worried about the long waits for an NHS diagnosis	21%
I prefer to use natural or alternative remedies (e.g, lions mane capsules, magnesium) for treating my ADHD traits	10%
I prefer to use ADHD coaching, ADHD apps or meditation to manage my ADHD traits instead of medication	9%
Other	8%
Don't know/can't remember	4%
My GP or other health care professional told me not to bother getting a diagnosis	1%

People who responded to our survey talked about dismissive GPs who cited long waiting lists as a reason not to refer them:

> **"I didn't bother asking for a diagnosis at first as I believe I would have just been dismissed. I first brought it up a few years ago but I wasn't told I would be referred and the thoughts of the long wait list put me off. I felt my symptoms started impacting my life more so I asked for a referral but through the right to choose pathway to try to speed things up"** White British woman, 24-49 (undiagnosed, awaiting assessment)

> **"My GP told me I didn't have it. Then said she'd refer me but she didn't. Tbh that was 18 months ago. They referred me last week. Almost 4 years waiting this will be"** White British man, 24-49 (undiagnosed, awaiting assessment)

People who hadn't got around to asking their GP for a referral yet or had decided not to seek a formal diagnosis also explained how long waits for NHS assessments, fears their GP wouldn't respond to their request in a positive way and other factors combined to stop them seeking a referral for an ADHD assessment.

People described the impact of worry about long waiting times, the possibility or reality of being dismissed by their GP and their lack of confidence in expressing themselves well enough to get an appointment.

> **"When seeking a referral the mental health nurse at my GP said it *"was trendy to have ADHD"* and *"you see one tiktok and think you have it"* no it's insanely debilitating day to day! I have done deep research including peer reviewed papers and verified sources, this is not a flighty fancy. It was incredibly hurtful what the nurse said, never mind a mental health nurse. I constantly struggle with imposter syndrome and it took a lot mentally to seek help. To be dismissed so casually is cruel. I insisted I wanted to be referred, she reluctantly gave me a link for the pre assesment screening quiz, which I had already done multiple of before seeking a referral. She didn't call me back as promised she simply referred me on the results alone. She was convinced because I managed education "there wasn't anything wrong", I strongly disagree."** White British woman, 24-49 (undiagnosed, awaiting assessment)

Long waiting times for assessments

People told us they had been waiting a long time for ADHD assessments. Over half (56%) of our survey respondents who were waiting for an ADHD assessment said they had been waiting for an assessment for over a year. Two in ten (20%) of these had been waiting for three years or more. And nearly three quarters (74%) of people who are already diagnosed said that the time taken from referral to diagnosis was a difficult part of the ADHD diagnosis process.

Waiting times also vary significantly by location. In a 2023 report, ADHD UK used FOI data to highlight this postcode lottery, with waiting times ranging from 12 weeks at Dorset Healthcare University NHS Foundation Trust to over 10 years at the Herefordshire and Worcestershire Health and Care Trust.

Currently most Liverpool referrals go to Psychiatry UK which at the time of writing has a waiting list of 8-10 months for NHS referrals.

At the time of writing, the local NHS provider Cheshire Wiral Partnership is closed to referrals with the following exceptions:

- Young people who are transferring from care provided by Child and Adolescent Mental Health or Paediatric services.
- People who are currently having treatment and are transferring from one NHS service to another NHS service.
- People who are considered Military Veterans
- People who have committed an offence in the past and who are considered to pose a risk of serious harm to the public under MAPPA3

> **"I have been waiting for 8 years for an NHS ADHD assessment in Liverpool! What impact could anyone think this has had other than a negative one."** White British man, 24-49 (undiagnosed, awaiting assessment)

> **"I am 99% certain I am ADHD. Multiple family members are diagnosed and medication makes a difference for them. I struggle massively daily, but wasn't taken seriously as I did well academically and mask heavily. I have multiple physical health conditions and at 30 years old I can no longer mask my way through. I've attempted suicide twice and ADHD had a large role in that. I know I'm *"different"* and struggling to find my place in the world when I've got 'hidden' disabilities."** White British woman, 24-49 (undiagnosed, awaiting assessment) respondent 52 – waited 3-4 years already

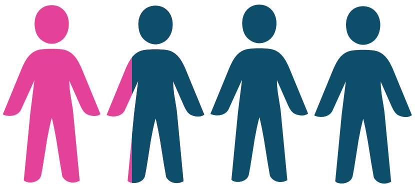
"I'm barely hanging on to my job, I've had five different jobs since being referred. My mental health is at rock bottom and I'm struggling immensely with my sleep but was told by my GP I can't be referred to a sleep specialist until I've had my ADHD assessment because they'll need the results of that to know what to do at the clinic." White British non binary person, 24-49 (undiagnosed, awaiting assessment)

"About half the time I've decided I have ADHD. The other half I think it's something else and I'm just broken. The wait, errors at the GP surgery, zero communication from the NHS ADHD team have all led me after 2 years to go private through Right to Choose. I need help. I'm struggling with work through ever decreasing concentration. I'm struggling with money. I'm struggling with my marriage and friendships. I know a diagnosis is not a silver bullet and that medication won't magically fix everything but I feel I need the diagnosis so I can hopefully get over the imposter syndrome, engage with support groups and having a feeling of a right to be there." White British man, 24-49 (undiagnosed, awaiting assessment)

"My life is on hold, I can't work at present due to waiting for ADHD and another diagnosis. I want to wait until I have everything in place before I can start looking for work again and apply for PIP" White British woman, 50-64 (undiagnosed, awaiting assessment)

Turning to private care

Over a quarter (29%) of those currently waiting said they were considering paying for a private ADHD assessment.



Over a quarter were considering paying for a private ADHD assessment

The second national poll found that the long waiting times are the main factor pushing people towards private assessments, with almost nine in ten (88%) of those considering a private assessment citing this as their main reason. In contrast, almost three quarters (72%) of those not considering a private assessment said it was because they couldn't afford it.

In 2021, a 'consensus group' of leading ADHD clinicians and researchers warned that long waiting lists, combined with a growing private assessments industry, were creating a 'two-tier health service' that failed those from less affluent backgrounds. Four years later, waiting lists have ballooned, and the demand for private care has only increased. Our survey found that 22% of people who were already diagnosed with ADHD had been diagnosed privately.

"I couldn't get diagnosed by NHS as 6 years ago I was put on waiting list at age 40 as there was 7 year wait… With help from my family I went private to [a Doctor at a small local private provider] who is amazing. He has helped me so much… I still don't even know if I'm on waiting list got one letter year in saying still 5 year wait had nothing off NHS since." White British woman, 24-49 (diagnosed)

In summary

This chapter outlines the challenges many face when getting referred and long waits once they are on the waiting list. It is particularly worrying that some doctors are reluctant to refer due to long waiting lists, which may deny many an assessment that may lead to a diagnosis.

With over half of those waiting for assessment telling us they had been waiting over a year, there is a concern about a 'two-tier' system emerging where only those who can afford private assessment get it.

4. The support that people need

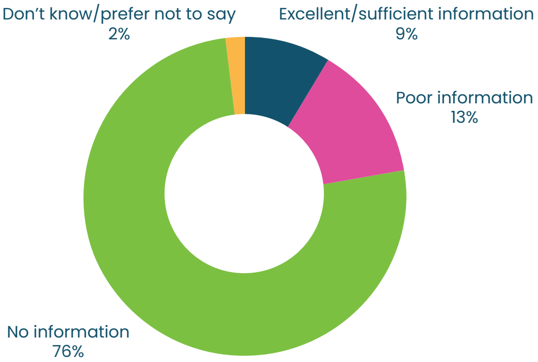
In this chapter we look at how people waiting for an ADHD assessment are coping, the support people want whilst they are waiting and people's experience of getting support at work.

How are people coping while they wait?

Our research shows that many people feel unsupported and that they are not kept informed during their long waits for an assessment.

Seven in ten of those (70%) who were already diagnosed cited a lack of support or resources as a difficult part of the diagnosis process.

What people thought about the information they got while they waited for an ADHD assessment



More than three quarters (76%) of those referred and awaiting assessment received no information at all about how to manage their ADHD traits while waiting. A further 13% said the information they received was poor. Just under one in ten (9%) said the information they received was excellent or sufficient.

> **"Psych UK has sent a wellbeing survey but there is not support for while you are on the wait list and no signs of medication to help in the near future"** White British woman, 24-49 (undiagnosed, awaiting assessment)

Someone who had received no support while waiting said:

> **"I'm left without any help to help keep me safe & function well. It means I'm stressed & anxious which impairs me further leading to self medication to manage. [...] My symptoms impact on all aspects of life, sometimes dangerously. The uncertainty of not knowing when I'll be assessed, if I'll be diagnosed & if I can access treatment is very stressful."** White nonbinary person 50-64, (undiagnosed, awaiting assessment)

> **"The wait times to be diagnosed is ridiculous and stressful, and the GP don't give you any updates and the assessment centres don't update you either"** White British man, aged 25- 49, (undiagnosed, awaiting assessment)

Some people awaiting diagnosis said that they had received valuable support from Ladders of Life:

> **"Thankfully, my GP also referred me to Ladders of Life, so I've been getting support whilst I wait. They are amazing people who have helped me in all aspects of my life. Other than that, being on a waiting list for such a long time is frustrating." And "Ladders of Life have been brilliant, and they've also helped my family to understand me better as well."** Black/Black British: Caribbean woman age 25-49 (undiagnosed, awaiting assessment)

Others noted the pressure on support groups:

> **"I had a survey to make sure I wasn't suicidal. Wasn't really a support more of a check in. The GP only reacts to me asking for something, no check ins. There is not enough capacity in support groups"** White British woman, aged 25- 49, (undiagnosed, awaiting assessment)

People waiting without support described the impact lack of support had on their lives. They talked about feeling left in limbo:

> **"I'm barely hanging on to my job, I've had five different jobs since being referred. My mental health is at rock bottom and I'm struggling immensely with my sleep but was told by my GP I can't be referred to a sleep specialist until I've had my ADHD assessment because they'll need the results of that to know what to do at the clinic."** White British non-binary person, aged 25- 49, (undiagnosed, awaiting assessment) Respondent

Others spoke of feeling alone and how this was a familiar feeling for them:

> **"I have never been supported"** White British woman, aged 25- 49, (undiagnosed, awaiting assessment)

> **"Trying to face it alone"** White British woman, aged 25- 49, (undiagnosed, awaiting assessment)

> **"I'm left to cope as I have been all my life."** White British woman, aged 50-64, (undiagnosed, awaiting assessment)

Support whilst waiting for an assessment

As waiting times for ADHD assessments can be long, people need support while they wait.

In our survey, the top three types of support wanted by people waiting for an ADHD assessment were a single point of contact about the wait for an assessment followed by advice on how to manage mental wellbeing, and information on local support groups (see below).

	% who put in the top three	
What type of support people want while they wait	**Healthwatch Liverpool Survey**	**Healthwatch England poll**
A single point of contact about the wait for an ADHD assessment	60%	44%
How to manage mental wellbeing	50%	63%
Information on local peer support groups	35%	16%
Help and support to hold down a job	29%	28%
Information on the organisations that can give advice on ADHD	24%	30%
Advice on maintaining relationships	19%	17%

Don’t know	12%	5%
Help and support to study	9%	22%
None of the above	3%	3%
Culturally sensitive information about ADHD	2%	7%

Support at work

We also asked people who were employed whether they had told their employer that they had or might have ADHD. We wanted to see whether employers could support employees with ADHD appropriately so that they could do their jobs to the best of their ability.

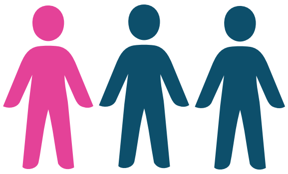
Equality law requires employers to make “reasonable adjustments” to ensure workers with disabilities or physical or mental health conditions are not substantially disadvantaged when doing their jobs. Depending on the employee’s condition, these could include improving physical accessibility, providing additional equipment, or changing work arrangements.

Entitlement to reasonable adjustments does not depend on having a diagnosis. Therefore, in this section, we consider the experience of both diagnosed and undiagnosed people with ADHD.

> **“Feeling over worked as I have to work twice as much to keep the same pace as everyone else, even if I am more knowledgeable on the subject”** White British woman aged 25-49, (diagnosed)

Although a diagnosis is not a requirement to getting support at work, not having a diagnosis can make it harder to get the right support.

> **“I have not got any support from the NHS. I have gone out and got a coach and therapist through my work, however without that diagnosis it’s hard to justify ADHD specific help and support.”** White British woman aged 25-49, (undiagnosed, awaiting assessment)



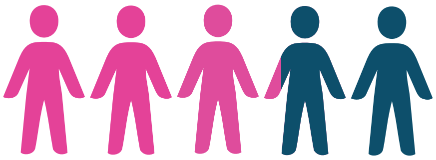
One in three employed people had told their employer that they had ADHD

Less than one in three employed people (31%) had told their employer that they had ADHD. This rose to nine in ten (91%) among those who had received a diagnosis.

Overall, around two in five (41%) people who discussed their potential or diagnosed ADHD with their employer were offered no reasonable adjustments. Where they were offered, the table on the following page shows the types of adjustment offered:

Reasonable adjustment offered	**Healthwatch Liverpool survey**	**Healthwatch England poll**
Flexible working arrangements	23%	35%
Additional guidance or check-ins with their manager	12%	30%
Working from home arrangements	17%	25%
ADHD coaching or support	8%	20%
Help with the Access to Work scheme	7%	19%
Specialised software	6%	11%

We found that reasonable adjustments could be beneficial to enable people with ADHD to work well.



Over three in five of those who had been offered reasonable adjustments said they had made a difference

Over 3 in five (63%) of those offered reasonable adjustments said they made a significant or moderate difference.

Some people talked about employers who put in place adjustments that would help them eg being able to work from home , working more flexibility or having ADHD coaching.

However, people also shared difficult experience with managers. After disclosing their condition, some individuals told us they felt like they were labelled as "difficult," "problematic," or "attention-seeking". Whilst employers can refuse adjustments if they are not reasonable due to practicality, cost and organisational size, some employers appear to be breaching their legal duty:

> **"Now I am diagnosed I can see how my previous employer didn't want to have to make any adjustments.. so it was easier to do the exact opposite that someone with ADHD needs so that I wanted to leave. I'd been there over 15 years with an excellent record and commendations- the moment I mentioned potential diagnosis my managers attitude just flipped. Looking back it was definitely discrimination but when you are not medicated you internalise all of this. … Legally I didn't have a 'protected characteristic' at the time to challenge this behaviour- but I did… it just wasn't written down."** Woman aged 25-49, (diagnosed), ethnicity not shared.

> **"My work has got worse, as they now see my diagnosis as a problem, rather than something to support me with."** White British woman aged 25-49, (diagnosed).

When asked why they hadn't yet told their employer, people cited barriers like not having a formal diagnosis and being worried about the implications for their job:

Reasons for not telling your employer	**Healthwatch Liverpool Survey**	**Healthwatch England poll**
I'm waiting until I have a formal diagnosis to tell my employer	35%	30%
It doesn't make a difference to the job I do	17%	39%

I'm afraid of the possible implications for my job	16%	23%
I don't want to disclose personal information	15%	26%
Other	8%	11%
Don't know/prefer not to say	8%	5%

People who responded to our own survey were unsure of the response they would get from their current employer if they told them that they had ADHD and were wary that disclosing would negatively impact their job. Many people were especially wary of disclosing before they had a formal diagnosis despite a diagnosis not legally being required for reasonable adjustments to be made.

What difference did reasonable adjustment make to those who received it?	**Moderate or significant impact**	**Little impact**	**No impact**
Flexible working arrangements	79%	15%	3%
Work from home arrangements	88%	4%	4%
Help with Access To Work	91%	9%	0%
ADHD coaching or support	15%	83%	0%
Specialised software	8%	17%	0%
Additional guidance or check-ins with manager	67%	28%	0%

In summary

This chapter highlighted how people cope and what support they want while waiting. There is a demand for practical and straightforward measures, such as regular check-ins, clear communication about waiting times, and a single point of contact that could be provided while people wait.

When looking at support at work, we found most people who hadn't yet received a diagnosis hadn't had a conversation with their employer about their diagnosis or possible ADHD. Concerningly, many said that this was due to fear of losing their job.

A large majority of our working respondents with a formal diagnosis (91%) had felt able to tell their employer.

Our survey shows that this can improve conditions at work for those affected by ADHD. Almost all (98%) of the reasonable adjustments provided made a positive difference, with over eight in ten (82%) having made a significant/moderate difference.

5. The benefits of diagnosis

In this chapter, we look at the impact of having an ADHD diagnosis on people's lives. We found that the journey to diagnosis was viewed positively by many, but came with its own challenges. Our results demonstrate that a diagnosis has a positive, wide-ranging and transformative impact on people's lives.

> **"My ADHD diagnosis has been a lifesaving diagnosis"** White British woman, 24-49 (diagnosed)

The diagnosis process

Around two thirds (69%) of people in our national poll who were diagnosed with ADHD had an overall positive experience of the process from referral to diagnosis. Those who were employed were more likely to have a positive experience, pointing to the potential of a diagnosis to unlock effective support at work.

Challenges in the process of being diagnosed are longstanding. Research from over ten years ago described the ADHD diagnosis process itself as an "uphill struggle", poorly designed for the traits and needs of those with ADHD. Responses to our own survey indicate this is still the case for people diagnosed more recently.

> **"My experience trying to get diagnosed via the NHS service was atrocious! I think I was referred something like five years ago to the NHS service. The only contact I have had with them is a yearly triage appointment where they ask lots of questions which bear no results whatsoever. At the time I've had at least two of these triage appointments I was in severe mental health crisis because of the impact that ADHD and other things were having on me; I was open and honest about my self-harm and plans for suicide etc.; and it was very clear that I should be in the top priority for being assessed, but when I received the letter confirming the outcome of those triage appointments I had been categorised as Green despite the clinician who did the appointment telling me I fell into the highest category of need. Since joining the waiting list I have seen three different mental health practitioners (including a private clinical psychologist that I've been seeing for two and a half years); 18 months later I joined the waiting list via right to choose, I've reached the front of that waiting list for assessment, I've been assessed. [...] Essentially, if I had not have gone through right to choose I would still be on a waiting list."** White British man aged 25-49, (diagnosed)

How did a diagnosis change peoples' lives?

Despite the difficulties outlined above, our findings show the impact of an ADHD diagnosis was largely positive:

	% Agree	
Area of impact	**Healthwatch Liverpool survey**	**Healthwatch England poll**
My ADHD diagnosis has helped me to understand the way my brain works and my behaviour	91%	84%
I find it easier to work	53%	46%
Since my diagnosis, I have new strategies (e.g. ADHD coaching, apps) that I can use to manage my ADHD traits	50%	58%
I find it easier to maintain relationships with my partner, close friends or family	50%	46%
The ADHD medication I have been prescribed has made it easier to manage my ADHD traits	49%	44%
I find it easier to take part in hobbies and personal interests	48%	51%
I find it easier to concentrate (e.g. at work or while studying)	48%	47%
I find it easier to carry out daily household tasks	45%	45%
I find it easier to socialise	37%	33%
I find it easier budgeting and managing my money	31%	30%

The most common benefit of a diagnosis, reported by 91% of respondents, was a better understanding of how their brain works and why they behave the way they do.

> **"Having my diagnosis has validated me and stopped the self loathing of there is something wrong with me, and being called crazy/weird for the majority of my life."** Mixed ethnicity woman aged 25-49, (diagnosed)

> **"The diagnosis not only changed my life for the better but also highlighted after medication I had autism. Which then much later after also NHS diagnosis has transformed my support structures and life. I'm not sure I could have carried on like I had without my GP suggesting ADHD."** White British woman aged 25-49, (diagnosed)

> **"It's helped me to flourish at work. To understand my relationships better and improve them and helped me get to grips with my finances"** – White British man 50-64 (diagnosed)

> **"I struggled with depression and anxiety a lot before my diagnosis. It has improved significantly since. I still struggle but no longer have big panic attacks. I think a lot of it stems from feeling over worked as I have to work twice as much to keep the same pace as everyone else, even if I am more knowledgeable on the subject" -** White British woman aged 25-49, (diagnosed)

We heard that mental health and wellbeing improved for many due to diagnosis.

> **"I struggled with depression and anxiety a lot before my diagnosis. It has improved significantly since. I still struggle but no longer have big panic attacks"** - White British woman aged 25-49, (diagnosed)

Some respondents reported that diagnosis had helped them come off antidepressant medication.

> **"Realising I have ADHD has been life changing for me. All those years of struggling and thinking I was just 'sensitive' or 'anxious'. It's been a confirmation. I get loads more work done and even have some free headspace for the evenings. I've been sleeping better too. I'm reducing down my anti depressants that I have been on most of my life. It's been so eye opening to me"** White British Gender fluid person aged 25-49 (diagnosed)

Some people, especially those diagnosed later in life, reported finding the diagnosis difficult to take in and some had a process of grieving lost opportunities.

> **"Overwhelmed at a diagnosis at 53 years old. Thinking what I could have achieved with in all those years undiagnosed." -** Asian/Asian British: Indian woman 50-64 (diagnosed)

> **"As somebody who has received a late diagnosis, I find it difficult to come to terms with how life could've been if I was diagnosed sooner. I have lost relationships, jobs and ended up in trouble which, in hindsight, could've all been prevented had I have been diagnosed earlier."** White British: Indian man 50-64 (diagnosed)

In our survey, the importance of validation and self-understanding was strongly highlighted. Emotional and psychological validation, alongside practical self-management strategies, plays a key role in improving outcomes. Half (50%) reported that since their diagnosis they had gained new strategies (e.g. ADHD coaching, apps) to manage their ADHD traits:

> **"I spent 26 years hating myself for my differences - this diagnosis has given me the tools to understand and accept them. It's easier to accommodate myself because I know why I find some things more difficult. Work is so much easier now because I can put things in place before things get bad. Previously, I'd get so stressed about being late but now I can ask for a reasonable adjustment without shame. ADHD coaching has helped massively too. I'm a different person now and I am better in my job, in my relationships, because I don't try to suppress those traits anymore. Instead I deal with the challenges using what I've learned and I give myself grace. I know why my emotions have always been so strong, why I am so much more sensitive than my peers. Things aren't perfect (it's still a disability!) but now I can advocate for myself and make things work for me.**" – White British woman aged 25-49, (diagnosed)

Medication

We heard from many people about the impact of medication. Some found medication hugely beneficial:

> **"Meds have saved me, I am sure I would have been fired again by now if not for diagnosis and medication. I'm able to have a more of a life now, spend less time unable to function, in and out of work." -** White British woman aged 25-49, (diagnosed)

> **"Getting an ADHD diagnosis was essential to my life being a functional one. Medication has allowed me to complete my academic studies to the best of my ability and maintain a job, as well as communicate with employers effectively about my difficulties." -** Mixed ethnicity woman aged 25-49, (diagnosed)

> **"I started medication which allowed me to concentrate a bit better, meaning I'm doing better at work and I'm also able to do more around the house without being overwhelmed. I've also managed to reduce my personal debt significantly and start saving money as I'm less impulsive**" – White British man aged 25-49, (diagnosed)

> **"I cannot describe how different the future looks to me now that I have ADHD medication full stop my entire outlook on life has changed. Life was so hard before and it is so easy now. It's impacted in every area of my life and has made me even more vociferous about advocating for ADHD people when people claim that ADHD diagnoses are false or that people only want diagnoses so they can get access to medication to use recreationally. I am not describing specifics because there are too many. Moreover I knew for years that I was having high blood pressure due to stress and almost wasn't allowed to take ADHD medication because of that high blood pressure. Since starting on my medication my blood pressure has gone down because I am less stressed. I have experienced side effects but almost all of them disappeared once I was on the correct dose and frankly I would put up with many more side effects than I have experienced because the pros outweigh the cons. The only downside from my perspective is that I'm now aware that I could have had this help for my entire adult life and I mourn for the wasted years, I mourn for what could have been. I have still achieved many things but I cannot put into words what having access to this medication earlier in my life would have done"** - White British man aged 25-49, (diagnosed)

For many people though the route to medication gelt a slow and frustrating one. After a Right to Choose diagnosis people found themselves on a new waiting list to await starting the medication process which in itself involves various health criteria and then a titration period

> **"[After diagnosis via Right To Choose provider] I've been put on the waiting list for titration, I've reached the front of that waiting list, I've been to the back of the waiting list because of my blood pressure, I've reached the front of the waiting list again and been discharged for not providing an update on my blood pressure (despite being told to wait until I was contacted to provide an update), I've been re-referred by my GP, I've been reassessed by a psychiatrist, I've been pulled back on the waiting list for titration, I've reached the front of the waiting list and begun titration, and now I've been started on medication. I've been up front and transparent with the NHS service about my diagnosis via right to choose and have been told that this won't have affected where I am on the waiting list for the NHS service in any way. I've also been told not to leave the waiting list with the NHS service because they will need a relationship with me going forward."** - White British man aged 25-49, (diagnosed)

Non-medication options

We also heard from people who wanted different support because medication didn't work for them, wasn't an option or had an additional wait. Some people who were diagnosed via Right to Choose, reported feeling lost after being given the diagnosis even if they had been happy with the provider and process. This may be because a national provider does not have the information on local support services to point people towards post-diagnostic support or local connections. The only offer is medication, after a further wait.

> **“I didn’t love the over-focus on medication though. I’d already been medically told by the NHS I can’t have stimulants or things like anti-depressants due to a heart problem. They didn’t seem to care, they just kept calling me severe and insisting I needed the medication. It was really disheartening, it made me feel like I’m pretty screwed but the reality is they probably just had no training in post-diagnostic support beyond offering meds. They were all current or ex NHS staff too.”** - White British woman aged 25-49, (diagnosed)

> **“Right to choose provider was good. The app was useful and the doctor was very nice. I don’t feel there is any support after the diagnosis, there is no offer of coaching or support.”** - White British woman aged 25-49, (diagnosed)

> **“It’s changed things for sure, but Right to Choose offers no coaching and it is an additional year to start titration for medication so I still feel a lot way from help” -** White Irish woman aged 25-49, (diagnosed)

Some who received community support highly praised it:

> **“Getting a diagnosis has been important to me, as I wanted to know. But not as crucial as going to Ladders and building up my managing and coping skills. These have helped me in my life.”** - White British man aged 25-49, (diagnosed)

This underlines that self-understanding and management strategies are valuable to people alongside access to medication. These areas deserve more attention in both treatment plans and policymaking.

Half (50%) of respondents reported finding it easier to maintain relationships with partners, close friends and family after diagnosis, and over a third (37%) reported finding it easier to socialise after diagnosis. This may be linked to the greater self-understanding reported by 91% of respondents.

Concerningly, only three in ten (31%) reported improvements in their ability to manage their finances, indicating that this remains challenging even after diagnosis and treatment.

Not only can it take a long time to resolve debt and financial issues, but we heard cases of financial issues being exacerbated by the costs of a diagnosis or medication. In some cases, this was due to the NHS not accepting shared care from Right to Choose providers or diagnoses from private ADHD assessment companies.

> **“The one thing I don’t agree with is struggle getting medications once diagnosed, with share agreements I was paying private for months, lucky I had family to help or I couldn’t done it.” -** White British woman, 24-49 (diagnosed)

In summary

While a long diagnosis process remains frustrating, the impact of a diagnosis is positive.

Beyond a straightforward story of access to medication, diagnosis can unlock self-understanding, effective management strategies, improved mental health, self-esteem, and concentration. These improvements extend to relationships, work performance, and daily household tasks.

6. Intersectionality and ADHD – the experiences of particular groups

Although our survey reached a self-selecting sample of people, the experiences of our respondents indicates that some groups of respondents experienced ADHD in the light of other features of their life – gender, menopause, ethnicity and autism.

Gender and childhood presentations of ADHD

Given that research and assessment criteria for ADHD was largely based on the presentation amongst boys, especially those with a hyperactive presentation of ADHD, the diagnosis rate among girls, who are more likely to have an 'inattentive' presentation has long been much lower. As a result there is what has been referred to as a 'lost girls' now seeking diagnosis in adulthood. This is reflected in the ADHD waiting list profile, in the gender breakdown of our respondents (see appendix 2), and in the experiences they shared:

> **"I don't think Adult ADHD is taken seriously in older women, fighting to get a referral then waiting years for an appointment isn't good enough when women are often overlooked due to masking and presenting very differently to men"** - White British woman (had been refused referral for assessment) aged 50-64.

> **"I wish someone had bothered to notice how ADHD presented in girls and women years ago! I'm in my 40's and the years I didn't understand myself are a loss. If I had medication then who knows how different my life might have been." -** Woman aged 25-49, diagnosed), ethnicity not shared.

Some felt that their gender and stereotypes about ADHD were still hindering their diagnosis as an adult:

> **"I believe that because I am a woman in my 30s I was completely dismissed during discussion. GP just didn't want to know and refused to engage in any dialogue"** - White British woman (had been refused referral for assessment) aged 25-49.

Perimenopause and ADHD

Perimenopause causes dopamine levels to drop and can make ADHD symptoms more obvious and more difficult to manage. Many of our older female identifying respondents identified this time as a key moment in their ADHD journey.

> **"Since reaching perimenopause my mental health problems have worsened and the ADHD symptoms I have dealt with for many years have now become unmanageable"** - White British woman aged 25-49, (undiagnosed, awaiting assessment)

> "**I would just like to know now, menopause is making my symptoms worse I suspect" -** White British woman aged 25-49, (undiagnosed, awaiting assessment) respondent.

A woman who had not yet seen their GP for a referral or told anyone at work because of worry about the 'label" said **"Perimenopause made it worse"** (British woman aged 50-64).

> **"It was manageable until I hit the menopause. Adhd gets me into trouble in work always being told off. I can't control emotions, RSD [Rejection Sensitivity Dysphoria] for example in meetings"** White British woman aged 50-64, (not seeking a diagnosis).

> **“Became worse when I started peri menopause really struggled listening to my job, memory shocking”** - White British woman aged 25-49, (diagnosed).

Some people found that symptoms that that felt were caused by their ADHD were instead attributed to the menopause:

> **“I didn’t feel listened to and continue to struggle with issues. I have twice been diagnosed with stress and anxiety and been signed off work. My doctor stated my symptoms were due to the menopause.” -** White British woman (had been refused referral for assessment) aged 50-54.

Ethnicity

Most of our respondents were White British (see appendix 2) however responses from those with diverse cultural backgrounds suggest that they might navigate ADHD with differential presentations and barriers. Understanding this will be vital in reaching these people and understanding potential hesitation.

For some people, intersectionality of their ADHD with ethnicity and religion made them more wary of sharing a diagnosis, being aware of how it may be viewed by those around them.

> **“Being of an ethnic and religious minority, I believe a diagnosis of ADHD/ASD is likely to impact my life negatively, which is why I have failed to disclose it to friends, family & work. My partner is unaware of my pending assessment, and I intend to keep a possible diagnosis - if received - to myself.”** - Arab woman, 25-49, awaiting diagnosis.

Autistic people

43% of our respondents consider themselves to also be autistic, (either diagnosed, awaiting diagnosis or self-identified). AuDHD, although not a medical term itself, is the term many people living with both conditions use to describe themselves. AuDHD people, living with a complex interaction of their ADHD and autism traits, can face additional barriers to diagnosis and finding support with their neurodivergent needs. Appendix 1 outlines some of what we heard from this section of our respondents about the challenges they faced especially as late diagnosed with ADHD or still awaiting diagnosis.

> **“Being both Autistic and ADHD is exhausting. Having a brain that likes routine, things done in a certain way, struggles with sensory overload but also having a brain that is complete and utter chaos is a nightmare. I can’t take my brain out to have a break, it is constant. The adhd medication does help to tone down the adhd traits so that I am able to function a little better, but this does then increase my Autistic traits. I wonder how different my life could have been if I had been diagnosed much younger (47 for Autism and 52 for ADHD).”** White British woman aged 50-64 (diagnosed).

In summary

People’s experience of ADHD and the diagnosis processes is impacted by the many other elements of someone’s life and identity. Gender, age, ethnicity, background, other elements of neurodivergence, other physical and mental health conditions, ecoonomic status and much more can all interact with the person’s experience and how others perceive them.

We stress the importance of remembering that there is no such thing as a ‘typical person with ADHD’.

Epilogue – Attitudes of others/public awareness

There is still work to be done to challenge attitudes amongst both members of the public and some health and care professionals. Some people reported frustration or hurt arising from public misunderstanding and misinformation around ADHD.

For some people this felt more of a challenge post-diagnosis:

> ***"The biggest challenge since my diagnosis has been the sheer amount of disinformation out there. This is a significant condition that affects every aspect of my life – I didn't just watch one video and decide I had it."*** - White British woman aged 25-49, (diagnosed).

> **"I haven't really noticed any change with communication and empathy among family members and peers, but has led to misunderstandings and/or stigma." –** Asian British woman aged 18-24, (diagnosed).

> **"Despite the diagnosis, the understanding I thought it would bring from colleagues, friends, and family of my challenges has not been there – either because of prejudice or misunderstanding about the diagnosis on their part, or because the diagnosis has become somewhat meaningless in their eyes since 'everyone is getting diagnosed with ADHD these days'."** - White British woman, 24-49 (diagnosed).

Some respondents identified a need for professionals to be more aware about neurodiversity and how to amend their practice to make it supportive to neurodivergent people.

> **"There is no access to ADHD specific psychotherapy on the NHS locally, just the generic TALK Liverpool offer. While ADHD specific psychotherapy expertise is likely to be in short supply for the demand in C&M, all practitioners to could have access to increased ADHD/neurodiversity awareness for their specific type of counselling and how best to deliver it for someone with neurodiversity." –** White British woman, 24-49 (diagnosed).

> **"I think there needs to be a programme of education of pupils, parents, teachers and health care professionals to enable a shared understanding of how to support the those with a neurodivergent diagnosis in the school setting; there seems to be much interschool variation, and many unmet expectations from all parties. Currently the expectation from parents is that the school should ensure that discomfort or anxiety is minimised for neurodiverse pupils, but that is not always the most helpful thing; neurodivergent or not, everyone needs to face discomfort, anxiety or uncertainty in their formative years and beyond in order to develop coping mechanisms to deal with those situations – if they never have to face them they will never learn increased resilience. I sometimes wonder if I had a diagnosis as a child whether expectations of me would have been lowered and I would not have enjoyed the successes and opportunities that I have done because according to the diagnosis I might have been 'let off' doing something challenging or not encouraged to expand my comfort zone."** White British woman, 24-49 (diagnosed).

Conclusion and recommendations

There has been recent media attention and discussion about the rising prevalence of ADHD. This includes commentary on the reasons behind the rise in demand for support and the ability of stretched NHS teams to deliver.

However, little has been reported about the experiences of people diagnosed with ADHD, those waiting for an assessment that may lead to diagnosis, and those who are reluctant to come forward for help.

Despite the hard work of NHS staff, our findings paint a picture of long waits, a lack of support, and the subsequent poor impact that ADHD traits and process delays have on people's lives.

> **"I cannot see how the system is functioning properly. This is problematic because when I asked to be referred via right to choose, the GPs I spoke to were very reluctant and argumentative against referring me. I was told that I wouldn't be able to get access to medication if I did this despite that not being true. This system clearly needs a big change and a lot of investment in Liverpool and Merseyside more widely."** - White British man aged 25-49, (diagnosed).

People with ADHD deserve to receive timely support when they need it, and people with unmet needs should be encouraged to seek help from the NHS and other teams to understand whether they have ADHD or another health condition and if support can be provided.

Healthwatch England, in their national report, presented a series of recommendations to support the work of the national ADHD Taskforce. These include for ADHD assessments to be delivered by community teams, allowing rising demand for diagnosis, treatment, and signposting to other support to be met, while freeing up specialist teams to meet more complex care needs.

We have added some local recommendations which local partners can work on alongside supporting the implementation of the national recommendations and the work of the ADHD Taskforce.

Healthwatch England national recommendations:

Healthwatch England have made recommendations to achieve key objectives including moving care closer to home, speeding up access to NHS care, and getting people the support they need.

We repeat these here because these changes would underpin the local additional recommendations we are making.

1. Use data to improve our understanding of current pressures

Recommendation	**The Department of Health and Social Care to support NHS teams to collect and publish official data on ADHD assessment waiting times. This must include demographic data to understand who is experiencing the longest waits and why.**
Current policy	National waiting times are not currently published, though work is underway to introduce official reporting.
Evidence	Healthwatch England heard from people without an ADHD diagnosis who were reluctant to approach the NHS for support due to long wait times. There may also be variation across the country in terms of access times. And there is a lack of understanding among members of the public as to how to navigate long waits.
How our proposal will help	While Healthwatch England welcome moves from NHS England to publish waiting list, referral, and assessment estimates from May 2025, a move to official waiting list data in the longer term will help decision-makers better understand the demand for ADHD support. Transparent data on NHS and Right to Choose wait times will allow people to manage their wait for ADHD and make informed and meaningful choices about their health.

2. Provide those waiting for assessment with the support they need

Recommendation	**NHS teams to implement new 'waiting well' guidance, produced by Healthwatch England and NHS England with the national ADHD taskforce.**
Current policy	There is currently patient communication guidance for elective referrals, but nothing specific for the ADHD pathway.
Evidence	Two-thirds of people with an ADHD diagnosis cited they received either no information or poor information while waiting for their assessment. The Healthwatch England report shows that the impact of ADHD traits affects many if not all, aspects of people's lives. The Healthwatch England research shows that long waits for assessments and the impact of a diagnosis also have substantial impacts on people's wellbeing. People wanted a wide range of support, including information on how to manage their mental wellbeing and a single point of contact about the wait for an ADHD assessment.
How our proposal will help	Given the impact ADHD symptoms, long waits for assessment, and an ADHD diagnosis can all have on people, more bespoke guidance – if properly implemented – would benefit people referred for assessment. While the guidance is currently in development, it will include signposting to non-NHS organisations who can help with employment, education and other support.

Recommendation	**The Department of Health and Social Care and NHS England to train and hire more care coordinators in primary care, and provide training to deliver admin support, interim support and care navigation for those with ADHD and other neurodiverse conditions.**
Current policy	There is no specific additional primary care role to support neurodivergent people in primary care.
Evidence	People referred for ADHD care require support while waiting for an assessment. This could be for a variety of needs across health, care, and other services.
How our proposal will help	Cultural and competency training in neurodiversity for care navigators will enable them to advocate for people when interacting with the NHS.

3. Develop new neighbourhood-led pathways for patients

Recommendation	**The Department of Health and Social Care to support the development of primary and community care pathways for the assessment and management of ADHD.**
Current policy	Specialist secondary care psychiatry teams manage ADHD assessments and treatment.
Evidence	The Healthwatch England report shows that people face long waits for ADHD assessments. Some people have been put off asking their GP for a referral for an ADHD assessment because of long waits.
How our proposal will help	Growing awareness and recognition of ADHD means demand could be better managed via the delivery of assessments and support from primary and community care teams. This could: • Reduce waiting times for assessment • Free up demand for secondary care teams to manage more specialised cases, including referrals for people with complex comorbidities or experience of trauma. • Enable primary and community care teams to provide notes and advice to people's employers on the benefits of reasonable adjustments to those with or waiting for a diagnosis. • Support the government's shift for more care delivered closer to people's homes.

Recommendation	**NICE to review NG87 to achieve a shift in more ADHD care delivered closer to people's homes.**
Current policy	NG87 covers recognising, diagnosing and managing ADHD in children, young people and adults.
Evidence	Healthwatch England evidence and existing evidence show that new models of care are needed to deliver ADHD support.
How our proposal will help	Should ADHD management move into primary and community settings, NG87 will require a review against best practice evidence to update guidance for appropriate teams. This review would also provide an opportunity to update the guidance on the recognition of ADHD in certain groups.

Recommendation	**NHS England, the General Pharmaceutical Council, the Royal College of Psychiatrists, the Royal College of GPs and NICE to promote annual medication reviews from primary care.**
Current policy	NICE QS39 sets out guidance for the annual review of ADHD drug treatment, including shared care arrangements for review in primary care based on patient choice.
Evidence	Healthwatch England evidence and existing evidence show that new models of care are needed to deliver ADHD support.
How our proposal will help	Collaboration between pharmacy and prescribing teams could: • Allow reviews to be conducted from primary care, speeding up annual medicine reviews for people treated for ADHD. • Lead to developing and piloting a future model of prescribing first line medication from primary care.

Recommendation	**NHS England to work with the Royal College of Psychiatrists (RCGP) and the Royal College of GPs to develop ADHD training for primary and community care staff, including promotion of the GP with extended role (GPwER) in ADHD.**
Current policy	The RCGP has developed a framework to develop GPwERs in ADHD.
Evidence	The Healthwatch England report shows that nearly two in five people currently waiting for an ADHD assessment needed more than one GP appointment before they were referred. Healthwatch England recommended shift for more ADHD care in the community will require training for staff in primary and community care.
How our proposal will help	Staff in primary and community care will be trained to deliver NHS support for ADHD outside of hospital settings.

4. Improve the support that employers provide to those with ADHD

Recommendation	**The Department of Health and Social Care, the Department for Work and Pensions, and the Department for Business and Trade to work with employers to raise awareness of, and incentivise, the proactive offer and delivery of reasonable adjustments to staff who would benefit.**
Current policy	Employers must make reasonable adjustments to make sure workers with disabilities or physical or mental health conditions are not substantially disadvantaged when doing their jobs.
Evidence	Healthwatch England research found that over three-quarters of those whose employer had offered reasonable adjustments said they made a significant or moderate difference. However, others are put off speaking to employers for a variety of reasons.
How our proposal will help	More proactive offers of reasonable adjustments will remove stigma from people requesting support, and ensure people get the help they need.

Recommendation	**The Department for Work and Pensions to maintain its central management of the Access to Work scheme and expand the scheme to provide:** • **Targeted funds to individuals to pay for workplace adaptations beyond reasonable adjustments.** • **A 'marketplace of support' for aids, appliances and assistive technology to reduce costs and spread their adoption.**
Current policy	The Department for Work and Pensions is consulting on the future of Access to Work, as set out in the Pathways to Work Green Paper.
Evidence	Over two-thirds (68%) who told their employer that they had ADHD were offered at least one reasonable adjustment. Over three-quarters of these said that the adjustments had made a difference.
How our proposal will help	Recent increases in applications for the Access to Work scheme highlight the need for more support to help people work. Making support more proactive and easier to access will ensure that people have the help they need to be able to work.

Healthwatch Liverpool's local recommendations

Recommendation	**Consider a joined-up pathway for those needing both ADHD and autism assessments. This might include referrers and assessors being familiar with:** • **Awareness of how the conditions may present when they co-exist** • **Suggesting screening for both if appropriate;** • **Potential for combined or coordinated assessments in future.** • **Advice, information and support provision which takes account of the complexity of living with both conditions.**
Who	**ICB**
Current practice	The ADHD and autism pathways for adults are currently completely separate. Different NHS Trusts are contracted to provide each of them and when, because of long waits, people are instead referred to a Right to Choose provider this is separate as well as disconnected from local support options.
Evidence	Half of our respondents felt they had autism as well as ADHD and found navigating two pathways complex, lengthy and off putting. Difficulties with life while waiting for diagnosis were common and support after diagnosis was limited. Generic advice aimed at people with just one of the conditions may not be as helpful to people living with both.
How our proposal will help	If the pathways were joined up the process could be easier to navigate, less resource intensive and the support could be tailored more appropriately.

Recommendation	**Local information about support** • **Consideration be given to how people referred for an assessment can be more reliably signposted to sources of information and support while they wait.**
Who	**Referrers**
Current practice	Waiting times are lengthy and although there is a local NHS commissioners support service (Ladders of Life) as well as a local peer social group there is not a consistent structured route for people to find out about these.
Evidence	Most of our respondents were not given information on sources of information or support while they waited. This is especially difficult with Right to Choose providers who have no knowledge of local provision.
How our proposal will help	Having heard about the lack of information while waiting Healthwatch Liverpool has developed an information page which referrers can point patients to with information on what to do while waiting. https://www.healthwatchliverpool.co.uk/advice-and-information/2025-09-12/what-can-i-do-while-waiting-adult-adhd-assessment. This page can be updated with any additional sources of support. If GP practices could share this with patients when they are being referred for ADHD diagnosis patients would be better informed about sources of support and information.

Recommendation	**Intersectionality: different barriers and experiences** **Services should be:** • **aware of the way ADHD can present with different groups and the barriers each has in receiving timely identification and appropriate support** • **willing to tailor their approach accordingly.** – **The presentation among women and the interaction with female hormones** – **The strong correlation between neurodivergence and diverse sexual orientations and gender identities.** – **The potential for additional levels of stigma among people in minoritised communities**
Who	**Health partners including referrers and assessors**
Current practice	The gender breakdown of people seeking diagnosis has changed with more awareness of female presentation. Awareness may be lower in minoritised communities with additional barriers to coming forward for and receiving a diagnosis.
Evidence	We heard from women about their late realisations about being ADHD and how hormones and menopause affected their experience. We heard from very few people from minoritised communities but did hear about stigma. We saw a higher than average level of people from diverse sexual orientations and gender identities.
How our proposal will help	Understanding who is affected by ADHD and the experiences and barriers they face is vital in providing person-centred, effective and equitable care.

Acknowledgements

We would like to thank everyone who took the time to respond to the survey with their personal perspective on this issue. We have not had the space to quote from everyone's answers, but they have all been read carefully and have helped us to write this report. We hope it reflects the wide range of experiences and feelings shared with us.

About Healthwatch Liverpool

Healthwatch Liverpool is the independent champion for people who use health and social care services. We're here to make sure that those running services put people at the heart of care. One of our main purposes is to understand the needs, experiences and concerns of people who use health and social care services and to speak out on their behalf.

As part of a national network made up of local Healthwatch organisations in every local authority area of England and Healthwatch England, the national body, our work contributes to a nationwide perspective of health and social care services.

At Healthwatch Liverpool we also provide a dedicated information and signposting service which helps to put people in touch with services and activities that can help maintain and improve their health and wellbeing.

Appendix 1 - Further experiences of respondents with possible ADHD and autism

In order to explore the co-existence of ADHD alongside other neurodivergent conditions we asked respondents to state whether they had or were persuing an autism diagnosis. The result of this was that 55% of respondents who replied to this question (43% of all respondents) consider themselves to also be autistic, (either diagnosed, awaiting diagnosis or self-identified).

AuDHD people, living with a complex interaction of their ADHD and autism traits, can face additional barriers to diagnosis and finding support with their neurodivergent needs. This appendix outlines some of what we heard from this group of our respondents about the challenges they face especially as late diagnosed with ADHD or still awaiting diagnosis.

Many of these respondents experiences are also cited in the main report but we felt grouping their experiences here highlighted the specific issues faced by this group of people while seeking diagnosis and living with ADHD alongside autism.

Impact of living with ADHD without a diagnosis for this group

"I am 99% certain I am ADHD multiple family members are diagnosed and medication makes a difference for them. I struggle massively daily, but wasn't taken seriously as I did well academically and mask heavily. I have multiple physical health conditions and at 30 years old I can no longer mask my way through. I've attempted suicide twice and ADHD had a large role in that. I know I'm "different" and struggling to find my place in the world when I've got 'hidden' disabilities" White British woman aged 25-49 (referred and awaiting ADHD assessment)

"My autism and ADHD prevented me getting an education and has kept me exploited in minimum wage jobs all my life. It has caused family friction because of misunderstandings and my inability to attend family celebrations." White British man aged 50-64 (referred and awaiting ADHD assessment)

"I feel incredibly overwhelmed and constantly feeling on edge of nervous breakdown. I was diagnosed dyslexic (numbers and processing) and dyspraxic. I did get some support in education for this but undiagnosed adhd and no support for adhd had cost me mentally and financially and in my relationships. I believe everything was blamed on dyslexia but that's not the issues. I am in debt I struggle with anxiety and relationships are difficult and I never been able to drive taken test 6 times and gets worse rather than better...I have terrible sleep and also routines and I know it seems like everyone's got adhd at the moment but the reality is I am yet to get a diagnosis but in mean time I struggle to exist" White British woman aged 25-49 (referred and awaiting ADHD assessment)

"In my house my condition affects my family greatly, and I have a brother who has autism who finds my behaviour a real challenge. My parents are juggling and walking on egg shells to deal with life on a daily basis and it's difficult for us all." White British man aged 24-49 (not yet sought ADHD diagnosis)

The combined effect of living with autism and ADHD

"Instead of spending ten hours outside each day as I used to, I don't manage more than eight hours a week. I barely see a soul. This isn't the impact of ADHD alone. It is the autistic burn out after decades of uphill struggle. I don't know if one or the other condition alone would have impacted my life so profoundly." White British man aged 50-64 (referred and awaiting ADHD assessment)

"It's hard. My mind has conflicts with itself it seems which is common if you have both autism and ADHD. I have always struggled with time and keeping appointments/interviews incredibly difficult. I find myself fidgeting if I have to stay still for a long time. I think I have always been good at masking though but I scream on the inside…" White British woman aged 25-49 (not seeking official ADHD diagnosis)

Experiences of seeking a diagnosis

"Getting help, including the initial diagnosis, is difficult. Without any form of screening, it relies on people to proactively seek assessment, which by the very nature of ADHD, people can become overwhelmed about or forget to actually pursue." White British man aged 24-49 (has ADHD diagnosis)

"I've been on 'hold' for 3 years, my mental health has worsened. I've not been taken seriously by a lot of mental health professionals. When seeking a referral the mental health nurse at my GP said it "was trendy to have ADHD" and "you see one tiktok and think you have it" no it's insanely debilitating day to day! I have done deep research including peer reviewed papers and verified sources, this is not a flighty fancy. It was incredibly hurtful what the nurse said, never mind a mental health nurse. I constantly struggle with imposter syndrome and it took a lot mentally to seek help. To be dismissed so casually is cruel. I insisted I wanted to be referred, she reluctantly gave me a link for the pre assessment screening quiz, which I had already done multiple of before seeking a referral. She didn't call me back as promised she simply referred me on the results alone. She was convinced because I managed education "there wasn't anything wrong", I strongly disagree." White British woman aged 25-49 (referred and awaiting ADHD assessment)

Some people are trying to go through the assessment process while also supporting other neurodivergent family members:

"I'm also trying to support my 12 year old daughter to get assessed for ADHD, ASD, dyslexia and dyscalculia. She also has a number of other medical conditions that involve numerous hospital applications. I haven't got the energy to chase up Right to Choose. It's totally exhausting!" White British woman aged 50-64 (referred and awaiting ADHD assessment)

Impact of long waits for diagnosis

As with our respondents as a whole, people reporting AuDHD found the long wait for ADHD assessment difficult and would have welcomed more information or support.

"It would have been nice to receive some information in the meantime, or updates on how long it may be." White British woman aged 25-49 (referred and awaiting ADHD assessment)

> **“Not knowing any coping methods or a better understanding of how to understand how this effects my every day life and work life. Had to seek talking therapy to help me deal with a better understanding”** White British man aged 50-64 (referred and awaiting ADHD assessment)

> **“The symptoms are difficult to deal with, however I’m lucky to have a supportive wife and family.”** White British woman aged 25-49 (referred and awaiting ADHD assessment)

> **“My work is a challenge. I hold a senior position and my ability to function is very difficult”** White British woman aged 25-49 (referred and awaiting ADHD assessment)

> **“Not being able to access accommodations, feeling like I’m stuck in a limbo”** White British man aged 25-49 (referred and awaiting ADHD assessment)

> **“It is causing me daily stress, I just don’t understand why it’s taking so long when you are referred by a GP because you’re on the spectrum through their test”** White British man aged 25-49 (referred and awaiting ADHD assessment)

> **“I feel like a ghost left in limbo. I don’t know anything. How long will it be, where will it be, what should I do to be prepared? It’s like an endless waiting room, waiting for a number that never comes.”** White British woman aged 25-49 (referred and awaiting ADHD assessment)

Some people who felt they had both ADHD and autism however reported particular difficulties while waiting for assessment:

> **“My life generally veers towards being chaotic. Support would have helped me to find a grounding.”**

> **“Struggling every day with extreme emotions”** White British woman aged 25-49 (referred and awaiting ADHD assessment)

> **“Symptoms are getting worse or at least I feel they are and I’m struggling with situations at work and home. I need help to make positive changes”** White British man aged 25-49 (referred and awaiting ADHD assessment)

> **“I stay home and don’t function well.”** White British man aged 25-49 (referred and awaiting ADHD assessment)

> **“At the moment living as an adult with adhd and no medication or help I am lost”** White British woman aged 25-49 (referred and awaiting ADHD assessment)

For some people, having felt unsupported for many years, not having support while waiting for assessment felt particularly lonely:

> **“I have never been supported.”** White British woman aged 25-49 (referred and awaiting ADHD assessment)

> **“I’m left to cope as I have been all my life.”** White British woman aged 50-64 (referred and awaiting ADHD assessment)

> **“Trying to face it alone”** White British woman aged 25-49 (referred and awaiting ADHD assessment)

The impact of receiving a diagnosis

Some of those who have already received a diagnosis described how it had changed their life, bringing a greater self awareness, helping them to advocate for their own needs and increased ability to draw on coping strategies.

> **"Having my diagnosis has validated me and stopped the self loathing of there is something wrong with me, and being called crazy/weird for the majority of my life. I asked if I had bi-polar, have suffered with depression and anxiety - was prescribed medication - but as it was undiagnosed ADHD - the medication did not work and I had adverse effects of a low dose medication for depression which nearly resulted in my being sectioned. I never took any medication for depression after that. I am more self aware and this enables me to explain that I may forget everything so please follow up with an email."** White British woman aged 25-49 (ADHD diagnosis)

For some, diagnosis was followed by a period of life review and processing of regret and grief.

> **"I cannot even begin to start describing to you the impact that my diagnosis has had on my life. It's not so much the diagnosis itself. I am autistic and received my autism diagnosis several years prior and my autism feels more Central to who I am as a person than my ADHD. Or rather, I am more aware of the downside of my ADHD than I am of the downside of my autism.... The only downside from my perspective [from diagnosis] is that I'm now aware that I could have had this help for my entire adult life and I mourn for the wasted years, I mourn for what could have been. I have still achieved many things but I cannot put into words what having access to this medication earlier in my life would have done, and how many of the difficulties I have experienced may not have occurred."** – White British man aged 25-49, (ADHD diagnosis)

Support after a diagnosis

As with our respondents as a whole people reported limited support options. The lack of a holistic approach to management is however more difficult when people also have autism and the internal dynamics that can bring.

> **"There is no onward help other than medication and 6 monthly checks on BP, pulse and weight. There is no regular checks ins with my GP to see how I'm actually doing. The psychiatrist who diagnosed me checks in once a year but the focus is on the ADHD treatment, not other things like how my anxiety is doing or whether I think I could also have ASD"** White British man aged 24-49 (ADHD diagnosis)

> **"The big impact for me has been ADHD medication. I am only four weeks into titration and already the results have been life changing. I cannot describe how different the future looks to me now that I have ADHD medication full stop my entire outlook on life has changed. Life was so hard before and it is so easy now. It's impacted in every area of my life and has made me even more vociferous about advocating for ADHD people when people claim that ADHD diagnoses are false or that people only want diagnoses so they can get access to medication to use recreationally. I am not describing specifics because there are too many. Moreover I knew for years that I was having high blood pressure due to stress and almost wasn't allowed to take ADHD medication because of that high blood pressure. Since starting on my medication my blood pressure has gone down because I am less stressed. I have experienced side effects but almost all of them disappeared once I was on the correct dose and frankly I would put up with many more side effects than I have experienced because the pros outweigh the cons"** White British man aged 25-49, (ADHD diagnosis)

> **“The diagnosis allows you to understand yourself better over time, but in itself it doesn’t help with anything as there is not after diagnosis support for autism or adhd (I have both). It would be helpful for adult diagnosis to have support afterwards as it’s a difficult time to adjust”** – White British woman aged 25-49 (ADHD diagnosis)

One person was very clear about what would make the difference to their life:

> **“I don’t want drug treatments as what is most important to me is stability and doctors seem to shove pills at me for all sorts and it’s just helpful. I want an adapted life and work style. I want freedom to change that which doesn’t not work well for me. I want to be given some understanding and some other options by businesses and services, such as being able to communicate by email only and not telephone. I need somewhere safe to socialise but that is currently unavailable so I do not socialise at all. I don’t feel safe around people at all. I need somewhere that has rules and hierarchy to keep others in line so that I don’t have to, because my reactions will likely be inappropriate in an effort to regulate someone else bad behaviour towards me.”** White British woman aged 24-49 (not yet sought ADHD diagnosis)

Sometimes receiving one diagnosis (autism or ADHD) brings increased self-awareness and highlights the possibility of also having the other:

> **“I now understand why I have struggled all my life, because I have a neurodiverse brain. ADHD has had an impact on every aspect of my life. I don’t know who I am. I am psychically and mentally burnt out from trying to fit in and hide various parts of my ADHD all my life. I struggle with anxiety and severe depression and feel there is not enough support for people like myself. Since learning more about myself and ADHD, I now think I may be on the autistic spectrum too and will soon be having an assessment to look into this.”** White British man aged 25-49 (ADHD diagnosis)

Given the high level of overlap between Autism and ADHD considering a joint assessment pathway, or at least screening for both at the same time might help people with both come to a fully picture of their needs sooner, saving a lot of additional stress and struggling.

> **“The dread of feeling like an alien in this world has haunted me every day since my very first day at school. After looking after my elderly father, I finally burnt out beyond recovery. I survive purely out of defiance. I know that sounds melodramatic, but all I’ve known is abuse or neglect or empty promises. That’s not entirely true. The occupational therapist commissioned by my employer identified my problem and set me on the path to diagnosis. She really fought my corner. My union rep saved my life by successfully challenging my employer, and the doctor at my PIP tribunal had a similar impact, so there have been rare occasions where people have understood and responded not just appropriately, but brilliantly.”** White British man aged 50-64 (referred and awaiting ADHD assessment)

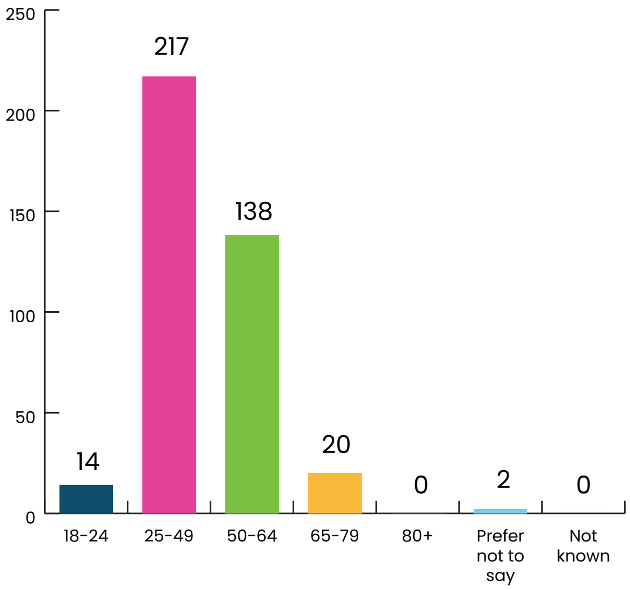
> **“I can struggle explaining to others why I’m feeling/acting a certain way… This can come across as blunt/confrontational etc”** White British woman aged 25-49 (referred and awaiting ADHD assessment)

> **“I’m left without any help to help keep me safe & function well. It means I’m stressed & anxious which impairs me further leading to self medication to manage.”** White British non-binary person aged 50-64 (referred and awaiting ADHD assessment)

“I’m concerned the recent changes around Right to Choose mean I won’t get an assessment at all now “ White British woman aged 50-64 (referred and awaiting ADHD assessment)

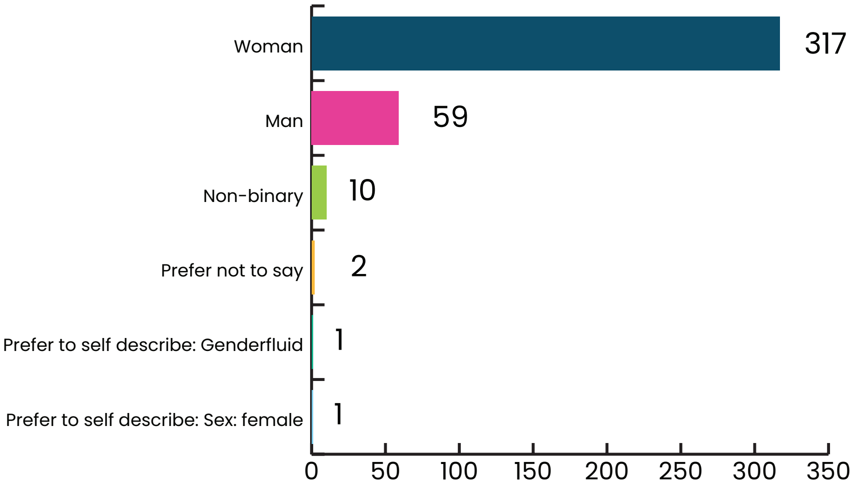
Appendix 2 – Who were our respondents?

Age



Our respondents ranged from 18-24 to 65-79 age groups. The majority of respondents fell into the 25-49 and 50-64 age groups. Allowing for the respective length of these age bands the proportion is almost identical between them (9 and 10 per year). The relatively low proportion (3.58%) of respondents in the 18-24 age group is notable. Future research could usefully intentionally oversample this age cohort to better understand their specific experiences.

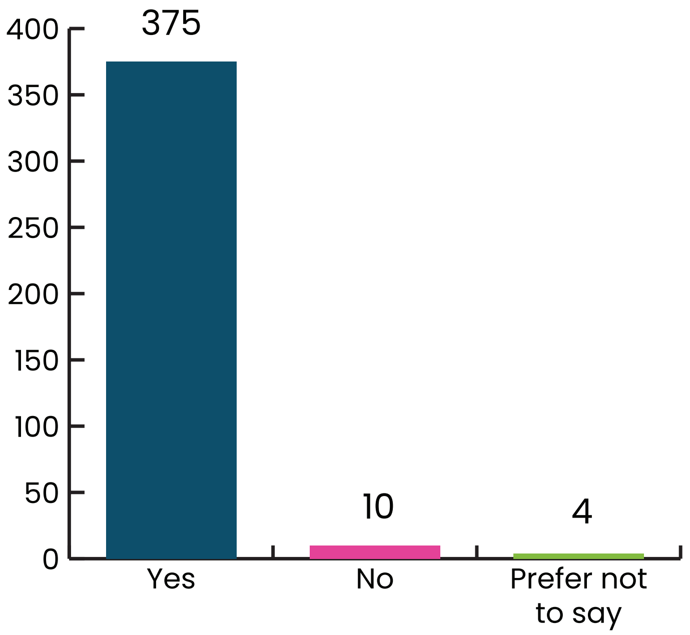
Gender



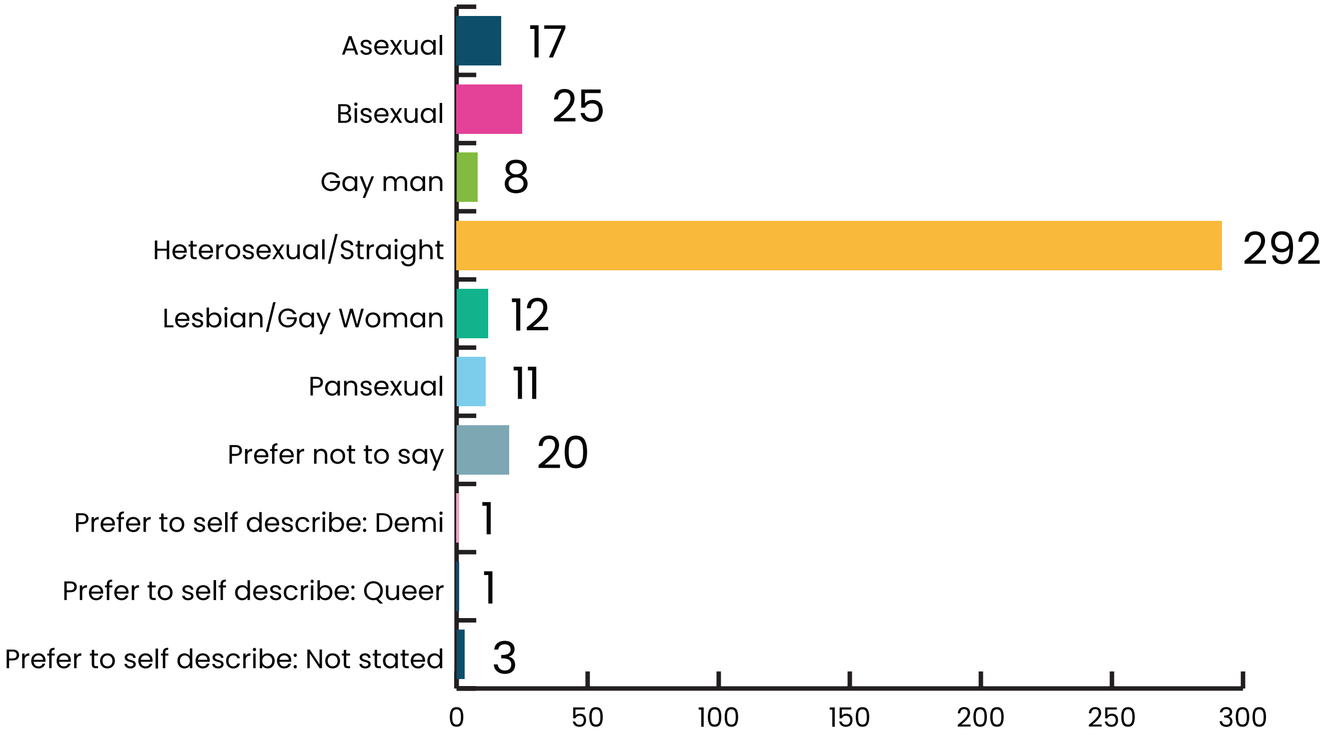
Our respondents were disproportionately female. This may partly reflect more women coming through for diagnosis when there was previously a large weighing towards men and partly a reflection of our self-selecting sample of respondents including through social media. Women may have be more likely to see and respond to social media surveys.

2.6% of respondents were non-binary. Although a small proportion it is significantly higher than the 0.06% of the national population which identified as non-binary in the last census. An almost identical proportion of respondents reported that their gender identity was not the same as recorded at birth. The higher prevalence of LGBTQIA+ identities with ADHD aligns with this report showing a strong correlation between neurodivergence and diverse sexual orientations and gender identities.

Is your gender identity the same as your sex recorded at birth?

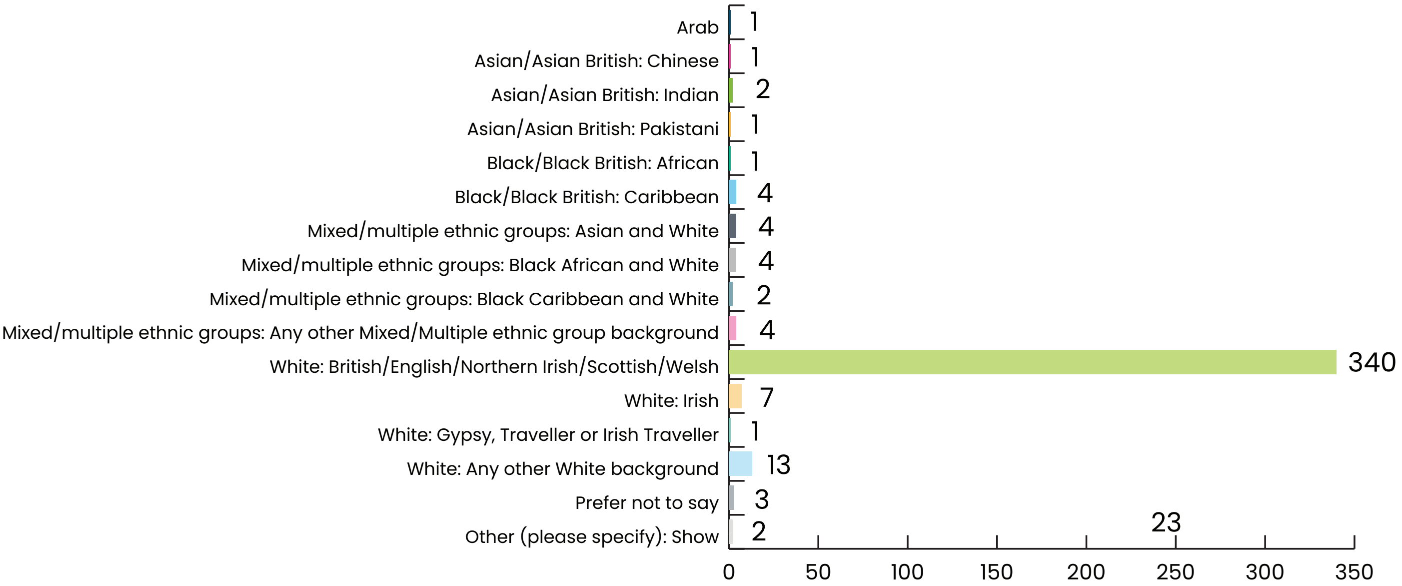


Sexual orientation



The majority of respondents identified as heterosexual but at a lower proportion than national census data: 75% compared to 93% in the last national census. 11.5% identified as Lesbian, gay or bisexual compared to 3.3% in the last national census. In addition, 4% identified as asexual and 3% as pansexual.

Ethnicity

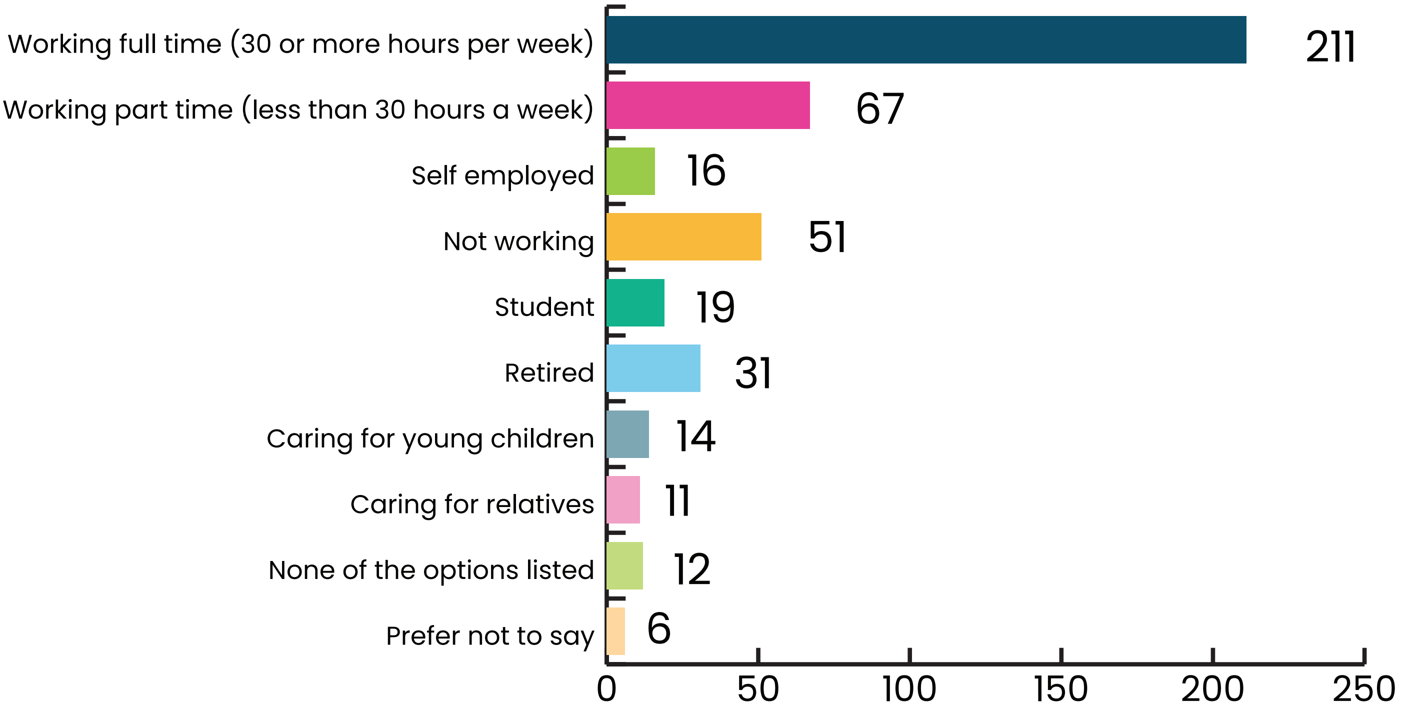


Respondents were predominantly White British, more so than our local population. This may be because of the reach of our survey but may also reflect awareness of/access to ADHD diagnosis in different communities. One respondent commented on the additional stigma they felt existed in their community towards ADHD to the extent where they were not planning to tell anyone about their diagnosis when it happened.

Future research on the specific experience of minoritised communities to better understand their specific experiences would be useful, including the barriers to identification of ADHD.

Employment status

Over two thirds of respondents were in some form of paid work (full or part time or self employed). Others were studying, caring, retired or not otherwise working.



Coexisting conditions

In order to explore the co-existence of ADHD alongside other neurodivergent conditions we asked respondents to state whether they had one or more additional neurodivergences, either formally diagnosed, awaiting diagnosis or self-diagnosed.

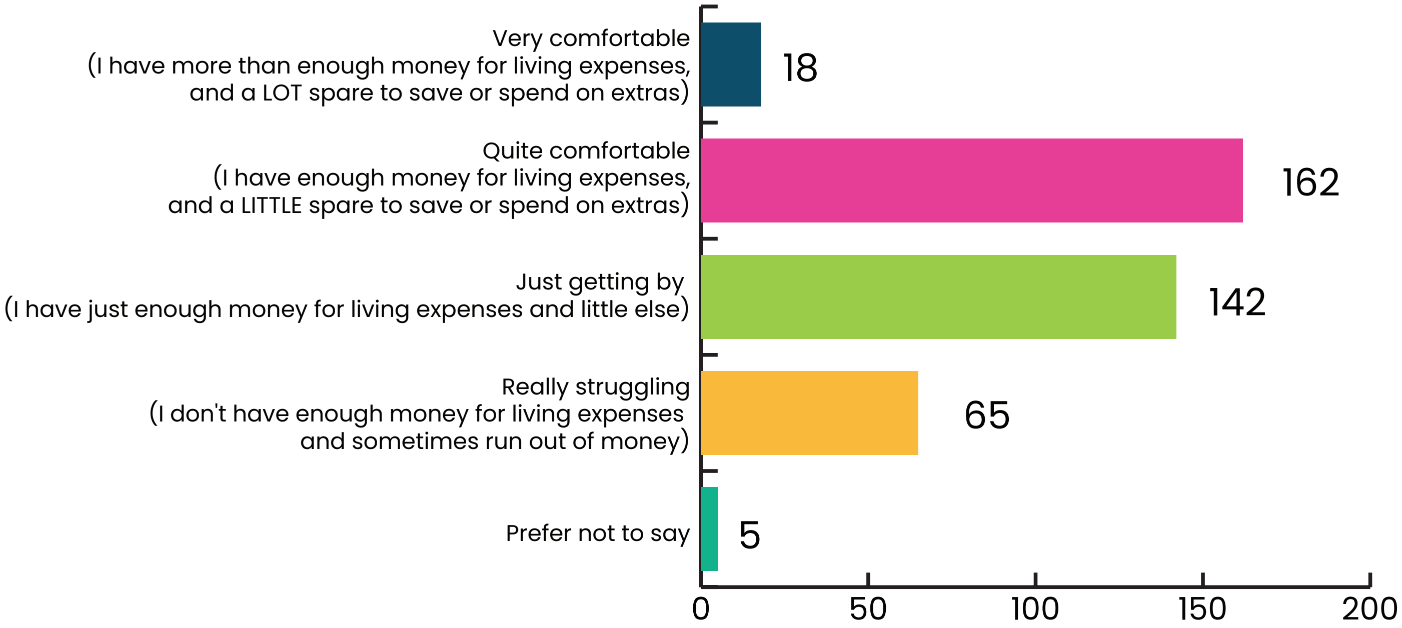
55% of respondents who replied to this question (43% of all respondents) consider themselves to also be autistic, (either diagnosed, awaiting diagnosis or self-identified).

85% of respondents to this question feel they have anxiety and 69% depression. This fits with various studies showing high prevalences of anxiety and depression among people living with ADHD.

Although we didn't specifically ask about dyslexia or dyspraxia in our survey, they were frequently mentioned in free-text answers about people's experiences of living with ADHD.

Income

Our respondents had a range of financial situations. With 53% either really struggling or just getting by, private diagnoses or private prescriptions were out of reach for most.



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