SPICe The Information Centre
An t-Ionad Fiosrachaidh

ADHD and ASD pathways and support inquiry: Summary of YourPriorities online forum submissions

The Committee agreed to use the online platform, YourPriorities, to gather the views and experiences of individuals seeking pathways to diagnosis, treatment and support for ADHD and ASD, their families, and people working in this area. The YourPriorities site was open for submissions from 23 June to 18 August 2025. The platform enabled participants to add their experiences and rate other experiences up or down using rating buttons.

All experiences were moderated by the clerking team for appropriate language and to redact identifying information. The moderated submissions shared on YourPriorities can be read at this link: ADHD and ASD pathways and support. Members may wish to be aware that a number of posts reference experiences of discrimination, abuse, self-harm and suicidality. Information and signposting for seeking support is available on NHS Inform.

This briefing provides a summary of the respondents to the YourPriorities engagement, and an analysis of the experiences provided to the Committee via the YourPriorities platform. These findings are based on a self-selected participation to a digital engagement exercise and should be interpreted as illustrative of personal experiences rather than representative of the wider population.

Organisations could provide evidence via a separate call for views. SPICe has provided an analysis of the organisational call for views in a separate paper.

Contents

Respondents to YourPriorities

1158 unique submissions were received during the YourPriorities engagement.

When registering to participate in the online engagement, respondents were asked to indicate their relationship with ADHD and ASD pathways and support, provide an indication of their age, and the first half of their postcode.

The respondent data reported in this section refers to absolute numbers (i.e., counts) and are not population adjusted rates. The size of groups may just reflect who responded to the digital engagement exercise.

Respondents’ relationship to ASD and ADHD pathways to support

Respondents were required to select one response from the following list to explain their relationship with ASD and ADHD pathways and support. There was no option for respondents to indicate they held or were seeking a dual diagnosis of ASD and ADHD. However, respondents regularly acknowledged or indicated in their submissions that they held or were seeking a dual diagnosis. It was also common for respondents to highlight the complexity of their circumstances in written submissions, with individuals often occupying multiple positions within pathways to diagnosis and support (e.g., a parent seeking diagnosis for themselves and their child).

The chart in Figure 1 shows the distribution of respondents’ relationship to ADHD and ASD pathways to support. 508 respondents (44%) were a family member or carer of someone seeking diagnosis, treatment or support. 231 respondents (20%) were waiting for diagnosis. 119 respondents (10%) were diagnosed with ADHD and receiving treatment or support. 97 respondents (8%) were diagnosed with ADHD and waiting for treatment or support. 76 respondents (7%) were involved in providing diagnosis, treatment or support to individuals with ADHD or ASD. 65 respondents (6%) were diagnosed with ASD and waiting for treatment or support. 39 respondents (3%) were diagnosed with ASD and receiving treatment or support. The remaining 23 respondents (2%) did not specify their relationship with ADHD and ASD pathways to support in the registration questions.

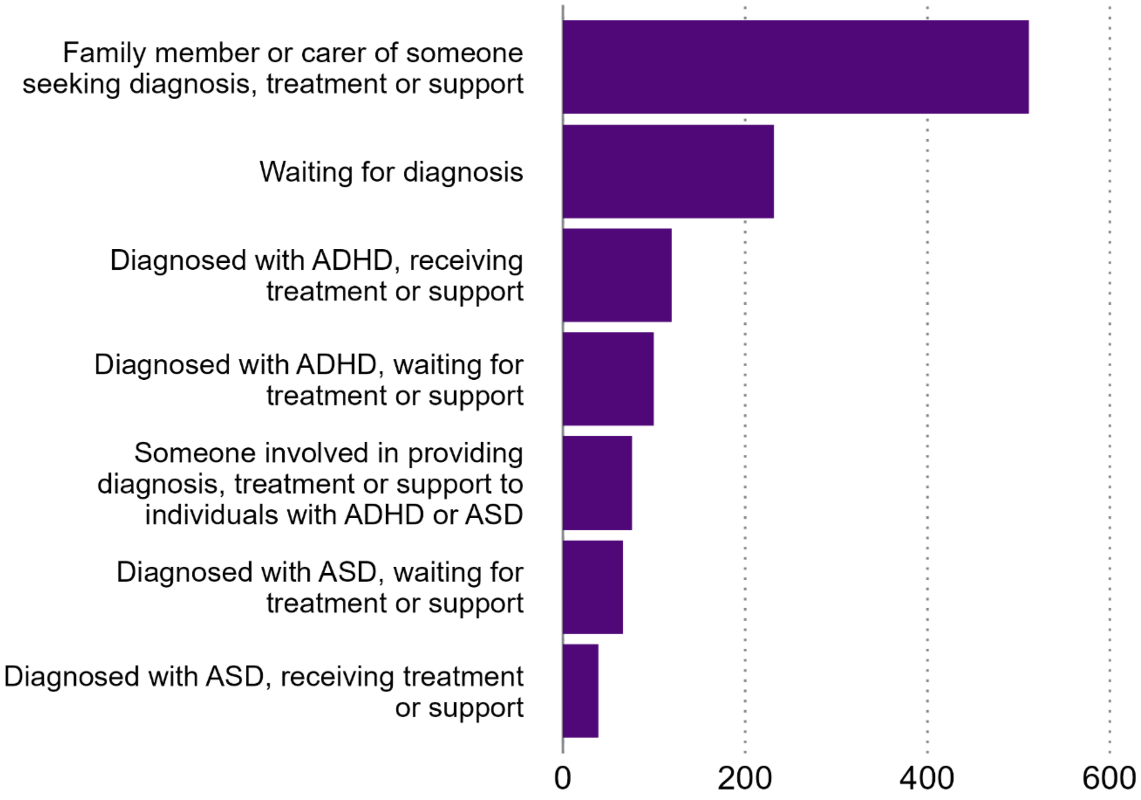

Figure 1

Age of respondents

The chart in Figure 2 shows the distribution of respondents by age category. 543 respondents (47%) were aged 40-54 years. 398 respondents (34%) were aged 25-39 years. 90 respondents (8%) were aged 55-64 years. 64 respondents (6%) were under 16 years. 39 respondents (3%) were aged 16-24 years. 14 respondents (1%) were aged 65 and over. 8 respondents (<1%) indicated they preferred not to say. The remaining respondents (<1%) did not complete the age question.

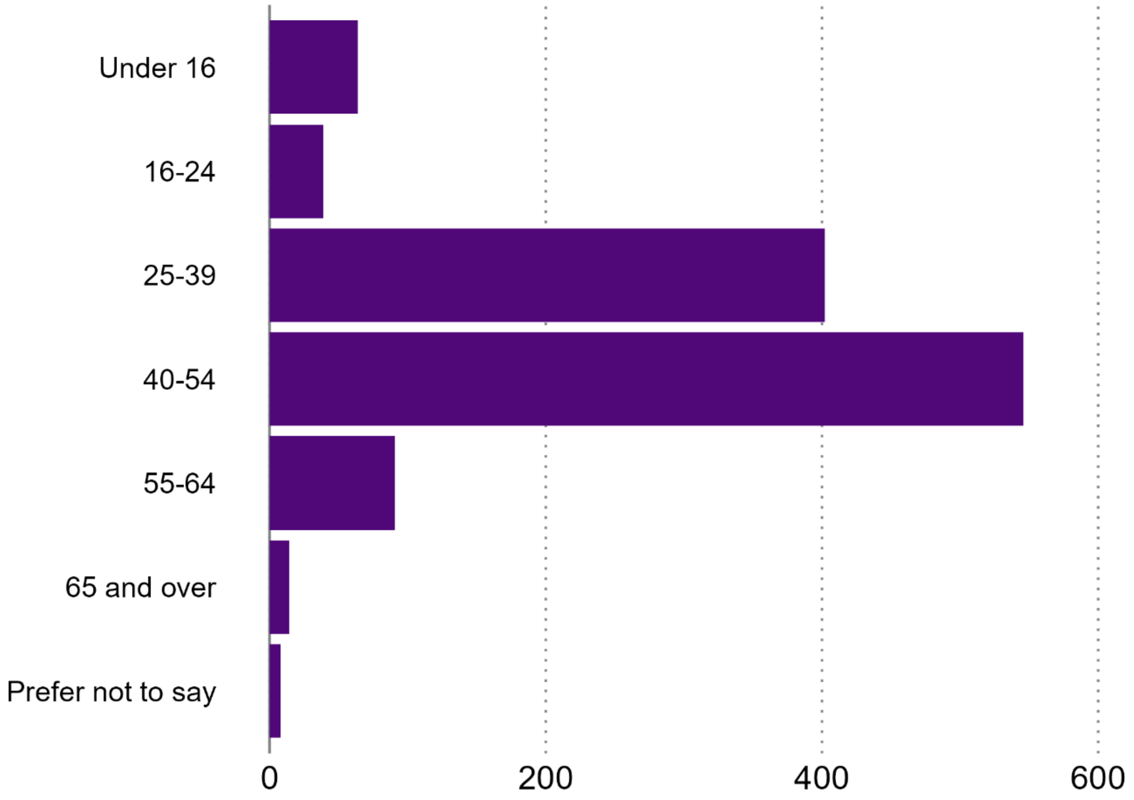

Figure 2

Respondents were then grouped by age and relationship to the ADHD and ASD care pathways. A visual representation of this analysis is shown in Figure 3.

ADHD (receiving or awaiting support)

Respondents with a diagnosis of ADHD who are already receiving treatment or support were primarily aged 25-39 and 40-54. 56% of respondents in the receiving treatment category were aged under 40.

Those diagnosed with ADHD but waiting for treatment were concentrated in the 25-39 age group. 61% of respondents in the receiving support category were under 40.

ASD (receiving or awaiting support)

Overall numbers of respondents in the diagnosed with ASD and receiving treatment category are small (39 respondents) with adults aged 25-29 as the most represented age-category. 56% of respondents were under 40 in the receiving support category (albeit the low overall number of respondents in this category means this percentage equates to 22 of 39 respondents).

Those with an ASD diagnosis and waiting for treatment show a similar age profile. 45% of respondents were under 40.

Family members and carers

As noted earlier, 44% of respondents identified as a family member or carer of someone seeking diagnosis, treatment or support. Most of these respondents were aged 40-54, followed by 25-39 and 55-64. 69% of respondents were over the age of 40.

Professionals

Professionals involved in providing diagnosis, treatment or support were concentrated in the 25-39 and 40-54 age brackets. 74% of respondents were over the age of 40.

Individuals waiting for diagnosis

Respondents waiting for a diagnosis of ADHD or ASD were typically aged 25-39 with 55% of respondents under 40.

In March 2025, the Health, Social Care and Sport Committee requested information from all 14 NHS Scotland territorial boards on neurodevelopmental pathways and waiting times. The responses are summarised in a SPICe blog, which explores where assessments are available, the size of waiting lists, changes over time, and average waiting periods.

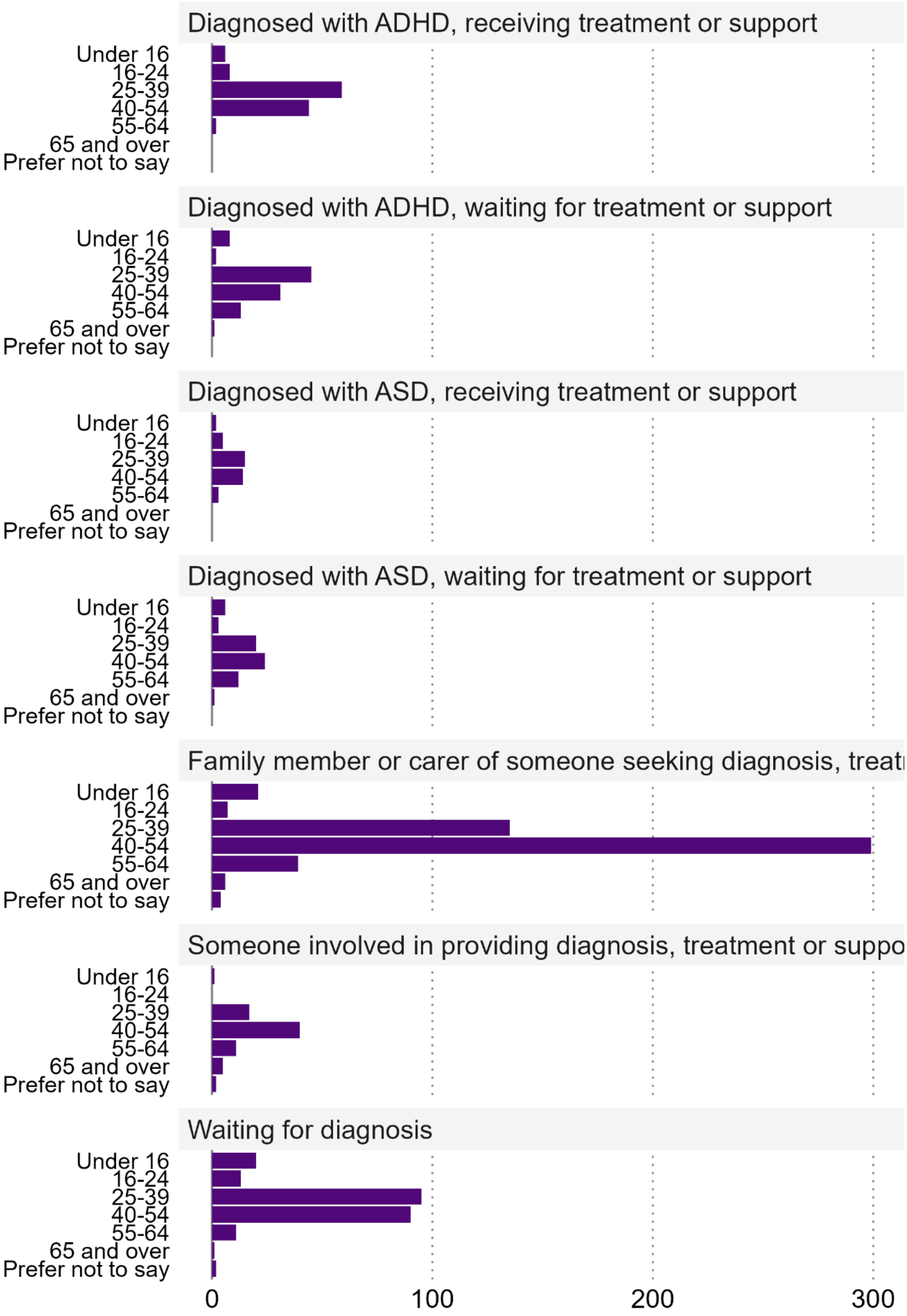
Diagnosed with ADHD, receiving treatment or support
Diagnosed with ADHD, waiting for treatment or support
Diagnosed with ASD, receiving treatment or support
Diagnosed with ASD, waiting for treatment or support
Family member or carer of someone seeking diagnosis, treat
Someone involved in providing diagnosis, treatment or suppo
Waiting for diagnosis
Under 16
16-24
25-39
40-54
55-64
65 and over
Prefer not to say
0
100
200
300

Figure 3

Location of respondents

Figure 4 shows a map of the number of responses by postcode district. Regional outlines within the map represent health board boundaries. Keyword analysis of the submissions indicated that each of the 14 health boards are referenced in at least one submission.

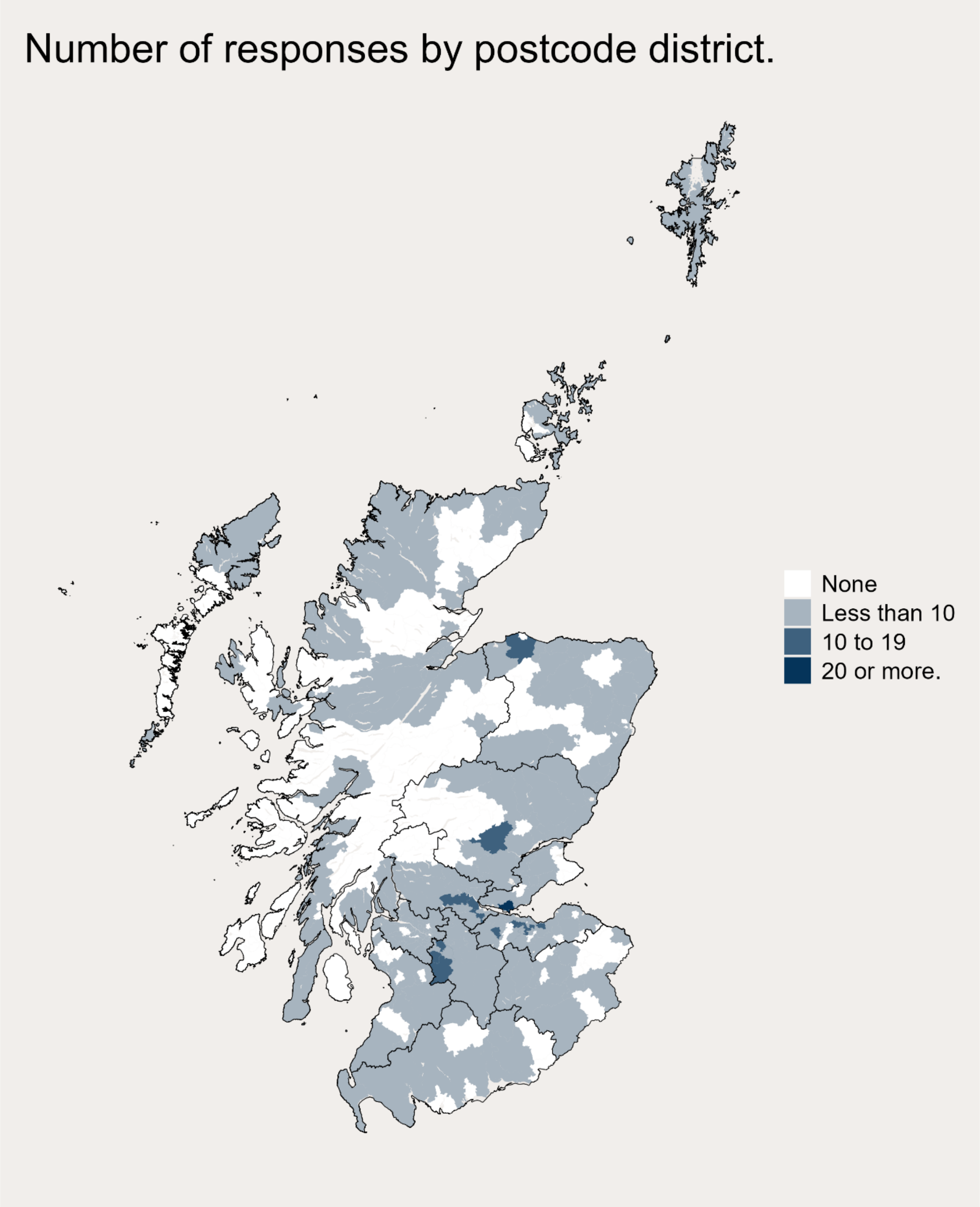

Figure 4

Experiences shared on YourPriorities

Respondents to the YourPriorities site could provide a title for their post and provide their experiences under three questions:

1. Please tell us about your experiences of seeking an ADHD and/or ASD diagnosis in Scotland.
2. Why did you seek a diagnosis?
3. Is there anything that would have made your experience better?

Quantitative analysis of content and sentiment of posts

SPICe used quantitative text analysis techniques on the post titles submitted by respondents. This was to get an overall assessment of the content and sentiment of posts. The corpus of post titles was processed prior to text analysis. Processing involved removing punctuation, special characters and "stopwords" (i.e., common words that are not informative on their own such as "it", "the", "an").

Frequent terms used in post titles

Titles were typically descriptive focussing on diagnosis and assessment, length of waiting time, support gaps and service routes (i.e., moving from NHS to go private). There was frequent reference to caregiving relationships (i.e., parent of child etc) and diagnosis in adulthood (e.g., “late diagnosis”). The most frequent two-word phrases across all post titles are shown in Table 1.

Table 1

Phrase	Count
long wait	24
lack support	21
still waiting	19
adhd diagnosis	17
waiting times	16
experience asd/adhd	16
asd/adhd pathways	16
awaiting diagnosis	16
waiting list	15
asd diagnosis	14
year old	14

asd adhd	13
go private	12
late diagnosis	12
private diagnosis	12
adhd assessment	11
waiting diagnosis	10
adhd asd	10
awaiting assessment	10
diagnosis support	9

Sentiment of post names

A sentiment analysis was conducted on the post titles to provide a quantitative indication of positive and negative experiences expressed through the digital engagement. The process included explicit handling of negation (e.g., “no support”, “not good enough”) to avoid misclassification. These results provide a directional view of sentiment and tone but should be interpreted alongside qualitative insights from full submissions.

This analysis indicated that post names were generally neutral (62%) or negative (37%). Negative or strained framing of experiences was frequent and associated with terms such as “waiting”, “denial”, “refusal”, and “failures”. Positive sentiment (<1%) appears rarely and usually in contexts of eventual success after long delays.

Examples of neutral post titles include:

- Primary Teacher Experience
- Experience as a woman
- Son diagnosed with ADHD

Examples of negative post titles include:

- 5.5 years waiting; no further forward
- Scotland ADHD treatment is behind & prohibitively expensive
- Too masked to be helped; too tired to keep fighting!

Examples of positive post titles include:

- Good support but takes years of fighting.

- Got there in the end... but it isn't accessible to everyone

Waiting times referenced in post titles

Since many post titles referenced wait times, an analysis of time-related terms alongside access-related language was conducted to estimate the waiting periods experienced by respondents to the digital engagement. Text pre-processing required time units appear near access-related words (i.e., wait, waiting list, assessment, referral) and excluded patterns like “year(s) old, yr old etc). The subset of responses of titles with a measurable delay indicated a median time for diagnosis or support of 4 years. The wait times identified ranged from 6 months to 26 years, with the latter example of 26 years representing a diagnosis journey that began with a misdiagnosis of a mental health condition.

Example post names included in the analysis:

- Waiting 3 years; another 2 at least
- 7 year wait for help for a child
- Waited 6 years for diagnosis. Now refused treatment.

Settings referenced in post titles

Many of the post titles mentioned assessment or diagnosis, with 353 references in total. Waiting times, delays, or waitlists appeared in 224 titles. A school or education context was noted in 241 titles. Mentions of specific services included the NHS, CAMHS, private providers, and GPs or doctors. There were also references to local authorities in relation to education, and to health boards in connection with diagnosis and support, although these were less frequent.

Gender referenced in post-titles

Respondents did not provide their own gender as a demographic variable on the YourPriorities site. However, gender was frequently referenced in submissions and post titles. To estimate how often experiences were described in gendered terms, a keyword analysis was conducted. This identified 96 post titles containing female-coded keywords (such as woman, women, girl, female, mum, mother, daughter, wife, or sister) and 195 titles with male-coded keywords (such as man, men, boy, male, dad, father, son, husband, or brother).

Since most respondents were parents or carers, many gender-coded posts referred to caregiving relationships. For example, the title “mum of 3 boys; 1 has ADHD diagnosis, 1 is in diagnosis pathway” was coded as both male and female. Most female-coded posts included the term “mum,” though in some cases it also reflected personal experiences of neurodevelopmental conditions, such as in “ADHD mum of ADHD teen and professional assessing ADHD/Autism.” Most male-coded posts referred to “son” or “boy.”

Some gendered experiences were not captured by the keyword analysis due to the use of colloquial or medical language. For instance, titles like “recently diagnosed lad" and "menopause and undiagnosed ADHD" reflect gendered aspects of experience but were not flagged by keyword matching.

Overall themes in post titles

SPICe grouped the post titles from the YourPriorities platform into themes using a text clustering method. This was conducted to corroborate themes and recurring topics in the qualitative analysis of people's experiences of ASD and ADHD diagnosis and care. The analysis identified 12 clusters of experiences. A summary of these clusters is presented in Table *2.*

Table 2

Number of responses in topic cluster	Name of topic cluster	Frequent terms
290	Unclear or complex support pathways	experience, support, adhd, pathways, lack, story, autism
151	Long or late diagnosis	diagnosis, awaiting, late, private, pathway, seeking
146	Children's assessments and parents advocating	asd, diagnosed, assessment, child, son, daughter, awaiting
126	Multi-year waiting lists	waiting, years, still, times, list, long
78	NHS barriers and decisions to seek private diagnosis	nhs, failed, private, forced, dismissed, pay
72	Families seeking support	children, left, limbo, parent, autistic, needs
72	Difficulty accessing assessment	wait, long, battle, assessment, lengthy
53	Perceived systemic failures	system, failing, broken, neurodivergent, scotland
47	Emotional experience of seeking diagnosis	lost, ignored, undiagnosed, frustrated
46	Educational barriers	school, help, unable, struggling, gp
46	Personal journeys and reflections	journey, delays, diagnostic, lonely

31	Difficulty accessing services once assessed	service, difficult, barriers, assessed

Qualitative experiences of ASD and ADHD care pathways

A mixed sampling approach was used to analyse the 1,158 submissions. Initially, a random sample of 15% of responses was selected followed by purposive sampling to include responses that reflected key themes and underrepresented perspectives, where applicable.

Many submissions indicated that individuals often had multiple, overlapping relationships with care pathways. For instance, someone might have already received an ADHD diagnosis while still waiting for an ASD assessment. Similarly, parents with their own diagnoses were also seeking assessments for their children. Professionals who contributed responses sometimes referred to their own diagnostic journeys or those of their children. Due to these intersecting roles and experiences, submissions from individuals who had received a diagnosis and those still waiting were analysed together in the qualitative analysis.

Reasons for seeking diagnosis

Many adult respondents described experiencing mental health challenges, sleep disturbances, executive dysfunction (i.e., difficulties with mental processes like planning, attention, and impulse control), relationship breakdowns, and the psychological pressure of “masking” to meet social expectations (n.b., masking is a term used in the autism community to describe the strategies individuals may use, consciously or unconsciously, to appear non-autistic). Many adult responses also included experiences of family members being diagnosed with ASD or ADHD and this prompting them to consider their own experiences. These cumulative life events and behavioural patterns often prompted individuals to reflect on their experiences and seek a diagnosis, not only to better understand themselves but also to access appropriate support for managing their wellbeing. For example, as these respondents state:

> “To live a better life, and bring my unique abilities to the table, making make a valued and positive contribution to Scottish society. To reduce dependency on benefits, and understand the pervasive influence my neurodiversity has upon my daily life, my relationships and my career.”

> “I sought diagnosis to help me take control of my life - to have a chance at the right support, to stop feeling like I’m constantly failing, and to understand how all of these conditions interact. Not for excuses, but for a chance to feel peace. To be proud of who I am. Diagnosis isn’t a fix, but it’s the first step toward hope.”

> “I spent 2 years researching ADHD and ASD and coming to the conclusion that I was neurodivergent in some way, likely ADHD-flavoured. I want an assessment to either confirm my self-identification, get me a diagnosis, and enable me to access help and support, or to disprove it and give me other

> directions to look in to explain why I am the way I am. I need support and help, most of which is only open to those who can prove they have a neurodivergence.”

> “We wanted diagnosis as a form of validation. Without diagnosis the regular person on the street will just dismiss you as a weirdo when you can't handle a conversation or you misunderstand someone's intentions leading to embarrassing drama etc. My experience has been one of frustration, humiliation and isolation. With a diagnosis there is no longer that social pressure to mask and appear what others consider 'Normal'.”

> “Most adult support organisations outside of NHS only allow you to access if you have an official diagnosis. Without a diagnosis my counsellor (which is a benefit of my work) cannot offer specific Autism support or services. […] Let me access support and services at work, in the community. Send me on my way and let me move on with my life.”

> “Kids were struggling with school experience. Their assessments meant understanding and knowledge to us all, and allowed them more support, accommodations and understanding from school. The kids’ diagnoses led generations of our family to wonder about themselves.”

Carers and family members supporting someone with ASD or ADHD also listed various symptoms and behaviours observed in the childhood, adolescence, or adulthood of someone with ASD or ADHD. However, these respondents were also more likely to report pursuing a diagnosis on behalf of the individual following suggestions from health professionals, nursery or school staff, or other friends and family members. In response to the question on why they pursued a diagnosis, family member and carer responses included:

> “I knew my son was different as a baby. He was stimming, not making eye contact and was nonverbal. A simple search on google and it didn’t take long to work out it was autism. I sought advice from our health visitor who simply said she could see red flags, we then worked with her and speech and language to begin the referral process.”

> “My son regressed and stopped speaking, making eye contact, forgot his own name, stopped eating well and sleeping etc.”

> “My daughter: she had a huge regression and we were worried, we knew very little about autism at this point. We needed to know why she stopped interacting and how to support her.”

> “[redacted] wouldn’t hold eye contact she also couldn’t crawl or walk until she was at least 2 and we just knew there wasn’t something quite right with her development.”

> “My son has struggled from birth with a huge amount of issues: auditory processing, lack of eye contact, extreme distress attending school or any crowded places, fear of the unknown, sleeping difficulties, OCD and anxiety as well as using stimming behaviours to regulate himself.”

> “School psychologist had highlighted potential issues and [redacted] was referred to CAMHS, we attended for 6 months and were advised we could return as she got older. We required an autism diagnosis so she could obtain a place at a base unit at high school and extra support at school.”

> “We didn't seek a diagnosis it was the paediatrician who saw the traits in him and recommended the diagnostic pathway to us as it seemed to be the right thing for him.”

> “Since my son was very young (from 2 years old) there were issues with his behaviour at nursery, school, clubs etc. I didn’t know what it was but just received perpetual reports, phone calls and messages home, teachers wanting to talk to me every day at pick up etc. My son was viewed as the naughty and disruptive boy. My husband and I felt like the parents who were failures to our only son. It wasn’t until a team around the child meeting at school when the educational psychologist said he was showing signs of ADHD. It was a kind of a relief. Although she couldn’t make a diagnosis, it felt like for once it wasn’t my son’s fault, or our fault as parents.”

> “From age about 2 when he started at a toddler group it was apparent he was not communicating/socialising with the other children. He also had speech delay for which he attended speech therapist and there was OT [Occupational Therapy] involvement too.”

> “My son showed signs of autism and adhd from a young age, lining up toys, delayed speech, minimal eye contact, distressed by loud sounds and environments. […] My family member is a mental health nurse who works in CAMHS and she was able to see he had ASD and ADHD. As a parent it is heartbreaking to watch your child struggle with day to day tasks and environments and having the diagnosis helps me to help him, by understanding how his mind works and why he does the things he does. Without a diagnosis he may not be able to access the support he needs.”

> “I didn’t know the signs for autism. It wasn’t on my radar it was picked up at private nursery my daughter attended and health visitor when my daughter failed to hit her milestones.”

> “Our son struggled to follow instructions within the classroom from day 1 of Primary 1 - from his first day of school we received regular calls from the school about his behaviour in class and understanding of instructions. We had a meeting with his teacher and depute head in Nov-2021 where they discussed this in more detail- at this point we asked if they believed he was neurodivergent and this lead to the referral to the neurodevelopment team.”

It was rare for respondents to share experiences of ASD or ADHD misdiagnosis, but there were instances of such experiences. For example, the respondent quoted below indicated their child was experiencing PTSD from a school bullying incident, with the resulting social changes being misperceived as ASD behaviours. The social changes at school were what prompted the school to advise on an ASD referral for the child.

> “We were misled. We would not have sought an ASD diagnosis for our child. He is the opposite of ASD at home. Not a single one of the many private professionals nor the schools our child has subsequently attended have thought our child is ASD. […] PTSD can look very similar to ASD.”

Among adult respondents awaiting or having received a diagnosis, difficulty coping at work and navigating personal life changes were frequently cited as key motivations for seeking assessment. Many described reaching a point of crisis and experiencing a significant deterioration in mental health. These experiences often led to a pursuit of diagnosis as a means to access support and improve their mental, emotional, and physical wellbeing. The following responses are representative of this theme:

> “I was beginning to not cope at work - and this caused everything else to spiral.”

> “It's a miserable life. It's constant effort to stay on par with your peers, it's difficult to maintain employment and place in the society, it's hard to have meaningful, long-lasting relationships. […] I was fortunate to be swept up by the newfound wave of awareness around ADHD/ASD and a benefit of other people in the community calling out how my behaviour & struggles reminded them of theirs, and how they were either diagnosed or in the process of being one.”

> “For most of my life, I masked well enough to survive - but recently, everything I worked so hard to hold together has fallen apart. The life I was trying to build now feels impossible. I sought diagnosis because I needed to know why I’ve always felt so broken and different. I needed hope, a starting point.”

> “Overwhelming symptoms fitting the criteria and my life being ruined by them; having to be on benefits for years because of them - I can't work.”

> “My mental health was deteriorating, I was struggling in college, in my workplace as a result of my symptoms. I had been misdiagnosed as so many things like depression and PTSD, and nothing seemed to align more than the symptoms of ADHD.”

> “I needed to take control of my life, in order to keep my life.”

The COVID-19 pandemic and the resulting lifestyle changes, often described by respondents as a shift to a “new normal”, prompted many to consider seeking a diagnosis of ADHD or ASD. For example:

> “But then the pandemic came along, and things were suddenly different. Whilst most people despaired at the lockdowns and social distancing, I don’t think I’ve ever been happier. I didn’t have to start every day dreading whatever social interactions were to come. I didn’t have to waste energy coming up with excuses not to go to the pub with colleagues on a Friday (and then waste more energy worrying that they would see through my excuses). When people asked what I’d been up to at the weekend, “Nothing” was suddenly a perfectly acceptable answer. As the restrictions started to ease, I

> found myself becoming more and more anxious. It wasn’t just that things were going back to the way they were, it was that things were going back to the way they were but now I’d had my eyes opened to how much easier and better things could be.”
>
> “That new normal meant I knew that I didn't have to suffer going into offices with bright lights, loud noises and high social interaction. Instead I could perform much higher at home. The diagnosis allows me to release some of the guilt I had about not being "normal" and I hope soon that ADHD medication might help me at work alongside continued therapy.”
>
> “We are seeking a diagnosis as my daughter is clearly struggling. Since Covid and starting high school, traits of being neurodivergent have become more obvious and are creating barriers for her learning and development and overall heath and wellbeing. We want her to have an understanding of who she is and for us to understand her and how we and school can best support her. Our current situation is very stressful.”

A common theme among respondents was the exacerbation of existing symptoms during menopause, which often prompted them to seek a diagnosis—typically for ADHD. Many simply cited “perimenopause,” “menopause,” or related terms as their reason for pursuing assessment, while others provided more detailed accounts of how these experiences manifested. For example:

> “As a 40 year old woman I was noticing that my concentration was changing and that it was affected by my changing menstrual cycle. I was having huge issues with focus and getting to grips with my work and I was not managing to keep to task and brain fog was becoming more common for me. I was also finding it very difficult to keep up with the paperwork and things that just didn’t track with my autism heavy neurodivergent experience to that date. I explored the diagnostic criteria and realised that when I looked at my experiences of the world as a child and young adult there was a lot of the criteria that I could identify with when growing up for both inattentive and hyperactive ADHD so that I would be likely to have either inattentive or combination adhd, though I have matured to a stage where I am better at handling and working around some of these issues and the effects can be muted by my autistic needs. With all of this I felt that getting a diagnosis and support to help with keeping myself focused and grounded at work so I can take in what others are attempting to communicate with me and on the information I need to share with them.”
>
> “When menopause hit, I thought I was losing my mind. All my previous coping strategies stopped working and I was struggling to function. I wanted to see if ADHD medication could help and the only route to this was seeking a diagnosis.”
>
> “Due to a variety of reasons, including personal factors (such as menopause, covid, MS and age) and environmental factors, especially at work (eg hotdesking, reduced admin support, more ‘self-service’, more use of IT, more admin, more time pressures), I felt a significant reduction in my professional capacity and increased work stress. I felt a formal diagnosis of ADHD would

> be protective in terms of adjustments at work and also might allow me access to treatment or support."

> "During Menopause, my coping strategies and learned skills no longer worked. My brain runs at 100mph 24/7, I struggle to sleep, I have anxiety about managing what others regard as simple tasks and my brain fog is extreme- despite maximising all HRT. It took me a couple of years to pluck up the courage to broach this with my GP, and she was fully supportive of the referral."

Experience of diagnosis

Across experiences of ADHD and or ASD diagnosis, individuals frequently described the diagnostic journey as marked by long waiting times, financial burdens, inconsistent processes, and a lack of support both before and after diagnosis. As highlighted by quantitative analysis, many submissions remarked that the journey to diagnosis spans years and sometimes decades. Examples of waiting time responses include:

> "I waited 5 years and 10 months for an NHS diagnosis […]. There is only one locum psychiatrist working one day per week."

> "It took 7 years of being on the waiting list for the autism one and I've been told it will be at least another 10 for the ADHD one."

> "I waited 4.5 years for a diagnosis. The assessor was very competent and also realised I had PTSD from childhood abuse."

> "I sought support for an ADHD diagnosis for years. I went through school and university struggling with symptoms of ADHD. Many of my family and educational professionals believe I have this. I was on a wait list for over 3 years in Tayside. Moved to Lanarkshire after graduation to not be given a proper ADHD assessment despite scoring highly. I recently got my medical records, I have been referred since I was a child and time and time again it was pushed back."

> "I sent away a self-referral form to the Grampian Adult Autism Assessment team in December of 2022. I then sat a pre-assessment video appointment the following June. I am still awaiting diagnosis, with no updates since then. I was told at the time that the wait list was roughly three years long, but given recent cuts to mental health & neurodivergence services in the UK, I'm not holding my breath & suspect it may take even longer. In the meantime, my lack of diagnosis leaves me feeling like I am not taken seriously by welfare institutions."

> "I have received a referral for an ADHD diagnosis in Q3 2022, but was warned that wait to get in front of a diagnosis board is several years long. Fast-forward to summer of 2024, when I called the NHS Lothian switchboard I was informed that they were seeing patients registered in 2018, indicating a 6 years delay and putting my assessment at ~2028, three years away from now."

> “My son who is 6 has been referred and we are being told to expect a 5 year wait. All I can do is hope that this doesn't affect his education in the meantime.”

Several responses associated the long waiting times with unexpected changes to the assessments they subsequently received. A representative response of this theme explains:

> “I waited just over 2 years before I had my psychiatry appointment. When it came about I was frustrated to find that somewhere along the way there had been a mix up, and I was only being assessed for ADHD and not both ADHD and ASD as I had originally been meant to. The appointment lasted just over an hour over video call, and the psychiatrist was able to diagnose me then and there, and then organise meds and such. […] I had to go through the process again of getting a referral for ASD, it has now been about 2 years and there has been no updates on anything. I don't know what's happening, if anything. I'm in the dark, and that is stressful.”

Many respondents diagnosed with ASD or ADHD attributed the feeling of being “forced” to go private to the long waiting times.

> “Getting a diagnosis for ADHD has been an incredibly frustrating and disheartening process. Schools and GPs constantly pass the responsibility back and forth, with neither willing to take the lead. It feels like you’re stuck in a never-ending loop where no one wants to take ownership. Even when a referral is finally made, you’re then told the wait will be several years. The whole system is inefficient, uncoordinated, and completely fails to provide timely support for families who are already struggling. I ended up paying privately to have this done. Even though my daughter is struggling each day the GP surgery has refused to offer any help at all because she does not have a CAHMS diagnosis, even though that will take years.”

> “We have had no option but to sell her car that she bought to learn to drive in, to pay to have her privately diagnosed. She has been assessed, diagnosed and her treatment is about to start, all within the space of 2/3 weeks. We are hoping that a combination of medication and therapy will help her live her life as best as she possibly can.”

> “Been on the NHS waiting list for over 2 years, decided to go private as daily struggles were too much.”

Respondents who chose to pursue a private diagnosis often highlighted the associated financial costs. For example, as these individuals explain:

> “I have received a referral for an ADHD diagnosis in Q3 2022, but was warned that wait to get in front of a diagnosis board is several years long. Fast-forward to summer of 2024, when I called the NHS Lothian switchboard I was informed that they were seeing patients registered in 2018, indicating a 6 years delay and putting my assessment at ~2028, three years away from now. In the meantime I had to go out and seek an assessment privately, which cost me £1,500 for the diagnosis and then £3,500 more for titration over 12 months

> with monthly appointments. On top of the £5,000 spent I am now expecting to spend further £5,000+ over the course of five years (2023-2028) obtaining medication which costs ~£60pm + £30 for private prescription. TEN THOUSAND pounds to live a normal life."

> "I paid several thousands of pounds, which I am still paying off four years later."

> "I had to spend £2,000 on a private ASD assessment… plus £4,000 for my children."

> "I have been trying to get an NHS diagnosis for almost 4.5 years. I still don't know how long it will take to get an appointment. Initially, my GP didn't believe it was the diagnosis, despite completing the RefHelp forms for NHS Lothian and scoring high on those. However, the referral was made. I waited another year to save the money to go for a private diagnosis. This was very expensive £1,800 just for the initial assessment, then £250/ £350 for each 30/60min follow-up and around £100 per month for medication. I also needed long-term psychotherapy, which I still receive today. Overall, I've spent over £8,000 in the last 4 years trying to get a diagnosis, a management plan and achieving my current level of wellbeing."

> "I was then lucky enough to unexpectedly get enough money to see a private consultant, who diagnosed me with ADHD. I took out a credit card so that I could afford the medication. For me, this choice was 100% worth it as it has transformed my life. I am now thriving at work, completing all my chores, and my physical health has also improved as I am able to make healthier choices. I am paying back my credit card debt but it's a slow process as I also need to pay for medication. It has been shocking to me how much I was abandoned by the NHS, especially as my condition is so treatable."

For some respondents, the costs were prohibitively high, and they faced challenges using private health insurance or other coverage for diagnosis, as well as difficulties planning for the ongoing expense of private prescriptions.

> "I got confirmation that they have agreed to see me but that I am now on a wait list. I have heard that these lists in some areas are up to a 5 year wait which is disgusting. I have tried to seek diagnosis privately but cannot afford it and tried to do it through my work but my work do not cover neurodivergence on their medical cover. Feels like a lost cause."

> "My 21 year old son was on a waiting list for 2 years - had attempted suicide and this was apparently the urgent list. He was prescribed antidepressants which only made him numb and zoned out. After waiting 18 months I paid for a private diagnosis. At this stage 2 years later he had reached the top of the list but was told that he would have to wait at least another 18 months for titration. He completely lost a year in University and had to resit 1st year as he was totally unable to cope. In desperation we agreed to pay again for titration as the gp had explained shared care. For 7 months we have paid in excess of £500 a month. My son is thriving on the adhd medication. He is off antidepressants and is able to study and cope with life again. We are not at

> the stage of transferring to shared care to be now told that the practice has stopped doing this. He is a student has no money and I am retiring soon, my husband is ill. We cannot afford to support this forever but on the other hand cannot not support knowing what the outcome could be.”

Many respondents then highlighted that a private diagnosis can affect the accessibility of NHS care or shared (private and NHS) care. A common theme was either the “refusal” or perceived reluctance of GPs to enter shared care agreements, even when the private diagnosis was carried out by psychiatrists who also work within the NHS. As these respondents shared:

> “I have also been told that they absolutely would not take on shared care, even though it would be a NHS consultant psychiatrist that would diagnosis me.”

> “It has been horrible - I am still on an NHS waiting list for over three years - I did go to a private provider AND was duly diagnosed as Autistic and ADHD, but my health authority will not recognise the diagnosis, and recently received a letter that basically informed that because of my age and not "having needed a diagnosis before" - I am not a priority.”

> “I first realised that i possibly had ADHD in 2022, after the birth of my second child. The symptoms were becoming debilitating, and I sought help from my GP. They were very dismissive but put me on a waiting list anyway. Eventually in late 2024 I couldn’t cope with the symptoms anymore, and took out a loan for a private diagnosis, after consulting my GP who assured me they would offer shared care. After diagnosis and trying different medications, I am now on the strongest dose of methylphenidate, which is very expensive. When the private doctor sent the shared care agreement to my GP, they were informed that the GP no longer offers shared care, as of the previous month. This has left me in limbo, still having to pay a high price for the medication that has been working for me. It’s very frustrating to have been dismissed so easily by the NHS.”

> “There is no shared care in place in NHS Lothian. The refusal of CAMHS after GP referral was a severe blow. GP Practice has said currently they will not accept private diagnoses from private providers despite them being NHS accredited and conforming to NICE standards which is accepted in NHS England. The waiting list is too long for those sufferers who are constantly battling to keep their jobs, families, mental and physical health, personal safety, relationships and daily life together and the damage that subsequent addictions that in my case has been alcohol have been causing to all of the aforementioned. I find myself in the situation where despite having battled with the symptoms of ADHD (and possible autism) undiagnosed my entire life not realising that this is what has been causing the constant anxiety and disorganisation that I have on a daily basis that despite what will be a formal diagnosis, accredited as such with other health boards across the country I will have no Shared Care agreement and will have to fund medication and any further care myself. It seems that this is a postcode lottery rather than a blanket acceptance of private diagnoses across Scotland.”

Despite the challenges many faced, a handful of respondents highlighted positive experiences, particularly when GPs took a proactive approach. For instance:

> “Fought to get referred in England put on wait list for 4 years. Went private. Fought to get shared care. Moved to Scotland 3 years ago. Was terrified shared care would stop. Thankful to pragmatic gp who prescribed the meds and referred me to psychiatry who agreed to review and take on prescribing.”

In contrast, other respondents reported having to restart the diagnostic process after moving between England and Scotland, as illustrated below:

> “I first sought a diagnosis when living in England and I waited over a year with no progress. […] I had to restart the whole process once I moved up here which was very frustrating and annoying. I was expecting another long wait of several year but luckily I only had to wait about 6 months before being called for an assessment. The assessment went very well and the doctor was very professional.”

Respondents also shared experiences beyond access and cost, highlighting issues such as stigma following a private diagnosis, the need for more holistic approaches to co-occurring conditions, and the impact of earlier misdiagnoses (particularly among women). These themes are illustrated in the following examples:

> “When you tell someone, they immediately ask NHS or private diagnosis, and you can be made to feel as if the private diagnosis is just made up.”

> “Getting an ADHD diagnosis gave me some clarity. But I also have hEDS, which causes daily pain and mobility issues. Studies link hEDS and neurodivergence, and I know my autism (still undiagnosed) plays a huge role in how I experience pain and overwhelm. Yet no one looks at the full picture. Everything is treated separately or dismissed entirely.”

> “After years of being prescribed medications for borderline personality disorder, depression and anxiety and nothing improving my mental health nurse queried ADHD. […] I waited around 4 years, however if I am being honest I actually waited around 20 years as was misdiagnosed the majority of my life.”

> “I have been wrongly diagnosed with many different things since I was a child. In the 90s, ADHD for girls was practically unheard of.”

> “I was treated for anorexia for almost 30 years and misdiagnosed with BPD / EUPD for all of this time - and treated terribly because of it. What I now know is autism and ADHD (e.g. meltdowns, sensory sensitivities, emotional irregulation issues, monotropism / intense interests, diofficulty with change and need for routine) was seen as symptoms of BPD and I was forcibly medicated, sectioned and transferred to hospitals all over the UK. It's been difficult to get appropriate treatment for my anorexia because of it and now I am told (frequently) that after 30 years of anorexia and with co-occuring autism, there's little hope / help for me.”

Many of the respondents described experiences of stigma, dismissal and bias while navigating diagnosis. Several respondents, particularly women, reported being told they were “too successful” to warrant assessment. Similarly, some respondents noted that attempts to obtain a later-life diagnosis were dismissed by health professionals, who often assumed that previous coping indicated no need for assessment. For example, as these responses indicate:

> “When I approached my GP about ADHD symptoms, having recognised that what I'd attributed to depression was actually ADHD-related difficulties, her response was sympathetic but ultimately dismissive. She refused NHS referral, stating that because I'm a professional with a degree who holds employment, I wouldn't be seen. This discriminatory gatekeeping ignores how adults, particularly women, develop masking strategies whilst struggling significantly.”
>
> “ZERO AWARENESS OF MASKING. This is especially important in women, those from low socioeconomic backgrounds or those late diagnosed.”
>
> “Complex cases are put aside rather than flagged for extra input in my experience.”
>
> “I had a deeply invalidating experience when I attempted to seek a diagnosis. Despite showing a strong clinical presentation in the initial screening arranged by my GP, I was told I didn’t meet the criteria for further assessment—because I was married, in employment, and therefore not considered distressed enough.”
>
> “I was told that at 56, I should be able to cope by now—and was even asked if I was just seeking medication. That left me feeling like I was wasting her time... ADHD doesn’t go away just because we’ve reached a certain age. Everyone deserves to be listened to and supported—especially when they finally find the courage to ask for help.”

Adoptive and foster parents frequently reported that adverse childhood experiences were often cited as the sole explanation for a child’s difficulties, leading to delays or dismissal of neurodevelopmental assessments. Conversely, some noted that trauma was overlooked when neurodevelopmental conditions were suspected. These families described significant stress in advocating for appropriate support, as illustrated below:

> “My son came to stay with us aged 2, having not been seen by an allied health professional and not properly assessed by the health/social care system based in South Lanarkshire. Despite being a health professional, and spotting signs of autism and ADHD, I was disbelieved by my social worker and unfortunately my son’s social worker left, and the new one didn’t know him. Obvious signs such as no shared mutual attention, obsessional interests, sensory issues, sleep disruption and hyperactivity were put down to me being oversensitive as a new mum. When I eventually got a referral to PACT (local assessment team) there was sufficient information to confirm autism diagnosis, aged 5, But we were told the first line of treatment for ADHD was

> meds which he wouldn't get until he was aged 8 minimum. He was referred to CAMHS 4 times (declined referrals from paediatrician, GP, and lost PACT team referral were not advised to us) and we were on our knees by the time the referral was accepted (it took me crying and shouting on the phone to be heard. In the meantime I clued myself up, got into different Carer groups and took every online course I could, to the detriment of my own health and career. He was diagnosed at 8, put on methylphenidate, and melatonin. Neither of which has really worked to date."

> "My child is care experienced having spent first 2 yrs in foster care. Adopted children have higher rates of adhd and often no medical history. Forth valley current weight 5 yrs to get diagnosis and medication, effectively denying him his right to education and medical treatment. Private diagnosis followed using all relevant guidelines. NHS refuse to recognise it and refuse to explain why. Refuse shared care. No prospect of treatment for 5 years by which time he will be in 4th yr at school. Won't even respond to letter of complaint. Completely abandoned. No sign of meeting The Promise in Forth valley. Can't engage in education without treatment. Now spending his disability benefit on private prescription he should be getting on NHS."

> "We adopted our son when he was 4 in 2011. He had suffered physical & emotional abuse, extreme neglect and witnessed domestic violence & drug taking regularly. His extreme behaviours immediately made me wonder if he had ASD/ADHD, but the professionals said it was attachment/his experiences and to give it time. He had been described to us as 'non verbal' as a toddler. We were told by Social Workers that it was an "angry statement for a toddler to make", not that it could be a sign of anything else."

A number of parent respondents described difficulties when relying on schools to initiate referrals. Frustration was also expressed regarding inconsistent referral processes between schools, GPs, and CAMHS, with some families experiencing repeated refusals and prolonged waiting times. A lack of interim support during these delays was a recurring theme. The following submissions illustrate some of the issues faced by parents navigating diagnostic pathways involving schools and the NHS.

> "Schools have been placed in a position where they are the gatekeepers to assessment. We approached our GP at one point and were advised referral to CAMHS from them would most likely be declined and that indicators from school are essential to acceptance. However, I am unsure if teachers have access to sufficient training to recognise more subtle features of autism. I also think there is a lack of understanding of Autistic Masking. I fear that schools are over-stretched and that there may be a bias against assessment as this places an onus on schools to meet those additional needs which they may not have the resources to do. Parents are often met with disbelief, judgement and lack of support."

> "My daughter was referred for neurodevelopmental assessment in Primary 5 by her new head teacher, after years of me asking whether the school believed something might be wrong possibly ASD. That was four and a half

> years ago. She’s now 13 and has just entered S3 in high school, still without a diagnosis or the support she needs. In that time, she has withdrawn socially, been bullied for thinking differently, and repeatedly placed in isolation because staff don’t know how to manage her needs. She was 9 when referred; now she’s navigating adolescence and hormonal changes without the understanding or tailored help she deserves. This delay has had a profound impact on her mental health, education, and self-esteem.”

> “My son still does not have the right support and the teaching staff are dismissive of his voice as they tell him off for not telling the truth that is how he sees the world and he is not wrong. Better training of autism in schools as they still get it wrong so many times which impacts our son and family.”

> “The whole process has been a shambles. Right from the moment over 4 years ago when CAMHS refused to accept a referral from school and insisted it come from a GP. A doctor my son has rarely seen in his life is better placed than the school he attends every day according to CAMHS. The process is made more difficult unnecessarily and has been nothing but stressful since.”

> “My son is suspected Au/ADHD. It was a struggle to even get a referral for him. We first asked the GP who told us we needed to go through the school, who then said they didn't recognise it at school and wouldn't do a referral. We tried to self refer but in the meantime the school changed their mind and decided the rolling about on the floor and screaming probably was something after all and put in a referral for us. We had an initial appointment with a CAHMs nurse who agreed that it was a likely diagnosis. We've since been waiting on an appointment for two years with zero contact. We tried to reach out for support with his sleep and met a dead end so have had to develop strategies by ourselves. So far in this journey the support from CAHMs has been non existent and now despite the school recognising there is likely neurodiversity, there is very little in place to support his learning and at times it feels like he's just been abandoned in front of a laptop because they know it will hold his attention. We don't have a lot of faith that an official diagnosis will change anything in the support he receives (which is currently nothing).”

Experience of support following diagnosis

For many, receiving a diagnosis brought relief and recognition but little practical help. Respondents frequently mentioned the “transformative” effect of medication, yet also described long waits, supply issues, and a lack of ongoing support. As these accounts show:

> “Diagnosis isn’t a fix, but it’s the first step toward hope. Right now, that first step is out of reach for too many.”

> “There is still so much that needs to be done regarding the world and autism/ADHD but just having recognition for your struggles and the correct medication makes the world of difference and I now can see a future ahead of me, not just sheer hopelessness.”

> "And now, whilst helpful on a personal level, the diagnosis has made no discernible difference to my life. Once diagnosed, the lack of follow up help is astounding."
>
> "As a family the diagnosis means nothing, it's a bit of paper that sits in a drawer, it is a degrading bit of paper and only points out my sons weaknesses and things he cannot do, it doesn't comment on his strengths. For us the diagnosis was simply a confirmation and we do not believe we would be any worse off without it. It's about how schools get it right for every child with or without a diagnosis, it's about educating the general public on what autism means, it's about businesses and government taking action to make life easier for autistic people and their families."
>
> "I have not had a review since, I was due one last year, but it had to get rescheduled due to scheduling conflicts, and I have not yet been offered a new one."
>
> "Since the biggest frustration has been managing to obtain the medicine because of the shortages. This was very frustrating because the meds help massively and being without caused a big interruption to my life."

Families who shared experiences of limited support after diagnosis highlighted the impact this continued "lack of support" had on their child's education, family wellbeing, and daily life. Respondents spoke of disrupted schooling, emotional strain, financial pressures, and the cumulative toll of navigating systems with little assistance. The following accounts illustrate these challenges:

> "My daughter was not getting the right support or medication. The GP was offering what they thought would help but the Educational Psychologist was unhappy with the medication she was on. She has now left school with no qualifications and no proper support for getting into work."
>
> "Education department has completely failed her. No enhanced transition to secondary. Suffered autistic burnout S1 and hasn't been able to attend for 3 years. Current school is deplorable and I'm considering taking legal action so she can get the qualifications she is well capable of obtaining if reasonable adjustments were made."
>
> "My child aspired to be a Dr, yet now has no qualifications at the age of 16. She has trauma as well as probable autism so her needs are complex. Had Camhs intervened at a much earlier stage, to give her the help she desperately needed at the start of the high school transition, then her future may have looked brighter. This has impacted her whole future, her physical and mental health and that of my family."
>
> "Due to no real support both kids dropped out of school with little to no qualifications and trauma from school experience. As a family we have been suffering through burnout, depression, lack of support, unemployment due to caring responsibilities and social isolation."

Where positive experiences of post-diagnostic support were reported, they were most often linked to third-sector organisations rather than public services. Respondents described these services as life-changing, offering practical help and emotional support that public systems did not provide. However, such provision was described as fragile and inconsistent. As participants explained:

> “The one stop shop in Inverness saved and continues to save my life. Without them, I wouldn't be who I am today.”
>
> “Now the only active adult support group (autism initiatives) has been withdrawn from Angus and we have been left stranded with no support.”

Experience and views of professionals involved in providing diagnosis or support

Professionals across education and healthcare described a system they view as fragmented, under-resourced, and shaped by stigma. Their accounts describe systemic barriers, misconceptions about families and adults seeking diagnosis, and the impact of long waiting lists on professionals. Many spoke of burnout and the frustration of working within pathways that fail to meet demand.

> “Adult ADHD diagnostics have been 'parked' which effectively means halted until further notice. This has created a mounting crisis for those seeking pre, mid and post- diagnostic support. Resources have been unduly concentrated on creating clinical diagnostics, with almost no resources diverted to supporting those at every stage of the diagnostic journey. Copious anecdotal evidence of the lived and living experiences gained from our community members which we hear on a daily basis supports the regularly used catchphrase; 'diagnose then adios' indicating that even when a diagnosis is finally made, there are few informed services or supports available. The overwhelming burden of interventions are passed on by statutory diagnostic services to the third/voluntary sector. Ironic, as it obviously requires expertise levels of clinical qualification to diagnose, but only voluntary experience to provide intervention.”
>
> “There is a perception amongst both of our professions that parents are seeking adhd/autism diagnosis for their child for illegitimate reasons, so that their children can gain an unfair advantage within school settings in some way, to unfairly gain social security, or simply because it is a "fashionable" thing across social media. And, that adults seeking diagnosis are doing so for similarly illegitimate reasons, including getting an advantage at work and in interviews. These perceptions are as a result of confirmation bias, because they are spoken about so openly and as if they are fact. We've seen no robust evidence of these perceptions being factual, though we have seen that the media can perpetuate some of them. There's nothing either of us feel we can do to "whistle blow" as its an endemic stigma. E.g. several of my colleagues have said that parents "shop around" different private providers until one of them eventually gives a private diagnosis. However, we can't see how this could possibly be factual. Private providers are regulated to the same standard as NHS services and professionals.”

> “Clinicians are working hard but the resource is not there to cope with the demand. We are having to tell parents and carers, and young people that their wait is going to be years for an assessment. This is not ok and clinicians experience moral injury due to this too.”

> “The amount of children not diagnosed by this age is shocking. This is not due to lack of pushing from school/parents but waiting times. These children are going to secondary school undiagnosed and without the label they do not get support. However, even with the label there is no extra scope for support in primary schools. We are under resourced and underfunded to deal with the high levels of need in our classrooms. We are not getting it right for any child as no one is thriving in the environment.”

> “Working in CAMHS is frustrating, I am part of a small but wonderful compassionate team of clinicians but we are burning out fast. Despite the rumours being that the waiting list is closed, it's not. Young people are added regularly, it's just that they need to meet the CAMHS criteria of having significant mental health problems to get through the door, we are a mental health service after all. […] It is not our fault the lists are so long, that it takes years to get through, we all know that each individual and their family is having a difficult time, we do try to do our very best for the young people we work with but there's not enough of us trained, not enough of us willing to work at such pressure for the money offered when we can have easier shifts pretty much anywhere else. I've stayed because I love my job but it eats me up inside knowing we could do better if we were properly equipped and supported.”

> “I have been involved in attempting to get children in mainstream school and specialist provision diagnosis'. As a professional the process is unclear, painfully slow and not transparent. […] As a teacher I feel often our opinion and observations are disregarded although we have to be professional enough to create practical strategies to support the children without any additional resource or people hours.”

Suggested reforms

Across submissions, respondents consistently called for a series of common reforms to improve ADHD and ASD care pathways. The most frequently reported factor that would have improved respondents’ experience of seeking care and support was shorter waiting times. Many respondents in addition called for more joined-up services. There was a strong emphasis on understanding the overlap between different diagnoses, as well as the impact of trauma and adverse childhood experiences. Respondents also argued against time limits on therapy and the segregation of services by age.

Several respondents advocated for the creation of a national ADHD pathway with communication of waiting times alongside formal recognition of private diagnoses under clear and regulated criteria. Additional proposals included allowing third-sector neurodiversity services to provide diagnoses to reduce waiting times, adopting language that avoids framing autism and ADHD as “disorders,” and ensuring that neurodiverse individuals are actively involved in decision-making about services.

Respondents routinely indicated that GP training on neurodiversity could reduce stigma and improve early identification, particularly for women and individuals with complex presentations. Training was also suggested for a wide range of professionals, including psychologists, mental health nurses, social workers, teachers, and staff in council services, and staff in Job Centres.

Courtney Aitken, Researcher

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