healthwatch
Hertfordshire

Support for Autistic Adults

Engagement: June – August 2025

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Authored by: Sam Foster and Chloe Gunstone

Contents

Key Themes

134 autistic adults, their loved ones and carers shared their experiences of support after receiving an autism diagnosis. They made suggestions for how services could be improved and what type of support should be available.

Many people waited years for an autism assessment on the NHS, with some paying privately to be assessed sooner. These delays and costs often had a lasting impact on their finances and wellbeing.

Most wanted support but nearly half did not receive any information, resources, or referrals following their diagnosis. Many people felt like they were left to process a life-changing diagnosis alone and struggled navigate services or find support.

Those who accessed support often had positive experiences but faced challenges in finding or accessing services. Having a single point of contact and greater autism awareness among professionals was seen as key to improving support.

Poor mental health was common before and after diagnosis. Mental health support was the most sought-after type of support, but many found that services lacked the training or awareness needed to adequately support autistic adults.

Support pathways were often described as fragmented, inconsistent, or lacking coordination. This made it difficult for people to access the care they needed and left many feeling dismissed or forgotten.

Many felt current services were inflexible or not tailored their needs. More targeted support, with greater personalisation and flexibility that reflects autistic adults' needs, challenges, and strengths would ensure they receive the most appropriate help.

Social groups and peer support were often praised as an invaluable source of support. Many called for greater awareness of these groups and organisations due to the lived experience and knowledge they offer.

Carers and loved ones were often responsible for coordinating support between different services. This led many to worry about how support would be managed in the future if they were unable to continue overseeing their loved one's care.

Recommendations

The findings of this report have highlighted various ways to improve the support for autistic adults following diagnosis. Suggestions provided by respondents have been shared with Hertfordshire County Council to inform its plans to commission services for autistic adults. They have also shaped the recommendations below.

Prioritise timely and appropriate diagnosis and referrals by:

- Ensuring adults who suspect they may be autistic are taken seriously and are referred for assessment.
- Increasing awareness of the Right to Choose[1] pathway to ensure people can access free assessments, reduce waiting times, and avoid private costs.
- Training professionals to recognise how autism may present differently in women and people from ethnically diverse backgrounds, supporting a fairer diagnostic process and access to services.

Improve personalised post-diagnostic support by:

- Supporting people based on their individual needs, strengths, and challenges as outlined in their diagnostic report.
- Undertaking targeted work to better understand the needs of different demographic groups.
- Offering a variety of support including one-to-one, peer or group support, online and in-person support to suit individual needs and preferences.
- Enabling autistic adults to choose and adjust the duration of support as they come to terms with their diagnosis, including opportunities to ask questions, such as periodic check-ins with a coach or support worker.
- Providing support outside standard working hours to improve access and flexibility.

Share clear information and signposting to support services by:

- Creating a central directory of local and national support services to be shared when people receive their diagnosis, highlighting resources most relevant to each individual. This information should be available in multiple formats to ensure accessibility.
- Increasing awareness and providing information about coaches and/or support workers who can help with administrative tasks including applying for financial support, navigating complex services, and signposting to additional organisations.
- Providing a single point of contact for any questions or concerns following diagnosis, enabling easier navigation and additional signposting support.
- Ensuring carers, family members, and loved ones are given clear guidance on how to access support for themselves and the autistic person they care for.

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[1] Right to Choose: ASD & ADHD Assessment Pathways - Cuckfield Medical Practice

Improve employment support for autistic adults by:

- Making autistic adults aware of the reasonable adjustments[2] they are entitled to under the Equality Act 2010.
- Sharing information about Access to Work and supporting people to obtain a grant.

Enhance financial support by:

- Sharing information about financial support and entitlements, such as PIP (Personal Independence Payments)[3], disability payments, and benefits.
- Sharing information about flagging neurodivergence on government records to ensure autistic adults are supported in navigating applications and completing forms if required.

Improve access to mental health support by:

- Training professionals to be culturally sensitive to how autism presents across age, culture, and gender, and how that may affect an individual's lived experience.
- Reviewing and improving the mental health support available on the NHS to accommodate autistic adults with mental health conditions.

Join up the services involved in the care and treatment of autistic adults by:

- Sharing their autism diagnosis across the health and social care system to ensure records are up to date.
- Reviewing any medications and treatments to check whether they are still appropriate or effective following diagnosis.

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[2] Reasonable adjustments: a legal duty - GOV.UK

[3] Personal Independence Payment (PIP): What PIP is for - GOV.UK

1 About Healthwatch Hertfordshire

Healthwatch Hertfordshire represents the views of people in Hertfordshire on health and social care services. We provide an independent consumer voice evidencing patient and public experiences and gather local intelligence to influence service improvement across the county. We work with those who commission, deliver, and regulate health and social care services to ensure the people's voice is heard and to address gaps in service quality and/or provision.

2 Aims

The purpose of this research was to gather the insights of Hertfordshire residents diagnosed with autism in adulthood, focusing on their experiences of support after diagnosis.

The aims of the engagement include the following:

- To establish the key concerns that autistic adults have regarding support in Hertfordshire.
- To understand the types of support that autistic adults would like to be made available to them.
- To explore barriers to accessing mental health support and how they could be addressed to improve access for autistic adults
- To make recommendations to health and care providers and professionals regarding the types of post-diagnostic support that autistic adults need.

3 Methodology

To achieve these aims, a mixed methods approach was adopted. An online survey about accessing post-diagnostic support captured the views and experiences of autistic adults across Hertfordshire. Autistic adults and their parents and carers were also invited to take part in one-to-one interviews to share their experiences in more detail. The engagement period ran from June – August 2025.

The survey was promoted via social media and shared with the NHS, other statutory services, and the Voluntary, Community, Social Enterprise and Faith sector across Hertfordshire to distribute via their networks, contacts, and social media channels.

In total we heard from **134** residents through the online survey and interviewed **15** people.
We would like to extend our thanks to the individuals and organisations involved in supporting this report.

4 Background

4.1 Introducing and defining autism

Autism is a lifelong neurodevelopmental condition which affects how people communicate and experience the world. It is considered a spectrum condition; autistic people may share similar characteristics, but all have varying support needs. It is unclear how many autistic people are living in the UK, but the total population in England could be over 1.2 million[4]. In 2017, there were 8,948[5] autistic adults living in Hertfordshire, which has likely increased.

4.2 Identifying autism in atypical groups

Autism can be difficult to identify in those who do not fit previously standardised and stigmatised perceptions. This includes adults without learning disabilities, minority groups, and women, which often leaves their needs unrecognised and unmet. This is partly due to autism previously being 'viewed as a paediatric condition, meaning that many autistic adults missed out on a diagnosis as children'[4]. Fortunately, autism is now increasingly recognised in adults due to greater awareness and understanding. The average age of diagnosis is 29, and women in their 40s currently make up the largest proportion of people receiving a diagnosis[6]. As a result, those diagnosed in adulthood are sometimes considered a 'lost generation'[7], living undiagnosed and potentially unaware of their autism.

4.3 Post-diagnostic support

The increase in adult autism diagnoses has also highlighted the lack of post-diagnostic support available. Autistic adults encounter many barriers to appropriate post-diagnostic support, which are often overlooked. A recent study found that 70% of autistic people received no post-diagnostic support, and of those who did receive support, only 6% felt it met their needs[8]. Moreover, support services are typically aimed at children or those with higher support needs, leaving many unable to access suitable support.

NHS Guidance Framework (2023)

The NHS published a guidance framework to provide an overview of the roles and responsibilities of autism assessment providers, which includes a responsibility to offer support or provide signposting to appropriate support, after diagnosis. Post-diagnostic support can be offered by a range of sectors, including health, social care, and voluntary sectors.

Post-diagnostic support for autistic adults can include:

- Further assessment
- Enhanced understanding of strengths

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[4] Autism in England: assessing underdiagnosis in a population-based cohort study of prospectively collected primary care data - The Lancet Regional Health – Europe

[5] Autism Spectrum Disorder JSNA

[6] Diagnosis for women and girls | Autism Central

[7] Identifying the lost generation of adults with autism spectrum conditions - The Lancet Psychiatry

[8] 'I cried': How people with suspected autism are doing their own research due to long waiting lists | UK News | Sky News

- Individual or group education about autism and mental health
- Individual or group support for family and/or carers
- Crisis intervention and prevention
- Liaison and signposting to other services and resources

Despite this framework, research into the provision of support by local services is limited. Therefore, little is known about the suitability and effectiveness of support beyond issues of awareness and availability.

Hertfordshire County Council has refreshed its All Age Autism Strategy and revised its core priorities:

1. Enabling equitable and timely access to diagnosis alongside support whilst people are waiting for a diagnosis.
2. Ensuring autistic people with co-occurring mental health conditions have equitable access to reasonably adjusted services.
3. Developing our community support offer to ensure autistic people and their families have access to a range of support in their local communities.
4. Ensuring autistic people can access and fulfil their potential in education, employment, or training.
5. Autistic people have equitable access to reasonably adjusted physical healthcare services when they need them and working to improve health outcomes for autistic people.
6. Ensuring that people who have ongoing care and support needs have access to appropriate services and support to lead a fulfilling life.

In particular, autistic adults have called for support with mental health and employment, however other areas include housing, reasonable adjustments, financial support.

4.4 Mental health support

93% of autistic adults stated that their mental health was impacting their lives, and those without learning disabilities are at the highest risk of dying by suicide[8]. The prevalence of mental health conditions among autistic people may be exacerbated by the assessment process and resulting diagnosis. Therefore, 'the provision of accessible effective mental health support to autistic adults as early as possible… may reduce the need for more intensive and… costly inpatient care'[9]. Taking a preventative approach may contribute to the reduction of suicide rates.

4.5 Employment support

Problems with mental health can further limit a person's ability to find employment, due to the level of support required. Autistic people face the highest rates of unemployment of all disabled groups. Only 22-29%[10] of autistic people are employed, despite most wanting to work, and just 16% are in full-time employment[11]. This is in stark contrast to the 81% of non-disabled people who are employed. 'Autistic people are also more likely to be underpaid… and poorly supported, with many… feeling unable to disclose that they are autistic'[10].

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[9] NHS England » Meeting the needs of autistic adults in mental health services

[10] Autistic people still face highest rates of unemployment of all disabled groups | Autistica

[11] Autistica releases report on workplace adjustments for autistic staff | Autistica

The Outcomes for Disabled People in the UK[12] report published in 2022 was the first time autism employment rates were compared with other disabilities. As such, the high unemployment rate shows post-diagnostic support could support employment for many autistic adults.

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[12] Outcomes for disabled people in the UK - Office for National Statistics

5 Demographics

Please note that it was optional for respondents to share their demographic information with us. There was a total of 153 respondents to our survey.

Areas where respondents live

- Broxbourne: 3% (3)
- Dacorum: 12% (11)
- East Hertfordshire: 16% (15)
- Hertsmere: 7% (7)
- North Hertfordshire: 14% (14)
- St. Albans: 16% (15)
- Stevenage: 3% (3)
- Watford: 2% (2)
- Welwyn Hatfield: 11% (10)
- Out of county: 7% (7)

Age of respondents

- 18-24: 17% (17)
- 25-34: 20% (20)
- 35-44: 18% (18)
- 45-54: 29% (29)
- 55-64: 9% (9)
- 65-74: 5% (5)
- Over 75: 2% (2)
- Prefer not to say: 1% (1)

Respondents who are carers, have a disability, or long-term condition

- Carer: 30% (32)
- Disability: 58% (61)
- Long-term condition: 53% (56)
- Mental health condition: 50% (53)
- Prefer not to say: 8% (8)

Gender of respondents

- Female: 63% (66)
- Male: 30% (32)
- Non-binary: 3% (3)
- Prefer not to say: 4% (4)

Ethnicity of respondents

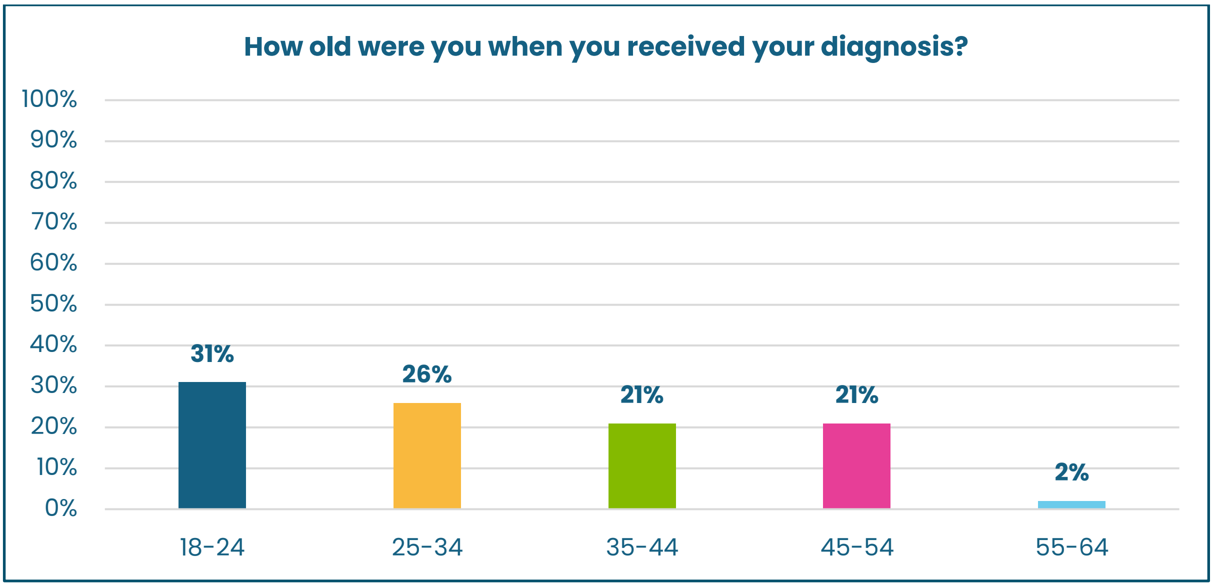
- Asian/Asian British – Indian: 2% (2)
- Mixed/multiple ethnic groups – Asian and White: 1% (1)
- Mixed/multiple ethnic groups – Black African and White: 3% (3)
- Mixed/multiple ethnic groups – Black Caribbean and White: 1% (1)
- Mixed/multiple ethnic groups – Any other mixed/multiple ethnic background: 1% (1)
- White British: 80% (84)
- White Irish: 1% (1)
- White: Any other White background: 8% (8)
- Another ethnic background: 1% (1)
- Prefer not to say: 3% (3)

6 Key findings

6.1 Respondents faced significant challenges in accessing an autism diagnosis

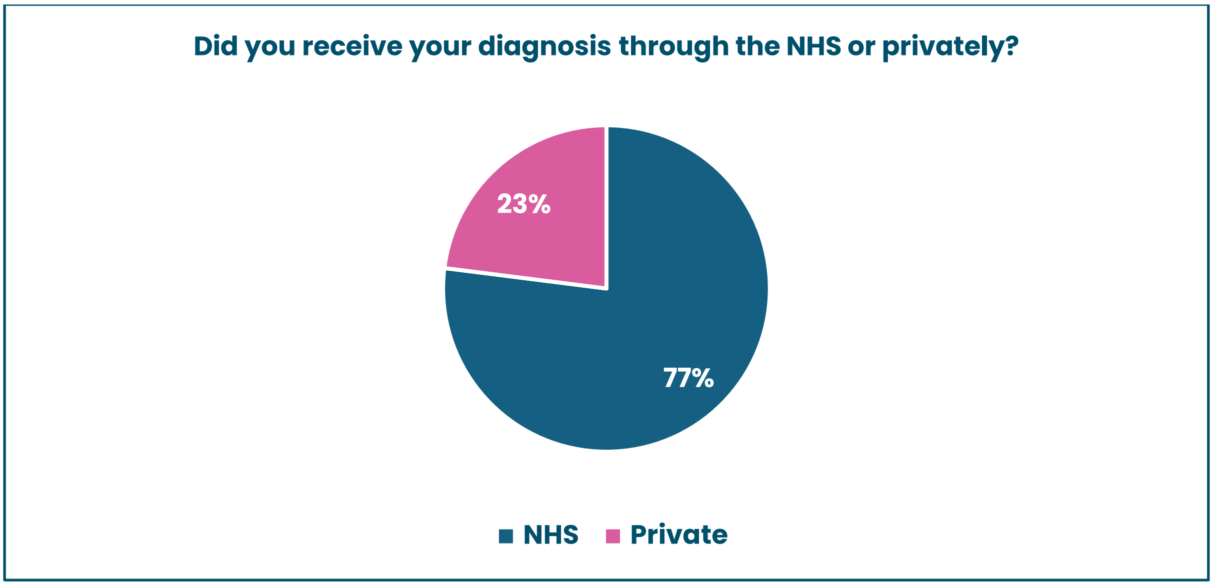
The majority of respondents struggled to access an autism diagnosis, with many being dismissed by healthcare professionals. This was a barrier preventing autistic people from receiving support sooner.

Over 40% (44% - 54) of respondents were diagnosed between the ages of 35 and 64. Over a quarter (26% - 32) were diagnosed between 25-34 years old and over 30% (31% - 38) between the ages of 18 and 24. Despite many of the respondents believing they were autistic from a young age, they were not diagnosed until adulthood and struggled to access support sooner. Many also felt they were not taken seriously or were dismissed by professionals when discussing autism.



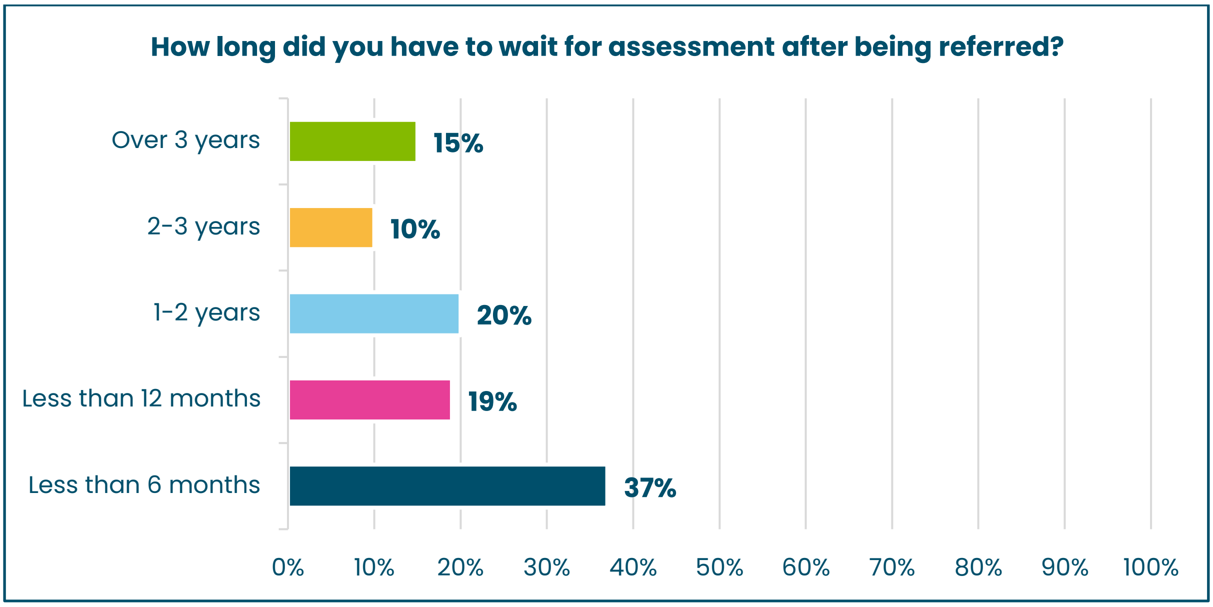
> ***"My GP… was opposed to sending me for an assessment – they could not see any benefit from a diagnosis."***
>
> ***"I was referred for diagnosis following admission to mental health ward in 2020. When readmitted under section 2 at the end of 2023 the consultant attributed my difficulties and suicidality mostly to autism even though I still hadn't been diagnosed."***
>
> ***"I had to beg the mental health team for almost six years to give me an ADHD/Autism initial assessment to finally having them agree to confirm that it was this the whole time and in fact added to my trauma."***

Another barrier in accessing support for almost a quarter of respondents (23% - 31) was the fact that they had to obtain a diagnosis privately. Most often this was due to long waiting lists on the NHS.



This is reflected in the graph below in which 15% (19) had to wait over three years for an assessment and 30% (38) had to wait between one to three years. 19% (24) waited less than 12 months and 37% (47) less than six months.

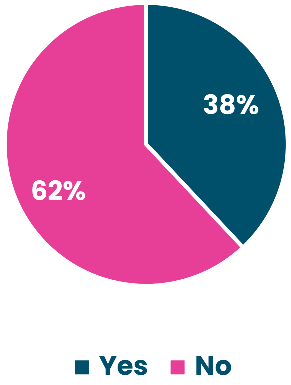
These figures were much higher for those who accessed an assessment via the NHS, with over a quarter (27% - 27) waiting over three years and 43% (43) waiting between one to three years. Only 17% (17) who received a diagnosis via the NHS waited less than six months. As such, long waiting lists for an assessment were a key challenge in accessing support.



> *“I got it through Right to Choose, because [the NHS] lost my referral for about a year. Then they realised what they'd done and I then went to another waiting list, but they did say, ‘If you want, we can put you on the Right to Choose.’ … Once it went to the Right to Choose people, I reckon it was about 5-6 months start to finish.”*

Linked to this, the cost of private assessments was often a barrier in receiving timely support. More than a third (38% - 49) said this was the case, with many referring to the cost of receiving assessments and reports.

Has the process of getting a diagnosis and post-diagnostic support created financial pressures?



> *“NHS refused to assess me, so I paid to be assessed privately - it cost a lot of money which I had to borrow.”*
>
> *“The NHS waitlist at the time - I was originally referred through my GP - was 3 years. I therefore went privately and put the cost on a credit card. As this accrues interest, this has increased my debts/outgoings each month at the same time as [the] cost of living crisis, and an increase in mortgage rates/rent.”*
>
> *“As the NHS wait for diagnosis was quoted as 18 months, I had to go for diagnosis privately. This cost £1,400, which was very expensive for me.”*

For one respondent, the time it took to afford their private assessment also caused delays.

> *“It [wasn’t quick because] it’s b****y expensive. I saved up for it and I used a company … and I think it was like £2,200 or £2,300.”*

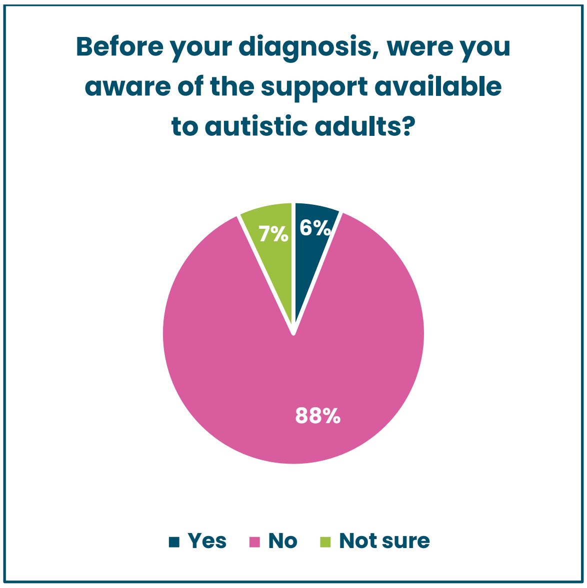
Respondents called for timely referrals and requests for autism diagnoses to be taken seriously by professionals. Improving the continuity of care from presenting to a professional to receiving a diagnosis would help ensure autistic adults can access the right support.

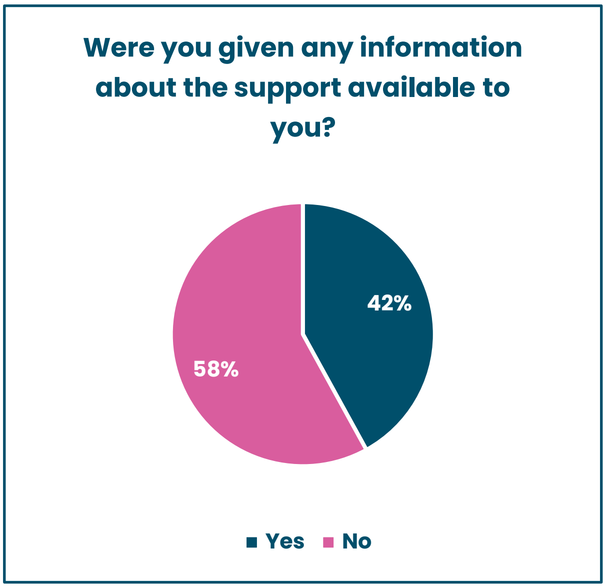
> *“It is therefore important that diagnoses are made earlier, as the diagnosis is the lynchpin behind receiving support and the information that is needed to ensure dignity and sanctity of life, as well as a fulfilling life.”*
>
> *“There is very little support or information for autistic adults, especially those diagnosed as adults. If you didn't have a school care plan then there are some services who won't support you, which is another reason why early diagnosis is so important.”*

6.2 Over 50% were not given any information during or after their diagnosis

More than half of all respondents were not signposted to any support services following their diagnosis. Most respondents also had no awareness of the support available to them, despite the majority wanting help to understand and navigate their diagnosis.

More than 8 in 10 respondents (88% - 112) were not aware of the support that should be made available to autistic adults. Although over 40% (42% - 54) were given information about support, over 50% (58% - 74) were not given any information. Throughout the engagement we found a clear demand for information and signposting to support. However, there is a systemic gap in providing timely, useful and accessible information about the support available to all autistic adults.





"It's hard trying to find help and if you do the waiting lists are so long."

"Nothing available or readily shared, I don't know where to turn."

"Accessing support and information as an autistic adult has felt like navigating a maze with no map. There is no central, accessible, neurodivergent-friendly source of information. It shouldn't be this difficult."

Respondents with lower support needs also noted there was limited support available, especially when compared to those diagnosed in childhood or those with higher support needs. Masking[13] can also contribute to later diagnoses and reduced access to support, as the needs of people who mask are often misunderstood or overlooked.

"There are very few resources for autistic adults that can live independently. We are expected to accommodate the neurotypical world instead of the other way round."

"The challenges and the - if you like - the characteristics that he (person with autism) has are hidden, so people make assumptions about his ability to function in different areas of his life, and then they are either surprised or upset or disappointed because he can't meet their expectations."

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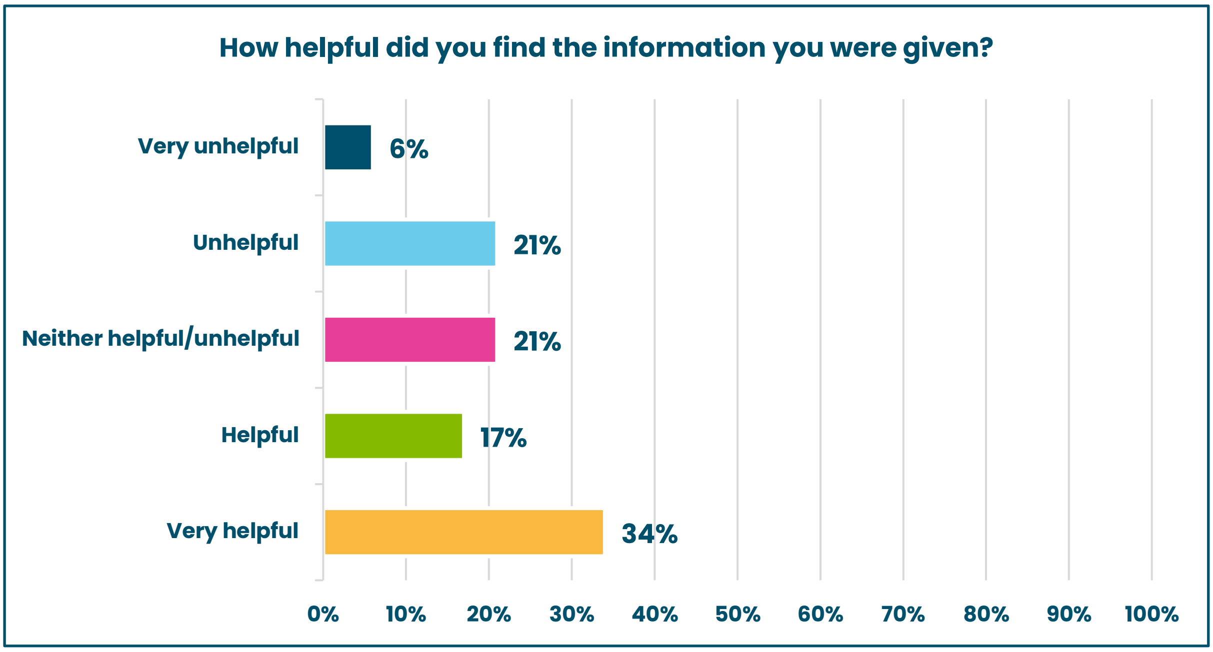
[13] Masking when you're autistic | Autism Space | Leicestershire Partnership NHS Trust

For those who did receive information during or after their diagnosis, common examples that were helpful included: signposting to mental health support (including therapy and coaching), support groups and local charities, and providing leaflets, website links, and book recommendations. Autism Hertfordshire was a key support service respondents were signposted to.

"My private assessment booklet gave a range of information and signposted to some local organisations."

"A detailed resource pack including various links and signposting, access to four webinars, information for family and friends, information re: workplace adjustments."

Positively, 51% (22) of those who were given information during or after their diagnosis found this to be helpful or very helpful. This suggests that there are positive outcomes for autistic adults who are made aware of support services and information at an early stage.



However, over a quarter (27% - 13) of those who received information during or after their diagnosis found it to be unhelpful or very unhelpful, while 21% (10) described it as neither helpful nor unhelpful.

Some respondents tried to contact the providers they were signposted to but received no response. Others said that website links they were given did not work, services were full, or the information was not suitable for their needs.

Much of the support available was online, and some were unable to access the internet to search for information. Many respondents felt the support offered was impersonal and difficult to access, leaving them without clear or meaningful next steps and often having to navigate services on their own.

"[I walked] out of the diagnosis... with some links that [didn't] work [and] websites that [said], 'No, we're not taking on any more people.'"

“Leaflets and signposting. But it was not personalised and was a standard pack which was not very caring, and I did not have the energy to go through it all.”

“I was given information on the National Autistic Society. I sent an email to them but received no reply. I also informed the NHS Mental Health Team, but again I received no reply. There has been no support.”

“I think I had one page printed off, with links to the National Autistic Society, but little else. It felt more like "Here's your diagnosis, good luck!"

Andrew’s* Story

Age at time of diagnosis: 44

Andrew described receiving his private autism diagnosis as a “bombshell,” expressing frustration that it wasn’t identified earlier despite lifelong struggles with mental health and identity. With no prior awareness of autism and no follow-up from his GP, he found the lack of post-diagnostic support frustrating. Private coaching and therapy helped him to understand his needs.

Andrew called for clearer information and working website links, tailored one-to-one support for autistic adults with lower support needs, and proactive communication from GP practices.

Processing the Diagnosis

“When you first get diagnosed, you’re like, 'Oh wow! That makes a lot of sense, I can really see it.' And you start going on Instagram and you start researching it, dealing with it, and then I found [my therapist], and you go through that initial euphoric moment of, 'Wow the world makes sense! I finally understand myself!' And then you go through that anger, where you’re like, ‘Oh my god, I could’ve done so much better in my life if I was given the tools to deal with this,’ and if I… understood overstimulation and knew what I needed. So, there was obviously that angry phase, and then eventually acceptance."

Navigating Support

“When I was diagnosed, I was sent this full report… and at the end there were links to places in Hertfordshire. One said they weren’t taking any more referrals, another was the same, and one was just a ‘Page not found.’”

“I’ve been pootling along in life, sort of struggling, and then I get this bombshell news… And nothing, not even like a letter [from the GP], ‘We just found out, do you want to come in? Is there anything you need?’ Nothing. I mean that’s horrendous.”

“I think if you [have higher support needs] then the support’s there for you, but you know, for someone who’s quite high-functioning and you know - I’ve been masking all my life and been hiding it well – there’s nothing.”

Accessing Private Support

“I found this wonderful woman – she’s like a coach and charges £35 for an hour. After the first session, I was driving home thinking, ‘Why am I not exhausted? I feel alright.’ It’s just little things like not being forced to make eye contact. That made a huge difference.”

Suggested Improvements

“It would’ve been nice to walk out of the diagnosis… [with] a package of information of what’s available… [And] even if there was just one session after diagnosis that you didn’t have to pay for – just to talk through what it means. And ask the right questions… Just spell it out. Be blunt. Lose the frills.”

“It would’ve been nice for the doctors’ surgery to bother to contact me and just say, ‘Right you’re autistic. This is what’s available to you.’”

**Please note a pseudonym has been used to protect their identity.*

When respondents were asked what information they would have liked to receive, over 22% (39) wanted information on accessing mental health support. This was followed by employment support at 21% (37), financial support at 16% (29) and generic information and signposting at 11% (19). Some mentioned increasing the awareness of support available overall. A smaller number of respondents also wanted information about peer groups, local charities and services, social care, education support, and reasonable adjustments.

"Support coming to terms with the diagnosis. Information on how you can be helped at work and what adjustments can be made. Information and support with any benefits etc. that [I] could be entitled [to]."

"More mental health and employment support. As well as benefit entitlements and ways to cope following a diagnosis."

"I was so lucky to find Autism Hertfordshire and then be signposted to other sources of support. But none of it is advertised or recommended."

"I would have benefitted from being made aware of what I'm able to access and the support available. It would have been good to know about Autism Hertfordshire. They have been so helpful but took a while to find as I didn't know they existed."

In terms of improvements, respondents wanted services to provide information packs and a centralised online directory of the support available to them. A few also called for information to be personalised, tailored, and delivered in a one-to-one setting by someone who understands autism. They also emphasised the need for alternative formats to ensure those who struggle to use the internet are still able to access support. However, a large number of respondents were not given any information, and their core recommendation was for services to ensure they provide autistic adults with information and signposting.

"[I] had to do a lot of searching."

"I would have liked someone to sit [with] me from the beginning and say that this is how it is and this is the way forward and here are your tools and assistance in case you need help."

"The information needs to be tailored through one-to-one support with professionals who have an understanding of what it is like to live as an autistic person."

"Links are all very well, but autistic people can't access the websites without support. Should be more face-to-face. Hand them with the relevant leaflets and talk to them."

Likewise, carers emphasised the need for clearer information on how to access adult social care and support for families and loved ones. One respondent highlighted the genetic link of autism within families. This further emphasises the importance of ensuring appropriate support is available for family members who may themselves be autistic or have other neurodivergent conditions.

“An explanation of how to get assessment through the ASC [Adult Social Care] team. I have several aborted attempts at finding anyone in the council who could advise us. I eventually did with much persistence, but it was extremely frustrating and stressful.”

“Support for family members. They live with it and don't know how to deal with it in a way that is helpful.”

“Where to go to ask questions… the questions come for days/weeks/months after the diagnosis.”

“The likelihood is there is going to be a connection within that family, so they will probably be caring for children who are as well. So they're not going to have loads of time to go and sort themselves out… I’ll spend so much time supporting my children that I’ve always kind of put myself on the back burner. It took me a long time to get my diagnosis, even though I had suspicions for a long time.”

6.3 Respondents often struggled to navigate the support available to them

Respondents reported difficulties understanding where to go or how to access help. Services were often described as unclear and uncoordinated, leaving family and loved ones in charge of finding appropriate services.

Many respondents described significant difficulties in navigating support services after receiving their autism diagnosis. The help available was often perceived as limited, unclear, or inaccessible, leading to feelings of confusion, anxiety, and being overwhelmed. Several individuals expressed frustration at being left to manage their needs alone without adequate guidance or follow-up. This lack of structured support contributed to stress, uncertainty, and in some cases, a decline in mental health.

> ***"It is hard being left to your own devices once you get a piece of life changing information and not knowing where to go for support."***
>
> ***"I was given and offered nothing and had to try and navigate possible help and support myself which was a struggle and added to my mental health issues."***
>
> ***"It's like, 'Congratulations, you've got autism. See ya!' Well, you know, well what the f***'s autism, though?"***
>
> ***"So often my needs have been overlooked or dismissed and things have been unfair or unsatisfactory as I'm poor at advocating for myself. I don't feel any better placed to navigate these things since being diagnosed. I constantly feel like I can't cope, and struggle to know what support I am eligible for unless it is very clear."***

Due to a lack of clear pathways or follow-up after diagnosis, some respondents reported having to source support independently or relying on friends and family members. This often involved online research, trial and error, or advocacy from loved ones.

Several described the process as overwhelming, confusing, and unsustainable — particularly for those already experiencing burnout, mental health challenges, or reduced executive functioning[14]. These experiences highlight the importance of timely support, and the vital role signposting can play in guiding people to the right support services.

> ***"None of this was offered to me, my mum fought to get all the support I had."***
>
> ***"Yes, I faced significant and ongoing challenges in accessing support. Nothing was clearly signposted. I had to find almost everything myself through online research, social media, or word of mouth. There was no joined-up pathway, no follow-up after diagnosis, and no one to guide me through what support was available."***
>
> ***"I had to find and coordinate everything myself - often when I was already overwhelmed, burnt out, or in crisis. That level of self-navigation is not sustainable or fair, especially for someone who is Autistic, has ADHD, and struggles with executive functioning and communication."***

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[14] Autism and executive functioning skills - Leicestershire Partnership NHS Trust

6.3.1 Fragmented and Inconsistent Pathways

Many respondents described current services as inadequate, pointing to a lack of integrated or consistent support pathways following diagnosis. This fragmentation and lack of coordination made it more difficult to access appropriate care, and contributed to respondents feeling abandoned or dismissed.

"I was passed from pillar to post. No one seemed to want to help me beyond a diagnosis."

"The biggest issue with the support I received was that none of it was joined-up, proactive, or easily accessible through the NHS or local services."

Several individuals reported that their GP practice and other NHS services failed to acknowledge their diagnosis or provide useful information and referrals. As a result, people were often left to chase support across disconnected systems, with little to no guidance.

"The hospital and GP, they work in complete silos and there's no real overlap."

"I've got a really detailed report… and they said, 'Oh, make an appointment with your GP and they'll point out support you.' The GP seemed really clueless. I said, 'I was told to contact you to find out what support would be available to me,' and they just didn't seem to know themselves. They directed me to a charity called ADD-vance, which I know for my children, but that's more of a young person/child charity."

"My diagnosis was sent to a GP, and they didn't contact me over it. I just have no faith and trust in the public sector."

"I had a… mental health crisis, and I went to [the NHS], and they said that my conditions were autism related, and their services will not be committing to autism. Where do I go? And they said, 'Go back to your GP.' And the GP said, 'Well, where can I send you?'"

Carers and family members frequently found themselves responsible for coordinating fragmented services, often encountering resistance or indifference from professionals. Many also expressed concerns about the long-term wellbeing of their autistic loved ones, particularly as their own health declines with age. This created anxiety about who would take over care responsibilities in the future, and whether appropriate support would even be available.

"The GP might just as well not exist… And yet, he's going to be quite crucial to [my son]'s care in the future."

"It's like a minefield really, for me and my husband. And obviously our health is degenerating as we get older."

"If I drop down dead tomorrow, what's going to happen? County's response is totally crisis reaction… I am counting down to my 80th birthday… and I may not be around much longer… and I'm thinking, 'What on Earth is going to happen to my lad… When I'm not there to advocate for him?'"

Respondents emphasised the importance of ensuring that professionals who interact with autistic individuals are knowledgeable about how autism presents in adults. This was especially highlighted in relation to women, whose traits are often misunderstood or overlooked. However, differences in how it presents across genders may be less distinct for those diagnosed later in life, highlighting the need for a more nuanced understanding.

Several participants also acknowledged the value of having neurodivergent professionals or those trained in autism involved in delivering their support.

“[My son’s] support worker… [has] her own son who's [autistic] - but she has to an extent learnt to understand [my son], and she can read him almost as well as I can and she's learnt how to manage his anxiety and to deal with the pressures that he feels by the world at large.”

“[My daughter’s] autistic coach [has] two sons who both have autism, and she was absolutely brilliant… [my daughter] would go on her own, and we would go with [my daughter]. So, we had all the different dimensions going on.”

Many called for post-diagnostic support that is tailored to individual needs and framed in a progressive and positive way, with clear guidance on how to act on the information they receive.

“Mental health and mainstream services (GP practices etc.) need to be more knowledgeable about autistic adults, especially how this presents in women. I still think the mental health support available through NHS Trusts is not adequate.”

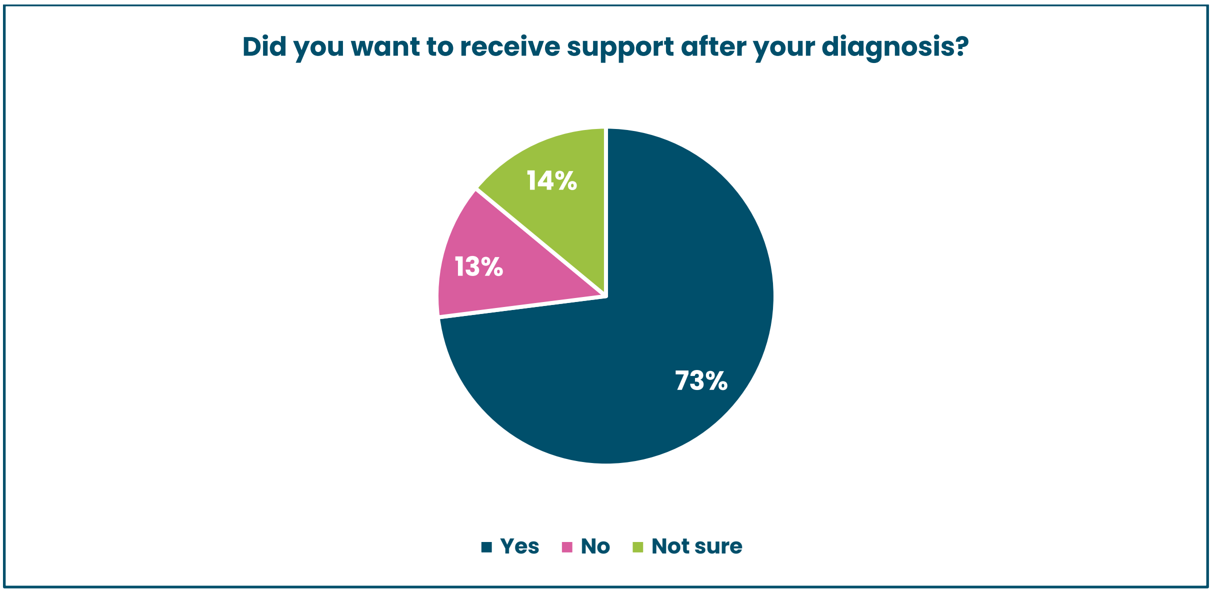
“Having access to some sort of support for post-diagnostic care to help understand my diagnosis, not just in the negative deficit way that the diagnostic criteria is written.”

“Having a proper pathway… [and] liaison between [the NHS] and social services… There is increasing awareness of autism and late diagnosis, but I just think linking things up a bit more.”

6.4 Over 70% wanted to receive support after their diagnosis, however nearly 50% did not receive any

Despite receiving a life-changing diagnosis, almost half of all respondents went without any form of support or follow-up from professionals. For others, the support they did receive was inadequate and left them feeling isolated. Many respondents already struggled with their mental health but did not receive support which took their autism into account and often worsened their mental health.

Almost three quarters (73% - 93) of respondents wanted support after their diagnosis, however, nearly half (47% - 54) did not receive any support. Respondents often noted that there was little to no follow-up after receiving their diagnosis.



"I didn't receive any support. In fact, I was told there wasn't any as an adult."

"I haven't been offered any support or additional information. Everything I have learnt I had to try and get myself."

A few respondents had reached out to their GP practice and other NHS services for support but received inadequate information or did not receive anything further.

"Shortly after my diagnosis I made an appointment with my GP to enquire about support available to me. They didn't have a clue and had to Google things during our consultation."

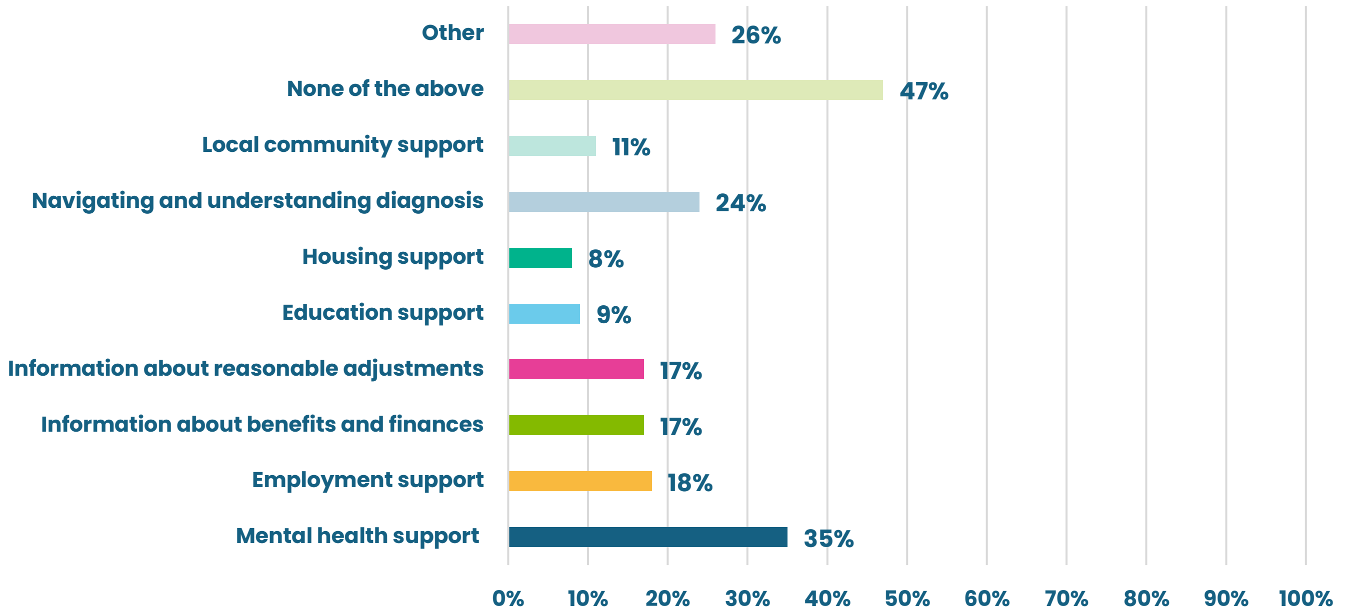
"Still trying to access NHS services for healthcare support but have been denied constantly."

Respondents highlighted an urgent need for autistic people to receive the support they are entitled to. This was especially important for those diagnosed later in life. Many had spent years facing challenges without understanding their needs or accessing appropriate help.

Several described the impact of a late diagnosis as both positive and disruptive. Without the right support, it can leave people feeling isolated and overwhelmed. This can have long-term effects on their wellbeing, work, and relationships.

> *"I feel there should be more support for adults who have already struggled through adolescence. Many of these adults have already faced challenges navigating life and social situations and are just left to get on with it once diagnosis received. More help should be offered for things such as employment and holding down jobs with suitable adjustments made."*
>
> *"Whilst my diagnosis is cathartic as I now know why I have struggled my entire life. It is disappointing to not be able to access or be made aware of any support."*
>
> *"All of a sudden I'm autistic - my marriage ended because of it… my whole life has been a massive struggle where I literally hated myself – always felt odd and different and didn't know why, and obviously the person I perceived myself as is completely different."*

Have you received any of the following support since you were diagnosed?



For those who did receive support, more than a third (35% - 41) had received mental health support, followed by support in navigating and understanding their diagnosis at 24% (28). Employment support was the third most common type of support received at 18% (21), closely followed by information about financial entitlements and reasonable adjustments at 17% (20) respectively. National and local statistics show that autistic adults are more likely to struggle with their mental health, be unemployed, and require financial support.

Other types of support mentioned by respondents included: social groups and activities, peer groups, courses, one-to-one support, therapy, medication and mentoring. Much of this support helped respondents to understand their diagnosis and what it means for them on an individual level.

> *"I have had support by and through numerous online learning course through Zoom for example. These have allowed [me] to understand my innate and go to themes, patterns and trends. They have enabled me to re-evaluate myself. I receive [one-to-one] therapy online which has done the same."*
>
> *"In person group of 6 sessions Zoom meetings for a women's group, a wellbeing group and education about autism."*

> ***“General advice and support with my diagnosis, helping me understand and accept how my autism affects my daily life. Counselling around issues I found challenging, advice on what I could do, what support I was entitled to at work etc.”***

Respondents highlighted the need for clearer, accessible information about local support services. Many only became aware of support by chance, often long after diagnosis. They also called for earlier autism diagnoses and co-occurring conditions by professionals, stressing that delays led to missed opportunities and lasting harm. Some felt that family and friends would benefit from guidance on how to provide meaningful support.

> ***“Information on all the support available and groups in my area I could attend.”***
>
> ***“I am a mum to an autistic child and only realised I was autistic after my child had been diagnosed, and I researched and fought for her... It's literally only because of that do I know of any support for autism, but I only know of support that’s given to under 16s.”***

6.4.1 Mental health support

Mental health support was the most called for type of support among respondents, however, many faced challenges in accessing this care. Respondents who received mental health support shared that it was often unsuited to their needs, and their diagnosis was not taken into consideration. Some described how they were told that services were not equipped to provide support for autistic adults, leaving many without any form of suitable support, despite the potential lifechanging effects of receiving an autism diagnosis in adulthood.

A significant number of respondents shared that they had been dealing with severe depression and/or suicidal thoughts. Sadly, many said mental health teams were often unequipped to support them, despite them being in crisis, leaving them without any help which increased the risk of harm.

> ***“I was disappointed that the adult mental health team discharged me after getting my diagnosis as they ‘weren’t equipped to help with the type of support I needed’ and they didn’t refer me to anywhere else.”***
>
> ***“I was in crisis (in my opinion) contemplating suicide, not sure what to do. I was shocked to learn that the diagnosis meant nothing as there was no support to help me.”***

This was reflected in both the qualitative and quantitative data. 67% (86) reported poor mental health before their diagnosis and 45% (58) still had poor mental health post-diagnosis. Unsurprisingly, mental health was the most sought after post-diagnostic support.

Answer choices	Good	Average	Poor
Before your diagnosis	3% (4)	30% (39)	67% (86)
Diagnosis confirmed	14% (18)	48% (62)	38% (49)
Since your diagnosis	19% (24)	37% (48)	45% (58)

6.4.1.1 Improving mental health support

As highlighted, mental health support was the most common type of support autistic adults received. However, some noted that the support offered to them was not accessible or staff were not equipped to accommodate their needs.

"I'm already a problem to them… they want to discharge me… their words were, 'We aren't a service for life,' and there is [nobody] in my local mental health service that I'm [aware] of that actually… understands autistic/ADHD adults."

"Getting mental health services to accept the diagnosis [was challenging]."

"My local NHS Talking Therapy service had no staff trained in ADHD and only a few trained in autism… Most mental health services are crisis-based or not available unless you meet a secondary care threshold, which excludes many Autistic and ADHD adults who are struggling but not 'ill enough' by medical standards."

Some respondents felt validated after their diagnosis and credited their therapist's understanding autism in helping them to feel understood and process their diagnosis. However, it is worth noting that most respondents who had positive experiences received mental health support from charities or accessed it privately, not through the NHS.

"My therapist I meet with virtually and she is a specialist in autism and trauma."

"I didn't really understand the impact autism had on my life - didn't really know what it was. So it's been a progressive journey with relation to that. Initially, I suppose I [felt] a bit too proud to admit that I was… disabled."

However, many respondents noted that the mental health support they received was not suitable for autistic adults. In some cases, respondents flagged this and were ignored, and others felt actively discriminated against. A small number of respondents noted that they were prescribed medication for conditions which, after being diagnosed, were no longer accurate. It is also worth noting that certain therapies such as CBT[15] (Cognitive Behavioural Therapy) can be unsuitable and potentially harmful to autistic people.

"Despite my suicidality being attributed to autism whilst under section two MHA, I received minimal input [or] information. The staff member who [was] meant to talk to me about it prior to my discharge didn't."

"As a young man I was diagnosed with depression and put on antidepressants and spent loads of money on counselling, when all it was autistic burnout and anxiety due to autism which could have been easily handled if not misdiagnosed."

"I had been given generic talking therapies and CBT, neither of which [have] worked. Requesting more appropriate therapy from professionals within the NHS has led me to a dead end, with no support being given and no referral."

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[15] CBT Limitations for Autism Explained

“I’ve had so much therapy that isn’t autism informed and some of it has been quite harmful over the years… makes you feel more broken.”

Sophie’s* story

Age at time of diagnosis: 34

Sophie was initially misdiagnosed with depression and anxiety at 16, then with borderline personality disorder (BPD) at 18. She faced a two-year wait for her assessment and inadequate support from Oxford House.

Sophie highlighted the need for better training and support for mental health professionals working with autistic adults. She suggested providing people with one consistent caseworker and prioritising making support services more accessible. AW emphasised the importance of addressing co-occurring needs and called for systemic changes in mental health care.

Initial Misdiagnosis and Diagnostic Delays

“I was seeing a therapist until a couple of years ago with Oxford House for BPD. I kept saying, ‘Look, I don't think this is right,’ but they wouldn't listen to me… And then it only took until, like the therapist left – just before he left, he put in the assessments, they all come back. And then, obviously, I had assessments and they came back autistic and ADHD.”

Inadequate Support

“They just don't have anyone [who can support me], and I don't think they're interested, to be honest. They're not interested in improving, and then if a complaint is made or raised, they literally use that person's abuses, disorder or whatever, against them.”

“A lot of the therapy was like ‘Your way of thinking is wrong, and you need to do this, and you needed that,’ and all this sort of stuff… So that's messed with my head a bit, so they don’t. Since I've had that diagnosis my local mental health service - I don't have a support worker currently, because I didn't get on with the last one, and I tried to complain about her, but then the manager decided to try and take over all my personal care so it didn't go out of anything. He won't see anyone else. And then he told me that after - and even my friend was there as well - trying to, like, help me get through this. And then he's trying to tell me that things weren't that way. And basically, turning around, like, turning around my autism and stuff, and making out I misunderstood, and there's a lot of gaslighting and that going on there. And they like, turn around, make it out, like, it's your fault, and any of the issues you raise is because you have a problem, and not because they're being insufficient in their job.”

“It’s always everyone else's fault… As soon as there's an issue, it's them against you, and you can't take it any further. You can't do anything with it, so nothing ever gets resolved. They keep it all in house.”

Suggested Improvements

“Reach out about it. Especially in adults that are late diagnosed because there probably is - especially a lot of women and stuff - a lot of trauma attached to it, not in the same way as it might necessarily be for neurotypical people.”

“If no one understands that or gets that sort of process, the way that we think, you're not going to come up with effective strategies and stuff, especially if you've been experiencing a lot of this and didn’t know what it was like.”

**Please note a pseudonym has been used to protect their identity.*

Almost a quarter (22% - 39) of respondents wanted to be made aware of the mental health support available to them. Others specified that they wanted help navigating their emotions with a professional who could help them to understand how autism affects them.

"Since I was late diagnosed at age 33 and was previously in mental health services both children and adults, I really needs mental health support as this new perspective on my life and how I function changed everything. All the last therapy was incorrect and should really have been re looked into [so] that I could [mentally] function properly, move on [and] adapt with appropriate coping techniques to address my CPTSD."

"Someone who was suicidal and dumped on antidepressants, mental health support after ASD diagnosis would have been good to help understand what is 'normal' for an autistic person to feel."

"I really need mental health support as this new perspective on my life and how I function changed everything."

6.4.2 Employment support

Employment support was the third most common type of support respondents accessed by autistic adults (21%). This often included information about requesting reasonable adjustments at work.

"I got some booklets about safety at work and one about bullying. But reasonable adjustment seems to mean different things to members of management."

"Diagnosis was useful for training team in NHS… my employer."

"I also have an employment referral service, and there's someone who tries to get me a job… They did my CV [and] the template they did for me, which included a photograph I thought, was quite good."

Some respondents received support from Access to Work[16] which enabled them to get the right equipment and support to help them perform at work. Other respondents noted that their employer was unaware of Access to Work and they had to help them to navigate the process.

"Autism Herts and Exceptional Individuals helped me with my Access to Work claim - without them I wouldn't have even known this was available, and even when I knew it was, I didn't know what I could ask for. Complex Needs helped me with admin and with setting up a longer-term PA/support worker."

"Access to Work and other schemes were confusing and admin-heavy, which made them difficult to navigate without help—especially when I was already overwhelmed. I am currently going through a reconsideration as they have not supported me with what I actually need, even though the workplace assessment advised it. This is an increase in my stress levels."

"[ProblemShared] also spoke about reasonable adjustments in the workplace and Access to Work, and that was the first time that I had heard about that, so that was helpful."

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[16] Access to Work: get support if you have a disability or health condition: What Access to Work is - GOV.UK

Due to the lack of awareness of what support is available to autistic adults, some respondents felt unsure about what could constitute a reasonable adjustment and what support they would be entitled to receiving.

"I don't know what reasonable adjustments I would need."

"So for example, in an interview, if I was to say, 'Oh, please can I have the questions ahead of time, because my processing isn't as good as maybe somebody that's not autistic,' would that be seen as a reasonable adjustment, or would that be seen as an unfair disadvantage to the other person?"

"At the minute we hotspot – I would like to suggest that I have my own desk, because then people aren't touching my stuff, it's really familiar to me… But you know, do we have the budget for that? Is that a reasonable adjustment or is that me being picky? It's really hard to know."

Linda* and Jake's* Story

Linda* cares for her 40-year-old autistic son Jake*, who faced workplace discrimination when seeking reasonable adjustments. She escalated her concerns to her MP, who pointed out discrepancies between policy and practice, and praised Jake's Access to Work coach for their understanding of autism.

She called for PA-style support workers for autistic adults with lower support needs who can provide tailored support with daily tasks.

Workplace Discrimination and Access to Work

"I went down to the local [supermarket] and I said, 'My son wants a job, and he cannot apply online.' … [Jake] declared his medical conditions; he wrote a few little notes… about what he needs in the workplace. The coach… just didn't understand about [his] autism… nobody realised about the reasonable adjustments… and [the coach] wasn't telling them. [Jake] said to the line manager, 'I'd like to be trained on the tills.' The line manager said, 'No… because of your disabilities,' but the coach said nothing. And Jake fortunately said, 'Yeah, but I worked on the tills… at [another supermarket],' so he was trained on those as well."

"So he was off sick… and they kept doing disciplinary meetings. Well, that word 'disciplinary' for Jake meant he was being punished for his medical conditions… We kept referring back to the Occupational Health report… but the manager's attitude was 'Nothing to do with his autism… I've made reasonable adjustments for him.' They were forgetting that his autistic characteristics are protected in law. The Occupational Health report [suggested a referral] to Access to Work… [who] offered to fund workplace strategy coaching done on Teams in Jake's own time… [The manager] wouldn't listen when he said it was funded by DWP."

"He was off sick [again]… and there was a meeting where they dismissed him with notice. He appealed on advice of the Union Rep, and we had an appeal hearing… [and] he was reinstated. He's gone back. The attitude has changed… [the manager] must have been told, because it came so close to tribunal, and no big employer wants to go to tribunal… I had been in touch with my MP, and he was going to intervene and ask [them] to reinstate him if he got the sack."

"We struck gold with the Access to Work coach: a chartered psychologist, an expert witness, and her daughter is autistic. Jake now has very useful notes on how to support him at work. It was agreed at the appeal hearing he should be referred to Occupational Health again, and I said I want a focus on his neurodiversity, not just his medical condition, because those notes will form part of the reasonable adjustments to support him."

Suggested Improvements

"I believe if you tick the box to say you've got a disability… you should be able to say you've got a neurodiversity disability, and that should flag up that this person needs a different route into applying."

"People on the autistic spectrum who are capable, who are articulate… they need light touch, intelligent and intuitive carers or support workers… They need more of a PA - a secretary who can just look after their daily diary and look after their medications and make sure they're in stock, to make sure they're not overdrawing at the bank."

**Please note pseudonyms have been used to protect their identities.*

Some respondents described the process of looking for, securing, and maintaining employment overwhelming. This suggests that some autistic adults may require support to manage the demands of working, particularly those who are demand avoidant[17]. Others felt elements of their job are inaccessible to them due to their needs. However, employment support often lacks integration, and it can be unclear how to access it.

> ***"Finding employment in my local area as an autistic adult is very challenging."***
>
> ***"Before I had my diagnosis, I had a reasonably well paid job. Now, once I had the diagnosis, it caused all sorts of work problems. I lost my job and have much lower paid job. I consider myself underpaid, but at least I'm employed."***
>
> ***"When you leave school, you're expected to get job and do all these demanding things. I always explain it and feel like everyone else my age kind of like, grew up, but I didn't."***
>
> ***"I could be really successful in what I do, if I could walk into a room and network, but I just can't."***

Employment support was the second most common type of support respondents wanted after receiving their diagnosis (15% - 21). Many wanted support to navigate conversations about reasonable adjustments at work, their rights, and what support they may be entitled to from their employer. Others wanted help in finding and maintaining employment or changing jobs. One respondent called for employers to make changes to the recruitment process and prioritise accessibility.

> ***"How to approach your HR person at work to explain your diagnosis – understanding what reasonable adjustments could look like (bearing in mind I was so worried about causing problems for my employer [and] that I am not a good advocate for myself in those types of meetings) … contacting… Access to Work."***
>
> ***"I want to change jobs but have no idea where to start – it's too overwhelming, so I'm stuck, and the feeling of being stuck in a job I hate does nothing for the mental health!"***
>
> ***"Employers should be recruiting in a more neurodivergent-friendly way, and finding alternatives to job interviews such as practical assessments."***
>
> ***"More help should be offered for things such as employment and holding down jobs with suitable adjustments made. Also for employers being more supportive, particularly for neurodivergent people, who may not present as a person with a disability as it isn't visibly obvious - support for them may also help make them more understanding and supportive within the workplace."***

Another respondent described how autism diagnoses can play a fundamental role in enabling people to access the right support and increase the number of autistic adults in employment.

> ***"So 22% of autistic people have any form of employment, part time, voluntary or anything… So by diagnosing people… we're gonna increase the chance of them getting a voluntary job… So voluntary jobs, a part-time paid job - it may actually reduce resources that are being used that aren't effective because the diagnosis hasn't been recognised. So you may be throwing resources out there, like some***

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[17] What is PDA? - PDA Society

sort of therapy, which isn't quite working for them… [so] even if it's like quite a lot of money, if it's a one off, and it's subsidised by the government, then if later on in life they're working like I'm now working, and they're contributing to society, you know, getting less… financial support, then over time, that may alleviate the demand on the state."

6.4.3 Financial support

Additionally, many respondents stated that they were not aware of their financial entitlements after receiving their autism diagnosis. This is particularly concerning, due to the number of autistic people who are unemployed and would require financial assistance to access support. Many respondents sought support from other autistic people and the loved ones who care for them for direct support on how to access financial support.

"If I am being honest, Hertfordshire have largely been useless, most government schemes make you feel stupid and scroungy. Now we just muddle along as best we can, using other parents as a sounding board."

"My experience with trying to even apply for PIP has been a nightmare, they seemingly go out of their way to make the process as difficult as possible for people with special needs. This includes having to make numerous telephone calls, being put on the spot in said calls (I usually have my mother close by in case I get overwhelmed on the phone, I was told this wasn't allowed), having to navigate an unintuitive website followed by a huge amount of forms with confusing questions. Not to mention the government is doing everything they can to take away PIP. This is a glaringly ableist hole in an otherwise positive support network."

"Struggled to receive direct payments to pay for day care."

As a result, respondents called for more accessible information and guidance on what benefits and financial support they are entitled to, and how to access them.

"More structured and guided support around what support and benefits I am entitled to at work and elsewhere."

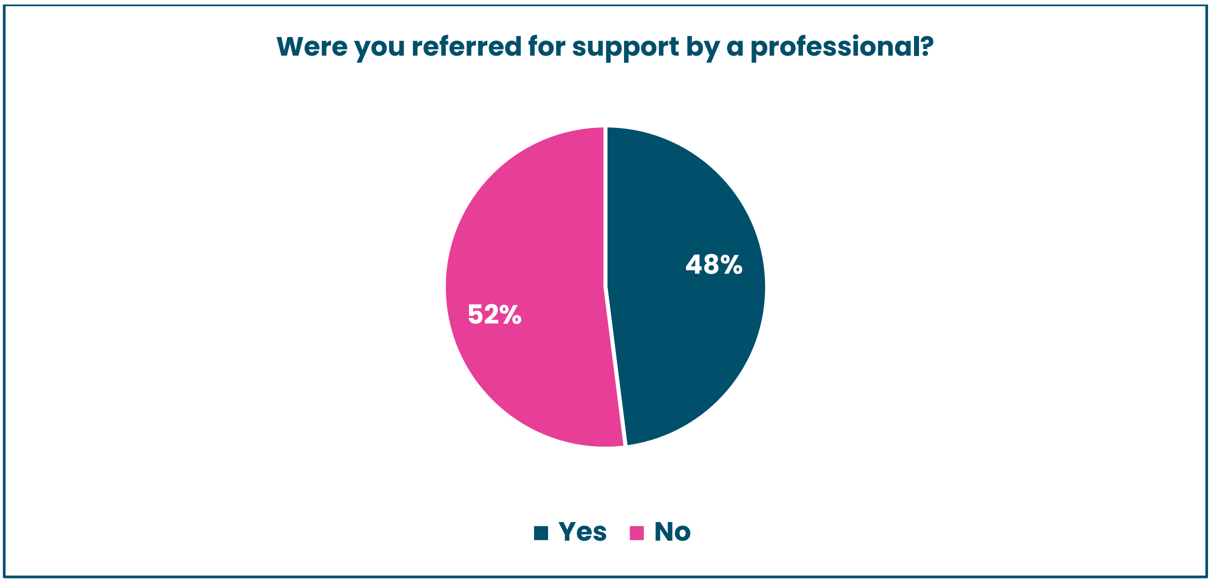
"Benefit support [and] help applying for disability payments."

"What if any benefits or additional support is available to myself with my own specific needs. Generic information can be hard to understand / relate to."

6.5 Almost 70% faced barriers in accessing support, but had positive experiences

Many respondents seeking support faced major barriers, including time constraints, long waits, and unsuitable formats. Services often did not accommodate working adults, lacked personalisation, or were inaccessible due to location, technology, or communication issues. Some also noted that support was overly child-focused, short-term, or provided by professionals without autism-specific training. Despite these challenges, most rated the support they received as good or very good.

For those who received support, 48% (26) were referred by a professional (including service providers, employers, and voluntary and community organisations) and over half (52% - 28) were not referred.


Were you referred for support by a professional?

Many respondents received support from more than one service. However, a large number of respondents accessed Autism Hertfordshire's services.

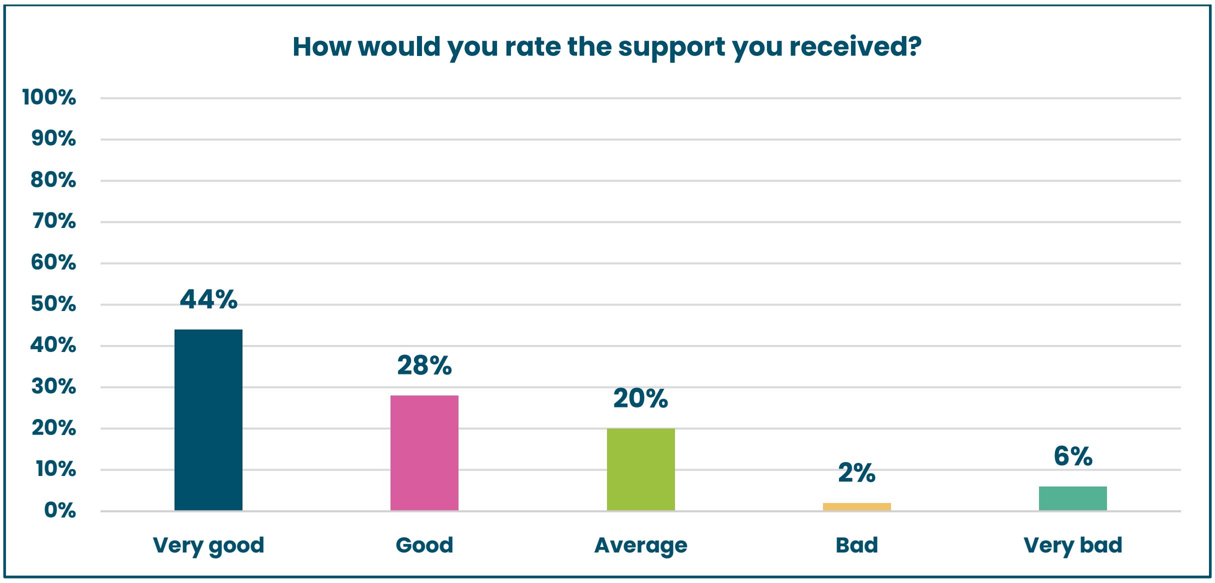
Public services accessed by respondents included: mental health services, adult social care, the Money Advice Unit and Access to Work.

Charities accessed included a mixture of national and local services, including: Guideposts, National Autistic Society, Autism Anglia, Neurodiverse Adventures, New Leaf College and Action for Neurodiversity. A few respondents also received support from the internet, social media and/or their employer.

> ***"I was diagnosed by the perinatal mental health team as I was pregnant at the time. They supported me with access to an OT and groups."***
>
> ***"I had peer to peer support with Mind."***
>
> ***"Autism Herts run practical online groups around self-development and understanding which are simple relevant and practical, as do Mind and New Leaf College."***
>
> ***"It's through the parent groups. We in Hertfordshire- one of the best resources we have is the SPACE group… [They have] experience over a whole age range."***

Positively, over 70% (72% - 22) of respondents who received support described the care they received as good or very good. Only 8% (4) said it was bad or very bad, and 20% (10) described it as average. In particular, respondents praised the support they received from Autism Hertfordshire and the range of services provided.

Respondents also tended to have positive experiences when support was delivered by autistic people or those who had direct experience caring for autistic people. A higher proportion of these individuals described feeling validated and understood. This is also reflected in the positive experiences of many respondents who accessed peer support and social groups.



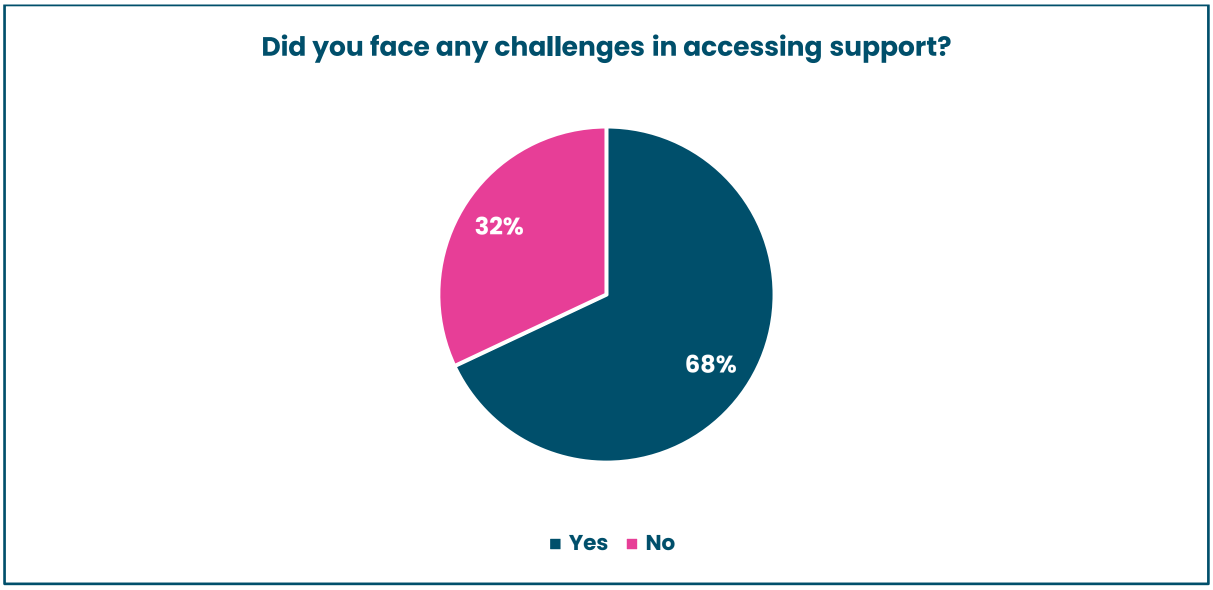
"Autism Hertfordshire has absolutely changed my life. When I first found them, I was struggling with accepting my diagnosis, felt completely alone and was housebound from agoraphobia. Now I have a job, a community and a social life all thanks to their support and care."

"The pre- and post-diagnostic support provided [by] Autism Hertfordshire has been absolutely priceless and essential. Being guided through the emotions as well as the practical side of things in terms of what support I am entitled to and what is available and how to access it."

"Carers in Herts: we used to have what they called a C4A (Carers for Autism) group... I don't think it exists anymore, but that was interesting because you get more feedback and ideas and knowledge from your peer group, your parent or your carers' peer group than you got from the authorities."

6.5.1 Barriers in receiving support

Almost 7 in 10 respondents (68% - 36) of respondents who received support faced challenges in accessing services.



Time constraints were a significant barrier that prevented respondents from accessing support. A large number said that services were only available during working hours, which meant that support was inaccessible to them.

"I joined [Autism Hertfordshire] to try and make friends, I was offered one-to-one peer support for post diagnosis but because I work 9-5 I was unable to get this support, work is a big part of my routine, so I don't like to disrupt it. It seems that support meetings and workshops are only during the hours of 9-5 so I haven't found any sort of help or support."

"It feels like most services assume that because you are autistic you are also unemployed. I work 30 hours a week which limits the support I can access as most services take place during working hours."

Other respondents mentioned that services had long waiting lists, particularly for mental health support or coaching, and turned to private care instead.

"It's hard trying to find help and if you do the waiting lists are so long."

"The waiting times are horrendously disgusting."

"I felt the information given was irrelevant because the groups were fully booked which is why I went the private route."

A large number of respondents also stated that the support available to autistic adults was not suitable. Respondents often wanted to choose whether they would receive one-to-one support and decide whether to attend in-person or online, depending on their needs and preferences. Others struggled to access services due to the location of services.

"I hate groups. Autism Hertfordshire just has loads of groups."

"Many things are done on the phone but I cannot use the phone. Also, I am selectively mute."

"Some of the courses on offer were in other parts of Hertfordshire and involved too much travel for me to get to them."

"I did contact Autism Herts, which was a terrible experience. I wanted to go along to one of their groups in the Liberty Tea Room and sought information about the setting, numbers of people, etc... and was just told to come along and see. The irony of an autism service not doing the basics right is terrible. There should be photos, a video, and written information to support people to attend an unfamiliar place."

Some also felt that support for autistic people prioritised children, causing them to feel forgotten by the system. One respondent described feeling dismissed as they were over 25 years old.

"Once an adult past the age of 25 everything melts away and you are just left to get on with it all."

"It is hard to find support as more support is for children or mental health, not neurodivergence."

"Autism Hertfordshire: I tried to contact them, because... [I] read that they have social events. But when I told them my age, they didn't really want to know. It seemed that the woman down the phone said that most of their clients were under 25."

Others were disappointed that the support they received was time limited and would have benefitted from more sessions and/or continued support.

"It's time limited and while I understand I can't go on forever, I do feel like it was a very short time to try and unwrap something to have lived with for 30+ years but only recently discovered."

"It only lasted six weeks. Not long enough."

"After my sessions with them the support stopped and I had no one to speak to."

A few respondents emphasised difficulties in completing forms to receive support, often because they either struggled with using technology or found the process challenging and overwhelming. Others had tried to access services but never received a response.

"When I applied for an introductory assessment I found the form difficult to fill in due to technology limitations."

"I faced significant and ongoing challenges in accessing support. The process [was] exhausting, lonely, and needlessly drawn out. I often felt like I had to fight for basic recognition, let alone meaningful help."

"I was referred to Autism Hertfordshire twice but never heard anything."

"I was recommended a list of support in different forms but when I tried to follow up and access it, I was told it was not available."

Some respondents felt that professionals often seemed to lack adequate training and awareness of autism. This suggests that there is a risk that autistic people may not be treated appropriately when receiving support.

“Professionals don't appear to have sufficient knowledge of what it is like to be an autistic [person], and the services are more focused on mental health rather than autism, especially for those that are high functioning.”

“Adult Social Care and GPs need to be given a lot more autism training.”

“Mental health and mainstream services (GP practices etc.) need to be more knowledgeable about autistic adults, especially how this presents in women.”

Several respondents noted that the financial pressures of seeking a diagnosis also extended to the barriers associated with accessing support. In particular, mental health support was often limited in availability which often forced respondents to pay for private treatment.

“[Had] to pay for my wellbeing... therapies, consultation charges for private psychiatrist in absence of not getting NHS psychiatrist.”

“Financial barriers also made a huge difference. The most helpful support I've had has been through private providers, but this isn't an option for everyone. Many neurodivergent adults are left with no suitable support simply because they can't afford it”

“Paying for a private diagnosis and accessing private support has cost thousands of pounds. We can’t afford diagnoses for everyone in our family who qualifies for one.”

“While I've accessed some workshops and support through Autism Herts and similar groups, I still don't feel I've ever received sufficient post diagnostic (of Autism and ADHD) support at all or mental health support through the NHS. That's ultimately why I've chosen to seek private therapy. But I also recognise that many people don't have the financial means to make that choice, and that's a serious barrier to equitable support for our community.”

As a result, respondents called for improvements across several key areas. Many felt that support was too limited in time and duration, with some requesting longer or ongoing sessions to better meet their needs. Others highlighted a lack of tailored support, noting that resources often felt generic or irrelevant, particularly for those diagnosed later in life. There was a strong call for greater choice in services and for professionals to receive better training to understand autism in adults and provide more personalised, appropriate support. This is particularly important given that the presentation of autism may differ across demographic groups, such as women and people from ethnically diverse backgrounds.

“I would have liked to be signposted to relevant services that were applicable to me. I was just given a link to the [National Autistic] Society website which I found hard to find information relevant to me as an autistic adult diagnosed much later in life.”

“Greater availability of professionals with lived experience [because that] was far more effective and relatable than anything I received through the NHS.”

“No decisions about me without me.”

Respondents also called for better autism-specific training for professionals, particularly in health and social care. They also stressed the value of having a single, informed point of contact — such as a trained support worker — to offer tailored guidance on daily life, relationships, and employment, rather than being left to navigate services alone.

“Would be nice to have a social worker/mentor to help with guidance. I feel like I burden my family with my struggles all the time.”

“I have been sent stuff in the past which is emails with lists of people to contact. Having one contact who can tell me who I need for what support face-to-face is important.”

“One of the recommendations was a therapist who was trained in autism, I think that would have really helped.”

Michelle's* story

Age at time of diagnosis: 51

Michelle was encouraged to seek a diagnosis by professionals who support her autistic sons. She found medication to be impactful as it improved her quality of life but faced challenges in obtaining a repeat prescription. She was also denied an Access Pass because it was not explicitly mentioned in her autism report, and felt her GP lacked adequate awareness of autism.

Michelle called for better training to improve autism awareness among GPs, including a holistic appointment to address the report and make referrals. She also emphasised the importance of early intervention to improve outcomes for autistic people.

Access Pass

"I've been working for 20 or 30 years up to my age with anxiety, and I've made it work. I don't get any benefits – I have never even applied… it's just been part of my life. So always my husband or someone will come with me and support me. If I've been to work, someone will come with me. So I tied to get an Access Pass… despite having this detailed 16-page report, because it doesn't specifically state that I need someone to be with me, they wouldn't issue it. If the doctor had said, "You might need this, you might need that," there was just none of that… there wasn't a lot of support at all. And I still don't feel very informed as to what is available to me."

Accessing Effective Medication

"My anxiety is horrific and because I didn't have a diagnosis, I didn't really know what it was related to. But five years ago, I had to have an MRI scan… I said, 'There's just no way I can go…' and they said, 'Ask your GP to prescribe you something.' And they… prescribed me diazepam… [which] lasted me over a year; I took it when I needed to do things I found really stressful, and it changed my life… It meant I could go on a train – I haven't got on the train for about 6 years… I haven't always even had to take the tablet, because I've had a positive experience so I can be calmer."

"Then I tried to get a repeat, and they said, 'Well, you don't really use it. You can't get a repeat.' Every time since being diagnosed I've had to fight to explain… [when] they could just read the diagnosis letter… I just wish it was [easier] rather than having to go begging, or I've had to put a formal complaint in."

Suggested Improvements

"Awareness is better than it was, but there needs to be a lot more training."

"It would be good… if the GP… read the report… [and went] through your difficulties so they can then refer you on… It would be great if it could be done as a holistic appointment at the beginning."

"As part of that follow-up GP appointment, they [could] look at medication and [monitor it]… rather than making me fight for it each time."

"I think if we could get it right with our children and have the right support in place… it would improve outcomes for autistic adults… Early intervention is key, and I think that the NHS needs to really look at… their lack of funding… They need to look at the bigger picture."

**Please note a pseudonym has been used to protect their identity.*

7 Conclusion

This research aimed to explore the views and experiences of autistic adults, their parents, and carers regarding the post-diagnostic support for autistic adults in Hertfordshire. The findings show that while many respondents gained validation from their diagnosis, most felt improvements could be made regarding the awareness and availability of support. This is particularly important for people diagnosed later in life. This also means that they may not be aware that they are entitled to support and reasonable adjustments which accommodate their needs.

It was clear that most people felt the **referral and diagnostic process** was lengthy and costly for those who choose to seek a private assessment, often due to long waiting lists. Many were also unaware that they were able to obtain a referral through Right to Choose, which can speed up the referral process. Respondents stressed the need for more timely diagnoses for other autistic people so they can gain a sense of understanding, self-acceptance, and access the support they are entitled to.

The lack of **information and signposting** respondents received following their autism diagnosis was concerning, as many were unaware of the services available to them. A large number of respondents received no support following their diagnosis. Providing a centralised directory of local services that is kept up to date would ensure people can access the support they need at a time that is convenient to them. Offering a coach or mentor to act a s a single point of contact and provide support and signposting could reduce the burden on people who may be dealing with burnout and reduced executive functioning, poor mental health, and other responsibilities.

Many respondents called for more **personalised and tailored support**, as the current support offered was often unsuitable and did not target their needs. It is clear that each autistic person has a unique set of strengths, challenges, and needs. This should be taken into account to ensure autistic people have access to the right support and can choose the support they think would benefit them. Support should also be flexible and accommodate autistic people's needs, preferences, and availability. Additionally, further targeted work is needed to better understand the needs of different demographic groups. Professionals should be trained to recognise how autism can present differently, particularly in women, to ensure a fairer and more accurate diagnostic process.

Mental health support was the most sought after type of support, and nearly half of all respondents said their mental health was poor following their autism diagnosis. Many found that mental health professionals lacked understanding or awareness of autism, and some were dismissive of their diagnosis. Training professionals to be aware of how autism presents in adults and reviewing the support available on the NHS to prioritise accommodating autistic people would ensure that they are able to receive the support they need.

Many respondents wanted to receive **employment support**, which included help with navigating conversations with their employers about securing support and reasonable adjustments. Autistic adults should be made aware of their legal rights and entitlements, Access to Work, and given information about how to access a coach or mentor to support them in advocating for their needs at work.

There was a lack of awareness of the **financial support** autistic adults were entitled to following their diagnosis. Autistic adults should be made aware of their financial entitlements at the point of diagnosis and supported in navigating forms and completing paperwork if required.

A large number of respondents stated services were **not joined up**. This made it overwhelming for many newly diagnosed autistic people to navigate the system and access the support they needed. Providers and services involved in an individual's care should update their records to reflect an autism diagnosis, fast-track referrals for other conditions if needed, and review any existing medications and support in place to ensure they are appropriate.