healthwatch
Gateshead

Autism & ADHD (Attention Deficit Hyperactivity Disorder) Support in Gateshead

Exploring Experiences of Post-Diagnostic Support for Autism and ADHD in Adults Aged 18-24 and Over 50 living in Gateshead.

About Healthwatch Gateshead

Healthwatch Gateshead is one of 153 local Healthwatch organisations established throughout England on 1 April 2013 under the provisions of the Health and Social Care Act, 2012.

Healthwatch Gateshead is an independent not-for-profit organisation. We are the local champion for everyone using health and social care services in the borough.

- We help people find out about local health and social care services.

- We listen to what people think of services and feed that back to those planning and running services, and the government, to help them understand what people want.

We help children, young people, and adults to have a say about social care and health services in Gateshead. This includes every part of the community, including people who sometimes struggle to be heard. We work to make sure that those who plan and run social care and health services listen to the people using their services and use this information to make services better.

Healthwatch Gateshead is delivered by Tell Us North CIC (company no. 10394966)

Healthwatch Gateshead would like to thank everyone who generously gave their time and expertise to assist with this report.

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Publication date: May 2026

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Executive Summary

In Gateshead, partners have told us that there are gaps in post-diagnostic support for autistic individuals and those with Attention Deficit Hyperactivity Disorder (ADHD) which are creating barriers to health and social care, and wider wellbeing. Conversations with partners also highlighted that the expectations of a diagnosis unlocking services are rarely met and practical support is often limited.

For young adults, support often drops sharply after the age of 18 or 21, creating a "potential service cliff", leaving people feeling isolated and "left to it" with a poor transition into adulthood. Those aged 50 and over who receive a diagnosis later in life often experience limited access to age-appropriate support and follow-up care. Across all age groups, there is inconsistent access to medication, shared care agreements and psychoeducation creating ongoing barriers to effective support. Short term funding and budget cuts to health organisations and statutory bodies also leads to inconsistent and unsustainable support to those who need it.[2]

This research set out to understand the lived experiences of post-diagnostic support for adults aged 18-24 and those aged 50 and over in Gateshead who have received a diagnosis of autism and/or ADHD. Healthwatch Gateshead's aim was to explore what support individuals received following diagnosis, what barriers they encountered and what improvements they believe are needed to strengthen services locally.

Data was collected over a fourteen-week period through online and in-person surveys, using a mixed-methods approach of numbers (statistics – e.g. percentages) and people's lived experiences (themes – e.g. Workplace support) to present the findings. In total, 33 responses were received, 14 from those aged 18-24 years old and 19 from those aged 50 years old and over.

Overall, the findings demonstrate that diagnosis alone does not lead to consistent or meaningful post-diagnostic support. While some younger adults reported receiving support through education or employment settings, this was often short-term and disrupted by poor transition planning. Most respondents aged 50 and over reported receiving little or no formal support after diagnosis.

Across both age groups, barriers included dismissive responses from GPs, lack of appropriate information and signposting, hard to access support opportunities and inconsistent medication or shared care pathways. Shared care agreements are formal agreements between specialist services, for example psychiatry or neurodevelopmental teams, and a person's GP. Supportive relationships with understanding managers, colleagues, clinicians and peer networks were frequently identified as the most helpful sources of support, often compensating for gaps in statutory and healthcare provision.

In response to these findings, Healthwatch Gateshead recommends that local partners establish a clear and consistent post-diagnostic support pathway, ensure psychoeducation is routinely offered, develop a single point of access to improve visibility of available support, strengthen transition planning for young adults, improve awareness among GP's, frontline professionals and employers, and increase transparency in medication or shared care agreements. Healthwatch Gateshead however do acknowledge that this evidence base consists of only 33 responses and specifically two age groups in which the findings may not fully represent the experiences of autistic and ADHD adults in other age groups.

In summary, it is evident that there is limited accessible, coordinated post-diagnostic support for autistic adults and adults with ADHD in Gateshead in these age groups. A system-wide, collaborative approach is required to ensure that diagnosis marks the beginning of sustained and meaningful support journey rather than an end point.

Introduction

This project has been supported by the involvement of several local partners and stakeholders, which are listed in the Acknowledgements section at the end of the report. Healthwatch Gateshead held discussions with these partners to produce a scoping document to better understand the current landscape around post-diagnostic support for those diagnosed as autistic and/or with ADHD across Gateshead.

Healthwatch Gateshead gathered information for the introduction section during the early scoping stages for the project before commencing with engagement and collecting any feedback from participants.

For the context of this report, the NHS definitions of Autism and ADHD (Attention Deficit Hyperactivity Disorder) have been included for information:

> **Autism:** "A lifelong developmental condition that affects how a person communicates, interacts and processes information.
>
> **ADHD (Attention Deficit Hyperactivity Disorder):** "A condition that affects people's behaviour, characterized by a brain that works differently to most people"
>
> Throughout this report, we use terms such as "individuals diagnosed as autistic and/or with ADHD" along with "people with autism and/or ADHD" when referring to those who have received a diagnosis. These terms are used interchangeably throughout the report to acknowledge that there are language preferences, maintain clarity along with being context dependent.

Data from the Gateshead Joint Strategic Needs Assessment (JSNA) estimates that there are over 1,200 working age adults and nearly 350 people of retirement age are diagnosed as autistic. This number is expected to grow, with the population of older autistic adults projected to increase by almost a third by 2030. Additionally, more than 300 children and young people in Gateshead have a diagnosis of autism. [1]

At Gateshead Jobcentre, many service users, particularly aged 18–24, report diagnoses of autism or ADHD, often attending with family members. Following conversations with partners us that a key challenge is the lack of post-diagnosis employment support, alongside wider issues such as families struggling to understand the diagnosis or where to access help. While organisations like the North East Autism Society provide one-to-one support at the Jobcentre, this is usually only temporarily funded. Many service users say they also feel anxious about approaching GPs, especially for 'fit for work' notes, as they often feel dismissed or encounter a lack of awareness of neurodiverse needs among healthcare professionals.

Partners also told us that many families and individuals approach diagnosis with the expectation that it will act as a “key to the door,” unlocking access to a wide range of services and support. In reality, this is not the case. While a diagnosis does allow individuals to request reasonable adjustments at work and healthcare settings, it can also provide them with the validation they have long sought, but it does not necessarily lead to wider practical support post diagnosis. Despite the stress of managing these issues, individuals often feel isolated once a diagnosis has been made, describing it as being “left to it” without meaningful follow-up.

Waiting times to receive a diagnosis also remain a significant challenge, with adults facing much longer waits than children. Increasingly, people are seeking diagnoses later in life, often in their 50s, prompted by recognising similar traits in younger family members. Discussions with partners again highlighted another concern which is that those who pursue private diagnoses may later find themselves unable to access NHS treatment or follow-up care.

Through conversations again with local partners, it was highlighted that following diagnosis, individuals often look first to medication, and later to mental health support, to help them manage their condition. The “Right to

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[1] Gateshead Joint Strategic Needs Assessment (JSNA) (2018) Available here

Choose" pathway, including options through organisations such as ADHD UK, has improved accessibility to some extent for diagnosis, but the process remains complicated. Titration services, essential for adjusting and finding the right balance of medication, are lengthy and require consistent support, which is not always available. Those with lived experience of ADHD in particular, felt as if the NHS were not spending the correct amount of time to get people on the correct medication.

Shared care agreements are formal arrangements between specialist services, such as psychiatry or neurodevelopmental teams, and a person's GP. They outline how ongoing care, particularly the prescribing and monitoring of medication will be managed after a diagnosis. However, these agreements are not applied consistently across GP practices. Through one of our discussions with partners It was raised that in many cases, whether a GP takes on prescribing responsibilities depends on individual choice: some GPs are willing to participate, while others are not. This inconsistency can leave patients without reliable or equal access to the support they need.

Discussions with partners highlighted a major gap is the lack of psychoeducation following diagnosis. This type of guidance, helping individuals and families understand the condition, process their experiences, and connect with peers. It plays an essential role in building confidence and reducing harmful behaviours such as masking. Without psychoeducation, families struggle to manage, and individuals are left without the tools to better understand themselves. In Gateshead, organisations such as Daisy Chain, divergence and Tyneside Mind and help to fill these gaps through peer and multi-agency support, but these provisions are limited and reflect constraints in the availability of ongoing, structured support within the system.

Services for people diagnosed as autistic or with ADHD decline sharply after the age 18 or 21 years old, creating a potential "service cliff" with limited transition planning into adulthood [2]. Adults face a lack of essential support and inconsistent provision which is caused by short-term funding and cuts

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[2] UK Parliament (2025) Written Evidence Submission. Available here

to health and statutory bodies budgets [3]. This instability makes it difficult to build sustainable partnerships and long-term services, leaving many individuals isolated or finding gaps in support.

Evaluation of support provided is another challenge, as group work and community outreach are often judged against clinical frameworks and performance indicators that do not reflect their true impact. As a result, valuable programmes risk being undervalued or discontinued. Gaps also exist in vocational training, job support, and life skills development, which could restrict opportunities for independence and community integration. The diagnostic process itself has it's limitations, often experienced as a set of subjective judgements that fails to capture the diversity of neurodivergent characteristics. This information highlights the need to embed lived experience into service design, ensuring that support is meaningful, holistic, and responsive to the realities of those who need to access it.

This research aims to explore the lived experiences of autistic adults and adults with ADHD in Gateshead following diagnosis, with a particular focus on those aged 18-24 years old and those aged 50 years old or over. The study seeks to understand what support individuals receive after diagnosis, barriers they encounter when trying to access it, and how this has impacted on their health, wellbeing and daily lives. It also aims to identify differences in experiences between younger adults transitioning into adulthood and those diagnosed later in life.

By amplifying the voices of people with lived experience, Healthwatch Gateshead will generate evidence to inform service improvement, provide recommendations on how to strengthen post-diagnostic pathways and advocate for more accessible and sustainable support across the borough.

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[3] British Association of Social Workers (BASW) (2024) Available here

Methodology

To recruit participants for this project opportunity sampling was utilised where Healthwatch Gateshead invited anyone who was willing to take part and provide their lived experience. The only eligibility criteria was that the participant must have had an official diagnosis of Autism, ADHD or both and fit within the two age cohorts of 18-24 years old or aged 50 years old and over.

Healthwatch Gateshead designed flyers for each age group with a QR code on taking them to the online survey questions, this was then shared across our social media platforms, our website and in our newsletter. Alongside this the flyers and communications for this project were distributed through a variety of partner organisations, stakeholders and further networks to ensure survey information was distributed further to the wider public. We use this widespread approach to make potential participants aware of the survey questions and allow them to participate and provide their lived experiences and inform findings for our project.

In addition to this, our team carried out in person community outreach in various locations across the borough, providing individuals with the opportunity to complete the questions in person and with support if preferred. The team utilised their electronic tablets if participants wanted to complete the survey online directly or provided the option of a paper version of the questions. Participants were given a choice of their preferred option of how they would like to provide their feedback. This was all done in addition to our usual offer of doing engagement via telephone, sending out papers copies on request and providing the questions in alterative formats, if requested.

The team promoted this project at a variety of drop-ins across all the localities of Gateshead, networking events, open days at some Gateshead Family Hub's and at several outreach events in which Healthwatch Gateshead had a stall to promote this work.

The engagement and data collection period was undertaken in just over 14 weeks from 15th October 2025 up until 23rd January 2025. There were several internal decisions made to extend the engagement period throughout this

14-week period from the original time frame of 5 weeks. This provided a further opportunity to gather more responses from these two age groups. This extension also allowed partners and stakeholders more time to distribute the survey and questions to their networks and any peers they believed would be relevant to participate.

In total we received 33 responses to the questions, 14 from 18-24 year olds and 19 from over those aged 50 years old or over.

The data analysis used a mixed methods approach where quantitative data (statistical – e.g. percentages) and qualitative data (thematic – e.g. Workplace support) was reviewed and explored to help present the findings in this report.

- Research objectives and survey questions for both age cohorts can be found in the Appendices for an in-depth understanding of what this research investigated.

Results and Discussion

The survey questions were sorted and named into following categories for the two participant cohorts.

- About you
- Getting support
- Life after diagnosis *
- Additional feedback

**The questions in this section of the survey differ between the two age groups when asking about their experiences of life after diagnosis. The full list of questions for each cohort survey can be seen in the Appendices*

To adhere to good General Data Protection Regulation (GDPR) guidance, demographic data was not collected for this research as it was not required to address the project aims and the primary focus was on the two age groups.

Participant Diagnosis Journey and Assessment

The first set of questions gathered information around the diagnosis and assessment journey of the participants. Firstly, we asked participants from both age cohorts what is their diagnosis for.

For the 18-24 year old's group (total of 14 responses) 8 (57%) were diagnosed with Autism, 4 (29%) with ADHD and 2 did not have a clinical diagnosis (14%).

For the over 50's age group, a total of 19 responses were received which 9 (47%) were diagnosed with Autism, 9 (47%) with ADHD and 1 (6%) with both Autism and ADHD. The breakdown for the two age cohorts is depicted in the pie charts below in Figure 1 and Figure 2.

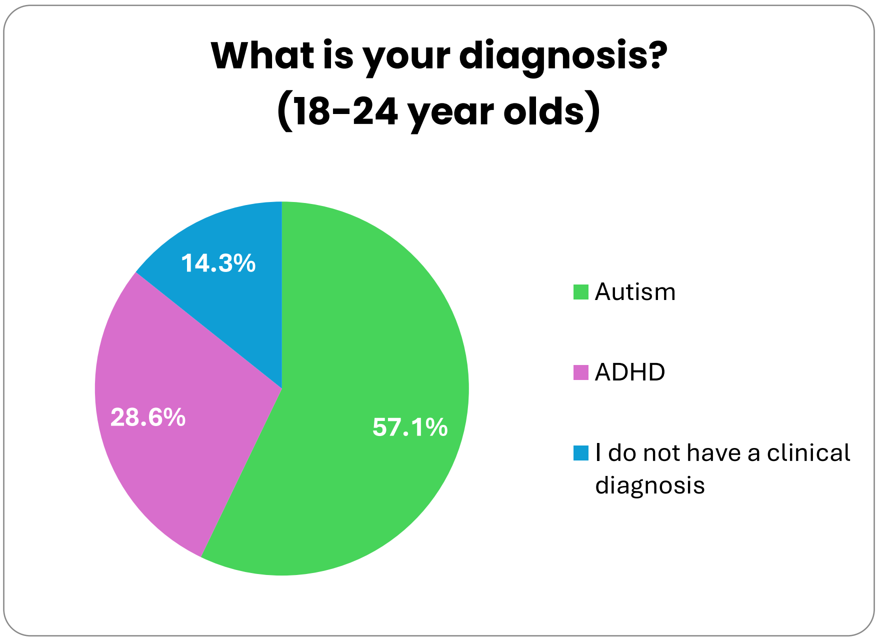

Figure 1. Pie chart demonstrating the percentage of diagnosis category between the 18-24 year old participants.

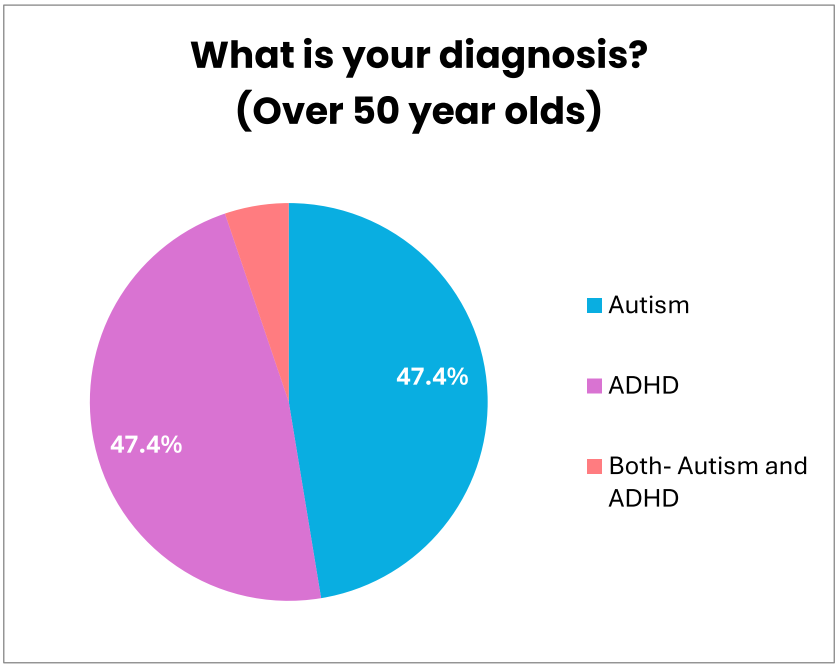

Figure 2. Pie chart demonstrating the percentage of diagnosis category between the over 50's participants.

Respondents were then asked how long they have had a diagnosis for. In the 18-24 years old age group, four respondents (29%) said they had a diagnosis between one to three years, three (21%) stated between four to seven years and two (14%) had a diagnosis for eight years or more. Five respondents (36%) in this age group did not answer the question.

For the participants who were over 50 years old, seven respondents (37%) had been diagnosed for less than a year, three (16%) between one to four years, six (31%) between five to eight years and the remaining 3 participants (16%) had been diagnosed for nine years or more.

The breakdown for each age cohort can be shown in Figure 3 and Figure 4:

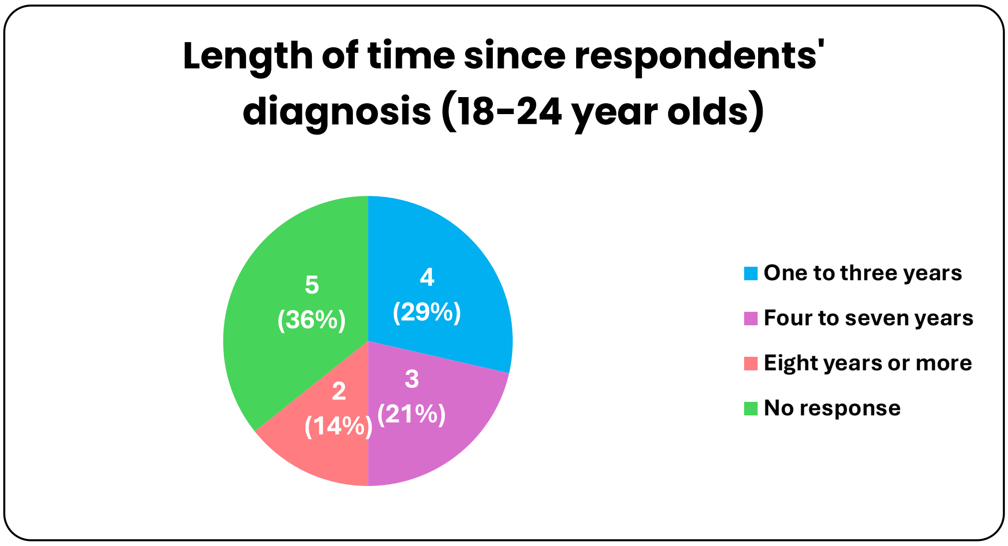

Figure 3. Pie chart showing how long respondents aged 18-24 year old have been diagnosed as Autistic or with ADHD

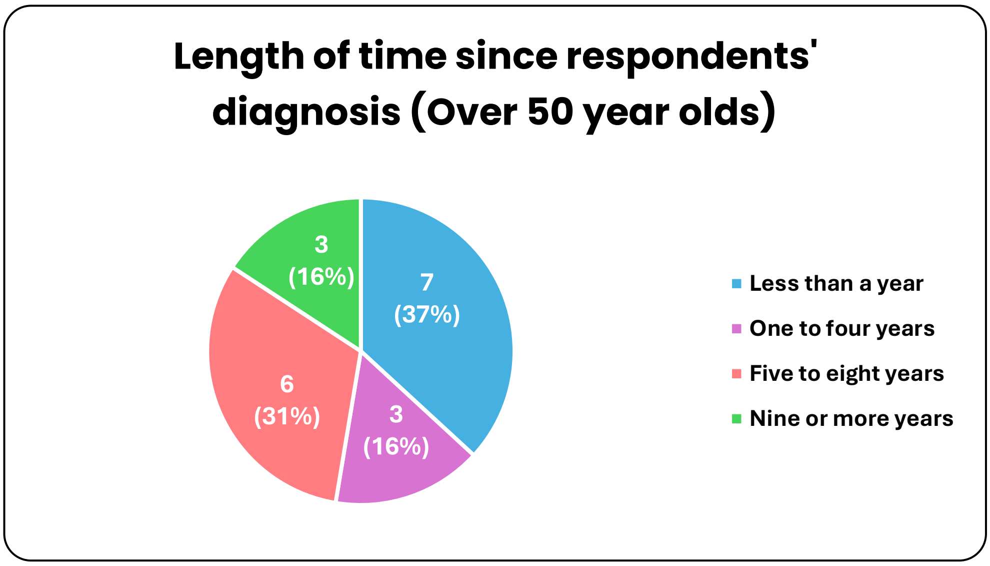

Figure 4. Pie chart showing how long respondents over 50 years old have been diagnosed with Autism or ADHD

The next questions asked participants of their experiences with the assessment process, with the first question asking how long did they wait for an assessment. The length of time spent waiting for an assessment in the 18-24 year olds age group is presented below in Table 1. From the four respondents between the ages of 18-24 years old, who waited less than a year for their assessment, one specified that they waited ten days for their assessment, whilst another mentioned they paid privately for their assessment and waited two months.

18-24 year olds	
Length of time waiting for assessment	Respondent answers
Less than a year	4
One to two years	4
Four or more years	1

Table 1. How long respondents aged 18-24 years old waited to get an assessment.

For the over 50's the breakdown for time spent waiting for their assessment can be shown in Table 2. Two respondents specified that they chose the Right to Choose (RTC) to select their preferred provider for an assessment, they both waited one year or less to receive an assessment for diagnoses.

Over 50's	
Length of time waiting for assessment	Respondent answers
Less than a year	7
One to three years	7
Four or more years	3
Unsure	1
Did not answer	1

Table 2. How long respondents aged over 50 years old waited to get an assessment.

Participants were also asked if they were receiving help to fill in this survey. For the 18-24 year olds, two (14%) said yes, seven (50%) said no and five (36%) did not answer. All respondents (100%) for the over 50's group reported that were receiving no help to fill in the survey.

Participants were then asked what made them decide to ask for an assessment, for example was it due to struggles with focus, feeling burnt out or getting advice from others. For the 18-24 year olds, the majority of the respondents reported that their difficulties were recognised by either themselves or a parent/carer as being linked to autism and/or ADHD. Table 3 displays the list of symptoms that respondents had been experiencing, leading them or their parent/carer to ask for an assessment.

Symptoms which led to assessment	Number of respondents relating to symptoms
Communications/speech issues	2
Panic Attacks	1
Sensory issues	2
Restricted diet	1
Lack of focus	2
Repetitive behaviours	1
Behavioural issues	1
Burnout	1
Emotionally overwhelmed	1
Did not specify	2

Table 3. Symptoms described by 18-24 year olds that lead them to getting an assessment.

For the over 50's, nine respondents reported recognising symptoms of autism and/or ADHD that prompted them to seek an assessment. These included feelings of burnout, difficulties with concentration, and challenges with emotional and mental wellbeing. A further four respondents said they sought an assessment after struggling to manage the demands of work and/or their personal life. Two respondents decided to ask for an assessment after completing an online screening test which recommended it, while another two were encouraged to seek assessment by professionals such as therapists or counsellors.

Participants were then asked how their diagnosis affects their life on a daily basis. The responses from the 18-24 year olds highlighted how their diagnosis affects their day to day activities in different ways. Some respondents required full support with all aspects of daily living and constant supervision to stay safe. Struggling to stay focused was also a common consequence which was highlighted by five respondents. Other effects of an autism or ADHD diagnosis included feeling burnout, struggling with emotions, mental health issues and also difficulty with relationships.

Two respondents mentioned that their diagnosis does not affect them on a day to day basis, whilst another respondent mentioned that their diagnosis helped them understand why they experience certain symptoms in the way they do.

For the over 50's participants, there was many ways in which their autism and/or ADHD diagnosis affects their day to day life. Ten respondents reported having low energy levels, nine respondents mentioned they were unable to stay focused and eight respondents said they find it difficult to socialise with people. The full breakdown of how respondents stated their diagnosis affects their life is in Table 4.

One respondent stated that their diagnosis does not affect their daily life and they find that there is a universal rejection that is the main issue, rather than the effects of their diagnosis. Three respondents did not specify how their diagnosis affects their daily life.

Ways diagnoses affect respondents	Number of respondents
Low energy levels	10
Hard to focus	9
Difficulty socialising	8
Effects on emotional health	3
Sensory overload	2
Overthinking	2
Difficulty sleeping	3
Poor organisational skills	2
Helps explain their struggle in aspects of life	2

Table 4. How receiving a diagnosis has affected respondents aged over 50 years old in their day-to-day life.

The findings relating to diagnosis, assessment and daily impact highlight the diversity of experiences across both age groups. While the 18-24 age group were more than likely to report an autism diagnosis; those over 50 showed an even split between autism and ADHD, both groups described lengthy and, in some cases, challenging assessment pathways. Many of the respondents sought assessment after prolonged periods of burnout, reduced functioning, or difficultly managing work and personal life. This was often followed on from self-recognition of symptoms or encouragement from family members, professionals, or online screening tools.

Across both age groups, diagnoses were reported to have significant impact on daily life, affecting energy levels, concentration, emotional wellbeing, social relationships and independence. While some participants described getting a diagnosis as providing clarity for long-standing difficulties, others highlighted the ongoing challenges of managing daily activities with limited support. These findings underline the sustained impact of autism and ADHD across the life course and reinforce the importance of timely assessment, clear communication, and appropriate post-diagnostic support, which will be explored further in the following sections.

Receiving Support

Following on from gathering insight into the participant's assessment and diagnosis journey, Healthwatch Gateshead wanted to know about the support they had received post diagnosis. Participants were firstly asked if they received any support after their diagnosis which could include mental health support, peer groups or psychoeducation.

For the 18-24 group, five (46%) responded with yes, six (54%) responded with no and three skipped the question. Whilst in the over 50’s group, three (16%) responded with yes and the remaining sixteen (84%) answered with no saying they received no support.

For the respondents that answered yes in both age groups, they were then asked what kind of support had they received, this included options such as medication, a support worker or employability support. Of the five respondents who were aged 18-24 years old and said they had received support, three of them explained their experiences further. Two of the respondents reported receiving support from school, with one specifying they attend a specialised school. This individual also added that they had a substantial care package through children social care services; however, they experienced a four-mouth gap in support due to a breakdown in transition planning when moving into adult services.

One respondent who is employed described receiving meaningful support after moving to a different team in their place of work, in which they were offered ADHD coaching and were able to apply for funding.

> *"I joined the Disabled Staff Network and they gave me ample support, both the chairs and the members. The person who gave me a diagnosis put me on a waiting list for medication but I would generally say my support came from the new team where there was management that cared and colleagues who understood me."*

For the three respondents who answered yes in the over 50's group, two of them said they received employability support. Whilst the other respondent mentioned several avenues of support they received such as a supportive and available clinician who was involved with their diagnosis and medication along with a supportive manager and work colleagues.

Healthwatch Gateshead then asked if respondents could name any of the organisations that provided support to them after their diagnosis. One respondent mentioned that their school supported them, whilst another named the Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust (CNTW) offered support following their diagnosis, but also added;

> *"Please note the team I was in before was also a part of CNTW and these were harmful, in my opinion, so I cannot say the organisation itself."*

The bullet points listed below were organisations and services named by two other respondents that provided them with support following their diagnosis:

- Children and Young Peoples service
- Community Learning Disability Team
- Key working Service (due to dynamic support register status)
- Paediatrician, Queen Elizabeth Hospital (Gateshead)
- Surgeon, Royal Victoria Infirmary (Newcastle)
- Community Occupational Therapist, Speech and Language Therapy, Psychiatrist, Psychologist
- Social Care, Children’s Continuing Care, Continuing Health Care
- Occupational Therapy Team at Hopewood Park

Of the nineteen total respondents aged over 50 years old, only two (11%) were able to name an organisation that supported them after their diagnosis which included; CNTW, North East Autism Society and Adult Autism Diagnostic Service.

One respondent who named CNTW and the Adult Autism Diagnostic Service named staff members who had helped them greatly since their diagnosis.

In relation to the support they had received post diagnosis, respondents were then asked what they had found to be the most helpful part of their support.

Three respondents of the 18-24 years old group answered with the following quotes:

"Children and Young Peoples Service, Intensive Behaviour Support Team (CNTW225) and Community Learning Disability Team"

"The ADHD Coaching. Gave me loads of tools to understand how to incorporate my learning style and emotions into every day work and I found what type of support I should be receiving and what support I can ask for too."

"The support from school was helpful."

Meanwhile in the over 50 years old group, one respondent said that they are content that their manager and some work colleagues are aware of their diagnosis, which helped them feel understood and supported in the workplace. Two other respondents provided the following quotes:

"I have been looked after"

"The diagnosis and feedback / information following my assessment was very quick and thorough."

Following on from being asked what support was the most helpful, Healthwatch Gateshead also wanted to know what made it hard to get support, for example was it a lack of understanding from the GP, waiting lists or cost.

Respondents aged 18-24 years old provided several different reasons as to why they had difficulties getting support and are listed in the bullet points below.

- Cost errors when jointly funded with Children's Social Care and Continuing Health Care (CHC)
- Poor communication and planning when transitioning from children to adult services
- Change and absence of social workers / CHC Case Managers
- Failure or lack of follow through (CHC) of recommendations and preferred choices.
- Failure to make necessary referrals despite reassurance it would be made (Children Gateshead Council's Social Care) - resulting in no respite being provided when transitioned into adult services
- Failure to progress referral (CHC) - resulting in reaching crisis
- Failure to make advocacy referral (CHC)
- Lack of information for treatment, process of assessment and waiting lists.
- GP being rude or dismissive

In comparison, most of the respondents (37%) in the over 50 years old group found that their GP often dismissed their symptoms or did not offer them any advice or signposting support. 32% of respondents followed on by saying they did not know where to look for information or support for their diagnosis. One respondent did mention they were offered support groups, but it was inaccessible as it was scheduled only during working hours.

Two respondents mentioned that since their diagnosis, they were only signposted to the NHS and there is no aftercare support available. A further two respondents also said that there seems to be a lack of understanding by companies in the employment sector where they can go to seek support post-diagnosis.

Finally for this section of questions, respondents from both age groups were asked what support they still require, or would they like to receive.

In the 18-24 years old age group there were several different types of support respondents shared that they require or would like to receive which included the following:

- Sessions to talk with autistic people with their family to understand more about the condition
- A suitable Continuing Health Care (CHC) Package in place that meets the needs of our loved one.
- Improved communication with CHC
- Local free activities and diversity groups that support Asian males
- Help and support to better understand ADHD and how to manage it better especially with managing emotions and communication (reported by three respondents)
- Support with adjustments that can be made in the workplace
- Mental health support specifically for those who have ADHD

One respondent did also specify that there is no support that they currently require or would like to have.

On the other hand, those aged over 50 years old mentioned some similar points to the younger age group, but also mentioned other support avenues they require or would find beneficial, these included:

- Someone to talk to about struggles and who genuinely cares
- More knowledge about their autism and/or ADHD diagnosis
- Acceptance from people who are neurotypical and not diagnosed with autism or ADHD.
- More tailored counselling
- Peer support groups
- Medication
- Coaching to manage symptoms

Alongside this, two respondents said they did not feel there was any support available to them.

Overall, these findings would suggest that post-diagnostic support for autistic individuals and those with ADHD in Gateshead is limited and inconsistently accessed across both age groups. While the younger age group of 18-24 years old were more likely to report receiving some support through education and employment, though this was often short-term and disrupted by poor transition planning. Whilst the group aged 50 years old or over reported receiving little or no formal support following a diagnosis.

Across both the age groups it was apparent that supportive relationships with work colleagues, clinicians and peers were valued, but barriers such as dismissive GP responses, lack of information and lack of services were commonly reported. Many of the respondents identified ongoing unmet needs around psychoeducation, mental health support, peer connection and workplace adjustments, highlighting that a diagnosis does not always result to adequate post-diagnostic support.

Life after diagnosis

In this section, Healthwatch Gateshead asked the respondents from both age groups about their experiences after receiving their formal diagnosis.

For the 18-24 age group, they were specifically asked "Have you felt socially included since diagnosis, or has a lack of support created challenges with friendships, community, or your independence?"

Of the nine respondents who answered this question, five (56%) said that they feel a lack of support has caused challenges with their family and also making friendships. On the contrary, two respondents expressed that since being diagnosed their friendships have improved, with one specifying that since they have started to go to a specialised school, their "social skills and friendships have improved".

The final respondent said they have not been taken seriously and feel that their emotions have been dismissed, they then followed on by saying they have not had any serious issues since their diagnosis and quoted:

> *"The more I have educated myself the more I have been better able to advocate for myself."*

Following on from that question, respondents were then asked when looking back, what do they think was missing from the support they had received after their diagnosis. Three respondents reported that there was no aftercare support at all since being diagnosed. Alongside this other responses included a lack of provision in children's packages, no community support for Asian communities and no compassion or honouring of neurodiversity differences by CNTW.

This then differed among the over 50 year olds age group as they were provided with different questions in relation to the experiences after diagnosis. Firstly, participants were asked if they felt healthcare professionals, such as GP's and specialists, understood their needs as a late diagnosed adult? 14 out of 19 (73%) respondents said that they find healthcare professionals are not understanding of their needs as a late-diagnosed adult. On the other hand, one respondent felt they were understood and another said it was more sporadic, as within the NHS some professionals do understand their needs whilst others don't. The final respondent felt that although GP's may show empathy, they do not always fully understand the needs of individuals with autism and/or ADHD, especially those diagnosed later in life.

The older age group when then asked if they felt there were enough opportunities for them to connect with peers, build skills or access meaningful community support. 15 respondents (79%) reported that they felt there are not enough of the above mentioned opportunities, with two respondents saying they were not sure if there was enough support. The remaining two respondents mentioned that there was some support opportunities, specifically a neurodivergent support group and “Meet-up” which is run by Tyneside Mind.

Finally, respondents were then asked what kind of support or follow-up do they think would have made things easier after their diagnosis. The majority (53%) of respondents mentioned being able to speak to a professional who is contactable, with the remaining suggestions depicted in the table below:

Types of support or follow up mentioned	Number of respondents
Speaking to professionals who are contactable	10
Receiving more information post diagnosis	2
Receiving regular follow ups with professionals	2
Local support groups	2
Being taken seriously	1
Nothing	2

Table 5. Types of support or follow up respondents aged 50 years old or over thought would have made their diagnosis process easier.

Additional feedback

Finally, participants from both age cohorts were asked if there is anything additional they would like to add after completing all the questions.

For the 18-24 year olds a total of 5 respondents answered this question, in which each of their quotes have been provided below.

"We have had the most horrific experience over the last few years and would be more than happy to share full details of our journey. We cant change the damage that has had happened to our family but willing to share in more detail in the hope that lessons are learnt to improve services for other families"

"It would benefit the local community if there was more local support around disability"

"I'm coping with it."

"I thought getting a diagnosis would really help me, but without further help and support to better understand my ADHD and be able to develop coping strategies it has been a real struggle"

"I am happy with the service (CYPs) and they generally helped me a lot, especially with my mental health and Autism."

For the over 50's there was some varied responses. Two respondents expressed thankfulness to Healthwatch Gateshead for carrying out this piece of research. Another two respondents said they received guidance from Marley Hill Community Centre and divergence which they were thankful for.

The other comments eluded to the necessity of early diagnosis to prevent mental health issues, a lack of funding for autism and/or ADHD services and the emotional effects of having autism and/or ADHD at a later stage in life:

"My diagnosis made a lot of things make sense in my life and I finally felt that the diagnosis of autism was what was the cause of me being "different " and "not fitting in anywhere " and not me being really weird"

"I feel more funding needs to be spent on offering support for neuro divergent people. There needs to be more professionals engaged in offering diagnosis to bring the waiting lists down. 8 years is way too long. This should be done within 6 months. This is people's lives and mental health we are talking about."

"Early diagnosis is important to avoid avoidable mental health issues including suicide. The NHS can offer a better service if ask the neurodivergent community to provide this North East Autism Society offer organisations to obtain a GOLD award from them which enables a better understanding tolerance and acceptance to our differences and makes the organisation a better place to work".

Additional data

Healthwatch Gateshead acknowledge the constraints of focusing on two distinct age groups and not placing a focus on those between the ages of 25 to 50. In an attempt to mitigate this, Healthwatch Gateshead included a link to our “Have Your Say” webform to give an opportunity for those not within the age criteria to also provide their feedback if they wish to do so.

Alongside this we have also extracted any feedback from our monitoring data which was submitted during the engagement period of this project. From this data, we received three individual responses relating to Autism:

- One was a request from a professional who wants to know more about services available
- One shared an experience: "My son is awaiting an assessment, first via NHS then via Right to Choose, and assessments have now been paused. This is affecting his well-being and education."
- Another said that they "Not offered any support for children living with autism." They were then signposted to the charity Daisy Chain by Healthwatch Gateshead

There was no specific data relating to ADHD from these data channels.

Conclusion and Recommendations

Together, the findings demonstrate that while receiving a diagnosis of autism and/or ADHD can provide clarity, validation, and a sense of understanding, it does not consistently lead to meaningful or sustained post-diagnostic support for adults in Gateshead.

Across both age cohorts, participants described lengthy and complex diagnostic journeys, followed by limited guidance, inconsistent follow-up, and gaps in support. Those aged 18-24 years old were more likely to report receiving some support through education or employment settings, though this was often short-term and disrupted by poor transition planning. On the other hand, adults aged 50 years old and over frequently reported receiving little or no formal support following diagnosis.

Common barriers were evident across the findings, including dismissive responses from GPs, lack of clear information and signposting, long waiting times, and inconsistent access to medication, titration services, and shared care arrangements. Many participants highlighted ongoing unmet needs around psychoeducation, mental health support, peer connection, and workplace adjustments.

Supportive relationships with understanding managers, colleagues, clinicians, and peer networks were frequently identified as the most helpful forms of support, often compensating for gaps in current support provision. Community and voluntary sector organisations play a vital role in addressing these gaps, but short-term funding and framework delivery requirements undermine their ability to provide sustained support to those who need it.

It is important to recognise that this research focused specifically on adults aged 18–24 years old and those aged 50 years old and over. While this enabled deeper insight into transition into adulthood and also later-life diagnosis, this targeted approach may have limited the breadth of lived experience captured and excluded perspectives from adults in other age groups. As a result, the findings may not fully reflect the experiences of all autistic adults and those with ADHD in Gateshead, particularly those navigating post-diagnostic support at different life stages.

However, the findings we have collected from the 33 participants highlight a clear need for more consistent, accessible, and holistic post-diagnostic support that extends beyond diagnosis alone. Embedding lived experience into service design, improving communication and awareness, and strengthening both statutory and community-based provision are essential to ensuring autistic adults and those with ADHD are not left unsupported following diagnosis. The following recommendations set out practical steps to address these gaps.

Recommendations

The findings and outcomes from this research have allowed Healthwatch Gateshead to propose recommendations. These recommendations are based on what we learnt from input from partner organisations during the scoping and development stage of the project, the 33 respondents we spoke with through our engagement and also internal discussions within the Healthwatch Gateshead Research and Engagement Team.

We present the following evidence-based recommendations below and have matched them with a responsible organisation or service in Gateshead.

Healthwatch Gateshead are asking:

- North East and North Cumbria Integrated Care Board (NENC ICB) and CNTW to **develop and communicate a clearer and consistent post-diagnostic support pathway for adults**. This pathway should support individuals at different stages of adulthood, ensuring those formally diagnosed receive clear and timely information about what support is available locally and how to access it following a diagnosis. This should include a consistent pathway, so individuals are not left feeling unsupported or uncertain once a diagnosis has been made.

- Commissioners within the NENC ICB to **ensure psychoeducation is routinely offered following diagnosis and available to individuals and families throughout different stages of life.** This could be delivered via voluntary and community sector partners, but dependant on longer funding and no clinical frameworks for evaluation. This should include structured opportunities for individuals and families to understand autism and ADHD, process the diagnosis and develop practical strategies for managing daily life, work and relationships. This would address the frequent misunderstandings and reliance on online sources of information highlighted in the findings.

- NENC ICB, Gateshead Council and CNTW to work together to **develop a single point of access or coordinated information offer for autistic adults and people with ADHD following a diagnosis.** This should outline what post-diagnostic support is available locally across the lifespan including NHS services, social care, voluntary and community sector provision, peer, employment and medication support. Information should be available in multiple formats and routinely offered at the point of diagnosis. This would reduce confusion about where to seek help and address the high proportion of respondents across both age groups who reported receiving no support post diagnosis.

- The Autism Strategy Partnership to **ensure that there is more information about autism and ADHD readily available to the public with links to local organisations that provide support across different stages of life.** This would increase family, friends and carers knowledge of autism and ADHD as well as helping them stay well informed whilst supporting individuals following a diagnosis.

- **Improved transition planning for young people moving into adult services** to be reviewed by Gateshead Council (Children and Adults Services) alongside CNTW (Children's and adult neurodevelopmental services) education providers and employment support services. Planning should begin earlier, be coordinated across services and clearly communicated with young people and their families to ensure a continuity of support beyond the ages of 18 or 21 years old during this critical period of change of entering early adulthood. This would help prevent the potential "service cliff" experienced by some young adults.

- Primary Care Networks, GP Practices, CBC Health Federation workforce development leads, DWP and local employment support services to **prioritise improving awareness and understanding of autism and ADHD in adults, including those diagnosed later in life.** Training should focus on recognising neurodivergent presentations, responding appropriately to requests for support and provide effective signposting. Improving awareness among professionals across health, employment and community services would help ensure individuals receive more informed and consistent support throughout adulthood.

Local employers and employment support services should also be encouraged to improve awareness of reasonable adjustments, ensuring individuals receive consistent and informed support in the workplace, to reduce any reports of dismissive experiences and improve confidence in seeking support.

- NENC ICB, CNTW and GP practices to **review local medication, titration, and shared care agreements to ensure consistency and transparency.** Clear information should be provided to individuals about prescribing responsibilities, expected waiting times and routes to care. Improving clarity within these pathways would help ensure individuals seeking treatment for autism and/or ADHD are able to access appropriate support regardless of their stage of life and minimise any feelings of confusion and being unsupported.

Overall, improving post-diagnostic support for autistic adults and people with ADHD in Gateshead should be a shared responsibility across statutory health bodies, local authorities, primary care, employment services and voluntary and community sector organisations. A coordinated and system wide approach is required to ensure that diagnosis isn't the end of the journey, but rather the start of accessible and sustained support plan. Strengthening communication, improving consistency across services and embedding lived experience into service design is essential to addressing issues and gaps identified in this report.

While Healthwatch Gateshead has provided an evidence base, key findings and recommendations for local partners, we once again recognise that this research focused specifically on adults aged 18-24 and those aged 50 or over. This targeted approach enabled for deeper exploration of transition into adulthood and later-life diagnosis, but it may not fully reflect the wider experiences of autistic adults and those with ADHD, particularly in other age groups. We have there outlined limitations and considerations for future research which can be found in the Appendices.

Acknowledgments

Healthwatch Gateshead would like to extend our thanks to those who participated in this project and contributed to their time to provide us with their lived experiences. We would also like to acknowledge the following partners and organisations in the list below for providing us with support and information we needed to complete this piece of work. Without this input we would of not been able to capture such valuable data, that helps amplify the voice's of the local people, inform the public and help suggest wider system improvements.

- Daisy Chain
- divergence
- Autism North East
- Tyneside Mind
- CNTW Community Clinical Business Unit
- Gateshead Mental Health Peer Support Service
- DWP Disability Employment Advisor

Response Statements

The following statements have been provided by our key partners, and some of the organisations and services mentioned in the recommendations of this report. These responses are intended to acknowledge, engage and address the research findings that have been presented by Healthwatch Gateshead.

- **Autism Strategic Partnership, Gateshead**

Anna English, Chair of Autism Strategic Partnership.

Gateshead Strategic Partnership Group

"The Autism Strategic Partnership in Gateshead is a multi-agency group who are responsible for overseeing the delivery of the Gateshead Autism Strategy. The partnership is committed to understanding the issues faced by autistic Gateshead residents and their families, and to working with our communities to improve access to support and facilities in the city. The insights provided to us through this report will be discussed and inform our work plan to ensure that we are working on the things that are most important to our autistic community. We will make sure that we reflect the recommendations that have been made in the priorities we set and the actions we take forward.

We welcome this helpful and informative report and extend our thanks to those who have contributed to it."

- **Cumbria, Northumberland, Tyne and Wear (CNTW) NHS Foundation Trust**

Anna English, Group Director Newcastle and Gateshead.

Cumbria, Northumberland, Tyne and Wear (CNTW) NHS Foundation Trust

Adult Neurodevelopmental Assessment Services (ADHD and Autism)

We welcome this Healthwatch report and would like to thank those with lived experience who contributed. The report is helpful in articulating the real and significant impact that delays, uncertainty, and variability in post-diagnostic support can have on people's daily lives, functioning, relationships, and wellbeing. Understanding this lived experience is essential to shaping services that are compassionate, proportionate, and effective and this is an area CNTW continues to prioritise.

Overview of the Adult Neurodevelopmental Assessment Service

CNTW provides specialist adult neurodevelopmental assessment pathways for ADHD and Autism, recognising that these are distinct pathways with different clinical requirements.

Adult ADHD pathway includes triage, diagnostic assessment, post-assessment follow-up, medication titration where indicated, shared care with primary care where applicable, and ongoing annual reviews.

Adult Autism pathway includes a diagnostic assessment, a post-diagnostic follow-up appointment, and discharge with information, education, and signposting.

We acknowledge that there is more follow-up within the ADHD pathway, reflecting the treatment arm of the service, particularly medication initiation and monitoring. In contrast, the Autism pathway does not usually include ongoing clinical intervention and follow-up is therefore time-limited. However, the Autism service endeavours to ensure that individuals and their support networks are appropriately supported, informed, and connected to relevant services prior to discharge.

Post-Diagnostic Support and Follow-Up

As part of the adult neurodevelopmental assessment process, post-diagnostic support is offered within both pathways. However, it is recognised that the service is currently commissioned to provide one follow-up appointment following Autism diagnosis.

Where there is complexity, uncertainty, or additional need identified, the service will endeavour to ensure that further follow-up or onward support is in place prior to discharge. This will include additional contacts within the assessment service, coordination with secondary care mental health teams and signposting or referral to other providers, including VCSE organisations.

Integration with Mental Health Services

CNTW recognises the need to ensure robust, shared understanding and clear agreements with psychiatry and mental health treatment teams, in line with national guidance. The Adult Neurodevelopmental Assessment Pathway is therefore working collaboratively with the North East and North Cumbria ICB, and Tees Esk and Wear Valley NHS Trust (TEWV) to agree a consistent service model that ensures people experiencing co-existing mental illness are assessed in a timely, coordinated, and holistic way.

As part of this regional work, individuals open to secondary care mental health services who have an ongoing treatment need will be offered ADHD and/or Autism assessment as appropriate. For these individuals, post-diagnostic support will be provided through their existing mental health care team, with input from the assessment service initially, and thereafter by the treating team. This ensures continuity of care and avoids duplication, while recognising neurodevelopmental needs as part of a person's wider presentation.

Understanding and Strengthening the Local Offer

Through ongoing regional collaboration the ICB, CNTW and TEWV are developing a broader understanding of the services available within each locality, including neighbourhood and voluntary sector provision. We recognise that availability varies across the region, however, improving visibility of non-NHS support options will strengthen transitions for those who *do not require ongoing NHS intervention and reduce uncertainty following diagnosis.*

This is particularly important for individuals who may not meet the criteria for secondary mental health services, or who have received a diagnosis through Right to Choose or private providers and are seeking post-diagnostic support.

Transitions from Children's Services to Adult Services

In line with CNTW policy, transitions into the adult neurodevelopmental assessment pathway can commence for young people from 17.5 years. Where a young person is awaiting diagnostic assessment and turns 18 while on the Children and Young People's Services (CYPS) waiting list, referral dates are honoured and the individual transfers to the adult pathway.

CNTW follows a CYPS to Adult Transition Policy, which ensures continuity regardless of whether an individual is at the assessment stage or accessing post diagnostic support through CNTW.

Children awaiting assessment are now offered a "Steps Ahead" welcome event, delivered in the pre-diagnostic period. These group-based sessions focused on introducing families and carers to the assessment team, providing education about ADHD and Autism, increasing awareness of local and multiagency support services and preparing some for a smoother transition in to adult services.

Older Adults Seeking Assessment

There is no upper age limit within the adult neurodevelopmental assessment service. We acknowledge a growing number of individuals aged over 50 seeking assessment and diagnosis, reflecting increased awareness of how ADHD and Autism may present later in life. Clinicians undertake a full developmental history to understand lifelong patterns and functional impact. This group of patients are offered the same post diagnostic support in CNTW and are signposted to services available in the areas they live.

Workforce, Training and Lived Experience

CNTW places significant value on lived experience and employs people with lived experience within neurodevelopmental services to help shape delivery and improve care. All CNTW staff complete mandatory learning disability and autism training, and ongoing workforce development supports trauma-informed and neurodiversity-affirming practice. Workforce representatives support managers to implement reasonable adjustments for staff and service users where required.

CNTW has also developed and delivered targeted training packages for primary care and third sector partners, increasing system-wide understanding of neurodiversity and supporting earlier recognition and support.

Waiting Times and System Pressures

We acknowledge the long waiting times for assessment and the impact this has on individuals. The regional collaborative programme is prioritising re-triage and information gathering for people on the waiting list for assessment, to ensure information about their current need and presentation is up to date and that people are directed to the most appropriate support.

Within the ADHD pathway, we also recognise the length of time medication titration can take, the impact that limited shared care arrangements place on CNTW capacity and the competing demands of new referrals, assessments, titration, and annual reviews.

These pressures directly affect the ability to progress medication treatment at pace and are being addressed through ongoing system discussions and regional work with neighbouring NHS trusts.

Private diagnoses, safe prescribing and shared care

We recognise discrepancies experienced by individuals who receive a private ADHD diagnosis and then seek NHS prescribing. CNTW must ensure safe and holistic care; therefore, prescribing teams need assurance that the original assessments are robust, valid, and reflect current presentation. This is essential to safe and appropriate prescribing practice.

We acknowledge concerns regarding inconsistency in GP participation in shared care arrangements. GP decisions to take on prescribing responsibility vary, and this can leave some individuals without equitable access to medication support.

CNTW executives and directors have been working closely with the NENC ICB and primary care to develop improved shared care arrangements through Local Enhanced Services (LES). While this is not yet consistent across all practices, this remains an active area of work with the ICB and CNTW.

Response to recommendations

Clear and Consistent Post-Diagnostic Support Pathway

We agree with the need for a clearer, more consistent post-diagnostic pathway. The regional programme of work is developing a tiered model of support, recognising that needs vary across the population:

A regional communication outlining the new model and setting clear expectations for post-diagnostic support is planned.

Coordinated Information and Single Point of Access

CNTW, TEWV and the NENC ICB are exploring options for a referral hub or coordinated access model to triage and coordinate pre- and post-diagnostic support. The ambition is to reduce variation, prevent a postcode lottery, and ensure individuals receive clear, consistent information about support available across NHS, social care, VCSE, peer, employment, and medication services.

Medication, Titration and Shared Care Consistency

We agree that medication pathways and shared care arrangements require greater consistency and transparency. CNTW leadership continues to work with the ICB and primary care to agree clearer, system-wide approaches. While challenges remain, this collaborative work is progressing positively and remains a priority.

In summary, CNTW welcomes this report, recognises the challenges described, and is committed to working with service users, partners, and *commissioners to improve neurodevelopmental pathways across the region. The findings of this report reinforce the importance of system-wide collaboration, clear communication, and proportionate post-diagnostic support that reflects individual need and lived experience.*

- **North East and Cumbria Integrated Care Board (NENC ICB)**

Lynn Wilson, ICB Delivery Director Newcastle & Gateshead

and

Levi Buckley, Chief Operating Officer

North East and North Cumbria Integrated Care Board (NENC ICB)

Thank you for sending us your latest report outlining people's experience of support for autistic people and people with Attention Deficit Hyperactivity Disorder (ADHD) in Gateshead.

As an ICB we are committed to ensuring that people who require a diagnostic assessment can do so in an accessible and timely way and that the support needed both pre and post diagnosis is in place, accessible and co produced with neurodivergent individuals. Our needs led approach means that people and those who support them have the information, advice and support they need to address any presenting issues both prior to a diagnosis or post diagnosis or for those who choose not to have a formal diagnosis.

We have provided a response to your recommendations below:

	Recommendation	Comments
1.	North East and North Cumbria Integrated Care Board (NENC	The ICB is committed to ensuring that children, young people and

	ICB) and CNTW could develop and communicate a clearer and consistent post-diagnostic support pathway for adults. This pathway should support individuals at different stages of adulthood, ensuring those formally diagnosed receive clear and timely information about what support is available locally and how to access it following a diagnosis. This should include a consistent pathway, so individuals are not left feeling unsupported or uncertain once a diagnosis has been made.	adults can access diagnostic assessment in a timely manner. Alongside diagnosis the ICB has commissioned Daisy Chain Gateshead Autism Hubs - Daisy Chain and Tyneside Mind James Triple A Experience – Tyneside Mind to provide pre and post diagnostic support. Both organisations work closely with CNTW to ensure people newly diagnosed and/or those waiting for a diagnosis have access to a range of support, including information, advice and support, peer support, individual counselling and psychoeducation. The ICB is working with both organisations to raise local awareness of the services and support they offer. NHS England commission the Anna Freud Centre to deliver Autism Central an online support service for families and supporters of people with ADHD or who are autistic. Autism Central - England's Peer Education Programme | Autism Central

2.	Commissioners within the NENC ICB could ensure psychoeducation is routinely offered following diagnosis and available to individuals and families throughout different stages of life. This could be delivered via voluntary and community sector partners, but dependant on longer funding and no clinical frameworks for evaluation. This should include structured opportunities for individuals and families to understand autism and ADHD, process the diagnosis and develop practical strategies for managing daily life, work and relationships. This would address the frequent misunderstandings and reliance on online sources of information highlighted in the findings.	The ICB currently Commissions Tyneside Mind to provide Psychoeducation for adults who are autistic or who have ADHD. This service is open to anyone over the age of 18.
3.	NENC ICB, Gateshead Council and CNTW could work together to develop a single point of access or coordinated information offer for autistic adults and people with ADHD following a diagnosis. This should outline what post-diagnostic support is available locally across the lifespan	The ICB is working with both Daisy Chain and Tyneside Mind to ensure that they are able to offer information and advice and support to individuals and their families in Gateshead. The ICB is currently reviewing the information offer to people across the ICB, including making available

	including NHS services, social care, voluntary and community sector provision, peer, employment and medication support. Information should be available in multiple formats and routinely offered at the point of diagnosis. This would reduce confusion about where to seek help and address the high proportion of respondents across both age groups who reported receiving no support post diagnosis.	a number of accredited self assessment tools. [Attention Deficit Hyperactivity Disorder (ADHD) and Autism | North East and North Cumbria NHS]() Information on local resources that offer information advice and support is also available through [Discover more... | OurGateshead]()
4.	The Autism Strategy Partnership could ensure that there is more information about autism and ADHD readily available to the public with links to local organisations that provide support across different stages of life. This would increase family, friends and carers knowledge of autism and ADHD as well as helping them stay well informed whilst supporting individuals following a diagnosis.	The ICB is an active member of the Gateshead Autism Strategic Partnership and will continue to work in partnership to deliver the outcomes set out in the Autism Strategy.
5.	Improved transition planning for young people moving into adult services could be reviewed by Gateshead Council (Children and Adults Services) alongside	Transitions from Children to Adult services has been recognised by the Gateshead SEND Board as an area for improvement and the ICB is working with the Local Authority and

	CNTW (Children's and adult neurodevelopmental services) education providers and employment support services. Planning should begin earlier, coordinated across services and clearly communicated with young people and their families to ensure a continuity of support beyond the ages of 18 or 21 years old and help prevent the potential "service cliff" experienced by some young adults during a critical period of change.	service and support providers on making improvements.
6.	Primary Care Networks, GP Practices, CBC Health Federation workforce development leads, DWP and local employment support services could prioritise improving awareness and understanding of autism and ADHD in adults, including those diagnosed later in life. Training should focus on recognising neurodivergent presentations, responding appropriately to requests for support and provide effective signposting. Improving awareness among professionals across health, employment and community	The ICB currently mandates the Oliver McGowan training programme to all ICB members of staff. This involves a whole day of training for GPs in learning disability and neurodiversity with the training being co-delivered by those with lived experience. This training will enable detailed discussions around reasonable adjustments. The ICB links with trust liaison learning disability and neurodiversity nurses to help with planning around anticipated hospital admissions and to help enable effective discharge planning with primary care.

	services would help ensure individuals receive more informed and consistent support throughout adulthood. Local employers and employment support services should also be encouraged to improve awareness of reasonable adjustments, ensuring individuals receive consistent and informed support in the workplace, to reduce any reports of dismissive experiences and improve confidence in seeking support.	The ICB currently offers all adults with a learning disability who are also autistic an annual health check and those who have a severe and enduring mental illness, who may also be autistic or have ADHD an annual health check. The ICB is exploring the option of an annual health check to all autistic adults.

Thank you very much for sharing this report and we look forward to reading the next one.

Feedback from Partners

The following feedback has been provided by partners in response to the research findings that have been presented by Healthwatch Gateshead.

- ### Cumbria, Northumberland, Tyne and Wear (CNTW) NHS Foundation Trust

Dr Louise Rutter, HCPC Registered Clinical Psychologist, CAT Practitioner.

Cumbria, Northumberland, Tyne and Wear (CNTW) NHS Foundation Trust

"Many thanks for sharing this. I was due to talk at the meeting about the work we have been doing in CNTW regarding our autism in later life pathway. I am really pleased you were able to get responses from 19 people aged 50+.

This is a surprisingly high percentage of the total number of responses."

- ### Daisy Chain

Jennifer Hewitt, Director of Services

Daisy Chain

(Partner organisation that supported with project scoping)

The findings of this report closely reflect what we hear from individuals and families accessing our support in Gateshead, particularly in relation to the lack of consistent post-diagnostic provision for adults. For clarity, our current commissioned offer within Gateshead is limited to the Gateshead Autism Hubs, which provide support specifically for parents and carers. This service does not provide direct support to autistic adults themselves, nor does it currently extend to families where ADHD is the sole diagnosis.

In contrast, we are commissioned to deliver psychoeducation and post-diagnostic support in other areas, including Durham, Newcastle, Tees Valley and York. Within these areas, our "Living Autistically" and "Living with ADHD" *psychoeducation workshops offer structured support to help individuals better understand neurodivergence, develop practical strategies and connect with peers who share similar experiences.*

We believe these models represent a meaningful response to many of the issues raised in the report, particularly the need for accessible, consistent and ongoing post-diagnostic support. We would welcome the opportunity to contribute further to discussions in Gateshead on how similar approaches could help address the identified gaps and strengthen local outcomes.

- **Divergence**

Billy Sayer, Development Officer

divergence

(Partner organisation that supported with project scoping)

This report provides a clear and well-evidenced reflection of the experiences people are describing in relation to post-diagnostic support.

This closely aligns with what we are seeing through our work, particularly in relation to ADHD, and more broadly for autistic people and those with co-existing neurodevelopmental conditions in Gateshead.

This is also consistent with findings from our public consultation across the North East, which identified similar themes around access, understanding and ongoing support needs.

A central theme reflected both within the report and in practice is that diagnosis does not, in itself, lead to meaningful or sustained support.

Many individuals and families describe a sense of being "diagnosed and then left to it", often without clear guidance on what to do next or how to apply that understanding in day-to-day life. Alongside this, there is often an expectation that diagnosis will act as a "key to the door" for support, which is rarely realised in practice.

Alongside the themes identified within the report, we are also seeing a number of ongoing system challenges that continue to affect access to ADHD assessment, diagnosis, treatment and ongoing support:

Individuals are regularly being placed onto NHS waiting lists that can extend for a number of years — in some cases well beyond a decade — often with little or no interim support

Awareness of alternative pathways such as Right to Choose remains inconsistent, meaning many people are unaware of the options available to them

Even where alternative pathways are accessed, there is often a further gap following diagnosis, including delays in titration, challenges accessing medication, and uncertainty around ongoing care

Variation in shared care arrangements across primary care can leave individuals without consistent access to prescribing and follow-up support

These themes are also reflected in our consultation findings, particularly in relation to access barriers, pathway variation, and the complexity of navigating services.

These challenges are often compounded by variation in awareness and understanding at a primary care and frontline level, which can directly affect the quality and consistency of information, advice and signposting that individuals receive.

We also frequently see individuals who are struggling to access ADHD or autism-specific support but are receiving treatment for co-existing mental health conditions, such as anxiety and depression, or for substance use and addiction-related difficulties.

While there is well-established evidence of higher prevalence of these conditions alongside ADHD and autism, people often report that their difficulties are being driven or exacerbated by a lack of understanding, support or treatment for neurodevelopmental conditions themselves. This can make it more difficult for wider interventions to have a sustained impact.

In addition, system navigation remains a significant challenge. This includes unclear pathways, limited follow-up, and processes which can unintentionally exclude individuals — for example where service design does not take account of executive functioning differences, an issue consistently highlighted through our consultation findings and ongoing engagement.

In practice, this can result in people disengaging from services or falling through gaps in provision.

The report's emphasis on psychoeducation is particularly important. From our perspective, this is one of the most significant gaps across the system.

While medication can play an important role for some individuals with ADHD, access to broader support such as psychoeducation, practical guidance, and support with adjustment remains limited.

Supporting people to understand how ADHD affects them, and to develop practical, personalised strategies, is a key component of longer-term outcomes.

The report also highlights the growing role of community and voluntary sector provision in responding to these gaps. From our perspective, this reflects an increasing need for accessible, non-clinical spaces where individuals can access information, share experiences, and engage with support in a way that feels practical and relevant to their lives.

Through the ADHD Exchange, we engage with individuals at different stages of the pathway — including those who are exploring ADHD, awaiting assessment, recently diagnosed, or further along in their journey.

Although the session is ADHD-focused, we also see a significant number of individuals with autism or suspected autism attend, reflecting the high level of co-occurrence and overlap in support needs.

Structured session insights are collated and synthesised into anonymised reports, enabling ongoing monitoring of emerging trends and recurring system challenges on a consistent basis. These patterns continue to align with both the findings of this report and themes identified through our wider consultation work.

We also recognise the report’s findings around transition, particularly the reduction in support experienced by some individuals moving into adulthood. This is something that continues to be reflected locally and can have a significant impact where continuity and planning are limited.

Overall, this report provides a strong and evidence-informed account of current experience in Gateshead. It reflects both the strengths and the pressures within the system, and highlights important opportunities to improve how post-diagnostic support is understood, accessed and delivered.

From our perspective, continued collaboration between statutory services, community organisations and people with lived experience will be key to developing more joined-up, accessible and sustainable models of support going forward.

Appendices

Research Objectives

a) **To examine lived experiences of post-diagnostic support:** explore how individuals with autism/ADHD, and their families, experience the period following diagnosis, including unmet expectations.

b) **To identify barriers to accessing ongoing support:** investigate systemic and practical barriers (e.g. GP reluctance, funding cuts, long waits for titration, lack of psychoeducation) that limit access to support and care.

c) **To explore the role of community and voluntary sector provision:** examine how organisations currently fill gaps left by statutory services, and the limitations of short-term funding models.

e) **To evaluate the impact of insufficient support on outcomes:** analyse how service gaps affect mental health, employment, education, independence, and social participation for different age groups (e.g. 18–24 vs. 50+ late diagnosis).

f) **To consider professional perspectives on service navigation:** investigate how teachers, GPs, Jobcentre staff, and social workers understand and communicate post-diagnostic pathways.

g) **To generate evidence-based recommendations:** propose strategies for improving post-diagnostic pathways, including better communication, balanced community partnerships, and inclusion of lived experience in service design.

Survey Questions

18-24 year olds:

About you

1) What is your diagnosis?
2) How long have you had your diagnosis for?
3) How long did you wait for your assessment?
4) Are you getting help to fill in this survey?
5) What made you decide to ask for an assessment? (e.g. struggles with focus, burnout, sensory overload, advice from others)

6) In brief, how do your diagnosis affect your daily life? (e.g. struggling with focus, social situations, energy levels….)

Getting support

7) After diagnosis did you get any support? (e.g. mental health support, peer groups, psychoeducation)
8) If yes, what support have you received? (e.g. medication, support worker, employability support, education support, social/community support….)
9) Can you name any organisations that have supported you after your diagnosis
10) Of the support received, what have you found to be the most helpful?
11) What made it hard to get support? (e.g. GP didn't understand, waiting lists, cost, lack of information, anxiety about asking)
12) What support do you still require, or would like to get?

Life after diagnosis

13) Have you felt socially included since diagnosis, or has lack of support created challenges with friendships, community or independence?
14) Looking back, what do you feel was missing from the support your received after diagnosis?

Additional information

15) Is there anything else you would like to add?

Over 50's

About you

1) What is your diagnosis?
2) How long have you had your diagnosis for?
3) How long did you wait for your assessment?
4) Are you getting help to fill in this survey?
5) What made you decide to ask for an assessment? (e.g. struggles with focus, burnout, sensory overload, advice from others)

6) In brief, how do your diagnosis affect your daily life? (e.g. struggling with focus, social situations, energy levels….)

Getting support

7) After diagnosis did you get any support? (e.g. mental health support, peer groups, psychoeducation)
8) If yes, what support have you received? (e.g. medication, support worker, employability support, education support, social/community support….)
9) Can you name any organisations that have supported you after your diagnosis
10) Of the support received, what have you found to be the most helpful?
11) What made it hard to get support? (e.g. GP didn't understand, waiting lists, cost, lack of information, anxiety about asking)
12) What support do you still require, or would like to get?

Life after diagnosis

13) Did you find healthcare professionals (e.g GPs, specialists) understood your needs as a late-diagnosed adult
14) Do you feel there are enough opportunities for older adults to connect with peers, build skills, or access meaningful community support?
15) What kind of support or follow-up would have made things easier after your diagnosis?

Additional information

16) Is there anything else you would like to add?

Limitations

1) Small sample size:
   Even after an extended engagement period we still only received a relatively small number of responses for each age group. This limits the ability to generalise findings to all those with an official Autism and or ADHD diagnosis and their experience of post diagnostic support, not capturing the full diversity of experiences.

2) Exclusion of individuals awaiting diagnosis:
   This study did not include individuals who are currently awaiting a formal neurodiversity diagnosis. As a result, the findings may not reflect the experiences or support needs of those facing delays in assessment, who may experience significant challenges both before and after diagnosis.

3) Voluntary participation:
   Participation in the research was voluntary, meaning the findings may be influenced by self-selection bias. Individuals who had particularly positive or negative experiences of post-diagnostic support may have been more likely to take part, potentially limiting the representativeness of the data.

4) Reliance on self-reported experiences
   The study relied on self-reported experiences, which may be subject to recall bias or differences in individual interpretation of support, services, and outcomes.

5) Variation in time since diagnosis
   Participants were at different stages following diagnosis, ranging from recent to long-standing diagnoses. This variation may have influenced perceptions of support and accessibility, making direct comparison of experiences more complex.

How can we improve Future Research?

Whilst this research provides valuable insight into post-diagnostic experiences for autistic adults and adults with ADHD in Gateshead, there are opportunities to strengthen future research.

This project specifically focused on adults aged 18-24 and those aged 50 and over, future research could widen participation to include adults across all age groups to provide a more comprehensive understanding of lived experience across the life course.

Future work could also include individuals who identify as autistic or ADHD but have not received a formal diagnosis and capture the experiences of those awaiting assessment or facing barriers to diagnosis. Alongside this collecting the perspectives of key stakeholders and providers would allow for triangulation of findings help identify system-wide issues.

Expanding engagement methods which include focus groups, interviews or co-produced workshops could provide a richer qualitative insight, particularly around sensitive topics such as mental health, employment and transition into adulthood. Co-production methods would also ensue people with lived experience are actively involved in shaping research priorities and recommendations.

healthwatch
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