

# Improving support for people with autism

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September 2024



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# About us

Healthwatch Wolverhampton is the city's health and social care champion.

We're here to listen to your experiences of using local health and care services and to hear about the issues that really matter to you. We are entirely independent and impartial, and anything you share with us is confidential. We can also help you find reliable and trustworthy information and advice to help you to get the care and support you need.

As an independent statutory body, we have the power to make sure that NHS leaders and other decision makers listen to your feedback and use it to improve standards of care.

Healthwatch Wolverhampton is part of a network of over 150 local Healthwatch across England.



## Introduction

### Background

Through our feedback system, engagement and partnership working, we have been hearing from people awaiting a diagnosis for autism. Concerns are being raised regarding extremely long waiting times for diagnosis and a lack of support and communication while awaiting a diagnosis. We are also hearing about people facing challenges in getting the care and medication they need, which is contributing to deteriorating mental health.

In June 2023, [NHS England Autism Statistics](#) showed that 143,119 people were waiting for an autism assessment in England. [NICE guidelines](#) state that people with possible autism who are referred to an autism team for an autism assessment, should have their assessment started within three months of their referral. However, nationally 83% of people waiting for an autism assessment reported waiting longer than 13 weeks to be seen for their first appointment after being referred for autism assessment.

Timely autism diagnosis and the right help and support during and after diagnosis is important. According to the [National Autistic Society](#), no diagnosis or delayed diagnosis may result in insufficient support, which may then contribute to people with autism facing additional difficulties with day-to-day activities at work and at home. These factors may also contribute to the development or worsening of mental health conditions such as anxiety and depression.



Government statistics (2021) estimate that around 700,000 people in the UK have a diagnosis of autism. However, studies by University College London in 2023 and the National Autistic Society in 2024, estimated how many autistic people (diagnosed and undiagnosed) were living in England, it was found that the total autistic population in England alone may exceed 1.2 million people, and current government figures may be a significant under representation. This further highlights the need to understand people's experiences of autism diagnosis and support, to identify areas for improvement and address the diagnosis gap.

## What we wanted to find out

We wanted to understand how long people are waiting to be diagnosed with autism, what support they are receiving while they are waiting, whether the waiting time is affecting their mental health, and what improvements they feel could be made. We will use this insight to advise those responsible for autism services how to develop and improve support.



Initially, we planned to focus on the experiences of adults with autism. However, it soon became clear that parents wanted to reach out to share their children's (under 18) experiences, so this report features a mix of feedback relating to the experiences of children and adults.

Through this project we have been able to give people the opportunity to have their voices heard to help bring about positive change in the services they use. This report features case studies of some of the people we spoke with.

## What we did

We worked on this project between January and March 2024, gathering feedback from 70 people at community events and via an online survey.

## Community engagement

In March 2024, we went out into the community to engage with people in places where they felt comfortable to talk about their experiences.

### Listening groups

We hosted in person listening groups at Wolverhampton Art Gallery Café and Bantock Café and gained four insightful case studies.

### Adult Autism Matters

We attended two meetings at the Adult Autism Matters peer support group. This is a self-run group which provides adults on the autism spectrum with an opportunity to meet up each month and socialise and share useful information.

We met 24 people in the two meetings we attended, and we were able to have in-depth one-to-one conversations with seven attendees.

A flyer with a colorful rainbow border at the top and bottom. The Healthwatch Wolverhampton logo is at the top right. The main text asks: "Are you waiting for an autism assessment? Or have been diagnosed and are waiting for support &amp; want to share your experience? Then why not be a case study for us?". It then lists two focus groups: "Focus Group #1" on 12th March at Bantock Cafe (12pm - 2pm) and "Focus Group #2" on 26th March at Art Gallery Cafe (12pm - 2pm). It includes contact information: "info@healthwatchwolverhampton.co.uk" and a note: "Please note - We can provide transport if needed once you have confirmed you attendance".

We liaised with a member of the group before we attended who advised us that using art would help to improve accessibility and build rapport with group members; we took art materials with us and did drawing with the group at the first session.

### Autism Café at Café Royale

We attended a session at Autism Café at Café Royale in Wolverhampton city centre. Autism Café takes place after closing hours. There were nine people attending this event, and we were able to develop one case study.

### Online group

We also attended an online autism group meeting to help us to reach people who may not be able to attend in-person groups. This group was called Adult Autism Roadmap and there were five attendees.



## Survey

We conducted a short online survey between February to March 2024 and received 28 responses (See page 14).

## Key messages

The key themes that emerged from what people told us centre around the need for information, better communication and support during the autism diagnosis process and after autism diagnosis.

- **Long waiting times:** People are spending a long time on the waiting list for initial autism assessment, much longer than the [NICE guidelines](#).
- **Lack of communication:** There is a lack of communication with people while they are on the waiting list and people feel that they are having to 'chase' to get an update and make sure they are still on the waiting list.
- **Not enough information provided:** There is not enough information provided about autism and the autism assessment process. People described having to research autism themselves to find the information they need.
- **Lack of support:** People require support while they are waiting for autism diagnosis and after diagnosis, but there is a lack of support, including for mental health. People who are having to search and seek out support themselves.
- **Tailored support for adults:** People would like to see tailored support for adults with autism and local peer support groups, particularly to help find employment and opportunities to meet other people with autism and make friends.
- **Stigma contributes to challenges:** There is stigma surrounding autism that may contribute to the wider societal experiences of people with autism.

# What people told us

## Case studies: one-to-one conversations

From the in-depth conversations we had with people, we developed five case studies to illustrate the issues and concerns raised. (All names have been changed.)

### Courtney's story

#### The impact of autism on mental health

Although Courtney felt that her experience of autism diagnosis was “surprisingly easy from hearing what others have been through”, her story highlights some of the mental health challenges that people with autism may face.

#### How did you find the process of being diagnosed?

In January 2021, Courtney became aware that she was autistic through a combination of her own research into autism and recollection of her earlier life experiences. She phoned her GP and asked for an assessment. She then received an initial assessment from [Healios](#), an NHS service which provides mental health, autism and ADHD services for children and young people. She was asked 10 questions over the phone. Courtney felt that the questions were designed for a young boy, for example, ‘Do you have a fascination with things like trains or mathematics?’ Courtney’s assessment score did not meet the threshold required to be considered for an autism assessment, but she discussed her symptoms and experiences with the person administering the questionnaire, and Courtney was then later accepted for autism assessment.



In August 2021, Courtney’s mum was asked some questions as part of Courtney’s autism assessment. In September 2021 Courtney received a call to say that she met the criteria and was diagnosed with autism.

#### Autism diagnosis felt unexpected but it explained a lot

Courtney had experienced feeling different and described thinking ‘Why am I not reacting like the other kids?’ as a child. She had previously been diagnosed with ADHD in the same year, which she felt was an obvious diagnosis. Courtney’s autism diagnosis allowed her to understand some of her earlier life experiences, but it felt unexpected.

The only autistic people that she had seen were a character from a TV show and someone she knew at university. A few months before this, Courtney had watched a YouTube video of Asperger’s syndrome in women. She felt that she wouldn’t have clicked on the video if the video title had said autism, as there is more stigma surrounding autism based on the stereotypes she had seen. Courtney said that her autism diagnosis answered every question she had about herself, she described it as feeling ‘whole’.

## How did you find the waiting time?

Courtney described the waiting time as 'like being in purgatory', but she felt 'lucky' that it was relatively quick, and she couldn't get further help without an autism diagnosis.

## Did you get any support while awaiting diagnosis?

Courtney did not receive any support while waiting for a diagnosis. She received a call to say that she would be getting an assessment, then a call to say that she had got an assessment, but there was no support or information in the meantime. Once Courtney had got diagnosed with autism, at the end of the diagnostic report there were a list of suicide prevention hotlines and links to autism forums, but she did not receive any other support.

## Did the lack of support have an impact on your mental health?



Courtney described facing difficulties with her mental health after diagnosis. She thought there would be more understanding and help after being diagnosed. One example she shared was her experience with her employer; she felt that management, although well-intentioned, showed a lack of awareness. Courtney asked for more consistent shift patterns, but management was not responsive to this. She felt that her needs were treated as preferences and therefore weren't viewed as necessary for her health and continuing employment.

While Courtney was at university she was prescribed anti-depressants, which seemed to help with her mood and she felt happier. After her autism diagnosis she lost all her friendships, because she felt that she had nothing in common with people and had been pretending to be a different person to who she really was.

## Complex Care said that she was 'too complex'

The combination of health issues and burnout, along with declining mental health after her autism diagnosis, meant that Courtney was unable to continue working. She moved back in with her parents for two years and tried to contact services to get support. However, these services said they were unable to help; she was referred to one service who then referred her back to the previous service. Complex Care said that that she was 'too complex' and told her to go back to her GP, who referred her to a mental health service. The mental health service then said this is something for the GP to provide support with. She felt that she was being passed around with no one helping.

At one point, for several months, Courtney was suicidal. An ambulance was called, and upon arrival to the hospital, Courtney was referred to the crisis team. She felt that the crisis team did not provide much support. She was told that she needed ongoing mental health support and when she asked what they could do to prevent her from ending her life, the team told her "Not much, but we hope that you don't".

## Supportive parents and private therapy

Courtney felt that things got a bit better when she realised that she must help herself after feeling that no one was going to help her. She had supportive parents, so was able to leave her job and her parents took care of her.

Alongside the challenges faced by Courtney while being diagnosed with autism, she was also diagnosed with premenstrual dysphoric disorder, which is a condition that can severely impact mood during the menstrual cycle.

Courtney sought out a private therapist, who said she would go through a grieving process following autism diagnosis. She described how the grieving process has taken two to three years, and she is only now 'starting to feel human' again.

### **Experiences could have been very different with earlier diagnosis or more support**

Courtney felt that if she had been diagnosed younger or if she had been given appropriate support along her journey of being diagnosed with autism and post diagnosis, her experiences could have been very different, and her mental health wouldn't have declined to the level that it did. She believes that she could have worked more and would not have become suicidal, needing to visit A&E in a state of mental health crisis.

### **What support would you like to see?**

Courtney says that she would like to meet other people her age who have autism. She would also find peer-to-peer support groups helpful. These groups should be local as she finds navigating public transport difficult. Many autistic people face additional challenges like this, so seeking support should not feel daunting, or have a 'you get what you are given' feel.

Courtney feels that people have the solutions and that they could work with local services to help improve people's experiences. She thinks the support groups in her area need to attract more of a variety of autistic people, as it can be equally as isolating to find no one to relate to in a space supposedly designed for them.

Courtney has come across some forums online where people are sharing their journey of being diagnosed with autism. She described these forums as people sharing their negative experiences and there being no positive outcomes. She feels these groups need signposting to positive and productive help, but also recognises why these groups are so negative; there are recurring themes of low or no support, isolation and lack of understanding from peers and employers. Courtney believes that with more awareness, understanding and support surrounding autism diagnosis, the forums will also become more positive because people will have more positive things to share, resulting in a friendlier and more comforting peer network.

Courtney would also like to see more awareness and understanding from mental health services regarding autism.





## Stephanie's story

### Autism diagnosis later in life

Stephanie shared how her experience of her grandchild being diagnosed with autism led to her requesting a referral for an autism assessment, and how a crisis she experienced at work highlighted the importance of having a diagnosis.

#### How did you find the process of being diagnosed?

Stephanie's journey of being diagnosed with autism began when her grandchild started nursery. The nursery staff noticed autistic behaviours in her grandchild and this led to an autism diagnosis. Stephanie began to reflect on the rest of her family who she described as 'all quite quirky', and upon further research she noticed autism and ADHD traits in other family members. She did not consider that she might have autism until someone in her family suggested that she should.



Soon after requesting a referral for an autism assessment through her GP, Stephanie's desk at work got moved to an environment that was not suitable because of the noise levels, and this resulted in what she described as 'a breakdown'. Stephanie had discussed her concerns with her employer on numerous occasions, but they did not understand. Her own research into autism gave her a better understanding of why she was so uncomfortable in the new workspace. Other people worked in this environment without experiencing any problems, and so without an autism diagnosis, Stephanie found it difficult to explain to senior staff members that this environment was not suitable for her.

Due to the waiting time of over a year, Stephanie decided to seek a private diagnosis. She was diagnosed with Asperger's syndrome, but as this is considered an outdated term, Stephanie didn't feel confident with the private diagnosis. It took around 14 months after referral from her GP, for Stephanie to receive an autism diagnosis through Black Country Health Care's Adult Autism and ADHD Service.

#### Did you get any support while waiting for diagnosis or after diagnosis?

Stephanie was not offered support and did not feel supported, either during the process of being diagnosed with autism or after being diagnosed. She did lots of reading and research into autism to find things out for herself and to seek support. Her own research into autism gave her a better understanding of her personal behaviour.

When she went to see her GP to seek autism diagnosis, she felt that she wanted to speak to someone about going back over her life and understanding her earlier life experiences, but she felt there was no support service available to allow her to do this.

While waiting for autism diagnosis, Stephanie sought online one-to-one advice sessions around sensory dysregulation from Autism West Midlands, who do not need a diagnosis to provide support. These sessions helped her to put into place some coping strategies to help manage sensory issues that she was experiencing. She found out about these support sessions through a friend.

## Reflections on autism diagnosis

Since diagnosis, Stephanie feels that her workplace 'has been better' as they now have an understanding.

She said that: "Having a diagnosis is like the last scene in the film *The Sixth Sense*, it all makes sense on reflection." She realised that many of the things that she regretted from her earlier life experiences were part of autism as she was a teenager with no support.

On reflecting on earlier life behaviours, Stephanie felt that she engaged in many high-risk behaviours and that she went along with everything as she didn't have a high level of awareness. She also felt that she was a bad judge of character. Stephanie feels that if she had been diagnosed with autism much earlier in life, maybe her parents would have been more protective of her, her academic experience could have been more positive and she could have received more support, rather than being 'thrown into the world'.

## Siberia's story

### Navigating life as an adult with autism

Siberia shared some of his life experiences as an adult with autism, and discussed key areas where he felt support could be better. He also shared how Autism Café has helped him with making new friends.

#### How did you find the process of being diagnosed?

Siberia was diagnosed with autism during early childhood, so he does not remember the process of being diagnosed. When he was older, he came across his special needs report and that's how he found out that he had autism. He described feeling different throughout primary and secondary school. He also experienced bullying.

#### Have you felt supported with your autism?

Though Siberia was diagnosed with autism as a child, he didn't receive any support at school, college or university. He described almost failing his degree due to a lack of support.

Siberia felt that there are many areas of life where support would be helpful, including with finding employment, making friends and finding a partner. He believes that people who are not autistic find it hard to talk to people with autism, as people with autism are seen as 'weird'. He also described how he feels that people think it is OK to ridicule or shame people for being autistic.

#### Employment support for people with autism

Siberia thinks that paid work experience may help people with autism integrate into the workplace. He observed that although there are schemes designed to increase workplace diversity, he has not come across any that focus on neurodiversity. He suggested that apprenticeships could also be a helpful way of people with autism getting into work. He would like to work in the film industry, however, he says that this industry isn't inclusive.



## Autism support at university

At university, Siberia would have liked support groups to help him with socialising. He would also have liked to see more tolerance from his peers and tutors; he felt that staff were negative and his university experience was not good.

The university provided Siberia with a note-taker, but he needed support like navigating and understanding what things meant. He believes that his low grades reflect the lack of support and not lack of intelligence. Siberia was able to complete practical course work but found essays and exams difficult. He feels that the option to do purely practical courses is needed, as in countries like Germany.

## Understanding, acceptance and a safe space to live

Siberia feels that people need to understand and 'accept us' (people with autism). He thinks that campaigns to help increase autism awareness could help people have a better understanding of autism.

In his home town, Siberia was a victim of hate crimes and was called offensive names which makes him feel sad. He shared that he had been targeted by one of his neighbours. When he complained to the housing trust he was threatened with violence by the neighbour. He experienced over a year of harassment before the police logged it as hate crime and stalking. Siberia feels that his safety is at risk and he just wants to live in a safe space.



## Autism Café and making friends

Siberia has found Autism Café a great way to make friends. He has made over 20 new friends since last year and he felt this would not have happened without Autism Café. As there are only autistic people attending the cafe, he doesn't feel worried about being judged on how he looks or sounds.

Siberia shared a negative experience he recently had at an autism group outside of Wolverhampton, where he was a victim of a verbal altercation which almost became physical. When he spoke with the group organisers about the situation that arose, he said: "They blamed it on me not understanding communication styles." He has been advised by Victim Support to report the incident to the police, but he needs help explaining his situation to the police. He has not been able to access suitable support to help him report the incident to the police yet.

## Christie's story

### A long and difficult wait to get the right support for her child

Christie shared her experience of waiting for her son's autism diagnosis while he continues to struggle in mainstream school without the right level of support.

### Secondary school recognised that her son may be autistic

The secondary school that Christie's son attended had recognised that her son maybe autistic and they referred him to the Child and Adolescent Mental Health Service (CAMHS). Christie had previously tried to refer her son to CAMHS but she had been told they are receiving referrals for 'children trying to kill themselves' and that her son was 'not an issue'.

## Inadequate support available at mainstream school

Christie shared that her son is very intelligent, but he has faced a difficult time in school and experienced bullying. She felt that he didn't fit into the system. He is currently receiving Special Educational Needs (SEN) support at school. However, Christie feels that the level and type of support provided is inadequate for her son's needs.

Christie commented: "Mainstream schools can't be expected to deal with everything", as there are not enough resources. She feels that schools do not always accept or reach out to external sources that may be able to provide additional support for children with SEN. Christie is hoping for her son to get a place at a school for children with SEN and she is currently awaiting the council's decision.



## The wait has been 'too long'

Her son had an initial assessment for autism in October 2022. He was then referred to the autism assessment panel who will decide whether to go ahead with further assessment to see if her son is autistic. Christie was told there was an 18-month waiting list for this stage of the diagnosis process, however CAMHS have said there is a three-year waiting list.

## No contact and no support while waiting for diagnosis

Christie feels that she has to keep chasing for updates because the waiting time is so long, and she worries that they may have been taken off the waiting list.

She said that she had to seek out her own support and many services won't see you until you have the diagnosis. The support she has received was mainly from voluntary sector groups that are independently set up as there were no other support services available. She stated: "Facebook is my saviour; I met other mums and have support/understanding from other parents."

Christie found out about the [Teen Life programme](#), but this also has a waiting list.

## Do you think that your son's experience of awaiting a diagnosis for autism has led to mental health problems?

Christie feels that her son's experience of school has been traumatic, which makes him feel scared and anxious to go to school. This is affecting his sleep and making him tired, which is further affecting his health. Christie described how parents are tired from fighting the system and fighting for assessments. Parents are also being fined for absences, without there being understanding of why the child is absent.

## What do you want from Wolverhampton's autism strategy?

Christie said she feels that diagnosis should be quicker and there should be provision of information while you wait for diagnosis. She also thinks that school resources and their approach to supporting children with autism and their parents should be looked at.

## Charlotte's story

### Challenges accessing support for autism while waiting for diagnosis

Charlotte shared her experience of the very long wait for her daughter to be assessed for autism and the ongoing challenges of accessing support without diagnosis.

#### When was your child diagnosed with autism?

Charlotte's daughter was attending a school for children with special needs since year two, as she has Hydrocephalus and learning difficulties. While at school, Charlotte's daughter started showing classic signs of autism. The paediatrician asked how long her daughter had been behaving in this way, but the school stated that this was just something she did. The paediatrician recommended that a diary should be kept tracking this behaviour. However, her daughter's school said they didn't have time to do this.

#### A two year waiting list for the first assessment

The paediatrician started the process of writing a report to send to the autism assessment panel. A report was also required from her daughters' school; Charlotte had to repeatedly check on their progress with this. The reports were sent off in May 2023, and in June 2023 they were referred to the autism assessment panel.

Charlotte hadn't received any communication from the panel so she discussed this with the paediatrician who told her this was usual. A short while later, Charlotte received a letter from the panel to say they had been accepted onto the waiting list and there would be a 24-28 month wait for the first assessment.

Charlotte has heard from people at [Voice4Parents](#) that once she goes to the first assessment panel, all professions meet to discuss reports and parents aren't always invited to that meeting, though it depends on who is running the panel. She has also heard that it can take up to five years to get to the panel meeting stage.

#### Autism diagnosis needed for additional support at school

Charlotte's daughter's teachers are saying that her daughter is showing all the sign of autism, but until she is officially diagnosed they are unable to record this on their system and access additional support. Autism diagnosis would mean that the school would be able to access extra funding and put extra support measures in place to better meet the needs of Charlotte's daughter.



A form tutor from the school rang Charlotte recently and said she was going to put in a referral for autism. She was unaware the referral had already been made because it had not been recorded on the school system. Within a week of the information being added to the school system, they had put in place sensory walks and a sensory diet and these measures are already helping Charlotte's daughter.

#### Unsure how to raise concerns

Charlotte does not know who to contact to follow up her concerns about the long wait for assessment. Although she has a phone number for the panel, they said they are unable to take follow up requests until the waiting list period is up for the first assessment and multiple assessments may be required.

## Survey results

The 28 responses we received through the online survey reinforced the issues raised during the more in-depth one-to-one conversations that took place during our community engagement activities.

### 1. Are you waiting to be diagnosed with autism?

Eleven people were waiting for a diagnosis, 17 were not.

### 2. If you have been assessed and/or diagnosed with autism, are you currently waiting for mental health support?

Six people selected 'I have been diagnosed with autism and I am currently waiting for diagnosis'.

Nine people selected 'I have been diagnosed with autism, but I am not currently waiting for mental health support'.

Two people preferred not to say.

### 3. What kind of support have you received while on the waiting list for an autism diagnosis?

Eighteen people said they are not receiving/have not received any support, and nine people said they are receiving/have received some support which some found helpful and some did not.

#### Comments from people who had not received any support:

🗨️ We were pretty much left to our own devices.

🗨️ I haven't even had a confirmation that I have been referred.



#### Comments from people who had received support:

🗨️ I do not think I received any support from my GP. Received informal support from Wolverhampton LGBT+ network.

🗨️ Autism group in Wednesfield and Pendeford meeting group

🗨️ I did not receive any support specifically for autism. I did obtain some support from The Recovery College for mental health. Mental illness is so common with autism.

🗨️ I am seeing a private psychologist.



- Q Very little! I was supported educationally via an EHCP, however received little input from health, other than a six-week course of peer support, with no follow on plan or strategy in place afterwards.
- Q Can't remember, as I got my diagnosis as early as seven years old, so the support I must have got was speech and language therapy as I was developmentally delayed.
- Q Nothing autism focused specifically. As I have mental health conditions, some of the support I get for that may inadvertently help managing traits.
- Q I was prescribed antidepressants that I didn't find helped all that much. Getting an appointment with my GP is extremely difficult.
- Q Online support sessions with Autism West Midlands.



#### 4. Has the support you received been sufficient?

Five people responded 'Yes', 20 people said 'No' and three people preferred not to say. Nine people provided detailed comments.

- Q We have had to fight for every bit of support given. We regularly heard of other parents who were given this support straight away. It seemed as if we were just thrown on the rubbish heap.
- Q No support apart from my family.
- Q There has been no direct support since I've had a diagnosis! All the support I currently have, I had to source for myself. There seems to be very little awareness of support for autistic adults within the NHS in the Wolverhampton area.
- Q Difficult contacting Social Services. There needs to be more support for adults over 25.
- Q Helpful advice and education around sensory processing, specifically coping with neighbour noise. Access to Work didn't understand my needs and suggested software and training that I didn't need, but couldn't offer the support I'd requested (around notetaking). My employer supported me with noise cancelling headphones and MindView [software].
- Q No support for high functioning females.
- Q My educational needs have been met, however my psychosocial needs less so. I have been signposted to groups within the community, but with no offer of support to attend. I find new places and new people very challenging, so while my mental health might/will improve with my attendance, I am unable to access these services without support.
- Q I got my diagnosis and was left to it. There is nothing in Wolverhampton for autism.
- Q It did not make me well, but it did help.





## 5. What further support would help?

All 28 respondents provided feedback for this question. Responses provided were analysed and the following key topics were highlighted around what further support people would like.

### Communication and provision of information

- Information about what the autism assessment and diagnosis process involves and what to expect.
- Information about what support is available throughout the different stages of the process of autism diagnosis, and signposting to relevant services.
- Access to autism specific information and resources that may help people while they are awaiting diagnosis. One respondent suggested “references to books or media to help support suspected autistic people on how to manage ‘life’ and understand the condition better.”
- Regular updates on waiting lists for diagnosis and what the expected waiting time is. One respondent had just been told “nothing will happen for at least 14 months.”

### Support services for people with autism

- One-to-one support to discuss feelings and concerns, for example, through a support worker or mentoring.
- Local peer support groups to connect with other people awaiting diagnosis.
- Practical classes and support tailored for autistic adults, to help with things like applying for PIP and other benefits, access card for autism, skills including travelling and planning a journey, and public speaking.
- Employment support to assist people with autism to find work.
- Increased understanding from health care professionals about the impact of autism diagnosis on other aspects of a person’s life and understanding of the conditions that commonly co-occur with autism, for example, mental health conditions such as depression.
- Provision of mental health support.

### Other factors

- Increased understanding in the community of sensory issues that people with autism may face, particularly regarding noise levels.
- One respondent stated: “Putting the necessary procedures in place to properly assess and diagnose, not wait until a young person ends up in a CAMHS unit for months, before they are diagnosed... and not in Wolverhampton as these facilities weren’t there.”



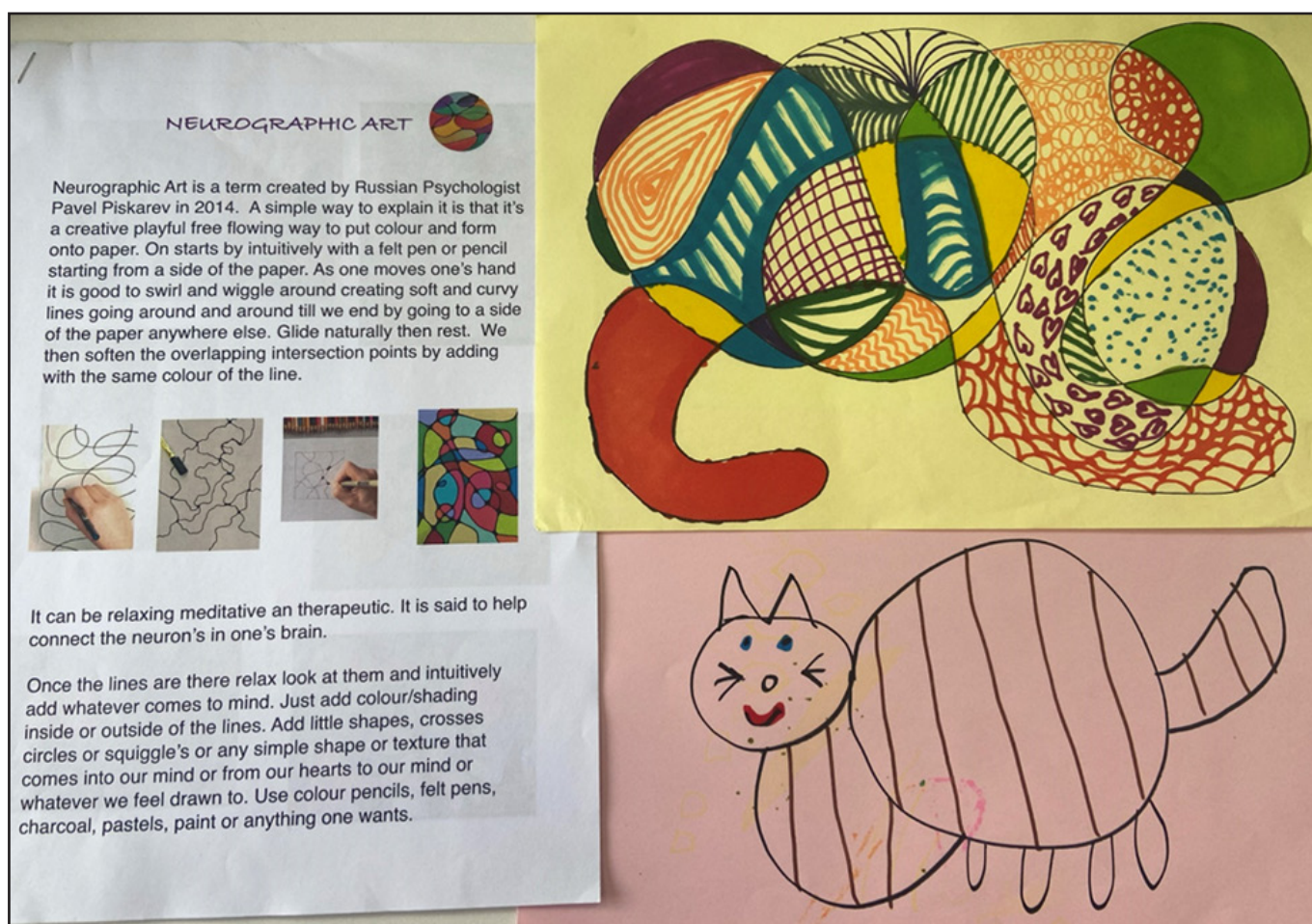
The following survey response summarises the wide range of issues and support needs raised by people who completed our survey.

The main issues for autistic adults mirror those of people with disabilities in general. Namely, accessing education and training; finding suitable employment and succeeding within a workplace (employment figures for autistic people are shockingly low, also underemployment is equally a significant problem); finding somewhere to live (most autistic people don't have financial independence and are therefore excluded from the housing market, often leaving them vulnerable to homelessness); loneliness and social exclusion (autistic people are far more likely to be isolated from the rest of society, spending much of their time alone and prone to developing depression and suicidal thoughts as a consequence). There's also an issue with, and/or a lack of, widespread understanding within the medical community about the additional health needs, associated medical conditions and co-morbidities that autistic people experience.



## Peer support group: Adult Autism Matters

The themes that arose across the case studies and the survey also reflect what we heard at the online listening group and at the two Adult Autism Matters (AAM) peer support meetings we attended.



*We did neurographic art with the AAM group to help people relax and communicate their thoughts and feelings.*

One person we spoke to at an AAM session described how they had been seeing a psychiatrist for over 10 years for a particular mental health issue, but it was when they were seeking support for a mental health problem at [The Recovery College](#) that someone advised them about seeking an autism diagnosis.

They also described that when they were diagnosed with autism, they didn't understand what it meant. It wasn't until they watched a documentary called *Inside our Autistic Minds* by Chris Packham that they were able to get a better understanding of autism, how it can impact behaviour and traits, and what 'masking' is (the conscious or subconscious suppression of autistic behaviours). This enabled them to understand some of the autistic traits and behaviours that they have. They felt that provision of information about autism when they were diagnosed, including on what masking is, would have been very helpful; it would have allowed them to have a better understanding of their autism diagnosis.



They also shared that they discovered the AAM peer support group on Facebook. They said that attending the group has been very helpful and they are not aware of any other peer support groups for adults with autism in Wolverhampton.

We also met someone who spoke about the experiences they had with their children. One child was diagnosed with Asperger's Syndrome in their teens and autism in their 30s. They shared how when their child was younger and exhibited traits and behaviours associated with autism, they were described as a 'bad parent' by people. They also described the impact this blame had on their emotional wellbeing. This person's experiences highlight two key points. Firstly, there appears to have been a lack of autism awareness which has resulted in some people being diagnosed with autism much later in life, even though they were in contact with healthcare professionals earlier in their lives. Secondly, the impact of late autism diagnosis and coming to terms with the impact that autism has had on people's earlier life experiences, can extend to family members as well as the individual themselves.

## Conclusion and recommendations

We have analysed what people have told us through community engagement and our survey. Through our research, we have heard about the long waiting time for autism assessment and diagnosis – this is a systems level issue that needs to be addressed. We have also identified the lack of communication, information, and support as key issues that people are experiencing in their autism diagnosis journey. We recommend the following actions to help those responsible for autism services in Wolverhampton tackle these key areas and improve support for local people.

### Information and communication

It is important to make it easy for everyone to access helpful and accurate information about autism, including information on autistic behaviours and traits, and the autism assessment and diagnosis process in Wolverhampton.

People described having to research autism themselves to find the information they needed. They also described a lack of communication and updates while on the autism assessment waiting list. Some people may not have the ability or the resources, like technology, to be able to search for the information they need. These differences in the information that people access could contribute to health inequalities. Having to search for information online may also expose some people to inaccurate or out-of-date information, which may be harmful to their health and wellbeing.

**We recommend:**

- Production of information leaflets and videos in English and other languages, addressing this information gap, and distribution in key community locations including primary and mental health care settings, and at autism groups to allow for easier access.
- Review of the frequency of communication between the autism assessment panel and people awaiting diagnosis for autism.

## Support

People lacked access to support while awaiting autism diagnosis and after diagnosis. Those awaiting diagnosis are unable to access some support services without a diagnosis.

A range of support services are required to help people diagnosed with autism and those awaiting diagnosis to acquire and develop the skills and social connections that they need, in order to navigate day-to-day life and manage the impact that their autism may have on their lives.

Areas where people discussed the need for support included peer support groups and making friends, skills such as planning a journey and using public transport, and finding and applying for jobs. Difficulty accessing mental health support is another key issue to address, as mental health conditions such as depression and anxiety often co-exist with autism.

Peer support groups and other community support groups provide people with an opportunity to talk with people experiencing similar things. They can also allow for the exchange of helpful information and help people feel less isolated, which may in turn also help with mental health.

**We recommend:**

- A review of what local peer support groups and mental health support is available for people that have been diagnosed with autism and people that are still waiting for autism diagnosis, followed by production of resources that can be used to signpost people to these support groups in the community.
- Identification, funding and promotion of the community groups available that can help people with autism in developing skills that would help them with everyday life.
- Employment support available for adults with autism should be reviewed by the Council.
- Parents should have access to local Special Educational Needs and Disabilities (SEND) officers while waiting for and following their child's autism diagnosis. The [Wolverhampton Outreach Service](#) offers support to mainstream schools to help them adapt their practices in order to facilitate the inclusion of children with SEN. This service could also be helpful to parents of children attending mainstream schools when communicating with schools regarding their child's needs. A review of how and where this service is promoted to parents who may find it beneficial, should be conducted.

## Awareness and tackling stigma

From conversations we had with people during our community engagement, we heard about the stigma that is still associated with autism. This can act as a barrier to people with autism, making them feel like they don't fit into society and the communities they are a part of. It may also be a barrier to people with autism making friends and finding employment.

## We recommend:

- Working with people with autism to co-produce, design and deliver information and educational resources on autism awareness, for use in schools and universities, and also for wider use in the community. For example, information leaflets to address the information gaps identified in this report.
- Co-production of a citywide public autism awareness campaign, for example during [World Autism Acceptance Week](#).
- The [Oliver McGowan Mandatory Training on Learning Disability and Autism](#) for health and social care staff, is designed to give staff the knowledge and skills that are needed to provide safe and compassionate care for people with a learning disability or autism. The design of similar training is to be used by employers, to help them and their staff better understand the needs of people with autism and what they can do to support them better in the workplace.



## Next steps

We have shared this report with the NHS Black Country Integrated Care Board (ICB) to inform their work looking at health inequalities and coordination of autism services and policies at the Black Country level. We have also shared our findings with the Wolverhampton Autism Board, who are in the process of implementing the Wolverhampton Autism Strategy which has been adapted from the National Autism Strategy.

## Thank you

We want to thank all the people who shared their experiences with us at events and by responding to our survey, and a special thanks to those who contributed to our case studies. We would also like to thank the Autism Café and Adult Autism Matters peer support group for allowing us to attend their meetings. Hearing about your experiences has allowed us to better understand some of the issues that people face, with autism and autism diagnosis, and this has allowed us to identify some areas where improvements can be made.

We would also like to thank all our volunteers who contributed to our community engagement work.

# Further information

1. **National Autistic Society:** [www.autism.org.uk](http://www.autism.org.uk)
2. ***Inside our Autistic Minds***, BBC documentary series with Chris Packham (TV licence required): [www.bbc.co.uk/iplayer/episodes/p0bbnh47/inside-our-autistic-minds](http://www.bbc.co.uk/iplayer/episodes/p0bbnh47/inside-our-autistic-minds)
3. **Voice4parents Wolverhampton:** [www.voice4parents-wolves.co.uk](http://www.voice4parents-wolves.co.uk)
4. **Dudley Voices for Choice:** [www.dudleyvoicesforchoice.org.uk](http://www.dudleyvoicesforchoice.org.uk)
5. **City of Wolverhampton Council Information Network**, information about other services and support, including the AAM peer support group, Autism West Midlands and SEN support: [www.wolverhampton.gov.uk/community/wolverhampton-information-network](http://www.wolverhampton.gov.uk/community/wolverhampton-information-network)



# healthwatch

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