



Adults with autism: People's experiences of the autism assessment process in Gloucestershire

February 2023

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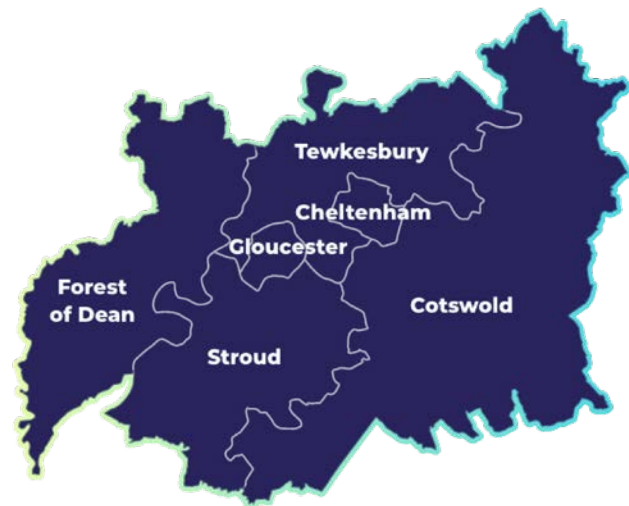
About us

Healthwatch Gloucestershire is the county'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. This report is an example of how your views are shared.

Healthwatch Gloucestershire is part of a network of over 150 local Healthwatch across the country. We cover the geographical area of Gloucestershire County Council, which includes the districts and boroughs of Cheltenham, Cotswold, Forest of Dean, Gloucester, Stroud, and Tewkesbury.



Introduction

Background

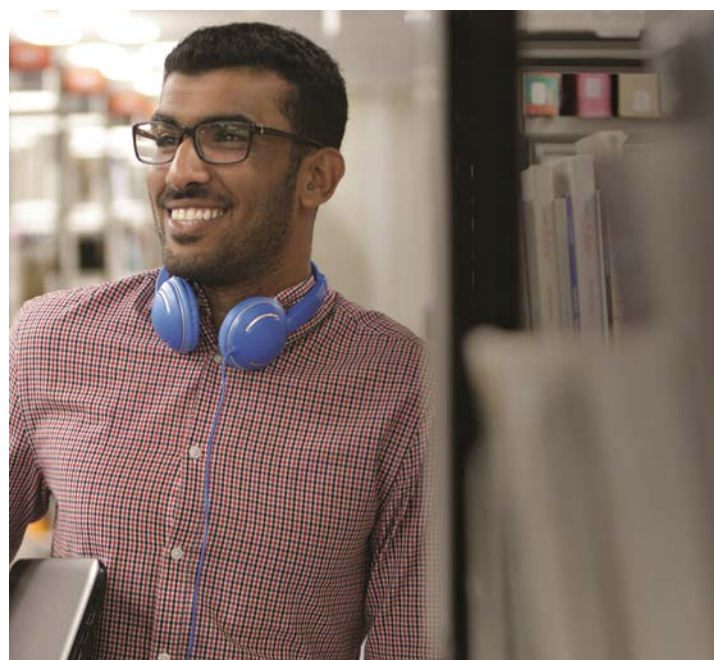
We have been hearing from adults who have asked to be referred for an autism assessment. Through the feedback we have received, we are aware that waiting times for assessment have increased recently.

We wanted to explore in more detail the experiences of adults with autism who do not have a diagnosed learning disability, and who have tried to access the assessment service in Gloucestershire.

What we wanted to find out

We wanted to hear people's experiences of navigating their way through the health and social care pathway for autism – from requesting a referral, to accessing the assessment service, waiting for an assessment, the assessment process, and getting support. We also wanted to learn about the outcomes – whether people were diagnosed and how their experience had affected their health and wellbeing.

Our aim was to understand what is good about the autism service and what could be improved. We also wanted to know if adults with autism experience barriers or difficulties when using primary care services (such as GPs, dentists, pharmacies, opticians), community care services, hospitals, or social care services.





What we did

We worked on the project from August to early October 2022, actively engaging with people about their experiences from September.

Understanding autism

Before starting this project, we worked with the Independence Trust, [Community Autism Support & Advice \(CASA\) Service](#) for Gloucestershire. They provided 'What is autism?' training for our staff and volunteers, and they made sure we asked relevant and appropriate questions. They also invited us to some of the drop-in sessions they run to support adults with autism.

Gathering people's feedback

We wanted people to be able to share their feedback using their preferred method of communication. We offered one-to-one conversations (in person, online or over the phone) as we were aware people might be more comfortable engaging with us in this way. We also provided an online and paper survey.

Volunteer research

A group of our volunteers carried out research to help us understand what information, support and signposting is available for the public in Gloucestershire about the health and care process to support adults with autism. We gave them a list of questions to investigate and answer (see Appendix 1).

Who we spoke to

One-to-one conversations

Fifteen people shared their experiences with us through one-to-one conversations. Two of the 15 have since decided that they did not want their feedback to be used, so their stories and comments have not been included in this report.

You can read a summary of what people told us in Appendix 2. You can also read people's full stories as case studies (pages 8-13) and in Appendix 3.

Survey

We received 12 responses via the online survey. The overall themes reflected those discussed during the one-to-one conversations (see Appendix 4).

Since this engagement project closed, more people have wanted to share their stories with us. We will continue to listen to people's experiences, and record and share their feedback to help services develop and improve for people with autism.

Key messages

The key themes that emerged from what people told us, and from our volunteer's research, are mainly around the need for better information, communication, awareness and support.

- There is no 'one place' in Gloucestershire for people to find accurate and up-to-date information about autism and the health and care support that's available.
- Most people do not know whether they are on the waiting list for an autism assessment or how long the wait will be.
- Once on the waiting list, people rarely hear anything from the service.
- When people are invited for an assessment, they are unsure of the process, how long it will take and who will be involved.
- There is a lack of awareness and training on women with autism, including around masking behaviours that women may adopt to hide/manage their autistic traits.
- Most people are not aware of any advocacy help available in Gloucestershire which might be available to support them in the workplace and with medical appointments.
- People who are advised that they are not autistic after assessment are left with no help and support.

Recommendations

We believe that health and social care providers can best improve services by listening to people's experiences. We have analysed what people told us and what we discovered through our research, and we recommend the following actions to improve care and support for adults with autism in Gloucestershire.

Information and communication

- Provide everyone who seeks support for autism with a leaflet or document outlining the process from referral to assessment, diagnosis, treatment and support. Explain clearly what to expect and when and use 'experts by experience' to help with writing and design.
- Everyone should receive a letter or email from the autism assessment service confirming they are on the waiting list, with realistic timescales for when they should be seen.
- The autism assessment service should contact people on the waiting list every six months to update them on waiting times and to check in on them.
- When people are invited for assessment, they should receive a letter explaining what will happen, how long it will take and who will be involved.
- Develop an information resource or place where all documentation is up to date and available to everyone, irrespective of where they are in the process.



Support

- Workshops to support people who have received a diagnosis should be offered in the evenings and at weekends, to accommodate those who are working.
- Offer different options for support and make these person-centred and tailored to individual needs as far as possible. For example, providing written, verbal, and visual support.
- Advocacy should be offered to assist adults with autism in the workplace and with medical appointments.
- When a person has been through the assessment process, the GP should receive details of the outcome to ensure their records are updated.
- Use Social Prescribers to contact people and their families once their GP records have been updated with the autism diagnosis. They should provide practical help, including signposting to relevant groups, websites and support in their area.
- People who are advised they do not have autism after an assessment, should be contacted and signposted by Social Prescribers or similar to where they can receive further help and support.

Experts by Experience

- Become more proactive by using Experts by Experience across the whole service. Employ people to provide their expertise, including by codesigning the literature and leaflets that are provided to people starting the autism assessment process.
- Work with Experts by Experience to develop an information resource that everyone can use to find out further information about autism and the assessment process. This should include links to available resources, groups, and professional services. It should also have clear details of the process to be followed, realistic timescales, who is involved, and any other advice and guidance to make sure every person can make an informed decision on whether to proceed. There should also be information and advice for those who have been through the process and are advised they are not autistic.
- Work with Experts by Experience to develop training around autistic women and masking, to raise awareness across the system.
- Employ Experts by Experience to offer help and support to those going through the process, and still on the waiting list.

Raising awareness

- In addition to the [Oliver McGowan Mandatory Training on Learning Disability and Autism](#), all health and care workers should receive training and awareness of women with autism and how they are able to mask.

In your own words

Diagnosis

Receiving this diagnosis has now changed my life.

This was a proper light bulb moment for me and when I reflected back to my earlier years, it made sense.

You cannot access a lot of help without a diagnosis, which is difficult and affects everything in your life, both physically and mentally.

I had permission to be me.

Having this diagnosis absolves me of all the negative labels.

Diagnosis has enabled me to peel the mask away and be myself.

Challenges

Managing my own thoughts and behaviour feels like dealing with a bucket of snakes.

Either I am really busy or I stop and there is nothing in between.

I feel pretty much dead inside because I have never been me.

Throughout my life there have been glass ceilings and I have had to try twice as hard to get half as far.

I know I have to take control of this journey to ensure it happens.



Support

I am ill and I need help please.

I do not feel terribly supported but I am used to that.

Attending the CASA drop-in sessions has changed my world.

Not wrong, just different

I have been living the past 40+ years in a field with horses where I was always trying to be a horse, but now I know I am actually a zebra.

I knew I was quite different from others – not wrong, just different.

We like connection, although we may not do it in the right way.

I like being me and wish the world accepted me the way I am!

Case studies

Julie's story

Diagnosis in her 60s felt like a new beginning

Son diagnosed in his 30s

Julie is in her early 70s and has three grown up children. As a child, her youngest had epilepsy and she had concerns about him but no one seemed to help. She had always known there was something different about him, but he was not interested in pursuing it. This changed in his 30s when a friend was diagnosed with autism, so he decided to get assessed, and he received the same diagnosis.

Mother diagnosed in her 60s

Julie is now retired and despite having a professional career, over the years she has wondered whether she too has autism. She has always experienced anxiety, depression, and social anxiety, and going to the GP practice made her feel uncomfortable.

When Julie moved to Gloucestershire her GP (wrongly) advised that she didn't think autism ran in families. Despite this, Julie decided to go through with the assessment; she was shocked when she received the autism diagnosis in 2018.



The assessment process was unsettling but positive

Julie's experience of going through the assessment process was very positive and she only waited about six to nine months.

The initial appointment lasted about two or three hours and the professionals also wanted to know why she wanted to explore this in her late 60s. The second appointment involved a lot of talking and puzzles – she cried all the way through this because she found it stressful, upsetting, unnerving, and unsettling. She described the assessment room as very uninviting and stark. She described the assessment process as 'poking the bear'.

At the end of the second appointment, Julie was asked to leave the room for 20 minutes and she was very anxious when she returned. She was then told that she had met all three of the criteria and was receiving a diagnosis of autism.

It took time to accept the diagnosis

Julie was very surprised to receive the autism diagnosis, her family were stunned and her daughter was very upset.



Julie said it took her about two years to accept as she needed time to process it, and she cried a lot. Also, given her previous professional role, Julie felt the diagnosis undermined all the work she had done over the years.

She said part of her surprise around the diagnosis was because while working, "I could feel other peoples' feelings and could not marry this up with my own diagnosis." During her life she has worked in schools and hospitals and she feels she was able to mask her autism well at work because she was approaching her role as a professional.

Once Julie had accepted the diagnosis, so much fitted into place. She joined some Facebook groups to find out more, and she feels there is a lot of misinformation on the internet about female autism, which is worrying.



Benefits of receiving a diagnosis

When asked about the pros and cons of receiving the diagnosis, Julie said it has been very stressful and helpful at the same time.

 **When I finally accepted it, it felt like a new beginning and I had permission to be me. I have always thought I was not good enough and it has improved my self-esteem.** 

Julie now realises, "you are a wholly autistic person and it doesn't just affect certain parts of your life."

The diagnosis has helped with some of her family relationships – she feels they have stopped blaming her and now realise why she sometimes has meltdowns.

 **I now feel I have lived my life with one arm and one leg tied behind my back. Having said the above, I would not have had my career had I been diagnosed earlier.** 

Support after diagnosis

After the assessment Julie was offered an eight-week course where different topics were covered and this really helped her to understand the breadth of the autism spectrum. She also saw someone about her sensitivities to light, smell, sound, and touch, and she was told that only two percent of the population are as sensitive as she is.

Looking back, Julie remembers even as a child she did not like any of her food touching another food, so the carrots must not touch the peas, and she used to eat one thing at a time, although she no longer does this.

Once you receive the diagnosis, you understand yourself better and do not beat yourself up anymore.

Content with family life

Julie has had difficulties with female friendships throughout her life and doesn't really have any. When they moved to Gloucestershire, she decided not to try to make any friends and does not feel the need to have anything else, as what she has is enough for her.

She and her husband socialise with their family and she has two of her three children living close by. They have dogs which they enjoy and Julie goes out walking with them, when she feels up to it (she has a number of health conditions including fibromyalgia, chronic fatigue and pain).

Julie always worked, even when the children were young and used to do some voluntary work, but she is now happy with the way her life is.

Aaron's story

His child's struggles led to his own diagnosis

A lifetime feeling 'out of phase'

Aaron is in his early 40s, married with children. He is an only child and his life has followed a conventional path. He went to school, where he always felt like the odd one in the class. He went to college, university, and started work. He had a few jobs, got married and had children. However, Aaron describes experiencing "a lifetime of feeling out of phase and not understanding why friendships were so awkward."

Relating to his child's struggles

Several years ago he started to notice his eldest child was really struggling in group situations and was reacting in slightly different ways to other children. He realised he could empathise, but at the same time, felt his child had not had the life experiences he had, so wondered how they could both feel the same way?

Seeking understanding and support from his GP

Aaron is very analytical and having spent a lot of time analysing the situation he decided the next step was to visit the GP with his child. He explained there was something 'not right' with the two of them and there were tears; "we had a moment." He also spoke to the school and got them involved.

The GP gave Aaron some research to do and he recommended the Let's Talk Service where Aaron had four sessions of Cognitive Behavioural Therapy (CBT), but he did not feel it helped or worked at all. He was then referred to the next level of Let's Talk which he describes as the 'semi-finals'.



Long NHS wait led to private assessment and treatment

Having waited six months for the first appointment, he became frustrated and decided to try to access the services through his work-based private medical insurance. He was referred to a psychotherapist and by this point he had already worked out he had social anxiety, which he was able to talk about. The psychotherapist referred him to a psychologist where it was confirmed he has chronic social anxiety and he was prescribed medication. These sessions continued for six months and at this point, Aaron felt they were going around in circles and he still felt there was something missing.

At Christmas 2017 Aaron's psychologist advised he clearly had chronic social and general anxiety, but he was not ticking all the boxes and felt it would be beneficial to do some autism checks. They completed the paperwork and continued with their discussions to explore this more.

At this same time, Aaron saw a documentary about TV wildlife presenter, Chris Packham's Asperger's (as ASD used to be called); Aaron said, "he described the world the way I see it."

Diagnosis after a life of 'masking'

The results came back in 2018 and it was confirmed Aaron is autistic and highly intelligent. The psychologist explained he had spent his entire life watching other people and mimicking and analysing them to see what they are like and then copying them. In effect, he had become a master at masking.

This was a proper light switch moment for me and when I reflected back to my earlier years, it made sense. Having this diagnosis has enabled me to peel the mask away and be myself.

Difficulties managing appointments alone

When asked about attending other appointments, Aaron explained he is very co-dependent with his wife and they tend to go everywhere together because he does not do well on his own. He has no sense of direction at all and if his wife is unable to attend appointments with him, he will either cancel or say he cannot make it, but he would never just not turn up.

His earlier life now makes more sense

When Aaron told his mum about his autism diagnosis, she felt it explained quite a lot about him as a child. As a child he never wanted to go anywhere and was much happier playing with his Lego and he did not have any friends. This did not change until he went to college, although he was still an introvert - one of his friends said to him, "an introvert often has friends when an extrovert drags them along."

Having had time to reflect on his earlier life, Aaron can now see he started to build the mask as a teenager and at the time this was put down to him 'being a teenager'.

This was the start of the hollowing out of myself to ensure I fitted in.





Let's Talk therapy services

During the CBT sessions, Aaron described some of the scenarios he was asked to imagine and how he struggled with them. When he turned the tables and asked how they would feel without their right arm, and asked what it was like, they could not answer.



He was still engaging with the Let's Talk service and now he was able to show the official paperwork confirming the diagnosis. "Despite this, I was not listened to until the end of the session, and then I was offered an additional NHS NICE Autism Assessment."

A 'horrible experience' with NHS autism assessment service

Aaron describes his NHS autism assessment as a 'horrible experience' which culminated in them advising him he was not autistic. He also felt he was treated with scepticism and was asked why he was pursuing this and what he wanted to get out of the diagnosis.

 **They viewed me like a typical male, whereas I present like a female and mask really well. One of the comments made was that I reacted to a joke one of the assessors made, so I couldn't be autistic. I feel I have lived half my life by adapting to others and masking, so of course I am able to laugh at a joke.** 


Thankfully, Aaron was able to make contact again with the private psychologist who was very shocked at what had happened and arranged for the diagnosis to be added to Aaron's NHS records towards the end of 2019.


 **When I first logged on and read this on my NHS records, I burst into tears, as this had followed a lifetime of confusion.** 

No support offered since diagnosis

Aaron has not been offered any support since his diagnosis was added to his NHS records, and no one has reached out to him or his family.

When asked about what help he needs or would find useful, he explained that he has no idea because no one has ever spoken to him about it, so he felt unable to answer.

 **In a perfect world someone would reach out and tell me what support there is and how I could access it. Everything I have learnt has been through my own research.**



I have struggled this long and will keep analysing and re-analysing. I have a duality of existence and I am in flux between masking and autism. I can often see and understand what is different and I am able to look at it from a third-person point of view and have a discussion with myself. 

Reluctant to seek further NHS care

The experience of going through this has made Aaron almost too scared to go to the NHS about anything else, because he is so worried he will be told once again he is not autistic when he knows he is.

Social and sensory challenges

Aaron describes how he feels very uncomfortable with people he does not know.

 **I am too weird to be normal and too normal to be weird. I feel pretty much dead inside because I have never been me.** 

When asked about sensitivities he explained he is happy with loud music if he has chosen it for himself and is in control of it. He has an issue with silence at home and if the family are not around, he has the radio on.

One of my coping mechanisms is by playing very loud music which is on so loudly that it quietsens my brain when I am trying to think. The loud music forces my brain down to a single point of focus.



He is very light sensitive, lives in sunglasses and does not like overhead lights at all. He does not like to be touched by people he does not know and although he has some friends who are 'huggers', he can cope with this because he is expecting it. He also has a very high pain threshold.

Managing with life after diagnosis

Aaron does not tell many people about his diagnosis and describes himself as "the most openly private person a lot of people have met."

I am quite scarred and burnt out from the medical profession so I do not tell them and I am very good at interception. I know I have to deal with things and it is the benefit and struggle with a late diagnosis. It does not occur to me to ask for a reasonable adjustment because I have always dealt with it all my life.



In his own environment Aaron is sort of able to be himself, but at the same time has to fit in. When talking about his wife, Aaron says in her world she did not meet an autistic person and met someone who was a 'bit funny'. Now he is starting to peel the mask away, she feels she does not know him and doesn't think she ever will.

Awareness and understanding

People know very little about autism and no one gets it because of 'our spiky profiles'.

Even though sometimes people get it wrong, Aaron would much prefer people give it a go and are not afraid to get it wrong.

The silence is far worse than someone having a go. I watch the world and this is how I have got this far in life.



Aaron explained that he has talked to his therapist about feeling like he has no self-awareness. However, the therapist thought Aaron has a lot of self-awareness and because of this he finds he cannot fit in society and at the same time he cannot see a way society can fit in with him.

I am still coming to terms with being autistic and it would have been great to hear from someone and be offered help and support – to have some help with the validation. Most of what I do is to normalise the conversation and it would be so nice not to have to do this.



How your feedback makes a difference

This report will be sent to the Gloucestershire Health & Care NHS Foundation Trust and we will share it widely with all partners directly and indirectly involved in the Autism Service, including the commissioners. We hope this will support the work of the Partnership Boards to facilitate and enable conversations on the future development of the Autism Assessment Service.

Stakeholder response

Gloucestershire Health and Care NHS Foundation Trust
John Trevains, Director of Nursing, Therapies & Quality
Director of Infection Prevention & Control



User feedback is valuable and welcome

We very much welcome this report from Healthwatch to help improve services in Gloucestershire. Feedback from people who use this service and community partners is invaluable to help us learn and better identify the needs of our local communities.

We are aware that many people have been waiting a significant length of time for contact with the service and for this we apologise. We also apologise to those that haven't been fully satisfied with the service they have received.

The points highlighted regarding the areas of need have been considered in detail and will help us, with commissioning support, to build on the service that we provide. It may be helpful to define our current service demand and also to outline some of the next steps to be considered.

Unexpected and unprecedented demand for assessment

We currently have a small dedicated team working to provide the best possible outcomes and experiences that we can. The Autistic Spectrum Condition (ASC) assessment service is experiencing an unexpected and unprecedented number of referrals following the Covid-19 pandemic and the demand for the service significantly outweighs the current service capacity and the original commissioning parameters of the service. At present there isn't a clear reason for this increase in referrals as the research is yet to be undertaken, but there is anecdotal evidence that increased public awareness has prompted/enabled individuals to seek support and a potential diagnosis.

The Gloucestershire ASC service is currently commissioned and resourced to provide **100 diagnostic assessments per year** which equates to approximately two referrals a week. **However, the service actually receives on average 572 referrals per year which equates to 11 referrals each week.** This is a **77% increase** in referrals from pre-pandemic levels. Sadly as a result, the current waiting times are on average **3.2 years** which we do recognise is far too long for people seeking an assessment.

Actions to reduce waiting times and improve service

We are working with our Commissioners to help better support our service and the Gloucestershire Integrated Care Board (ICB) have commissioned additional providers to work alongside Gloucestershire Health and Care (GHC) ASC service on a waiting list initiative, so we anticipate a reduction in the waiting times for ASC diagnostic assessment over the next six months. A working group has been established and is formulating a full options appraisal paper for further service improvements to present to ICB colleagues for consideration.

We particularly welcome the stakeholder engagement work that Healthwatch has undertaken and the teams are working on the suggestions made in the report such as:

- Following the suggestion from this Healthwatch report we are actively writing to individuals on our waiting list in order to keep in touch and maintain contact.
- The team is also holding a training session for GPs and other professionals to help with the referral process in order to improve communication and referral pathways.
- Providing everyone who seeks support for autism with a leaflet or document outlining the process from referral to assessment, diagnosis, treatment and support. Explaining clearly what to expect and when, and use Experts by Experience to help with writing and design.
- Ensuring that an information resource or place where all documentation is up-to-date and is available to everyone, irrespective of where they are in the process.
- Trying to offer different options for support and make these person-centred and tailored to individual needs as far as possible. For example, providing written, verbal, and visual support.
- Using Social Prescribers to offer support if consent has been obtained to provide practical help, including signposting to relevant groups, websites and support in their area.
- Working far closer with Experts by Experience in developing literature, training and awareness particularly around supporting women who may 'mask' their difficulties.

Thank you

Thank you to the Independence Trust (CASA) Service for their help and support throughout this project. The autism training for our staff and volunteers was invaluable, as were our visits to your drop-in sessions and all the other guidance and support given.

Thanks also to everyone who took the time to share their story with us. Your openness and honesty have provided us with a powerful insight into your day-to-day struggles, and your views about how the service could be improved will help to make care better for autistic people in Gloucestershire.

Thank you to our volunteers who spent hours looking for information and answering our research questions.



Appendices

1. Volunteer research

We asked a group of our volunteers to research what information, support and signposting there is for the public in Gloucestershire around care and support for adults with autism. Nine volunteers spent a total of 49 hours working on this research. These are the questions we asked them to research with a summary of their overall responses.

1. Look at the autism assessment process for an adult, including the following:

• How is a referral made for an assessment?

Almost everyone used Google to research this and found the Autism Spectrum Condition (ASC) Service, which clearly states most people will require a referral from their GP. The exceptions to this are when an individual is already seeing a psychologist or psychiatrist, or they are under the care of Gloucestershire Health & Care NHS Foundation Trust.

Lots of the volunteers found quite a bit of information on referrals for children and young people. Some came across information on private assessments, although one found this may not be accepted by the local authority, even if claimed to be National Institute for Health and Care Excellence (NICE) compliant.

• What is involved in the assessment process (eg time, appointments etc)?

Both online and over the phone the volunteers were able to find out that there are two assessment appointments, usually several weeks apart. They found out that the appointments are conducted by mental health nurses, they take around three hours or half a day, and they can take place in person or online.

Some volunteers found information on the two appointments, while others spoke of the second appointment being only for those deemed to be complex cases, with the person being asked to bring a family member or close friend with them.

• What is the current timescale for the whole assessment to take place?

Most volunteers who explored this question were advised the current waiting time is 2½–3 years, although one volunteer was advised the wait is now five years. Once the process begins, there is around 6–8 weeks between sessions one and two.

• Is there any support available while people are going through the referral and assessment process? If so, what?

Most of the volunteers struggled to find out about support available in Gloucestershire. They were advised the Autism Spectrum Condition Service are unable to provide any support during this time, and people should contact their GP, and if appropriate, ask them for a referral to [Let's Talk](#), NHS Gloucestershire's Improving Access to Psychological Therapies (IAPT) service. The GP could also give advice on how to manage their condition in the interim.

A few of the volunteers spoke directly to ASC staff and described this as 'very straightforward' and the staff as being 'very helpful'. One volunteer spoke to the Manager who wanted to speak to their communications team before providing further information on the assessment process and diagnosis, although this did not materialise.

• Is there any information available about how to get support (paper or online)?

Most of the volunteers struggled to find any information about support available during the assessment process; people are mostly left to their own devices.

• Is there anything else you can find that relates to the assessment process?

There was some confusion on what, if any, follow up sessions there were for those who receive a diagnosis. Some volunteers found information on a six session course, while others were advised of a seven session course involving weekly two-hour sessions of up to ten people.

Many volunteers found information relating to CASA (Community Autism Support & Advice) Service, although this appeared to only be available once an individual received a diagnosis.

Some information on websites was either out of date, took our volunteers down some rabbit holes, or was incorrect. Each time they advised the service of this, they were ensured the details would be updated where applicable.

There is little to no information available to those who do not receive a diagnosis.

2. Is there any support available to adults diagnosed with autism in relation to accessing publicly funded health and care services. Consider the following:

• What support is available and where can people find it?

Lots of the volunteers struggled to find appropriate and relevant information. Some found information through the [Autism Research Institute](#), although they did not feel this was particularly relevant.

One volunteer did find some information via the [NHS England website](#). There they found a direct link to the [National Autistic Society](#) and local support information can be accessed via this link: [Where to get support if you're autistic | NHS](#) which enables a direct search by postcode for support agencies in the immediate area.

Some found the [CASA \(Community Autism Support & Advice\) Service](#) although there was no specific information on their website on support about health and care services.

One of the volunteers read two Gloucestershire Autism Strategies and still struggled to find anything relevant.

• Who is the support available for?

Most of the support available (when it could be found) was for those who have received a diagnosis, although little relates directly to health and care services.

• What format was the information available in (online/leaflets etc)?

All available Information was found online, although it took some digging to find it.

• Were there any challenges in finding this information?

Many of the volunteers found themselves going around in circles trying to find relevant information, with one saying, "I ended up feeling rather frustrated and that, although relatively easy to ask for an assessment, it's likely to be a long wait with not much support."

3. Useful websites

- NHS website: www.nhs.uk/conditions/autism
- National Autistic Society: www.autism.org.uk
- Gloucestershire Health and Care NHS Trust: www.ghc.nhs.uk/our-teams-and-services/asc-service
- Independence Trust: www.independencetrust.co.uk

2. One-to-one conversations

Fifteen people shared their experiences with us through one-to-one conversations, but two people did not want their feedback to be included in the report. We used the following questions to guide our discussions and the main responses are summarised.

1. Have you had an autism assessment or are you still waiting?

Two of the 13 people we spoke to were still waiting for an assessment and 11 had already been through the assessment process. Five people had paid privately for their diagnosis, and four people had more than one assessment.

One person had a private diagnosis, but this is not being recognised, so they had to join the NHS waiting list again and their GP advised that the waiting time is now four years.

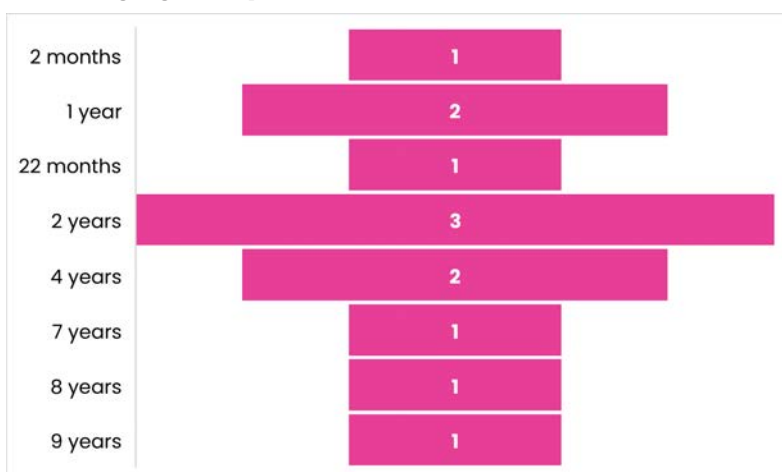
“I felt slurred and invalidated by the system.”

Another person paid privately for an assessment after waiting two years and being told they would have to wait a further 18 months. Despite going into debt, they felt unable to wait any longer and paid privately for their diagnosis. Only weeks later they received a letter advising that the NHS would pay for a private assessment, but as they had already paid privately the NHS refused to reimburse them.

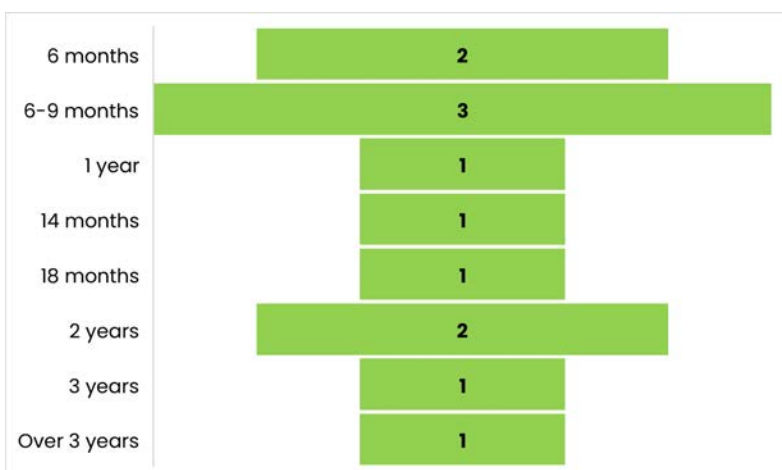
2. How many people were diagnosed with autism?

- Nine people have an official diagnosis of autism
- Two have been advised they are not autistic (both disagree with this)
- One person received a private diagnosis, but this has not been acknowledged by the NHS
- One person received a private diagnosis and was then offered an NHS assessment where the private diagnosis was initially overturned until the private psychologist became involved and ensured the NHS records were corrected to reflect the diagnosis.

3. How long ago did you have this assessment?



4. How long did you have to wait for your assessment?



5. What was your experience like and what, if anything, needs to be put in place to make the autism assessment process more accessible?

Most people were unsure of the autism assessment process and what to expect from it.

Some of those whose were assessed face-to-face, spoke of how uninviting, stark, and cold the room was. Those who were assessed online, described a lack of warmth and connection.

No one understood the relevance of being asked to narrate a story during the assessment.

“The process was absolutely horrible and stressful.”

“I felt like a freak and there were these people with clipboards writing about me.”

“They were poking the bear.”

“I was told that as I managed to make eye contact with the assessors, I was probably not autistic.”

Only one person assessed by the NHS described the experience as “positive”. Those who paid privately to receive a diagnosis, had a much better and more positive experience, describing the assessment as a discussion on their earlier lives and questionnaires.

“I felt understood, validated and not weird.”

“This diagnosis has meant I finally know who I am.”

6. Have you been offered any support?

Some people with a newer diagnosis were directed to CASA and have found this helpful.

One individual was offered five workshops but was unable to attend any as they were all during the day when they were working.

A lot of people have not been offered any support, or if it has been offered, it has not materialised.

“After the last session I thought it would open more doors, but it has not opened any.”

“I was shocked at the complete lack of contact from any professional within the assessment service.”

“I have been offered no support and no one has reached out to me or my family.”

“I am still coming to terms with being autistic and it would have been great to hear from someone and be offered help and support – to have some help with the validation.”

7. Do you have any other diagnosed conditions?



8. Have you experienced any barriers while accessing the autism assessment service?

The time delay was something almost everyone highlighted, as well as receiving no communication while waiting for assessment or any details on the process/steps to be taken.

Some people commented on the lack of support to complete the assessment paperwork which is extensive.

“It is like gathering information for a legal case.”

Not being heard and understood was voiced frequently, as was the request for more autism training to be available for GPs and other healthcare professionals.

“If you have met one autistic person, you have met one autistic person – we are not the same.”

9. If you have not been diagnosed with autism or you had to go through the process more than once, how has this made a difference to your life?

More than one person spoke about wanting to be listened to and taken seriously.

“You cannot access a lot of help without a diagnosis, which is difficult and affects everything in your life, both physically and mentally.”

“I would like to be heard by the professionals.”

“(Diagnosis) would enable me to access the right medication.”

“They viewed me like a typical male, whereas I present like a female and mask really well.”

“I wanted to try to find out what was wrong with me and why I am not a normal person.”

10. How do you deal with accessing other appointments?

Lots of people explained they struggle with this and some like to take someone else with them to appointments. Many people prepare well in advance to make sure they know what they want to say and get across.

A GP said to one person, “there is no cure for autism, so why do you want to know?”

One person explained they have other medical issues they do not address because of their issues communicating with the GP.

“I am very co-dependent with my wife and if she is unable to attend appointments with me, I will either cancel or say I cannot make it, but I would never just not turn up.”

“I find them very stressful and in particular any GP appointments, so try to avoid them.”

Others who have a good relationship with their healthcare professionals, did not struggle.

“When you have the diagnosis and share it with healthcare professionals, something changes, and people are more understanding and accommodating.”

One person described how they used to be overwhelmed visiting the dentist and avoided going for years. Since receiving a diagnosis, they have been again and had a more positive experience.

“I was open about my diagnosis and there was an immediate understanding.”

Another individual described how they are more than capable of navigating appointments, although they acknowledged how hard it is.

One person shared their delight at a recent online appointment where they were asked how they wanted to be treated, and whether they wanted to use the chat option instead of talking, which was refreshing.

11. What would be your top three priorities to better support for adults with autism in Gloucestershire?

Learn how to improve by involving people with autism

1. Use experts by experience within the whole process including the assessments.
2. Review and revamp the autism process and include autistic people in the design.

Better communication

3. Provide people with a leaflet right from the start which clearly details the process, and what to expect at each stage.
4. Improved communication including updates on waiting times.

More information and support

5. Have one place to go to access everything, including leaflets, peer support groups, general information, benefits etc
6. Offering practical support with the form filling and perhaps breaking it down into more manageable pieces.
7. Having a more person-centred service which is tailored to the individual, including communication choices.
8. Support for families and carers pre and post diagnosis.
9. Being offered the opportunity to meet other autistic people using different platforms.
10. Following a diagnosis, ensure the help and support promised, is offered, including follow up sessions to check in with the individual, which could be done by Experts by Experience.
11. An Advocacy Network to help with advocacy in the workplace, medical appointments etc.
12. Help and advice offered to those who do not receive a diagnosis.
13. Look at ways to cut the waiting times from years to months.
14. Autistic people to be offered an annual health check.
15. More awareness through ad campaigns and social media.
16. Campaigns to show the strengths of autism and what they bring to the table.

Raising awareness and understanding

17. More teaching, training and understanding for healthcare professionals everywhere.
18. Joining up the services, for example, make sure GPs are advised of a diagnosis.
19. Keeping family and loved ones involved in the process to improve their understanding.

3. People's stories of autism – case studies

Tabi's story

Realising that challenging behaviours might be related to autism

Tabi is in her early 30s and had her autism assessment at age 24. During the previous two years she read lots of studies on women being hard to diagnose, which led to her feelings that her symptoms were likely to be autism.

Tabi has a relative whose behaviour is very likely to be a manifestation of undiagnosed and unsupported autism, which can be 'chaotic' and quite challenging for other family members to deal with. Tabi describes seeing similar traits in herself, which she says were 'hauntingly familiar' to some displayed by her relation, and she felt worried that she might be acting in ways that her family would be annoyed or frustrated by.

When asked why she wanted to have the assessment, she said her partner at the time encouraged her: "If you know what is going on, you will know how to deal with it." This has since proven to be true, giving Tabi important context for many of her problems that she didn't know had solutions.

Positive experience with GP

When approaching the assessment, Tabi spoke to her GP, who was new to the surgery having just graduated, and was very open to patient-led requests, which Tabi found really positive and refreshing. It felt reassuring to be taken seriously without a lot of gatekeeping or undermining of symptoms and concerns. She said the barriers were not as bad as she expected and she was put on the waiting list for diagnosis, which at that time was nine months.

Family was uncomfortable and reluctant to get involved

At this point Tabi told her parents what she was doing, but they were reluctant to discuss it with her. Tabi's father was uncomfortable with her identifying as autistic and she feels quite protective of him. He has normally bottled up his emotions and has not been taught or empowered to voice them, and both he and Tabi's mum can sometimes project their own frightening or sad experiences onto their children in order to avoid them being hurt in similar ways.

Tabi's siblings mostly did not engage with her diagnosis either because it felt as though Tabi was pathologizing what they considered normal behaviour that in some cases they exhibited themselves.

Tabi said she completed all the assessment paperwork herself because asking her mum to help was quite complicated. Her parents were fairly young when they first had children and didn't have much awareness of what normal child behaviour was like, so didn't have a point of comparison to recognise that something might be wrong.

Learning to mask and self-manage

Apart from slightly delayed speech, subsequent speech therapy, and significant struggles socialising, Tabi didn't display obvious symptoms. She mainly came across as very shy and quiet as a child.

She said as a child in a large family with lots of complex activities and pressures, she was never in a good position to express her needs effectively because it was hard to articulate what she was experiencing as unusual or stressful.

She kept her head down and tried to just get on with everything and had a certain amount of passive validation for being low maintenance. It's taken a lot to learn to draw boundaries and even come to terms with the fact that she doesn't need to be physically uncomfortable all the time by masking.

"In school I was always in my own head, it felt too overwhelming to interact with most external elements. I would go to the library and read in a peaceful environment so that I didn't have to deal with the noise of the playground or unpredictable movements of the other kids.

“I feel like I had quite demanding needs as a child but never expressed them. I feel it was my responsibility to do it so have worked on improving communicating what I’m experiencing.”

“Managing my own thoughts and behaviour feels like dealing with a whole bucket of snakes and trying to find the more palatable, less intimidating candy-coloured ones to pass to my family for inspection.”

She also explained how her parents are just a single generation removed from a time when families absolutely never talked about their feelings – or if they did, they were dismissed or teased for being overly sensitive or grouchy. Tabi believes her father sees expressing emotion as too vulnerable to risk doing.

Autism assessment

When she first applied for the assessment/diagnosis, Tabi was not coping well and as there was a lot going on in her life, the assessment faded into the background. She had already found coping mechanisms for herself, even if they weren’t ideal, and describes being so used to being out of her comfort zone that she pushes herself in these situations. Her emotional tension was manifesting in poor posture, defensively hunched shoulders causing lower back and neck pain, and generalised anxiety disorder.

Within the assessment process, Tabi had two sessions around six weeks apart. On one occasion she was given a textless children’s picture book and asked to narrate the story, and she was also given an array of different objects that she needed to use to tell her own story. Instead of using the objects, including glasses and a feather, as items in a narrative, she characterised them of members of different races from different planets locked in a cycle of complex dynamics and interactions. “If they were expecting a children’s story, they did not get that.”

Support offered clashed with her work schedule

When asked about follow up support, Tabi said she was offered five workshops, but did not attend any of them because she was working full-time with the workshops taking place during weekday hours. She already felt as though there was enough on her plate negotiating her condition with her workplace, and it felt like too much to ask for further time off.

How has diagnosis has made a difference?

Tabi received her diagnosis of autism in 2014 and when asked what difference it has made to her, she described how it has contextualised so many things for her, although other people think it stigmatises a person. She sometimes feels as though she has a responsibility to act as an advocate for the condition as she doesn’t present as the typical one-dimensional stereotype of an autistic person.

She feels having this diagnosis has enabled her to use it for her own personal enrichment, and while she’s open about being autistic, she’s not comfortable sharing it too widely among certain people as it creates power imbalances: “In some ways, why share with insensitive people that you’re hypersensitive to loud sounds, disruption, or sudden movements? Some people can weaponize it without seeing the harm it does.”

She also shared how she felt a little ashamed after the diagnosis because of her family’s under-informed reaction to it and this culminated in her distancing herself from them for a few years.

“For a long time, I had this sense I should lock up my feelings to protect my family from having to confront their own insecurities and points of overwhelm. In fairness, they did need to unpack their own traits based on what they saw me going through, and they didn’t have any real support in this.”

She finds new experiences very overwhelming and exhausting and believes an earlier diagnosis could have helped a lot. There is a lot of misinformation available on autism and Tabi feels almost like she has ‘dodged a bullet’ by reaching adulthood where she is autonomous and able to manage her own treatment better.

Ongoing challenges

Tabi struggles to do small talk and describes the world as 'chaotic and incomprehensible most of the time'. Sometimes this is surreal and funny, but sometimes it's too much to take in.

As an example, she explained how when she sees a tin of beans, she finds this overwhelming as she sees it all – thinks about the beans and tomatoes, where they're grown, who planted and harvested them, who designed the packaging, how the cans are manufactured in the factories alongside the food being cooked and processed, etc. Her brain will automatically start asking lots of questions, trying to understand complex systems, and it is exhausting even as it's very interesting.

She says she is constantly analysing her behaviour and always considers her responses to things.

"There are lots of Tabi's inside me and they have lots of different ideas and questions, and ways of seeing or interpreting the same thing. It's bad enough having a legion of voices outside of me without all the examination taking place in my own head."

She remembers a phrase her mum often used when she was a child – 'that didn't need to happen'. This leaves her with the persistent feeling that bad things can happen for no reason aside from a lack of intervention or people caring, so she feels a bit pressured to forge meaning from the challenges she's faced to avoid problems arising in future.

"Time or objects do not exist very reliably for me; my self-regulation can be very poor, I can become very grumpy before being reminded I haven't eaten lunch, or I'll buy fruit that rapidly expires before I remember to eat it."

Experience of medical appointments

When asked about medical appointments Tabi describes how she always prepares well in advance for them and is generally very frank with people about her conditions. She recently had an online appointment and was pleased she was asked how she wanted to be treated, in a way that surprised her – being offered options, like using chat instead of speech, having closed captions, recordings and transcripts, etc felt very refreshing and inclusive.

She is not worried about specifically female healthcare professionals as opposed to male or other genders, since she doesn't feel discourteous or exclusionary behaviour is gender specific. She says she does not have the capacity to put on a front or act in a way that feels inauthentic, which sometimes throws people until they get to grips with the consistency of how she acts.

"I have to feel comfortable to act at my best. If you play the game and are not true to yourself, you win unpalatable prizes – it's not worth the effort of putting on a disguised demeanour. I feel it is normal for me to feel uncomfortable, which isn't great but also really gives me a perspective on anxiety. It's basically as difficult to give a speech to 200 people as it is to conduct a conversation with just one."

Life with her autistic partner has understanding, structure, and stability

Tabi is in a new relationship now with another autistic person, with whom she has a great deal in common as well as complementary behaviours and skills. This has given her a great deal of structure and stability.

"I feel very well-supported in my own household, I feel valued and understood and appreciated. We make a lot of jokes and spend a lot of time trying to impress each other in small ways throughout the day. We sometimes go for walks at night to see foxes and bats and talk about the problems we dealt with in the day so we can formulate solutions. I feel that my needs are being anticipated and met before I even need to voice them, and I feel much better about doing this in return, not just for my partner but with most people I meet."

Thoughts, fears and hopes

"I would describe myself as curious about the world and open-minded about how it works. Sometimes I need to check my immediate judgements to examine whether it's a fear response or how I actually feel. Having that level of self-reflection feels quite painful but it's almost always worth it, so long as I manage my own harsh self-criticism. My greatest fear is people not feeling comfortable around me – if I say something insensitive, miss something important, run tactlessly over their own boundaries.

"Sometimes I feel like a tree growing in a street – it grows taller and wider, and blooms and sheds leaves until it encroaches this arbitrary human idea of space or appearance, and then there is this sense of being tidied up, pruned or even felled just so you don't grow beyond these confines of expectation. People make it obvious that you're a pain for them to have to adjust to, and it's usually easier to grow small, stunt my own growth or presentation, squash myself up and make myself resilient and non-descript to avoid the aggro. Since this is energy-intensive, and nowadays I'm very tired, I am making much less of an effort to mask, and just trust the adults around me to behave like grown-ups and deal with it. I'm really not that challenging or unpleasant to engage with. And I wouldn't want to set an unfair expectation for other autistic people to hurt themselves just to be accepted.

"It is a struggle for autistic people to maintain all five points of the star (work, home life, family, friends and intimate relationships) and they should be given the tools to help them to do this. It's also important to understand our inner lives and interior experiences, and understanding that some social expectations are not mandatory, that we usually thrive in circumstances that some may consider unorthodox but actually help us become more well-adjusted.

"There should also be a strategy to support and equip us on how others may respond – setting boundaries, dealing with pushback, advocating for yourself."

Phoebe's story

Assessed in 2021 but no diagnosis

Phoebe is in her early 20s and went through the assessment process in January 2021 where she was advised the professionals do not believe she has autism. The reasons given were having a lack of special interests, but Phoebe felt the questions and explanations were not clearly explained.

First assessed in 2015 by children's services led to diagnosis of anxiety but not autism

Phoebe has been involved with the mental health services since the age of 12 or 13 and had an autism assessment in children's services in 2015, where they advised that she does not have autism. Although they believed she had the traits of autism, they felt this was because of anxiety.

While under children's services she experienced a lot of difficulties, and this improved when she was introduced to a new Care Coordinator who she describes as: "one of the best people I have ever met." Phoebe explained she has always had sensory issues and did not even realise that everyone else did not feel the same way. The Care Coordinator had undergone specific sensory training and when they went through the profile together, Phoebe scored a lot higher, due to not realising her differences to everyone else.

She also explained how she had learnt to mask even as a young child and had a lot of traits from a young age which have become more obvious now looking back. Her mum was also aware there was something different about her compared to other children.

Phoebe was advised she could not be referred again until she turned 18 and then she would go through the adult assessment process. It was during this interim period she researched and learnt more, which confirmed her experiences could be explained by being autistic.

Negative experience of the adult assessment process led to a formal complaint

Phoebe and her mum went through all the paperwork together and she describes the adult assessment as 'very different'. She said it took a while to get a referral and she really had to push for it. In the end she had to wait three years and her mum supported her throughout this whole time.

"I knew I was quite different from others – not wrong, just different. It can be hard to push things for yourself when you have difficulties."

Following the completion of the paperwork it took about a year until the first face-to-face appointment. Phoebe said she was confused about the actual process and had heard there were two parts to it; the first of which was just basic screening, which she now realises was not the case. She did not realise the basic screening before further assessment was part of the two-step diagnosis assessment and this was not explained to her.

There was a lack of consistency, and it would have been so much better for Phoebe and those assessing her to have the same people doing both parts. She does not believe they looked back at any of her notes and paperwork and if they had done so, they would have seen how inconsistent the previous assessment and conclusions had been. Neither had they looked at the sensory profile and she feels there is a lot of inconsistency in her medical records.

This is where things became a little confusing because after waiting for more than a year, she thought this was the start of the process and did not realise that when she had what she now knows was the second appointment online, it was also the final appointment.

Phoebe found the assessors rude and dismissive, making biased and inappropriate remarks throughout the assessment on several traits, characteristics, and experiences. Phoebe felt like she had more widespread knowledge and understanding from research than the person assessing her who was supposed to be the expert, but they seemed to pick and choose what they liked for different subjects without a more accurate overview and cross examination.

At the end of this meeting, Phoebe was told they had decided she was not autistic, which was overwhelming but not a shock since as the assessment went on it seemed more and more like they had already decided before even starting the appointment. Phoebe was also not able to have any input or able to defend herself at all since they took a break to discuss their conclusion between themselves without letting her talk about any of her experiences. She thought she would have a bit more time on another occasion, but this was not the case, and it was then over and done with. She became mostly non-verbal and shut down, so her mum and partner had to try and speak up for her and confront them about lots of things they hadn't covered or let her speak about.

After this online meeting Phoebe immediately wrote down all the issues so she would not forget. She knew she wanted to ensure all the details were accurate because when she felt able to, she wanted to make a formal complaint. Late that day, she emailed them a list of traits and difficulties which they had not allowed her to discuss during the session. Phoebe didn't get a response, and later in the year made a formal complaint.

She did not feel prepared at all and found the whole experience completely overwhelming and traumatic, like an interrogation. She was in shock from how the assessment had been carried out, and this caused intense disassociation; she needed time to process the whole experience.

Once the assessment report arrived, Phoebe felt unable to deal with the content and put it aside for a number of months. Phoebe explained she did eventually put in a complaint because of how awful the assessment and the whole process was.

She does not believe the service is equipped to support people with autism and cannot understand why Experts by Experience are not part of the process.

"When you realise you are autistic, it makes so much sense. I know that I am different, and it would be easier to explain to people why I am the way I am."

Phoebe did request a second opinion, but she was advised this does not happen in Gloucestershire. She does not feel she should have to start all over again and should be able to speak to someone else on the team. Once again, she has requested this, but is unable to find out and speak to the person in charge of the team.

Concerns about NHS assessment quotas

Phoebe feels there are a certain specific group of people who are diagnosed, which she finds very frustrating as it is a spectrum. She has since found out that between the autism and ADHD service they were only commissioned to do a couple of hundred or so assessments a year, but they have been receiving over a thousand referrals for a team made up of only three or so full-time roles.

She believes the problems with the service are mainly because of commissioning issues. She suggested there needs to be more funding for staff immediately and a start towards restructuring the whole assessment process, with coproduction from Experts by Experience as the main approach.

The impact of no formal diagnosis

Phoebe feels she is definitely neurodivergent in some way and is not yet diagnosed correctly. She believes this is holding her back from being able to access support and have necessary understanding from people involved in her healthcare.

“It affects my whole life and how I experience and am able to interact with everything; (diagnosis) would finally give me an answer and reason for why I am the way I am. I feel I have been excluded in being able to engage with people who are similar to me, and it feels isolating.”

She believes a lot of her mental health difficulties are not the cause of her autistic traits, and the mental health conditions they believe she has could have been explained better by her actually being autistic, not the other way around.

She also said her healthcare has suffered due to her autism being undiagnosed and she finds it difficult to engage with the professionals.

“Lots of us have multiple health conditions and it is one big circle. I am ill and I need help please.”

Lack of follow-up support has impacted her mental health

After the assessment and the written report, Phoebe did not hear from anyone and describes being ‘left on her own’.

She was still under the care of the mental health service and in a meeting shortly afterwards, for unrelated issues, with a psychiatrist she had never met before, she was asked why she wanted the diagnosis. Phoebe had not expected or wanted to speak about this as she was still feeling very fragile and so she shut down. She then asked if she could leave for 10 minutes and have a break, which was refused, so she describes sitting in an uncomfortable silence. She asked once again to leave, which she did and went back to her car and cried. At this point she said she was suicidal and yet no one made any contact with her and there was no follow up whatsoever.

After this event she asked to be moved to a different Care Coordinator and has received very little input since then. She said the service are now trying to discharge her and she does not know where to go from here. She has had CBT over the years, and it has not helped because of her neurodivergence and unrecognised trauma.

Phoebe has a new neurologist, who she says is very good, but she cannot see any treatment options left.

“You cannot access a lot of help without a diagnosis, which is difficult and affects everything in your life, both physically and mentally. There are some individuals within the system who are good and helpful, but not in specific services.”

Private assessment now feels like the only option

Phoebe has been looking into a private assessment as she feels this is her only option. She said it is hard to find the right place although there is one in Kent where she would like to be referred - it specialises in women and girls with multiple conditions, but it costs £2,500 and she cannot afford it.

Phoebe cannot stand the thought of waiting another three years or so to go through the diagnosis process again and she is worried about the same thing happening again.

Managing other appointments

When asked how she copes with other appointments, Phoebe said it has been her and her mum for years, who gives her lots of support, and she just has to get on with it. She describes having lots of physical health conditions and having had a lot of medical traumas.

Phoebe struggles with communication and only likes to use specific words and terminology. She said none of the services are connected and it makes her life even more difficult.

Due to things which have happened in her past, the professionals think they have been dealt with and do not realise that although they are separate, they are also all connected: "Everything dominoes into the other one."

Pete's story

Social interaction has always been difficult

Throughout his life, Pete has had problems with social interaction. Talking to people he doesn't know is an issue. He does not have emotional understanding and does not have feelings like others do. He has not been able to get close to people and love is something he just does not understand, although he does have a girlfriend.

As a child Pete liked to be on his own and had very narrow pursuits. He feels he was treated differently. He thinks and looks at things in a different way to other people.

High score on the test for autism

Pete completed the Baron-Cohen test (autism-spectrum quotient) and scored 80%, which he felt was more than a reasonable indicator that he was on the autism spectrum.

Pete has always known there was something different about himself. He talked about this with his mental health practitioner and felt he understood. His mental health practitioner explained that most autistic people do not fit the autism criteria exactly.

It took two years to be assessed

Pete can't remember if his GP or mental health practitioner referred him for the autism assessment, but due to Covid and lockdowns, it took about two years to be assessed. He did try to make contact with them during that time, but on each occasion, he was advised it was in the hands of the manager and he would hear from them in due course.

The assessment paperwork Pete completed didn't include information from his parents as he does not have a relationship with them. He has no friends from his school years, so he was unable to provide any information on his early life. And, as he struggles with completing forms and due to his memory issues, he could not provide any details prior to around age 26, as there is no one in his life now who knew him before that age.

Face-to-face assessment was an uncomfortable experience

Pete finally received a letter inviting him for a face-to-face assessment, although he describes this as a bit of a blur as his memory is not good. He does not like to attend appointments on his own, so he took his girlfriend with him.

Pete felt uncomfortable as soon as he walked into the assessment room. He described the assessors as 'shifty' and he told the male member of staff that he did not like him; he said they did not seem to pick up on this or discuss it at all during the assessment.

The first session lasted for about an hour and a half. It was focused on Pete's most recent experiences, and they spent little time asking him about his childhood and adolescent years.

He felt they had made their decision before he even walked into the room and asked the questions in such a way that he could not answer them in the way he wanted to. He felt they were ambivalent, and he was unable to work out whether they were taking the information he was providing seriously or not.

"The assessment was very surface level, and they did not seem interested in me. Unless you volunteered information they did not pry or ask any follow up questions. If you do not follow their script, they do not want to know."

The second part of the assessment happened on the same day following a short break. This part of the assessment involved puzzles and there was no interaction. He described this part of the process as 'very surreal' and felt there was nothing relevant or appropriate about it.

"Imagine being a rat in a laboratory and being observed – that is how it felt."

At the end of the session there was a bit of chat and his girlfriend shared details on how he reacts to certain situations.

The assessors then left the room for less than five minutes and returned to advise him he did not have autism because he could not back any of his comments up. The assessors went on to say they recognised he has experienced a very difficult life and reiterated that he does not have autism, although they hinted at post-traumatic stress disorder (PTSD).

No opportunity to discuss or understand the assessment outcome

Pete felt they did not listen to him; they had swept aside everything he said, and the outcome was not based on a balanced picture. He was surprised there was no opportunity for him to discuss their conclusions and he felt their attitude towards him 'stank'. He was advised there was no opportunity for a second opinion and he was not given any information on where to go next or who he should speak to. He felt the whole atmosphere of the appointment was cold and uncaring and there were crucial pieces of information which were not considered.

"I went away with my head spinning and none of it made any sense."

When he arrived home, Pete sat with his partner, and she was of the view: "they are the experts and must know what they are talking about." However, when he received the written report, they both read it and felt it did not resemble the way the day had unfolded, so much so, they even wondered if his assessment had been mixed up with someone else's, as it was so different.

Pete spoke to his mental health practitioner, but he was unable to help and so he went to see his GP for a second opinion. The GP was of the view that even if they did offer another assessment, it would not really help.

"I understood what he was saying, but it still does not make me understand why I am the way I am."

Pete has struggled with his mental health for a long time and feels this whole process has made it worse and has made him question himself.

Lisa's story

To understand why she has struggled all her life

Lisa was assessed for autism in 2015/2016. She explained that throughout her life she has encountered problems.

She has always found Maths, English and spelling very difficult, but she could not really explain why. Even after finishing school, Lisa struggled and she was bullied in the workplace for not picking things up quickly enough. She knew there was a reason for this.

Looking back at her early childhood she had struggled to learn to walk and was always falling over. She remembers one incident as a child, when they went away on holiday, and on the first day she fell from top to bottom down the steps to the beach. She knocked her teeth into her gums and cut her chin open and because of this, they returned home on the first day of the holiday.

Another thing Lisa reflected on was that throughout her schooling and earlier life, she has never been able to maintain friendships, apart from one.

While watching a television series about GPs, she realised that she should pursue this more, and that she needed to be careful about the language she used to describe how she was feeling to her GP. When asked why she wanted the autism diagnosis, she said she just wanted to know.

Weekly assessments over four months

Lisa went to see her GP. She explained that she knew something was not quite right and she wanted to pursue this further to find out what it was. With the help of the GP she started the autism assessment process.

This involved attending two-hour sessions every week over three or four months, which she did with her mum. There was a lot of detail involved which included looking at old school reports and her mum was asked about Lisa's birth and development as a baby and small child. She also confirmed Lisa had been slow to learn and used to fall a lot.

Although Lisa's mum helped her throughout the whole process, she could not really understand why she wanted to do it. Lisa explained to her mum that she really wanted to know why she was slow and 'learning clumsy'.

Diagnosis of autism and dyspraxia

After Lisa and her mum had attended all the sessions, she knew the waiting time was around 6-9 months, but was surprised there was no other help offered during this time.

Eventually, after about a year, Lisa received confirmation that she has autism and dyspraxia. This confirmed that she has a condition and is not 'clumsy' as she had been told as a child. A copy of her diagnosis paperwork was sent to her GP.

Autism affects every day life

Lisa said she is aware her autism affects her everyday life. She used travelling as an example, explaining that she does not like to drive anywhere she does not know, she cannot read a train timetable, and she needs to have all the journey details including what time she is leaving, where she is going and what time she will arrive.

Lack of support since diagnosis

She has been shocked at the complete lack of contact from any professionals within the autism assessment service since her diagnosis. As a bare minimum she expected a few follow up sessions to check in on her, but there was nothing.

"After the last session, I thought it would open more doors, but it has not opened any."

Mental health breakdowns triggered by bullying and job changes at work

When asked if she had any other medical conditions, Lisa explained she has had two breakdowns. The first one was brought on by workplace bullying by a previous manager more than ten years ago. It culminated in her being signed off sick with depression for more than a year and during this period she spent a long time in her room, sleeping, and would not come out. She said she was even frightened to leave the house.

Eventually her GP visited her at home and encouraged her to go out for a walk and to get some fresh air. During this time, she also had visits from the mental health team, twice weekly for a year. Over time they also encouraged her to leave the house and would go with her into town, with Lisa driving to build up her confidence. After 12 months she had a phased return to work and the individual who had bullied her had left and she was happy with this.

Shortly after this time, she was made redundant and with help from Remploy, Lisa secured further employment. She was happy until last year when changes were made to her role and her hours, with no consultation, and this affected her greatly. Lisa liked the role she was doing and her working hours suited her because she was able to work in the early mornings when it is a lot quieter. Once again, she was off sick for a number of months.

Autism and advocacy support helped her return to work

Thankfully, a member of Gloucestershire's Community Autism Support and Advice team (CASA) and a social prescriber became involved. They spoke to the company and explained they had to make reasonable adjustments due to Lisa's autism diagnosis. The store manager visited Lisa at home and heard what had been said to her – the ultimatum she had been given about her job was overturned immediately. Lisa had a phased return to work and was reinstated in her old role and working hours.

Lisa was also given information to pass to her employer to show them how to approach certain situations to ensure they got the best from Lisa as an employee. For example, they were advised to only put Lisa in small groups and to give her short bursts of information, which they should encourage her to repeat back to them to make sure she has taken it in and understands. Lisa said this has helped her enormously.

Ongoing support and giving back to help others

Lisa sees her GP once a year for a check-up. Until recently she did not realise that she was entitled to a double appointment to allow her more time and so now she always requests this. She is generally fine with all other appointments and pleased to now have the diagnosis so she can share this with healthcare professionals.

Lisa said that attending the CASA drop-in sessions has 'changed my world'. She now helps to run the groups in Cheltenham and Gloucester. She has also gained the confidence to start up her own group in Churchdown, because she was shocked at how little support there was following the diagnosis. She also strongly believes peer support makes a difference and wants to encourage more people to attend. She would like to share the knowledge she has gained since diagnosis to try to help others.

"I want to help others because I know what I went through."

In view of this voluntary work Lisa undertakes, and her involvement in a singing group who entertain residents in nursing homes, her employer has nominated her for the Unsung Hero of the Year Award.

Leigh's story

She always knew she did not 'fit in'

Leigh is 44, married with two children and she has a full-time job. She explained that it had been suggested through previous roles that she might be autistic, so completed the online questionnaire and then arranged to see her GP, who agreed it was worth pursuing.

When asked what she hoped to achieve by going through the assessment process, Leigh reflected that it may be about validation – she has always known she did not 'fit in' and perhaps this would give her a greater understanding; she felt she had nothing to lose.

A positive role model for her son who has autism

Leigh's oldest child has been diagnosed with autism and her youngest is going through the process. She feels she has a decent life and that she has learnt to manage. She wants her eldest son to see that being autistic is not a bad thing and he too can have a good and fulfilling life.

Leigh believes autism is portrayed at school and in the media as being a terrible thing and autistic people have to learn to fit in, but she has realised with age and experience that this is not how it is. She can now see that autistic people have a different way of thinking and actually this can be a bonus in many situations.

Long assessment forms and childhood information is not always easy to provide

Leigh completed the initial assessment forms which were sent to the Diagnostic Centre in Cheltenham. They sent her additional forms to complete, and these were submitted in March 2020, at the beginning of the Covid pandemic lockdown.

Leigh said the forms were very long and one needed to be completed by a parent, but her mum has MS so she struggled to remember how Leigh was as a child. The Diagnostic Centre said that as her husband had known her for many years, he could complete the other form. Leigh said her mum did not really understand why she wanted to pursue the assessment and felt she should leave it alone.

Two-year waiting list was extended by 18 months due to the pandemic

After sending back the assessment paperwork, Leigh was advised the waiting list was two years and they would contact her when her name reached the top of the list. The two years passed and she had heard nothing so she phoned the Diagnostic Centre to ask what was happening. She was asked if she was working, which she was, and told that due to Covid it would take a further 12 to 18 months, which came as a shock.

“Over the previous two years I had a lot of time to think about everything and I felt I had wasted a lot of time thinking and I just wanted to get on with it.”

Seeking NHS referral for private assessment proved challenging

The Diagnostic Centre then advised Leigh that NICE guidelines state if a person has been waiting for a certain length of time, their own GP can refer privately although the NHS will still pay for the assessment. She decided to pursue this rather than wait another 18 months.

Leigh saw a different GP at her practice who had never heard about that NICE guidance. Having already researched this, Leigh was able to explain it was a simple process, so the GP agreed to go away and look into it and contact her, but this never happened. Leigh ended up making a complaint to the practice as it appeared no one was happy to speak to her.

At this point she was advised she would need to find an NHS approved Diagnostic Centre herself and if she went down this road, she would be removed from the NHS waiting list. In addition, this did not mean they would pay for it, so it was a risky strategy, but entirely her decision.

“I felt I was being blackmailed and bribed into not pursuing this course of action and I felt very upset and shaken, because they had now moved the goalposts.”

Leigh took a few weeks to step back and think about what to do, as in her eyes none of the options were good. Eventually, despite knowing they would end up in debt, Leigh and her husband decided to pay privately, rather than wait another 18 months.

She hoped a diagnosis would help with difficulties at work

Leigh's work situation was changing following Covid and she was really struggling; this exacerbated the situation. She knew that receiving a diagnosis would make a difference as her employer would have to comply with reasonable adjustments.

“I felt I was stuck in a cycle of how awful the situation was, but I could not get out of it.”

Autism diagnosis has changed her life

During the late summer of 2022, Leigh proceeded with the private assessment. Despite feeling very stressed, within 30 minutes she was advised that she was displaying many autism traits and it looked likely that she would receive the official diagnosis, which she did.

“Receiving this diagnosis has now changed my life. I have been living the past 40+ years in a field with horses where I was always trying to be a horse, but now I know I am actually a zebra. Now I know who I am, I know I will be okay and I no longer need to try to be something I am not. I can communicate with others, while still being myself.”

Leigh feels it has also made a lot of sense on how she was as a child and why she doesn't like certain foods or sometimes struggles with lighting. She finally realises it is okay not to be like others, and to just be herself.

Greater understanding makes it easier to manage

In the past Leigh was worried about anxiety and depression, so she saw the GP about these issues. Her scores on the tests were always very low and she now realises these are a part of her autism and she is okay with that.

“It is okay not to be like others because I am me and not them.”

Leigh also realises receiving the diagnosis has given her the confidence to speak up if there is something she is not happy with, such as asking for strong lighting to be turned off and people are happy to do this for her.

In the past she was seen as being argumentative because she always asked lots of questions and she now realises this is because she is a fact-finder and needs to know all the details in advance and this is not her being difficult. As a child she was always being told she talked too much and understands the reason for this now.

“Having this diagnosis absolves me of all the negative labels. I feel like a new person and I have stopped trying to fit in with everyone else. If I fancy doing something I will, but if not, that is okay too; I have found my own lane.”

NHS withdrew their offer to pay for private diagnosis

Three weeks after receiving her diagnosis, Leigh received a letter offering the opportunity to go private, paid by the NHS, to be diagnosed at The Owl Centre, (Autism Support & Autism Assessments for Diagnosis) in Cheltenham.

She was absolutely stunned to receive this having been advised only weeks before that through the NHS she would have to wait a further 18 months to receive a diagnosis. The letter came from the Diagnostic Centre and when she phoned to speak to them, they made it clear they would not help her financially, despite her having to get into debt to pursue this, and as she had now received her diagnosis, she would be removed from their list.

“Most people do not know you can get a private diagnosis through the NHS and it brought a huge amount of stress and pressure not to pursue it. I spent all this money to get a diagnosis and had I waited three weeks I would have been sent to the Owl Centre anyway.”

Lack of support after diagnosis

Leigh said there is no further support available and she feels this is a bit of a let-down that there is no follow up or help after diagnosis.

She took her diagnosis report to her GP practice where she was advised it would be added to her file, but that was it. She feels it should be flagged on her file so that when she makes contact or sees someone in the practice they are aware of her diagnosis.

She explained that she has always had lots of issues going to the dentist and has already decided on her next visit she will be highlighting her diagnosis and asking for someone who understands autism to deal with her in an appropriate manner. Once again, she said she has had very bad experiences in the past and now understands why.

Leigh is fully aware it is not easy, but she wants to start to enjoy her life being the person she is and if this means having a few awkward conversations, then that is what she will do. She fully understands this is not an illness and she was born this way.

“Hopefully in the future there will be more accommodations for people with autism.”

More diagnosis, more advice, more support

When asked what help she would like, Leigh explained she would like to speak to people who could give her some advice and explain what is reasonable and what is not. She also commented and wondered why there are so many non-autistic people telling people with autism how to live their lives and why are more of the services not autistic led?

“I have spent my whole life as a masked autistic woman and I have been moulded into a shape that does not suit me.”

Leigh explained that she had discovered only so many people are allowed to be diagnosed as autistic each year and she does not understand why. She said two years ago the number was 91, but wondered what would happen if you have been waiting for two years and you are number 92?

“This would not happen if you were diagnosed with diabetes or MS, so why does it happen with autism? It is a very weird concept. There is no support so why is there a cap and what happens to the others?”

Leigh has tried to search for services and is aware of CASA but said she has not found anything else. She explained she is going on holiday soon and is anxious about the flight, which has sent her into a spin and she would like to be able to speak to someone about this, as well as receiving help and tips with everyday life and tasks.

Leigh feels strongly that she is against the wearing of the sunflower lanyards as she does not see why it is necessary to publicise yourself as being autistic.

There needs to be a lot of education in other services and Leigh said the best thing she has been involved in is the Oliver McGowan Training, which she also said doctors and nurses found beneficial and is now mandatory training. Leigh believes so many people could benefit from attending this training, including administrators, receptionists and everyone who has contact and dealings with autistic people.

“Lots of education is needed in other services to make the experience autism friendly. GPs and practice staff would benefit from this – teachers etc. The media do not portray autism as it really is and lots of people cannot understand that you may have an autism diagnosis, despite the fact you are not sitting in the corner of the room rocking.”

Leigh finished by saying she is aware the Diagnostic Centre is overprescribed, and this is a funding issue and not their fault, but it is still unacceptable.

Leigh is happy to share her story as she believes people’s voices need to be heard. She also said three people had sent her the information relating to this project and is pleased it is being looked at.

Mike’s story

Autism traits more noticeable after ADHD diagnosis and treatment

Mike is in his late 30s, married with a family. Over three years ago he went to his GP seeking an ADHD assessment and was told that the nearest adult ADHD service was in Bristol with a long waiting list. He decided to pay privately for an ADHD assessment and got a diagnosis. Through this he learnt a lot about the condition. Two years later he decided to explore prescribed ADHD medication which has helped a lot, but he has to pay for this himself and it is very expensive.

Mike was advised by his psychiatrist that once the correct dosage had been identified and he was happy with it, he could request shared care, where it will be funded through the NHS. A few months ago, he contacted his GP and has been advised they will no longer fund this as the medication has been removed from the approved payment list. Mike is aware he can appeal this, but feels right now, he is dealing with enough and does not have the space for another battle so has put it to one side.

He spoke to his psychiatrist about other things he has always experienced such as sensory challenges, repetitive behaviour, and social communication challenges which he felt might not relate to ADHD. His ADHD medication had really made him notice his autistic traits. He feels his ADHD has masked the autism and following a further discussion with the psychiatrist, they agreed he should explore this more.

Another member of Mike’s family had received an autism diagnosis and he could see similarities in himself. Also, he works every day with people with autism and had also connected with some Facebook pages around autism.

It’s important for GPs to listen and support

Mike then went to see the GP which took a lot of effort and time. He described his previous experience with the GP as ‘very poor and frustrating’, which is not the way he likes to approach things. The GP had

actually advised him to go privately for an autism diagnosis and was not at all supportive. Now, when he visits the GP, he goes feeling well prepared with all the information he requires. The GP he saw to request assessment for autism had a completely different approach; she listened to what he had to say and supported the approach he wanted to take.

Right to Choose – NHS referral to private assessor

Due to his previous experience, Mike wanted to approach this assessment through the Right to Choose pathway (this allows GPs to refer to an approved private assessor, paid for by the NHS). He had printed off all the relevant information to share with the GP, and despite not knowing anything about this, she listened and was great, which he was delighted with.

The GP was keen for Mike to go through the NHS pathway and even tried to do her own assessment, but he knew the path he wanted to take. He had already completed the first forms required, and the GP agreed to take them, scan and make a referral.

“I was so pleased and could not believe this, as before I had to battle for the ADHD referral and paid privately.”

Explaining his reasons for wanting to go down the Right to Choose pathway Mike said:

“I know they (NHS) only have funding for 100 people per year and the waiting lists are very long. The waiting time through Right to Choose is only six weeks currently. Based on experience and listening to others, I do not trust the NHS service. I have good knowledge of the systems through my work, and this allows me to navigate them well.”

Also, Mike explained that the ADHD and ASD service are managed by the same team. He is not happy with that, based on his previous experience with ADHD assessment, so he had no desire to deal with the service again.

“If I had not been able to follow the Right to Choose, I would not have continued with the diagnosis.”

A positive experience with private assessment

Mike received a text and email from Psychiatry UK confirming they had accepted the referral and advising him to log on to the portal. Mike was also pleased because within the email they asked how he liked to be communicated with. After about 10 days further paperwork arrived, which was amazing. Very clear instructions were received on what would happen next, detailing the documents he needed to complete online before booking the assessment.

“I only recently started this process and there are three extremely long forms, one of which has 75 questions, so I am working on it during the time I have available around work and family. Throughout my work I hear a lot about how we need to be more personable and face-to-face, and yet for me, I am happy to do this online.”

Diagnosis will make a big difference

Mike explained having the diagnosis is validating and although he would much rather be someone who does not need the diagnosis, it will enable him to understand his identity and allow him to support his family, some of whom also have a diagnosis, or are trying to receive one.

“I have seen what a diagnosis means and it is life affirming.”

He also believes receiving the diagnosis will enable him to receive the right support at work, as he says he masks all the time.

Mike has experienced burnout in the past, but has never been diagnosed with depression or anxiety, and feels these relate to his autism, although the medical profession have never joined the dots. He believes he should have been diagnosed much earlier in life and is now a very different person because he has learnt to operate and mask.

“Knowing what I know now, I would definitely be aware if a child was autistic.”

As a child all these things were put down to coming from a one-parent family and adverse childhood experiences (ACEs), which he disagrees with.

Mike has other medical issues he does not address because of issues with communicating and dealing with the GP which he finds challenging. He hopes having a diagnosis will make a difference.

“The communication needs to be improved and respected between a patient with autism and their GP.”

Service commissioners should involve and learn from people with autism

Through his work, Mike attends the Autism Partnership Board. He would like to see the commissioners taking more interest in the Board and to engage with autistic people and to include those with lived experience within the diagnostic service through co-design and co-production.

Gavin's story

His mum suggested the autism assessment

Gavin is in his early 30s. He did not realise he may have autism until he was in his 20s, a time in his life when he received help with his mental health, supported by his mum who attended some of the sessions with him.

It was his mum who suggested he needed the autism assessment as she had realised when he was young that there was something different about him. As a child, Gavin describes having lots of energy and always wanting to play and learn. Sometimes it was felt he had too much energy and sport was something that helped him with this. He also had difficulties forming relationships with people he did not know.

Assessment and diagnosis

In 2019, they started to explore Gavin having an autism assessment. His first appointment was due to take place in late 2020, but Covid slowed this down, so this happened in spring/summer of 2021. He had his autism assessment in late 2021.

The first thing that happened was a video call where his mum was involved. Following this, he had more tests and was assessed in more detail. Autism was suspected at that time, although it was not made official until October 2021.

Referred for community support, but no NHS follow up

Following his diagnosis, Gavin was referred to the [Community Autism Support & Advice](#) (CASA) drop-in sessions. The NHS autism service also offered some workshops to help him and they advised that he would hear more about this in due course, although nothing ever materialised – he would like to do the workshops because he believes everything offered will only help him.

Since receiving a diagnosis, Gavin has had zero contact from the NHS autism service. As he is already supported by CASA (part of the [Independence Trust](#)), he said it has not really mattered.

He did receive a letter recently, although it apologises for the waiting time he is experiencing for an ADHD assessment, which he is not waiting for. He believes the letter should be apologising for the lack of aftercare and follow up.

How has diagnosis made a difference?

Gavin felt relieved when he received the autism diagnosis and he felt it was especially important for his mum.

“It did help and it explained why I am as I am. Life is better now I have this diagnosis.”

He is aware that he is more of an outside person and he does not like loud music or crowded places, especially when it is dark. He also recognises that he used to have quite a temper and could not understand why he reacted in the way he did, but he now understands that much more and will only lose his temper if pushed. And he is aware that he struggles with basic things and yet complicated things are easy to him.

“You learn as you grow; I am an introvert and an extrovert at the same time.”

Gavin said his family now understand there are reasons for why he used to behave the way he did as a child. He has more tolerance than he did when he was younger and he describes himself as mostly positive although can become negative when affected by his mental health.

Gavin also said the diagnosis has made it easier to access other services, which has helped.

Managing his mental health and wellbeing

Gavin explained that when he was first diagnosed, he did quite a lot of research and watched lots of programmes on it, which he found helpful, especially because at that time he did not know anyone else with autism and no one in his family have been diagnosed. He now recognises when things are becoming difficult for him and what he needs to do. He says he can channel things a lot better now and has become more independent.

He has a few different part-time roles and a little while ago he had lots of issues with feeling stressed. He has now changed one of his roles and the pressure has subsided.

He is keen on sports and enjoys table tennis, walking and running, which all definitely help his mental health. He also occasionally helps at a community garden/Men's Shed project which is mostly attended by men in their 20s or 30s and he enjoys this. He enjoys interacting with the Independence Trust, whether it be via the Men's Shed or the CASA drop-in sessions, but apart from that, he has no interaction with any other organisations.

During the Covid lockdowns, Gavin was on furlough and struggled being at home the whole time. His sibling was also experiencing issues and he describes this as a difficult time. The mental health crisis team became involved and someone used to come out to see him and they would go for a walk and talk, which definitely helped and he felt well supported.

"There were too many people struggling at the same time and in the same space."

Gavin is on medication for his mental health condition, but as he is in a good place, there is talk about reducing the dosage slowly. He has tried lots of different medications, but feels the current medication works for him and he feels well taking it. He has had sessions with Let's Talk in the past but does not need to connect with them at the moment.

He is very happy with his GP and he does not have any issues with other medical appointments unless he is struggling with his mental health.

He prefers meeting people face-to-face, finds email fine but is not comfortable talking to people on the phone if he does not know them.

Gavin feels society is becoming more accepting of autism and people are more open.

Since early summer 2022 he has lived independently and is very happy to have his own space and says he has a lovely neighbour.

June's story

Learning about autism in others helped her understand herself

In 2000, June trained as a primary school teacher. She worked one-to-one with children who have special educational needs and she was particularly drawn to children with autism. Despite attending numerous courses and having a sibling who had been diagnosed with autism, June had never made the connection that she too could have autism.

Many years later, while working with a specific child and attending a course, she realised that what she was hearing applied more to her than the child she was supporting, and this made her wonder.

She has always struggled with what she considers to be 'normal life'. She becomes overwhelmed and bursts into tears, gets stressed, confused, and has sensory issues, none of which have ever been resolved.

As June's mum had been diagnosed with autism and her best friend's daughter had also received a diagnosis, she spoke in depth to both of them about it.

“I wanted to try to find out what was wrong with me and why I am not a normal person. I did not understand why I have been depressed since my teens.”

June started the process by looking online. She found and completed the AQ50 form, scoring two points away from the average score of females with autism.

“I realised I ticked all the boxes and it explained why I am as I am. My mum encouraged me and helped me a lot and together with my family we worked through it.”

From referral and diagnosis in six months

June took the completed form to her GP, who was very understanding and put a referral through in summer 2017. In December 2017, June had her first assessment appointment and the second one followed later that month.

At the end of the second session, June was advised that although she displayed lots of traits, they were undecided on whether she was autistic, so were not able to give her the diagnosis. The formal letter confirming this was received in early January 2018.

Assessment process was stressful and upsetting

June described the assessment process as ‘absolutely horrible and stressful’. She said it got her down for quite a while as she felt there was something wrong with her but did not know where to go next. She also described it as very intrusive because she had to share details she had never spoken about with anyone before.

“I felt like a freak and there were these people with clipboards writing about me. I had that feeling of really exposing everything about myself and then being told ‘no’. I then wondered what is wrong with me and why am I not normal? The whole process was totally invalidating and it felt weird and abnormal.”

“As an adult my issues were always put down to being in an abusive marriage, post-natal depression and generally struggling. That was all the professionals ever saw and no one ever looked at the bigger picture.”

Second assessment led to treatment for a mood disorder

In summer 2018, June asked to be reassessed. In August 2018, she had an appointment for three hours to get a second opinion. She went to this appointment well prepared and had written out all the autism criteria, together with relevant examples from her life.

At the end of November 2018, she received a letter advising her she did not display enough of the symptoms and therefore did not have autism. The letter said she had more of a mood disorder and they recommended that she speak to her GP about treatment options. June saw her GP and it was agreed she would start to take anti-depressants, which she continues to take.

Third positive assessment by a specialist in female autism

After a year, June was still experiencing sensory issues, and she continued to struggle with people and change. She returned to the GP to ask if she could be referred somewhere else as she believed she has autism.

The GP felt she met the criteria and wanted to help so approached the Clinical Commissioning Group (CCG) for funding, but they refused. The GP asked June for more information and wrote again to the CCG, and this time they agreed to fund an out of county assessment.

June waited about four months and the assessment took place via Skype during the first lockdown in 2020. It was carried out by someone who has written a lot about females and autism, therefore June felt whatever the outcome, she would accept the decision as she is an expert in her field.

This time the assessment was a completely different experience and she was not required to go through ‘all the weird tests and random stories with bits on the table’.

“I felt understood, validated and not weird.”

June finally received her diagnosis of autism in 2020. She took the written confirmation to her GP, who was delighted. She was not offered any other help with her autism during this time. She did go to see a private counsellor for a few weeks but had to stop because of the cost and she did not find it helpful.

How has diagnosis made a difference?

June said the diagnosis has changed her life completely - it has changed her attitude towards herself and she is now a lot kinder to herself.

“I do still ask myself why am I not normal? Although the diagnosis is not my whole identity, it does explain why I am the way I am.”

June said she is feeling much better and says other family members have also been diagnosed.

She is now part of some online communities and finds them to be very supportive. There are people who understand what she is going through and have given her the confidence to speak up.

“Having the diagnosis has made me feel stronger. When you see it you realise straight away and wonder why others cannot see it and do not join the dots.”

In the past June has been frustrated that instead of looking at the whole picture she was advised to go on parenting courses.

“It has given me the confidence and freedom to be myself and not worry about being different.”

June has also secured employment following her diagnosis as an Expert by Experience.

When asked whether it has changed the way she deals with other appointments, she said it has and has given her an understanding of the struggles she has experienced in the past. She used to get overwhelmed when visiting the dentist and ended up in tears. This made her avoid going and recently she attended a dental appointment for the first time in ten years. Now she feels she can openly say she is autistic and there is immediately an understanding. She had the same positive experience when attending a hospital appointment.

“When you have the diagnosis and share it with healthcare professionals, something changes and people are more understanding and accommodating.”

Support after diagnosis

During the Covid pandemic she received support from the Independence Trust (CASA) via regular telephone calls. She felt it ended very suddenly, which she found confusing and unhelpful. However, she then received a message via her work email with a positive reply which she was pleased about. Shortly after this she received a letter advising her that unless she has any specific issues, her time with them had come to an end.

“Everyday life is my issue.”

June understands there are lots of people who need support, but said she struggled with this as she felt there was no one she could turn to who understands when she is having a ‘crisis day’. June is not keen to attend support groups and says she needs one-to-one support as and when she needs it.

“I need structure and I cannot go to a meet up when I do not know what is going to happen and who is going to say what.”

Emma’s story

A history of mental and physical health issues

Emma is in her mid-50s, married with children. For many years she was a dentist - in the Forces and NHS. She developed a number of health issues and over the years has experienced depression and anxiety and described the GP as ‘often dismissive’ of her symptoms.

She had several referrals to mental health services and would always be seen as having depression or anxiety, but no one questioned what was causing it.

“I had a sort of functioning depression but burned out every so often and then felt bad for being unwell.”

She also developed gut issues such as IBS and chronic constipation and saw gastroenterology, and a colorectal surgeon, plus neurology for nerve pain symptoms, but sometimes the tests would come back as normal leading her to thinking she was imagining her symptoms.

More than ten years ago one of Emma’s children was diagnosed with dyspraxia and hypermobility and at this point she realised the similarities between them.

In 2013 Emma had two operations, the first of which was very traumatic and a difficult recovery leading to medical retirement in 2014. The surgeon who performed these operations was later dismissed from his post in the NHS.

After being medically retired, Emma returned to college, but at the end of the first year she became very unwell and experienced psychosis, was suicidal and admitted to hospital for two weeks. She later realised this was due to flashbacks from her surgery experiences in 2013.

Emma saw a rheumatologist in Bath privately, about her chronic pain and fatigue and she was initially diagnosed with fibromyalgia and joint hypermobility syndrome. The rheumatologist then saw her at his NHS clinic for more investigations and follow up including physiotherapy and occupational therapy. The fibromyalgia diagnosis did not sit well with her and she was diagnosed with hypermobile spectrum disorder in 2018.

She had also suffered from knee pain due to a fall in 2015, which caused a tear in the knee but only found this out through her rheumatologist in Bath who then referred her to see an orthopaedic surgeon privately for an operation. This took a lot longer to heal due to her hypermobility, which in turn impacted on her sense of self and fed into the depression and anxiety.

Assessed but not diagnosed with autism

In 2016 Emma asked the GP for an autism assessment. She is not really sure what made her ask but she had done some research and understood the correlation between anxiety and hypermobility was quite high, and at that time, she thought autism was quite likely.

When the assessment paperwork arrived Emma spoke to her mum about her childhood to get the required information. However, as her mum had her own issues when Emma was young, this was not helpful and she believed her mother was telling her what she wanted to hear and not the reality of it.

After completing the paperwork, Emma thinks she waited around 6–8 months for the assessment, although she said her memory of that time is not great: “I wasn’t sure if it got speeded up maybe because of my stress induced psychotic episode.”

During the process she had two separate assessments and at the end was advised she did not meet the criteria and did not have autism.

“They said I made too much eye contact and had good self-awareness and communicated well. They questioned if I knew the difference between a friend and a colleague; I gave them a good answer showing I understand the difference.

“The thing is, I understand the difference in theory as I am good at learning stuff, but still struggle with relationships/friendships in practice. I’m finding I connect with other people with autism and disabilities. I tend to look at people when I’m focused on listening to their voice. I’ve been trained to be a listener, deal with difficult facts and be good at analysing and processing a lot of information.

“This was hard as it left me feeling that I have all these issues and do not know why.”

She wondered if the way she was feeling was because of how much trauma she had experienced. She explained she grew up in a multi-generational family where ‘attachment parenting’ was not a thing. There was also a lot of stress and disruption in the family.

Seeking answers privately due to lack of support after assessment

Emma was advised she did not have autism, but she was not offered help to find out why she is the way she is. She did receive one phone call but there were no real answers, so she had to pursue this on her own and privately.

“I have put myself through a lot of psychological therapy which has allowed me to understand myself better and unmask and I am now more aware of sensitivities.”

Emma believes more help should be offered to those people who the professionals believe do not have autism, because clearly there is something going on: “It is not just about me; it is about everyone else who is struggling.”

Emma went back to university in 2018 and while she was there, she was diagnosed with dyspraxia.

University research team encouragement

She has also taken part in some research relating to her hypermobility and anxiety by a team at Brighton Medical School led by Dr Jessica Eccles. When she went through their screening, she felt much calmer and more grounded. The professionals undertaking the research suggested she probably was on the autism spectrum.

Emma then returned to the GP to ask for a further referral for an autism assessment and was advised this could not be funded. “I was again left with this rejection to deal with.” Dr Eccles recommended a colleague in London who did a private assessment online as it was over the time of the Covid crisis.

A more positive assessment experience

Emma describes this assessment experience as being very different. It was one-to-one and was based on a discussion of her history and questionnaires. It did not involve looking at books and making up stories, which she had struggled with during the previous assessment.

“In the first assessment they asked about my work and I broke down.”

“I also asked my young adult daughter to fill out the witness questions and she was much more objective about how I am. For example, I don’t understand jokes and have to do things in a certain way. I like doing things on my own and tend to find it difficult to not be in charge.”

“I found some things in the questionnaires seemed very geared to a male presentation of autism and did not take into account that women may have different obsessions or may be masking and fitting in.”

Autism diagnosis

Following this second private assessment, Emma was advised that she is autistic – her diagnosis is Level 1 ASC. She describes being overwhelmed with the report, and she had to take some time before looking and addressing it further, so she put it aside until early 2022.

The key things highlighted in the report were her sensory issues, the masking, and how when she obsesses and goes all out about some things. She used an example of her interest in counselling and how this took her down a rabbit hole.

Emma has struggled with the diagnosis – struggling to know what it is, and struggling to be linked with another condition in addition to her hypermobile spectrum disorder.

“I only really started to own the diagnosis recently; hypermobility and autism seem intertwined. I think it’s important to drop the ‘disorder’ and call it a condition as it’s less stigmatising. We need to see people as people not a label. It is an identity thing and for some it is their whole identity, but for me it is only a part of my identity.”

Despite struggling with the diagnosis, Emma feels it is ‘freeing’. When asked about navigating other medical services, Emma said she feels she is more than capable, but acknowledges it is still hard: “It has been terrible”. She is now quite adept at knowing how to deal with them and has just been diagnosed with sleep apnoea and rheumatoid arthritis; she is anxious about taking medication due to the side effects she may experience.

Care and support after diagnosis

Emma acknowledges how much private counselling has helped her. She describes having a disconnection between her inner and outer self that therapy has helped with, but the sensory issues are still there. She knows that she likes structure and organisation.

“Without therapy I could not have spoken to you the way I have; I did not have the language for my emotions. I am much more aware of myself, due to lots of counselling.”

She is not supported by any local autism services but receives good support from online groups. She has found the Recovery College helpful and is now training to be an Expert by Experience and a Peer Mentor: “Everything is trial and error.”

A number of years ago her GP told her she just had to get used to being hypermobile but did agree she could no longer do a full-time job. It has been a battle to get benefits and a Blue Badge. Emma has also had to navigate some new GPs and sometimes feels as though she is being told off ‘like a naughty schoolgirl’.

Things have got better now she is engaged with veterans’ charities and has found activities that help her feel fulfilled and physically fit without doing more damage.

Emma said the menopause has been a nightmare and as people with autism do not do transitions well, this makes it even harder.

“People get fixed on the idea that those with autism are wired differently, but we are all wired differently and that is what makes us individuals. I describe myself as having a spiky profile of abilities and difficulties. I always sensed I was different but never knew what it was; I felt like I had to fit in and conform. It took so much energy to be like that.”

The best help Emma has received has been through the Veterans Mental Health Service. She explained she was very unwell towards the end of last year and became suicidal again and yet it was impossible to get effective help.

“It was a nightmare because I’d be okay one minute and suicidal the next. The most important thing is to be listened to, believed and helped when I’m in pain or distress. If I’m suicidal I need to be in a safe cool place to calm down mentally and physically. I’m not being deliberately manipulative or dramatic. No one else is going to be as interested in my health and wellbeing as me.”

Chloe’s story

A long mental health journey eventually led to assessment for autism

Chloe is in her early 30s. She was diagnosed with autism in early 2013. She was also diagnosed with a mental health condition at the age of eight and has had anorexia from an early age which was officially diagnosed when she was 14.

During her first mental health assessment as a child, Chloe felt a lot of things were missed and she was initially diagnosed with a personality disorder as this was the only framework they were working with. She spent less than five minutes with a psychiatrist before receiving this diagnosis, so felt it was very hit and miss. Shortly afterwards, this was changed to a diagnosis of mixed personality disorder.

Chloe developed OCD when she was eight which affected her eating and by the age of 14 she had an eating disorder which the school flagged up. In the ongoing years she learnt her grandmother had anorexia, as do her cousin and sister. Chloe developed bulimia alongside the anorexia and was referred to Child and Adolescent Mental Health Services (CAMHS). She was around 16–18 by that time, so she had the choice of staying with children’s services or moving to adult services which, due to family circumstances, she decided to do.

Despite being under these services, during the ages of 16–21 Chloe started to deteriorate, and at the age of 18 she was admitted to a private clinic in Bristol through the NHS. This happened on three separate occasions, and on the second occasion she was a day patient.

At age 21/22 she was referred to a psychotherapist and a recovery team that worked with individuals who had not been helped by any other service. It was at this point the diagnosis changed from a personality disorder to perhaps being Asperger's.

Around this same time Chloe was admitted to Wotton Lawn, an acute mental health hospital in Gloucestershire. She was then placed in supported living in Stonehouse, where many residents had a learning disability and Chloe felt this was unsuitable.

During this time she was referred for an autism assessment and was advised the waiting time was around 14 months.

Autism diagnosis

While she waited for the assessment, Chloe did a lot of research. She was under the care of an 'amazing' psychotherapist at that time, who gave her lots of useful advice and strategies which she knew would help. Chloe feels this person was the only one who helped her during this time.

"It is like gathering information for a legal case."

Chloe felt she 'needed validation' and she hoped the autism assessment would give her that. She said her social worker did not understand why it was so important to her, but as her weight at this point was very low, she felt she needed the diagnosis to put everything in place.

Receiving the diagnosis has given Chloe coping strategies and she now knows how to arrange her life. She used to have meltdowns and be restrained but she is now able to deal with situations in a better way.

"I know how to manage things better."

Having the diagnosis has also helped her with funding, and she commented that she received amazing support from the staff and support workers at [OPENhouse](#) in Stroud.

Need for more awareness and training

Since receiving her diagnosis, Chloe has learnt that one in five people with restricted eating also have autism and ADHD and she hopes this is something that has been learnt by health and care professionals, as her diagnosis came years after her anorexia was diagnosed.

Chloe is aware she is a complex individual and says she falls between the different teams. She does see a social worker but was recently discharged from the Recovery Team and told to re-refer herself as a new clinician is starting soon.

She also believes there are lots of people working in the system who do care but feels many of them lack knowledge and have a lack of training.

"I do not feel terribly supported, but I am used to that."

Ongoing care and support

Chloe has had five social workers and some have been really good. She currently has a community psychiatric nurse she has known for years who knows how to communicate with her and gives her lots of advice on benefits and living. They often go out for a walk with the dogs so they walk and talk and that suits her well.

She is quite lonely a lot of the time and feels very isolated. She also has PTSD and finds that difficult to manage.

During the pandemic all the support she received stopped and she found that very difficult.

She feels although other support services do try, once again they lack training. She is seeing more people within the system now and is getting used to it.

"I can choose whether I let people know my diagnosis whilst others don't have a choice."

Chloe knows she has high support needs, but also feels it doesn't need to be like this. She is aware she is neurodivergent and yet cannot get the help she needs because she does not fit into that particular box.

She has had quite a lot of CBT and believes this is a tool, not a therapy, and should not be promoted in that way. The professionals should understand it has its limitations. She also feels DBT (dialectical behavioural therapy) is a symptom interruption and cannot work on the underlying reasons.

When asked how she deals with other medical appointments she said she finds them stressful and in particular any appointments with the GP, so tries to avoid them. If it can be arranged her social worker attends with her and she even struggles with the waiting rooms due to her medical PTSD. Her medications are reviewed every year by her psychiatrist, so she does not have to deal with the GP for this.

Chloe feels that if a child has been diagnosed with autism there are a lot of services and there is a lot of information for the parents. However, this does not apply to adults with autism and she would like to see more general information for people.

Many autistic people also have social communication disorder and it would be useful to see more information about this.

“It is not easy being autistic. We like connection, although we may not do it in the right way.”

Charlotte’s story

Parenting has been hard – the family’s neurodiversity was not picked up by professionals

Charlotte is in her late 40s and has three children. She believes all of them are neurodivergent and she has found parenting hard. She is surprised no one has ever picked up on this and she describes the family as ‘textbook neurodivergent’.

During her earlier life Charlotte was diagnosed with anxiety and depression and has been prescribed various medications over the years but did not take them. When her children were younger, she was constantly being sent on parenting courses and is frustrated no one looked at the bigger picture. She describes this experience by saying: “it broke me”, and culminated in her having a breakdown in 2018; it was at this point that Charlotte agreed to take medication.

The mental health nurse also taught her to schedule in breaks as part of her recovery.

“Either I am really busy or I stop and there is nothing in between.”

Charlotte says watching her teenage daughter is like ‘living her teenage years again’ as the similarities are uncanny and she does not want history to repeat itself.

“I want to give back to my kids and I can’t.”

Friend encouraged assessment after she struggled during lockdown

In her younger years she used alcohol as a coping mechanism but has not drunk for decades.

She has a very supportive employer and feels she has overcome massive adversity in her life, but still struggles.

During lockdown she could not work and because all the structure in her life had disappeared, she really struggled, to the extent her children went to live with their father. It was during this period a friend asked if she thought she had ADHD and this is what spurred her on to start the process.

Four years wait for NHS assessment, so went private

Charlotte undertook a lot of research on autism and then went to her GP to request a referral where the GP explained the waiting time is four years. She was not advised about the Right to Choose or Shared Care.

She felt she could not wait years to go through the process, so decided to seek private assessment. Her GP told her that if she went down this route and was diagnosed with autism, the cost of any medication or treatment would be picked up by the NHS, which encouraged her to continue.

Although her family does not have a lot of money, Charlotte asked them if they would help pay for a private assessment instead of Christmas presents and this, together with some savings, enabled her to proceed.

Private ADHD and autism diagnosis not supported by her GP

Charlotte was assessed by a private psychiatrist and diagnosed with ADHD and autism in December 2021.

She feels that her self-esteem has been tied up in it, throughout her life.

“This diagnosis has meant I finally know who I am. Throughout my life there have been glass ceilings and I have had to try twice as hard to get half as far.”

The psychiatrist provided Charlotte with a letter for her GP stating that she required an ECG (heart electrogram) and her blood pressure needed to be monitored, which the GP supported. However, the GP later phoned to explain the NHS Clinical Commissioning Group (CCG) had changed the policy and the NHS could not pay for any treatment because the diagnoses were only based on one psychiatrist’s opinion.

“I felt slurred and invalidated by the system.”

Charlotte was also told by the GP that the psychiatrist she had seen was incompetent and they suggested that Charlotte actually wanted illegal drugs. The GP questioned why it was so important for her to know whether she has autism, saying: “There is no cure for autism, so why do you want to know?”

At this time Charlotte was also experiencing severe brain fog at work and so she was put on HRT, but she continued to struggle.

Now waiting for a second assessment by the NHS

In spring 2022, Charlotte saw her GP and asked to join the waiting list for ADHD and autism assessments via the NHS. She believes ‘an approved diagnosis’ will help her enormously.

The process was explained by the GP but Charlotte was disappointed that she was still not offered the Right to Choose option (NHS referral to a private provider) and she commented that she needs to follow this up.

Charlotte is now on the waiting list and is waiting to hear from the assessment team. She is going to ask her GP to find out where she is on the waiting list as she has no idea and feels that psychologically that would be very useful.

What difference will diagnosis make?

Charlotte explained that an NHS diagnosis will enable her to access the right medications, and she will also be listened to and taken seriously, which does not happen now.

She also wants the diagnosis to give her family the chance to get the recognition and understanding they need, so that they are not ‘written off’. Charlotte has a sibling who has been diagnosed with ADHD and her mum is on the waiting list for an assessment elsewhere in the country. She also believes her children are neurodivergent.

“I have complete forgiveness and compassion for my family as I get it now.”

Charlotte describes her previous experiences of the health services as feeling like she has been ‘gaslighted’ and always being told to see the mental health team or do another parenting course, instead of looking at her as a whole person and asking what might be behind her feelings and behaviours.

“I would like to be heard by the professionals...I know I have to take control of this journey to ensure it happens.”

4. Survey

The 12 responses we received through the online survey have been valuable as they have confirmed and reinforced the issues raised during the more in-depth one-to-one conversations, including the struggles to navigate the system, and waiting times.

Are you currently on the waiting list for an autism assessment?

Yes = 2

No = 10

Of those that said 'no', they were either already diagnosed, had gone through assessment, struggled to complete the assessment or are hesitant to start the process (2 people).

"I am in my fifties, and I discussed with my GP. I was told a two-year waiting list and thought, perhaps, it may be better for a younger person to take the place."

How long did you have to wait for the assessment (those that said yes to having an assessment)?

Around a year = 1

Three years = 2

Not long = 1

Six weeks(private) = 1

Six months = 1

Don't remember = 1

What was your experience like and what, if anything, needs to be put in place to make it more accessible?

Had no support pre/post assessment = 4

Need a greater understanding of 'masking' as it affected the assessment outcome = 2

Process was straightforward = 1

What was your experience like of navigating the services?

Seven people answered this question, and all their experiences were negative.

Words quoted: challenging, inappropriate, difficult, pretty awful.

How supported do you feel?

Not supported = 5, with one stating "I felt attacked and traumatised."

Partially supported = 2

Do you have any other diagnosed conditions?

Yes = 6

No = 1

What would be your top three priorities for better support for those with autism in Gloucestershire?

More joined up care - considering other conditions (neurodivergent or other), support with benefits application/finance, better awareness of those who 'fall through the net' - women and girls, and those with high-functioning autism.

How old are you:

9 of the 12 people who completed the survey were aged over 25.

Which sexual orientation do you identify with:

4 of the 12 people who completed the survey identify as bisexual or lesbian.



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