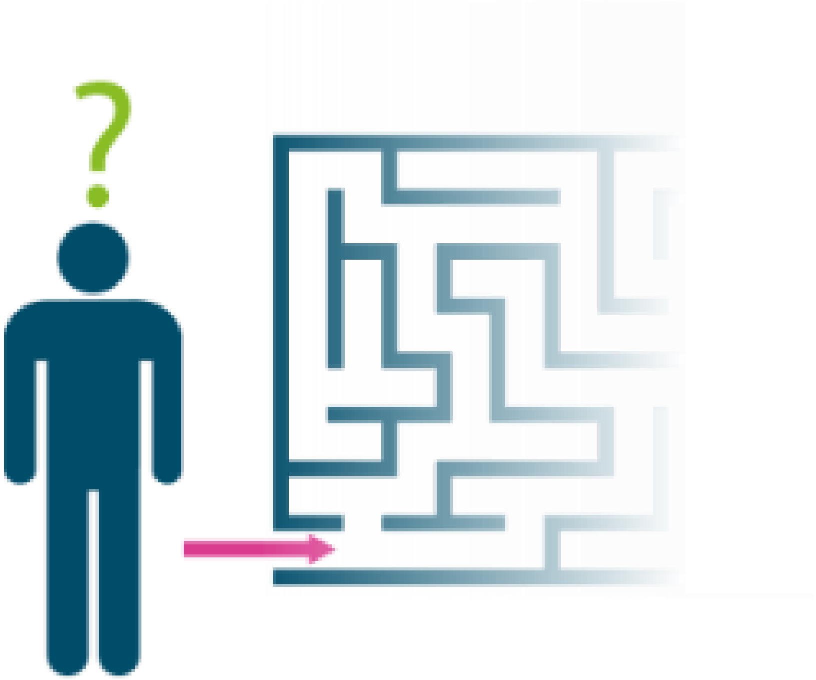


West Sussex Adult Autism Assessment Pathways

Understanding the impact of long assessment delays

June 2021

Content

Quality Standard, NICE, Statement 1: ‘People with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started within 3 months of their referral.’

https://www.nice.org.uk/guidance/qs51/chapter/List-of-quality-statements

Executive Summary

The current wait for an Adult Autism Assessment in West Sussex is approximately 3 years (as reported by people referred to the service and the service itself).

The service, delivered by the Neurodevelopmental Service of Sussex Partnership NHS Foundation Trust, is commissioned in West Sussex purely for diagnosis. It is currently funded for approximately one-third of the referrals it receives. The majority of referrals are appropriate and lead to a diagnosis.

The way the service is commissioned and funded impacts the whole service, including clinical and administrative capacity. This in turn impacts people entering the service.

There is limited support for people whilst waiting for an assessment, and the service is not commissioned (or resourced) to provide this. This pre-assessment support gap impacts family life, work and education opportunities, as well as peoples' mental wellbeing. Often support, e.g. reasonable adjustments at work or in education, can only be put in place with a diagnosis and people are struggling without the recognition achieved through an official diagnosis.

'The current service needs to be extended to cover consistently the four stages involved in diagnosis: (1) Pre-diagnosis - the reasons for seeking diagnosis and referral, (2) Assessment - interviews and questionnaires, (3) Communication of Diagnosis and, (4) Post-diagnosis - assimilation, next steps and map of the autism landscape. Whilst many agencies and individuals are involved across the four stages, a single organisation must take overall responsibility for the full four-stage diagnosis process to ensure that it is fit for purpose, end to end. This is essential as the people seeking diagnosis may indeed be autistic. They may experience high levels of anxiety during a process that challenges their need for control and certainty and may be overwhelming. Hence the need for a consistent and rapid end to end process in which the stages before, during and after are carefully and sensitively explained in language and through media that connects with those being diagnosed.' David Henderson, based on recent experience of accessing diagnosis in West Sussex as an adult.

People currently seeking an assessment, or who have recently had an assessment, told us about their experiences:

- There is concern that the pathway for an adult assessment in West Sussex is not easy to find out about, particularly for women and older adults. Some GPs have little awareness of the pathway, how to refer or about autism in general.

- People seeking assessment can feel disbelieved by some professionals, particularly if they are doing well academically or at work. They're not always listened to.
- There is a need to 'justify' why the person needs an assessment. GPs need a reason to refer for an assessment, but this is not always explained and can lead to people feeling challenged, disbelieved and their experience devalued.
- People are unsure where to go for help, e.g. with work, education or for daily living needs, and need support to research and navigate the options available. The information available can be too overwhelming to be useful.
- People said it was hard to find mental health support. This difficulty sometimes increased once they'd received an autism diagnosis. They were unclear which services they could access, and not all services had an understanding of autism.
- The long wait for assessment negatively impacts people's quality of life.

Recommendations

We have identified the following areas where the NHS service and commissioners must act swiftly to make sure West Sussex adult residents have fair and appropriate access to an autism assessment and the necessary support to stem negative impacts on family life, work and education opportunities, as well as peoples' health and mental wellbeing.

1. **West Sussex NHS Clinical Commissioning Group should ensure a robust commissioning review of services is undertaken promptly and the appropriate procurement action is taken to meet demand both in the Neurodevelopmental Service (to ensure people are assessed within three months of being referred) and mental health provision.**

2. **The Neurodevelopmental Service should provide, in writing, clear information about the process to individuals on receipt of a referral. This will help to manage peoples' expectations and avoid generating stressors that may harm the individual. This information should also be easy to find on the service's website.**

   N.B. There is information on the Sussex Partnership website, https://www.sussexpartnership.nhs.uk/neurodevelopmental-service, which links to other sources of information, however, it is unclear if people are aware of this resource. How can this information be more effectively shared? How does information reach people who are digitally excluded?

3. **Better communication from the Neurodevelopmental Service regarding the expected timeline of the process. Acknowledgement of referral acceptance and guidance of when someone should expect to hear from the team, and what to do if they don't, needs to be shared in an individual's preferred communication format. This should also be visible on the service's website.**

   > *'What made it first [sic worse] was not knowing how long it would take.'*

   There is information - https://www.sussexpartnership.nhs.uk/neurodevelopmental-service, but from the insight received, it is unclear whether many people are aware of this.

4. **All clinicians (GPs, Paramedic Practitioners, etc.) who are supporting someone seeking an autism assessment should explain the need to provide a reason for referral. This should be sensitively explored and explained to avoid people feeling disbelieved, challenged or devalued. Sussex Health and Care Partnership need to identify who is responsible for ensuring this happens.**

   Pathway(s) should signpost people to The National Autistic Society's Pre-diagnosis for adults guide. This guide also has information for GPs including a link to the NICE pathway. The resource is signposted to by the Neurodevelopmental Service website but needs to be more accessible to people seeking an assessment early on in the process.

5. **As people are currently waiting longer than the NICE standard of three months from referral to assessment, West Sussex Clinical Commissioning Group urgently needs to resource the Neurodevelopmental team, or another service, to *contact* people every month (or less frequently if agreed with the individual) for a welfare conversation to assess whether further support is needed whilst waiting for the assessment.**

   ‘Better follow-up support - post-diagnostic peer support group would be good. Maybe a welfare check… phone call a couple of days after [assessment]. To have support with accessing and making referrals to other services.’

6. **West Sussex NHS Clinical Commissioning Group should review the training GPs receive about autism in adults. Recognition of autism in women and older people, the referral process and co-morbidities to be embedded in practice.**

   ‘I asked my GP about an adult assessment and he said he didn’t think there was such a thing, and the NHS can’t fix everything.’ Adult male with severe anxiety

   ‘Women have physical and hormonal changes and it’s easy to miss things and end up being passed around services. You have to be assertive and not everyone can be. I was mega-sensory when I was pregnant – physical touch during labour was overwhelming – always on the back foot if autism isn’t recognised.’

   The neurodevelopmental service team do offer training within the Trust and have offered awareness training to GPs in other parts of Sussex. The service expressed a keenness to offer a training session about autism and the service to West Sussex GPs. Their webpage signposts to toolkits on the Royal College of General Practitioners website https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/asd-toolkit.aspx

   There is also the rollout of the Oliver McGowan Mandatory Training which is currently being trialled in some organisations https://www.hee.nhs.uk/our-work/learning-disability/oliver-mcgowan-mandatory-training-learning-disability-autism The evaluation of the trials will hopefully be completed by March 2022 and lead to co-produced and delivered mandatory training for everyone working in health and social care in England.

7. **The current mental health care pathways pre and post autism assessment should be reviewed by the mental health collaborative to address the confusion around access and to remove any limitations to needs-led mental health support. Support needs to be flexible to adapt to the specific needs of the person and providers need a sound knowledge base of autism to enable this.**

> *'I was also told that I cannot go down the Time to Talk/cognitive behaviour therapy [route] whilst awaiting assessment for Autism [as] only one referral can be processed at one time for mental health. Either I seek CBT or a diagnosis. I can't do both?'* Insight shared with Healthwatch.

> *'The support from MIND is groups, drop-ins and support on request which goes against every need [stated in my] psychology report.'* Discharged from Sussex Partnership Foundation Trust to Pathfinder.

8. **Healthcare professionals should be supported to use appropriate language, both in their verbal and written communications. We ask that West Sussex NHS Clinical Commissioning Group identifies what is available and how this could be embedded as part of personal development mechanisms and training.**

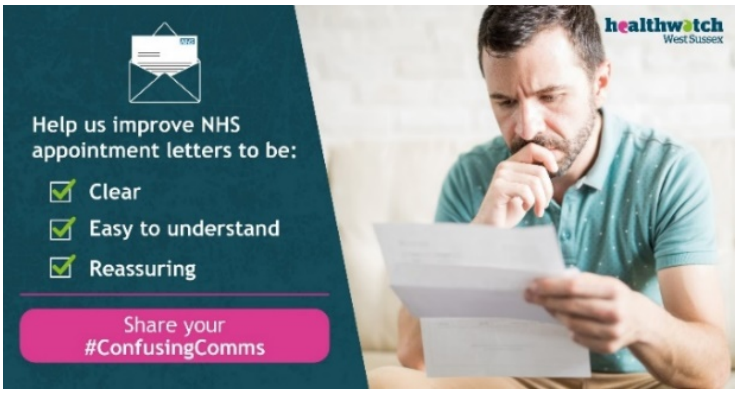
> *'You don't recover from Autism – you manage it'.*

This extends to everyone working with people, including GPs and mental health teams and there needs to be recognition of the impact language can have. We're aware that assessment reports have to contain diagnostic criteria, and that the Neurodevelopmental service try to balance reporting of 'deficits' as defined in the diagnostic criteria with strengths and a positive focus on neurodiversity, but feedback indicates the language used can still have a negative impact.

> *'Big rethink of the language used in diagnosis report letter! The word 'impairment' featured several times in mine, also 'autistic issues' it was very difficult to read, made me feel very hopeless and down about myself [and] actually resulted in suicidal thoughts.'*

Please note, through our #ConfusingComms Advisor and Community Partners we can support services to improve their written communications.

We are asking local people to send examples of poorly written NHS appointment letters, emails or texts. With your support, we can identify how local health services in West Sussex can improve their communications.



Share your #ConfusingComms

9. Sussex Health and Care Partnership Autism Lead to identify ways of creating a higher profile to Sussex Partnership NHS Foundation Trust's website to both GPs and the public – many of the issues highlighted by the survey are covered here, e.g. assessment procedures, how to get a referral, GP training etc. The CCG will need to provide funding to enable this to happen as the current level of underfunding impacts the service's administrative capabilities.

10. The West Sussex Clinical Commissioning Group need to resource and identify ways of making supported signposting and navigation to support networks and services available. This appears to be a large gap not filled by simply listing resources and it's unclear who, if anyone, holds responsibility for this essential service. The CCG will need to provide funding to enable this to happen. This is currently uncommissioned, leaving many people unsupported.

Introduction

The current wait to be seen by the Neurodevelopmental Service in West Sussex is up to 3 years. Over the last year, Healthwatch West Sussex has received regular insight from people who are struggling whilst waiting to be seen for an Adult Autism Assessment. Support for many of them within work and education is out of reach until an assessment and potential diagnosis has occurred. This is harming their mental health, and negatively impacting their life.

> *'Caller wanted to share that her adult son will have to wait for 3 years to get an Autism diagnosis. He had an assessment at work and they marked him as 7 out of 10 positive for having autism. The GP is aware and they have looked at going privately but some private tests are very expensive and may not be recognised by the NHS. His employers are wanting the confirmed diagnosis so that they can help support him at work and an organisation called LIMA would be able to support him but only after a confirmed diagnosis. Mum feels that this is an issue in West Sussex and wants their story shared and recorded.'* Shared with the Healthwatch Helpdesk.

After conversations with some of the people referred for assessment and with Autism support groups, Healthwatch West Sussex decided to explore the impact of these delays on people and what support was available to them before and after assessment. This is timely as a Sussex Wide Health Strategic Plan to improve outcomes for people with Autism and/or a Learning Difficulty is currently being developed,

Healthwatch used the starting point of the insight already gained. Working with community partners, we developed a questionnaire to share online (due to COVID restrictions). The questionnaire allowed people the opportunity to take part in a follow-up interview.

Questionnaires were shared on the Healthwatch social media channels and promoted by autism and health-based community support groups.

We also spoke to the Neurodevelopmental Service to provide context to what we were hearing from the public.

The interviews and conversation with the Neurodevelopmental Service are included in their entirety in the appendices and informed this report.

Thank you to all those who helped us and shared their often painful experiences. This report aims to magnify your voices.

Limitations

Due to COVID, we were unable to undertake public-facing engagement in the wider community. As such, we are aware this report has limitations, including engagement with people who are LGBTQ+ and those from different ethnic backgrounds and that their voices and experiences are not necessarily reflected in our findings.

Key themes

'Many adults with suspected autism have difficulties accessing a diagnostic assessment. Even if they manage to obtain a diagnosis they may receive no follow-up support because of the absence of appropriate services or an agreed care pathway.'

NICE Guidance Autism spectrum disorder in adults: diagnosis and management Clinical guideline [CG142]
Published: 27 June 2012 Last updated: 18 August 2016

Pathway: There is concern that the pathway for an Adult Autism Assessment in West Sussex is not clear or easy to find out about. There is information about autism in children, some specified boys, but less for adults, particularly for adult women. In addition, as an adult, it can be difficult to find the time to research the pathway with all their other responsibilities.

'There is so much information out there to guide one through autism in children and how to get a diagnosis and the necessary support. Support for adults who suspect they have autism is less advertised/visible/available.'

'We (women) don't present how children do when autistic. Some people don't believe we exist at all!'

Not believed: There is also a sense that people can be disbelieved, particularly if they are doing well academically or in the workplace.

'School said that as he was above 75th percentile there were no issues.'

'My daughter had always been a high performer but had relationship difficulties... SEN Coordinator at secondary school only interested in less able.'

Gaps in knowledge: Some GPs have little awareness of the pathway or autism in general.

'Had no idea how to be referred for an adult assessment and no professionals knew either. It only came to light when another adult parent/carer I know shared it with me.'

And some refuse to refer.

'We have been told for years that [they] have autistic traits but doc refuses to arrange tests/diagnosis as says the hEDS diagnosis is substantial.'*
* Hypermobile type Ehlers-Danlos syndrome

Signposting and navigation: Lack of signposting was a consistent message from both the insight received from enquiries to Healthwatch and through survey responses. People are unsure where to go for help and need support to research and navigate the options available. Wading through information can be too overwhelming to be useful.

Mental health support: There is confusion about what mental health support people can get and people are unclear which services they can access. Some people experience support being removed once they have an autism diagnosis as they are deemed too 'complex', and others that the support is inappropriate for autistics. It is also known that common therapies, e.g. Cognitive Behavioural Therapy (CBT) and talking therapies, need to be delivered with appropriate adjustments but not all services had an understanding of autism or of how treatments could be adjusted for an autistic person.

'I tried Time to Talk but they didn't have a good understanding of the impact of autism and kept calling it a difficult symptom.' 9 months wait for this service after a 2-year wait for assessment.

'Spent last 4 years asking for counselling under the NHS but refused as she is too complex and we need to go private. Not available under NHS for adults with autism.'

'It seems that because I would not carry out the act of committing suicide but have feelings of not wanting to be here that I do not qualify for being higher on the priority list.'

'Excluded from therapies and help because I am autistic. Sussex Partnership will now not help as I am autistic.'

In addition, accessibility to the support that is available can be hard to physically reach.

'Live near Crawley but could only access [appropriate] support in Worthing. I was good for nothing once I got there.'

Voice dismissed: Adults seeking an autism assessment do not always feel listened to. They can feel *'fobbed off'* or told they have anxiety or depression.

This is compounded by the need to 'justify' why someone wants to be referred for assessment. Autism.org.uk states, *'your GP needs a reason to refer you for diagnosis, so you will have to explain why you think you could be autistic, and how a diagnosis would benefit you'*, (https://www.autism.org.uk/advice-and-guidance/topics/diagnosis/pre-diagnosis/adults). However, many people experienced this as their voice and experience being invalidated secondary to that of other professionals.

The **Equality Act (2010)** places a requirement on public services to anticipate and prevent discrimination against people with disabilities, which includes people with autism. Many people have support and communication needs that, if left unmet, will put them at a significant disadvantage when trying to navigate the health care system and impact their long-term health.

> *'Diagnosis can't be something that adds limitations. It needs to enable and empower.' David*

But it appears this right is sometimes ignored in interactions with health professionals in West Sussex.

> *GP refusing 18-year-old girl [referral]for autism diagnosis. [She's] suffering as can't eat but will be put down to AN [anorexia].*

Commissioning: In West Sussex, there appears to be inadequate commissioning and existing services cannot meet demand in either the Neurodevelopmental Service or mental health provision. This negatively impacts people's lives, and some people are seeking private support that carries a negative financial impact plus highlights the inequalities in being able to access services.

> *"Due to the wait, they turned to private diagnosis with significant cost and have placed themselves into debt as a result. The assessment was needed for a work-related situation, they didn't want to lose their income or job and felt they simply had no option to pursue privately. As you can imagine, not many employers will be willing to wait for two years."*

The West Sussex Neurodevelopmental Service is commissioned purely for diagnosis and only has one full-time member of staff. They are currently commissioned for approximately a third of the demand and have more than 3000 West Sussex residents on their waiting list at any one time.

This impacts everything from waiting times and diagnostic capacity to the administrative capacity to keep the website up to date. Deficits in children's services also impact capacity as the Neurodevelopmental Service inherit young people waiting for an autism assessment when they transition to adult services. This, in turn, negatively impacts people trying to access the adult service.

The Neurodevelopmental Service provides assessments for all Sussex adults, but there are different commissioning arrangements in place for West Sussex, East Sussex and Brighton and Hove and therefore Sussex residents experience things differently depending on where they live.

Peer support: Insight gathered also indicates that people pre and post-diagnosis would appreciate support, both professional and from support networks, from other autistic people who will have a better understanding of their experiences and needs.

Loneliness: Although not mentioned explicitly in survey answers or interviews, loneliness also seems to be a key theme. Reflecting on the conversations and survey answers it feels that this may be a big part of how autism impacts people and another reason why diagnosis is important.

Conclusion

‘If you don’t know someone is autistic then you can’t investigate properly – need the complete picture to understand someone.’

There is no shortage of awareness of the need to provide better services for autistic people. A quick internet search highlights current and historic concern over GPs knowledge of autism, delays to referrals and assessments and the health inequalities, mental and physical, faced by autistic people. A search will also show extensive research and recommendations that have been suggested at varying times, including autism mental health pathways and autism featuring in key NHS strategies, including their Long Term Plan. The Royal College of General Practitioners declared Autism a clinical priority from April 2014 – March 2017. Yet, as this report shows, we are still hearing of persistent underfunding, disjointed support structures and people struggling to get an assessment let alone the support and understanding they need.

This impacts severely on all aspects of people’s lives, carrying a myriad of hidden costs both personal and to the system, and should no longer be acceptable. Support often hinges on the ability to get an assessment, and in West Sussex chronic underfunding is denying many autistic people even that basic right.

‘I was asked the timescales for the adult diagnosis pathway and they were horrified, so much so they’re not going to bother.’

Is this the reaction we want for West Sussex Services?

Appendix A -Autism Assessment Pathway Survey Analysis

25 people responded to the survey. 7 people responded for someone else.
16 people identified themselves as female and 6 as male.

Respondents lived across West Sussex in rural and urban locations. 12 out of 25 respondents lived in the northeast of West Sussex. The rest were spread across West Sussex.

Question: What are your reasons for wanting an assessment and diagnosis for autism as an adult? For example, some people may want this for peace of mind, others may need it to access provision and support in some area of their life.

The main reasons were:

Peace of mind or self-acceptance - 12 responses

'Better support, peace of mind and knowing if I have passed it on to my kids'

Mental Health factored in 8 responses

'Access support with mental health'

Support – 16 responses. Support for **education or work** was the reason given by 4 people. 7 people mentioned support generally (assuming from **health and social care**) and 1 person specifically mentioned peer support.

Understanding - 10 people stated *understanding* as an important reason for seeking a diagnosis, This, included other people understanding them and them understanding themselves.

'So that I have an explanation for why I think and behave the way I do. Hopefully, this will help other people understand me more and hopefully, it'll lead to more support.'

Legal protection - 2 people stated the need for legal protection, e.g. equality and anti-discrimination.

Confirmation - 3 people wanted confirmation of what they already know.

'I know without doubt that I am on the Autism Spectrum, but I would just like it confirmed so it solidifies what I already know and helps me understand why I feel/act the way I do sometimes.'

Suggested by someone else - at least 5 people requested an assessment at the suggestion of someone else, e.g. a friend or counsellor or doctor treating them for associated health conditions.

Recognised themselves when supporting their children – and some people recognised the traits in themselves when starting the assessment process for their children.

‘I questioned whether I had autism myself when filling in the forms for my son and saw lots of similarities between us it got me thinking if autism could describe my struggles with everyday life that have ultimately led to more significant problems with depression anxiety to disassociation and isolation.’

Listened to – and 1 person was explicit that without a diagnosis they’re not listened to.

Studies – 1 person took part in a study that indicated autism; The *‘Adapt study flagged it up so recommended I have an assessment’.*

DNA – 1 person had a DNA test – *‘I also input my raw DNA onto a site and I have an 88% higher chance than the normal public of having autism.’*

People tended to have multiple reasons for wanting a diagnosis.

‘For peace of mind and self-acceptance/understanding, leading to better mental health and less self-hate. To ensure better support and provision as I get older. For support and understanding on the workplace, plus protection from discrimination.’

Question: Was the referral straightforward? If no, what needs to be changed? Please tell us if you self-referred or were referred by someone else.

Responses were fairly equally divided with whether the referral process was straightforward or not, with 11 people saying the initial referral was straightforward and 9 disagreeing. The main referral route was via their GP (8 responders) or another health professional (4 people) and GP knowledge impacted whether it was straightforward or not.

10 people indicated stress points in the referral process were not being believed, having to justify their request for a referral and needing second opinions to enable the referral.

‘I spoke to my GP who sent a link to question to fill out. This part was simple. Now I have to write an explanation of why I want an assessment, this feels hard and stressful to do. I’m worried that I’ll be turned down if I don’t write the right things. A less overwhelming and more guided way to respond would be better.’

‘The only thing I would suggest needs to be attended to is having to justify needing the diagnosis. It is hard enough to approach the GP and make that initial appointment.’

‘I approached my GP, the one in our practice who leads on mental health issues. He was initially reticent and didn't want to refer me, although he didn't say why. I persuaded him, but he, in turn, insisted on getting a letter from my counsellor.’

3 people were unable to access the pathway via the NHS and paid for a referral/assessment.

‘Absolutely no success on NHS. Private referral.’

People highlighted several things in the referral process that they would like to change. They suggested better communication so that they were informed of the assessment timeline, including the waiting time and a response from the Neurodevelopmental Service to confirm receipt of referral. They also felt GPs needed better knowledge of the referral process and that information about it should be more accessible.

‘I went to the doctors with a list of concerns and they sent a letter to get a referral but heard nothing since.’

‘The process was fairly straight forward, but may have been helpful if I had a letter directly from the neurodevelopmental team confirming that they had received my referral and giving some indication of how long the wait for an assessment was likely to be.’

GP knowledge impacted whether the referral was straightforward or not, and there is variation between people’s experiences. Some GPs were pro-active, others asked for justification which people found stressful due to the fear of saying the wrong thing. Other people had to approach more than one GP for a referral or get advice to ensure the referral happened.

‘The process was fairly straight forward but I did have to tell my GP what it was and who to refer me to.’

Due to the lack of information, some people rely on their informal networks for help and advice.

‘Had no idea how to be referred for an adult assessment and no professionals knew either. It only came to light when another adult parent/carer I know shared it with me.’

Question: How long was the process, e.g. the wait to be seen, going through the assessment to getting the outcome from this?

From people contacting Healthwatch West Sussex, we are aware that the current wait is approx. 3 years. This is born out by answers given to the survey. However, some answers indicated that historically the wait was much less, only a few months.

‘Still waiting (so far almost a year).’

‘Years and no success so went privately as needed help.’

‘I've been waiting over 2 years and have heard nothing other than the initial letter saying I was on the pathway.’

These delays can be added to by GPs lack of knowledge and lack of communication from the service.

‘The GP took 3 months to refer me as it was unclear where to send the adult referral so he hadn’t completed the referral. Currently, I have been waiting 4 months on the list but my neurologist would like this expedited unfortunately until the service makes contact it is unclear how/who she speaks to about this.’

Administrative delays to referrals are not always recognised when people finally get onto the waiting list.

‘Referral went in over a year ago. Received a letter in April saying it was a minimum 2-year waiting list for an initial appointment and then the impact of Covid19 would further delay it as well... Heard nothing since....’

‘I had previously been referred and put on the waiting list for an autism assessment back in 2015. I was told by my psychologist in 2017, having waited over 2 years, that the service I was referred to for the assessment had closed down. This wasn't taken into account when I was rereferred in 2018/19.’

And some people appear to have fallen out of the system.

‘It took 6 months or so for me to be seen by someone at CAMHS. They said I almost certainly was and I should be seen by the psychologist. That was 4 years ago and I have never heard from them.’

Communication is often poor once a referral made and this can aggravate the issues above. Some people are informed that they’re on the pathway, but others hear nothing and people can not always find support whilst waiting.

Sometimes the waiting time is less due to cancellations.

‘I was told the wait would be 12-18 months. However, I was actually seen by 8 months. I was told that this was because I was able to have a virtual assessment during covid 19 and a cancellation had come up… I provided quite a lot of paperwork and screening questionnaire ahead of my assessment. As a result, my virtual assessment was only 1 hour long.’

Sometimes diagnostic letters and follow-up appointments are also delayed.

'I was told at the end of the assessment that I met the criteria for an ASC diagnosis. I didn't receive my diagnostic report letter for another 3 months and did have to chase this up. I also didn't have my follow up appointment until 3 months after my assessment when I had been told I would receive a follow up within 24 weeks. Again, I had to chase this up.'

Question: How did/do you feel about the waiting time and what impact did it have on you?

The impact of the wait is affected by several things, including whether people are kept informed, have support and the reason they're seeking the diagnosis. 15 people who answered this question felt the delay between referral and assessment impacted them negatively, affecting their mental health and delaying access to support they needed for work/education.

'It's so long it kind of feels pointless. I'll have finished uni by the time I actually get a diagnosis. It's also really frustrating having to wait for so long.'

'When it's affecting my life this much, 2 years feels like a very long time to wait. I'm already not really coping but can't access the support I need without a diagnosis.'

People who had been informed of the wait coped better:

'I was expecting a long wait, so in a way, it didn't affect me too much. It did have an impact in that I was not able to access some support services until I had a confirmed autism diagnosis.'

Sometimes information about the length of the wait came from peers rather than professionals.

'It was bearable, but what made it first [sic worse] was not knowing how long it would take. Once the referral was sent off it went very quiet. I had to rely on word of mouth from other people to know how long it would take.'

Some people were just pleased to finally get a diagnosis.

'We were just keen to be seen having waited 60 years for a diagnosis!'

'Fine - just good to finally be told she has autism. Only took 24 years for this to be finally confirmed.'

Other people felt the long wait underlined professionals lack of understanding of autism.

'It's just not good enough, nor acceptable. It creates further anxiety. If these so-called professionals really understood the condition and the impact situations like this have on us then there wouldn't be such a lengthy waiting time.'

'It's been horrendous! I've had to fight for every bit of support for her.'

Question: How do you feel about being assessed online due to COVID19? What are the difficulties and benefits of this? How would you like to be assessed?

People understood the need for online engagement during COVID and could see the benefits of certain parts of the assessment occurring online. However, the majority of respondents felt that there needed to be some face-to-face engagement for an accurate assessment.

4 people were very opposed to online assessments.

'I don't think they'll get the full picture if I'm assessed by a person online and it makes me feel anxious.'

'I would hate to have to do it online, I find it very difficult talking to people unless it's face to face.'

1 person felt they would prefer an online assessment.

'More than happy to chat via Teams or Zoom. This would be so much more helpful tbh [to be honest] as I'll feel more comfortable and won't have the added stress of going somewhere new.'

And 2 people didn't care how they were assessed – they just wanted it to happen.

'I'd like to be assessed by any means.'

The answers showed that even during the pandemic, there needs to be a choice in the methods of assessment.

'I would prefer to have that human connection to seek assurance that I am following the right path. However, an online assessment could possibly give one the chance to research before answering if unsure how to answer e.g. one's memory fails but perhaps family members can help one to recollect relevant material.'

Benefits*:*

- *I got seen sooner.*
- *Didn't have to travel somewhere for the appointment.*
- *Felt more comfortable having the assessment in my own home.*
- *Less anxiety about the journey and meeting new professionals face to face.*

Difficulties of virtual assessment*:*

- *I think it was harder for them to observe eye contact and body language.*
- *Some connection issues, but not too disruptive.*
- *I felt quite vulnerable after the assessment ie. to be told that you have an autism diagnosis and to then be left with a blank screen, on your own, in your flat felt a bit overwhelming.'*

Question: Were you signposted to services? Please describe how any support helped or did not help.

No signposting – 13 people

Signposting – 3 people

Given information – 3 people.

Overwhelmingly, respondents said they had not been signposted to support services whilst waiting for an assessment or after diagnosis.

'No. I think that this is a huge gap in what is available for those newly assessed as being on the autistic spectrum. I made it my business to find out what was available, but it took a long time as I didn't know where to look… NHS, local councils, charities, national government... Not everyone would have felt able or willing to do what I did! I discovered that there are many agencies involved, but they are not joined up. And I still haven't found any signposted map which shows all these agencies and how they are connected. THIS IS A HUGE HOLE!'

'I was advised there is no help and twice referred to ATS (Assessment and Treatment Service).'

Those people who were given information said it was overwhelming and they needed support to navigate the information.

'After my follow up appointment I was emailed a 30 page document of services I may be able to seek support from. This was helpful, but was also quite overwhelming. It was made clear that no referrals could be made for me, the onus was on me to self-refer. I didn't really know where to start and this delayed me seeking support.'

'Just given a list of reading material and a few websites, which was not very helpful.'

'I was given an information pack with suggested reading material and websites. I would have welcomed ongoing support of some sort, i.e. Adult social care assessment, access to support groups, professional support.'

2 people were signposted to LIMA (Low Intensity Management for Autism, https://westsussex.local-offer.org/services/1372) but this doesn't seem to be available in all areas.

1 person was signposted to *'an actually autistic run group in Sussex'.*

Signposting/navigating is a complex area. The Neurodevelopmental Service is only commissioned to provide a diagnostic service. They do provide information re further support on their website, but comments are that people are overwhelmed trying to find the services which are right for them. This appears to be a large gap not filled by simply listing resources and it's unclear who, if anyone, holds responsibility for this essential service.

Question: Thinking about what happened afterwards did this satisfy your reason for getting the assessment?

Yes – 9 people **No** – 4 people

Many respondents were unable to answer this question as they're still waiting for their assessment. However, the majority who had had an assessment agreed that it satisfied their reasons for embarking on this pathway e.g. understanding themselves and accessing support services.

'Yes. I had a confirmed diagnosis and letter, and I could access support from services that I previously couldn't without the diagnosis.'

'Yes, it was a huge revelation to me about me. It explained so much about the way I am, and it made a lot of sense of my life up until the present day.'

However, a key request was for more aftercare/support.

'Yes. I felt better for being assessed. Wish there was more aftercare or support though.'

'Yes, it really did but also I did need more help after, I only got one follow up and I needed mental health support. I tried time to talk… but they didn't have a good understanding of the impact of autism and kept calling it a difficult symptom. I had to wait 9 months for that service too.'

Others agreed that it had answered questions for them but had not improved their life as the support they needed wasn't available.

'Just had a diagnosis. After so many years it didn't make much difference. Battled all our lives so.'

Not at all. We still struggle each day.'

'Yes but no assistance from SP (Sussex Partnership).'

Question: Did your quality of life change? Please tell us how.

Yes – 5 people **Maybe** – 1 person
No – 6 people **Mixed** – 1 person

Once again, not everybody could answer this question as many responders are still waiting for an assessment. Those who wanted to understand themselves better were generally positive about the impact of having a diagnosis.

'Yes. I was able to accept myself. People I know and work with were able to support me better.'

‘It has improved my quality of life big time. For example, I recognise and manage rising levels of anxiety before they reach a meltdown; I now know that I need to balance my time with other people and my time on my own. It has also helped me become increasingly self-aware.’

But others have found the diagnosis has provided further barriers.

‘Excluded from therapies and help because I am autistic. Sussex Partnership will now not help as I am autistic.’

‘Worse as now I am autistic nobody wants to know.’

And others have a mixed response to the diagnosis.

‘I definitely felt better about myself and more accepting of myself. Having a diagnosis of autism made me feel more able to connect with other autistic people. I was able to start receiving support from the LIMA Project, which I have found really helpful. I also had my social package hours increased to cover social communication support. On the flip side, it didn't make a difference to some issues I experienced from my employers, in fact, the autism diagnosis escalated the situation prompted them to declare that my needs were 'too complex' for them to be able to support me in the workplace! Some friends and family have also responded negatively when learning of my autism diagnosis.’

‘Perhaps, but sad everyone ignored so many of us [women] for so many years and just focussed on children and boys.’

Question: How do you think the assessment process can be improved?

This question triggered a good response. People felt that better communication and clarity around timescales and guidance on what to expect would be useful. They also highlighted that GPs needed better awareness of autism and the referral processes. Shorter waiting times were also highlighted, along with aftercare and support. Some people felt there was a lack of interest by service providers and they were tired of being *‘fobbed off’*.

‘Clear timescale for waiting etc, initial contact explaining waiting time and clear guidelines as to what will happen in each appointment.’

‘Clearer guidelines for GP's making referrals. I had to tell my GP what the process was. Often you hear of GP's denying that the service even exists.’

‘Earlier diagnosis’

‘By letting actually autistic people run it. Not involved, run it equally if qualified.’

‘Shorter waiting time, more aftercare and support.’

‘Assessment over more than one session so can build up a rapport with the professional.’

‘To have support with accessing and making referrals to other services.’

‘Better follow up support post-diagnostic peer support group would be good. Maybe a welfare check, following assessment, e.g. a phone call a couple of days after.’

‘There is a strong case for assessments to be offered to everyone around the age of 20. Apart from those with extreme autistic characteristics and/or adjacent comorbidities, who will need to be assessed earlier in childhood, some adult experience of life is, I think, necessary before assessments are made where characteristics are less obvious. I think had I been diagnosed as a child, I doubt if I would have had the motivation and belief to live as full a life as I have, despite its many downsides.’

‘Listen and talk to close family members more as the Individual cannot truly identify their difference as it is norm to them.’

‘Reduce the waiting times drastically for an initial consultation!!’‘It should not depend on how much money you have and can therefore go privately.’

‘Speed up!!!!!!!!! Stop fobbing people off!!!’

‘Some people have to go through a telephone assessment first. This can be traumatic for a lot of autistics.’

‘Not everyone seems to get an ‘official’ diagnosis, just an indication that they are ‘probably’ autistic. This difference isn't explained at the time and can lead to being refused access to services in the future. All assessments leaving to diagnosis need to carry official diagnosis standards. Gold standard I think it's called?’

And it was suggested that the language used needs to be looked at.

‘Big rethink of the language used in diagnosis report letter! The word 'impairment' featured several times in mine, also 'autistic issues'. It was very difficult to read, made me feel very hopeless and down about myself actually resulted in suicidal thoughts. I think the diagnostic report should be more personal, strength-based in terms of language, speaking more of 'neurodiversity' and 'difference' rather than 'impairment'.’

Appendix B - Discussion

‘Autism impacts so much and people can interpret things differently… You need the diagnosis to get the right treatment, otherwise, we’re setting people up to fail. No diagnosis makes you vulnerable.’

Diagnosis and support for autistic adults is important. According to the Royal College of General Practitioners, the prevalence of autism is estimated at 1.1% based on children's studies but many adults – particularly over the age of 30 are unrecognized or undiagnosed. And, unofficial estimates place the prevalence of autism as far higher. This leads to poor health care without reasonable adjustments, missed opportunities to take part in health screening and potentially premature death. Being unrecognized or undiagnosed impacts significantly on education and work, with many people being unable to access adjustments or support.

‘Life is becoming increasingly difficult with uni refusing to help because I do not have an official diagnosis, distance learning has made it million times worse with anxiety levels through the roof and no way of planning a ‘back to uni’ routine myself without the universities assistance. I understand that everyone has struggled with COVID but the change in routine and uncertainty has wreaked havoc without knowing if I am even on the waiting list for an assessment.’

The Neurodevelopmental Service, the route to an autism assessment in West Sussex, is severely underfunded. Commissioning does not meet demand and a rising understanding of autism in adults, including women and older people, compounds this. Currently, the service has funding for approximately one-third of demand and demand is rising all the time. Manipulating criteria to reduce waiting times (one proffered solution that was rejected by the service) doesn’t solve any problems other than ticking a ‘reduce waiting times’ box. Instead, it widens a gap that does a disservice to those seeking assessment and clarity and will severely impact other services.

‘I feel I’ve had so many lost opportunities because the system doesn’t work for me, doesn’t recognise me. The way I learn and process information doesn’t fit.’

The support for adults seeking or having had an assessment is fractured. The West Sussex Neurodevelopmental service is only commissioned for diagnosis. This is not always known by those accessing it who may also need pre and post-diagnostic support. As illustrated elsewhere in this report, assessment and diagnosis is only one part of the jigsaw, and people need support in other areas of their life, including mental health, work and education. There is no structured support whilst on the waiting list or after assessment and it is often unclear where people should seek this help. Many services lack understanding about the specific needs of autism, and we hear reports of people being refused access to mental health services due to being autistic or not being able to access support without a diagnosis.

This is set against a backdrop of alarming statistics as referenced on autistica.org.uk:

‘Autistic people die on average 16 years earlier than the general population. For those with autism and learning disabilities, the outlook is even more appalling, with this group dying more than 30 years before their time.’
https://www.autistica.org.uk/downloads/files/Personal-tragedies-public-crisis-ONLINE.pdf#asset:1499

“Around 1% of people in the UK are autistic yet up to 15% of people hospitalised after attempting suicide have a diagnosis of autism.” (https://www.autistica.org.uk/our-research/research-projects/understanding-suicide-in-autism)

- **Almost 8 in 10 autistic adults will suffer mental health issues**
- **4 in 10 autistic people are diagnosed with an anxiety disorder**
- **4 in 10 autistic people have at least 2 mental health problems**
- **More than 6 in 10 autistic people have considered suicide**
- **More than 3 in 10 autistic adults have attempted suicide compared with 1 in 15 from the general population**
- **1 in 5 women with anorexia are autistic** and autistic women are much more likely to develop anorexia than non-autistic women.*

* NB, as pointed out by one of our interviewees *“sensory issues etc in autism can cause food issues. Using the term “anorexia” without explanation causes trauma and anxiety and adds to the feeling that we’re not believed.”* This points, once again, to how important a diagnosis is in accessing appropriate help and the importance of language.

(Statistics from Autistica.org.uk and MIND https://www.mind.org.uk/information-support/types-of-mental-health-problems/statistics-and-facts-about-mental-health/how-common-are-mental-health-problems/)

Healthwatch West Sussex is aware that other areas have similar problems:

‘A Healthwatch Cheshire East resident reported that their GP will not refer them for an assessment on the NHS as the waiting list is 4 years.’ (Workplace)

But other areas report far better scenarios:

‘Covid has impacted our waiting list as for many months we were unable to facilitate face to face appointments. We currently have 119 on the list - they are waiting 10-12 months for assessment interview and diagnosis. All have completed the screening phase (IAS contact, questionnaires and responses analysed) within 2-4 weeks of referral. For the last 2 weeks, numbers of new referrals were above 10 per week.’ (Milton Keynes)

Appendix C - Interviews

Interview 1

Fiona is 42 and was diagnosed as autistic in July 2019. She waited approximately 2 years from referral to assessment. Fiona has hypermobility and Ehlers Danlos Syndrome. When her daughter started school, it was recognised that she was autistic. Fiona met her partner a year before she was diagnosed and he started saying ‘I think you’re autistic’. Fiona now thinks her whole family, including her father and siblings, are neurodiverse.

> ‘People have kids [diagnosed] then recognise it in themselves – need wider recognition [of autism in adults].’

> ‘41 years of knowing you’re different; it’s a weird and difficult thing to process, suddenly knowing why.’

Fiona is a lecturer and is currently studying for a Masters. She is very good in academic settings but finds certain things overwhelming and will walk out of jobs. It can be hard for her to email someone or express ideas verbally. She deals with depression and anxiety and finds it difficult to maintain relationships/friendships.

Fiona says she appears ‘functional’ but this comes with a big ‘BUT…’

> *‘I landed my dream job but it’s killing me – 20 hours prep for 1-hour presentation.’*

Fiona puts this down to perfectionism. On the surface she is good socially but struggles inside both before and after any exchange, analysing every word that was said; *‘WhatsApp is my nemesis – makes me anxious – how do you respond? What’s appropriate? So anxious - most people aren’t analysing every bit of communication.’*

She sees autism as an inherent part of her character. She describes herself as an extrovert but recognises that this is a coping mechanism. She also said autism impacts how she evaluates her health; *‘sensations are hard to work out with autism – high pain threshold and heightened anxiety.*

Referral and Assessment

The first GP Fiona approached about a referral for diagnosis didn’t believe her. Fiona says this links to why she doesn’t want to tell people; *‘his reaction was you make eye contact, you can’t be autistic. That it doesn’t matter if your daughter is - there’s no genetic link.’* Fiona was advised to contact NAS as the law states that you are entitled to request an assessment. She went back armed with information and ready to fight but saw a different doctor (female) who was happy to make the referral.

> *‘The first doctor defaulted to the traditional stereotype. It made it difficult. As did my perceived confidence.’*

Once referred, Fiona had to message and phone to find out how long she would need to wait to be seen *'I was initially told 3 to 6 months. I thought I'd been forgotten. At the very least I needed a letter to say I was still on the list.'*

Fiona waited nearly 2 years to be assessed and for it to be confirmed that she was autistic. *'It was hard to wait that long as I needed to know (as I'm autistic) and it would have been helpful for it not to be so long… The whole thing was anxiety-inducing. It would be good to be told about the diagnosis process at the start of the process. People have a lot riding on the diagnosis'.*

NB - when Fiona was going through the assessment process there was a 9 month period when no one was delivering the service.

Impact

Diagnosis has enabled her to access support in her studies – she's studying at Sussex University and describes the disabled student support as good. She thinks she would disclose her autism if applying for an academic post but not necessarily for other jobs. It has also allowed her to be kinder to herself and understand herself better.

However, diagnosis has also thrown up difficulties, including disbelief that she could be autistic. Her best friend overtly disagreed with the diagnosis; *'she didn't believe me'*. Fiona wonders if this is to do with the stereotypes associated with autism; *'Articulate, empathetic woman can't be autistic? I thought getting the diagnosis would be liberating, but actually now feel less autistic. I've got imposter syndrome.'*

Support needed after diagnosis

After diagnosis Fiona had one follow up. She was also given a big pack of photocopies about services. But it was too much information. She looked through it but found it too overwhelming. Fiona says she needed longer in-person support with more than one follow-up. She suggests individualised signposting. *'I'm well resourced and can find things myself. But other people are really struggling.'*

Fiona also pinpoints the need for some therapeutic follow-ups; *'I can feel ashamed – not valid – I'm not as bad as others. I can cope/mask and then I diminish what it means to myself. If had more follow-ups then could tap into some of this.'*

> *'I thought it would be easier to talk about once I had a diagnosis. But I have lots of questions – should I reach out to old friends? But also, I don't want to. I experience an oversaturation of feelings – as a child, music would make me cry inconsolably. If my children are unhappy it causes physical pain.*
>
> *'I am a coper and present well. I don't meet the thresholds for support [mental health]. Time To Talk (Fiona waited 9 months to be seen by this service) described autistic traits as 'difficult symptoms' and dismissed them. Told me everyone has social anxiety, that everyone struggles in certain situations. I'm high masking and this stops me getting support from services. I make everything my own problem and intellectualize and analyse them and because I'm not posing a problem [e.g] calling services, neglecting my children, I'm not visible.'*

Eventually, Fiona decided to seek private therapy more suited to her needs.

‘We need talking therapies that are specialised, that understand autism in all its manifestations. My job shouldn’t be educating MH professionals. The default is to chuck drugs at it – but don’t want to medicate an essential part of myself – it’s not a disability, just a different way of being. But I need support [self loathing, low self-esteem].

‘I have a sense of grief for the past. I think back to being at school and sitting in the medical room – not allowed to go home but not able to cope’.

Fiona makes use of LIMA (Low Intensity Management for Autism) which she says is useful with its pragmatic approach. It offers self-reflection and helps with understanding. The group is collaborative and safe, and facilitates rather than leads groups but is small and limited in what they can offer.

‘LIMA is good for check-ins – hearing from other women. But it can feel like you’re going over a cliff edge – validation and self-recognition can be painful – it’s very complicated – something other people might not understand.’

Interview 2

‘Late-life diagnosis is hugely important. It explained so much for me. A journey of self-discovery and highlighted my need to understand myself. It has improved my quality of life big time… it has been the biggest wake-up call in my life.’

David is 70 years old and was diagnosed as being autistic after retirement.

‘I didn't want an assessment and diagnosis for autism. I didn't even know what autism was, other than having heard the word. I retired from my fulltime+ work as an extremely busy international business consultant in 2010. All was not well as I then became aware of a series of anger outbursts for which I had a course of Cognitive Behaviour Therapy. It helped to an extent, but I still had issues. I embarked on a full review with an experienced personal counsellor. In 2016 he suggested that I might have Asperger's Syndrome and that I might want to be assessed. I agreed to seek a referral as it seemed that it might provide some reasons for the way I was.’

After diagnosis, he was surprised to find that there was no obvious route map or next step and feels that he needed more, an *‘interactive map as it’s a challenge to find services.’*

Referral: *‘My GP referred me in May 2017, my assessment and outcome were in September 2017, around my 67th birthday.’*

GP experience: *‘I feel the GP is normally good – so this felt disappointing. A rejection. Made me flat and deflated.’*

David’s referral needed the professional’s voice to convince his GP and it was hard work to persuade his doctor that he needed it.

> *‘The GP experience was annoying and disappointing. In theory, we have a named doctor – I specifically asked for my doctor due to his knowledge of me and mental health. I hoped for more from him, instead, I detected a disinterest – not important – he obviously didn’t consider it important and I wonder if that was to do with my age. I had to be assertive otherwise I feel it would be dismissed. I had to push back. I asked how do I make it [the referral] happen. In the end, I needed a letter from my counsellor. The referral was ultimately dependant on what another professional said. GP education about autism/Aspergers in adults needs to be improved.’*

Waiting time: *‘The 6 months from referral to assessment felt an ok timeframe. The suggestion [of autism] took me by surprise so I needed to come to terms with it. I had no idea what it meant – researching helped fill the waiting time.’*

Assessment and signposting

> *‘The actual assessment was partially supportive. I had to pre-answer some questionnaires and then a conversation supplemented those questions – only about half an hour but confirmed the diagnosis. I was able to ask questions and my wife had a separate conversation with the assessor – she felt she needed to know how to support me.’*

But he says, *‘I didn’t think to ask ‘what do I do now?’ – they may have said something but it went over my head – so shocked at the diagnosis. The shock and surprise meant that I wasn’t really processing any other input and I wasn’t sure what I needed to know.*

They did suggest some reading materials – one book was very academic and she said it was only to dip into, but this suggestion I think was governed by my obvious academic interest. I don’t remember anything about organisations that could help and support me. I’d like a road map – the next steps – Index of where to go.’

David feels the process would be helped by supported signposting. *‘I don’t know if I’ve looked in sensible places for advice or information. I’m drawn to the research side but don’t yet understand the health and care side, who’s who and who does what. This is why I joined the APB (Autism Partnership Board).’*

David feels he is currently ok but knows he will need to research for answers in the future as his needs change. He is, however, *‘happy to research’*.

David was proactive in trying to find support and to understand more about autism. He also applied to SPFT (Sussex Foundation Partnership Trust) to be part of a supported research study but was rejected as too old. However, when he challenged them on this, SPFT asked him to join the Lived Experience Advisory Panel that advised the research study that he had been rejected from. David commented that organisations are not in sync. That people don’t know what’s available or what they all do.

‘I made it my business to find out what was available, but it took a long time as I didn't know where to look - NHS, local councils, charities, national government...Not everyone would have felt able or willing to do what I did! I discovered that there are many agencies involved, but they are not joined up. And I still haven't found any signposted map which shows all these agencies and how they are connected. THIS IS A HUGE HOLE!’

He was also surprised to find the use of the word ‘recovery’ as *‘you don’t recover from Autism – you manage it’.*

Ageism

‘I think there is ageism, a lack of awareness and understanding in older people and how it affects us or manifests. The focus is on the young and interest fades away as you get older.

‘There is very little research on later diagnosis but the legal requirement of the various Autism Acts since 2009 are not age limited. The current review of the Mental Health Act doesn’t appear to address such ageism.’

Ideal resource

‘My ideal would be a computerised system, a website where you can ask questions; where do I go if this happens? Who covers this? How does ageing impact autism? A directory of organisations and contacts that covers what they do, e.g. care, advocacy, support, education.

‘To be able to interact with it so that an individual can build a profile of ‘what my autism looks like’ and highlight areas that need support with a highly individualised plan.’

Reflections

‘Autism is one strand of who I am and made me realise I’m not the person I thought I was. I recollect characteristics from my childhood and I have evolved and changed. As an example, as a child, I would hate to look eye to eye, but at some point, I’ve developed that skill and now actively seek eye contact as I would rather connect than not. The change wasn’t conscious.

When I was younger I was really uncomfortable being around lots of people. I find it easier now. You tend to think of autism characteristics as being static – but I’ve changed. Would I have evolved if I knew I was autistic? Diagnosis can’t be something that adds limitations. It needs to enable and empower. Disability doesn’t deny abilities – we need to invert the language, highlighting the point and purpose – e.g. mobility parking, not disabled parking.

The System can be entrapping by its binary nature. Currently, you’re either disabled or not disabled. It becomes them and us. This must change.’

Given this, despite the positive way a diagnosis has now changed his life, David wonders if a diagnosis as a child would have ‘disabled’ him; *‘I think had I been diagnosed as a child, I doubt if I would have had the motivation and belief to live as full a life as I have, despite its many downsides.’*

Interview 3

Louisa is 54 and is currently waiting to be assessed for Autism. She has been told there is a waiting time of 3 years. She has Ehlers-Danlos Syndrome and was diagnosed with hypermobility at 11. It is now recognised that EDS and Autism can be closely linked.

> *‘I’m interested in getting a diagnosis as I’ve always felt different but I’m very empathetic so didn’t think I could have ASC (Autism Spectrum Condition). But the Dr said in women it’s common. She recommended books to read and I’ve read them and more things online. Women present very differently to the male ASC stereotype’.*

Will an autism diagnosis change things?

> *‘Yes and no. It gives an understanding of things e.g. why you’re getting anxious.’*

Louisa finds the link between EDS (Ehlers-Danlos Syndrome) and autism interesting and is curious about the connections. She feels it would explain things for her. *‘More females statistically have EDS. There’s a clear link with ASC & EDS so there must be so many women undiagnosed with ASC and/or EDS. I think we will find them in the mental health services as females are often not heard and just dismissed.’*

Pathway to being referred.

Louisa joined a Sussex group for EDS – *‘It was great – people who recognised what I was experiencing.’* They shared a study run by Brighton and Sussex Medical School looking at the link between EDS and anxiety. Participants were offered counselling, so Louisa decided to become involved. Brain scans were conducted as part of the study. Another study looking at autism and anxiety were also conducting scans and both sets showed similarities. Autism screening tools used on the EDS participants flagged autistic traits in Louisa and other people taking part.

The Uni psychologist wrote to Louisa’s GP who then referred her to the Neurodevelopmental service. Her GP has been very supportive – *‘brilliant – needs an OBE’*.

Being involved in the study was helpful for Louisa as resulted in referrals for the co-morbidities of EDS.

Assessment

'I had confirmation that the referral had been made via the GP (Nov 2020). Changes in my situation meant I needed to do a PIP application so I needed information about the referral – I spoke to the neuro services secretary and was told it was now a 3-year waiting list.

'There are support groups and signposting to them would be useful while we wait.'

Recognition

Louisa feels it's very important to be recognised as autistic, particularly as a woman. She says it seems to be easier to spot men on the spectrum, but much harder to spot women. With women, everything is blamed on something else – depression, anxiety, menopause, and things aren't always looked into thoroughly. This is amplified by doctors and other professionals focussing on one field and not seeing people as a whole. *'So much is missed with this approach. If you don't know someone is autistic then you can't investigate properly – need the complete picture to understand someone.'*

She was surprised by the suggestion that she may be autistic but then felt that it made sense. Her family are all similar to her so she hadn't thought of it before but said the suggestion *'makes me understand myself. I'm very straight talking and get frustrated when people can't see what is obvious to me or understand things.'*

Through her work in health advocacy, Louisa recognises how important it is to have a diagnosis. *'Autism impacts so much and people can interpret things differently. For example, your inner voice – autistic can end up being told schizophrenic when it's just their inner voice. Autistic people are put through the mental health system in a way that isn't appropriate. If you get a diagnosis treatment goes to a different funding stream and treatment can be provided by people who understand and in sensory-friendly environments. You need the diagnosis to get the right treatment, otherwise, we're setting people up to fail. No diagnosis makes you vulnerable'.*

Impact

'It's life-changing to even think this may be the case and the reason why I feel odd/different. Some situations are so difficult- so exhausting and I get so anxious. Need understanding of self – 'I am who I am'. I panic if I don't understand something and then avoid it so to understand why I find things difficult, for example, processing information but can research intensely when interested.'

For Louisa, the suggestion that she may be autistic answers questions: *'why I'm different from others, why I'm chaotic. I used to try and fail. It was demoralising but now I understand why certain things are difficult. This is psychologically helpful. If you have no legs you can't run. Autism is the same. It meant I could stop beating myself up.*

I feel I've had so many lost opportunities because the system doesn't work for me, doesn't recognise me. The way I learn and process information doesn't fit.'

The Future

Louisa believes more awareness of autism and how it impacts women is needed. *'I think we need gender-specific clinics – male and female presentations are very different. There is a gender bias in accessing services – needs are different and this difference needs to be acknowledged. Women have physical and hormonal changes and it's easy to miss things and end up being passed around services. You have to be assertive and not everyone can be. I was mega-sensory when I was pregnant – physical touch during labour was overwhelming – always on the back foot if autism isn't recognised.*

'Women need different information from men about autism There are extra challenges - periods, pregnancy, menopause. As a teenager, I struggled with periods due to the sensory overload – the smell, textures etc. For women, everything gets blamed on something else e.g. menopause, anxiety. As a mother you have to do certain things for your children, interact with other people and socialise. There is a gender divide and the ability to do this means you're even more likely to be overlooked and ignored.'

Interview 4

Paul chose to carry on the conversation with Healthwatch via email.

- **Can you describe how it feels waiting for so long to be assessed? For example, is it affecting your studying, work or family life?**
    - *'It's mainly a feeling of frustration, as I have no control over the situation and hearing an online friend only had to wait 3 months to get their appointment somewhere else in the country was quite upsetting. It feels like it is always in the back of my mind, and I am constantly thinking 'is Autism causing me to react in this way'. I very much get obsessed with subjects and spend a lot of time researching and Autism has become one of these subjects. With all the time I have had to wait I have read a lot of medical papers and watched countless hours of talks by doctors on YouTube, with everything I come across I become more and more certain in the diagnosis. I really hate the feeling of stuff hanging over me, and not even having a time frame just causes further anxiety.'*
    - *'I feel like my wife is bored of me constantly talking about it, which is understandable as I have been like this before when getting diagnosed with ADHD* (Attention deficit hyperactivity disorder)*, Fibromyalgia and hEDS (Hypermobile type Ehlers-Danlos syndrome). Possibly she sees it as a way of me using Autism as an excuse for my behaviour.'*

- **What do you think health care professionals should understand about living without a diagnosis?**
    - *'I've felt different, broken, lost and misunderstood my whole life, and now I am certain I have figured it out but I feel like I cannot start working on it without a proper diagnosis. It would feel like I was faking it or something. As much as I trust my self-diagnosis, it isn't real for me until a doctor tells me it is.'*

- **If you are diagnosed with Autism, how will this change things for you?**
    - *‘I feel like I would be able to understand myself better and hopefully get some extra support on how to improve myself and my relationships. Hopefully cut myself a break, as I can be my own worst enemy. Hopefully more understanding from family and friends.’*
- **How should people be supported whilst waiting for an assessment?**
    - *‘This is a really difficult question as not everyone that is waiting for an assessment will end up being Autistic, but obviously they are struggling in some way if they have reached this point. Since it is such a long wait I do feel people should be supported in some way. Possibly just checking in on them once a month by email. Information packs or recommended reading so the person can learn more and start helping themselves. Could do self-response questionnaires, so that it feels like the assessment process has at least started. Have a ‘waiting for assessment’ facebook group, so others are able to support one another.’*

I would of liked to write more but it's making me think about myself too much, which is causing me extra anxiety and affecting my mood. I hope my answers help, thanks for getting me involved.

Interview 5

Transitioning to adult services. The West Sussex Neurodevelopmental Service have an agreement with CAMHs that they will place young people transitioning into adult services onto their list and will respect the amount of time the young person has been on the CAMHs list.

> *‘C superficially fits in. She looks like all the other girls. She is top of the class, but won’t speak and masks effectively when outside the home, hiding her true difficulties. Because she can conform, she’s not getting the help she needs. Her intelligence gets in the way. She may be getting top marks but no one sees the anxiety driving this and the vicious circle it creates.’*

C is due to go to Uni in September. She turns 18 in July.

C is highly anxious and can become suicidal. She has severe OCD, emetophobia and perfectionist and autistic traits. She was referred by her GP to Horsham CAHMs for diagnosis and in May 2018 was referred to the level 2 autism assessment pathway.

> *‘The referral initially was fairly quick, about three months for the initial appointment. We were told that the wait for the assessment would be about a year.’*

However, it is now March 2021 and nearly 3 years on they are still waiting.

For C, puberty tipped the balance and made her mental health worse. They’ve been struggling to get her help since she was 12. The Education Psychologist they initially saw said she was *‘too bright’* [to be autistic?] and refused to refer her to CAMHs.

Since her eventual referral to CAHMs, C sees a psychiatrist every 4 months for a medication review as she is prescribed Cetrilizine which is not licensed for her age. However, they have seen 4 different psychiatrists in 3 years. C found it easier to talk to the female psychiatrist who has been providing cover during the pandemic and built up a good relationship with her. However, she is now on maternity leave. C clams up with the male doctors. However, they were not offered a choice in this. During COVID, support has been patchy, with appointments occurring on Zoom. As C engages better in person, this has not been ideal.

C is highly intelligent and masks beautifully. She is excelling in school since moving to a new school where they have a good pastoral support system. Her mum had to take C out of school and home tutor pre GCSE due to her high anxiety and lack of support from the school – *'they were all about numbers and achievements'.* The school where she is doing her A 'levels is more supportive and has put counselling in place.

'It's been horrendous! I've had to fight for every bit of support for her. I've had to swap schools for her which has been good as [the new school] have been great in supporting her needs unlike … school, that were awful!'

C hasn't got an EHCP as is academically brilliant, but socially she is very anxious with few friends. Her current school has made provision for this social anxiety e.g. her speaking and listening exam was allowed to occur with a small group of peers that she is comfortable with rather than with the whole class.

The pandemic has suited C in many ways as she can avoid people. She is currently excelling with school work but socially has ground to a halt and her OCD has become significantly worse (e.g. pacing and moving furniture to allow a clear path, closing shutters, food date checking and not eating non-uniform food). She previously had intensive CBT for her OCD (handwashing) to which was effective and has meant that this aspect of her OCD has not reoccurred, despite the current focus on hand hygiene. However, she has also become very germ-phobic and is very worried about returning to school.

The uncertainty around exams and schools reopening has increased C's anxiety levels. Her OCD has increased and she isn't eating. She is frightened of returning to school.

Her mum has spoken to Horsham CAMHs about the situation.

C's mum is proactive in enquiring about the autism assessment waiting time – she regularly asks about the waiting time, e.g. at appointments with the psychiatrist and rings the ASD social communication team.

Different people e.g. one of C's psychiatrists have tried to push the appointment forward but the system doesn't let it happen.

'About a year ago, the psychiatrist said that a private company was being employed to address the backlog of people waiting for assessment but this didn't happen.'

Impact

The delay in getting a diagnosis is having a significant impact on C and her family. They are fearful of her not having the right support in place for University. Without a diagnosis, this is unlikely to happen.

Without support, C is likely to burn herself out with her perfectionism. The greatest fear is that she will become suicidal again. It feels she is being set up to fail without the diagnosis. After nearly 3 years since the initial referral, nothing has been put in place for C, and they feel no closer to getting a diagnosis and support.

C needs reassurance and constantly asks her mum, *'will it be ok by September?'*. But her mum can't answer. This increases C's anxiety and is extremely distressing for her mum.

Stress and anxiety levels are rising for both of them and having the autism assessment would help alleviate at least some of this.

C doesn't want anyone to know that she's autistic and will not ask for help. She will never willingly share information.

Transition to adult services

I asked C's mum whether any planning had happened for transitioning to adult services – she said there has been nothing and wasn't aware that there should be.

One psychiatrist took the time to ring them before taking maternity leave to reassure them that when C was transferred to the Adult Autism Assessment waiting list they wouldn't have to go back to the beginning. But this is the only conversation about the transition that has occurred. They also don't know if C will still have to see a psychiatrist as her medication can be managed by a GP once she is 18. There has been no other conversation re transition into adult services or to a new area.

They are also worried as care will transfer to an unknown team in a new area when C leaves for Uni. To help mitigate this, C has chosen the Uni closest to home that offers the course she wants to do so that if she can't cope she has the option of commuting.

C's mum is scared that *'she'll work too hard and without support will burn out'.*

She is also concerned that in a new area C may shut down and ignore appointment letters without her being there to support her.

What they would like to see.

'Assessments need to be timely. This process started 3 years ago and we're still waiting.'

'We need the right support in place.'

'She needs to be assessed in person. She wouldn't engage online well.'

'I want C to be ready [for Uni] and happy. For that, we need the diagnosis and support.'

'It's got to the point where it feels like it's never going to happen'

‘Speed up!!!!!!!!! Stop fobbing people off!!!’

Fear

‘I’m afraid everything will escalate and she’ll become suicidal again and I won’t be there to help and there’s nothing in place.’

Conversation with Neurodevelopmental Service.

In West Sussex, the route for an Adult Autism Assessment is via referral from a GP or health and social care professional to the Neurodevelopmental Service at Sussex Partnership Foundation Trust. The person being referred needs to have a West Sussex GP. The Neurodevelopmental Service is a *‘multidisciplinary team who provide assessments for adults who may have a neurodevelopmental difficulty that is impacting on social functioning, well-being or access to healthcare and support. This may include an autism diagnosis.’* (https://www.sussexpartnership.nhs.uk/west-sussex-neurodevelopmental-service-neurodevelopmental-service)

In West Sussex, the service is commissioned to provide assessment only. Each person referred will receive an assessment and a follow-up appointment, but there is no funding for support before, after or in between assessment appointments and they cannot hold a caseload.

The Neurodevelopmental team is small with only 2.3 full time equivalent clinicians in West Sussex and as of the end of March 2021 there were circa 841 people on the services waiting list. As the list grows, so do the demands on the service, including admin and triage. Everything is affected, from capacity to update the website to the ability to carry out assessments. The service is currently receiving 3 times more referrals than capacity. The majority of these referrals are appropriate and result in a diagnosis.

The team are conscious of the impact that the long wait has on people trying to access an autism assessment and how important the diagnosis and recognition of autism is. They are trying to be as responsive as they can, but funding and capacity are significantly less than needed.

Some of the issues within the service are caused by commissioning across Sussex not being joined up. It is felt that Sussex-wide commissioning would help. In addition, West Sussex funding is provided under the Learning Disability budget and does not incorporate any mental health commissioning.

Suggestions have been made by the commissioners for ways to reduce waiting times, for example, seeing only those people from within mental health services. However, the Neurodevelopmental Service wishes to honour all those seeking an assessment and have chosen not to follow this path.

NICE guidance requires a comprehensive assessment that includes a developmental history meaning the assessments are lengthy. The team is committed to making sure these assessments are thorough and of a high standard. During the assessments, service users often feedback on the relief at speaking to someone who finally understands them The team have considered ways of making the assessments faster, but also feel it is important to ensure the assessment leads to positive therapeutic outcomes for individuals. They are a small resource set against a huge demand but don't want to abandon people.

Due to the way services are commissioned in West Sussex, the Neurodevelopmental Service often have to work beyond what is commissioned e.g. in Brighton and Hove, ADHD fits in with the service, however, in West Sussex it is separate and any work in this area is beyond their commissioned scope.

It's felt that the gaps are a victim of commissioning history and that commissioning needs to join up across Sussex to meet a level of common standards, particularly as the issue of capacity and demand is not being addressed.

The service has tried to react to some of the gaps highlighted by service user feedback. They have created targeted training for colleagues within SPFT, including a co-produced film made with autistic individuals with lived experience of inpatient admissions describing how to improve inpatient wards. The service is also due to provide autism training to SEACamb to educate about autism and different presentations and are happy to provide training to GPS. They are also creating a training film to aid referrals and pre-assessment support. But the success of these is partially what's driving the extended waiting times with each training session resulting in more referrals and the enthusiasm and passion of the team exceed the capacity to deliver services. In addition, the complexity of the referrals is increasing with more referrals from mental health services including acute services. There is a change in demographic with many more women being referred as awareness of the female presentation increases. There are neurodivergent staff within the service and the Trust has a neurodivergent staff network. This has increased awareness of neurodiversity across the Trust's workforce such that they have invested in the creation of a staff clinic funded by SPFT.

The service has a public-facing website with resources for both professionals and laypeople. Although this has plenty of useful information around practicalities, e.g. requesting an assessment, the assessment process etc, it is limited in scope for people struggling whilst waiting with little information of where to get support. Some of the services signposted to, we understand from public feedback, do not always understand the needs of autistic people.

The website has information for professionals, including links to the Royal College of General Practitioners website which includes a GP toolkit and information specific to adults and women https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/-/media/EC861F7CAD0D45A0BF36A11C14390BFA.ashx. The team uses a specific screening tool for females which is more sensitive to the female presentation and issues of camouflaging. This will be added to by a new electronic referral service with information being held on the GP portal which hopes to cut down on some of the misunderstandings around the presentation of autism in adults.

They were successful in a one-year innovation bid for funding from NHSE for 2 days a week of a peer support worker to offer post-diagnostic support specifically for those who may be at risk of admission. They will also be able to improve the resources and signposting the service recommends. They are also piloting the use of students to offer pre-diagnostic support in terms of helping prepare people for their assessment appointment. Neither of these valuable areas of support is commissioned in West Sussex.

We discussed the waiting times and the need for people to have a time frame, however, it is hard to give a generic waiting time for various reasons; the position of an individual on the list is dictated by their RAG (red, amber or green) rating, determining the urgency to be seen. In addition, when young people transition into adult services they are added to the assessment waiting list per their time on the CAMHs list. This is a recent agreement, and due to COVID, CAMHs has paused many of their assessments resulting in a backlog that adult services will need to manage.

Appendix D – Adult Autism Assessment Questionnaire

Q1. Are you completing this for yourself or someone else?

Q2. What are your reasons for wanting an assessment and diagnosis for autism as an adult? For example, some people may want this for peace of mind, others may need it to access provision and support in some area of their life.

Q3. Was the referral straightforward? If no, what needs to be changed? Please tell us if you self-referred or were referred by someone else.

Q4. How long was the process, e.g. the wait to be seen, going through the assessment to getting the outcome from this?

Q5. How did/do you feel about the waiting time and what impact did it have on you?

Q6. How do you feel about being assessed online due to COVID19? What are the difficulties and benefits of this? How would you like to be assessed?

Q7. Were you signposted to services? Please describe how any support helped or did not help.

Q8. Thinking about what happened afterwards did this satisfy your reason for getting the assessment?

Q9. Did your quality of life change? Please tell us how.

Q10. How do you think the assessment process can be improved?

Q11. Would you be interested in sharing your story with us in more detail? Your experience can help influence how autism assessments occur. If so, please leave your contact details below.

Q12. About yourself
- Your age
- Postcode
- Gender
- Ethnicity

Appendix E – Survey responses grouped by question

Q2. What are your reasons for wanting an assessment and diagnosis for autism as an adult? For example, some people may want this for peace of mind, others may need it to access provision and support in some area of their life.

‘Peace of mind/ mental health issues resulting from being undiagnosed Access to support in uni.’

‘I questioned whether I had autism myself when filling in the forms for my son and saw lots of similarities between us it got me thinking if autism could describe my struggles with everyday life that have ultimately led to more significant problems With depression anxiety to disassociation and isolation.’

‘Better support, peace of mind and knowing if I have passed it on to my kids.’

‘Peace if mind and self acceptance. Future Understanding and support, especially as I get older. Accommodations from employers.’

‘Just to show we exist. It isn't all about children or men! I deserve a right to have peer support and support from real autistic other women.’

‘Support at work, to understand myself and my life. Support with healthcare for other conditions.’

‘Peace of mind.’

‘Piece of Mind and understanding my life.’

‘Child autistic so parent displaying traits wanted diagnosis.’

‘My son Dylan did have a EHCP he has learning difficulties and was statemented from the age of 5 he had a social worker from the age of 19 to help support him who referred managed to get us a referral to Swandean Hospital to have a formal diagnosis for his autism he’s been waiting since 2017 still no referral.’

‘Adapt study flagged it up so recommended I have an assessment. I’m interested in getting a diagnosis as I’ve always felt different but I’m very empathetic so didn’t think I could have ASC. But the Dr said in women it’s common. She recommended books to read and I’ve read them and more things online women present very different to the male ASC stereotype.’

‘So that I have an explanation for why I think and behave the way I do. Hopefully this will help other people understand me more and hopefully it’ll lead to more support.’

‘I wanted a diagnosis to help me understand myself better, and to help others understand me better. A diagnosis was also needed in order to access some forms of support.’

‘I didn't want an assessment and diagnosis for autism. I didn't even know what autism was, other than having heard the word. I retired from my fulltime+ work as an extremely busy international business consultant in 2010. All was not well as I became aware of a series of anger outbursts for which I had a course of Cognitive Behaviour Therapy. It helped to an extent, but I still had issues. I embarked on a full review with an experienced personal counsellor. In 2016 he suggested that I might have Asperger's Syndrome, and that I might want to be assessed. I agreed to seek a referral as it seemed that it might provide some reasons for the way I was.’

‘A very good friend of mine recently admitted that for some time she has suspected I have autism and this may be the reason why I have struggled so much as a partner and parent, especially in dealing with the processes followed to secure support and a diagnosis of autism for my eldest and possibly our youngest too. My friend and I have known one another for many years, but she has seen me start to unravel in recent years as life has thrown too much my way for me to cope with at times. GP has given me antidepressants on several occasions since becoming a parent and I have never felt that depression was the correct diagnosis. I simply had too much on my plate! I only stayed on them for max 9 months at a time.’

‘My Husband has identified that as an adult he has been living on the spectrum for Autism. Traits we as a family all recognise and struggle with each day. It would help us to be listened to.’

‘I know without doubt that I am on the Autism Spectrum, but I would just like it confirmed so it solidifies what I already know and helps me understand why I feel/act the way I do sometimes.’

‘Access provision.’

‘My daughter was suicidal, highly anxious, suffered severe OCD and emetophobia and showed many perfectionist and autistic traits. She was referred to CAHMS Horsham for diagnosis.’

‘Access support with mental health.’

‘Because I am autistic and wanted confirmation of it.’

‘For peace of mind and self acceptance/understanding , leading to better mental health and less self hate. To ensure better support and provision as I get older. For support and understanding on the workplace, plus protection from discrimination.’

‘To access support and have legislation protection.’

Q3. Was the referral straightforward? If no, what needs to be changed? Please tell us if you self-referred or were referred by someone else.

‘The referral from the GP was very straightforward.’

‘I went to the GP to seek referral, the only thing I would suggest needs to be attended to is having to justify needing the diagnosis It is hard enough to approach the GP and make that initial appointment.’

‘I was referred almost a year ago by my ADHD. Doctor, Dr Kishore. Since then, I have been diagnosed with hEDS which has links to autism. I also input my raw DNA onto a site and I have an 88% higher chance than the normal public of having autism.’

‘Referral was straight forward.’

‘yes. I asked for a referral.’

‘The first GP didn't believe I could be autistic. I contacted the assessment service directly for advice and took info from NAS to a different GP who referred me without question when I asked.’

‘Yes, it was straightforward. After my daughter was diagnosed my GP referred me.’

‘I went to the doctors with a list of concerns and they sent a letter to get a referral but heard nothing since.’

‘Absolutely no success on NHS. Private referral.’

‘No not enough support or how to get a diagnosis tried GP and paediatricians many times but the only one who helped was the social worker.’

‘The adapt study by Jessica Eccles at Brighton and Sussex Uni wrote to my GP in Mid Sussex. My brilliant and super supportive GP Dr Jo Thompson made a referral to Linwood in Hayward’s Heath. I’m waiting for an appointment.’

‘I was diagnosed with ‘autistic traits’ when I was young and recently, things have been affecting me more. I spoke to my GP who sent a link to question to fill out. This part was simple. Now I have to write an explanation of why I want an assessment, this feels hard and stressful to do. I’m worried that I’ll be turned down if I don’t write the right things. A less overwhelming and more guided why to respond would be better.’

‘I was referred by my lead practitioner from my mental health team a community ATS. The process was fairly straightforward but may have been helpful if I had a letter directly from the neurodevelopmental team confirming that they had received my referral and giving some indication of how long the wait for an assessment was likely to be.’

‘I approached my GP, the one in our practice who leads on mental health issues. He was initially reticent and didn't want to refer me, although he didn't say why. I persuaded him, but he in turn insisted on getting a letter from my counsellor. He then agreed to refer me for assessment. From that point on, the process worked well. What needs to be changed is that GP education about autism/Asperger’s in adults needs to be improved.’

‘I now know what to do for children, but am unclear about the process for adults. I have considered speaking with Aspens about it, but I’ve so much going on with dealing with my children’s respective needs and quite frankly I’m feeling hesitant about how helpful such a late diagnosis will be for my personal circumstances other than a positive diagnosis perhaps making me feel less like I’m going mad! Also, it could make me feel less like a failure, wondering how all these mums keep house so efficiently and seem always to be able to cope with so much and not mind taking their children to countless birthday parties, sports activities and social events! There is so much information out there to guide one through autism in children and how to get a diagnosis and the necessary support. Support for adults who suspect they have autism is less advertised/visible/available.’

‘It took some time, and we were not believed and my husband offered medication.’

‘Had no idea how to be referred for an adult assessment and no professionals knew either. It only came to light when another adult parent/carer I know shared it with me.’

‘Referred by GP but no success. Decided to self refer privately.’

‘The referral initially was fairly quick about three months to have initial appointment.’

‘Referred to Worthing and daughter was diagnosed with high functioning autism. Spent last 4 years asking for counselling under NHS but refused as she is too complex and we need to go private. Not available under NHS for adults with autism.’

‘Yes.’

‘I asked my GP and she referred me. The wait was over two years. The process was fairly straightforward but I did have to tell my GP what it was and who to refer me to. The wait was ok, but a clear timescale in advance would have made it easier.’

‘Paper adult diagnosis between RMN and West Sussex Autistic consultant from paper records no face to face diagnosis! Private diagnosis £750.’

‘I had to ask my ADHD doctor, he didn't think I had it but I mentioned I had taken some tests online and the results strongly suggested autism. He was then happy to refer me, but mentioned it would take a long time.’

Q4. How long was the process, e.g. the wait to be seen, going through the assessment to getting the outcome from this?

‘I've been waiting over 2 years and have heard nothing other than the initial letter saying i was on the pathway.’

‘The GP took 3 months to refer me as it was unclear where to send the adult referral, so he hadn’t completed the referral. Currently I have been waiting 4 months on the list, but my neurologist would like this expedited unfortunately until the service makes contact it is unclear how/who she speaks to about this.’

‘Still waiting (so far almost a year).’

‘2 years.’

‘3 / 4 months.’

‘2 years.’

‘It took 6 months or so for me to be seen by someone at CAMHS. They said I almost certainly was and I should be seen by the psychologist. That was 4 years ago and I have never heard from them.’

‘still waiting. was told 2 years for adult diagnosis.’

‘A month. [private]’

‘Still waiting.’

‘Referral only made in November 2020.’

‘It hasn’t taken long to do the initial stage but I’ve told there’s about a 2 year wait for assessments at the moment.’

‘Please Note I had previously been referred and put on the waiting list for an autism assessment back in 2015. I was told by my psychologist in 2017, having waited over 2 years, that the service I was referred to for the assessment had closed down. This wasn't taken into account when I was rereferred in 2018/19. When I was more recently referred, I was told the wait would be 1218 months. However, I was actually seen by 8 months. I was told that this was because I was able to have a virtual assessment during covid 19 and a cancellation had come up. I am also an SPFT staff member and am told that the neurodevelopmental team prioritise staff referrals. I provided quite a lot of paperwork and screening questionnaire ahead of my assessment. As a result my virtual assessment was only 1 hour long. I was told at the end of the assessment that I met the criteria for an ASC diagnosis. I didn't receive my diagnostic report letter for another 3 months and did have to chase this up. I also didn't have my follow up appointment until 3 months after my assessment, when I had been told I would receive a follow up within 24 weeks again I had to chase this up.’

‘My GP referred me in May 2017, my assessment and outcome were in September 2017, around my 67th birthday.’

‘about a month.’

‘Referral went in over a year ago. Received a letter in April saying it was a minimum 2 year waiting list for an initial appointment and then the impact of Covid19 would further delay it as well.... Heard nothing since....’

‘Years and no success so went privately as needed help.’

‘She was assessed and was put onto stage 2 autism assessment pathway. We have been waiting for 2 and a half years for a diagnosis that we were told would take a year. She's now 17 and hopes to go to university. I really need her to have the right support at university.’

‘Six months.’

‘Not long.’

‘I waited over two years to be seen. The assessment itself took about two hours with a follow up appointment of about an hour.’

‘Months following mental health breakdown for paper diagnosis. Chance meeting with someone who’s husband had been diagnosed gave me a contact and both my children were diagnosed mid 20s.’

Q5. How did/do you feel about the waiting time and what impact did it have on you?

‘It's so long it kind of feels pointless. I'll have finished Uni by the time i actually get a diagnosis.’

‘It's also really frustrating having to wait for so long.’

‘The amount of time I am going to have to wait is unclear. My Daily life is significantly impacted And, ultimately my treatment outcome may change positively if the assessment could happen sooner rather than later.’

‘It is stressful, as I would like to know.’

‘At first, I was told 4 months, then a year and it ended up being 2years. The changes were unsettling and added to my self-doubts.’

‘Fine.’

‘It was hard to wait that long as I needed to know (as I'm autistic) and it would have been helpful for it not to be so long.’
‘It isn't good.’

‘Child being prioritised so they can be aided at school is important. But so is being a undiagnosed adult trying to deal with family and work life.’

‘Private. Sussex Partnership did not want to know years waiting.’

‘It’s been extremely disappointing I have phoned and they said to contact autism charities.’

‘Not an issue as just referred.’

‘When it’s affecting my life this much, 2 years feels like a very long time to wait. I’m already not really coping but can’t access the support I need without a diagnosis.’

‘I was expecting a long wait, so in a way, it didn't affect me too much. It did have an impact in that I was not able to access some support services until I had a confirmed autism diagnosis, or receive a review/reassessment of my social care package. My employers at the time were also not willing to make some reasonable adjustments for me until I had a confirmed autism diagnosis, although I know reasonable adjustments should be made by support needs rather than a diagnosed condition a point I did make to them at the time, though was still denied the support!’

‘ok.’

‘I am not sure what the process is for adults, but if I were to take the step to get a diagnosis, I would not want to have to wait too long for a result.’

‘We were just keen to be seen having waited 60 years for a diagnosis!’

‘It’s just not good enough, nor acceptable. It creates further anxiety. If these so called professionals really understood the condition and the impact situations like this have on us then there wouldn’t be such a lengthy waiting time....’

‘No support and really bad.’ [went private]

‘It's been horrendous! I've had to fight for every bit of support for her. I've had to swap schools for her which has been good as Oriel School Crawley have been great in supporting her needs unlike Hazelwick School that were awful!’

‘Fine just good to finally be told she has autism. Only took 24 years for this to be finally confirmed.’

‘None.’

‘It was bearable, but what made it first was not knowing how long it would take. Once the referral was sent off it went very quiet. I had to rely on word of mouth from other people to know how long it would take.’

‘Appalled. Felt ASD had led to son’s mental breakdown RMN said I was wrong.’

Q6. How do you feel about being assessed online due to COVID19? What are the difficulties and benefits of this? How would you like to be assessed?

‘I would hate to have to do it online, i find it very difficult talking to people unless it's face to face.’

‘I have found lockdown and appointment online easier than having to navigate lots of different people who I don’t know as this increases by stress I think the initial background/family history appointment Could most certainly be done online. However, to get a balanced view of the persons difficulties a face to face should take place as well.’

‘I would be happy with online but I feel in person is probably better for a diagnosis.’

‘It wouldn't bother me, but I'm used to working online. It might be an issue for some people.’

‘fine except it might need longer than one session and don't forget with older professional women we might not have family members to give a history of course. We don't present how children do when autistic. Some people don't believe we exist at all!’

‘I'd like to be assessed by any means.’

‘sometimes you need to be seen to be diagnosed. maybe an initial consult online but I feel a social distance meeting it needed.’

‘Not acceptable. Difficulty online.’

‘This would be better than nothing.’

‘I don’t think they’ll get the full picture if I’m assessed by a person online and it makes me feel anxious.’

‘Benefits:

- I got seen sooner.
- Didn't have to travel somewhere for the appointment.
- Felt more comfortable having the assessment in my own home.
- Less anxiety about the journey and meeting new professionals face to face.
- Difficulties of virtual assessment:
- I think it was harder for them to observe eye contact and body language.
- Some connection issues, but not too disruptive.
- I felt quite vulnerable after the assessment ie. to be told that you have an autism diagnosis and to then be left with a blank screen, on your own, in your flat felt a bit overwhelming.’

‘I think it would be ok.’

‘I do not really know what the usual process is and so do not feel I can comment accurately. I feel I would prefer to have that human connection to seek assurance that I am following the right path. However, an online assessment could possibly give one the chance to research before answering if unsure how to answer e.g. one’s memory fails but perhaps family members can help one to recollect relevant material.’

‘More than happy to chat via Teams or Zoom. This would be so much more helpful tbh [to be honest] as I’ll feel more comfortable and won’t have the added stress of going somewhere new.’

‘She needs to be assessed in person. She wouldn't engage online well.’

‘Fine.’

‘This wasn't applicable to me, but I wouldn't have minded. The worst way to be assessed would be by phone.’

‘Video call would be acceptable private diagnosis was face to face with preparatory paperwork being submitted.’

Q7. Were you signposted to services? Please describe how any support helped or did not help.

‘No, i wasn't.’

‘I have been referred and then left again I have not been signposted to any additional services.’

‘Just given a list of reading material and a few websites, which was not very helpful.’

‘an actually autistic run group in Sussex and Lima but wasn't available in our area.’

‘There is a lack of support for me in the local area. I have contacted LIMA myself and that is the further support I have had.’

‘No.’

‘No.’

‘No.’

‘Swandean Hospital.’

‘No but that may be because I’m only at the start of the process. I’ve tried calling the UK autistic society helpline a few times but they’re always too busy to answer.’

‘After my follow up appointment I was emailed a 30 page document of services I may be able to seek support from. This was helpful, but was also quite overwhelming. It was made clear that no referrals could be made for me, the onus was on me to self refer. I didn't really know where to start and this delayed me seeking support.’

‘No. I think that this is a huge gap in what is available for those newly assessed as being on the autistic spectrum. I made it my business to find out what was available, but it took a long time as I didn't know where to look NHS, local councils, charities, national government...Not everyone would have felt able or willing to do what I did! I discovered that there are many agencies involved, but they are not joined up. And I still haven't found any signposted map which shows all these agencies and how they are connected. THIS IS A HUGE HOLE!’

‘Referred to a psychiatrist who mis diagnosed social anxiety.’

‘None.’

‘I was advised there is no help and twice referred to ATS. Then advised SP are only commissioned for diagnostic services. However, they did not diagnose me as nobody wanted to know.’

‘GP signposted us.’

‘None.’

‘No.’

‘No. I was given an information pack with suggested reading material and websites. I would have welcomed ongoing support of some sort. I.e. Adult social care assessment, access to support groups, professional support.’

‘None.’

Q8. Thinking about what happened afterwards did this satisfy your reason for getting the assessment?

‘Yes. I felt better for being assessed. Wish there was more after care or support though.’

‘just had a diagnosis. After so many years it didn't make much difference. Battled all our lives so.’

‘Yes, it really did but also, I did need more help after, I only got one follow up and I needed mental health support. I tried time to talk health, but they didn't have a good understanding of the impact of autism and kept calling it a difficult symptom. I had to wait 9 months for that service too.’

‘Initial screening was fine. [But it hasn’t moved on from there so no support or actual diagnosis)’

‘Nothing at the moment nothing has happened.’

‘Yes. I had a confirmed diagnosis and letter, and I could access support from services that I previously couldn't without the diagnosis.’

‘Yes it was a huge revelation to me about me. It explained so much about the way I am, and it made a lot of sense of my life up until the present day.’

‘not at all we still struggle each day.’

‘Yes but no assistance from SP.’

‘Still waiting 2.5 years on!!!!!’

‘No.’

‘Yes.’ X 3

‘Son was more willing to accept his ASD. He had been bullied in his workplace for things he had no control of. Forced out of 3 jobs. Daughter realised how much discrimination she had faced all her life including Uni and work.’

? Q9. Did your quality of life change? Please tell us how.

‘I was able to accept my failings better, so yes.’

‘perhaps but sad everyone ignored so many of us for so many years and just focussed on children and boys.’

‘It has helped me be kinder to myself and released pressure.’

‘Excluded from therapies and help because I am autistic. Sussex Partnership will now not help as I am autistic.’

‘No.’

‘I definitely felt better about myself and more accepting of myself. Having a diagnosis of autism made me feel more able to connect with other autistic people. I was able to start receiving support from the LIMA Project, which I have found really helpful. I also had my social package hours increased to cover social communication support. On the flip side, it didn't make a difference to some issues I experienced from my employers, in fact the autism diagnosis escalated the situation prompted them to declare that my needs were 'too complex' for them to be able to support me in the workplace! Some friends and family have also responded negatively when learning of my autism diagnosis.’

‘It has improved my quality of life big time. For example, I recognise and manage rising levels of anxiety before they reach a meltdown; I now know that I need to balance my time with other people and my time on my own. It has also helped me become increasingly self aware. In conjunction with my wider personal counselling and the deepening of my Christian faith, it has been the biggest wakeup call in my life.’

‘It did not.’

‘Worse as now I am autistic nobody wants to know.’

‘I wish she could be seen ASAP!!!!!!!’

‘No.’

‘Not yet.’

‘Yes. I was able to accept myself. People i know and work with were able to support me better.’

‘Yes. Able to take aspects of diagnosis and look to see how they might be helped.’

Q10. How do you think the assessment process can be improved?

‘Clear timescale for waiting etc, initial contact explaining waiting time and clear guidelines as to what will happen in each appointment.’

‘Clearer guidelines for GP's making referrals. I had to tell my GP what the process was. Often you hear of GP's denying that the service even exists.’

‘By letting actually autistic people run it. Not involved, run it equally if qualified.’

‘Shorter waiting time, more aftercare and support.’

‘Completing it within 4 years.’

‘By wanting to offer a service and not trying to put people off.’

‘Earlier diagnosis.’

‘Shorter waiting list.’

‘Assessment over more than one session so can build up a rapport with the professional more.’

‘Better follow up support post diagnostic peer support group would be good. Maybe a welfare check following assessment phone call a couple of days after. To have support with accessing and making referrals to other services.’

‘Big rethink of the language used in diagnosis report letter! The word 'impairment' featured several times in mine, also 'autistic issues' it was very difficult to read, made me feel very hopeless and down about myself actually resulted in suicidal thoughts. I think the diagnostic report should be more personal, strength based in terms of language, speaking more of 'neurodiversity' and 'difference' rather than 'impairment'.’

‘There is a strong case for assessments to be offered to everyone around the age of 20. Apart from those with extreme autistic characteristics and/or adjacent comorbidities, who will need to be assessed earlier in childhood, some adult experience of life is, I think, necessary before assessments are made where characteristics are less obvious. I think had I been diagnosed as a child, I doubt if I would have had the motivation and belief to live as full a life as I have, despite its many downsides.’

‘listen and talk to close family members more as the Individual cannot truly identify their difference as it is norm to them.’

‘Reduce the waiting times drastically for an initial consultation!!’

‘I5 should not depend on how much money you have and can therefore go privately.’

‘Speed up!!!!!!!!! Stop fobbing people off!!!’

‘By actually getting help.’

‘I don't know.’

‘Not everyone seems to get an ‘official’ diagnosis, just an indication that they are ‘probably’ autistic. This difference isn't explained at the time and can lead to being refused access to services in the future. All assessments leaving to diagnosis need to carry official diagnosis standards. Gold standard I think it's called? Some people have to go through a telephone assessment first. This can be traumatic for a lot of autistics.’

‘Can’t say for the NHS as never had the opportunity as an adult and assessment during early secondary school concentrated on mum’s poor health and dad’s working away rather than son’s needs. School said that as he was above 75th percentile there were no issues. Diagnosis Borderline Asperger’s. GCSEs good, A levels struggled to pass and had mental breakdown following a relationship failure.’

‘Felt totally let down by Junior and Secondary School and CAMHS. Mental Health service for adults refused to accept Asperger’s.’

‘Daughter had always been high performer but had relationship difficulties but didn’t want to be seen like her brother given the problems he faced.’

‘Teachers need to be more aware of how ASD presents in individuals. SEN Coordinator at secondary school only interested in less able.’

Appendix F – Quality Standards, NICE

https://www.nice.org.uk/guidance/qs51/chapter/List-of-quality-statements

Statement 1. People with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started within 3 months of their referral.

Statement 2. People having a diagnostic assessment for autism are also assessed for coexisting physical health conditions and mental health problems.

Statement 3. People with autism have a personalised plan that is developed and implemented in a partnership between them and their family and carers (if appropriate) and the autism team.

Statement 4. People with autism are offered a named key worker to coordinate the care and support detailed in their personalised plan.

Statement 5. People with autism have a documented discussion with a member of the autism team about opportunities to take part in age-appropriate psychosocial interventions to help address the core features of autism.

Statement 6. People with autism are not prescribed medication to address the core features of autism.

Statement 7. People with autism who develop behaviour that challenges are assessed for possible triggers, including physical health conditions, mental health problems and environmental factors.

Statement 8. People with autism and behaviour that challenges are not offered antipsychotic medication for the behaviour unless it is being considered because psychosocial or other interventions are insufficient or cannot be delivered because of the severity of the behaviour.

Appendix G -Resources

This list is by no means exhaustive.

Information

https://www.autism.org.uk/advice-and-guidance/topics/diagnosis/pre-diagnosis/adults

https://www.sussexpartnership.nhs.uk/neurodevelopmental-service#locations-list-6312

https://www.autism.org.uk/

https://www.autistica.org.uk/

https://www.nhs.uk/conditions/autism/signs/adults/

https://www.nice.org.uk/guidance/cg142/chapter/Introduction

https://www.mind.org.uk/about-us/our-policy-work/equality-and-human-rights/mental-health-of-people-with-autism/

https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/-/media/EC861F7CAD0D45A0BF36A11C14390BFA.ashx.

https://www.hee.nhs.uk/our-work/learning-disability/oliver-mcgowan-mandatory-training-learning-disability-autism

https://skillsforhealth.org.uk/info-hub/learning-disability-and-autism-frameworks-2019/

Support and advocacy

https://www.facebook.com/ASSAWestSussex

https://www.aldingbournetrust.org/support-in-the-community.html (including LIMA)

www.aspergersvoice.org.uk

http://www.alongsideautism.co.uk/lima-project.html

https://www.theautismconnected.com/

https://www.westsussex.gov.uk/about-the-council/how-the-council-works/committees-and-decision-making/joint-arrangements/autism-partnership-board-apb/#:~:text=The%20Autism%20Partnership%20Board%20(APB,autistic%20people%20as%20equal%20partners.

https://www.westsussexconnecttosupport.org/how-to-live-well-with-a-health-condition-or-disability/autism/

https://impact-initiatives.org.uk/services/adults-and-older-people/

Talk to us

If you have questions about the content of this report, please either call 0300 012 0122 or email caroline.whiteman@healthwatchwestsussex.co.uk

How this insight will be used?

We recognise that all health and care services are under pressure at this time and have had to adapt their ways of working. We will share this report with the local NHS, Local Government, and other providers to help them understand where things are working well and services are adapting to meet peoples' needs, and to help them identify any gaps. We see this as a continuation of discussions taking place and will continue to use this fresh insight and the solutions presented to challenge for a better future.

For help, advice, and information or to share your experience

We are the independent champion for people who use health and social care services. We're here to find out what matters to people and help make sure their views shape the support they need.

We also help people find the information they need about health, care and community and voluntary health and care support services in West Sussex.

ADVICE AND INFORMATION

Here to help you on the next step of your health and social care journey

We have the power to make sure that the government and those in charge of services hear people's voices. As well as seeking the public's views ourselves, we also encourage services to involve people in decisions that affect them.

You can review how we performed and how we report on what we have done by visiting our website www.healthwatchwestsussex.co.uk

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