Health, Social Care and Sport Committee – 25.09.2025

Informal engagement with people with lived experience of autism and ADHD: ADHD and ASD pathways and support inquiry

Note: There were two parallel informal engagement sessions. The first was organised with autistic people and the second with individuals who have ADHD. However, some participants had experience of both autism and ADHD. Some participants also spoke from their experience as the parents of autistic children and/or children with ADHD.

Participants took time to share their personal lived experiences of accessing pathways and support, these are provided below. There was also a more open discussion about key issues which have been divided into themes below.

Session with National Autistic Society Scotland's Campaigner's Group

Personal Experiences

- Participant A

A first participant shared that in the early 1980s there was little to no understanding of autism in society. As a child they knew there was something different within themselves, but instead of being nurtured this was punished. They felt this was mainly due to not being able to learn in a neurotypical world. This caused severe mental health problems for this participant, along with financial issues in adulthood.

Eventually they managed to find work and have children. They noticed from an early age that their children showed similar behaviours to themselves but found it very difficult to get a CAHMS [Child and Adolescent Mental Health Services] referral for their children.

Although they did eventually receive a diagnosis, this took decades. Their children have also been diagnosed. However, this participant felt that very little has changed as a result of these diagnoses, and they have received very little help.

Reflecting on the present-day situation, they felt that society and education have not improved. They believe that social work are not well enough equipped to deal with autism and ADHD individuals.

They would like to see more research into why autistic people have a shorter life expectancy than neurotypical people.

This participant felt that advocacy was very important. They were able to act as an advocate for their children, something they had not had themselves, but reported that there are still very few avenues for support.

- Participant B

A second participant said that diagnosis has been quite a journey. They knew from an early age that they were different and tried to figure out why.

They also have neurodiverse children and, similarly to Participant A, they noticed differences with their child who was diagnosed while living abroad.

This participant has been diagnosed four times now but still feels that the NHS are sceptical of this diagnosis. Their child’s diagnosis was eventually accepted but it took months to be approved.

They found that issues arise when a diagnosis is rejected, competing with things like waiting lists, which keep getting pushed back. They reported that people can be rejected from NHS waiting lists by going private, despite the fact that the NHS can refer patients to private healthcare settings.

This participant described feeling like they do not have a voice.

They also reported that children can spend years on rural area waiting lists.

They described having had lots of experiences of friends, family etc. self-ending due to the stress that comes with ASD and ADHD.

They do not want their children to experience these difficulties their entire lives.

- Participant C

A third participant is also the parent of neurodiverse children and noticed behaviours. When they were eventually seen by CAHMS they gave lots of misdiagnoses, some of which made no sense whatsoever.

This participant shared that they have experience of self-harm.

Eventually, their child received an autism diagnosis, but this took extreme lengths for anyone to take them seriously. After the diagnosis they were given a piece of paper with the number for NAS, and that was it. They felt there was very little support before and after diagnosis.

Their other child also received a misdiagnosis. Nothing was picked up from the school as they did not have behavioural issues, but definitely showed signs of being neurodiverse.

They fought hard for a referral and were eventually seen. It took two visits to receive a diagnosis. They had been fighting for a decade for someone to properly diagnose their daughter, having experienced issues with the CAHMS waiting list.

They had also experienced issues with accessing ADHD medication, sometimes having to trawl around different pharmacies to find it.

They felt that nothing is changing despite the same stories being repeated time and time again.

They felt very lucky that they didn’t have to go private as they don’t have the cash to do this. At the same time, they noted that even those that can go private often find this is unsustainable given the long-term costs.

Themes

Difficulties accessing an assessment and support

- Participants shared experiences of it feeling almost impossible to get an assessment.
- At times participants reported being refused a diagnosis and having to pursue a mental health route instead.
- Participants reported experiences of being referred to psychologists their entire lives but, each time, finding that nobody was interested in giving a diagnosis for autism or ADHD.
- There was a general feeling that accessing assessments was becoming more difficult as time goes on.
- Participants described feeling that children who are quiet, who do not “kick off”, feel like they are invisible – and noted that these make up the majority of autistic children.

Waiting times

- Participants reported current waiting lists in rural areas as being predicted at around the 15-year mark.
- Participants argued they should not be waiting years for what is effectively an hour/hours long assessment.
- Participants expressed frustration that children often outgrow the waiting list and are then put into non-existent adult services or waiting lists.

Communication while waiting for assessment

- Participants found they heard nothing unless they chased.
- They described baseline communication as ‘dreadful’

- There were issues with a lack of communication between NHS GPs and the private sector practitioners.
- Experience of being stigmatised for chasing assessment up
- Participants reported feeling like a ‘helicopter’ hovering around to find out what is happening.

Support while waiting for assessment

- Participants felt they had practically no support after being placed on a waiting list.
- Support was reported as being generally provided by third sector organisations, often local community groups. However, it was also reported that this support is not available everywhere and has been impacted by funding cuts.
- Participants argued that, often, being kept up to date is one of the most important aspects of support.

Impact of a lack of support on wider services

- Participants argued that the lack of support while waiting can put pressure on other services e.g. the police often deal with people’s outbursts despite a lack of expertise in this area.
- The police were described as the first port of call and the last resort at times.
- Schools were reported as often bearing the brunt despite a lack of support for dealing with these issues in the classroom.
- Participants expressed worry that society is failing future generations by not offering adequate support at an early age.

Suggested improvements to pathways for assessment

- Participants felt that speaking to individuals with lived experience should be encouraged.
- Nurses who deal with autistic children should be consulted as they seem to go largely unheard.
- There should be an emergency and immediate stopgap – particularly for children and in the Highlands and Islands.
- There should be a wider input from all stakeholders to reduce the waiting times.
- There should be more investment into trauma therapy.

- There should be more investment in community groups to take the pressure off frontline services.
- Need for improved assessment processes for children at an early age.
- Parents should be listened to more.

Support after diagnosis

- Participants felt that there needs to be more effective support after diagnosis - currently it doesn’t feel like diagnosis improves any quality of life.
- Social workers often have a poor understanding of not only how to support autistic individuals but what autism actually is.
- It often feels like accessing effective support is about ‘luck of the draw’ or being in a privileged position.
- There needs to be much more support for mental health in general as well as trauma support.
- It feels like you struggle so much, and the public services that you pay for all your life let you down.
- There is a lack of peer-to-peer support - when this is available, it is a real positive. In particular for children, speaking to an individual not used to dealing with children can cause undue stress e.g. using adult terminology, assuming they know things they don’t.
- Those who provide support need to receive better training.

Stigmatisation

- The language used to talk about neurodiversity is often very derogatory. This goes for both adults and children with autism.
- Being autistic can feel very isolating, people can feel scared to reveal to others that they are autistic due to fear of discrimination.
- Even after receiving a diagnosis this can create a ‘culture of blame’ e.g. people asking where it has come from.
- Often people doubt the motivations behind saying you are autistic or seeking a diagnosis. For example, some suggest you are only doing this to access benefits.

International comparisons

- Participants suggested Scotland could learn from other countries. Sweden and Denmark were cited as examples, where different types of medication are prescribed and there is a less siloed approach to diagnosis and support e.g.

more collaborative working and knowledge sharing between different specialists.

- It was suggested that better availability of data on neurodivergence in Scotland was needed to allow for international comparisons to be made.

Session with ADHD Support Group

Personal Experiences

- Participant A

One participant reported having been denied access to ADHD care for almost their entire life. When they first exhibited symptoms, their mother was given anti-depressants. She was told that their child did not have a hearing problem but a listening problem. When the issue was raised as an adult with a GP in 2012, they were told it was not possible for them to have ADHD since this was something only children could have, that it had nothing to do with focus and that it was purely an educational issue.

Undergoing 12 years of therapies for depression and suicidal ideation, this individual was repeatedly denied referral for ADHD assessment by their community mental health team. They were forced to complain formally to gain access to a waiting list. After waiting for a year and having heard nothing more, they re-contacted their community mental health team but received no response. While being placed on the waiting list had put their suicidal ideation into remission, the ongoing delays took it back out of remission.

Eventually, they were able to force a meeting with the community mental health team to which they brought extensive evidence of showing symptoms of ADHD. However, this was ignored and the meeting ended with this individual running out of the building and into a busy road in a state of distress. This individual believes the community mental health team had breached multiple GMC guidelines and made multiple complaints to the GMC, the SPSO and others without success. They believed that the system will not improve for people with ADHD unless CHMTs, HSCPs, health boards, the GMC, and Ombudsman services face genuine legal accountability for malpractice. This participant felt publications such as the patient's charter of rights and responsibilities and GMC good practice guidelines are useless if they are not enforced.

Subsequently, they went private to access a diagnosis. Initially, their GP refused to offer shared care. Once they had received a diagnosis of ADHD, the GP changed their mind but then subsequently reversed that decision again, meaning that this individual has had to pay for medication themselves.

- Participant B

A second participant began by noting that one in five of the general population is neurodiverse. They also noted that it has only recently been possible to diagnose ADHD and autism together, having previously been thought to be mutually exclusive conditions.

This individual described only having realised in hindsight that they were disruptive at school. They suffered a few episodes of mental ill health during their time at university which they now understand to have been exhibitions of ‘neurodivergent burnout’.

They went on to note that neurodivergent people are vastly over-represented in prison populations and in A&E admittances and that the episodes they experienced during university were wrongly diagnosed as mental health related rather than being symptoms of neurodivergence. They argued that the caricature of ADHD is far from the reality, that women’s experiences of neurodivergence can be very different and that it isn’t just about badly behaved kids.

However, they also acknowledged that neurodivergent people can end up with chaotic lifestyles but that this is largely a coping strategy. As a health care worker themselves, they described developing PTSD from the experience of treating one of their patients. This experience led them to want to seek a diagnosis for themselves. Rather than a certificate, they wanted to receive a comprehensive diagnosis and felt reassured that their chosen community provider would be able to do this. In autumn 2024, they were prescribed stimulant medication which made them worse. They were unable to sleep and lost weight. They experienced an uncontrolled flood of symptoms which they now understand can happen to individuals who have both autism and ADHD.

Since there is no NHS treatment available for adult diagnosed Autistic Spectrum Condition, they were referred to another waiting list and are now receiving treatment under a specialist team. They are currently phasing back to full time work. As a health care worker, they are literate about the system but have nonetheless struggled to navigate it. They highlighted that medication is a very small aspect of treatment and emphasised the equal importance of other aspects such as speech and language therapy. They concluded that the current model of treatment is over-medicalised. They are now exploring the same journey with their own child and encountering the same challenges they experienced themselves.

They concluded by pointing out that neurodivergent people are more likely to suffer injuries which can be a burden on the NHS. Many more people have now been diagnosed and this individual is now much more aware of others, for example at their child’s school, who are exhibiting signs of undiagnosed neurodivergence.

- Participant C

A third participant began by pointing out that the entire process of accessing mental health services can be problematic for people with ADHD.

As an example, patients will initially receive a letter asking them to confirm if they wish to take up an appointment. If the patient fails to respond within a defined deadline, the appointment will be cancelled. This individual described how difficult it is for people with ADHD to deal with such a process. They themselves put this initial letter away and forgot about it.

They also described such a letter as feeling antagonistic and that a person with ADHD would interpret it as seeming to suggest that they were being accused of being the sort of person who could not be relied upon to attend an appointment.

They described having received a number of assessments for autism but that the staff carrying out those assessments appeared not to be very well informed about autism and ADHD. They described services as fragmented. One autism assessor suggested to this individual that the possibility of their having ADHD might be worth further consideration but they were given no further information or signposting beyond that.

They tried to access an ADHD assessment via the NHS after having experienced multiple episodes of burnout. They described this as being a not very supportive experience. They started by being triaged by a mental health practitioner who did not appear well trained. They felt their speech was a bit unconstrained during the triage appointment due to anxiety but that the mental health practitioner made no effort to calm them or direct the conversation. They told the practitioner about a prior experience of having taken the drug amphetamine at an earlier age and that this had badly affected their brain. The practitioner then laughed in their face which they found disrespectful and hurtful. The appointment lasted 2 or 3 hours but they left feeling they had not answered the questions well and tried to submit supplementary written replies but were doubtful that these were taken into consideration.

The practitioner referred this individual to a psychiatrist to continue the assessment. They found their experience with the psychiatrist even more distressing, as the psychiatrist did not diagnose them with ADHD but also did not justify this decision and threatened this individual with the police if they did not leave. They found out through a subject access request that the psychiatrist’s diagnosis was BPD and schizoid and psychotic traits despite this not being explained to them. They find this diagnosis offensive.

They then went to a private practice and found the difference in experience of seeking an assessment privately compared to via the NHS to be astounding. Contrary to the NHS, the private practice used proper diagnostic criteria, where the NHS simply barraged the individual with questions.

That said, this individual went on to say that the overall experience of private practice, although better than the NHS, was not that supportive either. They described the best support they have had throughout their journey as having come from interacting with other people with ADHD.

At another point in their treatment journey, this individual was prescribed Dextroamphetamine by a private clinic which caused a serious mental health episode of something that could be described as psychosis. They explained they had been put on too high a dose but struggled to recognise this at first, possibly due to their ADHD leaving them out of touch with their emotions. They explained that the clinic finalised titration after 16 days, they felt this may have been an admin error as this process would usually take months and this left them without regular reviews, putting them at risk. However, when they ultimately refused to go any further with this treatment, it made returning to the NHS to seek alternative support even more difficult because of their refusal to accept that previous treatment.

They were left with a feeling that they would end up being more stressed and antagonised if they were to take up the mental health support they needed due to their previous experience and that this discouraged them from doing so.

Themes

Stigmatisation

- On the subject of stigma, one participant reported that they had evidence to suggest that their community mental health team had intervened with their GP to block shared care and that they could see no reason for them doing this other than vindictiveness.
- Another participant felt that, throughout the assessment process, they were being treated as though they were faking the symptoms of ADHD in order to gain access to medication.

Written comments:

- “Stigma - amongst Doctors and Nurses, in and out of mental health services - ongoing societal issue…”

Screening and early intervention

- Participants suggested that there was a need for more early screening of people and that this would save money in the long term by helping to identify unmet support needs.

Written comments:

- “Screening populations - school (Educational Psychology might have more insight into how, and whom), new mental health symptoms or presentations (especially in secondary and higher education as well as those who are out of work), criminal justice “new” contacts (young offenders and those encountering the police for the first time and so forth)”
- There was agreement that treating neurodivergent people more proactively would stabilise them and mean they were less of a drain on healthcare services in the long run.

- One participant described having gone through a process of grief about how their life might have been different if their ADHD had been assessed and identified much sooner. They suggested many of their negative experiences could have been avoided if they had been diagnosed much sooner.

Staff training / adjusting services to meet the needs of neurodivergent people

- One participant argued that, based on their own experience as a health care worker, medical education is not really set up to give medical practitioners a clear understanding of neurodivergence and how to support / treat it. They noted that peer support groups have probably helped more neurodivergent people than many doctors or nurses. They also noted that medical services are really not set up for neurodivergent patients – noting, for example, the level of over-stimulus you will find in an A&E waiting room.
- Another participant suggested that, in their experience, doctors can be confrontational and can have their own agendas.

Written comments:

- "Move towards acceptance that the biopsychosocial model with adequate funding and investment in the broader Multidisciplinary team (psychology, occupational therapy, and speech and language therapy, among others) can meet the support needs of our neurodiverse population (1 in 5…) far better than an antiquated medical model"

Standardisation of assessments

- One participant argued for a standardisation of the assessment process that would allow mutual recognition of assessments carried out either through the NHS or private practice.

Written comments:

- "Structured assessment framework agreed, so that private assessments done to the standards required will be accepted as a diagnosis and for treatment under the NHS if required."

Support while waiting for assessment

- Participants were in agreement that there is a need for greater interim guidance, support and signposting for people waiting for a diagnosis or assessment.
- One participant pointed out that what helped them during this period was not access to medication but rather rest and exercise – and it would have been beneficial to have received more advice about that.
- It was also suggested that there is currently a vacuum between the point of submitting an assessment and receiving a diagnosis which needs to be filled

by greater support and advice. Otherwise, individuals are at greater risk of having need of other NHS services during that time.

- One participant suggested it would be helpful to have access to someone that wasn't a medical practitioner (such as a social worker for example) who would be a friendly face to talk to.

Medication

- One participant indicated they had found medication helpful in treating their condition. The medication enabled them to be articulate enough to explain how ADHD affects them. Without this medication, they felt they didn't have the emotional intelligence to be able to explain how they were feeling. They concluded that the medication had given them the focus to be less frustrated and to be better able to articulate themselves.

Self-medicating

- There was general agreement that harmful use of drugs and alcohol can often be a symptom of undiagnosed neurodivergence.

Resources

- There was some discussion of financial resources and current budgetary constraints. One participant pushed back on the idea that the NHS doesn't have the money to be able to support neurodivergent people. Their experience was that the NHS actively chose not to treat them when they had the resources to be able to. They argued the need for greater accountability and systemic change and suggested that, in this area, the NHS can afford to be pound foolish but fails to be penny wise.

Impact of diagnosis

- One participant argued that, since receiving a diagnosis, their life was a lot better. They were able to withdraw from antidepressant medication, were able to make friends and to get out more.

- Another described diagnosis as being the start of something. They started to look back at their own childhood and were able to rationalise why they had been such a handful. They emphasised that neurodivergence is very heritable and that diagnosis has helped them to understand their own children's needs as well. They described diagnosis as opening the door to self-understanding. Although medication for ADHD had made them feel worse, it did help to expose their autism and enabled them to achieve a full diagnosis of both conditions. They described shared care as "broken", arguing that, because GPs are independent practitioners, they don't have complete responsibility to accept shared care arrangements or to make them work. This needs some work to ensure consistency across Scotland.

- At the point at which they were able to access it, one participant described diagnosis as simply a hoop they needed to jump through since they already knew they had ADHD by that point. On a positive note, they noted that, by giving them access to medication, a diagnosis enabled them to get rid of their food and other addictions.

Suggested improvements

- One participant suggested that, as has been floated elsewhere in the UK, there should be a national Tsar on neurodivergence.
- They also indicated that they had been encouraged by a recent parliamentary debate in which a number of parliamentarians had identified themselves as neurodivergent or had recognised neurodivergent traits in their own behaviour. They felt this was extremely important in terms of destigmatising neurodivergence.
- They also called for neurodivergent conditions to no longer be referred to as disorders, arguing that they are differences rather than disorders.
- One participant regretted the Scottish Government's decision to pause progress in bringing forward a learning disabilities, autism and neurodivergence Bill and suggested that the effect of this decision was to undermine confidence in the system.
- Another participant called for more neurodivergent people to be involved in the assessment pathway. They indicated that they generally feel more comfortable around other neurodivergent people and that involving more neurodivergent people in the process would make the pathways friendlier.

Other written comments

- "With the prison population, a doctor can halt someone's release if they believe that the person will go on to commit a crime. And that this has been used for people with ADHD and autism, for indefinite confinement." (The participant explained this could be done by a judge imposing an Order for Lifelong Restriction based on a doctor's assessment. The participant felt treating people in prison who are currently underdiagnosed with ADHD would be a more effective means of rehabilitation).
- "There is a definite period of reassessment afterward, almost a mourning period. Perhaps that might be helped with post diagnosis support"
- "https://www.hidden20.org/podcast/nhs-adrian-james - for some further listening and thinking - some national leadership would be good to see, as they are moving towards in NHS England."
- "Some referenced rates of comorbid alcohol dependence, substance misuse and so forth:

https://chadd.org/about-adhd/co-occuring-conditions/ and https://pubmed.ncbi.nlm.nih.gov/22209385/”