OFFICIAL REPORT
AITHISG OIFIGEIL

Health, Social Care and Sport Committee

Tuesday 30 September 2025

Session 6

The Scottish Parliament
Pàrlamaid na h-Alba

Tuesday 30 September 2025

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HEALTH, SOCIAL CARE AND SPORT COMMITTEE

25th Meeting 2025, Session 6

CONVENER

Clare Haughey (Rutherglen) (SNP)

DEPUTY CONVENER

Paul Sweeney (Glasgow) (Lab)

COMMITTEE MEMBERS

*Joe FitzPatrick (Dundee City West) (SNP)
*Sandesh Gulhane (Glasgow) (Con)
*Emma Harper (South Scotland) (SNP)
*Patrick Harvie (Glasgow) (Green)
*Carol Mochan (South Scotland) (Lab)
*David Torrance (Kirkcaldy) (SNP)
*Elena Whitham (Carrick, Cumnock and Doon Valley) (SNP)
*Brian Whittle (South Scotland) (Con)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Kabie Brook (Autism Rights Group Highland)
Bill Colley (Scottish ADHD Coalition)
Dani Cosgrove (Stronger Together for Autism and Neurodivergence)
Matthew Day (Number 6)
Sofia Farzana (Scottish Ethnic Minority Autistics)
Rob Holland (National Autistic Society Scotland)
Lyndsay Macadam (SWAN Scotland)
Mark McDonald (Scottish Autism)

CLERK TO THE COMMITTEE

Alex Bruce

LOCATION

The Sir Alexander Fleming Room (CR3)

Scottish Parliament

Health, Social Care and Sport Committee

Tuesday 30 September 2025

[The Temporary Convener opened the meeting at 09:15]

Temporary Convener

David Torrance (Kirkcaldy) (SNP): Good morning and welcome to the 25th meeting in 2025 of the Health, Social Care and Sport Committee. We have received apologies for today’s meeting from the convener, Claire Haughey, and the deputy convener, Paul Sweeney. In the absence of the convener and deputy convener, I am required, as the oldest member of the committee present, to take the chair initially, with a view to appointing a temporary convener for today’s meeting. In this role, I propose to nominate myself as temporary convener for today’s meeting. Are members content for me to act as temporary convener for the remainder of today’s meeting?

Members *indicated agreement.*

Decision on Taking Business in Private

09:15

The Temporary Convener (David Torrance): The next item on our agenda is a decision on taking item 4 in private. Do members agree to take the item in private?

Members *indicated agreement.*

ADHD and ASD Pathways and Support

09:15

The Temporary Convener: Item 3 is the first of two oral evidence sessions as part of the committee's inquiry into attention deficit hyperactivity disorder and autism spectrum disorder pathways and support.

Given that some of the witnesses that we will be hearing from are individuals with ADHD or autism, or both, we have sought to make reasonable adjustments to support them in giving evidence to the committee this morning. This includes providing the witnesses with the questions that we plan to ask in advance of the meeting. If anyone attending today's meeting needs to take a break at any point, please indicate that to me or the clerks.

I welcome to the committee Rob Holland, director, National Autistic Society Scotland; Bill Colley, chair, Scottish ADHD Coalition; Dani Cosgrove, chief operating officer, Stronger Together for Autism and Neurodivergence—STAND; and Mark McDonald, media and policy officer, Scottish Autism.

We move straight to questions, and Emma Harper will ask the first question.

Emma Harper (South Scotland) (SNP): Good morning, everybody. The first theme is the role of diagnosis. I am interested to hear from our witnesses what impact a diagnosis can have for a person with a neurodevelopmental condition such as autism or ADHD. I will come to Rob Holland first.

Rob Holland (National Autistic Society Scotland): I am happy to go first. Thank you for the opportunity to give evidence today.

Receiving a diagnosis is a validating and life-affirming experience for many people. It helps autistic people to understand themselves and their identity more, as well as the strengths and challenges that they face. People will often say to us, "I thought something was wrong with me and that I was broken." A diagnosis can bring people reassurance and can start them, or help them, on their journey to understanding themselves, as well as allowing them to start to develop the strategies that they might need or to seek out appropriate support.

We also know that diagnosis can be a gateway to support, whether that is in education, employment, the social security system or healthcare. That should not be the case. Services and support should be available to those who do not have a diagnosis, but the reality is that public services are stretched, finances are under a huge amount of pressure, and sometimes support is prioritised or allocated on the basis of a number of factors, diagnosis being one of them.

The last point that I want to make on this question is that there are a lot of negative narratives out there about autism and its prevalence. People face on-going stigma and discrimination. People say to us that they are not always believed by professionals when they say that they are autistic. A diagnosis can be helpful, whether that is in education, social care or healthcare.

Emma Harper: Thank you for that. Does anybody else have any comments on diagnosis?

Mark McDonald (Scottish Autism): Thank you very much for the question. I will add a couple of things.

Scottish Autism has a community advice line, which is a national service. Over the past two years, our advice line has had more than 1,000 contacts regarding accessing an assessment. People definitely attach importance to assessment and diagnosis. That links into what Rob Holland said, as it is about an understanding of self. We will probably get into this a little bit later, but Rob is right when he talks about the fact that need should be at the centre when deriving support, but people also have a right to understand where that need itself derives from. Diagnosis can support and assist with that.

I want to quote a response that we received to a survey that we did in partnership with a group of autistic people's organisations, some of which you will hear from on your next panel. We were receiving evidence about why people attach importance to an assessment and diagnosis, and one response said:

> "It has allowed me to understand myself better, to support and advocate for myself, I am in employment for the first sustained period ever and I am more comfortable with myself than I have ever been before."

That summarises the importance of a diagnosis to the individual.

Bill Colley (Scottish ADHD Coalition): There is a critical difference between the ADHD population and those with ASD—although there is, as you will be aware, a huge overlap in comorbidity. In particular, without diagnosis, you cannot get treatment and although there is no medical treatment for autism, there is for ADHD and it is shown to be effective. If young people or adults are not being given access to assessment and diagnosis, they are not getting treatment for a treatable condition. That is a fairly significant difference between our two respective interest areas.

Another is more pragmatic and is on the emotional side of things. Diagnosis can be part of a healing process. That is what was being touched on, I think. People look back on their life and reflect, and the diagnosis can explain and rationalise some of the trauma that has been experienced. It can be good for looking back as well as for looking forward.

In everyday life, in the education system, the criminal justice system and in the workplace, a knowledge and understanding that someone has ADHD can allow the employer and the employee or the teacher and the school pupil, for example, to better understand what needs to be put in place. Diagnosis is pretty important.

Dani Cosgrove (Stronger Together for Autism and Neurodivergence): Thanks for inviting me today to speak on behalf of STAND and giving me the opportunity to shine a light on the views of children and parents. We are a relatively new grass-roots charity.

I do not have much to add, to be honest. Most of my points were covered, but it is important to recognise what a diagnosis is and how someone gets one. Diagnostic assessment for autism and ADHD identifies how best to address needs and how not to cause harm. On top of that, a diagnosis is required to start treatment for ADHD. When we surveyed parents and carers at the start of this year, almost 90 per cent said that that was vital to their child’s wellbeing.

Emma Harper: To what extent are neurodevelopmental conditions being overdiagnosed, or even underdiagnosed, in Scotland? Do you have any thoughts on that?

Mark McDonald: Yes. This perhaps leads on from Rob Holland’s point about harmful narratives, and there are harmful narratives out there right now about diagnosis and the concept of overdiagnosis.

Autism is obviously the primary area in which Scottish Autism works. Autism was first diagnosed less than 100 years ago, but that is not to say that autistic people did not exist before then—they did, in the same way that America existed before Columbus stepped off the boat. We just recognise it now—we understand it, and our understanding has grown. Over the time that our understanding has grown, the thresholds for diagnosis have changed. That has meant that people who historically would not have received a diagnosis are now able to achieve one.

It also means that we are playing catch-up with diagnosis. If you were to look at an age profile distribution graph, you would see a tail-off in autism diagnosis beyond the ages of, say, 40 to 50. That is because, historically, those people would not have met the thresholds and the criteria that existed 30 or 40 years ago. A lot of those people are now coming to understand that they perhaps require an assessment and a diagnosis. Often that is triggered as a result of somebody in their life, often a child, achieving a diagnosis.

That leads me into probably one of the concerning elements around what is happening in adult pathways at the moment. We are seeing adult pathways being restricted and, in some places, closed. At the point at which people are starting to come to understand themselves better and seek out assessment and diagnosis, we see a system in some areas where that is becoming less possible. That has the potential to lead to difficulties and to people having to go down the private diagnosis route. We may come on to discuss some of the issues that arise as a result of that.

There are two things. First, we are playing catch-up. We have a better understanding of autism than we have done historically as it has developed. Secondly, there has been historical underdiagnosis. It is not that there is overdiagnosis; in the past there has been historical underdiagnosis, but that is a result of our understanding and knowledge around autism developing over time.

Bill Colley: I echo everything that has been said so far about underrecognition in the more elderly population. We are talking about tiny figures. The most recent data that we have found was in a publication last year and relates to 2019 national health service figures for prescribing. For children, the prevalence range that we work on is usually between 5 and 7 per cent. If prevalence in the general population is 5 per cent, 73 per cent of children who have ADHD are not receiving treatment. If estimated prevalence is 7 per cent, the figure for children not receiving treatment is 81 per cent. That rather counters the press narrative that ADHD is being overdiagnosed.

For adults, the prevalence range is between 2 and 4 per cent. At 2 per cent, 91 per cent of adults with ADHD are not receiving treatment, and at the 4 per cent level, the figure is 96 per cent. Given that ADHD is a treatable condition, the vast majority of people who have it have not been assessed and diagnosed and are, therefore, not receiving treatment.

Emma Harper: Are any specific groups more affected by missed or incorrect diagnosis?

Bill Colley: The national guidelines identify groups such as any children going into the care system, any young persons entering the criminal justice system and young people who experience substance use disorder. We can bring in some of the concerns about vaping here, because it is likely that the availability of a substance such as nicotine in the environment will be attractive to someone who is trying to self-medicate. You get these pathways of vulnerability feeding through, particularly in certain groups. That is universally recognised.

Dani Cosgrove: We see that all groups can be affected by missed or incorrect diagnosis, to be honest. Research shows that particular groups are likely to be missed. For example, it is understood that girls are more likely to mask and, therefore, are less likely to be identified as autistic or having ADHD than boys.

However, on the whole, the children that we support are already so badly affected by the current state of affairs that it is difficult to distinguish between the varying degrees of harm and distress, and I would not be comfortable doing that anyway. For us, the most obvious group that is most likely to be missed or have a misdiagnosis is the huge cohort of children currently who require an assessment for autism and ADHD but who cannot get on to a waiting list because they do not have a co-occurring mental health condition.

Mark McDonald: You will hear later from witnesses from Scottish Ethnic Minority Autistics and SWAN Scotland, who can talk in more detail about this. When we talk about underdiagnosis, missed diagnosis or incorrect diagnosis of autism, the most prevalent groups tend to be people from ethnic minority backgrounds and females. A lot of people receive diagnosis for things such as borderline personality disorder, schizophrenia or an eating disorder before eventually receiving a diagnosis of autism. That is deeply problematic, because people are potentially being moved into treatment for conditions that they do not have, while at the same time not receiving support for their autistic profile.

09:30

Bill Colley: In the adult ADHD population, the majority of those that I described as not receiving treatment are being treated, but they are being treated for anxiety and depression rather than for the underlying cause, which is ADHD. Ineffective medication in those groups is a cost to the national health service.

Carol Mochan (South Scotland) (Lab): Good morning. I have three questions, the first of which is on pathways and thresholds for assessment. As part of the inquiry, the committee is considering petition PE2156, which describes a “postcode lottery” of access to pathways and support for people with ADHD. What is the impact of differing pathways for neurodevelopmental assessment across Scotland? What steps could be taken to address any differences in assessment pathways by area, if you have any knowledge of that?

Do you want to come in, Dani Cosgrove? You are nodding.

Dani Cosgrove: Yes, I can start. We see variation in more than assessment pathways. The variations cause inconsistency, confusion and inequity. It is not just that there is variation. The information for each area talks about assessment pathways and support. The support in each area is different and that information is unclear. Transparency for children and parents and carers is also lacking.

Parents rely a lot on peer support—that is how STAND started. We run WhatsApp peer support groups with over 700 members, which are divided by age, not geography. It is difficult for even those people to give each other peer support when they are in two different areas and the rules are completely different in each one. Even with those groups, families cannot support each other.

Our volunteers have tried to bridge that gap. We have been to several different cities to do empowerment workshops. However, it is difficult even for us to give correct advice. We could give a family in East Lothian advice and it would be different from the advice that a family in the Highlands would need. Worse still, when we try to learn how assessment pathways work, quite often the goalposts move and neither we nor the professionals know that they have moved. That makes it difficult for all people—not only parents and carers and children, but public services—to understand.

Rob Holland: I agree completely with that. There is a lack of consistency and transparency out there across the country, and different areas apply different processes to try to manage the demand. That means that there are different thresholds, and it is often not clear what those thresholds are, as Dani said. We hear a lot about the threshold of having a co-occurring learning disability or a severe mental health need. Age is applied as a metric, so we will find areas that do not have an adult pathway or where it is difficult to get on to the pathway in the first place. That is the reality right now.

We believe that the proposals in the learning disabilities, autism and neurodivergence bill that the Scottish Government has been working on will help with that. There is a proposal on local and national strategies to understand the population and how best to support it, and that will go some way to bringing consistency.

Carol Mochan: Thank you. Does anybody else want to add anything?

Mark McDonald: I have a couple of things. Rob Holland is right in mentioning the proposed learning disabilities, autism and neurodivergence bill. Of course, its draft provisions did not contain a section on assessment and diagnosis, which was the one absent aspect that we felt would have merited inclusion. At the time, we were told that that was absent because separate work was being undertaken, following the work that was done by the national autism implementation team around neurodevelopmental pathways, that would supersede the bill. We do not know where that work currently sits or what is being done to broaden the pathways.

Self-referral has a role to play here. In our evidence, we cited Aberdeen city health and social care partnership, which spoke at a recent meeting of the cross-party group on autism about the fact that it allows self-referral into its pathway. It is seeing a diagnosis rate of 87 per cent. In the evidence that it provided, the NAIT spoke about 86 per cent of people receiving a diagnosis, which suggests that when people seek a diagnosis, it is because they know that they require one. There is not the frivolity that sometimes is contained in the negative narratives that exist around diagnosis.

It is helpful to have a pathway that people can refer themselves into without having to go through a gatekeeping process, which often results in them coming up against lack of knowledge, a lack of understanding or outdated understanding. For example, a lot of traits that people might look for in an assessment can be based on outdated thinking. We have heard testimony from people who have said that they were told that they were not getting a referral for an assessment because they were able to maintain eye contact. That is extremely outdated thinking, but it exists out there and it results in people having doors closed to them.

Bill Colley: To add to that, the patient pathway does not begin when you go on a waiting list. It begins when you first recognise a problem. When someone goes to a general practitioner and says, “I think there’s something wrong with my child or something contributing to their difficulties,” and they are told, “No, I don’t think they have autism,” that becomes a null diagnosis. It is a hard diagnosis. Often, it means that parents will not revisit the possibility for a number of years, by which time the symptoms will have deteriorated.

One reason that we get these huge variations across the country is differences in professional expertise. There needs to be upskilling, particularly at primary healthcare level, but also higher up, on what constitutes the criteria for a diagnosis, or at least for an assessment for a diagnosis.

We are bombarded by adults who say that they have been refused assessment because they went to university and have a degree, and that means that they cannot have ADHD. Mark McDonald gave the example of eye contact, and people also say that you cannot have a sense of humour if you have autism. Those things mean that it becomes much more challenging for people to get the support that they need.

Carol Mochan: You have answered the second and third questions that I had, but I will ask them just in case there is anything that you want to add. One question was whether there are thresholds—witnesses have clearly described some of them. If you want to give any other examples, please do so. The other question was to ask your views on self-referral for assessments, which again you have addressed quite clearly. Is there anything to add?

Mark McDonald: I have one thing to add, which is that in those instances where people find that the door is closed on them as a result of an element of gatekeeping in the process or a lack of opportunity for self-referral, the only two paths left are to cope or to seek a private diagnosis. In the report that we put together based on our survey, we had evidence that people were spending thousands of pounds on private diagnosis. The issue that arises is that an element of the wild west exists around some of the private diagnoses out there in the wider sphere. There is a lack of provenance sometimes.

There is also a lack of knowledge about whether a private diagnosis will be accepted. You run a risk. First, if you can afford it, you can seek a private diagnosis. Some people cannot and some people have put themselves in debt to achieve it. You then present that private diagnosis, whether to the health service, an education provider or an employer, only to find that it is rejected or not recognised because it was obtained privately and potentially from a provider that does not meet certain criteria that you were not aware of when you sought the diagnosis.

Carol Mochan: I appreciate your point. Some of my colleagues will ask a little bit more about that as we go through the evidence. Thank you very much. Do you want to come in, Bill?

Bill Colley: Yes, I have a tiny point. In the criteria, quality of life ought to be a major consideration, rather than there being the hard criteria on severity and complexity that are set down at the moment. The question, particularly with a condition such as ADHD, which is treatable, is whether treatment could improve the person’s quality of life. That becomes an important question to ask.

Joe FitzPatrick (Dundee City West) (SNP): I am keen to ask about waiting times. We have had some evidence about people’s experiences, but can the panel give us their thoughts on the impact of waiting for a diagnosis on individuals and on their families? Can you say a little bit about whether there is good practice, particularly if there is a waiting time? Can things be done during that period, and do some areas do that well in spite of having waiting times?

Bill Colley: You raise a very good point about what happens when someone is on a waiting list, which is one of the points I was going to raise today.

Think about a young person aged 11 who is on a waiting list for four or five years, with all the changes that that young person is going through—puberty and environmental changes—and the demands that are being placed on them and the environmental risks that occur during that time. If a young person displays some of the characteristics of inattentiveness, hyperactivity and impulsivity, in particular, it is often the time when things go wrong and they disengage from family and from school. That is the pathway to substance use and to prison. Not getting the support early can have a profound impact on the trajectories of that population. It is important that, when there is a need for assessment and possibly treatment, it is done timeously.

Rob Holland: It is a common issue that comes to us from families who are waiting months or even years for a diagnosis for their child, with all the negative impacts that can occur from that. Ultimately, if they do not have the diagnosis, they will not necessarily know where to turn for support, what strategies are helpful and what strategies are essentially harmful.

An awful lot of evidence shows that a child who is diagnosed will not require mental health support later down the line, when they are an adult. However, the reality is that a lot of people have to wait for the diagnosis and struggle on, trying to manage their mental health to the best of their ability. In some cases, they can reach a crisis point, which impacts on their education, employment opportunities and so on. Particularly for children and young people, waiting 18 months or two years for a diagnosis during their formative years, while they are in school and when the diagnosis is a gateway to support, can be hugely detrimental.

Then, of course, as Mark McDonald mentioned, there is the issue of those who feel that they cannot wait and who have the financial resources to pay for a private diagnosis. That brings challenges as well.

Dani Cosgrove: We hear from our families that the longer they wait for the assessment, the longer it is before their child's needs are fully met and properly understood. Children are losing years of development, families are being left in limbo and support is being delayed or withheld. A parent spoke to me last week and described the waiting period as physically and emotionally torturous. Another family said that, even though their daughter is self-harming, they were taken off the waiting list that they had been put on and are now having to gather more evidence. We are putting children through the trauma of being on a second waiting list, which is difficult when these children are being so vulnerable and opening up to people—especially when it is people in education, because parents cannot self-refer.

09:45

Mark McDonald: You asked about good practice, which I suppose is fair, because we want to highlight not just where things are going poorly, but where things are working and whether that practice could be shared. In our experience, a lot of pockets of good practice exist out there, but it is not systemic and it is not universal. We could not point to any one particular health board or local authority area and say, "These people are getting it right."

In some places, you have a professional who has a level of understanding or a team that is working neuro-affirmatively. We had a lot of positive responses to the survey that we did around the experiences that people had with, for example, the Number 6 service in Lothian, who you will hear from on your next panel. That service was seen as positive because there was a group who were neurodivergent in the team who were working to support individuals through the process. It was a neuro-inclusive, neuro-affirmative process that people felt welcome and trusted within.

We have heard about good examples out there of people being provided with information during their wait. The difficulty that a lot of people face is being in limbo. They are put on a waiting list but they are not necessarily told what to expect, what the length of time will be, what will happen during the process, and where the end point of the process will be. We have heard of people being given outdated information by statutory services that are meant to provide community support opportunities, because they are not keeping up to date with what is out there in the community. People immediately start to lose trust in the process at that point. More connectivity is required to understand what is out there to support people while they are on that journey but also how to give people realistic advice about what the journey will look like.

The last thing I will say is particularly relevant to you, Joe. A decision was made in NHS Tayside to remove children from the waiting list unless they had a co-occurring mental health condition, which caused a great deal of anxiety and uncertainty for people. Not enough explanation was given for what that meant for people who were expecting to get a diagnosis and for people who were worried that their child might age out of children’s services before achieving a diagnosis. Would that mean that they faced an even longer wait for an adult diagnosis? If they were in an area that did not do adult diagnoses, what then?

Joe FitzPatrick: Thanks for that, Mark. Your point about communication and keeping people aware of what the pathway is and what they can expect right across the country could be taken on pretty quickly and pretty easily. Your example of NHS Tayside shows exactly the opposite and how people can get it wrong. Thanks for flagging that up. Everyone can learn from that experience—I believe that NHS Tayside has, or I certainly hope that it has.

It is useful to hear folks’ thoughts on the impact of waiting times. Does anybody have any thoughts on how we can get those times down so that people get a diagnosis without such a long wait? Can we do something across the system that will make a difference to reduce waiting times?

Bill Colley: I will speak from personal experience. In 2010, NHS Tayside recognised that there was a real problem with autism assessment. The wait time was about four and a half years. It held a kaizen blitz and, as a result, developed a multi-agency pathway for assessment. As an educator, I was invited on to that and I was trained in certain aspects of assessment. There were social workers, educational psychologists, psychologists and psychiatrists, but the bulk of the work in that pathway was done by allied health professionals—in particular, trained speech and language therapists, who did the bulk of the legwork around assessment. We brought wait times down from four and a half years to six months. It took probably two years to work through it.

It is doable, but it means breaking down some professional silos and training allied health professionals, who are a wonderful resource and perhaps do not get the respect that they are due. It also requires a new category of clinical professional called a clinical interviewer, who does the information gathering and takes that task away from the highly paid and very able consultant psychiatrists and psychologists. That should speed up the process immediately.

The developmental wellbeing assessment that is used by the NHS in England is a broad-ranging assessment tool that I have worked with and found to be extremely accurate and effective. In a pilot project, we managed to turn around assessment in 10 working days. That did not give a concrete diagnosis, but it did give a profile that was useful to parents.

Mark McDonald: I echo what Bill Colley says. The work that NAIT did around adult neurodevelopmental pathways broadened the team that can support and provide a diagnosis. We talked earlier about how the number of people seeking a diagnosis is increasing but the door through which those people can access that diagnosis has not been widened. If you widen that door and create a broader team that can support a diagnosis, by definition you will bring the numbers down. The key in all of this is moving to a different model to support that.

The challenge is that, in some places, there is an idea that closing down the model makes the issue go away. In Aberdeenshire, for example, a saving of £200,000 has been projected from closing the adult autism and ADHD assessment service, but the need for that service does not disappear. It gets displaced and potentially ends up being funnelled into crisis support services. Often, when we talk about these things, people say, “Ah, but there’s a cost attached.” A cost is attached to either end of this. The question is whether the financial cost outweighs the human cost, which also comes with a financial cost.

Rob Holland: I will build on that a bit and echo what Bill Colley and Mark McDonald have said. The current system is not set up for the current level of demand, so there is a gap between the workforce capacity and the demand for assessment. We think that funding is urgently needed at the moment to develop and train the workforce, but we also need longer-term funding. At the moment, the system is in crisis mode, so there are not the resources to plan effectively and develop innovative ways of identification, research, testing and so on.

To echo Bill Colley’s point, good assessment practice is having a case co-ordinator to keep the person up to date with the process, to gather the right information and to be a single point of contact. That is not always the case.

Joe FitzPatrick’s previous question was about support for those who are waiting. Because diagnosis is just one element of it, the Scottish Government has set up the autistic adult support fund, which provides pre-diagnostic and post-diagnostic support for autistic adults. A lot of good practice is being developed there, and I should say that we are a recipient of that funding. We know that an awful lot of good practice works to support people who might face a lengthy wait.

Joe FitzPatrick: Thank you. Dani Cosgrove, do you want to add anything?

Dani Cosgrove: Yes, in response to the question about addressing the long waits for diagnosis. We have worked on some things that could be done now and that would not take a lot of effort. Fair allocation of staff would be a start. The same multidisciplinary teams that assess kids in child and adolescent mental health services can assess autistic and ADHD children as well as those with co-occurrent mental health conditions. They could be allocated more fairly.

Echoing that, the support could start from the first concern, continue during the assessment and carry on after diagnosis. That would mean that the children on the waiting list would be supported throughout the whole process. There could be more transparency, with the ND waiting times routinely published so that the families are not hidden from the system. There could also be more consistency across Scotland, with one national framework so that children are not penalised for living in a different postcode or having a different professional involved in their care.

Elena Whitham (Carrick, Cumnock and Doon Valley) (SNP): Good morning, everybody, and thank you so very much for coming along. This is one of those times in life where, for me, lived experience converges with my role here as an MSP in taking evidence from you.

I want to spend a wee bit of time focusing on the availability of support. You have all touched on that already, but I want to think about the fact that access to support seems to be contingent on diagnosis a lot of the time. Have you experienced that in your organisations? Could you give examples of where a diagnosis is required? I understand the point about medication for ADHD, but in relation to the availability of all other types of support, diagnosis seems to be the blocker that is put in front of people. Who wants to start on that one?

Dani Cosgrove: I am happy to start. We all know that in theory the absence of a diagnosis should not exclude children from support, but in practice it does. It becomes a gatekeeper, because local authorities apply criteria for access to things such as risk in traffic blue badges and disability social work help—in East Lothian, an additional diagnosis on top is required to qualify. Many of the families that we support have issues with sleep, but they are not allowed to try things such as melatonin without a diagnosis. East Lothian's housing policy states that you have to have tried to treat autism, which is a dangerous narrative in itself. That reads as if autism is an illness that can be treated, which is factually wrong. If that is East Lothian's approach—if its view is that autism can be treated, which is obviously factually wrong—it is extremely unlikely that it would apply the housing points without a diagnosis.

Autistic and ADHD children have rights under the Equality Act 2010, but to enforce their rights, families need to show that their child is disabled. The diagnostic assessment provides the evidence most of the time, so we need to put children through the diagnostic assessment to get them protected under the 2010 act.

For families, this is not about chasing a piece of paper; it is about their children needing to be seen, to be believed and to be given a chance to thrive. When diagnosis is treated as an optional extra, the children that we see tell us that they are left feeling invisible.

I come back to the question. Children need the diagnosis to be believed. If a child has a meltdown at soft play or at the supermarket and their parent is able to say, "My child is autistic", they cannot be chucked out. However, they cannot say that without knowing it themselves, which comes through a diagnostic assessment.

I will stop now, because I could talk about this all day.

Elena Whitham: We could listen to you talk about it all day, however time does not allow us to. Rob Holland, do you have anything to add to that?

Rob Holland: Dani Cosgrove has articulated the position clearly. The system should not rely on a diagnosis for support to be offered, given that we have the getting it right for every child policy and the Equality Act 2010, for example. However, in the world in which we operate, resources are tight and in that scenario a diagnosis becomes more important. We hear from parents that they need a diagnosis for their child for the school to resource speech and language therapy, for example. Diagnosis can also be important in the social care setting.

10:00

I go back to the point that Dani Cosgrove made about being believed. The reality is that there are poisonous narratives about overdiagnosis out there.

Having a diagnosis can be important in an employment context as well, even though people should not need that. The Equality Act 2010 should mean that reasonable adjustments are made. Nevertheless, a diagnosis can be helpful in that context. It can also be helpful with health professionals, who might not be experts on autism but nevertheless have quite strong opinions. In those contexts, a diagnosis can be important.

Bill Colley: It is a given that you cannot get treatment without a diagnosis.

For a young person or an adult, having the diagnosis gives them a clear steer on where to seek support and the type of support to seek. Many will have been medicated for anxiety or depression for a number of years, or they might have been given a diagnosis of borderline personality disorder or emotionally unstable personality disorder. If they get the diagnosis of ADHD, they can, with greater clarity, seek whatever support is out there in the community. That is important as well.

Elena Whitham: I have a question about the classroom setting and children who potentially have ADHD. Rob Holland spoke about a diagnosis sometimes being needed so that support can be offered in the classroom. Should provision and support in the form of things such as movement breaks and the ability to use fidget toys be available to young people, regardless of whether they have a diagnosis?

Bill Colley: Having spent my working life in education, I am saddened that children spend so much time in buildings and not outside. They are not active. They are not challenged in outdoor settings with an outdoor curriculum. I worry about the length of some lessons—they may be too long, for example—and about open-plan classrooms. There are a lot of obstacles and challenges in the way in the education system. I could speak all day about that. Adjustments would not just benefit children with ADHD; they would benefit the school population.

There are also challenges in trying to address the educational needs of children with autism, who may require a different type of environment and the curriculum to be delivered differently. They may need less stimulation and a bit more structure. We have to be realistic. It is a complex picture and we cannot change the system overnight. It often depends on individual teachers within the system, who perhaps have lived experience and who then translate their own lived experience into making the difference for young people in a school.

Elena Whitham: In the written evidence that we have received, there is an assertion from the north Edinburgh CAMHS that

> “support provision must be fundamentally reimagined to prioritise individual needs over diagnostic labels.”

To what extent do you agree with that assertion? I will start with Mark McDonald.

Mark McDonald: I can deal with your previous question and this one in combination. In a perfect world, absolutely, support would follow need and we would not need a diagnostic label. However, as has been highlighted, this is not a perfect world and resources are finite. We have spoken about incorrect diagnosis and misdiagnosis, and about the idea that, without assessment and diagnosis, you cannot absolutely ensure that the support matches the profile of need. It may do in some cases, but this is also about empowering the individual. We have spoken about what a diagnosis means for an individual. It means empowerment, the ability to advocate and the feeling that they can talk about their needs and how those needs can be supported. Without that diagnosis, the conversation becomes potentially more difficult in some contexts and may lead to a refusal to provide support, which can create a negative spiral.

The ability to access an assessment, which can lead to a diagnosis, helps to unlock support. That sits at the centre of all of this. In some places, that support will flow anyway. Certainly, people can contact our advice line or access our community services at any stage on their diagnostic journey. They do not need to have achieved a diagnosis to access those support services. Broadly speaking, that is the approach that is taken across the third sector, often because support is not available already from statutory services. The third sector meets need that exists that the statutory services are not dealing with.

Elena Whitham: That is helpful to hear. Does anybody else have any thoughts on that?

Rob Holland: Diagnosis and needs-led support should not be either/or. Providing early interventions and meeting needs should be complementary to, and not instead of, a diagnosis. Both diagnosis and support are valuable. Diagnosis is a need in itself. I do not necessarily agree with the assertion in the CAMHS statement.

It is important to say that needs-led support is context specific. It supports someone at a specific point in time—in school, for example—and people have a variety of experiences, with different transition points and major events throughout their lives, and their needs will often change. Having a diagnosis helps that person to navigate through those transitions and build the strategies that help them in those situations. We should not delay diagnosis until somebody’s situation is acute or they are in crisis, because that is no good for the individual and no good for the system.

We are a little bit concerned that sometimes the debate in this space is focused on reducing referrals rather than making sure that we tackle the issue here. The issue is not a problem of demand; it is a problem of supply and ensuring that we have the right number of assessments and the right level of support.

Elena Whitham: I have a final question. What wider benefits could result from the appropriate supports being made available at the right time? What difference could it make for people if those appropriate supports started as early as possible and at the right time for them?

Dani Cosgrove: It should not be necessary to provide the wider benefits to justify timely assessment and support. It is important to remember that autistic and ADHD children have the right to healthcare like all other children, but it is true that when support comes at the right time, the benefits extend far beyond the child. It creates stronger families, calmer classrooms and reduced pressure on services because problems are prevented, rather than left to escalate.

Children and their families should be believed, supported and given the opportunity for diagnostic assessment when a child meets the criteria for that. For us, the right time for support and assessment is as soon as the first concern is raised, whether that is by the child, a family member, a teacher or another professional. Harm is caused not only to the child but to their family and to wider society.

The clearest wider benefit of acting at the right time is simply the prevention of unnecessary harm. A parent recently told us that the impact on their mental health and their other children, and even their relationships, has been huge, all because their child did not get what they needed at the right time. Other, wider benefits would include things such as better education for the child and other children, healthier communities and more efficient and responsible use of public resources and finance.

Ultimately, if every child is supported, nurtured and given the opportunity to thrive, society could get the benefit of what these children have to offer. Instead of our children being seen as, for example, distractable, stubborn and impulsive, they could be seen for who we believe they truly are, which is curious, determined and creative.

What is so heartbreaking for us at STAND is that many of the parents and carers that we see are in crisis mode. They are living hour to hour and day to day and have little capacity to think about the wider benefits of their child getting what they need. Parents and carers have told us that their children are barely surviving, let alone thriving. One parent told me this weekend that they cannot go on. I attend our in-person events every week. I hear these things first hand, and I witness parents and carers in tears pretty much every time I go.

The truth is that the wider benefits are obvious: better education, healthier families and stronger communities. However, parents tell us they cannot even think about that right now because they are just trying to survive today. If we act at the right time, children could thrive and society would gain so much, but, first, we have to stop the harm.

Elena Whitham: That was a powerful statement for us to hear this morning.

Bill Colley, you already touched on some of the issues that can develop in the life of a person with ADHD in the absence of diagnosis and support. Could you speak a little bit more about that?

Bill Colley: A recent study that was published in Sweden looked at treated versus untreated ADHD and gives a good picture. It did not compare against a normal population; it took the ADHD population and looked at outcomes for those who are treated and those who are not treated. That study found that treatment led to a 15 per cent reduction in suicide attempts, a 25 per cent reduction in substance use, a 4 per cent reduction in accidental injuries, a 16 per cent reduction in transport accidents, and a 25 per cent reduction in criminality. I translate that into the cost to society of traffic accidents, suicide attempts and everything else. Treatment saves money in other parts of the system.

We also need to look at the number of complex individuals who are in the care system. I say “complex” because often it is not simply ADHD that is involved; other things have happened. If we can keep families together by providing the treatment and the understanding when they are needed, there will be a huge saving to society from children not entering the care system. The state is not a good parent, generally, and it is much better if families are kept together. That is Government and national policy.

The Temporary Convener: Sandesh Gulhane has a quick supplementary. [*Interruption*.] I cannot hear you, Sandesh.

Sandesh Gulhane (Glasgow) (Con): Sorry, I was waiting to be unmuted. I declare an interest as a practising NHS general practitioner.

Dani Cosgrove, I want to come back to something that you were talking about when it comes to disruption in schools. I have a big concern about the presumption of mainstreaming. There is a lack of support teachers for pupils with ADHD and other diagnoses—those who are deaf, for example—who have additional support needs. Even with a diagnosis, do we see a big difference when it comes to schooling?

Dani Cosgrove: That is a good question. I can answer this personally because I have one child who is diagnosed and one child who is on a waiting list. Yes, it is very different, but that does not mean that more funding for a diagnosed child magically appears overnight. It means that I, as the parent, have the confidence to know that I am right, and that I will not be told that my child does not have these needs because I have the diagnostic assessment to prove that he does. It gives me the opportunity not only to fight for rights with the school but, if I do not feel that the school is fulfilling them, to take it to the local authority, which has to fulfil my child’s educational rights.

Mark McDonald: I am aware that we are potentially straying into the remit of the Education, Children and Young People Committee, but there is an important reason to do so. One reason why we were so supportive of the proposed learning disabilities, autism and neurodivergence bill and why we are so disappointed that it will not be passed in this session of Parliament is that it was focused on the whole life journey and the whole life experience. This committee is rightly focusing on assessment and diagnosis, but once the individual has achieved that diagnosis, that is not the end of their story. They then have to go into other areas of their life and access or identify support, or advocate to try to get support to be made available.

You asked about education, and I go back to Elena Whitham's point made about what support exists out there and the difference that the right support could make. I will give the example of the use of informal exclusions in education. Six years ago, Autism Scotland, the National Autistic Society and Children in Scotland produced a report on informal exclusions. An informal exclusion is when the parent gets a phone call, maybe at 10 or 11 o'clock in the morning, asking them to come and pick up their son or daughter because they are not coping at school, and they have to take them home. That happens almost daily and means that at least one parent is locked out of the workforce because they have to be available for the child coming home from school. It also means that the child does not access and benefit from education. Nobody benefits in that scenario. The education authority does not benefit, the child does not benefit and the parent does not benefit, but that practice persists. We highlighted it six years ago, and our advice line continues to receive calls about it.

10:15

Elena Whitham talked about the right support being available and Sandesh Gulhane rightly identified the issue of support within the education system. If we got that element right, it could unlock benefits in the economy, health and education—in all the different areas. If we look at things through one particular prism, we do not see the whole picture.

Patrick Harvie (Glasgow) (Green): Thank you very much and good morning to the witnesses. I am already learning a lot, so thank you very much for the evidence that you have been giving.

The issue of private diagnosis has come up a couple of times in the conversation already, and I wanted to ask some specific questions about that. We have heard the reasons why diagnosis is so important. We have heard the fact that private diagnosis may be quicker and easier to achieve if someone has the money. I am not quite clear whether that is entirely because of capacity in the private sector or whether it is because of different practices in the private sector.

We have heard about the unfairness and the amount of money that getting a private diagnosis costs. Mark McDonald mentioned people moving into significant debt because of that. He also used the phrase "wild west" with regard to the variation in standards, what private diagnosis consists of and whether it is recognised in other services. In the written evidence, we also see a big variation in what it costs and in the prices involved. Again, I am not clear on the reasons for that.

Can I ask you to either comment about the current situation or, ideally, say what the role of private diagnosis should be? Who would like to kick off?

Bill Colley: That comes up a lot in shared care, where a private diagnosis is given and then the treatment is refused by the GP. The patient has to go private and that costs between £150 and £300 a month for a treatable condition. That comes up an awful lot.

The landscape of private assessment in Scotland for ADHD is very varied. There are some good providers and there are probably some who are not so good. The quality of assessment can vary. The fact that we do not know the landscape is in itself quite interesting, because we ought to know. Some private providers are people who previously worked in the NHS and decided to get out and set up their own practices, primarily because they wanted to deliver a service that they did not feel they could in the NHS. They are not all driven by profit and greed.

We often think that private equals bad, but I am cautious about that. The Scottish ADHD Coalition takes a neutral stance on this. In the past, we tended to persuade people to go down the NHS route. Things have become so difficult at the moment that we do not put out that message any more.

We need a degree of flexibility. Private providers tend to be quicker and tend to have a much more personalised approach in terms of getting to know the patient. They tend to take a more long-term view that, once someone has a diagnosis, there ought to be some form of aftercare. However, it is difficult to generalise, because the standards are so variable across the country.

Rob Holland: To build on that, for autism a common question that we are asked is, "Can you recommend a private diagnostician?" Of course, we do not do that. We tell people to do their research and do their homework. We tell them to look at the clinicians who provide that service and the diagnostic tools that they use. Do they have membership of the right professional bodies? Essentially, we ask people to quality assure the private providers, because there is no quality assurance framework, so we cannot be confident in the quality. As Bill Colley says, there are some good reputable providers—former NHS clinicians using up-to-date tools and so on—and then there are others we hear about for whom that is not the case. It is an issue, and it is an issue in the context of long waiting lists and people increasingly seeking out private diagnosis.

It feels as if that marketplace is developing quite rapidly with demand, so it is an important part of the conversation. If we are to allow the marketplace to expand, we need to have serious conversations about how we quality assure it. The reality is that we know that people will go and get a private diagnosis and then the NHS will not recognise that diagnosis for exactly the same reason, which is that it cannot assure the quality.

Patrick Harvie: Can I ask you to say a little more about the variation within private provision? You have talked about quality, but there is also the price variation. How does that compare with the cost to the NHS of NHS diagnosis? We can acknowledge that somebody else is paying for it—the taxpayer is paying in one case and the individual is paying in the other—but does the cost of providing the service compare between the private sector and the NHS?

Rob Holland: That is a good question and perhaps other members of the panel have better insight than I do.

The cost of good-quality assessment in the NHS can vary depending on the context—for example, whether it is a child or an adult. Also, assessments should be multidisciplinary, with different clinicians involved. A child would need a paediatrician, an educational psychologist and a speech and language therapist; depending on the complexity of the individual, social work and nursing or other health professionals might be involved. I cannot quite answer the question, because the cost to the NHS would vary depending on the individual. Perhaps other members of the panel have a bit more insight than I do.

Bill Colley: There is an interesting discussion to be had within the clinical world about the degree to which some of the gold standard assessment pathways are absolutely necessary, particularly in a time of crisis. For example, I do the ADI-R, or autism diagnostic interview-revised. It takes about three and a half hours to do and about three hours to write up a report. That is a day’s work for one patient. Is it absolutely necessary to do all that work, or should we trust clinicians to use clinical judgment? Without compromising clinical integrity and without compromising the diagnosis and the diagnostic process, do we need to jump through all these hurdles? A workforce exercise needs to be done. Can we expedite this somehow? Can we make these patient pathways a lot slicker than they currently are? Those are questions for the clinicians.

Patrick Harvie: Thank you. Do any of the other witnesses want to talk about any aspects of this general theme of private provision?

Mark McDonald: I will make a couple of points. What Rob Holland was saying about the lack of quality assurance is where the “wild west” comment came from. We do not know the quality and provenance of a lot of providers. There are a lot of good providers out there, but the difficulty that we face, similar to NAS Scotland, is that we get people phoning our advice line, first, thinking that we can give them a diagnosis and, secondly, asking us, “Where can I go to get a diagnosis?” We do not feel that we can make a recommendation to direct people, because people may not receive a diagnosis. It is one thing to get an assessment, but it is another to get a diagnosis at the end of that assessment. Also, we cannot say with an absolute guarantee that, if they go to a private provider and get assessed and diagnosed, it will then be accepted by their employer, the school or the health board.

The key to this is what is driving people to seek private assessment? What sits at the root of this? At the root of it is people waiting significant lengths of time on NHS lists and then seeking an alternative route. If we deal with that root cause, we will see the number of people who are seeking private diagnosis reduce as a result.

You are right about cost variation. I am not entirely sure what drives that, but in the survey that we did in 2023, the highest cost that was reported to us was £4,500. I suspect that this has not been cushioned from inflation, so that upper limit will be even higher now. Some people can afford that, but you then get into a situation where those who can afford a diagnosis can seek one and those who cannot have to wait and potentially not achieve one. That creates wider inequity in the demographics that we are dealing with here. You will see demographic trends where, as a result, people are excluded from the opportunity to achieve a diagnosis.

Patrick Harvie: Dani Cosgrove, do you want to come in?

Dani Cosgrove: Most of my points were covered, but I will say that we hear from families that they are not going for a private assessment because they want to—they are going because they do not feel as if they have another option. They have described it to us as feeling as if they are paying for an assessment twice, once with money and then a second time with their child’s wellbeing because they are having to go through another assessment. If the same clinicians who are following the same standards can diagnose in the NHS, why would their judgment somewhere else not be respected, especially when families are not being given another reasonable option?

Patrick Harvie: May I check? Do you mean that some of the private providers are doing NHS work and private work?

Dani Cosgrove: Yes.

Patrick Harvie: The follow-up questions that I had about the variation in standards were mostly addressed, and there were also some comments about the desire for some clarity and consistency around shared care agreements.

My last question on this theme is this: if—and it is a big if—we need to use capacity outside the NHS to bridge the gap between the capacity and the demand that is there at the moment, is there a case for saying that that external capacity should be located in the third sector and that there should be an agreement between NHS providers and voluntary not-for-profit organisations that could operate to an agreed standard for an agreed price? That would be private in the sense that it is not the NHS, but it would not be paid for by individuals. Would that increase the capacity across the sector to meet demand more affordably and inclusively?

Mark McDonald: I suppose that we should declare an interest as members of the third sector. I spoke earlier about Number 6, which is not a Scottish Autism initiative but a service from Autism Initiatives in Lothian that received positive feedback. These things are possible.

The difficulty—and all of us from the third sector would speak about this—is that often the third sector finds itself chasing pots of money for innovation that are designed to provide support to statutory services but do not have a lasting effect. You build something up, you deliver it and you show that it works, but the funding is not continuous and, therefore, you then have to scale it back down or close it altogether. We saw that during the 10-year autism strategy, which sometimes felt a bit like 10 one-year autism strategies: lots of money was put out there for different pilot projects, but how much of that was embedded? I have analogised it to a snowbound airport with lots of pilots but nothing taking off.

That is the problem. If we put money into things, we have to embed the learning that we get from that into the systems that are out there. The evidence is not there to show that that has happened previously. The answer is yes, potentially, if you build on some of the evidence of good examples that exist out there, but there is also a wariness that we have seen this happen before and we have not seen it lead to systemic change across Scotland.

The Temporary Convener: Thank you. I am conscious of time, but I will extend this so that Brian Whittle can ask his questions.

10:30

Brian Whittle (South Scotland) (Con): Thank you, convener.

I thank the witnesses for coming to the committee. Like Patrick Harvie, I am learning an awful lot. I am taken by what Mark McDonald said about everyone having the right to health and the right to treatment to improve their quality of life, and about how, if we ensure that those rights are met, that will have a beneficial impact on resources, education, our economy, the workplace, welfare and justice. He made the point that we seem to take a siloed approach, rather than looking at the benefits across the piece.

There are a couple of areas that I want to ask about, the first of which is the topic of funding and workforce. What are the key funding and resource challenges when it comes to neurodevelopmental assessment?

Bill Colley: When the NHS closed the waiting list for children with a straight ADHD profile, one reason that was given was that it could not man the workforce—it could not find the clinicians to provide the capacity to meet the demand that was coming through. It struck me that that was an admission of poor workforce planning. Over a period of time, it has been very obvious that far more adults—adult women, in particular—would want an assessment. That trend was picked up in America about 15 or 20 years ago. We tend to get America’s weather when it comes across. If that was known about and anticipated, why was it not planned for?

There is an issue with workforce morale. CAMHS is a bit of a Cinderella service. It is a complex area. We must take into account the fact that, as well as undertaking the routine process of diagnosis and assessment, CAMHS staff deal with complex mental health issues, such as self-harm, suicide and so on. I do not think that the workforce is looked after. I am very pro-clinician. A lot of the issues that we face have been caused not by clinicians but by clinical managers. We need to consult that workforce and ask, “What do you think? How could we speed things up and improve things? How can we be more innovative?” There is a good question to ask about that.

Mark McDonald: The issue comes down to prioritisation. Many autistic people feel that their needs are not a priority for statutory services, and when we see pathways being closed, that feeds that narrative.

The committee's inquiry is welcome. However, if any other service that is provided by our NHS was to turn round tomorrow and say that it was going to stop providing assessment and diagnosis for children or adults, that would never be off the news. It would be raised at First Minister's question time every week. Although the issue has been raised, it does not feel as though everyone has rallied round and said, "This needs to be addressed. We cannot be content with the situation." That feeling of a lack of prioritisation filters down. We need a statement to be made to the effect that people across Scotland who require an assessment should be entitled to receive one. In effect, there needs to be a national guarantee.

Brian Whittle: How should we address those shortages and training gaps? How should we deliver that message? How can we deliver practical solutions?

Mark McDonald: That capacity issue cannot be addressed overnight. I get that. However, we have spoken about the broadening of the professionals who can be involved in the assessment process. That is how we begin the process of bridging that gap, which will allow resources to be diverted to training and to filling the roles that will be needed in the future to provide a more comprehensive team and a more comprehensive approach to assessment.

In the first instance, we must take the learning that we got from the neurodevelopmental pathway pilots that were done by NAIT and implement it across Scotland. Best practice is a bad traveller, but there is no reason why we cannot take the learning from those pilots and apply it elsewhere. In the intervening period, we should do an assessment of future need, ensure that the model is sustainable and do the work to build it up to scale.

Rob Holland: I echo what Mark McDonald has said. It is important that we look at the pilots of the national autism implementation team and the work that it did in the pilot areas.

I absolutely agree with the point about the need to expand the multidisciplinary team that can be involved in the assessment process. At the heart of the issue, there is a workforce shortage and questions about resourcing and funding. As well as short-term funding to deal with the crisis that the system is in now, a longer-term commitment is needed, because, as Mark McDonald said, we cannot turn the workforce situation around overnight. That will take time and resourcing.

The next set of questions is about data gathering. That is important in the context of workforce planning and resourcing, because much of the time—short of the odd freedom of information request or the odd press piece—the issues in this area are not well known by the general public. The situation with regard to data collection is different in England, where data on people who are seeking a diagnosis and on waiting times are routinely collected and published quarterly. That aids planning. There is a debate down south about the number of people on the waiting list and the resource that needs to be found to meet that demand, but we are unable to have that debate, because those figures are not publicly available for discussion.

Brian Whittle: You are right—I was going to move on to the issue of data. I presume that not having consistent, high-quality data makes workforce planning more difficult. How would access to high-quality, up-to-date information on demand for services help us to plan and deliver those services? What information do we routinely publish at the moment in Scotland? How does that need to develop?

Rob Holland: No data is routinely published at a national level on the number of people who are seeking a diagnosis or on waiting times. In England, that data is routinely collected and published, and it is disaggregated by region, age, gender and so on. That is the sort of data that we need to have in order to make planning—including planning for workforce development—more effective.

However, that is not to say that local areas are not collecting data—they are. From time to time, organisations such as ours will make FOI requests to seek that data, which results in it coming into the public domain. I notice that the Scottish Parliament information centre briefing for today's session tried to pull together all the bits of data that are out there, but it is very difficult to do that. Of course, not all local areas provide that data centrally, which means that it is very difficult to be confident about the national picture and the numbers.

Mark McDonald: At the moment, when we have a situation in which, in some places, no pathways exist, it is difficult to collect data. In some places, no one is waiting, because there is no waiting list for them to be put on to. Until we have the universality that ought to apply, it will be difficult to build the data to give us a true reflection of the situation that people face.

In addition, data on waiting lists will not provide information about the people who wait for a long time and then choose to go for a private diagnosis. Although those people have come off a waiting list, that does not mean that they have been seen as part of the NHS system; it simply means that they have come off the waiting list because they have sought a private diagnosis. It could also be the case that someone has become too old for child services and is now on an adult waiting list. Data is good to have, but it is difficult to fully extrapolate the stories that lie underneath it, and because some areas offer different approaches, it will be difficult to get data that will tell a meaningful story of the national picture.

We have spoken about the fact that people often ask why the learning disabilities, autism and neurodivergence bill was important for the autistic community, and why we were so supportive of it. We know from looking at people's life outcomes, whether in education, employment or health, that autistic people have significantly poorer outcomes than the general population. There is no equivalent for the autistic community of the Scottish Learning Disabilities Observatory at the University of Glasgow, which collects population data for people with learning disabilities. We think that a similar approach should be taken for the autistic community, which would help to achieve a better understanding of the main issues that affect the autistic community and how those can be addressed through public policy.

Brian Whittle: I have so many more questions to ask, but I realise that we are probably out of time, so I will leave it there.

The Temporary Convener: As there are no further questions, I thank the witnesses for their attendance today and for their evidence. We will have a brief suspension to allow for a changeover of witnesses.

10:41

Meeting suspended.

10:51

On resuming—

The Temporary Convener: We will continue our previous agenda item by taking evidence from a second panel of witnesses as part of the committee's inquiry into ADHD and ASD pathways and support.

As I mentioned at the beginning of the previous session, given that some of our witnesses are themselves individuals with ADHD, autism or both, we have sought to make reasonable adjustments to support them in giving evidence to the committee. That includes providing in advance of the meeting the questions that we plan to ask. If anyone attending the meeting needs to take a break at any point, please indicate that to me or to the clerks.

I welcome to the committee Kabie Brook, chair, Autism Rights Group Highland; Matthew Day, national one-stop shop manager, Number 6 service; Sofia Farzana, director and co-founder, Scottish Ethnic Minority Autistics; and Lyndsay Macadam, chief executive officer, SWAN Scotland. Emma Harper will start the questions.

Emma Harper: Good morning. Some of you might have been in the room for the initial session. I will go with aspects around diagnosis. I am interested to hear from you whether you consider that there are currently diagnostic gaps for neurodevelopmental conditions in Scotland and whether those vary by health board area.

Matthew Day (Number 6): Yes.

Lyndsay Macadam (SWAN Scotland): Yes, there are significant gaps that 100 per cent vary by area. That has changed over the last few years for the worse and few areas have a well-functioning pathway at the moment. The reality in most places ranges from no pathway at all to a pathway that has a high threshold to access an assessment—for example, you cannot get an assessment unless you are already accessing acute mental health support or, in the best-case scenario, there is a waiting list of many years.

Sofia Farzana (Scottish Ethnic Minority Autistics): As everyone knows, in NHS Forth Valley the autism pathway has closed down recently but, if you have significant mental health difficulties, you can go through psychology. It takes someone to get to a crisis point to then have access to an assessment. The ADHD pathway was closed down many years ago, citing shortages of medication. That has been the case for a long time.

Kabie Brook (Autism Rights Group Highland): At the moment, seemingly, each local authority does what it is minded to do. There does not seem to be any oversight or accountability. There is no national plan. A local authority can close a pathway or have its own thresholds for pathways and that is just how it is. It is what everyone calls the postcode lottery.

Waiting lists are the same; they are longer in some areas but in others there is no waiting list because t here is no service. Maybe we will come on to this later, but I will say it now anyway. People are going into debt because GPs know what the waiting times are and they tell people who consult them in order to be referred for assessment to go for a private assessment. Certainly, in my area the waiting list is seven to 10 years and that is not unusual. We have a pathway, although it is not a combined pathway, which I am sure will come up later.

People are spending money to go and get an assessment—although they are paying for the assessment, they might not get a diagnosis; people usually do, but they might not. If the assessment leads to a diagnosis they will go back to their GP and they will be told, “That was not an NHS assessment so we will not recognise it. If it is ADHD, we will not do shared care.” People end up with a piece of paper that they have paid a lot of money for, and that a GP or some other clinician may have told them to go and get. That is not on; it is not good. It happens because there is no national guidance.

Lyndsay Macadam: It is worth recognising that there is not a lack of willingness. Practitioners and diagnosticians want to be able to support and help people, but they are completely overwhelmed because of the way that the understanding of neurodivergence has changed in recent years and they are not able to meet the demand that is out there. They are not able to offer support to people because the support is not there.

It is challenging, is it not? It is incredibly frustrating, usually after many years, to get to the point of starting to understand what might be going on in your life, being able to talk about it and seek support and then not being able to access it. It is equally frustrating for the practitioners, who know what a difference it would make but are not in a position to meet the demand.

Emma Harper: Matthew, do you have anything to add?

Matthew Day: Not really. It has all been said.

Emma Harper: In the previous session, we heard about misdiagnosis, but you are talking about failure to diagnose. Sofia, you mentioned that some people end up in crisis because they cannot get any support or help. I am interested to hear any other examples of the consequences of the failure to diagnose or of misdiagnosis for the people you work with.

Sofia Farzana: An example would be not assessing for ADHD. That is quite a big thing, particularly for women, given the whole interaction of ADHD and female hormones. If that is not seen properly, females cannot access the correct hormonal support.

Another example is being prescribed the wrong medicine. For example, I had a case of someone who was refused ADHD assessment after successfully getting an autism diagnosis and who was then prescribed sertraline, which just made the ADHD worse, to the point where the person sustained an injury because of the hyperactivity and the inability to maintain focus or just have a bit of stability.

The misdiagnosis that is quite often made is for generalised anxiety disorder or bipolar. That is what we get when we are saying, “No, but I think I am ADHD.” That means that if someone is ADHD, they are not being looked at. There is a difference between burnout and depression and sleep issues—because they are also autistic. The person might be prescribed antidepressants for sleep but because of the ADHD they cannot take medication consistently. The whole understanding of ADHD is not there. Not being able to take antidepressants consistently has consequences and the person I am talking about experienced suicidal ideation.

Understanding the high risk of suicide in ADHDers or in people who also have trauma must all come together. Complex post-traumatic stress disorder, ADHD and autism can all be common in one person and not understanding that person holistically will lead to them being prescribed the wrong medication. Unfortunately, that can have bad consequences.

11:00

Emma Harper: I will quickly come to issues of neurodivergence in specific groups, including ethnic minority populations and also women and girls. To what extent do you consider that the current policy and pathways in place in Scotland meet the needs of ethnic minority people and women and girls, for instance, or, as we are hearing, do not meet the needs?

Sofia Farzana: Do you want to take that one, Lyndsay?

Lyndsay Macadam: I will respond, although obviously we can all contribute, but given that SWAN is a charity that is focused on working with women and girls and non-binary people, I will start.

In general, the pathways fail to take gender into consideration at all, largely because they are using diagnostic practices and tools that were developed a long time ago, before there was any awareness or understanding that it was even possible for women and girls to be autistic. Autism can present very differently across genders for a number of reasons.

The tools that are used for assessment and diagnosis are not fit for purpose for women and girls and people of other genders. They do not tease out the way in which autism might present in us. They do not necessarily pick things up. I think that there is also a much lower awareness generally of how autism presents and what the reality is of being an autistic woman or an autistic girl. That awareness is not there among practitioners, GPs, educators, employers, families—or ourselves.

A huge proportion of us have no idea that we are autistic until we are in our 40s, 50s or even later. If we do not have that awareness, it is no surprise that it is not there more widely. Women are more likely to mask and more likely to act in a particular way to try to fit in to society—that is common for women in our society. We live in a gendered society anyway and more so if you are autistic, so it is less likely to be picked up. The understanding, the tools and the openness to listening to and believing autistic women, to pick up what is going on, is not there.

To go back to diagnosis, we are often told, “It is just that you are anxious. It is just your hormones. Why do you not try this and why do you not try that?” That is not fit for purpose. We are frequently dismissed or invalidated when we finally go and seek help.

Obviously, it is costly to resource a massive change in the way that we are diagnosing things and how the pathways are put together, but there needs to be a shift. The diagnostic process is not fit for purpose. It is quite humiliating. It focuses on deficits and on making yourself incredibly vulnerable and talking about all the ways that you fail in society. The impact, however, of not having a pathway in place, in terms of mental ill-health, suicide figures, medication and patient care and the things that Sofia Farzana was describing, is much more costly in a range of ways.

There certainly needs to be significant change so that, moving forward, we are not waiting until the age of 50 or 60 to be diagnosed. Men and boys tend to be diagnosed younger—not all of them, but more often—so there is not a huge influx and burden of people looking for a diagnosis and there is not the impact of living most of the way through your life not knowing who you are, what your needs are and how to have those met. Do you want to add anything, Sofia?

Kabie Brook: I have got something to say. Do you mind if I go first? I am short, in all ways. [*Laughter*.]

I agree with what has been said. The crux of the matter, for me, is that it would help if diagnosticians kept up with research and learned about what it is like to be autistic, from all kinds of community groups, so that they have a relationship with and an understanding of autism from the inside. Clinicians do not tend to have autistic friends and a lot of them meet autistic people only in the clinic, which is a scary place. They have the assessment that they have to go through and it is all very sterile. It would be of benefit if they could get out into the world a bit more. I know that that sounds weird. It is also about recruiting diagnosticians from different backgrounds—actively encouraging people to go into the field so that they can relate more to the different people who end up sitting in front of them for an assessment.

Sofia Farzana: I was approached by a person who wanted to look into assessments and the first thing that he asked me was, “Do you know a clinician who either is minority ethnic or has experience of work with minority ethnics because I want to be assessed by somebody who understands me better?” The answer was, “No, I do not know anybody who is a minority ethnic who can privately diagnose.” As Kabie Brook just said, we significantly lack representation and understanding from the inside.

The first barrier that I have seen since working with SEMA is that, in our communities, people are not encouraged to seek an assessment because of the lack of understanding of autism and ADHD. Secondly—Lyndsay talked about masking—there is also code switching for minorities. Masking is extremely high if you are black or brown and female, because of the way that, in our communities, the gender roles are so defined. A lot of the autistic women that I speak to say that they have been told since childhood that they are too masculine to be girls.

In a lot of cultures—it is almost akin to applied behaviour analysis—we are trained to behave in a certain way, observe customs and not be true to ourselves. We get to a point where the mask just slips, we hit a crisis point, we do not know what is happening, we cannot connect with our own communities and we are struggling with work, home, relationships and education. On the surface, it looks like racism and it is; a lot of the time we are facing that prejudice. When we ask for support, the difference in our culture as autistic people is put down to racial culture. Just yesterday, I heard about that again.

There is a thing called autistic culture and it is only when you are with autistic people that you understand that it goes across different cultures. We are first judged by the idea that there is a different way of doing things because we have a different ethnicity, but there is also a different way of thinking because we are neurodivergent. There are layers there that we have to uncover before we can start advocating, using the right language, to seek assessment.

When we are at the assessment asking a GP to refer us, we are told, “But you have done so well so far. Why would you want an assessment?” I have had lots of people from our support group saying that they have been told, “You have children, you have a degree and you are working well. Why do you need an assessment here?” When you are sitting in front of the person doing the assessment—the clinician—you are asked about your support needs. Somebody like me—and I can only give myself as an example right now—is told, “You don’t need any help because you talk well; you speak eloquently.” That is the first thing that we get, from our own community and from professionals.“You speak too eloquently.

You do not need support. Why do you want a diagnosis? You look after yourself well, so your support needs cannot be that bad."

Given how I am dressed, no one can assume when I last brushed my hair. I have it tied up, so who knows? The way I dress is all masked up and that is my culture and I have been brought up in a way to mask everything anyway. It is a complete lack of understanding when a clinician says, "She does not have high support needs" and does not even acknowledge that support needs can fluctuate. They presume things and they do not understand.

I said that to the psychiatrist who did my diagnosis. He said, "You must be very mild". I said, "I am not mild when I cannot speak, I cannot drink water and I need help but do not have anyone to help me. If I have got to this point in my life where I have a degree, a business or I am working with my children, you do not understand what it has taken. You have not even asked me how many times I have been suicidal before getting to this point." Those questions are not asked. We have got to this point for survival's sake because, as racialised autistics or as racialised people, we have just been told to get on with it.

As kids, when we used to have the P word shouted at us and all that, we were just told to put our heads down. You cannot ask for help. You cannot ask for support. You cannot put your head up because you will be put down, because they will kick us out at any point. I heard that as a teenager, I heard it last year and I heard it last month. Why would we put our head up and ask for support when we know that we are not understood? We are marginalised from so many different angles.

Emma Harper: I have a final question. Is there work under way to improve diagnostic tools for allied health professionals? We heard in the previous session that they reduced the waiting list from four years to six months and that it was basically the speech and language therapists who took on the role of doing the assessment. Is there work under way to improve diagnosis?

Matthew Day: There has been. Certainly, we have been assessing for about five or six years and we had a contract in Edinburgh. After we had been doing that for a couple of years, the waiting list was a few months, but that work has stopped. There are pockets of things out there, but the trajectory is downwards: waiting lists are being closed and I do not see a lot of training on new ways of thinking for the people who are doing assessments in the NHS. I do not see any of the things happening that Kabie Brook mentioned about clinicians embedding themselves a bit more in the autistic community and getting a broader understanding rather than just a clinical one. I see that going backwards.

Lyndsay Macadam: There might be some changes happening that are down to specific practitioners, who, as you said, might be a bit more aware. They might be autistic or neurodivergent themselves, or have autistic or neurodivergent people in their lives, and so have taken the burden on themselves to make an effort.

There is work being done currently by the national autism implementation team to look at changing pathways, but there is such an issue with there being pathways and assessments at all that nobody has taken a step back to look at whether we can change the tools that we are using and make this a better process. There is no space for that right now. The focus is so much on, "My goodness, can we even handle this?" and there is no additional capacity to look more broadly at the tools that are being used, because the tools that do exist are not even being used in most cases.

However, I think that doing that could make a huge difference. There is a need for more education and understanding and a little bit of space and investment in that time. However, as Matthew Day said, at the moment the trajectory is moving far away from having space for that kind of reflection and improvement.

Emma Harper: Thank you.

Carol Mochan: Thanks very much for coming today. I will cover theme 2, which is the impact of receiving a diagnosis or waiting a long time for a diagnosis, and I know you have touched on that in responding to the first questions. What is the role of diagnosis in a neuro-affirming society? How much difference does that make?

Matthew Day: How would we know? I do not think that we are in a neuro-affirming society, so I worry about that question a bit. The potential implication of an answer that diagnosis does not have a role in a neuro-affirming society is that it will lead commissioners of services to think, "What we need is another campaign of awareness raising, because that is all we need and we do not need diagnosis." We are not in a neuro-affirming society, so I find it a difficult question to answer anyway, but I worry that, if that is just what we are aiming for, we will not think about diagnosing in the meantime.

Kabie Brook: I found the question confusing because I did not know whether you were implying that you thought that we live in a neuro-affirming society, which we absolutely do not. I do not think that I know any neurodivergent person who would say that we do. If we lived in a neuro-affirming society, life would be so different. We would know when we got there whether the role of diagnosis was still important, but it definitely is now and we know that now. It feels as though we are a million miles away. We can have small islands of neuro-affirming practice, but we could not say that we are a neuro-affirming society.

11:15

Lyndsay Macadam: There are two different questions there. One of them is, what is the role of diagnosis for neurodivergent people to survive and thrive in our current society, and the other is, how must society change to become neurodiversity affirming? They are two different things, and I do not think that we could answer the question about diagnosis in a neuro-affirming society—we were all challenged by it.

My personal view is that, yes, on paper, we should not need to be medicalised and pathologised for who we are. A few decades ago, people were diagnosed as being gay and we have realised how ridiculous that is. However, currently, this is the model that we have and it is fundamental to affirming and confirming people's identity and to enable them to move forward, generally by putting their own support and information in place. We cannot say that it is fine and that we do not need diagnosis, because we are absolutely not there at the moment, but alongside that we need to think about how our society can change to recognise neurodivergence as a normal part of humanity.

We are all neurodiverse in this room. Some of us are neurodivergent and some of us are neurotypical. We are all neurodiverse in the same way that we are culturally diverse and in the same way that the world is biodiverse. Neurodiversity is normal and natural but, as humans, we do not like that. We like things to be the same and, currently, we are in a position where we are not neurodiversity affirming; we are very much othering anyone who is not neurotypical. That is what needs to change but, in the meantime, we need diagnosis to be able to access the support that we need.

Sofia Farzana: The question ignores the fact that we still have disabled bodies and we still need assessment on needs that will fluctuate throughout our lives according to whether we are male or female and what part of our lives we are in—for example, pre-menopause or menstrual. We might have hypermobility. There are so many parts of our bodies that need extra support and help and for that we need an assessment of needs.

It does not matter how accepting the social model of disability is, it still needs to take into account that individuals have needs and need to be looked after and will need certain therapies and medications to help them get along with their day, just like every other disability. It is a hidden disability, which is why it gets overlooked.

Carol Mochan: I appreciate everybody's responses and it gives us a lot to think about in how, when we are reporting back, we place those things.

One of the other questions that I had was about what impact a neurodivergent diagnosis can have on people's mental health and wellbeing. You have brought that in already, understandably, so I might put that back to people but also ask what actions would enable neurodiverse people to access support to improve their wellbeing. What could we be doing now to help improve people's wellbeing? If anybody would like to add to that, I would appreciate it.

Kabie Brook: I was hoping that you were not going to skip those questions. I will start with what impact a diagnosis can have—there is a bit of a difference between diagnosis and identification, but that is more to do with the previous question. The impact is massive. It is about knowing who we are and being able to understand ourselves and understand what is going on for us as a way to get our needs met. Everyone has the right to know who they are, and everyone has the right to know not where they have come from, but maybe where they are going.

Before identification, it can feel as if we do not fit in, we are wrong and everything that we try is doomed to failure. That is because right from nursery age—right from the time we start getting out there in the community—we are constantly told, “I do not know why that is so noisy,” “I do not know why that is so scratchy,” and “I do not know why you are upset; other people do not feel that way,” and we do not know why. It is like a slow indoctrination in the view that you must be wrong: if everyone else does not feel that way, it has to be a problem with you—it has to be something wrong with you. That can lead to very poor mental health and suicidal ideation and sometimes to people going through with that.

In a way, it is like it is for any minority group. It feels as though we are constantly being pointed out by the whole of society and then people say, “It is your fault”. It is not our fault. As Lyndsay Macadam said, humanity is diverse and we are part of that. There is not anything wrong with us. We might need some support and some people might have particular needs, but everyone in this room has needs; it is just that they are different needs. I think that I might repeat myself so I will not do that. However hard we try, we are seen as wrong, and an identification or a diagnosis of that can be a relief.

More funding is needed to enable more support and improve wellbeing—that is a big thing. There should be better training for clinicians and less gatekeeping to assessment—it is so difficult even to get on to a waiting list. It should also be recognised that needs are not wants. We do not just want things; we need them. There needs to be bigger understanding from society as a whole.

There also has to be a change in the education system. We have to do something pretty huge with the education system. At the moment, right from a young age, children are not able to access education—it has a knock-on effect for the rest of someone's life if they get all those negative messages and are not able to access an education.

Lyndsay Macadam: If you will permit me, I would like to back up and illustrate what Kabie Brook said with a couple of quotes. These are not things that I had prepared for today. They happened to come over my desk on Friday because we were putting together a funding report. This is people talking about the difference that diagnosis made to their wellbeing. I think that it is important to bring that out, while we are here talking from our own experience.

These are literally the first few quotes that I was handed by a member of staff on Friday. These are people talking about the impact of a diagnosis:

> "I don't hate myself any more."
>
> "I was an inpatient. My mental health team are so happy now because I have found words and understanding to my life that I did not have before."
>
> "I am relived at finding that, after all these decades, I am not strange or stupid. I am just autistic."
>
> "It has made me realise I am not alone in the way that I think and experience things and I feel understood for the first time in my 40-plus years and so my depression has less of a hold on me and, last year, I tried my hardest to disappear from a world that simply did not want me. Now I have a space and people that have said that it is more than okay to be me. I do not quite know who me is yet but it feels okay to stay in the world and start looking."

I hear that every day and it still makes me emotional to hear it—to hear that something so simple is so incredibly huge and life changing for people. It absolutely illustrates what Kabie Brook said: that we have had this minority stress that has built up all the way through our lives that there is something wrong with us, but if we just understood that we are perfectly normal neurodivergent people, it would change an awful lot. There needs to be an investment in that and an investment in doing some difficult reflection as well on where there is gatekeeping, where we are listening to and involving neurodivergent people and where we are moving beyond inclusion and tokenism.

It is challenging, but there needs to be an understanding that people need to be able to be truly safe to be openly neurodivergent in public roles, in employment and in education, so that there is more real visibility and not just celebrities on television. I am sure that we all know people who do not feel comfortable in disclosing their identity; we know very well that there are people in this building who do not feel comfortable in doing that because they know that it will affect their careers. If there was more safety in doing that, people would see themselves reflected in other people and they would see the lives that they are safe and able to have, and would feel less wrong. It would have less impact on our mental health.

There is some hard work to be done in society to do that and to create spaces where people are able to do that and to have people leading on some of those areas of work. When we are going out and talking to allied health professionals, when we are creating neuro-affirming communities of practice, where are all the neurodivergent professionals who are leading those areas of work, creating that safety and visibility for people to understand that they are normal, they are valid and it is okay to be who they are because we are all surrounded by people who are different and have different needs?

Carol Mochan: Thank you, and thanks for sharing the quotes, of course.

Sofia Farzana: Going back to what Kabie Brook said with regard to access to school, I note that a report that came out last year, I think, said that more than 90 per cent of home schoolers or home learners are autistic. It is no wonder that the majority of people who cannot access school are neurodivergent or autistic.

There was quite a lot in your question; I do not know what order to put my answers in.

The reason why a diagnosis is necessary comes down to the issue of not being believed. If you are not being believed as an autistic male or an autistic female, imagine what it is like being black or brown and autistic. Your assertiveness is perceived as aggression. When you are pursuing medication that you need—it is not a want, it is a need—there is a perception that you just want meds, and you are only there to get a prescription. That is what actually happens.

There are many layers. Knowing that you are autistic or ADHD improves relationships because you know yourself better. It will help you understand that, for example, you are in a relationship that is not good for you, and it will empower you—because you have improved mental health, you have a better understanding and you are around people who understand you—to be able to say, "It's not just me." We know that ADHDers attract narcissists like nobody's business.

There is a lot of information about this area. We are living in 2025, and people are sharing their experiences more, and practitioners from all sorts of fields of support need to join all of that up. Autistic people have the highest rate of suicide and the highest rate of abuse, including domestic abuse. If you put those statistics together, you should not be surprised that it is quite common for somebody who is neurodivergent to also have complex PTSD.

We need to have proper holistic support services. People in our community groups are now interacting with five or six different professionals to get support because they are in burnout and crisis mode. It gets to the point where, because things have got so bad from many different angles, there are too many professionals involved, with people from the courts, the police, social work, education services, speech and language therapy, occupational therapy and the school all working with one family. The situation becomes profound at that end point. What are you supposed to do?

We have not yet mentioned the issues within families where children and adults are autistic. Consider the issues facing a parent or carer who has their own needs because they are autistic, they are in an abusive relationship and they cannot access employment because the recruitment processes are so linear—even last week, somebody told me that they could not get a job because their answers were not sequential, even though they had said, “My answers will not be sequential because I have ADHD”. If we cannot access jobs, we will not have financial or housing security, and, if our autistic children have education issues and face barriers to accessing school, we are not believed because we are seen as the problem. That is what our families are facing.

There has to be a holistic understanding that the situation is multidimensional. We are multidimensional humans. There must be a more joined-up understanding of the issues, and that comes back to holistic training. It is not just about taking a neuro-affirming approach; we must also have anti-racism practices and universal design. We need to be inclusive because those are all connected systems of oppression that need to be addressed.

Matthew Day: A lot of good stuff has been said. We hear the kinds of things that Lyndsay Macadam talked about all the time, and it chokes you up.

A diagnosis is important, as is the impact of not having a diagnosis. For a lot of neurodivergent people I have worked with, the impact of not getting a diagnosis earlier was that they ended up in prison or, in the cases of many women who were seen as seeking a diagnosis too aggressively, were diagnosed with borderline personality disorder, which is now termed emotionally unstable personality disorder. When we met those women, it was clear that they were autistic, but the way that they pushed for their needs to be met had been seen as symptomatic of a personality disorder.

11:30

There are definitely issues with more women finding it difficult to get to the point of diagnosis earlier, but there are also class issues, which can affect parents who are not as articulate as others. I often see women in their 20s or 30s whose parents suggested that they might be autistic when they were at school, and the first thing that happened was that CAMHS sent a letter to the school asking if there were any problems. If there were no problems at school, because they had kept their heads down, the situation was seen as being a parenting issue, and the parents were sent to parenting classes. I know a parent who was taken to court for not sending her daughter to school. I have spoken to her daughter, who is now an adult, and she told me that she could not get out the door and that her mum used to try to drag her to school. However, instead of being given help, that woman was taken to court. So, you can see that not having a diagnosis can have a big impact.

Joe FitzPatrick: Good morning. You almost came on to the area that I want to talk about, because I am interested in training and understanding in a wider context. We know that GPs are the gatekeepers, but everyone interacts with a lot more folk in public life and across society. Is there something that we or the Scottish Government could do to address some of the misinformation that is out there, and the stigma and discriminatory attitudes that neurodivergent people experience?

Kabie Brook: One of the things that springs to mind is schooling. I am not a fan of segregated schooling. I do not mean that all children should be sitting in a classroom at a desk doing the same work all together; I mean that we need to reduce class sizes and start looking at the schools as mini communities. Everyone should be able to go to their local school and the school should be able to support everyone who goes there, but that takes smaller class sizes and increased funding. I acknowledge that there is a crisis in relation to pupil support assistants—it feels as if there is a crisis in everything at the moment.

It seems to me that if you do not have an integrated school and if you are not teaching children from a very young age about what society is and who the members of our communities are, and if some people end up being segregated because they cannot manage to access school, school will continue to be a hostile environment for many neurodivergent people. That is not too strong a word: it is hostile. It is awful for many, many reasons. Also, this has already been said but you cannot tackle only one form of stigma or discrimination; the approach has to be holistic—you have to look at everything.

Sofia Farzana: I am a teacher, so I would stress the importance of teacher training. A lot of the young people involved get missed in primary school, and the transition from primary to secondary school can be quite traumatic, especially as that is when they become more apparently autistic or ADHD, as well as when adolescence hits.

Teacher training needs to be improved. The relevant training needs to be delivered by professionals who are themselves neurodivergent. It should not just be co-produced—that is not good enough; it needs to be delivered by professionals with lived experience. I would say that you should not have a white person giving anti-racism training or a man giving training on menopause, and it is the same with this.

There needs to be training and there needs to be representation, because then we will have teachers who are neurodivergent in our schools, rather than those who manage to get in by some luck but cannot stay in because the same hostile environment that affects the children affects those teachers. Where is the progression? If they are in the decision-making spaces, they can make more inclusive and holistic decisions that will improve the communities. Schools are mini communities that reflect the outside world.

There needs to be more representation in the Scottish Government, too, as that will naturally lead to more insight and an understanding of what needs to change, because the Government will be able to see the problems from the inside. It is important to have people with that lived experience who have the ability and power to make the necessary changes and decisions.

Lyndsay Macadam: I absolutely agree with what Sofia Farzana said, particularly that last point. The point that Kabie Brook made about people going out and meeting more people who are neurodivergent and developing those natural communities is important. We learn through empathy and understanding. We all change our hearts and minds because we get to know somebody. We say, for example, “Oh, I get it now. I understand that you will feel terrible after sitting under bright lights.” It can be as simple as that—it is not always a huge drama. If we all feel safe to express things like that, we will start to learn about one another and we naturally develop that knowledge.

Aside from education, another area where I see huge issues is in the workplace. There is a massive focus on getting autistic people into work—quite rightly so, because the unemployment figures are incredible and horrendous—but it potentially means that we are seen as being valid only if we are contributing to the economy. There are huge numbers of autistic people who are incredibly successful in their careers but who end up being unable to sustain that employment because of bullying and harassment. As Sofia Farzana said, there are statistics that back up all of this. For example, 50 per cent of autistic employees report experiencing bullying, harassment and discrimination at work.

I work with a number of incredibly high-level professional women, most of whom at some point end up facing disciplinary action at work and/or going off with mental health issues. Those disciplinary actions tend to be based on a complaint about somebody not liking the tone that the person used in an email or the way that they gave feedback to somebody they were supervising. Meanwhile—because of the type of society that we live in—men, whether neurodivergent or neurotypical, are allowed to be assertive, blunt and straight to the point. Women are expected to be softer, do the social housework and be gentler. It is a challenge that we all face in the world of work. If you add to that being autistic and communicating, moving and acting in a slightly different way—a bit like the person who was mentioned earlier who was seen as being aggressive for being very focused on what they were doing—it does not fit and it does not sit well.

A lot of autistic people excel in their jobs and it makes other people uncomfortable because they feel like we make them look bad. We have real attention to detail and tend to be perfectionists, so it can cause issues such as bullying in the workplace.

We need to look at both ends of that spectrum within employment and consider not only people’s ability to access employment—by which I mean appropriate employment for their skills, rather than jobs that result in their being underemployed—as well as their ability to sustain employment. There needs to be a real change. In principle, the employment law and equalities law that we have in place means that we are allowed to ask for adjustments, but we all know that the reality is not the same as that, and that people are ending up out of work or unwell and on medication because of what they are facing.

The answer to that is not simple but it feeds into everything else. We need a change of attitude and understanding, and societal change, so that we are able to be a bit more open about who we are and to learn from one another. In the focus on employment, we need to think a wee bit more broadly about what the reality is for people, because the situations that people face—the bullying, the othering and the constant battles—follow them all the way through from school and higher education and into employment, if they are lucky enough to be in employment or are in a position to be able to do that.

Matthew Day: I do not have a lot to add. The first thing that I always ask when I am asked about what can be done is, “What resources do you have to do it?” That would be nice to know. However, it is not all about resources; it is also about attitude and culture.

As I mentioned earlier, we know people who work in the Scottish Government who do not feel able to tell their employers that they have a diagnosis. I diagnosed a man who did not even want the letter to be sent to his GP, because there might come a point where people can access GP records, which might mean that the Scottish Government or their employer would know that he is autistic. I know that getting things right in-house is not easy—and every employer will have to deal with these kinds of issues—but it is important for the Scottish Government to do that before starting to think about external matters.

Joe FitzPatrick: We have heard in evidence that organisations, employers and public services sometimes do not use the right language, and that the language that is used reinforces the discrimination and stigma. I want to give you an opportunity to say how that can be rectified. Do you have any thoughts on how we can improve that situation?

Kabie Brook: The language that people use is important because, whether consciously or subconsciously, it informs their actions and the way that they think about things. I feel that there is an elephant in the room that no one has mentioned yet. The title of your inquiry includes the term “ASD”, but that term tends not to be popular in the autistic community. We have moved away from using it.

Part of it is about leading by example, but you have to be in contact with neurodivergent people’s organisations to be kept up to speed, if that is the right term. As you would for any minority group, you have to be sensitive to the language that is being used in the community and know the right words to use and the right ways to use them. It is important for that to happen across the Scottish Government and the Scottish Parliament. I have noticed that are differences. One area will use certain terminology and one of us will try to encourage it to use slightly different language, but then the next week we will see it pop up somewhere else—a different department or whatever will be using the terminology again.

The Scottish Government and the Parliament should be trying to get it right. They have been doing a better job more recently, but the title of this inquiry is a bit odd.

Joe FitzPatrick: Let us get the elephant sorted. If we have made a mistake, the committee has not done that deliberately and it would be good to hear what the preferred terminology is.

Kabie Brook: I would not have used the term “ASD”. I cannot remember the full title of the inquiry, but it should probably just include the term “autism”.

Lyndsay Macadam: The term “ASD” means autism spectrum disorder. We do not consider ourselves to have a disorder, and most autistic people do not. That is old medical language. Language changes, but in the community at the moment, there is generally a preference to say that we are autistic people rather than people with autism. It is just the type of person that we are; it is not a thing that we caught and we might get rid of. I guess that this could be called an inquiry into ADHD and autism pathways and support.

Kabie Brook: Or an inquiry into pathways for autistic people; the title just should not say “ASD”.

Lyndsay Macadam: It gets complicated linguistically when the two terms are put together. Some people use “ASC”, which means autism spectrum condition, but, again, that suggests that it is an illness or something that people have acquired. We really have to move past that, because it is inaccurate. It is like the difference between Macs and PCs: it is a different operating system and not a wrong one, as it has always been considered to be. We would generally suggest using the term “autism” rather than “ASD”, much as that might be the medical terminology.

You are absolutely right to be open to having that conversation, and it is the same for us. It is important to be able to have the conversation openly and ask people. It is the same with any minority language: if you are not sure, you should ask somebody what language they prefer to use.

Joe FitzPatrick: That is really helpful for us. It sounds like just a few letters and a word, but it is deeper than that. You expressed the difference between saying “a person with autism” and an “autistic person”, and you explained it really clearly. That is helpful for the committee and it is something for us to consider. This session is clearly a bit of training for us, in the wider sense.

The whole morning has been really good and the evidence has been helpful to us. How can we get that discussion going in wider society and particularly in public services? Everyone who works in public services will come across autistic people daily. How do we make sure that more people understand the right words to use and what will make a difference to ensure that someone who is autistic has a more positive experience? It will then be a more positive experience for the people on both sides of the conversation or transaction.

Lyndsay Macadam: It is a big question, is it not?

Sofia Farzana: It is.

Joe FitzPatrick: It is. You can take it in whichever way you want.

11:45

Kabie Brook: I start by saying that you should lead by example. You should try to get things right in your workplaces and constituencies and among the people who you work with, and you should go out to meet people and talk to them.

There are small things that can be done. Service providers, including the NHS, should be listening to what works. They should be listening to people who have had a good experience, finding out why it was good and using those islands of good experience to educate other departments or areas in the NHS. Breast care is often really good, because of the way that staff talk to you, the information that you get beforehand and the way that they do things. People often say to me, "If only they did it like that in other departments in the hospital". They can get it right in one place, but not in others. For some reason, occupational therapists seem to be the best—

Sofia Farzana: And speech and language therapists. I find them to be the best.

Kabie Brook: Yes. Staff in different roles should share experiences and work out how to get it right by asking autistic people or other neurodivergent people who use those services, because we know how it goes right and how it goes wrong.

Lyndsay Macadam: I do not know whether you are planning to ask about training separately, but it moves into that area as well, does it not?

Joe FitzPatrick: We can cover that now.

Lyndsay Macadam: We are looking at mandatory training as part of the learning disabilities, autism and neurodivergence diversity bill, or whatever we ended up getting it called. There is discussion about having two-tier mandatory training for people in the public sector, which is appropriate. However, we need to get that absolutely right because, otherwise, it will be a waste of time.

At the moment, there is a focus on training being for people who we think will come into contact with autistic people, such as the OTs and SLTs. They get it right because that is their profession and they want to be good at it. However, we need to remember that autistic people get cancer checks, have babies, break their legs, turn up at accident and emergency departments and go into in-patient care. Training on treating people well and listening to them, for example when they are in hospital, makes an enormous difference, but we must remember that that training needs to be for everyone, because we are everywhere. We walk among you. [*Laughter.*] We access the public sector. We turn up at the council to pay our council tax and so on. We need to look broadly and remember that staff need to be aware of language and to listen to people wherever they are. If somebody says, "I can't be in a big, busy ward because I'm autistic", it is a need and not a want. That is a really good phrase.

As the second tier, more in-depth, specialised training needs to be delivered to the right people. For example, specialised training is needed on perinatal, pregnancy and childbirth care; acute mental health care; and people turning up in accident and emergency departments in crisis. Where are we arriving? Where are we seeking support for domestic abuse? Where are we seeking support for eating disorders? That is where we end up when we get into crisis, and the understanding of how we present in those situations needs to be invested in. Work on that is being done under the LDAN bill, but it is important to get it right.

I go back to the point that that has to be led by neurodivergent professionals. That is not us sitting here touting for business; it is just true. As Sofia Farzana said, you would not go to a white woman to talk to you about black women's experiences. You would not necessarily go to a white man to hear about menopause if you had the choice of going to somebody who has that lived experience and is also a professional. We attend a lot of meetings in Government where we say that, but it is not heard properly. It is very challenging, because it is difficult for us not to get to the point of thinking that we are maybe saying it too often and just being difficult. There seems to be a barrier to people understanding that there are loads of autistic surgeons, social workers, politicians, elected members, council leads, nurses and midwives out there.

There is a contractual process that has to be gone through—I understand that things have to go out to tender—but if people just respond to a clause that says "You have to involve autistic people" by going and getting a wee quote from somebody and sticking it on a slide in the training, it will not be as effective as the training being delivered by somebody who has professional experience, lived experience and an understanding of how to go out and involve more people.

If that can change, it will be fundamental to the community and to autistic people. If we go back out to the hundreds and thousands of people that we work with, between us, and tell them that, after all this work, mandatory training has been put in place but it will be delivered by a load of folk who have never met an autistic person in their lives, people will just walk away and say, “Here we go again—it was a waste of time.”

We have an opportunity to get it right. In Scotland, we do well at that. We do well at looking at where things have gone right and wrong and doing things differently. It is important that people can trust the process and have trust that they are being seen and listened to. If we start to listen to neurodivergent people and involve them in leading the right bits of work, that will create a significant change on all levels.

Sofia Farzana: My head just keeps screaming, “Implementation!” It is not just about listening—we need implementation. It is not just about me saying what we need; it is also about you taking action on it. As Kabie Brook knows, we have been talking about this for a long time now, but movement is so slow. The people who can implement it do not implement it because they do not want to implement it. They are complacent. They do not understand what Lyndsay Macadam has just described—the value of it.

I spent 10 to 15 minutes with my child’s pastoral teacher talking about his needs and about our experiences and our lives, and she fed back that she had learned more about being autistic from talking to me, as a parent and a teacher, than she had learned in her whole career as a pastoral head in middle management. That is because I was talking about lived experience from the inside.

Language prefaces everything and it can determine whether we will get rid of prejudice or whether it will be enhanced. In our communities, we do not even have the language. When we try to talk about being autistic and what it is like, it is so deficit based. It is so colonial and so capitalistic. We need language to identify our real, authentic experiences in order for us to go forward and have the ability to access support and care.

At the risk of repeating what Lyndsay Macadam said, I cannot emphasise enough that, when it comes to the provision of support and care by the NHS, the police and so on, the ones who do not want to do the training are the ones who need to do it. That is the problematic part. I did training on autism as a teacher, and that is when the penny dropped. I thought, “Oh—that’s my child, and that’s me.” If I had not done level 2—if I had done level 1 and walked away—I would not have known any better. It was at level 2 that I got all that understanding of me, my child and my family, and that is how our journey started.

That training was not taken up very well in my local area. Not many teachers will find the time after work to go and do the training, because they think, “Why do we need it?” You need to understand that those who need the training are not just those who are voluntarily signing up. They are already good at what they do because they sign up for those things. It is the people who are prejudiced enough—and arrogant enough—to think that they already know what they need to know who need the training. The truth is that they do not know what they do not know. We need to make it mandatory and authentic. That is the approach that we must take.

Joe FitzPatrick: I do not know whether Matthew Day or Kabie Brook want to add anything, but I am conscious that we are running short of time, convener.

The Temporary Convener: As we are approaching the end of the time that has been allocated for this session, I ask the witnesses whether they are happy for me to extend it to allow all our questions to be asked and your evidence to be taken by the committee. I see lots of nodding.

Elena Whitham: As a neurodivergent politician, I can absolutely tell you that this place is not yet neuro affirming—there is a long way to go. It is really good to hear the way that you all have articulated the journey that we are on.

We are short on time, but I want to spend a wee bit of time on transitions. Some of them have been mentioned. We have the transition from child disability payment to adult disability payment, the transition from primary school to secondary school, and the transition involving the hormonal journey of a woman throughout her entire lifespan. Is there a need for a transitions framework for neurodivergent young folk? When people move from child to adult services, a lot of the time, they end up ageing out. They can be on one waiting list and then end up at the bottom of an adult waiting list. It feels as if there is no standardised approach across the country.

Kabie Brook: We definitely need that framework. There should be one, but I would be concerned that it might not be implemented. We already have a lot of legislation that is ignored such as ASN legislation. We definitely need a framework, but we need one that people will use.

Elena Whitham: That is to the point—absolutely. Does anybody else have anything on that?

Matthew Day: The questions mentioned the NHS Lothian framework. I have been around long enough to remember the transitions team in Edinburgh, which was called Aspire and was disbanded. It did some great work for children hitting the age of 16 or 17. I think that the team could work with people up to the age of 24 to help them to access adult services and think about where they were on the lists for children and adults. That team was disbanded, and now the area is looking at a similar way of doing things. I am not saying that that is not good, but we often have had good bits of practice that, because of money or political choices, were cancelled. Then something is presented as a new way forward when it has been there before. Those are not new ideas. However, we definitely need transition—

Elena Whitham: Can you explain a wee bit about what happened to people when that service or provision was stopped? Can you give a wee bit of context?

Matthew Day: From my experience, there were a few workers at Aspire who would work with people in school and bring them into the one-stop shops that we manage, and support them to access some of the groups. They were 16 or 17-year-olds who were maybe not so confident, and there were also older people in the groups. There was a lot more service use from those people. We noticed that that dropped off and, at that point, we did not know who the people were. We knew that there were people at school, but we did not know who the individuals were, unless they were supported to access us. It took a while—until we were involved in diagnosing some 16 and 17-year-olds—before people in that age range were using our services as much as they were when the transitions team was in place.

We noticed their absence more than anything but, because we did not know who they were, I can only guess at the impact. People were not using services. They might have been given a leaflet, but they were not being supported to transition in the way that they were in the past, and therefore the leaflet was going into a drawer, people's mental health was probably deteriorating and so on. A lot of people—although not all of them—need a bit of support to access that transition, rather than just being given information about where they can go.

Elena Whitham: That is powerful for us to hear. There is a big difference between being handed a leaflet that has support information on it and being supported to access that support. Are young people getting adequate support in the transition phase? I can see Sofia Farzana saying, "Absolutely not." Is there an urgent need to ensure that the support that they should be getting is being delivered?

Sofia Farzana: When you talked about leaflets, I wrote down, "Relationships—lack of." There need to be relationships with people between the ages of 16 and 24 and who are in that transition. They are not just transitioning out of school; they are transitioning into work or education, and as soon as you are 18 you are an adult. You are expected to call a GP and make appointments. To be honest, it is hard for an older adult to get a GP appointment, let alone somebody who has just entered the adult world. When it comes to moving out of home, with all the bills and so on, there is so much to consider. If you have a relationship with somebody, they can provide the help that you got beforehand with, for example, sleep or with moving from child disability payment to adult disability payment, or even with caring issues, if you are a carer. Again, we need to think about autistic families.

Relationships are not there, but that is what we need. We need someone who we can trust and can talk to. We need consistency. You do not have that when you leave high school to go to college or university. You have been supported all your life, and then all of a sudden you go to tertiary education and you are back to square 1, advocating for your needs in a completely different setting where everyone is an adult but you are just new to the adult world.

12:00

Lyndsay Macadam: It is important to recognise that these things are even more difficult for neurodivergent people. They are difficult for everybody. It is difficult for everyone to become an adult and start advocating for yourself, calling the GP and doing all the things that you do. However, for autistic people, whether an adult or a young person, going to an organisation where you do not know anyone, you do not know where the building is and you do not know what will happen is incredibly difficult and the chances of you doing it are next to nothing. With a lot of adults who access our services, we realise that we have to pre-meet them or have a call, and maybe we do a handover or a joint meeting with a support worker, therapist, friend or family member to build trust. That is just when people come to us as an adult as part of that transition.

I am sure that there is not a health and social care partnership in the country that would not like to have that in place, but the reality is that, if you have been on a CAMHS waiting list for six years, you have still not been seen and then have aged out of it, you will go on to another six-year waiting list. How does it work? How can that pathway and that handover happen? Again, it comes back to resources.

The point is important. It is a big transition period in life, and we should be aware of that. It is the time when you are moving out of a held period of your life when you have a parent and carer and educators who make decisions for you. You go out into the world and try to succeed in higher or further education or employment, and you might be trying to succeed in relationships or as a parent.

That is when you can fall through a massive crack and, much further down the line, end up in crisis support. The cost impact of that is much bigger than the cost of having a handover at that earlier time so that you learn to access services, build a community around you and are supported across that, rather than being left to try to face something quite insurmountable. Particularly for those who do not have family support to advocate for them, what happens to them?

Elena Whitham: Thank you very much. That clearly set out the early intervention and prevention stuff that happens during transition.

The Temporary Convener: To what extent is clear and consistent information provided to people who are seeking a diagnosis of a neurodevelopmental condition? Is there scope for improvement? How does the support and information vary across Scotland?

Matthew Day: It certainly varies across Scotland. I know of some areas where there is a bit of information along the way but, in most areas that I am aware of, if you are on a list, you might get a letter telling you that. Then either that is it or any other information that you get is really a way of seeing whether you reply so that, if you do not, they can take you off the list. It is a letter asking, “Can we check that you still want to be on the list? You have four weeks to tell us, otherwise you’ll be removed from the list.” That happens in a few areas, and it has happened for a long time. Some people take longer than that to think about opening the letter, let alone dealing with it, so some people get timed out of being on the waiting list. Very few people get much information at all.

Some areas that I know of run groups for people on a waiting list to give information about what assessment there might be or what might be available afterwards and that kind of thing. There is now a big drive in many areas, and I know that NAIT talks about waiting well and what we can do for people on waiting lists. I get a bit frustrated with that, because there seems to be more focus on what we can do for people on waiting lists than there is on assessing them. Let us get people assessed and then we will not have to think too much about waiting well. Let us not wait too long.

There are some areas where there is a bit of information. However, in most areas, the only information that you get is checking whether you want to remain on the list.

Lyndsay Macadam: I can give an example of some areas that are quite good. I will not say where they are but this is one of the quite good ones. In this area, when you get a letter informing you that you are on the waiting list, it says, “Thank you for returning your questionnaire. You are on the waiting list. Let us know if your details change.” A year later, you are told, “Thanks. You are still on the waiting list. We just want to confirm that you are on the waiting list and give you some resources and support.” That does not exist in most places. The resources and support part means providing a website where people can learn to do some breathing exercises and the number for Samaritans. That is good, because in most places people do not get anything. They are saying, “Keep breathing, stay alive, and we will come back to you,”—and that is a good example.

The Temporary Convener: I am a bit taken aback by that. How can the services improve that information?

Lyndsay Macadam: The problem is that the current approach puts the onus on individuals to have a look and see what is in their area and where they can refer people. Can people go to a group at Number 6 or to ARGH, SEMA or SWAN? I understand that there is always a difficulty for the public sector in referring to organisations when it is not necessarily sure of the quality of the support, but a lot of us have been around for a long time and are funded through Government funding. Certainly, people should be given the choice and be told, “There might well be help in your local area. Why not go and look? There are a lot of amazing books written by autistic people—maybe read some of them, as they might help you at the moment.” It can be quite simple things.

Realistically, there should be a pathway that brings people in for an assessment and sends them out to the support that is available. Money has been invested in the autistic adult support fund and previously in the post-diagnosis pilot, although not everybody who provides good services can access that funding.

There needs to be a proper pathway that involves setting out where people can get some support, whether they are waiting or have their diagnosis. Nobody is getting that. People are telling us that they have waited all their lives and have had all the issues that we have talked about today—all the challenge and the impact on their mental health—and then, when they finally get their assessment, they think, “Thank goodness, it will be the answer to all my questions.” However, they are told, “That’s wonderful. You are autistic. Thank you.” They cannot believe it. Whether you are on the waiting list or afterwards, you are left with nothing.

We need provision of services or certainly signposting to what is out there, and we need open conversations with people. We understand that there have to be waiting lists, but what are people meant to do in the meantime? There are things out there but, at the moment, those are in pockets. They tend to be where we in our organisations have built relationships with local services. We might have done training for them or met them at meetings and we have started to build relationships. That means that people in the services are now aware that, for example, they can refer women to SWAN or, in Edinburgh, they can refer to SEMA or, if they are in the Highlands, they know which services people can be referred to. However, that is not happening generally as part of the practice.

As I said, the example that I gave is a good example. Another letter then comes a year on to say, “You are still on the waiting list,” and that is from five years ago. What is that person meant to have done in the meantime? They are back to going on Google and, if they are lucky, maybe finding some support themselves, whereas access to services and community could have changed their lives in the meantime.

Brian Whittle: Good afternoon to the panel. Thank you for your evidence today. I will finish off by looking at joint working and what you think the benefits are of involving a multidisciplinary team in undertaking autism and ADHD assessments, and—since you have raised it already—what the third sector’s role in supporting neurodivergent people could and should be. Who wants to take that on?

Kabie Brook: It is essential to have a multidisciplinary team.

We should not be talking just about autism and ADHD, because we are missing out on things such as developmental co-ordination disorder and lots of other neurodivergencies. We know that once someone has been identified as having one form of neurodivergence—they might be autistic or they might be ADHD—they are way more likely to have multiple neurodivergencies. They are way more likely to have a cluster. It is like being a bit greedy, is it not? We do not just want one thing. [*Laughter*.]

It is essential to have a multidisciplinary team and, as we said earlier, it is essential to have a team that understands neurodivergent people, is connected to the neurodivergent community and is up to date on current thinking.

All assessments should be ND-wide and not just look at one or two things, because that leads to duplication, which wastes money, causes stress to people and makes the waiting list longer. It is ridiculous that someone might go for an assessment for autism, get an autism diagnosis, and then have another long wait to get an ADHD assessment, when it could have been done all at once by the right clinicians.

Moving on to the third sector, we all know that it is massively underfunded. Small grass-roots organisations in particular are finding it harder and harder to get funding. Even though we can do quite a lot with very little money, we still need money.

Also—you might not think that this is connected, but I do—the crisis in social care is having an impact on everything. I do not think that it is out of place to say that. It has an impact.

I cannot remember if you asked a question about community-based assessment.

Brian Whittle: Not yet, but feel free to answer it anyway.

Kabie Brook: I could answer it now if you like, then someone else might get a go in a minute. Sorry, guys.

Community-based assessments can offer a service that has an embedded, day-to-day connection with autistic and other neurodivergent people because they are generally based in places that have other services and are part of a community. I think they are more able to support people through the whole process of waiting, getting the assessment and then, if they go on to get a diagnosis, picking up after that.

I do not know whether you have read the report, “Experiences of Autism Assessment and Diagnosis in Scotland”, but I hope so. ARGH was involved in it, along with SEMA and Autistic Mutual Aid Society Edinburgh—which unfortunately was not invited to come to this meeting, which is a shame. People in that report cited Number 6 as being good provision because it was embedded in community and the support went the whole way through, if people wanted it to.

The drawback that I see is with differential diagnosis. We have to make sure that even when it is in a community setting, a service understands and can react to the different kinds of people who they will come into contact with, particularly if they are doing a neurodivergence-wide assessment, looking at not just neurodivergence but co-occurring mental health issues. Being autistic is not a mental illness, but neurodivergence is not protection either. Someone might well be autistic and have schizophrenia. It is not simple, but then I would say that about any diagnostic service.

I am a bit worried about the third sector question because I would not want to imply that the third sector can deal with that support and have it almost shoved away from the NHS. I would not like to see that happen, even though there would be benefits.

Brian Whittle: I do not think that the question was intended to imply that.

Finally, to layer on top of that—and we will bring everybody else in—it is all very well saying that a multidisciplinary team is required or is the way forward, but what is the reality?

Matthew Day: Multidisciplinary assessments and diagnoses do not happen, really. In a lot of areas there is a team that is multidisciplinary but, as an individual going for an assessment, you do not see that team—you see one person in it. Sometimes that person goes and speaks to someone else about you, but you do not meet the other person.

12:15

In one area that I am aware of, there are community psychiatric nurses who take information from people coming for assessment, go through some checklists, and then talk to a psychiatrist, who has never met the person, to give the diagnosis. I am not saying that that is a terrible thing, and their resources mean that doing much more would be difficult. However, we talk about multidisciplinary diagnoses and assessments, but it is rare that they happen. They happen in some areas, but usually you are meeting one person. There are areas where you will meet a couple of people, but that is not usual.

I worry about what people think “community-based assessment” means. There is an implication that it is an assessment that is somehow lesser or may not be as robust, whereas that might not be the case. Eight people could go to one mental health team in one area, and they could each have very different experiences. They will see people who have never been trained in the use of diagnostic tools once for 40 minutes, and they will be told that they are not autistic. There may be people who you could give a positive diagnosis to in 40 minutes, but I do not think that there is anyone who you should be saying no to in 40 minutes. You get very different experiences with mental health teams in the NHS. I would not want the implication to be that an assessment is somehow lesser if it is community based.

Brian Whittle: Okay. Does anybody else have any comments?

Sofia Farzana: On the community part?

Brian Whittle: Yes.

Sofia Farzana: Kabie Brook just talked about the third sector. The turnover for the third sector is really high. There is insecure funding and a lack of backing for maintaining structures and growth.

I have been doing community third sector work for the past 10 to 15 years, and we cannot get the right people in to work with us because people have contracts that finish within six, nine or 12 months. There is very rarely multiyear funding for them to have a career in my organisation, because everything is so temporary in the third sector.

On how communities can support services, an example from Scottish Ethnic Minority Autistics is that everyone who comes to us says that it is the first place that they have come to where they can be completely themselves. They go to one place and they are just brown people, or they go to another place and they are only autistic people. When they are with us, they are parents, they are carers, they are struggling with work, they are employees and they have been racialised and experienced prejudice on different levels. It is the only place where they can understand and be themselves. Think how wonderful it is for people’s mental health for them to be empowered.

I do not think that diagnostics should be exclusive to community-based care. However, when we see autistic, we see autistic. It is that peer review thing. We understand. We see through the masking and the code switching way more than a clinician who sees someone for one hour on the phone or in person.

There needs to be a more joined-up approach behind the scenes, so that we can inform the clinicians and practitioners. Having a multidisciplinary approach is important, because in community-based organisations you will not have all of those professionals, because of pay—have you seen the pay for third sector?—or insecure funding. You need to have people with specialisms, not just in neurodivergencies but also medical. We will not have that, so the system needs to be more joined up.

Community-based organisations have their benefits. We work and learn from the community, and help autistic people to get a diagnosis and provide safe spaces for they while they are getting a diagnosis. However, that cannot be exclusively provided by the community.

Patrick Harvie: Good morning. My question is on aspects that are quite close to what you have just covered in your answers.

I go back to Matthew Day’s comment, right at the start of our discussion, about his organisation’s experience. Matthew, forgive me if I picked it up wrongly, but it sounded as though you said that you were being used to clear the backlog but were then dropped because the funding had ended, and that there was some frustration around that. However, at the same time, I hear from witnesses that voluntary sector, third sector or community-based organisations can be really effective at joining the dots across the various forms of support that people need—and do so in a much more inclusive way that we might wish the NHS would deliver, but which is not happening.

During the rest of the committee's inquiry, and when we put questions to other witnesses, should we ask whether the voluntary sector should be given not just a temporary role to clear the backlog but an on-going, long-term role to deliver assessments and diagnoses in concert with other forms of support? Should we explore whether the voluntary sector could be effective not only in clearing the backlog but also in the long term? Should we consider whether it could meet people's needs not only in relation to assessment and diagnostic issues but more widely and holistically, and whether that approach could be cost effective when compared with scaling up capacity in the NHS?

Kabie Brook: I do not see how it should be more cost effective, because we need NHS clinicians to be scaled up anyway. I just get very nervous about the prospect of things that I feel should sit within the NHS not actually doing so. It is good that we have some services doing assessments, in some areas, to try to reduce the awful waiting lists. However, it feels almost as though, by using such a pathway, the NHS would be washing its hands of us. I know that it would not be a case of that—that is just how it feels, at least to me.

Neurodivergent people do not get free and fair access to NHS services as it is. It almost feels as though taking that aspect out of the NHS would make things worse. It would not send the right message, and it would make people think, "We already do not get to access other services, and now we cannot access that."

Patrick Harvie: I get the point, and I share that concern. However, I am also aware of other evidence that we have heard, especially in our earlier session, that many people who do not have access to the NHS find themselves being forced to go private and so going into debt. It seems to me that an approach that would involve contracting externally to the NHS, would not involve fees for individuals and families, and had an agreed standard of delivery so that its diagnoses would be recognised would feel better than what we have now.

Lyndsay Macadam: The model at the Number 6 service is exemplary. It is a properly embedded model where people can access a professional assessment and then be seamlessly streamlined into support and establish a relationship.

My concern is that if we went down the pathway that we are talking about, the contracts would be picked up by the big organisations that already have infrastructure but are predominantly staffed by non-neurodivergent people, albeit that they might have years of experience. There is a mix of people at Number 6, which is absolutely valid. Where does that leave organisations that are led by and for neurodivergent people, though?

From feedback from the reporting that we carry out for our funders, we know that people who use our service experience exactly what Sofia Farzana said earlier. In one hour with us, they get more help than they have had elsewhere throughout their lives. However, we are already struggling to access the funding that we need to be able to see them.

The pathway would have to be very carefully thought out and managed so that it did not create a bigger problem for people who are trying to access good-quality, community-based support because organisations were being priced out of the market. Instead, we should invest in building up those organisations so that, for example, a Muslim person would be able to see a Muslim diagnostician before moving into getting support. If they were not able to do that then, although we might be a bit further forward, we would not be where we could be. The situation is a bit more complex than that but, realistically, that is what would probably happen.

A bit of thinking should be done about how we could make things look a little different. How could we work in partnership? How could we invest in organisations that already work well in local areas—for example, with communities of identity—so that they are still able to do what they do, only better?

We represent good value for money. Kabie Brook made a good point: our services should not be cheaper, because we should be getting paid a lot better. However, the reality is that we are more agile and able to do a lot more with what we have. Last year, I had a team of three people. We ran 310 groups in 22 locations across Scotland, from Shetland to the Borders, with just those three people and a team of volunteers. Nobody else can do that apart from us. Luckily, there are now five of us, but I still hope that we will not all go off sick with exhaustion.

I hope that that gives the committee an idea of what we can do and the difference that such investment makes—the bang for the buck—because of what people get through our intervention and the added value of accessing the community and the other services that sit around it. That investment is worth while, but it needs to be done carefully.

Matthew Day: Wider access to assessments should be considered, but I share the concerns of

Kabie Brook and Lyndsay Macadam about who does them and why.

I have heard of people from England—I stress that I am not anti-English; I am English myself—who offer online assessments more cheaply. It is not that cheap, but it is cheaper than having someone employed in the NHS. However, I sometimes worry about how robust those diagnoses are and what happens at the end of the process, given that the people who receive them will not get post-diagnostic support. I would like to see links to the post-diagnostic side, so that people do not just get a diagnosis and that is it.

I am absolutely not saying that we are the only organisations who could do assessments. However, I would worry about anyone being expected to do them just because they are from the third sector. Using our services is certainly cheaper, although it should not be. It is cheaper simply because people working in the third sector are not paid as much as others.

Also, there is a greater commitment to getting the job done. Late-diagnosed autistic people often say, “I want to get through. I want to meet people outside 9 to 5 hours so that we can make sure that they can access that service.” We have had a lot fewer people—hardly any—dropping out of our services compared with the numbers in the NHS, because we arrange appointments directly with them rather than sending them a letter that, in effect, says, “You turn up then, or that is it.”

That commitment, plus the idea of not paying as much, makes using our services a bit more attractive for people. We can get through more assessments as well, because that is all that we are doing rather than it being just a part of our job. I know a lot of very good NHS clinicians for whom 0.1 of their job is doing assessments and so they are not getting to do much of them at all.

Patrick Harvie: Thank you all very much. That is really helpful.

The Temporary Convener: Thank you for your attendance today—and a big thank you for staying well past the time allocated for your evidence, which the committee really needed to hear. You are free to go now.

Subordinate Legislation

National Health Service (Common Staffing Method) (Scotland) Amendment (No 2) Regulations 2025 (SSI 2025/244)

12:28

The Temporary Convener: Our third agenda item is consideration of a negative instrument.

The National Health Service (Common Staffing Method) (Scotland) Amendment (No 2) Regulations 2025 amend the National Health Service (Common Staffing Method) (Scotland) Regulations 2024 to update the staffing level and professional judgment tools that must be used as part of the common staffing method for specified kinds of healthcare and provision.

The Delegated Powers and Law Reform Committee considered the instrument at its meeting on 16 September and made no recommendations. No motion to annul the instrument has so far been received.

As no member wishes to comment, I propose that the committee makes no recommendations on the instrument.

Members *indicated agreement.*

The Temporary Convener: At next week’s meeting, we will continue to take oral evidence as part of the committee’s inquiry into autism and ADHD pathways and support.

That concludes the public part of our meeting.

12:29

Meeting continued in private until 12:31.

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