OFFICIAL REPORT
AITHISG OIFIGEIL

DRAFT

Equalities, Human Rights and Civil Justice Committee

Tuesday 20 January 2026

Session 6

The Scottish Parliament
Pàrlamaid na h-Alba

Tuesday 20 January 2026

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EQUALITIES, HUMAN RIGHTS AND CIVIL JUSTICE COMMITTEE
2nd Meeting 2026, Session 6

CONVENER

*Karen Adam (Banffshire and Buchan Coast) (SNP)

DEPUTY CONVENER

Maggie Chapman (North East Scotland) (Green)

COMMITTEE MEMBERS

*Marie McNair (Clydebank and Milngavie) (SNP)
*Pam Gosal (West Scotland) (Con)
*Paul McLennan (East Lothian) (SNP)
*Paul O'Kane (West Scotland) (Lab)
*Tess White (North East Scotland) (Con)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Debbie Best (Differabled Scotland)
Dr Leonie Boeing (Royal College of Psychiatrists in Scotland)
Kabie Brook (ARGH Scotland)
Dr Jim Crabb (Royal College of Psychiatrists in Scotland)
Sofia Farzana (Scottish Ethnic Minority Autistics)
Helen Gibson
Marion McLaughlin (Aurora Autistic Consulting)
Iris McNab
Rachel Parker (Autistic Voices Advocating Together for Autonomous Rights)
Carolyn Scott (ADHD Right Now)
Leo Starrs-Cunningham (Autistic Mutual Aid Society Edinburgh)

CLERK TO THE COMMITTEE

Euan Donald

LOCATION

The James Clerk Maxwell Room (CR4)

Scottish Parliament

Equalities, Human Rights and Civil Justice Committee

Tuesday 20 January 2026

[The Convener opened the meeting at 09:30]

Neurodivergence

The Convener (Karen Adam): Good morning, and welcome to the second meeting in 2026 of the Equalities, Human Rights and Civil Justice Committee. We have received apologies from Paul O'Kane. Our only agenda item in public this morning is our first evidence session on our inquiry into neurodivergence. The inquiry was precipitated by the Scottish Government's decision in 2024 to delay the introduction of a learning disabilities, autism and neurodivergence bill. We will be focusing on the experiences of neurodivergent people in education, employment and the criminal justice system.

We will hear from the Royal College of Psychiatrists, and we will then move to a round-table format to explore the key themes of the inquiry with autistic disabled people's organisations and an attention deficit hyperactivity disorder—ADHD—organisation.

We begin with the Royal College of Psychiatrists in Scotland. I welcome to our meeting Dr Jim Crabb, policy lead, and Dr Leonie Boeing, child and adolescent mental health services psychiatrist and vice chair of the college's child and adolescent faculty. You are both very welcome. Thank you for attending.

I refer members to papers 1 and 2. We will begin with questions. I will kick off the questioning, and I will come to you first, Dr Crabb. Will you summarise the background to your report and any key points in it?

Dr Jim Crabb (Royal College of Psychiatrists in Scotland): I would be glad to. Thank you so much for allowing us to come and give evidence on this issue, which is probably one of the widest and most pressing issues that Scotland is facing just now. I am a general adult psychiatrist, so I work with people from the ages of 18 to 65. I have been the lead clinician for autism at NHS Forth Valley. Before becoming policy lead for the Royal College of Psychiatrists, I was an associate medical director, so I was responsible for running, managing and maintaining mental health services in a part of Scotland that is fairly representative. Forth Valley has pockets of real urban deprivation, right through to people in very rural communities. That has allowed me, personally, to become aware of the issue.

It is important to start by saying that the scale of the need that has been uncovered over the past 10 years is unprecedented, and it was unpredicted. It is probably also worth noting that Scotland is not unique. Every economically developed country in the world is facing the same need. No country predicted this need, no country prepared for it well and no country is managing the need particularly well just now.

We do not think that there is any value in pointing fingers, asking, "Whose fault is this?". We are where we are. The really positive thing is that we have the opportunity to think about the issue differently in Scotland, and we can show the world how to build a society and a system that can provide kind, compassionate and meaningful support to people who are neurodivergent.

Dr Leonie Boeing (Royal College of Psychiatrists in Scotland): I echo those thanks for convening this meeting and giving us so much time to present our evidence. As a bit of background, I have been a consultant child and adolescent psychiatrist for about 20 years this year—this is my big celebratory year—and I have been a neurodevelopmental specialist for about eight years now. I am lead psychiatrist for Borders CAMHS, although I am here today on behalf of the Royal College of Psychiatrists.

I am bringing together our neurodevelopmental pathways recommendations for under-18s, and I sit on the neurodevelopmental task force for children and young people, which is Scottish Government convened and has representatives from across a full range of professional groups and organisations who have been brought together to see how we can take the direction forward and develop things from the neurodevelopmental specification that was published a few years back.

I echo Jim Crabb's point. There has been an unprecedented rise in the number of referrals of under-18s to child and adolescent mental health services around the world. Mapping in the United Kingdom shows an increase over the past 20 years, so it is definitely a pre-Covid thing. In fact, the only way in which Covid affected the number of referrals was that it went down a bit in 2020, when people struggled to be seen.

There are multifactorial reasons why demand has gone up so much, and I am happy to speak about that in more detail if it would answer one of the later questions. I echo the sense that that is nobody's fault and that it was not foreseen. It feels as if the world has slightly tilted on its axis and become a less child-friendly environment in many ways. I have always seen children's mental health as a barometer of how the world is, so, when kids present in mental health distress, whatever shape or form that takes, that is a sign that the world and society are not doing all that well. Children's mental health is the canary in the coal mine.

The Convener: We move to questions from committee members, beginning with Maggie Chapman.

Maggie Chapman (North East Scotland) (Green): Good morning to you both. Thank you for being here today and for the detail in your report.

I am interested in a couple of different areas, one of which is diagnosis and its value. We have heard clear evidence that shows that having some kind of diagnosis of neurodivergence, whether that is of autism or ADHD, gives people something from which to work; it is validating and gives them something that they can explain to people. That leads me to two questions: how can we ensure that people without a diagnosis are still supported, and what can be done about the long waiting times for any kind of medical assessment? Some people are waiting years for a diagnosis. Those are two quite different questions, but I would be interested to hear your thoughts about how we can deal with the issue of validation through diagnosis.

Dr Crabb: That is a huge area. It is not an either/or situation; it is an and situation. That is one of the challenges. We are taught, particularly in the UK, to think in a binary way and to believe that there is a single, right or wrong, way of doing something. Diagnosis can be incredibly powerful and validating; for some people, it can be life saving. On the other hand, it takes four or five hours to do a proper assessment, and there are risks in the misdiagnosis and overdiagnosis of a condition. A huge number of people who have the traits of neurodiversity but do not meet the full diagnostic criteria will also need help and support.

I can give two examples from my practice to illustrate that. When I was working in an autism service, people would wait for five or six years to see me and have an assessment. However, for a large number of people, the help, advice and support that they needed was the same if they had a formal diagnosis of autism or neurodivergence as it would have been if they had traits. The tragedy was that people had been left for four, five or six years because no one wanted to make things worse. General practitioners did not want to say, "It might be autism," because they did not know much about that and did not want to make things worse. Primary care mental health nurses would leave those people alone. Schools, teachers and everyone would withdraw because they did not know what was going on.

What those people actually needed was advice about sleep, screen time, exercise and caffeine. They needed some coaching about how to manage lifestyle factors and busy environments and about how to feel more confident in social interactions. I would often give the same package of interventions to someone who had autism and someone who had traits, and the tragedy was that a person might have waited four or five years to see me and to be given that advice, yet I often would not have the time to follow them up and see how that advice was going.

That is one situation where we clearly need to ensure that we get help into the hands of people and their families years before they get so stuck that they need to see a clinician like me.

Another example from my practice relates to the other end of the spectrum. I saw a gentleman in his 50s who lived with his mother and had managed to maintain a part-time job. He needed his mother to help him to get dressed and prepare for the day and to help him with most activities outside of his part-time job. The health of his mother, who was in her 80s, was failing, so she said, "I won't be able to support my son any longer, and he won't be able to live independently." She was desperately worried about what would happen to him. In that case, an autism diagnosis opened up care packages from social work, and that man and his family could rest easy knowing that, over the long term, he would be able to live independently in the community.

For some people, a diagnosis is essential. However, if we are talking about having to meet the needs of 10 to 20 per cent of the population, we are thinking along the same lines as conditions such as obesity. Most people understand and accept that specialist surgeons and doctors are needed to help people with the most severe and complex forms of obesity, but a suite of interventions are needed across society, because an awful lot of people will not need to, or cannot, see specialist doctors.

Maggie Chapman: I will pick up on the second example that you gave. Clearly, in that case, a diagnosis was essential to opening up care packages. I am not at all trying to downplay the importance of getting a diagnosis, but should an assessment of need for a care package depend on a diagnosis? Given that these are straitened times with limited resources, a diagnosis might be what gets people to the top of the pile, as it were, but could we do things differently by taking a whole-system approach so that getting somebody the care that they need does not rely on a diagnosis?

Dr Crabb: Absolutely. We have recommended that as one of the 10 pillars of work that are needed across society. We should take a needs-based approach to support in schools, in other education settings such as colleges and universities, in the workplace, in the welfare system and in the criminal justice system. If people need support, that support should be made available to them. Often, straightforward practical adjustments make the difference between somebody progressing in life or becoming stuck in disability, and people should not have to wait four or five years, or have to undergo an assessment that lasts four or five hours, for those options to be opened up to them.

Dr Boeing: It is a fascinating question, and people have very different feelings about it. We must be sensitive to what an individual wants or needs, because this is all part of their story and identity. It is not for us to ordain somebody with a diagnosis. There should be a collaborative process, with decisions being shared. Together, we should create that story as we listen and inquire. That should be at the heart of the process.

However, the reality is that things have been very process driven and there have been bottlenecks in getting a diagnosis, so there is absolutely no way that we will be able to use diagnoses to address the current waiting list. More than 40,000 children are waiting for some form of neurodevelopmental assessment, and I suspect that that is just the tip of the iceberg, given the issue with underrecording in the data collection systems.

It is more important that children have their needs met when they have a need. Those needs will change over time, because, by definition, children change as they grow and develop. Expectations of them change, grow and develop over time, and they get much more sensitive to what other people around them are doing. They might be completely dependent on their carers, but they are obligated to go to school or access education. Therefore, those children's lives are different.

For example, a kid who has a communication disorder will have issues with understanding language, which is a crucial interface with the world. If those issues are not understood early, people will keep talking at that kid, expecting them to answer, so they will become more and more stressed and overwhelmed. It is crucial that those issues are recognised and that someone with specialist expertise helps that kid and the people around them to understand. The communication around that kid should be adapted to help them to cope with, enjoy and thrive in their environment.

09:45

If children can access that kind of understanding as they go along, that will translate into three key transitions as they go through nursery, primary school, high school and college. If their profile and neurotype are understood and people around them get them, life will go better, because they can thrive and grow as they develop. That should be the case whether or not it leads, at some point, to a diagnosis.

The two big diagnoses that we talk about a lot are autism and ADHD, but there are lots of different neurodevelopmental conditions and profiles. It is more about having a good understanding of the child. If a child has had that recognition, had their needs met and been understood as they go along—for example, they are making it into school with adaptations, or people know to use visuals instead of tonnes of words—and therefore are not, we hope, suffering the sequelae of not being understood, that means that when it comes to whatever point in their life that a diagnostic assessment might be helpful, it is much easier and less time-consuming for the people who do the diagnostic assessment.

We would advocate for pathways for assessment that build on themselves. Sometimes, if we really, really know the kids, we might be able to do quite an abbreviated, quick diagnostic assessment, confirming what everybody knows. I would have the families right at the heart of this, as well. Sometimes, undoubtedly, it is incredibly complicated. I am dazzled every day by the complexity of some of the children who I work with, so there is a place for detailed, complex and on-going assessments as we try to understand some children. It is a process, but we need to make sure that they get what they need as they go along, because it will change over time.

Maggie Chapman: Thanks to both of you—that is helpful. You talked about meeting needs when they arise. Some children go on to the waiting list as teenagers and, if current waiting times are sustained, they will be in their 20s when they get to the top of it, so they will no longer be eligible for that service. Given the long waiting lists and the significant amount of time that is involved, do you have any suggestions for the short, medium and longer-term steps that we need to consider? I will add a little to that. We are looking at a needs-based, whole-family approach that breaks down some of the departmental barriers and silos that exist. How do you see the work that we are doing around this table over the next few weeks supporting that approach? That was a big question.

Dr Crabb: The work is absolutely consistent with the pillars of work that we recommended in our multisystem report, which was published in October. As you pointed out, we cannot keep doing what we are doing. That is the definition of insanity—doing the same thing and expecting the result to be different. Alternatively, we could find a ring-fenced piece of money, do a waiting list initiative, invest in more assessments and do more pilot projects. In the next 12 months, we need to move to delivering the pillars of work that we have recommended, across society.

As you highlighted, it is about asking what reasonable adjustments are in schools, colleges and universities, and what reasonable adjustments employers can provide in workplaces. If somebody feels that they need those adjustments, they should be provided. I find it remarkable in my practice, when we speak to tutors at colleges, teachers at school or—with people's permission—employers, and they say, "Of course, I would have done that ages ago if I had known it would be helpful. That is not a big deal." It is about having really clear advice about reasonable adjustments across society, because they will be helpful whether someone has a formal diagnosis or traits. Even for a child or young person who is not neurodivergent, there may be a benefit to them if a school is able to offer things such as a movement break.

We ask the committee to use its influence to ensure that a cross-government approach is taken, because this is way bigger than just health or social care. We need clear guidance in the benefits system, criminal justice system, the workplace and the education system about what reasonable adjustments should be provided in practical terms, so that there is no delay, such adjustments can be put in place and people do not get stuck but can keep moving on in their lives.

The second thing is that we need to have really clear evidence-based advice for the public and family members, so that they do not get stuck waiting for people like us to tell them what might be helpful. We need services such as NHS Inform to make really clear evidence-based guidelines available to the public. People need to know where they are. Guidelines need to inform the whole system, such as health visitors giving advice on things such as screen time, exercise, caffeine and sleep, right through the life course, so that people can start to work through the factors that can make neurodiversity more challenging.

We then need to commission, at scale, on a once-for-Scotland basis, initial self-help and peer support groups for people. There are really good models in place—we have so many pilots across Scotland that show that you can take a range of approaches. The models usually involve coaching and peer support—which can be run by third sector partners—that people can access whether they have a diagnosis or not, and they can dip in and out of that support, depending on what is happening in their life. Those things are the bottom tiers of support that society needs to move to a better place.

Maggie Chapman: Thanks very much. Do you have anything to add, Leonie?

Dr Boeing: We need to adapt support for kids. The context is school, education and the need to mobilise the third sector. I have never met a more passionate, motivated, well-informed group of people than parents of kids who are neurodivergent. They are an absolute army and incredibly knowledgeable. We need to mobilise them through the third sector, community hubs and family support models.

There have been many pilots across Scotland as a sequel to the neurodevelopmental specification for children's services; there have been problems with the implementation because it got stuck in the area of health. However, the ND task force has been designed to move that work forward. A cross-government approach is really important. It feels like things get stuck in silos across Government. Given the energy and passion to tackle this wicked problem that we face as a society and a world, we need something in place within Government that transcends silos, so that funding does not get stuck and expertise does not get lost.

I wonder whether this committee can take a human rights approach and draw on the United Nations Convention on the Rights of the Child (Incorporation) (Scotland) Act 2024, because a lot of energy went into getting that into statute, but how do we mobilise to turn it into something meaningful? For example, I have never seen anything introduced that might be more effective at improving access for intellectually disabled children. They have the highest levels of mental and physical health needs, there is an appalling mortality gap and their parents are stuck at home, unable to get out and advocate for what their children need. That is an extreme example, but the access and equality issues are just horrendous. The United Nations Convention on the Rights of the Child is really clear that that should not be a barrier to access to services, so I really hope that this committee can mobilise that clear messaging, because everybody has to get their act together and work together.

Dr Crabb: It is about equality of access, which is why we need central commissioning in this area—the landscape is currently so fragmented. We have more than 32 different parts of the healthcare system, all of which commission different things locally, depending on need. My experience of having led such a service is that you face your own pressures in that system when it comes to what you spend money on. The result for the public is a postcode lottery, because you can go 10 miles down the road and get a very different experience. A great third sector support service might be commissioned, because the health part of the system has found the money and is able to do it for a year or two, but it then gets closed down because other pressures have come along.

All the bits of the system are competing with one another. It is a fiendishly complex system. Clarity needs to be provided, because this is important. Ten to 20 per cent of the population of Scotland need such evidence-based services. There needs to be clarity on how things will be run, along with clear standards of accountability and governance for those services, which must provide results and be accessible, whether someone lives in the Orkney Islands or the central belt.

Dr Boeing: One size will not fit all for every area. If we look at the workforce issues that exist, we can see that some areas have no child and adolescent psychiatrists at all, while others have more psychologists. The picture is very variable. I think that the principles should be based on the skills that people need to do such work. If people cannot access the expertise locally, they should be able to access it regionally or subnationally. Specialist expertise should be accessible to all.

The most important things that will make the biggest difference to children are the everyday things. The universal offer at school needs to be improved. If we are in a position in which 43 per cent of children have some sort of additional support need, something is not right. It is great that that is now recognised, but that is a sign that the universal offer is not okay.

I will give a small example. I might see a young person for years and get to know them because I am overseeing their ADHD treatment. From one year to the next, I come across issues such as what the young person's communication style is, whether the teacher gets them and whether they have a quiet place to go. The level of noise in the world is extraordinary, and if you are a kid who is more finely tuned, that will impact you more. It seems ridiculous that, as a specialist, for more than 20 years, I have been having exactly the same conversations in school meetings about the fact that such children need a quiet place to go.

The schools are open plan, and every square inch of space is allocated to something that involves a lot of noise. There also need to be outdoor spaces that children are welcome to play in. We are all doing our best, and we get a sense of self-worth by thinking that we can make a difference. I am sure that that is what motivated you all to go into politics. That is what motivates us to do our work with the Royal College of Psychiatrists and when we work every day as doctors. Everybody is involved in this game. The same is true for kids and young people when they are growing up—they need a meaningful sense of purpose in the world, and that will look different for different people.

Right from the get-go, when children start playing and learning through play, we need to think about what humans need in order to grow and thrive, which will be very different for different people. What will make the biggest difference is ensuring that we enjoy and nurture people's differences.

Maggie Chapman: Your comments—especially your point about the fact that inclusion is good for everyone, regardless of diagnosis or condition—provide a helpful foundation for the rest of our inquiry. We need to hold on to that.

The Convener: Before we move on to questions from Tess White, Paul McLennan has a supplementary.

Paul McLennan (East Lothian) (SNP): When I met you guys, a key thing that came through in our discussion was the need for a multi-agency approach. I think that you are right to say that the Government needs to lead on that. Jim Crabb mentioned the fact that there is a postcode lottery, but even within the same school, some teachers have a better understanding of the issue than others, and within the health service, some doctors understand it better than others. Therefore, the issue also needs to be looked at from a health board and a local authority perspective.

Workforce planning is important, too. Do we have enough qualified people in this area, given that there has been an explosion in the number of people who are seeking treatment? If we do not, do we need to start planning to address that now? We can clearly see the restrictions that there are with regard to the waiting list, so do we need to look at workforce planning? If we are to deal with the issue properly, we can put guidelines and structures in place, but if we do not have the people in place, that will cause delay. Do you agree that it is important that workforce planning—in local authorities, in GP surgeries and in the services that you provide—is looked at?

Dr Boeing: Yes, and that is a massive issue that we have been talking about for decades. It is an issue across the board, but I agree that there needs to be a universal understanding.

You might remember the iconic child protection report, "It's Everyone's Job to Make Sure I'm Alright". It is the same with ND—it is everybody's job to get it, and to understand that people are different and will need things to be done differently.

10:00

That needs to be part of the basic universal training, both for new people coming in and for those who are already in post; they would have to do their ND awareness training in the same way as they currently have to do child protection training. People who are providing supervision and support need to be aware of neurodivergence, because that is absolutely game changing for children. If the teacher gets it—for example, if they have built in movement breaks as standard, or provided a different offer or a quiet corner—it makes a huge difference.

The workforce issues are absolutely massive and should not be underestimated, and the situation is getting worse. Dr Crabb and I would certainly be more knowledgeable about what is going on in health; looking at the age of the workforce, it is not going in the right direction at all. For example, a fair amount of money has been given to CAMHS over the past decade, and it has gone towards increasing numbers in some professional groups, such as psychology. However, the number of psychiatrists has gone down, and there are not enough of them.

In addition, for the neurodiverse population, the allied health professionals such as occupational therapists and speech and language therapists make a real contribution—they bring a lot to that group of children and young people and to adults.

We need a richness of provision and, again, we need to mobilise people who have kids who are neurodivergent, who have a lot of knowledge.

Dr Crabb: To follow on from that, it is one of those situations in which the answer is, “Yes—and”. We always need more people in the workforce and we need to plan for that. However, if we think about the scale of the problem and the scale of need with obesity, for example, we might say, “Well actually, we will never be able to train enough specialist staff to meet that need.” We just cannot do that. We cannot have everybody in Scotland who is obese seen by a consultant surgeon; it is just not going to happen.

With neurodiversity, therefore, we need to think about what we do across the system. For example, we need to look at things like mandatory training: everybody in the public sector should be trained in neurodiversity awareness and in the relevant supports. One of the pillars that we have recommended in our report is about investing in a national training package so that people can access training no matter where they are in Scotland. We can then start to offer people support, because the issues are often not straightforward, but knowledge is power, and it is about understanding what can help.

In addition, we need to be conscious that we are currently in a public mental health epidemic. As Leonie Boeing said at the beginning, we are in an environment that is increasingly toxic to people’s mental wellbeing, whether or not they are neurodiverse. An analogy might be the crisis with lung conditions that we faced many decades ago in Britain, when a huge number of our workforce were incapacitated because of chest conditions. We not only built clinics to diagnose tuberculosis and asthma; we looked at smoking and air quality.

We absolutely have to get on the front foot here. Research is coming out all the time, and we now know that excessive screen time and social media use causes ADHD symptoms, whether or not someone has a diagnosis, and in particular if they are young. We do not simply want to create clinics. We do not create clinics only to diagnose asthma in young people or limit cigarette access only for young people with a diagnosis of asthma—we give clear advice, and we legislate to protect young people across society. We need to do the same for all the environmental factors that can make neurodiversity more challenging for people.

Paul McLennan: Thank you—that is very helpful.

The Convener: We now have questions from Tess White.

Tess White (North East Scotland) (Con): A few things that you have said have really resonated, and I thank you for the report. I want to pick up the point about what humans need to grow and thrive. Dr Crabb, you talked about working practices. My background is in human resources, and you touched on human factors and human factors engineering.

In your report, there is a very good section in point 2 of your 10-point plan, in which you raise some concerns about the ability of the population to concentrate and focus on daily tasks. You refer to factors—which you have also mentioned today—such as caffeine, psychoactive substances, alcohol and screen time as almost being our environment and the air that we breathe. Is there any world-leading research that is looking at that, and almost going back to the basics?

I grew up in the 1960s and 1970s; we drank water and we did not have all these other drinks. I understand that, for some people, 50 per cent of the energy that they consume comes from ultra-processed food. Is there any research out there that is connecting the dots and looking at the data on what you have been talking about?

Dr Crabb: The answer is yes. Research comes out all the time, but we have done rapid reviews of the evidence and have worked with colleagues in NHS Inform to update its guides for ADHD to include those factors.

As I mentioned before, those factors do not just affect a person if they have a diagnosis of ADHD; they affect the whole population. However, if someone has ADHD, they are more vulnerable and are more likely to be harmed by the effects. The environmental issues that you mention affect everyone's mental wellbeing and our ability to focus, concentrate, think deeply about problems and arrive at a flow state, which is important for young people's cognitive development. Those issues include the levels of high-quality sleep, exercise, screen time, social media use and caffeine intake. We can quickly summarise that evidence, and we need to take it to the public and be honest with them about it, because there is nothing to guide them just now. We do that in relation to alcohol, with the advice about limiting consumption to 14 units a week. We know that lots of people do not stick to that, but a heck of a lot of people do. We have clear guidance across society and the system that says, "This is what you need to do to stay healthy".

Before we do anything else, let us make sure that those things are under control, because, based on experience from my practice, nothing is more tragic than seeing someone who has waited six years for an assessment and finding out that those first-line things have never been tackled. I have to say to them, "You might have a neurodevelopmental condition, but first of all we have to sort all the other things out, because they might well be presenting like symptoms of ADHD". Of course, if someone has a diagnosis of ADHD, we still need to sort those things out.

The first thing that we should do is sort out all of those factors and ensure that, no matter where someone goes, they are given clear advice on how much they should sleep, their caffeine intake, their screen time, their exercise level and their intake of ultra-processed food.

Tess White: Noise is another issue, as Dr Boeing said. I wonder whether, when schools were designed to be open plan, anyone actually thought about the human factors.

I want to ask another question before I go on to my question about private diagnosis. An article on the consequences of ultra-processed foods on brain development, which is available on the National Library of Medicine website, said that ultra-processed foods contain

> "elevated amounts of sugar, fat, sodium, food additives, and dietary emulsifiers"

and pointed out that a lot of what people are eating and drinking has an effect on development in the womb. Dr Boeing, you are nodding your head. Could you say more about that?

Dr Boeing: It is not my area of expertise, but research has shown that ultra-processed foods are linked to increased mental distress and have an effect on performance, focus and concentration.

Research is being done into a range of lifestyle choices that can have an impact on people's mental health. Public Health Scotland has a working group on the digital determinants of mental health, which is doing good work and had its second meeting yesterday. Generation Scotland in Edinburgh University is also doing some fine-tuned work that includes hour-by-hour tracking of the effect of social media use on mood, mental health and sleep patterns.

Helen Minnis, a professor of child and adolescent psychiatry at Glasgow University, is doing some interesting and challenging work on the relationship between trauma, early attachment and neurodevelopmental conditions. She talks of a sort of double jeopardy situation, where if someone has both trauma and a neurodevelopmental condition, they have double the risk of experiencing poor health outcomes than someone who does not. All those risk factors go together and add up.

Keeping children safe and letting them grow, develop and play all helps.

Tess White: They used to play outside.

Dr Boeing: The digital stuff is a real hot potato at the moment, but there is a lot of work going on in that area. There is also a degree of urgency. Dr Jim Crabb is particularly passionate about this.

Dr Crabb: I am. We have the lessons from history. There was literally no argument about cigarette smoking and lung disease, but we waited decades before anything was done.

There is more than enough evidence that the lifestyle factors that you mention harm all of the population, but they disproportionately harm people who are neurodivergent. We cannot wait one, two or three years while another 10 or 20 studies are done. We have enough studies now to advise the public. We ask the committee to use its influence to make sure that we can issue national guidance for the public within six months, and we can then update that guidance every year as new evidence emerges. We must not fail the people of Scotland by waiting another five years to give them advice about how they can protect their and their family's mental wellbeing.

Tess White: You talked about 45,000 people waiting for diagnosis, and I think that more than half of them are children. Is there a huge risk arising from the fact that people are going for private diagnosis, because, as you said, that means that their condition will be looked at in a silo and not holistically?

Dr Boeing: We strongly advocate holistic assessments and what we call a biopsychosocial approach. That looks at biological risk factors in the family history, such as exposure to cigarette smoke in pregnancy, premature birth and so on; psychological factors, which might include trauma and life experiences; and social factors such as social exclusion. We advocate looking at all those factors, taking a trauma-informed approach, and looking across the board for neurodevelopmental differences. If you look only for autism, you will find autism, but you might miss the ADHD. If you look only for ADHD, it is very easy to misinterpret hyperactivity, impulsivity and distractibility, which might be caused by trauma or be seen in somebody who is autistic and is really dysregulated by their sensory environment. If you look only through a narrow lens, you will have blinkers on and you will miss the big picture.

Some places in the national health service are still doing single diagnostic assessments, but we strongly advocate that there not be separate waiting lists for different conditions. We also advocate that the private sector does holistic assessments rather than single diagnostic assessments.

Dr Crabb: There is a real danger in single condition assessments. To put it bluntly, if you have a hammer, everything looks like a nail. There are hundreds of different psychiatric conditions, many of which can present with features that seem suggestive of neurodivergence. People can present with neurodivergence and another condition. There need to be holistic assessments and we need to keep really high standards. We need that dual position.

The question is not whether diagnosis is good or bad. Diagnosis can be really important for some people, but it needs to be done to the highest standards by people who are properly qualified and supervised and trained to do that. Lots of people might not need a diagnosis to get the help that they need. Sometimes, the help and support that people need will be the same whether they have traits or a disorder. It is a tragedy when people wait years to get a diagnosis before those supports are offered.

Tess White: Do they need a diagnosis? You said that there could be multifactorial issues including diet, drinking and smoking, and those risk factors will need to be eradicated. Is data being recorded and kept to show that the person might not have ADHD and that it could be something else?

Dr Crabb: That is why we recommend that the different pillars be taken forward. There should be clear advice about lifestyle factors that everybody should follow, and it should say, “If you think that you might be neurodivergent, it is particularly important that you do this.” Initial, first-line supports can be provided in the community by the third sector, and, if people are still struggling, the step-up would be to consider whether we need to find out what might be going on.

I will make a few other points about the issues around diagnosis. There is a cultural component to this, and it can be incredibly difficult. When somebody has waited four or five years to see you and you have spent five or six hours assessing them, you might say, “You’re a complex human being and there are lots of factors here. You have traits of neurodiversity, but you don’t meet the diagnostic criteria.” People can become hugely upset and say. “This is a community that I identify with. Who are you to say that I’m not a member of it?” Often, there are complaints, and second, third and fourth opinions are sought. We can become stuck in a toxic cycle where people feel that they need a diagnosis to join a community that they identify with.

The Convener: I do not think that anybody would disagree that getting a good night’s sleep, eating properly, consuming less processed food and avoiding doom scrolling on our phones would do us all good. As you say, those things disproportionately affect people who are neurodivergent, but engaging in those behaviours could be an indicator of neurodivergence—it might not be a question of one leading to the other, but they could be indicators. Someone who has had a baby with ADHD could talk to us all day about sleep.

We have talked about misdiagnosis, and heard that people might be misdiagnosed as autistic or with ADHD. Are there people who are not diagnosed with ADHD or autism but have been diagnosed with personality disorders, for example? Also, a disproportionate amount of women seem to be diagnosed with personality disorders. There seems to be a gap, in that more men are diagnosed with autism. Is that straight-up misogyny in healthcare?

10:15

Dr Boeing: Gosh—that is an enormous question. To go back to your opener, just so that I do not miss it out, I agree that some behaviours and presenting issues such as poor sleep can definitely be indicators of neurodevelopmental conditions. I cannot state strongly enough that it is not an either/or—it is not about lifestyle adaptations or diagnosis; it is much more nuanced than that. It is complicated, because people are complicated. The main thing is to provide what people actually need in a timely way. That will almost certainly change over time, depending on where they are in life’s journey.

The issue about the gender differences is a multimillion-dollar question. The differences in how males and females show their behaviours relating to their underlying neurodivergence affect how obvious it is. I suppose that, because of human nature and overstretched systems, the boy who is externalising his angst will be picked up more quickly than the girl who goes quiet, is no problem to anybody and seems to be doing fine. We are undoubtedly getting better in that regard, but that takes us back to the need for universal training, so that every teacher has training and knowledge of neurodiversity and the different ways that it might present. I should have said earlier that that needs to be trauma informed as well, because those issues all overlap—life is messy.

That has definitely affected the situation. Interestingly, the data shows that referrals to CAMHS, which may or may not be for an underlying neurodevelopmental condition, have gone up exponentially over the past 20 years. Twenty years ago, it was about 50:50 between boys and girls, but now twice as many girls as boys are being referred to CAMHS services. That comes from research that Ian Kelleher, professor of child and adolescent psychiatry at the University of Edinburgh, published just in December.

There are differences. I think that the pick-up rate is changing. I also think that it is likely that girls are more sensitive at various vulnerable points to social media messaging.

The issue of personality disorder diagnosis is really complicated, and it will look different at different stages of people’s lives. Such a diagnosis can sometimes be really useful for someone in understanding why they have a lot of emotional lability and why they respond in certain ways, but that needs to be embedded within a helpful formulation. Again, that should not be something that we do to people; there needs to be a conversation and a shared narrative and understanding.

There will be overlap. As a general adult psychiatrist, Jim Crabb is probably more able to comment on that than I am, but the issue is really nuanced. We need to ensure that psychiatrists are trained well in understanding neurodevelopmental differences and how they might affect the way in which somebody responds in a social environment or sensory environment, as well as the role of overload. We should be able to think about people as the complex humans that they are.

The Convener: Dr Crabb, is there a lack of awareness or understanding? Does there need to be sufficient training for people to spot how women with neurodivergence present to the world?

Dr Crabb: The first thing to say is that diagnosis should always be completely objective, and there should never be any prejudice. It comes back to the point that we are dealing with the human mind and the human brain, which is the biggest supercomputer in the known universe. Most people do not fit neatly into one diagnosis or another—sometimes there are multiple diagnoses, and people can have traits of many different things. However, particularly in the UK, we are often taught to think in a very binary way: it is this thing, or it is another thing; it cannot be both things.

You are absolutely right that we need to have training right across the system so that people have that flexibility of thought. It comes back to the danger of people being offered single-condition assessments. If you look for only one thing, that is all you will find.

Many people can be neurodivergent and have traits of personality disorder. A point that we want to make really clearly is that personality disorder can be an incredibly helpful diagnosis for people. Most people who have personality disorder have suffered psychological trauma, so there is nothing wrong with having that diagnosis. The point of any diagnosis, whether it is a diagnosis of personality disorder, neurodivergence or something else, is to make sure that the person gets meaningful help, and that when they go from one person to another, that meaningful help looks the same and it does not change.

It is absolutely right to say that we need to have more awareness and more training right across the system. We must start from having a position, nationally, that we do not have single-condition assessments anymore. We should offer holistic assessments and, when there is a diagnosis, it should be done by somebody who is properly trained and qualified.

The Convener: We would all agree that having a diagnosis that is fit and proper would not be unhelpful to anyone. The data in regard to men and women is quite stark, so it is worth digging into the reasons for that difference. There should not be any shame involved in any diagnosis whatsoever, and finding out the reasons why someone has that diagnosis is helpful.

Marie McNair (Clydebank and Milngavie) (SNP): Good morning. A good majority of my casework has involved folk who have been trying to access diagnosis and support, which is a minefield to navigate, so I am interested in hearing what more can be done to help to remove those barriers. You have covered the question that I was going to ask, but I will ask it anyway, as you might be able to expand on what you have already said.

The college’s report calls for

> “A dedicated funding stream to address cross-societal approaches for autism and ADHD”,

and it mentions the need for a separate national strategy for mental illness and mental wellbeing. Could you expand on that? I know that you have touched on the issue several times, but it would be helpful to the committee to hear any further thoughts that you might have.

Dr Boeing: Most of the children and young people who I talk to spend most of their time at home and at school, not in a clinic, so it is more important to have the resource and the understanding where they spend their lives.

There is a lot of expertise in education and in communities, but that could be made less of a postcode lottery. There have been many test of change pilots across Scotland. There was one in Highland that was led by occupational therapists. In Fife, consideration is being given to educational psychologists joining up with ND services, and, in Lanarkshire, Children First has done a fantastic project based on a whole-family, multisystemic approach that involves life-experienced people supporting families to access what they need and to navigate the complexities of services.

There are many good examples of pilots on which there is evidence that they work, and we could be making the most of those. The provision does not need to look exactly the same in every area, but the same principles of accessible help should apply. There should be no wrong door, whether a kid's issues have been raised by the family or the GP, at school or nursery, or through paediatrics. They might present with functional symptoms or difficulties coping with a chronic condition, which is where it is realised that they could be neurodivergent.

There should not be any wrong door when it comes to access to specialist educational assessments—the improved universal offer helps everybody—or even to consultation, which could be provided when something more specialist, such as a CAMH service, is required. If we have the capacity to provide consultation, we should do that, rather than there being just one door and an endless waiting list. A little drop of our input could make a difference in helping people to get on with what they need to do, but some will always need a more complex assessment.

The National Autism Implementation Team—NAIT—has done an excellent job across sectors and professional groups, and we would endorse its no wrong door approach, just as we would advocate a cross-governmental approach to reduce siloed thinking. The same approach is needed in the community, across all stages.

Marie McNair: It is a question of being able to see the right person at the right time and in the right place.

Dr Crabb: I will add to that. We have suggested additional and separate funding. The specialist mental health system is designed and resourced to meet the needs of about 1 per cent of the population. In mental health services and psychiatry, we have traditionally seen people with severe and enduring conditions, such as schizophrenia, which affect about 1 per cent of the population. However, the area of need that we are discussing affects 10 to 20 per cent of the population. That is why we are experiencing a situation in which the whole system is in meltdown; we are trying to fit 20 per cent of the people in Scotland into a system that is built for 1 per cent of them. We therefore need different, dedicated, ring-fenced funding.

We are hugely excited about the proposal in the budget that that is coming. We are fully supportive of that. The next issue is about how that money is spent so that it does the most good for as many people as possible in Scotland. That is where the national commissioning approach is needed. We need really high, evidence-based standards. We need to walk it like we talk it in terms of our values so that what we commission is accessible and evidence based, that it helps as many people as possible and that there are no wrong doors. That will mean that people and their families get help way before they get stuck and they can keep moving on in their lives.

Marie McNair: One of the cases that I had involved a wait time of three years and eight months. The youngster was 14, so they were approaching 18 before they got a diagnosis. You have said that a person does not need a diagnosis to get support, but how realistic is it for someone in that position to get support? Support comes in many forms, including self-help and peer support, but people are not getting support, and that has an impact on the whole family.

Dr Boeing: Yes, the picture is hugely variable, which is part of the issue. What people will get is down to a postcode lottery. Three and a half years is quite quick when you look at things nationally—it is super speedy, unfortunately. Whether that is a suitable list for them to be waiting on depends on what they need. Again, governmental authority is needed on that to say that the process should be needs led, but it depends on what the young person needs.

Dr Crabb: I will make a connection with other areas. On obesity, for example, we would not countenance an approach whereby anyone in Scotland had to wait for five to 10 years to see a consultant gastroenterologist in order to be diagnosed with obesity before anything could be done about the problem. We need to move away from the current situation and say that, although we still need consultant gastroenterologists to help people with obesity, we need to have a whole tiered approach.

We also need to make sure that any money and resources that we have are spent wisely. It would be hugely easy to squander that money. The money that is proposed could be used to employ

20, 30 or 40 clinicians per year to do a few more assessments—that would make a tiny dent in the waiting lists and then all the money would be gone—or we could spend it in a different way, as we are proposing, which is to move that money out into society to get the help into people's hands.

Marie McNair: I do not think that you will have any problem getting the committee's assistance to lobby the Scottish Government.

Pam Gosal (West Scotland) (Con): Good morning. Before I ask my main question, I have a question on the diagnosis side. NHS England has been considering plans to test children who identify as transgender for autism. That was one of the Cass review's recommendations, which the Government claims to have accepted. Studies have found that those who identify as trans are three to six times more likely to receive an autism diagnosis. Do you believe that NHS Scotland should look into that as well?

Dr Boeing: Very often, the research is transferable, so if good-quality research is being done in England, we can learn from that. The University of Glasgow has been commissioned to do some form of work—again, this is not my particular area of expertise—to look at the relationship between transgender issues and wider presentations.

10:30

Again, that is why it is really important that we see people as whole, complex beings. Being trans is one element of someone's humanness, as is being autistic—it is not an either/or scenario. We must listen, with respect and without judgment, to people's feelings about themselves.

It is not an either/or issue, but it is crucial that we give children and young people space to grow and to try things out and find out who they are in the world, whatever shape or form that might take. I know that trans issues have become a real politicised hot potato, unfortunately, but it is all just about being human and asking, "Who am I in the world?" That is one element of that for people. It is more important that we just listen with respect.

Pam Gosal: You have said that we have to help every child and make sure that they are diagnosed correctly.

Dr Boeing: Absolutely.

Pam Gosal: That is probably the most important thing: to ensure that they have that diagnosis. Have you or Dr Crabb looked into the transgender aspect at all or done any work around it?

Dr Boeing: Not personally—again, it is not my area of expertise, other than that I have had a lot of experience within my general work in CAMHS of working with people who have transgender wonderings or feelings or who strongly present in that way. There is a whole spectrum of presentation around it. Again, I would think of them as complex humans.

Dr Crabb: My understanding of the research that was cited in the Cass report is that there is a large proportion of young people who identify as being trans who are also neurodivergent. I suppose that the issue is the degree to which that neurodivergency might influence their ability or wish to engage in treatment, including for other aspects in their life.

I support the point that, in assessing a young person, we should think not only about neurodivergency but about everything. There are hundreds of different mental health presentations and hundreds of factors that are not psychiatric that influence young people. That highlights the importance of having a really well-rounded, holistic assessment.

If you are assessing young people, whether you are working in a transgender medicine clinic or in a mental health clinic, you need to be doing a holistic assessment to a high standard.

Pam Gosal: Thank you for that. I will now move on to my main question.

What engagement have you had with the Scottish Government and with other public bodies regarding your report? How has it been received by autistic people and people with ADHD in Scotland?

Dr Crabb: We have had really positive engagement, and I express our thanks to all of you round the table today for inviting us here, and to all your colleagues across the Scottish Parliament.

Our paper, which we launched in October, has been endorsed by all the main political parties and by the Minister for Social Care and Mental Wellbeing. The Royal College of Psychiatrists in Scotland is part of Scotland's Mental Health Partnership, which is a coalition of 21 organisations representing lived experience, and they have supported our paper as well. We have also had individual meetings with third sector partners that represent third sector organisations working with neurodivergent people.

It is important to say that our paper is the start, not the end, of a process. We have identified 10 areas across this fiendishly complex landscape in which, if we take forward pieces of work, we can move the situation to a better place. It is incredibly important that we now engage with all stakeholders, and in particular people with lived experience, to ask what the end point should look like. It is important that we start to deliver so that, in 12 months' time, we are not just saying, "This is a really complicated area, there is a huge need and something needs to be done," but we can actually say that we have started to deliver the help and support that people need.

Pam Gosal: While—I am looking at your report here—there has been greater recognition of neurodivergence in recent years, with more coming out, neurodivergent people still face a lot of challenges. For example, autistic people are nine times more likely to die by suicide, with as many as 66 per cent of autistic adults—that is a shocking figure—having thoughts about suicide during their lifetime.

When we took evidence on the delay in the introduction of the proposed learning disabilities, autism and neurodivergence bill, we spoke to people with real-life experiences who said that they felt as though they were at the bottom of the pile when it came to the Scottish Government's priorities. Do you believe that neurodivergent people are being failed?

Dr Crabb: The current system is failing everybody in Scotland. To reiterate those terrible statistics, life expectancy is six to eight years less for someone who has ADHD compared to the general public. It is scandalous. It is because we are trying to fit 10 to 20 per cent of the population into a system that was always designed for 1 per cent of the population. Of course we are failing people and of course they are not getting the help that they need. They become stuck in their lives, despondent and filled with despair, with terrible outcomes.

That highlights the fact that we need to think differently about the situation and that we must start to deliver. It would be a terrible tragedy if, in a year, we had some ring-fenced money and had done a waiting list initiative and a couple of projects, but there was still a huge need and people were still waiting for years and decades for help and support. That would be a tragedy. We need to move forward and start to deliver this year.

Pam Gosal: Is there anything that you would like to add, Dr Boeing?

Dr Boeing: Yes, I agree. It is a pertinent question. For the most part, we are failing, but some areas of improvement are really exciting. It is important that we do not become too downhearted, but it is also important that we galvanise to make meaningful and sustained change.

In many of the areas where there are exciting and evidence-based really good outcomes, the problem is short-term funding that is not sustained. People put in a ton of expertise, work and relationship building and get good outcomes, but the funding does not continue, so what happens to all that work? That is an important aspect.

The awful statistics that you quoted show that it is a whole-society issue. There are social determinants of suicide, such as people being and feeling excluded and not feeling as though they have meaningful purpose and worth in the world. That is a complex issue, but it is important. People who are neurodivergent are much more likely to have co-occurring mental health disorders, which are treatable. Being able to have that identified and to get access to timely treatment and support for it is crucial, but that requires a multifaceted, joined-up approach. It is not an either/or.

The Convener: We are coming to the end of our session. Please correct me if you disagree, but I think that we are living in a society in which people seek to understand themselves a bit better. It is a positive thing for people to be self-reflective and to question why they behave or think in particular ways.

We have spoken a lot about the individual and adjustments for the individual. If we think about yesteryear, perhaps there was always the same number of neurodivergent people, but there was not as much self-reflection. Maybe behaviours were shamed in the past. Many people were in health institutions, many ended up in prison, and many ended up isolated and tagged as the eccentric in the village.

We now have a greater understanding of that, so as well as supporting the individual with adjustments, would it be better if we sought to take a whole-society approach that involved looking at how the world is created and set up for neurotypical individuals? Would it be better to take a bigger approach to ensure that society is set up for everyone and that adjustments do not have to be made all the time?

Dr Boeing: The statistic of 43 per cent of kids having additional support needs says it all. We need to take a societal approach. I keep reflecting on the fact that the universal offer needs to be more flexible and kinder.

It is good that we are all different—that has happened for evolutionary reasons. It is also wonderful that we are all more able to think about ourselves. The stresses of the way that the world is now mean that we have to think harder about that.

The world has developed so fast and our daily lives have changed so much in the past 100 years, especially in the past 20 years, with digital, that our brain evolution has not kept up, so we are having to think harder about how we survive and how things work, because our lives are different.

I could not agree more that we need a whole-society approach. It is fine for us all to be different—that is really not a problem; in fact, it is an advantage. The more we can support people to get through their daily lives and quietly or loudly thrive, the more they will be able to contribute to society. They will be able to pay their taxes, have wonderful ideas, bring joy and parent well—the list goes on and on. It will get us into a virtuous cycle if, from the get-go, we can accept that there are real advantages to people having differences.

Dr Crabb: I echo that. Leonie said it beautifully; I could not improve on that. Given that we are talking about 10 to 20 per cent of the population, we need to think about re-engineering society. Looking forward, it would make sense, in commissioning a public building, to think about making it neurodivergent friendly. Why would you not? If you were designing a policy or a procedure in an organisation, why would you not make it neurodivergent friendly? We absolutely agree that that needs to change across society.

However, we are where we are, and today's session is about asking what we can do this year to start to put things on a better trajectory. In my experience of trying to manage a small part of the health and social care system, millions of pounds could be spent on repurposing a single building. Unfortunately, we just do not have the resources this year to re-engineer all the things that we would like. That is why we have recommended that the pillars of work start with giving people advice and making reasonable adjustments. Maybe they should not have to be called reasonable adjustments, but that is a good enough starting position for now.

We must start to make things better. We cannot continue to fail people in Scotland. We can start to give people the help that they need so that they can navigate a world that is far from perfect and have the opportunity to flourish.

The Convener: That brings this part of the meeting to a close. I thank you for your evidence.

I suspend the meeting briefly to allow for a changeover of witnesses.

10:42

Meeting suspended.

10:48

On resuming—

The Convener: Welcome back to our second evidence-taking session, which will take place in a round-table format.

I welcome to the meeting Debbie Best, director, Differabled Scotland; Kabie Brook, chairperson, ARGH Scotland; Sofia Farzana, director and co-founder, Scottish Ethnic Minority Autistics; Marion McLaughlin, managing director and founder, Aurora Autistic Consulting; Rachel Parker, founding trustee, Autistic Voices Advocating Together for Autonomous Rights; Carolyn Scott, founder and researcher, ADHD Right Now; and Leo Starrs-Cunningham, treasurer, Autistic Mutual Aid Society Edinburgh. I hope that I got all of that right. You are all very welcome to join us this morning.

I will begin this morning's conversation by inviting everyone to very briefly introduce themselves. I am the MSP for Banffshire and Buchan Coast, and convener of the committee.

Maggie Chapman: Good morning, everyone. I am deputy convener of the committee and an MSP for the North East Scotland region.

While I have the microphone, I also want to declare an interest. Carolyn Scott and I worked together in my previous role at the Scottish Council on Visual Impairment prior to my being elected.

Pam Gosal: Good morning, everybody. I am a committee member, but I am also an MSP for the West Scotland region.

Carolyn Scott (ADHD Right Now): Good morning. I am from ADHD Right Now.

Marie McNair: Good morning, folks. I am the MSP for the Clydebank and Milngavie constituency in the west of Scotland.

Sofia Farzana (Scottish Ethnic Minority Autistics): Hi. I am the director of Scottish Ethnic Minority Autistics.

Leo Starrs-Cunningham (Autistic Mutual Aid Society Edinburgh): Hi. I am the treasurer of AMASE, or the Autistic Mutual Aid Society Edinburgh.

Iris McNab: Hello. I am here to support Leo.

Tess White: I am an MSP for the North East Scotland region.

Helen Gibson: Hello. I am here to provide support for Debbie Best.

Debbie Best (Differabled Scotland): Hello. I am Debbie Best, founding director, Differabled Scotland.

Paul McLennan: I am a member of the committee and the MSP for East Lothian.

The Convener: Thank you. We will now go to those who are joining us online.

Marion McLaughlin (Aurora Autistic Consulting): Hi. I am the managing director at Aurora Autistic Consulting, which houses Autistic Pride Aberdeen.

Kabie Brook (ARGH Scotland): I am here as a representative of ARGH Scotland, which is a charity run by and for autistic adults.

Rachel Parker (Autistic Voices Advocating Together for Autonomous Rights): I am founding trustee of Autistic Voices Advocating Together for Autonomous Rights—AVATAR—which is the autistic people's organisation for the Scottish Borders.

The Convener: That is great, and thank you all so much for joining us this morning.

We will now move on to the themes that we will be exploring this morning, and which committee members will take turns at introducing. Please indicate if you would like to come in on anything. If you are in the room, you can raise your hand or signal to me or the clerks—we will pick it up—and if you are online, please put an R in the chat. If you want to type out a question, that will be perfectly acceptable, too.

First off, I will go to Maggie Chapman, who has a question.

Maggie Chapman: Thanks very much, Karen. Hello again, everyone, and thank you for joining us.

The first theme that I want to explore is access to assessments and any treatment or medication that comes after. How long did you have to wait to get an assessment, and what impact did that have on you, from your experience?

I do not know who wants to pick that up first. Debbie, I saw you nodding. Do you want to go first?

Debbie Best: Okay. If we are talking about chronological age, I had to wait 53 years for assessment. I was diagnosed six years ago as autistic; it was also flagged up that I displayed ADHD traits, but that was not taken any further. It happened just before Covid. In other words, it took a lifetime, really, to work out that I was neurodivergent and doing everything differently. The process then took two years for me, but I am still on the wait list for ADHD assessment.

Marion McLaughlin: When I asked for an assessment, there was no assessment pathway available at all. It took six months of going back and forth and being told that I did not qualify for an assessment, because I had no mental health diagnoses. I have to say that I laughed heartily at that, because if anyone had looked at my notes, they would have seen that I had had anxiety pretty much my entire life.

It was not until I hit the point of absolute burnout, calling the hospital in tears in the middle of a shutdown, that I was able to access an assessment. At that point, they said, "Okay, Mrs McLaughlin, we'll see you in a month's time." Even then, I did not know what was going to happen. Therefore, I had to hit the worst mental health that I had ever had in my life to be assessed, which was at the same time that my child was going through their own issues trying to start primary school and so on. I do not think that people realise all the different things that are going on when you are trying to access an assessment.

I was in the fortunate position that, three weeks after I got my assessment, I was able to join the working group that ultimately set up the assessment pathway that we had in Aberdeen and Aberdeenshire, which, very quickly, filled up incredibly fast. People had a long wait, but they knew that it was coming and that it would be there in the end. When the assessment pathway started closing down, we had people getting in touch to say that they had lost hope. Not having access to that at all meant that they were questioning everything and thinking "What is the point?"—it made everything much harder.

Speaking for myself, knowing that I am autistic meant that I felt able to go and access the community; I felt better able to advocate for my rights; and I felt as though I could make a difference for my community in a way that I could not do before. It has been life changing and, I would say, life saving for me, as well.

Carolyn Scott: If I take Debbie Best's approach, I will be 57 by the time that I have an NHS diagnosis. I do not just look young for my age; in my health board, the wait list is now 17 years.

I sought a private diagnosis after being misdiagnosed with bipolar disorder when I was 20. The misdiagnosis was understandable; there were no diagnostic criteria for ADHD then, so you could not be diagnosed with ADHD. I went to my GP two years ago, and that was the wrong time, because lots of people were going for ADHD referrals, which meant that NHS boards started rejecting referrals and triaging them. Mine was rejected on the basis that my GP had not written about my childhood experiences; they had not been told to do so and did not know that they should.

By the time I had been back to the GP and filled in all the forms again—for someone with ADHD, that can take some time; we are not very good at that kind of stuff—the wait list had grown. I was deterred from joining it. I was asked, "What do you hope to achieve from an ADHD diagnosis anyway?". Having explained that I just wanted to know that all the things that had gone wrong in my life—the failures and the dropping out of uni—were because of a disability, I was finally put back on the wait list. However, having seen that the wait list was 17 years, I looked into getting a private diagnosis.

I do not believe in private healthcare, because I believe that it widens inequalities, but I was desperate. I could not afford it and I put it on a credit card. I thought that I would have access to medication, but I am in a health board that does not provide shared care, so it will be 17 years before I can get the medication through the NHS that, for the past two years of my life, has been absolutely life changing.

Sofia Farzana: I first realised that I was probably autistic after some teacher training, which was optional in my area. I realised that my son was autistic, too, which explained his mental health difficulties. As was the case for Marion McLaughlin, though, there was no pathway, and I was referred to a psychiatrist. When I said to them, “I would like to get an assessment because I think that I am autistic,” their response was, “No, some beta blockers would help you. Just leave your abusive marriage and you’ll be fine.”

Three years later, I had severe burnout, so I went back and I was put on a waiting list. I waited two more years, then finally got my diagnosis after two hours of seeing a psychiatrist. However, they said, “Oh, it must be very mild because you’ve got so far,” without them taking account of how difficult and painful life was or the fact that it was a miracle that I was still alive. When I asked for an ADHD assessment, I was told no and that it was just generalized anxiety disorder. I was given some anxiety medication, and that particular one is really bad for people with ADHD, which caused even more problems.

I had to keep pushing back with the psychiatry department. I went through five psychiatrists, one of whom prescribed me medication just to prove me wrong, but without any assessment or any questions asked. It was a case of, “Here you go—take some medicine.” He was surprised that my reaction was different from what he had expected, and, in fact, he had to admit that I had ADHD. I was told by that psychiatrist that, as you get older, ADHD goes down. Subsequently, when I challenged them and their attitudes, the following psychiatrist removed that from my medical records. My records have a letter to say that I have ADHD and another letter to say that I do not, and I do not know which of the letters in my medical records people will go for when I need extra help or support when I hit other parts of my life.

When I was trying to seek the ADHD diagnosis, I was told that the pathway had been closed because there was no medication, which was the reason why they were not doing assessments or taking referrals. We now know that all the assessment pathways in Forth Valley have been closed, so there is no way that I will go back to ask for my case to be reinstated and to get medicine. I do not know where I am standing now, because they refuse to look into my case.

Maggie Chapman: I think that Kadie wanted to come in.

11:00

Kabie Brook: It is Kabie. I was diagnosed at 30, which is more than 20 years ago, but my first interaction with a psychiatrist was when I was about 14. I was in and out of mental health services for the whole time between 14 and 30, with long periods of distress—my life was a mess and I did not know who I was. I was screened for lots of things but was told, “No, you don’t fit this, you don’t fit that.” Autism was never mentioned at all—it simply was not on people’s radar.

Eventually, the reason why I was referred for an assessment was that my child was going through one. When I got a lot of forms to fill in about what my child did that was unusual, I said, “But none of this is unusual. That’s me. That’s how I am. I’m all those things.” The clinicians involved in his assessment said to me, “You know, perhaps you should have an assessment.” It is quite common that autistic parents who are not identified as autistic are picked up or recognise themselves when they have children who go through the process.

Before diagnosis, I went through periods of burnout and the doctors thought that it was depression. I have had every antidepressant that you could ever think of—I mean, sometimes I was depressed, because my life was a bit of a mess—but no one understood me, and the major thing was that I did not understand myself. I simply thought that I was a broken human, that I was no good at being human and that I did not really deserve to be here because what use was I anyway.

The difference that the assessment and then the diagnosis made was that it gave me self-worth and validity to say, “I am a real human and I’m worth being here. I’m just an autistic human and that’s fine.” It also enabled me to connect with the autistic community, which pretty much became my only support, because not very many services exist. It was massive and life changing, and it saved the NHS a lot of money, because I stopped sloshing around in the mental health system and going to appointments that I did not really need, which were not very helpful and were sometimes harmful.

Maggie Chapman: Thanks for that, Kabie, and apologies for getting your name wrong.

Rachel Parker: I was not diagnosed until I was 25, following many years of what was explained away as mental health challenges, not being able to get “better” through cognitive behavioural therapy, taking multiple antidepressants and believing that I was just not trying hard enough to get better.

During that time, I dropped out of uni twice, had to leave multiple jobs and always believed that not being able to manage in a way that everyone else around me seemed to be able to was my own fault. Getting my diagnosis gave me the opportunity to understand myself better and to make requests for appropriate accommodations. I eventually completed my degree with first-class honours through the Open University—12 years after starting my higher education journey.

Although I had a supportive GP and I was under a psychiatrist and the community mental health team, it was only my occupational therapist who eventually considered that I might be autistic, after she attended a training about the gendered differences in autism presentations—she had been wondering whether that was why I kept giving her the “wrong” answers in my CBT assignments. After being given the AQ-10 screening test by her, I went home and googled it and found out what the questions had been about, and I then read a lot about autism in women. All of that made so much sense of my experiences and the challenges that I had been facing. However, it still took over a year and multiple complaints and support from my local representative for me to eventually get an assessment.

Carolyn Scott: I spoke of my lived experience of accessing assessment but, if I may, I will summarise some things that we have heard from people who we have worked with who have tried to access ADHD assessment. One of the most common things that we hear is people being told that they are too successful to have ADHD because they have a PhD or a degree. Somebody was told that they could not have ADHD because they were married and were holding down a long-term relationship. That is what people have been told by GPs. Women have been told that they are just hormonal and anxious, and are treated for anxiety. I do not blame GPs for that. There is a lack of understanding, education and awareness.

We also have the fact that 30 per cent of people in Scotland live in areas where they are unable to receive a neurodevelopmental assessment through the NHS at all. That has been highlighted in research that was conducted by the Scottish Parliament information centre. So, the fact that I am on a 17-year wait list makes me one of the lucky ones. In those areas, people are not allowed access to neurodevelopmental assessment unless they have significant co-occurring mental health conditions. That decision making has been done by GPs who are not given the support that they need to make the decision. Across Scotland, 30 per cent of people do not have access to assessment at all.

Leo Starrs-Cunningham: Unsurprisingly, my experience is different from all the others. I was diagnosed when I was six, which is well over 40 years ago now. Throughout my life, when I have had adequate support and been very successful, either doctors or environments that I have worked in have attempted to challenge my diagnosis and support requirements. Having the diagnosis has been really helpful in enabling me to hold the line and fight for the support that I need, which on the face of it lots of people do not expect.

I receive over 50 hours of support a week, which has enabled me to achieve multiple degrees, and I have done high-level jobs at executive level when I have had that support. However, quite often, when I start to achieve, I can get burnout. As the others have described, that is then seen as me just being depressed—it is the pull-your-socks-up mentality. Despite that whole experience and the weight of the diagnosis being behind me for all my life, that is still a challenge that I face quite regularly.

Maggie Chapman: Thank you all very much for sharing your personal experiences.

Leo Starrs-Cunningham and Rachel Parker talked about support or appropriate adjustments and accommodations. I would like to open up a discussion on that. What are the kind of things that you know work? Obviously, they will not necessarily be the same for everybody in different situations, but what are the kind of things that you know work and that we should be thinking about more generally across society, so that there is the awareness and understanding that Carolyn Scott indicated are so lacking in some healthcare professionals?

Leo Starrs-Cunningham: In my personal experience, what has made the most difference is being able to have my support present with me and having that personal contact—almost a mediator—which means that I can quite often process things afterwards in a way that is much more helpful for me and avoids misunderstanding.

The environment is the biggest challenge and the hardest area in which to get adjustments, because of the design of buildings. I know, having worked in different corporate environments, that it is quite often very hard to get corporations to make adjustments of that kind. That is partly because, essentially, the building should have been designed with people with different needs in mind.

There is still, in the environmental sense, very much a preponderance of focus on more visible disabilities. That is right and it should be there, but it leaves those of us with invisible disabilities on the sidelines—if we are lucky. When I challenge that, quite often my needs start to be questioned: "How are they valid? You've done the job successfully for X number of weeks or months; why do you need this change now?" I am thinking, "Well, I don't just need the change now—I actually needed it at the beginning, but it has reached a point where I cannot do what you want, or what I want, to do successfully enough without these adjustments."

Marion McLaughlin: Last year, I spent the day at our local jobcentre speaking with neurodivergent jobseekers. One of the questions that I asked everybody was "What reasonable adjustments have you asked for?" I got a look from everybody that said, "What do you mean by 'reasonable adjustments'?"

There are a lot of neurodivergent people out there who know, or suspect, that they are neurodivergent but do not know anything at all about any reasonable adjustments. They do not know that they can ask for such adjustments whenever they are going for job interviews, even before they are in a job, or when they are in education. They have no clue what a lot of the adjustments are.

That is one of the reasons why, on the Aurora website, I have a list of potential reasonable adjustments that people might want to access, because if people do not know what sort of things they can ask for, they might not ask for anything at all. Our rights in respect of access to reasonable adjustments need to be made very clear to us at all points when we are trying to figure out whether we are neurodivergent.

Sofia Farzana: One reasonable adjustment that helped me when I was going for job interviews was getting the questions in advance, along with being given time and being able to bring in notes. I am from the education sector and I had not heard of that beforehand—I do not know why it is not universal.

However, that did not help me to get any jobs—being given that reasonable adjustment and being openly autistic and ADHD with the people who were recruiting, and the fact that my answers to the questions were very ADHD, were the very reasons why my job application was declined. I can do all the preparation in the world, but I cannot change my non-linear thinking. Reasonable adjustments are, therefore, only as good as the understanding of why people are given them.

Maggie Chapman: Thank you, Sofia—that is a helpful point to hear.

Carolyn Scott: Given the difficulties with access to diagnosis, my point, first and foremost, would be that access to reasonable adjustments must be based on the lived experience of the individual and not on a formal diagnosis. I am lucky to work in an environment in which that is the case.

There are some things that help people with ADHD; they tend to be quite different and varied, and more individualised. ADHD coaching, for example, can be fantastic, but it can be expensive. You can get it through the access to work scheme for one year without having to go through too many hoops, but only by going on a six-to-12-month waiting list for the access to work call.

I work in an education setting and I am a university lecturer during the day. I work with students who do not have a formal diagnosis, and they cannot access ADHD coaching because they cannot access the access to work scheme, as they are students. Coaching is, therefore, not available to everybody, although it can be incredibly useful.

With ADHD, one of the best reasonable adjustments is having access to medication. It is not for everybody and it is not a cure, but it can mitigate the negative outcomes. Fundamentally, however, the biggest reasonable adjustment that we really need is a culture change. As Marion McLaughlin said, a lot of people do not know that they have a right to claim reasonable adjustments. They think that if they do not have a formal diagnosis, they have no right to claim them. We need an understanding and awareness of that aspect; we need people to feel more confident in asking for adjustments and understanding their rights; and we need people to start listening to, and believing, people with ADHD and autistic people.

Debbie Best: For me, the issue is probably the invalidation if you divulge your situation and ask for a reasonable adjustment. I am not talking about a work situation—I am talking about social and general situations, such as going to hospital, asking for help, problems in queues and not being able to wait in the phone queueing system for a general practitioner appointment. I received a response that asked why I should be treated differently from someone who calls up who has cancer. There was no validation of how difficult it is for me to sit and wait in the queueing system with music playing and so on. That kind of response sometimes makes people not want to divulge their vulnerabilities, because they are often judged. They say what they need, but the response is, "Why should you get anything different? You look and behave the same as others". I have been asked for evidence when I have said that I am autistic. People have said, "How do I know that you are?" My answer is, "Because I said that I am." That makes people revert or regress. They think, "I'm sharing this, but it becomes traumatic each time I share it, and I'm getting this judgment and stigma placed on me".

11:15

Something that works for me—the previous panel spoke about this—is quiet space on my own. Traditionally, quiet areas in schools and other places have still been shared spaces. I and, I think, many neurodivergent people want to be there and decompress on our own, in privacy, instead of in front of other people. People may start to engage and talk, which can really increase your arousal levels.

When my sons grew up and I realised that they had difficulty in queueing situations in relation to their neurodivergence, it became very apparent to me that I had difficulties. Help and support are important for people going into busy environments such as a cinema queue or an airline queue, but people are still having to evidence why they need to jump the queue when anxiety develops and the shutdown starts to happen for them.

More widely, accommodations are often controlled by social work, and the bar can be set very high. An example is self-directed support. At a personal level, I am receiving support for one of my sons at the moment, but no adjustments are made for me. I am treated in a bog standard way, and it has become a traumatic experience that has been severely damaging to my health and wellbeing.

Maggie Chapman: Thank you, Debbie. Rachel, do you want to come in on this?

Rachel Parker: The biggest change for me has been in accommodating the ways that I talk to myself and think about myself, and not blaming myself for not being able to do what other people can do in the ways that they can do it. That has had a really big impact.

At university, my accommodations primarily involved the fact that the course was designed to be modular and part time. I had a support worker funded through disabled students allowance to support me with planning, organisation and communicating with the course staff. My tutor also spent additional time with me to make sure that my understanding of the assessment questions was what was intended, rather than me being more literal in understanding the questions. When topics did not make sense to me, they provided explanations to make sure that I fully understood the content, rather than saying, “You just need to accept that that’s how it is.” I needed to understand why it was how it was, and they were able to provide those explanations. I was also given understanding and flexibility around assessment deadlines when other aspects of life contributed to stresses, and that allowed me to avoid more significant burnout.

At work, I have been able to accommodate myself, primarily by turning to self-employment and designing my job as a wholesale baker on purpose to minimise interactions and interruptions from customers. Compared with a more traditional bakery set-up, we have more regular orders and more predictability. That has been possible only with my access to work support of 40 hours a week, which has allowed me to set up and run a multi-award-winning social enterprise. I have support workers with me in person to support me with my executive functioning and communication.

I do not think that you can see them on the screen, but I have a support worker with me today as well. It makes such a big difference, particularly on phone calls, as it enables me to ensure that I get across what I intend to say and minimise the risk of significant misunderstandings and the additional stress that I would face in trying to do that myself in a world that is built for neurotypical communication styles. I have been able to receive self-directed support at home through social work, and that ensures that I am prepared for work and able to manage regular meals, medication and so on.

Kabie Brook: First, I would echo the point about how difficult it is to get any kind of reasonable adjustments as an autistic parent or a neurodivergent parent. Although the school or someone else might accept that my child needs support and reasonable adjustments—it is a bit of a nightmare, in fact, but they might accept it—if I need reasonable adjustments in the way in which I communicate with the school, health services or other people, it is almost as if they think, “Well, we can’t deal with two of you. We are already dealing with your child; you can’t be like that as well.” Because I am a parent, I should just be able to get on with it, and the idea that I might need reasonable adjustments myself is completely dismissed. That even goes for tiny adjustments, such as “Please don’t phone me out of the blue. Could you email me first?” I do not think that that is that difficult for a non-emergency situation.

Secondly, we surveyed our members, and there were a couple of comments that I particularly wanted to share with you, from two different people.

The first is:

> “Now I have a great job. Reasonable adjustments have been made and continue to be given at the time I need to make changes. I have supportive colleagues who really make an effort to support me in the workplace, encourage me and remind me to reinforce my capableness when I am not feeling very capable. I have flexible work hours in case I’m having a bad day and struggle to leave my home.”

That is a really good, positive one.

The second one is:

> “Although my son has a job that he has worked at for over 10 years, now he is still fighting to have the four basic

reasonable adjustments he asked for adhered to. His managers regularly make nasty comments and behave in a bullying manner towards him in front of other staff."

I wanted to read out those comments because they show very different experiences. That is at the core of it, in that it depends on your line manager, your colleagues, the teacher or the police officer that you come across. It is all luck. Whether you manage to talk to the right person, who understands and is quite happy to make reasonable adjustments for you, is down to luck. It should not be down to luck.

Maggie Chapman: Thanks very much for that, Kabie. I do not know if you could see, but there were a lot of people around the table nodding as you were speaking. What you were saying clearly speaks to other people's experiences as well.

Leo Starrs-Cunningham: I have two points to make. One of the things that I found most difficult to argue for regarding my support was that it needs to be professional and trained; it should not be provided by just anybody. That was a big challenge when I was at university, as people were always trying to persuade me to take other students. I felt that that was grossly inappropriate, because they do not have the specialist knowledge to support me. Also, they are my peer group. My support was also for my physical wellbeing, and that is a line that I do not think should be crossed. There are a lot of privacy issues there for me, and I felt that that was unreasonable.

AMASE surveyed its members, and we found that 37 per cent of our respondents said that it was extremely hard to get reasonable adjustments, about 25 per cent said that it was hard, and only 8 per cent said that it was easy and successful. That is pretty damning when it comes to accessibility overall.

Debbie Best: In relation to those of us who are neurodiverse and working the third sector, this is an issue that I have started to raise with funders. Reasonable adjustments are made across schools, colleges and universities, but applicants have experienced great difficulties with managing their time and so on. Is it possible to look into making reasonable adjustments for neurodiverse applicants because our processing is slower and there is a need to go back and check?

Yesterday, I submitted an application and they had a tech problem, so I shut down the whole day—I could not function after that. Some kind of support, similar to what is there as people move through life, could be really helpful.

Maggie Chapman: Rachel, you wanted to come back in.

Rachel Parker: I want to echo what Leo said. I, too, have found it incredibly challenging to recruit appropriate support workers, even with my active access to work award in place, because support worker stereotypes do not include people supporting the likes of a chief executive officer setting up a social enterprise. Autism expertise and business expertise are not expected to be combined.

Moreover, I do not think that the value of the access to work awards and the rates of pay that support workers are awarded recognise the level of expertise that is required to support someone to function at that level, although there is no reason why we should not be expected to function at that level.

Maggie Chapman: I will hand back to the convener now but I thank you all for your answers to that question.

The Convener: We now have questions from Marie McNair.

Marie McNair: Carolyn Scott, you spoke about medication. What are the issues with accessing it? I have examples from constituents of mine, but I want to hear from you.

Carolyn Scott: I am on medication right now, because I got a private diagnosis—I saw that, in light of a 17-year wait, I could probably manage the £750 fee. At the time, I thought that I would be able to enter a shared care agreement, in which the NHS would provide the medication for me based on that private diagnosis—that was the only reason that I spent the money on that. NHS Lothian then changed the rules, and shared care agreements are no longer allowed based on private diagnosis.

My medication costs more than £100 a month. Last year, I had to stop taking it because I could not afford it. I got sick within three weeks because of burnout and ended up off work. I was incredibly unwell. I have gone back on the medication and am basically putting myself in more debt right now, which encourages me to carry on fighting in order to rectify the situation in NHS Lothian.

Importantly for the remit of the committee, that policy is a failure to uphold the Equality Act 2010. I asked NHS Lothian for details of equality impact assessments relating to its policy, and it confirmed that it had not done any. It brought in a policy that restricted access to medication to a group of people with a disability but did not carry out a basic equality impact assessment on how that would affect them.

However, as I said, I am one of the lucky ones, because there are people across the country who cannot even get a diagnosis. If you cannot get a diagnosis, you cannot get access to medication.

The process of titrating medication and getting the right dose is long and difficult, but my personal experience is that medication is life changing. I have been in better mental health in the past two years than at any point in my life. Depressingly, I will probably have to stop taking medication again quite soon because of the lack of access to and the cost of it.

I know that medication does not work for everybody—I cannot speak on behalf of everybody with ADHD—but it can have a massive effect for some people. Moreover, research shows that medication, for people with ADHD, can hugely mitigate a lot of the negative outcomes that are experienced. The socioeconomic impact and cost to our society of the levels of suicide, accidental harm and accidental death mean that more people end up relying on other services. Take the number of people with ADHD in prison. The cost of imprisoning people is higher than the cost of diagnosing them and giving them access to medication, which can mitigate those negative outcomes massively.

Marie McNair: I have been given similar examples by constituents of mine who went down the private assessment route and were then refused access to medication. Is that the same for everybody else? Is that an issue across Scotland? Does anybody else want to come in on that?

Sofia Farzana: My experience was that I was not allowed to try anything beyond the two brands of medication that were given to me, which were a stimulant and a non-stimulant. Even though they really helped to make a difference and had a hugely positive impact on linear thinking, doing things in order and managing a household—I was the only adult looking after three kids—they had side effects. When I asked whether I could try different medication, the policy was that patients only get to try two. It is like you get two strikes then you are out. After that, you are discharged—you are done and on your own. I was accused of seeking a diagnosis or support from psychiatrists because I just wanted to get a prescription. That attitude is just not on.

On shared care, that is another problem that we have in Forth Valley. For people who can afford the diagnosis fee, there is an on-going cost if they have to keep going back. Whether there is any allowance for tweaking the medication, and for that back and forth, depends on who the practitioner is and on whether they ask what the patient needs.

11:30

Marie McNair: I clarify that the constituent who I was referring to was refused access to medication because they had received a private diagnosis.

Carolyn Scott: I will come back in on access to medication. Another huge barrier is the stigma around medication. There are, understandably, many parents who are not supported to understand what the medication is, its impact or its side effects. Often, they do not seek a diagnosis for their children because they do not want to put their children on drugs. There is such stigma around the issue. I have heard some people say, “You’re giving your kids speed.” People have said to me, “You just want an ADHD diagnosis so you can get amphetamines.” A lot of people are put off from accessing medication because of that societal pressure and the suggestion that they would be drugging their children.

Debbie Best: I am still awaiting assessment. I will go back to the point about whether assessment is important. Of course it is, because how could I possibly access ADHD meds without it? The reason I want to do so is that I have had lifelong anxiety, and, like many other people who have spoken today, nothing has quite worked.

A family member who went on to ADHD meds in adulthood told me that, for the first time in their life, their anxiety “melted away”. I feel that I should have that basic human right to go through that assessment process. I could probably save the NHS money and self-diagnose, but it is about trying that medication and seeing whether it improves my mental health, which would reduce overall costs to the NHS.

Marie McNair: Medication is not the answer for everyone, but I saw its effect on a school chum’s son. He was prescribed Ritalin at the age of six and it was life changing for him. He is now in his 20s. I think that it would be a different story had he not been able to access that.

Pam Gosal: I thank the witnesses for all the information that they have provided so far. I have two questions. My first question is on employment, which a number of you have touched on in relation to reasonable adjustments. It is estimated that the employment rate for autistic people is only 29 per cent, whereas Scotland’s national employment rate is 82.5 per cent and, for non-disabled people, is 50.7 per cent. Those figures show how much lower the employment rate is for autistic people. How can we help autistic people not just to enter the workforce but to remain in it over the long term?

A number of you mentioned the support that you need. Sofia Farzana, you mentioned how getting interview questions beforehand would make it easier. It would be good to hear from everybody on what additional things could help you.

Rachel Parker: In addition to the autism employment gap, there is also a pay gap between disabled and non-disabled employees, with autistic employees experiencing the largest pay gap of any disability. That pay gap was 27.9 per cent in 2024. Disabled employees are also more likely to be underemployed and in low-quality jobs, and 47 per cent report lower prospects for career progression.

In addition, 13 per cent of disabled workers are self-employed compared with 9 per cent of non-disabled workers. Disabled workers are more likely to be self-employed due to barriers in accessing traditional employment. As such, employment for disabled people is disproportionately found through self-employment. We need the entrepreneurial ecosystem that supports self-employment to be more accessible. Disability should not be treated as a taboo or a niche for which, in business support sessions, we are told, “Oh, we will talk about that separately.”

The “Road to Wonder” report highlights the value of disabled entrepreneurship and innovation and what we bring to the economy. It also highlights the need to incorporate wellbeing into a more holistic approach to entrepreneurial support. There are great individuals out there who provide fantastic support, but they are not necessarily representative of the wider organisations that they work for.

When funding for projects is short term, the reporting and, therefore, the data on their long-term success will be, too. The interventions will then be lacking and on-going support will not be available, particularly when the interventions are targeted at underrepresented groups such as women or those with disabilities.

The access to work system, which is intended to mitigate the impacts of a person’s disability in the workplace, is currently not fit for purpose, with around 62,000 individuals still stuck in a backlog and waiting for decisions about their award. The awards that are being made are being cut by 40 to 60 per cent, if they are not removed completely at the renewal stage. That results in a lack of support as well as difficulties in accessing the process itself, which has a massively detrimental impact on an individual’s ability to engage in traditional employment and self-employment.

Marion McLaughlin: I come at this question from a couple of different angles: not only as an autistic person who has had multiple different jobs in different sectors but as a former employer who employed purely neurodivergent people when I worked at a charity called Autism Understanding Scotland. We were able to get disability confident leader status when I was there, which we worked really hard to achieve.

The approach that we always took with our employees was very individual. We asked, “What do you need? What works best for you? How can we make that work around your family?” A lot of people forget that autistic people often have families, too, and often have children who might need a bit more flexibility. When I employed autistic people, our unofficial motto was “family first”. That was because, if someone is worried about their family, they cannot concentrate on their job.

We made sure that our employees had that flexibility so that they could do their hours at a time that worked for them. We gave them lots of understanding and support so that they could work around their needs and look after themselves. If they needed a mental health day, they could take a mental health day. If they needed a sabbatical, they had the opportunity to take a sabbatical, and their job was still there when they came back. Having all those things in the first place when we were building the organisation made that things much easier.

My employees would consistently tell me that having a boss who is also autistic and neurodivergent, and who needs flexibility, made the world of difference to them. They said that it was the most confident that they had ever felt in asking for reasonable adjustments, because they knew that they would not be mocked or misunderstood. They knew that they could have conversations about it. They knew that, if they started going through perimenopause and they needed something different, they could come and get it. There were all sorts of reasons why having such a boss made things much more accessible for them.

I am now self-employed, which works out well for me—I absolutely love it. However, being self-employed can make us incredibly vulnerable. If someone needs to take time off because they need surgery and time to recover afterwards, they cannot necessarily access the same supports that they could if they were in a larger organisation. However, there would also not be all the pitfalls that people might experience when working for a larger organisation. As a disabled individual, I feel that there are no good options available; every option has its pitfalls.

As Kabie Brook mentioned, you can be really lucky or really unlucky in who you get as a boss. You can work in an organisation for 10 years and have a brilliant experience then everything changes straight away when you get a new line manager. Our employment can feel very precarious at times. On some days, it is a toss of a coin as to whether we are understood.

Debbie Best: Just to add a bit of humour, I had so many jobs and career changes—that is probably the case for most people here—that I thought that it was because of my astrological star sign, since I am a Gemini, before I realised that I was autistic and that that was why things did not quite fit for me.

The thing that stands out most is the social anxiety that comes with working in large settings, particularly with lots of females, and managing the dynamics of those relationships. I used to always feel like I was on the outside looking in. Differabled Scotland is a very small organisation, and everyone on the team is either neurodivergent, suspects that they might be, or has neurodivergent children, which enables us to create what everyone needs to make work happen.

For many years, I was unemployable. We had a family business, and that is how I would sum it up: unemployable, except for working in the family business. That was because I used to get calls from my son at school, sometimes a dozen times a day. I had to stop work and leave. How can you be employed under those circumstances? If you are a neurodivergent mother, it is really difficult to maintain employment. If your child stops attending school or attends only part time due to emotionally based school non-attendance, how can you work? How can you maintain work? Will an employer really come forward and offer you adjustments? Some might, but it puts working parents in a really difficult situation.

For many people, fear of disclosure in the workplace can bring shame. Autistic Doctors International has given prevalent examples of how it can lead to burnout and poor mental health. The health aspect of managing employment and your neurodivergence, and potentially your child's neurodivergence, regularly leads a lot of people to mini-burnouts and to the edge.

Sofia Farzana: I am just looking at the responses that we got to our survey, which we sent out to folks in the past week. Fifty per cent of the people who responded said that they felt that they were discriminated against at work, and 58 per cent said that they did not feel that it was safe to disclose that they were neurodivergent.

I will share a couple of survey responses from people. One said:

> "I was bullied and pushed out of two workplaces by seniors who used my open nature against me. I have since worked for the same place for four years now, who have been supportive."

That is a recent example, and understanding of neurodivergence has improved in society since 2022.

Another example demonstrates what I said about getting work but not secure work, because their children were unable to achieve the threshold for permanent positions in schools, and feeling more vulnerable to racism due to their openness and their demeanour. The fact that they do not have secure work means that they do not have secure housing, which is an experience that I share. Whether paying private rent or getting a mortgage, if you do not have a secure income, people will not help you with your housing. The issue is not only work, education and family life; it is also your housing and finances being affected by not being able to work.

Another survey respondent talked about an occupational health provider. The person was assured that the nurse who they were working with had been trained in neurodivergence and awareness, but in turned out that they had not. In fact, they got the impression from the nurse that they were being difficult—when support was recommended for them, they had already explained to the nurse that such support had been tried and had not worked. They felt that it was a waste of time and an invasion of their personal life because they were asked things that were not even related to work, and now they have to explore alternative support for their employment.

If I think about my particular characteristics and the people who I support, trying to get support for work is difficult, because people lack confidence when it comes to asking for help. People like me already look different and face the stigma of not having representation, which people also talked about. Having representation at work or in an education setting made it easier for them, because it helped to improve their confidence, find the right words and have their needs understood. However, we do not have representation in the workplace.

11:45

If we go back to the discussion about HR managers, there is an incredible amount of gaslighting. When we ask for reasonable adjustments, the response is often, "Well, everyone is a little bit autistic." I heard that said not that long ago when someone who had been diagnosed had asked for adjustments. We are dismissed too quickly and are not believed. We might be told, "Everyone finds interviews very difficult," but there is a lack of understanding of the way in which we process things and experience life. There is also a failure to understand how people experience us through a prejudiced lens, which hinders recruitment and retention. That is when we hit burnout. It is not that we are not capable, but we need to be supported if we are to achieve our capabilities.

Kabie Brook: We—certainly, those from the autistic community—will know that school can be and is often extremely traumatic for autistic and otherwise neurodivergent students. Part of the problem is that the trauma of many bad experiences can build up. When someone starts work, if they are unlucky and do not have a good line manager, it can feel to them as though it is more of the same. Ninety-two per cent of people who responded to our survey felt that they had been bullied in the workplace, and 75 per cent had been discriminated against. Those are big numbers. Those experiences can bring misery, particularly if they come on top of previous trauma following experiences of bullying and discrimination.

Many autistic people who do not have support are just about managing their lives; they can just about scrape through and may be struggling day to day. Sometimes, it is almost a full-time job to keep going if they do not have support; that is all that they can do—they cannot work. For those who are managing to get into employment and are working, it is common to hear that all that they can do is their job. Every evening when they get home, they cannot do anything else: they keep the lights off and will go to bed early, as they have to try to reregulate. They do not have a social life and on the weekends, they will not go out or do anything. Again, that is rest time. All that they are doing is going to work, coming home and going to bed, and they may or may not be able to eat something. It is very hard.

The solutions are not only about providing support in the workplace. Although we need flexibility, support and employers who understand that, in order to get the best out of their employees, small adjustments can make a huge change, we also need to recognise that someone may need support at home as well as at work, as, without it, they cannot manage their job. We need to look at someone as a whole person.

That goes back to the difficulty of getting support. The times when people need support the most are probably the times when they would find it even more difficult to make the phone calls, fill in the forms, and do everything that they need to do to secure it. If they do not have support that enables them to get the support, they can end up with nothing.

I can see Marion McLaughlin laughing in recognition, I suspect.

Marion McLaughlin: I am laughing because it is true.

Kabie Brook: We need support to get more support. As with the disabled students allowance, there is no support to secure it; the support comes if you manage to fill in the forms and are granted the allowance. There is a huge gap in the provision of support that will enable people to get further support.

Leo Starrs-Cunningham: Going back to the issue of employment rates and what is hindering them, I can say, having worked for small outfits and multinational corporations at different levels, that what I have noticed—and obviously more so recently—is the use of screening software, essentially to spot neurotypical candidates. As a result, we are not even getting through the initial screening, because it is not even an actual human doing the initial sift.

The issue with employment goes across the whole system. Even if you manage to get the support to apply for something, you are already on the back foot, whether you disclose or not. Personally, I have had only one employer to whom I disclosed and it was okay; all the other employers found it quite difficult to wrap their heads around.

Also, just to touch on Rachel Parker’s point about the effect of the withdrawal of support, I had a very nice job with an international bank a couple of years go, but I lost that because, through no fault of my own, my support was withdrawn. My contract was not renewed, because I literally could not turn up to work—I did not have the support to get to work. Those are really common issues.

The issue, then, is not what happens once we are in work—the issue is literally getting into work. Even during the application process, if we ask for reasonable adjustments, not only is the onus quite frequently put on us to try to miraculously work out beforehand what adjustments we are going to need, when we do not necessarily know the format of the interview or assessments, but the adjustments that we are offered often come from a list and are really basic. The one that I am frequently offered is more time, but I do not need more time to do assessments; what I need is people to understand how to phrase the questions and to understand that my response is going to be different, because my thinking is literally structured differently. That can be hard to get around.

Carolyn Scott: I think that the question was specifically about autistic people, but, as we have heard, the issue with regard to all neurodevelopmental conditions is not just unemployment but underemployment. People would say that I am in a successful career now, but I certainly was not for a very long time, and I still feel like a failure. I feel like I have failed to achieve what I could have achieved. A lot of studies on people with ADHD show that they are more likely to be unemployed; more likely to struggle with work performance; more likely to demonstrate difficulty in maintaining job stability or in attaining any higher job status; and therefore more likely to face more financial hardships. A lot of that stems from the way in which symptoms of ADHD impact on education, because people with ADHD are more likely to be undereducated, relative to their intellectual ability, than those without ADHD.

We need ADHD-aware workplaces, and we need autism-aware workplaces. A lot of the symptoms of ADHD will stop people asking for help. In the past, rejection sensitivity dysphoria has forced me to leave good jobs instead of seeking the help that I needed to thrive there. I could have succeeded in the role if I had had an awareness of what to ask for and if my employers had had an awareness of what support would have helped me.

A lot of this stems from the need to tackle the issues in the education system, but we also need an awareness in workplaces of what might help, instead of their always relying on the individual to dictate exactly what support they need. Indeed, there needs to be a realisation that ADHD awareness, and neurodiversity awareness in general, could create more inclusive workplaces for everybody.

The Convener: I know that Rachel Parker would like to come in on this, but before I bring her in, would you be comfortable explaining what rejection sensitive dysphoria is?

Carolyn Scott: Absolutely. Rejection sensitive dysphoria is not actually a diagnostic criterion of ADHD, but it is an incredibly commonly held symptom that goes along with it. I am not a psychiatrist but, basically, it is a fear of being rejected that occurs before you are rejected. For example, I do not like to ask anybody for help—it is an issue that I have been working on. I will not ask for help, because I do not want to be a burden, and I have a fear that somebody might say no to me.

I think that I am ridiculous for having this—it is so irrational. It stops me sending emails or text messages, because I am scared of rejection. Actually, when rejection happens, I am capable of responding well to it— it is the fear of the rejection before it even occurs. When I express this to people—that I was scared that they might get annoyed or bothered by me or that they might reject me—they say, “Of course we wouldn’t do that.” They think that such thoughts are ill held and wrong, but I cannot help it. It is completely built within me that there are days when I cannot even send an email because I will just stare at the screen and be completely incapable of hitting the send button out of an utter fear of rejection.

Rachel Parker: The point about the level of intersecting factors that are involved in being able to maintain employment definitely resonates with me. Through the Neurodivergent Entrepreneurs Network Scotland, we brought together the voices of many neurodivergent entrepreneurs in the “We Speak Tangent” podcast, which is still available on Spotify. Those discussions highlighted that there are many themes that intersect in the ability to work, which makes them very relevant to this inquiry.

It would be remiss in any discussion on this issue not to include the intersectional factors in discrimination in employment, such as the examples that were highlighted in the report “Excluded by Design: Research on disabled women’s employment in Scotland”, which details the impacts of sexual violence on the employment of neurodivergent women. It impacts them not only through time off work for related appointments and distress but through company attitudes, with those who reported their experiences to their employer reporting that 62 per cent of them subsequently had their performance questioned at work.

In addition to our discussions, we reference that research. Further research in 2024 presents data suggesting that those experiences of sexual violence are disproportionately higher for autistic women, with nine out of 10 autistic women experiencing sexual violence in their lifetime, and seven out of 10 experiencing it from multiple perpetrators.

Solutions to neurodivergent employment need to be holistic and reflect the lived experiences of neurodivergent people, in addition to being trauma informed.

Pam Gosal: I have one more question, which is probably more directed to Sofia Farzana, but it is also open to anyone else who wants to come in.

The National Autistic Society has conducted research on why a large number of black and ethnic minority autistic people are not getting the support that they need. One of its observations was that disability can be stigmatised in certain communities and is sometimes blamed on the parents. It was also interesting to hear that some families said that they initially refused to acknowledge that their child was autistic. How can we ensure that BAME neurodivergent people get the support they need?

Sofia, I know that we touched on this issue.

Sofia Farzana: It is quite a big question. Again, it is about societal shift, and it is about not wanting to be a burden. I just wrote that down, because the concept of not asking for support and not being a burden is quite important in migrant families and racialised people. Because of the way we are treated in the system, there is that concept of not looking different, because we already look different. It is about the taboo of disability in itself, because we already have less value because we look different, and if we have a disability additional to that, we have less human value. That is how we are treated by the system, and the internalised ableism, which we have huge amounts of in our different communities, festers.

Even now, we still have the belief that autism was caused by vaccines or by parenting, and there is the concept that autism is talked about only in this country and there is no such thing back home. We have those kinds of concepts because it is talked about more openly here, and we do not have the language for it back home. Is it because we have spent the past 50 years trying to integrate into this society and have not given importance to our mental health, our wellbeing and our accommodations that are required?

Many people in migrant communities are self-employed, depending on the sector, because they cannot get employment, and for other reasons. There is a hidden intersectionality; is it because of racism or ableism?

People are in their own communities, and when you are in your own community, you cannot say anything different. It is about that lack of awareness in talking to people.

People who have difficulties trying to get support for their children can experience isolation. I have heard of even very highly educated people, such as doctors and psychiatrists, who have neurodivergent children and refuse to accept it because of the taboo and the stigma around it.

What we are trying to do at SEMA is demystify what autism is and what ADHD is. There is a conflation between learning disabilities, autism and what being autistic is like. For example, I was at the mosque the other night and an autistic boy was sitting next to me. He had learning disabilities and I do not. I felt connected to him, but I would get judged differently when I say that I am autistic and need support. The first thing that I am always told is that I speak so well. There is a lack of understanding, so we need a lot of community training. We have started that with a small project that we are doing.

12:00

I was born and brought up in the community in Falkirk and have a certain reputation. After I gave a talk about understanding autism, a lady came up to me and said two very stark things. One was that I had helped her to understand her child and how he reacts to things. The family had been trying to explain his reactions away with different ideas and labels and to get him to conform—conformity and hierarchy are big things in different cultures. She also said, “Now I understand you. I thought you weren’t very sociable because you just don’t like our community.” That was quite funny because I have been rejected by my community because I am autistic, but I am also rejected by the neurotypical community at large, so it has been very difficult for me to find my space and, therefore, I retreated quite a bit.

We need more of an antiracist approach in all our services that give a reasonable supports for children. Let us compare the situation for a white autistic or ADHD child to that for a brown one. If it was less difficult for the brown parent, they would find it easier to go for that support than they do because of the stress and strains of their life as it is without being disabled.

That is a living reality of our world in Scotland and we need to fess up to the fact that the discrimination is everywhere. Like one of the people said in my interview, they feel that they are more vulnerable to racism because they are autistic and have ADHD. That has been my experience. I am also self-employed because the schools where I live are too unwilling to make changes in their ethos and policies. The managers do not want the headache of addressing their racism or ableism.

Those experiences make you want to be a wee hermit and not come out at all. To go back to social work, we still do not have the support with form filling and language to access SDS. People do not know what is available, so they are struggling and do not leave the house. I know people who will not tell other folk in the community that they have an autistic child because of the shame. They just do not mention it and the kid does not leave the house.

We have culturally insensitive care when it comes to SDS. People would want to have family members—who understand their culture, religion food and clothes—to come and look after the child, but they are told that they need to have people from a certain agency for a certain amount of money. Neither the support nor the care is culturally sensitive at all. That negativity is an issue.

There is also the fact that we are hidden away, so those children will not come out in community spaces because their parents are so burnt out with trying to get support. Autistic adults are, as Kabie Brooke said, like autistic children. They will not leave the home and integrate with their community because of stigma. Not only do we have to have our voices heard within our communities and to readdress and re-educate our communities; support is needed from the outside.

This is a good point for me to tell the committee to come to our website. On the “Our Projects” page, there is information about a project that we did listening to the lived experiences of autistic people from racialised backgrounds in Scotland on the topics of education, work, womanhood and transitions. There are three extensive e-books that collect quotes from people telling us about their experience of different aspects of those topics, which the committee will find insightful and will help you to understand the stigma that we experience in our communities and from the outside.

Pam Gosal: It is terrible that the community is going through that but it is good to hear what you are speaking about, Sofia. As I said to you earlier, I spoke to some families that have autistic children. There are reasons beyond racism and discrimination that they do not want to face up to their children having autism.

In a lot of cultural settings, especially ones with arranged marriages and those kinds of relationships, putting a label on a child when they are so young can affect them later on. When that person grows up knowing that they are autistic, unfortunately, there will be more to it than just being named as autistic—a lot more will be said about it and that child's prospects will suddenly have gone. Never mind us talking about education and jobs—their marriage prospects, relationships and cultural aspects will all disappear.

It is a cultural matter in some communities, especially those with ethnic backgrounds. What is your view on what can be done differently there? People would rather say that their child is behaving badly or differently than say that that child has a disability, is autistic or needs help.

Sofia Farzana: It goes back to the stigma of the label. We have carers of young adults who are worried about their kids not getting employment or getting married—I have spoken to those parents and to those lovely young people. It is about that mindset of school, university, job, marriage—and that is your life already planned out for you. You have to be a doctor or an engineer. Being an engineer is all right if you are autistic: my oldest is also studying engineering—he is stereotypically autistic, that kid—but when it comes to him having a marriage, we are always talking about relationships and how to support him in his relationships. What people do not understand is that he does not have to take a set route in order for him to live a fulfilling life. It does not have to be that you are married by 25, otherwise you have failed. That is the kind of pressure that we have in our communities.

It goes back to community training. We have our places of worship and groups for different ethnic minorities—there are the Kenyan society, the Latin American one, Saheliya and loads of different community groups that can be worked with. They work with ethnic minorities and they have an influence in their areas. They need to be trained up—if they start talking about things more openly, we could challenge that issue. That is something that I do: I go into those groups and challenge them, and I get a lot of fight back. "This is not something that happened in our day." I have heard that quite a lot recently when I have been out in the communities. "This kind of thing is not for us."

One interesting thing that I hear is people saying, "It is because of the environment. Back home, the same person was fine, then they migrated to Scotland and now they're having all the issues." Their environment changed. I could say the same thing about me: when I worked in London, I would never have known that I was autistic. I only knew when I came back to Scotland. I faced multiple levels of discrimination, but I would not have known, had I continued working in London. My environment changed, the challenges changed, the way people treated me changed and, therefore, all of a sudden, I became autistic at 30—no I did not, I was always autistic; my environment had changed.

We have to understand that our environments are not natural to us, as people who need more vitamin D, iron, rest and socialising and who have a certain generational trauma that we are bringing to the table. Let us talk about that, too. We bring all those complex human experiences, they get mashed up and that is a barrier to understanding ourselves. We have been too caught up in those experiences.

Why did it take until 2023 for an organisation like SEMA to exist? It is because the support was not there. That is why I had to do it. The support was being pushed back by psychiatrists, doctors, employers, housing, social work, police and justice—all of it was being pushed back in every way. That is when we realised that we were really late to the table. Groups like AMASE and ARGH Scotland have talked about autistic rights—over here, we do not even know our rights as humans, let alone as autistic people.

We have been discriminated against and it has to be because of the fact that, especially these days, we get told to get back home. I heard that when I was a kid; I heard it this year, and last year. We were told that we would get kicked out if we did not behave—that is even more of a hindrance to us asking for support or being confident in understanding ourselves.

Pam Gosal: Thank you very much for sharing so much, especially about your experiences.

Debbie Best: On the cultural barrier, a lot of families are directed to us from CAMHS and social work. We are based in the greater Glasgow area. We are lucky that one of our colleagues speaks fluent Punjabi and Urdu and some Hindi and can help build that safe space and help with some of the cultural differences.

The language barrier is huge. We have a wide programme of accessible information, training and support. However, we are a third sector organisation and we have no budget for interpreters. More often than not, people end up locked out of gaining information and knowledge on their own neurodivergence or that of their child because of language.

If there was some support, such as through the health and social care partnership, or if there was a way of getting interpreters, we would be able to give a lot more support. Language can be the number 1 barrier when people come to seek support from us.

Paul McLennan: We had witnesses from the Royal College of Psychiatrists in before you, and a couple of key things came up. I remember meeting with them previously, and they talked about the cross-agency approach. All the evidence that we have heard this morning shows that there is not one, single solution.

There are a couple of key questions. First, awareness in workplaces is incredibly important, and can be very mixed. Is legislation required on that, or are guidelines enough? We have legislation on various other issues, which employers should be picking up on.

My second question is about the broader issues. You mentioned the health and social care partnership, and we talked about shared care. The health and social care partnership is one example, but education is key as well. We heard that some of you got a diagnosis when you were in your 20s or 30s, but there are kids who are getting diagnosed earlier, so does more need to be done in education?

I do some work with an organisation called Stronger Together for Autism and Neurodivergence—STAND, too—which some of you might know about. It talks about awareness in schools. In schools, the picture can be very mixed. It depends very much on teachers' awareness. There could be one teacher in a school who is very good, and another teacher in another classroom who does not understand the issues.

I suppose that that is about shared-agency working. Your outcome very much depends on who your employer is, what your school is and who your GP is, so we could pick that up and it could improve the situation for some people, but not others. Does that mean that we need legislation as well as investment into services?

Leo Starrs-Cunningham: As I said earlier, I have had difficult experiences with employers, and twice I have sued employers successfully as a result. Do I think that we need more legislation that is directly to do with employment? Yes, I do, but the issue is more to do with the systems of employment.

For example, I mentioned the use of automated sifting systems that are not designed for neurodivergent people. There is no regulation of that, so that is definitely an area to consider. There is no regulation of machine learning in general, and I would also challenge that, especially as we see machine learning entering more and more aspects of our life, including education. That concerns me.

I would challenge workplaces and the legislation. The legislation exists, but there is not much knowledge about it or about our rights. A main purpose of all the organisations here is to let our members know what their rights are. That falls upon us, but we are members of the third sector, and maybe it should fall upon wider Government and it should be taught to all children as part of their education. What are their rights? How do they fulfil those rights? How do they recognise when those rights are not being fulfilled? That could all be covered.

Can you legislate for that? To some extent, yes. Legislation serves a useful purpose in helping to push forward societal change. We can see that through things such as marriage equality and smoking. Decisions were made in the legislature that were ahead of thinking at the time, and those decisions then pushed thinking forward progressively. Therefore, yes, there is room for legislation, but it has to be the right legislation and it has to involve those of us with lived experience at every stage, or—frankly—it will not work.

Paul McLennan: That is an important point.

Last week, we were talking about the public sector equality duty, which is a duty on those in the public sector to make sure that there is equality in all their systems. I do not think that this area has been a focus. We have heard about figures that show that some 10 to 20 per cent of the population are neurodivergent. That is a huge amount of people. We might be able to influence how the things that we are talking about are embedded across those systems, either through legislation or the public sector equality duty. That is certainly a consideration that I will have when we talk about this in more detail.

12:15

Leo Starrs-Cunningham: I would point to one of my qualifications, which is a law qualification. One of the issues that disabled people face generally is this: thanks to what scholars would view as bad decisions in the High Court, disabled people face a very uphill battle because there has been a preponderance of decisions to fulfil financial requirements taking precedence over human rights. If legislation is considered, it would have to challenge that.

In my experience, organisations often do not understand what the public sector equality duty means in practice on the ground. That includes local authorities and, especially, people who are working on the front line, who do not understand that they have a duty to take into account disabled people's requirements and rights, which often get ignored as a result.

Paul McLennan: You are spot on, because, as we have heard colleagues say, you can go to school or to a GP, and some will be aware of that duty and others will not be. That is a real issue.

The Convener: I do not want to stifle the conversation, which has been really interesting and insightful, but, unfortunately, we have to keep to time. That is something that we have to be cognisant of. We have about seven or eight minutes left, and there is still a bit to go over. Please keep questions and answers as succinct as possible so that we can get through as much as possible.

Paul McLennan: Can I bring in Marion McLaughlin and then Carolyn Scott?

The Convener: Absolutely.

Marion McLaughlin: I will try to be fast. I am a former teacher and a parent. I have delivered training into all but two of the schools in Aberdeen City. Getting the training right is essential, and if the wrong people are delivering the training, it makes things so much worse. It is not just about whether we mandate training, whether we legislate for it or whether we make it part of our approach. We have to think about who the right people are to deliver and develop that training. My argument would always be that we need autistic professionals to be delivering autism training and need neurodivergent professionals to be delivering ND training.

I have been brought in to so many different organisations, schools, businesses, charities—all sorts of places—because they have had really poor quality training from what people would have expected to be good organisations. I have then had to work really hard to undo what they have learned before I can help them to learn what will really help us.

My last wee quick point is that every single school that I have worked with has known about the UN Convention on the Rights of Persons with Disabilities, which is brilliant, and most have posters up on the walls about it. However, I have never spoken to a teacher who had heard of the UNCRPD before I brought it up. We need much more recognition of that convention. If we want our children's rights to be met, then we need all of their rights to be met, not just on the basis of them being children, but on the basis of being disabled children as well.

Carolyn Scott: I agree entirely with Marion McLaughlin and with what Leo Starrs-Cunningham said about the public sector equality duty and equality impact assessments. The legislation that is really needed is the incorporation of all of our rights into law. That bill has been kicked down the road, but it would give us the right to education, the right to work, the right to health, and access to justice. Those rights are not being met right now.

None of them are being met for people with ADHD. My concern around that is that the right to life is not being met for people with ADHD. It is a condition that causes a six to 13-year reduction in life expectancy, and that right is not being met.

We need legislation. We need all of our rights to be available to us, and to be able to gain access to justice when those rights are not met; we need to make sure that easy access to justice is provided as well.

Rachel Parker: We believe that broader social change is required to ensure that current legislation—and any future legislation—is accessible to those who benefit from it, and that it is implemented in accordance with its intention and not ignored, or implemented only once that is forced through legal action, or as the very bare minimum.

Connected to that point, we are aware that a generalised reluctance to report abuse is exacerbated where our members have had previous involvement with the police, particularly where there have been inappropriate responses to a person being overwhelmed or experiencing a mental health crisis, which have not recognised or accommodated the needs of an autistic individual.

There are also significant challenges around engagement with the police due to there being such a heavy reliance on the use of phone calls to 101, social work and the police in order to report experiences of abuse or concerns for another person's safety or well-being. That is especially the case in rural areas where police stations are not staffed full time.

The 2021 study, "Anything but the phone!: Communication mode preferences in the autism community", highlights that reliance on communication via phone calls creates barriers. It also highlights the need for services to move away from a reliance on phone calls for communication. It recommends that they make sure that access to support is not dependent on the phone and that they offer written options such as email and live messaging, which are more accessible to many neurodivergent individuals. That is especially true for those individuals for whom using the phone is not only challenging but completely inaccessible.

As mentioned, all of that is exacerbated in rural areas, where in-person options, if they are present, are inaccessible due to issues such as travel costs. Those are issues that should be covered by existing legislation, but it is not being implemented in a way that is accessible and that is working to protect the people that it is there to protect.

Debbie Best: In relation to training, we always have to be careful because one person's experience of autism or ADHD or dyslexia or dyspraxia is simply one person's. During recent training that we did with the University of Glasgow, it was highlighted that it would be unlikely for a person to have fewer than three neurodivergences and that that would be a minimum. However, most people will not have those picked up; only one condition will be picked up. It is about applying the full spectrum of neurodivergence, from experience, rather than being specific, because a person will most likely also have other neurodivergences that have not been formally diagnosed.

There are also those who are not yet diagnosed, and who may never be, and who are potentially parents. It is also about bringing in their lived experience of their journey of neurodivergence and the impact on the whole family unit. That has a place in how we move forward, and it often brings in a different angle from that of the child. It is about seeing it from a different perspective, and there is validity in making sure that parents are included.

Kabie Brook: I will make a point about training. I agree with what Marion McLaughlin said. Our experience is also that we have gone into places and they have said that what they have had previously was not helpful. We need people with lived experience, but also additional professional experience, to be writing and delivering the training.

Part of the problem is that there are not national standards. I am a big fan of some sort of core capability framework that sets out what people should know and how that should be delivered. It is not about training written by Government, but rather a framework written by Government, led by and with the input of people with lived experience—that is, by the same kind of people who would be delivering the training.

It should also not be focused on positive behaviour support. A lot of training at the moment seems to push PBS as being the answer, which is a big problem, because it really is not. We would like to see a ban on PBS, and a lot of other disabled people's organisations would, too.

There was a final point that I wanted to add, but I forgot because I got distracted by PBS. Oh, yes—the point was that a lot of time seems to be spent talking about restraint and seclusion and doing training in that regard, but the same level or depth of training is not being put into how neurodivergent people think and how they can be supported in a practical way. I do not mean the theoretical stuff but the real, practical stuff that might reduce the need for restraint and seclusion.

The focus should not be on restraint and seclusion but on how to make the school environment—I suppose that we are mainly talking about schools—supportive in a way that protects everyone against things going horribly wrong. The focus should be on avoiding having inappropriate restraint—or even avoiding having restraint that some people might think would be appropriate.

Sorry, I will stop talking, because I know that we have been told that we do not have much time.

The Convener: Thank you. Unfortunately, due to time constraints, we are coming down to the last bit of the meeting, but I really do not want to stifle the discussion. In the remaining time that we have available before we close, which is just a couple of minutes, are there any points that the witnesses would like to get across? Please make them as succinct as possible.

Leo Starrs-Cunningham: One of the themes that we were told you might have time to talk about is the criminal justice system. I had an example of a systemic failure all the way through the system, but, to keep things succinct, I will not go into that. In the survey of our members that we did before this meeting, only 10 per cent of respondents felt that the criminal justice system was in any way accessible, or even partially accessible. Some 80 per cent felt that when they had needed to interact with the criminal justice system in any fashion, they had felt misunderstood, that their needs had not been met and that they had been discriminated against. Those are appalling figures, and such views were pretty consistent across all our members who did the survey.

Debbie Best: A phrase that has not been used in this meeting is sensory processing difference. It is important that there is an understanding and acknowledgement of the sensory difference that is experienced by the majority of neurodivergent people, although it gets tagged more to autism. It is important to understand that it is not just about lights and sounds but the whole sensory environment. We were talking a lot about work, but the sensory environment could be hit or miss in an employment environment, because people need to understand how that impacts neurodivergent people.

Rachel Parker: We believe that the biggest difference in supporting autistic people in Scotland across all areas, including education, employment and criminal justice, would come from having strong, sustainable, autonomous and appropriately funded APOs—autistic people's organisations. The often life-changing impact of finding your own community and the value of peer support networks appear to be underrated by decision makers at the moment.

A move towards ensuring that APOs are strong, sustainable, autonomous and appropriately funded would make those benefits more readily available without having a mental and financial cost on those who are involved in running the organisations. Such costs are often the current experience when there is limited support available and uncertainty about the cost of funding—if it can be secured at all.

Shared community has incredible value in and of itself for our quality of life. That was described in the 2025 study, "'A certain magic'—autistic adults' experiences of interacting with other autistic people and its relation to Quality of Life".

Supporting APOs would also allow autistic people to engage more effectively with broader societal and decision-making processes, ensuring that work to target issues that disproportionately affect autistic people is efficient, meaningful and, above all, autistic led.

Marion McLaughlin: Thank you so much for having us along today. I would echo Rachel Parker's point about the need for good, sustainable funding for autistic disabled people's organisations—as somebody who used to run one that had to close down because of lack of funding, I cannot overstress how important such funding is.

I want to finish by supporting what Kabie Brook was saying about the need to ban PBS and the ABA method, which do so much to traumatise our society and our community. That can and should be done, and it is very overdue. That is one of the most important things that could be considered in the party manifestos that are coming out, and in future actions and considerations for the committee in the future.

12:30

Sofia Farzana: I go back to the whole importance of the diagnosis. Someone mentioned that ADHDers are overrepresented in the criminal justice system, and I want to give an example of a case that I supported last year. The person, who had a diagnosis, had to come to court for an allegation of hurting somebody—an abuser. The person was very vulnerable and was abused, but they hit back, and they were the one going to court. Their diagnosis was what saved them—they got an absolute discharge. Without that, they would have been prosecuted very differently. That understanding and that solid piece of paper from the NHS made all the difference for that person. They were able to go on with their life and to do what they needed to do, rather than being charged and sent to prison for that, or for other consequences of what they had done. The understanding of that person was not there—where they had got to and how they had got in front of the court. There was no time for that. The importance of the diagnosis lies in how it helps to explain, not just to us but to everyone—our family, our friends, our work and those providing our education. Everything is explained. We then have openness in wanting to understand the language and the experiences of being autistic.

Going back to the criminal justice aspect, one thing that is really weird and failing concerns the need for AAC—alternative augmentative communication. That relates both to accessing the police and to accessing the court system, giving statements and evidence. Procurators fiscal need to do a lot of training to understand that, even if people speak at some points, that does not mean that they can speak at all points. They need to understand the impact of emotional dysregulation on people's ability. That could be because of trauma or sensory or communication differences—it could be for whatever reason—but the need for training and the rights of accessibility are much broader than what we understand them to be right now. AAC needs to be taken into consideration for all aspects of life.

Carolyn Scott: We desperately need a nationwide strategy for pathways to assessment and support. Right now there is a postcode lottery. That strategy needs to come from the Government. The Human Rights Act 1998 says that Governments must take reasonable steps to prevent avoidable deaths, such as by addressing systemic failings in healthcare. ADHD is causing avoidable deaths across Scotland. We need standardised referral criteria, triaging tools and national targets for wait times.

Redesigning a referral system does not need to cost a huge amount of money. It needs to involve a coherent approach, rather than a huge investment. It also makes socioeconomic sense. Untreated ADHD is costing us a fortune. It is estimated that, over the next 10 years, undiagnosed ADHD could have a total economic cost of between £6.5 billion and £11.2 billion across the UK. That is in our prison systems, our health systems and our education systems. There are higher rates of accident and emergency admissions because of people being prone to accidental injury. It would cost a lot less just to give us better access to diagnosis.

The Convener: I thank everybody so much for joining us today. This has been an incredibly helpful evidence session. The invitation is there: if things come to your mind after this meeting—things that you wish you had said or other contributions that you wish to make—the door is not closed, so please feel free to get in touch with the committee with anything else that you would like to add. For example, you had an example of a criminal justice system, Leo. It would be really helpful for the committee to get as full and rounded a picture as possible. Please do follow our inquiry over the next few weeks.

Thank you all once again. That concludes our business in public today, and I thank you all for your attendance. We will now move into private session to consider the remaining items on our agenda.

12:34

Meeting continued in private until 12:54.

Official Report
Room T2.20
Scottish Parliament
Edinburgh
EH99 1SP

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Published in Edinburgh by the Scottish Parliamentary Corporate Body, the Scottish Parliament, Edinburgh, EH99 1SP

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