OFFICIAL REPORT
AITHISG OIFIGEIL

DRAFT

Health, Social Care and Sport Committee

Tuesday 7 October 2025

Session 6

The Scottish Parliament
Pàrlamaid na h-Alba

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HEALTH, SOCIAL CARE AND SPORT COMMITTEE

27th Meeting 2025, Session 6

CONVENER

*Clare Haughey (Rutherglen) (SNP)

DEPUTY CONVENER

*Paul Sweeney (Glasgow) (Lab)

COMMITTEE MEMBERS

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

*attended

THE FOLLOWING ALSO PARTICIPATED:

Thelma Bowers (NHS Ayrshire and Arran)
Louise Bussell (NHS Highland)
Glenn Carter (Royal College of Speech and Language Therapists)
Anya Kennedy (Royal College of Occupational Therapists)
Dr Gill Kidd (Child Heads of Psychology Services)
Dr Cath Malone (NHS Tayside)
Dr Pavan Srireddy (Royal College of Psychiatrists in Scotland)
Dr Chris Williams (Royal College of General Practitioners Scotland)

CLERK TO THE COMMITTEE

Alex Bruce

LOCATION

The Sir Alexander Fleming Room (CR3)

Scottish Parliament

Health, Social Care and Sport Committee

Tuesday 7 October 2025

[The Convener opened the meeting at 09:00]

Decision on Taking Business in Private

The Convener (Clare Haughey): Good morning, and welcome to the 27th meeting in 2025 of the Health, Social Care and Sport Committee. We have received apologies from Sandesh Gulhane.

The first item on our agenda is a decision on take business in private. Do members agree to take items 3 and 4 in private?

Members *indicated agreement.*

ADHD and ASD Pathways and Support

09:00

The Convener: Our second agenda item is taking oral evidence from the first of two panels of witnesses, as part of the committee's inquiry into attention deficit hyperactivity disorder and autism spectrum disorder pathways and support.

I welcome Glenn Carter, head of Scotland office, Royal College of Speech and Language Therapists; Anya Kennedy, divisional lead occupational therapist, Royal College of Occupational Therapists; Dr Pavan Srireddy, vice-chair, Royal College of Psychiatrists in Scotland; and Dr Chris Williams, vice-chair, Royal College of General Practitioners Scotland.

We will move straight to questions from Brian Whittle.

Brian Whittle (South Scotland) (Con): I will start with Anya Kennedy. In its submission, the Royal College of Occupational Therapists said:

> "Investment in early intervention is difficult to secure."

It gave the example of children and young people's occupational therapy, in which funding for early intervention is ending. Could you set that out for us in greater depth and tell us where the ending of that funding might have an impact?

Anya Kennedy (Royal College of Occupational Therapists): First of all, thank you very much for having me here.

The Royal College of Occupational Therapists has rightfully brought the issue to public attention. Occupational therapists play a vital role in enabling individuals to live meaningful, fulfilling lives by supporting engagement in everyday activities that they need and want to do. Our profession is deeply rooted in understanding the interplay between health environments and occupations. Our dedicated workforce is adaptable and often works across various settings, including health, education, social care and employment.

In children's services, early intervention currently sits very much within educational environments and involves working with families and teachers. It explores universal offerings to discover how we can support environmental changes and adaptations to enable services to support individuals in reaching their potential and maximising their ability to engage in school and education. By providing support at an early age, when it is needed during their key developmental years, we help children to understand themselves, and how the world around them works, and to manage the various journeys within that.

In the examples that I can go on to discuss, the key aspect is funding for early intervention. The challenges there include accessing such funding.

As for how we currently work within our existing resources—in particular, in services for children, young people and families—I highlight that there are great ways of sharing skills that are more commonly used in adult services. We can follow how those are offered across digital resources and in various environments. We work with our multidisciplinary colleagues, in particular through allied health professionals lines, as well as with our colleagues in speech and language therapy and in medicine and primary care.

Occupational therapists often work within child development teams and within child and adolescent mental health services. However, the way in which that work is set up can sometimes create barriers to early intervention. We would like to get upstream and have the ability to access children prior to their diagnoses. We need to recognise the importance not only of the diagnosis but of what we could do before that point.

Children and families often require support long before they receive a formal diagnosis. Therefore, we must ask what we can do to support them during that process, so that, for example, they are not disengaging in the education setting. We have lots of key information on the importance of education to children and how it can make them feel part of a community and build empathy as well as offering them learning experiences. Those aspects are key to their engagement further down the line. If they already feel part of a community and of the education system, and they already feel that they have a right to be there, once they receive a diagnosis they are often able to build their resilience and form coping strategies to support themselves—so much so that they might not need medical intervention later.

Through early intervention we aim to support the pre-diagnostic aspect by improving children's and families' understanding and by building rapports and resilience to enable them to move forward through that process. As much as we would like the diagnosis process to be quicker—I hope that we will come on to discuss that today—right now, the reality is that it takes a long time and there are significant wait lists. By getting in earlier and being able to support children and families prior to diagnosis we can manage some of the difficulty and perhaps lessen the challenges that being on a wait list can pose for them.

Early intervention creates a ripple effect. By helping a child earlier we also support their parents, grandparents and siblings and the local community. That sends a public health message about the importance of such intervention for everyone's overall health and wellbeing. We know that people living with neurodivergence experience a lot of inequality in accessing public health services in general. If we are able to support them in the early part of the process, during their childhood, the hope is that they might be able to rely less on services later in their adolescence—for example, within CAMHS or the adult community mental health teams, for which there are significant wait lists.

Brian Whittle: Thank you very much. That is a really good start to our discussion.

In much of your response you described what your organisation would like to do. The committee would like to understand what the reality is. I will broaden out my question and ask the whole panel about barriers to achieving what we might call exemplary treatment, by which I mean treating our kids in the way that we would all want them to be treated.

Dr Pavan Srireddy (Royal College of Psychiatrists in Scotland): I am vice-chair of the Royal College of Psychiatrists in Scotland. I thank the committee for its invitation to contribute to today's discussion.

The barriers are manifold. First and foremost, we must recognise the sheer scale of what we are discussing. The increases in referral rates, in demand and in the numbers of young people and adults awaiting diagnosis are beyond anything that we have seen in the recent history of our healthcare systems apart from during the Covid pandemic.

The Scottish Parliament information centre estimates that in the past five years there has been an increase of more than 2,000 per cent in the number of people who have been referred to relevant services. We are not talking here about people who are struggling but who might not be accessing health services, or those who might be in school but require support. Therefore, the first barrier is presented by the sheer number and scale of what we are talking about. It has taken services, organisations and policy makers time to realise just how massive the demand is. However, for several years now, following the pandemic, our members and our colleagues on the front line have recognised that there has been a steady increase in referral rates for both children's and adult services.

The challenge is then considering how we could take a system-wide approach rather than using the specialist service or healthcare service based model that is currently in place. The reality on the ground is that our healthcare model is designed to meet the needs of 1 per cent of the population, but it is trying to meet the needs of more than 20 per cent of the population. That cannot and will not work.

Recognising the scale of that demand presents our first huge challenge. Doing so would then allow us to think about all the tiers that need to be put in place, because there is no single solution. It is such a complex issue, and the scale of it is so massive, that there is a need for multiple tiers of enrolment. That applies across almost all aspects of policy and government. It is not just an issue for the Government to address; it is also for local authorities, education and higher education providers, and employers.

I add that early intervention is not only about intervening early in an individual's life; it is just as applicable to an adult who is in their 30s or 40s. It is as much about recognising a need and putting modifications in place to prevent someone from developing other mental health disorders, or from presenting in crisis to mental health services with far more significant mental disorders that might require greater intervention.

Early intervention can exist in many different forms. I work within adult services and I see a lot of people who might have had difficulties for a long time, but a change in circumstances has brought those difficulties to the forefront. Others might have a child who has been diagnosed with autism or ADHD, which has made them realise that difficulties with which they themselves have struggled for many years reflect what they see in their children. Putting support in place and having access to such support early on still constitutes early intervention while people are waiting for a diagnosis. That is partly why we advocate for a process that puts support first. Providing access to good-quality information, and having a once-for-Scotland approach to intervention, can make a tangible difference to people's functioning that can be very helpful.

The issue lies partly in properly recognising the nature of neurodevelopmental conditions. They are not mental disorders or mental illnesses but conditions that cause differences that individuals have to live with for all their lives. They are not things that can be fixed or treated and which will go away. Therefore, the focus is on how people can adapt to living to with such conditions and the difficulties that they involve.

There are positives to what someone might have in terms of ADHD and ASD but, as I have stated, there are also difficulties. That requires using a fundamentally different approach from a healthcare-based model that focuses on someone's being well, or their being ill and their subsequent recovery. Neurodevelopmental conditions involve difficulties that are present lifelong. The approach should be all about how an individual can adapt. Early intervention is applicable at every stage in their life.

The Convener: Could witnesses be more concise with their answers, please? We have a lot of questions to ask after this theme. Thank you.

Glenn Carter (Royal College of Speech and Language Therapists): I agree with some of what Pavan said about barriers. The Christie Commission outlined a long time ago the principles for what needs to happen around public services—prevention, early intervention, co-design and integrated services. In Scotland, there are some excellent examples of that in this field, but the majority of services feel as though they are stuck in the refer-assess-treat model, through which we cannot possibly meet the demand.

We are dealing with barriers resulting from services that are overwhelmed with demand, which then raise the threshold for who can access those services. That means that people are not getting the support that they require. There are people in the system who are asking for help and who could be on waiting lists for many years before getting a diagnosis or not, but they are also not getting access to broader support, which I am sure that we will talk about later.

For adult services, there is some learning to be had from children's services, in that there is a greater multidisciplinary team within children's services. We would love to see more of that in adult services, with allied health professionals such as occupational therapists and speech and language therapists fully embedded in services to give a broad range of support to the people we are trying to serve.

Brian Whittle: Dr Williams, if there is such a huge increase in neurodiverse conditions, what is the public's awareness of that? The question is whether we should have some sort of public awareness campaign, for want of a better expression, if people are coming forward at such a pace. Where do we sit with public awareness?

09:15

Dr Chris Williams (Royal College of General Practitioners Scotland): I will just cover the question on barriers. I agree with Anya Kennedy's description of how things should be. Where children are in mainstream education, there should be resource for assessment and intervention even before there is a diagnosis, and for working iteratively so that the people who are seeing the children interacting with other children and with the learning activities are guiding what is happening.

In part, I am saying that general practice should not be an integral part of that. We should not be needing general practitioners to be making interventions because there should be fully staffed services. Mainstream education is under huge pressure and there is an absence of vital roles giving expert input—especially if people are spread across multiple schools and areas. If you have those gaps there will clearly be a barrier. As with all parts of our health service, staffing resources can play an issue.

There are some very different issues at work on the adult side of things. There is no team standing by in the wings, looking to pick up on aspects of people's interaction with the environment that are not beneficial, that have gone awry or that are harmful. The occupational health service in this country, for example, is not meeting the needs, especially when we have emerging mental health concepts that we did not have 25 years ago, which were not on people's radars. We have diagnostic formulations that we are still revisiting. The guidance coming from the national autism implementation team is a fabulous example of trying to keep up with the research, trying to keep up with what we know about how people are presenting, when they are presenting, what they are looking for and what works for them in terms of interventions, even before we get to medications.

Brian Whittle: I will leave it there.

David Torrance (Kirkcaldy) (SNP): Good morning. What should the role of a neurodevelopmental assessment be?

Dr Srireddy: I will start off. A neurodevelopmental assessment has many different functions depending on the context in which it is undertaken, and it differs from individual to individual. That is what we have heard from people with a range of neurodevelopmental conditions. Unfortunately, the current status of services is that a neurodevelopmental condition assessment is seen as the gateway for support and for access to input, health, modifications and treatment. We disagree with that process. We do not think that an assessment and then a diagnosis should be the only gateway for those things. There is absolutely a role for assessment and diagnosis, but we think that there should be multiple pathways into accessing support and that the pathway for accessing support should be a needs-based model, rather than a deficits-based or diagnosis-based model.

The advantage of a needs-based approach is that it allows tailoring of support and intervention based on the individual's needs and circumstances at that point in their life, rather than having a one-size-fits-all, where you need a diagnosis to then be able to access anything else.

The other unfortunate difficulty with the current strategy is that, all too often, a huge amount of effort is put into assessment and diagnosis and then there is nothing after that, so assessment and diagnosis do not lead to support and do not fulfil their original function. That is definitely the case for autism spectrum disorders. Many people wait for a long time to get a diagnosis of autism and then are not able to access support from education or local authorities or employers. That, again, is problematic.

There are huge benefits for people in undergoing an assessment. It gives them a better understanding of their difficulties. It gives real meaning to things that they might have struggled with for long periods of time. It gives people access to tools and strategies to better manage their difficulties. However, some of those things can happen even without undergoing a full assessment.

That goes back to the premise of the question about information and awareness. Unfortunately, our view and what we have heard repeatedly, is that there is a huge amount of misinformation out there. Most people tend to rely on social media. There was a very good study published not that long back that showed that just about half of all information on social media is inaccurate or, at times, overtly harmful. Having greater access to curated, good-quality information gives people the ability to access help and support based on what their needs are at that time, so the two go hand in hand. A proportion of those individuals might then proceed to undergo a full assessment with a view to getting a diagnosis and that can be hugely helpful. Another part of the assessment is understanding the impact on a person's life. Usually, people come along because they are struggling and finding things difficult, so it is about trying to give meaning to that.

Anya Kennedy: I am thinking about some of the things that have already happened across Scotland with regard to neurodevelopmental assessment and there is variation in what that looks like. Importantly, however, the evidence supports integrated neurodevelopmental assessments, rather than the siloed pathways that we currently have in children and adolescent services as well as in adult services. Somebody may be on the list for an autism assessment and also on the list for an ADHD assessment. They may get an autism assessment but have to wait longer for an ADHD assessment. That is inefficient and causes delays for the individuals, their families and their carers. It is also inefficient in the use of resources and skills.

There should very much be an integrated pathway for neurodevelopmental assessments. There should be one assessment, at the right time and in the right place. That is the important thing when we talk about people accessing an assessment. I agree with Dr Srireddy that the approach should be needs based. Children and adults should be able to access support when they need it, on the basis of their needs, without having to wait for a label or a diagnosis. However, in the current system we need a diagnosis in order to gain access to support, particularly within schools and employment. It is a layer of protection for an individual. We need to move forward into neuro-affirming practices and, as a committee member mentioned, public information should support the understanding of why we need such practices moving forward.

Another challenge is that assessments for adults sit within secondary care, which has very high threshold criteria, given current restraints and the waiting lists for other core mental health services. In children's services, they also have strict criteria for going between pathways within the child development teams and CAMHS, which, again, is a secondary care service.

We need to support a stepped-care model, in which people can access self-help materials and information that will support them, so they can inform themselves as to whether an assessment and a diagnosis will support them going forward. Then it is about them being able to access that in a timely manner, in a neurodevelopmental-affirming way, so that we are able to support individuals to understand themselves and what they can do for themselves, as well as supporting their health and wellbeing.

Glenn Carter: We need to reframe the idea of neurodevelopmental assessment to what people in Scotland want. What they want is help. Diagnosis, of course, is part of the help and that needs to be acknowledged. However, for lots of people the reason why they are driven towards the pathways is because things are not going so well at home, in school or in the workplace and the only help that they can see is the pathways. At the moment, quite a lot of people are not getting the support that they need and they do not have access to support as soon as possible after the concern arises, in order to prevent harm in the future. We need to think differently about how we frame and where we place resources.

David Torrance: I have no further questions, convener.

Patrick Harvie (Glasgow) (Green): Good morning. I will follow up on the same themes. I have come to the inquiry quite aware of how much I do not know about this topic. I have been trying to read as much as I can from the evidence that has been submitted. However, I do not know whether the severe delay in getting a diagnosis is purely down to capacity, or is the result of people wanting a diagnosis where the criteria are marginal, the judgement is difficult and they have to be seen many times, or whether it is purely down to the variation in practice in different health boards.

We are being told by a great many people that diagnosis is an extremely important part of not just understanding their own experience but addressing it. I do not know whether diagnosis is clinically necessary. We have been told that these are not disorders, diseases or things to be cured in any sense, but normal diversity. Is diagnosis clinically necessary or is it merely that support is not available without it, so it is therefore a necessary hoop to jump through, rather than clinically required? Can you answer those questions? The evidence that we have seen so far leaves me none the wiser.

Dr Williams: I might grasp the thistle. The tricky part is when people, especially adults, come to general practice recognising that something is wrong. Sometimes, they might have a sense of what is wrong. For example, there are lots of adults coming forward whose child has had some neurodevelopmental assessment, the penny drops and the parent or relative recognises something developing in the young person that is akin to what has happened in their life. There are people coming forward who have a good sense of what is going on.

There are other people with all sorts of mental health symptoms and all sorts of life circumstances who warrant further attention and closer scrutiny. We have seen a large increase in people from the less severe—the lower severity—side of the spectrum. We also still have people who are in the danger zone and who might benefit from medication.

One of the areas that is most difficult is that the guidance that we are using is based on the specialist diagnosis of conditions as a gateway to medication. That specialist diagnosis, which does not just rely upon a few self-assessment questionnaires or a few tick boxes, has historically not even been for the general psychiatrist to conduct; even within psychiatry there is a specialism.

When that is the starting point, referral pathways begin to be built around that. When your specialist services become saturated, workload wise, they will find different ways to slim down the waiting list or different ways to prioritise those who might need help the most, so you get to a point where lots of parts of the service become locked down. From the general practice perspective, we then see lots of people returning to us asking, "Why won't you refer me?" and in some cases we have to say, "The guidance we have from the health board is that you are not severe enough," or "You don't fit the referral criteria." For other people, we have to acknowledge that they have been waiting far too long and that we, as GPs, are powerless to influence that. We can send further updates, and we can give advice from outside the specialist setting. Without access to specialists for the most severe, it gets difficult.

09:30

Dr Srireddy: That is a very good question about why more people are getting diagnosed. The current research on the reasons for the increase in referrals over the past five years identifies a combination of factors. There is greater awareness of neurodevelopmental conditions. People are talking about it, which then prompts everyone to think about it. There is the likelihood of wider environmental factors at play. The supports, the frameworks and the structures that we had around us and that might have allowed us to cope with such difficulties were stripped away during the pandemic. All those factors led to an increase in demand, awareness and referral rates.

The current reality is that the increase has been so massive that all those factors that you have highlighted mean that the current model just does not work. I will use the analogy of obesity. The current model would equate to everyone with obesity being referred to see a specialist gastroenterologist in a hospital in order to be told that they are obese and then for consideration to be given to all the things that need to happen in order to help them. We are not suggesting that we do that for obesity, but that is what we have in place for neurodiversity, and that is the challenge.

Just as there is a spectrum for something like obesity, there is a similar spectrum for autism and especially ADHD. Some individuals are quite significantly impacted by their neurodevelopmental condition. They have significantly higher rates of suicide and premature death, and significantly higher rates of most mental disorders.

Patrick Harvie: Is it arguable that they do not have those experiences because of their neurodevelopmental status but because of the inability of society to accommodate that? We hear the phrase “neuro-affirming” being used.

I will frame the question differently. If we could imagine Scotland as a neuro-affirming society, would it be one in which diagnosis has the totemic status that it has at the moment?

Dr Srireddy: That is an excellent point. We, as a society, need to think about how we support people who are different. This is not about pathologising difference; it is about supporting difference and allowing people to thrive. That wider societal approach is absolutely needed. However, we do not know whether that will translate into a reduction of all those things—the evidence does not exist because those societies do not exist as we speak. However, there is very good evidence that the stresses and distresses that are associated with living with neurodevelopmental differences in day-to-day life, in a society and in an environment that is not supportive of and structured to that, contributes to the increase in a lot of secondary mental health disorders, which would suggest that having a more neuro-affirming society would absolutely have huge benefits not only for individuals but for society. The economic impact of neurodevelopment conditions is enormous in terms of lost productivity and employability.

Emma Harper (South Scotland) (SNP): We are talking about diagnosing people. I want to highlight that there is an overlap sometimes—people can have both autism and ADHD—so you cannae just pigeonhole people into one diagnosis.

Dr Srireddy: I will jump in on that. In fact, there is more than just an overlap, as around 40 per cent of people will be diagnosed with both autism and ADHD. That is a substantial overlap. As Anya Kennedy said, we are calling for a neurodevelopmental assessment rather than an assessment for ADHD or for autism. NAIT is recommending that, too. We need to think about the individual holistically.

We have significant concerns about single-condition assessments, especially within the private sector. If you look for something, you are more likely to find it, but you are also more likely to miss other things that might mimic those difficulties. We have real concerns about carrying out only ADHD assessments or only autism assessments. What we need to do is assess the individual and to think not just about neurodevelopmental conditions but about the whole range of other mental health conditions that can present comorbidly. I absolutely agree with that.

Carol Mochan (South Scotland) (Lab): Many of the written submissions that we received expressed concern about the level of variation across Scotland. What would be the possible advantages and disadvantages of developing and implementing national standards and pathways for neurodevelopmental assessment across Scotland? I will start with Glenn Carter.

Glenn Carter: I think that developing national standards would be a good idea. The principles would have to be aligned to what I discussed earlier about the Christie commission. The reality is that people should not need a diagnosis to gain the support that they require, and in some areas they do not.

An excellent example of that is the speech and language therapy services in Dumfries and Galloway. Those AHP-led services have managed to change the refer-assess-treat model to a request-for-assistance model, so that anyone can phone up, speak to a professional and get support as early as possible. It was feared that that would open the floodgates. Actually, that did not happen, because they are addressing the need as early as possible, which prevents harm over time, and that ensures that we are improving outcomes for people.

Guidance about what good practice looks like is critical, but we will have to think totally differently and embed allied health professionals closer to the population, including by having speech and language therapists in education. That would allow us to support kids as early as possible and to have conversations with teachers so that those kids are included and do not develop those behavioural challenges. Overall, we need to ensure that we are not driving demand downstream, because we need to deal with things further upstream.

Anya Kennedy: I agree with Glenn Carter that having standards would be really helpful in providing that consistent approach across Scotland, because we have lots of variations. As Glenn Carter mentioned, there are great pieces or examples of good work in children’s services, as well as in adult services, and we can learn things from both services.

A real difficulty is not having clear data and an understanding of the current picture across Scotland, which makes it difficult to measure those standards. If we are not reporting on, for example, wait lists or outcomes, we have no data to review or to provide evidence showing the changes that have been made.

We have core mental health standards in mental health services. We have a lot of neurodivergent people in our adult mental health services already with and without a diagnosis. A lot of that is hidden in the population. People can be in, for example, adult mental health services, perinatal health services, integrated drug and alcohol services and in the criminal justice system. I have occupational therapists working in all those areas, and I am very aware of how many of the people who they are working with have neurodevelopmental conditions. It is very important that we take a whole-system approach and look at the data around that so that we can get a clear picture and thereby ensure that we are targeting and supporting the populations with which we can make the most impact.

Dr Srireddy: I would go a step further and say that those things are not just helpful but urgently needed. The key reason for variance in adult services across Scotland is because there are no national standards and there are no nationally agreed pathways. Indeed, there are no locally agreed pathways for most areas. That goes back to my earlier point about the increase in referrals being unexpected and was not something that services had planned for.

Children and young people have a national service specification for neurodevelopmental pathways. That is hugely welcome. However, the elephant in the room is funding. Standards are not really helpful in isolation if the required funding to implement the standards is not in place. No service can see an increase in referral rates of around 2,000 people and continue to provide a safe and effective service. The national health service is currently facing that reality. Standards are urgently needed, but the other side of the coin is the resource to implement the standards.

Another quick point is that the standards for pathways, diagnosis and assessment is just one element of it. A wider national approach on reasonable adjustments within education and employment settings is required. What constitutes a reasonable adjustment? How do you access that? What might that look like in primary schools, secondary schools and in higher education settings? That is urgently needed. That is part of the conversation about accessing help first. That, too, requires national direction.

Dr Williams: There are clearly gaps and deficits, and a national approach might help to overcome that. That will require cross-board working and data. It will require some way of collecting data that shows not only that people are waiting to see a specialty. We need to know whether there are certain conditions—that we are suspecting or are trying to diagnose or receive support for—that have, as yet, unmet need, if we are to really bring down the extraordinary waits that we are seeing for some people in some parts of the country.

Carol Mochan: Those responses have answered most of my other questions. Just to be clear, are the witnesses saying that a single-condition assessment would not be the right approach for children or adults? I see that everyone is nodding. I thought that I had picked that up correctly.

I have a final, quick question. On the recommendation by NAIT to adopt a standard adult neurodevelopment specification, are there barriers to that or do people feel that that should and could go ahead?

Dr Srireddy: I am not quite sure that I understand the question.

Carol Mochan: Are there any barriers to the development and adoption of a standard adult neurodevelopment specification as recommended by NAIT? I would like to explore that.

Dr Williams: I should flag that resource will be a barrier, especially if you are relying on staff having specialist knowledge or specialist skills or working together as part of a multidisciplinary team. Do we know where the boundaries are? Can we define the roles of different professions within a team? I think that we can. There are areas of good practice, but if somebody defines that clear, gold-standard model, can we fund it adequately?

Carol Mochan: That is helpful. Thank you very much.

Elena Whitham (Carrick, Cumnock and Doon Valley) (SNP): Good morning, everyone. I want to explore the concept of a multidisciplinary team approach to neurodevelopmental assessments. Mention has already been made of the fact that, at the moment, we have a medical model, which creates bottlenecks everywhere in the system. What are the barriers to implementing multidisciplinary teams to undertake neurodevelopmental assessments and to the creation of pathways in that respect? What is stopping all those who are involved in the care of an individual coming together to do such assessments? What are the big barriers in that respect?

Dr Srireddy: It is simply a question of resource. Across the country, there are around 60,000 people on the waiting list for a neurodevelopmental assessment. That is an enormous number. The level of resource that would be required to undertake those assessments—I am talking not only about the financial resource but the workforce—simply does not exist. I work in Glasgow, where there are about 8,000 adults on the waiting list. The resource that would be required to undertake those assessments would be more than the combined mental health resource for secondary care mental health services in NHS Greater Glasgow and Clyde right now. That is the scale of the resource that we are talking about. It might be helpful to take that as the starting point.

Secondly, in the absence of pathways, it is impossible to create the necessary structures. The structures that we have are in specialist services or are downstream in primary care. There is a very clear divide in the way that our health service is structured. To go back to the point that I made earlier, the issue is not one for the health service; it is a societal issue. We need to think about how we shift the balance so that a much wider approach is taken to education and employment. Chris Williams mentioned occupational health. Our occupational health structures are not designed for a condition that is so ubiquitously present. The structural barriers are manifold—they extend across every element of our society, not just our health service.

09:45

Elena Whitham: How can we build something that takes account of the role that each individual plays in the setting that they work in? We have our allied health professionals and our colleagues in general practice, as well as specialist psychiatrists. How can we ensure that those teams come together in a multidisciplinary way to effect change in this area? It feels as though that is where we need to get to, but it feels as though we are a long way away from realising the potential of such empowered teams. I realise that resource is a huge part of that, but it would be helpful for us to understand how those roles could come together to create meaningful change for people.

Glenn Carter: The challenge is partly to do with the fact that teams are firefighting—they have their heads down and are trying to manage all the demand that is coming. We need to think totally differently. Your point is an important one.

The issue is partly about strong leadership, being courageous and taking the risk of doing things differently. NHS Lanarkshire is a great example of that. It has a multidisciplinary AHP-led speech and language therapy team, which involves nurses, dieticians, speech and language therapists and OTs all going into schools where there is particularly high demand and working together effectively. Their role is not only to manage the diagnosis but to offer support for whatever challenge the child faces, whether it relates to sleep, diet or inclusion in education. Of course, they must work with education and not cause unintended consequences.

That is a good example of how the multidisciplinary approach can work, but it requires strong leadership and a willingness to take a risk and be courageous enough to do things differently.

Elena Whitham: It is helpful to have that specific example on the record, because co-occurring issues with diet or sleep that can arise for someone who is neurodivergent are significant for the individuals concerned and their families. Such team working could make a massive difference, as it would mean that individuals and families would not to have to figure out where to go, and the GP would not have to figure out where to point them.

Does anyone else have any thoughts on that?

Anya Kennedy: You will be aware of the work that was done with NAIT. We had five test-of-change sites within children’s services and four within adult services. Those were great opportunities to look at different ways of working and how we could roll those out. Alongside the test sites, there were smaller pieces of work that were taken forward.

I work in NHS Grampian. Our adult autism team is an AHP-led service, and its clinical lead is an occupational therapist. That allows the team to provide a very holistic assessment. That team does not sit in secondary care or in the community mental health teams; it sits separately, in between primary and secondary care, in tertiary care. That means that it is able to support individuals to have a neuro-affirming diagnostic pathway.

The barriers relate to resources. We are talking about tiny teams, the funding for which has often been temporary. With allied health professionals and occupational therapists, we have a dedicated workforce that is keen to support and progress the development of such services and to support individuals. However, when we receive temporary funding, there are challenges in trying to sustain that support over a period of time, because we might only be able to offer temporary contracts. Many people are not able to take a temporary contract, due to their personal circumstances or other challenges. We need to think about how we can support the workforce to progress into those areas.

As allied health professionals, we need support to work differently within our resources. We are often a limited resource within our services, but we are the doing part and the living part, which involves supporting individuals to progress and to manage their own health conditions. That is really important when we are talking about neurodevelopmental services, because it is a lifelong condition. Issues such as sleep and food intake can be self-managed by an individual. However, the long-term effects of those issues over a period of time can have a negative impact on health outcomes, which can lead to other health complications. We know that the populations that we are talking about experience a lot of health inequalities, so it is really important that we think about how we can support them earlier, at the right time, so that we can improve their overall health and wellbeing.

Elena Whitham: My final question in this area is about the role that the private sector and the third sector play in relation to neurodevelopmental assessment. We know that there are pockets of good practice across the country, where the third sector is heavily involved in the process. We know, too, that some health boards involve the private sector in the assessment process and allow trusted companies to do some of that work for them. Is there a role for those sectors in multidisciplinary teams?

Dr Williams: I will begin by highlighting potential pitfalls with the private sector, especially in the context of long waiting lists and people feeling harm as a result of being on a waiting list and not progressing, or fearing harm. There are many private providers that advertise services, some of which have physical bases in Scotland. Those services are subject to some degree of governance by Healthcare Improvement Scotland, but I fear that operators that do things virtually and which do not have a physical base in Scotland can evade such scrutiny.

Even when it comes to private providers that are based in Scotland, I would highlight the difference between them and the NHS-to-NHS relationship that has historically existed, in which there are good governance structures and ways of ensuring that everything is working just so.

Pavan Srireddy spoke about single-condition assessments. In my view, in a situation in which a patient or the parent of a patient is desperately seeking an answer and is paying money to a private clinic that has been set up to provide a single answer, there is a risk, especially in the light of what has been said about overlapping conditions and the need to look for a range of different things that could be going on from a mental health perspective. I am glad to hear that there are health boards that are using specific providers to give extra capacity, but I know that there are a lot of providers out there that are not linked in in the same way.

From a general practice perspective, we see people returning to general practice after they have seen a private provider, who think that, because they have a diagnosis in writing and have taken that extra step that other people have not, that will bump them up the NHS waiting list. Worse than that, some people who have received a diagnosis privately come to us with the expectation that the NHS will be able to start them on a medication even though they have not been seen by the specialist service.

There are circumstances in which people are paying for certain services and having their expectations raised, but that does not change the gaps that exist in the underlying NHS infrastructure. There is definitely further work to be done to support people in that respect.

Elena Whitham: The thrust of my question was more about the trusted private sector providers and third sector partners that have been working hand in glove with local health boards. However, I hear loud and clear your point about the difficulties with shared care and the difficulties with assessment in the private sector, where there is not the same safeguarding with regard to the robustness of the services that are offered, and the difficulties that that can present for general practice.

Would anyone else like to say anything before I hand back to the convener?

Anya Kennedy: I completely agree with what has been said. With the private sector, the issue is very much to do with governance and assurances and safeguarding in relation to quality. We would want to ensure that any assessment tools that were used to look at developmental history were used in a multidisciplinary way, rather than by a uni profession. There are examples of how that process works well across Scotland, as well as in England, but I think that regulation is required. I would certainly call for that.

Our third sector colleagues—I refer to them as colleagues—are absolutely essential to what we do. A lot of what is currently provided is provided through the third sector. That is particularly the case when it comes to post-diagnostic work. Third sector organisations also involve a lot of people who identify as neurodivergent or have lived experience of neurodivergence. That is essential to working together to progress those services, because those people have knowledge and skills that cannot be learned, which come from their daily experience.

A challenge with the third sector is the temporary nature of organisations' funding. Third sector organisations often lose funding. They do an amazing amount of work on very small budgets. I would like to call out the amazing work that is done across Scotland by the third sector, because it is essential that we acknowledge that.

The Convener: Paul Sweeney will ask the next questions.

Paul Sweeney (Glasgow) (Lab): Good morning. It has been really insightful to hear what our witnesses have had to say about some of the absurdities of the current system and how it militates against good patient outcomes and good outcomes for public resources.

One of the recurring themes that the committee observes concerns the disconnect between national priorities for the healthcare system and localised funding decisions that are made by integration joint boards and health and social care partnerships around funding for autism and ADHD services. Do our witnesses have any insights, recommendations or perhaps wisdom to share from their professional experience about how we might get to a situation in which local services have stable funding that is also modelled to support good patient outcomes and better use of public resources than we see in the current, inefficient model? What could we do to improve it?

Dr Srireddy: One of the challenges with the current structure is that mental health service provision and planning are hugely fragmented. One of the unintended consequences of health and social care integration has been the fragmentation of mental health service provision, with responsibility being split between health boards and integration joint boards. I work in Glasgow, where there are seven IJBs that link into NHS Greater Glasgow and Clyde. Co-ordination of service provision across such a fragmented landscape is incredibly difficult. It is made even harder when you are dealing with something that is relatively new and is unprecedented in its scale. In such a situation, getting very different organisations to come to a consensus about funding models and planning is virtually impossible. That is the reality that our members have highlighted to us repeatedly.

That translates into a recognition across the board of things that can be helpful but also into an inability to plan strategically and implement those things because the organisational structures in place actively work against such planning processes.

One of the key gaps in accountability is the mismatch that Carol Mochan highlighted in relation to national priorities and local funding decisions. Things such as national standards and nationally agreed pathways can help with that if they are supported by appropriate accountability in delivery. The situation is amplified further with regard to funding decisions, with the board deciding how to spend the allocation that is made for the mental health budget. We have repeatedly highlighted the huge variance in mental health spending budgets from board to board. There is significant variation in how much is spent on mental health services at the board level. That variation is not accounted for by differences in population need; it is very much about differences in local approaches.

First and foremost, having nationally agreed pathways and standards can be of great help by acting as levers for change at a local level.

Paul Sweeney: Thank you, Dr Srireddy. Does anyone else have any comments on that issue or suggestions for organisational improvement?

Glenn Carter: I would just make a broader point about funding and how to manage the local relationships. We have just published a report in conjunction with the Convention of Scottish Local Authorities, the Scottish directors of allied health professions and the Association of Directors of Education in Scotland about not just how to transform those children's services, which include services for children with neurodevelopment disorders, but also how to manage the funding relationships. That is critically important because, sometimes, when there is a shared responsibility, people start falling out with each other. That fractures local relationships, which is bad for outcomes for local people.

The helpful principles around transparency, decision making, building local trust and shared responsibility and facilitating joint accountability are important, because the topic that we are discussing absolutely involves joint responsibility, and there is a risk that education services and local authorities can feel that the NHS is asking them to do lots of work on the issue at the same time as the NHS can feel that education services and local authorities are asking it to do lots of things. There is a need for people to agree to take joint responsibility and find a way forward together, which we know is absolutely possible because we have seen that done in certain areas of Scotland.

10:00

Paul Sweeney: Where have you seen it done well?

Glenn Carter: One example would be NHS Forth Valley, which focused on the needs within children's services—what the needs were for children and how to ensure that those children are safe, healthy, achieving, and so on—and stopped to listen to the population before co-designing an approach. Once it had the answer to the questions that it asked, it pooled its funding and delivered on that answer. That was a really effective way of approaching the issue through co-design.

Paul Sweeney: Does anyone else on the panel have anything to say on the issue of funding optimisation in an organisation?

Anya Kennedy: I was just going to add that boards and IJBs are not having to report on wait list numbers, for example, so we are very much speaking about a hidden population. There is no accountability with regard to what we are doing with people who are sitting on a wait list. In terms of how we link from the national priorities down to the local level, there needs to be a reporting structure that allows for escalation as well as accountability with regard to what is being done about these services.

Dr Williams: I might come back in again on referrals and the data side of things. If boards are stipulating specific criteria that must be met for a referral to be accepted, I hope that that is all being fed back so that somebody can see what level of demand is being turned away and what referrals that are made on behalf of patients are not being taken on by NHS boards, for various reasons.

Again, I come back to the role of the employers in wider society around some of the more low-level activity and problems that people encounter as employees, and the importance of trying to pick those up and consider our health in the workplace.

Patrick Harvie: I am sorry to drag you back to a previous discussion, Dr Williams, but I have a supplementary question on the back of the questions that Elena Whitham was asking you about the role of assessment and diagnosis in the private or third sectors. It seemed to me that your answer quite accurately described the problem, but I could not quite get a sense of what you think the solution to that is. Clearly, we have frustration being expressed in relation to the financial unfairness, with some people being able to make the choice to go private, others being forced into debt and others feeling desperate because they cannot do that, and there is a sense of frustration because people are not getting the same responses from different GPs about whether diagnoses will be accepted and acted on.

Are you saying that the solution to that is to restrict or prohibit diagnoses in the private sector that do not reach a certain standard and then to accept all those that do, or that the solution is only to expand capacity in the NHS? Where do we go from here?

Dr Williams: I will start at the end. In general, I do not think that general practices are in a good place to be able to recognise what is a gold level of assessment. We certainly might see some cases where we are less certain that a comprehensive assessment has been carried out—we might be able to see that the letter indicates that somebody has not been seen in person or that there has been a videolink to somewhere in London for an assessment. I note that people who are from socioeconomically deprived backgrounds are even more disadvantaged by this situation.

I highlight the phrase "shared care", which is sometimes misunderstood because it sounds inherently like a good thing. However, what it describes is a shared responsibility. Historically, that has allowed some specialist services to run very efficiently because general practice is mopping up some of the risk that is involved in organising blood tests, checking someone's pulse or blood pressure and other measurements. In areas such as NHS Highland, it would be difficult for people to travel to a psychiatric hospital to have those tests done, and that would not be a good use of anybody's time.

To get back to the resourcing and how things are funded, in the past, shared-care arrangements would exist for various high-risk medications and would be accepted by general practice, but—

Patrick Harvie: Forgive me, but I am aware that we are short of time. I do not mean to push back too strongly, but it feels as though you are describing the current state of affairs rather than a path forward. Is there a potential for a change that GPs would accept and would result in there being a consistent approach to dealing with those who have perhaps gone to the voluntary sector, and a clear sense of what standard would require to be met in order to have acceptance by GPs in a more consistent way?

Dr Williams: If there was a healthy relationship with certain clinics, with an understanding that there was a sufficient level of governance, and we were confident that there was a wide range of mental health conditions being considered as part of the assessment and that it was not simply a service that was taking money to put words on a bit of paper that matched the expectations of somebody who responded to an advert, for example, there would be circumstances in which GPs could be far more trusting of advice that is coming to them from outside their local NHS resource.

Emma Harper: I will pick up on the shared care approach. Does there need to be a once for Scotland approach? Dr Williams, you talked about governance, good practice, national guidelines and a national approach. Do we need to move forward in that way if we are going to have a shared care model where private healthcare is supporting the NHS, or vice versa?

Dr Williams: Under the current general medical services arrangements, shared care is not a funded arrangement, but, yes, there are examples of nationally funded bits of activity where things can be done to a certain standard and that benefit patients.

Dr Srireddy: I echo everything that Dr Williams has said about concerns around the quality of assessments undertaken in the private sector and the lack of regulation. Ultimately, if I am going to get an assessment from the private sector, I deserve to know that I am having a good-quality assessment to the same level as what I would get in the NHS, and I would deserve to know that the person undertaking the assessment has the right qualifications, has the right training and is the right person to undertake that assessment.

There is a need for robust regulation. Our view is that the regulation is not robust enough at present, because of the gaps that Dr Williams has highlighted. The current regulatory mechanism does not cover virtual assessments, where the service can be based outwith Scotland, and they make up a large proportion of assessments that are currently undertaken, especially post Covid. That is a huge gap. That leads to concerns about the quality of the assessment and the concerns that Dr Williams highlighted that general practitioners might not be in a position to determine whether such assessments are accurate or safe. I think that leads to huge problems, and that has been highlighted repeatedly.

There is also a lack of consistency in what constitutes a good-quality neurodevelopmental assessment. We have such standards individually within board areas, but there is nothing nationally that determines what a minimum good-quality assessment would look like. We would strongly recommend and advocate for a national standard, which could serve as the gold standard of what you would expect, no matter whether it is a private or an NHS assessment. I should be expecting the same quality assessment, irrespective of where I access that and whether I live in the Highlands, Glasgow or Edinburgh. Having such a national standard would be helpful.

Ultimately, the increase in private sector assessments is simply a consequence of the lengthy waits that we have in the NHS. That is the core of the issue. If I am a 17-year-old studying at university and I am told that I will get my assessment in seven years' time, I will lose that opportunity to gain an education and perform well, and that will have a long-lasting impact on the trajectory that my life is going to take. People feel desperate, which is why they access services and assessments in the private sector.

I am not criticising the private sector, but reflecting the reality of where we are sitting. Ultimately, the longer-term sustainable goal is everything that we discussed previously: increasing capacity in the NHS and having a wider model that provides support first, rather than focusing on diagnosis.

Emma Harper: You said that Healthcare Improvement Scotland does the governance checking of who is doing assessments, but not everybody is validated in relation to good practice. Would Healthcare Improvement Scotland be a way to make sure that governance and good practice is widespread across the whole of Scotland?

Anya Kennedy: We use the SIGN—Scottish intercollegiate guidelines network—guidelines for ADHD, and for a long time we have requested that they be reviewed. Those guidelines use the phrase "appropriately trained practitioner", which is obviously a very broad term. They do not identify professions, registrations or expected training, which I think brings in some of the confusion regarding the private sector. There is not guidance on who is qualified to be doing the assessments, and there is also the assurance aspect around individual practitioners.

Even if it was to be looked at within the private sector, we would encourage a multidisciplinary approach. It should not be a uniprofession approach, involving only a doctor or a lone AHP doing that assessment, because the assessment is multidimensional and looks at different areas. That is what we are calling for.

You asked about a once for Scotland approach, which would have real benefits. We do not have huge, endless amounts of resources and we are currently trying to work smarter across some of the resources that we do have. I am aware of some projects, such as the AHP-led digital resource working group that is working with NHS Education for Scotland to provide digital resources for people with ADHD, and there are resources to support people with other neurodevelopmental conditions. Obviously, NAIT has produced a lot of things as well.

We need to try to work smarter with the resources that we have. A once for Scotland approach allows us to pool resources and skills from across Scotland, and not just work within individual board areas.

The Convener: Elena Whitham has a very final brief supplementary.

Elena Whitham: I will be brief. Several times, mention was made of the fact that online assessments are maybe not robust. I just want to explore and challenge that a little bit, considering that a lot of people use Near Me to access psychological support services for addictions, and that some of the trusted partners that the NHS uses do online assessments that take five or six hours at a time or that take place over several periods. I would like to hear your response to that, because I heard that comment several times.

Dr Srireddy: I am in no way saying that an online assessment is not robust—quite the opposite. The person undertaking the assessment needs to have the right skills, so the issue is who is undertaking the assessment, rather than how it is undertaken. The point that I was highlighting was the lack of regulation of online assessment when the service providers are not based in Scotland. HIS cannot cover them, because of the regulatory process, and, therefore, it is impossible to know about the regulation of such service providers and the quality of the assessment that is undertaken.

Essentially, undertaking an online assessment with a person might be the same as travelling elsewhere and undertaking that assessment with the same person. The issue is that there has been an increase in remote assessments by providers who are not physically based on Scotland and are outwith our regulatory context. There are a substantial number of providers in Scotland who provide excellent-quality online assessments that are no different from face-to-face assessments and, within the NHS, we routinely provide online assessments and virtual assessments. In NHS Highland, for example, that is a reality. It improves access and it is hugely helpful in improving our sister services, so I want to clarify that.

Elena Whitham: Thank you very much for that. That is helpful.

The Convener: I thank the witnesses for their evidence this morning, which has been helpful to the committee. I will briefly suspend for a change of witnesses.

10:16

Meeting suspended.

10:27

On resuming—

The Convener: We will continue with agenda item 2 by taking oral evidence from a second panel of witnesses as part of the committee's inquiry into ADHD and ASD pathways and support. I welcome to the committee Thelma Bowers, head of mental health services, NHS Ayrshire and Arran; Louise Bussell, board nurse director, NHS Highland, who joins us online; Dr Gill Kidd, consultant clinical psychologist, child heads of psychology services; and Dr Cath Malone, consultant clinical psychologist and lead clinician, Tayside adult autism consultancy team, NHS Tayside.

We will move straight to questions from Patrick Harvie.

Patrick Harvie: Good morning to our new panel of witnesses. As you will be aware, we have heard a lot of evidence about the variation in waiting times, in service provision and in the various timescales and so on for referrals to pathways to access services across different parts of Scotland. Can you give us a sense of the extent to which that variation is itself fundamentally a problem, or is variation simply something that we should live with in a country with multiple health boards that provide services in line with their different priorities? What could the Scottish Government do if it chooses to reduce or eliminate that variation and establish a standard universal set of expectations for people? Do health boards look at one another's performance and treat that, informally, as what they need to be aspiring to? Is there any sense at all that health boards are trying to achieve not universality but some common expectations? I am happy to open that up to whoever would like to kick off.

10:30

Thelma Bowers (NHS Ayrshire and Arran): The committee has heard from various colleagues, the third sector and people with lived experience, and I think that the overwhelming response to the variation is that there should not be a postcode lottery. This is a public health issue that should be addressed at a societal level. What does that mean, then, in terms of the whole system for partners and organisations within the system and within our communities?

On the variation between board areas, as you will have heard, we do not have a performance dashboard or standards that we can report on nationally. However, I am completely sure and confident that every board area is trying to collate the data where they can for both children and adults. Certainly, that is the case in Ayrshire and Arran, and we regularly connect with other board areas through our heads of psychology services and psychiatry, and our allied health professional leads, and also through NAIT. We look at the good practice and learn from pilots.

It is a journey in that respect. It is about starting to grow the data and gathering information from people with lived experience, and then connecting together to see where things are working and sharing those areas of good practice as well as areas of challenge.

You asked what should be done next. We need to build on that—I am sure that that will come into other questions on which we can go into more detail. I think that it is about building on good practice and recognising that we will need investment to be able to do that. We certainly expect there to be a phased approach to that in our services.

Patrick Harvie: Does anyone else want to come in and react to what we have heard on that idea of building on good practice? Is that a reasonable phrase to use when practice is so widely varied? Some health boards simply do not provide adult assessments at all, for example, whereas others do.

Dr Cath Malone (NHS Tayside): I was going to pick up on the point about NAIT, which is a fantastic organisation that is bringing together different services across Scotland. It hosts quarterly meetings with different health boards at which representatives from different organisations come together to share good practice. In response to your question as to whether we need universal standards or local variation, I would say that we need both. We need a standard of practice that is consistent across Scotland, but with a local signature. It is about being able to be responsive to local need as well as offering a standard that people can expect across Scotland.

There are a multitude of reasons as to why the picture across Scotland is so inconsistent. A lot of the points that you have discussed over the past couple of weeks have come down to funding—that is undeniable—but it is also about using the resources in different ways. The NAIT recommendations around neurodevelopmental pathways are absolutely the way forward. In NHS Tayside, we have separate services around autism and ADHD, but we are also working together on a whole-scale neurodevelopmental pathway redesign that allows for that universal good practice to be implemented, but with the local signatures as well.

Dr Gill Kidd (Child Heads of Psychology Services): I suppose for children's services, the variation has happened in combination with the rise in demand, but also with how services were set up pre-Covid, and pre that rise. We know that all services are not set up equally. We had different pathways for autism and ADHD that were not able to then meet the demand that was coming forward. In the past few years, we have learnt that we need to look at ADHD and autism together to stop children bouncing between different pathways and services.

The capacity is not easily accessible. It is not co-located or joined up. In some health boards, services will be split across different directorates—between children's services and CAMHS, for example—and it is not easy to join them clinically. The other side of that is that some of that capacity sits within CAMHS, as do the waiting lists, so we have a tension between delivering on the mental health waiting list as well as trying to meet neurodevelopmental needs. We have the skills and the clinicians within CAMHS who can deliver that, but they do not have the capacity to do so because they are trying to meet the Government standards around mental health as well.

Therefore, on the variation, we know that there is a combination of demand and how services were set up, and we need a transformation of how services are configured to meet that demand. The answer is not purely to resource the waiting list; it is about resourcing the system of support around that. That can look different. We have talked about a public health approach, so maybe we could think about the national framework that we need, where parents and professionals, including those in education, can access resources and support at a national level, matching that with what then is delivered at a local level.

We have areas of good practice, such as making local consultations available for parents and people in education, where they can phone up to get an understanding of the child and the needs-based approach to formulation without the need for a diagnosis. There are some good frameworks that we could look at. We could also draw on some of the work of NES around trauma-informed practice and think about the skills and competencies that are needed to deliver a trauma-informed service. How do we develop that for ND? How do we identify what we need at a skills level through to what we need at a specialist level, and how do we get training to support skills development?

Patrick Harvie: I think that probably everyone has mentioned resources. That was unavoidable, so let us acknowledge that issue. Are there any other barriers beyond resources that you think we need to be aware of in delivering either the NAIT recommendations that witnesses have spoken about or the specification for children and young people that Dr Kidd talked about?

Thelma Bowers: I think that there have been workforce challenges. Although this is a public health issue—it is about seeking a diagnosis—it sat within mental health services because that is where all the skills and expertise lie. We are aware that we have a gap in our workforce, although psychology, psychiatry and allied health professionals have been seeking to continue to develop services where opportunity allows.

In Ayrshire and Arran, we have some variation because of the dedicated neuro-CAMHS service that was established with funding that came through the enhanced mental health outcome bundle. Adult services, which obviously involve primarily our community mental health teams, have been redesigned to try to respond to growing demand from a core mental health perspective, and they have absorbed diagnostic provision universally for the whole population. Unfortunately, demand is very high, so there are challenges in being able to deliver a diagnosis to and prioritise those people with a mental health need.

I think that there is something of a barrier there around the workforce. We should look at having a national workforce plan. This is a public health issue. How then do we align our existing workforce and expertise across the whole system, so not just in mental health but in education and the third and independent sectors? What can we deliver as a whole society at those different levels to grow that expertise?

Patrick Harvie: Were you looking to come back in, Dr Malone?

Dr Malone: I was going to say that another big barrier is how we shift from our current model to a more whole-scale neurodevelopmental pathway. The traditional model of referral for assessment has led to huge waits at the moment. In Tayside, we are trying to move towards a neurodevelopmental pathway redesign while still tackling the long waits. We are trying to utilise the resource in a way that enables the move to a neurodevelopmental pathway redesign but which completes the task for those who are already on the waiting list.

The Convener: Louise Bussell wants to come in.

Patrick Harvie: I was just going to say that I am conscious that we have an online witness from NHS Highland who may want to reflect on what has been said and on the experience of the NAIT pathfinder programme.

Louise Bussell (NHS Highland): Can you hear me okay?

Patrick Harvie: Absolutely.

Louise Bussell: Fantastic. Thank you. I want to go back a step to the question about consistency. I reiterate the point about the need to get to a level of consistency and some national standards. However, we also need to be able to look at how we do things differently in different areas. How can we have that innovation and good practice? Also, how do we benchmark, not just in Scotland but nationally, against the pockets of good practice without having standards that are so specific and rigid that they do not allow us to look at practice that would work better in different geographies—for example, in the Highlands as opposed to Glasgow? There will be quite different needs, given the way that we work, so there is something about having those national specifications or standards without tying us to them such that we cannot do things well or properly.

Reference has been made to workforce planning. We are all doing that in our individual areas and pockets. Again, where is that national look across, asking about the workforce that we need, how we build it and how we build on from there? Indeed, how do we build on the existing workforce? I do not just mean in health. We have good third sector support, we work with Highland Council and we work with Argyll and Bute Council. How do we ensure that that workforce plan is not just about the health component?

Patrick Harvie: Does either the Scottish Government or any individual health board currently seek to develop a policy for issues such as diagnosis recognition? I suspect that the answer to that will be no. We have heard about the extremely patchy responses that people get when they speak to their GPs about diagnoses provided outside the NHS. Does any health board seek to achieve consistency on that at the moment?

Louise Bussell: We are certainly not there yet. One of the challenges lies in the juxtaposition between what we are being given and what we can provide. We have not fixed that; I do not know whether any of the other health boards have done so.

Patrick Harvie: Unless there are any final comments on that, I will leave it there.

Dr Kidd: I will come in. The difficulty is that our services are set up around a diagnosis being required before people can access support. We need to make a fundamental paradigm shift away from that and towards an assessment for support being in place when it is needed—for example, to access evidence-based treatments for ADHD. We need to have a stepped care approach that is matched to our waiting lists.

Currently we have long waiting lists that are difficult to stratify to look at individual cases. Therefore, work needs to be done first to identify who is on a waiting list and what their needs are, and then to point them in the right direction towards either a consensus diagnosis or a more formal structured assessment where that is required.

That is where additional capacity is required—we cannot do that within our current capacity. If we had the right workforce, we could work towards being able to do clinical assessments as well as outreach work with our multi-agency partners and the education sector to build supports and strategies in schools.

Patrick Harvie: Can I just check a phrase that you used there? Was it “consensus diagnosis”?

Dr Kidd: Yes, it was.

Patrick Harvie: Will you unpack that a little, please?

Dr Kidd: That has come through NAIT, as a suggestion for how we can move forward where a young person, their family and the professionals around the table are all aware, and all agree, that the young person meets the autism criteria. The suggestion is that if everyone is in agreement, and there is enough evidence, we can give a diagnosis at that point, without needing to go through the SIGN and the National Institute for Health and Care Excellence guidelines-based approaches. Services have tried to implement the SIGN and NICE approaches, but they are outdated. However, it is not possible to deliver that alternative approach for every child.

Patrick Harvie: Is the consensus diagnosis approach ever used for adults?

10:45

Thelma Bowers: I will come in by highlighting the transformation programme in NHS Ayrshire and Arran. For three years, all partners have adopted a whole-system, multi-agency approach, and have worked together across education, social care, children’s services and mental health services to address issues within the resources that are available. Earlier in today’s discussion there was mention of using neuro-affirming practices. Implementation groups were set up in east, south and north Ayrshire, and the group in south Ayrshire implemented a multi-agency panel approach. Therefore, some of those ideas on consensus are already being explored.

We definitely need to think more about changing the culture and asking whether, in a given case, there might be enough information to create consensus without going through the more complex work that would otherwise need to take place.

Another step that Ayrshire and Arran took to enable a culture and paradigm shift was that our three IJBs invested in a neurodevelopment empowerment and strategy team. That is a universal offer to children and adults that runs on a drop-in, self-referral basis to provide support through listening, workshops, training, education, information, behaviour support and parental support. It has been instrumental in starting the culture change journey across our system.

Patrick Harvie: But that would not remove the requirement for a formal diagnosis if medication was being sought.

Thelma Bowers: Not everyone who has accessed NEST has been able to gain a diagnosis. The team is there to support people both before and following diagnosis. They will access the service at some point on their journey. Many people are not able to get a diagnosis, or are waiting to get one, but that work enables them to feel affirmed, validated, recognised and listened to.

Patrick Harvie: Thank you.

David Torrance: Good morning. How does workforce availability impact on waiting times for neurodevelopment assessments and services? What impact do long waiting times have on staff motivation and wellbeing?

Thelma Bowers: They have had a significant impact. I give the example of the areas within NHS Ayrshire and Arran where we have been able to develop a targeted neuro CAMHS service. We absolutely celebrate the fact that we have been able to develop a workforce model, and a multi-agency and multi-disciplinary team approach, but those are still not enough. There are still waits, which create burnout in our team and a sense of moral injury from not being able to support people in the way that clinicians would want to.

Because people either cannot get a diagnosis or they have a long wait—which could be two and a half years—we receive a lot of complaints and inquiries, which our team have to deal with at the same time. Unfortunately, we have some turnover among our staff. Once we have trained our team and they have become highly skilled practitioners, they often either leave for alternative roles or move to the private sector where pay and conditions are better and positions come with higher salaries and so on.

In adult services, there is even more of a challenge. In Ayrshire and Arran, we do not have a bespoke service for adults. I am aware of burnout within our teams because they are unable to respond in a timely fashion or to accept referrals. At least 30 per cent of all our weekly referrals are to our adult CMHTs. Sometimes we are not able to respond to a high number of people, which creates a challenge that impacts on the durability of our staff and on their morale.

David Torrance: Would anyone like to add to that?

The Convener: Louise Bussell wants to come in, but we will come to Dr Kidd first.

Dr Kidd: The committee will have heard that there are workforce bottlenecks, in particular around prescribing. There are insufficient medical and non-medical prescribers to meet the demand. Even if we diagnose ADHD, for example, there will still be a wait for prescribing and treatment. The diagnostic process generally sits with a small number of people so we have bottlenecks there, too. As I said, some of those services sit within CAMHS. Although the workforce and the skills might be there, some services have not been able to direct capacity to neurodevelopmental services because of the need to also address the waits for mental health services, so we are confounding two workforces.

Solutions might include better defining the workforce, looking at skills gaps so as to provide appropriate training, and having a better mix of skills. As the committee will have heard, we definitely have a wider workforce available through nursing, AHPs and psychology, who have the skills and competencies to deliver what is required. They could step into some of those roles if an appropriate service was set up—not only to provide diagnosis but to formulate an understanding of the child and of neurodevelopmental differences in the context of child development, and to support parenting and education strategies.

David Torrance: Louise Bussell, do you want to come in? [*Interruption*.] We cannot hear you.

Louise Bussell: Is that better?

David Torrance: Yes.

Louise Bussell: Thank you. I apologise for the connection issue.

Workforce challenges have a massive impact on our waiting times; they are the most significant factor in why we have the waiting times that we do. There are multi-faceted reasons for that. They are not all about being able to get people for the roles; they also include having the finance in place. As others have said, there is a small market for such positions, because only a small number of people can currently do that work. We need to build a much greater workforce, but first we need the finance to enable us to do so. Therefore, it is a case of having a double-edged sword.

On the impact more widely, there is an effect on mental health but also an impact everywhere else. There are people who come in to our paediatric services, and for whom we do not yet have diagnoses, whom we know would benefit from intervention and support. There are also people who come in to our acute services and our schools. Not having sufficient staff-wise has a knock-on effect across the system—not just within the core services that already cover that area.

It is also important to note the number of complaints that come in from families. It is often the people at the front door—the folk on reception and in admin roles—who absolutely bear the impact of people contacting them, asking “What is happening?” and, understandably, being very unhappy.

David Torrance: Louise, if you could just hold it there, please, you will probably be able to answer my next question. What is the impact of short-term or pilot funding on the delivery of services?

Louise Bussell: It is really challenging. As we have already said, the number of people who are ready and able to do these roles is small. They also want certainty. If there is a substantive job going, people will go for that much sooner than they will go for a temporary post, so we will always have an uphill struggle when trying to recruit. If there are hundreds of applicants for one job, people will be much more likely to go for a temporary post. However, when things are the other way around and only a few people are suitable anyway, they will go for certainty. That is a real struggle.

Planning is also difficult. If we do not know whether money will come to us permanently, we are constantly robbing Peter to pay Paul. That is a particular challenge for us as a lead agency, because we struggle with being unable to carry money over. It is certainly problematic for Highland in particular but, obviously, it will be difficult for all areas. It also raises the question of how we can plan for services five years down the line if we do not know what money will be available for them. We can only do what we might call boom and bust planning, so it is tricky.

Dr Kidd: I absolutely agree with Louise Bussell on short-term funding. We must also consider where funding has been directed to. For example, if it is coming into health only, then it would not support the wider framework that we are talking about. We need to think differently about how the whole system is funded and to use a multi-agency approach. Funding also needs to go into education, social work, children’s services and CAMHS so that we can all provide the bits of that service that we need to and for our services to hang together and be sustainable.

The short-term funding has been welcome—it is not that it has not been. The test of change that has happened in children's services has helped us to learn what to do and what not to do. However, that funding was never about providing the capacity that is needed. Learning from the test of change through a whole-systems approach would allow us to to know what funding we need and for that not to create siloed working in the way that is has done previously.

Thelma Bowers: I agree absolutely. Once you establish a service or an approach, it creates public expectation. It usually sits in one part of the system rather than all parts, as has been mentioned. Subsequently, you might have to retreat from that or take a risk prioritisation approach.

Notwithstanding the recruitment issues, it is exceptionally difficult to recruit to any fixed-term post. When short-term funding becomes available it is a question of taking a risk as to whether it is viable to go down a certain route.

I agree that the issue should be looked at from the perspective of the whole system and that we should ask what partners can do together to deliver alternative approaches. We always welcome receiving pilot funding and seed funding, but anything longer term sometimes raises an expectation only for us to have to retreat again, which is not fair on the public and our local communities.

David Torrance: Thank you. I have no further questions, convener.

Brian Whittle: Good morning. Thank you for coming in to give evidence.

I have a few questions on data. We know that the information on waiting lists for neurodevelopmental conditions, assessments and diagnoses is not nationally recorded or published. Why is that? What impact does not having the full picture have on people's treatment?

Dr Malone: One of the clear reasons for not being able to capture all that data is that assessments and interventions happen in a number of different settings. For example, my service, which is the Tayside adult autism consultancy team, covers the whole of Tayside, but not all autism assessments happen within my service.

Earlier you asked about the various models of assessment. We offer a consultation model in which clinicians who are already working with a patient will do the diagnostic work or can borrow our multidisciplinary team to arrive at a diagnostic decision. Alternatively, my colleagues in the community mental health team might carry out assessments with the clients they are already working with. Assessments happen in a range of different settings, and it is really hard to capture that when electronic systems often do not differentiate among the reasons for referral.

Brian Whittle: Is there a technical issue that we need to look at? Do we need to develop a technical model that would allow you to examine the data better?

Dr Malone: A model would be one way of doing it. Another practice that we have started with our reports is that we have agreed with GPs in Tayside the coding that it would be beneficial for them to record after we have done diagnostic assessment, so that we can look at that data. Our systems can do that; it is just a matter of working out how it can be done.

Brian Whittle: I will broaden that out. If we do not have accurate data and an understanding of the overall issue, what is the impact on planning support and resource, on workforce management and on understanding the state of play?

Thelma Bowers: In NHS Ayrshire and Arran, we have been working on that over the past three years. We hope that by the end of the year we will have a business case and a case for change. One of the first priorities of our work programme was to address how we can enable and collate data in such a complex system. In our area that involves capturing data from CAMHS, adult services and paediatric services as well as other types of data from our universal NEST service, and bringing all partners together to do that.

There are technical issues. In CAMHS we have invested in a system called Power BI, which is a workforce planning tool using a model originally developed by Benson Wintere. We are confident in the data that we have in CAMHS, and we are building data sets in other areas. Having standards, frameworks and a mandate around that agenda certainly would drive it forward and make it more of a priority. Unless we have data—real information about what is happening in our communities, our referral patterns, and our assessments at every level—it is difficult to inform what the future should look like and the changes that we need to make to the system. The situation has been made more complex because those issues run across the whole system.

11:00

Dr Kidd: I agree that there have been technical challenges. My understanding is that health boards have different electronic patient record systems that sometimes make it easy to pull data and at others make it more difficult. Waiting lists are held in different parts of the servicing system and are then amalgamated or collated in the same way. For ND services within CAMHS we might have data only from the CAMHS waiting list, and there are technical challenges in pulling that data out. For CAMHS, waiting lists have been split. Some services split their neurodevelopmental waiting lists from their mental health waiting lists to enable them to better report on the CAMHS referral to treatment standard.

It would be helpful to have national data reporting to enable us to be really clear about what you want us to report on and how you want us to do so and, beyond that, to consider how each health board could do that in a robust way.

Brian Whittle: I wonder whether Louise Bussell could come in to develop the idea that, in certain health board areas, data on neurodevelopmental cases is not disaggregated in CAMHS reporting. How does that impact your ability to properly treat people with these conditions, the numbers of which seem to be exploding at the moment?

Louise Bussell: Can you hear me okay?

Brian Whittle: Yes, we can.

Louise Bussell: The reason why we do not currently collect data nationally is that not all areas currently have the systems to allow them to do so. There has also been a relatively rapid trajectory in the rise in numbers on waiting lists and in referrals. It is not an area in which, even 10 years ago, we would have identified that we needed to look at issues nationally. The momentum of the rise in referrals has been such that we certainly would benefit from looking at them nationally, but the reasons that I have just given are probably why we have not done so to date.

It took us some time to disaggregate data, which we have done in NHS Argyll and Bute and also in NHS Highland. As this has become much more of an emerging situation, we have identified that it is really important to understand our own data and have our own picture. I do not know whether there are many areas that will not have disaggregated data, or at least started that journey.

Brian Whittle: Just to wrap up here—please tell me if I am assessing the situation wrongly—it seems that health boards currently record data in different ways, so if we are to get a national picture we will need to have a universal platform and a new way of delivering that data. Is it reasonable to suggest that?

Dr Kidd: Yes. It would need to apply across services for both children and adults—to patients of all ages—so that you could think about the transition, the impact on the waiting list curve across children's services, and how that would translate into adult services.

Thelma Bowers: Similarly, when developing integrated pathways you would need the data that comes in through education services. If we are looking to have a single point of contact, we must consider how we enable collection of data and achieve transparency in the referral journey. All that needs to be done through a systematic, digital way of working.

The Convener: I will move on to a slightly different topic: lived experience. During last week's committee meeting, we heard about the underrepresentation of people with neurodevelopmental conditions in the planning and delivery of statutory services. How do NHS boards meaningfully involve autistic people and people with ADHD in the development of pathways and services?

Thelma Bowers: As I have mentioned, in NHS Ayrshire and Arran, when we started the programme of transformation and reform three years ago, we recognised that we need to hear from people with lived experience, including children and families. We invest in our NEST service, which I have noted. Through that service, we have regular engagement—it happens at least quarterly—and gather information from people with lived experience about how they are accessing services. We have a huge amount of information that we have been able to use. It is a case of "you said, we did."

Every time we do that, we seek to make changes in our system. For example, after listening to feedback from families, we have made changes in education by creating parent groups, providing flexible curriculums and space and considering how agencies work together in relation to education. That is just one example, but there are many opportunities for listening and having that engagement. That work is critical in informing how we change what we currently do while we wait to get something better.

When we hear about people's experience of trying to access our adult services, which is a particular challenge, we think about how we can pick up support while people are waiting or if there are no alternatives for them at that point. We also have experience in our occupational health department, and our workforce is neurodiverse.

We need to understand the impact across our whole system, and we are doing that across the whole of Ayrshire.

The Convener: You talked about the "you said, we did" model of adapting services and responding to feedback, but how do you involve that community in developing services and pathways?

Thelma Bowers: Through the case for change that we have been developing over the past few years, we hope to have some options, and we will cost them and consider their feasibility. From an engagement perspective, we will involve our mental health network in developing and building on those options, and that experience will be captured in our case for change. That truly represents listening to our communities when developing alternative approaches.

The Convener: Do you think that that is enough? At last week's committee meeting, that was not felt to be enough.

Thelma Bowers: No, I do not think that it is enough by any means. However, we are listening to those with experience, we have noted complaints and we are seeking to improve the quality of what we do at every level. I agree that there is so much more that we, as a society, need to do, notwithstanding what needs to be done through our provision of health, social care and education services.

Dr Malone: I am really pleased that third sector and voluntary organisations came first in this conversation, because that is absolutely how it should be.

We have just appointed two peer support workers, and our test of change is in collaboration with Scottish Autism, which was represented at the committee's meeting last week. Those peer support workers are employed by Scottish Autism, but they will sit within the autism assessment team. The idea is to have genuine co-production and co-facilitation of some of our provision. That is one way of valuing our neurodivergent population as colleagues.

Another example was all stakeholders being round the table when the neurodevelopmental pathway redesign was beginning in NHS Tayside. That included service user organisations, social care workers, carers and other statutory services. That process has been one of genuine co-production.

The collaboration with Scottish Autism has also offered resource for patients on our waiting lists, so it is addressing unmet need in all areas. The Dundee connections service offers a resource for people who do not have a diagnosis or who decide not to go through a diagnostic process. That resource is very much service user led and service user provided. Such services are essential and can be done really well. We should be taking that move forward in better involving the third sector as equal and collaborative partners.

The Convener: It is perhaps easier to do some of that work with adults. How are you involving children in the development of services?

Dr Malone: I shall hand over to my colleagues in children's services, because I work exclusively with adults.

Dr Kidd: It is likely that we need to do that better, but there are examples of good practice, particularly with parents and families. As part of the test of change for the neurodevelopmental pathways, there were reference groups, which included parents, that were able to shape the development of the resources and referral pathways—

The Convener: I get that. Adults are involved in developing adult services and children's services, but I am particularly keen to know how you involve children and young people in service development.

Dr Kidd: We have been working on hearing the child's voice with our AHP colleagues, including speech and language therapists in relation to training staff in the use of talking mats, which you might have heard about. They provide an accessible visual way of having a conversation with children, particularly neurodiverse children, who might find it more difficult to put things into words. Supporting children with concrete visuals can be a helpful way of hearing their voice and getting their input. We know that such approaches are possible to deliver and accessible for children.

If we are not using those approaches, we can build on that and work with our colleagues in speech and language therapy to train the workforce in delivering them. We are using that approach for CAMHS in NHS Lothian to try to hear the child's voice and get feedback after assessment, before assessment and while they are waiting.

The Convener: Louise Bussell, do you want to come in on this point?

Louise Bussell: I do. We definitely need to do more in that area, but it is tricky, so we have to work out how to do things differently. As I mentioned, NHS Highland uses the lead agency model, so the majority of our children's services sit within Highland Council. There are quite strong links to how the council's children's plan was developed, and a number of pieces of work in that regard were co-produced, particularly using third sector organisations for support. We are trying to almost piggyback on that in relation to our new plans for a co-produced piece of work with Highland Council's health and children and families services.

As others have said, it is not easy, and we are still at a fairly early stage. If anybody has got the issue fixed, it would be good for us to use that as a benchmark across health boards and ask, "How have you managed to achieve that well?" We are all grappling with the issue a bit.

Emma Harper: I am thinking about referral processes. Our briefing papers mention that, in its evidence to us, the Royal College of Speech and Language Therapists referenced the use of open referral. It said:

> “Fife and Dumfries & Galloway, which both have strong”

speech and language therapy

> “representation in the pathway leadership teams, are excellent examples of good multidisciplinary collaboration”.

I am interested to hear about the advantages or disadvantages of open referral in neurodevelopment diagnosis, assessment and support.

Dr Malone: That is a big question. The worry has always been the volume of open referrals that will come through. Given that we do not have good data collectively about any areas of pathway within neurodevelopmental services, it is hard to know whether that is the case. NHS Grampian has been cited as an example of adult services where there is open referral. I would want to see better information about what the processes are post-self-referral as well, to see whether there are consistent referral pathways for us to identify how we are better triaging those referrals.

11:15

For example, there was a study done earlier this year that looked to assess patients who were rejected from an autism assessment service. All those patients were given a full diagnostic assessment and none of them met diagnostic criteria. Appropriate triage means that the right people are getting assessments in a timelier way. My concern about open referral is the volume of referrals that come in even when there is a criterion, but that is not well evidenced. We need to have better evidence of that but also know that there is good evidence that suggests that triage processes target assessments in the right area.

Dr Kidd: I suppose that you could have both. Open referral is a request for assistance for support and understanding of the strategies. In some areas, that is a new way of working that we can build on, spread and expand. To go back to the point about stepped and matched care, that is needed at the point where parents and education are requesting that support. Easy access to that would reduce the need for referrals for a diagnosis when that is not the requirement, but we also need a way of stepping up requests where a diagnosis and a formal assessment are required.

NHS Fife is working that kind of model, where there is open access for support but there is also the mechanism to refer in when further assessment is required. That decision is not made on a health basis but is made in a multi-agency way and in combination with health and education professionals. It can also fit alongside approaches such as the consensus diagnostic approach and the stepping up to where a more medicalised assessment is needed. I think that it is not either/or; it is both, but the challenge is how we resource that and have the systems in place for that to happen in a smooth way.

Thelma Bowers: In NHS Ayrshire and Arran, for children at least, we are looking at having a single point of contact working with education, primary care and children’s services. We are looking at digital solutions to do some of that work. We are also taking the same stepped approach, looking at the request for support approach and being able to channel that within the school or NEST and other support that might be available at third sector, and then the triage approach with CAMHS. We have a family support service as well that the IJB has invested in, which children with neurodiverse needs can be referred into. We are trying to build that pathway.

I will not say that we are at the point of open referral. We are looking at whether we can develop a single point of contact and be sure about how we are resourcing and navigating the referrals as they are coming through that process. That would probably be at a much later stage, but it is quite resource dependent because of the significant volume of referrals that that may precipitate.

Emma Harper: Do the referrals normally come from teachers or GP practices?

Thelma Bowers: It is split between education and GPs.

Emma Harper: Does more work need to be done to support those perceived gatekeepers to raise awareness of ADHD and autism and how people can have both? I like the language that Patrick Harvie used in the previous session, when he talked about the need for more neuro-affirming language, so that people who are working in the public sector have more knowledge and are more able to listen and learn. In Dumfries and Galloway, a group called Sleeping Giants did a consultation called think differently, which surveyed 185 people to help them get support, for instance. It was really well written and well done. It has now made recommendations, some of which are about awareness raising for the wider public sector.

Thelma Bowers: Yes, absolutely. As I mentioned earlier, we have our NEST service, which does a lot of that work in training and education. All our partners are on this programme of change and reform together. There is still a lot more that we need to do to build the pathway that I described and the options for service models and how we can phase our approach to get towards a better future. We are trying to develop how we work better with what we have currently.

Dr Kidd: I was just thinking about the competency frameworks. That fits with what we are saying about the need for an overall framework as to what skills people need at different levels: what do you need at a universal level, a skills level; what does your football coach need; what does the receptionist need? How do we share the neuro-affirming language and approaches and strategies at that level right through to what you need if you are diagnosing and doing specialist assessment? Neuro-affirming language is also a public health approach. How do we write reports? How does the Government write reports in a neuro-affirming way? How do we shift the language that is used so that it becomes the language that everybody uses and it is neuro-affirming and supportive of people at every level?

I was also thinking about the environmental adaptations that we need. It is not only about language and communication. It is about how our buildings are set up and how we provide information for people with autism and ADHD so that they know how to manage those areas—so that they know where the sensory overload is and where they can go to reduce that. We might not be able to change the fabric of our buildings, but we can certainly communicate and share how people who are neurodiverse can best navigate it. All of us could benefit from that. There are some good examples of sensory maps. At Edinburgh zoo, there is a sensory map that signposts families and children to where the busy areas and the quiet areas are. It is giving people some control over how to manage the environment that they are going into and to know what to expect of those environments, so that they can prepare ahead. It is about seeing the world through an autistic lens and then thinking about how we build those supports into the fabric of society.

Emma Harper: Even just giving people a heads-up to whether there is a quiet space that they can go to can be quite affirming if somebody has issues.

Dr Kidd: It is also for someone who is anxious. If someone has difficulties in imagining what a place will look like and holding in mind what a room will look like when they go into it, that creates an anxiety, but if we can provide information or videos—you have some good information for people coming here, including a video walkaround—that helps somebody prepare. They think, “I am going to go into that place, I know what it looks like, I know where I am going to sit, I know what the lighting will be like and I can have my own coping strategies to manage that.” It also helps people who are anxious but not neurodiverse. That helps everybody. It is not disadvantaging people who are neurotypical but, equally, it is very supportive for people who have neurodevelopmental differences.

The Convener: I think that Louise Bussell wants to come in.

Emma Harper: Yes, I was conscious that Louise Bussell has not spoken.

Louise Bussell: A fair amount of the points that I was going to make have been covered by other people anyway, so I will not elaborate much more. One of the challenges of self-referral, as people have said, is setting expectations when we do not necessarily have something there to support people sufficiently. We need to do the building work with people as to what services should and could look like, and get them into a better place, before we look at too much self-referral. I worry that people would be expecting something that we cannot provide unless there is an interim arrangement for support, as people have referenced.

We also have to work with our existing referrers to make sure that people are being referred to the right place, that we have the package working across systems and that not all referrals are to just one source. We notice that there is a huge spike in our referral rates just before the summer holidays—certainly in the past two years we have had an enormous spike at that time. We have to work with people throughout the year to make sure that, for example, children in schools are already getting the level of support that is right for them while they are waiting. We need to ensure that the referrers know where they are referring to, what they are referring to and what the pathways are.

Elena Whitham: The last part that Louise Bussell mentioned segues into the questions that I have about resources and information when people are awaiting assessment, or even when they are awaiting the triage that might happen at that point. All of us as parliamentarians get a lot of inquiries from constituents who say that they need a co-occurring mental health concern even to get access to some of the lists at the moment. How do we ensure that people can wait well during that period and that they have access to all the information that they need? How do we ensure that, when you are on the waiting pathway, you are informed of what will happen at every single stage of the journey? Sometimes things land out of the blue—we heard that in last week’s session—and you are given a couple of days to fill in massive questionnaires that you need to get back and then you do not hear anything for a year. That can feel quite isolating.

How do we ensure that resources are up to date and that the information is up to date, clear and helpful? If we look at NHS Inform now, we see that

ADHD is under mental health and autism is under brain conditions, but you really would not think to look there if you were trying to find information.

Thelma Bowers: It is important that there is a focus as a priority on that information. I will give again the example of NEST in NHS Ayrshire and Arran. The IJBs recognise that we are making changes in our system and people are not able to get diagnosis. How do we inform people and how do we offer alternatives? The training aspect is important. That is why there was the investment in NEST, which is quite a central point—building the website and creating information that is accessible, and having the ability to contact the service. NEST can be a central point for that as well as being able to contact the service for information about waits. NEST is linked into all our statutory services as well as our wider partner agencies, so it is pivotal in being able to flag if there is an issue.

We have also invested in waiting list initiatives. For children, we have worked with the third and independent sector to create alternative supports and options such as physical activities and programmes of therapy while young people are waiting. We will continue to explore and learn from that, and we have done that across Ayrshire and Arran. Those are some good examples, and we are investing in apps, which are another good way of keeping people up to speed.

Elena Whitham: To get information to people at a time that they want to access it and in an easy format.

Thelma Bowers: Yes.

Dr Malone: This goes back to the issue that has been mentioned a few times of whole-scale change. The children and young people national neurodevelopmental specification indicates that it should be needs led, and nobody has disagreed with the fact that services should be needs led. However, they are not. We need to provide wider services with the skills to work with neurodivergent people. People with neurodevelopmental conditions and neurodivergent people are overrepresented in the range of health services. On waiting well, what are people waiting for and why can services that are already involved with that person not support that? Whole-scale change is an aspiration that people are all wanting to work towards. It seems unachievable—that has always been the “but”. We should be working towards somebody’s needs, but there is not the resource for that. We still need to move towards it, so waiting well involves whole-scale change as well as provision for people while they are on the waiting list. The outcome should be an increase in the quality of life, not just necessarily a diagnostic assessment.

Elena Whitham: What is concerning us and why this inquiry has come forward is the fact that people tend to tip into mental ill health while they are waiting. They cannot get access to services, or they are perhaps in the criminal justice system, or they are dealing with substance use issues. There has been a clear gap in understanding what is happening for that person. Absolutely it is about the whole-systems approach and whole-systems change. I am glad that we heard the third sector mentioned, because this is a key area where we need to figure out how we empower and resource it to do a lot of the scaffolding that is needed underneath families and individuals in that circumstance.

11:30

Dr Kidd: I was thinking about once-for-Scotland policies from a health point of view. We have areas of good practice, and we can bring those together and have something that is consistent at a national level and a public health level. There are workshops and interventions for parents that could be delivered at scale online; they could be delivered nationally, so they would help with very rural areas and urban areas. Parents can book on to those without the need for a diagnosis and that could be easily accessible. Rather than being recorded, they can be delivered by skilled professionals who have ND expertise, so they are using the workforce in a scaled-up way. That is at a national level and should be at a universal level. Below that, at a local level, you have the ability for parents and education to get individual information about a child and the formulation and understanding about their vulnerabilities but also what are the things that are maintaining their current difficulties. It is about the national, local and individual levels and having that across the age range.

There was something else, but it has gone out of my mind.

Elena Whitham: I will briefly bring in Louise Bussell from a Highland perspective. Gill Kidd put context around the reality that you are facing and what can be delivered online. Do you have any other thoughts?

Louise Bussell: Yes, absolutely. We make very good use of online, for obvious reasons, but equally there are people who struggle with online, particularly for assessments and dedicated work, so we have to be flexible and offer both online and in person wherever we can. We work closely with a fabulous third sector organisation, Autism Initiatives, which provides a lot of support for people—one to one, groups, online activities and so on. There is very much a reliance on the whole picture and not just on what we can do to support people to wait well, which at best is limited.

Dr Kidd: Can I just come in on our general understanding about child development and the context in which children are living at the moment in relation to access to screens and the impact of Covid on their social communication and development? We cannot ignore that and the need to research and understand it and feed it into early intervention for younger children to ensure that we are maximising the opportunities for developing their social and emotional skills as well.

Elena Whitham: I suppose, in all that, there is a question about how the new world that we work in aids and abets masking and how those different things affect individuals who might previously have lived their whole lives without developing an issue.

Dr Kidd: And how that might be more difficult to move away from if you are neurodiverse.

Thelma Bowers: While people are on waiting lists, there should be robust approaches to escalation points. People's needs change while they are waiting, especially children, so that is important for risk management of all waiting lists. For children who are not able to access CAMHS, we also provide reach approaches into settings such as education from a CAMHS perspective to support young people and escalate risk as that emerges.

The Convener: I thank the panel for their evidence this morning. At our next meeting on Tuesday, 28 October the committee will conclude oral evidence as part of its inquiry into ADHD and ASD pathways and support with the Minister for Social Care and Mental Wellbeing. That concludes the public part of our meeting today.

11:34

Meeting continued in private until 12:02.

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