HOUSE OF LORDS

Autism Act 2009 Committee

Corrected oral evidence

Monday 2 June 2025

4 pm

Watch the meeting

Members present: Baroness Rock (The Chair); Lord Addington; Baroness Browning; Baroness Goudie; Baroness Hodgson of Abinger; Lord Hope of Craighead; Baroness Pitkeathley; Baroness Ritchie of Downpatrick; Lord Scriven; Lord Wigley.

Evidence Session No. 16 Heard in Public Questions 110 - 117

Witnesses

I: Simon Froud, Director of Adult Social Care and Statutory DASS, Telford & Wrekin Council, and Sponsor, West Midlands ADASS learning disability and autism network; Dr Emma Bradley, Consultant Paediatrician, Sirona Care & Health, and Chair, Royal College of Paediatricians specialist advisory committee for Community Child Health; Victoria Bates, Child autism assessment lead, Sirona Care & Health.

Examination of witnesses

Simon Froud, Dr Emma Bradley and Victoria Bates.

Q110 **The Chair:** Good afternoon. Welcome back to this meeting of the House of Lords Committee on the Autism Act 2009. We are now commencing our second evidence session of the afternoon. In this session, we will explore the commissioning and delivery of NHS and local authority services for autistic people in the context of the Act.

We are delighted to welcome Simon Froud, who is the director of adult social care and statutory DASS at Telford & Wrekin Council and a sponsor of the West Midlands ADASS learning disability and autism network; he is joining us in person. We are also delighted to be joined remotely by Dr Emma Bradley, who is a community paediatrician for Sirona Care & Health; and Victoria Bates, who is the child autism assessment lead at Sirona Care & Health. You are all very welcome. Thank you so much for taking the time to be here.

This is a public evidence session. A written transcript will be taken. I draw attention to members' interests as published on the committee's website. Having said all that, I ask Baroness Browning to ask the first question.

Baroness Browning: Who is responsible and accountable for ensuring that autistic people can access the support they need on a local and regional level? How clear are the lines of responsibility and accountability? What roles do the Autism Act 2009, the statutory guidance on the Act and the Government's autism strategy play in setting responsibility and accountability for supporting autistic people? Why do they play or not play an important role in setting responsibility and accountability?

Local authorities and NHS bodies must follow the statutory guidance on the Autism Act 2009 unless they have good reason not to do so. If they do not, they may be liable to judicial review or action by the Secretary of State. Yet, to our knowledge, no Secretary of State has ever taken such action since the Act came into force. Why is this?

Simon Froud: I will try to answer those in order; forgive me if I jump between a few bits.

On the responsibilities and accountabilities for ensuring that autistic people can access the support they need, currently, there are overlapping responsibilities and accountabilities between the NHS, ICBs—integrated care boards—and local authorities. The legislation that covers the legal duties of a local authority around the Autism Act 2009 includes the Care Act 2014, the Children and Families Act 2014, the Children Act 1989 and the Equality Act 2010. Our statutory duties are in those frameworks.

As the DASS, with the Care Act, I have a statutory responsibility to meet the needs of people who are vulnerable and who meet our eligibility criteria. I do not want to complicate this too much but the responsibilities overlap between health and social care, and it sometimes comes down to

an individual's diagnosis. If that diagnosis is around their autistic needs, we have a responsibility to support that person with different degrees of support. For example, for someone who has eligible needs, we could provide accommodation, support for daytime activity or some employment activities, as we have just heard. It is about looking at how we can enable that person to live life to the full. For example, their accommodation would be one of our responsibilities; we provide that as part of our local authority responsibility.

I turn to the spectrum of someone who has very complex needs across the area. If they have complex, challenging needs with autism, it becomes a joint responsibility between the NHS and ourselves in the local authority to support that person with their therapeutic needs or with some of the challenges and complexity around their demands. Sadly, this can sometimes result in the person being hospitalised because their needs are so great. I do not want to complicate things further but there are also lots of dual diagnosis needs among people with mental health problems, learning disability and autistic needs.

On how clear the lines are, as I have mentioned, they are sometimes blurred, but we work on a local basis with our health colleagues to join up and unblur those areas of responsibility. For example, we have some joint teams and joint working arrangements with our NHS trusts—the community trusts in particular—as well as some of the mental health trusts.

I shall move on to the roles and the statutory guidance. As I have mentioned, we have accountability for supporting people, but people do not meet our eligibility criteria sometimes. So we are working on providing information, advice and support to those families and individuals who have support needs in their local community. As an example, if someone has an autistic support need within their family but they do not meet our eligibility criteria, we can provide for them local community support and arrangements with our voluntary sector colleagues. We commission voluntary sector bodies—the local CVSs, as they are called—to support people in their local communities as well.

In terms of playing an important role and setting responsibility and accountability, the strategies and the Autism Act are not legally binding as such, but they give us guidance and make sure that we are carrying out our duties of care under the Care Act; that includes supporting families, children and the young people coming through children's services. One of the things that we are working closely on is preventive services—that is, making sure that people are prevented from coming into our service and our system by addressing their need for help at an earlier stage.

Early diagnosis is really important in making sure that we actually get to that point. When we have an early diagnosis, we can then look at the front levels of support and give information and advice. We have heard about employment today but the person may have a housing need or a social care need in terms of daytime-type activities. Some people also

have quite complex needs; they may need 24-hour care and support or what I call one-to-one support. Again, we provide for all those as well. So it is quite a large spectrum of support.

On the last part that you mentioned—why there has not been a judicial review from the Secretary of State—in the Autism Act and the strategy, there is no specific accountability or responsibility for a local authority to provide certain services. We come under the Care Act duty. If we are not providing certain services, we can get judicial reviews from individuals, but we have not had anything from the Secretary of State because the Act does not enable that, I think.

Having said that, we are being inspected by the Care Quality Commission, and we have a duty to make sure that we are providing the right levels of support. That means a duty of support for people with autistic needs and people with a variety of different needs in relation to neurodiversity; it cuts across the range.

There are different legislative requirements. We would obviously need to make sure that we are advertising what we provide and how we support autistic people within the local authority.

We may come on to this, but certainly we have autism strategies across most, if not all, 150 local authorities. There is great engagement with our partnership boards and people with lived experience. We are guided by the Autism Act, but also the national autism strategy, and then it localises down to a local autism partnership. We are working very closely with individual people with lived experience, on a local basis, to guide us in designing and co-designing the services.

I will pause there. I might have missed some bits, but I will come back if needed.

Baroness Browning: Thank you for that fulsome reply. Could I just question you on one aspect? You have mentioned more than once the question of diagnosis. We know that, for people who are not receiving the support they need—whether they have a diagnosis or, as is the case for many people out there, they do not have a diagnosis—there is a very quick downward spiral in mental health, which leads to very problematic crises sometimes.

We are going to come on in a minute to doctors who will be familiar with what happens when autistic people do not receive the support and services that they need. Are you saying that it is the diagnosis that triggers the local authority input? Have I understood that correctly?

Simon Froud: No. My apologies if I have given that impression.

Baroness Browning: Thank you. Could you just clarify that?

Simon Froud: We are not reliant on having a diagnosis as there is a two-and-a-half-year, or thereabouts, waiting list for quite a lot of diagnoses.

Baroness Browning: I am thinking of adults as well.

Simon Froud: For both adults and children, once we have identified that there is a need for health and/or social care, we have a responsibility to meet that need. We do a number of assessments: a mental capacity assessment, a mental health assessment and a whole range of other assessments.

We work with the individuals, their families and their networks. We do not necessarily need to have a diagnosis. I apologise if I have given that impression. A diagnosis does help because it gives you an area to work in with that person and their family. My colleagues will probably give a bit more detail on the medical diagnosis and how that operates.

There is a pressure on the system and the service for both children and adults in relation to diagnosis. It varies across the country.

Q111 **Baroness Browning:** Thank you very much. Could I move to Victoria Bates now, please?

The Chair: Could I make a suggestion to Victoria Bates and Dr Bradley that you decide between you which person will answer the question?

Victoria Bates: I will start. Just on a point of clarification, I am a nurse. My colleague here is a doctor.

On the questions around responsibility and accountability for ensuring that autistic people can access support, I very much echo what you have just heard: it should be a shared model between social care, health and education. Health should get involved only if there is a health need, rather than often being deferred to as the primary resource.

The lines of responsibility can be blurred. Especially in the face of cuts, it is not always clear what organisations do and who does what. There is therefore a risk that families and children may fall through the gaps.

So we need to be honest when we are thinking about making sure that the right support is being accessed. Organisations are often clear about their responsibility in relation to accessibility, but not necessarily in relation to delivery. That can cause confusion at all levels, for both professionals and service users.

People with autism often have other health or social needs too; that is important to recognise. There is a phrase: diagnostic overshadowing. These things can get conflated. People will think it is the autism that is the basis for the need; it can be hard to access support and services on the basis of a need that people think is being managed elsewhere.

This can also lead to autism services being expected to pick up and deliver a service despite it not being their area of expertise and not having the right skill sets.

I will hand over to my colleague to answer the next group of questions, but I want to pick up a point on the statutory guidance in relation to local authorities and local autism partnership agreements.

This is something that is working well. We have boards across all the local areas, as well as autism strategies. One of our areas has recently developed that, co-producing a strategy across different services.

The barriers that can impact on the establishment of effective autism partnerships often come down to commissioning arrangements and funding, where, as I have mentioned, it is not always clear who is responsible for each area.

As regards the NHS and local authorities, there is some real emerging evidence relating to the question of when support is best placed. Currently, it often happens at a crisis point. That means that we have more limited evidence in relation to prevention as compared to crisis management and reduction work.

However, there is hugely increasing evidence around early identification of need. As yet, we do not have the longitudinal evidence to demonstrate how that can impact on outcomes for children, young people and their families, but it is recognised that—just as you mentioned around early health—early support could prevent ongoing hospital admissions.

Also, early support and intervention, when it comes to education and maintaining engagement in education, will have positive outputs, in relation to an individual's ability to access the employment market, but also to potentially reducing their risk of criminal exploitation and entering the criminal youth justice system.

Young people are becoming more clinically complex, and so we see worsened outcomes relating to educational attainment, mental health, the criminal justice system, and, maybe, substance abuse. That increases the level of complexity and therefore the resource needed both to manage them in those associated areas, but also potentially in their diagnostic assessment.

Waiting times can be exponential—over five years in our area, far longer than Simon mentioned—and there is very little post-diagnostic support. We know about the importance of early identification of needs, and there is a growing body of evidence around neurodiversity profiling to support that early identification of need; so, moving away from diagnosis-focused approaches and services, making sure that people are getting the right support at the right time, reducing the perception of a requirement for diagnosis before you can access support. For example, in the case of an educational healthcare plan, you do not need a diagnosis to have one of those. What is needed is a recognition of the areas of need.

On the question of the strategy ending and what could be needed in the future, we could think about making sure that the aspirations of the strategy and guidance move towards earlier support and preventative

services rather than responding to crises. I will now hand over to my colleague.

Dr Emma Bradley: Thank you. I want to talk about what role the Autism Act, statutory guidance and the autism strategy plan play in setting responsibility. In principle we find that the responsibility is set out very clearly, but the commissioning arrangements across health, social care and education mean that that responsibility is often blurred; it is often not as clear as we would like it to be. The autism strategy is not really reflective of the current demand and the exponential rise in numbers over the last few years. It is very difficult; I do not think the Government could enforce at the moment or fund what they are saying autistic people should have the right to access. The strategy is very optimistic, but because the recommendations are not all funded it means there is a mismatch, and there can be quite a lot of frustration when families cannot access the support that they are looking for and are told that they should be able to get.

We do find that a lot of support is based on the medical diagnostic model. Without the diagnosis, it can be hard to access some services. It should not be, and we do a lot of work in our region about support needing to be needs-led not diagnostic-led, but families can find it very difficult not to have that diagnosis, and some services will want that before they will offer the level of support that is needed. We recognise that it would be much better to put the support in far earlier, and then we would avoid—as Vicki said—the crisis response.

The Chair: Thank you. Baroness Hodgson had a supplementary, and then we will move on. Without wanting to take away from the depth of your responses, which I am incredibly grateful for, between Victoria and Emma, maybe if one person answers the questions going forward, that would probably be quite helpful, and—just in terms of not wanting to keep you here for ever—could we sort of focus on the key elements to the question?

Baroness Hodgson of Abinger: Mr Froud, you talked about services when you become aware that support is needed. How do you become aware when support is needed, especially with adults?

Simon Froud: In Telford & Wrekin, for example, we have an autism hub where we advertise autism services in the community. It is about making awareness around the local area, with our GPs, our communities and a whole range of our partners. If someone has a housing need but they have identified autistic needs or they have support, they can refer into adult social care. Then we give that individual or that family advice, support and information on what their entitlements are, but also whether we can support them—or whether we need to support them. There is a risk of bringing people in too much into social care unless they absolutely need it, so we have got to be careful that we are not creating the wrong impression that people need social care at every stage.

A lot of it is around information, advice and guidance, and that information is important, working with our colleagues in primary care—the GPs and nurses—and within our mental health trusts as well, where you can get different types of support. It is about making sure that they have access to the information of referral that is easy and, as colleagues have mentioned, simple—that they can navigate their way through without getting complicated about who is supporting them.

Q112 **Baroness Ritchie of Downpatrick:** You are all very welcome. The statutory guidance sets out that local authorities and NHS bodies should jointly enable provision of an autism diagnostic pathway for adults and a clear trigger from diagnostic to local authority adult services for an assessment of needs. In your experience, to what extent do autistic people have access to the assessment, the diagnosis and support services they need? Also, why do they have or not have access to such services? What would be the most effective ways to improve this? Could I come to Simon first, and either Victoria or Emma?

Simon Froud: It does vary across the country. That would be a starting point; my colleagues may give a view on that. Certainly within my patch within the West Midlands, and also our integrated care pathway, we do have a good diagnostic and joint approach—a referral in from a GP or from us for the individual into getting a diagnosis. I am not medically qualified so in terms of the process I am not going to even try that; I will leave that to my colleagues there.

That joint approach does help us, between health and social care, to understand the need of the individual. Autism is a quite a large spectrum. It can start from something sensory—light, heat. There are a whole range of different needs for the individual and about what they might need, moving towards someone having a trigger that actually causes uncontrollable behaviour and also getting very frustrated, very confused, and very frightened as well. The levels there are tested through the autistic diagnosis but, as I say, that will come with my colleagues in a minute.

From across the country—from my colleagues in the different direct local authorities, the 150 DASSes—it does vary from area to area in terms of those needs. I think the reference was five years, but there is a sort of sliding scale for different areas where the resources are being managed on a local basis with that ICB and that local authority. The resourcing and the funding is a pressure across all of the systems, particularly in health as well as in social care. Currently, we are going through some changes as well within the ICB developments.

Dr Emma Bradley: This is an adult question, but we have got very similar issues for children. There are different commissioning arrangements for how you access assessments in different areas, and different groups of professionals will deliver the assessments in different areas. Most of the services will be commissioned only to deliver assessments, not as support services within health. That may be the right thing, because autism is not a disease and we are not looking to treat or

cure people in the way that you would if you had a chest infection, for example. But we do want to make sure the support is there, so it needs to be commissioned by an agency, whichever one that is. Often there are challenges around funding for the support services, but it is a gap sometimes that there is not enough support out there.

On what would be the most effective way to improve this, I think the answer is funding and then commissioning so that we can move away from the diagnostic model, where it is a very medical model, towards looking at early support and trying to get in early—like we have already said, trying to move away from crisis management to actually supporting people long before they get anywhere near a crisis. Also, there is removing the requirement to have a diagnosis before you can access certain things—so "Manage my need, not my diagnosis".

The Chair: Lord Scriven had a quick follow-up.

Lord Scriven: Just a quick one. Could I declare an interest as a vice-president of the Local Government Association? From your answers on this question and your previous answer, I am still not clear who is responsible. I think what you are saying is, "No one's responsible. We're responsible for bits of what goes on depending on what we are". Then you talk about commissioning. My question is based on that. What would need to change in the commissioning model to ensure that a joint diagnostic pathway was available and commissioned, and that there was accountability for the pathway rather than parts of the pathway?

The Chair: This is probably easier if we come to either Dr Bradley or Victoria on this question, I would imagine.

Victoria Bates: Moving away from assessment-only focus is the first area, because at the moment it is driven by the need for a diagnosis as opposed to the identification of need, with subsequent services thereafter. There is also the issue in terms of transition, so age—thinking about transitioning of services across the lifetime of an individual as opposed to focusing on childhood or adulthood, recognising that the right support at the right time will impact an entire individual's life and their outcomes. Then in terms of those services, there need to be specialist services for those high levels of need. Actually, what matters is meeting that need early as opposed to a crisis model of intervention.

There need to be specialist services for those high levels of need, but it is meeting that need early as opposed to a crisis model of intervention.

An example is ensuring that, if a child is struggling to access education, they return to education at the earliest point, as opposed to allowing a very prolonged period of absence, as I mentioned earlier. Then, other services potentially need to become involved.

Simon Froud: In terms of a joint pathway or responsibility, under the integrated care boards—now the partnerships—there is a system-wide approach to join things up between health and the local authority on how

things are commissioned. There are some things we cannot commission as part of local government, but, going back to your question, it is a joint pathway, so we would make sure that the person is connected all the way through. Some of the complications are that professionals have slightly different responsibilities and interventions as we go through. We need to make sure—and I think the Autism Act and the strategy pulled some of this together—that how we can improve work around that responsibility is in the conversation going forward.

Lord Scriven: Just to clarify, who is accountable for the delivery of the whole joint pathway? If I were a patient or a patient's advocate, which organisation or person would I hold responsible for the accountability of the delivery of the pathway, or is it different people within the pathway?

Simon Froud: It is different people within the pathway, yes. That is my understanding, unless colleagues have a different view.

Q113 **Baroness Pitkeathley:** You have referred to quite a few of the things in my question already, and we have taken note of those. One of the things that we have been told about, and you have referred to, is the difficulty accessing low-level support where people do not meet the eligibility threshold for social care. This links very much into the whole preventive agenda, of course. What are the main barriers, in your view, to commissioning low-level services to meet the needs of autistic people, and what would be the best ways to overcome these?

We have also heard, and you have mentioned, about long waiting lists for assessment and very little post-diagnostic support. In the context of service pressures, what approaches are being taken to prioritise accessing services for autistic people in different local and regional contexts? We would be glad to have examples of that. We understand, of course, that there is a relationship between seeking to reduce the waiting list for diagnosis and providing support before and after. Your additional thoughts on that, because I am aware you have already given some, would be very valuable. May I come to you first, Simon?

Simon Froud: On the first thing about those people who do not meet eligibility criteria, I can give examples from a local authority perspective of what we have done and do in my area.

We commission different types of low-level support, sometimes evening activities or community support. Sometimes the younger people and their families need to make sure that they are coming from school through the transition into adulthood. For example, there are various clubs, support networks, skills coaches and things that we are supporting through our commissioning budgets to make sure that those people have access to local communities. We have an autism hub, for example, which provides that support, and that is funded through the voluntary sector grants. It is not statutory or a requirement for me or the directors of children's services to provide those services, but we see the value in preventing people coming through. That gives us early information about the person, their needs and the support that they will need going forward.

For people with more complex needs—quite severe autistic needs, learning disability and autism, and profound learning disability needs—we provide daytime opportunities. Again, those services are not statutorily required but, having assessed a need, we need to meet that, to make sure that their families, carers or support are getting some sort of respite to prevent longer-term, more costly care. The person is staying in their own home with different levels of support, but they are not living in—I use the phrase lightly—institutional-type service and care. We also commission quite a lot of what we call supported living services: people live in their own houses or tenancies, so they can then live independently with different levels of support. We are using technology to support that.

All those different stages or parts are around prevention. Looking at the NHS 10-year plan, one of the key elements is to make sure that we prevent people coming into the service too early and diagnose or understand what that person's needs are.

On the diagnostic pathway and how that will be improved going forward, I am not an expert on this, but there will be some recommendations about how we need to look at that, certainly with our health colleagues, and how diagnoses are helping to improve managing or commissioning our services.

Baroness Pitkeathley: Before I come to the others, since the voluntary sector is enormously different from area to area, there is presumably a great range of difference in the services provided.

Simon Froud: There is very much a great range in what local areas can do. A lot of it is developed from within, co-designed with the voluntary sector. We are seeing such a huge demand for more complex needs, which is moving our resources in that direction. Unfortunately, we need to put more resources at what I call the front door—the communities. If we were able to have that, we could prevent a lot more. It is a strategy for not just autism but all services—certainly for local authorities—to make sure people get the right information and support. But it is putting pressure on the funds going forward, and we have a statutory responsibility to meet the most complex needs and at the best value as part of the Care Act.

Victoria Bates: If we think of our current pathways, they are focused on assessment only, as opposed to early identification of needs, but there is a national growing body of evidence to demonstrate that early identification of needs and putting support in place can have a hugely positive impact on the child or young person and their potential long-term access to other services, and can therefore be more effective.

When we think about funding, it is very difficult to evidence that prevention has saved money. Therefore, when we consider, as has just been mentioned, moving that money from high-up, high-need volume work down to the early front-door phase, it is really difficult to demonstrate that we have saved money by doing that, because you almost need to double spend to see the benefit in the future. There is a

national movement towards early identification of need, and that is being shown to be really effective across local authorities, education, our parent-carer forums—which are a really valuable resource—and our VSCE colleagues. While that differs considerably nationally, there is evidence that, across all those areas, an early identification of needs model is an effective strategy to support. That is not saying that there is not a role for a diagnostic assessment, certainly for certain individuals, but, when we think about the volume of individuals we have coming through and the resource available for diagnostic assessment, we ensure that we are using that resource effectively for diagnostic assessment but then thinking about our support resource being used effectively to support need.

The Chair: I have two supplementaries from Baroness Browning and Lord Addington.

Q114 **Baroness Browning:** Can I just take you back 25 or 30 years? At that time, as autism—in particular, Asperger's syndrome, at the more high-functioning end of the autism spectrum—was being understood more, there was a real problem because social services departments said, "Look, these people are behaving in certain ways, but they are not learning disabled because they have IQs of over 70". Now, can I bring you forward 30 years? We now know that, among the autism community, the suicide rate is greater than it is for other neurodiverse conditions.

I want to focus on that Asperger's group because if, in future—I am talking in particular about the move from the higher teenage years through into adulthood—we are going to say, for both health and social services, "We are not going to bother with a diagnosis. We are going to look purely at need", I can think of many people whom I have met and who are no longer with us who would not qualify for any extra services on first meeting. However, they are the ones who, as they went into their 20s and 30s, did not form social relationships or hold down jobs. They tried to be part of the community and society but, for them, it became far too much. How are you going to make sure that you pick up those people with whom it may not be quite as obvious? It may be obvious that these are very clever people who are able to cope with quite a lot of things in life, but, when it comes down to it, it is only when a crisis hits that you know they are in really serious trouble.

Victoria Bates: We need to recognise that we know that, unfortunately, that is what happens to many individuals. Again, it leans into the fact about making sure that support is there at the earliest possible point, as opposed to needing to meet the criteria for crisis intervention. Unless you feel able to access that crisis intervention, that is where the high levels of risk can happen, because you need to present yourself at a point where you can then be supported.

As I said, though, there still needs to be a role for a diagnosis and understanding someone's sense of self. At the moment, we are an assessment-only service; that is similar to what is seen nationally. So, you get a diagnosis but you get no additional support provided with it. I

would very much like to see all the support being there so that, if someone then wants a diagnosis, that becomes available, as opposed to it being the only thing that is on offer for an individual.

Simon Froud: I want very quickly to add to Victoria's comments. It is about training and awareness—that is, training our staff, our teams, our services and our front-line teams—being a trigger. If a person is in the community and has full capacity, which they will, and they just say, "I don't want any help and support", it is about how we steer and guide that individual through. It is about having training and awareness more generally as well as, as Victoria has just said, on top of this. This is something that we are trying to do.

It is also about having some specialists. I have a specialist autism social worker in my service because you get that information and you can then make sure that your teams and services have it. It is about making sure that you have a comprehensive approach.

The Chair: Are you individually driving that individual?

Simon Froud: No. That person sits in my learning disability and autism service, but they also advise and do a lot of work around ensuring that there is consistency both across the service, in terms of how we assess and how we support, and across our developments in the local community. There are others, too; I know of employment consultants for autism in other parts of the country. So there is a whole range of local authorities with different ways of approaching this.

Q115 **Lord Addington:** There was a small point made by the fact that you stated very clearly that you are being driven towards dealing with the extreme ends—the disasters, if you like; that might be one way of putting it—where there is a breakdown of that person going through. You have just spoken about this; I just want to ask you whether I have got this exactly right. You have a service that is not going to somebody who has a difficulty or a real crisis. You have talked about diagnosis being important; both of our medical colleagues here have also said that. Do you see any way of having some sort of recognition key in order to be able to say, without having a formal diagnosis, "Yes, we think they are", and thus to implement help? Can you see any way in which that could happen?

Simon Froud: We do that currently. Let me give you a brief example. We have something called a multidisciplinary approach. It is not just social care: it is health, social care and other key agencies and partners identifying the need for that individual. If they are starting to have a crisis—we do not want them to get to that—we do things on a local level; this happens in many other authorities as well. That low-level support is there in starting to identify a breakdown. As an example, last week, there was a—

Lord Addington: You said that it is after the start of a breakdown when there starts to be a recognition that this might be somebody who is

having minor difficulties or approaching things in an odd way—odd to a neurotypical person, that is—but it is about getting them in there quicker. Have you seen a way that might help with this by saying, "There might be one or two areas where we think this person is on the spectrum, but it is not formally recognised. They will need different approaches. By the way, have you had a look at this training or this leaflet?"

Simon Froud: As I say, that is where the training and awareness of the staff, the teams and the service comes in. My specialist autism worker works on some of that early identification, which then prevents—I hope that I am answering your question.

Lord Addington: We are going to get some clarity on that; we have gone about as far as we can with it, I think. The idea was that you have a structure that says you should get in there as early as possible. However, you are also talking about one specialist worker. I am just wondering how much further it goes.

Simon Froud: As soon as we get a notification from a GP or a family member—whoever it is—our service kicks in and says, "We need to focus on that". It is a priority; we call it a priority 1 risk. We then look at the individual in a very quick space of time, working with colleagues in the NHS in that multidisciplinary way, because an assessment that is done jointly between ourselves and our health colleagues might be needed.

Q116 **Baroness Goudie:** Good afternoon to all of you. The statutory guidance sets out how local authorities and National Health Service bodies should seek to ensure that general services are accessible to autistic people, including through training and the provision of reasonable adjustments. In your experience, how well do general, local authority and national health services meet the needs of autistic people, both diagnosed and undiagnosed? What are the main barriers to enabling general, local authority and national health services to meet the needs of autistic people? What are the best ways to overcome those barriers?

Dr Emma Bradley: I will answer this one. Trying to meet the needs of all of our vulnerable population can be a real challenge. A lot of health services rely on getting a referral in. They will then make contact with the patient or the patient's family. Often, the family are expected to respond to that. They need to be able either to use the phone or to open the mail. They need to have the confidence to ring up and request the appointment. Sometimes, if people do not respond, they can get discharged from those services. In the last few years, we have seen a move towards services making far more of an effort to contact people who are hard to reach, as opposed to saying, "Oh, they didn't respond, so they don't need our service". It is often those who are not responding who need our services the most.

We often have very long waiting lists to be seen. That can be a real barrier because, by the time people are being seen, are they still being seen by the right team and for the right condition? One thing may have settled but something else may have gone. That can be a real challenge.

There are always barriers around funding, as the demand is so overwhelming, and commissioning. A big thing we could change is having all-age commissioning, which Vicki has already touched on.

The transition of young people into adult services at 18 is a real cliff edge for them. They have to leave one service and go on to the waiting list of the adult service. Nothing in their life has changed other than a day; they have had a birthday, but they are the same person as they were when they were 17 and 364 days.

That cliff edge is there because of how we manage services. It is there to support the running of services rather than their users. So that would be probably the biggest thing we could do: have all-age commissioning, or commissioning until 25, perhaps, so that young people have moved into other aspects of adult services before having to change their health provision and social care provision.

Simon Froud: I will lead off on that point.

Baroness Goudie: That point was quite worrying.

Simon Froud: Having been in local government and health for many, many years—I am not going to say how long—I would say that all-age commissioning and all-age services are very important for the person and their family, as they come through the transition from SEND services and children's and young people's services.

In most of the authorities that I have worked in, but also across the country, there is that issue around jointedness and working relationships in the transition from younger persons into adults; the EHC plans are vital in that regard.

My own experience locally is that we have a very good structure in place with our children's and adults' services. They have both been rated as good, but that is not the only test. The test is what people are saying about how we are working together: the parents, the families, the individual, the younger person, the adult.

It helps with that pathway. The person would not necessarily need lots of long-term, complex services too early on in their life and their adulthood. It is about making sure that we are supporting that family and that person. In the majority of times, the family still wants to be involved, all the way through.

With all the services that I have previously mentioned around supported living, and with employment, it is about making sure that the person gets the right support.

Notwithstanding that, there is still lots of pressure within the health and social care system in relation to providers being able to provide what I would call very high-cost, high-provision services to meet people's complex needs. It is about how we manage and support that in the future.

Certainly, the commissioning approach is important. We are working on a local basis: as we are commissioning something or buying residential properties or commissioning different types of placements, we are asking the people who use those services what they want.

It is pointless us commissioning something that people are not going to want or use or need. We have to do it in the right way; that is about co-design. Whatever the strategy and anything else is going forward, it is important that we are working with the people who use the services and listening to them. That said, we cannot meet everyone's need or demand, so we have to work that through and be realistic about meeting expectations.

Q117 **Baroness Hodgson of Abinger:** The Government's current autism strategy ends in 2026. In an updated autism strategy and/or statutory guidance, what should the Government prioritise to enable local authorities and NHS bodies to provide autistic people with the support they need?

Victoria Bates: Adequate funding to meet the needs of children, young people and adults is essential. As I have mentioned before, as a diagnostic service, we are seeing only those with the highest levels of need. We are not able to move to early identification and support, and that means much more significant detrimental outcomes.

Also, not all children and young people who present with difficulties will receive a diagnosis. We need to recognise that those needs are still present; they just do not meet a very specific diagnostic criteria. It does not mean that their support and their needs are not valid. That is very important.

We need to consider adequate funding to meet the aspirations of the strategy and guidance. We need to move towards earlier support to allow the funding of preventative services rather than responding to crises; we need to move away from a diagnostic-only focused model to that early identification of need and support.

Simon Froud: I would certainly endorse everything that my colleagues have said. I would also add a few points: I have got a list here, but I will not bore you with it.

Baroness Hodgson of Abinger: Please do send it to us.

Simon Froud: I will. We will need a lot more data and information, as colleagues have previously said, about what the need is going forward. It will be about bringing that together in one consistent way. At the moment, we have different systems bringing in that information: health, social care and others, all giving information in different ways.

There should be some national standards around low-level and prevention services, and information about how those standards can be applied across the country.

Colleagues have mentioned mandated funding—although that does cost—where we are commissioning joint services across education, health and social care. That picks up on the all-age question about services to the type of person, and I think it should be all-age as a strategic approach. All of our strategies are moving in that direction.

We need also to be looking at accountability and oversight, and how that works on a local basis with the local ICBs and local authorities. We need to ensure that, at the heart of any strategy, we are looking at prevention and early intervention as one key strapline, as well as at how we diagnose, making that as simple and as easy as possible.

Criteria and eligibility are important so that we meet our statutory duties. We are not going to change the Care Act. We need to make sure that we are funding and supporting people in the right way.

We need to make sure of the connections across all the different government departments: housing, DWP and so on. There has been something about Jobcentre Plus, making sure that that all works as well.

If you do one thing in one area, it has a knock-on effect in others. It is about making those connections for the individual and their families. If they are going for a job, for example, there need to be reasonable adjustments to make that as successful and easy as possible.

If you get those standards working across the different areas, they can be simplified and all the different agencies and partners can work with them.

The Chair: Thank you so much. I am very grateful to our three witnesses for their time today. I think we have covered quite a lot of ground and in quite a lot of depth.

If you have anything else that you would like to send us in writing, we would be delighted as a committee to receive it as we are starting to think about the recommendations that we will be putting. On that note, the committee will meet again in public on Monday 9 June. In the meantime, this public meeting is concluded, and I draw today’s evidence session to a close.