



Autism Act 2009 Committee

Corrected oral evidence

Monday 23 June 2025

2.50 pm

Watch the meeting

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

Evidence Session No. 21

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Questions 150 - 158

Witnesses

[I](#): Fazeela Hafejee, Assistant Director of Adults with Disabilities, Bradford Council, and Representative, Association of Directors of Adult Social Services (ADASS); Nigel Minns, Chair of Health, Care & Additional Needs Policy Committee, Association of Directors of Children's Services (ADCS), and Executive Director for Children and Young People, Warwickshire Country Council; Professor Asif Zia, Chief Medical Officer, Hertfordshire Partnership University NHS Foundation Trust; and Chair of Mental Health Medical Director Forum, NHS Confederation.

Examination of witnesses

Fazeela Hafejee, Nigel Minns and Professor Asif Zia.

Q150 The Chair: Good afternoon and welcome to this public meeting of the House of Lords Committee on the Autism Act 2009. In this evidence session, we will scrutinise implementation of the Autism Act by local authorities and NHS bodies.

We are delighted to be joined remotely by Fazeela Hafejee, who is the assistant director of adults with disabilities at Bradford Council and the representative for the Association of Directors of Adult Social Services; Nigel Minns, who is the executive director for children and young people at Warwickshire County Council and the chair of the Health, Care & Additional Needs Policy Committee of the Association of Directors of Children's Services; and Professor Asif Zia, who is the Chief Medical Officer of the Hertfordshire Partnership University NHS Foundation Trust and the chair of the Mental Health Medical Directors Forum at the NHS Confederation. You are all very welcome. Thank you so much for coming and giving evidence today.

Our evidence sessions are on the record, which means that they are broadcast and a written transcript is taken for subsequent publication. The list of members' declared interests is published on the committee's website.

Having made that introduction, I will now ask the first question—please briefly introduce yourselves when you answer. What are the roles of the Autism Act 2009, the statutory guidance and the Government's autism strategy in determining how local authorities and NHS bodies plan, implement and deliver support for autistic people; and why do they play, or not play, important roles? In your answer, could you talk a bit about the statutory guidance to the Autism Act, where local authorities are meant to set up meaningful local autism partnership arrangements; how consistently and effectively those work; and whether there are any ways to improve them? I would like to start with Fazeela, please.

Fazeela Hafejee: Good afternoon, and many thanks. The Autism Act gives us a legal framework to ensure that we are providing the services that are required for autistic individuals. It is the only legal foundation that we have. It provides detailed instructions on implementing the Autism Act and, importantly, it outlines things around accessibility, co-ordination and responsiveness towards autistic individuals.

On the policy directions, I am conscious of time so I will keep this quite brief. The important bits around the Autism Act are that, if they are implemented, they are effective and can be monitored. They will promote a shared understanding of autistic people's needs, but I am really clear that one autistic person's needs are an individual person's needs and will, therefore, be individualised for that person. They should allow for and foster accountability and inclusive planning.

There are limitations to the Act: there is a lack of enforcement, and funding does not naturally lead from the Autism Act. Sometimes, what we see on the surface as compliance can actually be quite superficial. We know that it is really difficult to involve autistic people because their needs are so diverse and, sometimes, autistic people will have additional needs. We know that there are individuals who are autistic and will have further needs that are compounded by complex learning disabilities or mental health issues. So, from our perspective, that should begin to answer the first question. Would you like me to elaborate further?

The Chair: As we go through the questions, I expect that you, Fazeela, will elaborate a bit more. Thank for you that; it was very helpful.

Nigel Minns: I am the executive director for children and young people at Warwickshire County Council. I should say in passing that I used to be the director of adult social services at Warwickshire County Council, too, so I have a fairly holistic perspective. I currently chair the Health, Care & Additional Needs Policy Committee of the Association of Directors of Children's Services.

I am here to talk from the perspective of children. Your question is much more complex with regards to children in terms of the impact of the Act, because, of course, the Act was not originally written for children. Clearly, that has changed with the statutory guidance and the strategy that were issued subsequently, but, in between that, we had the Children and Families Act and the SEND code of practice. It is very difficult to identify whether something is happening because of this piece of legislation or that piece of guidance but another is happening because of that piece of guidance; it is quite a complex picture.

It has meant great opportunities in terms of all-age join-up, though. My local area, Coventry and Warwickshire, using the ICB footprint, has a single all-age autism strategy and a single all-age partnership board. This means to some extent that the elements in the Children and Families Act and in the SEND code of practice are not isolated: there is an all-through view.

I suppose that how it works in practice, in terms of people working together, is variable. There are some real positives. As Fazeela said, if everything happens in the way that it should, there are some real opportunities and there is a real framework to do that. My local experience is of good integrated commissioning arrangements, good joint strategic need assessments and the building of a holistic picture between, in particular, local health and public health authorities. You build a sense of things but one of the challenges for us is that it can all feel a bit bitty.

There are lots of really positive projects, pathways and pilots—whatever they might be called—where the funding is short-term funding. These include the PINS—partnerships for inclusion of neurodiversity in schools—project and some of the work around mental health in schools partnerships. These things are really showing opportunities for us in working together to support autistic children but, actually, they are often

funded in the short term: they come and go and they overlap. Every partnership and where they are will look slightly different.

The final thing I want to mention, in terms of your question, is local partnerships. They are really strong; they have some real benefits. With apologies to my colleagues, I have at times been critical in public about the NHS's commitment to co-production. I think that these are an exception. Many mental health trusts and community trusts, where autism arrangements often sit, understood the benefits of Experts by Experience early. My own partnership is co-chaired by an Expert by Experience, and there are others on the partnership. There are representatives, such as parent carer forums. There are young people with lived experience, too.

One of the really interesting things is that they picked up early the need both to recognise Experts by Experience in terms of what they were offering—that is, recognising that they were of equal value to paid professionals and what they were offering—and to fund those kinds of arrangements and pay for those experiences. That has been really valuable in terms of getting the right people into the right place.

Professor Asif Zia: Let me start by saying that the overall picture is, more or less, what has just been described. Most ICBs or mental health trusts have worked with local authorities to put some better offer in for people, although how it has been implemented across the board is, as Nigel described, quite variable.

In Hertfordshire, the local authority and the Herts and West Essex integrated care board have established partnership arrangements to lead on the development and delivery of improved outcomes for people with learning disabilities or people with autism. The learning disability and autism strategic partnership board is co-chaired with the local authority and the ICB, so it brings together the local authority, local partnerships and health to deliver better oversight of services. There is a strategic partnership board, which has led to an all-age autism strategy.

A number of these things are very similar to what is happening across the country, and the strategy is very much in line with the national strategy. Implementation is quite variable across the country. In Hertfordshire, we have areas of good practice and different organisations have co-produced their own strategies, which focus especially on areas that they are responsible for. They have involved service users, carers and families in those conversations to try to make something better happen.

The key challenges—particularly since 2019, although they were there before, particularly for health—have been around the demand that has come the way of organisations, which is way beyond what they can do to meet the needs of people. The challenge is recognising that there is significant demand around not just diagnosis but the care needs of people with autism, as well as around the whole neurodiversity population, which also requires diagnosis, treatment and follow-up. This has had quite a significant impact—particularly after 2022, although we can see that the

demand was going up before. I will stop there because I am sure that this will get picked up in the other conversations that we have.

The Chair: Thank you; that is very helpful indeed, from all three of our witnesses. I will now pass over to Lord Hope.

Q151 Lord Hope of Craighead: My question is about accountability. In what ways, if any, are local authorities and NHS bodies held accountable for the implementation of the Autism Act 2009, the autism strategy and the statutory guidance? Why are they held accountable—or not, as the case may be? I would be grateful if, in dealing with that question, you could consider what is to happen in the future.

As we know, until 2018, the Government ran a self-assessment exercise for local authorities on the implementation of the autism strategy and the statutory guidance. What would be the best ways to hold local authorities and NHS bodies to account for progress against a future autism strategy? Would it be, for example, the kind of self-assessment exercise that was conducted until 2018? Nigel Minns, can I begin with you, please? I will then go round the table.

Nigel Minns: Yes, of course. I would start by saying that there is little direct accountability from external sources. That is the first thing to say; I will come back to that shortly, if I may.

That is balanced by quite extensive accountability internally between partners. There are lots of opportunities: I can think of how the Autism Partnership Board holds partners to account and how the different governance structures—whether it is the ICB, the local authority council, the health and well-being board or others—hold partners to account within the system to help make sure that things are delivered in the way that all of us would expect.

From a children's perspective, I would argue that, if we are going to look to increase accountability in future from an external perspective, the first thing I would strongly argue against is another inspection framework or process. Children's services in particular are probably the most highly regulated—some would argue overregulated—sector in the country, with children's services inspections, SEND inspections, youth justice inspections and a whole host of different kinds of checks. I am not sure that another approach through inspection or regulation would be helpful. There is, of course, the opportunity to realign and to reconsider how we can use those inspections more, including how we can refocus them or focus them better in order to understand the way in which the needs of autistic children are addressed.

One of the ways that that currently works is through the area SEND inspection framework. Clearly, that is linked back to the SEND code of practice and the Children and Families Act, rather than to the Autism Act specifically, but it looks at many of the same things. One of the big challenges is that it does not have equal weighting with different partners. It is widely acknowledged that area SEND inspections are what

I have described publicly as a local authority inspection masquerading as a multiagency inspection. It does not really challenge all the other partners in the way it challenges local authorities. Of course, the only powers of intervention that flow from that are the powers of the Secretary of State for Education to intervene in local authorities.

There is some real rebalancing that could be done there. There would be a real opportunity to use Experts by Experience in some of those inspection processes, if that were to be the way to go. Taking all those opportunities into account, a return to self-assessment would probably be a more balanced approach in terms of the way forward.

Lord Hope of Craighead: Thank you very much. Could I come to you, Fazeela, next and put the same set of questions to you?

Fazeela Hafejee: Of course. Apologies—in my introduction, I should have said that I am the assistant director for adults with disabilities representing the Association of Directors of Adult Social Services. I have also been involved in the implementation of the autism strategy with the Department of Health and Social Care.

There are a couple of things in what my colleague Nigel has just shared that I would elaborate on. The Autism Act does not in itself provide the requirements for reporting or accountability in isolation. We have other pieces of legislation for adult social care that we must adhere to and, because it is in statute, there is a responsibility to adhere to the legislation.

In terms of how we remain accountable, that is the bit that is missing. There is no requirement for regular reporting. There is no requirement to respond to progress reports. There is very little out there in terms of benchmarking with other areas. We have independent oversight, a bit like children's services and Ofsted. We have been inspected for the first time in 15 years by the Care Quality Commission. There is independent oversight and inspection, but there is no specific requirement or focus on autism.

Where I practice, which is Bradford local authority, we have the Healthy Minds Partnership Board, which is responsible for mental health and learning disability. We have gone a lot broader than autism: we support neurodiverse people across the spectrum in recognition of the fact that it is not just about autism and that we need to recognise that neurodiverse people could have ADHD or anything across the spectrum. We have been quite forward-thinking, but there is no requirement to do that. We have done it as a partnership, and we work quite well with our partners. As Nigel indicated, we would not request any further inspection or independent oversight to be brought in around autism specifically, but there could be a requirement for a specific lens from existing inspectors.

We have talked a bit about stakeholder engagement. I can talk about Bradford specifically: we have been very inclusive, and we have been able to co-produce a lot of our strategies with autistic individuals.

However, we recognise that there will be other autistic individuals who have not been able to be part of those engagement exercises, either because they have profound disabilities or because they are a group of people who tend not to be able to engage. I am doing a specific piece of work around south-east Asian young women, who tend to mask autistic traits and would not normally come forward to engage in opportunities to develop strategies or be involved in shaping services, et cetera.

There is nothing around legal and policy enforcement measures. There might be the legal framework out there, and there are clear statutory obligations, but there are no remedies or sanctions should there be a failure to align with those requirements, either legally or by policy mechanisms.

The other thing that we are not really good at, either in the local authority or in partnerships, is using evidence and data to inform how we develop our future services. You may have heard from colleagues born in Bradford who do the longitudinal survey of people who are autistic, from birth and as they develop into adulthood. This is world-class research that we have at our fingertips, but there is a lot more work to be done around understanding that data and intelligence.

There might be some opportunities to incentivise improvement areas. As long as people are reliant on diagnostics—people are, because that seems to unlock the doors to services—we are not going to be able to offer preventive support, which is exactly what autistic people are telling us that we need: either preventive services or services that, once they have been diagnosed as autistic, support them in continuing what I would call a beautifully ordinary life.

Q152 Lord Hope of Craighead: Do you have a view on self-assessment as a means of checking whether policies are being implemented?

Fazeela Hafejee: Yes. The self-assessment process that we had previously was particularly helpful. A form of that previous process would probably be something that we should consider in future.

Lord Hope of Craighead: Thank you very much. Professor Zia, can you give us your views on these questions as well, please?

Professor Asif Zia: Let me start by saying that the Autism Act talked about people with learning disability and those who do not have a learning disability, and used the word “autism” for both. Services for people with learning disabilities really felt very accountable and continued to do a lot of work in trying to make sure that not only people got the diagnosis where it is needed, but the wider, reasonably good service for those people.

For the half of the population that is covered under the Autism Act—we can argue the numbers, but there we go—we work very hard, certainly in Hertfordshire, to get the diagnosis right earlier on and to provide appropriate support for people. I felt very accountable for that. People

are seen quite quickly after their referral within the NHS, and they are supported after working closely with the local authority.

Then there is another group of people: those who do not have a learning disability. It is also a significant number. There are services provided for that cohort, and there is a lot of recording of those services. However, the key challenges remain, as I mentioned earlier on, around the demand for services and making them accessible for people equally across the whole spectrum of autism. I totally accept the point that it is not always consistently available or accessible for people in different parts of the country.

Going forward, in my view, autism needs to be included in the next NHS 10-year plan so that it gets consistently prioritised across all NHS trusts. If equal responsibility were placed on the local authorities, they could certainly do a lot more than is being done now coherently to build a better, consistent service for people so that these issues around both diagnosis and care needs in the community do not arise.

If there is something in the NHS that is really valued and gets the right level of prioritisation when the national targets are set—or people are expected to see X number of people then have the right resources to follow into it—that area is prioritised. The same needs to happen around autistic people. My own sense is that, the earlier you diagnose, the better the clinical outcomes for autistic people; that is where a lot of the focus must be.

There is a debate about diagnosis and whether we can take preventive measures during the first five years after someone is born. For the vast majority of people, you can get a sense of what their needs going forward will be—not a full picture, but at least some picture. That is where a lot of the support needs to come in in order to help change the outcomes for the future. I will stop there because the question was about accountability; I have probably answered it the best I can.

Lord Hope of Craighead: Thank you very much indeed.

Q153 **Baroness Ritchie of Downpatrick:** You are all very welcome. Building on that question from Lord Hope and the answers we have received, we have heard in our evidence to date that mainstream public services and businesses are often inaccessible for autistic people. What should the Government, local authorities and NHS bodies do to change that?

Professor Asif Zia: As a health provider, for me, the key issue is tackling discrimination and inequalities and educating the public. In the review of the Autism Act, *Autism Act: 10 Years On*, we saw that there is still a lot of discrimination and inequality, particularly in public spaces. There is a huge amount of room for public education. For that to happen, we must use our children's and young people's education system, as that is where a lot of focus can be to help educate them on this issue. I also think of local community groups, where activities can be done to support

things. It is not an area of my expertise, however, so I will stop there and leave it for other colleagues to come in.

Fazeela Hafejee: As I mentioned in my introduction, I am the senior responsible officer in Bradford for neurodiversity at place. When I came into that role almost 18 months ago, one thing I recognised was that we cannot support autistic people in isolation as health and social care only. People's lives are not linear. Autistic people will not come to our door unless they are at a point of crisis or they feel that a diagnosis will unlock a particular service or door for them.

If you will humour me, in Bradford, we embarked on what we refer to as "a neurodiverse-friendly district of Bradford", which aims to engage sectors beyond health and social care to support autism by recognising that people need to be supported in every part of their lives. This resulted in a big, successful event across Bradford, including people from the arts, culture, leisure, tourism and transport sectors—everything that you, I and colleagues who are present today would take for granted—in making a pledge to make the smallest of changes but have the biggest of impacts to support people collectively. It might remind you of something that has been done before with dementia-friendly societies, which was an initiative supported by the Department of Health and Social Care. Our event and initiative were very much based on those principles, but we recognise that it is something that needs to be committed to by people outside of the health and social care system.

If we are to support people who are autistic into employment, we need to recognise that they bring a whole load of skill to the job and that they add so much to our economic business case. A lot of work has been done around that. How do we unlock it? There are really simple things that we can do around accessibility standards and awareness training for people. Autism will mean different things to different people, and it is a word that is not easily translated into other languages. Therefore, it is really about understanding how it can have an impact on an individual.

If I may, I will share a story of mine from this week. I have a little boy who has just had major surgery. We were in Leeds General Infirmary for a whole week. My son is neurotypical, and he suffered with sensory overload there. If we cannot get environments right for autistic people, we are not going to get many things right that will support them into the workplace or into anything else where we want to support them. We need to think about autism-friendly designs. We need to think about how to incentivise organisations that are not in the health and social care system to think about how valuable something is for them as well as for the autistic person.

I have loads to say on this area, because it is my passion, but I will pause there as I am assuming that you might want to call on Nigel at this point. I am happy to clarify anything if needed.

Baroness Ritchie of Downpatrick: Thank you, Fazeela. Nigel, what is your perspective?

Nigel Minns: First, I have to say that I agree with everything my colleagues have said. Having more public-facing campaigns and awareness raising is really fundamental. I gave the example of the partnerships for inclusion of neurodiversity in schools project earlier; that is very much about raising understanding of autism among children and school staff. From that, we have seen that it improves the experiences of children and their parents. We know that, when people are more aware, the situation definitely improves. There is something there about how we raise awareness and use the voices of local communities, faith groups and seldom-heard communities to engage them in leading on these initiatives.

There is probably a need to shift some of that awareness raising slightly. You could clearly argue that, if anyone looks at the SEND data over the last few years, there has been a huge rise in the number of children and young people who are autistic and who have an education, health and care plan. I think that understanding, both of what the need is and that the need exists, has risen massively.

I do think that what has happened is that we have not changed the system to adapt and to meet that need. It is really important in thinking about what we need to do, particularly from a school perspective, to say, "I'm not sure we can just ask schools to do more". We need to invest in schools, in order to enable them to do more, and to support them. We need to train them. We need to provide more training and more resources because, without them, things will not succeed.

There is a really important need to ensure policy alignment. I am not sure that there has been good alignment in education, particularly over the past few years. Some of the initiatives over recent years around attendance, exclusions and school uniforms have not taken into account the needs of autistic children. We have had a clash of cultures between the various elements. Last year, a group of autistic young people in Warwickshire created a video showing what their experience of school was like with autism. It has been watched by 25,000 people—including all of our school leaders on a regular basis, as we bring it to them. It is stark that there are some really simple things that could be different.

The final thing I want to say—I started to say this; it is probably triggered by something that Fazeela said—is about reasonable adjustments. It is about how you make sure that that raising of awareness is very much focused both on people's requirement to make reasonable adjustments and on how you might do that in practical terms. We locally produce reasonable adjustment guides. They started in a mental health space, and they spread. I was recently given a really good example of where it had spread: using those guides with leisure centres in order to help them to understand how things might work. You could look at a whole range of different sectors where that kind of experience works, so there are definitely things that we could all do.

Baroness Ritchie of Downpatrick: Thank you very much.

Q154 **Baroness Browning:** Good afternoon, and thank you; it has been very encouraging to hear what you have said so far.

We have heard that NHS bodies and local authorities often fail to support autistic people, both diagnosed and undiagnosed, with early support, meaning that opportunities to prevent crises are missed. What should the Government, NHS bodies and local authorities do to ensure that autistic people can access the support they need? We have also heard that there is usually no single budgetary responsibility for supporting autistic people. What are the main barriers to funding jointly and delivering support pathways for autistic people? What would be the best way to overcome those?

May I just add one little question of my own? Could you—Fazeela and Nigel, in particular—bring us up to date on direct payments for autistic people? Are direct payments still used? In your experience, particularly for school leavers and those above them in age, how does the autistic community fare in terms of accessibility to direct payments? Sorry—that is rather a lot of information that I am asking of you.

Nigel Minns: That is a lot of different things. Can I start with money? Lots of things come down to money in the end, I suppose.

You are absolutely right that there is rarely a single budgetary responsibility. Actually, there is no kind of direct funding that would support the autism strategy or the Autism Act in that way. In my experience, both in my local area and in others, what has happened is that people cobble together funding. Sometimes, that is short-lived: it is, “We can fund the activity this year or next year, then we will start worrying about it again”. Clearly, that is not helpful in terms of long-term planning.

If I were to argue for a really simple solution to that from a children’s perspective, I would probably highlight that the effectiveness, where there has been a multiagency challenge, around hospital discharge in adults was met very clearly by the Better Care Fund. The Association of Directors of Children’s Services has been arguing for some years for a better care fund for children, where money is jointly provided or provided in a pooled form to local authorities and to health colleagues and can be spent only on the area for which it was intended. That kind of joint ring-fenced funding is a real opportunity in taking this forward.

The challenge that we have in the current scenario—this comes back to your original point—is that, in times of financial challenge, all local authorities and health providers resort to their statutory responsibilities; at least, their statutory responsibilities come first in some ways. There is definitely a lost opportunity there in terms of early support and really engaging before we reach crisis point.

Direct payments are still used and are still available. I do not know about the balance between direct payments for autistic children and children

with, say, physical disabilities, but I am sure that that is something we could seek to provide to the committee afterwards if it would be helpful.

Baroness Browning: Thank you very much. I was thinking in particular of autistic adults who perhaps do not have a learning disability, as well as those who may have one. Would they be able to have a tailor-made package that they oversee and manage themselves?

Fazeela Hafejee: Direct payments would be available to an autistic person, as they would be to any other person who draws on care and support. The answer to your question—do we have many people on direct payments who are autistic?—is probably no.

There is a caveat to that. Since I came into post, we have created a social work service to support neurodiverse individuals in recognition of the fact that, historically, paths would lead to learning disability services for neurodiverse individuals, which are often not the right place to support neurodiverse people. We wanted to ensure that social workers had the right skills and the right knowledge in order to support those individuals when they did come to access local authority support.

That service has been running for about 18 months now. We have been able to support 100 to 200 people, but I have provided paid support to only a handful of individuals. The reason for this is that most of the people who have come to us have not needed a massive amount of support. They have needed a short-term intervention to support them in getting to where they probably were before they got into crisis, so they have not required long-term support. They have often been signposted to somewhere for peer support. They have probably been able to identify opportunities that they had not been able to identify previous to coming to the local authority. So, long-term support that you would need through a personal budget is not something that anybody has particularly required.

Baroness Browning: Professor Zia, post a medical crisis, might that lend itself well to direct payments and packages of care?

Professor Asif Zia: I will try to comment on that question but I want to put it at a slightly different level. Training staff in the mental health sector has been of huge benefit to them in relation to identifying people who are autistic and in trying to manage the crisis better than these people are used to doing. Having autistic people in A&E settings or in mental health Section 136 suites is something that I used to see happen a lot. Credit should go to the Oliver McGowan training that has been given to all front-line staff, certainly in our trust in Hertfordshire; it has had quite an impact, at least in identifying the need that is there and how best to manage the crisis.

My second point is that, whenever you are talking about crises and when they do happen, all of those other factors that are applicable to anybody—having a social network, being employed, having routine and

structures, and having a reasonable level of support available—make a big difference in this case as well.

Thirdly, when crisis support is required, it must be equally kind and compassionate. It has to understand the impact of sensory overload and to ask, “Can this be managed in a slightly different way?”

The point I am trying to make is that a lot of that support needs to happen in the community. I want to draw that distinction: hospital admission in a mental health setting is not always needed. Skilling up staff and getting them to manage this better in the community is the mainstay of where mental health services are focused. When people do come into a mental health setting, we need to have sensory rooms or places where people can be supported in a kind and compassionate way. The majority of the new estates—at least, the ones we have in Hertfordshire—do cater for those needs, which has made a big difference in managing and supporting people when they need to come in.

I hope that I have captured the various bits, but the key element has been the staff training; that has really made a big difference for us.

Baroness Browning: Thank you very much. I think, from what you have told us this afternoon, that, in Hertfordshire, you are moving ahead of where we hope the new Mental Health Bill will end up in making sure that there is more community support, rather than in-patient care.

Professor Asif Zia: With community support, we look after the majority of people in the community. Crises are managed and support is provided in the community, and admissions for people with autism happen only when they are absolutely needed. I will not go into the recommended changes to the Mental Health Bill because I think that there is quite a mixed view nationally; we just have to acknowledge that there is a different view among people in the professional groups. I will leave it there.

The other point I want to capture is that a lot of good practice that we talk about for managing crises applies not just to people with autism but in other settings. Providing kind and compassionate care, involving service users and carers in decision-making, and co-producing crisis plans are all good practices that apply in the crisis management of autistic people but, equally, in other settings as well. There is a lot of good, humanely delivered common practice. That is where the focus needs to be. Otherwise, you get tangled in some very specialist services and models that do not deliver the essential bits of care, which are about kindness, compassion, listening and involving people with autism.

My final point is that all those protective preventive factors, such as employment, stable relationships and housing, are equally as valid and helpful in preventing crises in people with autism as they are in people who do not have autism. I want to put that out there because we should not forget that a crisis does not happen in isolation. Also, it does not always happen because of something going wrong with an autistic

person; there are usually other environmental factors that also have a big impact.

I close by saying that employment, housing and relationships matter just as much, and that the crises triggered from them equally have an impact. We need to educate our society and ourselves in managing them better, rather than just relying on mental health services to manage the crisis.

- Q155 **Lord Wigley:** I am sorry to spring this on you, Professor, as you have had no notice of this question, but where you were leading us just now triggered me in terms of a case that came to my attention recently—that of a young person with autism. He is a high-flyer at PhD standard. In order to do his work, he needs help from the local health authority, et cetera. When he needs to move from area to area, he finds a barrier in that the help he needs may not be available; this precludes him from trying for jobs, and he fails to maximise his potential. Is that a general problem?

Professor Asif Zia: You are absolutely right. There is a problem. There are several issues, which I will try to summarise. One is that autistic people struggle with change anyway, but that should not be a barrier. Secondly, if the law was applied, reasonable adjustments would need to be made wherever the person went. Thirdly, if there was a clear recognition that his needs were such that he needed to move, the Care Act would equally apply. I am trying to suggest that there may be many barriers but there is also legal support that is available and applicable. We need to encourage autistic people to use it and to get the right advocacy and the support that is available to them.

Finally, let me say—not in anything other than a highly esteemed way—that there is enough evidence that, in the science subjects in all our big universities, there are very eminent people who have autism. I want to acknowledge that people with autism are high-flyers. They are doing PhDs, and this is the norm; it is not anything different. I am a great advocate for saying, “Let’s bring the best out of them by providing the right support to them, wherever they are”.

- Q156 **Baroness Pitkeathley:** We have heard that autistic people often face what is normally called a cliff edge in accessing support during their transition to adulthood. What should the Government, local authorities and NHS bodies do to prevent such cliff edges, which we assume exist? Perhaps I will come to you first, Nigel, because of your experience in the children’s sector.

Nigel Minns: I do not think that any of us would doubt that there are cliff edges in the support. There is a fundamental issue around the competing—or, at least, conflicting—legislation in this area. There are very clear differences between the Children and Families Act and the Care Act in terms of what may or may not be valid in support terms.

As a child, the person we have just heard about may well have met the criteria for an education, health and care plan, even though they are high-performing because they are autistic, but they may well not have

met the criteria for support under the Care Act. There are different eligibility thresholds in the legislation. Clearly, those thresholds can move between the ages of 18 and 25, depending on whether an education, health and care plan is in place. The cliff edge can fall at different points and anywhere in between; that is really important.

We need to ensure that we get the earlier interventions right. Certainly, by the time a child is approaching adulthood, they should have the right support in place to support them through their education. Some people argue—quite sensibly—that we should probably undertake reassessment as children transition to adulthood, focusing particularly on those who are not eligible for social care support.

Careers are really important in this. Unlike some of the other elements, career guidance, coaching and mentoring, et cetera, can be hugely variable from local authority to local authority. That support will be absolutely crucial in ensuring that people achieve as much as they possibly can.

We need to make sure that people understand those differences in the thresholds that I talked about. Some of my colleagues talk about ensuring a soft landing for those who will not necessarily have the same level of support that they might have had previously. Then there is the issue of what I broadly describe as “preparation for adulthood” plans, which are clearly laid out in statute for those with an education, health and care plan. There is very little in place for those without one. If you are an autistic child who does not meet the threshold, or your parents have never applied for an education, health and care plan, there is very limited support for your transition into further and higher education or into the world of work. We really need to think about and focus on that area.

Q157 Baroness Pitkeathley: That is very helpful advice, thank you. Can I come to you, Fazeela, for your experience of this cliff edge?

Fazeela Hafejee: Of course. Nigel has articulated beautifully the issues around the competing and conflicting legislation. The other issue, I suppose, is around engagement. At the point when you become an adult, the expectation is to engage. Often, when people do not engage for various reasons, such as poor experiences or the trauma that we have inflicted on individuals, the lack of engagement is seen as a reason not to provide services. Those are all issues.

From the point of view of preparation for adulthood, I do not think that the Autism Act is recognised as much as the SEND legislation, the Care Act and the children and families legislation; those have been referred to. If done really well, we can start supporting individuals at the age of 14. What happens in reality is that it is as though the 18th birthday is a surprise, as if we did not know it was going to approach, and we do not engage with people in the way we should do.

We have done a big piece of work with young people with disabilities. The four things that they tend to tell us are important to them are: having meaningful relationships with people beyond professionals; having their own key to their own front door, which obviously might not always be the case, but it is certainly about having appropriate accommodation; having something meaningful to do, which could be employment; and having hopes, dreams and wishes, which are things that we should absolutely be taking into consideration when preparing young people for adulthood.

This links back to why this does not happen. As long as you have organisations that are fragmented, we are not one homogeneous offer. You have children's services and adult services, then, on top of those, you have layered health services. There will always be a conflict. As long as we do not have infinite resources, this will be an area where we need to think differently and creatively if we are to achieve outcomes for our young people.

Baroness Pitkeathley: Thank you very much. I shall now come to you, Professor Zia, for your view on the cliff edge.

Professor Asif Zia: It does exist; my personal view is that we should acknowledge it. We probably do not educate and train families, carers and young people enough. The key thing about autistic children and adolescents is that, once they understand the process, they will follow it quite rigidly. If you draw an algorithm for them, they will follow it with timelines constructively and positively. I am in that space where I think, as has just been acknowledged, that there are challenges and cliff edges.

The only solution that I can offer in this context is to educate and train the families and the carers of young people with autism. They will help and direct their own care in some ways, and stop that cliff edge happening, because they are very much into structure and doing things in an organised way. I will leave it there because the other things have been covered.

The Chair: We are coming to our final question now. Thank you so much for all the evidence and information that you have provided for us to date. As you know, the committee has to make recommendations, as we start to look at publishing our report, so I am now going to ask Baroness Goudie to ask our final question of the session.

Q158 **Baroness Goudie:** The Government's current autistic strategy ends in 2026. In an updated autism strategy and any new statutory guidance, what should the Government prioritise to enable local authorities and health service bodies to provide autistic people with the support that they need, because it really needs joining up in some way?

The Chair: Perhaps we can go to Fazeela on this question first. What do you think the Government should prioritise?

Fazeela Hafejee: Dare I say it: it is the f-word—funding. Of course, we know that there are not infinite resources, but some funding that could be specifically prioritised for autism with some clear areas of focus would

be exceptionally helpful. They should recognise that diagnosis will always be something that people want; however, if we can get preventive and post-diagnostic services right, the pressure on and the need for a diagnosis would hopefully be alleviated.

You have asked about resources, accountability and pooled budgets. It would be particularly helpful if we could have something that recognised where we are mandating partner organisations to work collectively together and where there are protected resources around autism, like the previous Section 75 arrangements.

I have two other areas to prioritise; I am conscious that we are going on for time and that you probably want to bring in my two other colleagues. The first would be awareness raising and learning and development that goes beyond the Oliver McGowan training. The Oliver McGowan training has done a huge amount for us as a sector, but there needs to be a recognition that adult social care probably needs a different offer.

The most important thing is recognising that autistic individuals, families and carers are probably far more expert in their own care and support needs than any one of us sat around this table, so we need actively to support them to shape future services and policy direction.

Nigel Minns: First, I agree with everything that Fazeela said; helpfully, that should shorten things. I really would argue that any investment should be a joint investment—collaborative funding, if you like.

A priority area would be the workforce, specifically the need for an associated workforce. There is the diagnostic workforce and, of course, there is the support workforce, but things like speech and language therapy, sensory therapies and other kinds of support are really important at the moment. Even if we had the money, we probably could not provide them.

Another area is training for staff and the awareness raising that would come with that. If you get to the point where you have the funding and the investment, you can move to start mandating training and awareness raising, making that a much more formal and rigorous ask. It is really challenging to do that without the money. As I said earlier, a real focus in the new strategy on reasonable adjustments—on promoting reasonable adjustment and exemplifying, wherever possible, as many examples of what a reasonable adjustment might look like for any organisation or body—would be really helpful.

I want to come back to Fazeela's last point about autistic people being the best at understanding their lives and needs better than anyone else. One of the things that has been a real success for us locally—I know that this is true in other areas—is the use of autism champions. A national scheme, almost a branding scheme, for autism champions in order to enable them to promote and to make a difference would be really helpful.

Baroness Goudie: Thank you, Nigel. I agree that champions and

funding are very important.

Professor Asif Zia: I will give a list, because the points have been made. We definitely need to invest in neurodiversity as a whole, because such a backlog has built up around diagnosis, support and care. People are really struggling with that; it needs to be part of the 10-year plan.

Then there is an alignment between health and social care. When health and social care come together, we get really positive results. There is investment required not just in providing services but in helping people to live fuller lives, such as through the employment and housing support that people need to live their lives. Some live in environments that are very noisy and where the lighting does not work. In employment, the support is not there. Those types of things make a big difference, so reasonable adjustments have to be made.

Lastly, there is a need continually to skill up people who support autistic people, including in the NHS. We need investment in teaching and training staff continuously, because it is a very evolving and developing area of research and development. The new technology will probably come in research and development, and a lot of new investment will happen. I will close there because those are the areas that I wanted to capture.

Baroness Goudie: Thank you very much, Professor. I agree that more training is really important.

The Chair: Thank you, Baroness Goudie, and thank you to all of our three witnesses for a really helpful and informative session. There is certainly a lot for the committee to reflect on. We will send you a transcript for accuracy. We will continue in a moment with our second evidence panel; in the meantime, this first evidence session is concluded and the meeting is suspended briefly.