HOUSE OF LORDS

Autism Act 2009 Committee

Corrected oral evidence

Monday 23 June 2025

3.55 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. 22 Heard in Public Questions 159 - 169

Witnesses

I: Tom Cahill, National Director, Learning Disability and Autism Programme, NHS England; Dr Adrian James, Medical Director for Mental Health and Neurodiversity, NHS England; Dr Ken Courtenay, Consultant Psychiatrist in Learning Disability, NHS England.

Examination of witnesses

Tom Cahill, Dr Adrian James and Dr Ken Courtenay.

Q159 **The Chair:** Good afternoon and 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 are scrutinising national NHS implementation of the Act with a panel of NHS England representatives. You are all extremely welcome.

We are delighted to welcome Tom Cahill, who is the national director of the learning disability and autism programme at NHS England; Dr Adrian James, who is the medical director for mental health and neurodiversity at NHS England; and Dr Ken Courtenay, who is a consultant psychiatrist in learning disability at NHS England. All three of our witnesses are joining us in person; we are delighted to see you.

We were also to be joined by your colleague, Claire Murdoch, the national mental health director of NHS England and the CEO of the Central and North West London NHS Foundation Trust. However, we understand that she has had to withdraw from today's meeting due to unforeseen circumstances; we quite understand, of course.

This is a public evidence session, and a written transcript will be taken. I once again draw attention to members' interests, as published on the committee website. Having said all that, I will now ask the first question and invite you to answer in turn; please give a brief introduction as to who you are before you answer the question.

Who is responsible and accountable—we have been hearing a lot about accountability over the last couple of sessions—for ensuring that national, regional and local NHS bodies meet autistic people's needs? When you answer the question, please comment on how clear the lines of responsibility and accountability are. What are the roles of the Autism Act 2009, the strategy and the statutory guidance in setting responsibility and accountability for supporting autistic people in the NHS? Do they play important roles or not?

Tom Cahill: Good afternoon, everyone. On who is responsible, the NHS has a strong governance oversight framework that determines the relationship between the national and central bodies with local bodies like the ICBs. In saying that, we must remember that the ICBs are autonomous organisations as well, the core responsibility of which is the strategic commissioning of services for its population. So we have to manage that relationship.

We have a strong process of monitoring performance management; the regional offices play a role in that. We also have a system called planning guidance, which determines some of the key priorities at the very beginning of the year. For example, in this year's planning guidance, for 2025-26—I am trying to get my years right—we have stipulated that we would expect the number of autistic people in hospital to be reduced by 10% on last year and to move towards 30 per million.

We have issued that guidance, and we have now got plans back from all the ICBs through the regions on how they intend to achieve this. We will work with them throughout the year in managing their performance. If things are working well, great; if they are not, we have systems of escalation.

It is also built on a system of relationships. Both Claire Murdoch and I, and my colleagues with me, have strong relationships with people in the regions and with colleagues in providers; we are all from providers ourselves. We converse with colleagues about waiting times, the services provided, the numbers of people in hospital and how they are progressing in the informal setting, as well as in the formal setting.

The Chair: You mentioned avenues of escalation. Can you give us a little more colour around what those would be?

Tom Cahill: This is where we try to keep it very local. The NHS has now gone through some significant change and restructuring. As I talk today, that is evolving. For an ICB or a provider within an ICB not delivering what it needs to deliver, you would expect the escalation to be for the ICB to go to the care board, to have conversations and to understand what remedies are put in place. You can imagine that being escalated to the regional level, depending on the level and concern of the issue. Then, there is the opportunity to have a national conversation and national support.

We would be talking about support. We know that this is about supporting organisations to do what we all want them to do, particularly in this given circumstance: reduce the number of people in hospital who should not be in hospital. Hospital is right for some people, but not for everyone.

The Chair: That is brilliant, thank you. Can I ask you, Dr James, to build on some of the things your colleague has said?

Dr Adrian James: As well as the accountability structure that Tom has outlined, there is within each organisation an accountability structure, where you would have the chief executive, the executive team and, for clinical services, either the chief medical officer or the chief nursing officer, who would normally be accountable for the quality of care. It then comes down to individual practitioners. I am accountable for my professional practice to the GMC, so I have accountability in that way. I have internal accountability within my organisation, through the medical director of the trust—or the chief medical officers, as they are often called now—up to the chief executive. Both professional and line management accountability are really important in the local delivery of care.

Dr Ken Courtenay: I just want to say that, in terms of accountability, the statutory guidance has been very helpful to organisations in ensuring that people are accountable, but I think that it is a bit more than that. For me, supporting people with autism is everybody's business. We can

have clear lines but the people on the ground delivering services need to be aware of them, too.

Q160 **Lord Wigley:** By way of background, as I understand it, there is a need for local authorities and commissioning NHS bodies to have factual information about the numbers that they have to provide for. To what extent does the NHS have the evidence it needs to plan services for autistic people? How does NHS England identify and address the key gaps in that evidence—if there are gaps, as it is suggested there might be?

Also, what is NHS England's understanding of the recorded prevalence and the true prevalence of autism in England, including across different demographic groups? What is the difference between recorded prevalence and estimated true prevalence, and why is there that difference? Dr Courtenay, your colleagues are looking at you.

Dr Ken Courtenay: They certainly are; perhaps it is because of my role as national clinical director in the learning disability and autism programme.

In terms of the evidence around the demand, we are getting a lot of returns from local services around our waiting list; that is evidence in itself. This is being provided by providers to ICBs and is then fed into the programme nationally. So that is our understanding of the demand and our knowledge around the waiting times and the numbers. We have been waiting for assessment as well. We are also receiving informal feedback from voluntary organisations and other bodies around what is happening in local services. The data is not perfect and there are gaps in data collection, but, obviously, we are working on that and have been for quite a while. It is about the data infrastructure; that is where more support is required to ensure that the data is coming through.

You asked about the varying rates of prevalence. This is an area that has been challenging us, not just in clinical services but in academic services as well. What I mean by that is that the accepted estimated true prevalence is approximately 1.1% to 1.2%; that is based on research studies, in particular the Adult Psychiatric Morbidity Survey and the other sources that have contributed to it.

The interesting thing is that, when you look at the people who have a diagnosis of autism in GP records, that is where the prevalence appears to be higher. Therefore, you would assume, "Well, perhaps more people have been diagnosed with autism". That is the case, sure, but it does not necessarily reflect the true prevalence throughout at this stage, because things are changing. It could be because of how data is being collected through GP records and how the diagnosis is being recorded. Part of the reason why this and the increase in diagnoses could be happening is greater awareness among people around autism generally. We are seeing that among members of the public and, especially in clinical services, among professionals as well.

There is also the issue that people seem to believe that there is an overdiagnosis of autism occurring. In fact, when we have looked at the data more recently, there appears to be an underdiagnosis. It just appears that younger people are being overdiagnosed but, in fact, what we are finding is that autism is underdiagnosed among the cohort of older people. So, generally speaking, there would appear to be an underdiagnosis of autism.

As I referred to earlier, the reasons for that could include greater awareness, but it could also be because the criteria for diagnosing autism have broadened in recent years, particularly since 2013, when the DSM-5 criteria came out. Those criteria included one around sensory sensitivities, which was included for the first time and which has helped us understand more about both the needs of people with autism and their challenges. The previous criteria included qualifications around level of cognitive functioning which are not expected these days when you are making a diagnosis. Therefore, people without intellectual disability, for example, are now included in the criteria, so we can accept that people without those difficulties will meet the criteria for autism as well.

There have also been changes in clinical practice because of greater awareness of autism. Then there is the whole issue of misdiagnosis, where people have been given a diagnosis that was, in hindsight, erroneous, because people felt that they met the criteria for a certain diagnosis—in particular, personality disorders. Now, it is being reframed according to the criteria that we have in DSM-5 and ICD-11, which are more about meeting the criteria for autistic spectrum disorder or autism. This is a good thing because it means that the challenges that autistic people are experiencing are able to be addressed and people have an opportunity to be supported in the correct way.

I have seen this in my own clinical practice—in particular, how important it is to get the diagnosis, to scrutinise people's presentations and to consider whether they meet the criteria for a diagnosis. I have also seen that in general psychiatric services, people are now beginning to think a lot more about neurodevelopmental conditions; that is a good thing.

Dr Adrian James: The reduction in stigma in this area and across mental health has been a really important step and is, I think, to be much welcomed. It has meant that there has been more discussion: people talk to family and friends, they speak to their GP and they come forward.

As I am sure the committee is aware, the number of people being diagnosed has gone up hugely. Again, that is a good thing. We want to recognise and meet people's needs. However, this is something that we need to keep under review because, for many people, you need a diagnosis to get help and support. While the diagnosis is really important for some individuals—some people really value it—for others, that is not what they want. We must keep both options open: for people to have their care needs and their broader needs recognised does not necessarily mean that they have to go on to a diagnostic pathway. We need to be

careful that we are not manufacturing a system that forces people to get a diagnosis in order to get the help that they need; instead, we need one where people can access a diagnosis if they really need to.

I sat on the ADHD Taskforce; the committee will have seen that the interim report was published last Friday. Clearly, there is a huge interface between autistic people and ADHD: 40% of autistic people have a diagnosis of ADHD as well. When I started in psychiatry, it was not possible to have a diagnosis of autism and ADHD; now, we recognise that that is obviously not the case and actually, looking at the spread of co-occurring conditions is something that needs to be recognised and supported.

There have been some big changes but, now that the system has matured, we need to keep an eye on what is happening. Most importantly, we need to ensure that autistic people have their needs recognised and that we as a society respond. This is not just about health; it is about people's access for the health needs that they have.

Lord Wigley: Would I be right in interpreting this as that, previously, when the understanding of the statistics had not matured in the way it has now, there would have been people on the autistic spectrum who may have missed out?

Dr Adrian James: Absolutely. If we were talking about cancer, we would be celebrating the fact that more people who have cancer have that recognised and are coming forward. Again, when I started in medicine, cancer was stigmatised. People were ashamed. That seems ridiculous now. It is really good that neurodivergent individuals now feel very free to come forward and that their needs are recognised. There is certainly more that we need to do.

Q161 **Baroness Browning:** On collecting data and having a real feel for numbers, we talk about percentages but we do not really know the total for this whole area. In the Mental Health Bill, which is proceeding through the House at the moment, there is a requirement that we take people with autism and learning disabilities out of the Mental Health Act 1983. There will be a requirement to produce data at a local level on autistic people who are deemed at risk as far as mental health is concerned; we have not seen the secondary legislation, so the detail of how that will be collected and used is not properly available yet. How do you feel about that sort of information? One can see why it is needed and how it would help to prioritise, particularly in the field of mental health, but do you think that there is a case for requiring bigger databases? You mentioned GPs practising, but that is on an ad hoc basis. Should we be trying to collect this data?

Dr Adrian James: I am the senior responsible officer for the Mental Health Bill at NHS England; I have been very much involved in its passage through Parliament and have seen many of you speak in debates. It is really important. If the Bill is passed and becomes an Act—obviously, it is in the Commons at the moment—we know that autism will

come out of Part 2 of the Act and it will not be possible to detain somebody purely because of their autism.

At the moment, across autism and learning disability, there are 2,025 individuals in hospital and 1,800 individuals who are detained under the Mental Health Act. That is a very large number. In some areas, the numbers have gone up for autistic people. So, if this change is going to come in, it is very important that we know who the individuals are and what the numbers are so that we can plan for services in the community, which will provide for the needs of people with really complex needs. We know that some of the people who end up in hospital get good care, but we also know—and you will know—that the experience of care for many is not where we would want it to be. To provide that service outside of hospital will require a very considerable programme, and that will be commissioned and delivered at a local level.

The fact that there will be a requirement to keep that data at a local level, subject to the legislation passing, is an extremely good thing. It would allow that planning to take place, and it will be for people who are at risk of being detained. There will be a code of practice that will come in after the Act; there will be lots in that on how the Act will operate. My role will be central to ensuring that we have a mechanism to ensure that people have faith in the fact that we are collecting the data on those needs and, most importantly, that we are doing something with it and providing for those needs. I could say more on this; you may want to come back to it.

Probably none of us here would say that we have data that is as good as we would like. We have a 10-year plan that is due to be published. We know that, within that, the role of digital and data is really important. There will be a big push in this area. It is our job to ensure that autistic people are really going to benefit from that real push to make sure that we are collecting the right data both locally, for that planning, and nationally so that we have a handle on the whole picture.

Q162 **Lord Hope of Craighead:** I would like to come back to the issue of diagnosis. A particular problem is that demand for assessment far outstrips capacity. What is NHS England doing to enable mainstream and specialist services to address this gap, including managing any trade-offs between increasing capacity for autism assessment and providing autistic people with support both before and after the diagnosis? Can you also deal with the problems around scaling up autism assessments to meet the demand? What are the barriers to the scaling-up process?

We have heard that there is evidence to support a range of early interventions for children who may be autistic, such as paediatric autism communication therapy. What are the main barriers to rolling out interventions of that kind to support autistic people? What would be the best ways to overcome these barriers? Dr Courtenay, can I come back to you, if you do not mind? You said quite a lot about diagnosis; perhaps you could develop the problem about meeting the demand and all the other points arising out of it.

Dr Ken Courtenay: Thank you for that question. On the demand, as we know, there are long waiting lists for children and adults to have an assessment for a diagnosis. To my mind, what is really important to meet such demand is ensuring that we have a skilled workforce and people who are informed and educated around understanding autism and the needs of autistic people—that is one group, generally—as well as ensuring that we have people who are skilled in conducting the assessments.

We have done quite a bit of work around that. For example, the National Autism Trainer Programme has been in place and has trained a lot of clinicians and supported them in services. They are not just psychiatrists and psychologists but people across the multidisciplinary team. That has been very good.

Another programme has been developed to provide foundation and enhanced training to psychiatrists around the diagnostics of autism through the Royal College of Psychiatrists. The benefits of that include not just giving people the skills to do it but raising awareness among the population, which can then be disseminated into services as well. Other initiatives, such as the autism practitioner groups, have also been very helpful in managing the demand.

Regardless of that, we still have a lot of people coming for assessment. That has been a huge challenge for us. The approach should be less about ensuring that people have diagnoses and more about looking at the needs that they have and how they could be supported. We have seen in some services that just addressing the needs that the person has, rather than looking at an assessment for diagnosis, can in fact reduce the demand and provide the support that people need at an earlier point.

The other thing is, when people are on waiting lists—this is part of what you asked about—what level of support are they receiving before they have an assessment and post-diagnostically? It is not enough just to do the assessment and see whether people meet the criteria. How do we support people, especially if the waiting times are quite long?

This is where we will support ICBs to develop a broader commissioning package for supporting people. Often, what is missed out is what happens after people have received a diagnosis. Autistic people may require quite a bit of support, whether it is health-wise, to do with their occupation or through other forms of social support. If we can develop packages of care that are commissioned by ICBs, we should, hopefully, be able to meet those needs as well.

Q163 **Lord Hope of Craighead:** On interventions, the particular example given is paediatric autism communication therapy, which is a particular kind of intervention.

Dr Ken Courtenay: For any of the interventions, again, it is about practitioners understanding what they are being trained in. Key to it, in order to ensure that you have a good evidence base, is research. We

have some research coming through but we need to pay attention to how we are going to expand that further in order to ensure that we are providing truly evidence-based interventions to not just children but adults.

Tom Cahill: We know that the waiting lists, as we see them, are extensively long. ICBs are also seeing more people than they have ever seen before. Comparing the month of March this year to last year's, there has been a 30% increase. This tells us that ICBs are using their flexibilities and priorities to do things differently and meet those needs. That includes what Dr Courtenay talked about: not just focusing on the diagnosis end but looking at needs and trying to help people earlier. We have seen numerous schemes up and down the country where people are trying that. We must make sure that it is evidence-based and evidence-led, but we are seeing some great examples.

To your question about why we do not just roll stuff out, it is about what the local services want to do and how we can support them in doing it. We have a role nationally to support best practice, which is tested to make sure that it is there and available. Manchester and Stockport have adopted the best practice you are talking about here, but there are many other examples of best practice where people are trying stuff.

There is always a conversation about resource. I would say, hand on heart, that there will always be an ask for additional resource, but we know that people are using their local flexibilities. You can use local good practice to do things differently; that is proving successful. We will need to make sure that it is evidence-based.

Lord Hope of Craighead: Are people appreciating the value of the success that you are talking about? Can we look forward to improvement across the board?

Tom Cahill: I think that they are, but I would not want to pretend that this is not challenging when you have a long waiting list or young people waiting. However, people are genuinely trying to do the right thing for autistic people. In the face of a challenging time, they are finding solutions.

Dr Adrian James: We know that there is a huge crossover—we have mentioned it already—between different neurodivergent conditions. At the moment, in many areas, we have a fairly siloed approach; that is just the way it has evolved. Having sat on the ADHD Taskforce, we very much recognise the crossover of needs, most importantly. I always want to look at this from the perspective of a person who is trying to have their needs assessed and to access care or support.

Sometimes, a situation could arise where you are on one pathway to get a diagnosis in one area and that turns out not to be right, or there may be concern that there is something else going on so you have to join another pathway and, sometimes, another one. There is some emerging international evidence that, if you bring those together, so long as you

have staff who are trained in a particular area and you have the support available, there can be efficiencies from having a sort of one-stop shop where you have all of your needs assessed by an individual who is trained and is supported to assess those needs and make a diagnosis if that is necessary—but, most importantly, who can direct you to where you can have your needs met. In the case of ADHD, there may be a medical approach as well. There are some things that merit more discussion and exploration in terms of how we can bring things together, make it better for patients, most importantly, and make some efficiencies in the system as well.

Lord Hope of Craighead: Thank you all very much indeed for those very helpful answers.

Q164 **The Chair:** Can I ask you, Dr James, to build on your last point? The report that you published on Friday was clear that ADHD is not just the remit of health but is much wider; you have alluded to that already. Perhaps reading between the lines a bit, are you suggesting that the Government and the NHS should consider the future of autism and ADHD assessment as much more of a holistic service together; and that the silo approach we are seeing should be brought together in, in effect, a one-stop shop?

Dr Adrian James: It is not for me to say at this point. The taskforce has not made its final report, and the Government have not formally responded to it. The NHS is in a state of organisational change; that is important as well.

We should absolutely put people at the centre of planning. Is it something, for example, that will be published with the 10-year plan? We know that there will be a concentration on neighbourhood health; we know that people are talking about that. This provides opportunities in terms of diagnosis, assessment and support. So, there are many areas that need to be explored and taken forward, but we would not want to do that to the detriment of one particular group.

We know that there are organisations, lobby groups and charities that have lobbied hard and fast—rightly so—for their particular area. We need to make sure that that is respected and that those needs are met. If they can best be met by looking at things together, that is what we should do. If they can be met by an individual approach, we need to keep some flexibility in the system.

The Chair: That is very helpful. Obviously, the committee is considering recommendations; I am a great believer that with organisational change comes opportunity, so your considered view is helpful.

Dr Ken Courtenay: I have a very brief point: I am really pleased that the committee is considering additional diagnoses for autistic people, because they do not exist in isolation. It is very good that the concept of a siloed approach is being discussed because we need to move away from that. I have seen this in my own practice, particularly in ADHD clinics,

where a lot of people are presenting with signs of autism. Where do they go and who is going to assess them?

Q165 **Baroness Browning:** Looking at autism—in a silo, for the moment—it is a lifelong disability. It is going to be as challenging for somebody in their 60s, 70s or 80s as it is if they are in preschool. Not all neurodiverse conditions are going to be in that category. So, perhaps not on the grounds of an umbrella term that may well save a lot of money but will not necessarily deliver for the individual, how are you going to get that balance right?

I am particularly focused on some regions and areas where, as far as the autistic community is concerned, psychologists are available but psychiatrists are not, so a lot of autistic people who require medication are having to go out of their area, often at their own expense. All of those things start to come into play when you do not recognise a particular condition in a local area but you have an umbrella term and generic people dealing with generic terminology. Can you unravel that for me?

Dr Adrian James: I do not in any way see this as something that is watering down the care, treatment and support that an individual gets for their individual need—quite the reverse. For those individuals who have multiple needs, we take all of those things into consideration. I certainly would not want the system to diminish the hard-gotten gains of individuals who have striven to get services for those individuals. That is absolutely right; I completely see and agree with that. It is something that we need to build on.

In the neurodiverse world generally, the lifelong approach is something that has been lost and unrecognised. The neighbourhood health model gives us some hope there. Those close partnerships between primary care, local authority care and secondary care give us something to explore and build on where somebody needs a specialist approach with a specialist individual.

Something I feel very strongly about is models that we know work and where we have evidence on what works. We are very lucky: we have managed to keep the money to employ somebody who works for us on the evidence base and the research, which is really important, because everything we do must be reliant upon what works for individuals and where the evidence is. Each individual condition often has a very specific approach, as well as some generality, but we absolutely must not lose that.

Q166 **Baroness Hodgson of Abinger:** I want to pick up on that and whether it is even more difficult for people's needs to be met where the coexisting condition falls outside psychiatry into, say, neurology.

Dr Adrian James: It is a professional issue that we need to address. I have close contact with the neurology world—in fact, I meet with them regularly—and I think they recognise that. Whichever way you look at it, there are always boundaries in care needs and who can provide what. I guess it is about monitoring those boundaries. It is a challenge. Of

course, in psychiatry, we set up a whole speciality—liaison psychiatry—to ensure that mental health was in the physical health setting. I have often thought that it would be nice to at least explore having that the other way around. Neurologists and psychiatrists have a very close working relationship, so it is something we can explore and build on.

Baroness Hodgson of Abinger: We have heard that mainstream NHS services are often inaccessible to autistic people and fail to make adjustments for their needs. What is NHS England doing to change this? Also, what are the main barriers to making mainstream NHS services consistently accessible for autistic people? What would be the most effective way to overcome these barriers?

Dr Adrian James: I am sure you have heard evidence already about the health outcomes for autistic people, but it is worth repeating some of them. Autistic people die five and a half years earlier than non-autistic people. It is important to remember that, behind every statistic, there is an individual—a lost life and the family, friends and community around them. We know that, if you have a co-occurring learning disability, you lose more than 10 years. We know that 30% of autistic people have a co-occurring physical disability. One of the statistics—and, again, there is an individual behind each statistic—is that only 50% of autistic people would access breast screening; if you are a non-autistic person, it is two-thirds. It is very easy to see how people miss out.

What are we doing about it? The first thing I would like to say is that I am here in front of you. I am the very first national medical director for mental health and neurodiversity at NHS England. I have a seat at the table across the whole of medicine. I sit with people running cancer, cardiovascular and respiratory programmes, and the challenge I always make to them is this: I ask which individuals have the poorest outcomes, highlight who they are—autistic people are front and centre—and ask, "What is it within your programme that is trying to meet their needs?" I am very pleasantly surprised: years back, people perhaps would not have understood the question, and some would have been curious, but now people often approach me at the end of a meeting and say, "Come and have a look at what we are doing and how we have engaged with people with lived experience", or at least want to hear more about what they could do. I think that is number one.

The Oliver McGowan training has been very powerful: 3 million people have now been trained with the mandatory online training, and I think the training is excellent. I pay tribute to Paula McGowan for the work that she has done; it has been extraordinary. Last week, in Learning Disability Week, the code of practice was published as well. We are developing that all the time. Some 4,000 people have been on the "training the trainers" programme, across the whole of healthcare. Again, that is really important because those individuals can go on to train others. We have the reasonable adjustments digital flag, which went live in April last year. We do not have facts and figures around how much that has been taken up, but I think it has been really important. We also published national

guidance on health and care passports. These are a collection of your needs as an individual and, if you have a healthcare need, they can be passed to the providers so that they have advance knowledge of your needs, the reasonable adjustments and what needs to be done. We are revising the accessible information standard, which is just about to be published, and the sensory-friendly toolkit. A lot is being done.

I have just one reflection, which is on a personal experience I had. I was asked to come along, as the new medical director, to present to the Shelford Group, which is the group of probably the 10 biggest physical health trusts, particularly those that have big research programmes such as Oxford, Cambridge, University College, King's and Imperial. There are 10 trusts, and they are a huge part of the NHS budget. I went along to present on neurodiversity—the facts and figures and the people behind them and what the needs were. The chief medical officer in Sheffield produced a booklet and said, "We are doing this. We have learning disability and autism teams set up to engage with individuals. We have a board lead. We have a strategy. It has not been difficult to do, it has made a real difference, and the feedback is very good". For me to go along to that meeting is important but, if somebody sitting with the 10 chief medical officers of these big trusts is then talking about how important it is—and that it is possible and has benefited the whole organisation—that is really important. Addenbrooke's Hospital, for example, has programmes around surgery and out-of-hospital pre-assessment so that you do not have to come in for one or two pre-assessment visits; the hospital goes to you. With the 10-year plan, the Secretary of State has been talking about putting patients at the centre and bringing healthcare to them, rather than you having to go to healthcare. That gives us more opportunity.

Tom Cahill: We recognise that autism is not an illness or a disorder; it is a way of life.

Baroness Browning: I am glad you said that.

Tom Cahill: Autistic people have a right to services, care and support. They suffer like everyone else. The issue is that they do not often get access—it is not often easy—and, when it is there, it is not geared up for their needs. We recognise that autistic people are more likely to experience mental health issues, whether suicidal risk, eating disorders or sensory issues. We have done and are doing a lot to try to change the pathways of the care they receive. For eating disorders, we are working with our mental health colleagues, because autistic people will come through mental health teams. We want to make sure that they are equipped and supported.

Dr Courtenay was talking earlier about training staff. We want to make sure that people on the wards are aware, but also suitably skilled, to pick up and be able to support autistic people. We would expect them to have the core skills. We are working to make sure that talking therapies, which we talk a lot about, are suitable for autistic people. They work for a big

cohort of a population but not quite for autistic people in that way. There is quite a bit that we have to do and are doing.

We do not want to underestimate the sensory work we have done and our guidance to all areas about it. If you are building something new such as an A&E, you have to think about neurodiverse people and what that might look like.

I am a mental health nurse and I remember, back in the day, the way we built stuff was completely contrary to what we needed to do with open spaces, noise reduction and sensory awareness. There is a long way to go and there is a lot that has been achieved. I am struck by the fact that we need to remind ourselves that this is a group of people who will need lifelong support at different levels, and we need to adapt our world to let them thrive.

Dr Ken Courtenay: To my mind, services are not really sensitive enough to people. It is not just mental health or the hospitals, it is primary care as well. You can extend that to other agencies as well but let us look at healthcare. Autistic people have said not just to me but more broadly how difficult it is to even make contact with primary care—approaching the receptionist, for example. In the whole system and how it is set up, all these barriers seem to be there.

We need to ensure that the system is sensitive and is not just making reasonable adjustments but going beyond this as well and being creative in how they can do it. For me, they could do it through co-production, actually asking autistic people what would suit and help them rather than prescribing how things should be done, particularly in the built environment. That really is essential. It is about us having to change, rather than expecting autistic people to do it, to be honest.

Lord Wigley: I would like some clarification if I may, please, from Dr James on the figure you were using. Was it 5.5% of people on the autistic spectrum dying? Can I just be clear on that?

The Chair: It is 5.5 years, I think.

Lord Wigley: Ah, 5.5 years younger. In Mencap, we have been using parallel figures to that. Can you confirm that you are saying that people are dying from conditions that are totally unrelated to the autistic spectrum?

Dr Adrian James: Some 5.4 years earlier than non-autistic people.

Lord Wigley: Not because of anything related to autism?

Dr Adrian James: It is how the system has responded to their needs. It clearly is an issue, but it is not an intrinsic part.

Lord Wigley: No—that is the point. That has not caused the death, but there may have been challenges arising from the autistic condition that have then led to them failing to get some help that they might otherwise

have got, am I right?

The Chair: It is effectively one data capture point, is it not?

Tom Cahill: If I may, it is avoidable causes. We know that there are a significant number of avoidable deaths, more so than the normal population. It is usually about access, recognition, expertise and communication. Communication is a big issue. What we really want to do, which is the same for learning disability, is to really change the dial on that. We want people to get access to services quickly and for people providing that service to recognise that the reasonable adjustment flag is pivotal to this. When you turn up at A&E, they decide what works for this individual and this is what they need. These are game-changers, and we need to drive that.

Baroness Browning: Very briefly, the UCL research on autistic life expectancy actually changed the statistics that a lot of us had been using for some time. Are those the figures that you are using?

Dr Adrian James: I do not think that I am using UCL. I can get the figures back to you on exactly what we are reliant upon.

Baroness Browning: I was impressed with that research, yes.

The Chair: Perhaps you could write to the committee and let us know the detail around those figures. That would be extremely helpful, Dr James.

Dr Adrian James: We will. The other thing to add is that from 2022, autistic people are included within the LeDeR programme. That is a quality improvement programme. There has been a reduction in the numbers of years lost for those with a learning disability. I do not think that we can say that the LeDeR programme is entirely responsible for that, but it has been really very powerful. That is something we will need to monitor. Obviously, we want to focus on prevention and upstream things, but there is really important learning from that. There is nothing like looking at somebody's experience and seeing how this could have happened. Very sadly, the opportunities that were missed in terms of somebody's physical healthcare are very obvious—and then you can do something about them.

The Chair: You paid tribute to Paula McGowan earlier. The committee heard evidence from Paula, which was extremely helpful. She told her story, as you would imagine. That lived experience is incredibly important.

Q167 **Baroness Goudie:** Thank you very much and thank you for coming to us today. We have heard that the mental health services often fail to recognise and respond to autistic people's needs, meaning opportunities to avert crises are missed. What is the health service in England doing to change this and what are the main barriers to developing effective and constant pathways to meet autistic people's needs in mental health services, and what would you say are the best ways to overcome these

barriers?

Dr Adrian James: Again, some of the background facts and figures are really important to state. Behind every statistic is an individual. Autistic people die by suicide at a rate of seven and a half times the general population. We know that they are very much more likely to have a severe mental illness—40% have accompanying ADHD and higher rates of anxiety—so we know that they have very great needs that we need to meet. We also know that very recently the numbers in hospital receiving mental health treatment have gone up, so this is a very real issue.

What is happening and what are we doing? My appointment was important, but it is what you do with it; it is not the appointment that is important. We have published new guidance on meeting the needs of autistic people with 10 overarching principles. The centre of that was that services should be accessible and acceptable. If you ask autistic people about their hospital experience, number one is about the activities that are available. I saw that figure earlier on. New guidance was published in 2023 and updated earlier on this year.

The Culture of Care programme is going to be a game-changer in my opinion. This is a programme across the whole of mental health services, meant to look at the whole culture of our services. We know that we need to do more work in getting that right. It is run by the National Collaborating Centre for Mental Health and funded by NHS England. The National Collaborating Centre sits within the Royal College of Psychiatrists. Every single mental health provider, whether NHS providers or independent providers—58 of them I believe—is part of that programme. Everybody is engaged with it, and it is the biggest quality improvement programme that the college has been involved with.

Central to that is the therapeutic relationship and there are three approaches that they focus on. One is the anti-racist approach, another is trauma-informed, and one of the three main approaches is autism-informed. In fact, this morning I started in Newport at the international congress of the royal college, and the very first presentation was about this. There was an individual with lived experience who runs a community interest company talking about their engagement with this programme. This is an opportunity to transform how we actually provide care and make sure that it is always focused on the needs of individuals, and I am really proud that the focus on autism is there.

We have employed experts, as I have already mentioned, around making sure that we have fidelity to the evidence base around the needs of autistic people. We are publishing commissioning guidance around children and young people's eating disorder services. We know that is a particular issue for autistic people. That will be published soon and is full of reasonable adjustments to make sure that those individuals get their needs met. We have got a new suicide prevention strategy which is a couple of years old. NHS England recently published guidance on how that should roll out, and the needs of autistic people were a very significant part of that.

I have already touched on hospital care, but I could say more about it. There is the issue of detention under the Mental Health Act and the huge programme that will need to follow the Mental Health Bill becoming an Act; obviously, we need to see what the Act is going to look like.

What happens going forward? The Culture of Care programme is already receiving feedback; it is being evaluated, and we need to roll that out. We need to monitor the implementation of the standards. The standards are there; they are very clear, and they are co-produced. That is going to be really important.

We will have to move pretty quickly in developing those services for people with complex needs outside of hospital. We should be looking, at least, at exploring and piloting these in some areas to make sure we can do it in a timely way. Again, of course, we have the 10-year plan. When that is published, there will be a focus on prevention and early intervention. We know that, for example, we are looking again at a screening programme and evaluating that in terms of the physical health needs of autistic people.

Digital is going to be a really important part of that. I have already mentioned the flag, but there are huge opportunities. We know that autistic people often, but not exclusively, like to receive things in a digital way. They like to interact and give their feedback. They like to do pre-assessments using digital, and we need to make sure that they can.

Neighbourhood approaches also give us a real opportunity. I work very closely with Claire Fuller. She is the new co-medical director for mental health. She has a primary care background. That interface between the mental health services and primary care is absolutely vital.

The Chair: Mr Cahill, Dr Courtenay, would you like to build on that?

Tom Cahill: I am probably at risk of repeating some of the stuff. I would just point out: training; upskilling; creating awareness; creating that environment. Autistic people have the same needs. We know the propensity for mental health issues. We have done a lot of work around guidance for staff who are working in mental health services and seeing autistic people. Anecdotally, the feedback we get is that it is really helpful. If you have not worked with an autistic person before, people need support and that is where the Oliver McGowan training and other training is really helpful.

Dr Ken Courtenay: In addition to that, just because you have met one autistic person, it does not mean that you have met all autistic people.

The Chair: We have heard that time and time again in this Committee, as you would expect.

Dr Ken Courtenay: Just very briefly, what will underpin all that will be the evidence, the research work and looking at NICE guidance, for example, and taking every other opportunity to develop on that.

The Chair: That is very helpful. We will come back to that.

Q168 **Baroness Ritchie of Downpatrick:** Following on from the strategy and building on what you have already said today, could you tell us about what happens following the end of the current autism strategy in 2026 and after NHS England's functions are brought into the Department of Health and Social Care? What action will be needed to enable NHS bodies to improve outcomes for autistic people and to hold those bodies to account for progress?

Dr Ken Courtenay: What is really very important in terms of moving on from the strategy is ensuring that there are sufficient resources, not just in monetary terms but also people resources, as we have been hearing today. I would certainly hope that would be developed further as we move forward, because the workforce has to be skilled, as I said earlier. But we need to ensure that the training programmes are there—not just for the current cohort of people working in this area but extended beyond to people coming up—and really embedded in undergraduate curricula to ensure that people understand the needs of autistic people in whatever area of life they are going to work in, whether it is healthcare, social care, or other areas too.

You can see this most interestingly around the physical health of autistic people and how services are not necessarily sensitive to or understanding of how physical problems present, and how autistic people present with physical problems, which may not be the same as other people. It is very important that we get on and ensure that, particularly at undergraduate level, people understand that an autistic person coming in may not necessarily be able to identify, in the way that another person would, the particular problems that they have, especially around pain and being able to describe it accurately. It all ties into what I said at the beginning: it is everybody's business—everybody in healthcare and in other areas too.

Dr Adrian James: We do not know what the new combined organisation is going to look like, but the good thing is that we already have a good relationship with the DHSC, and in fact, the three of us recently met with Minister Kinnock; we already have that relationship with the department and officials. The most important people are those we serve—not us—and I am sure that a way will be found. Whomever is doing that, whether it is us or other individuals, I am sure that they will need to have that same focus.

Whenever there are discussions, it is our job to carry that out and make sure that autism is not something that is forgotten going forward. There are opportunities, as Baroness Rock has already said, in change, but there are risks that things can fall through the cracks, and we need to make sure that that does not happen.

Tom Cahill: On your point about change and the strategy coming to an end, I personally think that the refresh of that strategy is really important, at a critical time. It will help keep focus. We need to drive on the good stuff that we have achieved. We talk a lot about a reasonably

adjusted NHS or an autism-friendly NHS. There is real opportunity to drive that and continue with the training. The digital flag will be maturing. It is really important that we understand that. It is not just for autistic people; it is for everyone. We need to drive the commissioning strategy. We talked a lot today about diagnosis but equally a lot about a needs-led approach and really understanding that. We have now a good indication of what is really good practice. We have had our autism programme in the NHS running for about four years and, from day one to what it is now, we are in a different place. It is about putting that strategy back and refreshing it. We talked a lot about data today. We need to continue research: a lot of what we are recommending now is coming from it. There is also, of course, having a sensible conversation about what resource is required beyond that. The anchor point for us is a refreshed strategy that really focuses on autistic people, and I think autistic people deserve that.

Q169 **Baroness Ritchie of Downpatrick:** We have the Ministers coming next week. What would you like us to ask them?

Tom Cahill: First is about continuing to prioritise autistic people. Secondly, it is about not just mental health care but access to health. We have talked a lot today about it. Then, go beyond that—you are talking to three health professionals today. On education, we are talking about SEND. It is really about making sure that autism is very much on the agenda. When we met Minister Kinnock, we were assured and confident that it is. It is not always about money, and I probably would not start there, but I would not mind bringing it into the conversation as well. Clearly, it is about prioritising the life of people who are autistic.

Dr Ken Courtenay: If we get it right for autistic people, we get it right for a lot of other people too.

Baroness Browning: I am thinking of autistic people being admitted not for mental health conditions but the usual general admissions. I was very inspired a few years ago by a nurse consultant in one of our larger London hospitals who, on somebody with a learning disability being admitted, would immediately make sure to go to that person and identify their needs. It inspired me to take that into the world of autism with the National Autistic Society. What is your experience with this? I know that these are autonomous bodies now, and they decide what they do and who does it in these hospitals, but is there merit in encouraging nurse consultants in that sort of role?

Tom Cahill: Yes, we would agree with that. We know that, for learning disabilities, outcomes are better where there are learning disability nurses. We are trying generally to upskill all the staff. If you are going into A&E and you are an autistic person, you are not looking for the autistic nurse. You are looking for a basic understanding. Clearly, as people then require more intensive experience or support, you may then want to look for people who are more experienced or more skilled. I am not quite sure of the language I would want to use, but I am not quite

sure we would want to say, and we would want to be careful that we do not say, "That is the only person who sees the autistic person".

Baroness Browning: I am not suggesting that. I am just thinking that, when we ask who would do this, the nurse consultant seems to be a very senior person who is more than able to do the sort of things we have talked about today.

Tom Cahill: I know you are not suggesting that. I will finish with this. I am thinking of the whole concept of champions, who are people in departments who have gone and done some training and can provide guidance and support at a basic level. Then we are obviously talking about a level of expertise, such as that of our colleagues here, who would probably be more on the diagnosis end. Having champions, and making the NHS autistic friendly, is the avenue.

Dr Ken Courtenay: You are talking about having somebody in a senior position who can take decisions to support people because, often, people with less seniority are not really heard. Another model that I came across in North Middlesex University Hospital is the learning disability physician, where you have a senior consultant doctor who is specialising in the needs of autistic people—not so much providing the care but supporting them and speaking to other colleagues around it. This particular role, and person, is actually very sensitive and knowledgeable around the needs of autistic people as well, so they become a point of reference for them. What is key to what you are saying is having senior decision-makers in the organisation.

The Chair: Unless there are any more supplementaries, that probably draws our session to a close. As Baroness Ritchie said, we meet again next week, on Monday 30 June, where we will be hearing from Stephen Kinnock MP, the Minister of State for Care, from the Department of Health and Social Care. We will also be meeting with Alison McGovern, the Minister for Employment, and Catherine McKinnell, who is the Minister for School Standards. We look forward to hearing from them next week.

In the meantime, I thank you, our three witnesses, very much indeed. It has been a really enlightening session, and we have covered quite a lot of ground. You have given the committee a lot of food for thought. We look forward to seeing how the strategy and the inclusivity throughout the NHS continues. In the meantime, this public meeting is concluded, and I therefore now draw today's evidence session to a close.