

Autism Act 2009 Committee

Corrected oral evidence

Monday 31 March 2025

3.45 pm

Watch the meeting

Members present: Baroness Rock (The Chair); Lord Addington; Lord Elliott of Mickle Fell; Baroness Goudie; Baroness Hodgson of Abinger; Lord Hope of Craighead; Lord Wigley.

Evidence Session No. 7

Heard in Public

Questions 43 - 51

Witnesses

[I](#): Dr Mary Doherty, Autistic Doctors International; Professor Jeremy Parr, Professor of Paediatric Neurodisability, Newcastle University; Professor André Strydom, Chief Investigator, Learning from Lives and Deaths Review, and Professor in Intellectual Disabilities, King's College London.

Examination of witnesses

Dr Mary Doherty, Professor Jeremy Parr and Professor André Strydom.

Q43 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, and I once again draw attention to members' interests as published on the committee website.

I am now delighted to introduce our second panel of witnesses. We are very pleased to welcome Professor Jeremy Parr, professor of paediatric neurodisability at Newcastle University; Professor André Strydom, professor in intellectual disabilities at King's College London; and Dr Mary Doherty, founder of Autistic Doctors International. You are all extremely welcome and thank you for coming. This is a public evidence session and a written transcript will be taken. I will ask the first question and invite you to answer in turn. Please be kind enough to give a brief introduction before you answer the question.

What are the main inequalities in health outcomes for autistic people, including autistic people with co-occurring conditions? When you answer the question, can you include how important are access to and quality of healthcare as drivers of health inequalities? Could I start with Professor Parr?

Professor Jeremy Parr: Hello, I am professor of paediatric neurodisability at Newcastle University. I work in the NHS at Newcastle upon Tyne Hospitals NHS Foundation Trust, and Cumbria, Northumberland, Tyne and Wear NHS Trust. I work in a big mental health trust and a big acute trust, and lead research focused around autistic adults and children on the autism spectrum. There is some evidence from research that, compared with the general population, there may be earlier morbidity and mortality for autistic adults. That is for people with an intellectual or learning disability and people without a learning or intellectual disability. Just for people watching, that is an average. It does not mean that that relates to an individual person. It is likely that it is due to increased prevalence of physical health and mental health conditions, and the interaction between these and then people not having the same level of access to usual healthcare that people in the general population have.

Co-occurring conditions are common for autistic people, affecting most autistic adults and children. Evidence from our Autistica-funded research and other international studies shows that co-occurring conditions that are common in childhood persist through to adulthood. These include things like sleep difficulties, and eating and drinking difficulties that lead to restricted diets and dietary problems from there. Some neurodevelopmental conditions such as ADHD are common in young childhood and then persist through to adulthood. There is increased

evidence of physical and mental health conditions, and some evidence that physical health conditions are more common—for example, epilepsy. These are well known but, in recent years, gastrointestinal conditions such as obesity and fibromyalgia have been shown to be much more common for autistic adults than others in the population. You were hearing earlier about the prevalence of mental health conditions. In our big UK study,¹ 80% of autistic adults have one or more mental health conditions, including anxiety and, most commonly, depression. We have shown that these persist through the life course when you look at some people grouped by age. So it is highly likely that there is some sort of cumulative effect in relation to the conditions of childhood that then persist over the years. Someone who is having sleep problems and has a restricted diet might require medication for ADHD and develop anxiety in their teenage years, and then these conditions persist throughout their lives.

You asked about access and quality of healthcare, which is crucial. Our studies show that access is reduced.² People report not getting access to the physical and mental health services they need. That is, of course, going to have an impact on people's lives and their health outcomes. In terms of quality, the service is variable. Some people get an excellent service and report that. For some people, that is not the case. Part of this and thinking about how the Autism Act and strategy might have influenced things so far, and might do so in the future, presents a big opportunity to improve that.

Dr Mary Doherty: I am clinical associate professor at University College Dublin. My clinical background is anaesthesia, and my research interests focus on autistic healthcare and autistic healthcare professionals. As you mentioned, I am founder of Autistic Doctors International, which is a vibrant community of over 1,200 autistic medical doctors worldwide. I am also a parent of two neurodivergent young people. After my son was diagnosed, I received my own autism diagnosis in 2013, followed by ADHD two years later.

Looking at the inequalities, we have heard that life expectancy overall is reduced, with the greatest mortality gap being for autistic people with co-occurring intellectual disabilities. What I find particularly interesting is the cause-specific mortality. We might expect increased mortality from neurological causes because of the high rates of co-occurring epilepsy, for example, but why excess deaths from heart disease? Why is cancer mortality increased for autistic people? Consider screening services, for example. If a screening service is inaccessible to an autistic person, that might lead to loss of an opportunity for early diagnosis and early detection. That can translate into autistic people presenting late with a late-stage cancer rather than an early curable form. In our research, we

¹ Note from witness: Adult autism spectrum cohort UK. [Adult Autism Spectrum Cohort - UK; Adult Autism Spectrum Cohort - UK; Newcastle University](#)

² Note from witness: For a summary see [Publications; Adult Autism Spectrum Cohort - UK; Newcastle University](#)

have shown that the barriers to healthcare access are directly statistically related and associated with self-reported adverse outcomes.

So, in our research, 80% of autistic respondents reported difficulty accessing or visiting a GP. One in three reported a potentially life-threatening condition for which they did not access healthcare. The second part of our project was a qualitative study where we explored the stories behind the statistics and we saw some serious medical issues, such as participants experiencing a heart attack and not being able to phone for an ambulance. Another participant found a breast lump and was unable to go to a doctor. Some people with a ruptured appendix were not presenting to an emergency department for 24 hours. These were medically serious conditions. When we explored the data, we found a plausible pathway from those initial early barriers to the self-reported adverse outcomes.

Service delivery models also add to the inequalities. As an autistic person with co-occurring ADHD—that is a lot of us—you must access separate services. You have to wait for assessment twice, whereas a holistic neurodevelopmental approach could offer a much better outcome as well as a more efficient use of resources.

Finally, much of the inequality in mental health outcomes is due, in my opinion, to how we frame autism and that core deficit framing where autistic people are seen as defective, disordered and somehow “less than”. Neurotypical or non-autistic is seen as the bar or the goal to which we should aspire; we have to move away from that. Consider even how an autism diagnosis is delivered to a family who are new to the world of autism. It is often framed as a “breaking bad news” consultation. We have to move away from this tragedy narrative to a neurodiversity-affirmative approach. That, in my view, is the best way to optimise outcomes for autistic people.

We studied our members. Our study of autistic doctors showed an association between viewing autism as a disorder in comparison to viewing autism as a difference or a disability. Viewing autism as a disorder had a statistical association with prior suicide attempts; we know that there is emerging evidence on the link between masking and poor mental health, as you heard in the previous session. I really believe that it is imperative that we address this cause of preventable mental health problems because our children deserve the opportunity to grow up confidently autistic.

Professor André Strydom: Thank you for the invitation. I am a professor in intellectual disabilities at King’s College London. By background, I am an adult psychiatrist, so my perspective is very much on the adult side of things.

At King’s College London, we have a responsibility for analysing the mortality dataset put together by NHS England, which is called LeDeR; it includes the deaths of people with a learning disability, as well as those of autistic people. The aim of that is to understand avoidable causes of

death and to learn from the lives and deaths of both people with a learning disability and people who are autistic but do not have a learning disability. I will mention some of the findings from this.

Based on the last publication of the LeDeR dataset, in 2022, at that stage, not many deaths of autistic people without a learning disability had been reported yet. None the less, some of the findings were similar with what we know from the general literature: many individuals had died of suicide, misadventure or accidental death. When we looked in more detail at those deaths, it looked as though many of those deaths were suicide deaths, although the coroner may have recorded misadventure. In essence, these are avoidable deaths, so we should think about how to prevent them.

That goes with data from other countries. For example, Sweden did large population-level analyses that had similar findings, with increased deaths due to accidents, poisoning and self-harm.

As Professor Parr and Dr Doherty have already mentioned, we know that mental health conditions such as anxiety, depression and obsessive compulsive disorder—and, to some extent, substance misuse—may be common in autistic people. These could underlie the relationship between self-harm and suicide deaths. Again, these are treatable conditions, so there should be more of a focus on those.

My colleagues here have covered physical health conditions. One thing that might be worth highlighting is that we have used a large primary care dataset—the CPRD, which collects data from GP surgeries—to look specifically at the risk of diabetes and obesity in autistic people. That seems to be increased, but mainly because it has shifted to a younger age. Putting that together with the risk for cardiovascular conditions, which has already been mentioned, I wonder whether there is also an opportunity around lifestyle interventions, because these may drive some of those associations. Perhaps one could think about how to improve lifestyle interventions for autistic people.

Finally, another thing that we look at in LeDeR are the issues relating to poor care in autistic people who have died. So far, we have found that there can be a lack of adequate support services being provided—specifically in those that are tailored towards the needs of the person—or a lack of support to access services. Dr Doherty mentioned that some people have difficulty accessing services, so perhaps there should be specific support to help them access the service in the first place.

Then, in terms of mental health care, there can be a lack of crisis escalation plans, insufficient crisis plans and an overlooking of the impact of certain life events, which may have a bigger impact on some people who have limited care networks. There is also the lack of communication between different professionals and agencies; overshadowing of the impact of autism by other mental health conditions could perhaps impact here as well. Something that we are aware of is the lack of training,

awareness and understanding of the specific needs of autistic people in healthcare professionals.

- Q44 **Baroness Hodgson of Abinger:** Thank you for those answers; they were very interesting. I particularly want to pick up on what Dr Doherty was saying about co-occurring conditions. Do you think that, if somebody is diagnosed with epilepsy or ADHD, the autism side gets forgotten and, because they are not diagnosed as autistic, they do not get the support in the way they probably deserve?

Dr Mary Doherty: Absolutely; I totally do. That is classic diagnostic overshadowing, where individual conditions are not recognised. This makes it so difficult, particularly for autistic people, who need specific accommodations within healthcare. Most of us are multiply neurodivergent. These conditions and labels do not come alone. Most autistic people are multiply neurodivergent and most have co-occurring ADHD. To my mind, it does not make sense that the services are set up in such a way that this cannot be taken into account. It is better for children, where a more neurodevelopmental approach is generally taken. However, for adults, the services are difficult and very separated.

- Q45 **Lord Addington:** What has been the influence of the Autism Act and the statutory guidance of successive Governments' autism strategies in improving access to healthcare for autistic people? Have these been influential or not? How could the Autism Act and other levers be used more effectively to improve access to healthcare for autistic people?

Professor Jeremy Parr: The Act and the strategies that have come after it have been influential. There is an increased knowledge and awareness in the NHS. NHS England and other bodies have mandated professionals' training, improving knowledge that way. For example the Oliver McGowan training and others that preceded it. In the hospitals I work in, there are signs up asking whether staff are offering reasonable adjustments to autistic people and people with learning disabilities in the services that we run. We did not see that before, so there is some evidence of change.

Whether that is directly related to the Autism Act is slightly difficult to answer, but there are elements that have improved from that perspective. It is a step forward but there is a considerable way to go. Our research shows that increased knowledge about autism among health professionals is the thing that autistic people want the most. We have shown that time after time, and others have shown that as well.³

Thinking about how to improve further, we need consistency of approach and then to think about evaluation within our NHS services, whether that is in general practice, community care, out-patient or in-patient settings.

³ Note from witness: See [Publications; Adult Autism Spectrum Cohort - UK; Newcastle University](#)

There are not that many studies or that much knowledge about whether things have actually changed and whether people are getting the reasonable adjustments that they should be now. So, the next step in this area is gathering proof that there has been a shift.

There is some work around that going on in Newcastle now, and if that could be national, that would be fantastic. We all know that new knowledge is great, but it is a question of whether it really makes a difference to people and their short, medium and long-term outcomes.

Dr Mary Doherty: I think it might be useful to compare with the situation in Ireland, for example. We have no primary legislation or statutory guidance and we are many years behind you in service development. We do not even have, for example, an assessment and diagnostic pathway for autistic adults at this point. We have a report from the Joint Oireachtas Committee on Autism and a recently published autism innovation strategy, but that is not yet underpinned by legislation. The committee has evolved into an all-party group and a Bill has been introduced, modelled on the really progressive autism empowerment Act in Malta.

I agree with what you heard in the previous session regarding the lack of application. We need to consider autism and healthcare from a rights-based perspective. We are starting to see the use of equality legislation to challenge service providers on lack of accommodations and human rights abuses, and I think this will increase and put pressure on services to make the required changes. However, that is again an inaccessible option for many. Not many people can make a legal challenge, so we need accountability in this area to ensure that services act in line with their legal responsibilities, and we need realistic, accessible processes to challenge failures in this area.

There is another lever that I see as potentially the most beneficial, which is insider perspectives and role modelling. We are starting to have these conversations in medical education circles, which will ultimately lead to curriculum change. We need these in politics, too. We need to normalise being autistic in healthcare, politics and society more widely. Autism remains shrouded in shame and secrecy, and "autistic" is used as a slur and potentially weaponised against us, whether as medical professionals or as politicians. Until that changes, we are going to continue to see negative effects in terms of the loss of insider perspectives, but also, more widely, ongoing poor mental health for autistic people.

While homosexuality is not a perfect analogy, it is useful to consider that this is also something that is core to a person's identity and about which we have a choice whether to disclose. It used to be considered a mental illness; now we of course recognise that it is perfectly normal. Many of us here will remember that process of change and how that changed across society. Members of Parliament or indeed doctors might find it easy now to identify as gay; it is no big deal. However, we remember it was not that long ago that this was not the case. Up until quite recently, being

outed as gay was used as an act of political sabotage. The same thing happens now in terms of being autistic.

So, the real question is, how do we make that change when the risks of disclosure are very real? We have to start by acknowledging the problem and confronting the possibility of inadvertent harm, in terms of perpetuating shame and stigma, when autistic people in prominent and influential positions feel unable to acknowledge being autistic. We are everywhere, in all fields, like health, education, politics and public life, but in most cases, we are a hidden minority. It is not possible for all, of course—sharing one's identity is a personal choice—but the more of us who can be openly autistic, the quicker we will see the real change that is so badly needed. Currently, so many of the problems are due to autistic people being othered. As I said earlier, autistic kids need the chance to grow up confidently autistic, and they need to see that it is entirely possible to thrive as an autistic adult. That is why role modelling has such an important part to play.

Professor André Strydom: The Autism Act has certainly helped to bring more attention to the needs of autistic people. We see changes at service development level: more services are specifically targeted to the needs of autistic people. However, there are certainly still some gaps.

When I speak to autistic people, they say that more needs to be done, and they want things like access to specific services to address their needs. That includes sufficient access to diagnostic assessments, to expert psychological services tailored to the needs of autistic people, and specialist mental health teams. Speaking from a mental health perspective, these should be specialist mental health teams that can focus on the needs of autistic people, as well as individualised supports.

That is quite a big gap, but many autistic people do not need supports all the time or all their life. Of course, people with a learning disability who are autistic will need significant levels of support, but many people just need a little bit of support at times. That could help in crisis situations, help people to get into employment or could help them when there are concerns about mental health issues. This is a real gap.

Lord Elliott of Mickle Fell: I have a quick follow-up question for Dr Doherty. Could you tell us a bit more about the autism empowerment Act in Malta? Do you consider that to be the best practice, a benchmark if you like, for good legislation?

Dr Mary Doherty: Yes, I think it is. I am not very familiar with specific details of the Act but it is absolutely a very progressive Act. Importantly, going back to what I talked about on insider positionality, key people who were involved in the development of that were autistic legal professionals. That is what we need.

Q46 **Baroness Hodgson of Abinger:** How accessible are healthcare settings for autistic people? How can this be improved and to what extent should adjustments be specific to the needs of autistic people? I realise that this

is a slightly generalised question. Could Dr Doherty go first on this, please?

Dr Mary Doherty: As autistic people, we face two sets of separate but related barriers to healthcare. First, we face barriers getting into the healthcare system at all—by which I mean challenges making appointments, particularly if it involves use of the telephone. In our research, we found that this was the single biggest barrier to autistic people accessing healthcare. We also face challenges travelling to healthcare settings. Public transport can be really difficult. Often, autistic people need somebody to accompany them to medical appointments, so getting into the system in the first place is very difficult. In our research, we found that many autistic people reported being completely alienated from the healthcare system, entirely unable to access healthcare at all, despite experiencing healthcare needs.

Secondly, once in the system, there are challenges of availing of healthcare on an equitable basis. That is particularly around the sensory environment and communication challenges with healthcare providers. Making adjustments specific to autistic needs is a really interesting point. The thing is that the accommodations that benefit autistic people in general would be helpful for everybody: a quiet space, clear, unambiguous communication, predictable appointments and flexibility within the system. These would improve healthcare for everybody, but there is one really important point to be aware of: while they would benefit all people, for non-autistic people, they are often nice to have, but for autistic people, they are essential. They may make the difference between having a healthcare condition treated at all or not.

As a personal example, I have felt the need to leave a medical waiting room, to abandon my appointment entirely, just because the sensory environment became intolerable. That was despite knowing, as a doctor, that my appointment was to arrange investigations to rule out a malignancy. That is the impact of the sensory environment and barriers to healthcare.

Professor André Strydom: I agree with Dr Doherty. There may be other things to mention where there are difficulties. These include flexibility in scheduling, for example. Some people might prefer start-of-day or end-of-day appointments. Reminders as well: we often have to send people reminders before an appointment. Ensuring that supports are available: speaking as a psychiatrist working with people with intellectual disability, we often have to link with the caregivers to make sure that they are available to support the person.

One thing I want to highlight, particularly in regard to people with significant needs—those with real difficulty accessing services such as blood tests—is that we should be more willing to do assessments at home, to set things in place to take blood, do investigations or do physical assessments in the person's home, because that could be less stressful and would not require them to go into a stressful setting, with sensory overload. I have to say that we managed to do that during the

Covid pandemic. Services were very good at shifting their way of working around going to see people at home, but that does not seem to be happening any more. We need to learn from the Covid pandemic, see what we can put in place and have specific pathways for people to access treatment, assessments and tests at home. For those who need sedation to undergo certain investigations, hospital pathways are needed to allow for that, making use of the capacity assessment, appropriate supports and specific expertise.

Professor Jeremy Parr: We provide personalised healthcare in many ways within the NHS. We can now do genetic and immunological tests to work out which drugs to give for whichever condition. We spend a large amount of money on these things, yet the reasonable adjustments that people could request and we could put in place within the NHS are actually quite low cost. They are very difficult to implement across a whole organisation, in terms of organisational change across many layers of professionals in many environments, but they make a massive difference. Our research⁴ has shown that people do not get what they would like to get, and they have made it very clear that when they get the adjustments that are helpful for them, they have a much improved healthcare experience, in terms of their satisfaction, but also they are able to access healthcare at that point and probably down the line as well—so they are not put off by their experience.

We have done three lots of research recently around that. One was in relation to health checks for autistic adults.⁵ That clearly shows that reasonable adjustments have been effective in primary care in the UK and the results on the health outcomes from that study will be available at the end of May. I do not know what they are yet, so I cannot talk about those. We created an interview to be used in diagnosis of autistic adults (the Autism Clinical Interview for Adults), with a pre-interview questionnaire to be sent to people beforehand, finding out how they would like their diagnostic assessment to go in terms of the reasonable adjustments that could be provided for them.⁶

We have used virtual reality in the treatment of anxiety for children and adults to enable us to think about the adjustments that people would need in relationship to health psychology, improving people's anxiety through use of virtual reality scenes and giving them therapy in that way. That led to an NHS and university spin-out company called XR Therapeutics.⁷ It is a huge area for people to work on. The question is

⁴ Note from witness: See Brice et al: [The importance and availability of adjustments to improve access for autistic adults who need mental and physical healthcare: findings from UK surveys | BMJ Open](#)

⁵ Note from witness: See [About our Project | Health Checks for Autistic Adults | Newcastle University](#)

⁶ Note from witness: See [Autism Clinical Interview Adults Training \(ACIA\) | Neurodevelopment and Disability | Newcastle University](#)

⁷ Note from witness: See [XR Therapeutics - Award winning therapy treatments for](#)

how to implement this widely. I know that we are doing that in our own NHS practice and colleagues are doing that in Newcastle. As I said before, measuring how it is going nationally is key.

Q47 **Lord Wigley:** Could I address this to Dr Doherty first, and others in due course? To some extent, we may have covered a number of aspects to this question but what I have down to ask is: how well do health services identify and make adjustments for autistic people, and how could this be improved?

Dr Mary Doherty: Not very well at all, and certainly not consistently, although there are pockets of excellent provision. That is driven largely by individual practitioners with a personal interest. Many healthcare providers have not received training and are not confident in caring for autistic people. This absolutely needs to change. We need all healthcare providers to become not just autism aware but autism competent. What has been really interesting to me over the years in which I have been involved in delivering autism education and advocacy within healthcare has been the differential interest among doctors between supporting autistic patients compared to supporting autistic trainees and autistic colleagues.

I was researching and providing training on autistic healthcare for quite some time before I founded ADI and started to include autistic doctors and medical students in my work. I discovered that the interest in supporting autistic colleagues far surpasses the interest in autistic healthcare. That pains me greatly. But now my focus is on autistic doctors and leveraging our insider perspectives to improve healthcare for autistic people. When healthcare practitioners understand what it means to be autistic, even if that knowledge is acquired for the benefit of autistic colleagues, we can expect that that will translate to better care for autistic patients. Just to be clear, when I say autistic patients, I mean autistic people who are in the healthcare service because they are sick, not because they are autistic. The benefit of that is potentially maximised when we can use the same approach both for supporting autistic patients and supporting autistic colleagues and trainees.

That is an advantage of a framework that we have developed called the autistic SPACE framework. It was developed by myself and two other autistic doctors with the aim of providing a simple, memorable framework for busy practitioners who do not have a lot of time. SPACE is a descriptive acronym that represents what we believe to be the core needs of any autistic person, no matter what their profile of strengths and needs might be. The acronym stands for sensory needs, predictability, acceptance, communication and empathy. We also discuss physical space, processing space and emotional space. It was designed to support autistic patients but is much more widely applicable.

We mentioned sedation earlier. We have adapted it for anaesthesia, and we have published that in the *British Journal of Anaesthesia Education*. As

[anxiety phobias and more.](#)

well as supporting patients and colleagues, we have also published an adaptation of the autistic SPACE framework for use in social care. We have just submitted for publication an adaptation for use in education. It has been included in the national autism training programme for psychiatrists developed by the Royal College of Psychiatrists. It has also been cited in a consensus statement by the American Academy of Pediatrics on healthcare for youth with neurodevelopmental disabilities, as well as lots of other influential publications. The framework is openly available and is free to use. We have some preliminary evidence of its effectiveness in several settings but we need to build the evidence base before it could be widely adopted. If you feel it is appropriate, maybe recommending adoption of the framework across healthcare could potentially benefit autistic people.

Lord Wigley: I am glad I asked that question. If there is more stuff coming through, I am sure we would be very glad to receive it.

Professor Jeremy Parr: I talked earlier about pre-appointment questionnaires. Having the ability for people to input how they want an appointment to go beforehand is really helpful. We can put in our NHS letters, "If you require reasonable adjustments, please let us know", and that is a pretty low bar in terms of an opportunity for people to contribute. But if we were sending people a list asking them, "Would you like these...?" examples, then people can send that back and we can tailor our appointments according to what people need. That is far more likely to be an effective and implementable way of doing things. Certainly, the research evidence from our primary care trial in relationship to reasonable adjustments is pretty positive. People thought that they had got the adjustments that they requested.

The crucial thing is that it is not about that single appointment but about the future as well. We then need the health professionals to write or record that information somewhere where it is easy to find on the health record, and what the adjustments that someone needs are, so that when they come back in two weeks' time, we are absolutely clear from the beginning what that person would find helpful. In our research, it remains to be seen whether that has transferred into the records. There is a question of how you systematically enable people to give the information easily, implement that in services and then have some sort of evaluation process for the future to check that those adjustments are in place.

Professor André Strydom: I will be brief, but I want to highlight that the NHS is rolling out a new system, a digital flag, to identify people who need reasonable adjustments. It will sit on the NHS electronic record "spine", so it will be accessible wherever the person goes. We hope that this will make a real difference. It is not just for people who are autistic, but also for people who have learning disability and perhaps for other people who need reasonable adjustments.

For it to work, we would first need to identify people who have or require reasonable adjustments, as Jeremy mentioned, and then for professionals to enter that data on the NHS system. We need to know who has a

learning disability who is autistic. We hope that we would be able to help with that. We have recently been provided with an NIHR grant to see if we can use existing health records and machine learning methods to try and identify the kind of needs that people may have that are already recorded somewhere in the system, and then highlight that as part of the reasonable adjustment flag. This project will run alongside the rollout of the flag and will also hopefully help to evaluate the uptake of the flag and how that can be improved.

Q48 The Chair: Thank you, Professor. Could I just build on that and maybe ask the other two about it? As we are aware, there are obviously quite a lot of current pressures on NHS services. What would be the most effective and efficient way to reduce those health inequalities for autistic people? Perhaps I could come to Professor Parr, because it is building on some of the things that Professor Strydom just talked about.

Professor Jeremy Parr: It is a huge challenge in a stretched NHS; I completely understand that. I talked earlier about organisational change and delivering something across multiple levels of an organisation—someone working on reception knowing the adjustments required for someone who is coming in at 1.10 that afternoon, then the nursing staff also knowing that, if this is in-patient care, and the doctor knowing what is going on, especially if the doctors have changed if a colleague is away. That is a huge practical implementation challenge in relation to these low-cost interventions.

Education is absolutely key. The rollout of Oliver McGowan training, making sure that all professionals working within the NHS, whatever they do, are aware of the needs of autistic people, is something we can do across the board. Implementing adjustments as much as we can is likely to be beneficial. If we say that this is too hard because the NHS is in a tough position right now, that will not help. We would be better to implement two-thirds of that rather than saying that we cannot get it perfect and therefore we are not going to do it at all.

The Chair: Dr Doherty, do you want to add anything to that? You talked about this holistic approach earlier on in the session.

Dr Mary Doherty: I think it is just about becoming familiar with what it means to be autistic and understanding the needs of autistic patients. Training and education are hugely important, and the digital flag is very helpful, but only to the point where it is understood what it means to be autistic.

As a practical example, one of our leadership team in Autistic Doctors International, a consultant psychiatrist—who has given me permission to share this—has a digital flag on her records and recently went to her GP with an entirely unrelated issue. The flag popped up and she was asked why she was there alone and where her carer was, just because there was a flag. There is this association between being autistic and potentially having intellectual disabilities or complex needs.

As I said earlier, one way of understanding just what it means to be autistic is to normalise being autistic in healthcare, so that we can have these conversations. I regularly hear from autistic doctors, trainees, consultants, nursing staff and all sorts of staff in healthcare who want to be able to share their knowledge, particularly when they have autistic patients, but, because of the culture of ableism and the difficulties with disclosure, they feel inhibited from doing that.

We just need to have these conversations in the tearoom about what it means to be autistic. If I say to my colleagues, "No unnecessary words today, don't talk to me", they understand that this is because I am maybe a little overloaded. It does not mean that I am being rude, and it does not mean that I do not want to talk to them tomorrow, but they understand that that is where I am at today. It is about normalising being autistic in healthcare.

- Q49 **Lord Elliott of Mickle Fell:** A lot of this ground has been covered, but I will ask the question again in case you have more to add. How do barriers to communication between autistic people and healthcare professionals affect autistic people's health outcomes? How can these barriers be reduced? I will start with Dr Doherty.

Dr Mary Doherty: Autism is a disability that involves sensory and communication challenges, so of course that means that we experience difficulty with communication in healthcare settings. Support needs for autistic people, particularly support with communication ability, are not static for many autistic people. In our research, we have shown that sensory challenges and anxiety in particular impede the ability to communicate. Accessing healthcare can be inherently stressful, so it is not surprising that communication challenges are particularly impactful in healthcare settings. Some autistic people do not speak, yet alternative forms of communication are not facilitated in healthcare. This absolutely needs to change.

As we said, healthcare providers have generally not received training on autistic communication, but it is essential, because all healthcare providers need to become autism competent. Challenges with communication are traditionally framed in terms of deficits on the part of the autistic person, but the reality is that non-autistic people have just as much difficulty understanding us as might be the other way around. Therefore, autistic healthcare professionals might have an advantage in communicating with autistic patients over our non-autistic peers.

Recognition of autistic healthcare professionals—that we exist at all—is fairly recent, so we do not have much evidence beyond preliminary evidence on that point, but I have no doubt that autistic healthcare professionals can have a really important role to play in educating our colleagues around communication with autistic patients. We need this embedded at the earliest stages; by that, I mean in medical school. It needs to be embedded in the curriculum with catch-up training for ongoing opportunities for professional development for the existing medical workforce.

Professor André Strydom: I will draw again on the LeDeR data, this time thinking about what factors are associated with good care—when it goes well. Those factors include if there was an awareness of autism and what that means for the person, as well as efforts to make reasonable adjustments.

It is important to highlight that it is not just communication with the person, but it is also communication between services and the system that is really important, if there is complex care involved, as well as supports that are being offered to the person. If there are supports in place that can be offered, it needs to be explained to the person, what kind of supports are available and where can they access that? That can be tailored to the needs of the individual as well, with reasonable adjustments made to help service users access those services and support. Those type of things were all very helpful and resulted in good care.

Professor Jeremy Parr: I think there is a healthcare journey here, from someone getting an appointment, being reminded about it, going to it, and so on. The NHS has long made phone calls in relation to whether people are attending, or an automated phone call. Lots of people do not answer phone calls from numbers that they do not recognise—I do not, and you might not either. We know that lots of autistic people do not, because we have asked them about what their communication preferences are.

Communication preferences are key. What do people want, do they want to receive something by email or by text message, and can we get that into our system so that people are reminded about their appointment that way? One of our pre-appointment questionnaires focuses on some of the usual areas that we have heard about, as well as things like what happens to people's communication if they are particularly anxious or if they are in pain because of what is happening to them at that point. If people could write that down beforehand, then that information can be used in the appointment itself.

Having a really clear summary at the end of the appointment about what has happened and what the findings are is absolutely crucial. We would all want that, and for autistic people, it is particularly important.

Q50 Baroness Goudie: To what extent do healthcare services learn from autistic people's experiences, and from any failures to meet autistic people's needs? How could this be improved?

Professor André Strydom: As a researcher, I shall start from a research perspective to see what we can do to learn from when things do not go well and from data that we have within the NHS. At national level, data such as in the LeDeR mortality data set is important and can help us track issues, improvements and quality of care over time, as well as outcomes, particularly important outcomes such as mortality, for example. The LeDeR program was specifically set up to ensure learning from the lives and deaths of people with learning disability, and now

includes autistic people. We are hoping that over time these kind of efforts and analyses will help to improve care and allow us to identify specific areas where improvements can be made to services. This already has had a significant impact on learning disability services because the LeDeR initially focused on the needs of people with learning or intellectual disability. However, in terms of getting the experience of autistic people themselves, there are a number of ways in which that is done: patient experience feedback, for example. Although we all get a little fed up with having to give feedback the whole time about various experiences or access, none the less, from time to time that could be useful.

Access to PALS is important and people need to be aware of that. I had recent experiences with healthcare myself and had to make use of PALS, and it was effective. At a more management or trust board level, one thing that could be useful is to have service user advisory groups that can advise on the trusts and health services, particularly mental health services—that is the perspective I come from. That can be used for service users and caregivers to have a real say in how services are developed and set up. That gives an opportunity for trust managers and clinicians to consult with service users and caregivers on how to go about improving services.

Dr Mary Doherty: It is hard to see services learning from autistic people's experiences. We see example after example of autistic people being mistreated in healthcare settings. We see reports of autistic people being detained, restrained, abused or refused access to mental health care just because they are autistic. I know the ongoing human rights violations experienced by autistic people, particularly those kept in long-term seclusion when community services could potentially meet their needs, but such services are just not provided. It is hard to remain hopeful for meaningful change. It is the lack of accountability that allows this to continue because despite training, knowledge and staff, the reality is that all the relevant legislation—whether it is the Equality Act, the Autism Act or the Human Rights Act—is effectively ignored on the ground and within such settings. There is no accountability for the human rights abuses that autistic people are experiencing as we speak right now, today. There are few effective complaints processes. We need the creation of concrete processes to achieve accountability. That is vital.

Coming back to insider positionality, autistic people are alienated, dehumanised and othered within settings where these abuses occur. It is much, much harder to dehumanise autistic patients while you are simultaneously recognising and supporting autistic staff. Again, without accountability, such staff risk being penalised rather than supported. Along with robust accountability structures, we need to address the ableist culture in healthcare so that autistic staff as well as patients have the opportunity to thrive. The thing is that autistic staff can help with understanding autistic people's needs in healthcare settings. We experience dysregulation often caused by sensory overload or unpredictability. This can be misunderstood or overlooked by non-autistic caregivers. For example, a lovely recent research paper looked at a

simulated autistic meltdown in a workplace context. Understanding what had happened was far better for autistic compared to non-autistic participants. I have no doubt that if we replicated that in a healthcare setting, we would find the same thing. This could improve healthcare for autistic people. Encouraging autistic people into roles in health and social care will also support our employment rates. It is vital that we support autistic staff to enable them to care for autistic patients most effectively.

Professor Jeremy Parr: I agree that change within the NHS comes at senior management and board level in NHS trust organisations. In the organisations I work in, the trust boards have altered the environment on the ground. That is where those posters come from effectively, within our organisations. You talked about measurement. On PALS, I agree with that but the Care Quality Commission could require people to show that they have looked at the extent to which they are putting in place the adjustments and accommodations that people need within services, and show how services have changed.

Finally, there is something about innovation. We are talking today about potentially useful adjustments that we have known about for 10 or 15 years. But with technology, virtual reality and other techniques comes a real opportunity to put in place a raft of new things that could be useful—whether that is machine learning or new techniques like virtual reality. What about being able to show someone sat at home what their journey from the front door to the inside of the MRI scanner is going to look and sound like, and what is going to happen to them afterwards? Walking that through in a virtual reality setting before one comes in—these are things that we can do now.

Baroness Hodgson of Abinger: How well do you think the system copes with the transition from children to adolescents to adults? You are going to be changing from a paediatrician looking after you to various other specialities. The teenage years are not easy anyway regarding things like mental health.

Professor Jeremy Parr: We did some research on this some years ago, and the findings from that and our funded research programme led by Professor Allan Colver in Newcastle led to a change in the last version of the NHS plan.⁸ A discrete number of findings are clear in relation to how the process of transition and the moment of transfer from children's to adult services should be provided. One of the challenges for many autistic people is: where do they go to when transferring from a children's service to an adult service? That depends a bit on their needs. Everyone has a health professional involved with them through primary care. So there is some thinking around how people's needs as a child, young person or adolescent in their teenage years go through to their primary care provider effectively. That is a big opportunity.

Q51 **The Chair:** I shall ask each of you one final question. Obviously, this committee has to come up with a number of recommendations. If you

⁸ Note from witness: See [Transition; Transition; Newcastle University](#)

were to put yourselves in our shoes, what would be one recommendation that you would like to come from the committee? Apologies; I am only asking for one recommendation.

Professor Jeremy Parr: Use new technologies effectively to try to create change, because we have not had these before. There is a massive opportunity and amount of new work that could be done there.

Dr Mary Doherty: While I might suggest the autistic SPACE framework, I am going to go with accountability for the legislation that currently exists. We need accountable processes.⁹

Professor André Strydom: I would go for more focus on mental health support for autistic people.

The Chair: Is there anything else that the witnesses would like to say to the committee? No?

Thank you very much. You have given us a lot of information and I have made some notes of quite a few things. It would be helpful if we could come back to you with some of the areas where you have said there has been work. Professor Parr, you said specifically that you were going to have some work coming out at the end of May. It would be very useful if you could send that to the committee. I think there were also some other areas. If we may, we will come back to you with some additional asks for more information, if that is all right. I thank hugely each of you for a really inclusive and thoughtful discussion. You have given the committee a lot of things to go away and think of as we go towards Easter. That was our last meeting before the Easter Recess and we will resume our sessions when Parliament returns. In the meantime, today's evidence sessions are now concluded.

⁹ Note from witness: "I would like to add how incredibly helpful it was to have all the information that the Committee provided in advance of the meeting, as that hugely reduced the anxiety associated with a new experience and a daunting one at that. I wanted to say thanks and highlight the contrast, the fact that we do not generally have such advance information in healthcare, which obviously increases the challenges for autistic people attempting to access healthcare. Also, I would like to direct the Committee's attention to an interview published on 15 April 2025 in *The Times*, and particularly the closing quotation from Dr Anna Rebowska, an autistic Consultant Child & Adolescent Psychiatrist who is part of the leadership team of Autistic Doctors International 'What are we doing to the next generation if all the successful autistic people are in hiding?' If the work of the Committee can encourage influential autistic people such as autistic politicians to openly acknowledge being autistic, that would provide such valuable leadership and role modelling. I appreciate the political risk this might pose for some elected representatives, therefore Peers who are not subject to electoral risk might be the best placed group to take up this challenge?"

