

Autism Act 2009 Committee

Corrected oral evidence

Monday 31 March 2025

2.45 pm

Watch the meeting

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

Evidence Session No. 6

Heard in Public

Questions 36 - 42

Witnesses

[I](#): Dr Sarah Cassidy, Associate Professor in Psychology, Nottingham University; Tom Purser, CEO, Autism Action; Professor Ailsa Russell, University of Bath.

Examination of witnesses

Dr Sarah Cassidy, Tom Purser and Professor Ailsa Russell.

Q36 **The Chair:** Good afternoon and welcome to this public meeting of the House of Lords Select Committee on the Autism Act 2009. The committee has been appointed to examine how well the Autism Act and the Government's autism strategy are working, and to make recommendations about what the Government should do next. Today, we are focusing on the key issues in reducing health inequalities for autistic people. We are delighted to be joined by today's witnesses: Professor Ailsa Russell, professor of clinical psychology at the University of Bath; Tom Purser, the CEO of Autism Action; and Dr Sarah Cassidy, an associate professor at the faculty of science of the University of Nottingham. You are all extremely welcome; thank you very much for coming today.

We will continue hearing oral evidence on Monday afternoons most weeks when Parliament is sitting until the summer. We will also publish a call for evidence, which will be open to anyone to respond to, before the Easter Recess in April. The committee's job is to scrutinise the Government and their policies. We are not able to help with individual problems or complaints, and we do not permit personal criticism of individuals as they do not have the right of reply. Members of the public can watch our proceedings either online or in person but are not allowed to speak during a public session. Our evidence sessions are on the record, which means that they are broadcast and that a written transcript is taken for subsequent publication. The list of members' declared interests has been published on the committee's website.

Having made that introduction, I will now ask the first question. When you answer, please introduce yourself briefly. What is the evidence of the prevalence of mental ill-health among autistic people in all demographic groups, compared with the general population and with people with other disabilities? Please incorporate in your answer the main reasons for this and what impact mental ill-health has on outcomes for autistic people. Perhaps we could start with Professor Ailsa Russell then go to Dr Cassidy and, finally, go to Tom Purser.

Professor Ailsa Russell: I am a clinical psychologist and a professor at the University of Bath. To answer your question, we know from both individual research studies and population-level data that autistic people are disproportionately affected by mental health problems. They are more likely to have higher rates of mental health problems across the lifespan, through childhood and adulthood. That includes autistic people with intellectual disability.

For example, we know from United Kingdom primary care data on general mental health problems that 41% of autistic people are recorded as having a classifiable or diagnosable mental health problem. That is

much higher than the general population, where the figure is about 11%, and higher than rates recorded by the comparison sample of people with ADHD, where it is about 25% or 26%. We know that UK data is very consistent with data from other countries, such as the United States and Australia. There is evidence to suggest that specific mental health problems are more prevalent, such as anxiety, depression, obsessive compulsive disorder, attention deficit hyperactivity disorder and sleep-wake disorders. As well as more mental health problems, specific types of mental health problems are more likely to occur.

As for the reasons, we cannot be 100% sure; it is a complicated area. We can draw on what we know about risk factors for mental health in the general population. For example, not having access to the kinds of employment opportunities or occupations that you would really like to have can affect your mental health. The size of your social network and how protective it is can also be really important for your mental health. Stigma, discrimination and minority stress can really impact people's mental health, as can adverse personal experiences such as a lifetime of bullying.

Some factors are likely to be autism-specific, such as an environment not being compatible with someone's needs. The sensory overwhelm of educational facilities and workplaces can be very stressful for people, which, again, can exacerbate an existing mental health problem or contribute to the development of mental health problems. Additionally factors such as executive function challenges or a preference for routine we know from some longitudinal studies that those are important risk factors.

As for the outcomes, mental health problems have an impact on people's quality of life and their well-being for all sections of the population. There is no reason to expect that it would be different for autistic people.

Dr Sarah Cassidy: I am an associate professor at the University of Nottingham. To add to what Ailsa said, mental health problems are prevalent in not only diagnosed autistic people but undiagnosed autistic people. Recent studies comparing the rates between those two groups show very similar rates. Particularly in terms of interventions or preventive strategies, it is important that we do not see autism diagnosis as a ticket to get support; it is more about people's needs and addressing them more broadly.

A lot of research speaks to this point, showing that unmet support needs are a risk for increasing mental health difficulties—that is, the support that people would ideally like but do not get. This could be mental health support, help in the home, accessible employment or mentoring to help somebody access social spaces of lots of different kinds. Not getting that help can really increase the risk of mental health difficulties, regardless of whether you have an autism diagnosis.

Another factor, which Ailsa mentioned, is social exclusion and stigma. This means that autistic people, regardless of diagnosis, are excluded

from developing a lot of protective factors such as education, qualifications, employment and even access to healthcare. In response to feeling this exclusion and stigma, many autistic people describe something called "masking" or "camouflaging" their autistic characteristics in an attempt to try to access and cope in social spaces such as school and employment; and to try to access mental health care or any other kind of healthcare. That carries with it a lot of stress, anxiety and pressure. Lots of research studies now show that there is a consistent link between mental ill-health and camouflaging autistic traits or characteristics, regardless of whether a person has a diagnosis. They may be seeking a diagnosis or not even know that they might be on the autism spectrum. This association is present in everybody, regardless of autism diagnosis. It is really important that we think about how we can make society more inclusive and address people's needs at lots of different stages of their life, from education to employment and living independently.

Another important factor are the barriers to accessing mental health services or mental health care. Studies show that, particularly in late diagnosis of autistic adults, for example, one of the primary reasons for seeking help before getting a diagnosis is mental health problems. Autistic people can be diagnosed while under the care of mental health services for the first time, but many autistic people find it really difficult to get help from mental health services, even though they would like it. One of our studies showed that 60% of autistic adults in our sample wanted to have some form of support, and the primary support that they wanted was mental health treatment and support, but only 20% got it. There is a massive mismatch.

Autistic people describe lots of things about that barrier to receiving mental health help. In our qualitative research, we have had people describing how they were discharged because there was nobody there with the autism expertise to help them, even though they were in crisis. Autistic people also describe how, even if they manage to access mental health services, they are not right for them, and they feel as though they are somehow responsible for treatment not working when it is not adapted to their needs. That can lead to feelings of hopelessness, helplessness and a feeling that perhaps they cannot be helped or they are not worthy of seeking help. That compounds mental health difficulties.

We found from our research an outcome that all these issues can come together in a perfect storm and increase the risk of suicidal thoughts and behaviours. Studies have shown consistently, across both diagnosed and undiagnosed autistic people, that approximately 35% of autistic people will contemplate suicide at some point and 24% will attempt suicide, which is significantly higher than the general population. That figure is from a systematic review of all available studies worldwide. We have also found that many people who die from suicide are autistic. In a recent study where we looked at coroners' inquest records of those who died by suicide and talked to their friends and families, we found that 41% of those who died in two regions of the UK either had diagnosed autism or,

for most of them, evidence of undiagnosed autism; many of those individuals were on the waiting list for referral for being assessed for autism.

Tom Purser: I am the chief executive of Autism Action. We are an evidence-led charity that seeks to turn insight into action to improve autistic people's lives. I want to build briefly on one of Dr Cassidy's points around suicide and the impact that we see on autistic people's lives. As she set out, research establishes this elevated risk, and the incidence of suicide is seen very commonly. We also see it in official statistics gathered by the Government. These data insights are not brought together to give a consistent view of suicide among autistic people, even though they are remarkably consistent between these different pieces of data collection.

The National Child Mortality Database has identified that, for children without a learning disability, suicide or deliberate self-inflicted harm is the number one cause of death. The National Confidential Inquiry into Suicide and Safety in Mental Health has identified that suicide is a significant factor in the deaths of autistic people. The Learning from Lives and Deaths Review of people with a learning disability and autistic people—LeDeR; you will hear from André Strydom in the following session—also identifies suicide, misadventure or accidental death as a significant cause of death for autistic people.

My colleagues set out the big picture around mental health. We see in the data that suicide is the most egregious and extreme impact of poor mental health and a lack of support, but that is not being brought together and we are not seeing enough action from the Government to understand why this is so and what to do about it. We have funded some research, which Dr Cassidy touched on, conducted by Dr Rachel Moseley at Bournemouth University, which bore out some of the reasons that motivate autistic people to experience suicidality at a higher rate: hopelessness; loneliness; feelings of worthlessness or failure; mental illness; and, significantly, an inability to access help. They were the most significant factors that people reported in driving suicidal thoughts.

Q37 **Lord Scriven:** I should declare my interest as this is the first time I have spoken. I am the Front-Bench health spokesperson for the Liberal Democrat group in the House of Lords. Thank you very much for those answers. What has been the influence of the Autism Act 2009, the statutory guidance and successive Governments' autism strategies in improving access to mental health care for autistic people? When you give your answers, could you incorporate why they have been influential—or not—as well as how the Autism Act and other levers could be used more effectively to improve access to mental health care for autistic people? Shall we go down the line the other way this time, starting with Tom, then Sarah and then Ailsa?

Tom Purser: I will make two points to set some context. First, the language in the Autism Act is quite important in this regard. It says that the purpose of the Act is to improve "the provision of relevant services"

for adults. There is an extremely important lens for the committee to think about in asking these questions: have the Autism Act, the statutory guidance and the strategy led to a direct improvement in the provision of relevant services?

Secondly, is it possible to answer that question? To do so, you would have to know what the provision of services was like in 2009. I believe very strongly that there has been a failure across the 15 years of the Autism Act to set appropriate benchmarks; to put in place robust monitoring; and to measure progress in regard to that question around the provision of services. That applies to mental health services, but it will apply to every other issue that is examined. In many respects, this question is extremely difficult to answer because what are you measuring against? That is an almost fundamental failure of the last 15 years of policy around the Autism Act.

To pick up a specific point, I will give a short quote from the 2015 statutory guidance, which is relevant to mental health services. It says that NHS bodies and NHS foundation trusts should: "Ensure that health and care staff who are highly likely to support people with autism, such as GPs, psychiatrists, counsellors and psychiatric nurses are appropriately trained beyond general basic awareness about autism". That goes beyond the Oliver McGowan training, for example. It also says that they should: "Ensure that people with autism"—that is its language—"have equal access to local psychological therapy services", and that, if local services cannot help, "arrangements should be made" so that others can provide support.

My point in mentioning this is that probably all of us around this table, as well as many other witnesses you will hear from, would support the language of the statutory guidance and of much of the autism strategy; it is good. The problem is not the policy or the language contained in the documents. The problem is the application of those policies, and the biggest issue we face—this goes back to my earlier point—is a lack of measurement, appropriate baselining and accountability for following through with what these quite reasonable documents say. We should bear in mind that the Autism Act was passed under a Labour Government; that the first autism strategy was passed under the coalition Government; that the second such strategy was passed under a Conservative Government; and that, now, we have a Labour Government who are looking at policy. This is a cross-party issue where there is a huge amount of agreement on the policy itself, so the issue is in its application.

There are many reasons for this lack of application. It would be helpful for the committee to think about some of the mechanisms that could be reintroduced in future to ensure that future strategies are being held to account and appropriately monitored, and that there is accountability for their delivery. For example, the self-assessment exercise had its flaws, but it was the closest we have had to a monitoring exercise since 2018. There has been no place where the data is pulled together from sources

beyond that, for example, with suicide, to look at what can be learned. As we will come to later, with the sixth question, there are other huge scandals and extremely poor experiences—up to and including death by suicide and other means—where lessons have not been learned, despite the fact that the mechanisms have been established or should be there to make sure that it is happening.

To return to the question, as far as we know, the Autism Act and subsequent strategies have not been as influential as they should have been. We still hear about an extremely broad range of experiences in people's engagement with the mental health system. It is sometimes "reasonable" but mostly "poor" to "very poor". There is a need to think about how that can be prevented in future through the structures of delivery that sit around strategies. Sadly, I have to mention that funding—specific funding to deliver specific pieces of intervention and support that autistic people can come to rely on—is one of those factors. As it stands, we have had 15 years of challenging financial environments, in particular at the local authority level, which have made it extremely difficult for many of these provisions to be followed through.

As a final point, the autism statutory guidance and secondary legislation do not necessarily confer individual rights, but I do not believe that we have seen a single legal challenge brought under the statutory guidance. Now, that is not perhaps a matter for you all to make happen, but it is incumbent on organisations such as ours to think about how we are using the fact that there is legislation saying that certain things should happen to ensure that those things are happening. I, for one, would love to see a robust legal challenge brought that brings out many of the flaws, challenges and difficulties that autistic people face because of the failure to follow the autism statutory guidance.

Dr Sarah Cassidy: Just to add to what Tom said, I agree; the research evidence shows it. A number of recent studies have shown that, despite having the Autism Act in 2009, all these years later, autistic people, adults and young people are still describing difficulties in accessing mental health support and having reasonable adjustments made, such as reducing sensory overwhelm by having a quiet room in which to have an assessment or having time to process information. All of these guidelines have been made available by multiple charities and have been well known for years, but many autistic people are still saying that they are not being offered, for instance, some other way to make a mental health appointment aside from using the phone. I have seen lots of guidance that has said many different things, from the Royal College of Psychiatrists, GPs, the National Autistic Society and others—as well as from research groups in our research—but it does not seem to be worming its way into practice and being implemented, as Tom said.

Professor Ailsa Russell: I do not have a great deal to add except to say that things have obviously improved in that, when I previously worked clinically, before the Act, autism was sometimes a diagnosis of exclusion—for example, for psychological therapy services. That is no

longer the case but what is problematic, as has been described, is that services have not been given the tools or additional funding to deliver something different to what they ordinarily do when it is needed. Many providers have not been supported to do that despite being very willing to do so and interested in doing so; their structures constrain their ability to make adjustments, for example. Even with that simple example of having to make an appointment by phone call, it is difficult to shift the wheel on what seem like small changes but may make a big difference.

Q38 Lord Crisp: I am going to shift focus to a specific set of services. If I may, I am going to reverse the order and go to Professor Ailsa Russell first, then to Dr Cassidy and Tom Purser. How well do primary and community mental health services identify and address autistic people's needs, and what would be the best way to improve this? I will throw in a supplementary at the same time: when you are describing how well they do it, can you describe how that compares with other people's experience?

Professor Ailsa Russell: I do not think I can do that because we do not know how well they do it in comparison to a general baseline. That is partly because we do not know how many autistic people are accessing services. Sometimes it is because it is not captured in the recording system or they do not have a diagnosis. Although they may be an undiagnosed autistic person, they may be sitting on a very long waiting list waiting for that diagnosis, so they do not get captured and recorded; it is therefore hard for us to pull the data together and know. So I cannot really answer the question of how well primary and community mental health services are identifying and addressing autistic people's needs.

What we do know about is some things that might help them. For example, validated assessment tools to screen and assess mental health problems, which exist for other populations—for example, people with intellectual disability—do not exist for autistic people or have not been developed with them in mind. Some of the things that would really help services, such as training and support, are not routinely available or have not been built into the standard core curriculum. The sorts of tools that have been tried in research studies and can be very helpful, such as telementoring from specialist teams or making training routinely available, just have not been put in place for the NHS.

Dr Sarah Cassidy: I agree but I would add that, as I said before, many autistic people are coming for mental health help before they are even aware that they might be autistic. They may have been struggling for a very long time in lots of different areas, and the first time they come to services may be with a mental health problem. Lots of autistic people can be diagnosed with autism while under the care of mental health services but it is really tricky because, as Ailsa was saying, there is a lack of training. There is a particular lack of training among psychiatrists in diagnosing autism and developmental conditions because mental health research and developmental research have historically been very separate. That is one issue. Another issue when encountering services is

not having specialised support that is aware of autism and able to adapt quickly and efficiently to people's needs.

Tom Purser: I agree with Sarah and Ailsa. I would add one area where we have a few figures. The last self-assessment exercise, in 2018, asked local areas to report whether autistic people or their carers reported difficulty in accessing local mental health services after their diagnosis had been made. Some 74% of responding authorities said that that was the case, so the majority of local authorities were reporting that people were finding it difficult to access mental health services. A 2020 National Autistic Society report said that 58% of autistic adults needed counselling but less than half—21%—were actually accessing it. So there is an assumed gap in the numbers that we see.

On the point that Professor Russell made around training not being an established thing, we are 10 years on from the extract I read from the statutory guidance. So it has been the law for 10 years that everyone in the mental health system and supporting autistic people should have training beyond general awareness but, clearly, that is not the case; again, this supports my point about the lack of enforcement of the law.

Lord Wigley: Professor Russell, you said that validated assessment tools have not been developed. Is it that there are assessment tools that have not been validated? How does that compare internationally?

Professor Ailsa Russell: Many services use routine screening as a rapid and efficient way to detect mental health problems, for example, and those self-report questionnaires have not been developed with autistic people in mind. Some have been studied and investigated but they pose problems; the literal understanding of language, for example, may mean that some of the items really do not make that much sense. For example, people are asked, "How much have you been feeling down in the past week?", on a depression measure, with "Not at all" or "On a few days" as options. Many autistic people might struggle because it may have been on one day or two days, which is not "a few" and not "not at all".

So, even on this item level, with the measures that routinely detect mental health problems when people come forward to their GP or to a psychological therapy service in primary care, which is the first place they might get picked up, the measures that are routinely used are not really fit for autistic people. There has been a lot of effort from researchers to try to find out how good or bad they are. There have been efforts to make some specific measures for anxiety, for example, but these things are not then built in to be routinely used in the kinds of primary care mental health services where people generally get picked up, if that makes sense.

Q39 **Lord Hope of Craighead:** How effectively do acute mental health services and hospitals identify and address autistic people's needs? What would be the best way to improve this? By way of background, we have information that autistic patients still experience harm in mental health settings. The setting itself can be noisy, crowded and so on, but there is

also information that there is a resort to long-term seclusion for long periods and that physical or chemical restraint is used on many occasions—routinely rather than as a last resort. This is something we need to explore. Dr Cassidy, can you begin by exploring these problems in your answer?

Dr Sarah Cassidy: Absolutely. Autistic people are more likely to be detained for very long periods, as you said. Research that has explored this has shown that a big reason for that is that hospitals do not cater to the needs of autistic people; they are very overwhelming.

Lord Hope of Craighead: Just to interrupt you, where they resort to these measures, have the people been diagnosed as autistic, or is there a defect there in that they do not know they are autistic?

Dr Sarah Cassidy: It is probably both. My first point was going to be that, as I said before, there are many undiagnosed autistic people, including people who might not know that they are possibly on the spectrum and those who might suspect that they are autistic but have not yet got a diagnosis. Studies have looked at the rate of diagnosed and undiagnosed autism in in-patient settings. A recent systematic review reviewed studies that had gone into these in-patient mental health units, screened everybody for possible autism diagnosis and did a full assessment. Across those studies, approximately 10% of people in those settings could meet the criteria for undiagnosed autism.

Undiagnosed autism is absolutely overrepresented in in-patient mental health settings. Again, it is not just those who are diagnosed; there might also be undiagnosed autistic people whose needs are not being met by the hospital or in-patient environment. There is a lot of sensory overwhelm and perhaps a lack of ability either to adjust treatments or to take into account different ways of interpreting information. As Professor Russell said about the assessments, people may be seen as not conforming or not engaging with the therapy.

In response to that increased distress, there is a snowballing effect of increased restrictive practices and increased difficulty in being able to adjust or course correct to get people out of that snowballing of increasing restrictive practices. Sometimes there could be a legal challenge: "We have to get this person out of detention because this is illegal", and they have been in the in-patient hospital for 20 years. However, a community place might not be able to be found to meet that person's needs because the escalation of distress and behaviours in hospital is such that their needs cannot be met in the community. Sometimes transitions are rushed without a proper transition plan, then placements break down. There is then a revolving door effect of people coming back into in-patient mental health care.

Unfortunately, the Government have had a target of trying to reduce the number of in-patient long-term detentions but, if anything, that has gone up for autistic people over the years, not down. This is a very long-standing issue. An important way to try to address this is through

increased funding and training to ensure that, first, autistic people are not inappropriately detained in mental health institutions where mental health problems are not the primary need. It is perhaps a failure of community settings not being able to meet the needs of autistic people.

We need more places with the appropriate training and environments to care for and support autistic people in the community to live their best lives. We also need to ensure that, when they do need to go to hospital, autistic individuals who encounter mental health difficulties do not experience this snowballing effect; and that they have access to therapeutic interventions that are adapted to their needs. At the moment, long-term segregation has no therapeutic benefit whatever. It compounds mental health difficulties and leads to a never-ending cycle of distress.

Lord Hope of Craighead: Thank you for that very interesting answer.

Tom Purser: I will build on that with a few small points. As you are aware, the Mental Health Bill is making its way through Committee now. The key part of this—to broaden out to the question on the ways to improve things—is that the sufficiency duty on community services must be as proactive and broad as possible. The Government need to implement a programme of work that will meet this issue of wider community support in order to stop this conveyor belt, which Sarah just described, of people moving from one place to another and things breaking down, or one thing responding and reacting to the other and ending in long-term detention.

When I was at the National Autistic Society, we ran a helpline for people who were detained in mental health services. The majority of those who contacted the helpline had not had a Care and Treatment Review, which they should have had under the law; they were not on a Dynamic Support Register, as they should be under the law; and they were not accessing advocacy services. Again, we see good laws not being put into effect.

Lord Hope of Craighead: Had they been diagnosed as autistic persons?

Tom Purser: Again, it was a mixed picture, as Sarah described: some were and some were not. Some were going through the system of people trying to take their diagnosis away, saying, "Actually, you're not autistic. We think you have borderline personality disorder", for example. Individuals would have lots of fights about that, which, again, did not lead to improved outcomes and had no therapeutic benefit for people.

The last point is that there is not enough imagination in the commissioning of services that can help break that conveyor belt and cycle that Sarah described. Crash-pad services, particularly for autistic people with a learning disability, can be critical, when a placement has broken down in social care, in stopping a person going into in-patient care and getting stuck there. There are some really good innovative crash-pad services being commissioned; one in the Black Country is a great example that is really worth looking in terms of how it is stopping

that conveyor belt.

Professor Ailsa Russell: I do not have anything to add to those two answers.

Lord Hope of Craighead: That is a tribute to the other two witnesses for being so comprehensive in their answers.

Q40 **Baroness Goudie:** Thank you very much for coming to see us today. How effective are common mental health interventions for autistic people? How could they be improved?

Professor Ailsa Russell: I will start, if that is okay. We know from clinical trials and some routine service data that talking therapies for common mental health interventions can be effective for autistic people, particularly if they are adapted to meet their needs. If the therapist tailors their approach and works in a more individualised, neuro-affirming way, the standard interventions can be effective and can help people achieve their goals and suffer less from things such as disabling anxiety and depression.

On the second part of your question about what we could do to improve this, I may sound like a stuck record but it is about training. In standard psychological therapy training, there is nothing specifically to do with autism included in the curriculum. It is up to individual courses to decide whether they will accommodate or do something about that. It would be great if funding, room and space were made available in the core curricula for psychological therapists to have that training as part and parcel of what they are training to do.

How should services organise themselves? It is hard for them, with the way services are commissioned, to make room and space for the adaptations that are suitable for autistic people. For example, they need to be able to be more flexible in how they offer appointments and how many appointments they can offer. They may need flexibility to offer slightly longer treatment episodes than the standard episodes of care, which is what many autistic people need. They need to be able to do things a bit differently and offer autistic people choice, because it is not "one size fits all" when it comes to making adaptations to psychological therapies to meet the needs of autistic people. The talking therapy services offer a particular model of therapy but there is also emerging evidence from research that other ways of working, such as mindfulness, can also be helpful; however, that is not often routinely available. We need to be able to give people a bit more choice, rather than trying to get them to fit into the model that is on offer.

Dr Sarah Cassidy: I agree with Professor Russell. My research relates mostly to suicide prevention. In that regard, a lot of the same suggestions apply. Autism-adaptive safety plans have been created, are starting to be taken up by the NHS and have been recommended as an intervention to consider in the suicide prevention strategy recently published by the Department of Health and Social Care.

Again, we see the need to be flexible and to allow more time. Safety plans are a good practical example of that. The original safety plan was designed to be done very quickly in a variety of settings with minimal training whereas, in our autism-adaptive safety plans, we are finding that professionals, practitioners and supporters—whoever it might be—need training in how to make the communicative adaptations to a traditional safety plan to ensure that autistic people can understand and engage with its elements and complete it. In our research, and in others' too, we found that safety plans are widely used and well evidenced, including with autistic people, but that clinicians lack the confidence to make the adjustments needed to complete these types of interventions.

In addition to that, autistic people need more time, including more prep time. Parts of the intervention should be shared with them before the first appointment so that they know what to expect and can develop trust and rapport with the person they are working with. There should perhaps be some pre-work if the autistic person finds it difficult to describe their own internal warning signs, as this is a key component of a safety plan: "What are your warning signs that you are approaching crisis?" That can be really tricky; the person might need lots of support to identify it. We hear this a lot: "I don't know when I'm approaching crisis. It just happens".

We need all of these elements and more time. We found in our research that autistic people needed about three sessions of about 30 minutes each to complete the safety plan fully. When it was done, they used it, and many of them found it really usable and quite useful. Although making these adjustments can take more time, effort and training, they can make a huge difference and potentially save lives.

Tom Purser: To reiterate my earlier point, the need for training and some creativity and choice beyond simply talking therapies, which Professor Russell talked about, already has its basis in the statutory guidance—in the extract that I read out. That is already policy and the law so, again, this question applies: if that is the case, why is that not happening? Failing to get to grips with that question is at the heart of the lack of progress.

Secondly, although this is perhaps not a clinical mental health intervention, there is no autism-specific crisis helpline, telephone or text service in the UK. We see wonderful work being done by mental health charities, including Samaritans, Papyrus and many others, but no one offers an autism-specific version—or even an autism-adapted or trained version—of that service. Through some of our research, we are seeing a wish for something that could be accessed quickly and easily through a variety of methods, including by telephone, text message, et cetera. It is a real gap that needs filling. My charity is working on that and looking at how we can support charities to adapt what they are doing but, critically, there is no current strategic approach across the country to think about how that gap could be filled.

Baroness Goudie: That is amazing and surprising, given the figures we know and so on.

Q41 **Lord Addington:** Hello. I am the president of the British Dyslexia Association; I also deal with SEN in my Front-Bench duties. To what extent do mental health services learn from autistic people's experiences and from any failures to meet autistic people's needs? How could this be improved? You have covered some of this but going over it again would not hurt. Tom, would you like to start?

Tom Purser: I will speak broadly, rather than on an individual service level, because there is not really a policy that approaches how individual services should learn lessons; perhaps my colleagues will pick up on that point. Nationally, we see a culture of defensiveness and circling wagons when something goes wrong. Often, bereaved families take many years even to get to the inquest level, where lessons can be learned from the death of a loved one.

Those inquests can become quite difficult when state services do not take the opportunity to learn from what has gone wrong but try to defend and to stop that inquest becoming an Article 2 inquest. Where it does so, they might try to avoid what is known as a report to prevent future deaths being produced by the coroner. There is a culture of using opportunities where something has gone wrong not to identify what changes can be made but to protect reputation and to safeguard, perhaps, the good name of services, rather than learning what could be done differently.

I have personally overheard, at an inquest, a lawyer for the state in a car park delivering the good news to the organisation they were representing that the outcome of that inquest would be limited. These processes are being perverted to avoid lessons being learned. There are many processes in place but, as I said earlier, the data and outcomes from them are not being brought together and looked at across the whole picture.

Often, the Reports to Prevent Future Deaths are not responded to by the variety of local, regional and national organisations that are arms of the state, where recommendations are made for changes. Sometimes, the reports do not even receive a response. The Chief Coroner recently wrote to a huge number that had not responded and published their names in an effort to shame them into responding; that is the step she felt she had to take. There is no proper oversight mechanism to identify common themes from inquests and from prevention of future deaths reports. We feel very strongly that more can be learned from looking at the ultimate cases of when something goes wrong.

I mentioned LeDeR earlier, which you will hear more about. It is a critical way for lessons to be learned from the deaths of autistic people and people with a learning disability, but, unfortunately, a very small number of cases are going through it; it is a very small piece of the picture. Unfortunately, the reports seem to be delayed more and more every year. They are supposed to be annual. The previous report was in November; we are now almost in April and we have not had the subsequent ones. That is quite a delay. We have heard that services engaging with the completion of that data have been deprioritised within

the NHS. We are deeply concerned that the importance of engaging with that process of learning from deaths is not being taken seriously.

I should also mention the Lampard inquiry. For those who do not know, it is the UK's first statutory inquiry into in-patient mental health services. It is looking at more than 2,000 deaths over a period of 24 years in Essex. We have no reason to believe that Essex is an outlier at all, but it is critical that this thorough inquiry is used appropriately to ask questions around autism and the deaths of autistic people in in-patient care; that recommendations are appropriately made as to what needs to change; and that, crucially, the Government listen to the outcome of the inquiry. My charity has been working with the inquiry to ensure that the question of autistic people's experiences is appropriately heard.

The final point I want to make is on the national confidential inquiry that I mentioned, which has great data collection around deaths by suicide. It is relatively narrow in its scope; it looks only at deaths of people who were in contact with mental health services in the year prior to their death. As we have heard, many autistic people fall out of the system—they stop seeking help; they try once then they give up on it—so we think that there would be an opportunity to broaden the commissioning of the inquiry for the deaths of autistic people, in order to expand the lessons that could be learned there.

Dr Sarah Cassidy: I agree with everything that Tom said. I would just add that, again, we need to consider both diagnosed and undiagnosed autistic people in these various reviews and in learning about mental health services from autistic people's experiences.

Lord Addington: You have said that several times. Do you think that there should be a capacity, or an ability, to refer through as normal here? Is there any capacity in the system to diagnose somebody at the current time, or any process by which you could at least get to, "We suspect they are", but with some authority?

Dr Sarah Cassidy: That is a really important point. There is a big issue with wait-lists for diagnosis. A lot of people have been referred but are on wait-lists for many years before being diagnosed. That is a big issue that needs to be addressed. One way of doing that—this is why I keep bringing up undiagnosed autistic people—is that there are going to be a lot of people on these wait-lists who are possibly undiagnosed autistic people. We know how many people are on these wait-lists, so we know who could possibly be undiagnosed autistic. For instance, in the psychological autopsy study that I mentioned at the beginning, where we looked at coroners' inquest records and talked to the next of kin of those who died by suicide, many of those whom we identified with possible undiagnosed autism had been referred for an autism diagnosis and were on a wait-list but, unfortunately—very sadly and tragically—they died before their diagnostic appointment.

Q42 **Lord Addington:** The second part of that question is the fact that you are still dependent on the formal diagnosis. There is no way of saying,

“Strong possibility. We haven’t had the formal diagnosis. Please enact certain strategies”. There does not seem to be that, from what you are saying.

Dr Sarah Cassidy: Not at the moment. One way you might be able to do that, aside from looking at wait-lists, for people referred for diagnosis—it is something that we use in our research, actually—is to ask people whether they suspect that they might be on the autism spectrum. Another way of doing it is to screen people. There are validated autism screening measures, some of which are very brief and do not require any training to be completed, that could be done by a GP, for instance. Those could be made available to identify people. There are quite a few different routes that could be utilised. If we trained psychiatrists in developmental conditions, we could equip them with those tools to screen people who come into mental health services. We could also give training to identify some key signs so, if a clinician meets somebody who they think has high autistic traits or might have undiagnosed autism, they could adjust their treatment and support for that person on that basis. Training is another route that we have talked about quite a bit.

Another thing that we have identified, not just from our priority setting exercises but from others, concerns where we work in partnership with autistic people to try to come up with practical suggestions on how to deal with these issues. One thing that the autism community suggested was developing research and clinical partnerships with autistic people and services, with funding, to tackle this issue. What would be the best way, from the perspective of the community, those who support them and services, to identify undiagnosed autistic people? Is it through training? Could it be through autism screening across services? What would work for commissioners and those whom they support? There is some work to be done in relation to that.

Professor Ailsa Russell: I am not sure that this will answer your question directly but I want to raise it before we draw to a close. It is to do with young people, in that transition from being an adolescent to moving into adulthood, and their mental health. I have met many young people making that move, particularly at university, who have been well supported by children’s mental health services and educational services. They make that move to independent living and perhaps find that the adult mental health service has a very different structure and organisation and is not well placed to help them make a successful transition to independent living and adult life. My clinical experience has often been that that can be a time when young adults’ mental health is exacerbated; it sets them up for a quite difficult longer-term picture. They may drop out of university and may not carry on making the kind of progress that they could make and want to make.

Lord Addington: So would you agree on the defensiveness of the current system and the fact that it does not learn quickly?

Professor Ailsa Russell: I am not sure that it is learning from young people who are trying to make that move. As I said, I cannot answer

your question directly, but I think that it would be good to hear from young people who have had to try to make the shift from child services to adult services, which are very different models of support.

Tom Purser: Your question is the right question: is the system set up correctly if we are expecting people to sit on a waiting list for three years before they get any support? That very much seems to be the wrong way round. Can we start with what immediate needs they have and think creatively about how to meet them, rather than sitting them on a huge NHS waiting list for many years?

Lord Addington: I will take that as a win.

The Chair: I thank our three witnesses very much. We have covered a lot of ground in some very difficult areas, so I am very grateful to all of you for your input and your thoughts. We will send the transcript to you to check for accuracy. With that, I draw our discussion to a close; we will continue with our second evidence panel in a moment.