



Autism Act 2009 Committee

Corrected oral evidence

Thursday 24 April 2025

10.20 am

Watch the meeting

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

Evidence Session No. 8

Heard in Public

Questions 52 - 59

Witnesses

[I](#): Virginia Bovell OBE, founding parent of Tree House School, co-founder of Ambitious about Autism, and ex-trustee at the National Autistic Society; Paula McGowan OBE, founder, Oliver McGowan mandatory training on learning disability and autism; Dr Rachel Moseley, Principal Academic in Psychology, University of Bournemouth.



Examination of witnesses

Virginia Bovell, Paula McGowan and Dr Rachel Moseley.

The Chair: Good morning. Welcome to this public meeting of the House of Lords Committee on the Autism Act 2009, which has been appointed both 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 reducing health inequalities and building support in the community for autistic people.

We are absolutely delighted to be joined by today's witnesses: Paula McGowan OBE, the founder of the Oliver McGowan mandatory training on learning disability and autism, who is joining us remotely; Dr Virginia Bovell OBE, a former trustee of the National Autistic Society, a founding parent of the Tree House school and a co-founder of Ambitious about Autism, who is joining us in person; and Dr Rachel Moseley, the principal academic in psychology at Bournemouth University, who is also joining us in person. You are all extremely welcome, and I thank you for coming to today's session.

We will continue to hear oral evidence on Monday afternoons most weeks while Parliament is sitting, until July. We also published a call for evidence on World Autism Acceptance Day on 2 April; this is available on the committee's website and is open until 2 June to anyone who is able to respond.

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 to 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 is published on the committee's website.

Following that introduction, Lord Addington will ask the first question. When you answer, please introduce yourselves briefly.

Q52 **Lord Addington:** Hello. First, I have a declaration of interests: I am the president of the British Dyslexia Association and I cover special educational needs for the Liberal Democrats in the House of Lords. The question is—we might be here a while—can you introduce yourselves and tell us both about your experiences and why you advocate for better healthcare and care services for autistic people? Let us start with Paula McGowan and then go to Virginia Bovell, finishing with Rachel Moseley.

Paula McGowan: I will keep my comments brief. I am the mum of this beautiful teenage boy behind me. We were a normal family living a very average military life. Unfortunately, Oliver went into hospital in 2016



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because he was having seizures. We feel strongly that, because his autism and learning disabilities were not understood, he was prescribed medication that he did not want, did not need and should never have been prescribed. Oliver lost his life.

Obviously, I felt that it was so wrong for people like Oliver, but also for our health and social care, for there to be no real training in understanding autistic people, especially those who are compromised due to their healthcare needs. As a consequence, I launched Oliver's campaign, which led to the Oliver McGowan mandatory training on learning disability and autism. The training is for all regulated Care Quality Commission staff.

I continue to advocate for autistic people and those with a learning disability, especially regarding the inequalities in health and social care needs. I speak at many different conferences, highlighting how to make reasonable adjustments. My daytime job is teaching children and working with children who have additional needs. I could go on for a long time; I will stop there. Thank you.

Virginia Bovell: Thank you all for being here and being interested in autism. I am the mother of a 31 year-old man who has what I would call autism plus. Like Paula's son, my son has additional health needs. He has an additional, quite profound learning disability, and throughout his childhood and adolescence he was plagued by very severe gastrointestinal problems, which, not tragically, as in Paula's case, but none the less unfortunately, delayed the treatment that he should have had.

There are two things to say about those with autism plus—those with additional health problems. First, there is diagnostic overshadowing. His behaviour was challenging, he was self-injurious, and he screamed, cried and attacked me when he was in terrible pain. That was attributed to, "Well, he's autistic and has a learning disability. That is what we expect". It was very hard to convince the medical profession that there was something other than just being autistic—that he was in real pain.

So, there is diagnostic overshadowing—when everything is attributed to something that is not the cause of a behaviour. Secondly, it led to undertreatment. In his case, it took ages and ages to convince that he

1. Note from witness: Fabricated and Induced Illness (FII), formerly known as Munchausen's Syndrome by Proxy (MSbP) is also known as Factitious Disorder Imposed on Another (FDIA). Fabricated or Induced Illness is regarded in the UK as a form of child abuse and is a child safeguarding issue. See <https://www.nhs.uk/mental-health/conditions/fabricated-or-induced-illness/overview/>.



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needed major bowel surgery, and he has a stoma now. That was delayed and delayed until adulthood. Linked to that is that some parents are accused of Fabricated and Induced Illness for their autistic and learning-disabled children¹. When I suggested that he have a stoma, I felt that I was under suspicion—that somehow I wanted him to go through treatment.

It is for all those reasons that I advocate, but he has had a really good outcome in that we, unlike Paula, have been really lucky. We finally reached the right people, and, despite all his problems, we have had a good outcome, and that is what inspires me to go on advocating. I chair a group of family carers in north London, and we are all trying to make a difference. That is probably enough said.

Dr Rachel Moseley: Hello, I am principal academic in psychology at Bournemouth University. My research focuses on health and well-being in autistic people, specifically mental health and suicidality, as well as the experience of late-diagnosed people and women as they transfer through lifespan transitions. I am also autistic, diagnosed when I was almost 30.

I was the child who was naughty, spoilt, disobedient, rude and fussy, according to the adults around me, and the child whose peers did not want to stand next to in line, as though I might contaminate them. My primary school teachers told my mother that there was no point teaching me maths, because I would never go round a shop by myself. I did not have a diagnosis at that point, but that was that: case closed.

By the time I was a teenager, I had joined the many autistic-diagnosed and undiagnosed people who go round and round the NHS with mental illness and suicidality. Nothing really helped, but my family kept me safe from one crisis to the next. In my early 20s, with anorexia, a doctor once told me about all the NHS resources I was using up because I was failing to get better. That was very unfortunate because I was painfully aware of being a treatment failure and a burden, which is a mental state that we researchers have linked to suicide in autistic people.

I am so interested in health and social care for autistic people because so many of us do not receive appropriate treatment for mental illnesses, or indeed physical illnesses. In my case, I used up my allotted time as an NHS outpatient without getting better. I was still harmfully underweight with osteopenia and no periods, but no longer at death's door. I was discharged to nothing—nothing at all, except my family, who kept me alive for years while I was extremely ill.

It is really important to say that I am so lucky. Suicide has touched the life of every autistic person I know. I could easily have never met my partner and my closest friends. For most of us, it has been our families that have stood between us and that terrible outcome. One 2015 UK study called parents “care co-ordinators” and “life supporters” for autistic people in the absence of state support. They are our heroes and our champions.



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I am advocating today because autistic people live shorter lives in poorer health, with suicide a leading cause of death. I am here today because my family have saved my life again and again when systems failed or gave up. Many are not here because they did not have this blessing. I hope to share personal experiences at a micro level, but also at a macro level, based on recent research with over 4,000 autistic people in the UK. Thank you.

Q53 **Baroness Ritchie of Downpatrick:** You are all very welcome; thank you for your evidence so far. Since the Autism Act 2009 was passed, how have health and care services for autistic people changed? Why have they improved or not improved? Let us go to Virginia first, then Paula, then Rachel.

Virginia Bovell: I will try to keep it as brief as I can. It is important to distinguish between changes that have happened that are nothing to do with the Act and those that are. We all know about austerity and Covid, and that demands on the NHS and social care are rising because of demographic changes and staff shortages, possibly due to restrictions on those from overseas who can fill massive gaps. In a way, the whole nation is facing some problems with health and social care services, so it is not surprising that things have perhaps not improved as much as those who passed the Act were aspiring to, and thought might happen. In addition, since the Act, there has been the change in the diagnostic criteria, which may have increased the number of those seeking a diagnosis. There has been greater identification, which of course puts pressure on diagnostic and then support services.

There are all these things, but there are also improvements, and it is really important to state them. The first is the Oliver McGowan training. Paula, I am utterly in awe of you and what you, and Oliver, through his terrible death, have done to improve things; it is amazing. When I was campaigning, year after year we talked about training, asking, "Please give everyone more autism training". I did not succeed, nor did my colleagues, but Paula and Oliver did, so I say massive thanks for that.

Another real change is that more able and articulate autistic people are claiming the territory—including you, Rachel. That is fantastic. It is really important that autistic people have more of a voice and more of a presence, and that they can talk from their own expertise and experience. In the wider environment, this is spilling over. There are more autism-friendly screenings in cinemas. Some low-arousal shopping times have been made available. These are improvements. The Act really drove raising awareness and making all sorts of institutions think about what they could be doing better.

I am afraid, though, that I need to say what has not improved. For a start, it is about people and institutions. I will talk about the institutions first. Take the transition to adult services, for example. You get people who are specialists in children's services, and you get people who are specialists in adult services, but, for families and individuals going



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through that change, it is almost like you have to go back to square one. It is not just the people; it is the legislative framework. The entitlement to support can change. I hear many stories from colleagues of children whose parents are getting respite and packages of care, then, suddenly, you go into adulthood and there is very little social care support. That is compounded by eligibility criteria.

I am going to give you the example of a family I know—that of a young man with autism plus. He has intellectually moderate learning difficulties, in the old language, but he got his GCSEs. He also has ADHD. He has been well cared for under CAMHS (that is not always the case, I have to say). His ADHD medication needs upping because he has bulked up, now that he is in young adulthood, but he is no longer eligible for CAMHS or the learning disability specialist psychiatrist, who could prescribe an increase in medication. The core psychiatric teams say that they do not deal with ADHD, and there is a waiting list of three years to access the adult ADHD service. His GP does not feel able to up the dose. The only alternative is to go private, but that might cost £4,000 for a reassessment. You could argue that, without the extra medical help, this young man, who probably needs just a small increase, is at risk of entering the criminal justice system and/or failing some exams that could make him eligible for employment in the long term. This one common-sense failure in the system may have major knock-on consequences.

I suppose what I am saying is that eligibility criteria are useful if they are there to guide people into the right specialism—as we know, autism is such a broad spectrum; different people will need very different types of help—but they are not helpful when they shut people out. We need some common sense under the auspices of, I would say, Equalities legislation². Let us make Reasonable Adjustments and use the equalities legislation to say, “Look, sometimes these criteria are really unhelpful. Can you bend the rules? Let’s just get this young man a bit more of what he needs in his ADHD medication”.

I could go on at great length about all of this, but I should probably postpone until later some of the rest of what I want to say and let other people have a chance to say something.

Paula McGowan: I will give you my controlled answer first, then my answer that comes from the heart. It comes in two parts because, today, I have been looking through a lot of information. I have made a lot of notes. I did more and more research and I became, if I am honest, a bit cross; I then became a bit more cross as the day went on. So I will give you the controlled version, shall we say, first.

2. Note from witness: Equality Act 2010. London: The Stationery Office, available from:

<http://legislation.gov.uk/ukpga/2010/15/contents>.



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We all agree, I think, that the Autism Act 2009 was a real landmark moment, was it not? It was the first law of its kind. It recognised the specific needs of autistic people and gave them, their families and their carers real hope that this was the real start of real change. In some areas, we have seen real change. We now see better awareness of autism; it is not enough, but it is a bit better. We have seen the introduction of national strategies aimed at improving diagnosis and support, as Virginia said exactly.

However, let us be honest: awareness alone does not save lives, does it? It does not improve lives. Understanding, action and accountability do. In reality, the progress has been too slow. It is patchy, and it is definitely inconsistent. Too often, services are shaped around what suits the system. It is not about what autistic people need; it is about the system and what works best for it. Oliver was failed dreadfully because the professionals around him absolutely did not understand how his autism presented when he was having seizures and in a setting that he was not familiar with. They were not familiar with how his autism affected his health or how to communicate effectively with him when he was compromised.

I know from the work I do that, in terms of what happened to Oliver and to us, we are far from alone. So many families share similar stories with me. One of the biggest issues is definitely the lack of training. For me, it has to be designed by autistic people; Oliver's training is for those with a learning disability as well. It must be designed by these communities. We have to learn directly from them what works for them and what does not. It is ludicrous that that is not always the case and has not been the case previously. In the decade since the Autism Act was passed, healthcare professionals have been able to go their entire careers without receiving any training on autism, which is exactly one of the reasons why I have fought so hard to introduce the Oliver McGowan mandatory training on learning disability and autism. We all know that we have an absolutely long way to go in reducing diagnostic waiting times, improving support after diagnosis and making sure that all services, not just specialist ones, are autism friendly and trauma informed. There are still far too many people falling through the cracks.

I am now going to move on from what I wrote and talk about whether I think things have improved. From my heart, the evidence tells us that they have not. Let us look at what leads us: the learning from lives and deaths, which is now looking at preventable and avoidable autistic deaths, is clearly telling us that things have not improved enough—nowhere near. Where is the preventive care at the point of need, when our autistic people and their families need it, which is well before we hit crisis point? Then we hit crisis point—again, where is the support, and what does that support look like? It is certainly not what families are expecting, and it is certainly not what they get.



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Let us look at mental health services, which are sadly lacking. Today, I looked at a report from, I think, the National Autistic Society. It talked about the 1,435 autistic people who remain locked away in mental health hospitals. These people are not mentally ill; they are simply autistic. They should not be in these types of institutions purely through a lack of care, accommodations and understanding. There is a lack of preventive care. That is my honest view; the evidence tells us that not much has changed.

Dr Rachel Moseley: I feel so without words, having listened to you both. You have very much led into what I wanted to say. There has been progress, absolutely, but we have so far to go.

I am going to refer to work that I have been doing over the past 15 months. I and other academics, along with the charity Autism Action, have been collecting data on help and seeking experiences of suicidality from over 4,000 autistic people and over 500 people who support them. We are in the process of publishing this data, but I would really like to bring some of those voices in here today.

Our autistic participants identified feelings of loneliness, hopelessness, worthlessness, mental illness and inability to access help as driving factors in suicidal thoughts and feelings. These suicidal thoughts arose from living in “an uneducated and unempathetic society”, where they felt unwanted and worthless; from difficulties coping with everyday life in the absence of support; from feelings of being “abandoned” by health and social services; or from encountering services or professionals who were uncaring or antagonistic, including the “demeaning” and “cruel” benefits system.

People said that the following things contributed to suicidal thoughts: “having no access to support for mental health and waiting years for autism assessment”; “inconsistent and unpredictable support while waiting for decisions to be made by others”; “being misunderstood by everyone, especially professionals—teachers, doctors and consultants”; and “social services’ lack of funding to give me the care I need”, which is consistent with a 2020 report from the National Autistic Society that showed that two in three autistic adults did not receive the support they needed in the community.

One person said that suicidal thoughts were driven by sadness at “the way you’re looked upon by others, and then the government treat people disgusting by interrogation for benefits”. This is especially startling given this year’s welfare reforms, which the National Autistic Society has shown will be very detrimental for autistic people. Relating back to what my colleagues have said, there might be more awareness but unfortunately that has not come with acceptance.

Our data also highlighted that healthcare practitioners and professionals still lack the training and confidence to work appropriately with autistic people and to adapt psychological interventions. Around 70% of our autistic UK survey respondents did not seek help from the NHS when



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they last experienced suicidal thoughts, with two of the most common reasons being that, first, they did not believe that the NHS could help, and, secondly, there was no point because the waiting lists were too long. People who did seek help from the NHS for suicidal thoughts often reported that NHS staff responded inappropriately. One person said, "Because I had washed my hair and was wearing eyeliner, I was deemed okay by the person assessing me, despite telling them about my suicidal thoughts and plans to hang myself".

Autistic people and their supporters described how standard NHS offerings, delivered by professionals who seemed unable to cope with someone with both autism and mental health difficulties, actually worsened their situation. One person said, "Having been honest and said CBT wasn't helping, I was told I was being uncooperative and was discharged, which made me worse". A supporter explained how the service refused to refer their son until he completed online CBT training, which was inaccessible to him because of his support needs.

As Paula rightly said, we are still seeing what the National Autistic Society has called a "human rights scandal" in the number of autistic people inappropriately detained in unadapted and unsuitable in-patient environments. This continues and has increased by 137% since 2015, despite it being written into three successive strategies that the Government will reduce the number of in-patient admissions.

My summary is that, unfortunately, we see that services are still failing autistic people and those who support them. Our research shows that suicide in autistic people derives greatly from social factors such as insufficient health and social care, societal stigma, loneliness and financial employment distress, all of which are completely preventable.

Q54 **Lord Crisp:** Thank you very much for joining us and—I speak personally—helping us to understand. My question follows on very much from the previous question about the Government's autism strategy for 2021 to 2026. It set an ambition to reduce health inequalities for autistic people. In your view, what are the main barriers to achieving this goal? You have said a bit about that already. What would be the best ways to overcome these barriers? Let us start with Rachel Moseley, then go to Paula McGowan and Virginia Bovell.

Dr Rachel Moseley: I will mention three, based on the data I have been speaking about. The first is that autistic people are frequently not believed, or they are dismissed or invalidated when they ask for help, often because they are not displaying distress in ways that healthcare practitioners recognise or expect. Our data showed that these kinds of negative experiences make it less likely that people will seek help again in future when they are in crisis. In another one of my studies, autistic women told me that they would delay seeking healthcare until they were absolutely desperate, because it is such a traumatic and painful experience.



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In response to this, we have heard already how desperately GPs and all NHS staff need training. They need more thorough education and training in how to communicate and work appropriately with autistic people. This was identified as a top community priority by our survey participants. They said that training needs to be really expansive. It needs to be about communication differences between autistic and non-autistic people from a neurodiversity-affirmative approach—not that autistic people are deficient. It also needs to cover masking or camouflaging, burnout, trauma and how mental illness and suicidality might look different in autistic people. It will take time to rebuild trust between the autistic community and healthcare professionals but, as we have heard, involvement of the autistic community in designing pathways, strategies and training is absolutely essential to building that trust and showing the community that you are listening.

The second barrier is the lack of tailored and specialised services, professionals, interventions and assessment tools for detecting illness in autistic people. In so many areas related to physical and mental health, we lack evidence-based approaches for treating autistic people. We have heard again and again that people bounce between services and fall within the cracks in the system. They are denied treatment from mental health services because they are autistic. They are redirected to autism services that cannot help them because “This is a mental health issue”, hence they often do not receive any support.

As we have heard, the reality is that many, many autistic people have complex, intersecting physical and mental health needs, and the present siloed nature of the NHS means that it is very difficult for them to receive joined-up care. In response to this, our survey participants said that there is a need to develop services or pathways within services that are specialised for autistic people. We also need to build an evidence base for appropriate treatments and assessment tools for autistic people. We might need to implement measures to make sure that people do not fall between the cracks, such as care co-ordinators or caseworkers who can advocate for them.

The third and last thing I want to mention, which I have mentioned already, is the social causes of ill health. This ties into what Paula beautifully said about preventive measures. The Government have very much focused on crisis intervention, which is absolutely essential—do not get me wrong—but it is focused on crisis at the cost of prevention. Autistic people will never have better health or indeed lower suicide rates while they do not have equal access to education and employment; while they struggle with financial insecurity, lack social support and contend with social stigma; and while they grow up in environments which do not support meaningful connections, autonomy, independence, success, meaning, purpose and enjoyment in their lives. It is all connected and we need to work with the long view in mind if we really want to improve life expectancy and quality of life in this group.



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Paula McGowan: For me, the Government's ambition to reduce health inequalities for autistic people is absolutely the right one, but let us be honest: ambition alone will not change lives. We have to be honest about the deep-rooted barriers that continue to hold progress back. That includes culture—a deeply rooted culture that does not want to change. We have to address the prejudices and the bias, the ignorance and the arrogance that exists within our health and social care settings.

The first and most critical barrier is the lack of understanding and training. We keep talking about the lack of understanding and training across health and social care; it is not good enough. Too many professionals still do not understand how autism presents, and the little intricacies involved with that. It is not because they do not care; it is because they are just not equipped for it.

Secondly, there is the issue of systemic inflexibility. Health and care services often expect autistic people to adapt to systems that do not work for them—and never will—rather than the other way around. We know that the environments can be overwhelming. Communication simply is not tailored because our professionals do not know how to communicate. They do not know how to make reasonable adjustments, which are often seen as optional. It has to change.

I am going to tell a little story. During Oliver's inquest, we met a wonderful neurologist who tried his best for Oliver. He was asked on the stand, "Why didn't you make reasonable adjustments for Oliver?" He answered honestly: "I've heard about them, but I don't really know what they are". Of course, Oliver paid the price with his life, but it is not fair, either, on our doctors and medical colleagues, who want to get things right every time; we have to think about that. Services need to be designed with and for autistic people, and their voices have to be at the heart of every single decision. Again, it comes back to learning directly from these communities.

There is also a huge disparity in diagnostic waiting times, especially for adults. We know that people are waiting years for assessments, during which time their health and mental well-being is deteriorating. We definitely need more investment in autism diagnostic services and clear post-diagnostic support pathways so that no one is left feeling lost or alone.

Finally, we have to have accountability. People have to take ownership when things go wrong. We have to ensure that clear systems are in place to monitor how services are performing for autistic people and, of course, the consequences when they fail. It is not enough to have policies; we need measurable outcomes and a lived experience, leadership and culture that prioritise equality, safety and human rights. If we really want to reduce health inequalities, we have to stop seeing autism as a specialist issue. Autistic people use every part of our health and care systems. They are human like the rest of us. They use and utilise our GP



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surgeries and A&E departments, and every single part of the system must be ready to meet their needs.

Virginia Bovell: I agree with everything that has been said, which cuts down what I have to say now, which I am sure is welcome for everybody. The issue is that there is a dearth of the right kind of support at the right time. A lot has been said about prevention. Paula mentioned the word “investment”. I know that that can raise hackles as we think, “Oh gosh, there’s no money. We can’t afford it”, but investment in the right things at the right time will save money. I studied health economics for a while, and I am on such a big soapbox about this.

Jonathan Green, who gave evidence a while back, talked about how the Early Care Pathway seems to be saving money, reducing waiting lists and improving outcomes. That is because it is a sort of system redesign, but it can be done, if you support families at the right time. It is not the whole answer, which leads to the issue of the inflexibility of systems and people in their professional boxes. We need more early support for some young autistic and learning-disabled people³. If it is just left to schools to try to cope, teachers are not there primarily to deal with Special Educational needs, disability or autism-plus. They certainly need more training, but if schools are not supportive environments and are not making enough reasonable adjustments, then the person will end up in the mental health system because the environment will have been so punitive for all the reasons that Rachel said.

As she identified, the mental health system needs more specialist pathways. Autism itself does not need specialisms. As Paula said, all front-line professionals and receptionists will need some form of understanding, but we also need subsequent specialist pathways, which will hopefully prevent crisis and, I believe, will save money.

I will say one more thing, about the dearth of the right kinds of support at the right time. So many resources go into multidisciplinary team assessments, which are very resource intensive. Too often, you wait for your assessment, which has taken for ever and so much paperwork, and then there is nothing. Some of the skills are taken up with assessments and reviews, which is fine, but we need skilled people providing help on the ground. Families need post-diagnostic support if the child has been diagnosed early and they have additional needs. Sometimes I feel that the resources are going to the wrong people at the wrong time—or maybe to the right people but in inefficient ways. As I said, Jonathan Green’s early care pathway has shown that at an early stage, but I think it may also be true at a later stage.

³ Note from witness: See for example Beyond Autism’s *Early Years Group* project, which lies outside the formal services and is funded entirely by donations, but which has some very positive outcomes <https://beyondautism-earlyyears.org.uk/our-service/early-years-group#:~:text=We%20offer%20a%20flexible%20approach,techniques%20to%20apply%20at%20home>.



I will give one final example. A colleague set up a semi-educational provision for young people who simply cannot tolerate school. School can be really punitive for a lot of people for sensory, social and anxiety reasons. This specialist provision was doing really well but Ofsted said, “No, we’re going to shut you down because you’re not a proper school”, or “You’re not doing enough of what we consider to be appropriate education provision”. The inflexibility of systems and institutions is such a problem for so many of our young people and adults who do not fit into existing institutional or professional boxes.

Q55 Lord Hope of Craighead: My question is about another ambition in the Government’s 2021 strategy. It set an ambition to ensure that autistic people can access the support they need in the community, including social care, mental health and housing support. In your view, what are the main barriers to achieving this goal and what will be the best ways to overcome them? If you will forgive me, I would like to start with Virginia and then move on to Rachel and finally Paula.

Virginia Bovell: As I mentioned earlier, there are two things: people and institutions. On people, we have talked about the need for training, more caring attitudes and greater flexibility. We absolutely need that, but also within social care. I am passionate about how beneficial a good social care workforce can be, but they are incredibly low paid and have incredibly low status. A lot of good people do a lot of good work for about six months or a year and then go off to get more training to follow a different career pathway—or they may do an autism course at a university, which is fine, but it may not give them the hands-on and practical skills, experience, knowledge and confidence to work with people on the ground in the here and now. My worry is that they will do a course that perhaps penalises them for using the wrong academic reference system, and that will not help them work with autistic people and learning-disabled people on the ground.

It would probably be much more beneficial if they had a career path, and possibly a specialism path, that enabled them to work in a range of settings with a range of different people, and to be mentored, supervised and role-modelled by good senior practitioners who themselves have had incentives to stay in the job. The incentives they may need are a career path, recognition and better pay for years of service—and I do not mean years of service not being very good at what they do; I mean years of service where they have been mentored and role-modelled and have accessed continuing professional development.

This is not in place. Skills for Care has this month introduced an eight-tier career pathway⁴. Aspirationally, it is really important to up the status and career prospects of social care staff but is not enough without hands-on training schemes. We possibly need to partner social care providers and

⁴ Note from witness: Skills for Care updated its Care Workforce Pathway on 9 April 2025: see <https://www.gov.uk/government/publications/care-workforce-pathway-for-adult-social-care#full-publication-update-history>.



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training institutions. That is new and needs to be done; I do not think it has happened before.

I will say one more thing, on culture wars. Sometimes we need to lump together autism and learning disability, and sometimes we truly do not. I will give an example of meeting the needs of those with profound behavioural differences, whose behaviour may be self-injurious and whose despair and/or communication problems and/or dyspraxia—which are very different things—may all lead to an inability to communicate in a way that professionals can understand, and who may go on to challenging behaviour. There are culture wars here. We need Positive Behaviour Support⁵. The leaders in the profession say, “We are there for the learning disabled. We are not there to normalise autistic people who have good communication skills, who may not need an intensive, very tailored behavioural approach”. Those like my son - he was taught to ask for a break—the most important thing he can ever ask for - through a behavioural approach. I do not think everyone needs that, but I would be so upset if some of the turf wars around behavioural approaches that are not right for everybody, denied people like my son access to an approach that is helpful. I should leave it at that.

Dr Rachel Moseley: I want to follow on from several of the things that Virginia has stated so perfectly. First, there are two interrelated barriers, which we have heard already. The first is the lack of autism training and understanding in professionals but, as has been wonderfully stated already, we cannot blame them. There have been years of underinvestment in this sector, so we have a social care system where we cannot appropriately train and then retain staff. Even exceptionally, there are some fantastic professionals and services out there, but with the best will in the world, they do not have the capacity to provide the kind of specialised support that autistic people need to live fulfilling lives in their communities.

A 2023 report by Autism Alliance found that autistic adults and their families regularly wait over two years for social care, and around half of them say that the care that eventually comes does not meet their needs. The report also said that 77% reach crisis point while they are waiting for social care. This is what we have seen in our survey in the last 15 months or so. People sometimes tried to seek help from social services when experiencing suicidal thoughts. One person simply said, “They did nothing, and they don’t care”. Others said that they were told they were exaggerating their difficulties and that social workers seemed to victim-blame and suggest that things would not happen to them if they changed their behaviour. Some people said that they would get a phone call, but nothing would be followed up. One person said that their request for a

⁵ Note from witness: See recommendations on the social care workforce and Positive Behaviour Support in the Bubb Report: *Time for Change: The Challenge Ahead, Transforming the commissioning of services for people with learning disabilities and/or autism, ACEVO* 2014.



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home assessment for accessibility was refused, and “I felt worse going home to an inaccessible home”.

The people in our survey who supported autistic people confirmed this. Several parents said that social workers were often uncontactable, including when their child was in crisis. They were passed around, had to repeat information over and over, and sometimes services just never got back to them and support never materialised. One parent said, “They weren’t interested in helping”. Another simply said there were “insufficient time and resources”, which is at the bottom of it all.

We know that there is this good will and these fantastic professionals in a system that is struggling but, unfortunately, this sometimes manifests in a staggeringly cruel way for autistic people and their families. I know one autistic young man who had been sectioned with multiple suicide attempts. He had no peer group, but he had a support worker who took him out to do fun things that built his self-worth. Then, funding for this support worker was cut, and the young autistic man was told, “I am not paying for you to have friends”.

I want to echo what was said previously about how life-saving good social work is. This also came across in our survey, where one person said, “Having a social worker who understood autism was the only thing keeping me engaged with services. Without that, I would have given up entirely and I wouldn’t be alive to answer this survey that you are doing now”. We desperately need professionals who understand and accept autistic people at a profound level. There is no way around the fact that there must be targeted and efficient investment in this sector, increasing the capacity and services available for autistic people.

I want to follow on from what Virginia said. I certainly cannot claim to have any economic knowledge, but we often see what seems like wastage in the system, where great work has been done but it is not disseminated in a smart way: it does not get out there. It is done and then in a year or so, it is gone—it is lost. There is some fantastic work already out there, such as Skills for Care’s guide and the resources for local commissioners, but no one knows where it is. Yes, money is difficult, but we need to be so much smarter in how we invest.

Paula McGowan: It has been interesting listening to colleagues speaking and how they reflect my own thoughts and feelings, especially on the inappropriate and inadequate use of funding. I see that quite a bit, time and again. For me, the main barriers are inadequate funding and resources and, exactly as has just been said, how that funding is used. Of course, we know about the long waiting lists, the staff shortages and the limited funding that restricts the availability of those services. Even when support exists, demand far exceeds supply.

We have limited housing options. There is a lack of suitable sensory-friendly and supportive housing for autistic people. Many end up in settings that increase anxiety or reduce independence. As a result, many



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autistic people and those with a learning disability end up in institutions that they should never be in, often being physically and chemically restrained. That is down to a lack of suitable housing in the first instance.

The failings are also a fragmentation of services. Services are often siloed, meaning that there is little co-ordination between health and social care and housing support. This makes navigating support systems very difficult for autistic individuals and their families and carers. Again, it comes back to that lack of autism-specific training among professionals.

I often talk about and advocate for training that is standardised, as with Oliver's training. We have to be able to evaluate and track exactly what training people are having. Is it effective and is it having an impact? For me, it needs to be standardised for that to happen, so we need to make sure that all our professionals are receiving training that is meaningful and impactful.

As I have just said, many professionals in social care, mental health and housing lack adequate training in really understanding autism, especially autism with comorbidities and when it is in its diverse presentations. They have to really understand when an autistic person is scared. We often hear about challenging behaviour but, often, colleagues need to step back, question themselves and think about whose behaviour is challenging who. Is it the patient—the autistic or learning-disabled person—or is it the professional who is not understanding the situation? Or is it the environment? We need to look at those types of things.

We also have to look at the eligibility criteria and assessments. Access to services often depends on meeting rigid eligibility criteria. That does not reflect the nuanced needs of autistic individuals, especially those with co-occurring learning disabilities. Of course, if they do not meet those criteria, they do not access the support they need or the preventive care when they need it most. We also have to be honest and look at stigma and lack of understanding. Societal stigma and misunderstanding about autism result in autistic people being excluded and not taken seriously when seeking help.

I have been thinking about ways to overcome these barriers. There has to be increased investment in community-based services. It is not just about funding; investment can mean many things. It is about the public wanting to support autistic people in the community and wanting them to live beside them in meaningful accommodation. It is about changing culture, hearts and minds. Again, we have to prioritise early intervention. The way to solve this is to increase real understanding and training, but that training has to be designed, delivered and evaluated specifically by autistic people. I could go on and on about this, but I think my colleagues have already said enough about it, too.

Q56 **Baroness Browning:** Thank you, all, for the contribution you have made today. In a way, it has been a trip down memory lane for me, as a mother with responsibility for two autistic adults in my family. I am a



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little saddened to hear that what I experienced decades ago is still relevant to the findings that you have today.

How far do the NHS and local authorities learn from the experiences of autistic people and their families or carers, and from failures to meet their needs? How can this be improved? Do they learn as they go along? That is what this question is all about. Paula, may we start with you? Thank you.

Paula McGowan: That is a powerful and important question that cuts to the heart of accountability, learning and change within systems. Although there has been some progress, it is tiny. Many autistic people, families and carers still feel that their voices are not being heard or acted on effectively by the NHS and local authorities. In reality, learning from autistic people's lives—their lived experiences and past failures—is far too inconsistent.

Some local areas involve autistic individuals and carers in shaping their services, especially through autism partnership boards or coproduction forums, but it is not universal, and it is not always meaningful. We have to think about feedback mechanisms. I hear often from autistic people that they can feel tokenistic, and there is limited evidence to suggest real systematic changes or learning from serious incidences or failures such as inquests or safeguarding reviews. LeDeR often results in recommendations, but are they really heard and acted on? Let us be honest: implementation of any of that is very slow and, at best, very patchy.

Oliver died in 2016. Has anything really changed? If we are honest about it, not much has. Families frequently report having to fight for services when things go wrong. The system often feels defensive rather than open to learning. That is exactly our experience—even of the coronial system, which comes from a very defensive stance. It is all about damage limitation and protection of the service.

How can it be improved? We have to make coproduction the norm and definitely not the exception: always involve autistic people, their families and carers at every single stage, starting with policy design, service delivery and evaluation, and pay them for their time and expertise. It is shocking, isn't it, to think that any organisation thinks that it can expect autistic people and those with a learning disability to do work for them and not pay them? It speaks to the inequality, bias and so many other things. It has been the norm for these communities to not be paid for their time, so we have to make sure that we pay for their expertise. Again, it is about mandating learning from failures. I could go on and on, but I will leave it to my colleagues to speak further about it.

Dr Rachel Moseley: In my work in the sector around suicide prevention, I see that much more needs to be done to listen to autistic people and their families and to be willing to learn from mistakes. I have had the privilege of hearing from Ms Lisa Wolff, Ms Julia Hopper and others who



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back Matthew's Campaign, which, after a decade, has resulted in the Lampard Inquiry into the deaths of mental health patients in Essex. I am working with the charity Autism Action, which I mentioned earlier, which has made the case to the inquiry that many of those who died were likely to have been autistic, even if they were not diagnosed at the time. As such, it is vital for the inquiry to answer questions about how many of those who died were autistic. It was not originally going to look at autism, but the inquiry has subsequently agreed to formally examine the intersection of autism and in-patient mental health care.

The story of Matthew's Campaign and the Lampard Inquiry is staggering. It is appalling that these families had to fight for over a decade for this inquiry to happen, while seeing the same mistakes made and more deaths occurring. It was eventually necessary for this to be a statutory inquiry because NHS staff engagement with former individual non-statutory inquiries was shockingly low. One article I found said that 11 members of staff out of 1,400 agreed to attend an evidence session. It is clear—I agree 100% with what Paula said—that there is some degree of individual and/or systemic unwillingness to listen, learn and have accountability.

This is not the case across the whole country. As we know, there are great disparities in the provision and quality of care that people receive. To second Paula, to improve things fundamentally, autistic people and those who know them best need to be involved at the highest levels of decision-making in relation to how health and social care works for this community. There needs to be trust-building. As Paula said, part of that is respecting people as experts and valuing their time.

In terms of learning from the experiences of autistic people and their families, we need to be smarter and learn better from the data we have. For instance, the National Child Mortality Database in 2024 released a report identifying suicide or self-inflicted harm as the most common cause of death in autistic children. With Autism Action, I have been involved in some initial work seeing whether we can optimise the data collected about these deaths to understand better what happened and how children were at risk.

The data tells us a lot already, but improvements can be made and it is questionable why there is not, given the exceptionally high suicide rates in this community, a similar statutory process in place for autistic adults. The non-statutory nature of LeDeR—the learning from deaths report—means that it is very much an incomplete source of information. We hear about some deaths, but there are many we do not hear about. As such, implementing changes in the way we collect and learn from data could be very helpful in learning lessons.

Baroness Browning: In the course of that research, have you done anything on what is recorded by the coroners? As it happens, I have been pressing the DWP about disability benefits resulting in suicide, not just for autism but all disabilities. The Government are very reluctant to release



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that information, but I know that it is there. Have you gone down that route to see what coroners and others report?

Dr Rachel Moseley: I have not done so personally, so I am hesitant in what I say. Certainly, with autistic adults this information, to my awareness, is not collected as a matter of course.

Baroness Browning: It should be.

Dr Rachel Moseley: I agree with you 100%. It is slightly better for children. For children, there is a very detailed process after a child dies, including, if there is an indication that it might have been suicide, a great deal of information collected from a number of parties. This is not the case for adults.

Baroness Browning: So if coroners were required to release and record everything, would that help?

Dr Rachel Moseley: I think it would, but a lot of times coroners may not have access to that information, so there probably needs to be widespread change to get that information from many different parties. But, yes, it would be very helpful if there was legislation saying that this information should be collected.

Virginia Bovell: I have a bit of good news. I am going to trumpet my local authority in Islington, up to a point, which has a Reward and Recognition policy for co-production activities. For example, I have been involved, as have colleagues, in certain staff interviews, attendance at Partnership Board meetings, et cetera. We do not often take the payments⁶ up, maybe because they are quite cumbersome, but at least there is a policy of them being available, which is really important.

There is a staff training approach in our borough, pioneered by a family carer, that is based on videos and interviews with family carers, individuals and staff. It is about the often adversarial relationship, as Paula has said, that can grow up with gatekeepers. You can understand that, if resources are tight, people who go into caring professions in order to help may find that they are actually holding people back from what they need, which must be awful, but it can lead to mistrust and suspicion on all sides. These films, "Learn With Us" and "Mind The Gap(s)"⁷, devised by a family carer, have been rolled out and are really good at helping professional staff understand how they conduct themselves in very difficult interpersonal contexts.

Having said that, as always, there is an awful lot more to be done. I think that, when we were setting up Tree House, our local authority—it was not

⁶ Note from witness: Islington residents involved in co-production activities are offered a payment and/or voucher and/or donation to charity of their choice, to compensate for their time.

⁷ Note from witness: See <https://centre404.org.uk/learnwithus/>.



Islington—did not feel it was necessary. We as parents knew just from our own networks how many autistic children there were coming through the system and how few places there were to meet the needs of those with the most complex learning difficulties. We ended up doing it anyway, and now at Tree House there is a huge waiting list, and it has expanded and expanded. This is not meant to be an “I told you so” story, but often families and individuals know best what is needed.

Our request of commissioners and senior decision-makers in the NHS and local authorities is to listen to our suggestions. We do not always have an adversarial relationship. We can occasionally have some quite good ideas. Have the courage to respond to suggestions even if they require innovation, which is very hard, and even if they require hearing criticism, which is also not very comfortable if you are in caring professions. I think everything else has been covered brilliantly by Paula and Rachel, so I will shut up there.

Q57 **Lord Scriven:** There is a theme coming out. There is a lot of policy and guidance, but there seems to be a systematic lack of implementation. What do you feel is required to see better implementation on a systematic level rather than just an organisational level? What is missing or what extra pressure needs to be put on the system to ensure implementation?

Virginia Bovell: I was involved in a research study on implementing the 1992 community care legislation. We found that, for all the great guidance at central government level, there was a postcode lottery and incredibly different ways in which a uniform piece of legislation was actually carried out locally⁸. It was hugely diverse.

It is an incredibly important question. Implementation science is in its infancy but, aside from the academic side of all that, it comes down to all the things around calibre of people. One authority can be responding really well while another is not. It may be leadership, calibre or attitude, which hopefully the report you will finally write can highlight. In addition, it is the people who have the courage not always to go by the exact institutional criteria, rather than someone who is worried that they will not get promoted if they slightly bend the rules in a public authority. It is a shame, because you might actually need people to have courage and know when to use common sense. Use the equalities legislation and use reasonable adjustments. That is another way of saying common sense, you could argue, as long as it is backed by skills, knowledge, continual professional development and those incentives.

Paula McGowan: For me, it has to be accountability. Let us be honest: the Autism Act is a law, yet we have so many failings in our health and social care right across the board. We are talking about autistic people,

⁸ Note from witness: See Implementing Care Management: Issues in Relation to the New Community Care JANE LEWIS , PENNY BERNSTOCK , VIRGINIA BOVELL , FIONA WOOKEY *The British Journal of Social Work*, Volume 27, Issue 1, February 1997, Pages 5–24, <https://doi.org/10.1093/oxfordjournals.bjsw.a011196>.



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including those with comorbidities, being grossly mistreated. We hear about Whorlton Hall and all the other places in the media. We have a law that protects them. The Autism Act is there to protect them, and we have the Equality Act and the Human Rights Act.

Where there are obvious failings with these policies and so on, who is holding people to account? It appears to me that nobody is, because not much is done and there are not many changes. That is the crux of everything. People and organisations do not want to do what they are doing, but they are allowed to because there is no real fear of being held accountable. I feel quite strongly about that. I see it often. We see it in police settings quite often.

With Oliver's case, there was a full police investigation. It was the Crown Prosecution Service that did not want to progress things further. As I said, atrocities are happening in care homes and mental health/autism assessment and treatment units. It is often the CPS that does not progress things further. Where is the accountability? Who is watching and keeping an eye on things? I really do believe that that is where the problem lies.

Dr Rachel Moseley: I am a little bit lost for words; my colleagues have said it all so perfectly. Following on from what Paula just said, I was likewise going to ask where the overseeing body is to look at whether the law is being adhered to. Such an overseeing body should involve autistic people and those who support them, and it should be answerable to that community.

The Chair: May I check whether the witnesses are happy for us to extend the session by 10 or 15 minutes? This is so important, and I want to make sure that we cover everything you want to say. I also know that there are some further questions.

Q58 **Baroness Browning:** My question is only a small one. Who is accountable? Under the Autism Act, it is the Secretary of State for Health who has the power to call in if the Act is not being implemented. To our certain knowledge, that has never yet taken place despite the fact that the Act is 15 years old. So this is something we are very interested in as part of this inquiry.

Virginia Bovell: On the accountability issue, too often it is families who are resourced and tenacious enough to go through the courts. There is a tribunal process for special educational needs. It is very hard to get judicial reviews, et cetera, in social care. We have talked about the waste of resources—look at the amount of time, money and resources spent in judicial process. Because of the lack of accountability, it is up to individuals to follow through if they can bear it. That is crazy; I absolutely reinforce Paula's point.

Lord Addington: Just to clarify, are you saying that the tiger parent model in terms of getting the right support is still very much the reality?



Virginia Bovell: It is a reality. What breaks my heart is that, for every tiger parent, as it were, who goes to court, you have others who do not have the money or energy. They may be in poverty and not be resourced enough to take on the complexity of it all. All the invisible suffering is much greater than the visible signs of people becoming judicial.

Q59 **Lord Wigley:** As a lead-in to my question from the last discussion, which was very valuable, perhaps I could add that, back in 2006, I was a member of a special investigation committee looking into excess deaths among disabled people. We made very strong recommendations with regard to reasonable adjustments, but then you ask, "What has happened?" That almost fits into a pattern.

My question grows out of that, in a way. What should this committee recommend that the Government prioritise in order to reduce health inequalities and build support for autistic people in the community, following the end of the autism strategy for 2021-26?

Dr Rachel Moseley: I will give you the priorities from the more than 3,000 autistic people who took part in our recent research with Autism Action.

First, they said, "We need specialist services, pathways and interventions for autistic people, and those need to be delivered by professionals who specialise in autistic people". Something that Paula said earlier was really profound and stuck with me: autistic people use all services and all services need to be accessible to them—absolutely—but, as was mentioned earlier, we also need to recognise that autistic people have support needs that are different to those of non-autistic people. Hence our services need to be able to cope with that.

The people in our survey talked quite a lot about this. In the words of someone who supported an autistic person, "Precious time is wasted with generic services". An autistic person said, "We need to stop making autistic people start at GP level and jump through hoops before they can get to see anyone with knowledge and expertise in autism". Many of the individuals in this group cannot, as Virginia stated so beautifully, jump through hoops.

Relatedly, another priority of the community was to upskill GPs, front-line professionals and mental health professionals to understand autistic communication styles, masking, burnout and trauma—as well as, more broadly, how mental illness, suicidality and distress look in autistic people. We have heard already about the huge problems around diagnosis. In our data, participants made a very strong link between failures in the autism diagnostic process—that is, disadvantages faced by certain demographics such as women, including massive wait times, the unavailability of adult diagnoses and the lack of post-diagnostic support. They made links between these things and suicidality; this is a link that other research bodies and autism charities have all jointly emphasised.



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We know from our research that autistic people who grow up undiagnosed have worse mental health and higher suicide rates. Our most recent work has clearly shown how being undiagnosed makes people feel lost, broken and like a failure for not being able to do or to be like others. Priorities emphasised by the community were that autism assessment and diagnosis need to be both quicker and available for everyone of all ages across the country. We know about the immensely positive impacts of diagnosis, which some people in our study said had saved their lives; I can testify to that.

The other side of that is that there is a desperate necessity for post-diagnostic support because all the labels that a person picks up do not go away. Sadly, we do not shed them like a skin. The things that we have been through continue to affect our well-being and health. There is excellent work that the Government can learn from in terms of post-diagnostic support, and working with professionals who often share the news with someone that they are autistic; Laura has done some amazing work there.

The last priority that I want to pick up on links back, again, to the social care sector. People said that there needs to be a service that helps autistic adults with everyday living—including things such as shopping, managing finances and understanding other people—because, for many of us, those are things that our parents, as our life supporters, help us with, but they will not be here for ever. As an adult in my 30s, I can say that this frightens me every day.

This priority indicates the desperate need to fund the social care sector properly so that people are supported to live fulfilled and meaningful lives before they become ill and before they reach crisis; as Virginia said earlier, this will actually save money in the long term. We also need to support the transition to employment and look at what the employment environment is like for autistic people, as well as ensuring that those who cannot work do not live in poverty with no quality of life—as the new welfare reforms threaten.

Virginia Bovell: That was brilliant. I have written a mini manifesto, I am afraid.

We need to incentivise staff retention, backed up by even more training and continual professional development. We need to generate opportunities for that specialism, including in terms of when to move beyond the common access that all autistic people have, as Paula rightly said, through to knowing when to differentiate approaches and specialities. I am thinking within even the non-verbal group, which may be 30% to 40% of autistic people. One person may not be speaking because they have got dyspraxia, another person may not be speaking because they simply cannot do it, others because they are choosing not to. Likewise on literary skills, it is an interesting thing recently about how some non-speakers are very literate and can use a spelling board. Some.



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I am just offering that as an example of when you need specialisms that do differentiate hugely.

There is also exploring and evaluating pilots. People are coming up with ideas—autistic people, good clinicians, good commissioners, family carers. A lot of things are at an early stage of development, and they are too early necessarily to roll out mainstream, like all of statutory guidance or a new law. But pilot schemes, pilot interventions—if there could be more of those involving autistic people and their families, that could really help move things along.

Linked to that, there is an issue of flexibility. We have talked about flexibility of institutions. I just want to give you three tiny examples. 1. The specialist day centre in our borough is now realising that what it needs to do more of is to go out into people's homes and offer a sort of semi-consultancy. 2. It was school staff who helped a young woman learn to sleep in her own bed rather than her parents', because those school staff—those teachers—went into the home. 3. It was a behaviour analyst who taught a young autistic boy to administer his own insulin. We need people working outside their job descriptions, and likewise maybe at a more senior level people willing to take risks.

Paula, you mentioned housing schemes a while back. I do not know if it is a coincidence that the two innovative housing schemes for learning disabled and autistic people in our borough were instigated when there was a joint head of Adult Social Care and Housing. Again we are talking about crossing institutional boundaries, so that people think beyond their own performance criteria and KPIs into the actual needs of the people. Health, education, social care, housing—autistic people live in that institutional environment, but there may be many areas where you need crossover in terms of solutions. And one final thing: playgrounds. When children's playgrounds say you cannot go in at 18 and you are like my son - who thrives on going on a swing—that is such a simple, crazy thing that could be solved. There are lots of things where actually, criteria are arbitrary and could easily be changed.

Lord Wigley: There were quite a few priorities there, but thank you.

Virginia Bovell: Sorry.

Lord Wigley: I appreciate it. Thank you for your contribution, both of you. Paula, you have the last comment on this.

Paula McGowan: I have to say what an inspiration both Rachel and Virginia are. I have never met these two ladies before, and we are saying exactly the same things. We all come from different life experiences and different parts of the country, and are all reflective and, like I said, repeating exactly what we are all saying together.

What I would like to happen is, obviously, that you should think about expanding the Oliver McGowan mandatory training across all services to



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include education. You may not be aware that I did have a petition successfully debated in Parliament asking for an amended version of the Oliver McGowan mandatory training for all education settings, starting with early years, right through to universities. Again, it would be that standardised learning so that we can ensure that everybody is learning the same thing and has the same level of knowledge and understanding. It can all be tracked, it can be evaluated, and it can be amended. Now, that was successfully debated and then we changed Governments and sadly, that seems to have disappeared, which is a real shame. Obviously, with any training, it has got to be co-produced, co-designed and co-evaluated. I would also say that you need to create an autism health equity framework, and mandate NHS trusts and integrated care boards—the ICBs—to develop autism-specific health equity plans with measurable outcomes.

On diagnosis, wait times, treatment access and mental health support, it is essential that we fund specialist autism health teams in every single region, with GPs trained appropriately to be able to work with autistic patients. I currently work with a lot of GPs who tell me that they are not trained and do not always feel equipped to support our autistic communities.

No. 3: ensure fast, accessible diagnosis and post-diagnostic support. You have got to set and enforce national targets on maximum waiting times for autism assessments, and I would say no more than 13 weeks. Also, we should provide universal funded post-diagnostic support, including counselling, peer groups and care navigation.

We should fund local autism-specific community support hubs. Those support hubs are crucial. They give support to autistic people from autistic people. Those drop-in services offer advice, peer networks and skills development, and of course they should be co-run by autistic people.

You have definitely got to invest in supported housing and independent living. You have got to prioritise housing strategies that offer autism-friendly supported living options. We have got to tackle intersectional inequalities. We have got to target funding and policy at autistic people facing multiple disadvantages—those who may be from ethnic-minority backgrounds, LGBTQ backgrounds, migrants, women, and those who also have learning disabilities. It is important that you include people with complex support needs in all reforms.

You have got to make data accountability and lived experience central. You have got to require local authorities and NHS bodies to publish annual data on autistic people's outcomes in health, housing and social care. That would show real accountability, would it not?

We should appoint autistic people to decision-making boards and inspection teams. If you look around all those inspection teams, look at the CQC, and look at the boards, how many autistic people are sitting on



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those boards? I will guarantee you will not find many. Think about how many autistic people are employed by Parliament, in the House of Commons or even within the House of Lords. We have got to include stronger accountability measures for failure and to be able to act on feedback or any of the failings. We have to encourage people to look at our neurodivergent communities and see them as people first, rather than their additional needs. That is what I think we need to be focusing on.

Lord Wigley: Right. There are quite a few priorities there. No doubt we will have the challenge of prioritising the priorities. But thank you very much indeed, all three of you.

The Chair: I am not sure that there are sufficient words really to thank the three of you for your powerful insights that you have shared with us today. There is a lot for us to reflect on. I also think, on behalf of the committee, that we would like to thank you for the incredible and invaluable support and guidance that you give to the autistic community. Thank you very much indeed.

We as a committee are meeting again on Monday, the 28th. In the meantime, today's public meeting is now concluded.