HOUSE OF LORDS

Autism Act 2009 Committee

Corrected oral evidence

Monday 17 March 2025

3.05 pm

Watch the meeting

Members present: Baroness Rock (The Chair); 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 Wigley.

Evidence Session No. 3 Heard in Public Questions 15 - 22

Witnesses

I: Leo Capella, Trainer Consultant Employment Specialist, National Autistic Society; Zaynab Sohawon, Young Ambassador, National Autistic Society; Marsha Martin, Founder and CEO, Black SEN Mamas.

Examination of witnesses

Leo Capella, Zaynab Sohawon and Marsha Martin.

Q15 **The Chair:** Good afternoon and welcome to this public meeting of the House of Lords 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. A key priority is to hear directly from autistic people and others with lived experience.

We are delighted to be joined today by ZeZe Sohawon, the CEO of Emotion Dysregulation Autism and a young ambassador for the National Autistic Society. ZeZe is joining us in person. We are also joined remotely by Marsha Martin, the founder of Black SEN Mamas, and Leo Capella, a trainer consultant employment specialist at the National Autistic Society. We are delighted to see you all, and you are all very welcome indeed.

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 is 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 are very welcome and can watch our proceedings either online or in person, but they are not allowed to speak during a public session. Our evidence sessions are on the record, which means that they are broadcast and a written transcript is taken for subsequent publication. The list of members' declared interests has been published on the committee's website.

Having made that introduction, I now invite Baroness Browning to ask the first question and invite the witnesses to answer it in turn, beginning with Marsha, followed by Leo and then ZeZe.

Baroness Browning: Thank you, Lord Chair, and thank you all for joining us this afternoon. Can you introduce yourselves, telling us about the work that you do and why you do it? Marsha, can you please speak first, particularly about your work to improve support for the parents and carers of autistic children?

Marsha Martin: Hi all. I am autistic and the mother of three autistic children. I am a neurodiversity consultant. I train staff in the local authority—NHS social workers—on how to better support neurodivergent individuals and their family.

I am also the founder of Black SEN Mamas, as you heard. We are a charitable organisation supporting black mothers of neurodivergent disabled children in sourcing adequate mental health support. We also provide SEND advocacy services for the mums. We allow them to access it for free because we know that a massive barrier to access is having the funds to do so. We also do lots of research: we carry out studies and do reports. Oftentimes, the 4,000 black SEND families that we support are participants in the research that we do; it is mainly regarding SEND provision.

Baroness Browning: Thank you very much, Marsha. Leo, can you please speak next, particularly about your work to improve support for autistic people in the workplace?

Leo Capella: It is nice to meet you all. I am a former job coach and now I am a trainer consultant employment specialist at the National Autistic Society. My current work involves training different people, including on our autism in the workplace course. I also work on the Autism Inclusive Employer Award that we released last year. Basically, I am my department's representative—for lack of a better word—for what we do on employment.

Why do I do it? I actually have a lot of reasons for doing it, to be honest, so it is hard to pick one or two. I enjoy being on the cutting edge of one of the most intense parts of the human tapestry, for autistic and, more widely, neurodivergent people. I also see that, for all the not-so-good stuff, a lot of good people are out there who are willing to do the right things. It is really affirming to see that as part of my job. I hope that answered your question.

Baroness Browning: It certainly did, Leo. Thank you very much indeed. ZeZe, please can you speak next, particularly about your work to improve healthcare services for autistic young people?

Zaynab Sohawon: Hi everybody. I am a youth mental health advocate and an award-winning youth mental health speaker. I founded an organisation called Emotion Dysregulation Autism, a mental health peer support charity for autistic young people. We provide services in community settings, schools and in-patient mental health units for young people who are autistic and have additional mental health needs. I started my work mainly because I am autistic myself and I was also sectioned for a number of years in mental health units. I wanted to be the change that I wanted to see in the world and to be the person to others that my past self needed. That is why I set up the charity.

Baroness Browning: Thank you very much. How long did it take you to set up the charity?

Zaynab Sohawon: It took about two years. We have now touched 1,002 lives. We have helped 61 young people directly with one-to-one support.

Baroness Browning: It is very impressive doing that in two years.

Q16 **Lord Crisp:** I will ask each of you in turn the following questions. From your perspective, what are the main problems for autistic people today?

What is going well for autistic people today? How would you like this to change for the future? I will start with ZeZe.

Zaynab Sohawon: Brilliant, thank you. Some of the main problems that autistic people face are around being institutionalised. I was stuck in mental health units for about four years as a teenager, from the ages of 14 to 18. It is fair to say that I was institutionalised. I only needed probably one year of admission. The average length of stay for an autistic person in a mental health unit is about five and a half years, which is a really long time. That is a key problem for autistic people.

Another problem is the long wait times for diagnoses. In Birmingham, where I am from, it takes about four years to be diagnosed with autism, which is a long waiting list. During that time, people are not offered interim support or post-diagnostic support, so it is a real issue.

In terms of what is going well, there is increased awareness and understanding about autism among young people. I know that the youth community has good language and literacy around neurodiversity and is good at making reasonable adjustments and accommodations for those who are autistic.

How would I like things to change? As well as having support from provisions, such as public services, to deliver better interim and post-diagnostic support for autistics, we have to make sure that there are better protections in law for autistic people to be protected against being sectioned.

Lord Crisp: Thank you very much. I turn now to Leo and ask him the same questions.

Leo Capella: I will start with the bad news: autistic people are unemployed. I believe that the precise statistic is a 30.2% employment rate. We are underemployed, and 40% of autistic people said, in research that we did, that they would like to work more hours. We are also underpaid. That average pay gap is 33.5% less than that of non-disabled people.

This is because of a whole range of factors, which I am sure we will discuss. There is a gauntlet of barriers, starting from before people even think about entering the workplace. It ranges from careers advice to the cauldron that is education—and then, for instance, there is getting through the interview stage and being misunderstood. In the workplace itself, it can be a real struggle to survive because of misunderstandings with people.

The good news is that there is a lot of strength in depth, including with my fellow panellists today. That is so much so that, frankly, if we—and James Cusack, who appeared last week—were to be the only panellists who are autistic, you would be missing out on a lot of interesting, diverse and powerful people, including award winners and runners-up or people just doing their plain job. There is intense strength in depth. There are also diverse examples of employers getting it right and of new things on the horizon, such as people starting to think about how to support self-employment and restrictions being reduced. So it is not all bad.

How can we do that? I will try to avoid going scattergun. There is a whole lot that we can do, such as providing a consistent flow of information to employers on what is needed, as well as access to the support that is available for autistic people—both are needed in the same amount. We have to think about the pathways to get autistic people into places, whatever their age.

Lord Crisp: Thank you. Can I turn now to Marsha and ask the same questions?

Marsha Martin: Yes, thank you. When we consider the Autism Act and the statutory guidance it provides, it is clear that minimal progress has been made in addressing the gaps that autistic adults have historically faced. The issue is that many of the autistic adults that the Act intended to support are still being failed. So when we acknowledge that there are ongoing failures, we must then ask, "What of those autistic people who are still fighting to demonstrate the significance of their needs and those whose experiences are shaped by the barriers of not just disability but race?" Speaking as someone who is black and autistic and supports largely black and autistic families, when you exist as a minority within a minority—black and disabled—your experience of disability is significantly shaped by variables that the wider majority may never have to consider. We know this not just through lived experience but through empirical evidence. To truly address the current failures of the Autism Act for minorities, we must confront the reality that black autistic individuals and their families remain largely invisible in policy, in research, in support systems and so on.

My focus is largely on education and healthcare, because the families that I support are regularly accessing them. Through our work and statistical evidence, we know that black children are diagnosed with autism at higher rates, yet they are also diagnosed later, and they receive less support. They are more likely to be misdiagnosed or overlooked completely. The lack of early intervention has long-term consequences: it affects educational outcomes, it increases the likelihood of exclusion from school and it contributes to the overrepresentation of autistic individuals in the criminal justice system. When black autistic individuals do advocate for support, they are often met with systemic disbelief and inadequate resources, which leaves families to struggle alone.

To change this, we need greater visibility for these families, stronger public discourse, culturally competent training and a commitment to amplify black autistic voices. We have to ensure that the data reflects the specific challenges that black autistic people face in healthcare and education. We also have to ensure that professionals in these spaces are trained to recognise the racial disparities, and that black autistic individuals and their families are not just included in but actually leading conversations.

The Autism Act was meant to prevent autistic adults from slipping through the cracks, but many black autistic individuals still have to fight to prove that they even exist. If we are serious about equity, we must move beyond the recognition of these issues and take meaningful action to dismantle the systemic barriers that continue to fail them.

Lord Crisp: Thank you all very much for those very rich answers.

Q17 **Baroness Ritchie of Downpatrick:** You are all very welcome. I have two short questions, which I will first ask Marsha, followed by Leo and then ZeZe. From your perspective, how much public acceptance and understanding is there of autistic people? What would be the best ways to improve that?

Marsha Martin: The lack of understanding of autism is a massive factor behind much of the educational and healthcare disparities that black autistic people face today. Black disabled boys are 58% more likely to be excluded from school than their white disabled peers. The teachers that I have worked with will tell you that, when it comes to autism or neurodivergence in general, the training that they receive is woefully insufficient. At best, they have half a day's worth of training in special educational needs, which are all grouped together, throughout their entire careers. Worse than that, the training rarely acknowledges how autism presents across different identities, including gender, race and culture.

In the absence of training and knowledge, teachers will, unfortunately, fall back on implicit biases that are shaped by the same societal stereotypes that disadvantage both autistic and black children. Instead of recognising when a child's behaviour is a non-verbal expression of an unmet need, they interpret it through the lens of those biases. Instead of seeing distress, they will see disruption. Instead of seeing a struggle to communicate, they see aggression. Instead of recognising an autistic child in need of support, they see a problem that needs to be removed from their class. Those labels—"disruptive", "aggressive" and "challenging"—stick with these children; they follow black autistic children through their school years, impacting their self-esteem, opportunities and long-term life outcomes.

To address these challenges, schools need to implement comprehensive neurodiversity training. It needs to examine each neurominority in depth. Autism should not be grouped together with ADHD or dyspraxia, as each neurominority deserves to be understood separately. The training must also incorporate cultural competence. It needs to recognise diverse presentations of autism, because autism presents differently across different communities and different people.

Regular sessions should be provided to all educators and staff to ensure they can identify how autism presents in black or minority children and mitigate those racial biases that are present today. Additionally, independent assessments should be conducted to evaluate the effectiveness of training and its application within the classroom setting. Furthermore, I think autism awareness should be embedded into the curriculum. That teaches students about neurodiversity, and it fosters acceptance from a young age. Schools should actively participate in awareness days, engage in open discussions and collaborate with community disability organisations to provide direct learning opportunities for both staff and students.

The hope is that, with these efforts, teachers would be better equipped to recognise autistic traits in undiagnosed students and implement individualised classroom supports tailored to each child’s needs early. This is something that may reduce reliance on harmful stereotypes, punitive discipline, mislabelling and all of the things that negatively impact these children.

Baroness Ritchie of Downpatrick: Thank you. I will now ask Leo. Could you focus, in respect of both questions, on the areas of business and employment?

Leo Capella: With pleasure. Before I answer that question, I will say that Marsha gave an excellent answer. A lot of her points echo what I am going to talk about with business and employment.

First, we have to deal with the stereotypes. Autistic people can be dealt with as lonely and withdrawn—almost lone wolf stereotypes. If anything, we can play well in the team. One of the stereotypes I point out in my day-to-day work with employers is the idea of the team player: the person who will play in the team, as opposed to someone who will play for the team, to get to the same road—if that makes sense.

To counter this, we have to use cultural levers and show the diversity of autistic people. Our website has a lot of case studies of autistic people working and being in different fields, with different personalities and ways of doing things.

Another stereotype that feeds into this is “The IT Crowd” stereotype. We say that one of the advantages of autistic people is that we can have highly technical knowledge and an attention to detail—all of the elements that fit into “The IT Crowd” stereotype. But the reality is that, with the right support, autistic people could be working everywhere. While there is a lot of research that highlights the positives of having autistic people in the workplace, I think it is not about making it out to be a superpower.

The spiky profile that autistic people can have means that, at best, it is an uneven profile. I note that, in the information that was provided to you, I described it as a certain Japanese car that is front- and rear-wheeled. That uneven power works both ways. It is about being enthusiastically realistic with both businesses and the general public to get that deeper, richer understanding of autistic people—not just on a developmental basis, but on a human one too.

Baroness Ritchie of Downpatrick: Thank you, Leo. ZeZe, could you answer both questions, focusing on autistic young people experiencing mental ill-health?

Zaynab Sohawon: Yes. There is a lack of public understanding of autistic young people with mental illness. Specifically, I think there is a lot more understanding around the knowledge base of reasonable adjustments and autism in the workplace and in schools. My charity is working on a campaign called "Auty Not Naughty", which talks about autistic young people not being defiant, challenging or naughty but being "auty", as in autistic.

I want to echo what Leo and Marsha said about businesses acknowledging that autistic people have gifts that are good to use in the workplace. I also want to talk about young people with mental illness. There is a lack of mental health literacy in the public around autistic people and the overlap between autism and mental illness. I do not think the public are completely aware of how severe the crisis is in the system that supports autistic people with mental illness. A lot of autistics are being placed in mental health units. The number of people with autism and learning disabilities who are currently sectioned has slipped my mind, but it is really high.

I was restrained for one and a half hours at a time when I was in a mental health unit, which is a really long time to be on the floor with lots of people on top of you. That is the reality of what autistic people are facing right now. I was only 14 at the time. This is happening to young people and adults everywhere across the country. I would go so far as to say that it is a scandal. I think that it is happening nationwide, and I do not think the public are aware of it.

The good news is that young people are coming to know more about these issues now, and there is a lot of representation in the media about autistic people, whether on TV or in film and music. The only downside to that is that there is no representation of both autism and mental ill-health in those representations.

Baroness Ritchie of Downpatrick: I thank the three of you very much for the evidence you have supplied to us.

Q18 **Baroness Goudie:** Good afternoon. Thank you very much for agreeing to give evidence to us this afternoon; we really appreciate it. I have a short question. How good are providers of public services, businesses and other organisations at being inclusive and accessible for autistic people? What would be the best ways to improve this? Starting with you, Leo, could you also focus on business and employment in your reply?

Leo Capella: With pleasure. I would like to make a vital point on the previous question, so forgive me for being a bit of a rallycross car. ZeZe talked about cultural levers, which I think is something for the committee to really consider. As someone whose additional duties include script review for the National Autistic Society, I have seen and heard increasingly better stereotypes but, as you will find, we autistic people in the current climate are like a salmon or carp climbing up a waterfall in that we are still up against the general tide. It is about getting people in, which is the focus of your question, so thank you for allowing me that track-back. I want to start with employers and then talk about the services around them, if that is okay.

Baroness Goudie: Perfect.

Leo Capella: With employers, we are on the right track, but, from what I have seen, there are more things we can do. We are getting autistic advocates inside organisations, and we are starting to form autistic colleagues' networks or wider neurodiversity networks. Also, there are senior people, including late-diagnosed people, who are coming out and saying, "I am autistic", and then going on to do stellar work. The Institute of Neurodiversity, founded by Charlotte Valeur, who revealed that she was autistic, is one example. Another good example comes from—I better get his title right—former vice-admiral Nick Hine. We are trying to get that joined up too.

Where do we need work? It is about developing advocacy in the workplace, building up the skills of autistic people and building up both formal and informal channels. On an individual level, buddy and mentoring support can help with this, but we need more people to be trained up, whether autistic or non-autistic, as buddies and mentors.

We also need to have access from other channels—including, dare I say it, trade unions—and to think about how we can develop autistic leaders. Currently, I believe—although I am happy to stand corrected—Disability Rights UK provides a Leadership Academy Programme. I was part of RADAR's one before Disability Rights UK came into existence—I do not want to not get caught on spaghetti, but I believe that Disability Rights UK is the successor to RADAR. We need more efforts like that.

We also need to consider what efforts are actually doing. With public services, there is an understanding gap that needs to be addressed. The all-party parliamentary group report on the Autism Act—which I think was in 2019—says that 4% of autistic adults surveyed thought that jobcentre employees had a good understanding of autism. That was higher than the figure for families surveyed, which was 2%. The number of autistic adults who thought that support workers had a good understanding of autism was 19%, which was lower than the number of families who thought they had a good understanding.

We need more autistic support people getting into these places. We also need to think about co-production with businesses and services. It is not just about getting people into management or staff positions. As you conduct your research, you will see that there are many veteran autistic specialists who might not want the strain of leadership or who might not be an able manager; however, they will have incredible expertise in their specialist position that they can use to contribute. So this is about how they find the channels and establishing what channels are provided to get effective solutions to improve things at both a public service level and an employer level.

Baroness Goudie: Thank you very much, indeed. ZeZe, can you please answer next, focusing on how autistic people experience mental health?

Zaynab Sohawon: I would go as far as to say that public services are failing autistic people with mental ill-health. Something to note is that autism is not a mental illness—it is a type of neurodivergence—but the current statutory services are treating autism as if it were a mental illness. It is something that is used to section, and hold power against, people. This can really limit autistic people from being able to access a life worth living.

The services are really fragmented. For example, with in-patient services, I was transferred to a unit in Wales and then to a psychiatric intensive care unit in Sheffield; I am local to Birmingham, so both were really far away. There are massive disparities in the system that supports autistic people with mental ill-health in in-patient mental health units. Also, people are being sent to in-patient mental health units because there is a lack of robust services in the community. There are no services in the community, so they are being shipped off to in-patient services.

A campaign that my charity has interacted with is called "Lolly's law", which looks at improving the support for autistic people in mental health units and making sure that autistic people are protected. There was a Transforming Care agenda a few years ago—quite a while ago now—that aimed to protect autistic people who are in mental health units through a dynamic support register, to make sure that autistic people were known as being autistic and to tell commissioners to avoid them having to go into a mental health unit. But we need something that is more robust, stronger and rooted in legalities—and that is what Lolly's law is about. To answer your question, public services are doing a massive disservice to autistic people at the moment.

Baroness Goudie: Thank you very much, ZeZe. Marsha, while focusing on children and families, how do you feel that local authorities are being? Are they being helpful?

Marsha Martin: Lots of public services still fall short in being truly inclusive and accessible for autistic people, especially those on the intersection of race and disability, like me and the families I support, because we face additional racial biases daily that they do not know about or even consider. It is especially evident in healthcare, where systemic bias and a lack of cultural competence creates significant barriers to diagnosis, treatment and ongoing care. For example, black disabled men are three times more likely to face obstacles in accessing quality healthcare compared to their white disabled counterparts—that is a really big number.

This disparity is not surprising because both the black community and the autistic community have well-documented histories of negative or aversive experiences when accessing the medical system—so imagine facing barriers to healthcare not just once but twice over. The black community has long dealt with medical racism and being dismissed, misdiagnosed and not taken seriously. The autistic community also faces similar struggles, with doctors often misunderstanding or downplaying symptoms, especially when patients communicate differently. Now put those two realities together.

For black and autistic individuals, this means that healthcare is often not just difficult to access or navigate; it can feel actively harmful. Many of us—especially those with chronic illnesses, for example—rely on regular medical care to maintain a decent quality of life. So when seeking help means being ignored, misdiagnosed or even gaslit—when we are told that our pain is not real or we are just anxious or exaggerating—it then puts us in a terrible position. We have to choose either to suffer in silence or to seek help but be forced to endure mistreatment in a system that repeatedly fails us. The families that we support report these experiences over and over again. This is not new; this is extremely common. Parents fight for their autistic children to get the right diagnosis and support, only to be dismissed and gaslit. Adults who struggle with chronic conditions avoid hospitals altogether, because past experiences have taught them that they will not be believed.

It is not just frustrating; it is actually dangerous. Without access to proper care, black autistic people are left to navigate life with untreated conditions, worsening health and a poor quality of life overall. That is why we need to address the intersection of race and disability. It is not optional. It is urgent. If we do not, we are basically condemning an entire group of people to unnecessary suffering simply because the system just was not with built with them in mind.

Additionally, disability advocacy organisations often centre white autistic voices, and that leaves black autistic perspectives underrepresented, particularly in key decision-making spaces. Time and time again, black disability leaders and activists, me included, have reached out to larger organisations and urged them to recognise and amplify the experiences of black autistic individuals. We have asked for our stories to be included, for our struggles to be acknowledged and for real conversations about how race and disability intersect, yet time and time again we are dismissed and told that our voices do not matter, the narrative does not fit or our experiences do not appeal to the wider public. It is important to recognise that this is not just exclusion but erasure. It prevents meaningful conversations and meaningful progress because we cannot solve what we refuse to see.

The truth is that while all autistic people face challenges, black autistic individuals navigate additional barriers: medical, racism, misdiagnosis, or simple neglect—all things that I have previously discussed and that shape our experiences in a way that mainstream narratives continuously fail to address. They are never spoken about in public discourse. Understanding both our similarities and our differences is never about division. It is actually about making real, lasting change that benefits everyone. I think larger organisations need to stop gatekeeping whose voices and stories are deemed important. They need to actively seek out and collaborate with black-led disability organisations and groups and ensure that research, policy, advocacy and so on and so forth reflect the full diversity of the autistic experience.

Baroness Goudie: Thank you all for your answers. They have been most helpful.

Leo Capella: I have a quick point that involves a point that Marsha made earlier. In the "Not Enough" report—the statistics I referred to earlier—the committee should note that none of the roles surveyed scored above 50% among autistic people or their families, so I agree with what Marsha said about the lack of understanding and the gap. While time has passed, I think there is a huge amount of work to do, and it will need maximum effort to pull levers on that score.

Baroness Goudie: Thank you very much for the additional information.

The Chair: Yes, thank you. The committee has noted that point.

Q19 **Lord Hope of Craighead:** How effectively are autistic people identified and offered support? What would be the best ways to improve this? Marsha, I wonder whether you would be kind enough to answer first, focusing particularly on children and families?

Marsha Martin: I think that the refined approach that is really needed to better identify minority—in my experience, black—autistic individuals does not yet exist, so there is a huge disparity in terms of black autistic people being identified as being autistic and then getting the necessary support implemented even after being recognised as someone who will need that support. On prevalence and diagnosis of autism among black children, studies indicate that approximately 2.1% of black children are diagnosed with autism compared to 1.8% of all schoolchildren, so on the surface the suggestion is that there is a higher prevalence of autism among black children, and that is recognised, but despite the recognition that black children are overrepresented at diagnosis stage, when it comes to implementing appropriate intervention or support within the classroom, within school settings, healthcare, social care, black autistic children are consistently left behind. Again, that is empirically evidenced. This disparity is devastating, because we know there is a well-established link between the removal of interventional support and negative life outcomes for autistic people. We are looking at poorer educational attainment, increased likelihood of exclusion, placement in pupil referral units and, ultimately, young offender institutions and prisons, where undiagnosed and unsupported autistic individuals are also overrepresented.

Beyond access to support, black autistic children are also diagnosed later. So there is the recognition that we are overrepresented, but even still, the diagnosis comes later than for our white peers: the average is 5.4 years old, compared with the national average, which is 4.9 years old. It seems like a small gap, but timing is everything in the world of early intervention, and even a few months can delay and significantly hinder development and long-term outcomes. This has also been evidenced. The undeniable need for early intervention means that that is a travesty, because black autistic children, although they have high prevalence rates, are systematically denied this opportunity significantly more.

Compounding these disparities is the fact that 50.8% of black autistic children are diagnosed with an intellectual disability, compared with 31.8% of white autistic children. This suggests that black children without intellectual disabilities may be significantly underdiagnosed, so those of us who are heavily masking are less likely to be picked up.

This is where another crucial point lies: many black autistic individuals, both children and adults, have spent their entire lives masking their support needs, sometimes without realising they are doing so. Both masking and living with unsupported needs comes at a cost to one’s mental health. That has also been evidenced. Following the Covid-19 pandemic, I worked with countless families who had spent years advocating for support for their autistic children, only to be ignored by local authorities and schools. Then, when lockdowns disrupted their routines and the coping mechanisms that had enabled these children to survive, the weight of years of unsupported needs finally collapsed in on them. Parents told stories of their children experiencing severe mental health crises, being sectioned and receiving mental health diagnoses while their underlying neurodivergence continued to go unaddressed. So they were given mental health diagnoses but the underlying root cause, which was the lack of support for their neurodivergence, was never addressed. Instead of finally receiving the support they needed, they were pathologised, institutionalised and still misunderstood. Inevitably, if the root cause of mental health issues, which is unsupported needs because you are autistic, is not being addressed, you will inevitably fall back into poor mental health again because we are not addressing the actual issue.

Lord Hope of Craighead: I wonder if you could tell us a bit more about the best way of improving the problem you have identified. It is the second part of my question, because we would welcome guidance from you, particularly as to how to improve the situation.

The Chair: Apologies; I just wanted to let the witnesses know that we are likely to have a vote in in the coming minutes. Apologies if I cut you short, but let us continue until the Division Bell goes.

Marsha Martin: Speaking as someone who is black and autistic, to address these particular inequities we really have to start at what is causing the disparity. There are various things causing it but—and it feels repetitive—it is always going to be lack of visibility of our unique, culturally nuanced challenges that we face, living on the intersect of being black and disabled. There are things that we face that other people are unaware of. If there is no knowledge of those things, that means that when it comes to accessing support, treatment and so on and so forth, there will be a gap in what we are able to get because the unique challenges have not been addressed. We are seeing that there is overrepresentation of needs for black autistic people, but when it comes to schooling, social care and healthcare, the support that should be implemented is significantly less. That needs to be addressed within itself. We are looking at a very significant difference.

Roman-Urrestarazu did a research report recently—I believe it was in 2021—which stated that for every 10 white boys who were recognised as having SEND needs and were issued with an education, health and care plan, only one black girl was given a plan. The biggest part is really addressing why these disparities happen, because there is no reason why we should be overrepresented in terms of having support needs.

This is recognised and evidenced, but you are asking me what is to be done about it. Surely we should be implementing the support that the children need in the same way and there should be no disparity. That is not something that I can answer because I am not sure why there is a disparity. It is quite clear to me that if we are overrepresented, we should be prioritised so that we are not left behind.

Lord Hope of Craighead: Thank you very much indeed for that answer. ZeZe, I wonder whether you could answer my questions, particularly focusing on autistic young people experiencing mental ill-health.

Zaynab Sohawon: Yes, absolutely. I will talk a little bit about my lived experience in response to this. I first turned up to children’s mental health services when I was 11 years old. It was not until I turned 13 that I received an autism diagnosis, so for two years I had been with mental health services and seeing them every week—sometimes twice a week—without any of them realising that I was autistic. I went a while before I was diagnosed.

My story is quite common. There are a lot of autistic people who first turn up to mental health services with a mental health problem which is actually underlying autism. There is no specific service or provision that deals with that issue; it just happens. In addition, the system that supports autistic people and people with mental ill-health is the same system that causes harm in terms of epistemic injustice not being believed—the needs that someone presents with—but also in terms of maltreatment at in-patient mental health units and in services. It is about having to fight to say that you are ill enough to get to having high enough thresholds to reach adequate support. Those issues are all real barriers to accessing timely, helpful and relevant support for autistic people with mental ill-health. Sorry, is that the bell?

The Chair: Yes, ZeZe; thank you for drawing it to our attention. My Lords, the session is suspended for a vote in the House. We will recommence in approximately 10 minutes. Please, if the witnesses could stay online—in the room or on the Zoom call—we will reconvene as quickly as possible. Thank you very much for bearing with us.

Sitting suspended.

The Chair: This session is now resumed.

Q20 **Lord Hope of Craighead:** ZeZe, have you said all you wanted to say in answer to my questions?

Zaynab Sohawon: I would like to add an additional statement on how to improve support for and identification of autistic people. My answer to that would be around not just additional resource—that is, additional money put into the system that supports autistic people with mental ill-health—but better management of that resource. I am talking specifically around commissioning. We do not need just money injected into the system; we need the money to be managed better, in a more equitable and effective way, to make sure that autistic people with mental ill-health are supported and do not suffer maltreatment at the hands of the system that is meant to support them.

Lord Hope of Craighead: Thank you very much. Leo, can I come to you and ask you to answer these questions with particular reference to business and employment?

Leo Capella: I will start off with identification, if that is okay. I will then talk about being supported.

Lord Hope of Craighead: Please go ahead.

Leo Capella: Right. Let us talk about identification. On that note, we have to talk about disclosure, as it is relevant here.

Currently, the onus is on autistic people to disclose—that is, in many ways, rightfully as it should be; it means that the power is in our hands to disclose—but, actually, the key thing is making sure that there is a space for us to disclose effectively and have the skills to do so. We recommend that, at every opportunity, employers give the opportunity—whether that is on the application form they give out, through any application means or in the workplace itself—because this is a personal decision. For a lot of autistic people who may have gone from job to job having rough experiences, in that environment, their guard is effectively going to be up. That goes for people who have already been diagnosed, those who are mid-diagnosis and even those who are newly diagnosed and still figuring it out. We encourage employers to provide that warm, clear, precise welcome.

I, too, want to make a point on that side of identification. A lot of things happen with a lot of diagnoses. A lot of support comes in place when someone is in a state of crisis. I would say that, actually, the diagnosis should not be the issue, particularly given research from Ambitious about Autism. It showed that the young people surveyed in some research said that they do not tell potential employers that they are autistic because they are afraid of being treated unfairly, with over 70 percent of them saying that they do not disclose because of fear of discrimination.

The thing is, it is not about identifying the autistic person, whether they are undiagnosed or diagnosed. It is about supporting the problem. In employment, we do not really use the Autism Act, although it is there. We use and talk about the anticipatory duty of the Equality Act, which means solving the problem. For instance, if you noticed that someone was having problems in an environment, such as getting overwhelmed or having trouble taking briefings if they are in a crowded car park, would you ask, "Are you autistic? Should you get diagnosed as being autistic?", or would you stop the meetings being held in a car park? The solution is to stop the meetings being held in a car park.

At the National Autistic Society, our guidance on diagnosis is that it is not about asking the question or saying, "Look, you should get diagnosed, whether you are autistic or not". Autistic people do not have some special radar with which we can instantly pick up other autistic people. We say, "Look, unless you know the person closely, do not do it". To riff off "Field of Dreams", build it and they will come. In this case, if you build it, they will come forward.

One other thing: just because someone is diagnosed—newly or otherwise—does not mean that they will know what support they will need. I am someone who had support in school and university. Translating that experience into what I needed in employment was tricky. It is the same for other autistic people.

We have advice like our "Finding Employment" module that can give people the tools on that score, but it is about employers actually developing the expertise. I should also like to make a quick point on offering support. Everyone has their journey with being autistic—that was one thing I learned as a job coach—but not everyone will take support automatically. It is about doing what you can around it. I think it is because of the whole fear of, "Will I be making it clear in whatever form that there will not be any soft discrimination?", or that you will not be put into other places—you will not be put under, say, less demanding tasks than you are actually capable of, as well as hard tasks. It is about building the confidence whereby they will, where possible, keep control through the process. That is a big issue with the cause at the moment, that fear of loss of control: "Will I be empowered by this support in terms of that regular catch-up?"—that kind of thing. There will be people who, when offered support, will say, "Thanks for this but I do not really need it".

So the key thing is giving people the tools and making sure the support and adjustments are there, whether through access to work or through an adjustment that employers have to make, maybe by making sure that mental health support is there too, and maybe by giving the nudge if a problem is happening—gently and really carefully. But it is almost that old phrase: you can bring a horse to water but you cannot force it to drink. If you did that, apart from choking the horse, you might make it buck or become less strong than it was because of the loss of already perhaps brittle or low self-esteem.

Lord Hope of Craighead: Thank you very much indeed, Leo. Shall we leave it like that?

Q21 **Lord Elliott of Mickle Fell:** Good afternoon, everybody. My question is in two parts. How effectively are autistic people and the people who support them included in the decisions that affect them? What would be the best way to improve this? Can we start with ZeZe? Can you answer first, focusing on autistic young people experiencing mental ill-health?

Zaynab Sohawon: I think that autistic young people with mental ill-health and their supporters are not included in decisions that are made about them. Decisions are made about them without them, and when it comes to decisions around being sectioned or the status of being informal or not in a mental health unit, it is a big decision to be placed on a young person. It is done in a "done to", rather than a "done with" way. That is a real barrier to autistic young people accessing support that is going to be helpful and conducive to their mental health recovery, but also with understanding their autistic needs.

Supporting that can be done by enhancing the work of commissioners through the Transforming Care agenda, an agenda created to better support and protect autistic people in the mental health system and people with learning disabilities. More work around Transforming Care should be done to support autistic young people and their supporters to co-produce their own care in a specialised way, to empower them in their mental health journey, alongside enabling them to understand how their autism affects them.

Lord Elliott of Mickle Fell: Marsha, could you answer next, focusing on children and families?

Marsha Martin: Autistic people and their families are rarely meaningfully included in decisions that directly impact their lives. I say "meaningfully" because sometimes we are given a seat at the table. For example, you have invited me today. The general consensus is that these are just tick-box exercises whereby we are not necessarily listened to, and certainly our concerns are not acted upon. Policies, to echo what ZeZe has just said, are often made about us but without us, and usually by individuals with little understanding of what it means to be autistic, let alone the additional challenges of being autistic and a minority.

Nowhere is this more evident than in recent attendance policy changes, which basically impose fines for child absence. They are charging families for basically protecting the mental health of their children. They do not address the root cause of why autistic children are struggling to attend in the first place. The statistics speak for themselves: 92.1% of children with significant school absences are neurodivergent, and 83.4% are autistic. That is a huge percentage. These absences are not the result of parental neglect or not wanting to engage with education. They are a direct consequence of the school not providing adequate SEND provision for the children. When autistic children are forced into environments that are overwhelming, inaccessible and even harmful to their mental health, families are often left with an unfair choice—either to send their child into a setting that basically deteriorates their well-being or keep them home and then face financial punishment.

In terms of improving this, it feels almost commonsensical—like the answers for all of these questions, to be fair. Had autistic individuals, their families and SEND advocates been properly consulted and listened to, these policy changes and changes like them would never have been implemented in their current form. Instead of punishing families for protecting their children, the Government should be addressing the systemic failures in education—those that are causing the absences in the first place. Proper consultation means listening to those with lived experience, ensuring policies are based on real needs rather than assumptions, and working collaboratively to create solutions that support, rather than penalise, autistic children and families.

Autistic voices, especially those of black and other marginalised communities, must not just be included but prioritised because we are being failed immensely, and that is significantly evidenced. Consultation must not be an afterthought. It needs to be an integral part of the decision-making process and needs to happen every step of the way. I have never met a parent of an autistic child who did not have strong ideas about changes that could be made to better support their children but were either ignored or never asked. If policymakers continue to exclude autistic voices from decision-making, they will continue to create policies that harm rather than help us. True inclusion means not just inviting us to the table but actually acting on what we say.

Lord Elliott of Mickle Fell: Thank you so much, Marsha. Finally, Leo can you answer the same question, focusing on business and employment?

Leo Capella: I agree with everything that has been said. I made the point earlier regarding employment. On a policy level, I would echo the point of my fellow panellists, and I have witnessed it. I would also go so far as to say: autism and disability have been dominated by people acting with the best of intentions but, because they failed to include the actual voices of people on the ground, the worst of actions happened. Without meaning to be too waspish, I like the picture by Katsushika Hokusai, "The Great Wave off Kanagawa". I do not like great waves coming off certain government buildings. We need effective co-production that perhaps goes beyond advisory groups. I respect the fact that, with the benefits bill the way it is, that might be as welcome as a plague of cats coming into this committee room. I would prefer instead to think of it as autistic people and their families providing feedback on the sorts of adjustment that are needed on the ground, and doing so effectively. It may be about putting us together in the same room, on an equal pegging, with witnesses so that we can advise and maybe even have a direct democratic say in how policy is shaped and decided on. That way, we will get effective policy; it will be the equivalent of a rising tide floating all boats because everyone will be listened to. It will mean us having an accurate gauge and not writing people off, on the one hand, but also not literally overwriting them, on the other hand. We are not in a good place at the moment. We can get to a much better place.

Lord Elliott of Mickle Fell: Thank you so much.

Q22 **Baroness Hodgson of Abinger:** I begin by declaring that I have no interest. In your view, what are the most important things that the Government could do to improve the lives of autistic people and the people who support them? Can I begin with you, Leo, please?

Leo Capella: I have a rapid-fire set of things. First, you could lead by example. I am grateful to you for inviting me to speak virtually. If the Houses of Parliament could allow MPs to come in hybridly, that would be a huge—I have to avoid slang—example of inclusion focusing not on the diagnosis of people but on the practice of getting people into the same space, whether they are Peers or Members of Parliament.

It is about getting support on not just the physical adjustments but the mental one, such as through an employee assistance programme, job coaching or advocacy support, and getting a really effective campaign. Do not forget self-employment and entrepreneurship, either. Above all, it is about making sure that you do not just listen to autistic voices but empower them, whether in businesses, in employers or in the policy process itself. It can be done, I think. Grizzly old kaiju that I am, I hope that, by the time you come to review this Act in the next 10 or 15 years, we will be in a much stronger place for autistic people and their families.

Baroness Hodgson of Abinger: Thank you. Marsha, would you like me to repeat the question or do you have it there?

Marsha Martin: I have it here in front of me, thank you. If we are serious about improving the lives of autistic people and those who support them, the Government must move beyond surface-level policies—what feel like tick-box exercises—and commit to real, visible, measurable, systemic change. I will begin to sound like a broken record here but this is especially important for black autistic children and their families because they face additional barriers due to racial disparities in various aspects of their lives.

First, educational reform is critical. Schools and local authorities must be held accountable for providing proper SEND support, ensuring that autistic children—again, especially black autistic children, who are more likely to be excluded or underserved—receive the accommodations that they need. The Government must end punitive measures such as attendance fines, which are not fit for purpose; they punish families for a system that is failing their children instead of focusing on making schools genuinely inclusive environments for these children.

Secondly, healthcare must become accessible and equitable. This means tackling medical racism, improving autism training for healthcare professionals, and ensuring early and more accurate diagnoses for all autistic people so that black autistic children and minority autistic children are not left behind, as they are now. Mental health services must be properly funded. As ZeZe said, the money must be managed adequately and tailored to the needs of autistic individuals, rather than forcing them into systems that do not understand them or are unable to accommodate them.

Thirdly, autistic voices must be at the centre of policy-making; I touched on this earlier. There must be no more decisions about us without us. Government consultations must actively include autistic people and their families, particularly those from underrepresented communities, to ensure that policies reflect lived experiences rather than outdated assumptions, which they oftentimes can.

Finally, there needs to be a commitment to tackling intersectional inequalities. Lots of people do not necessarily know what we mean by intersectionality; that is a problem in itself. Black autistic individuals face unique challenges that require targeted solutions—it is not going to be a one-size-fits-all approach—whether that is through funding black-led autism organisations, ensuring that research includes information on racial disparities or addressing the additional discrimination faced in education, healthcare, criminal justice and employment.

Baroness Hodgson of Abinger: Thank you very much. I turn to you, ZeZe.

Zaynab Sohawon: First off, I would like to say thank you very much for giving me the privilege of being the final one to answer the final question. I really hope that we can use the energy in this room, where we are all here together, to make change; and that we can catalyse that energy into energy that is turned into transformative, meaningful change in autistic people's lives.

There are three main outcomes that I would like the Government to do to improve the lives of autistic people. They are quite simple. One is more funding; the second is better management of resource; and the third is improved protection of autistic people under the Mental Health Act.

I will talk a bit about the first one: more funding. This is evident from all of my fellow panellists' discussions. I think we all know that there needs to be an injection of more funding into the system to support people better, but I will give some context to make it come to life a bit more. One year of me being in a mental health unit as an autistic person cost my NHS trust £286,600; that was just for me for one year. I was in hospital for four years, so I racked up just over £1 million for my NHS trust to spend on me being in a mental health unit that was not actually helping me very much. When we put that into the context of lots of other young people who are autistic and have mental health needs, we are spending a lot of money but not in a very effective way.

That leads me on to the next point, which is about better management of resource and better commissioning. Lots of money comes with great expectations that everything is going to fix everything. I do not think that that is the case; I do not think that all the money in the world could fix every issue that the system has. It is about working in partnership with those with lived experience, clinicians and commissioning experts—that is, them working together to co-produce a better system and spend the money in a way that is effective for autistic people.

My third point is about better protections and legalities for autistic people under the Mental Health Act. I think I mentioned Lolly's law previously; it is a campaign that currently has 225,000 signatures, so it has a lot of traction. This law is something that the founder of that campaign wants to launch into Parliament to make it an amendment to the Mental Health Act. The idea is around making sure that there are better protections for autistic people who end up in mental health hospitals, to make sure that they are not sent hundreds of miles away from their home; that they are not mistreated; and that they are not sectioned for hours or restrained for hours at a time. It is about making sure that autistic people are given just, humane treatment.

With all those considerations in mind, those are my three outcomes that I think would be beneficial for autistic people. I would just like to thank everybody in this room for coming together, with all your interests, to improve services and, I hope, to make the world a better place for autistic people with mental health needs. Thank you.

The Chair: It is this committee who should be thanking you, ZeZe, Marsha and Leo for the incredibly informative, thought-provoking conversation that we have had today. The committee will really benefit from the experiences that the three of you have provided us with. We are incredibly grateful to all three of you for taking us through some of your journeys and providing us with some things that we should definitely be thinking about taking forward. I say thank you from every member of the committee here today. The next evidence session will be on Monday 24 March; in the meantime, today's evidence session is now concluded.

HOUSE OF LORDS