

COMMITTEE ON THE AUTISM ACT 2009

NOTE OF MEETING WITH EXPERTS BY EXPERIENCE, 1 MAY 2025

The House of Lords Committee on the Autism Act 2009 held a private meeting on 1 May with experts by experience, facilitated by NDTi. The meeting was to discuss how effectively autistic people are involved in making decisions about NHS and local authority services and how this could be improved in the future.

All participants had lived experience of trying to access health and care services as an autistic person, or for autistic children. Some participants had previous lived experience of mental health inpatient admission.

All participants had experience of working with the NHS and other organisations to improve services for autistic services. Between them, participants' experiences included creating and delivering autism training for health and social care staff; developing an autistic-led post-diagnostic support programme; acting as a panel member in Care (Education) and Treatment Reviews; supporting the parents of children diagnosed as autistic and/or having a learning disability; and being a school governor.

- I. In your experience, how effectively do NHS and local authority services meet autistic people's needs? What are the main barriers to meeting autistic people's needs effectively?**
 - **The Committee is investigating how well the *Autism Act 2009* is working. In your experience, what impact (if any) have the *Autism Act*, autism strategy and statutory guidance had on the provision of services for autistic people? Why have they been effective or not effective?**

Participants said that there are still large numbers of NHS and local authority staff who have not had any training on practical approaches to working with autistic people. The training that they have is basic and does not provide practical skills on how to approach the person in front of you.

There are some very good services, driven by individual professionals who participate in training and actively involve autistic people. There is a postcode lottery. A participant gave an example of where they had been commissioned to deliver voluntary training for health and care staff. They hosted about 300 people for each webinar. This shows there are lots of staff who are truly personally invested in taking up the training.

Barriers to meeting autistic people's needs include time, money and staff resources. For example, there has been a concerted effort to implement training programmes, but there are barriers to rollout and uptake. Staff don't always understand that doing training isn't just a day out of their time, it's a tool they can use with patients in front of them. There is an idea that you can teach everyone what autism is. That's not really possible, as autistic people are all different. It would be very powerful to empower autistic people to learn their own profile of needs and their rights and to communicate their needs to professionals. Professionals also

need to receive training on different profiles and how to respond to the needs of the person in front of them.

There is a need to address stigma and move away from the idea that autism is a disorder. This needs to happen in an intersectional way. Different community services and hospitals serve local populations with different needs. Black autistic people and people from other ethnic minorities are less likely to access the support they need. There is a need to listen to autistic people's experiences and perspectives and to make sure that they can communicate their needs. People need to be supported to understand their rights and what the law says.

A participant spoke about their experience of trying to access services. As an autistic person with co-occurring conditions, they spent years in the NHS going round the houses. They interpret pain differently. Professionals told them they were making it up and it was all in their head. They were undiagnosed and unsupported until they had a mental health crisis. In emergency situations in physical and mental health services, no adjustments are made for autistic people's needs. Autistic people can become unable to respond in the ways that professionals want them to. There is little support for carers and advocates. This has become worse since the pandemic. The sensory environment in psychiatric wards is a cocktail for an extremely difficult and traumatic experience. They were not supported to transition back into the community after leaving hospital and couldn't use the bus for two years after discharge.

Some services are trying to move away from diagnosis-led support to needs-led support, but this is challenging. There are long delays in diagnosis. This is a longstanding problem. The NICE recommendation of 13 weeks from referral to diagnosis was not being achieved even ten years ago. There is a need to ensure people don't have to receive a diagnosis to access support. However, society relies on diagnosis for everything from welfare benefits to access to railcards and bus passes.

The Autism Act has helped make the NHS aware of its duties, but many aspects of the strategy don't seem to have manifested. Barriers include a lack of focus on implementation and funding; the fact that the Act covers adults only; and barriers to autistic people becoming true leaders of service change and being paid fairly to do so.

2. In your experience, how effectively do the NHS and local authorities involve autistic people and families/carers in making decisions about the services they use?

- **What impact does this have on how effectively services meet autistic people's needs?**

Participants spoke about failures to involve autistic people and their families/carers in decisions about the support they need. For the families and carers of autistic children, it's not easy to deal with local authorities. An EHC plan might say that a child needs input from speech and language therapy, but then that doesn't happen in practice. This can mislead the family. During the transition to adulthood when the person is 17 or 18, services fight over who is responsible for what and move the goalposts, without really listening to the person or their family.

One participant said they needed a carer for almost all their appointments. They are very often patronised and their mother is spoken to instead of them. Decisions about the services they access are made about them, not for them. If they were given reasonable adjustments, their anxiety levels and communication needs would be completely different. They know services are under-funded and over-stretched, but even smaller adjustments feel like an unreasonable ask. Without adjustments, autistic people can become more insecure and likely to mask their needs. People in psychiatric wards (whether under section or not) lose their autonomy. They said the changes to the Mental Health Act don't do enough to prevent traumatic admissions. The Autism Act does not prevent this either.

Another participant spoke about their experience of reviewing the care and treatment of autistic people in inpatient settings. This ranged from cases of teenagers who had been in the criminal justice system and ended up in hospital to a case of a late-diagnosed autistic adult who had a history of employment blocking cyber-crime. When a local authority needs to find a placement for a person or set up a discharge pathway from hospital, they don't always really listen to the person and their family and find the right placement. Services don't really do early intervention. Often people are admitted to hospital because local authority services have failed and not really listened to the person and their family. The money comes after the person has been sectioned. This is traumatic for the person and their family.

Participants gave good and bad examples of involving autistic people in decisions about how services are run. There are some amazing projects with shared power and co-production, that allow experts by experience to be part of every aspect of the project and support them to share traumatic experiences in a safe way. For example, one participant spoke about working with a local authority board on transforming neurodiversity. Autistic adults on the board are consulted and involved in how services are developed and go out to inspect services.

Another participant said that they had been mined for trauma and used to rubber-stamp projects, particularly when younger and more vulnerable. It's a postcode lottery. There is not enough vetting of organisations. Some organisations don't practise what they preach and cause long-term trauma to the autistic people that they bring in to do that work. For example, experts by experience can end up talking about traumatic experience and not getting the right support, doing intense emotional labour and not being compensated properly for their time, and being used in a tokenistic way.

There is still a need to bring autistic people into permanent, decision-making roles. There is also a need to build up knowledge of how to co-produce services, particularly with autistic people with different communication needs. In the meantime, there is a lack of access to diagnostic services and mental health services that meet autistic people's needs. There are some community support services that are provided by autistic people and their families, but they are outside wider service frameworks.

3. What are the main barriers to involving autistic people and their families/carers in making decisions about services the services they use? What would be the best ways to overcome those barriers?

Participants spoke about the 'double empathy' problem: autistic people and non-autistic people struggle to understand each other. Society puts all the pressure to resolve this problem on autistic people. The barriers are made by systems that are not set up for autistic people. When an autistic person is in crisis, involving the autistic person and their family in decisions isn't prioritised. In reality, the crisis would be less lengthy if there was less uncertainty and lack of structure. There is also a lack of knowledge. Sometimes healthcare interventions are taken off the table because professionals believe it would be too difficult to make adjustments. Autistic people know their own needs better than professionals do and often interpret their bodies differently. Understanding and listening to the autistic person is key. Professionals are more likely to dismiss and fail to listen to autistic people who are also marginalised in other ways. A participant spoke about professionals telling them that their sexuality and gender identity were caused by their autism and being told they had 'naughty girl' syndrome when trying to access healthcare. There is a lack of use of alternative communication methods (including easy read and plain language versions). Adjustments are often not that difficult and expensive but they are not prioritised.

Another participant spoke about the need for more understanding of autism in the community. Their child finished university two years ago and has applied for hundreds of jobs but hasn't received any help from the local authority because of the label of autism. There is a need to prioritise jobs for autistic people more than others. They are put at the bottom at the moment. Local shops and supermarkets need support and training to employ autistic people. Without support, things can go in the wrong direction and autistic people can end up being admitted as mental health inpatients.

Services don't always invite autistic people to the table, or they do this in a tokenistic way. Sometimes they veto or knock back what autistic people say because it's not the way that things are done. It can take months for people even to be compensated for their time. Changes can take months or years to be implemented. An example was given of an autistic person who asked to be involved in panels for Care (Education) and Treatment Reviews. The process took a very long time and in the meantime panel meetings were not being held. Services need to do more to enable autistic people to tell services they have an idea and to listen to those ideas. Services don't listen to autistic people from different backgrounds enough. There are not enough non-white people and LGBTQ people in the room. There can be a lack of understanding of autistic people's behaviours and communication. Professionals can find autistic people difficult, angry and intimidating. This is also an intersectional issue: for instance, professionals are more likely to see a Black autistic woman as angry.

To overcome these barriers, there is a need for more representation and for real decision-making roles to be held by autistic people. There is a need for real consultation with autistic people in the community, including people from marginalised communities and people with significant disability. Organisations need to be held to account for tokenistic gestures towards co-production and for exploitation of autistic people. There need to be better ways to get things across to the NHS. Reverse mentorship could be part of this, enabling professionals to learn directly from autistic people.

4. The Committee's final report will make recommendations about what the Government should do following the end of the national autism strategy for 2021 to 2026. What do you think is the most effective thing

the Government could do to improve NHS and local authority services for autistic people?

Participants spoke about the need to spend money early. One participant spoke about their child not being able to access support from an educational psychologist even though they have an EHC plan because of a lack of funding. Earlier intervention would be more effective.

One participant called for autistic leadership to be embedded in service design and evaluation and for autistic people to be able to access support with identified needs regardless of whether they have a diagnosis. Struggling services should be supported and services that are doing well should be rewarded. There should be more carrot and less stick.

Another participant called for more training. The mandatory training on learning disability and autism is fairly narrow, particularly on specialised aspects of healthcare and on working with autistic people who have co-occurring conditions and/or are multiply marginalised. In an ideal world, every autistic person would have an individualised sensory assessment and their care would reflect their priorities and experiences.

Participants agreed on the need to reduce the numbers of autistic people in mental health inpatient settings. Being a mental health inpatient can be debilitating for an autistic person if they are in constant meltdown or shutdown. The statistics on this are very bad and not improving. One participant had met an autistic person who had been in the same hospital room and bed for 16 years. Two participants knew of autistic people in their local area who had been in hospital for more than 30 years.