

COMMITTEE ON THE AUTISM ACT 2009

NOTE OF MEETING WITH NHS AND LOCAL AUTHORITY PROFESSIONALS, 1 MAY 2025

On 1 May 2025 the House of Lords Committee on the Autism Act 2009 held a private meeting with professionals in the NHS and local authorities, facilitated by NDTi.

This 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 the participants in this meeting had experience of developing and co-producing NHS and/or local authority services for autistic people. Some of the participants were autistic.

1. 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 is a lot of variation. Some services are exemplary and others are far behind. It is a postcode lottery. One barrier is that autism is sometimes still viewed as something that affects children and young people, so the concept of autistic adults is novel and confusing. There is a big drop off in support beyond age of 18. Some children's and young people's services extend to 25. Though this perpetuates the infantilisation of autistic people, it does provide some continuity. Many people make patronising assumptions about how to communicate with autistic people and expect autistic people to conform to them. There are ever-increasing waiting lists. Some people seek private diagnoses, but services do not always recognise them. This wastes services' and families' time and money. Local authority assessments are bureaucratic and intimidating. Paperwork, interviews and assessments can cause severe anxiety and affect quality of life. Mandatory training on learning disability and autism is quite narrow and doesn't cover much on sensory processing or interoception. There are very low levels of employment and many dream of a life where they can have a job and contribute. At the end of the day, we are all human beings. The duties in the statutory guidance are very positive steps, but they don't go far enough and aren't enforced so they do not have the effect we would all like to see.

There are both successes and failures in the NHS and local authorities. Systems often address people's needs reactively. Eventually, there are successful outcomes, but in the process there is unnecessary trauma and distress. This has a significant emotional cost. Services are weighted too heavily towards treatment rather than public health approaches. Rather than spending more money, services need to spend it differently and earlier. Non-autistic professionals recognise behavioural difference, but don't support understanding of what it means to experience the world in a subjectively different way. If people aren't actively

supported to understand their own experience of the world, they rely on those around them. Culturally, we could do more to teach autistic people to understand and advocate for their needs. This would help wider society understand autism as a way of being.

The Autism Act gave local authorities and the NHS a statutory obligation to provide services. There is often agreement about what needs to happen. The Act and statutory guidance are used to guide us. For example, one participant said their local authority had carried out an autism review four years ago looking at services (primarily for adults) and how to improve them. They then developed an autism strategy and implementation plan, consulting with about 100 autistic people in the local area. The local strategy is aligned with the national strategy.

There are real challenges. There is a lack of community services and an over-reliance on mental health crisis services, which are not well-placed to help autistic people. Autistic people can fall between different services. Mental health services often feel an autistic person's needs are due to autism and refer them to social care, but colleagues in social care also under-equipped to help them. This is particularly challenging where someone is displaying behaviour which challenges, hoarding, Avoidant/Restrictive Food Intake Disorder (ARFID), and self-harm and what support or organisation would be best placed to provide meet the identified needs. Funding is another barrier. There used to be ring-fenced budgets as part of the Service Development Funding (SDF) via NHS England which has now stopped and this will likely result in a fall back to statutory obligations in services rather than being able to develop holistic services to meet the needs of the person as a whole. There are separate budgets for health and social care. This results in discussions between services about who is responsible and delays in a person getting the right services.

2. 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 said they were passionate about coproduction and making sure services meet the needs of their population, rather than making assumptions about what people need.

A participant spoke about the experience of their NHS trust. They were doing strategic work to identify why their services aren't working as well as they should be. At service level, the trust has moved from consultative to collaborative approaches. There is a board of autistic people paid a professional wage to carry out internal projects and build collaboration across health and care services. The board could be more diverse. The outcomes have been significant in terms of cultivating partnerships across different sectors, influencing organisational policy and practice, commissioning new services, and challenging services that are not neurodiversity-affirming. The board is bringing different voices to decisions. For example, the board identified that one service could be open for shorter hours later in the day, meeting people's needs better and saving money. Collaboration on children's and young people's services is less well-developed and the voices we need most are often missing. The participants wanted involvement of autistic people in services to become the rule, not the exception.

Another participant spoke about a community-led post-diagnostic peer support service. People in the local autistic community were involved in presenting the specification for the

service and monitoring the contract. Now the contract is being reviewed and autistic people are involved in that. There is a local coproduction board to keep commissioners on the right track. They act as a critical friend, advocating for their needs and how they can be met better. This is mostly focused on adults. There is a young commissioner programme to support children and young people's voice in services but this needs to be developed further.

Another participant said there is a lot of variation. Some NHS trusts have senior people who champion autistic people's voices being heard in all decisions. In other areas autistic people are widely ignored or told how their own lives should be. Overall, this drives anxiety and has a negative impact on people's experiences. There are horror stories of care failings, abuse and deaths. Autistic people can end up asking for services and having the door shut in their face. It can feel like betrayal, or like a stick is being used to beat you down with. But there can be recovery and hope too: involving autistic people in decisions, frontline innovation, getting people out of hospital after a number of years. There are opportunities to restructure staff teams to include autistic people as paid staff. It's important for autistic people who are in distress and trying to access services to see others like them on the other side. The impact of this can be breathtaking.

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

A participant said their local coproduction board was very strong, but it only represented a small proportion of the population and it only had white men on it. Members of the board do not always agree on the best way forward. This can make it challenging for a commissioner to take their advice. It can be difficult to cater to people's different access needs—for example, some people find it easier to meet online and others find it more difficult. Another challenge in coproduction is that not everyone is interested in all areas of policy and implementation. For example, the coproduction board looked at the local supported living strategy but the board members weren't interested because it didn't apply to them. There is a need to collaborate with a wider range of people, including people from different cultural backgrounds and people with more severe learning disability. It's key not to forget about people who can't easily advocate for themselves.

Another participant said their Integrated Care System was partway through its journey on involving people. The barriers are not insurmountable but they are significant. There is a need for genuine diversity of voice, particularly among people with complex needs. The workforce needs to be supported to adapt to new ways of working. Consultation is sometimes mistaken for coproduction. For this participant, the solutions lie in time, education, building clear evidence of the need for change, and standardising capabilities around the existing core capability framework.

Another participant said they felt that there was a lack of understanding of rights and responsibilities at all levels. EHC plans are an example of this: most families don't understand they have entitlements to support outside school too. There are staffing and funding constraints. If a service is focused on meeting key performance indicators, involving people is seen as a nice-to-have. There needs to be a change of values, towards a more collaborative and less hierarchical approach. There need to be honest conversations without

defensiveness, which takes bravery on both sides. Autistic people need to be directly employed and become fully integrated as professionals, so that autism is integral, not an outside thing. Defensive and inflexible thinking are unhelpful. Ironically, this participant said, in this sense NHS service providers can be more stereotypically autistic than 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?

A participant said they thought it was critical to bring in autistic people as a qualified and integral part of staff teams. Many autistic people still get bullied out of work. There are high barriers to employment due to a lack of understanding and stigma. Organisations can bring people from the outside in to help deliver services and make prioritisation decisions. This means people on the outside can see people like them on the inside fighting for them. This would have wider positive social and cultural effects. It comes back to hope and humanity.

Another participant said it would be helpful for there to be more clarity on the role of diagnosis. There are such long waiting lists that services shouldn't have to wait to support a person with an identified need. In mental health services, more clarity would help with challenging professionals for attributing a person's needs just to autism and writing them off as not needing treatment for mental health conditions. Mental health conditions may be more likely in autistic people but they can still be treated—it's just that a different approach may be needed. Local authorities are often working with rigid contracts. This can make it difficult to be flexible when new understanding comes to light about the population of autistic people and how to meet their needs. The Oliver McGowan training is a great start, but there is a need for more in-depth training for professionals. For example, in their area there are very few speech and language therapists who are specifically qualified to work with autistic people. Specialisms for working with autistic people should be developed in different professions.

Another participant called for a shift from a reactive model to a preventative approach to services. All health and care staff should be trained before they enter the workforce in working with autistic people, and this should be based on the Core Capabilities Framework for Supporting Autistic People. There should also be training on neurodivergence in schools and for employers. There should be legislative requirements for authentic coproduction in service design, commissioning and evaluation, moving beyond consultation to power sharing. This would help drive a culture shift, helping to reduce unnecessary costs, improve autistic people's quality of life, and develop public understanding of autism as a difference not a deficit.