COMMITTEE ON THE AUTISM ACT 2009

NOTE OF MEETING WITH THE HOUSE OF COMMONS AUTISTIC CHAMPIONS, 24 APRIL 2025

The Committee held a private meeting on 24 April with the House of Commons Autistic Champions, a group of autistic adults working with Parliament.

The role of the Autistic Champions is to review and provide feedback on Parliament's public engagement services from the perspective of autistic people, looking at experiences like visiting Parliament, going on tours and finding information on the Parliamentary website.

The meeting was an opportunity for the Committee to learn about the work of the Autistic Champions and to discuss key issues for autistic people from their perspective and priorities for the Committee's inquiry.

Participants in the meeting had a range of experiences of advocating for and supporting autistic people, including delivering autism training for the NHS and other organisations (including the Oliver McGowan Mandatory Training on learning disability and autism); working with NHS, local authority services, employers and the police to improve support; working with heritage organisations to make visits more accessible; supporting autistic children and young people and their parents; carrying out research into autistic people's experiences; and creating online content sharing their experiences.

Participants had been diagnosed as autistic at different ages and had different experiences of autism and co-occurring conditions, including ADHD, learning disability, epilepsy, eating disorders and chronic illness.

1. Key issues for autistic people

Several participants said it was important to improve understanding and acceptance of autism. A participant said we are still too medicalised in our approach. There is othering: autistic people are viewed as less than human and the default is that their way of being is wrong. Lots of the challenges they face are avoidable. There is a massive shift required to get that to change. Otherwise, we will be going round in circles. We often say 'autistic people have communication challenges', but what that really means is that the professional doesn't have an adaptable skillset. We need to rehumanise the autistic experience. Autistic people have lost possession of the word autism: it's seen as a medical thing detached from the human. They are an autistic person and exist as part of society. Autistic people have the same wants and needs as most humans.

Participants said that the roots of why autistic people have autistic traits are differences in the processing of information. Autistic people process more information and prune irrelevant information less, leading to overwhelm. So, even at the baseline they are processing the world from a position of overwhelm. We should look at support through a lens of the processing of information, not through the lens of behavioural traits.

A participant spoke about the importance of understanding autism in people with co-occurring conditions. Better understanding of autism in women and girls is key. They were

diagnosed with autism at 24, ten years after becoming very unwell with anorexia. They spent five years detained in hospital, two of them far from family in Scotland. The care they received was inappropriate and traumatic. They managed to get out of hospital. A key part of their recovery was finding out they were autistic, under the care of an open-minded psychiatrist who referred them for assessment and a nurse who was willing to adapt their treatment before they had had a formal assessment. They are now in the final year of university. It would have been much better for them to be identified as autistic when first in contact with mental health services. They were medicated, restrained and secluded in ways they shouldn't have been. When you get an autism diagnosis, those experiences don't go away. It's key to have trauma-informed care for autistic people with co-occurring conditions. They are still in recovery from mental health problems that came about from unrecognised autism. Part of their care is processing what they went through in hospital.

The participant also raised the issue of pilot schemes that are good and then stop. They had worked on the PEACE pathway pilot in children's and adolescent services, as the lead expert by experience. The pilot was great to be involved with. It drove better and quicker identification, reducing admission times. There was an amazing three years and then the funding stopped. Why? It saved lives and got people who were stuck on wards home and into a stronger place.

Participants spoke about improving access to education for autistic children and young people. One participant was prescribed Fridays off school by their doctor due to sensory shutdowns. That enhanced their attendance and got them from F to A grades. There was no point sitting through hours of neurotypical-focused teaching and learning. Every day autistic people are shut down they are losing the ability to function the next day. Another participant spoke about how using strengths to overcome challenges can help autistic people immensely. For example, their child is a big fan of Formula One. They encouraged them to apply the structure of Formula One to school learning, creating spreadsheets to help with inference in English literature.

Participants discussed the need to improve support in employment. A participant spoke about how their child got good academic results and a first class degree at university. The only time they didn't know where to go further was employment. Now they run an employment consultancy with programmes for young people who encounter cliff-edges in support after education, providing mentoring with a focus on empowerment and taking positive opportunities from adversity. Another participant was diagnosed at 18 after they tried working but it didn't work out. They were academically successful but struggled with the world of employment.

Another participant got a good graduate job but lost out on an opportunity to thrive because of the open plan office. They were the only graduate that didn't get promoted. It was a great job, but they and their colleagues didn't realise the impact that the open plan office was having. They were bullied out of one of their jobs and it nearly went to tribunal. There is a lot of wasted cost and resources. Education could prevent that. The participant said that people say they are unemployable but they have three jobs supporting and training others. Autistic people have a lot of untapped resource and potential. We shouldn't be waiting for

more suicides: we need to be proactive and provide training for educational professionals and employers.

Another participant said they had two paid jobs, but this is the only time they have had that opportunity. They struggled to get employment for five years and were told that they wouldn't get a job due to autism and learning disability. They have received job-appropriate training. As part of their work, they help advocate for people who are nonverbal. There might be people who are nonverbal who want to find work but need carers or advocates to support them.

A participant spoke about access to social housing and supported living. They were taken off the social housing list by the council because they needed supported living. They were hoping to go through the supported living process, but it didn't work out. That hurt them and knocked their independence.

2. Priorities for the Committee

Participants spoke about the need to improve public understanding and acceptance. Autistic people need understanding that they are humans and not lesser. It stems from education, training and media. It should be about giving people the benefit of the doubt and checking if people might be misunderstanding. The place to start would be education, so that everyone has exposure from the get-go and lives their whole lives with an understanding of autistic people. To raise public awareness, there should be training in schools and for employers, drawing on people's real-life experiences. There also needs to be more training on abuse including covert abuse. Autistic people don't always process if they are being abused.

A participant spoke about the importance of self-understanding. They didn't have a diagnosis of autism until adulthood and still don't have a diagnosis of likely dyspraxia. That means missed opportunities for self-understanding. As a neurodivergent person, they get to explore their understanding of what it means to be them. We should start at age five and enable people to start understanding their own brains. It would be a great starting place to stop the negative ripple effect throughout individuals' lives and through society. We should focus on using autistic people's strengths and passions to enhance their abilities.

Participants spoke about improving access to healthcare and mental health support. It's important for there to be validation of the autistic experience, particularly in mental health care. Everyone in the mental health system should be screened for autism (albeit that there are problems with screening processes). All professionals should be thinking about it. Mental health difficulties are often a result of unaccommodated autism. Adjustments like changing lighting levels can make a big difference and save so much time. There should be more autism training by autistic people. One participant said they know from personal experience that GPs don't always do training on learning disability and autism because it takes time and resource. Participants also said there should also be tailored research into the links between autism and trauma and into the impact of autistic people's information processing on chronic pain, endocrine and gut issues.

Participants spoke about improving access to education. Education should be tailored to autistic people's needs. There is unintentional gaslighting of autistic people in neurotypical education settings. What helps neurotypical people doesn't help autistic people. Autistic people are told to deny their lived reality. There should be more training for parents and tutors for support at home.

Participants spoke about improving access to employment. There should be steps into paid work. An autistic person should be able to start a job on limited hours to establish the level of support they need. They should be given reasonable adjustments and eased into the full job description. The right adjustments should be in place by the time they start full time. Another participant said they were raising employment as an issue with their MP and local election candidates. They highlighted the 'benefits trap' of losing benefits if you work more than 16 hours a week.

A participant said we need to start with accountability. There is no accountability at the moment. Committee members had said in the previous public evidence session that the Secretary of State is meant to ensure accountability, but that hasn't happened. There needs to be an independent body, that reports to a panel of autistic people or is made up of autistic and non-autistic people. It needs to be independent of government and come from the top. Like a conductor in an orchestra, it would drive improvements in diagnosis, public understanding, and education, ensuring better allocation of funding and saving money.