

## **APPGA Meeting on Autism Act 2009 Committee Report**

**Date:** Wednesday 21<sup>st</sup> January

**Time:** 16:30-17:30

**Location:** Room P, Portcullis House

### **Attendance:**

Alison Hume MP (Chair)

Cat Eccles MP (Vice-Chair)

Baroness Browning (Officer)

Lord Wigley

Baroness Hodgson

Jen Craft MP

Jo Platt MP

Sarah Hall MP

Alex Mayer MP

### **Agenda:**

#### **Meeting Opened at 16:35**

##### **1. Welcome and Introductions**

Alison began the meeting and introduced Baroness Browning, a member of the Autism Act committee, inviting her to give some background to the report.

##### **2. Overview of the Autism Act 2009 Committee's report**

Baroness Browning commended the briefing NAS put together and encouraged attendees to take a physical copy of the report available at the meeting. She noted that the report made many specific recommendations, many of which were very hard hitting. She added that the Government are expected to reply to the report at the end of the week.

She then went into the background of the report, noting that 2009 seems a long time ago, with those in the Commons at the time feeling like things had moved with respect to autism, but not nearly quickly enough. She paid tribute to Dame Cheryl Gillan, who submitted a Private Member's Bill and chose the Act as her number one choice at the end of Parliament. NAS stepped in to help write the Bill.

She added that autism is one of the only conditions with its own Act, but that the reason for this is obvious; autism is different. More so today than when the Act came onto the statute books, there is awareness of neurodivergent conditions and a greater appreciation for the whole spectrum of autism.

The recommendations show that autistic people are not only likely to die earlier than the general population but also compared to other neurodiverse conditions. She added that it is not rocket science – it is a communication disorder. Someone with a serious illness is less likely to get the treatment they deserve if they are unable to communicate to their fullest.

She reiterated that we are dealing with a spectrum, and that this was something that prompted her to put this report forward to be completed. She has questioned ministers about the strategy due this year, and asked when they intended to start consulting, to which they told her they planned to do this soon. She added that one of the big issues that has been raised recently is the number of children who are coming forward for diagnosis. While expectations of what these children's lives will look like now is much more positive than years ago, many are still being set up to fail – the transition to further education and adulthood should be seamless.

The worry is that some of the more able autistic people coming out of education are all too aware of the difference between them and their peers. More moderately able children lose the structure of the school day, and these differences become more apparent. She added that she knows many autistic people have tried to break through that glass ceiling, and that many of them give up. The suicide rate is far higher than it should be. She then introduced the House of Commons staff who worked with the committee, thanking them for their work in helping to produce the report. Stuart Stoner, Lucy Valsamadis and Abdullah Ahmad

The House of Lords Autism Act Committee Clerk Stuart Stoner confirmed the government is supposed to respond on Friday. The report will be published as a common paper and debated on the floor of the House of Lords.

Baroness Browning noted that the report received more written responses than any other House of Lord's report, with nearly 400 written responses.

### **3. Reflections on the report from National Autism charities**

Alison agreed this is a landmark report, and that a great deal of time and effort had been put into it. She then introduced Tom Purser, CEO of Autism Action.

Tom introduced himself as a member of a united group of autism charities: Autism Action, Ambitious about Autism, Autism Alliance, National Autistic Society, and Autistica. Collectively they represent more than a million autistic people. He stated we must urge the government to produce a new autism strategy, informed by this report. The extent of inequality autistic people face is routinely shocking, and with an absence of accountability, can only be addressed in very specific ways.

He added that autism is not niche, and that the stakes are too high to treat it as such. He stated that autistic people are on average more likely to die earlier than non-autistic people. He expressed that this is unacceptable, and that it comes as a result of systemic failures across assessment, diagnosis, health, education, employment, as well as the hardening of the rhetoric around autism and the questioning of the rights of autistic children to access education. He added that the language around welfare reform concerned them and autistic people, with 2026 threatening to be a trial where managing these changes may push us toward a politics where we stop asking how we can make people's lives better.

He then recognised the work Stuart, Lucy and team had put in, as well as Baroness Browning and the whole committee.

He added that we should consider how and why we've reached this point, and that we must acknowledge the lack of impact the Autism Act has had. When he started working at NAS the first statutory guidance was released. We shouldn't underestimate the good work done, but a real joined up approach is still needed to make sure it has the impact it should have across Government. We need to consider bolder approaches, with the new Autism Strategy designed to help mainstream services rather than rely on assumptions that public service reform will fix these issues. He added that if the new strategy is delivered properly, there may be great outcomes for autistic people. This is not just economic benefits, but fuller and longer lives. He added that he is mindful of the report the Secretary of State for Health and Social Care has commissioned on overdiagnosis. The autism charities had jointly written to Wes Streeting before Christmas asking for further

information on the timeline for the Autism Strategy but are still waiting to hear back. He then finished by adding that they are there to help the Strategy progress in whatever way they can, including further briefings, quick turnarounds of surveys, case studies and resources. Together we can and need to raise awareness and urgency of the issues facing autistic people.

#### **4. Feedback from new APPGA Survey**

Kate Wilson, the National Autistic Society's Assistant Parliamentary Officer and APPGA Secretariat introduced the survey as a replacement for the previous Advisory Group, as NAS felt this was more representative of a wider range of autistic people. The survey had received 71 responses from the NAS APPGA mailing list across 10 days. She then ran through key statistics:

- 58% of participants had previously heard about the report; 39% had not; 2% were unsure.
- 52% of participants agreed with the conclusions and recommendations outlined in the report; 10% did not agree; 38% were unsure.
- When asked, "How effective would you say the Autism Act 2009 and successive autism strategies have been at addressing the issues facing autistic people?", the average rating was 3.85 out of 10.
- When asked what respondents would like to see prioritised in the next autism strategy:
  - 29% wanted increased or improved mental health services and community support; 18% wanted increased or improved access and support in employment; 13% wanted increased or improved attention paid to health inequalities; 12% wanted increased societal understanding and acceptance; and 11% wanted increased or improved access and support in education.
- When asked to choose a single word they believed accurately described the current state of services for autistic people, participants said:
  - Inadequate (17%), Poor (11%), Dire (6%), and Patchy (6%)
  - Other prominent terms included "neglectful", "non-existent" and "diabolical".
- When asked to rate the accessibility of support and services for autistic people on a scale of 1-5, the average rating was 1.71.
- When asked the rate the quality of services and support for autistic people on a scale of 1-5, the average rating was 1.96.

She then ran through actions for parliamentarians, with major themes including directly engaging with autistic people, advocating for better access to employment for autistic people, and working for improvement to

the quality and access of mental and physical healthcare services for autistic people. She finished by noting that a copy of the data and written/oral questions will be sent to members after the meeting.

Jen Craft asked how we are representing non-verbal autistic people. Kate replied that the survey collects demographic information and is regularly reassessed to ensure we represent autistic people from all backgrounds, and that the survey can also be filled out by friends, family and carers of autistic people.

## **5. Discussion on the next Autism Strategy and group actions to be taken forward, e.g. letters, PQs, parliamentary events and debates**

Alison then opened the floor to next steps on the strategy.

Jo Platt introduced herself as the Chair of the ADHD APPG and mentioned that her and Alison met yesterday with the Chair of the APPG for Dyslexia and found a shared battle. She said that reading the report, she found lots of overlap in challenges faced and asked how we can go forward with this in mind.

Baroness Browning said she felt that while there is a lot of common ground, with lots to be gained, she feels that grouping them as a collective may risk limiting the resources available to individual neurodivergence groups, particularly for those on the more able end of the spectrum.

Jo agreed and clarified that she is speaking more broadly of the issues faced by neurodivergent people: access, early years provision, primary/secondary provision.

Baroness Browning agreed that there are many people with both ADHD and autism, and she does not agree with the notion that they have all “sprung up from nowhere”. She said that they have been very robust in the report – if someone presents with symptoms of autism, and wants a diagnosis, they should be able to get one.

Baroness Watkins added that she was previously a mental health nurse, and that a thorough assessment may also help identify needs beyond autism and things that may help with this. She also added that autistic people are one of few groups to prefer person-centred language, i.e. autistic person, where other groups do not like being referred to as their diagnosis, i.e. depressive person.

Baroness Browning agreed that autism is not a mental health condition and that we must hold on to that.

Jen Craft then introduced herself as Chair of the APPG on Learning Disability and a part of the Mental Health Bill Committee, and would be keen to compare the Autism Act and Down Syndrome Act and to see what this process looks like.

Alison Hume asked what can be done in Commons to build on the report and the Government response.

Cat Eccles said that we should definitely try to get a Westminster Hall Debate, working towards a Backbench debate. She said she'd be interested in putting this forward.

Baroness Browning agreed that they are currently in a stronger position in the Lords than the Commons with regards to ministerial engagement, and that we need to invite Ministers to private meetings moving forward. She said that we should be asking for an annual review of progress. She added that there is no real accountability if local bodies are not doing what they should, and so Ministers must be more engaged with the new strategy and its implementation.

Alison agreed that debates and private meetings are good suggestions; she asked whether NAS had put together some written questions for MPs and Peers.

Kate said yes, that NAS have put together some written and oral questions we will be sending around after the meeting.

Cat said we must be mindful that the date of the new strategy will come quickly and that we need to put plans in place sooner rather than later. She had concerns that the Oliver McGowan Mandatory Training was not being implemented properly and asked if any FOIs had been done to check this.

Baroness Browning agreed that the training was good, but it was very patchy.

Sarah said that she met with a mum about how the North West – where her constituency is – was one of the worst places for the training to be adopted.

Baroness Browning said that we must hold people accountable for each section of the report. She acknowledged that this was different for the last report as it was released during COVID, and that while these should not be arbitrary targets, we should consider what the outcomes might be.

## **6. AOB + details on next meeting**

Alison then moved on to Any Other Business. She explained that she went to an Autism Action event today which had mothers speaking about their autistic daughters whom they lost to suicide, as autistic girls are often overlooked. She asked the Secretariat to distribute a leaflet from the event to the Secretariat.

Danae clarified that the Autism Alliance represents many regionally focused autism organisations.

Finished with a discussion on plans for next meeting to be focused on SEND reforms and that Autism APPG Secretariat will work with Secretariats of ADHD and Learning Disability APPGs to plan for joint meetings on the topic.