THE ALL-PARTY PARLIAMENTARY GROUP
appg on Autism

APPGA Annual General Meeting

Date: Tuesday 25th November

Time: 17:00-18:00

Location: Room U, Portcullis House

Attendance:

Christine Jardine MP (Independent Nominated Chair)

Alison Hume MP (Chair)

Cat Eccles MP (Vice-Chair)

Baroness Browning (Officer)

Baroness Jones of Moulsecoomb

Lord Stone of Blackheath

Euan Stainbank MP

Julia Buckley MP

Jodie Gosling MP

Sarah Hall MP

Richard Quigley MP

Julian Smith MP

Alex Mayer MP

Claire Young MP

Agenda:

Meeting Opened at 17:15

1. **Welcome and Introductions**

All in attendance introduced themselves and some offered their personal and professional connections to autism. Christine Jardine introduced herself as the Independent Chair and read through the rules that must be followed for the AGM. She noted that the meeting was quorate.

2. Election of new Chair

Alison Hume was unanimously elected as Chair

3. Election of 3 Officers

Cat Eccles was unanimously elected as Vice-Chair, and Baroness Angela Browning and Lord Don Touhig were unanimously renewed in their roles as Officers.

4. Income and expenditure statement for publication

The income and expenditure statement was approved unanimously. The APPGA receives no funding other than the benefits in kind provided by the National Autistic Society as the secretariat.

5. Review of due diligence statement

The due diligence statement was approved unanimously. The APPGA receives no funding or interference by foreign governments.

6. Overview from National Autistic Society of issue of misinformation

Joey Nettleton Burrows, the National Autistic Society's Policy and Public Affairs Manager, offered an overview of the misinformation that is being heard repeatedly and how it increases stigma for autistic people.

- Claims linking autism to vaccines and painkillers are false and risk devaluing autistic people and undermining decades of robust research.
- Narratives on overdiagnosis are misinformed and not based on evidence. Whereas there is evidence of underdiagnosis in groups such as females and older adults
- Misinformation about access to EHCPs and diagnoses that are seen as 'golden tickets' to support when in fact both lengthy, difficult processes to ask and often don't result in extra support.
- MPs, Lords and particularly APPGA members can be vocal advocates for autistic people by calling out misinformation where possible and encourage the government to condemn harmful myths about autism.

Joey then asked if anyone had any questions or thoughts to share on the topic of misinformation.

Claire Young expressed that many autistic people are currently being accused of financially benefitting from their diagnosis, but this is easily disproven by the low employment statistics of autistic people. She would like to see this added to briefings.

Lord Stone offered to ask any questions that NAS or others can send him and encouraged others to do the same.

Baroness Browning added that every year, the House of Lords does four inquiries, and that in January of next year one of the subjects will be childhood vaccines where it will be important to recognise false claims about autism and vaccines and how these have been harmful.

Cat Eccles expressed concerns for repeated attacks from within Parliament, adding that they will only continue to build.

Euan Stainbank expressed concerns for a lack of capacity for responding to misinformation in context, and that the APPGA ideally needs to work toward combating misinformation in a proactive way.

> Joey agreed that this lack of understanding is at the national level, and that while accountability must be with national governments, the APPGA needs to supervise this process as much as possible.

Julia Buckley asked whether there is capacity for the APPGA to increase awareness of neurodivergence in Parliament. She suggested this sends two messages. This is firstly that MPs can be advocates for neurodivergent people, but also that there are more neurodivergent MPs than ever before and that this neurodivergence is an asset.

> Sarah Hall added this is a point she tries to make often, by noting that she has ADHD.
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> Lord Stone added that there are 47,000 people working across government. He noted that if he had a randomised group of people, he would hope that group is as diverse as possible. The fact that many of them are neurodiverse is a positive thing.

Richard Quigley mentioned he is a member of the APPG on eating disorder and suggested that there is not much connecting anorexia and eating disorders with autism despite the relationship between the two.

> Joey affirmed that we are happy to do joint APPG meetings and connection between autism and eating disorders is something that would be good to meet on, and that members should ask their secretariats to message NAS.

Julian Smith expressed concern that the information parliamentarians receive different lobbying information from different organisations, and that we should work together for cohesive purposes. In the context of education, he gave an example that one government bill is currently looking to penalise pupils for being late to school, but they likely haven't considered how this will disproportionately affect disabled students. He added that given the bill is delayed, there is an opportunity to contribute if needed.

> Joey responded that this will likely be a greater focus in January/February, when the SEND reforms are published and we can use the APPGA to share information and produce an aligned response.

Sarah Hall said that she is an Officer for the ADHD APPG and expressed a desire to hold a roundtable or otherwise collaborate with similar APPGs.

> Joey added that this is something we previously tried to do, but the meeting was disrupted because of tube strikes and we will of course look to do in the future as soon as possible.

Richard Quigley said that the press is increasingly arguing autism is over diagnosed, and that the ways autistic people are referred to by the press has meant that people think badly of those with autism. He asked, what information is there about prevalence of autistic people?

> Joey responded that generally the number is at 1 in 100 people, but it is difficult to give an accurate picture particularly due to under recognition and underdiagnosis, in women and minorities. He noted that on Thursday (27th November) the Adult Psychiatric Morbidity Study is being published, which will cover the prevalence of autism in adults and more research in general into prevalence is needed particularly focused on previously unrecognised groups

7. Introduction of new Advisory Group structure

Joey explained the new structure of the Advisory Group, which will transition away from a group meeting to a regular survey for APPGA mailing list members on the topic of the upcoming meeting.

> Alison Hume asked how members were being determined, and whether we can review how well it is working.

Joey affirmed that anyone could fill it in that wanted to, but this would be based on the current APPGA mailing list. He added that yes, this can be reviewed at future meetings once it has been implemented.

Agreement to review after around 6 months

8. Discussion on aims and future meetings of APPGA for 2024-25 (Led by new Chair)

Alison Hume discussed the Annual Report, noting that there were four meetings last year:

- September 2024: Inaugural General Meeting
- December 2024: Mental Health Bill Meeting
- May 2025: Government's Proposed Welfare Reforms Meeting
- September 2025: SEND Reform Meeting (Cancelled due to Tube strikes)

She then went through the Annual Plan, including the dates and times of future meetings. Alison introduced that the next meeting would discuss the Autism Act Committee Report.

Baroness Browning introduced the House of Lords Autism Act Committee Report, adding that the Autism Act 2009 was hard fought and hard won. It means that every five years, the government must produce a strategy explaining the priorities of autistic people, and how they might be supported by local and national authorities. She added that next July, the strategy is due for renewal. She noted that this report received more contributions than any other report the HoL has ever done. The committee recognise that money is not flush, and that they want the government to implement realistic, deliverable priorities. She added that regardless of the percentage of the population that is autistic, all of them deserve a certain level of support. She recognised that the report is long but encouraged APPGA members to at least read the recommendations. She hopes that the government takes the report into account when they create the new strategy.

She also added that in the new year, she will be working with the police to encourage their employment of autistic people in fields like detection of cybercrime and conversely preventing them from getting involved in those fields for the wrong reasons.

Joey responded that his hope would also be having another APPGA meeting on the report soon, and for Health Innovation and Safety minister Zubir Ahmed to attend as the minister with responsibility for the strategy, so members can emphasise the importance of the report and developing a new strategy to him.

Alison Hume expressed that it’s fantastic to have this report, and that she is delighted to take over at a point where there’s something we can get our teeth into. She agreed she will send a letter to invite Minister Ahmed to the next meeting.

> Joey added that NAS will put together a summary of the report and its recommendations for members.

Alison Hume asked whether anyone else had any thoughts on the annual plan and ideas for future meetings.

> Baroness Browning responded that based on the evidence we’ve seen, diagnosis is important for autism. We don’t need generic services for generic people – autism is a lifelong condition. Despite this, there is very little information on care and old age. Autistic people need appropriate old age care.

Alison noted that there isn’t a topic scheduled for the meeting in June, and that she’s really interested in the whole supported living for young people and as they age as this is not often discussed.

> Baroness Browning agreed, noting that it is difficult to be older and articulate what you want, and that from her own experience having and understanding the power of attorney is essential. She expressed that all autistic people should have someone they know and trust, and that they can communicate with. She discussed her personal experience with her autistic son and daughter-in-law, noting that when she dies there will be nobody else to support them. As a result, she has built a circle of friends that will be able to support them.

Alison Hume asked whether members agree autism and ageing could be a possible topic?

> Members agreed, and Joey added that NAS could create a more concrete plan based on what is suggested in this meeting.
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> Jodie Gosling expressed that there is much to be gained in understanding autism and family and the significance of nature and nurture.

Alison Hume asked whether Jodie is suggesting we look at families having those conversations?

> Jodie Gosling clarified that we should challenge narratives by looking at the generations of neurodivergence in families and its prevalence in

families over time. There is a significant underdiagnosis of the previous generation.

Alex Mayer suggested that there are many different debates on autism, but the titles look too depressing which can deter MPs. She suggested that we try and create a more positive conversation.

Joey suggested that this is something we could try and do for World Autism Acceptance Month (WAAM) and create an environment where MPs can talk about their experiences with autism.

Alison Hume agreed that this is something we could do in May (WAAM) She suggested we do a session on something more upbeat and maybe try involving some other high-level autistic people.

Joey suggested that he could reach out to some of NAS' celebrity ambassadors.

Meeting Closed at 18:00