



APPGA Inaugural Meeting

Date: Tuesday 10th September 2024

Time: 12:30 – 13:30

Location: Room T, Portcullis House

Agenda

1. Welcome and Introduction
2. Election of new chair
3. Election of 3 officers
4. Overview from National Autistic Society of key issues facing autistic people in the country
5. Discussion on aims and future meetings of APPGA for 2024-25
6. AOB

Attendees

Shockat Adam MP

Dan Aldridge MP

Sadik Al-Hassan MP

Catherine Atkinson MP

Baroness Angela Browning

Andrew Cooper MP

Josh Fenton-Glynn MP

Jodie Gosling MP

John Grady MP

Sarah Hall MP

Monica Harding MP

Alison Hume MP

Alex Mayer MP

Perran Moon MP

Jo Platt MP

Lord Jeffrey Sterling

Lord Andrew Stone

Peter Swallow MP

Marie Tidball MP

Lord Don Touhig

Apologies

Lord Tim Boswell

Julia Buckley MP

Kirith Entwistle MP

Bill Esterson MP

Baroness Anna Healy

Baroness Sheila Hollins

Baroness Jenny Jones

Kate Osborne MP

Vikki Slade MP

Baroness Mary Watkins

Welcome and Introductions

All in attendance introduced themselves and talked about their personal and professional backgrounds in relation to autism.

Election of new chair

Marie Tidball MP was nominated as chair. She spoke about her history working with Autism West Midlands, and her doctorate on autistic defendants in the criminal justice system and subsequent book. She emphasised her intention for the APPGA to involve autistic people's lived experience as much as possible in its work.

Marie Tidball MP was unanimously elected by the attendees.

Election of 3 officers

The following three members were elected as officers:

Alison Hume MP

Baroness Angela Browning

Lord Don Touhig

Overview from National Autistic Society of key issues facing autistic people in the country

Joey Nettleton Burrows, the National Autistic Society's Policy and Public Affairs Manager, outlined the key issues facing autistic people in the country. This included:

- Diagnosis crisis – 187,000 people are waiting for an autism assessment in England alone; 87% have been waiting longer than the NICE recommended 13 weeks. There is a need for a timely and standardized process that meets NICE guidelines to be developed over the coming ten years.
- Mental Health Scandal – Autistic people face inappropriate detention in mental health hospitals where they are subject to restraint and medication and are often placed far from home. Many are institutionalized due to a lack of preventative mental healthcare in their community.
 - The Mental Health Act (1983) defines autism as a mental health disorder which is inaccurate and allows wrongful detention. Upcoming MHA reforms must include a definition change.
- SEND crisis – the findings of the 2023 NAS education report were discussed, and mandatory comprehensive autism training provided by the Autism Educational Trust (AET) was suggested, in a similar vein to the Oliver McGowan training for health and social care staff.

Sarah Hall expressed interest in discussion of the underdiagnosis of women and Perran Moon raised potential gendered biases in diagnostic assessments.

There was enthusiastic discussion of the abilities of autistic people and their potential to bring strong skillsets to various industries; Lord Touhig referenced Autistica's finding that doubling the autism employment rate could generate £1.5billion for the economy.

There was discussion about autism being labelled as a disability. Marie Tidball MP mentioned the importance of differentiating between having an

administrative definition to apply legally and personal identification and social definitions (wherein there is a range of opinions within the community).

Baroness Browning spoke of the importance of ensuring autistic people have their entitlement to benefits upheld, referencing offensive questions from PIP assessment officers. She urged MPs in attendance to use their direct numbers to departments to advocate for their constituents who are being denied the access they are entitled to.

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

A number of suggestions for meeting throughout the year were made, including:

A meeting to discuss the Mental Health Bill (time of meeting dependent on passage through parliament) and inviting Baroness Merron in her capacity as Minister for Mental Health and Women's Health

A meeting to discuss a review of statutory guidance on autism, inviting Stephen Kinnock MP in his capacity as Minister for Social Care.

An event during World Autism Acceptance Week (WAAW), 2-8th April – focused on increasing understanding of autism.

A meeting to discuss the representation of autistic people in public life in various spheres (including politics and the media).

Other suggestions, if time allows, include meetings on SEND, employment and Criminal Justice.

A number of attendees expressed a desire to hear from outside speakers and those with lived experience.

AOB

Desire from members in the room to be notified of upcoming parliamentary activity related to autism. Hope (Secretariat) will coordinate this going forward.