

Cross-Party Group on Autism

20 November 2024, 6pm-8pm

Minute

Present

Note: bold font denotes attendance in person.

MSPs

Alexander Burnett (Convener)

Annie Wells

Invited guests

Lynn Campbell

Helen Mahood

Sarah Marshall

James Richards

Kate Sang

Tanya Milligan

Andy Williams

Declan McKendrick

Yvonne Barrowman

Non-MSP Group Members

Secretariat

Suzi Martin, National Autistic Society Scotland

Alexandra West, National Autistic Society Scotland

Mark McDonald, Scottish Autism

Marion McLaughlin, APO Representative

Non-MSP Attendees (some names are drawn from the Zoom attendee list, so surnames are only presented where these were present within usernames):

Robyn Fairley

Ellie

Evie Barrowman

Adele hill

Alex Paterson

Andrew Crosbie

Angie Ferguson

Declan Hogan

Donna Scott
Dorothy Barbour
Dr Catriona Stewart
Elaine Finnie
Emma Parker
Fiona Clarke
Lorraine Gillies
Ramon Hutchingson
John Grafton
Kabie Brook
Karen Spence
Kat Allen
Lauren Murray
Louise Carson
Louise Storie
Mark Phillips
Ailsa Lindsay
Ash Loydon
Helen Heppenstall
Max Rankin
Shaun Barr
Malika Bouazzaoui
Rob Holland
Lynda McLeod
Ma
Frank Maurice
Mr Anderson
Myles Fitt
Sally Cavers
Stehen Caulfield
Terri Rankin
S O'Reilly
Sofia Akbar

Apologies

David Nicholson
Cherie Morgan
Oliver Mundell MSP
Mark Ruskell MSP

Agenda item 1 – Convenor's Welcome

The Convener welcomed attendees to the CPG and thanked everyone for attending.

The theme for the meeting was 'The Autistic Employment Gap' and took place in a hybrid format with some members in the Committee Room and others joining online.

The Minutes from the previous meeting (held in September 2024) was approved as read, with no objections.

Alexander Burnett MSP welcomed everyone to the third and final meeting of the Autism Cross-Party Group of 2024 and outlined the housekeeping for the meeting.

Agenda item 2 – AGM

The Convenor read out the nominations for each role. Each role was supported and seconded with no contestation. Therefore, the following roles were elected as follows:

Convenor – Alexander Burnett MSP

Deputy Convenor – Daniel Johnson MSP

Secretariat – National Autistic Society Scotland, Scottish Autism, and Marion McLaughlin (APO representative)

Agenda item 3 – Meet the Member

Autistic ‘n’ Awesome (Central Advocacy Partners)

Central Advocacy Services are a member-led independent advocacy charity, providing advocacy across Forth Valley. They support young people between 12-24 in the Falkirk area.

Autistic ‘n’ Awesome started when young autistic people came together to create an environment where they felt supported. They especially wanted to support young people going through transitions to adulthood.

The workshop aims to:

- Build positive image of autism
- Develop self-advocacy skills
- Look at transitions and change

Young people attending the workshops are encouraged to work on personal development and make friends in a safe environment.

Autistic ‘n’ Awesome also puts forward the view that being autistic is not a bad thing and emphasises the positives.

Autistic Voices Advocating Together for Autistic Rights (AVATAR)

AVATAR is a newly minted APO working across the Scottish Borders, given that there is very limited support for autistic adults in the Borders.

They now have a board of six trustees.

Key goals:

- building community
- provide advocacy
- signposting support
- developing collective advocacy by working with services and local community.

They recently launched a digital community via a member only Discord channel. An online community was deemed most viable due to spread of Scottish Borders.

Currently developing self-advocacy training for autistic adults and hope training will give autistic adults the confidence and ability to advocate for themselves.

Agenda item 3 – Speakers

Understanding the workplace experiences of autistic women

Prof. James Richards and Prof. Kate Sang

Both noted their experience working in the area of autistic employment for approximately 10 years.

Current research looks at the chronic lack of fair work, which leads to high levels of unemployment and underemployment, which in turn leads to discrimination.

Research questions:

- What does work look like for autistic people?
- How do autism and gender intersect at work?

The research is aimed at trying to change policy and practice in the workplace via the Fair Work agenda. It has five dimensions: effective voice, opportunity, security, fulfilment, and respect.

Findings showed that there are statistically significant differences depending on the gender presentation of employees.

Lack of guidance on how to manage and support autistic employees due to a lack of research.

Regarding menstrual health at work, many autistic individuals coming forward to participate. It was noted that HRT also does not work for neurodivergent people as it does for neurotypical people.

Furthermore, perimenopause can be very difficult for autistic people whereby a monthly period was regular occurrence and almost a source of comfort and therefore the loss of periods through menopause became a cause of distress.

Pre-menstrual dysphoria disorder and premenstrual syndrome (PMS) became impossible for individuals to manage. They felt unable to access the resources which were made available.

This has been the first study around this intersection and more research needs to be undertaken to ensure that treatments and support for autistic people are appropriate and available.

Existing Fair Work approaches are not working to support autistic people. Looking at the disabling barriers rather than reasonable adjustments means not having to look through things via an individual deficit approach.

Into Work

Tanya Milligan

Into Work is a personalised employment advice and support for disabled people aged 16+ across Edinburgh and Lothians, which supports employers to recruit and retain disabled employees.

Autistic employment gap statistics don't cover underemployment or those who are undiagnosed. Nor do they cover the wider impact on autistic people, their families, society and employers.

Why does the gap exist? Lifelong discrimination and inequalities in education, health and society.

Barriers to employment include trauma, exclusionary recruitment practices, workplaces not set up for autistic people, negative impacts of autism disclosure, difficulty accessing reasonable adjustments, lack of understanding and support from managers and colleagues, and people may not be aware of the help available.

What works?

Supportive, flexible managers and working practices.

For example, managers/Human Resources being knowledgeable about reasonable adjustments, transparent recruitment practices, and training by autistic people with lived experience of employment.

Information about reasonable adjustments, support to develop confidence to set boundaries, increased understanding, and training by autistic people have all shown to work for autistic people in the aim to reduce the autistic employment gap.

It was noted that the Into Work training focused on shifting understanding and knowledge and employers valued a lived experience delivery.

DWP Access to Work, Autism Confident

Sarah Marshall, Helen Mahood, Lynn Campbell

Access to Work is a discretionary grant related to disability or health condition and has been in place since 1994.

Applicants do not need to have a diagnosis and can apply if they show traits of a particular condition. This is because the focus of the grant is on what aspects of your job you are struggling with rather than a formal diagnosis.

Access to Work grants can pay for multiple things such as ergonomic equipment, support worker/job coach, awareness training for colleagues, and communication support at an interview.

83 Job Centres are currently rolling out the Autism Confident program and are committed to deepening their understanding of autism and enhancing ability to support autistic individuals.

Regarding some successes, the Banff Job Centre has had great outcomes for autistic people, providing education for employer around the nuances of the individual applying for positions.

Disabled People's Employment Team

A written update from the Scottish Government's Disabled People's Employment Team was read out by Suzi Martin from the National Autistic Society Scotland.

A copy of the letter was distributed to CPG members following the meeting.

Agenda item 4 – Q&A; and comments

These comments were all made in the chat during presentations and addressed during the Q&A.

Point raised by Susan Chambers (PASDA)

Families of autistic people were hardly mentioned by any of the speakers at the meeting. Argued that, if families were not there to help, there would not be appropriate support in place for a lot of autistic adults.

Everything is about consultation, but nothing is happening and nothing is working for autistic adults. Action is needed rather than just words. How will the employment gap be addressed?

Q: Do we need mandatory training for employers – particularly in public sector workplace?

Prof. James Richards stated that work quality and job satisfaction has to be improved and training is about the last mile of that journey.

Tanya Milligan added that the IntoWork training is done over several weeks which enables a level of reflection. Working for a council, they never had training on something as basic as reasonable adjustments under the Equality Act. Therefore, there is a lot of very poor training, so quality needs to be introduced.

Sarah Marshall stated that within the DWP, all assessors have training across conditions. They are asking individuals what they need and are led by them.

Q: Can people apply for help to apply for Access to Work?

Sarah Marshall replied that the DWP are trying to upskill Job Centre staff to assist people to apply. She also added that, if people cannot apply online, they can apply via telephone calls.

[A point was raised that telephones are not accessible for many autistic people]

Lorraine Gillies began by stating she is a recently diagnosed ADHD and autistic individual. She was struggling to stay in the workplace, finding the workplace too difficult, but then moved to working freelance.

She added that there are lots of women coming out of the workplace due to it being too difficult and so is putting together a peer network for people similar. This is called The Wedge (www.thewedge.scot) which aims to support women at risk of leaving the workplace.

Prof. Kate Sang noted that menopause can often lead towards a diagnosis.

One CPG member added that they are still awaiting travel support for their children who are at the end of their teenage years.

Q: How much of a disparity in employment rates can be attributed to lack of reasonable adjustments and how much to lack of support in education and to transition.

Prof. Kate Sang noted that there has been a lot of work around science, particularly PhD students, but you need a bachelor's and master's degree, so you did well at school. It is about support at school but also family as well. People have been describing it as a cliff edge as they move from education into employment.

Prof. Sang also highlighted that the Equality Act requires pre-emption of support needs for students, but this does not apply to staff.

Prof. James Richards replied to the questions by noting that there are some people who fear being openly autistic would cost them their job and are, therefore, doing a lot of masking or working around issues. A social model of disability requires transference of obligation onto employers to do more.

Q: Difference between direct employment and indirect employment – role of agencies?

Tanya Milligan stated that they haven't worked with agencies directly but feedback from individuals is mixed as to whether they are good. It ultimately comes down to individual managers and how flexible they are.

Fiona Clarke added that there is no right way for everyone as it is about the individual person and taking a 1-2-1 approach.

Marion McLaughlin further added that temporary jobs can be good for autistic people. They allow individuals to put employers 'on trial' and see whether they are a positive employer for them and other autistic people.

Q: Can an employee ask for a specific agency to support them in work? DWP have in the past asked for three quotes.

Sarah Marshall clarified that this is about ensuring value for money. Access to Work will not choose a provider as that is for the individual to choose.

Q: Where is the next Heriot-Watt research going to be?

Prof. Sang stated she is looking at where trade unions can fit into this and also how can support be given around heavy menstrual bleeding.

Prof. Richards reported that he is speaking to a trade union looking at how to support and represent neurodivergent individuals across the rail industry both as a collective and on an individual basis.

Agenda item 5 – AOB

Learning Disabilities, Autism and Neurodivergence (LDAN) Bill

Ramon Hutchison referred to the letter from the Minister, Maree Todd MSP ultimately stating that the LDAN Bill has been kicked into the long grass. The point was made that expectations were raised by the consultation, but there has been a large transaction with no transformation. Ramond expressed significant frustration at this.

Agenda item 5 – Convenor's reply

The Convener thanked speakers and everyone for attending and commented that he is just waiting for another date and time to be confirmed for the next CPG so will get this out to everyone shortly.