

Cross Party Group on Autism

1st February 2021 at 1.00 pm via Zoom

Minutes

Attendees:

Alex Burnett, MSP (Chair)	Johann Lamont, MSP	
Oliver Mundell, MSP	Fulton MacGregor, MSP	
Mark McDonald, MSP	Bee Vellacott, Inspiring Scotland	
Louise Scott, Scottish Government	Kabie Brook, ARGH	
Charlene Tait, Scottish Autism	Lyndsay Macadam, SWAN	
Nick Ward, NAS	David Nicholson, Our Voice Our Rights	
Jan Savage, ENABLE	Rob Holland, NAS	
Jason Henderson, NAS	Helen Calley (Minutes)	
Rebecca Allen	David Allott	Dorothy Barbour
Neil Barbour	Steve Billingham	Julie Brown
Jay Brownlee	Patricia Cain	Stephanie Callaghan
David Campbell	Fiona Clarke	Fiona Culbert
Henna Cundill	Gyll Curtis-Machin	Dorothy Daldry
Pamela Duffy	Jerry Edwards	Angie Ferguson
Fran Foreman	Maurice Frank	Annemarie Gallagher
Felicity Goodhall	Michelle Graham	Pauline Grigor
Lorraine Harris	Annie Humphrey	Richard Ibbotson
Sheila Mackay	Leticia Martinez-Garcia	Andrea McKenna
Dorry McLaughlin	Marion McLaughlin	Leanne McNeill
Kate Monahan	Cherie Morgan	Louise Moth
James Muir	Puvan Muniandy	Fergus Murray
Angus Nelson	David Nicholson	Brendan Nisbet
Karen Priestley	William Rae	Lynn Reid
Eleanor Robertson	Eileen Ross	Philip Snaddon
Catherine Steedman	Catriona Stewart	David Weir
Julia Wells	Anne White	Paul White
Emma Whitney	Tom Wightman	Andy Williams

1 Welcome & Introductions

Alex Burnett MSP welcomed everyone to the meeting noting the presence of fellow MSPs Fulton McGregor, Mark McDonald, Oliver Mundell and Johann Lamont. He confirmed the chat function could be used for questions and no photos should be taken.

AB confirmed apologies from Annie Wells MSP, Cath Purdie, Susan Chambers, Eileen Waugh, Patricia Hewitt and Vanessa Morris.

2 Minutes from Previous Meeting & Matters Arising

The minutes were approved with Andy Williams proposing and Nick Ward seconding with no matters arising.

3 AGM – Office Bearer Elections

With no other standees, Steve Billingham proposed with Andy Williams seconding that Alex Burnett and Annie Wells continue as Co-conveners with Scottish Autism and NAS as joint secretariat.

4 Co-Convener's Update

AB confirmed he had written to the Minister regarding diagnostic waiting times and has received a reply which will be forwarded to attendees with the minutes.

5 Scottish Government Updates

Bee Vellacott gave an overview of the Increasing Understanding of Autism Programme; copy of the presentation available from this link. She expressed appreciation to all those who had contributed.



BV explained the background to the Programme as well as its structure; a Steering Committee including four autistic individuals and Advisory Forums, led by autistic organisations, which had been set up a year ago and were key to the success of the programme. Forums had external evaluation with positive feedback so it is hoped they will evolve through momentum of the Programme.

BV noted the three stages of the process and after testing, the 'Minds' creative was deemed best and publicity in the autumn through a variety of mediums resulted in a significant increase in visits to the Different Minds website.

BV shared a high level summary of how the campaign performed advising results will be shared with the Steering Committee and Forums. The results were, overall positive and will be used to feed into phase 2. Lastly BV referred to the Funded Charities Projects which are all now underway despite some delays due to the pandemic and also, it is hoped funding will be extended to September 2021.

Louise Scott said the feedback was good so far and would be passed to the forums and Steering Committee before being shared widely. She referred to the Transformation Plan in relation to the Autism Strategy as a transitional plan for autistic people and people with Learning Disabilities (LDs) which is being put to COSLA this week for approval with the aim of publishing by the end of February.

LS confirmed solutions in the plan will be different for autistic people and people with LDs but she noted the common ground, hence including both; she expressed thanks to all those who had contributed. The existing Strategy is being independently evaluated with local workshops taking places with HSCPs and other stakeholders. Evaluation will be published after the May elections and LS had no update regarding the budget as yet.

LS referred to the Post Diagnostic Support (PDS) Service which is now being piloted with independent evaluation and once published, it is hoped this will provide evidence to ensure the service becomes permanent. BV said the forums were not region specific and can be done widely and virtually across the whole of Scotland.

AB noted it was good to see visibility of the programme and plans in all areas and the feedback loop. He assumed the budget line for autism was tier 4 and LS confirmed

the budget included asks, eg, support for the transformation plan. Also, the plan will be approved by COSLA but all HSCPs can feed in including non-COSLA groups.

Fergus Murray queried if a joint plan with autistic people and people with LDs was the best option; LS said consultation had been widespread and in particular, many commonalities had been found between how autistic people and people with LDs coped during the pandemic with similar barriers and issues. She reassured that the plan would reflect the different needs between autistic people and people with LDs.

Stephanie Callaghan asked if the joint plan was already set; LS said it was but had separate priorities. AB confirmed that one purpose of the CPG was to explain the process and engagement methods behind plans. LS reiterated conversations were ongoing and was happy to answer questions via email.

Kate Monahan “because we matter” – asked for an explanation between how the plan connects and filters down to those who use the resulting services noting this was easier through charities as always a fight from local authorities (LAs). LS said the plan was not that specific but high level in what the SG will do, eg, deliver the PDS pilot and how to take forward actions will come through consultation once published.

Gyll Curtis-Machin was concerned with decisions being made by those without lived experience or involvement of the autistic community. She thought a joint plan was not helpful noting the challenges with autism diagnosis because of the links with LDs.

Mark McDonald highlighted the lack of accountability around LAs funding for local plans which weren't delivered and there should be a clear expectation that individuals with autism are embedded when developing plans. Also, although there are overlaps with autistic people and people with LDs, there must be recognition they are not one group.

6 Post Diagnostic Support Service

Kabie Brook explained the remit of ARGH including advocacy, lobbying and campaigning noting as autistic individuals are the experts, it was key for them to have high level involvement like the PDS service.

KB advised that ARGH is providing two courses; one for newly diagnosed (2 years) autistic adults to help them connect, learn about neurodiversity and talk about experiences to reduce feelings of isolation and help connect with autistic communities. The second course is for parents of autistic individuals to provide support, understanding, share experiences and again, reduce feelings of isolation. Course materials are prepared by autistic individuals and do not include negative language or stereotyping. https://www.arghighland.co.uk/post_diagnostic_support.html.

Charlene Tait expressed her pleasure that SG is supporting the PDS service as the lack of support has been an issue for many years. She explained that many organisations including ARGH, SWAN, NAS, etc, are involved in the pilot service providing support for those diagnosed in the last two years which will be independently evaluated to see what works and what doesn't.

CT noted the importance of support through peer, parents/families and community connections early as possible. She advised Scottish Autisms involvement is an extension of the existing work including the Get Set 4 Autism project in Argyll & Bute and online Right Click Programme. Recent evaluation of the Get Set 4 Autism project has been very favourable. Anyone seeking PDS can contact any of the organisations involved for support and if they cannot help, they will signpost to one of the other organisations.

Lyndsay Macadam explained SWAN's remit and that since the pandemic, they had moved most support online with their number of enquiries increasing significantly. With the PDS service, SWAN has added capacity to do provide extra services like webinars on managing anxieties.

LM said the level of engagement was high as some individuals are more comfortable with online services and moving to virtual meant reaching a wider audience across Scotland. SWAN also holds local online peer support groups led by volunteers, free counselling sessions, coaching and mentoring support. SG's support also meant SWAN now had admin support to co-ordinate services.

LM advised an additional, unplanned outcome from the PDS service is employment opportunities for autistic women. She noted the community environment provides a safe place for individuals to be themselves and not mask who they are which has a positive impact on mental health. LM summarised that although PDS is very effective, there is still an issue and barriers to receiving a diagnosis.

AB noted from the chat, attendees expressing the importance of peer-to-peer support and the lack of this during the pandemic but webinars and other engagement had proved successful as well as sharing good practice.

Jay Brownlee highlighted issues she had accessing the PDS service and the need for quicker diagnosis. CT said there were initial issues with the website but these were now resolved and to contact her for assistance.

Marion McLaughlin also offered to help advising of webinars being run in collaboration with Home Start Aberdeen which are open to all and available on You Tube.

Tom Wightman explained the work Pasda does to support parents and carers who are often forgotten and stated the need for sustained funding to continue this support. AB agreed this was a pertinent point especially at this time of budget setting.

7 “Our Voice, Our Rights” Campaign

AB noted this was launched last week with the aim of all political parties' commitment.

Nick Ward gave an overview of the campaign advising the response had been overwhelming encouraging attendees to visit the website and watch the videos. He said the decision for a joint campaign with LDs had been pragmatic as in order to achieve change, alliances were needed. Separate campaigns would limit actions so where there is crossover with issues, better to fight together to achieve results. He reiterated that although a joint campaign, autistic people and people with LDs are separate groups with separate needs.

NW then gave an overview and explained the five functions of the Commissioner including promoting human rights; ensuring autistic people are involved going forward in running and delivering services; ability to investigate issues of accountability; undertake individual case work and promote good practice.

Jan Savage said although ENABLE had made progress through campaigning for over 65 years for human rights for those with LDs, life is still not good enough for them. She highlighted many children with LDs also had autism and experienced seclusion and restraint in schools; also adults with LDs are often stuck in hospitals. She emphasised the message of the campaign that “enough is enough”, a Commissioner is needed to take ownership of the issues and make progress.

JS said the working group believed the Commissioner was the best option as it would give visibility and take leadership. She noted there is work to be done deciding the structure, how the commission would operate but it would have autistic people and people with LDs at the core. JS reiterated the similar challenges faced by autistic people and people with LDs noting both strategies are nearing the end of their cycles so with the May elections, this was timely for a joint campaign.

David Nicholson recognised progress since his diagnosis but there is still much to be done so autistic people and people with LDs can lead successful lives. He thought a Commissioner would help ensure their rights, fight for positive change, enable access to better support, make LAs accountable and ultimately bring about positive change. DN thought the collaborative work should be embraced to create something meaningful for autistic people and people with LDs.

In relation to chat comments, CT advised the Commissioner is not a panacea but a principle of an agent for change and can run alongside other ideas. She said the same arguments and challenges had been ongoing for many years and were systemic; services are siloed resulting in barriers. CT summarised that support is “in a mess” and emphasised the need to work together to ensure change.

Mark McDonald expressed his support for the campaign and that striving for perfect should not get in the way of good. He appreciated there was not consensus for a joint plan but was wary this could result in delays. MM agreed other campaigns can run alongside this but the campaign could be a powerful tool for real change at local level.

AB agreed noting campaigning is an art and that consensus will make it more powerful.

8 Response from the Co-Convener

AB expressed his thanks to all the speakers, Annie Wells MSP as Co-convener, the MSPs and to all those who attended. He noted the high level of attendance and engagement hoping this would continue going forward.

9 Date & Topic of Next Meeting

To be advised.

10 Any Other Business

No other items discussed.