

## **Cross Party Group on Autism**

### **Strand Four of the Autism Strategy “Active Citizenship”**

**15<sup>th</sup> January 2020 at 6.00 pm, Scottish Parliament**

#### **Minutes**

##### **Attendees:**

Annie Wells MSP	Fulton MacGregor, MSP
Alexander Burnett, MSP	Rob Holland, NAS
Nick Ward, NAS	Charlene Tait, Scottish Autism
Jason Henderson, NAS	Dorry McLaughlin, Scottish Autism
Louise Scott, Scottish Government	Helen Calley, Scottish Autism (Minutes)
Gillian Barclay, Scottish Government	Annette Pyle, Scottish Government
Ed Orr, Scottish Government	Andrew Busby, Scottish Government
Rachel Birch	Dorothy Barbour
James Barbour	Neil Barbour
Lorne Berkley	Andrew Busby
Susan Chambers	Fiona Clarke
Christine Collingwood	Aurora Constantin
Allison Crawford	Matthew Day
Angie Ferguson	Gordon Ferguson
Wendy Ferguson	Susanne Field
Sue Fletcher-Watson	Maurice Frank
Anne Marie Gallagher	Patricia Hewitt
Richard Ibbotson	Callum McCrosson
Lynda McLeod	Kate Monahan
Nathaniel Monahan	Louise Moth
Fergus Murray	Kirsten Mutch
Ed Orr	Ben Paechter
Nell Page	Cath Purdie
William Rae	Fran Ranaldi
Paul Surgenor	Tom Wightman

##### **1 Welcome & AGM**

AW welcomed everyone and advised the AGM would be taken first on the agenda with the election of Office Bearers. Fulton MacGregor MSP proposed that AW and Alexander Burnett MSP take on the roles of Co-Conveners. AW proposed that NAS and Scottish Autism continue their roles as joint secretariat. The meeting unanimously agreed to all proposals.

AW explained the agenda would focus on Strand 4 Active Citizenship and noted apologies from:

Jerry Edwards	Jenny Paterson	Steve & Sue Billingham
Dr Lorene Amet	Dr Catriona Stewart	Catherine Steedman
James Muir	Andy Williams	Morag MacDonald

AW stated the CPG will publish its review of the Strategy at the end of March and, as well as these meetings, there is an online option to feed into the consultation which is available until the end of January.

## **2 Minutes from Previous Meeting & Matters Arising**

The minutes were approved with addition to the attendees and there were no matters arising.

## **3 Overview of Strand Four: Active Citizenship (AC)**

Charlene Tait thought the first step was for autistic people to be regarded as citizens with the same rights and equalities as, although we have robust legislation, the law often overlooked. AC is about being recognised but there are challenges with service delivery and provision due to lack of responsibility between central and local government. She said a joined up approach is required to take ownership and responsibility.

CT noted the positive focus on employment in this strand and the recent funding around societal awareness but difficulties remain around getting into employment. She said there needs to be recognition that not everyone wants to be employed and a lack of understanding of autism continues. Programmes such as Modern Apprenticeships are typically designed for developing individuals and are not flexible enough to meet the needs of autistic people. CT referred to an initiative in the hotel industry in India noting there needs to be a significant change with education and society.

CT thought there was potential to make progress but highlighted the issue of sustainability due to short term funding so strong leadership and action were required. She believed different incentives and ways of support through to employment were required.

## **4 Scottish Government Update**

### **4.1 Understanding Autism Funding**

Louise Scott gave an overview of the programme developed from 2017 engagement analysis with £400k funding allocated to increase understanding and awareness which runs to March 2021. She explained the steps within the funding process and that Regional Autism Advisory Forums had been held along with online input; the ultimate decisions were made by the Steering Committee, 50% of which are autistic individuals.

LS said information of the successful organisations and their projects was available and then explained the next steps which include ongoing support by Inspiring Scotland and encouragement of collaboration. Work continues on the launch which will be later in the year.

### **4.2 Employability – No-one Left Behind**

Ed Orr agreed with CT's comment about lack of joined up provision and referred to the aim of developing a person-centred approach despite the barriers into work for some. He spoke about the needs of the individuals, closer alignment of services, work with

LAs, understanding what provisions are available and how to ensure access for all. EO referred to dignity and respect whilst being flexible to individuals' needs.

Andrew Busby spoke about employability and the "Fairer Scotland" report which includes actions through to 2021. He referred to the aim to reduce the disability employment gap by half in 2030 which, although a long timescale, is realistic and achievable without focussing on any specific impairments.

AB referred to the recruitment and retention plan for those with disabilities in Scottish Government giving an overview of its outcomes and actions including removing barriers to modern apprenticeships. He noted some progress since the launch of the plan but accepted there is a lot of work to be done and latest statistics can be found on the launch website.

EO referred to improvements in that some individuals with disabilities now had control over their employment journey but it can take time to gain employment and ongoing support might be required. He noted the statistics in the first annual report 'Fair Start Scotland' and next steps including discussions with those present to hear their views.

## **5 How has Pasda developed over the last 20 years?**

Susan Chambers said information from Pasda was available in the room which included key facts highlighting the costs of supporting autistic individuals. She also noted the NHS statistic that autistic people are 7.4% more likely to commit suicide, access to healthcare is not straightforward and 79% of adults feel isolated. SC stated that anxiety is profound in the autistic community.

SC explained the history of Pasda referring to the comprehensive information she had which, although helpful, made no difference to people's daily lives. SC spoke about the isolation and invisibility some autistic individuals felt which impacts on their families and that many people don't know where or how to find or access information and support. The result is people struggling, suffering from anxiety which can exacerbate as autism is often genetic.

Pasda exists to help engage autistic individuals and their families but constantly faces the challenge of how to do this. SC said plans are only pieces of paper unless they are made to happen. She summarised that the third sector wants to engage and help set agenda but needs to be consulted on the questions that need answering.

## **6 How Research Can Inform the Scottish Autism Strategy**

Sue Fletcher-Watson provided an overview of the Salvesen Mindroom Research Centre including its vision and aim; she highlighted the challenges with terminology and definitions around autism.

SFW said research can support the whole strategy through being evidence-based including evaluating new practices in relation to justifying funding, eg, One Stop Shops. Research also needs to be done in collaboration with other areas in the UK and worldwide. SFW spoke about recognising research can provide general statements which won't suit everyone so it needs to be personalised by practitioners for them to make specific recommendations for individuals. Also, it needs to be creative and use various methods.

SFW then highlighted the various barriers as to why research is not as effective as it could be including that it needs to be planned in advance to ensure it yields the information required. Also, research needs to be appropriately disseminated and explained so there is understanding around implementing it into practice. SFW said another key barrier is timescales as insufficient time is planned from brief through recruitment to research starting. Lastly, SFW spoke about the mismatch between professionals' goals and standards and summarised that it takes time to do quality research and time must be allowed for it to align with expectations.

SFW then suggested solutions to overcome these barriers including broadening minds around relevant techniques and academic disciplines, more consultation with other areas and building long term relationships to help define targets and align interests. SFW referred to the Research Evaluation Framework and the need for impact case studies to prove/show measurable impact on service provision. She finalised by saying research is a good tool for certain things but practice needs to be personalised.

## **7 Beyond the Basics**

WF stated she spoke from personal experience and hoped sharing this would highlight the struggle for quality of life. She gave background on her life, explaining her difficulties before diagnosis but now she knows herself better and can understand her previous challenges. Diagnosis has enabled WF to do more with her life rather than sitting at home.

WF then explained her thought process around going for a swim which, for many, seems a straightforward activity. She talked about the many, many thoughts, worries and concerns she went through and then read her poem which attendees greatly appreciated.

## **8 Response from the Convener**

AW thanked all the speakers recognising the Government's work around funding, WF's moving poem, Pasda's challenges and that research is powerful but is more in line with global change.

## **9 Discussion**

Maurice Frank raised the issue of maltreatment believing research needed to be linked to this to aid prevention and also attached to the strategy so cases raised are addressed and monitored. He also highlighted the problem of lack of accountability.

SFW said if a person relies on service providers then they automatically become vulnerable to potential maltreatment; she thought work should be done on education around how to complain and who to reach out to. Also, the need to ensure systems are in place for young people so they know it is acceptable not to fit in with traditional rules; patterns in the young need to be broken before adulthood.

CT agreed and referred to the systemic failings, accountability gaps and violated laws in that accountability at all levels is not robust enough to satisfy the degree of pain and stress felt.

There was wide-felt agreement that lack of accountability is a serious issue particularly by LAs. Nick Ward believed that the autistic community, third sector, groups, etc all had to advocate together to remove barriers in society.

Tom Wightman highlighted the lack of support for carers with Cath Purdie agreeing as social isolation affects not just autistic individuals but their families and carers as well.

Patricia Hewitt described her own difficult experience getting referral, diagnosis, support, etc, for her children who have Pathological Demand Avoidance (PDA) and agreed with the lack of accountability. She believed an expert group was required specifically to look at PDA. AW thought these were important points which she will look into.

SFW explained the documents doctors use which detail all conditions are only updated once a decade so PDA was not yet included. She said this was no excuse for the lack of services but an explanation behind the diagnostic process and believed a different way rather than top down was required.

There was further discussion around PDA in that it isn't specific to autism, parents need training and knowledge should be disseminated to aid understanding and reduce anxiety. Fiona Clarke noted that a small piece of right support can go a long way. FC also stated her hopes that the 'Coming Home' report could be a topic of discussion for a future meeting. AW accepted these points believing providing the right support in the right way was key to active citizenship.

Ben Paechter said his lived experience is that LAs are not providing adequate services or being held accountable; he believed the former was due to insufficient funding and individuals should have the ability to take LAs to account.

Susan Chambers also agreed with the economic argument, accountability and service provision points believing the Government and LAs shouldn't be in fear but should work with people raising the problems and experiencing the issues. She thought there had to be genuine listening and consultation and encouraged those with knowledge to work with the Government on a different approach.

SC said her plan would be to listen to those who have face-to-face contact. She thought researchers couldn't answer the 'how', they should look at the evidence of what works and then 'how' is by asking the right people to do the right things.

AW thanked everyone for their participation and comments advising these would be considered in relation to the report.

## **10 Date & Topic of Next Meeting and Any Other Business**

AW said the next meeting on 31<sup>st</sup> March 2020 will mark the publication of the CPG report on the Strategy written as a culmination of these meetings and the online responses. There was no other business discussed so AW closed the meeting.