

**Cross Party Group on Autism
Strand 1 of the Autism Strategy “A Healthy Life”**

28th May 2019 at 6 pm, Scottish Parliament, Edinburgh

Minutes

Attendees:

Annie Wells, MSP (Convener)	Alexander Burnett, MSP
Mark McDonald, MSP	Catherine Dempsey, Thistle Foundation
Charlene Tait, Scottish Autism	Kieran Massey, Thistle Foundation
Sonny Hallett, AMASE	Graeme Turnbull, Thistle Foundation
Fergus Murray, AMASE	Helen Calley, Scottish Autism (Minutes)
Wendy Ferguson	Sophie Castle, Office of Annie Wells MSP
Tom Wightman, Pasda	Aurora Constantin, University of Edinburgh
Nick Ward, NAS	Valentina Andries, University of Edinburgh
Jason Henderson, NAS	Annette Pyle, Scottish Government
Dorry McLaughlin, Scottish Autism	Rebecca Marshall, Salvesen Mind Room Centre
Libby Lightbody, Trainer	Stephanie Callahan, S Lanarkshire Council
Stephanie Melnick, SWAN	Steve Billingham, grandparent of autistic child
Louise Moth, Scottish Autism	Susan Billingham, grandparent of autistic child
D Barbour, Pasda	Leanne Anderson, Inspiring Scotland
Angus Nelson, Nordoff Robbins	Hazel Griffiths, Central Advocacy Partners
Jo Hamilton, NAS	Andy Williams, Central Advocacy Partners
Kabie Brook, ARGH	Arron Ashton, Scottish Government
Lynda McLeod, Into Work	Suzanne Kinross, Scottish Government
David Nicholson	Chloe Sliman-Millit, Central Advocacy Partners
David Cunningham	Jenny Paterson, Breakthrough Dundee
Nicola Wright	William Rae, Grampian Opportunities
Esther White	Kate Monahan, Because we Matter
Louise Scott, Scottish Government	Allison Crawford, Inspiring Scotland
Pauline Grigor	John Mitchell, Scottish Government
Simon Webster	Cathy Steedman, Autism Initiatives
Fiona Clarke	Adrian Ierna, NHS Glasgow & Clyde
Laura Bain	Rachael Davis, University of Edinburgh
Antony McGowan	Catherine Crompton, University of Edinburgh
Frank Beaton	Emily Kekwick, University of Edinburgh
Gabriel Gonzalez Villalba	

1 Welcome & Introductions from Convener

Annie Wells MSP welcomed everyone to the meeting and gave an overview of the agenda. Apologies received from Oliver Mundell.

AW said this is the first of four meetings looking at each strand of the Autism Strategy which will be reviewed next year. She urged attendees to remain focussed on “A Healthy Life” being the strand theme for this meeting. After these four meetings, NAS will produce a report so will contact attendees for permission to quote contributions.

2 Minutes from Previous Meeting & Matters Arising

The minutes were approved as read and there were no matters arising.

3 Update on Diagnosis Campaign

AW said she had written to the Minister for Mental Health Care in March to introduce a 3-month wait target from referral to assessment, waiting times to be recorded, published and monitored as well as audit to look at benefits of faster diagnosis. These calls were in response to an NAS survey with AW noting that diagnosis can be life changing.

The response advised these calls were a matter for the Regional Integration Authorities and HSCPs; around waiting times reference was made to various other avenues including the Strategy, a data set providing information on wait times, a national resource for consistent information, etc.

AW recognised that all people are seeking a diagnosis and the concerns that autism is often categorised under mental health. She questions where in the Strategy is the framework for HSCPs to delivery autism services and the expectation for funding; also more about the 'national resource'. AW said she would welcome the creation of the data set but queried how it would be used.

AW confirmed a copy of the response letter available on request and she is happy to include anyone's comments in her response.

4 Overview of Strand One: a Healthy Life

Charlene Tait echoed AW's comments advising she wanted to add value to existing information and noted this strand resulted from consultation with the autistic community.

CT noted the Scottish Governments intentions to add value but queried what was next. She noted autistic people say identity is important and central to their health and wellbeing so diagnosis and acceptance are key. She referenced availability of PDS for up to a year for other conditions but questioned the reality.

CT said health and wellbeing are the bedrock of good practice for all especially social care and education and to achieve this, strategy work must connect with other documents and strategies. She challenged reports around behavioural approaches referencing there is no such thing as autistic behaviour. CT noted the need to listen and respond accordingly starting with wellbeing so welcomed health being a priority.

5 The Barriers Autistic People Face accessing Healthcare

Sonny Hallett from AMASE gave an emotive talk believing autistic support is in crisis and that autistic people must be listened to. Results from an AMASE survey showed issues with accessing support, being denied mental health treatment and general misunderstanding.

Sonny detailed many of the barriers faced by autistic people, highlighted the high level of suicides and emphasised that in eight years there had been no improvements. She noted the benefits of One Stop Shops but recognised not all are the same. She referenced reports and reiterated it is essential that autistic people and professionals

are consulted. A full copy of her presentation can be read at <https://link.medium.com/uZSwlyNK6W>

6 The Silent Struggle

Wendy Ferguson said she had been diagnosed two years ago at the age of 41 and had struggled since, particularly with the lack of support provided. She then read a very [moving poem she had written](#).

7 From Labels to Badges: Planning for a Good Life after School

Catherine Dempsey explained the Thistle Foundation's work with young people's wellbeing around transition to adulthood (Big Plan). Their approach is that everyone has something to offer and using a unique combination of creative approaches to empower and enable young people to find their purpose and direction in life.

Graeme Turnbull said his son used the service very successfully as it gave his son a voice and a platform to succeed. Since then, GT has worked as a volunteer which has helped him see the future through his son's eyes and he now runs Big Plans to help other young people.

Kieran Massey then gave a very personal account of using Big Plans advising of his previous challenges and how much it changed his life, building his confidence as it makes ideas become reality. He now feels much happier and is treated as an adult summarising that "you define yourself".

8 Response from the Convener

Alexander Burnett MSP referred to the objectives of the Group and the principle that through regular meetings people become better informed; he noted the positive reputation of the Group and excellent attendance and contributions. AB thanked the speakers, advised there is a suggestion box and opened the meeting to questions.

9 Questions & Comments

Tom Wightman noted the lack of important services for autistic people and families.

Chloe Sliman-Millit appreciated the speakers input and then shared her experience of a young person with a recent diagnosis and the challenges she has had at college due to lack of understanding and support. However, she has succeeded in securing quiet rooms at college and emphasised the need for training asking what the Government's strategy was to ensure autistic individuals have equal opportunities and there is adequate training in the education sector.

AB said these point would be passed on and it was key to receive evidence around exclusions which can be then officially taken to LAs. CT referred to the Not Included report which included recommendations and stated the need for systemic change otherwise incentivised crisis will continue rather than "tinkering at the edges". Nick Ward agreed with CT's comments noting the requirement for sharing effective practice.

Kabie Brook said there needed to be understanding that all autistic people's brains function differently and highlighted the geographical challenge of psychiatric hospitals

meaning autistic people being exiled in their local areas. AB appreciated this is not resulting in a person centred approach.

Sue Fletcher-Watson highlighted the importance of autistic people leading training but the subsequent burden on them. She said there is a catch 22 situation as without sufficient resources and support the community cannot grow and then lead itself. Fergus Murray agreed noting the pressure on the few and even those autistic people can only give their own perspective, not others.

Mark McDonald MSP thought although other strands will fit in, it felt like this was beginning at the end. He noted there are positive areas as the statistics quoted in surveys are not 100% negative but work is need to ascertain if this is by chance or specific areas as well as disseminate good practice.

Kate Monahan agreed the autistic community needed to be heard but highlighted many have communication issues so they are particular vulnerable; how can they live a healthy life when contacting the doctor is a challenge.

CT agreed about the ethics of practice noting the low pay for social workers so they are not incentivised; underfunding is a general issue so ethical underpinning to services is needed. She recommended the NAT's challenge session of practice models to which autistic people have an input.

Kate Monahan asked why the law doesn't protect service users; CT agreed noting there are unannounced inspections in Scotland but not England. AB advised he has constituency cases around this and will look into others if sent to him.

Gabriel Gonzalez Villalba then gave a personal account of challenges getting a diagnosis, lack of support and explanation around the spectrum noting the importance for adults to have support at work with coping strategies and spaces for all needs.

Stephanie Callaghan raised the importance of involving families as well as the autistic person noting frustration can sometimes been taken the wrong way but is a result of not having support. AB agreed and thanked attendees for their points and questions.

GT said from experience, you have to become tough as a parent to fight for your child but noted a diagnosis can also be distressing for the parent; early diagnosis is crucial. SH agreed that families should also be heard and reminded that often people with a diagnosis later in life might not have families to support them.

NW also agreed that parents as well as autistic people should have a voice; he stated the majority of care is provided by families so strategy going forward must consider families. There are too many barriers parents have to fight through; the future must protect the rights of parents/carers and empower them.

MM thought solutions needed to capture a wide range rather than be specific and noted sometimes parents might be on the spectrum without realising it.

TW queried the setup of education psychology departments to help rather than psychiatrists and noted that LAs don't have funds to provide services but are not recording this as unmet need.

Steve Billingham told of rather than looking at where the right placement is, a psychologist is trying to make the local school suitable. He agreed with the lack of training but believed teachers were on the same page so better to engage with them and become allies.

Hazel Griffiths then gave her own account of the challenges she experienced at college and the lack of support resulting in her being taken off her course without explanation which she believed was discrimination.

Jenny Paterson said all the comments had resonated with her; she wanted focus on physical health for all and see more autism friendly/accessible buildings. She noted the challenges navigating the benefits system resulting in additional difficulties in people caring for themselves.

AB again thanked everyone for their contributions noting it had given much to think about.

10 Date & Topic of Next Meeting

The next meeting will be held on 27th August in Dumfries; topic will be strand two of the Autism Strategy, 'Choice and Control'.

11 Any Other Business

Aroua Constantine advised of a study she is undertaking around technology for children with autism to reduce anxiety through educational games. She called for volunteers to test the prototype and feedback comments.

AB thanked everyone for attending and reiterated there is a suggestion box for any questions and comments.

12 Suggestion Box

The following comments were contributed via the suggestion box:

- We need more MSPs from across the parties to attend the CPG.
- Autism is lifelong – how do we ensure support and structures for autistic people aged 40+ to ensure health and well-being, especially once parents and families have passed on?
- The Scottish Government needs to really support parents and carer roles should be recognised in co-production of strategies. We need to develop tools that use resilience.