

## **Cross Party Group on Autism**

### **Strand Two of the Autism Strategy “Choice & Control” and Autism in Dumfries & Galloway**

**27<sup>th</sup> August 2019 at 4.30 pm, The Usual Place Café, Dumfries**

#### **Minutes**

##### **Attendees:**

Annie Wells, MSP (Convener)	Oliver Mundell, MSP
Colin Smyth, MSP	Charlene Tait, Scottish Autism
Nick Ward, NAS	Sophie Castle, Office of Annie Wells MSP
Jason Henderson, NAS	Gillian Dykes, Office of Finlay Carson MSP
Annette Pyle, Scottish Government	Helen Calley, Scottish Autism (Minutes)
Louise Moth, Scottish Autism	Gillian Barclay, Scottish Government
Louise Scott, Scottish Government	Vanessa Morris, Dumfries & Galloway Council
Patricia Cain	Mhairi Jarvie
Susan Kirkpatrick	Maryann Benson
Dorothy Barbour	Caroline Maybank
James Barbour	Karen Priestey
Jean MacLellan	Elaine Murray-Bell
Vicky Keir	Hayden Keir
James McGlynn	Vanessa Morris
Laura O’Toole	Lesley Law
Lauren Asher	Heather Hall
Skye Hughes	Linda Fergusson
Lorraine Harris	Carolyn Kennedy
Lynda Middleton	Lisa Callander-Bone

#### **1 Welcome & Introductions from Convener**

Annie Wells MSP welcomed everyone and introduced Oliver Mundell MSP and Colin Smyth MSP advising this meeting would continue the review of the Scottish Strategy for Autism by discussing Strand 2: Choice & Control as well as local issues. She also introduced the speakers Charlene Tait and Patricia Cain then advised apologies had been received from:

Finlay Carson MSP	Linda Singer, Grampian Opportunities
Fergus Murray, AMASE	Dorothy Daldry, Grampian Autistic Society
Kabie Brook, ARGH	Jenny Paterson, Breakthrough Dundee
Jerry Edwards	Marion McLaughlin, One Stop Shop Aberdeen,
Michael McEwan	Catherine Steedman, Autism Initiatives
Fiona Clarke	

AW said the CPG will publish a review of the Strategy next year with NAS compiling a report so permission for quotes might be sought.

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

The minutes were approved as read with no matters arising.

### **3 Overview of Strand Two: Choice & Control (C&C)**

Charlene Tait said she was speaking from her perspective noting C&C mean different things to different people but believed these were limited for people with autism. CT said there is a gap translating theory and understanding into practice and recognised the value of the Right Click programme as well as SWAN. She highlighted sustainability is required to keep innovations fresh and accessible so welcomed the commitment to support initiatives.

CT referred to the unlawful exclusion in schools advising that Scottish Autism (SA) is working with the Scottish Government to refresh the Autism Toolbox at strategic level to support children with autism in schools. Recognising that mainstreaming does not suit all, CT stated the need for alternatives to avoid exclusion and give choice.

CT said lack of support for those without direct services is very concerning advising of a rise in calls to SA's advice line from this area. She welcomed the growing movement around practice-based research and hoped to see the proposed Research Consortium progress to help translate research into practice.

CT noted there is little choice over providers for services and was concerned with the move towards practices which individual with autism do not find helpful; she believed in the need for more informed choices. CT recognised the Policy Team is trying to include more individuals with autism stating they should be consulted as a fundamental aspect of C&C is participation.

### **4 Choice & Control in Dumfries & Galloway and Across Scotland**

Patricia Cain then spoke of her personal experience and lack of support accessing direct services, transfer of theory into practice and involving people with autism. She referred to her own diagnosis advising that others do not realise she is autistic as she comes across as 'competent'.

PC gave a summary of her background through education and then at Arts School in London which she found too much so left to study law the structure of which was much easier for her as she could live in a "third person way". After practicing medical law in Scotland, PC was drawn back to creative practice so attended the Glasgow School of Art but this meant she lost her identity due to the change of social aspects.

PC said that by taking C&C of her own life, she actually became lost as there are expectations to match into structures, processes and systems which actually take away C&C. She said there needs to be openness to different thinking styles as those with autism process differently with different filters/interpretation which in turn lead to different values and outcomes creating the challenge to fit in with systems not attuned to this.

PC explained the Millefolia social enterprise she had founded and its aims through autism and neuro-diverse projects, creating spaces, raising awareness and enabling ground up methodologies that respond to actual needs. PC focussed on the need to include individuals with autism and who they are, what they need to be rather than a top down system.

## **5 Response from the Convener**

AW thanked the speakers and agreed with the call to listen to everyone, ensure resources are in place and mainstream education is not suitable for all.

OM welcomed PC's interesting talk from a different perspective around challenges and noted processes might not work for some, eg, schools rules which matter but not in principle for all.

Nick Ward noted the challenge of C&C in times of crisis and the need for different levels of C&C as needs change during a person's lifetime, however, resources are not available so the Scottish Government needs to address this.

## **6 Discussion on Strand Two**

Louise Moth asked if figures were available on uptake of different options under SDS as these options gave C&C which individuals might not be aware of. It was understood that currently, figures are not recorded specifically for autism but a different system means these will be in future.

OM noted C&C is challenging in rural areas due to the availability of providers.

Karen Priestley raised the difficulty with C&C due to availability of appropriate services in the Dumfries area. CT said this can be similar in cities as often service provision is directed by LAs; she said broader thinking is required around practices and approaches and noted there are no standards to determine what is a specialist service or qualified provider.

Lisa Callander-Bone questioned C&C in education and if there is a need for a specialist school in the area. CT referred to the Not Included report and said education should not result in possible additional mental health issues.

NW agreed saying there are serious issues within education and mainstreaming was not realistic; the policy makes sense but teachers do not have sufficient experience. He asked who was holding LAs to account for the quality of education as Education Scotland only inspects on an exceptional basis.

One attendee noted that parents don't have a strong enough voice regarding C&C for their children, although her son had a good journey through school he has had no support since leaving. She said C&C is a partnership and there should be no wait lists.

LCB noted that although diagnosis is not always needed, it is beneficial for the person to know. She said the pathway was not fit for purpose and the new neuro-diverse pathway trial around diagnosis needed continued investment. She said much discussion so far had been around children and questioned support for adults with autism.

AW thanked attendees for their comments agreeing that choice was needed for families as well as individuals.

## **7 Discussion on Autism in Dumfries & Galloway**

OM opened the meeting to comments about autism generally in Dumfries & Galloway.

Hayden Keir spoke about his autism and as a prefect at school, had supported other students which although beneficial, had impacted on his schoolwork.

CT acknowledged there are wide issues for adults especially around diagnosis; she believed a “whole life” approach should be taken.

One lady spoke of her experience of diagnosis at 35 and her struggles with lack of support for her and her 18 year old son with autism. NW believed the NHS was a missing part of the support framework.

Vanessa Morris said D&G Council is working on an improvement initiative with Children in Scotland, being proactive with parents and using complaints as an opportunity to learn. D&G’s autism training course is now mandatory for staff but she acknowledged this will take time to filter through and embed.

There was a request to produce a directory of the different initiatives mentioned during the meeting with OM will progress.

Carolyn Kennedy said work was being done on producing a directory which would include the different initiatives mentioned at the meeting. She agreed with making things mandatory giving the example of teachers texting homework details to parents or having task lists written in classrooms for children who won’t ask. OM agreed as this would also make teachers lives easier; however, it was noted not all have access to smart technology but this could be loaned from the Council or a simple jotter used for reminders.

Colin Smyth highlighted the issue of not planning budgets more than a year ahead so initiatives are supported at first but then not sustainable. This was acknowledged as a key issue as well as education, especially as autism is not included in teacher training. However, CT noted that society and attitudes are also key as well as training.

AW thanked attendees for their contribution, welcoming hearing local voices and she recognised that what works in one area might not work in others.

## **8 Date & Topic of Next Meeting**

The next meeting will be held at 6 pm on Wednesday 20<sup>th</sup> November at the Scottish Parliament on Strand Three of the Scottish Strategy for Autism: Independence.

## **9 Any Other Business**

No other items discussed.