

# Cross Party Group on Autism – Meeting on Education

23<sup>rd</sup> October 2018 at 6 pm, Scottish Parliament, Edinburgh

## Minutes

### Attendees:

Annie Wells, MSP (Convener)	John Swinney, Deputy First Minister
Alexander Burnett, MSP	Daniel Johnson, MSP
Mark McDonald, MSP	Johann Lamont MSP
Nick Ward, NAS	David Mackenzie, NAS
Jo Hamilton, NAS	Charlene Tait, Scottish Autism
Chris Ross, Children in Scotland	Sophie Castle, Office of Annie Wells MSP
Jasmine Ghibli, SWAN	Gillian Barclay, Scottish Government
Rachel Birch, SWAN	Kabie Brook, Autism Rights Group Highland
Lisa Donnelly, ASK North East	Helen Calley, Scottish Autism (Minutes)
Tom Wightman, PASDA	Kate Monahan, parent of autistic child
Annette Mason, ASK North East	Steve Billingham, parent of autistic child
Catriona Stewart, SWAN	Nicole Bonner, parent of autistic child
Kara Christine, Artlink	Morris Frank, Edinburgh & Lothian Asperger Soc
Tom Whiteman	Fiona Clark, parent of autistic child
Scott Bathgate	Ross Wright, Govan Law Centre
Louise Moth, Scottish Autism	Leanne Anderson, Inspiring Scotland
Julie Brown, Triple As	Anne Marie Gallagher, NHS Glasgow & Clyde
Fiona Clark	Joshua Booth, Central Advocacy Partners
Richard Ibbotson, TRFS	Hazel Griffiths, Central Advocacy Partners
Lynda McLeod, Intowork	Laurie Margraet, Patrik Wild Centre
Fiona Moth, Spikin Autism	Jean Michelle, University of Strathclyde
Fergus Murray, Amase	Andy Williams, Central Advocacy Partners
David Nicholson	Laura Wilson, Central Advocacy Partners
Jenny Rae	Emma Stanley, Triple As
Annie Watson, Enquire	Dave Cunnington
Em Edmondson	Carole Brown
Simon Webster, Independent Review of Mental Health Act	

### 1 Welcome & Introductions from Convener

Annie Wells MSP welcomed everyone to the meeting and advised the agenda will change to ensure maximum discussion with the Deputy First Minister (after the speakers) as he has to leave by 7 pm. She then welcomed Nick Ward to the meeting as new National Director at NAS and thanked David Mackenzie for his contribution to the CPG noting his new role in London.

AW confirmed the meeting will focus on the 'Not included, not engaged, not involved' report launched recently which she found very insightful. She also recognised and appreciated the presence of the other MSPs.

Apologies were received from:

- James Fletcher – ARC Scotland
- Mike Penny - Lothian Autistic Society
- Cath Purdie – PASDA
- Gareth Jenkins - Highland Cycle Ability Centre

## **2 Charlene Tait, Scottish Autism**

Charlene Tait noted the report is a culmination of a year's work by Children in Scotland, the National Autistic Society and Scottish Autism in response to the recognised increase in enquiries each organisation had received about autistic children missing school. The report is available online [www.notengaged.com](http://www.notengaged.com) and includes real life issues which need to be addressed by partnership working.

CT recognised the high response rate reflecting experiences from children ranging in age from 3 to 19. CT referred to the findings around the experiences of missing school noting the high responses for exclusions, unlawful exclusions and part-time timetables. She noted the latter can sometimes be a positive alternative but only when managed well and should not be long-term. Regarding reasons for missing school other than normal childhood illnesses, anxiety was found to be the prime reason for absence.

CT said the charities do not claim that the results are representative for all but the issues seem to be systemic and offer insight into the barriers children are facing accessing education.

CT then gave an overview of some of the key statistics from the report highlighting that too many absences are lengthy and permanent, with over a third of respondents saying that they felt the need to keep their child at home due to lack of support or the school being unsuitable.

The report included two open questions which received over 800 comments each. In relation to the impact on children, CT said the top three were stress/anxiety, missed school and low self-esteem. Regarding the impact on families, again the top was stress/worry as well as the impact on the family dynamic and work-related issues for parents.

CT said all three organisations do not want education professionals to view the report as a criticism of their profession as they understand the pressures they are under. However, there are systemic issues which they believe need to be addressed beginning with the calls to action outlined in the report. CT recognised that organisations might have different ways to achieve them but these have been agreed as key aims. The report also includes a list of further actions needed.

## **3 Rachel Birch & Jasmine Ghibli, Scottish Women's Autism Network**

Rachel Birch introduced herself as a Trustee of SWAN and an autistic person. RB experienced great difficulties as a child accessing education as she was only diagnosed aged 14 so had no transitional support when starting secondary school resulting in social and environmental challenges.

RB's issue worsened in third year where her anxiety increased so started refusing to go to school and experienced panic attacks. This was seen by the school as bad

behaviour with blame placed on her and her mother who, as a single parent, then experienced mental health issues meaning she had to leave her job.

RB said the school then recognised she was depressed which resulted to a referral and ultimately her diagnosis which, although beneficial as it gave a reason for her issues, didn't help as the school did not know the best way to support her. The support provided meant she was singled out and made to feel different which had a further detrimental impact.

RB stated the support offered was in line with punishments for non-autistic individuals; ultimately she felt suicidal. Although she was finally offered a part-time timetable and the opportunity to sit her Highers, this was too little, too late.

RB acknowledged that the report proves her experience is not an isolated case and that an earlier diagnosis, more positive narrative around autism, better training for teachers on autism and adaptations to the school environment around sensory stresses would all have benefitted her education.

Jasmine Ghibli said she was diagnosed aged 4 and then felt ostracised. At school she was exposed to detentions and fell behind with her education as teachers did not understand autism and how to support her.

JG's last year in primary school was the worst; she was given a patronising book about autism which made the situation worse. Although she met the head teacher about being bullied, her experiences worsened and anxieties increased. JG said she felt like she had a target on her head. She said the biggest issue was not being included as children deemed with special needs were put in classes together with a single support assistant. When not in separate classes, JG was told to sit beside another autistic child and was not able to sit with her friends.

JG said she had attempted suicide and felt she had been condemned at birth. In the end, she decided to leave school and after receiving CBT, her situation is now improving and she feels better now she is not in an ostracising environment.

Annie Wells MSP expressed her thanks CT for her summary of the report as well as to RB and JG for sharing their personal stories.

#### **4 John Swinney MSP, Deputy First Minister (DFM) & Cabinet Secretary for Education & Skills**

John Swinney MSP added his thanks to the speakers for their contributions. He said he found the report and real life experiences profoundly disturbing and concerning; he stated the need to ensure these experiences are not repeated in the future.

JS said the report was helpful in demonstrating real life experiences of autistic people and the difficulties they can face in navigating the education system to Scottish Government, local authorities and schools; he reiterated the need to engage with the Calls to Action to improve experiences.

JS advised that before he responded to the report in Parliament, work had been done to map the issues which needed to be communicated to the public. He confirmed he

is meeting CiS, NAS and SA on 1<sup>st</sup> November to discuss taking forward and identifying steps to ensure improvements in the future.

JS referred to the Government policy of “Getting it right for every child” (GIRFEC) and that the report clearly shows this is not happening. Also, the report contradicts Government guidance so there is a need to ensure that when issued, guidance must be put into practice.

In relation to ‘inclusion’, JS said this must be a prerequisite; whatever the area of education, every child must feel included whether they be in mainstream or special education.

Finally, JS welcomed the collaborative approach of the three organisations in helping resolve the issues and said the report raised many concerns so it was also important to work with education to resolve them.

## **5 Questions from the Audience**

AW thanked JS for his response to the speakers and his thoughts on the report agreeing that the GIRFEC policy needed to be adhered to. She then opened up the meeting to questions from the floor.

Kabie Brook said she thought that children being home schooled by necessity rather than choice were not being counted and it can often be even more difficult for parents of autistic children if they are autistic themselves.

Lisa Donnelly noted often children have to fail at mainstream education and be home schooled before they can access specialist education meaning problems are already exacerbated. She had to take legal action to get access to specialist education.

Kate Monahan queried the focus on education believing medical input was also key and greater specialist knowledge was necessary.

Regarding home schooling, JS thought there can be legitimate arguments for this, however, it should be a choice, not forced. Ultimately, this is about getting it right for the individual child and quality of assessments.

In response to LD’s point, JS said legally there is the ability for parents to secure support of a tribunal to ensure the needs of their child are being met. However, he didn’t believe legal action was usually the best course as it can add strain to an already stressful situation. He reiterated that assessments need to be accurate to ensure the best option for individual children.

JS said there should be a link between education and medical support to give a whole needs plan for each child. Where possible plans should be driven by the child and not compartmentalised.

AW thanked JS for his responses and opened the floor to more questions.

Steve Billingham said his personal experience suggests there are cultural issues. His granddaughter was assessed as needing 1-1 support which the school applied for but said it knew it would not receive it and he was refused a discussion about CSP.

JG thought that rather than resorting to special schools, mainstream environments should be adapted. Scott Bathgate agreed noting Finland only has mainstream schools; he thought it important to identify every child's skillset as everyone is capable of working.

JS stated that being refused a CSP was not acceptable; he asked SB to email him details so he could investigate. JS said LAs are signed up to GIRFEC and although there will be issues around resources, there are obviously questions about attitudes.

Regarding specialist schools, JS said he was not suggesting all autistic children attend but rather this option does meet and fulfil the needs of some individuals.

JS advised there is a curriculum approach in Scotland which is adaptive. He agreed there are plenty of jobs autistic people can do which, in some cases, might need some reconfiguration in relation to individual needs.

AW again thanked JS for his answers noting it is likely he will receive more questions by email; JS reiterated his willingness to move forward.

Tom Wightman asked how autistic attendees thought about applause; some liked it but some didn't. AW said this would be queried at the beginning of the next meeting as it was important to ensure all attendees felt comfortable.

Morris Frank asked if all cases could be reviewed by the three organisations so each problem could be checked to ensure no issues are missed and can be covered in an awareness process. CT appreciated MF's thoughts noting the logistical challenge but agreed it was important to look at lived experiences.

Fiona Clark queried how best practice can be identified so opportunities are provided for all. AW agreed and will ask JS to look at this. CT noted the need for a holistic view as sometimes children can be seen as conforming at school but blow off steam at home so good practice needs to be seen as a whole.

Nicole Bonner, JG's mother, spoke about her educational challenges advising that JG achieved an A in English Highers although she had never been in the classroom. Late diagnosis can result in teachers not engaging as autistic children are seen as too much work; she noted teachers can be heroes or villains.

AW acknowledged these points and reiterated the need for a collaborative, holistic approach.

Annette Mason, whose autistic sons are now in their 20s, said she now supports other parents of autistic children as unfortunately little has changed since her sons' education. She took her LA to tribunal for discrimination as it had not implemented the Equality Act into any of its educational policies or procedures. She queried whose

responsibility it was to update these policies; AW asked the three organisation to discuss this with JS.

Nick Ward referred to the NB's comment that teachers can be heroes or villains saying they want to be the former but the report demonstrates they don't have the training. Therefore, this must be addressed to ensure support for autistic children.

Kara Christine thought the education system could not work in isolation. Focus needs to be on the individual skills and strengths of children which will lead to the right environments and connections. She believed the voluntary sector should be included in holistic education.

Ross Wright noted the apologies of Jennifer Barr who was due to speak and advised the Govan Law Centre has a helpline service which receives lots of enquiries around autism. The organisation can provide legal support and he offered his contact details to those wanting them.

AW referred back to RB's earlier comment agreeing there should be more support with transition from primary to secondary school. Also, in relation to AM's comments about lack of changes over the last 10+ years, AW said the Government should be held to account and change should happen through policies. She reiterated the focus should be on individuals and their skills, not negatives. There is a lot that can be challenged both in education and health.

AW summarised that she believed the meeting had been worthwhile as it had shone a light on what is really happening.

## **6 AGM**

AW advised she is happy to remain as Convener; she was then nominated by Mark McDonald MSP, seconded by Alexander Burnett MSP and agreed unanimously. AB was then nominated as Vice Convener by AW, seconded by MMcD and also agreed unanimously as was NAS and SA remaining as Secretariat.

AW advised other MSPs were interested in joining the CPG including Johann Lamont MSP.

## **7 Minutes of Previous Meeting**

The minutes of the meeting held on 29<sup>th</sup> August 2018 were agreed subject to adding Kabie Brook to the apologies.

## **8 Further Questions & Discussion**

NW said he was encouraged by JS's attendance but agreed in relation to the lack of change over recent years. He said the focus of the meeting on 1<sup>st</sup> November will be the Calls to Action and it is up to the autistic community, as a whole, to make its voice heard so JS keeps autism high on his agenda.

Tom Whiteman asked how strong current legislation is as there are no specific laws or Autism Act and guideline are ignored. AW referred to the 2011 Scottish Strategy for Autism and DMack suggested the next meeting focuses on reviewing the Strategy.

KM said her LA had failed her family; she asked who is held accountable and where is the scrutiny as her LA won't engage. SB believed the Head of Education was responsible advising he planned to email this question to JS; KM stated she had emailed before so AW said she would check with JS.

Jo Hamilton referred to the open letter to be sent to JS asking for action encouraging all attendees to sign it by Friday 26<sup>th</sup> October.

In response to a question about working at UK level, CT said this can be both beneficial and frustrating as Scotland either has to reinvent the wheel or "put a kilt" on others' good practice. She said Scotland values education and although it can learn from others and adapt, this will require resource and prioritisation.

Alexander Burnett MSP noted the guidance on recording exclusions was not being followed but hoped attendees were starting to see the benefit of the CPG. He thought JS's attendance showed a level of commitment and was a great achievement.

Fiona Clark referred to the new legislation around providing communication equipment meaning children are able to demonstrate their intellect and communicate on their terms; however, this is not happening.

MMcD referred to his meeting with NHS Grampian on autism diagnosis which resulted in a draft strategy being taken forward. He advised he was the parent of an autistic child and was lucky to get an early diagnosis meaning an appropriate placement was secured. He noted Aberdeen has two specialist schools with insufficient places for demand. MMcD said although some parents are able to articulate and argue their cases, many aren't so LAs "play the odds". He confirmed the report will be debated in Parliament giving the opportunity for MSPs to raise concerns so attendees should check for updates online.

KM noted that Govan Law Centre doesn't charge and there is Legal Aid for discrimination cases. AW asked KM to email details so it can be circulated to the CPG members. DMack said NAS also has an Education Rights service.

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

AW advised the date of the next meeting will be confirmed. She said that the first year of meetings had covered many topics and given MSP members a good understanding of people's concerns. It was agreed the focus of the next meeting would be reviewing the Scottish Strategy for Autism.

## **10 Any Other Business**

AW advised that anyone wishing to join the CPG as non-MSP member should email [sophie.castle@parliament.scot](mailto:sophie.castle@parliament.scot) and she reminded everyone in the room of the Suggestions Box.

Finally, AW reiterated her thanks to all involved appreciating everyone's honesty and openness in discussions.