

Cross Party Group on Autism – Meeting on Strategy

26th February 2019 at 6 pm, Scottish Parliament, Edinburgh

Minutes

Attendees:

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| Annie Wells, MSP (Convener) | Alexander Burnett, MSP |
| Mark McDonald, MSP | Nick Ward, NAS |
| Charlene Tait, Scottish Autism | Dorry McLaughlin, Scottish Autism |
| Rachel Birch, SWAN | Sophie Castle, Office of Annie Wells MSP |
| Jasmine Ghibli, SWAN | Gillian Barclay, Scottish Government |
| Ryan McQuigg, NAS | Annette Pyle, Scottish Government |
| Catriona Stewart, SWAN | Helen Calley, Scottish Autism (Minutes) |
| Kirsten Mutch, PASDA | Pauline Grigor, Borders Additional Needs Group |
| Tom Wightman, PASDA | Steve Billingham, grandparent of autistic child |
| Louise Moth, Scottish Autism | Susan Billingham, grandparent of autistic child |
| Julie Brown, Triple As | Leanne Anderson, Inspiring Scotland |
| Emma Stanley, Triple As | Anne Marie Gallagher, NHS Glasgow & Clyde |
| Fergus Murray, Amase | Hazel Griffiths, Central Advocacy Partners |
| Christine Collingwood, ANS | Andy Williams, Central Advocacy Partners |
| Cath Purdie, PASDA | Laura Wilson, Central Advocacy Partners |
| Cherie Morgan, Play Scotland | Arron Ashton, Scottish Government |
| Brenda Bradley | Lorene Amet, Autism Treatment Plus |
| Scott Bathgate | Gail McKeitch, Ellon Branch NAS |
| Libby Lightbody | Euan Hood, Grampian Opportunities |
| David Nicholson | Mary Leroy, Mental Health Commission |
| David Cunningham | Jenny Paterson, Breakthrough Dundee |
| Wendy Ferguson | William Rae, Grampian Opportunities |
| Sally Davies | Lynsey Stewart, ANS |
| Esther White | Lesley Thorpe, Highland Cycle Ability Centre |
| Nicola Wright | Dawn Ranson, Grampian Opportunities |
| Rennie Griffiths | Chloe Sliman-Millit |
| Suzanne Kinross | |

1 Convener Opening Remarks & Minutes of Previous Meeting

Annie Wells MSP welcomed and thanked all present for attending the meeting noting Alexander Burnett MSP (Deputy Convener for CPGs) and apologies from Graeme Deye. She noted it was the anniversary of the Strategy for Autism and the CPG had been formed to promote awareness and influence policy so the perfect platform to explore the Strategy's legacy, what has worked, what has not and where to improve with future meetings focussing on the four Strategy streams. Speakers will be sought in relation to key areas and outcomes for each stream.

AW advised today's three speakers will voice their experiences, both positive and the challenges of the Strategy with the opportunity for questions to them all afterwards. Apologies were received from Fulton MacGregor MSP, Jean McLellan, Jenny Rae, Jerry Edwards and Kate Monahan.

The minutes of the last meeting were approved as read with Mark McDonald MSP proposing and Alexander Burnett MSP seconding.

2 Gillian Barclay, Scottish Government Strategic Lead for Dementia, Autism & Learning Disabilities

GB said she appreciated the opportunity to present to the CPG and explained the Strategy Team was small with a budget of £2.2m depending on commissioned projects. She referred to her tabled report explaining the history of the Strategy and referring to the review in 2017 which was an extensive engagement exercise to establish priorities, this resulted in four streams:

- A Healthier Life – addressing “patchy” diagnosis through a commissioned team from QMU alongside AHPs as well as the COIA taskforce on a linked pathway. Improving the understanding of autism through a well trained workforce and developing best practice standards to support PDS.
- Choice & Control – GB noted the See Me campaign which removed the stigma from mental health feeling this should be the same for autism. The uptake of best practice needs to be improved through collaboration with HSCPs, ANS and a National Policy Review Group with improved training materials in all categories.
- Independence – representation and peer group support around involving those in local organisations and groups as well as working with Housing to help train their support workers’ understanding.
- Active Citizenship – work on reducing the employment gap, improving support and opportunities with universities and employers as well as targeted work on employers to improve understanding.

GB acknowledged there was a great deal of work to be done and reiterated the limited funds. AW thanked GB noting it was helpful to hear future plans.

3 Charlene Tait, Deputy Chief Executive, Scottish Autism

CT appreciated the opportunity to comment and queried if enough had been achieved since the original strategy. She queried why there was a strategy and not legislation noting neither should work in isolation and a strategy should succeed but appreciated some would prefer legislation.

CT noted the strategy focussed on neglect of diagnosis and support for adults and issues with timescales/spending; she highlighted the value of One Stop Shops (OSSs) and believed after ten years, more work should have come to fruition. Also, funding must be better allocated, eg, to LAs to develop partnerships and embed practice in mainstream service rather than fund something for year which then has to end.

CT called for funding for larger pieces of work which have potential for systemic change, research as well as ownership of recommendations. She reiterated the proven model of OSSs believing they were too important to lose believing the cost to be around £83 per person.

CT referred to Autism Network Scotland and to how it originated from the policy document "The Same as You". She felt that its original remit of establishing professional networks would have seen Communities of Practice evolve that would now be bearing fruit and that it was regrettable that this model had not been sustained. Although the network was established at the University of Strathclyde when CT worked in the National Centre for Autism Studies she did not feel and continues to feel that the network is not best placed within a university. Referencing the strategy as a whole, CT also commented that opportunities for learning from other countries were being missed. She appreciated the early strategy was aspirational but highlighted a less is more approach could be more achievable but would need local commitment.

CT thought there was a missed opportunities relating to a number of commissioned works such as the mapping project, The Microsegmentation report and the Research seminar series. She ended by stating systemic change is needed across all sectors for autism.

4 Gail McKeitch, Mother with Autistic Son

GM said that as well as being a parent of 3 young adults she was also ran a NAS Branch in Aberdeenshire and was present to speak for all of them. She noted the geographical challenge of providing autism services and their successful OSS had to close after a year due to lack of funding.

GM advised she supports and offers teen life training and a weekly Socialise event highlighting families depend on local charity as NAS and SA do not offer services in the area. She noted the long wait for a house for her autistic son.

Aberdeenshire Council is currently reviewing its 10 year strategy in which autism still sits under mental health so adults fall through gaps. GM said NHS Grampian is working towards a multidisciplinary pathway for over 18s and although the strategy had helped in some ways, there was still a great deal of work to be done, especially focussing on adults.

AW thanked GM for raising her points advising research and OSSs will be looked at.

5 Q&A Session

In response to Cath Perdie's question about mandatory training and more consistent support groups for carers, GB agreed advising the strategic aim of having high quality, accessible training but noted the challenges in making this mandatory.

Nick Ward said NAS, SA and CIN feel training is key and will take it to the roundtable meeting with John Swinney tomorrow. He reflected on the points raised by both speakers highlighting the lack of tangible progress from the strategy and the sad loss of many OSSs. He queried what had gone well from the strategy and what hadn't and whether this will shape future years. GB agreed OSSs are a great resource but noted the sustainability challenge and better engaged with HSCPs is needed as well as increased national work.

Jasmine Ghibli stated that modifications are needed in education along with better funding for employment opportunities for autistic people; she asked if alternative schooling will be recognised in the strategy.

GB referred to JG's powerful speech at the last meeting which JS had taken on board so further higher level meetings are being held to discuss education and autism. JG highlighted the need for more alternative teaching methods and mentoring projects.

GB said she did not have specialised education knowledge but is aware of different approaches and methods being used by teachers in the USA which are being shared.

Steve Billingham queried the different approaches and believed the strategy didn't have "teeth"; he noted there are only 14 attendees at an event in two weeks including only three LAs. CT agreed this was not good enough but hoped attendees would increase; she noted the cost of training and although people are motivated, sometimes it is not accessible. Also, the toolbox is not enough.

Annette Pyle said the refreshed strategy was coproduced with COSLA and under the original strategy, each LA would produce its own strategy with action plans. She noted the learning that funding from Government starts local projects but the local co-ordinators are not plugged into finances so become isolated. Also, the Network supported some strategies but unfortunately there is no consistency across Scotland.

MM believed the OSS funded by Aberdeen City stopped as the council said it was benefitting people outwith the area. MM raised concerns about transition to adulthood noting support has recently been withdrawn from his autistic son due to the eligibility criteria and those without assessed support, depend on local organisations and charities, without which they would have nothing.

AP said the eligibility criteria as not her area but acknowledged that sadly the majority of autistic people are not eligible for social care. She recognised that Scotland is reliant on the third sector so the Government needed to support them and ensure projects set up through the strategy continue to receive funds particularly OSSs. MM was cautious about the case for mainstreaming until it can be properly funded.

Jenny Patterson said she had worked in the area for many years including the front line advising the strategy has fallen short in areas; she agreed about needing OSSs and said she had never met a teacher who did not want autism training. JP said a fundamental change is needed noting the Autism Act in England has made a difference. AP said engagement in 2017 had highlighted training, awareness, education change and employment opportunities so focus had been on these.

Pauline Grigor said the charity she works for had been consulted but never had a OSS in the Borders; her charity supports autistic people and families but never received funding support. She noted person-centred planning for autism varies and no connection nationally and locally.

Dawn Ranson said adults and older people with autism must be a focus as well as getting it right for children. LAs block purchase services around the eligibility criteria and don't support local charities. She said when needs are less complex, there is not enough choice of service and LAs are not engaging enough with the community. CT said block purchase is a cheaper option and LAs are not investing in preventative measures but being reactive; she noted SA's Advice Line is fully funded by donations.

AP confirmed local consultation will continue in line with the strategy review; she said the Borders was a public meeting and it was important to have the right people at local sessions.

NW noted the funding process for small charities was not clear; AP agreed as there is an issue within the third sector as to who to connect with around statutory funding. AP advised a pilot was funded with ARK in some colleges to provide training on autism which went to the Scottish Funding Council and now being rolled out.

AP said local strategy teams are working to ensure consistent pathways so families are supported. A national team will also look at best practice and put together a source of information for families.

Rennie Griffiths highlighted that autism is a huge national concern and the Government's budget is not enough but what funding there is needs to be used effectively.

AW thanked attendees for their questions and comments noting key messages around working with higher education on training/work opportunities. Also, societal change and understanding is required rather than more awareness raising.

6 Any Other Business

AW advised that further to a FOI request around number of co-ordinated support plans (CSP) in 5 years and how many had been implemented, Steve Billingham had undertaken some research.

SB said the guidance on when a CSP is required is clear in legislation and his findings showed there is no agreed way LAs collate data; some showed implementation rates of 100% but others only 20%. Also, there is no consistency in number of CSPs as in some large LAs numbers were very low. SB said he had now successfully got a CSP for his grandchild but it had been very challenging. AW thanked SB for his work noting the startling results which will be shared with the group. MM said he will take the information to his meeting with the Cabinet Secretary tomorrow.

AW thanked all for attending noting it had been another good meeting and the key points would be looked into.

7 Date & Topic of Next Meeting

The next meeting will take place on 28th May at the Scottish Parliament and AW confirmed that the agenda, minutes and papers would be emailed before the meeting.