

Cross Party Group on Autism

29th August 2018 at 2 pm, Camphill School, Aberdeen

Minutes

Attendees:

Alexander Burnett, MSP
Mark McDonald, MSP
David Mackenzie, NAS
Helen Calley, Scottish Autism
Alison Wood
Nikki Brown
Tamsin Williams
Louise Strachan
Ian Cairns, MWC
Val Culley, Inspire
Ann Morrison, JCP
Julie Brown, Triple As
Alison Murray, AAOCA
Sue Hope, Work 4 Me
Janet Richardson, JCP
Alastair Meek, Triple As
Lisa Moir, Spikin Autism
Scott Bathgate, Triple As
Emma Stanley, Triple As
Eilidh MacKech, MSP Staff
Gillian Tosh, Spikin Autism
Fiona Culbert, Spikin Autism
Alex Busch, Camphill School
Cherie Morgan, Play Scotland
Connor McAspurren, Triple As
Kim Stewart, Rainbow Rogues
Lisa Donnelly, ASK North East
Audra Siegrist, Cornstone SDS
Laura Bain, LJ Autistic Services

Annie Wells, MSP
Martin Williamson, Scottish Autism
Charlene Tait, Scottish Autism
Lee McLachlan, Milltown Cmty Arbutnott
Antony McGowan, Antony McGowan Statistics
Marion McLaughlin, One Stop Shop & SWAN
Lesley Thorpe, Highland Cycle Ability Centre
Ben Payne, Milltown Community Arbutnott
Steve Billingham, Relative of Autistic Child
Dorothy Daldry, Grampian Autistic Society
Lindsay Gardner, Parent of Autistic Child
Jocelyn Peace, Parent of Autistic Child
Dawn Ranson, Grampian Opportunities
Eddie Fowler - ASK Autism North East
Lesley Parker, Aberdeen City Council
Linda Singer, Grampian Opportunities
William Rae, Grampian Opportunities
Euan Hood, Grampian Opportunities
Katharine Pain, Aberdeen City HSCP
Kay Johnston, Aberdeen City HSCP
Lisa Ranson, Grampian Opportunities
Bill O'Hara, Aberdeen City Council
Annette Pyle, Scottish Government
Gill Shuttleworth, Camphill School
Joanne Grant, Advocacy Service
Annette Masson, ASK North East
Jenny Rae, Aberdeen City HSCP
Gail McKeitch, NAS Ellen Branch
Cathy Steedman, Autism Initiatives

1 Welcome & Apologies

Alexander Burnett MSP welcomed everyone to the meeting and expressed his thanks to Alex Busch, Director at Camphill School, for hosting the event.

Alexander Burnett MSP introduced himself, Annie Wells MSP, Mark McDonald MSP, David Mackenzie, NAS, Charlene Tait, Scottish Autism, and Kabie Brook, ARGH. He asked that anyone commenting clearly states their name so it can be recorded in the minutes.

Alexander Burnett MSP advised there was a box for comments if people wished to submit these anonymously and that apologies had been received from:

- Prof Jean MacLellan from Autism Network Scotland
- James Fletcher from the Association for Real Change
- Richard Ibbotson from Richmond Fellowship
- Angie Ferguson from Perth Autism Support
- Eleanor Robertson from Disability Shetland
- Dr Sue-Fletcher Watson
- And Susan Chambers & Cath Purdie from Pasda

Previous meetings of the CPG had fixed topics but Alexander Burnett MSP said this meeting was not prescriptive and Speakers would talk about local service provision and their personal experiences.

2 Minutes of the Previous Meeting

The minutes of the previous meeting were not discussed so taken as read.

3 Matters Arising

There were no matters arising.

4 Introductory Remarks from Convener

Annie Wells MSP spoke before the General Discussion after the main speakers.

5 Speakers

5.1 Marion McLaughlin – Aberdeen One Stop Shop & Scottish Women’s Autism Network

Marion McLaughlin explained she is autistic as well as her son and wanted to talk about her poor experience around his education. She said teachers do not have enough knowledge of autism and what they do know is out-of-date. Although her son can read, staff wanted to start by teaching him the alphabet demonstrating they do not understand or have empathy for autistic people. Also, staff did not seek advice from Marion as a mother, autistic person and also a teacher herself.

Marion McLaughlin believed professionals have an important role and can be supportive but this could be improved by engaging more with autistic people. Although some teachers are starting to understand and see her son as more than an autistic child, staff need robust training with input from autistic adults to understand motivations and preferences.

Marion McLaughlin thought that when professionals engage effectively with the autistic community, schools become appropriate environments for autistic children to thrive. She called for autism appropriated spaces in all schools, arguing that, If improvements are made now, will find it easier to find jobs in the future meaning less social support required as adults. She acknowledged that Aberdeen City Council is improving its autism strategy including engaging autistic adults.

Marion McLaughlin gave an example of out-of-date information as she received a leaflet including a company using ABA techniques which have been rejected by the community due to links with PTSD and suicide.

Marion McLaughlin summarised by urging all professionals to engage with the wider autistic community.

Alexander Burnett MSP thanked Marion McLaughlin for her talk noting a report based on a collaborative piece of research involving Scottish Autism, Children in Scotland and NAS Scotland is being launched on the experiences of autistic children in education in September.

5.2 Lisa Ranson – Grampian Opportunities

It was noted that any questions regarding this talk should be submitted by email via David Mackenzie, Charlene Tait or one of the MSPs.

Lisa Ranson advised she had been diagnosed with autism in 2012 when she was 42. The focus of her talk would be her experience in mental health and service professionals. She said she has had mental health issues since she was a teenager with various diagnosis resulting in being housebound for 8 years. She used her own coping strategies and worked when she could but this changed when diagnosed with Asperger's Syndrome

Lisa Ranson said GPs do not have enough understanding of autism; visiting the surgery is a challenge for her as well as communicating with a GP. When explaining her life and anxieties, she realised that her GP did not understand the impact of autism on this. She stated that in her opinion, GPs needed specialist training on autism and lack of diagnosis can result in financial implications for the NHS or even worse, loss of life.

In 2012, Lisa Ranson explained there were no consultants to undertake diagnosis so she went private. She highlighted the lack of adult diagnosis pathway in Grampian noting a diagnosis helps recognise difficulties and access support.

Alexander Burnett MSP appreciated Lisa Ranson sharing her experiences and recognised the absence of a pathway advising this is being reviewed.

5.3 Euan Hood – Grampian Opportunities

Euan Hood advised he was diagnosed 12 years ago aged 39; he described himself as high functioning but covers up his struggles, for example, after giving this talk he may have a meltdown at home later.

At a basic level, Euan Hood said autism is about communication; it can be complex but sometimes simple but when in stressful situations then some autistic people find it harder to communicate. He experienced difficulties when moving to his own flat as, despite asking his GP and Mental Health Officer for help, no-one understood the support he needed so this resulted in contact with the police and being sent to Cornhill Hospital; he now has no confidence or trust in doctors.

Euan Hood stated autistic people cope differently in different situations which in the main, other people do not understand. He is now receiving expensive social work support which if given better support earlier, might not have been required. He said that autistic people are the experts on their communication needs and even though he knew and asked for help, it was not forthcoming.

Euan Hood has been in contact with a friend in Elgin who wrote a strategy around autism recognising challenging behaviour can be caused by other people's actions. The strategy included the assumption that autistic people cannot or do not want to conform but are expected to fit into society, however, he has attended Autscope where autism was the norm. He summarised that there cannot be an expectation for everyone to understand but respect goes a long way.

Alexander Burnett MSP agreed there is not enough discussion about mental health, the strengths autistic people have and that when sufficient support is not provided, this can result in higher costs. He thanked Euan Hood for speaking at the meeting.

5.4 Jenny Rae - Strategic Development Officer, Aberdeen City Health & Social Care Partnership

Jenny Rae opened by expressing how important it was to hear autistic people's experiences and thanked those in the room for sharing their experiences.

Jenny Rae is responsible for revision of Aberdeen City's Autism Strategy and Action Plan in conjunction with variety of people and organisations especially autistic people and their families including some of today's attendees. She noted previous challenges on plans and strategies advising these have been taken into account with the aim of establishing collective solutions.

The revised strategy is currently out for consultation and Jenny Rae asked all attendees to comment if they wished. The aim is for the strategy to make sense, be realistic, sustainable and deliverable with people at the heart. She said their might be other priority areas and acknowledged constraints on resources but everyone can work together to make best use of them and campaign for more.

The draft strategy can be access by clicking [Aberdeen City's Autism Strategy & Action Plan](#) and the consultation period ends on 1st October.

Alexander Burnett MSP thanked Jenny Rae for her update and recognised the importance of including autistic people and their families in the revised strategy.

5.5 Alastair Meek – Triple As

Alastair Meek explained Triple As is a peer support charity which he runs and said it was good that the majority of speakers today were autistic. As an autistic individual, he did not want sympathy but just to be recognised as different without others 'mourning' his difficulties. He explained how autism presents itself personally for him and although this gives some challenges, he has skills that others do not have. He said that parents are encouraged to bubble wrap children but with better communication, then the world can be changed.

Alastair Meek said that services for autistic people and their families in Aberdeen are nearly non-existent, support for schools has been cut and charities are struggling for funding. This causes frustration and MSPs do not understand as many autistic people do not qualify for specialist support although small interventions can fix many problems. He highlighted the problem of short-term funding for projects with unachievable timescales.

Alastair Meek believed that small, local autism charities are key especially around autistic people supporting each other. He said training often focusses on the wrong areas so he does talks and provides support from personal experience.

Alastair Meek summarised that autistic people are capable human beings and should be treated as such, local charities should receive more support and if people want to know about autism then they should ask autistic people.

Alexander Burnett MSP thanked Alastair Meek for his talk and his suggestions to improve the lives of autistic people.

5.6 Eddie Fowler - ASK (Autism Specific Knowledge) North East

Alexander Burnett MSP declared an interest, given ASK is based in the Banchory Business Centre.

Eddie Fowler said ASK has been helping autistic people and their families for many years and been filling the gaps left from the One Stop Shop. It is involved in education, social services, NHS, employment, etc, it assists families with SDS, blue badge applications, etc and supports children and parents with education, exclusions, support plans, discrimination cases, etc.

Eddie Fowler advised parents find it difficult to access a pathway to diagnosis and during this time children can be excluded from school resulting in additional stress and challenges. ASK assists with assessment or private diagnosis which can be expensive. They also attend multi-agency meetings with parents, social workers, teachers and many other professionals which can be costly and not have a suitable outcome.

Eddie Fowler thought better Autism advocacy was needed but to do this an understanding of autism is required; he queried if it was better for an autistic person to be trained as an advocate or vice versa. He also noted the challenges around transition from child to adult, and that employers needed better training and knowledge of autism.

Eddie Fowler said ASK is passionate about autism strategy and the local community will benefit when it is implemented. He was impressed by the Scottish Government/Scottish Autism Microsegmentation project believing if funding is used appropriately then it will result in long term gains. He closed saying he hoped ASK's new base will be a successful resource centre for all those needing autism specific knowledge and support.

Alexander Burnett MSP said it was difficult for MSPs to keep up-to-speed on everything and appreciated Eddie's input and that ASK was in place to provide help.

6 General Discussion

Annie Wells MSP reiterated Alexander Burnett MSP's thanks to all speakers for their insightful presentations. She noted the key themes as improving training/awareness, challenges with diagnosis so it would be beneficial to be told of any best practice, the difficulties for autistic children around education, and the need for charities to have more long-term funding.

Mark McDonald MSP, as a local MSP, noted his appreciation of being invited to the meeting advising he had a meeting tomorrow with NHS Grampian to discuss autism diagnosis; he asked attendees to email him questions and experiences that he can raise in the meeting. He recognised the challenges around funding noting these can have a greater impact for local charities than national.

Lisa Ranson advised Grampian Opportunities received £12k annual funding for 3 years for autism innovation enabling them to gain knowledge and expertise but then the funding stops. She agreed that local charities can stretch funding better and noted there was no representation from Moray or Aberdeenshire Councils today.

Fiona Culbert said her experience of support for parents of autistic children has been abysmal and only due to charities and the goodwill of others her children have a future. She thought there was an appalling lack of accountability from the Scottish Government noting the north east has the highest percentage of autistic people in Scotland.

Annie Wells MSP agreed noting the need to ensure a person-centred approach is being delivered.

Lesley Thorpe expressed disappointment that the Highland Cycle Ability Centre used to receive £9k funding but this had stopped even though they now support over 140 people. Annie Wells MSP acknowledged this comment and the challenges with funding.

Steve Billingham, whose granddaughter is autistic, referred to the supporting the Children with Additional Support Needs Act 2017 which he read in order to understand the support available and help his daughter who was finding it a daily battle to get assistance with her daughter's diagnosis. He knew a co-ordinated support plan was required but when asking professionals for this, it was not forthcoming. He summarised that getting help should not be as difficult as it is.

Annie Wells MSP appreciated the comments and said David Mackenzie could help share the Act with anyone requesting it.

William Rae asked why support was not the same for young people and children; Annie Wells MSP agreed that young adults need more support and the age of transition was being reviewed.

Tamsin Williams thought the needs of all autistic people should be looked at regardless of their ability to function. Although her daughter can cope to a degree at school, she described the 'coke bottle' effect when she gets home. Her daughter has

great potential but sometimes the coke bottle effect can impact on the whole family as it sometimes means they cannot attend planned events.

Steve Billingham noted speakers often mentioned understanding but he believed increased awareness was just as important. Gail McKeitch, a qualified trainer, noted the challenges around accessing and funding training.

Charlene Tait thought understanding and awareness can come from being a reflective person and noted that if you want a different outcome, then you need to do something different as practice is relational. She said a different view of training and understand roles within the stress dynamic may require practitioner change.

Charlene Tait urged attendees to read the Microsegmentation Report Scottish Autism has developed and support the calls to action it includes, some of which relate to issues raised at today's meeting.

Lisa Donnelly shared the bad experiences her son had at a mainstream school resulting in poor mental health and attendance at a special school which is a higher cost. She said lessons are not being learnt as teachers do not understand autism and no-one is being held accountable; she fears for her son's future as the damage caused cannot be reversed.

Attendees expressed their sympathy and agreement with Annie Wells MSP advising mainstreaming and accountability will be looked at.

Alison Murray, whose son is autistic, reiterated others comments about the challenges with professional engagement and the referral/assessment process as, in particular, the NHS is not engaging with the Council. Annie Wells MSP agreed there is an issue with agencies liaising with each other.

William Rae agreed there are failings in the system and urged attendees to read Aberdeen's "Me too" Magazine which includes lots of advice. He said he will discuss the Autism strategy with Jenny Rae as he had concerns actions would not be done in year 1, let alone years 2 and 3. He urged the Government to get rid of the "postcode lottery" around funding.

Anthony McGowan queried why discussions were only happening now and not 20 years ago; Annie Wells MSP said she could not answer historically but hoped the CPG would give more opportunity to discuss and develop matters. She assured attendees the group had been set up to make a difference and be relevant.

Anthony McGowan queried why funds are not being used for autism; Alexander Burnett MSP asked that specific questions be raised through local MSPs or when ministers are able to attend a CPG meeting.

Gail McKeitch highlighted the difficulties in the North East with recruitment, education and retention of staff around autism. Charlene Tait noted this is a national issue as those who work in and receive health and social care are undervalued. Annie Wells MSP agreed that workforce is national issue and confirmed the CPG would take this issue to the Government.

Nicky Brown spoke about his life experiences before being diagnosed in 2012 advising that some of his symptoms should have been clearly recognised as autism before then. He summarised the challenges he had around his own business and how personal trauma took him to the verge of suicide. Professionals took no responsibility but he has implemented self-help measures including his assistance dog Baloo, and endurance his charity rowing events.

Gillian Tosh shared the challenges and difficulties she experienced with support and education of her autistic daughter agreeing with previous comments that there is awareness but not enough understanding of the condition.

It was highlighted that Aberdeenshire Council's policies and procedures are out-of-date resulting in poor care for children and families.

Scott Bathgate thought help and support should be started as early as possible; the countries school system is archaic and lessons around mental health could be learnt from other countries, eg, Finland. He highlighted that autistic people are intelligent, able to work and the system can only be changed at Government level.

Annie Wells MSP agreed that change is needed to get it right; she acknowledged the issues highlighted at the meeting as well as the help and support that does exist. She noted the CPG is not about finding solutions and ensuring voices are being heard by decision makers.

7 Actions

Annie Wells MSP said that actions will be agreed and circulated to attendees after the meeting. If attendees had any specific questions then these can be sent by email.

8 Topic of Next Meeting

Annie Wells MSP confirmed the new education report by the National Autistic Society, Scottish Autism and Children in Scotland will be the focus of the next meeting. Charlene Tait advised the report shares experiences of pupils across Scotland and will be launched on 26th September.

Annie Wells MSP reiterated thanks to those who organised the event, the speakers as well as all attendees for their input.

9 Date of Next Meeting

The next meeting will take place on Tuesday 23rd October at 6 pm (including the AGM) in the Adam Smith Room (CR5) at Scottish Parliament

10 Any Other Business

No items were discussed.