

Minute of Cross-Party Group on Autism Meeting
Meeting 1: Autism and Mental Health – Children and Young People

Tuesday 27 March 2018, at Scottish Parliament at 18:00

Attendees:

MSP Members

Annie Wells (Convenor)
Graeme Dey (Deputy-Convenor)
Alexander Burnett

Speakers

Callum McCrossan
Dr Michael McCreaddie
Anne Marie Gallagher
Dr Mike Warwick

Non-MSP Member Organisations Attendees

The National Autistic Society Scotland (Secretary)
Scottish Autism (Secretary)
Autism Network Scotland
Scottish Women's Autism Network
The Richmond Fellowship Scotland
Autism Initiatives
Autism Rights Group Highland
Scottish Courts and Tribunals Service
Autistic Mutual Aid Society Edinburgh
Grampian Opportunities
Speak Out Advocacy Project
Artlink Edinburgh and Lothians
Lothian Autistic Society
Perth Autism Support
Central Advocacy Partners
Mental Welfare Commission
Pasda
Highland Cycle Ability Centre

Non-Member Attendees

Patricia Cain
Claire Ritchie
Laura Wardrop (Enable)
Libby Lightbody (Inverclyde Council)
Val Culley (Inspire)
Annette Pyle (Scottish Government)

1. Welcome & Apologies

Annie Wells MSP welcomed everyone to this second meeting, and noted that there were three apologies for absence: Sue Fletcher-Watson from the University of Edinburgh, James Fletcher from ARC Scotland & David Bain from Into work.

2. Minute of previous Meeting

Cath Purdie from PASDA requested 2 changes to the minute of the meeting 14 November 2017:

Section 3 – “in addition, PASDA were invited to join CPG as the only carer-led organisation” to be added;

Section 7 – “involve autistic people in the CPG” to be amended to say “involve autistic people and carers in the CPG”.

It was agreed that minutes are to be amended and published on the Scottish Parliament website.

3. Introductory remarks from the Convenor

Annie Wells MSP stated that Graeme Dey has received formal recognition for the CPG from the Standards, Procedures & Public Appointments Committee. The CPG now has its own page on the Scottish Parliament website where the minutes of meetings will be posted. Copies of the minutes will additionally be emailed to all attendees.

Annie explained the parliament building has the NAS Autism Friendly Award and detailed the facilities in place if people need to step out and adjusted the lighting to suit the group.

Annie introduced the topic for the meeting tonight and highlighted that mental health issues are often overlooked within the autistic community despite being more prevalent. Written updates on the Mental Health Strategy and current actions, audits and reviews in progress were circulated prior to the meeting and Annie talked through the main points. Annie introduced the four speakers and thanked them for taking this opportunity to inform the group and allow us all to influence policy.

4. Scottish Government Update

David MacKenzie introduced himself and spoke to the two helpful written updates provided by Scottish Government which were circulated prior to the meeting in the absence of a representative of the government attending in person.

5. Guest Speakers

5.1 Callum McCrossan, Personal Reflection

Callum shared his personal experiences of receiving several mental health diagnoses from the age of 12 throughout his teens prior to a diagnosis of autism at the age of 23. Callum highlighted the difficulty he had experienced in understanding and communicating how he was feeling to a multitude of different practitioners who were using a therapeutic language he could not relate to. One of the major issues was that support was given in short blocks of time preventing Callum from developing a rapport with the therapist, meaning the therapy was inevitably superficial looking at symptoms and behaviours and trying to treat those rather than identifying the underlying issue. Callum explained that he had had felt like a failure because he was not responding to traditional treatments in the expected way, he felt like a burden to his family and the NHS and this contributed to his depression. Callum stated that he now works for The National Autistic Society Scotland and that in his professional role supporting autistic people he has seen lots of examples of people getting late diagnoses, and examples of people getting mental health diagnosis with no follow up support. Callum posed the question “why is mental health support not working ideally?”

The group made several comments and posed several questions around:

- The importance of inter-disciplinary communication;
- The value of diagnosis in terms of contextualising behaviours and opening up access to a community and peer support and advice;

- The pitfalls of diagnosis in terms of the potential stigma and depression that can follow diagnosis alongside the difficulty of accessing services when a diagnosis can pigeonhole a person;
- The value of therapies and support that are adapted around the person's autism;
- The need for long-term support that is co-ordinated rather than short term, stop-gap measures that are aimed at only a single activity or aspect of a person's life.

5.2 Dr Michael McCreadie, Practitioner Psychologist

Mike highlighted the significance of transitional stages in people's lives, e.g. the move from primary to secondary school. Mike explained the pressures and stress that these changes, these new environments and experiences can place on an autistic person and their entire family, creating great vulnerability within their mental health. Mike stressed the importance of giving families practical advice in how to reduce this stress both in school and at home and how to deal with their own feelings in response to their child's reactions. Mike talked about the danger of behaviours which are actually reactions to stress being interpreted incorrectly as psychiatric conditions. There are three adolescent in-patient assessment centres in Scotland which cater to every type of psychiatric condition and autistic people can start to mimic some of the behaviours that they observe within other patients. There is a real risk of mislabelling someone who is autistic as having another condition, or actually replacing their autism diagnosis with something else. Mike clarified that a person can be autistic and also have a mental health condition or another health condition, but he warned of the danger of diagnostic inflation.

The group made several comments and posed several questions around:

- The ongoing erosion of the family and carer's health with adult autistic children still living at home and still requiring a lot of support;
- Low employment rates amongst adults with autism (16% in full-time paid work);
- The value of early intervention around communication needs, sensory issues, overloading, anxiety and depression;
- The value of specialised education provision;
- The importance of good communication and co-operative working when people transition from children's to adult services;
- The exaggerated effect of trauma, e.g. family break-ups, on autistic children.

5.3 Anne Marie Gallagher, Speech & Language Therapist

Anne Marie spoke about the adult diagnostic service she manages in Glasgow, highlighting that there is a significant demand for their service. She stated that 75% of referrals are self-initiated, usually following a difficulty at home or work. Of those referrals 70% have a significant mental health history. Anne Marie stressed that diagnosis is only the first step in a process, which will not help unless it leads to changes in the person's life. Diagnosis allows people to understand their behaviour and it lets them identify what enhances their well-being and what damages their well-being. Anne Marie talked about the importance of support immediately following diagnosis and the dearth of these types of services. Anne Marie warned of the danger of clinicians failing to adapt diagnosis techniques to autism as an autistic person can present mismatched verbal and physical cues. She gave some specific examples of clients being denied diagnoses or of having their severe depression misdiagnosed as mild depression. Anne Marie shared pictures of Andrew, who killed himself two weeks ago at the age of 22, immediately following the death of his maternal grandmother. Andrew had support from a CPN (**community psychiatric nurse**), who said upon first meeting him "I don't know about autism and I don't know how to help you". Andrew's dad asked for his picture and story to be shared at the CPG.

The group made several comments and posed several questions around:

- The training given to CPNs and whether that training is updated on a regular basis;

- The need for training to be applied to practice rather than just being theoretical knowledge;
- The benefit of involving knowledgeable and skilled autistic people in the training delivered to CPNs and other professionals;
- The complexity of the communication skills and needs of autistic people;
- The value of self-generated input from autistic people rather than top-down intervention;
- The importance of personalising support rather than trying to slot people into the support options already available;
- The extremely high rates of suicide within the autistic population, higher than in the neuro-typical population, also higher amongst autistic women than autistic men, which is opposite to the neuro-typical community.

Action: CPNs require appropriate and practice-focussed autism awareness training.

5.4 Dr Mike Warwick, Medical Officer, MWC (Mental Welfare Commission)

Mike informed the group about the role of the MWC as an independent organisation to protect and promote the rights and welfare of people with a mental and/or learning difficulty, which includes autism. He explained that it is staffed by practitioners with medical, psychiatric or social work backgrounds, with carer and/or lived experience. MWC visit hospitals, care homes and prisons as well as people receiving care in their own home. MWC try to identify what is working well and what is not working well and report back on general trends. MWC operate an advice line, monitor guardianship, promote best practice, provide information and publish annual statistical reports. MWC does respond to concerns raised, but they are not a regulatory body and have no power to enforce changes, aiming instead to influence policy by working co-operatively with service providers. The MWC is planning an autism themed visit in 2018 which will comprise specific care visits and guardianship visits as well as enquiring about autistic service users during standard visits. MWC has already started to engage with autistic people. Additional information may be sought from professionals via Survey Monkey about gaps in services, and by speaking to social work departments about autism-specific issues that they have come across.

Mike directed attention to a case study that MWC have published on their website regarding a 45year old autistic woman who committed suicide following being moved from hospital to a supposedly specialist care home. The woman had a long history of mental health issues. Many failures were highlighted in this posthumous report around the lack of information being shared, the lack of trained staff and the lack of a specialist assessment around her autism. This case gives an insight into the problems in the sector.

In response to a question Mike clarified that the MWC differ from the Care Quality Commission in that MWC does not inspect against care standards and are not a regulatory body. However, if MWC have concerns then it is likely that the provider is not meeting the care standards.

Annie Wells intervened due to limited time requesting that questions for Mike be deferred till after the session or were emailed in.

6. Actions to be Taken

Action	Responsibility
Question to be formulated & tabled: <i>What training do professionals in the criminal justice system, teachers, CPNs receive? How does that training relate to practice?</i>	Annie Wells
Question to be formulated & tabled: <i>Should we have standards around services that claim specialism?</i>	Annie Wells

Question to be formulated & tabled: <i>People are being moved from service to service, but how are services commissioned?</i>	Annie Wells
Question to be formulated & tabled: <i>We know that there are pinch points in people's lives but we are focussing on crisis rather than being pro-active. What can we do to change that?</i>	Annie Wells
Question to be formulated & tabled: <i>What support is provided immediately following diagnosis?</i>	Annie Wells
Question to be formulated & tabled: <i>NHS refer people to One Stop Shops but they are over-stretched and the funding is not secure.</i>	Annie Wells
Question to be formulated & tabled: <i>How will services be structured to ensure that there is equal access to diagnosis?</i>	Annie Wells
Enquire into the use and efficacy of 2 different autism identity cards / "keep safe" cards and feed back to the CPG	Graeme Dey & Annie Wells

7. Next Meeting

The group discussed potential topics: employability, diagnosis times & waiting time targets, education, long term housing. Group discussed the time and venue for the next meeting and agreed the following:

Topic:	Accommodation & employment – split session. Annie asked for suggestions as to speakers, and suggested that a Scottish Government representative be invited to address the Group.
Time:	6pm-8pm
Venue:	Scottish Parliament committee rooms
Date:	Dates still to be agreed as availability of venue needs to be checked

8. AOCB

- National autism identity card** – Graeme Dey highlighted a request from a constituent, a man recently diagnosed with autism, whose son has also been diagnosed. He proposed a national autism identity card. Graeme stated that he is aware of several local alert card schemes, that he is aware that there are lots of issues around appropriateness, potential stigmatisation, data handling, etc. but asked the group if it is worth investigating.
 Kabie Brook highlighted the Autism Rights Group Highland's own autism alert card and their report on its use and effectiveness, which she agreed to share with the convener and deputy convener
 A new "keep safe" card which encompasses autism was launched in the last parliament as part of a national initiative.

Action: Graeme Dey & Annie Wells will follow up regarding these 2 cards and feedback to the CPG.

- CPG Membership** – Annie Wells asked for and received approval for Daniel Johnson MSP and for the Mental Welfare Commission to join the group.
- Record of Attendance** – Annie Wells asked that everyone in attendance sign on their way out and provide an email address so that minutes can be issued.