

Governance Group meeting minutes
10th March 2015, 2:30 pm
University of Strathclyde, Glasgow

APPROVED

In attendance: **Kabie Brook**, Autism Rights Group Highland; **Maureen Bruce**, Scottish Government (Care, Support and Rights Division); **Michael Dawson**, an autistic person; **James Fletcher**, ARC Scotland; **Anne Marie Gallagher**, NHS GGC; **Beth Hall**, COSLA; **Ian Hood**, Learning Disability Alliance Scotland; **Richard Ibbotson**, Autism Initiatives; **Thom Kirkwood**, Parental Peer Advocate;; **Jean MacLellan** (CHAIR), National Autism Co-Ordination Project, Strathclyde University; **Donald Macleod**, National Autism Coordination Project; **Peter McCulloch**, Social Work Scotland; **Jess McPherson**, Scottish Government (Care, Support and Rights Division); **Jenny Paterson**, National Autistic Society; **Jayne Porter**, Autism Network Scotland; **Annette Pyle**, Scottish Government (Care, Support and Rights Division); **Alan Somerville**, Scottish Autism; **Ali Taylor**, Scottish Government (Care, Support and Rights Division)

Apologies: **Carolyn Brown**, Fife Council/Education; **Emma Hanley**, Autism Network Scotland; **Iain McClure**, NHS Lothian; **Jane Neil-MacLachlan**, Independent Advisor

Minutes by: Tracy Wenzl, Autism Network Scotland and National Autism Co-Ordination Project

- I. **Welcome, apologies and introductions** – The group introduced themselves to new members. Apologies were read.
- II. **Minutes** – minutes from 11 November 2014 were approved.
- III. **Improvement Work**
 - a. **AAA work on diagnosis waiting times:** AP reported that the Autism Achieve Alliance (AAA) launched their diagnosis work at the 3rd Annual Conference in December 2014. Scottish Government has developed a job description and plans to hire someone to drive work forward. It was unclear at present where this new position would sit within Scottish Government as this would depend on the successful candidate – update to follow when more information is available.
 - b. **Joint Improvement Team (JIT)/One Stop Shops (OSSs)** – AP reported that Scottish Government has appointed Julie Haslett, a lead from the Joint Improvement Team (JIT) to work with all OSSs. They recently attended a very successful learning event, led by Julie, to hear all about strategic commissioning in the new integrated health & social care environment. The objective is to help OSSs with future sustainability and build community health partnerships. Julie and SG officials will meet with the National Autism Co-Ordination Project (NACP) team soon to discuss further. Her wider role will also involve helping third sector with strategic commissioning.
- IV. **One Stop Shops**
 - a. **Evaluation report** – AP reported that the report will be discussed at the next partnership meeting and a decision on publication will be made then. The report shows a wide range of services and processes happening in the OSSs. Each of the OSSs is at a different place. JMCP commented that in hindsight, two years was probably not long enough to get OSSs up and running and that more initial planning/development time was needed.

KB commented on the fact that only current service users were surveyed during the evaluation process. She has heard from former users and non-users that they would also have liked to be included in the assessments. JMcP said that for future evaluations, they would need to be more innovative but that the current evaluation provided “what was asked for.” MD further noted that effort needs to be made to reach out to people who feel they have been marginalised. JMacL noted that the Governance Group is trying to do this. TK noted that wider partnership should be considered as OSSs solely for autism may have detrimental impact of structures and partnerships that are already in practice in some areas.

BH asked about expanding the OSS programme and if this group could address the broader question of additional rollout. JMcP says it is too early to think about wider rollout, there is more to do to embed existing OSSs in their communities. There is no one model for setting up a new OSS, but this is something to consider. BH noted there is strategic planning to be done about funding, community support, etc. beyond the short term. RI noted that two OSSs have been around for 10 years and that they may provide insight when considering a model, as well as sustainable funding. It was further noted in the group that at least two areas are making plans to launch their own OSSs without funding from the Scottish Government.

- b. **Additional funding** – all OSSs will be funded through March 2016.

V. **Overview of working group activity**

DM gave an overview of his submitted report (attached.) He requested that the Governance Group clarify the chairs’ roles and remit of the groups.

VI. **Updates from Working Group Chairs**

ACTION ITEM: TW to include Group Goal on minutes

- a. Working Group 1 – RI reported that Group 1 has met twice; the first meeting was to set the work plan, and the second meeting heard a report on the Scottish Strategy for Dementia and an update on the NES Training Framework. RI is reflecting on the key points from the dementia strategy and will send those to the group for further consideration. JMcP noted we could learn a lot from dementia strategy, but it isn’t parallel, the demographics are different –HEAT/LDP targets are difficult to implement, and NHS is moving away from targets.

RI is considering if anyone else should join the group; for example, a general practitioner. He has a contact at the Royal College of General Practitioners (RCGP). Discussion turned to the RCGP’s autism theme for the year, and what timeframe the year covered. JMcP noted the RCGP year runs April – March, so autism year is likely coming to an end. TK confirmed that monthly training sessions across Forth Valley are occurring, and some have been devoted to autism awareness and training. These have had an impact on services, resulting in better patient care. JMcP suggested looking at Locality Management Committees (LMCs) to develop inroads.

BH suggested that local planning to unite health and social care could be another opportunity.

ACTION ITEM: RI to send RCGP autism contact to JMcP

MB asked if RI was optimistic about the group's remit, RI replied that he was, and a number of things on the workplan have timelines that are progressing, allowing the group to focus on different things each meeting. RI noted that he is awaiting Tommy Mackay's report on microsegmentation. AS noted this was due to be published in June.

- b. Group 2 – JF reported that group two has met twice. They have been focused on evidence gathering, and have decided to focus on young adult transitions, ages 14-25. Association for Real Change Scotland (ARC) and Autism Network Scotland (ANS) have been hosting roadshows to gather feedback on the Principles of Good Transitions 2 (PoGT2) document – three have been held, with two more coming and a few more requests for events across Scotland. The group has discussed a draft report based on initial findings from the roadshow, which generated five recommendations the group is considering. Group 2 wants to see what is going on in local authorities, and to look at transitions-themed Autism Development Fund (ADF) projects. Emerging themes are:
 - i. Accountability for supporting transitions – not clear to local authorities due to confusion over local policy, or parents, who is supposed to be in charge of managing/overseeing transitions.
 - ii. Joined up working – the group wants to develop recommendations on what this should look like. Transitions leads and forums are among the ideas under consideration. There is a lot of variation among local authorities in their approaches to transitions across Scotland. Process issues are also key– success of transitions depends on having right people at the right times. Relies on involved parents, committed practitioners.
 - iii. Eligibility for services – Children are not getting social care support for transitions. Group 2 analysed available data and found that three times as many children are known to have autism diagnoses as adults – this suggests issues with transitions. Parents say they just need a little support, but it is not available. AMG noted that she sees lots of referrals for young adults who have not had supports outside of Education – they need supports as they move into higher/further education or employment, but often do not realise this until they have run into trouble. She notes that people who have not previously need much support may still need transitions support. KB noted that supports are often focused on parents, instead of building community for autistic children. The children sometimes do not know what it means to be autistic and struggle later to know what support they need. JF agreed and noted this had come up in the roadshows as well. MB asked if the issues were specific to autism, or transitions broadly. JF answered the events are autism-specific, but the issues are consistent everywhere. We know the issues, and now we need to figure out how to address them.

AS suggested speaking to Bill Colley and Ambitious About Autism for further information/research data. PMc noted that group should consider adding someone from Education, and JMaL noted that PASDA had said the same thing in a meeting the previous day. She asked if Governance should add someone from Education. JMcP suggested including someone from Education in Scottish Government

ACTION ITEM: JMcP to contact someone in Education/Scottish Government to invite to group

PMc suggested that someone should look at all the local strategies to see what has been done with transitions – it should be present in all of them. JF reported that IH had just completed this, and IH followed up to say that while everyone mentioned transitions, some strategies have plans to address this while others just note that it is a problem that needs to be addressed. There is more to be done and the plans could be used to monitor progress.

TK noted the success of Clackmannanshire, Falkirk and Stirling Councils who jointly with the Forth Valley Health Board designed and a set paperwork around Getting It Right For Every Child, which also meets the needs of the Children and Young Persons Act. When used properly in fully partnership, it delivers an informative and effective framework for transition from Children to Adult Services, as well supportive information in determining how best to use self-directed support. TK offered a sample set to JF, to be delivered after the meeting.

BH asked about the roles of Working Groups, and if they were implementing existing recommendations or generating new ones. JF answered that the group's work is within the current recommendations and that they are picking a few things to focus on and do well.

- c. Group 3 – JPo (for JNM) reported that the group first attempted to define “good autism practice” and settled on “it improves the lives of people with autism.” A key task is looking at what is out there – the group has looked at quality frameworks and standards and is working to collate them with an eye to publishing them online in the future. They are keen to see the outcomes from the Research Action Seminar, which is not yet available. They want to promote knowledge exchange for practitioners and are considering development of online knowledge exchange forums to sit alongside events. They are also considering the “share practice” button on the Autism Toolbox website and ways to use this concept. The group wants to see outcomes from the ADF projects to find examples of good practice. The group is also considering an event – “good practice festival” to tie in with annual conference in November. JPo raised a question to Governance on behalf of the group: How does information gathered on good practice affect commissioning?

BH asked how the group is tailoring approaches to different sectors? JPo replied that engagement between sectors is key, and that online knowledge hubs would allow specific sector breakdown. She gave the NES Training Framework as an example of a cross-sector document. TK questioned how families and people on the spectrum

are being considered in good practice. JMcP responded that the group will need to look at the results of the ADF projects to determine this. AS noted that the report format should be standardised so outcomes can be measured. JMcP said they need to think about how they will do this.

JMacL asked about the GAP Journal, and AP responded that it was a collection of research related to the Strategy. AT added that the dissemination of the GAP Journal was a task for the group. AP noted that people (practitioners) need support to write for academic journals. JPo noted that practitioners do not have access to GAP Journal (or other academic journals.) MB suggested that the matrix of psychological therapies might be a good model to use when considering how to disseminate good autism practice.

- d. Group 4 – AMG reported that her group started by clarifying terminology. Capacity means development of skills – the group wants to help improve skills. “People with ASD” was changed to “autistic people” in group’s remit. Discussion around what turns knowledge into skills led to suggestions of mentors and champions.

The group aims to increase awareness and capacity, bringing top level/specialist skills down (ie, learned more broadly) instead of referring people up the system. JMcP said it sounded similar to hospitals sending specialists out into communities instead of everyone needing to go to one hospital. AMG said there are too many people competing for too few specialist services. The group hopes to build capacity to prevent bottlenecks in services, and wonders how to make the greatest impact with minimal resources. In her own position, she is considering succession planning, with 4 of her 6 team members due to retire in the next few years. AMG also noted that developing local skills would help avoid out of area placements.

TK commented there are good examples in Council-run schools, where they are sharing knowledge within schools and social work. AMG wants to see side-by-side working to build capacity, but recognises the need for resources to accomplish this. JPo noted that the Autism Toolbox is meant to help teachers address autism in classrooms so they do not need to refer students elsewhere. ANS is connecting with teacher students to show them the Toolbox.

VII. **National Autism Co-Ordination Project update**

DM submitted a written report. To summarise, he reported that they are focusing their work on areas which do not yet have a written plan (4 remaining), and also are supported areas in implementation. There are questions around where an autism plan sits (local authority, education, health, etc.)

NACP held their first event for local strategy leads in January. The next event, April 29, will focus on complex care and out of area placements.

NACP is working with PMc and Social Work to develop performance indicators. The draft indicators are still under review, and came from a request from local authorities

and others to have benchmarks. JPo asked if they were based on social work. JMaL answered no, they are based on Strategy, and are still in very early stages of development. DM reported that the performance indicators will be circulated once review is complete.

MB noted that she was interested in the conversation about benchmarking, and suggested that an eye to high level integration would help local authorities achieve goals. JMaL noted that a couple of local authorities have already made those joins.

PMc noted that local authorities have bought into process and understand need for coordinated services. They are working out how best to move along together. He noted the feedback from the first NACP event was very positive, and that it was good for everyone to see common issues and different approaches. There is a need to develop resources across boundaries.

IH asked if out of area placements were being addressed at a national level. AP responded that in an upcoming meeting, she will be looking at out of area placement data for learning disabilities and autism. That data will help inform the next NACP event. JMCP stressed the need for strategic needs assessment.

VIII. Autism Network Scotland update

JPo (for EH) reported that the Network is looking at new ways to spread knowledge. The Employment Network is developing a website and resources for employers. Scottish Women's Autism Network (SWAN) is preparing to host a conference in April focused on diagnosis, education and wellbeing, in partnership with the Network. An advocacy resource is being developed for the website. The Network is holding a 2nd conference, following on the Scottish Strategy for Autism Third Annual Conference, geared towards people on the autism spectrum, their families and carers. A review of the virtual networks has revealed that the most successful have an attached face-to-face element – Employment, Scottish Borders and Dumfries & Galloway are the most used. The transitions roadshows are ongoing in partnership with ARC Scotland. The PoGT2 document will be edited based on findings from these roadshows.

The Network is dealing with a large number of enquiries across Scotland, from a range of people including people on the spectrum, parents and practitioners. JMaL noted the Network is seen as a last resort for people who are not finding services. MD asked about the organisations who are supposed to do this. JMaL replied that more analysis is needed, and that a detailed report was coming soon.

IX. Any other business

KB asked what happened to autism statistics that sit with Learning Disability Observatory. JMCP replied that they should be coming soon, and that Scottish Government is looking at other options as well.

KB suggested the Scottish Government mark Autistic Pride Day on June 18.

ACTION ITEM: KB to send further information on Autistic Pride Day to AP

AP reported the NES Framework project will receive further funding. The proposal and training plan can be shared in Working Groups 1 and 4 for further discussion.

JPa noted that she will be sending NAS reps to participate in the other working groups.

X. Next meeting

The next meeting will be held on June 16, Edinburgh.

KEY MESSAGES

The Governance Group heard updates on the progress of the four working groups, as well as the National Autism Co-Ordination Project and Autism Network Scotland. Scottish Government has appointed a Joint Improvement Team lead to work with the One Stop Shops on strategic commissioning, in order to improve sustainability through community support. The One Stop Shops will be funded by the Scottish Government through March 2016. The Scottish Government will soon appoint someone to carry the Autism Achieve Alliance's work on diagnosis times forward.

ACTION ITEMS

ACTION ITEM: TW to include Group Goal on minutes

ACTION ITEM: RI to send RCGP autism contact to JMcP

ACTION ITEM: JMcP to contact someone in Education/Scottish Government to invite to Governance group

ACTION ITEM: KB to send further information on Autistic Pride Day to AP

NEXT MEETING

Tuesday, June 16 in Edinburgh