

Governance Group Meeting Minutes

16th February 2017, 1.00pm

IET Building, Glasgow

APPROVED

Present: Gillian Barclay, Scottish Government; Kabie Brook, Autism Rights Group Highland; Carolyn Brown, Fife Council/Education; Michael Dawson, an autistic person; Lesley Evans, Autism Network Scotland; James Fletcher, ARC Scotland; Jo Hamilton, NAS; Ian Hood, Learning Disability Alliance Scotland; Richard Ibbotson, The Richmond Fellowship Scotland; Thom Kirkwood, Parental Peer Support; Jean MacLellan (Chair), Chair of the Scottish Strategy for Autism Governance Group; Donald Macleod, National Autism Co-ordination Project; Corrie McLean, Autism Network Scotland; Donna Nicholson ; Annette Pyle, Scottish Government (Care, Support and Rights Division); Cathy Steedman, Autism Initiatives; John Urquhart, COSLA

Apologies: Kjersti Fergusson, Scottish Government; Anne-Marie Gallagher, NHS GGC; Alistair Gilmour, Autism Network Scotland; Duncan McIntyre, Midlothian Council; Iain McClure, NHS Lothian; Robert Mitchell, Scottish Government; Darren Tierney, Scottish Government

I. Welcome, apologies and introductions

JMaCl welcomed the group to the meeting and apologies were heard. Introductions were made around the table due to new members joining the group – Gillian Barclay; Donna Nicholson and Jo Hamilton. Going forward Peter McCulloch of Social Work Scotland will be replaced by Duncan McIntyre, Midlothian Council.

Previous Action Point: *AP to provide the group with an update on the management structure of the Care, Support and Rights Division.*

Update: To carry forward to next meeting.

II. Minutes of previous meeting

Minutes were checked for accuracy and approved.

III. Matters arising

Action Point: *Any further comments re the measures taken to be taken by new strategic partners as outlined in the Policy paper to be sent to AG immediately for distribution.*

Update: Closed

Working Group Activity Reports (IV)

Action Point: *The Working Groups will discuss both at their next meetings and between each other what they would like to precisely focus on achieving and the process for doing so, with invitations to innovative and appropriate new members to follow. Outcomes must be both impactful and measurable.*

Update: To carry forward to their next meetings.

Policy Feedback (VII)

Action Point: *AP to share feedback on wider engagement events prior to next meeting of the Governance Group.*

Update: Tabled paper and will be discussed as Agenda item

Feedback on Mental Welfare Commission for Scotland, Investigation – The Death of Ms MN (VIII)

Action Point: *All Governance Group members to review the draft feedback report to the Mental Welfare Commission for Scotland Investigation into the death of Ms MN and suggest the points to feature in the final submitted version.*

Update: Tabled paper and will be discussed as Agenda item

5th Annual National Autism Strategy Conference (XI)

Action Point: *Suggestions of good autism practice to be showcased at the 5th Annual National Autism Strategy Conference to be communicate to AG.*

Update: Closed

IV. Updates by tabled papers only

- **Policy**

AP

AP submitted a paper in advance of the meeting highlighting some of the main policy activities and cross policy updates. Summarising ministerial activities was seen as a helpful inclusion.

In summarising the paper **AP** covered the following points:

NHS NES will be recruiting to fill Gail Milroy's post to continue their strategy work as she has secured a position with another Board.

The Innovation and Improvement Fund is proving to be very helpful for third sector organisations. The posters they helped Inspiring Scotland produce for the conference showcasing the volume and range of local projects was also deemed a success.

Principles of Good Transitions 3 and Autism Supplement – this was successfully launched at the 5th annual conference with officials continuing to support the Project Lead on the national transitions project which is due to report at the end of March 2017.

Commissioning Support to Third Sector – Workshops took place in November and December 2016, helping approx. 150 third sector organisations understand the ever changing health and social care integration landscape.

Policy Programme Budget – **AP** was not in a position to discuss further at this time.

Autism Network Scotland – Grant Retender – The timeline has been delayed and the specification is currently with Health Finance seeking a financial commitment of programme funding beyond March 2018. As soon as the budget is secured, the spec can go to grant tendering.

Autism Education Resources – Autism Education Trust presented on the resource which was developed through funding from Westminster. Those attending could see that the resources would be a cost effective way of delivering on GIRFEC and meeting the needs of autistic pupils in schools, building on the current Autism Toobox. **Laura Meikle** and **AP** are exploring how to “put a kilt” on this model and what levers would be needed to make this happen and at what cost.

- **TK** stated that additional resources would be welcomed by teachers, moving towards a more hands on approach and less theory, with **CB** agreeing, stating that many schools are getting deluged with the number of new cases but are moving to the “next new thing” with no evaluation having been done.

Mental Health Strategy – Focussing on 3 ambitions and 7 themes to improve the mental health of the people of Scotland, this is due to be published early Spring 2017.

Mental Health (Care and Treatment) (Scotland) Act 2003 – Phase 1 (scoping exercise) now complete with agreement in place by Scottish Ministers to start Phase 2 (the official review). **MD** asked what the timeline was for this starting and **AP** will advise when the Chair is in place.

NO ACTIONS REQUIRED

- **Autism Network Scotland Report** **DMcL**
DMcL submitted a paper in advance of the meeting. In summation, **DMcL** stated that as always, the focus on wider engagement continues with the first of a series of roadshows concentrating on capacity building in local communities commencing March 2017 in Argyll, where significant input has been given to revitalise the existing local strategy. Autism Network Scotland (ANS) also has an emerging focus on “autism friendly” localities as they start to support engagement with other Local Authority departments with the aim of improving the lives of autistic people within their home towns and cities.

NO ACTIONS REQUIRED

- **Working Group Activity Report** **JF**
JF submitted a paper in advance of the meeting.

Work Group 2 met 15.02.17 and had a lot of discussion on transitional activity. **JF** said the Autism supplement was very helpful and was confident that this and the Principles of Transitions document provide an effective framework to embed across the country. Other organisations are now looking to produce similar supplements on the back of the Autism Supplement.

A meeting with Leanne and Alison from Inspiring Scotland discussed running sessions with Innovation Funded projects to introduce the Principles 3 supplement in the Central Belt, Inverness then follow up with a secondary session addressing the sustainability of funded projects. Lynsey Stewart, ANS is involved.

The 1st session would be targeted at those already receiving funds (currently 43 projects) with the 2nd session's audience to be confirmed.

There then followed a brief discussion regarding these funded projects. **JU** said each local authority needs to think about what sustainability means for them, which was agreed by **JF**, who stated that strategically this has to happen as the Principles are transferrable, but how do they bring stakeholders together. **TK** said the financial impact would be extreme. When **JMcL** asked if older transitions would be addressed, **JF** said that Lynsey Stewart, ANS had already started to work on this and it would be good for the group to review.

AP told the Group that Policy officials know what the issues are they just need to deliver in order to ensure the good projects survive and are properly imbedded into society.

RI and Work Group 1 are to meet 20.02.17 to discuss their next move.

Anne-Marie Gallagher's group was discussed under Policy paper by **AP**.

ACTION: *Working Group 2 will start to gather examples of parent / carer peer support networks and seek opportunities to encourage this approach. They plan to link with the SG Carers team on this.*

VI. 5th Annual National Autism Strategy Conference

JMcL said that this year's conference was more ambitious with its diversity of programme topics whilst still honouring the original strategy and framework and asked the group for feedback on the day's proceedings and what learnings could be taken forward to next year's conference.

DN started the discussion by saying she was surprised and inspired by Project Search and thought overall that the conference was great with good attendance. She particularly liked the emphasis on the females with autism.

CS and **TK** both agreed there was benefit in the networking opportunities which arose, but felt the workshops were time constricted, which was echoed by **MD** and **JF**.

MD would like more detail on the content of the workshops to aid his choices and felt that attendees were not getting properly educated on autism or the supports available which **KB** seconded, saying she felt the conference was too practitioner based and people learn by listening to autistic people. To the question "what conduit do we have for hearing the autistic voice?" posed by **CB**, **DMcL** said local events are in place to encourage wider engagement to which **TK** added it's the consistency of these events which are in question.

RI also commented on the diversity of attendees and was also unsure if the conference was being pitched at the right target audience and echoed the need to acknowledge the autistic person more and consider this for 2018.

VII. Policy Discussion on Pathological Demand Avoidance Syndrome AP

AP submitted a paper in advance of the meeting.

AP thanked everyone who contributed to this petition.

The Scottish Government's view on the current petition is that Pathological Demand Avoidance Syndrome (PDA) has no official diagnostic status or recognition within current autism diagnostic practice, nor is it included in the *Scottish Strategy for Autism's* implementation framework for 2015 – 2017.

Policy position is that PDA is seen as a sub-diagnosis with no clinical identification in DSM-5 or ICD-10 and whilst acknowledging this to be the case, there was general consensus among the group that it may not solely be a sub-diagnosis within autism. **CB** said that PDA being seen as a sub-diagnosis may cause further confusion as Autism is so diverse anyway. **CS** agreed that further understanding is required as there are too many differing opinions.

"This is being pushed by Lothian parents who believe that the support should be person centred to whatever their needs are. **RI** worried that this terminology was too simplistic" with **TK** saying it was being driven by Social Media.

KB asked for link (<http://autismexperts.blogspot.co.uk/2013/03/natures-answer-to-over-conformity.html>) to Dr Damian Milton's paper to be included within the minutes and said non-autistic people don't understand PDA and that individuals are coping the best they can. A clinician in the Highlands is angering parents by stating that their children do not meet the criteria for an autism diagnosis but that they probably would for PDA but this is not diagnosed in Highland. This is leaving children and parents in limbo without support.

JMcL asked if there would be any alterations to Policy. The Group were broadly content with the wording but asked that "no acceptance due to no robust evidence" be added to the petition before the deadline of 17.02.17.

VIII. Conclusions on Mental Welfare Commission for Scotland, Investigation – The Death of Ms MN DM

DM submitted a paper in advance of the meeting.

The Group had all read the Summary and following a brief discussion around wording led by **KB**, it was agreed to add in a piece about the value of peer support as well as further emphasis on safeguards around prescribing and dispensing drugs as suggested by **TK**, and seconded by **MD**.

It was agreed that **AP** could submit the Final Response to the Minister.

ACTION: *AP to submit the Final Response to the Minister.*

V. Refreshing the Strategy – Identifying Priorities

JMcL

This topic was moved to end of the Agenda with the paper submitted to the Group for reading during the break.

JMcL advised this paper was not for wider circulation but for discussion purposes only and suggested discussion points to consider may include, looking at what's working, where the gaps are, is it necessary to adapt the current structure and what the next steps might look like.

The group agreed that it was very constructive having the Outcomes Framework which will conclude end March 2017 and moving forward the strategy needs to ensure the collective opinion is validated by far more voices than our own.

What's working: Beyond the strategy itself, the Outcomes Framework is welcomed as having given clarity and to have been provided in a format that is easily accessible. The National Co-ordination Project is working more closely with local authorities and health boards in their strategic planning. We are a community of practice with commitment.

The work undertaken on improved diagnosis and post diagnosis support is regarded as critical and is something which is universally agreed needs to continue in the next phase.

It was agreed by the group that we need to carry on with all the threads of our work as there is still much to be achieved.

There is a veiled threat for the legislation of autism, which on the plus side, means local authorities have to pay more attention to statute, with the negative view point being statute equals abject failure.

Gaps: Topics of particular concern are:

- Early Years
- Early Intervention
- More specialist knowledge and input within educational settings especially in primary schools – mainstreaming is the dogma
- More adult diagnosis, including where there is no co-occurring condition
- Health and Well-being – mirroring the policy within the Keys to Life
- Much greater understanding of the needs of those with autism who also have mental health needs
- Employability
- A sense of those with autism can find themselves in the criminal justice system inappropriately
- Housing and Homelessness
- Autism and ageing
- Public awareness of autism

Structure?

The question posed to the group by **JMcL** was “How do we move to something which is properly resourced”. We’re doing the “soft” stuff but we need outputs and outcomes, to which **AP** replied the outcomes were at a national level.

RI commented that last time there were sizeable work chunks and suggested a similar approach this time and/or match these themes to these outcomes. **TK** would like to see current outcome 4, split into Education and Employment to develop and bring a stronger focus to both, emphasising that employability is not and should not be constant or continual volunteering.

CS agreed that the Outcomes for 2015-2017 were still relevant and ongoing.

AP agreed with the broad themes listed under the Gaps heading, but asked how they can be prioritised. **TK** said he saw barriers re-emerging within education, which **CB** agreed with, stating, it’s important not to make the same mistakes and to consolidate what we have. **KB** then raised the issue of the built environment, in relation to autistic sensory needs and asked if anything could be done with new build schools?

KB also raised the subject of supported decision making and autonomy. What the person wants and needs is control over directing their life which is different to wanting independence. There is a need to adapt the communications to the autistic person and ensure they’re being heard.

JMcL then asked how we involve people and have their voices heard in the consultation process, to which **DMcL** said that discussions at a local level have already started to raise priorities.

Re the topic of ageing and autism, **JU** said shaping care for older people, dementia early diagnosis and other policies are already being tackled within Government.

Following the discussion around the gaps, **JMcL** then asked what the next step collectively and individually would be? How can we analyse the gap listings to move forward? **AP** recognised that certain gaps are already a national priority such as housing and we can connect into this. Acknowledging there is still a great deal to do **JMcL** stated that we need to focus on a couple of the gaps identified and take forward.

TK agreed saying we need to look at sustainability, with **CB** stating that cuts and bolt-ons increases the pressure on delivery of service and can this Group do anything to address this?

KB asked how the refreshed strategy aims and outcomes will affect local strategies and priorities to which **JMcL** replied we’re already working at a local level and will continue to do so.

ACTION: JMcL and AP to work on draft refreshed strategy proposal to distribute to the group by April.

IX. AOCB

No further points raised and the meeting concluded.

X. Date of Next Meeting

Date to be advised.

ACTION ITEMS

- **AP** to provide the group with an update on the management structure of the Care, Support and Rights Division.
- The Working Groups will discuss both at their next meetings and between each other what they would like to precisely focus on achieving and the process for doing so, with invitations to innovative and appropriate new members to follow. Outcomes must be both impactful and measurable.
- Work Group 2 will start to gather examples of parent / carer peer support networks and seek opportunities to encourage this approach. They plan to link with the SG Carers team on this.
- **AP** to submit the Final Response to the Mental Welfare Commission for Scotland Investigation into the death of Ms MN
- **JMcL and AP** to work on first draft of a refreshed strategy proposal to distribute to the group by April 2017.