

Autism Strategy Review Group Minutes

Friday 25th January, 1.00pm – 3.15pm

Number 6, 24 Hill Street, Edinburgh EH2 3JZ

APPROVED

Present: Gillian Barclay (Chair), Scottish Government; **Kabie Brook**, Autism Rights Group Highland (ARGH); **Fiona Clarke**, Parent representative; **Matthew Day**, Autism Initiatives; **Lesley Evans (minutes)**, Autism Network Scotland; **Sonny Hallett**, Autistic Mutual Aid Society Edinburgh (AMASE); **Richard Ibbotson**, The Richmond Fellowship Scotland; **Suzanne Kinross**, Scottish Government; **Thom Kirkwood**, Apex Associates; **Joseph Long**, Scottish Autism; **Prof Jean MacLellan**, Autism Network Scotland; **Fiona Milne**, Renfrewshire Carers Autism Spectrum Disorder Support Group; **Annette Pyle**, Scottish Government; **Janine Robinson**, NHS Education for Scotland (NES); **Marion Rutherford**, Queen Margaret University; **Nick Ward**, National Autistic Society (NAS)

Apologies: Arron Ashton, Scottish Government **Anne-Marie Gallagher**, NHS Greater Glasgow and Clyde; **Stephanie Rose**, Police Scotland; **Catherine Steedman**, Autism Initiatives; **Charlene Tait**, Scottish Autism; **John Urquhart**, COSLA

The agenda and accompanying papers were circulated to the Autism Strategy Review Group ahead of the meeting.

Welcome and Introduction

GB thanked everyone for coming and introductions were made.

1. Strategy Group Business – Gillian Barclay

Agreement of:

Terms of Reference

GB advised that individual comments had been received and asked the group if they were happy to sign off the document.

- Regional partnership meetings (open) will be arranged quarterly.
- Autism Strategy Review Group (closed) meetings to be arranged on an ad hoc basis as required.
- Membership of group to remain fluid to accommodate changes in posts and topics reviewed.
- Representative local groups such as APOs to be included wherever regional partnership meetings take place.
- It was agreed that **SH** redraft the Autistic Voice paragraph, to be approved by group email.
- Under the Remit paragraph the word “autistic” was inserted. The first paragraph now reads: “The Review Group will provide a review and monitor function to progress the Strategy’s priorities, aimed at improving outcomes for autistic individuals and families

Agreement of Terms of Reference (cont.)

living with autism. The group will help to ensure those involved in the delivery of the priorities work collaboratively together and involve autistic people”

Individual Member Roles: These will become apparent as the group moves forward.

Collective Roles and Remit of the Group: Collectively the group may not always agree. However it is the role of the group to help work through challenges.

Measuring impact and outcomes of the Strategy 2019 – 2021: The paper circulated prior to the meeting, “Workstreams and Priorities” will be used as a monitoring tool going forward, with progress updated at all meetings.

Working Groups Remit: Working groups have yet to be identified, although these may become more specific once the workstreams have been discussed and short term projects identified.

The group agreed in principle to the Terms of Reference.

ACTION: SH to redraft the Autistic Voice paragraph, which will be approved by group email.

2. Scottish Government Policy Update – Gillian Barclay and Annette Pyle

GB discussed the Workstreams and Priorities, Progress January 2019” paper, taking each work stream in turn.

The traffic light system used indicates the following:

Green: Activity is well established and ongoing

Amber: Activity is in its early stages and needs more work

Red: Activity has not yet started

Workstream: National improvement programme for assessment and diagnosis

GB advised there is a strong commitment to improve post diagnostic support and recognised the sporadic levels of service around Scotland. Scottish Government (**SG**) has been speaking with Marion Rutherford (**MR**) and Kirsty Forsythe at Queen Margaret University to establish a National Team to visit all regions over the next 2 years (approx.) to address this, with good practice of diagnosis to be covered within this work.

MR will be in post from end February/beginning of March 2019 and will work alongside an Occupational Therapist and part-time Psychiatrist.

JR advised NES has spoken with **MR** regarding the establishment of a small task group to ensure training needs dovetail with the National Team’s findings and assist a roll out of further training. This task group is in its early stages.

A general table discussion on diagnosis followed, with the following points raised:

- Disparity in waiting times – what are the key factors contributing to the variance (GPs having a lack of awareness of autism when they see it; movement in staff posts)?
- How do we reduce waiting times?

Scottish Government Policy Update (cont.)

ACTION: SG to ensure an autistic voice in an advisory capacity is associated to this programme.

Workstream: National Post Diagnostic Support Toolbox

GB advised they are currently commissioning expertise to lead on the work on a toolbox. Autistic people will be involved throughout this project.

FC spoke of the language used in the SIGN Guidelines. **FC** also spoke of the leaflet parents have access to and agreed to share a link to the document with the group.

ACTION: Signpost the group to the parental leaflet¹

Workstream: Supporting Integration Authorities to achieve national autism outcomes

GB advised Autism Network Scotland will continue its work on this workstream.

Workstream: Mental Health Strategy

GB advised more work is to be done here and meetings are planned with Mental Health colleagues.

Workstream: Explore alternative solutions to put of area placements for those with a diagnosis of autism

GB advised Dr Anne McDonald's report had made significant recommendations re residential care placements and suggested Dr McDonald be invited to a future meeting to address the group.

FC noted that communication support did not appear in the report and **KB** highlighted its omission from any of the workstreams. **GB** advised that the workstream paper is a summary of the agreed priorities.

ACTION: ANS to ask Dr Anne McDonald to present her report at a future meeting

Workstream: NHS NES Training Workplan

JR advised that since 2013, autism has sat on its own, however, this has changed in the last 6 months, with greater cross-collaboration now taking place, e.g. Jen Shields is currently working with a psychologist in the Children's Directorate and a Nursing and Allied Health Professional Group has been developed.

¹ https://www.sign.ac.uk/assets/pat145_parents_and_carers_large_print.pdf

Scottish Government Policy Update (cont.)

The big focus is on diagnosis; to rethink how the services are developed and how to deliver training to the right people.

GB stated that at the Borders meeting, the topic of training was raised several times and indicated that people were trying to re-write the Autism Training Framework on a local level due to it not being fully accessible. **JMacl** said information had also been gathered from attendees at an Autism Strategy Collaborative Business Meeting and Workshops to help make the Framework more accessible at a regional level. **JR** said she had not pulled this report together yet, but agreed re looking at the Framework's accessibility.

When asked by **SH** if co-occurring conditions was covered by the Framework, **JR** said this was an area requiring further expansion.

KB raised the question of women and girls. **NW** said there is a conference in May on women and girls and the intersection of gender and identity. **SH** also spoke about the gensex conference and agreed to send a link to the presentations.

ACTION: SH to send link to gensex conference presentations.

Workstream: Diagnosis and support for women and girls

GB advised that Right Click will continue to be promoted.

Workstream: Care Inspectorate

GB advised this work has commenced, with the next stage to roll out autism champions in the inspection teams. **TK** raised the subject of better communication tools, such as use of talking mats, PECS, etc for inspectors which **GB** said she would feed back to the Care Inspectorate.

ACTION: GB to speak to Care Inspectorate re communication tools

Workstream: Criminal Justice

GB advised this work is ongoing.

Workstream: Education resources for teachers – Autism Toolbox

GB advised there is commitment to review the Toolbox with a meeting planned in Alloa on 28.01.19.

A general discussion followed on the Toolbox, highlighting a lack of awareness of its existence in some schools and it not being a replacement to teacher training.

Scottish Government Policy Update (cont.)

NW updated the group on the campaign against exclusion which the National Autistic Society, Scottish Autism and Children in Scotland are collaborating on.

To date the formal response received from the Scottish Directorate in Education has been inadequate with further investment in training not seen as required. There is a further meeting in February.

GB said that the SCERTS training in September 2018 indicated an appetite for training and a further event is planned.

Workstream: Teacher Education - Autism

JMacl told the group that Autism Network Scotland was in the early stages of exploring pieces of work with the Education Department at Strathclyde University and is currently facilitating PDGE modules at the University which will run again in March. The Network is also working with Argyll and Bute, specifically 4 primary schools on Islay.

MR advised that The QMU undergraduate course is looking at their support needs.

TK stated teachers get all the theory, but no practical experience which **JL** related back to diagnostic support.

Workstream: Autistic Parents

FC agreed to share research document on support needs.

Workstream: Ageing Autistic population

TK advised there was a meeting in Edinburgh hosted by Catherine Crompton at Edinburgh University.

Workstream: Autism Research in Scotland

AP said that following a meeting with the Chief Science Officer, applications to change autism research into practice would be welcome, with the research community taking the lead. **AP** advised that SAG and the Participatory Autism Research Collective (PARC) currently exist. **KB** is the convenor in Scotland of the latter, with **JL** also a member.

Due to time restraints, **GB** finished the workstream discussion, with workstreams relating to Independence and Active Citizenship to be discussed and updated at the next meeting.

3. Neurodiversity and the autistic community – Kabie Brook and Sonny Hallett

KB introduced the group to ARGH and the services it provides, followed by **SH** introducing the group to AMASE and its purpose. **KB** and **SH** then gave a general presentation on the purpose and remit of Autistic people's Organisations (APOs). Slides and a summary paper of the presentations are attached as appendix 1.

KB and **SH** met with Ms Claire Haughey, Minister for Mental Health to discuss encouraging the creation of more APOs and how **SG** can help with this. **SG** is also providing assistance for **KB** and **SH** to host a 2019 Fringe event.

ACTION: **KB** and **SH** to send presentation slides and summary paper per organisation to **LE**.

4. Advocacy and Autism – Thom Kirkwood

TK gave a brief summary of his Advocacy and Autism Exploratory Report which is attached as appendix 2.

5. Next Regional Meeting

JMacL asked what the rationale is for choosing a particular region over another with **MR** agreeing that an objective approach is required and suggested setting a broad enough agenda to involve the community wherever the group decide to visit.

GB suggested Highland as the next region as the question of diagnostic services was raised during the consultation process. As diagnosis is a current workstream, this visit would inform the community of the national perspective. **MR** said the local autism plan would also highlight the challenges as well as the work being done to date.

A discussion then followed regarding choice of venue and lessons to be learned from the Borders meeting, with the following points agreed:

- Recognise the meeting be confined by the constraints of the venue
- Meet as a group prior to the open meetings
- Advance notice of room layout, agenda and papers, audience and other relevant information

The group agreed to visit the Highland region towards the end of April, with **KB** offering to help **LE** source an appropriate venue.

6. Scottish Borders Meeting

JMacL advised that the draft minutes were currently sitting with the Borders for approval.

GB agreed to Autism Network Scotland facilitating further dialogue on training and the diagnostic pathway with the Borders following the open meeting in December 2018. **JMacL** said having an autistic advisor present at the feedback session would be beneficial. **SH** agreed in principle that this would be good practice and is happy to discuss further.

ACTION: JMacL to provide a sentence on what would be expected of the autistic representative at the Borders feedback meeting.

7. AOCB

GB advised that unfortunately due to time constraints the papers provided by Inspiring Scotland would not be discussed in full on this occasion.

In summary, **GB** said that learning from the SEE ME campaign, that investment of £1m would be managed by SG marketing and Inspiring Scotland to raise autism awareness. This will be a social movement rather than a campaign and once this work has been developed organisations will be able to apply for funding. An advisory group of autistic people will sit within the governance structure to help decide how the fund is distributed, once the fund was opened.

GB advised that the national conference will take place on the 26th March at the TIC, Glasgow with a theme of post diagnostic support. The conference will consider the diagnostic pathway as well as launch the awareness movement. This year the conference will be aimed at 3rd sector, professionals as well as being open to autistic people and families across Scotland.

The meeting closed at 4.00pm

Appendices

**Appendix 1: APO Summary Paper
Autistic Community and Neurodiversity (SRG Meeting)**

Appendix 2: Autism and Advocacy Exploratory Report Summary