

Working Group 1 meeting minutes  
1<sup>st</sup> December 2014, 10 am  
Autism Initiatives, Edinburgh

**APPROVED**

**Members present:** **Richard Ibbotson**, Autism Initiatives; **Emma Hanley**, Autism Network Scotland; **Alison Leask**, Autism Argyll; **Marie Claire Shankland**, NHS Education for Scotland; **John Mitchell**, Principal Medical Officer, Scottish Government; **Tom Wightman**, Pasda; **Audrey Espie**, NHS Greater Glasgow and Clyde; **Basel Switzer**, NHS Borders

**Apologies:** **Ali Taylor**, Scottish Government (Care, Support and Rights); **Paul Lennon**, Autism Resource Centre Glasgow; **Kirsty Forsyth**, Autism Achieve Alliance/Queen Margaret University; **Jean MacLellan**, Local Area Coordination Project/University of Strathclyde; **Judith Piggot**, NHS Tayside; **Stella MacDonald**, Autism Consultant

**Minutes by:** Tracy Wenzl, Autism Network Scotland

- I. **Welcome and Introductions** – members all introduced themselves to the group.
- II. **Workgroup processes, operation and reporting** – RI would like to schedule four meetings over the year, one for each of the four priorities included on the remit of the group. He plans to be realistic about the group can do.
- III. **Review of work plan** - The group went through each of the priorities on the work plan and discussed them:
  1. **Improve diagnostic service provision and access to it: in particular, adult diagnosis where there is no co-occurring condition**
    - i. **Publish Autism Achieve Alliance report and roll out recommendation to NHS Scotland and Local Authorities – carry out appropriate level engagement to ensure buy in**
    - ii. **Engage with health boards through relevant Scottish Government health colleagues**
    - iii. **Consider the impact of new diagnostic criteria ICD 11, DSM-V etc – for example, how do we influence the World Health Organisation?**

Discussion about Priority 1: There have been improvements in diagnosis times for those with autism, but there is still little help for those (adults) without co-occurring conditions such as learning disability, mental health issues and/or developmental disabilities. There are many boxes that people can fit in, this can lead to difficulty in reaching appropriate care/resources. TW raised concerns about bad responses to meltdowns, including medications/sedation, which JM addressed, noting that NHS boards were piloting programs to find alternative responses that don't involve medication.

JM noted that a strategy for dementia has been implemented throughout NHS that may parallel what is needed with autism. The dementia plan includes a commitment to diagnose early and provide appropriate post-diagnostic treatment. This plan focuses more on providing social supports (not medication) as part of treatment plan. How this is being executed varies from board to board

across Scotland and is not being coordinated at a national level. EH asked if there were any boards doing this well, and JM will bring this back to the group at a later meeting.

**ACTION ITEM:** JM to provide good example(s) of dementia plan implementation to Group

AL wondered if NES has a framework for dementia; MCS responded that there is a framework and training package, and that it is an enormous piece of work. MCS also explained that autism training (child and adult) should be rolled out by March, but project funding ends March 31. RI noted there was a general lack of autism awareness and TW suggests greater awareness of autism should be taught in schools. JM mentioned The Scottish Government's "See Me" project focused on mental health awareness, and that they might be a good place to look for how to achieve wider awareness. RI questioned what the message about autism would be, and EH echoed this concern, noting Autism Network Scotland was prepared to provide communications supports but that key messages from the Group would need to be clear. TW noted an NHS program that promotes treating patients with "dignity and respect" but thought it wasn't as successful in Scotland as it is in England.

RI raised concern about how to shift from one-two people in a health board or local area being the drivers of the entire autism program – greater buy-in is needed.

Item 1.i – RI wants to see what is in the AAA report (presented at 3<sup>rd</sup> December conference) and wants to see what aspects of the NHS dementia program can be mirrored for autism

Item 1.iii – RI wondered about the impact of changing diagnostic requirements in DSM-V, how that would impact ICD 11. AE reported that ICD is more widely used than DSM in Europe, and that new ICD-11 was expected in May 2015. JM suggested a statement from the Group on which diagnostic standard was preferred (ie, ICD over DSM) but no statement was agreed upon at this meeting.

## **2. Improve post-diagnostic support and access to it**

- i. Complete and implement NHS Education for Scotland (NES) training framework and roll out to NHS, including appropriate level engagement to ensure buy in**
- ii. Revise the "Matrix" guide to delivering evidence-based psychological therapies in Scotland**
- iii. Engage with relevant Scottish Government health colleagues**
- iv. Increase engagement with practitioners, GPs, psychiatrists, NHS, local authorities, etc**
- v. Develop an engagement strategy**

Item 2.i – MCS – interesting that falls under post-diagnostic support – the framework is needed in diagnosis, support and transition. Draft roll out is planned for March, and can be shared with the group. Will use local autism plans, National Autism Coordination Team, Royal College of General Practitioners (whose focus this year is on autism). Not clear if RCGP Scotland has same focus.

Item 2.ii – MCS says the matrix issue is separate from the training issue

**ACTION ITEM:** MCS to update Group on progress from Item 2.i at next meeting.

It was agreed that next meeting will focus on Priority 2.

Item 2.v – MCS and EH to plan another NES framework event

JM recommended the group read a September 2014 report from the Royal College of Psychiatrists on diagnosis, good practice and management. That article can be found here:

<http://www.rcpsych.ac.uk/usefulresources/publications/collegereports/cr/cr191.aspx>

### **3. Influence local autism planning**

- i. Appoint national autism coordination team**
- ii. Scrutinise service maps, local autism action plans/strategies**
- iii. High level strategic engagement with community planning partnerships**
- iv. Engagement with local autism lead officers and local implementation groups.**
- v. Publish all plans/strategies/service maps on the Strategy web site.**
- vi. Publish Microsegmentation report and disseminate findings.**
- vii. Examine how self-directed support (SDS) is affecting the commissioning of services by liaising with Commissioners and SDS team**
- viii. Raise awareness of autism amongst Commissioners**
- ix. Redistribute autism SDS guide**

Item 3.i – EH reports this is done, with Jean MacLellan serving as Coordinator and Donald Macleod as project manager. They will look at local autism plans and support local authorities in moving forward. Event on 19<sup>th</sup> January will bring local authorities together for progress check, sharing of best practices. EH and MCS will coordinate on bringing NES framework to this event to provide tools to local authorities. About 20 plans are already done or in draft form. Plan is to share good examples with others at the event.

Items 3.ii – 3.v are in progress via National Autism Coordination Team.

Item 3.vi – Report of final findings from research group is expected soon.

**ACTION ITEM:** RI to contact Tommy MacKay to request a copy of the report when available

3.vii – 3.ix – **ACTION ITEM:** TMW to locate MacKay's presentation from final research event and forward to group

Video is online at <http://www.autismnetworkscotland.org.uk/action-on-autism-research-in-scotland-what-does-scotland-need-videos/>

RI is part of Autism Self-Direct, who has produced a guide for social workers. Guide is available online at Autism Self-Direct's web site (<http://autismselfdirect.org/wp-content/uploads/Autism-Digital-Leaflet.pdf>). Hard copies were sent to local social leads a while ago but they may need to send copies to more social workers. EH asked if Autism Self-Direct was offering any trainings on this, RI responded that no, they weren't at this time due to lack of funding for this. EH wondered if this could be offered to local authorities working on local autism plans. BS suggested the link be emailed out to local authority social work leads for dissemination in their teams. EH will provide the document to local authorities at 19<sup>th</sup> January event. TW suggested distribution through advocacy groups. RI said this had been done once, but would be worth doing again.

**4. Consider the future sustainability of the One Stop Shops – future funding is a critical issue (HIGH PRIORITY)**

- i. Appoint evaluator (URGENT), peer review report and publish**
- ii. Consider options for becoming self-sustaining**
- iii. Engage with local authorities – can they support the OSSs?**

4.i – RI reports the evaluator was appointed and the evaluations have been completed. The report is in draft form and under review. Two years was not long enough for the OSSs to become self-sufficient and the Government will support them for another year (through March 2016), with the expectation that other funding will be sought with an eye towards becoming self-sustaining.

4.ii – Even with local funding, OSS budgets still run from year to year. The impact of OSSs in communities is clear on an informal level, but there is a need to provide evidence of this.

4.iii - The Autism Development Fund was brought up; EH advised that it fell under the remit of Working Group 3. RI said if new funding becomes available there, it would likely be in 2016 at earliest. If there is funding, it is likely that award decisions would be made on a strategic level.

AL asked if local authorities have spent their £35K (to develop local autism plans) and wondered if that money would be recalled if the plans weren't completed? EH said that the National Autism Coordination Team is supporting the delivery of the plans.

Items IV – VI were covered in above discussion of priorities.

**VII. Membership** – RI is open to suggestions for new members. Ken Aitken was suggested. It was also suggested that a general practitioner would be a good addition. Discussion ensued about whether a GP would have time, and whether they might benefit more from a checklist or other information provision. It was suggested that RI contact the Royal College of General Practitioners' Miles Mack (Chair, RCGP Scotland) to see if he would nominate a member.

**ACTION ITEM:** RI to contact Dr. Mack on this, autism focus for year, etc OR suggest that this is done by Governance Group.

**VIII. Dates and Venues for 2015** – the group agreed to four meetings over the year, with two in Glasgow and two in Edinburgh. A Doodle poll will be sent out to determine the meeting dates.

Meeting adjourned at 12 pm.

#### KEY MESSAGES:

Workgroup One is looking at the Goal: *Access to integrated service provision across the lifespan to address the multi-dimensional aspects of autism*. The work plan for the group was reviewed and the four priority areas were discussed and it was agreed that whilst the whole work plan would be considered at each meeting, there would be a specific focus at each meeting around elements of the work plan agreed in advance. At the next meeting there would be a focus on the implementation of the NES training framework. There will be four meetings during 2015.

The group discussed membership of the group and agreed that others maybe co-opted into the group for specific agenda items as required as well as requesting information, updates and reports on the various research and reports that fall within this remit of this workgroup.

#### SUMMARY OF ACTION ITEMS:

**ACTION ITEM:** JM to provide good example(s) of dementia plan implementation to Group (contact provided to RI – DONE)

**ACTION ITEM:** MCS to update Group on progress from Item 2.i at next meeting.

**ACTION ITEM:** RI to contact Tommy MacKay to request a copy of the micro segmentation/research group report when available

**ACTION ITEM:** TMW to locate MacKay's presentation from final research event and forward to group (DONE)

**ACTION ITEM:** RI to contact Dr. Mack regarding autism focus for year, UK vs Scotland focus, timing of autism focus and if they would send a member to the group, etc. OR suggest that this is done by Governance Group.