

Working Group 1 meeting minutes  
4<sup>th</sup> June 2015, 2 pm  
Number 6 One Stop Shop, Edinburgh

**APPROVED**

**Members present:** **Audrey Espie**, NHS Greater Glasgow and Clyde; **Emma Hanley**, Autism Network Scotland (acting chair); **Paul Lennon**, Autism Resource Centre Glasgow; **Stella MacDonald**, Autism Consultant; **Gillian McCarthy**, National Autistic Society; **Marie Claire Shankland**, NHS Education for Scotland; **Tom Wightman**, Parent/Carer

**Guest Present:** **Jean MacLellan**, Independent Chair, Governance Group; National Autism Co-ordination Project/University of Strathclyde

**Apologies:** **Kirsty Forsyth**, Autism Achieve Alliance/Queen Margaret University; **Richard Ibbotson**, Autism Initiatives; **Alison Leask**, Autism Argyll; **Judith Piggot**, NHS Tayside; **Basel Switzer**, NHS Borders; **Ali Taylor**, Scottish Government (Care, Support and Rights)

**Absent:** **John Mitchell**, Principal Medical Officer, Scottish Government

**Minutes by:** Jean MacLellan, University of Strathclyde

- I. Apologies – apologies were read.
- II. Welcome and introductions – introductions were made.
- III. Minutes of previous meeting and action points
  - a. The minutes of the last meeting were accepted as an accurate record.
  - b. Action points
    - i. John Mitchell's <sup>1</sup>dementia presentation has been disseminated. Group members could not recall seeing it in order to be in a position to clear it for further discussion at the next Governance Group.  
**ACTION ITEM:** EH to forward key messages to group members and requested that they come back to her in a couple of days with their responses.
    - ii. TW has forwarded the Scottish Strategy on Dementia to group members.
    - iii. AE had tried to see what Autism Achieve Alliance (AAA) materials exist but had some logging on problems. Lynsey Stewart from Autism Network Scotland (ANS) is helping her to resolve this.
    - iv. PL has sent the Glasgow Training Plans to TW for onward distribution.
    - v. MCS and PL are going to meet to look at what Glasgow is doing in terms of the NES Framework and now they can collaborate going forward.
- IV. Review of work plan
  1. IMPROVE DIAGNOSTIC SERVICE AND PROVISION PRIORITY
    - a. Connectivity to Dementia Strategy - EH met with RI yesterday and reviewed the plan so she had some updates. Much of the discussion centred on the dementia material presented at the last meeting. Although there are clear and useful

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<sup>1</sup>Tracy Wenzl noted after the meeting that David Berry gave the dementia presentation at the previous meeting. Action point stated RI would report key points from dementia discussion to Governance; key points were forwarded via email to WG1 on 15 April and no further action has been taken.

parallels with this work, autism and dementia are very, very different. One of the successes of the dementia work was acknowledged to be that it is a significant driver for getting diagnosis and post diagnosis in place. Upskilling of the workforce is clearly critical and more broadly based community capacity building. Some members thought that some of the material within the dementia material is transferable to autism, the example of anxiety management was cited. The considerable scale of the task of getting material out to so many people who would have different training needs and different tasks to undertake within their roles was seen as a considerable challenge.

b. Data collection and collation

Members shared their knowledge and ideas in terms of material they thought would be useful. Some thought that the LD dataset was a starting point. Others thought it important not to overlook the housing element. TW thought that Health Boards needed to work more closely with parents and carers. This led to acknowledgement of the need for practitioners to collaborate more. Pathways work, local evidence and discussion of the value of known populations material were all considered. Some clarification of the work of the Observatory is also needed.

A detailed exchange took place about the desirability of targeting GPs to assist as they had with identification of those with dementia. Within this context, the importance of identifying unmet need was seen as critical.

c. Impact of new diagnostic criteria

The group are not clear about who or how to influence this work. It is thought that ICD 11 is delayed for another year.

2. IMPROVE POST DIAGNOSTIC SUPPORT PRIORITY - Much has been achieved here. The NHS Education for Scotland (NES) Framework is complete. The web page is going live via the Network imminently. The matrix is being revised (with the table that refers to children and autism) and is expected to be published soon. Scottish Government health colleagues are to be invited to present to the group in November around the Edinburgh Pathways work. In terms of increased engagement, there is a need for a national pack and NES intend to collaborate with AAA about this as well as the general practitioner group. It was agreed that there would be value in having protocols to get coherence.

The value of extensive consultation around the NES Work was acknowledged and it was agreed that post diagnostic work should follow this approach. ANS to help NES with this.

3. INFLUENCE LOCAL AUTISM PLANNING PRIORITY

Jean and Donald are to be invited to the next meeting on 24 August to provide a detailed input on this. Some discussion around the expected publication of the findings of the micro segmentation project suggested that the group is very unclear about its role here. Given the unavoidable absence of Scottish Government officials at recent meetings, the group is not up to speed on what work it should be undertaking to quality assure this project and its outcomes. It was agreed that the group had responsibility for overseeing this work and all the other priorities for which it has delegated responsibility. ANS will clarify where the project is in terms of proposed publication and will set in train steps to

get access to this in order to assess its value prior to being referred on to the Governance Group.

A lengthy discussion on Self-Directed Support (SDS) highlighted what are thought to be huge national variations in how this is being implemented. Both integration and eligibility criteria are impacting on this. The group felt they had insufficient information in order for them to make progress here and requested that an Scottish Government representative be invited soon to update them. Central to this is the need to develop an SDS skillset.

#### 4. FUTURE SUSTAINABILITY OF ONE STOP SHOPS

The group were updated on Julie Haslett's work. The group asked to have sight of the original one stop shop evaluation and to meet with Julie in due course.

- V. External comments/questions/feedback –none
- VI. Any other current business – none
- VII. Plan for next meeting – scheduled for Monday, August 31, Glasgow, venue TBD
- VIII. Key messages

#### **KEY MESSAGES**

Having reviewed those aspects of the work plan for which the Working Group has delegated responsibility, it is clear that the parameters of that responsibility need to be better defined and actioned. It was appreciated that the broad remit is to facilitate rather than being hands on but a balance needs to be struck whereby certain projects and plans are formally set up, monitored and evaluated. The synergy between this and other groups also needs to be enhanced. The Chairs of the Working Groups are to meet with Scottish Government and Autism Network Scotland representatives soon where it is anticipated that this will happen.

#### **ACTION ITEMS**

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