

Working Group 1 meeting minutes
2nd March 2015, 2 pm
University of Strathclyde, Glasgow

APPROVED

Members present: **Audrey Espie**, NHS Greater Glasgow and Clyde; **Emma Hanley**, Autism Network Scotland; **Richard Ibbotson**, Autism Initiatives; **Alison Leask**, Autism Argyll; **Paul Lennon**, Autism Resource Centre Glasgow; **Judith Piggot**, NHS Tayside; **Marie Claire Shankland**, NHS Education for Scotland; **Ali Taylor**, Scottish Government (Care, Support and Rights)

Guest Present: **David Berry**, Scottish Government Directorate for Health and Social Care Integration, Mental Health and Protection of Rights Division

Apologies: **Kirsty Forsyth**, Autism Achieve Alliance/Queen Margaret University; **Stella MacDonald**, Autism Consultant; **Jean MacLellan**, Local Area Coordination Project/University of Strathclyde; **John Mitchell**, Principal Medical Officer, Scottish Government; **Basel Switzer**, NHS Borders; **Tom Wightman**, Pasda

Minutes by: Tracy Wenzl, Autism Network Scotland

- I. **Apologies** – apologies from group members were read
- II. **Welcome and Introductions** – members introduced themselves to invited guest David Berry
- III. **Minutes of previous meeting and action points** – prior minutes approved, action items from previous meeting were reviewed:
 - a. **ACTION ITEM:** JM to provide good example(s) of dementia plan implementation to Group – DONE – to be presented today
 - b. **ACTION ITEM:** MCS to update Group on progress from Item 2.i at next meeting – DONE – to be presented today
 - c. **ACTION ITEM:** RI to contact Tommy MacKay to request a copy of the micro segmentation/research group report when available – report imminent
 - d. **ACTION ITEM:** TMW to locate MacKay’s presentation from final research event and forward to group - DONE
 - e. **ACTION ITEM:** RI to contact RCGP regarding autism focus for year, UK vs Scotland focus, timing of autism focus and if they would send a member to the group, etc. – DONE – we have a contact now
- IV. **Presentation on Dementia Strategy and implementation** – DB presented on the creation and implementation of Scotland’s Dementia Strategy. The plan covers Alzheimer’s and vascular dementia. The Strategy has been working in three-year segments and is currently in their second 3-year phase.

Key figures from the presentation are:

 - a. Estimated 86,000 people in Scotland have dementia
 - b. After implementing diagnostic target, 24% increase in diagnoses

The Strategy’s major components include:

 - a. Common Standards of Care in Dementia
 - a. People have the right to diagnosis and care – aims to inform people of their rights, to allow them to insist upon diagnosis/care as needed
 - b. Promoting Excellence – skills framework
 - a. Training through NHS Education for Scotland (NES) and Scottish Social Services Council (SSSC)

b. They trained front line nurses and home care ambassadors

The Strategy developers were asked to keep the plan short and deliverable.

In 2013, a post-diagnostic target was set – that all people receiving a diagnosis would receive a minimum of one year of support by a trained support worker. The support follows a non-medical model and is person-centred, and aims to find family and community supports, support legal planning, and address co-occurring mental health issues like depression and anxiety. The availability of these services should encourage early diagnosis and provides services regardless of qualification for social care. The support includes a comprehensive care plan, which addresses personal preferences among other things. Link (support) workers can help gain access to services as needed if dementia progresses.

Feedback they receive from people with dementia (and families) is that the system has been hard to navigate. The post-diagnostic supports are meant to address this.

The time to diagnosis and care is measured in two places – time from GP diagnosis to assignment of a link worker, and time from assignment to an appointment with the link worker.

Next, the Strategy plans to focus on how health boards are funding dementia supports. New funding has become available through the integration of health and social care. They are also testing home-based support for advanced cases and plan to evaluate this program in a year's time. The programme aims to keep people at home, rather than in care facilities, as long as possible.

A question was asked about the diagnostic target, and it was explained that it is a national health target (formerly a HEAT target, now called a local delivery plan (LDP) target.) Because of the national focus, local health boards must report on this regularly and manage the programme.

Discussion turned to similarities and differences between the Dementia and Autism Strategies. It was noted that the Dementia Strategy would mainly address health issues occurring in older people, where autism affects people across the lifespan. The idea of an autism diagnosis LDP target was largely supported by the group, though it was noted that the Scottish Government would ultimately have to bring that forward.

Concerns included the quality of service provided – while requiring service for everyone might mean they are getting it, the group questioned what the quality of service provision would be. The Dementia Strategy works to address this through their training programme, which has been quite popular with health workers. They train up dementia ambassadors and champions.

The question of how to motivate health workers to see autism training as important was raised. The impact of the integration of health and social care was also considered. The question of funding was also raised, with DB pointing out some of the ways dementia project funding had been secured. There is some money available for projects related to the integration of health and social care. DB noted that while boards have needed some money to implement dementia programmes, the amounts were generally not that high.

The discussion then turned to the importance of achieving buy-in from middle and upper management, both in health boards and in local authorities, and the question of how dementia managed to secure political backing. The idea of having a lead in each area was suggested. The group discussed local action plan writing and implementation with respect to diagnosis.

ACTION ITEM: RI will feed back key discussion points to Governance Group

ACTION ITEM: TW will find 2013-2016 Scottish Strategy on Dementia and forward to group <http://www.gov.scot/Topics/Health/Services/Mental-Health/Dementia/DementiaStrategy1316>

- V. **Priority 2 Activity I – NES Training Framework Update** – MCS updated the group on the latest developments. They are revamping the website and adding an e-learning module. The training plan will also be posted there, and linked to from Autism Network Scotland (ANS) and Scottish Strategy for Autism websites. They'll be doing a big communications push in April-May.

The Institute of Psychiatry is offering two trainings on adapting CBT for children and adults. The trainings are full and seem promising – NES wants to evaluate these trainings before offering more, and exploring other interventions that could be adapted. They are also following up with a group that did adult diagnostic training one year ago to see what changes have come since then (case studies, etc.)

Their future plans include a series of events to distribute the training plan, and will create materials for National Autism Co-Ordination Project (NACP) and Autism Network Scotland to take to local authorities. They attended the Royal College of Speech and Language Therapy Event, hosted by ANS, in February, and are participating in a COSLA event in June and a May event is with service providers who are not ASD-specific, also hosted by ANS.

Next year, NES plans to address training across awareness levels. One group is currently using the National Autistic Society's (NAS) Ask Autism modules (at cost) – this will be reviewed. A list of training classes will be posted to the ANS website. NES is also exploring offering training for private nursery staff.

NES may develop training around screening, making sure people know what to look for – likely to be offered as a face-to-face course. A gap in use of adult diagnostic tool use (despite training) has been noted, and NES is going to visit people who have been trained to work with them to improve competence/confidence as needed. NHS Greater Glasgow and Clyde is developing a DVD demonstrating adult diagnostic processes. Barriers to using diagnostic tools are that they are time consuming, and because they are used infrequently, they become inconvenient due to the work load involved.

Training at the highest level needs to support services for people with autism and co-morbid conditions – NES is looking at commissioning training and bringing in a range of experts (eg, ASD and ADHD) and follow that with peer learning groups.

The biggest gap in training identified by NES is transitions; they want to create a hub of resources, to be hosted on ANS website. One example is to operationalise Fife's assessment pathway.

ACTION ITEM: AE to look to see what AAA resources exist (GP letters, etc)

Another focus of NES is to enhance expertise: what is good practice in adapting assessments for ASD? RI mentioned a Glasgow University Research project looking at good practice in adapting.

NES is looking for other ways to widely distribute the Framework, and ways to keep training alive. MCS is keen to talk to people offering training and will link with PL on Autism Resource Centre trainings.

ACTION ITEM: PL to send training plan to TW for distribution to group

JP mentioned a network of service providers who are working together and offering trainings.

ACTION ITEM: JP to send contact information to MCS

VI. **Review of other work plan items** – delayed until next meeting

VII. **External Comments/Questions/Feedback** – a request for a list of private autism diagnosticians has been requested. The group suggested that the NAS searchable resource online be checked, but that they were otherwise not aware of this existing.

VIII. **Any other business** –none

IX. **Plan for next meeting** – review of other work plan items not discussed today, further discussion on key lessons from dementia presentation

X. **Key messages (discussion)**

- a. NES work will continue to be funded (per agreement with Scottish Government)
- b. The Dementia Strategy has many similarities to Autism Strategy: RI will summarise key lessons from presentation and circulate.
- c. Dementia now has a high profile; how do we get the push to make this true for autism?

KEY MESSAGES:

The group welcomed the news that NHS Education for Scotland will continue to be funded for their valuable work on the Autism Training Framework. Some of what was planned as the next stage was discussed and the specific details of what this involves are being finalised.

A presentation on the Dementia Strategy proved to be very useful in reflecting on the similarities and differences between this and the Autism Strategy and the reasons for those differences. A summary of this will be presented to the Governance Group.

The other elements of the group's work plan will be reviewed in more detail at the next meeting.

SUMMARY OF ACTION ITEMS:

ACTION ITEM: RI will feed back key discussion points (on dementia presentation) to Governance Group

ACTION ITEM: TW will find 2013-2016 Scottish Strategy on Dementia and forward to group
<http://www.gov.scot/Topics/Health/Services/Mental-Health/Dementia/DementiaStrategy1316>

ACTION ITEM: AE to look to see what AAA resources exist (GP letters, etc) for NES/ANS web resources

ACTION ITEM: PL to send (his organisation's) autism training plan/programmes to TW for distribution to group

ACTION ITEM: JP to send contact information for network offering autism training to MCS