

Working Group 1 meeting minutes

28 September 2016, 1pm

University of Strathclyde, Collins Building Rm 202, Glasgow

REVIEWED BY CHAIR

Members present: Audrey Espie, NHS Greater Glasgow and Clyde; Alistair Gilmour, Autism Network Scotland; Emma Hanley, Autism Network Scotland; Richard Ibbotson, The Richmond Fellowship for Scotland (CHAIR); Annette Pyle, Scottish Government (Care, Support and Rights); Alison Leask, Autism Argyll; Tom Wightman, Parent/Carer.

Apologies: Aline-Wendy Dunlop, University of Strathclyde; Kirsty Forsyth, Autism Achieve Alliance/Queen Margaret University; Kjersti Ferguson, Scottish Government; Paul Lennon, Autism Resource Centre Glasgow; Stella MacDonald, Autism Consultant; Gail Milroy, NHS Education for Scotland; John Mitchell, Principal Medical Officer, Scottish Government; Roo Philip, Tailor Ed; Judith Piggot, NHS Tayside; Cathy Steedman, Autism Initiatives; Lisa Sturgess, National Autistic Society; Basel Switzer, NHS Borders.

I. Welcomes, introductions and apologies

Gail Milroy has replaced Marie-Claire Shankland as the representative of NHS Education for Scotland but has had to offer her apologies for this meeting.

II. Minutes of previous meeting and action points

- a. DM to share newly updated distribution list of SDS leads with group via AP.

ACTION POINT – AG to contact DM to request this.

- b. CS to contact ANS to arrange for remaining hard copies of Guidelines for Assessing Adults with Autism for SDS to be delivered to them at the University of Strathclyde.

CS will deliver these to AG when attending the Governance Group on 6th October.

- c. ANS to investigate whether a straightforward method of evaluating the impact of the above document can be arranged.

To be carried over to the following meeting.

- d. Guidelines for Assessing Adults with Autism for SDS document to feature in the upcoming Scottish Strategy for Autism newsletter, inviting recipients to contribute comments on their previous experiences of its implementation ahead of the new edition.

ACTION POINT – ANS to discuss with local authorities whether the hard copies of the Guidelines that were delivered to them are being used in practice.

The Guidelines are currently available online via both the [Autism Network Scotland website](#) and the [Scottish Strategy for Autism website](#). As much has been learned since the original document's publication the group discussed how the Guidelines might now be updated. Autism Network Scotland is to lead this review, inviting people to read the original document and offer comments to be considered as it is being updated.

ACTION POINT – AP to pass her copy of the working document to ANS for editing (to be compared with document provided via email by CS.)

- e. CM to circulate document on Glasgow audit of SDS implementation.

ACTION POINT – AG to request document for circulation.

- f. DM to provide links to further information about SDS practices.

DM presented on SDS practices for autistic people at the meeting of the Autism Lead Officers and Support Providers Collaboratives at the University of Strathclyde on 14th September. The group discussed the information presented here and suggested that the next edition of the *Guidelines for Assessing Adults with Autism for SDS* could complement both the information DM presented and the practical work carried out by the National Autism Co-ordination Project in viewing service provision around Scotland.

- g. AP to share new SIGN guidelines after publication for discussion at next meeting.

AP has shared the link to the PDF which AG has circulated to the group.

ACTION POINT - AG to add link to SIGN Guidelines PDF to the Key Documents page on the Scottish Strategy for Autism website.

EH informed the group that she understands that the finished Guidelines are to be put to consultation and that Health Improvement Scotland (HIS) are discussing a potential event to publicise the new document. Autism Network Scotland would alternatively consider methods of publicising the Guidelines on HIS behalf. The booklets written for Parents & Carers, Young people, and Adults on the Autism Spectrum will each be updated following the publication of the new Guidelines.

The Fifth Annual National Autism Conference is to take place on 16th January 2017 and might feature an official launch for the new Guidelines.

ACTION POINT – AP to contact SIGN to discuss launching the document at the

Fifth Annual National Autism Conference.

- h. CS to speak to the Directors of Scottish Autism and the National Autistic Society, with a view to putting together a two page summary about the lessons to be learnt in regard to the commissioning of the One Stop Shops.

Carried over to next meeting.

- i. RI to initiate the writing of the Working Group's response to be shared by AG for others to then contribute.

Done.

III. Updates and review of work plan

The upcoming meeting of the Governance Group on Thursday 6th October will discuss the future role of the three working groups with the aim of reviewing their remits and membership. It was suggested that Working Group 1 might be better described as a 'review group' than a working group and that some aspects of the group's work plan might be outdated. With this in mind, the group reviewed the current version of the work plan in some detail.

Priority 1.

I. Improving diagnostic service provision.

Kjersti Fergusson (KF) is currently conducting a two-year review of diagnostic programmes to identify value for money in service provision. Issues have arisen where there are no available dedicated adult diagnostic services and appropriate staff must be located to perform adult diagnoses.

A successful diagnostic service, particularly in rural areas, relies on a GP doctor recognising signs or symptoms of autism and also knowing where to refer the patient to. Issues have arisen with people presenting to GPs but not then following any diagnostic pathway.

In more populous local authorities, GPs ought to be able refer to an adult autism team, like that available in Glasgow, while rural areas might be more reliant on more general mental health teams and out-of-area placements, pooling available resources or seeking private practitioners. It was suggested that milder cases of autism might be diagnosed by dedicated learning disability (LD) or mental health teams in local authorities, though this runs the potential risk of misdiagnosis by a team not looking for evidence of autism. In certain cases, the rigidity of criteria for access to support teams is preventing people with 'pure' autism accessing services primarily designed for those with LD.

The group discussed at length many of the issues faced in obtaining diagnoses in different parts of Scotland. It was recognised that an autism diagnostic team is an expensive service for local health boards and if a diagnostic service is not already being provided, health boards are unable to recruit or retain such services. Smaller health boards might not be able to financially justify the outlay,

leading to those presenting for diagnosis having to be directed to paid-for, out-of-area services. This may prove unsustainable in the current financial climate. Even well-funded, dedicated autism services are over-subscribed with waiting lists often exceeding 12 weeks. NHS services are moving towards greater focus on outcomes than targets, with Harry Burns recently appointed to examine the outcomes model.

TW is meeting with Clinical Psychology students at the University of Edinburgh to encourage them to specialise in autism.

KF is working with Mental Health colleagues and Healthcare Improvement Scotland in accessing data held by health boards to assess mental health services, describe the numbers and ages of people being diagnosed with autism that their services are reaching. Building a coherent picture of the number of autism diagnoses and of autistic people accessing services is critical as the allocation of resources to these services is evidence based. The Scottish Learning Disability Observatory (SLDO) are currently compiling data based on the 2011 Scottish Census on autism prevalence, with other work also being done in this area by Aspire, with the eventual aim of linking data to create a clearer picture (whilst protecting the privacy of patients). Targets will be created based on this data for CAMHS, AHPs and other services to improve integration. KF is due to feedback to the Governance Group on 6th October on the work she has done in this area to date.

ACTION POINT – AP to circulate one-page SLDO summary document to the group, via AG.

The working group feels that the work being done by other organisations in this area limits its ability to offer effective actions. The changing landscape requires that its work plan priorities be reassessed.

Priority 2.

Activity 3 is met by KF's work with Scottish Government colleagues in Mental Health on data sourcing.

ACTION POINT – AP to contact autism leads to share Lothian care pathway as an example of good practice.

Autistica have recently published a report into early death in autism; James Cusack in Aberdeen has also researched this topic and presented on this at the Autism Europe Congress.

The Mental Welfare Commission (MWC) is publishing information on guardianship and presenting data on this in the coming days. Cathy Taylor is working on a report on aspects of autism that should be covered by MWC.

AP and JMCP have discussed an evaluation of the overall progress of the Scottish Strategy for Autism.

ACTION POINT – AE to find out how a CPD course would become accredited by NES so that GPs will go on to access it.

Priority 3.

The National Autism Co-ordination Project (NACP) is implementing its assigned activities.

Prof. Tommy MacKay's Microsegmentation Report is set to be published in the coming weeks.

ACTION POINT – AP to contact TM regarding the sharing of the finished Microsegmentation report.

The upcoming 5th Annual National Scottish Strategy for Autism National Conference will showcase good autism practice. It was suggested that posters seen at the Autism Europe Congress showcasing Scottish examples of good practice might be again seen at the conference.

ACTION POINT – AG to circulate the date of the conference to all working group members.

The most recent NACP event was a meeting of the Autism Strategy Collaborative and Provider organisations, entitled *Strategic Commissioning - A National Event*. Delegates have been asked to suggest details on further service providers who might be invited to future events in order to wider the reach of these events.

Priority 4.

Advisors previously employed at the Lanarkshire One Stop Shop are now employed by HOPE for Autism in Airdrie and are working to assist people who previously accessed services at the shop to transition to their new services.

Julie Haslett's work with the NACP is now complete.

The Scottish Government regard the lessons from the outcomes of the one stop shops to be the importance of engagement of local communities to ensure the sustainability of the service.

IV. Any Other Business

The working group considers the effective commissioning of autism services and access to diagnostic services are the two remaining key priorities that require further attention. It is keen to identify the group's role in furthering these agendas and reaching the goal of integrated service provision. This issue will be discussed further at the Governance Group on 6th October.

Christina Naismith, policy lead for strategic commissioning at the Scottish Government, is currently conducting analysis of strategic plans for health and social care, including funding for commissioned services.

NHS Lothian has developed leaflets specifically stating their diagnostic pathway and who GPs ought to refer people to, which would make a useful template for other local authorities. The Scottish Government owns the copyright on this design.

ACTION POINT – AP to share NHS Lothian leaflet design with local authority autism leads as an example of good practice.

V. Date for next meeting

ACTION POINT – AG to share Doodle poll for date.

VI. Key messages (summary of meeting for circulation)

Working Group 1 has found that attendance at the group has begun to dwindle and members feel this may be a reflection of the need to review again the role and membership of the group and reconfirm its function. A number of its Work Plan activities have been achieved, such as the appointment of the National Coordination Team, whilst other priorities are felt to be out with what the group can realistically address, such as the sustainability of the One Stop Shops. Some activities have been overtaken by events or the work of others, such as considering the impact of new diagnostic criteria. Two remaining priorities which the group feel there remains significant work outstanding to bridge the gap between strategy and reality are diagnosis and commissioning.

In addition the group reflected that the overall Goal ‘Access to integrated service provision across the lifespan to address the multi-dimensional aspects of autism’ is too vague an aspiration to provide a sense of purpose for the group without further guidance.

The conclusion of the group is that clarity should be sought about what the Governance Group requires from the workgroup (that is achievable by the group), and the optimal structure and membership of the group to achieve this and in particular move forward the two priorities described above.

ACTION ITEMS

ACTION POINT – AG to contact DM to request updated distribution list of SDS leads for circulation.

ACTION POINT – ANS to discuss with local authorities whether the hard copies of the Guidelines for Assessing Adults with Autism for SDS document that were delivered to them are being used in practice.

ACTION POINT – AP to pass her copy of the working document of Guidelines for Assessing Adults with Autism for SDS to ANS for editing (to be compared with document provided via email by CS.)

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ACTION POINT - AG to add link to SIGN Guidelines PDF to the Key Documents page on the Scottish Strategy for Autism website.

ACTION POINT – AP to contact SIGN to discuss launching the new Guidelines document at the Fifth Annual National Autism Conference.

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ACTION POINT – AP to contact autism leads to share Lothian care pathway as an example of good practice.

ACTION POINT – AE to find out how a CPD course would become accredited by NES so that GPs will go on to access it.

ACTION POINT – AP to contact TM regarding the sharing of the finished Microsegmentation report.

ACTION POINT – AG to circulate the date of the 5th Annual National Scottish Strategy for Autism National Conference to all working group members.

ACTION POINT – AG to share Doodle poll for date of next meeting.