

ASD Ref Group Meeting

Monday 24 January 2011

CoSLA, Rosebery House, 9 Haymarket Terrace, Edinburgh EH12 5XZ

Minutes / Action points

Present:

Jean Maclellan, Head of Adult Care & Support Division, SG (Chair)

Peter Kelly, Adult Care & Support Division, SG

Nadia Hanif, Adult Care & Support Division, SG

Kirsty Butts, Adult Care & Support Division, SG (Minutes)

David Thompson, DLEARN : Support for Learning Division, SG

Scott Johnson, DLEARN : Support for Learning Division, SG

Alan Somerville, The Scottish Society for Autism

Prof. Aline-Wendy Dunlop, National Centre for Autism Studies, University of Strathclyde

Alison Leask, Chair, Autism Argyll and Parent

Dr Kenneth Aitken, Action Against Autism

Charlene Tait, The Scottish Society for Autism

Caroline Brown, Fife Council Psychological Service

Dr Iain McClure, NHS Lothian

Jane Neil-Maclachlan, NHS Lothian

Andrew Morrison, CoSLA

Ian Hood, Learning Disability Alliance Scotland

Jane Hook (parent)

Nigel Rooke, Autism Resource Centre, (GCC AND NHSGG&C) Glasgow

Stella MacDonald, Fife Council / NHS Fife

Sam Sinclair, Camphill Scotland

Alison Gray, Alternative & Augmentative Communication (AAC) on secondment to the SG Health Dept from NHS Glasgow.

Apologies:

Prof. Tommy Mackay, Psychology Consultancy Services

Dr Robert Moffat, The National Autistic Society (Scotland)

Richard Ibbotson, Autism Initiatives

Ryan Gunn, Adult Care & Support Division, SG

Idem Lewis, Learning Disability Alliance Scotland

Jane Cantrell, NHS Education for Scotland.

Valerie Sellars, Scottish Centre for Autism, Greater Glasgow & Clyde NHS

David Watt, HMIE

Linda Connolly, Social Work Inspection Agency (SWIA)

Agenda Item 1: Welcome, Introductions, apologies

Members were welcomed back to the re-convened group, introductions made and apologies given.

AP1 SG team to update nameplates

1.1 Membership was discussed. The main criticism is that the group is 'self-selecting', perceived as exclusive and not sufficiently representative of users and carers. The group needs to:

- define membership more closely, exercising caution regarding its size and who is recruited

- be transparent, particularly around who the members are and why /how members came to be part of the ASD Reference Group

- consider how the work of the group is tracked
- explore users and carer subgroups and consider selection, also with regard to geographical locations and adequate representation across Scotland. They should consider recruiting those with ASD who are more able and articulate, e.g. some people from No 6, Edinburgh (Aspergers centre).

1.2 Suggestions to increase transparency:

1. Involve more service users directly
2. A permanent sub-group of users / carers
3. A national event, hosted by ASD Reference Group.

1.3 Other suggestions made and considerations:

- Nigel Rooke suggested the use of web-based technology which would enable diverse input, involving more service users with ASD, with possible input from other national organisations and networks and linking this to a National Event. David Thompson expressed his willingness to input on matters relating to children.
- Important to support any individuals who joined.
- Be careful of group's dynamics; group needs to work quickly through priority tasks. Suggests minimal additions to group.

Summary

The suggestions were to increase the level of the group's transparency, supplementing the group by 1 or 2 users, if purposeful, ensuring new recruits are adequately supported and reaching more service users e.g. through web-based technology. The importance of managing any web-based information was stressed, regardless of its format, ensuring clarity of structure and any questions / information posted on the site.

1.4 There is currently inadequate representation of the following:

- Users/Carers
- Community asset approach: co-production, to strengthen community capacity, making a difference at local level, with consistency across Scotland.

- Adults - representation of 18+ age group
- Ageing/older people with autism. Need to be pro-active in this area and give longevity to Strategy.
- Medical perspective - currently only have Dr Iain McClure. Adult and General Psychiatry needs representation
- Autism and mental health in general
- Forensic evidence
- Professional groups
- Charities
- Higher education / educational perspective
- Social Work perspective

Joint working, from top to bottom, from Scottish Government downwards, was suggested

Regarding representation of users, it was suggested that we pilot someone from both the east and west of Scotland, for 4-5 meetings, choosing people from well-selected groups.

AP2. J. MacLellan to recruit someone from No 6 in Edinburgh.

AP3 West coast members to liaise and nominate someone within next few weeks

Ian Hood, LDAS mentioned that he needed to find a better way of connecting with charities like Carr-Gomm, a non-profit charity providing supported living and person-centred support to people with disabilities and mental health issues.

With regard to the educational and social work perspective, Andrew Morrison, CoSLA mentioned that Directors of Education and Social Work need representation on the ASD Reference Group and that Local Councils would welcome that involvement.

AP4 Andrew Morrison to enable this representation.

1.5 Further discussion around criteria for inclusion in group:

It was pointed out that the aims and objectives were more important than absolute proportional representation from each organisation or area and that we need the right people round the table, with depth of knowledge and expertise. Whilst there must be equality of opportunity to join the group and the group should be representative of organisations, charities etc, people come with individual skills. The group is open to public scrutiny and must be both transparent and representative. The Minister has been asked to look at formal membership of this group and provide an update of the Strategy to Parliament. As such, the suggestion was made to justify membership with a short written statement, such as 'This represents the best knowledge / skills around autism and is a balance between both representatives from organisations and charities and individuals with skills/knowledge/expertise'.

Regarding the approach to membership issues, Alan Somerville recommended working out the Strategy first, then building the structure to deliver that. The function of the group would then define its form.

In terms of formulating a Strategy for Autism in Scotland and including appropriate members in the ASD reference group to deliver this, the need for large-scale thinking was expressed, a staged-process which responds adequately to comments and criticisms and which includes missing perspectives.

AP5 ASD Reference Group to reflect on gaps in representation and comment and to consider which of the arenas to take forward, including a web-based approach.

In particular, representation for Adult Psychiatry is needed and must be addressed. Dr Andrew Stanfield, an Adult Psychiatrist based in Edinburgh who specialises in ASD was suggested.

AP6 Jane Neil-Maclachlan to ask him whether he'll join the group.

AP7 SG Care and Support team to write basic summary of above membership discussion.

Agenda Item 2: Minute of the last meeting and matters arising

The minutes of the last two meetings on 22 July and 23 September 2010 were approved.

Agenda Item 3: Update on Stage 1 Debate on Private Member Autism (Scotland) Bill

3.1 100 against, 5 in favour, 2 abstentions. Bill therefore fell. Onus is now on the ASD Reference Group to take forward the development of the Autism Strategy for Scotland and meet expectations for service users. The debate was perceived as positive, with many positive comments about the ASD Reference Group. Gratitude was expressed to Hugh O'Donnell for raising the profile of Autism through the Bill, for giving users and carers a platform and raising their profile and issues. The debate recognised that people with autism who do not have a Learning Disability need to be acknowledged as a category in their own right.

3.2 The ASD Reference Group needs to:

- ensure it communicates with and influences people by cascading information outwards.
- consider who has a dual function within the group. The ASD Reference Group is a policy group, although some members may have a campaigning function

Agenda Item 4: Update on the key themes arising from the Strategy consultation responses e.g. Service standards

AP8 Group to read list of key themes which emerged, discuss and build any new points into the Strategy.

4.1 Further omissions in current draft Strategy:

- Standards and Scrutiny - the language needs to change, i.e. 'This is what we're going to do and how' is missing. There needs to be mention too of what difference the Strategy will make in terms of changes implemented.
- Clarity around those who have autism and those who do not.
- Transitions

4.2 Regarding Recommendation 26 in the Strategy (Develop good practice transitions guidance), it was suggested that the Scottish Transitions Forum help the ASD Reference Group develop this guidance.

4.3 Developing the Strategy

- The recommendations in the Strategy are broadly covered in the key themes identified and circulated.

- It will be necessary for the group to prioritise what is important. Some things will take longer to achieve and this needs to be recognised.

- A 'controlling mind' is required.

- Re-write of Strategy requires quite a lot of redefining. Scotland leading the world, driving forward policy and strategy. We need to produce a very high quality strategy document, relevant to rest of world (many countries round the world are watching us). Rome is using our NHS SIGN guidelines.

Concern was expressed around the need to strike a balance between writing an excellent document and meeting the needs of users/carers etc who need help now and how we do this to make a difference at local level. We need an aspirational Scottish Standard for Autism, meeting all difficulties. Some mechanism is required to help people work together towards a holistic view of autism. This should link to a co-production, community-asset approach to strengthen communities. Hugh Morgan could help formulate the strategy, as he created a very good one for Wales

AP9 Alan Somerville to invite Hugh Morgan to come and talk to the SG Care & Support team about creating a robust strategy and to circulate the Welsh Strategy to the group.

Agenda Item 5: Role of the National Autistic Society

This item has been deferred to the next meeting.

Agenda Item 6: Creation of Sub-groups of the ASD Reference Group

6.1 Four sub-groups are to be created, each one led by two group members. These are:

- Diagnosis, Assessment & Intervention - Dr Iain McClure & Jane Neil-McLachlan

- Training (to include education, qualifications) - Charlene Tait & Alison Leask

- Adults (to include geriatrics) - Jane Hook & Nigel Rooke

- Transitions - Aline-Wendy Dunlop & Kirsten Gooday / Sam Sinclair

6.2 There was a suggestion that 'Scrutiny' should also be a sub-group

AP10 Jean Maclellan to talk to Social Care and Social Work Improvement Scotland (SCSWIS), the new scrutiny and improvement body for social care, social work and children's services in Scotland and to David Thompson regarding HMIE matters and report back on whether another sub-group for scrutiny is required.

AP11

- Dr Iain McClure, Jane Neil-McLachlan, Caroline Brown and Alan Somerville to scope remit of Diagnosis, Assessment & Intervention group.

- Charlene Tait and Alison Leask to scope remit of Training group

- Jane Hook, Nigel Rooke and Charlene Tait to scope remit of Adults group.

- Prof. Aline-Wendy Dunlop and Kirsten Gooday / Sam Sinclair to scope remit of Transitions group.

AP12 SG to provide a template for subgroup remits

AP13 Subgroup leaders to meet and write up the 'ASD Reference Group Subgroup Remit'.

Agenda Item 7: Remit / expectations of ASD Reference Group

AP14: ASD Ref Group to look more closely at the Strategy and add / send any comments (both short & longer term solutions) by email to the Care and Support team before the next meeting, including any thoughts about how to be more transparent. It is expected that papers are read before each meeting.

AP15: Kirsty Butts to ask Paul Reilly to arrange the next three meetings of the ASD Reference Group, to take place in February, March and April to discuss and move forward the development of the Strategy.

It will be necessary for the group to commit to some substantive pieces of work, some of which will require funding.

Agenda Items 8 & 11: Presentations - 1. Diagnosis and Assessment and 2. Managed Clinical Network for ASD assessment - Dr Iain McClure.

8.1

Item 8: Dr Iain McClure was asked to and has set up an Edinburgh-based project team to investigate an answer to the Minister's question:

'How many people are waiting for an ASD Assessment in Scotland?'

Assessment across Scotland and within age ranges is inconsistent. (see slides). Findings to the above question will raise other questions / issues of which the group may be unaware and which will change the group's dynamics.

Item 11: There is a need to set up a Managed Clinical/Care Network (MCN). Might this improve the situation at minimal cost? Waiting lists for assessment in Scotland are currently 1-2 years, which is too long. Dr Iain McClure posed the question as to what could be put in place which could produce better outcomes for people, both in the short and long-term?

8.2 There was a discussion around how you define someone awaiting diagnosis, with a distinction being made between a referral and an actual waiting list. There are different methods of referral (all received referrals):

- By GP
- By Child & Adolescent Team
- By parents who can self-refer

The diagnosis of adults is much vaguer. Adults may have queried whether they have autism with their GP or simply discussed their problem. GPs may have no-one to whom they can refer the patient.

Iain McClure's Project Team

Aim: to pick up the number of people on waiting lists for ASD Assessment in Scotland

Additional outcome: will also clarify how many professionals (& their location in Scotland) are able to assess / diagnose cases

Suggestion from Dr Iain McClure: two PhD students could collect this data (for medium to long-term sustainable solutions) to establish the number of people on waiting lists.

- This needs to be agreed as an Action Point next meeting, as not allocated to anyone at this meeting.

8.3 People currently on waiting lists

SG have some ISD data but need to establish numbers and locations in Scotland of people currently waiting for diagnosis and assessment.
Suggestion: submit FOI request in each part of Scotland to acquire numbers

Jean Maclellan asked what resources exist to address these waiting lists?

8.4 Good Practice

Fife: Children being assessed within 6 months, so waiting lists are being kept down. We need to identify LAs who are also keeping down waiting lists.

Edinburgh: Jane Neil-McLachlan reported no waiting list, as each case is allocated every month; this operates at a tertiary level.

Dr McClure commented that the need for a Managed Clinical/Care Network will emerge from the process of acquiring accurate numbers. It will then be possible to determine whether an MCN will improve the situation. We therefore need to establish a database of the numbers of people with ASD.

Suggestion: perhaps consult databases which exist within other areas, e.g. mental health, which hold perceived numbers within services, GP waiting lists etc, which might assist with the identification of numbers.

Glasgow: There was an initiative which greatly reduced waiting lists for children. However, it was a 'quick fix' and numbers have again risen.

8.5 Conclusion: Longer-term sustainable solutions are required. A quick solution does not work, particularly if people are diagnosed quickly but there is no follow-up. The ASD Reference Group needs to explain that the short-term pragmatic approach has been tried (and include some examples of good practice which have worked) but has not worked across Scotland, so there is a need to invest a small amount of money in more in-depth long-term research / solutions.

The group agreed that the MCN project was a good way forward.

Agenda Item 9: Autism toolbox and education - David Thompson

9.1 Graham Donaldson, HM Senior Chief Inspector of Education reviewed teacher education and teachers supporting pupils with autism. His report should lead to better services for children.

9.2 Autism Toolbox

There are two versions. There needs to be one complete version which is made available to teachers. An intervention section is being considered, as is a refreshed version of the document. Money for this is due to expire at the end of this financial year but may run on into the next one.

The next stage is to look at getting better value from the Toolbox. It is designed to support mainstream schools but often sits on shelves; active use by teachers needs to improve.

AP16 ASD Reference Group members to look at this report and feed back comments on this and any views regarding the Autism toolbox to David Thompson.

AP17 Training subgroup to take forward revision and improved use of the Toolbox.

Agenda Item 12: Alternative and Augmentative Communication (AAC). Presentations - Alison Gray

12.1 This item was inserted at this stage to break up the presentations given by Dr McClure.

Alison explained that she is a Speech and Language Therapist on a six month secondment to the SG from NHS and that her project ends in May 2011. The aim is to produce guidance on AAC.

12.2 Jane Neil-McLachlan, a Speech and Language Therapist herself, commented that all people she knows who use AAC have a learning disability. Alison Leask however reported on how she has seen someone with ASD and no learning disability use an i-pad and commented that his use of it produced phenomenal results. There are programmes for people on the spectrum. Technology must be made to work for them. Mechanisms developed so far have been targeted at people with learning disabilities. She mentioned an Australian University project where technology is successfully used for people with ASD. 'Fast-forward' technology is also being used, and an example of i-touch being used for someone with Aspergers was given. The comment was made that AAC is not a precise science across the spectrum.

AP18 Alison Leask to find the name of the program used in i-pad for communicating with people and report back to members at next meeting.

Agenda Item 10: Criminal and forensic issues and ASD - Brief introduction - Dr Iain McClure

10.1 Increasingly, Dr McClure believes that autism is a disorder of thoughts, rather than actions. The question is asked:

'Is ASD a mental disorder with regard to the Mental Health (Scotland) Act? There are arguments for and against this. A learning disability is considered to be a mental disorder, as are severe mental illnesses, such as schizophrenia. The same could therefore be argued for autism.

10.2 It is vital that people are not misdiagnosed. A significant number of people may be being criminalised (i.e. their ASD is not picked up in criminal investigations of aberrant behaviour) and / or possibly admitted to forensic psychiatry units such as Carstairs and medicated for possible 'false positive' diagnoses e.g. for schizophrenia (which has many symptoms and signs on mental state examination that overlap with ASD) when they are in fact undiagnosed autism. Such scenarios may lead to possible miscarriages of justice, as well as inappropriate clinical management approaches.

We must clarify numbers and be clear about diagnosis of ASD. New criteria will exist in 2012, 2013 onwards; Asperger Syndrome will disappear and everything of this nature will come under the term ASD. There will be more emphasis on behaviour.

Discussion followed. It was pointed out that it is not straightforward to diagnose adults with autism, let alone those in prison. Nigel Rooke mentioned a piece of work in Barlinnie Prison where structured interviews by diagnosticians were used. This included referrals from forensic services. He commented that there was a huge issue with these services and autism, around the Mental Health Act and how it is viewed. He believes this is very valuable as these issues need looked at although this is a very costly process in Scotland and good lawyers are required.

A valuable piece of work undertaken by Keith Bowden and Fergus Douds, yet to be published, exists - a workbook for those in Criminal Justice and people on the spectrum.

10.3 The ASD Reference Group need to look more into the area of Criminal Justice and people with ASD. Tools / models exist to work with people in the Criminal Justice system but these tools are not fit for working with people with ASD. A pilot scheme in Fife looked at practice, policy and partnership working and training. There are pockets of good practice but there is no consistency in training. Staff working in this area in the Scottish Prison Service lack competence / skills even if they have awareness.

Stella MacDonald aims to organise a national event, to be presented to ACPOS groups, highlighting:

- Opportunities for training
- Continuity in shared communication within Criminal Justice Services
- The problem is not only perpetrators; it is also victims

A group of people are working with ACPOS on this, including Stella MacDonald.

Keen to see different vocabulary used. Does not see Autism as an illness e.g. stop using words such as co-morbidity with regard to ASD.

AP19 Dr Tommy McKay to present on this subject at the next ASD Ref Group meeting

AP20 Stella Macdonald and Nigel Rooke to share materials in this area

AP21 Peter Kelly to send draft version of the SG workbook to Stella and Nigel.

AP22 Stella Macdonald to send links on problems of diagnosis to group.

AP23 Kirsty Butts to circulate the minute / action points of this meeting and copies of all presentations to the ASD Reference Group

Prof. Aline-Wendy Dunlop asked when the autism network will be reviewed in the workplan.

AP24 Kirsty Butts to put this item on the next agenda as well as 'Sleep', on which Dr Kenneth Aitken will do a short presentation

AP25 Monthly meetings to take place February, March and April and a workplan to be ready by Easter 2011.