

**ASD Reference Group Meeting
13 December 2012, 10:00 – 14:00
Conference Rooms A/B, St Andrew's House**

Present:

Alison Leask	Autism Argyll and Parent
Anne-Marie Gallagher	Autism Resource Centre, GCC and GGC
Annette Pyle	Scottish Government, Adult Care and Support
Bill Colley	Association of Directors of Education in Scotland
Charlene Tait	Scottish Autism
David Watt	HM Inspector Scotland
Ian Hood	Learning Disability Alliance Scotland
Idem Lewis	Learning Disability Alliance Scotland
Jane Neil-MacLachlan	NHS Lothian
Jean Maclellan	Scottish Government, Adult Care and Support (Chair)
Julie Crawford	Scottish Government, Adult Care and Support (Minute)
Kabie Brook	Autism Rights Group Highland
Kirsty Butts	Scottish Government, Adult Care and Support
Richard Ibbotson	Autism Initiatives
Dr Iain McClure	Consultant Child & Adolescent Psychiatrist, NHS Lothian
Dr Tommy Mackay	Psychology Consultancy Services
Prof. Aline-Wendy Dunlop	University of Strathclyde

Apologies:

Alan Somerville	Scottish Autism
Carolyn Brown	Fife Council Psychological Service
Jane Hook	Parent
Kirsten Hogg	Camphill Scotland
Paul Lennon	Autism Resource Centre, Glasgow
Robert MacBean	National Autistic Society Scotland
Robert Moffat	National Autistic Society Scotland
Dr Andrew Stanfield	Patrick Wild Centre for Research into Autism
Dr Ken Aitken	Ken Aitken Consultancy

Speakers:

Emma Hanley	Autism Network Scotland
Liz Catterson	Autism Mapping Scotland

Item 1: Welcome, Introductions and Apologies

1.1 Annette welcomed everyone to the meeting and explained that Jean would be joining the meeting shortly. She advised that Val Sellars had resigned from the group and welcomed Emma Hanley and Liz Catterson to the meeting.

Item 2: Minutes and Action Points from the meeting held on 23 October 2012

2.1 The Minute was approved.

2.2 The Action Points were cleared apart from the following:

AP 2: There are summary notes from the last ADSW meeting. Charlene will check and send to the group.

AP 4: Kirsty read out the response from David Thompson, Support and Wellbeing Unit.

AP 5: Geraldine Bienkowski from NES has been invited to attend to discuss the NHS Autism training materials. She is unable to attend on 12 February and has been invited to attend the 18 April meeting.

AP 7: This will be on the agenda at the next meeting.

AP 8: Emma Hanley to provide an update on the Autism Website

AP 9 This needs to be clarified with Peter McCulloch.

AP 14 This is to be carried forward.

AP 15 This is to be carried forward.

Action Point 1: From Action Point 15 from the meeting held on 23 October – Kirsty to invite a representative from NES to the next ASD Reference Group meeting and for them to be invited to join Sub-group 2.

Item 3: ASD Reference Group Sub-groups Update
Sub-group 1 – Charlene Tait

3.1 Having looked at Sub-group 3's 'Menu of Interventions' this sub-group advised that there are links within it to best value. Helen Morgan, Edinburgh City Council, sent the group her thoughts on this, highlighting that one goal should be access to mainstream services. The group is looking into resources available for this and also at what the Welsh autism strategy produced with regard to interventions.

3.2 The group have been looking into using the Knowledge into Practice action plan, part of the Knowledge Management Strategy from IRISS to set up a potential Communities of Practice for autism. This can be found on the IRISS website and people can sign up to receive other documents. Charlene recommended the site and thought some of the information might be of value to the Training Working Group.

3.3 The group discussed Good Autism Practice (GAP) which is a journal produced by BILD (The British Institute of Learning Disabilities). There has been a proposal to ask BILD to produce a Scottish version of this journal with a Scottish editor. They are looking for an electronic version to be produced and to be made available on the Scottish Government and other major autism websites in Scotland. They hope to deliver a GAP conference around recommendation 9.

Action Point 2: Charlene to send IRISS Knowledge into Practice document to Care and Support Team for circulation to ASD Reference Group.

Action Point 3: Charlene to feedback to the ASD Reference Group. BILD's response to Sub-group 1's proposal that BILD produce a Scottish version of Good Autism Practice. Care and Support Team to consider this proposal and feedback to the ASD Reference Group.

Sub-group 2 – Ian Hood

3.4 The group discussed the definition of training and how we identify training needs. It should not be all about qualifications – family carers should be involved, not just professionals. Some people do not have qualifications but have specialist knowledge and should be able to access training, as they are capable of doing an effective job. Tommy suggested that universal awareness-raising, e.g. in dental practices etc, taking a national approach, would make sense. There is a difference between education and training and there is a need to know what training is required, hence the importance of mapping what is already available. The group also discussed how new research can feed into training to keep training up-to-date and Aline-Wendy and Tommy plan to attend a sub-group 2 meeting to discuss the training framework. The group also discussed the gaps in training for people with co-occurring conditions. Other concerns raised include how to assess effectiveness of training and how to determine the standards for any training session.

3.5 The group discussed the development of good practice guidelines for transitions. However, it was pointed out that the best guidelines in the world do not necessarily help with transitions as people often need support, not just guidance. Putting guidelines into practice needs to be managed properly, suggesting a more interventions-related approach. Transitions can affect people with autism throughout their lives so there needs to be a lifelong approach taken to transitions, not solely focussing on the transition when leaving school. However, it is also essential that the crucial transitions are handled well (e.g. school into adult life, or following a good work or college placement which comes to an end, or when moving out of the family home). Many individuals are getting lost and losing direction at this stage, particularly in their late 20s onwards. Children moving to adult services may not be getting the appropriate services later in life so there is a need for a review of the person's needs, taking a holistic approach. It is about the individual and the situation they are in. Children need a voice in the planning of services as not getting the appropriate services can affect the individual's health and wellbeing in adult life. Children with apparently low support needs can be missed at schools; schools need to pick up on these and manage their transitions better. The Reference Group are looking at the outcomes of funded projects dealing with the transition from school to see what works and what best practice can be shared. Aline-Wendy suggested GIRFEA (Getting it right for every adult), to join up with the SG's GIRFEC (Getting it right for every child) – lifelong services for a lifelong condition.

Action Point 4: Aline-Wendy to send the group the paper on Transitions Capital.

Sub-group 3 – Jane Neil-Maclachlan

3.6 Jane advised that Iain McClure had presented to Sub-group 3 to discuss diagnostic waiting times. The group discussed how NHS Boards were implementing the strategy and Annette confirmed a letter will soon be issued to NHS Boards.

3.7 The draft Menu of Interventions received a positive response at the 1 November 2012 event. The Menu needs to be flexible as a guideline framework for local authorities. It was suggested that a seminar be held annually in each area to update on the progress of the Menu of Interventions. The Menu should go out for

consultation, including to COSLA reps. Scottish Government legal advice/clearance may be required.

Action Point 5: Annette to issue letter to all NHS Boards re adult diagnostic services.

Action Point 6: Jane Neil-Maclachlan to send the consultation questionnaire and updated Menu of Interventions to Care and Support Branch to issue to the sub-groups for consultation.

Sub-group 4 – Richard Ibbotson

3.8 The group have met with the leads of projects focussing on employment funded through the 1st round of the Autism Development Fund. There is a need to capitalise on information from the projects to share good practice. The group, with Autism Network Scotland, are proposing to hold an event for the employment-related projects to get together to share their experience and learn from one another. A representative from Scottish Colleges will be invited to the group.

Sub-group 5 – Ken Aitken

Ken gave his apologies so Kirsty updated the group.

3.9 There was some discussion around the possibility of producing basic 'how to' guidance notes on research. An introductory paper was circulated within the sub-group and a list of briefing documents. They discussed increasing the relevance of practice-based research in light of both the Behavioural Insights Group and the US developments in CER. The consensus was that the idea was reasonable but the time commitment would be beyond the resources of the group.

3.10 Ken gave feedback to the sub-group on the recent meeting held with NES about The Matrix. There was an agreement by NES to redraft the section on ASD to reflect points raised by the sub-group. It was agreed that NES (with Geraldine Bienkowski as Matrix lead) should attend the strategy group and present on their role in the production of ASD specific materials for the NHS Boards.

Action Point 7: Charlene Tait to provide Dr Ken Aitken with contact details for IRISS, who have practitioners' and researchers' training package for Sub-group 5's attention.

Action Point 8: Ken Aitken to send further information about the Behavioural Insights Group to the group.

Sub-group 6 – Kirsty Butts

3.11 Kirsty advised that the first meeting will take place on Tuesday 18 December 2012 and that the group have been sent papers, including Jane Neil-Maclachlan's Menu of Interventions for discussion. Jane will present on this Menu at the meeting, which has also been circulated for comment to e-consultation group members. Ideas

for future discussion, submitted by Sub-group leaders, have been carried forward as future agenda items.

Mapping – Liz Catterson

3.12 Local authorities have been sent a letter offering them £35,000 to develop autism action plans in their area. This money has helped them bring people together and has enabled the gathering of information. LAs have been asked what stage they are at with the 10 indicators from the strategy and what level of partnership they have. The mappers are looking for examples of good practice, as outlined in the 10 indicators. Some things which work may well be linked to only 1 indicator but still be good examples.

3.13 Liz explained that the remit of the mappers is to gather an evidence base to inform where the local autism co-ordinators will be best placed. In practice, they are mapping what's in place, how things work, where the gaps are. Kabie mentioned that people were expecting the highlighting of good practice, identifying gaps, so as to get consistent services across the country. Liz commented that what works well in one area may not work so well in another. There will be information on services but the purpose of the exercise is not to compile a directory on services in each area nor one of 'best practice', although examples will emerge from this exercise which might be considered as such, once evaluated; rather, it is to determine future decisions on funding local area coordinators, where they are best placed and what their remit will be.

3.14 Liz advised the group that there has been a good response to the online questionnaires although some people have experienced difficulty in completing them. The questionnaires are seeking to discover what would make a difference for people with autism and their families/carers. They invite stories, general information, feedback on individuals' experience of diagnosis, transitions etc. People in local areas are being used to test the autism questionnaires and ELAS are helping with this in Glasgow. Carers questionnaires are now ready and will be sent out once the testing of the autism questionnaires is complete. Events will take place throughout December and January.

Action Point 9: Kabie to send Annette the example of the previous exercise undertaken to identify good practice in autism services in Highland, for circulation to the ASD Reference Group.

Item 4: Application to the Scottish Universities Insight Institute for Knowledge Exchange Seminar Series: 'Action on Autism' Research – Aline-Wendy Dunlop

4.1 Aline-Wendy, along with other academics from the Universities of Glasgow, Edinburgh and Aberdeen, is proposing the development of a series of research workshops and events to map the state of autism research in Scotland, working across disciplines to maximise impact. They are also looking to relate this to international sources of knowledge and to consider how the Scottish Autism Strategy implementation groups can be supported to improve understanding of the impact of locally based as well as international research upon the lives of people with autism,

their families and the professionals that support them in Scotland. There is a need to engage with people carrying out research and establish the impact of their work in practice and to this end, they wish to propose an Action on Autism Research in Scotland Network. Iain commented that it is very important to involve academics in all Scottish universities who are doing autism research.

4.2 Aline-Wendy advised the group that she has given her presentation before any funding has been awarded by the Scottish Universities Insight Institute. The maximum award for this funding is £20,000 and advised that a further £30,000 of funding was needed to undertake the project.

4.3 If the application is successful there will be a steering group to help take forward the project and sub-group leaders will be invited to join. The project should be align with the 2, 5 and 10 year goals and there should be a research action plan to identify gaps will be developed.

Action Point 10: Aline-Wendy to send details of all the academics which will be involved in the Action on Autism Research to the group.

Action Point 11: Aline-Wendy to send Annette Pyle the Scottish Universities Insight Institute application for the Action on Autism project.

Item 5: Autism ACHIEVE Alliance waiting list research findings: Next phase of the project – Iain McClure

5.1 Iain presented the findings of the 1st year's work of their 2 year project being funded by the Scottish Government on the autism assessment issue (waiting lists). This is a multi-disciplinary collaboration between NHS Lothian, the University of Edinburgh and Queen Margaret University and will address the Strategy's recommendations 21-25. They were tasked to investigate the autism diagnostic process for children and adults, identifying the factors contributing to waiting times for assessment for autism and also to consider further training on ADOS etc. Iain explained to the group that the first stage of the project was quantitative data collection, in the form of a retrospective notes audit, in order to map services to find where services were across Scotland which diagnose autism. Focus groups were then conducted to establish solutions to problems that are arising in services, specifically the wait for diagnosis.

5.2 On average, it emerged that there is a longer waiting list for children's services from referral to the first appointment. From the last appointment to diagnosis, however, the wait is very short. They established that none of the services sampled consistently met waiting time targets for adults or children.

5.3 Iain advised that the Autism ACHIEVE Alliance has so far clarified the extent of delays in the diagnosis of autism and the established the causes of these delays. They have created a national action plan to address the causes of the delays and therefore to reduce them.

5.4 Autism ACHIEVE Alliance has been funded by the Scottish Government for a project to support adult services. This project will run from January to December

2013. They will work alongside adult services to help them implement the national action plan.

5.5 The group discussed Sub-group 3's feedback from the meeting with Dr McClure on the Autism ACHIEVE Alliance project. There was a discussion on the use of tools and the need for training. It was stated the use of such tools is not straightforward and there is a need to look at the whole context. Teams with high levels of expertise are less likely to use or rely on tools. Training is valuable but training in the use of tools does not necessarily guarantee effective use. The need to reduce the length of time waiting for diagnosis is important but it is equally important to ensure that the length of time for assessment is not reduced; shorter assessments do not necessarily make for better diagnosis.

5.6 Iain responded by advising that although using ADOS can make assessment easier, there is no pressure to use this and that those trained in ADOS can easily upgrade to ADOS 2 which will be compatible with the new DSMV diagnostic criteria. The process of assessment is qualitative and they do not want to reduce the time of assessment. Those who do not have autism have a right to be assessed.

Action Point 12: Tommy Mackay to send Iain McClure the points raised at the Sub-group 3 meeting regarding the Autism ACHIEVE Alliance research.

Item 6: Presentation on the Autism Network Scotland – Emma Hanley

6.1 Emma Hanley from the Autism Network Scotland (ANS) explained to the group that the aims of ANS are as follows:

- To share knowledge, understanding and values within and between groups.
- To develop a range of professional networks across Scotland, to better support communication about and awareness of autism.
- To develop networking opportunities for individuals on the autism spectrum.
- To facilitate independent consultation and/or networking for local authorities.
- To identify gaps in service.
- To signpost professionals and individuals to local and national services
- To create Scotland-wide resource
- To facilitate and enhance multi-agency working across the life-span
- To facilitate and enhance multi-agency working in rural and remote areas
- To provide a platform for sharing good practice
- To support the Autism Strategy

6.2 ANS will be launching a new website which Emma gave a demonstration of to the group and also aim to develop future projects directed by a steering group, hold networking meetings across Scotland and work in partnership with other organisations and people with autism to identify gaps in services.

6.3 ANS have a presence in the ASD Reference Sub-groups 1-5 and also work in partnership with SCLD on Project Search and with Scottish Autism / NHS National Clinical Assessment Service on the refresh of the Autism Toolbox.

Item 7: AOB and Close

The next meeting will take place on Tuesday 12 February 2013, 10:00-14:00, Room 4ER, St Andrew's House, Edinburgh.