

**ASD Reference Group Meeting
12 February 2013
Conference Room 4ER, St Andrew's House**

Present:

Ken Aitken (Dr)	Ken Aitken Consultancy
Kabie Brook	Autism Rights Group Highland
Carolyn Brown	Fife Council Psychological Service
Kirsty Butts	Scottish Government, Adult Care and Support (Minute)
Bill Colley	Association of Directors of Education in Scotland
Aline-Wendy Dunlop (Prof)	University of Strathclyde
Anne-Marie Gallagher	Adult Autism Services, NHS Greater Glasgow & Clyde
Kirsten Hogg	Camphill Scotland
Ian Hood	Learning Disability Alliance Scotland
Jane Hook	Parent
Richard Ibbotson	Autism Initiatives
Paul Lennon	Autism Resource Centre, Glasgow
Idem Lewis	Learning Disability Alliance Scotland
Robert MacBean	National Autistic Society Scotland
Tommy Mackay (Dr)	Psychology Consultancy Services
Jean Maclellan (OBE)	Scottish Government, Adult Care and Support (Chair)
Bernhard Menzinger	Camphill Scotland
Jane Neil-MacLachlan (Dr)	NHS Lothian
Annette Pyle	Scottish Government, Adult Care and Support
Alan Somerville	Scottish Autism
Andrew Stanfield (Dr)	Patrick Wild Centre for Research into Autism
Charlene Tait	Scottish Autism
David Watt	Education Scotland

Apologies:

Linda Connolly	The Care Inspectorate
Julie Crawford	Scottish Government, Adult Care and Support
Beth Hall	COSLA
Alison Leask	Autism Argyll and Parent
Stella Macdonald	Fife Council / NHS Fife
Iain McClure (Dr)	Consultant Child & Adolescent Psychiatrist, NHS Lothian
Peter McCulloch	Association of Directors of Social Work
Robert Moffat (Dr)	National Autistic Society Scotland

Item 1: Welcome, Introductions and Apologies

1.1 Jean welcomed everyone to the meeting and extended a warm welcome to Bernhard Menzinger, Camphill Scotland, who will attend meetings, alternating with his colleague Neil Henery, whilst Kirsten Hogg is on maternity leave. There was a quick round of introductions. Jean mentioned that the less busy agenda allowed for collective time for reflection and that we should use this opportunity to do so.

Item 2: Minutes and Action Points from the meeting held on 13 December 2012

2.1 The Minute was approved. Bill Colley had arrived late but was in attendance and asked for the Minute of 13 December 2012 to be amended accordingly.

2.2 Action Points arising:

AP 1, 2, 3, 6, 9, 11 and 12 – cleared.

AP 4, 5, 7, 8, 9 and 10 – carried forward.

AP 11 – Action on Autism research – funding agreed by the Minister for Public Health.

Item 3: ASD Reference Group Sub-groups Update

3.1 Sub-groups are requested to consider how better to join up sub-group work, sharing matters with each other which they are aware are important or relevant to the work of other sub-groups.

Sub-group 1 – Charlene Tait

3.2 Sub-group 1 has recently identified in which Sub-groups there are cross-over points with the work of their group, and have created a work plan, with the focus on outcomes / plans / costs. Future actions include:

(Rec 5) - inviting someone from Dr Tommy Mackay's research project team

(Rec 6) - a possible revision of the Commissioning Guidance, tying in this work with Sub-group 3's Menu of Interventions work

(Rec 7) (commissioning research on service provision in connection to quality of life, to inform revised guidance for commissioners), a mini sub-group is examining these issues and the key determinants of service provision that result in improved quality of life (Rec 8) in more detail.

Re Rec 9, the Scottish version of Good Autism Practice (GAP) (BILD Proposal) has been approved by the Minister. This will enable a national knowledge exchange on the subject, raise awareness, grow good practice and have an impact on all sub-group work and people on the spectrum.

3.3 Sub-group 2 are currently looking at shared stories of both successful and unsuccessful transitions. David Watt has collected information from schools which links with this information. Carolyn mentioned a possible Fife event in September 2013, which will link to Sub-group 1's work with GAP. This idea was welcomed, as local events such as these further the exchange of good practice. Charlene advised of a BILD event in November 2013 which will start the process of practice exchange. She expressed the wish to explore the potential infrastructure to capitalise on that model / event.

Sub-group 2 – Ian Hood

3.4 Sub-group 2 has produced a training paper, 'Guidance Note On Autism Training' for circulation. The points in this paper draw on the work of the National Training Framework for Scotland paper and further work by the National Autistic Society and Skills for Care. This work may help to support the discussion and presentation to be given by NHS Education for Scotland (NES) at the next meeting about a possible project to develop the training framework as part of the Strategy. Geraldine Bienkowski, (NES) is said to believe that the 4-stage approach taken to dementia training could be taken with autism. The group consider the NES proposal to the Scottish Government to be good and feel it would benefit from discussion.

3.5 The Scottish Government has asked NES to reconsider their proposal and the revised version will be discussed with the ASD Reference Group. NES will examine the Training Framework which provides a good basis and adjust it, in line with the Dementia Framework.

3.6 There is now agreement around the baseline for what a national standard for non-award bearing CPD training would look like and how it could be used to deepen knowledge of autism. Charlene is seeking a quick agreement on levels of training and where non-award bearing training would sit within this structure.

Action Point 1: Charlene to submit CPD training for validation with SQA

Following the presentation from NES at the next ASD Reference Group meeting on 18 April 2013, the ASD Reference Group will discuss and make a collective decision on levels of training.

Action Point 2: Care & Support team to include this discussion as an agenda item for the next meeting.

Action Point 3: Sub-group 2 to send their 'Guidance Note On Autism Training' paper to the Care & Support team for circulation to ASD Reference Group members for comment and further discussion.

Sub-group 3 – Jane Neil-Maclachlan

3.7 Jane clarified that their group's strategy recommendations relate primarily to 1. A Menu of Interventions and 2) Diagnosis

3.8 Jane presented on the Menu of Interventions to Sub-group 6 members at their first meeting on 20 February 2013. Members created a descriptive case of a typical male with autism which Jane wrote up and included in the Menu. She has replied to a number of consultation responses regarding this case. She will construct a child case, to be added to the document, and will sign-off the Menu of Interventions after final consultation responses to the Menu have been received.

3.9 Since the last ASD Reference Group meeting, Jane has met with Prof Kirsty Forsyth, Autism ACHIEVE Alliance and the Scottish Government, particularly with regard to adult diagnosis and the outcome of Phase 1 of the AAA research and regarding the whole group of people with autism without a Learning Disability or Mental Health diagnosis. Significant progress has been made. Kirsty Forsyth has agreed to join Sub-group 3.

Sub-group 4 – Richard Ibbotson

3.10 Geraldine Radcliffe, Scotland's Colleges, has joined this group and attended their last meeting. Richard reported a reduction in colleges funding for courses for people with a learning disability / autism and distance learning courses, which has had an impact on people with autism.

3.11 Sub-group 4 are keen to hold an event late summer on Good Practice in Employment and to restart the networking employment group, in order to share good practice and to benefit from input from new members and form new links.

3.12 Richard mentioned wider opportunities / access to work and the need to be inclusive of all who may take other routes rather than paid work, as other destinations may be more appropriate, or who may be preparing for work.

3.13 'A Day in the Life of Autism Scotland' will take place on 2 April 2013. Invitations to people on the autism spectrum to participate are being widely circulated. Liz Catterson, Mapping Projects Lead and Emma Hanley, Autism Network Scotland will video the best and worst thing which has happened to each individual with autism on that day, and create a short film to be published on a website, along with some of the best photos from the day, which they will also exhibit in The Gallery on the Corner in Edinburgh. Comments will be analysed and linked to the work of the mapping exercise. The overall aim is to raise the general awareness of people on the autistic spectrum.

3.14 Idem spoke about young people with autism and the implications for their future. Some parents are content for them to go to college but acknowledge that entering employment requires them to be supported. The impact which Welfare Reform is having on the lives of people with autism was acknowledged by Jean, who mentioned that there were a variety of initiatives in Scotland being undertaken and funding being made available to address this problem. Self-Directed Support is one such initiative and policy in education is also being revisited. Additionally, Sub-group 4 are looking at the whole area of employability.

Sub-group 5 – Ken Aitken

3.15 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.

Sub-group 6 – Kirsty Butts

3.16 The first meeting of Sub-group 6 took place on 18 December 2012. Jean Maclellan, who chaired, provided an overview of the Scottish Strategy for Autism and the work of the ASD Reference Group and Sub-groups. The role and remit of Sub-group 6 were also discussed. Jane Neil-Maclachlan presented on Sub-group 3's Menu of Interventions. The group worked through various questions to create an example of a typical individual with autism, which Jane will include in the Menu of Interventions. There will be a discussion around who chairs meetings at the next meeting on 20 February 2013.

3.17 Some members' had expressed concern regarding VQ as the venue for the next meeting because of its distance from the centre and how to get there. There was also concern about getting papers/an agenda well in advance of meetings. The venue was subsequently changed to a more central location.

Additional Item: Time to Talk

There was discussion about adult diagnosis. Adults usually have a history of problems by the time they seek a diagnosis and time taken to receive one needs shortened. Trained professionals have some knowledge of autism but lack hands-on experience and can fail to spot autism in some children as they lack the experience to understand how differently autism can present. They need access to CPD training to gain experience and support to put theory into practice. When undertaking CPD, participants should be required to evidence their learning.

Approximately two thirds of Educational Psychologists are lacking confidence in diagnosing autism in adults and agencies/practices are variable across Scotland. There is a need to create a national framework with suitable structures and processes. The setting up of regional diagnostic teams, local teams, then good quality training and monitoring of service provision is a model which has worked. However, there needs to be robust method for maintaining quality of services, once established.

Good quality practice in diagnosis is now becoming more widely available, e.g. training in the use of D.I.S.C.O. (Diagnostic Interview for Social and Communication Disorders) which is a useful tool for professionals with less experience when making a diagnosis.

Sub-group 3 will focus on the delivery of basic training; specialists look only at problems in their area of specialism and may not see that e.g. an eating disorder may be as a result of autism.

The second set of Scottish Government statistics will shortly be published on numbers of children with autism in Scotland. Approximately 25% young people with autism are attaining qualifications beyond a higher educational level. However, unemployment of people with autism has increased. People with autism and a learning disability often encounter barriers in gaining access to employment and being considered employable after attending college.

Action Point 4: All members to consider this conversation and contribute ideas on how diagnostic services can be improved.

Item 4: Parliamentary Debate around NHS Grampian Alert Cards. Discussion around national implementation of cards

4.1 MSPs supported the launch of the Grampian Alert Card and some spoke about Alert Cards available/used in their own areas. There was support for a national roll-out of an Alert Card. The ASD Reference Group have been asked to discuss how this card could be rolled out nationally, in consultation with the national police force.

4.2 Strathclyde Police lead on preventative policing, including a Glasgow pilot, Information Sharing, which was launched in May 2012 and will be reviewed in May 2013. People may not wish to sign up for this, but it is an additional facility. The consent 'pro forma' is available through ARC Glasgow.

4.3 It may prove helpful to work closely with Strathclyde Police on the roll-out of the autism alert card across Scotland. In consultation with those who have an autism alert card, they have developed a method to help those with a card. Strathclyde's police systems alert police going out on a call for someone with autism and will provide information on their behaviours.

4.4 There are already several models of an autism alert card in existence. Each card is maintained by a partnership. The Strathclyde Alert Card was sent out with a DVD which has received universal praise. This DVD could be used as a national resource.

4.5 Kabie mentioned that there is opposition to an ID card / national registration for people with autism. Many people hold a national card voluntarily but people with autism would be opposed to being put on a database. People with autism are concerned about how they would be treated generally if people check these cards.

Action Point 5: NAS to consider how a National Alert Card can be implemented and report back to the ASD Reference Group.

Item 5: NAS Report *Count Us In*: Key Recommendations for Scottish Government – for discussion – Robert MacBean

5.1 Robert reported back on the key recommendations for Scottish Government contained within the NAS *Count Us In* Report. He described a readiness of people to become engaged at local and national levels. A UK-wide survey was undertaken, which contained Scotland-specific questions and answers regarding important issues to be explored.

5.2 Last summer, NAS organised workshops, skilling-up and supporting people on the spectrum to help run these. David Breslin is one such person who is now in a position to run a workshop again or train others to do so. People were asked what had helped/ hindered them in life and NAS collated this information. 4 key areas emerged:

- 1) Sustained Employment – getting into and sustaining work, difficulties in workplace / discrimination / not being able to progress in work.
- 2) Choice and Control Advocacy – role of advocacy –ability to successfully self-advocate. Understanding of self and ability to communicate effectively.
- 3) Challenging discrimination – bullying / low-level intolerance and barriers which that causes. Direct / indirect discrimination and impact that has had.
- 4) Professional knowledge and access to support – positive / negative experiences of diagnosis / post-diagnosis. Stress of going through diagnostic process. Getting a good diagnosis and post-diagnostic support really made a difference.

5.3 The Summary of Key Recommendations was discussed within the ASD Reference Group and it was agreed that the Sub-groups would discuss more fully and report any suggested actions back to the ASD Reference Group.

5.4 Sub-group 4 have discussed the need to make better connections between the Strategy and SG employability agendas. Employability is now emerging as central to the well-being of individuals. Recognition and support for people with autism has been overlooked by employment services and employers and needs addressed by policy makers/agencies who need to find a way of raising awareness amongst employers as to how they can help people with autism in employment and providing them with the necessary skills to do so.

Action Point 6: Sub-groups to consider the 4 recommendations within the *Count Us In* report, as follows:

- Sustained Employment – Sub-group 4
- Choice and Control – Sub-group 2 (taking into account participation and work of SDS team)
- Challenging Discrimination – All Sub-groups to consider

- **Professional knowledge and access to support – Sub-group 3**
- **Sub-group 6 to discuss and consider all recommendations.**

Item 6: AOB and close

6.1 Aline-Wendy reported that funding has been secured to undertake the 'Action on Autism Research', a series of research workshops and events to map the state of autism research in Scotland. A Conference, which will be a half day event for dissemination of results, is to be held in May 2014 .

Action Point 7: Aline-Wendy to discuss with Sub-group 6 their level of involvement in the above.

6.2 Ken presented to the group on the need to find a way to react rapidly to more controversial press stories on autism, possibly via the autism website. New research can be misinterpreted by media and contradictory media articles can confuse parents. Autism Network Scotland and SG Research group colleagues are planning to meet to discuss this and will report on their views on how to react to such media stories.

6.3 Robert MacBean questioned the feasibility of reacting to press articles in this way. NAS have press officers on call around the clock who are trained in responding. It is necessary to have agreed lines based on consensus at Board level which are used to guide the press team as to what to say. Resourcing this is a major commitment. NAS have these resources and have put forward stories from the strategy to counteract negative press.

6.4 The Scottish Government policy team often have to clarify what is wanted with SG press officers, so as to correctly communicate the policy view, as part of routine business.

Action Point 8: Ken to send Care & Support team a copy of his presentation on responding to media coverage.

Action Point 9: Ken Aitken, Autism Network Scotland, National Autistic Society and Scottish Government to arrange a meeting to discuss this issue and present back to the ASD Reference Group at a future meeting.

The next meeting will take place on Thursday 18 April 2013, 10:00-14:00, Conference Rooms 4ER, St Andrew's House, Edinburgh.