

ASD Reference Group Meeting
Thursday 12 December 2013
10:00 – 14:00

Conference Rooms C/D/E, St Andrew's House, Edinburgh

Present:

Kabie Brook	Autism Rights Group Highland
Maureen Bruce	Adult Care and Support, Scottish Government (Chair)
Bill Colley	Association of Directors of Education in Scotland
Julie Crawford	Adult Care and Support, Scottish Government (Minute)
Aline-Wendy Dunlop(Prof)	University of Strathclyde
Anne Marie Gallagher	Adult Autism Services, NHS Greater Glasgow & Clyde
Ian Hood	Learning Disability Alliance Scotland
Richard Ibbotson	Autism Initiatives
Alison Leask	Autism Argyll/Parent
Paul Lennon	Autism Resource Centre, Glasgow
Idem Lewis	Learning Disability Alliance Scotland
Robert MacBean	National Autistic Society
Stella Macdonald	
Jane Neil-MacLachlan(Dr)	NHS Lothian
Peter McCulloch	ADSW
Annette Pyle	Adult Care and Support, Scottish Government
Alan Somerville	Scottish Autism
Ali Taylor	Adult Care and Support, Scottish Government

Apologies:

Ken Aitken (Dr)	Ken Aitken Consultancy
Jan Beattie	National Autistic Society
Carolyn Brown	Fife Council Psychological Service
Neil Henery	Camphill Scotland
Jane Hook (MBE)	Parent
Tommy Mackay (Dr)	Psychology Consultancy Services
Iain McClure	NHS Lothian
Charlene Tait	Scottish Autism
David Watt	HM Inspector, Education Scotland

Item 1: Welcome and Introductions

1.1 Maureen welcomed everyone to the meeting and apologies were noted.

Item 2: Minutes and Action Points from the meeting held on 22 October 2013

2.1 The minute was agreed.

2.2 The action points were cleared apart from the following:

- **AP 2** – This has been carried forward as the Sub-group Leaders meeting on 17 December 2013 was cancelled.

- **AP 3** – Arranging a meeting with Janine Robinson from NES is in progress.
- **AP 8** – David Simmons is a member of Sub-group 5 so it was agreed that Sub-group 5 should take forward the discussion on sensory issues and autism.
- **AP 9** – The directory of legal services for people with autism is on the NAS website and Robert MacBean will send the link to ANS to be added on to the Strategy website.
- **AP 12** – An announcement regarding the criteria for the EU Framework funding was due week commencing 9 December 2013 and further information will be available once the announcement has been made.

Item 3: Annual Autism Event – Maureen Bruce

3.1 Maureen advised that the Good Autism Practice event – run jointly by BILD and the Scottish Government was held on 21 November and was a great success. The Menu of Interventions was published along with the GAP Scottish Edition and the Mapping Report. The Autism Network Scotland quarterly report was also published and shows good progress. Also that Michael Matheson would be attending the Autism: Life in Colour event on 12 December 2013.

3.2 Maureen advised that the Sub-groups will be asked to produce an one page summary of their activity to progress the Recommendations and an action plan in 2014.

Item 4: ASD Reference Group Sub-group Updates

Sub-group 1 – Charlene Tait

4.1 Robert MacBean gave the update, in Charlene's absence, and agreed that the Good Autism Practice event on 21 November was a great success. The sub-group have had a discussion around the performance framework and the development of training work.

Sub-group 2 – Ian Hood

4.2 Involvement – Community Empowerment (Scotland) Bill has been published and people now have a right to influence local authority planning, and challenge and engage with local authorities. Self-defined carers community groups such as ASD will have a clearer say in planning. The sub-group are looking at other people's work to make it relevant for people with ASD as many people feel left out of decision making.

4.3 Training – Janine Robinson from NES came to the sub-group meeting and advised that the NES training project aims to achieve a 4-tier approach. With constraints on funding the project is just concentrating on NHS training and will look at other aspects of funding in the future. There was an understanding within the group that the project was to include social care training also and this was discussed.

Action Point 1: Annette to look at the original proposal for the NES training project.

Sub-group 3 – Jane Neil-MacLachlan

4.4 Jane advised that the Menu of Interventions was finally published and was launched at the Good Autism Practice event on 21 November 2013. Autism Network Scotland (ANS) have offered to run learning events for the Menu and this could be an one-off event or a series of events. It was discussed that ANS could organise regional events at the One Stop Shops and have a national event at the University of Strathclyde. We need to decide who the audience are and where they are, and develop a communications/marketing plan.

4.5 We need commitment from people to deliver goals and need to engage more with COSLA. 'How the Menu of Interventions can deliver in times of austerity' could be the name of the events.

4.6 Diagnostic services – Jane advised that she had been looking through the responses from the NHS Boards. Most have responded. Scottish Government will contact those boards who have not submitted.

Action Point 2: Sub-group 3 will put together a small group to discuss how to disseminate the Menu of Interventions.

Sub-group 4 – Richard Ibbotson

4.7 The sub-group met last week and had a de-brief on the employment event which was a success. The projects who attended valued the event so an annual event is being considered to focus on employers and how we can influence them. The sub-group is pulling together a document with 10/12 positive case studies on employment.

4.8 The sub-group discussed how to disseminate the employment guide. An electronic version will be available on the ANS website. There is a need for hard copies but it was agreed to develop a flyer with a summary of the guide to circulate widely. The guide is aimed at autism services not employers.

4.9 It was discussed that there is a need for a scheme for Scottish Government, NHS etc to lead by example as employers and we need guidelines for recruitment and interview techniques for employers.

Action Point 3: Richard to send costs for printing the flyer to Care and Support Branch – DONE

Sub-group 5 – Ken Aitken

4.10 Ken gave his apologies so Alan Somerville advised that the sub-group was trying to widen the membership of the group and are being more pro-active, for example, with the Autism Research Series seminar. The need for an autism database and models were also discussed.

Sub-group 6 – Kabie Brook

4.11 The sub-group discussed members joining other sub-groups. It was discussed that Sub-group 4 have members with ASD and carers but need permanent members and that Sub-group 3 is already a large group. Members from other groups could also join Sub-group 6 but it was discussed that it would need to be one-way so there are not too many people in Sub-group 6. Decisions will be made at the next Sub-group 6 meeting.

Item 5: Discussion on Autism and Ageing – Robert MacBean

5.1 Robert spoke to the group about the NAS report *Getting on* which details the experiences of older people with ASD. There is a substantial need for services for older people with ASD as the Strategy is intended to be a 'life-long' approach. The Public Bodies Joint Working Bill is also looking at older people under the integration agenda. It is important to get autism into the guidance. NAS have been working with ANS and Mark McDonald MSP, and a round table discussion took place at the Scottish Parliament where case studies were presented. The report will be circulated once published.

5.2 The group discussed autism and ageing and the following points were made:

- There is a need for guidelines for older people with ASD.
- Need for more research on older people with ASD – there are only 1 or 2 studies on people over 55.
- Health checks would be useful.
- Need to contact Observatory to find out main health conditions for older people with ASD.
- Need to establish training needs for older people practitioners and people who provide autism services.
- Need to prepare for the future – ensure older people with ASD are involved in the community.
- Access to advocacy is important.
- Need to develop preventative services for older people with ASD and appropriate services.

5.3 Older people with ASD can experience the same treatment in care settings as they did at school and bereavement can be an issue also. Transitions could be useful for this life stage. We need to understand the complexities of older people in general before looking at those with ASD. Older People's services, in general, need to be improved.

Action Point 4: Robert to circulate the report to the group once published.

Item 6: Autism Alert Cards

6.1 It was discussed that there is need to involve organisations such as ARGH and other people with ASD in the implementation of the Autism Alert Cards as many are not happy with a register/database holding records of people's details. There needs to be more awareness of how to deal with people with ASD and they should

not have to go on a database to have equal access to services. It was advised that the database does not hold much personal detail about the person – just name and address to record who has a card and where to send it. People agree to give their details to obtain the card so it is not mandatory.

6.2 The alert card scheme evolved from the issue of how the police deal with people with ASD and how they can identify themselves and there are other alert cards around. The learning disability sector have alert cards to identify themselves and to help with everyday situations such as transport. Michael Matheson asked that the ASD Reference Group look at the benefits of rolling out the alert cards across Scotland.

6.3 There is a need to discuss how information is stored and everyone should be involved in this discussion.

Item 7: Discussion on World Autism Awareness Day in 2014

7.1 It was agreed that this would be discussed as part of AOB.

Item 8: One Stop Shops – Richard Ibbotson/Matthew Day

8.1 Richard introduced Matthew Day to the group, who is the Manager of No 6 in Edinburgh and will be involved in the evaluation of the One Stop Shops (OSS). Richard advised that the OSS are at different stages and people using the service are mostly looking for similar services. Employment has been highlighted as an issue for people with ASD. The OSS do not currently cover all of Scotland.

8.2 There is time-limited funding for the 6 new OSS and there is involvement in the implementation of continuation strategies. Richard advised that the OSS cannot be funded through donations and they are looking at mixed funding sources from different organisations. The OSS need core funding to continue so the evaluations need to be independent and robust in order to secure future funding.

8.3 The group discussed options for evaluating the OSS. It was suggested that the evaluation could be done by those using the services by having a small group although the right type of approach is needed when involving stakeholders. It was agreed that money should not be spent on expensive evaluations which could be spent on services. The evaluation should be independent and the group could look at the role of an outside contractor to take the lead.

Action Point 5: Maureen to consider the proposal for evaluation from Richard.

Item 9: Discussion on the programme for meetings of ASD Reference Group in 2014

9.1 It was discussed that the Sub-groups are the main focus of implementing the strategy so it is an idea to see what the Sub-groups are doing first then arrange the Reference Group meetings around them. The group advised that they find the Reference Groups being arranged a year in advance is helpful so it was agreed to charge the Sub-groups to a longer term plan and rearrange the Reference Group meetings if necessary.

9.2 At the next meeting, a discussion will be held to examine where we are with the 2-year goals from the Strategy and the structure of the sub-groups. There is a need for a 2-year review then re-group to discuss a plan for the next year.

Action Point 6: Care and Support Branch to work out structure for yearly planning.

Item 10: AOB

10.1 The group had a discussion on how to mark World Autism Awareness Day 2014. It was discussed that the progress made in the strategy and the achievements made so far would be good to look at. It was also discussed that the day is about encouraging awareness of ASD and peoples' experiences, not just about the Strategy but these could be joined together. Autism Network Scotland could help facilitate any plans. Autism awareness in the community needs to be looked at and services need to be aware of what autism is. World Autism Awareness Day is a good way of doing this.

Action Point 7: Group to give ideas on how to mark World Autism Awareness Day 2014 by end January 2014.

10.2 An update on the Local Autism Plan was given. Some local authorities have asked for extensions but a list of those who have submitted their plans is being compiled and will be circulated. Most local authorities have agreed to have their plans published on the strategy website. A report will be sent to Michael Matheson once all plans have been received. Peter McCulloch advised that ADSW are happy to ensure that all plans are submitted and adhered to.

Date of the next meeting: Tuesday 25 February 2014, 10:00-14:00, 4ER, St Andrew's House, Edinburgh.