ASD Reference Group Meeting
Thursday 22 August 2013
10:00 – 14:00
Conference Rooms C/D/E, St Andrew's House, Edinburgh

Present:

Ken Aitken (Dr)	Ken Aitken Consultancy
Kabie Brook	Autism Rights Group Highland
Carolyn Brown	Fife Council Psychological Service
Liz Catterson	Autism Mapping Scotland
Bill Colley	Association of Directors of Education in Scotland
Linda Connolly	Care Inspectorate
Julie Crawford	Adult Care and Support, Scottish Government (Minute)
Ian Hood	Learning Disability Alliance Scotland
Jane Hook (MBE)	Parent
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	Fife Council/NHS Lothian
Jane Neil-MacLachlan (Dr)	NHS Lothian
Jean Maclellan (OBE)	Adult Care and Support, Scottish Government (Chair)
Iain McClure (Dr)	Consultant Child & Adolescent Psychiatrist, NHS Lothian
Peter McCulloch	ADSW
Annette Pyle	Adult Care and Support, Scottish Government
Alan Somerville	Scottish Autism
Andrew Stanfield (Dr)	Patrick Wild Centre for Research into Autism
Charlene Tait	Scottish Autism
Ali Taylor	Adult Care and Support, Scottish Government

Apologies:

Aline-Wendy Dunlop (Prof)	University of Strathclyde
Anne Marie Gallgher	Adult Autism Services, NHS Greater Glasgow & Clyde
Tommy Mackay (Dr)	Psychology Consultancy Services
Bernhard Menzinger	Camphill Scotland

Item 1: Welcome, Introductions and Apologies

1.1   Jean welcomed everyone to the meeting and apologies were noted. Jean advised that copies of *The keys to life* were available to the group and they should contact Julie for extra copies.

Item 2: Minute and Action Points from meeting held on 18 April 2013

2.1   The minute and action points were cleared apart from the following:

Paragraph 10.1 – This should be re-worded to reflect that the Autism Treatment Trust (ATT) believe that interventions can help in the treatment of autism.

Paragraph 10.2, second bullet point – There are data to suggest that gastric issues are substantial in people with autism.

2.2   Jean advised that the Autism Treatment Trust (ATT) had advised us that they have dissolved through lack of funding but some of their activities will continue to be undertaken by Dr Amet.

Item 3: ASD Reference Group Sub-groups Update

Sub-group 1 – Charlene Tait

3.1   Charlene up dated the group on the Scottish edition of the GAP journal and the conference. The edition will be split into 2 sections as it is clear that some papers are strategic and other are the sharing of good practice. There will be a foreword from Michael Matheson, Minister for Public Health. The Scottish Government is not endorsing the journal as an exemplar of good practice as such but rather as an opportunity to showcase examples of good practice. The journal will also demonstrate good progress on the Strategy recommendations and inform future work .

3.2   The conference will take place on 21 November 2013 at the Hilton Hotel in Edinburgh. There will be 3 speakers who will be confirmed soon and 6 workshops which will run twice on the day. The speakers need to link to the work and the aims of the strategy. It was suggested that Tommy Mackay could repeat his recent Belfast presentation and speak about the difficulties in implementing the strategy in order to set the tone of the day. Charlene hoped that the final arrangements would be place soon. ASD Reference Group and sub-group members will be invited to the conference.

3.3 Sub-group 1 have been working on the recommendation 11 and links to support more able people with autism and Charlene had attended the Sub-group 6 meeting on 3 June where they were given a questionnaire regarding Best Value to complete to examine how good practice links to quality of life. The data is still being collated and it seems that awareness is a key issue. There is scope for a generic checklist/indicators to help people with autism and work is on-going on this. Work is also being done on producing an Adult Autism Toolkit which could be useful in employment and other situations.

Action Point 1: Any suggestions for speakers at the conference should be directed to Charlene.

Sub-group 2 – Ian Hood

3.4   Ian advised that Scott Read and James Fletcher from Autism Resource Centre (ARC) Scotland have been invited to attend the next ASD Reference Group meeting to speak about the 'Good Principles of Transitions' Report which will set the foundations for transitions. ARC will attend the next ASD Reference Group meetingon October 22 2013.

3.5   Sub-group 2 hosted an event around Self-directed Support (SDS) on 25 June and submitted comments on the current legislation and guidance to engage people with ASD on SDS.

3.6   The group have submitted comments on the NAS 'Count Us' In report in particular on the recommendations regarding advocacy and waiting times. Need to think about what can make a difference to people's lives. People with autism should have access to independent advocacy and SDS will give people more choice and control. A national campaign to raise awareness about autism is seen as desirable but advertising is expensive. People with autism want to feel included and want to be seen as equal partners as well as having access to advocacy, so there is a need to listen to what people want. Health and education leads also need to be engaged.

Sub-group 3 – Jane Neil-MacLachlan

3.7   Jane attended a meeting with Scottish Government, COSLA and ADSW regarding signing off the final version of the Menu of Interventions. The wording of the Menu was discussed in detail. There was also discussion around including learning disability and the learning disability strategy. This is not mentioned as do not want to be prescriptive but will add a resources section to keep the Menu general. There is a section for people with mild ASD. All local authorities will receive a copy of the Menu.

ADSW confirmed they were content with the rewrite of the Menu.

3.8   There was some discussion around the use of the word 'interventions' in the Menu. Jane explained that when this is mentioned 'if required' is included and mentions the word 'supports' along with it. There is also a paragraph explaining why the language is used. 'Supportive Intervention' or 'Supports' were suggested as an alternative.

3.9   It was raised that there is a reluctance to diagnose autism if the person has a learning disability, especially when they are older. There is a need to work with people within learning disability services to help them think differently but this may take time. This is very stressful for parents. ARC have been asked to get clarification from NHS Boards on this and to explain the model of how to deal with situations like this.

Action Point 2: Peter McCulloch has invited Jane Hook to write expressing her experiences and to follow up on this in Glasgow. Julie to send Peter's email address to Jane.

Action Point 3: Paul Lennon will invite Jane Hook to the next meeting of the subgroup.

Sub-group 4 – Richard Ibbotson

3.10   The sub-group have organised an employment event which will take place on 24 October 2013 and will involve employment projects receiving funding through the Autism Development Fund. The group are also pulling together a guide to

employment strategies in Scotland which so far has shown there is an issue with this. This will be a factual document which can be published on the strategy website.

Sub-group 6 – Kabie Brook

3.12   The sub-group discussed what Best Value means and gave feedback to Charlene. There is a need to find the right staff in services and this can be an issue. Many people with autism are not included locally.

3.13   The sub-group would like to change the remit of the group. They wish to do their own work then pass it on to the other sub-groups. Papers need to be sent more in advance. The next meeting will be in September.

Item 4 – Presentation from Sleep Scotland – Jane Ansell, Director, Sleep Scotland

4.1   Jane Ansell gave a presentation on the work of Sleep Scotland to the group. Sleep Scotland aims to improve the quality of life for families of children with additional support needs and who have sleep problems by providing the most appropriate intervention. They offer 2 services – Sleep Counselling and Teens+.

4.2   The Sleep Counselling Service is run by a network of multi-professional and multi-agency teams of professionals who are trained to deliver behavioural and cognitive techniques to manage sleep problems of children with additional support needs. It was discussed that there is a need to focus on natural processes including sleep, not just medication as many people with ASD do not know what sleep is. There is a need to look at the environment people are sleeping in before the behavioural aspect. Jane advised that emails are sent about training in sleep counselling regularly and the training is adapted to take into account the particular situation. The service is for young people up until they finish their education.

4.3   Teens+ is a full-time project which offers young people with complex support needs a new educational option when they leave school. The options are communication, literacy and number skills for everyday living, life skills, creative arts and fitness and healthy eating. The young people taking the course graduate after 4 years and have the option to attend the Life+ course which is for a further 10 years. There are 15 people taking part and the project could offer 25 places but would financial backing.

4.4   Jean advised the group that Sleep Scotland's application to the Autism Development Fund did not fully meet the criteria and due to the high volume of interest was not funded. She asked the group to consider the issue of sleep for people on the spectrum.

Action Point 4: Julie to send the Sleep Scotland presentation to ASD Reference Group.

Action Point 5: Sub-group 5 to look at the Sleep Scotland's work and consider the link to the Strategy and report back to the Reference Group.

<u>Item 5: Autism Alert Cards Report – Robert MacBean</u>

5.1   Robert advised that the report is a review of the impact of the alert cards so far and looks at the schemes available in Scotland. 1350 cards have been issued and there have been 80 responses about the cards from people who have taken them up. All the schemes connect with the training of emergency services.

5.2   The group discussed that professionals may treat people differently if they have a card which could be an issue and many people do not have the card as they are concerned about being on a database ('Big Brother'). The focus should be on awareness and it would be an idea to explore a generic awareness card to be used in tandem with the alert card. It was advised that Michael Matheson gave a commitment that the Reference Group would consider the national roll-out of the card.

Action Point 6: Sub-group 1 to take forward the findings from the report on the Autism Alert Cards, link to raising awareness and report back to the group.

<u>Item 6: Autism Network Scotland – Information Gathering, Branding and PR Discussion – Emma Hanley, Autism Network Scotland (ANS)</u>

6.1   Emma gave the group an overview of progress being made and this includes:

- Face-to-face networks are going well and use a solution-focused approach.
- There has been an event in the Borders around raising awareness.
- Virtual Networks has now been launched after some technical issues.
- Project SEARCH has been launched.
- ANS has been working with Liz Catterson on the mapping project to collect data then analyse.
- ANS have good partnership working with other organisations such as Remploy and Values into Action.
- Not everyone is aware of the Strategy so there is a need to start getting information out to people.

Local Authority learning event will take place in Glasgow 28 Aug. Will look at mapping exercise, as well as collaboration, capacity building and co-production.

ANS has the knowledge and expertise and is keen to disseminate information to the public. Can subgroups help ANS to get info out there? It was recognised that the group had a role to play in making public the information on the strategy and the work of the group and sub groups. The strategy website must be updated with relevant information.

Action point: Subgroup leaders to provide ANS with information to populate the strategy website and provide timely all minutes from sub group meetings to enable them to be published.

<u>Item 7: Update on Local Autism Plans</u>

7.1 Annette advised that the only autism Action Plan which has been submitted is from Orkney Islands Council. Many other local authorities are waiting on the results of the mapping exercise. Local authorities have until November 2013 to submit their plans and a reminder will be sent to them.

Action Point 7: Liz Catterson to send Bill Colley contact details for the Local Autism Plan in his area.

Action Point 8: Julie to send the letter sent to the local authorities to the group.

Item 8: 24-Hour Helpline

8.1 Annette advised that the idea of a 24-Hour Helpline for people with autism was suggested by Sub-group 6. It was discussed that whether there is a demand for a help-line or not and that it could be difficult to organise and maintain. There is a need to see what services already exist and build on that.

Action point 9: ANS and NAS to work together to explore this further

Item 9: NHS Board Responses to request for details of diagnostic services

9.1 Annette advised that there has been 6 responses for far and that larger areas are focusing on mainstream services. These responses have been sent to sub group 3 for analysis.

Action Point 10: Care and Support Branch to send reminder to NHS Boards who have not responded.

Item 10: Mapping Exercise – Report and Service Maps – Liz Catterson

10.1 Liz advised that the mapping projected aimed to gather an evidence base which would help to identify functioning and non-functioning pathways between services, details the range and scope of services and support that is available and provide information on what needs are being met and how.

10.2 Some of the key findings are as follows:

- Inclusion – people with autism and their carers are not being viewed as 'equal partners' in the planning and design of services for people with autism, lack of support to carers and families and need for more community and social opportunities.
- Training – inconsistent approaches to training with few training plans in place for professionals, practitioners and parents.
- Information/Data sharing – agencies collect and share information with a noticeable flow of information between individuals, people and parents, some professionals and practitioners and specialist Autism organisations.
- Transitions – positives and weaknesses in all major life transitions
- Services – demand for more employability/employment opportunities, social challenges in education and need for more respite and advocacy services.

- There is a lack of service responsibility for people with Asperger's.
- Lack of awareness of autism although the Autism Alert Cards were seen by many as being a positive.

The next meeting will be on Tuesday 22 October 2013, 10:00-14:00, Room 4ER, St Andrew's House.