

**ASD Reference Group Meeting**  
**Thursday 18 April 2013**  
**10:00 – 15:00**  
**Conference Rooms C/D/E, 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                       |
| Liz Catterson             | Autism Mapping Scotland   |
| Julie Crawford            | Scottish Government, Adult Care and Support (Minute)              |
| Anne Marie Gallagher      | Adult Autism Services, NHS Greater Glasgow & Clyde                |
| Ian Hood                  | Learning Disability Alliance Scotland                             |
| Jane Hook                 | 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 Fife   |
| Tommy Mackay (Dr)         | Psychology Consultancy Services                                   |
| Jane Neil-MacLachlan (Dr) | NHS Lothian   |
| Jean Maclellan (OBE)      | Scottish Government, Adult Care and Support (Chair)               |
| Denise Martin             | Fife Council Psychological Service (attending with Carolyn Brown) |
| Iain McClure (Dr)         | Consultant Child & Adolescent Psychiatrist, NHS Lothian           |
| Laura Meikle              | Scottish Government, Support & Wellbeing Unit                     |
| Bernhard Menzinger        | Camphill Scotland   |
| Helen Morgan              | ADSW (in place of Peter McCulloch)                                |
| Annette Pyle              | Scottish Government, Adult Care and Support                       |
| Alan Somerville           | Scottish Autism   |

**Apologies:**

|                           |   |
|---------------------------|---|
| Bill Colley               | Association of Directors of Education in Scotland |
| Linda Connelly            | Care Inspectorate                                 |
| Aline-Wendy Dunlop (Prof) | University of Strathclyde                         |
| Peter McCulloch           | ADSW  |
| Andrew Stanfield          | Patrick Wild Centre for Research into Autism      |
| Charlene Tait             | Scottish Autism                                   |
| David Watt                | Education Scotland                                |

Item 1: Welcome, Introductions and Apologies

1.1 Annette welcomed everyone to the group and introduced Denise Martin, attending with Carolyn Brown and Helen Morgan who was attending in place of Peter McCulloch. She advised that Jean would be joining the meeting later. Jane Neil-MacLachlan advised that Dr Andrew Stanfield had to give his apologies.

## Item 2: Minute and Action Points from the meeting held on 12 February 2013

2.1 The minute was agreed apart from Paragraph 3.9 where it was advised that 'and regarding the whole group of people with autism without a learning disability or mental health diagnosis' should be removed.

2.2 All action points were cleared with the exception of the following:

AP 1 – Charlene gave apologies for meeting so unable to update on this.

AP 4 – Training Working Group met on 10 April 2013 and will be taking this work forward. Anne Marie Gallagher will present on DISCO.

AP 5 – The survey of the Alert Cards is now live and at the time of the meeting had been running for a couple of weeks. Robert MacBean is collating information on the structure of each scheme, who is running it, whether any advertising/training has been done and who is accessing it. The information will be written up by May 2013.

AP 7 – Aline-Wendy gave apologies so unable to update on this.

**Action Point 1: Autism Alert Cards to be on next meeting agenda.**

## Item 3: ASD Reference Group Sub-groups update

### Sub-group 1 – Charlene Tait

3.1 Charlene gave apologies so no update was given. Annette advised about the request for papers circulated to the group for the Scottish edition of the GAP journal. She encouraged people to submit articles and advised that although the issue may have a maximum number of pages there is no strict limit for the length of articles. There will be an event in November 2013 following on from the document being published.

### Sub-group 2 – Ian Hood

3.2 Ian advised that the Sub-group are involved in the Scottish Transitions Forum which is run by ARC Scotland which brings carers and professionals together. They are working on a paper Agenda for Change which will provide recommendations for change over 2 years for transitions from children's to adult services. This will be a practical guide to meet the recommendation. Once the report is finalised, it will be circulated to the group. It was discussed that psychological transfer should be included and how the transition affects the parent/carer. There is a need for a smooth transfer of information during the transition and how the journey is managed can be difficult. The report identifies 9 challenges.

3.3 The group have also discussed the launch of the new Self-directed Support Bill guidance and the involvement of people with autism in this. The group are organising a morning workshops towards the end of June 2013. Invites will be sent to the Reference Group and Sub-groups. There will be places for 50 people and the Self-directed Support team will be invited to speak at the workshop.

**Action Point 2: Care and Support Branch to circulate earlier version of the Agenda for Change report to group.**

**Action Point 3: Care and Support Branch to send ASD Reference Group link to the Self-directed Support consultation.**

Sub-group 3 – Jane Neil-MacLachlan

4.1 Jane advised that she has received consultation responses for the menu of interventions in different formats which have been a challenge to collate. There have been capacity and consent issues which will need to be discussed and added to the menu. She advised that there has been positive feedback and alterations to the menu were made at the last meeting. The menu will be published on the website and hard copies will also be available. NAS are to comment on the menu and will meet separately to discuss this as work is being developed within the One Stop Shops which is linked to the menu. COSLA need to endorse the menu as it will add authenticity to it as they have endorsed the Strategy. There have been no comments from COSLA at this time.

4.2 There is an issues with diagnosis for those who have autism and do not have a learning disability or mental health issue. There will be a report which will be circulated by the end of the month. A letter has been sent to the Royal Colleges for comments on eCPD and this is on the SIGN website also.

**Action Point 4: Annette to give COSLA the final version of the Menu of Interventions for final comments and to speak to Beth Hall/Ron Culley from COSLA about endorsement from them.**

**Action Point 5: Care and Support Branch to circulate link to eCPD and arrange for it to be added to the Strategy website.**

Sub-group 4 – Richard Ibbotson

5.1 Richard advised that the group are planning an event in September/October 2013 targeting employment projects funded through the Autism Development Fund. A representative from Values into Action attended the last sub-group meeting. Richard also advised that general public employer awareness of autism is a key issue.

**Action Point 6: Julie to send Richard a list of contacts for the projects receiving fund through the Autism Development Fund in the 2<sup>nd</sup> round.**

Sub-group 5 – Ken Aitken

6.1 Ken advised that at a previous Reference Group meeting there were concerns expressed regarding the Matrix. There has been a meeting with NES and amendments were agreed.

6.2 The sub-group have had a discussion about the recommendations and want to go out and ask people what research is needed. There is a need for a review of what is clinically available for people with autism.

6.3 SIGN are updating their guidelines starting in the Autumn. Iain McClure will be chairing this group and the process may take 2-3 years.

#### Sub-group 6 – Kirsty Butts

7.1 Kirsty advised that the group discussed employment at the last meeting and that Charlene and Richard will be presenting at the next meeting on 3 June 2013.

**Action Point 7: Sub-group leaders to feedback agenda items to be discussed at future Sub-group 6 meetings to Julie.**

#### Item 4: Statistics on Education Support Needs – Report to Parliament (Laura Meikle – Support and Wellbeing Unit, Scottish Government)

8.1 Laura advised that 18% of children/young people have additional support needs in schools which is a 2% increase on last year. More data about children is being collected and the quality of information is developing to build a better picture of people with additional support needs in Scotland. There is no specific collection of data – the information is drawn from other sources. There will be a meeting with COSLA to negotiate getting data on a collection basis.

8.2 There are concerns for children with severe autism and learning disabilities after they are 16-years old as adult services do not start until 18-years old. This issue is being looked at as well as the cost. The report to parliament looks at leaver destinations and qualifications and employment data which is fed into groups to see who is getting services and who are not.

8.3 Local authorities should be collecting data on people with additional support needs as in Recommendation 1. This is happening although data varies across Scotland and can depend on geographical area/size. The methodology used by the local authority to collect data is questioned if the data is questionable – the data is not just accepted as being a clear picture of that area. There is a need to make it clear that the data collected is not the final picture of people with additional support needs in Scotland.

#### Item 5: Update on the Autism Toolkit Website (Moira Park/Jim Taylor – Scottish Autism)

9.1 Moira advised that many people are not aware that the Autism Toolbox is available in schools so wanted to put it in an accessible format for everyone to access. A website is to be produced to supplement the existing Autism Toolbox resource to aid and support mainstream teachers who have pupils with autism. The website is to be user friendly and easily interpreted by teachers and relevant to all age groups.

9.2 Progress on the website at the time of the meeting was there has been an on-going consultation and collation of information for the content. Video dates are scheduled in June and the pilot should be running from August. The website will be continually updated until the end of the year. The website will be launched on 25/26 September at the Scottish Learning Festival at the SECC.

9.3 Local authorities need to be behind the Toolbox to ensure accountability and because it is being funded through the Scottish Strategy for Autism, we need to make sure that it is being used in schools.

**Action Point 8: Group to send any comments about the website to Moira for anything to be added to it.**

**Action Point 9: Laura Meikle to send Moira/Jim work that has been done on resources in relation to people with additional support needs.**

Item 6: Presentation from Autism Treatment Trust (ATT) (Hamish Mair – Autism Treatment Trust)

10.1 Hamish Mair from ATT spoke to the group about the paper *Medical Co-morbidities in Autism Spectrum Disorders* which has been written by ATT and Treating Autism. Hamish raised the point that ATT do not believe that no interventions can help in the treatment of autism although they do not claim to be able to find a cure for autism. The paper makes the point that autism can come with other medical issues and the purpose of the paper is to make health professionals and policy makers aware of this. Medical issues are often not recognised, are in advance stages or are difficult to treat which can be fatal. Many with autism are unable to articulate how they feel. Dietary changes can make a difference to people with autism.

10.2 The group were given the opportunity to comment on the paper and Ken led the discussion. The following points were raised:

- We cannot rely on single case studies for substantive evidence.
- There is no data to suggest gastric issues are substantial in people with autism.
- The document does not name the authors.
- The supporting documents do not give sufficient evidence which could be misleading.

10.3 In conclusion the group agreed it could not endorse the ATT publication due to the reasons above. The group came to this conclusion based on the lack of evidence and that authors were not named in the document.

**Action Point 10: Hamish Mair to send author details in relation to the document to Care and Support Branch.**

**Action Point 11: Hamish Mair to give feedback on the comments raised about the document to Annette.**

Item 7: NHS Education Scotland (NES) Autism-specific Training Materials for the NHS in Scotland (Geraldine Bienkowski – NES)

11.1 Geraldine advised that training implications arising from the Scottish Strategy for Autism were discussed at meeting with NES, Scottish Government and members

of the ASD Reference Group on 18 October 2012. While there are a number of high quality teaching and training resources available, it was discussed that a more strategic approach, which would include a training needs analysis, identify gaps in training provision and help match training to service role would be good. The *Promoting Excellence Knowledge and Skills Framework for People with Dementia and their Families and Carers* was highlighted as an example of a clear service-based approach to developing appropriate competences in the workforce and community.

11.2 Marie-Claire Shankland from NES attended the meeting of the ASD Training Working Group on 22 January 2013 to present an outline proposal for the development of an ASD knowledge and skills framework where a number of suggestions around costs and timescales were given. The ASD Reference Group were asked to consider the revised proposal comprising 2 options.

Item 8: Follow-up discussion and collective decision on levels of training

12.1 The groups discussed that it would be useful to have a representative from NES to be a member of Sub-group 6. Ken advised that Mike Rutter and Francesca Happe should be invited to a future ASD Reference Group meeting to discuss DSM-5 and ICD-11 as this could influence training. The group agreed that Option 2 of the proposal should be taken forward but with a view to extending the project beyond 9 months.

**Action Point 12: Ken to arrange with Annette for Mike Rutter and Francesca Happe to come to a future ASD Reference Group meeting to talk about DSM-5 and ICD-11.**

Item 9: AOB

13.1 Stella Macdonald advised that her post within Fife Council/NHS Fife will end on 28 June 2013.

**The next meeting will take place on Thursday 22 August 2013, 10:00 – 14:00, Conference Rooms C/D/E, St Andrew's House, Edinburgh.**