**ASD Reference Group Meeting**

**23 June 2011, 10am - 1pm**

**Scottish Government, Victoria Quay, Edinburgh**

**MINUTES**

**Present**

Dr Ken Aitken Ken Aitken Consultancy

Carolyn Brown Fife Council Psychological Service

Linda Connolly Social Care and Social Work Improvement Scotland (SCSWIS)

Prof. Aline-Wendy Dunlop University of Strathclyde

Ryan Gunn (Chair) Scottish Government - Adult Care and Support

Kirsten Hogg Camphill Scotland

Ian Hood Learning Disability Alliance Scotland

Richard Ibbotson Autism Initiatives

Idem Lewis Learning Disability Alliance Scotland

Robert Moffat The National Autistic Society Scotland

Stella MacDonald Fife Council/ NHS Fife

Robert MacBean The National Autistic Society Scotland

Dr Iain McClure NHS Lothian

Peter McCulloch Association of Directors of Social Work

Dr Tommy McKay Psychology Consultancy Services

Dr Jane Neil-MacLachlan NHS Lothian

Annette Pyle (Minutes) Scottish Government - Adult Care and Support

Charlene Tait Scottish Autism

Nigel Rooke Autism Resource Centre, Glasgow

Alan Somerville Scottish Autism

Dr Andrew Stanfield Patrick Wild Centre for Research into Autism

**Apologies**

Kirsty Butts Scottish Government - Adult Care and Support

Bill Colley Association of Directors of Education in Scotland

Ron Culley COSLA

Caroline Hamilton Number 6 User

Jane Hook The Scottish Society for Autism and Parent

Alison Leask Autism Argyll & Parent

Jean Maclellan Scottish Government - Adult Care and Support

Val Sellars Scottish Centre for Autism

David Thompson Scottish Government - Support for Learning

David Watt HMIE

## Item 1: Welcome, Introduction and Apologies

1.1 Ryan Gunn welcomed the members to the group and read out the apologies.

## Item 2: Minute of the last meeting held on 28 March 2011

2.1 Minutes agreed and action points discussed.

## Item 3: Protocol for ASD research- Presentation - Ken Aitken

3.1 Ken Aitken gave a presentation on his paper and draft Research Protocol. Ken stated that by adopting a joined up approach to funding research we can ensure that:

· research is targeted to relevant questions

· findings have the potential to alter practice

· results have the potential to alter practice

· cost saving implications are clear

3.2 Ken then explained that we needed to ensure that we had an efficient audit loop for Government funded research as there is currently no mechanism in place. He stated that the American OIG approach this would allow us to detail the financial impact of implementing and failing to implement recommendations. The members discussed Ken's presentation, which was well received, and the wider issues around research. The members agreed that the research protocol had to capture the accessibility of the research outcomes and how the research outcomes could be translated into practice. The members concluded that the ASD reference group's first priority was to produce a protocol for research the ASD reference group was commissioning not to take on a national process for auditing Autism research. Ken was asked to revise the draft protocol document to take this into consideration.

## Action Point 1

Ken Aitken to redraft the protocol for ASD research purposes and for it to be discussed agenda item for approval at the next ASD Reference Group meeting on 19 July.

## Item 4: Autism Classification and Reference Assessments Brief - Alan Somerville

4.1 Alan Somerville presented his paper stressing that the aim of the classification modelling project was to analyse the autism population with respect to their potential for improved quality of life, not for use as a diagnostic or assessment tool. He stated that in terms of the autism spectrum the complexity of different levels of care and the cost of delivering appropriate interventions makes it difficult to determine the required resources. He added that this mapping project would identify the escapable costs of autism to Scotland. The project would build on Professor Knapp's research and determine autism-specific care, providing evidence for decision making throughout the lifetime of the Strategy. Alan then listed the individual element of the project, these were as follows:

- mapping autism-space and measuring populations
- identifying life trajectories
- Identifying a list of interventions
- Identifying quality of life indicators
- Assessing the efficacy of indicators against the quality of life
- Assessing notional costs to Scotland

4.2 The members agreed that this was a major piece of work which would take up to 2 years to complete but agreed the outcomes would inform the decision making on how the 5 year and 10 year goals will be implemented. The members agreed that a multi-agency approaches to future services, a framework for delivery and what best practice would look like for delivering interventions would help in the delivery of the strategic goals. The members agreed to the undertaking of the project in principle but required more detail and for this to be discussed further at the next meeting.

**Action Point 2**

Dr Tommy McKay to provide a more detailed discussion paper on the proposed Autism Classification and reference assessment project brief for discussion at the next ASD reference group meeting on 19 July.

**Item 5: Scottish Autism Assessment Survey - Presentation - Dr Iain McClure**

5.1 Dr Iain McClure gave a presentation on the Scottish Autism Assessment Survey to be undertaken by the Scottish Autism Spectrum Disorders Research Coalition as commissioned by the Scottish Government to address Recommendation 10 which calls for an assessment of national waiting lists to clarify the extent of delays. Iain explained that by undertaking this research to identify how big the waiting list problem was but to expand beyond this remit at an additional cost would establish the nature of the waiting list and why the assessments are being delayed. Ian explained the cost implications for answering recommendation 10, which would consist of a mailed survey followed up by onsite visits to extract data. He explained that early scoping has identified 91 children's services and 20 adult services and added that a 12 month timescale would deliver an answer to the waiting list for children's services. He detailed the timetable of action over the 12 months to complete the work.

5.2 Iain explained that a broader strategy would create data to underpin five recommendations and critically provide clarity for decision making to address the problem.

5.3 The presentation was discussed by the members and prompted questions about the breakdown of the £250,000 cost. Iain advised that this was the cost of the resources required to undertake the research namely the cost of recruiting 2 full time researchers and the cost of travel and subsistence to visit the services to extract the data. The members asked for a fuller breakdown of the project costs.

5.4 The members asked Iain to explain why the adult waiting list could not be included in the first phase of the survey as the full waiting list picture would be needed within the 12 months timescale in order to deliver the goals. The members agreed that the adult picture was essential to ensure that the Local Authorities could plan the resources required to provide the services to meet the needs of both children and adults with ASD.

**Action Point 3**

Dr Iain McClure to provide a detailed cost breakdown for the ASD survey on waiting lists and for this to be discussed further at the next ASD Reference Group meeting on 19 July.

**Item 6: Update from ASD Writing Group - 9 June 2011**

6.1 Ryan Gunn explained that the Writing Group had met on the 9 June to consider the comments on the draft strategy from the ASD Reference Group. He added that the current version was progressing towards the final document and that the group planned to meet again on 6 July 2011.

6.2 The members discussed the current version and some expressed concern over the size of the document and the impact this would have on the reader. The members expressed that the bulk of the document was background and that the strategy would have greater impact if the published hard copy strategy was kept to chapter 1 and the background chapters published online. This was strongly endorsed by the members and they agreed that this would result in a more positive response from the public.

6.3 Dr Iain McClure asked about Recommendation 9 in which the Royal College of Physicians and Surgeons disseminate ASD materials in e-CPD format. He stated that he didn't think the College would agree to that. The members discussed this and possible options and agreed for the Recommendation to be amended, slightly to ensure compliance.

6.4 Ryan stated that the members needed to aim for a deadline in publication and following a discussion agreed that publication by the autumn was achievable. Members agreed in principle with all changes made to the strategy and were asked to provide final comments on the strategy to be fed back to Annette Pyle for discussion at the next writing group. It was agreed that the writing group would review recommendation to ensure accuracy before publication.

**Action Point 4**

Further comments from ASD Reference Group members on the latest version of the Autism Strategy to be fed back to [annette.pyle@scotland.gsi.gov.uk](mailto:annette.pyle@scotland.gsi.gov.uk)

for discussion at the next ASD Writing Group on 6 July.

**Item 7: Update from Sub -group meeting - 17 June 2011**

7.1 Charlene Tait stated that at the last meeting action point 6 called for a representative from each sub-group to discuss and produce a proposal for multi-disciplinary sub groups to take forward the strategy goals. She added that the sub group proposal paper for discussion was an accurate reflection of the meeting outcome. Charlene talked through the paper with the members and a discussion followed. The members agreed in principle to the proposal. The members also agreed to nominate themselves onto appropriate sub groups and consider suitable additional representatives based on the gaps identified in the paper and those individuals and organisations who have expressed an interest to be involved in the work of the ASD Reference Group.

7.2 Stella MacDonald spoke to the members about the second agenda 7 paper which she had produced along with Robert MacBean. She explained that the paper explored the strategy framework so far agreed by the ASD Reference Group and identified the need to map the work of external groups to avoid duplication of work. It was agreed that each subgroup would consider these points when agreeing their action plans.

**Action Point 5**

ASD Reference group members to nominate themselves onto Sub-groups based on Agenda Item 7 Sub-group proposal paper

**Action Point 6**

ASD Reference Group members to nominate suitable representatives for the sub group based on the Agenda Item 7 Sub-group proposal paper, providing a short description of their skills and experience which makes them suitable.

**Action Point 7**

Annette Pyle to draw up a list of those who have contacted the Adult Care and Support team and shown an interest in becoming members of the ASD Reference Group.

**Item 8: AOB**

8.1 Dr Iain McClure discussed with the members his invitation to represent the ASD Reference Group on the Expert Advisory Group. He stated that he will contribute to the Advanced Interventions Service (AIS) survey process, from the perspective of how people with autism spectrum disorder (in particular unidentified/identified ASD assessment needs) can be best supported if they present to the AIS. Ryan supports this and it was agreed.

8.2 Tommy McKay and Dr Iain McClure stated that they had submitted proposal papers to Jean MacLellan for consideration and had not yet heard the outcome. Annette Pyle agreed to look into this.

**Action Point 8**

Annette Pyle to check back past papers regarding the outcome of 23 February 2011 meeting and Tommy McKay's proposal.

**Action Point 9**

Annette Pyle to check back past papers regarding the outcome of Dr Iain McClure proposal sent to Jean Maclellan for consideration.

8.3 Nigel Rooke asked what the remit was for the funding priorities. Ryan agreed to produce a paper for circulation.

**Action Point 10**

Ryan Gunn to produce a paper which details the autism funding and priorities .

8.4 Dr Iain McClure stated that it was important to ensure that commissioned research did not overlap and it was agreed that a mapping exercise would be undertaken.

**Action Point 11**

Annette Pyle to map the proposed research proposals and link to the recommendations to identify any possible overlap.