

## **ASD Reference Group Meeting**

**19 May 2011, 10am - 1pm**

**Scottish Government, Victoria Quay, Edinburgh**

### **MINUTES**

#### **Present**

Dr Ken Aitken Action against Autism

Carolyn Brown Fife Council Psychological Service

Kirsty Butts Scottish Government - Adult Care and Support

Bill Colley Association of Directors of Education in Scotland

Bette Francis Scottish Government - Adult Care and Support

Ryan Gunn Scottish Government - Adult Care and Support

Nadia Hanif (Minutes) Scottish Government - Adult Care and Support

Kirsten Hogg Camphill Scotland

Ian Hood Learning Disability Alliance Scotland

Alison Leask Autism Argyll & Parent

Idem Lewis Learning Disability Alliance Scotland

Robert MacBean (in replace of Robert Moffat) The National Autistic Society Scotland

Stella MacDonald Fife Council/ NHS Fife

Peter McCulloch Association of Directors of Social Work

Jane Neil-MacLachlan NHS Lothian

Annette Pyle Scottish Government - Adult Care and Support

Val Sellars Scottish Centre for Autism

Alan Somerville Scottish Autism

Charlene Tait Scottish Autism

David Thompson Scottish Government - Support for Learning

## **Apologies**

Linda Connolly Social Work Inspection Agency

Ron Culley COSLA

Prof. Aline-Wendy Dunlop University of Strathclyde

Caroline Hamilton Number 6 User

Jane Hook Parent

Richard Ibbotson Autism Initiatives

Jean Maclellan Scottish Government - Adult Care and Support

Dr Tommy McKay Psychology Consultancy Services

Nigel Rooke Autism Resource Centre, Glasgow

Dr Andrew Stanfield Patrick Wild Centre for Research into Autism

David Watt HMIE

## **Item 1: Welcome, Introduction and Apologies**

1.1 Ryan Gunn welcomed Annette Pyle who is a new member of the Care and Support Team at the Scottish Government.

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

2.1 The minutes was accepted and agreed by the members of the ASD Reference Group.

## **Item 3: Self- Directed Support - Presentation, Bette Francis**

3.1 Bette Francis gave a presentation on the self-directed support policy and legislative developments and the relevance to people with ASD. SDS is the support individuals and families have after making informed choice on how their individual budget is used to meet the outcomes they have agreed. It is relevant to all ages and can support people to live independently through accessing employment and training. Presentation attached.

3.2 The strategy is about a cultural shift in the delivery of care and support that views people as consumers of services as opposed to service users, as equal citizens with rights and responsibilities. The strategy which commenced in November 2010 provides a 10 year framework for change in the way services are provided and improving the availability of self-directed support.

3.3 Implementation of the SDS strategy will take account of general and specialised information and training needs and will aim to target groups that are currently under-represented in the provision of direct payments. There are some issues with regards to the workforce sub-group. Some of the workforces are not all working for providers and may not be regulated service in delivering the outcomes. Moreover, there are no plans to regulate workforce and so we need to ensure carers have pathways.

3.4 The SDS Bill aims to consolidate current law on direct payments into one Act; to set a framework for self-directed support which incorporates direct payments and; to extend eligibility to various groups and circumstances that are currently excluded. Children and adults with autism are currently eligible for direct payments, unless subject to exclusions on specific grounds (such as the current restriction on those who lack capacity to consent.). There has been a consultation on the Bill and we hope it will be introduced to Parliament in autumn.

3.5 There were some questions after the presentation. Idem Lewis asked about the eligibility criteria for SDS and what will happen in Glasgow if the Bill went through. It was suggested that the issue of the eligibility criteria will be looked at in August for implementation and if the Bill does not work then the council have the right to say other options. Peter McCulloch then asked if there is anything on independent appeals. Bette Francis stated that there is no provision in the Bill for an appeal system as it will create tribunals etc. Robert MacBean then went onto to discuss the assessment process and suggested that it should be carried out by someone who knows and understands ASD. Moreover, if people have the right support, then they may become more independent and require less financial support.

#### **Item 4: Funding for research in remits - Val Sellars**

4.1 Val Sellars wanted to clarify the role in commissioning and monitoring the Scottish ASD Assessment Survey (SAAS) in relation to the ASD Reference Group and recommendation 10 that currently sits in the remit of the Diagnosis, Assessment & Intervention sub-group. The SAAS project has been commissioned to address this recommendation but in general terms it is unclear where the remit for commissioning research lies.

4.2 Ryan Gunn clarified that he was sitting in the group between ASD Reference Group and the SAAS project. Val Sellars stated that they hadn't looked at how the research was put together and there was no protocol for the project. Ryan Gunn stated that the protocol for the project has not been finalised and once a draft version has been made,

it will be brought to the ASD Reference Group. The project was set up as there was an urgent demand in finding out the number of people waiting for diagnosis.

4.3 The group as a whole felt that there needs to be more transparency about the research that is being carried on the ASD. Ryan Gunn confirmed that members of the SAAS project are to report to the ASD Reference Group and not the Diagnosis, Assessment & Intervention sub-group.

4.4 Charlene Tait stated that needs to be an overview on the research carried on Autism. For example, where does the research fit in the strategy and how long it will take? A research proposal should link in with the strategy, help outcomes of the strategy and look at allocating resources linked to aspiration and outcomes.

### **Action Point 1**

Ken Aitken is to draft up a protocol for agreement on ASD research and bring it back to the next ASD Reference Group meeting in June.

### **Item 8: Update from the Writing Group**

8.1 Alan Somerville discussed the development of the latest Autism Strategy. In the first ASD Writing Group meeting, the paper presented from Alan Somerville from the last ASD Reference Group meeting was put in as Chapter 4 in the strategy. Robert Moffat had collected the recommendations and the overarching principles and later the key messages underlined were added to that paper, such as quality of life and equal opportunity to employment. Then goals, objectives and principles were developed. At the end of the first ASD Writing Group meeting, the members decided to revamp Chapter 1 and call it 'Vision Values & Principles', renamed Chapter 2 as 'Review of Previous Initiatives' which looked at the context and what needs to change, called Chapter 3 as 'The Strategic Context' and added on a 4th Chapter 'The Scottish Strategy for ASD' which was based on the paper.

8.2 In the second ASD Writing Group meeting, the group decided to change the layout of the strategy and move Chapter 4 to a new Chapter 1. The strategy and all the other contexts were moved to Chapter 2 and 3. There is also a new version of Chapter 3 which introduces all of the recommendations. The text leads to each recommendation and then the complete list of recommendations will appear at the end. The decision to move Chapter 4 to Chapter 1 was to illustrate upfront what the visions and values are of the strategy and also when and what they are. It was to put the message across and make explicit aspirational and long-term commitment of the strategy. The ASD Reference Group agreed with the changes made to the strategy and the structure of the strategy, however they would like to make comments on it before it is finalised.

8.3 The ASD Reference Group agreed that the sub-groups should be based on the goals and not the themes. However within these goals, the themes will be selected. The working group would e.g come up with research and develop how it can be measured.

This would involve professionals where they can look at the timescale and how to measure the goals. It was suggested that the goals would look at what resources were available and how it can worked with those resources. The deliveries would be signed off by the group. On the other hand, Stella MacDonald thinks that these goals might be too broad and we may not be able to identify the themes.

8.4 Charlene suggested that the group should get the strategy agreed and then get the program work agreed which will then link to the goals and how we can measure it. Comments from the ASD Reference Group should be made with specific page number and paragraph.

### **Action Point 2**

Ryan Gunn to feed back to Jean Maclellan about the changes to date in the Autism Strategy and the restructuring of the sub-groups from single to multi-disciplinary groups, focussing on fulfilling the goals of the strategy.

### **Action Point 3**

Members of the ASD Reference Group to e-mail Nadia Hanif ([Nadia.Hanif@scotland.gsi.gov.uk](mailto:Nadia.Hanif@scotland.gsi.gov.uk)) with any comments on the latest version of the strategy, stating specific page numbers and paragraphs. The deadline for any comments is Friday 27th April.

### **Action Point 4**

Comments from ASD Reference Group members on the latest version of the Autism Strategy to be fed back to the members of the ASD Writing Group.

### **Action Point 5**

ASD Writing Group is to set up a meeting, look at the comments from the members of the ASD Reference Group and finalise the strategy.

### **Item 6: Update on the remits and the work of the Sub-groups**

6.1 There were some discussions about the sub-groups being created and based on the goals of the strategy rather than on themes. It was suggested that a member from each of the current sub-groups could meet together and discuss and set up a work plan, looking at which of the recommendations link with the goals and what skills maybe required for carrying the recommendations.

### **Action Point 6**

Val Sellars, Jane Neil-MacLachlan, Charlene Tait, Alison Leask, Kirsty Hogg and a member from the Scottish Government Autism Team to meet on 17 June, as initial pilot

multi-disciplinary group representing the four previous sub-groups and create a work plan which considers which of the recommendations link with the goals and what skills are required for implementing them.

### **Item 5: Representation from National Research Coordination Committee- Presentation, Ken Aitken**

5.1 Ken Aitken talked about having representation from the National Research Coordination Committee. Please see attached presentation slides.

5.2 The National Research Coordination Committee have knowledge of the work we are doing which may be important to other groups and vice versa. Ken has suggested that we have active links with the other National groups and centres developing research so we don't run parallel studies that could be more cheaply and efficiently form part of a UK and Eire-wide strategy (the National Irish Centre for Autism Research is joint NI and Eire funded), and we should have an active role in this process.

5.3 Ken Aitken suggested inviting Francesca Happé to the ASD Reference Group where she will talk about the implication of SM5 and what the criteria's are.

5.4 Val Sellers was concerned about the term Aspergers disappearing from text. Having the term has allowed families to understand what it means. However Alison Leak thought that having a term for Aspergers could be a barrier to services. Robert MacBean felt that there were a number issues with the term. Firstly, the draft strategy includes ASD plus Aspergers syndrome. If the term Aspergers syndrome will disappear then this should be taken out from the strategy. There also needs to be more on support mechanisms and the strategy should give more guidance to health departments.

### **Action Point 7**

Ken Aitken to invite Francesca Happé, Professor of Psychology, to an ASD Reference Group meeting to talk about ASD research and speak about the implications of DSMV for Autism.

### **Action Point 8**

Ryan Gunn and Ken Aitken to contact the DoH with regard to ASD research.

### **Item 7: Potential new members for the ASD Reference Group**

7.1 The division has received a number of notes of interests to join the ASD Reference Group. Ryan Gunn explained that there were two issues with regards to the membership of the ASD Reference Group. Firstly the is already big and includes Scottish Government members and managing a big group would be difficult, for instant arranging dates for the meetings. Secondly, there needs to be more consideration on

the note of interest from users as ASD Reference Group requires more members who are users.

7.2 Alan Somerville suggested that the group could get more new members involved in the working group however, the working group would make that decision. Ian Hood suggested that there needs to be more people from the spectrum or carers. The ASD Reference Group should not be about skill set and should make sure that it is not self selecting. It should represent the wider community in Scotland. Robert MacBean talked about how members who are on the spectrum could participate in the group and professionals in the group would contribute. However, a participating strategy has not been set up. Robert MacBean agreed with Alan Somerville that new members could be suggested to be involved in the sub-groups as the Reference Group should represent people from broader sectors. Peter McCulloch suggested that the group should decide what spread of membership it is looking for and look at the remit and the role in the strategy.

### **Action Point 9**

The Autism Team at the Scottish Government will re-circulate the remit for the ASD Reference Group.

### **Action Point 10**

Scottish Government 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.

### **Action Point 11**

Kirsty Butts to provide a summary analysis of details submitted by group members regarding their qualifications, work experience, strengths and skills, once all members have submitted these details.

### **Item 9: AOB**

9.1 David Thompson talked about the Autism Toolbox. The ASD Toolbox is currently being refreshed and he would like suggestions as to how ASD Reference Group could help in improving the education outcome for the ASD Toolbox. David Thompson has had meetings about how the Toolbox could be improved and how they can best do it.

9.2 Kirsty Butts has received a correspondence with regards to ASD and what is being done to help people with ASD and the impact the strategy will have. Alan Somerville suggested that the Strategy will impact Education, Social Work and Health care professionals across all disciplines. Idem Lewis suggested that more research is required on ASD, such as looking what caused ASD. Ryan Gunn reinforced that the group had a budget of £10 million for the next 3 financial year. Robert MacBean

suggested that in the financial climate, the health and social care strategy should identify resources that we do have are used best for best outcomes and at best value.