

ASD Reference Group Meeting

28 March 2011 (10:00 - 14:00)

COSLA, Verity House (19 Haymarket Yards), 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

Linda Connolly Social Work Inspection Agency

Kirsten Gooday Camphill Scotland

Ryan Gunn Scottish Government - Adult Care and Support

Caroline Hamilton Number 6 User

Nadia Hanif Scottish Government - Adult Care and Support

Jane Hook Parent

Richard Ibbotson Autism Initiatives

Alison Leask Chair, Autism Argyll & Parent

Idem Lewis Learning Disability Alliance Scotland

Jean Maclellan (Chair) Scottish Government - Adult Care & Support

Dr Tommy Mackay Psychology Consultancy Services

Dr Robert Moffat The National Autistic Society Scotland

Andrew Morrison COSLA

Jane Neil-MacLachlan NHS Lothian

Nigel Rooke Autism Resource Centre, Glasgow

Alan Somerville Scottish Autism

Dr Andrew Stanfield Patrick Wild Centre for Research into Autism

Charlene Tait Scottish Autism

Apologies

Jane Cantrell NHS Education for Scotland (NES)

Prof. Aline-Wendy Dunlop University of Strathclyde

Ian Hood Learning Disability Alliance Scotland

Stella MacDonald Fife Council / NHS Fife

Dr Iain McClure NHS Lothian

Peter McCulloch Association of Directors of Social Work

Val Sellars Scottish Centre for Autism

David Thompson Scottish Government - Support for Learning

David Watt HMIE

Item 1: Welcome, Introduction and Apologies

1.1 Jean Maclellan welcomed new member, Caroline Hamilton.

Item 2: Minute of the last meeting held on 22 February 2011

2.1 The Minute was adopted, pending several amendments:

Action Point 1

Richard Ibbotson to be marked as present.

Action Point 2

Item 3: Update from the Sub-groups. Andy Morrison to send a modification concerning the role of COSLA and their commitment to improving outcomes for people affected by autism.

Action Point 3

Item 5: Role of the National Autistic Society (NAS) - Overview, Dr Robert Moffat.

Dr Moffat to submit text for last paragraph.

Item 3: Sleep and ASD - Presentation, Dr Kenneth Aitken

3.1 Dr Aitken delivered a presentation to members on the sleep problems experienced by people with ASD and commented that very little had to date been written on this subject.

3.2 There was general agreement about the need to include the issue of Sleep problems and their link to ASD in the final Autism Strategy, as one component of a menu of early interventions and support for families, so that people with ASD acquire these skills at an early stage. Scottish Autism advisors work closely with those in Sleep Scotland but people need to learn to manage their own sleep difficulties. 'Capacity building in families' involves understanding the various issues, including sleep problems and looking at the resources needed to address these issues. The effect of sleep problems on adults and how this affects their lives should not be underestimated.

Action Point 4

The ASD Writing Group to write a few sentences, summarising these early interventions, also in relation to adults and incorporate within the Strategy.

Item 4: Proposed Road Map for the Strategy - Alan Somerville

4.1 In formulating a Strategy, Alan Somerville proposed the following stages:

- 1. Establish goals, which cover all issues and surround the individual, as part of the Toolbox, to help the individual throughout their life cycle
- 2. Establish the bigger picture
- 3. Set out broad timescales

Alan then stressed the importance of establishing stages 1 & 2, prior to moving on to setting timescales and developing tactical solutions (part of Stage 3), Whilst necessary, they must work well together for individuals and the Strategy needs to form a sound basis for this to be realised. It was

pointed out that some of these issues, such as adherence to commissioning guidelines, can be successfully addressed in the short-term.

Jean Maclellan acknowledged that Alan Somerville's presentation was very important and extremely helpful and agreed that a Strategy should first be put in place. At the same time, she expressed her concern with the urgency to meet the needs and expectations of those with ASD.

4.2 It was agreed that the group were in principle supportive of Alan Somerville's approach. The group said that they needed

- timescales
- to ensure the group are content with the Recommendations
- the Writing Group to look at the Recommendations, which are broadly supported and other results from the Consultation and Analysis Reports and pull this information together to produce a Strategy. A few issues, such as Forensics and Housing, need to be added to the Strategy.
- a whole day allotted to the initial Writing Group meeting, restricting the size to a maximum of 12 people.
- an addition to the Strategy which will demonstrate that there will be a tangible difference to families and people's lives. Consultation responses will add to and reinforce this message.

4.3 Dr Robert Moffat and Linda Connolly were keen to join the Writing Group and this was approved. It was agreed to replace the next ASD Reference Group meeting on 21 April with the first meeting of the Writing Group and to change the booking to run from 10-4pm.

Action Point 5

Nadia Hanif to add Dr Robert Moffat and Linda Connolly to the list of Writing Group members and email all members details of the first Writing Group meeting.

Item 5: Group Representation

5.1 Action Point carried over from the last ASD Reference Group meeting on 22 February 2011: members to discuss strengths, skills and experience they bring to the group.

Action Point 6

Kirsty Butts to circulate a template for members to fill in.

Item 6: ASD Sub-Groups - Update

6.1 All Sub-groups (i.e. Adults, Education and Training and Transitions) have submitted a draft Remit, with the exception of the Diagnosis Sub-group, who have yet to finalise their remit. The other sub-groups reported on the draft remit submitted.

6.2 Adults Sub-group:

This group submitted a broad aspirational statement as their latest draft, examining the Recommendations to determine which ones fit into the strategic overview. Steps for action were identified, as follows:

- Understanding need (the Writing Group work will help feed into this)
- Outcomes and interventions
- Mapping of current provision
- Identifying gaps (Writing Group broader framework will help here)
- Good Practice Recommendations
- Group Membership
- Resourcing
- Duration

Action Point 7

Nadia Hanif to add Idem Lewis to membership of the Adult and Transition Sub-groups at his request.

6.3 Under the proposed DSM V (Diagnostic tool), Asperger's will disappear as a term and the condition will simply be diagnosed as ASD. An English model could be used in Scotland.

There was a focussed discussion within the group on a number of issues in relation to the lack of consistency across local authorities regarding the services they offer to people with autism. It was pointed out that identifying those with autism can be very difficult, that many of the problems are often not known to those who provide an adult service e.g. Social Workers and that, with the recession, many people's needs are not being met and people with Asperger's are being overlooked when help is being given to people with Learning Disabilities. They are being told by LAs that they don't fulfil the criteria. The question was asked what can be done to address these problems.

6.4 There was also debate around the collection of data. Members agreed that there needed to be a more robust method of data collection and a number of solutions and examples of best practice were offered.

It is important to determine whether some geographical areas have higher concentrations of those on the Autistic Spectrum than others. It was suggested that such research could fit into Iain McClure's work.

Jean Maclellan suggested working with existing data e.g. on children and maximise its usefulness, taking in local models of good practice.

6.5 Education and Training Sub-group

The draft Remit is work in progress. The group are examining a number of national initiatives to improve training. They have considered strategic work to date and short, medium and long-term approaches. The group will form a work plan, map a national strategy and possibly expand the group to assist with short-medium term implementation. Medium term recommendations include looking at existing ASD training and whether it is being applied in practice, as part of the scrutiny process. Training in general is under-resourced and there is a lack of awareness of the HMIE document.

Regarding effective training, The Training Group might benefit from liaising with the Scottish Social Services Council who may have suggestions for practical approaches.

Action Point 8

Training Group to contact the Scottish Social Services Council (SSSC) to access practical approaches and available research on staff training for autism and to arrange follow-up meetings with HMIE and SCSWIS to discuss the use and scrutiny of autism-specific training in practice.

Jean Maclellan acknowledged the huge amount of time and effort the Training Group have put into this.

6.6 Transitions Sub-group

The first draft of the Transitions Remit was circulated to members. Transitions permeate many of the recommendations. As such, the Group expressed a desire to connect with the work of other Sub-groups and in particular the Adults Sub-group in order to anticipate future needs, when planning for life after school. Whilst the Group's main focus will be transitions from school to adulthood, they will also examine basic principles of transition, which inform other life transitions, the importance of which and how they affect those on the spectrum should not be underestimated.

It is recognised that there is a shortfall in transition services. Local services for school leavers / adults with ASD are not as well resourced as Children's Services. Individuals with low level needs are not a priority for Social Services compared to those with high level needs. Timely preventative services are vital. The Group recommended identifying the true cost of and money saved through investing in preventative services, scoping numbers affected and types of need. Whether Education Services could help more with transitions needs to be the subject of scrutiny.

6.7 Diagnosis, Assessment and Intervention Sub-group will report at a later date.

6.8 Research

There was discussion around who would lead on research and the need for scrutiny. It was agreed that Sub-groups should identify what their research needs are. Research issues out-with the remit of Sub-groups can be allocated externally; others can be taken on by Sub-groups and fed back to the ASD Reference group. Some relevant UK research also exists; there is also the possibility of collaborating with ongoing research work.

6.9 Criteria for Membership of Sub-groups

Membership of sub-groups is not restricted to members of the ASD Reference Group; anyone can apply. Representation on these groups, including the criteria for appointing people and how members are co-opted was discussed, as well as the size of sub-groups. Small groups were recommended to undertake the initial work. Any expansion to tap into the views of those affected by autism should wait until the Writing Group have written an overview.

6.10 Resources available for autism

The Minister for Public Health and Sport has made a commitment to allocate approximately 10 million pounds to autism over the next three years.

Item 7: AOB

Andrew Morrison moves to a new post within COSLA, so will not attend future ASD Reference Group meetings. Ron Culley will replace him on the group. Andrew mentioned sharing the final strategy with COSLA's Health and Wellbeing Executive Group and Council Leaders and the importance of getting buy in from these groups in relation to the Strategy as a whole.

Action Point 9

Alan Somerville to ask Hugh Morgan to attend the next suitable ASD Reference Group meeting.

Action Point 10

Dr Robert Moffat to forward the link to Hugh Morgan's full Welsh strategy and related documents to the ASD Reference Group.

Action Point 11

All Sub-groups are to have a leader/point of contact within the group. Sub-groups to scope the areas within their remit that require further research.

The ASD Writing Group will meet on 21 April. The next meeting of the ASD Reference Group will take place on Thursday 19 May in Conference Rooms 7 & 8, Victoria Quay, Edinburgh.