

ASD Reference Group Meeting

18 October 2011, 10:00 - 13:00

Room 4-ER, SAH, Edinburgh

MINUTES

Present

Dr Ken Aitken Ken Aitken Consultancy

Carolyn Brown Fife Council Psychological Service

Kirsty Butts Scottish Government - Adult Care and Support - (Minutes)

Prof. Aline-Wendy Dunlop University of Strathclyde

Ryan Gunn Scottish Government - Adult Care and Support

Beth Hall COSLA

Caroline Hamilton Number 6 User

Kirsten Hogg Camphill Scotland

Richard Ibbotson Autism Initiatives

Idem Lewis Learning Disability Alliance Scotland

Stella MacDonald Fife Council/ NHS Fife

Catherine Maclean The Celtic Nations Autism Partnership

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

Dr Iain McClure NHS Lothian

Dr Jane Neil-MacLachlan NHS Lothian

Nigel Rooke Autism Resource Centre, Glasgow

Val Sellars Scottish Centre for Autism

Alan Somerville Scottish Autism

David Thompson Scottish Government - Support for Learning

Apologies

Bill Colley Association of Directors of Education in Scotland

Linda Connolly Social Care and Social Work Improvement Scotland

(SCSWIS) - now Care Inspectorate

Ian Hood Learning Disability Alliance Scotland

Jane Hook Parent

Alison Leask Autism Argyll & Parent

Robert MacBean The National Autistic Society Scotland

Peter McCulloch Association of Directors of Social Work

Dr Tommy McKay Psychology Consultancy Services

Dr Robert Moffat The National Autistic Society Scotland

Annette Pyle Scottish Government - Adult Care and Support

Dr Andrew Stanfield Patrick Wild Centre for Research into Autism

Charlene Tait Scottish Autism

David Watt Education Scotland (formerly HMIE)

Item 1: Welcome, Introduction and Apologies

1.1 Jean welcomed Cathy Maclean, The Celtic Nations Autism Partnership, to the meeting. Brief introductions followed. Apologies were acknowledged.

Item 2: Minute of the last meeting held on 27 September 2011 and action points

2.1 The Minute was approved, pending comments from Iain McClure. In addition, Peter McCulloch to be marked as present at 27 September meeting.

Item 3: Matters Arising and action points from meeting held on 27 September 2011

3.1 The majority of Action Points from this meeting have either been completed or were tabled for today's meeting. Outstanding points being carried forward are

1. a more detailed discussion paper on the proposed Autism Classification and Reference Assessment project brief - Dr Tommy Mackay;

2. NICE clinical guidelines plus DSM V guidelines; and

3. Scottish Government to circulate outcomes of today's meeting (18 October 2011) to all members so that those not present can respond via email.

Item 4: Cathy Maclean - Celtic Nations Autism Partnership (presentation)

4.1 Cathy asked the group to consider how the Celtic Nations Autism Partnership could assist Scotland in meeting the needs of those affected by autism. The purpose of the Celtic Partnership is to encourage information-sharing, reflection and avoid duplication of work and effort. One such example, is the 14 generic booklets produced by Wales which could easily be adopted in Scotland.

4.2 Cathy's proposal: That the Scottish Government and the ASD Reference Group support a joint partnership event to help shape thinking and joint work. Each country would take a turn to host such an event.

4.3 Broad support was given by group members to the idea of holding a joint event, with one suggestion being to circulate two or three different formats / costings for information and consultation, then pick one. The group agreed they would like to invite England to such an event.

Action Point 1

Cathy to send her proposal to Ryan Gunn for circulation amongst ASD Reference Group members.

Item 5: Strategy Launch Update

5.1 Members were given an update on the work taken forward by both the Scottish Government and COSLA to reach agreement over the wording of Recommendations 1 and 10. Members were aware that the Strategy still had to be cleared by three COSLA committees. As a result, there are now two issues which COSLA require further work on, prior to sign-off. These are:

1. Recommendation 1. COSLA asked for the ASD Reference Group's Annual Progress Report to be signed off not only by Ministers but also by COSLA. The Minister for Public Health was content to approve this strengthening to the Recommendation, as this is led both by central and local government. The strategy's Foreword should also reflect this change.

2. Recommendation 10. Discussion followed regarding the wording of this recommendation. COSLA were concerned that councils are not in a position to deliver interventions on an 'immediate' basis, and could not accept the wording as it stands, believing it is unaffordable, unmanageable and would leave councils open to legal challenges. The ASD Reference Group considered the wording 'immediately available' critical.

5.2 During a lengthy debate, many members voiced their concerns with the ongoing debate around Recommendation 10. Whilst the urgent need to deliver health services / interventions is recognised as vital, the ASD Reference group agreed with Aline-Wendy's interpretation that the text refers to a menu of interventions, with the group's work being to support services to develop these services to be immediately available. It is not a demand for local authorities to immediately spend money.

5.3 Members were reminded that all Recommendations had been publicly consulted. Of the 17 replies received from local authorities, only one expressed some concern around the phrase in question. In addition, at the ASD Reference Group meeting in March 2011, all members, including a COSLA official, had agreed that Recommendations would stand.

5.4 COSLA officials, still have concerns that people will read this Recommendation literally and expect immediate support. A proposed amendment to the Recommendation was tabled by COSLA for consideration and endorsed by members. If members did not endorse the revised text, the issue would then be tabled and discussed by delegates at the COSLA Convention on 21 October.

5.5 All agreed that an attempt to resolve this issue was essential, so that Scottish Government and COSLA can work together for the benefit of those with autism and their families. A vote was taken amongst those still present as to whether Recommendation 10 should remain as it stands. The majority voted in favour of doing so. Those who voted the Recommendation should change did so for pragmatic reasons. The group's decision was therefore not to recommend to the Minister that the wording should change.

Item 6: ASD Reference Groups - Sub-Groups (Group Discussion)

6.1 Table 1 of the Strategy and the need to revise the proposed sub-group structure so that they reflected the headings in the table was discussed by members. During this discussion, members agreed that:

- Multi-disciplinary sub-groups had been previously agreed in order to ensure that none of the work under these headings would be omitted.
- There is a need for clear leadership within each sub-group in relation to the Recommendations. If all

Recommendations are anchored to particular sub-groups, then none should slip through the net.

- It is suggested that existing sub-groups meet to discuss how each of the headers can achieve the strategy goals.

6.2 Time for undertaking this work was discussed. A whole day programme for the next ASD Reference Group meeting on 12 December 2011 was agreed by the group.

Budgets

6.3 The discussion then focused on the need to ensure that the budget allocation for 2011-12 was used to start the work of implementing the Recommendations of the Strategy. Members were asked to detail what their spending suggestions and priorities would be and a list would be circulated thereafter.

Action Point 2

The Scottish Government Adult Care and Support team to put bids already received in a list, in order of priority and circulate to the group, in order to assist the group in coming to decisions on spend - (actioned).

6.4 These ideas will be taken forward and discussed with the Minister for Public Health, to seek his endorsement of the spending proposals.

Some of the proposals submitted by members included:

- Fund the recruitment of local autism co-ordinators to provide information, advice and support
- Support the Scottish Autism Services Network, which builds competence in the workforce to assist post-diagnostic support
- Help people access social care services
- Create a development fund of £1 million per annum, for which both local and national organisations can apply.
- Develop new one-stop-shop drop-in services for people with autism around Scotland.

6.5 It was decided that bids should be in before Christmas, as they need to be approved before March 2012. Distribution of funds will be discussed at the next ASD Reference Group meeting, with bids discussed at subsequent meetings.

Item 7: ASD Research Protocol - Presentation by Dr Ken Aitken

7.1 The last item on the agenda was the presentation by Dr Ken Aitken. Some of the issues raised by Ken included:

- Transparency regarding any conflict of interests for research
- A method for formally taking internet research into account, in order to inform clinical practice, is required
- A national register of those with ASD
- An annual overview of completed / published research and its impact

Research projects need to have:

- Links to real-life issues
- Study details
- Expected timeframes
- Ethical approval obtained
- Compliance with Declaration of Helsinki and Declaration of Ottawa on Child Health
- ECRN (Early Careers Research Network) Compliance
- An informed consent process

7.2 Ken mentioned that although much good work is going on in Scotland, very few people in Scotland are having research papers on autism published at the highest level. Different bodies need to link up to make this more obvious and address this issue. This could capture both higher level professional research and research which students are undertaking. The research should build on what Dr Ken Aitken has already done and the group should establish what research has already been undertaken, to what level. Research needs to be substantial to attract a grant and be sustainable.

Action Point 3

Ken to facilitate a Research Group, composed of Dr Iain McClure, Prof. Aline-Wendy Dunlop, Carolyn Brown, Charlene Tait, Dr Andrew Stanfield and Dr Tommy McKay.

Date of next meeting - 12 December 2011, 10.30-15:00, Conference Room 2, Scottish Government, Victoria Quay, Leith. Please note that it is no longer being held at the COSLA buildings.