

**ASD Reference Group Meeting
19 July 2011, 10am – noon
COSLA, Verity House, Haymarket, Edinburgh**

MINUTES

Present

Jean Maclellan	Scottish Government - Adult Care and Support - Chair
Prof. Aline-Wendy Dunlop	University of Strathclyde
Alison Leask	Autism Argyll & Parent
Dr Andrew Stanfield	Patrick Wild Centre for Research into Autism
Annette Pyle (Minutes)	Scottish Government - Adult Care and Support
Beth Hall	COSLA
Caroline Hamilton	Number 6 User
Charlene Tait	Scottish Autism
Ian Hood	Learning Disability Alliance Scotland
Idem Lewis	Learning Disability Alliance Scotland
Jane Hook	Parent
Dr Jane Neil-MacLachlan	NHS Lothian
Kirsty Butts	Scottish Government - Adult Care and Support
Linda Connolly	Social Care and Social Work Improvement Scotland (SCSWIS)
Richard Ibbotson	Autism Initiatives
Robert MacBean	The National Autistic Society Scotland
Ryan Gunn	Scottish Government - Adult Care and Support
Stella MacDonald	Fife Council/ NHS Fife
Val Sellars	Scottish Centre for Autism

Apologies

Alan Somerville	Scottish Autism
Bill Colley	Association of Directors of Education in Scotland
Carolyn Brown	Fife Council Psychological Service
David Thompson	Scottish Government – Support for Learning
David Watt	HMIE
Dr Iain McClure	NHS Lothian
Dr Ken Aitken	Ken Aitken Consultancy
Kirsten Hogg	Camphill Scotland
Nigel Rooke	Autism Resource Centre, Glasgow
Peter McCulloch	Association of Directors of Social Work
Robert Moffat	The National Autistic Society Scotland
Dr Tommy McKay	Psychology Consultancy Services

Item 1: Welcome, Introduction and Apologies

1.1 Jean Maclellan welcomed the members to the meeting and said that she was happy to be back. She thanked the members for the progress made to date. A special welcome was given to Beth Hall who has replaced Ron Culley as the COSLA representative. Jean asked Beth to give the group an overview of her COSLA role and introductions around the table followed. Annette Pyle read out the apologies. Jean explained that due to apologies of Dr Ken Aitken, Dr Tommy McKay and Dr Iain McClure a revised agenda had been tabled with revised timings which meant the meeting would close at noon, followed by lunch.

Item 2: Minute of the last meeting held on 23 June 2011

2.1 Minutes agreed and action points discussed, those outstanding were carried forward.

Action Point 11 from 19 May 2011 carried forward

Awaiting the details from a small number of the group members regarding their qualifications, work experience, strengths and skills to enable a summary analysis to be produced.

Action Point 1 from 23 June 2011 carried forward

Ken Aitken to redraft the protocol for ASD research purposes based on the discussion at the meeting about the benefits of the research and how to turn the research into practice. Final version will be sent out to the ASD Reference Group for approval before the next meeting of 16 August.

Action Point 2 from 23 June 2011 carried forward

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.

NB: To be carried forward to 16 August meeting Tommy and Alan to make necessary arrangements for Professor Martin Knapp to attend, if possible.

Action Point 5 from 23 June carried forward

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

Action Point 9 from 23 June carried forward

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

NB: To be discussed with Iain McClure on return

Item 3: Protocol for ASD research–update

3.1 Jean informed the members that due to Ken's other commitments he was unable to attend today's meeting and deliver his paper but that he gave assurances that his work on the revised protocol template for ASD research will be completed and distributed to the members before the next meeting.

Item 4: Autism Classification and Resource Assessments Brief - update

4.1 Jean informed the members that Dr Tommy McKay was not able to attend today. Unfortunately Tommy due to other pressures has been unable to progress this sufficiently to deliver to the group; however he will endeavour to get Professor Martin Knapp to attend the next meeting, if possible, to enable a full discussion on the proposed research.

Item 5: ASD and the Adult Picture – Dr Jane Neil-Maclachlan

5.1 Jean invited Jane to give her presentation. Jane stated that at the last meeting the discussion had been around the fact that we all recognised that the size of the adult ASD

population was unknown and that we knew it was out there but little had been done to address it. She added that she had over 30 years experience in Autism diagnosis and hoped that this strategy would make a difference by addressing the needs of the adult ASD population. Jane highlighted the main points in the presentation being:

- Research has found that the prevalence of ASD in adults is similar to that found in children
- Compared to 2000 the number of children under 16 with ASD has reduced, factors include birth rate
- Children are the tip of a very large iceberg – there are 4 times as many adults than children
- We know what they need this is backed by previous evidence and the consultation to the strategy
- The problem is how do we find them? and why diagnose?
- By finding them we can inform service planning and interventions which could reduce potential costs for Scotland
- Goal 2 and 3 within the strategy states we aim to remove barriers to adult diagnoses and post diagnostic support
- Addressing diagnosis in adults is a urgent priority
- Research and training play a part of the answer



Terra Incognita.ppt

5.2 Members fully supported the points raised by Jane during her presentation. There was also a lengthy discussion among members around the issues raised by Jane, these included:

- The need for medical staff such as GPs to have more detailed specific ASD training included in their core training and the importance of this been implemented consistently across the UK;
- Using learning from the Glasgow Autism Taskforce, where families' histories were used to inform services, to see whether there is anything else we can learn from it. The importance of research to inform the planning of future services was, as agreed by members, vital and should be pursued.
- Greater sharing of information from the other home countries to help address national issues.

Item 6: Scottish Autism Assessment Survey – update

6.1 Jean informed members that Dr Iain McClure was due to table this paper but had given his apologies. Jean stated that she would meet with Iain prior to the next meeting to discuss the costing paper and agree a way forward on the waiting list assessment survey.

Action Point 1

Scottish Government to meet with Dr Iain McClure to discuss the Scottish Autism Spectrum Disorders Survey costing paper and way forward.

NB: Post meeting note this has been arranged for 4 August.

Item 7: Update from ASD Writing Group – 6 July 2011

7.1 Ryan Gunn explained that the Writing Group had met on the 6 July to finalise the short strategy version. He added that the planned meeting on 26 July would not go ahead and that the way forward was for the Scottish Government to pull the document back for

final draft. He added that Aline –Wendy was still to finalise the Chapter 3 and this would be incorporated into the full strategy. He stated that the September deadline to get the strategy through COSLA Committees meant that by the strategy would need to be ready for sign of by the next meeting on 16 August. Beth stated that she would work with Ryan to meet those deadlines.

Action Point 2

Scottish Government to cancel the ASD writing group meeting on 26 July 2011.

Action Point 3

Scottish Government to pull together all the comments and amendments made to the strategy and bring a final version of the strategy to the next ASD Reference Group Meeting on 16 August for sign off.

Action Point 4

Scottish Government to meet with Beth Hall to discuss the COSLA consultation response to the draft strategy and the COSLA process through committee.

Item 8: Launch of the Autism Strategy

8.1 Jean stated that the with the commitment to publish in the autumn we needed to collect the memberships views on how the strategy will be launched and whether this would be high profile, low profile or somewhere in between. The members discussed ways of launching the strategy and agreed that it should not be launched in a lavish way which involved spending too much money. One suggestion was to launch in the Parliament. It was felt that this would be appropriate as it would help with the continuation of cross party support for the Strategy. The members discussed how important it was to have representation from MSP, Local government, Health and other stakeholders. The members were also keen to involve other nations either at the launch or at a four nations learning event.

Jean reminded members of the SNP Manifesto which commits £10m over the next 4 years. Jean explained that we are committed to publish in the autumn and have a budget of £2.6m in this financial year with a further £7.4m (which is still subject to due process). She added that we need to spend this wisely to make a difference. Ryan added that he will bring to the next meeting a governance structure which will satisfy that money spent will be allocated in an open and transparent way. Jean explained that Ryan's team will be responsible for this budget and the ASD Reference Group will oversee the spend. This was accepted by the membership.

Action Point 5

Scottish Government to put in place a governance process for funding proposals.

Action Point 6

Scottish Government to plan and arrange the launch of the Autism Strategy.

Item 9: AOB

9.1 Val asked for the NICE Clinical Guidelines to be discussed at the next meeting.

9.2 Stella stated that the Independent Living Movement Policy Network were seeking representation from someone on the Autism Spectrum. Stella agreed to forward the email she had received to be circulated to the membership.

Action Point 7

Scottish Government to put the latest NICE Clinical Guidelines on the Agenda for discussion at the next meeting.

Action Point 8

Stella MacDonald to forward to the Independent Living Movement Policy network email to the Scottish Government for distribution to the ASD Reference Group.

The next meeting will be on Tuesday 16 August 2011 at 10am at COSLA Verity House, 19 Haymarket Yards, Edinburgh.

Out with the meeting – A member of the group asked whether the group could propose funding proposal which link into the recommendations. Jean explained that any proposal for funding would be subject to the governance process but in principle proposals could be submitted by ASD members.

Annette Pyle
Autism Strategy
25 July 2011