

ASD Reference Group Meeting

16 August 2011, 10am - 1pm

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

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

Beth Hall COSLA

Bill Colley Association of Directors of Education in Scotland

Carolyn Brown Fife Council Psychological Service

Charlene Tait Scottish Autism

Ian Hood Learning Disability Alliance Scotland

Dr Iain McClure NHS Lothian

Jane Hook Parent

Dr Jane Neil-MacLachlan NHS Lothian

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

Dr Ken Aitken Ken Aitken Consultancy

Prof. Kirsty Forsyth Queen Margaret College

Richard Ibbotson Autism Initiatives

Robert MacBean The National Autistic Society Scotland

Dr Robert Moffat The National Autistic Society Scotland

Ryan Gunn Scottish Government - Adult Care and Support

Scott Johnston Scottish Government - Support for Learning

Stella MacDonald Fife Council/ NHS Fife

Val Sellars Scottish Centre for Autism

Apologies

Alan Somerville Scottish Autism

Dr Andrew Stanfield Patrick Wild Centre for Research into Autism

Caroline Hamilton Number 6 User

David Thompson Scottish Government - Support for Learning

David Watt HMIE

Idem Lewis Learning Disability Alliance Scotland

Kirsten Hogg Camphill Scotland

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

Nigel Rooke Autism Resource Centre, Glasgow

Peter McCulloch Association of Directors of Social Work

Dr Tommy McKay Psychology Consultancy Services

Item 1: Welcome, Introduction and Apologies

1.1 Jean Maclellan welcomed the members to the meeting and in particular Professor Kirsty Forsyth, Queen Margaret College, who was presenting on the Scottish Autism Spectrum Disorders Survey. Brief introductions around the table followed. Annette Pyle read out the apologies.

Item 2: Minute of the last meeting held on 19 July 2011

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

19 May Meeting:

Action Point 11 - carried forward

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

Action Point 1

Kirsty Butts to chase.

23 June Meeting:

Action Point 1 (Revised protocol for ASD research purposes - Ken Aitken) was taken forward as Item 5 on the Agenda but was postponed to the next ASD Reference Group meeting.

Action Point 2 - (a more detailed discussion paper on the proposed Autism Classification and Reference Assessment project brief - Dr Tommy Mackay) was re-scheduled for 16 August but Professor Martin Knapp was unable to attend.

Action Point 5 - (ASD Reference group members to nominate themselves onto Sub-groups based on Agenda Item 7 Sub-group proposal paper) - carried forward

Action Point 9 - cleared.

Action Point 2

Scottish Government to take forward Action Point 2 above.

Action Point 3

Scottish Government will take forward Action Point 5 above and chase.

19 July Meeting:

Action Points 1 - 4 - cleared.

Action Points 5 and 7 from the meeting held on 19 July were to be discussed under Agenda items 4 and 7 of the 16 August meeting. As requested, the title for Agenda item 7 had been amended to read 'NICE clinical guidelines and DSM'. However, due to time constraints, both items have now been postponed to a future meeting.

Action Point 6 (Scottish Government to plan and arrange the launch of the Autism Strategy) - in progress. A date has been set for 25 October 2011.

Action Point 8 (Stella Macdonald to forward the Independent Living Movement Policy network email to the Scottish Government for distribution to the ASD Reference Group) - carried forward. It will be distributed when available.

Action Point 4

Kirsty Butts to add DSM V guidelines to agenda item on NICE clinical guidelines for the next meeting.

Item 3: Finalising the Autism Strategy

3.1 The bulk of the meeting was given over to this item. Whilst Chapter 2 was agreed to be helpful and near completion, Chapter 1 was still not thought to be fit for purpose. Discussion centred on the need to ensure that key values and principles were retained and that the 10 Indicators for Best Practice were re-inserted. There was also concern that the 'Themes' had reappeared.

The Group worked through making the necessary changes in minute detail until consensus was reached. Much of the discussion centred on what would be acceptable to COSLA given that they are partners with Government on this and other policy developments. Aline-Wendy Dunlop agreed to work with the SG team in delivering a final draft together.

The discussion on the Strategy meant that it was necessary to defer Agenda items 4 (Governance on ASD Spend), 5 (Revised protocol for ASD research purposes - Ken Aitken) and 7 (NICE Clinical Guidelines & DSM - Val Sellars), in order to allow Prof. Kirsty Forsyth's presentation on the Scottish Autism Spectrum Disorders Survey (Agenda Item 6).

Item 6: Scottish Spectrum Disorders Survey - Professor Kirsty Forsyth

6.1 Jean invited Professor Forsyth, Queen Margaret College, to give her presentation. She expressed her appreciation for the group's engagement, enthusiasm and passion in developing a Strategy fit for purpose. Professor Forsyth presented the update on the Scottish Autism Spectrum Disorders Survey (SAAS) on behalf of the project team.

SAAS Background: This initiative came from the passage of the members bill when waiting lists were highlighted as a challenging issue. The previous Minister sanctioned the resource to complete a specific set of work focused on understanding waiting lists.

Professor Forsyth Background: Professor Forsyth is part of the SAAS project team. She has a PhD in Public Health and leads a Health Services Research team at Queen Margaret University, Edinburgh. This team is focused on improvement of services, in partnership with service users, whilst maximising resources. Previous research carried out by Prof. Forsyth's team was shared which created a significant reduction in waiting times for people with Asperger Syndrome entering vocational rehabilitation programme

(along with significant increase in people returning to work, reduced lengths of stay in service, increased service capacity and lower service costs).

SAAS update: Initial request was to focus on Recommendation 10 to clarify extent of delays. It was, however, argued that the resource may be more effective if it was focused on systematically understanding *why* delays were present (across adult/children). This would provide a stronger position to create national action to reduce waiting times. This approach was agreed by the meeting. SAAS will now move forward to recruit researchers to complete the work. The meeting also advocated that SAAS collaborate closely with Alison Leask who has previously completed work in this area. This was agreed by Dr McClure.

Other issues raised: Several members of the meeting were concerned about adults who had autism, however, were not on a waiting list as they were unidentified and/or in mental health, substance misuse or learning disability services. The Ministerial request for the SAAS initiative was specific to *waiting lists*, however, the team will endeavour to be inclusive of adult mental health, substance misuse and learning disability services.

6.2 Following the presentation, Jean suggested that, with her permission, the group be given Professor Kirsty Forsyth's email address, in order to work with her.

Item 8: AOB

8.1 Governance - Ken Aitken commented that it would make sense to use similar methodology to that used in England and that there needs to be clarity around costings. Jean confirmed that this will be addressed at the meeting in September under governance.

8.2 The next meeting of the ASD Reference Group is an extraordinary meeting to clarify Governance on ASD Spend. It will take place on 27 September 2011, from 10.30-12.30pm at COSLA, Verity House, 19 Haymarket Yards, Edinburgh EH12 5BH.