ASD Reference Group Meeting 21 February 2012, 10:00 – 13:00 Conference Rooms C, D & E, SAH Edinburgh

MINUTES

Present:

Dr Ken Aitken Consultancy

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

Bill Colley Association of Directors of Education in Scotland
Ryan Gunn Scotlish Government - Adult Care and Support – (Co-

Chair)

Beth Hall COSLA

lan Hood Learning Disability Alliance Scotland

Jane Hook Parent

Richard Ibbotson Autism Initiatives

Scott Johnston Scottish Government – Learning and Support

Alison Leask Autism Argyll & Parent

Paul Lennon Autism Resource Centre, Glasgow Idem Lewis Learning Disability Alliance Scotland Robert MacBean The National Autistic Society Scotland

Stella MacDonald Fife Council/ NHS Fife

Jean Maclellan Scottish Government - Adult Care and Support – (Co-

Chair)

Peter McCulloch Association of Directors of Social Work Dr Tommy McKay Psychology Consultancy Services

Dr Jane Neil-MacLachlan NHS Lothian

Annette Pyle Scottish Government – Adult Care and Support

Nigel Rooke Autism Resource Centre, Glasgow

Val Sellars Scottish Centre for Autism

Charlene Tait Scottish Autism
David Watt Education Scotland

Apologies:

Carolyn Brown Fife Council Psychological Service

Linda Connolly The Care Inspectorate
Prof. Aline-Wendy Dunlop University of Strathclyde

Caroline Hamilton Number 6 User
Kirsten Hogg Camphill Scotland
Dr Iain McClure NHS Lothian

Dr Robert Moffat The National Autistic Society Scotland

Alan Somerville Scottish Autism

Dr Andrew Stanfield Patrick Wild Centre for Research into Autism David Thompson Scottish Government – Support for Learning

Item 1: Welcome, Introduction and Apologies

1.1 Jean welcomed members and in particular Paul Lennon, ARC, to the group. Paul partly replaces Nigel Rooke, whose work focus is no longer autism-specific. Jean thanked Nigel for all his hard work in this field and on behalf of the group. Apologies received were acknowledged.

<u>Items 2 & 3: Minute of and Action Points from the last meeting held on 12 December 2011</u>

- 2.1 The Minute was approved and Action Points completed
- 3.1 Outstanding points being carried forward for future meetings are:
 - A more detailed discussion paper on the proposed Autism Classification and Reference Assessment project brief Dr Tommy Mackay; and
 - NICE clinical guidelines plus DSM V guidelines.

Action Point 1

Kirsty to carry forward these agenda items to the next meeting

<u>Item 4: ASD Reference Groups & Sub-groups – updates from first meetings, next</u> steps for new User and Carer Sub-group and Contract agreement

4.1 The reports from all the sub-groups are available on the Scottish Government website, click on the link to access the reports (**add link**)

4.2 New User and Carer Sub-group

Members agreed that, given the membership of this group, the remit and function of this sub-group had to be clear and concise. Further work was required to draft and develop the remit.

Action Point 2

Annette to draft a Remit for this Sub-group and circulate to ASD Reference Group members for comment.

- 4.3 Other issues raised during the discussion included:
 - Oversight of funding SG officials will work with the Minister for Public Health to monitor use and outcomes
 - COSLA has limited capacity for representation on Sub-groups but would prioritise this for areas of importance such as the political sign-up to the Strategy and holding teams to account for progress. Whilst local authorities are ultimately responsible for implementation, COSLA will try to influence / broker in this regard.

Action Point 3

Sub-groups looking for COSLA/Local Authority representation should contact Beth Hall who will broker/influence or appoint a COSLA representative to do so on their behalf.

4.4 Contract Agreement

Terms of Membership were endorsed by all members at this meeting.

Action Point 4

Kirsty Butts to email Sub-group leaders, requesting signed (hard or electronic) copies be obtained from all members and sent back to her.

Item 5: SASN – name change – Prof Aline-Wendy Dunlop – discussion paper 5.1 The Scottish Government have provided grant funding to re-energise the group and it was felt that a change of title would better reflect the re-energised network. To focus the discussion around this topic, a discussion paper with some suggestions for the new title of the network was circulated to members for discussion. Members agreed to consider the options within the paper and send their comments to Aileen-Wendy.

Action Point 5

Members to send their comments to Aline-Wendy.

5.2 SASN will host an 'Autism Adult Health and Wellbeing Conference – Autism and Policy Implementation' on 15 May 2012 in Perth. A provisional programme was circulated.

Action Point 6

Kirsty to put SASN on the agenda for a future meeting.

Item 6: Autism Spend – update

- 6.1 Members were informed that the process to recruit the Autism Mapping Coordinators to take forward the mapping and scoping of national services is ongoing. The three national organisations, Scottish Autism, Autism Initiatives and the National Autistic Society are leading in this exercise by taking responsibility for recruitment, line management, employment and project management. The Scottish Government will monitor the progress on the exercise. These posts will be fixed term. Following this, local autism coordinators will be established.
- 6.2 As the above work involves local authorities and the NHS, it was felt that input from COSLA, ADES and ADSW, as well as from Health Boards, was required in the planning process, as there are big implications for implementation. The ASD Reference Group is accountable for providing advice on autism spend and the Scottish government holds regular meetings with COSLA.

Action Point 7

Beth will map COSLA's time input for Sub-groups / ASD Reference Group and for representation on the larger group of 3 national organisations taking this forward.

Action Point 8

Kirsty to put the resource implecation of ADES, ADSW and NHS representation on a group to take forward autism coordinators on the agenda for the next meeting.

- 6.3 Discussion around the distribution of Scottish Government funding followed and the following points were clarified:
 - £1.2m has been allocated in 2011-12 for one-stop shops
 - Additional funding of £150k per one-stop shop will also be provided in 2012-13

- The £150,000 allocated to Glasgow and Edinburgh in 2011-12 is to help these services to expand on existing provision to meet the increased demand for their services.
- An Autism Development Fund of £1m per annum until 2015 was made available. £294,599 was allocated in the last quarter of 2011-12 to fund successful applications. Sixteen organisations were supported in the first tranche of funding and are named in a press release. 'Autism Strategy in action', issued on 19 February 2012. Further support will be announced in the next financial year.

Item 7: Celtic Nations event – 22 February 2012

7.1 The Celtic Nations event, hosted by the Scottish Government and COSLA, focuses on building the foundations to enable the Scottish Government and its partners to fulfil the Recommendations and achieve, by 2013, the strategic goals that make up the foundations of the Scottish Strategy for Autism. Facilitated by the Celtic Nations Partnership, this net-working event will provide an opportunity for all nations involved to share information / expertise. One desired outcome from the day is to develop the framework for a strategic action plan for Scotland.

<u>Item 8: Recent documents having a bearing on ASD services and discussion paper – Dr Ken Aitken</u>

- 8.1 A recent NES document has potential implications for the development of the Strategy. The aim of the document is to provide resource-neutral advice to commissioners, drawing on NICE, SIGN etc, on how to process waiting lists faster and meet targets. Within the report:
 - There are high cost implications for many interventions (so not resource-neutral)
 - Various research studies' recommendations are inconsistent regarding the beneficial effects of certain interventions.
 - Recommendations within available literature are either absent or the level of recommendation has been wrongly cited; meta-analyses have been omitted with no reason given.
 - A review suggests research will be published but there is no evidence of this 6 years later.

Action Point 9

This item to be carried forward as an agenda item for further discussion at the next ASD Reference Group meeting in April.

Action Point 10

Ken to send comments concerning the ASD sections of the above document, on behalf of the ASD Reference Group, to Cathy Richards, Clinical Psychology Lead, RHSC, Edinburgh for circulation to group members who compiled this section of the document. Ken to clear with Chair before sending.

<u>Item 9: Criminal Justice – feedback from the National CJ ASD Development Day – Stella Macdonald</u>

- 9.1 A summary report about the CJ ASD Development Day, Nov 2011 / evaluation papers were circulated. Stella summarised the main issues arising from the event.
 - Family Protection Unit The overall environment for people with autism is not sufficiently supportive / effective; this is the case across the board (education, health, police, courtroom etc). One of the biggest challenges for the Criminal Justice System is that the majority of adults are undiagnosed. A wide range of issues were discussed:
 - The full range of Criminal Justice Services need looked into (whether victim, witness or perpetrator).
 - Training / Localised training / Skills development
 - Advocacy database / skills development
 - Approaches / different models / Network development / Sharing of good practice
 - Referral pathway / screening tools / quick signs
 - Preventative measures
 - Forensic issues
 - Sexual health / orientation
 - Behaviour in relationships / employment and women being badly treated with things that have happened which should not have happened to them
 - Policy to ensure broadening out to cater for this group
- 9.2 Stella added that there is a real desire demonstrated by those present. Stella also added that work should be linked to the following:
- SAYIG , the Independent Living Agenda and the Scottish Transitions Forum. There is a higher likelihood of people with communication difficulties, including those with autism, committing a crime.
- 9.3 Tommy Mackay will address some of these issues, which are linked to Knapp research. Tommy commented that the CJ ASD Development Day event really helped to raise the profile of ASD issues for the Criminal Justice. Stella wants to ensure this issue is captured in sub-group work.

Action Point 11

Sub-groups to consider how the above issues raised with regard to people with autism and the Criminal Justice system can be integrated into sub-group work.

Date of next meeting – Thursday 19 April 2012, Conference Rooms C, D & E, St Andrew's House, Edinburgh, from 10-1pm.

Kirsty Butts Adult Care and Support