ASD Reference Group Meeting

27 September 2011, 10am - 1pm

COSLA, Verity House, Haymarket, Edinburgh

MINUTES

Present

Dr Ken Aitken Ken Aitken Consultancy

Carolyn Brown Fife Council Psychological Service

Kirsty Butts Adult Care and Support - (Minutes)

Prof. Aline-Wendy Dunlop University of Strathclyde

Beth Hall COSLA

Kirsten Hogg Camphill Scotland

Jane Hook Parent

Robert MacBean The National Autistic Society Scotland

Stella MacDonald Fife Council/ NHS Fife

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

Dr Iain McClure NHS Lothian

Peter McCulloch Association of Directors of Social Work

Annette Pyle Scottish Government - Adult Care and Support

Alan Somerville Scottish Autism

Dr Andrew Stanfield Patrick Wild Centre for Research into Autism

Charlene Tait Scottish Autism

David Watt Education Scotland (formerly HMIE)

Apologies

Bill Colley Association of Directors of Education in Scotland

Linda Connolly Social Care and Social Work Improvement Scotland

(SCSWIS) now The Care Inspectorate

Ryan Gunn Scottish Government - Adult Care and Support

Caroline Hamilton Number 6 User

Ian Hood Learning Disability Alliance Scotland

Richard Ibbotson Autism Initiatives

Alison Leask Autism Argyll & Parent

Idem Lewis Learning Disability Alliance Scotland

Dr Tommy McKay Psychology Consultancy Services

Dr Robert Moffat The National Autistic Society Scotland

Dr Jane Neil-MacLachlan NHS Lothian

Nigel Rooke Autism Resource Centre, Glasgow

Val Sellars Scottish Centre for Autism

David Thompson Scottish Government - Support for Learning

Item 1: Welcome, Introduction and Apologies

1.1 Jean welcomed members to the meeting and brief introductions followed for those who had not attended previously. Apologies were acknowledged. Jean explained that this meeting had been specially arranged as the discussion on the detail of the draft Strategy had taken up the whole of the last meeting. Today the main item was to consider together what the available expenditure for this financial year should be used for now that priorities had been clarified.

Item 2: Minute of the last meeting held on 16 August 2011 and action points

2.1 Beth wished to make an amendment to Item 3, Finalising the Autism Strategy 3.1, 2nd paragraph. Following group discussion, the text will be revised to reflect the result of this discussion and the updated version circulated to the group.

Action Point 1

Kirsty to amend text of 16 August 2011 meeting and circulate revised minute to group.

The remainder of the Minutes and action points were agreed; those outstanding were carried forward, as follows:

1. Revised protocol for ASD research purposes - Ken Aitken

2. A more detailed discussion paper on the proposed Autism Classification and Reference Assessment project brief - Dr Tommy Mackay

3. 'NICE clinical guidelines plus DSM V guidelines.

Action Point 2

These outstanding items to be added to future agendas.

Item 3: Update on the Autism Strategy and launch

3.1 Annette has been principally involved in negotiating times / venues for the launch of the Scottish Strategy for Autism. Beth expressed COSLA's broad support for the strategy but some concerns around the wording of two Recommendations, one of which needed clarification and the other changed to more realistically reflect how local government can implement it. Until the strategy has been cleared by COSLA, it cannot be launched. Once cleared, it needs to be launched as soon as possible.

The media event (launch), will take place at 12.30 on Wednesday 2 November 2011 at Number 6, Edinburgh, a service for adults (16 and over) with High Functioning Autism (HFA) or Asperger Syndrome (AS) who live in the Lothians. A submission has been put to the Minister for Public Health to hold the Reception in the early evening of 3 November 2011 at Parliament. The media event is intended to be small and will give some users and carers the opportunity to say what the Strategy means to them. The Reception will be larger, but much will depend on what venue is available. The SG team that leads on autism policy has had one meeting with those who specialise in communications within Government to make sure that any media coverage is appropriate and sensitive as well as demonstrating an understanding of people on the spectrum and their families.

Item 4: ASD Spend, priorities and governance

The Group split into three to discuss and make proposals about the available spend.

Group 1

This group considered that professional education and training is paramount and creates an opportunity for change in the wider community. Given this is a national strategy seeking change at every level, they felt a national drive was important to

improve knowledge and understanding of autism at all levels, including locally. Suggestions were made against a backdrop of building on what we have already begun to achieve, including an existing National Training Framework, the development of an Autism Training Approval Scheme (which would provide structure at a local level and include assessment, scrutiny and an award) and a Scottish Autism Services Network.

The group suggested that funding be allocated to offer the 32 local authorities and 8-12 other service providers the opportunity to take a nominated individual through training approval / accreditation for three consecutive years. The core group of approved autism trainers could then carry forward local strategy in each area of Scotland.

In summary, the idea is to develop a national network team, using approved Autism Trainers in local contexts, the focus being on the development of a framework for training staff within local authorities, partner services and other agencies, including voluntary agencies. The main aim would be to support local services to deliver and co-ordinate strategic planning and capacity building in local contexts. This would provide a foundation for addressing Recommendations 2,3,4,9,14,15,17,18 and 26. Training would involve Education, Health Services, Voluntary Services and service users to work in partnership to identify and address specific areas within their areas of competence relevant to the effective delivery of services to those on the autism spectrum.

The continued existence and functioning of the National Autism Network would support the above development through an Autism Trainers Network.

A transitions network could be funded to support individuals to find employment, along an employment spectrum.

These developments could potentially provide support and progression for individuals on the autism spectrum regarding employability skills and needs in relation to transitions. A National Employment Coordinator in Year 2 could work with local approved trainers, giving them training on transitions in order to improve knowledge and share best practice.

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Group 2

In contrast, Group 2 placed importance on Local Area Autism Coordinators, located within local authorities. Many of the Recommendations could then become outcomes, as Local Area Coordinators would progress and monitor outcomes for training, transitions, employability etc, reporting back on these at government level.

Recommendations identified which could be realised in this way by autism coordinators were 2 3,4,7,8,10,13,14,17,18, 21,22,26.

2 - Autism guidelines implementation

3 - Lead Officer roll-out

4 - Passing on knowledge of current developments

7 - Examine and compare outcomes between autism-specific and generic services

8 - Identify key determinants of service provision that improve quality of life

10 - Develop menu of interventions

13 - Develop user and carer capacity in local planning

14 - Autism and SDS development

17 - Training audit

18 - Transitions

21 - Local Waiting lists for diagnosis

22 - Diagnostic training

In addition, there are many plans already in existence which could currently be delivered by coordinators. The aim is to ensure community capacity building, taking a whole systems approach, possibly under the auspices of LAs or Health Boards and encompassing all agencies which have input. The argument for LAs is that they are spread out across the country and already in a position to coordinate local resources e.g. for housing, employment, social services etc. It was also felt that significant priority be given to Recommendation 6 to establish a baseline and that an audit of current service commissioning be undertaken by the Audit Commissioner.

The question remained: should priority of spend in year 1 be given to roll-out of Autism Coordinators across Scotland?

Group 3

Iain presented his group's perspective. This group were saying that all the ideas put forward by groups 1 and 2 were valid and deserved funding. The question is, however, is there a natural order of funding which will maximise efficiency of the Government's spend overall up to 2015? Therefore, Group 3 was suggesting that spending in the first tranche might be best focussed on finding out:

1. What are the key difficulties for people accessing assessment and what slows this process down? What service developments need to be implemented (especially for adult services) to change and improve this situation?

2. Which types of ASD presentation cost Scotland the most and why?

Answering these two important research themes will then help to set a more informed framework for the implementation that we all want to deliver, across health, local authority and third sector provision.

Iain also presented a personal perspective of how the Strategy's recommendations map onto the world of autism with which he is professionally familiar, as an NHS clinician involved in ASD assessment and intervention and in research. First there is a chronological concept, the journey of the person with ASD through the system, from early recognition (which the Strategy doesn't recommend on) through assessment etc. The second concept are the 4 themes of system function, evidence base, outcomes and training, which impact on all aspects of the first 3 chronological themes. (See attached word document for this section).

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In then summarising the various ideas from the sub-groups, Jean stressed that the focus must be on implementation. It was agreed that Kirsty would send out a summary of three groups' ideas to all ASD Reference Group members, inviting ideas from the remainder of the group who were unable to attend and also comments from the group. When this was finalised a submission would go to the Minister for his consideration and approval.

Action Point 3

Kirsty to send out summary of groups' ideas to all ASD Reference Group members.

Action Point 4

Aline-Wendy to produce a proposal on the Scottish Autism Services Network .
Scottish Government to circulate to the ASD Reference Group for comment.

4.5.4 Iain. McClure asked whether the ASD Reference Group were prepared to support further research to address the outcomes of the SAAS investigation into the current process of ASD assessment (across the age and IQ range) in Scotland. These will be considered in due course.

Action Point 5

Scottish Government to re-instate 18 October 2011 as a date and time to obtain clarity around who is in which sub-group, what their function is, who leads on which recommendations and whether funding is to fund recommendations or goals.

Action Point 6

Scottish Government to circulate outcomes of the above meeting to all members so that those not present, including Iain, can respond via email.

Action Point 7

Ken to present his paper on 18 October 2011

Date of next meeting - 18 October 2011, from 10.00-12.00 pm, Room 4-ER, St Andrew's House. Please note that it is no longer being held at the COSLA buildings.