ASD Reference Group Meeting 12 December 2011, 10:30 – 13:45 Conference Room 2, Victoria Quay Edinburgh

MINUTES

Present

Dr Ken Aitken Consultancy

Carolyn Brown Fife Council Psychological Service Kirsty Butts Adult Care and Support – (Minutes)

Bill Colley Association of Directors of Education in Scotland

Beth Hall COSLA

Kirsten Hogg Camphill Scotland

Ian Hood Learning Disability Alliance Scotland

Richard Ibbotson Autism Initiatives
Alison Leask Autism Argyll & Parent

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 – (Chair)

Dr Iain McClure NHS Lothian

Peter McCulloch Association of Directors of Social Work
Dr Tommy McKay Psychology Consultancy Services
Dr Robert Moffat The National Autistic Society Scotland

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

Alan Somerville Scottish Autism Charlene Tait Scottish Autism

Apologies

Linda Connolly Social Care and Social Work Improvement Scotland

(SCSWIS)

Prof. Aline-Wendy Dunlop University of Strathclyde

Ryan Gunn Scottish Government - Adult Care and Support

Caroline Hamilton Number 6 User

Jane Hook Parent

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

David Watt Education Scotland (formerly HMIE)

Item 1: Welcome, Introduction and Apologies

1.1 Jean welcomed members. Apologies received were acknowledged.

Item 2: Minute of the last meeting held on 18 October 2011

2.1 The Minute was approved, pending revised numbering of the final action point.

Item 3: Action points from meeting held on 18 October 2011

3.1 Action Points were completed or underway. The final action point should read 3, not 4. Some members had difficulty opening the ASD Ref Group spend suggestions word document embedded within the Minutes.

Action Point 1

Kirsty to amend numbering of action point before publishing minutes on website.

Action Point 2

Adult Care and Support Division to re-send list of spend suggestions to group.

- 3.2 Outstanding points being carried forward for future meetings are
- 1. A more detailed discussion paper on the proposed Autism Classification and Reference Assessment project brief Dr Tommy Mackay; and
- 2. NICE clinical guidelines plus DSM V guidelines.

Item 4: ASD Reference Group & Sub-groups

- 4.1 The successful launch of the Scottish Strategy for Autism both at Number 6, Edinburgh and at the Parliamentary Evening Reception on 2 November 2011 was acknowledged and the hope expressed that the implementation of this new Strategy will make a real difference to the lives of those with ASD and their families/carers. The £13.4 million (originally £10 million) announced by the Minister for Public Health has been welcomed by the autism community. The onus is now on all partners, the Scottish Government, COSLA and the ASD Reference Group to ensure that the money is spent wisely.
- 4.2 Members agreed that the original 4 Sub-groups (Training, Diagnosis, Assessment and Interventions, Transitions, and Adults) needed to be revised and that the 'roadmap' (Table 1 in the Strategy) would be used to align Sub-groups with each of the headings. The purpose of doing so is to ensure that the goals and recommendations within the Strategy are delivered through the work of the Subgroups.
- 4.3 It was agreed that the ASD Reference Group needed to establish the following outcomes from today's meeting:
 - What Sub-groups are needed
 - Remit of Sub-groups, to fulfil all the Strategy's goals and recommendations
 - Membership, including the co-opting of new members
 - Leadership
 - Regular commitment to meet regularly and prioritise this work, in order to deliver the Strategy's ambitious agenda.

- 4.4 Members raised the potential for a conflict of interest if someone who is a Sub-group member is also in receipt of money from the Development Fund. Also concern was expressed that funding for future years of a project may link with Subgroup work. The Chair made it clear that regarding bids for money, the ASD Reference Group will not be involved in the scrutiny / monitoring.
- 4.5 With regard to a Research Group, several points were raised:
- the need to ensure that there was no conflict of interest for any ASD members who were also on this group
- the importance of recognising its limitations and passing on work when appropriate e.g. to SIGN
- the need to widen the focus beyond a clinical one to include other research work e.g. from universities.
- 4.6 Following discussion, the following 5 Sub-groups were agreed:
 - 1. Achieving best value for services
 - 2. Cross-agency, user-collaboration and involvement
 - 3. Diagnosis, intervention and support
 - 4. Wider opportunities and access to work
 - 5. Research
- 4.7 To move the discussion forward, it was suggested that Sub-group meetings be held on a monthly basis, half-way between ASD Reference Group meetings. An A4 template will be provided, on which each Sub-group will be able to record details of meeting / date / outcomes / Sub-group decisions / action points for ASD Reference Group's consideration. Sub-groups would then report back by sending these to the Scottish Government Care and Support Branch, who will then provide feedback to the ASD Reference Group.

Action Point 3 Kirsty Butts to produce template for Sub-groups.

- 4.8 Regarding Sub-group recruitment, the ASD Reference Group includes service users amongst its members and it was agreed that user representation / involvement within Sub-groups was vital. Discussion on how best to recruit people with ASD in a way which balances the need to be open, transparent with being pragmatic followed. The following points were noted:
 - Consistency across groups is important
 - The importance of an open, fair process
 - Care and Support Branch hold a list of professionals / service users who have expressed an interest in membership
 - The need to consider the work of the SASN Employability Group in order to avoid duplication of effort
 - Consideration of a separate user / carer group or strengthening of the ASD Reference Sub-groups
 - The necessity for officials, possibly in conjunction with an NHS representative at Chair / CE level to monitor the Development Fund. The need to resolve where Recommendation 10 sits within Sub-group remits

A number of suggestions were made for recruitment; these include:

- Sub-groups could identify gaps in membership and seek the ASD Reference Group's approval to recruit suitable candidates.
- Users or carers could be recruited
- A variety of different approaches / types of engagement are required for different topics and people should be invited from different parts of the country. Potential members should be provided with appropriate support.
- A bulletin could be posted on all national organisation websites, to recruit service users. In addition, feedback could be sought directly with users/user groups at the end of the 2, 5 and 10 year stages as to whether they feel the Strategy's recommendations and goals are being fulfilled.

Action Point 4

Scottish Government Care & Support Branch to type up a list of Sub-group members, main points discussed and remits agreed and Care & Support Branch to circulate. Please see attached document below, which was correct at 12 December 2011:



ASD Reference roup.doc (46 KB.

However, an updated version will be issued as soon as Sub-group membership has been finalised.

Action Point 5

Scottish Government to invite all appointed leaders representing the 5 Sub-Groups to a meeting in early January 2012.

Item 6: Budget priorities for 2011/12

6.1

- Autism Development Fund is £1 million for 2011-12
- Deadline for applications is 12 December 2011
- Initial sift of applications to take place on 14 December 2011
- Assessment panel of selected bids to take place on 15/16 December 2011
- Sift panel to consist of a variety of high level professionals working within the field of autism
- List of those who applied, recommended bids and reasons for recommending these bids will be submitted to the Minister for Public Health
- Letters will be issued by the end of December
- Partnership working will be encouraged
- Overall spend and money for next 3 years will be considered in this process

6.2 Autism Coordinators – options paper – draft job description

The need to consider how local autism coordinators can be integrated across Health and Social Care Services in Scotland was raised as was the need to maximise their potential at local level, tying into the Strategy's goals and recommendations. Various

issues were discussed, including sustainability, number of posts and the need for flexibility as some local authorities have far more developed autism strategies than others. In addition, reassurance was given that posts are clear and not diluted.

- 6.3 Options paper draft job description further points expressed:
 - experience shows that these posts would best be hosted under Option 3, i.e. employing Autism Co-ordinators within national / local voluntary organisations.
 - Clarity of role necessary, danger that it could become casework-orientated
 - £35,000 in Shetland buys far more in terms of services per capita than £35,000 in e.g. Glasgow. In addition to the 3 options offered in the options paper, a further option of graduated funding was therefore suggested, grouping some local authorities in one price bracket, some in another, bearing in mind rural v. urban conurbation demands.
- Regarding Option 3, cost 1 in the Options paper, the following points were made:
 - There's a need to avoid dilution of work people do. Therefore, should consider 8 posts, for best starting point
 - Better to consider smaller rather than larger model
 - Would be more proportionate
 - Need to evaluate any work of this kind
 - Far better way to build successful outcomes and look at what best outcomes would be
- 6.5 Members were invited to submit their views on the draft job description.
- 6.6 Coordinators need to access the information which is already available in large organisations, directing people to resources / sign posting already available. It was also felt that a better salary would be more effective, attracting quality people to posts. To date, there has been no commitment to matched funding by LAs / Health Boards.
- 6.7 A further suggestion combining Options 1, 2 and 3 or any combination was suggested and that local community partnerships would be able to advise on the most appropriate mix. Other points raised
 - Distribution of coordinators should be national and include areas not well served
 - The majority of adults with autism have not been assessed / diagnosed so there is a need to consider how to improve these services and services to support them. The shift to incorporate this need over time needs to be included in the Autism Coordinator's role as this need will only become increasingly apparent over time. Concern was raised over the creation of posts which cannot be sustained and that the need for such services will not be immediately apparent, as information will not be immediately available to them to deliver in the most efficient way. There is, however, flexibility built into how the Scottish Government distribute the money available so these issues can be addressed and a good coordinator should develop capacity for the above.

- 6.8 One view was that a coordinator's role involves signposting on and is mostly strategic, building capacity in community and services and that one coordinator per local authority is important.
- 6.9 Accountability and whether local authorities are accountable to ensure that autism coordinators carry out their work was discussed, with reference being made to Recommendations 2 and 3. In Wales, 6 to 8 Coordinators were rolled out but this did not achieve consistency across the country. It was felt that roll out of community planning is missing from the job description. Best practice should happen within community planning. It was felt that a salary of £35k might not be adequate to attract the right calibre of person to the post.
- 6.10 One solution suggested was to have a number of posts with a 'roving remit'; a team with a mixed skills set which could act as a national resource i.e. a national development team with a small number of roving coordinators. The benefit of this option would be to establish the national picture.
- 6.11 One-Stop Shops. The group considered a paper summarising the development of One-Stop Shops in Scotland and some factual corrections to be made. The paper considered issues relating to the roll out of the One-Stop Shop model, such as Number 6 in Edinburgh and essential requirements for a One-Stop Shop were also discussed. These include:
 - Information / signposting
 - Running of small groups
 - Drop-in services
 - Sympathetic listener / non-judgemental environment
 - Possible location for autism coordinators

In addition,

- A diagnostic service needs to be available, either locally through NHS clinicians OR be available at the hub / One-Stop Shop. Post-diagnostic services are also essential with each linking to the other.
- Sustainability needs to be written into any service specification. An example
 was given from Number 6 where much of the manager's salary is paid from
 outreach services.
- Areas identified as needing hubs where there is little joined up or no practice include:
- Highland
- Dumfries and Galloway
- Tayside / Angus
 - It will be important to include existing providers

Date of next meeting – Tuesday 21 February 2012, Conference Rooms C, D & E, St Andrew's House, Edinburgh, from 10-1pm.