

**ASD Reference Group Meeting  
19 April 2012, 10:15 – 13:30  
Conference Rooms C, D & E, SAH  
Edinburgh**

**MINUTES**

**Present:**

|                          |  |
|--------------------------|--|
| Angiolina Foster         | Scottish Government Director of Health and Social Care Integration |
| Jean Maclellan           | Scottish Government Adult Care and Support – (Chair)               |
| Ryan Gunn                | Scottish Government Adult Care and Support                         |
| Annette Pyle             | Scottish Government Adult Care and Support                         |
| Kirsty Butts             | Scottish Government Adult Care and Support – (Minutes)             |
| Beth Hall                | COSLA  |
| Kevin Brook              | Autism Rights Group Highland                                       |
| Carolyn Brown            | Fife Council Psychological Service                                 |
| Prof. Aline-Wendy Dunlop | University of Strathclyde  |
| Anne Marie Gallagher     | Autism Resource Centre, GCC & NHS GG&C                             |
| Kirsten Hogg             | Camphill Scotland  |
| Ian Hood                 | Learning Disability Alliance Scotland                              |
| Jane Hook                | Parent   |
| Richard Ibbotson         | Autism Initiatives   |
| 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   |
| Dr Iain McClure          | NHS Lothian  |
| Peter McCulloch          | Association of Directors of Social Work                            |
| Cathy McKay              | Scottish Consortium for Learning Disability                        |
| Dr Robert Moffat         | The National Autistic Society Scotland                             |
| Dr Jane Neil-MacLachlan  | NHS Lothian  |
| Val Sellars              | Scottish Centre for Autism   |
| Alan Somerville          | Scottish Autism  |
| Dr Andrew Stanfield      | Patrick Wild Centre for Research into Autism                       |
| Charlene Tait            | Scottish Autism  |
| Jo Thompson              | Scottish Consortium for Learning Disability                        |

**Apologies:**

|                |   |
|----------------|---|
| Dr Ken Aitken  | Ken Aitken Consultancy                            |
| Bill Colley    | Association of Directors of Education in Scotland |
| Linda Connolly | The Care Inspectorate                             |
| Dr Tommy McKay | Psychology Consultancy Services                   |
| David Watt     | Education Scotland                                |

**Item 1: Welcome, Introductions and Apologies**

1.1 Jean welcomed Anne Gallagher, Clinical Lead, Adult Autism Services, as a new member and Kevin Brook, Autism Rights Group Highland (ARGH). Kabie Brook, Chair of ARGH will attend future meetings. Apologies received were acknowledged.

## Item 2: Minute and Action Points from the last meeting held on 21 February 2012

2.1 The Minute was approved, pending one update to Item 6.2

2.2 All Action Points complete. AP11 to be taken forward by Sub-group 2, with lead from Stella Macdonald.

2.3 Aline-Wendy provided an update on AP 5. SASN's name is being retained in the short term. Three new people have been appointed who will start on 14 May 2012.

2.4 Beth provided an update on AP7. COSLA does not have the capacity to attend each of the Sub-group meetings, so liaised with ADSW. Nominations from ADSW have been sought and received for each of the five Sub-groups.

2.5 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
- Update on the Matrix Document – Dr Ken Aitken

### **Action Point 1**

**Kirsty to amend Minute of 21 Feb 2012, Item 6.2. to clarify that the ASD Reference Group is accountable for providing advice on autism spend.**

### **Action Point 2**

**Peter McCulloch to contact ASD Sub-group Chairs with details of ADSW nominations.**

### **Action Point 3 (formerly AP11)**

**Sub-group 2 to consider issues raised at the CJ ASD Development Day with regard to people with autism and the Criminal Justice System.**

## Item 3 Autism Strategy Website – user testing – Cath McKay, SCLD (Item 5 on agenda)

3.1 The Autism Strategy Website aims to keep the wider public informed of work being carried out by the ASD Reference Group and Sub-groups. It will function as an interactive communication tool, providing links to relevant information. Cath sought feedback from members regarding its content, design and structure. The need to avoid duplication with other resources was emphasised, ensuring clear links and signposting. Website contents will be monitored, evaluated and safeguarded, whilst ensuring transparency and accessibility. An online Survey Monkey will be available for use by ASD Sub-groups and potentially for evaluation purposes. There will be a members log-in facility. The website will use colour approved by those with ASD and permit saving documents in a user-friendly mode. An audio version of each page was requested.

3.2 Two separate Scottish Government policies are to be merged, looking at how digital technology/IT and assistive technology can better support public services.

### **Action Point 4**

**Kirsty to note such IT possibilities as a future agenda item for the ASD Reference Group.**

The website will be ready by 15 June 2012 and will need testing.

## **Action Point 5**

### **Members interested in joining the website's User Testing Group to contact Kirsty Butts.**

Item 4: Update – One stop shops and mapping coordinators – Richard Ibbotson, Dr Robert Moffat, Charlene Tait.

4.1 One stop shops: Six locations have been identified, with each organisation leading on two locations, as follows:

- Fife, Lanarkshire – Scottish Autism
- Ayr, Aberdeen – National Autistic Society
- Highland, Perth – Autism Initiatives UK

Next steps:

- Involve local stakeholders/partnerships, identifying requirements.
- Six new groups for the above areas and a national group to represent and share interests of all groups will be created. The groups' operation and development will be evaluated.
- Priorities will be information, sign-posting, diagnostic support, sustainability. Each service will however be unique to the area and its priorities.

4.2 One stop shops will be established in a cross-section of rural and urban locations and have a core function but regional differences. As local partnerships will implement these, limited resources need to be placed where they reap maximum results. Priorities are how best to deliver the six new one stop shops, and refresh the two existing one stop shops in Glasgow and Edinburgh, ensuring best value for money and how to work nationally, ensuring capacity-building and a joined-up approach. Links need to be established with the 32 local authorities, to include clinical teams/diagnostic services in Health, as it will mainly be statutory agencies involved in the actual delivery of services.

## **Action Point 6**

### **One-stop shop Leads to meet with COSLA and SG Officials to discuss delivery of one stop shops, including links to health and local authorities.**

4.3 Role of Mapping Coordinators

Inequalities and regional service needs will be mapped, avoiding duplication of existing services/signposting so that money can be directed towards new services. Buy-in from local authorities is vital, as they will be key in assisting in the establishment and success of one stop shops and autism coordinators. There will be 7 mapping coordinators carrying out this exercise in 3 or 4 areas, 1 project leader and 1 administrator. A job specification for mapping coordinators has been drawn up and a post advert drafted. IT resources identified and costed.

4.4 Remit of Mapping Coordinators

This should be flexible to meet different needs in different areas. The remit is based on the Ten Indicators and takes into account which local authorities are currently successfully taking action to address the need for autism services. Mapping

Coordinators will plot this information, noting what is being and could be done, in each location over a period of 10 months and submit their recommendations to deliver improvements to services and inform the role of future local autism coordinators in each area.

4.5 Mapping is an essential component of understanding how money is currently spent and what progress there has been as a result. Coordinators will cover all of Scotland, linking with local providers and local authorities to discuss what is needed. They will work in partnership with COSLA, ADSW and others.

4.6 A clear pathway between diagnosis and post-diagnostic support and care in all areas, which is currently lacking in some areas, is needed, as children and young adults continue to fall between different services.

#### Item 5: SIGN / NICE guidelines – Dr Iain McClure and Dr Jane Neil-Maclachlan

5.1 This item was put on the agenda to discuss the merits / demerits of NICE and SIGN Guidelines, with a view to developing Adult Guidelines. Dr Iain McClure provided a presentation.

SIGN is the Scottish equivalent of NICE and is part of Health Improvement Scotland. SIGN is highly regarded globally in terms of robustness and validity of approaches and has been widely embraced. Its reviews are systematic and any recommendations made from scientific research are backed up by supporting evidence. SIGN guidelines aim to be both relevant and helpful to professionals looking for evidence.

5.2 SIGN and NICE guidelines look at the same areas but SIGN evidence-based guidelines are currently for children/young people only. Evidence-based guidelines for adults with autism are needed, as an increase is being seen in

- the prevalence of autism across all ages
- the rate of detection (faster at present in children but this rate will increase in adults), and
- the cost of assessment

There are significant disparities in multi-agency ASD provision in Scotland, most of which is still for children. Two Recommendations within the strategy highlight the need for adult guidelines.

5.3 Adult Guidelines would look at clinical intervention, be evidence-based and adhere to an underlying scientific approach. There may be sufficient national need to look at adult guidelines in terms other than those based purely on a scientific approach.

5.4 NICE guidelines are intended for England and Wales. Geographically, Scotland is very different and this informs our work. SIGN Adult guidelines would add to NICE by providing a Scottish perspective, reflecting the differences in legislative support to adults with autism, Scotland-specific recommendations for audit and research, a very robust literature evaluation and a robust clinical base. In Scotland, the need for improved diagnosis, assessment in the transitional phase for people

with autism and pathways for young adults who are unable to access resources, due to not falling into appropriate categories, could also provide a focus.

5.5 Debate followed around the merits of producing SIGN Adult Guidance at this stage. It will take 2-3 years for Adult SIGN Guidelines to be developed and as major change is expected as a result of the Strategy over the next few years, it was asked whether it was wise at this stage to put time/money into writing SIGN Guidelines, what the added value of SIGN Adult Guidelines was and the cost to the public sector. It was stated that Dr Tommy McKay's research results on micro-segmentation should inform this decision. An alternative would be to use NICE guidelines as a basis and in e.g. 3 years time, produce Adult SIGN Guidelines when enough evidence has been generated.

5.6 Dr Iain McClure has submitted an application to SIGN to develop Adult Guidelines and is seeking support from members for this application.

### **Action Point 7**

**Members to consult with their organisation on the recommendation to support the application to SIGN for ASD Adult Guidelines, given that it will take 2-3 years to develop these and that NICE guidelines are currently out for consultation. Members to report back at next ASD Reference Group meeting.**

### Item 6: Angiolina Foster, new Director of Health and Social Care Integration

6.1 Jean welcomed Angiolina Foster who spoke about her role and heard briefly from each Sub-group about the successes and challenges of their work in developing the implementation of the Strategy's recommendations.

### Item 7: Sub-group leader to provide an example of a success and of a challenge for Angiolina Foster

#### 7.1 Sub-group 1 – Achieving Best Value for money

Service planning is perceived as being inconsistent and not taking into account the ASD Guidelines. It has been crisis-driven and reactive, rather than focusing on proactive interventions, when minimal support would really help and on outcomes which are personally more relevant. There can be a high quality service but traditionally, outcomes have been very poor for those with autism. However, on the positive front, this issue is being tackled and good progress is being made.

#### 7.2 Sub-group 2 – Cross-agency collaboration and user involvement

The group is leading on how a range of organisations can learn to work together effectively to support people with autism and the need for those with autism to be consulted regarding service provision. They are also working on how to ensure the interests of families who support people with more profound autism are understood and how they can be helped. A positive is that the group are identifying areas of good practice.

#### 7.3 Sub-group 3 – Assessment, diagnosis and intervention

The challenge is how to get NHS Health Boards to take responsibility for people with autism who do not fit neatly into the categories of those with Learning Disability or Mental Health issues. Positively, the group reported it is on its way to making very good progress on implementation.

#### 7.4 Sub-group 4 – Wider Opportunities and Access to Work

People with autism should be seen as an asset. Challenges include engaging with employers; speaking to the non-converted and engaging with a wider audience. Many initiatives are focused on the under-25s; most of those needing support are over-25s. 'Reasonable adjustments' for people in the workplace can be 'light touch'; small changes can make huge differences to people. The whole population needs to make changes – and this includes the area of employment. On the positive front, some excellent work is underway around Scotland for employment opportunities, to which Scottish Autism Service Network are contributing.

#### 7.4 Sub-group 5 – Research

The group are awaiting findings from Dr Tommy McKay's work addressing Recommendation 5 (analysis of Knapp's work on the economic costs of autism and application to the Scottish context), a vitally important piece of work. Knapp's ground-breaking research into micro-segmentation identifies the demography of sub-groups of those with autism and provides projectories with and without intervention. It identifies models of good practice and provides quality of life indicators. The challenge will be to provide evidence to the Scottish Government of the costs of intervention versus the costs of those not requiring funding or intervention.

7.5 Members on the spectrum were asked whether they wanted to highlight to Angiolina the specific needs of those with autism.

Policy changes in Scotland and the UK are having an impact on people with autism. There are people with ASD who are in supported accommodation for people with a learning disability, housed in the wrong place and either not getting any or the correct priority services. People who have mild autism or are able-bodied need a small amount of support and have their own ideas as to what can help but cannot cope with change. If there is no proper intervention, such people can fall through the cracks and go into crisis. Concern at the lack of joined-up services for people with autism was expressed and the need to urgently address this predictable 'lost in the system' issue.

Regarding personally more relevant outcomes, the challenge of the autism spectrum is that some people need lots of support to achieve normal traditional outcomes but not all on the spectrum want these things. However, they should have access to them and they should be able to articulate what they want.

It was highlighted that self-understanding has been very important to individuals on the spectrum. Autistic people often feel they are being told what to do all the time. They are very self-critical and aspire to get things right. The majority of people with autism are not diagnosed. Capacity-building is very important for the individual and the family. Parents and the community need to acquire skills to support those with autism. Occasional input for those with autism but without a learning disability needs to be considered, particularly during transitional phases. A national contribution made by everyone to provide those with autism, ADHD, mental health and / or disabilities so that when they get to age 16, they can thrive and not sink would help.

Angiolina Foster expressed her thanks, saying she found the meeting an insight and very interesting. Reflecting on this meeting in her weekly update, Angiolina Foster commented that it was both moving and educative to witness the compelling way in which those members of this group who are on the autism spectrum articulated their aspirations for the service. It was also hugely positive to hear these stakeholders acknowledge the significant progress that has been made in recent years.

#### Item 8: ASD Reference Group Sub-groups

##### 8.1 Updates from second meetings.

This agenda item was deferred.

##### 8.2 Sub-group 6 – User and Carer Group -update

The ASD Reference Group are clear that any user / carer group would be central to the decision-making process. We are currently recruiting for this group. There has been a keen interest in such representation and a very healthy response so far to Scottish Government's advertisement. The deadline for applications is 27 April 2012 and a decision on group members will be made by the end of June.

Some people felt that the terms 'user' and 'carer' were not helpful and the ASD Reference Group has expressed an interest in reviewing these terms.

#### **Action Point 8**

**Sub group leaders were asked to highlight any issues from their second meetings to Kirsty.**

Date of next meeting – Tuesday 19 June 2012, Conference Rooms C, D & E, St Andrew's House, Edinburgh, from 10-2pm.