ASD Reference Group Meeting
19 June 2012, 10:00 – 14:00
Conference Rooms C, D, E, SAH
Edinburgh

MINUTES

Present:

Jean Maclellan	Scottish Government Adult Care and Support – (Chair)
Annette Pyle	Scottish Government Adult Care and Support
Kirsty Butts	Scottish Government Adult Care and Support
Julie Crawford	Scottish Government Adult Care and Support (Minute)
Kevin Brook	Autism Rights Group Highland (by video conferencing)
Linda Connolly	The Care Inspectorate
Prof. Aline-Wendy Dunlop	University of Strathclyde
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
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 Ken Aitken	Ken Aitken Consultancy
Dr Tommy McKay	Psychology Consultancy Services
David Watt	Education Scotland
Dr Andrew Stanfield	Patrick Wild Centre for Research into Autism
Charlene Tait	Scottish Autism

Apologies:

Carolyn Brown	Fife Council Psychological Service
Bill Colley	Association of Directors of Education in Scotland
Beth Hall	COSLA
Jane Hook	Parent
Peter McCulloch	Association of Directors of Social Work
Dr Ian McClure	NHS Lothian
Paul Lennon	Autism Resource Centre, Glasgow

Item 1: Welcome, Introductions and Apologies

1.1   Jean welcomed everyone to the meeting and introduced Kevin Brook from Autism Rights Group Highland via video conferencing. Apologies were received and noted.

Item 2: Minute and Action Points from the last meeting held on 19 April 2012

2.1   The minute was approved. David Watt requested that his name plate be updated.

2.2   **AP1** - The minute of 21 February was amended.

2.3   **AP2** - Peter McCulloch has written to sub-group chairs providing details of ADSW representatives. Sub-group 3 now have ASDW reps. Awaiting update.

2.4   **AP3** - The Criminal Justice ASD Development Day will be discussed at the next meeting of Subgroup 2.

2.5   **AP4** - This has been noted as a future agenda item.

2.6   **AP5** - Kirsty has received responses from Kabie Brook, Idem Lewis, Ken Aitken, Kirsten Hogg, Charlene Tait and Alison Leask.

2.7   **AP6** - This meeting is taking place on Friday 22 June 2012 in Alloa.

2.8   **AP7** – This will be discussed on today's agenda.

2.9   **AP8** – Sub-group leaders have submitted a number of comments regarding the User and Carer group via the Sub-group minutes templates and at the recent Sub-group Leaders meeting.

Item 3: Recent documents having a bearing on ASD services – Dr Ken Aitken

3.1   This looked at how we can commission best practice on ASD in Scotland through evidence-based practice. There are 3 phases to this: 1. research – which often has little impact; 2. using accepted methodology for best practice; and 3. practice-based evidence – evidence as to how and whether practice works in the real world. We need to use transparent, easy-to-use terminology and be able to identify gaps in the evidence base, carrying out research to address any such identified gaps. We need to be clear about the criteria. More importance should now be placed on Comparative Effectiveness Research (CER) and research looking at small numbers of people. Organisations relevant to Scotland are SIGN and NICE and Cochrane in England, which overlap in areas cover. In order to effectively review the research literature, there needs to be a protocol in place and a way of ensuring that results from these reviews are implemented.

3.2   There is an absence of research on the effects of intervention for adults with ASD in the UK and funding through the Autism Development Fund might be a way to address this. Research needs to be independent of pharmaceutical companies where there is a conflict of interest. There is a need to re-think methodology currently used, sponsor research to support that and provide an evidence base, through single-case studies, of which there are a large number which could be collated and through small group studies.

Item 4: Discussion paper on the Matrix document – Dr Ken Aitken

4.1   The Matrix is a paper which has been produced by NHS Education Scotland (NES) to inform the commissioning of Clinical Psychology services, including those for ASD. It is in the public domain and carries the Scottish Government logo. The document compares SIGN and NICE guidance and covers 5 separate client groups. The section on ASD is for children and young people's services and there is no mention of adult services. This would seem to give a misleading view of the potential role of Clinical Psychology services in ASD, providing a poor review of the relevant literature and failing to highlight the manpower and cost implications of its recommendations. Many of the studies included have no robust evidence or controls to prove their effectiveness so do not inspire confidence in terms of implementing the interventions suggested. As services refer to this document for guidance, the group

needs to make a decision on the best way to take this forward and whether they agree with the document.

4.2   Autism should be listed under all categories, not just that of self-injury, including psychological therapies, where it is currently only listed under clinical psychology. NES need to establish links with Mental Health as autism is a key area of the Mental Health Strategy.

4.3   The group needs to meet with the appropriate person in NES to discuss their concerns regarding The Matrix document.

Action Point 1
Ken Aitken, Jane Neil-MacLachlan, Val Sellars and Jean Maclellan to meet with the appropriate person in NES to discuss The Matrix. Kirsty Butts to co-ordinate availability and arrange date/time.

Action Point 2
Ken Aitken to forward appropriate sections of his presentations to Kirsty Butts for circulation to the ASD Reference Group.

Item 5: ASD Reference Group Sub-groups

5.1   We have received templates back from the sub-groups. Information in templates can be used to show what we can do to improve the sharing of information across the groups. The groups need to be pro-active with no duplication – people should not be approached if other groups have already done so. There is a need for a plan or roadmap, mapping who is engaging with whom. There are some overlaps between the recommendations.

5.2   There was a discussion regarding the Users and Carers Group and it was found that there have been 41 applications to join the Users and Carers Subgroup with c. 25% being users and 75% parents/carers. Aline-Wendy Dunlop and Alison Leask will help with the organisation of a workshop. Following some concerns expressed regarding the name of the group, it will be renamed 'People Living with Autism', if endorsed by the sub-group when established.

5.3   There were some discussions about people with autism and carers being on the same group and the size of the group, if additional support for were required. It also needs to be clear how the sub-group relates to the ASD Reference Group and what skills members need. In the interest of transparency, it was suggested that inviting applicants to a workshop to ensure that all applicants have an understanding of what the sub-group would involve and the best way forward. There will be a sift of the applications, following the workshop, with 13/14 people joining the group.

Action Point 3
Ken Aitken to ask Francesca Happe to come to the next ASD Reference Group meeting to discuss DSM-5.

Action Point 4
Kirsty Butts and Annette Pyle to produce a roadmap for the ASD Reference Group, providing an overview of actions/work undertaken to ensure there is no duplication of sub-group activity.

Action Point 5
Aline-Wendy Dunlop, Alison Leask and Kabie Brook to discuss the organisation of the workshop for applicants to the User and Carer Subgroup and provide Kirsty Butts with the details.

Item 6: Presentation on Report to Parliament on the Additional Support for Learning Act 2004 (as amended) – David Watt

6.1   Over the past two years, the Scottish Government has improved its statistical analysis of school children and young people with autism. In the past, schools were only asked in the Census for these figures but now schools and local authorities are being asked directly for this information. There is a variance across the education authorities. We are now getting a better picture of how many people are moving on after school and to which destination – employment or further education.

6.2   When asking for a primary diagnosis, the school will make the decision For this purpose, children and young people are classified as having either a learning disability or autism. However those children classified as having autism could also have a learning disability. There should be guidance to let higher education / employers know that the person has ASD and although transitions are a challenge, support for the person would be expected. Anyone not moving on to gain further qualifications are identified in the statistics. Skills Development Scotland do some tracking.

6.3   Although the statistics regarding qualifications of those leaving school with ASD reflects the expected prevalence, there is a chance that autism is being under-recorded. Some of the classifications do not match – learning disability is not the same as moderate learning difficulties. Figures for ASD show a very low outcome for employment but these need to be seen against those entering Further or Higher Education. Statistics are getting better but there is still room for improvement.

Action Point 6
Jane Neil-MacLachlan to circulate her Menu of Interventions for discussion at the next ASD Reference Group meeting on 23 August.

Action Point 7
Aline-Wendy to circulate The School Leavers' Destination Report, once she has approved it, to the ASD Reference Group.

Item 7: Autism Event – November 2012 – Discussion around planning (Recommendation 9) – Charlene Tait

Action Point 8
Charlene Tait will send her discussion paper regarding Recommendation 9 to the Subgroup Leaders regarding the Autism event to be held late 2012. Leaders will discuss through email.

Item 8: Discussion paper on the proposed Autism Classification and Reference Assessment project brief – Dr Tommy MacKay

8.1   The Microsegmentation Project looks at intervention and evidence-based practice. It identifies through cost-based analysis, the escapable costs of autism i.e.those that would not be incurred if there were suitable interventions for the ASD population and through the use of segments, the issues and challenges and maps results to create a basis for support The funding for this project started in March and the core research team consists of Professor Martin Knapp – London School of Economics, Professor Jim Boyle and Professor Tommy Mackay – University of Strathclyde and Michelle Dawson – University of Montreal. A steering group to implement the recommendations is being organised and will form links with the work of the ASD Reference Group Research Sub-group.

8.2   The project is made up of the following stages:

- Microsegmentation – A systematic review of all peer-reviewed population or clinical studies with details of samples defined in terms of DSM/ICD criteria for ASD and co-morbid conditions. This will include the assessment of relevant fields of literature and changes in diagnostic criteria (DSM/ICD), the construction of search terms and the extraction of data.
- Demographic Mapping – all relevant data to Scotland pertaining to ASD at national / local level will be collected and compared with data from other sources. A conceptual map will be created.
- Economic Analysis – Quality of life indicators, relevant to data gathered, will be constructed and quantified and intervention literature identified. Will analyse economic impact and cost benefits of interventions, and examine gross national costs for a wide range of service requirements, mapping the ASD population onto that and further break this down into categories, including ADHD, depression and criminal justice.
- Communication – there will be regular reports to the ASD Reference Group, ongoing liaison with the ASD Research Subgroup, a project report and peer reviewed articles and national and international conference presentations.

Action Point 9
Tommy MacKay to circulate his presentation on the proposed Autism Classification and Reference Assessment project to the ASD Reference Group.

Item 9: Development Fund and additional funding

9.1   An email, which includes an application form and full details widely distributed inviting them to apply for the second round of Autism Development Fund funding. The funding has been increased to £1.5 million for 2012/13 and will be the same for 2013/14 and 2014/15. Application forms are to be returned by 17 August 2012. As

before, there will be an external sift panel Successful applicants' projects will be monitored quarterly as before.

9.2   There were some discussion about avoiding funding projects if they duplicate current provision. It was suggested that someone out with the ASD Reference Group be on the sift panel who has knowledge of what is happening across Scotland.

Action Point 10
Members to provide Kirsty Butts by 3 July 2012 with suggestions for one additional member for the sift panel for the next round of the Autism Development Fund, bearing in mind that this person should have a sound knowledge of existing services in Scotland catering for those on the autism spectrum and taking into account any conflict of interest they may have being a member of this Sift Panel.

Item 10: Scottish Autism Research Application – Database of optimal methods for early screening and identification of ASD – Dr Ken Aitken

10.1   At the moment there is no effective early screening process in place which identifies ASD and overly inclusive assessments can result in a high demand for services but can be restrictive. Dr Ken Aitken and Dr Felix Agakov have researched this and the proposal is for funding to review evidence and develop an evidence-based screening process using the Cochrane protocol. Prevalence rates vary enormously around the world, using the same methods of detection but it is unclear why. Environmental factors appear to play a role. The findings will be used to establish a 'minimum useable database' and run a pilot study, to determine whether this data is helpful.

10.2   The question was raised if this would be worth doing and if it was necessary for Scotland and be unique. There is no-one else doing this in Scotland. The database would be able to track children over time and might help us understand children who improve significantly when diagnosed at a very young age. Ken reported that there are a large number of assessment tools but nothing which readily collates the information. This research would improve on and collate what is currently available. There were some concerns about funding being used for research but research is needed to produce better services.

10.3   The majority of the ASD Reference Group were happy for this project to be funded, initially for one year, with the pilot study forming part of this.

Item 11: SIGN Application – members opportunity to report back

11.1   Members were asked whether the SIGN or NICE guidelines should be used. The majority agreed that NICE should be used in the interim, until such time that enough evidence exists to take adult SIGN guidelines forwards, perhaps in a couple of years time.

Action Point 11
ASD Reference Group to provide responses to Jane Neil-MacLachlan's suggestion to go with NICE Adult Guidelines in the interim, until enough evidence exists to take SIGN Adult Guidelines forward, by 3 July 2012.

Item 12: A.O.B

12.1   To Note : The Public Consultation on the Children and Young Person's Bill is out for consultation from 4 July to 25 September 2012.

Date of the next meeting – Thursday 23 August 2012, Conference Rooms A & B, St Andrew's House, Edinburgh, 10:00 – 14:00.