ASD Reference Group Meeting
23 August 2012, 10:00 – 14:00
Conference Rooms A/B, St Andrew's House

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)
Dr Ken Aitken	Ken Aitken Consultancy
Kabie Brook	Autism Rights Group Highland
Carolyn Brown	Fife Council Psychological Service
Linda Connolly	The Care Inspectorate
Prof. Aline-Wendy Dunlop	University of Strathclyde
Anne Marie Gallagher	Autism Resource Centre, GCC and NHS GGC
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 Tommy Mackay	Psychology Consultancy Services
Dr Iain McClure	NHS Lothian
Peter McCulloch	Association of Directors of Social Work
Dr Jane Neil-MacLachlan	NHS Lothian
Alan Somerville	Scottish Autism
Charlene Tait	Scottish Autism
David Watt	HM Inspector Scotland

Apologies:

Bill Colley	Association of Directors of Social Work
Beth Hall	COSLA
Robert Moffat	The National Autistic Society Scotland
Val Sellars	Scottish Centre for Autism
Dr Andrew Stanfield	Patrick Wild Centre for Research into Autism

Item 1: Welcome, Introductions and Apologies

Jean welcomed everyone to the meeting. Apologies were received and noted.

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

2.1   The minute was approved.
2.2   **AP1** – The meeting with NES to discuss concerns about the Matrix has been arranged for 17 October 2012 - **Cleared.**
2.3   **AP2** – Ken Aitken's presentations from the last meeting have been sent to the ASD Reference Group - **Cleared.**

2.4   **AP3** - The invitation to Francesca Happe to come to the next meeting has still to be arranged by Ken Aitken - **Carried forward.**

2.5   **AP4** – The roadmap for the ASD Reference Group has been completed and sent to the Group – **Cleared.**

2.6   **AP5** – Aline-Wendy, Kabie and Alison met to discuss the organisation of the User and Carer Subgroup workshop – **Cleared.**

2.7   **AP6** – Jane Neil-MacLachlan to bring a draft of the Menu of interventions to the next meeting for discussion – **On agenda for discussion.**

2.8   **AP7** – Aline-Wendy Dunlop to circulate The School Leavers Destination Report, once approved. This item was carried forward.

2.9   **AP8** – Joint improvement Team are collaborating on the 1 November event in Stirling – **Cleared. On agenda for discussion.**

2.1.1   **AP9** – Tommy Mackay's presentation has been circulated to the group – **Cleared.**

2.1.2   **AP10** – No additional suggestions were sent to Kirsty. The same panel will carry out the Autism Development Fund sift on 30/31 August. There have been just under 100 applications with an even spread across categories – **Cleared.**

2.1.3   **AP11** – A submission was sent to the Minister advising that insufficient evidence exists to take SIGN Guidelines forward at this stage – **Cleared.**

Item 3: ASD Reference Group Subgroups – Update on Subgroup 6 and Workshop Event

3.1   The workshop took place on 6 August 2012 at Atlantic Quay, Glasgow. Around three quarters of the applicants attended and the consensus was that the morning session had been useful. The afternoon session consisted of 3 workshops: 2 parent/carer workshops and 1 for people with ASD. In the plenary session, the composition of the sub-group was discussed, including whether to keep it as one group or have separate groups for users and carers. To accommodate all views, Users and Carers will meet separately during the first half and the whole group will reconvene for the second half of meetings. Members felt strongly that the group's Chair should be independent. It was agreed that the group be limited in number and that members select a name for the group at their first meeting. Some people cannot commit to attending the meetings and all applicants who expressed a continued interest by returning forms stating their preferred mode of participation can be involved in the e-consultation group. Decisions on Sub-group membership will be made once all forms have been returned.

Action Point 1
Paul to create template for sift of applicants for sub-group 6.

Action Point 2
Julie to send Notes from the workshop to all applicants and a nomination form to all applicants not present on the day, to confirm their preferred method of participation. This form, which was issued to all workshop attendees on the day, to be returned by 31 August 2012 to Kirsty Butts.

3.2   Jane Hook advised the group that she was not made aware that the event was going to take place on 6 August.

Action Point 3
Julie Crawford to send information and nomination form to Jane Hook regarding Sub-group 6.

3.3   A number of attendees gave positive feedback following the event, including some who, after attending, changed their minds as a result of their experience that day and on hearing about the work of the Scottish Government, ASD Reference Group and Sub-groups and what the new Sub-group aimed to achieve.

Item 4: Presentation on the Learning Disability Observatory (Professor Anna Cooper)

4.1   Professor Anna Cooper gave a presentation on the Learning Disability Observatory to the group to consider whether it should be broadened to consider people with autism. In her opinion, neither the Scottish Public Health Observatory nor NHS Health Scotland adequately address the needs of LD/Autism populations in Scotland. The group were asked whether they felt the Scottish Observatory should also include the ASD population.

4.2   Accessing data on people with ASD is very difficult. High functioning adults on the spectrum slip through the net and the majority of adults are not diagnosed. Many with ASD have a learning disability but health professionals may not have picked up on the ASD aspect and most of this population is captured under LD data. LD/Autism together are easy to capture: capturing non-LD autistic people is more difficult. There would therefore be value in this work undertaking to collect autism data, both for LD/Autism and autism alone. It was pointed out that services can only respond to those who identify themselves, whilst recognising those who do not.

4.3   We need to think about both mental and physical health in relation to people with ASD and the co-morbidity between them, primarily anxiety issues. Currently only ADHD is captured in data by CAMHS, in relation to autism. Dr Iain McClure suggested recording co-morbidity in relation to autism, starting with under 18s. E-Say statistics would be particularly helpful/useful for people with autism and Learning Disabilities.

4.4   Issues with access and communication can be similar for both people with ASD and learning disabilities. Services need to be flexible so people have a choice. There are different issues for those living with carers and these groups who do not. We need to target these groups separately.

4.5   Such an Observatory provides a safe haven where data can be handled safely, stripping away all identifying information, and using approved people to analyse this data.

4.6   It was agreed in principle that a broadening of the Scottish Observatory to include people with autism should be considered and a meeting arranged to discuss how to take this forward.

Action Point 4
Kirsty Butts to send Professor Anna Cooper contact details for Frank Strang, Deputy Director for Primary Care, Scottish Government, to determine what the

issues are, how they will impact on broader issues and how this all joins up in practice. Once known, Anna to work with relevant agencies to address them.

Action Point 5
Peter McCulloch to provide Anna Cooper and ASD Reference Group with examples of good practice where autism services work together and link up with social work.

Action Point 6
Group to be formed who will work with Anna Cooper to forward the agenda in broadening the Learning Disability Observatory to include autism. Kirsty to provide details of the following members of the Group who would like to discuss how to take this forward – Stella Macdonald, Professor Aline-Wendy Dunlop, Robert Macbean and Dr Jane Neil-Maclachlan.

Item 5: Discussion on ASD Budget

5.1   This item was not discussed due to some members having to leave the meeting early.

Post Meeting Note: The Minister announced Autism funding priorities on 4 October.

Item 6: Update on Autism Achieve Alliance waiting list research findings (Dr Iain McClure)

6.1   Dr Iain McClure gave the group an update on the waiting list research being carried out by the Autism Achieve Alliance (AAA). The project based at Queen Margaret University is at the half way stage, due to complete in 2013. AAA have been commissioned by the SG to explore the process of waiting for an assessment and diagnosis of autism, clarifying the nature and extent of the problem of time being taken to be seen across the age range for all of Scotland.

6.2   Within the first stage of the project, 450 phone calls were made and 94 services across Scotland which carry out diagnostic assessment were identified. From this, 66 identified themselves as routinely carrying out diagnosis for autism. The average duration of diagnosis showed that for children, the average wait for the first appointment in the assessment process to get a diagnosis was 187 days (c. 6 months) and the wait for referral to diagnosis was 300 days (c.10 months). For adults the average wait for the first appointment was 68 days (c. 2months) and from referral to diagnosis was 155 days (c. 5 months). The findings regarding what affects time taken to diagnose will be explored further and reported back to the group. The discrepancy between waiting times for children and adults was highlighted.

6.3   Dr Iain McClure stated that it is important to know more about why people are waiting and what we can do about it. Team capacity to assess people, and whether it was adequate, was also discussed; such information will emerge through this research. This is important, to know what the child requires and to give appropriate

intervention. The group discussed the listing of ASD services and possible errors in detail.

6.4   In general, it was felt that many services are inadequate following assessment or stop when the person is waiting for a diagnosis and concern was expressed regarding what happens after diagnosis and how families can access services. The group discussed diagnostic standards and that current screening often misses autism as many behaviours are not picked up through this; a multi-agency approach, which should vitally include education services, would help address this issue. The project is looking at the patient journey and how it can be improved.

6.5   Iain was asked if people who are on the waiting list are involved in the project, as this is necessary. It was explained that this would not get through the ethics committee if families were involved.

6.6   It was stressed how important it is for the mapping exercise currently underway to pick up on this, gathering illustrative data to supplement AAA's research findings. It was agreed that a future agenda item should be Ethics and Autism.

Action Point 7
Members who disagree with the numbers of services being offered in any area for children or adults to contact Iain McClure directly.

Action Point 8
Dr Iain McClure to ask Dr Kirsty Forsyth whether she can link with those doing assessments/diagnosis and provide them with the information they require by the required deadlines.

Action Point 9
Carolyn Brown to forward Dr Iain McClure 25 returns from around Scotland (multi-agency process for diagnosis) received by Fife Council Psychological Service for him to take into account and circulate further.

Action Point 10
Dr Tommy Mackay to send email to Annette to forward to Iain, Dr Kirsty Forsyth and team regarding how the differences between assessment teams throughout Scotland be recognised and reflected in waiting list statistics. Of 16 assessment teams, either 14 or 15 are local; 1 or 2 are national.

Action Point 11
ASD Reference Group to consider the point of Ethics and Autism and ensure that the Autism Co-ordinator Mapping Exercise gathers illustrative data of those on waiting lists for diagnosis, as the AAA project doesn't include this data.

Item 7: Blue Badge Scheme (Sharon Grant/Graham Beale – Transport Scotland)

7.1   Sharon Grant presented on the Blue Badge Scheme reform, a 5 year programme is in its 3rd year currently focusing on mobility issues. Independent mobility assessments are about to be introduced and will now be carried out by

Occupational Therapists, not GP's. The 2010 consultation asked whether badges should be extended to people with dementia or severe autism. Ministers are keen explore people with autism getting Blue Badges but there is a need to widen to other conditions.

7.2   Wales has undertaken research on this and are keen for Scotland to pilot this scheme. The pilot needs careful planning, evidence of the value of extending the Blue Badge needs gathered and there are no guarantees this will be implemented. Any evidence emerging from a pilot needs to be robust and responded to in accordance with what the evidence indicates. Transport Scotland would like to meet with SG officials to discuss the feasibility of this and Beth Hall, COSLA would like to discuss the implications / impact for LAs / police.

7.3   A steering group is to be set up to agree a robust definition of criteria regarding to whom the scheme should be extended and to develop the pilot model.

7.4   There was further discussion around how people would access a Blue Badge, who would carry out the assessment, what form this would take and the appeal/review process. The Blue Badge is assessed for 3 year periods only.

Action Point 12
Kirsty Butts to email ASD Reference group seeking members or Sub-group members to help with forming a definition with regard to whom the badge should be extended and with developing a model for piloting.

Item 8: Update on Autism Event – November 2012

8.1   The framework for this event will be similar to that of the Sub-group 6 workshop on 6 August. Jean will chair and present on the Strategy and work of the ASD Reference Group and Sub-groups followed by Sub-group leaders who will deliver presentations on their work. There will be two afternoon workshops, the first of which will be offered around the work of Sub-groups, One Stop Shops and Mapping Coordinator work, the second of which will be based on regions, providing an opportunity to learn more about regional services for autism and gaps in these, and also hear about projects being funded through the Autism Development Fund 2011-12 in these areas, to gain insight into what is being delivered. The SG are working in collaboration with Michael McCue, a Joint Improvement Team associate, who is identifying good practice examples within these funded projects, which can be show-cased at the event.

8.2   The event will be an update of progress to date in work currently being undertaken to fulfil Recommendation 9 of the Strategy. As projects have yet to be evaluated, it is not possible to know outcomes at this stage. We will highlight that future events will seek to demonstrate best value and what is good practice.

Action Point 13
For the ASD November event, members should send Kirsty Butts their views on what the content remit of the afternoon workshops should be.

Date of the next meeting: Tuesday 23 October 2012, 10:00-14:00, 4ER, St Andrew's House, Edinburgh.

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