

**Notes of a Meeting of the Asperger Syndrome Subgroup
of the Lothian Joint Learning Disability Strategy
Review Board**

Held on 31st May 2006 at 'Number 6', 6 Melville Crescent

Present:

Les McEwan	<i>Chair</i>
Denis Rowley	<i>Project Manager</i>
Jane Neil-MacLauchlan	<i>Adult Autism Co-ordinator</i>
Cllr. Mark McInnes	<i>CEC</i>
Mike Penny	<i>CEC Housing</i>
Rebecca Dale	<i>Local Area Co-ordinator, CEC</i>
Pam Spence	<i>Scottish Society for Autism</i>
Moira Dickinson	<i>Steering Group, 'Number 6'</i>
Richard Ibbotson	<i>Director, Autism Initiatives</i>
Suzi Wong	<i>PASDA</i>
Isobel Bruce	<i>ELAS</i>
Duncan McIntyre	<i>Midlothian Social Work</i>

Apologies:

Don McKenzie
Lisa Dunne
Rona Laskowski
Tim Wheeldon
Bob Whalley
Vincent Kennedy

1. Note of Previous Meeting

a) Welcome: Denis Rowley welcomed Les McEwan to the meeting and invited him to take the role of Chair with immediate effect.

b) Attendance: It was noted that Mike Penny had in fact been present at the last Meeting. Apologies were offered by the minute taker!

c) Matters Arising: A meeting with Mental Health colleagues has not yet been organised. Possible dates for a meeting were discussed and Denis agreed to ask Phyllis Veitch to set this up.

Please note that this meeting has now been arranged for 10am on 13th July in MacKinnon House Board Room, Royal Edinburgh Hospital.

2. Report from the Strategy Review Board

Denis reported that he had presented the Draft Interim report to a meeting of the Strategy Review Board. There had been feedback on matters of style and presentation of the Report. A new version incorporating all the proposed edits will be produced and will be presented with an executive covering paper to the Executive Management Team Meeting of Lothians NHS.

As a result of the discussions at the Strategy Board it had now been agreed that two versions of the Interim Report would be produced, with an easy read version being commissioned via People First and FAIR.

Discussion ensued about the decision making process in regard to the final recommendations emerging from the Strategy. It was agreed that Denis would ask Ray Flint to clarify this.

Suzi recommended that the ASD/AS Report should be presented as an Appendix of the final Strategy Review Report.

Mike raised again the question of whether ASD /AS fits into the Learning Disability Strategy Review. It was noted again there is no ASD /AS content in the Mental Health and Wellbeing Strategy document. We should try to clarify with Mental Health colleagues whether there is any scope to rectify this.

It was noted that the Transitions Working Group were proposing a joint meeting with representatives of the Aspergers Working Group. Denis will contact Christine Schaffer, chair of the Transitions group to establish a suitable arrangement.

Please note that a date has not been successfully finalised. The first possible dates for Christine are:

Monday 31 July	pm
Tuesday 1 st August	11.00
Wednesday	am
Thursday	all day

3. Review of ASD/AS section of Interim Report

We spent some time reviewing the ASD/Aspergers section of the draft report.

a) We agreed that the most sensible way forward was to use the Taking Responsibility Report as a template.

Other points to be covered were:

b) We want to make the point up front that this group of people fall between stools and ending up being “nobody’s business”.

c) We need to ensure that there is a consistency in the recommendations in different sections of the report eg we need to ensure congruence between our recommendations and proposals being made by other Working Groups regarding person centred planning, local area coordination and “In Control”.

d) Jane reported that Maurice Harker, author of Tomorrow’s Big Problem has been finding that people with ASD and Aspergers can use a range of accommodation services from Keyring / Core and Cluster to Village Communities. Having services that are flexible and are done well at the beginning can result in better outcomes.

Suzi quoted an example of good local practice in which consistent support is provided from one named person in the provision of Repairs and Maintenance by Housing.

e) There was some discussion about the ways in which more generic/universal services could be supported to be flexible and responsive. This included how to help front desk staff of mainstream services (in accordance with the Customer Care Charter). Denis asked whether IT / technical solutions could be found that would help guide staff at the point of first contact.

Ideally guidelines should be available in any and every universal service.

f) In respect of the Higher Education sector it was agreed that there is a need for the procedures and protocols of Colleges and Universities to be Aspergers sensitive.

Moira suggested that a similar approach to that used by Intowork could be adopted by Higher education institutions.

We thought it would be useful to find out if there was a forum where FE professionals could discuss the special support arrangements require by students with Aspergers.

g) There followed a discussion about whether all generic service providers needed to know that a person had a label of Asperger Syndrome. For example would it be helpful or detrimental for a GP to know that a patient presenting at the surgery had Aspergers. Suzi argued that it would be helpful because the GP would be able to respond to known issues such as chemical sensitivities or atypical reactions to certain drugs.

Mike said that when he had asked some of his staff in Housing if they worked with someone with AS they had responded that it was more than likely - but that they wouldn't really know. The important thing was that they worked jointly with the person and dealt with presenting problems.

h) There was some debate about whether our report was concerned with everyone with Aspergers or about everyone for whom AS presents some difficulties. If it is the latter we must remember that a person may **episodically** have difficulties as a result of their AS.

g) Suzi confirmed her opinion that we should explore, as part of the pathway for diagnosis of Aspergers, ways of supporting GPs to refer directly to the ASD coordinator.

This led to a general discussion about whether assessment for services adequately identifies people with AS. There was a discussion about whether CARENAP could be amended or whether a specialist assessment should be introduced.

Also what happens if there are no services available to respond to a given persons need? In theory the CARENAP system should be able to identify service deficits but this facility is not always taken advantage of. The Shaping the Future Together tool being piloted in East and Midlothian also addresses this gap and is specifically designed to aggregate individual needs and assist in service design and strategy planning.

We need to find ways of testing the accessibility of existing processes of assessment (“Asperger proofing” them)

i) The lack of any specifically commissioned and funded Advocacy for people with AS should be raised in the report.

4. Housing Item

Suzi reported that she had heard that housing applicants with AS are not receiving “medical points” and that gold priority is based on medical need. Mike had investigated this and reported that the situation was more complicated than that in that the biggest element in the allocation of gold priority is mobility. It was also recognised that the kind of property most likely to be desirable for AS applicants i.e. detached/stand alone properties are at an absolute premium throughout the Lothians.

Denis will talk to Mike and equivalent colleagues in Mid, East and West Lothian about this issue.

Jane suggested that we might consider inviting Maurice Harker to come up to the Lothians to talk to us about ASD/AS and Housing.

5. Future Meetings

The next meeting will be held at Number 6 on 28th June from 2pm to 4pm.

The joint meeting with the ASD Working Group will be held at Number 6 on 29th August from 10am to 2pm.