

Lothian Joint Learning Disability Strategy Review Board  
ASD Sub Group Meeting - 24<sup>th</sup> October 2006

Minutes

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**Present:** David Bain, Isobel Bruce, Mike Bruce, Moira Dickinson, Claire Houston, Erica Hughes, Richard Ibbotson, Vincent Kennedy, Dawn Larman, Jane Neil-MacLachlan, Duncan McIntyre, Dennis Rowley, Carol Turnbull, Suzi Wong.

**Chair:** Les McKeown

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**Apologies:** Lisa Dunne, Caroline Johnstone, Rona Laskowski, Cllr Mark McInnes, Mike Penny, Tracy Sanderson.

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**1) Groups**

- Les asked the group whether the AS and ASD reports were too much together or not. Need for separate reports?  
Jane mentioned that for someone who does not know about Autistic Spectrum Disorder it might help to read it together.
- Les - on occasion exclusive to AS and then sometimes ASD. Could do with separating out/clarifying but may not need 2 reports (just editing). Carol agreed. Dennis stated that this group had the highest level of work/commitment of all the working groups and that it seemed wrong to just do a few pages for the LD report. He expects to distil it down as a chapter of LD report, then could take time to do something for ASD/AS and make further recommendations. Thanks were given to Tracey and Jane for their feedback/input on the report.
- There is a deadline for the report for the 1<sup>st</sup> week of December to go to the Board on 14<sup>th</sup> December.
- Jane asked whether there would be recommendations and/or key things to do, and Dennis said the plan was to get implementation plans and then groups can take this forward to produce action plans and targets.
- Denis can produce short version after today's meeting for feedback by 3<sup>rd</sup> week in November. Richard said it would need to be proof-read and Denis asked that we let him know of any editing errors and asked that the focus

for today be on recommendations (as he did not feel able to do them on behalf of the group).

- Les - could have bit in report about why 2 groups occurred
- Richard asked whether it will be one or two reports and Denis responded that it could be edited so that it more obvious what is referring to ASD and what is referring to AS.
- Moira suggested having column headings but clear info on each for ASD/AS and Denis stated that the decision makers were looking for clear, concise headings but with detail that backs it up. What they don't want is a long 'shopping list' which will be thrown aside. Moira said it is about how AS people will need something different rather than seeing them as just being 'in there' along with learning disabilities.
- Denis agreed to review - it will have a shared introduction then Autism and AS sections respectively, following the same headings then recommendations for Autism and AS. Tracy suggested 'Autism Spectrum Disorders' rather than 'Autistic Spectrum Disorders' and all agreed.
- Claire stated that as someone who doesn't know ASD well she personally found the introduction clear.

## 2) **Developments:**

- Les Felt that the 'Developments and Changes' section needed a description of each and themes arising in the different services and key areas that need addressing. These are things where development needs to take place (there was overlap in current services and this section).
- Jane suggested that the current service charts need re-defined as red doesn't show up very well. Denis agreed to embolden or put in italics.
- Denis told the group that this was the 2<sup>nd</sup> review as far as he was aware and Les agreed the first one was years ago. David suggested making it a wider context of other strategy reviews going on (i.e. Mental Health Strategy and lack of reference to ASD. Perhaps making a point of them falling between services and David suggested perhaps in Section 3. This isn't really definition and would be better in Section 4, but making it blunter. Les agreed there was a need to clarify and spell out clearly. Discussion took place as to what Section 4 was about e.g.: 'why do this review now?', or 'why look at ASD in terms of this review now?'

### **3) Case Studies:**

- Richard wondered what was happening with this. Denis has notes and will liaise with Richard and get information from David to add in to section 2.

### **4) Sections**

- Suzi stated that it costs her slightly less than half her income to care for her son which isn't reflected in section 5 - a footnote will be added to say that the cost of autism information is out of date.
- Mike Bruce suggested it would be better to tie this in to Section 3 (Prevalence). Also figure of 1 in 100 needs to be used with caution as this is for children only.
- Les suggested having a 'What is Autism?', Prevalence and Costs as 3 Sections, and to follow Costs on from Prevalence.
- Vincent asked whether we could get a current cost from Local Authorities, Denis explained that so far this had not been possible - there was a draft but it wasn't correct. He asked at the beginning of this strategy but as yet it has not been provided.
- Denis asked whether the £101 million was for Learning Disabilities and suggested that these figures would be very crude.
- Vincent felt that a Needs Analysis or Assessment was missing from the report i.e. what is happening to those without the services (unmet need). Les suggested that this also needs to be said with caution as politicians will say that if they are managing without the services then they do not need them.
- Moira asked about people in families who were not diagnosed (mainly anecdotal) and how this would be reported on.
- Vincent asked whether the Finance Sub-group looked at specific costs of different groups. And Denis stated that it would be hard to produce a whole report without the relevant financial information.

### **5) Current Services**

- For current services - Les stated that these can be described in more detail in the text and then refer back to the table

- Moira suggested that the Yard has funding to develop group for AS teenagers (recreation) which can be added. Claire asked where remote reporting would fit (current services or Criminal Justice).
- Jane said she had circulated a short version of current services (Education and Employment were missing)
- Les stated that any other services which were missing to let him know
- Mike stated that Section 6.5.5 is based on his thoughts and he wasn't sure whether everyone would agree. Dan stated that the ASD Group agreed with this and felt that there should be a 'link' person.
- Moira asked the groups thoughts on whether adults on the spectrum should be re-assessed when they reach adulthood and should they have the original diagnosis reviewed, and Jane reflected on who would do this.

## **6) Local Area Co-ordinators**

- Suzi told the group that one LAC has left and not yet been replaced.
- Duncan stated we would have to be careful as LAC's roles are different across the areas, and that there isn't an ASD specific role and takes up 3 pages and describes Edinburgh LAC services which have changed.
- Denis agreed that it should mention different areas and Jane stated that it had been mentioned at the ASD Reference Group as key in ASD.
- Mike suggested moving 6.5.5 to Section 7 as LAC's is about the future.
- Moira suggested that 6.4 should mention that not everyone can move into work. Richard suggested having corresponding headings in current services and Issues and Development section.

## **7) Developments and Changes section**

- Claire told the group how the police had introduced a 'Remote Reporting' scheme for witnesses. They have organisations that are conduits to the police for reporting crimes and would use a 3<sup>rd</sup> party candidate.
- Carol - do they divulge this information to Learning Disability services/nurses etc and are they supported to take that forward? Include this in section 7.7? Claire will discuss this with Richard re possibility of taking forward.
- Also vulnerable adult guidelines are used in the force (an initial referral discussion between Health, police and Social Workers and gaining an appropriate adult). This can be included.
- Les said they have discussed to what extent understanding of AS can be developed but there will always be people who slip through the net.

- Moira suggested a new section about transition from home to individual living and support for this. Richard suggested this could be put with housing etc.

## 8) Training

- Jane told the group that the NES website now has training resources and information leaflets. Les suggested we should work forward to how training shouldn't be seen as specialised but built in to mainstream training. Jane told the group how she goes every year to do training at the Edinburgh Medical School.
- Les suggested that every professional should have input and Dawn agreed that it should be wider than health, council staff, job centres etc.
- Suzi told the group she has been asked to take part in a video for council staff about AS.
- Denis said the impression is still that there can be no input in Social Work training.

## 9) Recommendations

- Put these under headings from throughout the report.
- Imbed ASD Awareness training in all basic training, and link to national initiative for accreditation.
- Diagnosis and referral - review at transitions stage of diagnosis. Adults have access to services after diagnosis (how to manage anxiety, SALT, advice for parents etc.
- Post diagnosis pack for adults
- 'Link' person meets with them immediately after diagnosis to link in to services.
- Entitlement to Community Care assessment/carers assessment and picked up as priority by LAC system.
- Employment and support - widen to include carer/day activities.
- Need to recognise that transition is an issue and services required (could use Equals at NAS Glasgow as an example).
- Aftercare in employment required i.e. support in the job.
- Co-ordinated approach to occupation and employment services - another title as 'day opportunities'.

**Any other business:**

It was agreed that the recommendations discussed would be written up by Denis and all are strongly encouraged to send any thoughts and recommendations to Denis before the end on Nov please.

There being no other business Les thanked everyone for coming and closed the meeting.

**Date of next meeting:** The group agreed to meet again in December. Location and time TBC.