

Lothian Joint Learning Disability Strategy Review Board
ASD Sub Group Meeting - 8th March 2006
MINUTES

Present:

David Bains (Intowork)
Mike Bruce (ELAS)
Bill Davies (Community Learning Disabilities Nurse)
Lorraine Cull (Parent)
Rebecca Dale (Local Area Co-ordinator - South Central Edinburgh)
Lisa Dunne (Local Area Co-ordinator - North Edinburgh)
Richard Ibbotson (Autism Initiatives & No. 6)
Liz Laporte (Parent)
Dawn Larman (Scottish Autism Service Network)
Jane Neil-MacLachlan (Adult Autism Co-ordinator - NHS Lothian Primary Care)
Mike Penney (Housing)
Gordon Simpson (Disability Liaison Office, Lothian & Borders Police)
Carol Turnbull (Community Learning Disabilities Nurse)
Suzi Wong (PASDA)
Lorna Wynn (Partners in Advocacy)

Apologies:

Duncan McIntyre, Gillian McConnell, Tracy Sanderson, Moira Dickinson, Denis Rowley

- 1) New and existing members of the group introduced themselves.
- 2) Minutes of the last meeting from 23rd January 2006 were discussed as follows:
 - a) membership:
 - The group discussed whether there were still any sectors or views not represented within the group. It was highlighted that no-one from Careers was represented or anyone directly from social work (although Rebecca and Lisa's roles are partially within social work). It was felt that someone with a transitions perspective should be represented upon the group, although there were no specific thoughts regarding who and it was felt that there was a gap in this area.

- Two transitions workers would be being employed in September (RD).
- There is a gap for a representative from leisure and recreation.
- Wednesday group for people with ASD is not longer running so JNM couldn't ask them about representation.
- There is representation for people with autism through the parents at the meeting and LL felt she could give views on behalf of her son.

Action point: Dawn to invite someone from Careers Scotland and leisure and recreation to further meetings

b) Numbers of people with ASD in the Lothian area:

- Denis should have numbers that Vincent had passed to him but Denis was not present today.
- The Scottish Society for Autism and Autism Initiatives were providing services to 58 people in the area. There are 126 people utilising no. 6 but these would not be included in numbers as they do not have learning disability (RI).
- There are at least 400+ people with ASD in the area (JNM).
- There is a danger of getting too caught up in numbers which should perhaps be mentioned at the beginning of the report (RI).
- There are more individuals being identified and expanding need (BD)
- Numbers are important in terms of those accessing mainstream services (MP).

c) Map of Lothian Services:

- JNM has details of health, social work and voluntary services etc which she will pass to Dawn

d) Cost of services:

- In what way are we looking at this (MP)?
- Concern around out of area packages and the cost of this (JNM).
- Can't put a figure on the support needed. It shouldn't be about that. Need to look at future developments (LC).
- Need to look at how there's not more money coming in and how services are equitable and what's the best and most effective way of using the money. We don't know the costs of services and this is something for the report (MP).
- All reports say that services need to be needs led but there's never enough money (SW).
- Need to look at the balance of that and look at the best services (MP).
- Need to look at where to provide for people as best as possible (LL).

- Have to battle for services. Being needs led has to come into it (LC).
- Need a longer term review of services and costs (RI).
- There is equity. It works with people with more extreme problems and their needs are being looked after, but for others with not as many needs their parents and their needs aren't being met. We can look at best value and what is best to justify the expense (BD).
- In providing services its also about providing for parents needs (CT).
- LW could put something in writing as she's working with several cases where people are grouped together after moving resource and their individual needs are not being looked at. Services are not forward thinking. The extent and size of care packages is a stumbling block and these are not being looked at creatively.
- Might need to create a guide to commissioning ASD services as to how to develop services for ASD (JNM).
- How about adopting the charter of rights (SW)?
- The reference group is already looking at this but some things which need to be considered are not in the charter, so they are looking at 'principles' (JNM).

ACTION POINTS:

DL to speak to Denis to see whether costs are being covered in the report separately and whether there are any figures for this.

LW to put some information in writing about those not receiving appropriate services

e) Case studies:

- DL asked if anyone had been able to pass on case studies as discussed at the last meeting.
- Concern re confidentiality (JNM).
- If someone can anonymise them first then RI will take them and use certain relevant bits to compile something for the report.
- DL will anonymise them as she doesn't know most of the people/service involved if people can pass her the case studies.
- LW might have some to pass on

f) AS being a separate sub group & separate in the report:

- This has not been done before and there is a gap for AS. This will help identify what's missing and how it could be addressed as a separate thing (JNM).

3) DL had passed on various reports from other areas to the group which she felt might give some ideas in direction for the report.

- SW had read all reports and felt the most useful/best ones were the Fife one and 'Taking Responsibility'.
- The Glasgow report is probably one of the most useful but is bigger than we'd want, but the layout is sound and we could use this as a basis (RI).
- DL will compile sections from the reports into one document for people to read look at more easily and will take titles from key sections of the other reports to consider for possible areas to consider in the groups report.

4) Board meeting on 23rd March:

- The group decided it might be best if DL attended and fed back from the group, as Denis had not been present at the last two meetings.
- DL to speak to Denis about this.

5) Benefits/financial support

- Need to look at benefits for clients and carers and satellite benefits and any charities that could give help (BD).
- Rowntrees Trust is helpful but stops at 16. Need to access funds for adults too as their needs are the same or greater (LL). For example LL's son is ripping clothes everyday and she would like to know if there's any extra financial help.
- Have to go through services to apply for funds and can depend on whether they are classed as having a learning disability (CT).
- Perhaps someone from the benefits agency could be invited? (DL)
- The 'needs, numbers and finance' sub group may be looking at this (RI).
- The benefits office had an information leaflet about autism which was helpful (SW).
- If do more than 21 hours at college you lose the carers allowance (LL).

Action: DL to find out if benefits are being looked at by the other sub group.

6) Need to look at links to other strategies:

- For example the homeless strategy has just been written. Some people with ASD will be massive users of those non specific services and therefore the needs of people whose needs impact on other generic services (such ASD) need to be focused on as well as those who need high levels of support and

utilise specialist services. Needs to link into other strategies such as housing, mental health etc. (MP).

- To what extent is ASD mentioned in other strategies and how can we liaise regarding this (RI)?
- Need to look at people with ASD who are high users of services in different ways (MP).
- Is there a process to ensure the appropriate people are represented on other groups/strategy groups (RI)?
- There isn't enough consideration of their complex needs (BD).

7) New members gave an overview of their role in terms of ASD:

a) Local area co-ordinators (Rebecca Dale & Lisa Dunne):

- The LAC's work with people with higher support needs and this has impacted on individuals. They can work with people specifically and have been working with a person in crisis with ASD.
- They have been told there is no more money though.
- They are trying to promote their role and do preventative work.
- They have 15 people on the waiting list and people with ASD are approximately half the case load (LD). However the LAC remit excludes every one except those aged 14 - 18 or age 45+ living with parents (LD).
- The LAC remit is different for different areas though (RD).
- A lot of energy goes into battling the department rather than doing the work (LD).
- There is a key worker requirement (JNM).
- From the advocacy view, they have keyworker roles but is a huge job across the city (LW).
- Need to look at siblings and the effects on them and if there's any training for them (LL).
- There is a young carers group through the Princess Trust (SW).
- There is an issue about the family impact as a whole when an adults with ASD lives in the home (DL).
- Family support does fit with the LAC's role but there is also overlap (RD).
- Maybe there's something the education dept could do specifically in terms of educating teachers and the needs and affects upon siblings of those with ASD (BD).
- The teachers support service (attached to Oaklands School) could give input to teachers about this (CT).
- The siblings issue is very important. Steve Coulson of the 'Edge' (funded by Princess Diana fund and social work) has done a 'Good Life After School' programmes for people with learning disabilities that includes

their whole family and a lot of siblings attend and get a chance to discuss the problems for them (RD).

- One person with autism attended and got on brilliantly (LD).
- They have been trying to transpose it for older adults (RD).

DL will find out if the Strathclyde University autism course covers this aspect within its units and suggest this.

DL to contact Oaklands school about support for siblings.

b) Lothian and Borders police (Gordon Simpson):

- To get a full criminal justice perspective we need views from the procurator fiscal.
- JNM had a meeting with the fiscal last year.
- The police are aware of autism and do diversity training which every employee gets but autism is not covered in any great depth).
- There is a disability section on their intranet which staff can access (voluntarily).
- They are required to have a disability equality scheme and action plan by the end of the year and GS is writing this. He will try to make sure it covers a range of disabilities including ASD and will liaise with the group.
- GS will be the Disability Liaison Officer in the diversity group within the police.
- Their officers experience of people with ASD tends to be when they end up being in crisis and so will need to consider the 'Adults in need of support' and Vulnerable Witness Act.
- They are currently managing the situations and then doing reports and passing these on to social work.
- They have a system where once someone with autism has been in the system, it could be flagged for future reference.
- There is a report on prison services and potential incidence of ASD.
- What if a person with autism were to do something and get arrested? (LL)
- Officers would quickly be able to read people and assess them and realise there was a problem (GS).
- Could the police service liaise with the group regarding autism alert cards? (DL)
- They are also welcome to access training at No. 6 (JNM)
- Nursing staff have heavy training, so could there be a link person for ASD within services like these who liaise and access training? (CT)

c) Partners in Advocacy (Lorna Wynn):

Lorna had spoken earlier in the meeting and as the meeting was drawing to an end, offered to put some information in writing.

8) Short life funding:

- There are problems with limited funding and some could perhaps be incorporated in mainstream services (LW).
- There are problems with large numbers of pilot projects and then mainstream services having to take them over when funding runs out. No exit strategies are in place for pilots and people taking over them need training. Need strategies for how these feed into other services (MP).
- There is not mechanism for feeding into mainstream from short life projects. Communication between voluntary and mainstream services needs improving to do this. Every project has particular remits and therefore people end up being excluded - for example people with AS.
- SAY funded projects are good but many are finishing next year (LW).
- Voluntary sectors are major service providers but their projects will always be relatively short term as they can't get open ended agreements.
- The complex multi-faceted needs of those with ASD need long term, high level commitments and we can't move away from that. This causes tensions for those buying services.
- 'Supporting People' was set up as a system for people to use money over 3 years but they've spent too much and the treasury need it back (MP).

9) Information for report:

- Dawn asked if all parties from specific sectors could put some brief information in writing regarding their roles with people with ASD, the type and level of contact, what services they currently provide, what other needs they see as being required, suggestions for future development before the next meeting. This information will be incorporated into the report as appropriate and will be helpful for the development of the report and the group.

Action point: All parties in the group from specific sectors to put information in writing about their role with people with ASD (as in point 9) before the next meeting.

10) Next meeting date:

- The date of the next meeting was agreed as **Wednesday 5th April 2006 at 10am at No. 6.**

DL

March 2006