

Minutes		Minute of Adults with ASD Planning Group Meeting Thursday 24th August, 10am-12noon. Committee Room 4, Highland Council Headquarters
Chair:	Marlyn Campbell, Co-ordinator, Integrated Children's Services	
Minute:	Martine Stewart, Senior Clerical Assistant, The Highland Council	
Present:	May Burr, Carers Group Representative Alan Jones, Clinical Psychology, NHS Highland Melissa Kay, North West Regional Officer, NAS Jonathan Gray, Nurse Consultant, Learning Disabilities, NHS Highland Kerry Brook, Consultation Group Representative Andrew Denovan, Consultation Group Representative Simon Webster, Autism Development Officer, The Highland Council	
Abbreviations:	ASD: Autistic Spectrum Disorder ASIST: Applied Suicide Intervention Skills Training CHIP+: Children in the Highlands Information Point+ CJS: Criminal Justice Services IQ: Intelligence Quotient LD: Learning Disability NAS: National Autistic Society	

ITEM	DISCUSSION / DECISION	ACTION
1	<u>Apologies</u> Myna Dowds, Donellen MacKenzie, Jean-Pierre Sieczkarek, Sarah Hartley, Dr Chris MacGregor, Carolanne Mainland.	
2 2A 2B 2C	<u>Involvement of Service Users and Carers</u> Set-up and operation of adults' group, and parents' & spouses' group Description of the Planning Group (changes to operation of the group) Interaction of these groups. Simon, Melissa, Andrew, Kerry and another adult with Asperger Syndrome had discussed and agreed the document "Arrangements and rules for the group for adults with ASDs, and for the group for parents or spouses of adults with ASDs". Simon described the format of these groups and how they fit with the Planning Group. The purpose of these groups is to ensure that the final recommendations are representative of the views of adults with ASDs (the Adults with ASD Consultation Group), and parents or spouses/partners (the Adults with ASD Carers Group). The Carers Group includes parents of children aged 14 or above. Notes are taken by Simon at each meeting of these new groups and are checked by group members before Planning Group meetings. Up to two	

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	<p>representatives from each new group will attend the Planning Group to give feedback, using the notes agreed by their group. Simon stated that this format could be changed if necessary. In addition to their existing representatives (Andrew for the Consultation Group, and May or Marlene Munro for the Carers Group), both the Consultation Group and the Carers Group will choose additional representatives at each of their meetings. The additional representatives could be someone different each time.</p> <p>Simon to enquire if the Robertson building at New Craigs could be used as a venue for future meetings for the Consultation and Carers groups.</p> <p>Consultation Group The Consultation group asked to have the minutes from the most recent Planning Group meeting prior to each of their meetings. Simon, Donellen and Martine will take this forward.</p> <p>Carers Group May Burr and Marlene Munro will alternate as representative for the Carers Group at Planning Group meetings. An additional representative will attend from the Carers Group whenever possible.</p>	<p>SW</p> <p>SW,DM,MS</p> <p>MB,MM</p>
<p>3</p> <p>3A</p>	<p><u>Minutes and Project Plan update</u></p> <p>Minute of Planning Group meeting 20 June 2006 & Matters Arising</p> <p>8.1 Training and staff cover “Simon to arrange a meeting with Jan Baird, Mike Perera and Marlyn Campbell”. Marlyn said she did not think her name should be included here and that it should actually be Donellen MacKenzie.</p> <p>Matters Arising</p> <p>8.1 Training and staff cover Simon confirmed that the meeting to discuss issues facing the SSA had not taken place, and will be arranged once data on suicide risk is available from Carolanne.</p> <p>Consultation Group The abbreviation ASD to be used in the minutes and not ASD/Aspergers. This is to clarify that ‘ASD’ does include Asperger Syndrome, and that services for people with Asperger Syndrome are not being considered separately from services for other people with ASDs.</p> <p>The importance of representation from Psychiatry at Planning Group meetings was discussed. Simon will contact Dr Lehmann-Waldau and Dr White to ask one of them to be present at future meetings (Dr MacGregor currently on sick leave).</p> <p><i>Minute of Adults with ASD Planning Group, April 2006: ASD Cafe</i> The idea of a Café for people with ASD and how beneficial this could be was</p>	<p>MS/DM</p> <p>CM</p> <p>MS</p> <p>SW</p>

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3B	<p>discussed, including set up and funding. Simon will contact Cairdeas Cottage (drop-in centre for people with mental health issues) to look at their set up and what they provide. He will feedback his findings to the Planning Group. The Consultation Group did not agree with the comment in the Planning Group's April 2006 minute that "it is important that contact is not just with others with ASD". The Consultation Group felt that contact with other people with ASDs is highly beneficial, and that an 'ASD Café' is needed.</p> <p>Project Plan</p> <p>Consultation Group <u>Advocacy consultation:</u> The questionnaire for NHS Highland's consultation on the 2007 to 2010 advocacy plan is available from Simon. Andrew, Kerry and others felt that the questionnaire was not appropriate and this will be raised by Simon at an advocacy consultation meeting later this month.</p> <p>Carers Group May added that the Carers Group had comments on the Project Plan which are relevant to other agenda items. These have been included in this minute.</p> <p>Project Plan update (Simon Webster) <u>Meeting with Senior Management:</u> There was a meeting with Senior Managers from Health and Social Work on 27th June where ways to fund future developments were discussed. Costs associated with out-of-area placements were also discussed. For people to return to Highland there would have to be an element of double funding in order to have the appropriate services in place. Costs would be expected to reduce over time, and savings might be expected in the medium to long term. It would need to be established that the services provided locally would cost less than out-of-area placements. Simon referred to a survey conducted in England which demonstrated that local placements are less expensive than out-of-area placements. May asked how new services for adults with ASDs would be evaluated. Jonathan explained that any tender for services would set out what the specific needs are for that service. After services are commissioned, there would be in-house monitoring to ensure quality assurance of services. Simon said that it would be important for a Senior Manager to have responsibility for ASD services, as stated in several guidance documents on ASD service commissioning.</p> <p><u>Consultation meeting with parents:</u> Simon reported that most of the consultation meetings with parents around the Highlands in July had not been well-attended, but that several issues had consistently been highlighted at these meetings. These issues included social and independent living skills training and accessing social groups; further and higher education; and information (on benefits, guardianship and direct payments, for example). In future, some meetings with parents may be held in local areas as extra sessions of the Adults with ASD Carers Group. An updated information pack for transitions could possibly be distributed</p>	<p>SW</p> <p>SW</p>

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	<p>through CHIP+. Marlyn, Simon and Marea Fowlis to take this forward. The current pack is to be revised and updated.</p> <p>Melissa stated that it is a function of the NAS to look at the funding of Social Groups. She will feedback to the Planning Group when she has further information as to when the NAS Inverness Social Group for adults with Asperger Syndrome will begin.</p> <p><u>ASD training for Mental Health and LD services:</u> Highland Suicide Prevention Working Group would consider funding 25% from the "Choose Life" budget if mainstream funding was provided for the other 75% of the cost, and if suicide prevention was a definite component of the training.</p> <p><u>Survey of Needs:</u> There have been changes to the format of the Survey of Needs. Most of these changes have been made on the advice of the ethics committee. The Survey questionnaires have now been distributed. The final versions of the questionnaires are available from Simon.</p> <p><u>Outline recommendations:</u> These have been widely circulated for comment. One respondent commented that the recommendations should be explicit about the decision by Learning Disability Health Services not to take on adults with ASD who have an IQ of 70 or above. Other respondents felt that it would be appropriate to say that "not many" or "most" LD services are not ASD appropriate. The outline recommendations should make it clear that staff are trying to make the most of existing LD services for people with ASDs, and that more ASD training should be available to those in LD services. The Carers Group stated that some LD services were appropriate and worked well, but that much more needs to be done to make LD services ASD-appropriate, and that more training is needed.</p> <p><u>Consultation with young people in transition to adulthood:</u> Simon is still trying to find an appropriate way to consult with young people in transition to adulthood. The Survey of Needs may not be appropriate for young people (14-16 years) as it may give them false expectations of what services they will receive post-school, and some parents have indicated that open questions may be unhelpful. Simon and others will meet with Highland Children's Forum to discuss how our consultation can fit with their consultation with young people in transition. It is important that our consultation samples a broad spectrum of views, to take into account the range of cognitive function of young people with ASDs. Marlyn flagged up that Highland Children's Forum transition project may become part of a 3 year project that will make an impact on young peoples' lives, and will be part of the work on the implementation of the children's plan. Simon acknowledged the work done by Janis Clark in this area.</p>	<p>SW,MC,MF</p> <p>MK</p> <p>SW</p> <p>SW</p>
<p><u>4</u></p>	<p><u>Project Evaluation</u></p> <p><i>Consultation Group</i> The Consultation Group had no comments on the evaluation.</p>	

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	<p>Carers Group The Carers Group were concerned that the evaluation will only cover the project itself, and will not report on whether more ASD-appropriate services are actually provided. NHS Highland and Social Work in-house quality assurance monitoring should ensure that any new services are appropriate.</p> <p>Planning Group There was a meeting with the evaluators on 18th August and work has now begun. The proposal and draft contract have been agreed, with some minor details to be addressed, and will be signed off in the near future. The independent evaluation of the integration of ASD children's services has several significant recommendations which should feed into the work of the evaluators of this project. If there are any major issues with the project, then the evaluators should alert the Planning Group about these in their initial report in December this year. It was agreed that the contract and proposal would not be circulated but that copies were available from Simon if anyone should want them, and that copies would be offered to the Consultation Group and Carers Group at their October 2006 meetings. The evaluators' report in December will include the criteria for the evaluation as agreed with the Planning Group. A draft of the final evaluation report will be submitted to the Planning Group in March. The evaluation team had asked the Planning Group to clarify what they see as their intended outcomes for this project. Simon went over the outcomes on page 1 of the Outline Recommendations and also the Outcomes section of the Planning Group's Remit. The group raised no objection to using these outcomes for the purposes of the evaluation.</p>	<p>SW</p>
<p><u>5</u></p>	<p><u>Outline recommendations</u></p> <p>Consultation Group Andrew highlighted the need for Psychiatric services to be more aware and understanding of ASDs. The outline recommendations refer to this need under Objective 3B. However, this objective, "Apply the Highland Choose Life Plan to adults with Asperger Syndrome", may need further work to be fully developed. Again it was stressed how important it is for a representative from Psychiatry to be involved in Planning Group meetings. NHS Highland is undertaking training in this area which could be useful (ASIST). Alan will obtain the name of a contact person. Melissa will also obtain information on this with regard to cost.</p> <p>The Consultation group had stated that out-of-hours services are virtually non-existent and have no awareness of ASD. Andrew described the experience of an associate involving the Police. Melissa and Carolanne are working with the Police, regarding their awareness and understanding of ASD issues, and will feedback to the group as necessary. Work is still ongoing following Melissa's presentation to Criminal Justice Services last December. Police are not recognising Autism Alert cards. Melissa explained that this is because they have not had training and that time to plan training is required. Simon will arrange a</p>	<p>AJ MK</p> <p>MK,CM</p>

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	<p>one-off meeting with all those concerned with CJS, to ensure that these issues are incorporated into the final recommendations.</p> <p>The Consultation Group said that LD (defined in terms of IQ) should not be a deciding factor in service allocation, and that ASD should be acknowledged as a separate issue. This Group felt that current service provision is about crisis management and that services should become pro-active - treating root causes instead of symptoms. This prompted discussion around the need to have good communication across services.</p> <p>Carers Group May provided the group with the remaining feedback from the notes of the Carers Group meeting. They felt that a dedicated service for people with ASDs would be required to ensure access to services that are needed. Current services should be preserved. Appropriate training should be provided for existing services, so that they become ASD-appropriate. Some general principles should be applied to how services are provided, such as openness about changes to service provision so that people with ASD can cope with changes that will occur.</p>	
<u>6</u>	<p><u>Housing</u></p> <p>This item was postponed due to insufficient time at the August meetings. Relevant papers will be available for the October meetings of the Highland Adults with ASD Project, and Housing will definitely be discussed at these meetings.</p> <p>It was agreed that Housing should be an item on the next agenda, and that Sarah Hartley (Housing Policy Officer) or another Housing representative would be asked to sit as a member of the Planning Group.</p>	<p>SW</p> <p>SW</p>
<u>7</u>	<p><u>Any other business</u></p> <p>Simon will issue the next newsletter in draft form for comment.</p> <p>Members of the Consultation Group and the Carers Group have been offered a meeting with the Social Work Inspection Agency in early November, and are interested in attending a meeting. Details to be confirmed.</p> <p>There is a conference in Newcastle on 17th November, "Valuing Good Practice in Autism". Details are available from Simon.</p>	<p>SW</p> <p>SW</p>
<u>8</u>	<p><u>Date, Time and Venue of Next Planning Group Meeting</u></p> <p>The date of the next Planning Group meeting has been changed to -</p> <p>Tuesday 31st October, 10am to 12pm , Committee Room 1, Highland Council Headquarters</p>	