

<h1>Minutes</h1>	<b>Minute of Adults with ASD Planning Group Meeting</b>
	<b>Friday 16<sup>th</sup> February 2007</b> <b>9.30am-12.30pm</b> <b>Seminar Room 1</b> <b>Centre for Health Sciences, Raigmore, Inverness</b>
<b>Chair:</b>	Donellen MacKenzie, Project Manager (Learning Disability), The Highland Council
<b>Minute:</b>	Martine Stewart, Senior Clerical Assistant, The Highland Council
<b>Present:</b>	Simon Webster, Autism Development Officer, The Highland Council Myna Dowds, Co-ordinator, Autism Outreach Education Service May Burr, Carers Group Representative Elke Kammer, Consultation Group Representative Kerry Brook, Consultation Group Representative Marlyn Campbell, Co-ordinator, Additional Support Needs (Disability) Alan Jones, Clinical Psychology for Learning Disability, NHS Highland Carolanne Mainland, Senior Autism Advisor, Scottish Society for Autism Mellissa Kay, North West Regional Officer, NAS
<b>Abbreviations:</b>	ASD: Autistic Spectrum Disorder LD: Learning Disability SSA: Scottish Society for Autism LIG: Local Implementation Group NHS: National Health Service ACCMs: Area Community Care Managers COG: Chief Officer Group (Community Care) NAS: National Autistic Society SLA: Service Level Agreement

ITEM	DISCUSSION / DECISION	ACTION
1.	<u><b>Apologies</b></u> Dr Chris MacGregor, Marlene Munro, Jean-Pierre Sieczkarek.	
2.	<u><b>Minutes and Project Plan Update</b></u>	
2A	<u><b>Minutes from the Planning Group</b></u> <u><b>Minutes: Accuracy</b></u> No amendments.  <u><b>Minutes: Matters Arising</b></u> <u><b>Consultation Group</b></u> <b>Page 1: Minutes from the Planning Group</b> Mental health services are a major concern for the Consultation Group. There is still no-one from Psychiatry in attendance at Planning Group meetings. The consultation group felt it should be possible for Psychiatry to send at least one representative to Planning Group meetings. Donellen explained the representative is Dr Chris MacGregor and that she has been on extended sick leave.  It was noted that the consultation group felt that the interests of people with an ASD are not being properly considered at LIG meetings.	

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	<p><u>Minutes: Matters Arising, continued</u></p> <p><b>Page 4: Suicide Risk</b></p> <p>The minutes refer to 'training on raising self esteem' as being critical in reducing suicide risk. The consultation group flagged up that sensory problems, which can't be addressed by psychiatry or psychology, are also a very important factor in suicide risk for people with ASD.</p> <p>Lack of consistency within psychiatric services causes an increase in suicide risk. One member of the group has consistently had support from one psychiatrist; this consistency has allowed the support to be successful. Other members of the group have each had support from several psychiatrists, many of whom do not read patients notes. The group felt that a service like this can cause more harm than good. The Psychiatric service should be set up so that you can meet your psychiatrist when you most need to, and mental health professionals should learn how to communicate with people who have an ASD.</p> <p>Sometimes a person can cancel or miss an appointment because they are not well enough to attend. Staff who take bookings for appointments may threaten to remove the person from the psychiatrist's list of patients. The group asked if this was NHS Highland's policy. Alan Jones said he did not think this was NHS policy. It was his understanding that patients are sent a letter if they persistently cancel appointments. He said that staff who take appointments should not be treating patients in the way the group had described, this could be due to huge patient waiting lists. Alan said he felt that this treatment was insensitive. The meeting discussed the unsuitable environment for appointments at New Craigs. Alan suggested that patients write a letter to the lead clinician regarding arranging and canceling appointments to establish a consistent system. The Consultation Group could write to Chris Macgregor for clarification of the policy.</p> <p>Alternative ways of working like home visits or meeting at a neutral venue were suggested. Alan said he thought that a GP has to write on the patient's behalf to request a home visit. Hospital staff are paid an extra fee for a home visit, and this fee may come from the GP's practice budget and could be time consuming. Alan further explained that there would probably be a fee involved in arranging appointments at a neutral venue outwith the hospital. Clinics held in health centres are a possible option but he was not sure how many Hospital staff do this.</p> <p><b>Carers Group Comments</b></p> <p>There were no comments from the Carers Group on this item.</p> <p><b>General discussion</b></p> <p><b>Page 3: Survey of Needs</b></p> <p>Donellen referred to the last paragraph on page 3 regarding short breaks/respite. She informed the group that a report has gone to Housing and Social Work Committee regarding adult placement schemes for all client groups. May flagged up training and support implications. Donellen agreed that a range of measures would need to be considered.</p> <p><b>Page 5: AOCB</b></p> <p>Donellen and Simon still to speak with Highland Council Support Services (Rosemary MacKinnon/Andy Grant) regarding the Committee Rooms at Highland Council</p>	<p>SW</p> <p>DM/SW</p>

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2B	<p>headquarters to ensure an ASD appropriate environment. Inshes Church and Culduthel Christian Centre were suggested as possible venues.</p> <p><b><u>Project Plan Update</u></b> A copy of the full plan is available from Simon.</p> <p><b>Comments on the report to the Chief Officer Group</b> It was agreed that this would be the last item on the agenda, and that Carolanne and Melissa would leave the meeting at that point so that issues concerning the Scottish Society for Autism could be discussed.</p> <p><b>Update</b> Papers regarding the project plan update had been circulated prior to the meeting. Simon talked the group through the papers.</p> <p><b>Inverness College</b> A report of the findings of the 'environmental audit' will be sent to college management, once it has been considered by the Committee for Additional Support Needs. The report suggests possible changes and could also influence the design of the new campus which is proposed for the college. A new Principal has been appointed at the college. The head of school with overall responsibility for these issues is now Ann Mackay, and an equality/inclusion post has also been established.</p> <p><b>Sensory Problems</b> Simon contacted TEC services (Hugh Logan and Sam MacNaughton) and as a result the volume level of audible signals has been reduced at a pedestrian crossing at Inshes. Elke had written to her local councilor, David Henderson, which had resulted in this being taken forward. Elke to let Simon know of any other crossings where the volume is unacceptable. Currently there is no national standard for the volume level and TEC services said it should be possible to make adjustments at other crossings.</p> <p><b>Evaluation</b> Simon will be sending out the evaluation questionnaires on Monday. This will be to around 100 people with an ASD and carers, with around 70 being sent to service providers. The questionnaire has been revised since the Planning Group meeting in December and is now more user friendly. Interviews will be conducted in person with some people with ASD and carers, and telephone interviews will be carried out by some service providers.</p> <p><b>Survey of Needs</b> The results of the Survey of Needs have now been posted to all participants. The results have been incorporated into the draft Final Recommendations. Support with various independent living skills and psychology for ASD were identified as highest priority service needs.</p> <p><b>Independent travel training pilot</b> This pilot project is now under way in some schools. A meeting will be held in March with the teachers involved, to find out how the pilot is going.</p> <p><b>Consultation with young people on planning for transition to adulthood</b> This is also now underway. Consultation is being carried in person and by email,</p>	<p><i>EK</i></p>

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	<p>depending on the preference of the young person. The consultation aims to find out what helps and what doesn't with regard to a young person planning for adulthood, and about how the young person can be in charge of the planning. Simon said it is separate from, but coherent with, the Transitions Protocol.</p>	
<p>3.</p>	<p><b><u>Exit Strategy</u></b>  <b><i>Consultation Group</i></b>  There will be a meeting on Thursday 1<sup>st</sup> March to establish a collective advocacy group for people with autism or Asperger Syndrome. No source of funding for this group has been identified, but there is strong interest in establishing a group before the end of the Highland Adults with ASD project. A decision regarding membership still has to be made. It was flagged up that people with ASD and an LD could find participation difficult. There was discussion regarding how people with an LD participate in the LIG meetings. At the Inverness LIG, a slot is allocated for people with an LD before the main part of the meeting at the Inverness LIG, to give them extra time to understand the issues. Simon stressed that the new advocacy group will be totally independent and its members will make their own decisions about how the group operates.</p> <p><b><i>Carers Group</i></b>  There were no comments from the carers group on this item.</p> <p><b><i>General discussion</i></b>  Donellen reminded the meeting that Simon's post will end in Mid-May. Donellen also informed the meeting of the imminent re-structuring of the Council, explaining that her own post is to be deleted. The council will have 3 Assistant Area Community Care Managers, one of whom will have responsibility for LD. Planning for ASD adult service will fall into this remit. The post holder will have a broad Highland-Wide remit but will be based in one of the three new areas. The new North area will incorporate Caithness, Sutherland and Easter Ross. The Mid and West area will include Mid and Wester Ross, the Black Isle, Skye, Lochalsh and Lochaber. The East area will consist of Inverness, Nairn, Badenoch and Strathspey. Donellen said she would keep the group informed regarding the re-structure.</p> <p>Elke re-iterated that with regard to providing training and awareness to staff it is best for a person with an ASD to provide this themselves and she hoped that this would be taken forward within the new structure. Donellen said that at the next meeting on the 27 April she would know who the Area Community Care Managers are and who has what responsibility.</p>	
<p>4.</p> <p>4A</p> <p>4B</p> <p>4C</p>	<p><b><u>Drafting of Final Recommendations</u></b></p> <p><b><i>Consultation Group</i></b></p> <p><b>Draft Final Recommendations</b>  There were no comments from the consultation group on this item</p> <p><b>Social activities, leisure, respite and support for carers</b>  The consultation group had not had enough time to discuss 4B</p> <p><b>Employment Support</b>  The consultation group felt that employers should be offered seminars on employment</p>	

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	<p>and disability, and free ASD training. Legislation alone is not enough to make employers change their behaviour. It was suggested that when Highland Council are <i>Draft Final Recommendations, Continued</i></p> <p>running training they could reserve some places for the business sector. Elke again stressed that people with ASD were willing to provide the training. Carolanne acknowledged that the input of people with ASD to recent SSA training had been insightful. Donellen explained that the current Service Level Agreement with the SSA is due to be reviewed and they could look at investing in people with an ASD to provide training. Carolanne said that there is a standard content that SSA has to deliver in current training and that it can be difficult to judge how much time to allocate to co-presenters who have ASD. There was further discussion around employment schemes in Highland and the Central belt. Elke stated that she would be happy to provide training in her own time provided travel expenses were covered. Simon stated that if people with ASD were to provide training on their own, they would require administrative help for the organisation of training. Donellen agreed to take this issue forward in the discussion regarding the SLA.</p> <p>Parents who have autism or Asperger Syndrome may need extra guidance on what their child may require for support through work experience. Preparation for work experience in schools can be patchy, with different practices in different schools. When schools are planning work experience, they must remember that pupils with ASD might not be ready to undertake work experience at the same time as other pupils. Suitable work experience placements would need to be identified.</p> <p>Kerry stated that pupils should not be expected to miss classes to attend social skills groups. Social skills input should be ongoing from early childhood, not starting at 14 years. Myna stressed that this is the message given to schools.</p> <p><i>Carers Group</i></p>	<p><i>DM</i></p>
4A	<p><b>Draft Final Recommendations</b> There were no comments from the Carers Group on this item.</p>	
4B	<p><b>Social Activities, leisure, respite and support for carers</b> Many young people with an ASD will require support for social and leisure activities in adulthood, but parents don't know what support (if any) is available. Parents need workshops on transitions issues, such as guardianship, well before the transition to adulthood. These workshops should include information about the minimum standards that parents and young people should expect in their transition to adulthood, and information about standard procedures for emergency care. May flagged up the need for parents to be made aware of the age at which young people can make their own decisions. Melissa said she would address this at her workshops. Donellen stated that the legal status of the young person is an item in the proforma for transitions planning contained in the Transition Protocol. Simon explained that the revised "It's my Choice" (directory of adult services) will contain information on the first page regarding how to access advice on this.</p> <p>Some adults with ASD and carers are not aware of provision in the legislation such as Guardianship for example. Donellen said that independent advocacy would have a clear role for many adults who have incapacity, and that training for advocacy services would</p>	<p><i>MK</i></p>

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<p>4C</p> <p>4D &amp; 4E</p>	<p>be required as advocates would need to have knowledge of the legislation.</p> <p><b>Employment Support</b> Some staff members at the Shirlie Project have had Prospects supported employment training from the NAS. The carers group asked if a system was in place to ensure that people who have autism or Asperger Syndrome are referred to these members of staff. The Shirlie Project are aware this is an issue but have been unable to come up with a separate system for ASD. Donellen said she would ask for this issue to be on the agenda for the SLA review with Shirlie. Melissa agreed to email Donellen about the key issues.</p> <p><b>Counselling / Training &amp; Education for Service Providers</b> There was not enough time at either the consultation or carer group meetings to discuss these items.</p> <p>Donellen reminded the planning group that any comments on the draft final recommendations should be sent to Simon prior to planning group meeting on 27th April.</p>	<p><i>DM</i> <i>MK</i></p> <p><i>All</i></p>
<p>5.</p>	<p><b><u>AOCB</u></b> Elke has written a book about her life "Discovering who I am" £7.99. It is available from the NAS website. There was commendation for Elke's achievement in writing her book.</p> <p><b><u>Report to Chief Officer Group 20.12.06</u></b> Carolanne Mainland (SSA) and Melissa Kay (NAS) left the meeting at this point. There was then detailed discussion on the proposed recommendations.</p>	
<p>6.</p>	<p><b><u>Date, Time and Venue of Next Meeting</u></b></p> <p>27 April, 9.30am-12noon, Multi-Purpose Room 1, Centre for Health Sciences, Raigmore Hospital, Inverness.</p> <p><b><u>Please be aware that there is likely to be a £1 charge for the car park.</u></b></p>	