

MINUTES

ESSEX AND SOUTHEND LINK

NE ESSEX LOCALITY GROUP MEETING

Date and Time Thursday 27 November 2008 at 12.00 –14.00

Location Bluebell Resource Centre, Jack Andrews Drive, Highwoods, Colchester,
CO4 9YN

Attendees: Reg McKenna, Keith Biggar, Marguerite Crunden, Marguerite Jenkins, Hazel Law, Vi Haddow, Harry Young, Nileema Vaswani, Rosalind Peek, Steve Wood, Mahbuba, Begum, Mashuda Hussain, Moshud Ali; Carolann Jackson, Mike Chapman, Aymero Gebremeskei and Tamanna Hoque.

Apologies: Sushila Karia; Dhirajlal Karia; Diane Stedman; Sara Ajala; Vijay G Vyas

	Topic	Discussion	Action by who/when
1	Welcome and Introductions	Reg McKenna welcomed participants and opened the meeting.	-
2	Minutes of the last meeting	<p>Minutes of the last meeting were presented by the Chair and approved by the meeting.</p> <p>Reg McKenna advised that agenda item 5 regarding Adults with Asperger Syndrome (AAS), should be presented to meeting before 'matters arising' as he had to leave the meeting at 1 .30PM. The meeting supported the chair recommendation and invited Carolann Jackson to open the discussion based on her paper on Adults with Asperger Syndrome which had been presented to the meeting.</p> <p>Carolann Jackson introduced herself as chair person for the Support of Asperger Families in Essex and as carer for her daughter who has the Asperger Syndrome. Carolann Jackson gave a brief introduction about Asperger Syndrome (AS) and talked about her experience as carer to her daughter.</p> <p>Carolann Jackson indicated that the estimated</p>	

number adults with Asperger Syndrome living in Essex are 5000 and highlighted the problems that this group has in accessing adequate services. This is mainly because the syndrome is not recognised as a mental health or disability problem. Also she described how under the current health and social care system there is a lack of adequate diagnosis services to understand the scale of the problem.

Carolann Jackson indicated that unlike many of us, people with AS have a different perception of their environment and their understanding of the everyday life is different from the average person in the society. **Carolann Jackson** indicated that one of the problems faced by people with AS is the lack of understanding about the problem by society.

Steve Wood commented on the problem of late diagnosis of AS, and highlighted how this has also created problems for service providers. He suggested the need for training in early detection of AAS.

Mike Chapman highlighted limitation of services available to people with AS, as the result of AS not been seen as mental health problem.

Carolann Jackson suggested that her experience regarding service provision indicates that there is very little service available to people with AS and in addition to this **Carolann Jackson** also suggested the problem has been exacerbated as a result of the high number of family breakdowns and suicide rates among the families and AS sufferers. She highlighted isolation, depression, lack of friends and social support as the main problems within the AS community.

Marguerite Jenkins commented on what the NE link can do to alleviate the problem. **Reg McKenna** acknowledged the problem and informed the meeting that the issue is noted by the PCT and he is also working to increase awareness among service providers.

Mike Chapman commented that the PCT and the NE trust are willing to work with the AS support group on service commissioning and he will raise the problem of AS in his next meeting.

Reg McKenna suggested that the NE LINK should setup an AS Task Group to work with **Carolann Jackson** to bring change in service provision and to increase awareness.

Carolann Jackson supported the idea of setting up a LINK AS task group to address the issues of

		<p>AS more effectively and to promote the welfare of AS suffers in Essex.</p> <p>Steve Wood suggested that to ensure everyone understands the main issues of AS and purpose of promotion that the AAS briefing document should be condensed. Carolann Jackson agreed to summarise the document.</p> <p>Aymero Gebremeskel invited the participants to forward their name to join the NE LINK AS Task Group.</p> <p>Keith Biggar, Reg McKenna, Mike Chapman volunteered and will join Carolann Jackson in forming the NE locality LINK AS task group.</p> <p>It was requested that CEMVO will circulate the contact details of members among the task group members.</p>	<p>Carolann Jackson to summarise the document</p> <p>CEMVO will circulate the contact details of members.</p>
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3	Matters Arising	<p>JSNA Colchester and Tendering</p> <p>Margaret Crunden highlighted 'deprivation' as the main cause of ill health for a high number of elderly people in Colchester.</p> <p>Reg McKenna invited members to raise specific issues from the document that the NE LINK can take forward.</p> <p>Rosalind Peek suggested that members looked at the priority areas of the JSNA.</p> <p>Vi Haddow suggested the NE LINK should look into the service requirements of elderly people and stated that in Tendering this is the foundation's priority strategy area. She also advised that the LINK investigates the link between the JSNA document and foundation trust</p> <p>Mike Chapman suggested NE LINK looks at the JSNA document from the patients' point of view.</p> <p>Marguerite Jenkins highlighted the importance of the JSNA and advised LINK to take the responsibility of making sure that the document is a practical document rather than 'lip service'.</p> <p>Reg McKenna recommended that the meeting sets up a working group to look into the JSNA.</p> <p>Reg McKenna, Keith Biggar, Marguerite Crunden, Marguerite Jenkins, Moshud Ali and Vi Haddow volunteered to join the JSNA focus group.</p> <p>CEMVO will send the Colchester and Tendering JSNA documents to members of the focus groups.</p>	-
4	Representation at PCT's and Hospitals Trusts.	<p>Reg McKenna informed the meeting that he has contacted the PCT and the Hospital Trust and was asked by the PPI panel to give an interview.</p> <p>Hazel Law suggested that NE locality group LINK also needs to contact Colchester Tendering and commissioning forum.</p> <p>Vi Haddow highlighted the problem of engagement with PCT and the Trust. Both the Hospital and the PCT board have recently changed their board format to try and address this issue. She suggests the LINK develops a new engagement and involvement strategy with the</p>	-

		<p>PCT and the Trust. In the meantime she suggested that public involvement is still possible under the new governance structure and LINK can explore the existing engagement structure with service providers and commissioners.</p>	
5	<p>Work plan / Strategy for next 3 – 4 months.</p>	<p>Hazel Law raised the issue of the PPI legacy document and suggest setting up the PPI Legacy focus group. Hazel Law highlighted the main important issues from the Legacy document and suggested the meeting agrees priority issues from the PPI legacy document.</p> <p>Margaret Jenkins suggested the NE LINK works on the following issues.</p> <ol style="list-style-type: none"> 1. Mental health 2. PCT 3. Hospital issues 4. Drug and Alcohol <p>The meeting agreed to set up a working sub group to develop the NE Locality LINK's work programme and the PPI legacy document. The following participants volunteered to be the members of the sub groups.</p> <ol style="list-style-type: none"> 1. Reg McKenna 2. Keith Biggar 3. Vi Haddow 4. Harry Young 5. Hazel Law 6. Marguerite Jenkins 7. Marguerite Crunden 8. Dan Kessler 9. Moshud Ali <p>Keith Biggar agreed to set up a countywide Alcohol and Drug subgroup.</p> <p>CEMVO update Aymero Gebremeskel briefed the meeting about the LINK newsletter and the importance of distributing the newsletter to promote LINK. He also introduced Tamanna Hoque as the new administrator for the NE Locality Link</p>	<p>-</p> <p>-</p>
6	<p>AOB.</p>	<p>Vi Haddow requested an explanation about the expenses policy, in particular the payment for mileage and how this is calculated.</p> <p>Rosalind Peek informed the meeting about the current travel expense payment policy which is 40p per mile. She also emphasised that the policy is trying to achieve a balance between</p>	<p>-</p> <p>-</p>

		<p>what we spend and the demand for expenses within a limited budget.</p> <p>The meeting agreed at the next meeting CEMVO would prepare Participant Name Plates for the purpose of identification.</p> <p>Vi Haddow requested that 'engagement with the public' to be one of the agenda items at the next meeting.</p> <p>Hazel Law recommended that the meeting venue and time is also an agenda item at the next meeting.</p> <p>Aymero Gebremeskel from CEMVO, will forward these agenda items to the chair for inclusion in the next meeting agenda.</p>	
7	<p>Date and venue of the next meeting</p>	<p>At the 23 October 2008 meeting the YMCA was identified as a possible venue for the next meeting and suggested by members as a means of involving young people in this forum.</p> <p>Marguerite Jenkins opposed the idea of having the next meeting at the YMCA because of the absence of available parking.</p> <p>Hazel Law suggested the next meeting be held at place Blue Bell Resource Centre or St Johns Ambulance Community Hall, Stanway.</p> <p>Carolann Jackson asked if the meeting could be held during evenings.</p> <p>Keith Biggar reminded the meeting that the issue of evening meetings was discussed in previous meetings and reminded participants of the decision made not to organise evening meetings on safety grounds until summer time.</p> <p>The next meeting will be held on 22nd January 2009, 12-2 PM. CEMVO will find out whether the St John Highwood's Community Hall is available. If the hall is not available the meeting will be held at the Bluebell Resource Centre.</p>	-