

Kent Acquired Brain Injury Forum (KABIF)

MINUTES

of meeting held on 7 June 2007 at 7.00 p.m.

**Royal British Legion Industries, Capel Morris Hall, Royal British Legion Village,
Aylesford, Kent ME20 7NL**

1. In attendance:

Jan Cartmell
Ros Eastwood
Tony Hart
Chris Merriman
Tony Merriman
Pam Munro
Frances Pierce
Sandra Rafferty
Mary Ryan
Dennis Smith
Joanne Stovold
Catherine Symington
Linda Theoff
Sue Ware
M Wowwacath

2. Apologies

Tom Balchin
Liz Bray
Louise Brown
Nicky Coffey
Sophia Chung
Alex Drake
Diane Drummond
Delia Elliman
Gerhard Florschutz
Elizabeth Francis
Bhavna Jones
Sheila Riches
Patti Simonson
Jennifer Stockley

3. Approval of Minutes of Meeting held on the 5 April 2007

These were approved subject to amendment to paragraph 4 – West Kent, which included Maidstone not Medway and Swanley not Bromley and paragraph 6 – West Kent should read Tunbridge Wells. Paragraph 8 LINKs (Local Involvement Networks).

4. Matters arising from the Minutes of Meeting of the 5 April 2007

Frances reported that Nicky Coffey had sent her an e-mail setting out the breakdown of the specialised commissioning groups and how they related to the PCT'S. A copy of the e-mail was circulated.

5. Neuro Rehab Stakeholders' Group and NSF Update

Nicky Coffey (see above)

6. Mapping Exercise/website update – Mary Ryan & Chris Merriman

Mary gave an explanation as to what we were trying to do on the website. She explained that the mapping exercise was complete and it should be up and running shortly. There was a need to look at the exercise and correct any spelling and grammar. She took the opportunity to remind members that if there was anything that needed to be added to the website in order to provide information on acquired brain injury then the members should draw that to our attention. Frances indicated that there would be an opportunity at the normal meetings to discuss services that were included on the website and to brainstorm as to any services that had been omitted.

7. Headway (Kent)

Di Drummond had sent her apologies because she was collecting an award tonight. Dennis reported Tunbridge Wells Headway had now had the keys to their new building handed over to them by the hospital Trust and reported that there was lots of work to be done to the building to make it suitable and that the builders would be there until September. Dennis gave us some idea as to the costs of the refurbishment and how Headway were busy raising funds and reported that they had some funds that they call on. They reported the appointment of an Appeals Director and indicated that they expected to raise somewhere in the region of £250,000.00 this year and efforts to raise that were going well.

He indicated that temporary premises caused some difficulty because it was temporary and they had had to reduce some activities but when they move into the new building activities are likely to be expanded considerably. There was no report from Canterbury or Ashford but Frances Pierce mentioned the plan to have a KABIF meeting in East Kent later on.

8. Focus on Young Adults with ABI - Ros Eastwood

Ros Eastwood explained where we were with this project and how it had been to try and gather information from young people. She explained how she had collated the responses she had received and asked in particular for suggestions from young people in order to make the information relevant for them. She explained that she was going to put together a questionnaire for members to go through with these young people and to ask questions and to get the responses. The object was to produce an information brochure that was user friendly and would deal with the specific problems encountered by young people with ABI. She said that she intended to include in the brochure examples of a successful practice so it could be seen how recommended services improved the lives of the young people concerned. The practical examples would, of course, be analysed very carefully.

Tony Hart wanted to know whether a young lady he was working with could be of any help and examples were given. There was a discussion around the need for a Case Manager and also discussion regarding those cases where Case Managers were not engaged.

Dennis Smith asked how it was intended to use the brochure and it was confirmed that the KABIF Steering Group were considering this. Frances Pierce indicated that it would need to be professionally produced.

9. PPI Forum – Dennis Smith

Dennis Smith gave a report on the local Government bill which proposed the abolition of PPI. He explained that it was likely to be abolished in March of next year and that there was concern amongst the volunteers as to what will take over. He explained the proposal for LINKs (Local Involvement Networks). He was not clear that it would work. The proposal emphasised local involvement but from the schemes that were being proposed he could not see how that would be. He explained that there was a pilot in Medway. All sorts of bodies were represented but he could not see how local people would be involved. He believed it was not going to be local in the same sense as PPI. Dennis indicated that he was trying to focus people in Tunbridge Wells to understand what PPI did. He explained that it was a statutory body and as such has access to management to make it's concerns known at the highest level. He hopes that he will be able to carry on with that. Frances Pierce explained that Greg Clark was coming to see us in December and it would be worthwhile dropping him a line mentioning the problems with the replacement for PPI when coupled with the problems that the members of the public had obtaining Legal Aid it meant the public had little say in what was going on.

10. Talk by Sandra Rafferty who was an advocate at the Independent Complaints Advisory Service (ICAS).

Explained how ICAS overlapped with PPI, also explained the differences. She explained that ICAS had several offices that operated throughout the South. She explained there were similar organisations who covered other parts of the country.

She explained that their work was patient centred and that their loyalties were to the patient and that they were there to support the patients.

She explained how they encouraged patients to discuss their complaints and to agree action points. Explained also that the complaints could be about any aspect of the service from treatment to hygiene in the food service etc. She explained that they in all handle about 10% of all complaints made to hospitals.

Sandra went on to set out how they were able to untangle situations that become lost in emotion and they were able to deal with situations where there was a problem with the English language. She indicated that her brief was based on the patient experience and how important it was to them to listen and learn as to what the patient's experience was and not put on their own interpretation. The emphasis was on it being the patient's complaint and not the organisations. She explained how traumatic the process can be to patients and how the reactions of patients can be different in an advocacy situation and their role was to try and coach them through that.

They had five offices, 8 ½ advocates.

She went on to explain that she could deal with a complaint against any NHS body. Often the body themselves could recommend the complainant to ICAS, particularly if they cannot articulate their complaint. She explained that they did not get involved in any internal investigations.

She dealt with the Pal's system. She indicated that the problem with that system was that it didn't help the patient to get treatment which is often what they wanted.

She explained the definition of advocacy as implemented by their organisation.

Sandra was asked about what occurred when the Receiver was appointed and she explained the procedure that was operated if the Receiver was in place or a Power of Attorney had been appointed.

10. Tony Hart – Queen Elizabeth Foundation, Banstead Place

He gave a talk about the Queen Elizabeth Foundation and explained that it was a brain injury rehabilitation centre and specialist college. He described the college and the facilities that were available. He indicated that the patients were usually those with severe brain injury between 16 to 35 years of age. They could be resident or non resident, usually they were funded and referred by their PCT. He explained the different categories of rehabilitation that the centre was involved in such as occupational studies, art. They could offer neuropsychology, group sessions and set out a fairly comprehensive list of rehabilitation activities. He went on to explain some of those, in particular vocational training. He indicated how to be realistic and to meet the individual and where they were. Explained how they go about work experience and the sort of work experience that was offered.

Tony then went on to explain what he thought the future of the project was and he indicated that the average stay at the centre was about 18 months.

Jan Cartmell at the end of the talk mentioned somebody who had been at Unsted and went on to Banstead and used the example as a demonstration as to how the agencies could work together to really improve the lifestyle of individuals with ABI. They all, however, experienced similar problems with regard to funding issues and the difficulty of getting individual funding for these people. There was some general discussion about whether we could get somebody down to talk about what could be done legally to persuade the authorities to pay funding when it was necessary.

11. Any Other Business

Frances Pierce mentioned the joint meeting there had been earlier on in the month of the three South East ABI forums and the need to be aware of the working time regulations when it came to employing carers and to make sure that the regime was within the law so far as the working time regulations were concerned.

Sue Ware reminded people that speech and language therapists had to be registered and it was possible to check their qualifications by going to the HPC (Health Professions Council) website.