

## **Kent Acquired Brain Injury Forum (KABIF)**

### **DRAFT MINUTES**

**Of Meeting Held on 15 September 2005**

**At the Maidstone Office of asb-law**

#### **In Attendance:**

Louise Brown, Legal Assistant, Thomson Snell & Passmore  
Jan Cartmell, The Regard Partnership  
Sophia Chung, Executive Director, S C Support and Care Services Ltd  
Di Drummond, Manager of Headway Tunbridge Wells  
Ros Eastwood, East Kent Hospitals Schools Service  
Tim Gilbert, Brain Injury Case Manager from Independent Living Solutions  
Mike Hope, ABI Co-ordinator for East Sussex, Brighton and Hove  
Tony Merriman, Solicitor, asb-law  
Pam Munro, Founder and Volunteer of Tunbridge Wells and District Headway  
Frances Pierce, Solicitor, Thomson Snell & Passmore (Chair)  
Mary Ryan, Occupational Psychologist, RBLI  
Dennis Smith, President of Tunbridge Wells and District Headway  
Linda Theoff, Brain Injury Case Manager, Buckland Hospital  
Hilary Whibley, Occupational Therapist at Community Brain Injury Team,  
Medway Maritime Hospital

#### **1. Apologies for Absence:**

Sue Anscombe, Occupational Therapist, Pembury Hospital  
Frances Beaumont, Occupational Therapy Services  
Janet Bjorn, Consultant Child and Adolescent Neuro-Psychiatrist  
Mrs J Mazur  
Dr Delamont  
Deborah Harding, Unit Co-ordinator, West Kent Neurorehabilitation Centre  
Mandy O'Brien, Brain Injury Case Manager  
Gerhard Florschutz, Director, Raphael Medical Centre  
Andrew Watson, Solicitor, Thomson Snell & Passmore  
Jennifer Stockley, Independent Paediatric, Neuropsychologist, Tadworth Court

#### **2. Approval of minutes of meeting of 30 June**

There were two amendments requested to the minutes (reference to Pam Wells being at Headway Court should read Headley Court and Headway Court 10<sup>th</sup> anniversary celebrations were on 14 September not 12 September). Subject to these amendments being made the minutes were approved.

### **3. Matters arising**

Pam said that it should be noted that Oliver Mills has been appointed as Director of Adult Services at Kent County Council. Sophia offered to make contact with him.

Pam informed the meeting that Harrowlands Hospital had now closed.

Di said that Headway had been negotiating with the Sevenoaks Rehab Unit with regard to their search for new premises but were actively looking for premises themselves now. Frances offered to put something on the KABIF website about this to help publicise their search.

Dennis Smith gave a summary of Headway Court's 10<sup>th</sup> anniversary celebrations. He said that Headway Court came together in 1995 after about three years of work. There are seven people living there, all of whom have suffered a traumatic brain injury and are tenants. The eighth flat is for the manager. There has been very little movement in the tenancies because those living there presently have nowhere else they could go to. Over this time they have acquired living skills and the support they have needed has become less and less. Their quality of life has improved immeasurably. John Grooms, the charity behind Headway Court, regard it as their flagship house and are now working on a similar house in Bristol.

Di commented that it is always important to make a note of the housing needs of an ABI sufferer so that correct statistics can be compiled showing the true position of the need for housing.

### **4. Information Exchange**

Di said that Kent County Council were launching a road safety campaign in October in Maidstone. The intention is to show how an RTA affects everyone, including family, friends and carers, apart from the victim themselves. They are looking for anyone who would like to take part in that campaign and Di can send out the information to anyone who is interested, including KABIF who can then put it on their website. It is a two-year programme so if the initial launch is missed there will be opportunities to join the campaign later on.

Dennis said that said that there is a service known as the Community Therapy Service which has teams of therapists, e.g. occupational therapists, physiotherapists, speech and language therapists. Dennis has had meetings with groups such as Parkinsons Disease Society, because the Community Therapy Services teams are concentrating on those people suffering from long-term needs. There is an assessment centre at Sevenoaks Hospital and Jane Cast is the liaison person based at Pembury Hospital. The service is 90% domiciliary-based, the therapists going out to homes and assessing needs and goals.

Hilary said that this service is based on a similar team at Medway Maritime Hospital. There is a community team there with over 16 therapists. It is a goal-based system with regular reviews being carried out. A conference was

recently held with current and previous clients to get an idea of user's views. It has been going for eight years now.

Mike said that the Brain Injury Social Work Group are organising a national conference in Sheffield next March. He was asked to email the information through so that it can be put on KABIF's website.

#### **5. Neuro-Rehab Stakeholders Group - Debbie Harding**

Debbie was not able to attend the meeting and so no update was possible.

#### **6. Website [www.KABIF.org.uk](http://www.KABIF.org.uk)**

Frances was unable to show the updated website as there was no internet connection available. However, she impressed on everyone that they could promote anything on the website and to please email items to her in order that they could go on. She encouraged everyone to use the site to keep up to date with the Forum's activities.

#### **7. Mapping Exercise**

Frances said that unfortunately our helper on the mapping exercise at Raphael Centre had had to give this up and we were waiting to hear from Gerhard with the name of a replacement.

#### **8. Project Sub-Committee**

Frances summarised the present position regarding the project which the sub-committee had discussed within the previous Steering Group Committee Meeting. She reminded the meeting of the various categories, as follows:

- housing
- independent living
- vocational training and a return to work
- adolescents and 60+
- Basic information about brain injury by using the mapping exercise
- Drugs and alcohol
- Dual diagnosis (i.e. a patient suffering from Huntingdons who then hits their head)
- Mental health
- Risk – share and assess

Unfortunately some members of the project sub-committee had been unable to attend today's SGC. As it was felt that their input in the decision-making process was vital it has been decided that this item should be put over to the next SGC meeting.

## **9. Talk by Stephen Carr of Partnership with Parents (PwP)**

PwP help to supply advice, support and understanding for children with additional or special educational needs, and are funded by KCC for parents, carers and schools, although they operate at "arms length" from the authority. They believe that the best results for all children happen when parent, schools, the local education authority and other agencies work together in partnership.

PwP offers advice and support via a helpline, the provision of leaflets and information sheets, tapes and videos, and also by offering a mediation service which can assist in resolving disagreements.

An Independent Parental Supporter (IPS) will help parents of children with additional or special educational needs to express their views and offer support. PwP can help decide who the IPS will be; it could be a friend, a relative or a volunteer with the PwP service. PwP run a training programme for volunteers to become an IPS and eventually work alongside parents and carers and provide them with information and impartial advice so that they can make informed decisions.

PwP meet regularly with parents, carers, teachers and voluntary organisations to help plan the way it works. They believe that communication between all those involved in a child's education is the key to good relationships.

## **10. Talk by Sue Woolridge and Margaret Little of the Expert Patients Programme**

Sue is an EPP support manager.

EPP is an NHS-based training programme that provides opportunities to people who live with long-term chronic conditions to develop new skills to manage their condition better on a day-to-day basis. Set up in April 2002, it is based on research from the US and UK over the last two decades which shows that people living with chronic illnesses are often in the best position to know what they need in managing a tangible impact on their disease and quality and quality of life generally.

The EPP course is free and takes place over two and a half hours per week for six weeks and are led by people who themselves live with a long-term health condition. Topics covered include exercise, relaxation techniques, diet, complementary therapies, effective communication skills, etc. It is hoped that by taking part in the Expert Patients Self-Management Programme, the person will acquire the following skills/abilities:

- Acquire or extend the knowledge of how to live with a condition
- Develop confidence to take control of the day-to-day management of a specific illness
- Meet with others who share similar experiences
- Work alongside healthcare professionals in deciding the best outcomes for the improvement of quality of life

- Have access to high quality information and a network of people with the same condition
- Contribute to the way health services are delivered to patients and have a say in changing them for the better

Margaret, who is a user of the EPP as well as being a volunteer tutor, gave the meeting a talk about her own personal experience of the EPP, having undertaken the course herself. It consisted of a four-day training course in London and she has since attended open days and seminar. She said that everyone on the course had a level of things with which they could not cope, be it managing daily tasks, suffering a lack of understanding even from doctors, coping with feelings of isolation, pain, fear, anger, depression. She said that the EPP course lived up to its name and she wished she had been able to do it when she first became disabled as it would have helped both her and her family.

Margaret said that she had recently had a chance to put the coping strategies into practice when she was going to see her specialist. Usually she had been unable to take in all the things he said at their appointments, but on this occasion she had been logging her various symptoms on a chart prior to the appointment so that she was able to clearly identify and discuss her symptoms. This led to an immediate diagnosis and stability in her condition. This is all thanks to the EPP.

Sue said that there is an EPP taster day taking place on 6 October . She said that they were always looking for venues where courses could be run. Frances offered to put a link to the EPP on the KABIF website.

## **11. Any Other Business**

Frances said that KABIF, as a regional group, had been asked by UKABIF to give consideration to certain terms as part of their 2005 Action Plan to review how local regional groups can be affiliated to UKABIF and establish a protocol. The terms were as follows:

- (a) The chairperson or equivalent must be a current member of UKABIF
- (b) The group would send an account of their activities for each UKABIF members newsletter (approximately five per year)
- (c) Any public statements must be passed by the UKABIF Executive Committee prior to publication; a quick response system for dealing with this has been established by the Committee.

Frances asked the meeting if there were any objections to these affiliation points. There were not. It was decided that Frances would write to UKABIF confirming there were no objections from KABIF although we would not be formally amending its Terms of Reference.

Mike said that they had had the same discussion regarding the UKABIF terms and had come to a similar conclusion.

Frances informed the meeting that she had made contact with Nicky Coffey who is Margaret Bentley's replacement at Maidstone Weald PCT and she had been invited to the next meeting.

**Next meeting:**

**Date:** 27 October 2005  
**Time:** 2.30 p.m.  
**Venue:** East Kent Hospitals School Service, City View,  
Canterbury, Kent CT2 8PT