

Kent Acquired Brain Injury Forum (KABIF)

MINUTES

Of the meeting held on 16 July 2004

At the offices of Thomson Snell & Passmore, Lonsdale Gate, Tunbridge Wells

In Attendance:

Pam Munro, Founder and Volunteer of Tunbridge Wells and District Headway
Deborah Harding from West Kent MHT NHS Trust
Adam Kenyon from the Brain Injury Rehabilitation Trust for the South and Midlands
Tim Gilbert, Brain Injury Case Manager from Independent Living Solutions
Dennis Smith, President of Tunbridge Wells and District Headway
Frances Pierce, Solicitor, Thomson Snell & Passmore
Andrew Watson, Partner, Thomson Snell & Passmore
Sheila Riches Solicitor, asb law, Brighton
Rosalind Eastwood from East Kent Hospitals School Service
Jan Cartmell, The Regard Partnership

1. Apologies for absence:

Dr Gerhardt Florschutz, The Raphael Medical Centre
Amanda Allen, Maidstone Weald Primary Care Trust
Gill Bond, DART
Gayle Easter, DART
Marilyn Goddard, Headway
Tony Merriman, asb law
Mandy Richmond, Harrison Associates
Victor Payne, Blackheath Brain Injury Centre
Linda Theoff, East Kent Neuro Rehabilitation Unit, Buckland Hospital
Jacqui Locke, Headmistress of West Kent Hospitals School Service
Janet Walker, Physiotherapist and parent of daughter with ABI
Sue McMachin, East Kent Coastal Speech and Language Therapy Service
Jo Clark-Wilson, Case Manager

2. Approval of Minutes of Meeting of 11 June 2004

These were approved.

3. Matters arising from the minutes of the meeting of 11 June 2004

The brain injury lecture run by Thomson Snell & Passmore Solicitors had been very well attended. It was agreed that Keith Andrews had been a perfect choice to encourage volunteers to help set up KABIF – a number of people had confirmed their interest, not all of whom were available to attend today's meeting.

4. Date and venue for public meeting

There was a discussion about an appropriate date. It was agreed that there were a lot of activities going on in October connected with brain injury, it was decided that we would need to be careful about the date and venue. It was

suggested that an hotel just off the M2 might be an appropriate venue. BIRT were having their conference there on 3 November 2004.

There was a discussion as to whether it would be appropriate for the forum to join forces with BIRT on that date. BIRT were providing in-house speakers. Consensus of opinion was that an evening would be a better time for the meeting.

5. Brain Storm Session e.g. Nature and Purpose of KABIF

To include children and young aged? Pam Munro helpfully referred to the Sussex Brain Injury Forum terms of reference and these were discussed at length. All agreed that the forum was going to be worthwhile and that it would benefit many people involved in brain injury activities in Kent. All agreed that it should be a focal point for consultation and that some aims and objectives could be agreed upon straightaway. All agreed that it was important that everybody had confirmation as to what the forum was going to set out to do. The following was settled upon: -

1. To develop, foster and facilitate greater awareness and understanding of current services and proposed developments in the field of acquired brain injury (primarily through information sharing and networking).
2. To be proactive in developing opportunities for people with acquired brain injury, their carers and other interested parties to obtain accurate and useful information and training related to acquired brain injury.
3. To be a focal point for consultation between the community, the health service, social services and voluntary organisations as well as the private sector and education department on the development and commissioning of services in the field of acquired brain injury throughout Kent.
4. To contribute to the development of life-long care pathways for people of all ages with acquired brain injury, with a view to maximising their independence.
5. To contribute to the advancement and development of localised community services for people with acquired brain injury.
6. To promote education and training in acquired brain injury for professionals working in that field.

As to the scope of people who the group would be willing to adopt, the UKABIF definition of acquired brain injury was considered: "to include traumatic brain injuries – such as open or closed head injuries – or non-traumatic injuries such as those caused by strokes and other vascular accidents, tumours, infectious diseases, hypoxia, metabolic disorders (e.g. liver and kidney diseases or diabetic coma) and toxic products taken into the body through inhalation or ingestion. Does not include brain injuries that are congenital or produced by birth trauma, or those of a degenerative nature."

The definition applies to all age groups. There was then a discussion as to whether the forum's current scope of expertise and activity would focus on adults exclusively or whether they could include a commitment to children as

there was expertise within the forum and a need to include children. All agreed that children would not be excluded.

ABI Services in Kent

Examples were given of models that already exist and brain injury initiatives that have been running for some time. All agreed that there was no need to reinvent the wheel and the Sussex Brain Injury Forum was respected and consulted widely. Kent Forum could achieve, with the right people onboard, similar success.

All agreed it was worth looking at what Sussex had learnt so far, but Kent wasn't to be a carbon copy of Sussex. Kent would naturally develop rather than mimic. It was accepted that there were probably a lot of initiatives and lots of really good models of care and examples of good practice going on in Kent. The key was to be able to have a forum that identified where these were and that they were followed wherever possible. It was clear that even within the Health departments, one department didn't know what another were necessarily doing. Although they naturally are quite protective atmospheres, it was noted that West Kent had set up a steering group. They had a robust plan for the next three to five years and had secured funding to move that forward. They had a lot of information that the forum would benefit from being able to share.

There was then a general discussion as to what those present wished to get out of KABIF. It was agreed that a database of services should be identified, both in the independent and public sector, that the forum should strive to ensure that the various providers of services complemented each other and that basically, people got to hear about what was available, hopefully from one source. A lot of people spent time networking for their own ends and didn't always share what they had found. KABIF could co-ordinate initiatives.

Website

All agreed that a website would be a very useful tool for KABIF and once the database was worked up, it could be accessed through that site. Adam Kenyon confirmed that he had a client at Headway Hurstwood Park who had a real expertise and interest in IT. He would speak to them to see if they would be willing to assist. TS&P agreed to assist with their resources where appropriate. Sheila Riches confirmed that someone from Headway had in fact set up the SABIF site free of charge. She could ask Emma Stevens of Headway Hurstwood Park to find out who that was to see if we could ask them to help with KABIF. Apparently the way in which that had been set up meant it was very cheap to update.

There was then a discussion as to whether a website could be shared with UKABIF but it was clear from the Sussex Minutes that UKABIF weren't in a position to umbrella local groups in this way. All agreed that it would be helpful to have a link across from the website to SABIF and UKABIF.

Headway

Dennis Smith confirmed that they had an outreach person who has a lot of contacts and information that might be able to assist. He confirmed that Headway have a help line that is run by Pam Munro and Michael Munro and there is also a national help line. He warned that not everyone has computers.

Sheila Riches confirmed that at SABIF, a carer had recently spoken to the forum and all who listened to the difficulties that that carer had had, and continues to have, realised that the problems that people have in getting the right services day to day are really a lottery. To hear first hand about the difficulties experienced was a very useful insight and just what a forum can achieve. SABIF have regular discussion groups, presentations from case managers and support workers, physios, OT's etc to discussions about best practice. Many use the forum to spread knowledge and expertise. SABIF is attended by a wide selection of interested parties. KABIF needs a wide audience and a good cross section of ABI interested parties to succeed.

West Sussex ABI Network have an 'open space' event going on on the 29 September. This initiative was to be applauded. SABIF were encouraged to see West Sussex PCT consulting widely.

6. Next Meeting

Everyone was keen to get more key people to the next meeting. It was therefore agreed to circulate the terms of reference and see how these are received. Everyone agreed to try and encourage those they knew to attend the next meeting. It was agreed that this would take place on **Thursday 19th August** at **2:30pm** at Thomson Snell & Passmore's offices in Tunbridge Wells.

Mike Hope was unavoidably delayed and arrived at 4.15pm.

The turn out for this meeting was disappointing. If terms of reference could be agreed upon, then all agreed they could be circulated prior to the next meeting and that might encourage more people to attend. Everyone was keen to get more key people to attend the next meeting.