

Kent Acquired Brain Injury Forum (KABIF)

MINUTES

of meeting held on 29 August 2007 at 3.00 p.m.

Thomson Snell & Passmore, 3 Lonsdale Gardens, Tunbridge Wells, Kent, TN1 1NX

1. In attendance:

Liz Bray
Lorna Buckwell
Jan Cartmell
Sophia Chung
Becca Coffey
Diane Drummond
Eddie Fardell
Rikki Gandolf
Kelly Hamer
Emily Heath
Mike Hope
Esther Lee
Catherine McDonagh
Chris Merriman
Pam Munro
Nathan Murphy
Chris Neale
Frances Pierce
Mary Ryan
Dennis Smith
Jenny Stockley
Martin Terrell
Linda Theoff
Sue Ware
Pam Wells
Kath Wilkinson-Carr

2. Apologies

Wendy Irons
Tony Merriman
Sandra Rafferty
Patti Simonson
Don Young

3. Welcome and Introductions

Frances Pierce encouraged all those who had not already done so to complete a Data Protection Form and return this to her. She confirmed that this form allowed KABIF to hold data for the purposes of the mailing list.

Frances Pierce said that a members and contacts list was being circulated within the meeting in preparation for this information being updated on the KABIF website. She asked everyone present to check their details and confirm on this list their up to date information.

4. Approval of Minutes of Meeting held on the 7 June 2007

These were approved subject to the following amendments: -

- Paragraph 7, 'Field Director' was amended to 'Appeals Director'.
- Paragraph 8, the penultimate sentence was amended from 'Dennis Smith asked what sort of application we intended to use for the brochure and it was explained that it was to be three to four pages of A5.' to read 'Dennis Smith asked how it was intended to use the brochure and it was confirmed that the KABIF Steering Group were considering this.'
- Paragraph 11 was amended from 'Sue Ware reminded people that chiropractors had to be registered and it was possible to check out their qualifications by going to the professional's website.' to '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'.

5. Matters arising from minutes of meeting held on 7 June 2007

With regard to the project focusing on young adults with ABI, Frances Pierce confirmed that her firm (Rix & Kay) and Tony Merriman's firm (asb law) were happy to jointly meet the costs of producing the leaflet and would like to have their logos printed somewhere on the leaflet, for example on the back.

Further to the joint conference held by KABIF, SABIF and SABIN, Frances Pierce confirmed that she had the slides about the Working Time Regulations and said that if people would like a copy they could email her (francespierce@rixandkay.co.uk).

6. Neuro-Rehab Stakeholders Group and NSF update – Nicky Coffey

Nicky Coffey was not available for the meeting, so this agenda item was deferred to a later date.

7. Mapping exercise/website update – Mary Ryan and Chris Merriman, www.kabif.org.uk (please visit the site, the mapping is now available!!)

Mary Ryan advised the meeting that she had held a meeting of the Website Committee and that great progress had been made. She confirmed that it is now possible to access the mapping exercise from the KABIF website.

Mary Ryan confirmed that the website now confirmed the up to date list of committee members.

It was confirmed that Chris Merriman had redesigned the questionnaire (the way in which people can add services to the mapping service on the website) so that the information can be more easily transferred on to the website. This included, for example, providing a tick-list of geographical areas that fitted the way these areas were represented on the KABIF website, rather than a question that allowed those completing the questionnaire to be vague or unclear as to the areas they covered.

It was agreed that at each KABIF meeting ten minutes or so would be spent on gathering updated information for the mapping service. Everyone was asked to review the website (www.kabif.org.uk) and let Mary Ryan, Frances Pierce, Tony Merriman or Chris Merriman have the names and contact details of further services in Kent so that these can be followed up so they are added to the mapping service.

Chris Merriman demonstrated the mapping service to the meeting and asked that everyone let him have any additional information they wanted to be updated about the existing services on the KABIF website (Chris@imperfections.freereserve.co.uk).

It was agreed that Chris Merriman, Tony Merriman, Frances Pierce and Mary Ryan would consider adding a facility on to the mapping questionnaire so that people could update their details through the use of a smaller questionnaire.

Mike Hope said that the SABIF website is being upgraded to follow a similar format to the KABIF website. Mike Hope will then work on the Brighton and Hove website to also follow the KABIF format so that there will be uniformity in the South East.

Mary Ryan said that there will be another website committee meeting so presentations from KABIF meetings can be added to the website.

Di Drummond asked whether it was possible to have PDF documents added to the website and Chris Merriman confirmed this would be possible.

Frances Pierce asked everyone to let her know of events for the forthcoming events page of the KABIF website. Dennis Smith and Di Drummond agreed to let Frances Pierce have the information about the brick appeal for Headway Tunbridge Wells to add to the KABIF website.

Rikki Gandolf advised the meeting that there was a Headway Conference coming up on 22 October, which could be added to the forthcoming events page of the website. She would email Frances Pierce the details in an electronic format for the website.

Mary Ryan said that the website committee were looking at ways of gathering statistics about how many people accessed the website and which parts of the site were visited most so that this information can be fed back at KABIF meetings.

8. Headway (Kent) – Di Drummond

Di Drummond said that Headway Tunbridge Wells should be moving into their new home in the first or second week of October.

Di Drummond announced that a Headway Junior was being developed for families of children with brain injuries. A proposal was being put forward to apply for funding for a support worker so that the appropriate personnel resources could be put in place.

She reported that Headway Tunbridge Wells were continuing to work towards Headway standards as across the country.

Rikki Gandolf explained that she was hoping to pilot an Information Pack in (East) Kent, which is based upon a pilot pack used successfully in Sheffield. The success of the implementation of the pack is very reliant upon stakeholder involvement and guidance and she has asked for anyone who is interested in discussing it further to contact her (se.regional.co-ordinator@headway.org.uk).

Pam Wells, Dennis Smith and Di Drummond advised that there was an information pack in Kent that was set up a while ago. Di Drummond said that Rosie from Headway Tunbridge Wells & District was working towards updating the information pack used in Kent, so it would be useful for Rikki Gandolf to liaise with Rosie to avoid duplication.

Pam Munro said that she feels the leaflets and booklets that Headway have are very good but not used regularly enough.

Rikki Gandolf said that the information pack being proposed for piloting was an A5 ring-binder with a couple of leaflets/booklets to go with it.

Di Drummond announced that Headway Tunbridge Wells & District had been able to secure a benefits officer to come to the centre on certain dates.

Pam Munro advised that she had spoken to Headway Kent and would liaise with Linda about what they would like for the meeting that they host on 11 September 2008, it would be good to include Headway in East Kent so that they could have some input at that meeting. Pam Munro agreed to liaise with Headway East Kent in preparation for that meeting.

9. Focus on Young Adults with ABI – Ros Eastwood

Frances Pierce advised the meeting that the project to produce a leaflet for young adults was nearing conclusion. Ros Eastwood had worked with young adults to gather feedback as to what was important to them. Independence was one of the key issues that arose. Ros Eastwood was collating the feedback to include information points based on young adults' experiences into a leaflet. Asb Law and Rix & Kay had agreed to pay for the production and circulation of the leaflet. Frances Pierce thanked all who had contributed to the project.

KABIF will now be looking to choose the next project and Frances Pierce asked everyone to let her know if they had any thoughts about the next short to mid term project that could be achieved within 12 – 18 months.

Dennis Smith put forward the idea of focussing on the elderly.

Jenny Stockley mentioned a programme on the ethics of treating people with learning difficulties that was due to be broadcast on Radio 4 on 29 August.

Mike Hope pointed out that there were issues with older people with acquired brain injury as there are a limited number of rehab resources who are willing or able to take people over the age of 65.

Sue Ware suggested it would be useful to find out how many NHS facilities for the elderly have ABI patients in them.

Frances Pierce asked what could KABIF add or achieve for this age group.

Mike Hope said that raising awareness was important. A couple of well publicised anonymous case studies, for example, would raise awareness.

Frances Pierce raised the idea of approaching an MP to raise and publicise issues.

Pam Munro remarked that it seems more people with ABI are being referred for psychiatric help and she proposed that some statistics should be gathered.

Jenny Stockley said that her husband was a stats co-ordinator and might be persuaded to assist KABIF in this capacity.

Dennis Smith proposed asking Julia Ross, Director of Civic Engagement (whose remit was to help patients) to speak to KABIF next year. KABIF could raise with her the issues of elderly ABI sufferers.

Dennis Smith said that Steve Phoenix of West Kent Primary Care Trust recently had a meeting on the topic of 'Fit for the Future'. Steve Phoenix was asked what his top priorities are. Stroke was his first priority, but the elderly were within the top six priorities.

Everyone was asked to email their thoughts for the next project to Frances Pierce (francespierce@rixandkay.co.uk) and the steering committee can consider these ideas.

10. PPI Forum – Dennis Smith

Dennis Smith confirmed he had been a volunteer with PPI (Patient and Public Involvement) for the last three years. The remit of PPI includes what the public and patients are concerned about with regard to their health services (including a review on dentistry). Dennis Smith announced that PPI is going to be abolished at the end of March.

In the place of PPI will be LINKs (Local Involvement Networks). Dennis Smith has a document entitled 'Getting Ready for LINKs'. LINKs will be a central body with a number of key people who will try to reach out to local individuals and organisations. At present PPI is only concerned with the NHS. LINKs will be concerned with other bodies as well, including Social Services. It is planned that there will be 150 LINKs in the country.

Dennis Smith confirmed he has decided that he would like to be a central part of LINKs, as he would like to represent long-term conditions within LINKs.

11. Talk by: Edward Fardell of Thomson Snell & Passmore and Martin Terrell of Rix & Kay – Receivership and the Court of Protection – What is a Receiver? and The New Mental Capacity Act.

Please see attached handout provided by Martin Terrell.

12. Any other business

The meeting was informed that a document relating to the new national framework about nursing could be found on the website www.dh.gov.uk/publications.

Liz Bray confirmed that the RCN were working on an assessment tool for children.

Pam Munro advised that there is a vacancy at Headway Court relating to their independent living project in Tunbridge Wells. The project involves eight self-contained flats offering independent living with support. Frances Pierce said that if Pam Munro gave FP the details she could send an email to KABIF members.