

Kent Acquired Brain Injury Forum (KABIF)

MINUTES

Of the meeting held on 3 November 2004 at 2.30pm

At the Royal British Legion Industries, Aylesford

In Attendance:

Diane Cloke, Retired Chartered Physiotherapist
Ros Eastwood, Head Teacher, East Kent Hospitals School Service
Delia Elliman, Brain Injury Case Manager, Harley Reed Consulting
Gerhard Florschutz, Director, Raphael Medical Centre
Karen Ford, Paediatric Speech & Language Therapist, Canterbury & Thanet
Deborah Harding, Unit Co-ordinator, West Kent Neuro-Rehabilitation Unit
Mike Hope, ABI Coordinator for East Sussex, Brighton and Hove
Sarah Keily, Trainee Solicitor, Thomson Snell & Passmore
Jacqui Locke, Head Teacher, West Kent Hospital School Service
Tony Merriman, Solicitor, asb law, Maidstone
Pam Munro, Founder and Volunteer of Tunbridge Wells and District Headway
Sharon Patmore, Work Psychologist, Jobcentre Plus
Frances Pierce, Solicitor, Thomson Snell & Passmore
Julie Reynolds, Solicitor and Chairwoman of CBIT Kent
Mary Ryan, Vocational Assessment and Occupational Psychologist, Royal
British Legion, Aylesford
Jennifer Stockley, Independent Paediatric Neuro-psychologist, Tadworth
Court
Janet Walker, Physiotherapist and parent of daughter with ABI
Andrew Watson, Solicitor, Thomson Snell & Passmore

1. Apologies for absence

Amanda Allen, Physiotherapy Manager, Maidstone Weald Primary Care Trust
Sue Anscombe, Occupational Therapist, Pembury Hospital
Jan Cartmell, Service Manager, The Regard Partnership
Sophia Chung, Executive Director, S C Support and Care Services Limited
Jo Clark-Wilson, Case Manager, Head First
Rosie Claxton, Headway Community Support Worker, Headway Tunbridge
Wells & District
Rosanne Corben, Chairman of Maidstone Weald PCT
Tim Gilbert, Brain Injury Case Manager, Independent Living Solutions
Judy Horwood, Chairman, Headway Tunbridge Wells and District
Mandy O'Brien, Brain Injury Case Manager
Julia Selby, Speech & Language Therapist, Adult East Kent Coastal Teaching
PCT
Dr Adam Skinner, Psychologist
Simon Truett, Senior Physiotherapist, Community Neuro Rehab Team, South
West Kent PCT
Susan Ware, Independent Speech & Language Therapist
Hilary Whibley, Occupational Therapist, Community Brain Injury Team, West
Kent NHS and Social Care Trust
Don Young, Director/Case Manager, Harley Reed Consulting Ltd

2. Approval of Minutes of Meeting of 30 September 2004

These were approved.

3. Matters arising from the minutes of the meeting of 30 September 2004

Ros Eastwood confirmed that her paper, which she kindly shared with those present at the last KABIF meeting was being perfected and this would then be emailed to Frances Pierce so that it can appear on the website.

The issue of whether meetings should continue to alternate between afternoons and evenings was considered and it was agreed that this format should continue. It was also agreed that the next few meetings would be set today so that everybody would have good notice of the meetings that were coming up, which hopefully would add to the attendance. It was pleasing to see so many attending this meeting, bearing in mind it was a new choice of venue.

4. Neuro Stakeholders Group

Debbie Harding provided an update. She confirmed that the report was still in its embryonic stages. They were working with PCTs on a staged assessment, with a single point of access/referral, ensuring a timely assessment through the acute stages to the rehab beds, making sure that health and social care providers across West Kent played their part.

An event had taken place on 22 October where fifty-eight delegates had attended, including people from Headway. Presentations were given from a number of established local NHS rehab services. It is an event that it is hoped will be an annual one and the next hopefully will be opened up more broadly.

There is a bid being made to the PCTs for funding to support neuro psychiatry service including inpatient beds. The outcome of the bid will be known in April 2005. It is hoped that there will be a specific neuro-rehabilitation development manager locally too. At present development work is being undertaken by Debbie and others on the back of other contracted employment. Debbie confirmed that she was committed to keeping KABIF informed about NHS initiatives in the West of Kent and Medway, although had a limited amount of time to be able to help out on issues arising. She is one of the members of the steering committee.

Debbie mentioned a pilot project of a Joint Neurology and Neuropsychiatry Epilepsy Clinic. This has commenced at the Darent Valley Hospital and is scheduled to run until end March 2005.

Pam Munro asked Debbie whether there was any truth in the rumour that the Sevenoaks Rehabilitation Unit was moving. Debbie confirmed that it would not be, but they were hoping that it will expand to ten inpatient's rehab beds and up to six neuropsychiatry beds, all for adults.

Janet Walker then asked Debbie what the provision was going to be in the county for children. Debbie confirmed that currently there are no plans for development of specialist in-patient head injury services for children. The current arrangement whereby under 16s are referred to Tadworth or Chailey Heritage funded by the relevant local PCT would remain in place.

Julie Reynolds asked whether the neurorehabilitation assessment team previously described would include children. Debbie confirmed that it would not. Children should continue to be referred to specialist providers such as Tadworth or Chailey Heritage by the Acute Paediatric Assessment Service providing the child's care. She explained that, because the numbers are relatively small in the county, it would be difficult to develop and maintain to an appropriate standard, such a specialist inpatient provision for children. She feels it is much better to liaise with the existing services, which are excellent, and not to develop specialisms for such a small number.

5. Website

Frances Pierce presented the website, which is now up and running, to those present. Its address is **www.kabif.org.uk**. A brain storming session then took place on the website including what people would like to see on it apart from the products of the mapping exercise in due course, what reports or research would be provided and what links to other sites would be necessary.

Frances Pierce asked for some help with the work necessary to get the website into a larger, more detailed format. A subcommittee was formed, which will include herself, Mary Ryan and Tony Merriman.

The purpose of the site was discussed, who it was targeting and Debbie Harding offered to get some feedback from her patients, which would be a helpful insight to how it is received. All agreed that the home page should have some form of signposting opportunity to minimise the number of searches that people would have to do to navigate round the site. A discussion then ensued about a message board and how this could be policed. The committee will take these matters forward.

8. Mapping Exercise

A summary of the exercise was circulated to those who attended the meeting. Those who would like a copy are welcome to one, please contact Rebecca Coffey, Frances Pierce's secretary on telephone 01892 701229.

The work that is going to be necessary to collate and to follow up and chase the outstanding questionnaires will require volunteers. Those who agreed to assist were Gerhard Florschutz, Ros Eastwood, Debbie Harding and Frances Pierce. Mike Hope also agreed to help by attending a later subcommittee meeting once further information has been collated.

There was then a discussion as to how the responses to the questionnaires should be presented. It was agreed that everybody would be sent a thank you letter and a sheet to complete confirming whether they would like to appear on the website. We would use those responses first of all to ensure that everybody was logged on with the appropriate disclaimer. The

subcommittee would then discuss what work would be necessary and if further volunteers should be sought.

9. Any Other Business

Open Space Event

There was then mention of the open space event that had taken place in Brighton last month. That had a facilitator. 120 people were able to flag issues that concerned them. Workshops looked at those issues and attendees came and went as they pleased for topics that were appropriate or relevant to them. The raw data is now going to be looked at and the issues raised to enable a more broad based approach to be given to the provision of ABI services. It will be interesting to see what happens as a result of the information that has been collated, although all agreed that as an initiative it was an excellent idea. It apparently is going to be repeated in six months time to see what progress has been made.

Pam Munro reported that "Open Space" had taken place at some of the Annual Headway weekends for their Groups/Branches with a specialist facilitator. It was a good way for everyone to be involved by putting forward their own ideas and concerns within workshops and discussion groups.

KABIF Objectives

All agreed that KABIF was going to be successful if we set realistic objectives and then achieved them and could report back and have a look to see how we had done. There was then a discussion on whether there was anything else we could do in the short to medium term and everyone went away with the request to have a think to see whether they could come up with anything appropriate. All agreed that seeing the results of the mapping exercise and focussing on gaps in that analysis would be a good start. Hopefully KABIF can share their mapping exercise with the Neuro Sciences Network and vice versa.

Future Meetings

We then went on to fix the next six meetings. Pam Munro said that Rosanne Corben would like to attend. The only time she could make was the afternoon of 8 December. As our next meeting is an evening one, it was decided that we would fit the next five and hopefully she will be able to come along to one of those.

We agreed on following dates: -

19 January 2005 at 7pm, venue Thomson Snell & Passmore in Tunbridge Wells.

24 February 2005 at 2.30pm, venue Royal British Legion Industries in Aylesford

6 April 2005 at 7pm, venue to be arranged (if not at Thomson Snell & Passmore)

18 May 2005 at 2.30pm, venue Royal British Legion Industries in Aylesford

30 June 2005 at 7pm, venue to be arranged (if not at Thomson Snell & Passmore)

The Steering Committee will meet 30 minutes before the main meeting.

AW confirmed that TS&P were always willing to offer their boardroom for the purposes for meetings in the evening, but it was felt that perhaps the Forum should try and move around Kent if it could and all members were asked to see if they could come up with venues more centrally, towards Ashford, Canterbury or Dover. The meetings would appear on the website.

It was agreed that it would be worthwhile for everybody to introduce themselves when they arrived at the KABIF meeting and then have an information exchange actually put onto the agenda each time so that the people could say what they wanted about conferences or things that were coming up and we could put these on the website.

On 6 December there is a Royal College of Physicians day conference with an excellent speaker in London at the Royal College. Gerhard Florschutz agreed to fax over the details to Frances Pierce so these could appear on the website.

6. SABIF Experience

Mike Hope then gave a talk about the SABIF experience. He confirmed that the Sussex ABI Group, which was referred to and had a link into the KABIF website, came about really from some work that he did at Headway Hurstwood Park. He was given a brief to get the public involvement in an exercise and to look at some issues to see if that would help in targeting services.

Mike had previously lived in Cambridge and had been impressed with the pioneering work done by the East Anglia Brain Injury Forum. He worked together with a number of people from Headway and asb law in Brighton. There was a launch meeting in May 2002 with Annie Gent from BIS and Des O'Mara from Northumberland. A hundred or so people attended and there was a lot of interest.

They went on to develop something on a regular basis and decided on meetings every two months. Twenty or thirty normally now attend, which is a good turnout and a good working size. There is a committee which steers it and agendas are drawn up in advance.

Meetings generally attract neurosurgeons, rehabilitation consultants, psychologists, frontline professionals such as the TBI nurse specialist, neuro trained therapists and some social workers plus a handful of ABI survivors or family carers. He said having the right balance was important. Service users and family carers need to be there to remind us of what it is all about.

He said SABIF have run a whole series of sessions on perspectives from different sides of ABI: neuropsychology, psychology, carer's perspective,

therapists, social workers, case managers, etc. They have also had the perspective of someone with an ABI who gave a powerful presentation, as did the wife of someone in rehab. He said the desperate issues that come up are important to ground those attending the meeting.

SABIF had received a commitment from Steve Sparks (who works to develop the Neurosciences across East and West Sussex and Surrey) who will come to speak to the meeting in January 2005. Skills for Health, a spin off from the NSF, are also due to make a presentation to SABIF. This was a working group looking at the developments of specific skills of people working with those with ABI. They are looking at care competencies across the board of professionals working with long-term neuro conditions. It has been noted that there seems to be little specific training in the field

He referred to the West Sussex Network and said that he was involved in that. He also referred to UKABIF, which is a big umbrella wider group under which we can all shelter.

When the NSF is published SABIF will hold a regional/national conference on Brain Injury Pathways. The date for this is 11 March 2005. He said it was important that the pathway from A&E to acute services and then the transition into rehab and back into the community was looked at. There will be talks in the morning and workshops (e.g. supported living and vocational retraining) in the afternoon. Everybody from KABIF is welcome to come along. Frances Pierce said that she would post details on the KABIF website.

The NSF on Long-term Neurological Conditions is now due to be published at the end of February. Dr Lyn Tuner-Stokes, who has been talking at a lot of the conferences recently is the deputy chair of the Framework Committee, has requested local and regional responses to the NSF. SABIF are going to respond to that when asked. KABIF may like to start to work up a response themselves.

He said that the conference will be a significant piece of work and a way of engaging public, statutory and independent services. He said that the NHS can't do it alone.

He referred to the fact that BIRT are establishing a new rehabilitation centre in mid Sussex (Horsham).

He said they have a growing group of therapists who come to every meeting and use their meetings often as an information exchange.

Future Meetings

It was agreed that it would be useful to have someone speak at each meeting. A lady from the Citizens Advice Bureau had liaised with Frances Pierce and will be speaking at one of the future meetings. Mary Ryan confirmed she had a lot of useful information to share about the Royal British Legion set up. Gerhard Florschutz from The Raphael Medical Centre confirmed that he was willing to speak in January.