

Kent Acquired Brain Injury Forum (KABIF)

MINUTES

of meeting held on 8 December 2006 at 2.30 p.m..

at the Headway House Day Centre, Pembury Hospital, Tunbridge Wells, Kent

In attendance:

Fiona Adcock, Head of Community Support Team for Children with ABI, The Children's Trust
Frances Beaumont, Occupational Therapy Services
Liz Bray, Head of Nursing, The Children's Trust, Tadworth
Louise Brown, Legal Assistant, Thomson Snell & Passmore
Rosie Claxton, Community Support Worker, Headway Tunbridge Wells
Amy Clements, Student Social Worker, Headway
Diane Drummond, Manager, Headway House Day Centre
Gerhardt Florschutz, Raphael Medical Centre
Tony Hart, Head of Vocational Department, Queen Elizabeth's Foundation Brain Injury Centre, Banstead
Polly Hodgson, Rehab Nurse Manager, The Children's Trust
Mike Hope, ABI Co-Ordinator for East Sussex, Brighton and Hove
Douglas Laurie, The Hadlows Acquired Brain Injury Rehab Residential Service
Lucy Lloyd-Jones, The Children's Trust, Tadworth
Jenny Mazur, Parent of Young Adult with ABI
Chris Merriman, website co-ordinator
Tony Merriman, Solicitor, *asb law*
Pam Munro, Founder and Volunteer of Tunbridge Wells and District Headway
Frances Pierce, Solicitor, Thomson Snell & Passmore (Chair)
Dennis Smith, President of Tunbridge Wells and District Headway
Sue Ware, Independent Speech and Language Therapist

1. Apologies

Sophia Chung, Executive Director, S C Support and Care Services Ltd
Delia Elliman, Clinical Case Manager, Case Management Services
Rikki Gandolf, SE Regional Co-Ordinator, Headway UK
Debbie Harding, West Kent Neuro-Rehab Unit
Wendy Irons, Physical Disabilities Team, Chatham
Lorna Morris, West Kent Neuro-Rehab Unit
Mandy O'Brien, Brain Injury Case Manager
Mary Ryan, Occupational Psychologist, RBLI
Patti Simonson, Principal Social Worker, Royal Hospital for Neurodisability
Jennifer Stockley, Independent Paediatric Neuropsychologist
Don Young, Brain Injury Case Manager

2. Approval of minutes of meeting held on 11 October 2006:

These were approved

3. Matters arising from minutes of meeting held on 11 October 2006:

Dennis said that the new West Kent PCT came into operation in October, covering West Kent, Maidstone Weald, Dartford, Gravesend and Swanley.

The PPI Forum still exists in that form up to a point although their demise is still being planned by the government. It will be replaced by LINKS which will operate through social services. Dennis said that he had concerns that it will not be local enough. A couple of pilot schemes are being run and it remains to be seen how they will work out.

Frances offered to draft a letter on behalf of KABIF about the concerns that Dennis has. Dennis thought we should keep this in mind for a later date when we had seen how things are working out - keep it on the back burner. They have already changed their views on some things and the long-term is unknown at present. They want to link it with commissioning to have a bigger say in the commissioning decisions.

4. Introduction and information exchange

Introductions were made and there was no particular information to exchange which was not covered in other parts of the meeting.

5. Neuro-Rehab Stakeholders Group and NSF update - Debbie Harding/Nicky Coffey

Debbie had sent her apologies for the meeting but sent a report as follows:

The West Kent Neuro Rehabilitation Unit is about to commence building work to expand the number of inpatient beds available at Darent House,

Sevenoaks Hospital. The newly funded Consultant Lead Neuropsychiatry Service has begun to run a regular weekly out-patient clinic. The recently appointed Consultant Neuropsychiatrist, Mayur Bodani, is also providing a liaison service for the inpatient neuro rehabilitation service. The Services are currently funded for patients from West Kent and Medway. Neuropsychiatry referrals can be sent to Dr M Bodani at the West Kent Neuro Rehabilitation Unit.

The Strategic Health Authority's Long Term Conditions, Neuro-Strategy Group continues to meet. The current focus on this work is still MS. On completion of this work, the Group will begin to focus on Services for people with Epilepsy.

6. Mapping exercise/website update - Mary Ryan:

Mary had sent her apologies for the meeting today. However, Chris was there and confirmed that the mapping exercise is coming along well and in fact pretty much finished. There have been a few problems with the data. Chris has updated the PCTs and the social care trusts. It will be ready by the time of the next meeting.

Rosie flagged up a potential problem with the mapping and falling foul of the advertising laws. Frances said that it was purely information that was being provided and not advertising. It is important that we are not perceived to be beating a drum for any particular organisation and that we are not recommending a particular body. Frances felt that the disclaimer on the website which states that no service was recommended adequately covered this.

7. Headway (Kent) - Di Drummond

Di said that she had received no information from Canterbury Headway. However, she could report that Headway across the country are working on an across-the-board set of standards which will come on stream next year.

Headway UK is trying to create identical standards throughout, since one "bad" Headway can tar all the others with the same brush.

With regard to Tunbridge Wells, this is the last meeting which will be held here as next week is the last Headway week at their premises in the grounds of Pembury Hospital, which is being demolished. The press are coming on the last day, Thursday. Headway has been on the site since 1992. They will be taking up temporary residence at Tonbridge Football Club and then moving to their permanent building in the summer.

A lot of Headway Centres are on NHS sites and therefore under threat of closure.

8. **Focus on Young Adults with ABI - Ros Eastwood:**

Ros was not at the meeting so Frances gave the update.

She said that Ros had decided to write to everyone who could contribute information to help with the leaflet for young adults. Frances has contacts with the police so can talk to them about who the youth custody officers are and who might benefit from the leaflet - CPS/magistrates/Victim Support/ education authorities.

Rosie flagged up the problem of having a blanket policy as each individual's needs are so different.

Frances Beaumont said that we had to be careful about keeping it updated. Headway have a pack already which we could take some information from.

Dennis said that we should not forget primary school children - if a young child receives a blow to the head at the age of four or five then the problems might only manifest themselves at puberty as behavioural problems.

Frances said that when we see the leaflet we will have a better idea of what goes in it but asked everyone to think of different places where it could be useful.

9. Talk by Liz Bray (Fiona and Lucy) on the Children's Trust

Liz introduced her colleagues Fiona and Lucy who would be giving the talk on the Children's Trust. Liz gave some background to the Children's Trust, saying that they are an independent charity now based in Tadworth, Surrey, although formerly based at Great Ormond Street Hospital. They have been in existence since 1984 and now have 72 children on site, including a school.

Liz handed over to Lucy, Deputy Nursing Manager, to talk about her work. She said that they currently had 11 inpatient children aged between two-and-a-half to sixteen years of age, on a 3-6 months rehabilitation programme. There is also a great range in their ability. There are doctors on site from Monday to Friday. Their families are also encouraged to stay. The team meets every Friday and discusses three children in depth. The children come from all over the country and even from abroad. They then provide a comprehensive discharge report and a reintegration package for children going back to school.

There is also a 6-18 month rehabilitation programme which obviously caters for those children with more complex needs. A comprehensive nursing plan is drawn up and regular family meetings are held, the child attending where appropriate.

Fiona is Head of Occupational Therapy. She started a community support team last year.

Fiona said that most children come with another problem in addition to ABI, e.g. dyspraxia, Tourette's syndrome. The team saw twenty children last year.

The main problem concerns PCT funding. These issues can be judicially reviewed although you need the assistance of a solicitor who does public law.

Attached to these minutes are the PowerPoint slides which Lucy and Fiona used to illustrate their talks and which give a synopsis of what they said.

Talk by Di on Headway

Di said that Headway work at the other end of the spectrum to the Children's Trust, mainly working with stroke victims and adults with ABI. She explained that Tunbridge Wells Headway is affiliated to Headway UK and Northern Ireland. Each Headway is autonomous and tends to vary greatly; for instance, not all of them have a day centre. Some of community-based workers. Kent also has a Headway in Dover, Ashford, Canterbury and Margate (known as East Kent Headway).

Headway Tunbridge Wells was set up by Michael and Pam Munro in 1988 and has grown considerably since then. It started with a group of people meeting at the post-graduate centre in the Kent and Sussex Hospital. It was originally run by volunteers but now has a four-day a week day centre with paid staff; the fifth day is taken up with administrative work.

Headway has now been in the grounds of Pembury Hospital for 14 years and Di herself has been there for two and a half years. As mentioned in Di's earlier Headway update, they are moving at the end of the year into temporary premises in Tonbridge and then a totally new site in Tunbridge Wells. Di feels it will be a very different experience being in town.

Referrals come from Social Services, often via rehab units, and Headway is open to all members of the community who need their support. They usually come in two days a week where they are helped to build up their confidence and self-esteem. Rosie is the community outreach person.

There are social evenings every two months when speakers are invited to come along and give a talk.

About 18 people a day come along to the centre - it varies from day to day. There are two members of staff in attendance and two volunteers. The nature of their injury means that they cannot go back to work. They may do arts and crafts, pottery, chat groups. There is no formal structure and it is kept flexible so that individual needs can be responded to. It is hoped that the support offered builds up self-esteem.

Headway Junior is a new initiative recently started although it is not too developed just yet and its development is being worked at.

Headway is partly funded by social services. Next year direct payments are being introduced and Headway will be involved in this.

Di gave a case study: a young man was assaulted on Christmas Eve. He was homeless. A concerned friend put him in touch with Headway as he had become suicidal. He came to Headway and they talked about his needs. They were able to arrange a care manager for him and funding for him to come to the centre one day a week. They then got him a flat in a housing association house. Gradually his confidence grew and he now has a temporary job. He is one of Headway's success stories.

Another case study concerned a man in his 40s with a young family. He suffered a stroke on the rugby field and had spent some time in neuro-rehab in Sevenoaks. He was then referred to Headway. He had been an extremely ambitious, strong person and did not like working in a social environment. He was very hard to work with as he was so insular, and so Headway tried working with him on a one-to-one basis. However, he was still not happy. His wife was very anxious, particularly as they had young children. He became aggressive, non-cooperative and a bit frightening. Funding for one-to-one treatment was withdrawn by social services. He decided that Headway was not right for him and he was reassessed by the DART team. He now has one-to-one care at home and although this was a good result in the end for him and the family, Headway were not able to help him but were able to find support that worked for him.

10. AOB and feedback on UKABIF meeting

Frances said that at the meeting she had reported on what KABIF had achieved. She handed round to the meeting a copy of the UKABIF mission statement, delegates list and her slides.

Frances wanted to report on what came out of the meeting and summarised the main focal points as follows:

- Training GPs - we will consider if this is appropriate in Kent. SABIF have done this and accreditation can be gained for it.
- PCT funding for mapping exercise.
- Expand steering committee - everyone was encouraged to think about joining it. Frances said she would invite long-standing members on this before the next meeting.
- NE Forum appointed someone to match services to ABIs. Looked at what services there were and matched them up.
- No London forum yet. The challenge is: 12,000 require treatment and there are 33 PCTs; various new forums are springing up in the regions.
- UKABIF AGM: Frances said she heard someone from the charity OPTUA UK - William Challis, Divisional Manager, Community Brain Injury Services. He tracks every ABI in his county (Suffolk). He could come and speak to us, like Chris Wall had done, at a joint meeting.

Mike Hope told the meeting about BIRT's new service at Kirwin Court, Horsham, which is opening in the spring of 2007.

Dennis said that he had heard of a newsletter (Voluntary Action West Kent) in which KABIF could advertise for free.

Hadlows ABI Rehab Residential Service: Douglas Laurie said that they would be having an open day on 22 December and he would email the details to Frances.

Pam suggested inviting Greg Clarke (our local MP) to one of our meetings - he is Shadow Minister for Charities.

Frances made a plea for new members to be considered and asked everyone to think of at least three possible people who she can contact re membership, particularly in health and social services. This will refresh and regenerate KABIF.

As this was the last meeting at the Headway Day Centre, Frances thanks Headway for their kind hospitality, which included homemade mince pies, and wished them the very best for their move.

The meeting ended at 5.00 p.m.

Next meeting:

On:

8 February 2007 at 7.00 p.m.

At the offices of:

**asb law, Horizon House, Eclipse Park, Sittingbourne
Road, Maidstone, Kent ME14 3EN**