

Kent Acquired Brain Injury Forum (KABIF)

MINUTES

**of meeting held on 08 February 2006 at 7.00 p.m.
at Thomson Snell & Passmore, Tunbridge Wells**

In attendance:

Dr Janet Bjorn, Consultant Child and Adolescent Neuro-Psychiatrist
Liz Bray, Head of Nursing, The Children's Trust, Tadworth
Louise Brown, Legal Assistant, Thomson Snell & Passmore
Jan Cartmell, Services Manager, The Regard Partnership
Nicky Coffey, Head of Specialist Commissioning, Kent and Medway
Gerhardt Florschultz, Director, Raphael Medical Centre
Keith Hutchinson, Hothfield Manor
Jenny Mazur, parent of child 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)
Mary Ryan, Occupational Psychologist, RBLI
Dennis Smith, President of Tunbridge Wells and District Headway
Linda Theoff, Brain Injury Case Manager
Lorna Tricker, trainee solicitor, Thomson Snell & Passmore

1. Apologies for absence:

Penny Bulley, Physiotherapist
Sophia Chung, Executive Director, SC Support and Care Services Ltd
Dr Delamont, Consultant Neurologist, Darent Valley Hospital
Di Drummond, Manager, Headway Tunbridge Wells
Delia Elliman, Brain Injury Case Manager, Harley Reed Consulting
Dr Elizabeth Francis, Consultant Clinical Neuropsychologist, Medway Maritime
Belinda Freeman, Psychotherapist, The Relaxation Centre
Tim Gilbert, Brain Injury Case Manager, Independent Living Solutions
Bhavna Jones, Executive Director, Unsted Park Neuro-Rehab Centre
Yvonne McWean, Hospital Director, Unsted Park Neuro-Rehab Centre
Sharon Patmore, Work Psychologist, Job Centre Plus
Mandy Richmond, OT and case manager, Harrison Associates
Dianne Rickard, Physiotherapist. Schools Service, Maidstone Weald PCT
Dr Paul Roome, GP With Special Interest in Neurology (*see below*)
Susan Roome, CAB Tunbridge Wells
Sue Ware, SALT
Affy Wajid, ABI Co-Ordinator, Bromley
Andrew Watson, solicitor, Thomson Snell & Passmore
Don Young, Brain Injury Case Manager, Harley Reed Consulting

2. Approval of minutes

The minutes of 1 December 2005 were approved subject to the amendments requested by Dennis.

3. Matters arising

Frances said that she had received an email from Dr Paul Roome, GP with Special Interest in Neurology who had attended the 1 December meeting and given a talk, that he had now resigned from this position, which was unfortunate as we had only just become aware of him. Nicky therefore offered to find someone else of a similar discipline.

4. Introductions and information exchange

After the introductions were performed, Frances asked if anyone had any information they would like to share with the meeting.

Gerhard informed the meeting that an eight-bed minimal awareness unit has now opened at the Raphael Centre.

5. PCT reorganisation update: Nicky Coffey, Head of Specialist Commissioning, Kent and Medway PCTs

Nicky said that there is a consultation document out at the moment and the consultation period ends on 21 March. The nine PCTs in Kent and Medway are being phased down to three, which will create stronger, bigger bodies more able to advance issues.

Nicky said that the boundaries of the PCTs will always be difficult to draw and they will never be ideal, but they have to exist to a degree albeit every effort will be made to make them as invisible as possible. The sort of problem that is arising is, for instance, the fact that Ashford is right in the middle of Kent and there is presently a big debate about whether or not it should come across into West Kent, where its social services are located, or move into East Kent where its hospital is.

6. Neuro-Rehab Stakeholders Group and NSF update - Debbie Harding

Frances said that unfortunately Debbie had not been able to come to the meeting today but had sent a report which Frances then read out as follows:

Report to KABIF, February 2006

Health and Social Care work towards the NSF for Long Term Conditions

All PCT reps have been invited to report.

A report has been received from Medway PCT and I understand Nicky Coffey from Kent and Medway Specialist Commissioning will be attending the meeting so may be able to add further.

Report from Medway:

Work has begun to set up a local implementation group for long term neurological conditions, including representatives from primary care, secondary care, rehabilitation services, social services (Medway Council), patient representatives and the voluntary sector.

Representatives from the group are currently working on the development of several initiatives:

- using other specialist health professionals in the community, rather than consultants, to result in shorter waiting times in secondary care*
- multidisciplinary training sessions for GPs and Practice Nurses on current thinking on long term neurological conditions*
- Work has begun on care pathways for MS patients*

Work on Acquired Brain Injury has been going on to improve patient pathways and to comply with the NSF standards. For example multi-disciplinary assessments, access to suitable rehab facilities, etc. More work is being done with the critical care network with regard to ABI, especially improving pathways between Kings and secondary care.

Kent and Medway Strategic Health Authority, (SHA)

The SHA has a strategy group with health and social care representation. There is a Neurosciences Sub group, which met for the first time last week. It seems likely that the first workstream from the neuro-subgroup might focus on services for people with MS, but lessons to be learned/implemented across the range of neurosciences services and into social care will be on the agenda.

Helpfully there is a strong sense of working across organisation boundaries and a need for a more Kent-wide approach.

I am happy to take comments to the strategy and subgroup meetings from KABIF.

*Deborah Harding
Service Development Manager
West Kent Neuro-rehabilitation Unit*

Thanks were extended to Debbie for forwarding to the meeting this very helpful update.

Nicky expanded on Debbie's report by saying that matters were proceeding very positively and they were starting to map out where they go now with regard to taking matters forward. The changes in the PCTs should strengthen things and give them a bigger voice. There is a lot bubbling away which is starting to move forward. The chief problem is trying to achieve a financial balance but the PCTs have made a commitment to keep Debbie's hard work going.

7. Mapping exercise/website update

As Chris Merriman, website co-ordinator, was present at the meeting, he was asked to give the update. He said that he was presently trying to put the mapping exercise onto the website. He was encountering some difficulties with the mapping questionnaire database which he was using in order to put the locate onto the website, for instance he was finding it difficult to search for data and information was contradictory in some cases. In addition to that, some of the information on the questionnaires was superfluous and he was having to decide what he could disregard. Essentially he was finding that the exercise was taking him longer than he originally thought it would. Chris felt that the best thing to do would be to address these issues at the next website committee meeting.

With regard to the map of Kent which we wanted to put on the website so that people could click onto the area they were interested in, this is going to be quite costly and Tony said that he was presently looking into it with a view to perhaps his firm paying for it. Nicky said that the Kent and Medway NHS Trust has a map on their website which might be ideal and she would sort this out for us.

8. Headway (Kent)

Di had sent her apologies for the meeting and Dennis had kindly agreed to give the update in her place.

In relation to Headway Tunbridge Wells & District, Dennis reported that he was pleased to say that Headway had at last found a new home at 3 Culverden Park. It is a large-ish house, seems to be workable and is probably the best opportunity Headway are going to get. It is a property of the NHS Trust, adjacent to the Kent and Sussex Hospital. There are still some hurdles to overcome, e.g. planning permission for change of use. The Trust are being extremely co-operative, since they are eager to see Headway re-homed, and are providing an architect and meeting the cost of this. The property itself costs £420,000 and, although Headway has some funds, a huge fundraising effort was being launched with the aim of raising £500,000. The launch will begin this Saturday and people will be invited to buy a brick. The feedback to this fundraising so far has been very responsive and the Mayor will be attending the launch, along with a representative from the Trust.

Frances asked if we could advertise the fundraising on the website, and in this regard Chris asked Dennis to send him a leaflet about it which he could put on the website.

Dennis also spoke about the Yippee night which had taken place the previous Monday. Yippee is an initiative for head-injured youngsters and the aim is to allow them to have a say in the sort of social functions they would like to attend. About 16 young people attended the Monday night meeting. One of the recent events they took part in was a trip to Iceland which was sponsored to the tune of £10,000 by Timberland following a presentation made by Yippee, which in fact impressed them so much that they doubled the amount they had initially pledged. Jenny, whose son Graeme went on the Iceland

trip, spoke further about this, and said that from Graeme's point of view it had been the trip of a lifetime. The organisation was phenomenal and everyone was indebted to the presentation which was made to Timberland. The trip had had a marvellous effect upon Graeme, who himself gave a presentation about it to the meeting on Monday. The point about the trip was that there was no set agenda to follow or targets to reach - it was all about having fun.

9. Focus on Young Adults with ABI - Ros Eastwood

Ros said that although several people had agreed to join the group it had been very difficult to get everyone together for a meeting. However, Jenny and Graeme came to the first meeting and the report of this meeting is attached to these minutes.

Ros said that housing had been flagged up as a major issue concerning young ABI sufferers and their wish to live independently. It is useful to know what other experiences people have had when researching the housing situation for themselves and so an exchange of ideas and experiences is incredibly useful.

Once suitable housing has been found, it is then necessary to consider whether they are getting the right support and whether periodic assessment of their needs is taking place, especially as many of them lack the basic skills which, given their age, they had never had time to acquire in the first place.

Ros hopes to have the next meeting attended by Jan, Mary and Debbie in order to flesh out the original ideas from the first meeting, and will then be able to return to the Forum with something a bit more detailed.

Frances asked the meeting if they were all happy to go along with what Ros had initiated and there was unanimous agreement to this.

Thanks were extended to both Ros and Graeme for their invaluable input in launching this project and for all the work they had done so far.

10. Talk by Keith Hutchinson, Centre Manager, Hothfield Manor Centre ABI Home

Keith was welcomed to the meeting, at which he spoke about the background and work that is done at Hothfield Manor. Attached to these minutes is summary of his talk which gives information about the valuable work which is carried out there.

Some questions were put to Keith about Hothfield Manor. Keith was asked if the home had a waiting list. He said that, given the nature of the injury and the need for treatment, there was no waiting list as such since, if there was no immediate bed available at Hothfield, people simply had to find somewhere else which did have a vacancy. Hothfield is always full.

Keith was asked about the background of the staff at Hothfield. He said that when he first arrived there, there was quite a turnover of staff and only three people had been there longer than three years. However, now 90% of the

staff have been there longer than two years and so a body of experienced staff is now building up. All the staff come from a care background.

Keith finally elaborated a little on the respite care aspect of the services offered by Hothfield. He said that you cannot have beds waiting for people and so he will take someone for respite care when he has a vacancy. The bungalows tend to be more popular and another bungalow is being built which might be used for respite since he is constantly being asked to provide this service.

Keith was thanked for coming and giving the Forum this useful and interesting insight into the work of Hothfield Manor.

Talk by Dr Janet Bjorn, Consultant Child & Adolescent Neuro-Psychiatrist, Chailey Heritage Clinical Services

Don Young of Harley Reed Consulting had been scheduled to talk in this slot but was unable to make meeting at the last minute due to unforeseen circumstances. Dr Janet Bjorn therefore kindly agreed to speak in his stead on the subject of the ABICCUS (Acquired Brain Injury Children's Community Service) project at Chailey Heritage.

Dr Bjorn said that she is a member of the Chailey Heritage "Children's Head Injury Service" (CHIS) Team. CHIS is a rehabilitation centre for children in the post-acute phase of Acquired Brain Injury for whatever cause.

Dr Bjorn had found that when children were leaving CHIS there were often insufficient and inadequate community services to continue their rehabilitation. Children with an Acquired Brain Injury in the community who had not received rehabilitation were also experiencing similarly poor services. In both instances, coordinated management planning and therapy was rarely available unless a private case manager had been appointed.

Often, the first indication that a child and family was struggling would be a child failing to cope in school. Unlike adults with ABI, children are necessarily monitored through the education service and this can both alert health professionals to significant problems as well as work with health professionals to support the child.

Dr Bjorn's project, ABICCUS, was prompted by an experience with a 17 year old girl who had acquired her head injury five years previously. Her care over those five years had been patchy and poorly managed. Dr Bjorn attempted to gather a relevant multi-professional team together to address a crisis situation but had considerable difficulty finding professionals with any knowledge of the girl. Dr Bjorn realised how important it was for every child after severe ABI to be followed up regularly by a Core Group of Professionals in order to manage their care through their school years.

ABICCUS now exists for about 20 children referred from Brighton and Hove area and continues to expand. ABICCUS aims to identify a multi-disciplinary team for each child in collaboration with the community paediatricians. Via ABICCUS, Dr Bjorn holds annual reviews and some interim meetings to which the child's team of professionals are either invited to attend or send a

report as appropriate. Each of these meetings considers current issues against the background of the original ABI. Consideration is also paid to the families and others who are involved in the child's care, e.g. class teacher. At the end of each meeting, recommendations are drawn up and action plans devised. Minutes of these meetings are distributed to all members of the child's multi-disciplinary team.

Dr Bjorn would like to extend ABICCUS to other geographical areas but is limited by her contract at present.

11. Any other business

Frances said that the Executive Committee of UKABIF had met recently and they are keen to support all local forums. UKABIF have requested that representatives from all local forums get together on 23 March in London to explore ways of enhancing the network. The meeting will be held at Irwin Mitchell's offices. Frances asked for 3 or 4 volunteers to go to this meeting and if people wanted to go along they should let her know so she could put the names forward.

Jan mentioned the ABI quality agenda in May 2006. Visit the website www.qualityagenda.co.uk for further details.

Pam said that the next South East regional Headway meeting was at Henley on Thames on April 20th (this had been changed from 4 April). It would be held at Headway, Thames Valley.

The meeting concluded at 9.00 p.m.

**Next meeting: 04 April at 2.30 p.m.
 at the Royal British Legion Industries
 Capel Morris Hall
 Royal British Legion Village
 Aylesford, Kent ME20 7NL**

N.B. Please note that the meeting will not take place in the usual location at the RBLI but at the Capel Morris Hall which is adjacent - see attached map for directions