

Kent Acquired Brain Injury Forum

Minutes

Thursday 11th October 2007 at 7.00 pm

asb aspire llp, Horizon House, Eclipse Park, Sittingbourne Road,

Maidstone, Kent ME14 3EN

In attendance:

Bruce Aitken
Claire Carter
Jan Cartmell
Nicky Coffey
Sally Collins
Ros Eastwood
Penny Fard
Gerhard Florschutz
Mike Hope
Denise McKeown
Chris Merriman
Tony Merriman
Frances Pierce
Mary Ryan
Dennis Smith
Juliette Stuart
Linda Theoff
Aggie Moreno-Lopez
Ann Newman

Apologies:

Frances Beaumont
Liz Bray
Louise Brown
Lorna Buckwell
Sophia Chung
Becca Coffey
Di Drummond
Delia Elliman
Kelly Hamer
Tony Hart
Jenny Hogg
Jenny Mazur
Pam Munro
Pam North
Mandy O'Brien
Patti Simonson
Sue Ware

1. Welcome and Introductions

Frances Pierce again reminded people of the need to complete the Data Protection forms.

Approval of the Minutes of the meeting held on the 29th August 2007. Frances had already been made aware of some amendments that were necessary.

Gerhard Florschutz asked for his name to be added to those who made their apologies. The Minutes were approved as amended.

2. Matters arising from the Minutes of the meeting held on 29th August 2007

Frances reminded us that Greg Clark MP was due to talk at the next KABIF meeting at Tunbridge Wells about his responsibility. She suggested that the Steering Group should put forward a letter to see if he is willing to help KABIF by putting forward major issues which affect brain injured people. Peter McKay pointed out that the biggest issue at the moment was whether the Government was about to abandon its service to long term neuro conditions. He was of the view that it was being abandoned, which had devastating consequences to people suffering from ABI.

There followed a discussion about the letter to Greg Clark suggesting that he should ask Government for information about the roles of individual PCTs and whether they were providing this service. Mike Hope made a suggestion that a letter was worded such that they would make enquiries of more than just one PCT. Nicky Coffey laid out how letters from Ministers would arrive on her desk asking for information.

3. Neuro Rehab Stakeholders Group – an NSF (National Service Framework) Update – Nicky Coffey

Nicky Coffey reported that the merged PCTs have been in place a year. She was now beginning to get some idea as to who the local contacts were. She was about to meet with the NHS Executive. There was a lot of good work being done in part, but she reported that it needed to become more cohesive and there was a need to avoid duplication amongst the Trusts undertaking head injuries.

She was working with King's College and was hoping to see some results of the work within about a month, but wanted to make sure that if there was an incident the pathway operated smoothly. If the patient was returned to the local area, she wanted to make sure that there was very good public health supporting work in the area. She mentioned that the Kent wide neuro rehab facilities were growing. There was a need to pull all the various bits that there were together. She was concerned that it was looked at from a bigger perspective rather than looking at the detail of the local facilities.

Nicky was asked whether her ambit included children. She indicated that it may do eventually, but at the moment her perspective was from the adults only.

Mike Hope made the comment that 65% of brain injury was non traumatic. Nicky's ambit was to deal with head injury, but Mike mentioned that even across East and West Sussex there was a system of referring. Nicky mentioned that non-traumatic was being looked at in liaison with Headway and that would include looking at non traumatic in children, with particular concern with younger strokes because they quite often fall out of the care pathways. Dennis Smith mentioned that he had had experience of dealing with non traumatic head injury and asked if Nicky was linking with all of those services. Nicky indicated that part of the discussion with PCTs was to see that ABI was co-ordinated throughout Kent. It was pointed out that Kent was a large area both in terms of geography and population. There was a need to

make sure that consent was obtained from all the major stakeholders. It was also mentioned that a leaflet had been produced by the NHS in the area, but the leaflet said nothing about ABI pathways or how to get help with neuro conditions. There was a discussion about neuro services and how the website could help individuals with the information about neuro services.

4. Mapping and Website Update

Mary Ryan reported minor changes to the website. Frances Pierce said that we need to work on how we access the mapping. Chris went through how the mapping currently works and pointed out that the mapping exercise was one of continued development and how important it was that members kept updating the information. It was reported that we would be clarifying the purpose of the questionnaire and changing the questions. There were also suggestions about changing the look of the website.

5. Headway Kent

Di Drummond was not present, but Dennis Smith gave a report. He reminded us that they had left their old premises and explained more about the nature of the temporary premises and the current accommodation. He mentioned that the accommodation was the best that they could have had, but was not exactly satisfactory. There were problems that the Members had and had not been able to offer anywhere near the services that they had at their permanent accommodation. He was pleased to announce that their new home would be ready at the beginning of November, although the lift to the second floor might not be ready. He mentioned that it cost £420,000 to buy and was a property that had previously belonged to the health authority and had no discount offered to them by the health authority on the purchase. It had cost them £230,000 to adapt. They have made major efforts to raise most of that money and he was pleased to report that the fundraising was going well.

6. Focus on Young Adults with ABI

Ros Eastwood reminded us of what the project was and that we were looking at the age group from 16 to 35. She explained that we had sent the questionnaires out to the young people of what they wanted and what would make like easier. She explained how she had brought all that information together and now the intention was to produce a leaflet of the information that the young people required. In that leaflet there would also be a case study showing how that person or individual had been helped, or possibly even more than one case study. The idea of the Leaflet was to provide individuals with basic information about brain injury services in accordance with what was needed from the survey. If there was anybody that wanted to input into that, then Ros was the person to go to.

7. PPI Forum – Dennis Smith

Dennis explained again what PPI Forum was and that they were all volunteers there to feed in what was considered to be the general public's views about NHS. He explained that that was all about to change at the end of March next year and explained that that was to go over to the LINK system. Last meeting for the existing PPI was to take place at the Angel Centre in Tonbridge and he explained his reservations about LINK.

He mentioned in passing a website <http://www.disabledgo.info/> which will enable disabled people to find out the details of access to a particular building and it is hoped that eventually this will cover the whole country.

8. Talk by William Challis (Head of Services, Optua UK ABI)

He explained what Optua was and how it had started in Suffolk. He explained that it was two charities working together, Optua and Icanho and they work very much in partnership. They did not have any beds that they operated themselves. He explained that they were not dealing with everybody that suffered brain injury. They were dealing mainly with those with cognitive behaviour problems who lived in Suffolk. The problem had developed for a long time whereby people with such conditions had been treated out of the county and then found it difficult to get back in again. One of the benefits of the set up is that they overcame that problem.

They often dealt with people who came out of hospital as part of the pathway, which they found to be effective. They provide case management co-ordination they pick up during rehabilitation and continue after rehabilitation has finished. As far as is possible they keep people within the local community.

They run a range of workshops for people with head injury across Suffolk and also Icanho support families of brain injured people. It is often the case with brain-injured people that they don't want to share accommodation, but they are a danger if left to their own devices. It is part of the scheme that they find independent accommodation that provides the backup resources that are needed to allow that person to live safely in the independent accommodation. They consider themselves to be an enabling organisation.

The families obviously appreciate the separate accommodation because it relieves pressure from the family, but allows them at the same time to spend quality time with the individuals concerned. As it is local, friends and relatives of the individual can help the individual to develop skills that they may have lost, e.g. cooking. He explained how they also recruit people to provide care with different life skills to make sure that as wide a life skills as possible are covered with the individual. William considers they have been very successful in managing difficult behavioural problems. The organisation is client focused and success is dependent on the close working relationships of the two organisations. He gave us some examples of the types of individuals they have helped and how people have been moved in together on occasions.

In addition to their Suffolk base, they have been developing services in the Shrewsbury area. Their organisation was a bridge between the health authority, the local authority and other organisations and they were quite often able to convince the local authority that financially they would not lose out by supporting the pathways that the organisation was putting in place by showing the cost to the community of not using their services. He explained that some of the houses provided could be for life but on the whole they were not. They were more of an intermediate home until the patients had their independence. He explained how important Icanho was as part of the overall process and how he involved the other agencies in that process. The overall strategy he was able to convince the NHS and local authorities would save them money, which was the business case, he was able to present to them.

It would free NHS beds and would work towards the patient being independent. In this way, he had been able to get money from PCTs and health trusts.

He mentioned also that they had very specific projects whereby an individual with funds of his own had helped out individuals that had only public funds available. The package that was provided involved and helped them all. He also emphasised that although the staff had a wide range of life skills, it was important that they understood ABI.

9. Talk by Jan Cartmell

She explained they shared similar aims and values to the previous speaker. She explained that she worked for Regard, which was established in 1994 by two nurses and the original unit was in Kent, although its head office was now in Kingston upon Thames. Regard's purpose was to provide support services and deliver care and work in liaison with the health authority. It was there to try and provide for the client the highest level of independence. Regard, like the previous company, was client based and set individual goals to try and move the individual to that level of independence within the community.

She explained they had neuro-psychologists and occupational therapists working as part of the team and that they trained support staff to understand ABI. They would put forward goals for individuals and then provide people with the appropriate life skills to help them achieve those goals. Accommodation was provided through housing associations, they came in really at the final stage of rehabilitation. They would provide care to an appropriate level but they could provide 24 hour care if necessary. They would also help the client to run their budgets and live within the means that they had. They also recognised the need of the family to be informed and work with the individuals' families.

She explained that part of their current services was Wren Park which provided 24 hour supported care for 5 people. They were encouraged to move on within 12-18 months. She explained the premises in Medway and some of the other services they provided. She gave an example of Earlsfield where 3 people wanted to live together and they had managed to acquire a house to enable them to do so.

10. Questions

Dennis Smith asked which Housing Associations were used and Orbit and Papworth were mentioned.

Dennis then explained the Headway Court setup and how they had 7 flats and a manager and they also put in place other measures to help individuals. It was generally agreed that there were pockets of this kind of care, but the provision was by no means wide enough.

Mike Hope mentioned that when the MP came next month whether we should devise a question that was connected with funding which related to the talk we have just heard. There was also some talk about the problems connected with the different budget purses of the health and social services organisations.

11. Any Other Business

Frances mentioned UKABIF and indicated that she had been invited to speak of Kent's experience in KABIF at the UKABIF meeting and she was going to speak about the positive outcomes of what had come through KABIF. She distributed copies of the PowerPoint slides and asked for comments.

Meetings for next year were mentioned and there was a general discussion about what speakers people would like.

Gerhard Florschutz mentioned that it was the 25th anniversary of the Raphael Medical Centre next year and that there was a public conference on the 2nd May 2008 with many eminent speakers. There was also mention of the fact that Raphael wants to set up a support group and asked if there was anybody prepared to help with that support group for the parents of brain injured children. Dennis Smith said that Headway tried that but found it was very hard going and had not been able to sustain it.

Mike Hope mentioned the conference of SABIF and the speakers that were going to be there.

Maggie Lopez who was a guest at the meeting mentioned her thesis on the effects that having brain injured parents had on children and the need for children that were prepared to talk to her and asked them to make contact with her.