

Kent Acquired Brain Injury Forum (KABIF)

DRAFT MINUTES

Of the meeting held on 18 May 2005 at 2.30pm

At the Royal British Legion Industries, Aylesford

In Attendance:

Margaret Bentley, Specialist Commissioner, Kent and Medway PCTs
Louise Brown, Legal Assistant, Thomson Snell & Passmore
Jan Cartmell, Service Manager, The Regard Partnership
Ros Eastwood, East Kent Hospitals School Service
Gerhard Florschutz, Director, Raphael Medical Centre
Tim Gilbert, Brain Injury Case Manager from Independent Living Solutions
Mike Hope, ABI Coordinator for East Sussex, Brighton and Hove
Bhavna Jones, Service Development Manager, Unsted Park Hospital
June Knight, Case Manager, Harley Reed Consulting Ltd
Jacqui Locke, Head Teacher, West Kent Hospital School Service
Pam Munro, Founder and Volunteer of Tunbridge Wells and District Headway
Sharon Patmore, Jobcentre Plus
Frances Pierce, Solicitor, Thomson Snell & Passmore (Chair)
Julie Reynolds, Chairman, CBIT Kent
Mary Ryan, Occupational Psychologist, RBLI
Dennis Smith, President of Tunbridge Wells and District Headway
Steve Sparks, Assistant Director, Commissioning, Kent, Surrey and Sussex
Specialist Commissioning Group
Linda Theoff, Single Incident Brain Injury Service, East Kent
Janet Walker, Physiotherapist
Pam Wells, DMRC Headley Court
Melanie White, Opus Living
Don Young, Harley Reed Consulting Ltd

1. Apologies for absence

Sophia Chung, Executive Director, S C Support and Care Services Limited
Diane Cloke, Retired Chartered Physiotherapist
Dr S Delamont, Darenth Valley Hospital
Tony Merriman, Solicitor of asb-law of Maidstone
Georgina Overell, Speech and Language Therapist, Herne Bay and Kent & Canterbury Hospital
Jennifer Stockley, Independent Paediatric Neuro-psychologist, Tadworth Court
Susan Ware, SALT
Andrew Watson, solicitor, Thomson Snell & Passmore

2. Approval of Minutes of Meeting of 6 April 2005

Tim Gilbert requested one amendment to be made to section 9: last sentence in penultimate paragraph should read: “.....it would be useful if.....” rather than “.....it would be better if”

3. Matters arising from the minutes of the meeting of 19 January 2005

There were no matters arising.

4. Information exchange

Mary Ryan said that she has just completed a vocational assessment pathway which is presently in diagram form.

Frances Pierce said that the Thomson Snell & Passmore Acquired Brain Injury Lecture was taking place on 30 June 2005 at the Spa Hotel. The next KABIF meeting will take place just beforehand, also at the Spa Hotel to make it easy for members to attend the lecture as well.

Gerhard Florschultz said that an 8-bed unit is opening hopefully next month at the Raphael Centre. It is state of the art for patients at the very acute stage.

5. Neuro-Rehab Stakeholders Group

Debbie Harding was not present so no update was available.

6. Website

Frances said that there was nothing further added to the website since the last meeting. We were presently waiting for the results of the mapping questionnaire to go on. Frances asked for suggestions to go on the website regarding future events which could be publicised. This brought forth various suggestions as follows:

Ros Eastwood said she had looked on the Encephalitis Society website where she saw that they advertised useful books with a link to Amazon, and wondered if KABIF could have the same facility on their website.

Bhavna Jones said that she knows of a company in Harrogate who are advertising a conference in London which would be useful.

Mike Hope said that UKABIF and Irwin Mitchell have a conference on 8 June and on 16 June there is the BABICM conference on case management outcomes.

7. Mapping exercise

Gerhard told the Forum about Donna Ledbetter and her input into the mapping questionnaires. Frances and Louise Brown had been out to visit Donna and hand over to her the task of completing the questionnaires, following up those who had not responded as yet and identifying other organisations who could be sent a questionnaire. They said that Donna had impressed them immensely with her enthusiasm and speedy grasp of the job which needs to be done and felt that it was now in very good hands. Gerhard thanked the Forum for allowing Donna to help as it had boosted her morale.

8. Sharon Patmore of Jobcentre Plus

Sharon, a Work Psychologist, gave us a talk about the work of Jobcentre Plus.

She said that the Jobcentre and the Benefits Agency had now combined to become the Jobcentre Plus. This was in order to provide a uniform service and prevents people falling between gaps, particularly if they are on different benefits. The Kent district is one of the last to be “rolled out”. Every Jobcentre has been refurbished.

There are now designated individuals in Jobcentres who offer a range of advice for the disabled. These are known as Disability Employment Advisers (DEAs) who provide more specialist services for people with disabilities including income benefits advice and disability employment advice as well.

Sharon and one part-time colleague cover the whole of the county of Kent. The first point of contact is the DEA who give support at the assessment stage. The DEA acts as a screen to make sure they are appropriate referrals.

Sharon said that her remit is now to include the disadvantaged as well as the disabled, e.g. drug and alcohol-dependent people.

Jobcentre Plus is also involved with organisations who employ disabled people and are trying to support them.

The work involves building a package for each individual and finding access to residential training or access to work by overcoming practical barriers.

There are specialist provisions for those with a brain injury whereby they can go to the Brain Injury Centre in Banstead, Surrey (part of the Queen Elizabeth’s Foundation) for up to 13 weeks. All contracts are presently being renegotiated and they were working hard to maintain them.

Sharon said that she was part of the regional team covering many counties and there was a psychologist in each county.

With regard to access to work, practical aids are identified to overcome physical difficulties which people might have, e.g. help with travel. It is about support for the individual, not the organisation, so aids can in theory move with the person. It costs millions to the Government every year. There are eight regions in all and the employer sometimes contributes to the process but it is up to the individual to contact Access to Work.

Pam Munro asked if DEAs have are trained to help people with ABI. Sharon said that each DEA will talk to her about anyone who presents with ABI but they do not have specific training in it. She said she has spent a considerable amount of time going through with the DEAs all types of problems and this includes ABI.

Mike Hope asked about the renegotiation of the contracts. He asked if it was accountant-led or will they specify particular pathways for vocational training? Sharon said that they are regularly consulted about what they feel is required, but she could not comment on what is coming down the line. This is down to the lobby groups.

Frances asked her how KABIF could help, for instance could we add Jobcentre Plus to the mapping exercise KABIF were presently carrying out? This was certainly thought to be a useful idea.

Sharon was thanked for coming along and taking the time to talk to us about an area which is extremely important to those suffering with ABI.

9. The Commissioning of Neurosciences : Steve Sparks

Steve Sparks, Assistant Director, Kent, Surrey and Sussex Specialist Commissioning Group, gave the Forum a talk about the future of neurosciences in Kent.

Steve talked about the following five areas:

1. What we do:

Steve said that the specialist commissioning team cover 24 PCTs and their task was to commission specialised services. The Department of Health recognised that there is a need for specialised services and that it would be sensible for the PCTs to collaborate, e.g. on cardiac services and those particularly that are low volume and high cost such as ABI. They could then share the risk and pool resources. He said that his team worked at the strategic level and local level for procuring services on behalf of the PCTs. They are accountable to the Local Specialised Commissioning Group cabinet and the local commissioning fora. He said that they had no money given to them by the PCTs so they have to fight with other services and battle for priority with them.

2. The neuroscience review:

This was founded around Hurstwood Park Hospital at Haywards Heath in Sussex on behalf of the PCTs and the provision of neurosciences generally. The idea was to build up a body of information. A stakeholder event was held in February 2002 and a review of the workforce carried out with regard to the EU working time directive, junior doctors' hours, increase sub-specialisations and training requirements. They wanted to establish clinical networks

where they have worked well in the North West which covers a population of 7m. For instance, the ISAT trial was a mode of treatment of people suffering sub-arachnoid haemorrhages, to see which was the most effective technique for dealing with them. The outcome was that people could be given a choice and therefore there was a need for more neuro-radiologists. The knock-on effect of that is that surgeons will be doing less, so this is another factor pushing them to collaboration.

3. The neurosurgery network:

They had to think about what areas they needed to cover and the fact that each science has a different focus. Steve said they needed to think about capital development as, for instance, Hurstwood Park Neurological Centre (HPNC) is in a very poor condition. Their proposal to move to new purpose-built facilities at the RSCH, Brighton, was published in the recent document *Best Care, Best Practice*. Steve said that the move will take 5-10 years but there is an ongoing commitment to invest in HPNC whilst the building plans are in progress. HPNC serves a population of 1.2 million, and Steve said that most patients in Sussex go to Hurstwood Park whereas those in Kent and Surrey go to King's College Hospital and St George's Hospital. The South Thames Neurosurgery and International Neuroradiology Group has therefore been developed to look at all the issues. The group has started work on head injury. Most people end up in the local DGH. Sub-specialisation was now being looked at and the issues around critical care, and also neuro-rehabilitation which links with neurosurgery. Also, the training needs of the workforce were being looked at. There is a real need for collaboration around the neurology services.

4. The neurology network:

This was about the improved co-ordination of services and staff. It is now up and running. In Sussex there is public consultation about services. There is a need to continue investment in Hurstwood Park. It will take 7-10 years to move it to Brighton. Neuro-rehab is patchy and being done to different standards. Sussex is working well with SABIF on this point.

5. The next steps:

To develop an outline business case for new build. Continued investment at HPNC in the interim and a need to develop neuro-rehabilitation strategy.

Pam Munro asked Steve if there has been a nominated person to lead the NSF. Steve said that they were identifying a PCT to monitor the NSF but do not have one at present.

9. The Commissioning of Neurosciences : Margaret Bentley

Margaret said that the main focus of the work was in Kent and Medway. A steering group has been developed along with two sub-groups.

There is also a neurological pathway via the primary care group and specialist GPs and nurses. She said that they have been working on several areas, from the initial telephone call up to rehabilitation. The final development is neuropsychiatry.

Attached to these minutes are copies of the powerpoint slides shown by Steve Sparks and Margaret Bentley which summarise the talks they gave on this complex subject.

Questions were put to them as follows:

Were these services going to be for both adults and children? Yes, they were.

Frances Pierce asked if it would be helpful if someone from KABIF to join the steering group. Margaret thought that the SE London Steering Group would be useful to attend and she would put that forward.

Bhavna Jones asked about the numbers which were placed in tertiary rehab. Margaret said it was difficult to track but that some data has been collected and it is quite a small number. She said that the rehab teams want to be aware of a patient as soon as they come into A&E as they are linking into the critical care nurses.

Gerhard asked why rehabilitation always takes place in the independent sector and why there is not greater collaboration with the NHS. Steve replied saying that it is likely that over the next nine months there will be a reduction of PCTs which will help. They will then be happy to secure services from wherever they are delivered.

Mike Hope said that much of the detailed complex work has not occurred in the NHS but has been left to the private sector, yet clearly almost all the cases have been publicly funded so there is a need to bring together commissioning services and the expertise.

Frances Pierce thanked Steve Sparks and Margaret Bentley for their talk and reiterated that KABIF can help as we have a body of expertise and looked forward to a closer working relationship with the Group.

10. Any other business

There was no other business.

Date of next meeting: 4.00 p.m. on 30 June 2005 at the Spa Hotel, Mount Ephraim, Tunbridge Wells, Kent TN4 8XJ