

Kent Acquired Brain Injury Forum (KABIF)

MINUTES

**of meeting held on 04 April 2006 at 2.30 p.m.
at the Royal British Legion Village, Aylesford, Kent**

In attendance:

Liz Bray, Head of Nursing, The Children's Trust, Tadworth
Louise Brown, Legal Assistant, Thomson Snell & Passmore
Martin Burke, John Grooms Housing Association
Sophia Chung, Executive Director, S C Support and Care Services Ltd
Ros Eastwood, East Kent Hospitals Schools Service
Roy Marcus, Case Manager, Harley Reed Consulting
Pam Mitchell, SE Regional Co-Ordinator, Headway UK
Lorna Morris, West Kent Neuro-Rehabilitation Centre
Pam Munro, Founder and Volunteer of Tunbridge Wells and District Headway
Ray Perry, Area Benefit Officer, KCC
Frances Pierce, Solicitor, Thomson Snell & Passmore (Chair)
Mary Ryan, Occupational Therapist, RBLI (our host)
Dennis Smith, President of Tunbridge Wells and District Headway
Sue Ware, Independent Speech and Language Therapist

1. Apologies

Jan Cartmell, The Regard Partnership
Di Drummond, Manager, Tunbridge Wells & District Headway
Debbie Harding, Unit Co-Ordinator, West Kent Neuro-Rehabilitation Centre
Elizabeth Francis, Consultant Clinical Neuropsychologist, Community Brain Injury Team
Bhavna Jones, Bhavna Jones, Service Development Manager, Unsted Park Hospital
Jenny Mazur, parent of ABI adolescent
Chris Merriman, website co-ordinator
Tony Merriman, Solicitor, *asb-law*
Tom Tagoe, Brain Injury Case Manager, Harley Reed Consulting
Andrew Watson, Solicitor, Thomson Snell & Passmore
Don Young, Brain Injury Case Manager, Harley Reed Consulting

2. Approval of minutes of meeting held on 8 February 2006

Subject to the amendments made by Dr Janet Bjorn to the section of the minutes relating to her talk, and to paragraph 8 of the minutes referring to "Headway Tunbridge Wells and District" and not "Headway", the minutes were approved.

3. Matters arising from minutes of meeting held on 8 February 2006

With regard to UKABIF, Frances said that they wanted to make sure that there is one framework in place for the all the Acquired Brain Injury Forums which are setting up and a meeting was due to take place to discuss this which was now scheduled for May.

4. Introductions and Information Exchange

Frances firstly extended her thanks to Mary for arranging the venue for today's meeting and the excellent signage in place to help everyone find the location.

Pam and Dennis, on behalf of Tunbridge Wells and District Headway, updated the Forum on the current situation regarding the acquisition of their new premises. Planning permission has now been obtained for the new venture. On the financial side, the "brick appeal" had been launched, with a target to reach of £500,000. So far there has been a very good response to this and the account now stands at £85,000. A mortgage will be obtained and there must also be sufficient time to carry out the necessary adaptations, bearing in mind that Headway must leave the Pembury Hospital site by 20 June.

Dennis also updated the meeting on the position with the new hospital, which will be signed off by December.

Pam mentioned the Headway coffee morning which would take place on 12 April.

Frances updated the Forum on the joint meeting with SABIF which is due to take place on 18 August. Chris Wall, expert in public law, will be talking us through the complex legislation. KABIF were encouraged to turn out in force to support this meeting. Because it will be necessary to hire a venue, there will be a cost of £10-£15 per head. This will just cover the cost of the hotel and the food - there will be no profit and Chris Wall will not be charging for his time. At present, the probable venue will be a hotel in the Gatwick corridor and Frances will prepare a flyer for the meeting. There will be 40 places for KABIF members and Frances asked for those who want to go to email her as places would be allocated on a first come, first served basis.

Frances asked if anyone wanted a slot to speak at one the meetings later in the year to let her know. At present there are available slots in October and December.

Pam Mitchell said that she would do a slot and said that the 8 December meeting would suit her. Liz Bray would also like to do a talk but can only do December so it was decided that she would do that as well and we would change Eddie Fardell, who is presently doing December, to October. Dennis offered to do a talk about the PPI Forum. He also mentioned that Jane Cast, Head of Therapy Services at Pembury and Sevenoaks, might be interested in

giving a talk, and Frances asked him to mention the possibility of doing one on 11 October to her.

Frances circulated to the Forum information she had been passed by Mike Hope entitled "*What's wrong?*" - *Public Survey and Brain Injury Information ... what are brain injuries?* which is attached to these minutes.

Mary said that on 10 May she would be giving a presentation to the Women of Kent Luncheon as they were fundraising for the Centre.

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

In the absence of Nicky Coffey this was given by Dennis, who said that the reconfiguration consultation had finished by 22 March and everyone had gone away to consider matters. The various options are: Kent to be split into three PCTs, Kent to be one whole PCT, Kent to be split into two PCTs with Ashford in East Kent. KCC wants one PCT for the whole of Kent. However, the Government's decision will not be known for about four or five weeks and then work will start on establishing the new PCT(s) by 1 October. One of the biggest concerns was how Ashford would sit if it fell between two authorities.

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

Debbie had sent her apologies for the meeting and Lorna Morris had attended instead. She brought with her a report prepared by Debbie as follows:

- (a) NSF LTC: The Neurological Conditions subgroup is now meeting monthly. Membership is statutory providers from health and/or social care. The group is currently looking at services for people with MS.
- (b) Kent and Medway NHS and Social Care Partnership Trust: The WKMHT and EKMHT merged and are now the Kent and Medway NHS and Social Care Partnership Trust was established on 1 April 2006. The rehabilitation services hosted by the Trust including the West Kent Neuro-Rehabilitation Unit are to remain part of a Special Services Delivery group and will continue under the same director which is very good news.
- (c) Neuropsychiatry Services: Interviews for the consultant post take place on 6 April. Local stakeholders, including patient and carer reps, have been involved in the selection process. There is unprecedented interest in the post. Seven people are due to be interviewed shortly. The aim is to have neuropsychiatry beds alongside ABI beds in the next 18 months or so.
- (d) Other ABI initiatives in Kent and Medway: Lynne Brown has replied but has nothing further to add other than the NSF groups. An out of office message has been received from Sandra Lamb and there is a meeting with Di regarding the provision of training, e.g. living skills.

- (e) WKNRU Patient Forum: This is to be set up for carers and past patients to help develop the service. Questionnaires have been sent out and are being collated. There was a good response to the questionnaires and there will be a Patient Forum day this coming Sunday. It is a growing and developing group and the following projects have been identified:
- Looking at a buddy system to support newly admitted patients
 - Collating biographies
 - Revamping patient information packs and making them more user-friendly
 - Gardening club
 - Quarterly Sunday afternoon meetings with speakers
 - Aim not to duplicate other initiatives but to add to them,
- (f) Stakeholders Group Symposium: Early planning is under way for the next symposium in October 2006. The focus is working with voluntary agencies, care pathways and presenting case studies. Links have been made with the SHA and they may be able to support it as part of the NSF/learning network activity.
- (g) Involvement with KABIF initiative: Rhian Cogger, OT from WKNRU, has joined the group looking at the Young People's Initiative. She is also exploring a community partnership with Charlton Athletic Football Club.

7. Mapping Exercise/Website Update - Mary Ryan

It is essential that a further meeting is arranged to discuss how we consolidate the information we have regarding the mapping exercise and then take the whole initiative forward. At the same time we can discuss the website and see how we can ensure that this is kept updated. Louise will arrange a meeting of the mapping/website committee for as early a date as possible.

8. Headway (Kent) - Di Drummond

Di had sent her apologies for the meeting and the Headway update had been covered by Dennis and Pam earlier in the meeting under "Information Exchange" when they informed the Forum of the latest position on the funding of the new centre for the Tunbridge Wells & District Headway.

9. Focus on Young Adults with ABI - Ros Eastwood

Ros said that she, Mary and Rhian Cogg had talked over matters. They were interested in the approach taken when someone from the forces comes in with an ABI and the positive way of supporting people with ABI. Mary said that the focus is on providing a nationwide service for service-leavers. Rhian has done some work on this and Ros said that she would email this to us.

The possibility of producing a booklet following a journey of young people with ABI, looking especially at follow-up which is where the RBLI ideas come in. For instance, vocational training which can help with employment and a field officer with whom they have built up a relationship and to whom they can go back if they have problems further down the line. Case studies would be needed in order to build up such a booklet covering such subjects as how they achieved independent living, obtained employment, made a successful transition to work, went on holiday etc. It might be possible to liaise with the RBLI regarding funding for this.

In essence, various ideas are starting to crystallise.

10. Talks were given by:

(a) Martin Burke, John Grooms Housing Association, gave a talk about the work of Headway Court

Martin explained that John Grooms Housing Association is both a charity and a housing association, with disability housing for people with wheelchairs. They manage 1,250 properties with an ethos of independence. They house people with profound difficulties and the handout attached to these minutes shows the client group at Headway Court, one of the Association's properties.

There are eight flats at Headway Court and there is always a manager/assistant manager on site. The tenants are assured tenants which mean they have the same rights as tenants with security of tenure.

Everywhere is accessible by wheelchair.

Presently there is a small turnover but the Association is looking at expanding to the next step of independence.

Care support is provided by an agency who offer encouragement, advice, mentoring and welfare benefits help. The level of support needed varies and can change. For instance, one tenant used to have forty hours' per week help and now only requires six hours. Most tenants tend to reduce the amount of help they need although conversely those who are aging can require their level of assistance to increase.

Funding is by the Housing Corporation, John Grooms Housing Association, and a mortgage. Only an ordinary rent is charged plus a service charge, the weekly rent averaging around £110 a week.

Martin said that he is talking to another Headway group at present with a view to setting up a similar model to Headway Court.

Martin's email address is mburke@johngrooms.org.uk if anyone would like to contact him or visit the website www.johngrooms.org.uk

(b) Ray Perry, Kent County Council Benefit Officer and Welfare Rights Officer, on incapacity benefit reforms.

This was a very extensive and wide-ranging subject and an edited version of Ray's talk follows. If anyone would like the full text, please email lbrown@ts-p.co.uk

1. IS THERE A NEED FOR REFORM?

In February 2005, Alan Johnson – the then Secretary of State – unveiled the Department of Work and Pensions 5 Year Plan, with the claim that what was about to happen signified, “*the biggest change in incapacity benefits since they were created*”. And as well as flagging up the breadth of planned reforms, he also explained the need for this change, with reasoning that will doubtless strike a familiar chord with you here today:

“It doesn’t make sense to have a system that lumps everyone together, treating in exactly same way, the person with back pain and the person with terminal cancer,” Mr Johnson said. *‘For people with conditions that the right support can make manageable, we should be rewarding steps towards work instead of the length of time on benefits. Our radical reform should mean that sickness benefit represents a pause in people’s life, not a full stop.’*

He then went on...*‘you can be assured that what underpins our approach is our desire to help people with a health condition or disability realise their own aspirations of a return to work. Such an approach benefits the individual, their family and both the local and national economy. But realising this aim means we need to continue to invest more in better quality support.’*

So let’s look at the current state of the benefits system and why the Government - and the agencies and organisations who advise and lobby ministers and government departments – believe the system needs to evolve. The facts speak for themselves.

- The number of people claiming Incapacity Benefit trebled between 1979 and 1997
- There are currently 2.6 million people in the UK claiming Incapacity Benefit
- The annual cost of funding Incapacity Benefit claims runs to 13 billion pounds.

But, as always, along with the facts there are the myths. Although 13 billion pounds is an enormous amount of money in anyone’s book, in many cases individual incapacity benefit awards fail to provide a decent income for people who are unable to work either because of long-term health problems or a disability. Not only do Incapacity Benefit claimants tend towards lower incomes than non-disabled people, they also face extra financial demands associated with their impairments - above and beyond the usual standards of living - such as transport costs, special dietary requirements and additional heating.

Before his inglorious exit, former Minister David Blunkett summed up government policy on benefits with his belief that: *‘Work is the best route out of poverty and dependence. The challenge is how the provision of financial benefits can be turned from a safety net into a ladder.’* His vision was to put the right support in place in order to raise employment, skills and productivity and improve social inclusion and cohesion. *‘We know that a million people on Incapacity Benefit want to work,’* he announced, *‘so we must end the stifling of ambition caused by the current system.’*

Mr Blunkett admitted – and no doubt many of you here will agree – that the current arrangements are too complex, failing to offer sufficient incentives to overcome concerns regarding the effect returning to work may have on people’s incomes. *‘We*

must open up work opportunities to people on Incapacity Benefit through new investment and proposals designed to reduce the barriers to work faced by disabled people,' he concluded. No small task but a necessary one as other DWP statistics prove.

The Department's own research shows that once someone has been on Incapacity Benefit for one year, they are likely to remain on it for an average of eight years. If they receive the benefit for longer than two years, they are statistically more likely to die or retire than they are to ever work again. Sadly, the term Incapacity Benefit can often become a self-fulfilling prophecy.

Besides the financial considerations for reform and the desire for social inclusion, there is also a great deal of evidence that being out of work, exacerbates poor health – particularly mental health. And considering that there are more claimants with mental health problems claiming Incapacity Benefit than the total number of people on Job Seekers Allowance, it's clear that reform of Incapacity Benefit is an issue not only for the DWP but also for the NHS.

Most of the charitable and not-for-profit organisations dealing with disability will feel the impact of benefit reform and most have given a cautioned welcome to the Government's proposals. A statement issued by SCOPE was both positive and encouraging: *'We look forward to working with the Government to ensure that the welfare benefits system supports disabled people to live independently, be free from poverty and exercise choice and control over every aspect of their lives.'*

Kate Nash, Chief Executive, of RADAR, was also in no doubt that change was vital in order to promote a positive message to Incapacity Benefit claimants. *'RADAR believes strongly that disability does not mean cannot work,'* she said. And Ian Charleworth of the SHAW Trust was equally adamant that the status quo must change when he remarked: *'Thousands are currently suffering from a system that punishes people who want to work.'*

Support for change comes from business quarters too. The Chartered Institute of Personnel and Development view these reforms as: *'An important tool to help UK employers fill vacancies and tackle skills shortages,'* although they were quick to warn the Government that it won't achieve its aims with changes to the benefits system alone, stating clearly that it also needs to tackle the concerns of employers and improve the employability of what it terms 'this core jobless group'.

So it's generally agreed that there is a great need for reform, not only relating to the Government's financial targets but also in realising the needs and aspirations of those on Incapacity Benefit, but there must also be concerns that these reforms will only work if they are part of a much bigger programme of change, involving the role of employers, GPs and full civil rights for disabled people. It will take more than policy ideas and press sound-bites to make any significant change.

2. SO WHERE DO WE START?

In recent decades, general unemployment has been so high, that successive governments have spent most of their time and effort pondering the plight of the unemployed, and the task of devising a strategy to help claimants off Incapacity Benefit and into work has slipped a long way down the list. Thankfully, with the highest number of people in employment since records began, this is about to change. Some of the basic changes introduced over the past six years have laid the groundwork for reform, which the Government hopes to build on. They are, briefly:

Permitted Work

The Permitted Work rules were introduced in April 2002 to replace Therapeutic Work and the scheme has proved to be a useful stepping stone into employment. Early findings are encouraging with just under a quarter of those people in Permitted Work moving on to full-time sustained employment. From the 1st October 2005, there was also an increase from 78 to 81 pounds in the weekly earnings limit for those on the two highest rates of Permitted Work, and there are proposals to further reform the Permitted Work rules from April 2006. The key points here are:

- Firstly, on entry to Permitted Work, claimants will be asked to sign up to an Action Plan committing them to 'consider the prospect of a move into full-time employment'.
- Secondly, Permitted Work will be extended to 52 weeks in all cases, with a review at 26 weeks to ensure that there is a 'strong ongoing commitment' or to review the action plan.
- The third part of these proposals is a special provision for those with severe conditions. It's a widened version of the Permitted Work provision enabling the individuals to work for a longer period of time.

Work-focused Interviews

This came into force from the 31st October 2005 and is a requirement that Incapacity Benefit claimants take part in a work-focused interviews to create and discuss an action plan for employment.

Linking Rules

New linking rules will be introduced from October 2006. The two key features are:

- Claimants who have to return to benefit from work because of incapacity will **automatically** be able to go back to their previous higher rate of benefit.
- Secondly there will be a single linking rule period of 104 weeks for all those leaving a higher rate of Incapacity Benefit for work.

Minimum wage

The Minimum Wage Act, as we all know, was introduced in 1999. From the 1st October this year, it will rise from 5.05 pounds per hour to 5.35 pounds an hour for those over 21.

Pathways to work

October 2005 saw a major expansion of the Pathways to Work pilot to cover approximately a third of the country, with plans to expand this to the whole of the country by 2008. The original scheme was launched three years ago and the early evidence is promising. Around 17,000 people on Incapacity Benefit in these selected areas have moved off benefit and into work, swapping, as Alan Johnson pointed out, 'Sicknotes for payslips and getting a salary rather than a benefit.'

Features of the Pathways to work pilots include

- Support from a personal advisor with contact every month in the first 8 months of the claim
- Strong local partnerships with the New Deal for Disabled people.
- Forty pounds a week Return to Work credit
- Twenty pounds a week Job Preparation Premium
- NHS Rehabilitation support so that claimants can learn to manage and cope with their condition, for example back pain or angina, so that they can get back to work.

Local Housing Allowance

The Government is also trying to sort out the mess that is Housing Benefit with the introduction of the Local Housing Allowance. Basically, local authorities will pay a flat

rate Local Housing Allowance, varying this allowance only by the size of the family and the area in which they live. It will not be related to the total rent of a house or flat as under the present scheme.

And finally, there was the introduction of much publicised Tax Credits system

The current Tax Credit System was introduced in April 2003. The Government's aim was to tackle child poverty, to help make work pay more than welfare and to ensure that people had incentives to move up the earnings ladder. Working Tax Credit would, the Government claimed; '*Tackle poor work incentives and persistent poverty among working people, building on the success of Working Families Tax Credit.*'

It was a sound idea, well-meant and there are currently 1.8 million Working Tax Credit recipients, but the Government's goals have been somewhat undermined by the major administration nightmares experienced by Her Majesty's Revenue & Customs. In fact recent research by the Joseph Rowntree Foundation has shown that – far from being a work incentive – the confusion and horror stories surrounding overpayments have made many people decide that they would be better off not working at all.

3. SO WHAT IS THE NEW BENEFIT SYSTEM LIKELY TO LOOK LIKE?

The Department of Work and Pension's 5-year plan, and the Welfare reform Green Paper published in February 2005 and January 2006, respectively set out the proposals for changes to the structure of Incapacity Benefit which we anticipate will come into force for new claimants in 2008.

The new Employment Support Allowance will be an integrated, contributory and income-related allowance, replacing current incapacity benefit and income support on the grounds of incapacity

The majority of claimants will be obliged to undertake work preparation or training in order to receive full payments. For those who co-operate however, the new benefits will be paid at higher rates. Although the changes are not expected to be fully implemented for another two to three years, pilot projects will be put in place much earlier. The likelihood is that areas with high rates of Incapacity Benefit, such as Glasgow, will be targeted first.

The plan is that claimants who are signed-off as sick will receive an initial 'holding benefit' – payable at the same rate as Job Seekers Allowance – until they have been examined under a reformed Personal Capability Assessment, normally within 12 weeks. The reformed employment and support assessment will look at the claimant's potential future work capacity rather than entitlement to benefit (and the mental health component of the PCA will be reviewed "to ensure that it reflects the type of mental health conditions prevalent today").

Following completion of this assessment a report will be given to the claimant's personal adviser and this will include a recommendation regarding a timescale for review. This will normally be within 12 months.

The majority of people (about 80%) who have been assessed as having more manageable conditions will be assisted in drawing up a personal action plan focusing on rehabilitation and eventually on work related activity. This may include such activities as work tasters, condition management programmes, childcare options and referral to the NHS Expert Patients programmes.

Claimants will receive more than the current long-term rate of Incapacity Benefit but those who completely refuse to engage will return to the holding benefit rate. Rules relating to possible sanctions have yet to be decided.

So what about those with the most severe health conditions or impairments (the remaining 20%)? Well, the Government has stated that these claimants will receive more money than under the present system because these are the people who are most at risk of prolonged poverty and most likely to face significant obstacles to getting work. They will, however, as now, still be required to engage in some work-focused interviews. They will also be encouraged to engage in return to work activity wherever possible, although there will be no requirement on them to do so.

Benefit levels will not increase the longer a person claims, nor will there be age additions or adult dependency increases as there is under the current scheme. There will also be a new reconsideration and Appeals process.

Existing claimants will remain on their current benefit paid at protected levels. However the government proposes to “work more proactively with this group of people balancing their responsibilities to prepare for a return to work with the need to treat them fairly”.

These claimants will also be subjected to regular reassessments with a new unit being established to undertake periodic checks to confirm ongoing eligibility.

Full use will be made of the current rules where people on JSA are allowed two spells of short-term sickness within a 12, month period. JSA claimants will have to exhaust these permitted spells of short-term sickness before claiming Incapacity benefits. There will also be a more pro-active sickness management arrangements with “return from illness” interviews and where necessary revision of the Jobseekers agreement.

As well as looking at changing the benefit system the Government is also looking at how to reduce new claims for Incapacity Benefit. It’s considering such measures as:

- Improving workplace health support to retain employees
- Piloting employment advisers in GP surgeries and rewarding primary care staff who help people back to work
- Revising the format of the medical certificate
- Reforming statutory sick pay to ensure it helps people stay in work

So how have the major disability and advice organisation responded to the Green Paper?

The Disability Benefits Consortium shared the views of many such organisations when it expressed concern about the possible emergence of a two-tier system, namely those who can and those who cannot work. They suggested that instead of threatening sick and disabled people with benefit sanctions, the government should concentrate its efforts on developing effective retention strategies which would help people keep their jobs.

11. Any Other Business

None

Next Meeting:

The next KABIF meeting will take place at **4.00 p.m. on 29 June 2006 at the Spa Hotel, Mount Ephraim, Tunbridge Wells, Kent**, immediately preceding the Annual Thomson Snell & Passmore Brain Injury Lecture given by Mr Henry Marsh, Consultant Neurosurgeon.