Acquired Brain Injury Forum for London (ABIL)
http://www.abil.co.uk

Response to Review: Specialist Disability Employment Support

Executive summary

Acquired brain injury (ABI)
A serious brain injury can be life-changing for the individual and their family. Traumatic brain injury (TBI) mainly affects young people, particularly in the age range 16 – 29, and about 25% of stroke survivors will be under 65 and 10% under 50.

Returning to work or other kind of productive activity is very important to people after a brain injury. It provides opportunities to rebuild self esteem and re-integrate into society, as well as the more obvious potential financial benefit.

The key to successful outcomes is involvement of services with specialist knowledge of ABI where these exist - unfortunately, they are by no means universally available.

Current employment support programmes for people with disabilities
DWP's current employment support programmes for people with disability-related barriers to work are not usually effective **on their own** for people who have sustained a brain injury, since they take no or insufficient. account of the need to address the complex mixture of cognitive, behavioural and emotional difficulties exhibited by this client group.

The effects of these difficulties are largely "hidden" and not easy to observe without specialist assessment, and their impact in the workplace may thus be ignored or underplayed. Thus, the involvement of advisers/organisations with specialist knowledge of brain injury are essential to:

- educate employers and their staff about the effects of brain injury in general and in relation to their potential employee;
- guide and support the potential employee in relation to performance and behaviour in the workplace, which can include job-coaching support, help with developing compensatory strategies, and guidance in terms of relating to other staff members; and
- be available to provide follow-up advice and guidance as the job/placement progresses.

If employers are able to learn how to relate to this client group, they will gain by retaining reliable and skilled employees.

The best outcome - where it can be achieved - is to provide support and assistance for the person to return to their pre-injury employer either in their previous role or in a less demanding but related one. This can be shown to be highly cost-effective.

This may, however, not be possible for a variety of reasons (see full response), and then opportunities will need to be explored for alternative employment or other occupation, including education, retraining and voluntary work.

ABIL aims:
to raise awareness of acquired brain injury in London
to encourage development & dissemination of good practice
to campaign for better services

In all cases, specialist input will be needed to support and guide the person with the brain injury and those working with him/her - as indicated above.

Measures of success
To try to maximize the 'employment rate' for disabled people is too simplistic a concept where people who have had a brain injury are concerned, and for many other client groups. Each person's situation will be different, and will need a tailored approach. It is wrong for government to issue 'blanket' edicts or to believe that 'one size fits all'.

What is important is for the person after a brain injury to be in a position where they feel they are a useful member of society, and are making their contribution in an environment where they feel comfortable and valued. This could be in a paid or voluntary position, or part of a social enterprise. Additionally, it should be such that it is in balance with the rest of their life.

Inter-agency working
For services to be most-effective for people who have had a brain injury, there is a need for inter-Agency working - as emphasised in the National Service Framework for Long Term (Neurological) Conditions (Quality Requirement 6 - Vocational Rehabilitation) (Ref 1) and in the guidelines produced by the British Society of Rehabilitation Medicine (BSRM)/Jobcentre Plus/Royal College of Physicians in 2004 and by the BSRM in 2010 (Refs 2 & 3).

This will involve different partner groupings in different situations, as for example:

- **Return to existing employer**
  - Local brain injury/head injury clinic (liaising with the employer) - for mild traumatic brain injury; and
  - brain-injury community rehabilitation team, together with the DEA and Access to Work - for moderate/severe ABI.

- **For preparation for & take up of new paid/voluntary opportunity (moderate/severe ABI)**
  - DEAs (and occupational psychologists),
  - Work Choice providers,
  - specialist brain injury vocational rehabilitation units,
  - community brain injury rehabilitation teams,
  - condition-specific voluntary groups (e.g., Headway or Different Strokes groups)

Importantly, in such partnership working there must be good co-ordination, and clear delineation in terms of leadership and acting as the person's main point of contact.

Resource issues
We have made it clear that organisations with specialist and/or first-hand knowledge of brain injury are essential partners in effective return-to-work/occupation initiatives for people after a brain injury. Their involvement at the right time and in the right way will be cost-effective either directly or when their (and their families') overall support needs are taken into account.

Involvement of such statutory and voluntary sector organisations in the ways suggested would enable many more people to have better lives after a brain injury, and contribute more effectively to society. Their involvement is also essential to build up a broader body of knowledge and experience in this area.

However, the existence and future viability of such organisations in London and, inevitably, in most other parts of the country is extremely variable (the usual 'post-code lottery'). This is a matter on which the United Kingdom Acquired Brain Injury Forum (UKABIF), ABIL, and Headway are campaigning and will be pressing GP consortia to address.

Full response

1. Acquired Brain Injury Forum for London (ABIL)

ABIL was established in 2007, and is a group of front-line professionals, commissioners, survivors of acquired brain injury (ABI) and carers working to improve the lives of people who have had a brain injury, and their family and carers, across London. It thus represents the views of a wide range of stakeholders. Its website is at http://www.abil.co.uk

2. Background

We give some background information to the causes of acquired brain injury, and the numbers involved, in Appendix 1 - this relates to London, but we can provide national figures if needed.

3. Effects of Brain Injury on the person and family - a hidden disability

A brain injury can happen to anyone at any time. A serious brain injury – from whatever cause – can be life-changing for the individual and their family.

As stated in Appendix 1, traumatic brain injury (TBI) mainly affects young people, particularly in the age range 16 – 29, and about 25% of stroke survivors will be under 65 and 10% under 50.

In many cases after ABI, there is limited physical or sensory disability, and a complex mixture of cognitive, behavioural and emotional difficulties. The residual effects are largely "hidden", and thus less easy to observe. This can result in misunderstandings, and thus loss of employment or other meaningful occupation, relationship breakdown, low self-esteem, social isolation, homelessness, alcohol and drug dependency, or finding themselves in the criminal justice system. The process of adjustment is very difficult for the person and the family/carers. The affected person will in most cases have a normal life expectancy.

Survivors of a brain injury largely go unrecognised by professionals and the public. Although it can have apparent similarities with a number of other conditions - physical disability, learning disabilities, mental health problems, and other long term neurological conditions - brain injury needs to be regarded as a condition in its own right.

To achieve the best level of recovery, people will need specialist rehabilitation and support services across the whole care pathway – both as an inpatient and in the community (see Appendix 2) - and often for the rest of their lives. Services in London are currently very patchy, and the situation is becoming more indeterminate during the transition to GP-consortium commissioning.

4. Meaningful occupation after brain injury?

Returning to work or other kind of productive activity is very important to people after a brain injury. It provides opportunities to rebuild self esteem and re-integrate into society, as well as the more obvious potential financial benefits.

However, after a serious brain injury, a person is often left with a number of impairments, most of which on their own, would probably be reasonably manageable, but in combination make it difficult for them to operate within society without support from other people who understand how the injury has affected them.

This particularly applies to the workplace, where it is often not the possession of the required knowledge and skills per se, but rather the less-tangible aspects of the job - including flexibility, the use of judgment, and relationships with others - which are key to successful outcomes.

There will be a mixture of cognitive, behavioural and emotional effects, which combine to cause difficulties, such as:

- Problems with attention, memory, speed of information processing, multi-tasking, language, and executive function (planning & problem-solving)
- Irritability, frustration, aggressive outbursts, disinhibition, and inappropriate behaviour

- Volatility, mood swings, anxiety, depression, lack of confidence

and, often:

- a lack of insight/awareness of how the injury has affected them - which can lead to unrealistic expectations in terms of the kind and level of job to which they should aspire. This often means that they are - unknowingly - setting themselves up to fail. This is particularly the case where they were in a high-level job before their injury and, although they may accept intellectually that their capability has been diminished, a part of them - emotionally - still feels they can perform at the same level.

Much of this will not be immediately apparent, being essentially invisible.

This is in addition to any physical and sensory problems and, importantly, issues of fatigue, which can lead to a rapid drop-off in performance and can affect the person's life outside the workplace. An important aspect of this is that the reduced cognitive abilities mean that everything is more of an effort than it was pre-injury, yet the person presents as quite capable! In such cases, part-time work may be all that is realistically possible.

The above can lead to the following kinds of issue in the conventional workplace:

- Poor performance - in spite of appearing to have the required knowledge and skills
- Reduced awareness, self-monitoring/management of work performance and behaviour
- Difficulty in adapting coping strategies developed in rehabilitation within the workplace
- Difficulty in planning, prioritising & organising work to achieve objectives and meet deadlines
- Difficulties in starting and/or completing tasks
- Difficulty in improving work skills / behaviour in response to feedback/supervision
- Difficulties (e.g. inflexibility) in coping with changes in role, duties or work practices
- Lack of awareness of impact of own work performance & behaviour on colleagues
- Poor judgment of behaviour (e.g. ill-judged humour, insensitive comments)
- Disagreement with managers (e.g. about the existence or cause of difficulties at work)

5. The kind of support needed

To avoid the kinds of situations referred to above, it is essential, in the great majority of cases, for advisers and/or services with specialist brain injury knowledge to be involved - often in partnership with others (see 7 - below). It is important to recognise that pan-disability vocational providers will not on their own have sufficient expertise and understanding of the effects of ABI to work effectively with this client group, and will need to liaise with or refer on to specialist brain injury teams.

Such teams work on an interdisciplinary basis, but neuropsychologists and occupational therapists have a particular role to play in helping the person to develop and use suitable strategies in the workplace, and also with the adjustment process after brain injury.

In such situations, peer support can also play an important role, such as that provided through group work in some brain injury rehabilitation centres and which is part of the whole ethos of local Headway groups.

6. Some different scenarios

Retention of current job or return to previous employer

This is obviously the preferred situation, where the person can remain in work, or make a phased return to work either in their previous role or a less demanding but related one.

It will be most likely in the case of mild or moderate brain injury, and in the former, there is obviously a very strong case for very early intervention, including close liaison with the employer, to help the person remain in work.

In cases of more-severe brain injury, it may be possible in favourable cases, where there is early specialist intervention, say, soon after the first 1 or 2 years post-injury, and there is a sympathetic employer.

In all cases, there will need to be good co-operation from the employer and, usually, initial support from a brain-injury team (this may be the community rehabilitation team - if one exists - that worked with them on their discharge from hospital, or a specific vocational rehabilitation team). They may need further support of this kind from time to time, when situations/people in the workplace change.

This is likely to be the most obviously cost-effective scenario, where it can be achieved.

Take up of new work (or volunteering) opportunities

In many cases, it will not be possible to return to the previous employer (or such a return is not sustainable). Many of these people will be young - just starting out on a career or still in training or education - so that there is effectively no job to return to. Some may have tried a number of possibilities, but have not been able to sustain them and/or there was not the necessary support/understanding in the workplace. They may thus have been without meaningful work/occupation for some considerable time.

A successful work or volunteer situation for such people requires the following kinds of support:

- education of employers and their staff about the effects of brain injury in general and in relation to their potential employee;
- guidance and support to the potential employee in relation to performance and behaviour in the workplace (this can include job-coaching support; help with developing compensatory strategies; and guidance in terms of relating to other staff members);
- availability of follow-up advice and guidance as the job/placement progresses; and
- allocation of a member of staff as a 'mentor' - to help the person navigate the various challenges they will encounter and provide support when needed.

Further information on the kinds of support needed are given in Appendix 3

Employers need to be open to learning how to relate to this client group, and in doing so will gain in terms of reliable and skilled employees.

Also, it is well known that, for a person after a brain injury, to find a sustainable job may involve several attempts before finding one that 'fits'; and this will need consistent support throughout.

Return to training or education will require similar support mechanisms. And of course, obtaining a qualification after a brain injury does not necessarily mean (even in better economic times) that it will lead to a sustainable and worthwhile job, in particular because of the people-skills and other qualities needed.

For some people, the best solution may be some kind of voluntary work, which matches their interests and enables them to mix with people of a similar outlook, and means that they make a contribution to society. This will require considerable preparation and specialist support if it is to be sustainable. They may in fact require more support initially, because of the relative lack of structure, but this can be an advantage for some people.

In some cases, the voluntary opportunity may provide a stepping stone to paid work, given the right kind of support.

Alternative models

A number of brain-injury units both in the statutory and voluntary sectors are now starting to look at alternative models, where groups of people after a brain injury join together to use their particular skills to develop projects which can help their local communities and which may become businesses in their own right (perhaps in the form of social enterprises). They thus provide mutual support and

create their own 'company ethos' which suits their way of working. This is done with support from others who can ensure good governance and help with partnership working with other organisations. This thus builds on intact skills in the brain injury community and provides the support needed where there are challenges caused by the brain injury. This is broadly along the lines of the 'clubhouse' approach, developed primarily for people with mental health problems, but which has been used in North America with people after a brain injury.

The lesson here is that there is no one right way. Each situation is different. It is wrong for government to issue 'blanket' edicts or to believe that 'one size fits all'. They need to understand that people after a brain injury often have complex needs, which require specialist support. This will be most effective for the person, and also cost-effective, in the long run.

7. Partnership working

This is essential if sustainable outcomes are to be achieved. The need for inter-Agency working has been emphasised in the National Service Framework for Long Term (Neurological) Conditions [1] (Quality Requirement 6 - Vocational Rehabilitation) and in the guidelines produced by the British Society of Rehabilitation Medicine (BSRM)/Jobcentre Plus/Royal College of Physicians in 2004 [2] and by the BSRM in 2010 [3].

Different groups will need to collaborate in different situations.

a. For the 'job/employer retention' situation, there is likely to be involvement:

- for MTBI - of a local brain injury/head injury clinic (liaising with the employer); and
- for moderate/severe ABI - of a brain-injury community rehabilitation team, together with the DEA and Access to Work.

b. For preparation for & take up of new paid/voluntary opportunities, the involvement is likely to be between some of the following (as appropriate):

- DEAs (and occupational psychologists),
- Work Choice providers,
- specialist brain injury vocational rehabilitation units,
- community brain injury rehabilitation teams,
- condition-specific voluntary groups (e.g., Headway or Different Strokes groups)

Importantly, in such partnership working there must be good co-ordination, and clear delineation in terms of leadership and acting as the person's main point of contact.

8. Resource issues

It is clear that organisations with specialist and/or first-hand knowledge of brain injury are essential partners in effective return-to-work/occupation initiatives for people after a brain injury. Their involvement at the right time and in the right way can be shown to be cost-effective either directly or when their (and their families') overall support needs are taken into account.

Involvement of such statutory and voluntary sector organisations in the ways suggested would enable many more people to have better lives after a brain injury, and contribute more effectively to society. Their involvement is also essential to build up a broader body of knowledge and experience in this area.

However, the existence and future viability of such organisations in London and, inevitably, in most other parts of the country is extremely variable (the usual 'post-code lottery'). This is a matter on which the United Kingdom Acquired Brain Injury Forum (UKABIF), ABIL, and Headway are campaigning and will be pressing GP consortia to address.

26th February 2011

References

1. The National Service Framework for Long Term Neurological Conditions (NSF), which reported in April 2005 http://www.dh.gov.uk/en/Healthcare/Longtermconditions/Long-TermNeurologicalConditionsNSF/index.htm

2. Vocational Assessment & Rehabilitation after Acquired Brain Injury: Inter-Agency Guidelines (British Society of Rehabilitation Medicine/Jobcentre Plus/Royal College of Physicians, 2004) - attached

3. Vocational assessment and rehabilitation for people with long-term neurological conditions: recommendations for best practice (BSRM 2010) - attached

1. Acquired Brain Injury (ABI)

An acquired brain injury is a non-degenerative injury to the brain that has occurred since birth. It includes: traumatic brain injury (TBI) which can occur as a result of road traffic accidents, sport or leisure pursuits, assaults, falls or battle; and non-traumatic brain injury – which may be caused by: strokes and other vascular events, including subarachnoid haemorrhage; tumours; infections; and hypoxic-ischaemic injury as a result of cardiac arrest.

2. Extent of ABI (and some economic implications)

TBI mainly affects young people, particularly in the age range 16 – 29 (and more men than women), whereas stroke affects in the main older people, although, importantly, about 25% will be under 65 and 10% under 50.

According to the NSF for Long Term Neurological Conditions and the National Stroke Strategy (2007):

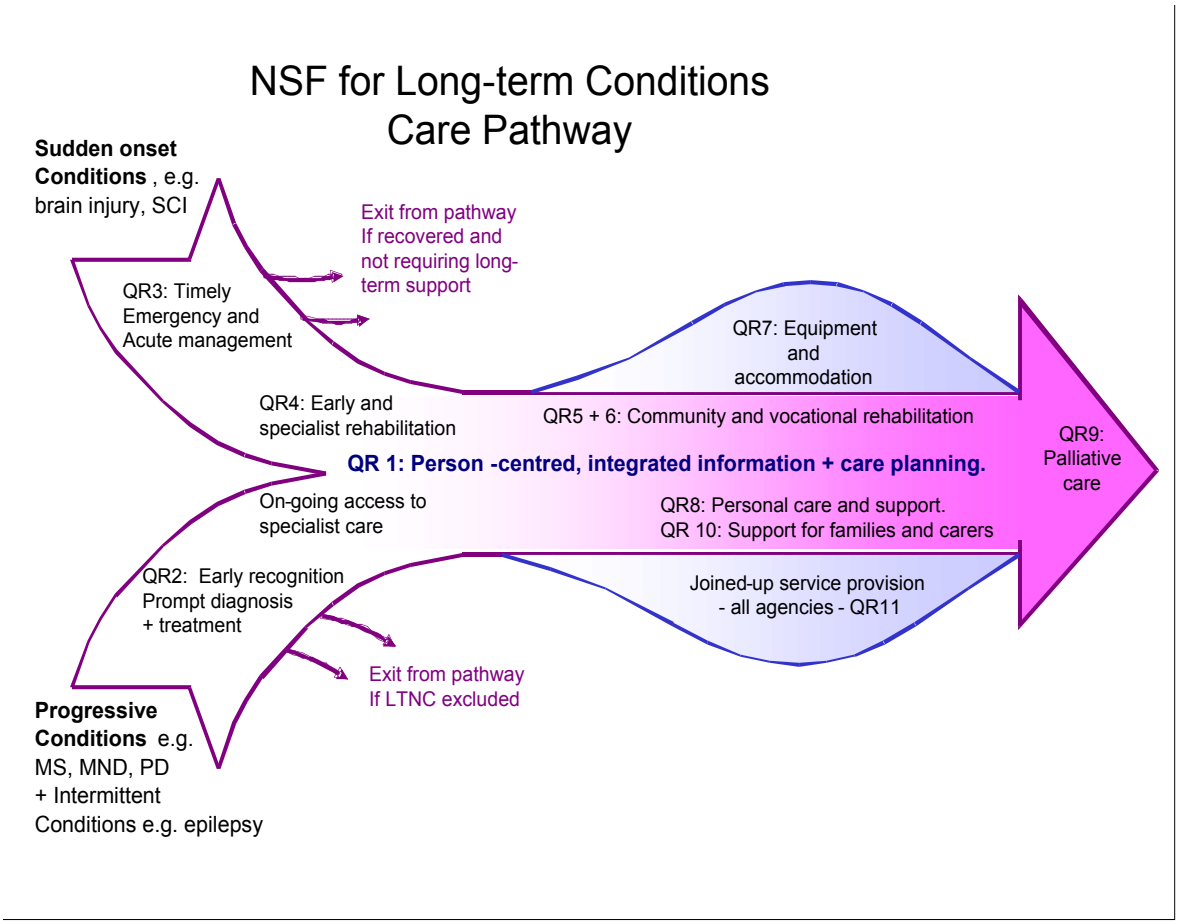
- Around 10,000 people of working age are hospitalised in London with a TBI each year - they will have sustained a moderate/severe TBI
- a much larger number (ca. 130,000 in London) attend A & E each year, with post-concussion syndrome (very short or no period of unconsciousness) – so-called 'mild TBI'. But even here, in up to 20% of cases, it can lead to long-term problems.
- about 3000-3500 people under 65 (approx 1000 under 50) suffer a stroke each year in London
- there are approx 55,000 people of working age living with the long-term effects of a TBI in London (there are no comparable estimates for stroke or other forms of ABI)

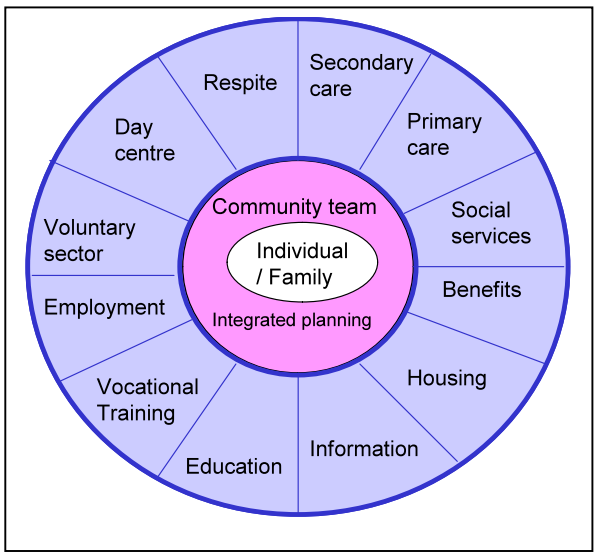
Not only the personal but also the economic consequences of ABI are enormous. In the UK the annual costs of direct and informal care and lost productivity after stroke and TBI in the UK are of the order of £14bn.

There is a strong evidence base that if the right interventions are made at the right time, then the cost savings can be substantial and the quality of life optimised for survivors and their family and carers. However, this often means spending money in one area to provide greater savings in another, which needs joined-up thinking and working to achieve the necessary outcomes.

The fish diagram illustrates the 11 Quality requirements of the NSF for Long term (Neurological) Conditions, and the cross section shows the type of services that need to be coordinated during integrated care planning

(Produced by Professor Lynne Turner-Stokes - who was Deputy Chair of the NSF External Reference Group)





Take up of new work (or volunteering) opportunities - kinds of support needed:

- prior engagement in a work-preparation programme run by people who understand about brain injury and its effects - and which inculcates basic work skills and habits

- an appreciation of the person's whole life and responsibilities, and current support system

- assessment of their abilities and performance in real-life situations, including the effect of fatigue on their performance in and out of work

- a matching of their skills/ abilities/ interests to the requirements of the job, together with work colleagues with similar interests (some of which may be related to their pre-injury interests)

- initial job-coach support from people trained in brain injury, to help the person break the job down into manageable tasks and identify those requiring most attention - and also to develop strategies for dealing with particular workplace situations, and as far as possible to understand some of the 'unwritten rules' of that particular workplace! This can either be provided by a specialist vocational brain injury unit or bought in separately and funded through Access to Work (with agreement with the local DEA)

- training of the person's manager and immediate colleague(s) in a basic understanding of brain injury, and how it has affected their employee. And how to react if the person appears to be behaving 'strangely'.

- allocation of a member of staff as a 'mentor' - to help the person navigate the various challenges they will encounter and provide unquestioning support when needed.

- the brain-injury team will still be needed on occasion, for example, when situations/people in the workplace change.