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

Specialist disability employment programmes. Consultation on the recommendations in the Sayce independent review *Getting in, staying in and getting on*

The Acquired Brain Injury Forum for London (ABIL) submitted a detailed response in relation to the original consultation in February 2011. Here we respond to the specific questions in the present document.

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); strokes and other vascular events, including subarachnoid haemorrhage; tumours; infections; and hypoxic-ischaemic injury as a result of cardiac arrest.

TBI mainly affects young people, particularly in the age range 16 – 29 (and more men than women). 25% of all strokes occur in people of working age.

Each year an estimated 1 million people attend hospital A&E departments in the UK following a TBI. Of these, around 135,000 people are admitted to hospital. The remainder are discharged with post-concussion syndrome (very short or no period of unconsciousness) – so-called 'mild TBI'. But even here, in up to 20% of cases, there can be long-term problems. Over 130,000 people have a stroke every year; of these, about 33,000 are of working age.

There are estimated to be 500,000 people of working age living with the long-term effects of TBI in the UK (there are no comparable estimates for stroke or other forms of ABI).

Thus people with ABI represent a significant client group, the needs of which tend to be misunderstood and overlooked.

Response to Questions

Question 1
We agree that, generally, for people who have sustained a brain injury, funding for vocational rehabilitation and support in the workplace should follow the person, and they should have the maximum degree of choice regarding the type of work they do. This should be in the open jobs market. It should be clear to all concerned how the funding can be accessed.

It is essential that the support received:

- is delivered by people who have the necessary understanding of brain injury and are aware of evidence-based models of good practice;
- includes an assessment of how their brain injury has affected the person being supported; and
- is tailored to their needs.

It is important to take into account their intact skills and help them to compensate for their difficulties. There is no one right way, since each situation is different.

The aim should be to help them make their maximum contribution in mainstream, paid employment where this is possible.

Some people who have had a brain injury may not be able to sustain paid work, even on a part-time basis, and for them, the best solution may be some kind of voluntary work, which is sustainable, matches their interests, enables them to mix with people of a similar outlook, and means that they make a contribution to society. They should also have the maximum degree of choice regarding the type of voluntary work available to them.

We agree that the number of 'stepping stones' should be kept to a minimum, but after a brain injury, people may need to undertake some 'placements' in different work environments as part of their initial vocational rehabilitation, in order to establish the most appropriate type of work and setting to pursue subsequently.

What is key is that, once a job has been identified, the person should be supported as intensively and for as long as is needed, in order to help them, and the employer, to adjust to the situation and sustain the relationship. In the case of brain injury, there may be the need for extended support - even some years after initial takeup of the job - due to subsequent change of immediate manager/supervisor or when the long-term limitations of the injury become more apparent, and the employer and employee need additional, expert support in working together effectively.

It may be that, in some cases, a number of different job situations have to be tried, until one is found which is sustainable in the long term. This is in line with the need - as proposed - for ongoing and flexible support for as long as is it is required.

Question 2 & 3 (re Access to Work)
We fully support the expansion, and better promotion, of the Access to Work programme, which we feel can be a key funding stream in providing the kind of support needed after a brain injury - for someone either to retain their existing job, remain with their current employer in a new role, or to find and stay in a new job/voluntary position.

After a brain injury, the resulting difficulties are often "hidden" and not easy to observe without specialist assessment, and their impact in the workplace may thus be ignored or underplayed. These can include: problems with attention, memory, speed of information processing, multi-tasking, language, and executive function (planning & problem-solving); cognitive fatigue leading to further reduction in attention and concentration;

poor safety awareness; reduced empathy and poor judgment of own behaviour and consequent issues with work relationships; and poor insight into how the injury has affected them.

There is thus a need for advisers/organisations with specialist knowledge of brain injury 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 their performance and behaviour in the workplace, which can include job-coaching support, help with developing compensatory strategies, and guidance in relating to other staff members; and
- be available to provide follow-up advice and guidance as the job progresses.

Access to Work can fund these kinds of interventions.

There can be considerable benefit in appropriate cases in providing taxis to work, as it reduces the cognitive fatigue experienced on arrival at work and thus enables the maximum productive output during the working day.

We strongly believe that Access to Work should be extended also to cover voluntary work, as referred to under Question 1.

Of the options listed in Question 3, we would give as the highest priorities:

- Enabling disabled people to know in advance what Access to Work support might be available;
- Training Jobcentre Plus advisers to give more support and advice to employers;
- Working more closely with user-led organisations, to provide services and peer support for people using Access to Work - in the case of acquired brain injury this would include Headway and Different Strokes groups around the country; and
- Extending Access to Work support to cover more work-related training, for example unpaid work experience, and also - in the case of brain injury, where paid, competitive work may not always be possible - to cover other approaches including community-based mutual or social enterprises (see below) and voluntary work.

Finally, we would strongly advocate that Access to Work is made as administratively straightforward as possible, so as not to discourage participation and, for example, transfer of awards from one employer to another. Previous experience has been that the system can be overly bureaucratic on occasion.

Questions 4 - 7 (re future of Remploy)
We do not feel qualified to comment on the future shape/nature of Remploy activities, but note the reference to community-based mutual or social enterprise type models.

An example of community-based activities in the brain injury field are those of the Headway East London 'Discovery Programme'. This is based upon co-production principles and looks in particular at what people can do after a brain injury, not just what they can't do. It acknowledges that, for some people after a brain injury, conventional vocational programmes can be ineffective - with a succession of placements not leading

to sustainable employment, and thus a debilitating loss of self-esteem. It adopts an alternative approach, by setting up a series of real projects that answer existing needs in the local community, and providing the long-term support to develop and carry these out. These include: a Time Bank which has over 100 members from the wider community; a film collective making short documentaries that address social injustice in London; and a Lunch Club - a food enterprise providing freshly made affordable lunches to an underserved part of Hackney. There is mentoring from outside professionals and, where appropriate, collaboration with local businesses. To date, 7 brain injury survivors have taken leadership roles in the projects, 2 have pursued one-off projects, and 54 have participated in the projects week-to-week. Two members have successfully returned to paid work following involvement in the programme.

Questions 8 & 9 (re Residential Training Colleges)
We are not in a position to comment generally on the proposals regarding future funding of Residential Training Colleges. One such college of which we do have some knowledge is Queen Elizabeth's Foundation for Disabled People (QEF) whose Brain Injury Centre at Banstead, Surrey is a National Specialist College. The Centre provides a specialist rehabilitation service for younger people who have sustained a brain injury. They adopt a strong holistic, interdisciplinary approach, and address their clients' physical, educational, psychological, independent-living and vocational needs. Their vocational work follows well-accepted principles and models for vocational support after a brain injury, and involves both work preparation and training (on a residential or day-place basis) and follow-on support in the workplace. This is currently funded primarily by PCTs and Local Councils. Clients can be cross-referred from the Brain Injury Centre to QEF Vocational Services at Leatherhead Court to train for sustainable employment. This is funded by the DWP. It is important that QEF continues to receive funding for its vocational work with clients who have sustained a brain injury.

Questions 10 & 11 (re Work Choice and Work Programmes)
As indicated above, these programmes will only work effectively for people after a brain injury if there is ongoing input from people/organisations with a good knowledge of brain injury and the application of models which have been demonstrated to be effective. This must be a guiding principle for these and any future programmes working with this client group.

As regards the proposal that, in the longer term, Work Choice and Access to Work should be merged into a single programme delivered through individual budgets, this would make sense since they are essentially complementary programmes, and the recipients would benefit from their being run together. However, it is essential that the new programme is flexible in giving individuals choice regarding the support they need.

We assume that it is not being proposed that they be run together with individual budgets being created through the 'personalisation agenda' within Local Authority Social Services departments. These programmes are moving quite slowly in many parts of the country, and should not be complicated further or, for that matter, the Access to Work/Work Choice programme itself be made more complicated.

Cross-government issues (No specific Question)
We fully support the view that disability employment is an area that requires close working and co-operation between government departments and agencies at a local level.

This is important if the best outcomes are to be achieved. The need for inter-Agency working has been emphasised in:

- the National Service Framework for Long Term (Neurological) Conditions (2005) http://www.dh.gov.uk/en/Healthcare/Longtermconditions/Long-TermNeurologicalConditionsNSF/index.htm and

- Vocational Assessment & Rehabilitation after Acquired Brain Injury: Inter-Agency Guidelines (British Society of Rehabilitation Medicine/Jobcentre Plus/Royal College of Physicians, 2004) http://bookshop.rcplondon.ac.uk/details.aspx?e=167 .

For the latter, an Inter-Agency Advisory Group, comprising members of the NHS, Jobcentre Plus, social services and independent vocational providers, looked at what was needed to assist people with acquired brain injury in securing sustainable employment or alternative occupation. It recommended that staff from local NHS brain injury services, Jobcentre Plus, local councils and independent vocational, occupational and educational providers should:

- undertake a joint review of services for people with brain injury and develop local protocols, both to assist staff in working together to facilitate appropriate and timely access to current services and also to identify gaps in local service provision

- establish ongoing service links (eg between brain injury neuropsychologist, occupational therapist, Jobcentre Plus Disability Employment Advisor and work psychologist) to discuss the vocational needs of individuals with brain injury

- adopt a joint approach both to increasing awareness of vocational needs and to the development of specialist skills training for all providers of vocational assessment and rehabilitation services for people with brain injury.

These principles still apply and should be reconsidered in light of the changes taking place in the NHS, local authorities and in the DWP.

Question 12 (any other suggestions for improving or changing specialist disability employment support not covered by any of the above questions)

As referred to above, it is recommended that greater account is taken of the vocational/ occupational needs of people after an acquired brain injury. This is a group whose needs have been largely neglected, but constitute a significant number of people, and for whom providing timely and specialist intervention would be cost-effective as well as improving immeasurably the quality of life of those concerned.

This also includes those who have sustained a ‘Mild TBI’, where appropriate intervention at the right time can help the person - and their employer - understand how they have been affected and facilitate a sensible plan for their return to work.

14 October 2011