



## **Acquired Brain Injury Forum for London (ABIL)**

### **Comments on Equal Life Chances for All Londoners - Draft Disability Equality Scheme 2010-2011**

We should like in particular to comment on the Health and Social care section of chapter 4 (pp 27-29)

#### **1. The London Health Inequalities Strategy**

ABIL commented in some detail on the draft Health Inequalities Strategy in January.

We welcome the broad Strategy document and the First Steps to Delivery to 2012 document published in April, and the commitment to targeted programmes based on the best evidence and experience. We were informed at that time that "further information including a comprehensive evidence base and consultation report will be available from the website in the coming weeks". This has however not yet appeared.

We also welcome the establishment of Community Voices for Health, to support ongoing dialogue with the voluntary and community sector. We note that this was officially launched on 18 March to enable voluntary and community sector (VSC) groups in London to influence the strategic direction of health in London, and that over 50 community groups attended the launch. Unfortunately, neither my colleagues from Headway - the brain injury association - in London nor anyone from ABIL was invited to the launch, and as far as we can tell, no further meetings have yet been held.

#### **2. Targeting of specific disability groups - including acquired brain injury**

We note that the section on Health and Social Care in the present document refers to the "need to monitor the progress toward reducing health inequalities in such a manner that data can be disaggregated by disability status and sub-categories of disability" and the need for "targeting programmes to areas or groups with highest need". We also note, and welcome, the intention to publish the Delivery Plan for the Health Inequalities Strategy in the Autumn of 2010, including more detailed performance indicators, investment plans and initiatives as well as information about targeting programmes to areas or groups with highest need.

We suggest that people who have sustained an acquired brain injury (ABI) - together with their family and carers - would be groups with high need. A brain injury can be life-changing for the person and their family/carers - as outlined below.

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

### Acquired Brain Injury - a neglected area

Brain injury is a neglected area as far as public and general clinical understanding and availability of appropriate services is concerned. This is despite two major reports in the last 10 years - The Health Select Committee study 'HEAD INJURY: REHABILITATION' (2001); and the National Service Framework for Long Term Neurological Conditions (NSF) (2005), the latter being the government's response in 2003 to the Health Select Committee inquiry.

### The present position in London

There are estimated to be 55,000 people of working age in London living with the long-term effects of a traumatic brain injury (TBI). This takes no account of the other major causes of brain injury.

Provision of specialist services in the community for people after a brain injury continues to be very much a post-code lottery.

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

TBI in particular mainly affects young people, who will have normal life expectancy. Their main difficulties will usually result from a complex mixture of physical, cognitive, emotional and behavioural problems, and typically a change in personality and a lack of awareness of how the brain injury has affected them.

In many cases, there is limited physical or sensory disability. The residual effects are often therefore subtle and largely hidden. This results in misunderstandings, and thus loss of employment, relationship breakdown, low self-esteem, social isolation for the person and their family, and can also result in discrimination from the public and statutory services. The burden on their families is immense. All of this represents a significant cost to society, much of which could be avoided with appropriate and timely interventions.

After the initial acute and post-acute phases, people after a brain injury are often largely left with a range of challenges of a psychosocial kind to which they are trying to adjust and with which they need help from people with knowledge and expertise in the area - and from society at large.

Such support will need to be long-term - often life-long - for a significant proportion of people. For many, this will be in the home and community setting - and will involve help and support for them to live as independently as possible and engage in productive activities (e.g., work, volunteering), and also support for their family and carers.

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. Otherwise it will continue to be marginalised and those with brain injury will continue to have difficulty in accessing the services they need.

Without appropriate specialist rehabilitation and follow-up support services (see 3 - below) in the community, brain injury survivors will continue to 'fall through the gaps' in service, and are at risk of social isolation, relationship breakdown, homelessness, alcohol and drug dependency, and criminality.

Finally, we should point out that access to appropriate Social Services support under Fair Access to Care criteria is, because of the hidden nature of the disability, often denied to people with a brain injury. Many people who appear on the face of it to have few problems will, if assessed by staff knowledgeable about brain injury, be acknowledged to have substantial needs.

### **3. The likely new commissioning landscape in London**

We refer to this, since the GLA will be concerned about how the new arrangements could affect groups with complex needs, such as those with ABI, and hopefully can work with us and others to help ensure that available resources can be used to best effect on behalf of such groups.

We note that much of what is in the White Paper “Equity and excellence: Liberating the NHS” is in general accord with the Health Inequalities Strategy and the current draft Disability Equality Scheme as far as Health and Social Care matters are concerned.

In its response to the White Paper, ABIL welcomed many of the policy intentions expressed in the White Paper. In particular: ownership and decision-making being transferred to professional front-line staff and patients; the move towards integration of Health and Social Services; and an increased focus on clinical outcomes.

We also welcomed the GP commissioning role in view of the failure of present arrangements as far as ABI services in the community in London are concerned. NHS London and the PCTs in London have patently failed to recognise, and address, the need for appropriate local community rehabilitation and support services for ABI on an equitable basis across the whole of London. Such provision is currently very patchy, and continues to be a post-code lottery, with services ranging from excellent in some PCTs through to non-existent in others.

We pointed out that the effectiveness of GP commissioning of specialist community brain injury services will require careful planning and consultation; it will be critical that GP consortia draw upon the experience of commissioners, professionals and patients and carers with first-hand knowledge of such services.

Since the number of GP consortia across London is likely significantly to exceed the current number of PCTs, we are concerned that, if suitable mechanisms such as collaborative commissioning are not put in place, this could lead to even greater disparity, and inequality of access, to appropriate community brain injury services across London.

We pointed out that the NSF provides a good basis for commissioning of ABI services, through its emphasis on person-centeredness and joined-up services and its quality requirements.

We recommended that new commissioning arrangements should:

- Primarily focus on community- and outpatient-based services, as there are already established mechanisms covering acute and specialised inpatient rehabilitation services.
- Recognise that services will need to be long-term - often life-long - for a significant proportion of ABI patients.

- Recognise that many patients with brain injuries initially felt to be 'minor', will go on to have persistent and disabling problems.

And to be effective and cost efficient, new services in the community will need to:

- Involve teams that are sufficiently specialist and knowledgeable.
- Be interdisciplinary in nature, and include specialist physiotherapy, occupational therapy, speech & language therapy and neuropsychology; support from rehabilitation consultants; and input as necessary from neuropsychiatry, neurology, and endocrinology,
- Integrate closely with social services - with social workers and support workers in the community also having specific knowledge and experience of brain injury.

We strongly urged that, if the new commissioning arrangements are to be effective and equitable, there must be input from front-line professionals and survivors and family/carers. This will include professional bodies such as the BSRM and those representing Allied Health Professionals, neuropsychologists, specialist social workers, etc, and organisations such as ABIL and Headway groups in London.

#### Role of the GLA

We ask that the GLA looks at the best way it can act as a catalyst and influence on those who will hold 'the levers of power' to ensure that the new arrangements for commissioning draw upon the expertise at all levels that already exists in London.

ABIL would be happy to discuss any of these matters further.

15-10-2010