



Acquired Brain Injury Forum for London (ABIL)

<http://www.abil.co.uk>

Comments on: Healthy Lives, Healthy People: consultation on the funding and commissioning routes for public health

1. Acquired Brain Injury Forum for London (ABIL)

ABIL 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.

2. These comments

These comments address many of the issues covered by the 16 template questions, but in a way that relates to the needs of people who have sustained an acquired brain injury.

3. Public health

The White Paper *Healthy Lives, Healthy People* outlines a radical shift in the way we tackle public health challenges, with a new role for Local Authorities in improving the health and wellbeing of their population.

This is welcomed as are the principles set out in the present consultation document, which we understand place the emphasis on a strong partnership between the NHS and local government, working in conjunction with the independent and voluntary sectors, to deliver improvements in health care, social care and public health on a cost-effective basis. Thus we welcome the establishment of Health and Wellbeing Boards, which - if properly constituted - should be well placed to help deliver such improvements.

We would advocate the need to take a broad overview of how and why services are delivered, and to adopt a joined-up approach, so that it is possible to initiate spending on services in one area to make greater savings in another.

We would encourage the consideration of Public Health within the broad context of Health overall, as defined by the World Health Organization (WHO) as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity".

This would mean taking a broader view than just prevention of disease - important though that is - to promote measures that ensure prevention of secondary disability and late deterioration in people with long-term conditions of all kinds. This requires the joined-up approach advocated above, focussing support that minimises the complications of disability and maximises quality of life, so that there can be an overall saving to society. Thus we would suggest that the scope and format of Table A - Public health funded activity - should be modified to take this key aspect of service delivery into account.

We are concerned in particular with acquired brain injury (ABI), which 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 brain injury

ABIL aims:

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

from other causes, including stroke and other vascular events, tumours, infections (eg, encephalitis, meningitis); and hypoxic-ischaemic injury as a result of cardiac arrest.

It is one of the long-term neurological conditions covered in 2005 by the National Service Framework for Long Term Neurological Conditions (NSF)

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4105361 which itself placed great emphasis on the need for integrated working between health and social care.

4. Prevention

Many head injuries are the result of unforeseen accidents that would be very difficult to predict or prevent. However, there are some measures that can be taken to reduce the risk and severity of brain damage in the event of a head injury. Currently there is no specific NICE guidance on prevention of TBI, the current guidelines being limited to triage, assessment, investigation and early management of acute episodes (**NICE clinical guideline CG 56** <http://guidance.nice.org.uk/CG56>). Survivors of TBI are also impacted by the wider public health policy debate that includes some of the following important areas of public life:

- Cyclists and motorcyclists can protect themselves by wearing properly fitting safety helmets. British standard safety helmets are a legal requirement for motorcyclists. Safety helmets can reduce the risk of serious head injury in the event of an accident by up to 85%;
- Public education about the hazards of exceeding speed limits on the roads, the importance of wearing seat belts;
- Public education regarding the need to wear helmets when taking part in certain sports, and to observe precautionary measures following a head injury on the sporting field (e.g., rugby, soccer);
- Education of GPs on what to look out for after a 'mild' head injury (post concussion syndrome);
- Public health education on the risks of driving under the influence of alcohol, drugs, etc;
- Despite the availability of robust clinical guidelines on the transfer of acute patients with suspected or confirmed diagnosis of TBI, it can still be a postcode lottery. If patients are admitted to the most appropriate treatment centres in a timely fashion, future long-term disability can be reduced. This has been addressed in London with the establishment of Major Trauma centres and trauma networks. Such regional networks are being set up across England, but the budgets for these are being threatened and need to be ring-fenced if the networks are to survive.

There is a need to educate young people about the effects of a serious head injury after an assault. Headway South East London North West Kent has done some very useful work with young offenders in this respect - by putting them in touch with people who have sustained a brain injury and to hear first-hand how it has affected their lives and those of their close family.

There is a greater prevalence of TBI - due to assaults and falls - among young people who are under the influence of alcohol or drugs, so that any measures to reduce such usage, would be beneficial in reducing such occurrences.

Also, there is a need to educate the public about the risk of excessive consumption of alcohol resulting in brain damage.

5. Promoting health and wellbeing after a brain injury

Acquired brain injury (ABI) is a condition that can affect anyone at any time and can be life-changing for the individual and their family. Life expectancy is usually close to normal. There is no cure, but people can be helped to adjust to and cope with their impairments, and lead a good quality of life. They will often need rehabilitation and support, of one kind or another, for the rest of their life, particularly in order to help them deal with key changes and transitions and maintain the gains made from specialist input.

TBI mainly affects young people, particularly in the age range 16 – 29. The main difficulties 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 largely “hidden”, and thus less easy to observe. This results in misunderstandings, and serves to compound their problems. Without appropriate rehabilitation and follow-up support services, 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, or finding themselves in the criminal justice system. 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.

i. Specialist rehabilitation and support

Providing specialist rehabilitation and support at the right time is essential to the future health and wellbeing of someone after brain injury, and is cost-effective when their (and their families’) overall support needs are taken into account. They will often need rehabilitation and support, of one kind or another, for the rest of their life, particularly in order to help them deal with transitions and changes in their life and also to maintain the gains made from specialist input. The aim should be both to promote maximum independence and counter social isolation.

Specialist vocational/occupational rehabilitation services will be needed to help as many people as possible return to paid work or, where that is not possible, education or some other form of productive activity, including sustainable voluntary work. In this way, people after a TBI can be helped again to contribute to society

All of the above will very much be matters for Health and Social Services working in an integrated fashion, together with other agencies such as Housing and the DWP, and in partnership with the independent and voluntary sectors.

ii. Role of the voluntary and independent sectors

Headway -the brain injury association

As regards ABI, local Headway centres and groups in particular have considerable expertise and knowledge of ABI and long experience of providing help and support in the community for people who have sustained a brain injury and their families/carers.

They provide social rehabilitation and advocacy and advice and, most importantly and uniquely, constitute a community providing peer support. They provide these services for as long as they are needed. They involve their clients as active contributors to the process (co-production), rather than merely as recipients of services. In addition, because of their unique situation, they are able to provide first-hand training and experience to those studying to work in the health and caring professions.

They are part of a strong country-wide network of such services - maintained by Headway UK - which shares and promotes good practice.

Such services are currently funded from a mixture of sources - primarily statutory (generally Local Authority Social Services) and independent (charitable trust and corporate and individual giving). They make use of trained volunteers to a significant extent - without whom their services would be much less effective and/or would cost significantly more to deliver.

Headway groups could do much more, and help many more people, if:

- their services were more widely recognised and supported as part of the proposed Public Health and ‘Big Society’ initiatives.
- these services were regarded as an essential part of the network of services needed after brain injury

- they worked more closely with community brain injury or neuro-rehabilitation teams (currently funded/commissioned by PCTs) - either as close partners or, in some cases, within new, social enterprise-type organisations.

Supported and residential accommodation

For some people, there will be a need for supported accommodation, with knowledgeable support onsite or otherwise readily available. This would be a partnership between Local Authority Housing and Social Services, but also involving others, such as Housing Associations, Headway and independent sector organisations. For others, who are unable to be supported in their own homes, there is a need for local specialist residential accommodation; provision currently is often inappropriate or a long distance from close family members.

iii. Other partners

There will need to be close working with:

- other advice services (eg, CABs and other voluntary advice/advocacy services)
- with services for other client groups where brain injury is or can be a significant factor:
 - drug- and alcohol-support services
 - services for the homeless
 - mental-health services (dual diagnosis)
 - young men in prison
 - injured service men/women on return from Iraq/Afghanistan

iv. Future funding/commissioning of brain injury services

Funding/commissioning of services for people after a brain injury has to date been a disorganised 'patchwork' (Health, Social Services, DWP, LSC), with no clear co-ordination or joined-up thinking, and also very much a post-code lottery.

Where services do exist, they are often sub-optimal in terms of specialist knowledge, capacity (not a critical mass of key staff), rationed, and lacking in follow-up support (thus effectively wasting much of what was provided).

These are all matters which will need to be addressed by GP consortia. For ABI, there is a strong case for a collaborative commissioning approach to be adopted, and for some involvement of the NHS Commissioning Board.

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