



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

<http://www.abilondon.org.uk>

### **ABIL RESPONSE TO THE CONSULTATION DOCUMENT ON THE LONDON HEALTH INEQUALITIES STRATEGY 2017**

ABIL is a group of front-line professionals, policy makers, survivors of acquired brain injury and relatives and carers. It aims to:

- raise awareness of Acquired Brain Injury (ABI) across London;
- encourage the development and dissemination of good practice; and
- campaign for better services for ABI survivors and their families and carers across London.

We welcome the Mayor's intention to address the main issues which lead to inequalities in the health of different groups of Londoners.

#### **1. Acquired brain injury (ABI)**

We would like to draw attention to a condition which is widespread in the community, but has been largely overlooked, to the detriment of those affected, including their families and carers, and to society and the economy as a whole.

A brain injury can happen at any time and to anyone, and can be caused in a number of ways: traumatic brain injury (TBI), caused by accident, injury, assault; and non-traumatic injury through, for example, strokes and other vascular events; brain tumours; infections such as encephalitis or meningitis; and hypoxia after a cardiac arrest (lack of oxygen to the brain). The effects can be wide ranging and different for each person. A brain injury can change a person's life completely, and the lives of their friends and family.

Brain injury survivors are ordinary people: they have been through many of the same experiences as everyone else (marriage, children, work, education). A considerable number of people after brain injury can find themselves homeless or in the criminal justice system, and many will suffer from mental health problems.

A very recent report <sup>1</sup>, drawn up by a large number of clinicians and others across the world, states that "A concerted effort to tackle the global health problem posed by traumatic brain injury (TBI) is long overdue. TBI is a public health challenge of vast, but insufficiently recognised, proportions." (see also item 9 - below).

It is estimated that there are 1.3 million people living in the UK with a TBI-related disability. The direct and indirect economic cost has been estimated as £15 billion pa across the UK <sup>2</sup>. This does not, however, include the human costs on survivors' and their families' wellbeing and quality of life, which is clearly the biggest cost

The number of people living in London with a TBI-related disability is estimated to be approx.100,000, and with ABI from all causes possibly twice that number.

Brain injury is often referred to as the hidden disability as the consequences are not always immediately apparent and are therefore often overlooked in provision of services.

Lifelong consequences of ABI can include a wide range of physical, mental, cognitive, emotional, and behavioural problems, which often result in financial hardship, social and family breakdown, loss of independence and unemployment.

There is a lack of recognition and understanding of those needs and, where there are specialist services available, they are often inadequate and dependant on where the person lives.

The isolation, and consequent depression and other mental health problems, that result can lead to alcohol and substance abuse, homelessness and entering the criminal justice system.

## **2. Brain Injury and the criminal justice system**

Brain injury in childhood and young adulthood is associated with an increased risk of offending behaviour and, relative to the general population, there is a high prevalence of brain injury among young offenders in custody.

Acquired Brain Injury is linked to earlier, repeated offences, a greater total time spent in custody and more violent offending. Because of the hidden aspects of ABI, many young offenders enter the Youth Justice System, but receive little or no treatment. Their needs and difficulties are not taken into account when sentencing is being considered. A key publication in this area was that by Professor Huw Williams in 2012: 'Repairing shattered lives: Brain injury and its implications for criminal justice' <sup>3</sup>.

## **3. Brain Injury and homelessness**

There is evidence of links between homelessness and acquired brain injury in other parts of the country - for example in Sheffield - S Grant et al, 2016. Experiences of Homelessness and Brain Injury <sup>4</sup> and in Leeds by the Disabilities Trust Foundation <sup>5</sup>. The GLA have recently funded a project led by Westminster City Council to explore the picture in London.

Acquired Brain Injury as a hidden disability is particularly susceptible to misinterpretation by staff working within homelessness and associated services. This leads to further health inequalities arising from a lack of support for some of the most obvious impacts of ABI. The absence of appropriate support means the costly and damaging cycle of homelessness continues.

## **4. Mental Health**

We note the Health Inequalities strategy emphasis on mental health. According to the Centre for Mental Health report <sup>2</sup>, having a brain injury doubles the risk of developing mental health problems. Many ABI survivors fall between physical and mental health teams as they will have a combination of physical and cognitive problems.

We hope that The Mayor can use his position as chair of the London Health Board partnership to advocate for Londoners to not only have "proper access to mental health services and a move towards parity of esteem between physical and mental health illness", as stated in the draft document, but also to encourage parity of treatment for all ABI survivors across London and help to close the health inequality gap in the resources allocated to treatment of ABI compared with that allocated to other diseases.

## **5. Children**

The Mayor is also placing emphasis on healthy children and this is another group who can be affected by ABI. The Archives of Disease in Childhood report 'Epidemiology of children with head injury: a national overview' (2016)<sup>6</sup> looked at 5700 children admitted to hospital with traumatic brain injury in 2009 - 2010 and found there was significant association of head injury with social deprivation.

## **6. Clinical Commissioning Groups and STPs in London**

We feel an important step in addressing the health inequalities for survivors of ABI should be directed toward educating Clinical Commissioning Groups (CCGs), and also Health & Social care commissioners, about the need for specialist services to maximise recovery and improve positive outcomes. There are limited services available in London - with a post code lottery - and, where they are available, they are often under-resourced with time-limited input. The provision of specialist community rehabilitation services for ABI should be included in the Sustainability and Transformation Plans (STPs) for all CCGs.

## **7. The voluntary sector**

We welcome the Mayor's plan to encourage more access to groups, places and networks that make their communities healthy, and hope that he will use his influence to encourage and support charities such as Headway which directly support ABI survivors on a long-term basis.

We note the Mayor's ambition is to support the most disadvantaged Londoners to benefit from social prescribing to improve their health and wellbeing. This is the approach used by Headway Groups across the country, and in London, for example, by Headway East London, which at its community hub encourages and facilitates its members, on a co-productive basis, to engage in a range of occupational and other projects  
[http://headwayeastlondon.org/uploaded\\_assets/art\\_images/Headway-East-London-DAY-SERVICE-2016.pdf](http://headwayeastlondon.org/uploaded_assets/art_images/Headway-East-London-DAY-SERVICE-2016.pdf)

Headway Groups in London vary from two large Groups with 5-day-a-week activities to four much smaller groups with more limited activities (<http://www.abil.co.uk/headway-groups-in-london/>) and there is a need for the latter to be supported to extend the reach and scope of what they do.

## **8. Prevention**

The Lancet Neurology Commission's report on TBI<sup>1</sup> states that "TBI is, to a great extent, preventable, and the benefits for society of decreasing its occurrence are far-reaching". There are useful pointers to action in that report.

As regards road safety, the promotion of seat-belts, child restraints and helmet use by motor-cyclists and cyclists, and the creation of dedicated cycle lanes, are crucial steps, as are traffic calming measures to reduce risk to both pedestrians and motorists.

Other safety measures should include those to reduce the incidence of TBI caused by falls, especially in the elderly, and concussion in sport (see, for example, <http://www.abil.co.uk/june-2017-conference-concussion-focus-sport/>)

Alcohol is a major contributor to the occurrence of brain injury. Of equal concern is the high proportion (over 50%) of adolescents and adults hospitalised for traumatic brain injuries who have had pre-injury substance use disorders.

Finally, for the high proportion of people in the criminal justice system who have had a prior traumatic brain injury, with the right rehabilitation reoffending could be avoided, with gains to them and their families, and also to society as a whole.

## **9. London to play its part to address the public health challenge of TBI**

The Lancet Neurology Commission report on TBI<sup>1</sup> emphasises the need for a concerted effort to tackle the global health problem posed by TBI which is a public health challenge of major proportions. Worldwide, more than 50 million people have a TBI each year, and it is estimated that about half the world's population will have one or more TBIs over their lifetime. It is the leading cause of mortality in young adults and a major cause of death and disability across all ages in all countries.

The Commission stresses the need to increase awareness of the scale of the challenge posed by TBI, and that efforts need to go beyond a clinical and research audience and to address the public, politicians, and other stakeholders. There is a need to:

- develop and implement policies for better prevention and systems of care in order to improve outcomes for TBI survivors;
- commit to substantial long-term investment in TBI research; and
- effectively translate progress in basic and clinical research into clinical practice and public health policy.

We note that this is an area where the UK, and London in particular, has significant clinical and research expertise and could play a major role in international collaboration. London took a lead in 2009 in establishing the London major trauma network - through which many more lives are now saved after TBI - and could follow this by supporting advances in the whole of the care pathway, as well as promoting preventative strategies and measures. The Mayor and the London Health Board partnership could take a lead in pursuing such matters.

## **References**

1. Traumatic brain injury: integrated approaches to improve prevention, clinical care, and research. The Lancet. Neurology Commission. November 2017. [http://www.thelancet.com/pdfs/journals/laneur/PIIS1474-4422\(17\)30371-X.pdf](http://www.thelancet.com/pdfs/journals/laneur/PIIS1474-4422(17)30371-X.pdf)
2. Traumatic brain injury and offending: An economic analysis. Michael Parsonage. Centre for Mental Health July 2016, <https://www.centreformentalhealth.org.uk/traumatic-brain-injury>
3. Repairing shattered lives: Brain injury and its implications for criminal justice [https://www.barrowcadbury.org.uk/wp-content/uploads/2012/11/Repairing-Shattered-Lives\\_Report.pdf](https://www.barrowcadbury.org.uk/wp-content/uploads/2012/11/Repairing-Shattered-Lives_Report.pdf)
4. S Grant et al, 2016. Experiences of Homelessness and Brain Injury <https://www.theguardian.com/housing-network/2016/oct/19/homeless-brain-injury-nhs> and <http://shura.shu.ac.uk/13718/1/Experiences%20of%20homelessness%20and%20brain%20injury%20FINAL%282%29%20Sept%202016.pdf>
5. The Disabilities Trust Foundation. Brain injury and homelessness. <https://www.thedtgroup.org/foundation/brain-injury-and-homelessness>
6. Archives of disease in childhood - Epidemiology of children with head injury: a national overview, BMJ March 14 2016. <http://adc.bmj.com/content/101/6/527>