

Department of Health and Social Care Acquired Brain Injury call for evidence: formal response.

## **About The Brain Charity**

The Brain Charity offers emotional support, practical help and social activities to anyone with a neurological condition and to their family, friends, and carers. There are hundreds of different neurological conditions, including stroke, brain injury, dementia, cluster headaches, and many rarer ones too - we are here for every single one.

Our mission is to enable all those affected by neurological conditions to live longer, healthier, happier lives. We will fight together for an inclusive and just society: a world where stigma, hardship and isolation are replaced by compassion and understanding.

We are a charity based in central Liverpool but serve the whole of the UK, offering support services including, but not limited to: counselling, welfare benefits advice, adult learning courses, confidence building courses, support groups for different conditions, employment support, carers advocacy, legal aid, supported volunteering opportunities and social activities for our service users.

We have presence in four Liverpool hospitals and also offer a national information & advice service which includes a library open to the public. We are also currently constructing a neuro specific gym for client use.

## On which areas could the strategy look to focus to better support people with an acquired brain injury or other neurological condition?

We are calling for the strategy to focus on the following areas: Specialist neurological mental health support; the prevalence of ABIs within the prison population; and the importance of diagnosing neurological conditions as early as possible.

## **1**. The strategy must have a focus on Specialist neurological mental health support. Too often we see those with neurological conditions unable to access the mental health support that they need.

1.1 In our most recent community consultation 62% of our clients told us they needed access to mental health support – up from 54% in 2020. We have seen a rise of more than 50% in the number of people seeking help from us at the point of severe mental health crisis.

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National support for all neurological conditions.









- 1.2 We know that for many of our clients, having a neurological condition also means having to deal with depression and/anxiety.
- 1.3 People with a neurological condition are nearly twice as likely to take their own life.<sup>i</sup>
- 1.4 Prolonged isolation and shielding during the Covid-19 pandemic has dramatically exacerbated this situation. NHS waiting times have clearly been exacerbated by Covid and we regularly encounter clients who are waiting months to access help and support. It is also worth noting that as a result of restrictions, community based services ceased to exist in any normal form throughout the pandemic.
- 1.5 We would welcome a commitment within the strategy to ensure that people with ABIs can access mental health services within 10 weeks of a referral.
- 1.6 We would welcome a commitment to ensure people hospitalised by ABIs will receive automatic community mental health support once they are discharged from hospital. We know from working with our service users that this transition period is of fundamental importance.
- 1.7 The strategy should also consider how best to ensure people with ABIs receive counselling from professionals with specific training in and understanding of ABIs, so that people with neurological conditions receive specialist help that is right for them.

## 2. The strategy must have a focus on the UK prison population, which is disproportionately made up of people who have neurological conditions (including brain injury, ADHD, autism spectrum disorder and learning disabilities).

2.1 The Disabilities Trust Foundation's research estimates nearly half of all male prisoners (47%) have a history of traumatic brain injury (TBI).<sup>ii</sup>

2.2 User Voice, a charity run by people with lived experience of the criminal justice system, interviewed 118 prisoners with neurological conditions for their 2021 report "<u>Neuro...</u> <u>What?</u>" Neurodiversity in the Criminal Justice System<sup>III</sup>. Most responders had never heard of the term neurodiversity, were never screened for neurological conditions and had never been offered any adjustments to support their neurological needs.

2.3 Currently, there is not enough specialist support for people with neurological conditions within the criminal justice system – despite their numbers among the prisoner population being disproportionately higher than the national average. Treatment and support to stop

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individuals reoffending needs to be tailored to neurological condition – a prisoner with a brain injury should receive the specialist help they need, instead of the current one-size-fits all approach.

2.4 Much more needs to be done to support the dedicated staff working within the prison system to raise awareness of ABI and other neurological conditions. While not everyone can be expected to be an expert, giving staff the knowledge and understanding to spot the potential signs of an undiagnosed condition or existing disability would help to ensure those who need it can access the right help and support. This in turn will reduce reoffending, support a safer working environment for staff and give offenders the equal opportunity to turn their life around.

2.5 The strategy needs to actively consider how early intervention can be made – as close to the point of contact with the criminal justice system as possible – to ensure that those with ABIs receive the help and support that they need. This must apply to witnesses and victims of crime as well as those accused of committing a crime. In particular, we would welcome a commitment to ensure people with ABIs can access an advocate, or link worker, who is then able to help them navigate their way through the justice system.

3. The strategy must focus on improving the understanding of neurological conditions amongst those working in the Primary Care sector. Our clients report time and time again that the process for receiving a diagnosis was often a long and frustrating one. Much more needs to be done to support GPs, Community Pharmacists, and other staff.

3.1 We would welcome a commitment to establish a best practice guide for the diagnosis of ABIs and other neurological conditions. While ABIs that are caused by traumatic incidents are often diagnosed quickly, rarer neurological conditions can be much harder to get a diagnosis for.

There are more than 600 neurological conditions - due to the rarity of some of these conditions, general practitioners will very rarely come across presentations of early onset symptoms their professional working life – the strategy must consider what support can be offered to GPs to help to reach the right diagnosis as early as possible.

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<sup>ii</sup> <u>https://www.thedtgroup.org/foundation/brain-injury-and-offending#LEE</u>

<sup>iii</sup> <u>https://www.uservoice.org/wp-content/uploads/2021/07/Neurodiversity-in-the-Criminal-Justice-System.pdf</u>

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<sup>&</sup>lt;sup>i</sup> Association Between Neurological Disorders and Death by Suicide in Denmark, Erlangsen, 2020: <u>https://bit.ly/3MWQYzd</u>