



**ENOUGH: THE INEXCUSABLE TREATMENT
OF BRAIN INJURED CHILDREN AND
YOUNG PEOPLE IN THE UK**

MP's BRIEFING NOTE

MAY 2019

1.0 Purpose

- 1.1 This Briefing Note is to inform MP's of the plight of brain injured children, young people and their families, who live in the UK and the daily discrimination they face by statutory bodies. It is hoped that the information in this Briefing Note will trigger legislative change to help improve the long-term outcomes of brain injured children and young people through the provision of high-quality neurorehabilitation services and support.
- 1.2 It is hoped that the findings and recommendations outlined in report will:
- trigger a sea-change that will legislate and start to transform services and support for brain injured children and young people;
 - will facilitate the provision of essential neuro-rehabilitation services; and
 - that that MP's and other statutory bodies work with Matrix to improve services for families through co-production and support so that we start to deliver better outcomes for brain injured children and young people.

2.0 Background

- 2.1 MATRIX Neurological is an innovative children's charity based in Middlesbrough, established to provide practical help and support to children, young people and their families who are living with the effects of an acquired brain injury (ABI). The founder of Matrix created the organisation because of first-hand experience of child brain injury. In 2010 her son sustained a severe traumatic brain injury. Despite engaging with several support organisations at that time, our Founder was unable to find any brain injury rehabilitation or support service that met the needs of her son and her family; be that in the public, private or third sector.
- 2.2 Our mission is: *"to work to remove inequalities for children & young people affected by acquired brain injury; and provide effective support to their families that makes a real difference"*.
- 2.3 In the UK, few brain-injured children and young people have experienced good outcomes, but where this has happened, it has only been through the resilience, hard work and determination of their parents; not the state or the private sector who provide little help. The poor outcomes that brain injured children achieve is the result of a lack of understanding, a lack of recognition of the effects of acquired brain injury; a lack of high-quality neuro-rehabilitation services and a failed public and private sector system. This must now change.
- 2.4 MATRIX was therefore established to try to bring about significant changes for brain injured children and young people as we feel those with the lived experience of paediatric brain injury are best suited to provide for the needs of these families. The sea change that is needed, must be led by families living with childhood acquired brain injury; not the 'professionals' who are only looking in from the outside and have a vested interest in the type and quality of services we receive.
- 2.5 Much needs to change regarding brain injured children and young people; to remove the prejudice, inequality and discrimination they face on a regular basis. This raises the question about what kind of society have we become when even our public services and government closes its eyes to their complex needs. The current lack of awareness, recognition, understanding and service provision is enormous across all statutory sectors.

3.0 Prevalence

3.1 Acquired Brain Injury (ABI) is the biggest cause of death and disability in children and young people across the UK; yet ABI remains the least understood and least supported childhood disability; with life-long implications.

3.2 The incidence of paediatric traumatic brain injury alone exceeds all other neurological disabilities as shown in the table below. A report entitled, “**Nobody made the connection**” was produced for the Children’s Commissioner in October 2012 and states the reported prevalence of certain disorders amongst young people in the UK population per disorder are:

| | |
|-------------------------------|-----------------|
| Autism | 0.6-1.2% |
| Learning Disability | 2-4% |
| ADHD | 1.7 – 9% |
| Dyslexia | 10% |
| Traumatic Brain Injury | 24-31.6% |

3.3 Far more young people have suffered a traumatic brain injury than those that have autism or dyslexia, and their issues are equally complicated and disabling. Yet there exists no legislation to provide for their needs and there is little recognition and understanding of the problems suffered by a child that has sustained either a traumatic or non- traumatic acquired brain injury.

4.0 What is an acquired brain injury?

4.1 An ABI is classified as damage to an otherwise healthy brain that has been caused by accident or illness. It is not a birthing injury; hereditary or a birth defect. There are two types of acquired brain injury:

| Type 1 Traumatic Brain Injury (TBI) | Type 2 Non- traumatic Brain Injury (NTBI) |
|---|--|
| <ul style="list-style-type: none"> • Falls • Road Traffic Accident • Sporting head injury • Concussion • Extreme sports • High velocity sports (i.e. golf) • Assault | <ul style="list-style-type: none"> • Stroke • Brain Tumour • Encephalitis • Meningitis • Drowning/ near drowning • Cardiac Arrest • Suffocation/strangulation • Chemotherapy treatment |

Fig. 1

4.2 Like autism, ABI is also referred to as a ‘hidden disability’ because survivors may have no physical evidence of their disability. Many of the impairments are not visible to others and it is only over time that the longer-term effects may become apparent. However, the negative consequences of ABI can severely and permanently change a child’s life; with many of the impairments only emerging many years later when they fail to meet their expected development milestones.

4.3 It is important to note that in the context of head injury **persisting disability is commonly ‘hidden’** as it derives from these cognitive and emotional changes that impact on day to day life and **more obvious physical disability is considerably less common**. Hence, in most cases there is no obvious outward sign of the head injury within a few weeks or months of the injury and the individual with a head injury and those that they interact with may not attribute their behaviour or difficulties to this injury. Hence, neither the head injured person nor those in contact with them make adjustments, seek help or make allowances for the brain injury.

5.0 THE BRAIN

- 5.1 The brain is one of the largest and most complex organs in the human body. It is made up of more than 100 billion nerves that communicate in trillions of connections called synapses. Any type of brain injury disrupts or breaks to these connections which prevents the brain from communicating to other parts of the brain. High quality neuro-rehabilitation services can use the brains own 'plasticity' (adaptability) to reduce the level of impairment an individual is left with by helping the brain to 're-wire'.
- 5.2 Both traumatic and non-traumatic brain injury is usually identified through brain scans or other imaging; but, they often only show any physical damage to brain tissue. i.e. bleeding, bruising, oxygen starvation, necrotic tissue etc. or deep brain intraventricular problems.
- 5.3 However, MRI imaging does not highlight sufficiently, which synapses (or 'connections') have been damaged at the time of the brain injury or caused by post injury swelling. As medics are unable to see these connections, they are unable to accurately predict an outcome, or tell parents how the brain injury will affect their child; or how their child will be different post injury. Medics also don't routinely carry out MRI scans on children and young people if they are conscious and because the costs are prohibitive.
- 5.4 The British society of Rehabilitation Medicine and the Royal College of Physicians acknowledge that a range of deficits can emerge following an acquired brain injury; as shown in the table below:

| PHYSICAL | COMMUNICATION | COGNITIVE | BEHAVIOURAL EMOTIONAL |
|---|--|---|---|
| <p>MOTOR DEFICITS:</p> <ul style="list-style-type: none"> • PARALYSIS • ABNORMAL MUSCLE TONE • ATAXIA (co-ordination) <p>SENSORY DEFICITS</p> <ul style="list-style-type: none"> • VISION • HEARING • SMELL • TASTE <p>DYSPHAGIA (swallowing difficulties)</p> <p>SEIZURES</p> <p>OTHER:</p> <ul style="list-style-type: none"> • HEADACHE • FATIGUE • PAIN • SLEEP | <p>LANGUAGE DEFICITS:</p> <ul style="list-style-type: none"> • EXPRESSION (finding the right words) • COMPREHENSION (understanding) • DYSARTHRIA (difficulty speaking) • DYSLEXIA (difficulty reading) • DYSGRAPHIA (inability to write) • DYSCALCULIA (problems with maths and calculations) | <p>IMPAIRMENT OF:</p> <ul style="list-style-type: none"> • MEMORY • ATTENTION • PERCEPTION • PROBLEM SOLVING • INSIGHT • SAFETY AWARENESS/ RISK TAKING • SELF MONITORING • SOCIAL JUDGEMENT | <p>DEFICITS:</p> <ul style="list-style-type: none"> • EMOTIONAL LABILITY (unstable emotions or emotional over-reaction) • POOR INITIATION • MOOD CHANGE • ADJUSTMENT PROBLEMS • AGGRESSIVE OUTBURSTS • DISINHIBITION • POOR MOTIVATION • INAPPROPRIATE SEXUAL BEHAVIOUR • PSYCHOSIS |

(Source: British Society of Rehabilitation Medicine (BSRM) and the Royal College of physicians (RCP); 2003

6.0 The Problem

6.1 Advances in medical practice means more and more children are surviving serious brain injury and illnesses; which leave them with complex and often hidden disabilities. Yet the level of understanding and recognition is extremely low; which then creates a barrier for a person receiving effective neuro-rehabilitation support.

6.2 Brain injury and NHS staff

6.2.1 It can take months and years before the real deficits start to emerge; after which the brain injury is often forgotten about. If there are no immediately obvious or presenting physical disabilities, the child is discharged and presumed to be OK. They are not followed up by Consultants.

[N.B. This is why a Rehabilitation Prescription will not work. At the point of discharge an individual's full rehabilitation needs may not be fully known. This will then be sent to a GP, who knows very little about Acquired Brain Injury and its complex effects; and the benefits of neuro-rehabilitation or where to source and commission good rehabilitation services.]

6.2.2 Neurological deficits and dysfunction arising from acquired brain injury, probably has the biggest negative impact on a child's life and long-term future. Parents are not provided with the information they need to be able to care for their child both effectively and safely; without which they are unable to be strong advocate for the complex needs of their child.

6.2.3 About 90% of hospitalised head injuries are classified as 'mild' and from which a good recovery should be expected. **However, one of the most significant risk factors for having a head injury is already having sustained a head injury** (Nordström et al 2013) **and repeated head injury tends to have cumulative negative effects associated with long term functional deficits** (McKee et al 2009). Unfortunately, this information is not recorded by the NHS.

6.2.3 Families tell us:

- that NHS staff do not explain acquired brain injury to them very well and they are often left **not** knowing:
 - what part of the brain is injured;
 - how it will affect them;
 - how it links to child development problems; and
 - what that means for their child
 - The mechanism of the brain injury
- discharge letters contain very little detailed information for parents and are written more for other medical professionals, i.e. GP's; and not parents.
- parents often struggle to understand the terminology and context of the letters; as do other non-medical and education professionals. Many do not receive anything.
- they are concerned at the level of negativity often portrayed by medical professionals.
- NHS Clinicians often have limited ambitions for their recovery and Consultants do not investigate a child's pre-injury abilities; which are important pre-injury factors that can contribute to a positive recovery.
- the rehabilitation needs of children and young people are also much wider than current NHS provision. (i.e. physiotherapy, OT, SALT and Neuropsychology etc.). The ongoing sensory, physical, emotional, psychological, cognitive development of the child are equally important.
- parents are often left 'in limbo' and feeling their situation is hopeless and these feelings can have a significant impact on parent wellbeing and contribute to poorer long-term outcomes for the child as a result.
- There exists very little age appropriate neuro-rehabilitation therapy is provided by the NHS.
- Children and young people often complain that NHS professionals make everything too clinical and boring. Nor do the activities relate to their lives and the real world.
- Families do not receive a long-term neuro-rehabilitation plan. Community therapists work to

internally agreed plans with little or no involvement or consultation with parents.

- The approach is often very piecemeal, generic, have no recovery aims or goals. Parents are the key to good outcomes for children and young people; hence they should be included in this process. However; families tell us there exists a mindset of 'we are the professionals and you know nothing' approach.
- Nursing staff often do not understand or are not very knowledgeable about acquired brain injury and its complex effects to be able to support families effectively. As such this indicates that more awareness raising could be done both through under-graduate programmes at university and staff learning and development training within the NHS.
- Brain injured children and young people have the potential to regain lost skills and abilities with appropriate levels of neuro-rehabilitation therapy and support. (As shown in our Case Studies.) Old school thinking was that as children's brains were still developing and by being in the school environment, children would naturally regain lost skills and abilities. We all now know this to be untrue; hence the need for neuro-rehabilitation therapy and support.

6.2.4 These problems particularly affect people from disadvantaged areas as they experience higher risk and incidence of brain injury and demonstrate poorer rehabilitation outcomes (Lequerica and Krch, 2014).

6.3 Post Discharge

- Acquired brain injury is little understood across a range of community professionals. As no legislation exists to protect them, this disability is often unrecognised, and families are left unsupported.
- Children fail to meet their expected development milestones and inevitably fall behind their peers.
- New research is showing that the severity of the initial brain injury does not determine the severity of the effects; meaning a child with a perceived mild head injury may have suffered significant deficits as a result.
- There has been little or no investment in neuro-rehabilitation services for 25-30 years so NHS professionals are significantly lagging behind in approaches, knowledge and skills development. This has a significant impact on poor outcomes for both the adults and children that they treat.
- Children's disability needs are often misunderstood, and it is not uncommon for them to be referred to CAMHS where they are often misdiagnosed as having Autism or ADHD; or worse still do not have a diagnosis
- medical professionals agree there is a direct correlation between poverty, deprivation and paediatric brain injury; hence these families need more support. The higher the levels of deprivation; the higher the incidence of brain injury. (The Tees Valley has some of the highest levels of deprivation in the country.)
- Brain injured children are:
 - discharged with very little knowledge, help or support available to them in the community
 - not included in the Register of Disabled Children held by local authorities;
 - refused access to services from Children with Disabilities Teams
 - refused Education Health and Care Plans
 - punished and excluded by statutory bodies
 - not helped and supported to achieve good outcomes post brain injury
 - labelled as being 'naughty children'
 - excluded from school
 - don't receive a proper education
 - are not supported to recover or improve
- Subsequently, children and young people do not receive the help and support they need in their ongoing neuro-rehabilitation journey; which can last for many years post injury. They

therefore never reach their true potential.

6.4 CAHMS

6.4.1 It is wrong to label brain injured children as having mental health issues. Poor mental health may also be a consequence of brain injury due to the lack of understanding and support brain injured children receive. Simply treating the emerging mental health issue will not resolve the child's underlying deficits.

6.4.2 Families have also reported:

- negative experiences with the Child and Adolescent Mental Health Service (CAHMS). It seems that brain injured children are often automatically referred to CAHMS by GP's and Social Workers if they are any presenting with behavioural issues.
- However, CAMHS are not neuro-rehabilitation providers; they treat mental health issues. Nor do they understand acquired brain injury. Most of our children have been through the CAHMS process; sometimes more than once without a final diagnosis or any positive rehabilitation outcome being made for the child because the underlying problem has not been recognised and appropriate support measures put in place. Brain injured children and young people, should therefore not be referred to CAHMS, when they require neuro-rehabilitation therapy.
- Standardised psychological assessment of neurological functioning often do not correctly identify a child or young person's rehabilitation needs post brain injury as their results often fall within the 'normal' range when compare to every other average child.
- Additionally, the tests are undertaken in a quiet clinical environment to enable the child to achieve a good result; which skews the outcome to the child's detriment. Nor does the assessment examine or test – what has changed for the child post brain - so how can they ever hope to regain what they have lost?
- As such many brain injured children and young people are excluded from receiving additional support at school because they function 'above the threshold'. Thus, they are not effectively rehabilitated or supported at school; which eventually leaves them falling behind their peers or excluded for behavioural problems.

6.5 Families

6.5.1 Research says that ABI has a significant psychological impact on families; resulting in family breakdown, withdrawal from services, unemployment, depression and a loss of self, which in turn leads to poor rehabilitation outcomes (Hockney, 2015). When a traumatic brain injury occurs in a child or young person, it is not uncommon for a parent to experience symptoms of PTSD. These symptoms often go untreated and unsupported until things reach crisis point within the family unit.

6.5.2 However, parents are:

- refused carers assessment and access to carers breaks
- not provided with the important information they need at the point of discharge for hospital
- then punished by other community professionals for the behavioural problems of their neurologically impaired children

Local authorities therefore inadvertently discriminate against these children and their families; which contributes to the poor long-term outcomes for brain injured children.

6.5.3 Local authority processes expect parents to have the most in-depth knowledge about their child and they must make choices based on the needs of their child. How can they do this when:

- a) they don't understand what has happened inside their child's head; and
- b) problems and issues are yet to emerge or are still emerging?

Parents need to be provided with all the information by they need by NHS professionals to make informed choices and appropriate decisions for (and with) their child with people who understand.

6.5.4 Post discharge any disability needs in children and young people are managed by Disability Social Workers, who have no knowledge of acquired brain injury; the deficits it creates, the rehabilitation needs of children and young people; or where to refer them for help. As such they are referred for counselling as opposed to neuro-rehabilitation therapy, which would be of more benefit.

6.5.5 This leads to repeated assessments by the wrong clinicians. One of our children, has been assessed by **ten** different organisations and has had **fifteen** assessments by different professionals. This leaves families angry and frustrated which then impacts on their own wellbeing and exacerbates family pressure.

6.6 Disability Living Allowance

6.6.1 Brain injured children are eligible for DLA depending on the changes that have occurred as a result of their brain injury. Child brain injury is classed as a disability for benefit purposes. Some of our children are in receipt of DLA, other families do not even know that they are eligible to claim it, despite their child having significant neurological deficits that are impacting on their normal child development milestones.

6.7 Local authority staff

6.7.1 Conversely, brain injured children are not recognised by local authority staff as having a disability. A child diagnosed with Autism, learning disability, ADHD or Dyslexia is, as is a child with a physical disability. Brain injury has a significant impact on a child's life, and disability now comes in many forms. Neurological disabilities, such as acquired brain injury, are no less important and have a greater impact on physical and neurological functioning. Paediatric acquired brain injury should now be acknowledged and recognised and prioritised due to its prevalence.

6.7.2 From our review of local authority strategies (Tees Valley), we have learned that childhood acquired brain injury and its associated pressure on parent carer health and wellbeing remains unacknowledged anywhere! Brain injured children and their families therefore consistently suffer discrimination and health inequalities.

6.7.3 Parents tell us they have been threatened with being fined - or worse still - arrested or having their child taken into care, because of the behaviours of their neurologically impaired child. Parents frequently tell us they are not listened to or believed by community professionals because often there is no recognisable disability.

6.8 Brain injury and Schools

6.8.1 Families say it is the cognitive, emotional and behavioural issues that cause the biggest disruption to family life. They are also the biggest issues that affect a child's successful integration/reintegration into school as well as their academic outcomes. Unfortunately, a lack of understanding in schools means brain injured children are often excluded from school and as a result; are punished again. Some of our brain injured children have not been in education for up to three years. This would constitute disability discrimination under the Equality Act.

6.8.2 Generally, where additional support needs are identified, a child works with SEN support staff. However they do not understand acquired brain injury and its complex effects; are not neuro-rehabilitation trained; nor do they have the skills of knowledge to support children and young people in their recovery. We are now receiving referral from Job Centre Plus to deliver neuro-rehabilitation support to young adults. As brain injured children their rehabilitation needs have gone unrecognised. Whilst they have received SEN support

at school, this has not alleviated or helped any of their neurological impairments; thus, these young people did not do well in their GCSE's and are now unable to either maintain or gain secure employment.

6.9 Brain injury and the criminal justice system

- 6.9.1 An acquired brain injury to create significant deficits in physical, communication, cognitive, emotional and behavioural aspects of neurological functioning. All factors are essential for successful integration into society. It is so easy for brain injured children and young people to fall into the criminal justice system where they display significant emotional and behavioural problems; which are sometimes significantly exacerbated by frustration on their part; and a lack of understanding on the part of others; particularly the police.
- 6.9.2 Impairments in cognitive functions (such as memory and solving problems) and in personality or emotional control (such as impulsivity, aggression, intolerance and lack of concern for others) are common after severe brain injury and are associated with neuro-behavioural changes that can easily lead to rule breaking. As persisting outward signs of brain injury are rare, antisocial behaviour is often not attributed to the brain injury, and appropriate interventions that may reduce repetition are not offered, or the ability to benefit from prison treatments that address offending behaviour is compromised.

7.0 Implications

- 7.1 The implications of not acting with regards to brain injury in adults and children will ensure the difficulties and discrimination these children and their families receive, will continue. They are both significant and costly to society and could be at the root of many of the UK's health and socio-economic problems. Whilst rehabilitation services may initially be costly at the outset, it will bring about significant long-term cost savings for the public purse across a range of sectors.
- 7.2 However, without legislation to protect brain injured children and their families, they will continue to face prejudice and discrimination and a lack of access to services, help and support to enable them to have better long-term outcomes. In turn this will continue to erode and exacerbate the UK's social and economic problems.
- 7.3 Continued lack of recognition of the needs of brain injured children, young people and adults, may leave public services open to legal challenge for discriminatory practice.

8.0 Solutions

- 8.1 It is the responsibility of public leaders and adult medical and other community professionals to keep up to date with emerging developmental problems in children and young people arising from an acquired brain injury; due to its high incidence and significance on a child's developing brain.

National Level

- 8.2 Many of the problems listed can be resolved through the creation of an Acquired Brain injury Act to provide protective legislation.
- 8.3 A cross sector, Rehabilitation Service Pathway should be created, supported by pooled budgets across the Departments of Health, Education and Social Care to provide neuro-rehabilitation for the needs of adults and children. This could also come under the remit of Public Health; rather than Mental Health Services. Rehabilitation should be aspirational, goals directed and include more than the 'usual' NHS led, clinically focussed therapies. i.e. physiotherapy, Activities of Daily Living, speech and language therapy etc. These

services have a long way to go in terms of outcome focused, innovative practice to enable brain injured people to function effectively in a modern technological world.

- 8.4 The government should create a national campaign to raise awareness of acquired brain injury to:
- help raise awareness of brain injury and the difficulties experienced by brain injured people;
 - the prevalence of brain injury as a hidden disability; and
 - disassociated brain injury from 'mental health' issues but link it to stroke for example.
- 8.5 Brain injured children and young people need access to high quality, frequent long-term neuro-rehabilitation therapy and support to enable them to achieve their full potential. This cannot be delivered through hospital based, clinically focussed, limited appointments that bear no relevance to a patient's real-life experiences. Changing how rehabilitation support is delivered and the intensity, may prevent the development of mental health problems in the future; thus, negate the current need for a referral to CAMHS. In the longer term this may facilitate better life chances in the future.
- 8.6 That **all** the ongoing neuro-rehabilitation and support needs of children and young people are considered across all domains; not just their physiotherapy, SALT and OT needs. Families will tell you that to function effectively in a modern connected world, purely focussing brain injury rehabilitation on the activities of daily living and the use of a Rehabilitation Prescription, whilst helpful to some; is simply not enough for the long-term futures of our children and young people!
- 8.7 That systems are implemented in A&E departments to record the number of head injuries children have sustained and flag up to paediatricians where more than one head injury has been sustained in children. These children should be red-flagged and closely monitored across all agencies.

Regional /Sub Regional Level

- 8.8 That the incidence of paediatric acquired brain injury is significant enough to be prioritised in the Joint Strategic Needs Assessment of all local authorities, so they can plan for the current and future health and well-being needs of local neurologically impaired children, young people and their families, and to inform the commissioning of health, wellbeing and social care services. This currently does not happen.
- 8.9 That children and young people who are living with an acquired brain injury should be included on the Register of Disabled Children to help to remove the discrimination they currently face.
- 8.10 That children and young people living with an acquired brain injury are recognised and be automatically accepted for an EHC Plan accordingly to recognise and provide for their rehabilitation needs.
- 8.11 That the parent carers of brain injured children are better informed by paediatricians and provided with the information they need in discharge letters to enable parents to properly care for their child; be aware of the potential risks; and make informed decisions in the community based on their child's needs. This information will also assist community professionals to recommend and commission the most appropriate service for children and young people.
- 8.12 Parents often ask us why it is so hard to get a medical diagnosis for their child's problems and why nobody listens or wants to help their child. We all struggle to understand why the needs of a child with Autism or ADHD take precedence over a sudden life-changing traumatic event that has occurred to a previously normal healthy child that is now living with an acquired brain injury? Parents should be included, listened

to, not judged and supported effectively through the provision of appropriate funding and access to Carers Support Services.

- 8.13 Specialist support should be provided to support parents to apply for DLA/PIP applications before the child or young person is discharged from hospital. Generic community-based advocacy staff do not possess the knowledge or questioning skills to complete these forms correctly, thus claimants do not receive the correct allowances.
- 8.14 DLA/PIP applications and Carers Assessment should also be completed for parents prior to discharge.
- 8.15 That Police, and other public bodies who question children and young people are made aware of the complex effects of acquired brain injury and the deficits it creates to children's neurological functioning (physical, cognitive, communication, emotional and behavioural) and its potential to impact on mental capacity. A shared database would help to provide this information in a confidential manner. Children should not have to carry a card to advertise their disability. It exposes their vulnerability and leaves them open to exploitation.

Author: Jan Rock
Founder and Chair
Date: MAY 2019

For and on behalf of the children and families working with:

MATRIX Neurological
TAD Centre
Ormesby Road
Middlesbrough
TS3 7SF

Appendices:

- A Case Studies
- B Enough: The Inexcusable Treatment of Brain Injured Children and young People in the UK Report.

