



Life After Brain Injury A Way Forward

Manifesto for Children and Young People
with Acquired Brain Injury

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Overview

- Acquired Brain Injury (ABI) in children and young people should be considered a chronic health condition with associated ongoing symptoms. It must be managed early to avoid long-term disability and to ensure rehabilitation is at its most effective, but also monitored long-term for problems arising post-injury
- Current care planning and service provision is inadequate; it must be patient-centred, managed by an interdisciplinary team, taking into consideration the physical, social, communication, cognitive, behavioural and environmental issues which may impact on the outcomes for children. It also needs to include the families as they have a pivotal role in managing the recovery of their child
- Education services play a crucial role in the care pathway for children and young people with ABI. Training is required, in particular for education professionals e.g.: head teachers, Special Educational Needs Co-ordinators (SENCOs) and educational psychologists, to raise general awareness of ABI
- Practical and easy access to information is required for children and young people, their families and all professionals involved in their care and support

To improve the lives of children and young people with ABI in the UK, those affected, their families and carers and the professionals working in this field are asking for the following:

- A National Audit of brain injury incidence and rehabilitation to collect and report accurate data on newly-acquired brain injuries from the acute to community services
- Record ABI (mild, moderate and severe) in the Personal Child Health Record and ensure long-term monitoring goals
- Facilitate the adoption of an ABI tool kit in the training programme for SENCOs
- The information available is signposted from an established website for use by healthcare professionals, social workers, education personnel, as well as families and carers

Introduction

Acquired brain injury (ABI) is a leading cause of death and disability in children and young people around the world (WHO 2009).

There is a general lack of understanding of the effects of ABI in this population, and a lack of awareness that over time, ABI in children and young people is a ‘developing disability’.

The needs of children and young people affected by ABI will differ substantially depending on the nature and severity of the injury and its consequences, but also on their goals and outcomes. The longer term consequences of the brain injury may also be affected by the stage of brain development taking place at the time of the injury.

This Manifesto outlines the need for acute and early access to rehabilitation for children and young people with ABI. This is a chronic condition and should be monitored long-term with the necessary care planning and service provision in place to address the physical, social, communication, cognitive, behavioural and environmental issues that may occur, together with support for the family as they play a key role in the child’s recovery. Training is required for all professionals especially those involved with education services. Practical information should be easily accessible to all professionals, the children and young people and their families.



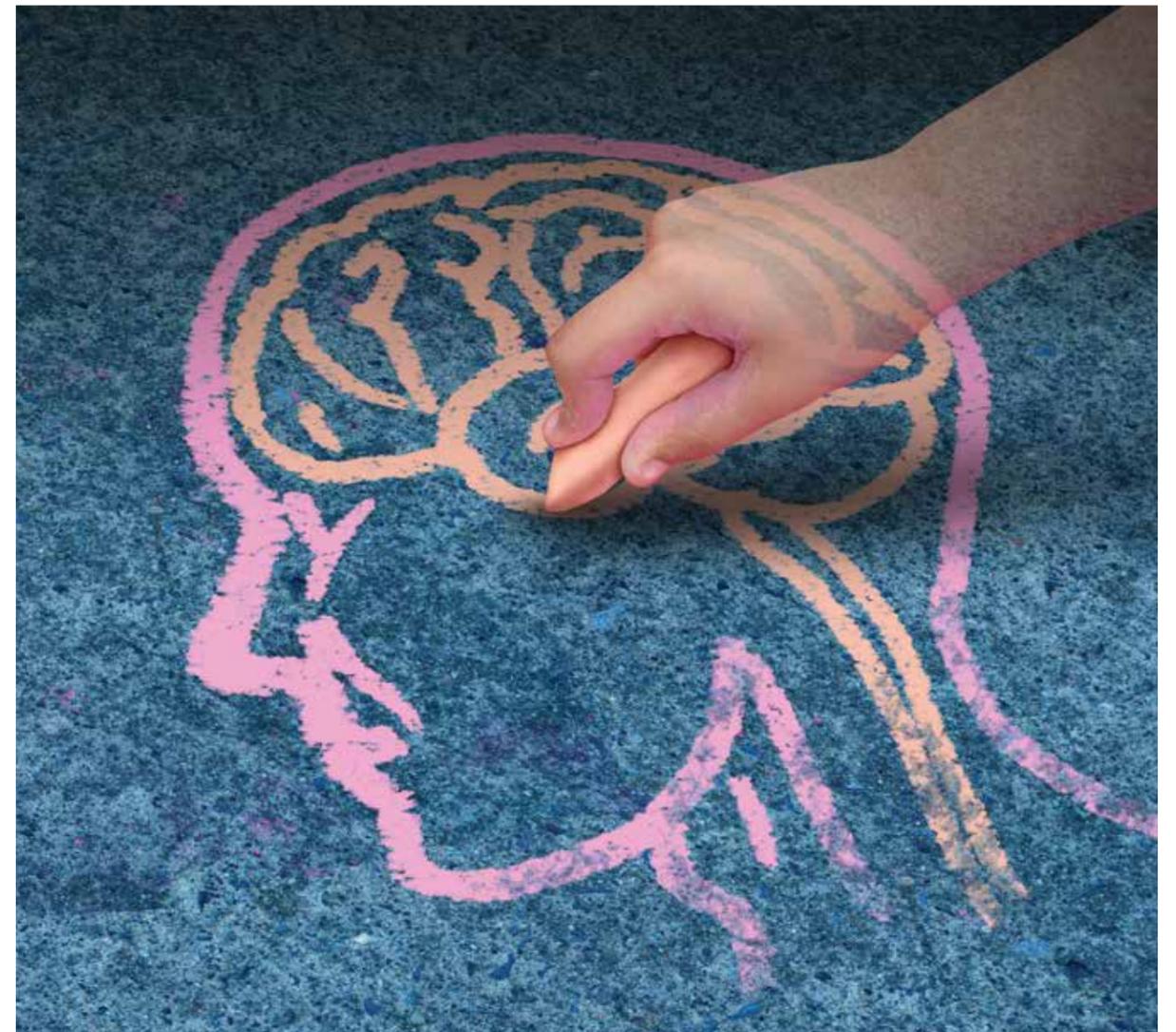
The United Kingdom Acquired Brain Injury Forum (UKABIF) is campaigning for greater awareness and understanding of ABI in children and young people amongst health, education, social care and criminal justice system professionals and families. The Manifesto makes its recommendations as a way forward to give these children and young people every chance of maximising their opportunities in later life.

UKABIF has worked with many individuals and organisations to develop this document and has endeavoured to encompass all viewpoints.

Acquired Brain Injury

Acquired brain injury (ABI) is non-degenerative injury to the brain that has occurred after birth. It includes traumatic brain injuries (TBIs) such as those caused by road traffic accidents and non-TBIs, such as those caused by strokes and other vascular accidents, tumours and also infectious diseases.

Road traffic accidents are the most common cause of ABI in older children and adolescents, whilst falls, being dropped or non-accidental injuries are more common in younger children and infants (Hawley 2002).



The Developing Brain

The brains of children, adolescents and young adults are not static; they develop in leaps and spurts throughout childhood and well into their mid-twenties (Savage 1999).

Post-brain injury outcomes are difficult to quantify and predict because the brain of a child/young person is undergoing dynamic development changes.

The impact of an ABI and the subsequent functional consequences are affected by the individual's age and developmental stage at the time of the injury (Anderson 2009, 2010). An important phase of brain maturation occurs in the child's early years (birth – five years of age) so an ABI before the age of five years may have devastating consequences because the injury occurred at a peak time in neurological maturation. Children with mild, moderate and severe ABI are at risk of developing cognitive, emotional and behavioural impairments as the young person gets older and grows into their adult years (Andrews 1998, Klonoff 1993). The adolescent years are also an important stage in brain development.

Conventional thinking suggested that the child's brain was resilient to trauma because it was much more 'plastic' than the adult brain and other parts of the brain would take over for the damaged parts. Neuroplasticity may enable individuals to recover better from focal injuries i.e. those occurring as a result of strokes and aneurysms, however, Savage (1999) reports that it most likely does not apply to more complicated brain injuries such as diffuse brain injuries, shearing injuries and injuries to multiple brain regions e.g. frontal-temporal injuries.

Young people who have severe brain injuries may also be at risk of manifesting a 'neuro-cognitive stall' during a second phase of brain recovery which was defined by Chapman (2007) as a halting or slowing beyond a year post-injury of cognition, social and motor development. So, despite a sometimes remarkable recovery during the first year post-injury, young people appear to 'hit a wall' or plateau and not meet later developmental milestones. In addition, this neuro-cognitive stall may emerge despite the individual seeming to have recovered cognitive abilities commensurate with their pre-injury level.

Epidemiology

The epidemiology of ABI is difficult to describe accurately due to inconsistencies in definitions and classifications, together with data collection discrepancies and inadequate reporting.

The prevalence rates of ABI in childhood are very high. NICE (2007) reported that each year in England around 200,000 under-15s attend Accident and Emergency departments with head injuries (TBIs). Most TBIs are minor but 1 in 10 are moderate to severe. The Child Accident Prevention Trust stated that in 2010/11 around 36,500 children under 14 years of age in England were admitted to hospital with head injuries.

According to NHS England, the incidence of hospitalisation for TBI in England has been reported as ranging from 280-500 per 100,000 children aged under 16 years, implying that the total number of children admitted to hospital is at least 35,000. Of these 2,000 will have sustained severe TBI, 3,000 moderate TBI and 30,000 mild TBI. Reports suggest that approximately 3,000 children acquire a significant new neurological or cognitive disability as a result of ABI every year (Sharples 1998).

Classification

ABI is classified as mild, moderate and severe. The Glasgow Coma Scale (GCS) is one of the most commonly used systems for classifying TBI severity and grades a person's level of consciousness on a scale of 3–15 based on verbal, motor and eye-opening reactions to stimuli. The GCS is likely to underestimate morbidity in children and is not always readily applicable in this group. Adaptations of the GCS include the King's Outcome Scale for Childhood Head Injury and the Neurologic Outcome Scale for Infants and Children, but they also have their limitations with different age groups.

Consequences

ABI is often referred to as a 'hidden disability' because sometimes no, or little physical evidence of the injury is apparent and many impairments are not visible. However, in children and young people, it is also crucially a 'developing disability' and the effects can be more difficult to identify at certain stages of childhood.

The consequences of brain injury in children and young people include loss of memory, loss of concentration, decreased awareness of one's own or others emotional state, poor impulse control and particularly poor social judgment. It is also associated with greater mental health problems, higher rates of depression or mood disorder and/or childhood developmental disorders including Attention Deficit Hyperactivity Disorder or disruptive behaviour difficulties. Behavioural problems such as conduct disorder, attention problems, increased aggression and impulse control problems are prevalent.





Long-term effects of ABI

- Impaired memory
- Reduced concentration and attention capacity
- Disorders of the executive system e.g. poor initiation and planning, lack of self-monitoring, poor judgment and poor impulse control
- Decreased awareness of one's own or others emotional state
- Sleep disturbances
- Mental health problems
- Impaired social and communication skills
- Motor and sensory impairments
- Further medical conditions e.g. post-traumatic epilepsy, hormonal disturbances

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Behavioural problems

Conduct disorder

Attention problems

Increased aggression

Impulse control problems

Cognitive problems and educational underachievement

Social/relationship difficulties

There is growing evidence of links between incurring a TBI in childhood and young adulthood and offending behaviour.

The study 'Self-Reported Traumatic Head Injury in Male Young Offenders', published in October 2010, highlighted the fact that 46% of young male offenders had a TBI, a significantly higher prevalence than that expected in society as a whole (Williams 2012). TBI may be linked to earlier and more frequent custodial sentences and more violent offending. The Criminal Justice and Acquired Brain Injury Interest Group was formed in 2011 to raise awareness and the means for addressing brain injury throughout the criminal justice process.

Impact on the Child

As a child recovers from the initial stages of ABI, and depending on which regions of the brain are injured, longer term effects may become apparent e.g. cognitive, behavioural or emotional, or mental functioning. For example pre-school children with injuries to the frontal-temporal regions of their brains may look 'medically fine' within a few weeks or months after injury (e.g., they can walk, talk, eat, sleep); however, as they get older and their brains mature, new cognitive, behavioural and motor deficits can emerge. Often the cognitive, behavioural and personality deficits, rather than the physical deficits, produce the greatest disruption to quality of life, and the extent of these impairments may only become apparent longer term.

Children who sustain an ABI have little prior knowledge and/or prior life experiences to draw upon to support their recovery, especially cognitive and behavioural functioning, and therefore have specific requirements in order to help them develop compensatory strategies.

Impact on the Young Person/Adolescent

Young people or adolescents are in a state of continuing development and have particular needs not shared by children or adults. Challenging the 'status quo' is an appropriate developmental phase in this group and they may be more impulsive and experience greater mood swings. However, it may be difficult to distinguish between these everyday behaviours and the effects of an ABI.

The specific needs of young people are frequently overlooked as their growing independence and increasing adult behaviour does not 'fit' with either the paediatric rehabilitation service, or the adult service which acknowledges patient autonomy but neglects development and family concerns.

Impact on the Family

ABI affects the entire family with both short-term and long-term effects. Family functioning can deteriorate with psychological distress and depression a key issue, particularly in mothers (Jordan and Linden 2013).

Short and Long-term impact on the family of having a child with ABI

Short-term	Long-term
Panic	Parental burden
Fear	Psychological distress
Shock	Deterioration in family relationships
Denial	Money issues
Anger	Coping ability
Guilt	Marital breakdown

People can perceive a stigma associated with brain injury and the subsequent disabilities; parents and families may find it difficult to be told that their child has a brain injury and this can divert attention away from long-term outcome monitoring.

Many children with mild ABI are increasingly told that they have concussion; this label is used because it is less alarming and more palatable to parents than the term mild brain injury, implying that the injury is transient with no significant long-term health consequences (DeMatteo 2010) and so long-term monitoring is less likely to occur.

It is important to understand the family dynamics and work with them; the family can play an extremely positive role in the child's rehabilitation process if they are adequately supported.



Rehabilitation

Rehabilitation is a process of diagnosis, assessment, acute and long-term management of people with complex disabilities. The individual is supported to achieve their maximum potential for physical, cognitive, social and psychological function, participation in society and quality of living. It is a goal-focussed learning process to optimise functional recovery, disability management and adaptation to loss and change. The patient goals for rehabilitation will vary according to the trajectory and stage of their condition (Turner-Stokes 2008, 2011).

Specialist neurorehabilitation is the total active care of patients with a disabling condition and their families, by an interdisciplinary team who have undergone recognised specialist training in neurological rehabilitation, supported by a consultant trained and accredited in neurorehabilitation medicine.

The Interdisciplinary Team

Early intervention and rehabilitation are key involving an interdisciplinary team appropriate to the age and needs of the individual. Integrated services and an interdisciplinary rehabilitation programme promote brain recovery and facilitate a faster recovery (Turner-Stokes et al 2011). Service provision in the post-acute stage depends on the underlying cause of the condition, complexity, severity and age of the individual. The composition of the team may vary but could include medical and surgical professionals, nurses, allied health professionals, clinical psychologists, social workers, neuropsychiatrists and the involvement of other agencies such as the voluntary sector, training and education.

Rehabilitation Requirements

The rehabilitation requirements will depend on the ABI classification. Children with severe ABI need acute and early access to rehabilitation services in hospital. This will include specialist inpatient care and intensive rehabilitation which may involve placement within a residential rehabilitation setting. They will then be discharged for community rehabilitation where they can develop the appropriate skills to adjust to the changes resulting from the injury, maximise independent daily living skills and participate fully in society. Mild to moderate brain injury may not result in inpatient treatment or short-term rehabilitation and these children are not currently monitored long-term.

Some types of interventions may be required for all forms of ABI in children such as neuropsychological intervention, environment modification, psycho-educational, family-based interventions and medication.

Types of intervention for children with ABI

- Neuropsychological
- Environment modification
- Psycho-educational
- Family-based
- Medication
- Educational differentiation for the child
- Occupational therapy
- Physiotherapy
- Speech and language therapy

Transition

Transition for young people with on-going health needs is defined as the 'purposeful and planned movement of adolescents and young adults with chronic physical and mental conditions from child-centred to adult-orientated healthcare systems' (Blum 1993). Transition is a process not an event; legally it can occur between 16 and 19 years of age, in social and educational terms it occurs at 18 years of age.

The timing of transition should depend on the developmental readiness of the young person, as well as the capabilities of adult providers to provide the required on-going services. Transition needs to be planned with the young person and their family at the centre of the decision-making process and information hub, with adequate time allowed for the process to take place.

Currently service provision for managing this transition process for young people with ABI is inadequate. The consequences of not undertaking transition, or not managing the transition properly, results in a range of negative outcomes for the young person, including dropping out of the system altogether and a resulting lack of care continuity (Kennedy 2007).

Service Provision

In comparison to acute medical treatment which is well-established, long-term service provision following discharge from hospital remains underdeveloped, not only for children and young people with ABI but also for their families.

The lack of service provision was highlighted by Cerebra, the charity for children with neurological problems, in a report published in 2010. The report detailed a lack of knowledge and understanding of the consequences and support services available, a lack of post-rehabilitation services specifically for children, services that are time-limited and children that were returning to education without psychological assessment or clinical input and teachers unaware of their injuries. The report also highlighted the lack of accessible information about ABI for everyone involved with the child including family, teachers and social services.

Unmet needs (Cerebra 2010)

- Lack of knowledge and understanding of the consequences and support services available
- Lack of post-rehabilitation services specifically for children
- Rehabilitation services are often time-limited
- Children often return to school without a psychological assessment or clinical input and have teachers who are unaware of their injuries
- Lack of local specialised support and geographical limitations
- Lack of accessible information about ABI

Cerebra highlighted the lack of specialist support: therapists need to be trained to recognise the 'interrupted' development that occurs in these children rather than the more widely understood 'developmental' delay.

The International Paediatric Brain Injury Society (IPBIS) produced Good Practice Recommendations following a workshop at the 23rd Annual Meeting of the European Academy of Childhood Disability in 2011.

The recommendations included the need for the education of healthcare and teaching professionals about on-going and often late onset problems, with case managers required to support children and their families across environments and through developmental stages. The IPBIS concluded that information sharing and liaison across all disciplines was a key requisite.

NHS England has produced a service specification for paediatric neurorehabilitation acknowledging the effectiveness and cost-benefits, especially when the relevant practitioners work together as a part of a coordinated interdisciplinary team towards a common set of goals. It states that early access to neurorehabilitation is crucial for those with sustained severe injury and some cases of moderate injury. There are also considerable limitations in the service provision with regard to school support services. Schools, which have been said to be the largest provider of services to children with ABI (Savage 1988, Ylvisaker 1991), are the primary service in children's lives.

As such they are hugely important in intervening and adjusting for potential cognitive and emotional and behavioural needs. Education services play a crucial role in any pathway for a child with ABI but there are issues regarding communication between health and social care services and schools, accessing the appropriate support, raising staff awareness and skill levels. Information regarding ABI should be included in compulsory training for Special Educational Needs Coordinators (SENCOs).

Children and young people with ABI require a joined-up approach to rehabilitation involving health, social and education services. The newly formed Health and WellBeing Boards can play a key role in ensuring changes to ABI service provision capture this approach.

Information Requirements

All healthcare professionals, teaching professionals, social workers and those with ABI and their families need to know where to access good quality, practical and appropriate information regarding ABI and local support services. The information needs to be tailored towards these different target groups and it is important that appropriate information is received at the right time.

Many third sector organisations provide excellent information and support for patients and families. In the case of brain injury these include amongst others The Brain and Spine Foundation, The Child Brain Injury Trust, The Children's Trust, The Encephalitis Society, Headway and The Meningitis Trust.



Case Study: David's Story

This case study illustrates the impact of ABI on the young person and on family members. David's close family were in need of support for themselves in order to be able to support him and ensure a positive outcome for all concerned.



At the age of 14 years David had a severe TBI following a road traffic accident which his younger brother, mother and father all witnessed. David was in hospital for six months including three in a coma. Following discharge from hospital David had a poor reintegration into school, suffered frequent aggressive outbursts and had significant cognitive changes including a weak memory. His fatigue levels were high, mood was flat, friendships decreased and he became bored and lonely. At the same time his family were not talking to one another, leading separate lives in the same house and all felt unbearable sadness and grief. His mother had severe depression and anxiety and together with her husband and David's brother, they all had symptoms of post-traumatic stress disorder (PTSD). There was no tolerance for David's behaviour and consequently the family felt high levels of psychological distress, stress and burden.

Recolo put a rehabilitation plan in place for David and his family with interventions tailored to both. For example David had individual support to improve his mental health, aggressive behaviour, mood, social functioning and daily routine. There was systemic intervention at a family level including shared narrative of events, brain injury education, enhanced coping, problem solving and communication in the family.

Over time David's behaviour improved and he returned to school, became less tired and his overall quality of life improved. Both parents returned to work and the family is now able to talk about the accident and their PTSD has reduced. The family also now has more realistic expectations of their son and a general acceptance of the rehabilitation programme.

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