

# **PAEDIATRIC ACQUIRED BRAIN INJURY A GLOBAL CHALLENGE**

Produced by the International Paediatric Brain Injury Society  
in collaboration with The Eden Dora Trust

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## **INTRODUCTION**

## **EXECUTIVE SUMMARY**

## **BRAIN DEVELOPMENT OVERVIEW**

## **ACQUIRED BRAIN INJURY**

**Classification**

**Prevalence**

**Causes**

## **PREDICTORS OF TRAUMATIC BRAIN INJURY**

**Gender**

**Age**

**Societal**

## **CONSEQUENCES OF ACQUIRED BRAIN INJURY**

**Impact on the child**

**Impact on the young person**

**Impact on the family**

**Long-term impact**

**Quality of life**

## **ECONOMIC BURDEN**

## **MANAGEMENT OVERVIEW**

**Guidelines**

## **SUMMARY**

## **REFERENCES**

## INTRODUCTION

***This report is produced by the International Paediatric Brain Injury Society (IPBIS), in collaboration with The Eden Dora Trust, to gain global recognition of Acquired Brain Injury (ABI) in children, adolescents and young adults, to highlight the challenges faced by individuals with brain injury, their families and the professionals responsible for supporting them, and to outline recommendations to steer a way forwards to maximise outcomes.***

Acquired Brain Injury (ABI) is any injury to the brain which has occurred following birth (Teasdale 2007). It includes Traumatic Brain Injuries (TBIs) such as those caused by trauma (e.g. a blow to the head from a road traffic accident, fall or assault), and non-TBIs related to illness or medical conditions (e.g. encephalitis, meningitis, stroke, substance abuse, brain tumour and hypoxia). The resultant damage to the brain can cause physical, cognitive, academic and psychosocial effects which may be temporary or permanent. ABI commonly leads to neurocognitive deficits which interfere with executive function, skill acquisition, adaptive deficits and academic failure (Anderson et al 2009, Jaffe et al 1993). The psychological issues arising from an ABI can affect interpersonal relationships and contribute to poor community, social and vocational integration, as well being a personal and economic burden for the family and community (Benz et al 1999, McKinlay et al 2002).

There is a paucity of information about ABI due to inconsistencies in definition and classification, data collection discrepancies and inadequate reporting. Consequently the figures for ABI, if available, present an underestimate of the global situation. Many of the children, adolescents and young adults with ABI will have life-long disabilities, so an accurate understanding of the numbers affected is vital for the planning of coordinated care and long-term management.

Incidence data for non-TBIs relates to the illness or medical condition; the long-term disability from any resultant brain injury is rarely documented. Most available data documents the incidence of TBI. Worldwide, TBI is the main cause of death and disability in children (Sergui-Gomez and MacKenzie 2003). The burden of TBI is prominent in low and middle income countries where there is a higher preponderance of risk factors for the causes of TBI, and inadequately prepared health systems to address the associated health outcomes.

There is a general lack of understanding of the effects of ABI in children, adolescents and young adults, and a lack of awareness that, over time, problems occur post-injury. The needs of these individuals will differ substantially depending on the nature and severity of the brain injury and its outcomes. Current care programmes and service provision for ABI are often non-existent or inadequate. There is a limited availability of guidelines that focus on children, adolescents and young adults with ABI. Some guidelines are available on a national and local level, but they tend to

focus on the acute phase of care and do not include post-discharge, long-term rehabilitation, the academic implications, transition and life-long management or encompass the crucial role of families.

The challenges presented by ABI need to be addressed. The detrimental impact of ABI will continue to increase and society is largely unaware of the magnitude of this 'silent epidemic'. The burden of mortality and morbidity that this chronic condition imposes on society worldwide makes ABI a pressing public health and medical problem that has significant, long-term, global economic consequences.

## EXECUTIVE SUMMARY

- Acquired Brain Injury is a major cause of morbidity and mortality worldwide; there are long-term economic and healthcare costs which impact on health policies and practices. An accurate understanding of the numbers of children, adolescents and young adults affected by Acquired Brain Injury is essential for healthcare planning, long-term management and optimising recovery
- Acquired Brain Injury in children, adolescents and young adults should be considered a chronic health condition with associated ongoing, often life-long symptoms. It must be managed early to prevent long-term disability, promote recovery, ensure rehabilitation is at its most effective and monitored long-term for problems arising post-injury
- Acquired Brain Injury is endemic in offender populations and contributes to criminal behaviour
- Acquired Brain Injury has a major detrimental impact on the physical, cognitive, academic and psychosocial domains; it carries a substantial burden for family and carers
- Current care programmes and service provision for children, adolescents and young adults with Acquired Brain Injury are either non-existent or frequently inadequate. Care programmes must be patient-focused, coordinated, involve a trained interdisciplinary team, take into consideration the physical, cognitive, academic and psychosocial domains, as well as the environmental issues which may impact on the outcomes. They must include families at every stage of the patient journey as they have a pivotal role in managing their child's recovery
- International guidelines and improved service provision are required to optimise recovery and facilitate life-long care. Where best practice does exist it needs to be shared and implemented nationally and globally

## **BRAIN DEVELOPMENT OVERVIEW**

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). The brain evolves rapidly during early childhood and the first two decades of life, and the developmental stages are crucial in the context of the timing of a brain injury.

Neurons migrate, differentiate, and build up synaptic strength in the first three years of life. The brain becomes constantly sculpted, a critical process known as cortical pruning, and the strength of the connections in a child's brain become increasingly myelinated (Brouwer et al 2012). Throughout childhood and adolescence there are peaks in brain development – at age three years, eight years, 11 through to 15 years, and even later at 19 years (Savage 1999). These 'peaks' are a minor indication of the complex underlying changes that are occurring in the brain and their related cognitive and emotional functions.

The frontal system begins to assume control over socio-emotional and purposeful behaviour from three to four years of age. From around seven to 11 years of age there is acceleration in the brain, with the ability to link behaviour and its consequences, and the development of language skills that allow logical deduction and more abstract thought (Savage 1999). As a result of these cognitive changes, a child has the ability to resist distraction by about age six years, and control impulses by ten years of age. These abilities continue to evolve during early adolescence, with planning and dual attention improving with age (Anderson 2009).

During late childhood and adolescence, there is a lack of synchrony in the development of two of the critical brain systems that enable fully adaptive behaviour. The 'rational' cognitive system, which allows for understanding a problem and arriving at a solution, appears to be well formed at age 16 years (Steinberg 2008). This seems to be in step with the maturation of frontal cortex, and on testing, a child may give appropriate, adult-like, answers (Williams 2012). However, the system for the effective use of information, in terms of balancing the long-term consequences with immediate social and emotional concerns, does not develop in synchrony with such rationality (Steinberg 2008). Adolescents and young adults become poorer at responding to problem-solving tasks when the complexity of emotion is added (Steinberg 2008). The 'gap' between reason and emotion is exacerbated by an underlying susceptibility for responding to immediate rewards that emerges early in adolescence. In the 'teenage brain' there is a surge of an infusion of reward-oriented neurotransmitters (dopaminergic activity) and an associated increase in reward-seeking behaviour (Williams 2012). It appears, therefore, that mesolimbic area, the brain system related to rewards, is developing rapidly, relative to the other systems (Williams 2012). The dorso-lateral prefrontal cortex is responsible for high level thinking such as impulse control and making judgments about the longer term, and

the lateral- prefrontal cortex only reaches adult levels of 'cortical thickness' in the late teenage years (Lenroot et al 2006).

The effects and consequences of a brain injury are therefore determined by the neuro-developmental stage of the child, adolescent or young adult. Ewing-Cobbs and colleagues (2003) have proposed that recovery from severe brain injury may be also limited to the skills that were already established at the time of injury. Furthermore, the recovery of previously acquired skills may not necessarily ensure continued development of new and later emerging skills, or skills in a rapid state of development at the time of injury (Savage 2015). Also, young people, unlike adults, have limited cognitive reserve, so children who sustain a brain injury have little prior knowledge and/or prior life experiences to draw upon to support their recovery, especially cognitive and behavioural functioning, and develop compensatory strategies. All interventions including physical, cognitive, academic and psychosocial must reflect the developmental stage of the child or young adult.

## **ACQUIRED BRAIN INJURY**

### **Classification**

TBI ranges from mild, where there is a brief change in mental state or consciousness, to severe, where there is an extended period of unconsciousness or amnesia after the injury. TBI can be assessed using the Glasgow Coma Scale (GCS) which comprises the sum score of the values from three components: eye-opening reactions to stimuli, motor, and verbal scales. A GCS 15–13 is classified as mild, GCS 13-9 is moderate and GCS < 8 is severe. However, factors such as hypoxia, hypotension, and alcohol intoxication can all affect GCS, leading to diagnostic confusion. 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 limitations dependent on different age groups.

The majority of brain injuries among children, between 80-90%, are classified as mild (Hawley et al 2003, McKinlay et al 2008). If they are hospitalised, the time in hospital is usually brief (Koepsell et al 2001). However, a significant number of children experience moderate to severe injuries and the latter are generally associated with Road Traffic Incidents (RTIs).

Non-TBIs are not classified in this way as they vary due to the type of illness or condition.

## **Prevalence**

Data recording non-TBIs documents the incidence or prevalence of the illness or medical condition and this is not necessarily an accurate indication of the resultant brain injury and disability.

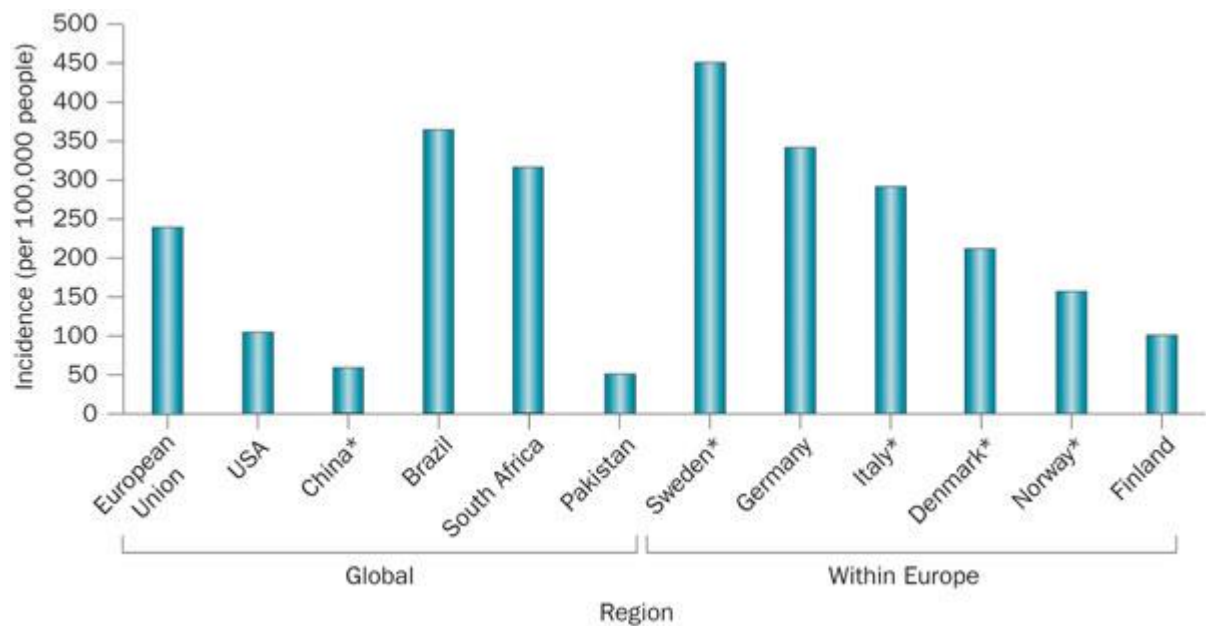
TBI is the leading cause of death and disability in children (Sergui-Gomez and MacKenzie 2003). It is predicted that TBI will surpass many diseases as the major cause of death and disability by the year 2020 (Hyder et al 2007). TBI is an urgent public health and medical issue with an estimated 10 million people annually affected, with the resultant mortality and morbidity burden. The burden is manifest in the developing countries due to the higher incidence of risk factors for the causes of TBI, and the inadequately prepared health systems to address the associated health outcomes.

Much of the data includes adults and is not specific to children, adolescents and young adults. However, in the USA it is estimated that around 5.3 million children are living with a TBI-related disability (Langlois et al 2005). In the European Union approximately 7.7 million people (adults included) who have experienced a TBI have disabilities (Tagliaferri et al 2006). Latin America and Sub Saharan Africa have a TBI incidence rate varying from 150 -170/100,000 respectively, compared to a global rate of 106/ 100,000. In India, RTIs and falls account for 45–60% and 20–30% of TBI respectively (Puvanachandra et al 2009).

Although countries document data differently, the incidence of TBI worldwide is thought to be rising, mainly due to injuries associated with the increased use of motor vehicles, particularly in middle-income and low-income countries (Maas et al 2008, Roozenbeek et al 2013). In Eastern China, 61% of TBIs were due to RTIs; of these, approximately one-third were motorcyclists, 31% pedestrians, while motor-vehicle passengers accounted for 14% (Wu et al 2008).

The estimates of TBI incidence (see Figure 1) show substantial variation between countries (Roozenbeek et al 2013).

**Figure 1: Incidence of TBI (Rozenbeek et al 2013)**



The USA Centre for Disease Control (CDC) states that almost half a million (473,947) emergency department visits for TBI are made annually by children up to 14 years of age (CDC 2013). A review of the incidence rates for all age ranges reported the lowest rates for the USA (103/100,000) and the highest rates for Asia (344/100,000), with 23 European countries reporting an average incidence rate of approximately 235/100,000 (Tagliaferri et al 2006). However, these data are not specific to children.

McKinlay et al (2015) looked at research over the last 10 years where the prevalence of TBI for children could be extracted and found it varied from 280-1,373/100,000, with the lowest rates where hospital admissions only are used, and the highest rates where hospital admissions, hospital presentations and General Practitioner visits are included.

Prevalence rates also vary with age, with most studies reporting higher rates for those under five years of age and those in the adolescent years (Hawley et al 2003, Kim et al 2012, Koepsell et al 2001, Langlois 2005, McKinlay et al 2008, Wu et al 2008). Recent research also reports that the data varies depending on race, with blacks being more likely to experience TBI than non-blacks (Langlois 2005).

Non-TBIs are recorded by illness or medical condition and not by the resultant brain injury or disability. Davidson et al (2003) reported a worldwide annual incidence of acute encephalitis in children ranging from 3.5 to 16/100,000. Similarly data from the USA documents the risk of stroke from birth through to age 18 years as nearly 11/100,000 children per year (Roach et al 2008), but the number of children with disabilities is not reported. A global incidence bacterial meningitis of 34/100,000



child-years was reported by Luksic et al (2013), with a median case-fatality rate of 14.4%.

### Data collection

Data estimates for TBI are based on the registration of emergency department visits, hospital admissions and discharge registries. In these registries, TBI is often identified using the International Classification of Diseases (ICD) codes. These definitions were more pathologically based in the ICD-9 compared with the more clinically orientated definitions in the new ICD-10. Both classifications are primarily intended for administrative use; consequently, their applications in epidemiological research are limited. Retrospective identification of patients with mild TBI using ICD coding produces substantial numbers of false-positive and false-negative results. The ICD codes seem to be sensitive for identification of severe TBI, although further classification by specific injury type is limited owing to variability in sensitivity and specificity of the coding. Epidemiological estimates for TBI derived from databases that use ICD coding should, therefore, be interpreted with caution.

It is generally accepted that there is an under-reporting of the number of people who have a TBI. For example, the parents of those children with mild TBI often do not seek medical help, especially if they consider the injury insignificant, or they live in rural areas where travel to a hospital will take time and incur costs, or in countries with less-developed healthcare systems. Those with very severe TBIs are often not registered if they die before reaching a hospital.

Overall, the epidemiology of ABI is difficult to quantify due to the lack of standardisation and incomplete capture of data on the incidence and outcome of brain injury, as well as the variability in definition. The variability in diagnostic criteria and case ascertainment also exacerbates the inconsistency of incidence estimation and makes study comparisons difficult. It is therefore difficult to be definitive about the rates of ABI in children due to the inconsistencies in definitions, classifications, data collection discrepancies and under-reporting. However, an accurate understanding of the numbers of children and young people affected by ABI is essential for the planning of health care and recovery management as many of these individuals will have long-term disabilities.

### **Causes**

There are many different causes of non-TBIs, some of which are extremely rare. Some of the more common causes include infection, lack of oxygen, tumours or bleeding on the brain. There may also be an overlap in the causes of non-TBI with TBI.

The most frequent cause of TBI is blunt trauma, with penetrating injury being much less common and accounting for only a small percentage of all childhood TBI events (McKinlay et al 2015). Generally the cause of the brain injury varies with age, with

falls being particularly prevalent among children under four years, and motor vehicle accidents being more likely for older children (McKinlay et al 2015). The predominance of falls and motor vehicle accidents as primary modes of injury for children is one of the most consistent findings in the literature (Kraus 1995). TBIs are often the result of motor-related accidents in young males.

The pattern of injury varies across regions: in high-income countries, individuals with TBI are generally motor-vehicle occupants, whereas in middle-income and low-income countries individuals with TBI are often vulnerable road-traffic users such as pedestrians, cyclists and motorcyclists (Roozenbeek et al 2013). Increased motorisation, combined with inadequate traffic education and slow implementation of traffic safety regulations is the main cause of an increasing incidence of TBI in low-income and middle-income countries. In many high income countries, improved safety regulations have led to a decline in traffic-related TBI (Maas et al 2008). In the UK 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 2003). For children under 14 years of age, falls and road traffic accidents are by far the most common sources of injury, regardless of geographic location.

## **PREDICTORS OF TRAUMATIC BRAIN INJURY**

### **Gender**

The incidence of TBI, in terms of number and injury severity, is higher in males than females. This may be due to a number of factors including higher engagement in risk-taking activities, more hours of exposure to high-risk activities and reduced supervision for male children (Hawley et al 2003, Koepsell et al 2001, Langlois et al 2005, McKinlay et al 2008).

### **Age**

Between 219 and 345/100,000 children experience TBI annually and 1 in 30 newborns will suffer a TBI by age 16 (Kraus 1995, Crowe et al 2009). Very young children are particularly at risk; those less than age three years have double the risk of TBI of any other group through childhood (Crowe et al 2009) and one in three survivors in this age group will sustain permanent impairment (Krauss 1995). In this age range, where the brain is developing and neurobehavioural skills are immature, there is an elevated risk of disrupted development.

### **Societal**

Social deprivation was not thought to be a significant predictor of TBI events, however, Hawley et al (2003) found a slight increase in RTIs for those in disadvantaged areas, but individuals from advantaged areas were more likely to be injured in assaults. Other factors that may increase risk include children that have

parents with higher levels of stress and who were younger at the time of the child's birth (McKinlay et al 2008).

Anderson et al (2006) showed that children with severe TBI were more likely to have lower socioeconomic status than the groups with moderate and severe TBI. Yeates et al (2005) found that measures of executive functioning after TBI were related to socioeconomic functions in families.

## **CONSEQUENCES OF ACQUIRED BRAIN INJURY**

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. This neuroplasticity may enable individuals to recover better from focal injuries i.e. those occurring as a result of strokes and aneurysms. However, Savage (2012) reported 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. Anderson et al (2011) concluded that neither plasticity nor vulnerability theories can explain the range of recovery 'continuum'.

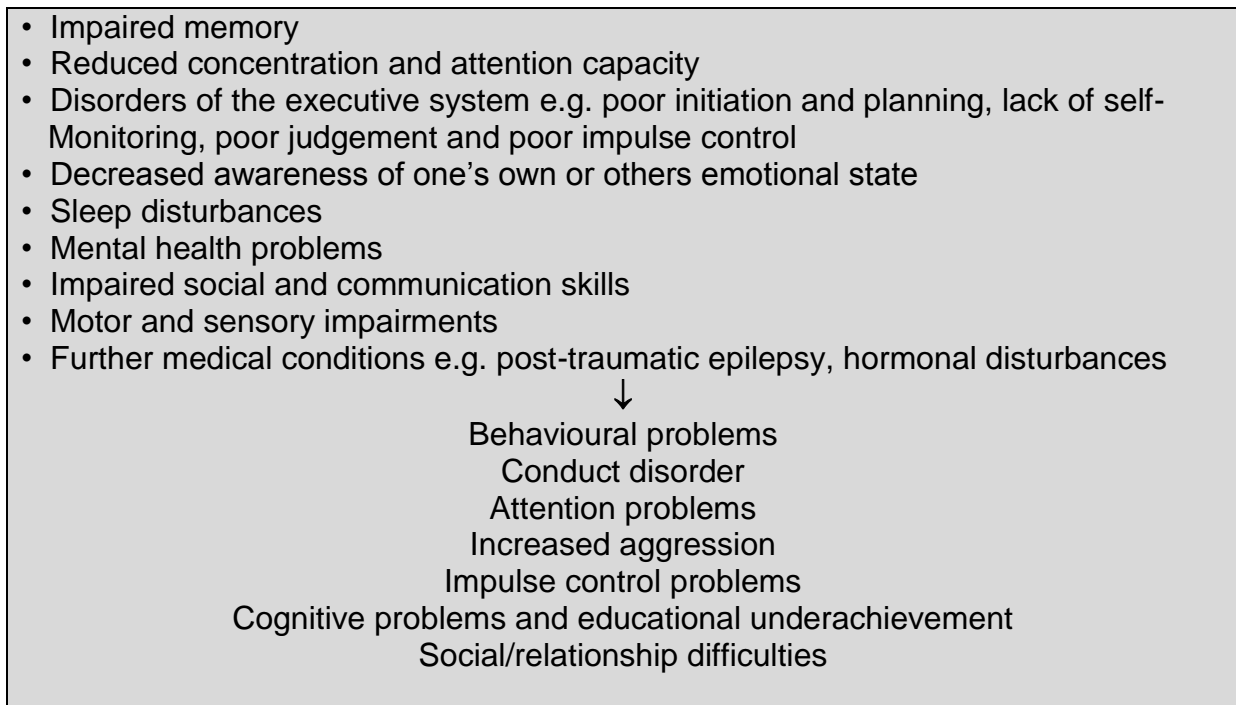
The consequences of brain injury in children and young people include memory deficits, loss of concentration, decreased awareness of one's own or others emotional state, poor impulse control and particularly poor social judgment. Brain injury is also associated with greater mental health problems, higher 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. These impairments may require life-long support. Severe TBI causes a sudden disruption of the child's developmental processes, in many cases across physical, cognitive, academic and psychosocial domains.

Impairments in self-regulatory behaviours can affect interpersonal relationships and contribute to poor community, social and vocational integration, and may lead to long-term placement in an institutional setting. Worldwide studies also show that the incidence of brain injuries amongst young offenders in custody is significant. The Children's Commission Report 'Nobody made the connection' (2012) showed that the prevalence of TBI among young people was between 24 per cent and around 32 per cent, however, in the custodial group of young people, it was between 65 per cent and 72 per cent.

As a child recovers from the initial stages of a brain injury, and depending on which regions of the brain are injured, long-term effects may become apparent e.g. a loss of physical, emotional, or mental functioning, short-term memory or the ability to

recognise faces. Often the cognitive, behavioural and personality deficits, rather than the physical problems, produce the greatest disruption to quality of life. The extent of these impairments may only become apparent when the child or adolescent returns to education.

**Figure 2: Summary of the effects of Acquired Brain Injury**



The 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 a brain injury and the subsequent functional consequences are affected by the individual's age and developmental stage at the time of the injury (Anderson 2009, 2010). Whatever stage of development the child or young person has reached, the brain injury disrupts the process of learning.

In developing countries the negative effects are often compounded by the impact of other health crises such as HIV/AIDS, as well as relatively few economic resources and a lack of neuropsychological rehabilitation services.

### **Impact on the child**

ABI is a frequent cause of disrupted development and more common than other conditions affecting the central nervous system e.g. childhood cancer. An ABI before age five years may have devastating consequences because the injury occurred at a peak time in neurological maturation. Children with a brain injury are at risk of developing cognitive, emotional and behavioural impairments as they get older (Andrews et al 1998, Crowe et al 2012, Klonoff et al 1993). Crowe et al (2012) showed that a moderate to severe TBI before the age of three years appears to be

associated long-term with lowered intellectual function and behaviour problems. In addition a child's environment influences cognitive and behaviour function after TBI.

An ABI before the age of five years may have devastating consequences because the injury occurred at a peak time in neurological maturation; where the brain is rapidly developing and neurobehavioral skills are immature there is an elevated risk of disrupted development. Clinical reports and available research suggest residual problems occur in cognition, attention, executive function and memory. These problems will interfere with skill acquisition, causing adaptive deficits, academic failure, and social and behavioural dysfunction, as well as a personal and economic burden for the family and community.

Anderson et al (2012) looked at the recovery of cognitive and functional skills after early childhood TBI to 10 years post-injury, and found that children with severe TBI had the poorest outcomes, with a high risk of persisting deficits. Recovery trajectories were similar across severity groups but with significant gains in verbal skills from 12 and 30 months to 12 months and 10 years. Children with less severe TBIs appear to recover to function normally (Anderson et al 2012). Contrary to speculation about 'growing into deficits', after protracted recovery to 30 months, young children make age-appropriate progress at least to 10 years post-insult. Environmental factors were also found to contribute to adaptive and social/behavioural recovery.

### **Impact on the young person**

Young people who have severe brain injuries may be at risk of manifesting a 'neurocognitive stall' during a second phase of brain recovery, 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 do not meet later developmental milestones. In addition, this neurocognitive stall may emerge despite the individual seeming to have recovered cognitive abilities commensurate with their pre-injury level (Chapman 2007).

The beginning of adolescence is marked by extensive social and emotional changes that impact the individual's relationship with family and friends, resulting in many challenges. This development phase is characterised by new cognitive, logical and hypothesis-forming attributes. Adolescents and young adults with an ABI can therefore have various problems caused by impulsiveness, aggression, social awkwardness and impaired social perception (Braga et al 2012).

### **Impact on the family**

The adjustment of the family and their support plays a crucial role in the child's recovery and ongoing development. However, the burden caused by ABI to the families is substantial. Families are often profoundly affected by a child's brain injury

and the injury-related consequences. Post-discharge is a crucial stage for families and creates a sense of abandonment and anxiety if ongoing support is not available.

Studies show that the long-term care often required following childhood ABI, places significant strain on the family (Armstrong et al 2002, Hawley et al 2003, Murray et al 2006). Research has shown that this strain can lead to the development of mental health problems within family members (Kreutzer et al 2009, Riley et al 2007), financial hardship (Nabors et al 2002) and social isolation (Gan et al 2010).

These families have many problems that need to be addressed. They need long-term, professional support including information about their child's issues and long-term expectations (Hermans et al 2012). It has been demonstrated that just social support moderates the psychological distress of caregivers, with its absence resulting in increased distress over time (Ergh et al 2002). Parents and families need support groups or networks so they can gather 'tips' and new coping strategies from other families and professionals.

### **Long-term impact**

Injury severity dictates the long-term outcome. A study following survivors of very early TBI into adolescence (Anderson et al 2012) found a high risk of persisting deficits, but after a protracted recovery period these children gradually stabilised and began to make some developmental gains. This suggests that intervention may be effective many years post-insult. Children with less severe TBI appeared to recover function normally and make age-appropriate progress at least to 10 years post-insult.

### **Quality of life**

In ABI populations, Quality of Life (QoL) is an important outcome to assess and can be measured as subjective well-being, achievement or utility/health status. Studies traditionally use one of these three QoLs and hence results are not always comparable.

A systematic review by Battista et al (2012) looked at the impact of TBI on QoL in survivors of paediatric TBI and the predictors in this group. The incidence of a poor QoL increased 5.8 times when the injuries were more severe. Good outcomes were contingent on milder injuries, proxy reporting and early assessment time points ( $\leq 6$  months post-injury), whereas poor outcomes reflect more severe injuries and later assessment time points ( $>1$  year post-trauma).

Survivors of severe TBI are particularly vulnerable to global impairments, including poor school performance, greater employment difficulties, poor QoL and increased risk of mental health problems.

## **ECONOMIC BURDEN**

Children, adolescents and young adults affected by ABI are likely to require extensive interventions and educational support to enable them to achieve optimal

recovery. Data from the USA states that the numbers of children, adolescents and young adults affected by ABI represents a significant financial burden, with charges for hospital visits estimated at around one billion dollars per year (CDC 2013).

The assessment of the economic burden of brain injury in children, adolescents and young adults is relatively new. Very little research has been published on the short-term and long-term economic burden that individuals with mild and moderate brain injury have on themselves, their families, careers and society as a whole. Further research is needed to estimate the economic burden on healthcare providers and social services and how this can influence health policies and practices.

All countries have economic and specialisation issues to a greater or lesser extent. However, children, adolescents and young adults with ABI will impose a significant long-term financial burden on all nations so it is imperative that they receive a timely comprehensive, care programme across all domains, and together with family support, they will be in a better position to make positive contributions to society in the future.

## **MANAGEMENT OVERVIEW**

Managing ABI is complex and involves healthcare, education and social service professionals covering physical, cognitive, academic and psychosocial domains.

Currently there is a great deal of excellent care available globally but it is largely implemented in small 'pockets' within countries and dependent on the availability of healthcare and social support networks. Frequently care programmes and service provision are non-existent or inadequate. Acute care is managed more effectively, and guidelines are generally available on a national level. However, post-discharge rehabilitation and long-term management is poor. Rehabilitation is not a priority, or even recognised by governments, and many countries do not have the necessary clinical expertise for implementation. Long-term management is often inconsistent and needs to acknowledge that the developmental stage of the individual will require different management strategies. The care programme for the individual with ABI is often not coordinated, patient-centred or involves the family.

Acute care and the medical aspects of care are well documented, but these protocols need to be extended to include all aspects of post-acute care and discharge.

There are many children, adolescents and young adults with ABI in education, with different needs and unknown long-term trajectories. The crucial role of the education system in supporting children and young people with a brain injury is rarely addressed in care programmes. The education system needs to be able to identify, manage and support these individuals, but rarely has the knowledge or 'tools' to do so. Medical practitioners are the 'front line' providers of care for children with ABI;

their recommendations when the individual is discharged will have a major impact on the interventions provided within the education setting. Communication and collaboration between the clinician, family and teachers, as well as information resources for everyone involved, are therefore crucial for ongoing support and maximising outcomes.

Cooperation and family involvement results in better outcomes for both the individual and the family; integrating the family as a care team 'member' is essential (Gan et al 2012). Three decades ago the SARAH Network of Neurorehabilitation Hospitals in Brazil originally created the so-called 'family-based methodology' for managing children with ABI. There is compelling evidence for organising cognitive and physical interventions, and support for children with TBI, around the everyday routines of their lives, together with intensive support for their families (Braga et al 2005). The role of the family in the development and daily life of the child starts to change in pre-adolescence, when friends become increasingly important and different management strategies are required (Braga et al 2012). A plethora of excellent tools have been developed to support families in this role, including needs assessment questionnaires and web-based support, however they tend to be used in very few countries and need to be 'shared' globally and incorporated extensively into care programmes.

There is also a wide-range of technology-based interventions available for the rehabilitation of children, adolescents and young adults with ABI that can be incorporated in care programmes. They include electronic organisers, pagers, mobile phones, web-based scheduling and voice recorders (Linden et al 2014). The use of smart phones has now also introduced the possibility of creating applications ('Apps') that can target specific cognitive deficits. However, there is a paucity of clinical trials to demonstrate the usefulness of many of these 'tools' and further research is required.

### **Guidelines**

The existence of national guidelines is a key indicator for management and outcomes. Guidelines detail best practice and include recommendations about prevention, diagnosis, treatment, long-term management and the provision of information and advice. They provide comprehensive and practical advice on how to treat the individual based on the best available evidence and expert consensus.

In the USA, since the first introduction of guidelines in 1995, albeit covering only the acute phase of care and for severe TBI, several studies have shown that their use achieved substantially better outcomes in terms of mortality rate, functional outcome scores, length of hospital stay and costs. These guidelines have subsequently been updated and translated into 15 different languages for use e.g. Eastern Europe, South America and China (Bullock et al 2007).

The majority of brain injury guidelines relate to adults. Some guidelines on the care of children, adolescents and young adults with brain injury are available on a national



or local basis. A review of a selection of these guidelines highlights that they often focus on the acute phase of care and in children and young people with TBI, rather than ABI (Linden et al 2013). Concussion has achieved increased awareness recently due to its prevalence in contact sports and as a result there are some guidelines available. Existing guidelines rarely look at the patient journey in its entirety including rehabilitation, long-term management and transition, or cover all four domains i.e. physical, cognitive, academic and psychosocial (Linden et al 2013). In some countries guidelines may not be embraced entirely by healthcare providers due to lack of knowledge and awareness, political decision making or economic pressures (Linden et al 2013).

Some examples of countries with guidelines for children and young people include:

#### Canada

The Ontario Neurotrauma Foundation has developed comprehensive guidelines for the diagnosis and management of paediatric concussion, and provides healthcare practitioners, schools, community organisations/centres, parents and caregivers with the tools needed for the provision of optimal care.

#### The Netherlands

The Dutch guideline 'Mild traumatic head/brain injury' was revised in 2012 under the supervision of the Dutch Institute for Healthcare Improvement (CBO). The guideline is applicable to both adults and children and looks at acute management; it can also be used in primary care. It does not address rehabilitation or long-term care of individual but it provides advice on reducing the risk of long-term symptoms.

#### Sweden

In addition to local guidance that includes long-term follow-up and return to school support (Linden et al 2013), national standards are currently being developed by the Swedish Paediatric Neurology Society.

#### United Kingdom

In 2014 the National Institute for Health and Clinical Excellence updated its evidence-based advice on the care of children, young people and adults with head injury entitled 'Head injury Triage, assessment, investigation and early management of head injury in children, young people and adults'.

The Regional Acquired Brain Injury Implementation Group in Northern Ireland has published an ABI pathway for children and young people. Communication with the family is seen as central from the acute care phase, through to family support on discharge. In addition to the establishment of rehabilitation goals and the assessment of carers' needs, the importance of effective discharge planning is highlighted. Effective communication between services and the provision of information and advice to both the child and family is seen as a core component to holistic assessment.

## USA

The Centers for Disease Control and Prevention (CDC) has established a Paediatric Mild TBI Guideline Workgroup. This Workgroup is charged with developing clinical diagnosis and management guidelines for acute mild TBI among children and adolescents that occurs both on and off the sports field. Comprised of leading experts in the field of TBI, the workgroup will create a multi-organisation endorsed guideline at a future date.

## **SUMMARY**

ABI is a major cause of morbidity and mortality worldwide; there are long-term economic and healthcare costs which impact on health policies and practices. An accurate understanding of the numbers of children, adolescents and young adults affected by ABI is essential for the planning of health care, recovery and long-term management.

ABI in children, adolescents and young adults should be considered a chronic health condition with associated ongoing, often life-long 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. ABI is endemic in the offender populations and contributes to criminal behaviour. ABI has a major detrimental impact on the physical, cognitive, academic and psychosocial domains and results in a substantial burden for family and carers with significant economic implications.

Current care programmes and service provision for ABI are generally inadequate. They must be patient-focused, family-centred, coordinated, involve a trained interdisciplinary team, taking into consideration the physical, cognitive, academic and psychosocial domains, as well as the environmental issues which may impact on the outcomes. They must include families, as they have a pivotal role in managing the recovery of their child. Many countries have developed useful management protocols for different stages of the patient journey but the entire journey needs to be addressed.

It is imperative that international evidence-based guidelines with best practice protocols are produced for children, adolescents and young adults from acute care to rehabilitation, long-term management including coordinated support in school and the community across all domains. There is also a need to emphasise the specific roles and needs of the family at different stages of the rehabilitation process. An awareness of existing best practice management and resources is required together with a global 'sharing' to facilitate improved service provision.

At all levels, training is required to ensure that the individuals with ABI, their families and professionals have the protocols and 'tools' required to optimise recovery.

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