



# NEUROPSYCHOLOGICAL REHABILITATION OF CHILDHOOD BRAIN INJURY

A Practical Guide

Edited by  
Jonathan Reed,  
Katie Byard and  
Howard Fine

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**A Practical Guide**

Edited by

Jonathan Reed, Katie Byard and Howard Fine

*Recolo UK Ltd, London, UK*

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*For Mandy for always being there for me,  
and for Luke, Simon, Poppy and Kitty for making  
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*For Andy, Mum and Dad, and Abby—thank you  
for your strong, steadying love*

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# 1

## Introduction

*Jonathan Reed, Katie Byard and Howard Fine*

Child brain injury is a potentially catastrophic event for the child involved, their family and for wider society. This book is about how child neuropsychology can help.

There have been great advances in neuroscience over the last decade, including our understanding of the mechanisms and effects of child brain injury (Anderson and Yeates, 2010; Anderson et al., 2012). Our understanding of how to help ameliorate these effects has been much slower. However, there are now a number of researchers and clinicians developing approaches to help children with brain injury. This book originated from our desire to have one central volume, which summarised these developments.

Child brain injury can be considered a chronic condition with life-long implications. As Elisabeth Wilde and colleagues conclude in their chapter in this book,

[B]oth clinical experience and research literature document residual deficits in a range of cognitive and behavioural domains, including academic achievement, attention, memory and executive function. In addition, recent investigations suggest that injury to the immature brain may also affect psychological and social development, and that problems in these domains may persist or increase as the child matures. Together, these deficits affect a child's ability to function effectively at home, in school and in their social environment, resulting in impaired acquisition of knowledge, psychological and social problems, and overall reduced quality of life (p. 28).

As well as immediate neuropsychological effects, child brain injury can result in long-term functional problems. As Shari Wade and Anna

Hung state in their chapter, 'Mounting evidence suggests that long-term consequences of childhood TBI [traumatic brain injury] are significant, contributing to an increased risk for criminal involvement/incarceration, lower rates of high school graduation, under- or unemployment, and homelessness' (p. 43). Therefore, it is vitally important that we develop effective ways to try and rehabilitate children with brain injury.

It is helpful to define terms at the outset. We see child neuropsychology as both the study of the developing brain-behaviour relationship, and the practice of helping children within the wider social context in which they reside. By 'child' we include adolescence and what is thought of as early adulthood. Although the legal definition of a child is those below the age of 18, from a psychological and neurological developmental perspective there is no straightforward cut-off point when a child becomes an adult, and the boundaries are blurred. We take the view that we are addressing problems with development. This book focuses on brain injury and by this we are referring to any injury that occurs to the developing brain. Some chapters are specific to traumatic brain injury (TBI) because that is where the research base is focused. Other chapters include causes of brain injury besides trauma.

The book starts by defining the scale of the problem. The opening chapter from Elisabeth Wilde and colleagues presents a comprehensive review of the neuropsychological consequences of child brain injury. Wilde and colleagues highlight the multiple neuropsychological manifestations of brain injury, including the impact on cognitive functioning (attention, memory, executive functioning and processing speed), academic achievement, behavioural and social functioning, and quality of life. The chapter also outlines contemporary topics in developmental neuroscience, including the susceptibility of the immature brain to brain injury, age and developmental issues in assessing TBI and its consequences, and developmental consequences of early injury (neuroplasticity, critical periods, growing into deficits, and arrested and altered development subsequent to TBI).

The chapter by Elisabeth Wilde and colleagues demonstrates that there are clear neuropsychological problems as a result of child brain injury. The chapters in Part II address these problems directly. These chapters all describe structured approaches to neuropsychological rehabilitation. By structured we mean clearly defined, standardised interventions with research evidence of effectiveness.

The chapter by Shari Wade and Anna Hung describes the Teen Online Problem Solving (TOPS) intervention. The TOPS intervention provides training in social problem-solving skills, communication skills and

self-monitoring/stress management to teens with TBI and their families. Central to this novel approach is engagement with families using an online programme. This intervention has been shown in randomised controlled trials (RCTs) to improve executive function and behaviour based on parent report and long-term functional outcome. It is one of the few interventions that has a robust evidence base.

The chapter on behavioural family intervention by Felicity Brown and Koa Whittingham also presents strong evidence in the form of RCTs. There is a high prevalence of behaviour problems following child brain injury and this chapter describes a structured intervention to support parents. They focus on an adapted version of the 'Triple P' positive parenting programme (Stepping Stones Triple P) for children with disabilities, which is a well-validated approach to helping families with behaviour problems. This intervention is delivered through parenting groups. The intervention also includes additional elements, based on acceptance commitment therapy, to support parents.

Child brain injury is associated with significant problems in cognitive functioning. Jennifer Limond and Anna Adlam introduce the paediatric neurocognitive intervention model to address this. This model focuses on how different cognitive systems nest or develop together, and how to intervene appropriately based on the corresponding developmental stage of the child. They review the evidence base for outcome on cognitive rehabilitation approaches, and progress to provide a systematic guide to intervention based on this evidence.

The chapter by Suzanna Watson and colleagues provides a practical guide to working with children with brain injury and behavioural regulation problems. The chapter reviews the evidence base for intervention and takes a developmental neuropsychological perspective. There is acknowledgement that behaviour problems occur within the family context and the wider social network. The chapter focuses on applied behaviour analysis, with an emphasis on antecedent behavioural management.

The point of rehabilitation of brain injury is to produce change. However, careful thought is required when defining what we are trying to change and for whom. In Part III, there are two chapters exploring these issues.

Sophie Gosling highlights the need to think about context when considering outcome. She outlines the value of thinking about different perspectives on change, including for the child, the family and for the wider system. The chapter discusses ways of measuring outcome meaningfully using both quantitative and qualitative methods.

Traditionally in medical outcome research, the RCT methodology is considered to be the 'gold standard', and there is clearly a need to develop standardised approaches that can be tested using RCTs. However, as Gosling highlights and as Part IV of this book outlines, in clinical practice it is not always possible to provide a standardised approach that will work for everyone. Every child, every family and every injury is different. The complex, cumulative interactions of these factors results in different presentations, which sometimes requires working in a less standardised way.

Despite the complexity there remains a need for rigour when defining and measuring what is to change. The chapter by Peter Tucker reviews a robust approach to defining and measuring individual change. This is based on goal setting and evaluation using Goal Attainment Scaling (GAS). The chapter provides a practical guide to the GAS process. This is a standardised approach based on clear psychometric analysis but which can also be used in complex, individual cases.

Part IV of the book focuses on working with complexity in child brain injury. Complexity can arise from the interaction between child brain injury and the social system around the child. The chapter by Katie Byard reflects on the systemic context in which child brain injury occurs. As Byard states: 'The systemic perspective allows the clinician to reflect on the wider multisystemic context for the child; their own brain system and functioning, their family, school and peer system, and, more widely, the therapy team and community in which they reside' (p. 175).

The chapter by Fergus Gracey and colleagues provides a constructive matrix for understanding and working with complexity: the complexity of rehabilitation and engagement model. The model conceptualises and addresses the psychological needs of children within brain injury by distinguishing between (i) technically complicated psychological needs; (ii) psychological needs in the context of social complication; and (iii) the interaction between technically and socially complicated issues. The chapter particularly focuses on the interdisciplinary team approach and the value of integration of neuropsychological rehabilitation and psychotherapy.

Alison Perkins engages with complexity by working psychotherapeutically with children with severe brain injury and significant issues of identity threat through loss and trauma. The approach she describes is child focused and child led. It is based on narrative therapeutic ideas and the use of documents created by the child to help them create the story of their brain injury and rehabilitation, and situate these events within their lifespan.

Part V considers new approaches to working with children with brain injury. Rebecca Ashton explains that '[M]ost children are in education for a large proportion of their waking life, whether in school, nursery, college or some other educational setting' (p. 237). Therefore, there is a need to provide neuropsychological services within the education setting. She argues that this requires professionals with specific skills and knowledge in education, and advocates for the development of a new discipline of 'Educational Neuropsychologists'.

Sarah O'Doherty and Rebecca O'Connor describe a dynamic, innovative approach integrating music therapy and neuropsychology. Music is central to how many people experience life; it influences mood, behaviour and memories. O'Doherty and O'Connor harness the power of music to help children with brain injury. They look at techniques using music to aid memory and orientation, to help with behavioural regulation and to support parent-child interaction. This chapter demonstrates that there is a constant need to think about innovative ways to help children with brain injury.

Our goal when planning this book was to review and summarise the work being done by neuropsychologists to help children with brain injury. We are very grateful to all the contributors for sharing and discussing their work, and making this possible. Working in child neuropsychological rehabilitation is challenging and exciting. Our understanding of what works, and for whom, is developing rapidly. However, there is still a lot we do not know, and a great deal of work still to be done. We would like to encourage others to use the ideas in this book to develop services, to carry out further research and continue to create innovative approaches to intervention. Ultimately, our aim is to provide the best possible outcomes for children with brain injury and their families. We trust that that this book can help to achieve this.

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## **Part I**

# **A Review of the Neuropsychological Consequences of Child Brain Injury**

# 2

## Neuropsychological Consequences of Child Brain Injury

*Elisabeth A. Wilde, Stephen R. McCauley, Sanam Jivani,  
Gerri Hanten, Jessica Faber and Shawn D. Gale*

Traumatic brain injury (TBI) in children has received increasing attention in recent years among parents, educators, clinicians and service providers, researchers and policymakers owing to the incidence and financial burden associated with injury during infancy, childhood or adolescence. Understanding the ways in which the immature brain may exhibit specific vulnerabilities to injury, how injury at a young age may interact with subsequent development, and anticipating the likely cognitive and functional consequences of child TBI is critical in detection of injury, monitoring recovery, and designing and evaluating rehabilitation strategies that may enhance recovery.

### **Incidence and Prevalence of Child TBI**

Incidence rates for children with TBI vary by global region and the methodology used for inclusion of cases (e.g. emergency department presentation vs. hospital admission vs. general practitioner visits, whether deceased individuals were included, the specific age range that was selected, variation in the definition of TBI used), but estimates suggest a range of 280–1373/100,000 based on review of research published over the last decade where rates of TBI for children can be extracted (McKinlay and Hawley, 2013). Epidemiological studies in the USA and other developed countries indicate that the rates of hospital admissions and emergency department visits for head injury in children surpass that of the general adult population, particularly among children under five years of age and in older adolescents (Hawley et al., 2003; Langlois et al., 2005; Rutland-Brown et al., 2006; McKinlay et al., 2008; Wu et al., 2008; Faul et al., 2010; Koepsell et al., 2011; Kim et al., 2012; de Kloet et al., 2013). Generally, across locations where data on mechanism of injury are recorded, falls



remain the leading cause of TBI in younger children (under 14 years), and road traffic accidents are a more common mode of injury for older children (McKinlay and Hawley, 2013).

### **Susceptibility of the Immature Brain to Injury**

Several features related to differences between child and adult patients in anatomy and tissue characteristics, the biomechanics of injury, and biochemical or physiological processes have been cited as factors that may increase vulnerability to injury in children. First, in terms of anatomy and tissue characteristics, the relatively thin and less rigid skull of an infant or very young child may increase the potential for diffuse injury (Margulies and Thibault, 2000; Case, 2008). Additionally, the disproportionately large and heavy head and weak neck muscles may increase the young child's susceptibility to rotational and shearing forces during an insult (Hahn et al., 1988; Margulies and Thibault, 2000). Differences in water content of the brain and incomplete myelination have also been considered important factors related to the potential vulnerability of the brain to certain forms of trauma-related injury in children. Mass lesions, subdural haematomas and tearing of the subcortical frontal white matter have been reported to occur more often after TBI in young children compared with older children (Hahn et al., 1988). Analysis of the distribution of findings on admission of computed tomography imaging indicate that child patients with TBI were more likely to have skull fractures and epidural haematomas than adults with similar injury severity, as measured by Glasgow Coma Scale (GCS) score (Sarkar et al., 2014). Although pathophysiological and repair mechanisms are incompletely understood, the immature brain may exhibit a more robust inflammatory response than in the adult brain, with greater disruption of the blood-brain barrier and elaboration of cytokines, a decreased response to oxidative stress due to inadequate expression of certain antioxidant molecules, and may be less able to detoxify free iron after TBI-induced haemorrhage and cell death (Potts et al., 2006). Increased age-dependent apoptotic neurodegeneration in the developing brain has also been cited as a potential deleterious mechanism of secondary injury (Bittigau et al., 1999). Finally, increased incidence of cerebral oedema, greater autodyregulation (Vavilala et al., 2004; Chaiwat et al., 2009) and the lack of maturity in excitatory neurotransmitter systems have also been cited as factors that influence vulnerability to TBI in children (Kochanek, 2006; Giza et al., 2007; Shrey et al., 2011).

## **Age and Developmental Issues in Assessing Acute TBI**

The two most commonly used acute assessment and prognostic tools for child TBI include assessment of loss (or alteration) of consciousness and post-traumatic amnesia (PTA), although some studies have indicated that time to follow commands may also be used as important predictor of functional outcome 1 year after child TBI in children of certain age groups (Austin et al., 2013).

### **Assessment of Loss or Alteration of Consciousness**

Historically, classification of TBI severity as mild, moderate and severe has relied upon the use of the GCS, a widely used scoring system to assess impaired consciousness and coma (Teasdale and Jennett, 1974; Rimel et al., 1981, 1982). Patients with scores of  $\leq 8$  are classified as having 'severe' injury, scores of 9–12 denote 'moderate' injury and scores of 13–15 are 'mild' injuries. Duration of loss or alteration of consciousness is a key diagnostic feature of TBI, but administration of the verbal component of the GCS assumes that language comprehension is sufficiently developed to assess reliably the ability to follow simple commands. Consequently, modifications of the GCS and use of child scales to measure impaired consciousness have been proposed for use with infants and toddlers. For example, for children under 36 months of age, a paediatric coma scale can be used, which is intended to approximate the GCS (Hahn et al., 1988; Simpson et al., 1991). Assessment of 'confusion' on the verbal component score of the GCS is also age-dependent. Although an experienced child clinician might be capable of evaluating confused speech in a young child, reliance on temporal orientation can be difficult because this ability is not reliably developed until approximately 8 years of age. Despite these caveats, the GCS continues to be widely used in emergency centres that treat children with TBI (Kapapa et al., 2010).

### **Assessment of PTA**

PTA is an alternate form of injury severity assessment. PTA refers to the interval following injury for which the child has no recall of events or periods where memory is not continuous and integrated. Although measures of PTA, such as the Galveston Orientation and Amnesia Test (Levin et al., 1979), can be administered to adolescents aged 16 years and older, such measures were considered insufficient for evaluation of PTA in children. Consequently, Ewing-Cobbs et al. (1990) designed the Children's Orientation and Amnesia Test (COAT) to evaluate PTA during

the acute and subacute phases of TBI in children aged 3–15 years. The COAT evaluates general orientation (e.g. person and place), temporal orientation (in children older than 8 years of age) and short-term memory, and scoring is based upon normative data obtained in typically developing children. Evidence for PTA is interpreted as a total score falling two or more standard deviations below the mean for the child's age. During the interval where PTA is present, cognitive performance is typically variable and often limited by fatigue and poor attention. Deferring more comprehensive neuropsychological assessment until after PTA resolves is advisable to obtain more reliable data.

### **Age and Developmental Issues in Assessing Longer-term Consequences of TBI**

Additional considerations for longer-term assessment of child TBI must also be made. Measures that are appropriate for the age and developmental level of the child should be used, and because some standardised assessment tools have normative data based upon a limited age range, multiple assessment tools may be required. However, this can be problematic in longitudinal studies or clinical assessment, particularly in younger children, when the equivalency of the measures is not well established. Additionally, many studies in child TBI utilise rating scales completed by the child and/or an informant; however, the sources of information can significantly influence data quality and veridicality, particularly for measurement of emotional/psychiatric features, cognition and behavioural disturbance. For example, how well can a very young child estimate and report his/her own memory impairment, difficulty in thinking or level of fatigue? Conversely, a parent or other caregiver may have difficulty accurately estimating the severity of a child's somatic and emotional symptoms, as these are subjective experiences not easily or precisely assessed.

Recently, an interagency initiative co-sponsored by the US National Institutes of Health (National Institute of Neurological Disorders and Stroke), Department of Education and other federal agencies was launched in an attempt to advance the field of TBI (Thurmond et al., 2010). Panel members on the original Outcome Workgroup were charged with the task of selecting a set of instruments that were recommended for use in TBI research, which resulted in the Common Data Elements (CDE) for TBI (Wilde et al., 2010a). However, the original CDE Workgroup did not include measures for specific use in infants, children and adolescents with TBI, and an additional set of working groups was

assembled to address this gap. As with the original CDE efforts, a range of professionals was involved, including physicians, neuropsychologists, psychologists and others with specific expertise in child TBI outcomes research in the Paediatric CDE Workgroup. Core measures identified included validated and widely applicable outcome measures with proven utility in child TBI from the domains of academics, adaptive and daily living skills, family and environment, global outcome, health-related quality of life, infant and toddler measures, language and communication, neuropsychological impairment, physical functioning, psychiatric and psychological functioning, recovery of consciousness, social role participation and social competence, social cognition and TBI-related symptoms (McCauley et al., 2012). The most recent version of the CDEs for TBI included a restructuring by injury severity and population, and the child elements were integrated in this effort (Hicks et al., 2013). The intent of the CDE is to present a starting point to stimulate further research and it is hoped that the limitations in the outcome measures currently available in child TBI will be addressed in further test development efforts.

## **Developmental Consequences of Early Injury**

The nature, degree, rate and consistency of the ability of the brain to adapt to injury or continue normal development is still the subject of ongoing debate and study, and there are undoubtedly a myriad of factors that may contribute to recovery, including numerous injury-related factors (e.g. mechanism of injury, injury severity, location of injury, etc.), host-related factors (e.g. genetics, age at injury, family and social environment) and intervention factors (e.g. access to, intensity and quality of rehabilitation services and school services), which require further consideration as elements or moderators in recovery from injury (Anderson and Yeates, 2010). Several concepts have emerged related to the presence of injury in the context of development—including neuroplasticity, arrested or altered development trajectories subsequent to injury, and injury during critical periods of development, which may preclude normal development—and ‘growing into’ deficits.

### **Age at Injury and Neuroplasticity**

Age at injury has long been a topic of interest in recovery from TBI, particularly in children, and plasticity theorists have asserted that the undeveloped brain is less committed and therefore less susceptible to residual effects of injury. Early primate studies led to formulation of the

Kennard Principle (Webb et al., 1996), which suggested the possibility of better recovery in young versus older children with acquired brain injury, based upon the finding that similar lesions in the motor cortex had differential effects on infant monkeys (less severe motor impairment) compared with adult monkeys (more severe impairment) (Kennard, 1936). This principle was based upon a theory of greater capacity for reorganisation and compensation in the developing central nervous system than an established one. Historically, the outcomes of TBI in young children were considered less severe compared with adults and adolescents with similar brain injury. However, more recent studies, both experimental and human, have challenged this view and have focused instead on the vulnerable nature of the developing brain (Levin et al., 2001). For example, Pullela et al. (2006) investigated the outcome of early TBI on cognitive skills in injured immature mice (postnatal day 21, which corresponds to a toddler-age child). Cognitive tests 2 weeks postinjury (corresponding to adolescence in humans) and 3 months postinjury (corresponding to adults in humans) showed that cognitive deficits did not emerge until adulthood. The cognitive decline at adulthood correlated with loss of neurons in the hippocampus.

A human–animal validation study was also conducted by Anderson et al. (2009), which investigated the effect of early brain injury on cognitive functioning. Children in this study were categorised by age at injury, with categories derived from experimental literature and corresponding to reported periods of neural growth. Children were categorised according to timing of brain insult—preschool (ages 3–6 years); middle childhood (ages 7–9 years); and late childhood (ages after 10 years)—and were assessed for intelligence, academic achievement and everyday functional skills. The authors found that early brain injury was associated with impairments in all of domains of interest. However, it should be noted that the relationship between age at injury and long-term outcome appeared complex. For example, there was an overall positive linear relationship between age of injury and long-term outcome on intelligence and academic ability (such that younger age at injury resulted in poorest cognitive outcome). The pattern was different with regard to everyday functioning skills; although the group with late-childhood brain injury showed relatively intact performance, middle-childhood injury was associated with greater risk in these domains. Moreover, children who acquired brain injury during preschool years performed the best in this functional domain. Although the literature seems to support the notion that brain injury sustained at younger ages results in worse cognitive outcomes, the results of the study by Anderson