



Participation following Severe Childhood Acquired Brain Injury

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Abstract

This study explores participation at home, school and in the community following specialist in-patient rehabilitation for severe childhood acquired brain injury (ABI).

Acquired brain injury is the most common cause of death and disability in childhood (Forsyth & Kirkham, 2012). Increased survival rates correspond with increased numbers of children left with chronic disabilities. Severe ABI during childhood changes neurological functioning that can result in wide ranging and complex learning, behaviour, communication, social/emotional and physical difficulties. These often persist for many years, and can be life-long.

Children's everyday settings of home, school and community are important contexts in which they learn and develop. The social model of disability represented in the International Classification of Functioning, Disability and Health - Child and Youth version (ICF-CY) (WHO, 2007) proposes that these contexts play a significant role in the extent to which a child is able to participate. Participation, a key concept in the ICF-CY, provides optimal opportunities for learning and development and is an important determinant of social and educational success (Eriksson, 2006). The impact of severe ABI commonly leads to restricted participation and increases the risk of social isolation and dependency.

The purpose of this qualitative study is to identify barriers and supports that influence participation in children's everyday settings following severe injury and their return to home and mainstream school after residential rehabilitation. It also aims to identify information and support needs of parents and school staff in their role of participation facilitators.

The study generated several themes including adaptation to a new way of life, managing changed needs at school, emotional well-being, and reconstruction of the child's 'self'. Many factors contributed to the extent to which participation was experienced including autonomy, supports, attitudes, services, accessibility, and the child's own emotional responses to the injury.

The implications of the findings for ways of supporting children with severe ABI, eliciting their voice, Educational Psychology practice, and further research are considered.

Glossary of Terminology and Abbreviations

ABI	Acquired Brain Injury
BPS	British Psychological Society
CAMHS	Child and Adolescent Mental Health services
CFFS	Child and Family Follow Up Survey
DfE	Department for Education
DSM	Diagnostic and Statistical Manual of Mental Disorders
EHCP	Education, Health and Care Plan
EP	Educational Psychologist
EPS	Educational Psychology Service
GP	General Practitioner
ICD-10	International Classification of Diseases Version 10
ICF	International Classification of Functioning, Disability and Health
ICF/CY	International Classification of Functioning, Disability and Health, Children and Youth version
LA	Local Authority
Neuropsychology	An area of psychology concerned with brain-behaviour relationships
NHS	National Health Service
NICE	National Institute for Health Care Excellence
SEN	Special Educational Needs
SEND	Special Educational Needs and Disabilities
SENCo	Special Educational Needs Co-ordinator
TA	Teaching Assistant
TBI	Traumatic Brain Injury
WHO	World Health Organisation

N.B. To avoid cumbersome phraseology, the word 'children' is used to include all young people.

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Chapter One: Contextualising the research

1.1. Introduction to Chapter

This study aims to explore supports and barriers to participation in children's everyday settings following specialist residential rehabilitation for severe ABI, and the information needs of parents and school staff who facilitate participation. Chapter one provides the significance and rationale of this topic including brief explanation of ABI, its impact on functioning, and the importance of contextual factors for children's participation. The relevance of the topic to Educational Psychology practice, and the researcher's historical context and motivation for the study are described.

1.2. ABI and its impact on functioning

ABI is injury to the brain since birth, following a period of typical development. It refers to structural change of brain tissue which leads to physiological disruption of normal brain functioning. On-going maturation is suddenly interrupted and injury to a developing brain alters the course of development.

Acquired brain injury (ABI) is the most common cause of mortality and disability in childhood in the UK (Wolfe, Macfarlane, Donkin, Marmot, Viner, 2014; Forsyth & Kirkham, 2012). Children with ABI are at risk of developing persistent cognitive, communication, emotional and behavioural difficulties (Limond, Doris, & McMillan, 2009; Hawley, 2004). Improved emergency response systems and medical advances greatly increase the survival rate of children with severe ABI but result in a corresponding increase in the rate at which children are left with chronic disabilities. It is estimated that "about 1300 children in the UK acquire major neurologic morbidity as the result of acquired brain injury every year, equivalent to the all-severity incidence of cerebral palsy" (Forsyth & Kirkham, 2012, p.1257).

There has been a commonly held belief that 'plasticity' of the brain enables children to make a much better recovery than adults receiving comparable injuries. However, the brain's ability to 'rewire' itself is more limited than once thought and there is now overwhelming evidence to demonstrate that the reverse is the case (Dennis, 2000; Anderson, Catroppa, Morse,

Haritou and Rosenfeld, 2005). Acquired brain injury compromises the ability to learn more than it impairs what has already been learnt and therefore the younger the child the worse the outcome because of the lack of an established knowledge and skill base. Difficulties can persist and be compounded as the child gets older – there can be delayed deficits associated with injury to parts of the brain that are responsible for skills that do not mature until later in a child's development. There is much research to indicate children may experience wide ranging, complex, learning, behaviour, social/emotional and physical difficulties. (Max et al., 2006; Ellison & Semrud-Clikeman, 2007).

1.3. Importance of context for participation

Contextual factors play a key part in learning, and in social, emotional and behavioural outcomes following ABI (Hawley, 2005; Anderson, Spencer-Smith & Wood, 2011). There is indication that the main predictor for positive outcome following ABI is not the injury itself but the child's environment (Taylor et al., 2001; Colver, 2009). This highlights the importance of their 'everyday' contexts of home, school and community. The social model of disability represented in the International Classification of Functioning, Disability and Health - Child and Youth version (ICF-CY) (World Health Organisation (WHO), (2007) proposes that these contexts play a significant role in the extent to which a child is able to participate (Coster, Deeney, Haltiwanger & Haley, 2012). Participation, defined by the WHO (2007) as 'involvement in life situations', is an important determinant of health, well-being and educational success (Willis et al., 2017). It enables children to acquire new skills, to influence positive self-concept and identity, and develop mentally and physically healthy life-styles. Conversely a lack of participation can lead to isolation, social exclusion, dependency, poor health, and be a barrier to learning.

1.4. Children with ABI in mainstream school

Including students with diverse needs in mainstream school is a central tenet of education policy and planning in Britain. 'Support and Aspiration', a government green paper (DfE, 2011) acknowledged that children with special educational needs (SEN) frequently fail to have their needs met, and hence have reduced opportunities for participation. SEN legislation in England (DfE, 2015) emphasised the need for a holistic approach to each individual child's education, health and care needs. Information and understanding about the participation of children

with acquired brain injury is therefore required to embrace this holistic approach in order to better support them to achieve and aspire.

Schools are considered to be the principal provider of on-going rehabilitation services (Ylvisaker & Feeney, 1998) and are arguably ideally placed to meet the needs of children with ABI, and so have a very significant role to play. However, school reintegration and child participation following ABI is poorly understood (Rosignano, Fleig & Knafl, 2015) resulting in the majority of children with ABI returning to school without adequate follow-up or support, even those with severe injury (Tomlin, Clarke, Robinson & Roach, 2002; Hawley, 2005). Schools may fail to be notified that a child has had a brain injury (Hawley, Ward, Magnay & Mychalkiw, 2004; Mackay, 2005), or relevant information may be received but not adequately disseminated, or teachers may be unaware of the injury's potential impact on learning and behaviour (Farmer & Johnson-Gerard, 1997; Hawley et al., 2004). Development of learning and behaviour difficulties, even years post-injury, are commonly attributed to laziness, or social factors (Ylvisaker & Feeney, 1998).

1.5. Relevance of the topic to Educational Psychology practice

Contemporary educational psychology has moved away from a child-deficit model and embraced social constructionist theory which now underpins much professional training and practice (Kelly, 2017). An ecological model based on the work of Bronfenbrenner (1979), and Bronfenbrenner and Ceci (1994) emphasises the importance of contextual influences for a holistic understanding of children's needs and difficulties. EP knowledge and experience of school systems and child-related settings are "unparalleled" (Mackay, 2005, p.14), making EPs ideally placed to appreciate and promote factors in the home and school that have a direct and indirect influence on participation and outcome (McCusker, 2005), in ways that clinicians are commonly not able to. For example, guidelines issued by the National Institute for Clinical Excellence (NICE, 2014) providing generic discharge and follow-up advice when returning home from hospital after ABI pay scant reference to the particular, very different needs of children.

EPs are also increasingly having to work in contexts in which neuropsychology informs understanding of problem areas that are central to their work (Mackay, 2005). The corollary of increased survival rates of children with severe ABI is the increase of children in schools

with significant special needs, and in particular anomalous behaviour and learning profiles. Research indicates a number of areas in which EPs could play a supportive role to improve outcomes for children returning to home, school and community following ABI but which are not yet well recognised by the Educational Psychology profession (Bozic & Morris, 2005; Ball & Howe, 2013). Limited knowledge of brain-behaviour relationships and neuropsychological constructs result in a lack of confidence “to base their own practice in this domain” (Bozic & Morris, 2005, p.108).

1.6. Situating the researcher in the research: historical context and motivation

The researcher’s personal experience, values and perceptions contribute to qualitative study. Lincoln and Guba (1985) consider that biographical information is a necessary element of this, and to specify what is sufficiently compelling and unknown to contemplate a research study.

Professional interest and concern for the unmet needs of children with ABI and their families is the motivating factor for carrying out this research. After working as a local authority generic Educational Psychologist, the researcher joined a team of clinicians in a specialist rehabilitation unit for children with severe acquired brain injury. At that time, over 20 years ago, appointing an EP was a controversial decision. The discipline of educational psychology and the potential role of an EP were viewed sceptically and suspiciously by some clinicians as being irrelevant for what was generally perceived to be an exclusively clinical field. The links between clinical sequelae of ABI and the concomitant functional impact on learning and behaviour following the child’s return to home and school were not widely acknowledged or understood.

The past two decades have seen dramatic shifts in focus and conceptual understanding of paediatric rehabilitation following ABI. Decontextualized clinic-based approaches for many aspects of paediatric rehabilitation have now been seriously questioned (Ylvisaker, 2003). There has been substantial growth in literature on outcomes following childhood ABI, and epidemiological studies emphasise outcomes are predicted more strongly by factors independent of the injury itself (Forsyth & Kirkham, 2012). There has been a change of emphasis to highlight the importance of intervention that is embedded in the child’s everyday life at home and school, supported by the ‘everyday’ people in those settings, with consultative help from specialists (Ylvisaker, 2005). “The goal is to organize the routines of life

at school and home to facilitate the child's successful participation in school and other culturally valued activities, and within that participation, improvement of cognitive processes and compensatory strategic behaviour." (Ylvisaker et al., 2005, p.99).

Despite the welcome change that now emphasises the importance of school and home for on-going rehabilitation, with significant implications for the role of the educational psychologist, there continues to be little evidence of understanding, and systematic organisation by local support services, of ways to achieve successful participation for children following severe ABI (Tomlin et al., 2002).

1.7. Summary of the proposed study

Children's return to home, school and local community to participate in everyday life activities following residential brain injury rehabilitation is an important rehabilitation goal. There is much research about clinical and academic outcomes following severe ABI. In contrast there is an absence of research in the UK on how contextual and personal factors may affect participation after returning to home and school with a changed profile of skills and needs (McCusker, 2005). There is an absence of data on the views and experiences of injured children as well as parents and school staff who play key roles in supporting their participation. The current study aims to explore participation from the perspective of children themselves, their parents and school staff. The information needs of parents and school staff are also investigated. Implications of the findings for educational psychology practice are considered.

Chapter Two: Literature review

2.1 Introduction to Literature review

This literature review is divided into three parts:-

Part One provides information about childhood ABI, the sequelae, and some of the significant factors that can impact on outcome. The concept of rehabilitation for severe ABI is explained, including associated key issues related to discharge from a residential clinical setting, and returning to the 'everyday' settings of home, school and local community.

Part two discusses classification of disability relating to the International Classification of Functioning, Disability and Health (ICF) and the influence of social constructionism that has helped to shape it. Participation, a central concept in the ICF, the facilitators and barriers that influence participation, and their relevance to ABI are described. Issues relating to communicating with and interviewing children with ABI are also addressed.

Part three presents a critical review of research of selected literature relating to the proposed research study questions. Finally, the current research study is introduced including its purpose and aims.

2.2. Literature Review strategy

A literature review was carried out to identify what was already known about the topic, to identify research related to the proposed area of study, and to identify gaps within that area. Literature was selected based on its relevance to the study aims and childhood ABI. The associated topics being explored and discussed include:

- The impact of severe ABI on child and family
- Rehabilitation for ABI
- International Classification of Function (ICF & ICF-CY)
- ABI Outcomes
- Return to home and school

- Participation
- School support - the perceived role, beliefs and perspectives of school staff associated with supporting a child with ABI
- Information needs of families and school staff
- Eliciting the voice of children with severe ABI

Inclusion criteria: Most of the English language peer reviewed literature on childhood ABI originates from highly developed countries in North America, Australasia and Europe. All of this was considered for inclusion. Restricting peer reviewed publications on participation following ABI to those originating in the UK may have been too limiting due to the paucity of UK research on this topic. Systemic and contextual differences between countries will be referred to whenever relevant. The time frame focused on the period 1985 – 2018. The lower limit was chosen based on the main body of references.

Exclusion criteria: Publications from developing countries were not included due to greater systemic and contextual differences than those referred to above. Literature relating to pre-school children, those in tertiary education, vocational training or employment and adults with ABI were excluded as the study was concerned with school-aged children attending full-time school at key stage 2 or 3. Publications about concussion or mild ABI and those with an exclusive medical focus were also omitted as the focus of the study was participation of children with severe ABI.

Key sources

A number of electronic data bases were used including PubMed, British Education Index, PsychInfo, ScienceDirect, Ovid, Google Scholar, Web of Science.

Keyword and key phrase searches were carried out relating to children, family, education and social needs after ABI, using the following terminology together with the terms brain injury, acquired brain injury, traumatic brain injury, head injury:

Pediatric/paediatric, Rehabilitation, Outcome, School, Education, Family, Home, Participation.

Generally unpublished theses were not included. However, names of established researchers in selected areas of study were searched for, using the search engines 'Google' and 'Google Scholar' and this occasionally provided their doctoral theses on relevant topics which were included. References from articles in the search were followed up. In addition, specific peer-reviewed journals relevant to the current topic were searched, including:

Brain Injury, Journal of Head Trauma Rehabilitation, Child Neuropsychology, Developmental Neuropsychology, Archives of Disease in Childhood, Developmental Medicine and Child Neurology, Support for Learning.

2.3. Part One: Overview of childhood ABI

Aspects of childhood ABI may be unfamiliar to many educators and so to help with orientation, the overview includes explanations of terminology and epidemiological information followed by description of common sequelae.

2.3.1. Acquired Brain Injury is an injury caused to the brain since birth, following a period of typical development. It refers to structural change of brain tissue which leads to physiological disruption of normal brain functioning. Acquired brain injury is an 'umbrella' term, including both traumatic and atraumatic/non-traumatic injury. It excludes brain damage that is congenital, as a result of birth trauma, or a degenerative disease (British Psychological Society, 2006). The term 'head injury' is sometimes used and invariably refers to ABI although it is inaccurate because injury to the head may not necessarily involve injury to the brain.

2.3.1.1. Traumatic brain injury (TBI) occurs as a result of external events involving physical force to the brain, usually when the head collides with a hard surface as can happen in a road traffic accident, fall, assault, or sports injury (Semrud-Clikeman & Ellison, 2009). The head does not necessarily have to collide with external objects for injury to occur, for example in cases of whiplash, non-accidental injury, sometimes referred to as shaken baby syndrome (Ashton, 2010) and other forms of physical abuse.

Focal injury in TBI refers to localised injury in the brain, whereas diffuse injury occurs over a more widespread area. Most commonly there is no sign of damage to the skull but

acceleration, deceleration, or rotation of the soft brain tissue causes bruising, swelling, stretching, tearing or bleeding of the brain (Semrud-Clikeman & Ellison, 2009).

2.3.1.2. Non-traumatic brain injury or atraumatic brain injury is associated with internal events such as disease, for example meningitis, encephalitis, brain tumour or abscess, toxicity from substances, aneurism, stroke, anoxia caused by reduction in oxygen to the brain from events such as choking, near-drowning, asthma attack, heart attack, severe blood loss, and metabolic disorders such as diabetic coma, kidney and liver diseases. Treatment-induced injury can also occur as a result of surgical or pharmacological intervention, such as chemotherapy, radiotherapy, and anaesthetic accidents (Chan, Pole, Keightley, Mann & Colantonio, 2016).

Despite the heterogeneity, children with traumatic and non-traumatic injuries have similar needs (Forsyth & Kirkham, 2012) and so the term acquired brain injury (ABI) is generally used throughout this thesis to include traumatic and non-traumatic.

2.3.2. Primary and secondary injuries

Primary injuries result directly from the brain trauma itself such as skull fracture, contusions, and lesions. Secondary, indirect injuries occur as a result of the complications arising from the primary injury such as raised intracranial pressure, brain swelling, hypotension, seizures. Acute medical management for most children focuses on secondary rather than primary injuries (Yeates, 2000).

2.3.3. Incidence and Prevalence

ABI is commonly misconceived as a low incidence event (Hooper, 2006) despite it being the leading cause of death and disability in young people (Wolfe et al, 2014; Forsyth & Kirkham, 2012). Reported rates of ABI vary according to the data source (McKinlay & Hawley, 2014). There are no accurate statistics of ABI in children and young people in the UK, due to a lack of a comprehensive recording system (Hawley, Ward & Long, 2002). Estimates and classification by differing age-ranges, severity, or geographical location vary. For example some systems include all of the UK, other data bases include England only; some systems include children up to the age of 16, others up to the age of 18.

Reported incidence for hospitalisation of traumatic brain injury of children in England under the age of 16 is between 280-500 per 100,000 (Hawley, Ward, Magnay & Long, 2003; NHS, 2013) implying that at least 35,000 children are admitted to hospital each year with TBI. Of those approximately 2000 will have had a severe TBI, 3000 a moderate, and 30,000 a mild TBI (NHS, 2013). Data for atraumatic ABI is by sub-type. For example, the total number of children who sustain coma associated with moderate to severe encephalopathy is about 4000 a year, brain tumours equate to about 525 cases a year, and there are 200 - 300 cases of paediatric stroke each year (NHS, 2013).

There is wide acknowledgement that the reported estimates and recorded incidence of paediatric ABI in developed countries significantly under-represent actual figures for a number of reasons (Bruns & Hauser, 2003). For example children with additional injuries, as well as a TBI, may only be treated and recorded for more obvious, visible concerns such as orthopaedic injuries. Some teenagers may be admitted to an adult ward and not be recorded in paediatric data. Incidence rates typically only include children who are admitted to hospital. Those with no obvious physical injuries may not be admitted or may not even attend hospital at all. Some children may only be seen in a clinic or GP surgery. Many receive no medical attention following TBI which Anderson, Hendy, Northam and Wrennall (2001) state accounts for 50% of children who are injured. This may be due to lack of, or unawareness of immediate obvious indicators of injury, or an absence of a supervising adult at the time of the injury.

The enormity of the problem is a cumulative one, with prevalence - the numbers of children affected by ABI (McKinlay et al., 2008) - being very much greater than incidence - the frequency of occurrence (McKinlay & Hawley, 2014), due to long-term, and often life-long effects.

2.3.4. Age at injury

ABI in childhood is significantly different from ABI that occurs in adult life because it occurs against a backdrop of on-going cognitive and physical development (Dennis & Levin, 2004). Acquired brain injury during childhood can cause changes to neurological functioning resulting in impairment to on-going development with significant and lasting consequences (Forsyth & Kirkham, 2012). Typical maturation is suddenly interrupted and injury to a

developing brain alters the course of development. Age at injury corresponds with the extent of cortical development and myelination with implications for functional commitment in relevant brain regions (Dennis & Levin 2004), and therefore the age of the child when the injury occurred has been found to be an important moderator of the effects of ABI. This is particularly salient because children account for a large proportion of individuals who are injured (Jennett, 1996).

2.3.5. Severity of ABI

ABI has historically been commonly categorised as mild, moderate or severe based on medical criteria at the acute period of the injury. Severity is a major determinant of outcome (Anderson et al., 2001; Vu, Babikian & Asarnow, 2011). Generally the greater the severity of injury the greater the magnitude of the deficits (Catroppa et al.,2009). The majority of injuries are mild, and mild ABI is a common phenomenon (King, 1997), often resulting in few significant sequelae (Vu et al.,2011). There is increasing evidence that a small proportion of children with mild injuries can experience enduring effects (Barlow et al., 2010) but symptoms usually resolve by 3 months after injury (Ponsford et al.,2001). In contrast severe ABI is a major cause of morbidity and mortality (Anderson et al., 2001; Popernack, Gray & Reuter-Rice, 2015). Deficits persist, with ongoing cognitive, emotional, behavioural, speed of processing, communication and personality disorders. These create significant changes to quality of life for injured children and their families.

Many research studies on the topic of children's ABI fail to make reference to level of severity and associated outcomes in their studied population. Conclusions can be confusing and misleading if this is not taken into account because of the extreme differences in outcome between children with mild and severe injuries.

2.3.6. Sequelae

The population of children with ABI is a highly heterogeneous one. Many factors impact on sequelae. For example, the age of the child, severity, location and type of injury, medical response and subsequent provision of support services are all highly significant. These factors interplay with recovery and development resulting in changes to cognitive capacity and behaviour over time (Dennis & Levin, 2004).

There is much research to indicate that children with moderate to severe injury can experience wide ranging, complex, learning, behaviour and social/emotional difficulties. (Max et al., 2006; Turner, Rey Casserley, Liptak & Chordas, 2009). It is rare that a child with ABI has a single deficit; multiple problems are common (Emanuelson, von Wendt, Lundälv & Larsson, 1996; Middleton, 2001). This can create unusual profiles of skills and abilities. There may be significant discrepancies due to retention of some skills, and loss or impairment of others, associated with areas of the brain which have been spared or affected.

2.3.6.1. Cognitive skills

A wide range of cognitive difficulties occur following moderate to severe ABI (Hawley et al., 2002). Some of the more common difficulties include:

Attention. The loss of control over many aspects of attentional processes can seriously compromise the ability to learn and socialise. Different aspects of attention - arousal, sustaining, selecting, dividing and alternating attention, may be negatively affected by ABI to differing degrees (Ginstfeldt & Emanuelson, 2010), and with persistent deficits.

Memory deficits Unique patterns of memory profiles following ABI can result in some aspects being compromised while others are spared. Numerous factors may be implicated such as age at injury, and location of injury, as well as functions that support memory acquisition such as attention, processing speed, and executive functioning. Knowledge prior to injury may be relatively well preserved which can lead to erroneous assumptions of good 'recovery' but difficulties with post-injury new learning may become evident over time (Savage, DePompei, Tyler & Lash, 2005).

Executive functioning includes a range of skills required to control and monitor intentional behaviour including ability to plan, organise, problem solve, self-regulate, self-monitor, initiate and inhibit behaviour. Difficulties or deficits with executive functioning skills seriously interfere with many aspects of everyday life - learning, socialising and behaving appropriately (Anderson & Catroppa, 2005; Ylvisaker & Feeney, 2002).

Information Processing The amount, complexity and familiarity of information, memory skills, physical comfort levels and fatigue may all impact on speed of processing abilities (Middleton, 2001). Slowed information transfer is considered to be a result of diffuse injury

to white matter (Wilde et al.,2015). It can be hard for children to keep up with typically developing peers in the classroom and in conversation. For example they may be able to generate constructive contributions to questions and discussion, but the time taken to process the information and formulate a response can result in their comments being perceived as inappropriate to topics that have already shifted in focus.

2.3.6.2. Cognitive-Communication disorders

Childhood ABI is associated with long-term difficulties in producing speech acts (Dennis & Barnes, 2000; Turkstra, Politis & Forsyth, 2015) of which the most common are cognitive-communication disorders (McDonald, 2017). Cognitive-communication disorders are a facet of cognitive disturbance (McDonald, 2000; Dennis & Barnes, 2000; Marshall, 2009), and can be described as problems with communication that have an underlying cause in cognitive deficits rather than a primary language or speech deficit. Traditional notions of language competence and language-based theories of communication based on phonological, syntactic and semantic skills often do not help to characterise the types of communication disturbances experienced by most individuals with ABI (Turkstra et al., 2015; McDonald, 2000). The primary language system of most children with severe ABI resulting from a range of causes, remains intact. Children may recover or retain the surface features of language competence which can mask more subtle significant difficulties relating to the use of language in a broad communication context. Problems with receptive language, word finding, verbal fluency, verbal comprehension, working memory, and pragmatic difficulties such as sensitivity to communication partners and turn taking can result in substantial difficulties processing language efficiently, communicating in an organised way and maintaining social functioning (Dennis & Barnes, 2000). Problems with non-literal and higher-level language uses such as meta-cognition and inference are particularly notable in children with severe ABI (McDonald, 2000).

2.3.6.2.1. Interaction between thought and language

Language plays an important role in directing attention to selected aspects of experience and then conveying that information linguistically (Dipper, Black & Bryan, 2005). Children with severe ABI may be able to form accurate mental representations but they may not be the same as their linguistic representations. Marshall (2009) refers to the “cognitive labour” (p.3)

involved in translating thoughts into language. At the easiest end of the continuum is language that is automatic and “barely mediated by cognition at all” (Marshall, 2009, p.3). Slobin (1996) terms the process of cognitive preparation and mediation as thinking for speaking. If a thought is intended for expression, it needs to be “filtered through language into verbalised events” (Slobin, 1996, p.71). Producing words that correspond in a very direct manner to their referents, as is the case for concrete nouns, is relatively straightforward but abstract language and verbs require much more cognitive mediation (Marshall, 2009).

Distinct forms of interaction between thought and language studied by Dipper et al. (2005) help to guide understanding of the processes involved in converting conceptual representations into linguistic representations, which children with severe ABI may have significant difficulties with. These include:

2.3.6.2.2. Need to relate parts to a whole for constructing events

Dipper et al. (2005) refer to individual aspects of conceptualised events or processes as subcomponents which can be perceptually unitary. They “can be pre-linguistically perceived as units because their subcomponents co-occur in space and time” (Dipper et al., p.419). Relational situations link subcomponents but these are not perceived or conceived of as units in the same way. In order to talk about a situation or process, it is necessary to refer not just to the individual entities involved, but also the relationship between them. “Relationships ... do not occur ready packaged for encoding into language but have to be constructed, unlike the separate entities involved in the event” (Dipper et al., 2005, p.418). Construction of events using verbs and sentences has to minimally include both temporal and relational information (Dipper et al., 2005).

2.3.6.2.3. Need for perspective taking and selective attention

Construction of these relationships involves perspective taking and selectivity; focusing-in on some aspects of events or situations and being able to ignore others. Dipper et al. (2005) describe this as a process of paring down a complex conceptual representation into a schematic linguistic form. This involves subcomponent processes such as focusing on some aspects of temporal, relational and perspective information, back grounding other aspects, and stripping away the rest. “This paring down mechanism must be constrained by linguistic

principles so that the pared down result is linguistically relevant and thereby acceptable as input to the linguistic system” (Dipper et al., 2005, p. 424). Dipper et al.’s (2005) theories accord with Chapman et al. (2004) who refer to discourse macro-level processing - the concept of extracting salient information from connected language which involves reducing and transforming language while preserving the central meaning. Macro-level processing is refined with increasing age. When summarising information, typically-developing young children rely predominantly on the strategy of deletion of less important details and retain important information. Older children are able to combine ideas and provide more comprehensive summaries, and in fewer words, but both age groups are able to successfully transform key information (Chapman et al., 2004). Evidence indicates macro-level processing is vulnerable to the effects of severe ABI in children. This leads to difficulties in formulating responses that demonstrate processing of the most salient parts of information conveyed to them although isolated facts may be recalled depending on task demand on memory (Chapman, Levin & Lawyer, 1999).

2.3.6.2.4. Need to organise thoughts

The linguistic processes operate in interaction with conceptual processing, in that there is a need to know which perspective or role options are available in language before beginning to organise thoughts to reflect this. “Impaired access to linguistic information will rebound on the organisation of thought, which, in turn, will make accessing of specific lexical items and linguistic procedures more problematic. The resulting utterances are likely to lack a main relational term such as a main verb, and corresponding linguistic structure. They may also contain entities that may not be relevant to a particular linguistic description, though they may be present in the perceptual or cognitive event” (Dipper et al., 2005, p.426).

2.3.6.3. Physical functioning

Mobility outcomes following ABI can range from total dependence for all movement to the recovery of preinjury mobility and gross motor skills. Generally children with ABI make a good recovery of gross motor functioning and at a faster rate than other affected functions (Curran, 2014). This can lead to false belief that recovery of less visible areas will be commensurate with the obvious physical gains. Also, a range of less apparent physical changes can endure, with significant implications for learning and socialising, for example sensory impairments,

problems with bowel and bladder control, headaches, sleep disturbance, fine motor skills, balance and fatigue.

2.3.6.4. Behavioural, social, emotional difficulties and personality disturbance following severe ABI (Anderson, Godfrey, Rosenfeld & Catroppa, 2012) can be the most disabling of all problems post-injury (Emanuelson et al.,1996) and present the greatest burden to families and those caring for the injured child because they are difficult to resolve. A wide range of reported changes include emotional volatility, irritability, egocentrism, impulsivity, disinhibition, anxiety, confusion, lack of initiation and interests, loss of social contact, and depression (Ylvisaker et al., 2007, Yeates & Taylor, 2006). Many factors may contribute to these changes. Parts of the brain responsible for self-regulation commonly affected in brain injury can reduce a child's capacity to control their own behaviour. The combination of cognitive, communication, behavioural and speed of processing deficits make it difficult to understand and respond to social cues, possibly leading to feelings of frustration, and emotional outbursts. Contextual factors can be significant, and behaviour difficulties may also be a reflection and magnification of pre-injury behavioural traits.

2.3.6.5. Post-traumatic stress

Post-traumatic stress disorder (PTSD) in survivors of severe ABI and their families are often not addressed or supported. Assessment of symptoms can be complicated by the child's limitations to reliably recall experiences related to the injury events due to compromised cognitive skills (Levi, Drotar, Yeates & Taylor, 1999). It is not surprising that parents as well as their children may experience psychological difficulties related to the child's injury. Parents commonly experience intense grief and loss, and post-traumatic stress symptoms. Parental anxiety, low mood or other PTSD symptoms may affect their capacity to support their child, understand the changes resulting from the injury, and sustain positive relationships (Gosling, 2015), all of which can impact on the child's participation in the family and community.

2.3.6.6. Social skills

Impairments in social functioning following moderate to severe ABI (Marsh, 1999) are associated with long-term deficits in social competence and social problem-solving skills (Janusz, Kirkwood, Yeates & Taylor, 2002). Children become isolated and lonely, have fewer

friends and feel socially dissatisfied (Papero, Prigatano, Snyder & Johnson, 1993; Prigatano & Gupta, 2006). They rely on their families for their social needs, more so than typically developing peers, and demonstrate lower social participation (Anderson et al., 2013; Yeates et al., 2007). Often reported social skill difficulties include impulsivity, immaturity, invasion of private space, inability to initiate and maintain social conversation, egocentricity and poor sensitivity to the needs of others (McDonald, 2000).

2.3.6.7. Impaired self-awareness

Lack of self-awareness is common following severe ABI. A lack of insight of one's own abilities and limitations can lead to unrealistic goals, and effect motivation. There can be lack of compliance when offered supports as the injured child may not perceive there to be difficulties which are obvious to others, and feed-back can be confrontational (Beardmore, 1999).

2.3.6.8. Sense of self: post-injury identity

A sense of self or self-identity refers to the unique and persisting qualities that define who we are (Ownsworth, 2014). One of the most devastating consequences of severe ABI is the challenge it poses to an individual's sense of personal identity. This arises from the effects of the injury itself and the emotional reaction to those effects (Gracey, Olsen, Austin, Watson & Malley, 2015). The loss of sense of self is typically associated with emotional distress such as anger, anxiety, depression and grief (Myles, 2004). The disruption to a person's core sense of self has been referred to as "almost the sine qua non of brain injury" (Jackson & Manchester, 2001, p.27) and a "crisis of the conceptualised self" (Myles, 2004, p. 487).

Sense of identity typically develops gradually from a very young age, and is closely intertwined with an individual's temporal memory, significant others and environmental settings (Sherwin & O'Shanick, 1998). During the pre-school years a positive or negative sense of self is associated with those to whom a child is attached and/or cared for including the degree of security and acceptance provided and the attributes which those others value and model in the way they live their lives. During school years, peer values and peer pressures play an increasingly influential role in how children think about themselves (Smith, Cowie & Blades, 2015). This developing process can become 'derailed' by acquired gaps in memory,

loss of skills and changes noticed in themselves and in comparison to younger siblings and peers. A child's perceived position in the family, and status at school, can be crushed as younger others overtake them in accomplishments. "It changes the young person's experience of being themselves. It alters how they experience the world, and how they think, feel and respond" (Perkins, 2015, p.215).

Despite growing interest in self-identity after brain injury there have been few evidence-based guidelines to support identity-oriented assessment and intervention practices (Ownsworth, 2014).

2.3.6.9. Self-esteem

Self-esteem refers to the child's subjective evaluation of their own worth as a person. Sense of self is not reconstructed from objective functional gains per se, but the personal meaning individuals derive from their everyday experiences following their ABI (Ownsworth, 2014). This is mainly in terms of their perceived competence in areas that matter to them, and which are frequently linked to happiness and well-being (Harter,1999). However, "lack of competence in one domain does not necessarily mean the child has low self-esteem provided that he himself and those whose opinion he values, regularly affirm his competence in areas that matter to him" (Smith et al., 2015, p. 215). Many children with ABI experience low self-esteem and this is closely linked to anxiety and depression (Hawley, 2012). This has also been associated with mood disorders, maladaptive coping and reduced community participation. (Longworth, Deakins, Rose & Gracey, 2018).

2.3.6.10. Hidden disability

Acquired brain injury is often referred to as a hidden disability because there are typically no physical markers indicating an individual has an injury (Simpson, Simons & McFadyen, 2002). Children typically make good physical recovery (Forsyth & Kirkham, 2012). They frequently look the same as they were prior to injury, retain their primary language system and hence their ability to speak, and can often access information in memory stored prior to injury. These help to mask underlying cognitive and communication difficulties and typically create an early assumption by family, friends and school staff that a full recovery has been made (Hawley, 2004), which may help to explain a lack of understanding of changed needs.

2.3.6.11. Delayed deficits

One of the defining features of childhood ABI is that some negative outcomes may not become apparent until several years after the injury (McCusker, 2002; Anderson et al., 1999). Injury to an immature brain can affect neural areas responsible for skills that are in the process of being acquired, or have yet to be acquired. Difficulties may therefore not become apparent until the child reaches a stage later in development when those skills would be expected to emerge and there may be failure to connect new problems with an earlier medical event (Hawley, 2003).

2.3.7. What is rehabilitation?

Rehabilitation aims to restore skills or functioning that have been lost due to injury or disease (Curran, 2014; Forsyth & Basu, 2015). However, recovery for children, unlike adult rehabilitation, cannot be characterised by restoration of pre-morbid functioning alone. The processes need to be conceptualised within a developmental framework, so focus also needs to include the acquisition of new skills and the meeting of further developmental milestones (Gordon & DiMaggio, 2012; Byard, Fine & Reed, 2011), together with help for children and families to adapt to loss and change.

2.3.8. Outcomes for children with ABI

The term 'outcome' is used extensively in healthcare and suggests an end product or ultimate stage that someone has reached. As indicated above, these need to be understood as transitional phases in children. They also need to be contextualised rather than being viewed as isolated points in a child's life because perceptions of the child, family and environment influence interventions (Gosling, 2005). One of the primary concerns associated with paediatric rehabilitation outcomes is the influence of supports to enable a child to participate in everyday life activities (Ylvisaker, 1998).

2.3.9. Rehabilitation in the child's everyday settings

Rehabilitation is commonly perceived to be a time-allocated health service delivered in a clinical setting but for most children, the important rehabilitation service deliverers are in the child's everyday life and locality, including family members, school staff, and local support service providers (Ylvisaker, 1998). Indeed, evidence for the efficacy of paediatric ABI

rehabilitation in clinical settings is limited, and “it is likely that interventions tailored to supporting the child and his or her family in the context in which they live will be the most effective” (Forsyth & Kirkham, 2012, p.1262). This underscores the crucial role of the child’s ‘everyday’ rehabilitation settings, particularly the family, the school, and on-going supports to optimise recovery of function. The need for timely responses from local services can be critical as it represents opportunity to influence recovery of neurological functioning (Lodh, Siddell, Jones & Morrall, 2017). The earlier the child receives rehabilitation to stimulate higher levels of cerebral activation, the greater the opportunities to maximise recovery, minimise potentially serious complications and prevent growing disability (Curran, 2014; Ylvisaker, 1998):

“Data on human brain injury rehabilitation indicates patients spend a large portion of their rehabilitation time with low levels of cerebral activation. In the context of paediatric neuropsychological rehabilitation.....such extended periods of low cerebral activation are particularly unfortunate, as youth no longer appears to be the inherent facilitator of recovery that it had once seemed to be”. (Penn et al., 2009, p.39)

Many difficulties do not emerge until after the child has been discharged from a clinical setting. Processes of re-integrating back into the family, the school and the community may be underway but research indicates that most children return to home and school following severe ABI without any support structures in place (Tomlin, 2002; Hawley et al., 2004). This can have a devastating impact on a child’s potential.

2.3.10. Family adjustment

Changes to a wide range of functions together with growing realisation that pre-injury routines and activities may never be resumed can have a profound long-term impact on the family (Semrud-Clikeman & Ellison, 2009). Disruptive effects to family life and the negative impact on parents and siblings have been well documented, and although different family members may be affected in different ways, there is evidence of a ‘ripple’ effect (Lezak, 1988; Gan & Schuller, 2002). Parents frequently experience intense feelings of prolonged grief, loss, hopelessness, and guilt - what is frequently referred to as ‘parental burden’ which does not dissipate over time, on the contrary there is evidence that it increases (Wade et al., 2006). High levels of psychological stress, health problems, social isolation, and feelings of

disconnection are often reported (Wade et al., 1998; Tyreman, Eccles & Gray, 2017). Lack of understanding and support, and parenting a different child were additional challenges highlighted by Tyreman (2015). Parents experience much anxiety and worry due to experiencing an “unexplicable rupture in their taken-for-granted worlds” (Guerrier & McKeever, 1997, p.113). They may also have financial difficulties due to extended time off work or relinquishing of employment while supporting their child (Hawley et al., 2003).

Siblings are often profoundly affected but their needs may be overlooked by service providers. They may have witnessed the circumstances leading to the injury, they may experience a high level of distress at the near loss of their injured brother or sister, and/or have difficulties in adjusting to the physical and psychological changes associated with the injury, the changes to sibling status, and to family life (Tyreman, Eccles, Gray & Murray, 2018).

Although support from family members plays a critical role in the child’s recovery and on-going development (Braga, Júnior & Ylvisaker, 2005; Tyreman et al., 2017), parental ability to pro-actively and effectively provide support for their child following the injury may be impacted by their own psychological adjustment to the injury (Brown, Whittingham, Sofronoff & Boyd, 2013; Tyreman et al., 2017). Gerring and Wade (2012) report a clear link between the home environment and outcome. For example, emotional and behavioural difficulties experienced by a child with severe ABI can be ameliorated by a supportive home environment (Bozic & Morris, 2005). Conversely, higher parent distress post injury has been found to be associated with poorer child outcomes (Taylor et al., 2001). There is substantial evidence to demonstrate a negative impact on family functioning after a child has suffered a moderate to severe ABI (Rashid et al., 2014; Wade et al., 2004). Predictors of family adjustment include pre-injury functioning, severity of the injury and the deficits, access to resources, support and information, family cohesion and parent coping styles (Aitken et al., 2009; Wade et al., 2004). The extent of family burden is greater in families who report high levels of stress and maladaptive coping styles. There is also a dynamic bi-directional relationship between outcome, family adjustment and competence (Taylor et al., 2001). This can be conceptualised in terms of “a negative spiral” (Taylor et al., 2001, p. 762) in which the effects of the ABI impact on the child’s behaviour and threatens family adjustment. Problems in family adjustment then make it difficult for parents to deal effectively with the child’s behaviour.

2.3.11. Parent information and support needs

Information and support that parents find useful may not only help them to address complex difficulties at home, in school and in the community, but as indicated above, can contribute to family adjustment which can have a positive impact on the child's progress and development (Savage et al., 2005). However, many parents report feeling abandoned by services after discharge home; anxious and alone with the responsibilities of caring for their child (Kirk, Fallo, Fraser, Robinson & Vassallo, 2015). Unmet needs include lack of hospital and school liaison, therapy services, emotional support, and help for understanding cognitive and behaviour changes following ABI (Rosignano & Swanson, 2011; Armstrong & Kerns, 2002). Parental concerns about the school return relate to the extended period of time their child has been absent, the social and academic implications of that, and the impact of ABI on learning and socialisation (Kirk et al., 2015).

Meeting information and support needs is frequently problematic as staff from services in a position to provide support frequently have insufficient awareness, knowledge and understanding themselves (Rosignano et al., 2015; Jones, Davis, & Tyson, 2017). This makes them unable to appreciate the need, and unable to provide the information required by parents. Rosignano and Swanson (2011) found that even when advice was forthcoming, parents sometimes felt it to be too premature in terms of deciding options, or information was too medically focused, or biased, and there was a failure by service providers to appreciate a holistic perspective.

In the face of a myriad of concerns, the lack of information and understanding by others means that parents may have to take on a number of different roles in addition to that of care-giver, and often have to proactively advocate, indeed may be the only advocate, for their children's additional needs to be accommodated (Rosignano et al., 2015).

2.3.12. Schools: important providers of on-going rehabilitation

Returning to what is familiar is extremely important to a child's sense of self following ABI (Sharp, Bye, Llewellyn & Cusick, 2006). The return to the school and the peers they know can be just as important as returning to the familiarity of home. Schools are considered to be the principal provider of on-going rehabilitation services for children following ABI (Ylvisaker,

1998). A range of school factors play a major role in determining the extent to which they are able to 'fit back in' (Sharp et al., 2006; Limond et al., 2009). It is generally agreed that considerable preparation is required for successful school re-entry but research evidence about this is limited. In a study by Glang et al., (2008) it was found that communication between the discharging clinical setting and the school to which the child returned was instrumental in providing relevant support; lack of liaison was associated with lack of support. The majority of children hospitalised with ABI are discharged without adequate follow-up or support, even for children with severe injury (Tomlin et al., 2002) and there is much criticism about education services failing to respond to the needs of this population (Hawley et al., 2004).

Although ABI can spare or impair any function or combination of functions, outcome is more commonly dominated by cognitive, behavioural and psychosocial difficulties than by physical impairments (Ylvisaker & Feeney, 1998). Upon return to school following ABI, determining the focus of educational goals and intervention can be difficult when the child has a complex profile of changed needs. Szekeres and Meserve (1998) highlight the "content-process dilemma" (p.395): the common educational focus on curriculum content such as catching-up on work that has been missed, versus focus on interventions to address impaired cognitive functioning such as inefficient information processing, memory problems, disorganisation of thought and deficient executive functions. Szekeres and Meserve (1998) emphasise the importance of both as being essential for successful outcomes. The need for post-acute neurorehabilitation after childhood ABI is increasingly recognized, and there is acknowledgement that intervention in the child's everyday settings are more effective than those that are clinic based, which underscores the importance of the school's role (Slomine & Locascio, G., 2009). School provides the most opportunities for rehabilitation because that is where they spend the majority of their waking day (Shaw, 2009). However, there is a limited evidence-base and absence of effective models for guiding on-going cognitive rehabilitation following childhood ABI which has led to a lack of clarity about intervention (Limond & Adlam, 2015).

An educational approach with potential for addressing cognitive difficulties that EPs are well placed to support school staff in implementing is 'Instrumental Enrichment' (Burden, 2000; Hill, 2015), a programme developed from Reuven Feuerstein's theories (Feuerstein,

Feuerstein, Falik, & Rand, 2006) which attempt to understand and improve an individual's cognitive ability. Its main theoretical components, structured cognitive modifiability and an active adult-directed process called mediated learning experience are based on Feuerstein's belief that cognitive ability is not static or fixed, but can, with appropriate mediation be modified to enhance learning potential. Provision of mediated learning experiences may provide useful insights and direction to help children with impaired cognitive skills following ABI, and provide a dynamic neurocognitive rehabilitation approach in schools (Dorfzaun-Harif et al., 2015; Lebeer, 2016).

2.3.13. Lack of knowledge in schools

Returning to a supportive school environment following ABI is critical for successful integration and participation. Schools may be well placed to meet the needs of children with ABI, but a proactive response usually requires staff to have knowledge and understanding about brain injury, information about the particular child's own brain injury, and how to support changed needs (Ashton, 2015). Given the lack of information and advice at hospital discharge, and within the EP service (Bozic & Morris, 2005), and insufficient in-service training opportunities for teachers, it is not surprising that school staff indicate lack of knowledge themselves (Linden, Glang & McKinlay, 2018; Howe & Balls, 2017). This commonly makes them ill-prepared to support a child with ABI, thereby reducing opportunity for successful participation (Galvin, Froude & McAleer, 2010). This can lead to reduced expectations and over-protection (Eiser, 1996). McCusker (2005) considers lack of knowledge can lead to teacher 'denial' of any problems; "denial avoids the dissonance of feeling unskilled" (p.25).

2.3.14. School staff perspectives and beliefs on inclusion

Including students with diverse needs in mainstream school is a central tenet of education policy and planning in Britain. Contextual factors help to determine the extent to which children are successfully included and able to participate at school (Laluvein, 2010a). This is important to understand because children with ABI are at increased risk of bullying and social isolation (Crothers, Linden & Kennedy, 2007; Muscara, Catroppa, Anderson & Eren, 2009) and exclusion (Hawley, 2004), all of which impact on participation, learning and development. Teacher perspectives and belief systems about the inclusion of children with significant special educational needs (Jordan, Schwartz & McGhie-Richmond, 2009; Savolainen,

Engelbrecht, Nel & Malinen, 2012) are influential factors. Level of teacher concern, indifference or rejection of children with disabilities can directly impact on children's educational experiences and opportunities to participate (Silberman, 1971; Cook, 2001). Teacher resistance to inclusive practices is sometimes explained in terms of fear of difference and the unknown, which Robinson and Goodey (2018) refer to as "inclusion phobia, disrupting their sense of wholeness and impacting on their capacity to practise inclusively" (p. 426). Robinson and Goodey (2018) argue that this phobia's deeper roots are underpinned and perpetuated by "systemic dysfunctions" (p. 426) within society, manifested in irrationalities and contradictions related to labelling, acceptance and rejection, and education policies. For example, Kvalsund (2004) asserts the label 'children with special educational needs' is synonymous with the categorisation of children as the "carriers of the problem" (p.160). It signifies child deficit and failure which averts attention away from contextual settings. Kvalsund (2004) emphasises the importance of understanding the operating mechanisms of inclusion; close scrutiny often reveals practices in schools considered to be inclusive can be disguised forms of exclusion.

The provision of special schools reinforces inclusion phobia in mainstream schools. It persuades mainstream school teachers that "they may not be sufficiently knowledgeable or sufficiently expert to help children who are experiencing difficulty: that they do not have sufficient technical expertise or theoretical knowledge to teach all children" (Thomas & Loxley, 2001, p. 7). This compartmentalisation and the framework in which it is set creates a loss of confidence, or feelings of inadequacy in teachers (Paliokosta & Blandford, 2010) and distracts attention away from the ways in which humanity and common sense should be used to make schools more inclusive (Thomas & Loxley, 2001). Children's additional and sometimes complex needs also place extra responsibilities and demands on teaching staff (Olsen, Seidler, Goodman, Gaelic & Nordgren, 2004) who may already feel overstretched. Paliokosta and Blandford (2010) explain teacher resistance to understanding, accepting and accommodating difference, to be a reflection of complex dynamics operating at different levels within schools such as a lack of flexibility at the systemic level; limitations in teacher training, resources, funding and time management at a sub-system level, and a lack of communication at the micro-system level.

2.3.15. Leadership in schools plays an important role in the extent to which difference is embraced, the ways in which positive or negative perspectives and beliefs are nurtured, tolerated or rejected. The commitment, support and active involvement of headteachers and other senior leaders are essential for the creation of fully inclusive schools (Mapp, 2002), which involves more than supporting teaching and learning. A critical lead is required “to reveal and challenge deeply entrenched deficit views of difference” (Ainscow, Booth & Dyson, 2006, p.175), both within school and in the wider society. The relationship between parents and teachers can be conflictual and contradictory (Laluvein, 2010b), characterised by diverse agendas, expectations and priorities. Leaders need to take decisions and actions, and demonstrate behaviours that are informed by a range of influences, tensions and differences embodied in the local community’s values and beliefs, as well as those in the wider society (Male & Palaiologou, 2017).

2.3.16. Teaching Assistant (TA) support in mainstream school

Models of support for children in mainstream school with additional needs rely extensively on the use of Teaching Assistant time to provide one-to-one support. This reliance has been referred to as “the solution to inclusion” (Rutherford, 2012, p.760) and described by Giangreco (2013) as a necessary mechanism: “Teacher assistants have become almost exclusively *the way*, rather than *a way*, to support students with disabilities” (Giangreco, 2013, p.94).

The appropriateness and value of practices associated with the deployment of TAs has been seriously challenged (Giangreco, 2013) and has created a paradox of inclusion in disabling schools (Kvalund, 2004). This ubiquitous model is one of the most restrictive methods of support in schools and inadvertently perpetuates low expectations (Butt, 2016). The close proximity of TAs has also been found to have negative effects on peer interaction, dependence and learning (Blatchford, Russell & Webster, 2012). This can lead to inadvertent detrimental effects including separation from peers and reduced peer interaction, increased dependence and discouragement from working independently, insular relationships between pupils and TAs, limited access to competent instruction, loss of personal control and increased risk of being bullied (Broer, Doyle, & Giangreco, 2005; Giangreco, 2010; Webster & Blatchford, 2013). One of the major findings is the negative relationship between the amount of support

provided and academic progress: the more individual TA support provided, the less progress children made (Farrell, Alborz, Howes & Pearson, 2010; Webster & Blatchford, 2013). Problems included the high frequency of TAs engaging in instructionally unhelpful approaches such as providing inaccurate or confusing information, supplying answers, and placing greater or exclusive focus on task completion than conceptual understanding. TAs may be “doing for” the children instead of encouraging them to “do for themselves” (Deci, Hodges, Pierson & Tomassone, 1992, p.457). This one-to-one model of TA support negatively impacts on the capacity of the supported child to be included, with the child experiencing feelings of separation and difference. It not only creates a barrier between the child with SEN and the other children in the classroom, but teachers inadvertently separate themselves from the educational experiences of that child (Giangreco, 2013). This mechanism for inclusion is perhaps a reactive stance by school staff who feel overloaded and ill equipped to embrace further special needs in the mainstream classroom.

The difference between teachers and TAs is commonly but erroneously portrayed as teachers having direct teaching input while TAs support pupil learning. Blatchford et al. (2012) highlight the increasing lack of clarity of role distinctions with concern for what they term “role-creep” (p.70) with TAs taking on too much of the teacher’s role, and the absence of compelling evidence about the effectiveness of such a support strategy. In relinquishing instructional responsibilities to TAs, teachers are frequently assigning the least qualified personnel to pupils who present with the most complex learning difficulties (Rutherford, 2011). Giangreco and Broer (2005) reported nearly 70% of TAs receive minimal supervision and make curricular and instructional decisions without oversight from the teacher in charge of the related lesson. They refer to serious equity concerns for students with disabilities, and question whether this “reflects the devalued status of some students with disabilities, disguised in a cloak of helping” (Giangreco & Broer, 2005, p.16).

2.4. Part Two: Research Literature about Participation

The term ‘participation’ is often used to describe very different processes (Kirby, Lanyon, Cronin & Sinclair, 2003). Broadly defined, participation can mean taking part in any activities or tasks, or more specifically it can denote consultation and empowerment whereby views of

participants influence decisions that affect them (Franklin & Sloper, 2006). This latter definition was developed by Arnstein (1969) with a typology of levels of empowerment represented as rungs on a ladder providing a hierarchical distinction between the extent of people's decision-making in community development. One of the fundamental values of the United Nations Convention on the Rights of the Child (UNCRC, 1989) was for all children to be heard, taken seriously and to participate in decision making. This stimulated various adaptations of Arnstein's model to represent the extent to which children make a contribution to projects. Two of the most widely referenced and used are Hart's (1992) 'Ladder of Participation' and Shier's (2001) 'Pathways to Participation'. They indicate hierarchical processes and infer positive action for enabling children to express their views and influence decision-making. For example, Shier's model is based on 5 levels of engagement: 1. Children are listened to, 2. Children are supported in expressing their views, 3. Children's views are taken into account, 4. Children are involved in decision making processes, 5. Children share power and responsibility for decision making. It does not have any equivalence to the lower 3 rungs on Hart's ladder that refer to non-participation: 'manipulation', 'decoration' and 'tokenism'. Shier's (2001) model was used as a reference guide when identifying appropriate methods for seeking the views of children in the current study.

The primary focus of the current study uses the term participation in the more broadly defined meaning of taking part in activities. The World Health Organization promotes participation as an essential part of healthy life and it is a key component in the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). This model provides common terminology for health, education and social care practitioners, researchers and policy makers (Simeonsson, Simeonsson & Hollenweger, 2008), and highlights the relevance of interactions between child and environment for defining outcomes (Simeonsson, 2005). It is therefore considered by the current researcher to be well suited for helping to contextualise participation in the home, school and community following childhood ABI. Discussion of participation is therefore preceded by information about the ICF and the children's version of the ICF.

2.4.1. International Classification of Functioning (ICF)

Terminology, definitions and classifications of disability change over time. Historically the use of taxonomies have focused on medical conditions within an aetiological framework in which disabilities are attributed to the individual as an intrinsic characteristic of the person, based on symptoms of pathology (Simeonsson, 2009).

The World Health Organisation's International Classification of Functioning, Disability and Health (ICF) (WHO, 2001), and the children's version, The International Classification of Functioning, Disability and Health – Children and Youth (ICF-CY) (WHO, 2007), see below, are relatively new conceptual frameworks in the fields of disability and rehabilitation. They provide a paradigm of disability in which the medical model of disability has been replaced by a bio-psycho-social model that recognises the social and cultural contexts of disability (Simeonsson, 2009). The ICF is so named because of its emphasis on health and functioning rather than on disability.

“Previously, disability began where health ended; once you were disabled, you were in a separate category. We want to get away from this kind of thinking. We want to make ICF a tool for measuring functioning in society, no matter what the reason for one's impairments” (WHO, 2002, p.3).

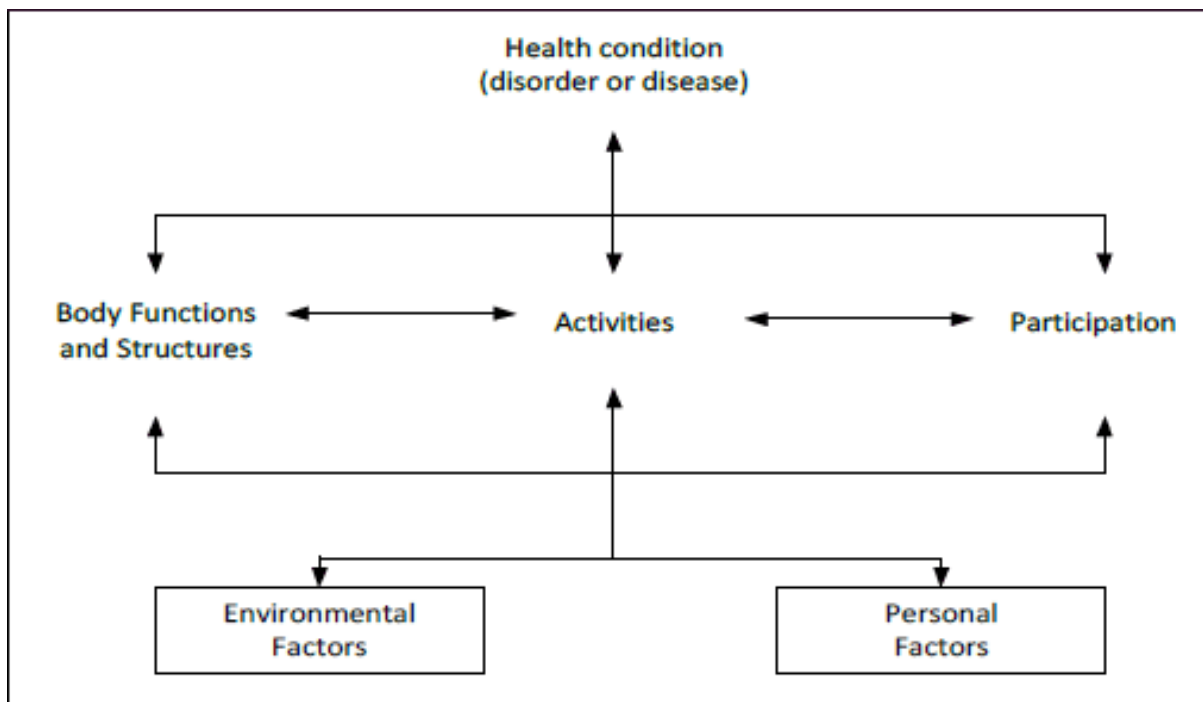
It constitutes a radical shift from a focus on disability and cause, to the impact it has on people's lives (McConachie et al., 2006; Adolfsson, 2011). The medical and social models of disability were often presented as dichotomous. The social model originally took an uncompromising stance that all disability is due to societal and structural barriers such as negative attitudes, segregated education, and lack of building accommodations to enable access for people with physical difficulties (Colver, 2009). The model has now been modified to acknowledge that disability needs to be perceived neither as only medical nor only social. It is multi-dimensional in nature, a dynamic interaction between health conditions and contextual factors (WHO, 2011).

2.4.2. International Classification of Functioning-Children and Youth (ICF/CY)

Acknowledgement that significant developmental changes occurring over the course of childhood, and manifestations of functioning, disability and health conditions in babies,

children and young people are different in nature, intensity and impact to those in adults led to the development of the ICF version for children and youth (WHO, ICF/CY, 2007). The ICF/CY is based on the original ICF framework but oriented to the specific needs, situations and patterns of childhood development, underpinned by Bronfenbrenner and Ceci's (1994) ecological model which conceptualises a child's adaptation as a function of ongoing bi-directional interactions between the child and the environment over time (Lee, 2011).

2.4.3. The ICF constructs



The ICF Model (WHO, 2001)

The three key constructs/components in the ICF and ICF/CY are:

- **Body functions and structures** This refers to the physiological functioning, and anatomical aspects. Problems are defined as impairments such as diseases, disorders or injuries.
- **Activities** This refers to the execution of tasks, for example walking or eating - what a child **can** do. Activity limitations can be difficulties that an individual may have in undertaking activities of daily living such as washing or dressing.

- **Participation** This is defined as “involvement in a life situation” (WHO, 2002, p.10) and refers to what a child **does** do in environments where children spend time (Adolfsson, Malmqvist, Pless & Granlund, 2011), most notably home, school and local community. Participation restrictions are problems a person may experience when involved in activities such as learning or socialising (WHO, 2001).

Although the ICF and ICF-CY provide distinct definitions of activity and participation, they do not clarify how to separately operationalize the two concepts. There has been much debate, with some ensuing consensus, that activity and participation are separate endpoints on a continuum of actions (Granlund et al., 2012).

2.4.3.1. Environmental and personal factors

The ICF recognises that the life, functioning and disability of an individual occurs in contexts. Impairments, activities and participation are influenced by environmental and personal factors (McConachie, Colver, Forsyth, Jarvis & Parkinson, 2006).

Environmental factors, or contexts, include the physical, social and attitudinal features of the settings in which people live their lives, for example, provision of increased access, family support, peer relationships, social attitudes, health and education systems (WHO, 2007). Children’s everyday environmental settings are important contexts in which they learn and develop. The social model of disability represented in the ICF-CY proposes that the interaction of the individual with aspects of their environment defines the nature and extent of participation (Simeonsson et al., 2001; Coster et al., 2012). Participation is about what a person does in real life and so is considerably influenced by the environment they are in. The environment is therefore an intrinsic part of the participation experience, acting as a pre-requisite and ‘scene-setter’ (Badley, 2008). Reduced participation does not result from any difficulty or problem intrinsic to the individual, but from interactions between the individual and the environment they are in (Colver, 2009).

Personal factors, include factors such as age, gender, race, values, beliefs, coping styles, habits, preferences, personal choice, past experience and social background (Colver, 2009; Adolfsson et al., 2011).

2.4.4. Common conceptual framework for interdisciplinary practice

The change of focus from discipline specific classifications to a classification of functional characteristics provides a shared framework and terminology for supporting children with disabilities which encourages 'joined-up' practice (Simeonsson et al., 2006). It is being increasingly used internationally within and between disciplines (WHO, 2007), especially in the field of rehabilitation, but to a more minimal extent in education (see below).

2.4.5. Application of the ICF/CY to education and educational psychology

Carlson, Benson, and Oakland (2010) in the USA describe a range of applications of the ICF/CY framework within education and school/educational psychology. However, a systematic literature review of the application of the ICF across education systems internationally (Moretti, Alves, & Maxwell, 2012) concluded that, despite clear potential, progress in embracing the ICF model by educationalists appears to be slow. Norwich (2014) regards recent changes in the English SEN system, The Children and Families Act (CFA, 2014), to be a missed opportunity in its disinterest and failure to embrace the ICF/CY framework, "suggesting a gap in contemporary conceptions of how to think about and develop appropriate educational identification systems" (Norwich, 2014, p.419).

Perhaps this reported lack of interest is actually a lack of awareness of the ICF/CY and its potential within educationally-related disciplines. Moretti et al.'s (2012) review indicated that articles about the applicability of the ICF/CY in education have been mainly published in non-education journals (Maxwell & Koutsogeorgou, 2012; Maxwell, Alves & Granlund, 2012). For example, a paper advocating the use of the ICF/CY as a basis for decision-making about additional or different educational support (Hollenweger & Moretti, 2012) is published in a medical journal, thereby making its exposure to professionals in education unlikely.

2.4.6. Participation

The concept of participation, a many faceted phenomenon, has become important for understanding and describing human functioning in everyday life. It is an essential condition for learning to occur (Simeonsson et al., 2001) and is important for well-being and improved quality of life outcomes for children with and without disabilities (Van Tol, Gorter, DeMatteo & Meester-Delver, 2011). Participation enables people to develop skills and competencies,

form friendships and relationships, achieve good mental and physical health, develop a self-identity, and determine meaning and purpose in life (King et al., 2003). It leads to increased independence, academic achievement, and social inclusion (Simeonsson et al., 2001; Eriksson, Welander & Granlund, 2007).

The ICF/CY classifies participation into nine domains: (1) Learning and applying knowledge, (2) General tasks and demands, (3) Communication, (4) Mobility, (5) Self-care, (6) Domestic life, (7) Interpersonal interactions and relationships, (8) Major life areas and (9) Community, social and civic life.

2.4.6.1. Defining participation

Although a key construct in the ICF/CY, there has been no universal agreement on the definition of participation, with continued debates and interpretations about its conceptualisation and measurement (Imms, Froude, Adair & Shields, 2016; Dijkers, 2010). The uncertainties associated with the definition may be due to dual conceptual roots relating to functioning within a context (Maxwell et al., 2012). The sociological perspective is about availability and accessibility to everyday experiences, akin to inclusion, and represents the social model integral to the ICF/CY that emphasises participation restrictions are socially constructed phenomena. The psychological perspective considers the intensity of involvement which reflects how individual children manage and experience situations. Participation has a strong social component within its definition (Bedell, Haley, Coster & Smith, 2002) with the commonly understood meaning of participation as one of experiencing being a part of (Almqvist & Granlund, 2005), or a feeling of belonging and engagement (Eriksson & Granlund, 2004) in an activity with others, often socially. However, the ICF/CY definition also includes involvement with basic tasks such as eating or personal care, for example toileting or moving around, and other activities which may be undertaken alone (Adolfsson, 2011). Eriksson (2006) states participation to be a multi-dimensional concept consisting of personal factors, interactions and contextual prerequisites. She acknowledges that this makes it hard to distinguish between participation and the factors related to it. She considers participation is more related to autonomy and interactions with significant others than disability type and general environment. Maxwell (2012) theorises participation from two perspectives – frequency and intensity of involvement. A review by Imms et al. (2016)

endorses this theory, stating that attendance and involvement seem to describe the essence of the participation concept. They highlight the need for researchers to define the construct and select measures carefully, as measurement choice is the mechanism through which the concept of participation is operationalized in research.

2.4.6.2. Subjective experiences of participation

It is argued that the contextual factors (environment and personal) in the ICF framework are objective dimensions which, without the subjective and lived experiences of people with disabilities, fail to capture the full meaning of participation (Imrie, 2004). The ICF/CY only accounts for the 'doing' but not the experience of doing, the feelings and perceptions about an individual's relationship with activities which are best evaluated by the children themselves (Adolfsson, 2011). On the basis that increased subjective experience of involvement is associated with better psychological health, there is much advocacy for it to be an independent dimension of functioning, and would also enable greater understanding of people with disabilities (Ueda & Okawa, 2003; King et al., 2013).

2.4.6.3. Difference between Participation & Inclusion

Participation and inclusion have close conceptual ties and are intimately linked but they are independent and complementary dimensions of engagement (Quick & Feldman, 2011). Inclusion is about being allowed or enabled to take part, whereas participation is about actually taking part (Davis & Hill, 2006). Inclusion is a societal ideology, and a process involving the creation of opportunities for those with disabilities to learn and live alongside their non-disabled peers. There has been a common assumption that inclusion is primarily about educating children with disabilities in mainstream schools which children with disability are not always fully included in. Ainscow et al. (2006) plead for a broader conception to include barriers to learning, and developing capacity to respond to diversity, which Roaf (1988) argues is about an agenda of rights. Asbjornslett, Engelsrud and Helseth (2015) consider a true inclusive pedagogical approach is about the creation of classroom communities in which everyone participates, which means ensuring schools place a high priority on educating all children in the same setting, with an associated concern for the educational experiences and outcomes of all children (Slee, 2001). This implies a "whole

school approach to social relations and production of meaning reached through processes of negotiation between parents, teachers and children” (Laluvein, 2010a, p.35). “Taken to its logical conclusion, inclusion is about comprehensive education, equality and collective belonging” (Thomas & Loxley, 2001, p.118). Inclusion provides opportunities for participation in environments. What actually occurs in those environments is the more important issue and mediates the relationship between inclusion and positive child outcomes (Simeonsson et al., 2001).

2.4.6.4. Participation: an under-researched area

For the past 20 years UK governments have embraced and promoted the development of an inclusive education system (DfEE,1997), providing much documentation to guide education providers. There has also been a plethora of research and publications on the processes and practices of inclusion, together with varying definitions which reflect differences in belief about what schools can and should achieve in terms of human interaction and organisational arrangements to embrace diversity (Dyson, Farrell, Polat, Hutcheson & Gallannaugh, 2004; Connor, 2014). In contrast, participation is an under-researched area. Participation is considered to be a key factor in the lives of children and young people with special needs but the mechanisms by which it influences outcomes are poorly understood.

2.4.6.5. Participation of children with disabilities

Children with disabilities have been found to participate less than typically developing peers at home, at school and in their communities with indications of many implicated factors in inclusive settings such as negative attitudes, unsupported physical and social environments (Law, Petrenchik, King & Hurley, 2007). Children with disabilities frequently don't have optimal opportunities to participate. Eriksson et al.(2007) found differences in participation at school to be dependent on the type of activity and also that participation was closely related to autonomy rather than age or type of impairments. However, age has been found to make a difference because perceived environmental barriers increase as children get older due to increasing expectations of independent participation at school, and as they seek to expand their recreation and leisure activities in the wider community (Stevenson, Pharoah & Stevenson, 1997; Law et al.,2007). Outside school participation of children with physical

disabilities is characterised by sedentary activities and fewer social activities, especially those of a spontaneous nature (King et al., 2003; King et al., 2009).

2.4.6.6. Participation of children with acquired vs congenital disabilities

Studies have explored the participation of children with disability, including children with ABI, and comparisons have been made to non-disabled peers. No research studies have been identified in the literature comparing participation of children with congenital disability to children with acquired disability. Research studies with adults indicate that those with congenital disabilities are generally better adapted than those with acquired disabilities (Bogart, 2014) which can play a crucial role in identity, self-concept and self-efficacy (Smart, 2008; Li & Moore, 1998; Bogart, Tickle-Degnen & Ambady, 2012). This suggests that participatory experiences may also be very different. Bogart (2014) found that adults with acquired deficits grieve over a loss of functioning whereas those with congenital disabilities may not have experienced any loss. Adults with congenital disabilities may have no pre-morbid identity and therefore may be more likely to consider their disability to be an inextricable part of themselves.

2.4.6.7. Participation in everyday life following ABI

Dematteo et al. (2011) consider there to be a lack of studies generally about participation in the home, school and community following childhood ABI. They attribute this to a paucity of specific measures for this population, and the fact that participation as an outcome has only recently been considered and so is not yet widely included in outcomes research. Research on adult participation outcomes following ABI is available (Curtin et al., 2011; Brasure et al., 2013) but there may be little shared basis for comparison with outcomes for children.

2.4.7. Including children in research

“It can be argued that without some kind of access to the content of a person’s experience, we have a very incomplete account, from a scientific perspective, of what it is that causes any person, adult or child, to act as they do” (Greene & Hogan, 2005, p.2).

Historically, research on children was about them rather than with them (Bucknall, 2014). Assumptions were made about age and immaturity rendering children incompetent and unreliable informants, incapable of understanding the research process, or making informed

decisions about participating. A significant shift in thinking was prompted in part by the United Nations Convention on the Rights of the Child (UNCRC, 1989) and the Children Act (1989) which emphasised the importance of enabling children to give their opinions on matters and decisions that affected them. Greene and Hogan (2005) ally the researching of children's experiences and opinions to a moral perspective on the role and status of children; there needs to be respect and promotion of their right to be considered as people in the 'here and now', to be perceived as equal human beings, with value given to their current perspectives and experiences, rather than them just being seen as representing future potential. Furthermore, "adults can learn much about ways to enhance children's lives by listening to them" (Dockett et al., 2009, p.285). It's also important that children themselves report on their health, functioning and well-being because subjective feelings can be known only to them (Topolski, Edwards & Patrick, 2004). Young et al. (1995) exploring the contributions of child self-reports during the development of a new physical disability scale declared children rather than adult observers or adult proxies, to be the preferred reporters – errors were associated with proxy reports (Sprangers & Aaronson, 1992), and abilities observed in clinical settings did not consistently reflect abilities in the community. Children in the Young et al. (1995) study were found to be competent respondents able to evaluate their own physical disabilities. However, research studies that rely solely on child self-reports rather than adult reports may not necessarily always provide as broad and useful a perspective as indicated by Young et al. (1995). Firstly, children with significant cognitive difficulties were excluded from their study. Also, self-awareness deficits are common following ABI (Bach & David, 2006; Beardmore, 1999) indicating that both a child perspective, characterized by the parent/carer's outsider view on the child, as well as a child's perspective, characterized by the child's insider view, are required (Sommer, Pramling, Samuelsson & Hundeide, 2010). Nilsson et al. (2015) perceive these as different ends on a continuum ranging solely from an adult's view of children, to solely the perspective of children themselves.

Working with children on research studies is different from working with adults, and these differences present dilemmas which have an impact on every aspect of the research: design, methods, ethics, participation and analysis (Punch, 2002). Discussions about doing research with children have mainly focussed on ethics especially the issues of informed consent,

confidentiality and the unequal power divide between the adult researcher and the child participant (Lewis & Lyndsey, 2000; Mayall, 2000; Punch, 2002). Alderson and Goodey (1996) consider the main complications of the power divide arise not from children's abilities or misperceptions, but from the position ascribed to children. Adults typically have authority over children - children are not used to being treated as equals and so can find it hard to assent, disagree or say things they think might be unacceptable (Mayall, 2000). An interview is a social exchange in which the social demands may outweigh the demands of the interview, and this can result in children giving answers influenced by their desire to please rather than their desire to be truthful (Morrow & Richards, 1996). There may also be a tendency for children to answer 'no' to closed questions they don't understand (Waterman, Blades & Spencer, 2001).

Punch (2002) emphasises additional issues for researchers working with children that she considers have not commonly been adequately accounted for. These include the importance of developing rapport, not imposing the researcher's own views and interpretations, the clarity of language used (children may have limited and different use of vocabulary and understanding of words), and the research context, for example many settings are adult spaces where children have less control. Cree, Kay and Tisdall (2002) identify significant gaps between the principles of good practice in research with children, and the practical realities: "it seems likely that there are no answers to the questions raised, but that the act of posing the questions may contribute to the development of better, more reflexive research with children" (p.47).

2.4.7.1. Including children with disabilities in research

Although the involvement of children is generally becoming increasingly common, there continues to be much child-related research that does not include them as active participants (Bucknall, 2014). This is even more so in research on children with severe disabilities, especially children with cognitive and/or communication impairments (Lloyd, Gatherer & Kalsy, 2006; Tangen, 2008). Researchers have generally avoided the practical and ethical difficulties often associated with interviewing individuals with complex impairments (Paterson & Scott-Findlay, 2002). Palikara, Lindsay and Dockrell, (2009) investigating the views of young people with language impairment found it to be "a challenging task, even for

professionals trained to work with this group of young people” (p.59). Reference has been made by a number of researchers working with children, to the importance of choosing flexible multi-method approaches that capture children’s interests and motivation (Lewis & Lindsay, 2000; Clark & Moss, 2001), and especially for eliciting the voice of child populations that are rarely heard. However, choice of methods to elicit the voice of children with severe and multiple impairments may be extremely restricted due to the nature of their difficulties.

2.4.7.2. Listening to the voice of children with ABI

Eliciting the views of children with severe ABI can be particularly challenging which may explain why few related studies include their voice. Boylan, Linden and Alderdice (2009) describe children with ABI as doubly vulnerable due to their immaturity and young age, compounded by the sequelae which accompany their injury. Reference has also been made in studies of participation to the absence of the child’s insider perspective (DeMatteo et al., 2008; McConachie, 2006). It is important to listen to children’s voices to help understand and develop inclusive practices and enhance participation, but more importantly taking their views and wishes into account is an essential part of being inclusive (Messiou, 2006). It is perhaps ironic that most studies on the participation of children fail to include the participation of the injured children themselves. Participants in the DeMatteo et al. (2008) study exploring living environments for children with ABI were described as ‘key informants’: “people with knowledge and experience in the field of acquired brain injury and children’s services, including acquired brain injury service providers, government ministries, and advocates” (p.1804). Children are arguably the most essential ‘key informants’ as indicated by the literature, yet their voice was not included, nor those of family members, or school staff.

Children with severe ABI commonly experience a wide range of cognitive difficulties that impact on their communicative abilities. Difficulties with information processing, abstract concepts, working memory, retrospective memory, and attention can lead to significant deficits in narrative production (Vu et al., 2011, Dennis & Barnes, 2000) and ability to respond to the kind of questions posed in interviews as well as the Child and Family Follow-up Survey self-report version reported above. Physical and behavioural difficulties such as impulsivity can also interfere with communication exchanges. For example, fatigue, very commonly

experienced by those with severe ABI, can increase physical discomfort, provoke behavioural, cognitive and communication difficulties, and lead to an unsuccessful interview scenario. Thinking is often literal and concrete, so making abstract concepts difficult to understand. Paterson and Scott-Findlay (2002) interviewing adults with brain injury found that participants struggled with broad open-ended questions, became agitated when prompted for more information, and were distracted by unrelated internal thoughts. Responses sometimes indicated contradictory or confused thinking. A study reported by Boylan et al. (2009) provides similar indications and appears to be the only published article specifically dedicated to addressing the difficulties of interviewing children with ABI. It provides validation of concerns experienced by the current researcher. However, although it is published in a peer reviewed journal, the article is devoid of basic and essential research study information relating to design and methodology which raises many unanswered questions. The introduction provides some brief epidemiological information about childhood ABI, followed by reference to the almost total dominance of quantitative studies on the topic, and the absence of the views and experiences of children themselves. Subsequent sections address some of the difficulties interviewing children with ABI due to cognitive impairment, lack of insight, attention difficulties, verbal comprehension problems, impact of behavioural problems, emotional disturbance, physical impairments and fatigue, together with advice about ways to mitigate the potential interviewing difficulties. Substantial extracts from interviews illustrate the difficulties. The introductory sentence of the first example, to demonstrate confusion, states "Josh was aged six at the time of his injury and eight when he took part in the interview" (Boylan et al., 2009, p.266). Apart from such scant information about children being interviewed, no 'scene-setting' is provided, there is no statement of the study purpose, no reference to ethical procedures, nor selection of participants, no description about data gathering, who the interviewers were, where they took place, nor how they were conducted. Ironically, this article which lacks information of the interview sources and methodology for eliciting the data, is included in an issue devoted to methodological issues.

2.5. Part three: Critical evaluation of selected literature relating to the proposed research study

Introduction:

Three studies were identified for exploring in greater depth, selected in relation to aspects of participation that did not appear to be well addressed in existing literature. Study 1 focuses on a broad overview of issues associated with childhood participation in children's everyday settings of home, school and community following ABI. There was researcher interest in both the methods and the methodology for collecting the data and whether a quantitative survey alone is able to provide a holistic view of participation. The importance of including the voice of children in research projects about themselves is acknowledged but there is an absence of the voice of children with ABI which is why a self-report youth version of a scale of participation (Study 2) was selected for evaluation. There is a paucity of information about daily classroom transactions involving children with ABI. Participation in formal learning contexts are important to contextualise given the importance of school life for all children. Study 3 was therefore selected as it appears to provide a detailed picture of support and interactions experienced by children with SEN in mainstream schools.

2.5.1. Study 1: Children's participation in home, school and community life after acquired brain injury (Galvin, Froude & McAleer, 2010)

This Australian study used a survey (Bedell, 2004) to describe participation at home, school and in the community, of 20 school-aged children who had sustained an ABI and were on roll at a mainstream school. Consistent with other studies (Bedell & Dumas, 2004), the most frequently reported participation restrictions were in the community, including team sports, other play, social, and leisure activities. It was found that the greater the extent of the child's impairments the greater the degree of participation restriction. It was suggested that a lower frequency of participation restriction at home can be explained by enhanced understanding and support for children's difficulties within the family, with modifications and other supports being provided to minimise problems. Parents have a vested and emotional interest in their child and so may be more willing to do whatever it takes to facilitate participation in the home (Bedell, Cohn & Dumas, 2005).

There are significant limitations to the Galvin et al. (2010) study. The study aimed to describe participation at home, school and in the community for children with ABI. This was done solely with the use of a quantitative measure (Bedell, 2004). Expressing the complexities and multi-dimensionality associated with dramatically changed lives for children and their families, in numerical terms using ordinal scale measurement may not enable as rich and full an understanding of participation as a qualitative approach. Qualitative research can offer “the texture and weave of everyday life experiences” (Mason, 2002, p.1) that may better enable the understanding of aspects of participation in a range of contexts. The Galvin et al. (2010) study may have been able to provide a more comprehensive picture of participation at home, school and in the community using a triangulated approach. Gathering additional information about interactions and supports in the child’s everyday contexts is essential for understanding participatory practices.

The survey was completed in a hospital setting when parents were attending an ABI clinic review of their child. This clinical setting may not have been a relaxing environment for parents to focus on the completion of a questionnaire during an occasion when they may already have been extremely anxious or distressed about an impending or recent consultation. Surrounding noise and activity common to hospital settings, as well as overseeing their child with an ABI and possibly other children too might not have allowed time and opportunity to reflect and consider appropriate responses to survey questions.

The children had all suffered a moderate to severe ABI and had been discharged from hospital for at least 3 months which was said by the authors to be time enough to return to activities at home, in school and in the community. From the current researcher’s experience, this is rarely if ever enough time for addressing a myriad of difficulties and new scenarios associated with returning home after moderate to severe ABI. For example, hospital discharges that take place prior to the start of the long summer school holidays have obvious implications for extended time out of school, reduced opportunities for access to regular community activities, and reduced opportunity for contact with friends who may be away from the locality. Also, bureaucratic processes, making contact with relevant personnel, and ubiquitous waiting lists can impede progress in establishing hoped-for services or acquiring essential equipment, all of which can be exacerbated during common holiday periods. Indeed, reference was made in the study’s discussion of results, to parental dissatisfaction with the

waiting time for the start of services. Also, family dynamics are usually dramatically changed, and adjusting to how family life is organised on a day-to-day basis can take, at least, very many months to achieve some kind of equilibrium.

An additional very significant limitation in the Galvin et al. study (2010) is the lack of contribution from other key players in the everyday settings in which children participate, most notably injured children themselves, and school staff who work with them. McConachie et al. (2006) emphasise the importance of choosing proxies appropriately when conducting research about children. Use of a parental quantitative rating scale alone is unlikely to provide a substantive picture of the participation experiences of their children, and most especially in relation to contexts where there is no parental presence. It is common for parents to have perceptions and views about their children's education, but in reality most parents have little direct experience of their child's daily educational transactions (McConachie et al., 2006).

2.5.2. Study 2: Youth version of CASP (Child and Adolescent Scale of Participation) (Bedell, 2011b)

Understanding the experience of participation following ABI is incomplete without the injured person having opportunity to express themselves and have their views taken seriously. Children may have different views and place different values on needs and provision compared to the adults around them (Eiser & Morse, 2001). Also, with increasing maturity young people spend more time away from home than with their family (Tuffrey, Bateman & Colver, 2013), and therefore it is important to understand participation in a variety of settings and activities that parents or other adults may not be part of. There has been concern about measures of participation that make no provision for the views of the young person themselves (McConachie et al., 2006; Adolfsson et al., 2011). This has been addressed with a self-report youth version (Bedell, 2011b) of the 'Child & Adolescent Scale of Participation' (CASP) (Bedell, 2011a), a fixed choice quantitative measure designed to ascertain the extent to which children participate in home, school, and community activities as reported by parents. McDougall, Bedell & Wright (2013) report the CASP to be "one of the very few measures of activity and participation at home, school and in the community for children and youth with chronic conditions/disabilities that provides both a parent and youth report" (McDougall et al., 2013, p. 515).

It is the current researcher’s opinion that many of the questions in this self-report youth version are extremely ‘wordy’ and could place excessive and unmanageable demands on the cognitive capacities of children with ABI, the population for whom the CASP was originally designed. To illustrate this, the introduction to the youth self-report version, and two examples of questions are included in the box below.

We are interested in finding out about the activities that you participate in at home, school and in the community. You will be asked about your current level of participation with activities as compared to others your age. For each item, choose one of the following responses:

Full participation, you participate in the activities the same as or more than others your age. [With or without assistive devices or equipment.]

Somewhat limited, you participate in the activities somewhat less than others your age. [You may also need occasional supervision or assistance.]

Very limited, you participate in the activities much less than others your age. [You may also need a lot of supervision or assistance.]

Unable, you can not participate in the activities, although others your age do participate.

Not applicable, others your age would not be expected to participate in the activities.

[Please select one answer by placing an X in one of the boxes next to each item. If you are not sure, choose your best guess]

Compared to others your age, what is your current level of participation in the following activities?	Full participation	Somewhat limited	Very limited	Unable	Not applicable
<u>HOME PARTICIPATION</u>					
1) Social, play or leisure activities with family members at home (e.g., games, hobbies, “hanging out”)					
2) Social, play or leisure activities with friends at home (can include conversations on the phone or internet)					

Part of the self-report Youth version of the CASP (Bedell, 2011b)

Other questions in the self-report youth version of the CASP are significantly longer and with more information-carrying words than the above examples. To be able to 'hold', understand and manipulate the information in these instructions and questions, and respond appropriately, requires ability to integrate a range of cognitive and communication skills, as well as reading skills, such as selecting, focusing, dividing and alternating attention, working memory, retrospective memory, information processing, executive functioning skills, semantic and pragmatic competence. These skills are frequently impaired following severe ABI (Semrud-Clikeman & Ellison, 2009). The current researcher does not share the views of McDougall et al., (2013) that the self-report version of the CASP is "a promising measure for assessing the activity and participation of youth who have chronic conditions/disabilities" (p. 521), but rather is of the opinion that children and young people would be extremely challenged by many of the questions, thereby making it an unsuitable tool for capturing young people's views about their participation.

2.5.3. Study 3: The Making a Statement Project (Webster & Blatchford, 2013).

This research study explored the support and interactions of children in mainstream schools who had a Statement of Special Educational Needs (SEN) for either moderate learning difficulties or social, emotional and behavioural difficulties. It is therefore not specifically about children with ABI but it is considered to be of significant relevance for understanding issues relating to the participation of children with SEN in mainstream school. School is a major part of children's lives, and positive school experience leads to successful participation and positive interpersonal relationships (Vance & Eiser, 2002). Information about daily educational activities and transactions are therefore considered important for better understanding of potential participation facilitators and restrictions.

Webster and Blatchford's (2013) 'Making a Statement' project used a mixed method approach. Extensive minute-by-minute systematic observations and detailed case studies were recorded involving 48 pupils with statements of SEN, and 151 average attaining 'control' pupils to provide a reference point for comparison. Each statemented pupil was shadowed for an entire week and observations of all verbal and non-verbal interactions (including inactivity) were coded at minute intervals providing a wide range of contextual and behavioural detail.

Semi-structured interviews, field notes, scrutiny of documentation relating to each child's SEN, and case-study reports increased the sources and the richness of the data. The study concluded that both the educational and social development of children with statements of SEN suffered as a result of a high degree of separation from their teacher, their classroom and their peers. Overarching concerns that were identified and considered to have significant implications for participation include:

1. The educational experience for children with a statement of SEN is strongly characterised by Teaching Assistant (TA) support and a high degree of separation from their class teachers, their classroom and their peers. Less time was spent in whole class contexts and the degree of 1-1 interaction with TAs was at the expense of peer interaction. There was an almost constant accompanying presence of the TA for each child.
2. Compared to their peers, children with SEN receive a less appropriate and lower quality pedagogical experience. In a previous study on which the 'Making a Statement' project was based, Blatchford et al. (2012) found that pupil interactions with TAs were qualitatively different to those involving teachers. Also, TAs were more concerned with task completion than learning, and more reactive than proactive – factors which were thought to influence the educational progress of pupils with SEN.
3. There are considerable gaps in both teachers' and TAs' knowledge about SEN. School staff reported being ill-prepared to adequately support the complex difficulties of pupils with SEN, and they indicated a lack of training and information.

This level of insight into English mainstream classroom life for children with SEN has not been available before and provides important indications about participation in the classroom, as well as adding to concerns about school staff's lack of training and knowledge on special needs. The aim of Webster and Blatchford's (2013) study was to provide a detailed description of tasks, context, personnel, and interactions involving pupils with high levels of SEN, and how this matched the stated provision. Although the focus of the study was not referred to as participation as such, there is a clear link because the descriptors being explored are factors related to it (Eriksson, 2006). Contrary to the study findings which strongly indicated the negative impact of TA support, Galvin et al. (2010) reported the most frequent support strategy for increasing participation to be the presence of a TA. These starkly contrasting

conclusions may be an interesting reflection of the differences in data collected. As reported earlier, the Galvin et al. (2010) study is a parental survey, and parents commonly consider that individual and dedicated support of a TA for their child at school signifies increased participation. This is despite parents having little direct experience and understanding of their child's daily classroom life, compared to Webster and Blatchford's (2013) study which was based on detailed 'inside' information about classroom life.

In respect of everyday scholastic participatory activities, only a partial picture of daily mainstream school life was explored by Webster and Blatchford (2013), namely the organisation and delivery of curricula activities for children with significant SEN. The study did not purport to include other important facets of the school day that can have additional key implications for participation such as playtimes, lunchtimes, getting to and from school, homework, and extra-curricular activities, any of which can matter to children in terms of 'fitting in' and participating.

The Webster and Blatchford (2013) study demonstrated rigorous methodology; its purpose was clearly stated, relevant background literature was reviewed, gaps in current knowledge were identified, and the need for the study was justified. The data gathering process was clearly described. Reliability and validity were discussed. There was triangulation of data providing robust information, and interview schedules were included in the appendices.

Similar or related findings to those identified by Webster and Blatchford (2013) are reported in studies specifically exploring participation in everyday classroom life. Asbjornslett et al. (2015) reported children with physical difficulties were sometimes given too much help by TAs and not enough help by teachers. Eriksson (2006) found that frequent class support reduced class participation, whereas being included and having many friends who provide emotional support facilitated participation.

A study of disabled children in mainstream school (Koster, Pijl, Nakken & Van Houten, 2010) identified four key themes related to social participation: friendships/relationships, contacts/interactions, student social self-perception, and acceptance by peers. The majority of students with special needs had a satisfactory degree of social participation although a large proportion of them experienced participation difficulties. They had fewer friends, were involved with fewer peer interactions and were less accepted by those without disabilities.

Even when not socially and educationally marginalised as a result of working individually with a TA, there are frequent changes within the school context which require adaptation to different activity demands; children with ABI may lack the executive skills to do this, and others around them may not make adequate accommodation to promote participation (Anderson & Catroppa, 2005). These studies above bring into question the perceptions, motives and misunderstandings of parents who identify academic and social benefits of mainstream school for their disabled child (Frederickson, Dunsmuir, Lang & Monsen, 2004) without the benefit of insider perspectives too.

2.6. Summary of literature review

Severe childhood ABI is associated with multiple, complex and enduring sequelae. Promoting participation in the everyday settings of home, school and local community for children with severe ABI is an essential feature of on-going rehabilitation following discharge from clinical settings. There is substantial research evidence to indicate that children with ABI have significantly reduced levels of participation. However, there is a paucity of information about the specific factors that may influence these outcomes. There is also an absence of research in the UK that documents the participation of children and young people in their everyday settings of home, school and community following severe acquired brain injury and a changed profile of skills and needs.

Participation is operationalised by what is measured (Hammel et al., 2008, Imms et al., 2016) and almost all research studies on participation have attempted to measure and explain it using quantitative approaches. The complex interplay of factors underpinning participation cannot be easily understood; no one measure can adequately indicate and describe participation (Van Tol et al., 2011), and nor can the use of quantitative measures alone provide a holistic understanding of participation (McConachie et al., 2006; Simeonsson et al., 2001). Available measures all have their limitations (McConachie et al., 2006), some issues are less amenable to quantification, particularly subjective experiences (Maxwell, 2012), and key players have their own meanings and 'knowledges' which makes triangulation of data and subjective information to be of considerable significance to help capture the bigger picture. Participation as conceptualised by the current researcher places experiences of those most intimately involved at its heart, making qualitative information a central part of the proposed

study. Additional methodologies for exploring participation would appear to be especially pertinent because of the on-going debate about the definition and defining characteristics of the participation.

The importance of providing children with opportunity to express their views is increasingly recognised and enshrined in legislation, but the voice of children with severe ABI has rarely been heard. Views and experiences of participation from the perspective of parents and education professionals who play key roles in supporting children with acquired brain injury at home and at school are also not well represented in the literature.

The literature review indicates a number of challenges in school, home and community, to successful participation after discharge home following severe ABI. Participation cannot be viewed in isolation from the context in which it occurs - the importance of environmental and personal factors in participation, a central theme of the ICF-CY, necessitates consideration of contextual and individual aspects. Critical appraisal of selected studies highlight a range of unacknowledged contextual and individual factors that may impact on the experience of participation and the reporting of those experiences: the absence of qualitative information from parents, school staff and children; potential barriers to approaches for seeking the views of children with ABI; and the importance of multiple perspectives to help understand the complexity of daily transactions at school and at home that may impact on the participation of children with ABI. This current research study proposes to address those gaps in the literature which could provide useful insights and increased understanding of why children with severe ABI experience lower levels of participation than their typically developing peers.

2.7. Purpose of Study The purpose of this study is to identify barriers and supports that influence participation in children's everyday settings, as perceived by parents, school staff and children themselves. The study also aims to identify the information and resource needs of parents and education service providers in their role of supporting the participation of children who have returned to home and school following severe acquired brain injury and discharge from residential rehabilitation.

2.8. Research questions that prompted the current study:

Primary question : **1. What are the barriers to and facilitators of participation in the home, school and community following severe childhood ABI?**

Primary question: **2. What are the information and support needs of parents, and school staff?**

Secondary question: **3. How can educational psychology services contribute to optimisation of participation following discharge from a clinical setting?**

The literature review indicates communication challenges commonly experienced by children with severe ABI, and an absence of their voice in research studies. Following increased familiarisation with and reflection on the collected data, and subsequent additional exploration of the literature, the researcher wished to add an additional secondary question considered to be an essential component of the research topic:

Secondary question: **4. The voice of children with severe ABI is rarely heard. In what ways may this study help to enhance optimal potential for eliciting their views.**

Chapter Three: Design of Study

3.1. Introduction to chapter

This chapter explains the research philosophy, including the epistemological and ontological positions which have informed the study, and the theoretical framework which underpins it. Methodology, methods of data collection, participant recruitment, the rationale for a multi-strategy approach and approach to analysis are described. The ethical implications of conducting the research, and ways in which rigour, trustworthiness and reflexivity have been demonstrated are also addressed.

3.2. Research orientation

Developing a study involves two important questions (Crotty, 1998): what methodologies and methods will be used, and what is the justification for that choice? These questions are underpinned by the researcher's assumptions - the theoretical perspective. Theoretical perspectives include 'what is' (ontology) and 'what it means to know' (epistemology) which influence the researcher's paradigm or set of beliefs to guide action. A paradigm is a conceptual framework within which theories are constructed (Braun & Clarke, 2013) and shaped by factors such as personal values, experience, history, culture, and views of the world.

3.2.1. Ontology

Ontology, or the nature of reality, attempts to provide answers to questions such as: What constitutes reality? What is there to know? (Willig, 2008). It is concerned with whether reality exists entirely separately from human practices and understandings or whether we think it cannot be separated, thereby acknowledging the importance of the human perspective in the acquisition of knowledge (Braun & Clarke, 2013). Ontological positions can be conceptualised on a continuum ranging from realism at one end which can be viewed as a single truth that is independent of ways of knowing about it. This approach underpins most quantitative research. Relativism, the position embraced by the researcher for the purposes of the study, is at the other end of the continuum and is associated with qualitative research methodology.

It rejects a single truth; social reality is multiple and is dependent on individual interpretation and knowledge.

3.2.2. Epistemology

What we regard as knowledge in the social world is epistemological. Epistemology is concerned with the nature of knowledge and the nature of knowing, including how individuals develop, interpret, evaluate and justify knowledge (Hofer & Pintrich, 1997).

In early childhood, epistemological belief is that reality is directly knowable, and knowledge comes from an external source. By school-age, children recognise that exposure to different information results in different knowledge claims but the sources of these claims are still in the external world; any difference is because someone fails to have the correct information or story. Conflicting representations of the same event are later perceived as legitimate interpretations of individuals' unique meaning-making efforts: "the multiplist level of epistemological understanding begins to take hold. Perhaps all knowing is only opinion." (Kuhn, Cheney & Weinstock, 2000, p.313). The greatest maturity in epistemological thinking, evaluativist belief, is a co-ordinated balance of objective and subjective dimensions of knowing (Kuhn et al., 2000), enabling some claims to have more merit than others.

3.2.3. Social Constructionism

Social constructionism is an epistemological, theoretical orientation to the social sciences. It takes a "critical stance toward our taken-for-granted ways of understanding the world, including ourselves." Burr, 2003, p.3). In contrast to positivism and empiricism that assume the nature of the world can be revealed by objective observation, social constructionism rejects a single ultimate reality - there is no such thing as an objective fact (Burr, 2003). This does not mean that we can never really know anything but indicates there are knowledges rather than knowledge (Willig, 2013). Understanding is subjective and phenomenological (Gameson & Rhydderch, 2017); knowledge is created as opposed to being discovered. Individuals are not passive receptors but are active participants, affecting as well as being affected by their surroundings (Braun & Clarke, 2013). Experience and understanding relate to cultural and historical contexts that influence how we perceive the world which "brings

things into view...and endows them with meaning, and, by the same token, leads us to ignore other things" (Crotty, 1998, p. 54).

Perceptions and experiences therefore need to be understood as individual interpretations of environmental conditions (Burr, 2003). Different people may construct meaning in different ways for the same phenomena.

The researcher has adopted a constructivist, interpretative approach to the study which assumes social reality is constructed and that the subjective meaning is a critical component of knowledge building. The aim of the study is to understand the multiple interpretations of children's participation (Hesse-Biber & Johnson, 2015) following severe ABI.

3.3. Qualitative research design

The selection of a research approach (qualitative, quantitative or mixed methods) is influenced not only by the researcher's belief system but also by the nature of the research problem or the issue being addressed (Creswell, 2014).

Qualitative research is an approach for exploring and understanding the meaning that people give to dimensions of their lives – how they perceive experiences, interactions and behaviours to make sense of their world (Willig, 2001). It refers to techniques of data collection and/or analysis as well as to a wider framework for carrying out research that does not use statistical procedures, quantification, or identify cause-effect relationships (Hewitt, 2007). New insights into social phenomena can be provided as the approach allows participants to reflect and reason on issues that are important to them and which quantitative approaches may fail to capture. The emphasis is on participants own framing around issues of significance, using their own terms of reference (Braun & Clarke, 2013). Qualitative data can be sourced from a diverse range of written, audio or visual material (Gibbs, 2007) and analysis covers a spectrum "from descriptive and exploratory through to more interrogative theorised and interpretative analysis" (Braun & Clarke, 2013, p.173). Descriptive analysis can help to raise awareness of issues that are relatively unknown while interpretative analysis goes further, "beneath the surface of the data" (Braun & Clarke, 2013, p.174), to seek understanding of how and why particular accounts were generated, and to offer some explanations.

3.3.1. Rationale for choice of a qualitative approach

The ICF/CY has increased interest in the concept of participation which is reflected in the increasing number of research studies on the topic. However, as indicated in the literature review, almost all research on the participation of children with ABI has used quantitative methodology and adopted a positivist perspective in the design, measurement, analysis and reporting of collected data. A positivist epistemology implies that the goal of research is to produce objective knowledge. It suggests “a straightforward relationship between the world (objects, events, phenomena) and our perception and understanding of it” (Willig, 2008, p.4). It is allied with quantifiable data that leads to statistical analysis. The focus is entirely on measurable facts for which a causal explanation is provided. The current researcher considers that quantitative approaches fail to capture the rich and textured human element important for understanding the concept and experience of participation and that a qualitative study exploring children’s ‘real-life’ contexts can offer new additional insights. A qualitative approach, supporting the social constructionist paradigm, was therefore selected to explore the participants experiences, perceptions and beliefs, the construction of their own realities, and to develop a rich narrative. This provided opportunity to seek depth of understanding for insights into the phenomenon of participation which is not well understood (Robson, 2002), thereby achieving a more holistic perspective. This form of enquiry also lends itself well to an inductive approach providing focus on individual meaning and the importance of reporting the complexity of the phenomenon (Creswell & Creswell, 2018).

3.3.2. Some approaches within qualitative design

There can be considerable overlap between various approaches used in qualitative research but some fundamental differences distinguish what is trying to be accomplished, and the methodology used. The processes used shape the ensuing narrative (Creswell, 1998). Data collection varies in terms of emphasis, such as using more observations in ethnography and more interviews in grounded theory. The extent of data collection varies too – phenomenology only involves interviews, in contrast to case study research which can involve multiple sources of data to provide an in-depth case picture. There are significant differences at the data analysis stage in terms of specificity, for example grounded theory which is most specific, while biography is less well defined. The number of steps to be undertaken is also

different; there are extensive steps in phenomenology and few steps in ethnography (Creswell, 1998).

3.3.2.1. Grounded Theory was one of the first attempts to develop a systematic method for analysing qualitative data (Glaser & Strauss, 1967). Explanatory theory of a particular phenomenon is constructed from patterns which emerge from the data (Strauss & Corbin, 1998). Sampling is usually on a relatively large scale, and individual accounts are used to illustrate the theoretical claims (Smith, Flowers & Larkin, 2009). This method was not considered relevant for the purpose of the current small-scale study which was to explore the experiences and perceptions of individual participants rather than making predictive statements and developing explanatory theories.

3.3.2.2. Interpretative Phenomenological Analysis (IPA) aims to provide a more detailed and nuanced analysis of the lived experience of a smaller number of participants (Smith et al., 2009). IPA is ideographic, an approach to knowledge production that focuses on the unique characteristics of the individual participants, their experiences and their interpretations of them (Braun & Clarke, 2013). Thematic Analysis (TA) and IPA have much in common because of the shared focus on the subjective lived experience. IPA was initially considered as the approach choice for the current study. However, TA was favoured to enable the use of multi-strategy approaches for collecting and analysing data, and using themes as units of analysis.

3.3.2.3. Thematic Analysis (TA) Thematic analysis was chosen as the most appropriate approach for this study. It is a widely used qualitative research approach for identifying, analysing and reporting patterns within data. It is distinguished from other methods by its lack of reliance on pre-existing theoretical frameworks and methods of data collection. It is not prescriptive in terms of data collection, epistemological or ontological frameworks, and can be applied to data in different ways. It was therefore chosen because of its flexibility and accessibility (Braun & Clarke, 2013). It can provide a rich thematic description of the whole data set and for this reason it is a useful approach when exploring new or under-researched areas. TA is a method, not a methodology (a theoretically informed framework for how to do research), with flexibility as its hallmark (Braun & Clarke, 2013). In contrast to the ideographic stance of IPA, TA focusses on patterns of meaning across

participants. It can be used across the epistemological and ontological spectrum (realist or constructionist), and underpinned by different theories. There are no specific requirements for sampling.

3.3.3. Multi-Method Approach

Mixed method and multi-method research, or triangulation, is the combination of different methods of data collection and/or data analysis within a study (Morse, 2003; Braun & Clarke, 2013). Triangulation originated from an approach used by land surveyors who increase the validity of a map by incorporating measures from different angles. By analogy, triangular techniques in research aim to explain more fully and enrich the description of a phenomenon (Malterud, 2001). Triangulation most typically combines qualitative and quantitative approaches, but can also refer to different methods of collecting data within an exclusively qualitative or quantitative approach (Morse, 2010; Hess-Biber & Johnson, 2015.) Some researchers distinguish between multi-methods or multi-strategy research - a mix of qualitative or quantitative methods within a research study, usually from a single paradigm, to contrast with mixed methods - the combination of quantitative and qualitative methods, in a single study using multiple paradigms (Brewer & Hunter, 2005). Multi-strategy approaches enable researchers to capitalise on the complementary strengths and differences of different methods of data collection; the strengths of one method to enhance the performance of the other method (Morgan, 1998). This can provide “different facets of a phenomenon yielding an enriched, elaborated understanding of that phenomenon” (Greene, Caracelli & Graham, 1989, p.258) leading to “more nuanced, contextualized, and corroborated conclusions about human flourishing and well-being” (Plano Clark, 2017, p. 305). Even if combining different methods create tensions, Creswell et al. (2011) see this as an opportunity to transform information from each approach into new knowledge through a dialectical discovery. “A pragmatic perspective draws on employing ‘what works,’ using diverse approaches, giving primacy to the importance of the research problem and question” (Creswell et al., 2011, p.4).

Bryman (2006) considers that “multi-strategy research frequently brings more to researchers understanding than they anticipate at the outset” (p.111). He devised a classification scheme to capture the range of reasons for conducting a multi-strategy research study which

identified 18 justifications. Justifications relating to the current mixed strategy study include 'Credibility' – employing two approaches to enhance the integrity of findings, and 'Completeness' – bringing together a more comprehensive account of an area of enquiry.

3.4. Interviews

Qualitative research interviewing is one of the most widely used techniques for conducting systematic social enquiry. It is a specific form of conversation mainly through direct verbal interaction (Kvale, 2007) initiated by the interviewer for the purpose of obtaining insight into the experiences, feelings, and social worlds of participants (Fossey, Harvey, McDermott & Davidson, 2002).

3.4.1. Multi-strategy interview methods

The current study used a qualitative-only multi-strategy approach consisting of different types of interviewing for gathering data relating to participation at home, school and in the community following residential rehabilitation for childhood ABI. The selected methods and processes are described below for each group of participants – parents, children and school staff.

3.4.2. The parent interview This was in two parts:

3.4.2.1. Part 1: Unstructured interview

'Unstructured' is perhaps a misnomer inasmuch as all interviews are structured in some way - "the interviewer (mostly) asks questions and the interviewee (mostly) responds to them" (Braun & Clarke, 2013, p. 78). Unstructured interviews have been referred to as controlled conversations (Jamshed, 2014) with the aim of gathering in-depth information. The use of this approach in the current study enabled maximum sensitivity to concerns and opportunity for the participants to talk about aspects of participation that mattered most to them. This approach is useful when there is little known about a topic (Barker, Pistrang & Elliott 2002) as there is no pre-arranged schedule of researcher-decided questions. It can provide rich and detailed information, and allow for exploration of any unanticipated and unexpected findings (Smith et al., 2009).

3.4.2.2. Part 2: Structured questionnaire

The second part of the interview continued with the use of an adapted structured questionnaire. This was chosen to complement information gained from the unstructured interviews. The rationale was one of seeking ‘completeness’ (Bryman, 2006) – bringing together a more comprehensive account of parental experiences of participation. The researcher anticipated that parents may have significant information and views about a wide range of issues associated with their child’s participation which might not necessarily be immediately recalled or voiced during the unstructured part of the interview. The questionnaire, The Child and Family Follow-up Survey, (Bedell, 2004) is described below. The researcher wished to adapt its use to fit with the study’s social constructionist epistemology but was concerned about using it in an unorthodox way. No exemplars for guidance were available but encouragement was provided by Frith and Gleeson (2012):

“No method should be fixed and inflexible, and most can be adapted, modified and altered to fit the particular needs of any research situation. Indeed, the most successful methodologies are those that allow for development and creativity. It is this adaptability that enables the researcher to ‘fit’ the method to their epistemology, to their research question, to their own skills, experience and ways of being in the world, to their participants and to the kinds of knowledge that they aim to produce. It is this adaptability that allows us to generate innovative, insightful and useful knowledge.” (p.55)

3.4.2.2.1. The Child and Family Follow-up Survey (CFFS) (Bedell, 2004)

The CFFS (Bedell, 2004) was developed in North America specifically to monitor and assess long term outcomes in activities and participation for children and young people with ABI following return home after residential rehabilitation. It was designed as a survey to be given to parents for self-completion, to provide information about a child’s current activities, needs and services and the wider family’s needs and services. It is based on the 9 domains in the ICF relating to participation and activity in everyday life, as described in the previous chapter (Bedell, 2009). It consists mainly of fixed-choice items relating to the child’s health and functioning, home and community participation, problems experienced in everyday life, and current services.

The CFFS (Appendix 3) is one of a very few measures of participation that has been found to have good coverage of all nine domains of the Participation and Activity component of the ICF/CY (McConachie et al., 2006; Adolfsson et al., 2011; WHO 2013). It was for this reason that it was selected for use in the current study, to serve as a 'platform' on which to gather more qualitative data. Data from the fixed response items were used descriptively in their word form and integrated during the discussion stage, but the prime interest relating to use of the questionnaire was the follow-up open-ended probing (see below) which was integrated during the analysis stage.

3.4.2.2.2. Development of the CFFS: follow-up probes

It is common to include an 'any other comments?' question at the end of questionnaires (O'Cathain & Thomas, 2004), as is part of the CFFS (Bedell, 2004). This is often a cursory exercise, and part of a debriefing process (Braun & Clarke, 2013). Waiting until the end of a detailed and wide-ranging survey may not make it easy for parents to express themselves in their own way if they so wish, to any of the items, nor provide detail so richly as might be possible in response to the immediacy of the issue being raised in the survey. It was considered that providing opportunity for the current study's parent participants to comment throughout the process of completing the questionnaire, as well as 'any other comments?' at the end could enable elaboration of issues to provide enhanced "breadth and representativeness of coverage of the phenomenon" (Singer & Couper, 2017, p.116).

Open ended probing is common in qualitative interviewing although not so common in fixed-response questionnaires (Singer & Couper, 2017), but it is not new. As long ago as the 1940's Lazarsfeld, described as "the founder of modern empirical sociology" (Jerábek, 2001, p. 229), advocated including 'open interview' probes in what he called 'straight poll' interviews, to elicit qualitative information. "Research progress consists of the art of doing things which at first seem incompatible. Good research consists of weaving back and forth between open interviews and more cut-and-dried procedures." (Lazarsfeld, 1944, p. 50). Schuman (1966) developed Lazarsfeld's idea of follow-up probes for eliciting qualitative information, prompted by fixed response survey questions. The probe doesn't replace the closed question but follows immediately after the respondent has made a choice from the options available. Non-directive phrases are used by the interviewer for the respondent to indicate what they had in

mind when making their choice. Schuman (1966) emphasises that the exact wording of the probe is not as important as the way in which it is posed - it is particularly important that the respondent's choice to the fixed-response question is not perceived as being challenged. In the current study, tone of voice, nodding and facial response were used to affirm all respondents choices.

3.4.2.2.3. Piloting of the CFFS with follow-up probes

Two parents (mothers) with children with ABI who had received residential rehabilitation a few years previously were approached and asked if they would be willing to pilot the questionnaire and follow-up probes which they agreed to. During the pilot interviews, they were invited to comment on any of the items. The feedback at the end was generally positive. Their information endorsed the proposal to include open-ended probing; they had both wanted to provide more information on a number of the items, to help explain the reasons for their choice to pre-defined response options. One parent commented on the difficulty of making fixed choices to some of the questions “as if it was black and white – it’s rarely like that”.

A couple of the questions in the survey’s environment-related section are personal and sensitive, referring to family finances and level of family stress. The parents who piloted the survey did not indicate discomfort answering them, despite the researcher’s concern about including them. However, to avoid possible embarrassment or discomfort on the part of parent participants, it was decided to include a verbal reminder, at the beginning of the section, in addition to the start of the survey, about choosing to ‘pass’ on any questions that parents did not wish to comment on.

3.5. School staff interviews

Interviews with school staff were unstructured to provide opportunity for them to talk about any aspects of participation that were of concern to them in their professional capacity. As referred to above, this approach enables opportunity for information to be voiced that may not be possible using a more structured interview format.

3.6. Child participant Interviews

Eliciting the views of children with severe ABI as part of a research study can be challenging because of the complex mix of cognitive, physical and communication difficulties. However, adult proxy views can differ significantly from children's own views, and so having the child's (insider) perspective as well as the child (outsider's) perspective (Sommer et al., 2010) is integral to the current study.

3.6.1. Considerations and methods

There are various models representing the extent to which children make a contribution to projects. Shier's (2001) model is based on 5 levels of engagement ranging from being listened to, to children sharing power and responsibility for making decisions. The researcher was not seeking to position herself at any of the levels but used the framework as a general guide to help with the process of reflexivity in terms of decision-making about effective ways and tools for communicating with children who may have significant cognitive and communication difficulties, and ensure their optimum participation.

Although face-to-face traditional interview techniques are useful for gaining the perceptions of adult participants, this approach was not considered a viable or appealing approach for children with significant cognitive and communication difficulties. It is important to use methods which are sensitive to children's particular abilities or interests (Punch, 2002). Features thought to be more likely to make the child participants feel at ease with an adult researcher included those that obviated the need for verbal responses and eye contact, were motivating, and provided choice and control.

3.6.2. Use of Visual methods

Language continues to be the central form of data production and for communicating findings in qualitative research. Mason (2002) refers to the 'extraordinary' dominance of talk and text in our research imagination and methods:

'extraordinary, because of the one-dimensional nature of this foray into, or construction of, what most would agree is a multi-dimensional, multi-sensory 'reality'. The idea that everything we are interested in exists in language or text, or is expressible in those ways, and

that we can explore it using words or reading text, can be argued to be a rather limited and uncreative one' (Mason, 2002, p.104)

There is now an increasing use of visual methods for research purposes (Flick, 2006) which have been described as 'formidable sources of information' (Denham & Onwuegbuzie, 2013, p. 670). Visual material can provide the ability to evoke embodied experience and therefore open up opportunities for verbal conversations that otherwise may not be generated. Visual methods of data collection and reporting may also be useful for working with research participants for whom language may create barriers rather than bridges. 'Visual methods take seriously the role of images for academic research, challenging traditional preoccupations with data in the form of numbers and words. Visual methods can be a creative and highly informative way of generating interactions with research participants'. (Dunlop, undated).

3.6.3. Tools for eliciting the child's voice

Several different visually-mediated methods for gaining the views of children have been developed such as the use of drawings, artefacts or taking photographs (Clark & Moss, 2001; Punch, 2002; Thomson & Gunter, 2006) to stimulate conversation, to be used as stand-alone data, or to provide the main means of presenting research findings accompanied by minimal words (Hearn & Thomson, 2014). A computer assisted approach for interviewing children was selected for the purposes of the current study. Computers are an enjoyable, and quickly engaging medium for children of all ages with or without additional needs, that can facilitate attention and communication in a familiar way (Berger, 2006; Barrow & Hannah, 2012). Augmentative and alternative communication (AAC) aids were considered. A task and symbol based tool (Proloquo2go) provides a voice for non-verbal communicators, has a large picture vocabulary and text-to-speech feature. It is customisable and thematic templates can be created. It was discounted because of its focus on text-to-speech voice and the type of symbols used which may have been perceived as patronising by the study participants who were attending mainstream school and were able to use spoken language to provide a basic level of communication. A computer-assisted interview tool using images, sound, speech and video, 'In My Shoes' (Calam, Cox, Glasgow, Jimmieson & Groth-Larsen, 2000) encourages reflection about experiences through dialogue, and was a potentially useful tool. This was

discounted on the grounds of the protracted time and stages required to carry out the computer-assisted interviews with children who may have excessive fatigue and attention difficulties, and nor did it provide as much ease of use, and control for the child as Digital Talking Mats.

3.6.4. Digital Talking Mats

‘Talking Mats’ was selected for use with the child participants. This is an established and interactive communication resource that uses a visual framework. Picture symbols, devised with reference to the concepts underpinning the ICF/CY, were used as a basis for communication (Murphy, 1998; Mackay & Murphy, 2012). Talking Mats is so named because the original version consists of using symbols on small cards which are manually positioned on a textured mat.

The digital version of Talking Mats, loaded onto a tablet computer (ipad), was selected as meeting all the researcher’s identified criteria (spoken language not essential, minimal fine motor control required, child-friendly, no expectation of eye contact or face-to-face interaction with the researcher) so possibly making it easier for the child to relax and communicate.

The core principles for use of Talking Mats include the Interviewer asking open questions, being neutral, and matching conversation to the interviewee’s level of understanding. Talking Mats can replace the spoken word but can also augment existing communication skills. A level of comprehension of at least two information carrying words is required (Murphy, Cameron, Markova & Watson, 2004).

Picture Symbols: ‘Topic’, ‘Top-scale’ and ‘Options’

Three sets of picture symbols are used – ‘Topic’, ‘Top-Scale’ and ‘Options’ together with the digital screen on which to display them. The associated concept for each symbol is also in written form.

Topic: The topic entitled ‘My wider World’ was selected by the researcher for the current study as best reflecting aspects of childrens’ home, school and community life, and the ICF/CY Activities and Participation domain.

Top Scale: This enables participants to indicate their views about the selected options and topic. 'Like', 'Dislike' and 'Unsure' were used in the study.

Options: These are related to the chosen topic. Digital symbols representing a wide range of options relating to the topic such as school, teachers, learning assistant, communication support, neighbourhood, being accepted, places to go, where you live, are able to be dragged onto the screen by the child one at a time and the child, in his/her own time, then places the symbol under one of the three top-scale symbols to indicate how they feel about each topic, or into a digital 'trash bin' if they don't want to use a particular topic. The primary school version which has 16 symbols and the secondary school version which has 18 symbols were used for the relevant age/stage of the child participants. Most of the topics in the two versions are the same but differences reflect changes in development, language and levels of independence. For example, the secondary school version includes the topics 'Future planning' and 'Neighbourhood'. The primary school version includes 'visitors to my house' and 'where you live'. Blank 'cards' are available for including additional options or comments by the researcher or the participant.

Talking Mats provide a visual scaffold to conversation that enables children to think about their views and to see the content of the interview. The symbols act as a support 'hook' on which to 'hang' meaning. The images help to make abstract ideas more concrete, and reduce the demand on the user to remember the question and to find the vocabulary needed to answer which makes it easier to focus on processing information and to respond. The framework can help divide information into smaller more manageable parts and the act of moving the symbols can help to organise thoughts in a logical way (Talking Mats, 2018).

Taking charge of the tablet gives participants control of the communication process which helps to reduce the power differential between researcher and participant. The child decides on the choice of symbols, where they are placed, and the pace of the process which removes any need to respond "relatively quickly in a correct manner" (Punch, 2002, p.335). It also enables turn-taking in conversation.

Digital Talking Mats produces an instant visual report/recording of the session as created by the child, and as provided in the next chapter.

3.7. Consent for study

The researcher's employing organisation stipulates that all research involving children who have been or are currently in receipt of its services must have National Health Service (NHS) research ethics approval. Research involving direct contact with children demands a full, rather than proportionate review of the application which requires attendance at an NHS ethics committee meeting for presentation and discussion of the project. A favourable ethical opinion was given (Appendix 1) subject to two changes, including the use of a two-stage process for contacting parents to eliminate any potential coercion. A letter was sent to parents from the Chief Executive of the organisation (Appendix 2), alerting them to the research project, and inviting them to get in touch if they wished to receive more information or to take part.

3.8. Participants

3.8.1. Sample size

In qualitative research, events, incidents and experiences, not people per se, are typically the objects of purposeful sampling (Sandelowski, 1995). The aim of qualitative study is detailed description. No attempt is made to assign frequencies identified in the data, and rare phenomena receives the same amount of attention as more frequent phenomena (Atieno, 2009). Findings are not regarded as facts applicable to the population at large, but rather as descriptions or theories within a specified setting (Malterud, 2001). One of the often-cited limitations of qualitative research is the small sample size which restricts capacity to produce generalisable findings. However, generalisability, replication, validity and reliability are not essential for qualitative research (Denzin & Lincoln 1994; Castro, Kellison, Boyd & Kopak, 2010) as qualified by Mason (2010):

“Frequencies are rarely important in qualitative research, as one occurrence of the data is potentially as useful as many in understanding the process behind a topic. This is because qualitative research is concerned with meaning and not making generalised hypothesis statements.” (Mason, 2010, para. 1.)

3.8.2. Sampling strategy

The study sample was purposive. Purposeful sampling involves identifying and selecting people with experience of the phenomenon being studied (Creswell & Plano Clark, 2011), and who are available and willing to be involved (Bernard, 2002). Sampling was also criteria-based (Braun & Clarke, 2013) – the child population needed to have experienced a very specific event (severe acquired brain injury), and to have been discharged from a specialist ABI residential rehabilitation programme, back to home and mainstream school.

3.8.3. Participant selection

Potential child participants were identified from the database of the organisation where the researcher was employed as an Educational Psychologist. Inclusion criteria, and exclusion criteria in brackets, were as follows:-

- having been in receipt of the ABI residential rehabilitation programme (Appendix 13) at the employer's organisation and therefore have a severe acquired brain injury.
- having subsequently been discharged and returned home at least 12 months previously. (Discharges that had taken place less than 12 months previously may not have provided time for family and school staff to assimilate, respond and adjust to many of the changes resulting from the ABI.)
- attending a mainstream school in England, and at educational key stage 2 or 3. (Children attending special school or other alternative educational provision may be more likely to have needs recognised and provided for, possibly related to easier access to therapies, smaller class sizes, slower pace of learning, and support from staff with a higher level of SEN training. The researcher was also concerned with how children fit back in to the kind of mainstream settings familiar to them prior to their ABI. Such settings usually have more formal learning expectations with a predominantly didactic focus. Children at Key stages 1 and 4 were excluded to avoid a wider spread of ages, and also key stage 1 children may have had little experience of formal school prior to their ABI.)

- living at home, within 100 miles of the researcher's employing organisation. (The study explored the child's everyday settings including their family home, thereby excluding children living away from home.)
- using English as a first language. (A first language other than English may have introduced additional extraneous factors when researching participation following ABI. For example communication restrictions may have resulted from English as a second language, rather than an acquired injury.)
- having a parent who was a fluent English speaker and who lived in the same home as their child. (Parents living apart from their child may not experience or understand participation at home to as great an extent as parents living with their child. Also, difficulties in communicating in English with staff supporting their child, and for the purposes of the study interview, may have created additional communication barriers.)

3.8.4. Study participants.

Following NHS ethical approval for the study, 10 parents were sent a letter from the Chief Executive of the organisation, as stipulated by the NHS ethics committee. Parents of children with severe ABI typically experience a high level of stress and burden on a daily basis (Hawley, 2003). To ask them to take the initiative, and opt-in to a research study by means of a circuitous route was thought by the researcher to be tantamount to discontinuation of the study. However, receipt of 4 response slips enabled the researcher to make direct contact with those parents who expressed interest. Information packs were sent that included a description of the study (Appendix 4), an amended version for their child (Appendices 6 & 8), what it involved for them and their child if they agreed to participate, consent forms (Appendix 5) and assent forms (Appendices 7 & 9) and to seek permission for the researcher to make contact with their child's school. One of the parents was willing to give agreement to participate on condition that the term 'brain injury' was not mentioned in any conversation with her child or with school staff. It was not possible to give that assurance. Three parents gave their agreement to take part in the study.

Following receipt of parental agreement each child's school was contacted. An information pack was sent to the Headteacher of the primary school, and SENCos' of the secondary schools, with an invitation to participate (see Appendix 10). This was followed up with a phone call a week later to check the designated recipient had received the letter. Each of the schools agreed to participate.

This led to 16 study participants comprising 3 parents, 3 children, 10 school staff (1 headteacher, 1 class teacher, 3 special educational needs co-ordinators, 5 learning support assistants.)

The researcher had previously met two of the parents during their stay on the rehabilitation unit, and during a visit to the schools to which their child was returning, prior to discharge. There had been no contact with their children apart from casual greetings while resident on the ABI unit, and no subsequent contact with the schools.

3.8.5. Interview settings

A major limitation of quantitative approaches is the detachment from 'real-life' contexts, sometimes referred to as decontextualization (Viruell-Fuentes, 2007). In contrast qualitative research recognises that participants come from, and are located within specific contexts (Castro et al., 2010.) The researcher therefore wished to conduct all participant interviews in a context in which they lived their everyday lives – their home, or school or local community. All parents chose to be interviewed at home. Children, in negotiation with parents and school staff, were offered a school location during the day or at home after school hours. Two were interviewed at home, in a room just with the researcher, but in proximity to their parent elsewhere in the house. One child was interviewed at school, accompanied in the room by his TA. The school wished this and explained that his acquired aphasia presented communication difficulties. His TA accompanied him at all times to support his communication efforts, if required.

All school staff chose to be interviewed on the school premises during the day, apart from a SENCo who needed to be off-site on the day of the researcher's visit, but who wished to be involved and agreed to a phone interview.

Cardiff university's lone working policy was followed.

3.9. Conducting the interviews

Interviews of parents and teachers varied in length from 45 minutes to 1 hour 45 minutes. Interviews with TAs lasted on average 15 minutes, and Child interviews lasted on average 25 minutes. After each interview, adult participants were given a verbal summary, and children a visual summary, to provide opportunity to amend or retract information. A post-interview 'debrief' explained the next steps of the research process and encouraged any further questions they might have. The researcher sent a card a few days later to each participant, and a paper record of the 'Talking Mats' summary requested by two of the children, to thank them for their involvement. Repeated contact details were included should they have any concerns or wish to discuss anything.

3.9.1. Conducting interviews with children

The 'Talking Mat' interviews with children are recorded in Chapter 4, and discussed in Chapter 5.

3.9.2. Conducting interviews with parents

Consideration had been given to the order in which information was gathered from parents. The unstructured part of the interview was held first "to prevent the interviewer's frame of reference being imposed on the interviewees viewpoints." (Flick, 2006, p.150) Also, presenting the structured questionnaire first, which covers a wide range of issues associated with participation, may have stunted the opportunity for parents to talk freely about issues of greatest significance in a detailed way, possibly because those issues were already covered in the questionnaire, albeit in a perfunctory way. The researcher and parent participant completed the CFFS paper-form together going through the questions and follow-up probes, sequentially. The researcher hand-recorded their verbal responses.

The researcher met each of the parents in their homes. Conversation started with 'neutral' preamble, over a cup of coffee. A relaxed and friendly manner was established to put them at their ease and build rapport. Information about the research study that parents had previously received in writing was reiterated, with opportunity to ask any questions or express any concerns before the interview started. Some generic open-ended and non-directed questions had been prepared to help steer conversation in the event of veering away from

participation-related issues but these were not required once the interviews were underway. They were initiated with the researcher asking parents: “How’s it been going since returning home from rehab?” The interviews were strongly participant led, enabling them to tell their stories, rather than the researcher directing the interview (Fossey et al., 2002; Braun & Clarke, 2013). Interjections were occasionally made to request clarification, and also to indicate interest and them being listened to.

3.9.3. Conducting interviews with school staff

These were unstructured and strongly participant-led. It was introduced by the researcher asking ‘How’s it been going since * returned to school? School staff were encouraged to talk about aspects of participation that were of significance to them. The researcher sometimes paraphrased or repeated responses to check for accuracy of understanding (Gray, 2009). A list of participatory settings at school (Coster et al., 1998) had been prepared to generate discussion if needed but this was not required.

3.10. Reflexivity and research bias

Qualitative research is vulnerable to bias and therefore critical reflection on knowledge that is generated, and the researcher’s role in the process is an essential component at every stage of the research process (Christensen & James, 2017). It is impossible to remain “outside of” one’s subject matter (Willig, 2001, p.10). Our values, beliefs and life experiences influence the construction of research questions, data collection and interpretation of findings. The subjectivity of the researcher, as well as the study participants, is therefore part of the research process. Researcher impressions, irritations, and feelings become data in their own right, forming part of the interpretation (Flick, 2006). Researcher effects cannot be eliminated, just controlled. These need to be “brought into conscious awareness if they are to facilitate rather than impede critical analysis” (Hewitt, 2007, p.1149). Research with child participants accentuates the researcher’s role in co-construction of knowledge. Children’s narratives don’t emanate in some kind of natural way and cannot be viewed as providing “authentic” insights but rather as “contributing to a more complex and multi-layered picture” (Elden, 2013, p.66). The issues become particularly salient when working with children who have no or little spoken language (Komulainen, 2007). In reporting and interpreting the data generated by the children, the researcher was particularly aware of the influence of the

research process on their accounts, and explicitly stated factors that may have shaped their contribution.

Braun & Clarke (2013) distinguish between personal reflexivity and functional reflexivity:

Personal reflexivity involves giving attention to factors about ourselves as researchers such as our age, gender, culture, appearance, perspective, power balance, and assumptions, any or all of which may influence the researcher-participant relationship and knowledge that is produced (Hewitt, 2007). The researcher's constructions and experiences were made explicit and these demonstrated the difficulty in remaining neutral. However, acknowledgement of them contributed to the study's critical analysis, and as referred to by Hewitt above.

Functional reflexivity involves giving consideration to the ways in which research tools and processes influence the research such as the methods that are chosen to construct knowledge, or the way or order in which they are presented. Spyrou (2011) emphasises the importance of critically examining the research process itself and asserts that reflexive researchers accept "the messiness, ambiguity, polyvocality, non-factuality and multi-layered nature of meaning" in the narrative that is produced (p.162).

Reference is made to both personal and functional reflective processes at various points throughout the current study in the researcher's attempts to understand their impact on research outcomes.

3.11. Bracketing

The researcher considered how her prior experiences, assumptions and beliefs might influence the construction of knowledge during the research process. Strong professional commitment to the topic instigated the study, but there was awareness that this commitment, together with associated knowledge and preconceptions could have a potentially negative effect on the research process, shaping perception and interpretation of data (Drew, 1989; Braun & Clarke, 2013). For example, many years of working with children with severe ABI provided the researcher with an acute awareness and concern for some of the significant 'hidden' difficulties that can impact on learning and socialisation and that commonly fail to be identified or provided for following return to home and school. Also, much experience of engaging with local authority service personnel throughout the country

may have given the researcher an advantaged position to identify strengths and shortcomings of school and community provision for children with ABI and their families. Appreciation of some of the dilemmas and concerns increased the risk of the study becoming “more a reflection of the worldview of the researcher, rather than that of the participants.” (Sorsa, Kiiikkala & Astedt-Kurki, (2015, p. 11).

In qualitative study bracketing (Smith, Flowers & Larkin, 2009) refers to the need of the researcher to temporarily hold ‘in suspension’ prior knowledge, assumptions, values, experience or belief about the phenomenon being studied. This is not to separate the researcher from the research but to enable it to be seen with fresh eyes. Perceiving it with an open mind helps to eliminate bias, to focus on and understand the participants point of view without prejudice, and create new meaning. In order to do this, preconceptions and experiences need to be identified and acknowledged (Smith, Flowers & Larkin, 2009). It can be a multi-layered process to access various levels of consciousness, a process of self-discovery whereby buried emotions and experiences may surface (Tufford & Newman, 2010). This was managed reflectively by the researcher in two ways; in notes made following each interview and during the analysis process, and also by holding discussions during the course of the study with a colleague, a social worker with many years of experience working with parents of children with severe ABI. These processes enabled the researcher to make prior emotions and experiences explicit and ‘off-load’ them to maximise separation from the study data.

Bracketing in the study was also guided in part by LeVasseur (2003) and Sorsa et al. (2015) who emphasise researcher approaches, behaviours and goals when interviewing to include versatility, sensitivity to nuance, avoiding interpretation, obtaining descriptions of specific situations, being open and naïve, and asking for clarification. LeVasseur (2003) advocates being persistently curious as a way of bracketing prior understanding. “We have to assume that we do not know or understand something in order to attain the philosophical attitude. When we begin to inquire in this way, we no longer assume that we understand fully, and the effect is a questioning of prior knowledge” (LeVasseur, 2003, p.417)

3.12. Demonstrating rigour and trustworthiness in research

The 'methodological trinity' (Tobin & Begley, 2004) of validity (whether research actually shows what it claims to show), reliability (the extent to which results could be repeated, for example by another researcher, in another context), and generalisability (ability to apply results of a study to a wider population) are important concepts in quantitative research. It has been argued that they are associated with positivism (Sandelowski, 1995), and are not meaningful terminology or goals for qualitative research. The concept of an objective reality to validate knowledge in qualitative research has been discounted (Kvale, 1995) because of the context-bound nature of knowledge and the interest in the detail of the phenomenon being investigated (Braun & Clarke, 2013). However, there has been concern that rejecting these concepts is paramount to rejecting rigour, and this undermines acceptance of qualitative research (Tobin & Begley, 2004).

Rigour and trustworthiness demonstrate integrity and competence in research (Fereday & Muir-Cochrane, 2006) and need to be judged by different criteria. Lincoln and Guba (1985) assert that this be done through establishing credibility (the 'fit' between the respondents views and the representation of them), transferability (the findings have applicability in other settings), dependability (ensuring the research process is logical, traceable and clearly documented, and confirmability (the extent to which the study findings are shaped by the data) (Nowell, Norris, White & Moules, 2017). Arminio and Hultgren (2002), reported in Tobin and Begley (2004), prefer the criterion of 'goodness' for establishing trustworthiness in an interpretative study. They consider a range of elements to demonstrate this, as listed below, should be embedded throughout a study, are essential to communication of the study, and need to be explicitly stated in the written report:

1. Provision of a philosophical stance that gives context to and informs the study
2. Methodology - clarity about approaches used
3. Method - explicitness about data collection and management
4. Representation of voice - reflection on the researchers relationship with participants and the phenomena under investigation

5. Meaning-making – the process of presenting new insights through the data and chosen methodology
6. Implication for professional practice – recommendations

Rolfe (2006) challenges the notion that rigour can be assured by any generic set of previously agreed quality criteria which should be abandoned in favour of individual judgements of individual studies. He emphasises the importance of reflexivity, the provision of a ‘super’ audit trail to recount the rationale underpinning the research decisions, and details of “the *actual* course of the research process, rather than the *idealized* version that the reader is usually presented with” (p.309).

The current researcher aimed to demonstrate triangulation, goodness, and reflexivity throughout the study, using both Arminio and Hultgren’s (2002), and Rolfe’s (2006) criteria of trustworthiness as described above. Representation of the participants voice was checked by verbally summarising what they said at the end of the interview, or reviewing the placement of the Talking Mat symbols, with opportunity to retract or change anything. Different sources for collecting parent, school staff and child data enabled a richer understanding of participation issues and strengthened the analytic claims (Smith, 1996). The study findings were discussed at two levels with colleagues from a paediatric ABI team, firstly to ascertain that the issues resonated with their own professional experiences. Response was a mixture of confirmatory and comments relating to their appreciation of increased understanding. Secondly, the study data and analysis were discussed with a consultant clinical psychologist, whose specialist knowledge and experience of childhood ABI is extensive, in order to check the credibility of the descriptions and the themes.

3.13. Ethical considerations

3.13.1. Storage and use of personal data

All personal information stored on the researcher’s organisation’s computer was password protected and restricted to those who needed access. The researcher’s laptop was only used for storage of data that had been anonymised, and information was password protected. Pseudonyms were used for case information. Only the researcher had access to the personal

data compiled during the study. However, if there had been a child protection issue, some personal data may have needed to be passed on in a confidential setting.

3.13.2. Consent and Assent

Two ethical principles fundamental to psychologists' practice are the notion of informed consent, and the individual's right to privacy and confidentiality (Gavey & Braun, 1997).

Informed consent is the agreement individuals give after being provided with information that enables them to decide whether or not they wish to take part in a research study. The researcher viewed this as a process of sharing information (WHO Research Ethics Review Committee, undated). Information was sent to participants beforehand, and opportunity was given for questions and concerns at the time of meeting, together with reiteration of the importance of declining to proceed with the study at any time if they so wished.

Assent

Research involving children must involve both parental permission and child assent - there is an important distinction. Permission indicates parental agreement to a child's participation which is different to assent, the child's agreement to participate in the study (Lambert & Glacken, 2011). A parent's protective responsibility as gate-keeper is crucial, but it is also important to respect the child's right to be involved in decision making and self-determination (Lindeke, Hauck & Tanner, 2000). Even if children do not have the maturity or experience to give fully informed consent, they must be given opportunity to express a wish to be included or excluded in a research study. Parent-child-researcher partnership guidelines (Lambert & Glacken, 2011, Appendix 12) were used as a reference to ensure all possible elements had been considered to establish consent, permission and assent. Verbal assent and consent was also re-negotiated at the start of meeting each of the participants.

Separate information sheets, consent and assent forms were prepared for adult and child participants (8-10, and 11-14 years old) and ratified by the NHS Ethics Committee (Wales REC3).

3.13.3. Confidentiality

Each child was informed about the limits of confidentiality – if they disclosed anything that led to the researcher having concerns for their safety or well-being, that information would need to be passed on to their parent or a relevant member of school staff.

3.13.4. Anonymity

Anonymity “is virtually impossible to completely guarantee” (Braun & Clarke, 2013, p.64). Pseudonyms have been used in the study for all direct quotations and individual case information. However, there is much data that could identify participants in other ways. There are relatively few children in the UK who have incurred a severe ABI and been in receipt of specialist residential rehabilitation. They could therefore be identified through specificity of age, type of brain injury, sequelae, school setting, family composition, and the geographical location they return to. Some identifying information was changed to increase anonymity, without altering meaning substantially (Guenther, 2009).

3.14. Transcription of interview data

The unstructured interviews with parents and school staff were digitally recorded and later transcribed. Hand written notes were taken as back up, but with efforts to minimise diversion of attention from the face-to-face discussion. The questionnaire interviews with follow-up probes were hand-recorded in front of the parents, on the printed sheets. Interviews with the children were not audio-recorded. It was considered the recorder might be overly intrusive or intimidating to children whose speed of processing and language production may be slow, lacking clarity, or even be non-existent. Indeed, one of the selection criteria for a tool to communicate with children was the obviation of spoken language.

Transcripts are representations, not facsimilies. The spoken words in the interviews that are audio recorded, make transcriptions ‘two-steps removed from the actual interview experience’ (Braun & Clarke, 2013, p.162). The transcript was generated from an interaction between the recorded voice and the researcher who did the transcribing and chose what to preserve and how to represent it. This resulted in some differences to the original communication exchange, but without altering the meaning.

3.15. Data Analysis

Data analysis involves grouping information, most commonly words, into larger meanings represented by codes, categories or themes (Creswell, 2014b). There are three data sets: children, parents, and school staff.

3.15.1. Children's data

Significant limitations in terms of data collected resulted in reporting, but not thematically analysing the child interview data. The researcher looked to other approaches for help with analysis; visual ethnography, and what has been referred to as 'polytextual' thematic analysis (Gleeson, 2012). Neither of these were suitable due to the limitations of the data. It was decided that further analysis would be inappropriate, tantamount to an over-analysis of the data. In one sense, there had already been an analysis in terms of the child participants' decisions about categories for symbol placement. However, some limited further interpretation on a participatory theme has been provided.

3.15.2. Adult data: Thematic Analysis

The parents and school staff data were thematically analysed. This is a process of searching for themes that emerge as being important to the phenomenon being studied (Daly, Kellehear, & Glikzman, 1997) and enable a rich picture of participants views.

3.15.3. Induction and Deduction: In qualitative research, two contrasting logics of explanation account for findings and conclusions. Deductive research ('top-down' approach) aims to test existing theory or relate prior data to the analysis that is being carried out. In contrast, inductive research ('bottom-up' approach) aims to generate new theories from the data. The current study took an inductive approach to TA. The development of themes emerged directly from what the participants said, rather than from pre-defined theories (Boyatzis, 1998). However, there is recognition that analysis is "always shaped to some extent by the researcher's standpoint, disciplinary knowledge and epistemology" (Braun & Clarke, 2013, p.175), making research more of a hybrid approach.

3.16. Stages of Analysis

The staged process for thematic analysis described by Braun & Clarke (2013) was followed, as below. However, although presented below as a step-by-step process, in reality it was an iterative and reflexive process (Tobin & Begley, 2004).

1. Reading and familiarisation

Analysis of the qualitative data started with ‘immersion’ in the data, reading and re-reading several times, “actively, analytically and critically” (Braun & Clarke, 2013, p.205) to increase familiarity with the content. This provided an overall impression of the data as well as awareness of more specific issues and concepts.

2. Coding

Coding provides the “building blocks” of analysis (Braun & Clarke, 2013, p.207) and enables themes to be developed. Coding is an evolving process involving progressive exploration of the data, comparing and contrasting different parts, and assigning words or short phrases to segments of the data that capture features and richness of the phenomenon (Boyatzis, 1998) to evolve a more sophisticated understanding. In the current study this was done manually, using the comments feature in Microsoft Word to make notes and assign the possible codes then ‘Post-it’ notes for grouping data extracts.

Complete coding (Braun & Clarke, 2013) was used in the current study which involved systematically working through the entire data set, assigning a code to everything of relevance to the research question and enabling repeated patterns and unexpected ideas to be considered. Both data-derived semantic codes reflecting explicit content based on the participants own language and concepts, and researcher-derived latent codes involving a deeper level of interaction by framing it in an interpretative way, were used.

The data was coded in as many ways as was applicable, changing or merging codes when increased data reflected similar ideas and concepts. Although there is no recommended minimum or maximum number of codes (Braun & Clarke, 2013), initial coding resulted in an overwhelmingly large set. This was repeatedly examined to achieve a more comprehensive set that continued to reflect patterns and diversity. All data extracts relating to each code were then collated together.

3. Developing themes

Whereas a code captures one idea, each theme contains a number of ideas. Larger sections of the data relating to the phenomenon, either directly observable or representing concepts, were developed into themes by combining different codes relating to the same aspect. A hierarchical structure was formed to include overarching themes which captured ideas from a number of themes, and sub-themes which captured specific aspects of a central organising theme. The importance of a theme does not necessarily equate with its frequency overall or within a data item. The significance is whether something meaningful is indicated in terms of answering the research question.

Thematic charts were drawn up to help explore the relationship between codes and themes.

4. Reviewing themes

Overarching themes, central organising themes and sub-themes were refined. Some were integrated into others when the concepts overlapped, some were divided up into smaller units when the data was too diverse to be represented by a single theme, some were re-named, and some were discarded if they didn't fit into the overall picture and relate to the research question. Checks were made to ensure the themes covered most of the data, and that all information considered important for answering the research question was included.

5. Defining and naming themes

This provided a focus and a boundary for each theme. There were 3 over-arching themes for both the parents and the school staff data, named for clarity and transparency.

6. Writing – finalising analysis

The final analysis, described in the next chapter, is the story about the content and meaning of the data. Themes in the current study are supported by excerpts from the data which were used either illustratively or to make interpretative claims (Braun & Clarke, 2013).

Chapter Four - Results

4.1. Introduction to chapter

This chapter includes three data sets: children, parents, and school staff. Digital Talking Mats was the visual and interactive medium through which the child participants expressed their views. The data from the child interviews is therefore presented, in the main, pictorially. A brief 'pen-picture' precedes each Talking Mat - the pseudonym of the child, the cause of the ABI, some significant sequelae, and their education key stage. Limited interpretative comments about participatory 'themes' follow each 'mat' together with some reflexive commentary relating to the context of the interview. Further discussion of the child interviews and the associated challenges are included in Chapter 5.

The data derived from interviews with the parents and school staff have been thematically analysed using the process described in the preceding chapter. Parent and school staff data were analysed and reported separately. For each data set, a table of overarching-themes, themes and sub-themes is provided. These are followed by exploration of each of the themes and sub-themes that emerged, together with illustrative quotations from the data.

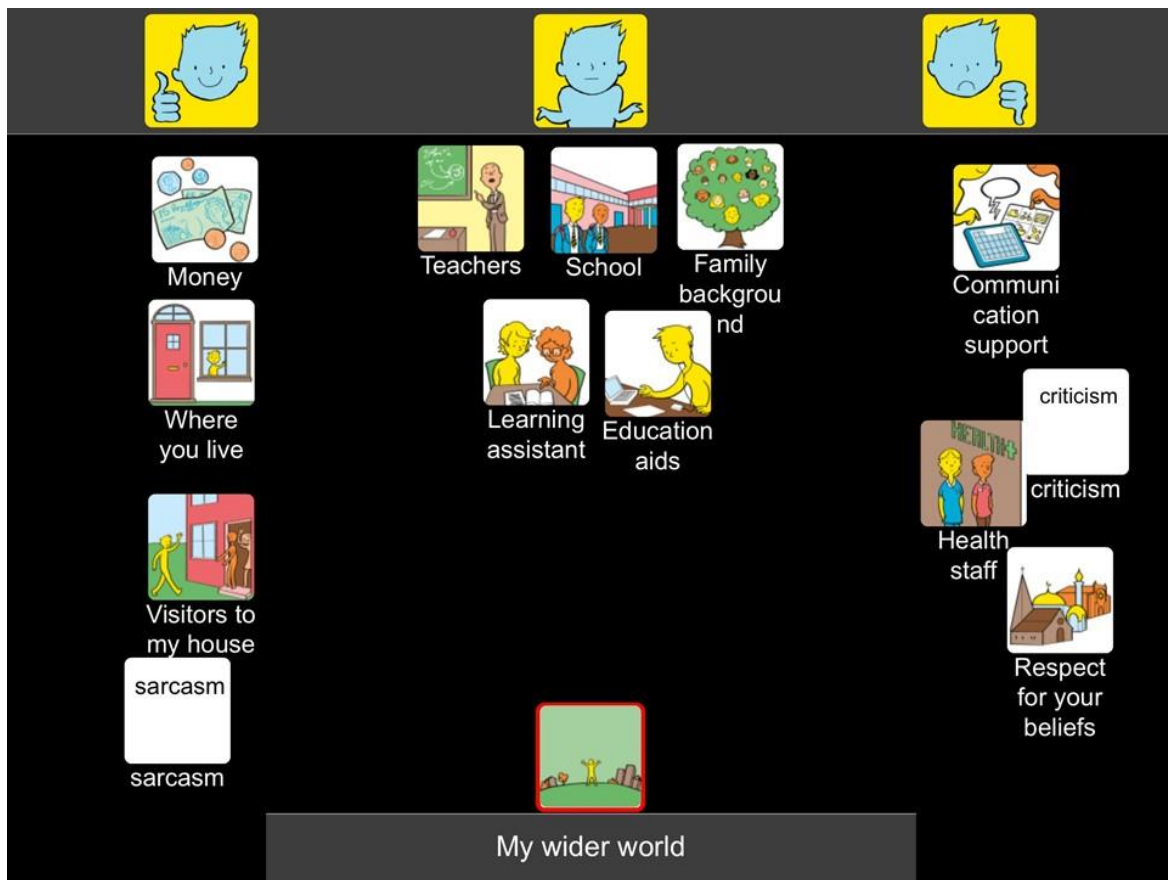
4.2. Child data

The completed mats provided some indication of how the children viewed participation in activities that mattered to them, and as described below their mat.

4.2.1. Jack

ABI resulting from Posterior Fossa tumour. Sequelae: Posterior fossa syndrome (a collection of symptoms following excision of the tumour including aphasia and ataxia) affecting co-ordination, balance, movement and speech. Wheelchair dependent, slow processing speed. Jack returned to the mainstream primary school (key stage 2) attended prior to brain injury.

Record of Jack's Talking Mat



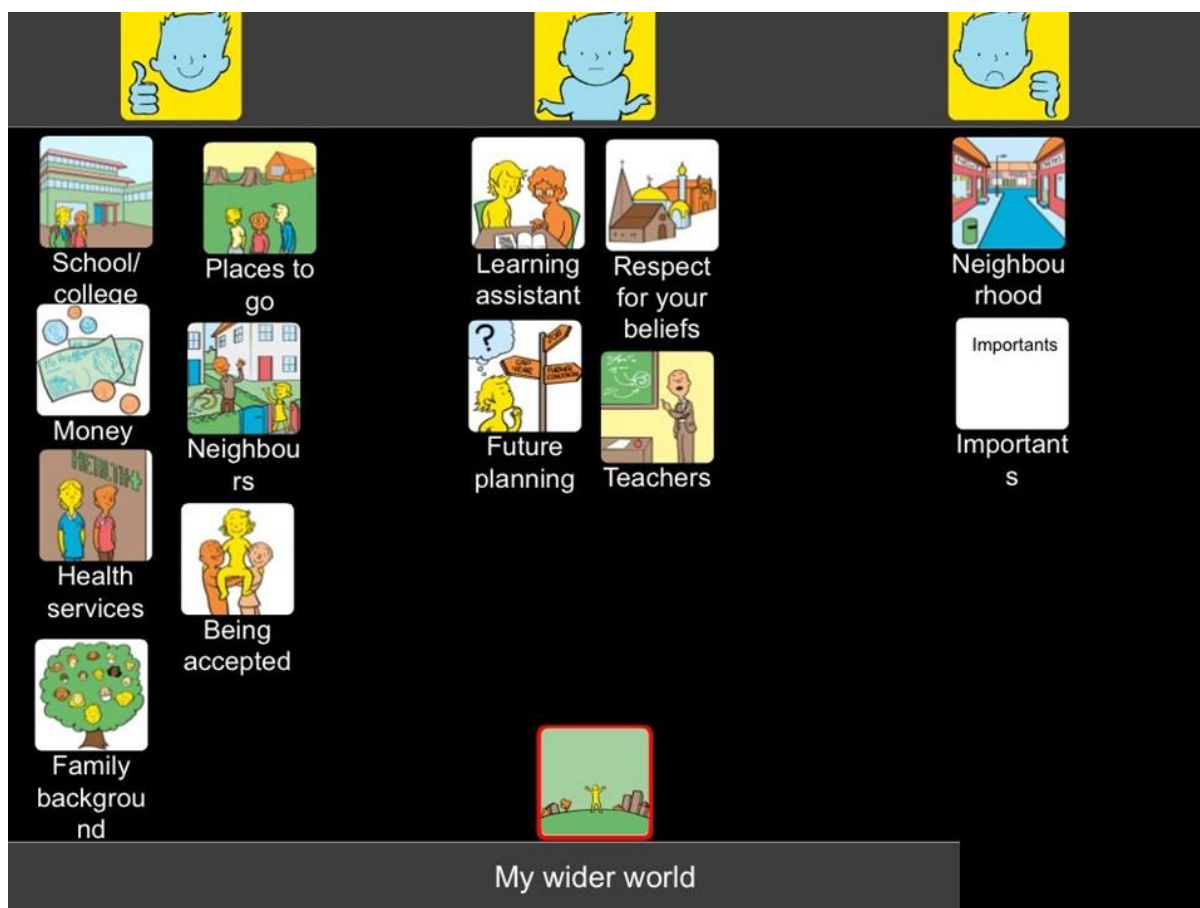
Participation for Jack as reflected in his choice of card placement was interpreted in terms of autonomy and control. Being at home provided him with greater control and independence, including computer activities on a par with friends. Pocket money enabled him to plan and make independent decisions in a world where he had very limited opportunities for control. His use of sarcasm, which he wanted to record using a blank 'card', may also be a means to exert some impact and influence on communication with others. The physical, social, communication and academic challenges of school-life for Jack demand effortful responses and being controlled by others. Jack also particularly wanted to acknowledge that his voice had not been listened to when he had requested cessation of intervention for a medical procedure, and which he considered he was harshly criticised for by medical staff.

4.2.2. Ella

ABI resulting from Posterior Fossa haemorrhage. Sequelae: Balance difficulties when tired, some cognitive difficulties, slow processing speed.

Ella returned to mainstream primary school (key stage 2) but subsequently transferred to mainstream secondary school (key stage 3).

Record of Ella's Talking Mat



Positive participation at school and at home for Ella was reflected by her comments and symbol placement relating to the importance of family and friends, and her engagement in typical age-appropriate activities. Her 'Importants' card was her wish to register concern about bullying at school, or what she called 'snitching', but she generally felt included, and in control, and appeared to have no indication of awareness of any cognitive difficulties for which she received TA support .

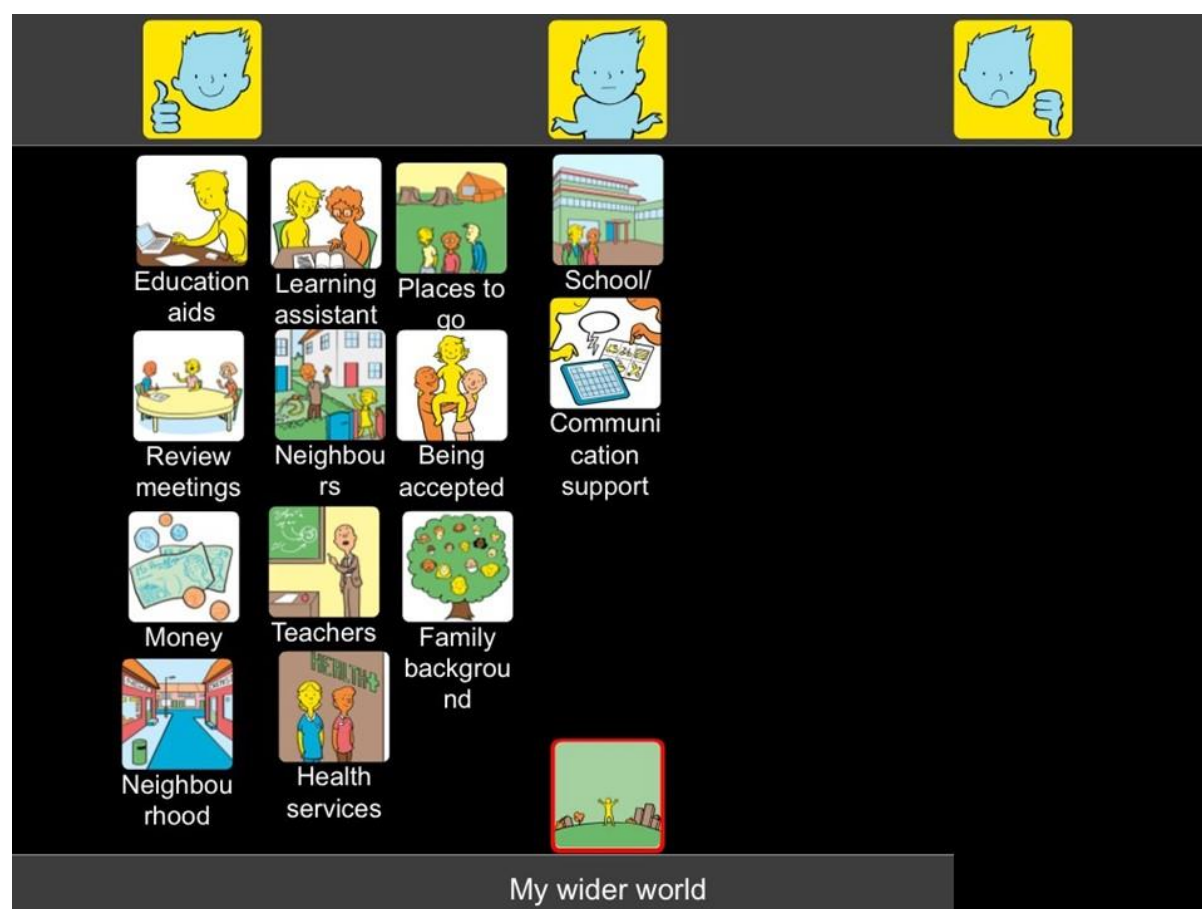
4.2.3. Ben

ABI resulting from to Encephalitis.

Sequalae: Profound hearing loss. Right-sided weakness, restricted mobility. Some cognitive difficulties.

Ben returned to the same secondary school (key stage 3) attended prior to his ABI. Significant resolution of hearing following a cochlear implant.

Record of Ben's Talking Mat



Ben was interviewed at home. He had no knowledge of the researcher from the time he had spent in residential rehabilitation. While in receipt of that, almost all, if not all his therapies and care had been provided by young staff, and generally delivered with convivial banter. His mother reported that he was looking forward to meeting with the researcher at his home at the end of the school day. However, upon meeting the researcher, Ben's facial and body expression suggested surprise and acute disappointment at meeting with someone much

older than he had anticipated. The researcher considered she did not meet his expectation of someone more representative of the members of staff he had been used to interacting with. He slumped onto the sofa, looked very disgruntled, gave very little eye contact, indicated disinterest, and was mono-syllabic. He did subsequently show some interest in the Talking Mats App when presented with the ipad, but he gave the impression that his responses were perfunctory rather than considered, although each of his comments were topic-related. Participation restrictions were suggested by reference to his team of TAs, so reducing opportunity for peer contact in school. Out of school he socialised only with family and with unknown 'friends' online. He did not wish to include 'Future Planning' on his mat, "I'm not bothered" which, given the topic's probable relevance and importance for his peers, and his age and stage, may have been too sensitive and difficult a topic for him to consider.

Each child was able to demonstrate understanding and use of the tablet and the Talking Mats App. They indicated enthusiasm for the task and were impatient to 'take charge' of the tablet while being shown a demonstration of the App. They enjoyed 'dragging' up the digital cards one by one and moving them around the screen. They appeared to have no difficulty making decisive choices about assigning each item to one of 'like' /'dislike' /no opinion or unsure categories, or to the digital wastebin. They were also able to verbally express some relational features to the concepts that the images on the 'cards' evoked. Ella and Jack's additional selection of blank cards enabled them to indicate what was of concern and importance to them, and also provided a measure of their engagement with the task.

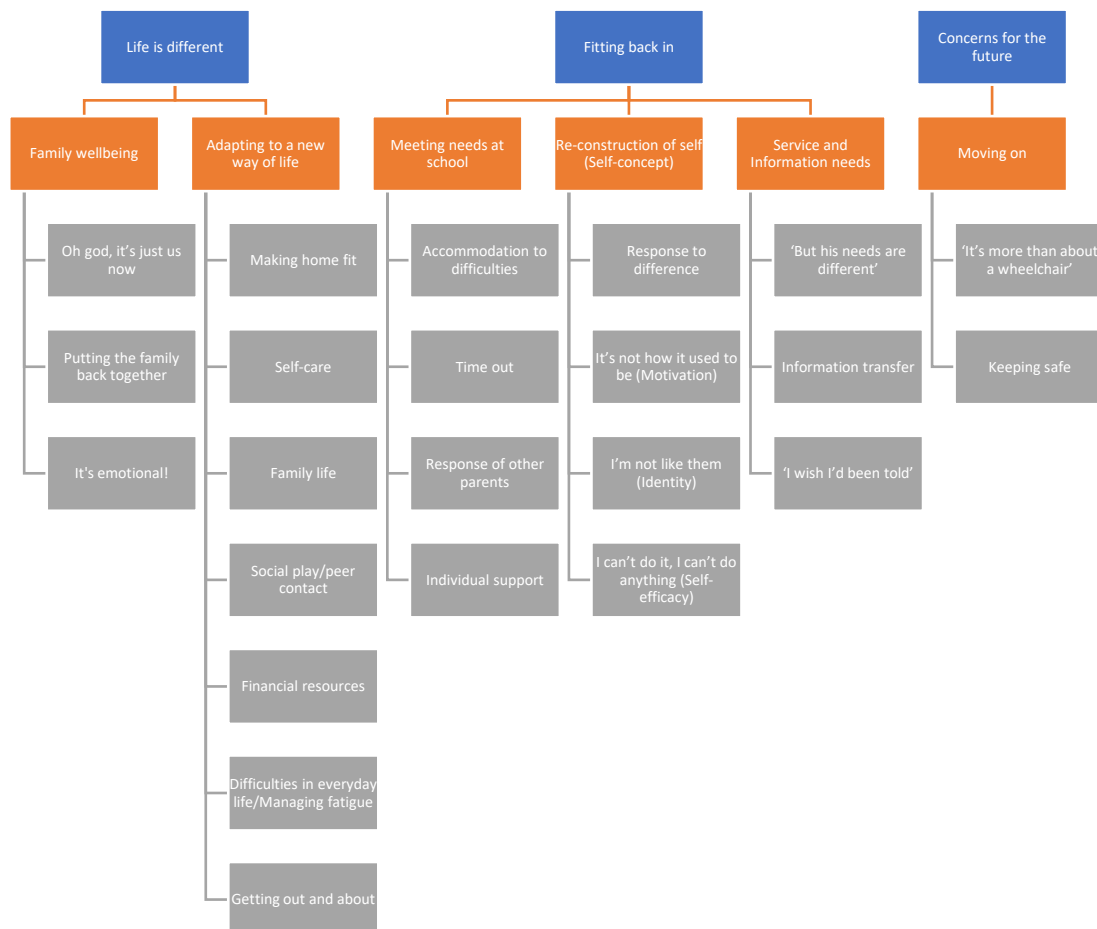
Jack and Ben's expressive language was predominantly at a concrete level. Ella was able to provide some reflective thoughts triggered by the cards. The researcher considered it important that the open questions be as simple as possible, as recommended by Midtlin, Næss, Taxt and Karlsen (2015), and so avoided any kind of 'interrogation' of their choices.

At the end of the interviews, final opportunity was given to each participant to further reflect on the choices they had made for the positioning of each topic 'card' and to make any changes if they so wished. When the child had verified the positions they had selected, a record was made of the completed 'mat'. They were asked if they would like to receive a printed paper version of their finished 'mat'. Ella and Jack wanted a paper copy which was printed and sent to them in the post, subsequent to the interview.

4.3. Parent data

Thematic Analysis of Parent data

Overarching themes, Themes and Sub-themes



4.3.1. Overarching theme: Life is different

Severe childhood ABI is a catastrophic event with devastating, life-long implications for the child, family well-being and the wider society. The study parents had all been overwhelmed by the extent to which the ABI had changed their lives, and the lives of their entire family. It was not until they returned from residential rehabilitation that the full extent of this profound impact began to be apparent. The return triggered a shift in the way life was perceived, changing from the clinical focus of the rehabilitation programme, to the familial, domestic

and educational focus of issues related to home. The parents indicated how the lives of each member of the family was so radically different now to how they used to be, and that their child's ABI had implications for adaptation to a new way of life in almost every aspect – their routines, their employment, their finances, their health and well-being, friends and family relationships, the organisation of their home, education, perceptions of their local community, and plans for the future.

Theme: Family well-being

Discharge back to home and school after having spent many months away from the family home in hospital and rehabilitation settings was a disarming and challenging experience for the parents. Life for both parent and child when in receipt of the highly structured specialist residential rehabilitation programme had been an immersion in an atypical intensive environment in which all staff and families were exclusively focused on and responding to the needs of children with ABI. Parents staying in the on-site family accommodation frequently found support, empathy and camaraderie amongst other parents who, like them, had been thrust into an alien, frightening and unexpected world. They were also surrounded by a large multi-disciplinary team who specialised in ABI. This had provided a sense of security in the knowledge that their child was 'in the right hands'. One mother said she and her son looked back with fondness at the months they spent on residential rehabilitation programme "even though you feel guilty doing that because everyone is there for awful reasons". Life was highly structured and "we did something every evening and weekend like table tennis and horse-riding." After returning home each of the parents became aware that no-one in their immediate surroundings - friends, extended family, neighbours, and school staff - fully appreciated or understood the concept of ABI, the profound implications of their child's injury and the extent to which life had now changed for the whole family. They all referred to feelings of fear and isolation, anxious and alone with the responsibilities of caring for their child. One parent likened it to the feelings experienced on returning home after giving birth to her first-born in hospital – returning with a completely new child, feeling scared and vulnerable about caring in a way she'd had no experience of, concerned about being able to cope, and knowing that life would never be the same again.

Parents were also concerned about relationships within the immediate family fuelled by thoughts and emotions associated with their own absence from the family for significant periods of time. These included not having been in a position to nurture and spend much time with their other children, the disruption to routines and activities for their other children when being cared for by relatives or friends, and the almost exclusive focus on the injured child. Parents wanted to “get their family back together again” (words of one of the parents) and to function as a cohesive unit, but yet were also sensitive to negative feelings experienced by siblings such as resentment, anger, jealousy.

A poignant and distressingly emotional experience was recounted by Jack’s mother. Jack had experienced much hospitalisation, painful and uncomfortable treatments, leading to his extreme distress with any kind of medical intervention. One night he needed an emergency admittance to hospital for complications with his ‘peg’ (percutaneous endoscopic gastrostomy). The procedure acutely distressed him which in turn distressed his parents who found it hard to witness their son suffering so much. He pleaded for the cessation of all further treatment; he did not want to go through any more procedures of any kind. This request profoundly shocked his parents and compounded an already difficult situation. When the procedure was completed they returned home during the morning. (His mother expressed some guilt to the researcher that she had kept him off school for the rest of that day due to them all feeling emotionally exhausted!)

Sub-theme	Illustrative quotations
<p>“Oh god, we’re on our own now.”</p>	<p>I’ve felt lost since getting back home. I thought ‘Oh god we’re on our own now’. No-one in our area understands what it’s like. With an ABI you’re not prepared. (B’s mother)</p> <p>I don’t think we were prepared for how we all might feel when we got back home. None of what had happened was processed until we got back. That’s when you realise you’re really on your own. You feel so vulnerable, scared, with a child who wasn’t like that before. (E’s mother)</p>

	<p>As a parent it puts your mind at rest when you can talk to another parent who has been through the same experience. (J's mother)</p>
<p>Putting the family back together</p>	<p>We've always been honest with P (older 9 year old son), we needed to maintain his trust. He came with us to kiss her goodbye in ITU when it was thought she wouldn't make it. We then couldn't return home with him as we had to stay in ITU. It was awful. I don't regret that he had that opportunity but I couldn't be a mother to him in the way I wanted to at that time. I wanted to protect him from that but wanted to be honest. We can't hide.....(started to cry).....</p> <p>Our other children were abandoned for 6 months, our relationships with them were on the back-burner. Our priority was Ella. When we got home it was all about making up for lost time.(E's mother)</p> <p>On return we provided lots of love and cuddles (to 3 year old daughter) but there was stomping anger that said 'you left me'..... We're trying to put us all back together, to be a family again. (E's mother)</p>
<p>It's emotional!</p>	<p>It's the hidden emotional needs that have been hard. It's about beginning to allow yourself to look ahead and not just do one day at a time. Psychology services and counselling are needed....The people you're involved with when you come back home such as the Physio, the Speech & Language therapist, the Occupational Therapist, the carers, are not 'touchy-feely' people there to enquire how children and family are doing emotionally. The ripples spread out to the wider family and they're going through it with us. You just want a big pair of arms to embrace us all to reassure us all that we'll properly enjoy life again. (E's mother)</p> <p>I thought he'd have a real problem with it [the wheelchair] but actually it was me. I'd never cried so much in my life.....I don't want</p>

	<p>him to think that it's the end [of him walking again] so we don't have it [the electric wheelchair] at home (J's mother)</p> <p>"Please, I don't want to do this anymore. I've had enough". We were so horrendously stressed. (J's mother quoting J undergoing intrusive medical procedure, and referring to their own parental reaction to their child's request.)</p> <p>It would be good to have some kind of service that's all about helping with the emotional side of life. It's so hard, there's no-one to turn to who understands (B's mother)</p> <p>I cry at the drop of a hat now, and when I think of the preciousness and futility of life., really knowing how temporary life is (E's mother)</p>
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Theme: Adaptation to a new way of life

Each of the parents had made adaptations to their homes and changed their life styles to accommodate the new needs of their child. Some difficulties were not easy to resolve such as restricted mobility impacting on access due to limitations of space or the steepness of stairs. Jack and Ella's mothers had relinquished their jobs subsequent to their child's ABI as they found that managing home life was no longer viable without full-time parent oversight. Jack's mother spent much of each day attending to his complex care needs: support for activities of daily living, transporting to and from school at irregular times of the day, returning home from school when excessively tired or needing a pad change (no facilities at school) and frequent hospital visits. Ben's mother had reduced her work commitments from full-time to part-time to be at home when her son was not at school.

Ben's mother reported a poor quality of life and felt there was no longer any time for doing anything pleasurable. She was a single parent and found it difficult to continue the social life she had prior to the ABI. She was worried about going out in the evenings leaving her son without adult supervision because of his vulnerabilities. Jack's mother had been used to frequent family holidays and weekends away prior to Jack's ABI. These trips had constituted

an important aspect of doing things together as a family which had been much enjoyed and she was disappointed that she and her family now had to forgo them due to the difficulties and uncertainties associated with her son's disabilities. Ella's mother reported family life to be good since becoming more established at home again. Ella had no gross motor difficulties and had resumed a similar social life to that which she had participated in prior to her ABI. Her family supported her return to structured activities out of the home – badminton, sea-scouts, tennis and swimming. Jack and Ben's social life had changed significantly. Both of them had been extremely physically active prior to their ABI. Jack maintained some pre-injury social activities with friends through the use of indoor activities - computer games and Lego, although his mother reported the need for an adult presence much of the time in order to access activities. His non-disabled friend tried to encourage other joint continued participation in pre-injury activities involving the use of the outdoors but which Jack himself did not initiate. Ben had become increasingly isolated because his friends continued to be very focused on physical activities. He now spent more time on the computer and on-line activities.

All parents mentioned fatigue having a huge influence on their child's abilities and emotions. They got easily tired which had a negative impact on their ability to learn, do homework, socialise and regulate their emotions.

One of the parents stated that her reduction to her hours of employment had placed additional constraints on family finances with implications for her son's access to extra-curricular and holiday activities which she could not afford.

Shock and surprise at the additional cost (£30 each way for a local journey) charged by a taxi driver for taking a wheelchair, had contributed to Jack's parents concern about the next stage of schooling for him. They didn't wish to rule out the possibility of a state-funded faith school in their neighbouring town but due to the closer proximity of another school catering for the same age-range they thought they may have to meet the daily travel costs.

All three children were taken to school in their parents car; the physical difficulties of Jack and Ben precluded walking. Each of the children was also accompanied by an adult if they went out of the home for leisure activities: Jack required adult help because of the need to use a manual wheelchair (the electric wheelchair stayed at school), Ben rarely went out for leisure

activities - social contact with his pre-injury friends had diminished due to his physical restrictions and his social trips were now adult initiated and led, and Ella was accompanied for reassurance of safety.

Jack's parents had complained about lack of wheelchair access into the cinema and reported an antagonistic response from cinema staff. This was extremely frustrating, disappointing and upsetting to them particularly as they perceived going out to see a film could, with wheelchair access, have been something for the whole family to enjoy together, and also provide a safe and managed activity that Jack could have done more independently with friends.

Sub-theme	Illustrative quotations
Making home fit	<p>We've put in a stair lift. His bedroom was on the top floor but he's now on the first floor, we've swapped it with the office (J's mother)</p> <p>The equipment takes up so much space; the hoist, the wombat chair, the wheelchair, the red chair, the physio balls, the resting chair, the walking frame – if we didn't have an open plan house I don't know what we'd do. (J's mother)</p> <p>If we were in a modern home it would be ok. But here the stairs are steep and there are narrow doors because it's an old house (B's mother)</p>
Self-care	<p>An adult needs to get his clothes out and bring him his washing things. (J's mother)</p> <p>He needs help with the loo. He uses a bottle. (J's mother)</p> <p>I help him due to his right-sided weakness. I help him get ready for school. He needs help with his top button, his tie and his shoelaces. (B's mother)</p>
Family life	<p>We've got a poor quality of family life now. We just get through each day, there's no time for more pleasurable things. It's not a normal family life because I'm a single parent. I can't work so much because I need to</p>

	<p>be at home when he isn't in school, and I need to pick him up and take him to school. (B's mother)</p> <p>Loads of people are booking holidays and things. We haven't, we haven't tried that yet. We used to go abroad once a year plus family holidays in England like about three long weekends away. We were very lucky but we've gone from that to zero. Having no plans like that is hard. (J's mother)</p>
Social/peer play	<p>His physical activity is limited but he likes his X-box and his Lego. If anything he wants to play older (computer) games...He loves the ipad, that gets him into Minecraft and playing with other children. There are loads of things he can do in his bedroom with his friends but I'm in there with him because he needs help to access things so it's not really age-appropriate. (J's mother)</p> <p>My friends son Mo, who is the same age, they're really close friends. Mo will come round here and they'll play X-box together, and Jack will go round his house to do the same. It's Mo who says would you like to go to the beach, to the park. (J's mother)</p> <p>He's recently lost confidence with his friends; they're moving more quickly and he can't keep up. His friends are usually on bikes, a physical bunch of kids, always out playing football. They probably don't think to ask him so he spends more time at home now. (B's mother)</p>
Financial resources	<p>He's good at managing money, he's very savvy like that, very money oriented. He used to charge people to come and see him when he was in hospital. He gave his grandparents a pensioner discount (J's mother).</p> <p>She doesn't handle money as everything is paid for by card (E's mother)</p> <p>Money's a big problem for me. I used to work full-time but I can't do that now, I can't work so much. Also more money's needed for activities in the school holidays. (B's mother).</p>

	<p>One time I booked a taxi and it was extortionate as the wheelchair cost an extra £30 each way. I was shocked as it was only to somewhere local. If it costs that much for a local trip I don't like to think how much a taxi to and from school in X (name of large town 5 miles away) every day could cost. (J's mother)</p>
<p>Difficulties in everyday life, incl fatigue</p>	<p>Managing fatigue and making sure she gets enough sleep is a really important part of her being able to do things. It affects everything if she doesn't get enough. (E's mother).</p> <p>His strength and energy levels are low, he gets tired so easily. (B's mother)</p> <p>Remembering things and his mood swings, and his attention and concentration, they're the big problems (B's mother)</p> <p>His disability doesn't show and so people don't give him the time he needs to do things. (B's mother)</p>
<p>Getting out and about</p>	<p>He can't get into the garden on his own now.(J's mother)</p> <p>We complained to the cinema because there's an absence of wheelchair access. We were told they wouldn't put a lift on the outside of the building because it would get vandalised. (J's mother)</p> <p>I wish there were more activities for people like him, especially in the holidays; there's not enough community facilities.(B's mother)</p> <p>If friends want to go to the park he needs (adult) help because of his wheelchair and he can't get onto the go-carts. (J's mother)</p> <p>Not everywhere has a ramp but shopkeepers will help. (J's mother)</p>

4.3.2. Over-arching theme: Fitting back in

There is common expectation of returning to the familiarity and routines of the life that was led prior to ABI, and the importance of this cannot be overstated. However, meeting needs

at school following a lengthy absence, and returning with very different skills and abilities is a challenge not only for the child and parents but for education, health and care service providers. The injury changes every part of the child's life in a way that no other injury can (Perkins, 2015). Changes to the child's "internal experience of being themselves" (Perkins, 2015, p. 215) constitutes a re-construction of self, altering how they think, feel and respond and creating a mismatch between expectation and experience.

Lack of knowledge and understanding about childhood ABI, and the idiosyncratic nature of the enduring sequelae some of which only become apparent over time can make it hard for the child's needs to be appropriately met. Unmet service and information needs are exacerbated by a range of additional factors such as the response and attitudes of others, the ways in which support is provided, and continued time out of school for clinical appointments.

Theme: Meeting needs at school

The parents felt generally very positive about ways in which their child's school had responded to the changed needs, despite concern about individual members of staff who might lack information and therefore not provide appropriate support.

Parents mentioned on-going medical appointments which involved time out of school. This often involved driving some distance and long periods of waiting time. Two of the parents, whose children had more significant physical and sensory needs, were extremely concerned about the extent of missed schooling, and worried about the impact this was having on their child's learning.

Jack's mother recounted her feelings of shock and upset to hear of reactions by other parents, a small minority, who had approached the headteacher to express concerns about Jack's return to school and their belief that he should be educated elsewhere. She was extremely gratified by the way the headteacher had managed the situation, providing a clear and positive response that strongly supported her son's return.

Jack and Ben received full-time individual TA support at school which pleased their parents as they associated it with a more inclusive approach to learning – they thought it meant their child would be able to learn more and do more than would be the case without such support.

Sub-theme	Illustrative quotations
Accommodation to difficulties	<p>School has been marvellous, I can't fault them. They've taken all the stress out of it for me. They're completely fine with whatever time he turns up. We usually get to school between 9.30 & 10. (J's mother)</p> <p>School's really good. The only thing is that when he needs a pad change there's nowhere to do that so he needs to come home to do that. (J's mother)</p> <p>She's got a coloured card to hold up to indicate she needs more time like when she's feeling overloaded and needs more processing time, or to go to the loo, or needs a drink. (E's mother)</p> <p>There's an element of protection on the part of the school. They know her and the family really well. They notice differences and talk to us about that. (E's mother)</p> <p>It's difficult to get him to go outside (at school). His wheelchair doesn't go on the grass. He does play football as his wheelchair takes up a lot of space so other children like to have him on their team. I've asked if he can do some learning while the other children are doing swimming. (J's mother)</p> <p>He does 'golden nuggets of learning; he's limited due to his time there. (J's mother)</p> <p>Some people at school don't realise or make allowances. Like his P.E. teacher complained because it took him too long to get changed, to get his shirt off. He's now stopped P.E., they said he could do extra maths support instead. (B's mother)</p>
Time Out	<p>We still have appointments with oncology, splint fitting, eye appointments, physio, hydro – the week is very full. This week there are two hospital visits; a splint clinic and an eye clinic. I asked if we</p>

	could do both at the same hospital on the same day as he's missing so much school. But it's not possible because the different consultants come in on different days. (J's mother)
Response of other parents	A few parents didn't want their child near him. They said their child got upset. Parents complained to the headteacher that Jack had returned to school. They didn't want their own child close to Jack because it upset them especially when he looked so poorly. They said that at their age it wouldn't be right to show them childhood cancer. The headteacher nipped it in the bud. (J's mother)
Individual support	<p>He's got poor balance so the TA accompanies him everywhere and carries everything. He's got a wheelchair but he won't use it. He'd get lazy anyway. (J's mother)</p> <p>He's got a one-to-one all the time so it's ok (re. difficulties with learning) (B's mother)</p> <p>If I have concerns about school I usually speak to the TA about it as she's with him all the time. She's like a second mum to him and she's very good. (J's mother)</p> <p>She works independently, she has no one-to-one support [at school] but she has a private tutor[at home]. (E's mother)</p>

Theme: Re-construction of self

Jack and Ben, whose ABI had resulted in significant physical disability, were reported by their parents to experience frequent negative feelings of difference. Prior to injury, physical activities, particularly bike-riding and playing football, and for Jack playing at the nearby beach, had been very important to them, had helped to shape their social life and define who they were. Awareness of their pre-injury capabilities and loss of functioning was making it extremely challenging to adjust to their new status. The parents too were finding it hard to adapt to the change. Jack's mother indicated on-going difficulties in her own adjustment to

her son's need of a wheelchair and she continued to hope that time and therapy would enable him to be an independent walker again.

The emotional well-being of Jack and Ben was of significant concern, and parents reported them to demonstrate many bouts of anger, frustration and low mood. Reduced levels of the child's motivation were mentioned by each of the parents, but most especially Ben and Jack due to restricted mobility. Motivation remained positive for activities perceived by the children as typical for their age group and that presented no access difficulties. For Ben and Jack, these were sedentary activities, predominantly computer-related. None of the children identified with others at school with any kind of additional need, and had rejected parental attempts to introduce them to any special groups or activities associated with disability. They had also rejected activities perceived as alternatives or adaptations to those they would have engaged in pre-injury. For example, Jack was provided with the opportunity to go to a special school for adapted P.E. sessions, but that arrangement had been discontinued because he refused to go again after the initial visit. The parents subsequently made private arrangements for additional weekly physiotherapy to increase his physical activity.

Jack and Ben's parents were worried about the lack of support for their child's emotional needs, and they had no knowledge of any professional who might be able to offer such a service.

<p>Response to Difference</p>	<p>He's up and down emotionally, it's very hard (B's mother)</p> <p>At the review meeting yesterday it was recommended that he go to a 'Team Talk' facility because of the reduction in the contact with his friends. He's much more isolated and lonely now. (B's mother)</p> <p>I took him swimming to the gym where I've got a membership, and it's got a lovely pool, very warm, very clean. He had a lovely session with me and P [his father]. Just as he was getting out he vomited; he didn't mean to it just came on really quickly. He was so embarrassed because some of it went in the water and he won't go again. Things like that are so hard because you want him to, you desperately want him to do</p>
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	<p>stuff, and there wasn't a problem with it. I cleared it all up, no-one else had a problem with it. It's just that he felt awful. (J's mother)</p> <p>It got to a stage where he wouldn't go [to restaurants]. We've conquered that now, just very small steps.(J's mother)</p> <p>I think he needs to realise he can still enjoy life but he's at a stage where he feels he can't do anything. He's lost all interest. (J's mother)</p>
<p>It's not how it used to be (Motivation)</p>	<p>It frustrated him that he couldn't run down to the water to get water for his castle and reach for different things like he used to. He's acutely aware of feeling different now and remembers what he could do before his illness. He gets angry, not talking, not holding his head up. (J's mother)</p> <p>He doesn't like being with others now that he's in a wheelchair (J's mother)</p> <p>He says he wishes he could play like he used to but he doesn't want to stand and watch. (B's mother)</p> <p>We keep saying to him 'would you like to do this, would you like to do that', trying to incorporate D's [older sister] views on it. (J's mother)</p> <p>He's tried (adapted) football and cricket but he's stopped it now because it wasn't how it used to be. He's lost all interest in going out with friends; he just isn't interested any more. (B's mother)</p> <p>He was invited to a friend's party where all the class went. He didn't go because it was a disco. He won't attend discos. He felt overcrowded and couldn't move. There was a party of a girl who lives down the road and he wouldn't go to that either. (J's mother)</p>
<p>'I'm not like them' (identity & self-concept)</p>	<p>I try to get him into activities and things, a sort of course for children in wheelchairs but he doesn't see himself like that and so he won't do it. (J's mother)</p>

	<p>I don't want him to think it's the end (of possibly walking again) so we don't have it [the powered wheelchair] at home. (J's mother)</p> <p>He joined the deaf children's activities once but he didn't want to continue. He didn't see himself like that. (B's mother)</p>
<p>I can't do it, I can't do anything (self-efficacy)</p>	<p>When it was a sunny day, D and his family went again to the beach and rang us and said are you going to meet us down here. But I struggled like mad to get Jack to go. I said we could walk along the pier, even just stay for 10 mins. I tried all sorts of ways to get him to go again but he said "I can't do it, I can't do anything, There's nothing for me to do there. I just have to sit there" I think it's like that for most things. (J's mother)</p>

Theme: Service and Information needs

After returning home from a specialist centre that had met all their child's therapy needs, parents were shocked and upset to find local provision presented a very different scenario. Ben's mother thought he should have more therapy but didn't question the levels provided. Jack's mother did question it and was affronted when told that Jack had already received more than other children in the community.

There were two aspects of concern about provision of information that each of the parents mentioned. They were worried that some school staff may not be aware of their child's additional needs which could create extra problems. Ella's mother was delighted with the response from school staff to an information session provided by a member of staff from the rehabilitation centre. She felt this signified school-wide interest in the topic of ABI and an indication that staff wanted to provide appropriate support for Ella. Ben's mother was upset that some of the staff at his school were unaware of his difficulties and didn't make allowances because his disability was not immediately visible when he was sitting in class.

The other concern expressed by each of the parents was access to information for themselves. Prior to their own child's injury they had had no knowledge of childhood ABI. They felt they'd been kept informed about current developments while their child was in

hospital and in receipt of residential rehabilitation, but after returning home felt they were in some kind of information void, aware that people and services locally lacked specialist ABI knowledge. They therefore didn't necessarily know what to ask about, they didn't know what to expect in terms of on-going support, and they didn't know who would be in a position to help them.

Sub-theme	Illustrative quotations
'But his needs are different'	I've had to fight to get any more rehab, to get physiotherapy. I was told that he's already had more than other children in the community. I said, but his needs are different from other children in the community (J's mother)
Information transfer	Anna (therapist) came from the rehab centre to talk to the school staff. She had over 30 teachers at the first of two sessions. It definitely made a difference. (E's mother)
I wish I'd been told that	<p>I'd like information as we've been going along but I've not known about things. (B's mother)</p> <p>Three years on and I didn't realise it was possible to get social care benefits which I would have been eligible for. I wasn't aware. I also didn't realise about the breaks and holidays that are available for families like ours. (B's mother)</p> <p>School has been very good but there's no crystal ball. There's no-one to guide us through the maze. We don't know what's going to happen or what to expect. (E's mother)</p>

4.3.3. Overarching theme: Concerns for the future

Brain injury has the potential to impede or alter development and parents in the study realised that earlier plans or possibilities for their child's moving on to the next stage of education and to adulthood were no longer relevant, requiring them to make significant adjustments to their hopes and plans. The acquired vulnerabilities of their child following the ABI engendered concern in all the parents about major decisions that would need to be made at times of transition, as well as post-school life and opportunities. Identifying realistic vocational goals, and responding to their child's demands and expectations for increased independence can be a significant source of additional stress.

Theme: Moving On

Thinking about the next stages of education worried all the parents: whether they would have the relevant information to make the right decisions, the potential impact of a major change on their child's learning and emotions and whether staff somewhere new would understand about ABI. The parents of one child who had already moved school, had been concerned to select a school where their daughter would not be defined by her ABI – they wanted to be assured of staff understanding but didn't want her to be treated differently. The other two parents were fearful of making an inappropriate decision and thought having someone who had understanding of many of the relevant aspects to talk it through with would be helpful. They all felt that there were staff at school who understood some of the issues, and they appreciated these being addressed.

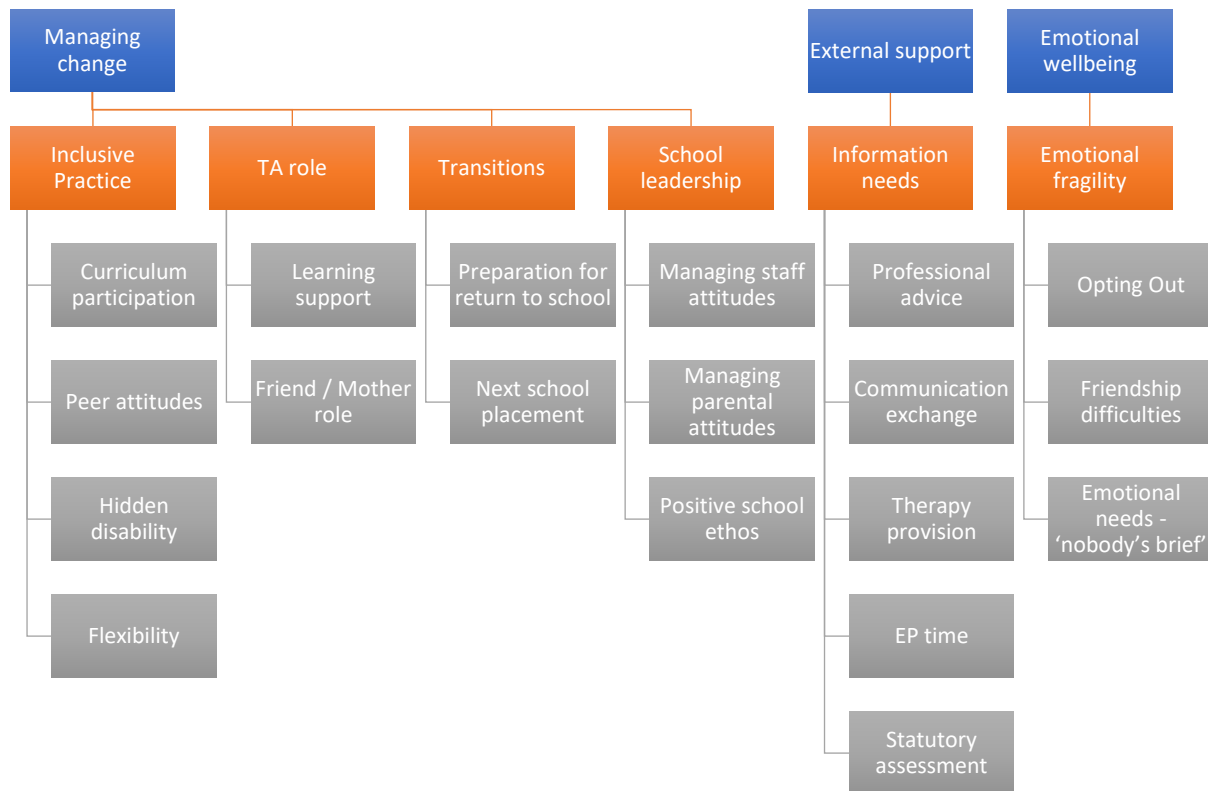
The uncertainties of developing increased independence, the future and prospective adult life for their injured children concerned each of the parents, but the predominant concern was the near-future, particularly inevitable changes of educational establishment and their child's social-emotional well-being rather than longer term outcomes such as career prospects.

Sub-theme	Illustrative quotations
<p>'It's more than about a wheelchair'</p>	<p>The transition to secondary school really worries me. The O.T. [occupational therapist] said I should take him to the local secondary school which is much closer, and his powered wheelchair won't fit in my car. I was knocked back when she said that – she said that would be the best school for him because it's wheelchair friendly. I don't want to put him somewhere just because it's wheelchair friendly. It's more than about a wheelchair, it's about him. We want to make absolutely sure about making the right choice of school. I want us as a family to look at the choices, to understand all the options, and what's best for him. (J's mother)</p> <p>She needed to go somewhere anonymous. We didn't want her to be labelled as the girl who had had the brain tumour.(E's mother)</p> <p>His future, I just don't know how it's going to be, I can't stop worrying about it because life's so much harder for him now. And its such a big decision about what he'll do after leaving school . (B's mother)</p>
<p>Keeping safe</p>	<p>One of my worries is her vulnerability unless she moves on from being so literal. It's about sustaining relationships; when she's mixing with boys, if he said ' if you love me you'd do that...'(E's mother)</p>

4.4. School staff data

Thematic Analysis of school staff data

Overarching themes, themes and subthemes



4.4.1. Overarching theme: Managing change

One of the most significant challenges for the study children was their return to home, school and local community following their clinical care. It involved a series of transitions requiring change and significant adaptations. There is a danger that gains made during their time away while in receipt of specialist rehabilitation services could be undone if managing their transitions is not well planned. The aim is to provide an environment that is conducive for ongoing learning and development. A key role of school leadership is to influence beliefs and capacity, to implement inclusive practice at school. This includes both academic and social participation, but which research indicates may be significantly compromised by a prevailing model of full-time TA support for children with significant needs.

Theme: Inclusive practice

Staff in all three schools voiced concern and a lack of confidence about whether they were getting everything right, particularly in terms of approaches to and support for learning. They wanted to make sure the children's needs were being met. They indicated they had little experience of working with a child with suddenly and significantly changed needs, and worried about the enormity of all the implications and their responsibilities. They delighted in perceived progress. The staff at Jack's school were less concerned about managing the physical side; they had been provided with information about manual handling, and some staff had been on courses about making adjustments in P.E. Staff at Ella and Ben's schools considered the children were missing out on P.E. while long awaited advice from a physiotherapist continued to be unforthcoming. Each school was appreciative of the support and liaison they had been provided with by therapists, teachers and psychologists at the rehabilitation service when the child had first returned, and also provided to the school to which one of the children had subsequently transferred to. School staff anxiety was partly related to whether they could build on the progress that had been made in the rehabilitation setting. Staff at Jack's school responded constructively to the restricted time he spent in school due to his shorter school day and attendance at clinical appointments. Their concerns had been allayed after working with, and reassurance from a teacher from the rehabilitation service, and they now focused on 'golden nuggets of learning' – what the basic essentials were that he needed to know rather than on all the information he was missing out on. They also held regular meetings to plan and discuss activities for maximum inclusion as they were very concerned about his lack of motivation. Some of the staff at Ben and Ella's schools failed to appreciate their slower speed of processing and were reported not to demonstrate the patience and extra time required.

Sub-themes	Example quotations
Curriculum participation	<p>We had a system of glass beads – adding one on when he’s been brave. It was huge, about 8-9 feet long, and staff explained to children what the significance of the bead chain was. (J’s Headteacher)</p> <p>We’re looking at ways he can be more actively involved in play. He wasn’t a hard-working boy before and he isn’t now. He was always the boy who wanted nothing except to play football. He loved going to the park with friends to play and climb trees. I need the TA to be more persistent to stick to her guns and get him to play. (Headteacher)</p> <p>We pick out golden nuggets of learning and pare away the rest, it’s what we really want him to learn, tailored to his individual need (J’s Class Teacher)</p> <p>P.E. can be tricky at times; we’re learning as we go along (Class Teacher)</p> <p>I think his needs are being well met. There’s nothing we don’t include him in except swimming. We’ve got a hoist but we need advice from the physio. (J’s Class Teacher)</p> <p>They need to be activities that others enjoy doing too, and not just because of Jack. At lunchtime some children are reluctant to be inside in good weather, and he’s reluctant to be outside. (J’s TA)</p>
Peer attitudes	<p>Children made him captain of the football team. The others respond 110% but he isn’t always willing to go along with them because it’s not what he would have wanted [i.e. to be physically restricted].</p> <p>The other children have been fantastic. They’ve all been together since reception, and they’re all involved at one level or another. (J’s TA)</p> <p>Friends try to motivate him; they stay in when the weather isn’t so good. They try to make sure he’s included. He has some very supportive friends, they’re accepting of all sorts (J’s TA).</p>

	<p>He can be domineering in his attitude with friends, but his friends ride that. He's being encouraged to be more inclusive of other children's views and wishes. (J's Class Teacher)</p>
Hidden disability	<p>It's difficult for the staff to keep remembering that there are any issues when she looks ok. You can't tell from appearances. (E's SENCo)</p>
Flexibility	<p>We've let parents say how much they want him in school. We're very flexible. (J's TA)</p> <p>In his first term back his timetable built up quickly, it was too much too soon and he was getting really tired. We now recognise that part of what's important is his routine at home, having breakfast and getting dressed. He still doesn't come in until 10a.m. There's no point in pressurising Mum and Jack. I don't know if Mr Ofsted would object. We've taken the line that in that first hour when he's showering and dressing, he's doing his physio, and his occupational therapy. We also have a child with cerebral palsy but that's a completely different scenario and we would be concerned if she didn't come in at expected times. If Jack and his family can start the day on an even keel it contributes to a more positive learning experience. We call it an authorised late otherwise it would affect our attendance records. (J's SENCo)</p> <p>The teacher keeps having to stop because Ella makes it known that she's not there yet. I don't think they (the I.T. teachers) have a lot of patience with the SEN pupils. (E's SENCo)</p>

Theme: TA role

Individual support provided by a teaching assistant (TA) for the injured child was highly valued by staff at all three schools. Teachers indicated that it enabled them to direct their attention to the needs of the rest of the class in the knowledge that the child with ABI was receiving more individual TA help. The teaching assistants were also generally satisfied with these arrangements. Some of them considered they had more knowledge about an individual child

than the teacher in charge, and indicated confidence to challenge teacher instructions if it was not in accord with the study child's needs.

TAs at all three schools indicated that their role was more than learning support. The TAs at Ella and Jack's schools referred to the maternal, caring aspect of their role as well as the education one. Ben had been allocated a number of TAs, most of whom were relatively young and with recent experience of being in full-time statutory education themselves. Two of these TAs considered their role to include friendship to compensate for Ben's reduced peer social contacts.

Sub-theme	Example quotations
Learning support	<p>Support full-time is great, I couldn't do without it. His pace of learning and his needs means he must have 1-1 (J's Class teacher)</p> <p>I rarely work with him as the TA does all of it. (Class Teacher)</p> <p>As they get older we put in TAs who are subject specialists. She's struggling in Science so we need to put in a TA who has a particular interest in science. (E - SENCo)</p> <p>The hard thing for staff is when there's no support available, particularly for managing unpredictability (E - SENCo)</p> <p>He has learning support for every lesson. One of us (TAs) always sits beside him. He doesn't like anything that's different but I think he's past the point of embarrassment. He leaves every lesson 5 minutes early and goes with the TA to the next. (B - TA)</p> <p>The teachers are expecting us to do all the one-to-one. (B-TA)</p> <p>At the start of the academic year a new teacher didn't know the system. He assumed everyone on the SEN register needed differentiated work. Ella was affronted and said 'I don't need this'. I told him he needed to look at the details in the SEN register, not just the list of the pupils on it. (E-TA)</p>

	When some teachers see a TA with him they leave us to it because we know all his learning needs. (B-TA)
Friend/ mother role	We TAs look after them. I think it's because most of us are Mums.(E-TA) We can relate to a lot of the students. It's not been long since we were teenagers ourselves so we get the whole attitude thing. (B-TA) We're more like his friends really. It's hard for him to make friends of his own age. (B-TA)

Theme: Transitions

Transition planning is a vital part of successful return to school, and for managing any other changes that the child will experience. Jack's school staff had appreciated the importance of keeping in contact with him while he was in hospital and receiving rehabilitation and they had done much to maintain an active relationship with Jack and his family.

Staff at each school expressed appreciation of the contact there had been with the residential rehabilitation service. Two or three members of school staff had visited the facility before discharge to have a better understanding of the child's programme, and this was followed by members of the rehabilitation team visiting the receiving school for a review meeting and to provide a staff training session on ABI.

Sub-theme	Example quotations
Preparation for return to school	It was important for Jack to be back with his friends. We kept up links. The class teacher hadn't really known Jack but every Friday she sent examples of work from other children so he knew what was going on. Tapes of children talking and singing. We worked hard to maintain links, we were desperate to get it right, we wanted to do whatever it took. (J-Headteacher)

	The support we got from the Rehab service just before discharge was a huge help. From that we could identify action points that needed to be addressed straight away.(E-SENCo)
Next placement	<p>I've now got to hand over to a new teacher. There'll be an open afternoon and I'll go with the parents to talk to next year's class teacher – we'll want to spend as much time as possible together as it's a big learning curve and we can pass on a lot of information and experience. It took us a long time to get up to speed to understand his needs and the best way to support him. But we want the new teacher to get to grips with the issues as soon as possible. (J-Class Teacher)</p> <p>When we know which school he's going to we'll go with parents and Jack. We'll want to see an extended transition. (J-SENCo)</p>

Theme: School leadership

Jack's illness and cancer treatment left him without hair, wheelchair dependent, and with speech and language difficulties. Negative attitudes about his return had been expressed to the headteacher by both staff and parents of other children, with the indication that his needs should be met elsewhere. Some school staff were anxious about the perceived increased teacher work load, meeting the needs of a child whose profile had significantly changed in ways they did not entirely understand, and being 'face-to-face' with evidence of an illness that distressed them. Some parents with children at school were also fearful. They objected to Jack's return and did not want their children to have awareness of or come into contact with childhood cancer and a child who now looked very different. The headteacher at Jack's school responded quickly and firmly to counter negative attitudes, and emphasised the importance of inclusion for all children in their community.

Sub-theme	Example quotations
Managing negative staff attitudes	<p>There was fear, anxiety, and murmurings of...(started to cry) whether this was the right school. I stamped on any rumblings immediately, they were partly driven by fear. It didn't take long to get them (staff) back on board. We tried to keep all staff 100% informed, and released them to come to meetings.(J- Headteacher)</p> <p>Teachers have felt overwhelmed. One of the teachers flew into a bit of a rage; " we're supposed to do this on top of everything else?" I answered 'yes', and directed that at all staff (J-Headteacher)</p>
Managing negative parental attitudes	<p>I had to deal with some difficult situations with other parents. When he was so ill some of them were upset that their own children were aware of that. Parents didn't like it; they said their children should be spared that knowledge. They didn't want them to see childhood cancer. They were quite angry and said it wasn't appropriate ...(started to cry). Little chap, how could they behave like this. It was a minority of parents who said it was distressing for their own child to see Jack like that..I told parents that they had to get it into perspective. Jack was so frail, his return was a day for rejoicing. (J-Headteacher)</p>
Positive school ethos	<p>My role is strategic, and to ensure we have the right ethos in school. We have to meet every challenge that comes our way. I'm not of the mindset that children go elsewhere. It's up to us to meet the needs of all children who come here. We need to adapt to meet their needs – I had to reiterate that to staff when Jack returned (J-Headteacher)</p>

4.4.2. Overarching theme: External Support

The myriad of difficulties following ABI necessitates staff from a range of disciplines to be involved. Joined-up' working between different services can be invaluable for ensuring a holistic approach. The range of **information needs** are extensive due to general lack of awareness of ABI, and the enigma of brain injury.

Theme: Information needs

School staff looked to a range of sources for information and advice; peers and within-school information exchange, statutory information, therapists, educational psychology. There had been a high level of therapy, teacher and EP support from the rehabilitation service, providing reassurance, information and advice with some staff questioning where that kind of support could come from when the links with the rehabilitation service ceased. Generally they indicated limited confidence about working with a child with ABI, particularly in terms of on-going changes and what to expect. They wanted guidance on how to support a range of aspects – learning, socialisation, and behaviour. There was particular concern from almost all adult participants about the emotional impact of the ABI on the child's learning, behaviour and socialisation with some expressing a wish for external sources of help for them to manage that.

Sub-themes	Example quotation
Professional advice	He's well supported by school but there's a whole lack of training. Time, not funds is the biggest enemy. (B-Special Needs teacher) I still find it hard, how much I should make in my planning to incorporate his therapy needs. And other things to do with his recovery, how can I join that up with his academic learning. He's lost a lot. I'd like more help with that. We're trying our best but it's a big thing for a teacher to include a child who has had such changed needs.(J-Class teacher)

	<p>Understanding the psychology of a child who has been through this trauma, how to support them emotionally. We could do with some training for psychology and emotional needs. It's hard to respond to questions like 'When will I walk again'. We don't know what to say.(J-Class Teacher)</p>
Communication exchange	<p>The teachers are supposed to look at the SEN information on the staff shared area (intranet) at the beginning of every academic year, and are reminded of any additions or changes as and when.(E-SENCo)</p> <p>There's been so much support from the Rehab service. Just having a contact is fantastic. We had huge problems with another child with severe ABI, but who didn't get any rehab. We sent the parents of that child, and the staff, all the non-personal information we received from Rehab about the other child.(E-SENCo)</p> <p>The communication system works really well. We have a 20 minute meeting with the SENCo every morning and are encouraged to attend lunchtime meetings to discuss any child that's of concern.(E-TA)</p>
Therapy provision	<p>We never get enough therapy for him, he'd benefit from weekly or even daily therapy. Perhaps we can't make it better however much he has. The speech therapy has been slowly cut back and now we have to do it ourselves. We're losing private therapy funded by the NHS because there isn't anyone available to take it on, so it's going to stop soon which is a concern.(J-SENCo)</p>
EP time	<p>I could apply for some core EP time because he's a child with a statement but we've had so much from the Rehab centre that we don't need it at the moment. Next year there'll be plans for moving on, that's another issue (J-SENCo)</p>
Statutory assessment	<p>Getting the statement and professional advisors on board was extremely difficult as the local authority wanted evidence of Jack in school. Writing educational advice for a child who isn't well enough to</p>

	be in school is an impossible task. We wanted to get the statement in place before he came back to school. We wanted to know what the advice in the statement said, to help guide us. (J-SENCo)
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4.4.3. Overarching theme: Emotional well-being

ABI is a major risk factor for developing emotional and behavioural difficulties. The clear links between the ABI and adaptation to it indicate the importance of addressing the child's emotional fragility that is commonly perceived by others. School staff play an essential role in supporting the children to make a positive difference. Much can be done to foster inclusion, participation and experience of success to enhance emotional well-being. The concerns of the school staff in the current study suggest that systemic and context-specific perspectives such as perceptions and beliefs about the behaviours that cause concern may be usefully explored, as well as the potential impact of the injury to the child's sense of self. Staff concerns also highlight the very significant limitations and inadequacies in community mental-health provision, and the need for specialist advice.

Theme: Emotional fragility

As well as wanting information themselves about how to support children in school with emotional difficulties due to suddenly acquired neurological changes, school staff expressed extremely significant concern about the need for specialist support for the child which they considered was not available. They were worried about the impact on the child's well-being, socialisation and learning, and the longer term outcome.

Sub-themes	Illustrative quotations
Opting out	<p>Sometimes he gets frustrated. Art was one of his preferred subjects before he became ill. He was asked to draw a face and he had little pencil control and he got frustrated. He doesn't like art anymore. (J-TA)</p> <p>When he got the motorised wheelchair the speed wasn't initially restricted on it. He was in the hall going round and round really fast, he wanted to go as fast as possible. He was told about the safety side and</p>

	<p>that he couldn't go at that speed as other children might get hurt. He got really angry and said repeatedly, 'Get my Mum, I want to go home'. He went home and the following day he wasn't keen to come to school, but he did come and he was ok. Since then he hasn't been speeding, and also a restricted speed is set on the wheelchair. (J-TA)</p> <p>We introduced the Haka (a dance). There's a lot of upper body movement he could do. The teacher wanted him to do the hand and arm movements. He didn't want to get involved. He clenched his limbs, put his hands between his legs and said he wanted to go home (J-TA)</p> <p>It's a tricky time when they're out on the field running around and he can't do it. He'll ask to go in. (J-Class Teacher)</p>
<p>Friendship difficulties</p>	<p>His friends don't have the best understanding of how he feels emotionally. (B-TA)</p> <p>He hasn't now got enough friends to make him socially happy (B-TA)</p> <p>He'll hear laughter and think its about him. He gets annoyed with them and then they get back at him. It's a vicious circle. He gets paranoid about people looking at him as he thinks they're looking at his cochlear implant. (B-TA)</p> <p>A meeting with some of the boys without him there would be really helpful. It's not that they don't care, it's just that they get caught up with being lads and forget or don't understand his needs. (B-TA)</p>
<p>Emotional needs – 'nobody's brief'</p>	<p>My biggest concern for Jack is his mood. He was always the boy who wanted nothing except to play football. (J-Headteacher)</p> <p>What's lacking across everything in terms of what all services can provide, NHS and Education, is helping him cope with the emotional impact. All stops were pulled out to check he'd got the right therapies, and the right equipment. But he's had a massive emotional trauma and it's not well recognised. The contacts we've been provided with have been speech</p>

therapy, occupational therapy and physiotherapy but nothing for his emotional needs. I know he's got anger in there. I feel there's a real lack of professional interest. I don't know if we as a school staff should go barging around (i.e. providing emotional support) in this area, we're not experts. We see a need, try to support as much as possible, but don't feel skilled to get deep down. There's a fear at school that if we try to help we could do more harm than good, like open-up a can of worms. If there's one aspect of his care that's desperately desperately lacking it's that. There doesn't appear to be any service or support to manage the emotional side. We're all concerned about that. It's the emotional side as he gets older too. Friends will go to town together on Saturdays, get girlfriends etc. How will he manage and feel about that? Will his friends stick with him or will he become increasingly isolated?

The emotional needs seem to be nobodies brief. The service doesn't appear to be there. It's mental health but the only route available is CAMHS. We make referrals to a primary mental health worker and that's hard enough to access. We use it for children starting to self-harm. Jack needs something quite specialist for what he's been through. Hopefully there won't be a crisis but that's what CAMHS is for, when there's a crisis. There isn't a service that can help him. There are various charities concerned with ABI but it's all about giving him a nice time. There's a huge mental health, well-being and esteem issue, and the gap is widening. (J - SENCo)

Chapter Five: Discussion and Conclusion

5.1. Introduction to chapter

This chapter examines each research question in turn; the original questions that initiated the study, and an additional question that was generated following data collection. Drawing on the overarching themes, themes and sub-themes from the data sets of the parents and school staff, an understanding of strengths and barriers to children's participation in their everyday settings of home, school and local community has been constructed. The information needs of those in a position to facilitate participation, parents and school staff, and ways in which local EP services could contribute to successful participation of this population of children are discussed. The additional research question addresses difficulties in eliciting the voice of children with severe ABI. These are discussed in the light of the researcher's experiences interviewing children in the current study, with reference to the literature. There is particular focus on cognitive-communication difficulties that, in the researcher's view, significantly influenced the ability of the child participants to express their views. The study's strengths and limitations in respect of the methodology, and ways in which results may have been influenced are reviewed. Suggestions are made for future research on the topic of participation following childhood ABI including methods for seeking the views of children with severe ABI. Finally, concluding comments and personal reflection on the overall process of the study are offered.

5.2. Original and additional research questions (RQ)

The current study aimed to address the following questions that initiated the research:

Primary Questions:

RQ 1. What are the barriers to and facilitators of participation in the home, school and community following severe childhood ABI?

RQ 2. What are the information and support needs of parents, and school staff?

Secondary Questions:

RQ 3. How can educational psychology services contribute to optimisation of participation following discharge from a clinical setting?

Additional secondary research question:

Prior to data collection, at the time of planning the study, account had been taken of possible communication difficulties when interviewing the child participants, hence the choice of Talking Mats to help elicit their voice. It had been assumed that the data elicited from these interviews could be included in the Thematic Analysis, together with that of the adult participants, making it possible to look across the data from three different sources – parents, school staff and children. More significant limitations in terms of child data than had been anticipated resulted in reporting, but not thematically analysing the child data. This prompted further reflection and an additional, late, secondary research question, as supported by Gibbs (2007) for emerging issues important for the topic under study:

RQ 4. The voice of children with severe ABI is rarely heard. In what ways may this study help to enhance optimal potential for eliciting their views?

5.3. RQ1: What are the barriers to and facilitators of participation in the home, school and community following severe childhood ABI?

Parents alluded to or explicitly described very powerful and at times overwhelming emotions of grief, loss, anger, despair, and fear. The influence of parents is an important determinant of children's participation (King et al., 2003) and underscores the importance of post-injury systemic support for families. Trying to make sense of and adapt to the sudden and profound changes created an almost relentless exhaustion for parents at the same time as doing what they could to support their injured child, hold everything together and maintain some semblance of family life. Similar experiences have been documented (Gerring & Wade, 2012; Roscigno & Swanson, 2011) and associated with negative changes to well-being, family functioning, managing behaviour difficulties and the ability to draw on resources.

After many months of a high level of professional support for themselves, and informal support from other parents, as well as specialist support and care for their child while on the rehabilitation programme, returning home to local services was a shock for the parents, as expressed by one mother “Oh God, it’s just us now”. The apparent absence of a local support structure or involvement of a local professional who was able to demonstrate concern and awareness contributed to parental feelings of isolation and loneliness as also reported by Tyreman et al. (2017) and Kirk et al. (2015). Having no-one they felt they could talk to who would understand about ABI, or ask advice from at a time when they were feeling extremely vulnerable, and fearful echoed others experiences (Guerriere & McKeever, 1997). This contributed to the challenges they faced in their parenting role and mirrored those reported by other parents following their child’s severe ABI (Kirk et al., 2015; Tyreman et al., 2017). Although they had begun to develop some understanding and knowledge about ABI while staying with their child on the rehabilitation programme, it was not until they had returned home that the wider and multi-faceted implications of caring for a severely injured and different child began to be realised. There was parental acknowledgement of the neglect of sibling needs while their injured child was in hospital and residential rehabilitation, as also reported by Tyreman et al. (2017) but the study parents felt they had no choice but to prioritise their injured child. The resulting difficulties in ‘putting the family back together again’ had a negative impact on family participation, which can also have significant implications for consistent parenting (McCusker, 2005).

Symptoms of trauma-related stress were reported by each of the study parents and which may be experienced to a greater extent than the child, possibly reflecting more mature cognitive capacities of adults to perceive threat to the lives of their children (Yalug, Tufan, Doksat & Yalug, 2011), and greater ability to recall events associated with the trauma. On-going medical intervention for one of the children served to increase both parent and child levels of stress, poignantly elevated by the child’s request of cessation of any further treatment. Children being administered what they perceive as traumatising medical procedures may see their parents as colluders or even perpetrators of the trauma (Yalug et al., 2011) impacting on family relationships, and participation.

Adapting to new way of life

The multi-professional transition and discharge planning – preparation for returning home – together with provision of information by the residential rehabilitation service and their contact details was much appreciated by parents and school staff. It helped orientate them to and prepare them for significant participation issues associated with the child's return. It provided a measure of confidence, forward planning and understanding to proactively meet participation needs at school.

Discharge planning is a priority feature of the rehabilitation programme that the study children, their families and receiving schools had engaged in, but there was indication that it was not a priority for staff in other local services that aim to provide social, psychological and therapy support. Only a very small minority of children with severe ABI receive specialist residential rehabilitation. They have complex and severe needs which cannot be provided for by their local healthcare trust. Paradoxically, their return home to limited or lack of services risks negating the gains made while in receipt of formal rehabilitation, thereby compromising optimal participation.

Difficulties in encouraging local professionals from health, welfare and psychology services to 'buy-in' to discharge planning is common (Tomlin et al., 2002, Kirk et al., 2015). This may be due to constrained resources (Glenn, Mulkearn & Withers, 2016) but staff in local services may also be unaware or feel professionally inexperienced and uncomfortable regarding their understanding and knowledge of ABI (Linden et al., 2013). They therefore may be unable to appreciate the needs and priorities for children and families following severe ABI, and their potential contribution to positive adjustment and outcomes (Yeates et al., 2007).

The family have an important effect on children's participation. Jack and Ella's parents played a pivotal role in creating opportunities for their child's social participation as has also been identified in other studies (King et al., 2003; Heah, Case, McGuire & Law, 2007). Meeting their child's needs took on the greatest focus in the lives of all three parents. They had relinquished or reduced their employment, mainly because of the practicalities and difficulties in balancing this with their changed family needs. Information from Ella's mother, who had been informed of her daughter's precarious hold on life while in ITU, corroborated other research that has found mothers may develop an enhanced appreciation for life, and embrace opportunities as

a result of the ABI (Guerrier & McKeever, 1997). This positive perspective may have contributed to Ella's high level of participation and well-being in the family, in community activities, and at school.

Parental involvement, such as arranging social play activities, taking them to a swimming pool or restaurant had a positive effect on the extent to which two of the three study children accessed community facilities and participated. Parents served as mediators between the child and the world at-large (Grove, Bunning, Porter & Olsson, 1999) which significantly influenced their child's participation. Pre-injury positive family functioning can serve as a buffer by reducing family stress, and contribute to increased participation (Brown et al., 2013; Wells et al., 2009). This may account for what appeared to be a higher level of coping in two of the families where there appeared to be partner support, emotional, social and financial resources. These families indicated much pro-action in trying to initiate and encourage their child's participation both in and out of the home. Over time they had also developed an appreciation of the activity demands and what was required for successful participation. For example, Ella's mother recognised that fatigue was a major factor in the extent to which her daughter participated, and so placed high importance on Ella's sleep and rest regime. Jack's mother and his school staff recognised that obviating stress in all the essential routines of getting ready for school each morning enabled a higher degree of scholastic participation, and therefore were accepting of a flexible school arrival time. Jack's mother made herself available at short notice to transport him to and from school when a pad change was needed, keen to minimise his time away from participating at school.

In contrast, Ben's mother indicated the impact of the injury had a profound and debilitating effect on her. She seemed overwhelmed by the injury-related social, emotional and financial burdens, concerns for the future, and what she perceived as an absence of local services for meeting his needs. She recognised his difficulties and his reduced participation but seemed to lack the emotional resources to mediate on behalf of her son, either at school or at home, projecting an overwhelming picture of personal grief, sadness, loss and helplessness. Poor adaptation, with both the school and the home reporting Ben's loneliness and isolation, his mother's report of dissatisfaction with life, their relative inactivity and dependency, appear to be indicative of the vicious cycle of emotional and psychosocial effects referred to by Taylor et al. (2001) in as much as the effects of Ben's injury impact on his mother's functioning, which

in turn impacts on her ability to effectively facilitate his participation (Brown et al., 2013, Hawley et al., 2003).

Getting out and about to access community facilities beyond home and school represents a more difficult environment to control and is one of the commonly reported barriers to participation for children with physical disabilities (Imms, Reilly, Carlin & Dodd, 2008) and as experienced by Jack. He was unable to go to his local cinema or use the play areas in his local park due to the lack of wheelchair access. His parents had anticipated that going to the cinema could be one of the few safe enjoyable activities he could do with his friends independently of adult supervision. The reported negative attitude of the cinema staff when this barrier was challenged was upsetting for his parents, and eroded their confidence to make further attempts to resolve the issue.

Social play/peer contact

Positive interaction and engagement with peers is a crucially important aspect of participation but presents challenges. The typically developing peers of the children in the study were becoming increasingly independent, spending more time away from home (Law et al., 2007) while the children with ABI are becoming more dependent and spending increased time at home. Also, the ability to initiate activity is often compromised following ABI – thought to be related to executive functioning and frontal lobe damage (Anderson & Catroppa, 2005). Many children with ABI are therefore relatively passive, unable to get started on activities that they may have the skills to carry out, but don't unless prompted by others. This underscores the important role of others to facilitate participatory activities and help other children develop ways to stay engaged.

References by Ella and Jack to feelings of belonging, and experiences that were facilitated by or with others indicate the significant contribution that meaningful interactions had in creating positive and engaging participation experiences (Willis et al., 2017). Opportunities both in and out of school were encouraged by the adults around them which elevated the extent of their social participation. In contrast, there appeared to be few adults in Ben's life consistently taking the initiative to facilitate social engagement. Consequently Ben spent most of his time both in and out of school in solitary sedentary activities. He felt excluded and isolated from his pre-injury friends and activities, and had turned to opportunities on the

internet at home for helping to counteract his loneliness. On-line communication, for example through the use of chat rooms or social media, may help to ameliorate feelings of being socially excluded or lonely, but increase a child's vulnerabilities and exposure to a range of abusive and exploitative cyber-crimes such as grooming or abuse (UNODC, 2015).

Comments by Ben's TAs suggest that help for his peers to understand his needs could enhance social relationships. Sensitivity to confidentiality may deter staff from providing specific information but adult facilitation is an important precursor for successful peer relationships. Adults commonly have difficulties understanding the concept of ABI and appropriate ways of supporting needs, and it is therefore not surprising that children have even less understanding or knowledge of how to stay engaged .

Making home fit

As has been found in other research (Bedell et al., 2005), children in the current study experienced fewer participation restrictions at home which could be explained by enhanced understanding and support for their difficulties within the family. Parents have greater emotional involvement in their child and so are more willing to do whatever it takes to minimise problems (Bedell & Dumas, 2004). It is also easier for parents to manage participatory activities in the home when having to balance competing demands on their time. Jack and Ben's parents had made adaptations to the home to accommodate their child's physical difficulties, and Jack's parents facilitated social peer play at home. However, this was limited by the need for an adult presence to access some aspects of social play which restricted Jack's opportunity for privacy, independence and self-determination.

Finances and their relevance to participation were of concern to two of the parents. Many families are impoverished by uncompensated extra costs and restricted employment opportunities consequential to their child's disability (McConachie et al., 2006; Beresford, 1995). Ben's mother was worried that she would not be able to fund out-of-school activities for him, which she considered important for helping to counteract his reduced peer contact and the limited range of activities now available to him. Jack's mother was concerned about the potential personal cost of transport to and from school if they selected a next key-stage school that was not their closest one.

Fitting back in – meeting needs at school

Each of the parents had been particularly worried about their child's reintegration to school. Jack's school had been very pro-active while he had been away, wanting to maintain communication to support him and his family, so contributing to a feeling of belonging and connectedness. Parents and school staff spoke particularly positively of the planned return to school and the arrangements that had been made. Schools felt supported by staff at the rehabilitation service who were able to act as skilled and knowledgeable intermediaries between school staff and other local professionals at a time when parents felt extremely vulnerable and emotional, and school staff felt anxious about the dramatically changed needs of a child in their care. Planned returns are critical for optimising scholastic participation (Sharp et al., 2006) and although common for all children being discharged from the residential rehabilitation service, are atypical in as much as most children with severe ABI return to school without any local planning or awareness on the part of local services including school staff (Hawley et al., 2002) who may not even realise the child has had an ABI.

Flexibility

Flexibility is a central tenet of inclusive practice (Symes & Humphrey, 2011). Flexibility and willingness to make adjustments to the status-quo has contributed to aspects of successful participation for the study children and provided significant support to the parent. Each of the parents appreciated the part-time and gradual re-entry to school as advocated by the rehabilitation service. One of the children had insisted on an immediate full-time return - a common expectation and wish for children with ABI, unaware of the difficulties they will face for meeting the everyday demands but anxious to resume how life used to be. This was counter-productive and reverting to a part-time attendance plan was necessary. Demonstrating awareness of highly individual needs as also advocated by Jordan (2008), the school removed the expectation of Jack being in school at the start of each school day for an infinite period. They appreciated the importance of his personal care routines at home and the practical difficulties in making time deadlines. Although there was some concern about meeting Ofsted requirements regarding school attendance, their priority was the child's well-being. They reasoned that not only were executing personal care routines in the morning equivalent to undertaking important physiotherapy and occupational therapy activities, but

minimising stress enabled Jack to arrive at school in a relatively calm frame of mind and therefore in a better position to learn. This was a supportive and individualised decision by senior school staff who indicated that such flexibility with regard to time spent in school would not be tolerated for their other children with more robust physical needs.

Parents indicated that schools' ability to show an empathic understanding of the child's holistic needs had a positive impact on parental emotional well-being. This highlights the need for good communication. Shared information increases the ability of school staff to understand the needs of the child and facilitate flexible arrangements.

Time Out

Despite the planned return, fitting back in at school and becoming a full participant in activities has been challenging for a range of reasons. As well as having been absent from school for a protracted period due to their time in hospital and residential rehabilitation, return to school post-injury for two of the children in the study continued to be marked by time out from typical school activities for clinical appointments. The extent and range of their acquired difficulties was commensurate with the number of on-going medical needs, and the amount of time away from school, and hence reduced opportunities for participation. Parents were concerned about how much school their child was missing, particularly when hospital visits involved much more time in cars and waiting rooms than the received clinical time. Also, it was impossible for appointments with different consultants to be arranged for the same day which could obviate the need for additional travel and out-of-school time.

Ella had few clinical appointments so time out of school was not a significant feature for her. Her levels of independence at school were associated with few participation difficulties. Although she did receive some TA support, she did not have a Statement of SEN and participated in the same activities as her peers.

School Leadership

The deputation to the headteacher by a small group of parents wanting Jack to be refused re-entry to the school following injury was an unexpected aspect of school inclusion and participation revealed through the interviews. This significant and surprising issue, which may not have come to light through the use of more highly structured interview techniques and

pre-defined topics, is an indication of the conflicting agendas, expectations, and priorities that can occur between parents and school staff (Laluvein, 2010a). Conflicting agendas and priorities were also indicated by the headteacher to be between some of the staff and the senior management team (Paliokosta & Blandford, 2010). The agenda of other parents with children at the school related to them not wanting their own child to have any contact with manifestations of childhood cancer. The agenda of some of the teachers who had also questioned the efficacy of the child's return to their mainstream school, related to concerns about additional responsibilities and work-load. The headteacher also considered these negative attitudes represented fear of the unknown. The headteacher's agenda, that it was the responsibility of her and her staff to meet every challenge that came their way and adapt to meet the needs of all children, is an embodiment of wider societal beliefs about the social inclusion of and social justice for children with special needs (Male & Palaiologou, 2017). She resolutely rejected any deficit views of difference (Ainscow et al., 2006), promoted a philosophy of acceptance (O'Hanlon, 2003) and affirmed the importance of an inclusive school (Mapp, 2002). She conveyed an unequivocal message to the entire school staff that negative attitudes about inclusion would not be tolerated. A whole school culture for facilitating a supporting, nurturing environment requires all members of staff to have a shared understanding of the aims and expectations of inclusion (Eldara, Talmora & Wolf-Zukermana, 2010). The positive impact of the headteacher's strong critical lead and embrace of difference may have helped to change the perceptions and attitudes of some of the parents and school staff, by challenging the limited ways in which disability was understood by them, and therefore making it more likely for the returning child to participate in activities (Wells, Minnes & Phillips, 2009). This may have accounted for a subsequent positive, united staff approach about the return of the child as voiced during the study interviews. Although given opportunity to talk in confidence, staff gave no indication of the initial staff dissent referred to by the headteacher. Their failure to mention it could relate to social desirability effects in as much as they may have been embarrassed to reveal negative attitudes to the researcher, or they may have become progressively more relaxed and supportive of the inclusion of a child with complex difficulties after experiencing it (O'Donoghue & Chalmers, 2000). This would accord with Sikes, Lawson and Parker (2007) who refer to understandings of inclusion

that are not fixed and definite, “but rather are ‘becoming’, developing and changing as they are articulated and lived” (p.367).

Although the school considered participation for accommodating the child with ABI to be a high priority, activities to promote this were restricted to the social sphere.

Role of Teaching Assistants (TAs)

TAs are one of the primary ways in which children with complex needs engage in mainstream school activities. It is therefore important to understand the role of the TAs in relation to the impact on the study children’s participation at school. Participation may have been significantly compromised, especially for the two children with more complex needs, as a result of full-time individual TA support. Research indicates that the majority of mainstream schools lack clear models of inclusive service delivery and unwittingly encourage unhelpful or detrimental approaches for supporting children with SEN in the way TAs are deployed (Giangreco, 2013; Blatchford & Webster, 2013). The three schools in the current study were no different in this regard in as much as individual support provided by TAs was perceived as the primary method of support for children with statements of SEN - individual TA support was the way, rather than a way of support (Giangreco, 2013), quantified in terms of number of TA hours provided for the individual child. There appeared to be an absence of any clear model of service delivery as referred to above - no indication of any conceptual framework based on pedagogic need, no systematic diagnosis of learning conditions, or the study children’s personal resources or alternative methods for supporting. The acknowledged role of the TA was to provide one to one support. This created a physical barrier between the study children and their peers, as referred to by one of the TAs: “One of us always sits beside him”. Ben and Jack received the vast majority if not all of their instruction from their full-time TAs. This close proximity of the TAs appeared to be in accordance with the negative effects on peer interaction, dependence and learning identified by Blatchford, Russell and Webster (2012). The TAs may have had no qualifications (Butt, 2016) in contrast to qualified teachers who provided the instruction for the study children’s peers. Parents and school staff in the study equated individual TA support with maximising opportunity for successful learning. They appeared to be unaware of the inequity of this or of the inappropriate consequences as highlighted in research findings including separation from and/or reduced interaction with

peers, dependency, insular relationships between pupil and TA, limited access to competent instruction and unhelpful approaches for learning (Webster & Blatchford, 2013). Their beliefs regarding the virtues of individual TA support may be indicative of an insidious focus on deficiencies and differences which Giangreco (2013) considers to be deeply rooted in our society. However, that was not the perspective of at least the parent participants who are unlikely to appreciate or recognise the exclusionary nature of full-time TA support because they are not familiar with their child in the formal learning context. Parents were also reassured by the degree of protection from the mainstream 'hurly-burly' that a full-time TA provided for their vulnerable child, perceiving the remit of the TA as also meeting needs other than academic. The parent of the youngest child was gratified by the maternal aspect of the TA role – "she's like a second mum to him". The young TAs who supported the older, teenage child, and aware of his isolation and loneliness, perceived themselves as providing additional social support ("we're more like his friends really"). Full-time support to these two study children enabled the TAs to be 'tuned-in' to the child's personal care needs, mood swings and communication difficulties – critical factors for learning readiness - in a way that may have been difficult for staff with a range of additional responsibilities. As also reported by Grigorenco (2013), aside from learning needs, the TAs may have had a better understanding of these additional needs than teachers did, and so teachers referred to the TA when information about the child was sought. The TAs felt valued in their role and there was regular liaison with the SENCOs who they felt were approachable. Indeed some TAs felt confident enough to challenge decisions by teachers when there appeared to be an absence of teacher awareness about the needs of the children. However, the lack of TA training and qualifications in terms of their pedagogical role challenges their capacity to positively support the children's learning, as also indicated in Webster et al. (2010) and Gregorenko (2013). The TAs considered themselves capable of meeting each child's needs and made no reference to their own lack of academic knowledge and training. The group of TAs assigned to support Ben was young. Those interviewed considered the relatively small difference in age between him and themselves had significant advantages. They considered their own recent school experiences enabled them to have a greater understanding of school processes, and a better appreciation of his needs and difficulties.

There is compelling evidence referred to above, indicating individual TA support to be a disguised form of exclusion (Kvalsund, 2004). The study children in receipt of individual TA support were not participating with their peers in academic activities. However, their complex difficulties and highly individual needs, together with the complexities of organising and managing a busy mainstream class with a large diversity of need, make the concepts of total inclusion/exclusion, and participation/non-participation unrealistic and present false dichotomies. Perhaps for the two children with complex needs there is a case for what Low (2007) calls moderate inclusion, with an associated level of moderate participation. Low (2007) argues that full inclusion is an ideological perspective, illusory and utopian. Although individual full-time TA precluded academic participation, Jack's primary school strove to achieve social participation, with a high level of commitment and success. School staff, sensitive to his needs, difficulties, and interests, had introduced focused interventions to increase social interaction opportunities. In contrast, there were no targeted interventions for Ben at key stage 3 other than being assigned individual TAs. This may relate to the degree of commitment and cohesion within individual schools, or at different key stages.

Reconstruction of self

Ben and Jack, as reported by their parents, did not wish to identify with children who may have had comparable physical or sensory disabilities; "he doesn't see himself like that". Changing their pre-morbid identity may involve one or more challenging processes. It is the only identity they have known, and which has defined much about their life – their routines, their friends, their preferences, their activities. They may lack awareness of the extent of their own disabilities (Jacobs, 1993). Even with some degree of awareness of pre and post injury differences they may not necessarily understand the chronic and possibly permanent nature of their deficits. The information each of the children have been given about their changed profile is not known. Parents find it hard to acknowledge and understand the chronic impact of their child's acquired deficits (see separate section below) and so may find it even harder to convey the long-term implications to their children. For example, Jack's mother had not given up hope that Jack would walk again, "I don't want him to think it's the end" (of possibly walking again), and her pursuit of on-going therapies was with a rehabilitation (recovery of lost skills) focus rather than a habilitation (maintenance of existing skills) focus.

The injury related changes to their physical abilities had a profound impact on Ben and Jack. Being denied access to activities central to their pre-injury social life provoked subjective negative changes to their experience of being themselves (Perkins, 2015), their identity and self-efficacy (Ponsford et al., 2014). Ella continued to have a positive identity – her mobility had not significantly compromised her return to activities in her local community that she had participated in pre-injury, which may have endorsed perception of herself as she was pre-injury. Children are more able to understand changes that can be seen, for example an injured limb, than changes to cognitive functioning (Beardmore, 1999).

Response to difference

“It’s not how it used to be” (motivation)

An important aspect of participation is engaging in the same activities as peers. Ben and Jack’s motivation for computer activities is undiminished as their ABI has not compromised their access. The extent of their physical impairments exclude them from participating at their pre-injury levels in typical peer-related activities such as playing football, climbing trees, riding bikes, and playing on the beach. They have also chosen to exclude themselves from these activities either as an observer of their able-bodied peers or in a more pro-active adapted way (“he isn’t always willing to go along with them because it’s not what he would have wanted”) that could enable greater peer contact, and as also reported by Eriksson et al. (2007). Their refusal and accompanying emotional outbursts suggest that witnessing others engaged in enjoyable activities that they can no longer engage in themselves is too stressful and painful a reminder of how things used to be. This indicates a qualitative difference to children with congenital disabilities who have been reported as wanting to participate in the same activities as non-disabled peers even though they cannot perform to the same level (Egilson & Traustadottir, 2009; Asbjornslett et al., 2015). Lack of initiation resulting from injury to specific brain areas can be misinterpreted as apathy or lack of motivation, but this is less likely to be a factor due to the study children’s accompanying negative emotional responses when encouraged to participate in physical activities alongside their typically developing peers.

“I can’t do it” (self-efficacy)

Understanding the negative behaviours of the children, alluded to by parents and school staff including low mood, opting out, and anger, may be explained partly in terms of self-efficacy and significant changes to their ability to control life events. Ben and Jack’s life-changing physical disabilities have had a profound impact on their sense of self and self-efficacy which has led to their reduced participation and places them at higher risk of social exclusion (Eriksson, 2006). They are denied access to the activities that had helped to define who they were and who they socialised with. They are no longer able to achieve their primary goals, with a brutal assault to feelings of autonomy, relatedness and competence which Eccles, Barber, Stone and Hunt (2003) consider to be essential elements for meaningful participation.

Individuals are innately motivated to exert behavioural control over their environments to achieve their desired goals (Heckhausen & Schulz, 1995; Monin, Schultz, Martire, Connelly & Czaja, 2014) and related to this is the negative effect resulting from loss of control. Although it was of concern to school staff and parents that the children refused to participate in activities that required adaptation, this could be explained as a positive protection strategy (Heckhausen & Shultz, 1995), rather than an escapist strategy (Brands, Wade, Stapert & van Heugten, 2012) – turning away from problems. Escapism is associated with poor mental health outcomes, and so it is important not to discount this possibility. Heckhausen & Shultz’s (1995) life span theory of development based on the concepts of primary and secondary control suggest that following disengagement from unattainable primary goals, there can be protection from poor mental health outcomes when motivational resources are channelled elsewhere and substituted with alternative (secondary) attainable goals. However, these secondary control goals need to be perceived by the individual to have similar value, create feelings of well-being and satisfaction and not selected indiscriminately. Jack had developed a significant interest in a popular interactive 3D computer game (‘Minecraft’) which he was able to play with, and on a par with, his peers at school and at home. Often, children without disabilities have a dominating role with disabled children acting more passively (Almqvist & Granlund, 2005) but this was an activity in which he could enjoy reciprocity and interaction on equal terms. From the perspective of life-span theory of control, he disengaged from unattainable goals that required levels of physical activity he could no longer achieve, and

developed secondary achievable ones. Ben had not developed any secondary goals in or out of school which may help to account for his low self-esteem, low level of peer interaction, and low level of activity.

“I’m not like them” (Identity)

There is indication that affirming one’s own disability can help and protect well-being (Bogart, 2014). However, there are considerable barriers for the study children to achieve any degree of affirmation. Ben and Jack don’t see themselves as disabled and so have declined opportunities to join or align themselves with others with disabilities. It is common for those with severe ABI to minimise or appear unaware of their deficits (Beardmore, 1999). Lack of awareness has considerable implications for their participation and emotional well-being (Fleming & Ownsworth, 2007). Also, attending mainstream school minimises their opportunity to meet others with disability, and there are no others in their immediate family with an observable disability. An additional barrier is that generally, non-disabled people in society, often well-intentioned, try to ‘normalise’ those with disability to fit in with the majority culture rather than fostering a sense of disability (Bogart, 2014). This presents a conundrum due to prevailing perceptions and sensitivities of the ways in which inclusion is achieved and difference minimised (Cigman, 2007). A further barrier is the lack of support to help the children adapt to their suddenly changed profiles and abilities. Jack’s school staff were fearful of attempts to address this, “we could do more harm than good, like open-up a can of worms”. Research literature affirms this concern (Cooper-Evans et al., 2008).

Emotional needs – “nobodies brief”

The perceived lack of resources for supporting the increasing emotional difficulties and mental health needs of the children was highlighted as a major concern by school staff. Their understanding of community mental health services was restricted to the traditional model of clinic-based services for crisis intervention, (CAMHS), but which they considered inappropriate for a child with potentially long-term significant emotional difficulties resulting from ABI. The sudden onset of the children’s severe disability with many complex inter-related factors is having a significant and downward-spiralling impact on their mental health. There is much research to support this (Anderson, Catroppa, Haritou, Morse & Rosenfeld, 2005b; Max et al., 2006). School staff considered this necessitated more

specialist urgent input that was beyond their area of professional expertise. Clinicians with specialist therapy, paediatric neuropsychology and neuro-rehabilitation skills may be required (Gracey et al., 2015). This creates a huge challenge because psychotherapeutic services for children with severe ABI are still at an innovative stage, and scarcely available. School staff were not aware of any other external sources of support for the child participants' mental health needs, and nor had they discussed their concerns with an EP. Access to psychological support in school is an important first step, in which EPs have increasing responsibilities (Dunsmuir & Cobbald, 2017).

Parental perceptions of child's abilities

The use of the questionnaire indicated inconsistent and contradictory ways in which the parents described their disabled child. When presented with fixed-choice responses, parents sometimes selected descriptive categories that contradicted the information they verbalised. For example, Ben's mother said his self-care activities such as eating, dressing, and washing were 'Age expected', but then explained that he required daily help with dressing; help that is not typical for teenagers. She categorised his emotional health and well-being as 'Good' but indicated that he was becoming isolated as he had no peer contact outside school, his friends had abandoned him, and he had relinquished all his pre-injury activities. Similar contradictions were apparent in the information provided by Jack's mother. The 'Age expected' category selected for communicating with other children and adults at school was at odds with the significant communication difficulties Jack experiences due to aphasia. When asked about people's attitudes at school or in the community, the selected 'No Problem' contradicted the negative attitudes of some parents who she reported had gone to see the headteacher to request that Jack should not be allowed to return to the school after his illness.

When completing the questionnaire, parents may not have been aware of contradictions in their responses. They too may have difficulties adapting to a disability identity. They may continue to perceive their child as they had done pre-injury, possibly in the hope that difficulties are temporary with recovery of pre-injury functioning. Although parents were able to verbally describe their child in a way that seemed consistent with the deficits, assigning them to inflexible categories associated with atypical or problematic issues may have

suggested a greater permanency to their child's situation than they could contemplate or emotionally tolerate.

These inconsistencies also question the reliability and validity of fixed-response quantitative surveys or questionnaires for measuring participation, especially regarding children with acquired deficits. Parents may have difficulties reconstructing an understanding of their child.

5.3.1. Summary of facilitators and barriers for participation include:

Facilitators

- Flexibility and understanding of holistic needs by school staff.
- Planned return to school with supportive intermediaries
- Strong leadership - Implementation of Inclusion policy
- Pivotal role of parents to facilitate activities and social contact,.
- Support of peers, friends and classmates
- Structured activities both in and out of school, e.g. organised youth groups

Barriers

- Reduced time in school
- Organisation of SEN resources - Individual TA support
- Poor adaptation to the changed self: Negative self-concept, self-efficacy and lack of disability identity
- Lack of child autonomy
- Disengagement of peers
- Lack of information and support to enable peers to maintain positive engagement
- Lack of community and information resources
- Absence of emotional support for parents
- Dependence on adults to facilitate activities
- Attitudes of others
- Financial hardship
- Lack of changing facilities at school

5.4. RQ 2: What are the information and support needs of parents, and school staff?

One of the interventions for increased participation indicated by families and school staff was provision of information (Semrud-Clikeman, 2010). Their seeking of “understanding to manage in an insecure world” (Tyreman et al., 2017, p.1556) mirrors the unmet information needs commonly reported in the literature (Kirk et al., 2014; Jones et al.,2017). School staff acknowledged lack of understanding about many of the multi-faceted and later emerging issues associated with ABI and were unsure about what to demand and what to expect of the child in their care. Parents wanted more information about ABI in general, and the impact to their child’s learning and social development. The comment by Ben’s mother “I wish I’d been told” epitomised a wider sense of a lack of information provision. Parents were unsure how to advocate for their child – they had no awareness of sources of support in their locality they could call on nor what kind of information they could usefully seek out. They were particularly concerned about the next stages of education. They wanted ‘not too little, not too much’ at any one time. Too much detail can confuse rather than provide help, but having opportunity to understand the injury and its implications is important in order to advocate for and optimise successful participation. Feeling informed also increases confidence and provides a sense of control (Penrod, 2007) especially when living with uncertainty.

There was positive acknowledgement for the support and information provided by the ABI rehabilitation service for staff at each school in the study. This had served to increase confidence in the abilities of those staff who had been in receipt of information, to support a child with an unusual profile of needs. On roll at one of the schools in the study was another child also with a severe ABI who had returned directly from hospital without any discharge meeting or information provided for the family or school staff. Following receipt of information from the rehabilitation unit about ABI and the study child, the school SENCo realised that much of it had significant relevance for the other child with ABI. The information was anonymised and distributed to all the staff working with the other child, and to that child’s parents. It was reported to be enlightening, helpful, and to make a difference. With knowledge about ABI, schools and parents are in a position to be more pro-active and to adopt strategies to minimise the negative impact on an already damaged brain.

Information alone may not be sufficient. The families in the study indicated the need for support over the longer term, not just the immediate post-injury period. Pro-active intervention such as individual counselling, liaison to monitor and support understanding of changing needs and adaptation over time may be required. Information and support needs for siblings and peers also need to be addressed.

5.5. RQ3: How can educational psychology services contribute to optimisation of participation following discharge from a clinical setting?

It is considered that EPs have a vital part to play in supporting effective participation of children with ABI. This role does not yet appear to be well recognised by EPs themselves (Mackay, 2005; Bozic & Morris, 2005), perhaps borne out by the absence of involvement of local EPs with any of the study schools and families. In a clinical setting ABI is primarily a medical concern, but on discharge ABI becomes primarily an educational and social concern. The erroneous assumption that ABI is a medical and a low-incidence event may be a factor that discourages EPs to dedicate time and training for ABI-related issues, and therefore they lack the knowledge base on which to practice (Bozic & Morris, 2005). All EPs do not need to be 'experts' on the subject in order to make a significant and positive contribution. Themes, and sub-themes supported by quotations in the current study indicate a number of areas in which EPs could, with relevant information, play a supportive role for making a positive difference to the study children's participation.

EP Support for families

The study parents felt isolated and scared after returning home ("Oh God it's just us now") worried about caring for and making decisions on behalf of their dramatically changed child, in the belief that there was no-one in the community who might be in a position to support them. Although the study parents communicated with school staff about specific issues that cropped up at school, there was no-one they felt they could talk to in their locality about their anxieties and 'bigger picture' of concerns, especially related to their child's on-going development, educational opportunities and management of out-of-school issues. This had a negative impact on their own well-being and ability to promote their child's participation. The child's participation in family and school life post-injury is vital for positive adjustment and key to successful outcomes and it is therefore imperative that the family, who are typically

the primary source of support for a child following ABI, are themselves adequately supported. EP support to help families understand child changes and responses to those changes (Gosling, 2015) would address some of the challenges that the study parents were facing, help to reduce the parental stress and better manage the burden as also reported by Andersson et al. (2016) and Aitken et al.,(2009). Demonstration of EP interest and concern could have made a significant difference to the study parents, with reassurance that they were not on their own, and as also reported by Tyreman et al.(2017) who found that parental sharing of emotional burden with professionals offered an outlet and was helpful in validating their experiences. EPs understanding and experience of working with families could provide the emotional support that the parents continued to find was unforthcoming since returning home but which each of them wished for. As one mother said, “It’s the hidden emotional needs that have been hard”. Sensitivity to their grieving process, and the needs of siblings are also important aspects of working with families.

Parents also wanted information and help “to guide us through the maze”. The unparalleled knowledge that EPs have of SEN, school practices and processes (Mackay, 2005), and their awareness of other relevant support systems, make them well placed to support families and schools in making informed choices.

EP support for school staff

“I still find it hard, how much I should make in my planning to incorporate his therapy needs. And other things to do with his recovery, how can I join that up with his academic learning. He’s lost a lot. I’d like more help with that”. (Jack’s class teacher)

Consultation is a collaborative way that EPs commonly work with schools, enabling reflective conversations that can help school staff to “take a step back and examine things in a way that helps thinking to shift towards ...a wider repertoire of possibilities for change” (Wagner, 2017, p.203). Consultation may highlight effective ways for EPs and school staff to develop a shared focus and interventions to address concerns arising from significant changes resulting from the child’s ABI.

School staff in the study who had not been in a position to participate in the training provided by the rehabilitation service indicated a wish for more information about ABI. It represented

a concept they knew little of, and that generated feelings of uncertainty and lack of confidence. This is a common experience of school staff who support children with ABI. (Linden, Braiden, Miller, 2013; Howe & Ball, 2017). There is a need for training and information, particularly regarding the long-term effects of brain injury, and specific information related to the individual child (Bozic & Morris, 2005, Ball & Howe, 2013).

A number of key issues relating to the study of children's participation at school would not necessarily demand increased understanding of ABI, but rather understanding and knowledge of inclusion and ways in which participation can be enhanced. The adult participants were all seemingly unaware of any detrimental impact of full-time one-to-one TA support. EP skill and knowledge of research findings could encourage school staff reflection on classroom organisation and practice for the promotion of contexts for learning (Mackay, 2005) such as alternative ways to deploy TAs to the benefit of children and staff, and effective instructional processes. EP challenge of the narrowing of Ben's curriculum, substituting P.E. with more maths support, despite ABI increasing rather than decreasing his need for physical exercise, could perhaps help school staff to reflect on ways of increasing his participation and opportunities for a broad and balanced curriculum. Removal of P.E. from his weekly timetable also served to further restrict peer contact.

Dynamic assessment and mediated learning experiences may be a constructive feature of EP service delivery to help school staff identify "what is happening, who is involved, why there is a problem and what can be done" (Hill, 2015, p.134) to support a child's changed profile of needs and difficulties.

EP Therapeutic work with children

Jack's school staff had no awareness of the potential of EPs for supporting and helping to address the very high level of concerns about his emotional well-being. This is an increasingly important area that EPs may be in a position to be involved with. They may also advise schools about children who need to be referred on to specialist mental health services. For a child with severe ABI it is particularly important that a case can be made for more unique and expedited approaches to specialist support than a child's name merely being added to a ubiquitous CAMHS waiting list. Individual therapeutic work with an EP could also help to slowly build a cohesive understanding of the child's experiences, and help them to develop a

positive identity (Perkins, 2015). This does require a highly skilled approach to minimise the risk of eliciting emotional distress which EPs would typically be sensitive to.

EP Peer group support: “It’s not that they don’t care, it’s just that they get caught up with being lads and forget or don’t understand his needs.” (Ben’s TA). EP advice about ways of promoting social inclusion, and supporting peers to positively engage with Ben, may have ameliorated his feelings of loneliness and isolation. It is important to help peers understand why and how their friend has a significantly changed and unusual profile, and ways in which they can sustain a positive relationship. Without this understanding and knowledge there is a danger of reduced participation for the child with ABI.

EP Advocacy for a continued rehabilitative approach

Parents experienced difficulties in securing on-going regular therapies for their children’s acquired difficulties. Jack’s mother “had to fight to get more rehab” having been told he had already received more than other children. She also had to advocate for it herself which may have been a daunting task when already feeling emotionally vulnerable. Jack’s school SENCo’s statement that “speech therapy has been slowly cut back and now we have to do it ourselves”, is of concern given Jack’s acquired aphasia and the resulting difficulties in being understood. Ben too was not in receipt of regular physiotherapy which his mother was unhappy about but did not feel able to challenge the system. EP knowledge and understanding of the important difference between habilitation and rehabilitation, the neuropsychological implications and time-limited ‘window of opportunity’ for regaining lost skills, as described by Penn et al. (2009) make them well placed to advocate for on-going additional resources for children with ABI by helping service providers understand the impact of ABI and the need for a different approach to allocation of resources than for children with congenital difficulties.

5.6. RQ 4: The voice of children with severe ABI is rarely heard. In what ways may this study help to enhance optimal potential for eliciting their views?

Encouraging the children to talk about their participatory experiences was challenging in a number of ways. Lack of motivation for the task did not appear to be an issue. The impact of the researcher was undoubtedly a factor, but other factors were also significant. As described

in the previous chapter, all the interviews took place in the afternoons of school days. The researcher was aware of the implications of this – overwhelming fatigue experienced by most individuals with severe ABI can have considerable impact on cognition and behaviour. Unfortunately the overall logistics and participant-preferred locations and days for the interviews of everyone in the study made alternative arrangements for mitigating fatigue difficult. Two of the children appeared to be particularly tired after the end of their school day. As well as expressing themselves through mediated communication the child participants used a range of non-verbal cues such as facial expression, engagement, and body language. The researcher tried to be open and honest about not always understanding verbal responses, which especially occurred when interviewing Jack who has aphasia. Clarification was requested but there was reluctance to do this repeatedly for the same piece of information, to minimise ‘unsettling’ him. On these occasional instances, eye contact was made with the teaching assistant who had accompanied Jack. (She sat at a distance but within hearing, to minimise her presence in the interview. She had been described by the headteacher as better attuned than anyone else at school to interpreting Jack’s expressive utterances when they lacked clarity.)

As discussed in the literature review, there have been very few research studies that have incorporated the views of children with severe ABI, and yet the subjective experiences of children themselves are essential to understand their participation (Adolfsson, 2011). Including their voices in the study was considered particularly pertinent because the study aimed to understand their experiences of participation in their everyday settings. Communication difficulties were anticipated which is why a tool, Talking Mats, that obviated the need for verbal responses was selected. In this respect the choice of tool was a successful one – it helped to facilitate the child participants engagement, involvement, understanding, and independent control – they participated!

Following the interviews, the researcher considered a more detailed appreciation of communication and memory processes most commonly impaired following severe ABI – the processes for converting thought into language, and autobiographical memory (see below) – were essential prerequisites to discussion of the participants difficulties, and also for consideration of ways in which the voice of children with severe ABI may be more effectively elicited in future research studies. This necessitated further review of literature.

Voice of the child participants: Cognitive overload ?

Seeking the views of the child participants on aspects of their everyday lives needs to be conceptualised as talking about relational meanings – the child’s relationship with the people and settings in their lives. Understanding thought processing in terms of relational meanings requires perspective taking and selective attention, both of which have been frequently and negatively implicated in research studies about ABI (Anderson et al., 2001). The constructional, cognitive effort to package thoughts into a ‘whole’ for coherent verbal expression (Happe, 1995), may help to explain the communication difficulties and the limited verbal contributions of the child participants. Their responses indicated the Talking Mats activity provided access to meanings related to the symbols on the digital cards, and they were able to carry out the tasks appropriately. Producing words that corresponded in a very direct manner to their referents, as is the case for concrete nouns, was relatively straightforward – hence, the participants engagement with the cards symbolic representations indicated understanding at a basic rather than a more abstract level (Chapman et al., 2004). For example, ‘My teacher is always nice to me. She gave me a massive packet of biscuits’. The use of more abstract language and verbs referring to participatory activity requires much more cognitive mediation (Marshall, 2009) and macro-level processing (Chapman et al., 2004) than participants were able to demonstrate. Problems with accessing language, and difficulty in converting perspective-taking into lexical concepts may have made it hard for them to frame ideas in ways which were language compatible. With reference to the theories of Dipper et al. (2005) and Chapman et al. (2004), they may not have had access to words and more complex meanings to anchor their thoughts, restricted by difficulties with macro-level processing. Encouraging verbal explanations for their choices may therefore have been, at times, tantamount to cognitive over-load; it was too complex a task for them, especially when tired.

Eliciting views of the study children’s experiences of their participation in school, home and community activities were also dependent on their ability to remember personally experienced past events. Autobiographical memories are stored as narratives involving episodic and semantic knowledge. They also require an awareness of the self as having experienced the event including the integration of perspective, interpretation, and evaluation (Fivush, 2011). Short and long-term memory difficulties resulting from ABI make it hard to

maintain a coherent and continuous narrative of experience (Hall & Powell, 2011), so creating memory voids and the possibility of confabulation (Metcalf, Langdon & Coltheart, 2007).

5.7. Strengths of study

The current qualitative study was able to harness unique, individual and “richly textured understanding of experience” (Sandelowski, 1995, p.182) associated with participation of children with severe ABI, which adds to information from quantitative studies. The unstructured component of the interviews allowed adult participants to raise issues of their choosing related to the study child’s participation. This may not have been possible with the use of a more prescriptive or structured approach, and indeed the qualitative data resulted in unexpected information. This flexible design to the study was considered important for a topic that is associated with a high degree of sensitivity, emotion, limited awareness and understanding. The follow-up probes associated with the parental survey achieved a more comprehensive picture of participation issues than emerged through the unstructured interviews alone. This endorses the assertion by Singer and Couper (2017) that the technique holds significant promise. Additional unexpected interest was also generated when checking the participants responses to the survey’s fixed alternatives, against data elicited from the related probed questions (Cohen et al., 2000).

The conflicting information resulting from the use of this technique was further evidence that quantitative data alone may provide a skewed and far from holistic understanding of participation. Crotty (1998) asserts that a piece of quantitative research can look very different when it is informed by a constructionist epistemology. “For a start, it makes a big difference to the truth claims proffered on its behalf” (p.16).

The views of children with severe ABI are considered essential to a comprehensive understanding and promotion of their meaningful participation. A strength of the present study, relative to most research studies about this population of children was their active involvement. Conversely, the difficulties of including a more robust representation of their participatory experiences is a significant limitation. It is hoped that the researcher’s perceptions of reasons for the difficulties and suggestions for alternative ways to garner the views of children with severe ABI may enable greater success in future research.

5.8. Limitations of study

This was a very small-scale study that identified a range of supports and barriers for participation.

There was a low response rate to parental invitations to take part in the study. Reference has already been made to parental burden associated with caring for a child with severe ABI, suggesting response to anything other than essential daily transactions may be ignored. The restriction by the NHS ethics committee for no direct contact to be made with potential parent participants by the researcher may have contributed to the low response rate.

Each of the parents were mothers which may bias the results to maternal experiences rather than parental experiences. Also, the parents were white and of Anglo-Saxon origin. Experiences and understanding of participation may be very different in families from different racial, ethnic or cultural backgrounds.

The current study only collected information at one point in time. This gives limited indication of needs over time.

The accuracy of participant recall of some events and feelings about what happened, sometimes many months after the event, could be perceived as a limitation. However, the researcher was more interested in the participants interpretations and constructions of meaning of their experiences and did not therefore consider this to be a limitation.

Limitations of the child participants cognitive-communication skills have been discussed in relation to exploring ways in which eliciting their views could be enhanced. Their difficulties placed limitations on reporting their participatory experiences but this initiated the researcher's further interrogation of the literature to help understand those limitations.

An additional highly relevant dimension to the current study could perhaps have been achieved through interviews with local authority educational psychologists. Although invited to do so by the rehabilitation service, no local EPs had been actively engaged with the study children's return to school. Also no involvement of local EP services had been sought by schools for a number of reasons (Extensive involvement by the rehabilitation programme's own EP service; training and information for school staff by the rehabilitation service which continued to be referred to and satisfied schools current perceived needs regarding EP

support; awareness of limited number of hours available from local authority EP services so schools wanted to 'save up' EP time for more urgent occasions; unawareness of the potential capacity of EPs for supporting children with mental health difficulties.)

Another limitation inherent to qualitative research is the researcher subjectivity, and how that might have influenced results. The results chapter describes the apparent dis-interest by one of the teenage child participants and the researcher's interpretation of his behaviour. However, his disgruntled attitude and perfunctory responses may have been a manifestation of a range of factors related to general attitude, well-being, fatigue, how his school day had gone, or 'being a teenager'!

5.9. Future directions for research

Difficulties adapting to acquired disability in childhood appear to significantly interfere with successful participation. Research with adults indicates that those with congenital disabilities are better adapted than those with acquired disabilities. A literature search suggests a paucity of research or models to help explain the process of adapting to acquired disability in adulthood (Brands et al., 2012), but there appears to be a complete absence of processes or models in childhood. This is an important, complex aspect of childhood ABI in which research is much needed. Understanding differences relating to identity, self-efficacy, motivation and self-esteem between children with congenital disability and children with acquired disability could provide a key basis for enhancing the mental health and well-being of children with ABI.

A child's home, school and local community are important influences on participation. Further exploration of the dimensions of these contexts may help to identify additional factors impacting on participatory experiences. For example, there were considerable differences of the extent to which Ben's and Jack's school responded to participation needs. A larger study comparing participation at different key stages may contribute to enhanced understanding of associated factors.

The current study related to children with severe ABI who were known to external support agencies. By virtue of their residential stay on the specialist ABI rehabilitation programme, discharge planning meetings were held in the child's locality with invitations extended to a range of local professionals. However, most children with severe ABI are discharged directly

home from acute care without the benefit of any educational planning, multi-disciplinary discharge meeting, or supports in place (Tomlin, Clarke, Robinson & Roach, 2002). The study children are therefore part of an atypical population of children with severe ABI. Increased understanding of participation of children with severe ABI could therefore be enhanced by including the more typical population of children with severe ABI who do not receive any formal rehabilitation.

The parental perspectives on participation were reported by mothers. As indicated above, the perspectives of fathers may provide additional information, as may including the views of siblings and peers.

Future directions in research to elicit the voice of children with severe ABI

Including participants subjective experiences and views is essential for a wider understanding of their participation and would increase the validity of the construct of participation. As was borne out in the current study, it is extremely challenging for young people with severe ABI to provide views that require autobiographical memory i.e. recollection of personally experienced past events, and out-of-context recall. Also, communication following severe ABI is commonly indicative of literal thinking, and restriction to the 'here and now'. Many other aspects of compromised cognitive functioning such as attention, and information processing and excessive fatigue contribute to the difficulties. The construct of participation includes situational understanding (the perception of environmental elements – knowing what is going on around the individual) which is an abstract concept. Difficulties with the child participants recall and communication were not unexpected given what is known about sequelae following severe injury, and hence the use of Digital Talking Mats to elicit their views. 'Ecological Momentary Assessment' (EMA), sometimes referred to as the 'Experience Sampling Method' (ESM) may be a more appropriate technique for gathering their views about participatory experiences. EMA is a set of methods derived from social psychology research (Stone & Shiffman, 1994), which helps researchers gather participants views in 'real time' (or close to it) in the environments in which their thoughts, feelings and activities naturally occur, so avoiding a reliance on retrospective and out-of-context recall (Shiffman, 2009). Use of this technique would also provide more comprehensive and pertinent information about the two dimensions of participation referred to in the literature review –

doing an activity, and the subjective experience of involvement (Granlund et al., 2012). The method also provides for more richness when information is collected at a number of different points rather than just relying on one point of time.

A number of additional factors may enhance the elicitation of the voice of this population such as a longer 'lead' time for the child participants and the researcher to develop rapport, as well as the child's greater familiarity with the tools used to support communication. Learning how to express an opinion involves a developmental progression (Shier, 2001), and increased familiarity with appropriate techniques for doing so would also be beneficial.

Interviews held at a time of day when child participants are most alert may reduce the influence of excessive fatigue on cognitive functioning.

Some degree of analysis of adult data prior to interviewing child participants would have highlighted issues related to the participation of each child. Interviews with child participants could then have focused on a more meaningful and restricted number of (Talking Mat) items associated with those raised by the adults, rather than them being presented with a generic set. For example, it may have been useful to explore Ben's views about the removal of P.E. from his school timetable (because of the length of time it took him to get changed) which his mother said had now been replaced by extra Maths support. Also his views, as a teenager, about current arrangements for travel to and from school with his mother, and other aspects of his daily transactions such as full-time TA support that may have implications for peer contact.

5.10. Summary and Conclusion

The current research study explored supports and barriers for participation in a child's everyday settings following severe ABI, and the perspectives of parents, school staff and children themselves. Understanding participation in mainstream school is important as research indicates children with severe ABI are at high risk of reduced participation leading to a range of negative outcomes such as isolation, loneliness, stunted academic, social and emotional development.

The ICF/CY has had a significant impact on the way in which the participation of children with disabilities is conceptualised. It emphasises that body, environment, and participation are

related. Participation is multi-dimensional and affected by both intrinsic impairment and the physical, social and psychosocial aspects of the environment. Findings from the study data are consistent with this conceptualisation and indicate that the participation of children with severe ABI is restricted compared to their typically developing peers, as has also been reported in other studies (Bedell & Dumas, 2004). Although functional limitations contributed to the extent to which the study children participated in their everyday environments, environmental and personal factors had a very significant influence and were inextricably linked. Context, and the characteristics of each child, aside from intrinsic impairments, accounted for different levels of personal adjustment and the extent to which participation was experienced. These included autonomy, supports, attitudes, services, accessibility, and the child's own emotional responses to the injury. Positive peer interactions and relationships create and facilitate positive participatory experiences. All children, typically developing and those with ABI require adult led support and provision to enable this.

The study indicates some key processes underlying children's engagement and highlights dimensions that may need to be considered when trying to increase participation. The important focus needs to be on variables that are modifiable, creating and capitalising on opportunities for intervention and change, to maximise participation. Meeting participation needs in a given setting requires sensitivity to a range of factors requiring fine-tuned support to embrace diverse requirements. Addressing concerns about the possible exclusionary practice of allocating TAs as full-time supports for children with significant learning needs could be a major contribution for optimising participation in school with potential benefits for all children. It is important to consider context specificity when developing interventions and the relationship between support and participation. Participation depends on being provided with necessary support and establishing a 'not-too-much-not-too-little' level; full-time individual support for Ben and Jack at school appeared to compromise their participation.

The child's own response to the injury, particularly in terms of self-esteem and self-concept, plays a crucial part in motivating and engaging them in participatory activities. There is an outstanding need for much greater focus on meeting emotional needs, and ways to enable

children to achieve higher levels of control, following ABI. These are relatively unexplored aspects of severe ABI sequelae.

Although there were considerable difficulties in eliciting the views of the child participants, there was indication of their engagement, involvement, understanding, and ability to express their views. Understanding factors associated with cognitive-communication and autobiographical memory deficits may help to develop approaches to successfully enable their voice to be heard.

Personal reflections

The motivation for initiating this research project has already been outlined. The motivation for continuing and completing it in the face of many difficulties has been the goodwill, passion and enthusiasm of the adult participants who willingly gave their time in their invariably busy lives. All of them expressed concern about the lack of awareness of the concept of ABI, and wanted to talk about their experiences and opinions if it could help others in similar circumstances. They indicated in one way or another that it was too important a topic not to pursue, and that prior to the interview they had not had an opportunity to speak freely and at length before about the ways in which ABI had affected their personal or professional lives. The three parents indicated their wish to 'give something back' (words of one parent) in relation to the residential rehabilitation service which they and their children had participated in and about which they held strongly positive views.

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List of Appendices

(N.B. All relevant information has been anonymised: identifying gender replaced with s/he, names removed and replaced with *, and the logo of the researcher's employing organisation removed.)

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Appendix 1: NHS Ethical Approval

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru



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31 July 2014

Ms Susan Walker
Educational Psychologist

Dear Ms Walker

Study title: Participation in the home, community and school following in-patient rehabilitation for severe childhood acquired brain injury.
REC reference: 14/WA/0142
IRAS project ID: 96967

Thank you for your letter responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered by a Sub-Committee of the REC at a meeting held on 31 July 2014. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Dr. Corinne Scott, corinne.scott@wales.nhs.uk.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

- The section on the information sheets titled "What if I think my child needs held that he/she isn't getting" should be amended so that the current text is removed and replaced with "If you think your child is not getting held which you think he/she needs, please contact [name of person, telephone number and email address] at [redacted]"

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to

facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

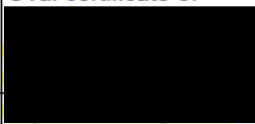
Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper	signed Susan Walker	03 April 2014
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)	Oval certificate of 	28 March 2014
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UM Association Certificate of Insurance - Cardiff University]		26 July 2013
Interview schedules or topic guides for participants	Interview topics and prompts; version 1	03 April 2014
Letter from sponsor [signed Dr KJ Pittard Davies, Cardiff University]		25 June 2014

Letter from sponsor		07 April 2014
Letters of invitation to participant [Teacher]	2	16 July 2014
Letters of invitation to participant	Child; version 1	04 February 2014
Letters of invitation to participant	Parent	04 February 2014
	no version or date	
Other ["About talking mats"]	no version or date	
Other [HPC certificate of registration - Mrs Walker]		
Other [Child and family follow up survey]	UK version October 2008	
Participant consent form [Parent]	2	16 July 2014
Participant consent form [Teacher]	2	16 July 2014
Participant consent form [Consent / Assent form for children]	2	16 July 2014
Participant information sheet (PIS) [Teacher]	2	16 July 2014
Participant information sheet (PIS) [Parent]	2	16 July 2014
Participant information sheet (PIS) [Child aged 8-10 years]	2	16 July 2014
Participant information sheet (PIS) [Child aged 11 + years]	2	16 July 2014
REC Application Form [signed electronically by Mrs. Walker; Helen Falconer, sponsor's representative; Carolyn Dunford, Academic Supervisor]		16 July 2014
Referee's report or other scientific critique report		
Research protocol or project proposal	1	
Summary CV for Chief Investigator (CI)	Mrs Walker	03 April 2014
Summary CV for Chief Investigator (CI)	Dr Nicola Canale	03 April 2014

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely

pp **Dr. Maurice Buchalter**
Vice Chair

E-mail: corinne.scott@wales.nhs.uk

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments
"After ethical review – guidance for researchers"

Copy to: [REDACTED]

Wales REC 3

Attendance at Sub-Committee of the REC meeting on 31 July 2014

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr Maurice Buchalter	Vice Chair / Hospital Consultant (Cardiologist)	Yes	
Mrs Monika Hare	Alternate Vice Chair / Lay member	Yes	
Ms Nicola Heales	Lay Plus member	Yes	
Dr Pete Wall	Chair / Clinical Physiologist	Yes	

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Dr Corinne Scott	Co-ordinator

Appendix 2

Letter from Chief Executive inviting potential parent participants

Date

Dear ----- (name of potential participating parent)

██████████ is committed to an on-going research programme with a view to helping families and children who have had an acquired brain injury. We are keen to understand more about the services that may be provided at school, at home and in your local community following discharge from the acquired brain injury residential rehabilitation programme at ██████████. As part of this programme a member of our staff, Susan Walker, is planning a research study. It will involve parents and children who have used the residential rehabilitation services of The ██████████ over one year ago.

Susan is an educational psychologist at ██████████ and she would like to know your experiences and views, and those of your child, of going back home and your child returning to school following the rehabilitation programme. She would also like to know your views about services or information in your local community that you think may be helpful for families where there is a child with an acquired brain injury.

If you would like to consider taking part in this project please can you contact Susan, using the contact details below, or by completing the attached sheet and returning it in the stamped addressed envelope enclosed. Susan will then send you more information about the project and what is involved.

Yours sincerely,

██████████
Chief Executive

Returning to home and school following the residential rehabilitation programme at

[REDACTED]

I would like to receive information about this research project.

Name of Parent.....

Address.....

Telephone

Please return this sheet in the enclosed stamped addressed envelope, or contact Susan by phone or Email:

Telephone: [REDACTED]

Email: [swalker@\[REDACTED\]](mailto:swalker@[REDACTED])

Address: Susan Walker, Educational Psychologist, [REDACTED]
[REDACTED]

Thank-you very much!

Appendix 3

Description of Child and Family Follow-up survey (Bedell, 2011a)

Section 1. General information includes 6 questions about the actual functioning of the child using fixed-choice responses (physical and emotional health, primary mode of mobility and communication).

Section 2. Home and Community Participation This section focuses on children's participation levels and restrictions at home, at school and in the community compared with same-age peers. It contains 20 items divided into 4 sub-sections: Home Participation; School Participation; Community Participation; Home and Community Living Activities. Each item addresses a broad participation domain with examples provided for each. The fixed-response items are rated on a 4-point scale (Age expected, Somewhat limited, Very limited, Unable) with an additional 'Not applicable' option. Three open-ended questions follow about equipment, modifications or strategies that are used to promote the child's participation.

Section 3. Problems experienced in daily life This consists of 15 items that focus on child health-related problems with cognitive, psychological, physical and sensory functions as a result of the ABI-diagnosis, and 18 items related to physical, social and attitudinal environmental problems that children and youth may experience at home, school or in the community. Each fixed-response item or problem is rated on a 3-point scale: no problem, little problem, and big problem. There is also a question about health or medical restrictions on the child's daily activities.

Section 4 The child's and the family's current services This includes fixed-response questions about the child's current educational placement, rehabilitation, health services, and satisfaction with services, followed by questions about the family's quality of life, current services and needs.

Section 5. Suggestions and additional information includes two questions; one to ask for suggested ways to improve rehabilitation services, and the other inviting the parents to comment on anything not covered in the survey.

N.B. A slightly amended UK version of the CFFS was used for the purposes of the study. Amendments reflected English spelling (for example, change of the word behavior to behaviour) and some educational terminology (for example, change of 'regular school' to 'mainstream school', and recognised levels of SEN support at the time of the interviews.) The researcher explained the American origin of the questionnaire to the parent participants. Any remaining American terminology was 'translated' at the time of reading/using, for example the word 'recess' was changed to 'playtime'.

Appendix 4



Participant Information Sheet (Parent)

Introduction

Dear

This is to ask if you and * would like to take part in a research project about being back at home and school after discharge from the acquired brain injury programme at *. Before you decide if you want to join in, it's important to understand why the project is being done and what it will involve for you. The information below will tell you more about it.

Project title

'Participation following childhood acquired brain injury'

('Participation' in this title means taking part in everyday activities – activities that are relevant to being at home, at school and in the local community such as learning, spending time with family and friends, travelling to school, activities available for your child in your locality etc.

*The wording of the title is adjusted for Primary School- aged children as 'Being back at home and school after leaving *')*

What is the project about?

* (Name of rehabilitation facility) wants to help ensure successful participation in everyday activities for children with acquired brain injury. Research has found that over half a million children each year return home and go back to school after having had an acquired brain injury. Little is known about whether existing services are meeting their needs. The purpose of this current project is to find out about ways in which children with acquired brain injury participate, or would like to participate, in everyday activities at school, at home and in the community. The study also aims to find out what information

and services children, parents and teachers consider important for enabling children with acquired brain injury to participate at school and in their local community. This may be helpful for the planning and provision of future services both at * and in your area.

Who is involved in organizing the project?

The research project is being undertaken by me, Susan Walker. I am an Educational Psychologist who has worked on the Rehabilitation programme at * for many years. I am now carrying out this project which is part of a doctoral programme at The University of Cardiff and is supervised by two members of research staff - one at the university, Dr Ian Smillie, and one at *.

Why have I been chosen?

You have been invited to be included in the study because:

- * participated in the acquired brain injury rehabilitation programme at *.
- She/he has returned to a mainstream school in England at least 12 months ago.
- She/he is between the ages of 8 and 14 at the time this letter has been sent out.

Do I have to take part?

No, it's up to you to decide whether or not to take part. You should only participate if you want to. Please ensure that you have read and understood the enclosed information. If you decide to take part in the project you can still change your mind at any time without giving a reason.

What will happen if I decide to take part?

We can talk more about the project and go through the information sheet. You can ask any further questions. If you would like you and * to take part, you will be asked to give your consent first. You will be given a copy of this information sheet and a signed form for you to keep.

What does it involve for me and my child?

If you agree to take part in the study, I will come to talk to you at a time and place that suits you. This will be to find out about your experiences and views about how * is getting on at school, the services and provision available for * at school and in your locality. This may take about 60 minutes. I will make notes during the interview about what you say. I'll ask you if I can record the interview using an audiotape to help me remember all the details of our discussion, but this would only happen if you agreed.

As well as hearing about your views and experiences, I would like to talk to * at a different time, to hear about his/her experiences at school and outside school since leaving *. The meeting could take place at home or at school depending on the preferences of you and *. She/he can have you present during the interview if wanted.

What kind of questions will be asked?

During the interview I will ask questions about what you think of the provision at school for *, and ways in which you think she/he can best be helped to learn and be happy at school. I will also ask your opinion about local community services for you and * since returning home from *, and any information needs that you may have.

I will ask * about how things are going at school, what she/he likes doing, ways in which she/he is helped and anything else about school and life outside school that is important to her/him.

If there are any questions that you or * don't want to answer you don't have to and you don't need to give a reason.

Is information being collected from anyone else?

If you give permission I would like to seek the views of a teacher from *'s school about provision and information considered helpful for children with acquired brain injury to learn and participate at school. I would also like to read the documents (the statement of special educational needs or Education, Health and Care Plan, the record of annual review or individual education plan) that set out provision for * at school.

What are the possible disadvantages of taking part?

Some of the interview questions may remind you about difficult feelings that you might have experienced as a parent following *'s acquired brain injury. I will aim to minimise any potential distress by being sensitive with my questioning, and supportive if you get upset. We can pause or stop the interview at any time and you can also choose to withdraw from the study at any time. Following the interview, I will offer you an informal debrief and/or can arrange for you to talk to another professional if you so wish.

What are the possible benefits of taking part?

Taking part is an opportunity for you and * to talk about your own experiences in the way you want to. No-one else has had exactly the same experiences and so what you have to say is important. It may or may not benefit you personally but having a better understanding of the views and experiences of parents and their children who have returned home and to school after an acquired brain injury may help with the planning of future services for other parents and children. The longer-term aim is to ensure successful participation in everyday activities for children with acquired brain injury.

Will what I say and my child says be kept confidential?

Yes, protecting the privacy of you and your child is extremely important. It's also important to be able to speak honestly and openly without worrying what other people might think. Everything you and your child says will be completely confidential** and will be anonymised. That means the interview will be written up in a way that no-one else will be able to identify you or * from the things either of you say or talk about. The names of you and * will not be published or available to anyone. Only the people directly involved in the research will know who took part and what was said.

Information gathered during the study will be kept and locked securely in a filing cabinet in a locked office, and be password protected. All information will be coded with a unique code rather than by name. These codes will only be known to myself. Data will only be accessed by me, the academic supervisor and the research supervisor. All audio-taped information will be destroyed when the research study is finished.

(*If you share any information that is potentially a child safeguarding issue then I may have to share that information with another professional.)

What will be done with the information I give you?

Information from interviews and from educational documents will be used to help understand more about provision and participation for children with acquired brain injury. This will be put together in a report for a doctoral thesis at the University of Cardiff. You will then be sent a letter to tell you what the conclusions of the project were, but there will be no reference in the letter to what individual parents or children said. Anonymised information from the project may be published in a professional journal and presented at a conference to share knowledge with others who have an interest in acquired brain injury.

What if I think my child needs help that he/she isn't getting?

When we get together you will have opportunity to talk about any help that you might think your child should be having but is not receiving. I will not be able to provide the help myself but I can suggest what you can do/who you can contact if you wish to take your concerns further. I will follow this up with providing you with specific contact details (names, addresses, phone numbers) relevant to your concerns.

What if there is a problem?

If you have any concerns about the involvement of you or * in the study or the way it has been carried out, you must let me or * at * know as soon as possible so that you can be given advice. There are names and contact details at the end of this information sheet. If you remain unhappy and wish to complain formally you can do this. Please contact Dr Ian Smillie.

Who has reviewed the study?

All research at * is firstly reviewed by its own research committee. Following approval, it is then looked at by an independent group of people to protect your interests. The study has been reviewed and approved by a National Health Service Research Ethics Committee, called Wales REC 3.

Who should I contact for further information ?

Please don't hesitate to ring or email to talk or leave a message at any time.

Susan Walker, Email: walkersr@cardiff.ac.uk

If you have any concerns about the project please contact me (details above), or, if you would prefer, either of the following people :-

***** (Head of research)

***** (Name of rehabilitation facility)

Dr Ian Smillie, School of Psychology, Tower Building, University of Cardiff, Cardiff, CF10 3AT

Tel: 02920 875474

Email: smillie@cardiff.ac.uk

Appendix 5



Project Title: Participation following childhood acquired brain injury

Consent Form: Parent

Please put your initials in the boxes if you agree with the following statements:

1. I confirm that I have read and understood the information sheet for the above study. I have had opportunity to consider the information, ask questions and have had these answered to my satisfaction.

2. I understand that taking part in the study by myself and by my child is voluntary and that we are free to withdraw at any time without giving any reason and without any legal rights being affected.

3. I understand that I may be quoted in the study but that anything I or my child says will be anonymised so that we will not be personally identified.

4. I understand that data collected during the study may be looked at by * and/or Dr Ian Smillie at the University of Cardiff. In addition to the researcher, Susan Walker, I give permission for these individuals to have access to the data.

5. I agree to the audiotaping of the interview

6. I give permission for Susan Walker to contact my child's school and to access *'s statement/Education, Health & Care Plan or annual review record of special educational needs.

7. I agree to take part in this project

Parent signature..... Date.....

Parent name (Please print).....

Name of my child to be included in the study.....

Signature of Researcher (Susan Walker).....Date

Appendix 6

Participant Information Sheet – Child (8-10 years)

Dear *

Introduction

This is to ask if you would like to join in a research project to help find answers to the question:

*What is it like to be back home and in school again after a brain injury and leaving *?*

Before you decide if you want to join in, there is some information below to tell you more about it. Please talk to your family about it too.

Information about the research

Research study title

Being back at home and school after leaving *

What is research?

Research is a way we try to find out answers to questions.

Why is this project being done?

We want to make sure that things go well for children after they have had a brain injury and left *. It is very useful to know what you have or haven't liked doing, or things that have or haven't gone well since being back at home and at school. What you have to say is important and may help other children when they return home and go back to school.

Why have I been asked to take part?

You have been asked to take part in the project because you had a brain injury and went to * to help you get better. After you left there you went back to school. I am interested to know what it's been like for you since being back at home and at school.

Do I have to take part?

No, it's up to you and your parents to choose whether to take part. No-one will mind if you want to say no! Even if you say yes, you can change your mind.

What will happen if I decide to take part?

If you decide to take part I will make one visit to meet you at home or at school, whichever you prefer. I will ask you questions about what it's like to be back at home and school since leaving *. You don't have to answer any questions that you don't want to, and you don't have to give a reason why. (I will bring some picture activities if you would prefer to use pictures for talking instead of, or as well as words. *To be inserted if appropriate following discussion with parents about child's communication preferences.*)

What kind of questions will I be asked?

The sort of questions I would like to ask you will be about the things you do most days, e.g.

How do you travel to school?

What are the things you like about school?

If there are things about school that you don't like, what are they?

Who helps you at school?

What do you do at break-times at school?

What would you like to do when you leave school?

What do you like doing when you're not at school?

Is there anything that might upset me?

If any of the questions upset you, you can tell me you want to stop and have a rest or that you have had enough questions. I will let your Mum or Dad know and they will look after you.

Will joining in help me?

I can't promise that the study will help you but the information you provide may help other children in the future.

What will happen with the things I've said?

I will write down things you say but it will be kept confidential. This means I will only tell those who need to know.

Did anyone else check the study is ok to do?

Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee. They make sure the research project is ok to do. This project has been checked by a committee called Wales REC 3.

What will happen when the project is finished ?

I will look at what you and all the others I've talked to have said. I will use this information to write down recommendations about the best ways to help children and young people who return home and go to school after a brain injury.

What if I have some questions that aren't answered here?

You can ask me any questions you want. You can contact me:

- by phone (my number is.....)
- by email (my email address is)
- by asking your Mum or Dad or teacher to contact me

or, if we meet up to talk about the project you can ask me anything you want to.

After checking with your Mum or Dad please can you sign the attached form to say if you would like to take part or not.

Thank-you very much!

Appendix 7: Child Consent/Assent form for 8-10 year olds

Project Title (for 8-10 Year olds): Being back at home and school after leaving *

Please put tick or cross in box: ☑=YES or ☒= NO, and your initials.

1. Has somebody explained this project to you?.....
2. Have you asked all the questions you want?.....
3. Have you had your questions answered in a way you understand?.....
4. Do you know that it's OK to stop taking part at any time?.....
1. Do you understand things you say may be written for other people to read but in way that no-one else will know who has said them.

Please tick one of the following boxes:



I would like to take part in the project



I don't want to take part in the project

Name of Child

Signature of child.....Date.....

Signature of Parent/Guardian.....Date.....

Signature of Researcher.....Date

Appendix 8

Participant Information Sheet – Child 11+ years

Dear

Introduction

This is to ask if you would like to join in a research project to help find answers to the question:

*What is it like to be back home and in school again after a brain injury and leaving *?*

Before you decide if you want to join in, it's important to understand why the project is being done and what it will involve for you. The information below will tell you more about it. It may be helpful to talk to your family about it too.

Information about the research project

Research project title

Participation following childhood acquired brain injury

What is research?

Research is a way we try to find out answers to questions.

What does the word Participation mean?

It means the activities you do everyday – such as the kind of things you do at school, and things you do when you're not at school.

Why have I been asked to take part?

You were chosen because you had a brain injury and you went to * to help you get better. After you left there you returned home. I am interested to know what it's been like for you to be back at home and back in school. Up to 10 children are being asked to take part in the project, including you. I also want to ask your parents and teachers at your school about any things they think are helpful for children with brain injury at school or home or in your area.

Why is this project being done?

We want to try and help make sure that things go well for young people after they have had a brain injury and have left *. In order to do that it's very useful to know about your experiences such as what you have or haven't liked doing, or about things that have or haven't gone well since being back at home and at school. Your views are very important, and what you have to say may help to make changes for the better when other children return home and go back to school after a brain injury.

Do I have to take part?

No, only take part if you want to. Even if you say yes you can still change your mind. You don't have to explain why you might not want to take part, and it won't make any difference to what happens at school. No-one will mind if you want to say no!

What will happen if I decide to take part?

If you decide to take part I will make one visit to meet you, at home or school, whichever you prefer. I will ask you questions about what it's like to be back at home and school since leaving *. You don't have to answer any questions that you don't want to and we can stop at any time; you don't have to give a reason why. Our meeting may take about half an hour. (I will bring some picture activities if you would prefer to use pictures for talking instead of, or as well as words. *To be inserted if appropriate following discussion with parents about child's communication preferences*)

What kind of questions will I be asked?

The sort of questions I would like to ask you will be about the things you may do most days e.g.-

How do you travel to and from school?

What are the things you like about school?

If there are things about school that you don't like, what are they?

Who helps you at school?

What do you do at break-times at school?

What would you like to do when you leave school?

What do you like doing when you're not at school?

What do you think might be helpful for other children who return to school after a brain injury ?

Is there anything to worry about if I take part?

Thinking about personal experiences can sometimes be upsetting. If anything upsets you we can stop the interview at any time. We don't have to continue with it if you don't want to. I will let your Mum or Dad know so that they can be supportive. If you think there are issues that you would like further help with, I can also tell you about people outside the family who could provide support.

Will joining in help me?

I can't promise that the project will help you personally. The information you provide may help other young people returning home and going back to school after leaving *.

What will happen with the things I've said?

I will write down things you say but I won't use your name or any other information that identifies you. This means that no-one will know what you've said, it will be confidential. If you don't mind I may also use an audiotape while we talk to help me remember important things you say. However, I will not use it if you don't want me to. I will then look at what all the other children and young people I've

talked to have said. I will use this information to write down recommendations about the best ways to help children and young people who return to school after a brain injury.

Who has reviewed the project?

Before any research goes ahead, it has to be checked by a research ethics committee. They make sure that the research is ok to do. This project has been checked by a committee called Wales REC 3.

What if I have some questions that are not answered here?

You can ask me any questions you want. You can contact me, (Susan Walker):

- by phone (my number is.....)
- by email (my email address is)
- by asking your Mum or Dad or teacher to contact me

or, if we meet up to talk more about the project, I will ask if you have any questions or things you might like more information about.

After checking with your Mum or Dad please can you sign the attached form to say if you would like to take part or not.

Thank-you very much!

Susan Walker

Appendix 9: Consent/Assent form for 11+ year olds

Project Title: Participation following childhood acquired brain injury

Please put tick or cross in box: =YES or = NO, and your initials.

1. Has somebody explained this project to you?.....

2. Have you asked all the questions you want?.....

3. Have you had your questions answered in a way you understand?.....

4. Do you know that it's OK to stop taking part at any time?.....

2. Do you understand things you say may be written for other people to read but in a way that no-one else will know who has said them?.....

Please tick one of the following boxes:



I would like to take part in the project



I don't want to take part in the project

Name of Child

Signature of child.....Date.....

Signature of Parent/Guardian.....Date.....

Signature of Researcher.....Date

Appendix 10

Participation Information Sheet: School Staff (to be sent only after receiving parental agreement)

Introduction

You are invited to take part in a project exploring the ways in which children are involved with life at school, home and in the community following discharge from the acquired brain injury residential rehabilitation programme at *.

Project title

‘Participation following childhood acquired brain injury’

(‘Participation’ in this title means taking part in everyday activities – activities that are relevant to being at home, at school and in the local community such as learning, interacting with peers, spending time with friends and family, travelling to school etc.)

About the project

Research has found that over half a million children each year return home and go back to school after having had a severe acquired brain injury. Little is known about whether existing services are meeting their needs. The purpose of this current project is to find out about the experiences of parents, their children and views of school staff after returning to school following discharge from the acquired brain injury rehabilitation programme at *. The project aims to find out about the ways and extent to which children with acquired brain injury participate in everyday activities at school, at home and in the community. The study aims to find out what information and services children, parents and teachers consider important for enabling children with acquired brain injury to participate at school and in their local community. This may be helpful for the planning and provision of future services both at * and in local communities.

The research project is being undertaken by me, Susan Walker. I am an Educational Psychologist for the Acquired Brain Injury programme at *. The project is part of a doctoral programme at The University of Cardiff and is supervised by two members of research staff - one at the university, and one at *.

Why has your school been contacted?

- A student (X) is on roll at your school. He/she participated in the residential rehabilitation programme at * following a severe acquired brain injury.
- X’s parent, (name), has given permission for me to contact you with a view to discussing his/her return to education following residential rehabilitation.

What’s involved ?

If you agree to take part in the study, I would like to meet you at school at a time that is convenient for

you. The attached consent form will need to be signed. The meeting may take up to 30 minutes. Your perceptions of X's re-integration to school and your views about educational provision for meeting the special educational needs of a young person with a severe acquired brain injury will be sought. I will make notes during the interview about what you say. I will ask your permission to audiotape the interview but this will only be done if you agree.

Additional information collected at school

With parental permission, I may wish to read the statement or annual review record of the student's special educational needs and associated documentation to gain some understanding of the views and advice of additional contributors to the special educational needs assessment process.

The student's own views will also be sought. If the student chooses to be interviewed on the school premises rather than at home, it is hoped that a quiet space may be possible to use.

Confidentiality

Everything you say will be completely confidential and will be anonymised. All information will be kept securely, with a unique code rather than by name. These codes will only be known to me. Data will only be accessed by me, the academic supervisor and the research supervisor. All audio-taped information will be destroyed when the research study is finished.

How information will be used

Information from interviews with participants may be included in a doctoral thesis. A summary of the study findings will be made available to you and other participants. The results may be published in a professional journal and presented at a conference to share knowledge with others who have an interest in acquired brain injury.

What if there is a problem?

If you have any concerns about your involvement in the study or the way it has been carried out, please let me or * at * know as soon as possible. There are names and contact details at the end of this information sheet.

Review of the proposed study

The study has been reviewed and approved by *, Cardiff University, and a National Health Service Research Ethics Committee (Wales REC 3).

Contact for further information or to comment on the project

Relevant contact names, emails, phone numbers and addresses inserted here for the researcher, the researcher's employing organization, and Cardiff university.

Appendix 11: Consent Form: School Staff

Project Title: Participation following childhood acquired brain injury

Please put your initials in the boxes if you agree with the following statements:

1. I confirm that I have read and understood the information sheet for the above study. I have had opportunity to consider the information, ask questions and have had these answered to my satisfaction.

2. I understand that taking part in the study is voluntary and that I am free to withdraw at any time without giving any reason and without any legal rights being affected.

3. I understand that I may be quoted in the study but that anything I say will be anonymised so that I, and the school I work in, will not be identified.

4. I understand that data collected during the study may be looked at by *at * and/or * at the University of Cardiff. In addition to the researcher, Susan Walker, I give permission for these individuals to have access to the data.

5. I agree to the audiotaping of the interview.

6. I agree to take part in this project .

School staff signature.....Date.....

Name (Please print).....

Signature of Researcher (Susan Walker).....Date

Appendix 12

Elements for establishing Child-parent-researcher partnership (Lambert & Glacken, 2011)

Elements of consent

- C: Consider person's competence/capacity to consent/make a decision
- O: Offer adequate/sufficient and appropriate information (to make a decision)
- N: No pressure is applied (not coerced)
- S: Search for subtle signs of refusal
- E: Evidence of understanding sought and demonstrated in questions and feedback
- N: Negotiated continuously
- T: Time to think about decision

Parent permission

- P: Permission for researcher to invite child to participate in research
- E: Ensure parent is aware of the need for the child to decide to participate, or not
- R: Right to refuse permission to approach children is stressed; no pressure is applied
- M: Mindful of obvious and subtle signs of parent refusal
- I: Involve parents in the process of informing the child about the research project
- S: Seek parent's understanding of what the research entails for his/her child
- S: Source for parents' to ventilate their concerns/views considered
- I: Individualised process; adequate time for discussion according to parent needs
- O: Offer adequate and appropriate information
- N: Negotiated at outset and re-negotiated as deemed appropriate

Elements of assent

- A: Assess child's capacity/readiness to assent and engage with child to build rapport
- S: Supply child with adequate and comprehensible verbal and written information
- S: Search for signs of refusal (subtle or obvious) and ensure no pressure is applied
- E: Evaluate evidence of the child's understanding through questions and feedback
- N: Negotiate assent continuously
- T: Time is allocated for the child to think about whether to participate, or not

Appendix 13

Description of the residential rehabilitation programme from which the study children were discharged.

A UK-based national charity provides specialist services for children with severe acquired brain injury, including a residential rehabilitation programme undertaken by children in the current study. There is provision for 26 children, and during a 12 month period 2016-2017, 78 children from across the UK were in receipt of the rehabilitation service. It is a third sector provider (Hayes et al., 2017), a term used to describe organisations that are neither public nor private. Typically, children transfer to this residential programme from an acute care hospital following a severe acquired brain injury. The funding is provided by central government's NHS Specialist Commissioning Service, and has been for periods typically of between 2 and 6 months, but lengths of stay are now significantly decreasing. In addition to on-going medical and nursing care, the multi-disciplinary programme has included Physiotherapy, Occupational Therapy, Speech & Language Therapy, Clinical Psychology, Educational Psychology, Music Therapy, Play Therapy, Play & Leisure services, and Family Therapy. A high degree of family involvement during the child's residential stay is strongly encouraged and there is family accommodation. Education is provided by a medical pupil referral unit.

An integral part of the residential rehabilitation programme is discharge planning - preparation for children to return to their home and school. Primary goals of rehabilitation for young people are to enable optimum functioning in their home and school environments, and to help prepare local services to support the return of a child with significantly changed needs. Discharge planning begins prior to the child's entry to the programme, and is of very high priority throughout it. Detailed multi-disciplinary reports, updates and discharge reports are compiled and sent to all relevant key professionals in the child's home locality – health, social services and education, including local authority educational psychology services, and from whom pro-active communication and involvement is sought. Local Educational Psychologists and school staff are strongly encouraged to be involved in planning meetings held on the site of the rehabilitation programme and in the school to which the child is returning. Training about ABI, tailored for their disciplines, and to help understand the needs of the returning child is offered and is typically undertaken at the returning child's school.