Childhood Acquired Brain Injury: Experiences and perspectives of children, parents, teachers and educational psychologists and implications for professional practice

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I hereby declare that, except where explicit attribution is made, the work presented in this thesis is my own.

Signed: ______________________

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Abstract

Background: Research relating to children with Acquired Brain Injury [ABI] has tended to focus on the deficits that children and families experience instead of exploring the perspectives of children and key adults in terms of identification of needs and to address these needs. Teachers work with these children daily and Educational Psychologists [EPs] are often key professionals with a role in identifying the strengths and needs of these children in collaboration with their parents and teachers.

Aims: The current study aimed to explore the experiences and needs of children with ABI and the perspectives of their parents, teachers and EPs. The research considers the support that has been offered to these families and professionals, the factors that lead to better outcomes for these children and asks how best children, families and schools can be supported in the future. Support in terms of the EP role with children with ABI is particularly explored.

Participants: Thirty-seven qualitative semi-structured interviews were conducted which lead to the generation of four distinct datasets: children, parents, teachers and EPs. Children (n=6) from one London Authority [LA], with an ABI that had occurred in the last four years, were interviewed using semi-structured interviews and visual prompts. Parents (n=9), teachers (n=9) and EPs (n=13) were interviewed.

Method: Semi-structured interviews explored the impact of the ABI on the child and family and school, the support offered, EP involvement and facilitating factors. Further recommendations for children, their families, and professionals in similar circumstances were considered. Rating scales were also used. The interviews with teachers and EPs additionally explored issues of training, support, moderating factors and future recommendations. Each interview was transcribed, and a thematic analysis was carried out for each dataset.

Results: For the children's interviews, the emergent themes included the importance of protective factors and change. For the parents' interviews, emergent themes included adjusting to being a parent of a child with ABI, facilitators of support and the need for psychological and specialist support. For the teachers' interviews, the themes included the need for professional leadership and specialist knowledge, the responses to emotional needs and the challenges for the school. For the EPs' interviews, the themes included the roles and functions of the professional network, the needs of families and the need for specialist professional support for children with ABI, as well as their families and teachers.

Conclusions: Findings highlight recent experiences of children with ABI and their families, teachers and EPs, and demonstrate that there is a need for improved professional liaison and specialist input, especially in terms of emotional support. Practical implications for parents and educational professionals are outlined.

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Chapter One – Introduction

The following chapter offers a summary of the contexts – professional, national, and local - that have influenced development of the current study. The aim of this chapter is to introduce the reader to ABI and information about its incidence, as well as provide the reader with background information about the context in which the research took place.

1.1 What is ABI?

ABI is:

> *“damage to the central nervous system resulting from an incident or incidents of traumatic injury, illness or infection during the lifetime of the individual. It includes Traumatic Brain Injuries [TB]), arising from, for example, assaults or road traffic accidents, strokes, tumours, cerebral infections, and anoxia”* (British Psychological Society [BPS], 2006, p.3).

The injury must have occurred to the brain after birth and the immediate neonatal period to be considered an ABI (Walker & Wicks, 2005).

The Glasgow Coma Scale [GCS] (Teasdale & Jennett, 1974) is used regularly in clinical settings to determine the severity of post-traumatic unconsciousness in cases of acquired brain injury. The scale consists of a 15-point scale and is made up of three components: eye, verbal and motor. The person’s best observed responses are recorded. A mild brain injury is typically scored ranging from 13-15, whereas moderate and severe brain injuries are typically scored ranging from 9-12 and 3-8 respectively. However, there are controversies with regard to the use of the GCS. For example, there have been reports that in 51% of cases, the score given is inaccurate (see Crossman, Bankes, Bhan & Crockard, 1998).

Some research, especially studies carried out in the United States [US], is only relevant to children with TBI. This will be indicated when appropriate. The researcher chose to include TBI literature in the current literature review as TBI is a sub-group of ABI and it may have indications for ABI in general.

1.2 Incidence and prevalence

The experience of children and families with ABI is an important topic in terms of education. Some research suggests that about half a million pupils a year in the United Kingdom [UK] return to school after an ABI (Hawley, Ward, Magnay & Mychalkiw, 2004). In terms of TBI, research suggests that the incidence rate is 5.6 per 100,000 per year in the UK and Ireland (based on children aged 0-14 years admitted to intensive care, see Parslow, Morris, Tasker, Forsyth & Hawley, 2005).

However, it is difficult to put an exact figure on the number of children who are affected by ABI in the UK for a number of reasons. Firstly, many injuries may not be reported to the hospital, especially if the injury is considered mild. Secondly, if and when an injury is reported, the data are not usually collated in a systematic way across various hospitals and local authorities. For example, the recruitment process for the current study was hindered by a lack of record-keeping in the borough on children with an ABI. This did not mean that there were no children with ABI in the borough but that, instead, most children known to the Special Educational Needs [SEN] department in the borough were filed under their educational need, e.g. language and communication needs. Also, many students with an ABI may have already been registered for a SEN that arises from their ABI but are not registered as having an ABI. Moreover, the origin of any disability is not always known to the school or local authority and some children may not have become known to SEN as a result of their injury (Ylvisaker et al, 2001).

Nevertheless, there are various studies which indicate the numbers of children affected by the subtypes of ABI in the UK. According to the BPS (2006) these are as follows (references as cited in BPS, 2006):

- Traumatic head injury: the figures most widely cited for paediatric head injury in England and Wales are 4.5% per 1000 hospital admission rate per annum diagnosed with head injury (Crouchman, 1990). However, there is clearly a need for more up-to-date figures. In a study of head and brain injuries in a UK health district in Devon, 36% of 11,700 head injury attendances at Accident and Emergency departments over six years were under the age of 15 years (Yates, Jenkins, Ellett, Harris & Williams, 2004);

- Neoplasms, i.e. brain tumours – 5 per 100,000 indicated (Walker, Robins & Weinfeld, 1985);
- Cardiovascular conditions – varies between 2.3 per 100,000 (Fullerton, Wu, Zhao & Johnston, 2003) and 8 per 100,000 (DeVeber, 2003);
- Infections – incident rates change with age; it is estimated that approximately 12 cases per 100,000 children per year of death and coma result from cerebral infections (Forsyth et al., 2001).

Middleton (2001b, p. 166) summarises the statistics by concluding that 'as many as 2.5% of children may have sustained a head injury leading to attendance at A&E during childhood, a higher incidence than epilepsy, which affects about 1 in 100 children'. Most recently, it has been suggested that just under half a million children less than 16 years of age in the UK present to hospitals with head injuries every year (Royal College of Surgeons, 1999). National Health inpatient statistics in the UK indicate for the period 2009/2010 35,541 children aged between 0-14 years were given a primary diagnosis of 'injuries to the head' (Hospital Episode Statistics [HES], 2009-10). Overall, the above research and statistics appear to indicate that ABI is prevalent amongst school-aged children in the UK.

It is reported that TBI is the most common cause of death and disability in children (Kraus, Rock & Hemyari, 1990, cited in Hawley, 2004). This is officially recognised with regard to ABI in the US (Butterfield, 2009). It has been reported that the children at most risk for TBI are male, preschool age, have pre-existing social and behavioural difficulties, and are from disadvantaged backgrounds. The most common cause of injury is dependent on age, e.g. pre-school injuries are usually linked to parental interaction or lack of supervision, whereas school-age injury is more likely to occur due to the child's own behaviour (Anderson, 2011).

Recently, it was suggested that advances in medical treatment means an increasing number of young people are surviving head injuries and that this results in an average of one young person with ABI per mainstream secondary school in England and Wales (Rees & Skidmore, 2008a). This has implications for service providers but greater evidence is needed to substantiate this claim.

1.3 Research contexts

1.3.1 The Professional Doctorate

The professional doctorate is underlined by particular beliefs and models which influence the development and practice of the trainee EP. The core philosophy and ethos of the training programme is based on an inter-actionist (Lewin, 1936) and social contructionist perspective (Burr, 2003), appreciative inquiry (Annis Hammond, 1998) and the multi-level application of psychology with child, family, peer group, school, community, local authority (Bronfenbrenner, 1979). The core philosophy of the training programme penetrates the approach of the current study.

Of particular interest and relevance to this study is the multi-level application of psychology. Bronfenbrenner (1979) proposed a systemic framework (based on general systems theory) which regularly underpins EP practice. This systemic framework emphasises the interactions between a person and the differing levels of systems that impact on the person's life (see Figure 1).

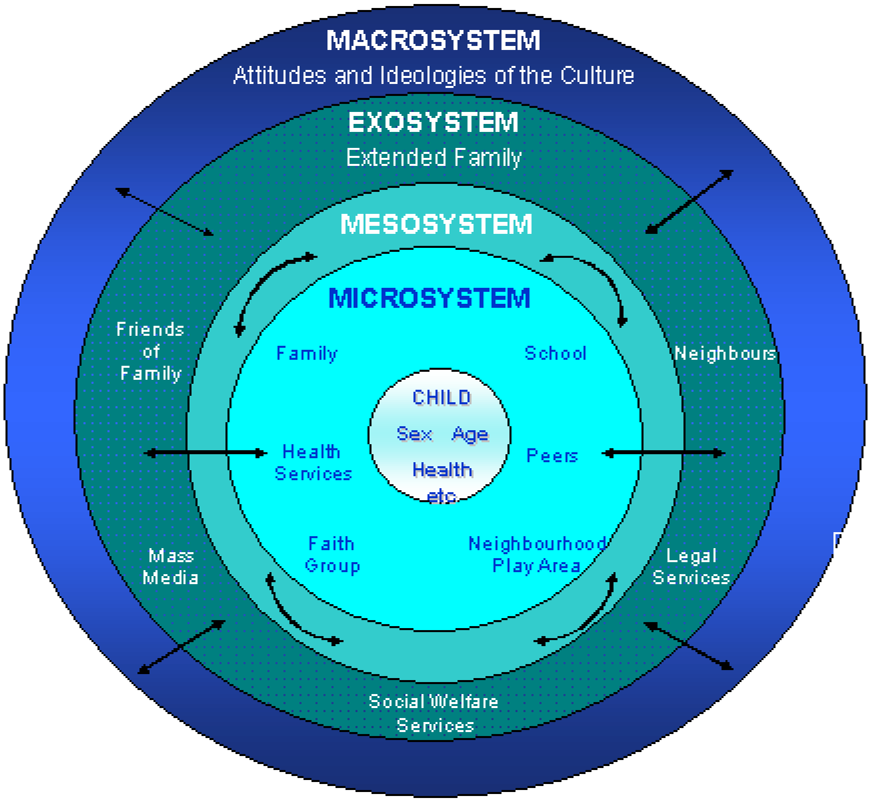

Figure 1. The eco-systemic model (Bronfenbrenner, 1979)

Evidence of the influence of systems theory can be witnessed in both inter-actionist and collaborative inquiry approaches through their emphasis on small changes. This theory is very relevant to contemporary EP practice in that it supports the notion that the EP can work with part of the child's micro-system (e.g. teachers or parents) and that interaction between the exo-system (the EP) and the micro-system (the teacher) can be enough to promote change in the child's life.

For children with brain injuries, specific frameworks have been proposed based on the eco-systemic model presented above, for example, an 'interaction systems model' which emphasises important changes in the interpersonal system of the child (at home or at school) and the intrapersonal system (cognitive and emotional factors) (McCusker, 2005). The benefit of this framework is that it allows for greater understanding of the experience of the individual within their context as well as expanding the range of interventions that could be used with the individual. Another framework that is proposed is the 'ecological-transactional framework' (Bozic & Morris, 2005, based on Cichetti, Toth, & Maughan, 2000) which has been developed to outline how an EP could intervene in various ways in the environment for a child with TBI (Bozic & Morris, 2005). This will be discussed further in section 1.4.

1.3.2 The national context

Since the 1944 Education Act, there has been a gradual move towards inclusive practice in education. For example, the Warnock report (1978) and the Education Act (1993) laid the foundation for legislation such as the SEN Code of Practice (Department for Education and Skills [DfES], 2001a), the SEN and Disability Act (2001), the national policy of Removing Barriers to Achievement (DfES, 2004) and the Children's Act (2004). The SEN Code of Practice (2001) acknowledged that there is a continuum of needs stated that local authorities need to arrange advice and information for parents. The Removing Barriers to Achievement publication (DfES, 2004) embedded the concept of SEN and disability in mainstream policy and practice.

Under the national framework of Every Child Matters [ECM] (2005), the approach taken by the last government towards the well-being of children and young people aged from 0 to 19 years emphasised a broader conceptualisation of need, an acknowledgement of diversity and moved away from meeting the needs of individuals towards meeting the needs of all. In this way, ECM makes outcomes for children central to integrated Children's Services that form a team around the child and family in the context of community and school (Farrell et al., 2006). Further to this, the recent publication of the SEN and Disability Green Paper (Department for Education [DfE], 2011) aims to minimise the difficulties experienced by families of children with SEN in response to frustrations reported by children, families and professionals. Current suggestions include a new approach to SEN identification, a move towards a single multi-agency assessment process and providing greater control to parents.

Regarding children with ABI, the only explicit government material is the 'Best practice guidance' on ABI which was written by both the DfES and the Department of Health [DoH] which outlines the exemplar journey of a child, Jack, with ABI who transitions from hospital to school (2004). The guidance emphasises collaboration between health professionals and education professionals with clear reference to the role of the educational psychologist within this structure. Guidelines from the National Institute for Health and Clinical Excellence [NICE] (2007) recommend that hospitals should send information to schools on all children who have a Computed Tomography [CT] scan after a TBI and that a school staff member should be invited to the discharge meeting. There is little evidence that guidelines are currently being implemented (e.g. Hawley et al., 2004; Tomlin, Clark, Robinson & Roach, 2002).

There has been government guidance in the last fifteen years that applies to those working with children with medical needs which would cover ABI, for example, the document called Supporting Pupils with Medical Needs (DoH & Department for Employment & Education [DfEE], 1996). However, it is alleged that in over half of the LAs considered, the policies and procedures for children with medical needs did not reflect the guidance of these government documents (Office for Standards in Education [Ofsted], 2003). As a result, it was recommended by Ofsted that LAs clarify their roles, have stronger links with outside agencies and monitor these children.

1.3.3 The local context

The current study was undertaken in an outer London LA which was the trainee's work placement for her final two years of the Professional Doctorate. EPs in the LA aim to include the application of psychology to enhance the development and well-being of all children and young people, at home, at school, and in the wider community, the maximisation of access to, and inclusion within, educational settings and society as a whole and the recognition that early intervention and preventative approaches are the most effective. The Educational Psychology team employ a consultation model of delivery.

In communication with EPs in the LA prior to the undertaking of the current research, it appeared that most EPs had had involvement with at least one child who had an ABI in the last two years. However, given the above statistics on prevalence and research that indicates that EPs are involved in only 50% of brain injury incidents (Tomlin et al., 2002), it is likely that there are more children with ABI in the LA than those known to the EPs.

Nonetheless, there was no policy or delivery plan in the LA for how EPs should support children with ABI. Upon further investigation and discussion with the SEN department, it was found that there is no record kept in the local authority of children who have an ABI. The SEN department found that when a search was done on their system using the following words 'acquired brain injury', 'head injury' and 'brain damage', there were children on their records with SEN statements that met the criteria, but there was no record kept of how many there were in the LA. Hence, it is impossible to currently estimate how many children in the LA are affected by ABI. Even with the information from SEN, it is likely that there are other children with ABI who have statements in the LA but their ABI is not mentioned, or that there are children in the LA who do not have a statement of SEN but do have an ABI.

1.4 Educational Psychology

The DfES (2005) report on Educational Psychology Service states EP work in very broad terms as providing 'assessment, consultation, advice and training to Early Year's settings, schools, families and the Local Education Authority' (as cited in Cameron, 2006, p. 290). Cameron highlights that as EPs begin to draw more on their psychological knowledge-base they will begin to form connections with other disciplines such as clinical neuropsychology (McKay, 2005),

The ECM framework promotes the EP role to work more diversely and creatively with children, schools, and families, expanding their role towards work in the community as well as retaining individual casework. Thus, the role of the EP is evolving from 'psychologist as expert scientist' towards 'psychologist as co-creator and facilitator' (Redpath & Harker, 1999, p. 121). Farrell et al. (2006) suggest that 'Educational Psychology services are likely to become more community focused within the new Children's Services with a reduced emphasis on school based work'. This ties in well with a systemic model of practice (e.g. based on Bronfenbrenner's eco-systemic model). However, the Green Paper (DfE, 2011) could alter the previous direction of the EP role as it could pose a challenge to methods of EP delivery, e.g. through traded services.

Specifically applied to children with ABI, an ecological-transactional framework has been proposed (Bozic & Morris, 2005, based on Cichetti et al., 2000). This builds upon the suggestion that EPs could intervene at different levels of the framework when supporting the needs of a child with a brain injury. For example, they suggest intervention at each systemic level: at the onto-genic level, supporting the children with ABI directly in developing coping strategies; at the micro-systemic level, offering advice to parents and teachers; at the exo-systemic level, supporting schools in terms of planning for children with brain injuries; at the macro-systemic level, conducting research and projects that can influence cultural beliefs and knowledge of ABI. The Bozic & Morris study (2005, p. 117) concludes that brain injury is an 'underdeveloped dimension of EP service delivery'.

1.5 The contribution of the study to professional practice and academic knowledge of Educational Psychology

This study intends to make a valuable contribution to research and professional knowledge as it aims to co-construct the direct experiences of children who have had an ABI and what that experience was like for them and their parents. By also interviewing teachers and educational psychologists, the educational professionals' perspective will also be considered and used to contribute to the holistic view of the experience.

Educational professionals need to be informed about ABI, to know how best to liaise with health professionals to support a good transition back to school and to understand the needs of children with ABI on their return to school. Educational psychologists are well-placed to do this work and are named as key professionals in this process (DfES & DoH, 2004). As an evidence-based profession who are often in high demand, it is vital that educational psychologists use their expertise and knowledge of research to investigate what contributes to best outcomes and experiences of parents and children and incorporate this into their work with ABI. This research endeavours to aid professional knowledge and contribute to evidence-based practice of professionals who work with children with ABI and their parents.

Chapter Two – Literature Review

The following chapter outlines the literature relevant to the research questions of the current study. It aims to summarise and analyse previous research and provide a legitimate basis for undertaking the current study. This review does not include all literature on children with ABI but does aim to reflect a fair and unbiased account of the wide-range of information available.

In order to carry out informed practice through intervention, we must first look at what past research has revealed about what works and learn from the findings and the wider implications.

2.1 Needs of children with ABI

The needs of children with ABI can be wide-ranging, rarely discrete (Middleton, 2001a) and can have long-term consequences. There is no signature profile. The wide-ranging sequelae experienced post-ABI can include the following:

- cognitive difficulties affecting executive functioning (Jantz & Coulter, 2007; Slomine et al., 2002), attention (Anderson & Pentland, 1998), meta-cognition (Hanten, Bartha & Levin, 2000), memory (Mateer, Kerns & Eso, 1996; Prigatano, O'Brien & Klonoff, 1993) and novel learning (Hunter & Donders, 2007; Levin & Eisenberg, 1979);
- social and behavioural difficulties (Andrews, Rose & Johnson, 1998), such as problems with social and adaptive living skills (Perrott, Taylor & Montes, 1991) and social interaction and adaptation difficulties (Prigatano, et al., 1993) that leave the ABI child ostracised by peers and which alienate teachers (Butler, 2011b) and with few friends (Prigatano & Gupta, 2006);
- learning difficulties such as reading (Barnes, Dennis & Wilkinson, 1999), specific learning disorders (Lord-Maes & Obrzut, 1996), language comprehension (Moran & Gillon, 2004), and 'higher order' language function (Prigatano, et al., 1993);
- increased emotional and behavioural problems (Yeates & Taylor, 2006) and psychiatric disorders (Luiselli et al., 2000);
- Many types of physical difficulties, e.g. 'clumsiness' (Prigatano et al., 1993).

Overall, common sequelae appear to include reduced speed of processing and attention skills, difficulties with novel learning and aspects of executive functioning and higher-level communication skills (Hunter & Donders, 2007). Any of these resulting difficulties can interact with and exacerbate other difficulties and result in a complex array of needs for the children and their families. Therefore, it can be said that there is ‘heterogeneity in their developmental trajectory’ (Yeates, 2011). However, it must be noted that some research indicates that head injury of the mildest type does not increase the probability of new behavioural and academic problems (see Light et al., 1998).

As well as the host of difficulties that can be caused or exacerbated by an ABI, there is also the issue of the amount of school that children miss as a result of hospitalisation and appointments linked to their ABI. For example, on average, a child who experiences TBI in the US misses 40 days of school (Yeates, 2011). This, in itself, could cause a child to experience difficulties in adjusting to going back to school, following routines, and catching up with missed teaching input and learning. However, there seems to be more to ABI than this as although children with TBI miss a similar number of days as comparable controls, i.e. orthopaedically injured children, the control group appear to not have the same difficulties with transition and long-term, complex needs (Yeates, 2011). Thus the question arises: what is different about having an ABI? Interestingly, recent research shows that 10-15% of children with TBI had SEN before their injury and proposes that the child’s SEN is often a causal agent in acquiring the injury. Pre-existing SEN is reportedly more likely in children with mild-moderate ABI than in children with severe ABI (Yeates, 2011).

2.2 Key issues

2.2.1 Issues often arise from difficulties of executive functioning

Executive functioning involves the ability to plan, organise, problem-solve, self-monitor, self-regulate and initiate and inhibit behaviour. These are skills that are required to carry out most everyday tasks and a difficulty in such skills affect various tasks, from following instructions to behaving appropriately. Of all the sequelae of ABI, difficulties of executive functioning are claimed to be the cognitive deficit that has the most impact on a child or adolescent's academic progress (Jantz & Coulter, 2007). It is also claimed that paediatric TBI almost always causes impairments in executive control (Ylvisaker et al., 2005). Often for the individual and for those close to the individual, it can appear that the individual's personality has changed.

2.2.2 Children with ABI have different special needs and may need more support than other children with special needs

It has been proposed that children with ABI have different special needs to other children with SEN for the following reasons: they often maintain a pre-injury self-concept; there are often significant discrepancies in ability levels; there are marked contrasts between pre- and post-injury capabilities; they have an academic and behavioural profile that changes frequently; there may be delayed deficits; and, family members experience an ongoing grieving process (Walker & Wicks, 2005).

It is suggested that support for children with TBI takes more money, time and intervention than typically needed for other children with SEN (Steensma, 1992). This is due to the potentially changing nature of their difficulties and the need for consistent, structured intervention that needs constant monitoring and review.

2.2.3 The needs of a child with ABI can be missed

It is concerning that the needs of this population are often missed: recent research (Molloy, 2008) indicates that symptoms of brain injury may be misconstrued as common behaviour or academic problems in the school system. Children with ABI often look the same as they did prior to the ABI or have a 'typical' presentation. This causes confusion for the adults in their lives as they cannot 'see' that anything has changed or that the child's psychological recovery has not kept up with the child's physical recovery (Hawley et al., 2004). To complicate the issue, sometimes it may not be until sometime after the injury e.g. 2-3 years, that concerns to do with the injury emerge and by this time subtle psychological and psychiatric problems may be established (Middleton, 2001b).

It is also reported that children with TBI do not perform particularly badly on traditional assessments compared to how they achieve in the classroom (Yeates 2011). This could because children with ABI have difficulties with novel learning (Hunter & Donders, 2007) and because children may have a pre-injury cognitive ‘reserve’ (Chapman & McKinnon, 2000). There have been recent claims that when assessing children with brain injuries, the EP should be exploring the ‘cognitive constructs’ relating to loss, change and future worries (McCusker, 2005). Equally, it is reported that the behavioural and social difficulties of children with ABI may not be picked up on psychiatric diagnostic criteria as their difficulties are ‘elevated’ rather than ‘pathological’, and therefore may not meet mental health thresholds (Anderson, 2011).

2.2.4 The consequences of ABI are typically long-term

It is thought that ABI can lead to long-term difficulties. For example, in 1975, it was suggested that 50% of children who had a severe or moderate head injury had not made normal progress at school 10 years later (Kleinpeter, 1975, cited in Middleton, 2001b). A 23-year follow-up of children who had head injuries found that there were significant long-term consequences in terms of social adaptation (Klonoff, Clark & Klonoff, 1993).

A more recent example of the long-term outcomes for children with ABI is the number of children who go on to achieve university degrees post-ABI: 5% of those who had severe ABI in childhood and 15% of those who had a mild ABI in childhood respectively (Anderson, Brown, Newitt & Hoile, 2009). US research on children with severe TBI indicates that only 20% are employed as adults and 80% live with their parents (National Institute on Disability and Rehabilitation Research [NIDRR] Conference, 2007, as cited by Prigatano, 2011a). Although recent research indicates that in the long-term TBI has the most dramatic outcomes in terms of quality of life (Anderson, Brown, Newitt & Hoile, 2011).

The majority of children who experience an ABI return to their families and re-enter the school system. It has been suggested that many ‘families and communities are unprepared for managing the immediate and potentially lifelong medical physical, cognitive, psychosocial, and neuro-behavioural consequences of brain injury that their children face’ (DePompei & Bedell, 2008).

Many difficulties are not always obvious in the first stages post-ABI as the focus is on recovery, therefore sometimes, it is only when abilities or skills fail to come ‘online’ during development that it is noticed that the child has difficulties (Anderson, 2011). For example, the learning of skills such as literacy and numeracy can deteriorate over the five years post-injury (Ewing-Cobbs et al., 2004). Difficulties in novel learning can lead to frustration for the child as well as parents and teachers, especially for children who previously had no difficulties with learning. Feelings of uncertainty and lowered self-esteem can arise (Clark, 1996) although this can be lessened for children who learn compensatory strategies to overcome these difficulties. Transitional times are highlighted as crucial and careful management is needed. This is especially true for children with ABI in adolescence as overprotective parents can compromise their autonomy. For example, it is reported that adolescents with TBI can experience changes to their self-identity, lowered self-esteem, decreased social abilities and perceived decrease in independence (Bergland & Thomas, 1991, as cited in Prout & Brown, 2007).

2.2.5 An ABI could affect a child more than an adult

TBI is also said to have a more devastating effect on a child than on an adult because, as a child develops, expectations increase in terms of learning, independence and social behaviour (Masel, 2006, as cited in DePompei & Bedell, 2008). It is thought that this is the case for not just TBI but ABI in general. Indeed, it is proposed that what is seen in adult ABI is different to childhood ABI as the injury the brain is more vulnerable to damage when it is in a stage of rapid development (Anderson, 2011). For example, it is suggested that children that experience an ABI at less than seven or eight years old, do not recover in a similar way to adults and children who have an ABI at an older ager (Anderson & Moore, 1995). Therefore, the age of the child at injury is often critical.

Compared to adults, children with TBI are less likely to die, but are more susceptible to swelling of the brain and to experience delayed effects (Donders, 2011b), and should therefore not be thought of as ‘mini-adults’.

TBI can affect a child differently as children’s brain functions are still emerging and developing, they are less mature and have less language skills, and there is the possibility of the brain ‘growing’ into deficits. Also, children are typically cared for by parents and siblings, and people are more tolerant of their difficulties than they would be with an adult. In fact, it is now thought that if a child experiences a TBI under the age of 6, consequences are more likely to be diffuse and wide-ranging (e.g. Ewing-Cobbs et al., 2006), and that left hemisphere injuries can lead to worse outcomes than right hemisphere injuries (see Barnes et al., 1999). Indeed it has been suggested that the earlier the injury occurs, the more likely worse outcomes are (see Ewing-Cobbs et al., 2004). In more specific terms, it has been suggested that the age at injury may interact with reading ability more than maths ability (Yeates, 2011) as it is indicated that maths is usually affected regardless of the age of injury.

2.2.6 ABI could lead to some positive outcomes

Recent research indicates that some adults who have experienced TBI (from mild-severe) exhibit positive changes in their outlook over time and that the severity of injury did not impact upon this (Hawley & Joseph, 2008; Powell, Ekin-Wood & Collin, 2007; McGrath & Linley, 2006 on ABI). This has positive implications for working with people who have experienced an ABI. It is recommended that this potential capacity for psychological growth must be taken into account when planning intervention for individuals (Hawley & Joseph, 2008). With regard to children, it has been recently suggested that by using a tool such as the Posttraumatic Growth Inventory [PTGI] (Tedeschi & Calhoun, 1996) with children and their parents, positive outcomes can be encouraged and worked towards (Cadena, 2008).

2.3 A 'family affair'

The effects of the child’s ABI can also have significant impact on the child’s family (Conoley & Sheridan, 1996; Florian & Katz, 1991) and affect the attitude of their peers towards them (Crothers, Linden & Kennedy, 2007). Indeed, recent research with families of children with disabilities (e.g. Bennett, 2009), supports reference to the effects of brain damage as a ‘family affair’ (Lezak, 1987).

Research has explored the effects of ABI on specific members of the family such as the effects of having a child with an ABI on parents (e.g. Collings, 2008; Hawley, Ward, Magnay & Long, 2003) and on siblings (see Middleton, 1997; Orsillo, McCaffrey, & Fisher, 1993). This can happen as family members are often put in the situation of becoming a carer to the child with a brain injury, causing massive changes and considerable adjustments to the lives of parents and siblings which have implications for their quality of life. Families may find it difficult to parent their child and manage their new caring role as well as other children and/or work. As a result their psychological well-being can be affected, e.g. reports that anxiety is more commonly reported than depression amongst families following severe head injury (Novack, Bergquist, Bennett & Gouvier, 1991). Families can also feel overwhelmed and experience emotions such as guilt, anger and blame (Middleton, 2001a) associated with the ABI, sometimes towards themselves and sometimes towards those who were present when the ABI occurred.

Feelings such as grief and loss for their child can also be prevalent. For example, parents often have a clear sense of the loss that has occurred, i.e., 'the loss of a 'normal' future, and the loss of the hopes and dreams associated with such 'normal' development' (Collings, 2008, p. 1). Feelings of non-finite loss can be experienced by parents. It has been pointed out that 'losses may not be actual but perceived' (Middleton, 2001b, p. 176), meaning that although the child is still alive and living with the family, the family could be mourning for the child they had, and for the child that the child could have become. Parents may also experience isolation and denial (Walker, 2009). The emotional impact of the experience is likely to have an impact on a parent's ability to parent consistently and their ability to act as an advocate for their child (McCusker, 2005).

However, the impact of ABI on the family is not always only negative. The concept of resilience has more recently been acknowledged in the research with children with ABI and their families. Resilience can be defined as 'a dynamic process encompassing positive adaptation within the context of significant adversity (Luthar, Cicchetti & Becker, 2000, p. 1), or in other words, the 'flexibility that allows certain children and young people who appear to be at risk to bounce back from adversity, to cope and manage major difficulties and disadvantages of life, and even thrive in the face of what appear to be overwhelming odds' (Dent & Cameron, 2003, p. 5). For example, a fairly high level of resilience in parents has been reported, in that the parents had been able to adjust to their changed circumstances, maintain their general life activities such as work and time with other family members as well as maintaining spiritual frameworks (Collings, 2008). Not only this but most participants could think of positive outcomes of their experience and name their hopes for the future which Collings (2008) claims shows that grief is not necessarily a destructive experience. It is important that research such as this is incorporated into any support for parents with children with ABI and could be thought of as a demonstration of a positive coping strategy and resilience rather than denial and avoidance.

2.4 Return to school

Educational difficulties can occur due to the wide-range of possible neuropsychological difficulties, as outlined previously. Consequently, they can result in negative school experiences for the child and affect their future. Hence, there is an urgent need for schools to develop their capacity for supporting the learning of students with ABI on their return to education (Rees and Skidmore, 2008b). Indeed it has been proposed that long-term social isolation is the biggest problem for children with a TBI (Prigatano, 2011a). He suggests that the reason why could be to do with the difficulties these children can have with appropriate social interactions.

There are only a few recent studies in the UK that report on how the transition back to school for children with ABI is being managed. For example, in one particular study, it is reported that only 32 of the 82 children in their study were known to have had an educational planning meeting before discharge from hospital (Tomlin et al., 2002). The researchers aired concern that 54% of children in their study lacked coordinated planning and 43% lacked any contact between hospital and mainstream school. They also report that an explanation of the head injury was given to the school in only 32 out of 82 cases. They conclude that in only half of their study's population was planning for return to school achieved.

Another study highlights that there is a frequent absence of information from hospital sources to schools. For example, for only one child out of twenty-one was the school informed about the brain injury by the hospital, instead parents were left to inform the school for over 50% of the sample (Hawley et al., 2004). The same study also found that most children were 'discharged home without assessment, support, or advice about return to school' (p. 140). This leaves schools without specific knowledge of the child's ABI, and in turn, unable to know in what way to provide for the child's education in an individualised way upon return nor know what to expect (Hawley et al., 2004).

To address this issue, there have been a growing number of suggestions. For example, it is suggested that children with head injuries should follow a 'care pathway' straight through from hospital discharge to at least the first two years post-injury (Doherty & McCusker, 2005). This marries well with both government guidance and NICE guidelines. More recently, studies are highlighting how with better transition from hospital to school, professionals and families can play an important role in supporting the child with an ABI back into education (Molloy, 2008). Unfortunately, it is suggested that many professionals (from medical and educational backgrounds) felt that education was 'letting down' children and young people with ABI (Flowers, 2008). The interviews highlighted that many parents think that a Statement of SEN would address the needs of their child. However, due to the changing profile of needs of these children, it has also been suggested that the 'statementing' process is not wholly appropriate and a more flexible approach should be adopted by LAs (Tomlin et al., 2002). As well as this, it been suggested that 'students experiencing neurological recovery require Individualised Education Plan [IEP] reviews that are more frequent than the legally mandated annual review' (Ylvisaker et al., 2001, p. 89). A suggestion has been made that a mechanism such as the Common Assessment Framework [CAF] could be used to identify and monitor needs (Longley, Prosser, Harris, & Collins, n.d., cited in Walker, 2009).

In the US, it has also been reported that despite the important role of transition services for children with TBI, there is a lack of communication between hospitals and schools (Yeates, 2011). To address this issue, research is being undertaken in the US to improve such transitions (see Prier, Glang, Todis & Ettel, 2011). Key elements of this intervention includes: ensuring that the hospital informs the designated person in the state's Department of Education; a transition facilitator is put in place for the child and family; parents receive information and advocacy training; teachers receive support from the facilitator and a booklet; and on-going contact and support for all. Findings from the preliminary analysis indicate that for the above to work, a number of things were key (Yeates, 2011). For example, actively experimenting with the school's support and working collaboratively (as opposed to offering proscriptive advice), having on-going reviews, inclusion in regular classrooms and routines (as their preliminary data indicates that exclusion can be helpful educationally but not psycho-socially). Overall, Yeates (2011) reported a ‘sense’ that the transition project had made a big difference and had a positive impact on terms of success in school and in supporting parents. Official results from this study will provide further enlightenment.

A key part of the above intervention is the involvement of parents as it is reported that parental anxiety levels increase if they are not involved in the child’s management (Anderson, 2011). However, it is highlighted that although supporting the needs of parents and siblings is key, therapies need to be balanced with time for the child to experience normal children’s activities too (Anderson, 2011).

Another key aspect is the transfer of information from the medical professionals to home and school as it is usually schools and families who provide the long-term support for children with ABI that help them achieve better outcomes and quality of life (Savage, Pearson, McDonald, Potoczny-Gray & Marchese, 2001). Although families can provide the school with copies of medical records and other important documents (as suggested by Savage et al., 2001), it would be better if the medical and educational professionals worked together with the family to ensure that information provided to school is specific and unbiased.

With regard to the role of the EP in transition, specific recommendations have been given for their involvement. One of the steps in the 'Jack's Journey' exemplar following Jack’s return home is ‘Rehabilitation and Follow-up Care’ (based on the government 'best practice guidance', DfES and DoH, 2004, p. 23). In the section on ‘Early provision of individual educational needs’, the following is stated ‘It (early provision) also includes an early appointment for Jack to see an educational psychologist organised by the LEA, as requested in the paediatric clinical neuropsychologist’s report. Close liaison between education and clinical neuropsychologist is critical throughout the entire process’.

This exemplar draws attention to the importance of the involvement of the educational psychologist in the transition process and how educational psychologists can play a key role in promoting change. This exemplar is supported by medical professionals who have emphasised that an interface between health and education and every stage of the child’s development and transition is needed (Tomlin et al., 2002). For example, it is suggested that each child should be followed up for at least 2 years and at critical points in development such as adolescence, even if the child had sustained an early childhood brain injury. There is also a suggestion of careful examination timetabling for these children as well as for a clear pathway for education professionals to contact the community health team.

The Child Brain Injury Trust [CBIT] (Flowers, 2008) have also produced guidance on transition from hospital to school and recommend that the notes outlining necessary support for the child from the hospital Discharge Meeting are sent to the school EP. Following these guidelines appears to be crucial to transition as it has been found that a lack of planning for the return to school can cause frustration for children and adults (D’Amato & Rothlisberg, 1996).

2.5 Systemic Intervention

Since the proposal of the social model of disability (see Union of the Physically Impaired Against Segregation [UPIAS], 1975), the traditional within-person interventions for people with a disability have gradually shifted towards the systems around a child that interact and impact on a child’s life experiences. As previously mentioned, the eco-systemic model (Bronfenbrenner, 1979) is helpful to gain insight into how each interacting system, e.g. the health system, the education system etc., impacts on and interacts with the lives of children with ABI and their families. This theory links to the concept of resilience: for example, Bloom (1996) suggests that contexts, systems, and relationships could provide ‘social resilience’ instead of resilience coming from within the person.

With reference to head injuries, it is recommended that intervention should not be restricted to the child with the head injury as the child is only one part of an overall system (Doherty & McCusker, 2005). Proposals such as the ‘interacting subsystems’ approach (McCusker, 2005) and the ‘ecological-transactional’ model (Bozic & Morris, 2005) offer frameworks within which systemic intervention can be addressed.

2.5.1 Environmental moderating factors

The child’s family environment has been strongly indicated as a predictor and moderator of outcomes for children with ABI. For example, it is claimed that pre-injury family characteristics can predict behavioural adjustments post-injury (Yeates et al., 1997), and that post-injury family environment can impact upon psychosocial outcomes (Yeates et al., 2010). Environmental modifications must be improved for children with brain injuries as trying to improve weakened skills, such as speed of processing, can be frustrating for all and may not be possible (Butler, 2011b). These findings have serious indications for the importance of family support for children with ABI as they show the impact of family environment on children’s academic skills.

In line with the above, research has moved away from the medical model of intervention for children with ABI from a within-child perspective. Instead, it has been proposed that a systemic approach could be taken (McCusker, 2005). This looks at how interventions to the interpersonal system (at home and at school) or aspects of this system can be adjusted to support the child’s adjustment. This supports the concept of the ‘poor fit’ between children with ABI and the environmental expectations of them (Dise-Lewis, Lewis & Reichardt, 2009). For example, what appears to be a change in personality, behaviour and emotions could be understood instead as ‘the child’s response to the poor fit between the environmental expectations held of him and his current neuro-developmental capabilities’ (Dise-Lewis et al., 2009, p. 168).

This indicates that by targeting interventions at the environment in which the child lives, i.e. the family system, the school system etc., rather than at the child, the potential consequences of ABI could be lessened and outcomes improved for the child. This is a solution-focused and pragmatic way of thinking about the needs of children with ABI and how professionals can enable change to promote best outcomes for them. In support of this, it is argued that by looking at the child’s needs and the possibilities for intervention in this way, the range of interventions open to the practitioner are expanded (McCusker, 2005).

There are many different approaches and interventions that have been proposed to manage post-ABI such as the treatment oriented approach (Rourke, Fisk & Strang, 1986), environmental modification (Feeney & Ylvisaker, 2003), family-based training and support (Braga, DaPaz & Ylvisaker 2005), family-based problem-solving (Wade, Carey, & Wolfe, 2006) and cognitive behavioural interventions (for a research review see Slomine & Lascascio, 2009). However, a recent review of 28 cognitive and behavioural interventions post-ABI (Laatsch et al., 2007) identified only the following three evidence-based guidelines and options: provide an information booklet for parents (e.g. Ponsford et al., 2001), consider involving the family in the intervention process (e.g. Braga et al. 2005) and provide cognitive remediation, with a particular focus on attention skills. The first two guidelines have been recently promoted as recommendations for evidence-based practice, along with positive behavioural support (e.g. Gardner, Bird, Maguire, Carreiro & Abenaim, 2003; Ylvisaker, Jacobs & Feeney, 2003). Laatsch et al. (2007) also assert that intervention with the family can be better than other intervention, especially in terms of addressing anxiety and depression. This research has implications for how EPs should be promoting intervention for children post-ABI as well as tying in well with current EP ways of working, e.g. having a focus on how to intervene at different systemic levels that interact with the child's micro-system using a consultation based model.

2.5.2 Intervention with families

It is 60 years since the importance of involving families in treatment for children with a brain injury and working towards 'normality' for the child was emphasised (Bender, 1951). The importance of offering support to families and putting them in touch with appropriate family support groups has been highlighted (Taylor et al. 2001). This research also suggests that there is a relationship between post-injury family-functioning, parental psychological distress and the perceived (rather than actual) impact of burden of injury on the family and the outcome for the child. Kreutzer, Serio and Bergquist (1994) found that when family needs were assessed, families often ranked their own personal needs as of least importance but that a high proportion of these families also felt that their need to discuss their fears and doubts was unmet. Prigatano (2011b) asserts that the needs of the parents must be met first, then the needs of the child. This should be accompanied with 'clear, honest information, support and contact with those with similar experiences are most highly rated by families' (Middleton, 2001b, p. 177).

‘Signposts’ is an Australian program for families that puts in place similar recommendations to those discussed (Hudson et al., 2003). Specific materials have been developed for TBI as follows: information about TBI; information about managing a child with TBI; support to parent in identifying problem behaviours and analysis; support in how to develop a consistent response; and, modifying responses when necessary. The preliminary data indicate good results which appear to show a reduction in family burden and a decrease in reported parental depression and anxiety (Anderson, 2011). Both telephone- and group-delivered programs reportedly demonstrated equal success which has implications for reaching families who live in rural areas or further away from professional bases.

There is a need for research to explore whether parents’ needs are unmet because of the lack of community resources, or because available resources do not adequately target the needs of parents of children with ABI (based on suggestions of Armstrong & Kerns, 2002). This research also indicates that the needs of families with a child with an ABI have unique characteristics and that family needs are not due to the traumatic nor chronic nature of the medical needs. This has implications for how support is developed for families with a child with ABI.

2.5.3 Intervention at school

It has been stated that no other educational disability demands more of rehabilitative professionals and the resources available for teaching and learning and that TBI ‘may represent the greatest challenge that education has yet to meet’ (D’Amato & Rothlisberg, 1996, p. 682). This could be because schools are more comfortable with ‘static disability’ rather than a ‘changing disability’ such as brain injury which can change dramatically over weeks and months. However, despite this challenge, when conducted appropriately, intervention in school can dramatically change children’s success and subsequent behaviour (Middleton, 2001b).

In general, there seems to be consistency across research that children with TBI or ABI need clear structured routines in school and need clear boundaries and expectations for behaviour (see D’Amato & Rothlisberg, 1996). However, it must also be kept in mind that we need to know *“how to help children with impulse control without robbing their individuality”* (Prigatano, 2011).

It has been pointed out that although a lot is not known about what works in terms of intervention for children with TBI (and possibly ABI), there is a lot known about what interventions work for children with SEN (Yeates, 2011), for example, evidence-based instructional approaches such as systemic, explicit instruction and practice, systematic introduction and modelling of component skills, use of scaffolding, teaching to mastery, and frequent and cumulative review (see Glang et al., 2006). These are all methods of intervention that are also applicable to children with ABI and use resources that are already out there in schools and understood by teachers.

In terms of systemic classroom intervention and ABI, research indicates that the following are likely to help: a structured classroom; well-rehearsed and predictable routines; consistent discipline; and, multi-modal teaching (McCusker, 2005). More specifically, it is suggested that children with ABI work best in classrooms which ensure the ‘slowing down the pace of the lesson and providing clear structure, with breathing spaces means that these pupils are able to take a greater part in the lesson’ (Rees & Skidmore, 2008b, p. 94). In another study based on classroom observations, the same researchers (Rees & Skidmore, 2008a) propose the PEDER model (Point out, Explain, Demonstrate, Encourage, Repeat) as an appropriate style of teaching for children with ABI. Interestingly, it is also suggested that this style of teaching could have benefits for other children in the class, especially children who have difficulties with choice, attention, word finding and verbal instruction. This research highlights how a change to teaching strategy in the classroom can have a positive effect on not only children with ABI but other children who also find learning difficult. For example, a teacher reported that ‘having D in school means I teach the other children better’ (Rees & Skidmore, 2008a, p. 389). Indeed, it is purported, in general, that how the classroom and school are organised can affect emotional and behavioural difficulties (Evans, Harden & Thomas, 2004).

Intervention based on supporting children’s self-management skills has shown positive results, for example, in terms of self-monitoring (Selznick & Savage, 2000). Indeed, it has been proposed that what adults need to do is to *“act as their frontal lobes”* (Yeates, 2011), meaning that the children's executive functioning needs to be structured and supported accordingly.

US research has highlighted successful and practical ways of supporting those close to children with brain injury. For example, results from the evaluation of a web-based programme indicate that it was successful in increasing parents' positive parenting skills with children with TBI (Wade, Oberjohn, Burkhardt & Greenberg, 2009) and pilot data from the BrainSTARS team-based intervention programme indicated an increase in the competencies of parents and educators with children with ABI (Dise-Lewis et al., 2009).

A good example of how children with ABI can be supported through professional interactions within their micro-system was recently described by Braga (2011). In the SARAH network of neurorehabilitation hospitals (located in Brazil) which includes nine centres for rehabilitation for children post-ABI, the focus has moved away from the previously dominant idea of "*professionals as gate-keepers of knowledge about rehabilitation*" for children. Braga (2011) emphasised that professionals must remember that *"parents know their child best and interact with them daily"* and explained that it was because of this belief, parents are now included in the rehabilitation process. For example, after a two-week evaluation for professionals and parents - which establishes a joint approach with the family and child and teachers and parents about their child's development - the family are given an individualised manual to use at home with the child, with specific, easily attainable, realistic goals. Bi-weekly visits then occur during which the parents and child visit the centre for assessment, new goals, changes to the manual, parent support groups and information meetings. As part of this process, each family is appointed a 'case manager' out of the health professionals in the centre. The 'case manager' is the family's main point of contact and coordinator.

Braga (2011) admitted that this novel approach to support and rehabilitation for children with ABI, did initially meet with resistance from some professionals, as they *"worried about transferring hard-earned knowledge to lay people"*. This echoes the concerns that have been raised in the 'giving away psychology' debate (Miller, 1969; Kay, 1972; for specific reference to the EP profession see McLeod, MacMillan & Norwich, 2007). Parents also expressed concern because they were worried that they did not have the knowledge and training to participate. However, recent randomised control tests indicate that the home, parent delivered treatment leads to significantly better cognitive and physical outcomes for the children in comparison to clinical, specialist-delivered treatment (Braga et al., 2005). Their research results also indicate that parental education levels did not influence outcomes for the children. Braga proposes that this approach works better as having the 'rehabilitation' at home allows for it to be more frequent, in a more appropriate context and is influenced by the affective relationship between the parent and child. This changes the professional role from working directly with the child to that of a 'family guide' and 'counsellor' who works with the key adults in the child's life rather than directly with the child (except for initial and follow-up assessments with the child). Braga added that when a cost-effective analysis was done on the two approaches, not only did the parent-based approach lead to better outcomes for the child, but it was four times less expensive to operate. Given the current economic climate, this is a good incentive for professionals who work with children following ABI to re-think their specialist-driven approach. Braga concluded by saying that "*school is a very important place as the child spends much of their time there"* and *"if the school is not involved, our results are very poor"*. This indicates a possible role for the EP in the UK context.

Indeed, other research supports the findings that intervention involving the education of parents and education professionals is more successful at reducing deficits in children than intervention which is conducted at the individual level (e.g. Ylvisaker et al., 2001; Glang et al., 2006). Such results need replication but could have a significant impact on intervention planning for children with ABI. They highlight the need for professionals to be working with those who are in the most direct contact with children with ABI rather instead of simply working directly with the children with ABI.

The above approaches are linked to inter-actionist theory (Lewin, 1936), appreciative inquiry (Annis Hammond, 1998), general systems theory (Bronfenbrenner, 1979) and Vygotsky's theory of social learning (1978). These are all approaches and theories that EP training is also based upon and, given the important role that the school is said to play in the rehabilitation of children following ABI, indicate that there is a need for professionals in the school system who can introduce this way of working to schools and support them in the process.

If education was to adjust to the child’s needs in this way, this could have a important impact on family functioning. Contact-a-Family (Bennett, 2009, p. 32) found that 50% of parents report that ‘an education to meet my child’s needs’ would make their family stronger practically. Although this research was open to families of children with disabilities in general, it is likely that this research is relevant to families with children with ABI. Such research highlights the importance of education to families and how by enabling a child with a disability to access education, the family as a whole is supported.

The question arises: If we already know the above, why is it not happening in our education system? There are limitations to the interventions, for example, engaging the family can be time-consuming. This could be because the intervention may be not focused on the child or parent’s main concern (e.g. health for parents and friends for children) or due to the hidden nature of needs, thus engagement may not be optimal.

However, there is not enough research on how effective these systemic adjustments could be for the educational inclusion of a child with ABI. Bozic and Morris (2005) look specifically at how the EP could play a key role at the different systemic levels (e.g. the micro-systems, exo-system and macro-system) within the ecological-transactional model (linked to Bronfenbrenner’s eco-systemic model, 1979, but based on Cicchetti et al., 2000 as cited in Bozic & Morris, 2005). For example, at the micro-systemic level, it is suggested that EPs could provide advice for parents and liaise with agencies. At the exo-systemic level, it is suggested that EPs could engage in consultation, in-service training [INSET] and involvement in planning with schools. At the macro-systemic level, it is proposed that EPs could conduct research and in this way influence policy and practice. Such a framework opens up the methods in which professionals can intervene and support best outcomes for the child with ABI.

2.6 Experiences and perspectives of the family

In order to provide the best support possible to children and families, it is important to ask those who have lived through the experience about the aspects of support that they value and desire.

Something that has not been researched thoroughly is the perspective of the child with ABI (although limited research has been conducted with adults with TBI). For professionals to be able to truly work with and support children who have ABI, it has been emphasised that psychologists must be *"compelled to write down experiences as much as conduct studies"* as *"it is important to understand the phenomenological experience of the individual"'* and that without that professionals are *"inept without this broad sense of information"* (Prigatano, 2011b). An attempt at understanding the individual perspective was carried out in Australia with adults who had experienced TBI (Crisp, 1993). It was concluded that the 'variety of respondents' perceptions concerning self, disability and handicap highlights the need for greater flexibility in interpreting or diagnosing psychosocial adjustment to disability' (p.402). It is possible that this is also the case for children with ABI.

2.6.1 Children

Children's main concerns post-TBI are reported to be (in order of importance): friends, schoolwork and health (Bohnert, Parker & Warschausky, 1997). This is in contrast to what their parents main concerns are reported to be (in order of importance): health, schoolwork and friends. This discrepancy highlights the conflicting views of the children and their parents and needs to be taken into consideration when working with a child and their family, as it could be that neither group will be able to work on other needs until their needs of most perceived importance are met.

Research also indicates that there can be disagreement between parent and adolescent reports of functional impairment (Kramer et al., 2004). This is particularly the case for questions on relationships with friends, peers' delinquent behaviours, and leisure activities. It was also found that clinicians perceive problems reported by parents to be more serious than problems reported by adolescents only. This could also be the case for younger children, highlighting the importance of asking the adolescent or child as well as the parents to ensure the most complete picture of the experience is achieved. The above also highlights professionals' own bias towards the perspective of the parent. EPs are often cited as playing the role of 'advocate' for children and need to aware of the biases of other professionals as well as their own.

There is some recent information on the perspectives of children with ABI and their siblings (CBIT, 2010) which indicates that the following are key issues:

- Respect from others, e.g. being seen as a person with a head injury rather than a head-injured person;
- Family needs, e.g. support for family members;
- Information, e.g. information given early on and directly to the child, not just to their parents and teachers;
- Independence, e.g. support to develop independent skills and be listened to;
- Schools and teachers, e.g. need for more understanding of their experience;
- Friends, e.g. the need for friends but also issues of friends' lack of understanding;
- Support groups, e.g. the need for availability of these groups for parents and child.

According to guidelines for researchers and multi-professional practice, researchers should not only recognise children's and adolescents' rights but also actively work towards eliciting their views (Lewis & Porter, 2004). It is imperative that when research is conducted in relation to the experiences of children that the researcher does as much as possible to include the voice of the child. According to the United Nations Convention on the Rights of the Child (1989) children have a right to express an opinion and to have that opinion taken into account in any matters affecting them. This right has been taken on board by legislation and, in the UK in the past decade, there has been a huge emphasis put on pupil participation , for example, guidance given in the SEN Code of Practice (DfES, 2001a), the SEN Toolkit (DfES, 2001b), the Education Act (2004), and Every Child Matters (DfES, 2005).

Specifically in relation to EP practice, it has been suggested that developing professional practice that enables the perspectives of child and young people to be heard should be of central concern to every EP (Todd, Hobbs & Taylor, 2000). Not only that but EPs are considered to be 'well-placed to ensure that children's views are both elicited in a neutral way and included in plans being proposed' (Educational Psychology Services Report of the Working Group, Kelly & Gray, 2000, p. 7).

Therefore, it is every EP’s duty to ensure that children and young people are given a chance to voice their opinions on what an experience has been like for them and what support they have found to be helpful. From their professional training on working with children with additional needs, EPs are skilled at not only eliciting the views of children and young people through a variety of media and making sure children’s voices are heard but also in taking on the role of advocate for these children.

2.6.2 Parents

Research indicates that parents of children with brain injuries rate teachers and professionals as being more important in terms of support than family members (Waaland et al. 1993, cited in Middleton, 2001b). This implies a strong reliance of families on good support from professionals. With regard to what type of information parents need and value, it is suggested that information about procedures in terms of getting their child extra help in school and information about national and local support groups is most important (Kreutzer et al., 1994). It has also been reported that when professionals are unsure of the outcomes for the child, parents find it more useful for the professionals to admit to the problems in predicting the future for the child and give the parent time to talk about the uncertainties (Middleton, 2001b).

The following are the reported needs that parents rate as most likely to be unmet (Armstrong & Kerns, 2002):

- health/medical information;
- professional support;
- community support networks;
- involvement in their child’s care.

Their research indicates that when compared to control groups made up of parents with children with other medical needs (children with diabetes and orthopaedically injured children) parents of children with TBI have fewer needs met. Interestingly, this study highlighted how an information support group actually increased parents’ anxiety and depressive symptoms but how a stress management support group decreased the parents’ anxiety and depressive symptoms. The authors state that their study indicates that 'effective intervention methods cannot be designed solely on the medical community's perspective of family needs' (p. 149). This research emphasises the importance of exploring the parents' perspective and subsequently supporting parents in a way that works for them. It also highlights that by simply providing more information to parents, their needs will not be met. Support needs to involve more than just information for parents' anxiety and depressive symptoms to decrease.

In a qualitative US study with parents of children with TBI, the following was reported as causing the highest levels of distress: concerns about school performance, anger management, apathy, social interactions and isolation and fears about the future implications (Prigatano & Gray, 2007). Quotes from the parents indicated feelings of anxiety, guilt, depression, anger and uncertainty.

Qualitative research which asked families of children with disabilities about what makes a family with a disabled child stronger was recently conducted (Contact-a-Family, Bennett, 2009). The main barriers that stand in the way of families were identified as: lack of services; attitudes towards disability; and, a lack of support from professionals. The biggest priorities for families for making them stronger were identified as: more opportunities to enjoy play and leisure time; a choice in the activities they take part in; seeing their child reach their full potential; a support package to meet their child's needs; and, regular short breaks.

Upon further analysis, results of the research showed that over 60% of families of families reported having a 'poor' or 'unsatisfactory' experience of being listened to by professionals. The authors suggested that the comments reflect the families' frustrations about professionals failing to understand their (the parents') expertise in knowing and understanding the child's condition. The survey adds that it was clear from the parents that they were not just frustrated by health professionals but also professionals from education and social care. It is reported that parents felt that their children's needs were being dismissed because of their disabilities. One quote from a parent in particular is especially relevant:

> *"We have to fight for all our requirements including suitable arrangements for my brain damaged child. There are barriers after*

> *barriers to overcome and no respite at all to speak of. Action is required to stop family break-ups".*

Promotion of family functioning should be of high importance for professionals when working with families with a child with ABI given its role in moderating outcomes for the child (as previously discussed). Some researchers have gone as far as reporting that family functioning may have a larger impact on the child's functioning than the severity of the head injury itself (Armstrong & Kerns, 2002).

2.7 The experiences and perspectives of education professionals

"The main support is what the school will do…but they don't know how to do it", Prof. Robert Butler (2011b).

2.7.1 Teachers

Schools are the primary service providers for children following an ABI (McCusker, 2005). Classroom teachers spend the most amount of time in contact with a brain injured student within the educational setting (Jantz & Coulter, 2007). Therefore, it is important for school and educational staff to understand the needs of children with ABI and to be able to take into consideration the possible physical, emotional, behavioural, cognitive and social outcomes of ABI. This view is supported by research which highlights that a specific unmet need of parents of children with TBI is the desire to have their child's teachers and peers understand their child's problems (Armstrong & Kerns, 2002).

The Department for Education and Employment [DfEE] (1994, as cited in Rees & Skidmore, 2008a, p. 88) wrote that 'mainstream schools and, indeed, many educational psychologists are unlikely to be knowledgeable about the special problems involved in recovery from a serious illness or injury. In particular, even the most skilled mainstream teacher who has had no previous experience of teaching a brain injured child will need advice on potential changes'. It would be valuable to learn if this has changed, and, if not, would education professionals such as teachers and educational psychologists value additional training. Fourteen years later the following warning was given:

‘classroom teachers, unfamiliar with the nature of brain injury impairment, may inadvertently overlook or misinterpret significant indicators of brain injury related deficits’ (Jantz & Coulter, 2007, p. 88).

Eiser (1993) suggested that it is common for teachers to not have the training or knowledge to equip them to work with children with chronic illnesses and disabilities and that ‘denial avoids the dissonance of feeling deskilled’. Indeed, just over ten years later, it was reported that 33% of teachers did not know about the child’s ABI and that not only is information not passed to schools from professionals but that knowledge is also not often transferred when the child changes class or school (Hawley et al., 2004). The same research also indicated that teachers are not aware of the long-term implications of ABI.

One suggested solution to this is for all teachers to access to a TBI (or in this case an ABI) specialist for consultation and suggested that teaching and behaviour management approaches may need to be reconsidered when working with a child with TBI (Ylvisaker et al., 2001). The reason given for this was that teachers, who are used to focusing on content, may find it uncomfortable to need to emphasise cognitive and executive functioning processes in the classroom. A video and booklet with teaching strategies for working with children with ABI has been developed for teachers to go some way towards tackling this issue (Walker, Wicks & Forsyth, 2003).

2.7.2 Educational Psychologists

Some US research has been conducted (Hooper, 2006) in regard to school psychologists knowledge of TBI. This study found that although education professionals such as school psychologists performed slightly better than the lay public in a survey about myths and misconceptions about TBI, they still held false views about TBI (Hooper only focused on TBI; the definition of ABI used in this study incorporates TBI as well as Non-Traumatic Brain Injury). This research supports previous research that suggested that both school staff and parents can have misconceptions about the consequences of brain injury in children (D’Amato & Rothlisberg, 1996). This research points out that even though there has been ‘federal legislation mandating the need for special education services for children identified under the TBI classification, few school psychologists are specifically trained in the various nuances of TBI' (p. 670). However, school psychologists in the US may play a critical role in facilitating the hospital-school re-entry despite a lack of knowledge in the area (Hooper, 2006).

Recent research in Northern Ireland, sought to outline the views on ABI of the lay public (Linden & Boylan, 2010). On a positive note, the study reported an increase in awareness about the challenges facing people with ABI. However, in general, there appeared to be a failure to note that ABI is a 'hidden disability' and most participants focused on outward manifestations of the injury. This supports the suggestion that those without appropriate training or experience in ABI may have misconceptions about ABI.

Additional training for professionals such as school psychologists who work directly with children with TBI in the US has been called for (Hooper, 2006) and it is suggested that additional training is also needed in the UK for educational psychologists, perhaps in terms of increased coverage of the topic in initial training or as a specialist option (Bozic & Morris, 2005). It has been suggested that TBI is an underdeveloped dimension of educational psychology delivery and that educational psychologists in 80% of their study's cases had little or no preparation for working with these type of issues (Bozic & Morris, 2005). This is worrying considering it was reported that in the majority of these cases, the educational psychologist was the most qualified educational professional involved and the only psychologist. It is claimed that training of this type for school-based psychologists 'may serve to lessen the secondary negative effects on a survivor on their re-entry into the educational setting…and improve the chances of school-based success' (Hooper, 2006, p. 181).

If the suggestions that increasing numbers of children are surviving injuries due to medical advances and therefore returning to school are accurate, it is likely that ABI is becoming more prevalent. The increasing prevalence of ABI and potential fundamental role EPs can play in promoting best outcomes for children with ABI indicates that training on this topic could be of benefit for EPs.

Educational psychologists are well-placed to be part of the improved knowledge base given their experience and practice in providing INSET to schools, their ability to work systemically, their focus in inclusion and through their direct involvement with children, teachers and families. It has been suggested that in-service training should be received by teachers and staff members (Steensma, 1992) but it could also be helpful to provide advice and support for parent and family groups. Ylvisaker et al. (2001, p. 80) suggest (albeit for TBI but also relevant to ABI) that ‘because ability and behaviour profiles of students with TBI can be confusing, school staff, family members, and relevant community providers may need intensive training and counselling’. In this way, by improving the knowledge base of EPs in the area of ABI, EPs could promote better outcomes for children with ABI in their school and family settings.

2.7.3 The unique role of the EP

It is proposed that ‘educational psychologists are in a unique position to help school staff address the needs of this population’ (BPS, 2006, p. 8). This is especially true given that children with TBI (and probably ABI) are likely to be in state schools without specialist neuropsychological support (Bozic & Morris, 2005). EPs could play a key role for the following reasons:

- **EPs are well-placed in the child’s system**

EPs are well placed to liaise between hospital and school given their close links with and understanding of psychology and school contexts. In this way, it is possible that EPs could ‘influence events at most of the levels within the ecological-transactional model’ as proposed by Bozic and Morris (2005, p. 114). EPs also have an overview of schools in their local authority and are well placed to support the parents in making decisions on school placements as well as providing expert advice about the child’s needs and strengths. They are also well-placed to run school INSET for school staff and support the school in educating children about disability and ABI (as recommended by CBIT, 2005).

There is also an argument that EPs could play a role in the prevention of ABI, for example, through psycho-education for parents and schools and identifying and working with families who are most at-risk. Parslow et al. (2005) suggest that targets for community based injury prevention are indicated by the late afternoon and summer peak in injury occurrence for 0-10 year olds. An early prevention strategy is currently in place in one particular US state, in that new mothers reportedly must watch a video about the prevention of child-abuse TBI (Dias et al., 2005, as cited in Donders, 2011b). This has reportedly led to a decrease in TBI cases in that area of the US. Other preventative work could be done on the importance of wearing safety-belts on transport, wearing bicycle helmets properly and ensuring sports concussion rules are followed in schools and communities (Donders, 2011b).

- **EPs can liaise between health and education**

The BPS (2006, p. 9) highlights that ‘EPs with expertise in children with acquired brain injury are required to translate the knowledge and advice from neuropsychological assessment into practical rehabilitation programmes within education. Lack of appropriate educational psychology resources will result in suboptimal rehabilitation provision within schools’.

It has been suggested in the US too that ‘ideally, a school psychologist and a hospital neuropsychologist will collaborate in a comprehensive psychological or neuropsychological evaluation prior to school re-entry’ (Foster Tucker & Colson, 1992, p.200). The advantage of the liaison of the neuropsychologist and the EP is that the neuropsychologist can explain to the EP the extent of the neuropsychological impacts of the head injury and the EP can interpret how these impacts could affect the child’s ability to access the curriculum and how the school environment could adapt to enable the child to be included to achieve. As the school EP, the EP is then ideally placed, being a regular visitor to the school, to monitor the child’s progress and the support the school in meeting the child’s needs. Children with an ABI can have a changing profile of needs which creates a need for regular monitoring and reviewing for the best outcomes to be achieved.

- **EPs are skilled in flexible approaches to assessment**

Although, there is currently ‘no mechanism in our mainstream education system at present for assessing the progress of children returning after brain injury’ (Tomlin et al., 2002, p. 836), ‘there are a few ‘hard’ guidelines regarding the neuropsychological assessment of children with TBI’ (Hunter & Donders, 2007, p.98). However, it is warned that *"psychology can make the mistake of too many cognitive assessments and forgetting the social and emotional adjustment"*" (Donders, 2011a). This issue could be addressed through the skills of the EP. EPs are skilled and flexible in their approach to assessment. It has been suggested that school psychologists (or EPs in the UK) may need to adjust their usual assessment procedures to accommodate the changes of the child as well as taking into account that the student does not exist in isolation from his or her environment (D'Amato & Rothlisberg, 1996). Also, Prigatano (2011b) proposes that the cardinal sin of assessment with children with TBI is said to be using a *"test for adults scaled down for children"* and that *"assessment of function in TBI"* is less a case of proving brain injury than of translating that medical condition into educational services and pointed out that the school psychologist could be the logical person to liaise with medical and educational staff. A particular warning has been given to EPs relating to 'cultural values and practices that encourage greater levels of financial and professional investment in forensic process than formative assessment for intervention' (Bozic & Morris, 2005, P. 113).

In terms of assessment, it is argued that psychologists should be equally concerned about emotional functioning and that it is important to ask the parents for their perspective on this as they know their child best (Prigatano, 2011b). He purports that it is crucial to look at a child's 'dynamic behaviour' instead of being 'locked' into a model that asserts that *"if a number is attached to it, it's important*", and then goes as far as to say that to rely solely on such quantitative assessments is dangerous when working with human beings. For example, EPs are increasingly using methods such as Dynamic Assessment [DA] which refers to 'an assessment of thinking, perception, learning, and problem-solving by an active teaching process aimed at modifying cognitive functioning'. (Tzuriel, 2001, p.6) The use of DA rather than standardised assessment is particularly relevant to children with ABI as DA focuses on how the child learns instead of what the child knows. Currently, training courses in the UK do educate trainee EPs in DA which means EPs are increasingly skilled and flexible in their approach to assessment and are, therefore, well-placed and appropriately skilled to work with children with ABI.

Doing a standardised assessment with a child with ABI could lead to misleading results as children with an injury can show reasonable levels of knowledge and academic skill but have significant difficulty learning and acquiring new knowledge and skill, and effectively regulating behaviour in unstructured or stressful contexts (Ylvisaker et al., 2001). They suggest that neuropsychological training could be offered to school psychologists through workshops and customised training materials and/or including, in the training of school psychologists, information on brain injury (Ylvisaker et al., 2001). They also suggest that the validity of standardised assessments for use with certain disability groups should be questioned, and instead, school psychologists 'should be trained to collaborate with educators in contextualised, experimental assessment of students' needs for purposes in formulating an effective intervention plan' (p. 82).

The importance of asking the child and family about what a typical day is like for them and how the issues that the child and family face impact on their daily life is a recently emphasised approach (Prigatano, 2011b). It is also suggested that standardised rating scales can be used to measure this aspects through questions (directed at parents) such as 'what level of distress do you experience when caring for your child' and 'what understanding does your child have of his difficulties'. In terms of working with the child, Prigatano (2011b) emphasises the importance of asking the child questions such as 'what was most fun', 'what didn't you like' (as this can show whether the child has any insight), 'did anything happen today that surprised you', as well as the importance of going through the test materials with parents and giving the child feedback so that the child understands why they were tested. This humanistic approach to assessment provides additional information to assessments purely based on numbers. He calls this type of assessment a 'comprehensive' assessment as it allows for child's brain-behaviour relationships to be approached *"within the context of the complexity of the child's personal and social situation"* (Prigatano, 2011b). As well as this, comparing pre-injury school records should be a required part of the assessment (Donders, 2011a). This is something that EPs have access to and routinely look at and can make sense of.

- **EPs are skilled at working in multidisciplinary teams**

The management of the transition from hospital to school can have a profound impact on the child's development and without an effective transition that supports children in gaining understanding of their needs, it is warned that 'they may build up a wall of denial and defensive behaviours to cope...this may become as debilitating as the injury itself' (Steensma, 1992, p. 208). This supports earlier research claims that difficulties in adjustment following failure upon return to school after hospitalisation can lead to children with brain injury running the risk of developing psychiatric problems (Brown et al., 1981, as cited in Scrutton, 1999). It has been reported that ‘a team approach’ and ‘good communication’ are pivotal points to success of re-entry into education for children with head injuries by Tomlin et al. (2002, p. 828) from their reading of research by Clark (1996).

In summary, EPs appear to be well-placed, appropriately skilled and have previous relevant experience in working in multi-agency teams, key skills to bring about positive change for children and young people with ABI.

2.8 Aims and objectives of the current study

As highlighted in Chapter One, the overall aim of the current study is to explore the real-life experiences of children with ABI and the ensuing educational support from the perspectives of the children with ABI, parents, teachers and educational psychologists. Qualitative methods that value each individual’s personal experience will be used. The focus will be on each group's response to the ABI, which aspects of the transition and educational support they found most helpful and any recommendations for the future they would like to make. Additionally, teachers and educational psychologists will be asked about their experience of ABI before working with a child with ABI, their professional training and support, and any recommendations for other professionals working with ABI. Through this, the current study aims to inform future EP practice, to improve outcomes for children with ABI.

2.9 Research questions

The current study has two main foci. They will be explored in the context of one London local authority:

1. What characterises the experiences of children with ABI and key adults in their lives, in home and educational settings? [RQ1]

2. What type of support has been experienced by those affected by ABI in home and educational settings, and what type of support should be implemented in the future, particularly in relation to the EP role? [RQ2]

Chapter Three - Methodology

The following chapter firstly outlines the context in which the current study was undertaken. It then explains how the data collection was considered and approached and how the resulting data were analysed with regard to the research questions and objectives.

3.1 Context of research

3.1.1 Epistemological and ontological considerations

At the beginning of the research process, taking a pragmatic approach, the following question was considered: 'what method will support the exploratory nature of these particular research questions and what is it that they are trying to explore?'

My research questions sought to explore the phenomena of those affected most by a child with ABI and their interpretations of their experiences. *"First class data"* has been described as data that *"allows you to understand something you didn't understand before and that you can translate into care"* (Prigatano, 2011b). To gain insight from a number of perspectives, e.g. the child, the parents, the teachers and the EPs, on how this phenomenon has affected their lives, the current study implemented qualitative methods to data collection and took a social contructivist approach to the data analysis, based on the process described by Braun and Clarke (2006) (this is described in detail in section 3.5). Constructivism 'describes knowledge not as truths to be transmitted or discovered, but as emergent, developmental, non-objective, viable constructed explanations by humans engaged in meaning-making in cultural and social communities of discourse' (Fosnot, 2005, p. ix). It considers the person 'as having an active role in the creation of their experience' and acknowledges that 'each person perceives the world differently and creates their own meaning from events' (Burr, 2003, p.19). A relativist approach, ontologically speaking, was decided on as the most suitable way to design and analyse this research topic. Relativism acknowledges the multiplicity of interpretations of the world (Willig, 2001). This research was considered a process, with the researcher in the role of 'constructor' rather than 'discoverer' (Willig, 2001).

The majority of previous research on ABI has used quantitative methods, such as assessment, surveys and questionnaires, and a positivist perspective has been applied in the design and analysis of the data collected. A positivist approach purports that 'there is a straightforward relationship between the world and our perception and understanding of it' (Willig, 2001, p. 3). This perspective implies that there is a 'truth' that research can 'discover'. Qualitative methods, such as thematic analysis, can be carried out based upon a positivist view of the world, however, for the purpose of this research, a qualitative method aligned with social constructivism and relativism, as previously described, was employed. This approach emphasises the way in which each individual makes sense of the world as well as the language that they use to describe it and takes this as reality for that individual. This research aims to fill a gap in the literature as the methods used and approach taken are in contrast to much of the existing literature on the perspectives of those who have been affected by ABI.

3.1.2 Reflexive analysis

It was acknowledged that the researcher's previous training, life experience and epistemological and ontological approaches could influence the data collection process and analysis (Yardley, 2003). Steps were taken to minimise researcher effects on interviews, as researcher effects cannot be eliminated only controlled (Breakwell, Hammond, Fife-Shaw & Smith, 2006). This was minimised by giving interviewees equal time to respond, limiting interpersonal responses, ensuring all interviews took place in quiet settings with reduced chance for disruption and keeping to the interview schedule order of questions and to question wordings. In terms of the data analysis process, assumptions and influences were minimised through professional supervision which involved inter-rater analysis and tentative coding which lead to evolving conceptualisations and data themes. Peer supervision which involved the checking of transcription, coding and links to themes, was employed meaning that the data analysis process was subjected to rigorous scrutiny at each stage of the evolution from transcription to final themes and subthemes (see section 3.2.7 on reliability and validity for more detail). Codes and subsequent themes were developed using an inductive method from the data, i.e. the codes and themes are data-driven. This method influenced the resulting data, and is likely to have resulted in different data than would have been presented if a deductive, or theory-driven, method had been used (see

Boyatzis, 1998). It is assumed that the findings of the current study would not be exactly replicated in another context, with different participants or if analysed by another researcher. However, by capturing the experiences of this study's participants, this information could be helpful when working with similar participants in other contexts (Yardley, 2003).

3.1.3 Ethical considerations

This research was carried out under the ethical guidelines of the British Psychological Society. Ethical approval was gained from the Departmental Ethics Committee at the Department of Psychology and Human Development at the Institute of Education, University of London.

3.2 Design

3.2.1 Settings

In the design of the study, it was considered that the context in which the interviews took place could affect the interviewees. Hence, parents were given the choice of the child's school, a meeting room in the building in which Educational Psychology is based or their own home. All of the children and parents chose to be interviewed in their own home. All of teachers chose to be interviewed at their school. All of the EPs were interviewed at their work base.

3.2.2 Sampling

This is a qualitative study; therefore, due to the amount of rich, in-depth data that was generated from each participant, it was appropriate to have a small number of participants in each dataset. This takes into consideration the 'time-cost factor' of qualitative data collection and analysis.

In terms of choosing participants, issues of efficacy, efficiency and ethics were considered (see Boyatzis, 1998). To be a potential participant, children had to have experienced an ABI as set out by the definition of the current study, as well as the following: the injury must have occurred in the past four years; and, they must be currently attending a mainstream school, or a unit within a mainstream school. Parent participants had to have parental responsibility and live permanently with a child who met the above criteria. Teacher participants had to be currently teaching, or have taught in the past three years a child with ABI who had returned to mainstream school or a unit within a mainstream school. EP participants had to have worked with a child with ABI within the past five years who had returned to a mainstream school or a unit within a mainstream school.

The intention of the study was to employ a ‘purposeful sampling’ strategy, i.e. participants selected due to particular characteristics (Patton, 1990). To identify potential child participants, a number of methods were attempted. Firstly, the SEN department of the borough conducted a search on their database. Search words included ‘acquired brain injury’, ‘brain injury’, and ‘head injury’ but no children were identified through this process. It was realised then that no data is currently held in Children’s Services in the LA with regard to the number of children living in the locality or attending local schools who have experienced an ABI.

Next, the Head of Therapies in the local Primary Care Trust was consulted to enquire as to whether Health Services had any records of children in the LA who have an ABI. However, although it was noted that they had three children on record that fit the research criteria, due to information-sharing difficulties between Health and Education, in accordance with the Data Protection Act (1998), no information was subsequently provided. The researcher was told that the participant information packs were sent to the parents of these three children but no participants were recruited in this way.

As neither of the above methods proved fruitful, the sampling strategy became ‘opportunistic sampling’, i.e. pursuing new leads during research development, being flexible and taking advantage of the unexpected opportunities (Patton, 1990). The researcher asked, at an Educational Psychology Professional team meeting if any of the EPs knew of any children, parents, teachers or EPs who fit the participant criteria. Emails were also sent out to each school in the borough asking if they knew of potential participants. These methods provided the researcher with all of the participants who took part in this study.

The sample of each of the four datasets allowed for rich data of personal experiences to be collected. In total, thirty-seven interviews took place, which is a large sample size for a qualitative study.

3.2.3 Participant recruitment

- Children and parents

Due to information sharing restrictions, each professional who believed they knew of a child who fit the criteria first contacted the parent to request permission to provide the child and family's details for the research purposes. Nine parents were approached and all of the parents agreed to participate in the research. These parents were then sent, via post, the following materials:

- an introductory letter;
- an information leaflet;
- an audio-visual CD for children containing information on the research;
- an adult consent form;
- a child consent form.

If parents did not contact the researcher within three weeks, the researcher contacted the parents to make arrangements for an interview date. All of the nine parents who were sent the information pack agreed to take part in the research and none dropped out. Of these nine parents, six parents agreed for their child to be interviewed for the research. Reasons for refusal provided by parents included: the parents believing that the child was too young; the parents felt that it was inappropriate for a stranger to ask their child questions about their injury; and, that they felt that their child did not fully understand what had happened as they had not yet explained it to the child. However, the parents who agreed to their child's participation indicated that they were glad that their child would be able to speak out about their experience of what had happened to them and felt that it was important that their child's opinion to be included in the research. Of the six children approached to take part in the research, all six consented to be interviewed (please see section 3.3.4 Consent and Information for further details).

None of the children or parents who were interviewed dropped out of the research process.

- Teachers

Potential teacher participants were identified by EPs in the LA who knew of a child with ABI who had attended the teacher's school. EPs provided the name of the child's school and the researcher called the school and asked if the teacher of the child would like to participate in the research. The parents of the children with ABI were asked permission for the researcher to interview the child's teacher before the interview took place. The teachers who participated were given the information leaflet before the interview. All nine teachers approached consented to be interviewed. Eight out of nine of the teachers were teachers of the child discussed in the parent interviews. One parent did not consent for the teacher to be interviewed as she felt that she had such a bad relationship with the school that it was inappropriate. The eight parents who consented all indicated that they thought it was a good idea for the school's perspective to be heard and included in the research. None of the teachers approached and interviewed dropped out of the research process.

- Educational Psychologists

At a Professional Team Meeting, all EPs in the LA were asked if they had had involvement with a child who met the criteria for the current study's definition of ABI. If they had, EPs were asked if they were willing to participate in a semi-structured interview for the purpose of the research. EPs were given the information leaflet before the interview. All of the thirteen EPs consented to be interviewed and none dropped out of the interview process.

All interviews were carried out from May 2010 to October 2010. These interviews were then analysed in separate thematic analysis datasets. However, although each interview highlighted the unique individual experience of the each participant, definite common themes could be identified across the datasets. RQ1 will be answered according to these common cross dataset themes.

Notably, the main difficulties in participant recruitment lay in the identification process. It was difficult to find and access any database which identified the people in the LA who had been affected by ABI or whether there were any children in the LA who had experienced ABI. However, once this difficulty was overcome, there was 100% take-up from identified potential participants, giving strong indication that this population is eager to have its voice heard. In total, the sample included thirty-seven participants, which are divided into four distinct datasets: children with ABI (n=6); parents (n=9); teachers (n=9); and EPs (n=13).

3.2.4 Semi-structured interviews

Semi-structured interviews were deemed the most appropriate form of data collection for the purpose of this research as they allow for the exploration of individual views (Marshall & Rossman, 1995). They are ‘unavoidably interactional and constructive’ (Silverman, 2010, p. 152) and therefore married well with my epistemological and ontological stances of constructivism and relativism respectively. In this way, semi-structured interviews provide the researcher with greater flexibility to follow up poignant responses of interviewees and are especially appropriate when discussing a topic of a personal and/or complex nature (Smith, Harre & Langenhove, 2005), which ABI certainly is. This method of data collection is advantageous as it is ‘open-ended and flexible enough to facilitate the emergence of new and unanticipated categories of meaning and experience’ (Willig, 2001, p. 15).

Specifically designed semi-structured interview schedules were prepared for each dataset in this research. Interview questions were in-part theory-driven and were made up of the most common and consistent issues identified in the literature review. The design of the interviews was discussed with academic and EP supervisors and both provided helpful recommendations and adjustments before the finished interviews were piloted.

Semi-structured interviews were used with all participants. The semi-structured interviews cover the same topics, i.e. before the ABI, after the ABI, the affect on the child, the affect on the family, the experience of the transition from hospital and the return to school, although the semi-structured interviews for teachers and educational psychologists included an additional topic on experience, training and support.

Careful planning was ensured for the children's semi-structured interviews (see suggestions of Boylan, Linden & Alderdice, 2009). For example, prompt pictures and cards were used during the interviews with the children. This method was previously been used successfully by the CBIT (2010).

Rating scales were used in some parts to structure questions.

3.2.5 Pilot

A pilot interview was carried out for each dataset. This was to ensure that all interviews were as clear, understandable and appropriate as possible. Subsequently, a few adjustments were made to the interview schedules, e.g. the question 'is there anything that you felt poorly prepared for?' was deleted from the teachers' interview schedule, and scaling questions were introduced to provide comparison measures. For example, in the EPs' interview schedule, the question 'how confident did you feel about working with a child with ABI?' was rephrased to 'how confident were you on a scale of one to ten about your ability to meet the child's needs compared with other children you have had involvement with?'

3.2.6 Other preparatory work

Careful planning and preparation was put into the information media that were developed to inform parents and children about the research. For example, the information for parents was presented clearly in an introductory letter as well as an information sheet, whereas for the children a visuo-audio CD was provided. Given that the level of the each child's ability could not be known to the researcher before sending out the information pack, it was attempted for the CD to be as accessible as possible for a wide-range of needs. For example, a slide-show was created on which each page a different aspect of the research was addressed. Simple, clear pictures were included on each page accompanied by large font text. Each page also had a icon that could be clicked that would activate the audio-text which corresponded directly to the visual text.

Details were given at the end of the slideshow on how to contact the researcher using a variety of communication media.

3.2.7 Reliability and validity

Reliability is typically referred to as ‘the consistency or stability of a measure; for example, if it were to be repeated, would the same result be obtained?’ (Robson, 2002, p. 93). Reliability is a borrowed word from quantitative research. In qualitative research, due to its focus on individual experiences and meanings and use of words rather than numbers, it has been proposed that the word ‘dependability’ is more appropriate (Guba & Lincoln, 1989; Mertens, 2010). Therefore ‘dependability’ (rather than ‘reliability’) can be an indicator of the quality of the data collection that ‘can be determined by a means of a dependability audit in which the change process can be inspected to attest to the quality and appropriateness of the inquiry process’ (Mertens, 2010, p. 259). Dependability in the current study was enhanced by recording each interview, closely followed by a verbatim transcription of each interview (all carried out by the researcher). A recheck of the transcriptions was then conducted by playing the recording aloud while re-reading the interview transcription, and using a peer-reviewed thematic analysis coding process as outlined by Braun and Clarke (2006) (please see section 3.5 Data Analysis). A ‘paper trail’ (see Marks & Yardley, 2008, p. 16) of how this process evolved through the structured stages of analysis can be requested.

Validity can be described as ‘the degree to which it (the research in question) is accepted as sound, legitimate and authoritative by people with an interest in research findings’ (Yardley, 2008, p. 235). Again, similar to the term ‘reliability’, ‘validity’ is also a borrowed term from quantitative psychology. ‘Credibility’ has been proposed as a more appropriate term when employing qualitative methods (Guba & Lincoln, 1989; Mertens, 2010), especially when a constructivist approach is taken. To ensure credibility (or validity) was strived for in the current study, the core principles for evaluating the validity of qualitative psychology were considered including: sensitivity to context; commitment and rigour; coherence and transparency; and, impact and importance (Yardley, 2000). For example, an ‘inter-rater comparison’ was carried out in professional supervision with an experienced researcher on 100% of the interview data and together the data were analysed according to the Braun and Clarke (2006) thematic analysis process. There, all potential codes were discussed with an experienced researcher who was familiar with the research data and all potential themes were then reviewed, amended, and discussed with the experienced researcher before themes and subthemes were finalised.

3.3 Procedure

3.3.1 Interviewing

The researcher was aware of the need to be flexible in her approach to the interviewing of the children due to their range of needs and, consequently, in terms of the questions asked, the aids used, the consent forms, the explanation of the research. The researcher had in mind that conducting research with children is not necessarily the same or different to adults but instead reflects a continuum along which one can move back or forth depending on a number of factors (Punch, 2002) such as the individual child, the type and severity of ABI, previous experience and relationships with adults, the setting, and the time of day.

The current study aimed to also elicit the views of children with ABI through conducting interviews with the child with an ABI. The guidelines (Lewis & Porter, 2004) around informed consent, confidentiality, feedback, communication and methods were taken into consideration.

All interviews were recorded using a portable electronic device and all interviews were subsequently stored on the researcher's computer system, under a double password. A practice recording period was conducted with each interview to put the participant at ease with the recording device.

After each interview, each participant was given a verbal 'post-interview debrief', as well as a written version of this information (see appendix XI) to explain the next steps of the research process and to provide further helpful information. Any questions that participants had were answered. Parents were offered an information pack from the CBIT, which could be arranged by the researcher.

Interviews with parents, teachers and educational psychologists varied in length, from 25 minutes to 1 hour, and were on average 45 minutes. Child and young person interviews were shorter and on average lasted fifteen minutes.

3.3.2 Transcription

Each interview was transcribed by the researcher from the electronic recording. After the transcription of each recording, transcriptions were re-read while listening to the interview recording to allow for amendments and any adjustments and additions to be made to the transcripts. Interviews were transcribed as close to verbatim as possible in effort to produce ‘orthographic’ transcriptions (see Poland, 2002). Consistency of transcription was ensured as all transcripts were transcribed by the researcher and a dual transcription analysis was carried out, i.e. a small percentage of each dataset were checked independent by an independent researcher.

3.3.3 Confidentiality

It was explained to all participants that participation in the research was on a voluntary basis and that the research was part of my doctoral thesis. Participants were assured that they could stop the interview at any time, without having to give a reason for doing so if desired. Participants understood that any information shared with the researcher would be confidential and would only be shared with my research supervisors. All hard data was stored in a locked cupboard in the borough and all electronic data was only accessible through a double password system on the researcher’s computer. This is in accordance with the Data Protection Act (1998). The interviews will be destroyed once the thesis examination process is complete.

3.3.4 Consent and information

All participants, including children, signed a consent form provided. The children’s consent form was adapted to support the child’s understanding, e.g. the inclusion of a happy face for agreement to consent and a sad face for no consent.

It was ensured that all participants understood the purpose of the research and were given an outline of what to expect if and when they participated in the research. An information leaflet was given to parents, teachers and educational psychologists to provide this information. An audio-visual child-friendly CD was provided for children. Before each child interview, I presented the audio-visual slideshow to the child again. In this way informed consent was strived for.

3.4 Data analysis

The data corpus is comprised of four datasets: children's interviews; parents' interviews; teachers' interviews; and, educational psychologists' interviews. A thematic analysis was carried out on each dataset. Thematic analysis is a 'process for encoding qualitative information' (Boyatzis, 1998, p. vi). This method of analysis was chosen as the most appropriate due to its many advantages including the flexibility of the method, i.e. it is not tied to a particular epistemological perspective, it can highlight differences and similarities across the dataset, it can generate unanticipated thoughts and it can be helpful when thinking about policy development (Braun & Clarke, 2006).

The following is a summary of *how* the thematic analysis was conducted, based on the phases recommended by Braun and Clarke (2006). The process described was used consistently across all four datasets but the recursive nature of this process should be noted.

Phase 1 – Familiarization with the data

As the researcher was actively involved in the all of the data collection and subsequent transcriptions, this phase commenced at the moment of the first instance of data collection. It was at this point that the researcher first began to form ideas for potential themes of the data. As a result, the researcher began the 're-reading' process with initial thoughts and ideas about the data. This 're-reading' process involved reading all the printed transcripts twice; the first time while playing the recording of the transcription to ensure the meaning of the words was accurately understood and noted, e.g. editing of punctuation (see Poland, 2002). This commenced as soon as all transcriptions were complete. This was a lengthy process, and, upon the second reading, notes were taken that were to inform coding development and all relevant and interesting data extracts, i.e. textual quotes, were identified through the use of coloured ‘post it’ notes.

Phase 2 - Generating initial codes

All the data extracts were then given initial codes, and according to these codes, organised into meaningful groupings, i.e. all data extracts were collated and those with similar codes were put together. Codes were simple descriptions of the data, and are therefore different to themes in that they have a narrower scope. Codes were primarily data-driven although it is acknowledged that the interviews were in-part, theory-driven. The coding process was carried out manually and aided by the use of ‘post-it’ notes which allowed for the researcher to manually group data extracts. Dual researcher coding analysis was employed to ensure that coded groupings were reflective of the data extracts and to ensure that all the data extracts under each code reflected the same type of information. Through this dual process, codes were edited, amalgamated and dismissed, until codes were agreed to be reflective of the overall dataset. However, when codes reflected data extracts from only one transcription, and deemed inappropriate to amalgamate with other codes, they were retained in order to reflect the diversity of experiences.

Phase 3 - Searching for themes

The focus of the analysis then shifted to arranging the codes into overarching themes. A theme is ‘a pattern found in the information that at the minimum describes and organizes possible observations or at the maximum interprets aspects of the phenomenon’ (Boyatzis, 1998, p. vii). Themes were identified at ‘the manifest level (directly observable in the information) or at the latent level (underlying the phenomenon) (see Boyatzis, 1998, p. vii). All coded data extracts were used in this process. Coloured ‘post-it’ notes provided visual representations of the codes that could be manually manipulated and easily edited. All of the codes generated over-arching themes, themes and subthemes and no data was excluded at this point. In supervision with an experienced researcher, to ensure inter-coder reliability, themes and subthemes were edited, amalgamated and dismissed until it was agreed that the themes represented an accurate reflection of the codes and the data extracts. These over-arching themes, themes and subthemes were visually represented on an electronic thematic maps.

Phase 4 – Reviewing the themes

In this phase, over-arching themes, themes and subthemes were refined. All were combed to ensure that there was enough data to support them, or, when too much diverse data was found under one theme, themes were broken down further. Internal homogeneity and external homogeneity (see Patton, 1990) was considered, respectively meaning that data under each theme was coherent and that there were distinct differences between the themes.

The data extracts under each theme and subtheme were then re-read to make certain that a coherent pattern had been formed. Next, themes were considered in terms of the whole dataset and adjusted accordingly to represent the meanings of the entire dataset. The electronic thematic mind-maps were then edited again.

Phase 5 – Defining and naming themes

Theme and subtheme names and definitions were edited to ensure clarity and transparency. In the children's dataset, two themes were indicated. In the parents' dataset, the teachers' dataset and the EP's dataset three themes were indicated respectively.

Phase 6 – Producing the report

The following chapter represents the final analysis of the four datasets using thematic analyses of the four datasets. The most vivid examples of data extracts have been included alongside the subthemes within the over-arching themes and themes. Each section is considered to 'tell a story' and will be reported on separately. However, themes that are pertinent across the datasets will be organised into an overall cross-dataset thematic map to aid coherence and discussion. This meta-analysis was constructed using the same thematic analysis process.

Chapter Four - Results

This chapter presents the results and findings from the data analysis described in Chapter Three. Firstly, a few pertinent points concerning the responses of participants and the interview process will be given. This will be followed by a detailed description of the overarching themes, themes and subthemes and the data extracts that support them. Each of the four datasets, i.e. child interviews, parent interviews, teacher interviews and EP interviews, were analysed separately and will be reported separately. Within each dataset, the summary data of the participants interviewed will be presented, followed a summary table of the dataset's over-arching themes and themes. Subsequently, the emergent sub-themes for each theme will be presented separately within the datasets. To summarise, some brief cross-data observations will be presented and overall themes identified.

While six of the parents interviewed were related to the children interviewed in the study, the teachers and EPs who were interviewed do not directly correspond to these, i.e. it was not possible to have complete datasets across the child, parent, teacher and EP interviews in order to present multiple case studies.

4.1 Preface

Evidence suggests wide-ranging and rarely discrete needs of children with ABI and the children in this sample also had various needs as a result of their ABI. All of these needs were considered complex and long-term. Although not a homogenous group, all of the children interviewed and discussed were considered to have experienced an ABI of some form as set out by the definition given at the beginning of this study. A variety of responses was given by participants in each dataset and perhaps this is reflective of the sample's heterogeneity. However, even though a wide range of responses were reported, clear, discrete themes still emerged in each of the datasets. These themes both emphasised previous findings in the literature, identified new perspectives and insights into the phenomenological experiences of the children and the keys adults in their lives, and highlighted how these experiences could be used to develop better support systems for children with ABI.

Interestingly, many of the EPs approached at the initial stages of data collection, responded to the request to be interviewed by saying that they had never worked with a child with ABI. Yet, when the definition of ABI was given, most of the EPs then realised that they were either currently working with a child with ABI or had done so in the recent past. Secondly, many of the teachers and EPs began their interviews by saying that they had not thought of the child they were discussing as any different to any other child with special needs. Nevertheless, during the course of the interviews, these same EPs and teachers all appeared to, upon reflection, identity unique aspects of working with a child with ABI, as well as conclude that if they worked again with a child with ABI, that they would do things differently than they had before.

In fact, many parents, teachers and EPs alluded to feeling that they had reflected and learned a lot through the process of participating in the research interview. For example, parents indicated that they had not had a chance to sit down with a professional to simply reflect on what had happened, think about their emotional responses to the ABI and formulate what could help them and their family move forward. Indeed, many of the parents (almost half) cried at some point in the interview, demonstrating their level of emotional involvement. That said no parent wished to discontinue or withdraw from the research. Conversely, all of the parents indicated after their interview that they were glad that someone was doing research on this topic and they all expressed gratitude for being given the opportunity to participate in a study which meant a lot to them and their family. Most of the parents reported that they hoped that the study could make a difference to the experiences of children and families who will experience ABI in the future. One parent indicated that she is now going to support her local hospital in working more successfully with parents who have a child with ABI.

Many of the teachers and EPs spoke about how their involvement with the child with ABI had been one of their more complex challenges of their careers. Most of the teachers and EPs indicated that the research interview had been a helpful process in that it allowed them time to reflect on ABI from the perspectives of the child and the parent, as well as the role of their own profession. Some of these educational professionals felt that having time to reflect was in itself a good support intervention for their professions, as many alluded to the pressures of time and capacity which does not often allow for practitioner reflection.

Firstly, these additional qualitative observations could indicate that many educational professionals are either not familiar with the term ABI or do not understand what it means. They could also indicate that educational professionals are not currently considering the unique additional needs that often come hand in hand with ABI. The absence of any specific training or professional information on ABI that is directed at teachers and EPs could contribute towards this. That said, there are best practice guidelines and BPS guidance but perhaps due to the low incidence of ABI in the general population, it is an often neglected area of professional development.

Secondly, the observations regarding the helpful nature of the interview process, indicating that giving key adults in the lives of children with ABI space and time to reflect on processes and their role, could in itself be a simple, cost-effective intervention.

Thirdly, all of the parents approached to participate in the study did so and none finished the interview early or withdrew consent (despite how emotional the interview became for them). At the end of their interviews, all participants expressed strong feelings about how important they thought the topic is. From these observations, it is clear that the parents of children with ABI are an important participant group who are eager for their voice to be heard and used to make a difference.

The next sections will now outline the findings from the semi-structured interviews for each dataset respectively.

4.2 Children's data

The following table summarises the relevant information on the child interviewees:

Child	Gender	Type of Injury	Age at Interview	Age at ABI	Interval between ABI and interview (months)	SEN register
1	Male	Brain haemorrhage	10:05	7:11	30	School Action +
2	Male	Brain tumour	15:04	13:01	15	Statement of SEN
3	Female	Road Traffic Accident	5:01	01:11	38	School Action +
4	Male	Playground Fall	8:02	06:05	21	Statement of SEN
5	Female	Chemical Poisoning	7:06	03:07	47	Statement of SEN
6	female	Stroke	14:10	14:00	10	School Action +

Table A. Summary of child participant details

In summary, six children were interviewed (n=6; range = 5 to 15 years; male to female ratio = 1:1; average interval between ABI and interview = 27 months; interval range between ABI and interview = 10-47 months). None of the children interviewed were known to have any SEN before their ABI but all were registered on their school's SEN register post-ABI. Three of the six, had been given a Statement of SEN since their ABI.

The following table is a summary of the overarching themes, themes and subthemes:

Over-arching theme	Themes	Sub-theme
Adaptation to change	Initial confusion and chaos	Appointments and pressure
		Physical and sensory adaptation
	Reorientation to school	Feeling lost
		The familiar feeling strange and different
	Challenges to learning	Accepting help
		Learning to learn again
		Fatigue
Protective factors	The role of the school	Responding to practical needs A positive environment
	The role of parents	Support for learning
		Emotional support
	Interactive support	Being asked what helps by professionals
	Self-help	Seeking help when needed
		Keeping positive

Table B. Over-arching themes, themes and subthemes of the thematic analysis on the children's data

4.2.1 Adaptation to change

Four of the children spoke of or indicated the need to adapt to changes, in terms of life routine, familiar experiences such as school suddenly seeming strange and new challenges to their learning, in their life post-ABI. Unfortunately, most of these changes were experienced in a negative way. However, for all except one, things had gradually improved.

4.2.1.1 Initial chaos and confusion

Sub-theme	Example quote
Appointments and pressure	“I was almost chaotic: going to school, then when I came home, going to hospital and then we didn’t get back ‘til later evening and then it was a rush to go to sleep and then get up the next day and do it again!” (Child 6)
Physical and sensory adaptation	“At first I struggled as I couldn’t see as well and it was hard to get around. I couldn’t remember the routes to get anywhere.” (Child 2)

These subthemes highlight how difficult life can be for these children in the period of transition back to school post-ABI in terms of the adjustment back to a ‘normal’ way of life alongside the pressure of continued professional input and familiarisation. Four of the children appeared to have good insight about this.

4.2.1.2 Disorientation

Sub-theme	Example quote
Feeling lost	“(at school) I feel scared sometimes…when I don’t know what’s going on…I feel dizzy…I don’t know where I am.” (Child 4)
The familiar feeling strange and different	“I didn’t really remember school much so I had to get used to it again.” (Child 1)

Although all of the children expressed positivity with regard to school in general, all of the children expressed similar views about how school seemed a strange and confusing place at first. They spoke about re-adapting to experiences that they knew should be familiar but were, when experienced post-ABI, confusing and anxiety-provoking. Few seemed to have had support with these issues and had to make their own personal adjustment.

4.2.1.3 Challenges to learning

Sub-theme	Example quote
Accepting help	“I had to get used to going back and having help, which I had never had before.” (Child 5)
Learning to learn again	“Nothing was easy, everything was difficult. I had to learn everything from the beginning again when I went back to school.” (Child 1)
Fatigue	“I was tired all the time.” (Child 3)

Three of the children had insight into how much learning as a process had changed for them since the ABI. Two of these children had been considered ‘high achievers’ pre-ABI and spoke about how it was a difficult adjustment for them to accept support at school which they had never previously needed. The three children with the most insight on learning indicated that they had to learn how to learn again and spoke about what a frustrating experience this had been for them.

4.2.2 Protective factors

All of the children frequently referred to protective factors which impacted on them post-ABI, such as their teachers and their assistants at school, the importance of being asked by the adults in their life for their perspectives on what helps, the supportive role of their parents and what they have done for themselves to get to where they are today.

4.2.2.1 The role of school

Sub-theme	Example quotes
Responding to practical needs	“The things that made the most difference to me were the scribe and the laptop because it helped a lot, especially when I first went to school because I couldn’t write and I got tired quickly.” (Child 6)
A positive environment	“Happy (points to a happy face), when I’m at school.” (Child 4) “I like school, we make things there.” (Child 3)

All six of the children indicated that they liked school and saw it as a positive part of their lives. They each, in various age-appropriate ways, showed that they appreciated school for providing helpful resources, e.g. a laptop in one particular case. Although, some difficult aspects of school were highlighted (see theme 2), all six children implied that they want to attend school.

4.2.2.2 The role of parents

Sub-theme	Example quote
Support for learning	"My mum helping me with learning has helped me get to this stage." (Child 1)
Emotional support	"You have to stick by your child no matter how hard it is. That's what my mum did and now things are going alright." (Child 2)

Five out of the six children expressed very positive views of their parents and spoke about how they had been supported by their parents throughout their ABI experience. The three eldest children appeared to have a lot of insight into how much their parents had done for them academically and emotionally, and made specific links between this parental support and better outcomes.

4.2.2.3 Interactive support

Sub-theme	Example quote
Being asked what helps by professionals	"Asking the young person if what they're doing is helpful or not, so they know if they can help or change things for them." (Child 2)

The three eldest children made reference to how much they appreciate being asked by professionals for their opinion about support and interventions. Each of these children named professionals that they had particularly liked, e.g. a teacher, an EP and a physiotherapist respectively, who had made a difference simply by asking the child what helps rather than imposing strategies on them.

4.2.2.4 Self-help

Sub-theme	Example quote
Seeking help when needed	"If you need something that you don't have, then ask. Ask your parents or teachers at school if you need to so steps can be taken so that it's possible for you to have it." (Child 6)
Keeping positive	"You have to keep your head up and don't let it get you down. I've done that before and it ruins your life." (Child 2)

The three eldest child interviewees, when asked about what has helped them get to this point, all emphasised the importance of asking adults for help. Also, each of these interviewees spoke about how important it is to stay optimistic about the future. One of the children in particular, spoke of how he had learned this the hard way and had realised that being negative did not help him move forward.

4.3 Parents' data

The following table summarises information on the parent interviewees:

Parent	Gender of child	Type of Injury	Age of child at interview	Age of child at ABI	Interval between ABI and interview (months)	SEN register
1	M	Brain tumour	04:08	1:06	34	Statement of SEN
2	Male	Brain haemorrhage	10:05	7:11	30	School Action +
3	Male	Brain tumour	15:04	13:01	27	Statement of SEN
4	Male	Brain tumour	7:03	6:09	6	Statement of SEN
5	Female	RTA	5:01	1:11	38	School Action +
6	Male	Fall	8:02	6:05	21	Statement of SEN
7	Female	Brain tumour	7:05	05:02	27	School Action +
8	Female	Chemical poisoning	07:06	03:07	47	Statement of SEN
9	Female	Stroke	14:10	14:00	10	School Action +

Table C. Summary of parent participant details

Nine children in total were discussed by nine individual parents respectively (n = 9; children's age range = 4-15; male to female ratio = 5:4; average interval between ABI and interview = 27 months; interval range between ABI and interview = 6-47 months). Seven out of the nine children discussed had experienced a non-traumatic brain injury, whereas the other two children had experienced a traumatic brain injury. Only one of the children was on their school's SEN register pre-ABI, due to a diagnosis of Asperger's syndrome. Post-ABI, the child's needs were amended on his Statement of SEN to more accurately reflect his 'new' needs related to his ABI. All children were on their school's SEN register post-ABI and five out of nine had Statements of SEN. Only two out of the nine parents indicated that there had been direct liaison between the hospital professionals and education professionals post-ABI and these two parents who had experienced liaison described it as satisfactory. In both of these cases, a paediatrician had liaised in meetings with the class teacher and the school EP. The other seven parents who did not experience liaison between health and education professionals all felt strongly that this should have taken place but admitted that they, as parent, ended up as the link person between the professionals (please see section 4.3.1.2 'Practical responses'). All of the nine parents interviewed felt that EPs had a role to play with children with ABI and that this role should be enhanced (please see section 4.3.3.1 'Educational psychology: The parents' experience').

The following table is a summary of the overarching themes, themes and subthemes:

Over-arching theme	Theme	Sub-theme
Adjusting to being the parent of a child with ABI	Emotional adjustment	Emotional impact on parents
		Uncertainty
		Isolation
		A sense of loss
	Practical responses	Being proactive
		Negotiating complex systems
		Parents as ‘lead professional’
The surrounding systems	Protective factors	Valuing professional support
		Multi-professional network
		Family
	Perceived responses of school	Lack of recognition of needs
		Individual needs
		Good relationship can lessen parental anxiety
	ABI as a unique and poorly understood SEN	Parents out of depth and confused
		Lack of professional understanding
		Not fitting into current SEN categories
Need for psychological and specialist support	Educational Psychology: the parents’ experience	Need for direct access to services
		Not knowing what support is available
		Valuing professional perspectives
	Specialist support	Long-term
		For the emotional trauma
		Parenting

Table D. Over-arching themes, themes and subthemes of the thematic analysis on the parents' data

4.3.1 Adjusting to being the parent of a child with ABI

Each parent alluded to coming to terms with having a child with ABI and the adjustments that had to be made in their lives. These adjustments ranged from emotional responses and how this affected the family to how the family had to proactively engage with professionals and take on new roles.

4.3.1.1 Emotional adjustment

Sub-theme	Example quote
Emotional impact on parents	"You do feel like giving up, you do. Not because you're a bad mother or a bad person, it's just the fact that every person has their own limit." (Parent 1) "Back then, I was so stressed I couldn't even clean my teeth." (Parent 4)
Uncertainty	"No one can ever tell me answers to my questions, like 'would she be like this if there was no accident?'." (Parent 5)
Isolation	"When you leave the hospital, you feel like you're on your own and when you arrive home, you don't know what to do. I didn't feel brave enough because there's no one else out there to help me. After you leave, you've still got lots of questions buzzing around in your brain and you think 'who do I ask, I can't ask the doctor as I'm not due to see him yet so who do I ask?'." (Parent 6)
A sense of loss	"Anyone who knows him says that he's a completely different kid, that they don't recognise him." (Parent 6)

All nine of the parents spoke about the uncertainty of outcomes that they faced when their child had the ABI, as well as the perpetual uncertainty that they must manage when trying to find out future outcomes for their children in terms of their functioning and ability. Seven out of the nine parents alluded to feelings of isolation when their child was discharged from the hospital and to feeling at a loss in terms of knowing who to contact to discuss next steps and support. The two parents that felt more positively supported after the hospital, felt this way as they had a professional who they could call to discuss any issues with at any time. Both of these parents reported that just knowing that there was someone at the end of the phone that they could contact if needed, allayed their anxieties, helped them manage their uncertainties and helped ward off feelings of isolation. Over half of the parents also expressed that they felt or feared that their child was a different child to the child they had before and spoke about their difficulties adjusting to the 'new version' of their child. For these parents who perceived their child in this way, feelings of loss and bereavement were common as they spoke of mourning for the child they used to have and the child that they had imagined their child could have been in the future.

4.3.1.2 Practical responses

Sub-theme	Example quote
Being proactive	"Don't ever feel that you can't ask a question. That has been fixated in my head. No matter how small it is, ask it. To be honest, it's sometimes those smaller niggling questions that got me very far." (Parent 1) "You will have to fight for it as it won't be there for you on a plate. You have to make lots of phone calls and lots of arranging and lots of sorting but it will be worth it in the long-run." (Parent 4)
Negotiating complex systems	"I've always had this feeling that it's been more fighting against the system than the system being there for us." (Parent 8) "I have worked in the public sector for a number of years so I know my way around the system and I had extreme difficulty. If I was somebody who wasn't literate, wasn't coherent and couldn't make a case for myself, God help that child. That's all I can say." (Parent 9)
Parents as 'lead professional'	"It was up to us to tell the school what had happened so they knew about it." (Parent 7)

Most of the parents expressed strong views about the necessity of being a proactive parent and 'fighting for their rights'. Most of the parents felt that in order for to receive support for their child or for anyone to listen, they had to push and push for it, as support and advice from professionals did not come otherwise. However, even the most proactive parents explained that finding their way through ‘the system’ was difficult, even for the parent who had worked in the public sector and thought that she understood the LA education processes. Most of the parents also felt that the responsibility lay with them to inform the school and the health and education professionals. For the parents that spoke about being the person ‘in the middle’ of the professionals, each of them found this an onerous task in terms of the practicalities involved, e.g. phone-calls, transport, and in terms of their understanding of the information that needed to be passed on to the school and the questions that were asked by professionals about recommendations from other professionals.

4.3.2 The surrounding systems

In more recent literature and research, there has been increasing emphasis on the systems that affect the child’s environment and how that impacts on their outcomes post-ABI. Not surprisingly, parents in the current study echoed their appreciation of both professional and family support and how this support, when it was there, has been vital to moving them and their child towards more positive outcomes.

4.3.2.1 Protective factors

Sub-theme	Example quote
Valuing professional support	Q. What has made the most difference to you and your family? “Having professionals who know what they are doing and offering helpful advice to me as a parent and to the school.” (Parent 3)
Multi-professional network	“The fact that I set up meetings and had them (professionals) present, I think it did make a difference in terms of getting some outcomes.” (Parent 9)
Family	“My main support came from my family. I guess I’m lucky in that I have lots of close family living nearby who have been able to call in and look after X if needed and have a chat. I’m really lucky like that.” (Parent 3)

All of the parents clearly valued any support they had from both health and education services. They particularly valued professionals who spoke to them about how to manage everyday issues at home and at school, and who took the time to work with the school on the identified issues. Although only a few parents experienced multi-professional meetings, those that did unanimously agreed that these meetings were useful as the professionals could talk to each other directly, put together a joint plan and consider all perspectives as opposed to having isolated targets and plans with many professionals that were unrelated to each other. A small number of the parents also spoke about the support of their family members and relatives. For these parents, the family members all lived close by and this provided an informal network of support. These were also the parents that reported feeling less isolated than other parents did (see section 4.3.1.1 ‘Emotional adjustment’).

4.3.2.2 Perceived responses of school

Sub-theme	Example quote
Lack of recognition of needs	“That’s been my general feeling with the school….well, she looks ok so she must be ok.” (Parent 9)
Individual needs	“I would like them to be proactive in terms of support and looking at the individual child’s needs rather than having a blanket idea in their head. It’s not one size fits all.” (Parent 9)
Good relationship can lessen parental anxiety	“The school, they seem nice and the people were manageable and they had experience of working with children in similar circumstances so that was a relief.” (Parent 8)

With regard to school, a wide variety of views were given. For approximately half of the parents interviewed, the parents reported that the child’s school did not have an understanding of their child’s ABI. These parents related this perceived lack of understanding to the school judging the child by their seemingly ‘normal’ physical appearance. These parents found it frustrating that their child’s needs were often overlooked as their child *seemed* ‘normal’. All of the parents felt strongly that professionals need to focus on their child’s individual needs and provide support and resources based on these unique needs. In contrast, the parents who reported a positive relationship with the school felt that this reduced their anxiety levels and had more positive views of their child's educational outcomes. This appeared to be linked to better attendance at school.

4.3.2.3 ABI as a unique and poorly understood SEN

Sub-theme	Example quote
Parents out of depth and confused	"I was in the middle. Whatever information I got from the hospital, I'd have to pass back to the school and vice-versa. I was still a bit confused about what was going on so I was thinking how can I explain to somebody else if I don't really know what's going on." (Parent 6)
Lack of professional understanding	"The social worker came and he saw…I never forget the report until now…All it said was that my house was clean and I looked well in the sense…clean, dressed well, whatever. I think what they found very hard, until now to understand is that they look at every child physically. I did say this to the social worker 'you only understand physical disability, you don't understand other disability. You say it's a disability team but you only understand physical disability.'." (Parent 1)
Not fitting into current SEN categories	"We were told that he doesn't fit the criteria. He never seems to fit any criteria. He is always in between. I think they need to broaden out the criteria, they can't just categorise people into severe disability, medium disability, etc. I think a lot of parents who have children who don't fit a category find this very hard because if you don't fit the professional's categories, you're lost and that child gets lost." (Parent 1)

Over half of the parents reported that they experienced confusion about their child's needs. These parents were often relied upon to take on a 'lead professional' role for their children in terms of liaising between hospital and school and passing information on. Due to the parents' confusion about their child's needs, this often left parents feeling bereft and uncertain about information, which in turn left the professionals they were liaising between uncertain and confused. Although many of the parents had met individual professionals who had been helpful and understanding, almost all of the parents had had at least one negative experience with a professional from health, education or social care. These negative experiences primarily stemmed from insensitive comments about the child's needs, either stating the child's outcomes too negatively or not acknowledging that the child has any additional needs at all. Again, from the parents' perspective, this was often linked to the child's physical appearance, usually the seemingly 'normal' physical appearance of the child. Parents also expressed frustration at the categories that professionals tried to box their child into as these categories were often irrelevant or inappropriate and as their child typically did not fit any of the categories, which meant that their child and family were considered ineligible to receive particular services.

4.3.3 Need for psychological and specialist support

All of the parents interviewed reported that they would like more outreach support from professionals who had a better understanding of ABI as well as more direct support from psychologists for their child, their family and their school. They felt that overall, ABI was poorly understood and that more specialist support should be available. However, this theme must be treated with caution as the researcher who conducted the interviews was a trainee Educational Psychologist and it was a specifically posed question.

4.3.3.1 Educational Psychology: the parents' experience

Sub-theme	Example quote
Need for direct access to services	I tried to go about calling in the local EP for the school and we were told that we weren't allowed to do that directly and that it had to come through school. The previous EP, unless the school approached them, we weren't allowed to even talk to them." (Parent 7)
Not knowing what support is available	"Educational Psychology, that was requested by the school. Parents don't know these things exist." (Parent 2)
Valuing professional	"We thought he would have to end up in special school. The EP pointed out that in his view, it is very important that X be around a

perspectives	language-rich environment; therefore, he should be around as many ‘normal’ children as possible in a school environment. I remember that telephone conversation with him only a few months in and that was when I first felt hope again.” (Parent 4)

Four of the parents indicated frustration at the difficulty in accessing psychology services such as the LA Educational Psychology team. They had battled with their schools for a referral to the EP but had not been prioritised by the school. The parents could not understand why they could not access the service directly. That said, two of the parents reported that they did not know what services existed, and that they had not heard of Educational Psychology until the school suggested it. Because of this, in the months immediately after the ABI, these two parents did not realise that there were any support services available to them or that schools had access to any. They spoke of feeling very isolated at this time and frustrated that nobody had directed to any services until the school did. When talking about the role of the EP, many of the parents acknowledged the value of EP input, especially the fresh perspective that the EPs reportedly brought to meetings, e.g. an emphasis on strengths and a solution-focused attitude. These parents reported that this allowed them some hope amid the many deficit-based reports on their child.

4.3.3.2 Specialist input

Sub-theme	Example quote
Long-term	“I did not want support in the beginning because I wasn’t ready, it would’ve been admitting that something was wrong. But now, nearly 4 years later, I am at a point where I can accept support. I’m glad someone is still offering it to me.” (Parent 5)
For the emotional trauma	“My main concern was that she didn’t have a psychologist after such a massive trauma…you know, to help her to try to come to terms with what happened her.” (Parent 8)
Parenting	“Explain to parents more about what’s going on with their child and offer them leaflets to support them, not just send them on their way, you know rush them in and rush them out.” (Parent 6)

Three of the parents (those whose child's ABI had happened less recently), admitted that despite their current strong feelings about having specialist professional support for them and their child, in the months after their child's ABI, they were not ready to accept any professional help and had pushed services away. One parent in particular, who has recently begun to ask for support for her child, reported that she had gone through a long period of denial after the ABI occurred but was now very glad that she can still access support a few years on. Over half of the parents indicated that they would have appreciated some professional emotional support after the ABI, both for themselves as parents and for their child. The parents of the younger children also expressed a need for parenting support in terms of behavioural management strategies. They tended to report that the child's behaviour at school was appropriate but when the child came home after school, the parents experienced many difficulties in managing their child's behaviour and emotional outbursts. However, only one of the families had received any support (from an NSPCC sponsored organisation) for these sorts of difficulties.

4.4 Teachers' data

The following table summarises the information on the teacher interviewees:

Teacher	Gender of child	Type of ABI	Current age	Age at ABI	Interval between ABI and interview	SEN register
1	Male	Brain tumour	4:08	1:06	38	Statement of SEN
2	Male	Brain tumour	15:04	13:01	27	Statement of SEN
3	Male	Brain haemorrhage	10:05	07:11	30	School Action +
4	Male	Brain tumour	07:03	06:09	6	Statement of SEN
5	Female	RTA	05:01	01:11	38	School Action +
6	Male	Fall	08:02	06:05	21	Statement of SEN
7	Female	Brain tumour	7:05	5:02	27	School Action +
8	Female	Brain haemorrhage	14:01	17:03	38	School Action +
9	Female	Chemical poisoning	07:06	03:07	47	Statement of SEN

Table E. Summary of teacher participant details

Nine children in total were discussed by nine teachers respectively (n = 9; children's age range = 4-15; male to female ratio = 5:4; average age between ABI and interview = 30 months; interval range between ABI and interview = 6–47 months). It should be noted that of the nine children discussed with the teachers' interviewed, eight of the children are also discussed in the parents' interviews. Unfortunately, it was not possible to interview the teacher of one of the children in the parents' sample. Equally, it was not possible to interview the parent of one of the children discussed in the teachers' sample. Again, seven out of the nine children had experienced a non-traumatic brain injury and two of the children had experienced a traumatic brain injury. All of the children except one were not on their school's SEN register before their ABI but all were added to the

SEN register post-ABI. Again, five of the children had Statements of SEN. All of the teachers reported that there were more than three outside professionals involved with the child but that their primary source of information about the child's ABI and needs came from the parent. Only one teacher felt that there had been an effective liaison between health and education professionals in the transition period from hospital to school. Most of the teachers said that the only information that they had received from the hospital was paperwork which they found difficult to understand. The teachers rated their confidence in working with a child with ABI (as compared to other children they work with) on a rating scale from 0-10, where 10 equated to the highest level of confidence possible and 0 equated to the lowest level of confidence possible. Their responses ranged from 5-10, with the average confidence rating being 6, indicating an overall moderate level of confidence. This is surprising given the fact that none of the teachers had had any previous experience working with a child with ABI and none of them had ever received any training that related to working with a child with ABI. All of the teachers felt that EPs should have a key role in working with children with ABI and supporting the school in meeting the child's needs.

The following table is a summary of the overarching themes, themes and subthemes:

Over-arching theme	Theme	Sub-theme
Challenges	Child's emotional response	Lack of confidence in learning
		Emotional needs
	Lost in transition	From hospital to school
		Between school years
		Primary to secondary school
	Inclusion	Peer support
		Reactions of peers
	Challenging but rewarding experience	Challenging
		Value of experience
Response to needs	School as a protective factor	Support for parents
		Support for the child
	Mediating and leadership role	Lack of information
		Impact of multi-professional network
		EP as helpful 'link' person
	EP Professional knowledge and skill	Alternative perspectives
		Teachers' isolation
Need for professional leadership and specialist knowledge	Support for schools	Need for practical strategies
		Training and support from outside professionals
	Support that schools could offer	Emotional support for parents
		Preventative not reactive

Table F. Over-arching themes, themes and subthemes of the thematic analysis on the teachers' data

4.4.1 Challenges

Although there was a wide-range of views, four distinct themes emerged with regard to particular challenges faced by the school when working with a child with ABI. These were the child's emotional needs, transition, inclusion and a challenging but rewarding experience.

4.4.1.1 Child's emotional response

Sub-theme	Example quote
Lack of confidence in learning	"He felt that he wasn't confident enough to do this piece of learning on his own and he kept asking me 'how much can I do?'" (Teacher 2)
Emotional needs	"The first couple of days she came in, she was quite nervous. She came in for an afternoon first and then for a day. She found it all quite overwhelming." (Teacher 1)

Almost all of the teachers reported issues about their child's lack of confidence in learning post-ABI and how this lack of confidence affected their engagement in classroom lessons and ability to work independently. This lack of confidence was reported to have a negative impact on their learning. In fact, teachers reported general emotional difficulties for all of the children discussed, especially in the first few weeks back at school post-ABI. In many of the experiences reported, the child's transition back to school had to be staggered due to how overwhelming the experience it was for the child. Teachers reported that how this transition was managed was critical to the child's success at school.

4.4.1.2 Lost in transition

Sub-theme	Example quote
From hospital to school	I think it would have been beneficial to have perhaps to have gone to the hospital or if someone from there had come to the school. We had the paperwork but there's nothing like talking to somebody." (Teacher 8)
Between school years	"It is really important that X is passed on to a teacher who is aware of her needs." (Teacher 6)
Primary to	"What will be really important for him is for all this information that

secondary school	we have now, to make sure that it goes to the secondary school." (Teacher 5)

Most of the teachers highlighted three different transitions that warrant particular attention. The first, the transition back to school after the hospital, posed most issues in terms of information-sharing between professionals. When the teachers reflected on the transition process that they had experienced, they all felt that there should have been more multi-professional liaison and that, if given the opportunity again, they would do things differently. Secondly, over half of the teachers spoke about the difficulties that children can experience when passing from one school year to the next and when the teacher changes. All of the teachers felt that this was a vital aspect of transition but almost half reported that the information had not always been passed on successfully from one year to the next. All of the primary school teachers (n = 7) put forward strong views about the importance of the child's information being passed on to the child's secondary school and felt that this would be crucial to the secondary school's understanding of the child and the success of the child at that school.

4.4.1.3 Inclusion

Sub-theme	Example quote
Peer support	The children are very accepting of him, they understand and are very adaptable." (Teacher 4)
Reactions of peers	I think people feel sorry for him and don't know how to manage him so then they're behaving different around him. I think they needed some support…this is what you could expect and this is how you could help him" (Teacher 2)

The primary school teachers (n = 7) tended to report that the other children in the school had responded well to the child with ABI and gave examples of how the children included the child and accepted the child. However, in contrast, the two secondary school teachers made more reference to the children having difficult social relationships with their peers, not always because of the child's difficulties but because of how the other children reacted to the child with ABI. Both of these teachers suggested that the child's peers could have benefitted from some support and guidance as to how to best support a peer with an ABI.

4.4.1.4. Challenging but rewarding experience

Although most of the teachers found the experience of having a child with ABI in their class to be rewarding, all but one made much reference to how difficult the experience had been, usually due to the multitude of uncertainties about the child's ability and difficulties.

Sub-theme	Example quote
Challenging	"I've done my job for 26 years…it was the biggest challenge I had because I needed to fulfil his needs educationally and be there for him medically. Plus I had to juggle questions about am I giving him too much work to do and am I over-taxing him?" (Teacher 2)
Value of experience	"The breakthroughs have made it all worthwhile." (Teacher 3)

4.4.2 Responding to needs in an educational context

All of the teachers spoke of the emotional effect they felt the ABI had on the child and of the importance for the school to respond to both the emotional needs of the child and parents.

4.4.2.1 School as a protective factor

Sub-theme	Example quote
Support for parents	"It's about support for the family as well. I think we were supportive academically. It helped manage the parents' anxiety knowing that the school were doing everything they could." (Teacher 7)
Support for child	"I think school has given him his confidence back because he genuinely didn't have any." (Teacher 2)

All of the teachers saw their school as a protective factor in the child's life and as a contributing system to the child's post-ABI development. The teachers appeared to believe that going to school offers the child emotional support. Many of them also reported school to be a place which offers emotional support for the parents too. These teachers felt that by managing the child's learning and social development and by giving the parents respite, the school played a major rehabilitative role.

4.4.2.2 Mediating and leadership role

Sub-theme	Example quote
Lack of information	"We didn't have anything, we just had to rely on information from parents to tell us what was going on. Or the child herself." (Teacher 1)
Impact of multi-professional network	"It was reassuring to have everyone working together on behalf of the child, the medical and educational sides and seeing it all together. At the meeting, we were taking in everyone's views." (Teacher 3)
EP as helpful 'link' person	Because EPs are outside the school and separate from parents, they are well-positioned to play a mediatory role. It was helpful for the parents to have someone to talk to who understood the school so well but was external to the school." (Teacher 9)

One of the strongest themes that emerged across all of the teachers' interviews was frustration at the lack of information provided by health professionals and the hospital. All of the teachers wanted more information and felt that by having more information about the child's ABI and information about their strengths and needs, this would facilitate them in providing better support for the child. In many of the situations, the parent was the sole provider of information and, in another school setting, the child was solely relied upon to relay most of the information to the school.

None of the teachers indicated that they played a ‘link’ role in terms of liaising between various professionals. However, they acknowledged that the parents were often put in this position and that this sometimes put a strain on the relationship between the parents and the school staff. It also sometimes put the school in a difficult position in terms of having conversations with parents about very personal aspects of the parents life. Most of the teachers either reported that the EP had played a semi-link role or that EPs should have the capacity to play the link role on behalf of the child, parents and school. They also felt it to be important that the parents have a professional to discuss matters with who is external to the school.

4.4.2.3 EP Professional knowledge and skill

Sub-theme	Example quote
Alternative perspectives	“It always helps to have the EP come in as they always have a different perspective.” (Teacher 1)
Teachers’ isolation	“The EP was the only link I’ve had to the ABI, the EP is the only person who has given me that information, extra information specific to ABI so if it wasn’t through the EP, where else would I get it? It’s not coming from anywhere else. So I think the link that we have with the EP is essential. If the EP doesn’t have the information, it’s not getting to us. I mean we don’t have anything specific in our training.” (Teacher 5)

All of the teachers acknowledged the essential role of the EP when working with a child with ABI. Most of the teachers reported that they valued the alternative perspectives that a consultation with the EP brings. Many of the teachers reported experiencing professional isolation when they had a child with ABI in their classroom and that the link with the EP had been their only source of information about ABI.

4.4.3 Need for professional leadership and specialist knowledge

Similar to the parents' thematic analysis, all of the teachers emphasised the vital role that specialist support and professional advice plays in their ability to develop the child's strengths and meet the child's needs.

4.4.3.1 Support for schools

Sub-theme	Example quote
Need for practical strategies	"It's the day-to-day running that I need to know - how she is in the playground, how she is in the classroom. That's what I need to know as a teacher, those practical day-to-day things." (Teacher 7)
Training and support from outside professionals	If they had given us an information sheet, you know, e.g. 'what is a brain injury', what parts of the brain can be affected, how can you help. You know the way you get it with ADHD or ASD, you know, a factsheet or some INSET." (Teacher 8)

All of the teachers felt strongly that although they valued alternative perspectives and information about ABI, what they want more than anything else is practical strategies that can be implemented in the classroom on a daily basis. They also reported that outside professionals should be able to provide them with more general information on ABI or deliver training. This was a strong theme across the interviews, i.e. it was mentioned by nearly all and mentioned frequently by each who did mention it, demonstrating the pressure that the teachers are under in terms of managing a child with unique needs under circumstances providing limited information and background training.

4.4.3.2 Support that schools could offer

Sub-theme	Example quote
Emotional support for parents	"The next steps for the education professionals will be to support the parents in their letting go of X and improving his school attendance." (Teacher 9)

Preventative not reactive	"I think it's important that the intervention is ready to be used rather than her missing out or time being spent trying to get her support." (Teacher 6)

Almost all of the teachers indicated that the school can play a large role in the support for the child and their family. For example, 5 of the teachers, all of which had experienced situations in which there appeared to be a separation anxiety on either the child's or parents' behalf, suggested that the school had a role to play in supporting the parent and child in 'letting go' as well as providing a place in which the child can develop his/her independence and where parental relief and, possibly, respite is provided. Three of the teachers made reference to the importance of preventative intervention instead of reactive intervention and speculated that with more knowledge and training, this could happen in the future.

4.5 EPs' data

The following table summarises the information on the children discussed by the EPs' interviewees:

EP	Gender of child	Type of ABI	Current age	Age at ABI	Interval between ABI and interview (months)	SEN register
1	Male	Brain tumour	4:08	1:06	26	Statement of SEN
2	Male	Brain tumour	15:04	13:01	27	Statement of SEN
3	Male	Brain haemorrhage	10:05	07:11	30	School Action +
4	Male	Brain tumour	7:03	6:09	6	Statement of SEN
5	Male	RTA	14:04	11:09	31	Statement of SEN
6	Female	RTA	05:01	01:11	40	School Action +
7	Male	Fall	08:02	6:05	21	Statement of SEN
8	Female	Brain tumour	08:01	04:06	43	Statement of SEN
9	Female	Chemical poisoning	07:06	03:07	47	Statement of SEN
10	Female	Stroke	11:02	7:07	43	Statement of SEN
11	Male	RTA	14:06	12:04	26	Statement of SEN
12	Male	Fall	12:08	9:01	43	Statement of SEN
13	Male	RTA	13:01	09:06	43	Statement of SEN

Table G. Summary of educational psychologist participant details

Thirteen children were discussed in total (n = 13; children's age range = 4-15; male to female ratio = 9:4; average age between ABI and interview = 33 months; interval range between ABI and interview = 6–47 months). Seven of the children discussed in the parents' interviews made up the thirteen children (six of these seven children were discussed in the teachers' interviews). The other six children were discussed by EPs only, and although recent cases, they were not currently open to the EPs in question. Six of the children had experienced a non-traumatic brain injury whereas the other seven had experienced a traumatic brain injury. Only two of the children were on their school's SEN register before the ABI, one for a diagnosis of Asperger's Syndrome and the other for a Hearing Impairment. However, these children's needs changed considerably after their ABIs. Eight out of the thirteen children had Statements of SEN. The EPs rated their confidence in working with a child with ABI (as compared to other children they work with) ranging from 2-7, with the average confidence rating being 5. Only one of the EPs had had previous training in working with children with ABI. In all of the cases discussed, there had been a multitude of professionals involved from health and education and in some cases, social care. Four of the EPs reported that they had had good experiences of liaison between health and education professionals but nine of the EPs did not. All of the EPs interviewed thought that EPs have an essential role to play for children with ABI across a wide-range of contexts but that in many cases EP involvement is restricted, e.g. to statutory assessment [SA] work.

The following is a summary of the overarching themes, themes and subthemes:

Over-arching theme	**Theme**	**Sub-theme**
Family-wide effects	Changes to the child's identity	A sense of loss
		Wanting to be 'normal'
		New dependency
		Difficulties with novel learning
		Complex and long-term needs
	Changes to family systems	Impact on siblings
		An evolving process
		Emotional impact on parents
		Resilience
		Feelings of loss and bereavement
Roles and role tensions of the professional network	The statutory assessment process	Determinator of who funds the child's future needs
		A sense of security
		Not always necessary
		An interdisciplinary facilitator
	Information-sharing	Poor communication between agencies
		The value of shared knowledge, skills and expertise
		Lack of access to medical reports
		Lack of liaison between health and other agencies
		The 'fear' factor
	Educational setting	Managing uncertainty
		Issues around provision
		Managing support
	The current EP experience	Working against the deficit-model
		Careful assessment approach
		Creative approaches to intervention

		Including children in planning their future
		Normalising responses to traumatic experience
Moving towards solutions	Managing transitions	Good immediate care (from medical teams) v. poorer long-term care (specialist outreach)
		Need for emotional support for families
		Comprehensive intervention
		The relevant skills are already out there
	Using a systemic framework	Moving from a medical model to a social model
		Careful assessment approach
		Support for key adults
		Family functioning as a predictor of outcomes
	The enhanced EP role	More training
		Lead and mediatory role in ABI transitions
		'Translation' of medical reports
		Psychological support for families
		Guidelines for Educational Psychologists

Table H. Over-arching themes, themes and subthemes of the thematic analysis on the educational psychologists' data

4.5.1 Family-wide effects

All of the EPs made much reference to how an ABI affects the child in terms of their self-identity as well as how it affects the people in the child's environment, in particular, the family of the child.

4.5.1.1 Changes to the child’s identity

Sub-theme	Example quote
A sense of loss	“There is a bereavement issue about the brain injury as he’s lost some of his functioning and what he perceived himself to be.” (EP 4)
Wanting to be ‘normal’	“I remember the child asking me clearly “how long do you think it will be before I am ‘normal’ again and we talked a lot about how it is difficult to say.” (EP 11)
New dependency	“There is the issue of developing some independence from his family, that wasn’t there before the injury.” (EP 2)
Difficulties with novel learning	“His availability for learning was significantly reduced after his accident.” (EP 3)
Complex and long-term needs	“I think there’s enough evidence that these are likely to be slow and complicated recoveries that we could be proactive and preventative about responding rather than reactive.” (EP 12)

In terms of the child who has experienced an ABI, although a wide-range of needs were mentioned, there were certain similar sub-themes that emerged across the EP dataset. These themes all linked to the changed identity of the child: how this affected the child and the child’s response to this. A sense of loss was evident in almost half of the cases, and especially relevant to the adolescents that were discussed. The EPs in these cases felt that these children went through a type of bereavement for the self that they used to be. In many of the reported cases, EPs made reference to the children wanting to be ‘normal’ again and wanting to go back to their former selves. Some of the children had difficulties with accepting help and support as it was something they had not experienced before and had not needed before. For two of the adolescents, the EPs reported that getting support in school symbolised that they were not ‘normal’ and highlighted their differences. Almost all of the EPs reported that the children had difficulties in gaining independence post-ABI. In most cases, this was an interaction between the child’s new difficulties and perceived loss of function and their parents’ anxieties about ‘letting go’. EPs reported that this two-way separation anxiety often impacted on the child’s development in terms of learning and behaviour.

Most of the EPs reported that there were issues around new learning for the children and that this often only became apparent over time when back at school. All the EPs acknowledged that the child's needs would be long-term and complex and felt strongly that preventative support should be put in for these children on a long-term basis.

4.5.1.2 Change to family systems

Sub-theme	Example quote
Impact on siblings	"The siblings were feeling quite neglected because everything is about the other child." (EP 7) "The sibling went into school and said to his teacher 'I might as well not exist, I'd have to get run over for people to notice me.'" (EP 12)
An evolving process	"There's three phases of what happened: there's what the family life was like, then you have this awful injury take place, then you have the relief that the child will live but the trauma that they're not going to be the same again and there's the transition to the next step, the future and what that will be like." (EP 3)
Emotional impact on parents	"It's parents' instincts to fight against anything that might impact negatively. They don't want it to be forever impacting on their child…it's like a constant cloud over them." (EP 9)
Resilience	"It's been really hard for mum as she must be experiencing bereavement but they organised themselves well and got new housing and organised things for the child." (EP 4)
Feelings of loss and bereavement	"When mum talks about the expectations in her family and everybody is high achieving and then about the expectation she had for her daughter…it's hard." (EP 9)

All of the thirteen EPs referred to the impact of the ABI on the family of the child with ABI. Eight of the EPs reported the impact that it had on the child's siblings. These children often experienced some form of neglect but were not reported to have been offered any support. Indeed, many of the EPs realised over the course of their involvement that the siblings often felt left out and forgotten. All of the EPs acknowledged the huge impact and pressure that an ABI puts on the functioning family system (which is linked to the neglect of siblings) and the traumatic emotional journey that entails. All of the EPs reported that the parents of the children had had a negative emotional response to their child's ABI. They reported that many of the parents felt that they were, in a way, bereaved and had spent much time mourning the loss of the child that they once had. However, four of the EPs spoke about the resilience of the parents they had worked with in terms of picking up the pieces and getting their lives back on track. Unfortunately, in the other cases, some negative outcomes such as family break-up and mental health difficulties prevailed.

4.5.2 Roles and role tensions of the professional network

All of the EPs interviewed frequently talked about the issues of professional roles. A wide range of opinions were aired and these emerged as themes across four contexts: the statutory process; information-sharing; the educational setting; and, the EP role.

4.5.2.1 The statutory process

Sub-theme	Example quote
Determinator of who funds the child's future needs	"I think the whole issue around statementing and not statementing becomes a focus of anxiety and it's not so much about meeting needs and whether the needs are being met. Instead it becomes a battle and different professionals are trying to force somebody else's department to bear the brunt of the costs." (EP 13)
A sense of security	"It's the security for the family of knowing that these resources cannot be taken away on a whim." (EP 12) "That process made them all feel protected: that their child's needs were not going to get lost or neglected as there was legal protection for them. That makes a big difference." (EP 11)
Not always necessary	"Rather than whether she gets a label or whether she gets a statement, as long as her needs are being met, that's all that matters." (EP 6)
An interdisciplinary facilitator	"Through writing the statutory advice, information was forced together. That's why the statutory process is good." (EP 4)

As EPs play such a key role in SAs of SEN, it is unsurprising that all of them expressed strong opinions on the subject in relation to children with ABI. All of the EPs reported that the statutory process acted as a protection for the child's needs and was often received with relief by the family. However, some of the EPs, indicated that while a Statement of SEN provided a sense of security to the family, it was not always necessary. By this they explained that having an ABI did not automatically mean that a Statement was needed because the needs of the child with ABI could be met at School Action Plus. Two EPs made the interesting point that sometimes the issue of giving a child a Statement of SEN is not always about the child's needs but who funds extra resources and support for the child and family and in this way, it can turn into a battle between health, education and social care. However, many more of the EPs felt that the statutory process facilitated interdisciplinary working and that, through this process, information-sharing between professionals was achieved more successfully.

4.5.2.2 Information-sharing

Sub-theme	Example quote
Poor communication between agencies	"There's often no communication and it's not satisfactory. Getting people around the table isn't always easy but as long as there is some form of correspondence by telephone or email." (EP 3)
The value of shared knowledge, skills and expertise	"A report through from the hospital helped shed some light on some things that people could then have more of a conversation around. For example, one of the effects of the medication was tiredness and we could then talk around strategies for when she was tired and have more of an understanding of what she is going through." (EP 5)
Lack of access to medical reports	"It would be much more helpful if the hospital could send the information to us but they are not always aware and they tend to send to the school and GP and you just have to try to get copies." (EP 3) "Mum is confused about what the doctors are saying and she is asking me what she should believe. I would like to know more medical information from the doctors to support mum to

	understand." (EP 6)
Lack of liaison between health and other agencies	"It's been very much mum seeing the hospital then getting a bus and going to see the school and then seeing the professionals linked to the school, so it's not a very joined up process." (EP 8)
The 'fear' factor	"Hearing the words 'road traffic accident' and 'brain injury' really got the school quite anxious." (EP 6)

Similar to the teachers' interviews, the theme of information-sharing was one of the most dominant themes in the EP interviews and a topic that all of the EPs felt strongly about. Almost all of the EPs reported feelings of frustration in terms of accessing information from health and social care and felt if information had been shared more readily and directly that this would have improved outcomes for the child. For example, it was indicated that shared information from other professionals could further promote other professionals' understanding of the child. Unfortunately, in ten out of the thirteen cases, it was reported that there was inadequate liaison between agencies, a lack of communication between agencies and difficulties for EPs who wanted to access medical reports for the purposes of offering more informed advice to the school. EPs also made reference to the fear and anxiety that using terms such as 'brain injury' and 'road traffic accident' can cause, especially for schools and teachers, but in some cases fellow professionals, e.g. a speech and language therapist.

4.5.2.3 Educational setting

Sub-theme	Example quote
Managing uncertainty	"It needs to be monitored regularly. We really don't know the impact of it. It's a difficult balance for professionals because they shouldn't say everything will be fine but they shouldn't scare parents either. It's especially hard if there is a multitude of professionals involved coming from different view points." (EP 6)
Issues around provision	"It's less to do with being in a place where learning opportunities are good but more to do with a place where parents feel supported and the child feels more supported." (EP 5)

Managing support	"Schools struggle more with less tangible needs and they are better with more concrete needs." (EP 4)

All of the EPs referred to the difficulties with regard to professional roles in educational settings. For example, most of the EPs acknowledged how difficult it is for schools to provide for a child amid uncertainty regarding the child's ability and future outcomes, especially when both school and parents hear conflicting information from professionals. Ten out of the thirteen EPs felt that the school had a large part to play in relation to support for the parents and child. Overall the EPs reported that, in their experience, schools dealt more successfully with concrete needs, e.g. visual impairment, than less obvious needs such as the executive functioning difficulties which are common with ABI, e.g. problem-solving.

4.5.2.4 The current EP experience

All thirteen of the EPs saw their role as changing the focus of the other professionals and families from an emphasis on deficits to an emphasis on strengths and solutions, in terms of their approach to assessment, intervention and support. However, this was not always what was expected by other professionals and, in some cases, parents.

Sub-theme	Example quote
Working against the deficit-model	"My remit was very narrow and what mum was requesting was a cognitive assessment and that's all mum wanted. That's what my involvement became all about….what difficulties she has." (EP 9)
Careful assessment approach	"It's assessment over time and it is dynamic assessment…although it can be difficult to define. It's not just psychometric, it's your observations, your consultations and how they approach learning." (EP 3)
Creative approaches to intervention	"He had difficulties remembering who people were so, as he was very musical, we developed musical themes for all the important people in his life which helped him to sort of tune into who that person was." (EP 12)
Including	"It became apparent that allowing him to be part of the discussions

children in planning their future	was really important in reducing his levels of anxiety and having a sense of ownership and control over who he was and who he will be." (EP 11)
Normalising responses to traumatic experience	"The EP role was also in providing emotional support to the parents, not in terms of therapeutic support, but in terms of validating and normalising the parents' experiences." (EP 7)

Some of the EPs felt that they were working against a deficit-based model when they became involved with the child with ABI. The EPs that experienced this tried to focus on the strengths of the child and how things could be moved forward for the child and family but some felt that other professionals and the parents were only interested in the child's difficulties. Most of the EPs concerned felt that a careful assessment approach had to be taken, especially when it came to interpreting results of cognitive assessments. Five of the EPs emphasised that progress over time, and exploring how the child learns through observation, consultation with key adults in the child's life, and dynamic forms of assessment were better tools for moving towards solutions. A few of the EPs reported that they had to think very creatively about their approaches to intervention and individualise these interventions around the child's strengths, with negotiation with the child. Including the child's views in the assessment process was a strong theme and many of the EPs felt that their role was as an advocate for the child. Although most of the EPs spoke about their supportive role with parents, none of the EPs had had the capacity to do any therapeutic work with the parents. However, three of the EPs emphasised that they felt that they had played an important, albeit brief, role in validating and normalising the parents' feelings in response to the ABI experience.

4.5.3 Moving towards solutions

All of the EPs were in agreement that there is a need to focus on solutions for children with ABI and their families in order to improve outcomes for them. The dominant themes that emerged across their suggestions covered better managing of transitions, using a systemic framework in terms of support and intervention, and the enhanced role of the EP regarding further training, offering training to schools, playing a mediatory role between professionals, and offering more support for families' psychological well-being.

4.5.3.1 Managing transitions

Sub-theme	Example quote
Good immediate care (from medical teams) v. poorer long-term care (specialist outreach)	“What was interesting was that those who had been in X (a short-term specialist provision for ABI), had cutting edge support whilst there. But it was very hard for that outreach to extend geographically 3-4 boroughs along so it was more of a difficult transition because of all the transfers of therapeutic roles.”(EP 13)
Need for emotional support for families	“I don’t know what aftercare families get for children who have had a car crash, but children with ABI should get the same, you know, it’s similar as it’s something very sudden that changes things forever.” (EP 1)
Comprehensive intervention	“The key thing is that she finds it difficult to retain information so there should be some kind of joint medical professionals and school professionals approach on how best to support him with that.” (EP 8)
The relevant skills are already out there	“Sometimes people think that the usual interventions cannot be run, e.g. when I raised the issue of having a Circle of Friends, the school said ‘but how could we do that because she’s different?’” (EP 5) “What made the real difference to me was realising that although ABI is new to me, it’s the same but different to other children I’ve worked with in terms of identifying the needs of the child and knowing that my knowledge of developmental stages is still relevant.” (EP 7)

It was highlighted by the EPs that the families experience excellent specialist support when the child is at the hospital and that they have access to a multitude of professionals during this time period. However, almost all of the EPs noted that when the child was discharged from the hospital, families often felt bereft and confused about the next steps. The EPs reported that this should be a better transition for families. The

EPs also indicated that more emotional support should be available to parents in dealing with the sudden trauma. There was little evidence of this being offered or being available to any of the families discussed. Most of the EPs also indicated that comprehensive intervention is needed, i.e. it should be a joint plan put together by all the professionals involved, in order to help alleviate parental stress and confusion. On a positive note, the EPs reported that professionals with the relevant skills already exist and that it is about tapping into existing resources, e.g. the role of the EP, rather than funding new 'programmes' or training new professionals. Over half of the EPs admitted that it took them time to realise that they already had the skills they needed to make a positive contribution to the child's life. These EPs thought some previous training could have made them feel more confident and realise their skills at an earlier point.

4.5.3.2 Using a systemic framework

The majority of EPs emphasised the need for professionals to use a systemic approach when working with children with ABI and their families. They indicated that this approach has a more effective impact on outcomes, and in some circumstances can be a predictor of long-term outcomes for the child.

Moving from a medical model to a social model	"I worry about professionals trying to label her and trying to put her in a box and being focused on the diagnosis rather than focusing on what her strengths and needs are." (EP 6)
Supporting for key adults	"They (parents) need to acknowledge their own needs because I think there is a sense of guilt around 'I'm being self-indulgent, I'm not the one who had the terrible accident'. But actually, if the parents don't get support to accommodate how their child now is or what their child needs, it can be very unhelpful to the recovery process." (EP 13)
Careful assessment approach	"There were real issues with the use of IQ tests as we know that these children are making huge amounts of progress in very short periods of time." (EP 10)
Family	"The mother's behaviour was having a larger effect than the brain

functioning as a predictor of outcomes	injury. It felt like a really nasty life experience was being magnified and amplified and he wasn't being allowed to recover." (EP 11)

Over half of the EPs had experienced working with professionals who applied a medical model to the experience of the child with ABI. These EPs felt that it was more powerful and productive to focus on the child's strengths and, in intervention, to adapt elements of the child's environment. In this way, the EPs indicated that it was crucial for the key adults in the child's life to be supported and have their needs met, as this, in their experiences, had a knock on effect on the children's recoveries. Almost half of the EPs indicated that the child's family functioning was possibly beginning to have a significant effect on the child's development and outcomes. This has implications for how professionals should support a family with a child with an ABI.

4.5.3.3 Enhanced EP role

All of the EPs agreed that there is a unique role for EPs with children with ABI. However, all but one of the EPs interviewed had had any previous training in relation to ABI.

Sub-theme	Example quote
More training	"I didn't get any training on it when I was training to be an EP. We did get talks on things like dyslexia etc. but maybe we need some basic training on children with medical needs." (EP 9) "Maybe having some initial training on ABI in the current training…once qualified you can follow this up but initial basic training is important. You could do your own research on it with the references that you have." (EP 8)
Lead and mediatory role in ABI transitions	"In terms of liaison between school and hospital and family as we have knowledge of education for the child's development." (EP 2)
'Translation' of	"I think some people are completely intimidated by it, i.e. if you see

medical reports	some of the reports that come from the specialists…we need to interpret them into meaningful language that teachers and parents can work with and understand.” (EP 12)
Psychological support for families	“Providing emotional support to the parents, not in terms of therapeutic support, but in terms of validating and normalising the parents experiences themselves.” (EP 7)
Guidelines for Educational Psychologists	“Having a policy on it in the Educational Psychology Service (EPS) would be good, even if it’s just one side of A4 saying they need close monitoring, these are common outcomes, this is what ABI is, and, as EPs, this is how we need to look at how it affects school learning.” (EP 1)

Concerning an enhanced EP role, various suggestions were made but there were five main sub-themes that emerged across above all. Firstly, although most agreed that as experienced psychologists who work regularly with children with complex needs, they already had many skills to work with these children, all indicated that more support and training for EPs on the unique aspects of ABI would enhance their knowledge and the contribution they could make to the lives of these children. Secondly, it was suggested that EPs could play a lead or mediatory role in transitions for children with ABI. For example, the EP could play a ‘link’ role which could involve mediating between the family and the school and the hospital. Thirdly, linked to that suggestion, it was put forward that EPs sometimes currently have, and could increasingly have, a role in terms of ‘translating’ reports from health professionals into understandable language for schools as well as liaising with schools on how this information has implications for the child in an educational setting. Fourthly, all of the EPs spoke about the emotional anguish of the parents and suggested that EPs, building on their knowledge on child development and complex family systems, could play a more therapeutic role. Finally, it was suggested by six of the EPs that Educational Psychology Services should develop brief policies on working with children with ABI and their families. Leading on from that, several of the EPs suggested that EPs could use their experience of delivering INSET to schools to develop schools’ knowledge of ABI, as well as providing brief information leaflets for teachers.

4.6 Participants' recommendations

The following section will summarize the recommendations that were suggested when participants were asked about how outcomes could be improved for children with ABI and their families, and how educational professionals could assist in the process.

4.6.1 Children

To other children with ABI:

- Stay positive and optimistic;
- Ask for something if you need it;
- Ask questions if you do not understand something;
- Tell an adult if you do not agree with something.

To parents of children with ABI:

- Stick by your child, be there for them emotionally and help with their learning.

To schools:

- Ask for the child's opinion about what would help before they return to school;
- Provide easy access to technological aids, e.g. laptops;
- Treat the child as 'normally' as possible;
- Allow young people some independence, e.g. do not have a teaching assistant with them all day every day.

To professionals:

- Include children's views in intervention planning and review.

4.6.2 Parents

To parents of children with ABI:

- Ask professionals lots of questions, even if you think the question is only something small;
- Be proactive and seek out charities that can help;

- Keep going, no matter how hard it gets.

To teachers:

- Read the reports from other professionals and ensure you know the strengths and needs of the child in your class;
- Have a hand-over meeting with the child's new teacher when he/she changes school year.

To schools:

- Provide support for friendship development;
- Transfer information to the child's next school in time for the new school to plan for the transition.

To professionals:

- Share information with other professionals to ensure all are informed and that there is a unified plan in place for the child;
- Treat each child as you would your own.

To EPs:

- Visit the school to conduct training with the staff;
- Act as an advocate for the child and parents.

4.6.3 Teachers

To parents:

- Encourage your child and be an advocate for them;
- Try and get support in the home too.

To other teachers:

- Provide a safe place for the child at school;
- Attend multi-professional meetings for the child;
- Talk regularly with the child's parents and discuss learning and behaviour at home and at school;

- Seek support from your fellow school staff and the education professionals attached to the school.

To schools:

- Make a ‘passport’ for the child that details all their strengths and needs that can be given to other school staff so all are informed;
- Have termly IEP meetings.

To EPs:

- Provide the school with an information factsheet about ABI and about what the school could expect;
- Visit the school to conduct training with the staff.

4.6.4 Educational Psychologists

To teachers:

- Give parents honest, but positive feedback;
- Acknowledge the parents worries but reassure parents about learning.

Advice to schools:

- Attend the hospital discharge meeting;
- Plan ahead for the child’s return to school;
- Provide career guidance support for adolescents with ABI.

To other EPs:

- Have a policy and procedure on ABI for your professional team;
- Normalise the feelings of children and parents;
- Be creative and flexible in intervention;
- Have a creative assessment approach that measures novel learning;
- Include a session on ‘working with children with medical needs’ in initial professional training.

Advice to the LA:

- Keep a record of all the children with ABI in the LA;
- More support for the child’s emotional and social well-being;
- Provide family and parenting support;
- Long-term follow-up for children and families;
- Psycho-education on ABI for families;
- Support for schools and teachers in how to support families affected by ABI;
- Provide child-friendly information for the child and for siblings;
- Raising awareness of ABI in the borough;
- Therapeutic support for child, parents, siblings;
- Be an advocate who is external to the school for the child and parents and who could oversee the child’s support.

Advice in general:

- Understand that your skills and knowledge of child development are still relevant and applicable;
- Keep in mind that the child’s needs will change over time and need regular reviewing;
- Include the child in intervention planning and review as this will help to reduce their anxiety;
- Write reports in language that teachers and parents can understand;
- Give parents information on the emotions that they may experience after they leave the hospital;
- Support the family, not just the child with ABI;
- Attend multi-professional meetings.

4.7 Summary

Although all of the four distinct datasets of interviews were analysed separately, there is clear overlap, interaction and contrast between the over-arching themes, themes and sub-themes across the views of children with ABI, parents, teachers and EPs. Due to the cross-dataset recurrence of particular over-arching themes, themes and sub-themes, as well as to increase coherence for the reader and aid discussion, Research Question 1, ‘What characterises the experiences of children with ABI and the key adults in their lives, in home and educational settings?’, will be answered according to nine cross-dataset themes (see Thematic Map 5).

However, Research Question 2, ‘What type of support has been experienced by those affected by ABI in home and educational settings, and what type of support should be implemented in the future, particularly in relation to the EP role?’, will be answered according to the four data-set groups.

In conclusion, the results of this study indicate that children with ABI, their parents, teachers and EPs have had a range of experiences in relation to the transition from hospital back to school, in terms of the support offered, the professionals involved and the recommendations made for future consideration. Nonetheless, dominant themes have been identified within and across the datasets and although it is clear that there is no one solution, there are many factors that could be addressed at various levels across the child’s eco-system.

Chapter Five - Discussion

It is helpful to relate the results of this study to the previous literature. Therefore, the results presented in Chapter Four will be considered and interpreted in light of the literature discussed in Chapters One and Two and in relation to the research questions preceding the current study. The methodology of the current study will then be reviewed in terms of its limitations and strengths and how this could have influenced the study's results. Implications of the current study will then be discussed in terms of their influence on theory and practice, with a particular focus on EPs. Suggestions will be made for future research followed by a short personal reflection on the overall process of the current study to conclude.

5.1 RQ1. What characterises the experiences of children with ABI and the key adults in their lives, in home and educational settings?

Through the exploratory method of the current study, the perspectives of children with ABI, parents, teachers and EPs were sought in order to attempt to characterise the ABI experience as well as to identify pertinent issues.

By drawing on the over-arching themes, themes and sub-themes that emerged across the datasets, a general idea of the experience for the participants was constructed. The main issues that arose can be summarised as follows and will be subsequently discussed:

- Transition and adaptation;
- Assessment procedures;
- Unique aspects of ABI;
- Emotional impact and needs;
- Advocacy and resilience;
- Information-sharing;
- Multi-agency working;
- The EP role;
- Professional knowledge and training.

5.1.1 Transition and adaptation

Firstly, the period post-hospital was reported by the children to give rise to feelings of chaos and confusion about every day issues. For example, at school, the children reported that things that they knew should feel familiar, e.g. learning in a classroom, felt new and strange post-ABI. This period of adaptation appears to be an on-going process that does not have a fixed end point. The current study extends the literature about the experiences of children with ABI beyond a focus on the child's deficits as it brings to the fore further information about how chaotic and disorienting the transition from hospital to school and home can be. Although for most children it appears that these anxieties lessen over time, there was no conclusive end-point to the period of adaptation. This supports research that has suggested that transition post-ABI is an evolving process that requires ongoing long-term support (e.g. Anderson et al., 2011; Klonoff et al, 1993). Facilitators to the transition process will be explored further in the subsequent research question.

Secondly, relating to the management of transitions back to school, the teachers indicated that, ideally, there should be a managed transition between the hospital and school, during which information can be shared and the relevant professionals can liaise with each other. Only two out of the nine teachers had experienced such a transition. The positive transitions that the two teachers reported involved multi-professional working and information-sharing as part of the transition process and they indicated that this had been helpful e.g. one of the teachers had visited the child's hospital pre-return to school, lending support to the proposals of multi-disciplinary working[1] as a protective factor. All of the teachers agreed that transition planning for return to school is important but that when transition is not done well, it can be frustrating. This builds on previous research in that it suggests that teachers as well as parents and children find the lack of transition planning frustrating (see D'Amato & Rothlisberg, 1996). Most of the teachers implied that transition back to school should involve multi-disciplinary working and information-sharing, as well as monitoring and review. These suggestions were interesting in that teachers made these suggestions, not knowing that this process is

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[1] Multi-disciplinary working can be defined as 'professionals working in parallel, carrying out their own assessments which are then brought together by the team head to give recommendations' (Barclay & Kerr, 2006. p. 37).

already outlined (e.g. DfES & DoH, 2004). It is also alarming that government, NICE and BPS guidelines were not implemented for the majority of the children but sadly this reflects the findings of previous research (e.g. Hawley et al., 2004; Tomlin et al., 2002).

Finally, with regard to the social inclusion of children with ABI (previously claimed to be a long-term difficulty, Prigatano, 2011a), there were mixed reports. Despite the small numbers interviewed, younger children were reported to be more accepting and inclusive of a child with ABI in their class. It is indicated that the older children had more difficulty with friendship groups, usually because they were not given (or could not be given) as much independence as other adolescents or because other adolescents did not know how to react to having a young person with ABI in their class. This could support suggestions that long-term social isolation is a consequence of ABI (Prigatano, 2011a) and also offer support to the claim that, at least in the case of older children, having an ABI can affect the attitude of peers towards the child (Crothers et al., 2007). Although these findings need further exploration and replication, they could be evidence of the concept of 'poor fit' between the child with ABI and the environmental expectations which seems to widen as children get older (Dise-Lewis et al., 2009). This has implications for how the needs of the child with ABI are perceived and understood, as well as how interventions are implemented, i.e. directed at the child or through the adjustment of aspects of their environment. Future transitions for children with ABI should be wary of this possibility.

5.1.2 Assessment procedures

Firstly, the thematic analysis indicated that most EPs became involved with a child with ABI through the SA process. Therefore, it is not surprising that all of the EPs discussed the SA process. Most EPs indicated that their main involvement with children with ABI was initiated by an SA request. This is surprising given the 'best practice guidance' and all the previous research that indicates that EPs (or school psychologists) should be involved in terms of transition planning for the child's education as well as worrying as it indicates that schools are adopting a reactive approach to meeting the child's needs instead of a preventative approach, i.e. involving the EP in transition-planning. Research that suggests that EPs are only involved in 50% of ABI cases (Tomlin et al., 2002) indicates that it is unlikely that best practice guidance is being followed.

Secondly, EPs had mixed feelings on the usefulness of the SA. Although it forced EP involvement, for some EPs, it reportedly limited the EP's initial involvement with the child and family, i.e. in the role of SEN expert instead of a consultation-model psychologist. It also reportedly influenced how the role of the EP is viewed by teachers and families, e.g. they saw the EP as the professional who administers cognitive assessments, instead of in the role of co-intervention planner and therapeutic support. However, these were not always mutually exclusive roles and EPs tended to favour engaging in a combination of these roles. However, on a positive note, the statutory process was reported to have played a key role in the bringing together of information from various professionals, i.e. a form of multi-professional working, which had not been done before. In this way, the statutory process was seen as helpful as it provided the child with 'protection' in terms of having their needs met and prevented the child from getting 'lost' in the system. It was noted that a SA was not thought to be required for all children with ABI as it should be more dependent on the child's needs and the resources that are required rather than a blanket rule for all. However, it was pointed out that a Statement of SEN provides security to the family of the child and makes parents feel more certain about their child's needs and less anxious that their child will be 'lost' in the system. Some EPs reported that from their perspective, a systemic approach which would require the EP in a role as supporting parents and school in how to best support the child would be preferable and felt that in some cases, this could have mitigated the need for the expensive SA process. Some EPs hinted that it should not be a question of 'to do an SA or not to do an SA', but that a more appropriate process should be given priority given the changing and unique needs of children with ABI, e.g. an intervention similar to the Pastoral Support Programme (PSP) used in schools with Looked After Children (LAC) including termly reviews with a person from the borough LAC team or interventions that have researched in the US including the STEP program (see Prier et al., 2011) and the BrainSTARS program (see Dise-Lewis et al., 2009).

Thirdly, relating to approach to assessment in general, most of the EPs indicated that cognitive assessments are not always most appropriate as they do not always provide an accurate reflection of the child's strengths and needs. Such assessments do not capture the child's ability to engage in novel learning, one of the most common sequelae of ABI (Donders, 2011a; Middleton, 2001a) but instead could tap into the child's pre-injury cognitive ‘reserve’ (Chapman & McKinnon, 2000) which could lead to misleading results. As well as this, the EPs were conscious that the needs of children with ABI fluctuate and change over time (as suggested by Walker, 2009) or become more apparent as the child develops and expectations change (Masel, 2006, as cited in Pompei & Bedell, 2008), which may indicate that the scores of a cognitive assessment could become invalid quickly. Regular reviewing and monitoring was deemed necessary. Some of the EPs mentioned the use of DA, such as the approaches endorsed by Feuerstein (1980) and Tzuriel (2001), which they felt may capture the child’s ability to learn new information more appropriately than cognitive assessments. The use of DA approaches with children with ABI requires further research to determine the extent of its usefulness.

Finally, another issue of concern to the EPs relating to assessment was the nature of assessment reports written by health professionals. For example, neuropsychological tests which typically focus on memory, executive functioning and cognitive ability had in most cases been conducted with the children but it was reported that such reports were often difficult for parents and teachers to interpret and apply to everyday circumstances, which in most cases, had lead to uncertainty of needs and lack of support for the child. The solution could be for neuropsychologists and EPs to work closely together when a child transitions back to school post-ABI (Flowers, 2008; BPS, 2006; DfES & DoH, 2004) to allow for the neuropsychological report information to be translated into the educational context for the school and parents.

Another issue relating to assessment was the importance of context. This issue questions the value of assessments administered to children out of their natural environment, e.g. at the hospital instead of at school or home, and how relevant such assessments are to the child’s everyday functioning. There have been calls in the US for school psychologists to be given training to perform these types of assessments in schools in order to make them more context-based and relevant (Ylvisaker et al., 2001). It seems the options in the UK are as follows: either EPs learn how to conduct these assessments in the child’s context or the neuropsychologist role becomes peripatetic and administers the assessments in the child’s context or, as suggested above, neuropsychologists and EPs could collaborate together, i.e. neuropsychologist could bring their expert knowledge of executive functioning and brain development and collaborate this with EPs expert knowledge of the child in context and dynamic uses of assessment. It is assumed that this is one of the reasons why the implementation of 'best practice guidance' (DfES & DoH, 2004) and BPS guidelines for children with ABI is so important. It would be interesting for further research to seek the opinions of neuropsychologists on this matter as well as practical solutions.

5.1.3 ABI as a unique SEN

Unsurprisingly, all EPs reported ABI as having a marked impact on the functioning of the child. These difficulties were wide-ranging but it appears that the way in which ABI can alter the child's functioning and sense of self is unique, especially for children who are very conscious of the changes that have occurred. However, this could be reflective of the fact that most of the EPs had been involved in the more severe cases that ended in SA, meaning that they might not have had experience or knowledge of the less severe end of the ABI 'spectrum'. Almost half of the EPs reported that the child's beliefs about themselves as a learner and as an individual were challenged post-ABI. For example, some of the children seemed to have good insight into how difficult some tasks became post-ABI and, in some cases, they indicated that they had to learn how to learn again. The older children reported that they found this frustrating as they could remember a time when they used not to have difficulty with the things they now struggled with. This echoes claims suggesting that the loss associated with the change in the sense of self and implications of the injury is the biggest issue for this population (Prout & Brown, 2007). This makes ABI different to other types of SEN. Their frustrations and upset could be interpreted as a form of bereavement for the person they used to be, e.g. some children asked when they would be 'normal' again. This links to previous research that suggests that parents experience feelings similar to loss and bereavement (Collings, 2008) and suggests that this could also be the case for children. The current study also highlighted how difficult it is for some previously independent and high-achieving children to accept adult support and to have support in the classroom for the first time. For example, one previously high-achieving child had to adjust to having a teaching assistant for the first time at the age of 15. This links to research that reported that adolescents with ABI can experience changes to self-identity, in terms of lowered self-esteem (Clark, 1996), as well as a feelings that their 'self is changed, if not lost entirely' (Prout & Brown, 2007, p. 437). These findings offer support to the claim that children with ABI have different needs to other children with SEN (see Walker & Wicks, 2005), as well as highlighting the possible emotional consequences of ABI (see Yeates & Taylor, 2006) that may need intervention.

It could be tentatively said that the children who appeared to have insight were children whose ABI had occurred at an older age. However, the EPs of the younger children reported that these children did not appear to be conscious of their changed level of functioning. This supports previous claims that pre-injury self-concept remains intact (Walker & Wicks, 2005). Both consequences – having insight or maintaining a pre-injury self-concept – can be problematic. For example, for the children who have insight it can be difficult for them to adjust to their new SEN and this can generate feelings of wanting to be 'normal'. Whereas for the children who maintained their pre-injury self-concept, difficulties arose in terms of their understanding of why they needed help as well as frustration when they could not do things that they thought they could do. Previous research indicates that children that have experienced ABI at under seven or eight years of age, do not recover in a similar way to older children and adults (Anderson, 2011), thus, whether a difficulty with insight is impacted upon by the age of injury warrants further investigation.

As well as this, in some cases, EPs reported that parents and teachers often indicated that the 'personality' of the child had changed. This could be linked to the child experiencing difficulties of executive function (see Jantz & Coulter, 2007; Ylvisaker et al., 2005; Slomine et al., 2002) which can lead others to feel that the child is a 'different' person. This could also cause key adults, such as parents and/or teachers, to adjust their behaviour around the child which in itself could lead to changes and difficulties for the child and influence the child's beliefs about 'being different'. This also links to reports of parents experiencing a grieving process (Collings, 2008) post-ABI for the child that they used to have or believe they could have had if the ABI had not occurred. This again indicates the need for intervention for families and schools, e.g. in terms of supporting them in dealing with the emotional responses that can arise when a child experiences an ABI. Systemic intervention as suggested by the ecological-transactional model (Bozic & Morris, 2005) outlines how EPs could intervene at different levels in the child's environment.

5.1.4 Emotional impact and needs

The current study supports the concept of ABI as a ‘family affair’ (Lezak, 1987). EPs indicated that ABI puts pressure on the whole family (supporting Conoley & Sheridan, 1996; Florian & Katz, 1991), including parents (supporting Collings, 2008; Hawley et al., 2003) and siblings (supporting Middleton, 1997; Orsillo et al., 1993). The experience for parents appears to be dominated by strong emotions related to the ABI and the child’s health needs (similar to the findings of Bohnert et al., 1987). The emotions reported by parents were similar to previous literature: denial (Walker, 2009), guilt and anger (Middleton, 2001a), grief and loss (Collings, 2008; Walker & Wicks, 2005; Middleton, 2001a). EPs expressed concern about how these negative feelings impacted on family functioning, such as routine and discipline, and commented on how, in their experience, parents had to deal with more difficult behaviour at home than is reported in the classroom. This could be due the parents’ diminished ability to parent consistently (McCusker, 2005) and again highlights the need for systemic intervention.

The children, although they appeared to have insight into their own feelings and learning issues, did not make reference to the emotional impact that the ABI had on their parents or siblings. This could be explained by Piaget’s theory of child egocentrism (see Smith, Cowie & Blades, 2003) combined with adolescent egocentrism (see Elkind, 1967).

In terms of response to needs, almost all of the teachers implied that school was a protective factor for the children with regard to offering emotional support for both child and parents. This is interesting given that parents reported a lack of emotional support provided by education professionals. This could indicate a mis-match in terms of the emotional support that teachers believe they offer versus the emotional support that parents want and/or need, or it could highlight that teachers and parents have very different perspectives on emotional support. Also, it could be reflective of social desirability effects on the interview responses, i.e. the teachers did not want to admit to not providing adequate support to the researcher. Or equally, parental responses could have emphasised the need for more support in hope of further support for their family as they knew that the researcher was a LA EP. However, if social desirability effects or parental agendas do not account for the mis-matched responses of parents and teachers, options for future intervention need to be considered. For example, either teachers need to be given more training on how they could meet emotional needs better, e.g. in accordance with Social and Emotional Aspects of Learning [SEAL] (DfES, 2005), or parents need to understand that is it not from schools that they should expect such emotional support. The former could involve professionals such as EPs offering further training and support to teachers and schools, whereas the latter could involve more specialist support directed at parents and child. This raises the issue of the rise of therapeutic intervention in education and could be an aspect of support that EPs could address (e.g. MacKay, 2007). Further research could explore the advantages and disadvantages of both options.

Similar to recently issued information (CBIT, 2010), children discussed issues relating to their independence and the need to be listened to by others (especially professionals). Again, similar to the CBIT information, children reported that school is a positive place but that they need more understanding and say in the support they receive. As previously suggested by (Bohnert et al., 1997), knowing the main concerns of the child is important, as they may need support with relationships and learning before addressing a wider range of needs.

It is disappointing to observe that most of the parents reported at least one negative experience with professionals (mainly professionals from education and social care). Although it has been indicated previously that 60% parents of children with disabilities rate their experience with professionals as ‘poor’ or ‘unsatisfactory’ (Bennett, 2009), the current study indicates that parents with children with ABI typically have at least one negative experience with professionals. When the reason for the negative experience was explored, it appeared that it was mainly in terms of professionals reportedly having a lack of understanding of the child’s needs and parental concerns. This reflects previous research which has indicated that education professionals are unlikely to be knowledgeable about ABI (e.g. Hawley et al., 2004). It also supports claims that a specific unmet need of parents of children with TBI is the desire to have their children’s teachers and peers understand their children’s problems (Armstrong & Kerns, 2002). Much reference was made to professionals thinking that because the child looks ‘normal’, that they must be ‘normal’, indicating support for claims that the needs of children with ABI are often missed, or symptoms of brain injury misconstrued (Molloy, 2008) and reports that teachers may overlook and misinterpret brain injury related deficits (Jantz & Coulter, 2007). It could be that this apparent lack of recognition of needs is linked to research that shows that the lay public focus on outward appearances (see Linden & Boylan, 2010), which is an indication that those without any training may have misconceptions about ABI. This could imply that some professionals without any training or support for working with families affected by ABI could practice professionally according to similar beliefs as those of the lay public. This is a cause for concern given the complex and long-term needs typical of children with ABI. It is also concerning as it indicates that parents are not feeling supported by professionals, which could have a knock-on effect on their ability to support their children (who look to their parents for primary support).

However, when a positive relationship with the school, and/or a particular professional, was reported by parents, they linked this to feelings of relief and ability to cope. This supports research that reports that when education meets a child's needs (in terms of disabilities in general, the family feel stronger (Bennett, 2009).

5.1.5 Advocacy and resilience

The current study suggests, similarly to previous research that parents are often forced into the role of child advocate and 'link person' for the professionals, e.g. in terms of telling schools about the ABI and sharing further information between health, education and when appropriate, social care (e.g. Hawley et al., 2004). For the majority of parents, this was reportedly a stressful, time-consuming and confusing role for them as they were under extreme emotional stress as well as adapting to parenting a child with ABI. Many of the parents felt uncertain of the role and reported that they lacked the knowledge required to fulfil it (supporting previous research by Hawley et al., 2003). The combination of the emotional impact and new advocacy duties could mean that they are under so much pressure that it affects their parenting (suggested by McCusker, 2005).

Most of the parents reported actions such as being proactive, negotiating complex systems, and acting as a 'link' person between professionals that they undertook which mitigated the aforementioned negative feelings. EPs reported that some families demonstrated elements of resilience building on the research on resilience in parents of children with TBI (Collings, 2008). Not only is this form of resilience found for the parents but the older children's interviews also indicate resilience. For example, their references to the importance of 'self-help' in terms of asking questions and staying positive indicate that fostering resilience can play an important role in recovery from traumatic circumstances, e.g. as suggested for chronic illness (Wells & Schwebel, 1987) and massive trauma (O'Dougherty-Wright, Masten, Northwood & Hubbard, 1997). It is uncertain as to whether child resilience emerges from the modelling of parental strength and resilience, vice-versa or as a result of an interaction of both. The current study purports that, for many children and parents, levels of resilience seem to emerge over time and enable them to overcome some of the difficulties and that parental factors play a key role in fostering resilience in children with ABI.

This has implication for how professionals work and approach intervention with these families. For example, EPs could foster this potential for resilience within children and families through the use of tools such as the PGI (Cadena, 2008; Hawley & Joseph, 2008). The EPs indicated that some of the families that demonstrated resilience had initially gone through a period of denial which could suggest that denial is a coping mechanism (Collings, 2008) that allows these families to get to the next stage in their ability to cope and should not be dismissed by professionals. It is interesting that none but one of the teachers made reference to any positive emotional outcomes of ABI such as resilience, suggesting that teachers may need support to enable them to look for strengths and positive growth in children and families post-ABI.

5.1.6 Information-sharing

Lack of information from professionals was a dominant theme across all the adult datasets. Parents found this frustrating in terms of dealing with uncertainties about their child's outcomes and this had a huge emotional impact on the parents. Although it is suggested that professionals should be honest and tell parents when they are uncertain about the child's outcomes (e.g. Middleton, 2001b), it is evident that parents found professional admission of uncertainty very difficult to deal with. There appeared to be a pre-ABI belief amongst parents that professionals can predict outcomes for children, e.g. what their child's potential is and what the child's abilities will be like in ten years time, which was shattered when parents were told by professionals that they could not predict this. This could be indicative of macro-systemic influences such as cultural beliefs and attitudes of the general public that are only confronted when a parent is put in the sudden position of parenting a child with ABI.

Parents who reported better outcomes tended to be the parents who had professionals who shared information. This appeared to make it easier for parents to cope. However, professional information-sharing was not the norm. There are obvious difficulties with addressing this issue, e.g. medical professionals cannot share information without parental permission (in accordance with the Data Protection Act, 1998). However, parents cannot ask medical professionals to share information unless they know that there are professionals who could help them when the child leaves the hospital, e.g. one parent had never heard of educational psychologists and it was for this reason that he said he never asked for the information about his child to be shared with educational professionals. Therefore, it must be put to parents by hospital professionals, perhaps at a discharge meeting (if they have one – see Tomlin et al., 2002, for their research on this), that 'best practice guidelines' recommend that this information should be shared with education professionals such as EPs and for informed consent to be gained at that point. It has been previously suggested that parents need and value information about how to get support in school and about local and national support groups (see Kreutzer et al., 1994). Parents need to be given this information pre-transition, ideally at pre-hospital discharge.

Lack of information from other professionals (primarily health professionals) was cited as the single largest difficulty faced by teachers. Teachers overwhelmingly reported that they were not given adequate information about the child's injury and needs on return to their classroom. Although in a few of the cases, a school representative had either visited the hospital or attended a multi-professional meeting, sometimes this had been the school Special Educational Needs Coordinator [SENCo] rather than the child's teacher. This supports previous research that claims that there is a frequent absence of information from hospital sources to schools (Hawley et al., 2004). The teachers reported that they found the lack of information from outside professionals frustrating but for different reasons to that of the parents. The teachers wanted the information in order to be able to plan better strategies for both classroom learning and emotional support for the child. Teachers seemed to have difficulty understanding the children's difficulties and linked this to a lack of information from other professionals, e.g. some teachers had not been given any information on the child's needs. This offers an alternative perspective that education is letting down children with ABI (see Flowers, 2008) in that it indicates that educational professionals are not given adequate amounts of information from health professionals to enable them to meet the educational needs of children with ABI in the first place. A video and booklet with teaching strategies has been developed (Walker et al., 2005) but none of the teachers had knowledge of this. The point is not to pass the blame from educational to health professionals but to highlight the need for a co-ordinated procedure.

5.1.7 Multi-agency working

Teachers reported that there is not enough multi-agency working in practice. Although never directly stated, teachers appeared to be a very isolated group from the professional network. All of them repeatedly mentioned issues about the lack of information they received about the child's ABI and, even when they do receive professional reports about the child's ABI, they do not know how to 'translate' it into practical strategies in the classroom. This is worrying given that teachers are considered the primary service providers for children following ABI (McCusker, 2005) and spend the most amount of time with children in an educational setting (Jantz & Coulter, 2007). The current study implies that professionals, both from Health Services and Education, need to work harder to include teachers in planning for children with ABI. This has its challenges given the time pressures of the teacher's working day but it should be strived for.

Secondly, although EP experiences varied considerably, overall there was consensus that accessing information from health professionals was problematic – similar to the experience of teachers. EPs found the lack of information available from health professionals and the difficulties with multi-professional liaison challenging for similar reasons to that of the teachers in that it left them with little information upon which to base their assessments and interventions, and lead to a forced position of uncertainty when asked by teachers and parents about future outcomes. This has been previously indicated by research (Hawley et al., 2004; Tomlin et al., 2002). The few EPs that did experience multi-professional liaison reported positive outcomes as a result of this and it was seen as a major facilitator of support for children and families and could possibly be conceptualised as a factor towards social resilience.

5.1.8 The EP role

EPs were highlighted by the teachers as having a key mediatory and leadership role, as well as providing valuable perspectives. Worryingly, some of the teachers reported that the EP was the only professional who had given them any information on the child's needs (similar to the findings of Bozic & Morris, 2005), highlighting again the isolation that teachers can feel from the professional network. This has implications for the amount of support that the child will receive from their immediate educational environment.

Parents, who did know about EPs but had difficulty accessing the service, emphasised the need for greater EP involvement in ABI. However, this theme must be treated with caution as parental knowledge of the researcher's role as an EP in the LA could have influenced interview responses. Also, it was clear from some of the parental comments that parental views and expectations of the role of the EP and the actual role of the EP were not compatible, e.g. one parent appeared to expect an EP to play an almost psycho-analytical role in helping her child deal with the trauma of the ABI, while another expected a full cognitive assessment which she assumed would predict her child's potential future abilities. These issues again could be explained by macro-systemic level cultural beliefs about psychologists and the purpose of assessments. They are potentially conflicting issues that affect EP involvement and need to be addressed macro-systemically at both local and national levels. The recent call for responses to the SEN and Disability Green Paper (DfE, 2011) gives EPs the opportunity to have their say on topics such as the future EP role. It is up to EPs to take opportunities such as this to address issues pertaining to their role. They could also do this through the provision of local information and training and possibly through greater involvement with the media. Byron (2010) recently held a seminar asking why clinical psychology is not a public-facing profession; perhaps the same should be asked of educational psychology? Increased cultural and parental knowledge of the EP role and the purpose of assessments combined with open-mindedness from EPs in how they could address these issues could ensure greater public knowledge.

5.1.9 Professional knowledge and training

None of the teachers had received any training on working with a child with ABI in their professional training. This is understandable given the low incidence of ABI in the general school population and unsurprising because it is common for teachers to have no training for working with children with disabilities (Eiser, 1993). Most of the teachers reported that they received most support from the school SENCo. Three of the teachers had been given specific information about ABI from their school EP but the rest of the teachers had not been given any specific information on ABI from anyone, even though they are the main educator in the child's daily life. For the three that were given additional, specific information on ABI, they reported that this helped them to understand the needs of the child better, as well as helping them to understand what the parents might be going through. They reported that this means that they could better support the child's learning needs at school indicating that better informed teachers can make a difference to the education of children with ABI (and EPs are well-positioned to take on this role). Further research is needed to replicate this on a greater scale. The aforementioned frustrations of teachers, goes some way to explaining why the education system was accused of 'letting down' children with ABI (as claimed by Flowers, 2008). The thematic analysis on the teachers' interviews would indicate that the system is not set up to enable the education system to optimally respond to the needs of children with ABI.

Many EPs indicated that, at first, they were intimidated by working with a child with a brain injury and all except one of the EPs said that they had had no prior experience or training in ABI. None of the EPs had had coverage of ABI in their initial professional training. Interestingly, most EPs reported that, with time and independent research, they realised that they had the skills to identify the child's strengths or needs. That said, throughout the interviews, many of the EPs indicated that upon reflection that if they worked with a child with ABI again, they would approach some aspects of working with ABI differently, e.g. assessment approach or considering the emotional impact on the parents and siblings in greater detail. They also indicated that they had to do a lot of independent work in terms of gathering information on ABI and their role would have been easier if they had had previous introductory training or access to resources specifically for EPs and working with children with ABI in the education system. Indeed, there are a few resources that do exist for EPs and ABI (e.g. Walker, 2009) but none of the EPs had heard of them or used them.

This, along with previous research - which indicated only 2.6% of EPs reported high coverage of TBI/neuropsychology in their initial professional training, in terms of the taught curriculum (Bozic & Morris, 2005) – indicates just how little specific training EPs receive on ABI, even though they do work with children with ABI, and, as the aforementioned TBI research has pointed out, EPs are sometimes the only psychologist or only professional that the school and parent liaise with for learning and behaviour when the child is no longer in hospital. This is worrying, especially in light of recent international findings. For example, school psychologists (in the US) only performed slightly better than the lay public in a survey about TBI, and surveys on the lay public (in Northern Ireland) indicate a general failure to note that ABI is a 'hidden disability' (Linden & Boylan, 2010). This could indicate that professionals without appropriate training do not have better knowledge of ABI than a lay person.

The current study supports the statement that TBI is 'an underdeveloped dimension of EP delivery' (Bozic & Morris, 2005, p. 117) and suggests that this is the case for ABI in general. However, taking into account the role outlined for EPs in 'best practice guidance' (DfES & DoH, 2004), BPS guidelines (2006) and NICE guidelines (2007) as well as research indicating the long-term consequences of ABI, it is important for EPs to be informed about ABI and appropriate procedures – especially at a time in the identity of the profession during which Educational Psychology is looking to expand its role and face the challenges hinted at in the SEN and Disability Green Paper (2011).

5.2 RQ2 What type of support has been experienced by those affected by ABI in home and educational settings, and what type of support should be implemented in the future, particularly in relation to the EP role?

5.2.1 Children

The thematic analysis of the children's interviews highlighted how dependent children with ABI are on their parents for support, both emotionally and for learning, rather than professionals, indicating that the children perceive the role of their parents to be most important in their recovery. This finding adds further weight to the concept of systemic intervention, e.g. professionals should target their support towards parents (similar to the approach taken by Braga, 2011).

When asked about what professionals could do to help them, the sentiments of the older children supported information issued by CBIT (2010), i.e. they would like professionals to listen to their views and include them in intervention planning. For example, one child recalled fondly a physiotherapist who did just that. This was a rare example. Participation in issues that affect them is reported to be beneficial to children's development (Cavet & Sloper, 2004), e.g. listening to and valuing children's views about education may help to increase their confidence and improve attitudes to learning (Owen, Hayett & Roulstone, 2004). This is also noted in the SEN Code of Practice, which states that encouraging SEN pupils to track their progress will contribute to improved confidence and self-image (DfES, 2001a). This has implications for the use of consultation[2] (Wagner, 2000) and solution-focused approaches (Ajmal & Rees, 2005) directly with the child – approaches which are frequently employed by EPs.

Overall, the children's recommendations were very within-child focused and demonstrated how children depend their recovery upon adults in their immediate and daily environments, e.g. parents and teachers, rather than professionals. This could be reflective of child and adolescent egocentrism (Smith et al., 2003; Elkind, 1967) but also supports suggestions that professionals should be targeting the key adults in the child's micro-system alongside working with the child (e.g. Braga, 2011).

5.2.2 Parents

The findings of the current study indicate that most of the parents of children with ABI, unlike their children, perceive themselves to place heavy importance on professionals and their child's school for support. This supports previous research (Waaland et al.,

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[2] EP consultation has been promoted as a 'voluntary, collaborative, non-supervisory approach established to aid the functioning of a system and its inter-related systems' (Wagner, 2000).

1993, as cited in Middleton, 2001b) that reported that families rated teachers and professionals as more important than extended family in terms of support. For parents, recommendations revolved around the need for greater support for their children and the desire for greater understanding from professionals (an unmet need also proposed by Armstrong & Kerns, 2002). They indicated that they would like more information about services available to them post-ABI (again supporting Armstrong & Kerns, 2002). There were mixed views expressed about support for the child, e.g. some parents wanted their child to have therapeutic support to deal with the trauma of the ABI, whereas other parents did not want their child to be singled out and treated differently to other children in the class. However, the consensus seemed to be that all the parents wanted professionals to be knowledgeable about ABI and for resources and support to be easier for their children to access than they have currently experienced.

Parents also made reference to protective factors such as multi-professional liaison (relieving parents of the 'lead professional' role) and knowledgeable professionals with experience of ABI. It is these protective factors that should be incorporated into any intervention planning for children returning to school post-ABI. Positive relationships were also reported in relation to EP involvement in all but one case. Many of the parents commented especially on they appreciated the EP's emphasis on the child's strengths instead of deficits and maintained a solution-focused approach to meeting the child's needs. This reflects the philosophy and ethos of EP training which is based on appreciative inquiry (Annis Hammond, 1998) and incorporates solution-focused approaches in schools (e.g. Ajmal & Rees, 2005).

Many parents reported stories about their child not fitting categories and not reaching thresholds for certain resources and this frustrated them. Judging by the level of frustration expressed by parents and their unrelenting eagerness to tell the researcher about the need for better support; it indicates that currently, the needs of parents with children with ABI are not being met. There could be a number of reasons for this, it could be due to: a lack of knowledge about the available services; difficulty accessing the desired services; or simply a lack of services in the local area. For example, in some cases, where the parents requested support with parenting, it was simply not available.

Although Middleton (2001b) suggests that for families, the most valued type of support is information and contact with other families who have been affected by ABI, the parents in the current study appeared to have contrasting views. For example, some parents reported that meeting other parents made them feel worse and that they would prefer to try to fit in and meet with ‘normal’ families as much as possible. Conversely, other parents (mainly the parents who were single parents or had few nearby family members) reported that they would like to be in contact with other families affected by ABI. Two of these parents even reported that they would like their child to meet other children with ABI, so that they would know that they are not the only one. Such findings indicate that recommendations that are desired by some families may on the other hand be undesired by other families and that should bear this in mind when planning intervention. It must also be kept in mind by professionals that some interventions, although implemented with good intentions, can cause harm, e.g. research that reports that an information support group for parents of children with TBI increased anxiety and depressive symptoms (Armstrong & Kerns, 2002). This leads us back to the point that the most important thing with any intervention is to adopt a consultation approach with the family that empowers the family to decide, based on informative expert guidance, what would work best for their unique set of needs. Thus, overall, it is recommended that when working with parents, professionals such as EPs should adopt a consultation-based approach to intervention planning and review and work towards supporting families to reduce their reliance on professional support.

5.2.3 Teachers

Given that research shows that school and classroom organisation can impact on emotional and behavioural difficulties (e.g. Evans et al., 2004), it is important to improve systems in schools. Teachers’ recommendations largely revolved around having more information: about the child’s ABI, about the typical learning and emotional needs, likelihood of future outcomes, and practical strategies of how to support the child best in the classroom (e.g. Rees & Skidmore, 2008a; Rees & Skidmore, 2008b). Literature also indicates that teachers could benefit from information on how to support children’s self-management skills (e.g. Selnick & Savage, 2000) and support on how to “*act as their frontal lobes*” (Yeates, 2011). Teachers appeared to be very isolated from professional networks and often the only professional they had spoken to about the child was the school EP. The teachers' thematic analysis indicates that teachers would welcome more practical resources, e.g. information leaflets, books, and evidence-based strategies. As some of these resources already exist (e.g. Walker, 2009, and various publications from the CBIT), it is a matter of creating a system that enables teachers to have access to informed advice and support about ABI. If EPs could improve their knowledge and resource-bases on ABI, they could be well placed to take on this pivotal role.

Many of the teachers felt it unfair and unhelpful that when information is not passed to the school, it is left solely up to the parent to play an information-sharing role. The teachers reported that this is often unsuccessful as parents are often too busy or traumatised or because the parent simply does not understand the ABI themselves. They would appreciate more direct contact with health professionals, or a professional who could take on the mediating role for the parents to address the information-sharing issue.

5.2.4 Educational Psychologists

As regards recommendations for the future, all of the EPs were systemic and solution-focused in their orientations. Recommendations concerning transition management, systemic approaches to support and intervention and the enhanced role of the EP regarding training, mediatory roles, psychological support and developing policies in relation to ABI, were dominant.

EPs were of the opinion that schools and LAs need to develop planning and support procedures for children with ABI, however most EPs emphasised that schools will need support from the LA to do so. Although recommendations did not go as far as a previous claim that all teachers should have access to a TBI specialist for consultation (Ylvisaker et al., 2001), the EPs did feel that teachers and schools should be supported by key professionals who already work with the school, e.g. EPs. All of the EPs strongly supported the role of the EP with children with ABI, and all agreed that EPs are ideally placed to play a supportive role across the child's eco-system.

To address issues of working towards multi-agency working Hughes (2006, p. 63) suggests ‘a ladder of multi-agency involvement’ moving up the ladder from along a continuum of cooperation to integration. This could be a useful framework for EPs upon which to base future efforts towards building multi-agency working for children with ABI. However, Hughes (2006) cautions against assumptions that multi-agency working is ‘a good thing’ and he endorses the need for ‘form to follow function’, i.e. that children’s needs, service needs and staff experience, skills and location should be considered first (Warren House Group, 2004, as cited in Hughes, 2006).

Although, the previous research question indicates that resilience can emerge within children and parents, it could be that their resilience is actually a form of social resilience (Bloom, 1996) that is reliant on the environment around them. This again emphasises the importance of applying an ecological systems approach (Bozic & Morris, 2005; Bronfenbrenner, 1979).

5.3 Implications for practice

This section will outline how the findings of the current study could inform professional practice. The focus will be on the profession of Educational Psychology and the unique role of the EP. The ways in which an EP could implement key recommendations are suggested within the ecological-transactional framework (Bozic & Morris, 2005).

5.3.1 Professional Practice of Educational Psychology

Previous research has identified support for TBI as an ‘underdeveloped dimension of EP service delivery’ (p.117, Bozic & Morris, 2005). The current study builds on and extends previous research by highlighting further ways in which the EP could intervene for the child with ABI (and not just for children with TBI).

The following is a summary of how EPs could better promote educational outcomes for children with ABI based on the results and interpretations of the current study and according to the ecological transactional model:

At the onto-genic level

- Work directly with the child using consultation and solution-focused approaches to empower them to co-develop and co-review strategies and intervention;
- Support the development of a ‘story’ of the child’s experience, e.g. using narrative approaches;
- Support the child in development of communication skills and confidence to ask for help and voice opinions;
- Have a flexible approach to assessment, e.g. DA approaches and conducting assessment in context and over time.

At the micro-systemic level

- Provide information on ABI to parents including: normalisation and validation of feelings that ABI might evoke; details of local services and/or charities that parents can contact for more information;
- Provide information to parents on the EP role and how they could support outcomes for the child;
- Provide the school with information, support and access to resources specific to ABI;
- Work with siblings to develop their understanding of ABI and empower parents to take on this role at home and in the future;
- Support the school in transition planning for the child’s return, and preparation for future transitions, e.g. make a ‘passport’ for the child that accompany them at transition points and can be updated;
- Offer regular consultation and review to the child’s teacher and SENCo;
- Encourage the school to promote social inclusion and SEAL and support information-sharing with the child’s peers;
- Offer parenting support and/or therapeutic services.

At the exo-systemic level

- Ensure that local hospitals are aware that they can contact, and know how to contact, EPs to tell them of any children with ABI who may be returning to school in the area;
- Attend multi-professional meetings, e.g. the discharge meeting, CAF meetings;
- Information-share with other professionals (with parental permission) and seek information from other professionals;
- Promote awareness of ABI in schools, e.g. information materials, offer staff training;
- Ensure that the EPS has a policy and procedure for working with children with ABI;
- Promote ABI awareness amongst EPs through introductory sessions in initial professional training, e.g. 'children with medical needs'.

Beyond professional practice and the LA – the macro-system

This is the most difficult part of the system to induce change, however, if achieved, it could be the most effective way to enable long-term change for children with ABI. One of the key recommendations that arose from the current study is the need for LAs to keep a database of children with ABI. This would enable LAs to know the size of their ABI population and where they attend school and enable the LA to know where to target services. This system could be set up in conjunction with local (and national) hospitals. Through this database, research could be more easily conducted with the ABI population and allow for local evidence-based practice to emerge over time. This may not be a realistic, immediate outcome but the first steps need to be made to bring this about. For instance, this could be something that Educational Psychology as a profession – given their well-placed position within LAs, knowledge of child development, experience in educational settings as well as their research skills – could make a priority. To establish how this can be best be put into practice, one or more 'pathfinder' LAs could be set up under the remit of local Educational Psychology Services to address this issue in the short-term and enable long-term change.

Changes to cultural attitudes and ideologies are also needed and will penetrate all of the other parts of the system more successfully than any other intervention. For example, it would be beneficial for professionals such as EPs to talk to the media about ABI and how it realistically affects children and families. Professionals and experts should aim to and help families strive for equal rights for their children and support services which offer adequate support. Parents need to be helped to get out there and be heard, e.g. in local communities or perhaps in local schools and hospitals, working with staff on how best to work with families or working directly with families who are going through what they previously experienced. Famous people or those of influence who have been directly or indirectly affected by ABI could discuss matters pertaining to ABI in a number of ways: through the media (e.g. Olympic gold medallist James Cracknell's appearance on the BBC, 2011); through the use of technology, e.g. social network forums or blogs; or, through political lobbying. In terms of EPs, EP knowledge and expertise in this area could be increased through introductory sessions in initial professional training on topics such as 'children with medical needs' or through Continued Professional Development [CPD] activities and an EP interest group. It is only through these actions that cultural attitudes and ideologies will shift towards more understanding for those affected by ABI, and in turn, offer more hope and understanding, and ultimately, inclusion for children with ABI. Furthermore, appropriate and timely support is very likely to reduce costs and enable better outcomes for these children and their families, and society in general.

5.4 Review of methodology

The results of any study should always be considered within the limitations and strengths of the methodological design.

5.4.1 Limitations

Any 'real-world' research will have unavoidable limitations in its methodological approach. Differences in methodology of the current study could account for differences in the results of this study in comparison to the previous literature.

At first glance, a limitation of this study appears to be the small sample size of children with ABI (n=6). One of the main reasons for this was the difficulty in identifying who in the LA had been affected by ABI due to a lack of any formal recording system being in place in Children's Services. As well as this, ABI is a low incidence disability which makes it difficult to conduct research with a large sample size when focused on one particular geographical area. The only other information gathered in a qualitative manner from children with ABI (CBIT, 2010) also had a sample size of 6 children with ABI – across six counties - indicating how difficult the recruitment process is, even for a national charity with a formal database of children with ABI. Bringing this knowledge into consideration, the current study's sample size of six children within the same borough appears satisfactory. However, it must be considered that, although interviews were only conducted with six children with ABI, the total number of children with ABI discussed across the datasets in total is greater (n=16).

Secondly, the make-up of the sample may be influenced by the 'opportunistic sampling' strategy that had to be employed in the absence of an LA database of those affected by ABI. For example, the sample may only be representative of participants who are known to EPs, and may not take into consideration those who have never been known to an EP. As previous research indicates that EPs are only involved in 50% of ABI cases (Tomlin et al., 2002), it could be assumed that the sample of parent and teacher participants in the current study may only be representative of half the borough's child ABI population and is therefore biased to the more extreme end of the continuum. The sample could also be biased as there may be significant differences between ABI cases known to EPs and those that are not known, meaning that the current study only explores the experiences of those children, parents and teachers who have had EP involvement.

Thirdly, it is not possible to generalise the findings to the whole population of children with ABI, or their parents, teachers and EPs. All that can be concluded is that these experiences, perspectives and recommendations given by the participants in this research go some way to explore the experiences of those affected by ABI. The recommendations given by the participants should be taken into consideration when working with similar populations but it should not be assumed that the recommendations made in this study are automatically transferable to the generalised ABI population. Indeed, the information gathered may only reflect the needs of this particular demographic group in this area of London.

Finally, another limitation was the way in which the interview process relied on self-reported and retrospective reflections, sometimes up to five years old. This has implications for the accuracy of the data gathered. On top of this, the children interviewed all had SEN which for some included memory difficulties. This could have influenced their self-reports and their ability to engage in the interview process. However, this was unavoidable as it is impossible to interview children who have experienced difficulties post-ABI who do not have any form of SEN.

5.4.2 Strengths

Firstly, although the small sample size of child participants is a limitation, the total number of interviews, 37, is a relatively large sample size for qualitative research of this nature. The large number of interviews, along with the rich data that these interviews provided, allowed the current study to be the first piece of in-depth qualitative research that explores the holistic experience of ABI in the home and educational settings from the perspectives of children, parents, teachers and EPs.

Secondly, another strength pertains to the effort which was made to ensure that all child participants' gave informed consent when interviewed for the study. The audio-visual slide-show shown to children before the interviews aimed to promote the child's understanding of who the researcher was and what the research was about as much as possible. Not only this, but when appropriate, visual aids were used when interviewing some of the children (e.g. see guidelines of Lewis & Porter, 2004).

Thirdly, another particular strength of this study was the quality of the data analysis. In terms of the thematic analysis, strict guidelines (see Braun & Clarke, 2006) were adhered to. The analysis bears most of the markers that are considered important when employing qualitative methods (see Yardley, 2000).

Finally, a strength of the methodological design of the study was that it enabled the research questions to be answered thoroughly, as well as allowing for rich data to be obtained. The use of semi-structured interviews with open-ended questions enabled flexibility within the interview process and, therefore, allowed participants to express their views without the restriction that closed questions could impose. This allowed topics that emerged during interview to be explored thoroughly and ensured that the data was driven by the participants' perspectives.

5.5 Future research

Firstly, future research on the experiences of those affected by ABI, could aim for a larger number of participants, over a greater geographical area. This would enable findings to be more generalisable across the ABI populations.

Secondly, it would be beneficial for a future research study to also interview an age-matched control group of children (e.g. orthopaedically-injured children), and their parents, teachers and EPs in order to compare the hospital-school transition experiences of each group. This could help determine whether there are marked differences between the transition back to school and subsequent support needed by those affected by other medical needs in comparison to ABI.

Thirdly, due to the time-cost factor of the current study, it was only possible to conduct one interview with each participant, and due to the low incidence of ABI, the researcher did not have the opportunity to be more selective about duration since injury. However, future research could be conducted over a longer period of time and repeated, longitudinal interviews could be timed to be held at key moments in the child's life post-ABI, e.g. when the child first leaves hospital, after the child's first term at school, after the child's first year at school, five years afterwards, to explore whether there is a typical transitional and emotional trajectory that the child and parents experience post-ABI.

Finally, if recommendations from the previous literature and the current study could be put in place, it could be beneficial to follow-up on children and parents who have experienced 'best practice guidance' and explore their experiences of the recommendations in practice and refine them accordingly. Thus leading to a more robust knowledge base of what works for children with ABI and their families.

5.6 Research implications

The current study has implications beyond the further recommendations of the participants. This section will outline general recommendations that arose from the current study.

Firstly, with regard to the key adults in the child's life, although it was not directly recommended by participants, it is interesting to note that many of the adult participants in the study commented on how helpful the interview process itself had been in helping them reflect on the process and how things could be done differently. This in itself indicates that time for professional reflection for teachers and EPs is a helpful strategy (linked to Schon's 'reflective-practitioner' model, 1983). Many of the parents also commented that the interview was the first time that they had sat down for a significant amount of time with a professional and focused on their own emotional responses and how the ABI had affected the family. These parents, although many became upset, felt it was a worthwhile process. A consultation model of practice could support professionals and parents in their need to reflect and move things forward for themselves and the child.

Secondly, it is clear from the one hundred percent participant agreement rate, zero percent drop-out rate, and the length and depth of the parental interviews that parents of children with ABI are anxious to have their voices heard and to have opportunities to do so. Some of the parents spoke for over an hour and emphasised how glad they were that someone was conducting research on the ABI experience. Most of the parents were very eager to tell the interviewer about the unmet needs of their child and family. Not just this, but they clearly had many ideas on how things could be improved for children with ABI and their families. This highlights how strongly parents of children with ABI feel and how many suggestions they have. However, in the literature, they appear to be an under-represented group. Although none of the children had as much to discuss as their parents, they all provided valid suggestions, thus showing what an untapped resource they are in the ABI literature.

Thirdly, there seem to be very mixed views on the role of the EP on behalf of parents, teachers and even the EPs themselves. Some of the parents had assumed that the EP should be involved in therapeutic support for their child and were frustrated when this expectation was not met. Some parents and teachers believed that a cognitive assessment administered by an EP would tell them the child's 'potential' for the future and were frustrated when EPs (and other professionals) were either reluctant to administer cognitive assessments or were vague in their interpretation of them. One parent went as far as to say that EPs were told what to do by the LA and that EPs were more concerned with budgets than helping children. In contrast to that, the majority of parents and teachers felt that the EP's advice and expertise was a vital factor in improving outcomes. All these perspectives indicate that there is much confusion about the role of the EP and what EPs do. Therefore, EPs should think about how they could inform parents and teachers of their role and promote their role appropriately. Indeed, this may be a difficult task for the EPs given that the EPs themselves also had varying views of the role of the EP, e.g. some believed that EPs should operate a consultation-based service that emphasises the parent and teacher as 'expert' and the EP as their facilitator (based on Wagner, 2000), whereas others believed that EPs were the experts in measuring child strengths and needs through assessment and that this should be their role. However, despite disagreement over approaches to practice, all of the EPs agreed that they had a unique role to play with children with ABI and their families.

5.7 Concluding comments

5.7.1 Contribution to the knowledge base for ABI

The current study plays an active part in building on previous research as it asks the child directly about their experience, explores the range of emotions experienced by parents and why, explores the experience of teachers working with ABI in the classroom, and further explores the role of the EP in relation to ABI. The experience of educational professionals was considered important to explore as it had been previously reported that teachers (Jantz & Coulter, 2007; Hawley et al., 2004; DfEE, 1994; Eiser, 1993) and educational psychologists (Hooper, 2006; Bozic & Morris, 2005; DfEE, 1994) are unlikely to have prior knowledge about or training on ABI. Previous studies have carried out research on the perspectives of teachers and EP through questionnaires (e.g. Hawley et al., 2004) and surveys (e.g. Bozic & Morris, 2005) but exploratory interviewing on the education professionals' experiences of ABI had not been conducted. The solution-focused heart of the current study moves the knowledge base of ABI away from a within-child deficit focus and towards using information from those directly affected to implement intervention at various points in the child's environment. The current study does so with a particular emphasis on the role of the EP and suggests how EPs could support and develop their systems to promote better outcomes for this vulnerable population.

5.7.2 Personal reflections

Research that is carried out in the 'real world' can be said to be carried out in an 'open system', i.e. all aspects of the research are not under the researcher's control. However, while real world research cannot predict the future, 'the past can be explained by establishing the particular configuration which was in existence' (Robson, 2002, p. 41). True to these claims, the current study was a difficult and unpredictable process. For example, as there was no database for children with ABI within the LA, it made the identification of children with ABI very difficult and meant that the researcher had to rely on information from colleagues and opportunistic sampling. Not only was this a far from ideal sampling strategy but it was time–consuming for the researcher. This meant that the sampling and participant identification stage of the research took much longer than anticipated. The limited time-scale available to the researcher further compounded this process. It is highly desirable, in the future, as continued research in this field is vital, a database should be set up in LAs to not only assist research opportunities but so the LA knows how large their population of children with ABI is and can provide support accordingly.

A particularly rewarding aspect of the research was how enthusiastic and passionate the participants interviewed were about the importance of the research. All without fail emphasised how important they felt it was for the children and the key adults in their lives to have a voice and to have a say in how their support is managed. Such enthusiasm encouraged the researcher to persevere against the adverse research conditions and continue with the research project. Without the passion and enthusiasm of the participants, this research would not have been possible. This allowed the research questions to be answered and a significant contribution be made to the knowledge base of the experience of ABI in children and the key adults in their lives.

5.7.3 Summary

The research aimed to explore the experiences and needs of children with ABI and the perspectives of their parents, teachers and EPs. The results highlight the complexity and wide-ranging needs of children with ABI and their families and suggest that there is a need for improved professional liaison and specialist input, especially in terms of emotional support. A number of practical recommendations are made, especially in terms of practice for EPs. As with any research, findings are constrained by methodological limitations, but many strengths of this particular research are also present. The current research contributes to the knowledge base of the experiences of childhood ABI, especially in home and educational settings, and contributes to professional practice through recommendations and research implications across the child's eco-system. This is of particular relevance to EP practice and professionals working within both Health and Education Services.

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Appendices

Appendix I - Introductory Letter

Leading education
and social research
Institute of Education
University of London

Experiences of Children who have experienced an Acquired Brain Injury, their Parents, and teachers and EPs who have had involvement

Dear Parent or Carer,

My name is Laura Carroll. I am a trainee Educational Psychologist at the Institute of Education, University of London and also work with Educational Psychology in the London borough of Hounslow.

I am writing to ask you if you and your child would like to take part in the 'Experiences of Children who have experienced an Acquired Brain Injury, their parents, and teachers and EPs who have had involvement' project. The project aims to explore the experiences of children who have experienced an Acquired Brain Injury (ABI), their parents and teachers and EPs who have had involvement, in particular their experiences of the transition from back to school and the support received. ABI refers to any injury occurring to the brain after birth and the immediate neonatal period. I am interested in contacting any families in the area of Hounslow who have experienced this to find out their views. This project is being undertaken by me as part of my training for a Doctorate in Professional Educational, Child and Adolescent Psychology.

I was given your details by __________ , you informed me that you had spoken together and agreed for your contact details to be shared with me.

With this letter, you will find enclosed the following:

1) **Parent fact sheet** which explains what taking part in the project would involve for you and your child;

If you decide to support your child's participation, please show he/she the enclosed :

2) CD that explains the project in a child friendly way. This CD aims to support your child in making an informed decision about whether they would like to take part.

3) Green interest form has been enclosed for you to sign as evidence of consent;
4) Blue interest form has been enclosed for your child to sign as evidence of consent;

These can be returned to me using the:
5) Stamped addressed envelope.

I hope that in this pack I have answered all your questions and enabled you to make an informed decision about your participation. However, if you would like to discuss anything further, please do not hesitate to contact me on the details supplied below. If after two weeks I have not had any contact from you, I hope you will not mind if I follow-up this letter by contacting you by telephone.

I very much look forward to hearing from you and your child.

Best wishes,

Laura Carroll
Trainee Educational Psychologist
020 xxxx xxxx
Lxxxxxxxx@xxx.ac.uk
Laura.carroll@xxxxxx.gov.uk

Appendix II – Information leaflet

Leading education and social research
Institute of Education
University of London

Experiences of Children who have experienced an Acquired Brain Injury, their Parents, and teachers and EPs who have had involvement

Introduction

Children and parents are being invited to take part in a project exploring the experiences of children with Acquired Brain Injury (ABI) and their families of the transition from hospital back to school. Teachers and EPs are also being interviewed to hear about how they have experienced involvement with children and families who have been affected by ABI. ABI refers to any injury to the brain after birth and the immediate neonatal period. Please take some time to read the following information before deciding if you would like to take part.

The researchers

The project is being carried out by me, a trainee Educational Psychologist, as part of my thesis for my Doctoral qualification in Educational, Child and Adolescent Psychology. The project is being supervised by Vivian Hill and Professor Ian St. James Roberts both based at the Institute of Education, University of London.

What is the project about?

Research has found that that about half a million pupils a year in the UK return to school after an Acquired Brain Injury. These figures highlight the growing importance of exploring the experiences of the children and families affected. However, most literature focuses on the deficits that can come with ABI. More recently, research highlights how with improved transition from hospital to school, professionals and families can play an important role in supporting the child back into education. This project would like to find out about the experiences of children with ABI and their families in terms of their transition back to school. The project will also explore the views of teachers and educational psychologists. The project particularly wants to explore the aspects of the transition process most helpful in supporting children and families.

What will taking part involve for me and my child?
If you and/or your child is interested in taking part, I can come and visit you in your home/school or somewhere else where you both feel comfortable talking to me. On this visit, I will tell you more about the research and answer any questions that you and/or your child may have. I will also ask you and your child if you still want to participate in the study. Your child can have you present during their interview if desired.

During the interview (approximately 30 minutes each):

- I will ask you questions about the support you were offered from the hospital, school and/or charity organisations, which aspects of support you found to be most helpful and how you think the experience can be improved. During the interview with your child I will ask he/she questions about what it felt like when they left the hospital and started back at school and about what things helped he/she make the transition back into school life. Visual prompts (e.g. a picture of your child's school) may be used to facilitate your child in the interview.
- You and your child will be able to tell me to stop or request a break at any time. If there are any questions that you or your child does not want to answer, you will not have to answer, nor explain why. If necessary, I will practice saying 'no' or 'pass' with your child before the interviews begins.
- I will take notes, and I will also ask if I can record what is said. Recording of the interview will only happen if you both feel comfortable about this.

What will be done with the findings?
Findings from the interviews will be written up in a report as part of my doctoral thesis. Your child can be sent a shorter child-friendly version of this report detailing the findings. Education professionals who work with children with ABI and their families will be given feedback from the study to inform their practice and help them provide an improved service for other families. It is possible that the report will be published in a journal relevant to ABI. This would enable the findings to reach other professionals and families. In all of the above reports, all personal details will be altered so that you and your child are not identifiable.

If you are happy for the school to give me your name and address, I will send you an information pack.

What does the information pack contain?
The pack contains an introductory letter for you and a CD for your child to let you both know:

- Who I am
- Why I want to speak to them and what the project is about
- What I want to talk to them about
- Answers to questions he/she might have

- That he/she can contact me if he/she would like to ask me further questions
- That if he/she is unsure whether to take part, he/she can talk to someone else to help them make up their mind

The pack is designed to support you and your child in making an informed decision about whether you would like to take part. There will be a **Green Interest form** enclosed for you to say whether you are interested or not. There will be a **Blue Interest form** to say whether your child is interested or not. Both can be returned using the stamped addresses envelope. You will then be contacted by me to organise the interview at a convenient time.

What are the benefits of taking part?

Taking part in this project will enable you and your child the chance to tell 'your story'. This may or may not benefit you personally. However, the project aims to help understanding of children's and parents' experiences of Acquired Brain Injury, and may help towards guiding the types of support that are currently available to families who experience similar events and improving the experience for them.

If after reading this information sheet you would like to discuss any aspect of the project further, please contact **Laura Carroll** on **020 xxxx xxxx** or email me at: laura.carroll@xxxxx.gov.uk.

Appendix III – Adult consent form

Adult Consent Form

Please return this form using the provided **stamped addressed envelope** to indicate whether you are happy to take part in the 'Experiences of Children who have experienced an Acquired Brain Injury, their parents, and the teachers and EPs who have had involvement' project.

Please tick one of the following sentences:

I **am happy** to take part in the project. ☐

I am not happy to take part in project. ☐

Comments:

Name: ____
(please print)

Signature:____

Date:______________________

Appendix IV – Child consent form

Child Consent Form

Dear Parent, please support your child to fill out this form if necessary.

Please return this form using the provided **stamped addressed envelope** to indicate whether you are happy to take part in the ‘Experiences of Children who have experienced an Acquired Brain Injury, their parents, and the teachers and EPs who have had involvement’ project.

Please tick one of the following sentences:

I am **happy** to take part in the project

☐

I am **not happy** to take part in the project.

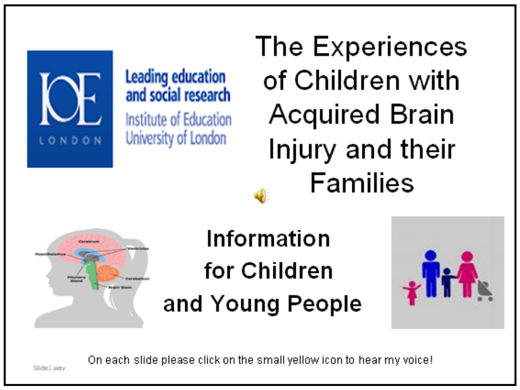
☐

Name: ____
(please print)

Signature:____

Date:__________________________

Appendix V – Audio-visual slideshow



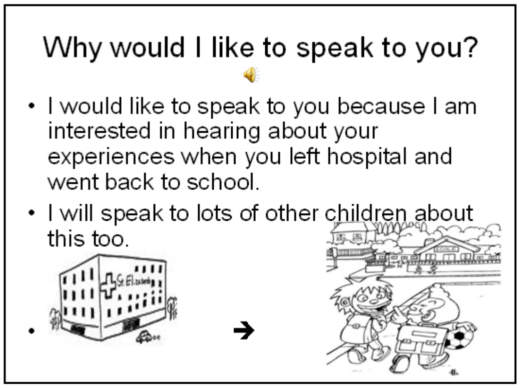
The Experiences of Children with Acquired Brain Injury and their Families

Information for Children and Young People

On each slide please click on the small yellow icon to hear my voice!

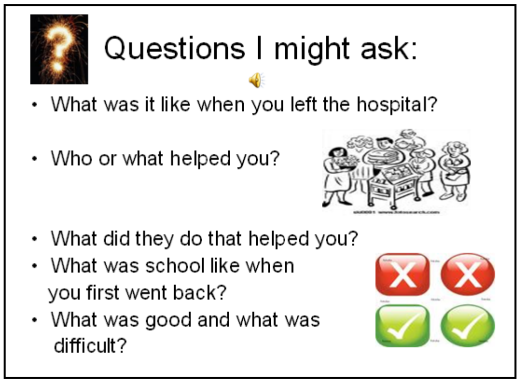
Who am I?

- My name is Laura Carroll.
- I work as a trainee Educational Psychologist. That means that I work with lots of children, families and schools and help them with any difficulties.
- Because I am still learning, I also go to university.



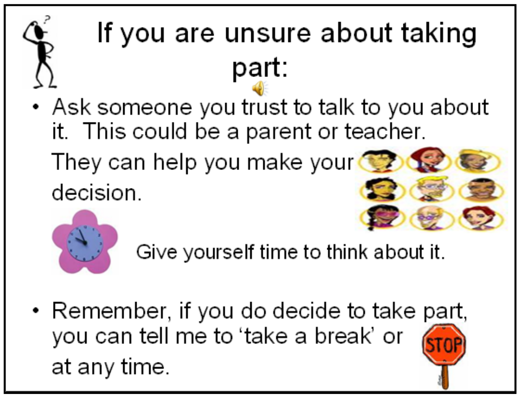
Why would I like to speak to you?

- I would like to speak to you because I am interested in hearing about your experiences when you left hospital and went back to school.
- I will speak to lots of other children about this too.



Questions I might ask:

- What was it like when you left the hospital?
- Who or what helped you?
- What did they do that helped you?
- What was school like when you first went back?
- What was good and what was difficult?

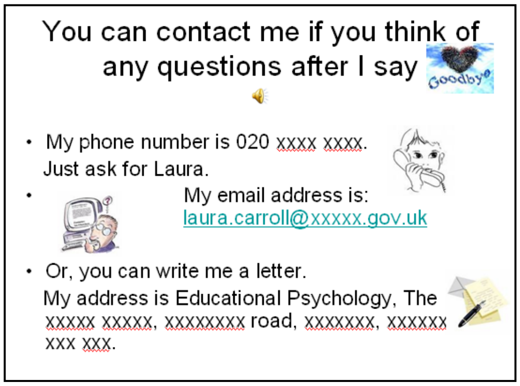


If you are unsure about taking part:

- Ask someone you trust to talk to you about it. This could be a parent or teacher. They can help you make your decision.

Give yourself time to think about it.

- Remember, if you do decide to take part, you can tell me to 'take a break' or at any time.



You can contact me if you think of any questions after I say

- My phone number is 020 xxxx xxxx. Just ask for Laura.
- My email address is: laura.carroll@xxxxx.gov.uk
- Or, you can write me a letter. My address is Educational Psychology, The xxxxx xxxxx, xxxxxxxx road, xxxxxxx, xxxxxx xxx xxx.

Thank you and Goodbye!

Appendix VI – Child interview schedule

General information (this information can be taken from the parent)

Name:
Current age:
Age at time of Acquired Brain Injury:
Type of Acquired Brain Injury, i.e. Traumatic or Non-Traumatic Injury (if TBI, was it a road accident or fall; if NTBI, was it a stroke, tumour or other?):

On the SEN register at school: Yes No
If yes, do you have a statement of SEN?

ABI

What things at school did you find a) easy b) difficult before your _______?
What things did you enjoy about school?

Do you remember being in hospital?

What feelings did you have when you left hospital? (show child feelings chart consisting of different facial expressions)

How did you feel about going back to school? (show child feelings chart consisting of different facial expressions)

What was it like when you went back to school? (show child feelings chart consisting of different facial expressions)

Did anyone at school do anything to help you when you went back to school? Did anyone at home do anything to help when you went back to school?
What made going back to school easier?
(prompt with 'Did your teacher help you? What did he/she do?', 'Were the other children nice to you? What did they do?')

Was anything different when you went back to school compared to before?

What were things like when you first went back to school? Did this change in any way over the next six months?

How are things now compared to when you first went back to school?
If an improvement, what has helped improve things for you at school?

Is there anything you would have liked anyone do to? (prompt with 'How can your teacher (and school) help you at school? How can your parents help you?').

What would you like to do when you grow up?

Is there anything you would like to tell other children who have also had a ________?

Appendix VII – Young person interview schedule

General information

Name:
Current age:
Age at time of Acquired Brain Injury:
Type of Acquired Brain Injury, i.e. Traumatic or Non-Traumatic Injury (if TBI, was it a road accident or fall; if NTBI, was it a stroke, tumour or other?):

On the SEN register at school: Yes No
If yes, do you have a statement of SEN?

Pre-ABI

What aspects of school did you find a) easy b) difficult before your _______? How serious were these difficulties (scale from 1 to 10)?
Had there been any previous contact with professionals such as an Educational Psychologist, Speech and Language therapist etc. before your ________?

The ABI

Which professionals are now involved?

What support did you receive in the first six months after? Was any support offered after this time? How effective was this support on a scale of 1 to ten?

Did you seek support from any other professionals/support services/charity organisations? How long did this support last and how effective did you think it was on a scale of one to ten?

Has there been any EP involvement? At what point did the EP become involved and for what reason? What involvement did the EP then have with you?

Since then, has there been any EP involvement? And, if so, how has the EP been involved?

You and school

How did your ______ affect your school experience initially? A) learning? B) socially?
How does your ________ affect your school experience six months later and now?
What support do/did you receive in school? How effective is this on a scale of one to ten? In your opinion, which aspect has made the most difference to you at school?

What are your views and experiences of how you and your family were looked after a) during the transition from hospital to school; b) upon your return to school; c) currently (if relevant)?

The family

How did your _______ affect your family's experience initially? How did it affect the family experience six months on? And, currently? What support did your family receive since your ______?

How do you feel your family has coped? Which aspect has made the most difference to your family?

Are you currently getting any support?
a) If no, would you like to have support? If so, what type of support would be helpful and how would this make a difference to you?
b) If yes, what type of support are you getting and how does it make a difference to you and your family? How adequate would you rate this support on a scale of one to ten? Can you suggest how the support could be improved?

Overall, what has been the most helpful support you have received?

Future

What are your hopes for your future?
What would you like from your school and education professionals?

Is there any advice you would like to give to a) other young people who go through similar circumstances; b) the professionals involved?

Why are these things important?

Appendix VIII – Parent interview schedule

General information

Name of child:
Current age of child:
Age of child at time of Acquired Brain Injury:
Type of Acquired Brain Injury, i.e. Traumatic or Non-Traumatic Injury (if TBI, was it a road accident or fall; if NTBI, was it a stroke, tumour or other?):

On the SEN register at school: Yes No
If yes, does your child have a statement of SEN?

Pre-ABI

Were there any concerns before your child's _______ (insert type of ABI) at home or at school? a) learning; b) behaviour? How serious were these concerns (scale from 1 to 10)?
Had there been any previous contact with school due to these concerns?

The ABI

Which professionals were involved?

What support services did your child receive in the first six months after? Was any support offered after this time? How effective was this support on a scale of 1 to ten? What support did you receive in the first six months after? Was any support offered after this time? How effective was this support on a scale of 1 to ten?

Did you seek support from any other professionals/support services/charity organisations? How long did this support last and how effective did you think it was on a scale of one to ten?

Was there any EP involvement? At what point did the EP become involved and for what reason? What involvement did the EP then have with your child and you?

The child and school

How did your child's ______ affect his/her school experience initially? A) learning? B) socially? How does your child's ________ affect his/her school experience six months later and now?
What support does/did your child receive in school? How effective is this on a scale of one to ten? In your opinion, which aspect has made the most difference to X at school?

When your child returned to school, was there any liaison between you and the hospital and the school? Is there currently any liaison?

What are your views and experiences of how your child and your family were looked after a) during the transition from hospital to school; b) upon his/her return to school; c) currently (if relevant)?

The family

How did your child's _______ affect his family's experience initially? How did it affect the family experience six months on? And, currently? What support did your family receive since your child's ______?

Which aspect has made the most difference to your family?

Are you currently getting any support?
a) If no, would you like to have support? If so, what type of support would be helpful and how would this make a difference to you?
b) If yes, what type of support are you getting and how does it make a difference to you and your family? How adequate would you rate this support on a scale of one to ten? Can you suggest how the support could be improved?

Overall, what has been the most helpful support your child has received? What had been the most helpful support you have received?

Future

What are your hopes for your child's future?
What would you like from your child's school and education professionals?

Is there any advice you would like to give to a) other parents who go through similar circumstances; b) the professionals involved?

Why are these things important?

Appendix IX – Teacher interview schedule

General information

Name of child:
Current age of child:
Age of child at time of ABI:
Type of ABI, i.e. Traumatic or Non-Traumatic Injury (if TBI, was it a road accident or fall; if NTBI, was it a stroke, tumour or other?):

On the SEN register at school: Yes No
If yes, does your child have a statement of SEN?

Pre-ABI

Did you know X before the ABI occurred?

Were there any concerns before the ABI? (e.g. learning, behaviour at home or school)

The ABI

How did the school learn about X's ABI?

How much information were you given about the ABI?

Did your training as a teacher include anything about ABI (initial or subsequent training)?

Did you seek support from any other professionals?
What did you find helpful?

What (if anything) did you find poorly prepared for

Was there any liaison between you and the school and the hospital? How effective was this liaison on a scale of one to ten
What, if anything, could improve this process?

X's experience

How does/did X's ABI affect his/her school experience initially? A) learning?
B) socially

How does your child's ________ affect his/her school experience six months later and now?
What support does/did X receive in school? What, if anything, might be improved?

What are your views and experiences of how X was looked after a) during the transition from hospital to school; b) upon his/her return to school; c) currently (if relevant)?

In your opinion, which aspect has made the most difference to X at school?

X's family

How does X's ABI affect his family's experience? What support did X's family receive since the ABI?

What are your views and experiences of how X's family were looked after a) during the transition from hospital to school; b) upon his/her return to school; c) currently (if relevant)?

How do you feel X's family have coped? Which aspect has made the most difference to X's family? Is there anything else you feel that could be done for families with children with an ABI?

Future

What, do you think, could be the biggest obstacle to X's future? Do you think those are a result of X's ABI?

What are your best hopes for X?

What do you think educational professionals (including schools and those working in the LA) can do to ensure best outcomes for X?

Experience/support/training

How confident were you on a scale of one to ten about your ability to meet the child's needs compared with other children you have had involvement with?

Had you any previous experience of working with a child with an ABI?

What support/training had you had previous to your involvement with the child?
Did you have any support/training since becoming involved with this child?

What has made the most difference to your ability to meet the child's needs?
Which aspects of support/training have been least helpful, if any?

Do you think EPs should receive more training on ABI? If so, how do you think this could be addressed?
Do you think EPs have a role to play with children with ABI?

Appendix X – Educational Psychologist interview schedule

General information

Name of child:
Current age of child:
Age of child at time of ABI:
Type of ABI, i.e. Traumatic or Non-Traumatic Injury (if TBI, was it a road accident or fall; if NTBI, was it a stroke, tumour or other?):

On the SEN register at school: Yes No
If yes, does your child have a statement of SEN?

Pre-ABI

Was X known to Educational Psychology before the ABI occurred?

Were there any concerns before the ABI? (e.g. learning, behaviour at home or school) How serious were these concerns (scale from 1 to 10)?

The EP involvement

When was your involvement first sought?
Who sought your involvement?
For what purpose was your involvement sought?

How much information were given about the ABI?
Where did you get this information?

Which other professionals were involved? Had you worked with any of these professionals previously?

Was there any liaison between you and the school and the hospital? How effective was this liaison on a scale of one to ten?
What, if anything, could improve this process?

X's experience

How does/did X's ABI affect his/her school experience? A) learning? B) socially?
What support does/did X receive in school?

What are your views and experiences of how X was looked after a) during the transition from hospital to school; b) upon his/her return to school; c) currently (if relevant)?

In your opinion, which aspect has made the most difference to X at school?

X's family

How does X's ABI affect his family's experience? What support did X's family receive since the ABI? How adequate is this support on a scale of one to ten? What, if anything, could be improved?

What are your views and experiences of how X's family were looked after a) during the transition from hospital to school; b) upon his/her return to school; c) currently (if relevant)?

How do you feel X's family have coped? Which aspect has made the most difference to X's family? Is there anything else you feel that could be done for families with children with an ABI?

Future

What, do you think, could be the biggest obstacle to X's future?

What are your best hopes for X?

What do you think educational professionals (including schools and those working in the LA) can do to ensure best outcomes for X?

Experience/support/training

How confident were you on a scale of one to ten about your ability to meet the child's needs compared with other children you have had involvement with?

Had you any previous experience of working with a child with an ABI?

What support/training had you had previous to your involvement with the child?
Did you have any support/training since becoming involved with this child?

What has made the most difference to your ability to meet the child's needs?
Which aspects of support/training have been least helpful, if any?

Do you think EPs should receive more training on ABI? If so, how do you think this could be addressed?
Do you think EPs have a role to play with children with ABI?

Appendix XI – Post-interview debrief

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Post-interview debrief

Thank you

for your participation in the interview for the 'Experiences of children who have experienced an ABI, their parents, and the teachers and EPs who have had involvement' project.

Your participation will help towards us gaining a better understanding of what the experience has been like for you and how we can move forward towards offering the best support possible for other families who experience similar circumstances in the future.

All information you have provided is confidential. When the research is written up and presented, all names and personal details will be altered to ensure participants are not identifiable.

The recording of the interview will be destroyed after the research analysis has taken place. You are of course entitled to withdraw the information you have provided at any time.

Some participants enjoy having time to speak their mind about a topic they feel strongly about but, sometimes, some participants can find it distressing. The following are helpful resources for people who have been affected by Acquired Brain Injury:

The Child Brain Injury Trust (CBIT)

- Support for both families and professionals at www.cbituk.org or email helpline@cbituk.org for more information;
- Helpline telephone: 0845 6014939 10am – 1pm (Mon, Tues, Wed, Fri) or 24-hour answering service.

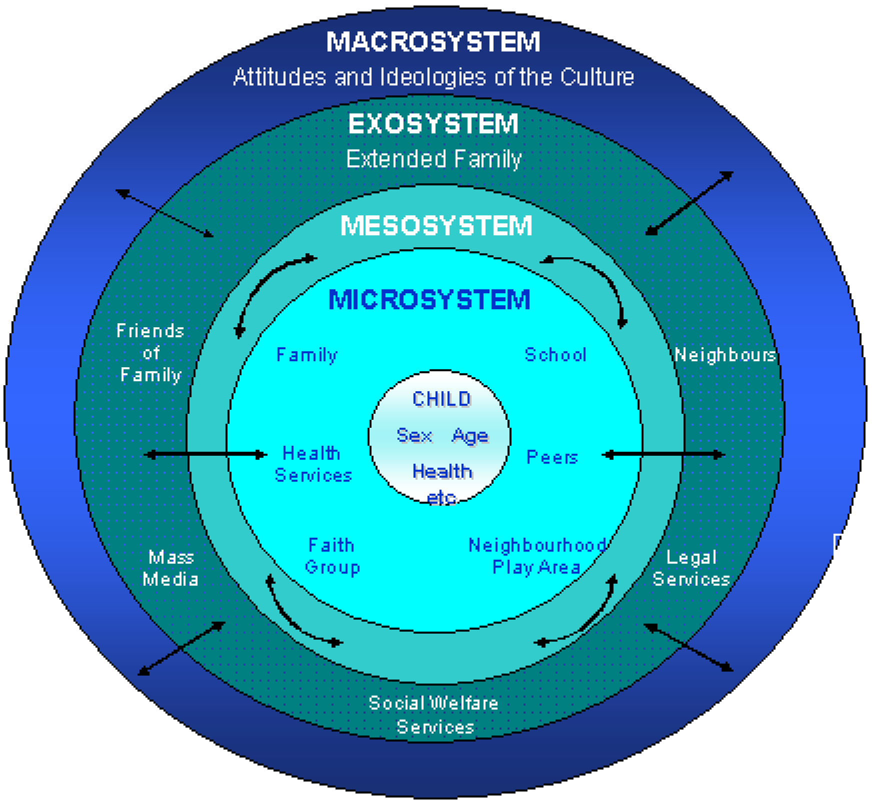
The Children's Trust

- Provides services for children with multiple disabilities at www.thechildrenstrust.org.uk;
- Telephone: 01737 365 000.

You can also contact me at any time in the future. My details are as follows:

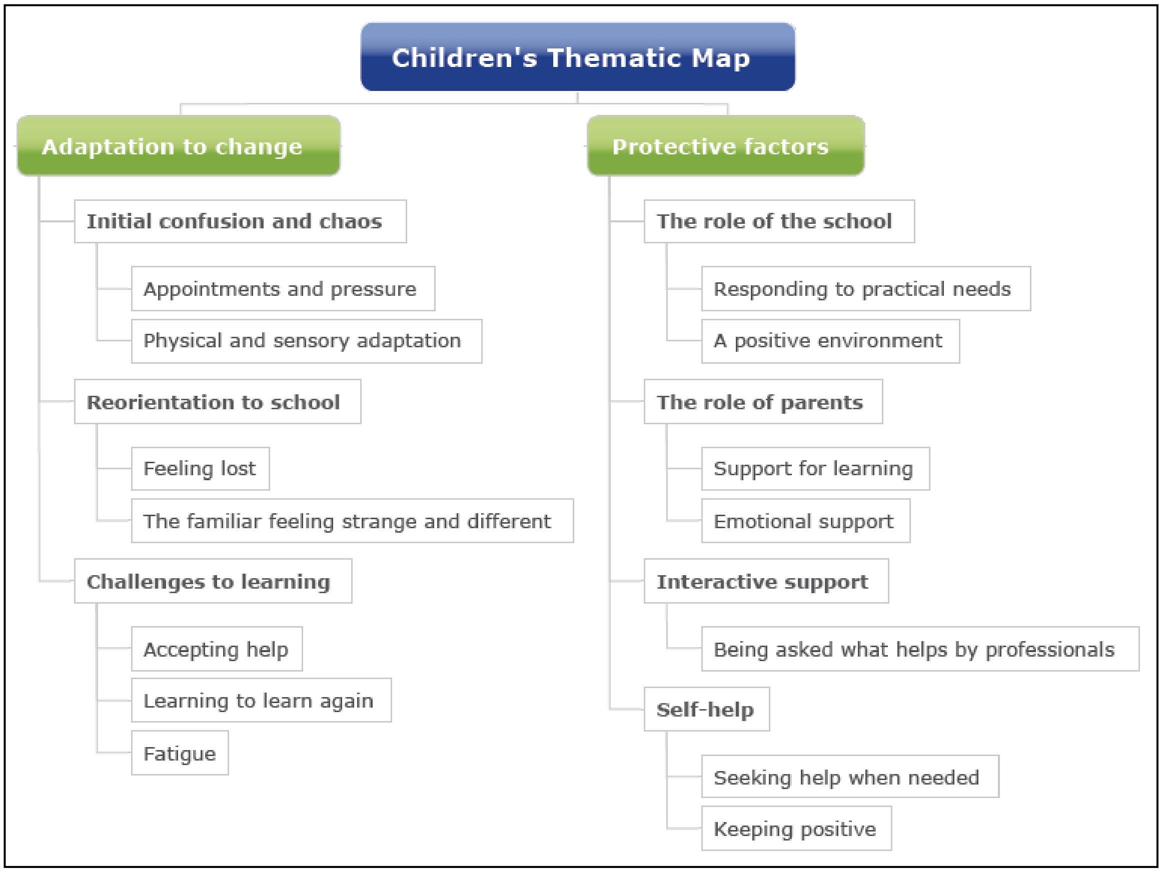
Laura Carroll (trainee Educational Psychologist and researcher)
Telephone: 020 xxxx xxxx
Email: Laura.carroll@xxxxx.gov.uk

Appendix XII – Bronfenbrenner's eco-systemic model

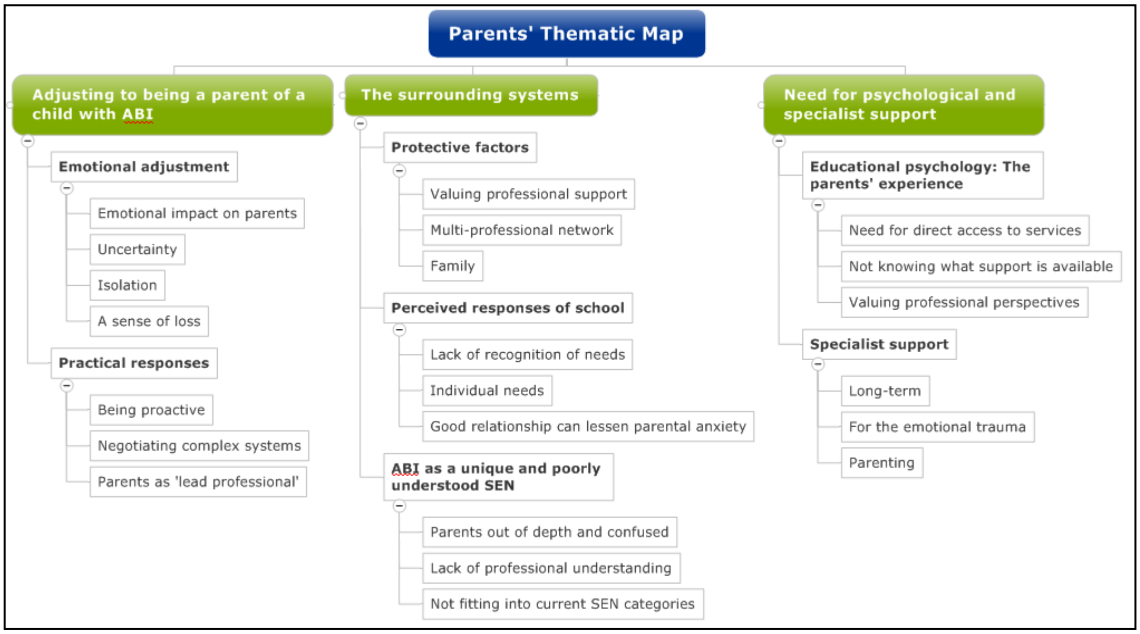


Thematic Maps

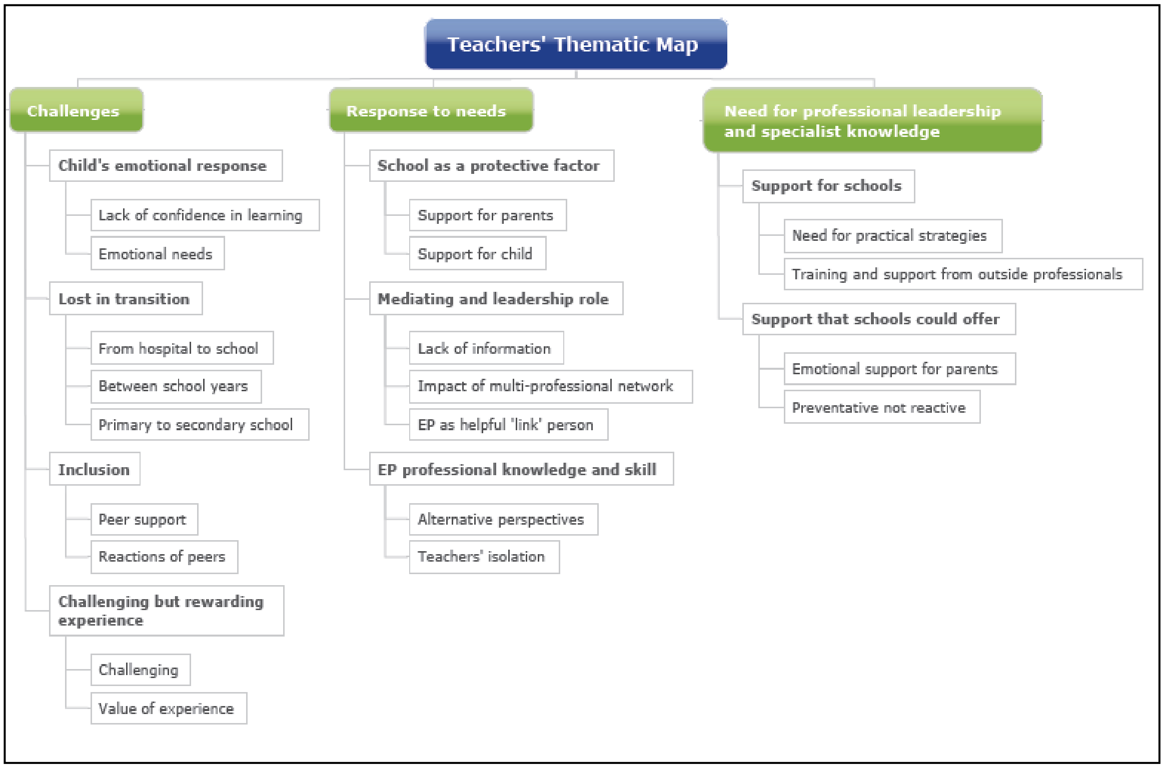
Thematic map 1 – Children’s thematic map



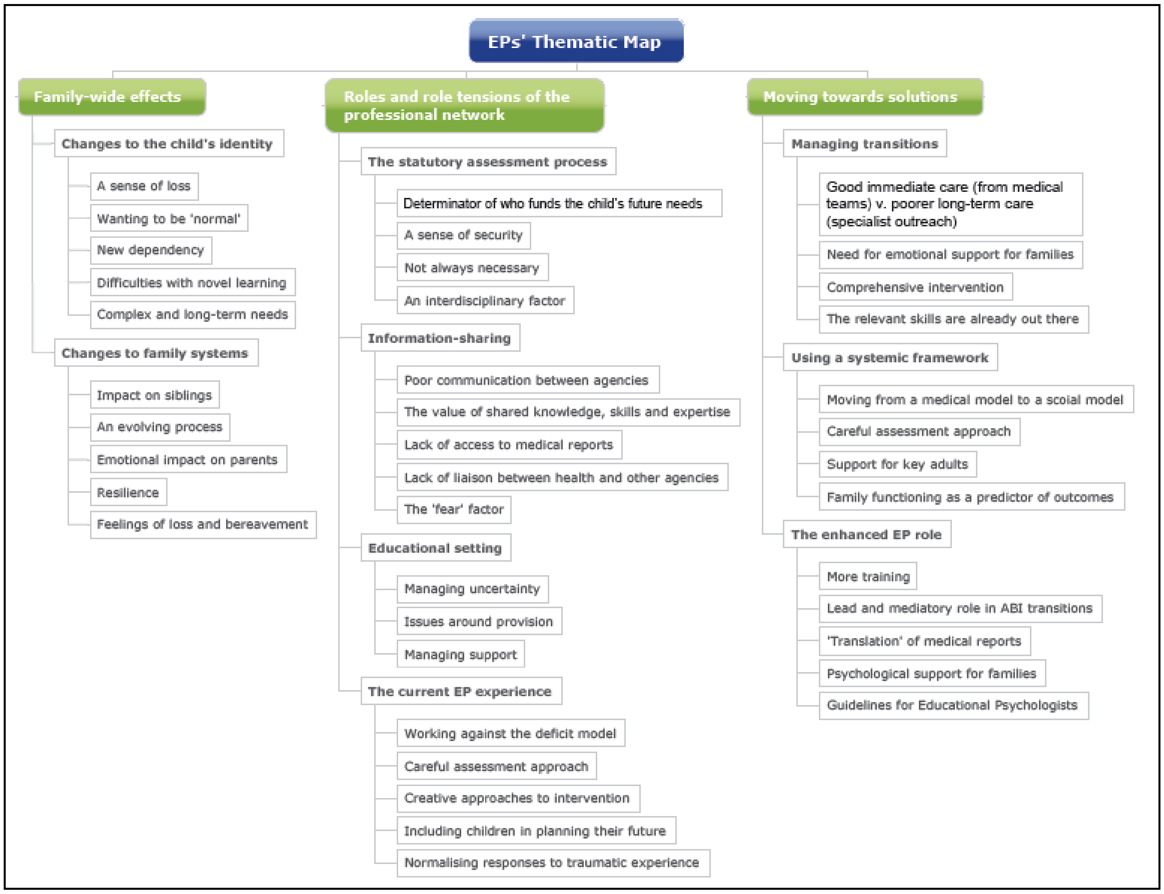
Thematic map 2 – Parent's thematic map



Thematic map 3 – Teacher's thematic map



Thematic map 4 – Educational Psychologists' thematic map



Thematic map 5 – Research question 1. Cross-data thematic map