How are the psychological needs of children with ABI responded to and by whom?

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ABSTRACT

Paediatric acquired brain injury is the leading cause of death and disability in children and young people internationally. Whilst there is a wealth of research examining cognitive and physical sequalae, comparatively fewer explorations of the psychological impact of ABI in childhood have been conducted. Furthermore, there is a dearth of literature examining how the psychological needs of children and young people are being responded to. This study aimed to converge multiple perspectives from across the child’s ecosystem (parents and professionals involved in the care of children with ABI) to identify contextualised psychological needs and consider how these are being met, and to contribute to a greater understanding of the risk and resiliency factors for positive adjustment and psychological wellbeing in this population.

The study employed a mixed methods design. Semi-structured interviews were conducted with eight parents, and an online questionnaire was completed by 36 professionals. Data were analysed using Thematic Analysis and two overarching themes were constructed, consisting of five themes and 11 subthemes. Descriptive statistics were also included in the analysis.

The findings indicate that participants construed the considerable psychological impact of childhood ABI as a product of factors related to participation, identity development and social exclusion. This was juxtaposed against narratives of very little formal psychological support and missed opportunities for support in naturalistic environments such as schools, as well as a lack of understanding and awareness of paediatric ABI and associated needs amongst the workforce, resulting in unsupported needs that have the propensity to worsen over time with significant consequences for children and young people. Participants outlined sources of support and resilience for CYP including parents, positive peer relationships, meaningful participatory experiences and professionals who could provide continuity of care. The findings and implications of the study are discussed.

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1 INTRODUCTION

Acquired brain injury (ABI) is the leading cause of death and disability in children and young people worldwide (UKABIF, 2018). Whilst there is provision for physical rehabilitation, emerging evidence indicates poor cognitive, psychosocial, educational and vocational outcomes with a lack of formalised support for these needs. Characterised by this 'walking wounded' profile, ABI is often termed a 'hidden injury' (Hayes et al., 2017), resulting in a hidden epidemic (UKABIF, 2018).

This chapter gives an overview of childhood ABI, its prevalence, physical and cognitive outcomes, impact on family, and current neurorehabilitation provision. This is followed by a literature review examining psychological impacts in detail and how these are currently being supported, both in formal and naturalistic settings, concluding with a rationale for the current study.

1.1 Overview of Paediatric ABI

1.1.1 Definition and Prevalence of ABI

ABI is an insult to the brain after birth or a typical period of development (McKinlay et al., 2016). The origins of an ABI are extremely heterogenous; it can be caused through traumatic means (such as a blow to the head caused via a road traffic accident) i.e., Traumatic Brain Injury (TBI), or through non-traumatic means e.g., neurological infections, cerebrovascular events (e.g. a stroke) or tumour (Chevignard et al., 2010).

It is estimated that 40,000 children sustain an ABI per year in the UK (The Children's Trust, 2022) and that 17% of children will sustain a TBI over the course of childhood (McKinlay et al., 2008). This translates to a child sustaining a brain injury every 30 minutes (Forsyth & Kirkham, 2012), and one child in every classroom having a brain injury by the end of their compulsory period of education (Morley et al., 2022).

Certain risk factors are associated with sustaining a TBI, e.g. age (younger children through falls), gender (males through sports related accidents) and socioeconomic status (Amram et al., 2015; Hawley et al., 2013; Jim et al., 2022; Laflamme et al., 2010; Trefan et al., 2016). Non-traumatic ABI risk factors tend to be specific to developing certain medical conditions; e.g. higher incidence of stroke with sickle cell disease (RCPCH, 2017).

1.1.2 Brain Development and ABI

Childhood ABI can disrupt normal brain development and the emergence of associated skills (Anderson & Catroppa, 2005). The brain undergoes a protracted period of development that occurs in a stepwise hierarchical nature, with structures associated with higher order functions developing latest, underpinning cognitive development. Periods of neuronal pruning are concomitant with the brain becoming specialised to functions accompanied by a reduction in grey matter density (Gogtay et al., 2004). Cell loss alongside an increase in white matter volume (via myelination and increased coherence in organization of white matter tracts); continues into the mid-20s (Giedd et al., 1999; Lebel et al., 2008). ABI during this period can derail typical brain development in unpredictable ways with associated late-emerging difficulties across all domains.

1.1.3 Outcomes Following ABI

CYP with ABI experience a range of adverse physical, cognitive, psychological and social outcomes. Physical outcomes are dependent on many factors, e.g., age, severity, injury location (Bedell, 2008). Cognitive outcomes are wide ranging; commonly, CYP with ABI may experience difficulties with attention, speed of processing, new learning and memory, language and communication (Anderson et al., 2012; Anderson et al., 2011; Middleton, 2001; Yeates et al., 2002). These can impact on academic attainment, behaviour and social outcomes; e.g. processing speed issues impacting on a child’s ability to keep up in class may result in them using alternative and disruptive sources of stimulation. Cognitive changes can affect psychological wellbeing; growing insight into their difficulties can lead to social withdrawal and loneliness as differences with their peers are apparent (McCusker, 2005).

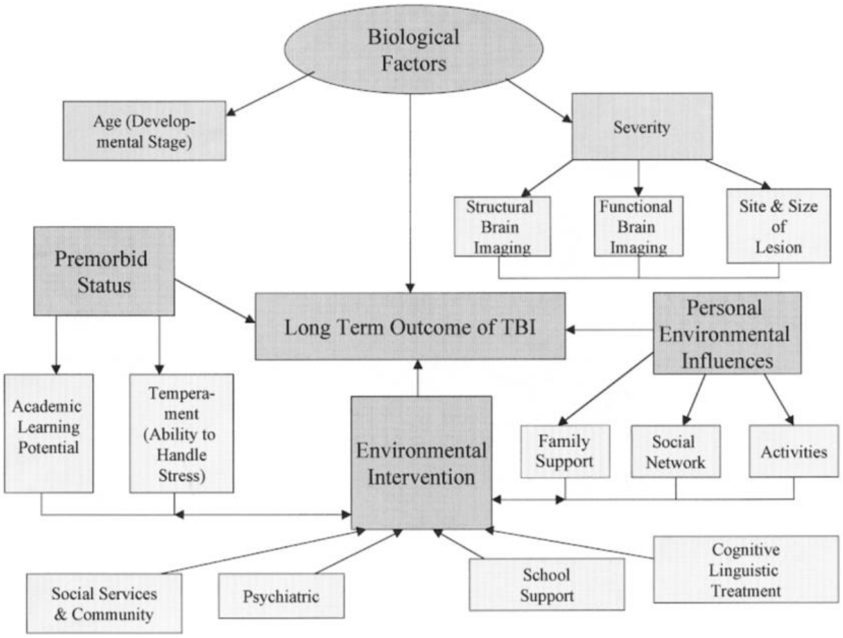
CYP with ABI have increased risk of poor psychological wellbeing and social participation (Anderson et al., 2012; Ryan et al., 2016). Generally, motor abilities show better recovery trajectories and rehabilitation efforts often reflect this.

1.1.4 Factors that Can Influence CYP's Outcome

Adaptation to paediatric brain injury occurs over an extended period of time and is influenced by many factors, e.g., severity and site of injury, age/cognitive stage of the child, reserve (e.g. premorbid abilities) and psychosocial resources e.g. family functioning, peer relationships, school support (Chapman & McKinnon, 2000; Dennis et al., 2007) This is demonstrated in Figure 1.

Figure 1

Factors that can influence outcome following paediatric ABI



Note. From Chapman & Mckinnon (2000)

1.1.5 Neuroplasticity

Neuroplasticity is a term used to describe the brain's unique ability to reorganise neural networks with an associated change in function, and can be seen as structural and functional changes that are observed after damage to the brain (Buchwald, 1990). In this context, it represents a reorganisation of neural networks to compensate for the effects of injury on brain functioning.

1.1.5.1 Age

The impact of an ABI may be influenced by age and developmental stage. Contrary to previous theories about early plasticity acting as a protective factor in ABI in very young children, more recent evidence highlights that severe brain injury sustained in very early childhood (before the age of three) results in poorer outcomes. This has been termed the 'double hazard' of brain injury; where the impact of the brain injury is amplified by the lack of reserve inherent to the early developmental stage of the child resulting in fewer skills to fall back on for recovery (Anderson et al., 2005). Younger children may be seen to 'grow into' their injury as impairments in later emerging skills become apparent and gaps between their abilities and those of their peers widen. This model of 'early vulnerability' highlights a need for availability of intervention and services throughout the lifespan to support with needs that unfold over time (Jim and Cole, 2020).

1.1.5.2 Severity and site of Injury

More severe injury has been posited to result in poorer outcomes, with suggestions that severity of injury and outcome are linked in a dose response manner (Anderson et al., 2012; Babikian & Asarnow, 2009; McKinlay et al., 2008). However, even mild injury can result in adverse outcomes (Anderson & Catroppa, 2005). Injuries can be focal or diffuse; focal injuries may result in specific difficulties in associated functions e.g., frontal lobe injury is often associated with difficulties in executive functions in adults.

1.1.5.3 Psychosocial factors

Socioeconomic status (SES) and family functioning are better predictors of long-term outcomes than severity of injury alone (Anderson et al., 2006; Yeates et al., 2010). Associations between family functioning and behavioural/social outcomes, and SES and verbal ability have been reported (Anderson et al., 2012) and poorer psychological outcomes are more likely to arise in the context of poor family functioning (Yeates et al., 2010). There is a complex interplay between the above factors and outcome; for example, cognitive reserve and psychosocial support may act as buffers against poor outcome e.g. in the case of severe brain injury (Anderson et al., 2006).

1.1.6 Wide-ranging Impacts on Families Affected by ABI

Paediatric ABI has a significant impact on family functioning and parental mental health (Wade et al., 1998; Rashid et al., 2014), and is associated with difficulties within family relationships (Cole et al., 2009). Some authors assert that the impact of ABI on family functioning is greater than in other medical illnesses (Ergh et al., 2002). Psychological distress in parents is common (Rivara et al., 1992) and families may experience injury related burden (Wade et al., 1996) coupled with processing trauma and grief over a number of years whilst adapting to their new circumstances (Wade et al., 2002, 2006).

Certain factors such as premorbid family functioning, caregiver resources and socioeconomic status appear to moderate the impact of a brain injury on caregivers (Wade et al., 2006). As noted above, family functioning has been shown to influence outcomes following childhood ABI; poorer psychological outcomes are more likely to arise in the context of poor family functioning (Anderson et al., 2005, Yeates et al., 2010) and an interaction between parenting style/family relationships and behavioural outcomes has been observed (Moscato et al., 2021; Wade et al., 2003). Attending to the current family environment and family coping is paramount as ABI is a life-long condition that also permutates over time (McKinlay et al., 2016).

1.2 Neurorehabilitation

Neurorehabilitation is an approach to restore lost functions and reduce the impact of disability on a person's quality of life and more recently has been framed as an attempt to improve wellness through maximising participation, environment and relationships (Gracey et al., 2015; McCarron et al., 2019; Perkins et al., 2022). Although policies and pathways such as national service specifications for paediatric neurorehabilitation aim for equitable access to services across the country (NHS England, 2013), it is widely accepted that this is far from the reality of availability and access to services, which are frequently described as a 'postcode lottery' (Keetley et al., 2021).

Pathways of care following childhood ABI are generally dependent on the severity of injury, and typically begin with admission to a critical care unit/ a and e/ major trauma centre. From there it is recommended that CYP are transferred to a regional paediatric neurosciences centre (there are 18 in the UK) or to local specialist paediatric teams who can provide a neurorehabilitation assessment determining acute and longer-term support needs. Once medically stable, categorisation according to level of rehabilitation need is made (category A; most support needs to Category D; least support needs); rehabilitation services are concurrently organised to match the level of rehabilitative need.

Whilst medical advances have led to an increase in CYP surviving brain injury, simultaneously the criteria for accessing services and receiving support has become stricter (Jim et al., 2020). In the UK, 1.3 million individuals live with the cost of brain injury, which amounts to 10% of the annual NHS budget (Centre for Mental Health, 2016). Adequate neurorehabilitation represents one of the most cost-effective interventions in the NHS (UKABIF, 2018), and has been shown to improve outcomes and quality of life by increasing children's social, educational and economic potential (NHS England, 2016)

Failure to provide early rehabilitation is recognised as increasing the probability of long-term disability (NHS England, 2016). The fact that physical interventions are more established may reflect better understandings of the aetiology of these difficulties versus those for psychological and emotional recovery (McCusker, 2005). Rehabilitation plans often neglect the long-term impact that ABI may have on a child's life (McKinlay et al., 2016), although it is widely recognised that childhood ABI should be framed as a chronic condition which unfolds over time (Lundine et al., 2019).

1.2.1 Provision of Psychological Care

While there is a commitment to meet the psychological needs of CYP and families (CYPF) during hospital stays (NHS England, 2013), there is no clear directive to provide psychological care beyond that point, despite the known risk to mental health and the ‘sleeper’ effects of childhood ABI with difficulties that emerge some time after the original injury (Jim et al., 2020). Children with ABI tend to fall through the gaps in service provision, with referrals often rejected from Child and Adolescent Mental Health Services (CAMHS) or Learning Disability (LD) services, even if their profiles do not differ from those accepted into mainstream services (Gracey et al., 2014). In the context of continuing budget cuts and pressures on CAMHS services, clinicians may feel that the presence of a brain injury is a reason to exclude (Jim et al., 2020). There is a neglect of longer-term psychological needs and a lack of mental health provision when it is needed, although it has been recognised that difficulties in accessing appropriate services and interventions compound the psychological and participation issues that those with childhood ABI face (Anderson et al., 2012).

2 LITERATURE REVIEW

The literature review aimed to provide a detailed understanding of the psychological needs of CYP affected by ABI and how these are currently being responded to. I was interested to learn how these needs are conceptualised and responded to across a child’s system, given the significant influence of social-environmental factors in determining outcome. I conducted a systematic literature search to identify experiences of CYP, families and professionals.

2.1 Scoping review

A scoping review was deemed appropriate to capture research using a variety of methodologies to summarise headline findings and identifying gaps in what is known about the psychological needs of CYP with ABI and how these needs are met/responded to by people in their naturalistic environments (Arksey & O’Malley, 2005). The protocol was developed in line with JBI scoping review methodology and the review was planned using the Population, Exposure, Outcomes framework (Peters et al., 2022), which was informed by my clinical and research experience. The literature search involved searching EBSCO APA, Academic Search Complete, PSYCH INFO, CINAHL, and Child Development Studies for the following terms, derived from the initial narrative review.

(“Children and young people” OR Child* OR adolescen* OR youth OR paediatric) AND (“Acquired brain injury” OR ABI OR “traumatic brain injury” OR TBI OR “brain injur*” OR stroke OR “brain neoplasms”) AND (Needs OR “needs assessment” OR “unmet needs”) AND (“mental health” OR mood OR wellbeing OR emotion* OR psychological*) AND (rehabilitation OR neurorehabilitation OR “Mental health services” OR “Community services” OR school OR education)

The search returned 1,147 results. Abstracts were individually screened using the PEO framework and recorded on a spreadsheet to filter for appropriateness/pertinence to the literature review. The PEO framework is summarised in Table 1.

Table 1

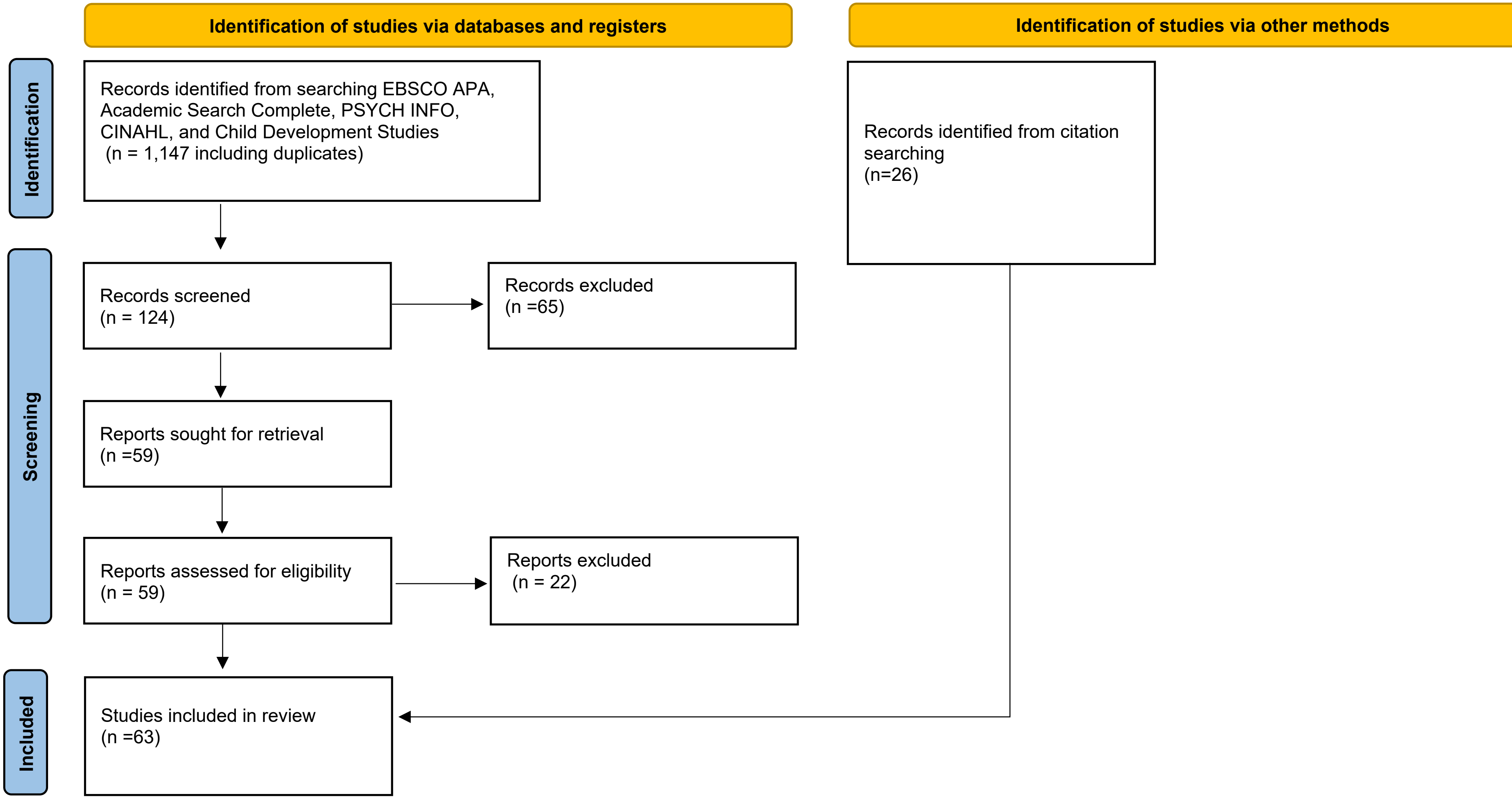
PEO Framework summary

Population	Interest in CYP with ABI, Parents of CYP with ABI, healthcare, social care and educational professionals working with CYP with ABI
Exposure	Capturing literature examining the psychological needs of CYP with ABI and/or how these are being responded to in different contexts e.g. in acute care, post-acute care, school, home
Outcome	Experiences and opinions of these people

Papers were included in the review if they satisfied the PEO framework, were published in peer-reviewed journals (e.g., doctoral theses were not included), and were written in English. There was no date limit imposed on the search. Qualitative, quantitative and mixed-methods studies were included to capture multiple aspects of psychological need following ABI. Original research, scoping reviews and systematic reviews were included in the review. Whilst a formal quality assessment tool was not used (as these are considered optional for scoping reviews), following the screening, papers were critically appraised for face and content validity, reliability and applicability to CYP with ABI. Following the removal of duplicates, screening according to the PEO framework and quality assessment, A total of 37 papers pertinent to the scoping review were identified. A further 26 relevant articles referenced in these papers were included in the literature review. A general flowchart of the paper screening process can be seen in Figure 2.

Figure 2

Flowchart of paper screening process



2.2 Themes arising from the literature review

2.2.1 Psychological Outcomes Following ABI

It is fairly well established that CYP with ABI are at risk of multiple adverse psychological, behavioural and psychiatric sequelae. A large number of studies document this; the majority gathered information from parents or CYP themselves. Fewer studies focused on the perspective of educators, with none highlighting the views of other professionals.

2.2.1.1 An increased risk of diagnosable neuropsychiatric/ mood disorders

Questionnaire based measures identified a significantly increased risk of novel psychiatric diagnoses (49%) such as 'externalising disorders' and ADHD identified in CYP with TBI relative to orthopaedic injury (13%) even within the first three months following injury (Max et al., 2012). Lifelong psychological consequences of childhood ABI are worrying, with one study reporting a 50% increased risk of psychiatric inpatient hospitalisation and psychiatric visits in adulthood (Sariaslan et al., 2016).

The incidence of low mood and depression has been shown to be significantly elevated in children with TBI (Durish, 2018; Li & Liu, 2013). A Randomised Control Trial (RCT) found that the risk of developing a mood disorder was almost doubled for CYP with TBI relative to those without (Tsai et al., 2014). One study documented that up to 25% of CYP with TBI develop a depressive disorder (Max et al., 1998). Another found that 50% of CYP with TBI were in the borderline/clinical range for anxiety, which was maintained over different time points (Hawley, 2003).

Parental ratings have indicated significant rates of internalising problems (such as anxiety, depression and somatic complaints) and externalising problems (such as inattention, hyperactivity/impulsivity, oppositionality and conduct concerns) in children with moderate to severe TBI, with between 24 and 38% of parents reporting significant problems in these areas (Fisher et al., 2021; Narad et al., 2019). Parents of children with ABI from various aetiologies have reported significantly increased rates of emotional distress (Tonks et al., 2010). These reports rely on quantitative measures to estimate the likelihood of the occurrence of diagnosable psychiatric conditions, and it could be argued they miss the depth and richness of qualitative accounts of psychological adjustment and wellbeing that could be achieved through multi-modal and multi-informant assessments (Durish, 2018).

The few identified qualitative studies corroborate these findings, with direct qualitative enquiries of CYP demonstrating significant psychological risk associated with ABI. Macartney et al. (2014) interviewed CYP treated for brain tumours; 50% described emotional problems e.g., sadness, irritability, worry, stress, nervousness and anger, which they related to functional impairments caused by the brain injury. Survivors of childhood stroke have described feelings of anxiety, sadness and frustration; sometimes in the context of a diagnosis of depression or anxiety disorder (Champigny et al., 2023). CYP with TBI have described persistent sadness and anxiety, as well as post-traumatic symptoms such as intrusive thoughts related to their injury. These symptoms were also recognised by parents, highlighting a need for psychological referral (Minney et al., 2019).

Qualitative parental reports also demonstrate concerns in social, emotional and behavioural domains (Brown et al., 2013; Upton & Eiser, 2006). Multi-modal accounts from parents of children with brain tumours indicate significantly elevated emotional symptoms (Upton & Eiser, 2006), and 70% of parents whose children experienced TBI reported significant emotional symptoms (Hawley, 2003).

2.2.1.2 Emotional regulation

Childhood ABI can interfere with CYP's ability to process, regulate and express their emotions. Children with TBI described difficulties with emotional regulation, citing mood swings, emotional lability, and difficulties with managing anger (Hawley, 2003; Mealings et al., 2012). Miley et al. (2022) explored child and family needs following early TBI and reported parental concerns about their child's emotional dysregulation, and behaviour such as impulsivity. Hermans et al. (2012) found that the majority of parents they interviewed reported issues with emotional outbursts, aggression and irritability. It is important to note that behavioural changes are often misunderstood in the context of cognitive effects, such as executive dysregulation, and fatigue (Jones et al., 2018).

2.2.1.3 Associated impact on self-esteem and self-concept

CYP with ABI frequently report reduced self-esteem relative to age and gender matched controls (Andrews et al., 1998; Hawley, 2012; Pastore et al., 2015). Poor self-esteem has been related to the impact of the injury and a resulting sense of loss; Champigny et al. (2023) found that children described losses related to inability to participate in hobbies and passions, and feeling ‘left behind’. A systematic review of the experience of students returning to school following a TBI described emotional issues related to feelings of loss and adjustment, and noted reduced confidence or self-esteem alongside symptoms of depression and anxiety (Mealings et al., 2012). The impact of loss of function and opportunity (alongside emotional difficulties) on CYP’s self-esteem has also been described by parents (Brown et al., 2013). Poor self-concept and self-perception has also been documented in the wider paediatric ABI population (Hendry et al., 2020; Pastore et al., 2015).

2.2.1.4 Identity: changing sense of self and personality

Identity changes following ABI are extensively documented in the adult literature. Although less frequently examined in the paediatric population, some studies are pertinent to this phenomenon. CYP have communicated a loss of past self and characterised attempts to minimise discrepancies between current and past selves (Glennon et al., 2022). Changes to identity have been related to loss of academic ability, sport activities, peer groups and roles in the family (Ankrett et al., 2023). Mealings et al. (2012) drew comparisons between the reviewed paediatric and adult TBI literature around identity, with similarities reflecting a reconstruction of self and personhood following the experience of loss. Gagnon et al. (2008) identified needs related to participation and reintegration with their social environment in adolescents with TBI.

Personality change, rather than identity change, has been reported more frequently in CYP, with one systematic review stating personality change as the most common novel 'disorder' following TBI, occurring in 10-20% of CYP with TBI (Li & Liu, 2013). Personality changes were also highlighted by parents and children (Hawley, 2003; Rennie & Goforth, 2020).

Identity rehabilitation is key to adult adaptation following ABI (Gracey et al., 2009) and more recently this has been applied to CYP (Perkins et al., 2022), where participation focused interventions are seen as central to paediatric neurorehabilitation. Identity development is seen as key to successful neurorehabilitation, as the child's self-evaluation influences engagement, self-regulation and emerging self-awareness (Perkins et al., 2022).

2.2.2 Social Outcomes and Peer Relationships

2.2.2.1 Social Isolation, limited friendship circles and loneliness

Changing friendships, increasing social isolation and reduced social competence is a commonly described outcome for CYP with ABI (Donders & Bollard, 1996; Max et al., 1998; Yeates et al., 2004). CYP with ABI, parents, practitioners, and adult survivors of paediatric ABI have described losses of relationships and feeling isolated (Ankrett et al., 2023). Similarly, Glennon et al. (2022) found that adolescents and mothers highlighted changed friendships characterised by rejection and withdrawing connection.

Loss of friendships is an issue consistently raised by parents and CYP following TBI, regardless of injury severity (Hawley, 2003); although some have argued that there is negative relationship between injury severity and social isolation (Prigatano & Gupta, 2006). Increased rates of loneliness are shown in CYP with TBI, as well as feelings of social incompetence (Andrews et al., 1998), with one study highlighting a mediating role between peer-related loneliness and self-esteem (Khan et al., 2023). Disruptions to social functioning have been shown to contribute to psychological distress and reduced self-esteem (Rosema et al., 2012).

Parents have expressed concern over their child’s shrinking social network, with more than one third reporting social difficulties for their children (Hermans et al., 2012), and significantly increased rates of peer relationship problems reported by parents (Tonks et al., 2010). Upton and Eiser (2006) interviewed mothers of children who had been treated for a brain tumour and gathered teacher ratings of strengths and difficulties (SDQ); 50% of mothers said their child was socially isolated, while teachers rated children as having greater peer relationship problems relative to population norms.

2.2.2.2 Bullying and lack of acceptance

In their systematic review of return to school following TBI, Mealings et al. (2012) found that students often described the challenges associated with being misunderstood and treated differently by others, leading to difficulties of finding and fitting in with peers and maintaining friendships with pre-injury peers. They also described bullying and teasing. A scoping review of the needs of CYP with traumatic injuries (the majority of them brain injuries) found that they desired acceptance from their peers, and raised concerns about bullying (Jones et al., 2018).

2.2.3 Primary and Secondary Impacts of ABI

Poor psychological outcomes can be related to both organic factors (e.g., damage to regions of the brain responsible for emotional regulation) and secondary factors related to functional deficits and adjustment to life after brain injury e.g., difficulties with attainment at school and peer relationship problems. Causal directions are difficult to establish, but it has been suggested that poor mental health outcomes such as low mood and depression are likely to be secondary to the injury itself (Durish, 2018).

2.2.3.1 The interaction between primary effects of brain injury and peer relationships

A number of studies have highlighted the impact of cognitive and physical difficulties on peer relationships, including the impact of difficulties with emotional regulation (Di Battista et al., 2014; Rosema et al., 2012). Parents and CYP have linked social isolation and peer relationship problems to some of the difficulties CYP may face with emotional regulation (Ankrett et al., 2023; Sharp et al., 2006) as well as personality changes (Rennie & Goforth, 2020). The relationship between changed behaviour (e.g. increased aggression; Upton & Eiser, 2006) and the difficulties peers may have in understanding or making sense of changes post TBI has also been acknowledged (Roscigno et al., 2015). Parents have linked this lack of understanding with consequential negative attitudes from peers that have an impact on social inclusion and status of their children (Roscigno et al., 2015), with a systematic review finding that ableism amongst peers contributed to poor peer relationships (Lindsay et al., 2023).

Changed cognitive abilities are important to consider, as brain injury in childhood has been hypothesised to disrupt the development of social functions and their underlying neural components (Rosema et al., 2012). Metacognitive skills have been shown to predict peer relationship problems in a cohort of CYP with ABI (Gracey et al., 2014) and significantly increased difficulties with social problem solving has been noted in children with TBI (Janusz et al., 2002).

2.2.3.2 Impact on participation

The changes CYP experience after ABI can significantly impact their quality of life and participation in school, community and home activities (van Tol et al., 2011). The World Health Organisation (2001) defines participation as ‘involvement in a life situation’ (International Classification of Functioning, Disability and Health). Participation is an essential component of child development which has been associated with improving quality of life in adolescents with and without disabilities, and is considered a human right that facilitates the acquisition of skills, a sense of competence and physical and mental health (Law, 2002).

A narrative review of the literature found that CYP with ABI faced participation restrictions in all domains 18 months post discharge (van Tol et al., 2011). Law et al. (2011) discovered that CYP with ABI participated in fewer activities and were less frequently involved in diverse activities compared to typically developing peers. Studies examining unmet needs highlight participation and restricted participatory opportunity (Ankrett et al., 2023; Gagnon et al., 2008; Keetley et al., 2019; Mealings et al., 2012).

Evidence demonstrates the wide reaching impact of paediatric ABI with significant risks to social and emotional functioning across the spectrum of injury severity (Hawley, 2003; Luis & Mittenberg, 2002; Yeates & Taylor, 2005). The following section will review provision for these evident needs.

2.2.4 Existing Provision and Unmet Needs

A number of studies highlight a lack of support for emotional wellbeing or substantial rates of unmet need in this area. All indicated high rates of need for mental health services coupled with high rates of unmet need (Dahl et al., 2023; Fisher et al., 2021; Fuentes et al., 2018; Narad et al., 2019). Fisher et al. (2021) reported that 77.8% of children with TBI who needed a mental health service did not have their needs met, whilst Narad et al. (2019) found that up to 82% of CYP who had need for mental health services were not receiving these at 6.8 years after injury. Kurowski et al. (2013) examined rates of mental health service utilisation in the first 6 months following moderate and severe traumatic brain injury. Approximately 25% received mental health support, with a large proportion having unmet needs. The majority of these studies were conducted internationally, although there is evidence indicating that this situation is mirrored in the UK. In their systematic review, Jones et al. (2018) found that support needs for emotional, cognitive and social problems were highlighted frequently, including desiring support for low mood, depression, and feelings of frustration. Keetley et al. (2019) also identified that CYP reported unmet needs relating to communication, emotional, social and overall wellbeing. Hawley (2003) found that out of 97 children with TBI, only two children had been seen by a psychologist.

The overshadowing of emotional needs has been explicitly documented in the literature and may be due to a variety of factors, including the visibility' of need, the 'sleeper' effects of ABI, and the over medicalisation of brain injury. Greenspan and MacKenzie (2000) found higher rates of unmet need for mental health services in children with the least severe head injuries, indicating that the visibility of needs may dictate the level of support attained. Indeed, families have reported that their children's physical issues are recognised and responded to more frequently than emotional, cognitive and social problems, and CYP feel as though needs relating to their emotional, social, behavioural and cognitive problems went unmet (Jones et al., 2018).

'Sleeper effects' and latent psychological needs often emerge months or years after ABI, once acute support subsides. This is raised frequently in the literature. Brenner et al. (2021) examined Transition Plan Checklists for CYP with a TBI between 1-18 months post discharge. At discharge the probability of psychological need was lower than other needs (such as medical needs). However, 18 months after discharge the probability of need had increased to 100%, while the probability of *unmet* need for psychological support was 30% at 18 months post discharge. Similarly, they identified a high level of unmet need for community/family support services (40%) at 18 months. Keenan et al. (2020) gathered parental reports in the first year following childhood TBI, finding at three months after injury 14% of had unmet or unrecognised need, with 26% being unmet socioemotional need. At 12 months after injury, 7% had unmet needs, with 68% being socioemotional needs.

These studies highlight the unfolding psychological needs associated with childhood ABI which largely appear to go unmet, despite evidence that they are at significant risk of poor mental health and social outcomes. 'Sleeper' effects are not met in acute services, and the importance of continuity of support for CYP with ABI (as well as early support) has been referenced, in recognition of the fact that professional support falls away over time (Ankrett et al., 2023). Difficulties in providing this model of support is shown internationally, with one study demonstrating that all community/medical rehabilitation services stated they provided psychosocial care but had difficulty providing ongoing mental health support and managing stigma around mental health (Botchway et al., 2022). The literature heavily indicates a mismatch between level of need and availability of services to address the need.

2.2.5 Examining Naturalistic Sources of Support

2.2.5.1 Return to school: lack of awareness of needs

Returning to school is a key transition and can mark the return to normality. Schools are widely acknowledged as default rehabilitation centres (Bate et al., 2021), which is particularly pertinent given the lack of provision of formal sources of support. However, unmet needs appear to be frequent in a school setting, largely related to a lack of understanding of ABI and associated needs. Hermans et al. (2012) interviewed caregivers of children with ABI and found that 36% reported unmet needs on returning to school, while Jones et al. (2018) found that return to school was a key point in which needs were unmet, with particular issues being a lack of understanding amongst educators about a child’s injuries limiting the support given and leading to a misunderstanding of needs (e.g. mistaking poor memory or fatigue as bad behaviour). In their systematic review, Mealings et al. (2012) reported that students highlighted a general lack of understanding within the school community making the experience of returning to school more challenging. Students also raised issues around reduced participation from extra-curricular activities owing to their injury.

It is generally acknowledged that there is a failure to equip educational professionals with knowledge and understanding of ABI (Linden et al., 2013), in spite of the fact that educational professionals often provide the majority of rehabilitation hours and much of the burden of rehabilitation is placed on them (McKinlay et al., 2016). Teachers are often unaware that the child has sustained an ABI and rely on parents to inform them about this and long term consequences (Hawley et al., 2004) with poor communication between healthcare professionals and educational teams often cited as leading to poor experiences (Andersson et al., 2016; Botchway et al., 2022). There is evidence that CYP and parents desire more support from educational settings in relation to emotional and social wellbeing (Andersson et al., 2016; Gfroerer et al., 2008; Mealings et al., 2012).

The need for training around ABI has been reported often amongst educational professionals; studies have identified that only a quarter of educational staff received such training despite regularly being in contact with a much higher proportion of CYP with ABI (Howe & Ball, 2017; Morley et al., 2022), and another demonstrated a lack of expertise and experience amongst school staff (Rennie & Goforth, 2020).

2.2.5.2 Perspectives from educational professionals

There are fewer studies examining the educator experience of a pupil's return to school following childhood ABI. Educational professionals have identified increased emotional and social problems in students with brain tumours (Upton & Eiser, 2006). Bate et al. (2021) interviewed professionals who had recently facilitated a transition back to school, who described becoming increasingly aware of children's social and emotional difficulties, and being concerned about a deterioration in the child's mental health. They linked this to a loss of abilities, loss of friendships and communication issues with the wider peer group. Participants had made urgent referrals to CAMHS and highlighted that mental health support sessions were provided in school- although supporting mental health felt challenging due to the inaccessibility of typical approaches (e.g., emotional literacy sessions in the context of difficulty processing emotions). Educators also stated they needed specialist training to provide the appropriate emotional support. Hartman et al. (2015) found that the lack of training and awareness of ABI amongst educators rendered them uncomfortable and unsure of their competence to meet the needs of CYP with ABI.

2.2.6 Supporting Parents to Support their Children

Some studies highlighted the importance of equipping parents with the tools to support their children. Minney et al. (2019) found parents felt least supported dealing with their child’s emotional and behavioural symptoms. They also reported that the TBI led to an increase in family stressors and that they themselves required mental health support.

Brown et al. (2013) found that parents needed to advocate for appropriate support for their child, and reported the limitations in the support provided. Similarly to the findings of Minney et al. (2019), parents desired strategies for behaviour management and other difficulties their child experienced. Healthcare professionals referenced the importance of supporting parents in order to support their emotional wellbeing. Miley et al. (2020) found that 32% of parents highlighted that they needed support to help manage their child’s mood.

The need for more information for parents was highlighted by a number of studies. Gagnon et al. (2008) found that both parents and adolescents raised the need for further information about the potential sequelae of injury. Similarly, Jones et al. (2018) identified from their systematic review that parents and CYP raised information needs relating to recovery trajectories and possible outcomes.

2.2.7 What do CYPF feel is Helpful? Conceptualising Support

2.2.7.1 Towards naturalistic sources of support

A strong support system was cited as key to recovery by childhood survivors of stroke (Champigny et al., 2023). CYP included peers, family, teachers and hospital rehabilitation teams as part of this system. Findings from children who had survived brain tumours were similar, mentioning the importance of keeping up friendships and positive relationships with family members (Macartney et al., 2014). Adolescents with TBI cited friends or parents as people they felt most comfortable with providing support (Gagnon et al., 2008).

CYP have highlighted the importance of peer support for adaptation to post injury changes, and cited peers as providers of practical and emotional support (Di Battista et al., 2014; Minney et al., 2019; Mulligan et al., 2023). CYP have highlighted the importance of belonging and not being perceived as different; ideas for improving peer relationships included building understanding and prioritising meaningful social connection including peer to peer support (Ankrett et al., 2023). Importantly, positive peer relationships and a sense of belonging have been shown to contribute towards maintaining a sense of identity in adolescents with ABI (Mealings et al., 2012). Opportunities to socialise and participate in activities were highlighted; CYP highlighted the importance of community support provided through clubs and schools (Minney et al., 2019), whilst parents referenced social and recreational organisations as important (Diener et al., 2022).

2.3 Formulating the Current Risks and Resiliencies for CYP with ABI: Ecological Systems Theory

Bronfenbrenner's (1979) ecological systems theory (EST) is helpful in considering risk and protective factors in paediatric ABI as well as rehabilitative potential. As the theory describes, children develop through interactions with their environment with proximal and distal factors; in the context of paediatric ABI, the environment plays a central role in neurorehabilitation. Gerring and Wade (2012) emphasise that these interconnected environments can be conceptualised as risk and protective factors for a range of outcomes in paediatric TBI; social and emotional outcomes in particular are thought to be moderated by psychosocial factors. This also counters the 'deficit model', which positions the aetiology of problems as being within the child and due to a 'damaged' brain, rather than exploring how the environment hinders/facilitates the child's latent and emerging skills (McCusker, 2005). It is recognised that systemic and family based interventions play an important role in rehabilitation following paediatric ABI (Braga et al., 2005; Roberts et al., 2022).

2.3.1 Rehabilitation and Ecological Systems Theory

2.3.1.1 Microsystem: Family

Families play a key role in rehabilitation. Research has highlighted the relationship between long term outcomes and family adjustment (Taylor et al., 1999, 2001), and family-supported intervention has been found to result in improved behavioural and emotional functioning in CYP with ABI (Wade et al., 2006) . Despite this, studies have identified unmet needs relating to parents and caregivers e.g., information needs and the need for professional support (Jones et al., 2018). These studies point towards the crucial role that parents and caregivers play in the ongoing rehabilitation of CYP with ABI, yet there is no known research explicitly documenting how they themselves respond to the needs of CYP with ABI, and what supports them to do this.

2.3.1.2 Microsystem: School

While it is known that there has been an increase in children returning to mainstream primary and secondary schools with new physical disability, cognitive and communication profiles and a complex set of learning needs following ABI (Hayes et al., 2017) the evidence suggests that educational professionals generally do not receive adequate training to meet these needs. There is a paucity of research specifically examining professional perspectives on the psychological needs of CYP with ABI and how these are recognised and responded to in a school environment.

2.3.1.3 Microsystem: Healthcare

Availability of rehabilitation services varies regionally, and formal psychological support is sparse. There are inconsistencies in the services made available to CYP with ABI; for example, children who are admitted to inpatient rehabilitation are more likely to access psychological therapy and be referred to appropriate outpatient therapies (Dodd et al., 2019), whilst those involved in RTAs may secure psychological support through litigation. While the evidence points to a dearth of services that are intended to provide psychological support to this population, it is not known how those working in such services (e.g., clinical psychologists, educational psychologists, allied health professionals, and social workers) currently respond to the needs of this population, and how this is achieved.

2.4 Research Gaps and Relevance of the Current Study

There is a constellation of emotional and social needs in the paediatric ABI population, evident regardless of severity of injury. The need for support in these areas is within a backdrop of very little support. The current study aims to bring together the perspectives of individuals from across the child's ecological system (e.g. parents, allied health professionals, social workers and educators) to identify psychological needs in context and understand how these are currently being met.

There has been little research that exclusively focuses on examining young people's emotional response and adjustment following paediatric ABI (Roberts et al., 2022). Furthermore, there are no identified studies that characterised exactly how psychological needs are responded to, for example, stories of positive or negative experiences. This is crucial for informing best practice in terms of how to respond to the needs of CYP with ABI. While some studies converged data from both parents and educational professionals, or parents and CYP, the majority used a single source of information, and no studies gathered the insights of parents, teachers, educational and healthcare professionals to deepen the understanding of psychological needs and how and where these are being met (or neglected) as conceptualised by a range of stakeholders that are integral to a child's system. This is important given that CYP themselves have cited these as being crucial elements of their support system. The aim is to contribute to a greater understanding of the risk and resiliency factors for positive adjustment and psychological wellbeing in this population, and to begin to conceptualise what early intervention in naturalistic environments might look like.

Research Questions:

1. What is the current understanding of psychological needs in the context of paediatric ABI among stakeholders?
2. What are the perceived barriers/facilitators to meeting the psychological needs of CYP with ABI?
3. What are the implications for our understanding of risk and resiliency factors for psychological wellbeing following paediatric acquired brain injury?

3 METHODOLOGY

3.1 Overview of Chapter

This chapter outlines the methodology and methods used in this research. An account of epistemological and ontological assumptions is provided, alongside reflections on my role as a researcher on the interpretation of the data collected. The research design, research processes and ethical considerations of the research are outlined, followed by an account of the analysis of the data.

3.2 Epistemological and Ontological Assumptions

This research is rooted in realist ontology and critical realist epistemology. Ontology describes ‘what there is to know’ and epistemology describes ‘how we know what we know’. A realist ontology adopts the position that there is a reality to be known, and one that we seek to know through research. A critical realist approach assumes that the data gathered does reflect some authentic reality, but that this is mediated by factors such as social influences, and therefore we can never fully ‘know’ the reality that we strive to know through our research (Braun & Clarke, 2013).

3.3 Reflexivity

Researchers should remain reflexive and curious about the positions they hold in relation to the research being conducted (Braun & Clarke, 2006); these assumptions will bear influence on the conception, execution and interpretation of the research. Reflexivity is the process of attuning to and critically evaluating the impact of one’s own views and experiences on research (Harper & Thompson, 2011).

Prior to clinical training, I completed a PhD in the field of developmental neuropsychology. My research focused on cognitive outcomes of a population considered to sustain occult brain changes due to a health condition. Through the process of the research, I discovered how often emotional and psychological wellbeing went unaddressed in a population with a significant health problem, and that efforts were focused medical management and medical outcomes. During this time, I also worked with CYP with ABI, their families and teachers in a public engagement project where I heard first-hand accounts of life growing up with an acquired brain injury and understood more about the phenomenological experience of CYP with ABI, which included emotional and psychological wellbeing. Here, my interest in childhood ABI and the needs of this population was formed.

It is important to highlight that throughout the process of data collection I was working in a in a specialist paediatric neurorehabilitation (PNR) service, where the psychological needs of CYP with ABI are prioritised. However, conversations with colleagues around their experiences and views informed my assumptions about how psychological needs are met in this population, in different settings. I have been disheartened to hear so many stories of psychological and emotional wellbeing not being prioritised, of CAMHS referrals being rejected, and of CYP who have ‘fallen through the gaps’ (Jim & Liddiard, 2020; Gracey et al., 2014).

These experiences on clinical training combined with my pre-training experiences have resulted in a strong ‘pre-assumption’ (Burnham, 1992) about how psychological needs were met (or unmet) in this population. This experience shaped the research from conceptualisation, design and data collection; for example, in pursuing certain topics in research interviews. I found it helpful to reflect on this in research supervision to consider different narratives and stories, and conceptualisations of support.

Another factor that will have affected my engagement and analysis with the data is becoming a parent myself throughout the research process. I was pregnant throughout the data collection phase and had had my baby by the time I engaged in data analysis. As a new mother I found the content of the interviews occasionally challenging and emotionally distressing. The identification and perceived saliency of some of the themes identified in parental interviews will have been affected by my own position and experience as a mother.

3.4 Methods

3.4.1 Collaborating Institutions

My supervisor facilitated contact with the PNR service prior to my placement there. I presented my research to their research committee, alongside submitting a research proposal. They provided some feedback on the design of the research and agreed to be collaborators on the project; namely in assisting with identifying consultants from their Patient Public Involvement (PPI) committee and facilitating recruitment.

3.4.2 Design

This study employed a mixed methods design, collecting both qualitative and quantitative data as a form of triangulation, to gather different sources of evidence on the same phenomenon. Mixed methods are deemed appropriate for critical realist research (Willig, 2013). Using Brofenbrenner's (1979) Ecological Systems Theory (EST) as a guiding framework, I sought to include the voices of parents/carers and professionals (such as clinical psychologists, educational psychologists and teaching professionals) to gain a breadth of perspectives on what the psychological needs of CYP with ABI are, how these needs are currently being met and barriers/facilitators to meeting these needs, and what the perceived risk and resiliency factors for emotional and psychological wellbeing are.

Initially, I had planned to recruit psychology and educational professionals, but following a review of the literature and my experiences of clinical practice in PNR, I broadened the professional categories to include other professionals such as social workers, speech and language therapists and occupational therapists. This decision was made following recognition of the multidisciplinary teams that often surround CYP with ABI, and the interdisciplinary working which is practiced in PNR. The ethical approval and amendment can be seen in Appendices A and B.

To allow for parental voices to be privileged, which is a feature often lacking in childhood ABI research (Lundine et al., 2019; Audrey McKinlay et al., 2016) and to ensure that experiences and perspectives could be explored sensitively, parents and carers were invited to take part in a semi-structured interview, held over Microsoft Teams. Semi-structured interviews are deemed appropriate methods of data collection for perception and experience type research questions (Braun and Clarke, 2013) allowing for the researcher to follow up unexpected avenues that give a fuller picture, thus affording flexibility that is lost in structured interviews or questionnaires (Smith, 1995).

To reach professionals in busy working environments, an online semi-structured questionnaire was created. Whilst I anticipated that the data collected would not be as rich as the data obtained from semi-structured interviews, an online questionnaire allowed me to reach a greater number of professionals and collate responses from a wider range of perspectives across the ecological system.

3.4.2.1 Designing the interview schedule and questionnaire

A review of the literature and my experience of working with parents of CYP with an ABI informed the interview schedule and questionnaire. For both the interview guide and the questionnaire, I explored a variety of questions related to the topic, keeping in mind my ideas about what the interview should cover (Smith, 1995). I then arranged the questions into topic areas and considered their sequencing (Braun and Clarke, 2013).

Consultation

Having worked professionally in public engagement with research prior to clinical training, I wanted to involve individuals with lived experience in the conceptualisation of the research. The collaborating PNR service was able to facilitate a connection with three parents of CYP with ABI from their PPI panel who agreed to act as consultants at the conceptual stage of the project. I sent each individual my research design, research questions, recruitment material for parents and semi-structured interview guide. We subsequently met using MS teams where feedback was given and incorporated – this was most pertinent to the interview guide, where consultants suggested a range of modifications. The finalised interview guide, produced with consultants and my supervisor, can be seen in Appendix C.

I also applied this principle to the questionnaire intended for professionals. The questionnaire was designed by me, with guidance from my supervisor, and three professionals (two clinical psychologists, one educational psychologist) acted as consultants and provided feedback on the initial drafts. One point that arose during feedback was the distinction between emotional and psychological wellbeing, and whether it would be confusing for participants to consider them as an overarching concept. Many papers refer to emotional and psychological wellbeing interchangeably, and papers on 'emotional wellbeing' often cite research on psychological wellbeing to inform their arguments. This occurs without explicit mention of psychological wellbeing in their working definition of emotional wellbeing (see NIH 2018 for an example). I decided to include 'emotional and psychological wellbeing' in questionnaire questions, rather than choose one over the other. I made this decision in consultation with my supervisor, after considering that using one over the other might have limited the responses and considerations of professionals or incurred an overly restrictive engagement in the questions. In making this choice, I hoped to allow a broad an uninhibited conceptualisation of emotional and psychological wellbeing, that did not impose my understanding of the concept too heavily (Feilzer, 2010). The finalised questionnaire can be found in appendix D.

3.4.2.2 Designing semi-structured interviews

Opening statements were constant, and the interview guide was designed holding the importance of building rapport in mind (Braun and Clarke, 2013). I was conscious of the sensitive nature of many of the questions I intended to ask, and initial interviews were opened with demographic type questions to build rapport (e.g. about the participant's family structure and local area). However, this was time consuming, and as questions resembled a structured interview that could be translated into a questionnaire collecting demographic information, I condensed the opening questions into a demographic questionnaire (Appendix D). This did not appear to affect the rapport building process of subsequent interviews.

I devised open questions that were arranged into topic areas. Questions covered a broad array of areas, including asking about parent's understanding of emotional and psychological wellbeing, what their child's emotional/psychological needs were following the ABI, and how emotional and psychological wellbeing was being supported, including at home and at school. Questions about barriers to supporting emotional and psychological wellbeing were asked, as well as what better support would look like. A funnelling approach was used, allowing participants to give broad answers before prompting responses to specific areas of interest (Smith, 1995). A 'clean up' question allowed participants to offer any other perspectives that they deemed important to share (Braun and Clarke, 2013).

3.4.2.3 Designing the online questionnaire

The online questionnaire for professionals was created using Qualtrics, and consisted of open and closed questions, arranged into topic areas (role and experience of working with CYP with ABI; emotional and psychological wellbeing following childhood ABI; supporting emotional and psychological wellbeing as a professional; barriers and enablers to emotional and psychological wellbeing). The nature of my research questions demanded a primarily qualitative approach to data collection and thus open questions with free text responses made up a significant portion of the survey. Closed questions were also devised. Combining open and closed questions allowed both the collection of clear and unambiguous data relating to participant views and experiences, and qualitative data derived from encouraging participants to elaborate on their answers and provided more insight into their phenomenological experience (Feilzer, 2010). The questionnaire closed with a series of questions collecting demographic variables. The final questionnaire can be found in appendix E.

3.4.3 Recruitment

Participants in both groups (parents/carers and professionals) were recruited using a mixture of purposeful sampling techniques (convenience and snowball sampling) to identify participants able to provide information rich data to analyse and generate insight and understanding of the topic (Patton, 2002).

Parents of CYP with ABI were recruited through social media channels including twitter and Facebook pages of relevant charities (Brain Injury Hub, The Children's Trust; Child Brain Injury Trust, Eden Dora Trust). In addition, information about the research was circulated to a pool of parents of CYP with ABI who had signed up to receive notifications about current research projects through the collaborating PNR service. The research poster for parents and carers can be seen in Appendix F.

Twitter was also used to recruit professionals, and the research was advertised through the twitter pages of relevant organisations (e.g. the National Acquired Brain Injury in Learning and Education Syndicate - N-ABLES). The research poster can be found in Appendix G. The research was also advertised within the PNR service collaborating on the research project, the medical pupil referral unit located within the service, and was advertised on a professional newsletter from the PNR service. I also gave a presentation about the research during a bi-annual meeting of a paediatric neurorehabilitation special interest group hosted by the PNR service; information about the project was shared to their mailing list.

3.4.4 Inclusion and Exclusion Criteria

The study was open to any parent of a child who acquired a brain injury before the age of 18, who were living in the UK. No restrictions on aetiology or severity of the brain injury were made. The decision to have broad inclusion criteria was driven by the desire to gather as many parental perspectives as possible, to facilitate a wide understanding of their perceptions and experiences. Much of the existing research has been focused on highlighting outcomes after TBI; I wanted to include ABIs from a variety of aetiologies (particularly as services made available through litigation may lead to a different experience of rehabilitation). This decision was also informed by recognising that support needs following an ABI are dependent on a very complex interplay of factors, including psychosocial functioning, and not necessarily severity (Anderson et al., 2006). Therefore, inclusion criteria were not limited to a particular aetiology, severity or age of ABI. Inclusion criteria for professionals was defined as any health and social care or educational professional (e.g. psychology professional, educational professional, social worker, speech and language therapist) working in the UK who had worked with CYP who sustained an ABI before the age of 18.

Parents and professionals who participated in the research needed to have a good level of spoken English, as there were no funds attached to the research project for an interpreter. It is very possible that this was a barrier for some parents considering participating in the research. This is discussed further in the critical review.

3.4.5 Participants

Eleven parents got in touch regarding the study, and eight parents of CYP with ABI consented to participate after reading the information sheet. I had aimed to recruit eight parents, to satisfy the criteria for data saturation allowing the identification of high-level themes (Guest et al., 2006). However, Braun and Clarke (2021))argue that the concept of 'data saturation' is less applicable in qualitative research and is driven by positivist ways of thinking, recommending that 'data saturation' should be informed by the richness of the data obtained, homogeneity of the sample, and monitoring of recurrence of themes across the dataset. It was felt that the data obtained from the eight participants satisfied these criteria.

The online questionnaire was accessed 68 times and completed by 36 professionals. Eighteen did not complete past the consent page, and 14 respondents began the questionnaire but abandoned answers beyond the first topic area.

3.4.5.1 Demographics

All parents who got in touch about the research and participated were mothers. Participants were based across England and Wales in London, Buckinghamshire, Surrey, Devon, Birmingham and Newport. Four participants described themselves as working class, one as upper middle class and three as middle class. Table 2 summarises the demographic characteristics of participating parents.

Table 2

Demographic details of parents involved in the study

Participant pseudonym	Ethnicity	Age	Age and Gender of Child	Age at injury	Aetiology
Alex	White British	46	Male, 11	7	Brain tumour
Jayne	White Welsh	48	Male, 14	1	TBI (following fall)
Julia	White	55	Female, 15	4	Acute Neurological Disorder
Carol	White British	49	Male, 8	1	Stroke
Sophie	White British	47	Male, 12	7	Brain Abscess
Faye	Black British Caribbean	58	Male, 19	14	TBI (RTA)
Zainab	British Pakistani	51	Female, 14	12	Stroke
Susan	Black British	36	Female, 15	11	TBI (RTA)

Professionals worked across a variety of settings; in acute rehabilitation (such as hospitals); post-acute rehabilitation (such as PNR), the community and medicolegal rehabilitation. The majority of participants (69%) had worked with children with ABI for more than five years. Table 3 gives an account of their occupations.

Table 3

Occupations of professionals who completed the online questionnaire

Occupation	**N**
Clinical Psychologist	11
Teacher (Specialist Provision)	5
Educational Psychologist	4
Speech and Language Therapist	3
Occupational Therapist	2
Support Worker	2
Brain Injury Nurse Specialist	1
Headteacher (Specialist Provision)	1
ABI Coordinator	1
Music Therapist	1
Brain Injury Specialist (AHP background)	1
Leisure and Activity Lead	1
Physiotherapist	1
Trainee Clinical Psychologist	1
Specialist Play Worker	1

3.5 Research Processes

3.5.1 Semi-structured Interviews

Once potential participants had emailed me expressing an interest in the study, they were sent an information sheet outlining the background of the study and its aims, what their involvement would entail, confidentiality and security of the data (Appendix H). I also outlined the process of the interview, including that it would take place on MS teams, and that it would take around an hour. If they were happy to participate following reading the information sheet and receiving this email, we arranged a convenient time to meet and I sent a calendar meeting invite. Parents were also asked to complete a demographic questionnaire (appendix D and sign a consent form (Appendix I).

Interviews began with an opening introductory statement that outlined the background of the research and its aims, the expected time the interview would take, and the nature of the questions I intended to ask. A reminder of anonymity and the limits of confidentiality were covered, as well as consent. Interviews lasted between one hour and one hour and forty minutes, from beginning to ending recording. Once the interview was finished and recording had stopped, a debrief with participants took place, thanking them for their time, enquiring about their experience of the interview and highlighting both the details of the research team and relevant external organisations they could contact if further support was required. Participants were also sent a debrief letter via email (Appendix J). I adopted a flexible approach to interviewing, attempting to help participants to feel at ease by holding a warm and empathetic stance and using their language.

3.5.1.1 Transcription

Interviews were listened to and transcribed verbatim by me, using a notation system outlined by Braun and Clarke (2013). For the purpose of this research higher levels of transcription were not used (Jefferson, 2004).The transcripts were checked several times for accuracy, which acted as a means of familiarising myself with the data. The identity of participants was protected with the use of pseudonyms.

3.5.2 Online Questionnaire

The questionnaire (Appendix E) was prefaced with a participant information sheet detailing the background and objectives of the research, the expected length of the questionnaire, and confidentiality. Participants were informed that they would be able to withdraw their data up to three weeks after completing the questionnaire, after which time data analysis may have already begun. Participants were required to complete a consent form before beginning the survey. The main questionnaire consisted of 22 questions. Demographic information was collected at the end of the questionnaire.

3.6 Ethical Considerations

In the context of the Covid-19 pandemic, ethical considerations were informed by the BPS Guidance of Research During Covid-19 (2020), as well as the BPS Code of Internet Mediated Research (2021). In addition, this research was guided by the BPS Code of Ethics and Conduct (2021) and BPS Code of Human Research Ethics (2021).

3.6.1 Ethical Approval

This study was approved by the UEL School of Psychology Ethics committee. The ethics approval letter and subsequent amendment can be found in appendices A and B, respectively. The study was also approved by the research committee of the collaborating PNR service.

3.6.2 Informed Consent

Parents and carers of CYP with ABI were each given an information sheet (appendix H) to read before agreeing to participate in this research study. This was briefly revisited before beginning each interview. Each participant gave their full consent to participate in the research study and signed a consent form prior to the interview (Appendix I). Professionals accessing the online questionnaire were also required to read an information sheet (Appendix E) and sign a consent form before beginning the questionnaire.

3.6.3 Confidentiality and Anonymity

Through the participant information sheets read by both parents and professionals, participants were informed that any personal data would be kept confidential and that their responses would be anonymised. To allow me to ascertain an understanding of the range in nature of acquired brain injury, parents who took part in interviews were asked questions about their child's brain injury, such as age incurred, aetiology, and severity. In doing this, parents were also given an opportunity to tell their story at a pace that suited them, facilitating a sense of safety, connection and empowerment, rather than a retelling of 'patient history' which may occur in disconnection (Rixon, 2022).

In addition to this, parents sometimes referenced their experiences of services, bringing up some challenging themes. I assured participants that I would anonymise the information they gave to the degree that the aetiology of acquired brain injury and information about services was placed in broad categories or made unidentifiable. This was important, as some ABIs are incurred through rare aetiologies, disclosure of which could compromise participants' anonymity. Participants were informed that the only occasion in which confidentiality would be broken would be on disclosure of information concerning the safety of themselves or those around them. All parents were satisfied with this and did not communicate any concerns inhibiting them from taking part in the research.

Recordings were listened to and transcribed only by me. Transcribed interviews were anonymised and uploaded to my UEL Onedrive account, in accordance with the Data Management Plan (Appendix K). Only myself and my supervisor had access to the anonymised transcripts.

3.6.4 Risk

Parents who took part in interviews were made aware of processes that would arise in the case of any concerns relating to risk. No current risk issues were disclosed in any of the interviews. A risk assessment was included in the ethics application and a plan was agreed between myself and my supervisor about contact in the event of a risk issue arising. In addition to this, we agreed procedures for arranging a debrief in the event of the content of the interviews being emotionally challenging.

3.6.5 Renumeration

Parents of CYP with ABI were offered a £10 Amazon voucher as a token of appreciation for their contribution. Two parents declined the voucher.

3.7 Analysis

Reflexive Thematic Analysis (Braun et al., 2018) was used to analyse interview data and qualitative questionnaire data. Other forms of analysis were considered and deemed unsuitable. Grounded theory was not considered appropriate as the research was not intended to generate an explanatory framework for understanding participant's experiences and perceptions. Interpretative Phenomenological Analysis (IPA) was also considered for the analysis of interview data, as it seeks to take accounts of experiences and position them in a wider social and cultural context (Willig, 2013). However, IPA is primarily suited to experience and perception type research questions and is concerned with how people make sense of their lived experience; often in the context of significant life events that have implications for identity (Braun and Clarke, 2013). Therefore, IPA was deemed inappropriate for this research.

Reflexive Thematic Analysis is a theoretically flexible approach which is appropriate for critical realist research, as it can be used to address questions about personal experiences and conceptualisations (Willig, 2013). It is a method for the identification, analysis and reporting of meaning-based patterns within a dataset, where themes are conceptualised as patterns of shared meaning underpinned by a central organising concept (Braun and Clark, 2013). Here the researcher plays an active role; the themes identified will reflect both the epistemological stance of the researcher and the nature of the research questions, rather than passively residing in the dataset. The active role of the researcher in knowledge production is the reason behind naming the approach *Reflexive* Thematic Analysis (Braun et al., 2018). As highlighted above, I remained aware of my personal experiences and how these would influence data analysis, including my pre-assumptions about psychological needs in the paediatric ABI population and my experience of becoming a mother during the research process.

I took an inductive approach to analysis; this is a bottom-up approach whereby the themes that are identified are inherently linked to the data itself, rather than being driven by the researcher's theoretical interest in the topic (Braun and Clarke, 2006). Although some have argued that an inductive approach to thematic analysis is enhanced by not engaging with literature prior to beginning analysis, others have argued that that sensitivity to features of the data can be enhanced through engagement with the literature (Tuckett, 2005).

It is important to acknowledge that although I took an inductive approach to data analysis, in the process of conceptualisation and design of the research I had engaged deeply with the literature prior to beginning analysis. In line with the critical realist epistemology that this research was rooted in, themes captured both implicit ideas that lie beneath the surface of the data, as well as explicit and concrete meaning elicited from the data. This approach is suitable for use across both interview transcripts and textual analysis of surveys (Braun, et al., 2018). Although semantic level themes were identified, in analysis I aimed to focus more on latent level themes, looking beyond the surface level to provide a coherent interpretation of the data.

As recommended by Braun and Clarke (2006), I also kept a journal (Appendix L) during the process of transcription of interviews and initial data analysis, adopting a recursive approach to analysis that moved back and forth between the data set, initial codes, and the analysis of the data produced from analysis.

I followed the six steps defined by Braun and Clarke (2006); first familiarising myself with the data by reading and reading it. I then generated initial codes, which is a process of grouping segments of data into meaningful categories (Tuckett, 2005). I took the advice of Braun and Clarke (2006) and was liberal in my approach to coding (coding for as many potential themes as possible), whilst also ensuring that context was not lost by employing an inclusive approach to coding – keeping a little surrounding data. Once these first two steps had been completed, I began the search for themes, arranging and organising the coded data segments into potential themes underpinned by a central organising concept that was related to the research questions. An example of transcription and coded data extracts is shown in Appendices M and N.

I then began reviewing and refining themes, first examining the coded data extracts within each theme to ensure that a coherent pattern and organising concept was evident, and then reviewing the themes in relation to the entire dataset. I remained reflexive and kept in mind the importance of not being wedded to initial themes; an important consideration to avoid analytic thinness (Braun et al., 2018); thus there were various iterations of theme definition (Apendices O-Q). The final stage of thematic analysis involved producing a written account of the analysis, which can be seen in the results chapter.

Simple descriptive statistics were used to analyse quantitative data generated from the questionnaire.

4 RESULTS

4.1 Chapter Outline

The themes identified through analysis of interview and survey data will be outlined and discussed in this chapter. The themes can be found in Table 4. Two overarching themes were identified, encompassing five themes and 11 subthemes. The following section will provide a detailed description of each theme and subtheme, supported by data extracts.

Table 4

Overarching Themes, Themes and Subthemes

OVERARCHING THEME: PERSONAL AND RELATIONAL IMPACT OF ABI	
Theme 1	**Under Threat**
Subthemes	*Threats to sense of self*
	Threats to social connection and attachment
	Threats to psychological safety
Theme 2	**The need to be understood and accepted**
Theme 3	**Sources of resilience**
OVERARCHING THEME: SOURCES OF SUPPORT	
Theme 4	**Naturalistic support**

Subthemes	*Parents and families: a crucial support against the odds*
	Parents and families need support
	School: revealing and heightening vulnerabilities
	The potential of school as a support
Theme 5:	**The need for services/formal support**
Subthemes	*There is no support*
	What you see is what you get help for
	Challenges to supporting
	What does good support look like?

4.2 Overarching Theme: Personal and Relational Impact of Childhood ABI

This overarching theme explores the impact that ABI has on CYP internally and relationally. Parents and professionals mentioned significant impacts on CYP following ABI, encompassing feeling different and adjusting to new limitations, being confronted with changed relationships and experiencing psychological distress. Participants described the difficulties that CYP with ABI faced in feeling a sense of belonging and the negative feelings borne from comparison with others. Related to the above, participants also highlighted sources of protection and restorations of a sense of self and identity. Each theme and subtheme will now be discussed in turn.

4.2.1 Theme 1: Under Threat

This theme summarises how participants conceptualised the impact of ABI on CYP's sense of self, relationships and mental health, and ideas about what contributes to these affects.

4.2.1.1 Subtheme: Threats to sense of self

The impact of changes to abilities and level of functioning alongside loss of skills was spoken about by many parents and professionals. Most parents and many professionals explained CYPs frustrations at not being able to do activities that they could previously or that they wanted to do. Parents spoke about how this could lead to lack of participation or participatory experiences, highlighting the potential impacts of a lack of participation or disengaging from previously enjoyed activities that formed a central component of their child's identity.

"*When Joshua – if I say he wasn't depressed, but when he came home he wanted to get back on the track but he couldn't because he couldn't run he couldn't he his coordination had gone and everything, and I used the words were erm – he was hungry for the track*" Faye, Parent of Joshua, aged 19

"Coming to terms with new difficulties (upper limb/ speech/ emotional regulation etc) Not being able to do the things that they could do before (playing football/riding a bike)" P28, Specialist playworker, Residential Rehabilitation

Parents often reported that children felt negatively about lack of participation, and some relayed that their children had disengaged from activities that served as a reminder of their new limitations, perhaps as a defence against a threat to their sense of competence. Sophie (parent of Lewis, aged 12) recalled '*then he just gave up football because that was no fun anymore he was getting all this grief and aggravation*'. The impact of this on CYP's psychological wellbeing was outlined by many and some linked the loss of participation in activities to losses to, or threats to identity; as Susan (parent of Alice, aged 15) reflected '*it's taken its toll where she's like you know 'the one thing I was good at I can't even do*'. The notion of threats to competence was often brought up in the context of school environments; parents relayed a sense of young people finding themselves constantly reminded of things that they find challenging and affecting their sense of competence or reinforcing losses to identity. For some this affected their participation in school.

"*George will often say no to stuff erm even before his attempted it it's almost sort of 'no won't do it'… 'Cause he I think he feels he's going to fail so just putting someone in that sort of environment where you feel like you're gonna fail or be rubbish all the time*" Carol, Parent of George, aged 8

Some parents and professionals explicitly made reference to CYP having an altered sense of self or self-concept following ABI; in many cases, parents and professionals connected an altered sense of self to changed abilities, whilst for others there was a sense of just 'feeling different'. Professionals rated the impact of ABI on a child's sense of self or identity as severe (82%) or moderate (18%). The impact of physically looking different and needing to adjust to this was also mentioned. Many explicitly relayed that having an altered sense of self was a cause of psychological distress for CYP with ABI. Some parents communicated that they felt their children had changed significantly; Jayne (parent of William, aged 14) reflected that her son "*was always happy he hardly every cried… and then he just went I mean after that he just went absolutely bonkers for want of a better word*".

"*Mum I can't remember what I used to be like, but I know it was better than this*" Sophie, Parent of Lewis, aged 12

"For children with ABI they often have to learn to accept a new self - adapting and accepting changes to communication, physical ability and cognitive or academic ability" P12, Teacher (specialist provision)

Some participants spoke to the challenge that CYP may face when adjusting to an altered trajectory in life, redefining parameters of success and receiving a label of being 'disabled', perhaps highlighting unconscious and internalised ableism. Some parents highlighted that the focus on deficits and impairments in processes and procedures that are intended to secure support, such as EHCP documents and neuropsychology reports could reinforce negative self-evaluations. The importance of embracing difference and celebrating positives was mentioned. Participants also highlighted that retaining or restoring autonomy and independence that may have been lost as a result of ABI was crucial.

"*I've realised she had this really bad erm ((laughs)) narrative about er (.) the word dis-disability and what disabled means and stuff*" Susan, Parent of Alice, aged 15

"*They have things like erm their own erm small holdings which Louise can walk to on her own which is you know great for her independence*" Julia, Parent of Louise, aged 15

"*Teaching him that a brain injury is a strength not- everything, everything is all about what he can't do and how he can't do it*" Sophie, Parent of Lewis, aged 12

4.2.1.2 Subtheme: Threats to social connection and attachment

Relationship changes or difficulties with relationships following ABI were mentioned by a number of parents and professionals and were spoken about in the context of friendships and family relationships. More than half of parents relayed accounts of their child experiencing generally difficult peer relationships and social isolation, with many stating that they felt their child had no 'true' friends and some expressing concerns about bullying. Difficulties with peers were mentioned both by parents whose child had a brain injury in infancy as well as in later childhood. Reflecting on friendships, parents and professionals spoke about the influence of acquired cognitive and behavioural needs and on social interactions, and the difficulties that peers may have accepting or understanding a 'changed' friend. All professionals stated a significant impact on friendships following ABI and associated needs; 79% stated a severe impact and 21% stated a moderate impact. Social isolation was mentioned by multiple professionals as a common issue following paediatric ABI with a propensity to worsen over time; 91% of professionals stated that difficulties with peer relationships was a risk factor for poor psychological wellbeing.

"*I do remember once when he'd finished treatment erm like he never got invited to a play date after school*" Alex, parent of Lucas, aged 11

"*I don't think he's got real friends to be honest*" Jayne, parent of William, aged 14

"*I think it's been a gradual decline over time as things have as his friends dropped away- that was a blow*" – Sophie, parent of Lewis, aged 12

"*The evidence shows that social outcomes often get worse over time for these young people*" P18, Educational Psychologist, Post-acute rehabilitation

Changes in family dynamics and relationships following brain injury were mentioned multiple times by professionals and by some parents, where ABI may have affected parent-child relationships or sibling relationships, particularly in the context of feeling that their child had changed and the potential for attachment to be threatened. When considering the impact of ABI on home such as on family relationships, 61% of professionals felt that childhood ABI resulted in a significant impact on home, 33% felt this impact was moderate and 6% felt it was minimal. Professionals mentioned the heightened nature of family relationships following ABI and the potential for conflict in relationships to arise – some referencing the importance of good family functioning to support rehabilitation.

"*I felt like I'd been given back a different child that I didn't know I couldn't relate to and didn't like very much (.) and I was a little bit scared of… I'm his mum he's gonna feel all of that off me*" Sophie, parent of Lewis, aged 12

"*Change in family dynamics, impact of blame*" P9, Occupational Therapist, Community rehabilitation

4.2.1.3 Subtheme: Threat to psychological safety

All professionals and all but two parents explicitly named mental health problems or psychological distress experienced by CYP with ABI. Sometimes, these were a direct result of the circumstances surrounding the brain injury, such as trauma and potential diagnoses of PTSD or associated symptoms such as hypervigilance. Julia (parent of Louise, aged 15) relayed that she felt her daughter was '*hypervigilant about everything'* while Sophie (parent of Lewis, aged 12) stated that her son's psychiatrist "*has said he probably has PTSD".* Both professionals and parents also touched on feelings of grief and loss that may be felt by CYP following an ABI; Julia (parent of Louise, aged 15) reflected that "*one of the issues for Louise emotionally is is a huge sense of loss*". Anxiety was mentioned by half of parents and almost half of professionals and appeared to be a very common issue in CYP with ABI – sometimes this was expressed in terms of the YP's sense of safety.

"He he would often tell me he feels scared even in the ho-house you know sort of overnight he he'll wake up several times and say 'I'm scared' er he needs me to sit with him as he goes to sleep" Carol, Parent of George, aged 8

A sense of CYP struggling with feelings of self-worth was communicated, with a number of parents and professionals highlighting low self-esteem and poor confidence as a pressing issue for CYP with ABI. When discussing an exercise requiring her son to highlight what people liked about him, Sophie (parent of Lewis, aged 12) noted "*'what do people like about you' and Lewis puts 'I have no idea'"*. Carol (parent of George aged 8) described how her son's "*self-esteem in the past year has at times been rock bottom"*. Low mood and depression, suicidal ideation and self-harm were also mentioned a number of times, with two parents communicating occasions of self-harm or suicidal ideation.

"And he had a knife and he put it to his neck and my daughter was there, she was four, and he said 'Mum I don't want to be like this anymore' – Sophie, Parent of Lewis, aged 12

"Then we had an incident where Alice had er cut her wrists with scissors" – Susan, parent of Alice, aged 15

Episodes of behaviour that can challenge were recounted by some parents, and anger was communicated as a potential area of difficulty for CYP. Participants understood this as a reaction to ‘why has this happened to me’ and sometimes as a communicative tool for feelings of frustration; as Carol (parent of George, aged 8) mentioned “*it’s really frustrating him erm and and so he shows that frustration through anger*. The impact of fatigue on emotional needs was also touched upon.

“*I think she sometimes, you know, with her cognitive and physical fatigue, her resilience and her problem solving drops*” Zainab, parent of Aisha, aged 14

4.2.2 Theme 2: The Need to be Understood and Accepted

This theme reflects the need for CYP with ABI to feel a sense of belonging and acceptance, alongside being understood by those around them. Many participants explained that this often felt in jeopardy, either as a product of CYP feeling different to peers and not fitting in, not feeling accepted for who they are in social circles or at school, and a desire to be treated ‘normally’ which was sometimes at odds with their needs. A number of parents relayed that their child only felt accepted in specific groups such as adults, or much younger children. Many parents made direct reference to their children negatively comparing themselves to their peers, highlighting difference and sometimes reinforcing a threat to competence, and spoke about the distress that this caused.

“*He’s OK with younger kids as well with younger kids there’s no like expectation because he can he functions at their level or slightly above you know he feels they match and the same with adults; adults don't expect much from a child*” Jayne, parent of William, aged 14

“I think children are just expected sort of to get on with it and be resilient and they’re all they’re doing is comparing themselves to their peers” Carol, parent of George, aged 8

The teenage years were highlighted as a heightened time of vulnerability with many interacting factors coinciding; parents identified the rapid brain changes and development that occurs in adolescence, combined with the acute need of teenagers to feel understood and be part of a group, as clashing with CYP's awareness of 'not fitting in'. This was also juxtaposed against the sometimes unforgiving or unkind attitude of teenagers and difficult secondary school environments. Ninety-four percent of professionals highlighted the transition from primary to secondary school as a factor that increases emotional and psychological needs in CYP with ABI. Parents and professionals highlighted that being around those who 'get it' or who are 'tolerant' was cited as a potential source of resilience, whether that be hypothetical or based on experience.

"I mean teenager girls would be the least, you know, of the gene pools that would be forgiving and understanding of this" Zainab, parent of Aisha, aged 14

"*He's different, secondary school is is all about fitting, in and the fact that he associates with the other kids that are different makes them a group target*" Sophie, parent of Lewis, aged 12

"*His dad can empathise with him. And he's been on the same journey as him, and he knows what's what*" Faye, parent of Joshua, aged 19

"Support for families - drop in clinics / opportunities for children and families to meet with others in a similar circumstance" P32, Teacher (specialist provision)

Many parents and professionals also described difficulties that CYP with ABI experienced with emotional expression and regulation, perhaps affecting their ability to be understood and to understand themselves. When asked what helps her son cope with big feelings or emotions, Jayne (parent of William, aged 14) said "*I don't think he can to be honest… he's really struggling*". A sense of YP sometimes feeling out of control of their emotions and actions was communicated by some; Sophie (parent of Lewis, aged 12) mentioned that her son "*hated what he did he he he couldn't stop his temper he couldn't manage his emotions at all*"; the sense of distress caused by this was clearly communicated by parents. Difficulties with emotional regulation were also noted by a number of professionals.

“*Emotion regulation difficulties, mixed up feelings which they can't control which feel scary, or make you act in a way you can't control*” P14, Educational Psychologist, residential rehabilitation

4.2.3 Theme 3: Sources of Resilience

This theme captures participant’s ideas around protective factors for psychological wellbeing, both internal, relational and environmental. Some professionals spoke to the varied nature of psychological outcomes following ABI, highlighting that for some, the impact on emotional and psychological wellbeing is minimal. Some participants mentioned the important role that resilience as a character trait plays in maintaining emotional and psychological wellbeing following ABI, afforded by the temperament and character of the young person who may have a positive attitude in the face of adversities, and family narratives of perseverance.

“*He's got a really positive attitude and he just he just kept going yeah*” Alex, parent of Lucas, aged 11

“*Joshua just gets on with it he’s very laid back like his dad. Nothing phases him and he won't get stressed*” Faye, parent of Joshua, aged 19

Participants spoke to the importance of participation in activities that were enjoyed prior to the brain injury (adapted or not) and having the opportunity to participate in new activities, facilitated by individuals (usually parents, educational or healthcare professionals) who were aware of the importance of participation. Often this was spoken about in terms of restoring identity and continuity of self, but it was also referenced in relation to restoring a sense of competence. Some parents spoke about participation in activities as therapeutic in themselves.

“*Sport has played a pivotal part in his wellbeing (.) because he’s always been sporty - he was always running from he was born, he was always running always running, you know, never standing still*” Faye, parent of Joshua, aged 19

“*When he came back from it yeah when the it was a day trip and he came back and he was like talking just non-stop about what he'd been doing and yeah so I think it really boosted his self-esteem and confidence”* Alex, parent of Lucas, aged 11

“*Finding other things that he can do and is good at has been really important*” Sophie, parent of Lewis, aged 12

“*I think finding meaning … this could be something very small like being able to pick something up off the floor when it's physically difficult, or larger like finding an activity that brings joy and meaning through competence in that activity, the social aspects of doing that, meeting people or both*” P24 Clinical Psychologist, community paediatric rehabilitation

Participants also highlighted the importance of supportive peers and friendships. Parents of CYP who did not report negative peer relationships spoke about the incredibly protective nature of friends and friendship groups on their child’s emotional and psychological wellbeing; friends were positioned as protecting CYP with ABI from threats to competence, where peers may act as champions and cheerleaders, also encouraging CYP with ABI to participate. In this sense friends were positioned as being important in facilitating a sense of normality, belonging and continuity of self.

“*They are his sort of almost a bit like an anchor you know for him erm and they’re his reason for going to school when he finds everything else really hard when it gets out to the playground and he's just like them*” Carol, parent of George, aged 8

“If she gets upset they're very good at trying to put that confidence back and saying ‘ohh Alice you done really well’ especially when Alice gets like really bad results so what they do is they don’t ask each other their results in front of Alice” Susan, parent of Alice, aged 15

Many parents named that it was important that their children felt like home was a safe space; somewhere that they could return to when the outside world felt difficult or overwhelming, and made reference to home as restoration of or strengthening of attachment. They spoke about providing their children with unconditional positive regard and love and support.

"*Give her a safe space where she can feel safe and to reduce her anxiety levels*" Julia, parent of Louise, aged 15

"*George feels so out of sorts at school that when he gets home it really is important that you know here you feel safe and secure*" Carol, parent of George, aged 8

4.3 Overarching Theme: Sources of Support

This overarching theme summarises the sources of support available to CYP with ABI that was identified by participants, alongside an evaluation of the effectiveness or potential effectiveness of the type of support. Considerations for how sources of support could be bolstered are explored within this overarching theme. Each theme will be discussed in turn.

4.3.1 Theme 4: Naturalistic Support

This theme explores the role of families and schools in providing naturalistic support to CYP with ABI and the challenges that may be faced within this.

4.3.1.1 Subtheme: Parents and families: a crucial support against the odds

Reflecting on their journeys with childhood ABI, every parent involved in the research acknowledged themselves as being the biggest source of support for their child's emotional and psychological wellbeing.

"I don't normally say this I very rarely say this talk about myself like this, but actually she's got me as a mother" Julia, parent of Louise, aged 15

“Interviewer: …Who or what do you think has been helpful in supporting George’s emotional wellbeing psychological wellbeing - that sense of safety and security that you mentioned

Carol: Can I say me?” – Carol, mother of George, aged 8

There were many challenges relayed within this position. Most parents explained feeling that there was a lack of clarity surrounding a brain injury diagnosis, including the nature and extent of it. Some parents communicated that they were unaware that their child had an ABI and that it only transpired later when problems began to emerge; many were sent home from an acute setting without any information about ABI and longer-term consequences, and they communicated a sense of being left to navigate a new world alone and abandoned by services with whom they had little to no contact, despite feeling acutely in need of professional support. Julia (parent of Louise, aged 15) described the lack of information shared as ‘*like a conspiracy of silence really, you felt that people didn't really want to tell you*’. Some parents reflected that the uniqueness of ABI and uncertainty surrounding outcomes may have led to a failure to outline potential outcomes or trajectories of recoveries. No parents were given information about the potential psychological impact of an ABI.

“*Was just sent home and they said he'll be fine take him home and that was it”*
Jayne, parent of William, aged 14

“I kinda feel like oh finally someone's asking you know like erm (.) I dunno it’s a lot cos I feel like I I feel like we dealt with it with a as a family but to some degrees like I feel like you kind of just get left” Susan, parent of Alice, aged 15

In relation to feeling as though they had been left to their own devices, parents spoke often of a constant need to advocate for their child to ensure they received appropriate support in their rehabilitation or education; this was often communicated in terms of fighting a system. Some parents pointed out the lack of case management and expressed a desire for a central coordinating point to take charge of their child's rehabilitation. There were multiple accounts of parents 'skilling up'; independently seeking out information about ABI and emotional and psychological wellbeing, and acting as both care coordinators and therapists.

"*I feel like her erm - I have to be her advocate*" Zainab, parent of Aisha, aged 14

"*So erm and then having read all the things on the brain hub that talk about you know going to secondary school and how sometimes erm it can be a real challenge for children with acquired brain injury I thought it's probably a good idea to get him on the SEND registry now"* Alex, parent of Lucas, aged 11

Many parents relayed that they had to actively take charge of their child's rehabilitation and put in place supports for their emotional wellbeing, such as learning about activities to boost self-esteem. Some parents referenced the stresses and strains of needing to be a parent plus a therapist, highlighting that it sometimes felt overwhelming.

"*All I want to do Georgia is be Aisha's mum but I'm her nurse her counsellor her doctor her punch bag and I know a lot of that falls under Mum's remit, but...*" Zainab, parent of Aisha, aged 14

Many expressed a feeling of being out of their depth or questioning their competence in supporting emotional and psychological wellbeing. For some there was a belief that it required professional knowledge that they did not possess, which was heightened by the absence of formal support.

"*I just I just think (…) he would have adjusted much better- we we couldn't help him we needed professional support*" Sophie, parent of Lewis, aged 12

"*I've seen people had people who are depressed but I don't really know how to deal with depression in that sense*" Susan, parent of Alice, aged 15

In turn, this sense of ‘not being expert’ appeared to be compounded by parents’ experiences of services who did not respect their parental expertise, or feeling as though their accounts of their child’s needs had to be corroborated by another authority. In contrast to this, professionals highlighted the importance of being alongside parents and families and treating them as expert partners.

“*They really don't understand erm you know how he ticks and you try to explain to them and they're like ‘oh we're the professionals”* Jayne, parent of William, aged 14

“I do not often have direct contact with young people, but rather work with parents to develop strategies” P21, Support worker, charity

4.3.1.2 Subtheme: Parents and families need support

Many parents and professionals highlighted the impact that childhood ABI has on the whole family, with parents and family members also needing to come to terms with and adjust to new circumstances, and sometimes struggling with this.

“*I’d had I had a typical child and suddenly I was dealing with behaviours whereby he would get overwhelmed and he would go into the conservatory, roll in a foetal position and scream and not be able to be touched or communicated with*” Sophie, parent of Lewis, aged 12

“’*Alice, you’ve got siblings’ cos that that I think Paul my son was also crying saying ‘mum I miss you I just want you to stay at home for one day’ and I thought I thought I've spent all this time with Alice and it’s almost like you’re having to tear yourself in parts*” Susan, parent of Alice, aged 15

“*To respond to the needs of the family as a whole, ABI has an impact on the family, not just the child and families should not need their needs to be pathologised, emotional impact on a family and young person post ABI is to be expected and access to services should be available”* P8, Educational Psychologist, Inpatient rehabilitation

The importance of parental mental health was mentioned by a number of parents and professionals. The majority of parents spoke about the impact of ABI on their mental health; most parents recalled traumatic experiences where they witnessed their child in life threatening situations (in many cases as a result of seemingly innocuous childhood events such as viral infections) and preparing for their death. Some parents had diagnoses of PTSD following their child's ABI, and many had sought or were currently seeking professional psychological support. These factors were mentioned both by parents and professionals as being a barrier to supporting children and young people's emotional and psychological wellbeing following ABI. Support for parents was expressed as extremely important by both parents and professionals; parents cited faith, friends and family and formal psychological support as key in their own management of their difficult circumstances.

"*You can't help your child if you're actually (.) er feeling guilty (cries) feeling erm (.) vulnerable yourself f-feeling frightened out of your depth*" Sophie, parent of Lewis, aged 12

"*Poor support for parents and lack of recognition of both their emotional needs and the importance of their role in supporting their child*" P33 Teacher, Specialist Provision

"Parents who were overwhelmed/had their own needs, often untreated PTSD (which when treated them moved things on for everyone" P1 Clinical Psychologist, community rehabilitation

4.3.1.3 Subtheme: School: revealing and heightening vulnerabilities

Many parents positioned schools as a place where lots of problems emerged. Professionals cited significant impacts of ABI on educational engagement or attainment; 75% reported severe impact while 25% reported a moderate impact. One parent explained that they felt that their child was an entirely different person when removed from a school environment that they found challenging. Other parents expressed concern that their children experienced distress as a result of an unforgiving school environment, often framed as a result of threats to competence and identity; for example, in not meeting target grades. Some explained that their children coped with these threats by absconding from the classroom or refusing to engage in class-based learning.

"He's told me he he's wanted to kill himself. He's told me (.) he wished only sort of six seven weeks ago he told me that the stroke was rubbish; he wished it had never happened to him 'it's not cool mum' it's you know so it's sort of (.) but that's primarily because of school" Carol, parent of George, aged 8

"*Like if he couldn't do something he'd just run when he was younger*" Jayne, parent of William, aged 14

Many parents spoke about the demands of school as being overwhelming for their children, finding the school day exhausting as a consequence of 'holding it together' and 'fitting in', resulting in meltdowns or time needed to regulate at the end of the school day. The need for reduced timetables and modified expectations was communicated.

"He was amazing he really managed to hold it together at school. But normally by the time we got home he had had a complete (.) breakdown. Tears, screaming, shouting, rocking, you know it cost him so much all day to reign it all" Sophie, parent of Lewis, aged 12

For both parents and professionals, the lack of awareness and understanding of ABI amongst educational professionals was seen as a significant issue. Many parents expressed both feeling that within the school system there was a general lack of understanding about childhood ABI and its potential impact, as well as feeling that their child's specific ABI and associated needs were not understood by teaching staff. Some linked this poor awareness and misunderstanding of needs to children being labelled as badly behaved, or leading to inappropriate referrals for neurodevelopmental assessments. Many parents and professionals communicated a belief that ABI training for educational professionals was required, with some suggesting that it be mandatory and included as part of professional training, alongside delivering tailored brain injury education on a case-by-case basis. Furthermore, professionals often cited poor understanding of brain injury from educational professionals as a barrier to their own ability to provide support to CYP, or resulting in poor support for emotional and psychological wellbeing.

"*Was just frustrating to watch where (.) I'm listening to some of the reports and then there's the things that they're complaining about are part of Alice's injury*" Susan, parent of Alice, aged 15

"*More training on ABI in schools (e.g. in teacher training) and top ups (e.g. mandatory training), funding for training for schools/parents on young person and the ABI specifically*" P29 Clinical Psychologist, Paediatric Neuropsychology, outpatient assessment and intervention

"*My work is reliant on schools recognising that children with ABI have hidden needs… It is also harder due to lack of knowledge of ABI in professionals, especially schools*" Educational Psychologist, Inpatient rehabilitation

Some parents communicated feeling as though schools did not know how to best support their child, and that their needs were overwhelming both for teaching staff and the school system itself. The majority of parents expressed a belief that specific knowledge and experience relating to ABI was required in order for CYP to be supported appropriately; in turn expressing understanding that this may be beyond the capacity or realistic expectations of a mainstream education provider.

"*I guess you know with these schools that they're not experts in this field and… I feel like it needs more specialist you know intervention*" Alex, parent of Lucas, aged 11

Many parents explained that they felt there were no appropriate educational placements for their children with a sense of children falling between the gaps of educational provision, where their children did not ‘fit in’ to either mainstream or specialist LD placements.

“*But Aisha’s neither a special needs - you know she doesn't need to be in a specialist school*” Zainab, parent of Aisha, aged 14

4.3.1.4 Subtheme: The potential for school as a support

Participants highlighted the impact that a supportive school environment could have on the psychological wellbeing of CYP with ABI. An often-mentioned contributor to good support was in accounts of schools receiving brain injury education to help them better understand the needs of CYP, delivered both to educational professionals and to peers. Some parents described how their children created and shared their own narratives about brain injury.

“*George did his own presentation on using the the stroke association did some children's videos about what happens when you've had a stroke… erm so he presented that to the class; so everyone in the class knows that George has got brain injury*” Carol, parent of George, aged 8

“*Delia went in and spoke to the teachers on brain injury*” Faye, parent of Joshua, aged 19

Parents with positive experiences of school support described how important this was in terms of supporting their children’s wellbeing, and positioned schools as powerful influences who were completely invested in supporting their children. This was relayed both as care given by individuals and by the broader school system. Accounts were provided of school providing psychological support through emotional literacy and support sessions, or providing spaces for regulation. The scope of school as going beyond just education was relayed, as schools were positioned as facilitators of participatory experiences and social connection.

"*With the teachers on a rota basis during the six weeks the PE teacher brought the school van down with six of his friends in, twice a week on a rota basis, for his wellbeing - that's what you call wellbeing, yes*" Faye, parent of Joshua, aged 19

"*The school are very much on Lewis's side very much on top of that*" Sophie, parent of Lewis, aged 12

"Social participation focus - educators understanding the importance of attending school to see peers and not necessarily to attend lessons" P9, Occupational Therapist, Community

Many parents named the importance of individuals within the school whom their child had a good relationship; this was often described in relation to their children feeling 'understood'. Related to this, some explicitly named the role of understanding and acceptance in positive school experiences, perhaps afforded by experience of additional needs. Many parents named the potential of an intervention at a school level in terms of raising awareness and understanding amongst educators, peers and their parents.

'*Oh mum I really like her, I just feel like she understands me you know*' Susan (Recounting Alice's description of her SENCO), parent of Alice, aged 15

"(…) *I don't know whether they could have had a erm almost like a meeting for the parents or something to explain to them"* Alex, parent of Lucas, aged 11

"And the teachers came. Different teachers, they all came, sat with him head teacher it it it it reverberated from the head teacher right down to the pupils – the whole school knew about Joshua" Faye, parent of Joshua, aged 19

4.3.2 Theme 5: The Need for Services

This theme explores participant's views on the status of formal support for emotional and psychological wellbeing, the challenges of supporting emotional and psychological wellbeing and what good support looks like with examples of positive practice. Participants painted a bleak picture of the formal support available to CYP with ABI in the context of a stretched healthcare system under austerity, combined with the need for expertise that does not currently reside within statutory services.

4.3.2.1 Subtheme: There is no support: existing withing a stretched healthcare system

When reflecting on what was available to them in terms of support following discharge from an acute setting, every parent recalled a lack of input from services. This was described both in terms of a contrast to acute care, where transition to the community felt like being stripped of support, and as a general lack of appropriate services in the community, access to which felt at the mercy of a postcode lottery. Many parents expressed a sense of battling to secure appropriate services for their child; from housing, educational support and the involvement of medical professionals such as the assignment of a paediatrician for monitoring. A lack of appropriate services in the community was also mentioned by a number of professionals, who frequently cited having no services to refer on to as a barrier to supporting the emotional and psychological wellbeing of CYP with ABI. Most parents made reference to the strain on statutory services, detailing waiting lists that were too long and community services that were not set up to meet the needs of their children. Multiple professionals cited 'stretched' services as a barrier to supporting CYP with ABI and the impact that properly funded services could make. They reflected on their own experience of working with or within such services, often highlighting constraints on time and resources as a limitation in their ability to provide good support. The impact of time restrictions was expressed both in terms of interventions provided but also in relation to the time needed to build a trusting relationship with CYP as a basis for intervention.

"Interviewer: Could you describe that kind of community rehab erm?
Sophie: OK er woeful" Sophie, parent of Lewis, aged 12

"[Name of rehabilitation centre] have done a lot (.) erm they had meetings with

the teachers erm they had there were so many things that they did do to (.) you know assist Alice back in to like that whole community home living and stuff but erm it's just I feel like when [name of rehabilitation centre] stepped out the services also went missing" Susan, parent of Alice, aged 15

"*Not having services within the community to refer on to*" P30 Clinical Psychologist, acute and post-acute rehabilitation

Many parents communicated a sense of losing faith in the healthcare system; for some parents this was communicated as a general mistrust of the NHS and professionals within it, while for other parents, and many professionals, a lack of faith in Child and Adolescent Mental Health services was apparent. Professionals appeared to dismiss the notion of CAMHS as a viable option of support, citing negative experiences of referring on to CAMHS where ABI is very often seen as a reason to reject referrals. Many made reference to children with ABI falling between the cracks of service provision, which was framed as a result of services misunderstanding their needs. Many reflected that CAMHS professionals may feel that supporting CYP with ABI was outside their competence.

"*Very very rarely have statutory services seen this as their work or within their competencies*" P24 Clinical Psychologist, Community paediatric rehabilitation

"*This has historically been difficult as CAMHS services do not feel they have adequate expertise or staffing to take on the work*" P5 Clinical Psychologist, Residential rehabilitation

A feeling that the needs of CYP with ABI overwhelmed services who did not know 'what to do with them' was conveyed by some parents and professionals, and this lack of understanding and competence was sometimes linked to services stalling or rejecting referrals. Parents and professionals with experience of referring to or receiving support through CAMHS frequently reported it as negative, with services failing to understand the idiosyncrasies of brain injury. Many parents relayed experiences of their children having profiles that overlap with neurodevelopmental profiles although not fitting neatly into diagnostic categories which served to either deny or grant access to services. Related to this, parents often reflected on the lack of parity in service provision for children with ABI compared to neurodevelopmental populations.

"*When a child falls between the cracks 'such as - age or the emotional needs of the child are too overwhelming for the service' very little is encouraged for onwards referral advice or support to the child or/and the families"* P16 ABI coordinator, acute and community

"*They said he's autistic but they weren't sure if he was, that was another (.) really bizarre er cause I took him I think it was three years because they said he acted like he was autistic but they dunno if it's from the brain injury or not because the symptoms overlap"* Jayne, parent of William, aged 14

In contrast, the majority of parents recounted very positive experiences of support obtained through charity and third sector services, some of which were specific to brain injury such as the Child Brain Injury Trust, Supporting Head Injured Pupils in School and The Children's Trust; Faye (parent of Joshua) recalled the support provided to her and her family and the pivotal input a charity had in supporting her son's transition back to school. A number of professionals commented on the reliance on third sector organisations to provide support in the community. Many parents had paid for support from their own finances; this ranged from psychological support such as counselling and play therapy to paying for physical rehabilitation. Related to this, parents and professionals both reflected on the inequalities in access to services depending on litigation, with a whole world of rehabilitative therapies potentially closed to CYP without a litigation case.

"*Well I need a lot of money so I can go and buy in to clinical services privately as if she'd had a road traffic accident and we got insurance money*" Julia, parent of Louise, aged 15

"*There is a lack of provision for this group and parents who can fund privately or have access to things like medico-legal have the greatest access to psychological support*" P8, Educational Psychologist, Inpatient neurorehabilitation

4.3.2.2 Subtheme: What you see is what you get help for

For many parents and some professionals, the hidden nature of their child's brain injury represented a significant barrier to accessing appropriate support. This was communicated both in terms of accessing services and follow up care and securing appropriate adjustments at school; some parents reflected on the particular challenges that educational professionals in mainstream schools may face due to the hidden nature of their child's brain injury – not being experts in the area and needing to hold in mind the needs of multiple other students, some of whom may have more visible needs. The hidden nature of brain injury was also discussed in relation to wider societal responses and understanding, with some parents and professionals expressing the belief that increasing societal understanding of childhood ABI would improve emotional and psychological wellbeing.

"*if you were to meet George in a social situation and non low demand - you'd you'd never guess anything had happened to him… that that's been to his almost detriment being in being in school because it's not an obvious -you know he's not dragging his leg behind him or or whatever you can't you can't see it so anyway*" Carol, parent of George, aged 8

"*I think the biggest problem that that we've got is erm lack of a recognition of brain injury in society generally*" Julia, parent of Louise, aged 15

Many communicated feeling as though physical rehabilitation was prioritised over emotional and psychological support, and relayed a sense of psychological wellbeing being overlooked entirely, even where support was provided by specialist centres. Many explained that they felt that nobody was looking out for emotional and psychological wellbeing, and that it was not enquired about.

"*Yeah no emotional hasn't even no one's done an assessment you know it's not even on the radar*" Alex, parent of Lucas, aged 11

Related to this, parents relayed a lack of support for psychological wellbeing following ABI even when there were needs that emerged immediately after the brain injury, and a number of professionals expressed a desire for clinical pathways to support emotional and psychological wellbeing following childhood ABI. They highlighted the importance and potential impact of early intervention to support with psychological needs, and the propensity for unmet psychological needs to escalate and worsen over time in the absence of support.

"*Treating him for depression or they did and that's what they put it down as erm (.) and it probably was, you know, by that point he'd been hating himself for a number of years and there was no sign of any improvement erm (.) so it probably it probably was er I think that could have all been avoided actually erm with early intervention*" Sophie, parent of Lewis, aged 12

Many parents mentioned the significant role that Allied Health Professionals such as Occupational Therapists, Speech and Language Therapists and Physiotherapists played in supporting their child's emotional and psychological wellbeing, indicating the complex interplay between physical rehabilitation and psychological wellbeing, and highlighting that professionals other than psychologists regularly provided emotional support. This was also mentioned by a couple of professionals when reflecting on examples of positive practice.

"*For all the professionals supporting (th)e child to understand how they can contribute and influence emotional and psychological well-being - not just the job of the psychologist or CAMHS*" Occupational Therapist, community rehabilitation

4.3.2.3 Subtheme: Challenges to supporting

Many parents and professionals reflected on the uniqueness and individuality of brain injury, and the difficulty in projecting a clear trajectory of rehabilitation particularly in the context of childhood ABI and the developing brain. For many parents, a sense of frustration and angst over this uncertainty was communicated, leading to worry about the future for their child and how their needs may unfold over time, as well as creating uncertainty over how best they can be supported. Professionals also mentioned often the uniqueness of ABI and the difficulty in knowing how a YP may be psychologically affected in terms of tailoring care.

"*Recovery is so different for different people… it can be very difficult to know how somebody is going to rehabilitate*" Julia, parent of Louise, aged 15

"*you can read as much as you like, but your child's ABI is different to the next child's ABI, which is different to the next child's*" Sophie, parent of Lewis, aged 12

Some highlighted the importance of respecting the YPs readiness to engage when considering the support given. Professionals who worked in acute settings spoke to the difficulty this posed in their ability to support CYP, especially as acute settings may be the only spaces where specialist psychological care is provided. Relating to the uniqueness of ABI and associated outcomes, the importance of a flexible and individual approach to supporting CYP was mentioned by a number of professionals, perhaps touching on the difficulty of achieving this in the context of a stretched healthcare system.

"*In short placements young people may not feel ready to explore identity explicitly for example, while they are still re-gaining physical skills and perhaps don't yet have insight into the extent to which their brain injury has impacted them physically, cognitively and emotionally*" P17 Music Therapist, post-acute rehabilitation

4.3.2.4 Subtheme: What does good support look like?

Many parents and professionals conveyed a strong sense that supporting CYP with ABI – whether that be formal / naturalistic emotional and psychological support or support for other areas of functioning such as speech and language – does require a level of expertise and understanding. Generally, parents relayed a sense of their child not being properly ‘understood’ until meeting professionals with experience of brain injury, and that support received by inexperienced or unknowledgeable professionals was inadequate, leading to a failure to properly assess and address their needs. Professionals also made reference to the importance of experience and skills acquired through specialist training in their own ability to provide appropriate support to CYP with ABI, with many conveying the importance of possessing clinical expertise in ABI when working with this population and in helping them to feel competent. The importance of expertise and experience was mentioned in relation to professionals across the education and healthcare system, with many professionals stating that improving understanding and awareness of ABI for all professionals working with CYP through specialist training would improve emotional and psychological wellbeing. Professionals generally reported feeling fairly competent in being able to support the CYP they worked with (3% ‘extremely well’; 56% very well; 26% moderately well; 15% slightly well).

“Better understanding of ABI in services” P31, Clinical Psychologist, Neuropsychology service and neurorehabilitation team

It was clear that a number of parents adamantly believed that it was essential for formal psychological support to be provided by clinicians with expertise in childhood brain injury. Sophie (parent of Lewis) and Susan (parent of Alice) both reflected on the psychological support that their children received and concluded that it was inadequate because of the clinician’s lack of understanding around brain injury, leading to their children feeling misunderstood, or unable to engage in therapy sessions which had not been adapted suitably. In contrast, Zainab (parent of Aisha) spoke positively of the support her daughter received from an Educational Psychologist who was highly experienced in acquired brain injury. Similarly, a number of parents dismissed the idea of formal psychological support provided by those without experience and expertise, as they believed it would be unhelpful. The view that a specialist provision for psychological support following childhood ABI was required, for example through a subdivision of CAMHS, was communicated by many. Some professionals also mentioned the possibility of providing alternative specialised therapies such as music therapy and play therapy for younger children or those with a greater level of cognitive need.

“She would phone and have little conversations with Alice but Alice is also a child who's got an acquired brain injury and you've got someone who was dealing with her in that respect but she was giving her a lot of papers a lot of words to go through she she just her attention span is not going to fix with that” Susan, parent of Alice, aged 15

“*There was this lovely lady there who runs the outreach program can't remember her name maybe Paula can’t remember she was wonderful Oh my God - so she came along in year two so our SENCO got in contact and it was the first time someone got George- that was the very first time*” – Carol, parent of George, aged 8

“*A widespread sub-division of CAMHS that deals with direct support for mental health of young people with brain injury with specialist clinical psychologists*” P21 Support Worker, Charity (community support)

“*Training/information for those supporting children with an ABI - to increase understanding of areas to monitor to promote accessing support in timely manner*” P13 Speech and Language Therapist, Community

Professionals often mentioned the positive impact that feeling competent and possessing knowledge and expertise had on their ability to feel able to support CYP with ABI, or that feeling out of their depth made it more difficult to support CYP with ABI. A desire for more training and CPD opportunities was expressed by some, alongside the wish for a greater evidence base to inform clinical work.

"*The system I have worked in and the knowledge I have from professional training and neuropsychology training. Experience helps me to feel confident*" P8, Educational Psychologist, Inpatient rehabilitation

A significant number of professionals spoke to the importance of having a team around the child. This was expressed both in terms of supporting CYP with ABI but also referenced in relation to what helps professionals feel able to support CYP. Professionals often mentioned that they valued being part of a multidisciplinary team that combines different expertise, believing that everyone had something valuable to offer and that being a part of a team helped them feel able to better support CYP with ABI, perhaps in relation to feeling incompetent or de-skilled, or speaking to the complexities of working with childhood ABI. All professionals involved in the study reported that they had worked with others when supporting CYP with ABI. Professionals often mentioned that processes that are part of MDT working such as regular meetings were helpful in supporting them to work collaboratively and effectively. In stark contrast to the experience of those families involved in this study, many professionals asserted that CYP with ABI needed an MDT to be properly supported. Some parents also reflected on examples of positive experiences such as multi-professional meetings in advance of transitions back to school.

Parents and professionals spoke to the crucial nature of good communication between members of the team around the child; some parents framed themselves as part of the team around the child and expressed frustration when information was not passed on to them. A number of professionals referenced poor communication between parties supporting YP as a significant barrier to supporting their emotional and psychological wellbeing, and highlighted good communication as important in helping them work with other professionals to support emotional and psychological wellbeing. Many highlighted how important it was for those supporting the child to be on the same page through information sharing in terms of understanding needs through team formulations, strategies for support or working towards shared goals. This was also reflected in some parent's accounts.

"*You know I just feel like maybe everybody needs to be on the same page so if a more maybe having a team of people who she's familiar with who know her (.) and stuff and and just making sure that everybody knows what they need to know*" Susan. Parent of Alice, aged 15

"A good team around me for supervision and discussion, collaborative working within the MDT and good communication between us. Shared formulation of what is happening for the child and family" P14 Educational Psychologist, Residential Rehabilitation

"*When all services and people supporting the young person were able to communicate and share recommendations and strategies and were taking a consistent approach. This includes parents, other immediate and extended family, health, education and social care*" P30 Clinical Psychologist, Acute rehabilitation and post acute rehabilitation

Many professionals mentioned the need for time to be able to build trusting relationships with CYP and families. Related to this, many relayed a belief that continuity of care in terms of consistency of professionals involved was important especially when considering supporting unfolding needs or transition from acute to community services. One professional reflected that it felt helpful knowing there would be a sense of continuity for families, and expressed a desire to stay alongside CYPF and know what the future held for them, gaining an insight into how effective interventions had been. A sense of regret/frustration that these desires were often incompatible with the realities of working within a stretched statutory system was often expressed. A number of parents referenced the importance of continuity of care either hypothetically or from experience, and gave accounts of professionals staying alongside them and consistently being a part of their journey, often playing advocacy roles.

"Professionals who stay with the child to help with changing needs over time" P4 Educational Psychologist, Medicolegal rehabilitation

“*Being able to be involved over a longer time-period, after the child is discharged home*” P36 Post-acute rehabilitation service

“I didn't mention in terms of emotional support but somebody who was really amazing was erm we were like assigned district nurse at the beginning before Lucas got diagnosed and we've seen her all the way through we still see her now” Alex

“*And she’s got TAs it's not- the the SENCO that is at the school at [name of school] is the SENCO that she had at [name of primary school]”* Julia

Many professionals highlighted that CYPF should be considered as part of the ‘team’, outlining the importance of including and involving parents and CYP in all work and treating them as experts and co-workers. The importance of working in a child and family centred way was reflected on by many professionals who characterised good care as that which prioritised the voice of the YP and shaped the nature of the support wherever this was feasible. Faye reflected on her positive experience of MDT meetings where her son’s voice was amplified and listened to.

“*With all the professionals, including Joshua’s school teacher and the SEND teacher and erm and what I liked was he asked Joshua what he wanted*” Faye, parent of Joshua, aged 19

“*Involving the child/young person as much as possible where this is appropriate and possible*” P13 Speech and language therapist, community

5 DISCUSSION

5.1 Overview

This chapter presents a discussion of the findings of this study in relation to the research questions and relevant literature. A critical review of the study is presented acknowledging strengths and limitations. Implications for clinical practice and policy, as well as wider systemic interventions at a societal level, are considered. Finally, conclusions of the study are presented.

5.2 Summary of Findings in Relation to the Research Questions

5.2.1 What is the Current Understanding of Psychological Needs in the Context of Paediatric ABI Among Stakeholders?

The subtheme ‘Threats to sense of self’ demonstrated that psychological distress experienced by CYP was not only due to changes and losses in their abilities, but in relation to a threat to a foundational sense of self. Expressed as primary and secondary effects of the brain injury, parents and professionals spoke about CYP feeling (and sometimes looking) ‘different’ to their pre-injury selves, but also experiencing discontinuity in their sense of self and threats to self-concept. Such threats were attributed to limits on their participation and participatory activities, social comparison with others and comparison to pre-injury selves, and, frequently, difficulties in peer and family relationships.

5.2.1.1 Limitations to participation compound identity losses

Changes in ability (and often desire) to participate in previously enjoyed activities or new activities was highlighted frequently by parents and professionals and cited as a cause of psychological distress, as CYP grappled with losses to their pre-injury identities or were forced to confront negative comparisons to their peers. The dominant narrative from parents and professionals centred around systemic disablement of participatory opportunities related to a systemic misunderstanding of needs. This compounded avoidance of participation due to activities themselves reinforcing changes in their abilities, resulting in negative comparison with others.

5.2.1.2 The risk of social exclusion and negative social comparison

Previous research has identified difficulties with social competence, social adjustment and social participation (Anderson et al., 2012; Ankrett et al., 2023; Kakonge et al., 2022; Lindsay et al., 2023; Sharp et al., 2006) and reported negative social comparisons (Di Battista et al., 2014; Glennon et al., 2022). The findings of this study replicate this; significant social difficulties were reported by the majority of parents and professionals. The subtheme *'Threats to social connection and attachment'* demonstrated strong themes of restrictions in social participation and social exclusion. Most parents and professionals expressed concern over CYP's friendships, highlighting changing/declining peer relationships (including bullying) or the complete absence of a peer group. Alongside unfavourable peer comparisons highlighted in the theme '*The need to be understood and accepted'*, this was conceptualised as reinforcing losses to identity and having a direct effect on emotional and psychological wellbeing. The impact of acquired cognitive needs such as emotional regulation and expression on peer relationships was also highlighted, positioned as influencing CYP's ability to understand themselves and be understood by others. This mirrors previous research demonstrating that difficulties with emotional regulation and social competence negatively impact peer relationships (Di Battista et al., 2014; Kakonge et al., 2022; Sharp et al., 2006).

5.2.1.3 ABI in adolescence: a sensitive period for identity development

ABI can interrupt or clash with the central developmental tasks of adolescence such as identity development and independence (Kakonge et al., 2022; Mulligan et al., 2023). Adolescence is also a period in which the need for peer acceptance and inclusion is heightened (Buckeridge et al., 2020; Kakonge et al., 2022); research has suggested positive peer relationships can act as a buffer against identity changes (Glennon et al., 2022; Mulligan et al., 2023), therefore difficulties with peer relationships may interrupt the development of identity in adolescence. In the theme 'the need to be understood and accepted', participants highlighted the heightened needs arising in adolescence, characterised by the clash of wanting to fit in alongside an awareness of difference and negative peer comparison.

Some authors posit an optimistic perspective on the impact of early ABI vs later injury on identity, as the injury becomes part of the identity of the CYP rather than posing a discrepancy that leads to distress (Buckeridge et al., 2020). The findings of this study would contest this assertion as (i) a broad range of age at injury is represented, yet problems related to or firmly rooted in the arena of identity appear to be apparent regardless; (ii) the data highlights that the impact of ABI prior to adolescence has the propensity to disrupt identity development; and (iii) the impact of ABI on friendships and identity is felt both in those who experience an ABI in early childhood, and by those who have not yet reached adolescence.

5.2.1.4 Importance of friendships and adjustment

In seldom accounts of positive social experiences, friendships were positioned by parents as important for maintaining a sense of normality and belonging, providing a feeling of continuity for CYP. Where parents perceived greater issues with peer relationships, they often gave examples of their children seeking out alternative peer groups to minimise differences and foster a sense of ‘normality’. The protective and restorative power of friendships has been alluded to in previous research, where friendships have been positioned as central in recovery narratives, providing a sense of fitting in (Mulligan et al., 2023).

5.2.1.5 Changes in primary family relationships

Participants mentioned changed relationships with family members, frequently conceptualised as threats to attachment. Parents were confronted with feelings that their child had ‘changed’ and needing new ways of connecting and being with them. This supports existing literature examining the experience of mothers of adolescents with ABI expressing grief over changed aspects of their child (Glennon et al., 2022).

5.2.1.6 ABI's potential to influence the trajectory of identity development

This study demonstrates the far-reaching impact of ABI on relationships for CYP and the central threat to the human need for love and belongingness (Maslow, 1945). This shows alignment with social identity theory (Haslam et al., 2008) and is comparable to research in adult survivors of brain injury, where qualitative examinations found that people make sense of themselves in terms of meanings and felt experiences (the experience of self) of social and practical activity (Gracey et al., 2008). Therefore, meaning and doing are considered connected in the reconstruction of identity following brain injury.

This may be particularly evident in CYP, as the individual 'self' is understood more in the context of the social arena; for adolescents, it has been shown that peer-relatedness is crucial for the perception of the self (Di Battista et al., 2014; Glennon et al., 2022). Loss of 'self', or significant discontinuity between pre-injury and post-injury self, is thought to lead to poor mental health outcomes in adults (Cantor et al., 2005). As the 'self' is thought to be significantly influenced by parent and peer relationships (Harter, 2015), it is unsurprising that the quality of peer and family relationships was highlighted by so many parents and professionals as being central to psychological wellbeing following ABI and framed as a potential protective factor.

5.2.1.7 Wanting to be 'normal' and internalised ableism

The desire to appear 'normal' and a rejection of the label 'disabled' by CYP was demonstrated in the theme 'threats to sense of self'. Parents counteracted this by attempting to promote a positive narrative around disability and a positive reframing of brain injury. A felt sense of being different may be compounded by post-injury diagnoses of ASD and ADHD - a common experience of parents who participated in the study (alongside the diagnosis of mental health conditions such as PTSD).

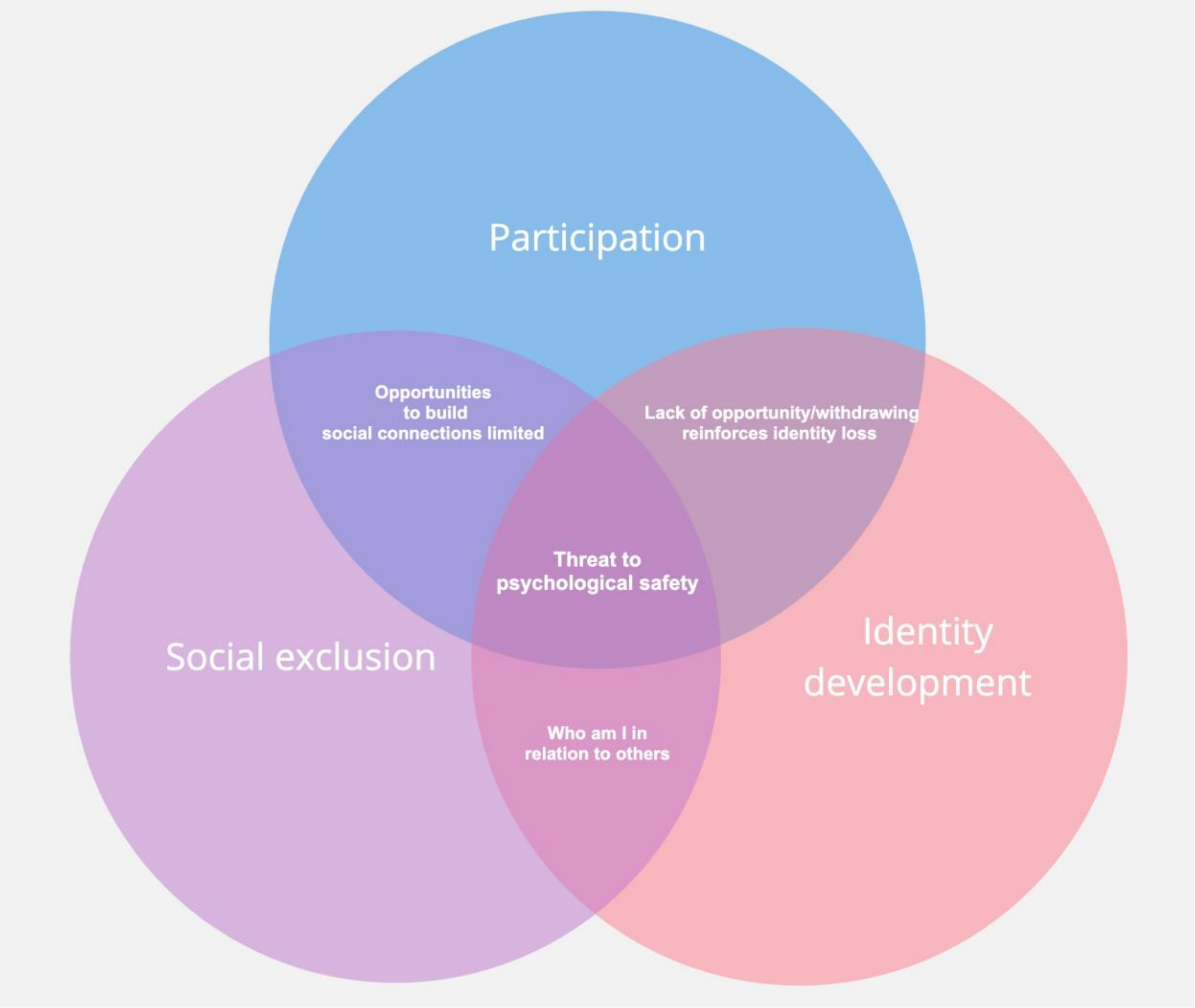
Neurodevelopmental conditions such as ASD have been shown to be overrepresented in the paediatric ABI population (Porter et al., 2023) and up to 20% of children with an ABI develop a clinically significant attention problem, often labelled as secondary ADHD (Mckay et al., 2019). Keeping in mind the narratives in this study that CYP struggle with being perceived as different on top of adapting to life post ABI, labelling outcomes likely related to the brain injury should be carefully considered, as pathologising narratives could potentially be more damaging to the ability of CYP to successfully adapt and achieve a positive sense of self (Jim et al., 2023).

5.2.1.8 A threatened sense of psychological safety

Alongside trauma responses directly linked to the experience of the ABI, participants described the secondary impact of participation restrictions, changed relationships and a feeling of not being normal as leading to poor emotional wellbeing and relayed a threat to the CYPs sense of psychological safety. A particularly salient element of parental reports was low self-esteem in their children, as well as anxiety and low mood. The experience of functional deficits, reduced participatory experiences, loss of peer relationships and increase in dependence for activities of daily living have been hypothesised previously to contribute to poor emotional wellbeing (Kirkwood et al., 2001). This study adds the importance of considering identity and how ABI in childhood threatens this. Figure 3 summarises the above section considering interacting factors and how these may contribute to poor psychological wellbeing following childhood ABI.

Figure 3

A summary of interacting factors contributing to a threatened sense of psychological safety



5.2.2 <u>What are the Perceived Barriers/Facilitators to Meeting the Psychological Needs of CYP with ABI?</u>

5.2.2.1 A lack of understanding

A lack of understanding of ABI and it’s acute and longer-term effects from those directly involved in the care of CYP and in wider society was a recurring theme. Negative impacts of a lack of understanding of associated long term needs in social care, education and healthcare has been identified previous studies (Keetley et al., 2019; Mulligan et al., 2023). The impact on CYP's psychological wellbeing as perceived by parents and professionals is described below.

5.2.2.2 Schools: Boom or Bust

The theme 'School: revealing vulnerabilities' showed parents and professionals frequently referring to school as a challenging experience; both borne out of it being a heightened social arena, and through a failure of educational professionals to understand the needs of CYP with ABI. Parents expressed feeling it was beyond the capacity of mainstream schools to accommodate their child's needs, simultaneously stating that their child would be unlikely to be accepted into (or feel a sense of belonging) in mainstream education. The lack of awareness of ABI amongst educators has been documented multiple times in the literature (Bate et al., 2021; Hartman et al., 2015; Morley et al., 2022). Extant research indicates that educational professionals might feel ill equipped to support emotional wellbeing needs in particular (Bate et al., 2021; Hartman et al., 2015).

As aforementioned the need for training and awareness raising for educational professionals has been highlighted in the Time for Change report (All Party Parliamentary Group, 2018) which was followed by the establishment of N-ABLES, with a mandate to identify ways to support educational professionals in awareness raising of ABI. N-ABLES have produced training material and recommendations to this end (N-ABLES, 2021) such as an individual return to education plan for each CYP with ABI. Others have also called for promoting flexibility with the curriculum and learning activities, encouraging hospital visits from school staff, and promoting collaboration with rehabilitation teams (Botchway et al., 2022).

Positive accounts of school experiences were frequently linked to the school receiving appropriate brain injury education from trained professionals and giving CYP a platform to share their narrative. This can be conceptualised as promoting mentalisation- the ability be attuned to your own and another's internal world (Allen et al., 2008). In addition to this, schools that provided emotional literacy sessions and generally operated on trauma informed principles (such as having 'regulation' zones) were highlighted as providing positive experiences for CYP, and were often framed as places that held and facilitated friendships to grow. Indeed, schools are considered crucial in in identity development following brain injury as they facilitate emotional and social development (Sharp et al., 2006).

5.2.2.3 No services, little expertise that have potential to harm

The theme ‘The need for services/formal support’ demonstrates poor provision of NHS rehabilitation services for CYP after discharge from acute settings, with inadequate provision of formal psychological care provided by professionals with expertise in childhood ABI (despite specifications stating that long term rehabilitation is offered by community disability teams; NHS England 2013). There were frequent accounts of rejected referrals to CAMHS. Participants highlighted the following as contributing factors; the invisibility of brain injury, ‘sleeper effects’ in relation to later emerging emotional difficulties once support had fallen away, and a stretched ‘postcode lottery’ healthcare system that does not have the resources or professional expertise to identify and meet their needs.

Whilst the over-medicalisation of needs may overshadow needs that are not physical and not visible (Jim and Cole, 2020); the services for this population are not reflective of its prevalence (TBI alone has an estimated prevalence of 32% - excluding non-traumatic brain injuries; greater than that for CYP with ASD, ADHD, LD and dyslexia put together), pointing to social inequality within the healthcare system, and institutional ableism (Jim et al., 2022; Lindsay et al., 2023). This is driven by the (incorrect) belief that the ABI population is small and that CYPF bounce back (Jim et al., 2022).

Accounts of care provided by psychological professionals with no experience of or understanding of ABI were wholly negative, for example, with little adaptation of material that would typically be expected for people neurological conditions such as ABI (BPS, 2017). Objectively, this could be considered as damaging relationship to help and causing iatrogenic harm.

The provision of formal psychological support for this cohort is clearly lacking. Professionals alluded to the importance of feeling clinically competent achieved through specialist training. Jim et al. (2020) report from clinical experience that clinicians often cite feeling overwhelmed and under skilled; this is likely to be the case across other AHPs and social workers. Considering what may help imbue a sense of competence (alongside specialist training) is important.

Existing within a stretched public sector was reflected heavily in the accounts of parents and professionals, where a lack of continuity of services and poor communication between services (for example, between hospital teams and schools) was outlined. This is discussed further below. Professionals often expressed a desire to provide continuity for the CYPF they work with by staying alongside them; perhaps wanting to strengthen relationship to help and provide a secure attachment. In the accounts given by parents, the continued presence of a trusted professional (for example, a physiotherapist, a SENCO, or a nurse) was highlighted as very positive and beneficial to the wellbeing of CYP. Previous research has alluded to the importance that adolescents with TBI placed on having a trusting relationship with a professional who was competent (Gagnon et al., 2008), and the benefits of a continued relationship with one trusted professional has been echoed by adult survivors of adolescent TBI (Mulligan et al., 2023).

Many professionals highlighted the importance of CYP’s readiness to engage which may clash with the availability of formal services (in the acute period). Parents and many professionals relayed that they felt that expertise and experience was required to appropriately support CYP with ABI, and that CAMHS as it stands are not able to provide appropriate care for CYP with ABI (even if they are accepted, which is unlikely).

5.2.2.4 Parents and families as first responders to psychological needs: advocates who need accurate information

Every parent involved in this study acknowledged that they were the main source of support for their children, describing being thrust into a multiplicity of new roles with no support or guidance and independently ‘skilling up’ to support their child and a new set of needs. A lack of information about brain injury and what to expect was strongly communicated, with many describing a sense of abandonment and disempowerment- being left to navigate a new world requiring new expertise alone. It is recognised that families need support to navigate the chronic nature of childhood ABI (Lundine et al., 2019) and failure to provide parents with appropriate information has been documented in the literature previously, with parents being left feeling ill-equipped to meet the new needs their children have (Jones et al., 2018; Minney et al., 2019).

Professionals often commented that the trajectory of recovery is hard to predict and parents highlighted the challenges of not knowing what the future might hold or what recovery might look like, which has been echoed in previous research (Savage et al., 2005). Clinicians may be reluctant to provide prognostic information for a number of reasons such as not wanting to cause distress and that fact that such predictions are inherently complex in this population. However, it is possible to provide families with a degree of post-injury information and psychoeducation (Minney et al., 2019); for the parents involved in this study, this rarely happened.

The theme ‘Parents and families need support’ demonstrated the impact of CYP ABI on parental mental health, which was highlighted by professionals as a risk factor for poor psychological wellbeing in children, as parents with their own mental health difficulties may struggle to attune to and meet the emotional needs of their child. This reinforces the positioning of paediatric ABI as a systemic event; much like ABI effects the whole brain and has wide reaching impact on functioning, so too does it affect the family system.

5.2.3 What are the Implications for Our Understanding of Risk and Resiliency Factors for Psychological Wellbeing Following Paediatric Acquired Brain Injury?

5.2.3.1 Normalising the need for early and preventative intervention

In the theme ‘The need for services/formal psychological support’ parents and professionals highlighted the importance of early psychological intervention and the benefits of preventative rather than reactive support. Accounts of formal psychological support were often imbued with a sense of ‘too little too late’, and parents in particular expressed that early, specialised support was needed. When considering formal psychological support, it is important to reflect on the desire of CYP with ABI to appear ‘normal’ and to fit in. Some have cautioned against further marginalising CYP who do not want to be seen as different or needing help (Gauvin-Lepage & Lefebvre, 2010) and that the need for psychological support might go unrecognised both owing to the invisibility of brain injury, combined with the desire of CYP to ‘get on with it’ and fit in (Mulligan et al., 2023). Sensitivity around this and normalising the need for psychological support is warranted to minimise the risk of pathologising adjustment needs. As the subthemes ‘what you see is what you get help for’ and ‘what does good support look like’ demonstrate, the majority of parents and professionals were clear that they felt formal psychological support should be provided, rather than relying on naturalistic sources of support. This is in contrast to assumptions made at the conception of the study.

An obvious candidate for early intervention is within a school setting, and this was highlighted in the theme ‘the potential of school as a support’. Encouraging trauma informed principles in schools was highlighted by professionals as important in supporting emotional wellbeing of CYP with ABI. In positively oriented frameworks for neurorehabilitation that focus on maximisation of developmental potential (as opposed to restoration of deficits) the environment has a powerful potential for facilitating resilience, identity development and psychosocial adaptation following ABI (Perkins et al., 2022). The current research highlights potential avenues for adaptations in the environment of CYP with ABI; examples of contextualised intervention are explored below.

5.2.3.2 Reinforcing social connection

The subtheme ‘threats to social connection and attachment’ and theme ‘the need to be understood and accepted’ highlight the impact of ABI on peer relationships, regardless of age at injury, and the resulting negative impact on psychological wellbeing. The demonstration of the restorative power of positive peer relationships is reflected in the theme ‘sources of resilience’ and indicates that a potentially fruitful avenue for bolstering naturalistic support for CYP with ABI exists in intervention with their peer group. CYP with ABI have suggested improving understanding amongst their peers through additional brain injury education sessions (Ankrett et al., 2023) which may encourage mentalisation, thereby improving social experiences. Retaining agency and control over how (and what) information is shared with their peers has also been highlighted as very important (Rødset, 2008).

The opportunity for bolstering peer relationships through shared activity outside of school has also been suggested (Ankrett et al., 2023); in keeping with some of the narratives within this research, where parents frequently felt that their children had no friends or social connection outside of school. In supporting CYP with their peer relationships and participation, a feeling of connectedness to others may be fostered, thereby supporting positive self-concept (Mealings et al., 2017). As adolescence appears to be a time of particularly heightened needs, the timing of/repetition of this intervention may be considered. There is currently very little evidence of the efficacy of peer intervention but given the evident importance of peers in recovery and rehabilitation, this is a potential avenue for future research.

5.2.3.3 Feeling understood: the potential for peer-to-peer support

Many parents and professionals suggested that peer-to-peer support may be a helpful avenue for supporting the psychological needs of CYP with ABI, as reflected in the theme ‘The need to be understood and accepted’. The desire for peer-to-peer support in adolescents with moderate TBI and a range of health problems has been documented (Gagnon et al., 2008). Although limited evidence for the psychosocial effectiveness of peer-to-peer support in adults with ABI has been found, benefits include feeling connected, interacting with others, and providing and receiving support (Hughes et al., 2020). As peer relationships may be particularly acute for identity development and self-esteem in childhood, it is possible that children with ABI may benefit more significantly from peer-peer support relative to adults.

5.2.3.4 Post-traumatic growth mindset

Parents emphasised the difficulties that their children had with being perceived as ‘different’ and receiving a label of ‘disabled’, but explained that viewing the brain injury as an experience that resulted in strength was helpful. Rennie and Goforth (2020) highlighted the benefits of positive attitudes and narratives of strength and survivorship in CYP with ABI. This can be linked to post traumatic growth; a sense of a positive change through a traumatic experience (Di Battista et al., 2014). For CYP with ABI, negative narratives around disability and a lack of positive disabled role models might inhibit the potential for post-traumatic growth, although it has been reported in the adult literature (Nochi, 2000); opportunities for peer-to-peer support might provide an avenue for deconstructing negative narratives around disability and encourage the identification of positive disabled role models. Parents also referenced the importance of temperament and attitudes of their children, stating that an existing resilience allowed them to ‘get on with it’ – this is a finding replicated in the narratives of adult survivors of childhood brain injury (Mulligan et al., 2023) and CYP with ABI (Champigny et al., 2023).

5.2.3.5 The vital role of identity rehabilitation for CYP with ABI

The current research highlights the negative consequences of restricted participation and compromised social experiences on identity and psychological wellbeing, as well as the benefits of finding new and meaningful avenues of participation. Whilst well documented in the adult literature, the importance of identity rehabilitation following childhood ABI has been less well recognised, although a guide to identity focused rehabilitation in CYP has recently been formulated (Perkins et al., 2022).

Participation in valued and fulfilling activities has been considered as key to identity rehabilitation following ABI in both adults and children (Gracey et al., 2009; Perkins et al., 2022). Avoiding situations where losses to identity are reinforced has been conceptualised as a ‘safety behaviour’ (Gracey et al., 2008, Perkins et al., 2022) and this in turn is bolstered by unequal access to participation in valued activities (Jim et al., 2022). As a result, CYP are denied the opportunity to acquire a sense of achievement and mastery gleaned through successful negotiation of challenging activities, which may have a detrimental effect on psychosocial adaptation following ABI (Perkins et al., 2022). Psychoeducation around the importance of exposure to/opportunity to engage in new participatory experiences may be beneficial and could be provided to all of those within a child's system.

Limits on participation following ABI have been well documented and shown to be long lasting (De Kloet et al., 2015), and to exist regardless of injury severity (Law et al., 2011). Previous research suggests that CYP feel changed following a brain injury owing to the cognitive and physical changes that result in constrained or limited participatory activities with related social ramifications (Sharp et al., 2006). Restricted participation as identified in this study has the potential for far reaching detrimental consequences, both on identity and on mental health.

5.2.3.6 Supporting parents

Parental wellbeing was highlighted as paramount by many professionals, and parents frequently relayed the impact on their own mental health, simultaneous to being the primary responders to their children's psychological needs. In providing support to parents, there exists an opportunity to bolster one of the most significant sources of support for CYP with ABI; there is extensive research supporting the notion that the psychological state, parenting style and coping strategies of parents is key to determining outcome in childhood ABI; Beauchamp et al. (2021) have termed this the 'parent factor'. Interventions could vary from individual psychological support, peer-to-peer support, or, as detailed above, parents may find that being given information around what to expect is helpful as a form of early intervention. Parents may benefit from psychoeducation /brain injury education and being formally 'skilled up', which could also affect rehabilitation potential (Brown et al., 2013; Fisher et al., 2021).

5.2.3.7 Workforce readiness

A question of competence

The findings from this study highlight a significant gap in workforce readiness to support CYP with ABI that is evident across training programmes sponsored by the department of health and social care such as clinical psychology, social work and

AHPs, and also the department of education. Given the prevalence of childhood ABI, a 'skilling up' of those who care for CYP seems imperative. Currently, little priority is given to providing an understanding of a holistic overview of brain development, the impact of brain injury (primary and secondary) and the importance of being responsive to needs that might unfold over time (Jim et al., 2021). Whilst a lack of training amongst educators has been well documented, this study highlights that CPs, AHPs and social workers may not feel equipped or competent in supporting CYP with ABI in relation to their psychological wellbeing. This was compounded by a belief expressed by both parents and professionals that providing support for psychological wellbeing required expertise and specialist training.

A whole team approach

Interdisciplinary teams are recommended in paediatric neurorehabilitation specifications (NHS England, 2013), but the experience of the majority of parents who participated in this study did not reflect this. As demonstrated in the subtheme 'What does good support look like?', a team approach is necessary and professionals and parents were clear that CYPF need to be at the centre of this (and considered part of the team) and have their voices heard. The importance of connecting clinicians, educators, families and CYP in interventions has been highlighted previously (Lindsay et al., 2015). Professionals stated the benefits of belonging to an MDT where knowledge and expertise could be shared, and also alluded to the shared responsibility across those supporting the child to support emotional wellbeing and psychological adjustment, in the context of too often deferring to psychology. McCusker et al. (2005) highlights that there is an artificial separation of problems relating to professional input and that this failure to acknowledge interacting subsystems creates siloes, in turn limiting holistic formulations that only act in detriment to the CYP.

Good communication across and between teams was also highlighted as essential and ensured that all parties involved in the care of CYP were aware of their current needs. Poor communication feeds into poor understanding and information sharing of a child's injuries with primary care and information services, impacting on the potential for a child to participate fully in everyday activities and education. This is hypothesised to be most prominent when there are no visible injuries (Jones et al., 2018).

5.3 Summary

The findings from this research demonstrate that the primary responders to the psychological needs of CYP with ABI are their parents. Stories of support provided by third sector organisations were also prominent. Although the title of the research project is ‘how are the psychological needs of children with ABI responded to and by whom’, both parents and professionals were focused on pointing out that there is very little support available, particularly past the acute period. Participants voiced that responses to needs were inadequate and that there was potential for support that was frequently missed, and that needs were not being met, with a range of systemic and individual risk factors interacting to contribute to the vulnerabilities that were pointed out in this research. Contrary to assumptions about naturalistic support being the most appropriate and least pathologising form of support for psychological wellbeing following ABI, parents and professionals strongly indicated that they felt specialised services (such as through a subdivision of CAMHS) were needed.

The research findings point more towards what could be done to support CYP with ABI and where there is potential to make a difference. Participants were clear that the needs of this population are being neglected. It was therefore perhaps difficult for participants to conceptualise ‘how’ CYP are being supported. It could be argued that the title of the research is a red herring and that a more appropriate title would be ‘How do we understand the psychological needs of CYP with ABI and what supports are needed to meet them’. In light of this, implications of the research are focused on potential avenues that could address these factors.

5.4 Critical Evaluation

I used questions posed by Spencer and Ritchie (2011) to assess the quality of the research.

5.4.1 Contribution

This study is the first to gather perspectives of parents of CYP with ABI, healthcare professionals, social workers and educational professionals who have worked with CYP with ABI, to qualitatively examine psychological needs in context and barriers/facilitators to meeting these, providing an understanding of contextualised needs and risk/resiliency factors across development. Previous research on psychological wellbeing following childhood ABI has typically employed quantitative methods, and there are very few qualitative examinations that exclusively focus on psychological wellbeing following childhood ABI and how this informs our understanding of risk and resiliency factors for psychological wellbeing. This study has identified a desire for formal psychological support alongside identifying opportunities to bolster naturalistic supports. Comparing findings with existing literature has helped to demonstrate correspondence with existing research such as the impact of ABI on social exclusion/identity and family roles and parental mental health. Novel findings in benefits of maintained social relationships, the potential for naturalistic support in school, at home, and suggestions for improvements in formal supports have also been identified. In the following section I have contextualised the findings in relation to an existing model to envision how the recommendations might be operationalised in practice. I intend to share the findings of this thesis with parents who wished to be informed of the outcomes via an accessible summary, and to prepare a manuscript for publication.

5.4.2 Credibility

Credibility is characterised by plausibility and believability of the research, and whether conclusions have been substantiated. In conceptualising this project, I sought advice from parents with lived experience on the study design including the interview schedule. I also set up a working group of professionals to provide feedback on the questionnaire, to ensure that questions were considered robust and relevant.

Through triangulation of the data I attempted characterise a holistic understanding pf psychological needs, risk and resiliency factors. To achieve this convergence of wide-ranging data, I essentially undertook two small research projects, analysing contributions via semi-structured interviews from eight parents alongside analysis of questionnaire data from 36 professionals. Throughout the results section I have included relevant data extracts to support my interpretation of the data. Thematic analysis by its nature does not capture any contradictory views within individual accounts, so the voices of individual participants may be lost (Braun & Clarke, 2013). However, I hope that those who were involved in the research who read this thesis will find their experiences and perceptions reflected in the content.

5.4.3 Rigour

Assessment of rigour in qualitative research including thematic analysis involves a consideration of the researcher's reflexivity. Throughout the research I have attempted to provide consideration of my personal and professional positioning and how these have influenced the research. I have given an account of how my pre-training experiences working with parents, clinicians and CYP who experienced ABI has shaped my preconception of the needs of this population. It is also important to consider how my experiences of working in a PNR unit as a trainee influenced my understanding of needs of CYP and potential risk and resiliency factors and missed opportunities for intervention. During this time I had the opportunity to work within a 'best practice' setting, where practices for supporting professionals such as trauma informed supervision were set up. I recognise that for many services who are doing their best to meet the demands of the populations they serve in the context of increased financial and societal pressures, this is not feasible. Finally, I have provided an account of how my experience of becoming a mother during the process of the research shaped my relationship with the data and its interpretation. All of the parents who took part in the research were mothers (this is discussed further below) and as I became a mother throughout the research process, I was particularly moved by their stories, which were often challenging to hear and immerse myself in. I am aware that this will have affected the themes I identified within the data and their perceived saliency.

5.5 Limitations

5.5.1 <u>Participants</u>

5.5.1.1 Educational professionals

The recruitment of professionals proved to be more challenging than expected; in particular, the voices of educational professionals working in mainstream environments are not represented, and few professionals working in community settings participated in the research. The lack of representation of mainstream educational professionals renders the operationalisation of findings in educational settings hypothetical. Future research could focus on educator's experience of providing psychological support in schools, perhaps using focus groups with school teams to identify salient experiences and issues.

5.5.1.2 Fathers

The study exclusively involved mothers of CYP with ABI; no fathers expressed an interest in taking part in the research, limiting generalisability of results in terms of parental experience and support needs, which could be interpreted as 'maternal' support needs rather than 'parental' support needs. I had intended to capture the voices of both mothers and fathers, so the absence of fathers voices this study warrants some reflection. Overwhelmingly, research involving parents of children with ABI represents mothers, whether this is intentional in the research design or not, although the little research involving both mothers and fathers implies that fathers report significantly greater psychological distress than mothers and struggle to cope emotionally (Brown et al., 2013; Yeates et al., 2010). This has implications for the way that services are designed in terms of supporting parents and points to a potential failure to address the support needs of fathers. Future research could focus explicitly on capturing the experiences of fathers.

5.5.1.3 CYP with ABI

I recognise that the voices of children and young people themselves are often excluded from the literature, and most research including young people directly involves adolescents. This study did not include the voices of CYP themselves. This was a decision that was made intentionally to gather perspectives of those surrounding the child to understand needs and what the barriers to meeting those needs are, aligning with an Ecological Systems Theory of development and mental health. Inclusion of the voices of CYP may have required a different study design and could present certain ethical challenges (for example, how to gather experiences in a way that felt safe for the CYP) that feel beyond the scope of a thesis contained within a Clinical Psychology Doctoral programme. However, the reports of parents may not accurately reflect the views of CYP themselves (Jones et al., 2018). Failure to include the voices of CYP has been criticised in previous research and risks further subjugating the voices of CYP- paradoxical to this study's intention. The 'proxy problem' has been recorded previously, where parental accounts are discordant with their children's (Glennon et al., 2022). In general, there has been a dearth of qualitative examinations focusing on the subjective experiences of CYP rather than relying on parental informants (Di Battista et al., 2014). Future research should be inclusive of the voices of CYP with ABI to capture their own experience and perception of what good support looks like.

5.5.1.4 Aetiology and timing of brain injury

In recognition of the fact that much of the ABI literature is focused on TBI, I intentionally recruited across a broad spectrum of injury aetiology. I also did not impose limitations on how much time needed to have elapsed between injury and participation in the research. This has some important implications; firstly, those parents whose children had experienced a brain injury very early in life and were now teenagers may have had different early experiences in terms of care provided in the current healthcare system. Second, some have criticised broad variation in time since injury and participation in research which has been seen by some as a limiting factor (Mulligan et al., 2023), as the time for adjustment is varied. However, qualitative accounts from parents whose children sustained an ABI early in life and who are currently teenagers were not significantly different from those whose children had experienced an injury more recently. Finally, this research involved parents whose CYP did not have the most severe acquired needs; therefore the findings of this study may not be generalisable to those CYP with the most severe acquired needs.

5.5.2 Methods of Data Collection

Limitations in data collection methods should also be addressed. I encountered some difficulties with synthesising and combining data gathered using different approaches; at times I struggled to 'hold on' to the data – as there was such a huge volume of it. There was also disparity in how 'close' I was able to get to each dataset – the process of listening and transcribing interviews with parents resulted in becoming quite absorbed in their narratives. Reading accounts from professionals was a different experience. The interpretations were naturally more constrained as responses themselves were likely inhibited by the nature of the questions asked and the method of data collection of (e.g. an uncontrolled environment where time pressures and interruptions are quite likely). I was conscious of gathering perspectives from professionals in the least time intensive way for them. However, perhaps a focus group for professionals would have provided a richer data set and alleviated some of the difficulties with data convergence. It is also important to mention that the timeframe between data collection and analysis was protracted owing to maternity leave. It is likely that this gap influenced my perspective and interpretation of the data; returning to the reflective journal (Appendix L) I kept over the period of data collection was helpful in foregrounding my interpretation.

5.5.3 Integration of Qualitative and Quantitative data

The quantitative data acquired (e.g. from the professionals questionnaire) were analysed and presented primarily to bolster and add to the richness of the qualitative findings; for example, the qualitative accounts of peer relationship issues were echoed by analysis of quantitative data from professionals considering this to be a significant issue. I felt that the themes emerging from the analysis of qualitative data presented a strong narrative, and this sense, I followed the narrative of the data, which was also important for my personal and professional development given my previous experience in quantitative research. Although I had intended to consider how certain demographic factors (such as how parents perceived their social class) impacted their experiences, the pool of data (n=8), with variety of social class represented, was too small to deduce any statistically meaningful associations. However, it was clear that despite parents being from different social classes, their experiences converged in terms of the adversities they and their children faced.

5.6 Implications of the Findings

5.6.1.1 Early intervention: Operationalising the findings through a trauma informed model of care

The findings of this research can be contextualised and operationalised within a trauma informed model of care, drawing specifically on five principles of intervention following traumatic events (disasters and mass violence); ‘safe’, ‘calm’, ‘connected’ ‘control’ and ‘hope’ (Hobfoll et al., 2007). Table 5 expands on these principles and how they have been formulated for care of CYP in educational settings following a critical incident (UK Trauma Council, 2023). Hobfoll et al. (2007) highlight that promotion of a felt sense of safety is in part a restoration of ‘the protective shield’ that underpins much of early development and family life. They also point out that interventions must include a social systems perspective. Using these principles and training developed by the Anna Freud Centre and UK Trauma council, the responsibility of care for psychological wellbeing can be reframed as being everybody’s role, and within everybody’s remit to support. Guidelines have been developed for application in educational settings following critical incidents – but these can be applied to considering how to meet the needs of CYP with ABI too.

Trauma exposure can undermine an individual's sense of competency in handling events they have to face. There is a developmental trajectory in schematisation self-efficacy and efficacy of others that is important to consider with children and adolescents; with emotional regulation and enhanced problem solving skills said to be particularly important components (Perkins et al., 2022). This is critical to remember in CYP with ABI as these very abilities are typically undermined by the brain injury itself; so self-efficacy is threatened by the primary effect of the injury, and the secondary effect of the trauma related to it. If clinicians and educators feel that supporting CYP with ABI is outside of their competence, these universal guidelines demonstrate how effective mentalisation can occur and how a level of early intervention can be provided by all of those caring for CYP with ABI.

Table 5

Five Principles of Intervention Following Traumatic Events

Principle	**Meaning**
Safe	Meeting basic needs, protection from further traumatic events – acknowledging that what has happened to CYP has changed they see themselves, the world and others. Understanding the impact of ongoing health needs.
Calm	Helping CYPF and staff to regulate their emotions (those working in educational settings do this frequently)
Connected	Connection, relationships and social support can be very helpful to mitigate

	against trauma. This could also apply to parents as well as professionals.
Control	Self efficacy – believing that you can exert a positive influence over things around you which can be threatened or destroyed by the critical incident. Ensure a sense of empowerment, doing things ‘with’ CYP rather than ‘to’ them
Hope	Fostering realistic positivity about the future

Note: Adapted from the UK Trauma Council’s guide to Critical Incidents (2023)

5.6.1.2 Building competence: training for those working with CYP with ABI

As highlighted previously, the findings point to a workforce readiness issue. Given the prevalence of ABI in childhood, there is an argument for including training on doctoral level courses; mirroring the provision of training for working with individuals with ASD for example. In light of the suggestion that provision of psychological care from those with no training or expertise might do more harm than good, there is an argument for facilitating greater availability of specialist outreach to universal services, in skill sharing and building a community of practice; for example, third sector organisations with expertise in supporting CYP hosting CPD sessions or consultation with professionals in universal services. Previous studies have highlighted that receiving expert opinion from other professionals has been positive for (and desired by) educational professionals (Bate et al., 2021; Hartman et al., 2015); the same may be true for AHPs and social workers. CPs and other AHPs could engage in policy work to encourage funding for such initiatives alongside the provision of specialist services. The first NICE guidelines for rehabilitation of chronic neurological problems is being written, representing an exciting advance in the recognition of the need for services and specialised care for CYP with ABI.

5.6.1.3 Awareness raising

Often, the answer to the question ‘what would improve the psychological wellbeing of CYP with ABI’ was answered with ‘greater awareness’, whether that be at the level of school or society. As mentioned above, there is already a campaign for raising awareness of ABI within schools and amongst educational professionals led by N-ABLES. Campaigns at a broader societal level may be beneficial as a form of early intervention, encouraging mentalisation from all of those around CYP with ABI.

5.7 Conclusion

This study explored the psychological needs of CYP with ABI as understood by parents and professionals, and considered how these needs are currently being responded to. The findings indicate that the considerable psychological impact of childhood ABI can be understood as a product of interacting factors related to participation, identity development and social interaction and exclusion, resulting in a threat to psychological safety.

Parents considered themselves as the primary (and sometimes only) responders to psychological needs of their children. The study found that overwhelmingly, parents and professionals felt there was inadequate support for supporting CYPs psychological needs, both as a function of an absence of formalised support and missed opportunities for support in naturalistic settings (such as schools). This was understood to be a consequence of systemic misunderstanding of paediatric ABI and associated psychological needs, combined with a lack of capacity or opportunity for the workforce to skill up and rise to the challenge of meeting these needs. Participants felt that early, specialised support needed to be offered to prevent worsening psychological distress in CYP with ABI, and the importance of supporting parents to support their children was highlighted. Alongside this, the restorative power of social connection and participation were relayed.

The study triangulates the voices of those providing care for CYP with ABI and puts forward a consideration of how psychological needs can be better supported, through enhancing the supportive potential and expertise of both naturalistic and formalised settings.

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7 APPENDICES

7.1 APPENDIX A: ETHICAL APPROVAL

School of Psychology Research Ethics Committee

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

REVIEWER: Jeeda Alhakim

SUPERVISOR: Lorna Farquharson

STUDENT: Georgia Pitts

Course: Prof Doc in Clinical Psychology

DECISION OPTIONS:

1. **APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.

2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below)**:** In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

3. **NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below)**:** In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY
(Please indicate the decision according to one of the 3 options above)

APPROVED

Minor amendments required *(for reviewer)*:

Major amendments required *(for reviewer):*

Confirmation of making the above minor amendments *(for students)*:

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name *(Typed name to act as signature):*
Student number:

Date:

(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)

ASSESSMENT OF RISK TO RESEACHER *(for reviewer)*

Has an adequate risk assessment been offered in the application form?

YES / NO

Please request resubmission with an adequate risk assessment

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

☐ HIGH

Please do not approve a high risk application and refer to the Chair of Ethics. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not approved on this basis. If unsure please refer to the Chair of Ethics.

☐ MEDIUM (Please approve but with appropriate recommendations)

☐ LOW

Reviewer comments in relation to researcher risk (if any).

Reviewer *(Typed name to act as signature)*: Dr Jeeda Alhakim

Date: 28/09/2021

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee

RESEARCHER PLEASE NOTE:

For the researcher and participants involved in the above named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UELs Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard

7.2 APPENDIX B: APPROVAL OF MINOR AMENDMENT TO ETHICS APPLICATION

School of Psychology Ethics Committee

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

For BSc, MSc/MA and taught Professional Doctorate students

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology

Note that approval must be given for significant change to research procedure that impact on ethical protocol. If you are not sure as to whether your proposed amendment warrants approval, consult your supervisor or contact Dr Trishna Patel (Chair of School Ethics Committee).

How to complete and submit the request	
1	Complete the request form electronically.
2	Type your name in the 'student's signature' section (page 2).
3	When submitting this request form, ensure that all necessary documents are attached (see below).
4	Using your UEL email address, email the completed request form along with associated documents to Dr Trishna Patel: t.patel@uel.ac.uk
5	Your request form will be returned to you via your UEL email address with the reviewer's decision box completed. Keep a copy of the approval to submit with your dissertation.
6	Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

Required documents	
A copy of your previously approved ethics application with proposed amendment(s) added with track changes.	**YES** ☒
Copies of updated documents that may relate to your proposed amendment(s). For example, an updated recruitment notice, updated participant information sheet, updated consent form, etc.	**YES** ☒

A copy of the approval of your initial ethics application.	**YES** ☒

Details

Name of applicant:	**Georgia Pitts**
Programme of study:	**Professional Doctorate in Clinical Psychology**
Title of research:	**How are the psychological needs of children with ABI responded to and by whom?**
Name of supervisor:	**Jenny Jim/Lorna Farquharson**

Proposed amendment(s)

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	**Rationale**
To broaden inclusion criteria of educational/psychology professionals invited to participate in the study via an online questionnaire to include other professionals involved in the rehabilitation of children and young people (CYP) with acquired brain injury (ABI)- such social workers, occupational therapists and speech and language therapists.	This study aims to gain perspectives from across the ecological system on barriers and enablers to emotional and psychological wellbeing following paediatric acquired brain injury, as well as understanding more about risk and resiliency factors in this population. As many professionals are involved in the rehabilitation of CYP with ABI and will hold valuable perspectives on emotional and psychological wellbeing in this population, including professionals such as social workers, speech and language therapists and occupational therapists will allow the research questions to be addressed more fully.
Proposed amendment	Rationale for proposed amendment
Proposed amendment	Rationale for proposed amendment
Proposed amendment	Rationale for proposed amendment

Confirmation

Is your supervisor aware of your proposed amendment(s) and have they agreed to these changes?	**YES** ☒	**NO** ☐

Student's signature

Student: (Typed name to act as signature)	**Georgia Pitts**
Date:	**08/04/2022**

Reviewer's decision

Amendment(s) approved:	**YES** ☒	**NO** ☐
Comments:	Please enter any further comments here	
Reviewer: (Typed name to act as signature)	**Trishna Patel**	
Date:	**08/04/2022**	

7.3 APPENDIX C: INTERVIEW GUIDE

1. **I'd like to ask you some questions about your child's acquired brain injury Is there anything you don't feel able to talk about at this point?**

- How old was your child when they sustained their brain injury?
- How did it happen? (e.g. traumatic brain injury, stroke, brain tumour, radiotherapy)
- Was it a mild/moderate/severe brain injury?
- Did your child spend time in hospital and/or residential rehabilitation? For how long?
- Where do they live and when did they return home?
- What sort of information was given to you about living with ABI before you returned home? Were you given any information about emotional wellbeing and what to expect? Who gave you this information?
- Was any community rehabilitation offered? Could you describe this?

2. **I'd like to move on to talking about emotional wellbeing.**

- What comes up for you when you hear the term 'emotional and psychological wellbeing?

- How was your child's emotional wellbeing before the brain injury? Is it different to now?

- **Can you tell me a little bit about the emotional or psychological needs that arose after the brain injury?**
    - *At what point did you notice these needs emerging?*
    - *Have these needs changed over time, or in different situations?*
    - *Has your child had any mental health diagnoses?*

3. **I'd like to ask you some questions about how your child's emotional wellbeing and needs have been supported, and how well you think they are being responded to.**

- Who or what do you think has been helpful in supporting your child's emotional wellbeing? (Use their language for emotional wellbeing)
    - *Where have the main sources of support been for you child?*
    - *Who or what has helped them feel able to cope with emotions and feelings?*
    - *Are you aware of any services that could have helped with your child's emotional wellbeing?*
    - *Was your child referred to any services to help with their emotional wellbeing (e.g. a GP, child and adolescent mental health services, charitable organisations).*
    - *If not, do you think that referral to an organisation or mental health service for support would have been useful? In what way?*

- What helps you feel able to support your child's emotional wellbeing at home?
    - What is working well?
    - Have there been any challenges in supporting emotional wellbeing at home? What has helped you to overcome these challenges?

- How is their emotional wellbeing being supported by school?
    - Is anything working well?
    - Has anything been challenging?
    - *Mainstream or specialist?*
    - *Transition back to school and what that was like*
    - *Were teachers aware of what had happened?*

- How important have x's friends been in terms of emotional support? In what way do you think they have helped for x?

- Has anything or anyone else been important in supporting your child's emotional wellbeing, or in helping them cope with feelings and emotions?

4. I'd like to find out (some more) what you think the barriers are to supporting your child's emotional wellbeing

- Can you tell me a bit about some of the challenges/issues you have faced?
- Have there been times where you felt the emotional needs of your child weren't being met?
- What impact has this had on your child?
- What do you think could be/could have been done differently to support your child's psychological wellbeing?

- What would better support for your child's emotional wellbeing and adjustment look like?

7.4 APPENDIX D: DEMOGRAPHIC QUESTIONNAIRE FOR PARENTS

How are the psychological needs of children with ABI responded to and by whom?

Demographic Information

Thank you for agreeing to take part in my research. To help me to learn about the range of people who are contributing to this research, I would be grateful if you could answer the questions on this form. You do not have to answer any questions that you don't want to. If any of the questions are not applicable to you, please indicate this by stating 'NA'. ***All information will remain confidential.***

Questions about you

1. How would you describe your ethnicity?

   ____

2. What is your age?

   ____

3. What is your gender

   ____

4. What is your relationship to the child we will be talking about (e.g. mother/father)?

   ____

5. Who lives with you at home?

   ____

6. Is there anyone else at home who has caregiver responsibilities?

   ____

7. What is the first section of your postcode (e.g. EC1)

   ____

8. Do you feel that your local area is well resourced and that you have access to the services you need?

____

9. How would you describe your social class?

____

Questions about your child

1. What is your child’s age?

____

2. What is your child’s gender?

____

3. How would you describe your child’s ethnicity?

____

7.5 APPENDIX E : QUESTIONNAIRE FOR PROFESSIONALS

How are the psychological needs of children with ABI responded to and by whom

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Start of Block: Introduction

Q1

How are the psychological needs of children with ABI responded to and by whom?

Participant information sheet

Hello! Thank you for taking the time to complete this survey. Before you begin, please take the time to read the following information. The purpose of this page is to provide you with the information you need to decide whether to participate in this online study.

Who am I?

I am Georgia Pitts, a Trainee Clinical Psychologist at the University of East London. I am carrying out this research project as part of my training.

About the research

I am conducting research into how the psychological needs of children and young people with acquired brain injury are being recognised and met in different settings (for example, at school). It is recognised that children and young people with ABI may have longer term adjustment/psychological needs, yet there are no guidelines on the promotion of psychological wellbeing following an ABI. This research aims to gather the perspectives of parents and professionals involved in the care of children with ABI (such as educational and psychology professionals, speech and language therapists or social workers) to better understand the needs of children and young people with ABI and how these needs are met, as perceived by those involved in their daily care. I hope that by gathering the views of parents/carers, teachers and professionals involved in the care of children with ABI, this research may pinpoint some of the factors that help and hinder the child's psychological wellbeing and positive adjustment, and identify examples of positive practice. The results may inform guidelines intended for those who are involved in supporting children and young people affected by ABI. The research will be completed in May 2022.

Why am I being asked to take part?

You are being asked to take part in this online survey as a professional who has worked with children and young people affected by childhood brain injury.

About the survey

The survey should take approximately 20 minutes to complete. The questions are a mixture of multiple choice and free text responses. You will be asked to provide basic demographic information (e.g. gender, area of work). The survey questions focus on your experiences of working with children and young people with acquired brain injury and your views about the needs of this population, and how these are currently being met.

Confidentiality of the data

All personal and questionnaire data will be anonymous and only identifiable by a unique participant code. On closing the online study all data will be downloaded and stored on the researcher's UEL OneDrive account. Data will only be seen by the researcher, supervisor and thesis examiners. Data will be kept for a maximum of three years after the research has been completed, after which time data will be destroyed and all files deleted. Group data will be used for publication and/or dissemination, but no individual data will be identifiable.

What will happen to the results of the research study?

The results of this project will be written up as part of a doctoral thesis and may be published at a later point in an academic journal. The anonymised extracts from the qualitative parts of the survey will be used in the thesis (which is read by the project supervisors and examiners) and may be used in subsequent publications.

What if I change my mind?

Taking part in this study is entirely voluntary. If you agree to participate you are free to withdraw at any time up to 3 weeks after you complete the survey. At the beginning of the survey, you will be provided with a unique participant code. Please note down the unique participant code, as you will need this if you decide to withdraw. Should you decide to withdraw, the data from your survey will not be used in this project. You do not need to give a reason for your decision.

What support is available after I have taken part?

If you have any further questions about the research project or want to discuss any issues related to the questions asked, please feel free to contact the research team.

Georgia Pitts (Researcher): u1945524@uel.ac.uk

Dr Lorna Farquharson (Director of Studies): l.farquharson@uel.ac.uk

Dr Jenny Jim (Research Supervisor): jjim@thechildrenstrust.org.uk

Online data protection

The online version of this questionnaire has been constructed as an anonymous survey, meaning no emails, IP addresses and/or geolocation data will be identified in the responses. HTTPS survey links (also known as secure survey links) have been used, giving Secure Sockets Layer (SSL) Encryption while a questionnaire is being completed. During the study data collected online will be stored on an EU-based server and will be subject to EU Data Protection acts. All online data will be completely destroyed following completion of data collection.

Ethical approval

This research project has ethical approval from the University of East London

Page Break

*

Q2 **Consent to participate in a research study: How are the psychological needs of children with ABI responded to and by whom?**

Please tick all boxes

☐ I have the read the information sheet relating to the above research study (1)

☐ I have had the opportunity to discuss the details of the research and ask questions about this information, and these have been answered satisfactorily. I understand what is being proposed and the procedures in which I will be involved have been explained to me. (2)

☐ I understand that my involvement in this study, and particular data from this research, will remain strictly confidential, and that only the researcher(s) involved in the study will have access to identifying data.It has been explained to me what will happen once the research study has been completed. (3)

☐ I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. (4)

☐ I understand that if I withdraw from the study, my data will not be used (5)

☐ I understand that I have three weeks from completion of the survey to withdraw my data from the study (6)

☐ I understand that the results of this study will be written up as a doctoral thesis and that anonymous extracts may appear in material relating to the research, such as conference presentations and journal articles. (7)

☐ I agree to participate in the above study (8)

Q3 Here is your participant ID number: ${e://Field/Random%20ID}

End of Block: Introduction

Start of Block: Your role and experience of working with children who have an ABI

Q1 Which of the below best describes your profession?

○ Assistant Psychologist (1)

○ Clinical Psychologist (2)

○ Educational Psychologist (3)

○ Occupational Therapist (4)

○ SENCO (5)

○ Social Worker (6)

○ Support Worker (7)

○ Speech and Language Therapist (8)

○ Teacher (mainstream school) (9)

○ Teacher (specialist provision) (10)

○ Teaching Assistant (mainstream school) (11)

○ Teaching Assistant (specialist provision) (12)

○ Other (please describe) (13) ____

Q2 Please describe the setting in which you work (e.g. school, acute rehabilitation, post-acute rehabilitation, CAMHS)

____

Q3 How long have you been working with children with acquired brain injury?

○ <5 years (1)

○ < 10 years (2)

○ 10+ years (3)

Q4 Have you worked with children who have: (please tick all that apply)

☐ Mild brain injury (1)

☐ Moderate brain Injury (2)

☐ Severe brain injury (3)

☐ Unsure (4)

Q5 What is the age range of children with ABI that you have worked with? (please tick all that apply)

☐ <3 years old (1)

☐ 4-7 years old (2)

☐ 8-11 years old (3)

☐ 12-16 years old (4)

☐ 16-18 years old (5)

☐ If the majority of your work has been with a particular age group, please indicate which age group here: (6)

____

End of Block: Your role and experience of working with children who have an ABI

Start of Block: Emotional wellbeing following childhood ABI

Q6 What comes to your mind when you hear the term 'emotional and psychological wellbeing'?

____

____

____

____

____

Q7 Thinking about the children you have worked with, what are some of the common emotional and psychological needs that you are aware of?

____

____

____

____

____

Q8 Are any of these more important or pressing? If so, why?

____

____

____

____

____

Q9 In your experience, what impact have the needs you identified in Q7 had on the child or young person? (please select all that apply)

	Minimal (1)	Moderate (2)	Severe (3)
School (engagement / attainment) (1)	○	○	○
Home (e.g., family relationships) (2)	○	○	○
Peer relationships (3)	○	○	○
Sense of self or identity (4)	○	○	○
Other (please describe) (5)	○	○	○
Other (please describe) (6)	○	○	○

End of Block: Emotional wellbeing following childhood ABI

Start of Block: Supporting emotional and psychological wellbeing as a professional

Q10 How able do **you** feel to support the emotional and psychological needs of children and young people with ABI?

	Not well at all (1)	Slightly well (2)	Moderately well (3)	Very well (4)	Extremely well (5)
How able do you feel to support the emotional and psychological needs of children and young people with ABI? (1)	○	○	○	○	○

Q11 What helps you, as a professional, to feel able to support emotional and psychological wellbeing in children and young people with ABI?

____

____

____

____

____

Q12 What makes it more difficult for you, as a professional, to support emotional and psychological wellbeing in children and young people with ABI?

____

____

____

____

____

Q13 Have you worked with others (e.g., other professionals or parents) to support the emotional and psychological wellbeing of children and young people with ABI?

○ Yes (1)

○ No (2)

Q14 If the answer to the previous question was yes, please indicate who you have worked with

- ☐ Clinical Psychologists (1)
- ☐ Educational Psychologists (2)
- ☐ Occupational Therapists (3)
- ☐ SENCOs (4)
- ☐ Social Workers (5)
- ☐ Speech and Language Therapists (6)
- ☐ Support Workers (7)
- ☐ Teachers (8)
- ☐ Teaching Assistants (9)
- ☐ Parents/carers (10)
- ☐ Other (please describe) (11) ____
- ☐ Other (please describe) (12) ____
- ☐ Other (please describe) (13) ____

Q15 What has helped you to work effectively with others to support the emotional and psychological needs of children and young people with ABI?

____

____

____

____

____

Q16 Have you made onward referrals to mental health services (e.g. CAMHS, non-statutory organisations) for children and young people with ABI?

○ Yes (1)

○ No (2)

Q17 If the answer to the previous question was yes, can you describe your experience of this?

____

____

____

____

____

End of Block: Supporting emotional and psychological wellbeing as a professional

Start of Block: Barriers and enablers to emotional and psychological wellbeing

Q18 Please think of the times when you felt the emotional and psychological wellbeing of young people you have worked with was supported very well. What factors contributed to this?

____

____

____

____

____

Q19 Please think of the times when you felt the emotional and psychological wellbeing of young people you have worked with was not supported well. What factors contributed to this?____

____

____

____

____

Q20 In your experience, which of the following factors can increase the emotional and psychological needs of this population? (please select all that apply)

☐ Severity of injury (1)

☐ Age at injury (2)

☐ Family stressors (3)

☐ Difficulties with peer relationships (4)

☐ Transitions (e.g. from primary to secondary school) (5)

☐ The child's understanding of/insight into their brain injury (6)

☐ Other (7) ____

Q21 In your view, what would help in being able to support and promote emotional and psychological wellbeing in children and young people with ABI?

____

____

____

____

____

Q22 Is there anything else you feel is important to share?

____

____

____

____

____

End of Block: Barriers and enablers to emotional and psychological wellbeing

Start of Block: Demographic questions

Q36 What is your gender?

____

Q37 Please specify your ethnicity

____

Q38 What is your age?

____

Q39 Where is your place of work?

- ○ North East England (1)
- ○ North West Englad (2)
- ○ Yorkshire and The Humber (3)
- ○ East Midlands (4)
- ○ West Midlands (5)
- ○ East of England (6)
- ○ London (7)
- ○ South East England (8)
- ○ South West England (9)
- ○ Scotland (10)
- ○ Wales (11)
- ○ Northern Ireland (12)

End of Block: Demographic questions

7.6 APPENDIX F: RESEARCH POSTER FOR RECRUITING PARENTS

Understanding what is important in supporting your child's emotional wellbeing after ABI

An invitation for parents and carers

What? An invitation to take part in research
I'm Georgia, a trainee clinical psychologist at the University of East London. As part of my training I am carrying out a research project.

Many children have worries and different emotions and feelings after Acquired Brain Injury (ABI). I'd like to hear about who and what has been important in supporting your child's emotional wellbeing and adjustment following a brain injury (for example people at school, family, community services). *The aim of the research is to better understand what is currently being done and what could be done better to support children and young people's emotional wellbeing after ABI.*

Who? Parents/carers of children who have an ABI
If your child sustained an ABI before the age of 18, I really want to hear your voice as a parent, so that any guidelines we may be able to influence reflects your experience, and so that others can feel more confident about the care their children might receive.

How? A conversation with me
If you would like to take part in the study, you will be invited to take part in a one hour conversation which will take place online (using Microsoft Teams) or over the phone. I am interested in hearing about all perspectives and experiences you wish to share.

Please email me, Georgia Pitts, at u1945524@uel.ac.uk if you are interested in hearing more about the study or would like to express an interest in taking part.

If you decide to take part you will receive a £10 Love2Shop voucher as a thank you!

University of East London

7.7 APPENDIX G: RESEARCH POSTER FOR PROFESSIONALS

How are the psychological needs of children and young people with acquired brain injury responded to and by whom?

What this study is about

It is recognised that CYP with ABI may have longer term psychological needs, but there are no guidelines on the promotion of psychological wellbeing following an ABI. This research aims to gather the perspectives of professionals involved in the care of children with ABI (such as educational and psychology professionals, speech and language therapists or social workers) to better understand the needs of children and young people with ABI and how these are met in different settings.

Who can take part?

I am looking for professionals who are working in the UK and are involved in the care of CYP (up to 18 years) with ABI to complete a short online survey. The survey should take approximately 20 minutes to complete.

Please click on this link: https://uelpsych.eu.qualtrics.com/jfe/form/SV_1HNCdVulyDwQvaK or follow the QR code to access the survey. Thank you!

Please email me (Georgia) u1945524@uel.ac.uk if you have any questions

This research forms part of my Doctorate in Clinical Psychology and has been approved by the UEL School of Psychology Ethics Committee.

University of East London

7.8 APPENDIX H: INFORMATION SHEET FOR PARENTS

PARTICIPANT INVITATION LETTER

How are the psychological needs of children with ABI responded to and by whom?

You are being invited to participate in a research study. Before you agree it is important that you understand what your participation would involve. Please take time to read the following information carefully.

Who am I?

I am a Trainee Clinical Psychologist in the School of Psychology at the University of East London. I am studying for a Professional Doctorate in Clinical Psychology, and as part of my studies I am conducting the research you are being invited to participate in.

What is the research?

I would like to learn more about how we can help to support the emotional wellbeing of children and young people who have experienced an Acquired Brain Injury (ABI), by hearing from parents/carers about your experiences. I am interested in who/what you think has been helpful in supporting your child's emotional wellbeing and adjustment after a brain injury, as well as finding out what has not been helpful, or where you think needs haven't been met.

Research shows that children and young people who have experienced an ABI may have longer term adjustment/psychological needs, but currently there are no guidelines on the promotion of emotional wellbeing following an ABI.

We would seek to ensure your voices are heard and embedded in any guidelines that are influenced, so that others can benefit from you sharing by your experiences, ideas and dilemmas. It is hoped that this research will contribute to a greater understanding of what support is available at present and what is lacking.

This research aims to gather the perspectives of parents, educational and psychology professionals to better understand what the needs of children and young people with an ABI are, and what helps or hinders meeting these needs. I hope that by gathering views from people who are involved in the care of children and young people with an ABI, this research may lead to a greater understanding of the things that have helped your child to cope and adjust, and the things that haven't been helpful and need to change. The results may inform guidelines intended for those who are involved in supporting children and young people affected by ABI. The research will be completed in May 2022.

My research has been approved by the School of Psychology Research Ethics Committee. This means that the Committee's evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

Why have you been asked to participate?

You have been invited to participate in my research as you are a parent / carer of a child affected by ABI. We are interested in hearing from parents and carers of children with an ABI (incurred before the age of 18). Despite the recognition that families are experts on their children's needs, these voices are heard less frequently in the literature. I emphasise that I am not looking for 'experts' on the topic. You will be treated as an individual, not judged or personally analysed in any way and you will be treated with respect.

You are quite free to decide whether or not to participate and should not feel coerced.

What will your participation involve?

If you agree to participate you will be asked to participate in an hour-long conversation which will be held online, using a secure platform called Microsoft Teams. The conversation itself will last no longer than an hour, however I will ask for an hour and half of your time to allow enough time for questions and a debrief. I may ask some specific questions such as asking you to tell me about your child's injury and what it was like going back to school. However, you don't have to answer these if you don't want to. I will audio-record our conversation so that I am able to transcribe them once we have spoken. Your participation would be very valuable in helping to develop knowledge and understanding of my research topic. In recognition of your contribution you will receive a love2shop voucher worth £10.

Your taking part will be safe and confidential

Your privacy and safety will be respected at all times. To ensure that the information you provide about you and your child's experience remains confidential, I will anonymise all of the conversation transcripts so that you won't be identified from the transcripts, or in any of the write-up of the research. The only time confidentiality would need to be broken would be in the event of concerns about your safety/the safety of others, which I would try to talk to you about first. You don't have to answer any of the questions asked of you and you can decide to stop participating at any time during the interview. If you decide you would like to withdraw your consent from the project after the interviews have taken place, you can do so up until 3 weeks after the interview. After that point data analysis may have already begun and it will not be possible to withdraw your anonymised data from the research.

What will happen to the information that you provide?

All identifiable data such as your name and contact details will be securely stored and kept separately our conversation. Our conversation will be recorded and this will be transferred onto the researcher's UEL OneDrive account within 24h of the interview taking place.

All written material arising from conversation (e.g. transcript, doctoral thesis) will be anonymised – this means that you won't be identified from the information you provide. The data will be written up as a doctoral thesis, and anonymised extracts of interviews will be used in the thesis, which will be publicly accessible from UEL's institutional repository. Some broad demographic information may appear in the thesis and works based on it but this will not be such as to permit the identification of individuals. Anonymised extracts of interviews will be used in presentations, reports, and publications such as academic journals and blog posts for organisations such as NR times and Child Brain Injury Trust. The hope is that this project will contribute to an understanding of how the psychological wellbeing of children and young people with ABI can be better supported.

After the transcription of conversations has been completed and the research has been completed, audio-recorded conversations and any personal information provided will be destroyed. Conversation transcripts may be seen by my supervisor and the examiners of my thesis. Transcripts may be kept for up to three years after the research is complete, to allow the development of the research for publication. This would be kept on a UEL secure server, only accessible by myself (the researcher) and my supervisor.

What if you want to withdraw?

You are free to withdraw from the research study at any time without explanation, disadvantage or consequence. Separately, you may also request to withdraw your data even after you have participated, provided that this request is made within three weeks of our conversation (after which point the data analysis will begin, and withdrawal will not be possible).

Contact details

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.
Name: Georgia Pitts e-mail: u1945524@uel.ac.uk

If you have any questions or concerns about how the research has been conducted please contact the Director of Studies: Dr Lorna Farquharson, School of Psychology, University of East London, Water Lane, London E15 4LZ. Email: L.Farquharson@uel.ac.uk.

You may also contact the Research Supervisor: Dr Jenny Jim, Consultant Psychologist, The Children’s Trust, Tadworth Court, Tadworth, KT20 5RU. Email: jjim@thechildrenstrust.org.uk

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.patel@uel.ac.uk)

7.9 APPENDIX I: CONSENT FORM FOR PARENTS

UNIVERSITY OF EAST LONDON

Consent to participate in a research study

How are the psychological needs of children with ABI responded to and by whom?

I confirm that I have read the information sheet dated 07/12/2021 (version 1) for the above study and that I have been given a copy to keep. ☐

I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

I understand that my participation in the study is voluntary and that I may withdraw at any time, without providing a reason for doing so. ☐

I understand that if I withdraw from the study, my data will not be used. ☐

I understand that I have 3 weeks from the date of the interview to withdraw my data from the study. ☐

I understand that the interview will be recorded using Microsoft Teams. ☐

I understand that my interview data will be transcribed from the recording and anonymised to protect my identity. ☐

I understand that my personal information and data, including audio recordings from the research will be securely stored and remain strictly confidential. Only the ☐

research team will have access to this information, to which I give my permission.

It has been explained to me what will happen to the data once the research has been completed. ☐

I understand that short, anonymised quotes from my interview may be used in the thesis and that these will not personally identify me. ☐

I understand that the thesis will be publicly accessible in the University of East London's Institutional Repository (ROAR). ☐

I understand that short, anonymised quotes from my interview may be used in material such as conference presentations, reports, articles in professional and academic journals resulting from the study and that these will not personally identify me. ☐

I would like to receive a summary of the research findings once the study has been completed
and am willing to provide contact details for this to be sent to. ☐

I will offer you an Amazon/Love2Shop voucher as a token of appreciation for your participation. However, HMRC regulations require that recipients must provide details of their name, address and National Insurance Number. If you wish to receive a voucher you should tick to indicate that you have been informed of this requirement. ☐

I agree to take part in the above study. ☐

Participant's Name (BLOCK CAPITALS)

……………………………………………………………………………….

Participant's Signature

………………………………………………………………………………..

Researcher's Name (BLOCK CAPITALS)

………………………………………………………………………………..

Researcher’s Signature

………………………………………………………………………………………

Date: …………………….…….

7.10 APPENDIX J: PARTICIPANT DEBRIEF LETTER (PARENTS)

University of
East London

PARTICIPANT DEBRIEF LETTER

Thank you for participating in my research study on how the psychological needs of children and young people affected by acquired brain injury are responded to and by whom. This letter offers information that may be relevant in light of you having now taken part.

What will happen to the information that you have provided?

The following steps will be taken to ensure the confidentiality and integrity of the data you have provided.

All identifiable data such as your name and contact details will be securely stored and kept separately from your interview. Our conversation has been recorded and this will be transferred onto the researcher's UEL OneDrive account within 24h of the interview taking place.

All written material arising from our conversation (e.g. transcript, doctoral thesis) will be pseudonymised – this means that you won't be identified from the information you provide. The data will be written up as a doctoral thesis, and may be published in relevant academic journals and as blog posts for organisations such as NR times and Childhood Brain Injury trust. The hope is that this project will contribute to an understanding of how the psychological wellbeing of children and young people with ABI can be better supported.

After the transcription of conversations has been completed and the research has been completed, recorded conversations and any personal information provided will be destroyed. Transcripts of conversations may be seen by my supervisor and the examiners of my thesis. Transcripts may be kept for up to three years after the research is complete, to allow the development of the research for publication. This would be kept on a UEL secure server, only accessible by myself (the researcher) and my supervisor.

What if you have been adversely affected by taking part?

It is not anticipated that you will have been adversely affected by taking part in the research, and all reasonable steps have been taken to minimise potential harm. Nevertheless, it is still possible that your participation – or its after-effects – may have been challenging, distressing or uncomfortable in some way. If you have been affected in any of those ways you may find the following resources/services helpful in relation to obtaining information and support:

1. Headway: Support for people affected by brain injury: 0808 800 224 | (Monday-Friday 9am-5pm)
2. Mind – Mental Health problems: 03001233393 | www.mind.org.uk | (Monday-Friday 9am-6pm)
3. Rethink Mental Illness: 03005000927 | www.rethink.org | (Monday-Friday 9.30am-4pm)
4. Samaritans for distress/despair 24-hour helpline: 116123 | www.samaritans.org.uk
5. SANEline emotional support, information, and guidance: 03003047000 | www.sane.org.uk/support | (daily 4.30pm-10.30pm) | peer support forum: www.sane.org.uk/supportforum

You are also very welcome to contact me or my supervisor if you have specific questions or concerns.

Contact Details

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Name Georgia Pitts e-mail: u1945524@uel.ac.uk

If you have any questions or concerns about how the research has been conducted please contact the Director of Studies: Dr Lorna Farquharson, School of Psychology, University of East London, Water Lane, London E15 4LZ. Email: L.Farquharson@uel.ac.uk.

You may also contact the Research Supervisor: Dr Jenny Jim, Consultant Psychologist, The Children's Trust, Tadworth Court, Tadworth, KT20 5RU. Email: jjim@thechildrenstrust.org.uk

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.patel@uel.ac.uk)

7.11 APPENDIX K: RESEARCH DATA MANAGEMENT PLAN

UEL Data Management Plan

Completed plans must be sent to researchdata@uel.ac.uk for review

If you are bidding for funding from an external body, complete the Data Management Plan required by the funder (if specified).

Research data is defined as information or material captured or created during the course of research, and which underpins, tests, or validates the content of the final research output. The nature of it can vary greatly according to discipline. It is often empirical or statistical, but also includes material such as drafts, prototypes, and multimedia objects that underpin creative or 'non-traditional' outputs. Research data is often digital, but includes a wide range of paper-based and other physical objects.

Administrative Data	
PI/Researcher	Georgia Pitts
PI/Researcher ID (e.g. ORCiD)	0000-0001-5075-1919
PI/Researcher email	U1945524@uel.ac.uk
Research Title	How are the psychological needs of children with ABI responded to and by whom?
Project ID	
Research start date and duration	12 months, proposed start date July 2021

Research Description	Children affected by Acquired Brain Injury (ABI) are at increased risk of poor psychological and emotional outcomes, affecting participation and activity. However, rehabilitation plans tend to focus on physical aspects of recovery, in spite of the recognition that the psychological and emotional effects of ABI may unfold over time. This research aims to understand how the psychological and emotional support needs of children and young people affected by ABI are being recognised and responded to by family and professionals in naturalistic settings (school, home), which may be points of access to early intervention. Through bringing together the perspectives of parents, educational and psychology professionals, this study aims to explore the following questions: 1. What is the current understanding of psychological needs in the context of paediatric ABI among stakeholders? 2. What are the perceived barriers/facilitators to meeting the psychological needs of CYP with ABI? 3. What are the implications for our understanding of risk and resiliency factors for psychological wellbeing following paediatric acquired brain injury?
Funder	
Grant Reference Number (Post-award)	N/A
Date of first version (of DMP)	10/03/2021
Date of last update (of DMP)	07/07/2021 - v.4 updated to reflect change in title
Related Policies	e.g. Research Data Management Policy
Does this research follow on from previous research? If so, provide details	No
Data Collection	

What data will you collect or create?	Teams recordings in .mp4 format Transcriptions in .doc(x) format Questionnaire responses (including basic demographic information) in .xls format Qualitative data from semi structured interviews will be analysed using thematic analysis. This will result in the creation of codes, sub themes and themes. Free text responses from the survey will be analysed using content analysis. SPSS will be used to analyse quantitative data Personal data will be collected on consent forms (names) and email/telephone numbers will be recorded for the purpose of arranging the interview. Parents will be asked to provide basic demographic information (geographical location, family structure) and sensitive data regarding their child (child's ethnicity, gender, age, age at injury, severity of injury) via completion of a demographic questionnaire. At the point of interview transcription, identifiable information will be anonymised. On uploading to UEL OneDrive, any files stored locally on the researcher's personal laptop will be deleted, and at the point of download automating syncing and backups to personal cloud services will be disabled.

How will the data be collected or created?	Eight parents of children with ABI will be interviewed by the researcher, either in one sitting or split over two sessions. Interviews will be semi-structured and last up to one hour in total. All interviews will be recorded and transcribed by the researcher. Each participant will be assigned a unique ID number (in chronological order of interview date). Semi structured interviews will take place online (over MS Teams), recorded directly from MS teams, and be uploaded to the researcher's UEL OneDrive. Interviews will be transcribed on a computer as Word document Fifty psychology professionals and 50 educational professionals will be invited to complete an online survey. Respondents will be automatically assigned a unique identifier, and responses will be anonymous. Respondents will be asked to provide basic demographic information (e.g. employment category, geographical location) and questions will consist of a mixture of multiple choice and free text response formats. Anonymous links and anonymise responses options will be used for Qualtrics, to ensure that identifiable data (e.g. email address, IP address) is not required or collected from the respondents. The online survey for professionals will be created using Qualtrics, a software licensed to the UEL School of Psychology. Raw survey data will be accessible only to the researcher and will be exported into an excel database.
Documentation and Metadata	
What documentation and metadata will accompany the data?	Consent forms, participant information sheets, interview schedule, participant debrief sheets, MS teams recordings of interviews, files, transcripts of interviews and an excel database of survey results.

	Methods pertaining to this research project and any alterations to / reflections on these methods will be kept in a single document on the researcher's personal computer. This will include the process for establishing a working group to inform development of project including codesigning the interview schedule/ online survey, and the suggestions put forward by the working group. Data analysis procedures will be documented within the methods document. A hierarchical file structure will be used Files will be named according to document detailing folder structure An anonymisation log will be created, detailing anonymisation techniques such as replacements, removals, aggregations. This will be created as an encrypted .docx file and will be kept in a separate folder on the researcher's UEL OneDrive account to interview transcripts/survey data.
Ethics and Intellectual Property	
Identify any ethical issues relating to the data and their collection and how these will be managed	Parents/carers will be given a participant information sheet, and written consent will be obtained prior to interviews commencing. •Professionals completing the survey will be asked to read a participant information sheet and consent prior to completing the survey • All participants will be advised that their participation is voluntary and that they can withdraw their consent to participate during the interview/survey without needing to provide an explanation. Participants will be advised that they can withdraw their data (which will be destroyed) within a three-week window of completing the interview/survey (as by this point analysis will have begun).

	• Only the researcher will transcribe interview data in order to protect confidentiality and anonymity. • Identifying data, such as participant names or identifying references, will be removed from the data. Indirect identifiers such as age, geographical location will be aggregated into broad categories. Disclosive free text responses in survey data will be replaced with general text • Parents/carers may find speaking about their child's experiences and needs distressing. The safety and wellbeing of participants will be ensured through the researcher being alert to changes in emotional state. The potential for distress to be caused will be discussed beforehand and a mutual plan agreed on how to manage this situation if it were to arise (e.g. taking a break, agreeing to stop). The researcher will ensure that participants are signposted to relevant support services via the debrief letter, which will include the contact details of relevant services.
Identify any copyright and Intellectual Property Rights issues and how these will be managed	**N/A**
Storage and Backup	
How will the data be stored and backed up during the research?	Consent forms obtained over email will be uploaded to the OneDrive for Business Personally identifying data (names, contact details etc.) will be stored separately from anonymised transcripts and spreadsheets, in a separate folder on UEL OneDrive. Raw interview recordings will be uploaded directly from Microsoft teams and accessed via the researcher's password protected laptop within their UEL OneDrive cloud service. Transcriptions will be saved as .docx files which will be encrypted. Once interviews have been transcribed, they will be stored on the , OneDrive for Business in a separate and encrypted folder from the consent forms.

	Each interview recording will be named with the participants' initials followed by the interview date. Each interview participant will be attributed a unique participant number in chronological interview order. Transcription files will be named e.g. Participant 1. No list will be kept associating participant numbers and identifying information. Survey data will be kept within the researcher's UEL OneDrive cloud service, in an encrypted .xlsx file. Participants who complete the online survey will be named e.g. Participant 001.
How will you manage access and security?	During the research, only the researcher will have access to the data via their personal non-networked laptop, with the password known only to the researcher. Only the researcher, supervisor and examiners will have access to the anonymised interview transcripts and anonymised survey responses. Anonymised transcripts will be shared via UEL's OneDrive for Business with the research supervisor via uel mail, as will anonymised survey responses.
Data Sharing	
How will you share the data at the end of the project?	Extracts of transcripts will be provided in the thesis and subsequent publications (any identifiable information will be removed). Interview transcripts/survey data will not be shared openly via UELs Research Repository as I will not be seeking consent to share this data openly. This is in recognition of the personal nature of the data collected, and to ensure that families and survey respondents are assured their privacy is respected. A large proportion of the data collected will be qualitative, therefore replication of results is less applicable.

Are any restrictions on data sharing required?	
Selection and Preservation	
Which data are of long-term value and should be retained, shared, and/or preserved?	Interview recordings and electronic copies of consent forms will be kept until the thesis has been examined and passed, after which they will be erased Transcribed interviews, anonymised demographic questionnaires and anonymous survey responses will be retained.
What is the long-term preservation plan for the data?	Once the research is completed, anonymised data (transcripts, demographic questionnaire and spreadsheet) will be retained for three years (in line with UEL school of psychology recommendations) and stored on the supervisor's UEL OneDrive This will be accessible to the researcher and supervisor. After this time, all data will be erased.
Responsibilities and Resources	
Who will be responsible for data management?	Georgia Pitts (the researcher) Dr Lorna Farquharson (DoS; responsible for data storage post project and deletion of data after three years).
What resources will you require to deliver your plan?	
Review	

	Please send your plan to researchdata@uel.ac.uk **We will review within 5 working days and request further information or amendments as required before signing**
Date: 09/04/2021	Reviewer name: Penny Jackson Research Data Management Officer

Guidance

Brief information to help answer each section is below. Aim to be specific and concise.

For assistance in writing your data management plan, or with research data management more generally, please contact: **researchdata@uel.ac.uk**

Administrative Data

Related Policies

List any other relevant funder, institutional, departmental or group policies on data management, data sharing and data security. Some of the information you give in the remainder of the DMP will be determined by the content of other policies. If so, point/link to them here.

Data collection

Describe the data aspects of your research, how you will capture/generate them, the file formats you are using and why. Mention your reasons for choosing particular data standards and approaches. Note the likely volume of data to be created.

Documentation and Metadata

What metadata will be created to describe the data? Consider what other documentation is needed to enable reuse. This may include information on the methodology used to collect the data, analytical and procedural information, definitions of variables, the format and file type of the data and software used to collect and/or process the data. How will this be captured and recorded?

Ethics and Intellectual Property

Detail any ethical and privacy issues, including the consent of participants. Explain the copyright/IPR and whether there are any data licensing issues – either for data you are reusing, or your data which you will make available to others.

Storage and Backup

Give a rough idea of data volume. Say where and on what media you will store data, and how they will be backed-up. Mention security measures to protect data which are sensitive or valuable. Who will have access to the data during the project and how will this be controlled?

Data Sharing

Note who would be interested in your data, and describe how you will make them available (with any restrictions). Detail any reasons not to share, as well as embargo periods or if you want time to exploit your data for publishing.

Selection and Preservation

Consider what data are worth selecting for long-term access and preservation. Say where you intend to deposit the data, such as in UEL's data repository (https://repository.uel.ac.uk) or a subject repository. How long should data be retained?

7.12 APPENDIX L: EXTRACT FROM REFLECTIVE JOURNAL

Reflections following interview

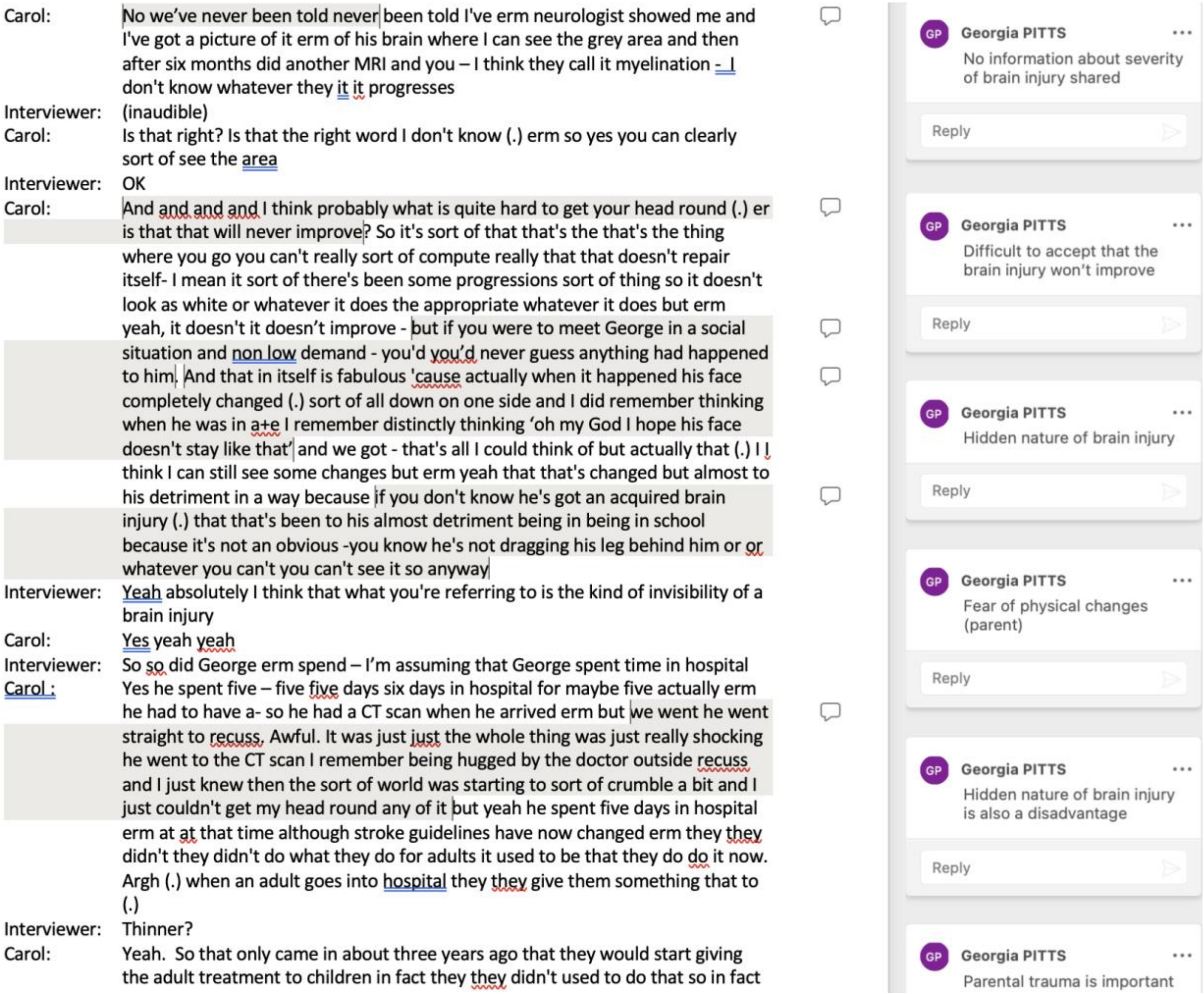
There was a high level of distress throughout the interview and at points it felt hard to contain this given that we were on MS teams. Generally it felt hard for this parent to give specific examples or reflect on things and she mentioned diagnoses of anxiety and PTSD. Given how current everything is for her perhaps the question around the circumstances of the brain injury would have been better asked over an email format; may have felt safer and more contained for her? This really brought home the trauma experienced by so many of the parents participating and difficult it might feel to discuss their experiences in this format. As data collection draws to a close I feel very aware of the generosity of parents reliving traumatic experiences knowing it will not have a positive impact on them but deciding to take part in the research anyway.

As with other interviews, this one ran over (by 30 minutes), but it felt important to allow time to reflect and for her experiences to feel heard, especially given how alone she feels in managing everything. Again, the importance of supporting parents with their mental health feels paramount.

It was distressing to hear these experiences and bear witness to the visible distress currently experienced. Especially given that the brain injury occurred following such a typical childhood illness – I can feel that as I progress with my pregnancy these accounts are resonating on a more personal level. I'm aware of this being a 'hidden' part of my identity to participants because of interviews being conducted remotely. I wonder how it might change the interaction if it were not hidden.

Potential themes around the sudden new expectations and roles placed on parents, feeling deskilled or out of depth, the importance of consistency of professionals, the importance of supporting mental health of parents.

7.13 APPENDIX M: EXAMPLE OF CODED TRANSCRIPT



Carol: No we've never been told never been told I've erm neurologist showed me and I've got a picture of it erm of his brain where I can see the grey area and then after six months did another MRI and you – I think they call it myelination - I don't know whatever they it it progresses

Interviewer: (inaudible)

Carol: Is that right? Is that the right word I don't know (.) erm so yes you can clearly sort of see the area

Interviewer: OK

Carol: And and and and I think probably what is quite hard to get your head round (.) er is that that will never improve? So it's sort of that that's the that's the thing where you go you can't really sort of compute really that that doesn't repair itself- I mean it sort of there's been some progressions sort of thing so it doesn't look as white or whatever it does the appropriate whatever it does but erm yeah, it doesn't it doesn't improve - but if you were to meet George in a social situation and non low demand - you'd you'd never guess anything had happened to him. And that in itself is fabulous 'cause actually when it happened his face completely changed (.) sort of all down on one side and I did remember thinking when he was in a+e I remember distinctly thinking 'oh my God I hope his face doesn't stay like that' and we got - that's all I could think of but actually that (.) I I think I can still see some changes but erm yeah that that's changed but almost to his detriment in a way because if you don't know he's got an acquired brain injury (.) that that's been to his almost detriment being in being in school because it's not an obvious -you know he's not dragging his leg behind him or or whatever you can't you can't see it so anyway

Interviewer: Yeah absolutely I think that what you're referring to is the kind of invisibility of a brain injury

Carol: Yes yeah yeah

Interviewer: So so did George erm spend – I'm assuming that George spent time in hospital

Carol : Yes he spent five – five five days six days in hospital for maybe five actually erm he had to have a- so he had a CT scan when he arrived erm but we went he went straight to recuss. Awful. It was just just the whole thing was just really shocking he went to the CT scan I remember being hugged by the doctor outside recuss and I just knew then the sort of world was starting to sort of crumble a bit and I just couldn't get my head round any of it but yeah he spent five days in hospital erm at at that time although stroke guidelines have now changed erm they they didn't they didn't do what they do for adults it used to be that they do do it now. Argh (.) when an adult goes into hospital they they give them something that to (.)

Interviewer: Thinner?

Carol: Yeah. So that only came in about three years ago that they would start giving the adult treatment to children in fact they they didn't used to do that so in fact

Georgia PITTS
No information about severity of brain injury shared

Georgia PITTS
Difficult to accept that the brain injury won't improve

Georgia PITTS
Hidden nature of brain injury

Georgia PITTS
Fear of physical changes (parent)

Georgia PITTS
Hidden nature of brain injury is also a disadvantage

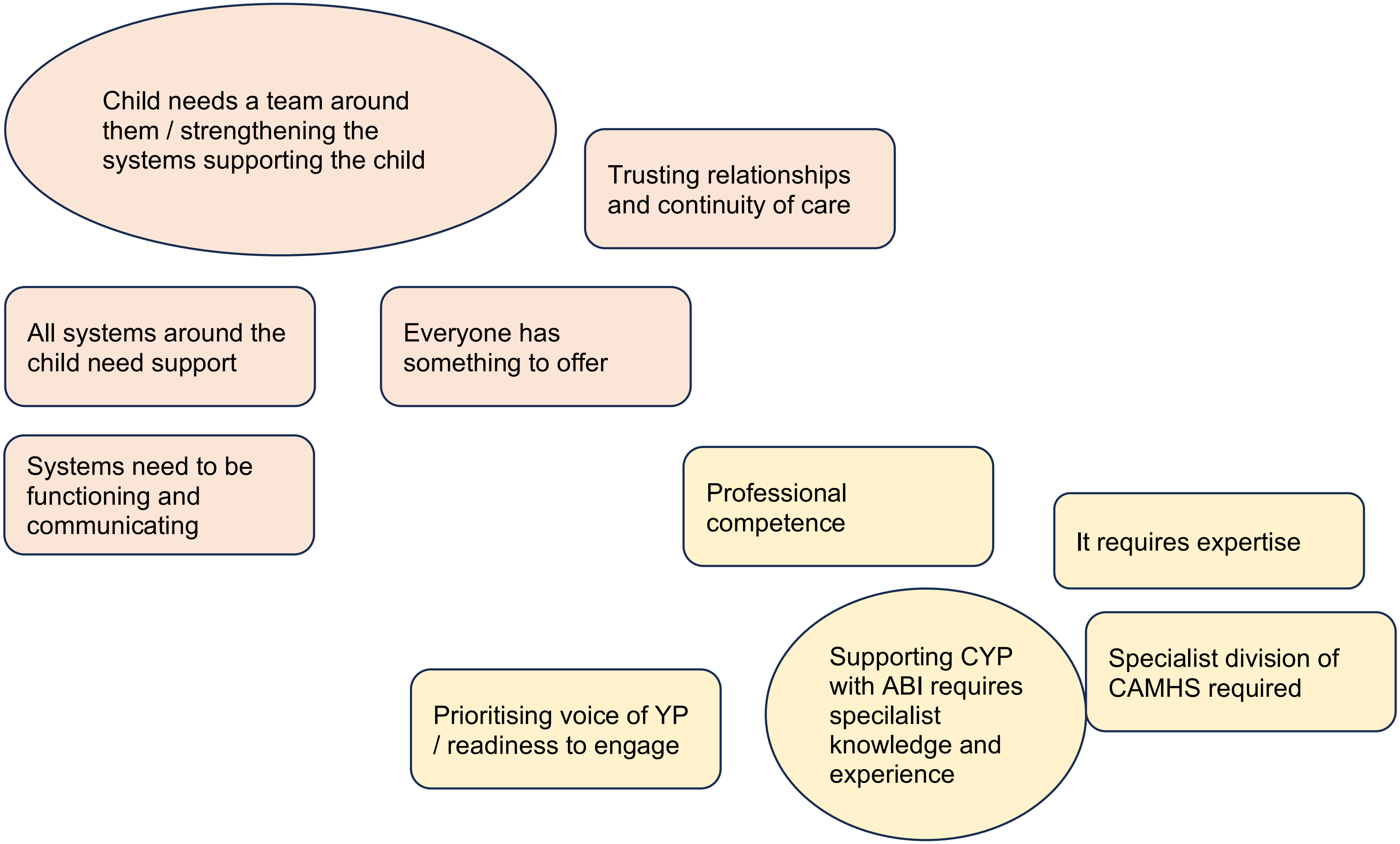
Georgia PITTS
Parental trauma is important

7.14 APPENDIX N: EXAMPLE OF COLLATED CODED DATA EXTRACTS

	Changed sense of self	
SOPHIE	‘mum I can't remember what I used to be like, but I know it was better than this’	CN: Changes in identity, changes in ability
FAYE	He has been frustrated due to his accident because he can't get things done as quickly as he would want	CN: frustration at chages in ability n
SOPHIE	. He found that he could no longer play football because he would miss the ball more often than he would kick it	CN: changes in ability CN: Reduced/removal of participation in favourite activities
SUSAN	in the bottom set for everything especially things like PE she was Alice was quite erm athletic Interviewer: Mm Susan: She was very very good at PE she's got foot drop dexterity in her fingers and hypertonia in the right arm she's ver- she's she can no longer do things like netball and stuff which she loved doing	CN: changes in ability CN: Reduced/removal of participation in favourite activities Threat to competence
SOPHIE	he had to relearn himself	Having to adjust to a new sense of self
SOPHIE	And that's what he was struggling with - being different, not recognising himself and	CN: Feeling different CN: Being changed
SUSAN	She feels like she's not meeting her target grades so you've got someone? who's very who was very determined such a hard worker and then no matter what she feels she does it’s never enough	CN: Adjustment CN: Changes in abilities
P7, P10, P12, P14, P20, P22, P23	(common needs) Adjusting to a new sense of self	

P14,P18, P21, P22, P26, P28, P35	(CN) Loss of skills / fear of loss of skills	

7.15 APPENDIX O: INITIAL THEMATIC MAP



Child needs a team around them / strengthening the systems supporting the child

Trusting relationships and continuity of care

All systems around the child need support

Everyone has something to offer

Systems need to be functioning and communicating

Professional competence

It requires expertise

Supporting CYP with ABI requires specilalist knowledge and experience

Specialist division of CAMHS required

Prioritising voice of YP / readiness to engage

Statutory services are stretched and under resourced

Falling through the gaps of service provision

Who is looking after EPWB

Hidden needs

The potential for early intervention

Needs can overwhelm

Demands of school can be overwhelming/heighten needs

Awareness and understanding is needed

Parents are the main source of support

Parents skilling up

Conspiracy of silence

Acceptance for who you are

School as a place where problems emerge

ABI can threaten to overwhelm the family system

The role of parents

Secondary school and teenage years are a risk factor

SEN classes

Affects the whole family

Threats to identity

Expressions of the self/ being

Changed sense of self

MH Problems /

Continuity of me

Threats to competence

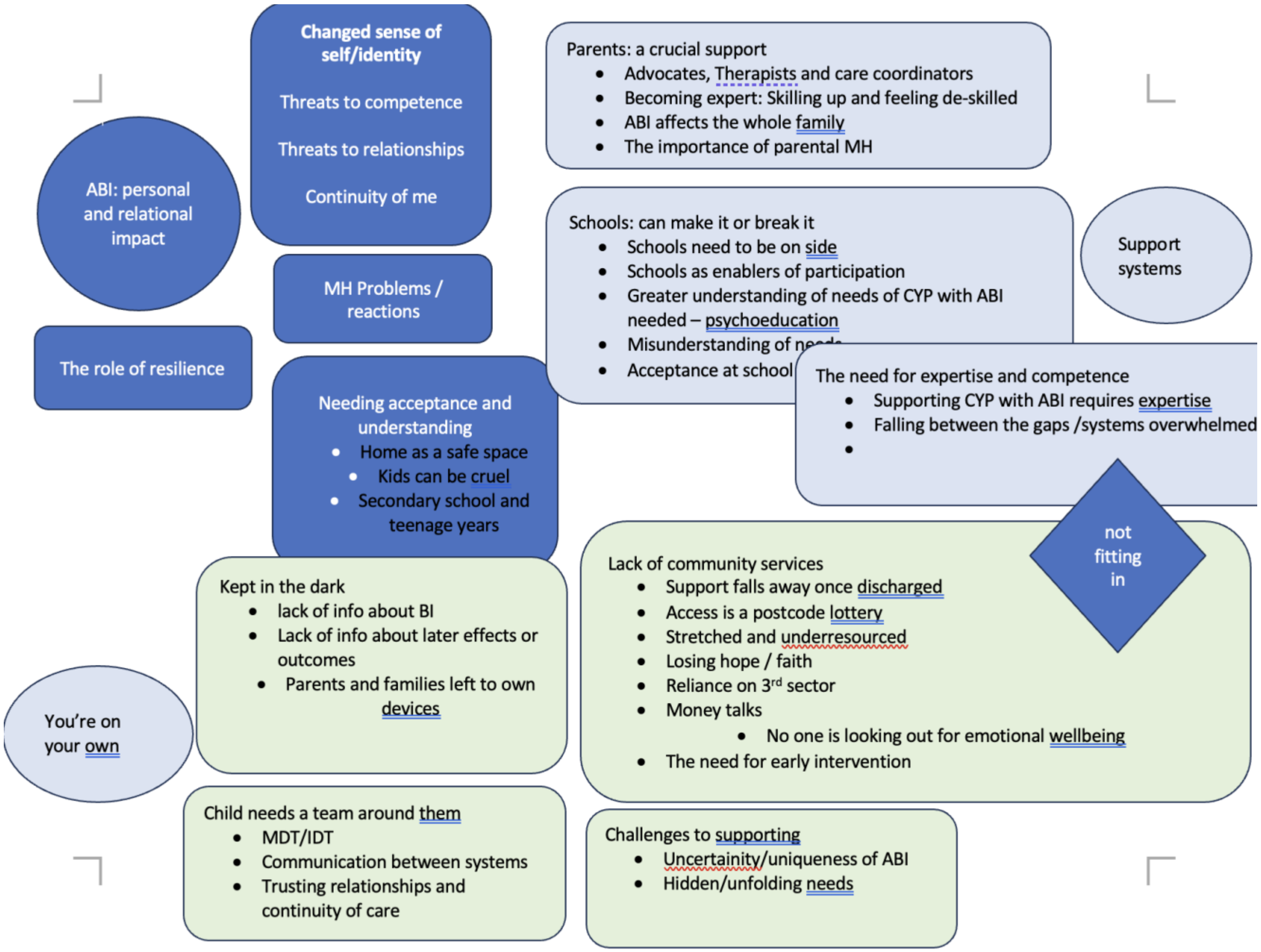
CYP with ABI

The role of resilience

Lack of acceptance

Threats to relationships /

7.16 APPENDIX P: INTERMEDIATE THEMATIC MAP



ABI: personal and relational impact

Changed sense of self/identity

Threats to competence

Threats to relationships

Continuity of me

MH Problems / reactions

The role of resilience

Needing acceptance and understanding
- Home as a safe space
- Kids can be cruel
- Secondary school and teenage years

Parents: a crucial support
- Advocates, Therapists and care coordinators
- Becoming expert: Skilling up and feeling de-skilled
- ABI affects the whole family
- The importance of parental MH

Schools: can make it or break it
- Schools need to be on side
- Schools as enablers of participation
- Greater understanding of needs of CYP with ABI needed – psychoeducation
- Misunderstanding of ne
- Acceptance at school

Support systems

The need for expertise and competence
- Supporting CYP with ABI requires expertise
- Falling between the gaps /systems overwhelmed
-

not fitting in

Kept in the dark
- lack of info about BI
- Lack of info about later effects or outcomes
- Parents and families left to own devices

You're on your own

Lack of community services
- Support falls away once discharged
- Access is a postcode lottery
- Stretched and underresourced
- Losing hope / faith
- Reliance on 3rd sector
- Money talks
  - No one is looking out for emotional wellbeing
- The need for early intervention

Child needs a team around them
- MDT/IDT
- Communication between systems
- Trusting relationships and continuity of care

Challenges to supporting
- Uncertainity/uniqueness of ABI
- Hidden/unfolding needs

7.17 APPENDIX Q: FINAL THEMATIC MAP