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Student Number: 1501170      Course Code: M4

Unit Name: Doctorate in Child, Community and Educational Psychology

Unit Number: M4 Year 3      Submission Date: 16/05/2018

**Word Length (not including appendices and end/footnotes): 37032**

Essay / Dissertation Title (if applicable): An exploration into the parental experience of Emotionally Based School Non Attendance in young people: an Interpretative Phenomenological Analysis.

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*An exploration into the parental experience of  
Emotionally Based School Non Attendance in  
young people: an Interpretative Phenomenological  
Analysis.*

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A thesis submitted for the degree of Doctorate in  
Child, Community & Educational Psychology

Tavistock and Portman NHS Foundation Trust/  
University of Essex

Date of submission: May 2018

## **Abstract**

School refusal, school phobia, school anxiety and emotionally based school non-attendance are all interchangeable terms used to describe children who experience high levels of distress and anxiety that prevents them from going to school. Emotionally Based School Non Attendance (EBSNA) in young people is a complex and multifactorial condition which can be a symptom of an underlying mental health disorder (McShane & Rey, 2001).

This study explored the experiences of parents of young people aged 13-15 years old who present with EBSNA, who no longer attend mainstream school and who attend an alternative educational provision. Interviews were conducted with five parents and transcripts were analysed using Interpretative Phenomenological Analysis (IPA), leading to four superordinate themes: 'It turns your life upside down'; Power and the battle to be heard; Loss and fear and Retrospective clarity. These themes captured the far-reaching effects on parents which impacted on relationships within the family, their own mental health and poor relationships between home and school. Parents shared their concern for their child's future and described the need to understand the origins of their child's condition.

Implications for Educational Psychologists (EPs) and other professional agencies suggest that it is important to increase our understanding and awareness of the parental experience and consider ways of improving the quality of parental and professional relationships.

## **Acknowledgements**

There are many people who I would like to thank for their encouragement and support, not only in this research but over the last three years.

Firstly, my two wonderful sons and my husband for their patience and understanding, we have had to climb a mountain of obstacles, but we have survived! Also, to my mother for holding the fort, keeping us fed and watered and endless childcare.

I would like to thank my supervisors at the Tavistock and at my Educational Psychology Service for their support.

To my fellow Tavi trainees, who are all inspirational women and provided much needed containment!

To my close friends and family who have been cheering me across the finish line and had complete confidence in my ability to succeed.

My thanks and deep appreciation goes to the wonderful parents who participated in this research, without them this thesis would not have been possible.

This thesis is dedicated to my beloved mother, mentor and spiritual touchstone Venita Adams.

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## **1. Introduction**

### **1.1 Chapter Overview**

This chapter will focus on the subject of ‘Emotionally Based School Non-Attendance’ (EBSNA) and other terminologies used to describe this phenomenon. I will explore the definitions, labels and dominant discourses and narratives on this subject, which will be followed by a consideration of government legislation and policy in regard to parents and school attendance.

### **1.2 Terminologies and Definitions**

There are a range of terminologies ranging from ‘school refusal’, ‘school absenteeism’, ‘school phobia’ to ‘extended non-attendance’ all of which are used to describe the phenomena of children and young people who are unable to attend school due to an emotional barrier which can manifest as anxiety.

The term ‘Emotionally Based School Non-Attendance’ (EBSNA) will be used throughout this thesis instead of the terms ‘school refusal’ and ‘school phobia’, and these terms will be used only if directly quoted from the literature or if in reference to the literature that employs them. My choice to use the less popular term of EBSNA is an attempt to frame the nature of this condition in a way that is descriptive and has less emphasis on the ‘within child’ model and to consider a more ecological model, which explores systems and relationships around the child. Lauchlan (2003), uses the term ‘chronic non-attendance’ and similarly, Pellegrini (2007) chooses to use the term ‘extended school-non-attendance’, arguing that while some authors defend the use of the term ‘school refusal’, as it refers to the full spectrum of school non-attendance problems (Kearney & Silverman, 1999), he believes that it creates the image of a defiant and wilful child, who presents with challenging behaviour. Pellegrini (2007) also rejects the term ‘school phobia’ suggesting that it implies psychopathology, which may not be the

case, as some non-attenders may not display any clinical characteristics of anxiety or a conduct disorder.

School refusal, school phobia, school anxiety and emotionally based school non-attendance are all interchangeable terms used to describe children who experience high levels of distress and anxiety that prevents them from going to school. Children exhibit psychological and physical symptoms such as sadness, panic, aggression, tummy pain, nausea and headaches. (Berg, Nichols and Pritchard (1969). It does not refer to children who have persistent levels of absenteeism in general but focusses on the emotional distress and anxiety experienced which results in the child feeling unable to go to school.

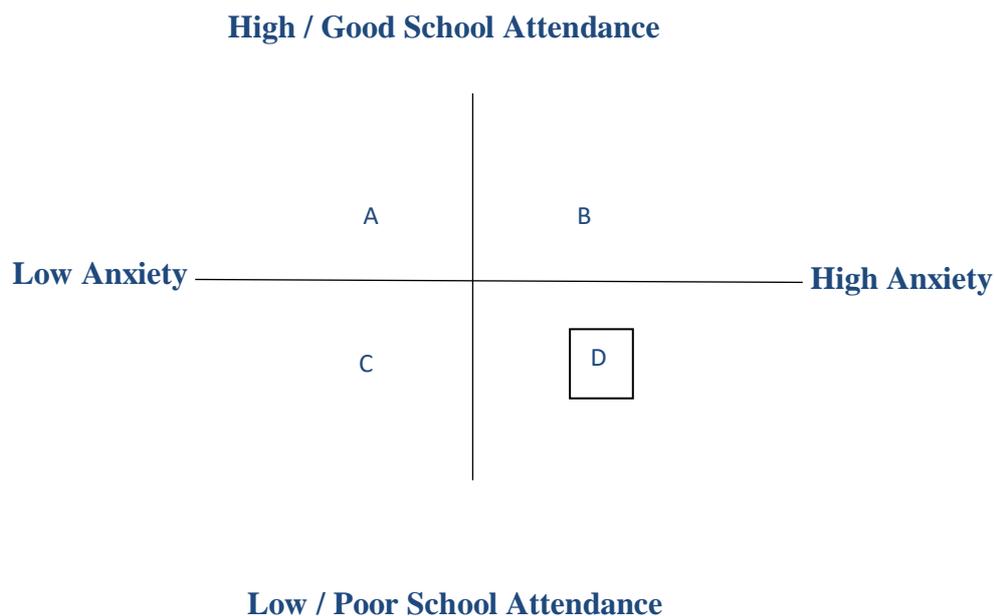
The absence of a clear and universally accepted definition of school refusal makes it challenging to develop a thorough understanding of this complex problem. Thambirajah, Grandison & De-Hayes (2008) chose the use the neutral term 'school non-attendance' as it is a broad umbrella term which is used to describe all pupils who do not attend school. It also labels the behaviour without making any inferences or suggestions about the cause or attributing blame. Thambirajah et al., (2008) consider school non-attendance as a spectrum of different behaviours, which can range from occasional reluctance/occasional absence to extreme reluctance and persistent non- attendance. They highlight that *'children who fail to attend school are not a uniform group and school non-attendance, especially when it is prolonged and persistent, remains a puzzling and complex problem'* (p11).

The West Sussex Educational Psychology Service (2004) adopted the term 'Emotionally-Based School Refusal' to include the range of symptoms identified by Berg et al (1969). In their study Berg et al (1969) selected a sample of 29 children (mean age of 12years, 10 months) who had been admitted to psychiatric hospital with a diagnosis of 'school phobia'.

They describe it as the following;

1. A severe difficulty in attending school which often amounts to prolonged absences.
2. Severe emotional upset which is shown by symptoms such as excessive fearfulness, anger, frustration, tantrums, misery or complaints of feeling ill without obvious organic cause, when faced with going to school.
3. Staying at home with the knowledge of parents, when the child should be at school.
4. Absence of significant antisocial disorders such as stealing, lying, wandering, destructiveness and sexual misbehaviour.

West Sussex County Council Educational Psychology Service (2004) emphasised that ‘Emotionally Based School Refusal’ (EBSR) is fundamentally characterised by the presence of anxiety, which can greatly impact on a young person’s attendance and behaviour at school. The authors illustrate the relationships between anxiety and non-attendance within the following matrix.



**Figure 1. Emotionally Based School Refusal: The relationship between anxiety and non-attendance (from West Sussex County Council Educational Psychology Service (2004)).**

Children who are included in section A have low anxiety and good attendance. Section B includes children who are very anxious but can maintain good attendance. Section C would

include children who may be considered as truants as they have low school attendance, but they do not display anxiety as the primary cause of their non-attendance. **Section D would include the children who are highly anxious and refuse to attend school, resulting in low attendance. The children in this section will be the focus of this research.**

### **1.3 Epidemiology**

EBSNA affects many children and young people, approximately 1% to 5% of all school-aged children are reported to have experienced anxiety which has affected their school attendance. (King, Ollendick, Tonge, 1995). Reviews have reported that school refusal behaviours with an element of anxiety affect about 1–2% of school aged children (Elliott, 1999; Kearney, 2008). Prevalence rates are similar across genders, and it tends to be more common in children who have started primary school and who are transitioning to high school.

Attendance records kept by schools are detailed and are divided into authorised and unauthorised absences, but despite the prevalence of EBSNA, there are no specific statistics which measure the frequency of it in the UK. This highlights the problem of lack of professional clarity in the area, which was found in research commissioned by the Local Government Agency into attendance by Archer, Filmer-Sankey and Fletcher-Campbell (2003). They found that the schools and Local Education Authorities (LEA) did not have a clear definition to describe children who persistently do not attend school due to anxiety and only 17% of the schools involved recognised it as a separate issue. Archer et al. (2003) research found that 74% of the schools that participated did not keep attendance data specifically on those who presented with school refusal/anxiety and only one school had any written guidance on the issue. Thambirajah et al. (2008) found that the lack of awareness around the issue of school refusal results in schools and parents failing to recognise it. They also suggest that

mental health problems in general are often misunderstood or fail to be acknowledged by school staff.

The presentation of school refusal behaviours tends to emerge gradually and is often seen in conjunction with depression and anxiety (Fremont, 2003). In addition, Bernstein, Warren, Massie, & Thuras, (1999); Flakierska-Praquin, Lindstrom, & Gillberg, (1997) highlight many short and long-term consequences including; academic difficulties, peer relational problems, family problems, academic underachievement, poorer occupational and employment outcomes, and increased risk of adult psychiatric problems.

Research into EBSNA has tended to focus on the child and the clinical characteristics of their condition. Thambirajah, et al. (2008) identified the spectrum of school refusal behaviour, ranging from occasional reluctance/occasional absence to extreme reluctance and persistent non- attendance. They highlight that: *'children who fail to attend school are not a uniform group and school non-attendance, especially when it is prolonged and persistent, remains a puzzling and complex problem'* (p11).

The heterogenous nature of EBSNA means that it becomes difficult to make generally assumptions and cases may be very different from each other, making professional intervention more challenging. There may be a variety of reasons which can impact the child's willingness to attend school and while there is limited research into the area of EBSNA, studies have shown that certain groups of children and young people such as those from the Traveller community and young carers have low levels of school attendance compared to other groups. Data from the Department of Education (2018) shows that Gypsy/Roma and Travellers of Irish heritage have school absence rates of 18%. Research from the Audit Commission (2000) revealed that that a half of young carers surveyed had missed school because of their caring role. However, there is no clear evidence that their low attendance rates are due to EBSNA.

#### **1.4 National Context: School Attendance and the Law**

The Education Act (1996) states clearly that parents must ensure that their child has access to an education. In cases of low/non-attendance, parents are held accountable as it assumed they have the capacity to enforce their child's attendance. Research has suggested that supporting parents with behaviour management skills can support a child's attendance (Lauchlan, 2003). Local authorities have the power to prosecute parents who fail to comply with a school attendance order (section 443 of the Education Act 1996) or fail to ensure their child's regular attendance at a school (section 444 of the Education Act 1996).

The Department for Education created a list of recommendations that were aimed at improving levels of attendance. The focus was placed on the parent's responsibility to "ensure their child attends school, failure to ensure this results in financial penalties" (Improving attendance at school, DFE, 2012). The DFE advise local authorities to use parenting contracts, parent orders and parenting courses, which are aimed to help parents change their child's attendance rates (DFE, 2015). 'Parenting Contracts' were designed to improve attendance by creating a formal written and signed agreement. When parents fail to comply to the programme agreed, this is used as evidence in court against them. A further strategy involves 'Parenting Orders' which compel parents to attend parenting support classes or education, where support lasts up to 3 months. Failure to adhere to the Parenting Contract or Parenting Order can result in Penalty Notices and fines for families.

Pellegrini (2007) suggests that the legal interventions listed above, highlight the dominant discourse held by governments which identifies parents as the 'locus of the problem' (p67), where the child and young person are passive and do not have their voice heard. He argues that the focus on the family means that important systemic factors are ignored.

The use of financial penalties and legal action is used as a way of ‘motivating’ parents to improve their situation. However, it is argued that the threat of punishment is an ineffective way to bring about change. (Behaviour change; School attendance, exclusion and persistent absenteeism. BPS, 2014). There is no mention of the subject of school refusal in guidance from the DFE as no data is recorded by local authorities.

Shepherd (2011) argues that despite years of government interventions aimed at improving attendance through sanctioning parents, there is no evidence that legal sanctions improve attendance. Figures from the Ministry of Justice in 2010 showed that parental prosecutions for poor attendance in England increased between 2007 and 2009 by 27.6% to a total of 10,697 parents in 2009 but did not correlate with any improvement in levels of attendance.

Shepherd (2011) believes that the complexity of the origins of low school attendance are complex in nature and require a more nuanced intervention strategy rather than penalising parents.

### **1.5 Dominant and alternative discourses**

This section explores how the concept of school attendance and school refusal is considered in different contexts and cultures.

Discourse, as defined by Foucault, refers to ‘*ways of constituting knowledge, together with the social practices, forms of subjectivity and power relations which inhere in such knowledges and relations between them. Discourses are more than ways of thinking and producing meaning. They constitute the ‘nature’ of the body, unconscious and conscious mind and emotional life of the subjects they seek to govern*’ (Weedon, 1987, p. 108).

The challenge of not having a clear definition of EBSNA invites the construction of a range of discourses. Pellegrini (2007) considers how 'extended school non-attendance' is used in conjunction with clinical language and psychopathology. Terms such as 'treatment', 'diagnosis', 'symptoms', 'disorder', 'co-morbidity', 'in-patient treatment', 'family history of psychiatric illnesses' are common in the literature and are the building blocks of a dominant clinical discourse which constructs a mainstream view of extended school non-attendance. He argues that the 'within child' model has become the dominant perspective held by professionals and promotes a limited view on a highly complex issue, although he points out that many children and young people are supported by mental health specialists. Place (2000) highlights the importance of recognising the interaction between the child, school and environmental factors, and believes that it will help to generate a range of alternative discourses on this subject.

The dominant discourse on the subject of EBSNA is reflected in the national context and legal discourse, where parents are held responsible for their child's attendance to school. School non-attendance is typically viewed as the result of the parental disaffection with education and a lack of parental authority. (Pellegrini, 2007).

Stroobant and Jones (2006) also offer an alternative discourse on the subject and challenge the 'within child' model. They interviewed female university students who had previously been school refusers, and in their analysis they discuss the view that young people who school refuse should not necessarily be viewed as maladaptive or problematic, as their behaviour; *'may be a perfectly rational and adaptive response by a distressed individual to an aversive school environment'* (p. 213). The young women felt the labels associated with their unwillingness to attend school were wholly negative, i.e. unhappy, disturbed and hypersensitive, and were disempowering and demoralising. They argue that the dominant narrative is that school is 'necessary and good' and that refusing to attend school is in direct opposition to the social

norm. The researchers acknowledge the potential for bias given their own personal experience of being school refusers as children.

Yoneyama (2000) explored the purpose and the importance of school attendance in Japanese culture and considers the meaning of 'Tôkôkyohi' (school phobia/ refusal). He believes the school experience goes beyond learning and education and he reflects on the hidden agenda of socialisation and considers school a place where young people become homogenous citizens and individual drives are minimised and 'tamed'. From this perspective, 'Tôkôkyohi' is seen as threat to the foundation of Japanese society, which views itself as 'conformist and highly educated' (Pellegrini, p 67). The desire for conformity and homogeneity through a strict school uniform policy has been associated with higher levels of school attendance and attainment. (Gentile and Imberman, 2012).

### **1.6 Truancy vs School Refusal**

The term school non-attendance is an umbrella term and does not provide any explanation for why the child is not attending. According to Thambirajah et al., (2008), it is essential to clarify the reason for their non-attendance. They assert that when a child presents with a reluctance to attend school, the first step is to try and discover which category of school non-attendance they most closely align with or to at least distinguish between school refusal and truancy.

It was Broadwin (1932) who was the first to make a distinction between young people who displayed anxiety and fear when attending school and those who truanted. The behaviour of students who truant is different from those who present with EBSNA. Truants are associated with anti-social behaviour within a group of peers and more likely to hide their school absence from their school and parent (Galloway,1983).

However, Lauchlan (2003) disputes the usefulness of this distinction claiming some children may exhibit characteristics of both truancy and school refusal. He argues that the differences between truanting and school refusal are far more nuanced than this simple distinction suggests as it fails to recognise the fact that children refuse to attend school for a whole range of reasons. He argues that there is a common view that school refusal is emotionally based, while truancy is based on poor behaviour and that this narrow narrative is unhelpful. The narrative positions the young people who are fearful of school and whose parents are aware of their absence as being worthier of sympathy and truants as anti-social and disruptive. Lyon and Colter (2007) consider this to be an 'undesirable effect' of making a distinction between truancy and what they describe as anxiety-based school refusal. They reject the notion that school refusers deserve support and sympathy while truants deserve to be reprimanded.

## **1.7 Theoretical Frameworks**

To help improve our understanding on the concept of EBNSA, it will be explored using a range of different psychological 'lenses' to help understand the aetiology, looking at both the within child and ecological models.

### **1.7.1 The Behavioural / Functional Model**

A significant amount of research has been conducted in the USA, led by Christopher Kearney (1990; 2004). Taking a behavioural perspective and using a model of functional analysis to explore school refusal, Kearney and Silverman (1990) identified the following functions;

- 1) Avoidance of general over-anxiousness and fear related to the school setting.
- 2) Escape from difficult social situations, e.g. being alone in the playground, bullying or difficult learning experiences in class.

3) Attention-getting or separation anxious behaviour, which may be related to somatic complaints or tantrums, e.g. this behaviour can ensure the parents attention and contact with the child.

4) Rewarding experiences provided out of school, e.g. the child gains opportunities to engage in preferred activities; watching TV, time with parent at home away from siblings.

According to this perspective, being at home may be highly preferable to being at school. The relief a child experiences when they can avoid going to school only serves to increase anxiety the next time they are required to go, thus, the avoidance maintains the school refusal.

Pilkington and Piersel (1991) explored the literature on the subject of school refusal and highlighted the importance of considering how contextual factors within school could be provide either positive or negative reinforcement to students who are refusing to attend school. For example, external factors such as the size of the school, classroom routines, classroom practices can feel distressing and confining for some students. They suggest that school refusal behaviour could actually be an appropriate response to a possibly hostile environment. These factors relate to the functional model of school refusal assessment and the dimensions derived from the School Refusal Assessment Scale (Kearney, 2002).

Darling-Hammond (2004) argue that some schools, particularly in economically deprived areas can be rather aversive, resulting in a reluctance in the student's desire to attend school.

### **1.7.2 Separation Anxiety**

Separation Anxiety originated from Bowlby's (1969) Attachment Theory and raised the important significance of the early relationship that exists between the infant and the caregiver. Ainsworth (1982) determined that the quality of that relationship will impact on the child's

relationships in the future. According to attachment theory, separation anxiety occurs naturally at around 12 months of age when the child experiences separation from his or her main carer and forms part of the process of the development of psychological attachment.

The majority of the research has focussed on the relationship between mother and child, with some researchers suggesting that overprotective mothers may facilitate separation anxiety, leading to an ongoing over-dependency on the part of the child and sometimes the parent (Berg & Mcquire, 1971). However, research by Egger, Costello and Angold (2003) which explored the association between anxious school refusal and truancy and psychiatric disorders found that among their sample of 4500 children aged between 9 and 13 years displaying school refusal and truanting behaviour, separation anxiety was low. They conclude that anxious school refusal behaviours are not synonymous with separation anxiety. However, this is an American study and their sample may not be representative of the UK population.

A psychodynamic perspective on EBSNA was conducted by Christogiorgos and Giannkopoulos (2014). They explored the case of a 12-year-old boy who was a school refuser. In this case, the child was the focus of the therapeutic intervention and there is not an exploration of the mother and her experience. They acknowledge that school refusal is a complex multi-faceted subject and identify that the relationship between parent and child is vital to understanding this issue.

Thambirajah et al (2008) also acknowledge that *'parents' attitude towards the teacher and other educational authorities are usually coloured by their previous experience with teachers, authority figures and, especially, their own experience of schooling'* (p84).

Parents who have unresolved issues regarding their own school experiences, may influence their child's experience both consciously and unconsciously. This links with Klein's (1946) theory of 'Projective Identification' where parts of the self can be 'projected' into another.

### **1.7.3 The relationship between mental health and EBSNA**

Figures from the most recent national survey into the mental health and wellbeing of children and young people found that around 10% of children between five and sixteen had a clinically diagnosed mental disorder. (Office of National Statistics, 2004), with 50% of all adult mental illness starting before the age of 15 and 75% before the age of 18.

There is an ever-growing prevalence of mental ill health, particularly for behavioural and emotional conditions such as anxiety, depression and conduct disorders and schools offer a critical role on the front line.

Research has shown that there is a high level of psychiatric comorbidity among young people who present with EBSNA, with anxiety and depression being identified as the most prevalent (Egger, Costello, & Angold, 2003; Fremont, 2003).

Egger et al (2003) identify two other types of anxious school refusers from the clinical literature; those with social phobia and those who are anxious or depressed. Social phobia is defined in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) as a marked and persistent fear of social or performance situations in which embarrassment may occur, which interferes significantly with the person's normal routine, occupational (academic) functioning, or social activities or relationships, or where there is marked distress about having the phobia. However, there is some debate in the literature as to whether all school refusers are anxious. Some researchers have observed that anxiety is not systematically correlated with school refusal (Francis, Hersen Kazdin & Strauss, 1987), however, in reviewing Kearney and Silverman's functional model of school refusal, Brandibas, Jeunier, Claret & Fouraste (2004) conclude that anxiety is a key feature of school refusal. Elliott (1999) concludes that individuals prone to anxiety, depression and social difficulties may be more likely to develop school refusal behaviour than others. Berg, Butler, Franklin, Lucas & Sims (1993) identified that young people who presented with school refusal behaviour also

demonstrated high levels of anxiety and depressive or mood disorders. These studies highlight the ‘within child’ nature of EBSNA, but they do not explore the systemic factors that may be at play.

### **1.8 Professional conceptualisation of EBSNA**

As previously mentioned, Thambirajah et al (2008) have noted that official school non-attendance figures do not include statistics for school refusal, they also recognise that there is a deficit of information for professionals in this subject, which increases the difficulty that schools have in recognising the problem.

Research by Malcolm (2003) revealed that teachers believed that parental attitudes and home environments were the main reasons for truancy and low school attendance.

Research commissioned by the Local Government Association in 2003, indicated that educational professionals appeared to have a limited understanding of the issue of school refusal. Archer, Filmer-Sankey and Fletcher-Campbell (2003) investigated how educational practitioners conceptualised school refusal. They explored the different perceptions associated with ‘school refusal’ and ‘school phobia’ and how schools and local authorities supported children, young people and families experiencing this issue. They revealed that half of all local authorities did not distinguish school refusers from other non-attenders. They found that very few schools had any written guidance and it appeared that knowledge on the issue was lacking amongst professionals.

These findings are mirrored by Reid (2006) who found that the majority of school staff and educational professionals, including EWOs did not have any specific training on the subject of

EBSNA. In addition, the few that had participated in the research described it as being 'insufficient'.

Archer et al (2003) report that three quarters of the LEAs included in their survey (from a total of 60) offered alternative provision to some young people with school refusal behaviour and for over half of this number the alternative provision took the form of a pupil referral unit (PRU). Section 19 of the Education Act 1996 says that if a child of compulsory school age (between 5 and 16 years old) cannot attend school for reasons of illness, exclusion from school or otherwise, the local authority must make arrangements to provide 'suitable education' either at school or elsewhere.

For children and young people who are presenting with EBSNA, a specialist education provision which can be offered as an alternative to help prevent further isolation.

In his book "Can't Go, Won't Go" Mike Fortune-Wood (2007) explored how families are treated by a range of schools and professional agencies and argues that there is a need for better communication and strategies from service providers from schools to psychologists.

Interventions and treatment for EBSNA have been shown to be helpful in a meta-analytical study by Heyne, Sauter, Ollendick, Widenfelt and Westenberg (2014), who explored a range of unpublished and published studies between 1980 and 2013. They found evidence that a psycho-social approach; which combines the influence of the environment and psychological factors and included individual support for the child and parenting support, was effective in improving the school attendance rates for children and adolescents who present with EBSNA.

Research by Epstein and Sheldon (2002) found that when schools implemented strategies involving the family and community, attendance rates amongst students increased. Strategies included regular home visits, positive rewards for attendance and focussed on building inclusive and supportive strategies to families. Simmons & Farabaugh (1999) suggest that this

type of approach is likely to produce better outcomes which are based upon positive consequences for participating rather than threats of punishment and fines for school non-attendance. Social groups associated with school non-attendance such as children from the Traveller community have found improvements through collaborative participation with education professionals. (Department for Children, Schools and Families, 2009b)

### **1.9 Rationale and aims of the research**

The complexity and pervasive nature of EBSNA has been explored in this chapter, however there remains a dearth of research in how this issue affects parents and carers. This is particularly important as parents bear the brunt of legal consequences when action is taken the schools and local authorities to address the issue of non-attendance.

This is an emancipatory piece of research which aims to give a voice to parents and an insight into the lived experience, with an aim to improving our understanding of how this issue can impact the family. It is hoped that by increasing our professional understanding of the parental experience, we can improve outcomes by helping to develop effective and collaborative approaches of support. Prior to advising families and offering strategies about what they need to do, professionals need to understand the parental experience and recognise the challenges they face, otherwise our advice and guidance is based upon assumptions and not knowledge, which is likely to produce poorer outcomes.

The exploration of the family experience aims to examine this subject beyond the ‘within child’ or ‘within family’ model and uses an ecological model (Bronfenbrenner 1979) to learn about the interactions between home and school/professional systems and the impact of that experience on the individual.

It is very important to state my personal relationship with the subject as I had a sibling who presented with EBSNA as a child. To help maintain ethical validity, I kept a reflective research diary to maintain my awareness during the research process. I have reflected on those extracts from my diary and have added my thought processes to the end of each chapter to help the reader to understand my thinking and my attempts to maintain objectivity and ethical awareness.

### **1.10 Chapter Summary**

This chapter has provided the context and rationale for the current research. The scope of the subject has been explored and both popular and alternative discourses on the subject of school non-attendance has been discussed.

## **2 Literature Review**

### **2.1 Chapter Overview**

The purpose of this chapter is to review the most relevant literature on the subject and to demonstrate a rationale for why this is an area of importance and deserves to be researched further. The literature review The literature review will explore two main questions;

- 1. What does the research tell us about the parental experience of those who have a child who presents with Emotionally Based School Non-Attendance (EBSNA)?**
- 2. What does the research tell us about the role and the influence of the family on Emotionally Based School Non-Attendance (EBSNA)?**

The rationale for the literature review questions originates from the desire to explore the parental perspective on the subject of EBSNA. While the experience of the child and young person is important, I wanted to solely focus on what the research tells us about the parental experience.

A search of the literature was undertaken through a collection of databases including; PsychInfo, Education Source, ERIC, Psychology & Behavioural Sciences Collection and the PEP archive, using combinations of different search terms related to the following;

- Parent\*
- Famil\*
- School
- Non-attendance
- Anxiety

- Refusal
- phobia

All of the searches were limited to peer reviewed studies, which had been published in academic journals between 1995 until present and which had been published in English. The rationale for this time frame is based upon the 1996 Education Act which reminds parents of their duty to secure education of children of compulsory school age.

Given the limited number of relevant studies, research from outside the UK was included. The search yielded 9 studies (See Appendix A for search results) which were relevant to the literature review questions below. Studies which did not have any relevance to these questions were rejected, this included the following;

- Research which assessed the effectiveness of treatments and interventions of EBSNA.
- Research which was not specific to school or education, i.e. general anxiety and mental health.
- Research which had a medical aspect including the use of medication to treat anxiety or when the school non-attendance was linked to a medical condition which directly affected the child's physical capacity to attend school.
- Research which focussed exclusively on school factors with no reference to the family or parent.

Studies were also sourced from the references of particular pieces of research.

To help assess the reliability, value, relevance and trustworthiness of the research, I implemented the use of the Critical Appraisals Skills Programme (CASP) to systematically examine each study. (See Appendix B). The CASP is an extremely useful tool which helped to narrow down the literature search and fully explore the value and relevance of key studies to this particular research study. The systematic approach of the CASP helps to eliminate research

studies which are poorly implemented, where the results could be unreliable and invalid, and which could skew the findings of the literature review.

## **2.2 Question 1: What does the research tell us about the parental experience?**

There is an absence of the voice of the parent in the research, which has tended to explore professional conceptualisations on the subject. However, four studies from the literature search were highlighted as exploring the experience and perspectives of parents. They will be reviewed starting with the most recent.

### **2.2.1 Sibeoni, Orri, Podlipski, Labey, Campredon, Garadin, Revah-Levy (2018)**

This French research aimed to explore the experience of adolescents who present with what the researchers describe as ‘Anxiety Based School Refusal’(ABSR) and their parents following their treatment of psychiatric care. This study was published in English.

The researchers recognise the importance of the research by highlighting that around 90% of young people who refuse to attend school may have a psychiatric disorder (Ek and Erickson, 2013).

They argue that the lived experience of these young people and their parents is critically important to their treatment, leading to better patient reported outcomes. Their use of Thematic Analysis is an appropriate qualitative methodology as their focus is not on assessing the effectiveness of a given treatment but seeks to take a closer look at how patients and their parents experience the treatment process. Thematic Analysis (Braun, Clarke & Terry, 2014) aims to allow the identification of key themes which emerge from the data without prior theoretical notions or preconceptions.

The study took place in three different adolescent psychiatry departments in France, which provide specialist support for young people with ABSR. Participants were chosen specifically by clinicians who considered them likely to provide the most information and who met the following criteria;

1. The young person should meet the criteria of ‘school refusal’ as identified by Berg et al (1969) and would not have attended school for at least one month.
2. They should have a diagnosis of a DSM-V anxiety disorder (excluding Obsessive Compulsive Disorder and Post Traumatic Stress Disorder).
3. There should be absence of a DSM-V conduct disorder.
4. Parents were aware of their child’s school non-attendance, meaning these young people were not engaged in truanting from school.

The participants were interviewed twice by the same researchers who were either clinical psychologists or psychiatrists working at the treatment facility, using a semi structured interview technique.

The research identified two key themes;

1. **Goals of psychiatric care;** which included the subthemes of
  - *Self-Transformation:* The young people interviewed tended to consider themselves as the source of their problems. They did not blame school as the cause but recognised it as the place where their underlying issue manifested and expressed itself, the problem of school refusal was a secondary issue.
  - *Problem Solving:* The parents viewed treatment as a solution to their concerns regarding the academic consequences of their child’s school non-attendance and their social isolation and lack of a peer group. Parents reported concerns

regarding the conduct of school teachers as being strict, placing too much pressure on students and the lack of flexibility in the school structure.

**2. Therapeutic levers identified as effective;** This included the subthemes of

- *Time and Space:* The young people felt that the time taken for their treatment to be effective was worthwhile and useful. However, parents expressed some frustration with the time it takes for treatment to be effective and hoped for quicker resolutions.
- *Relationships:* Both the young people and their parents highlighted the importance of being able to speak out and be heard in a trusting relationship. They identified the psychiatrists as being the ‘professional’ in the facility who seemed more distant and focussed on managing treatment. Teachers were described as being ‘kind, patient and altruistic’ (p.47) which the young people found to be a healing experience.

The researchers identify several important areas which have implications for the role of mental health and education professionals, the value of the therapeutic relationship and the time needed to bring about change. However, the researchers do not make it clear if they themselves were involved in the treatment of the participants and whether this presents the potential for bias. The study reports how psychiatrists were viewed by the participants and it needs to be considered whether the perception of the researcher and their role, could impact how participants responded. The interviews also took place in the treatment facility and not a neutral location, which may have affected how comfortable participants felt to fully express their thoughts and feelings on their treatment. The researchers also chose participants purposively and do not provide further information on why some participants were not approached to take part in the research. They also did not consider the relevance of Autistic Spectrum Disorder (ASD) to their participant group.

The researchers acknowledge that as their study took place in France, there may be limitations in its ecological validity and whether results can be applied to different countries and cultures. I would agree, particularly at a time of austerity in the UK and the difficulties reported in accessing specialist mental health services.

### **2.2.2 Bussard, Haarf, Sibeoni, Radjack, Benoit & Moro (2015)**

This research also is a French study which explored the experience of parents who have an adolescent child who presents with ABSR. This study is only available in French and has not been published in English. Translation services were used to read this study, however limitations in the critical analysis should be acknowledged given the language barrier.

The researchers interviewed 24 parents (20 mothers and 4 fathers) whose child no longer attended school and who was currently receiving treatment at a specialist psychiatric facility in Paris. Parents were interviewed using the Five-Minute Speech Sample (FMSS) and Expressed Emotion (EE) measure. The FMSS-EE rating is comprised from statements made by a child's parent/relative during a 5-minute monologue, which is free from interruption. Parents are required to talk about their feelings and thoughts in their own words and describe the relationship between them and the child. The transcript from the FMSS is audio-recorded and coded according to the content of the transcript, including emotions, feelings and attitudes and tone of the speech.

The FMSS and the EE measure are seen as being an effective method of exploring the relationship between parental attitudes, behaviours and child development in both normal and pathological children. (Laghezza, Mazzeschi, Di Riso, Chessa, & Buratta, 2010).

The information gathered in the FMSS was analysed using Interpretative Phenomenological Analysis (IPA) (Smith 2009). IPA is a qualitative methodology which seeks to shine a light in

the experience. Parents free flowed their thoughts for 5 mins, which were then analysed by at least 2 researchers, aiming to ensure greater validity, after this in-depth analysis, a transverse study was undertaken to look for/ elicit different recurring themes in the parent's speech.

The following superordinate themes emerged from their analysis of the data;

**The origin of the troubles:** Eight parents mentioned a traumatic incident that happened at school as a trigger for school refusal. The majority of parents identified a family role in the troubles their child faced (separation, conflict, over-protection, overly ambitious academically).

**Consequences:** The parents reported concerns regarding their child's academic future and how this would affect their capacity to become successful adults. There were also concerns regarding their child's relationships with their peers and their level of social isolation.

**Emotional journey of the parent:** Parents reported being made to feel like a failure and comments from professionals that suggested that they were not implementing their parental authority. They reported feeling helpless and excluded from school. They expressed a need for a parents group in order to share their experiences with others in a similar situation.

**The experience of different institutions:** Parents described the lack of support they received from school and the pressure they felt when having to justify their child's absence from school. Parents reported feeling like they were being 'pushed out' of the school and felt that when their child no longer attended school, there was no professional system who would take responsibility for their child. Parents received specialist psychiatric support with relief and felt like it was the only place where they had received support and reassurance.

**Recognition of the disorder as a disease:** Thirteen parents mentioned their difficulty in accepting the symptoms in their child as an illness, with particular reference to education, which was so important to them it impacted their ability to accept the problem as a mental health issue. There were differences in how parents made sense of their child's issue, in

particular with the terms used to describe the behaviour. Eight of the parents found that by using a term felt that a label of school phobia helped them to understand their child's situation, while two parents opposed the phrase and the diagnosis feeling that it suggested the child was the problem. Fourteen parents used less specific terms such as disengagement, de-schooling or school difficulties. This group of 14 had a less clear idea of the issues their child faced, and had greater difficulty understanding it.

This research reveals important information about the parental experience and is able to identify the key difficulties and the emotional impact. The FMSS has been shown to have concurrent validity and reliability (Calam and Peters, 2006), with more researchers using it given the rapid time it takes to gather and code data. However, the use of IPA as a data analytical technique may not be entirely appropriate. Smith et al (2009) reject the idea that two researchers can review the same data in order to improve reliability. They describe IPA as being phenomenological as it relies upon the individual's perception and acknowledges the inevitable subjectivity that emerges. The individual interpretation of the data is coloured by their autobiographical experience, in the tradition of the double hermeneutic the analysis relies on 'making sense of the participants ways of making sense' (Smith et al, 2009). Therefore, two researchers may find that they have very different interpretations of the data. In addition, IPA relies on the richness and detail in the transcribed data, which may not be present in the FMSS.

### **2.2.3 Havik, Bru & Ertesvag (2014)**

The study takes a systemic perspective which places less emphasis on the child and recognises that there may be external factors which are creating feelings of fear and anxiety in the child. This study aimed to explore the parental perspective on the role of school factors in school refusal. While this research does not offer an in-depth analysis of the parental experience, it is able to provide us with a useful understanding of how parents make sense of their child's school

refusal. The researchers acknowledge that this is an area which has been under researched and used Thematic Analysis (Braun and Clarke, 2006) to identify themes and sub themes in their hope to illuminate the experiences of the participant.

Participants were recruited by staff in educational and psychological counselling services from special schools and from an organisation for parents of children who present with school refusal. Participation in the research was voluntary and the researchers do not make any reference to why some people chose to participate and why some chose not to.

Data was collected through semi structured interviews, using open ended questions which encouraged parents to discuss areas not specifically targeted.

The results revealed four major themes;

1. Demanding factors in school, this included;

- Noisy and disorganised classrooms
- Frightening teacher behaviour
- Social demands from other students (including bullying and social exclusion)
- Academic demands and a fear of failure.

2. Teacher support, including;

- Emotional support from teachers. Parents felt that having a supportive teacher dramatically changed their child's perception of school.
- A need for organisational support and predictability in the learning environment.
- Good home and school communication was considered to be of great importance to parents.

3. Support from fellow students, including;

- Being valued and having friends. The importance of this was reported by nearly of the parents interviewed.

4. Other Supportive factors, including;

- Communication between teachers
- Resources
- Size of the school or class

The researchers recognise that the information provided to parents has come directly from their child, which raises the possibility that the child's perspective may not always accurately represent the situation and from direct school communication.

The analysis of the data was assisted by the use of the computer programme QSR NVivo 9 (2012) and checked by a colleague to ensure worthiness. In addition, results and quotations from the data were sent back to participants to confirm whether they felt the results were representative of the content of the interviews.

The researchers identify that the importance of good student and teacher relationships is compounded by the fact that in Norway, students remain with their teachers for several years, this can be either a help or a hinderance depending upon the type of relationship had between the student and the teacher.

The education system in Norway is different from the UK education system therefore these findings may not be transferable. However, a number of their findings are also reported in a UK study by Davies and Lee (2006).

#### **2.2.4 Davies and Lee (2006)**

Davies and Lee (2006) interviewed 13 school adolescent school non-attenders from schools defined as having severe attendance problems. The details of these interviews are summarised into the information below.

They identified the following key areas of concern for parents;

- Home/school communication systems are poor.
- School are deemed to be arrogant towards parents and students.
- For some parents, the Education Welfare Service as a whole is not seen as a major source of support.
- Learning mentors, Connexions personnel, alternative education providers and individual Education Welfare Officers are identified as helpful.
- The content of the curriculum is not regarded as problematic and it is useful in career terms.
- Alternative provision works to get students to re-engage with learning.
- Schools need to address the problem of bullying in a more effective manner.

There was no evidence from the views expressed by the parents of students with chronic non-attendance problems of an anti-school/education culture in the home. All the parents were eager for their children to attend school and some felt they themselves had been deprived of education.

However, the researchers do not identify clearly how their participants were chosen and whether an inclusion and exclusion criteria were implemented. The participants seem to fall under the umbrella of having a child who presents with chronic school non-attendance, but this does not indicate that these young people presented with any form of anxiety or emotionally

based school non-attendance patterns as identified by Berg et al (1969). In addition, the researchers do not demonstrate how the data gathered from the interviews was recorded or analysed.

### **2.2.5 Carless, Melvin, Tonge and Newman (2015)**

This Australian study by Carless, Melvin, Tonge and Newman (2015) has been included for the Literature Review question as their research explored the role of Parental Self-Efficacy (PSE) amongst parents of school refusers. The notion of Self Efficacy is derived from Bandura's (1977) social-cognitive theory and refers an individual's sense of personal competence in performing tasks effectively. PSE (Bandura, 1997) considers how parents conceptualise their parenting role and their confidence in how successfully they can perform on parenting 'tasks'. The relationship between self-efficacy and lived experience is closely related.

They compared two groups of parents of adolescents aged 12-17 years old who were school attenders or school refusers and gathered data from the young people and their parents using a range of self report measures, including The Beck Depression Inventory-II (BDII; Beck, Steer, & Brown, 1996) used to assess the adolescents; The State-Trait Anxiety Inventory (STAI; Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983) which was used to assess parental anxiety symptoms and The Efficacy subscale of the Parenting Sense of Competence Scale (Gibaud-Wallston & Wandersman, 1978) was used to measure PSE.

They revealed that parents who had low self-efficacy and viewed themselves as not having the knowledge or skills to support their child, were more likely to have a child who refused to attend school. However, when they considered family dysfunction, adolescent and parental depression, the importance of parental self-efficacy as a predictive factor for school refusal was reduced. This study did not explore the type of family dysfunction and did not identify how

long these young people had been school refusers. They acknowledge the small sample size and the generalizability of the findings. To fully understand the relationship between school refusal, PSE, family dysfunction, and familial psychopathology, longitudinal studies are needed to understand the direction of the associations between school-refusal. The researchers recognise that their results may lack reliability due to the self-report aspect of the assessment tools to gather data. However, as the Australian education system is similar to the UK education system, this research may have ecological validity.

### **2.3 RQ2: What does the research tell us about the role and the influence of family history and family dynamics on Emotionally Based School Non Attendance (EBSNA)?**

There is a dearth in the literature which can provide insight into the family epidemiological characteristics of this subject and which looks at the issue systemically.

The *mesosystem* component of Bronfenbrenner's (1979) Ecological Systems recognises the relationships of various setting or microsystems and acknowledges the relationship between the family context and school, yet Lyon and Cotler (2007) have identified that this relationship as not been fully applied to the subject of school refusal.

The literature review search identified 4 major studies which specifically explore the familial traits in EBSNA. These studies will be critically analysed one by one, starting with the most recent.

#### **2.3.1 Bahali, Tahiroglu, Avci, & Seydaoglu (2011)**

Bahali, Tahiroglu, Avci, & Seydaoglu (2011) explored the relationship between parental psychological symptoms and familial risk factors of children and adolescents who exhibit school refusal. The study was performed on 55 pairs of parents who had children exhibiting school refusal, who were compared with a control group of parents who did not have children

with school refusal. Participants who volunteered to take part, were required to have a child aged over five years old who presented with school refusal which was defined as the inability to attend school due to emotional problems.

The Beck Depression Inventory, the State-Trait Anxiety Inventory, and the Symptom Checklist-90 revised were applied to these parents to gather data.

The research revealed that the school refusal group of parents had higher anxiety and depression scores than the controls. They conclude that parents with psychiatric disorders appeared to be associated with development of psychiatric disorders in their children.

They also suggest that the treatment of their children and adolescents who exhibited school refusal is negatively affected by parents who present with a psychiatric disorder. They argue that is therefore vital to treat psychiatric disorders of parents with the children having psychiatric disorders, parents should be included in their children's therapeutic process.

It is important to note that much of the data came from self-reported inventories, which have the potential to lead to participants demonstrating social desirability bias in their responses. This study was conducted in Turkey and results may lack ecological validity to a UK population. The researchers themselves acknowledge that no parent interviews were conducted to help validate and expand on the data gathered through the inventories. The control group of parents who did not have a child with school refusal was not chosen randomly which creates the potential for bias.

### **2.3.2 Egger, Costello and Angold (2003)**

Egger, Costello and Angold (2003) conducted a large-scale piece of research involving a representative sample of 4,500 children aged 9, 11, and 13 years, who were recruited through the Student Information Management System of the public school systems of 11 counties in western North Carolina, USA, using a household equal probability design.

They aimed to explore the relationship between school refusal and DSM-IV psychiatric disorders and the association between school refusal and specific fears, sleep difficulties, and somatic complaints. They also explored associations of difficulties in peer relationships and difficulties within the home to help identify the factors which contribute to the child's school refusal.

Participants were selected through the use of a screening questionnaire, which consisted mainly of questions about behavioural problems, was administered to a parent (usually the mother), by telephone or in person. Children who scored above the cut-off point, were recruited for interviews. These interviews explored the child's psychiatric status using the Child and Adolescent Psychiatric Assessment (CAPA) (Angold and Costello, 1995), which generated a wide range of *DSM-IV* diagnoses.

The group was split into anxious school refusers, truants (non -attenders who did not exhibit anxiety) and mixed school refusers (who were both anxious and truanting). They found that 40% of anxious school refusers and 75% of mixed school refusers, had a biological parent who had been treated for mental illness. This suggests that interventions that are aimed to resolve the issue of school refusal should acknowledge the needs of the parent too. The study did not explore the details of the frequency or intensity of the school refusal behaviour and does not make a distinction between children who may have dropped out of education or who attend school but suffer from anxiety.

### **2.3.3 Berstein and Borchot (1996)**

In a large scale quantitative piece of research, Berstein and Borchot (1996), explored the family dynamics of 134 families of children with school refusal, using the Family Assessment Measure (FAM). The FAM is a self-reported measure used to identify areas of difficult family

behaviour and explores how families communicate, problem solve, follow family rules, roles and routines and the level of emotional cohesion within the family.

The families were divided into seven types based on adults in the home. Single-parent families were overrepresented in this sample compared to the general population. Their research indicated that mothers of school refusers in these single-parent families reported significantly more family problems on the FAM compared with mothers living with the children's fathers. In these single parent families, issues around role performance and communication were highlighted. Fathers of school refusers were found to have more symptoms associated with depression, phobic anxiety and psycho-somatic medical conditions, when compared to mothers.

The results of this research suggest that children in single parent households have an increased risk of presenting with school refusal as opposed to families where both parents live together.

This research demonstrates the relationship between family dynamics and school refusal, which suggests the problem is affected by systemic factors and is not just a 'within child' phenomenon. The data produced from this research relies on a self-reported measure which may present a problem with reliability as participants may feel pressure to provide socially acceptable responses.

### **2.3.4 Kearney and Silverman (1995)**

Kearney and Silverman (1995) explored the nature of family dynamics in the school refusal population. From an extensive review of the research, these authors suggest that several familial subtypes are characteristic of the school refusal population.

They identify five different familial relationships

- 1. The enmeshed family:** This pattern is associated with separation anxiety and usually involved an over dependent relationship between the parent and child. Mothers are described as overprotective, as a way of compensating for feelings of incompetence and inadequacy and fathers are reported to be withdrawn and passive within the family. Research by Waldron, Shrier, Stone and Tobin (1975) compared families of children who presented with 'school phobia' to families of children with other mental health needs. They suggest that 41% of school phobic families displayed at least moderate levels of parental separation anxiety, where mothers seemed to be unable to recognise the need to separate from their child. Kearney and Silverman, present limitations to this study, highlighting a lack of clear methodology and a failure to represent the views and feelings of the family.
  
- 2. The conflictive family:** This pattern describes families where there are high levels of conflict and hostility appear to have higher incidences of school refusal. Parents are unable to maintain clear boundaries with their child, leading to inconsistency and conflict. Kearney and Silverman cite a number of studies including, Frick (1964) psychodynamic perspective views the conflict within the family as the expression of repressed hostility held towards the child by the mother, which results in a joint sense of ambivalence held by both parties. A behavioural perspective is taken Patterson (1982) who suggests that the conflict that emerges in families when a child presents with school refusal, is the result of attempts made by the child to get the parent to agree to their demand to not attend school. The presence of violent conflict is found in research by Mihara and Ichikawa (1986) in their study of 140 Japanese families with children who presented with school refusal. They assert that 48% of families presented with some 'some violence' or 'severe violence' at home. Kearny and Silverman suggest that an inevitable characteristic of school refusal is conflict within the family.

- 3. The detached family:** In these families, parents are unaware and unconcerned about their child's thoughts, feelings and activities until a crisis point is reached. Parents may prioritise their own needs above the needs of their child and are not vigilant to the needs of the child. Hersov (1960, cited by Kearney and Silverman, 1995) describes the passive and withdrawn fathers who seem unaware and separate from the family unit. Weiss and Cain (1964) analysed the family dynamics in 16 cases of school refusal and identified the 'withdrawn mother' who seemed overwhelmed by their child's needs.
- 4. The isolated family:** This family is insular and isolated. There is little contact with others outside of the home. Kearney and Silverman (1995) concede that it difficult to gain accurate statistics on the frequency of this type of family as they tend to not seek out professional support. They theorize that of the families that enquire about initial professional support but who do not accept follow up consultations, a significant percentage may include this type of family.
- 5. The healthy family:** This is characterised as a family which is 'relationship orientated' and has higher than normal levels of cohesion and low levels of conflict. Bernstein, Svingen & Garfinkel (1990) found that many families of school refusers do not present with any impairment in their levels of family functioning.

Kearney and Silverman acknowledge that not all families fall into one of these five categories and that school refusal is found across all types of families. While they have explored the research extensively, their research has been criticised for its lack of robust evidence and its reliance on research that includes anecdotal evidence (Pellegrini, 2007). Much of the research cited in their work dates back to the 1960's where roles within the family may have been

representative of the culture at the time. For example, mothers were seen as the key person to link with schools and many fathers may have had very limited involvement due to social expectations, rather than being withdrawn.

#### **2.4 Conclusion of the literature review**

This literature review has explored two key areas to help increase our understanding of how parents make sense of the situation of having a child who presents with EBSNA and how they experience their involvement with various professional agencies. The research shows that parents are deeply affected by their child's issue of EBSNA, which highlights the challenges they experience with schools and education professionals but also the relief of being supported by specialists. (Lee and Davies 2006; Sibeoni et al. 2018; Bussard et al 2015).

The impact on how parents view themselves and their confidence in their parental ability is impacted when a child presents with EBSNA (Carless et al 2015).

The research suggests that there may be generational/ familial patterns of anxiety and a history of familial dysfunction which is associated with an increase in the likelihood of a child presenting with EBSNA (Bahali et al, 2011; Bernstein and Borchot, 1996). However, there is evidence to suggest that parents are supportive of education and want their child to have academic success and believe it to be of great importance to their success into the future. (Davies and Lee, 2006).

These studies identify the impact and influence of the family and also on the parents of children who present with EBSNA. This supports the rationale that exploring the experience of parents is critical to furthering our understanding of this subject.

### **3. Methodology**

#### **3.1 Chapter overview**

This chapter will describe the design of this research, the methodological principles and my rationale for the choice of epistemological stance and ontological position. The process of how participants were recruited and how data was gathered and analysed will be described in detail. Ethical issues and matters of reliability and validity will be explored.

#### **3.2 Research Aims**

There is a dearth of academic literature which has explored the experiences of parents who have a child who presents with EBSNA. This research will be an exploratory and emancipatory study which aims to give a voice to a group who have been under researched and to shine a light onto a hidden area to reveal the lived experience and the impact of EBSNA on the family. This knowledge of the lived experience is vital to expanding our professional knowledge and awareness, leading to improved outcomes in our professional practice.

As noted in the previous chapter, the responsibility of school attendance is held with the parents or legal guardian. It is hoped that by increasing our knowledge and understanding of the experience of parents that local authority and school professionals who are involved with these cases thus leading to a greater collaboration between professional agencies and the family.

#### **3.3 Research Question**

This research has a single question at its centre; **‘What are the lived experiences of parents who have a child who presents with EBSNA?’**

The value of a single research question allows a sense of freedom and the space for exploration where the overarching question focusses on how parents make sense of their experience and the impact on their lives.

Prior to commencing a research project Carter and Little (2007) highlight the importance of researchers positioning themselves on an epistemological scale, as their world view will impact the type of research methodology chosen. A quantitative or a mixed methods methodology was rejected in favour of a qualitative approach as this research does not seek to test a hypothesis or seek a universal truth, instead it will focus exploring the lived experience. The analysis process will be led by the findings which are revealed from the data and not driven by existing theory and literature. The value of learning about the lived experience is critical to the development of our professional practice as educational psychologists and helps us to understand the impact of our work with families.

### **3.4 Ontology and Epistemology**

Ontology is a philosophical approach which considers how we view the world and our existence (Crotty, 1998). In other words, ‘what is reality?’ This leads us to move beyond the question of ‘what is’ and into ‘how do we know, what is?’. This is the concept of epistemology, which is concerned with the theory of knowledge and attempts to answer the question of ‘how and what do we know?’ (Willig, 2013).

Willig (2013) suggests that researchers should first ask the question “what is there to know?” and “what is the nature of reality?” and should clarify their epistemological stance prior to starting the research.

Madill, Jordan and Shirley (2000) suggest that it is helpful to view epistemological positions on a continuum rather than as separate positions. On one side is the realist perspective which believes that knowledge exists as an objective truth, the researcher’s role is to discover this truth through an objective and detached approach. The other end of the continuum is the radical constructionist perspective, which argues that knowledge is a social construct which cannot exist outside the realm of language, which means that all experiences are subjective. My

position lies somewhere in the middle of this polarity scale, but closer to the radical constructionist perspective and will take a Relativist position. Relativism asserts that there is no absolute truth as we view the world through our own subjective lens, which is affected by our personal, historical and cultural context which is subject to change over time. (Schwant, 2003). This subjectivity allows for the creation of multiple perspectives of how we view the world. (Gadamer, 1975).

My position in this research recognises that despite my participants sharing a similar experience of having a child who presents with EBSNA, their lived experiences may all be very different. I hope to gain an understanding of how individual participants perceive and interpret this phenomenon and how they make sense of it in their world.

It will be important to recognise that the participants will each have their own history and social and cultural context which is unique to them in their story. In this way, Relativism and Constructivist perspectives cross over in a similar way.

### **3.5 Interpretative Phenomenological Analysis (IPA)**

This study will adopt a constructivist epistemological stance. This position asserts that we are active creators of own knowledge. Through our own experience and reflection, we begin to make sense of the world, therefore knowledge is unable to be generalised, predicted or controlled (Robson, 2002). Our own subjective interpretations determine how we make sense of the world around us.

The qualitative approach of Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009) is an appropriate tool for analysing this research, which is concerned with the concept of 'experience'. It is concerned with personal experience but also involves interpretation, involving a consideration of context.

IPA emerged as a research methodology as a reaction to the frustrations regarding the over-emphasis placed on the importance of quantitative approaches in research (Smith, 1996).

Smith (1996) believed that to develop a deeper psychological understanding, there needed to be a paradigm shift within the field of research, which explored the nature of an experience in greater detail.

Smith et al., (2009) identify that IPA focuses on in-depth exploration of personal experience and how people understand, perceive and give meaning to the world around themselves. They suggest that people are always actively engaged in the world and are constantly reflecting on their experiences in order to understand them (Smith et al., 2009).

While the IPA approach originally was popular within the field of health psychology, it's in-depth approach to exploring the lived experience is gaining momentum in other psychological fields.

The phenomenological aspect of IPA explores how people make sense of their world and their experience, without attempting to reduce it to *'predefined or overly abstract categories'* (Smith et al., 2009, pg 1).

The Interpretative aspect considers what is known as double hermeneutic in which the researcher is trying to make sense of the participant trying to make sense of their experiences (Smith & Osborn, 2008; Smith et al., 2009).

The aim of this research is to help reveal the emotional experience of having a child who presents with EBSNA and to identify the details of the experience held by the participant group. IPA is concerned with the detail in its depth of analysis of individual cases and does not assume to make sweeping generalisations, as it recognises the importance of context, but it hoped that knowledge of the shared experience is revealed (Smith & Osborn, 2008).

Hermeneutic or interpretive epistemology assumes human action and behaviour is understood and interpreted within the context of societal and cultural norms, therefore research will be filtered through our own subjective views when we attempt to interpret the experiences of people in specific contexts (Cohen, Manion and Morrison, 2003).

### **3.5.1 The Philosophy of Phenomenology**

Phenomenology can be defined as the philosophical perspective of exploring the human experience and how things are perceived through our mind and consciousness. (Landridge, 2007).

Key figures of this approach include Husserl and Heidegger among others. Husserl is described as being the founder of phenomenology, which is defined as the philosophical study of the human experience. (Landridge, 2007). The focus of phenomenology is on the ‘lived experience’ and “*the way in which things are perceived as they appear to consciousness*” (Landridge, 2007, p.10).

Husserl (1927, cited by Smith et al., 2009) asserted that ‘intentionality’ was a key factor in the concept of consciousness. He asserted that our consciousness is always reacting and responding to an object in our world, therefore the relationship with the ‘object’ was critical as it is impossible to not relate objects in the lived world, we inevitably will perceive and interact with said object (Giorgi, 1997). The idea of intentionality helps us to understand that the experience of consciousness, is in relation and response to our consciousness of ‘something’, this may be something that is seen, remembered, judged but where our awareness has been stimulated (Smith et al., 2009). In Husserl’s words “we must go back to the things themselves” (cited by Smith et al., 2009), in this way we go back to the experience and attempt to make sense of it, with a deeper meaning, without our preconceptions and presuppositions. This is also known as

“epoche”, which is translated as the ‘suspension of judgement’ in Greek philosophy or “phenomenological reduction” (Giorgi, 1997). Husserl felt it was possible to isolate the ‘essence’ of a phenomenon in order to explore its essential features which were able to transcend context and provide a universal meaning (Larkin, Eatough and Osborn 2011).

Heidegger (1962) criticised Husserl’s approach and led it to a more existential phenomenological approach. He argued that our interaction with the world around was intentional however, he did not believe that people cannot be separated from their social context which includes language and culture. (Smith et al., 2009). Heidegger (1962) developed the term ‘dasein’ which describes our ‘being-in-the-world is always in relation to other people, as a result it is not possible for us to achieve ‘epoche’ and suspend our judgements and assumptions. (Landridge, 2007). However, we can try to achieve it through reflective and reflexive awareness (Smith et al., 2009).

Sartre (1956/1943, cited by Smith et al., 2009) shared Heidegger’s belief that we are embedded and immersed in the world and seek to make sense of the experience. However, Sartre identifies the concept of ‘nothingness’. This is in contrast to Husserl’s notion of ‘going back to the thing’ and highlights that the things which are absent are as important as what is present, when we are defining who we are in the world (Smith et al., 2009).

This chapter explores how phenomenology can help us gain an insight into understanding the human experience. Unlike Husserl, I will not be trying to distil my research to a point where a universal ‘essence’ is defined, however it will be important to condense my data into themes in accordance with the process of IPA. I do agree with Heidegger that it is not entirely possible to fully extract our preconceived notions and assumptions, however it does highlight the importance of maintaining good reflective and reflexive thinking when approaching research.

### 3.5.2 Hermeneutics

Hermeneutics essentially means the theory of interpretation and has its origins in the interpretation of biblical texts and raises questions about the intentions and meanings of the author when exploring texts. (Landridge, 2007). IPA engages in a double hermeneutic “*whereby the researcher is trying to make sense of the participant trying to make sense of what is happening to them*” (Smith, 2011, p. 10).

Smith (2011) acknowledges that this is the most complex part of the IPA process and it requires the researcher to be highly involved in the interpretation process.

This section will explore the work of hermeneutic theorists including, Heidegger, Gadamer and Schleirmacher, in relation to psychological research.

Heidegger (1927/62, cited by Smith et al., 2009) connects the worlds of phenomenology and hermeneutics through his concept of ‘dasein’, where he suggests that we experience the world through our own context and will bring our prior experience knowledge when making meaning, resulting in the inevitable process of interpretation, which is founded upon ‘fore conception’. (Smith et al., 2009). In this way, we can acknowledge that there is an inevitable subjective aspect in the interpretative process of IPA.

Gadamer (1960/75, cited by Smith et al., 2009) states that “*the important thing is to be aware of one’s own bias, so that the text may present itself in all its newness and thus be able to assert its own truth against one’s own fore-meanings*” (p. 238). This quote raises the issue of internal bias but also facilitates conscious awareness to be able to recognise the bias, which in turn creates the space which allows new knowledge to emerge. The importance of good reflective and reflexive thinking is highlighted through this quote and highlights the need to bracket off our preconceived notions to prevent claims being imposed upon the data. Gadamer (1960/75) argued that the primary aim of interpretation is to understand the content of the text rather than

the author and he argues that the interpreter does not have greater authority over the text than the author.

Schleirmacher (1998, cited by Smith et al., 2009) offers a different perspective and proposes that interpreting text involves two distinct levels; grammatical (objective textual meaning) and psychological (subjective individuality of the author). He boldly suggests that through interpretation we can gain an understanding of the author better than they understand themselves (Smith et al., 2009). Smith et al., (2009) puts this in context by arguing that it is critically important to analyse the claims made participants, by looking beyond what is said explicitly. This process is expanded by looking across cases and with regard to psychological theory.

To help the researcher understand and make sense of what the participant claims, Smith et al., (2009) highlight the importance of ‘standing in their shoes’ and ‘standing alongside’ the participant. There is a move beyond empathy and a shift into the process of ‘hermeneutic questioning’. The concept of the hermeneutic circle is critical to the process of IPA and shows the importance of the relationship between the part and the whole (Smith, 2007). Smith et al., (2009) explain this as a recognition that the meaning of a part can only be fully understood in relation to the whole.

The process of interpretation in IPA is circular and requires a repeated process of engagement with the text, contrasting single words, to sentences, to complete transcripts. The interactive nature is also present in the emphasis IPA places on the process of meaning making in both the participant and the researcher, i.e. the double hermeneutic position and trying to make sense of how others interpret their experience through our own interpretation.

### **3.5.3 Idiography**

IPA is distinguishable from other research methodologies in that it does not seek to create overarching, universal claims that can be applied to human behaviour. The priority is given to understanding the experiential phenomena of a particular group within a particular context. This approach prevents the loss of personal perspectives and experiences which can occur when data is condensed to make group level claims. (Smith et al., 2009).

Smith et al., (2009) highlight that IPA can in fact make a valuable contribution by focusing on single cases, however, most researchers tend to achieve the idiographic element by focusing on the detailed examination of each individual case before moving on to search for convergence and divergence across participant accounts (Smith, 2011).

### **3.5.4 Rationale for choosing IPA**

My research question is concerned with the notion of 'experience' and seeks to explore how participants make sense of their world. It does not seek to measure quantifiable phenomena, create a unifying theory or test hypotheses but aims to increase our knowledge of the individual lived experience. My values as a researcher are grounded in the notion that we view the world through our own lens in the context of our knowledge and experience. It was important that my chosen method of research and analysis allowed me to explore the subject with depth and with an understanding of the emotional and lived experience.

IPA serves as an appropriate method of analysis as its primary function is exploratory rather than explanatory (Smith et al. 2009). IPA recognises the idiopathic nature of its approach and takes an in-depth look at the phenomena to understand how participants interpret, conceptualise and make sense of their experience. (Larkin, Watts & Clifton, 2006). The inductive approach in the analysis of data allows the researcher to gain an insight into the experience by using an

open -minded, curious, empathic and flexible approach when listening to the stories of the participants. Which helps us to understand how experiences and behaviours are shaped by the individuals social, emotional, and historical world. (Finlay, 2011). The IPA approach is helpful in exploring less explored and less understood topics such as EBSNA, which benefit from a more detailed and in-depth approach, which can help bring new information to the forefront (Creswell, 2013). Stake (1994) reminds us that unique experiences of the participants, exist in wider group which suggests a level of transferability is possible as a result it will be vital that I ensure that the data I collect is as comprehensive and detailed.

### **3.6 Choosing the most appropriate methodology**

At the start of the research process I considered a number of different qualitative approaches, including; Psycho-social (using the Free Association Narrative Interview technique (FANI)), Discourse Analysis, Thematic Analysis and Narrative Analysis.

#### **3.6.1 Psycho-social – Free Association Narrative Interview**

Holloway and Jefferson's (2000) approach to psycho-social research is characterised by the use of the Free Association Narrative Interview (FANI). This interview technique is based upon the psycho-analytical principles and aims to explore unconscious intra-psychic phenomena in relation to social circumstances of a person's life. (Gadd and Jefferson, 2007). The FANI follows "*emotional rather than cognitive logic and priority is given to meaning inherent in the links and not just within the statement*" (p. 140, Holloway and Jefferson, 2013). This approach recognises the unconscious processes occurring within the relationship between the researcher and the participant and acknowledges subjectivity. However, this approach has been criticised for allowing the researcher too much power in their subjective interpretation of the interview data. Frosh and Baraitser (2008) disliked '*the loose and sometimes pious way in which psychoanalysis has been theorized within psychosocial studies*' (p.346). They also disapprove

of ‘*an interpretive practice that seems always to know best, or at least to know subjects better than they know themselves*’ (p.347). My decision to not use this method was due to my desire to ensure that the voices of my participants would be expressed without such a high level of subjective interpretation.

### **3.6.2 Discourse Analysis**

Discourse Analysis (DA) is defined as being concerned with language use beyond the boundaries of a sentence and is concerned with the interrelationships between language and society. (Stubbs, 1983). In this way, DA shares some similarities with the IPA, where meaning is explored beyond the words. However, DA takes a more sceptical approach to the process of eliciting cognitions (i.e., thoughts, reasonings and understandings) and meaning and is more focussed on how language is used to construct our social reality.

IPA differs from DA in that it acknowledges that cognitions may not be visible directly from the interview transcript and uses a deeper analytical approach which allows is to make sense and explore the meaning behind the words. (Smith, Flowers & Osborn, 1997).

This research is primarily concerned about the lived experiences of parents and while it is recognised that societal discourses influence our understanding of school attendance, it felt more important to use a qualitative approach that explored the individual experience.

### **3.6.3 Thematic Analysis**

Thematic analysis (TA) is a method for identifying, analysing, and reporting patterns (themes) within data. (Braun and Clarke, 2006). It is a useful methodological approach which allows for the examination of different perspectives, highlighting similarities and differences and new insights.

TA can be used to summarise key features within a large amount of data and insists on the researcher implementing a well-structured approach to organising data, which can lead to clear and organised research findings. (King, 2004).

One of the main criticisms of TA is its lack of an epistemological position, which is particularly noticeable when it is compared with other qualitative research methods, such as Grounded Theory and IPA. Simple TA cannot make claims about the meaning behind the use of language (Braun and Clarke, 2006), but more complex TA maybe able to do so.

While thematic analysis is flexible, it has been suggested that this flexibility can lead to inconsistency and a lack of coherence when developing themes derived from the research data (Holloway & Todres, 2003).

While this approach would have yielded helpful themes within my participant group, my preferences for IPA over TA was on the grounds that TA would not have allowed a deeper meaningful exploration of the data.

#### **3.6.4 Narrative Analysis**

Narrative Analysis (NA) is defined as a dynamic approach to understanding how we identify ourselves and make sense in a world that is constantly changing. (Murray, 2003). It considers how people position themselves in the context of the social world. This approach was considered in this research as there is a temporal factor in how my participants share their story and how it has shaped their understanding of the world and their identity. McAdams (1985) discusses the value of this process,

*An individual's story has the power to tie together past, present and future in his or her life. It is a story that he is able to provide unity and purpose individual identities may be classified in the manner of stories. (p.19)*

NA is also a social constructionist approach concerned with meaning-making, however, NA is only one way of meaning-making and so it was felt that IPA could include consideration of narrative in the sense-making of participants, without being constrained by this focus (Smith et al., 2009).

### **3.6.5 Limitations of IPA**

While IPA has many advantages and is the chosen methodological approach for this research, it is not without its criticisms.

It has been suggested that IPA has the potential to be too ambiguous and has a lack of standardisation. It also can produce results which are too descriptive and lack interpretative depth. (Giorgi, 2010). IPA does not attempt to explain why people experience certain phenomena in certain ways. Instead, it is concerned with describing, exploring and understanding individual perceptions. Willig (2013) argues that this is a potential drawback as the lack of explanation could in fact restrict our understanding of phenomena. She also argues that the importance of language is not recognised in comparison to other methodologies, however Smith et al., (2009), rebuff those claims arguing that the process of meaning making always takes place within the context of the narratives and the discourse, which is intertwined with language. Eatough and Smith (2006) also argue that there are limitations to language as it is an imperfect way of representing the individuals experience.

Another criticism levied at IPA is that the phenomenological component is always subjective, and the interpretative nature of analysis means that the researcher's world view and autobiography will influence the research findings. (Brocki & Wearden, 2006).

While Smith et al., (2009) consider this to be an inevitability to a certain degree, they argue that good personal reflectivity, self-awareness and self-analysis is critical to ensuring that the voice of the participant will be heard.

Giorgi (2010) suggests that IPA is suited to eloquent and articulate participants, which means less eloquent participants will be excluded from the research, creating a form of elitism. However, this criticism could also be true of other methodologies which rely on a narrative approach.

IPA does not seek to find overarching answers to questions what seek to explore the ‘how, what and why’, to produce societal findings that can be confidently generalised across a wide population, as the focus is on understanding the lived experience of participants. Smith et al., (2009) defend IPA as always using hermeneutic, idiographic and contextual analysis to understand how social and cultural can affect the experience of the individual.

### **3.7 Participants**

IPA requires a fairly homogenous sample as it is important that the sample represent ‘*a perspective, rather than a population*’ (Smith et al., 2009). This research topic is quite specific; therefore, the method of sampling was purposeful, in order to have a participant group who share a similar experience. In line with guidance from Smith et al., (2009) who suggest a participant group of between 4-10 for doctoral level research, my research involved five participants. This smaller sample size is more appropriate for IPA research as it allows for the in-depth analysis of the individual’s experience. I did not have any previous professional involvement with any of the participants in my capacity as a Trainee Educational Psychologist (TEP).

Participants were all parents of young people aged between 13-15 years old who have presented with EBSNA and who are no longer attending a mainstream secondary and who attend the same Alternative Education Provision (AEP) within the Local Authority (LA). They were selected by the senior staff team as being participants who met the inclusion and exclusion criteria, which is as follows;

### Inclusion criteria

1. The parents must have a child who is recognised as having emotional based school non-attendance by themselves as parents and the Education Welfare Service.
2. Parents must have a child whose school non-attendance and anxiety has resulted in them being unable to attend a mainstream school for a minimum period of 3 months and who are attending an alternative educational provision.
3. Parents must have a child who is currently attending or who has previously attended the out of school provision in the last 3 years.
4. Parents must be able to speak a good level of spoken English.

### The exclusion criteria

1. Parents of children/young people who have low attendance caused by a specific medical or health issue and who do not present with anxiety will not be chosen as participants.
2. Children or young people who are still attending a mainstream school will not be able to participate in the research.
3. Parents of children/young people who have low attendance due to truancy will be unable to participate.
4. Parents of children/young people who are receiving psychiatric care will not be included.
5. Parents who are receiving psychiatric care will not be included.

The process of inviting participants to take part in the research followed the following steps;

1. Senior staff members at the AEP were sent an information sheet and consent sheet regarding my research to ensure they understood the purpose of the research. Staff

members contacted potential participants over the phone or in person and explained the nature of the research and asked for permission to share their contact details with me, if they were interested in participating.

2. When verbal consent to share contact details was given, I contacted participants over the telephone to introduce myself and the research and provided an opportunity for potential participants to ask any questions. An interview was arranged for a time that suited my participants and I emailed information sheets and consent sheets directly to them.

My participants included 3 mothers and two fathers, to ensure confidentiality and to protect their identity, pseudo names have been given and personal details about their context have been avoided unless deemed relevant to the research. One mother and father in the group are a married couple, who I interviewed separately. The rationale for separate interviews is based upon the importance of hearing the unique experience of each participant. While this couple have lived through the same events and share children, their experience and how they make sense of their experience may be very different.

A total of 5 parents of 4 children who present with EBSNA were interviewed and no distinctions were made between whether their child was male or female.

Participants are identified as; Andy, Dee, Kerri. Amanda and Martin: who are a married couple.

The participants all shared the following traits;

- All were married to a partner of the opposite sex and lived in the family home with their spouse and children.
- All had two children.
- All were working parents or had worked until recently.

- There has been CAMHS involvement in each of the families in form of the following:
  - Autism assessment
  - Family therapy
  - Cognitive Behaviour Therapy delivered by a specialist CAMHS teacher.
  - There has been historic involvement of psychiatric care for Amanda and Martin's older son, however he has now left school. They have another son, who presents with EBSNA and who currently attends the AEP.

There were two parents who agreed to have their contact details shared and who expressed an interest in being part of the research. However, attempts to arrange a time for the interview were unsuccessful or when a time was arranged the participant cancelled at short notice. A message was sent to these participants to remind them that their involvement was entirely voluntary and to contact me if they would like to reschedule another time. This approach helped to reduce the possibility that potential participants may have felt pressurised to agree to be interviewed and gave them freedom to not participate without having to name their desire explicitly. This may suggest that these particular participants may have felt less confident and felt more anxious than the parents that did participate in the research.

### **3.8 Data Collection**

As the aim of the research was to explore the lived experience of my participants, the use of semi-structured interviews as directed by Smith et al., (2009) was the chosen method of collecting data. They identify the importance of having good data to analyse, which is dependent on a good interview process. The benefits of using a semi-structured interview format meant that while I could change the direction in terms of the information I hope to gather, there was flexibility and scope to explore the issues in more detail. Doing the interviews

in a face to face setting as opposed to a telephone interview, allowed for the observation of body language and non-verbal communication which may be relevant. The use of open ended questions, prompts and probes assisted in allowing the participants to expand on their thoughts and feelings. (Robson, 2002).

The use of very loose interview schedule supported the flow of dialogue and helped to maintain a rhythm. (Smith and Osborn, 2008).

It is essential that participants feel empathy from the researcher and there is a level of trust within this partnership. Smith et al., (2009) urge researchers to consider intricate and inherent power dynamics that may exist and to create balance. It is important that participants recognise that they are the expert in their own story and feel confident and reassured that they should use the interview space to express themselves and feel free from judgement.

I took care to help the participants feel relaxed by spending 5-10 minutes before each interview to talk informally and to express my thanks for their participants. I utilised my experience of my former role as a Parent Support Advisor, to help build rapport quickly and to help the participants to feel more comfortable.

### **3.8.1 Interview Procedure**

All participants were offered a choice of locations to conduct the interviews as it was important to choose a space where they would feel comfortable. Four of the interviews took place at the Alternative Education Provision (AEP) and one at the Local Authority (LA) public office. While some parents spoke about conducting the interviews at home, they were reluctant to be interviewed while their child was at home and they felt it would hinder their capacity to talk openly.

Prior to turning on the audio recorders, which included a mobile phone and electronic dictaphone, I read through the information sheet and consent sheet with each participant prior

to signing it and reminded them of their right to withdraw from the research at any time. (See Appendix C &D).

Each interview lasted between 60-90 minutes and included open ended questions which aimed to be expansive and open new lines of expression.

As directed by Smith et al., (2009) my verbal input was kept to a minimum and encouraged the interview to have a steady rhythm, where I ensured that space was given to the participants to consider what they wanted to talk about but where I also included prompts to help expand their thinking and to help prevent awkward, long silences which have the potential to shut down the interview process and make it feel very uncomfortable.

I encouraged a temporal sequencing approach (Smith et al, 2009) by asking participants to start to tell me about their child from infancy, which encouraged the flow of information which was free from the pressure of trying to analyse and explain. At times, I paraphrased what my participants had said to help me clarify the meaning of what they had shared. It also helped my participants to feel actively listened to which was important to encourage them to feel able to express themselves. I used various probes and prompts where it felt appropriate to help facilitate the interview process.

Smith et al., (2009) suggest particular types of questioning to facilitate the expression of more in-depth information. These include;

Descriptive: This involved encouraging the participants to explain details and content of their experience to help me understand what it looks like. E.g *“Can you say some more about how your child behaved? What did it look like?”*.

Narrative: This approach helped to build a story of the participants experience and the events that had occurred until this point. E.g. *“Can you tell me about how the problems began?”*

Structural: This helped me to understand the different stages that had occurred within the family and how they were connected. E.g. *“Who did you speak to first when the situation started?”*

Contrast: Participants were encouraged to think about the differences in their experience, both the positive and negative. E.g. *“How different is your child on a good day compared to a bad day?”*

Evaluative: I would ask participants how a situation made them feel to encourage the use of emotional labels. E.g. *“How do you feel when you cannot get your child to school?”*

Prompts: I would ask participants *“can you say a bit more about that?”* to encourage them to describe their experience in more detail.

Probes: To help participants explain further when they used particular phrasing and, in an attempt, to ‘expose the obvious’ (Smith et al., 2009), I would ask participants what they meant. *“What do you mean by unfair?”*

Debrief: At the end of each interview, participants were given the space to debrief off record. This time was to help talk about the process of being interviewed and how they found the experience.

### **3.9 Data Analysis**

The process of analysing the data from the interviews was a complex procedure, which involved moving from a descriptive level to an interpretative one (Smith et al., 2009). Smith et al., (2009) recognise the process of analysing data is not linear and the experience can be *‘collaborative, personal, intuitive, difficult, creative, intense and conceptually demanding’*. (p80).

I spent a great deal of time ‘immersing’ myself in the data, paying close attention to the internal responses that were elicited and noting them in a reflective journal. In accordance with the structured stages of analysis from Smith et al., (2009), the data was analysed through the six stages of IPA.

**Stage 1: Reading and re-reading:** The starting point at this stage is to ‘stand in the shoes’ of the participants and to immerse oneself into their world. The transcript was read whilst I listened to the recording at the same time. This allowed me to listen carefully to the participants voice, their change in speech, pauses, emphases and tone. This is key information that may not be clearly captured by the written transcript.

Any emotional responses or thoughts that came up during the process were written down in the reflective diary in an attempt to ‘bracket off’ those impulses and to maintain focus on the transcript.

**Stage 2: Initial noting:** This stage is recognised as being the most detailed and time consuming of the stages (Smith et al., 2009). To develop a deeper understanding and to identify key concepts, I made detailed exploratory comments in a section alongside the transcript. The exploratory comments can be divided into three areas;

- Descriptive comments- This involves describing the objects of concern to help understand the what the participant is communicating.
- Linguistic comments- This involves paying close attention to the specific use of language.
- Conceptual comments- asking questions of the data and moving towards a more conceptual understanding of what it means to have these concerns in this context.

Smith et al., (2009) highlight the importance of engaging in the analytical dialogue in the transcript to ask questions about what the participant means.

### **Stage 3: Developing emergent themes**

This is the stage that Smith et al., (2009) suggests that a shift occurs from being a participant to being a researcher. The importance of the interpretative analysis is now critical as exploratory comments are transformed into emergent themes, which capture and reflect the experiences described by the participants. (See Appendix F).

**Stage 4: Searching for connections across emergent themes:** Emergent themes are brought together by identifying common features, which creates a number of subordinate themes using the following concepts:

- Abstraction: where similar emergent themes brought together.
- Subsumption: where emergent themes are transformed into subordinate themes.
- Numeration: which considers the amount of times an emergent theme is repeated.
- Function: This relates the function of the emergent themes.

The subjects that are connected and have key words/statements that repeat can brought together as an emergent theme. These emergent themes were clustered into subordinate themes and distilled further into superordinate themes. For example, the emergent theme of a parent describing how their child's complex needs dominated their lives, was shared with another emergent theme which described their desire of wanting to escape, this clustering of emergent themes, leads to the creation of a subordinate theme of 'being trapped'.

### **Stage 5: Moving to the next case**

The process of analysis was repeated for the remaining transcripts.

## Stage 6: Looking for patterns across cases

This stage involved searching for connections *across* cases and the subordinate themes were drawn together further, and this resulted in the creation of Superordinate themes for the group. Subordinate themes that were not recurrent in at least half of the transcripts were discarded. Relational connections between the subordinate themes helped to bring together areas of experience which demonstrated convergence and divergence of the same theme under the umbrella of a Superordinate theme. (See Appendix G).



**Figure 2: This shows how emergent themes are clustered together into Subordinate themes, leading to Superordinate themes.**

### 3.10 Reliability and validity

It is well established that a key tenet of evaluating research is its capacity to be reliable and valid. However, the criteria of reliability and validity is more complicated when dealing with

qualitative research methods, as Willig (2013) suggests, the usual criteria for reliability and validity is more applicable to positivist or realist epistemological positions. As a result, qualitative researchers assess the value of their research through credibility, quality and trustworthiness (Golafshani, 2003).

Yardley (2000) suggest several ways in which the qualitative researcher can increase the validity of their work.

1. **Sensitivity to context:** There should be evidence that the researcher has immersed themselves in the subject and has explored the subject in depth. I ensured that I was aware of the wider context of EBSNA and was familiar with the literature over a long period, through conducting a systematic literature review on the subject. I also spent a great deal of time exploring the theoretical foundations of IPA.
2. **Commitment and rigour:** By demonstrating a rigorous selection process for participants and by carefully following the steps of IPA, validity can be increased. The inclusion and exclusion criteria for participants ensured a homogenous participant group and care was taken during the interview process and data analysis which ensured that each of the steps were followed exactly as described by Smith et al., (2009). Smith (2011) argues that the analysis undertaken should be thorough and interpretative, identifying the prevalence of each theme and showing extracts from a range of participants. I have attempted to achieve this throughout the analysis and write up stages.
3. **Coherence and transparency:** Coherence ensures that readers of the research can clearly see the relationship between the research question and the methodology selected. By having a solid theoretical understanding of IPA and of my epistemological position, I have been able to provide a consistent approach to the research which clearly

demonstrates the methodological and epistemological relationship. Transparency demands that the procedures used in regard to collecting data and how data was analysed is clear for all to see. I have also included transcript extracts in the results section to help the reader to reflect on my interpretations and consider possible alternatives. This is important as it allows the reader to reflect on their own interpretations and possible alternatives.

### **3.11 Testimonial Validity**

It is argued that the trustworthiness of a research project can be increased through credibility checks or audits (Smith et al., 2009) to help support good reflective and reflexive thinking. I considered sharing my findings with the participants after the analysis to ‘check back’ and ensure that my results finding were validated by the participants. Upon much consideration, I decided to not use this approach as I felt that the inevitable subjective, interpretative nature of IPA, means that two people may not always agree with the same themes (Smith et al., 2009). There was the potential that themes which may have seemed significant to me, may have been rejected and this would have forced me to exclude potentially important findings. Instead initial findings were discussed in supervision and peer supervision.

### **3.12 Reflexivity**

Reflexivity refers to the awareness of the researcher’s role in the practice of research, process and outcomes of research. Weick (2002) reflects on how we can “see ourselves in the data”. Researchers ‘*need to go further than questioning the truth claims of others, to question how we as researchers (and practitioners) also make truth claims and construct meaning*’ (Cunliffe, 2003, p. 985).

Haynes (2012) suggests that researcher reflect on the following questions.

- What is the motivation for undertaking this research?
- What underlying assumptions I am bringing to it?
- How am I connected to the research, theoretically, experientially, emotionally?
- What effect will this have on my approach?

My interest into this research area was led by having a younger sibling who experienced school anxiety and was a school refuser. This creates the potential for researcher bias both consciously and unconsciously. My personal relationship with subject of EBSNA has been laid out from the start of this research and I have taken steps to ensure that I maintain high levels of reflexivity and reflectivity.

Haynes (2012) makes the following suggestions to help facilitate the process, which I have related to my research.

- *Keep a research diary noting down thoughts and feelings about the research process.*
- *Keep fieldwork notes of observations, interactions, incidents, conversations, emotions and responses.*
- *Listen to tape recordings, or watch video clips, of your qualitative data gathering noting how your presence or interaction as the researcher affected the process.*

I kept a reflective journal throughout the research process, which was critical in maintaining my conscious awareness and to prevent unconscious biases from infiltrating the research. This process was integral and as a result I have decided to embed extracts from my reflective journal throughout this thesis, (including at the end of this chapter) as opposed to including a section

in the appendices. This is hoped to help reassure the reader, that I have insisted on high levels of self-awareness and self-analysis to produce a valid piece of research.

### **3.13 Ethical Considerations**

Prior to contacting participants, I received ethical clearance from the Tavistock Centre Trust Research Ethics Committee (TREC) (See Appendix C). My initial application for ethical approval was rejected on the grounds that term “Emotionally Based School Refusal (EBSR)” seemed too judgemental and there were questions from the committee about who defines the behaviour and characteristics of the child or young person and diagnoses EBSR. However, this was clarified as there is no diagnosable condition known as EBSR in the DSM-V, but the involvement of other professionals from Education Welfare and the AEP with these families would ensure the suitability of the participants.

The ethical guidelines from the Health Care Professionals Council and the Code of Human Research Ethics from the British Psychological Society (2014) were also followed throughout this research. They highlight the importance of researchers needing to act with respect, competence, responsibility, honesty and integrity and operate in the best interests of those we work alongside (BPS Ethics, 2014; HCPC, 2008).

To prevent any ambiguity, it was explained clearly to participants that their involvement in the research project did not include support from the Educational Psychology Service (EPS). Their participation also did not include therapeutic support from the Tavistock and Portman NHS Foundation Trust.

### **3.13.1 Consent and Withdrawal**

Before giving their consent, all participants had the information and consent sheets read to them before they signed them. A reminder was given to participants that their involvement was entirely voluntary, and they were free to withdraw from the research at any time without penalty. In addition, they were told that any information that would be collected from their involvement would be removed from the research, unless the data had been enmeshed with wider research findings and cannot be extracted.

### **3.13.2 Confidentiality and Anonymity**

Participant information has been anonymised by using pseudonyms. Personal information that would identify participants will be removed to ensure their anonymity. Professionals involved with the participant and who are aware of the research were reminded that information remains confidential and that I would not discuss any information from the interviews with them. The only exception would be in the case of a child protection/safeguarding issue. Under these circumstances a referral would be made to the appropriate agency and support would have been sought from supervisors both on placement and at the Tavistock before taking any action. The parent would have been informed of any concerns prior to any referral taking place.

### **3.13.3 Participant safety and risk**

The welfare of the participants was a priority. The interview process had the potential to lead to discussions that raised difficult issues. A debriefing session was offered after every interview and when recording had ceased. The space was used to provide participants with the opportunity to reflect on their feelings and on the interview process.

### **3.13.4 Data Safety**

Information was stored on encrypted and pass word protected documents. Written and printed information was stored in a locked cabinet. Names were replaced with initials.

### **3.14 Impact and implications**

Educational psychologists are often the first line of support for schools and parents when school refusal is identified as affecting a child's absence. As such they are best placed to assist and inform early therapeutic interventions for both the family and the child. In my placement borough, severe school refusers tend to be referred to CAMHS by Education Welfare, which suggests that the problem has escalated to the point where concerns are acute. Early intervention led by Educational Psychology Service have the potential to prevent the problem from escalating.

Exploration of the parental experience of children support services is vital to developing effective interventions and practice. The applicability of this research has the potential to influence how practitioners extend their support to include parents. While it is common practice to administer forms to measure outcomes, they tend to measure superficial responses. It may be helpful to offer parents a space to provide more in-depth feedback on how supported they felt by EP involvement.

School refusal is recognised as being multi-factorial and complex and highlights a need for systemic intervention (Kearney and Albano, 2004). Educational psychologists are uniquely placed to work with the child, family and school to help implement change.

### 3.15 Conclusion

This chapter has clarified my position as a researcher and has explicitly stated the research aims, process and participant sample. Issues around the potential for bias, validity and reflexivity have been explored and discussed.

The following chapter will discuss the findings from my research.

#### Reflective Box- extract from my reflective journal

27/11/2017

There were times during the interview process where I experienced intense emotional responses to the stories parents shared about their experience. I would feel upset and frustrated on their behalf and wanted to respond in sharing their outrage on how they and their child had been treated. It felt important to maintain an empathic but neutral attitude during the interviews and to not collude with what parents were telling me. I also felt it was critical to maintain a conscious awareness of my internal drivers especially given my personal relationship with the phenomenon of having a sibling who presented with EBSNA as a child. I wondered about the effect of what Freud (1920) described as transference and countertransference, this is defined as the redirection of thoughts, feelings and impulses which can occur in therapeutic interaction. I reminded myself of my role as the researcher and was able to quieten down some of those impulses.

I interviewed two parents in one day, both of whom shared powerful and raw expressions of their experience. I noticed upon leaving the AEP that my back felt tense and painful and I wondered if I had inadvertently injured myself. During research supervision, I discussed the experience with my supervisor and we reflected on my feeling of carrying the 'weight' of these important stories and perhaps these parents were feeling the 'weight' of living with these emotionally heavy experiences, which I unconsciously taken on and somehow manifested physically.

## **4 Results**

### **4.1 Chapter Overview**

This chapter presents the results of the data analysis under the headings of four superordinate themes; 'It turns your life upside down', 'Power and the battle to heard', 'Loss and grief' and 'Retrospective clarity'.

Each of the superordinate and subordinate themes will be explored in turn and supported by extracts from the transcript. These will appear in the form of quotations to help present the phenomenological core and how my interpretations developed.

To help provide context, I will present each of the participants separately and provide a summary of their superordinate and subordinate themes. I have aimed to sample the quotes proportionally across participants so that individual voices can be heard, and individual experiences can be illuminated.

Extracts from at least half the participants who related to each subordinate theme will be included to support the claims made (Smith, 2011). Throughout the narrative, I have aimed to explore both depth and breadth, whilst also highlighting both shared and distinct experiences.

It is important to state that I did not interview any professionals associated with the participants and parental accounts are their own perspective and have been viewed as such, therefore it is important to recognise that the events may be described differently by the staff in schools and other educational professionals.

## 4.2 Summary of individual participant themes and context

This section summarises the context and themes from each participant interview, which helps to illustrate the different experiences.

Each participant transcript has been analysed using IPA, leading to the creation of subordinate and consequent superordinate themes. This is to ensure that the unique experience of each participant is captured within this chapter.

\*All the names of the participants, their spouses, their children and education professionals have been changed.

### 4.2.1 'Dee'

*Table 1: Dee's superordinate and subordinate themes.*

Superordinate theme	Subordinate theme
Retrospection: looking back for clues	The need for clarity
	Underlying issues
	'Putting concerns to the side'
Impact on the family	Managing her child's anxiety
	Keeping the peace
	Stress on whole family
	The need for respite-escape
The battle for support	'The school did not get it'
	Not being heard
	The fight for assessment
	Assumptions about parental capacity

Loss and grief	The loss of the child that used to be
	Loss of childhood
	Loss of confidence as a parent
Fear for the future	Lack of employment opportunities
	Reduced educational success

Dee’s son Matt began to suffer from severe anxiety just before he started high school, which resulted in him suffering from EBSNA. His anxiety issues are pervasive, and he has become increasingly withdrawn, however, he attends the AEP daily. Dee believes that Matt is on the autistic spectrum, however, he has never met the criteria for formal assessment from CAMHS. During the interview, Dee used words ‘heart-breaking’ frequently, this captures the intense feelings of loss and sadness she expressed at times.

#### 4.2.2 ‘Andy’

*Table 2: Andy’s superordinate and subordinate themes*

Superordinate theme	Subordinate theme
The need for clarity	Underlying causes: Autism
	Not knowing what was wrong
	Confusion of professionals
Battle with the school	Being blamed
	Feeling powerless
	Feeling unsupported
Impact on lives	Impact on relationships
	Loss of freedom- feeling trapped
	Loss of confidence as a parent
	Effect on work
	Stress and anxiety within the family

	Avoiding subjects to keep the peace
Fear for the future	Lack of relationships in the future: Will he ever have a girlfriend?
	Future employment: Will he have a job?
	Independence: Staying safe in the world

Andy’s son Adam had shown signs of anxiety for several years, but it escalated at the end of year 6, when he reported that he was being bullied. His anxiety increased further once he began high school and over the next three years, he missed a great deal of school. Andy describes his sense of being confused and lost in how to support his son, which created such high levels of stress that relationships with his family broke down. Adam was recently diagnosed with autism and this has provided much needed clarity for the family who are learning to understand him better and for Adam himself, who is starting to accept his condition and he attends the AEP daily.

#### 4.2.3 ‘Kerri’

*Table 3: Kerri’s superordinate to subordinate themes*

Superordinate theme	Subordinate theme
Contagious anxiety	Emotional wellbeing
	Trying to keep the peace
Battle with the school	Feeling persecuted
	Not being heard
	Feeling attacked
	Issue around power
Impact on lives	Impact on relationships
	Loss of freedom- feeling trapped
	Loss of confidence as a parent

	Loss of childhood-having friends
Retrospection and hindsight: What should have been done differently?	Not knowing what was wrong
	Looking back for clues missed
	The guilt of should I have done more?
Fear for the future	Will it always be like this?
	Recognising that she is growing up
	Reduced educational achievement

Kerri's daughter Emma started to present with depression and anxiety after a family bereavement which occurred as she was starting high school. Kerri expressed her experience by describing powerful metaphors which highlighted how overwhelmed she feels by the whole experience and her own recent diagnosis of depression. Emma does not always attend the AEP and receives outreach teaching support several times a week.

#### 4.2.4 'Amanda'

*Table 4: Amanda's superordinate and subordinate themes*

Superordinate theme	Subordinate theme
Issues around power	Parenting as a team
	Reclaiming parental authority
	Leading the professionals
	Educating yourself-increase understanding of child's issues.
The battle with the system	Being blamed
	Lost in the system
	The enemy in the authorities
	Failure in the system

Impact on lives	Loss of career
	Loss of freedom- feeling trapped
	The value of a support network
Emotional turmoil	Emotional wellbeing/depression
	Carrying the weight
	Impact of trauma
	Loss of confidence as a parent

Amanda has two sons who have both attended the AEP. Her older son who has now left formal education, has autism and mental health needs and she has been involved with accessing specialist services for her children for several years. Her younger son suffers from anxiety and depression which has resulted in EBSNA, he receives outreach teaching support as he finds it difficult to attend the AEP. Amanda is married to Martin (below) I interviewed this couple separately as it was important that the individual experience be explored. Amanda’s experience revealed she had focused all her time and energy into ensuring that her children had access to support. There was a persistent theme of battling with the ‘system’ and seeing it as ‘the enemy’.

#### 4.2.5 ‘Martin’

*Table 5: Martin’s superordinate and subordinate themes*

Superordinate theme	Subordinate theme
Issues around power	Parenting as team
	Professional privilege
	Not being heard
The enemy in the authorities	Accusations, judgments and betrayal
	Fighting a constant battle
	Abandoned by the system
	Leading the professionals

'Keeping the peace'	Feeling less skilled than partner
	'Trying to say the right thing'
	Pressure to be an expert
	Loss of confidence- parental self efficacy
Impact on family	Work as an escape-need for respite
	Constant pressure
	Pressure on marriage
	Managing relationships with children
Fear for the future	'Will it get worse?'
	Impact on relationships in the future

Martin's frustration with the system dominated his experience and the challenges of having two children with complex needs. Martin revealed his need to be vigilant and self-aware in his parenting capacity, which he felt was lower in comparison to his wife, to ensure that he maintained good relationships with his children. He and Amanda have supported each other as a team against a system Martin describes as 'the enemy'.

### **4.3 Summary of Superordinate and Subordinate themes**

The findings from the individual participant analysis were brought together to create superordinate and subordinate themes for the participant group.

Each superordinate theme has a number of related subordinate themes which are listed below.

Table 6: Superordinate Themes and Related Subordinate Themes

Superordinate Theme	Subordinate Theme
<b>'It turns your life upside down'</b>	Keeping the peace
	Impact on family relationships
	Feeling trapped
	Contagious anxiety
	Loss of career- impact on work
<b>Power and the battle to heard</b>	Loss of trust in professionals
	The importance of professional awareness
	Power imbalance
	Accusation and persecution
<b>Loss and Grief</b>	Loss of childhood
	Loss of confidence as a parent
	Fear for the future
<b>Retrospective Clarity</b>	Looking back for clues: 'I wish I knew back then'
	The need for clarity: 'Why my child?'

#### 4.4 'It turns your life upside down'.

This superordinate theme captures how the problem of having a child with EBNSA permeates and impacts every part of their family life. The problem does not remain within the child/young person and has far-reaching consequences. Table six shows how this experience was shared across all the participants

Table 7: Subordinate Themes Relating to Superordinate Theme 1

Subordinate theme	Dee	Andy	Martin	Kerri	Amanda
'Keeping the peace'	X	x	x	x	
'Feeling trapped'	X	x	x	x	x
'Contagious anxiety'	X	x	x	x	x
'Impact on family relationships'	X	x	x	x	x

#### 4.4.1 'Keeping the peace'

Four of the five participants highlighted how there was a constant pressure to manage the emotional needs of their vulnerable child. This resulted in parents often sacrificing their own feelings of hurt or frustration to help 'keep the peace', to prevent doing or saying something that might trigger a response from their child.

Kerri describes the challenge of trying to avoid conflict with her child:

*It never leaves you. Now, I've learnt now, I'm quiet. You know, if Emma starts shouting, I become quieter, to respond to anything feeds it, feeds the fire and I'm trying really hard. (Kerri, p.23 Line, 17-19)*

Kerri seems to describe an oppressive situation where she feels she must constantly try to maintain balance and try to detach herself from potential conflicts, which seem in danger of happening at any time. She uses the metaphor of fire to illustrate the potential things 'burning' out of control and the potential for destruction.

In the quote below, Kerri again describes how she feels unable to understand her daughter, which appears to leave her feeling inept despite her best effort to try and understand:

*Really difficult, because you know, I'd listen, but obviously, everything ... With listening, you interpret, and I interpreted everything incorrectly. Whatever, I thought she said, I got it wrong. (Kerri, p.9. Line 30-33).*

The notion of 'keeping the peace' is addressed by Martin who describes his anxiety of saying the wrong thing, which leaves him constantly analysing his actions and berating himself for not saying the 'right thing'. There is a sense of having to keep this frustration inside so that it is not revealed to his child:

*You always beat yourself up, "Could I have said that differently?" The other day, it was only on Tuesday actually and I'm thinking, is he now going to refuse to go again because I've ... I don't think I said anything wrong it was just the way I said it, and so you then beat yourself up, then you think, "What did I say that was actually so wrong?" And it's very hard and you've got to be very thick-skinned in a way... (Martin, p.8 Lines 9-11)*

The notion of being 'thick skinned' appears to be a way to compartmentalise feelings so that they do not impact anyone else and are kept safely inside but also to protect himself from the potentially difficult feelings that are directed at him from his son.

He explains further about the 'bubble' speaking:

*You're always, it's a fine line, don't get me wrong, I get frustrated, "Go to school, just go to school. Everybody has to do this, all your friends are going to school so why can't you?" It's the bubble speaking, you would never say that to them, but you do get frustrated and it's very hard. (Martin, p.8. Line 9-12).*

Martin seems to describe how it feels unsafe to reveal his frustration with the situation as his child is vulnerable and the impact of him saying the thoughts that are 'in the bubble' could be damaging, so it seems important to ensure that they are kept safely away.

Both Dee (p.15. Line 26) Andy described the 'defensiveness' their child displayed whenever conversations felt uncomfortable or if they took the meaning of something that was said literally, which resulted in certain topics being avoided.

*No, he doesn't like talking about it. That's the thing. You couldn't even mention school. If you mentioned school he would just go ... You wouldn't be able to say anything. Even if you said you've got school tomorrow, let's go to bed. That's it, vroom. It would send him off. (Andy p.22. Line 8-12).*

The vulnerability of their children meant that parents seemed to prioritise their child's feelings over their own.

#### **4.4.2 'Feeling trapped'**

This theme was reflected in all five of the participants, who described the sense of being trapped and having no escape from a situation that felt overwhelming at times.

Amanda describes occasions where she would threaten to leave as a way of showing her family that she felt crushed by the weight of the situation and as a way of asking for help. It was important for her to seek solace and find a place to release her feelings on her own:

*I was like, "I'm going to go home to my mum," and they're going, "You can't do that!" I'm going, "I've got a credit card and a passport, of course I can. Heathrow's 20 minutes down the road. I can get a tube there." They're going, "You can't leave," and I'm going, "No, I'm not going to leave," I said, "But, what I'm trying to say to you is that you have to be kinder." We have an allotment. I'll just go to the allotment, in the shed, and cry. So, there's lots of crying involved throughout all this time, because it is so hard. (Amanda, p. 27. Line 17-20).*

Kerri describes the feeling of being lost and having no escape:

*It has been very difficult, there's no escape and when she's in a bad place, it affects absolutely everything. It just permeates the whole atmosphere in the house and we all get pulled down by it. (Kerri, p.9. Line 5-7).*

I asked Kerri to say some more about this:

*It's just a grey stillness. My husband doesn't ..... He copes with it very, very badly and he prefers, quite rightly, because of his reactions, tried not to engage with it. And I just feel like I'm drifting through this deep, dark, grey, soup. I don't feel I can ... When it's in a really bad time, it's impossible to communicate. Because she quite rightly says, "You know, you don't know." (Kerri, p.9 Line 1-6)*

Kerri describes her feeling of being trapped in a powerful metaphor, the colour grey creates a picture free from light and joy and her ability to find a way out of the 'deep, dark, grey soup' does not exist. The greyness permeates every space and the beginning and the end of the 'greyness' is unclear. There are points here where Kerri becomes emotional and finds it hard to finish her sentence and to find the words to express herself. It feels like a very isolating and lonely experience, where she cannot communicate with her daughter and where her husband avoids being drawn into the 'soup'. There is a sense that Kerri wants to validate her husband's desire to avoid the 'soup' but also a frustration that he can choose whether he is in it or not, as for Kerri it feels unavoidable. When her daughter, tells her that Kerri 'does not know', it actually seems that Kerri 'does know'. While she admits to not living her daughters experience, her own experience of depression and may feel very similar.

The notion of wanting to escape was also expressed by Martin, who describes the internal conflict of both wanting and not wanting to go to work:

***...all you're thinking about is, "I should be at home." Then you realise I can't be at home I have to be at work. But in a way it was also an escape: you're at work so you're not in the midst of it and having to deal with a lot of it, but when you go home, every time you walked in the door, "What's happened today (Martin, p.4 Line 22-24)***

With the situation feeling anxious and oppressive at home, Martin describes how work became a way to escape but was coupled with a sense of guilt which felt tricky to resolve.

All five of the parents described situations where attempts to spend time away from the home either with their family or alone with their spouse were impacted by their child's anxiety. They reported that sometimes it had been years since they were able go out as a couple and when they did, their child's anxiety would result in constant phone calls and panic.

Andy describes his experience of when he tried to get his mother to babysit one evening:

***One day we were planning a night out and they were staying the night at my Mum's and he couldn't do it. He couldn't stay the night. He was just non-stop phoning me, but my Mum***

*took it badly that they didn't want to stay and she didn't understand why. (Andy p24. Line 21-30).*

Kerri reports a similar experience when her and her husband go out for an evening:

*And then when we go to our phones, there'll be three or four phone calls, "When are you coming home?" I think it's that sort of feeling that, even out of the house, you're chased by it. (Kerri p.10. Line 31-33)*

There is a sense that you are never free from the problem, which seems to follow parents out of the house. Kerri describes being 'chased by it', which feels exhausting and quite intimidating.

Dee's son Matt has severe anxiety, which means he has missed out on going on holiday with his family, this has resulted in her taking her other child on holiday instead, which gives her some respite from the situation:

*Just to be able to get away from him [laughing] to be honest, because we have him all the time. Because when you've got a child who is anxious, doesn't do anything or go anywhere, it's just oh gosh, it's just like... (Dee, p.30. Line 20-23).*

Dee does not finish her sentence here, but it feels like having to witness her son's difficulty every day is incredibly painful and the days that she is away from home provide some much-needed relief. She laughs when she confesses her desire to be honest about having time away from him, which feels like it is tinged with a sense of guilt at having confessed this feeling. Where can they go to 'confess' and to 'escape' from the difficulties and challenges at home? The tension in the home seems unavoidable and parents reported their own experiences of anxiety and depression, which is explored in the following theme.

#### **4.4.3 Contagious anxiety**

This theme reflects how an anxiety that manifested as an inability to attend school, seemed to 'infect' others in the family. All of the participants described feelings of worry and anxiety and in two cases they themselves had been diagnosed with clinical diagnoses of depression.

Kerri finds herself mirroring the life of her daughter Emma, who has a diagnosis of depression which creates a vicious cycle which impacts both of them negatively.

*Anyway, I have depression, so at the very, very beginning and I was on the sofa and we barely talked to one another and didn't really communicate. We were, I think, quite bad for one another. (Kerri p.8, 26-28).*

She describes the feeling of uncertainty which threatens to overwhelm them all at any time.

*You just feel like you're riding a wave the whole time, and you never know when you're going to topple off the edge and sort of come tumbling down. Which we do periodically. (Kerri p.2. Line 21-23)*

Andy describes the cycle of anxiety that he finds himself caught up in whenever his son had to go to school:

*No help from anyone so every day the same thing just over and over and you just wait until the weekend. The weekend was just ... Sunday comes again and then you know it's going to happen again. (Andy, p. 26. Line 29-33).*

There is a perpetual sense that the problem never leaves, in this way the contagious anxiety is also inescapable, which feeds the tension.

Amanda's mental health was challenged when her second son also began to present with similar school anxiety issues, her description of the experience is painful to read:

*"I was super distraught. I cried, and I cried, and I cried for about a month or two. It was a grieving, because I thought, "Oh no, not again." I self-harmed a bit..... just to get away from that feeling. Yes, it was awful." (Amanda p. 25. Line 28-32).*

Amanda's grief at now having two children with mental health needs was overwhelming and her confession of self-harming, shows the way patterns between the parent and their child. Her desperation to get away from her feelings reveals the depth of her emotional turmoil.

#### 4.4.4 The impact on family relationships

This theme presents the impact across the whole family unit, particularly between the parents, which can fracture relationships.

Andy described how the situation with his son nearly tore his family apart as his wife felt the situation was unbearable:

*It just changes your life. Honestly, I could have had nothing now. I could have no kids. It was that bad. My wife was going to move away. Just get away and try and start again. She didn't think she was having any help, nothing. It's just constant, non-stop. (Andy, p.39. Line 10-14)*

Andy reflects on how close his marriage came to breaking down, he says that his wife 'didn't think she was having any help', which made her feel like she needed to escape. It seems that the help she desired was not present in the family, whether that is an accurate perception or not, it shows how parents seemed to project their frustrations into each other. The sense that the situation was 'non-stop' highlights the feeling of being trapped.

Martin shared this experience of how his marriage was affected:

*It's almost like you didn't want to leave in the morning but you didn't want to go home in the evening either, because you know that you were just walking into a ... and for the best will in the world.... but she would take her frustration out on me, then you're thinking, "Why am I going home to that? I'm going to be yelled at," it was just through the stress (Martin p.5. Line 7-10).*

He is able to acknowledge the effect of stress on his wife, which helped him to feel less attacked. But he describes the sense of internal conflict of trying to contain his own anxious emotions while recognising that he needs to support his wife. There was a gender imbalance present where the mothers reported feeling like they carried more of the burden, but this was attributed to the different working commitments and time availability.

Although parents reported that the difficulties with their child had a negative impact on their relationship, there were also reports of them working together to support each other, especially when being challenged by professionals:

*There are times when maybe we've said a few things we shouldn't have done or blamed each other for it. It was really tough, but we'd always got each other's back if anyone else said anything (Andy, p.31. Line 27-30).*

The two fathers describe the tension of feeling blamed and associated with being part of the problem but also trying to be part of the solution and protecting their spouse.

#### **4.4.5 Loss of career- impact on work**

This theme captures how parents manage their work demands when dealing with a child who does not attend school. Three of the parents had made decisions about giving up work completely to support their child but recognised their unique position to be able to do this. Two parents revealed that they would have no choice but to leave their child at home, which was stressful for both the parent and the child.

Amanda sacrificed a successful business to stay home with her children who she felt needed her more:

*I had a business. So, I had a practice, so I closed that down because it just wasn't working. You know, my son really needed me more than the clients did. We're all bright people, and can just find somebody else (Amanda p12. Line 6-8)*

Martin describes the level of involvement that a parent is required to have in order to support their child, which makes working incredibly difficult:

*it's a full-time job and that's what people don't realise is you have to give up so much because even though he's in a residential school now you still have to be dealing with his medication, talking to the psychiatrist, talking to your doctors, talking to the school, making sure things are running smoothly and it is a full-time job just to do that.(Martin, p.4. Line 15-18).*

Kerri’s decision to leave her job was not entirely due to her daughter’s non-attendance but it played a very important role in her decision:

*So, I handed my notice in. As soon as I handed my notice in, I went on sick leave and I haven’t worked for about two months. So, now I’m at home with Martha 24 hours a day, because she’s just not going to school at all now. (Kerri p.8. Line 2-4)*

In some situations, parents left their child at home alone while they went to work. Having to leave their anxious child at home alone was an action that parents took reluctantly but felt they had no choice. It would require them to be on the phone to their child frequently during the day or rush home at lunch to check on them. The support their employers provided was critical, and this varied between the participants, with Andy describing how his boss was able to let him work flexibly.

This section captures the pervasive impact on the lives of the whole family, in essence ‘it turned their life upside down’. In all areas of their life, the needs of their vulnerable child came first.

#### **4.5 ‘Power and the battle to heard’**

This superordinate theme captures how parents experienced interaction with schools and other professionals. Issues relating to this theme occurred the most often for every participant in every transcript and was a dominate feature of their experience.

**Table 8: Subordinate Themes Relating to Superordinate Theme 2**

Subordinate theme	Dee	Andy	Martin	Kerri	Amanda
‘Loss of trust’	x	x	x	x	x
‘Lack of professional awareness’	x	x	x	x	x
‘Accusation and Persecution’	x	x	x	x	x
Issues around power	x	x	x	x	x

#### 4.5.1 'Loss of trust'

Participants reported feelings of having lost trust in professional services, which included the school, CAMHS, GPs and Education Welfare Officers (EWOs), which led to feelings of frustration and confusion.

Dee's attempts to get support from her GP led to her feeling rejected and confused:

*Going to the GP is a waste of time. A complete waste of time going to the GP, yeah. I went to the GP and even asked for a referral to a paediatrician, and she said it'll just be, it'll just be bounced back, yeah. So, I don't really understand what, how to get a referral if you know what I mean, I just don't understand it. (Dee p.35. Line 34-37)*

In this way it feels like Dee has been left to hold the problem with her son on her own, the notion of it being 'bounced back' feels like a rejection and invalidation of her concerns, which leaves Dee feeling lost and confused.

Amanda described how a lack of professional support resulted in her having to provide therapeutic support her children and a failure in the system, which is rigid in its approach.

*For both of them, because there's no outreach work for CAMHS, because there's not the funds or the thinking around it, basically, because they can't get into see a clinician of any description, it's left down to ... well, up until recently, it was just me trying to deliver some sort of therapy to help them with the anxiety and the depression, whilst coping with all of this, and in terms of the working systems that just don't work at all. So, he's been, sort of, stuck. We had seen an improvement in services, but it's difficult enough (Amanda p.13. Line 17-25)*

Andy's faith and trust in the professional support his son was challenged, while he acknowledged they were kind, he felt that they did not actually help, as they were guessing rather than identifying his needs.

*I like the people, but to be honest with you, I don't think it really helped. It only helped when we found out what was actually wrong with him. It was always guessing really. Just doing*

*stuff that was irrelevant because they were just guessing what was wrong with him. He has got anxiety and we were trying to deal with that. (Andy p, 18, 32-36)*

To be able to clearly identify the root cause of the problem is essential, however the next theme demonstrates how parents felt they were blamed for causing their child's difficulties.

#### **4.5.2 Accusation and Persecution**

This theme captures the highly emotional experiences described by parents, where they felt attacked and blamed for their child's difficulties. The mothers reported incidents where they felt that they were accused of being a bad parent, while the fathers reported incidents where they felt their wives were being blamed. This is an interesting gender imbalance and seems to reflect a social construction of parenting.

Parents rarely named individuals when describing the incidents, using the term 'they' or 'the school' and gave a sense of a faceless, powerful, judgmental entity.

Andy's pain at recounting this experience was visible during the interview:

*They didn't believe us. It was really bad. They accused us of being bad parents. They accused my wife that it was all down to her. I've sat in meetings and they've said it's your fault. One teacher said it's your fault and I was fuming. I was actually fuming. At the end of the day, it doesn't matter whose fault it is. We want him to get better. We don't know what it is. Everyone was telling us different things, everyone. (Andy, p.8. Line 15-21).*

Andy's description of 'they' and 'everyone' emotes an image of he and his wife facing the collective opposition, which feels confrontational and not supportive. Andy's reiteration that he was 'actually fuming' highlights him feeling anger and frustration towards the accusing teacher. The lack of clarity around why his son was having these difficulties, adds to the frustration and the sense of confusion Andy seems to experience.

Amanda describes similar accusations against her parenting which leave her feeling very distressed:

*I had one woman who has now gone, a teacher in this centre, told me that I had to control my child, and show him who was in charge. Basically, she said it three times. The first few*

*times, I cried, because I just was so distraught, and the second time I just kicked her into touch, and then I made a complaint about her, but she still stayed in post. (Amanda p.15. Line 1-4)*

The impact of the statements made by professionals which target the parent's capacity to support and manage their child landed deeply. Amanda describes how this statement was repeated three times and reduced her to tears, however, she 'kicks' back. This sounds like a fight, but where Amanda defends herself but her complaint was not taken seriously where the initial attack goes unchallenged by the 'system'.

The concept of being in conflict with the 'system' is powerfully described by Martin, who labels them the 'enemy':

*And what we did is we made the authorities the enemy, and so instead of it being the two of us it was the authorities, and if you focused on that and you make sure that you are the team that are working together to get everything for our son and you are not the enemy between yourselves, it kind of helps. (Martin p.5. Line 16-19)*

Martin presents a situation which is so stressful that it impacts the relationship with his wife, by establishing themselves as a team, they are able to direct their frustrations into the 'system'.

I asked Martin to expand on the concept and he explained further:

*They are the enemy because they treat you as the enemy. When children have mental health issues or they are being abused or whatever, the parents you are guilty until proven innocent, so as soon as you walk into hospital because he's taken an overdose or he has self-harmed, you are treated like a criminal. You are treated, "Right okay, what have you done to make the kids do this?" And until they find out that actually it's nothing you have done you are held at arm's length, you are not treated very well, they look down on you, (Martin, p.5. Line 24-30)*

Martin's situation with his son goes beyond EBSNA, into significant mental health needs, however, he describes the sense of being blamed to the point of feeling like a criminal, who 'has done something to do this child', which does not facilitate trust between himself and the professionals. It seems to fuel a sense of paranoia and where he feels he has to prove himself as an honest parent who is worthy of support.

Amanda and Martin positioned themselves as a team in an attempt it seems to protect themselves from the accusations and to challenge the system to ensure support for their children:

*At some point in that process, we decided that the enemy was the system, and that we just had to throw everything, all the resources that we had, which is just, basically, our wits, and then work the system to get what we wanted for our children (Amanda, p 17. Line 1-6).*

Martin also describes the accusations levied towards he and his wife:

*...but some of the teachers there just turned round to her and told her that she was a bad parent. And again, they had no idea so they are meant to be a specialist provision but they had no idea of how to deal with him..... He would go in sometimes and then he would refuse and he would escape and run away and abscond and all that, and basically I think my wife was in tears a number of times when we were told what kind of parents we were and she should be doing more and forcing him to come to school. (p.10. Line 6-12)*

Martin's description seemed to capture a frustration with the specialist provision, who he perceives as being unable to manage his son but seemed to blame them as parents who were not doing enough and there is a suggestion the problem is a lacking in firmness and discipline.

The accusations do not only come from professionals, parents reported that they would also come from within their own family.

Dee describes how her family offered advice seemed to not appreciate the challenge she was experiencing and over simplified the problem:

*I think I heard it a lot from my family, like drag him to school and then I had a lot from my brother, "You've got to put your foot down, take him to school, drag him to school" but then I started reading up, as soon as I found out that he wasn't going to school and I was talking to my colleague at work, and I started reading these books etc. and blogs around parenting, kids not going to school and I just thought, dragging is the worst thing you could do. How are you going to drag a child that's taller, you go to school, it's not possible. It is not possible to do. (p.28. Line 12-20)*

The sense of it 'not being possible' appears to indicate Dee's frustration of other people who have not shared her experience, offering advice without any understanding of the issue.

Amanda describes the impact of having the threat of prosecution hanging over her, but with no access to support to help her:

*I got very depressed myself, and it was difficult because there was no help to be had. We were fighting the system, rather than it helping towards it. Felt enormous pressure to get him into school, and felt really, almost, paralysing fear that we were going to be prosecuted, which, you know, that was always being bandied about, “Oh, it’s the law. You need to get him in. It’s your job to get him in.” I’m like, “Yes, but how? (Amanda p.14. Line 10-18).*

This tension described by Amanda suggests a lack of clear and helpful guidance at a time when she feels at a loss at what she should do, and it feels like the support requested has replaced with threats and intimidation.

#### **4.5.3 The importance of professional awareness**

This theme reflects the feelings of parents who felt that professionals did not seem to understand the complexity of the situation and who viewed it as a ‘challenging behaviour’ which could be dealt with through straight-forward solutions. However, the support from specialist staff at the AEP was described by parents as being helpful and reduced the levels of stress at home.

Kerri’s interaction with the school’s Education Welfare Officer (EWO) highlights her frustration of feeling like she is not being listened to and with the EWO’s lack of awareness of the problem:

*For quite a long time with the school, the person we dealt with most was the Welfare Officer, who could only ever see her as an attendance figure. So, who would tell us all about the legalities of what would happen, academically, how it would affect her. Well, I trained to be a teacher and my husband’s a lecturer. And it didn’t matter how many times we told her, “Please stop patronising us with this, because we fully understand all of the implications, but this isn’t as easy as you think it is...(Kerri p.4. Line 1-7)*

The assumptions made by the school's EWO are felt to be patronising by Kerri and appear to undermine the challenging situation that she and her family were experiencing. There is a sense that the focus on the legalities of attendance, meant that the emotional aspects were ignored, leading Kerri to feel attacked as being labelled as 'stupid'.

*You know, if it was that simple, I would have dealt with it. I think people could only see it in a certain way. And I think one of the reasons I got very angry with this Welfare Officer was that I'm not stupid, I work in education, I told you, we're educated people and education is important to us. Please don't tell me about how this is affecting Emma's future, just listen to us and try and provide what we believe you need to provide. But she was unable to do it. (Kerri p20. Lines 4-9).*

*Yes, so she thought she'd solved the whole problem because I couldn't keep taking Emma in and out, so they'd send a taxi, she didn't quite see that the problem wasn't just about the journey. She just couldn't see it, it didn't matter how many times I tried to tell her that it was way, way more complicated and layered than that. (p.20. Line 16-20)*

This lack of professional awareness was reported by all parents who felt that it led to a breakdown in the relationship between themselves the school. Dee feels that the school were unable to recognise how complex her son's needs were.

*....the school had never been very supportive about his anxiety in the first place, and that's I believe is one of the factors as to why he never made it, it wasn't successful, because I think they didn't understand it. They thought he was a school refuser, they didn't understand that actually he's not refusing school and sitting and shoplifting or involved in a petty crime or going out, he's actually very, very scared. They didn't understand and they didn't really want to understand it. We had a lot of difficulties with trying to get the school, it was a constant battle, (Dee p.8. Line 23-31).*

For Dee, the issue of school refusal is not relevant as the problem lies in her son's problem with anxiety. The concept of school refusal to her feels associated with anti-social behaviour and her level of frustration with the school is clear; 'they did not try to understand'.

The lack of 'understanding' was described by Andy, who recounted this story of the police forcibly taking his son to school with emotional intensity, which highlighted the pain the situation had caused him and his family. He explains:

***They said because he's being naughty, if you're naughty and you don't go to school then the police come. The police came around and he was petrified, in the corner crying his eyes out. They picked him up and took him, put him in the van and he was screaming, he was really bad.(Andy p.10. Line 18-22)***

***I said to them that they don't understand. No one knew what the hell was going on..... No one understood. The policeman came straight back to my house and he said, "We won't be doing that again." I said, "Okay." He said he'd never ever seen ... He said they were going to speak to the thing (school) because it's not normal what they've just done.....He did come back. He saw that I was upset (Andy p12. Line 20-28).***

The concept of the faceless system is present in the use of 'everyone', 'them', 'they' and 'the thing' which is how Andy describes the school. The school's attempt to resolve the non-attendance revolves around their understanding that the problem is a lack of discipline, so the solution appears to be to invite the police to deliver the discipline that they feel is needed. At no point does Andy use the term 'we' which would suggest a sense of the school working with the family and being involved in the decision-making process.

Andy describes his distress as he tries to explain that 'they don't understand', but 'no-one knew what the hell was going on', including himself. This made it difficult to challenge the school and the police and he relies on their knowledge and perceived expertise. The return of the policeman to the home to speak to Andy compounds the idea that indeed, everyone involved did not understand what was happening and demonstrates a lack of knowledge, awareness and expertise in a complex situation.

Andy also felt that the school were not motivated to help solve the problem:

***I don't think \*\*\*\* School wanted him to be there to be honest. They said they did, but they knew he wasn't going to do anything. I got the impression that he was just a hindrance (Andy p.38. Line 26-28).***

An awareness of the situation and a recognition of how parents feel is very important and Kerri describes speaking to a senior member of staff at her daughter's school, who secretly confesses after a meeting that she also has a child with similar problems. However this confession comes after the school decide to take Emma off roll and insist that she attends the AEP:

*And she was lovely, and she was going to be Emma's mentor, but it came too late. Because actually it was the first time, I spoke to anyone in that school that I felt understood as a parent. Because she said she was listening to Frank and I talk, and she didn't want her colleagues to know, because she was listening to Frank and I talk, thinking, "This is us, we've been here." (Kerri p.18. Line 8-12)*

This feeling of being understood feels very important and was a powerful experience for Kerri who for the first time felt like she had been heard and her feelings validated. This experience was also marred by frustration as it came as Emma was told that she would be leaving the school, despite expressing a desire to stay at her school.

Kerri reveals that she never had the opportunity to speak to the Special Educational Needs Coordinator (SENCO) and questions whether the school did not recognise that Social, Emotional and Mental Health (SEMH) needs come under the umbrella of SEN.

*So, I think if she could have been involved, a lot earlier, it might have been handled differently. But the staff kept it at a lower level, I don't even think it even got to SLT. It was just kept at a really ... I never saw a SENCO ever at the school. I asked, but I didn't see one. I don't think they talked to their SENCO, not realising that depression and anxiety is a special need. (Kerri p.18. Line 12-15).*

Martin expressed a sense of frustration with professionals who seemed to offer poor advice and support:

*I think one of them once said when Jake was being very violent, she just turned round and said, "You should call the police." What, you would call the police on a 10-year-old child who is seriously ill? I just find sometimes because they've got a title doesn't means they are experts in their field, it's very hard sometimes. The most frustrating thing is they won't listen to the parents; you live with the children, you've got a good idea of what's going on but they won't listen to you. (p14. Line 12-17)*

His frustration highlights an imbalance where a professional title seems to carry more gravitas than the testimony of the parent, even when it seems like there is a lack of understanding. He seems to suggest that just having a professional role does not equate to expertise and it is possible that they parent may be the expert in their child's life.

In contrast, all of the parents spoke positively about the AEP and especially the outreach support, which maintained a link to education, despite their child's non-attendance. They expressed a sense of relief when speaking to staff who understood the complexity of the problem and were flexible. The professionals in the provision were seen as understanding their child's complex needs and did not judge them as parents this was reported to have helped to improve things at home for the whole family.

Three parents reflected on the impact:

*This place has been brilliant and they're really nice. They understand because sometimes he has a bad night and he can't make it in in the morning. They ring me up and ask if he's going to be in. He'll always come in an hour later if he psyches himself and does whatever he does. (Andy, p.18. Line 25-28).*

*Coming to AEP has created a calmer house. (Kerri, p.23. Line 11-12).*

*you can't fault the school for the amount of support and skilled and the expertise they have done wonders with him, really. And, if he didn't have that, he would be at home, just rotting really because what would there have been for him, there wouldn't have been anything out there, because every school would have said, "We can't meet his needs" and eventually he would just be at home, so it's tragic but that's the reality of it. (Dee, p.20. Line 12-18*

Parenting support in the form of parent programme called Non-Violent Resistance (NVR) was valued highly by Amanda who felt the course was able to help her and Martin learn skills to manage the challenges at home.

*I think that gave us a real confidence to do something different, and embracing it fully. It's been really, really helpful. You can do NVR for anxiety. We've not cracked that, or school refusal, but, in terms of our whole approach, because our stress levels reduced, then everything became easier. Amanda, p.24. Line 25-28)*

Having access to useful support from professionals who understand the complexities is seen in this theme as being of great importance.

#### **4.5.4 Power Imbalance**

This theme captures the issues around power between parents and professionals, which was reported as being weighted in favour of the professional agencies, leaving parents feeling powerless.

Amanda illustrates the feeling of frustration of having her knowledge and experience ignored by professionals:

*The problem is with being a parent, even if you're a really bright parent, even if you can quote law and you can quote medical journals and evidence-based research, you're just not believed. So, the overwhelming thing was being told that I'm a bad parent, I'm not doing enough, what do I know. (Amanda p.15. Line 2-7).*

Martin expresses a similar feeling of feeling invalidated:

*And its things like that, it's just a feeling we have that as a parent it doesn't matter what you say really, the teachers seem to know best. (Martin p.14. Line 23-24).*

Andy felt powerless to challenge the school's plan to have police officers forcibly take his son to school:

*I had no choice in the matter, that's what they said. They said if you don't do this you could end up in jail. They didn't know what was wrong. We didn't know what was wrong. (p.11. Line 11-14)*

Andy's sense of agency and parental authority seems to be usurped by the 'system', 'they' said if he didn't allow this to happen then he could end up in jail. The threat of prosecution and jail seems to be used in Andy's case as a way of getting him to comply.

The need for parents to have their voice heard is described by Kerri whose frustration at having her views ignored impacts her relationship with the school. Kerri's assertion that she and her husband are 'educated people' and not 'stupid' (p.20. Line 15-17) feels like a desperate plea to be heard and an acknowledgement that know what their child needs.

This frustration adds to the anxiety experienced by parents and the following theme explores the fears and experience of loss for parents.

## 4.6 Fear and Loss

This theme comprises of the anxiety and pain parents described when they reflected on their experience, which featured two key components of fear and loss.

**Table 9: Subordinate Themes Relating to Superordinate Theme 3**

Subordinate theme	Dee	Andy	Martin	Kerri	Amanda
Loss of childhood	x	x		x	
Loss of confidence as a parent	x	x	x	x	x
Fear for the future	x	x		x	

### 4.6.1 The loss of childhood

This theme captures the painful experience parents reported of watching their child lose the joy of childhood and also the loss of the child that they used to be.

Kerri reflects on how Emma was as a younger child:

*When she was little, in fact, lots of people talked about it. She was this really lively, free spirit and she had a great big grin on her face, always a leader. But also, although she's bright, she always, sort of, measured herself against everybody else. (Kerri p.1. Line 9-12)*

This description shows a contrast of then and now and perhaps a desire for those qualities to come back.

Dee explores the contrast of 'then and now' too:

*When he was young, he was a chatterbox, he wouldn't stop talking, now it's a combination of him being really talkative, and domineering the conversation, not allowing anyone to speak, as well as, as well as being very control, withdrawn at times, so it's been, and hitting adolescence I think was really the turning point I think because every, all the difficulties, the little difficulties that he had as a child, when he hit adolescence they all became very big. He was just like a ticking time bomb, and I think that's what happened, it just all came out, and he just couldn't cope with life basically (p13.Line 34-36, p.14, line 1-4).*

She continues:

*Well, my husband and I say, it's like watching a child die, that's exactly what's been, it's like the old child that we had has died, and this new one... It's just, he's just not a fully functioning individual, a child. It's like he doesn't have a childhood, it's really sad. (Dee p.15. Line 1-3).*

This quote from Dee was difficult to hear and her sense of loss is palpable, it feels as though the life she had hoped for her son, that she envisioned in the future, no longer exists and she grieves for that child.

One of the most painful things that Dee reflects on is her son's lack of a peer group as she values the social interaction aspect of school.

*Heart-breaking for us, because for me people, I remember family members were saying, well just take him out of school, home tutor him, he'll be fine, but for me that wasn't the point, the whole point of him going to school was to meet other people and to have a life outside of the home. Because he's at home all the time, it wasn't to, I just wanted him to be able to know what it's like to laugh and have with other kids, and they can kick a football around, something like that. (p. 18. Line 31-34, p.19 line 1-2)*

Throughout my interview with Dee, she used the term 'heart-breaking' (p.18. Line 17-19; p18. Line 31; p.20. Line 16; p.30. Line 33) many times, which is a very powerful term and feels very emotionally intense and painful. The notion of heart break seems to represent how the experience has 'fractured' her life and the life of her son.

The sense of loss in Dee's interview seems to be at the centre of her experience. She describes her sadness that her son is no longer able to attend a mainstream school but has been grateful for the support from the AEP but it has been difficult to accept.

The loss of social relationships is a major source of worry and concern for parents, and Martin describes the effect of being socially isolated had on his older son, when he was younger which resulted in a number of attempts at suicide.

*When Richard stopped going to school, 2 or 3 of his friends tried very hard, because he was in such a bad place in the end they just gave up, so he ended up with no friends and so it was very hard because he then became so isolated that all he did was sit in his room and then obviously that's a slippery slope, the more you get isolated the more you don't engage, the more depressed you become and it ended up where we are now with all the suicides and that (Martin, p.20. Line 22-28).*

As a result, Martin was desperate to ensure that his younger son would continue to maintain social network, even if it was much smaller.

Andy worries about his son's lack of friendships and his rejection against any attempt to encourage him to develop his social interaction.

*I said to him the other day, why don't you invite him (a child from the AEP) around? He only lives up the road. No. What about going to the cinema with him? Do you want to go to the cinema? No, he doesn't like the cinema. What about going to Pizza Hut or something, I don't mind dropping you off there with him. No, we just play online. It's very weird. They were meant to meet up to go to Thorpe Park over the summer holidays. We got his Mum's number so we tried to arrange it, they just didn't want to know (Andy p.28. Line 28-35).*

While Andy finds it 'weird', that the only interaction the boys have is online, which may actually an acceptable way of communicating for young people these days. Andy's persistent attempts to try and persuade his son to go out with his friends, shows how important it is for his son to have relationships with his peers.

#### **4.6.2 Loss of confidence as a parent**

This theme addresses how parents seemed to question their confidence in their parenting ability and experienced a sense of failure.

Kerri describes the sense of failing in her role to make 'everything right' and to prevent the experience of depression on her daughter:

*You know, your job as a parent is to make everything right, and I couldn't make anything right. Sometimes, there would just be no lightness for days on end. And she's gone...It has just been really, really difficult. (Kerri p9. Line 24-26)*

The sense of powerlessness and helplessness elicits feelings of not being able to protect her child, which seems to leave Kerri feeling like she is failing as a parent. She describes her daughter as being 'gone', which feels like Kerri has lost control and her ability to bring her daughter back in those moments.

Dee tries to find ways to reassure herself that she is a good parent by reminding herself that her other child is ok.

*Sometimes we, my husband and I have a conflict over parenting, and sometimes we think, you know, are we bad parents? But then we've looked at our approach with Marie, we're doing the same parenting, and she's fine, so we don't think it's our parenting. (Dee p.26. Line 26-30).*

There is an overlap with the subordinate theme of 'Keeping the peace' where Martin tries his best to be a 'good parent' but has a sense that he doesn't always know how to say the right thing.

#### **4.6.3 Fear for the future**

This theme encapsulates the fear that parents expressed when contemplating their child's future, particularly in terms of their career and relationships.

In the quote below Andy is conflicted when thinking about how his son will cope in the 'adult world', on one hand he feels confident that his son can work in any field, but is worried about how his anxiety will impact his relationship with others and his capacity to function:

*He's capable of doing any work. It's just getting him there and if anything happens at work, because I know for a fact, he wouldn't be able to do my job because the banter and the mickey taking, even though it's not meant to be, he won't be able to handle that. He doesn't like getting the mickey taken out of him. He takes it really bad. I don't know. That's what I'm worried about. I think he would be all right if he made a friend. It's just how is he going to hold a long term job down if he can't go in some days because he's worried about something happening that's not going to happen? (Andy, p.36. Line 1-8)*

Kerri's fear that her daughter will always struggle with depression is palpable; she repeats the word 'worries' three times in this short sentence, which shows how emotionally charged this subject is for her:

*Her future worries me. It worries me, whether this is a temporary thing that she will learn to overcome or whether this is a lifetime thing which we're all going to have to be fully aware of. And whether it will be something that handicaps her for the rest of her life, that worries me. (Kerri p. 15. Line 2-6)*

Kerri considers the issue as something the entire family will have to manage, not just her daughter and it is something that they will have ‘all have to be fully aware of.’

Dee’s realisation that her son will not have the same access to education in the AEP than in a mainstream school, is painful for both her and her son.

*...he’s also has started picking up on the fact that his access to education was slightly, it was restricted because although he’s got the option of doing GCSEs, he doesn’t have a wide curriculum like he would have done in mainstream school, and that’s the reality of it. They don’t have those resources, so that isn’t, that’s heart-breaking for him really. (Dee p.20.Line 16-21)*

There is a recognition of her son growing up and the fear that he will not be like his peers and his education deficit may not be the only area where he is lacking. There is perhaps a sense that while their child is fairly young, they can protect and support them, but there is also an awareness that they are also parenting young adults, who cannot be protected in the same way for much longer.

#### 4.7 Retrospective Clarity

This theme captures the experience of hindsight, where parents looked back to the past to help them make sense of their child’s development, and to look for the origins of the difficulties.

**Table 10: Subordinate Themes Relating to Superordinate Theme 4**

Subordinate theme	Dee	Andy	Martin	Kerri	Amanda
Looking back for clues: ‘I wish I knew back then’	x	x		x	
The need for clarity: ‘Why my child?’	x	x		x	X

##### 4.7.1 Looking back for clues: ‘I wish I knew back then’

The interview process followed a temporal sequence where parents described a recognition of characteristics and traits that were later to become significant as their child got older.

Andy's reflections on his son highlighted his feelings of self-reproach as he reflected on behaviours that previously went unnoticed.

*We didn't really notice anything up for a long time, to be honest with you. I always thought that when he was with other kids he was very childish as he was getting older. He'd try too hard with other kids and he didn't have many friends. Everything was fine. It was more I noticed things when I used to take him to my friend's houses or something like that. It was always that I'd have to make an excuse and leave because he was being, not naughty, but he would do things a bit out of the ordinary. (Andy p 2. Line 18-26)*

Andy describes the contrast of saying that 'everything was fine' but in reality, he had already noticed that his son's behaviour was different from others, which impacted their social interactions with others. This sense of trying to minimise his internal concerns and to tell himself that 'everything is fine' was present in Dee's story.

Several times during the interview, Dee described how concerns were raised about her son in primary school, but at the time were not considered to be that important.

*when he reached Year 6 in primary he started to get a little bit anxious over silly things, which I thought were not very important, and about was it going to be picked up from school, where would I be standing and all these kind of things that were a bit concerning... and a couple of times he didn't go into school... (Dee p.3. Line 23-29)*

This was repeated....

*Then his anxiety came to a head when they had a school trip in Year 6, they were going to the Isle of Wight for a week, and we didn't really pick up on it, but he was saying that he didn't want to go to the trip, or he didn't think he needed to go, but obviously the trip wasn't voluntary, it was for everybody, so we packed his bags and everything, and on the morning that he had to go, he would not leave the house... (Dee p.4. Line 9-14)*

There were several other incidents which Dee would report;

*...we thought, "Let's leave that, let's park that to one side and let's not worry about that". (p.6. Line 14).*

There seemed to be a hope that 'everything would be fine' and this was compounded by others including the school reporting that there were no concerns. However, it highlights perhaps that parents find it difficult to name and 'shine a light' on the problem, preferring instead to allow their concerns to be soothed away.

Kerri described a strong sense of guilt when she looked back at opportunities for support that were not accessed. She described how an incident at a drama club upset Emma greatly:

*You know, when you look back, this is in hindsight. At the time, although we were really sad, it didn't have significance. But she's always been a glass half empty, type of person. But she started to become quieter and not as confident and that slowly developed during primary school. Some of the PASS tests that she did ... I worked at the school, so particularly in Year 6, I remember being asked, "She's come out of this really negatively, you know, other children we would perhaps put on some, kind of course, I'm trying to think what it's called, anyway, something that they used to do.*

*And I said, "Oh, no, no that's Emma, she's just a bit negative," but perhaps, again, with hindsight, that was significant, I don't know. I wish I hadn't been there to be asked, because they would have just done it. (Kerri p. 2. Line 29-34, p.3. Line 1-3).*

The notion of hindsight feels important, there is a sense that Kerri feels that things may have been different and there is a sense of remorse and self-guilt, where she seems to blame herself for working at the school and the consequence that had. She also seems to feel guilty for not realising that her daughter's problems were more serious than initially thought.

Kerri also highlights that early intervention could have made a difference.

*I think some specialist support, at the very beginning, I think would have made a big difference. I really do believe this, to recognise it for what it was, rather than a child that just didn't want to go to school. So that the necessary things could have been put in place. (p.17. Line 1-3).*

Dee describes her frustration at not having support implemented at an earlier stage, which she feels would have made a big difference:

*It's definitely different in other boroughs, I know that, yeah it is, yeah we've got a high waiting time, I think it's two years for... And, one of my grievances is, that I feel that if Matt had help early on, I don't think that he would have got as bad as now, and that is because he didn't get the help, and because the council are overstretched and if you don't meet the criteria, the threshold, then you don't get the help, so you really are waiting until you're very sick, which I think is very, you know, is wrong. We don't have the resources. (Dee p.38. Line 1-8)*

This frustration seems to be connected with the feelings of not being heard highlighted in Superordinate Theme 2, when parents tried to raise their concerns at an earlier stage but felt rebuked.

#### **4.7.2 The need for clarity: ‘Understanding why?’**

This theme revealed the confusion and lack of clarity on their child’s issues and how this impacted the relationship with their child and their wider family.

Andy describes how when his son began to present with anxiety at the end of primary school, he and his wife felt at a loss at what to do:

*It was hard to explain because no one knew what was wrong. You didn’t know if he was being naughty or what was wrong. Looking back now, there are so many things that now we know, but we didn’t have any help. We didn’t know what was going on. (Andy p.5. Line 28-32).*

The experience of not knowing why his son was having difficulties feels isolating at the time and incredibly stressful for the whole family. There is a sense of frustration when Andy reflects on the ‘many things’ that he knows now, that he didn’t before, that would have helped entire family back then, but he ‘didn’t have any help’.

Dee describes how the lack of clarity creates a confusing tension:

*I’m constantly in trying to work out what is wrong with Matt, my husband and I. He is the focus all our conversations, and he gets most of our time.. (p.13. Line 16-18).*

*But, what can I do? I really don’t know what else to do. We do as much as we can as parents, but at the end of the day, if he’s not capable of doing things, then we’re pretty much stuffed really, we can just, it’s about him being really want him to be independent, desperately, desperately. He’s full of contradictions, he’s able to do some things, but he’s not able to do others, so I don’t understand. I don’t know whether that’s the anxiety, I don’t understand, whether that’s adolescence or part of, or some of the problems that might exist, that I’m not diagnosed now, I don’t know. I really don’t know. (Dee, p.33. Line 18-28).*

Dee appears desperate to understand what the problem is with her son, she has her own instincts about what the problem is but without professionals sharing her concerns he has never met the threshold for further investigation. The need for clarification revealed a connected theme, where parents looked for ‘clues’ to help them identify the root cause, which allows them to make sense of the situation. The uncertainty of ‘not knowing’ is echoed with parents and professionals.

This theme explored how parents were able to identify reasons that allowed them to make sense of their child’s situation. Despite parents expressing a deep frustration with the school; school factors were not named as specific causes for the EBSNA.

There were traits that existed even from infancy in some cases, separation anxiety was a factor for two of the participants children when they were younger. The need to identify the origin of the problem was important to parents and lack of clarity around the issue only served to amplify their anxiety. For Dee, she is convinced that her son has an underlying issue that has not been diagnosed, which seemed to leave her feeling confused and with the desire to have a clear reason which will allow her to make sense of the situation.

***He’s got I see it as a disability, but it’s invisible to everybody else, and they will not help him. If he was blind people would open the doors, you know, or help him, but they won’t do it because if you look at Archie, he looks fine. (Dee, p.23. Line 4-7)***

***We feel that there is something that, something is stopping him accessing education and I think that’s causing anxiety, but I also think he has other issues that we’re not entirely sure what. (Dee p. 13. Line 1-4)***

Dee’s sense that there is ‘something’ wrong feels instinctual, she feels that he has other problems that are feeding into his anxiety, but there is no clarity only uncertainty.

Andy reflects on the contrast of ‘then’ and ‘now’. From not knowing why his son struggled with anxiety, in the past, to now having an awareness of the problem which has helped his son to understand his anxiety better than before. The issue of how he communicates his feelings of anxiety still remain, but improvements seem to be happening slowly.

*It was hard to explain because no one knew what was wrong. You didn't know if he was being naughty or what was wrong. Looking back now, there are so many things that now we know, but we didn't have any help. We didn't know what was going on. (Andy p.5. Line 28-32).*

*He's understanding the anxiety where he didn't before. The teachers will ask why can't you do it, I don't want to, I can't. They'll say that's no excuse, but he doesn't know how to express himself. Everyone just thought he was being naughty. I can't do it. I don't want to do it. You can't say you don't want to do it. You've got to do it. (Andy p. 17.Line 1-6)*

#### **4.8 Conclusion**

The superordinate themes which emerged from the data included: 'It turns your life upside down'; Power and the battle to heard; Loss and Grief and Retrospective Clarity.

These themes reveal the emotionally intense experience of having a child who has EBSNA and reveal that the impact of EBSNA goes beyond attendance and into the realms of mental health in young people and reveal the consequences that shake the foundations of the relationships in the home.

The parent's experience of engaging with schools in particular was largely negative and parents felt blamed, unheard and ignored, which resulted in a breakdown in the home and school relationship. They felt that there were inequities in the power dynamics and felt that their views and concerns held less gravitas than that of the profession. This resulted in incidents where parents felt powerless and without a sense of agency.

Despite this poor relationship with schools, parents did not blame the school for the cause of their child's EBSNA, instead they spent a great deal of time looking inwards, reflecting and looking for evidence and clarity, which would help them to understand their child's experience. These retrospective reflections highlight that parents had noticed traits in their child that did not seem significant at the time, but which preceded the emergence of a more serious problem.

This resulted in feelings of self reproach and guilt and a sense that they should have done things differently.

### **Reflective box: Extracts from reflective diary**

16/03/2017

My personal relationship with this subject means that it is critical that I maintain high levels of reflectivity and reflexivity.

The experience of listening to the stories of parents is extremely powerful and I'm struck by the emotional intensity of their experiences and the desire to share their stories with such honesty. The process of analysing the data is taking a great deal of time and I feel exhausted by the constant need to interpret using the double hermeneutic. I am particularly aware of my relationship with the topic and I'm conscious of not colluding with parents and to keep an open mind when analysing the data.

I was struck by the emergent themes in regard to professional involvement, which seemed negative and which were expressed by all the participants. I have returned to the analysis repeatedly to ensure that I am not inadvertently drawing out those themes at the cost of others. I was also struck at how little involvement parents had with EPs and wondered why they had not been involved with supporting these young people. I'm concerned that the research may portray schools and support agencies in a broadly negative light and I'm wondering if perhaps my participant group included parents who chose to be involved due to their difficult experiences.

In supervision, I have been reminded that it is important to recognise that my research did not involve interviewing professionals, who may have a different perspective on events than the parents.

## **5 Discussion**

### **5.1 Chapter overview**

This chapter will consider the research findings in relation to the previous literature review and psychological theories and frameworks. It is hoped that the findings will further what is known about the experience of parents who have a child who presents with EBSNA. This new knowledge will be explored alongside relevant research literature.

### **5.2 The Research Question**

This research had one clear aim; to explore the lived experience of parents who have a child with EBSNA. The interpretative phenomenological analysis of the data revealed four superordinate themes which help to illustrate the experience and to increase our knowledge and understanding. The themes are;

1. 'It turns your life upside down'
2. Power and the battle to be heard
3. Loss and fear
4. Retrospective clarity

There was shift in my thinking as a researcher during the data analysis stage, where I recognised that I was exploring the lived experience of parents who have a child with mental health needs and a recognition that EBSNA or school refusal is a symptom of a variety of disorders (McShane and Rey, 2001). The implications of this will be explored throughout this chapter. My initial intention to explore and discuss each of the superordinate themes separately in relation to the relevant literature, revealed an overlap in lots of areas, leading to an 'interconnectedness' between the superordinate themes. This overlap will be acknowledged and explored in relation to new ideas and the current literature.

### **5.3 “It turns your life upside down”**

This theme captured the far-reaching impact of having a child with EBSNA and the effect on the parent and the whole family. The impact was felt in their relationship with their family, their mental health/emotional wellbeing, and had financial implications, through having to change employment arrangements. There was pervasive impact on all areas of the parent’s life and this resulted in a new reality where the needs of the vulnerable child took precedence over everything else.

The subordinate theme of ‘Keeping the peace’ highlighted the complexity of supporting emotionally complex and vulnerable young people. Parents were mindful of their child’s needs and took care to show sensitivity and awareness, even if it created difficult feelings for them, which they had to put to the side. It revealed the motivation of parents to try and maintain a relationship with their child, even when they felt rejected by them at times. Stapley, Midgley & Target (2015) explored the experience of parents of adolescents who had been diagnosed with depression and revealed a similar theme that they call ‘Walking on Eggshells’. They found that parents admitted to changing their behaviour to avoid having confrontations with their child or out of fear of upsetting them. The parents in my research also adapted their behaviour, ignoring aggression and maintaining a high level of self-awareness to prevent saying ‘the wrong thing’, which could result in their child becoming emotionally escalated.

#### ***Loss of confidence as a parent***

There was an overlap with the theme of ‘keeping the peace’ and ‘loss of confidence as a parent’. It also highlights the notion of parental competency and confidence, which has been explored by Ohan, Leung & Johnston (2000). They suggested that the parental sense of competence is comprised of two attributes: one’s perception of his or her ability to be effective as a parent

and one's satisfaction or contentment with parenting. Their study of 110 mothers and 110 fathers of 5- to 12-yr old boys and girls, found that mothers and fathers who reported a more easy-going, low-conflict parenting style were more satisfied in parenting. This pattern of low conflict parenting was also associated with higher levels of parental self efficacy in mothers.

Preyde, Van Donge, Lazure-Valconi, et al., (2014) explored the relationship between what they call 'parental self-competence' and the child's mental health. They revealed that when the child's mental health symptoms were more severe and challenging that this corresponded with lower parental self-competence.

This anxiety is illustrated by Kerri:

***You know, your job as a parent is to make everything right, and I couldn't make anything right. Sometimes, there would just be no lightness for days on end. And she's gone...It has just been really, really difficult. (p.9. Line 22-24).***

The impact on parent's sense of self and their confidence in their parenting capacity is highlighted by research by Harden (2005). This study looked at the experiences of 25 parents of adolescents with mental health issues and captured the parent's feelings of helplessness and powerlessness in a theme called 'parental deskilling'. Their confidence in their ability to support their child was shaken and while these parents were sure that they were doing the best parenting job they could, the presentation of a mental health condition left them feeling as failing in their role as a parent. Feelings of being helpless caused by the lack of knowledge and experience to support their child through their difficulties were also reported. In addition to their own self reflections on their reduced parenting capacity, the study showed how parents experienced further degeneration in their confidence when they felt their actions and behaviour were being scrutinised by professionals. This notion of being scrutinised and judged by professional emerged in the theme of 'accusation and persecution', where parents felt blamed for their child's difficulties. Research by Bussard et al., (2015) found that parents described

being made to feel like a failure and comments from professionals suggested that they were not implementing their parental authority.

However, Harden (2005) also reveals a second theme that she describes as ‘parental reskilling, where parents actively educated themselves on psychiatric issues and felt able to critique the approach to care advised by the professionals. While this did not emerge as a theme for the participant group, it did feature as a subordinate theme for Amanda and Martin, who utilise their recognised privilege of being well educated and articulate to educate themselves and challenge the ‘system’. This sense of ‘parental reskilling’ (Harden, 2005), is also highlighted by Moses (2010), who explored the views of parents of adolescents who were receiving mental health treatment. It was shown that 22% of the parents reported a substantial reduction in their feelings of self-blame over time as parents had found ways to reason and resolve those feelings by recognising that they were doing their best and it was “good enough” (p. 111). They also reasoned that the lack of mental health needs in their other children, stood as evidence for their good parenting skills. This type of reasoning was also revealed by Dee (p.26. Line 26-30) to help reduce her anxiety in regard to her and her husband’s parenting.

### *Feeling trapped*

In the subordinate theme of ‘Feeling trapped’, parents reported persistent and constant feelings of stress and the desire to escape the pressure of the situation. Parents reported a lack of respite support where parents could have time away to manage their feelings. They described how attempts to spend time away from their child with just their spouse were often disrupted by the actions of their anxious child, who would insist they come home. There was a sense that the problem seemed to ‘follow’ them wherever they went. This notion of having your freedom curtailed is reported by Stapley et al., (2015) who found that parents were reluctant to leave their vulnerable child at home and had decided to place their social lives ‘on hold’ (p.625).

Parents reported how their job became a mechanism to escape the situation at home but was also associated with feelings of guilt of leaving your spouse to manage alone and on occasions having to leave an anxious child at home unsupervised. There is an overlap with this theme of 'feeling trapped' and the theme of 'impact on work', with some parents giving up successful careers and jobs in order to look after their child. Obviously, this was not an option for all the participants, but the impact on their job was reported by each of them. Two of the parents reported having supportive employers who allowed them to work flexibly and to continue to stay in employment. Research by Epstein & Sheldon (2002) shows the how EBSNA can affect how a family functions, as parents may be required to leave their job; leave children at home unsupervised which can lead to financial pressures and increased conflict within the home.

In the subordinate theme of 'Contagious anxiety' the parents described how they also experienced episodes of anxiety and depression. There seemed to be similarities between the child's emotional state and the parents, however, parents seemed to describe their anxiety as a response to their child's difficulties. However, this had not been validated and further research would be required to clearly ascertain the origins of the parent's anxiety.

Stapley et al., (2015) research produced similar findings and revealed that parents of young people with depression experienced had significant higher levels of strain and stress. In a theme they named 'emotional turmoil', parents reported feelings of worry, anxiety, guilt and self-blame.

The effect of a child's mental health on parents is reported by Martin, Cabrol, Bouvard, Lepine & Mouren-Simeoni (1999), they observed that there was a higher prevalence of anxiety disorders in children of parents who also had diagnosed conditions related to phobias or anxiety. Similar findings were reported by Bahali, Tahiroglu,, Avci, & Seydaoglu (2011) in their exploration of the relationship between parental psychological symptoms and familial risk

factors of children and adolescents who exhibit school refusal. They revealed that the school refusal group of parents had higher anxiety and depression scores than the controls and conclude that parents with psychiatric disorders appeared to be associated with development of psychiatric disorders in their children.

*The impact on family relationships.*

The impact of EBSNA on relationships within the family illustrates the pervasive nature of having a child with mental health needs, which affected the parent's relationships with their spouse, their child and the siblings of the affected child, who parents felt had been ignored. Parents felt conflicted as they recognised the impact of the situation on their other child but saw them as less vulnerable and as having more skills to cope.

Andy painfully recounted the comparison between his daughter and his son and how she has to manage her brother's difficulties:

***I feel so sorry for her. The thing is as well that, because he can't understand what's going on with him, he sometimes does get a bit angry. He's not a violent person but he gets a bit angry and takes it out on whoever he can and it's Helen he normally takes it out on. She is totally different. She's got loads of friends, but it must have been hard for Adam knowing that she is so popular and he feels like he hasn't got any friends. It breaks my heart sometimes. (Andy, p.15. Line 1-8).***

Research by Barnett and Hunter (2011) highlighted the effect on siblings of children who have mental health difficulties and revealed that they have higher rates of psychopathology and internalised behaviour disorders. This suggests a need for support for the whole family and not just the child affected by mental health difficulties. Preyde et al., (2014) suggest that when a child presents with a mental health disorder, there should be a community response, which

includes the involvement of different agencies brought together to provide support for both the family and the young person.

#### **5.4 Power and the battle to be heard**

This theme dominated every parental interview with relationships with schools and professional agencies being broadly framed as being negative. The names of professionals were rarely used, instead terms such as ‘the system’, ‘the school’, ‘they’, ‘them’, ‘the authorities’ and even ‘the enemy’ which elicited a sense of a faceless, nameless almost non-human entity. Parents did not use the term ‘we’ when describing the relationship between themselves and professionals, instead with a theme of ‘them’ and ‘us’ emerged, which is discussed further in this chapter.

##### *Loss of trust*

The subordinate theme of ‘Loss of trust’ revealed that parents frequently felt unsupported by their child’s school and professional agencies and revealed a sense that parents felt that schools did not trust them. In their study on the parental experience of what they describe as anxiety-based school refusal (ABSR), Bussard, Haarf, Sibeoni, Radjack, Benoit & Moro (2015) found that parents viewed educational institutions negatively, seeing them as malevolent and unsupportive. Parents felt that the school was keen to remove their child from school and to pass the problem on elsewhere. This sense of being ‘pushed out’ was reported by all five participants, who felt that their child was viewed as a ‘hinderance’ (Andy, p. 38. Line 28) and who seemed keen to have them attend the AEP, rather than help them to stay in a mainstream setting.

It could be helpful to consider the psycho-dynamic concept of ‘Organization-in-the-mind’, which is defined by Reed and Bazalgette (2006) as:

*‘a construct focussed around emotional experience, task, roles, purposes, boundaries, rituals, accountability, competence, failure and success within the enterprise’ (p.6).*

School attendance is recognised as being a key factor in educational success and schools are under increasing pressure to achieve results and keep high attendance figures, which are essential for a successful OFSTED rating. The ‘primary task’ is defined as the shared sense of purpose in regard to an organisation. Establishing a clear and shared understanding of the primary task, i.e. what the organisation is primarily intended to achieve, is critical for the work to be effective (Zagier Roberts, 1994). If a school defines the primary task as teaching academics, it can make it difficult to create space to be able to consider the emotional needs of the child. School staff can find themselves caught in the difficult position of having to prioritise the responsibility of responding to the primary task over the emotional needs of the child, which impacts the relationships between the school and family. I do not suggest that this is the case in all schools, but it may be useful to consider the school’s culture in such matters.

The value of positive and trusting professional relationships was highlighted by research by Sibeoni, Orri, Podlipski, Labey, Campredon, Garadin & Revah-Levy (2018), who explored the experiences of parents of adolescents who present with ABSR and who have received psychiatric care. Parents valued the relationships with teachers in the psychiatric unit who were described as being *‘kind, patient and altruistic’* (p.47) which the young people found to be a healing experience. This is in contrast to Bussard et al., (2015), where school staff were viewed negatively but shows the difference in staff in schools and specialist provisions where the ‘primary task’ may be very different as the priority is the child’s emotional wellbeing. The parents in my study were positive about their experience with the AEP, who they felt

understood the needs of their child better than the school and had greater levels of knowledge and awareness. This helped to reduce the anxiety at home for both the young person and their parent.

### *The importance of professional awareness*

The perceived lack of awareness of the complexity of the problem from professionals was highlighted, which resulted in situations which parents felt were poorly managed or where unhelpful advice was offered. Archer, Filmer-Sankey and Fletcher-Campbell (2003) examined definitions of school phobia and school refusal among local authority and school staff across England in a large-scale piece of research which involved 60 Local Authorities (LAs) across the UK. They found that just over half of the LAs which responded indicated that they distinguished school refusers and phobics from other nonattenders and just under a third of LEAs which responded also said that they had specific written guidance for school staff or parents on school refusal or phobia. Their research showed that Education Welfare Officers (EWO) were most likely to identify 'school refusal or school phobia' but only 6 out of the 60 LEAs had a psychologist assessment to identify the reason for school non-attendance. A number of teachers from their study reported that they felt that school refusers and phobics were more likely to come from disadvantaged or dysfunctional backgrounds where school was not valued. This professional perspective was reported by several of the parents, which they felt was an inaccurate portrayal of their circumstances and which felt insulting and accusatory to them. It should be recognised that this current research does not suggest that socio-economic factor play a part in the topic of EBSNA but the participants in this particular study were from a higher socio-economic group but felt that the same assumptions about disadvantage and

dysfunction were being applied to them. Attempts made by parents to challenge these assumptions seemed to be unrecognised by professionals, leaving parents feeling frustrated:

*And I think one of the reasons I got very angry with this Welfare Officer was that I'm not stupid, I work in education, I told you, we're educated people and education is important to us. Please don't tell me about how this is affecting Emma's future, just listen to us and try and provide what we believe you need to provide. But she was unable to do it. (Kerri, p.20. Line 15-19).*

This sense of not being listened is found in research by Harden (2005), who reported that parental confidence was diminished when their concerns about their child were rebuffed and they were often being accused of overreacting to what were regarded as normal adolescent behavioural changes. Parents felt that their expertise and knowing of their child was ignored and undermined by the responses of professionals who did not seem to recognise the problems and concerns that were being raised by parents, particularly at the start, when the problem was emerging. Similar findings were also reported by Davies and Lee (2006), who revealed that parents of school refusers, found that home/school communication systems are poor, schools are deemed to be arrogant towards parents and students and for some parents, the Education Welfare Service as a whole is not seen as a major source of support. However, support staff such as Learning mentors, Connexions personnel, alternative education providers and individual Education Welfare Officers were identified as helpful.

In my research, parents had attempted to downplay their concerns at the start and help from professionals was only sought when the problem became fully evident and difficult to manage.

The issue of how schools recognise Social, Emotional and Mental Health Needs (SEMH) was highlighted by the parent's feelings of frustration that their child school non-attendance was viewed as a disciplinary or behavioural issue, when they viewed it as a SEMH issue. Parents had been active participants in the process of accessing support from CAMHS, however, they reported that the process of trying to get support could be very difficult as the threshold criteria is set very high as Dee describes here:

*We eventually got an appointment with CAHMS, we'd raised a number of concerns that we thought Archie had over the years with our doctor, but never really got a referral to CAMHS because obviously their criteria and their waiting list, they're so stretched that you literally have to be poking your eyes out with knives before you get an appointment. (Dee, p.6. Line 31-36)*

Blum (2007) interviewed mothers of children with 'invisible disabilities' such as Attention Deficit Hyperactivity Disorder (ADHD) and used the term 'vigilante' to describe two aspects of behaviour particularly from mothers. The first refers to the intensified monitoring of their child and their self that these mothers engaged in, and second, was the advocacy these mothers presented on behalf of their vulnerable child to obtain the support, services, and treatment necessary to ensure their child's success.

#### Accusation and persecution

The lack of perceived professional awareness by parents formed the basis of the subordinate theme of Accusation and Persecution. This theme was present in all the participant transcripts and elicited the strongest emotional responses from the parents, who felt blamed, attacked and the pressure of being at risk of legal prosecution. The accusation that they were responsible for their child's experience had an impact on parents. Harden (2005) also found that parents were at times implicated by in the diagnosis of their child's mental health need and held as being causally responsible for the condition by professionals. To explore this theme, I have taken a psychodynamic perspective to look at the possible unconscious processes that may be at play and considered the interaction of other superordinate themes which are connected. When taking a psycho-dynamic perspective, findings should be viewed tentatively and not as hard evidence but in a way that illuminates current thinking. Parents reported the level of distress and emotional turmoil they experienced in superordinate theme 3- Loss and Fear, when having to witness the pain of their child's depression and anxiety. The notion that they could be responsible for causing this experience, is highly distressing and possibly unbearable,

especially when parents seemed to spend a great deal of time reflecting on how this situation was created. In Superordinate theme 4: Retrospective Clarity, parents frequently looked back for 'clues' to help them make sense of their child's difficulties. They often reflected on their own behaviour and actions, thinking about things that they may or may have not done and the impact that this had on their child. When professionals accuse parents of being the causal factor of their child's mental health issues it could be seen an attack on their self-identity and their role as a parent. However, the accusations made specifically by teachers could also represent a 'defence' against their anxiety as they may feel impotent and powerless and have little capacity to improve the situation.

The child's rejection of school may also be felt personally as rejection of them and the concept of school. The concept of 'splitting' and 'projection identification' (Klein, 1946) could be relevant in this situation. Klein's (1946) theory of splitting and projective identification suggests that the failure to integrate both the good and the bad, creates an anxiety that splits the psyche into a paranoid/schizoid position, where all the 'good' is located in one place and the 'bad' in the other. In this sense, professionals may be locating the 'bad' in the parents, thus allowing them to not hold onto the anxiety that perhaps there has been a failure within them or the school which may be responsible. However, in the same way, parents may also be projecting their anxiety into the 'system' as a way of protecting against their difficult feelings of their role in the situation and also as a way of preventing their frustration with their child. Supporting a child with complex mental and emotional needs can be exhausting, in this research parents did not attribute blame to their child despite feeling hurt and frustration at time.

Accusations of poor parenting and blame towards the mothers in my study impacted parents deeply. Hoskins and Lam (2003) identify the tendency in the field of psychology towards mother-blaming and how it leads to mothers sometimes assuming that they may be the causal

factor. Mothers reported feeling that they bore the brunt of the situation and there was an interesting gender imbalance where mothers were targeted as being responsible for causing their child's problem, with this being reported by both mothers and fathers. The social construction of gender may be useful to consider and as Gray (1993) recognises, mothers seem to take the role and responsibility of representing their family to the world. Francis (2012a) observes that parenting is synonymous with mothering and he suggests that parenting:

*'is characterized by an ideology of "intensive mothering" in which parents, particularly mothers, are held entirely responsible by society for all areas of their children's lives and development.'* (p. 374).

### Power imbalance

The subordinate theme of power imbalance represented the oppositional and sometimes combative experience of professional interaction reported by parents.

The language used by parents to describe their experience included terms such as 'battle', 'fight', 'enemy' and 'the system', which elicited images of a powerful opponent that parents faced in order to get help. Systems such as school and the Education Welfare Service (EWS) were viewed unfavourably compared to specialist provisions such as the AEP and CAMHS.

In the literature review, we explored the dominant discourses on the concept of school attendance, which seems to be dominated by clinical and legal discourses. Pellegrini (2007) comments on the notion that the importance of school attendance as an essential component to the development of a society, as school is place where children learn to the skills and values that teaches them how to be a good 'citizen'. In this sense, school non-attendance is a danger to wider society and a rejection of school could undermine the foundation of our society.

As Pellegrini identifies the problem of EBSNA is generally located within the family, they are positioned as having the 'locus of control'. This is reflected in how government guidance which focusses on parental responsibility. The guidance from the Department of Education (DfE) recommendations for improving levels of attendance focusses on the parent's responsibility to ensure their child attends school, a failure to ensure this results in financial penalties. (Improving attendance at school, DFE, 2012). The DFE also advise local authorities to use parenting contracts, parent orders and parenting courses, which are aimed to help parents improve their child's attendance. (DFE, 2015). This legislative guidance seems to feed into how schools approach non-attendance and may underpin the feelings of persecution reported by parents, rather than feeling than supported with a collaborative approach. School staff and EWO's are directed to follow guidance which focusses on changing the behaviour of the parent as a way to improve attendance, this may result in a lack of curiosity to explore the situation in more depth.

The SEND Code of Practice (2015) highlights the importance of collaborative partnerships between home and school and places the family at the centre. However, the parents in this research did not report feeling valued or collaborated with, instead there were reports of feeling unheard, ignored and powerless. In Andy's case he seemed to suppress his own parental instincts and trust the perceived expertise of professionals who took action which caused distress to the family. For Andy, his instinct as a father to protect his child was challenged by his confusion of the situation, which led him to feel powerless when he was threatened with legal prosecution.

The need for a collaborative system is highlighted by research by Widmark, Sandahl, Piuva and Bergman (2013), who explored the parental experience of collaboration between welfare professionals regarding children with anxiety or depression. Their findings reveal how parents experienced the interaction with professional agencies in a way that deeply affected them. They

highlight the importance of having good communication and coordination links, which facilitated the process of a collaboration between parents and professionals. They also found that when professionals showed empathy, commitment and shared information with parents, it lay the foundation to building positive and trusting relationships.

The lack of professional support for parents was highlighted by parents, who felt that they had no respite and few places where to offload and share their own difficulties, instead informal networks with friends became very important to some of the parents. Two of the parents had access to family therapy through CAMHS which they found helpful.

The importance of having positive and empathic relationships with professionals is captured in this quote from Amanda:

*Oh, it's so nice to be able to speak and to be listened to, without being judged." So, if all the professionals involved could learn that bit, that would be the change, and we've, obviously said, "Yes, we know people are over-stretched, and we know there's no funding, and it's not getting any better," but, actually, changing your mindset on how you approach a family actually doesn't cost any money. None at all, and if professionals can achieve that, and that alone, and, in words and deeds, show that they're supporting the parent, or at least trying to understand, because, unless you've lived it, you won't know what it's like. (Amanda, p.35. Line 29-35, p.36. Line 1-6).*

In this quote Amanda clarifies the importance of having her story heard and the need to be understood.

## **5.5 Loss and fear**

This theme captures the intense emotional experience of parents, which included feelings of grief from reflecting on what had been lost from the past and their fear for the future.

One of the most difficult experiences reported was having to watch their child lose what they felt was the freedom of childhood, which they grieved for as parents. Dee powerfully illustrates this point:

*... it's like watching a child die, that's exactly what's been, it's like the old child that we had has died, and this new one... It's just, he's just not a fully functioning individual, a child. It's like he doesn't have a childhood, it's really sad. (p.15. Line 1-3).*

The start of adolescence also heralded the start of an escalation in their child's mental health needs, which seemed to identify a split between then and now and the loss of the child that used to exist. Adolescence is known to be a period of development which is associated with an increased risk for the onset of mental health problems, including depression and anxiety. (Stice, Shaw, Bohon, Marti, & Rohde 2009). It also coincides with the start of the transition from primary to secondary, which was a critical period for each of the children of the parents in this study and marked an increase in their anxiety and EBSNA.

The experience of emotional turmoil was reported in this theme, with parents reporting the loss of confidence in their parenting skills, which left them feeling unsure and self-conscious in how they interacted with their child and sometimes helpless in knowing how to support them. This is also reported by Stapley et al., (2016) whose study of 48 parents, mostly mothers, of adolescents who had been diagnosed with moderate to severe depression. A thematic analysis revealed four main themes: parents' 'lack of awareness' that their child was experiencing depression or that their child was experiencing any problem at all; the 'emotional turmoil' that parents were experiencing alongside that of their child; parents' feelings of 'helplessness'; and 'parenting in overdrive'. The parents in my study also presented with similar themes, for example 'lack of awareness' shares the feelings parents described in 'Retrospective clarity' where they felt that they had missed signs or where they initially had not fully recognised the extent of their child's difficulties. The theme of 'emotional turmoil' and 'helplessness' is

captured in my theme relating to ‘loss and grief’, where parents described feelings akin to bereavement and a loss in their confidence as a parent. The theme of ‘parenting overdrive’ shares similarities with my theme of ‘power and the battle to be heard’ where parents challenge and assert themselves in the quest to ensure support for their child.

They reported feeling helpless and excluded from school and worried about the consequences of their child missing education in the future. Parents in my research also highlighted their fears and worries for their child in the future; fears that their problem with anxiety would continue into adulthood and prevent them from achieving their potential. There was a recognition that their child was growing up quickly and that there was a limited amount of time before their compulsory school ended. The desire for their child to overcome their difficulties and to live a ‘normal’ life was highlighted by the quote from Andy in section 4.4 who worries about how his son will cope in the real world

### **5.6 Retrospective Clarity**

This theme encompasses how parents reflected on the past and on their actions and their desire to have clarity about the origins of their child’s difficulties, to help them make sense of their experience.

The notion of hindsight revealed that parents had been aware that their child had a subtle, underlying difficulty, however, until adolescence the problem seemed to exist below the surface. In Kerri’s case, when the school PASS questionnaire raised concerns about her daughter, she did not fully recognise the significance of those PASS results at the time and did not realise that the problem would evolve as it did, which created a sense of self remorse and guilt for not recognising and understanding the problem before. Stapley et al., (2016) also found a subtheme of ‘guilt and self blame’ (within the theme of ‘emotional turmoil’) in their research,

where parents reflected on whether they had caused the problem , by being too angry or neglectful, or had passed on faulty genetics.

Bussard et al., (2015) also reported on the parental understanding on the ‘origin of the troubles’. In their study, eight parents mentioned a traumatic incident that happened at school as a trigger for school refusal. The majority of parents identified a family role in the troubles their child faced (separation, conflict, over-protection, overly ambitious academically).

Each of the participants in my research were able to identify potential triggers for their child’s unwillingness to attend school, including; autism, bereavement, traumatic experiences and bullying. While they had criticisms of the how the school managed their child’s EBSNA, they did not blame the school as being the cause of it.

For three parents (two of them share a child), Autistic Spectrum Disorder (ASD) was a key feature in their child’s EBSNA, along with another parent who felt it could be a factor. Research by Munkhaugen, Gjevik, Pripp, Sponheim & Diseth (2017) suggests that children with ASD are more likely to present with EBSNA. Their research included a cross-sectional study of 216 students, including 78 students with ASD and 138 typically developing(TD) students and found that school refusal behaviour was significantly higher in students with ASD as compared to TD students and conclude that school refusal behaviour is pervasive in students with ASD.

The need for clarity and an explanation of how their child developed these difficulties was a source of frustration and which led parents to feel guilty about their ‘not knowing’ and actions they took in past when they were less knowledgeable. This notion is mirrored Stapley’s (2016) theme of ‘Dealing with the unknown’, where parents expressed the desire to understand their child’s experience.

## **5.7 Impact and implications**

Educational psychologists are on the front line and are able to provide valuable consultation and early intervention to support children and families in cases of EBSNA, anxiety and mental health issues. The participants in my study had little involvement with the Educational Psychology Service, which would only be accessed through a referral from the school directly. This is specific to my particular EPS and this may not be the cases in other LAs, however, it does highlight the variation in how the topic of EBSNA is addressed by the educational psychology profession and suggests that we may have more significant role to play.

A key finding from this research highlighted the uneven power dynamics perceived by parents between themselves and professionals, who felt their knowledge, experience and contribution was not valued and held less influence than that of the professional. It is recognised that there is an inherent imbalance that occurs when offering and receiving ‘help’ (Schein, 2009) and how the receiver of the help holds less power than the provider of help. Schein argues that this dynamic is unavoidable, but the consultant/professional must ensure that awareness of the imbalance is recognised, and steps are taken to reduce it as it takes time to build a relationship which feels equitable with the family, who are at the centre of the process. Families will benefit from having their story being listened to carefully without assumption. This is what Schein describes as the importance of ‘accessing your ignorance’ and taking a genuine/humble approach when exploring a situation. Humble inquiry allows for three important things to occur; to help the client/parent feels empowered as it is acknowledged that they are the keeper of important information, it shows the client that we are emotionally interested and committed to the situation and it allows for the discovery of important information.

EPs have a role in supporting schools to facilitate helpful consultation and to developing more positive, collaborative relationships, which empower and support rather than ‘deskill’ parents

(Harden, 2005). The key tenet of this research recognises that our practice as professionals is improved when we listen carefully and try and understand the lived experiences of the people we are positioned to support.

Schools need to be supported to ensure that they follow the legislative guidance from the SEND Code of practice (2015) and ensure that the child and the family remain at the centre of any collaborative, multi professional work. The lack of the term 'we' in my research highlights the lack of positive, collaborative involvement that parents had with professionals and suggests that professionals should consider ways in building more positive and balanced relationships with parents. However, the current pressures on schools and support services also needs to be considered, especially in the current political climate of 'austerity'. Public services are under increasing strain, particularly in the NHS, which includes CAMHS, which affects the accessibility of support from the service. Schools too are under increasing pressure to ensure high whole school attendance figures which are monitored by Ofsted, which may result in pressure on attendance being passed through to students and families. The priority becomes the attendance figure which possibly means the needs of the child can be lost.

The value of an early warning system which helps to identify EBSNA and provides targeted support could be a key factor in preventing the situation escalating. Early intervention is also known to be extremely important when tackling the topic of school refusal and it is important that school staff and EWOs who deal with the issue of attendance first are aware of the multifactorial aspects of EBSNA and remain open to the possible causes and potential solutions that can be offered. The process of being heard and having their concerns respected was of critical importance to parents, this does not suggest that professionals should collude and not challenge parental perspectives but highlights the value of constructive partnerships based upon trust.

The period of adolescence and the transition to high school is recognised having an increased risk (Stice et al., 2009) of the onset of mental health difficulties and highlights the importance of supportive pastoral care when children start high school and schools should be vigilant and be knowledgeable to the signs and symptoms. Improving home and school relationships, where parents feel heard and supported may help to resolve problems before they escalate.

### **5.8 Discussion of methodological issues**

The literature review searches revealed that there were very few studies that had explored the experiences of parents of children with EBSNA and highlighted the need for further exploration of the subject. The choice of IPA as a tool of data analysis was an appropriate one as this research was not concerned with measuring outcomes or developing a unifying theory-it had one clear purpose, which was to increase our understanding of the lived experiences of these parents. IPA allowed me to conduct an in-depth exploration and served as an emancipatory piece of research where the parent's voice can be heard. I was faithful to the IPA process of an analysis as described by Smith et al (2009). The use of a semi-structured interview format allowed parents to direct the interview and to discuss new areas of importance. It was essential that the parents felt able to lead the discussion and there was a sense that they had been waiting for an opportunity to be heard in honest detail, possibly for the first time. I have aimed to be as transparent as possible by explaining the process of analysis and including extracts from the transcript which demonstrate my interpretations but also to allow the reader to reflect on their perspective on the meaning of the transcript and to consider other potential alternative meanings. The interpretative nature of IPA means that there is an inevitable bias, as each of us has our own autobiographical lens through which we understand the information. (Smith et al.,

2009). However, I have tried to ‘bracket off’ my preconceived notions and maintain reflective and reflexive integrity.

### **5.9 Limitations of research**

The purpose of IPA is not to identify far reaching conclusions that can be applied to a wider population, therefore there are limitations on how generalisable these findings are. However, this research has allowed for a deeper level of understanding and awareness of the experiences of parents of children with EBSNA. The small sample size is an additional reason for the lack of generalisability and the inclusion of a couple in the participant group could be a confounding factor and may have influenced the development of the major themes in the study.

The participants in this research formed a fairly homogenous group, as per IPA guidance (Smith et al., 2009), in terms of socio-economic group, relationship and family group. However, the majority of the participants had a white British heritage and were from a middle-class background. The issue of diversity and difference on this subject has not been addressed and it is possible that with a different participant group the findings could be very different. It is important to recognise that participant involvement was voluntary and that parents who felt more confident and perhaps had experiences that they wanted professionals to know about were more likely to participate, which may have influenced the findings in this study.

My decision to not check back my findings with the participant group is discussed in section 3.11, however this does reduce the testimonial validity of the research.

### **5.10 Dissemination of findings**

The findings from this research will be shared in the following ways;

- A short summary identifying key findings and implications will be sent to each of the participants and to the AEP.

- A presentation will be made to my EPS and the local authority Education Welfare Service.
- A presentation will be made to fellow TEPs and tutors at the Tavistock in July 2018.
- Publication in part of the research in a journal.

### **5.11 Future research**

This study included parents whose child had experienced such a severe level of EBSNA that they were no longer able to attend a mainstream secondary school; further research could explore the experiences of parents whose child is in the early stages of EBSNA and who are still attending school, but with low attendance rates.

The experiences of parents of primary school children with EBSNA have not been explored before and could reveal a very different experience from parents of adolescents. It may also offer useful information that could facilitate the development of early intervention strategies.

The impact of EBSNA on parents from different social and racial groups may be an area of useful exploration in the future, in particular in the area of parental and professional relationships.

This research took a qualitative approach, however larger scale quantitative research could help generate findings that could be applied to a wider population.

## **6. Conclusion**

This research aimed to explore the lived experiences of five parents of young people who present with EBSNA, which has resulted in their attendance to an AEP. An interpretative phenomenological analysis of the data from the semi-structured interviews revealed 4 superordinate themes, which were; 'It turns your life upside down'; Power and the battle to be heard; Loss and fear and Retrospective clarity. The results show the pervasive impact on the whole family and on virtually every aspect of the lives of the parents. This included their confidence in their parenting capacity, relationships with their spouse and children, employment and career, and the impact on their own mental health and emotional wellbeing.

Parents reported that they did not feel supported by schools who they perceived as accusatory and blaming, they expressed frustration in the difficulties they had accessing specialist services and the power inequity that made them feel that the system was adversarial and did not hear their concerns and recognise their needs. However, the alternative education provision was viewed as being a source of support, with staff who understood the complexities of their child's needs. This support helped to reduce the levels of stress and anxiety within the home.

Parents experienced emotional turmoil in the form of loss and grief; loss for the child that used to exist and for the loss of the joy and freedom of childhood, that their child was no longer able to enjoy. Parents expressed fears and uncertainties about how their child would cope in the future and worried they would have difficulties building a career or having typical adult relationships.

Parents expressed the desire for clarity, to help them make sense of how and why their child developed this condition. Reflecting on the past brought up feelings of guilt of not recognising the problem earlier and how they responded to their child in the past.

The research findings illustrate that the experience of having a child with mental health needs is a challenging and painful experience for parents. The need for a holistic approach where the entire family can be supported is critical to improving the relationship between parents and professionals. Our own practice as educational psychologists can be improved when we can truly empathise and understand the experience of the family, which leads to greater clarity on how we can best support others. The value of collaborative and trusting relationships is a key tenet in the SEND Code of Practice (2015) and by increasing our understanding of the parental experience we can facilitate positive and lasting outcomes for children and families.

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## Appendix A: Literature search

Search 1: Databases used: Psychology and Behavioral Sciences Collection, PsycINFO, Education Source, ERIC, PEP Archive

Terms used 'School Refusal' and 'parent\*' on 1<sup>st</sup> February 2018

Date restriction: 1995-2018

Peer reviewed academic journals in English only = 82 Results

Relevance to literature review questions: 8

Author	Date	Title and Journal	Included/excluded	Reasons
Sibeoni J, Orri, M., Podlipski, MA., Labey, M., Campredon, S., Geradin, P., Revah-Levy, A.	2018	The experience of psychiatric care of adolescents with anxiety-based school refusal and of their parents: A qualitative study. <u>Journal of the Canadian Academy of Child and Adolescent Psychiatry</u> [01 Jan 2018, 27(1):39-49]	YES	
Bussard, D., Harf, A., Sibeoni, J., Radjack, R., Benoit, J. P., & Moro, M. R.	2015	The parents' experience of school refusal in adolescence]. <i>Soins. Pédiatrie, Puericulture</i> (286), 31-36. doi:10.1016/j.spp.2015.07.006	YES	
Bernstein, G. A., & Borchardt, C. M	1996	School refusal: Family constellation and family functioning. <i>Journal of Anxiety Disorders</i> , 10(1), 1-19. doi:10.1016/0887-6185(95)00031-3	YES	
Bernstein, G. A., Warren, S. L., Massie, E. D., & Thuras, P. D.	1999	Family dimensions in anxious–depressed school refusers. <i>Journal of Anxiety Disorders</i> , 13(5), 513-528. doi:10.1016/S0887-6185(99)00021-	YES	

Carless, B., Melvin, G. A., Tonge, B. J., & Newman, L. K.	2015	The role of parental self-efficacy in adolescent school-refusal. <i>Journal of Family Psychology</i> , 29(2), 162-170. doi:10.1037/fam0000050	YES	
Christogiorgos, S., & Giannakopoulos, G.	2014	School refusal and the parent-child relationship: A psychodynamic perspective. <i>Journal of Infant, Child &amp; Adolescent Psychotherapy</i> , 13(3), 182-192. doi:10.1080/15289168.2014.937976	NO	
Coulter, S	1995	School refusal, parental control and wider systems: Lessons from the management of two cases. <i>Irish Journal of Psychological Medicine</i> , 12(4), 146-149. doi:10.1017/S0790966700014294	NO	Unable to access full text
Davies, J. D., & Lee, J.	2006	To attend or not to attend? Why some students chose school and others reject it. <i>Support for Learning</i> , 21(4), 204-209. doi:10.1111/j.1467-9604.2006.00433.		
Egger, H. L., Costello, E. J., & Angold, A.	2003	School refusal and psychiatric disorders: A community study. <i>Journal of the American Academy of Child &amp; Adolescent Psychiatry</i> , 42(7), 797-807. doi:10.1097/01.CHI.0000046865.56865.79	YES	
Havik, T., Bru, E., & Ertesvåg, S. K.	2014	Parental perspectives of the role of school factors in school refusal. <i>Emotional &amp; Behavioural Difficulties</i> , 19(2), 131-153. doi:10.1080/13632752.2013.816199		
Kearney, C. A., & Silverman, W. K.	1995	Family environment of youngsters with school refusal behavior: A synopsis with implications for assessment and treatment. <i>American Journal of Family Therapy</i> , 23(1), 59-72. doi:10.1080/01926189508251336	YES	
Levy-Warren, M. H.	2014	A resumption of adolescent development: Discussion of 'School refusal and the parent-child relationship'. <i>Journal of Infant, Child &amp; Adolescent Psychotherapy</i> , 13(3), 198-201. doi:10.1080/15289168.2014.939030	NO	
Martin, C., Cabrol, S., Bouvard, M. P., Lepine, J. P., & Mouren-Siméoni, M.	1999	Anxiety and depressive disorders in fathers and mothers of anxious school-refusing children. <i>Journal of the</i>	NO	There was no specific reference to the concept of EBSNA/ School refusal

		<i>American Academy of Child &amp; Adolescent Psychiatry, 38(7), 916-922. doi:10.1097/00004583-199907000-00023</i>		
Sapountzis, I.	2014	The space to be: Commentary on 'School refusal and the parent-child relationship'. <i>Journal of Infant, Child &amp; Adolescent Psychotherapy, 13(3), 193-197. doi:10.1080/15289168.2014.937977</i>	NO	

**Search 2: Databases used: Psychology and Behavioral Sciences Collection, PsycINFO, Education Source, ERIC, PEP Archive**

**Terms used 'School Anxiety' and 'parent\*' on 1<sup>st</sup> February 2018-**

**Date restriction: 1995-2018**

**Peer reviewed academic journals in English only =18**

**Relevance to research= 1**

Author	Date	Title and Journal	Included/excluded	Reasons
<b>Yaffe, Y.</b>	2008	Establishing Specific Links Between Parenting Styles and the S-Anxieties in Children: Separation, Social, and School. <i>Journal Of Family Issues, 39(5), 1419-1437. doi:10.1177/0192513X17710286</i>	<b>No</b>	

Search 3: Databases used: Psychology and Behavioral Sciences Collection, PsycINFO, Education Source, ERIC, PEP Archive

Terms used 'School Phobia' and 'parent\*' on 1<sup>st</sup> February 2018-

Date restriction: 1995-2018

Peer reviewed academic journals in English only =63

Relevance to research= 4

Author	Date	Title and Journal	Included/excluded	Reasons
Brumariu, L. E., & Kerns, K. A.	2010	Mother-child attachment patterns and different types of anxiety symptoms: Is there specificity of relations?. <i>Child Psychiatry And Human Development</i> , 41(6), 663-674. doi:10.1007/s10578-010-0195-0	NO	Specific to separation anxiety not school refusal
Carless, B., Melvin, G. A., Tonge, B. J., & Newman, L. K.	2015	The role of parental self-efficacy in adolescent school-refusal. <i>Journal of Family Psychology</i> , 29(2), 162-170. doi:10.1037/fam0000050	YES	
Carroll, H. C. M.	2015	Pupil absenteeism and the educational psychologist. <i>Educational Studies</i> , 41(1-2), 47-61. doi:10.1080/03055698.2014.955731	NO	
Egger, H. L., Costello, E. J., & Angold, A.	2003	School refusal and psychiatric disorders: A community study. <i>Journal of the American Academy of Child &amp; Adolescent Psychiatry</i> , 42(7), 797-807. doi:10.1097/01.CHI.0000046865.56865.79	YES	

Search 4: Databases used: Psychology and Behavioral Sciences Collection, PsycINFO, Education Source, ERIC, PEP Archive

Terms used 'School Non-Attendance' and 'parent\*' on 1<sup>st</sup> February 2018

Date restriction: 1995-2018

Peer reviewed academic journals in English only: 6

Relevance to literature review questions: 1

Author	Date	Title and Journal	Included/excluded	Reasons
Havik, T., Bru, E., & Ertesvåg, S. K.	2015	School factors associated with school refusal- and truancy-related reasons for school non-attendance. <i>Social Psychology of Education</i> , 18(2), 221-240. doi:10.1007/s11218-015-9293-y	NO	No reference is made to the experience of parents or family dynamics

**Search 5: Databases used: Psychology and Behavioral Sciences Collection, PsycINFO, Education Source, ERIC, PEP Archive**

**Terms used 'School Refusal' and 'Famil\*' on 1<sup>st</sup> February 2018**

**Date restriction: 1995-2018**

**Peer reviewed academic journals in English only: 96**

**Relevance to literature review questions and not repeated from previous searches: 1**

<b>Author</b>	<b>Date</b>	<b>Title and Journal</b>	<b>Included/excluded</b>	<b>Reasons</b>
Bahali, K., Tahiroglu, A. Y., Avci, A., & Seydaoglu, G.	2011	Parental psychological symptoms and familial risk factors of children and adolescents who exhibit school refusal. <i>East Asian Archives of Psychiatry</i> , 21(4), 164-169	YES	

**Search 6: Databases used: Psychology and Behavioral Sciences Collection, PsycINFO, Education Source, ERIC, PEP Archive**

**Terms used 'School Anxiety' and 'Famil\*' on 1<sup>st</sup> February 2018**

**Date restriction: 1995-2018**

**Peer reviewed academic journals in English only: 9**

**Relevance to literature review questions and not repeated from previous searches: 0**

**Search 7: Databases used: Psychology and Behavioral Sciences Collection, PsycINFO, Education Source, ERIC, PEP Archive**

**Terms used 'School Anxiety' and 'Famil\*' on 1<sup>st</sup> February 2018**

**Date restriction: 1995-2018**

**Peer reviewed academic journals in English only: 9**

**Relevance to literature review questions and not repeated from previous searches: 0**

**Search 8: Databases used: Psychology and Behavioral Sciences Collection, PsycINFO, Education Source, ERIC, PEP Archive**

**Terms used 'School phobia' and 'Famil\*' on 1<sup>st</sup> February 2018**

**Date restriction: 1995-2018**

**Peer reviewed academic journals in English only: 36**

**Relevance to literature review questions and not repeated from previous searches: 0**

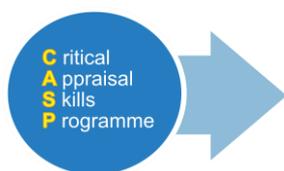
**Search 9: Databases used: Psychology and Behavioral Sciences Collection, PsycINFO, Education Source, ERIC, PEP Archive**

**Terms used 'School non-attendance' and 'Famil\*' on 1<sup>st</sup> February 2018**

**Date restriction: 1995-2018**

**Peer reviewed academic journals in English only: 15**

**Relevance to literature review questions and not repeated from previous searches: 0**



## 10 questions to help you make sense of qualitative research

### How to use this appraisal tool

Three broad issues need to be considered when appraising a qualitative study:

- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions.

There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

**Referencing: we recommend using the Harvard style citation, i.e.:**

**Critical Appraisal Skills Programme (2017). CASP (insert name of checklist i.e. Qualitative Research) Checklist. [online] Available at: *URL*. Accessed: *Date Accessed*.**

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# Screening Questions

1. Was there a clear statement of the aims  Yes  Can't tell  No of the research?

HINT: Consider

- What was the goal of the research?
- Why it was thought important?
- Its relevance

---

2. Is a qualitative methodology appropriate?  Yes  Can't tell  No

HINT: Consider

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal?

## Is it worth continuing?



### Detailed questions

3. Was the research design appropriate to  Yes  Can't tell  No address the aims of the research?

HINT: Consider

- If the researcher has justified the research design (E.g. have they discussed how they decided which method to use)?

**4. Was the recruitment strategy appropriate to the aims of the research?**  Yes  Can't tell  No

HINT: Consider

- If the researcher has explained how the participants were selected
  - If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
  - If there are any discussions around recruitment (e.g. why some people chose not to take part)
- 

**5. Was the data collected in a way that addressed the research issue?**  Yes  Can't tell  No

HINT: Consider

- If the setting for data collection was justified
  - If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
  - If the researcher has justified the methods chosen
  - If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?
  - If methods were modified during the study. If so, has the researcher explained how and why?
  - If the form of data is clear (e.g. tape recordings, video material, notes etc)
  - If the researcher has discussed saturation of data
-

6. Has the relationship between researcher and  Yes  Can't tell  
 No participants been adequately considered?

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during
  - (a) Formulation of the research questions
  - (b) Data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

7. Have ethical issues been taken into consideration?  Yes  Can't tell  
 No

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

---

8. Was the data analysis sufficiently rigorous?  Yes  Can't tell  No

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?

- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

## 9. Is there a clear statement of findings?

Yes     Can't tell     No

HINT: Consider

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researchers arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

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## 10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy?, or relevant research-based literature?
- If they identify new areas where research is necessary

- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Quality Assurance & Enhancement  
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Rachel Browne

**By Email**

19<sup>th</sup> September 2017

**Re:** Research Ethics Application

***Title: What are the lived experiences of parents of emotionally based school nonattenders who attend or who have attended a specialist provision?***

Dear Rachel,

Thank you for submitting your updated Research Ethics documentation. I am pleased to inform you that subject to formal ratification by the Trust Research Ethics Committee your application has been approved. This means you can proceed with your research.

If you have any further questions or require any clarification do not hesitate to contact me.

I am copying this communication to your supervisor.

May I take this opportunity of wishing you every success with your research.

Yours sincerely,

Best regards,



Quality Assurance Administrator  
T: 020 938 2659

Appendix D- Consent Form

**What are the lived experiences of parents of emotionally based school non-attenders who attend or**

**who have attended an alternative educational provision?**

**Please initial the statements below if you agree with them:**

<p>1. I have read and understood the information sheet and have had the chance to ask questions.</p>	
<p>2. I understand that my participation in this research is voluntary and I am free to withdraw at any time without giving a reason.</p>	
<p>3. I agree for my interviews to be recorded.</p>	
<p>4. I understand that my data will be anonymised and personal details changed so that I cannot be linked to the data.</p>	
<p>5. I understand that my interviews will be used for this research and cannot be accessed for any other purposes.</p>	
<p>6. I understand that the findings from this research will be published and available for the public to read.</p>	
<p>7. I understand that my participation in the research is not therapy or counselling</p>	
<p>8. I am willing to participate in this research.</p>	

Name.....

Signed.....Date...../...../.....

Researcher name: Rachel Browne

Signed.....Date...../...../.....

Thank you for your help

Appendix E- Information for parents

The Tavistock and Portman   
NHS Foundation Trust

## Information Sheet

**What are the lived experiences of parents of emotionally based school non-attenders, who attend or who have attended an alternative educational provision?**

### **Who is doing the research?**

My name is Rachel Browne and I am studying a course in Educational Psychology. I am doing this piece of research as a part of my course.

### **Would you like to take part in research?**

I would like to invite you to take part in my research study. Before you decide whether you would like to take part, you need to understand why the research is being done and what it would involve for you. Please take time to read the information carefully and decide whether or not you wish to take part.

### **What is the aim of the research?**

This research aims to explore the experiences of parents who have a child who does not attend mainstream school, due to anxiety and attends or who last attended within the last 3 years a specialist educational provision.

### **Who has given permission for this research?**

Hounslow Educational Psychology Service has given me permission to do this research with parents who would like to take part. The training institution that I am studying at is called the Tavistock and Portman NHS Foundation Trust and they have given me ethical approval to do the research.

### **Who can take part in this research?**

I am looking for parents and guardians who have a child who is anxious and unable to attend mainstream school and now attends or who has attended a specialist educational provision within the last 3 years, who are able to talk with me about their experiences.

### **Do I have to take part?**

You do not have to take part, and it is up to you to decide. You are free to withdraw (stop taking part in the research) at any time, without giving a reason. This will not affect any support and involvement you have with the Educational Psychology Service or any other service.

### **What will happen to me if I take part?**

You will be invited to come and meet me at Hounslow Civic Centre or I can visit you at your home. When we meet, we will talk for a short time (up to 90 mins) about your experience. I would like to make audio recordings of our meetings to help me remember and think about things that were said during them. The recordings will be stored anonymously, using password-protected software. You can ask for the recordings to be stopped or deleted at any time. The recordings will be deleted once I have typed them up.

### **What are the possible benefits of taking part?**

There is not much research that looks at how parents experience having a child who is anxious about attending school and who refuses to go. Your opinions and thoughts are really important for my research because it is all about the experiences of the family. It is important to remember that being part of this research project does not mean that you or your child will receive therapeutic intervention in regards to their issue of school non-attendance/anxiety.

### **What will happen to the findings from the research?**

The findings will be typed up and will make up my thesis which will be part of my Educational Psychology qualification. I will share some of the findings with the Educational Psychology Service so that they find out about what parents' experiences are and there might be times where I share the findings with other professionals working with young people who have anxiety regarding going to school. I would like to tell you about the findings of the research if you would like. We can talk about the ways in which you would like to know about the findings such as me explaining them to you in person or me sending them to you.

### **What will happen if I don't want to carry on with this research?**

You can change your mind at any time and if you want to stop, you can leave at any time without explaining why. Any research data collected before your withdrawal may still be used, unless you request that it is destroyed. If it has reached the point that it has been anonymised to the point that I can no longer retrieve your data I will not be able to remove your data and it will not be traceable to anyone, including me.

### **Will my taking part in this study be kept confidential?**

**Yes.** I will follow ethical and legal practice and all information about you will be handled in confidence. All information that is collected will be kept strictly confidential. All records related to your participation in this research study will be handled and stored appropriately. Your identity on these records will be indicated by a pseudonym rather than by your name. The data will be kept for a minimum of 5 years. Data collected during the study will be stored and used in compliance with the UK Data Protection Act (1998).

**Are there times when my data cannot be kept confidential?**

If you tell me something that makes me concerned about the safety of you or someone else then I might have to share that information with others in order to keep you or someone else safe. However, I would always aim to discuss this with you first when possible.

Because I am meeting with between 4-8 people, there is a chance that you may recognise some of the things you said in my research. To protect your identity, your name will be a pseudonym (a made up name) so that others are less likely to be able to recognise you and what you said. Changes will be made to your age, gender and family circumstances so that you will not be identified by others.

**Further information and contact details**

If you have any questions or concerns about any aspect of the research, please contact me:

Rachel Browne

Email: [rbrowne@tavi-port.nhs.uk](mailto:rbrowne@tavi-port.nhs.uk)

Telephone: 07776 238 760

**If you have any concerns about the research then you can contact Paru Jeram who works for the Tavistock and Portman research department. Contact details are:**

Email: [academicquality@tavi-port.nhs.uk](mailto:academicquality@tavi-port.nhs.uk)

Telephone: 020 7435 7111



	Original Transcript	EXPLORATORY COMMENTS: <u>Linguistic comments</u> Conceptual Comments	Emergent themes
<p>1:1 1:2 1:3 1:4 1:5 1:6 1:7 1:8 1:9 1:10 1:11 1:12 1:13 1:14 1:15 1:16 1:17 1:18 1:19 1:20 1:21 1:22 1:23 1:24 1:25 1:26 1:27 1:28 1:29 1:30 1:31 1:32 1:33 1:34</p>	<p><b>Well thank you ever so much for coming to meet with me.</b></p> <p>R: That's okay.</p> <p><b>I: Let's kind of, hear a bit about your story, if we kind of start from the beginning, if you could tell me a little bit about Emma, how she was when she was very young?</b></p> <p>R: When she was little, in fact, lots of people talked about it. She was this really lively, free spirit and she had a great big grin on her face, always a leader. But also, although she's bright, she always, sort of, measured herself against everybody else. She always appreciated that she's in the top part of the class, but always said, "Well those two people are better than me." So, always sort of measured herself.</p> <p>And then something happened. I appreciate it's never one incidence, but we can look back and we can think. She used to do drama, she was brilliant at drama, very confident. She was in a group with much older children, which was never an issue. But the drama teacher ... this was at the [s.l. art set 00:01:05] in *****. And she'd just come back from maternity leave and she was obviously struggling, and they were about to do their, sort of, assessments.</p> <p>And she turned to the group and went, "Nobody's learnt their lines, you aren't fit to even flip the burgers in McDonalds." Emma came out of that and she was devastated and never went back. We couldn't persuade her, even at the age of about eight, never went back. And that sort of negative part of her personality started to become much more prominent.</p> <p>You know, when you look back, this is in hindsight. At the time, although we were really sad, it didn't have significance. But she's always been a glass half empty, type of person. But she started to become quieter and not as confident and that slowly developed during primary school. Some of the PASS tests that she did ... I worked at the school, so particularly in Year 6, I remember being asked, "She's come out of this really negatively, you know, other children we would perhaps put on some, kind of course, I'm trying to think what it's called, anyway, something that they used to do.</p>	<p>Comparisons to then and now- sense of sadness that she doesn't show those qualities now. Is there a sense of loss?</p> <p>Looking back, trying to find where things changed- need for clarification to help make sense of things.</p> <p><u>"And that sort of negative part of her personality started to become much more prominent"</u> Kerri recognises that Emma always had a side that struggled with her emotions.</p> <p>The primary school highlighted that there was a problem, but at the time, Kerri does not fully recognise it. Was there a desire to minimise the problem?</p>	<p>Making sense through looking back.</p> <p>Not recognising the problem in the past</p>

<p>2:1 2:2 2:3 2:4 2:5 2:6 2:7 2:8 2:9 2:10 2:11 2:12 2:13 2:14 2:15 2:16 2:17 2:18 2:19 2:20 2:21 2:22 2:23 2:24 2:25 2:26 2:27 2:28 2:29 2:30 2:31 2:32 2:33 2:34 2:35 2:36 2:37 2:38 2:39 2:40 2:41</p>	<p>And I said, “Oh, no, no that’s Emma, she’s just a bit negative,” but perhaps, again, with hindsight, that was significant, I don’t know. I wish I hadn’t been there to be asked, because they would have just done it.</p> <p>But in the beginning of Year 7 my Dad died on 3<sup>rd</sup> September, the very beginning of the year and so she started in her secondary school without me, I was away for two months. And it turned out my Mum had dementia and couldn’t live independently. So, I was away for about two months, trying to look after her and then every other weekend, I was going down to Devon to look after my Mum. So, the beginning of her time at secondary school was pretty difficult.</p> <p>Then at the beginning of Year 8, she suddenly arrived at school and they’d changed all the classes and ... No, they hadn’t, they’d created another class and they selected a few children out of each class, to form this new class and she was one of those children that was selected. And she moved into this room with nobody that she knew and that was the time where we all became really aware there was a serious problem.</p> <p>So, by Christmas, we’d got a letter about her attendance, it didn’t seem too significant, but her attendance had slipped to something like 80-85%. And it was a day here and a day there. Then after Christmas to Easter, her attendance has slipped to such an extent, that I think she was in the 60s.</p> <p>So, she’d go on this wave. So, we managed to improve and during that time, obviously we went to see the doctor, we got a referral to CAMHS but there was a long waiting list. I think they considered her quite urgent, because her attendance was slipping the whole time. So, we didn’t join a massive waiting list, but I still think it was about three or four months.</p> <p>But her attendance went up and down, and for quite a long time with the school, the person we dealt with most was the Welfare Officer, who could only ever see her as an attendance figure. So, who would tell us all about the legalities of what would happen, academically, how it would affect her. Well, I trained to be a teacher, I’m a Teaching Assistant, and my husband’s a Law Lecturer. And it didn’t matter how many times we told her, “Please stop patronising us with this, because we fully understand all of the implications, but this isn’t as easy as you think it is, because she’s quite a big girl.”</p> <p>It wasn’t that she was getting up and roaming round the house, she was just pulling the duvet over her head and saying, “I’m not going anywhere.” And once she did that, we couldn’t move her, and she would stay under that duvet all day. She was very, obviously depressed.</p>	<p>Lots of looking back and trying to think about were things started to go downhill. What would have made a difference? <u>“I don’t know. I wish I hadn’t been there to be asked, because they would have just done it.”</u> <u>Does she feel guilty for not allowing Emma to take part in the course?</u></p> <p>Family bereavement- loss for both of them</p> <p>Being in a new class escalated the problem- did that feel like more loss for Emma? loss of mum, grandfather.</p> <p>The recognition of serious problem when her attendance drops significantly.</p> <p>Able to get access to CAMHS support</p> <p>K feeling patronised by professionals? Assumption about education not having value. Trying to explain that the problem was more complex than the welfare officer recognises.</p> <p>The realisation that her daughter has depression</p>	<p>Guilt and self reproach</p> <p>Loss</p> <p>Loss</p> <p>School assumptions and judgements about family values</p> <p>School not recognising extent of the problem</p>
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<p>3:1 3:2 3:3 3:4 3:5 3:6 3:7 3:8 3:9 3:10 3:11 3:12 3:13 3:14 3:15 3:16 3:17 3:18 3:19 3:20 3:21 3:22 3:23 3:24 3:25 3:26 3:27 3:28 3:29 3:30 3:31 3:32 3:33 3:34 3:35 3:36 3:37 3:38 3:39 3:40 3:41 3:42</p>	<p>And we went through quite a few contacts, we kept on being passed on to people at the school. And finally, I had another very difficult conversation with the Welfare Officer, and I was in tears, this was when I was at school and we have a parent liaison person at the school. So, I went to her and said, "This is my situation." And at the end, "I just do not now what to do, we're with CAHMS." But she at that point, didn't have a diagnosis and all the people were changing, every year they change because this is their training for a year. "I'm at a complete loss."</p> <p>And she put me in touch with Mrs S and for a while, that was actually quite productive, but I think even she ran out of ideas. So, this is going on over about a year, a year and a half and Emma has just gone down. If you look at an average of her attendance during Year 8 and Year 9, it was 60%. And really, she now hasn't been at school since September. She managed about two weeks in September, and that was it.</p> <p><b>I: So, you mentioned, it wasn't feigning illness, it was literally her covering her head and just saying, "I'm not going"?</b></p> <p>R: Yes. "I can't." She would say "It's going through the school gates." I think she's quite unusual in the fact that she's actually got a really good circle of friends, who she still sees, she goes to Guides, although she doesn't always go to Guides.</p> <p>But for her, it was physically walking through the school gates, she found it almost impossible and whereas she used to be quite lively at school, I understand, and you mentioned she seemed quite quiet.</p> <p>I think because she missed so much school, she didn't understand what was going on in lessons, so she actually found it easier to pretend to be asleep during the lesson. That way she avoided having to interact and admit that she didn't know something. But the phrase that she always uses, "I cannot do it."</p> <p><b>I: So, when she says that to you, what comes up for you in terms of, it feels like (multiple speakers 00:07:43)? How do you imagine it feels?</b></p> <p>R: The image I have in my head is her standing outside the school on the other side of the road, looking at those gates, not that this situation ever happened, but I can see... As I parent, I didn't know how to overcome it, I didn't know. I tried all kinds of things. So, a couple of times ... (Laughter)(The school bell rings)</p> <p><b>I: That's the changeover.</b></p>	<p><u>"I just do not now what to do, we're with CAHMS</u> <u>Not knowing what the true situation was-lack of clarity, sense of confusion.</u></p> <p>Initial support was helpful but did not change the situation. Is the problem being given back to parents?</p> <p>The anxiety peaks for Emma at the school gates, despite having good peer support.</p> <p><u>"As I parent, I didn't know how to overcome it, I didn't know. I tried all kinds of things."</u> Feeling powerless and deskilled as a parent, unable to solve the problem</p> <p>Kerri leaves her job to go home to get Emma and bring her to school. Impact on her work situation.</p>	<p>Lack of clarity</p> <p>Lack of a solution</p> <p>School out of ideas</p> <p>Powerless and deskilled</p> <p>Impact on work</p>
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<p>4:1 4:2 4:3 4:4 4:5 4:6 4:7 4:8 4:9 4:10 4:11 4:12 4:13 4:14 4:15 4:16 4:17 4:18 4:19 4:20 4:21 4:22 4:23 4:24 4:25 4:26 4:27 4:28 4:29 4:30 4:31 4:32 4:33 4:34 4:35 4:36 4:37 4:38 4:39 4:40 4:41 4:42</p>	<p>R: So, a couple of times, working in a school, I would leave at break, go and collect her and drive her to school and I would drive her through the school gates and would stay and would take her out of the car. That happened a couple of times.</p> <p>Only once, did I drive her at that time. I phoned and said, “She’s coming in at breaktime,” because they had to all go and sign in, “I’ll drop her off at breaktime.” And the Welfare Officer was standing there, with a board, at the gate and shouted at her. So, that never happened again.</p> <p>What I found very difficult was that she lost trust with the school and she set up lots of little tests for them. “Well, if they do this, I know they care.” And as a parent, I just didn’t know how to overcome all of that. It was really, really hard and I appreciate there are two sides to this.</p> <p>There’s the school’s side and working in a school, I did understand the school’s side but there was her side and when I listened to her stories, I thought, “Oh my God, they don’t understand, they are treating her badly, they are as far as she’s concerned, not living up to their promises.”</p> <p>You know, Mrs S would say to Emma, “I will come and check and make sure everything’s alright.” Well, Emma expected her to come and say, “Are you alright?” Mrs S didn’t, she did it at a distance, she’d look through and see if Emma was in the class or she’d speak to the teacher.</p> <p>Well, that’s what she understood by, “I’m checking on you.” Emma really did expect somebody to come up and physically say, “How are you?” And that didn’t happen, so Mrs S lost all credibility for us as far as Emma was concerned, because she didn’t do what she said she was going to do, as far as Emma was concerned.</p> <p><b>I: No.</b></p> <p>R: And for a long time, Mrs S was our contact. And I would have to go in and talk to her and she was lovely, and she’s got a child with special needs herself and she had full understanding. But somehow, I couldn’t communicate to her, that what she was saying didn’t match up to Emma’s expectations. And that, I found, really, really difficult.</p> <p>Just for whatever reason, I just couldn’t get it across that it didn’t matter if Mrs S was doing all of the right things, because Emma didn’t believe she was. And I felt a failure as a Mum, because I just could not get it through.</p> <p>And Emma then would be so angry, at the school and at me because I couldn’t communicate what she wanted or needed. But it didn’t help that we had so many different contacts, because I think Emma was a case that they just ... And this was just, as a parent</p>	<p>Frustration with EWO lack of support, escalating problem rather than reducing it.</p> <p>Emma loses her trust in school, Kerri acknowledges that there are two sides but feels that the school are not supporting Emma.</p> <p>Loss of credibility of school Individuals in school are pleasant but did not do what Emma felt they should</p> <p>Attempts to communicate with her daughter are unsuccessful-sense of frustration and feeling like a failure as a parent?</p> <p>Lots of changes in the school prevented a consistent supportive strategy.</p>	<p>Lack of awareness from welfare officer</p> <p>Issues of trust</p> <p>Sense of failure as parent</p> <p>Lack of consistency</p>
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<p>5:1 5:2 5:3 5:4 5:5 5:6 5:7 5:8 5:9 5:10 5:11 5:12 5:13 5:14 5:15 5:16 5:17 5:18 5:19 5:20 5:21 5:22 5:23 5:24 5:25 5:26 5:27 5:28 5:29 5:30 5:31 5:32 5:33 5:34 5:35 5:36 5:37 5:38 5:39 5:40 5:41 5:42</p>	<p>seeing this, that we just kept being passed because each member of staff wasn't successful, so she'd be moved onto the next one and then she'd be moved onto the next one.</p> <p>Unfortunately, the one teacher that she did get on very well with, had some depression herself, which is probably why Emma got on with her, but then she had her difficulties and had to take time off, so we were moved on again. And that didn't help, that there wasn't a consistency.</p> <p><b>I: Yes. So, how did that make you feel?</b></p> <p>R: Completely lost within the system.</p> <p><b>I: Yes.</b></p> <p>R: And I know the system, and I felt lost in it.</p> <p><b>I: Yes, and thinking about the impact, because you describe her attendance being so low, and obviously you have to work, how did you have to manage that, in terms of...?</b></p> <p>R: Well, my husband normally works from home one day a week. I have two afternoons off. I lived about a 10 or 15-minute walk from home, so I would run home at lunch times to check that everything was alright.</p> <p><b>I: Yes.</b></p> <p>R: But I had to leave her. But this term, quite a few things contributed towards this. I've given up work, because one, I was depressed, the work situation was terrible. Work had been the place where I would go to, to escape some of the home problems and then something happened at work, where I just felt like I had no value, I was part of the furniture, people didn't have to talk to me about where they were going to assign me. I was just moved around without any discussion and I couldn't deal with that. And [s.l. with all the home 00:13:19]...</p> <p><b>I: Yes.</b></p> <p>R: So, I handed my notice in. As soon as I handed my notice in, I went on sick leave and I haven't worked for about two months. So, now I'm at home with Emma 24 hours a day, because she's just not going to school at all now.</p> <p><b>I: Yes. Do you have other children as well or is it just Emma?</b></p>	<p><u>Feeling lost in the system-needs not being met?</u></p> <p><u>She knows the system but still feels lost, what does that say about the system? Or does it suggest that Kerri cannot manage the system?</u></p> <p>Having to leave work to check on Emma-stressful</p> <p>Work as a place to escape from the problems at home but K leaves her job as she feels unseen and unvalued- is that mirrored anywhere else in her life?</p> <p>At home with Emma now- maybe leaving work was influenced by a desire to be home to look after M.</p>	<p>Impact on job/work</p> <p>Impact on siblings</p>
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<p>6:1 6:2 6:3 6:4 6:5 6:6 6:7 6:8 6:9 6:10 6:11 6:12 6:13 6:14 6:15 6:16 6:17 6:18 6:19 6:20 6:21 6:22 6:23 6:24 6:25 6:26 6:27 6:28 6:29 6:30 6:31 6:32 6:33 6:34 6:35 6:36 6:37 6:38 6:39 6:40 6:41 6:42</p>	<p>R: I've got a 19-year-old, she's just gone to university.</p> <p>I: <b>Okay.</b></p> <p>R: But she's very different, she's very academic but as is Emma. Emma's a bright girl too, but Dawn's very bright, but she's also incredibly focused and knows exactly what she wants. So, in a different way, she's quite difficult to live with because she just goes on the straight path and you know, I'm sure Emma has affected her, but she's been able to cut some of that stuff out because she always knew what she wanted to do and she's not at the university she wanted, doing exactly what she wanted. So, yes, it's a very different way of dealing with things.</p> <p>I: <b>So, now you are at home and you're at home with Emma all the time, what kind of impact has that had? Do you feel some difference, or is there any shift?</b></p> <p>R: Well, I think at the very beginning, bear in mind it's only about two months, but it was incredibly difficult at the beginning. Because I'm now depressed, and without sob stories and things, when my Dad died, my Mum developed ... Well she must have had dementia, but she very quickly, within a few months, couldn't live independently. And now, she's in the very advanced stages of dementia, where she doesn't know me. And so, there's that thing.</p> <p>And almost as soon as I finished work, my Mum was admitted into hospital and has now been diagnosed with a heart condition, which she didn't have before. You know, you just think, "Oh my God, stop, stop."</p> <p>I: <b>Yes.</b></p> <p>R: Anyway, I have depression, so at the very, very beginning and I was on the sofa and we barely talked to one another and didn't really communicate. We were, I think, quite bad for one another.</p> <p>But I think a couple of things have come into play now. It has been very difficult, there's no escape and when she's in a bad place, it affects absolutely everything. It just permeates the whole atmosphere in the house and we all get pulled down by it.</p> <p>I: <b>What does that look like?</b></p> <p>R: It's just a grey stillness. My husband doesn't ... He copes with it very, very badly and he prefers, quite rightly, because of his reactions, tried not to engage with it. And I just feel like I'm drifting through this deep, dark, grey, soup. I don't feel I can ... When</p>	<p>Effect of the situation on the sister.</p> <p>Depression caused by consecutive family problems. Mum's dementia- she doesn't know me....loss of mother, perhaps loss of her child too?</p> <p>The feeling of life being overwhelming- too much to manage at once</p> <p>When Emma is depressed, <u>it just permeates the whole atmosphere in the house and we all get pulled down by it.</u> Voice is emotional- pain and grief still feels raw. Everyone is affected</p> <p><u>'Grey stillness'- 'drifting through this deep, dark, grey, soup'. It feels cold, suffocating and like the beginning and the end cannot be found.</u> <u>Husband copes with it badly and tries not to engage.</u> The pressure on Kerri seems to increase, if her husband doesn't engage,</p>	<p>Impact on emotional wellbeing</p> <p>The depression/anxiety is contagious</p> <p>Feeling overwhelmed and lost</p>
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<p>7:1 7:2 7:3 7:4 7:5 7:6 7:7 7:8 7:9 7:10 7:11 7:12 7:13 7:14 7:15 7:16 7:17 7:18 7:19 7:20 7:21 7:22 7:23 7:24 7:25 7:26 7:27 7:28 7:29 7:30 7:31 7:32 7:33 7:34 7:35 7:36 7:37 7:38 7:39 7:40 7:41 7:42</p>	<p>it's in a really bad time, it's impossible to communicate. Because she quite rightly says, "You know, you don't know."</p> <p>She won't get out of bed, we've both put on a lot of weight, but she put on a lot of weight because she would just come down to the cupboards, grab food and go back and eat under the duvet. And she wouldn't get dressed for days. I'm just thinking of the effect that it had on me.</p> <p>You know, your job as a parent is to make everything right, and I couldn't make anything right. Sometimes, there would just be no lightness for days on end. And she's gone...It has just been really, really difficult.</p> <p><b>I: Yes.</b></p> <p>R: Really difficult, because you know, I'd listen, but obviously, everything ... With listening, you interpret, and I interpreted everything incorrectly. Whatever, I thought she said, I got it wrong. So, she's moved into her sister's big bedroom and we're going to decorate it, but they've got a lot of stuff and it has to be moved.</p> <p>Like that, you know, Dawn's stuff has got to go into Emma's bedroom, or Emma's stuff has got to go into Dawn's bedroom and there's stacks of stuff. And we're now living with a real mixture of the two between two rooms, it's chaos.</p> <p>And the other day, I started tidying up. She was saying, "I can't get my head straight in this room, it's such a state, I can't find anything, I can't find my clothes." So, I thought, "Alright, I'll do her a favour, it's insurmountable, I've asked her to tidy it up, she can't, I will do it."</p> <p>So, I started and she came upstairs and found me, and I thought she'd join in, because actually it was quite therapeutic in a sense, to be sorting out this mess. And she went screaming and shouting and it went on for about an hour and a half, screaming and shouting and "I got it wrong, I don't listen, what was I doing touching her stuff. She didn't want me to touch her stuff, she didn't want me to go into the bedroom."</p> <p>So, she slammed the door in my face, fine, I went and sat on my bed to calm down and then she came out of the room and said, "Well why aren't you tidying it up?" And I was like, "You closed the door on me, so I was giving you the space that you needed." So, the shouting went on for another hour. God knows what our neighbours think, I don't know what our neighbours must think.</p>	<p>does that leave her left to manage the situation her own?</p> <p><u>'can't make it right....no lightness for days on end... its's the parents job to make it alright'</u> The sense of feeling like a failure as a parent, unable to do the task of fixing the problem and making things better.</p> <p><u>'She's gone' - there is a sense that she has 'lost' her child-lost in the darkness of the 'grey stillness'?</u></p> <p>Unable to understand Emma, despite trying her best to interpret events-but getting it wrong</p> <p><u>"think it's the not being able to escape it. And I feel guilty for saying it, it's my child, but sometimes you need some space"</u></p>	<p>Increased burden on her as husband finds the situation too difficult.</p> <p>Sense of failure as a parent</p> <p>Can't communicate-trying to find the right way.</p>
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<p>8:1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39</p>	<p>And in the end, I came to have a bath, it's the only door in our house with a lock on it, the bathroom door. So, I went into the bathroom and ran and bath, got into the bath, and she was banging, screaming on the door trying to get in.</p> <p>I think it's the not being able to escape it. And I feel guilty for saying it, it's my child, but sometimes you need some space. We've got lots of good friends, we have a good social life, we'll go out and we know we'll be followed by phone calls or go to the theatre and we'll have to just as the lights have gone down, we'll have to say, "The lights have gone down, we'll be out of contact for this amount of time."</p> <p>And then when we go to our phones, there'll be three or four phone calls, "When are you coming home?" I think it's that sort of feeling that, even out of the house, you're chased by it.</p> <p><b>I: Yes.</b></p> <p><b>R:</b> There's nothing, there's no...A couple of weekends ago, I found this last couple of months really, really dark and my husband's a sweetheart so he arranged for our elder daughter to come back from university to look after Emma for a weekend. And we've got friends with a flat in Barcelona, so we went out and stayed there, and went to see a band and you know, it was just really lovely.</p> <p>But that whole time, there were phone calls. It wasn't too dramatic, but it was, you know, just even you know, it followed us to Barcelona and it's our main topic of conversation.</p>	<p>Why should Kerri feel guilty about wanting to have some space? Is it wrong for a mother to want space from her child?</p> <p><u>"even out of the house, you're chased by it."</u></p>	<p>The guilt of wanting to escape</p> <p>Feeling trapped</p>
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**Appendix G: Superordinate Themes and Related Subordinate Themes Across Participants**

<b>Superordinate Theme 1: 'It turns your life upside down'</b>		
<b>Subordinate theme</b>	<b>Emergent theme</b>	<b>Sample of quotes</b>
'Keeping the peace'	<p>Keeping frustrations about your child inside</p> <p>Not responding to their emotional escalations</p> <p>Avoiding talking about particular subjects with your child</p> <p>Trying to say the 'right thing'</p> <p>Making deals/ultimatums</p> <p>Highly emotional adolescents</p> <p>Perpetual uncertainty of when the young people might become upset.</p>	<p><i>Really difficult, because you know, I'd listen, but obviously, everything ... With listening, you interpret, and I interpreted everything incorrectly. Whatever, I thought she said, I got it wrong. (Kerri, p.9. Line 30-33).</i></p> <p><i>You always beat yourself up, "Could I have said that differently?" The other day, it was only on Tuesday actually and I'm thinking, is he now going to refuse to go again because I've ... I don't think I said anything wrong it was just the way I said it, and so you then beat yourself up, then you think, "What did I say that was actually so wrong?" And it's very hard and you've got to be very thick-skinned in a way... (Martin p.8 Lines 9-11)</i></p> <p><i>The thing is as well that, because he can't understand what's going on with him, he sometimes does get a bit angry. He's not a violent person but he gets a bit angry and takes it out on whoever he can (Andy p. 15. Line 1-4)</i></p>
Impact on family relationships	<p>Pressure on marriage</p> <p>Unable to communicate with child</p> <p>Mediating between spouse and child</p> <p>Effect on siblings</p> <p>Guilt of less affected sibling having less attention and support.</p> <p>Child as the centre of the family</p>	<p><i>It just changes your life. Honestly, I could have had nothing now. I could have no kids. It was that bad. My wife was going to move away. Just get away and try and start again. She didn't think she was having any help, nothing. It's just constant, non-stop.(Andy p.39. Line 10-14)</i></p> <p><i>It's almost like you didn't want to leave in the morning but you didn't want to go home in the evening either, because you know that you were just walking into a ... and for the</i></p>

		<p><i>best will in the world.... but she would take her frustration out on me, then you're thinking, "Why am I going home to that? I'm going to be yelled at," it was just through the stress (Martin p.5. Line 7-10).</i></p> <p><i>He is the focus all our conversations, and he gets most of our time.. (Dee p.13. Line 16-18).</i></p>
Feeling trapped	<p>Unable to have a social life</p> <p>The need/desire to escape from the stress</p> <p>Threats to leave home</p> <p>No access to respite</p> <p>Unable to talk to others about the problem</p> <p>Using work to escape from the problems at home</p>	<p><i>One day we were planning a night out and they were staying the night at my Mum's and he couldn't do it. He couldn't stay the night. He was just non-stop phoning me, but my Mum took it badly that they didn't want to stay and she didn't understand why. (Andy p24. Line 21-30).</i></p> <p><i>And then when we go to our phones, there'll be three or four phone calls, "When are you coming home?" I think it's that sort of feeling that, even out of the house, you're chased by it. (Kerri p.10. Line 31-33)</i></p>
Contagious anxiety	<p>Parental depression and anxiety</p> <p>Constant stress</p> <p>Worry about child's wellbeing</p>	<p><i>Anyway, I have depression, so at the very, very beginning and I was on the sofa and we barely talked to one another, and didn't really communicate. We were, I think, quite bad for one another. (Kerri p.8, 26-28).</i></p> <p><i>No help from anyone so every day the same thing just over and over and you just wait until the weekend. The weekend was just ... Sunday comes again and then you know it's going to happen again. (Andy p. 26. Line 29-33).</i></p>
Loss of career- impact on work	<p>Giving up career to stay home</p> <p>Taking early retirement</p> <p>Phone contact with child while at work</p> <p>Getting to work late</p> <p>The need for flexible employers</p>	<p><i>I had a business. So, I had a practice, so I closed that down because it just wasn't working. You know, my son really needed me more than the clients did. We're all bright people, and can just find somebody else (Amanda p12. Line 6-8)</i></p> <p><i>So, I handed my notice in. As soon as I handed my notice in, I went on sick leave and I haven't worked for about two months. So, now I'm at home with Martha 24 hours a day,</i></p>

		<i>because she's just not going to school at all now. (Kerri p.8. Line 2-4)</i>
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<b>Superordinate Theme 2: Power and the battle to heard'</b>		
<b>Subordinate theme</b>	<b>Emergent theme</b>	<b>Sample of quotes</b>
Loss of trust	Regretting placing trust in school staff Difficulty in accessing specialist services Referrals being rejected Mismanagement of care Breakdown in relationships with school	<p><i>Going to the GP is a waste of time. A complete waste of time going to the GP, yeah. I went to the GP and even asked for a referral to a paediatrician, and she said it'll just be, it'll just be bounced back, yeah. So, I don't really understand what, how to get a referral if you know what I mean, I just don't understand it. (Dee p.35. Line 34-37)</i></p> <p><i>We did ask for that to be addressed, but it wasn't ever taken, I don't think, seriously. (Amanda p.4. Line 4-5).</i></p> <p><i>For both of them, because there's no outreach work for CAMHS, because there's not the funds or the thinking around it, basically, because they can't get into see a clinician of any description, it's left down to ... well, up until recently, it was just me trying to deliver some sort of therapy to help them with the anxiety and the depression, whilst coping with all of this, and in terms of the working systems that just don't work at all. So, he's been, sort of, stuck. We had seen an improvement in services, but it's difficult enough (Amanda p.13. Line 17-25)</i></p>
The need for professional awareness	Delay in including key school staff Poor advice Limited understanding of the problem Schools using police to resolve problem Specialist AEP is helpful The school did not want to understand	<p><i>Ever since he's come here our relationship, me and my wife, everything at home it's just brilliant. If it wasn't for this place he wouldn't have got an education. (Andy p.18. Line 18-22)</i></p> <p><i>I like the people, but to be honest with you, I don't think it really helped. It only helped when we found out what was actually wrong with him. It was always guessing really.</i></p>

		<i>Just doing stuff that was irrelevant because they were just guessing what was wrong with him. He has got anxiety and we were trying to deal with that. (Andy p.18, 32-36.)</i>
Accusation and Persecution	<p>Authorities as the enemy</p> <p>Adversarial nature</p> <p>Blamed as being the cause of the problem</p> <p>Accused of being a poor parent</p> <p>Feel trapped within the system</p> <p>Faceless system: Use of 'they' 'them' 'the school' lack of names.</p> <p>Fighting a battle</p> <p>Assumptions about capacity to cope</p> <p>Judgements</p>	<p><i>They didn't believe us. It was really bad. They accused us of being bad parents. They accused my wife that it was all down to her. I've sat in meetings and they've said it's your fault. One teacher said it's your fault and I was fuming. I was actually fuming. At the end of the day, it doesn't matter whose fault it is. We want him to get better. We don't know what it is. Everyone was telling us different things, everyone. (Andy p.8. Line 15-21).</i></p> <p><i>I had one woman who has now gone, a teacher in this centre, told me that I had to control my child, and show him who was in charge. Basically, she said it three times. The first few times, I cried, because I just was so distraught, and the second time I just kicked her into touch, and then I made a complaint about her, but she still stayed in post. (Amanda p.15. Line 1-4)</i></p> <p><i>And what we did is we made the authorities the enemy, and so instead of it being the two of us it was the authorities, and if you focused on that and you make sure that you are the team that are working together to get everything for our son and you are not the enemy between yourselves, it kind of helps.( Martin p.5. Line 16-19)</i></p>
Issues around power	<p>Betrayal from school staff</p> <p>Parental instincts suppressed and ignored</p> <p>Lack of collaborative interventions</p> <p>Parents viewed as having less knowledge</p> <p>Threats of prosecution</p> <p>Professional seen to less accountable for their mistakes</p>	<p><i>The problem is with being a parent, even if you're a really bright parent, even if you can quote law and you can quote medical journals and evidence-based research, you're just not believed. So, the overwhelming thing was being told that I'm a bad parent, I'm not doing enough, what do I know. (Amanda p.15. Line 2-7).</i></p> <p><i>And its things like that, it's just a feeling we have that as a parent it doesn't matter what you say really, the teachers seem to know best. (Martin p.14. Line 23-24).</i></p>

		<i>I had no choice in the matter, that's what they said. They said if you don't do this you could end up in jail. They didn't know what was wrong. We didn't know what was wrong. (Andy p.11. Line 11-14)</i>
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<b>Superordinate Theme 3: Fear and Loss</b>		
<b>Subordinate theme</b>	<b>Emergent theme</b>	<b>Sample of quotes</b>
Loss of childhood	Loss of the child that used to be Loss of relationships and friendships Losing the carefree, happy days of childhood Social isolation	<p><i>Well, my husband and I say, it's like watching a child die, that's exactly what's been, it's like the old child that we had has died, and this new one... It's just, he's just not a fully functioning individual, a child. It's like he doesn't have a childhood, it's really sad. (Dee p.15. Line 1-3).</i></p> <p><i>I said to him the other day, why don't you invite him (a child from the AEP) around? He only lives up the road. No. What about going to the cinema with him? Do you want to go to the cinema? No, he doesn't like the cinema. What about going to Pizza Hut or something, I don't mind dropping you off there with him. No, we just play online. It's very weird. They were meant to meet up to go to Thorpe Park over the summer holidays. We got his Mum's number so we tried to arrange it, they just didn't want to know (Andy p.28. Line 28-35).</i></p>
Loss of confidence as a parent	Feeling like failure Unsure how to help Expected to be an expert Given the role of therapist Unable to 'make things right'	<p><i>You know, your job as a parent is to make everything right, and I couldn't make anything right. Sometimes, there would just be no lightness for days on end. And she's gone...It has just been really, really difficult. (Kerri p9. Line 24-26)</i></p> <p><i>Sometimes we, my husband and I have a conflict over parenting, and sometimes we think, you know, are we bad parents? But then we've looked at our approach with Marie, we're doing the same parenting, and she's fine, so we don't think it's our parenting. (Dee p.26. Line 26-30).</i></p>

<p>Fear for the future</p>	<p>Fear that the situation is permanent  Loss of academic success  Reduced employment opportunities  Impact on their adult relationships later in life</p>	<p><i>Her future worries me. It worries me, whether this is a temporary thing that she will learn to overcome or whether this is a lifetime thing which we're all going to have to be fully aware of. And whether it will be something that handicaps her for the rest of her life, that worries me. (Kerri p. 15. Line 2-6)</i></p> <p><i>...he's also has started picking up on the fact that his access to education was slightly, it was restricted because although he's got the option of doing GCSEs, he doesn't have a wide curriculum like he would have done in mainstream school, and that's the reality of it. They don't have those resources, so that isn't, that's heart-breaking for him really. (Dee p.20.Line 16-21)</i></p>

**Superordinate Theme 4: Retrospective clarity**

Subordinate theme	Emergent theme	Sample of quotes
<p>Looking back for clues: 'I wish I knew back then'</p>	<p>What did I miss?            Should I have done more?            I didn't know what was going on?            Recognising that the problem had existed for a long time before it escalated</p>	<p><i>We didn't really notice anything up for a long time, to be honest with you. I always thought that when he was with other kids he was very childish as he was getting older. He'd try too hard with other kids and he didn't have many friends. Everything was fine. It was more I noticed things when I used to take him to my friend's houses or something like that. It was always that I'd have to make an excuse and leave because he was being, not naughty, but he would do things a bit out of the ordinary. (Andy p 2. Line 18-26)</i></p> <p><i>You know, when you look back, this is in hindsight. At the time, although we were really sad, it didn't have significance. But she's always been a glass half empty, type of person. But she started to become quieter and not as confident and that slowly developed during primary school. Some of the PASS tests that she did ... I worked at the school, so particularly in Year 6, I remember being asked, "She's come out of this really negatively, you know, other children we would perhaps put on some, kind of course, I'm trying to think what it's called, anyway, something that they used to do.</i></p> <p><i>And I said, "Oh, no, no that's Emma, she's just a bit negative," but perhaps, again, with hindsight, that was significant, I don't know. I wish I hadn't been there to be asked, because they would have just done it. (Kerri p. 2. Line 29-34, p.3. Line 1-3).</i></p> <p><i>But we just didn't, we didn't pick up on the fact that he was experiencing anxiety, you know, not wanting to go to the dentist is quite a common anxiety that people have, and we just thought, "Look, this is quite common, not wanting to go on a plane is also a very common fear of flying", but actually not getting on it, was the bit that, and not actually</i></p>

		<p><i>going through the treatment, and not even going to the hospital, where he would have been put to sleep. Refusing to do any of that, was a bit that then started to cause concern for us really. (Dee p.11. Line 5-11)</i></p>
<p>The need for clarity: ‘Why my child?’</p>	<p>Why are they like this?  Is there an underlying problem?  Looking for a reason  Uncovering hidden issues</p>	<p><i>It was hard to explain because no one knew what was wrong. You didn't know if he was being naughty or what was wrong. Looking back now, there are so many things that now we know, but we didn't have any help. We didn't know what was going on. (Andy p.5. Line 28-32).</i></p> <p><i>He's understanding the anxiety where he didn't before. The teachers will ask why can't you do it, I don't want to, I can't. They'll say that's no excuse, but he doesn't know how to express himself. Everyone just thought he was being naughty. I can't do it. I don't want to do it. You can't say you don't want to do it. You've got to do it. (Andy p. 17.Line 1-6)</i></p> <p><i>We feel that there is something that, something is stopping him accessing education and I think that's causing anxiety, but I also think he has other issues that we're not entirely sure what. (Dee p. 13. Line 1-4)</i></p>