Listening to the stories of parents whose children have experienced school non-attendance

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Abstract

Accessing a formal education is often viewed as being beneficial to the holistic development of Children and Young people (CYP); providing them with the opportunity to gain qualifications and to develop important life skills (Le Riche, 1995). A wealth of literature exists which attempts to conceptualise attendance difficulties experienced by CYP and to measure the effectiveness of interventions designed to improve their attendance. However, the research typically employs quantitative methodologies and is often situated within the medical model. This has encouraged a within-child and -family view of non-attendance and has meant that the voices of those affected have been given little attention.

Appreciating the heterogeneity of CYP attendance difficulties I sought to explore the individual experiences of four parents whose children: had experienced school non-attendance; and were described as being worried about school.

A critical realist positionality was adopted and narrative interviews were employed to enable parents to share their stories. Interviews were audio recorded, transcribed and individually analysed using the Listening Guide (Woodcock, 2016). This process of analysis enabled me to attend to the individual voices and experiences of participants. Further, the use of voice poems facilitated a rich understanding of parental experiences of professional involvement.

Findings were considered in relation to previous research in the field and the power threat and meaning framework. This supported an understanding of how parents perceive and experience their child's non-attendance within a context of professional power and legal threats. Implications for educational psychologists are discussed. Educational psychologists are encouraged to: be mindful of the power they and other professionals hold; use narrative approaches to enable parents' stories to be heard; and to use consultation skills to support shared understandings of CYP non-attendance ensuring CYP and parent views are at the centre enabling them to be the experts in their own lives.

Contents

Acronyms:

CYP: Child or Young Person

DfE: Department for Education

EHA: Early Help Assessment

EHCP: Education Health and Care Plan

EP: Educational Psychologist

EPS: Educational Psychology Service

EWO: Education Welfare Officer

IPA: Interpretative Phenomenological Analysis

LA: Local Authority

LG: Listening Guide

SEN: Special Educational Needs

SENDIASS: Special Educational Needs and Disabilities Information Advice and Support Service

SNA: school non-attendance

PTMF: Power Threat and Meaning Framework

Chapter 1: Introduction and Literature Review

1.1. Introduction:

Before beginning the doctorate I worked for a local authority (LA) service which provided educational support (tutoring and mentoring) to students who were not attending school. Initially the service was conceived as a way for the LA to ensure they met their legal duty to provide suitable full-time education from the sixth day of a child or young person's (CYP) exclusion (DfE, 2017). Although the situations of the CYP I was working with were complex, I felt that there was a clarity about their next steps, and therefore, my professional role.

The referrals to the service quickly diversified and I began to work with a growing number of CYP who had not been excluded from school but who expressed worries about school and had not attended for prolonged periods of time. I felt they were invisible to the services typically available to CYP and their families. It was common that ours was the only service the students had been referred to and that the referrals were made when the CYP had been out of school for a prolonged period.

As a Learning Mentor I would visit the CYP to develop a relationship with them. During times when I was unable to engage with CYP I would sit in their homes to give them the opportunity to join me. These days seemed particularly challenging for parents and they often sat with me to express their thoughts and concerns about the situation. I believe the containment I was able to provide was valuable, however I often left sharing parents' feelings of 'being stuck'. As a professional myself I was unsure of how I could enable change. There was little supervision available to me in my role and I was encountering situations where CYP were experiencing significant distress. I would raise my concerns and encourage procedures such as setting up Early Help Assessments (EHA) to try to raise awareness of the families I was working with and to enable them to access other agencies. However, I never felt that I was able to do enough. As I began the doctorate these experiences stayed with me and I initially decided to focus my research on attendance difficulties to develop my own practice in the area.

My motivation for the study as it is presented here was shaped by my exploration of the literature and the relative absence of parent and child voice in this area. I spent some time deliberating whether to listen to the stories of children or their parents. However, I eventually settled on listening to the voices of parents. I believe this was in part driven by my experiences of sitting with parents in similar situations in the past and my feeling that they remained invisible to services even when they were asking to be heard. Further, it is parents: who typically seek professional involvement; who often attend meetings with professionals; and who are legally responsible for their CYP's attendance at school (DfE, 2015a; DfE, 2020). I wanted to listen to the experiences of parents, of children whose attendance is reduced and who view worry as a factor of the reduced attendance. My hope was that I could raise their voices and help professionals to better understand how they can support families in these situations.

1.2.   Literature Review

Compulsory education was introduced for children in Britain in 1906 (Lansdown, 1990). It is now the expectation in the UK that from the age of five children access fulltime education (DfE, 2020; Lansdown, 1990). Accessing a formal education is often viewed as being beneficial to the holistic development of CYP; providing them with the opportunity to gain formal qualifications and to develop important life skills (Le Riche, 1995). Over the past three decades, successive governments have raised concerns about CYP with low rates of school attendance (Baker and Bishop, 2015; DfE, 2020; Reid, 2014). This is perhaps unsurprising as non-attendance is typically considered to have negative implications for CYP's lives. In the short-term non-attendance has been linked to family and social difficulties and low academic attainment (DfE, 2016; Elsherbiny, 2017). In the long-term non-attendance has been associated with having fewer qualifications and experiences of mental illness and unemployment (Elliott, 1999; Elsherbiny, 2017; Tobias, 2019).

This review will begin by discussing the discourses and terms commonly seen within literature pertaining to school attendance. It will predominantly focus on an area of non-attendance often referred to as 'School refusal'. I will define this term whilst acknowledging

the heterogeneity of its use within the literature. I will argue that the term School Non-Attendance (SNA) offers a more helpful understanding of the CYP that 'school refusal' has historically sought to represent. Following this I will consider the needs of CYP experiencing SNA and the current understanding of the reasons behind SNA as identified within the, primarily positivist, literature. I will then discuss the evidence base surrounding interventions for extended SNA. The implications of an overwhelmingly positivist research base, on our understanding of SNA, will be considered. I will argue for the need for further qualitative research within this area to broaden our understanding and to give a voice to the CYP, their families and the school staff who are affected. Finally, I will highlight and review the limited qualitative research before discussing the identification of my research questions.

1.2.1. Key terms in the school attendance literature

Attendance difficulties are depicted as a spectrum ranging from occasional absences to situations where CYP remain out of school for prolonged periods of time and in some cases indefinitely (Richardson, 2016). School refusal and truancy are terms used within the international research literature to differentiate between groups of students experiencing difficulties with attendance (Lauchlan, 2003). These terms should not be confused with those used in national government policy documents. For example, the term "persistent absence" which is used by the UK Department for Education (DfE) to highlight cases where a CYP's school attendance has fallen below 90% (DfE, 2019).

Truancy is used in the literature to describe CYP who avoid school and hide their avoidance from their parents. These CYP are typically portrayed as being uninterested in the curriculum or reluctant to conform to school rules; they are not considered to experience worry or distress related to school. This understanding is considered problematic as it views truancy as behavioural at the expense of other understandings. Some authors suggest that this behaviourist understanding can mean that other factors, for example, CYP mental health needs, are not given adequate attention (Lauchlan, 2003). Links have been made between the justice system and CYP experiencing truancy (Ingul, Havik and Heyne, 2018)

and it has been suggested that these CYP may engage in anti-social behaviour whilst they are not in school.

In contrast researchers use the term 'school refusal' to describe CYP, of compulsory school age, who have difficulty attending school or staying in class throughout the school day (Ingles, Gonzalvez-Marcia, Garcia-Fernandez, Vincent and Martinez-Monteagudo, 2015; Kearney, Cook and Chapman, 2007; Kearney and Silverman, 1999). This difficulty is often associated with strong negative emotions such as anxiety and fear (Havik, Bru and Ertesvag, 2014; Munkhaugen, Gjevik, Pripp, Sponheim, and Diseth, 2017) which can lead to somatic symptoms and behaviours that are challenging for adults (Kearney and Bates, 2005). CYP identified as experiencing school refusal have parents who: are aware of their difficulties; know when they are not in school; and have tried to ensure their attendance (Ingul et al., 2018).

School-refusal has been identified as a concern within all countries with a mandatory school system (Melvin et al., 2017). The broad definition of school-refusal means that it represents a very heterogeneous group of students (Ingles et al., 2015); Pellegrini (2007) and Kearney and Bates (2005) highlight that CYP's academic ability, ethnicity, gender and socio-economic status have not been associated with school-refusal. However, there are times in CYP's education where they are more vulnerable to experiencing school-refusal; for example, during transitions between year groups and in particular the transition to primary or secondary school (Kearney and Bates, 2005; Pellegrini, 2007). Although school-refusal can affect CYP of all ages, its impact on the amount of school missed is often greatest in older students. Students who struggle to attend school can progress along a continuum of non-attendance (from difficulty remaining in the classroom to avoiding school entirely) with each school year (Beckles, 2014). Therefore, it is common for the most entrenched and profound SNA to be seen amongst older students (Taylor, 2012).

1.2.2 Numbers impacted

The UK literature suggests that 1-2% of students are affected by school-refusal behaviours (Baker and Bishop, 2015), however many have argued that this is likely to be an under-

estimate. Schools record full or half day absences within their attendance data (Kearney, 2008), but this data is notoriously hard to use to identify students with school-refusal behaviours. It is possible that for many CYP within this population absences are recorded as authorised sick days owing to the somatic symptoms experienced. Further, attendance data does not allow for an analysis of the numbers of CYP who are affected at the lower end of the school-refusal spectrum; for example, those who find it particularly difficult to come into school in the mornings or to stay in class. Thus, it is not unusual for estimates of the proportion of CYP experiencing school refusal behaviours to vary widely across the research. Havik et al., (2015a), reported that estimates in the literature vary between 1% to 28%.

1.2.3. What's in a name? Is School Refusal an appropriate definition?

This review focuses on the area of attendance often described as 'school refusal' within the literature. However, it is important to acknowledge that the term has been criticised and researchers have offered alternative language to describe students who meet the definition of school refusal provided above.

The behaviours defined by the term school refusal have been of interest to researchers for several decades and early articles on the topic typically referred to its presentation as 'school phobia' (Johnson, Flastein, Szurek, and Svendsen, 1941). Johnson et al., (1941) described 'school phobia' as a feeling of great anxiety which often leads to serious absences from school (Johnson et al., 1941). Johnson later rejected this term suggesting that 'school phobia' would best be conceptualised as 'separation anxiety' which could occur both in a CYP's early and later years (Carroll, 2015). Following this period many researchers chose to use the terminology 'school refusal' (Elliott, 1999; Hersov, 1960; Caroll, 2015) which remains in frequent use today (see: Kearney and Bates, 2005; Melvin et al., 2017; Munkhaugen et al., 2017).

It is important to consider the language used within this area of research and the impact this has on our understanding (O'Toole and Devenney, 2020). In the school refusal literature two dominant discourses can be identified: a legal and a clinical discourse. These discourses

focus our attention on families and individual students (Pellegrini, 2007; Carroll, 2015; DfE, 2015a). The legal discourse is drawn from the legislation used by governments to ensure school attendance. In the UK, this legislation places the responsibility of CYP attendance on parents and enables LAs to prosecute parents when their child's attendance falls below certain thresholds (DfE, 2015a). This approach suggests that student attendance difficulties stem from, and are the responsibility of, their families.

The literature mirrors this focus on CYP and their families and much of the research draws on medicalised 'within' child/ family discourses. This is perhaps unsurprising given the wealth of research published by journals representing medicalised professions; for example, child psychiatry journals (See: Melvin et al., 2017 and Egger, Costello and Angold, 2003). Terms such as 'disorder', 'phobia' and 'treatment' are common in these articles and they often focus our attention on within child and family factors. As Pellegrini (2007) identifies, the emotional distress experienced by many CYP exhibiting school refusal means that acknowledgement and support of CYP mental health is important. Therefore, it is understandable that there has been a clinical focus within the research. However, not all children exhibiting these behaviours have a diagnosable mental health disorder (Lauchlan, 2003). This is concerning as a heavy clinical focus within the literature means environmental factors influencing non-attendance can be overlooked.

The use of the descriptive term 'school refusal' risks further entrenching this approach. The term focuses our attention on the individual and suggests that CYP identified as 'school refusers' are absent from school by their own volition. Typically CYP are not offered the choice as to whether they attend school. Legislation within the UK requires that students access a formal education within a school setting unless their parents elect to home educate their children (DfE, 2019b). The law sees schooling as a contract between parents and schools; a contract which children are not included in (Burke and Grosvenor, 2003). Some CYP have voiced that they would prefer not to attend school and amongst those who typically view attending school to be positive, there are things about their school they would like to change and days when they would prefer not to go (Burke and Grosvenor, 2003). Regardless of these views the majority of students do attend school on a regular basis. The term 'school refusal' is suggestive that the non-attendance is a behavioural decision that

CYP are making. The focus on the behaviour detracts from findings within the school refusal literature which recognise that many students experiencing school refusal report that they want to go to school and are prepared to attend (Elliot, 1999). However, when it comes to going to school they find it too difficult to manage (Elliot, 1999). The term risks focusing our attention on the individual behaviour of a CYP and, therefore, away from factors which could be contributing to the non-attendance; including external factors, for example, the school environment (Havic, Bru and Ertesvag, 2015b).

Thus, some researchers, for example Pellegrini (2007) and Carroll (2015) have argued for more neutral definitions such as 'extended school non-attendance' and 'pupil absenteeism' respectively. I agree with O'Toole and Devenney (2020) who suggest that power should be given to CYP to choose the language that is used to frame their experiences. Therefore, I am not wedded to any definition. However, due to the current absence of opportunity given to CYP to name their experience, and the possible implications of the term 'school refusal' on adult understanding (Bacchi 2009, 2012), for the purpose of this study I will employ the more neutral term school non-attendance (SNA).

1.2.4. Factors involved in SNA as understood within Quantitative Research:

Research has predominantly employed quantitative methodologies to explore the reasons behind SNA (Dannow, Esbjon and Risom, 2018). Therefore, I will begin by presenting some of the insights gained from the quantitative literature base.

Clinical Links:

Whilst SNA is not a diagnosable condition within psychiatric classification systems (Melvin et al., 2017), there is an association between SNA and several diagnostic profiles. These include: separation anxiety disorder; phobic anxiety; social anxiety; anxiety and depression (King and Bernstein, 2001). Elliott and Place's (2019) review of the literature highlighted that research indicates that many children experiencing SNA are likely to meet DSM-V criteria for diagnoses of an anxiety disorder (for example, separation anxiety or social anxiety) or depression. This research includes several large-scale studies which have used structured

diagnostic interviews to assess CYP with SNA (for an example, see: Egger, Costello and Angold, 2003).

In their recent systematic reviews of the literature Finning et al., concluded that there is a positive association between SNA and diagnoses and/ or symptoms of anxiety (Finning et al., 2019a) and SNA and symptoms and or/ diagnoses of depression (Finning et al., 2019b). However, Finning et al., (2019a and 2019b) highlight that the absence of longitudinal studies exploring the relationships between SNA and anxiety and SNA and depression means that the direction of causality between these variables is unclear (Finning et al., 2019a and 2019b); it is difficult to identify whether depression and anxiety are causes or consequences of SNA. It is possible that the symptoms of depression (for example, tiredness, loss of motivation and social withdrawal) and anxiety (for example, somatic symptoms) could lead to SNA. Alternatively, the isolation and inactivity which often occurs as a result of SNA could mean that CYP experiencing SNA are more vulnerable to depression and anxiety. The relationships between these variables warrant further investigation. The presence of worry, fear and anxiety is often considered key within the 'school refusal' literature (Havik, Bru and Ertesva, 2014); CYP's attendance difficulties are often associated with strong negative emotions such as anxiety and fear (Havik, Bru and Ertesvag, 2014). Longitudinal studies to explore these relationships are important as they could impact, the approaches used for early identification of SNA, and the way CYP experiencing SNA are supported.

Whilst studies have identified high rates of anxiety amongst CYP with SNA, it is acknowledged that the majority of CYP who experience anxiety, continue to attend school (Ingul and Nordahl, 2013). To gain an insight into why some students with anxiety are more vulnerable to SNA Ingul and Nordahl (2013) asked students to fill in questionnaires measuring a range of factors hypothesised to be influential in SNA; the questionnaire included scales measuring: resiliency, life events and personality traits. 865 students returned the questionnaire and the findings suggested that students, with anxiety, who regularly attend school have protective factors which support their engagement in education. These factors included having fewer behavioural or family problems. Although the study identifies some interesting trends it is unable to identify the causality of these.

Family Factors:

The role of the family has played a key part in the early understanding of SNA. Early research focused on separation anxiety disorder (Carroll, 2015) meaning that the relationships between CYP and their carers were highlighted within the literature. Although separation anxiety continues to be recognised as a precursor to SNA in some cases (Hella and Bernstein, 2012) it is no longer assumed that separation anxiety explains most SNA (Elliott and Place, 2019). Indeed, some researchers have highlighted that many CYP with SNA are able to separate from their caregiver, to socialise with peers, outside of the school environment (Elliott and Place, 2019).

However, researchers exploring 'within family' factors have found that parental psychopathology is related to SNA (McShane, Walter and Rey, 2004). Further, the importance of parental engagement in their child's education has been recognised by researchers. Parental engagement behaviours such as monitoring CYP attendance (Sheppard, 2005) and co-operation with school staff (Lyon and Cotler, 2007) have both been found to reduce the risks of SNA.

School Factors:

Following the findings of a small number of qualitative studies which recognised the contribution of the school environment to SNA Havik, Bru and Ertesvag (2015b) conducted a large scale research study which sought to investigate the association between school factors (including, classroom management and student relationships with peers and school staff) and SNA. The study conducted in Norway recruited a total of 5,465 students, aged between eleven and fifteen, from 45 schools. Students were asked to complete a self-report questionnaire which included questions about the reasons behind any absences. The results suggest that school factors are closely linked with SNA and, therefore, that this is an important area of study.

Findings showed that difficulty with peer relationships was a key risk factor for SNA. Further, a moderate association between social isolation and SNA was reported. The study also

identified the importance of teachers in CYP peer relationships; the findings showed that good classroom management had an indirect effect on SNA by supporting the social relationships of the CYP in the classroom (perhaps by reducing bullying). The study also identified that predictable classrooms and emotionally supportive staff are important to ensuring high attendance rates.

Havic et al's., (2015) study is one of the few quantitative studies to have investigated school factors in SNA. Their study is a welcome addition in a subject area historically dominated by clinical research. The study's large sample size improves the generalisability of results. However, it should be recognised that the study took place in Norway and that similar studies are needed to identify whether CYP with different cultural upbringings have similar views. The use of CYP self-report questionnaires was valuable as it enabled the researchers to gain a first-hand insight into the factors affecting SNA. However, the use of a structured questionnaire with fixed items means that CYP voice was kept within the bounds of topics that researchers had pre-determined to be important in SNA. This approach risks losing important CYP views that lie outside of the parameters of the questionnaire. Further, although the study highlights some important correlations, it is not possible to identify the processes behind these relationships and the directions of causality are unclear; for example, it is possible that absences from school could increase a CYP's risk of bullying as opposed to bullying increasing a CYP's risk of SNA.

1.2.5. Interventions:

Interventions and Intervention Timing:

A wealth of research exists which has employed quantitative methodologies to evaluate the success of interventions. The success of interventions is typically defined by an increase in student attendance. Interventions can include psychological therapies (predominantly CBT), behavioural programmes (for example, exposure techniques), family therapy approaches and changes to the school environment (Elliott, 1999; Eliott and Place, 2019).

SNA can progress along a spectrum of severity and there is widespread recognition within the literature that the earlier attendance difficulties are identified, and supports are put in place, the more likely it is that the CYP's attendance will improve (Lyons, 2016). For example, Reid (2012) suggests that early interventions are six times more effective than interventions put in place when a CYP's non-attendance has become persistent.

Psychological therapies:

Perhaps unsurprisingly given the clinical discourse around SNA in the literature, many interventions have been focused on supporting CYP to manage diagnoses such as depression and anxiety. Of these interventions CBT tends to be the preferred approach (Baker and Bishop, 2015; Elliott and Place, 2019).

A recent meta-analysis which contained six studies using CBT and anxiety medication to support CYP with SNA was conducted by Maynard et al., (2015). They found that CBT had a positive effect on CYP school attendance but did not decrease CYP's feelings of anxiety. They concluded that their meta-analysis offered tentative support for the use of CBT amongst students with SNA.

Behavioural Approaches:

Behavioural approaches employed to support students improve their attendance following prolonged periods of SNA have primarily focused on graduated exposure techniques (desensitisation approaches) and immediate enforced return to school (flooding). Although it is a highly controversial approach flooding techniques have been employed by researchers who argue that early and immediate intervention helps to support school attendance (Elliott, 1999). In contrast, desensitisation approaches are likely to start with CYP returning to school during quiet times or for preferred activities. These approaches are often used in conjunction with CBT (Elliott and Place, 2019).

Family Involvement:

Early views that SNA was linked to separation anxiety means that the role of the family within SNA has been well researched. It is acknowledged within the literature that considering the influence of a CYP's family is important when putting supports in place (Berg, 1992; Elliott, 1999; Kearney and Silverman, 1999 and Nuttall and Woods, 2013).

School Adaptations:

Pellegrini (2007) argued that there is a lack of research into environmental changes that could be made within schools to support CYP with SNA. The main argument being that because research has been saturated in a 'within-child' model, the role of the school has not gained sufficient attention. Schools are well placed to run group-based interventions, for example 'Circle of Friends' and 'Social Skills Groups', however no research has evaluated the impact of these approaches on SNA to date (Carroll, 2015).

Reviewing the Interventions:

Much of this research has been situated within the medical model (Elliott and Place, 2019) and has therefore, typically explored 'within-child' interventions at the expense of exploring environment-based changes (such as improving structure and routines in school). This is concerning given findings which suggest the school environment has an impact on SNA (Havik et al., 2015b). Further, much of the research reviewing interventions involve participants who meet thresholds for, or are accessing, clinical care (Lauchlan, 2003). This means CYP experiencing SNA who do not meet these thresholds are not represented in these studies.

Much of the research has used CYP's attendance data as a measure of effectiveness, suggesting that the priority is to ensure students are in full time education. It is difficult to know whether this is the desired outcome for CYP, as their voice is largely absent from

research exploring the effectiveness of interventions. However, more recent qualitative research has suggested that CYP, and their parents, often prioritise CYP wellbeing over attendance when evaluating which interventions have been supportive (Mortimer, 2019).

Lauchlan (2003) has argued that research is yet to find conclusive evidence in favour of specific interventions. Therefore, it is possible that a more holistic approach to interventions could be beneficial.

1.2.6. Frameworks for identifying and understanding SNA:

The heterogeneous nature of SNA and the multitude of contributing factors identified by research has led some researchers to create models to identify SNA and aid understanding of individual CYP experiencing SNA.

To encourage early intervention Ingul, Havik and Heyne (2019) have developed a framework to support the identification of CYP at risk of SNA. With reference to the literature they highlight key risk factors for SNA and identify approaches to help adults monitor for these in schools (for example, using checklists and observations). They encourage schools to give staff members clear roles to support the identification of CYP at risk of SNA. They also highlight the need for clear systems to be put in place in schools to ensure that staff members: meet regularly; share knowledge; and involve external agencies (for example, EPs) in a timely way.

It is widely recommended that, when working with individual CYP experiencing SNA, professionals work to identify the primary function of the SNA (Richardson, 2016). Thus, it is unsurprising that a key model within the non-attendance literature seeks to aid understanding of the motivations CYP may have for SNA. Kearney and Silverman's (1999) taxonomic model of non-attendance is based on four key functions of SNA (Kearney, 2008):

1. Avoidance of stimuli within the school environment which cause the CYP worry.
2. Avoidance of social or evaluative situations which cause the CYP worry.
3. Access to attention from loved ones.

4. Access to reinforcers that exist outside the school environment (e.g. preferred activities) (please see Appendix A for a more detailed account of each of these functions).

Research suggests using Kearney and Silverman's (1999) model to identify the function of a CYP's SNA behaviour is more successful at predicting CYP non-attendance rates than traditional clinical measures of anxiety or depression (Kearney, 2008). This highlights the importance of gaining a good understanding of the circumstances and reasons behind CYP non-attendance when identifying and responding to cases of SNA.

A recent framework which has been developed by psychologists to support a compassionate and holistic understanding of emotional distress (O'Toole, 2019) is the Power Threat and Meaning Framework (PTMF). It does this by encouraging us to move away from the medical model and to develop an understanding of the power, threat and meaning present in our lives (Johnstone and Boyle, 2018). The framework has been found to support teacher understandings of mental health and wellbeing (O'Toole, 2019).

Broadly speaking the framework encourages us to consider:

- How power has operated in an individual's life or a group of people's lives; what has happened to them?
  This could include: legal power (for example, the ability to impose sanctions or prosecution); coercive power (for example, the use threats and aggression to ensure compliance); economic and material power (for example, the ability to access or to deny access to services); and ideological power (this is considered one of the more hidden forms of power and involves the control of meaning, language and 'agendas', for example the power to validate or undermine the perspectives of others or to have our experiences and perspectives validated).
- How negative uses of power affect individuals or groups; what kind of threat did the power pose?
  Core threats can include: emotional threats (for example, feeling overwhelmed or unsafe); value based threats (for example, loss of values and beliefs); threats to knowledge and meaning construction (for example, the ability to access information

and to develop your own understanding or meaning, this can be impacted by unequal power relations which can enable different meanings to be imposed); relational threats (for example, isolation, shame and threats to an individual's autonomy); and economic/ material threats (for example, poverty or access to services that enable individuals to meet their basic needs).

- The sense the individual or group made of these experiences; what meanings have they developed because of these experiences?

  These can include: feelings; beliefs about ourselves; and beliefs about others. For example, feeling trapped, isolated, blamed, controlled, guilty, shamed and a sense of injustice.

- How the individual, or group, respond; what strategies did they employ to keep themselves safe?

It is important to highlight that the power, threat, meaning and responses are inseparable experientially; they impact and are impacted by one another (Johnstone and Boyle, 2018). Arguably the PTMF could be particularly supportive in SNA; SNA is dominated by medicalised mental health discourses and embedded in legislation which encourages the use of legal powers (DfE, 2015). Use of this framework could encourage an understanding which considers the complexity and heterogeneity of SNA.

1.2.7. The importance of voice and qualitative research:

Research into SNA has predominantly employed quantitative methodologies (Dannow, Esbjon and Risom, 2020). These methodologies have been used to develop an understanding of SNA and to identify risk factors. Researchers have largely focused on clinical, within-child and family, factors and their use of diagnostic scales and closed question questionnaires has meant that there has been little opportunity for participants to raise other issues which could be contributing the SNA. The focus on within-child and family factors in the literature encourages the use of interventions which are situated within the medical model. In the last ten years a small number of qualitative studies have begun to explore the views of CYP affected by SNA and their parents. These studies have drawn

attention to the role of the school environment (Dannow et al., 2020) and have further highlighted the heterogeneity of SNA (Gregory and Purcell, 2014).

The importance of gaining family and CYP views regarding matters affecting them is well documented in national legislation. Within UK law the Children and Families Act (2014) stresses the importance for professionals to consult with CYP, with Special Educational Needs (SEN), and their families in matters that affect them. Therefore, the limited research considering CYP and parental voice within the SNA literature is surprising. Qualitative research lends itself particularly well to hearing individual voices and understanding their experiences. Whilst quantitative research works to test hypotheses by categorising and measuring variables related to CYP and their families qualitative research can enable researchers to explore the meanings and complexities of a situation. Qualitative research can support understandings of an experience through the eyes of those affected (Hardy and Majors, 2017).

1.2.8. Qualitative research involving parents:

I believe it is important that parent voices are heard. Parents have a legal obligation to ensure their child's attendance at school (DfE, 2014) and some of the interventions identified for SNA in the literature require a high level of parental involvement. For example, it is likely to be parents who escort CYP into school when graduated exposure techniques are employed (King et al., 2001). Further, researchers have raised the importance of working with parents in cases of SNA (Kearney and Silverman, 1990; and Woods and Nuttall, 2013) and studies have found that parental attitudes towards school and the ability of school staff to effectively engage parents in interventions are important factors in improving CYP attendance (Dannow et al., 2020; Harris and Goodall, 2008). Despite the importance of their role there is little research that has enabled the voices of parents to be heard (Heyne et al., 2020).

Due to the focus of this thesis on parental experience I have not reviewed qualitative research pertaining to CYP voice in this literature review. However, it is worth noting that this research has offered challenge to some of the discourses seen in the quantitative literature base (Stroobant and Jones, 2006) and has highlighted the importance of employing a systemic perspective when working with CYP experiencing SNA (Beckles, 2014) (see Appendix B for further information related to this research).

By exploring the literature I was able to identify a small number of qualitative research studies in which parents have participated. I have chosen to explore UK based studies within this review (see Appendix C for information on studies conducted elsewhere in Europe). The following qualitative studies were identified as being the most pertinent to this research:

- Nuttall and Woods (2013) sought to explore what contributed to effective interventions for students experiencing SNA. Their research involved two case studies. For each case study interviews were conducted with CYP, their parents and school staff. Interviews were analysed using thematic analysis and several factors were identified that occurred in both case studies. Based on this research Nuttall and Woods (2013) developed a "ecological model of successful reintegration" which draws on systemic theory (for example Bronfenbrenner, 1979). They emphasised the importance of: supporting the psychological needs of the young person (for example, ensuring a sense of belonging and supporting self-esteem); involving the adults around the child; and considering the broader relationships and systems which CYP and their families sit within. This highlights the need for multi-agency working and the use of individualised responses to SNA.

- Using Interpretative Phenomenological Analysis (IPA) Gregory and Purcell (2014) explored the experiences of mothers and their children, who had elected for home education following lengthy periods of SNA. Their study highlighted the individual and complex nature of these cases arguing that prioritising medicalised research has meant that some complexities have been lost; they noted that participants drew on a mix of within-child and environmental factors when explaining the SNA. In reflecting on the use of IPA Gregory and Purcell (2014) suggested that some of the

interrelated nature of the themes had been lost using this approach. Therefore, they presented additional information to allow them to explore this.

- In his doctoral thesis Baker (2015) used discourse analysis to explore the way parents and professionals understand SNA and the impact of these understandings on the experiences of CYP. Baker noted some commonality between constructions of SNA, but highlighted the variety that existed between adults, even when they shared the same role. Baker (2015) highlighted the importance of attending to individual understandings of SNA and the resulting parenting or professional practice.

- Myhill (2017) conducted a doctoral thesis which aimed to identify barriers and facilitators to parental involvement with schools in cases of SNA. The views of eight parents were explored using semi-structured interviews and analysed using thematic analysis. The research identified that parents felt supported when they had positive, trusting relationships with school staff, who were sensitive to their emotional capacity. Parents without these relationships found it more difficult to disclose their concerns about their child's attendance with school staff. Myhill (2017) suggested this was further impacted by fears of prosecution. Parents indicated that they felt better able to engage with school staff and to work with them to improve CYP attendance when they were listened to, understood and included in decision-making processes.

- Mortimer (2019) conducted a doctoral thesis which took an appreciative inquiry approach to explore what worked when supporting students experiencing SNA to return to school. The research considered perspectives of students and their parents; three parents were interviewed as part of the study. Results acknowledged the importance of trusting relationships with school staff and suggested that these relationships underpin the success of the provision put in place. She also suggested that CYP emotional wellbeing should be considered when evaluating the success of interventions. Based on these findings Mortimer (2019) developed a two-tier model which considered factors which can support the return of CYP to school (see *figure 1*):
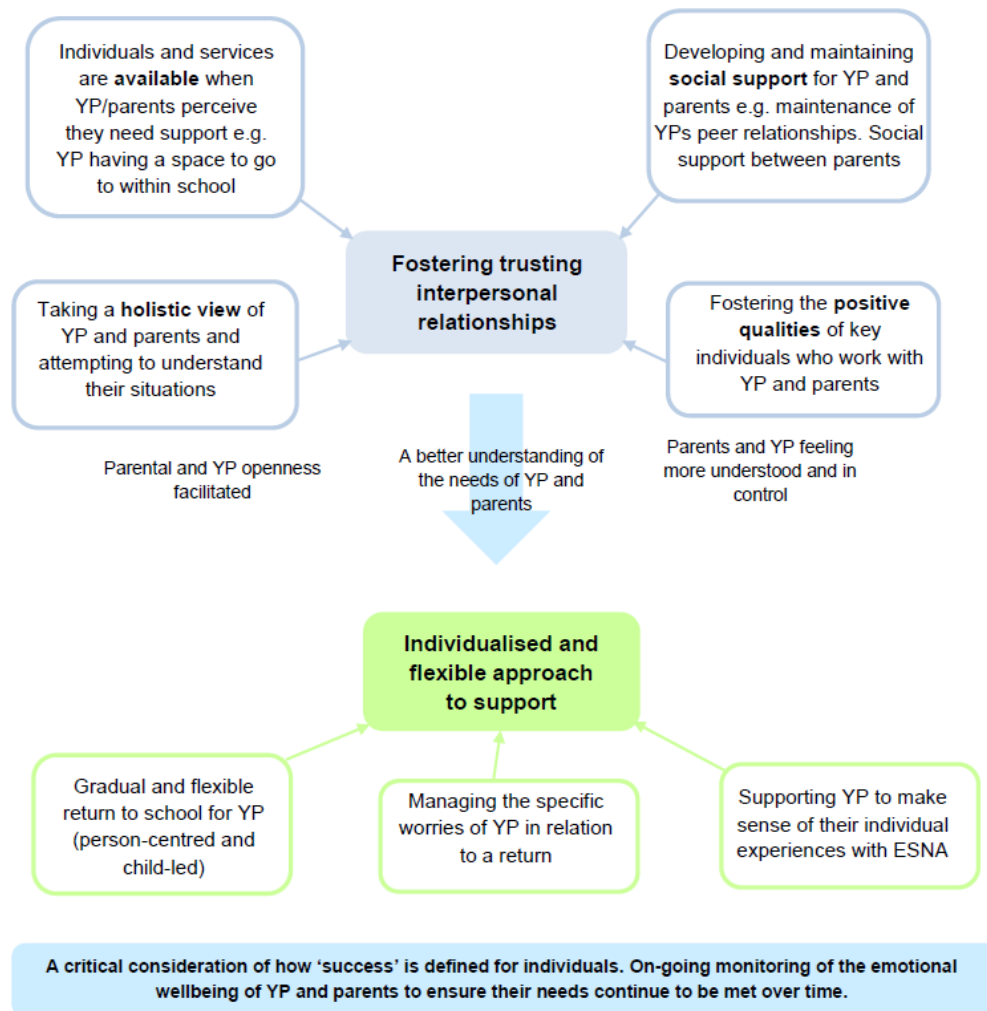
Figure 1 (Mortimer, 2019, P. 134)

- Epstein, Brown and O'Flynn (2019) posted an online questionnaire onto sites used by parents to discuss childcare. Their questionnaire was designed to explore the reasons behind non-attendance and to ask parents: about the problems the non-attendance had created for their family; how schools responded; and whether or not parents were threatened with, or prosecuted for, non-attendance. They had 126 responses. Almost all parents reported that their child had experienced anxiety. 16 of the parents who filled in the questionnaires had off rolled their children; most of these cited fear of prosecution as a reason. They conclude that a punitive approach is ineffective in improving attendance and can cause harm. Therefore, they recommended that non-attendance be viewed as a civil issue concerning child welfare rather than a criminal issue.

Reflections on the qualitative research to date:

Inherent in qualitative research is an issue of generalisability. In the study with the largest sample size (Epstein, Brown and O'Flynn, 2019) participants were recruited from childcare websites thus suggesting parents were actively seeking support from online communities. Therefore, the views of parents who had not engaged with these communities were lost. However, it should be recognised that qualitative research does not seek to be generalisable to the wider population. By providing adequate information it can offer readers the opportunity to identify whether the findings are transferable to their own situations (Kuper, Lingard and Levinson, 2008). I felt that the studies, particularly the theses offered enough information to allow me to do this. However, the use of thematic analysis in some studies where both parents and CYP were interviewed made it difficult to distinguish between these voices (for example, Nuttall and Woods, 2013).

The studies identified all employed analytical approaches which sought to identify commonalities between participants (for example, using thematic analysis or IPA). There were occasions where the authors themselves seemed to question this approach highlighting the differences in views between participants (Baker, 2015) and in some cases exploring the interview data further outside of the analytical approach chosen (Gregory and Purcell, 2014).

1.3. Development of Research Questions:

Similarly, to Gregory and Purcell (2014) I wanted to attend to parental experiences of CYP SNA. Due to the heterogenous nature of SNA and the differing views amongst adults (Baker, 2015; Gregory and Purcell, 2014) I wanted to listen to the individual experiences, and voices, of parents related to their CYP's SNA. This is different to previous qualitative research which has typically brought experiences together through thematic analysis or IPA approaches.

I believe there is value in gaining rich insights into individual experiences and that these insights can support the practice of EPs and other professionals who are involved with CYP experiencing SNA, and their families.

Therefore, the following research questions were developed:

1. How do parents experience their child's SNA?

2. How do parents experience professional involvement (including both school staff and external agencies)?

3. What can educational psychologists learn from these experiences?

(please see Appendix D for further reflections on these research questions).

I sought to speak to parents of children:

- Who were in year eight or above. This decision was made because the transition to secondary school is known to be challenging for CYP. I wanted to speak to parents whose children had had the chance to move through this transition; parents were able to reflect on this transition as they shared their stories.

- Who were on role at a school. In contrast to Gregory and Purcell's (2014) research which considered the experiences of mothers who had made the decision to home educate their children I wanted to speak to parents whose children were still on role.

- Whose attendance had been less than 90% over the last two terms. I chose to approach parents whose child's attendance was lower than 90% because this is the current threshold for the government's definition of 'persistent absence' (DfE, 2018). Once a student misses 10% or more of school, staff are encouraged to 'take action' and to work to increase the attendance (DfE, 2011). I believed this criterion would help me to answer my second research question as it would mean that participants should have had involvement from school staff.

- and who were considered by adults to be 'worried' about attending school. I chose to use the word worry to enable parents to participate regardless of whether their child had a formal diagnosis.

Chapter 2: Methodology

2.1. Chapter Introduction:

In this chapter I will discuss the philosophical basis of the study as well as the methodological decisions made.

2.2. The development of an ontological and epistemological position:

My initial leaning to this area of research was out of the hope that by immersing myself in the topic I might feel more skilled when I encountered SNA in my practice. I had no fixed idea about the type of research I wanted to carry out, but reasoned that by exploring the literature I would be able to identify a gap worthy of further inquiry. Therefore, I believe that the early stages of my research were driven by a pragmatic, rather than a theoretical, position.

As identified within the literature review there is a wealth of research into SNA. However, what struck me as I read through the research was the absence of CYP and parent voice (Baker and Bishop, 2015; Gregory and Purcell, 2014). Studies looking at the causes of SNA often considered the role of parenting (Carroll, 2015) and several studies identified the importance of parental involvement in CYP attendance (Berg, 1992; Sheppard, 2005). However, despite being the focus of much research parents were rarely given the opportunity to share their views and experiences. I felt that this was a disservice to the families I have worked with; by denying parents the opportunity to share their lived experiences, valuable insights into SNA can be lost. It was my reaction to the absence of parental experiences within the literature that encouraged me to think about my ontological and epistemological position.

Ontology refers to our underlying assumptions about the nature of reality (Guba and Lincoln, 1994; Hepburn, 2003); it considers what exists in our social world as well as the form and nature that things exist in (Creswell, 1998). If we consider ontology as a continuum then at opposite ends would be relativism and realism. From an extreme realist perspective there is one reality which exists, independent of human interpretation, and this reality is

fixed (Maxwell, 2011). Today social scientists tend to hold more nuanced interpretations of realism. From a post-positivist perspective there is an external reality, but researchers are unable to achieve a fully accurate representation of this reality with certainty (Spencer, Pryce and Walsh, 2014). In contrast, from a relativist perspective there are multiple versions of reality, that are shaped by context and experiences, and depend solely on the truth which we attach to it (Rorty, 1991).

Epistemology considers what constitutes knowledge and how we can generate and understand knowledge (Barker, Pistrang and Elliott, 2002; Greene and Hogan, 2005). At opposing ends of the epistemological continuum sit positivism and interpretivism/ constructionism (O'Gorman and Macintosh, 2015). Positivists believe that reality is 'knowable'; that there are absolute truths that can be objectively measured (Proctor, 1998). Post-positivists sought to amend this view. Although post-positivists believe that knowledge should seek to come as close to the truth as possible they recognise that previous theories and researcher beliefs can influence the generation of knowledge. Post-positivist researchers view all measurement to be biased and they attempt to control for this bias as far as possible within the design of their research. For example, post positivist researchers may use triangulation or control groups to improve the reliability and validity of their research (Spencer, Pryce and Walsh, 2014). In contrast, Interpretivists/ constructionists reject that there are absolute truths and instead believe that our knowledge is developed through our experiences, social interactions and beliefs. Therefore, different truths/ realities exist for different individuals. Researchers with an interpretivist/ constructionist epistemology are more likely to use qualitative research methodologies which enable them to explore these individual truths.

I believe that my own positioning is most closely aligned to critical realism; I believe that reality exists independent of our perceptions but that there are limits to our ability to capture this (a realist ontology). I also believe that as individuals our knowledge of that reality is constructed through our social interactions and personal experiences (an interpretivist/ constructionist epistemology) (Maxwell, 2011). I am drawn to critical realism as it enables researchers to accept and acknowledge very real structures and mechanisms that affect individual lives (Bhaskar, 2013). It acknowledges that the social interactions between people (for example, the distribution of economic wealth and opportunities),

society's social structure (for example, the use of austerity politics) (Bhaskar, 2013) and the 'involuntary placement' of class, gender and race (Archer, 1995) impact on our lives and perceptions of the world. Although we might not be able to see these structures their reality can be observed through human experience. Further, Critical Realism asserts that we develop individual agency that enables us to exert power over our lives, the lives of others and the wider world (Archer, 1995). Archer (1995) believes that this agency is developed through our inner conversations and our ability to reflect.

In relation to my own area of research, SNA, I felt that by taking a Critical Realist position I would be better able to consider the real structures that families could encounter (for example, the statutory processes around RSA). If participants commented on what they perceived were 'real' underlying factors which contributed to their experiences of their child's SNA then I wanted to be able to give these factors credence within the research. Although I did not begin the research seeking to identify the reality, I hoped that by acknowledging a reality that exists, independent of our constructions, that this research would be better placed to comment on the possibilities for change. Further Critical Realism would allow me to acknowledge the agency of individuals and to value their unique experiences and voices.

2.3. Identifying a methodology:

Methodology refers to the research design. It shapes our choice of and use of different methods (Jupp, 2006). Although I had been exposed to a range of research methodologies in seminars during the doctorate I did not have a strong leaning towards any one approach. I believe that the methodologies employed by research should be chosen based on their ability to answer the research questions (Holloway and Todres, 2003).

A qualitative research methodology would enable me to answer my research questions and would fit with my epistemology. Critical realism acknowledges that individuals will each have their own constructions of reality based on their social interactions and experiences. Qualitative methodologies are well placed to support researchers to explore unique life experiences, and individual points of view, to help their understanding of a phenomenon

(Mutch, 2013). I felt that a qualitative approach would better support me to gain the rich understanding required by my research questions and allow participants to share their unique stories in a way that was meaningful to them.

2.4. Identifying a Method:

I needed to identify a method that would allow me to gather rich data to explore participant's experiences related to their child's SNA. In my search for an appropriate method, I considered Interpretative Phenomenological Analysis (IPA) and Narrative approaches.

2.4.1. Rejecting IPA:

Consistent with a critical realist positioning (Fade, 2004) IPA seeks to gain insight into the subjective experiences of individuals (Willig, 2014). In many respects I believe that IPA offered a good way of answering my research questions. However, the approach assumes homogeneity amongst participants and requires that researchers follow a process of analysis which seeks to find themes between participants. I had some concerns about this as previous research acknowledges the heterogeneous nature of SNA (Gregory and Percell, 2014 and Nuttall and Woods, 2013). Indeed, some researchers have questioned whether these students can be regarded as a group (Miller, 2008).

After exploring parent and CYP experiences related to SNA Gregory and Purcell (2014) commented that although IPA had helpfully allowed them to cluster themes they felt that some of the interrelated nature of these themes had been lost as a result of the analysis process. I wanted to explore forms of analysis that might better enable me to capture these complexities.

Further, I had some reservations about the double hermeneutic interpretation involved in IPA; within IPA the participant tries to make sense of their world and the researcher tries to make sense of the participant making sense of their world (Smith and Osborn, 2008). As researchers seek to understand how the participant experiences their world, they can explore aspects of participant experience that the participant themselves may not be aware

of (Smith and Osborn, 2008). I wanted to prioritise individual participant stories, independent of one another, and to view participants as experts in their own experience. I felt reluctant to deviate too far from what participants explicitly voiced. For these reasons IPA was rejected.

2.4.2. Selecting a Narrative Approach:

Narrative practitioners believe that individuals make sense of their experiences through stories that they narrate. This is a natural part of our lives; in retelling an experience, we bring together characters and events to create a plot. As the events, or incidents, are connected and organised into a whole during the process of story telling a dominant plot is developed which generates meaning (Polkinghorne, 1988). Therefore, narrative shifts our attention from 'what happened' to the way individuals makes sense of what happened (Reissman, 2008). Narrative approaches are different to other types of qualitative research as the data in narrative research is in the form of a story. The stories we tell about our lives can give an insight into the human experience (Reissman, 2008). I believed listening to participant stories would provide a helpful and natural way to gain answers to my first and second research questions and that it would offer a unique approach to this area of research.

I believe the familiarity, and universal use, of stories provides a key advantage in narrative research. Previously social researchers have been criticised for using methods which have alienated those participating in research (Oliver, 1997). The fact that stories can showcase human experience in an accessible and transparent way means that narrative research findings have the potential to be readily understood by a wide audience. The stories captured in this narrative research may resonate with parents with similar experiences, they may also have the power to draw other audiences in and offer a powerful insight (Rorty, 1989) into the experiences of parents of children experiencing SNA. It is the ability of narrative research to do this that has led to some researchers arguing that narrative inquiry has more worth than other forms of social research (Sparkes, 1995).

Reissman (2008) claims individuals often provide contextual information within their narratives, which can support social justice. Narratives mediate between our inner worlds (thoughts and feelings) and our outer worlds (for example, observable actions and events). Therefore, I hoped that by giving the participants the opportunity to share their narratives, I would be able to identify some of the aspects of their experiences which have been supportive or challenging. This would help me to answer my third research question which considers what professionals can learn from parental experiences of their child's SNA.

A narrative approach values the story-teller and their understanding of their experiences (Reissman, 2008). Given the absence of parental voice within the literature and my discomfort around this it felt particularly important that I use a research method which would respect and value the experiences of the individuals I spoke to. This was particularly important to me because in my work as a TEP I have been privy to conversations where professionals have ascribed blame, for CYP's SNA, to parents. I hoped that by using a narrative approach my research might have the potential to be emancipatory by facilitating the voices of parents who have otherwise been marginalised within the literature (Bhaskar, 2013; Oliver, 1992).

There is no strict approach to analysis in narrative research and a wealth of different approaches to analysing narrative data have been developed. This felt appealing to me because it meant that I could look for an analytical approach which respected the individual stories of the participants; I would not need to combine the stories of different participants and could attend to their individuality.

2.5. Selecting narrative interviews:

Narrative inquiry is a particularly broad area of research and there are varied understandings of 'narrative' within the literature (Andrews, Squire and Tamboukou, 2013); for example, some researchers favour personal, sociocultural, experience-centred or events-based narratives. Further, these narratives are available to us in a variety of forms: for example, they can be written, spoken or drawn (Linde, 2001). Therefore, it is unsurprising that researchers have identified a variety of approaches to narrative inquiry and several

narrative forms which can be used as data within such an inquiry (Andrews, Squire and Tamboukou, 2013).

For this research I chose to collect oral narratives through audio recorded interviews with participants. I felt that parents would be able to articulate their experiences more naturally through this form; it was likely that some of the stories they told me had been rehearsed in other situations for example, whilst talking to friends and family members or professionals. Within this study the 'narratives' or 'stories' are those that have been composed at a particular moment in time with myself as an active participant in the process (Rapley, 2001). Although it was expected that the spoken elements of the interviews would largely be contributed by participants, there would be aspects of the interviews that would be conversational in nature (Reissman, 2008). I did not intend to use a structured approach to the interview, rather I hoped to allow participants to play an active role within process, enabling them to select the information that they thought was most important to share. I would use active listening techniques to show my interest, acceptance of their stories and to help elicit further information. The active role of both participant and researcher in the story-telling process can help to ensure a more equal relationship which helps to safeguard the rights of, and value the role of, participants during the construction of knowledge (Graham, 1984). I felt that this process would help to ensure that the stories I elicited during the process were those that were important to the parents I spoke to. Further, I hoped that by using open-ended interviews I would collect data that provided detail and depth enabling me to answer my research questions.

2.6. Quality in Research:

The standards applied to quantitative methodologies (for example, reliability, validity and generalisation) are not viewed as appropriate to assess the quality of narrative research (Guba and Lincoln, 2005; Reissman, 2008). Several approaches have been developed to help researchers evaluate qualitative research. I have found the criteria proposed by Tracy (2010) and Yardley (2000) to be helpful when considering the current study.

Tracy (2010) identifies the following eight criteria: worthy topic, rich rigour, sincerity, credibility, resonance, significant contribution, ethical, meaningful and coherence. However,

she acknowledges that researchers are likely to balance these criteria in line with their personal priorities.

Yardley (2000) identifies four criteria for qualitative researchers to consider; she encourages that researchers interpret these flexibly to prevent a prescriptive approach to research evaluation. Yardley's four criteria are:

1. Sensitivity to context: this encourages researchers to show an awareness of the perspectives of participants and the setting of their research. It asks that researchers are mindful of the context of the research and how this can influence what participants might say and the way in which researchers might interpret this. Specifically, it requires that researchers work to remain committed to considering the meanings posed by participants, rather than imposing their own preconceptions onto the data.

2. Commitment and rigour: This values researchers' in depth engagement with the topic at all stages of the research. Including: their choice, and use of, research methods; thorough data collection; and ensuring a detailed and in-depth data analysis.

3. Transparency and coherence: This requires the researcher to clearly show how they have reached their interpretations from the data.

4. Impact and importance: This asks that researchers help to generate knowledge that is useful. This might be in terms of its practical use, its ability to generate hypotheses or its potential to change how we think about the world.

Yardley (2000) suggests researchers use these criteria to reflect on their work and to justify the decisions that they make.

I have had an active role in all aspects of this research. I have actively participated in interviews and have also shaped the way interviews were transcribed and analysed. I have worked to provide explanations for my decision making and clear descriptions of how I have undertaken the research at all stages to enable readers to see the rigour within the research as captured by Yardley's (2000) quality framework. Further I have considered the impact of my research and plan to disseminate my findings.

Narrative research seeks a deep and rich data set which can aid understanding. Thus, generalisability is not an aim of this inquiry. Due to the small number of participants recruited in narrative research it is not appropriate to generalise the findings to a wider population (Reissman, 2008). However, the term transferability can be used to consider how research might be applicable in similar situations (Kuper, Lingard and Levinson, 2008); although researchers do not try to force shared experiences it is possible that readers may find, and relate to, similarities that exist between the research and the situations they have encountered or are encountering. In order to enable readers to make an informed decision about whether any of the findings are transferable it is important that I provide an honest account of the research and an insight into the contexts of the participants I spoke with.

I have tried to be reflexive throughout the research process. Reflexivity is seen as particularly important within narrative research (Reissman, 2008) and qualitative research more generally (Tracy, 2010). Tracy (2010) encourages researchers to share their reactions as they proceed along their research journey. She argues that this approach promotes honesty amongst researchers. I have sought to be reflective by sharing my motivations to undertake the research. I have ensured a clear reflective approach throughout my analysis by sharing the transcripts and documenting my reactions to their content. I hope that this will provide the transparency proposed by Yardley (2000).

Chapter 3: Procedure

3.1. Chapter Introduction

In this section I share aspects related to the planning of the research, for example, participant recruitment and ethics. I also discuss the interview process and transcription and analysis of the data.

3.2. Participants

3.2.1. Participant Recruitment:

I aimed to recruit three or four parents of children:

- Who were in year 8 or above

- Whose attendance had been less than 90% over the last two terms.

- Whose attendance was affected by worry about attending school.

This small sample of participants is typical of narrative research which values the quality of interviews over quantity (Reissman, 2008). I sought to recruit participants through my placements in second and third year. Initially it was difficult to recruit participants this way and EPs fed back that they were not currently involved in cases of this nature.

When I started my third year placement I: spoke to all three secondary schools on my caseload; met with the Education Welfare Team within the LA; and liaised with a pupil referral unit which supported students who were worried about attending mainstream schools. Although the individuals I spoke to were involved with families who met the criteria for my research it proved very difficult to recruit via these services. Finally, I reached out to neighbouring services for help from trainee and EP colleagues.

Eventually I recruited three participants through my placement EPS and one participant through a neighbouring EPS.

3.2.2. Who were the Participants:

I spoke to four mothers living in South Yorkshire. Three of these parents lived in the LA I was in placement in and one parent lived in a neighbouring authority. Although I expressed an interest in speaking to any parent whose child's attendance was below 90%, the participants I spoke to all had children who had been out of school for at least four months. This may have been due to the fact that I recruited through EPs; it is possible that schools are less likely to ask for EP involvement before SNA has become entrenched. Recruiting via EPs who had worked with the families meant that parents were introduced to me by someone who had spent time building a trusting relationship with them. During the interviews it was apparent that most parents I spoke to had previously felt judged by professionals and I felt that being associated with a professional who they had had a positive experience with was very important in ensuring that participants felt safe speaking with me. When speaking to parents it was notable how much they had to share within our interviews and how much they valued the experience of being listened to; three of the four interviews lasted close to two hours.

3.2.3. Unheard Voices:

I am aware that my difficulty recruiting participants and my reliance on EP colleagues to identify and introduce me to parents means that many voices remain unrepresented in this research.

Experiences of SNA are steeped in emotions and are situated within the wider context of the family's circumstances. Amongst the families I spoke to this included significant health concerns amongst family members and experiences of loss and bereavement. For many families, in these situations finding the capacity to give up time to speak to a researcher could feel like a big commitment and possibly an additional pressure. The parents I spoke to were all mothers with partners and they all reflected that their experiences could have been more difficult without the support of their families. I wondered whether the protective factors they mentioned enabled them to reach me. If this is the case it would suggest that myself and my research may have been hard to reach for some families.

3.3. Interviews:

3.3.1. Interview Influences:

Being new to qualitative research, and the process of interviewing, I felt some apprehension about my role in supporting participants to share their stories. Prior to meeting with participants, I read work by Kvale and Brinkmann (2009) and Holloway and Jefferson (2005). I believe this reading influenced the approach I took during the interviews. Kvale and Brinkmann (2009) identify that interviewing is a craft and that interviewing skills are developed through practice. I share this understanding and believe that I am likely to have approached the interviews differently with each new experience. Viewing interviewing as a craft supported my confidence in employing largely unstructured interviews and I allowed for my own learning within the research. I was struck by the writings of Holloway and Jefferson (2005) who shared their experiences of narrative interviewing. Of note, was their recognition that valuable insights can be gained by allowing, and encouraging, participants to share stories uninterrupted, even if their relevance to the research is not immediately recognisable. This reading encouraged me to invite participants to continue sharing their stories by echoing phrases and showing interest.

In my practice as a trainee educational psychologist it is important to me that I try my best to utilise active listening skills and to maintain an unconditional positive regard (Rogers, 1967). These values influenced and supported the interview process.

3.3.2. Interview Process:

I met with participants in a quiet, confidential, space of their choosing; I offered to meet participants in their home or to book a room in a community centre nearby. Three of the interviews took place in parent homes, and one interview took place in a meeting room of an LA building that one of the parents worked within. I had planned to offer refreshments, but this was more difficult when visiting participant homes and quite often I was offered a cup of tea as parents went to get one before we started the interview.

All participants were sent a copy of the information sheet and consent form prior to the interviews (see appendices E and F). When we met and I went through a copy of these documents with them offering them the opportunity to ask any questions. This helped to ensure that they were able to give informed consent.

I started interviews by asking participants to think back to when they thought the SNA began and asked them to share their story from this time. I had some prompts to support the interviewing process (see appendix G), however, I rarely referred to these. I tried to use approaches which invited participants to continue telling their stories if they wished, for example, by responding with "yeah?" and by echoing what they had told me. In line with narrative approaches I attempted to use the participant's own words as much as possible to ensure that I did not impose my own meaning on their stories, this encouraged me to listen to their stories rather refer to the prompts.

Throughout the interviews I worked to accept what participants said and did, listening to them without judgement Rogers (1967). I believe this helped to develop a safe, trusting relationship that enabled participants to share their stories.

All interviews were recorded. At the end of each interview I thanked participants for taking the time to speak to me and sharing their story and allowed time for a debrief. I reminded participants that they would be invited to read and comment on the analysis of their stories if they were interested in doing so.

3.3.3. Member checks:

Narrative researchers have suggested that having long term interactions, or repeated conversations, with participants can help to thicken the narratives (Creswell and Miller, 2000; Reissman, 2008) and adds to the rigour of research. Due to time constraints involved in completing this research, long term participant involvement was not feasible. However, in line with my aims to give participants voice, it was important to me that I gave participants the opportunity to see my initial analysis of their interviews and that I allowed their comments to shape and refine this. Reissman (2008) encourages this suggesting that

researchers should not rely on a single interview but should share their retellings of stories with participants.

Therefore, I contacted all four participants after completing my initial analysis giving them the opportunity to engage in this process. I was unable to regain contact with two of the participants. However, two participants spoke with me and were keen to see my analysis. One participant extended her story telling me of events that had occurred since we met. I considered adding these, however much of what was said could have been represented by the themes already identified within the analysis. Further, it was always acknowledged that the analyses would reflect participants' ongoing stories at a point in time. Therefore, I chose not to extend the analysis by adding new events. One significant circumstantial change that both participants mentioned was the impact of the COVID epidemic on child learning and there was some regret expressed that schools had not accommodated alternative means of education prior to COVID.

Both participants felt that the analyses provided an accurate representation of their stories and Sarah commented: "reading it was like an out of body experience.. ..It's our story (.) It's us". Therefore, these conversations did not lead me to make changes, but were instead felt to confirm my analysis.

3.4. Ethical Considerations:

I gained ethical approval through the University of Sheffield (see appendix H) and adhered to the ethical considerations within my ethics application throughout the study. I also followed guidance provided to researchers by the HCPC and BPS (BPS, 2014 and HCPC, 2016).

Similarly to Smith (2005) I believe that ethics should not simply followed to meet the regulations set by institutions and professional bodies. It is important to me that researchers consider the needs and views of the communities they are working with. In

relation to this I considered my role as a researcher and the power this position gave me in relation to those participating in the research.

To help readdress the power imbalance between myself and participants I worked to be transparent about the research and its aims. I also acknowledged the power I held in determining the stories that were told as a result of the research (White and Epston, 1990). Due to the wealth of data some stories were lost in the analysis process and I had control over which ones were prioritised in this study. I hoped that by returning stories to participants to be member checked (Reissman, 2008) I would be able to minimise some of the effects of this; I offered participants the opportunity to amend or retract information when I took my analysis back to them.

I sought informed consent throughout the process, reminding participants of their rights to withdraw at the beginning and end of interviews and when I took their stories back to them. During one of the interviews a parent wanted to share a part of her story with me which she did not want to be included in the analysis. I was pleased that she felt empowered enough to ask for this, and comfortable enough to choose to share a story which had been difficult.

I was aware of the vulnerability of parents who have a child experiencing SNA. Often the issues surrounding SNA can be very emotive (Pellegrini, 2007). I hoped that using narrative interviews and taking the lead from participants would mean that they had more control over what they shared with me. Researchers have suggested that the process of sharing stories is often helpful to those who participate in narrative research (Reissman, 2008).

Although all social research will pose ethical questions (Cohen, Manion and Morrison, 2013) the narrative nature of my research and the inherent lack of structure that came with the interviews meant that unanticipated ethical issues could arise (Roulston, DeMarrais, and Lewis, 2003). Therefore, it was important that I remained open to the possibility of new and potentially unanticipated ethical concerns as the research progressed (Speziale and Carpenter, 2007).

I considered the rights of the CYP who were likely to have aspects of their stories shared as part of the research process. With my supervisor I explored ways I could protect them. It was decided that I would offer parents the opportunity to consider whether they wanted to tell their child about the research. If they wanted to, I would offer to explore how they could approach this conversation with them.

Emihovich (1995) argues that for narrative research to be ethical it should have a moral purpose, otherwise it can be limited to an exercise that satisfies the curiosity of the researcher. Therefore, it felt important to consider how my research could be disseminated and I have had discussions with my placement supervisor about how my findings can be used to shape the work of our service and, potentially, support change in other areas of the LA. This is particularly important to me as some of the parents I spoke to expressed a desire for change and, although I was clear about the limits of this research, I would like to help raise their voices.

In recognising that the sample size of my research is small, it seems important to consider all those families who are experiencing similar circumstances, but whose stories are not heard within this research.

3.5. Transcription:

I personally transcribed the audio recordings from interviews onto my laptop. Throughout my transcriptions I used black font for the participant's voices and red font for my own voice. I used notations adapted from Riessman, (2008) and Emerson and Frosh (2004) to support the transcription process (full transcripts can be seen in appendices: I-L):

Notation	Meaning
(.)	Pause of under a second
(1)	Pause of a number of seconds. The number within the bracket indicates an approximate length of the pause in seconds.
[	Overlap in speech between speakers
[smiles]	A non verbal event or action is indicate

	within the brackets.
Italics	Words in Italics are those that were emphasised by the speaker.
/	A change in tone

3.6. Analysis: The Listening Guide:

Gilligan devised a feminist qualitative analysis technique termed the 'Listening Guide' (LG) (Brown and Gilligan, 1993; Gilligan, Spencer, Weinberg, and Bertsch, 2006). I chose to use this technique as it aims to help researchers to hear and understand the voices of participants (Koelsch, 2015). Further, it attempts to help researchers to raise previously silenced voices and to stay as true to participants' stories as possible (Woodcock, 2016). This was particularly important to me as I believe that the dominance of quantitative research in the area of SNA has meant that it has been harder for individuals to share their experiences in a way that holds meaning for them.

The LG's emphasis on human relationships meant that my role in the development of knowledge during interviews and in the analysis would be recognised (Woodcock, 2016). For example, although my verbal contributions during the interviews were minimal, my non-verbal communication and the questions I asked are likely to have encouraged some stories to be told and to have silenced others. I was aware during the interviews that different parents appeared comfortable with different lengths of silences and I felt myself responding to this to ensure that they felt comfortable; for example, I was quicker to engage both verbally and non-verbally in some interviews than in others.

The LG suggests four stages that researchers can follow to analyse their data. Within the LG researchers are asked to listen to the interviews several times to develop a rich understanding of the participants' stories. Woodcock (2016) has provided guidance on these stages:

Stage 1: During the first listening researchers are asked to identify what is significant for themselves and what is meaningful to the participant. Plots, and repeated words and

phrases are identified to help develop an understanding of the shape and landscape of the story and to provide a brief, but rich, synopsis. Researchers colour code themes as they arise and are encouraged to honestly reflect on, and note down, their reactions to the story. They are asked to consider: where they identify with or distance themselves from the person; where they feel confused; and their emotional responses to the story (Brown and Gilligan, 1992). During this listening researchers are also asked to identify the silences within the interviews. Although, I noted the silences I veered from the Listening Guide as I avoided interpreting what was unsaid; my reasoning for this is that the parents I spoke to expressed a frustration that they had not been listened to in the past and I felt uncomfortable about taking a heavily interpretivist approach by interpreting their silences. Instead I worked to hear what participants had said (an example of this stage of the analysis process can be seen in appendix M)

Stage 2: During the second listening researchers return to their research questions and use these to focus on trends relevant to their areas of inquiry. Researchers begin to listen to the interviewees' first-person voice by creating 'I' poems. These poems allow researchers to listen to the participants' wishes, needs, internal conflicts and desires.

I was influenced by the work of Balan (2005) who created voice poems, in addition to 'I' poems at this stage of the analysis. Voice poems are created by listening to first person singular pronouns (I, me, my and myself), used to hear the participants' first person voice, as well as first person plural pronouns (we, us, our), third person pronouns (they, them, their, she and he) and second person plural pronouns (you, your). Within this research I refer to third person pronouns which occur when the parent speaks about professionals as 'they' voices and third person pronouns which occur when the parent speaks about their child as 'she' or 'he' voices. To create the poems the researcher takes the pronoun as well as the verb and any other important information, maintaining the sequence that these occur in and placing them on separate lines to create a poem. Researchers are asked to identify whether any noteworthy 'I' or 'voice' poems exist amongst the themes by focusing on a couple of segments at a time. I initially presented my 'voice' poems in tables to help me to attend to each of the voices (see appendix N).

The use of 'I' and 'voice' poems was important to me as they supported me to answer my first and second research questions. By incorporating third person pronouns I could directly explore the interaction between first and third person pronouns; thereby hearing how parents experienced professional involvement. For clarity within the poems presented, where a parent spoke about a professional using 'he' or 'she' I replaced this with 'they', 'their' or 'them'. This enables the reader to clearly differentiate between places where parents speak of their child or a professional. Including voice poems enabled me to hear the interactions between these voices, and therefore, how participants spoke of themselves in relation to others (Balan, 2005; Petrovic, Lordly, Brigham, and Delaney, 2015; Woodcock, 2016).

Stage 3: During the third and fourth listenings researchers continue to hold their research questions in mind and create voice poems. They also begin to begin to identify how the themes, emerging from the transcripts, interact with one another. Attending to the interactions between themes can support researchers to recognise where themes react with one another and where tensions between themes exist. This allows a richer understanding of participant stories (an example of my exploration of relationships between themes can be seen in appendix O). This stage of the LG enables researchers to be sensitive to the complex and interrelated nature of themes within an individual's story.

Stage 4: Finally, in the fourth stage of the LG researchers bring together their listenings to create the analysis.

Chapter 4: Analysis

My analysis brings together the four listenings included within the listening guide for each participant individually. Within the write up of my analysis titles have been used for the main themes identified during the listenings. Subtitles are used to mark subthemes that exist within the main themes.

I use voice poems and full quotations interchangeably within the write up of my analysis. Quotations remain in full where I believe the full context will support the reader's understanding or where there is less emphasis on different voices. Voice poems are included where they support the reader to see the interaction between voices in the themes (the relational characteristics of the themes) or to support a particular voice to be heard. Aspects of the analysis which consider the 'they' voice exist to answer my second research question: 'how do parents experience professional involvement'. The remainder of the analysis answers my first research question: 'how do parents experience their child's SNA?'

School non-attendance can be very difficult for families. Asking parents for their stories inevitably meant that they spoke about some of the environmental factors which contributed to their child's non-attendance, as well as some of their child's individual needs. However, within their stories some parents also captured their child's strengths and interests. I created 'she' poems that depict these to introduce the children that the parents spoke about (these can be seen in appendix P).

4.1. Sarah and Erin

When I met with Sarah, she shared that she had re-read the information sheet that day and had been thinking about her experiences and the things she wanted to share. She had captured her thinking in a notebook and she used this to guide some of her story telling within our interview. The interview with Sarah lasted one hour and fifty minutes. Due to the length of Sarah's interview and the amount of time it covered I chose to retell her story, mainly using her own words, arranging the events and experiences in chronological order (please see appendix Q). This supported my understanding of her story and enabled me to write about the plot and the landscape.

> Reflective Box:
>
> I felt that there was very little I needed to contribute verbally to encourage Sarah's story telling. I sometimes wondered if I should have explored more of what Sarah said with questions. However, I had told Sarah that this was her space to tell her story and I wanted to respect the time she had taken to consider what was important to her and to allow her to share this with me in her own way.
>
> Sarah had clear ideas about some of the things that she would like to change for children who experienced worry and related RSA. Her desire for her experiences to affect change for others made me feel that I need to share her voice and ensure I disseminate the findings of the research to encourage change.

4.1.1. The Plot and the Landscape:

When I met with Sarah she was living at home with her husband and their youngest daughter Erin. Their eldest two children had moved out for study and work. Sarah explained that Erin "started to be a little unsettled towards the end of year six". As she prepared for the transition to secondary school Erin experienced some challenges with her peers and her brother left home for University. Erin began to experience somatic symptoms and she voiced to Sarah that she did not want to go to school. This continued as Erin transitioned, with a small number of familiar peers, to a large mainstream secondary school. Erin had had periods of non-attendance since her first term, in year seven, at this school. As a result of the difficulties she was having, and on the recommendation of a member of the school's pastoral team, Sarah and her family made the decision to enrol Erin at a smaller mainstream secondary school in her final term of Year 7. Erin's attendance at this setting remained low, and when Erin was in school, she spent most of her time in a small resource provision away from her mainstream lessons. Erin remained on role at the second mainstream setting until the beginning of her time in Year 10 when an Education, Health and Care Plan (EHCP) was agreed and a specialist setting named within this. At the time of the interview Erin was on role at this specialist school (students attending the provision all had an EHCP and a clinical diagnosis of anxiety and/ or depression), but was not attending and had been out of school for over four weeks (please see appendix R for a voice poem capturing this plot).

At the time of the interview Sarah was working full time in the LA. Sarah's job role meant that she had an 'inside' understanding of the different services available to CYP and their families. Sarah's story spans four years, she speaks of trundling along within a system she is familiar with, but which feels difficult to manage. Sarah's journey feels lonely and long, she reaches out for helping hands along the way but is often unheard or misunderstood. In the lowest points of Sarah's journey I felt that her family had become invisible as individuals within the system; it is in these moments that procedures take over which create traumatic events for the family. I felt that Sarah wanted her experiences to be recognised.

Reflective Box:

As the interview with Sarah was coming to a close she made the following comment:

"If there's anything that can be done to make it joined up better, to make it less judgemental, to make it less (.) blamey. You know, I think it's that really. People, us, parents, children, families are not doing this because we enjoy it. We (.) It's a situation that we find ourselves in. I've, I've never dreamed I'd be in this situation (.) Having brought two children up without any (.) issues really, apart from that they were a bit shy, but they'd got through the schooling and gone to university, (3) but, I, I'd never have dreamed that this would have happened (2)"

My desire to ensure that Sarah is heard meant that I kept this comment in mind during the analysis of Sarah's story and it is likely to have influenced some of the decisions I made.

4.1.2. Understanding invisible visible needs: *"he were able to put the evidence on the table"*

Sarah identified the ways in which Erin's non-attendance has been understood by the adults around her. She speaks about the difficulty professionals appear to have with giving weight to more qualitative information about Erin's situation; suggesting that professionals relied more heavily on medical diagnoses to inform their decision making. This has consequences for the way that they interact with Sarah, and her family, and the way in which attendance legislation is applied:

"we did get an assessment (.) with one of the psychiatric nurses from CAMHS and he did an assessment and he said that Erin, were showing signs of social anxiety, social phobia, selective mutism…

….he came to the meeting and he were able to put the evidence on the table (.) because what school were saying is that because there was no reason for Erin not to be attending school (.) then they had to treat her as a non-school attender

Mmm

and then from that point they seemed to back off a bit with all the threats of fines (.) and prison and all of this sort of stuff."

The diagnoses Erin receives seem to support staff to reconceptualise Erin's non-attendance therefore enabling them to move away from the legislative systems that exist. It should be recognised that, from the time Erin's reduced attendance began, Sarah waited for over a year to gain access to services that could assess Erin's needs in this way. Sarah expresses significant regret that these 'bits of paper' were needed and that whilst Erin did not have a diagnosis time was spent 'punishing' her family rather than exploring why Erin's attendance had reduced:

"for me early on (.) I would have liked to think somebody would have seen that there were something that were amiss (.) and not just think about attendance targets and punish us with fines (.) if if there were as much effort to supporting us and in realising that something weren't right, just because we didn't have a bit of paper that said, she'd got social anxiety or whatever, (.) or even autism, you know just because that bit of paper weren't there she were clearly showing signs of struggling (.) and all school wanted to do were fine us and punish us and that really really frustrates me"

When I listened to Sarah's reflections it felt that there had been occasions where her, and her family, were not heard or seen under the systems that exist. Although the diagnoses seem to provide evidence that Erin was showing 'signs of struggling' I felt that these signs remained elusive to educational professionals. Sarah wonders whether Erin's inward expression of emotion meant that Erin's needs could go unnoticed:

she doesn't show

her emotions,

she rarely cries.

she just turns it all inwards,

she like,

she closes down.

I

I sometimes wish

she would scream

she doesn't,

she's

she's

I think that sometimes if

she were (.) not well behaved,

she did kick off

she might get noticed

she doesn't

The 'she' voice initially describes Erin closing down when she experiences emotion. In the 'I' voice Sarah then expresses her wishes and thoughts. This shifts the 'she' voice into describing the sorts of behaviours that Sarah perceives could raise more awareness and gain help from professionals.

Mental Health:

Here Sarah draws on discourses around the invisibility of mental health comparing this to the visibility of physical health:

"of late there's lots of talk about putting mental health (.) support and training people in schools to help kids with mental health issues (1). Again and I do feel so frustrated that Erin is expected to compromise (.) her academic (.) education because she's got a mental health (.) issue. If she'd got a physical (1) a broken leg, or (.) you know, and she were out of school because of a physical thing I'm sure the homework would keep coming and I'm sure I think (.) I feel sure the support would be a lot different then (.). I don't think people understand mental health (1) as much as physical health cos you can't see it mmm (.) as as easy."

Sarah suggests that although mental health is 'talked about' it is harder to see and therefore understand. She perceives that this impacts the provision Erin receives and expresses her belief that the provision would look different if Erin had a physical need that was visible and, by extension, better understood.

Mental health diagnoses appear to raise the visibility of Erin's needs. However, Sarah's story suggests that more support was needed to support those around Erin to understand her needs and she comments that access to training for school staff, and for herself following Erin's autism diagnosis (see appendix R), was not forthcoming. This impacts the way that adults work with Erin in school and the extent to which advice from external agencies is followed:

I think at school (.)

I know

they've all got

Erin's best interests

I think

they lacked a lot of understanding.

promised her

they'd set this thing up

she went into class for

Erin looked (.) comfortable (.)

Erin came home

she were (1) a wreck

she came home

she were just drained (.)

I know

they were well meaning

they were as keen

they weren't following advice

They,

they were trying

hurry her along

quicker than what she were prepared

I think (1)

I know

they hadn't had the proper training

I

heard them,

they were having the training (.)

Erin were going through all of this

Here Sarah talks about the support in school. Her 'I voice' speaks with conviction when interacting with the phrases in the 'they voice' which pertain to the intentions of school staff; her use of 'I know' suggests that she is certain that they care for Erin. In contrast the 'I'

voice expresses uncertainty when she talks about the understanding of professionals; "I think they lacked a lot of understanding". The 'they voice' can be seen to interact with the 'she' voice and shows the impact of staff intentions and understanding on Erin. It appears that the desire of staff to help Erin get back into school, combined with their lack of understanding, meant that Erin was put in situations she was not ready for.

4.1.3. Stories of judgement, blame and guilt: *"and then you start all the blame and the guilt"*

Throughout Sarah's story she speaks of different people searching for an understanding of Erin's non-attendance and there are occasions where it feels that professionals attribute Erin's non- attendance to Sarah and her husband's parenting:

"I think that were important as well, not being judged.

You've felt judged?

We have felt judged, yeah, a lot of the time we've felt judged, yeah. (.) so you know, (1) it's felt to me many times as though, and this might just be me, but its felt as though people thinking 'you've got a child and you can't parent that child properly'."

Sarah reflected on occasions where she questioned her own parenting and experienced feelings of self-blame:

"as a mother you start then (.) to think (1) what have I, why haven't I made her as resilient as she needs to be and then you start all the blame and the guilt (.) and you know she's shes' (.) she's our youngest child….
……you start thinking have we spoilt her because she's youngest [ah laugh] so there's all that going off in your mind"

Although it is possible that professional judgement might have compounded Sarah's sense of guilt there are instances where it encourages her to reflect and question the legitimacy of

this. Sarah acknowledges some of the individual differences between her children and highlights that: "Erin (1) has found it (.) harder, a lot harder than what they did"

Sarah's experiences of blame create an internal dilemma between her desire to protect and safeguard Erin and a need to demonstrate parenting that: enables others to take her concerns seriously; gain help for Erin; and gain access to external agencies. The moments in Sarah's story where she is asked to give more weight to one of these priorities creates emotional tension. In a key event in Sarah's story where she and her husband meet the demands of professionals and forcefully bring Erin to school in a state of distress, she experiences significant regret:

<div align="center">

We just thought

We'd tried everything

I went to see

education welfare officers

they said

they

they didn't tell

me to do it

they says you might

Try taking her

In her pyjamas

Her uniform in a bag

We did

Against our better judgement

We did

Worst day ever of our life

Probably hers

Her downstairs kicking

I can see

Her now

Banging her head

</div>

Picked her up

Carried her out to car

I sat in back

We put child locks

She just were wanting to jump

She said

She wanted to die

I am so (2) Urm (1) angry

I suppose that it were even suggested

People couldn't see

she was clearly struggling (.)

their perception was

we weren't doing enough

to get her to school

I think (.) and knowing that

we (1) took the collective decision

if they don't think

we're doing enough,

we'll show em

what we've tried to do'

I will regret that for rest

my life

doing that to her.

I mean

Erin is the one who matters,

she's in the centre

we are trying to

protect her (.)

safeguard her,

things that were being said to us

we felt

they were in criticism

of us

our parenting

of Erin,

Within this poem a number of voices are at play. In the first stanza, I hear exhaustion within the 'we' voice; after trying everything it feels difficult for Sarah and her husband to argue against the advice of a professional, seen in the 'they voice', even though it does not sit comfortably for them. The impact of this advice is seen in the 'she voice' where Erin's distress is felt. This stanza speaks to the power professionals have; professional suggestion has weight and its impact is not always neutral.

Within the third stanza the 'she' voice captures Sarah's desire to keep Erin safe and to ensure that she is not lost sight of. The 'she' voice appears to come into conflict with both the 'they' and the 'we' voices. I get the sense that the misunderstandings of others, in this case professionals heard in the 'they' voice, mean that Sarah, and her husband, struggle to maintain enough power to ensure the safety of Erin that is prioritised within the 'she' voice. In the second stanza there is a shift within the 'we' voice which gives the sense of collective action being taken to regain some of this power. The implication of the conflict between these voices is felt within the 'I' voice where Sarah expresses feelings of regret and anger.

4.1.4. Friends and foes: "he tried absolutely everything"

When we met, Sarah shared experiences of therapeutic relationships with professionals. Sarah reported some of the qualities of a counsellor she had seen with her husband, describing him as someone who: was lovely and supportive; asked how they were; listened and did not judge (see appendix R). These qualities appear to have enabled a space where Sarah and her husband could reflect on and express their thoughts and feelings; this seemed to be something that Sarah really valued and she stated: "he really helped". Similarly, Sarah spoke about her perception of the approach a CAMHS worker took when supporting Erin and the positive impact of their involvement:

Erin speaks to

them now.

she's

her sessions

she's painting,

she's done loads of paintings

she can paint,

she can talk.

She doesn't have long conversations,

They are getting

something out of her

she engages with the homework

they give her

we,

we have a session together for 10 minutes

I think

Erin feels more comfortable talking

with them

me not there

I think (.)

she should be entitled to that

she's got a really good

relationship with them

In the 'She' and the 'They' voice Sarah explains her understanding of the sessions between Erin and the CAMHS worker. We can hear that Erin is given access to an activity which she can focus on during the sessions (painting). I get the impression that the sessions allow Erin to share what she wants, but do not put much pressure on her. Sarah comments that although they do not have long conversations, Erin is engaging with the CAMHS worker and that they have a very good relationship. I felt that Sarah valued working with professionals

who could connect with Erin. Between the 'I' and 'She' voices we can hear Sarah share her belief that it is important for Erin to have a private space to talk to someone outside of her family. Sarah shared that Erin had had several sessions with CAMHS and that she had seen Erin's confidence socialising with her family members grow because of the work she was doing there.

The next voice poem speaks to the importance of the relationships individuals from services build with families. Sarah discusses her experience of involvement with two different members of an EWO team:

<div align="center">

I think (.)

I just think,

the officer at [School1] was supportive.

they tried absolutely everything.

the officer at [School2] (.) was not

they said

Erin were being (.)

they

call her, like insolent,

they would

because Erin wouldn't speak (.)

they were coming

to see Erin at home,

I remember

Erin were sat

they were trying

talk to her

get her to converse,

they couldn't,

she (.)

she found it hard

</div>

they just said

she were being insolent.

In the first stanza Sarah shares her experience of working with an EWO who 'tried everything'. Within her interview Sarah reported that the EWO focused on pastoral care and she seemed to value this. In contrast in the second stanza we can hear Sarah's experience of a difficult interaction with an EWO. Much of the interaction between voices happens between the 'they' and the 'she' voice where we can hear Sarah's perception of the EWO's understanding of Erin's behaviour; Erin does not engage in conversation with the EWO and is viewed as insolent. Within the 'she' voice Sarah explained that Erin had found it difficult to speak. Within this excerpt I hear Sarah share a story about a professional misunderstanding Erin's needs and blaming Erin. This created strong emotions for Sarah who told me "I didn't want her into our house"

Finally, Sarah discusses her experiences of working with SENDIASS:

they've been absolutely amazing.

I mean

I've been at a point of just accepting

I didn't really (1) understand all the

they've been with

me at the meetings

they've been a voice

when you just can't,

you don't know what to say or do (.)

you're so emotionally involved

they've been that voice (.)

they've been really really good

I was on verge of pulling

Erin out of school

we spoke about whether (.)

concentrate on her studying (.)

we'd pay to have access to online learning

their view

she would be better stopping on school role

we've come that [gesture- fingers close together] far (.) from doing it

I

I don't think that would be best

for Erin

she's best going back

In the first stanza of the poem a 'you' voice is present. I understood this voice to represent the feelings of Sarah and others in a similar situation; within this voice Sarah describes the difficulties that can be experienced as a parent in meetings with professionals. She speaks of feeling too emotionally involved to be able to know what to say or do. The 'you' voice interacts with the 'they' voice where Sarah's experience of working with SENDIASS is shared; I hear the 'they' voice play a rescuing role, a voice in meetings when parents feel unable. In the second stanza Sarah speaks of the discussions had regarding the possibility of electing to home educate Erin. I felt the situation was driving Sarah to consider options that she did not always think were in Erin's best interests and that SENDIASS had enabled her and her husband to push for what they believe Erin needs.

4.1.5. 'Trundling' along in a familiar system: *"nobody seems to want to grasp the nettle"*

Although Sarah works within the LA it often feels difficult for her to navigate the systems in place. Sarah reflected on the number of professionals who had been involved during Erin's experience of SNA and spoke of being 'batted' between services with no one wanting to take responsibility:

"There has been lots of support, in terms of professionals involved (.).....It seems as though there is lots of talking and lots of (.) planning and noise and, but (.) trying to get solutions in place is so time consuming……

…….I think they (2), you're getting passed around from GP to school, to school nurses (.) and nobody seems to want to grasp the nettle and (.) progress things and help you. They just want to pass it to somebody else and I guess that comes down to resourcing, (.) everybody's got limited resources (.)……..

………you're constantly constantly pushing. It takes over your life, it really does take over your life."

She shared her experience of reaching out for help and not receiving any. Sarah considers this within the context of limited resources and the impact this might have on the willingness of services to help. Listening to Sarah, I felt a sense of exhaustion as she explained she had been 'constantly pushing' to get provision in place for Erin. This is captured in the I poem below where Sarah's use of the words 'keep, keep going' give a sense of how challenging this can be:

I just think
you just have to keep, keep going
I just think it'll not go on forever (.)
I hope
I live in hope
I'm tired,
I'll be honest,
I am tired

There are times in Sarah's story where it takes an escalation in Erin's distress, and professionals witnessing this, to enable Sarah to access involvement from external agencies. For example, Erin's access to CAMHS occurs after she made a statement suggestive of

suicidal ideation, during an experience of significant distress. Sarah explained her frustration that, on this occasion, accessing support was at the expense of Erin's wellbeing:

"she had pressed that button……..It, it were as though, (1) it was as though it were a line that she'd crossed and now she had crossed that line it would open a lot of doors (.) and I thought /'well to do that to a child'"

Sarah is clear that she has felt supported by some professionals along her journey but expresses that their roles and responsibilities need to be clearer. She shares her desire for services to work more collaboratively towards a shared goal. This appears to be difficult due to the systems that exist around attendance. Sarah reflects on the dual role of the LA: to support families and to follow the legislative guidance on attendance. She talks about services, who are involved with the family, working in opposition to one another:

"I think you've got on one hand, you've got (.) It's really weird because you've got one part of the department (1) that's like (.) the police arm

Ok

And then we've got (.) SEND who are doing their best (.) to help, and then we've got educational psychologists who are helping probably the same kids that Education Welfare are trying to prosecute (.) and then you've got (.) SENDIASS who are trying to help the parents of (.) children who colleagues are trying to (.) prosecute the parents. It just, (.) it doesn't seem right to me. It's not joined up.

Mmm, it's disjointed

Yeah, yeah you'd think, we should all be working the same, towards the same goal (1) and it doesn't feel like it."

Sarah reported concerns that the systems do not adapt to effectively support families and that this has meant the support has not felt 'person centred':

"I've found that it's not person centred, it's (.) it's all about one size has got to fit all and (.) I think kids are all different (.) "

4.1.6. Wider family impact: "lines were getting a bit blurred"

Sarah talks about how her family unit had been affected by their experiences. Sarah's eldest daughter's profession, social work, perhaps meant that it was more likely that she could end up playing two roles, that of a sister and of a professional. This appears to have created some tension within family relationships and Sarah reported that her eldest daughter expressed a desire to prioritise her role as a sister:

"as a mother I feel awkward because [eldest daughter] is a social worker so I (.) have relied on [daughter's] advice a lot of the time ….. And [daughter] said to me, she says 'I'm going to have to back away'… I think lines were getting a bit blurred and, she said "I'm not a parent, I'm not a social worker, I'm her sister" mm so that were a bit fraught (2)"

Although Sarah's husband had been closely involved, there were times in her story where she wanted to protect him due to his health. I got the sense that Sarah's efforts to protect members of her family sometimes created an additional pressure and might have meant that there were times that felt quite lonely for Sarah:

"I've tried to (.) shield him (1) as much as I can….. he has been involved(.) but a lot of this I've dealt with (1) away from our home and trying not to (1) worry him too much because he's had enough on his plate with his own health. It is really really hard and it has been hard."

4.1.7. Emotional hot spots

Non-attendance is an emotional topic and it was difficult not to connect emotionally with Sarah's story. There were moments in Sarah's interview where she was emotionally expressive and in turn I felt emotionally affected. These were perhaps strongest when Sarah expressed a sense of loss and grief for the experiences that Erin was not having:

"How did you feel during that time?

Awful, absolutely awful and not just for Erin (.) all (1) all I wanted to see, /[tearful] I used to walk down to, and this gets me quite emotional

That's ok

I used to walk down to buses for work and see young kids as old as Erin just (.) trotting along catching school bus and I used to think I just wish she could be like that (.) mm for her really, for her. Because all (.) all she wants is to learn."

Some of the key events along Sarah's journey feel unresolved. In particular I felt there were moments of trauma imposed on Sarah and her family by the system that I work within and it was difficult not to feel angry that this had happened to her. In listening to Sarah I often pictured the systems she was trying to work with actively working against her and in some cases this triggered events which were traumatic in their nature. Here Sarah describes her time at an attendance panel with Erin:

"So it were this massive grand room, [mm were] all really horrible, formal, and someone suffering from anxiety sat in that area…

…her face was so blank (.) and it didn't matter what they said to her it just went over her head and they concluded by saying that, to her, that if she didn't go to school, that we could be fined, we could go to court, we could even go to prison and it would all be in the papers and I just found that /appalling (1) /and when I asked for a copy of the minutes from the meeting they said they didn't record it but they could send the scribbles that the education welfare officer had made and when I got the scribbles /[speech slows] they contained none of that (1) what they'd said to Erin and I wanted a record of that"

In listening to Sarah describe this event it felt that the gravity of these procedures were not fully understood by those running them. It seemed Sarah was asking professionals to recognise what had happened to her and that her experience was reduced; Sarah speaks of the records of her experiences being 'scribbles'. There is a feeling that the system is not one that cares. In other parts of her interview Sarah describes the Education Welfare system as the 'police arm'; there is a clear distinction made between care and law and order.

4.1.8. Concluding comments

Within Sarah's story the first theme 'understanding visible invisible needs' plays a central role. This theme interacted with all three of the other themes discussed. This is perhaps unsurprising as the way we understand a situation heavily influences how we respond; in Sarah's story it appears that the way in which attendance is perceived by those around the child affects relationships (as seen in themes two and three) and how the systems are used and experienced (theme four).

For example, in the following voice poem we can see the interaction between themes one and four where the misunderstandings of Erin's needs affect the family's ability to access support:

<div align="center">

She had pressed that button

she'd crossed

she had crossed that line it would open a lot of doors

I thought 'well to do that to a child'

she have,

she'd have been about 13.

I am so (2) Urm (1) angry

I suppose

people couldn't see that

she was clearly struggling (.)

</div>

It takes Erin to outwardly express distress for the family to access CAMHS. In the 'I' voice Sarah expresses her anger that this had to happen to Erin for her to be seen.

4.2. Natalie and Zeke

I met Natalie in her home. At the time of the interview Natalie was experiencing some health difficulties which were impacting her ability to complete everyday activities. Although she was in some discomfort and I reassured her that we could do the interview another time, Natalie shared that she had been looking forward to participating and "talking to an adult". Natalie's interview lasted one hour and thirty-one minutes.

> Reflective Box:
>
> I felt that Natalie was a little nervous sometimes during the interview. Where there are pauses in the transcript Natalie often shrugging and smiling, and I think I jumped in, earlier than I might have with other participants, when there was a silence because I worried that she felt uncomfortable. Natalie shared how isolated she had been feeling due to her situation and I was aware that having adults to talk to was important to her. I stayed and talked with Natalie for a little while after the interview and I was conscious of my own feelings of 'wanting to help'.

4.2.1. Plot and the Landscape:

At the time of the interview Natalie was living at home with her partner and her son, Zeke, who was in Year 8 and on role at a local mainstream secondary school. Natalie's partner often travelled for work and there were periods of the week where he was not at home. Natalie explained that Zeke had been living with her for the past four years; Zeke had previously been living with his biological dad. During the last year of his primary education Zeke attended a specialist provision which caters for students with SEMH needs. Natalie reflected that Zeke enjoyed this school; he had a hundred percent attendance and often came home with certificates for good work. Natalie believed that the specialist setting would be Zeke's "forever school" and she requested that he remain at this through

provision for his secondary education. However, Zeke was placed at a mainstream school which he attended for the first two terms. Following the Easter holidays in Year 7 Zeke remained at home; he had been out of school for over ten months when I met with Natalie.

Natalie reported that the non-attendance started with Zeke's Xbox; Zeke stopped going to school, and some of his friends stopped visiting him, at the time the Xbox became more important for him. She reflected on her and Zeke's experiences as she had tried to make sense of the situation. Natalie voiced how challenging her experience of Zeke's non-attendance had been and I recognised a feeling of 'being stuck' as she told me that she often hit 'brick walls'. Despite how difficult Natalie had found the past year she explained that she always looked for 'glimmers of hope' and she highlighted how she had found friendships and support amongst parents in similar situations. It was important to Natalie that Zeke attend school and she told me: "getting him to school, for me that would be better than winning the lottery it really would."

4.2.2. Making sense of a difficult situation: "Everything has just rolled into one"

When we met Natalie considered some of the events and difficulties that might have led to the experiences she was having with Zeke and the non-attendance.

Xbox and the outside world:

Natalie opened her story with the sentence: "Pretty much it started (.) it's all been from his Xbox" and she reports that Zeke's relationship with gaming had contributed to the non-attendance. In the following voice poem Natalie explains her and her partner's experiences of trying to limit Zeke's Xbox use:

> Zeke started getting obsessed
> Xbox became his life.
> he was
> we were trying
> stop him playing
> we

taking it off him

we did all

we needed to

we kept turning everything off

he was losing

his temper

he was going around the house wrecking

he physically

attacked me (.)

I had the police around

I

push him

he explodes

he can go just like that

quiet time for me

while he's on there

I don't want

him to be on there

he should be in school

my only

my house getting wrecked

me getting hit

I have to

let him

I have to

I've got no choice

In the 'he' voice Natalie reports Zeke's response to their interventions and we can hear the high level of emotions that were experienced; Zeke used physical aggression to express his upset and Natalie called the police for help. In the 'I' voice we can hear Natalie explain that although she wants Zeke to be off the Xbox and in school, she is unable to enforce this due to the physical aggression she has experienced.

Within her interview Natalie identified that gaming addictions had recently been acknowledged by the NHS and she wondered whether this might be an avenue through which she could gain support (see Appendix S). Natalie shared the 'obsessional' nature of the gaming; she explained that Zeke had been staying awake to play (see Appendix S) and expressed her belief that he needed to keep playing to ensure that he won:

"it's like he's got to beat (.) to be the best at everything all the time…… what's going on in his head in trying to be the best mm it (.) it must be overpowering for him…… So from that side of the obsession of it is probably why he wants to play it all the time, because he thinks if he lets up for one second (.) he's going to be beaten. That's maybe not how he sees it (.) that's how I see it

if he doesn't he might lose

When I say obsession it's (.) it's beyond obsession. (2) I, I keep saying it, I keep repeating myself that's his world, that's his real world. (1) *This* isn't his real world."

Within this excerpt Natalie is careful to explain that this is her theory and she prefaces sentences with 'I think' and 'I don't know' capturing her feelings of uncertainty. She emphasises her belief that the gaming has become Zeke's 'real world'. Natalie considered why Zeke may be trying to escape the real world:

I think
element of that in him
his dad's not stepping up
I've had Zeke four years now.
I'm glad
Zeke's here
I know
he's not getting pushed to one side

He's obviously got all of that

in his head.

he won't talk

to me about

I've just got to guess.

I've got to presume,

I shouldn't

I say

if he

spoke to us

we would understand more.

he won't

he's making it

worst for himself, holding it all up there

just playing his games.

He doesn't like the real life because of what it's done

he sticks with the gaming

because he's got control

he's more in control

Within this voice poem Natalie reports some difficult life experiences that she and Zeke have lived through with regards to his custody and her understanding of how this might still be impacting Zeke (please see Appendix S for the full voice poem). In the final stanza Natalie captures the safety that she perceives Zeke has found in gaming; it allows him an escape from 'real life' and 'what it's done'.

Autism as a lens for understanding:

At the time we met, Zeke was going through the assessment process for autism. Natalie shared that the difficulties related to the non-attendance were impacting Zeke's life beyond

school; Zeke was not leaving the house and professionals had suggested to Natalie that this could be due to sensory needs associated with the autism (See Appendix S).

Natalie reflected on some of the experiences she had with Zeke through an autism lens; when they had gone out in the past, Zeke had found it difficult to connect with and speak to people in the community (See Appendix S). Zeke often thought about things differently, for example he wanted the curtains shut in the day, as he believed this is when they were needed to keep the sun out, and open at night (See Appendix S). Laura explained her uncertainty about the reasons behind Zeke's needs and she seemed to be trying to understand which of Zeke's behaviours could be associated with autism:

<blockquote>
part of the autism thing I think

I don't know

Sometimes I think

maybe he is putting it on

sometimes I think

maybe he isn't.

I've got to try and differentiate
</blockquote>

The secondary school environment:

At the time we met Natalie reported that Zeke was having strong reactions when school was mentioned:

> "School to him is a swear word, a proper swear word. If I say it to him he goes {imitates angry face and holds up clenched fists} and kicks the door on the way out."

She reflected on Zeke's experiences at the specialist provision he attended during his time in Year six:

<blockquote>
he went there for a year

I think

his attendance
</blockquote>

he went every day

he got awards

he had done well in subjects

he loved it

and contrasted these with his time in his mainstream secondary school:

he was supposed to go back

He just would not go

he said

he kept saying to everybody

he didn't like wearing his uniform

he didn't like being told what to do

he didn't like the lessons

he did say

he was being bullied

he could have been doing the bullying

teachers have said

he's gone from about 60 pupils up to about (.) 1,500

I think

maybe he, it's been a bit of a shock

he's maybe found it's too big

Natalie reflected on the change in size between the two settings and suggests that this might have been "a shock" for Zeke. She said that "there wasn't really that transition either from [Specialist] to (.) to [Mainstream]" and she wondered whether having a transition might have helped Zeke.

Natalie said that Zeke's specialist primary school had access to provision which supported Zeke and his peers:

they had lots of teachers

they've got all the lights and the soothing

they can

She contrasted this with the resources available in his mainstream secondary school and there was a suggestion that the school was unequipped for students with Zeke's needs:

they can't do that on [Mainstream]

they're not equipped for kids.

what can they do

Looking for answers:

When we met, Natalie seemed to be trying to make sense of the situation. She shared feelings of being 'against a brick wall'. Natalie had struggled to gain Zeke's perspective to support her to understand (See Appendix S). In an effort to understand Natalie compared Zeke's behaviour to her own when she was younger, and to his peers. Natalie questioned whether she should be making comparisons but recognising these differences seemed to be a way for Natalie to build an understanding of Zeke's needs:

I (.)

I'm comparing things

I think

should I be

shouldn't I be?

I'm being positive,

I'm being negative,

I'm trying to be negative to be positive

I'm trying to think

things in my head to understand (1)

he's (.)

I say not normal,

I don't say that in a really horrible way,

he just.

He just doesn't do what other kids do

Natalie's experiences with Zeke alerted her to discourses and information around mental health and she seemed to identify with the stories she had heard:

"there's more about mental health and everything nowadays, autism, ADHD they've got all these different names for every different (.) different thing. And my ears prick up all the time now whereas before I would have thought /'oh my child won't do that'."

4.2.3. The Emotional Impact: "it still affects us as parents"

Natalie reflected on her past with Zeke and I felt there was a sense of loss as she shared the time they used to spend together:

"I used to take him everywhere, we went swimming, we we went bowling"

The time that Natalie looked back on felt far removed from her situation at the time we met. Zeke was struggling to leave the house and, therefore, Natalie was also spending a lot of time at home. It was affecting her ability to socialise and to attend appointments related to her health. Natalie explained the emotional impact this had had and she expressed feelings of being unable to "move any further".

he can't,

he won't go out

I can't pretty much go anywhere

I've had to cancel

hospital ones I've had to go

I'd have had to wait

I had to go

without him

I had to leave

him

he's had tantrums

he didn't want to go

with me

my anxiety levels start to rise

nothing I can do

he's putting

me in such a spot

I stand there

I think what else

can I do,

I end up crying

I do cry,

I cry a lot

I can't move any further

I felt that the situation had isolated both Zeke and Natalie. Natalie shared that there was "still so much that we're going to have to go through", she questioned what the future was going to look like and wondered whether there were things in the past she could have changed. Holding all these questions felt overwhelming and Natalie shared:

"every single thing that goes on for Zeke and the situation, it still affects us as parents, (1) we, we have it hard as well, (.) and all the what ifs. (.) Could we have done better? Can we try this and then the emotions start. It's like wishing I could go back to square one, start all over again"

4.2.4. Finding support and hope: "keep me going"

Natalie said that a friend of hers had linked her to a support group on Facebook for parents
who were having similar experiences:

I mean

we have a laugh

a serious side to it as well. We all relate,

we've all been through,

we're all going through

I chat a lot

you can say whatever

you want,

no one's going to judge you

You can swear,

you can do

letting off steam people who understand

keeps me up

I'm not thinking

I'm going through (.)

I am thinking

I'm going through but (.)

I'm not down,

I'm not getting to the point

I think (.)

I'm going to have a break down (.)

we all keep each other's spirits up

good thing for me.

I wish

I could be in a room with them

we'd be there forever

you get vetted

I had a recommendation

friend of mine

I wouldn't have

I'm bloody glad

I did

'it's not just me.

you do feel sometimes,

why me,

why me,

you start

feeling sorry for yourself

these lot say 'snap out of it' [laughs] and we do the same to them

I've got that

keep me going

for me (.) well it's a life saver

I've felt that down

I think

What do I do, sit here and cry, or just chat.

it has a big effect on you it does. (5)

Here we can hear Natalie identifying as one of the parents in the group through the 'we' voice; this shared experience seems to be very important to Natalie. Within the 'I' voice we can hear how Natalie can feel without this support as she explains that it "keeps me up" and has enabled her to know "it's not just me".

Natalie spoke of experiencing 'glimmers of hope'. Even when she felt stuck these 'glimmers of hope' seemed to enable her to try to: boost Zeke's mood; and to look for new ways to support him.

"I always have that glimmer of hope that maybe just maybe something might just give yeah
But it never does. But I still cling onto that that something's got to work somewhere"

4.2.5. Professional involvement and developing next steps: "they'll come up with a solution"

Natalie reported that she had felt supported by professionals and although she had initially been worried about measures linked to attendance legislation (for example, fines), her worries had been alleviated by professionals who made it clear that she would be exempt from these systems:

"I thought I was going to end up in prison because or fined (1) but…..
…lady that used to come she said: "don't worry, that, that has to be put in place so that *we do our job* to try to get your child back into school" mm…
...I had that written in black and white as well that that's not going to happen I was like: 'oh thank god'."

The number of professionals who she had worked with and the acronyms used meant that it sometimes felt confusing:

"people keep coming to visit me (.) they're all from education something, but they do it in abbreviations EHA, YOT, so I (.) I've got an A4 side of paper that's just got abbreviations so I have to go Google or ask them...…… there's a lot of abbreviations and it's like oh god, so then I'm getting confused cos I've got so many people that are (.) visiting that I have to see"

However, Natalie seemed to feel reassured that they had visited her home to meet Zeke:

we have school meetings
they have to come
I have about 6 or 7 people here

at least they can see

what he's doing

what he does

I think some people think

I'm lying

I say

they've all been here

they've all been upstairs

tried to speak to him

he's just (3)

they'll come down and go 'see what you mean

a lot of them are mothers

their kids are doing normal stuff

Zeke is total opposite

In the 'they' voice of the above poem, Natalie reports that professionals were understanding because they had seen her situation first-hand. Natalie questioned whether professionals might also be finding Zeke's behaviour difficult to understand; it seemed that this shared feeling of 'not knowing' meant that she was able to sit with professionals and to explore ways forwards. This is captured within the 'we' voice in the poem below:

I think

they (.)

they can't understand

why he is doing

what he is

they're trying to understand as well

we have sat

we've tried to

get him into school

they've said 'well I'm at a loss here

Natalie was hopeful that staff would find an answer and she spoke about some of the plans discussed to support Zeke back into school; staff were preparing to support Zeke to return to school by allowing him to do some gaming in school, in a quiet area with an adult. She explained that staff would need to keep his interest to ensure that he continued to attend (see Appendix S). Although Natalie felt confident that school staff wanted this plan to be a success she expressed some concern about how they would support him to leave the house and about the availability of school resources:

"if there is something (.) I really want that to be a success and they do as well (.) but it's not something they'd normally do for one particular child (.) especially in a school that's not geared up for that kind of (2)"

Natalie explained that there was only so much the school could do and that she was reliant on professionals telling her what was possible:

I understand

they can only do so much

resources they've got

if they,

if they have to go above

they still have to have permission

their higher uppers

they have to literally go by the book

I don't know

what they know

I don't know how the system works

I've just got to rely

what they

tell me (.)

they can and can't do

When I listened to Natalie I felt that there were limits to how collaborative her work with professionals could be because there seemed to be information that Natalie was not privy to; therefore, there seemed to be an understandable reliance on professionals to "come up with a solution."

4.2.6. Concluding Comments:

Listening to Natalie's story I felt that she was still trying to make sense of the situation and the plans in place for Zeke felt quite tentative. Perhaps some of the clarity with which parents spoke in the other interviews meant that I felt I had captured a version of their story as they had viewed it at that point in time, in contrast Natalie's own understanding was significantly shifting and developing as topics were revisited.

4.3. Gemma and Claire

I met with Gemma in her home and our interview lasted an hour and forty-five minutes.

Reflective Box:

I sat parallel to Gemma, on her living room sofa, and she often looked ahead as she shared her story. There were times when I felt it was difficult to create as comfortable a space to talk as I would have liked, and I thought my positioning might have affected this. Occasionally Gemma paused to check whether what she was saying was helpful.

Just as Gemma was finishing her story, she touched on a very difficult experience that had occurred during Claire's non-attendance. I wondered whether she might have been trying to find a way to share this whilst we spoke.

4.3.1. The Plot and the Landscape:

At the time of the interview Gemma was working part time and living with her husband and their two children. Claire, Gemma's youngest child, had not attended school for nine months at the time we met. The non-attendance had started as Easter approached during Claire's first year of secondary school. Gemma's story describes three stages of the non-attendance. At the 'beginning of missing' it seemed school staff did not yet understand that there was an 'issue' and fines were mentioned as Claire was pushed to attend school.

Following this there was a point about two months into the non-attendance where fines were no longer mentioned, and professionals began to offer school-based provision to Claire, although it often did not seem to meet Claire's current needs. When Gemma and I met it appeared that staff had begun to find ways to support Claire onto the school site during after school hours.

I felt Gemma had been on a long, and ongoing, journey which had been quite unclear and uncertain. Gemma talked about 'bumbling along' in the unknown and expressed a desire for clearer guidance and reassurance. Gemma revisits the importance of "keeping positive" throughout her story and she self identifies this as a significant message: "I think that's my theme for the talk (1) keep positive, but it's really difficult". For Gemma, keeping positive involves taking actions that support Claire's wellbeing, for example by highlighting Claire's strengths and recognising and rewarding her when she has been able to engage in an activity. It felt that the responsibility and focus of building Claire's wellbeing sat with Gemma and her husband and that this priority was often overlooked by professionals.

4.3.2. Understanding 'missing': "she's not identified any particular cause"

Gemma considered her understanding of Claire's non-attendance; she drew on a range of experiences and difficulties which could have contributed to this. These included: school-based difficulties; anxiety; and loss.

School based difficulties:

Many of the difficulties Gemma believed Claire had experienced in school are captured within this voice poem:

she's not identified any particular cause

she tries to go

she just

she can't

she just has to run

She feels safe at home.

she had around about March 2019

she had

she fainted in class

hit her head

she had

she

she came home.

a bit mean to her

called her a name or

I don't know, it was nothing major

I don't think it was an ongoing

called her a name

really upset her

she didn't play

she was struggling with the homework

I think it became

she's always been very very, given 110%

she's always

done her homework

she always tries

I think

she was finding it really difficult

I was finding it difficult

me having to Google

she's,

she's got dyslexia

queries whether she's dyspraxia

she hasn't had a test

she's got well it's dyslexia and dyscalculia

she struggles with both

I am sure

it was very very difficult for her

things like organising herself

girls call for her every morning

nobody was calling for her

I was

I'm sure there were some friendship issues mixed in

She wasn't

just one friend she had from

she says there wasn't any bullying

she says it's nothing to do with friends, it's nothing online

I think it has accumulated

she can't say why

She says "I can't, I don't know"

I think it's (1) over (.) load (1) in that environment

she feels *completely* (.) unsafe

I think that's

I think that's the other thing

I don't think

she

she doesn't feel safe

I think (3) although

she looks very confident

she's very able

she just doesn't feel, didn't feel safe

Here the 'she' voice dominates as Gemma talks through her perception of Claire's experiences in school prior to the non-attendance. Gemma is careful to emphasise that there has not been a single identifiable cause for the non-attendance and that Claire has not been able to articulate why she is finding it difficult to attend school. Gemma appears to make sense of Claire's non-attendance by viewing it as a reaction to an accumulation of difficulties.

In the fourth and fifth stanzas Gemma talks about the secondary school environment and the growing complexity of work that Claire was expected to complete. She considers the probable impact of Claire's literacy difficulties on her ability to manage this. Claire's peer relationships are revisited throughout the poem. In the 'I' voice I can hear Gemma explore her understanding of the significance that friendship issues play in the non-attendance. Where her own and Claire's understandings appear to diverge is captured within the 'she' and 'I' voices. For example, Gemma highlights that although Claire does not consider friendships to be a reason for her non-attendance, Gemma believes that relationship issues were likely to have been 'mixed in'.

Within the interview Gemma contrasts Claire's "massive" secondary school with the safety of the primary school environment where Claire: was taught in one room with the same peers; was loved and valued; and had a secure friendship group (see Appendix T).

Gemma shared her understanding that Claire has not felt safe at secondary school and it seemed that Claire did not think that the difficulties she had encountered are unique to that school. Gemma believed that moving schools would be even more challenging for Claire due to the lack of familiarity of a new setting:

"we looked at, did she want to move school /[quotes Claire] "NO I don't want to move school" / because obviously it's not the, that's not the problem because moving schools is like, oh my god that would be even more scary going to somewhere *completely new"*

Loss:

Towards the end of our time together Gemma touched on some difficult family circumstances that occurred when Claire was missing school:

I

I was going through

particularly bad time myself

about the time she

she stopped going

my best friend died

I think

I think it just (.) important to be aware

my best friend

I had to

I was off work

I was off work for ten weeks

I was doing

I'm still looking after

I was thinking

am I spending too much time sorting things out and not with Claire

I was

I mean

she was already missing

Within this poem Gemma shares the loss of her best friend. She reflects on the additional responsibilities in her life as a result of this bereavement and I can hear the pressure that she must have been under. It seems important to Gemma that it is understood that there were "other things going on" for her family and that difficulties for Claire were wider than the school environment. However, Gemma appeared to question how much this had contributed to the non-attendance as Claire was "already missing school at this point."

Anxiety:

Gemma makes specific reference to anxiety as a construct that supports her understanding of Claire's 'missing'. She describes her perception of the panic Claire experiences in difficult situations:

she gets

she's in a place

she feels

she can't escape.

just my (1) *theory*

if she's in a building

she can't escape,

she finds it stressful

she panics

she doesn't think

she can get out of a situation

she's not enjoying

Gemma identified that Claire tries to avoid the places where she experiences panic and seeks to stay where she feels safest; at home. Listening to Gemma's story it seemed that anxiety had trapped Claire in a cycle that is very difficult to get out of:

"she started getting I think anxiety attacks and then obviously the way of not having anxiety attack is to avoid that situation isn't it and then and then that's it then, and then you're, you're stuffed aren't you, once you (.) once you start with anxiety it's a really difficult, really difficult (1) thing to manage."

Gemma explained that anxiety is difficult for individuals to understand and particularly difficult for Claire who, because of her age, does not yet have the life experiences or

awareness needed. Within Gemma's interview she wonders whether this is part of the reason that Claire has not articulated a reason for the non-attendance:

"It's not anything anybody can understand is it?....

......we've all had like, time when we've missed school or we've missed *work* [Yeah and we've been off and that going back in is horrible isn't it? mmm......

.....But once you're in there, you're in there aren't you? It's a kind of build up to it, but you know trying to explain that with (.) to someone with sort of anxiety problems and at the age of eleven, twelve, they don't *know* that yet do they?"

School Refusal:

Gemma explained that her, and her husband's, research had revealed that other families have had similar experiences and that 'school refusal' is a term often used to describe students who are having difficulty attending school:

"she's incredibly, she does want to do the work, so (1), I think that's, that's sort of key to school refusal isn't it, they do want to do it, it's just (.) they can't (.) cope with whether it's the environment um I mean I don't know, any (.) I've just heard the term, you know that people (1) this is a thing coming through now"

Gemma spoke about her discomfort with the term 'school refusal' because it implied that the non-attendance was choice based. Gemma indicated that without a label it had been more difficult to: access guidance; gain reassurance; or know that other families are experiencing similar situations. This seemed to make the experience feel lonelier (See Appendix T).

4.3.3. Beginning of missing: "I don't think she'd come across it before"

In this theme Gemma discusses her family's experiences at the beginning of the non-attendance when Claire's needs are often misunderstood; Claire's 'missing' is often viewed as choice-based behaviour by professionals:

"they were just like, (.)…

…'you're being naughty girl' and. Nobody ever *said that* but you can tell in a person's (.) tone of voice and their (.) kind of, frus, that you're, that you are being a naughty, *that you are being a burden*, it's like '*come on I'm really busy*'"

Gemma reflects on the pressures that she perceives staff are experiencing in the school system as she describes being viewed as 'a burden' and suggests the need for an 'extra post' in school which could enable a staff member the time needed to work with her family.

Hearing Gemma's story did not often seem to be a priority for professionals; as I listened to Gemma, it felt that school staff had jumped to conclusions and solutions. Gemma describes the impact of this as 'harrowing' and she felt staff had been uninterested and judgemental:

"it's harrowing, it's really harrowing um, because, like I say, they're not interested in your, they don't understand (.) they just think you're being (.) a weak parent (.)"

It appeared that staff understanding of the non-attendance as a choice-based behaviour meant that they used, and encouraged Gemma and her husband to use, punitive measures:

'"*Remove everything from them*', they were basically saying, until they go back to school"

"at first they refused to send work home because they said: 'well we're not going to send work home because that gives the impression that you can just stay at home and do it'."

Gemma reported that adults spoke directly to Claire about the prospect of fines, for example in this meeting involving school staff and an EWO:

"they basically said (.): 'why can't you come? And (.) you've got to come……. you know what will happen to your mum and dad (.) if you don't, if you don't come to school, we are going to have to fine them ah do you want your mum and dad to get fined ah I just, I can't believe' and they were quite, really *really* negative, so that was difficult.

Mmm fines were mentioned

Yeah… this is in the early stages I think when I think you really need (2), they always say, you know, catch these things early don't they, but (2) um (4), but there's been (.) school have done what they can and they've been very good and we haven't received any fines or anything"

Gemma suggested that it would have been beneficial to identify and understand Claire's needs early. My understanding from this comment and from listening to Gemma's story as a whole is that this was not the case; Claire's needs felt misunderstood at the beginning of the non-attendance. This meant opportunities for support were missed and time was lost.

Influenced by the recommendations of school staff and worries about fines, Gemma felt that she had to 'push' Claire to attend. Using the 'I voice', Gemma reflects on these pressures:

I suppose nine months on it's absolutely horrendous

I was constantly anxious

we were going to get fined

I was constantly anxious

I was doing *the wrong thing*

you question everything

you do

I was,

I was sort of guilty

I was sort of like "if you go to school then you

Gemma shared that she questioned everything she was doing and describes searching back through Claire's childhood to identify whether she had done anything to 'make her anxious' (See Appendix T). Looking back at the period she expresses a sense of guilt that she had 'pushed' Claire to attend school. She reflected that employing approaches aimed at 'pushing' Claire (for example, removing her phone and talking to her about fines) had negative consequences, resulting in Claire becoming more isolated:

"That doesn't work, that just makes her even more depressed, isolated, mmm. This is not a person who's like, 'ah I can't be bothered today, I'm going to stay in bed'. It's not that"

Gemma contrasted her early experiences of Claire's non-attendance with what she felt she needed, as a parent, at this time: to be reassured.

"really in those first few days we just needed someone to/ 'look it's OK' (1)"

4.3.4. Turning points and shifts in understanding: "we've *got to come at this another way*"

Within Gemma's story I heard noticeable shifts where staff understanding changed and where Gemma and her husband decided to alter their response to the non-attendance.

Gemma touched on a difficult event (forcing Claire into school when she was distressed) which led to a shift in Gemma and her husband's thinking:

when she

she first started missing

we would drive

her up to school

she'd refuse to go in

teacher would come out

tell her

she had to

several teachers come out and say "you have to

we couldn't get her to

There was one incidence

she was screaming

she was obviously very very distressed

my husband

took her

he said "should I physically drag her

teacher says "well yes you'll have to"

really really distressing morning for both my husband and Claire

he sort of dragged her in

we've got to got to come at this a different way.

our point of view.

I mean

we didn't

we didn't really have

any input from them

other than (1) them saying "she's got to

In the final stanza Gemma shares her reaction to this event; Gemma and her husband decide to seek a different approach to the ones encouraged during the beginning of Claire's 'missing'.

It appears that, for school staff, a similar shift in thinking occurs further into the non-attendance (a few months after Claire had stopped attending school) and is marked by the absence of some conversations (for example, warnings about fines) and the exploration of new strategies and provision. This is illustrated when Gemma shares that once staff understood that there was 'a problem' they began to explore new strategies:

"Once they got their head round, they got their head round that there was a problem there, that she wasn't just being a naughty girl (.), they did a reduced timetable"

4.3.5. School provision: "if she's not in the building then there's nothing we can do"

Gemma reflects on the provision that was offered once there was an understanding that Claire "wasn't just being a naughty girl". Although this shift in perception appears to encourage staff to explore different provision it seems that there is not always a comprehensive understanding of Claire's needs; this is highlighted when the provision offered does not meet Claire where she is:

"so they did that timetable, but that came home, that got ripped up (1) because the problem is get, is not the lessons it's the actual just the anxiety getting into the school"

"their excuse is always, 'well if she can't, (.) /if she's not in the building then there's nothing we can do'. (1) So you know 'we can (.) trial her with different colours on the screen, we can, do different lessons with her, we can…..but (.)"*

Although Gemma had some clear ideas about what could help she often felt her ideas were unfeasible for staff members to implement (see Appendix T) due to the demands made of teachers and the numbers of pupils they support. Gemma perceived that these staff pressures, combined with the non-attendance meant that Claire was invisible to her teachers:

<div align="center">

they always

let teachers know of issues

no teachers have tried

to contact her

nobody's um

nobody's actually sort of popped round

seen how she is

she's just

invisible to them

I get

they've got hundreds of pupils

</div>

Reflective Box:

I felt sad listening to this; it felt that Claire was forgotten, and I imagined how disconnected from the school community she could have felt.

There are times in Gemma's story where she voices frustration with the provision offered and she suggests how resources could be employed in a way that was more sympathetic of Claire's needs:

"they've said, 'if you don't come up to school, we're going to have to come down to the house to do a welfare check, to check she's alright', which I get and which is fine (1) but, it's kind of like 'if you can come down and do that, can't you, can't you do something a bit more fun with her……some kind of art thing that then she can colour in, hand back and you can go 'oh well done' and something positive like that"

Gemma explained that a more holistic understanding that allowed staff to focus on Claire's wellbeing could have been helpful. In Gemma's story it feels that as staff focus on improving Claire's attendance they lose sight of her needs:

"if you focus on what *they want* which is getting her in there (1) then it all, it, it, then you lose track of Claire…. how she is in herself and *for her to get in there* she's got to be alright in herself so that's the focus. That's the chicken and the egg isn't it."

Gemma reported that, more recently (nine to ten months into Claire's non-attendance) school staff had stopped 'pushing' and had begun to take a "softly, softly approach", for example, by checking in with Claire that she felt able to do what was suggested and inviting her to spend time with a staff member after school when it was quiet. Gemma shared that this had led to some very gradual progress and that Claire had recently been going into school.

4.3.6. Maintaining relationships: *"we want to work with the school"*

When I listened to Gemma I felt that there was some tension between her desire to maintain good relationships, and work, with school staff and her frustration with some of the experiences she had had:

I mean

I think

I will say

I hope school

back me up

we (.) have

we want to work with

we've always been thankful for (2) for *anything*

they've done, although it hasn't

I think

we're building on things

Although we've not had a lot

they have

they've

they've worked

with us

They've said 'right, lets try'

They've offered

we have always said thank you

Within the 'they' voice Gemma highlights that school staff have always tried to work with her family and that they have offered and suggested provision.

Gemma questioned whether speaking to the school governors could encourage the exploration of other strategies:

"whether or not I can go to the gov, parent governors and say: look this has been my experience, we've had basically a timetable thrown at us and (.) a reduced timetable and you've not fined us, thank you for not fining us but is there anything else you can do?"

Gemma did not seem to have been made aware of some of the services available to her. Towards the end of our interview, during our debrief, I mentioned the Local offer and SENDIASS and she commented:

"Oh I've not heard of those. Nobody's mentioned them to us. See what you, what you could do with, almost is like a kind of, somebody [to say cribsheet]"

> Reflective Box:
>
> I felt quite frustrated that in the nine months of Claire's non-attendance no one appeared to have mentioned SENDIASS or the Local Offer to the family. I wondered how easy it would be for Gemma to advocate for what she felt Claire needed without an understanding of the systems and services available.
>
> It could be difficult for families to self-advocate particularly if they are: encountering difficult personal circumstances; worried about schools imposing fines; and feel that their parenting has been judged.

4.3.7. External services: "you've got to have something"

Gemma reported that she had often had to wait for external services; her family had to wait a 'little while' for EP involvement and, at the time we met, Gemma was on the waiting list to be seen by CAMHS.

"we've got about another twenty-three weeks to wait now, so (1) and that's for CAMHS. So that'll be well over a year (.) so waiting for the services is (3)"

Gemma was understanding that services had to prioritise some CYP (see Appendix T) but knowing this did not take away from the challenges her family were experiencing. Gemma explained how reassuring it had been for her that her family were able to, privately, seek therapeutic involvement to support Claire's mental health:

at least we've got this counselling

we've got one thing

you

you've got to have something

If you had nothing

you would just (1)

It was very important to Gemma that there was a professional 'on board at all times' to provide support and she shared how difficult it could be without this. Gemma communicated that external support was positive when it used a "softly, softly" approach and modelled this type of approach to staff. Here, in the 'they' voice, we can hear examples of how an EP employed this sort of approach with Claire:

they're coming in

talking to her

things she likes

doing little beads things with her

engaging her

they're very (.) gentle and very (.) softly spoken, and (2) not pressuring

asks Claire (2) "is that OK"?

they're

working for Claire rather than (.)

Not all experiences of professional involvement were positive and Gemma shared the anger and disappointment she felt following an event in her story where she had met with a professional from a service provided by the LA following a referral made by school. Within this event, although Gemma had been given the space to share her story and the

background to the non-attendance (see Appendix T) it seemed that she was not been heard. This had implications for the way the professional engaged with Claire and meant that Gemma's family were unable to access a service that they had hoped would help them:

"the lady came and she sat for 20 minutes, with Claire, and said "you know (.) your mum and dad are going to get fined don't you if you don't go back to school" and (.) Claire got upset, walked out the room and then we got a letter from them saying '*Claire* wouldn't engage so we are discharging you from our service' (2) So that was *really* disappointing, really disappointing."

4.3.8. Missing Out: 'you have to keep things positive'

In this theme Gemma emphasises the importance of Claire's wellbeing and the impact that missing school has had on this; she shares the need to protect Claire's wellbeing by 'keeping things positive':

<div align="center">

we've had to

I say,

positive for her

she

she will cry

she'll go "I don't want to","why am I different"

you say "it's alright, you're fine, you're wonderful"

She was due to

she missed out

she's lost out

she's been screaming

at me

</div>

trying my best

she

she screams (.)/ "you've done nothing

you have tried (.) everything

you don't know what to

it's killing you

they are screaming that, that is really really difficult to take (.) and to try to keep it positive

I've got,

I've had quite a lot of

I'm the one here

Husband he'll come home

he can sort of take over

he's been very good, keeping it very positive

I've had a really really hard day,

good that he's been able

In the poem I can hear a 'you' and a 'they' voice; these voices are used interchangeably with 'I' and 'she' voices. I understand the 'they' pronoun to represent Claire, and children who are missing school, and the 'you' pronoun to represent Gemma, and parents of children who are missing school. In the first stanza some of the worries Claire has shared with Gemma are captured and we gain an insight into how the non-attendance can affect Claire's self-esteem. Gemma's response to Claire in these moments suggested a desire to protect Claire and ensure that she does not view herself negatively. In the third stanza I felt a sense of the overwhelming emotions Claire and Gemma have both experienced during the non-attendance and how difficult it has been for Gemma to 'keep positive'. In the final stanza Gemma shared that she often experienced a lot of Claire's emotions because her role in the family meant that she spent more time at home; she highlights the benefit of being able to hand over to her husband when it has been difficult.

4.3.9. Wider Family Impact: "it's a difficult juggling act"

Availability and work demands:

When we met Claire had started accessing some work on the school's homework page. Gemma discussed some the difficulties involved in supporting Claire's learning at home:

"I mean she needs someone sort of to explain it with her…..what I'm finding difficult is that she needs some really quite intense support with things and with us both working that's really difficult to find time to do that (2)"

Gemma reported that it had been highly stressful despite having supportive flexible workplaces and she commented:

"I can see a lot of families would literally break down with the stress of it".

Ensuring the needs of siblings:

Gemma discussed the probable impact on her son and her desire to ensure that his needs were not lost to the situation:

Her

brother

her

brother has been really good

I think,

I think all the screaming

we're at a good stage now,

shouting will probably, impacted against him

she's getting rewards

Brother's not being left

I'm like

Brother,

Brother is going to school,

he's doing

his,

he's doing

his homework

I've got to like make sure

you've got to make it even

haven't you

not to have him feeling left out

Parental Wellbeing:

Throughout her story Gemma touched on the emotional impact of her experiences. In the 'you' voice in the poem below we can hear Gemma thinking about the importance of maintaining parental wellbeing:

you just need to go and (.) just lie down, it's (1)

You have to look after

yourself

You do,

you do have to

look after yourself,

I'm going down to the gym,

I'm going to burn off

you're in a situation

you've got other children,

you're on your own

<div align="center">

you'd need,

you'd need some serious input.

You really would.

I'm not sure

if you said

I'm not sure what there is

you went out

said my child's

I'm having a flipping nightmare

I'm not sure what

you'd get

I

I could do

I haven't tried

</div>

In the final stanza Gemma shares her uncertainty over what support is available. She explains that the support parents need is probably unavailable within her LA:

"they haven't said ring this number this person could help you because there probably isn't anything like that in *LA*"

4.3.10. Concluding Thoughts:

Throughout the interview Gemma identified provision that could have been put in place to support Claire. In listening to Gemma's story I felt that she had not always been enabled to shape Claire's provision; I got the sense that some of Gemma's understanding and ideas had not always been heard by professionals. I wondered how easy it is for parents to assert their ideas if they are unaware of the systems and resources available.

4.4. Laura and Josh

I met Laura in her home. When I arrived, Laura checked that I still wanted to talk to her as, although Josh was still on role at school, she did not want him to return to school at this time. Laura and I spoke for fifty-one minutes.

4.4.1. The Plot and the Landscape:

When I met with Laura she was living at home with her husband and two of their children who were very close in age. Laura and her husband had older children who had moved out for work and study. Laura was working part-time. Her son Josh had been out of school for eight to nine months before we met and things had 'come to a head' in June the previous year. However, Laura shared that Josh had been finding it difficult to go to school for several months prior to this and she reflected on this time when we met. Laura identified that Josh had found it very difficult to tell adults how he felt and had tried his best to go to school. Laura expressed some guilt that she was unaware of his difficulties at this time.

Laura shared that routines are very important to Josh, so when the non-attendance began she knew there was '*something really wrong*'. She described her family coming to a shared understanding and making the collective decision that school was not currently an option for Josh; Laura shared that school attendance as something to work towards was creating a constant worry for Josh and she wanted to prioritise Josh and his happiness. This did not always feel easy with school staff expressing the need to improve his attendance and the possibility of fines. Laura felt that Josh had been seen as '*just a number*' by his school and this often made it difficult for her to access support and external agencies; Laura had to find out about services such as SENDIASS and EPs independently. She had to fight for help from school to fill in a referral form for an autism assessment. Although much of Laura's experience had clearly been very difficult it felt, at the time I met her, her family had come through it together. Laura shared that Josh was now learning online at home and that she had learnt a lot over the last year too. She described Josh as happy and I got the sense that she felt secure in the knowledge that the decisions made had been the right ones for Josh.

4.4.2. A newly discovered past: now when I think back (.) I just think 'wow, he really did try'

Within this theme Laura reflected on the time before Josh stopped going to school. This is captured in the voice poem below:

when I think back

he was struggling (.)

I sort of didn't *see it*

I think back

I can see it now in hindsight

one day (.) he simply just refused

I knew

he weren't being lazy

he's not

I know that sounds biased

he likes

his routine

I knew there was something really wrong (1)

I went up to the school

with him

he really *really* was scared

now when I think back (.)

I just think 'wow,

he really did try' (.)

force himself in.

He thought

he'd get over it, but.

In the 'I' voice we can hear that Laura developed much of her understanding of this time after the non-attendance began. The emotional turmoil of this is felt in the quote below:

"he couldn't get on the bus and go to school because he was busy being sick (.) m so he had to go on his bike (2) so that he had the choice to stop and (2) be sick *I suppose* (.) and then carry on (.)…

…(2) I I've learnt this since (.) every first lesson hand up "can I go to the toilet", be sick, (.) *didn't tell them that*, just said he needed toilet. (.) because he couldn't *explain* (.) *he weren't poorly* (.) he were just (.) feeling *anxious* that made him sick yeah so (2) but that's he went through that every day for months. (11)

That sounds like that's something that, that's quite hard for you to know (.) now.

Yeah, it's awful yeah. (.) That's where the guilt (1)/{wobble} hits you. But (.) *I know* I shouldn't feel guilty because it weren't nobody's fault (.) it it weren't a fault, it were just a feeling that he had and he couldn't explain, so he couldn't tell nobody (2)"

With hindsight Laura could see some changes in Josh's behaviour during the time he was struggling to attend school:

When I,
I think back now
I think (.)
how could I not tell
he was pale every day? (2)
His,
his head down
he shrunk, shoulders were down
his head was shrunken. (1)

I think back

I feel guilty (1)

I didn't see that

I wondered whether the internalisation of emotions might have meant they were more difficult to see. At the time Laura and I met she described Josh as "more relaxed" and "happy". It seemed the change in Josh's wellbeing had allowed adults to see how he previously felt.

Laura reported that it had been hard to find a 'reason' for the non-attendance. She explained that Josh had a good group of friends in school and that he had not been bullied (see appendix U). She reported that Josh's attendance at primary school had been good; he found the first day back after school holidays difficult but this eased once he settled in. She described his experience at secondary school as being "like that first day after school holidays *every* day". Laura felt that Josh found it difficult to explain the non-attendance and that he associated school with anxiety:

he just associates school with anxiety.

in his head, that, (.)

maybe not in his head but it's associated,

when he goes to school,

he feels anxiety,

he's scared,

he's shaking

he's physically sick. (1)

the school itself

he can't explain

it's just scary for him.

4.4.3. Making a decision in a pressured environment: "I had to look at the bigger picture"

Laura explained her family's decision to drop the focus on school attendance and prioritise Josh's health and happiness. Laura shared her experience of her family coming together and listening to one another; this seems to have enabled them to accept and understand Josh's feelings:

"as a whole in the family (2) we, (.) we all agreed and stuck together I suppose. Mm It weren't an (1) argument of (2) or (1) It were more *understanding*. Instead of (.) everybody arguing and "oh you you've just got to go to school and that's that stop being silly" mm (.) it's because (2) you've got to *talk* (.) and you've got to listen and that's what we did. So and then it's like understanding (2) not closing (.) your mind off because you don't have them feelings that they don't exist because *they do*. So yeah just *talking* (2) like I said and listening to each other."

With an understanding of Josh's feelings Laura began to move her focus from school, to the 'bigger picture':

all you want

for your children

you need them to be happy and healthy

I had to look at bigger picture and think right

his health and happiness

or his education.

Within this voice poem we can hear a 'you' voice. I perceived this to represent Laura's understanding of a universal desire amongst parents; Laura shares her belief that all parents want their children to be happy. For Laura this seems to mean looking at the 'bigger picture' and making decisions based on Josh's health and happiness. Achieving this was not without worry and Laura said she had concerns about being fined and the implications for Josh's future:

I were worrying

about him not going

I was thinking about the future

about his GCSEs

what's he going to do in future?

what's he going to do when he's older?

you've sort of got to break it down

you've got to think tomorrow and today

he's here. (.)

when your child says I'd rather not be here, (.) I'd rather die (1) than be feeling this feeling

you

think to yourself right what is important.

you've got to think of today.

He's here

he's happy today

Laura's needs often seemed to be at odds with the priorities of school staff. In the voice poem below Laura shares her perception that school staff prioritised their attendance data over Josh's wellbeing:

They wanted it to look good on paper, (1)

that's how I feel.

all they were bothered about

they were like

we need to get him into school,

we need this

I'm like no

we need him to be healthy,

we need him to be here.

we don't need him in school.

Fines and the role of SENDIASS:

Decisions regarding Josh's attendance were made in the context of external pressures created by the possibility of fines and the implications of these on the family's finances.

"I'd get just a phone call saying 'just so you know and so you're aware that it is a (.) that it's a sixty pound fine. But you're not thinking (.) oh it's a £60 fine, because then it can be per term or per half a term (.) and it's like when you work part-time it's your wage at end of year."

Laura explained the importance of SENDIASS in helping to relieve this pressure and her frustration that staff members perpetuating this were not aware of the advocacy services available for parents in this position:

head of year

in the meeting with me

he had to Google what SENDIASS was,

he (.)

he didn't know.

I (.)

I'm not saying it were his job to know but

telling me all the time

I'm going to get fined

you think

I'm like picturing police knocking

not fair (.) for them to make

you feel like that

have you worrying,

making you feel

you're doing the wrong thing

you're trying

your best. (1)

you've got (.)

I suppose

I had to prioritise

how they felt at school or

It's your child isn't it.

you start to get from (1) upset to angry, like who are you talking to

I'm going to get fined.

I've been worrying for weeks, (2) like really worrying

I met with the lady from (.) is it SENDIASS?

they made

me feel a lot better

for them to come

to the meeting with me (.)

since they did, nothing, nothing has been mentioned about getting fined

Within this poem there is a 'you voice' I understood this to represent Laura and parents in a similar position to Laura.

In the first and second stanzas, within the 'I' and 'you' voices, Laura explained the worry experienced as a result of staff suggesting she could be fined; she speaks of imagining the police knocking at her door and highlights that she was trying her best. In the 'they voice' Laura shares a sense of injustice that she was made to feel this way by school staff, particularly when they were not aware of services, such as SENDIASS, that could advocate for Laura.

In the second stanza Laura describes a shift in her emotional response to the reminders about fines; moving from feeling worried to feeling angry. This shift in feeling seems to coincide with her deciding that she needed to prioritise Josh's needs over the schools. I wondered whether the decision to protect her son helped to empower her to question the 'threat' of fines.

In the final stanza Laura talks about the support she received from SENDIASS; the result of this can be seen in the final line where Laura shares that fines had not been mentioned since SENDIASS accompanied her to a meeting.

4.4.4. Accessing external agencies and provision: "I kept googling, googling, googling"

Laura reported that she had to push for support and that she did a lot of her own research to find out about the different services within the LA. It seemed that offers of support from school staff were not forthcoming:

I didn't know (2) anything (.)

I didn't know EPs existed,

I didn't know SENDIASS existed (3)

I don't

I know (1)

I've obviously heard of family support workers and CAMHS (.)

I've heard

I'd never even heard of Ed psych, never heard of SENDIASS

I weren't informed (1)

I've learned myself.

Once Laura had identified services she describes having to push for access. Josh's needs were given as a reason as to why the family could not access external agencies and Laura shared her frustration that she had not been heard:

"I went in and I mentioned ed psych to them and they were like 'no you can't have the support off them because Joshua's not in school….. I was like you don't understand I *need* the support *because* he's not going into school (.) but school were saying if he goes into school ed psych will help him and I was like we're going around in circles (.) you're not listening to me. (1) They just weren't listening….. That's why that took a bit longer because they just weren't listening to me"

The nature of Josh's needs also seemed to impact upon the provision he was offered. In the first stanza of the voice poem below Laura talks about her efforts to ensure that Josh received work while he was at home.

<div align="center">

I didn't feel supported from school

I was like (1)

Can he have,

can he go (.)

I know

they do computers

I asked (.)

I spent a lot of time up at school

can he have some work,

a site he can go on?

can you give me any work?

they were like

Can't give him work

encouraging him to stop at home.

they just weren't getting it. (1)

They just didn't understand

giving him some work (.)

eased his anxieties.

</div>

because school

weren't helping him, (2)

I think

they kind of (1)

lost his trust

he doesn't trust (1)

them (2)

I think.

He hasn't said

that's what I think. (.)

Since they won't help him.

he was

asking for it himself.

He was asking, (.) "can I have all this work

school were just: "no, can't encourage

In the second stanza we can hear Laura's perception of the beliefs of school staff. It seems that staff have misunderstood Josh's needs and she shares that teachers would not give Josh any work because they believed that this would encourage him to stay at home. In the final stanza, in the 'he' voice, we can hear the impact that this has on Josh; Laura believes that he lost trust in school staff when his requests for help were rejected.

Although Laura shares that some school-based provision was offered (for example, Josh was invited to enter and leave school when it was quieter and was given the option to spend time in a resource base) it did not appear to meet Josh's needs (see appendix U). My impression was that provision was offered before adults had spent time exploring what Josh was finding difficult. In the first stanza of the voice poem below Laura expresses some frustration that school staff had not investigated Josh's situation:

I mean

we've got (.) one child (.) out of school with 0% attendance.

We've got another child, same age, in school 100% attendance

I think (.)

If they would have looked

they'd have seen it's not a case of (.) 'oh them parents don't care

he's not going

If they had done a bit of research

he always had a good attendance

his reports were always good

they just didn't care

He was just a number,

they wanted attendance up

because it makes them look good (3)

In my opinion

I don't know. (.)

I suppose

you can't really say that

you don't actually know

what they're thinking

impression that I got (2)

In the 'they' voice in the second stanza we can hear her perception that adults in school did not care about Josh; she feels that they were more concerned with ensuring their attendance data was good.

4.4.5. A new normal: I do feel we've done the right thing

Laura reflects on the decisions her family have made together. At the time we met Laura reported that Josh returning to school was not a current goal for the family:

"in the near future, it's not, because he's *more relaxed* and he's more happy because we're not forcing it. It's not like 'oh eventually we have to go back' because that's a constant worry and *nobody wants a constant worry*. So to lose sleep, to lose your appetite, (1)…. we don't need (.) that worry"

Laura shared her experience of adjusting to a new life where a home-based education is the norm for Josh. I felt that Laura had settled into a new way of doing things and she seemed secure in the decisions that had been made:

he might do an hour's English.

I do pay for it

if he was going to school

I would be paying bus fares

instead my money goes to that

he

he's

he's got

his rules,

he does so much, an hour's English, an hour's maths

you feel better (.)

he's doing something.

I,

I've learnt loads of new things

I need to be a home educator,

I'm not a teacher

I can't do that,

I simply can't.

I went online,

you just Google it 'what do other parents do'

I found loads

you,

to know you're not the only person.

at first you feel like a bad mum

but you aren't (.)

I've learnt

I'm not

I might have said that wrong,

I know

I'm not a bad mum

I don't

out of your depth maybe?

you don't know

what you

can I do to help.

you (.)

you want help

I think in our case (.)

we helped each other

You just (3)

I look back now

I think (1)

I couldn't have really done anymore

I don't think,

I should have done this,

I should have done that,

I just simply didn't know (.)

I do feel

we've done the right thing (2)

can't force him to feel like (1)

In this voice poem we can hear that Josh has a daily routine at home and that Laura has funded some online learning to support him with his English and Maths. In the second stanza she considers her own learning within this. Laura shares that she has accessed online support around home schooling and that she has learnt that her family are not alone in this. In the fourth stanza Laura identifies that she, and other parents in this situation, want help; it seems that in Laura's case external help might have felt absent, but she recognises that her family helped.

4.4.6. Concluding thoughts:

Throughout Laura's story there is an absence of external help. Although Laura had recently had involvement from an EP, which she described as supportive when we met, it had come quite late. I got the impression that this involvement had arrived at a point when the family felt quite settled, "after helping each other", rather than when Laura had really needed help.

Across themes I heard a lack of knowledge amongst school staff of services available for parents. The impact of this is captured in themes two and three where Laura speaks of finding out about information and services herself.

Reflective Box:

Although, Laura and her family had reached a place they were happy with I felt quite disappointed that the interactions she had with professionals along her journey had been so difficult.

I wondered how the journey might have felt if Laura had met professionals who informed her of the support available and proactively offered help so that Laura was not in a position where she had to ask.

I felt the absence of support quite strongly in the voice poem below where Laura shared that parents want help, but that in her case, her family had helped one another:

<div align="center">

you (.)
you want help
I think in our case (.)
we helped each other
You just (3)

</div>

Chapter 5: Discussion

In this chapter I will begin by reviewing some of the research findings in relation to previous literature and the taxonomic model developed by Kearney and Silverman (1999). I will then use the PTMF (Johnstone and Boyle, 2019) to help explore the parental experiences shared in this study. Following this, attention will be paid to the third research question where the implications of the research are discussed for EPs and school staff (further implications which consider SNA in the context of the COVID pandemic can be seen in Appendix W). Finally, I will consider the limitations of the current study and discuss possible future directions for research around SNA before offering some final reflections and conclusions.

5.1. Findings in relation to previous research:

5.1.1. Seeking an understanding:

Throughout each parent's story was a process of coming to understand their child's needs. Parents spoke of a range of factors which may have contributed to the non-attendance and many of these are reflected within the literature.

All four parents used mental health or wellbeing discourses to understand their child's non-attendance. Parents identified that their child was struggling with their mental health, regardless of whether a clinical diagnosis had been made, and that this was impacting their attendance. This is supportive of the literature which suggests that parents are often concerned about the wellbeing of CYP experiencing non-attendance (Baker, 2015; Pellegrini, 2007) and that many students experiencing non-attendance either have a clinical diagnosis or would be likely to meet the diagnostic criteria for one (King and Bernstein, 2001; Elliott and Place 2019). The possible impact of autism was discussed by both Sarah and Laura, this is an area of attendance research which has previously received little attention. However, recent studies suggest that the vulnerability of students, with autism, to anxiety and social anxiety can mean that they are at increased risk of experiencing SNA (Munkhaugen et al., 2017).

In line with previous studies, parents often touched on school based environmental factors as possible reasons for the non-attendance (Pellegrini, 2007). In particular, they highlighted: child concerns about academic achievement or ability to access work (Havik et al., 2014; and Beckles, 2014); difficulties with relationships with staff and/ or peers (Dannow et al., 2020; Havik et al., 2015b; Lauchlan, 2003; and Wilkins, 2008); and the transition to bigger secondary school environments (Pellegrini, 2007; Kearney and Bates, 2005). Other possible contributing factors that parents touched on included: loss and bereavement (Elliott and Place, 2019) and family factors (Kearney, 2008).

The combination of these factors and weight which parents gave to them varied across the stories. This is representative of the research which suggests that CYP who have SNA are a heterogeneous group and that there is often a complex mix of factors which can contribute to SNA (Gregory and Percell, 2014; Nuttall and Woods, 2013 and Walter et al., 2008).

As parents spoke of their search for an understanding, they often touched upon the difficulty they had had gaining the views of their children. At the time I met Natalie I felt she was still in the process of developing her own understanding of Zeke's non-attendance and his view seemed particularly important to her in this process. In Claire's story Claire reported that Gemma had become 'trapped' in a cycle of anxiety; Claire felt that, due to Gemma's age, this was too difficult for her to explain to adults.

Claire's understanding of Gemma's anxiety entering school seemed to lead her to critically evaluate the term school refusal; she shared her discomfort that the term seemed to apportion blame to Gemma for making a behavioural choice. This term has been criticised by researchers in the past who argue that the term focuses attention on within child factors at the expense of considering environmental reasons behind the SNA. Research interviewing young people who have previously experienced SNA has further suggested that CYP themselves are critical of within child terms. Using Discourse Analysis, Stroobant and Jones (2006) interviewed seven female university students who had had periods of SNA during their time in compulsory education. Their responses challenge some of the dominant discourses held within SNA research. For example, the research highlighted that, although many of the participants used psychological discourses they did not all agree with them. In a discussion with the researcher one of the participants stated:

"I remember Mum telling me that she had said I had school phobia. . . . I remember thinking that was really stupid for some reason. . . . I remember thinking . . . that makes it my issue rather than the school's issue." (Stroobant and Jones, 2006, P.218).

5.1.2. Professional Misunderstandings:

Parents all talked about times where they perceived professionals to have a different conceptualisation of the non-attendance. This often seemed to occur at earlier stages of the SNA before staff had taken time to listen to parents and to explore possible reasons behind the SNA. Parents often expressed their perception that whilst they were becoming increasingly concerned about their child's wellbeing professionals were apportioning blame to themselves and/ or their children for the non-attendance. This is particularly evident within Sarah, Laura and Claire's stories; Sarah, Laura and Claire suggest that their children's non-attendance was initially considered, by some school staff and external professionals, to be caused by poor parenting or their child's 'naughty' behaviour. Differences in understandings between professionals and parents were highlighted within a large study conducted by Malcolm, Wilson, Davidson and Kirk (2003) which sought the views of parents, professionals and students from across seven LEAs in England. Their findings suggested that whilst school staff and professionals were more likely to attribute attendance issues to family factors, parents and students were more likely to highlight school-based factors. In a more recent qualitative study conducted by Finning et al., (2020) sixteen secondary school practitioners were interviewed to explore their beliefs about the risk factors of non-attendance. The study identified that professionals perceive family life to play a key role in attendance problems. The practitioners interviewed viewed parents as obstructive to CYP attendance when they had low aspirations or were disinterested in education. The idea that parents are disinterested in their child's education was heavily disputed in this study with all parents expressing concerns about the impact of the non-attendance on their child's learning and futures. There is a risk that these beliefs about the causes of non-attendance are applied before parents are properly listened to. This could account for the feeling amongst parents that they were being blamed for the non-attendance.

Gemma suggested that early misunderstandings had meant time had been lost because Claire's needs had not been identified quickly. The importance of adults being able to recognise SNA quickly is widely recognised within the literature. Research suggests that the earlier attendance difficulties are identified, and interventions are put in place, the more likely it is that the CYP's attendance will improve (Lyons, 2016). For example, Reid (2012) suggests that early interventions are six times more effective than interventions put in place when a CYP's non-attendance has become persistent. Further, Sarah explained her desire for staff to have more training to support them to understand the needs of her daughter. This mirrors the findings of Havik et al., (2014) who reported that parents wanted school staff to have a greater awareness of SNA and how to recognise risk factors.

5.1.3. Punitive responses:

Parents within this study shared that punitive responses were often used by parents and encouraged by staff in the initial stages of the non-attendance. For example, Claire described staff members encouraging her to remove everything from her daughter until she returned to school. Further parents spoke of staff employing punitive measures in order to encourage students to return to school. For example, Sarah, Claire and Laura each shared that school staff had initially refused to provide any work for their children due to concerns that this would encourage the SNA. This mirrors the perceptions of the four secondary aged students who took part in Baker and Bishop's (2015) study. Students in this study reported feeling blamed or punished. They discussed the pressure imposed on them to return to school and often reported finding the speed at which they were expected to return difficult. Students did not feel listened to when they asked for a more gradual approach to reintegration.

5.2. Current Findings in relation to the Taxonomic Model for Non-Attendance:

As parents shared their stories they identified factors which they believed contributed to their child's SNA. Many of these factors could be considered using Kearney and Silverman's (1999) taxonomic model of non-attendance. The model can be used at an individual child

level and provides a means for adults to begin to understand the motivations CYP may have for SNA. The four key functions of SNA identified within the model are:

1. Avoidance of stimuli within the school environment which cause the CYP worry.

2. Avoidance of social or evaluative situations which cause the CYP worry.

3. Access to attention from loved ones.

4. Access to reinforcers that exist outside the school environment (e.g. preferred activities) (Kearney, 2008).

Given the recognised heterogeneity of SNA it is unsurprising that within this study the range of reasons parents identified for their child's SNA and the functions the SNA seemed to fulfil varied across the interviews.

In Laura's interview the reasons shared for Josh's SNA were represented by just one of the functions in Kearney and Silverman's (1999) model. Laura reported that there had been no social concerns for Josh and that he had always had a good group of friends in school. Her perspective was that the 'whole school' environment just became too difficult for Josh and he began to feel 'anxious' about school. She shared that Josh often became physically ill as a result of the high levels of worry he was experiencing. This suggests that Josh's SNA falls into the first of the functions of non-attendance listed above; avoidance of stimuli within the school environment which cause the CYP worry. Kearney (2008) suggests that students represented by this factor can experience anxiety and somatic complaints.

In contrast Sarah, Natalie and Gemma discussed a wide range of reasons for their child's SNA. Their stories suggest that their child's SNA met several functions in Kearney and Silverman's (1999) model. For example, Gemma expressed her understanding that Claire had become trapped in a cycle of anxiety that was preventing her from attending school. She reported that Claire had had some friendship issues in school and had found the work too difficult and the school building too big. Gemma also questioned whether the additional caring responsibilities she had taken on, following the bereavement of a close friend, might have impacted on the amount of time she had been able to spend with Claire. Therefore, it is possible that Gemma's SNA met the first three functions of Kearney and Silverman's (1999) model listed above: to avoid stimuli in the school environment that cause worry; to avoid social situations which cause worry; and to access time with loved ones at home.

When parents spoke about their understandings of the non-attendance their ideas were often tentative and it was not always clear how much weight they gave to these. This is perhaps due to the complexity of the situations and the number of possible of reasons involved in the SNA. For example, Gemma viewed Claire's non-attendance as an accumulation of a number of difficulties. Within their stories parents often touched on some difficult personal circumstances: for example, personal health concerns, concerns about the health of their partner or experiences of bereavement. Using Kearney and Silverman's (1999) model these experiences could be seen to contribute to SNA by motivating CYP to stay close to their loved ones. I wondered whether parents could feel more comfortable thinking about these experiences in relation to their child's SNA using Kearney's model. The model could allow parents to draw on these experiences whilst maintaining a holistic view of the SNA. The model enables individuals to consider the feelings of anxiety or worry a CYP may be experiencing whilst giving attention to the environmental factors which could be contributing to this. This is important because, in some of the stories parents shared within this study, environmental factors felt as though they became lost due to professional misunderstandings or a heavy emphasis on clinical diagnoses.

However, by focusing on the reasons for non-attendance the model is problem saturated. Used in isolation the model risks losing sight of the protective factors around a child and opportunities to learn from times where a CYP has attended school regularly and has experienced good mental wellbeing. Many of the parents in this study reflected on times before their child's SNA and the aspects of the school environment that were supportive of their attendance. For example, Gemma shared that during primary school Claire had a 'secure friendship group', 'felt safe' and 'felt loved and valued' in school. I wonder whether it would be helpful for professionals using this model as a structure to explore SNA with families to also think about times when a CYP has regularly attended school and which factors might have encouraged this. For example, using similar headings adults could think about which environmental and social factors had encouraged CYP attendance at school. This may draw out aspects which contributed to CYP wellbeing, which was particularly important to parents in this study.

5.3. Current Findings as understood in Relation to the PTMF:

The analysis in this study indicates that parents' experiences of their child's SNA are shaped by: the way professionals engage with them; their individual, social and cultural contexts; and the meanings they ascribe to them. The impact of power and threat is visible in the stories with the positive and negative impact of professional power recognised by parents. The PTMF provides a framework through which responses to situations can be understood by developing an understanding of the power, threat and meaning present in our lives (Johnstone and Boyle, 2018). A visual representation of this framework can be seen in figure 2.

In line with the theoretical orientation of my study I will consider each participant's story in relation to the PTMF individually. To support me to do this I used the structure of Figure 2 to map out each participant's experience (these can be seen in Appendix V).
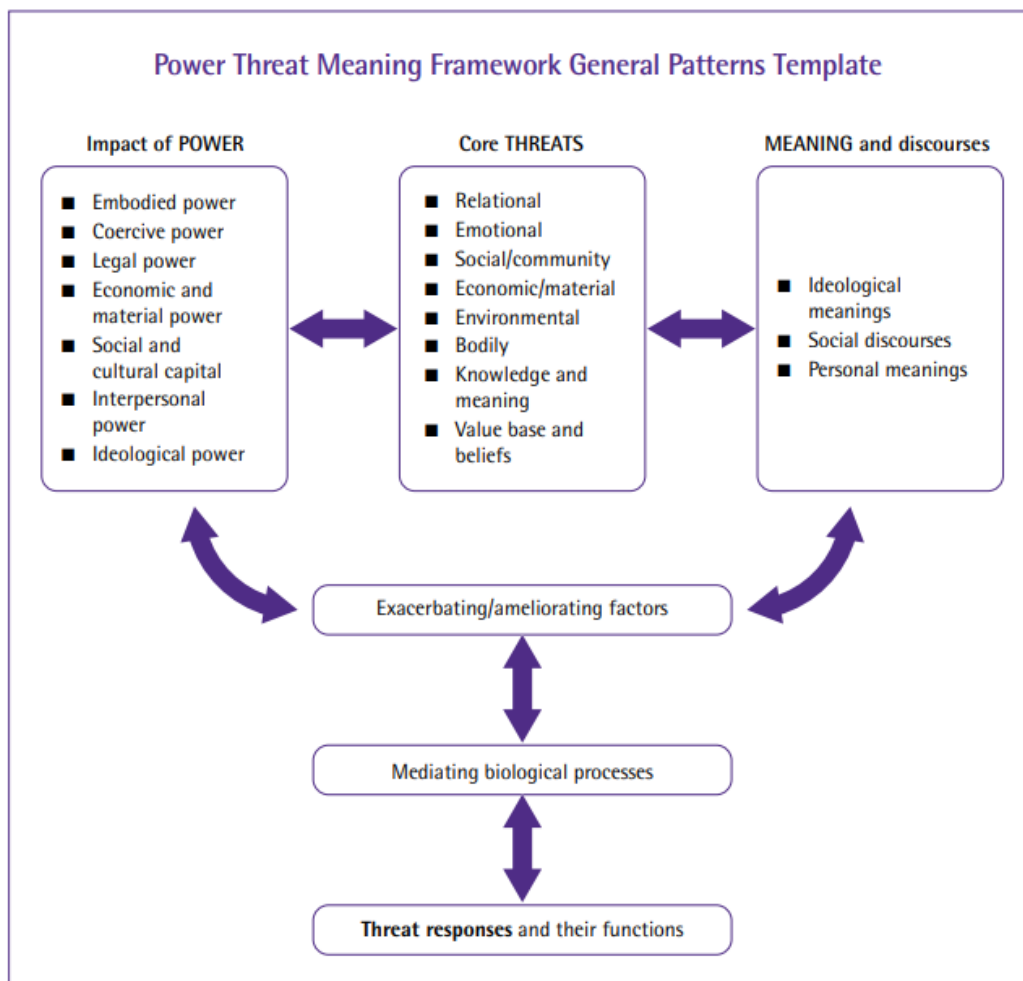
Figure 2. PTMF visual representation (Johnstone and Boyle, 2018, P.34)

5.3.1. Sarah and Erin:

In the early stages of Sarah's story the impact of power and threat are felt in a number of forms. The legislative power held by the LA and Erin's school leaves Sarah facing economic threats. This combined with the power of professionals to determine the understanding of Erin's SNA leaves Sarah feeling judged and blamed as a within-family understanding is developed.

This seems to make it difficult for Sarah to reject professional advice even when it does not align with her own beliefs and preferences. In Sarah's story she takes the advice of a professional and forcefully brings Erin into school. The distress Erin experiences as a result seems to encourage Sarah to draw on discourses surrounding parenting to highlight her role, as a mother, to protect Erin. When she reflects on experiences where this role was jeopardised by professional power she expresses feelings of injustice. Sarah regains some

power over the understanding of Erin's needs in school by seeking the support of other professionals who can introduce a within-child medicalised understanding by diagnosing Erin. Although these diagnoses align with Sarah's own understandings it seems that the more holistic understanding, she had of Erin's needs gets lost.

It is perhaps more manageable for parents to shift the understanding of their CYP's SNA to a within- child mental health need than to maintain a holistic view. Pushing a holistic understanding, would have meant raising the school-based environmental difficulties that Sarah had identified as pre-cursors to Erin's SNA. This could be particularly challenging for parents to do when schools have the power to pose a financial threat.

5.3.2. Natalie and Zeke:

When I met with Natalie she shared feelings of 'being stuck' and feeling helpless. Natalie reported that when her son Zeke experienced strong emotions, she felt threatened by his physical power. As a result, she felt unable to put boundaries in place to change the situation at home. Zeke was not leaving the house at the time I met with Natalie and this impacted on Natalie's ability go out and to socially connect with her friends and she sometimes expressed feelings of isolation and loneliness (Natalie had accessed a strong online community with other parents which was very important to her and she told me: "it keeps me going").

Natalie seemed to be developing her understanding of Zeke's needs when we met and spoke of professionals working with her to develop this understanding. A number of services were working with Natalie and although she had some ideas about the provision that could benefit Zeke she seemed to have little power to push her ideas; Natalie shared that it was all down to budgets and she had to wait to find a solution and see what staff could do.

5.3.3. Gemma and Claire:

Gemma shares the impact of legislative power and economic threat due to possibility of fines. Claire gave a rich picture of the factors which could have contributed to Gemma's non-attendance (including friendship issues, the secondary school environment, difficulty

with schoolwork, and an experience of loss and anxiety). Gemma was clear that she felt these had all "mixed together" to account for Claire's SNA. However, she identified that the ideological power of school staff and external professionals had meant there were times where an understanding was created which positioned Claire as "a naughty girl". This affected Claire's access to support and Gemma talks about Claire being denied homework. As she rejected the understandings posed by staff I felt that the rich picture that Gemma had shared with me to explain Claire's SNA slipped away; she was left using an understanding of anxiety to challenge the ideas that Gemma was avoiding school of her own volition.

Claire was keen to maintain relationships with school staff and I felt that there were occasions where she believed these relationships could be threatened if she posed too much challenge to the support or understandings offered. I wondered whether this concern stopped her from making requests for provision for Gemma and from pointing out some of the school-based factors that could have contributed to Gemma's SNA.

I felt that Claire was quite disempowered, there was a sense that she was accepting of what was offered regardless of how helpful she thought it would be and she did not seem to be afforded the power needed to shape Gemma's provision. Claire was not aware of services that could support her to advocate for herself and Gemma in school (for example, SENDIASS). Further there seemed to be a belief that those holding the material power had no resources to give, and therefore that there was no point requesting provision. I wondered whether this was in part influenced by experiences of austerity.

Claire expressed gratitude for the material power her own family had access to and highlighted how important it had been to her that she had been able to pay for counselling for Gemma. Laura talked about the threat of the situation to Gemma's wellbeing and it was important to her, in her role of a parent, that she was able to take action to protect this. This was particularly important as LA professionals had used their power to discharge Gemma from services.

5.3.4. Laura and Josh:

Laura learnt that Josh had been struggling to attend school several months after his difficulties began. At this time it appeared that Laura felt that was a significant threat to Josh's health, and therefore her role in caring for him. Although threats of fines were worrying and Laura commented that they could take her yearly salary, she noted that her primary concern was Josh's health. Laura employed some cultural capital to identify different services. Laura found out about SENDIASS and supported by their power she was able to remove the threat of fines. Laura had used some material power to ensure Josh could learn from home. However, her experiences of threats of fines and the use of school staff material power to prevent her from gaining access to schoolwork for Josh seemed to have damaged the relationships between home and school. Laura discussed her perception that Josh felt that the adults did not care, and she seemed comfortable in her decision to remove the pressure posed by having school as a target for Josh to work towards.

5.4. Implications for educational psychologists:

The findings of this study highlight the need for EPs to be aware that when working with CYP and families who are experiencing SNA, they are likely to be entering highly emotive situations with parents who may have had negative experiences with professionals previously. Parents who participated in this study commented on the interview experience as being a positive opportunity to share their stories and I felt that they valued being listened to. Employing narrative approaches (White and Epstom, 1990) and an unconditional positive regard (Rogers, 1967) when listening to parents could be particularly supportive; such approaches could enable parents to share the difficulties they have encountered and could begin to empower them to develop their own meanings and understandings of the situation. Further, I felt that by enabling parents to share their stories I gathered a lot of the information that could have supported me to work with schools and parents to collaboratively develop next steps.

The research highlighted the importance of developing a shared understanding of a CYP's non-attendance which takes account of the child and family within their unique context

(Beckles, 2014) and is sympathetic to the CYP's wellbeing. It is important that a purely within-child or within-family understanding is avoided as this can create blame and inhibit staff from taking action to support CYP. I believe that EPs are well positioned to help facilitate this work using consultation: consultation involves working collaboratively with key adults who know the child best. During consultation EPs can facilitate discussions which enable key adults to explore any issues around the focus CYP and to begin to identify possible solutions. The role of facilitator enables the EP to position key adults as the experts (Wagner, 2008). This multi-agency approach could be particularly valuable in the area of SNA in cases where parent and child voices may have been marginalised. EPs could use the consultation to ensure parents and CYP are included in the development of outcomes and provision in cases of SNA (CoP, 2014).

This study used the PTMF (Johnstone and Boyle, 2018) to support an understanding of parent experiences of their child's SNA. However, the framework could be particularly helpful within consultation to create a shared understanding of CYP's SNA. The framework encourages adults to consider wellbeing outside of the medical model and would support a more holistic and compassionate understanding of CYP's SNA. The taxonomic model (Kearney and Silverman, 1999) could also be used by EP's, in collaboration with families and schools, to develop a holistic understanding of a CYP's SNA. However, alongside using the model to identify possible reasons for a CYP's SNA I would encourage practitioners to think about the different areas identified in this model in relation to periods where the CYP has experienced good attendance and mental wellbeing. For example, by attending to the social situations and aspects of the school environment which may have supported their attendance. This could help adults: to identify protective factors which have existed in CYP's lives; and to develop next steps which are supportive of CYP wellbeing.

The findings in this study suggest that EPs need to be very sensitive to the power they, and other professionals hold. It may be supportive for EPs to encourage other professionals to reflect on their power, and its possible implications, through supervision. This is particularly important as the findings in this research, suggest that the use of professional power can have negative implications for CYP and their families who are experiencing SNA.

Many of the parents in this study were not informed of services which could have been supportive, particularly when they were encountering legal and coercive power. This made

it particularly difficult for them to assert their needs and the needs of their children. It is important that all parents are aware of the Local Offer and services, such as SENDIASS. EPs should ensure they alert parents to these resources.

This study suggested a discrepancy in response to CYP who internalise rather than externalise their emotions. The impact of this can be seen when contrasting the response of agencies in Natalie's story to other stories in this study. EPs could encourage more sensitivity towards to CYP who internalise their emotions. Delivering training designed to build staff understanding of anxiety and SNA may be a helpful way for EPs to do this. EPs could also help schools to develop and implement systems which support staff to identify CYP experiencing SNA and to put appropriate strategies in place to support these students.

Finally, EPs can and should work to shape policy. I believe that the use of fines in systems designed to improve student attendance should be questioned. This research and the wider literature suggests that the threat of fines can have a negative impact on CYP and their families and that fines do little to improve attendance (Epstein et al., 2019 and Jones 2014). Further this research suggests that clearer policies on the education of students experiencing SNA could be beneficial. Within the stories presented in this study CYP were out of school for a significant amount of time before they were able to access any learning and in some cases work was withheld from them. This has implications for pupil feelings of connectedness to school and for their confidence returning to the classroom. Encouraging policies, similar to those for students experiencing school exclusion, could help to ensure that students are able to continue accessing some learning (Child Law Advice, 2017).

5.5. Recommendations for Schools:

Schools play a very important role in supporting students who experience SNA. It is likely that they will be the first professionals to recognise CYP attendance difficulties and to have conversations with families about these.

Within this study parents spoke about professional misunderstandings which occurred in the early stages of their child's SNA and Gemma wondered whether early

misunderstandings had meant time had been lost because Claire's needs had not been identified early. Identifying SNA early, and ensuring that interventions are put into place quickly, improve the likelihood that a CYP's attendance will improve (Lyons, 2016). Therefore, it is recommended that schools have clear systems and policies in place which support adults to recognise when students are beginning to experience SNA. The recent framework created by Ingul, Havik and Heyne (2019) offers some helpful guidance to support schools to develop these systems. Ingul, Havik and Heyne (2019) suggest that awareness of SNA, and the risk factors for this, should be raised amongst all staff members. Their framework also encourages schools to ensure that staff members are given clearly defined roles to support the identification of SNA. They propose that a key member of staff is named who teachers can go to to raise any concerns regarding SNA. The key staff member should meet regularly with adults in school who monitor attendance data so that they can combine their knowledge to help identify students at risk of SNA.

This study suggests that school staff should also listen to the perspectives of parents to help them to identify students experiencing SNA quickly. Parents in this study reported that their children often internalised their emotions in school. They highlighted that this could make it difficult for school staff to recognise when CYP were struggling. Attending to parental experiences is likely to help staff to identify, and understand the needs, of students experiencing SNA.

This study highlights the importance of sensitive early interactions with families when SNA occurs. Parents in this study shared experiences of feeling judged by professionals and in some cases this made it very difficult for collaborative working between professionals and parents. Therefore, it is particularly important that school staff are able to demonstrate an unconditional positive regard when working with parents (Rogers, 1967). Employing active listening skills is likely to be supportive of this.

Working with parents to develop a shared, holistic understanding, of a CYP's SNA could help avoid apportioning blame to any individuals. Using models, such as Kearney and Silverman's (1999) taxonomic model may support school staff to work with families to do this. Taking time to try to develop a holistic understanding of SNA is particularly important for school

staff; the stories in this study suggest that when professionals make recommendations prior to exploring the issues behind a CYP's attendance difficulties, they can have a negative impact on a CYP's wellbeing. Developing a shared understanding is likely to support the identification of strategies which could be supportive of CYP attendance and wellbeing. For some students these interventions may need to consider peer relationships and the impact of bullying.

Parents in this study often expressed a desire to protect their CYP's wellbeing. Some parents in this study suggested that staff should have access to training on anxiety, mental health and wellbeing so that they are better placed to support students experiencing SNA in school.

Within Sarah's story she talks about being 'batted' between different services with no one taking responsibility. Schools should have clear policies in place which are based on the graduated response (CoP, 2014) and help staff to identify when to involve external professionals (including the school nurse and EPS). This could make the system feel clearer for parents and prevent them from being passed between services. It should be recognised by school staff that CYP and their families may be experiencing wider challenges, for example, the experience of a bereavement of health difficulties. School staff also have a role in sign posting CYP and their families to services which may offer additional support (for example, bereavement charities).

Finally, parents in this study discussed the isolation that CYP can experience during SNA. It is important that school staff maintain regular contact with CYP, and their families, when a CYP is experiencing absences from school. Ensuring opportunities for positive connections with students (for example, using letters, phone calls and home visits) could help staff to build or maintain relationships with students experiencing SNA. These relationships could support CYP to return to school.

5.6. Limitations:

This is a small-scale study which seeks to capture and share the stories of the four participants involved. Therefore, it is important that some recognition is given to those voices which are not heard within this research. It is worth highlighting that all participants were mothers, and therefore, the voices of fathers are absent. Further, those interviewed all had a husband or partner who they lived with and they shared a perception that their experiences would have been more challenging without the support of their partner. I wonder whether this helped them to feel that participating in this research was manageable and how different parent experiences might be without the support of a partner. Data shows that mothers, and particularly single mothers, are overrepresented when it comes to prosecutions for CYP non-attendance (Jones, 2014). Therefore, it is possible that their experiences, and/ or the way that professionals respond to them could be quite different. I was introduced to potential participants by a colleague who had already built a trusting relationship with them and I believe this supported the recruitment process. It is likely that this research was hard to become involved in for many parents. I should have given more time to considering what I could do to make the research easier to access for individuals who might have wanted to take part.

I have had an active role in this research, therefore, my involvement will have impacted the findings. It is likely that I will have shaped the information gathered during the interviews (for example, by encouraging some stories and possibly silencing others) and the way in which the data was transcribed and analysed.

This was the first time I have conducted qualitative research employing interviews. I was aware of the power dynamic within interviews and although I tried to limit this by being clear with my aims and explaining that I really valued hearing what participants were comfortable telling me, I was aware that this approach was more successful with some participants than others. For example, some participants seemed very keen to help me and I wondered if this shaped their narratives.

The analysis process was subjective and other researchers might have identified different themes, they may also have taken different information from the quotes presented. Likewise, it is possible that those who read this research will understand and respond to the quotes and poems presented differently.

It was not the intention of this research that the findings would be generalisable. This research shares a small number of individual stories which are situated in their own social and cultural contexts. However, it is hoped that I have provided enough detail to enable readers to identify whether it is transferable or relevant to their own situations.

I was able to contact two parents who participated in this research to share their stories with them. However, I was unable to do this with the remaining two stories. This means that those participants have not had the chance to highlight any discrepancies and I have been unable to respond to these to ensure a more honest retelling of their stories.

5.7. Future Research:

I believe there is a need for future research to extend the selection criteria of this study, for example, by including the experiences of fathers and parents of children in primary schools.

All parents in the present study spoke about concerns regarding fines. For three of the parents warnings about fines from school staff, and some external professionals, were commonplace during their experiences. No parents in this study were prosecuted, however, Sarah was called to an attendance panel. The attendance panel was a particularly difficult experience in Sarah's story and I believe it would be worthwhile for research to explore the experiences and voices of parents who have been called to an attendance panel or have experienced prosecution related to their CYP's attendance. This is particularly important because prosecutions disproportionately affect single women from lower socio-economic groups and have been argued to be ineffective in improving attendance (Jones, 2014; Epstein, Brown and O'Flynn, 2019). Further, some researchers have suggested that these processes are damaging to relationships within families and between families and schools (Jones, 2014). Having a richer understanding of these family experiences of SNA may support professionals to consider how they can work with families at risk of prosecution more effectively.

I would encourage researchers to consider approaches which would make their research easier to reach for participants and which could support the empowerment of participants.

The participants in this study frequently spoke of being unheard or misunderstood and they often had clear ideas of how parents could be better supported. I wondered if participatory research might have enabled parents to regain some power and perhaps have supported them to create change by collaboratively disseminating their findings. A participatory approach could be valuable in future research.

Lastly, Laura expressed her frustration with the lack of clarity and direction, and it seemed that, for her, a label for the experience of SNA might have provided some clarity in an uncertain situation. Laura expressed her discomfort with the term 'school refusal' due to her perception that it situated the problem within her daughter and suggested that the SNA occurred due to choices her daughter made. Previous researchers have also highlighted the within-child focus that the term can encourage (Pellegrini, 2007). It may be helpful for future research to support CYP and their families to explore the discourses around SNA and to enable them to determine how their experiences are labelled (O'Toole and Devenney, 2020).

5.8. Final Reflections and Conclusions:

During this study I drew on Yardley's (2000), and Tracy's (2010), criteria for qualitative research to support my decision making and to enable me to reflect on my work. Similarly, to Tracy's (2010) 'worthy topic' and 'significant contribution' criteria, Yardley (2000) asks researchers to consider the 'impact and importance' of their work. Yardley (2000) and Tracy (2010) ask that researchers help to generate knowledge that is useful. This might be in terms of its practical use, its ability to generate hypotheses or its potential to change how we think about the world.

Although this is a small study which does not intend to be generalisable, I believe that aspects of the study are likely to be transferable to some cases of SNA and, therefore, to have practical applications for the work of EPs and school staff.

Further, this study invites readers to engage with the lived experiences of parents whose children are experiencing SNA. I believe that this is important because the dominance of quantitative studies in the SNA literature can mean that these voices are often unheard.

Sometimes individual stories can shift our understanding and inspire our engagement with a topic in ways that numbers often do not (Cook, Cook and Landrum, 2013). It is my hope that the stories shared in this research may create understanding and empathy amongst readers and encourage them to reflect upon the way professionals engage with parents of CYP experiencing SNA. I believe that the use of the PTMF (Johnstone and Boyle, 2018) was particularly helpful in raising the role of professional power and the impact (both positive and negative) this had on the experiences of parents who participated in this research.

Using the PTMF I was able to reflect on times in participant stories where professionals held: legal power (for example, the ability to impose fines as a result of the non-attendance); economic and material power (for example, the ability facilitate or deny access to LA services); and ideological power (this involves the control of meaning, language and 'agendas', for example the power to validate or undermine parent's understandings of the SNA).

Three of the parents in this study spoke about periods where their child's needs were misunderstood by professionals. For example, parents perceived that professionals initially believed the non-attendance was caused by parenting problems or CYP 'naughty' behaviour. In contrast parents reported their belief that school-based factors and CYP mental health and wellbeing needs were contributing to the SNA. In some stories parents valued the support of medical labels as they gave credence to aspects of their own understanding of their CYP's SNA (in particular, needs related to anxiety and autism) which seemed to be unrecognised by professionals previously. The involvement of professionals who could provide a diagnosis for these needs seemed to help shift adult understandings in school. However, I felt that there were occasions when more nuanced understandings of CYP SNA were lost to these labels (for example, aspects of the school environment).

This is mirrored within the research literature which places a heavy clinical emphasis on SNA. In some respects this study supports a clinical focus; several of the CYP who parents spoke about had diagnoses of anxiety and/ or autism and those who did not were on the waiting list to be seen by CAMHS. Interventions should be put in place which support CYP wellbeing and therapeutic approaches, explored within the clinical literature, are likely to be beneficial. However, there are many factors which can impact upon CYP wellbeing and SNA and these should also be taken into consideration within the literature. I would encourage

both researchers and professionals to listen carefully to families so that they can continue to develop their understanding of SNA.

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Appendices:

Appendix A: Kearney and Silverman's (1999) taxonomic model:

1. **The ability to avoid stimuli within the school which cause the CYP some worry.** Examples of stimuli avoided by CYP include; periods of unstructured time, certain lessons or subjects, physical areas of the school and transport into school. Kearney (2008) suggests that CYP represented by this factor can present with generalized anxiety disorder, somatic complaints and pleas for non-attendance.

2. **The ability to avoid social or evaluative situations which cause worry.** Examples of evaluative situations students may seek to avoid include: tests, presentations, eating in the canteen and athletic performances. Students seeking to avoid social situations can be isolated from, or have difficulty interacting with, their peers. Students represented by this factor can present with social or generalised anxiety disorder, shyness and/or withdrawn behaviour.

3. **The ability to gain attention from loved ones (predominantly parents and carers).** Rather than avoid the school environment due to worry, children represented by this factor are actively seeking time with their carers. Students in this factor are often younger and prefer to be with loved ones than at school. Kearney suggests that the behaviours likely to be seen amongst CYP in this group include running away from the school and non-compliance. In some circumstances this factor is associated with separation anxiety.

4. **The ability to access reinforcers that exist outside of the school environment.** This factor typically represents older CYP. It includes CYP who avoid school in order to engage in preferred activities outside of the school environment, for example spending time with friends or playing video games. Kearney identifies this factor as being similar to the descriptions of truancy provided in the literature.

(Kearney, 1999 and Kearney, 2008).

Appendix B: Qualitative research considering CYP voice in relation to SNA:

As Baker and Bishop (2015, P. 356) identify: "*despite recognition of the need to examine individual experiences, the voice of the child is barely represented in extended non-attendance research*". I will consider the limited qualitative research, capturing CYP voice, which has been completed to date.

Using discourse analysis Stroobant and Jones (2006) interviewed seven female university students who had had periods of SNA during their time in compulsory education. Their responses challenge some of the dominant discourses held within SNA research. For example, the research highlighted that, although many of the participants used psychological/ therapeutic discourses they did not all agree with them. In a discussion with the researcher one of the participants stated:

"*the deputy principal, said I had school phobia. . . . I remember Mum telling me that she had said I had school phobia. . . . I remember thinking that was really stupid for some reason. . . . I remember thinking . . . that makes it my issue rather than the school's issue.*"

Interviewer: Mm, like they were saying that there was something wrong with . . .

. . . with me, rather than the fact that there was something incredibly wrong with the school. I think I said that, I said like 'it's not that I'm scared of the school, it's that the school is incredibly evil'. So . . . it's not my issue, it's their issue." (Stroobrant and Jones, 2006, P. 218).

Rather than seeing themselves as individuals with phobias, many of the individuals interviewed referred to "outwitting" the education system. For example, a participant stated:

"*there was no compromise on my part, I couldn't actually compromise, because it was just like life or death and you can't really have a middle ground between those two . . . it was like [mum] actually did not comprehend what she was doing to me and seeing she was deluded (laughs), I really had to look after myself. I couldn't just, I couldn't just let her bully me into going.*" (Stroobant and Jones, 2006, P.219).

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Further some participants, through their University studies, had begun to challenge the discourses surrounding the importance of compulsory schooling. A participant who was undertaking a sociology major stated:

"*I think enforced schooling of children . . . totally serves the interests of the state to get people into the mindset of what they're going to have to be prepared to do for the rest of their life. Which is live a life of utter drudgery and depression . . .*" (Stroobant and Jones, 2006, P. 218).

Their findings are important as they offer challenge to the dominant discourses shaping the literature around SNA. The study poses some important questions surrounding practice; in particular it questions the assumption that school is a good and necessary part of individuals lives. The individuals involved in the study had had a significant amount of time to reflect on their schooling and, despite periods of SNA during their compulsory education, they had accessed further study at university. This may not be typical of all students experiencing SNA. Therefore, similar research with CYP currently experiencing SNA would be worthwhile to identify how they conceptualise their experiences.

Using interpretative phenomenological analysis, How (2014) analysed interview transcripts from semi-structured interviews with five students in their final year of a mainstream secondary school. The themes drawn from her analysis included: passivity and lack of control; values and priorities; personal competence and control; and the school system. Her research makes an important contribution to the literature, in particular the theme 'personal competence and control' highlights the value of listening to student voice. How (2014) describes the student's competence and their desire to actively influence what happens within their lives. It is important that professionals recognise this when working with CYP with SNA and include them in decision making.

Also employing interpretative phenomenological analysis Baker and Bishop (2015) conducted interviews with four secondary students who had SNA. The students interviewed had all been absent from school for over a year and were receiving support from the Local Authorities home education service, or were registered for selective home education. Amongst their findings was a sense from the students that they had been blamed or

punished; for example, one student reported "the school just thinks you're being, like, naughty". The study highlights a perception amongst students that there was a lack of support for their needs; some students referred to the school's focus on attendance statistics and noted lack of concern amongst staff which they put down to the pressure on schools to support high numbers of CYP. Students discussed the pressure to return to school and often reported finding the speed at which they were expected to return difficult. Students did not feel listened to when they asked for a more gradual approach to reintegration. Such research is particularly important given the historic use of 'flooding' techniques to improve CYP attendance.

Unlike Baker and Bishop (2015), Beckles (2014) sought to gain the views of CYP during the early stages of SNA. She used semi-structured interviews which were analysed using Thematic Analysis. Her findings suggest that factors which negatively influence a CYP's sense of belonging or academic self-confidence can deter them from attending school. Beckles (2014) argues the importance of employing a systemic perspective when supporting CYP with SNA, rather than a 'within-child' or 'within-family' focus which is often seen within the literature.

Appendix C: Qualitative research outside the UK

The following studies were conducted outside of the UK:

- Havik et al (2014) employed semi structured interview guide to speak to seventeen Norwegian parents about the contribution of the school environment to their CYP's SNA. The interview questions were informed by previous research into the school environment, however, they enabled parents to share additional information by posing the followin introductory question: "Could you please tell your story about your child in order to try to throw some light on some of the possible reasons for school refusal?" (Havik et al., 2014, P.136). They found that parents: often felt that the differentiation of their CYP's work was inappropriate; were concerned about bullying; felt their children needed predictability and calm learning environments;

believed that school staff needed more awareness of SNA and how to recognise the early signs of this.

- Dannow et al., (2020) conducted research in Danish schools. Both parents and students took part in their semi-structured interviews which were designed to explore issues related to low attendance (below 85%). Following thematic analysis of the interview transcripts several themes were identified. These included: the effort expended by parents seeking support for their children and contacting the school; student teacher relationships; and schools as organisations.

Appendix D: Reflections on research questions

Initially I intended to focus my research on the experiences of mothers. However, I later sought and was granted extended ethical approval to enable me to speak to both parents.

My initial reasoning for focusing on mothers was partly due to my experiences of sitting with mothers in this situation in the past. Further, there were factors which made me want to privilege mothers voices. These included:

- The general trend in the distribution of care roles in the UK: although there have been some slow changes, at the moment, women still take on the majority of care roles within the UK and are more likely to reduce work hours to care for their children.

- The prosecution of parents for non-attendance: women are disproportionately affected in terms of prosecutions related to school attendance. In 2017 74% of convictions related to non-attendance involved women. Further of the ten custodial sentences given to parents concerning school attendance nine of these were received by women.

However, as I reflected on this decision I wondered whether these assumptions regarding care roles could be further entrenched by excluding fathers from research involving the care of their children. I think it is important that fathers voices are heard and generally research

involving SNA has more female participants. Therefore, I extended my ethics to ensure that I was able to speak to both mothers' and fathers'. However, I was unable to reach fathers within this research.

Appendix E: Information Sheet

When child worry affects school attendance: Parents' experiences related to their child's reduced school attendance.

Invitation to Participate:

You are being invited to take part in a research project. Before you decide whether or not to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the project's purpose?

This study is being undertaken as part of the requirements of the Doctor of Educational and Child Psychology course at the University of Sheffield. The researcher is currently completing their training to become an Educational Psychologist. They have chosen to focus the research on parents' experiences related to their child's reduced attendance at school. The research is particularly interested in experiences of parents whose children are worried about attending school.

To date there has not been much research into the personal experiences of parents of children who find it difficult to attend school. It is hoped that by increasing our understanding of these experiences professionals will be better placed to help families in similar situations in the future.

Why have I been chosen?

You have been chosen because you have a child who is between twelve and sixteen years of age (in year 8 or above at Secondary school) and whose school attendance has been lower than 90% over the last two terms. The researcher seeks to interview three or four parents whose children are finding it difficult to attend school.

Do I have to take part?

It is up to you to decide whether or not to take part. It is important that you know there will not be any negative consequences if decide not to take part; the support you and your family receive from

professionals will not be affected. If you do decide to take part you will be given this information sheet to keep (and be asked to sign a consent form) and you can still withdraw at any time before March 2020.

What if I change my mind?

You can withdraw from the study any time before March 2020. If you withdraw before this date none of the data collected during the interview will be used in the study. You do not have to give a reason for withdrawing and there will be no negative consequences if you do withdraw.

If you wish to withdraw from the study please contact Hannah Munroe Burrows using the following email address:

hmunroeburrows1@sheffield.ac.uk

What will happen to me if I take part? What do I have to do?

| I will participate in an audio Recorded Interview (lasting between 0.5 and 1 hour) | → | The interviews are typed up and analysed by the researcher (I don't need to do anything) | → | The researcher will share their analysis of the interview / their retelling of my story with me. I will be asked to comment on this; I can tell them if I think they have got my story right. (this will take about an hour). |

You will be asked to participate in an interview. The interview will be audio recorded and is likely to last between 0.5 and 1 hour. This study intends to use a narrative interview technique; this means that you will be asked open ended questions that invite you to answer in a narrative form (to retell stories or experiences related to the topic). It is likely that these stories will help to identify some of the things that affect your child's attendance (what makes or has made it difficult for your child to attend school as well as what makes or has made it easier for your child to attend school). It is also likely that the stories will cover the support you and your family has received from different professionals. It is up to you how you answer the questions; the research is interested in your personal experiences so there are no right or wrong answers. This information will help our understanding of the reasons young people may have reduced attendance at school. Further, it could help professionals to think about how best to support families, in similar situations, in the future.

The interview will then be transcribed and analysed for the study. It is important that my retelling of your story (the way I present your story in written reports documenting the research) is as accurate as possible. Therefore, as part of the research you will be asked to spend some time reflecting on the researchers retelling of your story with the researcher. This is likely to take up to an hour. During this time, you will be able to tell the researcher if you think they have misunderstood anything and you can ask them to remove anything you are not comfortable with.

Interviews can take place in your home or in a private room in a local community centre. It is important that interviews take place in a quiet place where you can speak freely.

What are the possible disadvantages and risks of taking part?

To participate in the research you will have to give up some of your time. It is possible that you will also be asked to travel to a local community centre.

It can be very difficult for parents when their child is struggling to attend school. It is possible that you will experience a range of emotions when you are sharing your experiences during the interview. There is no obligation for participants to share any aspects of their experience they do not wish to talk about.

What are the possible benefits of taking part?

Whilst there are no immediate benefits for those people participating in the project, it is hoped that this work will enable professionals to better support families, in a similar situation, in the future.

Should I tell my child that I am taking part?

It is up to you if you tell your child about this study; some parents will want to tell their child and others will not. Once the interview has finished there will be time to discuss this in more detail; if you do want to talk to your child about the interview, the interviewer can spend some time thinking about how you would like to do this with you.

Will my taking part in this project be kept confidential?

All the personal information that we collect about you (for example, your name and contact details) during the course of the research will be kept strictly confidential and will only be accessible to members of the research team.

It is important that you are aware that the researcher will follow safeguarding procedures if this becomes appropriate. This means that if you disclose any information which suggests that you, or someone you know, is at risk of harm then researchers will contact the appropriate services.

What is the legal basis for processing my personal data?

According to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). Further information can be found in the University's Privacy Notice https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

What will happen to the data collected, and the results of the research project?

Researchers involved in this study will have access to any personal information (name and contact details) you give as part of the research they will also have access to the audio recordings of the interviews. These will be stored on a Google Drive secured by The University of Sheffield. Your interview will be transcribed (put into writing) by a researcher. During the transcription process the researcher will use pseudonyms to replace any of the names you have used during your interview, including your own name.

The research will be written up to form the researcher's thesis; theses are often made accessible to other researchers, students, professionals and members of the public via an online server (when completed the thesis will be accessible via: https://etheses.whiterose.ac.uk/). It is also possible that the research will be written up and published in other forums in the future (for example, a peer reviewed journal article). You will be able to access these write ups. Although you will not be identifiable within study write ups you are likely to recognise your story or quotes from your interview, however ant identifiable data (for example, names) will be removed or replaced (for example, by using a pseudonym).

All data containing your personal details will be destroyed in March 2020; as it will no longer be required for the purpose of the study. Pseudonymised data will be destroyed two years after the researcher has passed their thesis: data is likely to be destroyed in 2022. Pseudonymised data may be used by the researcher to answer different research questions at a later date.

Will I be recorded, and how will the recorded media be used?

The audio and/or video recordings of your activities made during this research will be used only for analysis. No one outside the project will be allowed access to the original recordings.

Who is the Data Controller?

The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly.

Who has ethically reviewed the project?

This project has been ethically approved via the University of Sheffield's Ethics Review Procedure, as administered by The School of Education.

What if something goes wrong and I wish to complain about the research?

In the first instance you should contact the project supervisor (Dr Antony Williams: Anthony.Williams@sheffield.ac.uk).

If you feel that your complaint has not been handled to your satisfaction, by the project supervisor, then you can contact the Head of Department, who will then escalate the complaint through the appropriate channels.

If the complaint relates to how your personal data has been handled, then you should raise a complaint following the University's Privacy Notice, which can be found at: https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

Contact for further information:

If you wish to discuss this study further you can contact:

1. Hannah Munroe Burrows (Lead Researcher): hmunroeburrows1@sheffield.ac.uk

2. Dr Antony Williams (Project Supervisor):
   Anthony.Williams@sheffield.ac.uk

Next Steps:

Should you wish to participate in this study please let the lead researcher know. If you agree to participate you will be given a copy of this information sheet and asked to sign a consent form which you can keep.

Thank you for your time!

Appendix F: Consent Form

When child worry affects school attendance: Parents' experiences of their child's reduced school attendance.

Please tick the appropriate boxes	Yes	No
Taking Part in the Project		
I have read and understood the project information sheet dated 22/04/19. (If you will answer No to this question please do not proceed with this consent form until you are fully aware of what your participation in the project will mean.)	☐	☐
I have been given the opportunity to ask questions about the project.	☐	☐
I agree to take part in the project. I understand that taking part in the project will include participating in an audio recorded interview that will last between 0.5 and 1 hours.	☐	☐
I agree to being audio recorded during the interview.	☐	☐
Following the interview I agree to meet with the researcher again to discuss how they have written up my interview in the research (I will be able to tell them if I disagree with anything that has been written). This will take up to an hour.	☐	☐
I understand that my taking part is voluntary and that I can withdraw from the study at any time before the 01/03/2020; I do not have to give any reasons for why I no longer want to take part and there will be no adverse consequences if I choose to withdraw.	☐	☐
How my information will be used during and after the project		
I understand my personal details such as name, phone number, address and email address etc. will not be revealed to people outside the project.	☐	☐
I understand and agree that my words may be quoted in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs; I will be given a pseudonym (a different name) in the research.	☐	☐

I understand and agree that other authorised researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.	☐	☐
I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.	☐	☐
So that the information you provide can be used legally by the researchers		
I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield.	☐	☐

Name of participant [printed]   Signature   Date

Name of Researcher [printed]   Signature   Date

Project contact details for further information:

Hannah Munroe Burrows (Lead Researcher): hmunroeburrows1@sheffield.ac.uk
Dr Antony Williams (Project Supervisor): Anthony.Williams@sheffield.ac.uk

Professor Elizabeth Ann Wood (Head of the School of Education: Sheffield University): e.a.wood@sheffield.ac.uk
Professor Elizabeth Ann Wood is not personally involved in this project. However, she can be contacted should you wish to raise a complaint about the study.

All of the above individuals can be contacted at the following address:
The School of Education
The University of Sheffield
241 Glossop Road
Sheffield
S10 2GW

Appendix G: Interview Prompts

Run through Info and consent forms: ask whether participants have any questions.

Reminders for Participants:

There are no rights and wrongs, it is your experience I'm interested in.

Share what you are comfortable with.

I'm not going to ask a list of questions, I would like to give you time to share your story.

I might ask some questions to follow up what you have said/ to make sure I've understood- I might take some notes to help me do this.

Interviews will be recorded- double check this is OK

Main Question:

Please could you think back to when you think [Child's name]'s difficulties with attendance began and share your story from there.

Prompts:

Try to attend to what is said and the chronology of this.

Try to use the phrases of participants

What were your thoughts about?

How did you feel about?

Why do you think that?

Can you tell me more about ….?

Yeah?

Can you tell me about:

- A time you have felt well supported by a professional
- A time you haven't felt supported by a professional

To End:

Thank you!

Is there anything else you would like me to know?

Experiences of the interview?

Discussion about talking to CYP- do you want to talk to your child about this? If yes- would you like to think about how you could do that with me?

Reminder re the opportunity to see and discuss analysis- interested?

Appendix H: Ethical Approval Certificate

The University Of Sheffield.

Downloaded: 31/08/2020
Approved: 09/05/2019

Hannah Munroe Burrows
Registration number: 170109965
School of Education
Programme: Doctorate of Educational and Child Psychology

Dear Hannah

PROJECT TITLE: Experiences of mothers whose children have reduced school attendance.
APPLICATION: Reference Number 025825

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 09/05/2019 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 025825 (form submission date: 23/04/2019); (expected project end date: 01/09/2020).
- Participant information sheet 1060354 version 1 (22/04/2019).
- Participant information sheet 1060353 version 1 (22/04/2019).
- Participant consent form 1060356 version 1 (22/04/2019).
- Participant consent form 1060355 version 1 (22/04/2019).

The following optional amendments were suggested:

reduce length of interview; specify appointment link

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Your responsibilities in delivering this research project are set out at the end of this letter.

Yours sincerely

David Hyatt
Ethics Administrator
School of Education

Please note the following responsibilities of the researcher in delivering the research project:

- The project must abide by the University's Research Ethics Policy:
  https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/approval-procedure
- The project must abide by the University's Good Research & Innovation Practices Policy:
  https://www.sheffield.ac.uk/polopoly_fs/1.671066!/file/GRIPPolicy.pdf
- The researcher must inform their supervisor (in the case of a student) or Ethics Administrator (in the case of a member of staff) of any significant changes to the project or the approved documentation.
- The researcher must comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.
- The researcher is responsible for effectively managing the data collected both during and after the end of the project in line with best practice, and any relevant legislative, regulatory or contractual requirements.

I think initially (.) going back things started to urm (3) Erin started to be a little unsettled towards the end of year six you know. She was preparing to transition [up mm]

to senior school. Um her brother went to university (1) at the start of year six and that really unsettled Erin, I hadn't realised how much that would unsettle her to be fair. I knew she would be upset, but I hadn't realised how upset.

Yeah

And then she seemed to settle down urm and then (.) she started presenting with emm like /[voice softer] colds, coughs (1) *reasons* for not going to school urm (.) towards the end of year six and there had been a couple of incidents at school errr when she'd felt silly because, for example one of the incidents the kids in class moved her chair away (.) and she sat on the floor. Then there were another time when (.) they hid her shoes, they had been doing P.E. and the kids hid her shoes and they laughed at her and (1) she's *always* (.) since then more so had this big fear about what other people think of her, [mm but] when she started not wanting to go to school towards end of year six and I went to head teacher at school (.) and special needs coordinator 'they said they were all ready for moving on. They were growing up ready for moving on and she'd settle'. So she moved up to the (.) first senior school that she went to at [Sec1] and she'd only been there a matter of a few weeks

(1.45)

They felt she was getting ready and that she would settle? How did you feel?

Yeah, emm (.) a (.) a part of me felt a bit reassured actually because I thought (.) they are professional teachers and they've probably seen this time and time again and (.) you know the fact that kids were playing pranks on each other [mmm I] I just thought they're getting giddy and they're getting ready, for growing you know into that senior school so they're going to stop, you know, being primary school children so they were probably playing the last few pranks and then I felt, I believed really what they said.

(2.23)

And then as I say she went up to [Sec1] school and within weeks of going (1) emm (.) started again not wanting to go (.) emm (.) so between September, October time and Christmas we'd had quite a few time when /[speech slows] she'd got headaches, she'd got tummy aches, she'd got all these *aches and pains*. *Pains* in her legs all this sort of stuff and couldn't get her out of bed on mornings (1) she just would put covers over her head she just wouldn't engage anything at all. /[speech returns to typical pace] So we took her to the doctors, urm, they didn't really (.) offer any help at all other then say go back to school, there's a school nurse and the school nurse will be able to help and I felt at that time as though we were just being battered about from one to other.

(3.19)

Mm

I was starting to get really worried about her mental health at that stage because she seemed really *down*, (.) she wouldn't emm (.) go outside out of school she'd not really have friends. You know other kids all went to different schools. She'd gone up to senior school with some of her friends but she wasn't seeing them out of school socially.

Right

(3.44)

we (.) had support at that time from the education welfare officer who were really, *really* good (.) and he used to come out to our house on a morning and try and engage with Erin and talk to her and she would just put covers over her head. I remember one day when em she ran into back garden and locked the door behind her

mm

 so she wouldn't have to

(4.12)

Face him /[voice quicker] or us emm (.) we even tried to climb over gate, cos gate were locked, so we tried to climb over gate to get to her.

Right

emmm we managed to get her in, she ran back into house and her dad were waiting in kitchen, um (.1) and she'd get *so upset* (.) emm and then [EWO1] arranged her to be (.) erm again there were a couple of incidents at school (.) where the teacher, one of the teachers emm (1) mistook her for another girl and he gave (.) well he rung me at home to ask why she hadn't turned up for detention (.) and I said well I didn't know that she had detention and he said yes she'd been put in detention for being *chatty* and laughing and loud which I thought, is not Erin really.

No

(5.01)

And when she came home from school that night she walked through the door (.) and she looked and I said to her 'have you been given detention' and she said 'no'. She was *mortified* if she'd thought of doing anything wrong she was mortified.

That was difficult for her

Yeah. So when she went back to school, so it had been a long bank holiday weekend so she'd worried about it all that weekend

(05:22)

And she went back and, I rang up and they looked into it (.) they said they'd *mistaken* her identity (.) so I said well I think can you apologise to her (.) so when they went into class to apologise to her they didn't know who she *was* (.) so again that was something else thing that caused her to feel, urm (.) *as though she were* like *insignificant really* (.) so she were having all these kinds of issues herself and then (.) other people were *reinforcing* how s*he were feeling*, urm (.) and then as I say [EWO1] arranged for

(05.57)

Her to spend time in their facility called the [Resource Base].

Ok

So when she felt the need to *escape* (.) she used their facility called the [Resource Base] and do her work and then when she felt as though she could engage in class then she went to class and he said she were using it just as it had intended to be used and then again (.) you know, there were another incident where (.) one of the other pupils tripped her up

(06.20)

In the corridor and she went flat *out* and *again* (.) laughing at her and feeling that, feeling embarrassed (.) and gradually and gradually over time (.) erm (1) she she she were showing no signs of getting any better and [EWO1] at [Sec1] felt that the school that she had gone to

were probably too big for her (.) and he said if, if Erin were his daughter (.) he would think about moving her to a school that were smaller, that were more nurturing, and (.) *on his advice* really and through his experience that's why we chose [Sec2] down at [Sec2 location] and so at the end of year 7 (.) they took her for the last month I think it were of year seven. She started off OK and then straight, not long after er (.)

(07.07)

started showing same, same signs, repeat behaviour that she (.) and she *she wanted to make a clean break of it* from [Sec1] and she wanted to go to [Sec2], [mm but] then shortly after arriving the school tried to sit her with a group of girls (.) to form friendships (.) but then she, very early on she found that hard (.) and then she started in year 8 (.) and for year 8, year 9 it's been a similar pattern that she's (.) she might have gone for a few weeks and then somethings (.) just I don't know what's got to her but she just hasn't been able to cope.

(07.52)

Emmm (1) she found it really hard to sit in a class and so they put things in place where they promised her they wouldn't ask her questions [right because] she didn't want to speak infront of other kids (.) emm and then she started to use their (1) bubble facility at [Sec2], it were a bit like the [Resource Base],

Ok

(08.18)

Emm and and eventually she were spending most of the school days in the bubble. She formed a really good bond with one of the teaching assistants down at [Sec2], [TA first name], [TA first and second name] and that's where [EP name] spent some time with her, (.) erm but what we found is that her attendance was getting lower and lower (.) and the education welfare officer at *that school* weren't as erm *supportive* in terms of like pastoral type care as [EWO1] at [Sec1] had been(.) and before long we found, we were getting letters from education welfare you know to /[speech slows] improve attendance and if we didn't (.) emm you know threats of court and all fines and all of that kind of thing (1) ur and then (2) at that time the year head (.) suggested that we started to conduct team around the family meetings [OK and we, we started to go down to school

(9.29)

and *met* (.) with school erm and I think [EP] came, EP came to a couple of those meetings and then *their* (.) safeguarding learning mentor were involved with these meetings as well and she really tried with our Erin she really did (.) emm (3) mm but it took *so long* to, to get things to get anything, any support in place urm and then as I said before long we got a letter to go to attendance panel. Urm I particularly remember one meeting that we'd been to before the attendance panel (.) and the people around the table (.) seemed to be suggesting to me and Erin's dad that we weren't doing enough to get Erin to school (1) and I had taken advice from our education welfare officers here in terms of what what they thought we could do because we had absolutely tried (1) erm you know withdrawing all her (.) treats, her gadgets, her phone and all you know she'd got nothing in her room no television, no

(10.35)

Err (.) computer game any em nothing we'd took it all, all away erm. But *even that* didn't make a difference to her, you know her mind set was so emm (1) it was though she was that frightened to be there it didn't matter what we'd done, but it didn't, it just didn't make a difference (.) erm (2) but she could be so convincing as well so for example there were one occasion she wanted this tortoise (.) and she (.) you know, she really really wanted it and we drew up a contract with her urm and she signed it 'yes she would go to school' and all [this mm] because the man *said* he (.) he were giving us first refusal otherwise he'd got

somebody else and she wanted it so much and [mm] cos her, her old one had *died* so (.) so we got this tortoise and within a *week* (.) she'd renade on the contract and, you know, you though we should of seen it coming but (.) we just thought we'd tried everything and

(11.42)

When I went to see one of the education welfare officers upstairs she said you might, you might *want* to try and she she didn't *tell me to do it*. She says you might want to try taking her to school in her pyjamas and putting her uniform in a bag. (2) /[voice change, lower pitch, slower] So we did, /[voice returns] against our better judgement we did and it *were worst day ever* of *our life* and probably hers. Me husband had had a heart attack only a couple of months earlier [oh and] he carried her downstairs kicking and screaming and (.) I can see her now, just sat in (.) living room *banging her head* against (.) ur wall (.) concrete wall (.) ['deep breath in' so] he picked her up and carried her out to car and I sat in back of the car and we put child locks on cos she just were wanting to jump out and she said she wanted to die. So we got to school and [E's Dad] went in to tell school we were ere and then *they*, a couple of education welfare officers and learning mentor came out and said well / [voice slower] now she's said that

(12.44)

Take her up to hospital and (.) you'll get the assessment /[voice returns to typical pace] because I'd been asking for a CAMHS assessment for *months* and months and as I say we were just being battered between the doctor, and the nurses and the school (.) and just going around in circles (1) so we took her to hospital (.) she saw (.) urm a doctor, a paediatrician,

Mm

(13.05)

Emm and again (.) at that time because [FF - local mental health support service- NHS based] had been involved (.) to try and support us as a family and, and one of their practitioners had tried to work with Erin while she were at urm [Sec2] (.) they said we couldn't work with CAMHS *and* [FF] even though we weren't getting nowhere fast with [FF right], it's, it's like the [MS- new name for FF] now,

Ok

Soo (1) before long we did get an assessment (.) with one of the psychiatric nurses from CAMHS and he did an assessment and he said that Erin, er, were showing signs of social anxiety, social phobia, selective mutism

Right

And then we (1) it were the day before that we actually went to the attendance panel and that were the most horrific (.) erm [experience mm]. *We managed* to get her there, well *I* managed to get her there because [E's Dad] had got a medical appointment

(14.04)

Got her there by (.) erm (.) you know it's like like carrot and stick (.) I said "we'll go in café, there's a lovely café, we'll have (.) you know a hot chocolate and a piece of cake and", and she came along and we came along and we sat there in one of the *formal* committee rooms in town hall (.) and there were the two senior education welfare officers, Erin's education welfare officer and the learning mentor from school and then me and Erin. So it were this massive grand room, you know [mm were] all really horrible, urm *formal*, and someone suffering from anxiety sat in that area

(14.40)

And she *sat there* (.) she was sat there and I was sat here (1) and it just went all over her head, her face was so blank (.) and it didn't matter what they said to her it just went over her head ermm and and they concluded by saying that, to *her*, that if she didn't go to school, that we could be fined, urm we could go to court, we could even go to prison and it would all be in the papers and I just found that / [speech slows] appalling urm (1) / [speech returns] and when I asked for a copy of the minutes from the meeting they said they didn't record it but they could send the scribbles that the education welfare officer had made and when I got the scribbles /[speech slows] they contained none of *that* (1) what they'd said to Erin and I wanted a record of that so I wrote back and asked them to put (.) it on her notes that that is was what I had heard them saying, /[pace of speech returns] but again as I say that it didn't make any difference to her because she were oblivious to it all (.) and then (.) urm (.)

15.50

And then well we had a further meeting at school after the day, the day after the panel we went to CAMHS and that's when Ben assessed her and then he were *really* angry (.) urm *as a professional* that we had even gone through all of this and he came to the meeting and he came to the meeting and he were able to put the evidence on the table (.) *because* what school were saying is that because there was no *reason* for Erin not to be attending school (.) then they had to treat her as a *non* school attender and we weren't getting her in school obviously we were *trying* but *failing*

Mmm

Urm and then from that point they seemed to back off a *bit* with all the threats of fines (.) and prison and all of this sort of stuff. And I think one of the things that I have found, (.) even though I found it hard (2) and it's been, I wouldn't say it's an advantage but because I've *known* different people in our department

yeah because of working

Yeah different contacts and networking what I've found really difficult is that the people who were sending the letters to me were *my own staff*, so the people in my own *team* who support

17.00

Education welfare (.) were writing letters to their head of service putting in this way and the other.

yeah, the people in your own team were writing the letters

Yeah but to be fair to the staff they've all been so professional about it that erm (1) *I know they know* and they know I know but, they've, you know it's been (.) it's been really discrete but it's (.) you still feel exposed (.) because it's personal. It's personal to me.

(17.30)

Mmm (.)

erm so then once (.) we got, erm we got Erin (.) well we were trundling along at [Sec2] and the staff were so lovely but I found that they hadn't had (.) the right training. I still feel as though they didn't understand (.) what were happening and I think things went on *far* longer at [Sec2] than they should have done.

Ok

With all the best intentions I think they were really trying to be nurturing and supporting her (.) and and Erin (.) you know, would go and sit in the bubble and, and get on with all the work they gave her

18.12

but what I found as well is that she were doing all this work and she were churning it out but she *weren't getting* no feedback. [right She] weren't finding out whether what she were doing were good enough (.) and that were (1) demoralising for her. But despite that she carried on doing it, urm she's very academic (.) err and all she wants is to learn (.) ermm so we went through all of that, so like I said for Year 7, year 8, year 9 (.) and then *I* started to notice things in Erin that I hadn't (.) *seen* before really (.) she started to get really urm (4) funny about certain things like she would only eat her dinner off a white plate (.) and if her plate had got a pattern on it there were no way that she would touch it

19.04

OK

And then things like err knives and forks had got to be a certain type, she stopped using any perfumed toiletries she just went onto simple (.) non perfumed things (.) she started ermm (1) just surrounding herself in these little fluffy blankets, you know really soft fluffy sensory things and started cutting labels out of her clothes she couldn't stand anything like that.

What were your thoughts about that at the time?

I started (.) I'd been (.) I'd, I'd got my suspicions that (.) she was showing signs of autistic traits and (1) the more I read into it and the more and more I were convinced (.) urm, she'd got little twinkly lights all around her room (.), you know, and if we came into town, *if we came into town* because she started then not wanting to go on buses (.) urm, but if she did come into town she wouldn't go in places like boots because she said she couldn't do it with the smell and she hated going anywhere that were busy (.) [ok urm] and when I mentioned it to different people they said it were probably her anxiety, its' anxiety and it's the things that she can control that she is controlling (1) ermm

20.29

mmmm

So I accepted that but there were a part of me that still weren't quite sure (.) urm and it were really hard and then (1) it was in year (2) it were last (.) it were year 10 and I was despairing, because her dad had been unwell, he's had heart surgery now so hopefully he's on the road to recovery, but (.) it were really hard and I were just desperate and despairing one day and my sister said to me (.) because she works at [GP surgery] (1) urm (.) do you want me to have a word with one of the doctors to get some advice *because I'd tried everything* I just didn't know what else to do (.) urm and she did, and and she said well bring her into one of my clinics

21.18

and I'll have a chat, so we got a cancelation the following week and we spent an hour with [GP] and straight away she said she's showing signs of autism (.) and I want her to have an assessment so she did she had speech therapy assessment and (.) mmm different urm appointments with different people (2) And (.) because she'd also had as well, art therapy at CAMHS with the hope for CBT after that to try and get her talking, but unfortunately, in error CAMHS discharged her after the art therapy and it took us another year or so to get her back. It were round about the same time we got an appointment with [GP].

How did you feel during that time?

Awful, absolutely awful and not just for Erin (.) all (1) all I wanted to see, /[tearful] I used to walk down to, and this gets me quite emotional

That's ok

I used to walk down to buses for work and see young kids as old as Erin just (.) trotting along catching school bus and I used to think I just wish she could be like that (.) mm for her really, *for her*. Because all (.) *all* she wants is to learn.

Yeah

22.36

And her (.) anxieties (1) and her worries and her, and her (.) fears and her inhibitions (1) just prevent her and just get in the way and /[typical speech] then (.) you know, as a *mother* you start then (.) to think (1) what have I, *why haven't I* made her as resilient as she needs to be and then you start all the blame and the guilt (.) and you know she's shes' (.) she's our youngest child um and there's quite a gap between her older sister and her older brother mmm so her older sisters [AGE (OVER 20)] (1) and her brothers [AGE (OVER 20)] (.) and Erin's 15 (.) so there were like a bit of a gap so then and then you start thinking have we spoilt her because she's youngest [ah giggle] so there's all that going off in your mind and then (.) I knew that *physically* (.) she were well (2) and but mentally because you couldn't see it. *You could in her behaviour*, but (2) I, I used to think if she'd got an broken leg (.) would would things have been any different if it were physical condition that she had rather than a mental health condition. mm Erm (1) and and I think (.) you know, I ended up and sometimes I don't sometimes know how I've got through, urm, seeing our occupational health councellor because trying to come to work and do a good job here and then that *with [E's Dads name] being ill* that got difficult, urm

You've been managing a lot

Yeah it has been really hard. Erm (.) and then when (1) she had the (.) assessment and [GP] said that she were on the autistic spectrum (1) that were it [laughter] I don't know what we expected, I honestly don't know what we expected. It answered *some* questions for us OK and it gave us a bit of an understanding as to why Erin (1) was showing some of the behaviours that she was showing (.) but to this day I am still waiting for the sygnet training (.) for (.) help and that (.) has been cancelled twice. (1) It starts on [DATE]

(25.09)

touch wood that that don't get cancelled because I don't know, I(.) I (.) you know, I've read stuff (.) erm (.) I've got work books, the workbook that EP had, I bought that to try and work through some of the things. I bought work books for Erin (.) so that she could understand (.) er what you, you know, to try and answer some of her feelings and thoughts about how she (1) might feel about, what it is all about, (.) being autistic

(25.37)

And (2) at the minute she just doesn't engage, she doesn't want to know ok and I just think (1) if that's how she (.) prefers to deal with it, I, I have got a feeling that she's not, (.) she's very bright and she's probably done her own research and she chooses not to share that with us mm erm (1) and you know it was funny because yesterday *Chris Packham* (.) were on telly and she knows Chris Packham yeah and [laugh laugh] and I, I made a comment /[voice change- mimicking her own speech] "oh look that's Chris" /[voice change- representing daughters voice tone] "*I know I know* all about Chris Packham" so I (.) *that* to me suggests that she has done a bit of her own research Ok but (.) you know she struggles with certain things like for example (1) to this day (3) You know from, I mean her period (.) she, she struggles to cope with her periods mm there were never a time that she's gone to school on her period (.) she's *always* took to her bed (.) right wouldn't come out of her bed, wouldn't come out of her bedroom (1) urm (2) I thought, you know, I mean all of this and then not knowing what else to do I applied for a special educational needs assessment (.) cos I were worried that she were falling so far behind and I couldn't get one, they wouldn't assess her (.) they said she were too bright (2) right

(27.09)

/ [voice speeds up. flat, factual] She didn't need one.

/ [voice returns] And then when we got the err *autism* (.) diagnosis then they did do one, (1) urm and suggested (.) lots of different things (.) urm and one of them *was* to erm go to the [NAME OF SPECIALIST PROVISION at LOCATION NAME].

Ok

Ermm (2) and Erin were quite up for it (.) and she went. She, she just cut ties with [Sec2] like she'd done with [Sec1] and she just *went (.)* up to [Sec1], ah no [SPECIALIST PROVISION]. She got in the minibus, she got up every morning and she were ready to go out at 20 past seven (1) emm (1) she seemed

(27.46)

So happy between like February March up until (2) beginning of June this year and then when the news came through that the unit were moving from [CURRENT LOCATION] up to [NEW LOCATION] near [SCHOOL NAME] she came, they'd been on a visit, they went on a visit one day and she came home from school. She went straight to her room (.) *and that were it.* She just (1) disengaged. (1) Err I think we managed to get her to school a couple more times after that and then there had been an incident, with a young lad. She had made a *friend* (.) erm a young lad. Sat next to each other, they were learning together and then all of a sudden I got a message from school that they had had to split em up.

(28.33)

Erm /[voice change soft/ disebelief/ questioning] and I said "*why*?", /[voice returns to typical] you know because it were the first friend that she had ever made and they said it were because they were worried that they were getting too close (.) and they didn't want one or both of them to end up getting hurt

Ok

So again in, you know, Erin's world, *she's embarrassed*, (1) because this has happened (1) urm (.). *And I didn't find out* until only a couple of weeks ago (1) er when I had a conversation with one of the teaching assistants up at school because when we went down to the meeting a few weeks ago (.) erm (.) at school to look what we could do to put things (.) in place [yeah to] try to get Erin back into to school. (2) They talked about the situation with this young lad and then two of the staff stepped

(29.21)

out of the room and I thought /[voice change, questioning] I don't get why (.) I don't *understand* /[voice back to typical] and then when I spoke to the teaching assistant she said 'did anyone ever explain to yer what had happened' and I said "*other than* they didn't want them to get hurt (1) she said "well we found them holding hands under table", (2) ok so because they had been holding hands they split them up. Erm and I don't know to this day whether it were attention that Erin (.) welcomed or didn't welcome mmm I'm not sure and nobody ever *asked her* mm (1) they just decided to split em up. (1) So (.) and I know that she were in touch with this young lad because they, they exchanged text messages and things (.) so school told me. Urr (.) I didn't know from Erin because she never told us (1) erm (.) and, and then she *decided* (1) cos it's a special school she won't go back. I (1) So it's really hard and I still feel that that is the best place for her to be (.) I really do. Urm she did her GCSEs (.) two of them, (1) mm in May and passed both Maths and English, with Bs

That's fantastic

(30.39)

But erm the school are not satisfied with that they want her to carry on doing her maths and English GCSEs to improve on the grade

wow

so *I would rather*

(30.51)

Her (2) be satisfied with what she's *achieved* and look to get different subjects so she's got enough GCSEs to get into college OK because what she wants to do at college. (1) Because what she wants to do at college, she wants to do art (.) urm (1) and they'll only let her do an *hour* (.) an hour a *week* because they say that she's good, she'll easily pass it urm (.) and one of the things I found really hard and Erin can't really understand it, is because she is so bright and, very academic, and just wants to (.) learn she hasn't got time and I think because she finds it uncomfortable for all the nurture stuff (.) so you know, like they have (.) urm they go in on a morning and they have a nurture breakfast OK

(31.35)

So so she has to socially interact with all the other children and she hates that (1) urm and then they have these down times, like reading times, settling in times, this time that time (.) and she keeps saying that's time I could be doing this and that's time I could be doing that mm *and in fairness to school* they have said, recently, that she can. She can go into school and when others are doing nurture she *can* have an hour of art, but I think what's happened is with Erin she's really unforgiving and (.) once something has (1) troubled her (.) she doesn't seem to be able to (.) urm (1) forgive. Barriers go up (1) and that's it. That experience has happened and there's no going back, she's she moves on

(32.32))

To something else. She's stuck. mm, she's moved on.

So and you know and I had a conversation with [lead teacher at specialist] today and said I really do wish that she could get back to [SPECIALIST PROVISION] because erm we're seeing careers officer tomorrow, we took her down to school yesterday (.) we keep (.) *trying* to get her in (.) urm to pick homework up and things like that, down at the new school but by the time we get to school she's (.) she's her anxiety levels are that high she's grey, she's white, (1) and she's she struggled to get out of the car, she's managed to get into the unit once. The rest of the time we've gone she's just laid in the back of the car.

How are you feeling when you're helping her to go to school

It's awful, her dad drives her there cos I don't drive but it's awful, it is absolutely awful (1) and, you know (2) I'm on edge thinking what's it going to be like by the time we get there and true to form by the time we get there, it's it's got the better of her. She had a panic attack

(33.37)

In CAMHS a couple of weeks ago (1) urm and I and in a funny kind of way I'm glad it happened because it it it showed she could get through it (.) and the test for me came the following week cos in true Erin style she went into reverse (.) but she didn't she went in to see [CAMHS worker name], she went for her appointment. And she said while we were waiting in the waiting room that she felt unwell (1) but we worked through it and she managed to take deep breaths and she managed to get in the session. Ahh So she did really well.

(34.24)

And as I say [CAMHS worker name] is giving her homework to do (.) because it's not just at school its things that, you know, in her own family. So we go to see my mum on Saturday and for *years* Erin's not, never spoke. She *did* when she were little but as she's grown older (.) urm she's never spoke and she just sits there and she's taking it *all* in. mm. You can see her listening, taking in all what's going off (.) and her Aunties will come down and em (1) if they ask her a question she'll look straight to me (1) for me to answer and I try my hardest not to without embarrassing her, too much. OK. Well not at all really, I don't want to embarrass [laugh laugh] no it's hard her but I'm trying to encourage her all the time and (.) you know [CAMHS worker] gives her homework now from CAMHS (.) so like for example, we went down to my mums a couple of weeks ago (.) and she'd got to speak so to help her to do that we took trivial pursuit cards OK so she could read off the cards *and she did it* yeah and then last weekend that, that were just with me mum, me dad and Erin (.) and then last weekend the aunties were in as well so that were an houseful. But she did it, she read off the cards urm (.) and then this week she said that she wants to speak to her aunties and so this and so *tomorrow*, one of my sisters has got an allotment so we are planning to go on to allotment and plant bulbs mm to (.) try and get her to engage and speak and be comfortable speaking. But *it's hard*. It's *so hard* (.) and you take three steps and forward and five back and (.) [Name of colleague] one of the girls who I work with (1) she rang me yesterday because I were working from home yesterday and I felt dreadful.

(36.06)

Erm (.) and she said 'you're worrying aren't you again about Erin" and *I am* and she says "I can tell" because *I'd had a meeting* with my manager (.) a couple of weeks ago and he said to me (.) he says "you're worn out and (.) you're drained and you're worn out" (1) and I said to [colleague], I dread to think what I must look like for him to comment like that (.) and she said "it's not what, it's not anything, she says it's your demeanor she says, you can tell, (.) its wearing you down again" and she said "when Erin was going to school earlier this year, she were happily going into school, it made such a difference." (.) We were all so uplifted and happy and er finally thinking as though she'd come out of it nnn, (.) you know she were

(36.53)

going to make progress and everything were going to be fine again (.) and in *Erin's world*, (1) Erin has got this thing in her mind (.) that as soon as she leaves school (2) all of this will be sorted. She has a thing on her whiteboard in her bedroom so many days left at school and (.) she's marking them off.

She's marking them off, counting down

Yeah, and I hope for her sake (1) *it is* and I haven't got the heart to burst that bubble for her at the minute because it's something that's it's important to her, (1) but I do worry what will happen (1) when she does leave school (.) and how she'll cope at college, how she'll cope in world of work. I I just, I do worry about her. I mean she's quite, (1) she's quite self sufficient in terms of (.) she can cook for herself, she can look after herself, that's great you know she's really good at those kind of things (.)

Erm

(37.51)

She manages her money so her pocket money goes into her bank and she buys things online, but its all *isolating* (.) the things that she does is isolating so she's erm (.) you know, learning (.) in her room, reading books, reading (.) BBC bitesize. So she's doing all that, she's making progress. (1) But it's isolating erm.

A lot of that time is spent alone?

Yeah, but but she loves that , she she *she hates* being with other people. She prefers to be with adults than other children. (1) Urm, but given a choice (.) she'd rather (1) be on her own, or in her room, or urm with her sister. She's got a really good strong relationship with her sister

(38.41)

Urm and that that's sometimes (1) again as a mother I feel *awkward* because [E's Sister] is a social worker so I (.) have relied on [E's Sister] advice a lot of the time, urm (2) to the point a few weeks ago [E's Sister] came to one of the meetings and she said Erin were really offhand with [E's Sister]

mm

And erm [E's Sister] said to me, em she says "I going to have to back *away* (.) from being as involved because (.) [E's Sister] wants Erin to feel as though she's got somebody

(39.23)

That she can go to and trust

Mmm

That's her sister, not her mother you know or her father but, you know, (.) a big sister erm (.) mm and I think lines were getting a bit blurred and, you know, she said you know "I'm not a parent, I'm not a social worker, I'm her sister" mm so that were a bit *fraught (2)* and then I suppose other thing (.) because [E's Dad's name] been so unwell (1) I've tried to (.) urm (.) shield him (1) as much as I can, obviously he is involved and he has been involved(.) but a lot of this I've dealt with (1) away from our home and trying no to (1) worry him too much because /[speed of speech increases] he's had enough on his plate with his own health. /[pace returns to typical] It is really really hard and it has been hard. *But then,* you know I've got a friend whos son died oh (.) a couple of years ago (.) and I just think (1) I've got another friend who's lost a granddaughter and other granddaughters, erm, got cancer (.) and I just think in the grand scheme of things (.) it's (.) you, you know, put it into perspective and *it could be a lot*

(40.43)

Worst than what it is. At end of the day she's physically well (2) its. She's happy in her own world you know, so

Yeah

And I I think I stopped trying (2), not trying, I stopped getting as anxious and upset mm, ok infront of her as as what we both did in early days because we was frustrated (1) and we lost us temper (.) Urm (2) you know it were *really hard* and then I just thought, /[expression change, quoting self thought] '*it is what it is*' (1)/[speech back] urm (.) and hopefully, /[speech speeds up] I mean I even remember going to see our GP and

(41.26)

He said to me /[voice returns to usual pace] 'my own son didn't go to school for *four years* (.) mm and he is now just qualified at university'

Yeah

And I just thought (.) 'well if (.) if if it worked for *his son*, and *he's a doctor*' [laughter laughter}

That sounds like it was reassuring

/ [speech quicker and higher in pitch- in agreement] Yeah yeah /[speech back to typical] and then I think the other thing as well is that /[speech slows] the more I spoke to people, different people the more I realised that there were other people, *a lot of* other people in the same boat.

mmm

(41.57)

Urm

How did you find these people? Were they already people in your life that you opened up to or..?

Yeah /[speech returns to typical] I mean people I worked with yeah people you already knew? yeah and I think one of the other things that I found really hard while working here (.) was listening to things like business planning (.) you know in different services, when services are doing their business planning and (.) they talk about /[speech slower, heavier] ohhh all the good things that they do and it's wonderful this and it's wonderful that and my blood used to boil (.) because *it's not that wonderful* and

(42.34)

/[voice back] I remember sitting in one of the business planning sessions (.) and (1) giving my experiences as *a parent* not as an *employee* and that went down like /[speech tone change- awkward] a tonne of bricks to be honest /[voice returns to typical] but, and I had to be *so careful* sometimes because I think sometimes, I think I bordered on being a bit unprofessional. But it were really hard ah, it's hard when those two things become so merged Yeah, yeah (.) but, but, you know, I think sometimes the services have got this (.) *impression* (2) that they are so much better than what they *are* (.) and I, I don't know. Sometimes (1) where the feedback comes from (.) I mean as a child. As a mother of a child with a Special Educational Need

(43.22)

I have *never* (.) had any of the questionnaires that I read about that parents are sent. Urm (.) you know, to inform OFSTED inspections mm and all this and *I've not had anything*, I've not had anything like that. I think *individually* the people I have dealt with have been OK and the latest (.) urm (.) there's, there's been a lot of staff gone through our special educational needs service urm, in the last twelve months, that I've been involved with.

Right

So I, *I think* that I'm onto the *third person* now that I'm dealing with and (1) she's come with a lot of (.) different ideas and is *fresh* and different and, and I think the other thing I've also had support of has been (.) SENDIASS they've been absolutely *amazing.*

Can you tell me about that?

Yeah, I mean [SENDIASS Name F] and [SENDIASS Name M] (.) have (.) urm (.) you know when I've been at a point of just *accepting* (.) the *EHCP*

(44.29)

because I didn't really (1) *understand* all the ins and outs of it (.) urm and [SENDIASS Names F and M] advice were 'well really we need this (.) so we really ought to be pushing for that (.) mm for Erin's benefit'. Urr and planning for her *future* (.) ur and you know her next steps and things like that, and that wants building in and (.) erm. So that's been really useful. And they've been with me at the meetings

(44.56)

183

And they've been a voice you know sometimes when you just can't, you don't know what to say or do (.) and because you're so emotionally involved it's hard to be objective and they've been that voice (.) ur so they've been really

(45.09)

Really good. (1) Because, you know, a few weeks ago I was on verge of /[slows speech] pulling Erin out of school, (.) off school role and you know me and [E's Dad] spoke about whether (.) to, you know, not to go through all this stress and that again in last year of school

Right

To just concentrate on her studying (.) and *we'd pay* to have access to online learning, urm but SENDIASS' view was she would be better stopping on school role in the hope that (.) with support they can get her back in(.)to school for those final months but it it, you know, we've come that [gesture- small space between fingers- close to] *far* (.) from doing it that mm But I *I don't think that would be best for Erin*, she's best going back to school if we can get her back to school.

(45.59)

Yeah

She's really bright, and I've not brought my own phone (.) but, you know, her drawings and her paintings she does (.) are *wonderful*, are absolutely wonderful. (.) And she learnt, she *started learning* music when she first went to [Specialist Provision] and urm (.) she used to go down to Mainstream [School Name] on a Thursday and they used to do, urm, different lessons and things, like P.E. and things which *she'd never done before* and then when it were (.) she had her Christmas money and her birthday money and she decided to buy herself a digital piano

Ahh

(46.41)

So she did and we installed, well *she installed it* because she's really good at stuff like that and I expected her to just start plonking [taps table like a piano] [laughter laughter] but she started playing Beethoven [laughs] with all fingers as though she had been playing it for years, wow she did and it were lovely.

(47.01)

She's really good at putting things like furniture together, ahh so you know like flat pack furniture like you get from Ikea. She she had a desk (.) a er six foot tall bookcase and a bedside cabinet mmm and she put all of that together, just so meticulous and so methodical, she's got some [brilliant skills and it's] not an effort for her, so I (.) I keep saying I'm going to hire her out [laughter laughter] /[laughs as finishes sentence] for IKEA furniture. She'd love it.

Ah

But I suppose, you know, I mean looking back, urm, I'd say it's not just school that she finds hard it's social things erm (.). There has been lots of support, in terms of professionals involved (.)

(47.56)

Like so we've had CAMHS, we've got the local authority, we've had [FF] which is now [MS], (.) erm (1) she had a tutor at the library, we've had SENDIASS *involved* (.) and it and it and again when we were at [Sec2] we had all the team around the family meetings. It seems as though there is lots of *talking* and lots of (.) *planning* and *noise* and, but (.) trying to get

solutions in place is *so* time consuming. When Erin first stopped attending [Specialist Provision] in June, I got in touch (.) *straight away* with both the school and special educational needs and said (.) 'I don't want September to come and there's been

(48.42)

Missing weeks and weeks, I want something putting in place for straight away and we we're already nearly at half term (.) and we've had two or three meetings, but because Erin (.) still doesn't feel as though she (.) is able to get into school at the minute (2) it's (1) we're not getting very far and I and I you know I I spent about one hundred and twenty pounds couple a few weeks ago, a couple of weeks ago, buying her all the school guides, the higher level revision guides for [right the] subjects she wants to, you know, err the History, English, maths, science (.) all so that she can be learning because that's all she wants to do (.) erm and then when we went down to school yesterday, bearing in mind what this is *fifth week* mmm they gave me a higher level maths guide (.) and I said "well it's OK because we've bought it"

So that was the sort of thing that you were asking for those three meetings ago?

Yeah, yeah, yeah and, you you know, it's (1) I can see the dilemma, they're not wanting to give her homework as such too much

(49.53)

Homework so that she gets comfortable being at home (2) but by the same token she's still finding her homework to do in the guides so I'd rather *they* gave her the work so that she is keeping up (.) with the others in school and urr I asked [Sec2] whether she could have access to online learning, whether she was could put a link into classroom, so that she could sit in bubble and have a link into the teacher were teaching the class so she could hear mmm and it's as though (.) because it's not been done before (2)

(50.33)

At that school, they they wouldn't do it. Urm and I've found that it's not person centred, it's (.) it's all about one size has got to fit all and (.) I think kids are all different (.) erm. Erin feels really (.) erm a bit insulted really that when we went down to school (.) and we sat with a teacher (.) and went through a timetable. The way they presented the timetable to her were diagrammatically so there were like for cooking there were a picture of somebody baking (.) buns OK and then there were things that I'd not heard of, you know like there were a symbol. It were a bit like Makaton (.) urm there were a symbol for news and newsround and I said "what is that?" and she said "it's where they put CBBC on everyday for 15minutes and we have to watch newsround" I said "and how do you feel about that?" and she said "well I'd rather be doing this or I'd rather be doing that" mm so I think,

(51.53)

She finds it really hard (.) because when I have raised it what school is saying is she's got to compromise. Urm (.) she can't expect to be doing the same type of classes that she were doing in mainstream school (1) by being at [Specialist Provision] (1) and all Erin has said to us recently is that she would love to be back at mainstream school to be able to access the subjects (.) mm, that's the right learning for. Yeah, but err the anxiety prevents her from doing it, so she's in a bit of a (.) you can see she's in a bit of a dilemma with herself (.) and it's really hard /[voice softer/ quieter] to watch her (.) you know, and she's a bit up and down (.) and her body clocks a bit all over the place at the minute erm, /[voice back to typical] but erm in saying that she takes melatonin now and she has done for about, probably ten months because, before that she were calling me every night, sometimes between 2, 3 and 4 times a night, sometimes sending me a text message (.) ohh urm 'mam' and all these messages used to go 'mam mam mam mam' [laughs]

You've not had much sleep either

No, no, but since she's been on melatonin it's helped me a lot [laugh laugh] because *I have.* I do sleep better although sometimes I do lie awake waiting for the text coming but it's been very few and far between now it really is, so that's helped her (.) *it really has*. But so and in terms of urm, I think I think one of the things about the *special school* thing is that when, when she were up at [Specialist Provision Site] they wear a *different uniform* to the kids in the mainstream school ok

(53.22)

And at first I don't think, (1) I don't think she realised, (1) right (1) *I don't think she did*. I know she's bright, but I know, I don't think she realised and then it were only when she moved to, (.) well the school said they were moving to [Location Name] that's when this thing started cropping up about a special school. OK So I think, and, and again they've got (.) it is a nice are what they've got, but again they go in on the mini bus or in taxis (1) and they'll *look different* to the other kids [mm because] their uniform is different.

So perhaps that location makes them more (.)

Yeah yeah, visually yeah it sets them apart from the others and (.) one of the other things that they had said that they would try and do for not just Erin but some of the other kids is to see if they, if the school, the mainstream school, would allow them to access the history lessons (1)

[OK Which] is all well and good, but again (.) there'd be two or three of them going in to a mainstream history lesson looking particularly different mmm to the others in the class and (.) kids can be cruel can't they so it's urm, (.) but that's not happened because she's not been in school (1) urm (1) and then I think in, you know, in terms of, I were just having a think what what could improve, what would improve and I think (.) *for me* early on (.) I would have liked to think somebody would have seen that there were something that were

(54.57)

a miss (.) and not just think about attendance targets and punish us with fines (.) if if there were as much *effort* to er supporting us and in realising that something weren't right, just because we didn't have a bit of *paper* that said, she'd got social anxiety or whatever, (.) or even autism, you know just because that bit of paper *weren't there* she were clearly showing signs of struggling (.) and all school wanted to do were fine us and punish us and that really *really* frustrates me yeah

(55.35)

Urm as I say we felt that we were failing (.) and we felt that others felt that we were failing as well (.) erm you know and you think (.) as a parent, you know as a parent we've got three kids. Two of them have gone through (.) school and university and have both got good jobs, (1) that neither [E's Sister] or [E's Brother] are the most *outgoing* mm because their personality is that (.) they're not really extravert I'd say they're more on the introvert side but they've *got through* where as Erin (1) has found it (.) *harder* , a lot harder than what they did, erm (.) again I think they (2) you know, you're getting passed around from GP to school, to school nurses (.) and nobody seems to want to grasp the nettle and (.) *progress things* and help you. They just want to pass it to somebody else and I guess that comes down to resourcing, (.) everybody's got limited *resources* (.) and then I think again another thing again with CAMHS, the practitioners we've *seen* have all been absolutely lovely and helpful and you know Erin has engaged well with

(56.57)

All of them, (1) but the time it took to get into CAMHS (.) and then the year delay that we had where they discharged her in error mm you know, that, that really took some sorting out, I mean they did apologise, (1) but

It sounds like you've been doing a lot of chasing

Yeah yeah and that's it you're constantly constantly pushing. It takes over your life, it really does take over your life. And I think at school (.) the staff again were all well meaning and urm (1) you know I know that they've all got Erin's best interests at heart, (2) but I think that they lacked a lot of understanding. Urm, so like for example, one of the teaching assistants who *were lovely* (.) and *really* keen for Erin to get back into class, promised her that, they'd set this thing where she went into class for (.) five minutes and then ten minutes and again this were all based on advice from EP, but what happened

(57.59)

Is that they'd gone into the history lesson, they were doing about the Vietnam war (.) and (1) they'd been in five, five minutes and because all the lights were down and they were watching this video (.) the teaching, urm, assistant decided that /[voice slows] because (.) Erin looked (.) comfortable (.) she didn't leave her in for five minutes, she left her in for forty five minutes. *She sat with her* /[voice returns to typical] mm but by the time Erin came out she were (1) a *wreck* and when she came home from school that night, straight to bed (.) and that were it she were just drained (.). Urm, and I know that they were well meaning and they were as keen as what anybody were to try and get her to (.) try and get her back in. But they weren't

(58.46)

Following advice that EP had given them. They, they were trying to hurry her along (.) quicker than what she were prepared to go at and I think (1) you know, and I know they hadn't had the proper training (.) because I heard them, you know, in conversations with them that they were having the training (.) at the same, you know, time that Erin were going through all of this. Urm

What were your thoughts around all of that at the time?

Erm (3) It it (1) again (.) *it's concerning* (2) but not surprising (.) Urm because I realise schools have got such a tough job and I think (.) the number of kids that are presenting at schools with problems, I don't think there's enough (2), I I I think schools are too governed by targets and by performance and so if they've got somebody that's displaying some behaviours that's not the norm (1) you know, and and I know and, you know, working here and hearing about kids that are getting expelled (.) just to get them off school *role* (.) just because they don't want them to drag the school *down* (.) urm, but yeah, they're getting forgotten and they're getting lost. It's so

Hmm I suppose your job lets you see some of the wider system

Yeah, yeah it's, you know, and again I think I know you know of late there's lots of talk about putting mental health (.) support and training people in schools to help kids with

(1.00.26)

Mental health issues, (.). Urm, again and I do feel so frustrated that Erin is expected to compromise (.) her *academic* (.) education because she's got a mental health (.) issue. If she'd got a physical (1) urm, a broken leg, or (.) you know, and she were out of school because of a physical thing I'm sure the homework would keep coming and I'm sure I think (.) I feel sure the support would be a lot different then (.). I don't think people understand mental health (1) as much as physical health cos you can't see it mmm (.) as as easy. Urm again I think you know it's not person centred and one size doesn't fit all, (.) it's hard to

navigate your way around the different things and I found that hard even working here mmm and *the time* that it takes for things to be sorted (.) you know, we're in year 11 so this happened, came to light anyway in Year 7 and what they said to us is that (.) when I read all of Erin's reports from being at primary and even as far back as nursery (.) and I read them all and you know when you read them *a year apart* mmm it doesn't really (.) resonate, but then when you read them all together. I sat with them one night and I read everyone one after the other after another and that common theme came through about how shy she was how reserved she was, how the target for next year was to improve her confidence and then I look back and I think well what were anyone really doing to help her do that mmm *they were just words on a piece of paper* but there were nothing *actively* (.) that I could see that were being done at primary to help her (1) and what what one of the assessments said (.)

(1.02.16)

is that she had done a lot of work to *mask* (.) how (1) she'd (.) found things, how hard she'd found things, but that it were easier for her to *copy* and *mimic other* children's behaviours (.) because at that age they are all more or less learning the same and coming along the same, but once they (.) started to go their own ways at senior school (.) and develop their own (1) *teenage* personalities (.) it was harder for her to (.) *mimic* anybody because everything was so different and that's when all of the problems really started to come to light (.) so urm I do understand that, and I can see mmm way back, you know, what they mean.

But (2) but, you know it is what it is (.) and I think because we've become more *accepting* and relaxed and less stress stressed and I wouldn't say stressed because it does stress me, but less *fraught* about it (.) then we are just getting on with it and (.) doing as best we can to help Erin to achieve really (.) erm *and* not just academically, but socially and *even though* I know that some things that we do really take their toll on her (.) we still (2) when I say force her to do it, we encourage her to do it. So for example, [E's Sister] did great north run

(1.03.55)

Right

Er, she done it two years on trot and each time, both times we've gone and (.) the first time we went Erin spent the next two days in bed (.) because it were *so busy* erm (.) and it just drained her (.) and then last, then *this time* when we went, she knew what to expect. She didn't really want to come, but she went because it were [E's Sister], mmm she wanted to support her (.) erm (.) she weren't as bad this time, (.) but it did drain her. Urm (1) but we *do try* to urm (.) *encourage her* to do these things because she's got to (.) overcome em erm (.) and you know like even sitting in CAMHS waiting room, last week, and she were starting to get all panicky (.) and starting to recognise that, and /[voice quickens] I mean I even carry a brown paper bag in my handbag for her to breathe into [laughs], /[voice returns to typical] we've not needed to use it yet, but it's there *just in case*. But I just don't know, (1) as I say we we've read things, we've watched programmes, we've read *all literature* that, that we've been able to, I've been on (.) Ur, I went to a thing that Occupational Therapists were running a few months in the summer holidays to *try* and understand (.) ur

(1.05.20)

A bit better and to do things a *better* for Erin. (1) Waiting for the cygnet training, hopefully, that will help us understand even better (.) erm (1) *but at end of day* I wouldn't, you know you, I couldn't change who she is, because she is who she is. Urm she's got a lovely sense of humour, although sometimes (1) her sense of humour is different to mine [laughs laughs] she's so not touchy feely, (.) she, she. I can't remember the last time I *hugged her*. She'll not let me hug her, she'll not let me kiss her. The only person who she's comfortable with is [E's Sister] or dog. Yeah She'll sit and kiss dog and loves the dog to pieces aww. But *if I*, and I do it sometimes on purpose, if I just touch her it's as though I've like (.) *burnt her*. She just *pulls away* because she just doesn't want any (.) physical (.) contact. It's urm, she doesn't show

her emotions, she rarely cries. Urm (.) she just turns it all inwards, she like, she closes down. I, I sometimes wish that she would scream and shout (.) but she doesn't, she's she's and, you know, and I think that sometimes if she were (.) not well *behaved*, if she did *kick off* a bit more, she might get noticed a bit more, mmm erm (.) but she doesn't and, you know, she always turns out for school, she's always immaculate, (.) her hairs always neatly platted and I don't know how she does it, because I can't do it, but she had all these *rituals* at one time and (.) you know, I used to have to do her hair on a morning (.) and she (2) she wouldn't let me go to work unless I'd done her hair (.) and then I'd go to work and she'd take it out and do it again, [laughs laughs] but I had to still do it even though it would make me late I had to do it as part of this ritual we had as part of the morning. And, you know, getting her up on a morning if I went in at a certain time and she'd say (1) but I get up a 7.43, so if I'd go in at 7.40 she'd say, but it's not 7.43 yet, so you know (1) it was really *really* weird stuff, (1) but as I said she is who she is and we love her to pieces (.) urm and *she'll get there one way or another, I'm sure,* but we'll just see.

mm, you keep going

(1.08.02)

Yeah, Yeah That's all you can do, because (1) if you don't, I think if you just stop, what, *she needs us*, *she needs us to help her*, urm (.) *we want to help her*, we want to help get her there, erm (2) and I think she, she's quite powerful (.) *as well* in some ways, she is quite powerful. And there have been times when I've thought is she having me on here [laughs, laughs].

Can you tell me about that? What does powerful look like?

You know, you know in just I don't know *it's like (.) her mindset* it's so (.) she has really (2) determined, OK you know, if she's made her mind up (.) there's no way (1) I can convince her or her dad can convince her, well probably he can convince her a bit more than I can, because *she is her dads daughter*, (.) very much because *he's been at home with her* all the time, you know, he finished work when I had Erin, because other two had been to see childminders, but when I had Erin (.) erm (.) it were going to be really costly to have three of them with the childminder, and you know, he would, he'd been through a tough time at work, so he said "look I'll stop at home and we'll reverse roles and you'll go back after maternity leave, I'll stop at home" *and he has* and it's it's been fine and it's worked really well. Urm (.) I think sometimes though she's got (.) a bit of an attachment

(1.09.29)

To him, *too much*, and so when he's been *poorly*. (.) I think that's affected her. It made it harder? Yeah, yeah (.) I remember the day that he had his operation, when he had his new heart valve in April and she came home from school, *she'd been to school,* but she came home from school that day and again went *straight to her room* (.) she didn't want didn't want (.) anything to do with anybody

Mmm

And she wouldn't see him in hospital (.) she wouldn't until she knew he were alright, (.) even though we went to hospital she wouldn't go into ward to see him (.) ur and it were only, I think it were only a couple of days before he came home (.) that she finally, she did she did go to see him and went in to see him (.) when she could see that he were alright and we showed her a photograph of him (1.10.21)

Erm (.) and he /[ighter tone of voice] was *smiling* and eating his dinner and it was as though she had accepted that he were going to be OK. /[voice back] But again I think that were her way of (.) she it's avoidance isn't it she avoids situations and she's (.) when I say she's powerful she's powerful in her *avoidance*, it's as though she (1) puts this thing up and (1) *no*

way will she even try sometimes (1) and I don't know if it's because she's being stubborn or if it's just because she doesn't know how to (.) It's really hard.

(1.10.58)

And when you know at one of the meetings a couple of weeks ago, when one of the staff said about her being, they said "we've offered this, we've offered this, we've offered her that and she's just school refusing" (1) and I sat and I thought (.) and *luckily* [CAMHS worker Name] from CAMHS spoke up and said "it's *not* just a straightforward case of school refusal, (.) it's linked to (.) anxiety and mental health issues, it's not as though she's just doing it for sake of (.) it"

How did you feel when that was said?

Erm, (.) *annoyed*, really annoyed and when once the special educational needs staff, erm (.) because she were new to the case a couple of weeks ago and she asked me to give her background and she said at end of meeting "you're being very (.) diplomatic, and very calm and patient" she said "in your situation I'm not sure that I could be the same"

(1.12.01)

But (.) I I think it doesn't achieve, it doesn't achieve out does it, by shouting and stamping erm, (.) well it doesn't achieve much by not shouting and stamping to be honest, but (1) I just think you just have to keep, keep going on, erm, and at some point I just think it'll not go on for ever (.) and at some point (.) something'll (.) click (.) /[whisper] I hope [laughs] /[voice back] I live in hope.

Mmm, it sounds like it's been a *long* journey

I'm tired, I'll be honest, *I am tired*, and I found this last erm (.) I think from when Erin went to school and the *euphoria* that we felt mmm when she were attending school everyday up at [School Site] and she were happy to be going *there* (.) and she were up on a morning, bed on a night, *really* knuckling down and the euphoria that I *felt* (.) and I think what I found harder this time is that it's all gone down again and it's been a *big* bump this time. I'd say this time I've been, (.) it's been a rollercoaster over last four or five years but this latest *blip* (.) has been hardest.

Yeah, and that was partly due to a change in location?

Yeah yeah yeah it has. Because we saw what she were like, and seeing what she were like, and so happy and laughing and, you know, *enjoying life* and even *going out*, you know, on weekends and that and enjoying that. Urm and then all of a sudden she's like reverted back and that's been a *big*, a big, urm (.) and I think knowing that I'm coming up to the last five, six months at work (.) that, that's hard as well, trying to keep that momentum going. (.) Urm so I just feel so worn and out and tired.

Mmm, sometimes it is harder when you're close to the end isn't it yeah yeah [it's like it's being stretched along it can feel like you're crawling] to get there, yeah, and it's getting further away instead of nearer [laugh laugh] you just want to collapse over the finish line.

(1.14.17)

Yeah, I even thought this week I might buy an extra weeks special *leave* just so that I can have extra (.) week off, but (.) then I think *get a grip* you've not got long to go. [laugh]. So it is, (.) but it has been hard, but again you know individually people have been *really* lovely, *really* well meaning, really supportive (.) but I think (.) institutionally and organisationally OK I just think it's erm, (1) it's hard. It's really hard mmm And erm (.) it needs joining up better together and the pathways need to be *clearer* (.) and who does what needs to be *clearer*, (.) it's erm (.) it's difficult.

(1.15.16)

But as I say, I know we are just the tip of the ice burg and I know there are a lot of people a lot worst off than what we are really. You know, she's *not* (.) self harming she's not, (1) you know, she eats *well (.)* and I think it could be a lot worst (.) and I'm just thankful that it's not erm (1) and I think, (.) she'll, she'll get there (.) in some shape or form [laughs] We live in hope, like I say. (2)

She's got lots of wonderful skills hasn't she

She has, she has, I just wish she'd learn to wash up [laughs laughs) that would help wouldn't it!

When she cooks, and bakes and stuff (.) she thinks she's Mary Berry

1.17.09

Asks questions about what I do next with transcript- will I transcribe it? Yes

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1.17.52

From some of the things that you were saying as you went along, I had a few questions. Please don't feel that you need to say more, but I did wonder (1) It must have been a very difficult event (1) what were your mixed thoughts/ emotions when you've got Erin in a car and you're being asked to take her into school?

That, that is something that will stay *with us forever* and her dad, I think *her dad* more so than me, em. (1) To listen to your child (.) being hysterical, ur (.) and *physically* harming, wanting to bang, well physically banging her head on concrete wall and hearing it crack (.) erm (.) and the strength that she had as well you know trying to get her into the car. And you know I said she didn't, she doesn't show emotions, but she did that day, she were absolutely (.) *distraught* erm (1) and I was so angry when I got to school (.) urm and it was as though because she had pressed that button and said "I want to die". (.) It, it were as though, (1) it was as though it were a line that she'd crossed and now she had crossed that line it would open a lot of doors (.) and I thought /[frustration/ anger] 'well to do that to a *child*' you know, I mean what would she have, she'd have been about 13. /[voice returns] (2) And I am so (2) Urm (1) angry I suppose that it were even suggested in the first place (.) mmm that people couldn't see that she was clearly struggling (.) and their perception was that we weren't doing enough to get her to school and I think (.) and *knowing that* we (1) took the collective decision "well if they don't think that we're doing enough, *we'll show em* what we've tried to do' and it were that and I will regret that for the rest of my life doing that to her.

That must have been really difficult for you both, that decision is very understandable in that situation though.

Yeah, (.) but I think the sad thing is, (.) *again* working and and liaising with parent partnership and, and I've relayed that to them (.) *sadly* they've said that that's not the first time that they'd heard of it.

Mm that (.) that has happened for other families?

Yeah, *yeah* and that other people have said that that's been suggested and said to them em. (1) I think you've got on one hand, you've got (.) It's *really weird* because you've got one part of the department (1) that's like (.) the police arm

Ok

And then we've got (.) SEND who are doing their *best* (.) to help, and then we've got educational psychologists who are helping probably the same kids that Education welfare

are trying to prosecute (.) and then you've got (.) SENDIASS who are trying to help the *parents* of (.) children who *colleagues* are trying to (.) prosecute the parents. It just, (.) it doesn't seem right to me. It's not joined up.

Mmm, it's disjointed

Yeah, yeah you'd think, we should all be working the same, towards the same goal (1) ur (.) and it doesn't feel like it.

So they felt very distinct? So education welfare (.) that felt quite (.) well like a police arm? That's how it felt?

Yeah, the police arm, and *I thought* the clue was in the title Education *Welfare*, but it (.) it's clearly not. I mean I *remember* the day we went to the attendance panel and the Education Welfare officer had to come and see us before we went because we had been in hospital the day before and we hadn't signed the forms and gone through it with her. (.) And I remember now (.) to this day, as I read the forms. She posted them through the letterbox that night and she came to collect them the morning before the panel. And all the way through the forms she had called Erin [Other Child's Name]. (.) So she got the name *wrong* all the way through and I just thought /[whisper, exasperated] God.

Yeah, that was difficult.

/[voice back to typical] It were obvious it were a template and it'd been typed over, so (1) [Other Child's Name] had been going through exactly the same as what Erin was going through.

Yeah, it's that bit about personalisation.

Yeah, yeah, it's (.) but then again, *being fair*, I realise that everybody is so under pressure. I can see, I can see (.) people here, (.) how busy everybody is (.) and I know from listening to [E's Sister] and observing [E's Sister] how busy she is as a social worker mm, of course and she'll say "mother it's a simple *mistake* (.) I've probably done the same" (.) so (.)

Yeah you can understand what it's like. You're working in it as well, so (.) I imagine you sometimes see it through a different angle. But it doesn't always make it easier for you, as a mum to Erin.

(1.22.33)

No, no it doesn't (.) it really doesn't. It's been *hard* and (.) as I say, that urm (1) I've felt sometimes as though I've got to be on my best behaviour, because of working here. Like and I felt as though if I were (.) being too troublesome mmm Even though I wanted to get the best for Erin, but I I think sometimes (.) I've been a bit mindful about how I've behaved and (.) because I (.) I don't want to be coming across as *awkward* or (.) you know belligerent or whatever. But at the same time, I think if I hadn't have worked here it, I might have been a bit different (.) mmm you know, but then as I say, on the other hand because I have worked here, I've probably had more of an *insight* into (.) how to get certain types of help and where to go for certain things than if I hadn't have worked here yeah and I, and I just feel (.) for all the people who are out there who haven't got a clue. It must be so hard.

About all the different teams?

Yeah, it must be really hard, really hard.

Mmm, you've met a lot people in a lot of roles.

(1.24.19)

Earlier you were talking about these things that started to happen that you hadn't noticed before, like the cutlery and needing a white plate? Were they completely new? Or were they, was it more of an awareness?

Yeah (.) it all started to happen over a period of, a short period of time, things that she hadn't *done before*. You know and I think, because the other thing I remember, we used to have a caravan (.) when Erin were younger and we took caravan all over and then we stopped taking it on continent. We took it up to North Yorkshire and Erin out of all the three of our kids at that time and I think she were what, 8, 9 something like that

Mm

She seemed to be the one who were more outgoing than the other two and played outside the caravan park, with kids on the scooter. You know on the scooters and (.) urm (.) and then all of a sudden, like I say she started to get *older* (.) that's when it started to (.) like emerge and all these little (.) weirdy type things started (1) like I say, and *even now,* even now, she's so particular about certain things, she really (.) she'd rather not eat her dinner (1) than have it on, if you put it on wrong plate, and sometimes I put it on wrong plate to see what she does (.) but she'll not eat it and I have to put it on a different plate.

It just get left

And for ages and ages, when she was having her periods (1) she weren't wearing towels, you know she were just throwing her knickers away. She just weren't accepting it, urmm (1). And I think it were [EP name] that said it were probably *sensory* (.) it's like a sensory issue and a feeling of being *dirty* and (.) I mean she's always in shower and she'll go in for an hour at a time. And, and I have sussed out, I've sussed out when she's having her period because she'll go in the shower all the time.

1.27.38

You know, she'll not use the toilets at school, she just wouldn't have a drink at school so she'll not have to use the toilets.

1.28.21

I wonder if there has been a time where you've felt really supported by a professional and whether you could tell me about that, what was that like?

Yeah, yeah I think [EP name] was really supportive and Erin really engaged well with H, (.) she really did, and [CAMHS Worker Name] at CAMHS, well the, the art therapist that Erin had at CAMHS [Art Therapists name] (.) *really* engaged (.) and Erin engaged well with her as well. But I I, what I found with A (.) although Erin engaged well with her I didn't get feedback, from A. **OK** H used to contact me and let me know, what they'd been doing and she'd ex-explain things to me that I could probably do with Erin (.) and I think with S as well at CAMHS (.) urm, I think, how many times has she been? I bet she's been (.) I bet she's seen [CAMHS workers Name] now about fifteen times easily (.) urm (.) and they've got that *relationship* and Erin speaks to her now. **mmm** Urm (.) all the times that she's in her sessions she's painting, she's done loads of paintings for her, but it, it means that she can *paint*, but she can talk. **yeah**. She doesn't have long conversations, but at least [CAMHS Workers Name] is getting something out of her and the fact that she engages with the homework that (.) [CAMHS workers Name] gives her to do. **mmm** Yeah you know, and we, we have a session together for 10 minutes altogether and then 5 minutes all at the end and then rest of the time is theirs.

Yeah, yeah, it's a balance isn't it because (.) I think Erin feels more comfortable talking on a one to one basis with [CAMHS Workers Name] and me not there and I think (.) she should be entitled to that (.) privacy mmm and er *it's working,* it is working and she's got a really good relationship with her, so yeah CAMHS have been really good. H has been really good. Urm I, I think [FF] to be fair when me and [E's Dad] were seeing urm (.) [E's Dad] he were really *really* lovely and supportive and it were nice to go and talk to him.

1.30.00

Yeah (.) what was it about him that made it feel supportive and nice to go and see him?

He listened and um (1) quite a lot that, I'm not saying that he offered solutions, he didn't. He, he used to ask us how we felt, (.) how did that make us feel and we reflected on how we felt and it helped us get our feelings out. Erm, (2) but we had, I think we had about ten sessions with him and then after a certain *number* (.) it stops. Right. So although our problems have carried on, we had the sessions, I think we had ten or twelve sessions with him (.) and he were lovely and he really helped and he was supportive and it were nice to go and talk to him and not be *judged.* I think that were important as well, not being judged.

You've felt judged?

We have felt judged, yeah, a lot of the time we've felt judged, yeah. (.) Urm, so you know, (1) it's felt to me many times as though, and this might just be me, but its felt as though people thinking 'you've got a child and you can't parent that child properly.' And that's what it feels like (.) you know, and no *I can't* parent properly because I don't understand. You know we parent, parent her in terms of (1) loving her, looking after her, bringing her up, mmm, all that. But I don't I just don't, I don't understand enough about (.) who she is as a (.) like the autism and how she works. It's really hard to understand that. (.) Urm (.) I wish I did understand a bit more.

That's why you wanted the cygnet.

Yeah, yeah and it's taken a year, it's taken a year for that to come through (.) Urm (.) *but,* better late than never.

(1.33.07)

Mmm, I suspect. Urm (.) that will give you some information. But, you know, you know her better than anyone else can.

Yeah, yeah, we know her and we love her. Yesterday were my birthday.

Happy birthday!

Thank you, so she got candles except she stuck them the wrong way around. On purpose.

Ohh so you aged a few years (laughs)

Yeah, yeah so she's got a very wicked and dry sense of humour and (.) she can be hurtful aswell. She can be hurtful with some of the things she says and she doesn't know (.) or, she doesn't appear to realise some of the things that she says (2) and I think we've learnt over time not to take things to heart because that's just who she is. Mmm But she makes up for it by being funny, in a quirky way. So I wouldn't change her, I wouldn't change her at all.

Can you talk about a situation where you haven't felt supported as a parent.

I think the first GP, because we changed GPs, but the first appointment with a GP. I found that really frustrating. The fact that they didn't want (.) appear not to be bothered.

(1.34.39)

And wanted the school nurse to refer Erin to CAMHS and then school nurse said, well doctor can do it and I were just going from one to other to other. That, that were really hard. And I think (.) the education welfare, urm, experience were really (.) not supportive *at all*. Urm (.) I just think, you know, that (.) the Education Welfare officer at [Sec1] *was* supportive. He tried absolutely everything. But the education welfare officer at [Sec2] (.) was not supportive. (1) It it were more (.) urm (.) she said that Erin were being (.) what did she call her, like insolent, she would and because Erin wouldn't speak (.) so, so when she were coming to see Erin at home, before going to school on a morning. I remember Erin were sat in hallway one day, just sat infront of dogs cage and the officer were trying to talk to her and get her to converse, but she couldn't, but because she (.) she found it hard and then she just said she were being insolent.

How did that make you feel?

Awful, I just wanted to punch her to be honest [laughs laughs] mm it sounds like you wanted to protect Erin mm and it got to the point where I didn't want her in the house. Urm (.) I think I even said (.) at one of the meetings that I didn't want her to come into our house. URm (.) and it's funny because the woman who runs [Local Mental Health Charity] (.) cos cos we tried getting Erin through [Local Mental Health Charity] mmm to (.) urm try and get her some support there ok. And ur (.) she used to be an education welfare officer *here* and knew particular officers that supported, well didn't support, used to come to our house (.) and she said "she's either with you or not with you and in your case it sounds very much as though she's not with you" and she weren't. She she, as I say it were as though we'd pressed that button by forcing Erin into school and because she'd said that thing she did (.) that were it. (.) And, and I think that that were because she didn't know any (.) any different, any better. Did she not know what to do, had she run out of ideas as well, you know, (1) and as I say the whole of the Education Welfare system, *wasn't* welfare at all (.) It were punishment.

1:37:33

I suppose when I'm listening I'm hearing that you're sort of in the middle of (.) you've got these people who are telling you to do things yeah and when they're not supportive, it feels judgemental, but you kind of feel like *got to* to toe the line yeah yeah and at the same time in doing that (.) you know you're going to upset Erin yeah yeah it feels like you're trapped a little bit.

Yeah, yeah, all the time (2) Yeah. I mean at the end of the day Erin is the one who matters, she's in the centre of it and we are trying to protect her (.) and and safeguard her, but then some of the things that were being said to us we felt that they were in criticism of *us* and our parenting or Erin, which we were doing us absolute best because we just didn't understand what was going off, but then to be fair (.) professionals didn't understand either. Because it took while she were (.) nearly 15 to get a diagnosis and that were only because (3) me sister worked at [GP Surgery] and spoke to one of the doctors who invited us in (1) and I just thank god for that, because I think if she hadn't we'd have still be going round in circles.

Does that feel like it was down to chance, um (.) a bit of luck?

Yeah, oh yeah. That's that (.) you know I just feel that it (.) I felt *bad* as well. There were a part of me felt *grateful* and glad that we'd *finally* turned a corner. But then I felt bad that we'd jumped the queue if you know what I mean, so we'd (.) urm (.) not gone through the proper channels. Because I *Knew* that one of my friends was still going through this with her son (.) and she couldn't even get the appointment. But (.) but we did /[whisper] rightly or wrongly. But with everything else (.) if we got one little in road then it makes up for everything else

195

and times when things didn't go well. But even though, and I understand, as I say that as a department we have put a lot of money into (.) diagnosis of (.) autism. But there's not the same amount put into, (.) once you've got the diagnosis, the support. It's as though you're then just like left. You know, and in some ways it answers some of your questions and explains things but then in other ways, you think, 'so what (.) what happens now'. It's really (.) it's a funny one, it's a funny one.

Mmm, I wish there was more money in that bit.

Yeah, I mean I know there's only so much money isn't there, but it's hard.

1.41.29

If there's anything that can be done to make it joined up better, to make it *less judgemental*, to make it *less* erm (.) blamey. You know, I think it's that really. *People, us*, parents, children, families are not doing this because we *enjoy it*. We (.) It's a situation that we find ourselves in. I've, I've never dreamed I'd be in this situation (.) ur. Having brought two children up without any (.) *issues really*, apart from that they were a bit shy, but they'd got through the schooling and gone to university erm, (3) but, I, I'd never have dreamed that this would have happened (2) and as I say its not end of world, she's (.) she's physically well and happy in her own way, and that's the main thing. She's thriving, she's academically doing well. Urm (.) I just worry that she's not going to achieve her potential because of the situation that we are in (.) mmm but then I think learning is *lifelong*. Yeah If she comes to the end of her school years and she's not achieved everything that she could have achieved (.) she's got the rest of her life to do it. Mmm, she's got time.

1.43.17

You know [Name from the SEN team] said to me in SEND, she said to me, "try not to think of though it's a disadvantage for her because, in this day in age", and she's right, id not thought of it like this, "people *remote* work, they work from home, you know they have offices in their own homes. I know [Colleagues Name] does who I work with now, her husband, runs his own urm (.) events business from his own house. Yeah

You know, she wants to design sets for films and things like that (.) and I think, well she could do that, she could do it anywhere it doesn't have to be always it's lovely she's got an idea I just hope it works for her, I really do.

I don't have any other questions. Do you [have no, no,] it's been nice to share really.

Are there any questions you have for me?

Is this typical? Is it typical that other families find this that hard. You know, I have friends and I know they find things hard, and I'm guessing that this is typical on a lot of people. In terms of In terms of the difficulties that people have navigating their way through this like quagmire of services and (.) it's just so hard.

Yeah, I mean I think (.) everyone's experience is unique, but these experiences can be really difficult for families. I don't think services have ever been perfect (.) I think (.) there are always things we can learn.

I just (.) I don't understand why, you know, educational psychology and education welfare and, (.) they, they're just not together more. I mean they're all in different business units and. When you look at social care, they've go the frontline, you know, the initial assessment bit, umm and then there's the child protection, but they *they're all together* they're all all in the same office. I just think that they're just more joined up.

Check in re talking to Erin- Erin knew mum was having this conversation and mum was happy to talk to her about it. They were going for dinner together after

Appendix J: Natalie's transcript

(00:34)

Pretty much it started (.) it's all been from his Xbox OK and he used to have friends coming round quite a lot well two friends mainly and they all used to play where they split the screens so they've all got their own controllers to play the same game but they've got their own little screen on the TV screen, I don't know because I'm not into games, And they all used to start fighting. But with Zeke (.) It was like 'it's my house you do what I say', But then I'd say but you're all playing the same game you've all got your characters in this game (.) And it's supposed to be a you work as a team in this game right, OK you're not supposed to be fighting against you know like you sitting there with your controller

he wanted them to do what he wanted

Zeke wants to be the boss but when you're in a game like that you're supposed to work as a team and I think he thought well yeah 'I'm going to tell you what to do' anyway as time going on on it didn't happen all the time but they were coming round and boys being boys that doing little shuffles in the living room pushing and I said that's enough erm (.) anyway [Friend 1[and [Friend 2] stopped coming round quite so much (.) and but Zeke Started getting obsessed with the games and the Xbox *became his life.*

(1:52)

There was no outside world apart from the Xbox (.) nothing else is real apart from food

Right ok

And if needed the toilet. It was like a horse blinkers but totally the whole way round (.) you know and he was we were trying to stop him playing at night-time when we go to bed taking it off him you know putting a timer on parental controls everything we did *all that* that we needed to do and but when we kept turning everything off he was losing his temper

(2:23) ok

But he was going around the house wrecking the house punching doors walls he physically attacked me (.) *a lot* I had the police around here more times than they were at the station but because of his age they couldn't do anything about it. But they've got all my details anyway I've got all the relevant in place with them. I had to send photos of injuries everything like that. (1) He Stopped physically attacking me but he's now verbally attacking me He's using a heck of a lot of bad words really bad words Now we don't swear are as a rule but I think he's picking up it up off games and things.

(3:04) Right still playing

 yeh Now when he got he started getting really bad was when that fortnight game came out

(3:09) right

It's like it took him over it's like as if it'd come through the screen and dragged into actually into to the you know like into another world and he was staying awake he were awake for about 18 hours at a time (.) and then he would go to sleep for 18 hours at a time. There was days I mean at the moment now he hasn't been asleep since 10 o'clock yesterday morning (3:34) right How does he stay awake so long? mmm

So because every time he is awake (.) and my partner he has to get up really early like he had to get up for work like 4 this morning but he gets up early anyway but Zeke thinks that night time is day time you can make as much noise as you want (1) he doesn't see that there's a daytime and a night-time. Day times when you can make noise and stuff but night time is quiet time night time is bedtime nighttime is sleep time

(4:05) yeh but it's like you've got this well it goes dark it gets light it goes dark it gets light What's the difference. He's got no concept of time you know that kind of scenario

(4:14) mm did he always find sleep difficult even when he was

1. Put it this way to say irregular is an understatement there's no sleep pattern whatsoever so of course I mean (4:25) and he's creeping up and down stairs on a morning Between 2 and 3 and 4 o'clock and he wants to be on that all the time but he also wants the sound up

(4:34) ok Which isn't acceptable at that time of the morning so of course and I'm awake anyway and I say like Zeke can you please turn the sound down. No. So I have to Tiptoe around him all the time (.) because I feel like anything when he says 'no' that's it if I push him further that's when he explodes and he can go just like that (1) and so this is it quiet time for me at the moment because while he's on there even though I don't want him to be on there he should be in school (.) this is my only you know to stop my house getting wrecked and me getting hit or whatever

2. (5:13) yeh

1. I have to let him do it I have to I've got no choice (1) so because like just before you came what's I said, if there's a knock at the door it will either be a parcel or be Hannah And even when he knocked on the door he doesn't move straight away (.) you know he doesn't make the effort Because I was in there And I thought Zeke He went: "yeah I heard it".

(5:35) ok This is it all the time and he's just so blunt he doesn't think about what he's saying and if he says something to hurt anybody he doesn't feel no guilt or remorse about what he said. He's just blank he's just (5:51) It's not feeling like you're getting much emotion?

No none at all. (1) When he chooses to use it you can get a laugh out of him, or a bit of excitement out of him, or you know and that's fine for me that I like it when he laughs mmm it just doesn't happen often enough. (1) I'm feeling that whatever mood he's in (.) I've got to try and get into the one the next stage up a happier mood so I'm trying to keep one step ahead of him all the time but I know what mood he's in already so it's always at one level so even though I'm trying every single day I'm still doing the same thing but I always have that glimmer of hope that maybe just maybe something might just give yeah But it never does. But I still cling onto that that there is some things got to work somewhere and at the moment we've tried everything p*ossible* (.) you know what else can we do?

(6:54) feeling quite stuck Yeah. So [Name] the lady that comes around and who else (.) yeah [Name] sorry. Because I want to get him back into school they are going to they've said that they'll let him go into a class with computers in it

(7:12) ok and let him do cause that's what he likes doing computers and gaming and stuff and let him do that and gradually kind of take him away from that and get him into normal lessons and things because academically he's good

(7:25) he's bright

he's above average, he's really bright ok But because I think he thinks he's like going that fast foot forward that fast that he's meeting himself coming back and he gets bored so easily once he's learnt something (.) Oh I've done that I want to move on to next thing

(7:43) ok That's how quickly he's moving in his head I think well that's how I see it anyway so. yeah So pretty much everything the whole reason for his behaviour, his attitude urm (.) is to do with the gaming

(8:00) ok If I took that away now (2) it'd be world war three so (.) yeh so /{shurgs}

(8:08) and that has an impact on the relationships by the sounds of it

yeh it is I mean [Partner's Name] and me we've had a couple of arguments not Major major but you know (.) he keeps saying well can't you do this can't you do that well [Partner's Name] I've tried. I've tried everything and [Partner's Name] been here when you know he's lost his temper and things. We've even taken the router out of the house (.) try and stop him playing games at stupid hours and he's just gone off on one like I say he don't care what time of day or night it is. It doesn't affect him (1) time is not of the essence to him you know

(8:43) No So that's the reason It's just the gaming If he hadn't have got so obsessed with it (.) or if he'd kept it like at a decent level and done like, you know gone, to school, come home (.) then he could go on it and if he would go to bed at a decent time, you know, just pretty much them two most important things then he gets his rewards (.) you know work first play later (.) but he wants to play play play play

(9:16) And that's hard for him to get out [of He] is beyond obsessed. There was something on TV a couple of weeks ago about the NHS were going to start to treat children that have got obsession with gaming

(9:32) ok Because it's an addiction now it's classed and as an addiction (.) in kids so I don't know whether to you know branch out to that area to see if I can get any help from NHS maybe and but you see the other thing is he won't leave the house

(9:52) Ok He will not go out that front door. so he's not leaving at all at the moment No soon as when that door opened it's like oh heck Another world it's the real world out there I don't want to go (.) You know what I mean

(10:02) Ok so it's a bit (.) that real world is too much at the moment Because he's been assessed for autism as well has he? The, [Name] from CAMHS the youth offenders team (.) Urm she thinks it's sensory side of it (.) where he doesn't like the loud noises and crowds. Urm (.) He has complained of like he doesn't like flashing bright lights but yet he stuck to the screen all the time, you know, that screens always there that's all he ever looks at so that could be it could be the (1), you know, I don't know if it's affecting his eyes or (.) You know we can't get him to the doctor's to get him checked which he's only been the once which was about a year and a half ago

(10:50) That's because he's not leaving the house? He won't go he won't leave the house. It took us a year to get him to get his haircut his hair was nearly the same length as yours but he got

(10:59) [laugh] mines quite long! Yeah more than that [laugh laugh] He had a *massive* lump of matted hair (.) and it was (1) *awful* it was like a rats nest and there was also a time when he was staying in bed And he wouldn't even get out of bed for about 6-weeks? He was coming down for something to eat and going back upstairs on his iPad So of course his head on his pillow you know drooping on his pillow it was matting his hair even more and it was getting that bad (.) when he lifted it up at the top at the bottom his scalp was going *pink* So the more his hair (.) it was pulling on his scalp you know the tighter it was getting matted And anyway we managed to get him to get his haircut on Christmas Eve all nights And that's why he's now got short hair

(11:50) did someone come to the house to do that or did? No my partner's son-in-law (.) [Partner's Son-In Laws Name] he said he was going to get his hair cut. he said right Zeke come with me now because (.) [Partner's Son-In Laws Name]'s he's forceful but not in a (.) he's like Zeke now because your head needs sorting OK and he went

(12:05) He has got a little bit of *fear* of (.) certain people but *women* he will not do what a woman tells him at all. Even at school the lady teachers but when a man teacher told him (.) it was yes sir, you know

(12:21) he followed erm but (1) I think he's also getting to the point where where it doesn't matter if you're a man or a woman now (.) he just goes: 'so what can you do to me' that's his attitude he don't care [laughs]. And I mean you know blackmailing and bribing and I shouldn't have to do it but that's sometimes the only way I can get him to do something (1) it's like we put the bins out tonight and that's his one job that he has stuck to every week

(12:56) yeh he's doing that Because I can't get to to because we've got to put the dustbin down at the end of the lane and I physically cannot do it myself at the moment so he's been doing that. So (.) [laughs] it's little things but all these little things are all building up and you know or they have been for the last year, 2 years. (.) Urm and not only that like I say because he can't, he won't go out of the house *I can't* pretty much go anywhere I've had to cancel appointments left right and centre (.) erm like these recent hospital ones I've had to go because otherwise I'd have had to wait another 6 months for an appointment for an MRI scan so I had to go without him I had to leave him but he's had tantrums because he didn't want to go with me (.) erm then my anxiety levels start to rise because there's nothing I can do do, he's putting me in such a spot (.) And I stand there and I think what else can I do, you know, and I end up crying. I do cry, I cry a lot but /{cries] (1)

(14:01) It sounds like you feel really stuck sometimes

/{through tears} Yeah it's like erm it's like having these hurdles, jumping over these hurdles and there's a brick wall so I can't move any further but now I feel there's no hurdle to jump over. /{cries (3). I'll be alright in a minute.

(14:23) it's alright /{laugter through tears (2) } do you want a tissue or anything? er dear It is difficult. It is It sounds like you really want things to change (.) [it's He's] just he's totally blaze to everything. (1) Like I said that's the only important thing is what's in there (2)

(14:53) yeh It's like trying to wean a druggy of drugs you know like it's going to be the same it's going to be a long slog, it really is, If that's the road we're going to have to take with him (2)

(15:06) You feel like you've got quite a long way ahead

Yeah this is the other thing because I know there's nothing going to happen overnight to cure it you know if I had a magic wand [laughs] But you know it's wishful thinking it's never

going to happen (1) So in that effect (.) because there's still so much that we're going to have to go through with him (2) and not knowing what to expect is it going to work is it not going to work is it going to change him is he going to end up going to school properly (.) is he going to have a future? (1) you know or is it all going to be down to that. Is that going to be the rest of his life? (2) So (3) yeah I don't know

(15:47) you are thinking all those things yeah. My head's just like I'm surprised it's not exploded yet to be honest. (4) But that's I think pretty much every parent would tell you the same. You feel like there's something (.) you know you've done what you can and you're trying to think of other ways. I've got people coming in pretty much all of the time, the authorities and that, you know, (.) and they're recommending this and that and I keep saying *I've tried all that*. I've tried it. I mean even the teachers at school they've been coming to pick him up on a morning or they did do (.) they were doing and he told them point-blank 'no I'm not going, I'm not going'. I mean there's probably been more teachers up in my Zeke's bedroom when he's been in bed and not got out of bed than have been in the classroom at school [laughs] you know just trying to get him out of bed to go to school. 'No I'm not going'. (2) I, I mean I just wouldn't dare speak to people like that but he's either not aware or knows he's doing it and he just doesn't care. But if it's like another side to the autism (2) I don't know cos like I say I'm waiting for [Name] to (.) to see if he is going to be registered as autistic. Ok and

2. (17:16) that's why all the different authorities have been coming in doing their assessments on him and everything and () you know they've seen him in action *as well* because (.) sometimes I think they feel like I'm lying but I'm not. It's not something you can lie about It really is it. You couldn't make it up [laughs no] so it hurts emotionally sometimes I think maybe a physical hurt would be less pain and especially when it comes out the same as it does when it's like man I don't have Mum as a name anymore it's a swear word. (2) He calls me Mum when he wants something and mostly I say yeah but when I say no no he goes 'ha you're not mum anymore are you?' He calls me words (1) and it hurts. (3) so but this I think for me is part of how to cope with this because as it is at the moment it's not going to change (1) so I'm having to get used to it I am used to it now but everytime he says an awful thing to me (.) it's like being stabbed It's right there (.)

I don't know it's so obviously for that reason I'm over compensated in my head you know everyday it's like what can I do to make it better? But there isn't anything really even if I said Zeke do you want to go to the pictures? No. Do you want to go swimming? No Because I used to take him everywhere

(18:57) ok We went swimming we we went bowling, (.) Pictures we used to go out for burgers and stuff museums and it all pretty much (.) because of that thing in there his game? Yeah it's just knocked everything on the head. (2) we've been to Cyprus twice yeah he came to Cyprus with us [laughs]. Ah, that sounds nice (19:27)

He didn't have a choice then he didn't have a choice then and it was alright (.) he didn't take his iPad And he kept moaning I'm bored this that and the other and he was in the pool everyday but (.) when it came to the Night-Time we had a meal and all that and watched the entertainment like you do and the minute we got back up to the room he'd be like he'd start doing *TAP TAP TAP* and He had this rhythm thing going on that you can tell when he starting to get annoyed so he starts off quiet you know and then gets up starts huffing and puffing and kicking chairs or whatever (.) and then it gets all, you know, but that was when we were away. If it were here, he'd have just kicked off straight away. (20.11)

(5) I don't know what else to say, that's just how it is. Yeah. Did not going to school feel overnight then, [yeah pretty much or was it a slow?] Because [Friend's Name] his friend who lives over there, he used to knock on the door on a morning (.) they used to walk to school

together (.) and it was (3) April Easter holidays I think, and when them holidays finished (.) pretty much the day he was supposed to go back was when it started. He just would not go (2) then he said, he kept saying to everybody that he didn't like wearing his uniform (1) he didn't like being told what to do by the teachers, he didn't like the lessons, he did say he was being bullied but there was no proof of that, there's every chance that he could have been doing the bullying, but there's no proof of that either. Urm but because the school was a lot bigger. The school he went to before [specialist provision/ LA PRU] I don't know if you've been there, you might have heard of it have you? Yeah, I've not visited it but yeah I do know of it yeah, well he went there for a year. It's a special needs school you know and there's only about ten children per class, but each class had different aged children in it, so they were all mixed right OK (.) and I think his attendance was nearly 100%, he went every day, he got awards and certificates wow to say, you know, that he had done well in subjects urm (.) and he *loved it* urm all being, he got picked up on a morning by a taxi and went home by a taxi cos then he said 'oh I don't like walking anywhere mum' like you know walking down to the school which is five minutes down the road from here [school name] urm (.) but his attendance at [Specialist Provision] so when it came to signing the forms to transfer school I put [Specialist Provision] because I was under the impression that that would be his forever school OK, so this was primary school? Yeah, because they cater up to school leaving age (.) So anyway, I put [Specialist Provision] first and second and [Mainstream] third and [Mainstream] came up as the main choice. (.) So went through the, you know, getting his uniform ready and he went to school that first day back after the six week holiday with [childs name] because they were the same age and starting at the same school at the same time, and he, he seemed alright. (1) but then like the teachers have said when they've been here because the school, (.) he's gone from about 60 pupils up to about (.) 1,500 or 1,200 in [Mainstream School] right and you know, it's a lot, it's a the (.) the difference in school is worlds apart. Yeah. And I think maybe he, it's been a bit of a shock. (1) and so he's maybe found it's too big, it's too noisy, there's kids a lot bigger than you and (.) you know, there's no one younger than you because you're the youngest in the school at the *moment* because you're the new year in there, "oh that means I can't be a boss to anybody" (1) that's how I saw him thinking. (.) He can't be the boss of anybody (1) because everyone is bigger than him or, you know, (1) to me, I think that's a lot of it he likes to be in charge, doesn't like being told what to do. (2) that is one of the things that he has spoken about. He doesn't like being told what to do. (1) and the uniform thing meant he had to do what he was told.

23.45

Cos (.) OK because the dress code is like a respect, you've got to respect. But then he would say 'well why is that teacher wearing that and I've got to wear this?' (.) because Mr [Teacher's Name] wears Paddington style suite, you know, with the checks, [yes Paddington] Bear with the yellow trousers, yeah I know what you mean, that's a bright suit! Yeah and then because the women wear skirts and normal clothes (.) how comes she's got a glittery jumper on? (1) I've got to wear a blazer and trousers and a shirt and a tie (1) so and you know, I've said, but Zeke all the other kids have got to wear uniform, it's not just you "I'm not wearing it"

24.28

He started telling me his trousers were to tight, and I thought, now that's an excuse so he doesn't have to go. Right, OK. And then he started coming home with holes in his trousers (2) so my first question is how did that happen? 'oh someone picked on me at school and pulled me around' (1) I said 'what by your trousers?' But it was a clean, you know it wasn't a jagged break in the material and he was doing it himself. He was ruining the trousers that I'd been buying him, saying that they had been split and this that and the other (2) he was ruining the clothes that he had to wear for school. (2) why do you think [he don't] know, he'd written all over his tie, one day he hid it down the back of the settee. He must have been

doing it at school, I picked it up and there was biro all over it. (2) I don't know, but what he is doing it's so obvious and he thinks he can pull the wool over our eyes 'we we're stupid' and he thinks that he can fob us off with a story that's just not possible mmm you know

26.33

And then it's like (.) if, if you've caught him out (1) he can't accept that he's been caught out because he thinks he's been clever, do you know what I mean. But (.) to us it is obvious, but he doesn't see it that way. (1) So this is another part of the autism thing I think, I don't know. (1) Sometimes I think maybe he is putting it on and sometimes I think maybe he isn't. Sometimes I've got to try and differentiate (.) if it is or it isn't (1) that's, that's my psychological sort of side to thing to try and yeah, mm it doesn't sound like it always feels clear no, no so then I'm testing myself then and thinking [laughs] (.) I'm thinking, I'm testing the logic I've had in my head for fifty years which is (.) to other people it's normal logic, but I think (.) I don't know how he sees normal logic or if he does see normal logic. Mmm it's as if he twists everything around

27.36

He just, it's like he's trying to create his own being or existence. I don't know {laughs laughs] yeah it feels like you both have very different views of the world. Yeah it's like for him everything is opposite mm he does things like switching lights on in the day time and off at night, he has the curtains shut in the day time, but open in night and he'll say (.) but there's sun shining through the window. So I say Zeke please open the curtains yeah and he says no it's too bright and he's sat there with the iPad right in front of him. Which is brighter do you think yeah, it can be hard to understand he won't let me open his bedroom curtains [laughs] so the bedroom curtains are always shut.

28.51

It's just little things like that and I (.) I think why is he doing that? Is he? I'm trying to understand why he is doing it. right (.) if he could maybe try to explain to me why he's doing it (.) but he doesn't talk, he hardly talks to me. I try to ask him questions and he just blanks me out or tells me to shut up. So that's another barrier that I'm up against. (3) It's another hurdle he won't let me jump over, because he's a brick wall at the other side of it so (.) mm It's hard, well it's not, it's us trying to understand what he does isn't it mm, yeah trying to make sense of it yeah.

30.00

I will ask him questions, but he just doesn't answer (.) so of course I've got lots of questions that I just can't answer because I need it from his point of view right. I'm trying to keep myself sane aswell [laughs laugh] yeah, it's important you look after you as well isn't it yeah, I mean when I said to you on the phone that he's one of a kind. I wasn't joking [laughs laughs] yeah we're all individuals aren't we, but I suppose sometimes we find some people easier to understand than others yeah (5)

I'm in limbo (.) I'm still trying to understand. On one hand we're trying to get Zeke to work with us, but I think 'we can't help you, if you don't help us' we're doing all the work. When we don't get anything back (.) you know, we tap our fingers sometimes because we don't know what to do. (2)

31.53

So I'm hoping if [School Staff], if they can get him in, away from other kids so it's not so busy around him (.) mm and get him into something with computers and they said that he can do a bit of gaming if he wants and we'll do our, our bit to slowly get him way from that and um (.) keep doing it stage by stage yeah, so it's gradual yeah, obviously it can't really be any other way can it but (.) like I say it's getting out of the house mm, he's got to make that (.) yeah, yeah that step (.) and it's also even the first day, you know if he does go the very first day they really *need* to keep his interest (1) m OK if, if he shows when he goes to school, 'oh yeah I really want to do this' then that's one battle won mm because once you've got his interests then he'll go again the next day and you know, keep doing it like that.

32.50

OK But the minute you veer off that track that he has chosen to take because he likes that certain thing, you veer off that (.) you'll go back to square one again. Right so it's obviously got to be something to (.) but I mean at the same time school have said 'you know it's really not our curriculum', but if they're prepared to give it a go yeah so if this has to (.) maybe be a part of the schools (1) you know, in the future where they help kids like Zeke, because really it's not their job at the moment other people from other departments, they've got their own (.) like assessors and people like that (.) it's not really the schools job, the schools job should be only teaching the subjects that they're supposed to teach and (.) not taking kids out of classes and saying 'well we'll do this because you don't want to do what other kids are doing' (.) it's not actually *their* (.) they're not there for that. But they have said they'll give it a go (.) so you know, if they can *believe in* Zeke, that's he's capable of actually being turned (1) then they'll try it so that is another possibility, but (.) that's not going to happen overnight either, like I say it's going to be gradual yeah like everything is, obviously they've got the resources and things to think of and man power and things like this and I understand that totally, you know, (.) but (.) people keep saying if it takes forever it takes forever, but I don't want it to take forever [laughs] I want it to be sooner than that so (.) basically it is like I say, it's a waiting game. It's not going to happen overnight (2) so (2) when are they planning to oh as soon as they can, obviously they've got to put things in place. They've got to have someone there with him all the time pretty much. I (.) I don't know how they're going to work it but they'll come up with a solution I know they will

34.52

They have meetings quite often, urm, (2) all these people keep coming to visit me (.) they're all from education something, but they do it in abbreviations EHA, YOT, so I (.) I've got an A4 side of paper that's just got abbreviations so I have to go Google or ask them 'what is it for?' (1) urm so, mm that can feel like a lot yeah there's a lot of abbreviations and it's like oh god, so then I'm getting confused cos I've got so many people that are (.) visiting that I have to see (2) It's even if we have school meetings they have to come here (1) I have about 6 or 7 people here sometimes because Zeke won't come to school [laughs laughs] so they're happening here, is he taking part in the ones here? No (.) no because he's in bed but, like I said at least *they can see* what he's doing is what he does all the time (.) you know like I said, I think they think I'm lying when I say things some people (.) and they've all been here and they've all been upstairs one by one (.) tried to speak to him and he's just (3) and they'll come down and go 'see what you mean' [laughs] but you know, a lot of them are mothers with kids themselves (.) but all their kids are doing normal stuff, going to school and doing everything and where as Zeke is total opposite and so I think they (.) they can't understand why he is doing what he is doing. (.) so for them (.) they're trying to understand as well. (3) so (.) mm everyone's still trying to understand yeah and even when we have sat and we've tried to come up with all these different ideas, how to get him into school, this that and the other (.) and even they've said 'well I'm at a loss here' (3). Oh dear How long has he been out of school for now? (.) how long, um April last year, because last year was his first year at [Mainstream] and before that he was at [Specialist] so (.) and so there wasn't really that

transition either from [Specialist] to (.) to [Mainstream] you know how they do transition don't they? Mm so I don't know if that (.) even if that had been I don't know if that would have helped (2)

37.53

Because of course when he stopped going I was getting worried because I thought I was going to end up in prison because or fined (1) um but obviously, you know, like because they've kept in touch with me and I've kept in touch with them (.) and [Name] that were another lady that used to come she said 'don't worry, urm that, that has to be put in place so that *we do our job* to try to get your child back into school' you know ok so that was a weight of me shoulders, because I'm terrible when I get a worry (1) I hold onto that worry and I keep think 'ahh' so and I had that written in black and white as well that that's not going to happen I was like 'oh thank god'. But at least I'm still, you know, I was getting the help, I'm still getting the help (.) but obviously none of us can move any further forward (2) so we're all kind of pinning our hopes on what the school can do now (1) you know mm (2) everything is waiting but we, you know, I understand and I understand that they can only do so much with the resources they've got (.) urm (.) if they, (1) if they have to go above and beyond anything no no matter how minor it is (.) they still have to have permission from their higher uppers (.) you know, 'can we try this?' and whatever (1) urm otherwise they have to literally go by the book

39.14

You know, it's for everyone's protection as far as the law goes, you know, I don't know what they know. I don't know how the system works properly so I've just got to rely on what they tell me (.) they can and can't do OK (1) so (3) if if they can actually come up with something (.) if there is something (.) I really want that to be a success and they do as well (.) but it's not something they'd normally do for one particular child (.) especially in a school that's not geared up for that kind of (2) it's not even teaching really is it, it's like um (2) what would you call it (.) like a re (.) yeah but having to let him do what he wants rather than being told rather than being told, do you know what I mean. (.) m, doing something different so he wants to be there yeah, so basically it's just waiting for that now yeah so I'm, I'm just sat here

40.32

Thinking (3) do you know what I mean, take me to a spa or somewhere and bring me back refreshed (.) but it's not going to happen is it [laughs laughs] mm you want a bit of a break Yeah you see that's the other thing because we're with each other all day everyday (.) and there's nothing new, there's no new input coming into the house so normally the kids go to school and they come home (.) they say 'I've done this today mum' and you'd say 'oh great' or I'd say 'what have you don't today at school'. It's extra *input*, (.) it's not the same thing day in day out. It's not ground hog day every day.

41.20

School to him is a swear word, a proper swear word. If I say it to him he goes {pulls face, clenches fists and holds up} and kicks the door on the way out. Mm he really doesn't want to be there at the moment does he, he'd be clenching his fists mm, it's like every time you say the words to him, it's like he's got this flash straight through his head 'school' and maybe what's made him hate it so much (.) but then again (.) because he's always on his iPad and his games. Once that flash is through his head, he's back to his iPad and back to his games again straight away. He talks about games where you have to earn money to get to the next level (.) to learn a new skill or car or I don't know (.) item of clothing or something like that. (2) the way he talks about it it's like it's real life. In respect to him it is real (.) real life doesn't

exist around those games m if I gave Zeke a fiver and said go to the shop, he'd have that fiver about a month later. One because he won't go (.) he knows he can but he won't and two because he won't care about that 'what about that fiver? I've got more money in the game' (.) do you see what I mean mm, the money in the game is more important to him yeah, he thinks that money is real.

Can you tell me more about not leaving the house at all?

He just won't go anywhere (.) the shop down the road (.) this is another think that I've noticed for quite a long time now. If he had come with me, say like to the take away (.) if I'd given him the money and said 'ok Zeke, now you pay for that and I'm just going to nip into the shop next door and I'll come back and then you know' and he'll say no I'm not doing it. (.) It's like he doesn't want that confrontation with that person behind the counter. Ok (1) so this is just an example say I said 'now what do you want to eat' and he'd say 'can I have a chicken burger' and we'd be stood right in front of the lady and she'll say 'do you want any sauce on it?' and I'll say 'what do you want Zeke?' 'barbeque' (.) well I'll say 'well, do you want to tell the lady what you want?' (.) 'no you tell her' right (.) so then I tell the lady (.) 'do you want a drink with that' 'yeah can I have the Dr Pepper' and he's always looking at me, never at the lady. So then, even though she's heard him I have to say it to her and he's always behind me, even when we got on the bus, it's like he's wanting me to be in between him and the person that it (.) it could be a confrontation with and when I say confrontation I don't mean, it's not a horrible one, you know, yeah (.) it's just a normal, it's like he can't deal with that connection. He (.) he wants to be in charge in the house (3) but he can't be in charge of himself out of the house. I have thought, what if one day he's on his own and (.) say like he goes to the shop. Because like he did go there once (.) I asked him to get a jar of (.) and I knew they had it, but he came back and he goes 'they didn't have it mum' so I'm thinking what did he do? Did he go there and just come back and say they didn't' have it (.) or did he sit at the corner for a bit, you know. I mean that's the autistic side of it possibly (.) but it could also be that stubborn side (.) 'oh I'm not doing it, you do it' [laughs] it sounds like it can be difficult to tease apart. Yeah (.) I think (.) cos maybe things at the house are his own bubble (.) he's in charge of it while he's here, well he's not, but he thinks he is (.) where as he's not in charge when that front door opens (.) so he's got no, you know, he can't do what he wants. Mm That said, he can kick off in public. He just goes. It can be one thing. He'll be playing a game even that sets him off, if you get killed in a game you've got to start from the beginning again and all, that sets him off. Mm it can be frustrating for him But then he says things 'ah I've got a better score than him now' 'he was better than me before' (.) but he's *busted his* (.) but to make himself better than the other person in the game, it's like he's got to beat (.) to be the best at everything all the time. So (.) so he's doing his utmost to be the best. So what's going on in his head in trying to be the best mm it (.) it must be overpowering for him.

48.07

I think that's what he's wanting maybe (.) I don't know. He looks out for what you call newbies oh right, on the games new people in the game he can you know, and I've said to him 'you were new once' but it got to the point 'I'm not a newbie anymore, I don't like newbies, I can kill newbies'. But then obviously he comes across people who have been playing that game a lot longer than him and then he makes that effort to become better than them and mm he wants to be up there and everyone down here.

49.16

So from that side of the obsession of it is probably why he wants to play it all the time, because he thinks if he lets up for one second (.) he's going to be beaten. OK That's maybe not how he sees it (.) that's how I see it yeah if he doesn't he might loose.

50.05

When I say obsession it's (.) it's beyond obsession. (2) you know I, I keep saying it, I keep repeating myself that's his world, that's his real world. (1) *This* isn't his real world. mm

There is a girl that he's, when I say, not got attached to (.) she lives in Wisconsin in America and she's one of the characters on one of the games that he plays. Anyway, he's been speaking to her and playing these games with her for about (.) phwo I don't know (.) maybe two or three years (.) urm but he's only recently. He's just started talking to her on facetime (.) I've *actually let her* (.) and Zeke's been on face time OK, he's making a friend? I've spoken to her myself she's seventeen, but I've spoken to her myself, I've seen her, spoke to her, we text on message quite a lot. Urm (.) I think he's got a bit of a thing for her, like I've said that's his real world (.) but now he's seen her, spoke to her (.) that's now become a little bit of an obsession but I've explained to [girl] how he is, for autism, aspects of autism (.) she understands totally. She keeps reminding him Zeke it's a game. She is doing a good job, she's keeping it on an even keel.

She's helping me to help with him even though she's over the water but that's by the by, she might as well be in our living room you know what I mean mm so she's (.) she's one. I don't know how (.) she she's not like a helper, but you know she's doing what she can to keep him (.) normally you bribe kids with sweets or something don't you, I've had to bribe him with [girls name] but in the nicest kind of way [laughs] you know mm, it sounds like he's found a friendship yeah yeah, but

Conversation about hairy legs- not transcribed

55.26

We've both got raging hormones [laughs, laugh] he's going through puberty, I'm going through menopause, so there is (.) there's times when we are at logger heads with each other. But (.) I mean I'm one of the most passive people you could ever wish to meet, but because of menopause [laughs] I do loose it (.) you know things irritate you a lot more when you get older (1) and I have to try and simmer myself down, which I do straight away, pretty much straight away (.) but he goes on, he carries it on (2) so it takes him longer to let go of emotions? yeah, yeah. (.) he does take a lot to heart, he he (.) I don't know example, if someone did something to him and (.) 'I don't like you because of that' he will bear a grudge and I (.) I don't know how long he'd bare a grudge for. But (.) but when he gets into the adult world this is going to be an effect isn't it, if he can't let go of something that's happened (.) and accept as well. Because me (.) when growing up it (.) it's in the past now leave it, you know, unless you make it happen again you stay away from something you don't like, you learn by it, but I don't think he does (3) or he's just choosing not to. (2) It's there's always that one end of the scale to the other and I (.) I'm comparing things all the time and sometimes I think should I be or shouldn't I be? I'm being positive, I'm being negative, but I'm trying to be negative to be positive it's (3)

Can you tell me a bit more about that? Being negative to be positive?

It's just I'm trying to think of things in my head to understand (1) you know, he's (.) when I say not normal, I don't say that in a really horrible way, he just. He just doesn't do what other kids do, you know. (3)

Sometimes recognising that can feel positive?

It depends, there's always (.) there's a positive and a negative to everything OK (2) and it's just, it could be anything. I can't even point to anything. To me it's normal and logical, but to him it's the other way round (.) so it's just like thinking why's he thinking like that? You know everything is opposite. I I can't explain it any other way, that's just how I see it. I can't see it any other way [laughs] yeah

58.15

You've had (.) obviously lots of people who have come in from different agencies and it sounded like sometimes that's been quite (.) confusing yeah because of the number possibly, the number of different people with different jobs. Could you tell me about a time where you've felt really well supported by [? I have] felt supported by all of them (.) pretty much because a lot of them they they do actually share the same office as well a lot of them [laughs] OK from different departments you know and different areas and of, whatever they deal with. Urm some of them (.) they've seen this kind of thing before *not often* (1) urm but they have had experience (.) with some kids that are similar (.) some of them have said that he (.) he is a bit urm *more* (.) how can I explain it (.) when I say they've like seen Zeke before, but he's a little bit further up (.) further advanced maybe [OK in] in the condition that he's got, well whatever they choose to call it (.) urm and then (2) and obviously they talk about their kids sometimes they've gone through similar stages and (.) and I'd say yeah but Zeke's gone through that stage, but it wasn't what I'd call normal stage. You know there's not right say like there's no (.) they're sitting and saying well their kids they do this and do that and I'll say well (.) I wish Zeke would, you know, just anything. Just going to school would be the absolute golden egg for me it really would and just getting the extra input that he needs (.) get some sun on his bloody face for a start, you know get some (.) it was like (.) cos yesterday morning it was snowing wasn't it and [child] came round because [child]'s not at school at the moment, his mum's having problems with him (.) this that and the other, his mum's learning how to be a social worker oh OK, she's at [Location Name], well learning there. Anyway, Zeke was in bed, [child] came in and he says is Zeke (.) [child] comes quite a lot he's Zeke's best, one and only best friend ohh *real friend* you know not a game friend yeah that's nice and um (.) and he says 'is Zeke in bed' I says 'yeah' (.) so I went up to the toilet and [child] had gone on the Xbox, I don't mind that. And I went past Zeke's window and I said 'Zeke it's snowing' and (.) 'urr' you know, nothing *excites him*

He won't wear any clothes that are tight, you know he wears joggers and hoodies, and you know if he's comfortable wearing them that's fine

1.01.31

At Christmas time (.) opening his presents he was like (.) I got him a new urm iPad and a couple of games and he was like 'oh year'. I think he got some deodorant and he was like 'oh I like that' so he was happy with that (.) urm that was it, he just didn't, it was just like 'uh' and that was it. That day didn't seem exciting for him? no

1.02.18

But then his dad doesn't help (2) his dad (.) he had him last not this weekend gone, the weekend before and that was the first time he had seen him in about a year so there's that he's got to contend with as well. (1) but that's another huge story mm he just doesn't, you know if you said take him once a month for a weekend, but no he just (3) cos I send texts like at Christmas ' do you want Zeke over Christmas?' or (.) he can have him for as long as he wants I'm not bothered to get into a blooming argument about anything cos we've done all that court stuff years ago (.) urm and he and Zeke was under a court order at one point (.)

Zeke was took off me so I was the one for about 5 years going every fortnight (.) school holidays I must have spent thousands and thousands in travel (.) anyway after all the court stuff, the family mediation, the whole lot I got a text off him one day saying 'do you want Zeke back' all that fighting *all* the money that [Z's dad] and me spent trying to get Zeke back and I was like 'yeah course I do', you know, he's made me sweat all those years just for him to turn round and say 'do you want Zeke back' and it turned out because he's got two younger children with his current girlfriend (.) urm 6 and 4. And it turned out that Zeke wasn't getting the attention. As baby's they were getting all the attention, Zeke was pushed to one side (.) so Zeke started hitting and [Z's Dad's new partner] was upset because there was a possibility he could have hurt the babies so that's why his dad asked me. So I think there's an element of that in him as well because his dad's not stepping up to the plate anymore. I've had Zeke four years now. That must have been very difficult for him Yeah, but you see (.) when I try to talk to him, he just won't (.) he just clams up. I can't ask him questions because I don't want to upset him for no reason.

1.07.33

I'm glad that Zeke's here because it's one on one, you know, I know he's not getting pushed to one side because of there being other kids to think of (.) so. He's obviously got all of that going on in his head. But he won't talk to me about it (.) I've just got to guess. I've got to presume, which I shouldn't, but, you know (.) so there are all these different factors going on, but like I say if he spoke to us we would understand more. But he won't speak so he's making it worst for himself, you know holding it all up there

1.08.01

Mm it's difficult for him to talk about, it feels like he's holding onto it yeah, yeah just playing his games. Everything has just rolled into one. He doesn't like the real life because of what it's done so he sticks with the gaming life because he's got control over it. Mm it's safer yeah he's more in control in the game. He can make his character do what he wants (.) and not be told what to do. (.) Yeah. (.) so

1.08.53

And for every single thing that goes on for Zeke and the situation, it still affects us as parents, you know, (1) we, we have it hard as well, (.) and all the what ifs, you know, (.) could we have done better? Can we try this and then the emotions start, you know. It's like wishing I could go back to square one, start all over again, but you know. That can be hard. Yeah, yeah it is, but like I say just getting him to school, for me, that would be better than winning the lottery it really would. Just, just to get him to school, to get him some different input. (.) you know, real life input (.) we'll see, I keep saying that, you know 'we'll see' [laughs] like I say we'll see what happens mm he can't go on like this forever, he can't be doing that when he's supposed to be out working, socialising, you know, he's not going to have any life skills. (.) If if he could do anything with computers and gaming (.) we do actually have a friend who has written a lot of the music scores for a lot of the popular games.

Story about a wedding in cyprus- met music composer

10.10.44

Now on that Cyprus holiday Zeke spent a lot of time talking with [music composer] (.) and I was like, I was so like, 'yeah there's a result here' (.) but the only downside was that when we left Cyprus (.) [music composer] was going to go back to his, you know, I don't know where he lives and Zeke was going go back to what he's doing, but just that *one week* (.) when [music composer] was happy to talk about gaming to Zeke, cos he knew games and

all the games and telling Zeke about all the music he was writing for the games Zeke was playing (.) he had a connection (2) and he even told me about a computer m (.) I don't know if it's a course or something, I don't know if they call it SMASH or something, but basically you can start you kids on the basics and if they've done all the basics then they move up a level and then you can go on to (.) you can do anything with computers can't you yeah (.) and get him into that.

1.12.37

So [music composer] has always said that if he does happen to get into a (.) a computer education kind of mm not forgetting that he's still got to do all of his Maths and English as well yeah that he, he will lend a hand if he can ah that's very kind yeah, it might be over internet or (.) you know it won't be face to face or anything like that, but he's said if he's got any questions he'll try to answer them (.) get on face time or (.) so we've still got that option, but he needs to go to school first

12.13.15

It's like I keep saying 'you have to go to school Zeke' (.) you need your Maths and computers, you've got to know how to spell (.) it's things like that, it's basics that you learn at school that set you up for life. And Zeke's like 'oh yeah yeah I'll do that' but once we got on that plane back home (.) if it would have been consistent it would have been a different world.

I keep like I say, these glimmers of hope, there's some somewhere. Yeah.

It's just keeping that anger and temper off him as well because he explodes just like that. He can go off at any minute. (.) So (.) and he eats like a pig [laughs laughs] ah he's hungry, a growing hungry teenager [laughs laughs] what he eats in a day would last me a week honestly. I get full just watching him [laughs] soo that's pretty much the gist of it.

Ah thank you

Have there been any times where you've with people and you haven't felt supported? In what way? Oh you mean everyone coming in? yeah like the professionals.

1.14.45

No, no they've all been very good (.) some of them (.) they haven't come, you know to do a job, they've *come as a friend* (.) Ok and you know that, (.) you know, helps, because at the end of the day we're all mums as well and we can all still relate to certain things (.) and obviously because they, they want to help the kids that have got the problems and they've said many a times (.) "I'm so bloody lucky that my kids," you know, and she says and I'm not saying that to make you feel (.) because your child's not doing (.) not conforming." She says you know, "don't (.) I'm not in any means trying to put you down (.) I think you're doing a great job," she says, you know "I couldn't do it" and she says "it's alright me sitting here saying (.) giving you advice" but, you know, she said "that that's my job, I'm trying t make a difference" but they still get tied up by the rules, by the regulations, by the *system*

1.15.46

You know, so they can only do their best so (1) talking as if you were a friend and not an *actual* (.) you know it makes, a big difference. It takes a lot of the weight off, you know. It's like knowing that when they come through the door they haven't come to point a finger at you for any reason, (.) they are there to help you, and you know, like I say they've done

really well, you know yeah when I say really well, they're just doing what they can, but they've been consistent.

1.17.05

And adults in school? Well (.) as teachers (.) they (1) they obviously have to have the wellbeing of the child in particular. They have a big school to work in (2) bearing in mind (.) urm there's been a couple of times where I've had to go to [Mainstream] for a meeting, when Zeke was in school, I've had to go in and I've been sat in reception waiting and there's been maybe up to five, six kids shouting at the teachers and pointing their fingers at them (.) so there's been every chance if Zeke's seen that when he's started at the new school, he's been thinking (.) that's how kids treat teachers here, you know, (.) teachers, they obviously have to be careful what they do in a situation that could turn into something nasty urm (3) so they've got their hands tied, they've got to be careful with what they do and what they say. If Zeke's seen that and because he's come from [Specialist] where they had lots of teachers there and they had a, they call it the time out room, where if any of the kids had meltdowns they could go there and they've got all the lights and the soothing music and things, and they can put the kids in there and then they open the door and say 'are you alright there' and the kids say 'yeah fine' but they can't do that on [Mainstream] because they're not equipped for kids.

you said that sometimes professionals might be doing their best but their hands [might be tied yeah it's just the systems] by systems (.) can you tell me more about that?

Yeah well, when a kid kicks off in school (.) what, what can they do, they can't shout at the child.

I think that maybe if Zeke has seen that (.) he hasn't liked it you know (.) I know he can be (1) himself but (.)

1.22.47

I find it funny as well because when you're in this situation and, you know, you've got all these different agencies come in (.) and all of the sudden it seems like every child on the news (.) it's all over the place. But because I wasn't in that situation before I wasn't taking, paying much attention mm (.) to it, but it's always been there, you know all these other kids that have been affected by whatever (.) but because I'm going through it I'm proper alert to every child that's on the news or on newspapers (.) you know and there's more about mental health and everything nowadays, autism, ADHD they've got all these different names for every different (.) you know (.) different thing. And my ears prick up all the time now whereas before I would have thought /{voice lower} 'oh my child won't do that'. OK yeah (.) but it just shows you how things can progress (2) well they could start and you wouldn't have even noticed (.) but obviously as things gone on you think, oh (.) it's getting a bit serious, and when you think (.) you should have stopped it at some point, well you didn't realise what was happening. (2) m you didn't know so you know, you're trying to keep things as normal as possible. (1) But (.)

Topic not transcribed at N's request

1.24.01

It sounded like you have found some good people (.) oh yeah, that face book group's amazing (.) some of the ladies on (.) I mean we have a laugh and a joke about normal things

like 'oh I hate it when they take a toilet roll and don't replace it with another one' you, know just every day things, but there's a serious side to it as well. We *all* relate, we've all been through, or we're all going through the stages of everything (1) and especially as far as the kids are concerned (.) I chat a lot with, like I say it's an open group, you can say whatever you want, no ones going to judge you for anything. You can swear, you can do whatever. It's like letting off steam people who understand, which is a good thing (.) urm and there's people who give you advice because they've already been through it. Or you can give some advice based on what you're going through cos they're just starting. So we all help each other out (.) there's women from all over the world in this group. There's some in Fiji and, they take photos, they're on the beach and it's tropical, they take photos and there's palm trees and we're like 'we're so jealous of you because we're in England and it's rainy and it's cold' but they're going through it as well. It doesn't matter where you are in the world (.) it's happening all over, but like I say if it weren't for me going through what I'm going through, I wouldn't have known (.) so that's me, that's like my daily diary and you know, we all keep up with each other (.) urm so we do this thing, sending cards on a milestone birthdays around the world. That's good. That keeps me up yeah (.) I'm not thinking about what I'm going through (.) I am thinking about what I'm going through but (.) I'm not down, I'm not getting to the point where I think (.) I'm going to have a break down (.) we all keep each others spirits up so, you know, that's a good thing for me. Yeah it sounds like a good thing yeah it is, the women are brilliant. I wish I could be in a room with them all [laughs laughs] But we'd be there forever because there's so many, there's about 2-3 thousand in this group and it's a good group because urm (.) there's a lot of serious stuff in there so you get vetted before they let you in. So it's quite a good group to get in and I had a recommendation from a friend of mine and other than that I wouldn't have got in there, but I'm bloody glad I did because 'it's not just me. Because you do feel sometimes, why me, why me, and then you start feeling sorry for yourself and, you know. But these lot say 'snap out of it' [laughs] and we do the same to them, you know, we can all relate and they're all you know women of similar ages. So (.) I've got that to keep me going yeah which for me (.) well it's a life saver sometimes, I've felt *that down* you know, and I think what do I do, sit here and cry, or just chat. So it has a big effect on you it does. (5) [laughs] oh dear, I don't know (.)

1.28.44 But yeah, that's, that's pretty much

Ah, thank you so much

Oh it's fine, I hope I haven't gone on too much no you haven't at all, I'm inviting you to go on for as much as you want I think [laugh laughs] I could be here all day, all month I think there's all these little snippets that jump in, you know, because you think I need to start here and jump up, but then all these little bits come in and you think 'ah I remember that now, yeah' yeah that happens doesn't it when you start talking but yeah [laughs] Ok is there anything else you'd like to share? No no, I imagine something will come, when you've gone, but

Discussion about opportunity to look at analysis

Appendix K: Gemma's Transcript

It's completely up to you what you say or don't say so please…

OK, right so you want from where it started

and sort of important events from around that time.

OK so it was, we are getting on for nearly a year now it was around about the end of march last year um just before the er Easter holidays (1) there was a few incidents at school but its important to notice that Claire (.) that this (.) that she's not identified any particular cause for the absences

It's just (.) when she tries to go into school it's a complete ummm sort of anxiety, fear response and she just has to, she can't do it she just has to run away. She feels safe at home. um but it's something to do with the school and going into the school building and all that all lessons, that's that's the problem. The problems that she had around about March 2019 was she had she fainted in class at one point and urr in a history lesson and hit her head a bit and she had to she urr she came home.

And there was an incident with friends after school at the football team, they were a bit mean to her they umm (2), they called her a name or something, I don't know, it was nothing major and I don't think this was an ongoing issue ummm, but they called her a name and that really upset her and she didn't play in the football team that evening

(2.30)

Ummm (2) she was struggling with the homework as well, I think it became quite um (2), shes always been very very, given 110% in everything and she's always done her homework

(2.45)

And she always tries really really hard but I think she was finding it really difficult and to be honest I was finding it difficult as well

[Laughs Laughs]

Some of the things they were giving them was really really difficult things like you know in English they wanted to discuss about you know what would their utopian future look like and what does freedom look like to them. You know quite complex things. The maths you know was (1) fairly difficult. Ummm there was a lot of me having to Google it.

But anyway she's, she's got dyslexia as well umm (2) and the dyslexia centre queries whether she's dyspraxia, dyspraxia as well but she hasn't had a test for that. Umm and she's got well it's dyslexia and dyscalculia so so she struggles with both those things, so yeah I am sure it was very very difficult for her and just (1) umm and it was just um things like organising herself

04.00

and umm (4) with the changing school it started off really well, there was a big group of girls call for her every morning for school

and then that all trailed off (3) and nobody was calling for her and I was like, So I'm sure there were some friendship issues mixed in with all that urrr.

Yeah

Umm She wasn't placed in a class umm (2) with a large group of friends just one friend she had from the last school and everyone was very split up into different houses and different classes. So it was a massive, it was a complete change of friendship group, and everything.

Mmm, it's a big change.

Umm (2) when she first when she first started missing we would drive her up to school in a car umm (2) she'd refuse to go in, umm there was a teacher would come out and (2) tell her she had to come in and umm several teachers come out and say "you have to come in, you have to come in".

5.07

And there was one incidence where one of the teachers says (3) you know we couldn't get her to go in she was screaming she was obviously very very distressed (3) umm my husband took her one day and, you know, he said "should I you know should

(05.25)

I actually physically drag her in" and the teacher says "well yes you'll have to" (2) so that was a really really distressing morning for both my husband and Claire because he sort of basically sort of dragged her in [laugh] and that was really really distressing

But after that then it was just a case of right we've got to got to come at this a different way. Well from our point of view. (2) School were a little bit, umm I mean we didn't really we didn't really have any input from them at all other than umm (1) them saying "she's got to come in" (2) umm for the first couple of months.

How did that feel?

06.08

Umm (1) well obviously you know you feel you are being judged because umm you feel like you're umm (6) you're being (06.20) umm you know (2) the general consensus is when you say to anyone "she's not going to school" is "well I'd just make her go" that's the general sort of thing it's kind of like 'well she's got to go, make her go'. And it's like 'oh right, ok'.

And well that was the head of house who was very (3) umm I don't think she'd she'd come across it before I think. She was like well we've had one girl and she was a school refuser and she she wouldn't come and umm (2) I think it was sort of viewed as a sort of "well you're just letting them stay at home".

H: Ok

And there is sort of a general I mean there has been a change of

(07:05)

head of house since then who has been to the house once and just not really said anything. Umm (3) The SENCo the head of the SENCo , she's, she's not been but there's a higher level teaching assistant and a student support lady, name and name, they seem to have been designated the task of supporting Claire. But what they can do in amongst *all* their other duties is extremely limited. It's basically "can you come at half past three Claire and we'll be there and we'll meet you (.) for a bit"

07:48

H: Ok, so at the end of the school day

Yeah or (.) you know they have said to her come in at lunch time but obviously lunchtimes are a bit more busy so its we're kind of trying to build up to that but this is *nine* months and we've just got her going in at half, at three o clock, (.) two days a week for half an hour.

08:04)

Mmm

And that has taken like nine months (.) to get to that stage (5).

It's taken a long time.

Ummmm (.) at first they refused to send work home because they said well we're not going to send work home because that gives the impression that you can just stay at home and do it.

Now she does access some work (1) umm (.) on the show my homework page and she's doing all that (.) any work that she gets she does do

She's doing some work?

(08:45)

Yeah, I mean she needs someone sort of to explain it with her and last week I had to go through the maths with her (2) annnd yeah explain and yeah basically it was a sort of one to one session. I mean what what I'm finding difficult is that she needs some really quite intense support with things and with us both working that's really difficult to find time to do that (2) umm (1) we did book her some classes at the dyslexia centre but again she refused to go and I *don't know* why that is at the moment. (4)

(09:18)

Mmm

I think again its when the lady did the initial meeting it was for about (3) for, she had her in there on her own for about forty five minutes and I think that was too long for Claire and I think it's that (.) umm panic she gets when she's in a place and she feels that she can't escape.

(09:37)

(fast speech) And this is, this is, just my (1) *theory* umm but if she's in a building she can't escape, and she finds its stressful then that's when she panics if she doesn't think she can get out of a situation (.) that she's not enjoying and that they're pressurising her to concentrate and she finds that difficult obviously because of her dyslexia (3).

Umm (2) we had some very *very* brief input from [SUPPORT SEVICE PROVIDED BY LA] which

(10:07

was umm (4) which is is still really really umm (.) which I'm still really quite angry about and that is umm (.) we had a lady come and meet us at the school with the teachers. That was me and [C's Dad] and the teachers umm and I gave her a big long umm discussion about everything that had happened you know umm could be dyslexia, friendship issues, anxiety, fainting, all of these things seem to have kind of built up. (1) Then she says "well I'll come and have a couple of meetings with Claire I'll try and get her to you know umm (.) engage and see what work we can do, it might take me a couple of sessions for her to get used to me umm (1) and we'll see what we can do" so we were really hopeful about that.

Anyway the lady came and she sat for 20 minutes, with Claire, and said um "you know umm (.) your mum and dad are going to get fined don't you if you don't go back to school" and um (.) Claire got upset, walked out the room and then we got a letter from them saying '*Claire* wouldn't engage so we are discharging you from our service' [laughs]. (2) So that was *really* disappointing, really disappointing cos

(11:17)

we had kind of waited for about, I don't know, about 12 weeks for this [SUPPORT SEVICE PROVIDED BY LA] thing which was a disaster. (5) So and then umm (5), I'm trying to think what else has happened. Oh yeah we did have a, one meeting which me and Claire did go up to the school, after school, and we had a meeting with (umm) the head of house, (1) ur miss la page and the (2), now what, there's a lady called the um attendance officer.

Mmm

So there were those three sort of ladies sat infront of us and they got up there and (.) um (.) and they basically said um (.) "you know, you know, why can't you come? And (.) you've got to come, you know, and urm (.) we are going to you know what will happen to your mum and dad (.) if you don't, if you don't come to school, we are going to have to fine then ah do you want your mum and dad to get fined ah I just, I can't believe" and they were quite, really *really* negative, so that was difficult.

(12:27)

Mmm fines were mentioned

Yeah, so she's had that from (1) yeah from the head of house and (1) yeah and this is in the early stages I think when I think you really need (2), they always say, you know, catch these things early don't they, but (2) ummm (4), but umm there's been um (.) school have done what they can and they've been very good and we haven't received any fines or anything like that so they do appreciate that there's a problem *I think*, but the actual (3) input that we've had has been very limited (.)

(13:06)

So yeah um mention [EP name] the Educational Psychologist she's been brilliant (1) she has *come* and she has come on a weekly basis and she, it's been a very (2) um

(13:18)

(6) if you push someone they'll kick back (1) and push away if it's an anxiety issue I think, but [EP name] 's been a very (.) softly softly approach and she came for a good few sessions and did some *fun* activities with Claire (.) and ur built up a good *rapport* and then um (1) yeah, she (.) she has made some really good head way.

(13:47)

Um (1) Claire also goes to (.), which we pay for privately, um *art therapy* and she does enjoy that (.) but again I think it's about getting her out of the house and doing something she enjoys uh (1) because she has been just basically left at home em and she's got very bored.

(14:11)

And just very isolated um so you've just got to do everything that you can to um (.) remind them that they're worthy and special cos it can be, I can imagine that um very quickly people just go completely (2) get completely depressed. Um, she (.) obviously in the first few months it was *really* really difficult, there's a lot of tantrums, screaming, shouting, (1) um being OK one minute and then switching very very quickly, like no emotional regulation at all, but getting

(14:55)

Very very distressed and anxious (1) um flying off the handle, being OK sort of at certain times, um on Friday being OK and then on Sunday night (.) just flipping for no reason um (.) so that's extremely, extremely difficult to to manage because (1) you feel helpless, totally helpless (.) and ur so it's been a bit of like a I've got, I've had quite a lot of the backlash because I'm the one here and then [C's Dad] he'll come home and he can sort of take over erm

(15:40)

(1) And he's been very good, keeping it very positive and rewarding her for little things that she has done (.) urm (.) so it's been really really keeping it positive and trying to keep Claire positive, but it's been extremely difficult.

(16:01)

Mmm It can be really hard being at the receiving end of things

Mm and not when she's in full blown meltdowns, it's very hard, yeah. (.)

(16:12)

Cos you're distressed *for them* and there's literally nothing you can do to calm them down, it's very, it's very, you know distressing cos you don't want to see them that distressed but at the same time [laughter] they're ripping into you.

(16:26)

You can't urr [she's sharing her emotions in quite a physical way sometimes?

Yeah, yeah um shouting, yelling, throwing things, you know, tearing things up, you know, um they did, they did um (.) erm reduced timetable at school, '*this* is what we would like you to try and do'

Right

Once they got their head round, they got their head round that there was a problem there, that she wasn't just being a naughty girl (.) urm, they did a reduced timetable, urm (.) and they got them to, they got Claire to highlight the lessons she would, she likes and they thought that was going to get her to go in, (1) urm

for the lessons she liked?

Well, well, they wanted her to yeah, but she's still not been in school since (.) March, since April last year, to any lessons at all

(17:33)

Umm so they did that timetable, but that came home, that got ripped up (1) Ummm because the problem is get, is not the lessons it's the actual just the anxiety *getting* into the school umm so then they sort of said well you don't have to come for any lessons but it's *still getting* over that anxiety of getting into school and now it's been such a (.) now (.) after maybe two weeks or whatever everyone is wondering (1) you know where she's been [voice change] "oo where's Claire, has Claire moved to another school" and there's all that business, so, umm

Her peers are asking where she has been?

(18:19)

Yeah, I mean her peers will have all moved on now and formed all their groups and done whatever and she (.) you know, now she's got to sort of try um, she's got some friends outside of school, but none in her year. So urm (1) and it's quite difficult to sort of (1) invite her friends round school when they're not in her year (.) cos they all got split up you see when they moved from Y6 to Y7. So yeah, so yeah that's really been the last nine months really (3).

Mm… at the beginning you mentioned a cluster of events

Yeah (1)

(19:34)

I think there is but because with, with her age she probably doesn't (2) urm (.) at, you know she says there wasn't any bullying, she says it's nothing to do with friends, it's nothing online (.) urm (2) it wasn't to do with the fainting, but at the same time everything is kind of I think has accumulated, but she can't say why, this is why I don't want to do it.

(20:09)

She says "I can't, *I don't know*" but just, she had (1) it, it's just she started getting I think anxiety attacks and then obviously the way of not having anxiety attack is to avoid that situation isn't it and then and then that's it then, and then you're um, you're um stuffed aren't you, once you [laughs] once you start with anxiety it's a really difficult, really difficult (1) thing to manage umm. There's no, there's no groups that she can attend in school time (1) that's out of school if you know what I mean. So there's nowhere for her to go and do things out of school time, she's just in the house. (3) So I have Mondays off so sometimes, it's you know Mondays, we'll go to the shop we'll go and walk the dog, we'll do stuff

(21:22)

Urmm (1) [C's Dad], and myself are quite lucky, we can work from home if we need to (2) umm but it's a difficult juggling act (1) and I can see a lot of families would literally break down with the stress of it.

That's how it's felt?

Yeah, *yeah* (2) urm, (.) her brother, did, her brother has been really good but again I think you know I think all the screaming and shouting can have urm (.) we're at a good stage now, but in the earlier months, you know, it was kind of like, you know (.) all the screaming and shouting will probably you know impacted against him as well (1)

It affects the whole (.)

Yeah because it's not anything anybody can understand is it? When it's an anxiety issue. It's very, (2) because the way to get over being anxious about something is to do it *isn't it*? But you can't do it [smiles/ exasperated face]

(22:39)

You can't do it because you're too anxious about it so. (1) urm you know just saying to someone "you'll be fine when you get there", do you know what I mean? */ doesn't work.* [giggles]

(22:52)

Mmm, that wouldn't be helpful for her

Well we've all had, we've all had like, time when we've missed school or we've missed *work* [Yeah and we've been off and that going back in is horrible isn't it? But once you've been in there for like five minutes, ten minutes, it's like you've never been away, but that initial, (.) you know, even on a Sunday night sometimes when you've got to go back to work Monday morning, you're like 'ugh' aren't you

(23:14)

Mm

But once you're in there, you're in there aren't you? It's a kind of build up to it, but you know trying to explain that with (.) to someone / {softer voice, slower speech} with sort of anxiety problems and and at the age of eleven, twelve you know they don't *know* that yet do they? (.) so that doesn't work.

(23:32)

We've we tried all sorts of things like just driving up to the carpark, we would go up to the car park, sit in the car for (.) fourty five minutes and then just drive home again / {faster voice, more emphasis on words} and it's kind of like "well done, you've done that, that's really good". (.) umm but then sometimes it's kind of like / {softer voice, slower speech} after, after the third day "well can you try going up to the door now?" and then "I don't want to do that" and then it all breaks down again and (1) umm it's it's a constant, constant right what are we going to do next, what are we going to try next / {speed of speech reduces, softer voice} um (3) and just, you know, I didn't think that it was once she first started missing the odd (.) odd day um and then when she first had, the first couple of weeks *I did not know* that at nearly a year later we were still going to be here. (1) And we've had (.) *fortunately* we've had [EP

name] and *fortunately* the school have been understanding in that we've not been fined, but other than that there's been, (1) there hasn't been anything. (2)

(24:40)

Umm (.) I guess what what we kind of *need* almost is a teacher to come down and do some one to one and that is not what's going to happen is it. (4) You know just somebody to kind of (1) *do* a little bit more. You know, like come down to the house and maybe do ten minutes of maths

(25:08)

With her once a week and then gradually build that up and then say you know (1) "Claire are you going to come to my lesson" you know or, there's there's just been basically like I I guess teachers they're they can't. (4)

Umm the Art Therapy you know that's costing a lot of money, so there's big financial pressure urm (3) and then you think is it worth getting another, a private tutor but then (1) she is starting to do some work at home now so that is helpful.

Yeah

(3) Emm (.)

(26:24)

But yeah she's sad cos she is missing out on a lot of things (1)

Mmm

(3) like she was due to go on a ur um choir trip last year that she missed out on, they were going to go to Germany (1) um and this year they were going to go to Barcelona with the Football team but you know she's lost out on all of that so um that's why it's really really important that (2) to (2) even though it is incredibly hard to keep positive and to keep it positive for the child because they are missing out on a lot (1) and (3) they will you know it's (3) when there's been hours when she's been screaming at me and you know for (.) and trying my best and she, she screams like um (.) / {impression} "this is all you fault" and (.) "you've done nothing to help me" when, when literally you have tried (.) you know everything and you don't know what to do and you know when it's killing you and when they are screaming that, that is really (.) you know really really difficult to take. (1)

(27:40)

And to try and keep it positive (3) you know and do keep rewarding her for little things that she's done and stuff like that, you know (.) my mum says "why're you, what are you rewarding her, what are you rewarding her for, she hasn't done anything" / {giggles} you know but it's, you've got to keep it positive [yeah cos it could go (.) down hill very quickly.

You're trying to recognise the positives, the little things that have gone well

Ur yeah just or even things that have just *gone,* (1) [smiles- giggle] / {slight exasperation and humour} not necessarily well. / {returns to quiet considered} but urm (1) em (2) but yeah I mean she's incredibly, you know she does want to do the work, so um (1) you know, I think that's, that's sort of key to school refusal isn't it, they do want to do it, it's just (.) they can't (.)

cope with whether it's the environment um I mean I don't know, any (.) I've just heard the term, you know that people (1) this is a thing coming through now

(28:45)

Urm (.) but she does want to do the work and she doesn't want to be at home, but she can't be in that environment so (.) you know, what do you do. She's started her own lip gloss business

Has she

um, she's (.) um (1) done a business plan for a dog hotel she wants to do so it's kind of like saying "oh you know, you're really good at these things" and trying to find things that she enjoys to do. Umm (1) trying to keep motivated which is hard in this *weather*, [laugh you know getting out for exercise and things like that.

Yeah

(29:33)

Urm (2) / {whisper} what was I going to say / {back} so yeah, just sort of keeping positive, things she's good at doing, like she's creative, and you know, focusing on that sort of thing rather than the fact that she's not *doing* (3) *the* curriculum (.) but she's doing other things. Ooh one thing that I Googled (.) was um (.) [Name of Farm] (1) and [Name of Farm] (.) trust do (.) sessions for children I think who are having problems at school and that sort of thing. So I rang them up and said you know "*can you do anything*" {clears throat} because she's really into animals anyway and they said "oh well it's got to come from the school really" so I mentioned it to the school and they're looking into that there's {throat clears} there's no spaces (1) excuse me, I've got a bad throat

Don't worry, are you OK?

Urr there's no spaces at the moment but she's, they are looking into it now (.) so again you're (.) the constant you're constantly looking around thinking 'what can we do, what can we do' you know and trying to find anything that they can get involved in umm (.) / {voice becomes slower} but the difficult thing is (1) because they sort of start to become a bit insular and isolated and panicky (.) the nature of panic and anxiety is you feel safe at home, so trying to get em (.) them interested in things and getting them out and doing things is (.) is a constant battle, because they don't want to, because their safe haven sort of thing is at home so you say "oh do you want, oh what about woodcraft folk", you know, you say "oh what about dancing, what about / {exasperation/humour in voice} you know what about ice skating you know [mm all these ideas / {back} it's difficult to, if you've got a child, I mean fortunately she's got a couple of friends outside of school who she met when she was diving, (1) um she, she gave that up in the end (1) but she's still got those couple of friends from diving.

(31:43)

If she hadn't have had, have got those couple of friends she'd be in (.) she'd be extremely, *extremely* isolated

Mmm

Umm (3) she did go down to the fair, with some girls from school actually, it was in the summer around about June time and we thought / {hopeful} 'oh this is *amazing* (1) she's

seen the girls from school and she's gone to the fair, oh surely' you know /{back to slower pace} 'they'll encourage her back' and um (1) you know they'll help her but um (1) but no there wasn't any sort of anything, anything after that, so that was disappointing.

(32:17)

So you, you constantly getting let downs (.) you know you think, /{excited voice for thoughts} 'oh this is going to be' it and (.) 'oh she's been in the car park today oh this is' you know 'this is it, we're going to be, we're going to be back to normal' / {back- disappointment} and it's just, still, you know, nearly a year on, we're still here. (1) {sigh} so it's constant let downs, got, so, keeping positive is really really difficult. I think that's my uh {giggle} {giggle} theme for the talk (1) /{humourous, frustrated tone} 'keep positive, but it's really difficult' (1)

(32:46)

Mm, it sounds like you have these peaks where things go well

Yeah

And then I suppose, they don't quite go where you are hoping it will go

No

That can be (.)

Yes that's it, it's ur (.) I've almost kinda *written off* (3) any, anything to do with like, the school attainment or anything like that or getting (.) you know (2) GCSEs or anything. It's been a complete switch to kind of like getting her into school to (2) /{pace slows} just making sure her mental health's OK.

Yeah, that's become the [priority

That's the] priority

(33:28)

Rather than (.) a*ny* homework, any lessons, anything. It's like, lets just keep this positive and, and focus on that. Um (1) there, there isn't, fortunately there isn't any pressure at the minute (.) with GCSEs and that sort of thing, but the focus is on, *just be happy* (1)

That's what you'd like

Yeah (.) umm (1) and keep, you know, that's not just 'forget about school and give up', but (.) if you focus on what *they want* which is getting her in there (1) then it ur all, it, it, then you loose track of Claire as, you know as how she is in herself and *for her to get in there* she's got to be alright in herself so that's the focus. That's the chicken and the egg isn't it, but {laughs} but yes (.) so I've just completely, you know, I say /{worried, concerned voice} 'oh the work she's missing ohh' and 'oh', you know it's like 'ooo' [pulls face] (.) /{back} *but* it's got to be if she's alright in herself then that's the main thing and she can always go to college after after school and *do* GCSEs then, so how do we keep things, how do we get to that stage and forget about school really at the minute and just make sure she's happy. (1)

Do you feel like that's been a different priority for you and the school?

Yeah,

You said, they want to get her in

I guess that's it really, their priority is getting her there and it hasn't been focused on right lets just forget the lessons for a minute and lets just focus on (.) doing stuff to make her feel better about herself. (1) And at home, and outside, she's an in, (.) the good thing is she's an incredibly (.) you, you wouldn't think she's got any anxiety issues at all.

(35:38)

She's very confident, / {excited/ proud tone} she's very *eloquent*, (.) you know, she's very *creative*, you know, she's extremely fun to be around, she gets on really well, she makes friends [*easily* yeah] umm (1)

She's got a lovely character (2)

Yeah, she's you know, and (2), /{slower, sadness} school has really brought that *down* (2) which, which is a shame. (2)

(36:10)

Especially in those early few, early few months, which were really, really hard, they were just like, (.) you know, 'oh you're being really', you know, 'you're being really', you know, (.) 'you're being naughty girl' and. Nobody ever *said that* but you can tell in a persons (.) tone of voice and their (.) kind of, frus, that you're, that you are being a naughty, *that you are being a burden*, it's like '*come on I'm really busy*'. 'I I've, either you come in', you know, I, I suppose it's frustration for them as well because they haven't got the time to input, (.) but I, there should be some, (.) an *extra post* I guess (.) for someone to deal with these really extreme situations. (2)

(36:59)

Um, whether or not I can go to the gov, parent govenors and say look this has been my experience, we've had basically a timetable thrown at us and (.) a reduced timetable and you've not fined us, thank you for not fining us but is there anything else you can do? (1) umm you know, you can tell that teachers (.) you got to a meeting, they'll do all different sort of suggestions (.) well like 'we're going to reduce the timetable' oh (.) um she's got um (3) /{frustration} *their excuse is always*, 'well if she can't, (.) /{back to typical} if she's not in the building then there's nothing we can do'. (1)

(37:40)

So you know we can umm (.) trial her with different colours on the screen, we can, do different lessons with her, we can do um, there's lots of nurture groups and things like that. They've offered all *these things*, but (.) if she can't, if she doesn't come in then there's nothing we can do. (2)

(38:02)

Mmm, was that offered after she had stopped going in?

Yeah, so after she stopped going in, urm (.) after about, sort of a few months they sort of said well you know if she can just come in for the nurture group which is (.) nine o'clock in the morning on a Monday morning (1) umm (2) but then that she couldn't. She couldn't do that. So then it was kind of like 'well right 'we've offered that, she's not doing it, so that's it'. (.) And I'm sure that's not the way they're seeing it, and I am being a bit unfair but erm you

know this is (.) I guess that's my frustration that nothings happened yet. But em offering a nurture group is fine, but it hasn't worked, what next? Urm (2) oh what I should say is (.) em (1) frustratingly (1) um around about the time, round about the time this very first happened em the Doctor (.) sent Claire off for physical tests she, cos she fainted.

(39:07)

(2) so (.) I'm just trying, she was constantly complaining of um "I feel sick. I can't go into school I feel sick, I feel dizzy" (.) urm (1) so there was a lot of physical (1) symptoms as well along with the anxiety. So the Doctor said (.) "right well we've got to get all these checked out". (1) So we had, so it took probably till about (.) from April to about (1) October to get all these tests and everything done, she had to have a, she had an ECG, she had a sleep monitor (1) urr you know 24 hour ECG, she had a sleep monitor thing (.) umm blood tests (.) umm (2)

(40:00)

So they were very thorough with that which is great. (1) umm (.) it did take quite a long time to get the blood tests done because she's got a needle phobia {laughs} umm *as well* and they ruled everything out (.) physically (1) urm (.) cos I was worried at one point that you know, is she eating enough (1) cos when she fainted apparently she said she'd not had any breakfast. So I thought *right*, I don't, I don't want eating disorders in the mix with everything else

OK

(2) So you're constantly thinking, / {pace of speech increases} 'what can it be? what can it be?' Umm (.) but it's not that, it's not so um, / {pace of speech slows} but I think important to sort of mention that (.) they can, you know (1) the physical side of it as well. (1) urm. I just rang [SUPPORT SEVICE PROVIDED BY LA] again and they said well you've been on the waiting list for five weeks umm (.) you've probably got about another 23 weeks to wait. Oh sorry for CAMHS, for CAMHS, so we've got another six months to wait before we get to see, so that will be (3) oh well, well over a year (1). I mean when I first went to the GP that was back in (2) June, July time

Ok

(2) but urm CAMHS say you've got to have all the health things ruled out before they'll take you on (1) so (2) so yeah we've got about another 23 weeks to wait now, so (1) and that's for CAMHS. So that'll be well over a year (.) so waiting for the services is (3) is not, /{voice change and facial expression- emphasising point} I've been really, *really impressed* with the psychologists [laughter]. *The educational psychologists* have been very good [laughter laughter] but um, everything else has been a bit rubbish.

/ {voice back to typical} Fortunately at the minute (2) I don't think there is, you know (1), I think you've got to be (.) wary that you know, (.) there's so much can go wrong whether it's eating disorders, self harming um, depression, along with the anxiety (1) umm. We're not, *fortunately* we've managed to avoid that so far, but um, I'm sure there's other children out there that are experi(.)encing it and you know they have to prioritise don't they, so I understand that, um. (3). But yeah it's been really hard, its its definitely had an ur urm impact on the whole family (.) urm (1) [C's Brother's Name]'s OK. He's really, he's really chilled out with it now and things have, are in a lot better position now urm (2). I guess as well, I think in the beginning I was really *really* pushing for her to go to school as well because I was *so*

scared we were going to get fined. (1) I was really really worried about that, I thought (2) and you know that would come up in (.) you know, in conversation it's like "well you're going to have to go back, we can't afford to have a fine"

(44:05)

You know so then it gets, it all gets all like, it's kind of like/ {voice change- impression of giving consequences} "oh you can't have any Christmas presents if we're going to get *fined*" and you don't, you don't, I mean if you think about it it sounds awful but it's kind of like well (.) you know it's (2) it's a really *really* big pressure and I think now that pressures off and and we're able to just manage it (1)

mmm

Without that pressure has been *key*.

Yeah (2)

I mean it's still there in the back of my mind, but they've not mentioned it for so long now so, so I'm hoping they understand that this is a (.) a, you know, once they've seen that we're not just, (.) you know, letting her stay at home for no reason. It's not just a case she's a naughty girl and doesn't want to come to school. Once they've accepted it's a actual problem, they sort of backed off, but that really, that really scared me for a good, (.) a good four months, for four five months I thought 'when are we going to get fined, when are we going to get fined?' and that was a real worry and that's when you're constantly pushing them to get in I think, when really in those first few days we just needed someone to "look it's OK" (1) and basically say "this and it's going to be like this and we're going to do this and don't worry" and have something for her to do, and help her a bit, but uh (.) /{voice slows and quieter} that's what you really needed (2)

(45:53)

Umm (5) we we looked at you know, did she want to move school / {voice change- mimicking an unhappy reaction} "NO I don't want to move school" /{voice back to typical} cos obviously it's not the, that's not the problem cos moving schools is like, oh my god that would be even more scary going to somewhere *completely new*

Right

Umm (1) I wonder if she'll have to move back a year, but (.) they've not, not mentioned that so (.) umm (2) so yeah (5)

You, umm you mentioned 'it's the school' have you ever got a sense of what it (2)

Umm (1) umm I'm not sure (1) I think it's (1) over (.) load (1) in that environment um (1) coming from a school where, you know, they've all been in the same class *together*, in the one *room* from um foundation, right up to Y6 and having quite a very firm, secure (1) well *very* firm (.) um social group (.) um you know, she was probably seen as kind of (1) you know probably a really sort of loved and well respected and valued member of that group and never any friendship issues *at all* (.) and going from that into a school where umm (2) a massive school, where she feels *completely* (.) unsafe. I think that's the, I think that's the other thing. I don't think she, she doesn't feel safe (1) and I think (3) although she looks very confident and she's very able she just doesn't feel, didn't feel safe and having a few of the things that she's (2) you know that we've all had to deal with and we know what it's like at school (.) umm (2) the majority of people get on with it but I you know, I did wonder if there

was sort of (.) issues with sort of sound and and focusing and um and sort of additional needs umm you know like um (.) the dyslexia centre, which was a private, *another* private test that I've had done, which cost four hundred pounds, because they said that she didn't have it. Um (1) so constantly fighting to get things, but I do, I did wonder if ur, the dyslexia centre, you know, she mentioned dyspraxia aswell. Now I don't know much, anything about dyspraxia (.) but I think also it's (.) just, (.) you know like people get *over stimulated* by things don't they and then they find it difficult to manage an environment especially when you're dyslexic and you're having to move from different classroom to different classroom.

(49:24)

(3) different lessons, different teachers, urm (.) the strange thing was that it seemed to start off very well. (2) It *seemed* to when she started secondary school. She started in September and then things started to go wrong about March time (1)

Ok

So the first term (2) /{speech slows} and the first half of the second term seemed to be going alright /{back to typical pace} but then it seemed to sort of go down hill. (2) umm (3) so yeah, so (.) I don't know. (5)

I mean it's just a very umm (1) it was just a really um, I don't know, you couldn't put your finger on anything specific (.) umm because she did faint and then she did go back in again after that. So, again, I think that why we thought that art therapy would help, because, that is, that is somebody who she can talk to anonymously, so if she doesn't feel she can tell school anything, she doesn't feel she can tell us anything then that's somebody (.) to

You wanted her to have somewhere she could

Yeah if she, I mean she veh vehemently denies all (.) problems (.) with bullying and that sort of thing and it didn't appear that there was (.) you know the odd thing, but nothing, you know, nothing constant, you know, the odd situation that everybody gets, but um if it was something like that, if she needed something like a completely confidential area to say and then um obviously then if there was something really major then (1) then they could have let us know, but (1) um (.) so again I think it's really important to know that there's *somebody* on board at all times. So even though [SUPPORT SEVICE PROVIDED BY LA] were rubbish and even though school were rubbish (1) urm, sorry, I don't mean that 'school you've been great', but [SUPPORT SEVICE PROVIDED BY LA] you've been rubbish. (1) [EP name] was good, we had to wait a bit of time for [EP name] to come on board urm, but yeah, initially it was like at least we've got this [Name of Private Therapy Cantre], [mmm which] is just down the road. [Name of Private Therapy Cantre] counselling. At least we've got one thing in place and you, you've got to have something there, if you had nothing you would just (1) yeah it would be really stressful.

I'm waffling, what do you need to know? [Giggle Giggle]

It's not waffling. I'm wondering, when you've been supported well, what that feels like, what that looks like. There might have been a time where you've felt really well supported? Could you tell me about that?

(52:58)

Urr I think it's when somebody understands that em (3) it's when somebody understands the situation. They're not being judgemental in the fact that you're being a rubbish parent urm your child is being naughty not going to school, (2) umm. It's been a very relaxed sort of (.)

softly softly approach. So i.e. not dragging her into school, but you know, well I'll, you know, (.) well just come for, just come at half past three for an hour. You know, *that's worked*. That's like you know on Mondays and Wednesdays (1) so when everyone has gone she can just go in and start getting in to that. (1) But we, we waited nine, ten months for that. So the very softly, softly approach. [EP name] coming in and just talking to her about things she likes and you know, just doing little beads things with her, engaging her, just urm, [EP name] 's very urm (.) gentle and you know very um (.) soflty spoken, and urm (2) not pressurising at all and just you know em always asks Claire (.) you know (2) 'is that OK?' and that sort of thing. You can tell that, she's definitely um (.) working (.) for Claire rather then, and school now are working, you know, 'can you manage this?' 'OK right'. These things have worked, /{pace of speech picks up} where as when it's we're going to fine you or urm (.) come in come in for this lesson. Um well she can't *do* lessons or trying to push her too fast, too soon that has been um disastrous. (.) so yes in a way I guess it has, it will take a long time um (3) um offering different things as well, sort of just, (.) you know um (3) they've said, you know 'if you don't come up to school, we're going to have to come down to the house to do a welfare check, to check she's alright'. Um, which I get and which is fine (1) but um, it's kind of like 'if you can come down and do that, can't you, can't you do something a bit more fun with her, like ur, you know, um (1) come down and (.) you know, I don't know *bring something fun for her to do in the house*, keep her occupied and I don't know, some kind of art thing that then she can colour in, hand back and you can go 'oh well done' and something positive like that, instead of 'ah well we've got to come and do a welfare check if she's not at school and /{very quiet} it's like 'Ok we're here' /{picks up volume} but they never have actually *done that*

They haven't

Cos we've managed to get her up to the car park and then they've come out and spoken to her in the car, so they can see that she's not you know being beaten up and everything. (.) urr (3)

(56:54)

Yeah we've had to do everything to do everything to sort of, keep it, like I say, (1) you know positive for *her,* so um*, (2)* because you know she, /{voice softer and slower} when there is you know, she will cry, you know she'll go "I I" you know, (.) "I don't want, (.) I don't want to", you know /{voice volume back up} "why am I different" and all this sort of thing so there's definite, you know, so you say "it's alright, you're fine, you're wonderful" you know, to keep, and then, then it's *alright*

Right

but it's obvious, you know, (3) she'll (.) she'll not say um (.) I don't think that they can process at that young age. She'll not say /{voice softer, and quieter} "oh I'm missing so much and I'm really worried about what I'm missing and ohh I feel isolated and ohh I feel depressed" /{voice back up} but it does come out as more sort of *anger*.

Ok

(58:08)

Urm (1) And (1) that's when it's hard to remember that it's them, that *they're* going through the bad stuff, *not the school* with their sort of (.) attendance records, you know /{voice changes} "oh this looks bad" /{voice back} Urm (.) uh (.) and things like that. Urm I mean if you've got an Educational Welfare Officer, I mean what does that person do, do they just come along and say well 'you're not in school, I'm going to fine you'? I mean thats not a

welfare officer is it. I mean there's nobody to come down and actually look at the welfare of the child [exasperated laughter- 2 secs] it's just a box ticking exercise it seems. (2)

(58:39)

Did you work with the school's education officer? Is that what (.)

We went up, we went up to school for one meeting where they all sat in a room infront of us and said how awful we were, but that's the only time we've seen them (1) that's the only time we've seen her. (4) we've seen head of house once (1) umm (2) but again they have said 'if she's not in school there's nothing we can do'. (2) but (3) so yeah.

How have those meetings felt?

Oh, it's harrowing, it's really harrowing um, because, like I say, they're not interested in your, they don't understand (.) they just think you're being (.) a weak parent (.) umm (3) they've (1) they've said things like 'you know' umm, I mean to begin with we were like, right you can't reward her for being at home

Mm

So it was like, right so, you you're going to have no phone, (1) no internet, nothing like that (1)

Ok

So being at home is *boring* it, it'd be better. (1) You need to make it so they (.) they be at school.

(1:00:12)

That doesn't work, that just makes her even more depressed, isolated, um (.). This is not a person who's like, 'ah I can't be bothered today, I'm going to stay in bed'. It's not that, so this, so they kept saying, you know, (1) umm, they kept sort of, kind of pushing us, you know, sort of, why are you not (.) you know um well you know, you've got to say, well you're not going to have, not going to have that if you don't go to school.

(1:00:43)

You know, it's definitely a sort of (2) *Remove everything from them*, they were basically saying, until they go back to school and then. Um, but that didn't work,

mm

it was that, it was that sort of pushing them that just (.) didn't work at all.

(1:01:00)

There's a pressure to do (.)

Oh yeah, I mean I suppose nine months on it's absolutely horrendous the, I was constantly anxious that they (.) that we were going to get fined. I was constantly anxious that I was doing *the wrong thing* by (.) you know, you question everything that you do, it's like well you know (1) she shouldn't have any pocket money if she's not going to school um (.) taking everything away, but in in, that's just making them more (.) anxious and depressed, because they haven't got anything then. (2) and you know (.) and I was, you know, I was sort of guilty

as well, I was sort of like, you know "if you go to school then you can have that *back*" (.) you know (.) ummm (1) and you're constantly, you are constantly questioning yourself what (.) I'm doing this wrong, I'm a rubbish parent (.) umm (2) nobody else is having these problems, so it must be my fault (1) but blaming yourself, it's really really hard, umm, (.) what have I done to cause this? (.) umm, you know, umm (1) was it, you know, making her go to pre school, [draws deep bre ath, followed by laughter laughter] *you know*

It feels like you're searching through everything, (.) for anything

/{speech quicker and louder- agreement} *Yes,* no you do it's like, /{typical speech pattern returns} what, what about that time, that you know, (.) umm (2) you know, did I take her to enough play groups umm (.) what have I, have I criticised her too much in her life, urm blame you know, constantly thinking what have I done to make her anxious. (2) Have I done anything wrong like that? (.) you know, (4) so yeah, so you, you are very (.) very negative to yourself as well. (1) umm (3) um. Think it's, [C's dad's name]'s been very good, because he's (.) not had it as much, because he's not around as much and I sort of tend to do the taking to school and that sort of thing, he's always around when he can be, but (.) he's definitely (1) she's yelled at me a lot more. She's sort (.) it's been a very good cop, bad cop sort of situation, where, umm Claire's been all sweetness and light as soon as he's walked through the door and then, (.) you know (.), um "you're a terrible mother", you know, so (1) it's kind of like /{tone change- emphasis- frustration} "but you're not seeing" umm, you know, with me and him it's (.) "well you're not seeing what it's really like", you know. (.) ["you're not they're slightly] different experiences?

Yeah I mean he does, he does, he understands, and you know, he's not stupid he has seen it when it's been bad. (1) umm (2) so he's been a very good at keeping it (.) with the rewards system, but that's been a little bit different

(1:04:20)

Different for me, because, she's got a reward (.) for going up and (1) maybe sitting in a car park for five minutes (.) and (1) umm then coming home and yelling at me for half an hour and she's got a reward for that (.) and that makes you question the parenting (.) skills, umm, you know well 'she shouldn't, I don't think she should get a reward /{whisper} for that (1) /{typical voice returns} umm (1) and he's like 'no, no everything' so he's been really good at keeping it positive, when I've been having a really bad time of it. (.) Umm, but then you know you've got to make sure, if she's getting rewards, then [C's Brother's Name]'s not being left, [OK I'm like] [C's Brother's Name], [C's Brother's Name] is going to school he, he's doing his, he's doing his homework and as much as a teenage boy does. (.) and you know, so I've got to like make sure that other children, you know, you've got to make it even haven't you.

Mm, you want to recognise him too

Not to, not to have him feeling left out. So yeah, (.) especially when I've had a really really hard day, it's been *good* that he's been able to (.) umm, you know, be positive, because I can imagine if, you know, I have thought some days, if I'm a single parent on my own dealing with this (2) you know, I'm in (.) quite a fortunate situation really. It's uh, (.) you just need to go and, you know, just lie down, it's (1) wake up the next day and go again really.

You have to look after yourself

You do, you do have to look after yourself, that's right, you know 'I'm going down to the gym, I'm going to burn off some (2) but you know if you're in a situation where you've got other children, and you're on your own it's ah it's aw, (.) it would be *incredibly* hard, you'd need, you'd need some serious input. You really would.

From other? (.)

From, from other people. You, you always, as I say have one other person on board, but we we've had [Name of Private Therapy Cantre]

Ok

If we hadn't have been able to afford to pay for that, and it is quite, it is £50 an hour every week. It's not cheap, but (.) if we hadn't have had that then, you know, (2) it would be really, really hard and that and if you've got sort of school fining you on top of that (4) really really hard. Um (1) and again just working around it, as I say I'm very fortunate that I can work from home if I need to but (3). *We're in a very fortunate position and it's still* been incredibly, *incredibly* difficult to ur (.) deal with.

(1:07:35)

(4) stressful um, (.) depressing um, (.) you know, like I say you criticise yourself a lot. (1) Umm I mean school actually gave us something /{gets up to get leaflets} last week. They said 'oh we realise how stressful it is on parents'. (.) I've not actually looked at it yet. 'oh we, realise these sorts of things can be stressful on parents' so they've given us this. This, this is all we've had in the way of help for *us.* And this was last week we got this. (.) So (1) we've had that, positive parenting (5) /{thumbs through leaflets}. I mean, I honestly, don't think I've got the energy to take anything else on at the minute, I've got quite a stressful job myself, um and just 'oh, what to do when school appears in' you see I'll have to read this when you've gone [laughs laughs] (1) right (10) /{looking through papers} you see we've really done all this. (3). I mean I think one thing that um I will say, (.) *and I hope* school will back me up on this (.) is that we (.) have (.) urm (1) always said we want to work with the school, we've always been like thankful for (2) for *anything* that they've done, although it hasn't been yet been successful. I think it's all ur, (.) you know we're building on things (.) isn't it (.) urm. (.) Although we've not haad a lot from school they have, you know, they've, they've worked with us

Mmm

They've said right, lets try a new timetable, lets (.), lets have a meeting, lets offer the nurture group umm 'just come in whenever you want Claire' 'just come in to learning support' um (.) Abby will be your key worker.

They have offered things

They've offered things, and we have always said thank you, we've not bowled up there and gone "your schools, this schools terrible, you don't support children" and (.) em (.) we've really, well we haven't felt the need to do that, but uh, I know that um, when I've spoken to other people (1) they've said to me 'well what are school doing' and I've said well um

(1:10:39)

(2) there's not a lot they can do /{impression of outrage} "ah, well I think that's awful, I'd be up there" you know /{voice returns} "I'd be up there yelling and screaming at them", but ur (2) I think that's something we, we've done, I mean it says here, contact the governors if you (2) if you're still unhappy. It's not, (.) not that we're not unhappy (1) it's just (3) these things happen, so (.) anxiety going to school. I mean they've done things like yeah (1) given her a card so she can get out of classes if she needs to (.)

Ok

ummm (4) they always let teachers know of issues, however no urm, no teachers have tried to contact her or, nobodies umm (1). You know people have said "oo, where's Claire?" but nobodys actually sort of popped round and seen how she is or, (2) she's just invisible to them, and I get that, they've got hundreds of pupils, but umm (3) yeah, it it's all good to know isn't it.

Yeah, It is helpful to know what's out there

There's anxiety Uk here (4) gosh, one in, one in six sixteen to twenty four year olds have suffered from an anxiety disorder (9). So yes, so I'll have a look at those.

(1:12:41)

Do you want to have a look at some?

Mmm that would be interesting

[offers leaflets- I accept them]

Thumbing through them.

Sheffield, mmm, Sheffield parenting, young mind. [reading from booklet] Why do young people become anxious, having difficulty at school, being bullied [commenting on] (5) yeah, school worries (12) yeah, (5), I mean the other, umm (.)

(1:13:28)

I, I was going through a particularly bad time myself round about the time she uh um (3) she uh (.) stopped going to school, mm, my best friend died

I'm so sorry to hear that

So um, (.) so I think that was (3) I think it just (.) important to be aware that there are things going on as well, other than school, other than just school sometimes, (1) umm so it was my best friend they actually committed suicide (.) uhmmm and um they'd got um (.) so it was a big shock and they'd got a brother as well umm with learning difficulties um um so I had to (.) so I was off work for (1) I was off work for ten weeks, cos as well as sorting out the funeral they were in the process of selling the house so, sorting out the funeral, selling the house um looking after the brother with learning difficulties and urr Claire not going to school.

That must have been incredibly difficult, you took a lot of things on

Yeah I was doing all that, yeah I'm still looking after him now. /{speech slows} Umm (1) so there was a lot going on for me personally as well so it, (.) in a way and then then of course I was thinking well am I spending too much time sorting things out and not with Claire, you know. (.) It's it's very difficult to manage *additional* things on top of the um

That's a (.) that's a very difficult

Yeah, so whether or not, you know I was like, I mean she was already missing school at this point, (.) when this happened, but, whether or not this is a. Anyway I had about ten weeks off work, so I was determined to go back to work, (.) because I wanted her to see that even though, you (.) /{speech quickens} have time off work and things are *bad* you you, you know, you could still carried on and things, you know you'd come through the other side, um, but yeah (.) but that didn't help [laugh]

(1:15:47)

She didn't just suddenly pick up her bag and go 'oh mum's gone back to work, right I'll go back to school then' [laugh laugh] So yeah, so that didn't happen.

You wanted to model it?

So, yeah, yeah (1) if you do go to the GP parent wise and um, like myself, you know you say you know you are (.) um stressed or depressed or whatever, they do offer you IAPT umm, which in my experience is not (2) it's pretty useless. /{slower speech} Uhm (.) but yeah there's no kind of (.) counselling or, or (1) formal kind of help that I'm aware of for parents who (.) /{picks up/ returns to typical pace} are having a difficult time I guess. Certainly (2) I I don't know, I've not tried to access anything, so um

Yeah

I'm not sure what if you said, (.) I'm not sure what there is if you went out there and said my child's not um going to school I'm having a flipping nightmare. I'm not sue what you'd get offered. I I could do that. I haven't tried to access anything, the first thing we've been given is this last week, so (4)

Mm, it's not forthcoming

Yeah, no they haven't said ring this number this person could help you because there probably isn't anything like that in *place name*

Mm there can be different things about, dependent on the area you are in. Most areas will have services like Mind the charity.

Yeah, I guess you would have hoped some of those things might have come through [SUPPORT SEVICE PROVIDED BY LA]

In terms of advocating/ providing parents with support in things to do with Education, there is also SENDIASS; so they can do things like go to meetings with you in school.

Oh I've not heard of those. Nobodys mentioned them to us. See what you, what you could do with, almost is like a kind of, somebody [to say cribsheet]

Yeah, yeah, somebody to actually say, I know people don't want to label,

Mmm

But nobody's said 'this is school refusal' , (.) nobody's said that to us.

OK

Nobody's said this is school refusal, don't worry, (.) expect this, contact these people, this is what we're gonna do. It's just you're bumbling along unknown

mmm, how did you come across school refusal as a (.)

Oh I Googled it, (.) urm, and [C's dad] joined a facebook group (.)

Right

called um (1) school refusal and anxiety I think, (.) which is just a lot of parents on there going "Help we're getting fined" and, and all these horrendous things um, (1), we're getting no support and (2) yeah (.) um (1)

(1:20:15)

So kind of I'm googling around (1)

Mm and you've found other things.

Yeah, but again 'school refusal', I think that's, that's a really, I don't like that term at all cos it's like, the person, I don't like it

Mmm

She's not refusing to go to school.

No

She's not saying, "Claire will you come to school?" "no". She's not refusing it in making that capacitous choice to not go.

No, it's not a fair term

Checks whether anything else I want to know- I say no, is there anything you wanted to say? Or to ask?

No and no

Appendix L: Laura's transcript

0:00
1-its your story that i am interested in. there aren't any rights or wrongs and you can tell me whatever you are comfortable with saying. I just wondered if you could think back to when for you it all started. Name was finding it difficult.

I think it came to a head (.) in June last year but (1) when I think back he was struggling (.) but I sort of didn't *see it* [yeah but] when I think back I can see it now in hindsight and I think he did (.) he struggled to get to school (.) every day (.) and and he *dreaded it* and some nights he'd say 'oh I really don't want to go to school tomorrow *please* don't make me go and, you know, and then it just one day (.) he *simply* just refused to go but (1) I knew he weren't being lazy or out, because he's not and I know that sounds biased but he likes his routine Yeah so I knew there was something *really* wrong (1) so I went up to the school with him and we had a meeting ok and teachers discussed like that he could go later and urm come out and so, erm *but* it just, it were just the anxiety in the end. OK The anxiety of going to school./ {voice quieter} he really *really* was scared. (2)
1. and he was telling you some of that at night that that was
2. mm so yeah like if (.) I think, I don't know *how many* months but I know it were months. He *really* did struggle to go and he was sick on a morning (.) m he were literally *sick* (.) every

morning because he was that scared to go. So he struggled to go though he really did try and now when I think back (.) I just think 'wow, he really did try' (.) force himself in. He thought he'd get over it, but.

1. he was trying really har[d yes]

2. yeah he really *really* was (1) but (1) it came to a head and it was like we can't do this anymore. He's *pale* (.) all his energy was going into just getting to school and he weren't his self

1. how was that for you

2. it was awful. it was (3) it (.) were like /{voice softer} just (.) /it made you feel physically sick that he were unhappy because that's all you want for your children you need them to be happy and healthy mm and it were like, I had to look at bigger picture and think right what's important, (.) his health and happiness o*r* his education. That's what it had to come down to. I mean we went to A&E with him, to doctors, went to school meetings right (.) we (.) because at one point we went to one school meeting (.) and I mean I were with him, his sister was with us and he was *white*, he was *shaking* just by being in school environment made him (.) physically sick and I'll I was *with* him and it (.) still could see him and the SENCo up at school she says I think you need to take him to a doctor, like look at him and she could see it straight away. (.) So we took him to the doctor (.) and the doctor advised me to go straight to A&E with him so he could see CAMHS soon*er.* (.) OK Urm (1) and as soon as (.) it was like 'right you don't have to go to school, stop worrying about that' (.) after and then *I were* worrying about him not going to school. It were like *I* was thinking about the future *long term* like what about his GCSEs? what's he going to do in future? what's he going to do when he's *older*? And then (1) you've sort of got to break it down and not think (.) that far ahead you've got to think tomorrow and today that he's here. (.) because when your child says /{wobbles} I'd rather not be here, (.) I'd rather die (1) than be feeling this feeling that I am feeling (.) then you think to yourself /{self assured, clear} right what is important. Mm (.) So you've got to think of *today*. He's here and he's happy today yeah (1) and just break it down then and think of tomorrow. He's here and he's happy and he's a different, you know, and not look that far ahead yeah (1) and that's when you you've got to get your priorities and think right he's (.) he's happy now, he's healthy (1) and he doesn't want to die. (.) That's what's important. Not GCSEs yeah *at the moment*. He's got and like when he does get (.) he's got *a lot* more confidence now and I don't worry about him not going to school now (.) which was a *massive* worry. I mean I weren't sleeping, I was physically sick. I was that worried for him but (.) now I think (1) I'm glad I don't worry like that. (.) We're not being selfish. When I break it down he's happy.

1. and that's what matters [yeah to you]

2. That's what's important and I think any parent would agree that's what's important. Yeah Not what's on paper. (1) So (3)

05:41

1. when you were worried about him not being at school, was it the GCSEs and

2. it was education, (.) it was social (2) you know it's (.) it's like I suppose you think (3) {big breath out, brr} it's not normal, *but it is* normal, *he* is normal (.) and for him to think he's not normal and for (.) your child to say (1) I wish I was normal like everybody else (.) that's heart-breaking (.) cos then you convince them *you are* normal this is your life this is *your normal life* it might not be somebody else's normal life but it's your normal life yeah (.) and he's very happy. He, he likes his own company which (.) is good. and I'm glad *I've learnt* myself that he's (.) happy and yeah it is his normal life (1) and (.) you, you never know you can think oh in three years, two years, one year he might think 'oh I want to go to college and get my GCSEs. mm you just don't know what's going to happen in the future (1) so /{pace faster} you can't make up a story about what you think is going to happen and worry about something that might not happen mm so yeah (.) /{voice slows} he's a lot happier which /{assured voice} if he's happy I'm happy yeah

..

07:30

2. so yeah (7) it's now, I don't know (.) you can see a *difference* in him. You know, when I, when I think back now I think (.) how could I not tell that he was pale every day? (2) His, his head down and he shrunk, shoulders were down and his head was shrunken. (1) and I think back and I feel guilty (1) that I didn't see that (.) but, like (.) *at least now we know* and, you know, it, it hasn't gone too far, as he hasn't harmed himself or (1) you know (.) [mm but] you do, you feel guilty that you've like sort of said "oh just go to school, just stop being *lazy*" mm (1) mm which /{voice slows} I think most parents would mm "oh you, you're just tired, you're just tired yeah and (.) you're all really really worried and anxieties, (.) nerves (1) which he does in some situations still.

1. in other areas of .. is that in different places ..?

2. he yeah, if we go somewhere new (.) yeah He's alright here, he's alright *with us* yeah but (1) I don't know how to explain it he's (.) I think it's like (.) he's getting diagnosed or he's getting assessed for autism OK (.) we think its stemming from

1. and they're assessing that at the moment mm yeah

2. . yeah he's going to next level of (2) but yeah (2) but I think we've all us, (.) *I have anyway*, and some other family members, (.) have all seen the sign (.) of some sort of autism but not enough to *diagnose* it because it weren't affecting his life, but now obviously it is. Well, I say it is. I don't *know*. (.) It is because he doesn't go to school mm but (.) we don't see it as a *problem*. (1) It's, you know, it it's just (.) it is what it is, basically. Mm (.) so (2) but yeah we've turned a corner yeah (2) and to go, and there's a lot online actually because when I was thinking (.) he he is at home *everyday* but we've got rules and he *likes* to stick to them. Ok so, so he needs that routine so when the alarm goes off /{pace quicker} he's got to get up /{back to typical} which is when we go to work yeah so when at the same time he'd get up if he was going to a school. So he's got to get up. He's got to have a wash, which you want [laugh laugh] yeah brush his teeth, get dressed yeah have your breakfast (2) and do some *work* (.) which he does online (.) OK (.) ur it's called IXL right and it's an education site. Ok it's good, it's good (.) so that keeps his, so he might do an hour's English. *I do pay for it* but it's worth it. Because like (2) if he was going to school I would be paying bus fares and dinner money OK (.) and uniform [yeah so] instead my money goes to that and he does, he's he's got his rules, he does so much, an hour's English, an hour's maths and (1) that's, *that's good* (1) and it makes you *feel* better (.) because he's doing something. Yeah and I, I've *learnt* loads of new things like, like I need to be a home educator, well *I'm not* a teacher *I can't* do that, *I simply can't*. mm but then when I went online, like, you just Google it 'what do other parents do' and I found loads, *loads*. And like all these reviews (.) and that helps OK and you, to know you're not the *only* person. (.) because at first you feel like a bad mum /{softer} but you aren't (.) no, I've learnt I'm not [laughs laughs] no not bad, no, I might have said that wrong, not feel like a bad mum but feel (1) I *don't know* I don't know what word is (1) like you're not doing something right. I don't know, not *bad* cos I know I'm not a bad mum but (2) I don't know what the word is like (2) out of your depth maybe? you don't know mm what you can I do to help. (.) But yeah we're a lot happier now, (.) *everybody's* a lot happier now [laugh laugh]

13:05

(2) so (11)

1. so you were saying it was the whole going to school and the being in that environment was making him anxious

2. yeah it just seems to be the school environment, it (.) and it's not the people. He, cos just like he got offered to go to school, like after school when everybody has gone home right but he just associates school with anxiety. (1) so it's in his head, that, (.) or maybe not in his head but its associated, so when he goes to school, he feels anxiety, he's scared, he's shaking and he's physically sick. (1) Whether there's people there or there's people not there. (.) Just the school *itself* so (.) and *he can't* explain it. no It's hard to explain. (.) so (1) yeah it's just the school environment, the place. it's not *the* school, it's *a* school, *any school* mm (2) it's just scary for him.

1. the whole, the whole place

2. mm hmm (7)

14:30
1. he's secondary school age isn't he now. so primary school?
2. he went through primary school, yeah he were fine. He (3) he *used to*, (2) on his first day back, *so* Easter holidays, Summer holidays mm (1) first days back were always hard for him. *Always.* After all the breaks. Yeah, so, (.) But once he got in and settled and he was comfortable, mm (2) he were alright. And I used to *hate* school holidays, well first day back I did, the *Sunday especially*,
15.13
(1) Sunday were always a hard day for going back to school next day. So, but he were, it were just (.) *back then* it were a case of getting that first day over and done with *and then he was fine* yeah but then when he got, (.) like last year, it was like that first day getting it over and done with was *every single morning* (1) and then new feelings came back every morning (.) every time he woke up and he had to go to school. That it was like that first day after school holidays *every* day. (3) so (1)
1. it didn't go away for him
2. no, it was all brand new next morning. (.) so and it were and I'd say "you're not going to feel it though, you like school, you don't get bullied." I mean a lot of times he's been asked do you get bullied. He's got friends, he's got a lot of friends. He doesn't get bullied. Yeah (2) just It was just *fresh for him* every morning, that feeling (2)
16:25
2. and he couldn't go (.) and he couldn't get on the bus and go to school because he was busy being sick (.) m so he had to go on his bike (2) so that he had the choice to stop and (2) be sick *I suppose* (.) and then carry on (.) and then get to school and then in his first lesson (2) I I've learnt this since (.) every first lesson hand up "can I go to the toilet", be sick, (.) *didn't tell them that*, just said he needed toilet. (.) because he couldn't *explain* (.) to em that *he weren't poorly* (.) he were just (.) feeling *anxious* that made him sick yeah so (2) but that's he went through that everyday for months. (11)

2. That sounds like that's something that, that's quite hard for you to know (.) now.

1. Yeah, it's awful yeah. (.) That's where the guilt (1)/{wobble} hits you. But (.) *I know* I shouldn't feel guilty because it weren't nobody's fault (.) it it weren't a fault, it were just a feeling that he had and he couldn't explain, so he couldn't tell nobody (2) so, he just, that's how he felt he couldn't explain how he felt. (.) so at first you just feel really guilty but that's eased now because you, you've got to tell yourself, you know, it's not your fault (2) you didn't cause it (.) just his feelings. (8)
18:33

It sounds like it would have been very difficult for anyone to know yeah he couldn't say and you couldn't have been there when he was sick in school no (8)
Earlier you mentioned there was a feeling of being out of your depth?
Yeah (2) and (1) you (.) you want help (3) erm (2) but I think in *our case* (.) we helped each other in the end mm (2) You just (3) I look back now and I think (1) yeah, I couldn't have really done anymore mm (3) I don't think, oh I should have done this, I should have done that, because I just simply didn't know (.) so and I do *feel* we've done the right thing (2) can't force him to feel like (1) When your child, he never expressed feelings of wanting to kill himself (.) It didn't get that bad. But he did say, which is a *difference*, he'd rather not be here than feel like that. (2) So then you'd hear that and it's a case of you'd take him out of that situation where he has those feelings because that's what you got to do. (.) And I know in life you've got to do some things you don't want to do, (.) but (3) not to that extent.

No, it sounds like you wanted to protect him from that
Mm Like any parent I suppose yeah (8)

20:40
1. Yeah. You said you both helped each other can you tell me more about that (2)

2. I just think *as a whole* in the family (2) we, (.) we all agreed and stuck together I suppose.
Mm It weren't an (1) argument of (2) or (1) It were more *understanding*. Instead of (.)
everybody arguing and "oh you you've just got to go to school and that's that stop being silly"
mm (.) it's because (2) you've got to *talk* (.) and you've got to listen and that's what we
did. So and then it's like understanding (2) not closing (.) your mind off because you don't
have them feelings that they don't exist because *they do*. So yeah just *talking* (2) like I said
and listening to each other. (1) yeah (6) yeah (3)

The understanding kind of grew through listening and talking (4)

2.Yeah. It's, it's um (3) what's the word? *more* (2) common than what you think (3) There's a
lot of people going through what are (2) people with (2) anxiety. m (1) And I know sometimes
the word depression comes with anxiety but *he's not depressed* he's just (.) he has anxieties
in certain certain situations. So (.) but no it's not not depression (8)

22:53
1. Can you tell me more about the situations he might feel (.) anxiety might visit him in?
2. Um (.) yeah ur (1) meeting new people (3) urm he (4) he doesn't get so much (3) urm
what is it how can I explain? (1) he gets uncomfortable m if he yeah (2) and he doesn't like
(2) to *talk* about how he feels to other people (2) because (1) he doesn't see a reason
to. Why (2) Without being rude. he doesn't mean it being rude. He's definitely not a rude
person but he'll be like 'why should I tell somebody how I feel? I know how I feel (1) you
know I've already told you why can't you tell me' or (.) urm for example if we have (2)
somebody new coming to the house, like with changing hairdressers for an example ok so (.)
he'll like he'll not go to a hairdressers. Or he would at a push but he will feel
uncomfortable. Like if he goes to a barbers (.) and they're talking away to him he doesn't
want to (.) he doesn't want to small talk to somebody in that situation. Yeah he's more
comfortable in surroundings, he gets to know his surroundings and then he's
comfortable. Yeah (1) So like we tend to go (1) to the same place for Sunday dinner
Yeah So you know what I mean mm or (.) he (.) *cinema*, same cinema, cos he knows his
surroundings. So if we go somewhere new, if we went to a *different* cinema for example he
like (.) he sort of walks in and he's eyeing it up m (1) he's, he's getting his bearings and he
doesn't like loud noises that hurts his ears and it's somewhere new basically he has to find
his bearings (.) and where he is and get (.) *familiar* with his surroundings I'd say. Yeah (3)
1. It starts to feel less new 5:30
2. *Yeah,* yeah, and then he starts to relax then (2) gets comfortable with the place and (15)
1. It sounds like (.) urm (1) you said before we started, that school is not an option any
2 *no* because, in the near future, it's not, because he's *more relaxed* and he's more happy
because we're not forcing it. It's not like 'oh eventually we have to go back' because that's a
constant worry and *nobody wants a constant worry*. So to lose sleep, to lose your *appetite*,
(1) to, you know (.) colour goes out of your face and we don't *need* (.) that worry (1) that it (.)
or eventually we're working towards yeah cos that were the goal, we were working towards
(1) gain your comfort and get back into school. It were a constant worry. So now that's not
the goal and then it (1) it's not a constant worry yeah
1. (2) it was hanging over him when he thought that was
2. Yeah, (.) yeah. (5)
27:20
1. I suspect kind of inevitably that when these things happen that different people start to

get involved from school and other services. Can you tell me about your experiences?
2. So (3) like (.) only person we've really had support of is EP, so (.) obviously educational psychologist yourself, she's helped. We were asked if we wanted a family support worker from school right and they did help me so the forms out for us to get a family support worker and that were months ago and we've not heard anything. right I know obviously there's waiting lists, I know that but now urm (.) I feel we don't really *need* mm I mean some families will yeah But we we're alright. We're (1) but at *school* we weren't supported one bit. They just *assumed* (2) that he didn't want to go. (.) And it (.) to me (1) I *feel* like he's just a number to them. They, they want the attendance up and they wanted it to look good on paper, (1) that's how *I feel*. M That (3) that's all they were bothered about (2) n (.) yeah. Think (.) they were like urm we need to get him into school, we need this and I'm like no we *need* him to be healthy, we *need* him to be here. Not (.) we don't *need* him in school. We're not, you know (.) like urm attendance lady, I mean she's *lovely*, she is lovely, I've spoke to her *but* It was like I was getting a lot of (3) off of head of year mm (3) I don't really want to say out bad about them *but*, I did (.) not threatened (.) I don't know what the word is, maybe (1) they kept mentioning *fines*. "If you don't get him into school you're going to get fined. Don't want you to get fined" So then *that* made *me anxious*, not anxious (.) like worried. I can't afford to pay fines, so then we had, we had an appointment with CAMHS, a *lovely* lady there and she told me about ur (.) SENDIASS? [Yeah yes] (.) so I ur phoned them for a meeting at school, and one of the ladies from there, urm (2) when we went to schools, head of year that was in the meeting with me didn't know (.) he had to Google what SENDIASS was, he (.) he didn't *know*. I (.) I'm not saying it were his job to know but it were like (.) you're telling me all the time about (.) I'm going to get fined and *it's scary*. It's scary when you think you know (.) I'm like picturing police knocking on the door yeah (1) and that's not *fair* (.) for them to make you *feel like that* and (.) and (1) to just have you worrying, making you feel like you're doing the wrong thing and all you're trying to do is like your best. (1) and then you've got (.) I suppose I had to prioritise (.) *who* were more important m how *they* felt at school or Joshua *obviously*. Yeah (1) It's your child isn't it. So (.) then you start to get from (1) upset to angry, like who are you talking to, I'm going to get fined. I've been worrying for weeks, (2) like *really* worrying (1) about and then (1) when I met with the lady from (.) is it SENDIASS? It is yeah *she* made me feel *a lot better* did she yeah (.) and for her to come to the meeting with me (.) and ever since she did, nothing, *nothing* has been mentioned about getting fined and I think there was still a bit more she could explain a bit better for me. Yeah you know it was nice to have her support and (.) so they helped me. I'd never heard of them, school never told me. *I'd never even heard about ur educational psychologists* the school *never* mentioned it. And they were like, and I mentioned it to them because I kept /{quick pace} googling, googling, googling /{back} ur reading things urm I think it were, I don't know if it were CAMHS actually (.) can't remember now.(1) Sometimes I wish I had made notes from the beginning because there's that much (.) urr told me so *I* phoned went off, I phoned the school or I went in and I mentioned ed psych to them and they were like 'no you can't have the support off them because Joshua's not in school. You get Josh into school, you'll get the support. And I were like you don't understand I *need* the support *because* he's not going into school (.) but school were saying if he goes into school ed psych will help him and I was like we're going around in circles (.) you're not listening to me. (1) They just weren't listening.
33:38

33:38 And I don't know how I got them to listen in the end. That might have been sendiass as well (2) That's why that took a bit longer because they just weren't listening to me. At school they just assumed (1) 'oh he doesn't want to go' (.) another naughty kid (.) but really all they had to do was look at his reports and see what (1)
1-it wasn't like that
2- Yeah (.) all his, you know his (.) very good reports. There weren't a single bad one. Never has been all his life. So (.) if they'd have just looked him up and not treated him as a number (.) /{discouraged, sad} they'd have known that m (.) but (5)

34:36
2- so yeah I didn't feel supported from school at all (5) and then when it was first happening I was like (1) Can he have, can he go (.) I know they do computers at school so I asked (.) urr head of year again, (.) went to another meeting (.) I spent a lot of time up at school yeah [laugh laugh] can he have some work, is there a site he can go on for any of his lessons. can you give me any work? (.) No, we can't support work at home because then that's supporting him that's encouraging him not to come back to school. (.) and I were like, yeah but now you're making his anxieties *worse* by not supporting his work at home (3) OK yeah and they were like yeah but we can't give him work to go home because it's encouraging him to stop at home. (2) No we're not encouraging him, we're (.) they just *weren't* getting it. (1) They just *didn't* understand at all that giving him some work (.) eased his anxieties. So because school weren't helping him, (2) I think they kind of (1) lost his trust then m (2) /{way it is} so he doesn't trust (1) doesn't trust them (2) I think. He hasn't said that, m but that's what I think. (.) Since they won't help him.
36:16
And he was asking for it *himself*. He was asking, (.) can I have all this work at home and school were: just no, can't encourage that (3) Hm, thank you. [laughs laughs] he was asking mm (11)
36:40
Senco lady (.) up at the school (1) yeah she helped me fill (.) I phoned (.) I think she just got a new job so there were two ladies but the one that just got the job that I was (.) dealing with, I asked her if we could fill a form out for autism and she said that it weren't her job to do that and that your GP has to do it. (1) Luckily on *my behalf* my daughter's Senco herself right in ur (.) preschool though And I know it's different ages (.) but (1) I were telling her that (.) you know this lady here says she can't fill the form out and I have to go to GP. Have to do it myself. She was like I know it's a different age group but *I'm sure* (.) Because I said to her on the phone (.) how can I go to the GP (.) to fill a form out for Josh (.) when he doesn't see him on a regular basis (.) and it was the senco lady at the school that *advised me* to go to the GP (.) so she could see straight *away*. And she said I think (.) you know 'you can tell he has no eye contact, he has trouble with his ears,' you know, and some other things you could pick up on, she were like 'he's fidgety'. But then she told me she couldn't fill the form out, and then when I spoke to my daughter she said yes she can it's actually *her job to*, (.) I wouldn't have known that so if someone else were in the same situation m and (.) they didn't have their daughter to tell them but yeah it is their job I'd have not got that form filled out so when I phoned her back and I said like said it is your job and she was like alright and *then* she met with me and filled the form out and we sent it off. But you know if I wouldn't have pushed it I wouldn't have known what to do, (1) there's just no support *at all* from school. (19)
39:10

1-So you've had to fight for a lot of (.)
2- *everything*, yeah basically (7) yeah there were no information (.) I didn't know (2) anything (.) I didn't know you existed, I didn't know SENDIASS existed (3) I don't even think I know (1) I've obviously heard of family support workers and CAMHS (.) But that were just like what I've heard other people say (.) but I'd never even heard of Ed psych, never heard of sendiass, never And I weren't informed (1) it's just what I've learned myself.
39:58

1-lots of Googling
2. yeah (3)
1-And family members by the sounds of it.
2-mm hmm yeah
1-it sounds quite isolating (2) to just hit brick walls yeah and be told No by everyone

2- Yeah, yes it's no we can't do this and no we can't do that, or (.) go to them like (.) then it's like yeah, just yeah (1) I think especially if you were(.) if, I'm not, if you were a single parent I think it would make it a lot harder as well because then you would be on your own wouldn't you. (5)

1- yeah, had that made quite a big difference having the support of the family

2-yeah (.) yeah.(3) Yeah, I've got a good family (8)
41:28

1- can you tell me a bit more about your meeting with Sendiass and what they did that made you feel (.)
2. ur I think that was more (.) I think they're more to do with the legal side of things aren't they, yeah, they [advocate for parents so that was more] like to put my mind at rest with the money side (.) and *pressure* at school, trying to get him into school. I think, sort of, when the lady came to the meeting *with me* (.) *then* they sort of (.) how can I put it (.) backed off. they weren't pressuring me as much, so that was a bit of a relief (.) that I weren't getting pressured by the school that he needs, he *needs* to be in, (1) that if you don't get him in (.) er can I, can you just be aware of the fines and (1) you know, it were like, I was getting a text *every morning*, er no every day, but school wanted me to phone them every single morning and say he will not be in today, and I was like, I keep, you know: I get up and go to work, you know he's not going to be in and I know it's only a phone call (1) but then I get a text saying (.) er your child has not been into school today blah blah blah blah blah, can you give a reason? Although I phoned up that morning and said he will not be in school today you are aware of this, there are ongoing, (1) you know, explaining myself over and over again every day to em (.) when they knew the situation. It's a bit draining. Yeah It, you know, It's like you know, *you know* why I'm saying the same thing. I felt like recording myself, and just putting it on record when when I got through, it were just everyday saying the same thing (1) and it, and then I'd get just a phone call saying 'just so you know and so you're aware that it is a (.) that it's a £60 fine whatever. But you're not thinking (.) oh it's a £60 fine, because then it can be per term or per half a term (.) and it's like when you work part-time it's your wage at end of year. Yeah [laughs] And I've got bills to pay for [laughs laughs]. I (.) weren't *just* thinking about money obviously, but it were just extra pressure yeah (1) that the school put on me. (1) so (.) it weren't nice (3)
1- no, no not when you're already worrying about somebody you really care about Yeah (2) No you don't need more heaped on on top of that
2- no no (1) that's a *massive* worry in itself. You, you know (.) obviously you're trying to, the child comes *first* but like I said it were just extra (.) just on top of it (.) that you could do without yeah (20)

45:25
1- is there anything else that you want to share about
2- No I don't think so, no I'm thinking (.) I think that's it (7) I think that is it
I mean we've got (.) one child (.) out of school with 0% attendance. We've got another child, *same age*, in school 100% attendance all the time. M (1) and I think (.) if school would have looked at that (1) they'd have seen it's not a case of (.) 'oh them parents don't care if he's not going to school'. (.) If they had done a bit of research and seen that he always had a good attendance and (.) yeah top marks, you know, (.) his reports were *always* good, *always*, (.) but they just didn't care about that. He was just a number, they wanted attendance up because it makes them look good (3) In my opinion mm (11) Yeah I *think* that is everything I can think of. . .
1- schools have looked at parents as if
2- I don't know. (.) I suppose you can't *really* say that because you don't *actually* know what they're thinking (.) but that's the *impression* that *I got* (2) mm they did (.) to be *fair*, right at

the beginning, (.) they did *try* (.) a little bit in where they said, (.) urm and *I mean a little little bit*, (.) what if you can't come into school and you're anxious, (2) this is what they said to him: why don't you come in 5-minutes later and go home 5 minutes earlier, (2) that were it basically, (.) er and he just said yeah (.) I'll do that but he said that to shut them up so he could get out of school quicker because he was anxious being in school and he was like yes I'll try that. OK And then that obviously didn't work, he'd just come out of school and that's when I had to take him to A&E because he was like 'oh wow' (.) thinking he had to go back into school next morning so that's solved nothing. (1) Yeah Urm (.) and then let me think actually then they offered for him to go into what you call [resource base] in a school (1) but it's where all those children were going that were misbehaving. Right Like, Not isolation (.) but like a separate room with not as many children in (.) yeah will he be more comfortable there yeah and I'm like he's a (.) you know he's not a trouble, he's not a (.) he doesn't want to be with these children who are misbehaving (.) because he doesn't misbehave, he's not like that. (.) So I I don't see how, he were like 'I don't want to go in with all them' that made him *even worse*. (.) So no, I just, I feel like they were just (.) 'oh go in that room you'll be alright' (1) you know. (.) No, so, you know (2) I don't know if to say (2) they didn't (2) yeah I do know to say that, they, they do think of him as a number and they did want attendance up, that's definitely m the impression I got (.) so. (2) In fact I'm sure I heard them, I heard attendance lady and head a year in a meeting mention numbers and I did actually say (1) my child is not a number (.) he's a person. And it was like 'oh no we didn't mean that' and they were like and 'numbers aren't important to me', (.) you know and that sort of (3) upset me to be honest because your child's most important, not your numbers and I can't believe you just said it in front of me, (3) so

50:17

50:39

1- thats a hard thing to hear (6) anything else you want to share?

2-...no (5)

1- Thank you, I'm sorry some of these have been your experiences they're not all . .

1- As a parent sendias never gets mentioned from an educational.. that came through the medical side by the sounds of it

2- mm (2) definitely yes

51:55

Appendix M: An example excerpt from a transcript analysed using the LG

(25:08) With her once a week and then gradually build that up and then say you know (1) "Claire are you going to come to my lesson" you know or, there's there's just been basically like I I guess teachers they're they can't. (4) Umm the Art Therapy you know that's costing a lot of money, so there's big financial pressure urm (3) and then you think is it worth getting another, a private tutor but then (1) she is starting to do some work at home now so that is helpful. Yeah (3) Emm (.) (26:24) But yeah she's sad cos she is missing out on a lot of things (1) Mmm (3) like she was due to go on a ur um choir trip last year that she missed out on, they were going to go to Germany (1) um and this year they were going to go to Barcelona with the Football team but you know she's lost out on all of that so um that's why it's really really important that (2) to (2) even though it is incredibly hard to keep positive and to keep it positive for the child because they are missing out on a lot (1) and (3) they will you know it's (3) when there's been hours when she's been screaming at me and you know for (.) and trying my best and she, she screams like um (.) / {impression} "this is all you fault" and (.) "you've done nothing to help me" when, when literally you have tried (.) you know everything and you don't know what to do and you know when it's killing you and when they are screaming that, that is really (.) you know really really difficult to take. (1)	Parental hopes for provision- gradual, relationships with staff Reality of provision- capacity- can't Provision/ Services (private) Provision/ Services (private)- parents seeking Missing out- being at home Missing out- school trips- "lost out on all that" Missing out- need to keep positive Parenting- Receiving end of emotions- Emotional Impact- "when it's killing you" My feelings- empathy- connect to this

| Transcript	Analysis
beads things with her, engaging her, just urm, Jo's very urm (.) gentle and you know very um (.) sofity spoken, and urm (2) not pressurising at all and just you know em always asks Claire (.) you know (2) 'is that OK?' and that sort of thing. You can tell that, she's definitely um (.) working (.) for Claire rather then, and school now are working, you know, 'can you manage this?' 'OK right'. These things have worked, /{pace of speech picks up} where as when it's we're going to fine you or urm (.) come in come in for this lesson. Um well she can't do lessons or trying to push her too fast, too soon that has been um disastrous. (.) so yes in a way I guess it has, it will take a long time um (3) um offering different things as well, sort of just, (.) you know um (3) they've said, you know 'if you don't come up to school, we're going to have to come down to the house to do a welfare check, to check she's alright'. Um, which I get and which is fine (1) but um, it's kind of like 'if you can come down and do that, can't you, can't you do something a bit more fun with her, like ur, you know, um (1) come down and (.) you know, I don't know bring something fun for her to do in the house, keep her occupied and I don't know, some kind of art thing that then she can colour in, hand back and you can go 'oh well done' and something positive like that, instead of 'ah well we've got to come and do a welfare check if she's not at school and /{very quiet} it's like 'Ok we're here' /{picks up volume} but they never have actually done that They haven't Cos we've managed to get her up to the car park and then they've come out and spoken to her in the car, so they can see that she's not you know being beaten up and everything. (.) urr (3) (56:54) Yeah we've had to do everything to do everything to sort of, keep it, like I say, (1) you know positive for	Good support for C: very softly sofity Good support for C: safe/ enjoyable topics and activities for C Good support for C: engaging, gentle, softly spoken, no pressure "is that Ok?" "can you manage this" Good support for C: working for Claire Reflections: wonder about other pressures/ systems/ beliefs that might lead to not working 'for Claire' Good support for C: successful/ has worked Poor support for C: threats/ fines, pushing too fast, directive "come for this lesson" Time: recognition- lengthy process Welfare Checks:time, if have capacity to do, can they be beneficial for C. Welfare Checks/ C safety: perceived purpose- not being beaten

Appendix N: A table for voice poems

I (Sarah)	We (parents)	They (professionals)	She (Erin)
I think at school (.) the staff			

I know			
		they've all got	
			Erin's best interests
I think			
		they lacked a lot of understanding.	
			promised her
		they'd set this thing up	
			she went into class for
			Erin looked (.) comfortable (.)
			Erin came
			she were (1) a wreck
			she came home
			she were just drained (.).
I know			
		they were well meaning	
		they were as keen	
		they weren't following advice	
		They,	
		they were trying	
			hurry her along
			quicker than what she were prepared
I think (1)			
I know			
		they hadn't had the proper training	
I heard them,			
		they were having the training (.)	
			Erin were going through all of this

Appendix O: An example of stage 3 of the listening guide, exploring links across themes
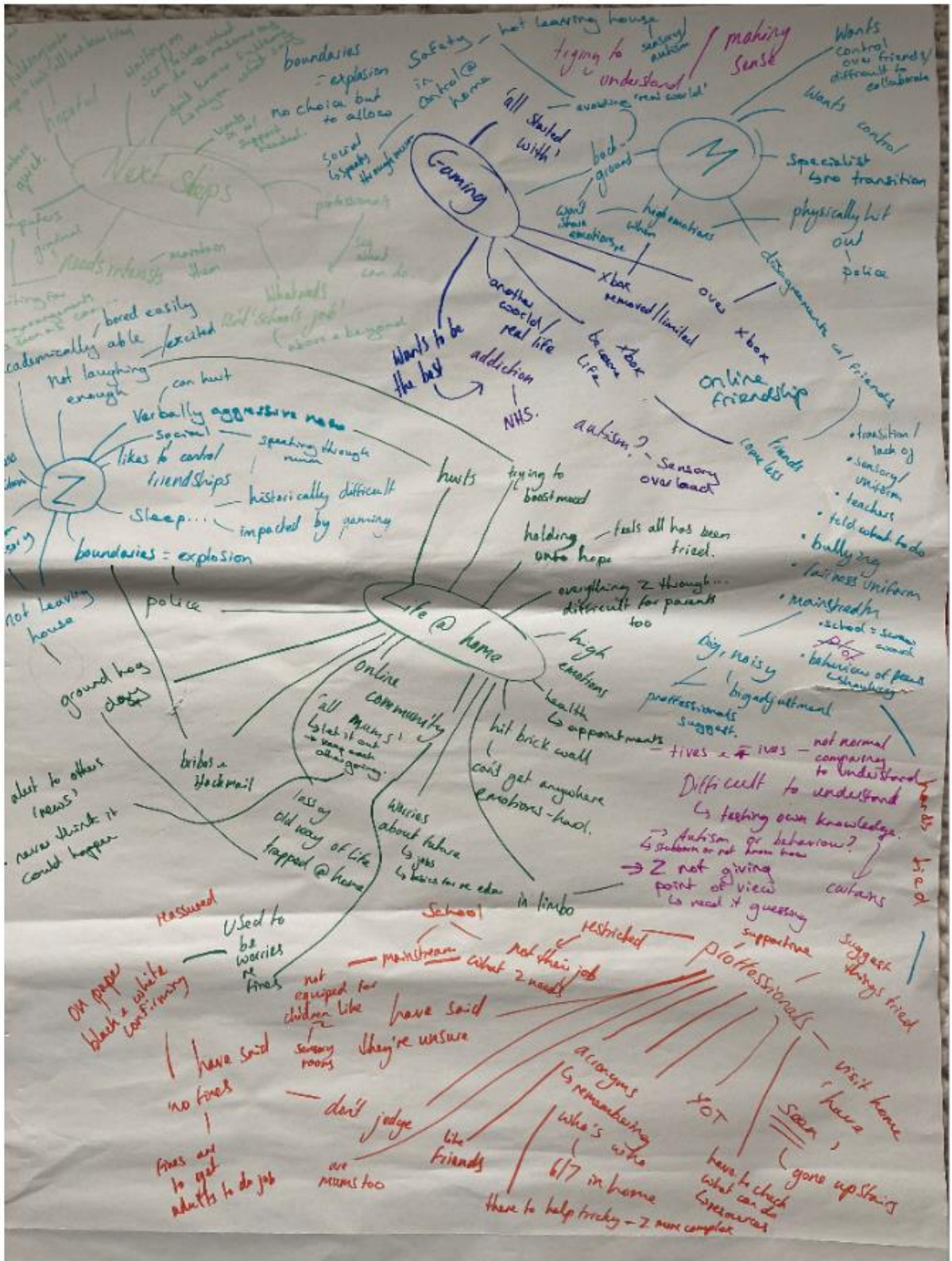
Appendix P: Voice poems introducing the CYP

A 'She' Poem Introducing Sarah's daughter, Erin:

she's quite, (1)
she's quite self sufficient

she can cook for
herself,
she can look after
herself,
she's really good at those kind of things

She manages
her money
her pocket money
her bank
she buys things online,

the things that she does is isolating
she's erm (.) you know, learning (.)
in her room, reading books, reading (.)
she's doing all that,
she's making progress.
she loves that,

she wants to
she wants to do at college
she wants to do art
she's good,
she'll easily pass

her drawings
her paintings
she does (.) are wonderful, are absolutely wonderful. (.)

she learnt,
she started learning music
when she first went
she used to go down
she'd never done before

she had
her Christmas money
her birthday money
she decided to buy

herself a digital piano
she did and we installed,
she installed it
she's really good at stuff like that

expected her to just start plonking
she started playing Beethoven [laughs] with all fingers
as though she had been playing it for years,
she did and it were lovely.

She's really good at putting things like furniture
She
she had a desk (.) a er six foot tall bookcase
she put all of that together,
not an effort for her,

she's got a lovely sense of humour,

she is who
she is
love her to pieces
she'll get there one way or another

A 'She' Poem Introducing Gemma's daughter, Claire:

she's very able
she's incredibly
she does want to do the work
she does want to do the work
she doesn't want to be at home

She's started her own lip gloss business
she's (.) um (1) done a business plan for a dog hotel
she wants to do
she enjoys to do.
she's good at doing
she's creative
she's not doing (3) the curriculum
she's doing other things
she's really into animals

she's got a couple of friends
she met when she was diving
she, she gave that up in the end

she's still got those couple of friends

at home, and outside, she's an in, (.)
she's an incredibly (.)
wouldn't think she's got any anxiety issues
She's very confident,
she's very eloquent
she's very creative,
she's extremely fun
she gets on really well,
she makes friends
she's you know,

if she's alright
in herself then that's the main thing
she can always go to college after

Appendix Q: A retelling of Sarah's story

I noticed that Erin felt unsettled in Year 6 after her older brother moved away to go to University. Towards the end of Year 6 there were some incidents at school involving Erin's peers; Erin's peers hid her shoes and moved her chair away so she sat on the floor. Erin was laughed at. Since then Erin has been very worried about what others think. At the end of Year 6 Erin started to experience coughs and colds, reasons for not going to school.

Erin moved up to Secondary school with some of her friends, but her other friends had gone to different schools. She moved up to her first secondary school, but after two weeks she did not want to go and she started to have aches and pains. I took Erin to the Doctors, but the Doctors sent her back to the school nurse; we were battered about from one to the other. It was difficult for us to get her out of bed in the morning and I felt very worried about Erin's mental health because she seemed very down.

There was a case of mistaken identity in school and one of Erin's teachers mistakenly believed that Erin had been given a detention and that she had not shown up to it. Erin feels mortified if she thinks she has done anything wrong and she worried all bank holiday weekend. I asked the teachers if they could apologise and they tried to, but when they came to Erin's class to say sorry they didn't remember who she was. Erin was already having all these negative feelings and they reinforced them. They made Erin feel insignificant. Erin was tripped up in the corridor and everyone laughed. Erin was showing no signs of feeling better. The EWO was supportive, he came out to our house and tried to talk to Erin. He thought the school might be too big for Erin and on his advice we looked to enrol Erin in a smaller more nurturing secondary school. Erin was happy to make a clean break and moved to a new school at the end of Year 7.

Erin's new school tried to sit Erin with a group of girls to form friendships and she found this hard. She went to the school for a few weeks, but then something got to her. We didn't know what, but Erin could not cope. She had wanted to move schools. Staff tried to put things in place, they said they would not ask Erin questions in class, so that she did not have to speak in front of anyone and she was allowed to use a quiet wellbeing room. Erin had a good relationship with a Teaching

Assistant. Eventually she was spending most of her time in the quiet room away from her peers. Erin did all the work she was given in the room, but never got any feedback. Her attendance was getting lower and lower. It took a long time to get any support in place, and the Education Welfare Officer at the second secondary school was not as supportive, she suggested Erin was being insolent. I didn't want her in the house. Before long we were sent threatening letters about courts and fines. The school suggested TAF meetings. All the professionals met together, there were lots of meetings, lots of talking and lots of planning but it took so long to get any support in place. Sometimes it felt like professionals were saying we weren't doing enough to get Erin to school, but we were trying everything, we took all her treats and gadgets away, we even drew up a contract with Erin; we said we would buy her the tortoise she really wanted if she promised to go to school. But it didn't matter what we did it was as though Erin was so frightened she did not care.

During Year 8 we got a letter asking us to come to an attendance panel. I looked for support from professionals. I even went to one of the EWO's in the building I work in and asked their advice. They suggested that we put Erin's school clothes in a bag and bring her to school in her pyjamas. My husband, had had a heart attack two months earlier, but he carried Erin into the car and we put the child locks on and brought her to school. Erin was very distressed. She tried to jump out of the car and she said she wanted to die. It was the worst day of our lives, probably Erin's life too. When the Learning Mentor and the EWO at school heard what Erin said they said we should go to A and E so that Erin could get the CAMHS assessment I had been asking for for months. The problem was that I had been been pushed between services and hadn't been able to get an assessment. No one grasped the nettle and. I guess that was because of resources and everyone having limited resources. It was as if what Erin had said had opened a door. I felt angry, angry that people would suggest that we do this to a child, and that they couldn't see Erin was struggling.

The day before Erin's CAMHS appointment we took her to the attendance panel. It was the most horrific experience. We sat in a formal committee room with the professionals in front of us. It was a very difficult environment for someone suffering from anxiety. Erin's face was blank, it all went over her head. They concluded the meeting by saying that if Erin didn't go to school we could be fined, we could be sent to court and even prison. It could be all in the papers. I found it appalling that they would say this to Erin and I was glad it had gone over her head, but I wanted a record of what had been sent. I asked for a copy of the record of the meeting. They said they hadn't recorded the meeting but that I could have their scribbles. When we got the scribbles they didn't say any of the things that had been said. I asked that they record what I had heard them say to Erin on the notes. I wanted our experience to be acknowledged.

The day after the attendance panel Erin was assessed by a psychiatric nurse at CAMHS. They said that Erin was showing signs of social anxiety, social phobia, selective mutism. The nurse was really angry, as a professional, that we had gone through what we had. He came to a meeting with me at school and he was able to put the evidence on the table. The school had been saying that because there was no reason for Erin's non attendance they had to treat her as non-school attender. After they got the evidence they seemed to back off a bit, the threats about the fines stopped. I wish they had put all the effort they put into threatening and fining us into supporting us and recognising that something wasn't quite right.

I had found getting all the letters about courts and fines difficult at work too. My job means I was managing the people writing them. They were really professional about it, but it was still hard because I knew they knew and they knew I knew. I felt a bit exposed because that information was really personal.

After the diagnoses all the staff at Erin's secondary school were being really nurturing. I could tell they wanted the best for Erin and they wanted to move things forward like I did, but I still don't think they really understood. They had had no training. Erin kept doing her work in the wellbeing area even though she often got no feedback. She really wants to do well at school and she's very bright.

I started to see things during Erin's first few years in secondary school that I had not noticed before. Erin had all these twinkly lights in her bedroom and she didn't want to go into shops like boots because she said she found the smell too much. I had my suspicions that Erin might have autism traits, but I was told that it was her anxiety and that she was just trying to control the things she could control. I accepted that, but then last year I as just despairing. Erin's dad had just had a heart attack, he's had heart surgery now, so hopefully he is on the road to recovery, but I was trying to protect him from everything and help Erin and I was trying to keep doing a good job at work. I was just getting desperate. I spoke to my sister, she works at a Doctors and she said she would try to get me an appointment so I could get some advice. She got me a cancellation the following week and straight away she said Erin was showing signs of autism so we had different appointments with different people like Speech and Language Therapy. The Doctors said she was on the autism spectrum.

I was finding it really hard at that time, thinking back to it makes me feel emotional. I would walk past children at the bus stop, the same age as Erin, just trotting along getting the bus to school. I used to think 'I wish she could be like that', for her, because all she wants is to learn and her anxieties and her worries, they just get in the way. You know, as a mother I started to think, what haven't I done, why haven't I made her resilient. I mean she was well physically, but mentally, you couldn't see it, well you could in her behaviour, but I did used to think 'would this be different if she had a broken leg or you know something you could physically see. The autism diagnosis explained things a bit, but I don't really understand it. I've tried to read around and to help Erin to answer any questions she might have about it, but the training for parents has been cancelled twice and I haven't been able to have that. It does feel a bit like, we spend lots of money on the diagnosis, but there isn't much afterwards. I think Erin might have been doing her own research; she knows who Chris Packham is. For all these diagnoses though, I still don't think staff really understood. You know the EP gave advice about gradually getting Erin back into class. She was meant to go in for five minutes and come back out. But the Teaching Assistant, she was well meaning, but she wanted Erin to get back in and I think because Erin appeared OK. She looked it on the surface but she wasn't inside. The teaching Assistant kept her in the class for 45 minutes. I just don't think she understood. They've not had any training. When Erin got home she just went straight to bed. She was a wreck. You know there's been all this talk about mental health training, but I don't think schools have had it and mental health is invisible. You know, it's on the inside isn't it. If Erin had had a broken leg people might have seen. I sometimes wish she would scream and shout. People might have noticed a bit more. I don't think people understand it.

Sometimes I don't really know how I've got through. I've spoken to Occupational Health at work and for a while me and Erin's dad got counselling. That was really good because he didn't judge us, he just asked questions and helped us to move through our emotions.

I was worried with Erin's low attendance that she was just falling behind, so I tried to apply for an Education Health and Care Assessment. At first we didn't get that because they said that Erin was too bright, but after the autism diagnosis we did and that meant Erin could go to the specialist provision for children with anxiety in Year 10. She was doing really well there. She was getting up every day and going to school. She's even taken a GCSE early and she got a really good grade. She

wants to do Art at college so she can do set design, she'll pass that easily, she is very talented. She found some things at the specialist school difficult, but not all of them. She didn't like all the focus on nurture and the social stuff, she just wanted to learn. Then recently they started talking about a move in site. They took Erin and her peers to see it and because the new site is near a mainstream school, it was like Erin suddenly realised she was in a special school. She's not silly, I just don't think she had thought about it. So that was it then, it was like she drew up the shutters and she just won't go back. She can be powerful, she is powerful in her avoidance. She just won't even try and sometimes you do just think is she being stubborn or because she doesn't know how. It's not straight forward school refusal, CAMHS said in a meeting, you know she's not doing this for the sake of it, it's linked to anxiety and mental health issues. She also had a bit of an issue with a peer, they were caught holding hands under the table, I don't know to this day if it was something Erin wanted, but the staff told me they were worried they were getting too close and that one of them might get hurt. They split them up. I wasn't told about it till a while after. So again I think Erin was embarrassed about that and it was her first proper friend. We're still trying to take her there, but it's as if she just can't she gets in the car and by the time we get there she's white and she's grey, she just can't go in.

This time has been really hard, the euphoria we felt when Erin was going to school. I was so happy she was happy, happy in herself, even going out at the weekends again. And she was learning. This experience has been a rollercoaster, but this time, has really felt like a big bump, it's been harder.

Erin has been making some progress at CAMHS, I've felt really proud of her. It's not just school, in her own family Erin… Ern wants to talk to her family. We go to visit my mum every Saturday and Erin will sit there listening, taking it all in, but as soon as anyone asks her a question she looks straight to me. I try my hardest not to answer. I don't want to embarrass her, but I want to encourage her to do these things. She gets homework from CAMHS and two weeks ago we took some trivial pursuit cards down to my mums and she had to read off the cards. She did it, she read off them and next week we are going to try doing some planting at the allotment with her Auntie, Erin wants to speak to her Auntie. Sometimes though it is like one step forwards and three steps back. Other people notice that too. My colleagues have noticed how much more uplifted I was when Erin was happily going to school. We felt that she had come through it, that she was going to make progress and it would all be fine. Coming down from that has been the biggest bump.

Erin's sister is a social worker and she has been helping at meetings, but recently she has said to me that it is not good for her relationship and she needs to be Erin's sister, not her social worker. I think the other thing is I have dealt with a lot of this away from the home so Erin's dad can focus on his health. Obviously he has been involved and has always been involved but I have dealt with some of it away from home. You are constantly pushing, it takes over your life. It has been hard, it has been really hard. I think sometimes working here too, I go to business planning meetings and I listen to all the services big themselves up, and I'm sat as a parent thinking this isn't that great. All these questionnaires they talk about with the positive feedback. I've never been sent one and I'm a parent of a child with SEND. My blood boils. I have said something once but it went down like a tonne of bricks. I think that is one of the reasons SENDIAS are so good, they can talk for you when you know, sometimes you're so emotionally involved you don't know what to say or do and it can be hard to be objective. But they can be your voice. They've been really good. They sat with me when I've thought about taking Erin out of school, you know just giving up with it. But I don't think that would be the best thing for Erin. She is bright and she wants to learn. She has some amazing talents. She once got a piano, she saved for it, all her birthday and Christmas money. And she set it up and I thought it

wouldn't be very good, but she sat down and she started playing Beethoven with all her fingers like she had been playing it for years. It was lovely.

I do think specialist is the best place for her, she has been very happy there. I know she doesn't like all of it, like the social side. I mean Erin has said that she wants mainstream lessons again for the subjects, but the anxiety. I think she's in a bit of a dilemma with herself. She's been a bit up and down recently.

But then, I have another friend and she has lost her son. Sometimes things like that give you some perspective. You know, Erin is physically well. In the grand scheme of things it could be a lot worst. I don't think you achieve much as a parent by shouting and screaming, I mean you don't achieve much by not doing that either, but. You just have to keep going. We'll get there eventually. My Doctor, he told me his own son didn't go to school for four years and he's a doctor so if it's good enough for him! You know, learning is life long isn't it. If she doesn't do these things now she'll be able to do them in the future. We live in hope.

Appendix R: Excerpts from Sarah's story

Voice Poem Capturing the Plot of Sarah's Story:

End of Year 6:

> Erin started to be a little unsettled towards the end of year six
> She was preparing to transition
> Her brother went to university
> that really unsettled Erin
> she would be upset,
> she seemed to settle down
> she started presenting with emm like colds, coughs
>
> she'd felt silly
> Kids in class moved her chair
> she sat on the floor
> hid her shoes,
> hid her shoes
> laughed at her
> she's always (.) since then
> fear about what other people think of her,
> she started not wanting to go

Time in Year 7 at Secondary school 1:

> she moved up to the (.) first senior school
> she went to
> she'd only been there a matter of a few weeks
> she went up to S1

she'd got headaches,
she'd got tummy aches,
she'd got all these aches and pains.
Pains in her legs
couldn't get her out of bed
she just would
covers over her head
she just wouldn't engage anything
she seemed really down,
other kids all went to different schools.
She'd gone up to senior school
with some of her friends
she wasn't seeing them out of school socially.

the teacher,
one of the teachers emm (1) mistook her
(1) mistook her
they gave (.)
they rung
why she hadn't turned up for detention
they said yes
she'd been put in detention for being chatty
not Erin really
She was mortified
she'd thought of doing anything wrong
she was mortified.
she went back to school,
she'd worried about it all that weekend
she went back
they looked into it (.)
they said
they'd mistaken
her identity (.)
apologise to her (.)
they went into class
apologise to her
they didn't know
who she was
caused her to feel,
she were like insignificant
she were having all these
kinds of issues herself
other people were
reinforcing how she were feeling,

EWO1-S arranged
Her to spend time

their facility
she felt the need to escape
she used their facility
do her work
when she felt as though
she could engage in class
she went to class
he said
she were using it just as it had intended
one of the other pupils
tripped her
she went flat out
laughing at her
she went flat out
laughing at her
she
she
she were showing no signs of getting any better

A decision to change secondary school:

EWO felt that the school
she had gone to
too big for her
they said if,
Erin
were theirs
they would think about moving
her to a school that were smaller,
on their advice really
through their experience

Erin's time at secondary school 2:

took her for the last month
She started off OK
she
she
she wanted to make a clean break
she wanted to go to School2

the school tried to
sit her with a group of girls
she,
she found that hard
she started in year 8

she's (.)
she might have gone for a few weeks and then
don't know what's got to her
she just hasn't been able to cope.
she found it really hard to sit in a class

they put things in place
they promised
her
they wouldn't ask
ask her questions
she didn't want to speak infront of
she started to use their (1)
eventually she were spending most of the school days in the [quiet room]
She formed a really good bond
one of the teaching assistants
EP name spent some time
with her
her attendance was getting lower
education welfare officer at that school weren't as erm supportive

Seeking assessments:

I'd tried everything
I just didn't know what else to do
Dr said well
bring her into one of my clinics
an hour with Dr Xx
Dr said
she's showing signs of autism
she did
she had speech therapy assessment
appointment with Dr

she had the (.) assessment
Dr said
she were on the autistic spectrum (1)
I don't know what we expected,
I honestly don't know what we expected.
It answered some questions for us

I thought, you know
I mean all of this and then not knowing what else to do
I applied for a special educational needs assessment (.)
I were worried
she were falling so far behind

I couldn't get one
they wouldn't
assess her
she were too bright
She didn't need one.
we got the err autism (.) diagnosis
they did do one

Time at secondary school 3 (specialist provision):

Erin were quite up for it
she went.
She,
she just cut ties with SECONDARY SCHOOL 2
she'd done with SECONDARY SCHOOL 1 and
she just went
She got in the minibus,
she got up every morning
she were ready to go out at 20 past seven

she seemed so happy
she came,
she came home from school.
She went straight to her room (.)
She just (1) disengaged. (1)
I think we managed to get her to school a couple more

She had made a friend
I got a message from school
they had had to split em up.
I said "why?",
first friend that she had ever made
they said it were
they were worried
they were getting too close (.)
they didn't want one or both of them to end up getting hurt
Erin's world,
she's embarrassed
I didn't find out until
I had a conversation
They talked about the situation
I don't get why (.)
I don't understand
I spoke
the teaching assistant
they said
I said "other than

they said "well we found them holding hands
I don't know to this day whether
Erin (.) welcomed
I'm not sure and nobody ever asked
they just decided to split em up.
I know
she were in touch with
I didn't know
she never told us
then she decided
cos it's a special school she won't go back.

Voice poem capturing Erin's powerful avoidance:

if she's made her mind up (.)
no way (1) I can convince
her way of (.)
she it's avoidance isn't it
she avoids situations
she's (.)
when I say
she's powerful
she's powerful
in her avoidance,
she (1) puts this thing up
no way will she even try sometimes (1)

Autism diagnosis and accessing training:

"when (1) she had the (.) assessment and Dr Xx said that she were on the autistic spectrum (1) that were it [laughter] I don't know what we expected, I honestly don't know what we expected. It answered some questions for us OK and it gave us a bit of an understanding as to why Erin (1) was showing some of the behaviours that she was showing (.) but to this day I am still waiting for the sygnet training (.) for (.) help and that (.) has been cancelled twice."

A voice poem capturing the qualities of a counsellor:

he were really really lovely and supportive

nice to go and talk to him.
He listened
I'm not saying
he offered solutions,
he didn't
He,
he used to ask
us
how we felt, (.)
how did that make us feel
we reflected
on how we felt
it helped us
our feelings out.
he were lovely
he really helped
he was supportive
nice to go and talk to him and not be judged.
I think that were important as well, not being judged.

Appendix S: Excepts from Natalie's story:

A condition: Gaming addictions

"There was something on TV a couple of weeks ago about the NHS were going to start to treat children that have got obsession with gaming because it's an addiction now it's classed and as an addiction (.) in kids so I don't know whether to branch out to that area to see if I can get any help from NHS maybe"

Staying awake for gaming

he started getting really bad was when that fortnight game
took him over
he was staying awake
he were awake for about 18 hours
he would go to sleep for 18 hours
he hasn't been asleep
How does he stay awake so long?

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Full voice poem exploring Zeke's desire to escape the real world:

his dad (.)
had him last not this weekend
first time he seen him in about a year
he's got to contend with

Zeke was under a court order
Zeke was
took off me
I was the one for about 5 years going every fortnight (.)
I must
I got a text off him one day saying 'do you want Zeke
me spent trying
I was like 'yeah course I do'

Zeke wasn't getting
Zeke was pushed to one side (.)
Zeke started hitting
he could have hurt the babies
his dad
asked me.

I think
element of that in him
his dad's not stepping up
I've had Zeke four years now.
I'm glad
Zeke's here
I know
he's not getting pushed to one side

He's obviously got all of that
in his head.
he won't talk
to me about
I've just got to guess.
I've got to presume,
I shouldn't
I say
if he
spoke to us
we would understand more.
he won't

he's making it
worst for himself, holding it all up there

just playing his games.
He doesn't like the real life because of what it's done
he sticks with the gaming
because he's got control
he's more in control

Autism: professional suggestions regarding sensory needs:

he won't leave the house
he will not go out that front door
he's been assessed for autism
youth offenders team (.) Urm they think it's sensory side
he doesn't like the loud noises
He has complained
he doesn't like flashing bright lights
yet he stuck to the screen

Autism: Connecting with people in the community:

I've noticed for quite a long time
If he had
come with me, say like to the take away (.)
if I'd given him the money and said 'ok Zeke, now you pay
I'm just going to nip into the shop
I'll come back
he'll say no I'm not doing it.
he doesn't want that confrontation
an example say I said 'now what do you want to eat
he'd say 'can I have
I'll say 'well, do you want to tell the lady
he's always
looking at me, never at the lady.
even though she's heard him
I have to say it to her
he's always
behind me,
even when we got on the bus,
it's like he's wanting
me to be in between
him and the person
I say confrontation
I don't mean, it's not a horrible one
like he can't deal with that connection.

He (.) he wants to be in charge in the house
he can't be in charge
himself out of the house.
I mean that's the autistic side of it possibly (.) but it could also be that stubborn side
I think (.) cos maybe
things at the house
his own bubble (.)
he's in charge of it
while he's here,
well he's not,
he thinks he is (.)
where as he's not in charge when that front door opens (.)

Autism: A reason for a different world view:

He thinks
He can pull the wool
over our eyes
he can fob
us off with a story
if you've caught him out
he can't accept that
he's been caught out
he thinks
he's been clever
to us it is obvious
he doesn't see it that way
another part of the autism thing I think

I don't know
Sometimes I think
maybe he is putting it on
sometimes I think
maybe he isn't.
Sometimes I've got to try and differentiate

I'm testing myself
I'm thinking,
I'm testing the logic
I've had
in my head for fifty years
I think

I don't know

how he sees normal logic
if he does see normal logic
he twists everything around
He just
like he's trying
create his own being or existence
I don't know
for him everything is opposite
he does things like switching lights on in the day
he has the curtains shut in the daytime
he'll say (.) but there's sun shining
I say Zeke please open
he says no it's too bright

Searching for an understanding: wanting Zeke's perspective:

I think
why is he doing
I'm trying to understand
why he is doing
he doesn't talk
he hardly talks
to me
I try
ask him questions
he just blanks
me out
barrier that I'm up against
he won't let
me jump over
he's a brick wall
us trying to understand
what he does
I will ask
him
he just doesn't answer
I've got lots of questions
I just can't answer
I need it from his point of view
I'm trying
I said to you
he's one of a kind
I wasn't joking
I'm in limbo
I'm still trying to understand

Keeping Zeke's interest:

I'm hoping
if [School Staff]
if they can
get him in
not so busy around him
get him into something with computers
they said
he can do a bit of gaming

I say it's getting out of the house

if he does go the very first day
they really need
keep his interest
if he shows
when he goes
once you've got
his interests
he'll go again the next day
the minute you veer off
track that he has chosen
he likes that certain thing
you veer off that
you'll go back to square one

Appendix T: Excerpts from Gemma's story

The safety of the primary school environment:

"coming from a school where, you know, they've all been in the same class *together*, mm in the one *room* from um foundation, right up to Y6 and having quite a very firm, secure (1) well *very* firm (.) um social group (.) um you know, she was probably seen as kind of (1) you know probably a really sort of loved and well respected and valued member of that group and never any friendship issues *at all* (.) and going from that into a school where umm (2) a massive school, where she feels *completely* (.) unsafe."

School Refusal Choice based:

"I don't like that term at all cos it's like, the person, I don't like it

Mmm

<div align="center">

She's not refusing to go to school.

No

She's not saying, 'Claire will you come to school?' 'no'. She's not refusing it in making that choice to not go."

</div>

However, it seemed that having a label might have supported an understanding and, perhaps, given some direction:

<div align="center">

"nobody's said 'this is school refusal' , (.) nobody's said that to us.

OK

Nobody's said this is school refusal, don't worry, (.) expect this, contact these people, this is what we're gonna do. It's just you're bumbling along unknown"

</div>

Questioning parenting in early childhood:

<div align="center">

you're constantly,
you are constantly questioning
yourself
I'm doing this wrong,
I'm a rubbish parent
my fault
blaming yourself
have I done to cause this?
I take
her to enough play groups?
what have I,
I criticised her too much?
I done to make her anxious?
I done anything wrong
you,
you are very (.) very negative
to yourself

</div>

Unfeasible ideas:

<div align="center">

"Umm (.) I guess what what we kind of *need* almost is a teacher to come down and do some one to one and that is not what's going to happen is it. (4) You know just somebody to kind of (1) *do* a little bit more

</div>

mm, somebody to do a little bit more

You know, like come down to the house and maybe do ten minutes of maths with her once a week and then gradually build that up and then say you know (1) "Claire are you going to come to my lesson" you know or, there's there's just been basically like I I guess teachers they're they can't. (4)"

Prioritisation by services:

Fortunately at the minute (2) I don't think there is (1), I think you've got to be (.) wary that you know, (.) there's so much can go wrong whether it's eating disorders, self-harming um, depression, along with the anxiety (1). We're not, *fortunately* we've managed to avoid that so far, but um, I'm sure there's other children out there that are experiencing it and you know they have to prioritise don't they, so I understand that (3)."

Involvement from an LA based service:

"we had some very *very* brief input from [LA Service] which was (4) which is is still really really (.) which I'm still really quite angry about and that is (.) we had a lady come and meet us at the school with the teachers. That was me and [dad] and the teachers and I gave her a big long discussion about everything that had happened, you know, could be dyslexia, friendship issues, anxiety, fainting, all of these things seem to have kind of built up. Yeah (1) Then she says "well I'll come and have a couple of meetings with Claire I'll try and get her to (.) engage and see what work we can do, it might take me a couple of sessions for her to get used to me (1) and we'll see what we can do" so we were really hopeful about that mm.

Appendix U: Excerpts from Laura's story

Josh and friendships

he's been asked do you get bullied.
He's got friends,
he's got a lot of friends.
He doesn't get bullied.

		they did (.) to be fair, right at the beginning, (.)	

	they did try (.) a little bit	
	they said, (.)	
and I mean a little little bit,		
	they said	
		to him: why don't you come in 5-minutes later

A new normal:

he is at home everyday
we've got rules
he likes to stick to them.
he needs that routine
he's got to get up
we go to work
he'd get up
as if he was going to a school.
he's got to get up.
He's got to have a wash,
which you want
brush his teeth, get dressed
he does online (.) ur it's called IXL and it's an education site
his,

"I suppose you think (3) {big breath out, 'brr'} it's not normal, *but it is* normal, *he* is normal (.) and for him to think he's not normal and for (.) your child to say (1) I wish I was normal like everybody else (.) that's heart-breaking (.) cos then you convince them *you are* normal this is your life this is *your normal life* it might not be somebody else's normal life but it's your normal life yeah (.) and he's very happy….. I'm glad *I've learnt* myself that he's (.) happy and yeah it is his normal life (1) and (.) you, you never know you can think oh in three years, two years, one year he might think 'oh I want to go to college and get my GCSEs. mm you just don't know what's going to happen in the future (1) so you can't make up a story about what you think is going to happen and worry about something that might not happen mm so yeah (.) he's a lot happier which if he's happy I'm happy"

Appendix V: PTMF illustrations for each of the stories:

Sarah and Erin:

Sarah:

- Power:	Threat:	Meaning:
Ideological, Legal and Coercive: threats of fines and the ability of school staff and professionals to shape understanding of Erin's needs (as within- child and family) and the agenda	Economic, Relational and knowledge and meaning construction: Concerns about the economic impact of fines, threats to perception of ability as a parent, difficulty developing own understanding of Erin's needs under the weight of professional understanding	Blame and judgement: parenting judged and blamed for Erin's non-attendance.

Response:

1. Submission to and appeasement of professional views and wishes: taking Erin to school in a state of distress

2. Reflection on the situation

+ Power:	Threat:	Meaning:
Material power: access to professionals that diagnose and have ideological power to change the agenda	Following staff wishes would threaten internal value base (need to protect child)	Parenting and Mental Health Discourses: Our role as parents is to protect Don't want Mental Health to get 'worst' Feelings of injustice: what happened was wrong and unfair

Response:

Responses that support Sarah to protect Erin- finding other professionals, not forcing school etc etc

Natalie and Zeke:

Natalie:

Power:	Threat:	Meaning:
- Ideological: professionals have the answers and will shape agendas and decisions re provision (waiting for provision)		Emotionally overwhelmed
		Trapped- Helpless/ powerless
- coercive power, threat to own physical safety when saying no to Zeke	Social- isolation	
	Bodily- physical safety	Isolated and lonely
+ Ideological: professionals don't know why either, so we're working out an understanding together	Relational- threats to boundaries	
+ material power (access to a range of services was readily given)		Professionals care and support me

Response:

Difficult to put boundaries in place due to own safety

Wait for school staff and professionals to find a solution

Access peer group- gain high level of support

Gemma and Claire:

Coercive- others determining the agendas- has strong ideas of what can help but believes none are feasible

Economic power:

- denied access to provision by school budgets

+ive can afford access to councelling

Material: - Is not aware of services which could support her to argue for provision she feels would be helpful

Ideological- others have labelled Claire as naughty an barred her from accessing services

Economic threats re fines

Threats to employment attending meetings

Relational- maintaining Claire's wellbeing and brothers

- Maintaining relationships with school staff.

Empty/ hopeless- Grateful for anything

Reassured re counselling- hopeful

An acceptance of things being like this- frustration mixed with gratitude/ not wanting to rock the boat.

Lists a really holistic set of reasons but then limits this to anxiety as pressure from school mounts

Laura and Josh:

Interpersonal power: power to look after Josh threatened by levels of unhappiness	Threats of fines- economic impact- that's my salary at the end of the year	Guilt- not knowing
	Emotional: overwhelmed	Couldn't know- I am a good mum
Material: Had tried to ask for schoolwork but not got the power to enforce	Relational: upset re impact of unknown period on Josh	Job as a parent= to ensure your child is happy
Legal+ Brings SENDIASS in- fines (coercive) no longer mentioned		

Rejection of school- they've not helped

School is not a priority- my child's health is

Appendix W: Implications in the context of COVID

Given the timing of this research it would be remiss not to consider the mass return to school that is due to take place after a long period of non-attendance. Whilst it is hoped that most students will return to school without any difficulty it is likely that some students are going to find this more challenging. There are some risk factors which ought to be recognised by professionals:

- Transition points have been widely recognised as a risk factor for SNA, with key transition points (for example primary to secondary school) identified as times where some students are particularly vulnerable to SNA. The return to school for all students following the pandemic can be seen as a significant transition and one which may make it harder for students beginning primary or secondary school for the first time.

- Preparation for transitions is typically an important protective factor. The transition support children will have received during COVID is likely to have varied in quality due to restrictions imposed by the pandemic.

- Students who experienced difficulty with attendance, prior to March 2020 when lockdown began, are likely to be at greater risk of SNA.

- Students who have been shielding (taking extra precautions during the pandemic) for themselves or a relative could experience additional worry about returning to normal.

- Some CYP might have experienced loss during this time (loss attributed to COVID as well as other causes). Further, it is worth acknowledging that some demographic groups have been disproportionately impacted COVID and, as a result, some CYP may have experienced multiple bereavements (Ferguson, 2020).

- Some CYP are worried about returning to school and some research that has taken place during the COVID period has highlighted that students are particularly concerned about: being behind with their learning; how they will be kept safe and protected from COVID-19; and what the hygiene routines will be (Popoola, Looney and Gulliford, 2020).

Many schools and EPS's have been working to employ approaches which will enable positive transitions for students returning to school (Nottinghamshire Educational Psychology Service, 2020). Arguably, for many students these will provide a protective factor for SNA. However, it is likely that there will be some individual children who find it very difficult to return to school, and whose attendance will be impacted. I would urge EPs to raise the topic of attendance during planning meetings and conversations with schools. Schools and LAs will need to think carefully about how they identify and work with CYP at risk of SNA and their families. It will be very important that attendance is carefully monitored to ensure that any difficulties are identified early. Professionals should take a sensitive and curious approach when exploring these issues with parents and CYP. It is important that school staff, and external professionals, recognise that children and families will have had a unique and diverse range of experiences during this period and it will be important that professionals carefully listen to their stories viewing CYP and their families as the experts in their own experiences. Training to support staff understanding of SNA could be particularly

valuable at this time. It could enable staff to develop their awareness SNA and how to identify CYP at risk of extended SNA early. Further the training could highlight the importance of being sensitive to parents and CYP emotions and may prevent parents from entering situations where they feel threatened and judged.

The government has warned parents that they will face fines if their children do not return to school in the Autumn term of 2020, however, anecdotal evidence suggests that headteachers disagree that this is the best approach (Coughlan, 2020) and Geoff Barton leader of the Association of Schools and College Leaders head teacher's union has argued that a period of grace needs to be applied before fines are reinstated. Findings in this research would suggest that the worry of fines and encouragement of punitive approaches can have a negative impact on parents and CYP. I would encourage schools and LAs to use their resources to explore how these families could be supported using a welfare rather than a criminal approach where possible.

During the pandemic schools have been asked to provide an education to students who are learning at home. Arguably the success of this has been variable, however, it poses a possibility for some students who are experiencing SNA. Three of the four parents interviewed in this study shared their frustration that schoolwork was withheld from their CYP due to staff concerns about encouraging non-attendance. The impact of this appears to have been negative with parents sharing that it was harder for their child to return to school due to additional worries about missed learning. Further, parents shared that this response left CYP feeling unheard and uncared for. This is particularly worrying as positive relationships with adults helps CYP to feel safe and cared for in school and are key to supporting CYP attendance. I would encourage staff to consider how they can continue to implement some of the good practice developed during COVID. For example, CYP experiencing SNA could be offered opportunities for online learning and to maintain and develop trusting relationships with school staff and peers through regular online contact. This enable students to feel that they are keeping up academically and support them to feel connected to their school whilst the SNA is explored, and provision developed.

Potential Research in the light of COVID:

In the current context it might be worth considering what the impact of the pandemic on transition processes has been and whether the restrictions imposed due to COVID might offer some protective factors for students at risk of SNA. For example, many secondary schools are operating 'bubble' systems where students will stay in a classroom with teachers moving around the school. The lack of requirement for students to move between classrooms may relieve worry for some students and therefore, for some CYP this might act as a protective factor during the transition into to secondary school. Changes in light of COVID could be explored in terms of their costs and benefits.