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**Behind The Scenes Pushing: Experiences of
Parenting a Child Identified as Having Social,
Emotional and Mental Health (SEMH) Needs**

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Abstract

This research considers how mothers make sense of their experience of parenting a young person with Social, Emotional and Mental Health (SEMH) needs. It considers the impact of their interactions with practitioners who support their child, individual psychological experiences, in the form of the unconscious, and what influences these have on subjectivity. I consider how findings from parent narratives can be used to inform practice for educational psychologists and other practitioners working with parents.

A narrative methodology, adopting feminist principles, which privilege the voice of mothers in the research process was applied. The research engages in an exploration of mothers' experience and considers the influences of social narratives around neurocultural and individualising psychological discourses that impact upon relationships between practitioners and mothers. I adopt a critical realist perspective and use Lacanian Psychoanalytic concepts to bring together psychological and social factors that influence experience.

The analysis highlights the influence of dominant discourse on how mothers make sense of themselves and their experiences of interacting with practitioners. It reveals the possibility that mental health needs, such as anxiety, depression and eating disorders, may be understood in specific ways which do not apply to other conditions, such as attention deficit, included in the SEMH category of difficulty as outlined in the Special Educational Needs and Disabilities Code of Practice (2015). Apparent commonalities and distinctions are highlighted as well as parent views on what they would find supportive when engaging with services and practitioners regarding their child's needs.

Key words: Mothers, SEMH, subjectivity, psychoanalysis, narrative, psychosocial

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Introduction

I have chosen to focus my research around the experience of parents and feel that this and the approach I have taken to this study have been heavily influenced by my own historical contexts and interests. Prior to training to become an educational psychologist (EP) I worked within two large secondary schools, working particularly around developing young people's understanding of psychological well-being and the culture within which we live. I regularly worked with young people who were described as having mental health and social difficulties, which appeared to reflect a particular stigma attached to this identification from the adults around the young person. When reflecting back on conversations I was included in during this time I can recognise the narrative of blame and responsibility which persisted in these interactions and how they would change depending upon who the interactions were between. Staff would often engage blaming parents and the young person themselves citing a lack of boundaries at home as the primary reason for a young person's difficulties. In conversation with staff and parents there appeared a tendency to discuss a young person's difficulties with a mind to indicating parent responsibility, which was often tempered with a medicalised element to a conversation (i.e. indicating a GP or referring to Children and Adolescent Mental Health Service (CAHMS) as a response to parents).

Whilst teaching I also began to work more closely with the local Parent and Carer Forum on joint projects designed to help establish systems for promoting co-production between parents and practitioners. I was able to spend a great deal of time listening to the stories of parents who had emotive experiences which they often indicated had not been heard. Their use of narratives was very apparent and was instantly recognisable as a means of making sense of and communicating to others what they had been through. At the same time I began to work with the Youth Offending Team completing restorative justice panels for young people as an alternative to the judicial system they might otherwise have been shaped and identified within. My work in this area enabled me again to see how narrative could be used to elicit views and provide a better understand of the experiences of young people which had led them to their actions. It was also a powerful way of helping

young people and those who had been harmed to consider different perspective and influences in events. These experiences helped to consolidate my view that narratives could help individuals to make sense of their experiences and communicate them to others.

I feel a further influence on my choice of research area and method comes from studying undergraduate Philosophy and being introduced to concepts of knowledge and truth, psychoanalytic theory and the philosophy of language. Consideration of the intricacies of language and its function in epistemic and ontological considerations remain areas of interest for me and I felt would be appropriate in securing the foundation of my research in a position which values marginalised voices within wider systems. My early introduction to these ways of thinking have proven invaluable during my training to be an educational psychologist, as they help me to consider alternative world views and ways of thinking which can produce creative spaces for new ideas to evolve. In this respect a philosophical way of thinking psychologically guides my practice and the research I have presented in this thesis. It felt fitting then to consider the often marginalised view of parents and how the adoption of narratives and Lacanian psychoanalysis could be used towards an emancipatory endeavour.

Chapter 1: Literature Review

1.1 Introduction

Parents with children who are identified as having Special Educational Needs and Disabilities (SEND) may experience difficulties not only in their interaction with practitioners and services, but also psychologically (Broomhead, 2013; Van Wyk & Leech, 2016). Parents are reported to experience feelings of guilt, blame, shame, embarrassment and sadness maintained not only through their interactions with practitioners but also from a sense of loss within the parent (Hugger, 2009). Research also indicates that the nature of the SEND that a young person is identified with can also influence the experience parents have when engaging with adults who work with their child (Broomhead, 2013). Parents of children categorised as having Behavioural, Emotional and Social Difficulties (BESD) experience a greater sense of guilt and blame from their interactions with school practitioners compared to parents of children with learning difficulties (Broomhead, 2013, 2014). Existing literature reports children classified as having behaviour difficulties are associated with views of ineffective and poor parenting (Francis, 2012; Harborne, Wolpert & Clare, 2004; Peters, 2011; Ryan & Runswick-Cole, 2008; Rogers, 2007a). The new SEND Code of Practice has seen the removal of the BESD category to be replaced by one which attempts to recognise Social, Emotional and Mental Health (SEMH) needs that may underlie behavioural difficulties (DFE, 2011; DHE and NHS 2015). This sees a move towards a more medicalised narrative around young people (MacLeod, 2006) and orientates discourse toward a deficit model view of children (Thomas, 2005) which holds implications not only for children but also for their parents (Runswick-Cole & Goodley, 2018). Though parent interaction and individual psychological experience are important features of parent subjectivity there is limited research within the SEMH literature that considers them together along with current parenting discourses (Ryan & Runswick-Cole, 2008; Runswick-Cole & Goodley, 2018).

The aim of this research is to consider mothers' subjectivity, as expressed through narratives considering their encounters with practitioners and individual psychological experience of having a child identified as having behavioural or SEMH needs. I also aim to highlight how social discourse around parenting is potentially

present within parent subjectivity. Though often mother and father are presented synonymously in the parenting discourse it is highlighted that this “neoliberal neutral language masks the gender dimensions of parenting; women still perform the vast majority of caring roles and are expected to take responsibility for this” (de Benedictis, 2012, p.3). Therefore, this research is focused around the subjectivity of mothers.

The remainder of this chapter aims to consider how parent experiences of having a child with SEND are discussed in the current literature. I aim to highlight the variation in experiences and move to reflect the increase in focus on engaging with parents. I focus my discussion on how the current literature reports that there are specific experiences related to different types of SEND (e.g. learning difficulties, SEMH) culminating in how social discourses around parenting may influence these narratives. I conclude that SEMH is an under researched area requiring further exploration of how parents make sense of their experiences of having a young person identified within the SEMH category of need. I further argue for the necessity to consider social discourse surrounding parents that may influence parent interactions and narratives.

1.2 Experiences of parents with children identified with Special Educational Needs

From the existing literature it is possible to recognise how parenthood is profoundly influencing and that when a young person is also considered to have SEND further challenges and experiences are recognised. Becoming a parent is argued to be a transitional developmental process beginning with the realisation of being pregnant to the actual birth (Benedek, 1959; Lester & Notman, 1988). It incorporates fantasies surrounding the imagined child, the unknown but experienced foetus and finally the realised child at birth (Brazelton and Cramer, 1990). It is thought to have a profound effect on the individual parent shaping their sense of identity, qualities and personality (Bibring, 1959; Schwartz, 1984). Mothers are reported to work to manage fears of their ability to parent, changes in the physical appearance of their body, concerns over the demands of being a parent, changes to professional identity and

potential for changes to the existing relationship with their partner (Brazelton & Cramer, 1990; Trad, 1990). However, growing research points to distinct experiences parents have when their child is recognised as having SEND; related both to their internal psychological experience and their interactions with others (Broomhead, 2013; Hugger, 2009; Mangan, 2015; Van Wyk & Leech, 2016). For example some mothers were recognised to be unable to consider the future given their child's precarious positions (Bingham, Correa and Huber, 2012). Some parents developed views that only they were capable of caring for their child at home (Nicholl & Begley, 2012) as a result of knowing their needs better than practitioners (Redmond & Richards, 2003). Some mothers, through their intensive observation of their child, viewed themselves as being the only person able to understand the needs of their child in the absence of the child's communication (McKeever & Miller, 2004). Mothers' evaluation of their abilities has been associated with how well they managed to cope irrespective of the high demands of a SEN child, often considering signs of fatigue as representing them as "bad mothers" (Rogers, 2007a). This was reported to lead some mothers to be reluctant to express the need for support and wishing to hide the difficulties they might be facing (Redmond & Richardson, 2003). Mothers would sometimes wish to overtly demonstrate the value of their child by purchasing expensive clothing and spending more money on clothes for their SEN child than for other children (McKeever & Miller, 2004). Further reported are occasions where parents have been recognised to attempt to mask their child's disability (Van Wyk & Leech, 2016). Some parents wished to enable their child to avoid stigmatization as a result of their SEN needs (Green, 2007) feeling it was of utmost importance to prepare them for inclusion in their community and society (Fiamenghi, Vedovato, Meirelles, & Shimoda, 2010). It was also reported that parents may experience hostility in their interactions with health care practitioners (McKeever & Miller, 2004).

From completing unstructured interviews with 24 parents of children considered to have learning disabilities, Rogers (2007a) highlights a number of experiences within parent narratives. Some parents are reported to feel 'loss' for the child they expected to have and for their future and dreams for their child. Levels of

disappointment are reflected in the research rooted in the notion of parents having “dashed expectations” (p. 138) of their relationship with their child. Some parents found it difficult to manage a move from their expectation of having a ‘normal’ child. Moreover, coming to terms with differences in their experience compared with “internalised norms for parenting” (p.142) was also reported to be difficult for some parents. Rogers (2007a) further notes the response of some parents being an ‘interpretive denial’ (Cohen, 2001). This denial “places the difficulty into a less severe bracket” (Rogers, 2007a; p. 139). Rogers offers the example of parents who consider their child’s autism diagnosis as *only* a speech and language difficulty (Rogers, 2007b) as a means of lessening the child’s difficulties. Feelings of blame and shame when their child is perceived to behave outside of the expected norm are reported as well as higher levels of stress and suicidal feelings. Though this research makes reference to children’s behaviours it focuses on learning difficulties.

Mothers of children identified as autistic have reported experiencing higher levels of psychological distress (Bromley, Hare, Davison, & Emerson, 2004). A study of 68 mothers who completed a range of questionnaires including Developmental Behaviour Checklist (DBC: Einfeld and Tonge, 1994) and the General Health Questionnaire 12 (GHQ-12: Goldberg and Williams, 1988) to consider psychological well-being of mothers in relation to behaviour of their child was completed. Bromley, Hare, Davison, & Emerson (2004) report an association between challenging behaviour and mothers’ distress. Though this research relates to children with autism it reflects that challenging behaviour above other factors considered (including sensory needs, language development and physical development) correlated with higher levels of distress. Further research has identified differences between parent experiences of stress related to the type of SEND. Hayes and Watson’s (2013) meta-analysis of current literature reflected that parents of a child with autism reported higher levels of stress compared to both typically developing young people and those with other physical disabilities indicating the potential for variation in experience related to SEND category. However, the relationship between stress and challenging behaviour implied in this research perhaps does not consider the influences of parent interactions with others. Furthermore, the use of

questionnaires may make it difficult to consider the complexities of mothers' experiences which could offer a better understanding of the proposed correlation. Absent from consideration, at its simplest level, is what sense participants made of the questions they were asked; this critique recognises that meaning making will differ from person to person when asked the same question (Hollway & Jefferson, 2013).

Harborne, Wolpert and Clarke (2004) conducted research into being a parent of a young person with an Attention Deficit Hyperactivity Disorder (ADHD) diagnosis. The research sought to consider how parents understood the cause of ADHD and was investigated through semi-structured interviews with ten parents. A grounded theory approach was applied to transcripts used to generate themes and issues. They highlight battles, emotional distress and blame as being common within the experience of those that took part. Blame was considered to be related to feeling that other people considered poor parenting was at the heart of a young person's difficulties; whilst parents themselves felt there was an underlying biological basis for the condition. The experience of being blamed by practitioners led to some parents blaming themselves or someone else in the family for their child's difficulties and to seek diagnosis as a means by which to diminish feelings of responsibility; parents reported feeling less blame when a diagnosis was received. In some instances, parents compared adult responses to their child's difficulties to those for children with conditions such as Down's syndrome. The comparison appeared to serve as a means of highlighting the unfair judgement they received, because the biologically based condition responsible for their child's difficulty was felt to be less obvious. Harborne et al. (2004) indicate that parents felt it necessary to battle for recognition and respect from practitioners; this was particularly in relation to feeling frustration that others did not view the cause of their child's difficulty in the same way parents did. Parents described experiences of unsympathetic and patronising practitioners. Some felt that teaching staff were sceptical of the validity of an ADHD diagnosis and that interactions were often felt to be hostile within school. Finally, parent experiences are reported to have a negative impact on the psychological wellbeing of parents with some participants highlighting feeling depressed and

having suicidal thoughts. ADHD is included as an example of an underlying difficulty in the SEMH category of need as outlined in the SEND Code of Practice (2015), however, it is only one example with others including “anxiety or depression, self-harming, substance misuse, eating disorders or physical symptoms that are medically unexplained” (p.98) being unconsidered in this research. Given the possibly of different experiences being related to the way a young person’s needs are framed it highlights the need to conduct research that considers the SEMH category more broadly.

Not only do parents hold a sense of blame, responsibility and guilt internally they also report feeling anxiety, anger and depression when their parenting is challenging (Fouquier, 2011; Rallis, Skouteris, McCabe, Milgrom, 2014). This is also recognised to act as a motivation for seeking a diagnosis or label for their child depending upon the nature of their child’s Special Educational Needs (Broomhead, 2013; Landsman, 2005). However, the perceived desire for diagnosis is reported to depend upon the category of SEN a young person is identified within (Broomhead, 2013) and is discussed further in the next section. Recognising parents’ experience of feeling blamed perhaps helps us to begin to understand aspects of subjectivity, however, further individual psychological features may also be important when considering parent experiences. Hugger’s (2009) case work with mothers highlights the experience of grief a parent may have when their child and their idealised view of their child are different. It is proposed that when the child is recognised as having SEND it can present as a personal failure (Hugger, 2009). Internal psychological experiences for parents have been considered in the psychoanalytic literature for some time with some describing the experience as constituting a fundamental reorganisation of a parent’s identity (Bibring, 1959). A number of psychological processes have been discussed; for example, Benedek (1959) proposes that feeling your child is unhappy and you are unable to satisfy their needs can become introjected and identified within the parent.

The mother’s gratification in satisfying her infant’s needs as well as her frustration when she is unable to do so affect her emotional life and again reciprocally that of the child... reciprocal interaction between mother and

child which, through the process of 'introjection-identification', creates structural change in each of the participants. (p. 392)

The mother's sense of self is proposed to be positively affected though feeling that she is able to satisfy the needs of her child, "Good mother" is equal to "good self", and negatively affected when the mother feels that she is not meeting the needs of her child, "bad mother" equals "bad self". Benedek (1959) further argues that parents' hopes for their child are intimately tied to their own meaning that difficulties faced by their child can feel as threats to themselves. Processes such as those reflected in the psychoanalytic literature serve to highlight the relevance of considering the not only external interactions but also individual psychological experiences which further aid an understanding of parent subjectivity. In this sense psychoanalytic theory can be considered as offering a further means by which to consider parent subjectivity. Therefore, it is necessary to consider not only the external interactions but also the individual experiences which may impact upon a parent's view of themselves, their child and the external world they interact with.

1.3 Engaging with Parents

There is an increasing focus on supporting the involvement of parents in children's education (Corbett & Norwich, 1997; Corzier, 1997; Tan & Goldberg, 2009) which has become enshrined in the SEND Code of Practice (2015). However, parent interactions with staff in educational provisions has been identified as presenting a number of difficulties. In a systematic review, including only six studies, of qualitative research related to the relationships of mothers of a young person with a diagnosis of ADHD and teaching staff Gwernan-Jones, Moore, Garside, Richardson, Thompson-Coon, Rogers, & Ford, (2015) highlight an overarching theme they title *Mothers were silenced*. This silencing seemed to be both self-imposed or as the result of actions of those they were interacting with. They indicated that silencing in part is related to societal expectations where by each mother is judged by how their child may present (Carpenter and Austin, 2008). Mothers were found to feel stigmatised by the

diagnosis of their child which was closely linked to blame. Their efforts to interact in varying ways did not appear to affect the experience of being dismissed or feeling frustrated (Malacrida, 2001). Gwernan-Jones et al. (2015) report conflicts were associated with mothers feeling that their child was unhappy in school causing an increase in parent intervention. Initiation of contact by school staff was seen to revolve around problem behaviours and was experienced as 'being told' (p. 290) rather than as a conversation. Mothers felt both criticised and pressured by teaching staff to seek clinical assessment for their child or a family assessment to identify the problem. These child or family deficit model conversations were understood as being criticised by a professional and felt to reflect an inequality of power. Challenges to judgements for staff and practitioners was also felt to have been interpreted as defiance and "familial deviance" (Watson, 2011).

Gwernan-Jones et al. (2015) further found that parents understood themselves as being seen as different, experiencing "otherness", and that staff identified ADHD as a deficit. The presentation of ADHD is further reported by parents to be associated with the school environment and felt in some research to be an "artefact of the school context" (Gwernan-Jones et al., 2015; p292). Conflict was noted to rise when mothers felt blamed for their child's behaviour within school. There was some evidence of resistance by parents to practitioners when mothers felt they were unable to trust the professional knowledge or perceived they were being unfairly judged. In response some parents were noted to conduct increasing levels of research into ADHD which was shared with practitioners and teachers. These attempts were often felt to be dismissed and viewed as threatening to professional integrity (Malacrida, 2001). Gwernan-Jones et al. (2015) further highlight that some mothers further entered into "assertive resistance" through activities such as keeping meticulous records of involvement, becoming involved in advocacy, moving school and home schooling. However, ultimately mothers were found to be limited by power within institutions and practices (Malacrida, 2001). The limited research, between 1996 and 2011, which is focused upon parents of children with an ADHD diagnosis highlights the need for further research. From the literature it is possible to see how interactions influenced the experience of parents while attempting to

engage with others and though they may express instances of feeling blamed and being seen as different this research does not highlight the individual psychological experience also potentially influencing subjectivity.

1.4 Different need, different experience

Specific differences in parental experiences of their interactions with schools have further been highlighted depending upon the type of SEN categories their child is understood through. Broomhead (2013) found parents of children perceived as having BESD felt blamed for problems experienced by school staff leading to internal feelings of guilt. In contrast parents of children with other categories of SEN did not report feelings of being blamed nor experiences of guilt. Broomhead (2013) applied an interpretive phenomenological analysis to semi-structured interviews with 22 parents and 15 educational practitioners. Her research highlighted how educational practitioner discourse, from class teachers, teaching assistants (TA) and Special Educational Needs Co-ordinators (SENCO), both in mainstream and specialist provisions, identified bad parenting as the reason for experienced difficulties which were attributed to the child. Staff described the home lives of these children as “chaotic”, “dysfunctional” and “lacking boundaries” firmly placing responsibility for difficulty with parents. Though the research did find evidence that practitioners recognised the complexities of BESD, which could not be simplistically reduced to bad parenting, when contrasted with discourse around learning difficulties there appeared to be a marked difference in value judgements indicated through expressions such as “real special needs”, “born with”, and “how [the] brain’s wired”. This discourse reflects the notion of legitimacy, through a ‘brain-blame’ narrative (Ryan and Runswick-Cole 2008), whereas in relation to BESD a ‘mother-blame’ view is apparent. This serves to highlight how the framing of difficulty within a neurological narrative influences views of responsibility. Furthermore, parent experience is indicated to differ in that non BESD parents did not report feeling guilt whereas BESD parents experienced intense guilt; “...I did it, I made it, pre-womb, inside womb, after womb, and so all blame lands on me...” (Broomhead, 2013; p. 17). This perhaps reflects parent internalisation of a ‘mother-blame’ discourse (Ryan and

Runswick-Cole, 2008) influencing mothers' perspectives, opinions and feelings. Given the move in legislation towards SEMH represents a change in the conceptualisation of difficulty it is possible parents' experience of interaction has changed. Whereas BESD was perhaps related to parent-blame, SEMH, positioned in a medicalised discourse, may be more related to brain-blame.

Further research identifies concerns for how educational practitioners work with parents from working class backgrounds (Cruddas, 2010; Gillies, 2010; Klett-Davies, 2010; Lacey, 2001); for example some parents have been reported to feel intimidated by teachers and that there is a lack of shared discourse leading to a negative impact on the development of relationships between parents and teachers (Reynolds, 2005; Desforges & Abouchaar, 2003). Further concerns highlight practitioner perceptions of 'good parenting' related to 'middle class practices' (Klett-Davies, 2010; Perrier, 2010). Broomhead (2014) sought to consider educational practitioners norms and values or parenting and education with specific reference to working the children understood as BESD. An interpretative phenomenological analysis was applied to interviews with 15 educational practitioners from both mainstream and BESD settings. Broomhead (2014; p.140) reports practitioners felt parents did not have 'appropriate' expectations of children with some highlighting "it's just downright bad parenting and it's no wonder the child is the way they are". She further highlighted that some practitioners viewed those working in educational provisions as the only way young people could gain a sense of stability; this was considered to be what children needed to escape chaotic and dysfunctional family lives. Educational practitioners presented views highlighting the upbringing of parents as being the reason they did not appear to follow appropriate norms of behaviour. Broomhead (2014) describes the difference in values between parents and practitioners as a "clash of two worlds" which may aid us in understanding why interactions can be viewed as negative and intimidating by parents.

1.5 Parenting discourse – Admonishment to Hollow Redemption

The Department for Education (2011, p.70) proposed the need for consideration of the “underlying reason” for behavioural difficulties that has precipitated the removal of BESD from the SEND Code of Practice (2014). An emphasis has instead been placed on recognising SEMH difficulties as potentially related to “challenging, disruptive or disturbing behaviours” (DFE and NHS, 2015, p.98). This represents a move towards a medicalised discourse (MacLeod, 2006) which has implications for parenting narratives. It is important to consider how social discourse, around parents, influences their subjectivity as individuals are positioned within the language and interactions around them (Willig, 2008). Furthermore, consideration of dominant discourses can generate space to hear individuals and alternative voices as equal to others (Rimehaug & Helmersberg, 2010). Given the consultative work embedded within the activities of Educational Psychologists it is possible for practitioners to consider discourses which may be obscured from view as ways of conceptualising problems. This activity may help to cultivate alternative narratives for parents and young people within our practice and highlight otherwise unseen solutions.

In consideration of cultural norms and narratives around parents of children identified as disabled Runswick-Cole & Goodley, (2018; p.234) argue:

The neoliberalisation and psychologisation of the family demand individual self-governance and wilfully obscure the role that contemporary political and societal structures play in family life.

Though their discussion is related to disability studies the narratives around parents hold particular resonance as the SEMH category of difficulty (DFE & NHS, 2015) moves closer to a medicalised view. The increased focus on parenting and families is argued to be sustained by a number of common discourses prominent within a Neoliberal-ableism (Goodley, 2014) which values individuals that are able to sustain themselves. The centralisation of “good parenting” within social and political narratives (Jensen, 2012) has been supported by the increasing influence of a neurocultural discourse (Lowe, Lee & Macvarish 2015) which at heart promotes the

fundamental importance of brain development in early childhood above other times. This has brought about the prioritisation of 'early intervention' focused on parents and families as a cost-effective means of preventing increasing difficulties (Jensen, 2012). This has produced the impetus for becoming involved with young people at an early age to consider their in-child difficulties as generated through their early (usually family based) experiences. For example, Briggs-Gowan, Carter, Skuban and Horwitz (2001) recommend the need for early intervention for families who report high levels of "emotion problems" but do not appear to express concern for their child's behaviour. Equally, there is continuing research into the effectiveness of parenting programme to reduce disruptive behaviours in children (De Graaf, Speetjens, Smit, de Wolff, & Tavecchio, 2008)

The focus on brain development and psychology has led to a conceptualisation of the importance of parenting within an individualising discourse; "parenting in England has been re-imagined as an individualised task" (Runswick-Cole & Goodley, 2018; p. 233). This view of parenting and neurocultural discourse in effect focuses problems and difficulties within the family diminishing the potential for recognising other influences (e.g. socioeconomic factors). Runswick-Cole and Goodley (2018) argue that parents of disabled children are equally framed within a narrative of representing a financial burden. The importance of class and status is recognised in what de Benetictus, 2012 highlights to be the discourse of the 'feral' parent, whereby problem behaviours of children are firmly attributed to parents seen within a conceptualisation of working-class mothers as 'feral'. Broomhead (2014) appears to reflect this class distinction reminiscent of the feral parent narrative in teacher perceptions of behavioural difficulties. The implications of the individualising narrative and parent responsibility is perhaps apparent within the views of youth crime and poor parenting (Goldson & Jamieson, 2002). Hutchinson, Parada & Smandych, (2009) demonstrated the relationship between a young person's behaviour and the parent responsibility as a strong cultural narrative. Goldson and Jamieson (2002) attend to the historical association between youth crime and parenting and its psychologisation through discourses such as maternal deprivation

narratives associated with the work of John Bowlby. They make clear the foundations of the relationship are intimately associated with a view of agency:

From the “improper conduct of parents” at the beginning of the nineteenth century, to the “wilful refusal of parental responsibility” at the end of the twentieth century and the outset of the twenty first century, a discourse rooted in individual agency has served to displace any sustained analysis of structural context (Goldson & Jamieson, 2002; p.95)

It brings to the forefront the importance of considering agency and subjectivity as well as research to reflect on the context within which parents are positioned and make sense of their experiences.

Neurocultural narratives and the establishment of mainstream psychological norms (de Benedictus, 2012) has paved the way for the continuous monitoring of children and their families (Ryan and Runswick-Cole, 2008). “Good mothers” are those perceived to support intervention which strive to bring their child closer to the proposed norm (Curran and Runswick-Cole, 2014). Deviations from the trajectory of “normal development” are then associated with parents and families. However, medicalised disorders and diagnostic labels centre the problem outside of the mother-child dyad offering a redemption from the ‘bad mother’ narrative (Runswick-Cole & Goodley, 2018). Ryan and Runswick-Cole (2008) highlight diagnosis offers a shift away from ‘mother-blame’ to ‘brain-blame’ and has often been considered a positive move for women (Singh, 2004; Blum, 2007). Furthermore, labels are identified as providing parents with ‘capital’ for accessing support from services in health, education and social care fields (Ryan and Runswick-Cole, 2008). However, Runswick-Cole and Goodley (2018, p.236) argue in escaping blame parents are faced with having to accept “psychological difference and pathological disorder and a devalued and stigmatised identify for the child”. Runswick-Cole and Goodley (2018) seek to remind us of the cultural specificity of development and the role of the mother suggesting that attention should be paid to its historical and cultural context. Other cultures can be seen to value a collective rather than an individualising approach in parenting where the whole family and community are valued above the individual relationship (Chataike and McKenzie, 2013). This offers an alternative

social narrative to the dominant individualising perspective within western culture. Runswick-Cole and Goodley (2018) offer an alternative means by which it is possible to conceptualise family and parenting which move away from an individualising model. It demonstrates the possibility of alternative discourses and ways of conceiving families and young people, which perhaps provide useful alternatives to common individualising narratives that are associated with blame.

In consideration of existing research around SEND parents, Ryan and Runswick-Cole (2008) highlight the grief narrative which is often present within the literature (Bruce and Schulz, 2002). Parents have been reported to be either unable to cope, considered to be delusional or denying the reality of their child's difficulties if parents do not appear to reflect a sense of grieving within their family (Darling, 1979; Taylor and Bogdan, 1995). This generates an inescapable narrative for parents associated with grief within the research literature; it is expected that parents will be seen to be grieving and if they do not they must be in denial.

Different social discourse is thought to influence the positioning of parents which may impact upon how they make sense of their experiences. Subjectivity reflected in "the subject's sense of life" (Lacan, 2006a; p. 558) can be understood in how individuals speak of themselves in relation to their experiences. Shifts in the framing of behaviour within the SEMH category of difficulty may then present changes to how parents see themselves and how they experience interactions with others.

1.7 Summary and Research Focus

Current research highlights the notable experience of parents supporting a young person with SEND (Van Wyk & Leech, 2016). Specific differences are also reported in parent interactions and how they feel relative to the category of need their child is identified within (Broomhead; 2013, 2014). Further noted are cultural discourses which may influence how parents both position themselves and are positioned by others (Ryan, Runswick-Cole, 2008; Runswick-Cole & Goodley, 2018; Willig, 2008). The new SEMH category introduced by the SEND Code of Practice (2015) marks a noticeable shift in direction towards a medicalised understanding of behaviour

(MacLeod, 2006). However, little research has been conducted in this area given its very recent introduction. Literature related to other categories of SEN provide the impetus to consider the rationale that parents may have experiences specifically related to having a child identified with SEMH difficulties influencing their subjectivity. To understand this influence it is necessary to consider cultural discourse, interactions with others and individual psychological experiences which contribute to parent subjectivity.

1.8 Research questions:

1. How do mothers with children identified as having SEMH difficulties make sense of their interactions and psychological experiences?
2. What are the implications of SEMH discourse on mothers' subjectivity?
3. In what ways can mothers be supported when positioned as having a child with SEMH difficulties?
4. What implications are there for the practice of Educational Psychologists when working with parents, young people and practitioners?

Chapter 2: Methodology

2.1 Overview

In this section I highlight the methodological foundations upon which this research is based. It is through a consideration of the position of women in research and the conceptualisation of subjectivity which aligns this study with a critical realist perspective. I outline the positioning of this research as a psychoanalytically informed narrative approach. Lacan's concept of the subject and the unconscious are explained as a means of recognising the complex nature of voice and to understand how individual psychological experience, in the form of the unconscious, and social discourse are can be recognised to influence interaction and subjectivity. Consideration is given to the necessity of adopting a reflexive approach and I explore issues related to concepts of validity, reliability, generalisability and ethical research.

I am mindful of perpetuating a patriarchal system given I am a man completing research with women. The culturally inherited privilege from being a man is well documented (Case, Iuzzini, & Hopkins, 2012; McIntosh, 2010; Wildman 2000,) as is the perpetuation of this privilege through an unwillingness to recognise its influence (McIntosh, 2010). For myself this has meant it is necessary to recognise the discrepancy of power between myself as a male researcher and female participants. I have attempted to address this tension through conducting this study with an approach rooted in a feminist position. The reflexive nature of the method I have adopted is detailed and was purposefully employed as a means of making myself visible within the research in the hope to offer transparency and openness in the interpretations I have made. I have aimed to engage with the power dynamics within my relationships with the mothers who volunteered to tell their stories. I have aimed to recognise these influences and conduct my research both responsibly and sensitively in line with my emancipatory conceptualisation, which is aligned with seeking social justice. I have specifically considered issues relevant to validity and the decisions I made around my approach to sharing interpretations with mothers. Within the focus of this research is cultural discourse and its influence on how individuals make sense of their experiences. I recognise that as the person completing this research I am influenced by the narratives that surround me and that

within this context I hold a position of power. I have attempted to hold this in mind whilst completing this project and would propose that the analysis I have completed reflects one way of interpreting this data. I do not claim to be revealing a 'truth' in mothers' experiences; I simply hope to reflect its complexity and offer possible ways of examining these narratives.

The remainder of this chapter seeks to argue for a view of individuals that retains agency and recognises the complex nature of the self. I further propose the need for recognising how individuals speak of themselves through a narrative based method. I argue that on accepting a complex subjectivity (Parker, 1994) it is necessary to consider both the psychological and social influences on how individuals understand their experiences. I further propose that through the application of Lacanian psychoanalytic concepts it is possible to understand the complex nature of the self, which is constituted in relation to social discourse (the *Other*). Lacan provides a means by which to understand how the unconscious forms not as a hidden element of individual psyche, but rather as fundamentally connected to language (the symbolic) and therefore the *Other*. For Lacan the unconscious is structured like a language, as it is formed from the language and culture we are born into.

Due to the complexity of concepts recognised to underpin this research project I have attempted to provide an extensive justification of my methodology. I feel that without the depth of explanation the subtleties of the project could be missed leading to a misunderstanding of my analysis and discussion.

2.2 Educational Psychology and Psychoanalytic concepts

Psychoanalytic concepts continue to be used within the educational field in the support of both young people and those working with them (Billington, 2006a). Hyman (2012) highlights the potential for schools to act as holding Environments. From the application of Winnicottian theory (1965) and Fonagy and Target's (1998) concept of mentalisation, Hyman (p. 206) argues for the benefit of "keeping the other's mind in mind" as a means of facilitating better attunement within the school setting. Hyman draws attention to how adults are often "objects for internalisation" and that the awareness of processes such as transference and countertransference

can help adults to modulate their responses. The school as a holding environment is emotionally soothing, offers validation to the feelings of young people within it, and leads to a greater sense of security. Pellegrini (2010) proposes that mechanisms such as splitting and projection (Klein, 1946) can be important in understanding the interactions within which EPs may be involved. He offers two case study examples where the psychodynamic concepts of splitting and projection provide a means of making sense of responses; in a multiagency meeting whereby members of the meeting appeared to identify one individual as good while heavily criticising another and during a training session where Pellegrini feels to be the focus of projected frustrations. The use of a Systems Psychodynamic approach (Eloquin, 2016) in EP practice is also a way of considering how defences against anxieties influence group dynamics within organisations. From consideration of the work of Bion (1961) on Group Relations Theory the Systems Psychodynamic approach formulates a means of understanding how groups may work to alleviate anxieties which perhaps run counter to their recognised aims. Billington (2006b) highlights the inseparable nature of feeling, thinking and learning, understood through the work of Bion (1962), as a key concern for practitioners working with children:

So no matter what the presenting concerns, the responsibility of the professional would be to consider the impact of any work upon the child's emotional life because this will impact on their ability to think and thus to learn (Billington, 2006b, p.93)

Bion provides the framework through which to develop an understanding of the relationship between emotion and thought. This can serve to facilitate the consideration of how those we work with feel and reaffirms the importance of the relationships we develop with others. Billington (2006a, 2006b) outlines the significance of our role in relationships and how we work with others, noting the potential for psychodynamic theories to aid in this process, specifically how we listen to ourselves.

Lacanian Psychoanalysis offers further understanding to the significance of how we work with others when we consider the limits of language to communicate experiences. Lacan (1977b) highlights how words and meaning, understood through the signifier and signified, do not remain constant and can allude to more than can

be captured in the word. Therefore the use of Lacanian theories can aid EPs in resisting simplistic and reductionist explanations, to open up new possibilities (Billington, 2006a). Billington (1995) provides an example of how Lacan's adoption of a Structuralist model of language, combined with psychoanalytic concepts of displacement and condensation, open up a way of considering the discourses we create and encounter. In a poignant example, examining the interaction between an Educational Psychologist and the parents of a boy viewed as having 'behaviour difficulties', it is possible to see how discourses related to being a 'good father' influence the narrative and exchanges within the conversation. Billington (1995) further draws out the importance of recognising the power, privilege and influence EPs have within conversations and the need to acknowledge our presence within our work. It is within this notion that I orientate my research; accepting the importance of listening to myself and others while acknowledging the possibilities born out of the limits of language.

2.3 Epistemological and Ontological Foundations

This research aims to consider the subjectivity and meaning-making of women who have a child identified within the SEMH category of need from the SEND Code of Practice (2015) framework. I recognise the historical context of women in research as being marginalised voices in how they speak of their experiences (DeVault, 1991; Spender, 1980; Stanley and Wise, 1983). Luke (1994; p.213) highlights the power, position and language of women in a variety of fields (e.g. political, educational, research) has been "historically male defined, written and exercised. Rational argumentation, not deferral to narratives of experience, counts as authoritative discourse" (Luke, 1994; p.213). This serves to highlight the need for consideration of women in research and to count narrative experience as a valid and authentic form of knowledge. A careful consideration of subjectivity is required to ensure that the agency of women is sustained within its conceptualisation, which holds implication for the epistemological foundations of this research.

2.3.1 Complex Subjectivity and Critical Realism

Parker (1997) identifies two trends in the conceptualisation of subjectivity; *blank subjectivity*, *uncomplicated subjectivity*, before offering a third alternative, *Complex Subjectivity*, through the careful application of psychoanalytical concepts. Each view of subjectivity holds important implications for understanding the agency of individuals. Within the *blank subjectivity* trend individual experience is considered “an effect of language or a work of fiction” (Parker, 1997; p.481). Individuals conceived as solely written through narrative and discourse leads to a dismissal of any notion of investment or recognition of interest or intention someone may have in a conversation (Parker, 1997; Hollway & Jefferson, 2013). Attributions to the individual are given by another speaker within the linguistic process; any individual with agency is simply a position in language (Benhabib, 1995). It treats the subject as a “blank space which discourse circulates” (Parker, 1997; p.481) that Parker indicates is both flawed and brings fears of a determinism (Billig, 1991; Curt, 1994). In recognition of the difficulties of identifying agency within *blank subjectivity*, *uncomplicated subjectivity* offers the opposite position; within this conceptualisation a ‘core self’ (Burr, 1995) is brought into being with the ability to use language and discourse in different contexts and for different purposes. In this view “it is as if the self is there before, and independent of social context” (Parker, 1997; 482). Here we are given the impression of having access to a simple rational unified self (Henriques, 1984; Hollway 1989) that can be recognised and understood within the research context. It proposes an uncomplicated research relationship in which it is assumed that a direct connection between language and experience exists and that the researcher can have a transparent reading of meanings within the text (Parker, 1997). This reflects a ‘tell it like it is’ view of participants discourse which Hollway and Jefferson (2013; p.3) identify as the “transparent account problem”. In this view it would fail to recognise the social relations within which research is undertaken and produced (Oliver, 1992).

A critical view of subjectivity is necessary and fits within the feminist and emancipatory endeavour of my project. In accepting a blank subjectivity there is potential for failing to recognise the subjugation through the exclusion of voice

within the research. However, uncomplicated subjectivity may lead to an assumption of transparency and common meaning within language, thereby failing to recognise the interview practices that influence participants (Mishler, 1986). This could equally act to silence mothers involved in the research. Furthermore, it does not appreciate the social relations upon which research is built (i.e. the researcher/researched dyad which has an implicit power dynamic through the “belief that it is the researchers who have specialist knowledge and skills” (Oliver, 1992; p.3)). In proposing an uncomplicated agent there is potential to simultaneously empower and deny authority over a person’s story through choices made within the research process. Frosh (2007) highlights how narratives can present multiple stories within them and that often the role of the researcher has been “to make some sense of them [stories], to tell, that is, a better story” (Frosh, 2007; p.636). Which plots and stories are centralised and listened to becomes purely an act of the researcher within which there is an inherent power dynamic. Within this research I wished to acknowledge power in the relationship of researcher and participant. I did not take the view that it was possible to eradicate this dimension in research and therefore I wished to adopt a methodology that would serve to highlight it within the process.

In taking seriously the application of psychoanalytic theory to aid the development of a view of *complex subjectivity* Parker (1997) reflects that it is important to recognise that it is the influence of psychoanalytic discourse in western cultures that enables us to use it in this manner. It is this influence which gives it its applicability and usefulness as a framework for understanding; it is not to present it as a “correct” theory. Psychoanalytic theory and language is useful precisely because of how it is embedded within cultural discourse and therefore can be used to influence our understanding of subjectivity. It does not offer an objective *truth* by which to shine a light on a “correct” relationship between discourse and subject; it too exists and is influenced by culture. However, it does provide an alternative language by which to consider the subject and its relationship with cultural narratives.

Rejecting the view of a psychoanalytic theory that can provide objective *truth* was felt to be important for my research as I aimed to reflect the complexity in meaning making of the mothers who chose to share their stories, presenting a possible way of

understanding mothers' experiences through the application of psychoanalytic concepts. I do not aim to present a revealed "truth". In this sense it is seen as an emancipatory science (Habermas, 1972) which "respects interpretation, experiential resonance and understanding in the reading of text" (Parker, 1997; p.485). Recognising psychoanalysis as a cultural discourse aims to avoid elevating it above all others as a means of illuminating a transparent reality.

Importance is given to interpretation and therefore the position of the researcher to the text requires a recognition of their influence. It moves towards Barthes' (1977) view of the "death of the author" to the "birth of the reader" (Parker, 1997). However, in this sense it is not a simple, straight forward reading where language makes experience transparent. It allows for what Stern (2000) describes as the "return of the subject", one which can be understood as positioned by the constructing nature of language whilst still enabling some sense of ability to be an agent within their narratives. To this end Butler's (1995; p.134) incorporation of agency within the performative act as "one which bring into being or enacts that which it names" allows for agency whilst being situated in a social context.

This agency is performed through the potential for resignification to occur. Frazer (1995; p.67) recognises the unification between stances (blank and uncomplicated subjectivity) in indicating "although the subject is itself the product of prior signifying processes, it is capable of resignification". It does not require an a priori agent acting as a control centre within social and cultural discourse, whom we might seek to view in a pure and transparent fashion. The notion of the possibility of simple transparency through language is difficult to maintain (Parker, 1994). It is possible then to recognise that agency does not simply happen in relation to a specific subject; reflected in Butler's (1995) assertion of the plurality of subject. This aligns with the psychoanalytic notion of the fragmented or multiplicity of selves (Frosh, 2007). Complex subjectivity then "takes serious both the intentions and desires of the individual and the operation of social structures and discourse" (Parker, 1997; p.491). This approach affords a way of not only considering the experienced self, but also the self that is constructed in language, through discourse and in the symbolic (Madill, Jordan & Shirley, 2000). Here we begin to embark upon a "terrain" which resists the

assimilation of ideas of an individual and a social world to familiar understandings, which divide “them into inner and outer or same and different” (Frosh & Baraitser, 2008; p. 350). Therefore, complex subjectivity offers a means to understand the multiplicity of the subject which has agency and is constructed in its social and cultural relations.

My research is based upon a critical realist epistemological position that accepts it is only possible to understand the world around us from the subjective experience of each individual. Though meaning and understanding are created through conversation is it not a purely co-constructed project. Language and cultural discourse, which we are born into, equally shape the ways we make sense of experiences. Parker (1997; p.480) highlights “as well as moving language... people are moved by language” reflecting that through interactions we shape how we speak of our experiences, however, we are also shaped by the discourse around us. The research is based upon a notion that cultural discourse exists beyond each individual, influencing meaning and understanding of experiences whilst also accepting how, through conversation, we continue to co-construct our experience. However, this does not mean to position individuals as passive subjects with no influence, nor active subjects who are not influenced. Instead it aims to reflect “the return of the subject” (Stern, 2000; p.109), one which is understood to be an active agent within narratives. This research is therefore positioned in a critical realist framework.

2.3.2 Implications for this research

Placed within this context a focus of the research was understanding how complex subjectivity may be recognised within how mothers speak of their experiences. It attempts to acknowledge the marginalisation of women’s voices in research and propose a methodology which attends to narrative experience. In this sense it is an emancipatory approach, which is critical of structures that may serve to oppress and subjugate individuals at both the social and individual psychological level (Smith-Chandler and Swart, 2014). I employ a critical perspective which aims to empower voices of marginalised individuals through challenging the “status quo” (Alvesson and

Deetz, 2006). In seeking to listen to the voice of others it is felt to offer a potential opportunity to empower individuals (Nind, Boorman and Clarke, 2012). It is necessary to also consider notions of “authentic voice” recognising that voices exist within a complex dynamic which does not sit independently of social discourses (Nind, et al. 2012). As Frank (2012) indicates, an account or story is subjective as it is told, it belongs to the individual as they speak, and is yet still external to them as it is “always borrowed in its parts” (p. 36). It is then necessary to consider where the potential for listening lies as Frosh and Baraitser (2008) point out that an emancipatory approach should listen to the margins of voice. It is in the margins that there is potential for “newness” and that a resistance to being “completely absorbed into the conforming norm” (Frosh and Baraitser, 2008; p.68) may happen. Though elements of stories may be “borrowed” there still exist the potential for “newness” within the individual experience.

This research considers the experience of mothers who have a child identified as having behavioural or SEMH needs whose voices can be marginalised through narratives of poor parenting (Broomhead, 2013). I aim to explore how mothers make sense of their experiences, set within a SEMH and parenting discourse (Runswick-Cole & Goodley, 2018); I also consider the implications for subjectivity being influenced by individual psychological and social experiences. The use of a narrative approach has already been stated as a way to challenge male determined conceptions of knowledge which is consistent with the feminist approach I have applied to this research; the following section continues to provide a justification for the use of a narrative approach. Given the conceptualisation of subjectivity and the influence of agency as well as social discourses I then provide a justification for situating this research in a psychosocial paradigm. Lacanian psychoanalytic theory is then outlined as a means of understanding the concept of the self (*the subject*) and the influence of social discourse (*the other*). From consideration of the Lacanian subject I have argued for the need to recognise the multiple voices within how individuals speak and how we can recognise the individual psychological influences (the unconscious) in speech. I then move to explain how reflexivity is essential in

supporting the recognition of myself within the research in order to continue to attend to the voices of mothers which is consistent with the emancipatory approach.

2.4 A Narrative Approach

A narrative approach was adopted which enables the opportunity to consider voices within a wider social and cultural context whilst also engaging with the subjective meaning-making apparent in individual discourse (Emerson & Frosh, 2004; Gilligan, Spencer, Weinberg & Bertsch, 2006). Narratives can “shed light on the intersections of the individuals and his or her familial and cultural contexts” (McLean, Wood and Breen, 2013; p. 433) therefore allowing the ability to be able to consider interactions as an influence on stories (Gergen, 2015). This approach fits well with the aims for my research as it allows mothers the freedom to be able to describe and make sense of their experiences, potentially with multiple meanings. Narratives also enable the recognition that language is more than simply expressive (Gergen, 1993; Rogers, 2007c) and that it has a constructing function within a linguistic community (Wittgenstein, 1963). It also reflects Bakhtin’s notion of a dialogic nature of language, which includes polyphonic voices (Rogers, 2007) and the recognition that stories, individual phrases and words must be understood in relation to past words and meanings (Wortham, 2001). As I aim to consider different influences on subjectivity a narrative approach enables me to be able to consider multiple voices, which perhaps reflect different positions within subjectivity, and their meaning in association with context and cultural discourse. Furthermore, Bruner (2004) indicates how “narrative modes of knowing” are an important aspect in the construction of identity and the self. This view of language as a constructive force within a linguistic community aligns with Bruner’s (2004) view that individuals are continually constructed in relation to social and new situations (Bruner, 1990) and therefore in researching the subjectivity of mothers I felt a narrative approach was necessary.

Narratives are understood as “an extended story about a significant aspect of one’s life” (Chace, 2005, p.652) which offer individuals a way to organise and interpret

events (Murray, 2003) and create an understanding of ourselves and others (Polkinghorne, 1995). These stories do not sit independently to cultural narratives (Frank, 2012; Polkinghorne, 2004) and are influenced by those around us as Bruner (1990, p.114) indicates when saying “just as knowledge... gets caught in the net of culture. So too self becomes enmeshed in the net of others”. This reflects the possibility that narratives of ourselves can be expressed and understood in different ways; being spoken through multiple voices (Murray, 2003). Though this conceptualisation sits well with social constructionism I argue that it is not possible to fully understand subjectivity from this perspective, as it “tends not to explore the particular mechanisms or processes that generate the subject as unstable and open to re-articulation” (Aranda, Zeeman, Scholes, & Morales, 2012; p.553). It offers no means of understanding the interest, investment or intention someone may have in a conversation (Hollway & Jefferson, 2013) which can be achieved when individual psychological experiences are theorised as an influential factor. It would lead us back into a *blank subjectivity* whereby we are simply a produce of social discourse. I argue that it is necessary to consider the nature of subjectivity and its relationship to both our psychological and social worlds through a narrative approach, as it enables mothers the freedom to make sense of their experience and consider the individual psychological experience and the influences of social discourse.

2.5 Psychosocial Research

With the conception of a subject produced in social discourse, a being born into language, that is able to enter into acts of resignification we must begin to consider social and individual factors relevant to narrative or experience. However, it is necessary to develop some clarity in understanding how the individual, or psychological, and social come together as this is central to this study. The psychosocial paradigm for research has multiple approaches highlighting the variant and variability of the conception of the approach (Clarke, 2006; Hollway, 2004) which as such has no set prescribed method (Frosh, 2003). Differences reflect both philosophical and ethical considerations which hold relevance for constructs of knowledge, power, assimilation and emancipation (Frosh and Baraister, 2008;

Hoggett, 2008). In this section I consider different conceptualisations of the paradigm (Psychosocial as Additive, Psychosocial as Revealing and Psychosocial as Opening). I argue that a psychosocial approach consistent with the aims of my research and the emancipatory ethic must be viewed as more than an additive analysis. It must also avoid a model which positions the researcher as a top-down expert revealing “truths”, but rather offers a means by which to open up a text to consider its functions for the speaker and the listener (Frosh & Baraister, 2008).

2.5.1 Psychosocial as Additive

Academically, psychological and social fields have been distinctly divided between studies of the social environment and studies of the individual leading to a marked separation; where they have come to interact it is often through the means of one being subsumed into the other (Frosh, 2010). This conceptualisation of psychosocial research fails to consider the integration of the approach instead viewing it as “an additive treatment of different levels of analysis in the same research framework” (Hollway, 2006). This does not reflect a synthesis of the areas and continues the dominant view of them as distinct and separate.

2.5.2 Psychosocial as Revealing

One conceptualisation of the psychosocial research approach is to consider the unconscious as something hidden beneath the text that can be revealed through the application of psychoanalytic concepts, such as defence against anxiety and distress. Hollway and Jefferson’s (2013) approach includes the application of psychoanalytic object relation theory to understand the psychological process within the psychosocial model. They present a defended subject influencing the construction of narratives (Hollway & Jefferson, 2013). Hollway (2006, p. 467-468) indicates:

In this perspective, we are *psycho*-social because we are products of a unique life history of anxiety-and desire- provoking life events and the manner in

which they have been transformed in internal reality. We are *psycho-social* because such defensive activities affect and are affected by material conditions and discourses (systems of meaning which pre-exist any given individual), because unconscious defences are intersubjective processes.

At heart it presents the view of a dynamic internal conflict underpinning and inevitable in human subjectivity and intersubjectivity, but as Frosh and Baraister (2008) highlight it assumes an “innerness” which is there to be revealed from the expertise of a psychoanalytic knowledge base. The “out there” and “in here” distinction continues to be present. The continuing dualism of the inner psychic realm born from the application of object relations theory means that psycho and the social are kept distinctly separate. However, Jefferson (2008) argues that it becomes difficult to understand where the debate exists between psychological and social, particularly with the rejection of the ‘inside-outside’ distinction. He argues it is difficult to see how one realm is simply not subsumed into the other (e.g. social discourse is explained and reduced into psychological theory or vice versa). Hoggett (2008; p.382) goes on to highlight “An overarching metanarrative of social construction drew attention away from individuals’ unique histories and relationships” (p. 382). Here, Hoggett reflects the potential for the assimilation and merging of the individual, somehow eliminating specific and unique individuality. However, care must be taken in the preservation of the individual as it may reflect a view that the social and individual exist distinctly without considering how they are constructed that can “obscure the mechanics of subjectification” (Frosh, 2010; p.197). If we are to accept Jefferson’s proposition we return to the difficulty of how to understand the interaction between the psychological and social. In recognition of the continuing distinction between inner and outer Hollway (2015) proposes the notion of a “psychic reality” that may be understood with the application of what Winnicott (1971) terms Transitional Space:

My claim is that if there is a need for this double statement [individuals with an inside and an outside], there is also need for a triple one: the third part of the life of a human being, a part that we cannot ignore, in an intermediate area of experiencing, to which inner reality and external life both contribute. (p.3, original emphasis)

From this notion Hollway (2015) proposes a way to recognise the distinction between the psychological and the social, but also retain a space within which we can envisage an interaction without the reduction from one to the other. However, this does not overcome the problematising nature of having a separate innerness that is to be revealed by an expert knower, someone who is positioned as knowing better than the individual. It may be seen to fall prey to the implementation of a “top-down” view of knowledge and understanding that an expert, with an expert knowledge received from psychoanalysis, can apply to recognise certain “truths” about subjectivity leading to a ‘researcher knows best view’ (Billig, 1997; Wetherell, 2003). An application of psychoanalysis in this sense would have implications for the emancipator endeavour within which I wish to place my project. Furthermore, the interaction and constructing nature of these three distinct realms must still be understood. Indeed, some have suggested that Hollway and Jefferson’s unconscious conflicts can be as easily explained by recognising these as a conscious conflict between different viewpoints of the individual (Spears, 2005) and unnecessarily complex (Young and Frosh, 2009). A further difficulty presented by the adoption of Object Relations Theory and defences against anxiety is that these mechanisms are established from early development and so may be viewed as static or fixed processes (Frosh, 2007) that simply respond in social interactions. We therefore lack an understanding of how they can be transformed by social interactions (Wetherill, 2003). The production of defences from this developmental history seems to offer at best predictability and at worse a determinism (Frosh & Baraister, 2008).

2.5.3 Psychosocial as Opening

For Frosh and Baraister (2008) it is necessary to continue to practice a critical examination of the assumptions of “in here, out there” and aspire to a reflexivity around “a space that is neither “psycho” or “social”, and is definitely not both, but is something else again” (p. 350). Frosh (2010) advocates the application of Lacanian psychoanalysis that focuses attention on language as a way of understanding the

unconscious coming into being in interactions. Consideration is not made of a consistent 'inner world' of an individual subject, but rather the discursive formations within which the unconscious is situated. Frosh (2010) argues that critical psychoanalysis can be used differently, not as a provider of truth, but rather in a disruptive form to examine the fundamental blocks used for meaning-making. In this sense the focus is on "the way language works around the researched, the researcher and the phenomenon" (Young and Frosh, 2009; p.3). From the application of Lacan's (2006a, 2006b) view of language and signifiers it is possible to recognise how we may be able to understand the unconscious within the text, rather than beyond it. This therefore reconceptualises the psychosocial and provides a mean by which to begin to see the connection between the unconscious and the social world.

Lacan (2006b) proposes that the unconscious is structured like a language and that it is created through the repression of signifiers whose affects have originally been too difficult to deal with (Bailly, 2009). Given that signifiers are not static and formulate chains of meaning with other interchangeable signifiers "pointing beyond themselves" (Rogers, 2007; p.107) they can provide a means by which to recognise the unconscious in speech. This helps in understanding what Rogers (2007; p.105) indicates when she says, "I kept hearing something in the narrative I could not grasp: the presence of the unsayable in words, in language, which also fell between sentences, between words". Meaning-making is therefore the object of research for which we should aim to "open up the text by disrupting and disorganising it so that its functions become clearer, including its functions for us" (Parker, 2005; p. 177). Consideration should be paid not simply to the content of the text but also the structure and its form (Young and Frosh, 2009). From this we can then begin to understand its functions in relation to social discourse and the unconscious as revealed within the text. Frosh's (2010) conceptualisation of psychosocial research begins to aid an understanding of how subjectivity can be considered with regards to the individual psychological experience, as conceived in the Lacanian unconscious, interactions and social discourse. A key element in this approach is the opening up of the text as a way of considering its functions for the speaker and the listener. For this reflexivity becomes an essential process within the research method.

Though this view of the psychosocial approach can begin to aid an understanding of the connection between discourse and the unconscious a number of concepts remain in need of further explanation. It is important to make clear how multiple voices are proposed to be present within the ways that individuals speak and therefore how an unconscious could be conceived to exist within how individuals speak. It is also necessary to consider how it is possible to recognise the unconscious in conversation. To this end I move on to consider how Lacanian theory can help to understand a subject that speaks with multiple voices, how the unconscious can be examined in speech and how reflexivity is understood and enacted within my research.

2.6 The Subject in Lacanian Psychoanalysis

As I have already indicated the performative nature of agency (Butler, 1995) allows for a sense of a multiplicity in identity. This aligns with Lacan's view of a fluid and fragmented subject where the notion of a unified self is a "misconception, a place of illusion" (Rogers, 2007, p. 108). This fragmentation is recognised within the mirror stage of Lacan's (2006b) theory where the child identifies with a mirror image of itself or another child. The mirror image within the *imaginary order* represents a new unified understanding of self. Until this encounter the child's experience is of a fragmented body for which the mirror image provides a powerful sense of wholeness (Kenny, 2012). Though this produces a pleasurable sense of unity it further functions "to establish a relation between the organism and its reality" (Lacan 2006a). The image becomes confused for the self and "actually comes to take the place of the self" (Homer, 2005; p.25). This leads to a sense of alienation understood as a lack of being; the mirror image provides a sense of self beyond the being of the subject.

Expressions (in language) of this image see the move of the self into the *symbolic order*. This highlights an important shift in the child attempting to identify with the symbolic. For Lacan there is an oscillation between the alienating image, giving an imaginary sense of unity and wholeness, and the fragmented experience of the body. This leads to the desire to recapture the state of pleasure experienced within the

unified experience through identification with the symbolic (Kenny, 2012). However, the symbolic, or discourse, used in this identification comes from the *Other* which Kenny, (2012; p.1176) highlights as being “laws, norms, rituals and cultural beliefs that are prominent, along with the language we use”. This is because our use of language is inherited from our cultural situation and to this end meaning-making, through signifying chains, remains beyond our control reflecting a view that language speaks through us rather than the other way around (Homer, 2005). The subject then must be constituted in the discourse of the *Other* (Bailly, 2009).

Lacan highlights the desire for identification and recognition (Lacan, 2006c); indicating the consequence of such a need in saying “I identify myself in language, but only by losing myself in it like an object” (Lacan, 1977; p. 94). The ‘I’ signifier which may be used to stand for our identity as a subject in language is unstable and is simply a function of its use at the time of being spoken (Sarup, 1992). Here we see the importance of the functions of speech for the subject; the subject is understood through these functions which vary. Lacan (2006c, p. 255) reflects the view that there is no one single subject beneath the text. In the origins of the subject we are constituted through the discourse of the other; these constitutions are related to history, law, language, the *epos* of our culture and are communicated symbolically. There is therefore potential for encounters with discourses that can constitute “another entity”, encounters which would “cause him [the subject] to have been altogether differently” (p.255). Lacan (2006c; p. 154) states that there is “an incessant sliding of the signified under the signifier” and temporary stability in signification comes through the ‘*point de captation*’; these are anchoring points related to the specific discourse in which meaning appears to be fixed. As all signifiers, and language, create meaning in relation to each other and *the Other* our expressions can be seen to communicate more than they intended (Rogers, 2007). For a subject this means that expressions of ‘I’ are shifting, referring to something beyond the self (Sayer, 2004). This leads Rogers (2007) to outline that the implication for subjectivity is that we cannot know anything “directly and wholly, least of all ourselves” (p. 106). Different voices, and multiple subjects, are inevitable within speech as we encounter discourse in different interactions. In attempting to understand subjectivity it is

important to listen to the multiple voices within a narrative otherwise it would present a limited view where, perhaps, one voice could be elevated above and at the expense of all others. This would represent a choice by me as a researcher to privilege some ways of speaking rather than trying to hear as many others as possible.

2.7 The Unconscious in Speech

Lacan's conceptualisation of the unconscious as structured like a language come from his view that it is through the repression of signifiers that the unconscious originates (Lacan, 2006b). For Lacan language is not a vehicle for the expression of each individual; individuals are situated within and constituted by language: "what I seek in speech is a response of the other. What constitutes me as a subject is my question" (Lacan, 2006c, p. 247). From the symbolic, which is constituted by the discourse of *the Other*, the unconscious begins to emerge. Repressed signifiers in the unconscious therefore continue to have connection with *the Other* and "they emerge from time to time in a form and structure dictated by this Other" (Bailly, 2009; 67). In this sense Lacan has a radically different sense of the unconscious as not a hidden aspect of an individual's mind but rather "the unconscious is the Other's discourse" (Lacan, 2006d; p.10); the *Other* being the laws, norms, cultural beliefs and language we use (Kenny, 2012). Through this Lacan offers a means of understanding how the individual psychic and the social world interlink (Butler, 1997; Kenny, 2012). Importantly, Lacan does not view subjectivity in a sense of being *blank*. Instead he considers it necessary for the subject to take a position in relation to the *Other* which provides "an element of choice that allows for the possibility of change beyond the inescapable determination of the symbolic" (Homer, 2005; p. 74). Speech expression, which brings into being the subject, reflects the agency within the performative act (Butler, 1995).

To recognise the unconscious Lacan (1981; p.59) argues that it can be "apprehended in its experience of rupture" in the symbolic chain, symbolic chains are created from the transient connections of signifiers which provide meaning at any one given point.

These chains are not static and are able to make multiple connections at once, thereby illuminating more than what is intended in speech. As meaning is not fixed and through the sliding signifier chains the unconscious can appear. It is seen as the point when language fails (Homer, 2005) and is thought to be present in free association (Evans, 1996). Sarup (1992; p.55-56) indicates that the subject can be found through listening without preconceptions:

The way that subjects give account of themselves, with all their hesitations and omissions, ambiguities and denials, their imaginary formations such as dreams, delusions and phobias, and their moments of incoherence, are phenomena which reveal the mental life of the individual.

Recognising the unconscious in speech as “those negations, evasions, erasures, omissions, revisions, and silences” (Rogers, Casey, Ekert, & Holland, 2005) reflect the limits of signification. Lacan (1990, p. 3) identifies the importance of when “words fail” as it is “through this very impossibility that the truth holds onto the real”. Lacan’s notion of the real relates to that which is completely resistant to symbolisation (Fink, 2017), considered in the margins and in a state of “being not quite there and yet also not quite gone... something in the gaps that is not completely covered over by the Symbolic” (Frosh and Baraister, 2008; p. 68). The significance of this is to highlight how the unconscious is present in speech and is something that exists in the margins. The margins are reflected in the words themselves when considered with “negations, evasions, erasures, omissions, revision and silences” within speech. Listening to the margins offers a “space from which something new might emerge” (Frosh and Baraister, 2008; p. 74). Given the view of the subject as manifest through speech, not a consistent singular whole, it is necessary within my research to consider the margins and multiple voices in order to better understand mothers’ subjectivity. As Frosh (2010, p.210) writes:

That is, the ‘truth’ of psychoanalysis lies in its power as a social sense-making discourse. Research is not a process of uncovering (even relative) ‘truths’ about people, but rather exposes the ways in which subjects are positioned by the theoretical structures used (by them as well as by researchers) to understand them.

The implications for my research mean that interviews should be considered not only in the form of their content, but also the functions of speech recognising the multiple presentations of the subject in order to further consider subjectivity. However, it is necessary to avoid the orientation of this research towards what Lacan describes as 'Discourse of the Master' (Lacan, 1991 cited in Parker, 2005), whereby the researcher imposes an interpretation under the mask of knowledge leading to the barring of subjects (Parker, 2001). The analysis may look to be disruptive of the presented narrative, however, this is necessary to consider the complexity of the subject as presented within the text. The presentation of a unified self would be inconsistent with the foundations of this research. Analysis is therefore not presented as a 'truth', but rather a possible way of recognising the subject in speech. As mentioned previously, reflexivity is a fundamental principle for my research to attempt to recognise the influence of myself on the project and to be mindful of becoming positioned as a "master" within the study.

I recognise that the concept of the unconscious is debated (Thorton, 1999). For the purpose of this research I follow Hollway and Jefferson (2013, p.2) who propose that the concept of the unconscious and its influences can aid in understanding why narratives are "littered with contradictions and inconsistencies". It provides a means by which to understand subjectivity.

2.8 Research Design and Reflexivity

Consideration of the position of women in research mentioned previously has influenced the manner within which I have chosen to conduct this myself within this project. The application of Lacanian concepts is consistent with the rejection of myself as an 'expert' revealing a 'truth' within the experience of mothers. It is hoped that this goes some way to addressing power differences within the project, however it is not possible to eliminate them completely. Therefore a reflexive approach is necessary to be as conscious as possible of these dynamics. Equally, it would not be consistent to consider narratives at face value. This would fail to recognise the multiple ways in which mothers speak of themselves in relation to their interactions and therefore offer only a narrow consideration of the complexity of subjectivity.

Recognition within the intersubjective experience has implications not only for participants but also ethical implications for the researcher (Pollard, 2008). The recognition of the marginalisation of women within research reinforces the necessity to apply an approach which attempts to recognise my influence as a researcher within the project. As indicated in a large quantity of qualitative research “interpretation of data is a reflexive exercise through which meanings are made rather than found” (Mauthner & Doucet 2003; p. 414). Being able to access an objective reality from a neutral position is not possible (Frosh, 2010). The influence of the intersubjective experience upon the data collected continues to resonate within the analysis. I therefore felt that it is necessary to adopt a reflexive approach. Doucet and Mauthner (2008, p. 404) argue that “how we come to know narrated subjects relies strongly on the role of our own subjectivities in knowing” but that it is not possible to have a complete awareness of our influences. To this end they recognise that there are degrees of reflexivity (Doucet and Mauthner, 2008).

In particular, we suggest that reflexivity is not confined to issues of social location, theoretical perspective, emotional responses to respondents, and the need to document the research process, aspects of reflexivity which are highlighted within current literature. We demonstrate how more neglected factors such as the interpersonal and institutional contexts of research, as well as ontological and epistemological assumptions embedded within data analysis methods and how they are used, can deeply influence research processes and outcomes” (Mauthner and Doucet, 2003; p.418)

For this research I argue that in hearing the voice of mothers it was necessary to conduct open-ended interviews. This interview approach has been shown to be an effective way of eliciting views given they can be flexible and “allow the research to follow up on vague, confusing, even contradictory information, sensitively and systematically (Rogers et al. 2005p.3). This approach further accepts that relationships are fundamental in how human experience is understood and organised (Gilligan, 1996). The epistemic position described here continues to recognise that an interpretation of the narratives of others reflects an opening up of the text and that other interpretations are possible. Consequently, it is necessary to

consider what is understood by notions of validity and reliability when considering the quality of the interpretations offered.

A reflexive approach is also necessary in relation to genuineness in the presentation of this data, the plausibility (not 'truth') of analysis and the ability to bring others along in the interpretative journey (Reissman, 2008). Reliability is replaced with trustworthiness (Mishler, 1990) and so a marker to the quality of the research lies in my ability to demonstrate to the reader the process, consistent with my epistemic and ontological foundations, that has been followed. More is said on reliability in the next section. Trustworthiness in this sense seems to echo the difficulty that Frosh (2010) recognises as "wild analysis" in the application of psychoanalytic concepts. I aimed to minimise the potential for "wild analysis" and offer a transparency to the research process through my reflexive approach. To this end recordings were made of interviews to ensure the integrity of voice was maintained. Within the analysis full transcriptions are included demonstrating the co-constructions of narratives created within the interview situations and allowing the reader to observe how the analysis is produced from within the interview text.

2.9 Validity, Reliability and Generalisability

Within the critical realist epistemology it is accepted that knowledge and "the way we perceive facts, particularly in the social realm, depends partly upon our beliefs and expectations" (Bunge, 1993, p.231). This has significant ramifications for how objectivity and reliability are conceived. Equally the connection between the repeatability of research and achieving the same result is questionable. As Parker (1994; p.11) indicates "it is certainly possible to repeat the work that has been described, but the repetition will necessarily also be a different piece of work". However, acceptance of the influence of subjectivity does not afford the option of simply rejecting such concepts without an explanation as to why questions around reliability and validity may not be addressed (Parker, 1994).

An initial difficulty with these terms lies in how this research is positioned. It is felt that bringing to light researcher subjectivities offers a means by which to give a more

complete account of the research process (Pidgeon & Henwood, 1997). In attempting to offer a fuller description we can attempt to assess the project as situated in the “perspective and traditions that frame it” (Reissman, 2008; p. 185). This is particularly important for my research as it frames an understanding of subjectivity in relation to perspective, traditions, discourse and epoch (*the Other*). From this position it is possible to accept the view that there is no one reality which can be examined through the correct use of a methodology (Giorgi, 1995). Rather the aim should be to articulate the perspectives taken in the approach to analysis, (Wilkinson, 1988) which will reveal the researchers own personal constructs (Miller, Velleman, Rigby, Orford, Tod, Copello, & Bennett, 1997).

Though it has been argued that coherency in narratives can be used as a sign of validity (Reissman & Quinney, 2005) this may result in failing to appreciate the complexity of subjectivity through the application of coding schemes involving single static categories (Gilligan, Spencer, Weinberg, & Bertsch, 2006). Indeed, coherency may lead to assumptions about the transparency of language used by a unified single-self, which would not be consistent within the approach proposed to investigate subjectivity. Reissman (2008) also notes it may not be possible for coherent descriptions to occur in relation to traumatic events, which leaves open questions about the plausibility of this as a criteria for validity. Rather than reduce complexity to a coherent whole Frosh and Baraitser (2008) highlight the need to consider the complexity of narratives in such things as the “niggling” gaps and contradictions which may be found in the margins of the text:

They offer slight pricks to the bombastic claims of truth-mongers; they bring down to a human scale the over-passionate gestures of intellectual (and other) saviours; they are sideways-on, ironic, fragmentary and silly (p. 70)

Appreciation of the complexity of the text is recognised through the application of a dialogical method in the Listening Guide (Gillian, 2015), which attends to the polyphonic nature of voice. Previous research has highlighted that though the Listening Guide is informed by psychoanalytic theory it does not provide a framework for considering the unconscious within language (Murphy, 2017). It was therefore

necessary to add a further layer of analysis to the Listening Guide method which could consider the unconscious within the text. Following the example of Murphy, (2017) I have included a stage of analysis which examines the *languages of the unsayable* (Rogers, 2007). A description of this phase of analysis is contained within chapter 3. Rogers (2007; p.113) applies elements of Lacanian theory in narrative research to consider how the unconscious may be identified through “negations, revisions, smokescreens (diverting attention to a safer place), and silences”.

A further means by which to support the integrity of qualitative research is to consider testimonial validity (Stiles, 1993). This process may take the form of a consultation with a participant around the researcher’s interpretation. This was considered within the approach of my research, however it was felt to potentially create an inconsistency within the project with regards as how to consider consultation on the interpretation in the analysis. A second interview about the analysis would present a new situation within which responses would be subject to the influence of the intersubjective experiences and cultural discourse. To stay true to how the research is positioned it would therefore be necessary to analyse second interviews in the same way as the first to recognise the multiple positionings of the subject in relation to the analysis. In attempting to support the validity of these second interviews on the analysis it would be necessary to re-apply a testimonial validity approach again through a third interview. This would produce what I describe as an infinite validity paradox whereby each attempt to verify an account is equally in need of verifying through the same process.

This may appear to present a tension between how I have outlined the positioning of women historically within research and the exclusion of a second interview for mothers to influence the interpretation. I would argue that all research, implicitly or explicitly, faces this difficulty of including marginalised voices within interpretive analysis. The Lacanian informed approach I have applied recognises the multiplicity of voices in speech and offers a way to attend to the complexity of meaning-making in experience. In attending to the voices of mothers in this research I attempt to empower them though having space to be heard. Without a recognition of the

multiplicity of voice within speech this research would only offer a privileged hearing to one voice; which voice is heard would represent a choice by the researcher and fail to acknowledge the complexity of the experiences of mothers. I also attempt to consider this problem through transparency within my research by including full transcriptions and details of the analytic process. Equally I position myself not as an expert revealing the 'truth' of the experience of mothers in this research, but simply offering possible ways of understanding and recognise my influence on the research throughout the process. Full details of research procedure and analytical strategy is contained within the next chapter.

My interpretation of the interviews were shared with participants in order to support the reflective process. This is important for the transparency of this research project, although not as a means of validating the analysis. Discussion with my supervisor was held before analysis was shared with participants given the necessity for caution recognised in the existing research literature (Hollway & Jefferson, 2013). Though it was felt that some analysis may provoke difficult experiences it is recognised within the existing literature these are not necessarily harmful (Hollway and Jefferson, 2013). Careful consideration was taken when sharing analysis and parents were signposted to avenues of support if they felt they needed them (further details of available support is contained in the next chapter).

In committing to an emancipatory approach to research critical of structures and discourse which may subjugate women it is important that space is given within which alternative views and marginalised voices can be heard. This research has been designed to attend to the multiplicity of voice in order that it may be recognised by a wider audience. I am drawn to Stake's (1995) view that though narrative research may not produce knowledge which is generalisable it can offer a way to challenge common generalisations which may support structures of oppression. This echoes the resistance to "truth-monger" Frosh and Baraitser (2009) envisage when listening to the margins.

2.10 Ethics

Ethical approval was obtained from the University of Sheffield's Ethics Board before any data was collected. Interviews were conducted after informed consent was received from parents interested in being involved in the research (appendix A) in accordance with British Psychological Society (BPS – 2018) and the Health and Care Professions Council (HCPC) guidance. Participants were made aware of their right to withdraw at any time before an interview and up to four weeks after without reason. This gave participants time to reflect on whether they wanted their interview data to be included in the research, but was limited to meet the time restrictions for completing the thesis. The consent form included contact details for both my supervisor and myself which participants were able to use if they had concerns either about the research or my approach.

Interviews were held in a neutral place that was familiar to participants and myself, in a quiet room, with support from other parents close by at the local Parent and Carer Forum premises. Given the potential for the interview to elicit difficult memories for parents an agreement was made between the Parent and Carer Forum and myself that participants would be able to access support through their on-site counsellor if necessary. Parents were informed that they could end the interviews at any time if they felt uncomfortable.

Feedback of interpretations of interviews was managed with great care. A discussion with my supervisor was held to consider what may provoke difficult experiences for parents and how they may be managed. Confidentiality was ensured for participants throughout the research giving them the opportunity to choose pseudonyms for themselves and others in their interviews. All data was anonymised at the transcription stage and was stored securely on an encrypted laptop.

In order to support the transparency of the research an open invitation will be issued to attend a presentation of the research findings within the Local Authority. All participants were made aware of the event and assured that their anonymity will be maintained. It is hoped that this will form part of the basis for the dissemination of

the research which will begin the steps towards action in supporting parents who have young people identified as having social, emotional and mental health needs.

2.11 Summary

I have argued for the application of a psychoanalytically informed narrative approach within my research. This offers a means by which to understand the complex nature of subjectivity whilst maintaining the possibility of recognising the agency of individuals who are influenced by social discourses. Lacan's concept of subject and the unconscious further enable a means by which to consider the multiplicity of voices individuals speak in and how we can begin to recognise unconscious influences in speech itself. Consideration of individual experiences (the unconscious) and social discourse firmly positions this research as a psychosocial project. Furthermore, I have addressed the tension between being a man conducting research with women in a patriarchal culture and proposed the use of a reflective approach which aims to keep my influence as visible as possible within the research project.

Chapter 3: Procedure

3.1 Overview

This chapter details the process of recruiting participants, the conducting of interviews and the stages of analysis which form the basis of the research. The research took place in a local authority in the north of England. A pilot study was initially completed and is detailed in Appendix C.

3.2 Sampling

Volunteer sampling was used as a means of recruiting participants. An invitation (Appendix A) was drafted detailing the purpose and aims of the research study. The invitation also indicated the initial inclusion criteria for participation related to being a parent of a young person identified within the Social, Emotional, Mental Health SEN category in the SEND Code of Practice (2015) or behavioural difficulties. Behaviour difficulties were included given that the SEMH category of need has only recently been introduced into the code of practice and some parents may not recognise the SEMH category. It was then possible, from further discussion with interested parents, to determine if they met the criteria for inclusion; however this was not always successful and is discussed further in this chapter. The invitation was constructed in conference with my research tutor, an Educational Psychologist from the Local Authority and representatives of the local Parent and Carer Forum. The invitation was then emailed out to the Parent and Carer Forum mailing list on my behalf (Appendix A). The invitation made clear the small number of parents the research time frame would allow me to work with and therefore participation would be on a 'first-come' basis. I felt that inviting parents via the Parent and Carer forum would support those that wished to volunteer in feeling comfortable enough to tell their stories. From my experience of working with the Parent and Carer Forum there are many active members who may already have experience in communicating their narratives to others. I felt that this would increase the likelihood of a parent feeling confident enough to meet with me to discuss their personal experience.

My decision to work with the Parent and Carer Forum was based on a number of reasons. Firstly, the ethical concerns for the wellbeing of participants. It was possible

to offer continuing support for a participant after an interview, which may evoke painful or difficult memories, through access to the Parent and Carer Forum counselling service. Secondly, I am conscious of my position as a person working for the local authority as well as a researcher. I felt that through working with representatives from the Parent and Carer Forum it was possible to demonstrate the collaborative nature of the research project, which may act as an encouraging factor for those who wished to take part. Thirdly, from working closely with the local Parent and Carer Forum on both local and national projects, I was aware of the experience many parents had in describing their stories to large groups of people. I felt that this positive experience of sharing their stories would potentially mean that those who offered to take part in the research would feel confident to participate (having either already shared their experience on a previous occasions or having witnessed others doing the same in a safe environment). Fourthly, it was necessary to take a pragmatic view of the research time constraints. For example, it may have been possible to advertise for participants using alternative means (e.g. local advertisement, use of social media). I felt that these methods would not reflect the collaborative nature of the research in the same way as working with the Parent and Carer Forum. Furthermore, time restraints have meant that I felt it necessary to invite participants in the most effective way possible.

I am mindful that there are many parents who would fit the inclusion criteria for this research who may not be part of the Parent and Carer Forum. I recognise the importance of working with marginalised voices who may wish to speak, but do not necessarily have trust in speaking to others about their experience. This would be an area to consider for a future research project. Furthermore, I was unable to offer to pay expenses (such as travel costs or child care coverage) which may have enabled other parents who wished to participate. This meant that limiting economic factors to participation were not addressed. Though I feel that it is unlikely this would have significantly affected my research, given the very small sample size, I am conscious that I may have inadvertently excluded those parents from lower socioeconomic backgrounds.

From this process four parents, all female, elected to take part in the study. The invitation process did not necessarily exclude the possibility of male participants being included, however, responses to the invitation were only from women. One parent did not attend a scheduled interview meeting which was seen as a non-verbal sign of wishing to withdraw from the research. A follow up email was sent to the participant in case a particular issue had prevented them attending. It was made clear that if the participant still wanted to take part we could arrange another time to meet, but that they could also withdraw from the research by simply not responding to the email. No further communication was received and so the participant's information was removed from the research database.

The research study is particularly interested in the experience of mothers given the ways that women can sometimes be excluded from speaking for themselves (DeVault, 1991; Spender, 1980). I recognise that the narratives of fathers also offer a rich and insightful understanding of their experience of parenting a young person identified as having behavioural or SEMH needs. I feel this is potentially a further research project to be considered. The lack of interest from fathers may also be related to the demographic makeup of active Parent and Carer Forum members. Fewer fathers may have received the invitation due to there being less of them on the mailing list. If any fathers had been interested in this research I feel it would have added a further dimension to considering how their experiences compared.

3.3 The Reflective Process

The need for a reflexive approach has been highlighted within the methodology. In order to remain present within the research I have included reflection boxes (see blue box immediately below) which aim to highlight questions I have had and possible examples of my influence upon the analysis of the data I have collected.

Reflection

I wonder if the lack of fathers to volunteer to participate could potentially reflect a general difficulty in engaging in research or whether given the focus on SEMH

needs this is possibly a more specific difficult to this area. Do fathers find it harder to discuss their experience of having a child with SEMH needs?

3.4 Data collection

Narrative interviews were conducted as a way of understanding how parents make sense of themselves in their experiences (Bruner, 2004). Interviews were conducted in a neutral environment on the premises of the Parent and Carer Forum at a time that suited each participant. One parent indicated their preference to conduct the interview at home. Lone working procedures, as set out within the Local Authority Educational Psychology Service, were followed in order that the participant was able to take part.

Before interviews were conducted the consent form (Appendix B) was read out to participants and they were asked to sign and date the form. It was made clear that they could end the interview at any time and withdraw their information from the research up to four weeks after the interview. Interviews had an informal structure allowing for participants to tell their stories in their own way. The interview schedule was adapted from discussion with my research supervisor. It was modified after the pilot study had been completed (Appendix C) and aimed to provide the opportunity for participants to dictate the direction of the narrative. A general orientating question, relevant to the research questions, was given to open the direction of the conversation. The semi-structured nature of the interviews attempted to maximise the opportunity for the participants to express their own meaning frames (Hollway & Jefferson, 2013), rather than researcher imposed, and provide a means by which rich data could be gathered (Emmerson & Frosh, 2009). It gave flexibility to the interviews. I felt the open nature of each interview was an appropriate way to address power differences in the research relationship through the restoration of control to participants as much as possible (Way, 2001) and provide a space for parents to determine how they were represented (DeVault, 1991; Spender, 1980).

Parents were encouraged to tell their story in their own way, based around specific events and period of time (Hollway and Jefferson, 2013), deciding what they thought

was important to them. I informed them that though my research was interested in hearing their experience of parenting a child identified as having behavioural difficulties or SEMH needs there was not a specific 'thing' I was looking for; I was just interested in their experience. Follow up questions were offered during the interviews at pause points such as "how does that feel?" "can you tell me a little more about that?" as well as those asking about specific terms or reference used (e.g. "So you said 'a parent from hell' and what do you mean by that?" – this can be found in the full transcript of Judith's interview in appendix D, line 381). Following the interview I signposted services within the Parent and Carer Forum that participants could access if they felt the need for continuing support.

Though every effort was made to ensure participants were able to lead the direction of the conversation there are some instances when my questions appear to lead the interview, which reflect the co-constructive nature of the narratives. During the conversation with Caroline she reflects on her relationship with her daughter saying:

Caroline: affected mine and my daughter's relationship (.) cos I've had to put pressure on her, you know, come on get ready, you need to get to school, why aren't you going? (.) I know you can do this, you know, you've done it one hundred times before why aren't you going? I thought it was because she didn't want to go, and that's how the school treated you, like (.) you just didn't want to go

Scott: Right so did you feel you had put pressure on because you were told that she just doesn't want to go?

Caroline: Yeah, yeah (.) And it wasn't a behavioural issue (.) erm yeah teenagers do dig their heels in if they are pushed into corners, (.) erm that is a trait you know (.) but (.) generally I think they'll, (.) I mean (.) I can talk about my daughter and I know she's-she was a good student (...) erm and (...) er I know that if she could've carried on with what she was doing she would have cos even to this day she still doesn't accept that

Caroline identifies a conjunction between her thoughts and the treatment from school. My follow up question makes the link much more explicit in identifying the school as the reason Caroline places pressure on her daughter: "did you feel that you had to put pressure on because you were told that she just doesn't want to go?". This reflects the causal association that I make between Caroline's views about her

daughter, her actions and the treatment from school. Though Caroline confirms the relationship it demonstrates how the narrative is being constructed between Caroline and myself. It highlights the need for a reflective approach to the research.

Interviews were audio recorded and lasted for 56 minutes and 57 seconds (Judith), 85 minutes and 10 seconds (Caroline), and 77 minutes and 29 seconds (Louise). After each interview reflective notes were made (Hollway and Jefferson, 2013). Interviews were later transcribed verbatim (Appendix D, G, J) using selected Jefferson (2004) conventions:

Table 1

Symbol	Description
(.)	Pause of less than a second
(4)	Pause length in seconds
((sigh))	Non-verbal communication
[Speech overlaps
(inaudible)	Unable to determine speech in recording

3.5 Data Analysis

A voice-centred relational approach (Brown & Gilligan, 1993) was taken to the data collected from the interviews completed. Given the Lacanian conceptualisation of the subject (Lacan, 2006b) as multiple in nature I felt it was necessary to employ a method which can attend to the different ways individuals may speak of themselves. The Listening Guide (Brown & Gilligan, 1993; Gilligan, 2015; Gilligan, Spencer, Weinberg, & Bertsch, 2006) was employed given its emphasis on the multiplicity of voice and the view that “because voice is in language, it also joins psyche and culture” (Brown & Gilligan, 1993; p. 14-15); this is consistent with Lacan’s view of the unconscious as the discourse of the *Other*. Furthermore, the guide is conceived as a feminist methodology (Woodcock, 2016) which I felt provides a means by which to acknowledge and reflect on the privileged position from which I speak (McIntosh, 2010). The method moves away from a tradition of qualitative research presenting a singular story as a coherent whole (Sorsoli & Tolman, 2008). I felt that it would

complement the psychosocial approach to research I have taken and is consistent with the ethical and philosophical foundations of my study.

Though the Listening Guide has a semi-structured process Brown and Gilligan (1993; p.15) highlight that they “have created a ‘Listener’s Guide’ – a pathway into relationship rather than a fixed framework for interpretation”. A series of *listenings* are essential within the approach which aim to highlight and focus upon the complexity of voice at each stage. The first stage involves listening to the “landscape of the interview” (Gilligan, 2015; p.71) with the aim of hearing the plot so as to be able to “articulate a succinct, yet rich synopsis of the basic trends and themes emerging from the first listening” (Woodcock, 2016; p.3). Consideration is also made of recurring words, themes and phrases (Gilligan et al., 2006; Gilligan, 2015). Alongside this listening a “reflective reading of the narrative” (Doucet & Mauthner, 2008; p. 405) takes place, the significance of which is summed up by Brown and Gilligan (1993; p.15):

this first listening requires that we reflect on ourselves as people in the privileged position of interpreting the life events of another and consider the implications of this act.

In this privileged position it was important to consider the nature of power and the influence I have upon the narrative. The reflexive approach aims to bring to light the effects of my own thoughts and feelings on my understanding and interpretation of the narrative. To this end, reflective notes were completed in green alongside the transcripts during the first stage; sections of the transcripts were also highlighted in green to indicate what section has triggered the reflection (Appendix E and H).

The second Listening requires a consideration of first person references; I statements (Gilligan, 2015). *I poems* are created from the first person references as they offer a systematic means of highlighting patterns in the first-person voice (Woodcock, 2016). Gilligan (2015; p.72) argues that this stage of the Listening Guide provides a way of recognising the “associative stream” of the first person that permeates the narrative. *I poems* were constructed by identifying and exporting statements beginning with “I” and any verb or apparently significant accompanying terms which

were clearly attributed to the participant. “I” statements which were not attributable to the participant (e.g. when the I statement was a quote from a character within the narrative and not a first person statement by the participant) were not included. For example, Caroline recounts a conversation with her daughter related to whether they should take Lydia’s friend on holiday with them:

I said “I’m not, (.) I’m not sure about her, (.) cos I am not sure of her motives, she just using you for the holiday, cos she’s dumped you before” and things like this (.) and I said “Are you sure she is not going to do that?” she said “No I am not sure (.) really” and I said “Well do we still take her do we not take her”, “No mum, can we still take her, I’ll be fine it will be okay”. (...)

Within this description we can see times when the I statement is attributed to Lydia and not Caroline, so these were not included within the constructions of Caroline’s I poems. When the I statements had been identified from the entire text they were extracted from the narrative and ordered sequentially to construct *I poems*. The formation of particular *I poem stanza’s* come from listening to where there is a shift in direction of the I statements (Gilligan, 2015). I paid close attention to how the I statements sat within the themes identified from the first listening as a way of hearing the first-person voice within the complex context.

In the third phase of analysis I listened for *contrapuntal voices*. This enabled me to return to my research question and considered the different voices apparent within the narrative. This stage recognises the complexity of narratives and that they often include inconsistency when considered as a coherent whole (Hollway & Jefferson, 2013). Contrapuntal voices “thus picks up the tensions, the harmonies and the dissonances between different voices, and underscore the musical aspect of listening where the goal is to listen for nuance” (Gilligan, 2015; p. 72). From repeated listenings of the text I was able to consider different voices which cause tension to become apparent within the narrative. For example an ambivalence was noted within Judith’s narrative when describing her experience of the process of diagnosis: different voices highlighted the relief experienced from receiving a diagnosis, but also the loss that she felt; the desire for diagnosis, whilst also indicating a view of not

wanting “anything to be wrong”. Contrapuntal voices were identified in the transcript and highlighted in blue (Appendix E and H).

The fourth phase of listening involved listening for *languages of the unsayable* (Rogers, 2007). Here I aimed to consider instances of “negations, revisions, smokescreens (diverting attention to a safer place), and silences” (Rogers, 2007; p.113). The text was examined taking into consideration times when the conversation was quickly moved away from part of the narrative (e.g. D, 438; “but we won’t go there” diverts the conversation away from Judith’s sense of blame and bad parenting), times when inconsistency appeared to be present between statements within the narrative (e.g. D, 413; Judith’s statement “it was lovely” is perhaps inconsistent with the rest of her narrative), when statements are revised (e.g. D, 275-276; Judith’s revision of fortunately to unfortunately) and when pauses created silences indicating *the real*, difficult experiences where language fails and the unconscious is potentially revealed in the rupture (Lacan, 1981) (e.g. D, 526-527; “like grief, (...) that you wouldn't want your child (.) to be any different”, Judith’s pauses perhaps reflect the unconscious in speech). Languages of the unsayable were identified within the transcript and highlighted in pink (Appendix E and H).

I recognise that there are other psychoanalytically informed approaches that consider the unconscious in a research setting such as Hollway and Jefferson’s (2013) Free Association Narrative Interviewing. This approach attempts to appreciate forms of communication and knowing beyond language (Reissman, 2008; p. 141) through consideration of defence mechanisms such as Transference, Counter-transference and Projective Identification (Clarke, 2002; Hollway, 2015; Hollway and Jefferson, 2013). However, I felt that approaches such as Free Association Narrative Interviewing may not be consistent with my epistemological and ethical foundations for this research. The assumed inner unconscious that is revealed by the expertise of the researcher and their psychoanalytic knowledge base (Frosh & Baraister, 2008) has the potential to disrupt processes for attempting to address power imbalances which may exist within the researcher-participant relationship. Furthermore, complications can arise from what Frosh (2010) describes as the possibility of wild analysis which may happen when moving beyond the spoken words. Given that I am

not psychoanalytically trained I did not feel it was appropriate to move beyond a theoretical application of concepts grounded in the visible transcripts. I have, therefore, chosen then to situate my project within the text. I recognise the potential for communication beyond the language which could influence the interpretive process and attempt to address this through making reflective notes after each interview and throughout the process of analysis. In attempting to consider the *languages of the unsayable* I wish to add to the complexity of participant voices which may aid a development towards further appreciation of subjective experience.

3.6 Analytical write up

The construction of the interpretive analysis was achieved after all phases of the analytic strategy were complete. It was necessary that each listening was “brought back into relationship with one another so as not to reduce or lose the complexity of a person’s expressed experience” (Gilligan et al., 2006, p. 267). This was to reflect and respect the complex subjectivity of each parent’s story. The depth of analysis and recursive nature of the process mean it is a time intensive project and therefore suited to small scale case study research (Reissman, 2008; Rogers, 2007).

Two documents, the Listen Guide Stages Description (Appendix E and H) and a Composition of Analysis (following the style of Murphy, 2017: Appendix F and I), were created during the stages of the listening guide to aid tracking the analysis through each phase. During the listening stages, for each interview, the transcript was highlighted and annotated in the Listen Guide Stages Description documents (Appendix E and H). After each stage was complete the Composition of Analysis document was completed (Appendix F and I) to act as a guide to the Listening Guide Stages Description and the analysis. The right hand column of the Composition of Analysis document lists the different stages of the listening process (Reflective Listening, Listening for the I, Contrapuntal Voices, Languages of the unsayable). Items listed under Reflective Listening, Listening for the I and Languages of the Unsayable reflect what was being considered during that stage. Items listed under the Contrapuntal Voices reflect the voices that were heard in this listening phase.

Boxes on the left hand side indicate the plot themes identified in the narrative in order of how they appear in the analysis. The two-way arrows indicated that each stage of the listening process was applied to each of the plot themes.

In order to remain close to the text throughout the analysis and discussion section references are made to the transcripts. For example, the first reference in Judith's analysis is for when she says "he was a lively child" in the interview and can be found in the full transcript in appendix D at line 36; to save time this reference is written as (D, 36). All quotes from transcripts are referenced in this manner in order to attend to the words of participants.

3.7 Data that did not meet the inclusion criteria

After parents had shown an expression of interest in the research, conversations with the three remaining volunteers appeared to indicate that they met the inclusion criteria for the research. Interviews were completed over a three month period. However, while completing the third interview with Louise (transcription – Appendix J) it became clear that the young person's needs were around autism and a chromosome duplication. Though the participant did mention during the course of the interview "naughty children" when asked if she felt this had been the view of her son she indicated not (Appendix J, 297-302). I felt that this did not meet the necessary inclusion criteria to consider subjectivity in relation to having a child identified within the SEMH category. Given that the interview had been conducted a brief review of the data was completed to identify themes using the approach set out by Braun, V., Clarke, V., & Terry, G. (2012) and a discussion was had with Louise regarding how her interview would be analysed within the research (details of the treatment of Louise's data can be found in appendix M). My decision did provoke some ethical consideration, given the positioning of my research. I have tried to remain consistent with the focus of my research questions while retaining an ethical approach. Though my analysis is different for Louise's narrative, I felt it would be more unethical to exclude her voice entirely from the research. Key themes of Louise's narrative are presented in this body of work to continue to offer space for

her voice to be heard, however, I do not claim to have considered possible ways of understanding Louise's subjectivity within her experience. A further interview for the research was not sought given the rich data that had already been gathered from the first two interviews.

Reflection

I feel that in considering future research I would need to ensure that the inclusion criteria was met before conducting an interview. Though I did make efforts to try and communicate the focus of the research on parents of young people identified to have SEMH or behaviour difficulties (e.g. in the invitation) this was not as successful as I had hoped. I think it is possible that I felt myself and Louise were referring to a shared understanding of what is included within the SEMH category when perhaps we had different conceptions of it. I would need to be mindful of this in future research.

3.8 Sharing the Interpretation

Analysis was shared with parents as part of the reflective process for this research. Reflections on the research are contained within the conclusion of the last chapter.

3.9 Summary

This research was designed in accordance with the British Psychological Society Code of Ethics and Conduct (2018). Participants were invited to take part in the research through an open invitation sent out by the local Parent and Carers forum on my behalf. Inclusion criteria was established based on whether parents had a child who was identified as having SEMH needs, as outlined in the SEND Code of Practice (2015). Participants were interviewed around their experiences with open ended questions. Interviews were transcribed verbatim using a selection of conventions based on Jefferson's (2004) approach. Transcripts were then analysed using the stages of the Listening Guide (Gilligan, 2015) and a further stage considering the Languages of the Unsayable (2007). A reflective approach was maintain throughout

the process and interpretations were shared with participants to inform my reflections.

Chapter 4: Analysis and discussion

4.1 Overview

This chapter presents the analysis of each narrative and a discussion relevant to the existing literature. I felt that this would provide greater clarity as to how the narratives maybe seen to be influenced by psychological factors and social discourse. This approach is also consistent with previous researchers who have applied the Listening Guide method (Majzler, 2016; Murphy, 2017). I have highlighted some examples of how Lacanian concepts can be seen within the narratives.

4.2 Judith's Story

4.2.1 Narrative Synopsis

Judith is a mother of two, with her husband Ryan, in her mid 40s. Her daughter is the eldest of the two at age 14 and Benjamin is 11. Judith has had a large amount of experience (twenty years) as a teacher and has recently taken on a new role as a counsellor supporting other parents of children with additional needs. I met Judith at the local Parent and Carer Forum where the interview was conducted. Judith begins by identifying that Benjamin started to experience difficulties once he entered education. Though there are times when Benjamin is able to cope the difficulties escalate, for which Judith feels accountable. She seeks to understand Benjamin's experience through the pursuit of a diagnosis, which appears to provide some containment for her whilst also generating further difficult emotional experiences.

4.2.2 *I found him very, very difficult (D, 88)*

The narrative begins with a brief introduction and starts with the identification of difficulties from an early age, "he was a lively child" (D, 36-37). Here we see a description of Benjamin which shows a tentative approach to the interview situation, even though the tone is light hearted. The notion of a "lively child" seems a smokescreen which masks a more complex relationship. The Lacanian notion of the

limits of language to convey experience is apparent here, the “lively child” speaks beyond its signifier to other possible meanings. This perhaps reflects the difficulty in expressing the story to a new person. Judith also adds “I try to be very positive towards him” (D, 37-38). Though the story is one that Judith appears to have told many times the experiences it reveals means that it needs to be introduced with care to gauge the listener’s response. The narrative begins with a light hearted tone, however, anticipation of difficulties are reflected in Judith’s expression that “we knew we were in for it at that point” (D, 41) and “that should have been a forewarning” (D, 41-42). This is quickly followed with an indication that “problems began first arising” at around the age of 2 years old (D, 49) and relate to a specific incident in nursery from which Judith is “absolutely devastated” (D, 60-61). It is not until later that Judith’s emotional experience of parenting her son is made explicit; “I found him difficult” (D, 88). This voice of difficulty is pitted throughout the narrative and elicits strong emotions. Judith indicates that getting Benjamin to school resulted in him “screaming” and her “dragging” him, reporting it as a time “which broke my heart” (D, 277-278), and seems to conflict with the parent Judith desires to be:

But then someone told me about picking your battles and so I started doing that which improved our relationship a bit (.) with Benjamin because it felt like I was constantly on his back (.) and I did not want that type of relationship with him. (.) I’m his parent foremost (.) I have got to discipline him (.) but I want to give him love, I want to give him encouragement, (.) and it was turning quite negative so I stopped (D, 454-459)

Here we see the difficult relationship between the voice of the ideal parent and the interplay it has with finding Benjamin difficult and feeling the need to discipline him. Lacan’s view of the subject as a function within discourse is demonstrated here. Judith’s notion of herself as a parent is entwined with a good parenting discourse. Judith’s description feels reminiscent of Rogers (2007a) identification of how parents report difficulties in coming to terms with internalised norms of parenting that do not match their experience. This discord seems to resonate with her own childhood experience:

And so I was determined that when I got children I was going to bring them up differently. (2) I was going to give them the opportunities that I didn’t get, I was going to encourage them however small. I wasn’t going to put them down like my dad put me down (D, 694-697)

Judith's conflict is around disciplining and managing Benjamin's needs, possibly trying to avoid the blame associated with this dominant discourse (Broomhead, 2013). The theme of blame is quickly revealed in the conversation when Judith indicates "then we started at that point being labelled he was a "naughty child", "you're spoiling him" (D, 118-119). This also marks the beginning of conflicts within Judith's relationship:

And mum used to look after him because I was a teacher at the po-point and I had dropped to part time to give mum a bit of rest bite erm "he's, he's spoilt that child (.) and-and he-his behaviour even now (.) when it's change the does come across as a spoilt brat (.) that bit has changed (.) erm so we got quite a lot of conflict and everyone was telling us "he needs a damn good hiding" (D, 123-128)

Here there seems to be a negation in Judith's speech in that she highlights his behaviour even now is difficult, leading him to seem like a "spoilt brat", to also saying "that bit has changed". This possibly reflects a distancing from the narrative of "spoilt brat" to which Judith has been exposed. The term "spoilt" instils responsibility within Judith and the assessment of her son as "brat" seems difficult to hold, leading to the assertion that this has changed. Perhaps here it is possible to see the experience of being criticised consistent within the literature (Gwernan-Jones, et al. 2015).

Judith recounts a period when she feels that she was being viewed with suspicion; "and he was qui-and his teachers were questioning me" (D, 226-227) which seems to coincide with a shift in her sense of control:

I was explaining
I felt like a really bad parent
I could control
But I can't control
I've got
I felt that
I was
I don't know
(D, 227-238)

Judith portrays a difficult relationship with practitioners when saying "we got accused of, well we got advised" (D, 261). The revision here may signify a further distancing from the gaze of blame that seems to have an impact on Judith's control.

Perhaps the term advised further reflects the nature of the conversation; there appears to be a sense of “being told” and being criticised by practitioners (Gwernan-Jones et al., 2015). There is a continuation of the difficult relationship with practitioners some of whom indicate that Benjamin “needs to be sorted out” (D, 428) which Judith explicitly links with being viewed as a bad parent; “a lot of it was implied that it was our parenting skills” (D, 431-432). This could reflect the way that staff potentially feel there are different expectations on Benjamin at home (Gwernan-Jones et al, 2015) which sustains the positioning of Judith as being responsible for the problem in a blame narrative (Harborne, et al. 2004). Judith highlights the feeling of judgement she experiences and notes the label of “naughty boy” that was circulating in the discourse of other parents (D, 440). Though Judith feels judged by others she also indicates that she did “berate” herself (D, 446) for not noticing behaviours in Benjamin, which eventually lead to an explanation for the difficulty she feels with him. Comparison between “good parent” norms (Rogers, 2007a) and the blame Judith perceives from others is perhaps internalised, leading her to feel psychological distress described through the word ‘berate’ (Bromley et al. 2004). There is, therefore, a sense of blame and guilt within how Judith speaks of herself. I wonder if Judith possibly feels that she missed important indicators in Benjamin’s behaviour because of doubts that could have been introduced with feeling blamed or the poor parenting narrative.

Reflection

I am conscious here of how I am outlining Judith’s experience of blame which is perhaps a reflection of an empathy experienced with Judith’s narrative. Judith reflects that she berates herself for not noticing something which appears significant to diagnosing Benjamin. This evokes a strong emotional response within me.

Judith appears to struggle with narratives around Benjamin and her own experiences of finding him difficult:

So I was getting a lot of hassle off the parents at the gate, (.) “your Benjamin’s done this, your Benjamin’s kicked so and so”, I’d say “I am really sorry (2) I

will deal with it and will challenge him”, “Well you ought to get him sorted”. (4) And he was being labelled the naughty bad kid, (.) which devastated me because he’s not a-a bad child, (.) and I am not saying that cos I am his mum (.) but he’s a good lad, (.) he can be a handful, well he is a handful (2) (D, 551-557)

During this time Judith is addressing a specific person beyond the interview. She seems drawn back into the situation as seen through the way she is speaking directly to an individual she imagines the conversation with. This is perhaps an effect of the experience of being judged by peers, which is apparent in the existing literature (Gwernan-Jones et al. 2015). It is a conversation with links again to the narrative of “naughty bad kid” which Judith says “devastated me”. She quickly indicates that “he’s not a-a bad child” which appears to indicate a wish to separate Benjamin from this narrative. Judith’s expression “and I am not just saying that because I am his mum” seems to wish to appeal to an objectivity which would serve to rescue Benjamin from this negative image presented to her from others. However, Judith may be struggling to contain her experience of difficulty whilst rejecting the narrative of “naughty bad kid”. She resolves to indicate that “he can be a handful” aiming to provide a separation between Benjamin and “naughty kid” followed by an acceptance that “he is a handful”. The function of the term “handful” could be to act as a smokescreen that masks the full complexity of Judith’s feelings around Benjamin. I wonder here if Judith feels compelled to defend both Benjamin and herself from a “bad kid” narrative that holds connotations with a criminality discourse (Hutchinson, Parada, & Smandych, 2009).

4.2.3 *The Battles I had (D, 108-109)*

Judith closely associates elements of the difficulties she experiences with Benjamin to battles and conflicts which were had on multiple fronts (with her husband, with school, with other parents, within her own family, with CAMHS). The first identification of a sense of battle happens in relation to Benjamin and his pram (D, 109) which quickly begins to impact upon other relationships; “me and my husband were nearly rowing so it-it did cause quite a lot of tension” (D, 115-116). The blaming

of oneself or others in the family is identified within the literature (Harborne et al. 2004); given that individualising psychology narratives set out a child deficit model related to early experienced, which would act to bring parent interactions and home life to the forefront, it is perhaps unsurprising that family tensions are cultivated from the internalisation of this discourse around development and parenting. We can perhaps see this connection being played out in Judith's relationship with her own family; her mother states "he's spoilt that child" (D, 124-125) which leads Judith to state "so we got quite a lot of conflict" (D, 126-127). The Psychologisation of development narratives narrowed to individualising discourse is perhaps apparent here (Runswick-Cole & Goodley, 2018).

When Judith indicates that the first battle in school began it is related to a moment of accusation; "we got accused, well we got advised, (2) children who don't have the experience of taking turns and things in a family situation will find it more challenging at school" (D, 261-263). Again, it may be possible to see how Judith's responsibility is implicit within the parent/child dyad. Other factors (such as social or environmental) which may contribute to Benjamin's experience are notably absent and potentially obscured by other more powerful narratives (Runswick-Cole & Goodley, 2018). The revision of "accused" to "advised" by Judith perhaps reveals the experience of being criticised (Gwernan-Jones, et al. 2015) within her interaction with others. Again, we hear echoes of a blame narrative in Judith's speech and the comment seems to bring judgement regarding what is happening at home. Judith goes on to highlight her recognition of the importance of family times involving turn taking which may suggesting she feels her professional expertise and experience, the twenty years she has had in teaching (D, 133-134), is not recognised by school staff. The role of experience is then made explicit in Judith's understanding of the difficulties being faced at school and the battles it was leading to:

Then he went into Year 1 and the teacher was less experienced (.) and to cut a long story short he spent an entire year under a table and that is not an exaggeration, (.) to the point where every night my mum was picking him up and it be like "Benjamin's Nannan can I talk to you please? Oh he has done this and that" and it was very negative. (.) And he was constantly in trouble (.) so he began to hate school. (3) Getting him there in the morning became an increasing battle (D, 269-275)

Judith links difficulties and the inexperience of the class teacher. In also saying “to cut a long story short” a potential silence is manifest which functions to evade the difficult experiences of interacting with the Year 1 teacher. During this period of time there appears to be a powerful sense of responsibility felt by Judith leading to her making a difficult choice: “I gave my job up because my-my son’s, I thought why am I looking after all these other children, helping them when my own son’s needs obviously (.)” (D, 279-281). The word “obviously” perhaps is to indicate to the listener the clear need for the action and potentially aims to bring a sense of agreement without explicitly seeking it. I was struck by this action as it seems to represent a sacrifice on Judith’s part. This has a significant impact on her sense of identity late in the narrative when she indicates she went “from being an independent woman, to asking for handouts off my husband”(D, 534-535). Within the wider narrative experience and knowledge are considered important, sometimes being linked to being professional which has power. Judith punctuates the early narrative with reference to her teaching experience (D: 53, 123, 133, 288) often further referencing her expertise and knowledge from having been so.

An explicit description of the relationship between power and professionalism is present in an interaction with the Child and Adolescent Mental Health Service (CAMHS) with whom Judith had had “three years of us battling” (D, 444):

once they knew about my background, and they knew about my husband’s background as well, they actually turned round and said “we can see you are professional people” (3) erm “and we can see the input you’ve had in” (D, 512-515)

This quickly leads to a resolution recognised as “then we got the diagnosis of autism” (D, 520). Prior to this recognition of professionalism Judith indicates that “we did have quite a battle in that meeting” (D, 507-508). Judith and her husband, Ryan, had been pushed to escalate it to get “things back on the ball” (D, 497-498). Within this exchange a further reference to professional status is made; “and he [Ryan] is a professional negotiator so duck” (D, 495-496). His professional involvement further leads to an admission from CAMHS that “they’d lost our papers” (D, 496-497). Again,

a resolution is achieved as “that’s when erm we got the diagnosis for ADHD” (D, 498). There appears to be connection between professionalism and resolution to difficulties, reflecting the power of the status. Perhaps it is also possible to recognise times of feeling hostility from engaging with health care practitioners (McKeever & Muller, 2004).

This voice around professionalism and power may be linked to the ability to be heard. The resolutions related to interaction with CAMHS demonstrate a time when Judith’s or her husband’s voice is heard and accepted. She describes the conversation where her voice is heard and challenges the view of the CAMHS practitioner:

She [CAMHS practitioner] said (.) he actually came very low on the ADOS test and I asked specifically what and she says “well he knows how to socially interact, he says good morning”. I said “no, I’ve taught him that, I have been drilling it into him since he was three years old” (2) which affected the thing (D, 503-507)

Judith’s intervention here is accepted by the practitioner and leads to a change in the outcome of the assessment. Judith reflects this time as a positive moment in the narrative, which can be contrast with times when Judith’s voice appears as not being heard. In a conflict with her family Judith notes that she “was trying to argue the case” (D, 132) and again relates this to the experience she has had as a teacher. The term “trying” provokes a sense of not yet achieving and that in this case Judith’s voice was neither heard nor accepted. She gives the sense that difficulties within the family continue until after an autism diagnosis is gained; “it helped also to go to his parents and say look he has got something called autism and ADHD here’s some information leaflets read them” (D, 625-627). The difference in being heard here is related to a diagnosis. The means by which a neurocultural discourse (Lowe et al. 2015) can create capital to be able to negate blame is apparent in this engagement. However, Avdi, E., C. Griffin, and S. Brough. (2000) report mothers seeking diagnosis for their own need rather than the child. It seems that mothers are perhaps situated in a difficult position which continues to contribute to a poor parenting narrative. Within the individualising developmental narrative they are positioned with responsibility for a child’s socially unwanted behaviour. It seems that they are left with two

choices; either to sit in a position of blame, or, seek an externalising narrative which alleviates this (but is potentially met with suspicion as to whose needs it is serving). Being situated between an individualising psychology and neurocultural discourse seems to provide limited options and highlights the necessity to remain critical of simplistic medicalised models of behaviour.

Reflection

I am mindful of my consideration of Judith's description of her professional identity and her interaction with others. I myself perhaps present to Judith another "professional" with whom she has engaged. In this respect I recognise my desire to present Judith and myself as having equal status, which could have influenced the way in which I heard Judith talk about her experience of professional identity.

A further example of Judith possibly not being heard is referred to when she speaks of staff in school as "they were still telling me there was nothing wrong" (D, 308-309). The lack of voice here further serves to remove Judith's agency, she is unable to influence the narrative around Benjamin. Further interactions with specific teachers also highlight the potential relationship of conflicts with not being heard:

Where when he went into Year three, (.) his first target, which made me laugh, was to sit on a chair still, I thought hold on getting him sat on a chair is a good target, sitting on a chair is a-still is another target (2) and she says "well it is not a big target" and I said "maybe not to you and me (2) but to him", so we had a bit of a ((rubbing hands together)) at the beginning of the year ((laughing)) (D, 375-381)

There appears to be some resistance to Judith's knowledge of the appropriateness of the target envisaged for Benjamin, perhaps it is felt as a threat to the teacher's knowledge (Malacrida, 2001). There is a symbolic expression of conflict in Judith's action coupled with the expression of "had a bit of a" and highlights how Judith feels positioned within these interactions. The lack of expression around the conflict projects a silence that helps to distance her from it and the laughter she exhibits at the time may further serve to protect her from the difficult emotional experience of

conflict. It is followed by the statement “I turned into a parent from hell” (D, 381), which could reflect the negative sense of herself that is generated from the conflicts she is engaged in due to not being heard. In later conflicts with teachers Judith again reflects that she is not listened to. She highlights that rather than speaking with the teacher she goes straight to the Head “because the teacher always (.) “he’s done this, he’s done that, oh he’s done the other”” (D, 549-550). She presents an image of a staff member who speaks over her concerns giving a sense of not entering into discussion with Judith; as if being told (Gwernan-Jones et al. 2015). The frustration from what Judith could see happening and not being heard appear prominent for her at this time:

I could see
I knew
I didn’t feel
I was back to battling
I didn’t
I went straight
I was getting a lot of hassle
(D, 545-551)

Judith’s experience of not being heard and blamed progresses through the narrative and are regularly associated with times of conflict which, as she says, she “started challenging it” (D, 431). Perhaps this represents an act of resistance to authority (Gwernan-Jones et al. 2015). Here we start to see a voice of resilience presented in Judith’s narrative:

I remember
I said
I started challenging
I know I am not a perfect parent
I think
I am not doing a bad job
I think
I have got a pretty good idea
I do try to bring children up respectful
I remember
I have worked
(D, 430-437)

It is possible to recognise a hesitation in her view of her parenting, the shadow of “bad parent” still permeates Judith’s view of herself, however, she pushes forward her belief that she is “not doing a bad job”, has a “pretty good idea”, that she does “try” and has “worked” which may be considered signs of resilience given the difficulty she experiences. The negations “not a perfect parent” and “not a bad job” further highlight the potential inability for Judith to accept that she can be a “good parent”. She does indicate that she has a “pretty good idea” which is closer to a sense of herself as a “good parent”, but still distanced by the term “pretty” and also is still only in reference to an idea; idea being noticeably different from her actually being. In Judith’s hesitance toward perceiving herself as a “good mother” it is perhaps possible to recognise the difficulty she has in reconciling her experience of being a mum with internalised cultural norms around parenting (Rogers, 2007a).

There is a moment where Judith reflects on the conflicts she has also experienced within her teaching career with other parents and uses them as a way of understanding herself within the conflicts. Judith indicates “my teaching was challenged all the time” (D, 410) by the parents of children in her class and quickly emphasises “it did me good cos it made me challenge myself” (D, 410-411) then going on to describe the experience of foreboding she had when parents would come to see her (D, 411-413). There seems to be a level of tension between the view of this having been good for her and her view that she “never wanted to be a parent like that” (D, 414-415). I wonder if Judith has a view of herself which is difficult to accept that prompts a justification in the sense of “it did me good” and therefore it must have done others good. It may be seen as a challenge to her identity in that it is difficult to consider herself similar to parents she never wanted to be like.

In the midst of the battles with practitioners Judith talks of the desire to work together closely (D, 57) and in partnership (D, 382-383) with teachers. Judith notes working closely with nursery staff (D, 57) early in the narrative when difficulties begin to arise. Though she felt “devastated” (D, 60-61) at this time there is a lack of conflict in the narrative in this account. This may suggest that working together prevents conflict from arising. In discussing a change in teacher for Benjamin from one who “was awful” (D, 353-354) to one that Judith “could work in partnership with” she

recognises herself as feeling “much better” and “I was able to actually (.) go into the classroom” (D, 358-359). This served to restore her agency which is lost in other situations when she is unheard. Judith gives a sense of the importance of building a relationship with the teacher:

I got to know her quite well (.) which was really, really lovely and she was very, very supportive (2) erm she wouldn't-wouldn't mince over things, she'd say he's done ABC and D, and it's like okay what can we do, cos I am a very proactive-what can we do to actually improve this (D, 368-372)

Here again Judith's agency is felt as she sees herself as “very proactive” in this situation. She expresses a sense of being heard and listened to through being able to hold a conversation about how Benjamin is presenting in school. Judith seems to indicate that collaboration in partnership makes a difference to her experience, reflecting positive interactions when working together. This may be unlike the experience of parents reported by Malacrida (2001) who suggests that even when a parent varied their approach this made little difference to whether they felt dismissed or frustrated. Of course, Judith's experience may be as a consequence of the willingness of the member of staff to also build a relationship with Judith and not feel threatened by her knowledge rather than simply Judith's approach.

As the transition to Year 3 brings a new teacher and a new relationship there is a resurgence in the conflict narrative and an appeal within this to again working in partnership with the teacher; “I said I want to work with you, I want to work with Benjamin, I want to work in partnership” (D, 381-383). Partnership seems to restore Judith's agency within relationships and produces a shift in her subjectivity from combative to being together with others. This is most strongly reflected when working together does not happen:

I never wanted to be a parent like that, I wanted to work with school, to get the best out of your child (.), and I felt in the early years Benjamin's school (.) I-I wasn't doing that, I was complaining (.) (D, 414-417)

It appears that when Judith feels unable to work in partnership and unheard it limits her agency, leads to conflict and generates a negative view of herself. The limiting

of Judith's agency is also apparent from her description of her relationship with the Year 1 class teacher. When attempting to instigate conversation Judith highlights that the response is a rejection of her involvement; she reports the words spoken by the teacher with a stern and accusatory tone, "you don't know how busy I am" (D, 284). Judith's response, "actually I do" (D, 207), mirrors the tone and reflects Judith's sense of how the conflict has grown. Perhaps here we can see how Judith experiences what Hibbitts (2010) describes as being different and *otherness*. When the narrative reflects partnership Judith is able to speak fondly of the teacher potentially reflecting being much closer and with the practitioner; not in a state of otherness. When partnership is absent from the narrative it could highlight how Judith is pushed away and othered.

Though partnership is presented as sometimes distant in Judith's experience she does make clear her view of the demand that was placed on her by the school. This is linked to a relationship with the class teacher which "deteriorated to the point where I used to go in every morning" (D, 294-295). Judith seems to suggest the Year 1 teacher is resistant to engage with her, yet Judith is accepted into school for her to take "him out of registration" (D, 303-304) to complete "one to one" (D, 304) with Benjamin. Judith highlights the increase in expectation on her:

Judith: and are used to get numerous phone calls from school saying he is under the table screaming and no one can get him out (2) and there used to be three or four members of staff trying to coax him out from under a table (.)

Scott: And was that a telephone as if [to say

Judith: [come and sort it out. And because they knew I had packed up work, so then the phone calls increased tremendously at that point (D, 310-317)

Reflection

I have worked within my Local Authority to aid the development of processes and practices that encourage partnership between parents, young people, schools and practitioners since before training to be an Educational Psychologist. Judith's reflections on working in partnership resonates strongly with me and may

potentially influence how I present this element of Judith's narrative within my research.

The increase in demand on Judith is linked with giving up her job as a teacher. It is possible here that Judith is eluding to feeling pressured, meaning her capacity for choice is undermined by this expectation. There is an interruption in the question being asked that could reflect the experience that Judith was regularly interrupted to "come and sort it" and although this expectation is felt it co-exists with a sense of resistance to her involvement; "so there was a lot of barriers up at that point in school" (D, 321-322). Again this presents a challenge to her agentic self; Judith is both expected to take responsibility and accept the resistance to the level of involvement she desires. Phone calls represent the power to demand from Judith and barriers the way to resist her. She also indicates the phone calls are "from school" representing not an individual, but a large organisation or entity which may seem daunting and difficult to influence. Judith lacks a sense of control, a sense of power and an agency of her own to support her son in the way she feels he needs.

Reflection

I am struck by the presentation of resistance and engagement Judith experiences; she seems to indicate that school both did and did not want her to be involved. Perhaps this sense of resistance is salient to me within the narrative because it is something I am attempting to attune myself to given that it is an important element of my research.

The battles happening between Judith and her extended family and with practitioners are also accompanied by conflict within her relationship with her husband: "so you can imagine that it caused a lot of conflict between-in our relationship, we went to erm marriage counselling (.) and identified the conflict" (D, 571-573). It can be seen that Judith's experience of her immediate family in conflict is difficult to discuss. She seems to obscure the complexity of the experience in saying "the dynamics in the family were quite interesting at that point (4)" (D, 576-

577). The final part of this sentence “but what doesn’t kill you makes you stronger” (D, 577-578) seems to act to divert attention, as a smokescreen, away from the painful experience of the family dynamics to a commonly used statement which serves to highlight an assertion that a positive outcome will come from a difficult experience.

4.2.4 What we now know with the diagnosis (D, 105)

The voice of knowing seems to be important in how Judith comes to terms with her experience; “but now knowing ADHD it all fits in” (D, 73). It appears important for Judith to have a recognisable condition that aids her understanding and making sense of the difficulty she has faced, as she repeats later “it all fits in now” (D, 192-193). Judith continues to appeal to a diagnosis narrative which aids her coming to terms with events. Expressing her relationship with her son as “turning quite negative” (D, 459) she searches for an explanation represented in her statement “but I said there must be a reason for all of this, and we were going through CAMHS erm (.) and I think it was in three years that he got his diagnosis” (D, 460-462). The desire to find a reason could reflect the need to reject the blame that she feels is being focused on her and challenges her as a parent, as well as a professional, who has worked with children for a long time. Runswick-Cole and Goodley (2018) refer to the sense of relief provided by labels that externalise blame and which appear to be consistent with Judith’s experience. It also highlights the internalisation of a medical and individualising discourse.

Reflection

I wonder to what extent there is a comparison in the function of a diagnosis narrative for parents and a poor parenting narrative for teaching staff in this case. A diagnosis narrative may bring a form of redemption, a reason which does not hold Judith responsible. The poor parenting narrative perhaps functions in a similar way for school staff and practitioners. It equally moves them away from a poor teaching/practitioner narrative which may be difficult to hold and contain. This could reflect a splitting and projecting process happening within the

relationships between parents and practitioners. By acknowledging this feeling in a way which displaces the sense that it is an intentional judgement and blaming process it may provide space to build better relationships which understand the difficulties faced by different individuals. However, this reflection may also demonstrate the influence of psychoanalytic discourse upon my consideration of what could be happening around Judith.

However, there is still a level of ambivalence in how Judith speaks:

They were still telling me there was nothing wrong (3) And I-I didn't want anything to be wrong (.) but my gut reaction by this point was saying this child has got quite challenging behaviour (D, 308-310)

This ambivalence perhaps relates to an effect of the signified sliding beneath the signifier; diagnosis labels 'slip' in their meaning, presenting Judith with a sense of relief in one understanding and unease in another. The hesitation in Judith's pauses reflect the contrapositions she presented in her words. There is both a commitment that something is "wrong" and yet a rejection at the same time. Again later she indicates that she "didn't particularly want him to have a label (2) of autism (.) however I wanted him to get the correct support" (D, 508-509). The stigmatisation of diagnosis seems apparent here (Runswick-Cole and Goodley, 2018) which Judith wishes to avoid (Green, 2007). Again, pauses in speech give a sense of something difficult to say; *the other* that Judith struggles to express until asked later how receiving the diagnosis felt:

Judith: and then we got the diagnosis of autism. (.) But then you are just, as every parent says you're just thrown out and left on your own. (2) It is like you've got a diagnosis, you've got a piece of paper that says your child has got autism (2) Bye (4)

Scott: How did that sort of [feel?

Judith: [very isolating and I tell this to parents now (inaudible), I tell parents now you can go through a period of (.) like grief, (2) that you wouldn't want your child (.) to be any different because they are your child but then you grieve for them because they are not normal, (.) and I hate using that word, (.) neuro typical, (.) erm and-and it's an adjustment and it is-I can't-it's hard to explain but (.) it's that difficulty to actually think that my child is not (2) And you start worrying about what's the future for

your child. (2) And every-and I think that's-it took me a while to adjust (.) at the time (.)
(D, 520-533)

The lack of pronouns in Judith's explanation of the feelings that a parent "can go through" may serve to distance her from them. She is implying she has had this kind of experience but she does not include herself directly. *The other* which remains unsayable is possibly shrouded in the grief that she describes. The description "like grief" hints to something else. It is not qualified and consideration of the pauses in her statement may offer a glimpse of *the other* that Judith cannot say "(2) that you wouldn't want your child (.)". Again perhaps we can identify the language of the unsayable when Judith says "it's that difficulty to actually think that my child is not (2)". The "not" here may denote a sense of existence; Benjamin post-diagnosis is not Judith's child or that her child now does not exist. This is not to say that Judith does not want Benjamin, it is clear in how fondly she speaks of him that she does. The difficulty in speaking of *the other* here seems reflected in the repeated terms ("and-and"), revisions ("and it is-I can't-it's hard to explain") and the silences opened up from the hesitations in her speech. How Judith makes reference to both "normal" and "neuro-typical" highlight the influence of neurocultural discourse (Lowe et al., 2015) and its relationship with normal development narratives (Runswick-Cole & Goodley, 2018). What is apparent is that the medicalised view of need is reflected in the way Judith speaks. In reference to "normal" Judith states "I hate using that word" and demonstrates how the discourse of the norm push parents towards the adoption of a neurocultural narrative. "Neuro-typical" would appear less judgemental than 'normal' making it more appealing than the normal discourse and being seen as 'not normal'. Within this relationship perhaps these discourses serve to sustain each other. We also see a sense that Judith, once Benjamin's diagnosis is received, feels she is left on her own. The capital for accessing support associated with diagnosis (Avdi, Griffin & Brough, 2000; Ryan & Runswick-Cole, 2008) does not appear to be evident here.

The emotional landscape of the narrative during discussions of the process and the results of receiving a diagnosis seems uneasy. The conversation seems to reveal an

emotional experience which challenges Judith as a parent. “Grief” appears to belie an experience which she cannot talk of explicitly, but nonetheless must somehow be contained. Judith’s success in holding her experience is indicated later when saying Benjamin is “an amazing individual to have around” (D, 785). Judith’s experience is clearly difficult and related to feelings of loss and grief however I wonder if it is brought to the foreground and amplified because of a medicalised narrative. Grief perhaps reflects the influence of a normal development discourse suggesting Benjamin is in some way deficient and not the child expected, not the idealised child (Hugger, 2009). However, this within child deficit model is not the only way by which to understand experiences of Benjamin’s behaviour. Through the use of a social model it may be possible to negate the within child difficulty and the stigmatisation of there being something not “normal” about a young person.

The ambivalence to diagnosis is perhaps seen in the connection of the profound sense of loss Judith experiences, but also the redemption she finds in the recognition of the diagnosis: “erm it helps knowing that there’s a reason (2) that, because at one point I did blame myself, I brought him up wrong (3) I was doing a really bad, I was blaming myself as a bad parent” (D, 620-622). The notion of “brought him up wrong” again may hold some resonance with the youth crime discourse (Hutchinson, et al. 2009). The connection is made between diagnosis and experiencing a sense of blame is consistent with the current literature (Harborne et al. 2004) and helps to recognise the need for an explanation that externalises the problem away from Judith. It appears that interactions instil a sense of blame and therefore mean that a diagnosis is a desirable solution (Runswick-Cole & Goodley, 2018). It is therefore possible to consider blame as an experience motivating a desire for an explanatory label. Judith highlights “it helped also to go to his parents and say he has got something called autism and ADHD” (D, 625-627) demonstrating the function of the diagnosis; again Judith reiterates that “it has helped a lot them knowing (.) he’s got autism” (D, 635-636) and also in relation to school “so yeah it did help and I think it helped with the school to actually say look he's got autism, (.) we've got a label here we know (3) we know what we are dealing with” (D, 638-641). This perhaps reflects

the sense of dilemma, wanting a medical explanation but which brings about feelings of loss, Judith further describes in relation to diagnosis.

Diagnosis brings an uneasiness which accompanies Judith's journey and represents the sense of having to make difficult, but necessary, decisions. After an ADHD diagnosis is received a further dilemma is presented regarding whether to medicate Benjamin or not:

But we chose at the time not to even put him on Ritalin, (.) that was partly me because I had seen a lot of bad experiences in my teaching career, (.) of children zoned out (D, 475-477)

After researching potential side effects, Judith indicates that alternatives to medication ("through behaviour management" – D, 482) were adopted. Still this dilemma persists to the present time "we are looking at the moment where we do need to actually look at maybe putting him on something. (2) but I must admit there's a dilemma there for me with that at the moment (3)" (D, 485-487). The narrative reflects the undesirability of the situation and the ambivalence it produces. Decisions are not easily made and Judith feels the burden of them:

I had seen a lot
I know they've got to
I think it's made our life a bit harder
I definitely know it has
I must admit there's a dilemma
(D, 476-486)

Reflection

I feel diagnosis is central for Judith's narrative, but I am also conscious of my own experience of encountering narratives of children who have a diagnosis in my practice. It perhaps places this feature of Judith's experience at the forefront of my mind while listening to her story. The value that Judith appears to experience from gaining a diagnosis has challenged me to consider alternative ways of experiencing a medicalised description of a young person. In this sense this

element of Judith's narrative is perhaps a focus within my analysis because of the differences between how Judith and myself might feel about diagnosis.

4.2.5 I turned into one of those (D, 324)

Judith's narrative describes a variety of changes which she perceives herself to go through. A key change is linked to her professional life that she gives up (D, 278-279); Judith frames this in a decision making process and reflects her sense of agency:

I think
I gave (up my job)
I thought why
I made that decision
I was very proactive
I went in
I got
I try to instigate
(D, 278-284)

Though the decision is related to questioning herself regarding her role in helping her son she presents it as a "decision" she makes leading to the opportunity for Judith to be "proactive" and go into school to "instigate" interactions. Judith seems active in this process whilst responding to how she feels she should be supporting Benjamin as a parent. However, there is a further impact on Judith's subjectivity which she later describes:

I think I probably got depressed as well, but it-the depression sort of linked to me having to give up my job (.) and suddenly from being an independent woman (.) to asking for handouts off my husband, (.) which he didn't begrudge (2) but it was my own (.) self-esteem and change, and I recognise this now I am doing the counselling (2) and it was dealing the changes within me. (D, 533-538)

There is initially a tentative introduction of feeling depressed made by Judith when indicating she "probably got depressed" which "sort of linked to me having to give up my job". This distancing from the experience gives the impression that she is uncertain about its relationship to giving up her job. We also see a change in the

sense of control expressed by Judith earlier in the narrative to now “having to give up” her job, presenting a lack of choice. Her psychological wellbeing is raised as a salient point in her experience, the description of depression resonates with the experience of parents reported in previous research (Fouquier, 2011; Harborne et al. 2004)

Reflection

I wonder if Judith’s sense of loss of control and “having to” reflects the influence of remembering how she felt during the diagnosis process. Does the experience of the interview itself spark emotional memories that impact upon her description of things? The change from “I made the decision” to “having to” could be due to remembering the battling and lack of agency within the diagnostic process and it is this that influences how she then talks of what had previously been her decision.

Judith has to manage moments of doubt related to her parenting. In relation to her feeling “like a really bad parent” (D, 228) she makes an uneasy comparison between her abilities as a teacher and her abilities as a mother: “how come I could control a hall of 400 children in school (.) but I can’t control this wild child I’ve got at home” (D, 228-230). Here again we see the potential tension between her professional life and her personal one; she implies she is an accomplished professional which is not the experience she has as a mother. Lacan’s view of the subject seems apparent at this point; Judith speaks of herself favourably in a teaching discourse but less so within a parenting discourse. There is a further difficult shift presented in how Judith speaks of herself as a parent: “And I hated-I-H-I turned into one of those parents I hated as a teacher, (.) but I had to be” (D, 324-325). That is again reiterated later when she later describes herself as turning “into a parent from hell” (D, 381). Here again we see the agentic nature of Judith’s experience reflected in her expression “but I had to be”. Judith’s lack of choice is made apparent, along with the difficulty it causes for her, later in the narrative: “I never wanted, and I said at the time I never wanted to be a parent like that” (D, 414-415). When Judith is asked about her meaning of the expression “parent from hell” she prefaces it with “this is my interpretation” (D, 401) distancing the label from any sense of objectivity, it is firmly rooted in a subjective

understanding, which could reflect that my question may appear to be a judgement of her. She describes her understanding in relation to her own experience of being a teacher and working with parents who would challenge her teaching (D, 410). She reflects a sense of foreboding in her experience of interacting with those parents and indicates “they had a way of twisting things” (D, 413). The transition in Judith’s subjectivity is reflected in how we can see her speaking of herself:

I went
I had been
I hated
I-H-I turned into (one of those parents)
I hated
I had to be
I instigated
I put forward
(D, 322-326)

What Judith “had been” and then is compelled to become is wrapped in feelings of hate directed both towards viewing that she has to change and also to that which she perceives herself to become. “I went” and “I had been” may represent a loss of the self which needs to be reasserted; “I had to be”, “I put forward”. It is possible “to be” has an existential tone to it in that there is a need to assert an identity and purpose. Judith’s identity as a parent, her professional status, voice and power go through significant changes that may present a challenge to her subjectivity. She has an experience of abandonment within her interactions with CAMHS practitioners: “as every parent says you’re just thrown out and left on your own” (D, 521-522) and feels depression associated with the changes to who she is and the loss she describes for her child.

A further significant change permeates the later part of the narrative which Judith delineates when describing herself as becoming “more laid-back (2) and accepting his behaviour a bit more” (D, 650). Previous incidents related to Benjamin’s interaction with others and presentation would have caused Judith to get “very embarrassed”, however she is now able to “laugh it off (.) and I just say “autism”” (D, 684). The identification with being “laid back” seems important to Judith and is

further emphasised (D: 728-729, 741-742, 760-761) even though it is situated in the narrative around experiencing continuing difficulty; there are still times when she will “feel shocking” and wishes to have “five minutes, or half an hour my own” (D, 731-732). Judith presents a sense of feeling able to manage situations and perhaps not find them as emotionally charged as previously experienced. The easing nature of the label is made apparent here, however in the context of the narrative it has been necessary to come to terms with a sense of loss and continue to manage concerns about the future. Though it is apparent that Judith feels better about her experience with a diagnosis in place, I wonder to what extent she would have felt the necessity for a label if there were alternative dominant discourses around difficulties and parenting. Alleviation of blame at this point may be replaced by future difficulties around stigmatisation.

Other relationships are also recognised to have improved as Benjamin and his “dad are gelling more” (D, 753), as well as the relationship between Judith and her husband:

And we worked, since we worked through our own issues (2) and we worked through the issues of how we deal with Benjamin, (2) we do do a lot of tag (.) erm which has helped and there’s been once or twice I have actually let my husband have Benjamin more, and he realises how challenging, he finds it hard (.) (D, 704-709)

Protection and trust may play a part in Judith’s narrative. Judith appears to give more time for her husband to adopt the role of primary carer and recognises that “he finds it hard”. Judith had indicated earlier in the narrative, before the diagnosis, that Ryan would shout at Benjamin (D, 567). It is possible that Judith’s experience led to a desire to protect both Benjamin and Ryan from conflict and now having worked “through the issues of how we deal with Benjamin” (D, 705-706) trusts that Ryan’s approach will be similar to her own. Perhaps we also see the influence of a medicalised understanding of Benjamin’s difficulties for his father, he is able to hold a narrative that does not position him as responsible.

The transformation in Judith's narrative is explicitly linked to her knowledge of autism and ADHD: "I think also the more understanding I have got of autism and ADHD (.) the more I can just let things go (.) and the more I (.) find it easier to laugh at the situations" (D, 763-765). Implicit within this is the effect of receiving a diagnosis, it is an enabling feature to Judith's subjectivity. She has been able to "google autism and challenging behaviour" (D, 642) rather than just researching "challenging behaviour" (D, 641) and makes reference to educating herself through the desire to read and develop "more knowledge" (D, 643-644). I feel Judith finds it easier to engage with Benjamin's perceived difficulties as the narrative has been able to shift from a mother-blame to a brain-blame position (Read, 2000). The identification of autism has enabled Judith to be able to act, providing her with the sense of agency and control that appears absent in the earlier part of the narrative. More fundamentally it also gives Judith control in how others can speak of their experience of Benjamin's difficulties; she has a means by which she can challenge blame narratives. This is perhaps a more profound experience of agency for Judith.

The sense making nature of the diagnosis is also apparent:

yeah that did help a lot but one thing I found difficult was (.) that I can't separate the ADHD and the autism (.) and in my own mind I wanted to (.) but the two merge too much (.) and I can't say that bits autism and that bits ADHD because it-it's Benjamin (D, 644-647)

The idea of autism, ADHD and Benjamin can be held together by Judith. Though she would like to be able to attribute specific behaviours to each condition she is now able to hold the view that they are all Benjamin.

Reflection

I wonder here if it is possible to get the sense of Bion's idea of containment from a diagnosis. Bion's (1962) notion of the projection of unmanageable feeling into the primary care giver, who then reflects them back to the child in a manageable way, aids us in understanding the function of diagnosis for Judith. The difficult behaviours are reflected back, by narratives around autism and ADHD, in a manageable way. The more Judith learns about these conditions the more she

begins to speak of being “laid back”. Perhaps the power of diagnosis is not just the externalisation, but also the containment it gives to difficult experience.

The final change in Judith’s sense of being is indicated through the support she now gives parent groups (D, 798) as part of her counselling work. She is able to offer “that peer-to-peer support” (D, 803) saying “parents find it useful” (D, 803-804). Judith indicates she listens “to the stories of what other parents say” (D, 799) highlighting the power of listening and being heard, perhaps related to times when Judith has not felt this has been the case for her. In her new role Judith finds other mothers who feel “the husbands are on the spectrum as well, undiagnosed” (D, 801). Here autism seems to be used to understand other relationships within the family based in a biological reductionism. It highlights the powerful influence of the medicalised discourse and how it might be used to contain and manage other experiences of blaming others within the family or feeling blamed.

Reflection

There was a feeling of ease during the interview at this time which may be related to the experience Judith has in being able to discuss the new sense of self she has. An optimism is apparent which can be contrast to the foreboding at the start of the interview. I get a real sense of a journey that has been undertaken. Judith has more control over things, has a professional role again, the diagnosis has enabled her to transform from being a subjugated individual to having an agency to make a difference to herself and others. I wonder if this is related to how I feel I experience narratives in general; a challenge or difficulty is presented, a journey is undertaken which leads to a new (often better) experience.

4.2.6 Summary

Judith’s experience resonates with much of the existing literature. She experiences blame in her interactions with practitioners, family members and peers. The emotional experience perhaps helps us to understand the need to identify an

externalising cause for the difficulties being experienced. Though she reports that she did not want there to be anything wrong she seems positioned into needing to seek an understanding of Benjamin's behaviour through diagnosis. However, this produced further difficult emotional experiences which Judith describes as "like grief". The statement "like grief" implies an experience which is not quite grief; an *other* which is difficult to put into words.

Through consideration of the discourses which seem to appear within the narrative a further understanding of Judith's subjectivity may be possible. Internalised medicalised discourses are identifiable in Judith's description which may be determining factors in her story. A norms saturated narrative and a medicalised discourse encourages an understanding of the problem as being specific and internal to Benjamin, which if identified will lead to acceptance and support. However, though it may alleviate experiences of blame it is accompanied by other powerful emotional experiences, concerns for the future and potential stigmatisation of Benjamin. It seems that this medicalising discourse is both the origin and resolution of a problem. School staff, reflecting the internalisation of a development and individualising psychological discourse, position what are seen to be Benjamin's difficulties within him and the family environment (e.g. experience of taking turns in the family situation). A neurocultural narrative, which supports an individualising conceptualisation of development, then appears to offer a solution. It perhaps presents a self-maintaining narrative:

- Neurological descriptions of development support in individualising young people and psychology
- Developmental norms provide a means by which to recognise when there is a "problem" or difficulty, individuals that are different to the norm highlights a difficulty
- Due to of the dominance of an individualising narrative the "problem" is conceptualised within the individual themselves in a deficit medical model

- Neurocultural discourse enables a means by which to identify the problem and therefore how to support it

Neurocultural, medicalised and individualising discourse at once appear to create and maintain problems as well as offer some form of solution to them. However, they do not completely resolve the emotional difficulties they help to create; leaving fear of the future, stigmatisation and feelings of loss for parents to manage. With the introduction of alternative discourse for understanding needs we may perhaps offer different ways of making sense of experience which does not evoke these difficult emotional experiences.

4.3 Caroline's Story

4.3.1 Narrative synopsis:

Caroline is mother to Lydia, her only daughter. She is in her mid-forties and lives at home with both Lydia and her husband. Caroline's narrative highlights her daughter began to experience difficulties during her time at secondary school. Prior to this point she was a happy and successful young person who was recognised for her efforts in school and her willingness to become involved in a large variety of sporting activities. During her time in secondary education Lydia began to experience a painful series of bullying which led to her changing schools. Though this move was hoped to bring an end to the bullying experienced by Lydia it continued in her new school. At a similar time Lydia began to show signs of what would later be diagnosed as Chronic Fatigue Syndrome. It became increasingly difficult for Lydia to attend school which appears to be framed, by school staff, as her refusing to attend. This view impacted upon the relationship Caroline had with staff, as they seem to indicate that the difficulties are related to a problem with Caroline's parenting; Caroline was threatened with prosecution. During this time Lydia's condition deteriorated and she was further diagnosed with mental health difficulties, a potential eating disorder and a sleep disorder. Caroline struggled to engage services in providing the support Lydia needed, feeling that processes and service criteria acted as barriers to getting help.

4.3.2 *It was like you were shouting but no one was listening (G, 419-420)*

Caroline reflects the feeling of being unheard in both her requests for help and for others to recognise the impact of her daughter's mental health difficulties on the family as a whole; summing up her experience as "it was like you were shouting but no one was listening" (G, 419-420). There are a number of moments when she feels that she is not heard by practitioners working with her. From early in the narrative Caroline depicts a feeling that professionals were "just trying to sweep everything under the carpet" (G, 14) and that it was not possible to be heard as her experience left her feeling that she was ignored; "they took no notice of me whatsoever, nothing what so ever" (G, 70-71). Her lack of influence and power, consistent with previous literature (Malacrida, 2001), is apparent when describing how it was necessary to ask the school nurse to intervene in requesting that a supporting letter was sent to Lydia's school from her local hospital detailing her daughter's chronic fatigue condition. As Caroline describes "as soon as she got in touch with the hospital then they (school) got a letter (.) even though I was contacting the hospital" (G, 66-67) showing the power of practitioners. Caroline describes the experience as "that's what you feel (.) that as a parent you're actually, you're absolutely powerless (.) erm there's no sort of (...) respect for you (.) at all" (G, 71-72). Perhaps here it is possible to get a sense of distancing from the experience of powerlessness through the use of the second person perspective "you're absolutely powerless" rather than "I was absolutely powerless". In saying "there was another break of communication" (G, 364) and "again they don't listen" (G, 464) she makes clear the multiple instances of feeling she is not being heard. The response from school to Lydia's bullying is indicated by Caroline to be something that Lydia had "already tried that and that's not worked, and that was it, (.) that is all they did" (G, 736-737). Caroline makes clear the sense of not being respected, which is reminiscent of parents fighting to be recognised and respected (Harborne et al. 2004).

The inertness of voice appears to be experienced due to the level of engagement she has from practitioners. In an exchange with an NHS consultant she indicates "but we have already tried this (.) and my daughter has not been able to do it" (G, 490). The exchange is in relation to the proposed treatment for her daughter suggesting Lydia

goes “to see the nurse and doctor each week and spend some time (.) and (.) go for a walk” (G, 492-493) in the hope of raising Lydia’s “energy levels and her exercise” (G, 494). Within the narrative Caroline reflects why she feels that this is going to be difficult as Lydia “had not long since nearly been put in hospital for malnutrition (2) and she didn’t have the energy” (G, 495-496). This exchange reflects how Caroline was challenging the proposed intervention potentially being positioned within the poor parenting discourse (Curran and Runswick-Cole, 2014). During Caroline’s engagement with practitioners at this time in the narrative we can see a collection of times when she repeats “I said”:

I said “there is something going on”
(can) I get her
I did say
I said
I explained
I said
I need something
I said
(do you know what) I mean?
I got her there once
I said
I said erm what can we do
I need some help
(G, 477-507)

The move within Caroline’s I statements perhaps reflects this sense of feeling her voice has no power within her interactions. The I poem moves from beginning with highlighting that “there is something going on” and is followed by repeatedly indicating that she was speaking and explaining. Caroline states that she “needs something” which is later reflected in asking “what can we do” and explicitly reiterated in saying “I need some help”. The moves within these statements appear to mirror the frustration in engaging with practitioners from Caroline’s position. The limited engagement in hearing Caroline’s voice led me to wonder how those conversations were managed. Gwernan-Jones, et al. (2015) comment on how parents often felt they were “being told” rather than engaged with. Here I feel it may be possible to see how the “good mum” narrative, being a parent that is seen to support interventions and does not challenge practitioners, influences Caroline’s

experience (Curran and Runswick-Cole, 2014). Having indicated that proposed options had already been tried this is quickly followed by her stating that her daughter “just agreed” (G, 491). There is perhaps a sense of being resigned to this proposed course of action even though she has concerns around her daughter’s health preventing her from achieving what was suggested. Caroline’s narrative makes apparent the difficulties that Lydia has experienced prior to this course of action perhaps reflecting her doubt in the effectiveness of this intervention plan. Though she voices this doubt it does not appear to have an impact leading to the implementation of the approach which is unsuccessful. Caroline’s lack of agency appears to be exposed.

Reflection

During this time in the interview I was led to consider my own challenges in considering the voice of young people and the voice of parents. I am aware of my own difficulties in attempting to ensure all voices are heard even when an apparent tension exists between them; I have found this particularly difficult when parents and young people disagree. Perhaps my experiences influence how I have listened to Caroline’s story. In her case practitioners perhaps felt that though Caroline is voicing her concerns Lydia is agreeing with a course of action. The resonance of this situation could influence my reading of Caroline’s narrative.

Caroline offers a comparison between her experience of feeling unheard and another parent she knows whose daughter was at risk of being groomed for sexual exploitation. The comparison to this discourse is perhaps to emphasise the degree to which Caroline wishes to express this is a problem and convey the frightening nature of experience. She identifies aspects of the other parent’s experience which resonate with her own reflected in the following conversation she recounts:

“erm she was the same (.) phoning the police all the time, (.) “she’s gone missing, I don’t know where she is, I’m afraid that she’s with a group of people that aren’t safe”,
"well er she’s 16 she can do what she wants",
erm "But she’s missing, she’s missing"" (G, 439-442)

It is possible to see an appeal to an authority for support when a young person is missing, which is perhaps similar to Caroline's feeling of losing part of her daughter and looking for help. The comparison may serve to communicate Caroline's emotional experience without a direct discussion of the feeling itself. She poignantly says "so she could have lost her that day" (G, 443-444) possibly acting as a signpost to her own experience. Caroline describes how the parent she refers to had their concerns unheard and that when attempting to gain support it was viewed "like the parents were just shouting the odds and err there was nothing really going on" (G, 447-448). This experience of being dismissed and ignored seems to resonate with the notion of things being swept under the carpet.

Though not being heard is seen within the interactions Caroline has with some practitioners there is also some absence of communication reflected as well. It is felt that somethings were not explained to her which she feels would have offered an alternative way to support her daughter. She says "she-she could have gone to college from the age of 13 (2) and I wished, I wished I knew that" (G, 541-543). There is a sense that Caroline could have investigated an alternative provision for her daughter which would have given the family the kind of support she has been looking for. Caroline feels that it "would have been easier" (G, 554-555) for her as she "would have had more (.) back up, more support" (G, 564-565) from a college setting.

A poignant moment in the narrative comes when Caroline feels that the difficulty she and her family are facing is heard, recognised and acknowledge by a practitioner in a different city. Caroline indicates to the practitioner the difficulty she is experiencing who then demonstrates a level of empathy and recognition of her emotions by saying that things must be hard for Caroline (G, 432). This acknowledgement not only serves to hear Caroline, but also has a containing effect reflected in her saying "and just having someone say that (.) just meant the world" (G, 433-434). Caroline has a further sense of "relief" (G, 474) when it appears that a CAMHS practitioners indicates "we can't let you carry on like this" (G, 473-473) referring to the difficult situation the family seemed to have been in for some time. This again reflects a time when Caroline feels heard by another. It appears from these examples that being heard and being contained make a difference to Caroline's subjectivity.

4.3.3 An absolute fight, everything (G, 171-172)

The discussion of feeling that fighting is a prominent part of Caroline's experience is reflected in the following interaction:

Scott: So you've talked a lot about sort of erm-using the word fight quite a lot, do you think that has been your experience?

Caroline: Absolutely. Everything's an absolute struggle, absolutely yes, (.) an absolute fight, everything. (2) You're fighting to be heard as a parent (G, 169-172)

Within the interview I refer to the use of the word "fight" as being used "quite a lot". Though this term is used it appears on only three occasions before I draw attention to it, which has a clear influence on the direction of the narrative. Reflecting back on the interview I felt that "fight" was a description frequently used, however, it does not appear to have been mentioned as regularly as I thought. Although I feel this was something that Caroline was communicating, my questions guides our conversation; this acts as a reminder as to how the narrative is co-constructed.

Reflection

It is possible that my impression of Caroline's experience of fighting come from other forms of communication happening within the interview situation. Perhaps other methodologies may offer a means of identifying those communications which may be argued to exist beyond the text. Reissman (2008, p.141) points attention to "other forms" of communication such as gesture, body movement and sounds, whereas Hollway and Jefferson (2013) refer communication through projection and transference.

There is a clear connection made between fighting and being heard, which further serves to highlight the importance of Caroline having her voice recognised within her interactions. There is, though, a further sense of having to struggle and fight beyond just being heard through the view of being blamed and Caroline's sense of resistance

from services to engage with her. Caroline highlights that “school (.) ((deep sign)) just wasn’t (.) supportive (.) at all (.)” (G, 10) instead reflecting an experience of being blamed through indicating “at one point they were going to prosecute me” (G, 40) and “that’s how the school treated you, like (.) you (Lydia) just didn’t want to go” (G, 195-196). This feels reminiscent of a “naughty child” narrative. The discourse of the Other seems to influence the ways in which Caroline is understood; the cultural values around the behaviour of a young person and the implication of the identity of a parents are exposed. The consideration of prosecution perhaps reflects the impact of an individualising psychology discourse (Runswick-Cole & Goodley, 2018). The difficulties faced may be being positioned within the family (Willig, 2008), between Caroline and Lydia, rather than considering broader systemic factor such as the school environment. Furthermore, this description fits with previous research that highlights how parents feel criticised by school staff (Broomhead, 2013; Gwernan-Jones, 2015). Interaction with a consultant paediatrician also demonstrates the difficult relationship Caroline has with those engaging with her daughter. She highlights that she had to “fall out with a few people” (G, 79) and that to receive post-diagnostic care Caroline and her husband “had to go and sort of (.) fight for that” (G, 92). The notion of falling out highlights Caroline’s perception of hostility from Health Care Practitioners (McKeever & Muller, 2004). Even with the recognition of Lydia’s chronic fatigue diagnosis Caroline describes continuing difficult encounters within school, which she relates to there being a lack of understanding around her daughter’s condition:

again I were still fighting with the school, still having meetings with school erm (3) like I said she did go, she did go back for a while (.) and she did like what you’d call a phased return, (.) and that is because they were threatening us that she got to, she’d got to do this, erm (.) which she just relapsed, it made her worse (4) erm (2) and so (2) as a condition on its own it was just getting worse (.) and there was no sort of (.) understanding of it, you know, no sort of help or support (G, 100-106)

This lack of understanding is proposed as a catalyst for the worsening of her daughter’s condition and is framed in a feeling of being threatened with little support. The lack of support is reflected elsewhere in the narrative along with a view that parents were in some way responsible. Caroline highlights that her daughter

was viewed “as that naughty child” (G, 425-426) and that she herself was view as “the person that’s (.) over-reacting” (G, 402). These interactions are described as provoking a powerful emotional experience:

Scott: So you got that sense of (.) people sort of thinking this is, this is a family issue, it's a parent issue?

Caroline: Yeah, yeah, yeah, and you deal with it. (3) Your child is misbehaving and it's a behavioural problem between you and your daughter and you, you sort it (5)

Scott: And how did that kind of make you feel?

Caroline: (4) ((sighing)) Just, just despair, (.) just despair really. (.) It made me want to become a politician ((laughing)) and make it all different. Just, (.) just makes me determined really (2) to sort of do something (.) to try and change something (.) but I don't know what yet (4)

Scott: Oh wow (...) it sounds like it has been a real journey (G, 452-461)

The hesitance and sigh before Caroline’s use of the word despair perhaps signify silences around the experience that are difficult to communicate. It appears that Caroline’s parenting is being questioned leading to this powerful emotional experience described as despair, though the language used to describe this emotional experience is different it is in keeping with reports of parents feeling anger, depression and anxiety (Fouquier 2011). Caroline quickly moves on to explain how it has made her want to become a politician, injecting a humorous moment and laughing which may serve as a smokescreen to the emotion that is present. Caroline seems galvanised in indicating how it moves her to want to act and do something, which perhaps again serves to move the conversation away from this experience and distance the emotion. She leaves a long pause presenting a silence which is then filled by a shocked expression from me and a comment which allows the conversation to move on.

Reflection

At this moment in the narrative I wonder to what extent I found it difficult to manage Caroline’s expression of despair and subsequently moving on from it. I feel that my comment (“oh wow”) aimed to recognise the gravity of such an experience and give an opportunity to move the conversation on to relieve the

uncomfortable experience for myself as much as for Caroline. Perhaps there were further questions that could have been asked to consider the experience further, for example: was the feeling of despair created in relation to Caroline feeling that she had been left alone to support her daughter or that she felt blamed for her daughter's difficulties? I feel this reflects the way that the narrative is continually constructed between myself and Caroline even when not fully aware of this.

A further sense of battling is perceived between the school and other services which has a direct impact on Caroline's experience as a parent. She indicates that there "was a battle between school and the-the service that provide the home tuition" (G, 112-113) highlighting that the service was delayed in being introduced to support her daughter. She states that "we got knocked back a few times" (G, 114) identifying family pets as being the reason given. Caroline gives the impression that this reason is difficult to accept and perhaps feels that she has little power within this situation. In addition to feeling powerless, Caroline presents a sense of resistance to offering her support. She reflects that "it was the process (.) of getting, (.) it was the school making everything difficult" (G, 129-130) potentially highlighting a sense of barriers being put in place given a perception of parental responsibility.

Though Lydia receives diagnoses for a number of conditions including chronic fatigue, eating disorder, depression and sleep disorder they do not appear to give Caroline further comfort or access to support: "All these disorders erm but no still nothing really" (G, 528-529). Instead she indicates "((sigh)) (.) They're just names aren't they, they are just titles aren't they" (G, 534). Though diagnosis is given, for Caroline, they appear to be *just* labels giving the impression they do not bring further containment, support or minimise her experience of fighting for help; they do not give Caroline more power. Perhaps here we see a challenge to the view that diagnoses are felt to bring capital for accessing support (Ryan & Runswick-Cole 2008). Lydia's diagnosis does appear to bring further support or change how she is positioned within a blame narrative by practitioners. It is possible that Caroline's experience is unique however, it could also reflect the potential for diagnosis related to SEMH difficulties (such as depression, eating disorder etc.) to be met with scepticism (Horborne et al. 2004). It

leads me to question whether there are different perceptions of medicalised narratives for SEMH difficulties. Though they may produce a language of cause which reduces feelings of blame within parents (Runswick-Cole & Goodley, 2018) this may not necessarily influence the views of practitioners. A further explanation of Caroline's experience may focus around the availability of support. A move towards medicalised narratives of SEMH needs may produce a systemic difficulty between schools and support services. An increased medicalised narrative could increase the demand on services such as the Child and Adolescent Mental Health Service (CAMHS) placing the service under further strain. This discourse could maintain the high demand further by generating a second narrative around who is appropriately trained to meet mental health needs. Caroline indicates that school staff "weren't equipped to deal" (G, 752) the kinds of needs her daughter had. Educational practitioners, perhaps, do not feel sufficiently trained to support a young person with a medical 'brain-blame' condition, meaning they feel unable to help. This might be reflected in Gwernan-Jones et al. (2015) reporting parents feeling pressured from school staff to seek clinical assessment and diagnosis. A stretched service, meaning parent and young people experience long waits to access them, and teacher views, of not being appropriately skilled to meet needs, could create a space "behind the scenes" within which young people and their parents become stuck.

There is a notable occasion when Caroline feels supported by practitioners who appear to be "fighting" on her behalf. Caroline's description of her experience of an NHS service in a different authority is positive. She states that there "was a doctor that was fighting (.) for me (.) with X town to say she needs an assessment straight away, (.) she needs help, she needs admitting" (G, 303-305). In this Caroline feels she is supported. Perhaps Caroline's experience of feeling powerless in her interactions means she has hope when someone perceived to have authority offers their voice in support of her.

4.3.4 Behind the scenes pushing it all (G, 399-400)

Caroline's sense of agency appears to have been challenged; not simply from the point of view of not feeling heard, but also from a sense of not being seen either. Within Caroline's narrative there is a sense of being "non-existent" (G, 396-397) and being obscured and excluded within her interactions with others. Caroline talks of how she has felt practitioners have not wanted her in meetings and she relates this to the deterioration in relationships with others: "she didn't want me (.) there in that meeting (.) She tried to get rid of me (.) because I'd had a few sort of battles with her not sort of all out arguments but battles" (G, 386-388). This leads Caroline to express that specifically as a parent she feels "non-existent":

So (.) all in all the experience as a mum from start to finish of all this (.) has been like I've just been non-existent (G, 395-396).

This impression of being obscured is further encapsulated in stating her position as being "behind the scenes (.) pushing it all" (G, 399) continuing to find obstacles, "hitting all the brick walls" (G, 400). Being behind the scenes implies she is obscured and not seen by those with whom she is attempting to engage. Specifically, as a mum, it appears Caroline has little sense of her ability to influence the situation; though she attempts to act her agency is challenged by the "brick walls". Caroline has a continuing experience of feeling rejected, excluded and obscured referencing again "not wanting me in-in meetings not wanting me (.) to be present" (G, 404). It seems Caroline presents an experience akin to those reports of parents feeling silenced (Hibbitts 2010). For Caroline it seems that because Lydia is an older young person, practitioners expect Caroline to have a reduced level of involvement. This has an impact on how Caroline engages with practitioners at times:

so I used to just sit there most of the time as quiet as I could to be and then I'd fill her in. (.) She'd ask a question and she'd (Lydia) just be sat there with her head in her hands and she be like that, (.) like that and I'm thinking she's going to like (.) melt down in a minute (2) So I'd speak up for her and erm erm (2) she just tell her "yeah I'm alright, yeah I'm okay" (G, 407-411)

Caroline is moved to being quiet, perhaps through feeling unwanted and obscured. This example of how Lydia's views are elicited appears to be familiar to Caroline; she previously indicated the need for "different ways, different (.) techniques and an-a-

certainly a different approach” (G, 176-177) for asking for a young person’s views. As with the example of her daughter’s response indicating she was “okay”, Caroline reflects on the expectation of young people to be able to “know their own mind, (.) and to be able to verbalise it” (G, 174-175). Here the desire of practitioners to hear the voice of a young person, and their expectation that this young person can express their views verbally within a consultation format, leads to the exclusion and marginalisation described by Caroline.

Reflection

Again I feel the resonance with my own practice potentially guiding how I have listened to Caroline’s narrative. This draws me back to a potential difficulty in advocating for a young person whilst also ensuring that parent voice is recognised. Perhaps if parents do not have confidence in the method by which a young person’s views have been gathered they cannot have confidence in the authenticity of the voice, particularly if their experience may indicate a different sense of their child’s views.

A further experience of excluding and obscuring may be reflected in Caroline’s reference to criteria used for accessing support. From interaction with NHS staff from outside Caroline’s local area concerns are raised around the possibility of her daughter having an eating disorder. Caroline describes her attempts to access support locally where she is faced with the need to fit a particular criteria:

Caroline: but that didn't fit the criteria (.) for anorexia (.) and eating disorders don't always fit the criteria-it's that's not always anorexia, if you've not got anorexia or bulimia or you are not cutting your wrists (.) and you are not wanting to jump off a cliff or something (.) then that's it (4)

Scott: And how did that-that period in time make you feel as a parent?

Caroline: Erm (.) ((sigh)) I-I just can't put it into words (5) Just (.) helpless, (.) helpless. Just (.) seeing your child (.) go from one thing to (.) this other thing (.) that was in your house and you didn't know what was going off (G, 317-324)

The witnessing of a change in her daughter and the inaccessibility of support through not fitting the criteria is difficult for Caroline. The experience is described as

unsayable “I just can’t put it into words” and though “helpless” is the description used it is punctuated with silences represented in the hesitations in Caroline’s speech. After indicating being unable to put her experience into words her sentence reflects a change to a second person perspective pronoun, “you”, perhaps helping to distance herself from the experience. The distress is encapsulated in the statement “I was absolutely (.) at my wits end (3)” (G, 328) and related to a difficult time for her husband who “couldn’t function” (G, 329).

The language of “criteria” and “crisis” appear to bring frustration to Caroline’s experience of looking for support:

(3) Erm So I was phoning them (.) for help and support (.) all the time, what-what should I do? You know we were phoning them, (.) they shut though at five so then you can only phone the crisis team (.) and then you get told (.) they can't do anything (2) because for one she is not old enough, there is that as well, and the other thing is they'll only take her in if she fits these criteria (2) erm. If she is basically what they call in crisis. (2) But we were in crisis at that time (.) and erm we-we were just absolutely appalled (.) and thought how are we supposed to deal with this w-what are we supposed to do, (.) you know (G, 340-348)

Notable in this extract is the sentence “what they call” as it separates Caroline’s understanding of crisis from the practitioners with whom she is attempting to engage. There is a continuing sense of resistance from services and feeling excluded from accessing support when Caroline recounts her engagement with NHS staff who indicate “well she’s (Lydia) not got anorexia because she doesn’t tick all of the boxes for that” (G, 476-477). Again, it is possible to see the dictation of a criteria that is not made accessible to Caroline. She responds by saying ““No but’ I said ‘there is something going on that (.) we aren’t equipped to deal with and she needs some help”” (G, 477-479). It seems that Caroline’s concerns are muted at times through a language of *criteria* and *crisis* within professional services. Caroline is not completely silenced within these engagements, however, she is unable to articulate a notion of *crisis* which is accepted within the discourse of support services. The influence of power dynamics seems apparent leading to what feels like an almost pleading and desperate experience for Caroline who is left without power and agency to influence

the situation. Perhaps barriers to support here are designed to resist pressures from increased demand.

Reflection

I am reminded of Ardener's (2006) Muted Group Theory. The language of crisis and criteria seems to have been developed within the dominant "professionals" group who hold the power within their interactions with those seeking support. I wonder how criteria is experienced and understood by both practitioners in services and those attempting to access help. In some respects it aims to offer an equality of the distribution of resources, however, perhaps it is felt as an exclusionary device unless you understand and master the language within which this discourse sits. The process of scripting concepts of 'criteria' and 'crisis' is perhaps significant in attending to the problem of producing a muted group. Practitioners are often referred to as "professionals" which attributes a power saturated authority for making decisions regarding the language and its meaning accepted within their services. I also recognise that practitioners are steeped within authoritative discourses which are derived from a community of academic research; what might be termed "evidence-based practice". Therefore, decisions regarding the language of *criteria* or *crisis* will also be imposed from cultural and academic discourses. However, perhaps if the language within services is determined without engagement with those that may seek their support (i.e. families and young people) it has the potential for developing a muted group. This may present a need to strive to see the importance of co-construction and co-production between parents, young people and practitioners.

There are also systemic processes which lead to the exclusion from services apparent within the narrative. Caroline describes delays caused by the process of being referred from one service (chronic fatigue) to another (CAHMS) meaning that "by the time we got to see her (CAMHS paediatrician) (.) erm it were, you know, too late" (G, 370-371); again Caroline is left having to "wait again" (G, 372) meaning that "in between that time there wasn't anything (.) at all" (G, 379-380). Whilst engaging with CAHMS Caroline highlights having only "three chances" (G, 503), then they "take

you off the books” (G, 503) when unable to attend appointments. This appears to instil a sense of desperation, pleading with practitioners to not discharge her daughter from the service: ““please don't do that” I said “erm what can we do?”” (G, 504-505). Perhaps here we can see a lack of power for agency within Caroline’s experience. Criteria appears as a barrier leading to a change in how Caroline views her relationship and role; “I-I feel like I’m not a parent anymore, (.) I’m a therapist now” (G, 348-349). There appears a difficult shift in how Caroline sees herself, which is not chosen and is accompanied by further fears regarding how to manage. Caroline reflect this in asking:

how do I know when she is going to slit-cut her wrists (3) How do I know what thoughts she is having in her head and (.) what, you know, what I'd look out for (3) I'm a mum (2) I am going to try and do everything I can to sort of (2) help her f-what-whatever, that could have been the wrong way, (.) you know, (.) she needed professional help (G, 351-355)

Caroline questions her ability to be able to provide the support that Lydia needs worrying that she may do things “the wrong way”. This questioning perhaps presents a sense of uncertainty and lack of confidence in how to help her daughter. Unlike from literature in other areas (e.g. children with disabilities) Caroline does not present herself as the only person to understand her daughter’s needs (McKeever & Muller, 2004) or that she is the only person capable of caring for Lydia (Nicholl & Bagley, 2012). This could indicate experiences which are related to specific SEND categories of need. Caroline’s feeling of uncertainty may also link to feeling that there is a lack of consideration for her and how she is feeling:

it was just a general sort of feeling there was never any (.) consideration for what you were going through with your child, there was never no (.) erm (2) Just thought for you as a human being there was just nothing, (.) you know. (2) (G, 428-431).

Perhaps this lack of consideration holds a relationship with feeling obscured.

4.3.5 *We were so close (.) she used to tell me everything (G, 693)*

The relationship between Caroline and her daughter is a prominent theme in her narrative. There is a clear reference to loss for the relationship when Caroline says they have “lost a part of our daughter” (G, 189), which has affected Caroline and Lydia’s relationship (G, 191). When framed in the experience of the loss felt by Caroline we can perhaps understand the importance of recognising her connection to Lydia through similar shared experiences. There are a number of Caroline’s experiences which appear to mirror those she highlights for her daughter. Caroline describes the view of her daughter from teaching staff as a “different child (2) that was basically non-existent really (6)” (G, 247). In Caroline experience of attending a parents evening she encounters teaching staff that “apparently they didn’t know her (Lydia)” (G, 217-218) and so “nobody would give (.) a statement about her” (G, 233). This leaves Caroline with a feeling of being “disgusted” (G, 236) and both her and her daughter being “let down massively” (G, 249). This sense of Lydia being non-existent resonates with Caroline’s similar description of how she feels as a parent.

Later Caroline further describes her own experience of being bullied as a young person (G, 637-638), that she “suffered (2) emotionally” (G, 647-648) and was “let down by-by the school” (G, 649). Caroline refers to being “the one that still kept trying, (.) was still doing everything right but got classed the same as everyone else” (G, 651-652). There is a sense that Caroline is not recognised by school staff in a similar way that Lydia is not. Equally Caroline’s view of being “let down” holds parallels with Lydia’s experience of feeling unsupported. Caroline contrasts Lydia’s experiences as a young person who “wanted to get on with the work and it was important to her to do that” (G, 746) and being “conscientious and all those things” (G, 747) with other times when Lydia was a student who “just got left behind” (G, 747), other young people “got more attention and more help and more support” than her (G, 754-755). It is felt that Lydia did not get “that same encouragement” (G, 757) and “basically got a telling off from someone for crying” (G, 729-730). Caroline further notes that her own response to her experience in school was to go travelling “and that is exactly what my daughter wants to do, she wants to go travelling” (G, 655-656). This connection in experience enables Caroline to indicate a level of

understanding of what Lydia has gone through. However, she expresses a sense of resistance from Lydia and Caroline is hopeful for a future time when she and her daughter can share their experiences and regain that sense of being close, which is felt to have been lost (G, 666):

so I do understand, you know, er where kids are coming from and where my daughter's coming from, perfectly understand that, (.) but she won't accept that I understand that ((laughing)) cos that's (.) just (.) the, you know, difference between me and her she wants to have her own experiences, she doesn't want to have my experiences and she doesn't want me to relate to her because (.) hers are hers and she doesn't want me to impede on that. (.) So, (.) you know, (3) I'm sure when she's older (.) she will (.) have a chat with me (.) and sort of agree "yeah, yeah that happened to me, yeah that happened to me" (3) ((laughing)) (G, 660-668)

Perhaps the description of the similarity in experiences functions as a way of remaining connected to Lydia at a time when she feels their relationship is not what it used to be. It may give Caroline a means by which to make sense of her relationship with Lydia and potentially defend against an experience of loss that is present within the narrative.

The narrative appears to describe multiple experiences of loss. The changes in her daughter, noted before, are described as Caroline losing "part of" her daughter (G, 189) and changes in Caroline's employment status which could represent the loss of her identity as an independent working individual. Caroline highlights she "had to finish" her job (G, 330). It is not clear to what extent this is related to the difficulties Lydia was experiencing, however, Caroline does earlier in the narrative speak of taking Lydia "into school just one hour a day cos that's all she could manage" (G, 41-42) and that had "a massive (.) impact on me and my husband cos we both were working" (G, 43-44). Previous literature also notes an impact on parent's ability to work (Leiter, et al. 2004; Lewis et al. 1999).

There are two further experiences of loss that Caroline refers to within her narrative. She explains: "We've lost all that community, (.) they've been destroyed so there is no community feel where people are supporting each other (.) and people are just excluding people" (G, 791-793). Perhaps here again we see this sense of being excluded on a wider scale. Todd and Shearn (1996) indicate the experience of

mothers of disabled children feeling that they are left on the edge of society in the margins, where they are in a position of isolation and exclusion. This loss of the community is closely linked to the moving on of a Head Teacher who is highly valued by Caroline:

but when the headmistress was in that school (.) she had a profound influence on the whole area (2) because before she came it was-it was a bad area, a bad school. She came along and turned it all around (G, 794-796)

The feeling of loss and significance of this relationship is made apparent by Caroline when she says she “nearly cried when she left ((laughing)) (2) I was like oh God (.)” (G, 874-875). The high regard in which this individual is held is related to how she would engage with families, young people and teaching staff. Caroline indicates how the Head Teacher would talk to parents saying:

“I know they drive me mad, and I tell them that every day that they drive me mad” she says “but I love them” she says “I tell them they’re fantastic every day that they are”. (.) And that has a massive influence on the families (G, 798-801).

This experience for young people is felt to be extremely significant aiding them in making a choice to turn away (G, 819-820) from drugs. Caroline explains the school had an inclusive ethos where “whatever problems you’ve got you can come here and you can forget about it” and that the young people “had that security (.) and somebody believing in them” (G, 865-867). That this individual influences families potentially reflects Caroline’s sense that the Head Teacher saw parents meaning they did not feel obscured or ignored. Caroline’s impression of how this Head Teacher engaged with individuals appears important to her, feeling that her daughter’s experience could have been different under this Head Teacher:

if she had seen my daughter crying like that she’d have been straight on the phone to me, (.) she'd have been trying to get to the root of it, to the bottom of it, and she would have put a stop to it, all of it erm (G, 816-819)

I was left with the impression that Caroline feels her daughter’s, and therefore her own experience, could have been different if the approach of practitioners around her had reflected a sense of valuing Lydia as well as having an inclusive ethos. Perhaps implied is that this approach, embodied in the Head Teacher, would enable

the young people and their families to feel secure and supported. It is possible that Caroline feels that this would have had a wider impact on the community as a whole.

I think it is important to note I have used a grief narrative, which within disability research has been found to be a potentially limiting discourse (Ryan & Runswick-Cole, 2008), as a means of making sense of Caroline's narrative. Though it is Caroline who introduces the experience of loss early in the narrative, (G, 189) and explicitly returns to the feeling on two other occasions, it may be a limiting medicalised discourse that has become internalised by Caroline. I feel it is important to be reflective when applying this narrative as an interpretive framing given the way it may inadvertently limit ways of understanding both how Caroline makes sense of her experience, but also how I, as a researcher, interpret this. It highlights the need to adopt a reflective position within the research.

4.3.6 Just knowing that someone else is there (G, 167-168)

It is possible to begin to see in Caroline's story a number of ways that things could have been made better for her during this difficult period. An empathetic approach from individuals which feels supportive and secure has been important for Caroline as she describes these as positive encounters with practitioners (G, 433-434). Specific individuals stand out from her narrative when they appear to recognise the difficulties Caroline is facing, when they appear supportive of her, when they listen and are flexible in when and how they support her.

She further acknowledges the importance of peer support. From feeling there was no support for parents Caroline highlights it is "why I got involved with the parents forum" (G, 162-163). This has offered her the opportunity to share her experience with others who have had similar experiences: "just knowing that someone else is there to er (.) erm that's gone through similar things" (G, 167-168). This perhaps provides an experience of being heard and having others recognise the difficulty experienced by Caroline. This group has also been able to help through "signposting to different places, different agencies, organisations" (G, 166-167). Caroline's experience at this time in the narrative reflects a sense of inclusion:

I've come
I got involved
I've had the support
(G, 161-166)

This appears very different to Caroline's description of engaging with services:

I was contacting
I find
I've got to say
I've had experience
I've been
I would have
I had to kind of fall out
I got a diagnosis
I just got a letter
I had to fall out
I had to go
(G, 70-87)

The interaction here is punctuated with a sense of compulsion and lack of control, Caroline uses "had to" on three occasions with two relating to a "fall out" and the last as reflecting a sense of having to go. The ease in becoming involved and finding support seems absent within this experience compared to accessing peer support. We might understand through recognising how Lacan indicates the subject is positioned within discourse. Caroline highlights that Lydia got a diagnosis, but this does not appear to reduce the tension she feels within her relationships with practitioners.

Two features of Caroline's narrative centre on being supported. Caroline regularly indicates that she feels there is no support (G: 160, 162, 401) or that support does not come early enough (G: 302, 371):

I-I do believe that if she had the support sort of early, early on (2) and (.) er, you know, we had the right doctors and we had the right (2) procedures (.) err she might have been able to carry some (.) because at that point she wasn't at the point where she was saying I can't, I can't do anything, I can't, I can't, you know (G, 151-155)

Early practitioner intervention is important to Caroline: “if you give my daughter this help now this is going to help you through” (G, 420). She also indicates that she was “going to try and do everything I can to sort of (2) help her” (G, 353) but that “could have been the wrong way” (G, 354). Caroline makes a clear statement of uncertainty and not knowing how to respond to her daughter’s needs.

4.3.7 Summary

There are some notable experiences in Caroline’s narrative which resonate with the current literature. Caroline highlights experiences of feeling unheard and that she has limited power within her interactions. She feels that she is fighting to be recognised and respected and is often left obscured by those with whom she is trying to interact. Her conversations with practitioners seem to hint towards “being told” rather than engaging with her. She is placed in a position of blame within the narrative, which is exemplified by the threat of her being prosecuted by school. She also appears to reflect an experience of frustration from perceiving practitioners to have an alternative view to her own about the cause of Lydia’s difficulty. It is possible to make sense of Caroline’s narrative when considered through neurocultural discourse, which emphasises the normal development within an individualising psychology. Within this framing Caroline is seen as responsible. There feels to be a significant departure from the current literature in relation to the effect of diagnosis. These are viewed to be just names and do not hold any further capital for accessing support. This raises questions as to whether this is unique to Caroline’s situation or reflects the potential for a specific experience related to specific SEMH difficulties.

Through the consideration and use of cultural discourse it is possible to formulate a systemic problem between school and service which would impact upon Caroline’s experience. Through this approach it is hoped that we can see how it is possible to reframe difficulties which can highlight alternative directions for intervention. This formulation is summarised in the follow points:

- Medicalising discourses of SEMH needs increase demand on services such as CAMHS

- This medical narrative also creates a belief that those in the medical profession are trained to deal with SEMH needs and school staff are not
- Parents feel pressured by school to seek assessment (because they are not trained to meet needs)
- This increases the number of requests for assessment and access to support
- In order to manage this pressure services implement strict criteria for involvement based around professional discourse (academic evidence base)
- This creates a language around criteria and crisis which is not always accessible to parents
- Parents and young people can become stuck between a school narrative committed to young people needing professional support from the Health Care Practitioners (as they are trained to deal with mental health needs) and a health care service such as CAMHS who are unable to meet demand sufficiently

A number of approaches may be suggested from a conceptualisation of the problem in this way offering different ways to punctuate the system. Initially there are concerns around the medicalising and individualising discourses. Encouraging to view these difficulties from a social model, rather than a medical model, may help to re-engage practitioners who feel the needs of the young person are beyond their experience, training and expertise. A further way to puncture this system is to consider the potential training needs of staff to upskill them in recognising how they can support SEMH needs. A further way in which to improve parent and potentially young people's experience is to work co-productively in the formulation of such things as criteria and crisis. This may help to develop a shared language which is understood by parents, young people, school staff and service practitioners.

4.4 Louise's Story

4.4.1 Narrative synopsis

Louise is a mother in her mid-thirties. She has two young children, her daughter aged 7 and Riley aged 4, with her husband, Ian. Riley was recognised to have special educational needs when he entered nursery at two and a half years old. Louise indicates that she began to experience difficulties engaging with services and her originally desired primary school for Riley. There are some notable individuals who Louise feels care about and support Riley. Riley originally was given a diagnosis of autism, which Louise indicates she has limited experience with meaning that it is difficult to understand what this means for her and her family. A further diagnosis of a chromosome duplication further contributes to Louise's difficult experience of understanding what this means for Riley. Though Louise's experience often reflects difficulties in communication, gaining support and experiencing blame she frequently highlights the optimism she has and her ability to cope with the situation. Four key themes were identified from an analysis of the transcript (appendix K and L):

- Communication and contact
- Support and containment
- Difference
- Being positive

4.4.2 Communication and Contact - "it can be fun to try and contact her (K, 27-28)

Communication seems to be a noteworthy theme in Louise's narrative. She highlights difficulties in being able to contact individuals (K: 27-28, 35), not having things explained or in ways that are intelligible to her (K: 30, 32-33, 286-287, 325-328, 336-339, 408, 424-429, 852-853), being ignored and responses being delayed or limited (K: 43-44, 128-131, 158-161). When communication and contact is made it can often be felt too insensitive and impersonal (K: 171-173, 174-179, 336-339, 601-603). The contact that is made is felt to be rigid and not flexible enough to consider

the needs of her and her family (K: 56, 64-65, 589-591). Louise sums up her feelings of interacting with practitioners when she says they “feel like the gods of the situation” further highlighting the need to “liaise and flatter them in order to get what you want” (K, 733-736). Louise reflects the difference in power that she has in these situations to the extent that some interactions are describe as being used “as a stick to beat me with” (K: 40, 415) and that “everybody kind of knows what is going on but me” (K, 428). Louise indicates that she feels that there is not enough information “out there” (K: 154, 408) leaving her to feel she has to research things for herself (K: 132, 383, 488, 554-555, 574-575, 708-709). The knowledge Louise develops from her research is thought to be felt as threatening by practitioners (K, 552). Conflict also occurs when little effective communication can lead to experiences of needing to battle with others (K: 406-408, 557-560).

There are examples of times when communication and interaction are felt to be good, (K, 619-622) which lead Louise to feel that she is not going to have to battle (K, 622). Louise indicates that there are times when communication is good, such as when individuals respond to her in a timely manner even though they are busy (K, 125-126), when written reports reflect that they know Riley (K: 256-258, 259-261), or they connect with Louise’s experience leaving her to feel more at ease with a situation (K, 619-622).

4.4.3 Support and Containment - people who don’t seem to be all that bothered (K, 400-401)

Having support is recognised as a positive experience for Louise; she describes it as “just-just amazing” (K, 79) and reflects a sense that someone else knows how she feels (K, 84-85). Individuals are praised highly when felt to be supportive and reassuring (K: 103-105, 110-111, 195-197, 357-358, 391-392, 394-396). Family members are considered to be supportive (K, 247-248), however, Louise does indicate “I don’t think they get it” in regards to some who may say things which are not supportive (K: 814, 818). Furthermore, Louise feels positive when she is able to share what she knows with other parents to support them (K: 267-268, 270-272, 850-852).

Support for Louise's emotional experience is not always felt to be available, such as after receiving Riley's diagnosis (K: 135-137, 435-436) with Louise indicating that she feels that "nobody seems to be interested, I just feel that they are on their own path" (K, 168-169). Some people are felt to not "seem to be all that bothered" (K, 400-401) or would not understand (K, 824-827). Louise reflects feeling unsupported in her desire to find what she feels would be an appropriate provision for Riley (K: 186-189, 190-193, 104-207, 207-209, 211-212, 235-237), which can leave her to feel that there is "little compassion and understanding for parents" (K, 241-242). There are also occasions when Louise feels challenged by practitioners in the support she is seeking for Riley (K, 569-571) leaving her feeling that she is "under the microscope" (K, 580).

4.4.4 Difference - I'm gonna have to adjust everything I know (K, 341-342)

Louise has an experience of difference that influences how she feels in terms of both worry and blame. It is indicated to be a "massive blow" when Riley is reported to not be presenting as a neuro-typical child (K, 85-86). Even when Riley is described in relation to one condition (autism) it changes to another (chromosome duplication) and he is thought to be contradictory of the usual presentation of the condition (K, 100-103). Louise is left with a level of uncertainty (K: 285-286, 288, 293-296, 320-323) which is described as "devastating" (K, 311-312). Louise describes a painful period of adjustment (K, 341-345) which generates feelings of responsibility and being to blame (K: 363-366, 919-922, 942-945, 950-951). How Riley is different also presents Louise with health conditions that she now has to accept as realities for her and Riley (K: 446-447, 449-451, 469-472); her feelings are reflected in reference to the Pandora's Box idiom (K, 496). Guilt continues to be a feature of Louise's narrative highlighted when saying she feels she must have "done everything I possibly can do (.) and then the guilt has gone" (K, 887-888). It appears to galvanise Louise into action.

Louise highlights that Riley's condition seems to be perceived differently to other categories of SEN from which barriers develop (K: 603-605, 779-782, 791-794) noting that for her daughter's needs (development of gross motor skills and core muscles)

she “never had to fight for that at all” (K, 777). This begins to reflect a further feature of Louise’s story around conflict.

4.4.5 Being positive - your glass is half full or half empty and I-I want it to be half full (K, 476-477)

A prominent feature of Louise’s narrative focuses on being positive. She indicates that she has to have something positive for her family (K, 252-254) giving the adversity that she faces. Louise presents a sense of being able to act in the situation she finds herself in (K: 492-493, 747-750) as well as consider the positive outcomes of difficult engagements (K, 691-639). She takes time to highlight the positive aspects of having Riley (K: 518-520, 545-546, 901-904) indicating that she “would never change what happened” (K, 528-529). Although there is difficulty and uncertainty about the future Louise says she still has to stay positive (K: 649-651, 747-750) feeling that she is able to cope with these difficulties (K, 966-969, 977-978).

4.4.6 Summary

Louise’s narrative recognises some of the experiences that are reported in the previous literature, such as experiencing a sense of guilt and blame (Harborne et al. 2004; Rogers, 2007a), dashed expectations for the future (Roger, 2007a) and interactions where she feels she is “being told” (Gwernan-Jones et al. 2015). Though there are prominent difficulties which can be recognised within the literature there is also a frequent reference to being positive and being able to cope. From this brief analysis it is possible to see a reference reflective of the internalisation of the Neurocultural (Lowe et al. 2015) and normal developmental discourses (Runswick-Cole and Goodley, 2018), which may indicate the influence of cultural narratives on how Louise makes sense of her experience.

Chapter 5: Further discussion

5.1 Overview

Within this chapter I consider the individual narratives in relation to each other, the existing literature and frame this section in relation to my research questions. I provide a consideration as to how these narratives may be understood together based on the in-depth considerations I have already given within each individual narrative. For example, neurocultural discourse, blame and grief narratives can be recognised to provide ways of making sense to parents and their engagement with others. I simply aim to highlight what may be considered common and distinct features rather than offer generalisations from one narrative to another. The methodology within which I have grounded my research is designed to consider subjectivity which is fundamentally individual. Therefore, I accept that the presented commonalities and differences are only possible ways in which to see experiences together. However, parents within this research identify being with others who have similar experiences as important to them (detailed later in this section). This would suggest that though subjectivity is fundamentally individual, expressed narratives provide the shared element of experience. This is consistent with the foundations of my methodology; subjectivity is experienced individually but it is understood through narratives which are in part culturally created and invested. Through the consideration of these stories together I further attempt to open up the text between narratives. This opening can offer further possibilities (and future research) to consider when hearing the voices of parents who have a child understood through an SEMH discourse. I move on to consider the limitation and implications for EP practice.

5.2 How do mothers with children identified as having SEMH difficulties make sense of their interactions and psychological experiences?

From examination of the narratives of Judith, Caroline and to some extent Louise it is possible to recognise common understandings of their experiences of interactions which may be attributed, in part, to the cultural discourse that surrounds them.

Runswick-Cole and Goodley (2018) highlight that the brain-based view of development holds the central assertion that early experiences are fundamental in the emotional and cognitive development of children, thereby bringing parenting and family interaction to the forefront of child development. Neurocultural discourse (Low et al. 2015) and the establishment of child development norms (Nadesan, 2005 – in Runswick-Cole and Goodley, 2018) have further consolidated an understanding of development in an individualising psychology fundamentally shaped by parenting. Behaviours experienced as problems are, therefore, situated within a child deficit narrative that shifts focus and responsibility to parents.

Glimpses of these discourses can be seen within the different narratives. Judith and Louise both use the phrase “neuro-typical” (D, 529; K, 86). Judith potentially highlights one reason why there is an internalisation of a neurocultural discourse to understand their experience; the power of this language is seen when she contrasts it with “normal”. Judith and Caroline reflect how the medicalised view of difficulty aids them to move outside of the blame narrative. Grief narratives have commonly been identified in the existing literature (Bruce & Schulz, 2002) and this experience is made explicit within the narratives of Judith and Caroline (D, 526; G, 189). Louise highlights having to adjust how she thinks about the future for Riley (K, 341-342), which has been referred to within the literature as a loss for future relationships and dreams (Rogers, 2007a). The narrative of loss seems to aid parents in making sense of their emotional experience of having a child that is judged by practitioners and those around them to not be developing in line with psychological norms.

A significant difference between Judith and Caroline’s experience related to diagnosis. For Judith labels of ADHD and autism help her make sense of her experience (D, 73) and brings a transformation within her narrative within which tensions in her interactions and personal relationship are much reduced. It appears that an autism narrative also helps her make sense of the relationship she has with her husband (D, 738-739) reflecting the powerful sense-making provided within this position. Caroline, however, does not appear to find the same level of comfort in Lydia’s diagnosis, she describes them as “just names” (G, 534). They do not contain additional capital by which to access support in the way that is identified in the

previous literature (Avdi, Griffin & Brough, 2000; Ryan & Runswick-Cole, 2008). Judith also reflects on the experience of receiving a diagnosis followed by a feeling of being “left on your own” (D, 521-522) raising the question as to what kind of capital diagnostic labels are experienced as having. It may also reflect how parent experiences differ depending upon their child’s category of need. Avdi et al. (2000) research was with parents of children understood as autistic which is not included within the SEMH category of difficult in the SEND Code of Practice (2015); autism falls into the area of Communication and Interaction. Though Benjamin (Judith’s son) is given diagnosis for Autism he is also identified within an ADHD category. Therefore, Judith perhaps has access to other cultural discourse, which Caroline does not, for making sense of her experiences and interactions with others.

Caroline continues to experience difficulty even after diagnosis, unlike Judith whose interaction with others is transformed by them. Judith appears to feel a greater sense of control through an autism and ADHD understanding of Benjamin, which may reflect her ability to be able to act within conversations to move them away from blame narratives. Broomhead (2013) reports different parent experiences depending upon the SEN category of need their child is identified through. Again, perhaps it is possible to identify an experience specific to parents of a young person identified as having SEMH needs. Judith’s son is initially identified through a behaviour discourse, although he is ultimately understood through autism and ADHD narrative. The dual positioning of Benjamin means that there is not a clear identification of him within the SEMH category, which could offer further ways for Judith to make sense of her experience that are not available to Caroline. However, Caroline’s experience may also indicate that within the SEMH category there are further complexities which are understood through different narratives. Caroline’s experience may highlight that although ADHD and mental health conditions, such as depression and eating disorders, are placed together within the SEMH category they are understood differently in terms of origin and associated parental responsibility. This in turn could perhaps lead to questions as to how this category of need was constructed and whether it is felt to be of value to those included within it.

Caroline describes the inaccessibility of support within her narrative, which appears to produce a space between services and education within which Lydia and Caroline are positioned. The focusing of SEMH needs within a medicalised discourse may leave those in an educational setting feeling they are unable to support a young person because they need support from healthcare practitioners (Watson, 2005). Caroline repeatedly faces criteria that she is unable to meet meaning she is unable to access support. Equally from considering Caroline's narrative, diagnosis and identification is not an easy process which can lead to being moved between services (e.g. between chronic fatigue service, CAMHS and eating disorders teams - G, 365-367). This move between services seems to open a further space within which Caroline feels unsupported. This space appears to be created, in part, from the language of criteria and crisis. In saying "what they call in crisis" (G, 345) Caroline demonstrates how she is unable to articulate an experience of crisis which reflects the language within services. In this way she is positioned outside of the remit of the service and again in to a space between.

Though diagnosis may appear to support some parents through reducing the feelings of blame it comes at a cost. Runswick and Goodley (2018) argue that diagnosis offers a cruel optimism in that accepting diagnosis parents also have to accept negative implications such as social stigma. This does appear to be part of each of the narratives in this research as well as a powerful psychological experience of loss which also accompanies a label. There is perhaps a relationship between the experiences of blame, stigma and loss and the developmental discourse in an individualised psychological framework. Due to the prominence of this norm-based perspective parents are driven toward a medicalised neurocultural discourse that supports a brain-blame deficit discourse around children and young people. Perhaps if a social model of SEMH was introduced in the consideration of the needs of young people the experience of parents and young people could be different. I acknowledge that there are recognised challenges in the conceptualisation of mental health in a social model (Beresford, Nettle & Perring, 2010) and that further work would need to be undertaken to consider an appropriate formulation of this model.

5.3 What are the implications of SEMH discourse on mother's subjectivity?

As outlined Judith and Caroline appear to make sense of their experiences within different discourses (e.g. through grief narratives, neurocultural discourse and individualising norm based psychological perspectives) which influence their interactions and subjectivity. Their narratives also indicate the way they feel others understood and positioned them as reflected through their children (for example the prosecution of Caroline and Judith being advised on ensuring turn taking experiences happen in the home). Overall, they appear to experience themselves as having limited power but being given absolute responsibility. Fighting and battling highlight their positioning as being responsible and also that it is expected that they should accept "expert" advice without challenging it (de Benedictis, 2012; Runswick-Cole & Goodley, 2018). Judith appears to feel like a bad parent indicating a sense of responsibility and questioning her ability as a mother compared to her ability as a teacher (D, 228-230). Here we see Judith's subjectivity as positioned within the narratives of being a parent and of being a teacher presenting her with different views of her ability. These narratives perhaps produce the polyphonic nature of voice the Listening Guide (Gilligan, 2015) is designed to appreciate; the multiplicity of the subject as understood through Lacanian psychoanalytic concepts seems apparent. The influence of the individualising discourse is perhaps evident here; as a mother she feels responsible and this impacts on her sense of her ability, whereas as a teacher she is not focused within a discourse of responsibility increasing the view she has of her ability.

Caroline has a sense of being both visible and obscured. The experience of responsibility and blame indicate the central position she has early in the narrative. In this position she is engaged within a limited way reflecting a sense of being told rather than included in conversation (Gwernan-Jones, et al. 2015). As the discourse around her changes to the medicalised one she begins to reflect feeling an experience of not being wanted and silenced in meetings (Gwernan-Jones et al. 2015) or muted when attempting to access support. With a limited voice within these narratives she appears to experience a lack of agency, however she also reflects some

ability to act when identifying herself as “behind the scenes (.) pushing” (G, 399). Here the complexity of Caroline’s subjectivity seems to be evident.

Positions within which power is experienced are noted within the narratives of both Judith and Caroline. Each reflects a limiting of their power within engagements with practitioners and services consistent within the previous literature (Malacrida, 2001). However, there are also important differences between Caroline and Judith’s sense of power after their children receive a diagnosis. For Caroline diagnosis appears to make little difference to her power, as she is still unable to gain the support she feels is necessary for Lydia. The influence of her voice is not increased by the diagnosis and she is still left in a submissive position when interacting with services such as CAMHS (G, 503-505). However, Judith appears to gain control in conversations when Benjamin is diagnosed, as she is able to refer to it when she feels challenged in her interactions (D, 625-627).

5.4 What do mothers indicate is or would be supportive for them?

A number of elements of the narratives are considered to be supportive and make a difference (e.g. shared experience, peer support, partnership with others and early help). The importance of shared experience resonates within each narrative. Caroline states “just knowing that someone else is there to er (.) that’s gone through similar things” (G, 167-168). It acts as a containing experience. There are further examples of Caroline feeling contained related to when practitioners recognise the difficult experience she is having (G, 432-434). When a practitioner says, “we can’t let you carry on like this” (G, 473-474) Caroline states “so that was a relief to hear” (G, 474) reflecting the importance of having her experience recognised so she is visible to others.

Being able to support other parents is equally a positive experience in both Judith’s and Louise’s stories. Judith indicates she goes “round parents groups now and support them” (D, 798-799). This highlights the importance of peer support. Caroline and Louise say that signposting and sharing are important and that this is something they have experienced more when engaging with peers (G, 162-167; J, 850-852).

Judith discusses times when she has been able to work in partnership with teaching staff (D, 359). Judith notes how she felt able to “go into the classroom” (D, 359) reflecting a sense of being welcomed or included into the school. She also reports that “I could say” (D, 360) denoting a view of having a voice within the situation. Her views appear to be heard giving a feeling of being valued and included. There are developments in relationships when Judith feels like a partner with the class teacher and she feels supported.

Caroline indicates the importance of getting support for her daughter earlier than her experience:

I-I do believe that if she had the support sort of early, early on (...) and (...) er, you know, we had the right doctors and we had the right (...) procedures (...) err she might have been able to carry some (...) because at that point she wasn't at the point where she was saying “I can't, I can't do anything, I can't, I can't”, you know, (G, 151-155)

Caroline makes clear that through earlier intervention she feels that her daughter may not have experienced the degree of difficulty she has which would have influenced Caroline’s experience also.

5.5 What implications are there for the practice of Educational Psychologists when working with parents, young people and practitioners?

It is possible to recognise a powerful discourse around parents who have a child identified through the SEMH category of SEND. It is considered within this research that a neurocultural discourse has a potential benefit to parents in that it can often be seen to challenge a blame narrative associated with a young person’s needs and parental responsibility. However, it is also highlighted that the neurocultural discourse sustains a norm based and individualising psychology that focuses the difficulty within the young person and their relationships with their parents. In essence the neurocultural discourse provides a relief to something which it has helped to create. The medicalised view of SEMH difficulties continues to centre problems in a within child discourse, which narrows the ways in which the problem

is conceptualised and therefore limiting responses. Potentially this narrow conceptualisation produces spaces that parents and young people fall into between education and healthcare practitioners and between services that support SEMH needs themselves. Educational Psychology practice can aim to highlight the complexities of needs through the introduction of a social model of understanding for SEMH through the consultation process. Through this it may be possible to disrupt narratives and move away from within child (and consequently within family) problems to consider how difficulties can be recognised to be manifest within a social relationship. Gwernan-Jones et al. (2015; p.292) note the view of ADHD as an “artefact of the school context”, which could indicate how difficulties are situated within the social environment of a school. Rather than a brain-based problem it reflects a difficulty situated within a specific environment. This would help to challenge the individualisation of difficulties and offer further ways to support young people, families and practitioners. This serves to highlight the importance of the consultation process for EPs. Farrell (2006) argues that positive change can be enacted within the consultation process through a recognition of the multi-faceted nature of difficulties. This research highlights the importance of broadening conversations out through offering alternatives to the individualising medical discourse within. The use of a narrative approach by an EP in consultation (Bleakley, 2005; Launer, 2003) may also enable opportunities for opening up conversations to consider alternative ideas; it could provide new ways of making sense of experiences that can have a creative power when considering interventions. Furthermore this would aid school staff in understanding the roles they can play in supporting young people identified with SEMH needs through both training and intervention planning.

Educational Psychology practice can also aim to illuminate the spaces within which young people and families may fall as a means of continuing to support parents who perhaps feel forgotten or “just thrown out and left on your own” (D, 521-522). It may help to support educational practitioners in recognising the ways in which they can support children and families whilst also working with other services to recognise gaps that can be created between services.

The positive impact of feeling that Judith was able to work in partnership with school appears to be powerful. The Lamb Inquiry (2009) has also indicated the need for open communication, which is felt to be positive and trustworthy in order to build parents' confidence in the practitioners with whom they work. From considering Judith's narrative she highlights that this includes a sense of practitioners being approachable, being heard and having her opinions valued and included. Working with schools, parents and services to understand how to build partnerships could be included in the role of an EP. One potential way to work with services is to examine how language around *criteria* and *crisis* are understood and used. Working together to create understandings between parents, young people, schools and services may aid in limiting the spaces within which families can find themselves.

A key element of this research is to consider how the findings of this research are important for EP practice, but also how Lacanian concepts can be applied to broaden the approach of EPs.

As mentioned, the positive change that is possible within consultation (Farrell, 2006) would be an essential place in which to observe the potential utility of the Lacanian based approach I have adopted. From the use of this methodology we are offered a means of recognising possible influences, both from dominant cultural discourse and powerful individual experience that may not be obvious within how an individual speaks. The recognised benefit of the consultation approach to practice (Wagner, 2000; Dinkmeyer, Jon, Michel, 2015) provides the environment for ways of attempting to understand the individual subjectivity of those involved. The application of Lacanian concepts can further open up conversations within which a creative space for intervention might be established and a deeper appreciation of experience can be fostered.

As highlighted in the methodology, and reflected within the analysis of parent narratives, it is possible to see how individuals understand themselves through discourse and therefore how, within this relationship, the subject changes. Judith appears to experience this as a specific challenge to her identity. She makes a comparison between herself as a teacher and herself as a mother which bring her to question her competence ("how come I could control a hall of 400 children in

school(.) but I can't control this wild child I've got at home(...)" – D 188-189). This challenge exists because Judith sees herself as one unified subject rather than being constituted by the discourse within which these statements sit. This means Judith is presented with a contradiction to her sense of competence which is difficult to make sense of; she feels she is both able to cope with the needs of multiple children and yet not her own child. Here the potential could be that Judith is positioned in two ways: to see her son as being more difficult than other children, bringing about the emergence of a deficit model for understanding her son, or as an inadequate mother who is to blame. Lacan highlights how encounters with the discourses of the Other mean that the subject can be constituted differently (Lacan, 2006c). Judith does not have to see this apparent contradiction as either meaning she is inadequate or that there is something different about her son. From the application of Lacanian concepts it is possible to aid a better understanding of multiplicity of identify and that, in this specific case, Judith does not have to feel that she lacks some level of competence due to feeling inadequate as a mother or that her son is a "wild child".

A further benefit of recognising the multiplicity of subject is in considering why conversations may present an individual in contradictory positions within the same narrative. It can offer a means of helping practitioners and parents move away from a sense that there is a lack of consistency, and therefore truthfulness, within conversations. Within my practice I have had many conversations with practitioners and parents who have made comments such as "first they say one thing, then they say another, we just don't know what is going on". Though in some cases there may appear to be a specific reason why a feeling of confusion or mistrust is apparent (e.g. when an action is agreed but then not put in place) there are other times when it is not obvious. These may be occasions when Lacanian theory can aid us in supporting others to move away from a view of confusion or mistrust to have a greater appreciation of how individuals may be positioned in different ways.

From consideration of Lacan's (1977b) notion of the 'point de caption' we are perhaps provided a way for EPs to observe the framing of conversations around specific discourse. As such it is possible to recognise the temporary nature of meanings within conversation as related to the narratives sounding them. For

example the discourse of grief in both Judith and Caroline's stories provide a point de caption within which they find a meaning to their experience. However, particularly for Judith's, it is possible to see a more complex experience that exists in the margins of her words; she describes it as "like grief". Lacanian theory aids us to recognise how meanings may change within the "incessant sliding of the signified under the signifier" (Lacan, 2006c, p. 154) and that it is possible to open up alternative understandings within practice. Furthermore in recognising Lacan's view of the limits of language EPs are well placed to be able to expose the limitations in authoritative description, labels and the psychologisation of individuals and their experiences. This sliding opens up the possibility of moving beyond concrete medical or psychological descriptions and diagnosis that can allow EPs to present different ways of thinking within situations. It can also help EPs to consider the implications of sliding meanings on the experience of parents and young people. Billington (2006a) makes this point in recognising the potential for the relief provided by diagnostic labels to become something else (e.g. social stigma). The descriptions of young people are intimately related to descriptions of parents, as seen in the move between 'mother blame' and 'brain blame', meaning an appreciation of the limits of these descriptions would also open up new possibilities for parents and how they are viewed. As we see in Louise's narrative the different labels that her son receives do not appear to express her experience. The apparent concrete nature of diagnosis leave her feeling a sense of uncertainty which is uncomfortable and worrying. EPs can offer challenges to the concrete "truths" within diagnosis and illuminate the implications of these labels thereby allowing for new possibilities within the descriptions and labels often applied to young people and situations. As we see with Judith, Caroline and Louise (to varying degrees) diagnosis does not bring all that is hoped for and that labels evoke new challenges which they are forced to face.

This research reflects that having a voice and feeling heard provides a powerful experience for participants. However, Judith, Caroline and Louise feel they were often positioned within specific discourse meaning the ways in which they were heard were perhaps limited, impacting upon their subjectivity in specific ways; for example Caroline is heard in a parent trouble maker discourse. This reflects the

importance of considering the discourse within which parents are heard and therefore spoken of. Lacan (2006b, p. 247-248) highlights:

If I call the person to whom I am speaking whatever name I like, I notify him of the subjective function that he must take up in order to reply to me, even if it is to repudiate this function.

Consistent with Lacan's observation, Billington (2006b) reminds us of the importance of how we speak, write, and listen to both those we work with and ourselves. Lacan's theory of the discourse of the Other supports the recognition of the ways in which individuals are framed, positioned and limited and helps us to begin to reflect on those narratives which influence how we understand and speak of those we engage with.

5.6 Reflections

I feel the reflective process I have adopted has been essential in ensuring that I remained visible throughout the research. As detailed previously I am mindful of the position of privilege I occupy as a male researcher. I have attempted to maintain the voices of mothers at the centre of this study whilst accepting the complex nature of subjectivity and how it may be understood within the text. Though sharing interpretations with participants did not further add to the analysis completed, as detailed in the methodology, I did wish to reflect on the process with the parents involved. All three participants wished that their stories could be used to aid other parents in similar situations; this is consistent with the positive experience reflected in how they speak of peer support. They were keen to know how their words would be used to engage with other parents, practitioners and services which I was able to explain. This again reminded me of the importance of taking this research into practice and finding a means by which to disseminate it to others. All of the participants felt that telling their story had been a positive experience, as it had given them an opportunity to reflect on their journey so far. Though they recognised they still had "battles" ahead they had continued to feel as though things were changing for the better. Conducting my research in this way enabled me to consider the

benefit of using narratives to understand experiences and for individuals to recognise themselves in the stories of others. The application of psychoanalytic concepts further offered a means by which to understand the complex nature of narratives, which perhaps may otherwise be treated with suspicion. Apparent inconsistency in stories can be understood not as a reflection of a misrepresented “truth” but rather as one aspect of subjectivity among many.

5.7 Limitations

This research has attempted to consider mother’s subjectivity through an examination of the narratives they speak of themselves. I have aimed to consider individuals psychological experience (the unconscious), and cultural discourses with the application of Lacanian psychoanalytical concepts to understand how these can be seen to interact. The approach has relied on continuing to be reflexive as a means of recognising myself within the research and provide a greater openness to the process attempting to establish the trustworthiness of the study. However, I recognise that it is not possible to fully recognise my own subjectivity as an influencing factor on the research as a whole (Butler, 2005, Doucet & Mauthner, 2008). Though I have attempted to listen to the multiple ways in which participants have spoken of themselves it is possible that I have neglected to attend to difficult elements of mother’s experiences. I feel an example of this can be seen in the interview with Caroline when I did not ask more about her feelings of despair (G, 409-412), this perhaps reflects the limits of being able to listen and hear (Rogers, Casey, Holland, Nakkula & Sheinberg, 1999). Equally while completing the analysis it may be possible that there are elements that I have (and have not) attended to due to the influence of my own emotional response and discourse around me.

The research is firmly situated within the text of the interviews as a means of understanding subjectivity, however this could lead to criticism that I emphasise spoken communication over other forms (Reissman, 2008). Hollway (2009; p. 463-464) argues that other methods can offer ways to move beyond the text “towards a focus on practices and embodied, affective expressions of states of mind and mind

as they are enacted". I feel that though this may be the case it would not be consistent with the approach of this research.

I feel it is also important to return to the tension identified and discussed within my methodology of being a man conducting research with women. I have attempted to continuously reflect upon the position of privilege I hold both as a researcher and a man who is inevitably influenced by patriarchal discourses contained within social discourse during the research process. However, it may be identified as a limitation to this research given my inability to be fully conscious of my influence within this research.

5.8 Further research

This research indicates that though there may be some comparable experience between mothers with a young person identified through a SEMH discourse there are potentially other experiences which are related to specific medicalised conditions. For example, there may be specific experiences that result from an ADHD narrative compared to young people positioned within depression, eating disorder or chronic fatigue narratives. Further research could seek to investigate this possibility. Inclusion criteria for participants in my research is in part based on SEND categories of need as identified in the SEND Code of Practice (2015), which has formalised the SEMH category and that which is contained within it. Given the potential for differences in experience between such conditions as ADHD, anxiety, depression and an eating disorder perhaps future research could consider how parents view and experience the implementation of this document and the grouping of different needs together. Notably absent from my research is the voice of fathers. Though I wished to consider the experience of mothers as a marginalised group future research could consider father experience as they may be influenced by other social discourse and cultural narratives.

I feel further research could consider the use of a narrative approach to consultation for parents who have a child understood through the SEMH category of need. The application of this approach as a means of recognising parent experience within their

interactions with practitioners could perhaps serve to increase parents' sense of voice and agency. Future research would be able to consider this as an intervention to support parents, examining its impact through further interviews with parents.

5.9 Summary

This research attempts to highlight the influence of cultural discourse and individual psychological factors on the experiences of mothers who parent a young person identified as having SEMH needs. It potentially suggests that SEMH needs (e.g. ADHD, depression, anxiety, eating disorders) are understood differently although they are placed together in the SEND Code of Practice (2015). It leads to questions as to how this category has been constructed placing together such medicalised conditions. Within parent narratives it seems possible to argue that dominant cultural discourses (e.g. neurocultural, individualising psychology) influenced their experiences of interacting with practitioners and of themselves. There are perhaps a number of impacts from the adoption of these cultural narratives which include; parents desire to seek diagnosis, perpetuating a view that educational practitioners are unable to support young people with mental health needs and creating a space between practitioners within which families can become stuck. However, mothers felt that there were things that had helped them during difficult times including: peers support, containment of their experiences and being able to work in partnership with those supporting their child. Implications for educational psychology practice are related to introducing alternative ways of understanding needs (e.g. using a social rather than a medical model) within the consultation process leading to further creativity in consideration of intervention. A role that Educational Psychology Services could consider is in offering training to support school practitioners in understanding the important role they play and interventions they can do to support young people with SEMH needs. EPs can help other practitioners (e.g. CAMHS, Social Care) in recognising where gaps may exist between services which families could fall into. EPs can also support the development of systemic practices which enable parents, young people and practitioners to work

together in co-production. This could be working to build a joint understanding of the languages of criteria and crisis which makes sense to families and practitioners.

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Appendices

Appendix A: Invitation to Parents



The
University
Of
Sheffield.

Invitation to Parents/Information sheet for participants:

My name is Scott Johnson and I am a Trainee Educational Psychologist with the University of Sheffield. As part of my course I am looking to complete a piece of research which aims to hear the voices of parents of children described as having social, emotional and mental health needs or behavioural difficulties. This research aims to support a better understanding of the experiences parents have in relation to interactions with practitioners (e.g. teachers in education, or people working in health care or social care). The aim of the research is to hear the rich experiences of parents, consider how these can be interpreted and used to inform those that work with them and their children. As a Trainee Educational Psychologist working in Rotherham Schools I am keen to support parents and schools in order to secure the best outcomes for children and young people. I feel that there is great value in sharing the experience of parents as part of a process to consider ways to foster positive relationships.

I am looking for between 3 and 5 parents to talk about their experiences of being a parent. If you chose to participate you will be included in two interviews which will take place in the Rotherham Parent and Carer Forum premises. The first interview would be an invitation for you to talk in depth about your experiences. This would potentially last for an hour however this would depend on the level of detail you would like to share regarding your experience. A second interview would be to discuss further the best ways to understand your story and how it might be used to support the development of relationships when working with practitioners. Though you are being asked to share your experience you would not be identified in any reporting of the research. The research would be reported as part of the Thesis I am completing for my course or potentially in a peer reviewed journal. Interviews will be digitally recorded so that I am able to respect the ways you describe your experience and not rely on paraphrasing or my memory of what has been said. This recording will be stored on an encrypted laptop and only accessible to myself or my

research supervisor. Once the research is completed and passed the recording will be destroyed; your anonymity will be maintained at all times.

If you chose to take part in the research you have the right to withdraw at any time without giving a reason before an interview. For up to a period of four weeks after an interview has taken place it is also possible to withdraw from the research. This is to ensure that anyone taking part has time to consider whether they would like their experiences to be included in the research after an interview and also to enable me to work with a new parent and complete the research in keeping with my university set deadline. If you chose to withdraw after an interview has taken place any recordings will be destroyed and notes from the interviews returned to you. Your narratives would then not appear in the research.

As this invitation is being offered to a large number of parents it may not be possible to interview everyone who is interested in being involved. Though I would love to speak with as many parents as possible I am unfortunately restricted by the amount of time I have to complete this research. Consequently I will only be able to interview parents on a first come basis. For all those who were interested, but it was not possible to interview, I will be holding an event in Summer 2018 where it will be possible to share this research and invite you to share your reflections to continue to consider how we aid practitioners and parents foster positive relationships.

If you are interested in becoming involved in this research and sharing your stories, or would like to ask further questions, please contact me on the email address below:

Email: sjohnson1@sheffield.ac.uk

Telephone: 07711864740

On the day of the interview it would be necessary to complete a consent form. If at any point you felt uncomfortable with the research, research process or wished to find out more from the University of Sheffield it is possible to contact my supervisor Dr Sahaja Davis on the contact details below:

Dr Sahaja Davis
388 Glossop Rd,
Sheffield,
S10 2JA
Email: t.s.davis@sheffield.ac.uk

Thank you for taking the time to read this invitation.

Best wishes,

Scott Johnson

Appendix B – Consent Form

Consent Form

Title of Research Project: Parent experiences of having a child described as demonstrating “behaviour difficulties” or social, emotional, mental health needs.

Name of Researcher: Scott Johnson

**Participant Identification Number for this project:
box**

Please initial

1. I confirm that I have read and understand the information letter explaining the above research project and I have had the opportunity to ask questions about the project.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline.

Please email sjohnson1@sheffield.ac.uk or message on 07711864740

Scott Johnson if you wish to withdraw from the research after the interview has

been completed (though it is possible to withdraw from the research after the

interview it is necessary to restrict this to within a 4 week period as it would be

necessary to find a further participant)

3. I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.

4. I agree for the data collected from me to be used in future research

5. I agree that the data collected can be anonymously published

6. I agree to take part in the above research project.

Name of Participant
(or legal representative)

Date

Signature

Lead Researcher

Date

Signature

Copies:

Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, the letter/pre-written script/information sheet and any other written information provided to the participants. A copy of the signed and dated consent form should be placed in the project's main record (e.g. a site file), which must be kept in a secure location.

Please note that if at any point you felt uncomfortable with the research, research process or wished to find out more from the University of Sheffield it is possible to contact my supervisor Dr Sahaja Davis on the contact details below:

Dr Sahaja Davis
388 Glossop Rd,
Sheffield,
S10 2JA
Email: t.s.davis@sheffield.ac.uk

Appendix C - Pilot Study and interview Schedule

I was conscious of the sensitive nature of the area I had chosen to research and wished to conduct a pilot study to consider the best way to approach the research that would provide a safe space in which to have potentially difficult conversations. I was aware I would not be able to guarantee that parents in the research would not feel some level of discomfort from telling their stories, however, I sought to consider how I could do this in the most sensitive and caring way. I felt that my experience of working as a trainee Educational Psychologist meant that I had experience of engaging in a supportive way in difficult conversations but wished to practice my approach to the open ended interviews before working with any participants.

I was fortunate to have a member of the Educational Psychology Service (who wished her pseudonym to be Rebecca), in which I have been on placement, who was interested in my research and was also a parent of a young person with additional needs. She agreed to support me in telling her story and help me reflect on the process and the questions I asked. I was mindful that I was asking questions about experiences I had not encountered personally and that therefore I may inadvertently appear insensitive in my questioning or responses. The benefit of working with Rebecca on a pilot study was: she had lots of experience of working with local parents and talking with them about their experiences, had completed doctoral research herself, had an older son with autism and was interested in the psychoanalytic and narrative foundations within which my research was based.

We initially met to talk through the approach and aims of this study. I began by explaining what I was interesting in investigating based around psychoanalytic and narrative concepts. From talking with Rebecca she was able to offer a view as to how to introduce the research to parents. She felt that the interviews should be introduced from a narrative perspective indicating wanting to hear parent's stories. We considered how it might be possible to inform parents of the psychoanalytic foundation at the start of the interviews. Rebecca felt that a number of issues may arise in attempting to explain some of the more complex concepts: that it may be intimidating to parents who appear to be being scrutinised by an "expert" psychologist, that it perhaps gave the impression that I would be looking for parents to say specific things about their unconscious rather than focusing on telling their story in the way they would, that psychoanalysis may be understood by parents in a different way to my use of it in my research given its prevalence in western culture already. I felt these were good points to raise as I had not fully considered them. This influenced how I introduced my research to parents at the start of each interview; I firmly emphasised my desire to hear their stories and that I wasn't looking for anything in particular other than what their experienced had been like having a young person identified with SEMH needs.

Prior to conducting the pilot study I had discussed my interview schedule with my supervisor which I was then also able to consider with Rebecca. Originally I had

composed six interview questions that I left related to findings in the existing literature:

1. Can you tell me about your experiences and feelings of being a parent while your child has been/was in school?
2. Can you tell me about the feelings you have experienced from realising you were going to be a parent (before birth)?
3. Can you tell me about what you expected parenthood to be like?
4. What was it like from the moment of actually becoming a parent?
5. Can you tell me about any feelings of blame since you have been a parent with your child in school?
6. Can you tell me about loss since your child has been in school?

From conversations with Rebecca, my supervisor and considering the theoretical underpinnings of my research I felt that these questions were too structured for the purpose of the study. Though I wished to offer some orientation around which parents could focus their narratives these questions appear to be too leading and impose a meaning frame upon parents rather than giving them space in which to tell their stories. As a consequence I limited my questions to two:

1. Can you tell me your experiences of being a parent of a young person with SEMH needs since they have been in school/nursery/involved in services?
2. Has your experience of being a parent been what you expected?

My questions were focused in this way to offer parents the opportunity to decide what was important to their experience themselves. The previous six questions had clearly highlighted various experiences (e.g. blame, loss) I was interested in learning more about which would have imposed a greater emphasis within the conversations on these elements. I felt this was too leading and may not allow parents the opportunity to tell their stories as they wanted to. Rebecca and I felt that having this limited number of open ended questions was both more freeing for participants and consistent with the theoretical principles of my research. Upon reflection I feel that I originally constructed a schedule of six questions as this made me feel more comfortable in conducting the interviews. A consequence of having only two questions was that I was concerned that the interview would be difficult if a participant wasn't particularly confident in chatting. Rebecca and my supervisor suggested that I should consider my interviews in a similar way to conducting consultations in my service; where I would normally follow the direction of the conversation and ask follow questions (e.g. "could you tell me more about...?").

I was able to complete an interview with Rebecca around her experience using the questions we had discussed. Though Rebecca had a detailed knowledge of my research focus and methodology, which may have influenced the direction of conversation inadvertently, we were able to complete an interview giving me experience of what the process would be like. This experience was invaluable as it aided me in considering what prompt questions I may ask when attempting to elicit

further detail. Rebecca and I spent time after the interview reflecting on the process and how it was experienced from both our perspectives. I had felt that the interview had been easier than I had expected from just following the direction of the conversation determined by Rebecca. What I had not anticipated was my emotional response to Rebecca's story during times when she was describing difficult experiences. Rebecca indicated that she felt that the experience had been difficult at points as it involved recalling times when things had not been easy. However she felt that it had been a positive experience to be able to tell her story as it reminded her of how far she had come in her journey. In this sense Rebecca felt that it had been a therapeutic experience to have someone listen closely to her narrative. In discussing how Rebecca had felt being asked questions around her story she thought that I had been inquisitive without being intrusive and that it felt good to be able to decide where to go with her story. We both felt that the limited questions were sufficient enough to begin a conversation about experiences and that the open-ended nature facilitated a narrative response (Rebecca's narrative was presented in a narrative way with a start, a middle and an end).

Rebecca and I discussed the experiences of silence within the interview. I had previously been aware of the importance of silences but experienced them as prompting moments of anxiety within myself. Rebecca reminded me that silences are important and that I should allow them to exist as it may reflect a time when a participant is thinking about their response. My temptation was to view silences as a moment when the interview had stopped and required me to offer some kind of question or prompt. I felt Rebecca's view of silence was important to remember as without allowing silence to exist within the interview I would perhaps have appeared to be imposing more structure on a person's story than perhaps they would wish.

Overall Rebecca highlighted that being part of the interview had been positive and that the open-ended nature of the approach was useful particularly when reassured at the beginning of the interview that it was her story to tell in the way she felt she wanted. Having ownership of her narrative was important to Rebecca as it felt like I wasn't looking for something in particular, rather that I was just interested in what she had to say.

As a consequence of the pilot study and conversations with my supervisor I limited my interview questions to two orientating questions:

1. Can you tell me your experiences of being a parent of a young person with SEMH needs since they have been in school?
2. Has your experience of being a parent been what you expected?

The first question was designed to give a starting point from which each participant was then able to tell their story. The second was to provide a chance to reflect on their experience further.

Appendix D – Judith Transcript

- 1 Scott: Erm So the research is about what parents experiences of having a young
2 person with additional needs around social, emotion or “behaviour” erm
3 while they have been in school erm and it's it's anything that you erm want
4 to talk about or has been part of your experience and how you felt about
5 things er and it is very open, just to get any kind of sense of what your
6 experience has been like
- 7 Judith: Is it the young person just in school or is it just generally?
- 8 Scott: Young person in school, in specific situations, so er but he could be like
9 when you erm I don't know if you've had cause to err interact with
10 practitioners
- 11 Judith: Yeah we have
- 12 Scott: Well feel fre[e
- 13 Judith: [Okay
- 14 Scott: Anything that kinda comes to mind(.) erm I have very limited question[s And
15 I'm just going
- 16 Judith: [Okay that's fine yeah
- 17 Scott: to try and follow erm your lead
- 18 Judith: Okay but direct me if you need to [I am quite happy to follow

19 Scott: [Will do erm I might just come back to you
20 and ask you a few little [questions around some of the other things to see if
21 we can get more and more

22 Judith: [Yeah

23 Scott: detail so if I scribble things down it is because I am just trying to make a note
24 of [what was

25 Judith: ((Laughing)) [it's okay, I know

26 Scott ((Laughing)) erm and I am no expert in this [so I will just...

27 Judith: [I'm doing counselling studies at
28 the minute so it's just its quite similar stuff ((Laughing))

29 Scott: Well you will know better than me

30 Judith: Yeah ((Laughing))

31 Scott: So erm my main question is is can you tell me a little bit about your
32 experience of having a young person with additional needs while they have
33 been in school(.) through any periods

34 Judith: Okay well erm introduction, Benjamin is just 11 years old er he was
35 diagnosed with autism, ADHD(.), dyspraxia, Dyslexia and he has also got
36 bowel issues. Erm I knew from a young(.) Youngish age(.) He was a lively
37 child(.) I think that is the way I put it politely. I try to be very positive
38 towards him, it w-but it's what makes him him erm the fact that I gave birth
39 to him on the hospital floor probably(.) told me what I was getting, two

40 pushes and my husband caught him like a rugby ball on the hospital floor so
41 we knew we were in for it at that point ((laughing)) that should have been a
42 [forewarning erm

43

44 Scott [Eventful

45

46 Judith: he was very Active from a young age, I'm talking 4 months so he's
47 Caterpillaring, which is quite a young age for a baby to be moving and I
48 remember doing baby massage and I was trying to catch him across the
49 blanket ((Laughing)). Erm(.) problems began first arising when he was about-
50 he was a wilful two-year-old(.) but I just put it down to terrible twos and just
51 being quite a wilful child and my daughter is quite headstrong as well
52 whose 16 months older so you get on with it(.). Erm my previous
53 experience, I've been a primary teacher as well, so I am quite used to(.)
54 development stages(.). At nursery when he was about two and a half/three
55 he started being quite disrupted in his behaviour, jumping around leaping
56 on people's backs(.) erm, very inappropriate behaviour, I mean he was
57 pulled back at the private nursery about it(.) and we work together closely
58 with them by the time he got to about three and a half to four(.) he was
59 exhibiting some violent behaviour erm three-year-old behaviour but he kick-
60 he kicked the nursery leader in the er shins, I remember being absolutely
61 devastated about it(.) erm and then he was (sigh)(.) I can't remember
62 exactly what was said but he wasn't on track and they realised that to stop

63 him being as they labelled “naughty”, fortunately when they moved him to
64 the top room there was a man in there who was quite experienced, Martin,
65 and he seemed to relate better to erm men than he did women at that time.
66 So Martin took him under his wing(.) and kept him busy the entire time he
67 was in nursery, which seem to sort the problem out(.) as soon as Benjamin
68 came off task(.) he was back onto another task and if Martin had to go
69 anywhere he used to take Benjamin with him(.) And he used him as a study
70 and at that point that er the nursery, the lady who owned the nursery
71 whose doing her degree in child care was observing him and she said “he
72 has got no sense of fear at all” and there was one incident which(.) at the
73 time I didn't realise but now knowing ADHD it all fits in(.) But erm things like
74 he'd thrown a ball over the fence and he's so high, and fence is so high
75 ((raising hand)) in a secure setting so he went and got a plank off something
76 else and put it up against the fence and got his friend to hold it while he
77 walked up it(.) And it was that sort of problem solving(.) and he's a bright
78 lad(.) erm and he will-you can see how he will work through it and it was
79 interesting to look at this study(.) to see how he uses-uses problem-solving
80 skills to get what he wanted(.) but as I say no sense of danger whatsoever(2)
81 and that continued for quite a few years, no sense of danger, I daren't leave
82 him anywhere(.) err even in a playground if he climbed up a climbing frame I
83 had to be under it because he'd suddenly shout "mum I'm jumping" and he
84 will just jump(.) and there was no-I remember I've never sprinted so fast
85 across a playground and my husband at the other side(.) and he had jumped
86 off the-you know the great big pointy things, he jumped off one and how he

87 didn't hurt himself or us I don't know(.) erm so it was-I was always quite
88 anxious(.) And I-I don't know, I found him very, very difficult to deal with(.).
89 Erm he didn't talk until he was two years old(.) not even a word, he would
90 just go ((imitating grunting sounds)) and that was it(.) when my daughter
91 was quite fluent but I knew again at the time I wasn't worried_because girls
92 err are generally more advanced in-in their talking and she was probably
93 talking before him(.) and then one morning it was two days after his second-
94 no two days before his second birthday he walked in our bedroom and he
95 just said erm "I want my breakfast ",(.) and I remember me and my husband
96 just looking at each other, "is that sure Emily or Benjamin" and it it was in a
97 clear sentence "I want my breakfast"(.). "Benjamin" I said "pardon" he said
98 "I want my breakfast ", "okay I will get you some breakfast, do you want
99 Weetabix?" ((Imitating Benjamin's response to question))(2) And I
100 remember (.) and it was just-so he had obviously been taking it in(.) he just
101 hadn't chosen to speak at that point(.) and his behaviour was just ((sigh))
102 very wilful very challenging(.). We couldn't(.), we used to have difficulty
103 getting him in the car but at that point it was what's(.) a normal two year
104 old's behaviour?(.) And trying to exhibit their own independence(.) and what
105 was what we now know with the diagnosis we have got, so putting him in
106 the car strap, erm car seat was the bane of our life erm en-and the pram we
107 have to physically push him down while the other one clicked it in place and
108 if you were on your own (audible response) ((action hand to the table)) and
109 the battles I had with those prams and once he started crying there was no
110 soothing him(.) And er and I remember we were on holiday er just on the

111 east coast(.) at(.) I think it was Flamborough or Filey and we just drove to
112 erm(.), Oh what is it called, Flamingo Land(.), and it was about an hours
113 drive and he screamed the entire journey(.), and the only time he stop
114 screaming was if I took him out of his car seat(.) But we couldn't do that
115 because we were going to a place erm and by the time we got there me and
116 my husband were nearly rowing so it-it did cause quite a lot of tension
117 between the two of us cos we were like ((exacerbated expression))(3) And
118 then we started at that point being labelled he was "naughty child", you're
119 spoiling him(.)

120 Scott: Who was saying that? Interruption

121 Judith: Our parents

122 Scott: Alright okay

123 Judith: And mum used to look after him because I was a teacher at the po-point
124 and I had dropped to part time to give mum a bit of rest bite erm "he's, he's
125 spoilt that child"(.), and-and he-his behaviour even now(.), when it's change
126 he does come across as a spoiled brat(.) and that bit has changed(.) erm So
127 we got quite a lot of conflict and everyone was telling us "he needs a damn
128 good hiding"(.)

129 Scott: Right wow(.)

130 Judith: Which I understand it's my parent's generation(.) and you got a smack "well
131 it didn't do you any harm"(.), but it wasn't the way that I believed I should
132 bring up children and when I was trying to argue the case(.) that I had been

133 a teacher for 20 year-well not that point but I had been a teacher to 20
134 years and I had never had to raise a hand to anybody to get discipline(.). It-
135 you do it different ways and I'm very much, my philosophy is positive
136 reinforcement(.), and it had worked fantastically with my daughter but
137 nothing seemed to work with Benjamin(.). erm Sticker charts you could give
138 (audible sigh)(.) That is if you could actually stop him quick enough to
139 actually put a sticker on him(.) so we just kept him very, very busy and very
140 active. He went to school and we had(.) n-or was it the week(.) Just before
141 he went to school some of the health problems started(.). He had-he was
142 about four/four and a half he was four in the May and he went to school in
143 the September(.) and he had had constant runny nose so we ended up
144 having his adenoids removed erm just before his fourth birthday, around
145 the same time we'd gone on holiday in August and in the caravan and it
146 rained for two weeks in Cornwall, it was great ((sarcastically)), with a four
147 and a five-year-old in a caravan it was(.) ((facial expression)). So at that
148 point, I had always maintained at that point erm we weren't going to have
149 DS, we had DSs then, and the children weren't going to have electronic toys
150 until they were a bit older cos I believed they should be playing out and(.)
151 But again that's my values(.) and we gave in(.) because there was only so
152 much of Peppa Pig even we could live with ((laughing))

153 Scott: Surprising how transfixed kids are with it

154 Judith: I know, so yeah, but when you do Peppa Pig from 5.30 in the morning(.)

155 (Laughing) and er at the point I didn't realise he had a stigma with his eye,

156 you know when the eye's go in(.) and he had spent three or four days on
157 this new DS(.), playing on it(.) and I looked and his eyes had gone in(.) and of
158 course I blamed that not realising that at the time and the optician put me
159 right she said afterwards actually it were when he went to school and
160 started concentrating(.) and I said "why has it not come before now?", She
161 said "has he ever sat down and (inaudible)" and I said "he's never even sat
162 down as a child(.) so no" and she said "it's probably the first time he's
163 actually sat down and focused on something close up(.) and that's why his
164 eyes have gone". So we were under the hospital for quite a few years for
165 that and still until now(.) we have to have erm six monthly check ups(.) but
166 he seems to have stabilised with his glasses. So that was problem number
167 two out the window(.) and then he started school in September(.) and he
168 seem to erm like the challenge. They had er a-a cloud, different clouds, they
169 had a sun , a cloud, and then a really stormy cloud and it was behaviour
170 policy in school(.) and I am sure Benjamin just thought it was just great to
171 get on the stormy cloud(.) until eventually I had to go in and say "this is not
172 working" (laughing) cos every day it was like he was on the storm cloud(.)
173 and behaviours seem to get very challenging at that point erm his glasses
174 got broken about every 10 days to fortnight, so we had three pairs(.) on a
175 cycle(.), we were on first name basis with the optician at that point, "Hello
176 it's us again". She said "Oh you've have managed 11 days this time"
177 ((laughing))(.). But that was his frustration at that point he found it very
178 difficult to sit on the carpet(.), he wouldn't conform to normal rules in
179 school(.) He(.) was using his hands to push other children(.), erm I don't

180 think he's intentionally violent(.), but he is quite boisterous even now(.). An-
181 And he seemed to spend more time on timeout than he actually did
182 engaged(.) and then he would get in trouble and so erm which now I know
183 with his behaviour need crawl off(.) under a table and refuse to come from
184 under the table(.) erm-or hide his glasses for attention and then see-then
185 start screaming because he had hid his glasses(.) It was-it looks like
186 attention seeking behaviour

187 Scott: Is that what was being said to you?

188 Judith: Yes at the time

189 Scott: Who was saying that?

190 Judith: The class teacher(.) And before I even started the forum I always believed in
191 working closely with teachers anyway, so are used to be in there(.) we set
192 up a reward system(.) erm And I remember that point they said to us, it all
193 fits in now, they said to us about "what does he play with Lego, cars?
194 What's his treat?" and me and my husband together went wires"(3)
195 ((Laughing)), they looked at us with this look of dread and said "what sort of
196 wires?", "any sort of wires(.), USB, scart, headphones, anything, any sort of
197 wires" so they said "okay"(.). So we went round and collected this box of
198 wires and that was his treat(2) er but that leads us back again at home he
199 was obsessed with wires from being a young child and erm (.) used to want
200 to pull the plug. You'd be vacuuming when he was 1-2(.) and he just come
201 an-vacuum would stop suddenly and Benjamin has got the plug in his
202 hand(.). "Put the plug back in Benjamin", and we had to teach him from a

203 very small age to actually turn the switch off(.) before he removed it
204 because we did put the cover over(.) but he recognise that if he got
205 something sharpish he could pull the covers off and pull them out of the
206 plug and we gathered it wasn't going to be more dangerous in doing that
207 then actually teaching him how to use the thing properly(.). So yeah he has
208 had obsessions with the wires from being very, very small, which has been
209 quite challenging in the home(2). So he'd go an half inch extension cables
210 from the cupboard and he would plug something in in his bedroom and then
211 extension cable it around the house. So apart from having extension cables,
212 the fact we'd got them all plugged into each other(.), we had an IKEA lamp,
213 which was like top open Square basin one and I was upstairs(.), I was busy
214 playing er sorting things-er laundry out when the children were in their
215 bedrooms, I am on the landing and the bedroom's there and there(.) and
216 you know you just glance and I thought that light looks funny in that room(.)
217 I went in_to investigate, he'd only filled the lights up with water(.) and it's
218 fortunate I'm a scruff, I don't dust inside the lamp enough and my husband
219 who fortunately knows a lot about electric says "it's actually the dust that
220 has sealed it", so the water didn't get in and electrocute us and blow us all
221 up(.), so it was that sort of safety issue(.) I had to keep on top of safety cos
222 he's got no sense of(.) any danger. Same with the stair gate erm(.) swinging,
223 as it went round, we've got stairs that go around, he'd actually managed to
224 get the gate open and then he'd used the gate to propel himself round the
225 stairs, throw himself almost down the stairs(.), so the gate came off(4). An-
226 And he was going to school with lots of bumps and bruises, and he was qui-

227 and his teachers were questioning me(.) and I was explaining what was
228 happening but I, at that point, felt like a really bad parent, how come I could
229 control a hall of 400 children in school(.) but I can't control this wild child
230 I've got at home(2). Things were getting broken a lot at home which caused
231 a lot of tension(.), er he'd be bouncing balls, you'd hear clinging at
232 something, a light shade's gone or something(.)

233 Scott: Yeah, so it was-you were kind of feeling that erm that-that you weren't a
234 good parent?

235 Judith: Yes definitely(.)

236 Scott Okay and was that erm just from you? Where you just thinking that?(...)

237 Judith: I felt that mainly my husband was just getting annoyed at him(.) but I was
238 being and I don't know if this is from my education background, erm(.) I
239 believe that behaviour is a form of communication (2) But this child he
240 communicated well put it that way (2). And it was-it-he seem to break
241 everything (.) and I know children do (.) but he seemed the one that was
242 causing us a lot of expense. Erm we have got an integral fridge (.) and he
243 found out that if you got his stool-as I say he is a bright little monkey as well,
244 if he had got the stool to the-he was about 2/3, to the toilet, so he could sit
245 on the toilet (.), put in the kitchen he could open the fridge and get his own
246 milk out, which I promote independence(.) but then, and he got two hands
247 and I was encouraging him(.) and he put it back but then he use the step and
248 he realised that if he held onto the door of the fridge he could swing it and
249 as it won't open it stopped and it flung him across into the dining Area (2).

250 So the door fell off the fridge ((laughing))(.). I mean I've got to laugh at it
251 because (2) yeah and I remember shouting at my husband this fridge has
252 broke, Well you must've put too much milk in it, it's designed for that
253 ((mocking arguing)) and we were at loggerheads and we just both watched
254 him do this and that's why the fridge is broken ((laughing))(3)

255 Scott: And so in school were the[y (interrupting)

256 Judith: [He was equally-his behaviour got a lot worse.(2) Er
257 We got the head teacher involved, they put him on erm an IEP at that point,
258 the wires was used as treats, and actually his first teacher(.) didn't handle
259 him too bad(.). It was challenging, it again he had-the danger was the issue
260 outside,(.). Err he couldn't take turns, which I know now is autism but at the
261 time (2) we got accused of, well we got advised (2) children who don't have
262 the experience of taking turns and things in a family situation will find it
263 more challenging at school. (2) Erm I took it on board, but I knew very well
264 I'd played games with him (3). We'd played card games snap and things as
265 family (.) and at that-up to that point we used to go out for dinner quite a
266 bit er at weekends(.) and eat out and while the dinner was waiting to come I
267 knew that if I just let him sat there he'd be running wild, (.) so we used to(.)
268 play card games and things to keep him occupied. So that is when the first
269 battle began (.). Then he went into year One, and the teacher was less
270 experienced (.) and to cut a long story short he spent an entire year under a
271 table and that is not an exaggeration (.), to the point where every night my
272 mum was picking him up and it be like "Benjamin's Nanan can I talk to you

273 please? Oh he has done this and that" and it was very negative (.), and he
274 was constantly in trouble (.) so he began to hate school (3). Getting him
275 there in the morning became an increasing battle(.) which fort-
276 unfortunately my mum took the brunt of it (3). But-and even, and even
277 sometimes I had to dragging up the school pass screaming, (.) which broke
278 my heart, so then eventually I think it was by about Christmas (.), January
279 time I gave my job up because my-my son's, I thought why_am I looking after
280 all these other children, helping them when my own son's needs obviously
281 (.) so I made that decision (2). We identified that registration, and I was very
282 proactive in this, I went in_and said what are the things of the day, I got a
283 home-school diary, which (.) wasn't kept very well (4) And every time I try to
284 instigate_it "you don't know how busy I am" ((Said in and accusing tone
285 aggressive)) (3)

286 Scott: So that kind of response

287 Judith: And it was like actually I do, because at that point I was (2) erm I'd just
288 finished teaching but I was also erm a m-mentor, an advanced mentor for
289 teacher training at Hallam University, (.) so I was used to sitting in
290 classrooms and observe-observing(.) student teachers, (.) and I was used to
291 putting interventions in place and also I did a little bit of PPA so I would
292 work round the whole age range, so I'd got a lot of wide experience (.) of
293 working in the school and with special needs, (.) even though I wouldn't
294 have labelled him at that point. (.) Erm that deteriorated to the point where
295 I used to go in every morning (.) with him, get him into school, (.) and I

296 started teaching the social normatives about saying good morning to people
297 (.), so as we would walk through school they'd say "good morning" and he
298 just blank them (2) So I used to stop him and say "Benjamin, Mrs so-and-so
299 has just said good morning to you, we look at their face, we say good
300 morning" (2). So I was modelling the behaviour and it took a while but we
301 did get there. (.) Erm but I will tell you later on that was held against us (.)
302 when we went through the process, when we went through the erm the
303 diagnosis but later on. Erm (.) so I sort of went through that, I took him out
304 of registration and I used to do one-to-one with him because even by that
305 point his reading and writing was dropping behind. (.) Erm I did a lot of
306 multisensory (.) worked with him (.) and we made no progress whatsoever,
307 (.) even though I'd worked, (.) he wouldn't work at home but he would work
308 in a school environment, (.) and they were still telling me there was nothing
309 wrong (3) And I-I didn't want anything to be wrong (.) but my gut reaction by
310 this point was saying this child has got quite challenging behaviour (.) and
311 are used to get numerous phone calls from school saying he is under the
312 table screaming and no one can get in and out (2). And there used to be
313 three or four members of staff trying to coax him out from under a table(.)

314 Scott: And was that a telephone as if [to say...

315 Judith: [come and sort it (.). And because they knew I
316 had packed up work, so then the phone calls increased tremendously at that
317 point. Erm in between all of this he had been soiling himself with his bowel
318 problems (.), so every time he soiled himself I got a phone call to say come

319 and sort him out (2) So I then put on-I can veil most of the time but I can't
320 always, "well he is going to have to come home, we gonna to have to get
321 something to sort it", so there was a lot of barriers up at that point within
322 school (.) especially this year one teacher, till eventually I went into the
323 headteacher and instigated a meeting (2) and I had been in the classroom
324 enough by that point. (.) And I hated-I-H-I turned into one of those parents I
325 hated as a teacher, (.) but I had to be. Erm I instigated this meeting, (.) I put
326 forward what I'd actually observed, (.) what was working what wasn't in the
327 plan, (.) the headteacher did take it on board, (.) she'd also seen the very
328 charming Benjamin, because he had stood up for school council as year one
329 (2) And he's like that ((facial expression)) because he is very eloquent, (.)
330 erm and cut a long story short the head did put one to one in place for year
331 two, he had a pretty good year two, but Benjamin-but, a very experienced
332 teacher (.) who (.) was more (.) tactile, (.) probably a bit more like my style,
333 (.) she was more a mumsie teacher (2) And she gave-whenever he would
334 start getting wound up, she would've just put her arm around his waist,
335 would say "come here Benjamin let's have a look at this" and she could
336 bring him down but there were things that came out, he used to poo himself
337 a lot, so then we started having to go to the hospital to get that sorted (.)
338 erm he decided to take himself to his own little table, (.) even though she
339 had put him on a table, (.) he wanted to sit on his own, but then the girls,
340 she used to say he had his own harem, cos of the girls ((laughing)) used to
341 take it in turns to sit with Benjamin in a morning to read with him, (.) and
342 she had to put a timetable up on who is going cos there was arguments

343 ((laughing)). And he became the focus of attention with all these girls and
344 still is actually (2), he loves it. But he would walk around the classroom
345 collecting objects and he still does that now (.) and put them on his table
346 and the teacher just would laugh at the end of the day she says there's a big
347 pile of objects she'd have to go and put away ((laughing)) at the end of each
348 day and he-he still does that now at home, (.) which drives me round the
349 bend to be honest(...), "Where is my lipstick", it is probably in Benjamin's
350 bedroom somewhere

351 Scott: So, you had-you had this first teacher, who seem to be alright, the next
352 [teacher

353 Judith: [was
354 awful and I hate to say that about a professional

355 Scott: And this teacher was better

356 Judith: Much better yeah

357 Scott: And what was-what was that experience like?

358 Judith: ((Intake of breath)) I, as a parent, I felt much better because I felt I was able
359 to actually (.) go into the classroom, I could work in partnership with her (.)
360 and I could say to her okay, and it would be almost a signal at the door (2)
361 And she used to go ((beckoning with finger action)) ((laughing)) (3) And she
362 would go ((whispering)) "we have not had a brilliant day ". So (.) it used to
363 be at the door everyday (.) where she used to give me feedback and I would
364 go in_and anything that might disrupt the erm lesson or him he was out of

365 the ordinary (.) erm I used to go in and and support him, so school trips if he
366 had a meltdown, (.) which was quite normal, just anything so they had a like
367 a food festival where parents came in and I supported Benjamin throughout
368 all of that, (.) and I got to know her quite well (.) which was really, really
369 lovely and she was very, very supportive (2) erm She wouldn't-wouldn't
370 mince over things, she'd say he's done ABC and D, and it's like okay what
371 can we do, cos I am a very proactive-what can we do to actually improve
372 this, (.) but she was also realistic in the fact, he couldn't sit on the carpet (.)
373 but when he was walking around the classroom he was taking it in, (.) she
374 says it-it looks like he is not listening, (.) but you ask him what he has got to
375 do and he can tell you, (.) So she actually accept that where when he went
376 into year three, (.) his first target, which made me laugh, was to sit on a
377 chair still, I thought hold on getting him sat on a chair is a good target,
378 sitting on a chair is a-still is another target (2) and she says "well it is not a
379 big target" and I said "maybe not to you and me (2) But to him", so we had a
380 bit of a ((rubbing hands together)) at the beginning of the year ((laughing)),
381 so I turned into a parent from hell ((whispering)), (.) and I said I want to
382 work with you, I want to work with Benjamin, I want to be able to work in
383 partnership, if he has been misbehaving and misbehaving and I'll jump on
384 him (.) and I will make sure he apologises, (.) if it is his autism, or whi-which
385 we didn't know at that point, or ADHD, (.) erm can we work around what is
386 causing the behaviour (2) And we, (.) we got there, (.) she went on a course
387 and he had one-to-one (.) and I think his one-to-one found it quite
388 challenging (2) erm And it was it was small things like ((laughing)), I have got

389 to laugh now he used to come out and he said one day erm "can he not
390 wear"-I got him a very thin waterproof jacket for Summer, and he went "can
391 we not wear this waterproof jacket anymore please Mrs Parker?" and I said
392 "why not?" and she says "you see that bit of stitching there" I said "yeah",
393 he said "apparently that's his magic shield, (.) I said "okay" and he says "he
394 used to press that shield and say "I've got my magic shield on I can't hear
395 you anymore"" (2) And wouldn't do any work because he couldn't hear him
396 (3) So apparently the jacket was banned in school ((laughing)). You have got
397 to laugh haven't you ((laughing))

398 Scott: ((laughing)) It is one way around it

399 Judith: It is. ((laughing)) And he is a stubborn little thing as well (4)

400 Scott: So you said "apparent from hell "and what do you mean by that?

401 Judith: (.) Err well this is my interpretation, when I used to be in teaching, (.) I used
402 to-I have worked in various types of schools and it was more, and this is
403 more me generalising, (.) your more middle class, higher socioeconomic
404 group (.) used to coming and I used to work in Lincolnshire in a small village
405 and it's nice big houses and lovely country school (2) And it was like (.) "why
406 is my so and so-we've gone through all the white reading books why are
407 they not on the pink level", "because of the comprehend-they can read but
408 they don't understand the comprehension that is why I am keeping them on
409 this level". "Well you're wrong, you're stopping my child progressing" (.)
410 and my teaching was challenged all the time in that school, it did me good
411 cos it made me challenge myself, (.) but it like oh gosh they are here again,

412 Mrs so-and-so is coming what's wrong now? What have I done? What have I
413 said? (.) And they had a way of twisting things in that village, (.) it was lovely
414 (.) and so-and it, like and I never ever wanted, and I said at the time I never
415 wanted to be a parent like that, I wanted to work with school, to get the
416 best out of your child (.), and I felt in the early years Benjamin's school (.) I-I
417 wasn't doing that, I was complaining. (.) In the first two years say well-
418 apologising first, (.) but then saying well why haven't you follow these
419 procedures through, (.) two weeks is not long enough (3) erm They'd got a
420 behaviour support in by this point, in school, they had got a learning support
421 in, (.) and I can't remember the exact dates but it was all around year 2/3, (.)
422 his behaviour was becoming more challenging he was spending more time
423 in the heads office, who dealt with him really well, but her husband was also
424 head of behaviour support in the town at the time (.) And he'd actually got a
425 good relationship with the headteacher Benjamin, which was positive, erm
426 so year 3 (.) it-it felt like there were lots of obstacles put in us way (2) And it
427 was his behaviour, cos it was Benjamin's done this, Benjamin's done that, (.)
428 he needs to be sorted out with this (2)

429 Scott: "He [needs to be sorted out]"

430 Judith: [And I remember that and I said "what exactly does he need to be
431 done?" and I started challenging it (.) and a lot of it was implied that it was
432 our parenting skills (2) And all although I know I am not a perfect parent,
433 nobody is I think (.) I am not doing a bad job, (.) and I think I have got a
434 pretty good idea, (.) and I do try to bring children up respectful, (.) we do try

435 to bring them up with decent values and respect for people (2) erm And I
436 remember at the time thinking he should have worked with some of the
437 parents_I have worked with in city school, believe me you'd know what bad
438 parenting is (3) erm But we won't go there (.) So yeah, yes I felt very judged
439 (3) And er Benjamin by that point had been labelled by the other parents as
440 a "naughty boy", (.) so I think we were pushing at that point trying to get, I
441 don't know if-I think they had started the procedures to go through CAMHS
442 (2) When he was in year one, but they were changing over to Harrington
443 Place at the time (.) and it took us three years to get a diagnosis (3) Three
444 years of us battling (.) with school erm (.) and I remember the initial
445 assessment, the lady came out (.) and it was things which I hadn't noticed
446 and I did berate myself for not noticing (.) him flapping, (.) erm He got
447 excited and he was flapping and he was jumping up on his tiptoes, but he's
448 like a Tigger anyway he is constantly bouncing (.) and jumping everywhere,
449 anyway erm and running round 100 miles an hour and sliding down your
450 hall on your knees, (.) he's that type of child, enter a supermarket on his
451 knees ((laughing)). "up!"(instant voice imitating what she would say to him)
452 (2) I do a lot of deep breathing ((laughing))

453 Scott: Good test of patience

454 Judith: But then someone told me about picking your battles and so I started doing
455 that which improve our relationship a bit (.) With Benjamin because it felt
456 like I was constantly on his back (.) and I did not want that type of
457 relationship with him. (.) I'm his parent foremost (.) and I have got to

458 discipline him, (.) but I want to give him love, I want to give him
459 encouragement, (.) And it was turning quite negative so I stopped (.) that
460 and tried to turn it round positively, but I said there must be a reason for all
461 of this, and we were going through CAMHS erm (.) and I think it was in year
462 three that he got his diagnosis, (2) Aaannd I am trying to think what, what
463 was it, oh we went down and I met a wonderful nurse in CAMHS, it was the
464 ADHD nurse, and we were chatting things through, dead down to earth, (.) I
465 mean we still laugh about this now and erm (.) she said at the time, er she
466 said-you had to-you're doing your questionnaire for the different er levels of
467 activity and (.) things and I did it and she phoned me back about two hours
468 later, she says "well it's out of 100", she said "the closer to 100 it is" she says
469 "the more he is on the ADHD". I thought "ADHD, I didn't know you were
470 even looking for that ", (.) she says "well I just picked up on something". So
471 er she says "are you waiting for it? School were 79/100" and-and I said "my
472 goodness that is pretty high" (.) and so she said "yes" and I said "well what
473 was it like at home?" she said "91" ((laughing)) (.) "Okay". She said "I think
474 with that we can clearly see that you have got a diagnosis of ADHD".
475 ((laughing)) (2) But we chose all the time not to erm put him on Ritalin, (.)
476 that was partly me because I had seen a lot of bad experiences in my
477 teaching career, (.) of children zoned out, (.) we'd also researched it quite a
478 lot err, we were worried about the side-effects with the potential heart-I
479 know they've got to, (.) my husband and myself had actually researched it
480 quite a lot, (.) and we did make the decision, and the final one was with-it
481 could cause bowel issues and he'd got enough problems with his tummy

482 already, (.) so we decided to do it through behaviour management (.) which
483 (.) on the whole it has been successful I think it's made our life a bit harder,
484 (.) I definitely know it has made our life harder (.) and now we are looking at
485 the moment where we do need to actually look at maybe putting him on
486 something. (2) But I must admit there's a dilemma there for me with that at
487 the moment (3)

488 Scott: Erm you said "battling with" was that with CAMHS?

489 Judith: Yes, (.) they-they said erm first of all they didn't even acknowledge (.) we'd-
490 we'd seen somebody, I've forgotten is it first contact, first (.) person who
491 comes out, I can't remember the (.) terminology now it's been a long time,
492 (.) the first lady came out (.) then we had an initial meeting and then it went
493 quiet and she said "oh it could be up to 6 months", and I said "it has been a
494 year" (3) So then they eventually admitted, after we had escalated it, my
495 husband took over and went into, (.) and he is a professional negotiator so
496 duck ((laughing)) if he gets involved, (.) erm and it-they admitted they'd lost
497 our papers in the move(.) so then Ryan escalated it and things got back on
498 the ball then (.) and that's when erm we got the diagnosis for ADHD and
499 then they went for the ASD and they did the erm gosh what's the test
500 called (.) not A-ASOS

501 Scott: ADOS?

502 Judith: ADOS that's it. The ADOS test (2) an-I don't know a lot about it but I am
503 assuming one of the social things is in there (.) and she said (.) he actually
504 came very low on the ADOS test and I asked specifically what and she says

505 “well he knows how to socially interact, he says good morning”. I said “no,
506 I’ve taught him that, I have been drilling it into him since he was three years
507 old” (2) which affected the thing. We did have quite a battle in that
508 meeting. I didn't particularly want_him to have a label (2) of autism, (.)
509 however I wanted him to get the correct support if it was autism (2)

510 Scott: How did they respond to you saying “I’ve taught him how to do this from an
511 early age”?

512 Judith: They were actually very good about it they said it makes sense and once
513 they knew about my background, and they knew about my husband's
514 background as well, they actually turn round and said “we can see you are
515 professional people” (3) erm “And we can see the input you’ve had in”. And
516 I was very, and _fortunately I had kept a log of everything I had tried
517 intervention with him (3) erm I said “we've tried these sort of approaches,
518 we’ve done family sharing, we play cards a lot, we try and play g-board
519 games but we don't always succeed” and these sort of things and we’d-and I
520 document_it very carefully and then we got the diagnosis of autism. (.) But
521 then you are just, as every parent says you’re just thrown out and left on
522 your own. (2) It is like you’ve got a diagnosis, you’ve got a piece of paper
523 that says your child has got autism (2) Bye (4)

524 Scott: How did that sort of [feel?

525 Judith: [very isolating and I tell this to parents now (inaudible), I
526 tell parents now you can go through a period of (.) like grief, (2) that you
527 wouldn't want your child (.) to be any different because they are your child

528 but then you grieve for them because they are not normal, (.) and I hate
529 using that word, (.) neuro typical, (.) erm and-and it's an adjustment and it
530 is-I can't-it's hard to explain but (.) it's that difficulty to actually think that
531 my child is not (2) And you start worrying about what's the future for your
532 child. (2) And every-and I think that's-it took me a while to adjust (.) at the
533 time (.) and I think I probably got depressed as well, but it-the depressions
534 sort of linked to me having to give up my job (.) and suddenly from being an
535 independent woman (.) to asking for handouts off my husband, (.) which he
536 didn't begrudge (2) but it was my own (.) self-esteem and change, and I
537 recognise this now I am doing the counselling (2) And it was dealing the
538 changes within me. So I don't know if it was Benjamin's behaviour, CAMHS,
539 (.) the whole process (.) got me quite depress-I got quite depressed (.) and I
540 remember behaviour at school was escalating again cos he'd moved up to a
541 different class and they didn't handle him very well (2) And they'd removed
542 his one-to-one support off him

543 Scott: What's this after he'd got his diagnosis?

544 Judith: Yes. (3) And they said he was becoming too reliant on this one-to-one
545 support, (.) which I could see but he was just going to get general TA support
546 in the room (.) and I knew he needed putting on task more (3) and I didn't
547 feel he wasn't getting that. So then it-I was back to battling again, but I
548 didn't battle with the teacher this time I went straight to the head (.)
549 because the teacher always (.) "he's done this, he's done that, oh he's is
550 done the other". He was constantly in fights at this point (.) with other

551 children in his class (.) so I was getting a lot of hassle of the parents at the
552 gate, () “your Benjamin’s done this, your Benjamin’s kicked so and so”, I'd
553 say “I am really sorry (2) I will deal with it and I will challenge him”, “well
554 you ought to get him sorted”. (4) And he was being labelled the naughty bad
555 kid, (.) which devastate me because he's not a-a bad child, (.) and I am not
556 saying that cos I am his mum (.) but he's a good lad (.) he can be a handful,
557 well he is a handful (2)

558 Scott: So you were getting that experience of parents saying that and you felt like
559 you were battling with [the class teacher

560 Judith: (Interrupting) [school-school and parents, and my own (.) parents also didn't
561 quite understand how to (.) err handle his behaviour. (.) And it was-it
562 must've been about the same time, trying to think 2013 so (2) it was around
563 that time-ish (.) it's put a big strain on our relationship, (.) erm Ryan my
564 husband is also on the spectrum even though he is not diagnosed (.) and he
565 finds it hard to deal with Benjamin’s behaviour, he is getting better (.) but I
566 was the prime caretaker of Benjamin’s behaviour and Ryan’s approach to it
567 (.) was to shout at him (.) because his dad had said “well I shouted at you (.)
568 and (2) sorted you out” (.) and the worst you can do to Benjamin is shout at
569 him because he goes ((performs action)) and then everything is boom in the
570 air. (.) When you-you need to keep a very common approach I was told by
571 my husband I was being too soft on him. (.) So you can imagine that it
572 caused a lot of conflict between-in our relationship, we went to erm
573 marriage counselling (.) and identified the conflict (.) but at that point Ryan

574 was recognising what we were going through with Benjamin was reflect a
575 lot on his behaviour not the challenging things but some of the other autistic
576 (.) behaviour and he was finding that difficult to deal with. So the dynamics
577 in the family were quite interesting at that point (4) but what doesn't kill
578 you makes you stronger. (.) But I was learning as well with Benjamin's
579 behaviour (2) Constantly how to deal with it and I did lots of research, did
580 lots of reading, (.) erm I became involved with the forum, (.) which has been
581 the best thing I have ever done, (2) erm yeah er amazingly supportive
582 people and I remember coming in some mornings and being like that,
583 ((action expression)) our mornings have got easier, but (2) getting him to
584 school-mornings were really stressful point than they are now, even getting
585 him dressed and I've got a perfect routine so one of the things, I had to put
586 his clothes on the floor in a certain place, in a certain way, in a certain pile
587 (2) We'd only got to have certain types of pants, which I'd go and buy to
588 Primark and buy 20 packs of them (2) People look at me gone out, "yeah (2)
589 We like the pants in our house". ((Laughing)) (.) You've just got to laugh
590 about it but unless you have got a child that's on the spectrum or has
591 sensory issues parents don't understand (.) and I do hear "what are you got?
592 Pants?" (inaudible). (2) See-there was quite a discrepancy between myself
593 and my husband on how to deal with challenging behaviour. (2) Erm Sitting
594 down at a table even, having a family meal, (.) which I thought was a good
595 value to have as a family, (.) he is constantly like this ((moving on chair)) on
596 his chair, (.) then he knocked something over, then it would go all over my
597 husband's dinner, my husband can't have anything touching his- (2) Breathe,

598 then he'd get annoyed at Benjamin because he's being clumsy which we
599 now know is his dyspraxia, (.) and he wouldn't sit down, he's constantly
600 getting up and sitting back down ((action)) but the has-been thing at the
601 dinner table, and he managed to wreck four chairs to the point they broke.
602 (3) Yeah, so erm and he used to wreck the dining room chairs cos he was
603 rocking on them constantly like that (.) So we ended up er buying second set
604 of chairs (.) and keeping the-in fact we've got the table in the shed still
605 because it was cheaper to buy a whole set rather than just the chairs. (2) I
606 know, and I-and everyone was complaining that Benjamin's chairs legs, his
607 legs were all spread in different directions, so I actually went and wrote the
608 names on the bottom of each person's chair. (2) So we all have our own
609 chairs with our names underneath it which is really sad I know (2)

610 Scott: ((Laughing)) Does it work?

611 Judith: Yes it does, because if you just-this doesn't feel like my chair, cos I am sure
612 my daughter is on the spectrum as well (2) Even though she's not got a
613 diagnosis but she'll sit on a chair and (2) "This is not my chair this doesn't
614 feel right". It is like living in the Big Bang Theory in our house I can tell you.
615 ((laughing)) (2) Let it go. Erm so that sort of sorted it out and the ADHD bit
616 (3) But there are lots of things erm I'm trying to think (3) What's the
617 challenging? (2) It is change that he finds it very difficult (2) So go on (.)

618 Scott: Have you-have you found it since having the diagnosis things have changed
619 at all, things been better or, do you feel better or anything like that?

620 Judith: Erm It helps knowing that there's a reason (2) that, because at one point I
621 did blame myself, I brought him up wrong (3) I was doing a really bad, I was
622 blaming myself as a bad parent, (.) erm and how come I was feeling so
623 miserable it when I was trying so hard and I was successful at teaching, (.)
624 but yet why was I failing so badly as a parent and that took quite a lot of (.)
625 dealing with myself (.) so I suppose the diagnosis did help with that and it
626 helped also to go to his parents and say look he has got something called
627 autism and ADHD here's some information leaflets read them, (.) Ryan's
628 parents were a bit more reluctant to come around (.) but they've learnt (.)
629 erm and they're a lot more understanding, the fact that he sits there on his
630 tablet and doesn't communicate to them or he comes up to them and just
631 talks to them about a car for 10 minutes (2) and walks away and goes
632 "you've not got biscuits I like". (2) And then fortunately at the same time my
633 sister-in-law er went to be a TA and she works with children with autism, so
634 her understanding (.) increased tremendously as well and I think she's
635 helped (.) put a bit in so actually it has helped a lot them knowing (.) he's got
636 autism and I think Kay also, my sister-in-law, working with them she can
637 recognise the signs in Benjamin and She'll go "Oi! Benjibob get here" (2) erm
638 And auntie Kay is God according to Benjamin so that's okay (.) so yeah it did
639 help and I think it helped with the school to actually say look he's got
640 autism, (.) we've got a label here we know (3) we know what we are dealing
641 with and I could then go away instead of googling challenging behaviour (.) I
642 could google autism and challenging behaviour, (.)and I-I am a firm believer
643 you self educate yourself and I love reading anyway so I was, I want more

644 knowledge ((whisper)) (2) So yeah, yeah that did help a lot but one thing I
645 found difficult was (.) that I can't separate the ADHD and the autism (.) and
646 in my own mind I wanted to (.) but the two merge too much (.) and I can't
647 say that bits autism and that bits ADHD because it-it's Benjamin, (.) does
648 that make sense? (2) And there are elements of his ADHD behaviour (.)
649 Which (3) I don't, it (.) it explains a bit more to me (.) and I think I've become
650 more laid-back (2) And accepting his behaviour a bit more so we were er-it
651 was about two years ago, (.) we had to go to the incontinence service at the
652 Children's Hospital, and we are in the out patients and the lady said, the
653 nurses are fantastic, they are really amazing there with him, (.) but there
654 was-we went in one day and it was a different doctor, in a different room (2)
655 erm And I saw Benjamin's stress levels just go up through the – "Why am I in
656 this room? This room's different, this is not the normal room mum. You're
657 not my doctor, what are you called? Why are you not there? Why are you
658 not my doctor?". (2) And the mum in me is like Benjamin you are being rude
659 (2) And then I thought do I-and I says Benjamin when we talk to a person
660 like that it sounds rude, (.) so she said "No, don't worry". So he said "where
661 do I sit?", so she said "You can sit wherever you want", so he took her
662 literally and sat on the window ledge like a Buddha. (2) This windowsill was
663 this high and he just ran, jumped onto the examination bed, sat on the
664 windowsill, sat with his arms and legs crossed like that, (.) and she-she
665 looked really taken back, and she said-and she says er "Oh". "You said I
666 could sit where I want", and he'd just challenge her like that a lot, so you've
667 got to be very careful with your use of language with him (.) erm and she

668 said "well you are going to hurt yourself" and he said "Well I am not moving.
669 You said I could sit where I wanted, this is where I want to sit". (.) So I
670 intervened and said "Look, I am happy (.) for him to sit up there if you're
671 happy to do the er consultation. (.) If he falls down I will take full
672 responsibility (.) for anything what happens". So she looked a bit
673 uncomfortable. The nurse was killing herself behind me because she knows
674 what he is like. (2) She said "life is never dull with this lad around is it?". It's
675 like no. (.) So we did this interview with him ((laughing)) (2) sat up on (2)
676 ((laughing))

677 Scott: It is where he wanted to be

678 Judith: Yeah and he was quite happy and then as soon as she said "jump down" and
679 I went "NO! ((panicked)), climb down. Can I just tell you something? Can
680 you be a bit more careful with your choice language when you have got a
681 child on the spectrum who takes you literally". (2) So yes it has been things
682 like that. I think at one point I would have got very embarrassed about that
683 (.) now I laugh it off (.) and I just say "autism".

684 Scott: So do you erm just sort of thinking about how far you have kind of come, (3)
685 when, before you were sort of a parent (.) and does it kind of match up to
686 your expectations of what being a parent kind of were? Do you think that it
687 would be different or anything like that?

688 Judith: Erm I suppose it's quite different but this is my own sort of stuff I am
689 carrying I was_brought up on quite a strict background and had quite a
690 dysfunctional family, (.) so I was determined-my parents divorced when I

691 was 10 and it was just nasty. (2) So I was determined erm to get away from
692 that working class background, (2) to educate myself and I had to battle to
693 get through university because my parents went behind me er people like us
694 didn't go to university. (2) And so I was determined that when I got children
695 I was going to bring them up differently. (2) I was going to give them the
696 opportunities that I didn't get, I was going to encourage them however
697 small. I wasn't going to put them down like my dad put me down (.)
698 because my dad has got narcissistic tendencies. (2) Erm So I suppose being a
699 parent was quite different (.) and I have to a certain degree lived up to that.
700 (3) I-I don't always get it right, I know I don't, (.) and I am the first one to
701 hold my hands up (.) but my husband is very good erm (.) he will tell me
702 when I am wrong. (.) We have stopped doing it in front of Benjamin because
703 ((mocking tone)) "daddy says you were wrong", "Yes I know". (2) An-And I'll
704 actually ask to him and say to him (.) "Did I handle that right?". And we
705 worked, since we worked through our own issues (2) and we work through
706 the issues of how we deal with Benjamin, (2) we do do a lot of tag (.) erm
707 which has helped and there's been once or twice I have actually let my
708 husband have Benjamin more, and he realises how challenging, he finds it
709 hard (.) and I think the fact that he just talks at you non-stop, (.) at least
710 Ryan's interested in what he talks to him about, I'm not. He's got an
711 obsession with cars (2) ((spoken at speed)) "Mum did you know that's a
712 Mercedes. That first form of Mercedes was actually first brought into the
713 country in 1979. However they change the spec of that wheel from being a
714 so-and-so inch to a so-and-so inch and they change the component of the

715 alloys. Did you know also that the exhaust changed and now they use so-
716 and-so in the car?", "yeah". "It is a six valve. What's yours? Yours is only a
717 4 valve isn't it mum? (.) 1.4 can you catch it mum?", "No I can't darling",
718 "why not?", "Because I value my licence and our lives" (.) "Oh mum you
719 have caught it, you're brilliant mum", "No, the traffic's caught up to it"
720 ((Laughing)). Which it doesn't sound much but that constant rattling in your
721 ear, and then my daughter gets annoyed and is like "shut up Benjamin! (.)
722 We don't want to know about cars Benjamin", and so he puts his
723 headphones in a lot now when he's in the car and we both go ((sigh of
724 release action)). (.) Mercedes-and you'll be having a conversation, and that's
725 the attention bit, and he'll (.) he'll be talking about something about school
726 and things and will say "Mercedes over there, oh wow that is a so-and-so,
727 that is a-look at that exhaust mum", it's like "Yes, can we go back to this
728 please", "No I want to talk about that exhaust". (2) But I think we have both
729 become more a bit laid-back, and sometimes I'll walk in and I will just say to
730 my husband you need to take over, (.) or he will go "you look shocking", "I
731 feel shocking ", "I'm going upstairs, I'm having five minutes, or half an hour
732 on my own". (2) An-and I hate to say this but we've had to put a bedroom
733 lock on our door (3) erm that if one of us just needs that sanctuary (.)
734 because we-we got there now, we've actually got them to knock on the
735 door, (.) but that has taken 11 years and it is not through want of trying I can
736 tell you. (2) The knock does not open the door Benjamin. (2) But he is very
737 clever as well and he'll, (.) he's always trying to outwit you, (.) so-and he is
738 too smart for his own good to be honest (.) erm so my husband, I says he's

739 on the spectrum, he's high functioning, very high functioning, (.) he's two
740 points below being a genius and so he has told me quite a lot in 20 years
741 ((Laughing)) which (.) Yeah get on with it and-and I think I'm fairly laid-back
742 (.) and he doesn't do sport he doesn't do anything so his ac-ac-activities-he
743 enjoys doing technology (.) so I just let him get on with it and (.) it makes
744 him happy. (2) But everything is so high tech knowledge in our house we
745 can't just have a doorbell, it has got to be a RingGo where I-even from here I
746 can see who comes to the front door (.) and I can talk to them. (.) We've
747 have got sky boxes in four rooms and all of the skyboxes all link to each
748 other via the cabling through the cavity walls so you can watch a-a sky box
749 from the bedroom in any other room. Why? Because you can. (2) We had a
750 phone system in that you needed to press 9 to get an outside line
751 ((laughing)) like an office. You could conference call each other, (.) and
752 that's the sort of environment he's been brought up in (.) erm and Benjamin
753 is very much like that, (.) and him and his dad are gelling more. So the day I
754 moved my desk in my office and erm he was really chuffed because he could
755 plug all of my monitors back in again and plug my speakers in and (.) and set
756 it up, and said "You get better surround sound at this point", and I had to sit
757 in the chair (.) and watch (.) the aeroplane go across the screen, cross two
758 laptop screens, going from right to left and see if the sound went right to
759 left or left to right, to make sure they had put the wires in the right way. (2)
760 Ten minutes of my life I am not going to get back. ((laughing)) So I think I am
761 fairly laid-back ((laughing))

762 Scott: And that kinda-you feel that is different to your childhood experience?

763 Judith: Very, and I think also the more understanding I have got of autism and
764 ADHD (.) the more I can just let things go (.) and the more I (.) find it easier
765 to laugh at the situations (2) (Inaudible) ((laughing)). He tied himself to a
766 lamppost last week with his bike chain. (2) How dare I put the bikes on the
767 erm-I better get off in a minute-how dare I put the bike chains on the bike
768 rack err and not watch him for a few minutes age 11? (.) And he just comes
769 up "mum, mum!" ((shouting)), I was like "what?", "I have tied myself to the
770 lamppost", he was laughing, I says "well get yourself untied", he said "I can't
771 cos I have moved the digits round to the other side of the lamppost and I
772 can't move it back round and I can't see what the numbers are", "Wally". (3)
773 So anyway then he wouldn't let his sister undo it cos then she will know his
774 code (2) so that-you know the fact that we live in the same house (.) and we
775 use the same bike sheds has got nothing to do with it, but anyway that point
776 I said to come here but he'd started panicking by that point cos he couldn't
777 remember his code, so I am going through every code with him whilst this
778 child is at the lamppost screaming. (2) "Hello" people walking past

779 Scott: Thank you so much

780 Judith: Is that the sort of thing

781 Scott: That's brilliant thank you so much for sharing that

782 Judith: It's alright

783 Scott: It's-it's great just to be able to hear people stories and to have them share
784 them. With me I'm ever that if stranger, so yeah

785 Judith: And actually he is an amazing individual to have around, life is never dull in
786 our house, (.) as you can probably imagine

787 Scott: Well yes it sounds very interesting, well thank you for sharing [that
788 Judith: [it's okay, if you
789 need anything else just shout I am quite happy to

790 Scott: Thank you. So what I will do is I am going to take all the er information I get
791 from different people an and transcribe that and look at what I can pull out
792 of it and then come back and have another chat with [you around that

793 Judith: [Yes that's absolutely fine

794 Scott: It will probably be after the summer (.) so it gives me time to be able to have
795 a go at it as well. So then we will just have a chat around whether you think
796 that yeah that is something that you think is reflected in what we've said,
797 because I am interested in (.) what your feelings are around it

798 Judith: It has been interesting in actually because I go round parent groups now and
799 support them. (.) I was listening to the stories of what other parents say and
800 they say to me (.) er "do you find this as well?" And the thing with-we are-
801 find a lot of the husbands are on the spectrum as well, undiagnosed. (.) And
802 the mums especially sit there and say "well how do you handle this? (.) Or
803 how do you handle that?" and that peer-to-peer (.) support I think parents
804 find it useful. I mean I have done a lot of reading there is a fantastic book on
805 asparagus-Living With a Partner With Asperger's, (.) and that is very, very
806 insightful and it actually helped me understand Ryan a bit and helped me

807 understand Benjamin more. (2) But I am a firm believer that if you
808 understand (.) you can actually, you are halfway there to challeng-tackling it
809 and improving it, most times (2)

810 Scott: Just been able to understand it helps

811 Judith: Yeah (.) You see these days where you're coming and I'll be rocking_and I say
812 I'm gonna kill him

813 Scott: Well thank you very much

Appendix E - Listening Guide Stages Description – Judith transcript

Transcription	Comments
<p>Scott: Erm So the research is about what parents experiences of having a young person with additional needs around social, emotion or “behaviour” erm while they have been in school erm and it's it's anything that you erm want to talk about or has been part of your experience and how you felt about things er and it is very open, just to get any kind of sense of what your experience has been like</p> <p>Judith: Is it the young person just in school or is it just generally?</p> <p>Scott: Young person in school, in specific situations, so er but he could be like when you erm I don't know if you've had cause to err interact with practitioners</p> <p>Judith: Yeah we have</p> <p>Scott: Well feel fre[e</p> <p>Judith: [Okay</p> <p>Scott: Anything that kinda comes to mind(.) erm I have very limited question[s And I'm just going</p> <p>Judith: [Okay that's fine yeah</p> <p>Scott: to try and follow erm your lead</p>	<p>I am very quickly trying to put Judith at ease and make her feel relaxed and think of this as like a conversation</p>

<p>Judith: Okay but direct me if you need to [I am quite happy to follow</p> <p>Scott: [Will do erm I might just come back to you and ask you a few little [questions around some of the other things to see if we can get more and more</p>	<p>Things seem to start well. Judith makes me feel relax about the interview</p>
<p>Judith: [Yeah</p> <p>Scott: detail so if I scribble things down it is because I am just trying to make a note of [what was</p> <p>Judith: ((Laughing)) [it's okay, I know</p> <p>Scott ((Laughing)) erm and I am no expert in this [so I will just...</p>	<p>This statement is in part to address the potential power differences between researcher and participants. I am attempting to ensure Judith recognises the equal role we hold within this relationship The equality in our roles</p>
<p>Judith: [I'm doing counselling studies at the minute so it's just its quite similar stuff ((Laughing))</p> <p>Scott: Well you will know better than me</p>	<p>Showing the desire to be seen as equal in the research process</p>
<p>Judith: Yeah ((Laughing))</p> <p>Scott: So erm my main question is is can you tell me a little bit about your experience of having a young person with additional needs while they have been in school(.) through any periods</p>	

Judith: Okay well erm introduction, Benjamin is just 11 years old er he was diagnosed with autism, ADHD(.), dyspraxia, Dyslexia and he has also got bowel issues. Erm I knew from a young(.) Youngish age(.) He was a lively child(.) I think that is the way I put it politely. I try to be very positive towards him, it w-but it's what makes him him erm the fact that I gave birth to him on the hospital floor probably(.) told me what I was getting, two pushes and my husband caught him like a rugby ball on the hospital floor so we knew we were in for it at that point ((laughing)) that should have been a [forewarning] erm

Scott

[Eventful

Judith: he was very Active from a young age, I'm talking 4 months so he's Caterpillaring, which is quite a young age for a baby to be moving and I remember doing baby massage and I was trying to catch him across the blanket ((Laughing)). Erm(.) problems began first

Smokescreen – gaging my response before talking about her emotional experience?

Resilience voice – “I try” denoting the difficulty but aiming for the positive

The sense of difficult again

There is a lot of humour – is this a smokescreen? Difficulties start

arising when he was about-he was a wilful
 two-year-old(.) but I just put it down to
 terrible twos and just being quite a wilful
 child and my daughter is quite headstrong as
 well whose 16 months older so you get on
 with it(.). Erm my previous experience, I've
 been a primary teacher as well, so I am quite
 used to(.) development stages(.). At nursery
 when he was about two and a half/three he
 started being quite disrupted in his
 behaviour, jumping around leaping on
 people's backs(.) erm, very inappropriate
 behaviour, I mean he was pulled back at the
 private nursery about it(.) and we work
 together closely with them by the time he got
 to about three and a half to four(.) he was
 exhibiting some violent behaviour erm three-
 year-old behaviour but he kick-he kicked the
 nursery leader in the er shins, I remember
 being absolutely devastated about it(.) erm
 and then he was (sigh)(.) I can't remember
 exactly what was said but he wasn't on track
 and they realised that to stop him being as

Judith's voice of
 experience – does this
 give authority? Power? Is
 she using this to make
 sure she is heard

The emotional impact –
 must have hard to
 contain

they labelled “naughty”, fortunately when they moved him to the top room there was a man in there who was quite experienced, Martin, and he seemed to relate better to erm men than he did women at that time. So Martin took him under his wing(.) and kept him busy the entire time he was in nursery, which seem to sort the problem out(.) as soon as Benjamin came off task(.) he was back onto another task and if Martin had to go anywhere he used to take Benjamin with him(.) And he used him as a study and at that point that er the nursery, the lady who owned the nursery whose doing her degree in child care was observing him and she said “he has got no sense of fear at all” and there was one incident which(.) at the time I didn't realise but **now knowing ADHD it all fits in**(.) But erm things like he'd thrown a ball over the fence and he's so high, and fence is so high ((raising hand)) in a secure setting so he went and got a plank off something else and put it up against the fence and got his friend

Knowing – it makes sense

to hold it while he walked up it(.) And it was that sort of problem solving(.) and he's a bright lad(.) erm and he will-you can see how he will work through it and it was interesting to look at this study(.) to see how he uses-uses problem-solving skills to get what he wanted(.) but as I say no sense of danger whatsoever(2) and that continued for quite a few years, no sense of danger, I daren't leave him anywhere(.) err even in a playground if he climbed up a climbing frame I had to be under it because he'd suddenly shout "mum I'm jumping" and he will just jump(.) and there was no-I remember I've never sprinted so fast across a playground and my husband at the other side(.) and he had jumped off the-you know the great big pointy things, he jumped off one and how he didn't hurt himself or us I don't know(.) erm so it was-I was always quite anxious(.) And I-I don't know, I found him very, very difficult to deal with(.). Erm he didn't talk until he was two years old(.) not even a word, he would just go

Difficult – causing constant worry about him?

This feels like a powerful statement – an honesty which catches me by surprise. Finding him difficult. There is a sense of not being able to be in control or being powerless

((imitating grunting sounds)) and that was it(.)
when my daughter was quite fluent but I
knew again at the time I wasn't worried
because girls err are generally more advanced
in-in their talking and she was probably
talking before him(.) and then one morning it
was two days after his second-no two days
before his second birthday he walked in our
bedroom and he just said erm "I want my
breakfast ",(.) and I remember me and my
husband just looking at each other, "is that
sure Emily or Benjamin" and it it was in a
clear sentence "I want my breakfast"(.).
"Benjamin" I said "pardon" he said "I want my
breakfast ", "okay I will get you some
breakfast, do you want Weetabix?"
((Imitating Benjamin's response to
question))(2) And I remember (.) and it was
just-so he had obviously been taking it in(.) he
just hadn't chosen to speak at that point(.)
and his behaviour was just ((sigh)) very wilful
very challenging(.). We couldn't(.), we used
to have difficulty getting him in the car but at

that point it was what's(.) a normal two year old's behaviour?(.) And trying to exhibit their own independence(.) and what was what we now know with the diagnosis we have got, so putting him in the car strap, erm car seat was the bane of our life erm en-and the pram we have to physically push him down while the other one clicked it in place and if you were on your own (audible response) ((action hand to the table)) and the battles I had with those prams and once he started crying there was no soothing him(.) And er and I remember we were on holiday er just on the east coast(.) at(.) I think it was Flamborough or Filey and we just drove to erm(.), Oh what is it called, Flamingo Land(.), and it was about an hours drive and he screamed the entire journey(.), and the only time he stop screaming was if I took him out of his car seat(.) But we couldn't do that because we were going to a place erm and by the time we got there me and my husband were nearly rowing so it-it did cause quite a lot of tension between the two of us

Difficulty

The difficult experienced causes conflict in Judith's relationship with her husband

<p>cos we were like ((exacerbated expression))(3) And then we started at that point being labelled he was “naughty child”, you’re spoiling him(.)</p> <p>Scott: Who was saying that? Interruption</p> <p>Judith: Our parents</p> <p>Scott: Alright okay</p> <p>Judith: And mum used to look after him because I was a teacher at the po-point and I had dropped to part time to give mum a bit of rest bite erm “he’s, he’s spoilt that child”(.) and-and he-his behaviour even now(.) when it's change he does come across as a spoiled brat(.) and that bit has changed(.) erm So we got quite a lot of conflict and everyone was telling us “he needs a damn good hiding”(.)</p> <p>Scott: Right wow(.)</p> <p>Judith: Which I understand it's my parent's generation(.) and you got a smack “well it didn't do you any harm”(.) but it wasn't the way that I believed I should bring up children and when I was trying to argue the case(.) that I had been a teacher for 20 year-well not</p>	<p>Blame</p> <p>Professional experience shown in this</p> <p>Blame from parents leads to conflicts</p> <p>Earlier saying I try to stay positive now saying “spoilt brat” – Revision? He does come across as spoilt but that has changed</p> <p>Conflict</p> <p>I found the language here quite strong and thought this must be hard to hear as a parent</p> <p>This again feels like it could reflect blame – is it perceived that parents aren't disciplining? Judith's values around parenting – the ideal parent</p> <p>Judith reflects her wealth of experience perhaps this is to support her credibility – maybe she feels that others have not recognised her experience before</p>
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that point but I had been a teacher to 20 years and I had never had to raise a hand to anybody to get discipline(.). It-you do it different ways and I'm very much, my philosophy is positive reinforcement(.), and it had worked fantastically with my daughter but nothing seemed to work with Benjamin(.). erm Sticker charts you could give (audible sigh)(.) That is if you could actually stop him quick enough to actually put a sticker on him(.) so we just kept him very, very busy and very active. He went to school and we had(.). n-or was it the week(.). Just before he went to school some of the health problems started(.). He had-he was about four/four and a half he was four in the May and he went to school in the September(.). and he had had constant runny nose so we ended up having his adenoids removed erm just before his fourth birthday, around the same time we'd gone on holiday in August and in the caravan and it rained for two weeks in Cornwall, it was great ((sarcastically)), with a

I wondered if this statement also reflects a view of what Judith feels would be my values as a trainee educational psychologist

four and a five-year-old in a caravan it was(.)
((facial expression)). So at that point, I had
always maintained at that point erm we
weren't going to have DS, we had DSs then,
and the children weren't going to have
electronic toys until they were a bit older cos
I believed they should be playing out and(.)
But again that's my values(.) and we gave in(.)
because there was only so much of Peppa Pig
even we could live with ((laughing))

Scott: Surprising how transfixed kids are with it

Judith: I know, so yeah, but when you do Peppa Pig
from 5.30 in the morning(.) (Laughing) and er
at the point I didn't realise he had a stigma
with his eye, you know when the eye's go in(.)
and he had spent three or four days on this
new DS(.), playing on it(.) and I looked and his
eyes had gone in(.) and of course I blamed
that not realising that at the time and the
optician put me right she said afterwards
actually it were when he went to school and
started concentrating(.) and I said "why has it
not come before now?", She said "has he

ever sat down and (inaudible)" and I said
"he's never even sat down as a child(.) so no"
and she said "it's probably the first time he's
actually sat down and focused on something
close up(.) and that's why his eyes have
gone". So we were under the hospital for
quite a few years for that and still until now(.)
we have to have erm six monthly check ups(.)
but he seems to have stabilised with his
glasses. So that was problem number two
out the window(.) and then he started school
in September(.) and he seem to erm like the
challenge. They had er a-a cloud, different
clouds, they had a sun , a cloud, and then a
really stormy cloud and it was behaviour
policy in school(.) and I am sure Benjamin just
thought it was just great to get on the stormy
cloud(.) until eventually I had to go in and say
"this is not working" (laughing) cos every day
it was like he was on the storm cloud(.) and
behaviours seem to get very challenging at
that point erm his glasses got broken about
every 10 days to fortnight, so we had three

Agency

pairs(.) on a cycle(.), we were on first name basis with the optician at that point, "Hello it's us again". She said "Oh you've have managed 11 days this time" ((laughing))(.). But that was his frustration at that point he found it very difficult to sit on the carpet(.), he wouldn't conform to normal rules in school(.) He(.) was using his hands to push other children(.), erm I don't think he's intentionally violent(.), but he is quite boisterous even now(.). An-And he seemed to spend more time on timeout than he actually did engaged(.) and then he would get in trouble and so erm which now I know with his behaviour need crawl off(.) under a table and refuse to come from under the table(.) erm- or hide his glasses for attention and then see- then start screaming because he had hid his glasses(.) It was-it looks like attention seeking behaviour

Being positive

Difficulties around being seen as attention seeking

Scott: Is that what was being said to you?

Judith: Yes at the time

Scott: Who was saying that?

<p>Judith: The class teacher(.) And before I even started the forum I always believed in working closely with teachers anyway, so are used to be in there(.) we set up a reward system(.) erm And I remember that point they said to us, it all fits in now, they said to us about “what does he play with Lego, cars? What’s his treat?” and me and my husband together went wires”(3) ((Laughing)), they looked at us with this look of dread and said "what sort of wires?", "any sort of wires(.), USB, scart, headphones, anything, any sort of wires” so they said “okay”(.). So we went round and collected this box of wires and that was his treat(2) er but that leads us back again at home he was obsessed with wires from being a young child and erm (.) used to want to pull the plug. You'd be vacuuming when he was 1–2(.) and he just come an-vacuum would stop suddenly and Benjamin has got the plug in his hand(.). “Put the plug back in Benjamin”, and we had to teach him from a very small age to actually turn the switch</p>	<p>I think this reflects the influence of the Charter and Genuine Partnerships work</p> <p>Knowing – sense making</p>
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off(.) before he removed it because we did put the cover over(.) but he recognise that if he got something sharpish he could pull the covers off and pull them out of the plug and we gathered it wasn't going to be more dangerous in doing that then actually teaching him how to use the thing properly(.). So yeah he has had obsessions with the wires from being very, very small, which has been quite challenging in the home(2). So he'd go an half inch extension cables from the cupboard and he would plug something in in his bedroom and then extension cable it around the house. So apart from having extension cables, the fact we'd got them all plugged into each other(.), we had an IKEA lamp, which was like top open Square basin one and I was upstairs(.), I was busy playing er sorting things-er laundry out when the children were in their bedrooms, I am on the landing and the bedroom's there and there(.) and you know you just glance and I thought that light looks funny in that room(.) I went in

Signs of difficulties that continue in the home

to investigate, he'd only filled the lights up with water(.) and it's fortunate I'm a scruff, I don't dust inside the lamp enough and my husband who fortunately knows a lot about electric says "it's actually the dust that has sealed it", so the water didn't get in and electrocute us and blow us all up(.), so it was that sort of safety issue(.) I had to keep on top of safety cos he's got no sense of(.) any danger. Same with the stair gate erm(.) swinging, as it went round, we've got stairs that go around, he'd actually managed to get the gate open and then he'd used the gate to propel himself round the stairs, throw himself almost down the stairs(.), so the gate came off(4). An-And he was going to school with lots of bumps and bruises, and he was quiet and his teachers were questioning me(.) and I was explaining what was happening but I, at that point, felt like a really bad parent, how come I could control a hall of 400 children in school(.) but I can't control this wild child I've got at home(2). Things were getting broken a

There are multiple examples of using humour while making a point. It might be being used here to help built the relationship

Perhaps this would be difficult to manage

Blame

Again this feels like a moment of honesty which is difficult to express. However there are no hesitations so does it reflect Judith trying to give me the kind of information she things I want?

Not really being the mum she wants to be – poor parenting narrative

<p>lot at home which caused a lot of tension(.), er he'd be bouncing balls, you'd hear clinging at something, a light shade's gone or something(.)</p> <p>Scott: Yeah, so it was-you were kind of feeling that erm that-that you weren't a good parent?</p> <p>Judith: Yes definitely(.)</p> <p>Scott: Okay and was that erm just from you? Where you just thinking that?(...)</p> <p>Judith: I felt that mainly my husband was just getting annoyed at him(.) but I was being and I don't know if this is from my education background, erm(.) I believe that behaviour is a form of communication (2) But this child he communicated well put it that way (2). And it was-it-he seem to break everything (.) and I know children do (.) but he seemed the one that was causing us a lot of expense. Erm we have got an integral fridge (.) and he found out that if you got his stool-as I say he is a bright little monkey as well, if he had got the stool to the-he was about 2/3, to the toilet, so he could sit on the toilet (.), put in the</p>	<p>Competent professional but not feeling like a good mother? Conflicts</p> <p>Judith views this question in a slightly different way to that which I think I intended. I am pleased that she imposed a meaning on it different to my own</p>
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kitchen he could open the fridge and get his own milk out, which I promote independence(.) but then, and he got two hands and I was encouraging him(.) and he put it back but then he use the step and he realised that if he held onto the door of the fridge he could swing it and as it won't open it stopped and it flung him across into the dining Area (2). So the door fell off the fridge ((laughing)). I mean I've got to laugh at it because (2) yeah and I remember shouting at my husband this fridge has broke, Well you must've put too much milk in it, it's designed for that ((mocking arguing)) and we were at loggerheads and we just both watched him do this and that's why the fridge is broken ((laughing))(3)

Scott: And so in school were the[y (interrupting)

Judith: [He was equally-his behaviour got a lot worse.(2) Er We got the head teacher involved, they put him on erm an IEP at that point, the wires was used as treats, and actually his first teacher(.) didn't

handle him too bad(.). It was challenging, it again he had-the danger was the issue outside,(.). Err he couldn't take turns, which I know now is autism but at the time (2) we got accused of, well we got advised (2) children who don't have the experience of taking turns and things in a family situation will find it more challenging at school. (2) Erm I took it on board, but I knew very well I'd played games with him (3). We'd played card games snap and things as family (.) and at that-up to that point we used to go out for dinner quite a bit er at weekends(.) and eat out and while the dinner was waiting to come I knew that if I just let him sat there he'd be running wild, (.) so we used to(.) play card games and things to keep him occupied. So that is when the first battle began (.). Then he went into year One, and the teacher was less experienced (.) and to cut a long story short he spent an entire year under a table and that is not an exaggeration (.), to the point where every night my mum was picking him up and

This is a revision – could be a smokescreen. Being accused if difficult to manage – it also reflects a conflict with school, Judith knows this and staff perhaps assume she doesn't. I wonder if school staff view Judith as a “poor parent”

The importance of experience

A silence – cuts the story out

it be like "Benjamin's Nanan can I talk to you please? Oh he has done this and that" and it was very negative (.), and he was constantly in trouble (.) so he began to hate school (3). Getting him there in the morning became an increasing battle(.) which fort-unfortunately my mum took the brunt of it (3). But-and even, and even sometimes I had to dragging up the school pass screaming, (.) which broke my heart, so then eventually I think it was by about Christmas (.), January time I gave my job up because my-my son's, I thought why am I looking after all these other children, helping them when my own son's needs obviously (.) so I made that decision (2). We identified that registration, and I was very proactive in this, I went in and said what are the things of the day, I got a home-school diary, which (.) wasn't kept very well (4) And every time I try to instigate it "you don't know how busy I am" ((Said in and accusing tone aggressive)) (3)

Scott: So that kind of response

The revision – perhaps it is felt that it was fortunate as this must be difficult for Judith to experience. It is followed closely by “broke my heart”

Difficult things Judith had to do

Responsibility - Is guilt at play in this decision?

Agency

Agency

The tone here possibly reflect the aggression of battle

Judith: And it was like actually I do, because at that point I was (2) erm I'd just finished teaching but I was also erm a m-mentor, an advanced mentor for teacher training at Hallam University, (.) so I was used to sitting in classrooms and observe-observing(.) student teachers, (.) and I was used to putting interventions in place and also I did a little bit of PPA so I would work round the whole age range, so I'd got a lot of wide experience (.) of working in the school and with special needs, (.) even though I wouldn't have labelled him at that point. (.) Erm that deteriorated to the point where I used to go in every morning (.) with him, get him into school, (.) and I started teaching the social normatives about saying good morning to people (.), so as we would walk through school they'd say "good morning" and he just blank them (2) So I used to stop him and say "Benjamin, Mrs so-and-so has just said good morning to you, we look at their face, we say good morning" (2). So I was modelling the behaviour and it took a

Professionalism – I wonder if Judith is conscious of the need to explain to me why she could say she did know how the teacher was feeling

Knowledge

This point is referencing the timeline for assessment and diagnosis but I also wonder if it reflects a level of acceptance of the situation which wasn't always there – the transformation???

Agency – Judith is actively trying to support Benjamin

Agency

while but we did get there. (.) Erm but I will tell you later on that was held against us (.) when we went through the process, when we went through the erm the diagnosis but later on. Erm (.) so I sort of went through that, I took him out of registration and I used to do one-to-one with him because even by that point his reading and writing was dropping behind. (.) Erm I did a lot of multisensory (.) worked with him (.) and we made no progress whatsoever, (.) even though I'd worked, (.) he wouldn't work at home but he would work in a school environment, (.) and they were still telling me there was nothing wrong (3) And I-I didn't want anything to be wrong (.) but my gut reaction by this point was saying this child has got quite challenging behaviour (.) and are used to get numerous phone calls from school saying he is under the table screaming and no one can get in and out (2). And there used to be three or four members of staff trying to coax him out from under a table(.)

Scott: And was that a telephone as if [to say...

Conflict

I think this section gives a lot of detail about the things that mum was doing to be supportive – is it direct my attention to everything she was doing whilst also eluding to what others perhaps weren't doing?

Judith seems frustrated as if she is not being listen to or heard
This is interesting – does it reflect I don't but I do want there to be something???
Demand on Judith to act – it is expected that she will sort things out. Does she have a lack of control because of the demand of school

Judith:

[come and sort it

(.). And because they knew I had packed up work, so then the phone calls increased tremendously at that point. Erm in between all of this he had been soiling himself with his bowel problems (.), so every time he soiled himself I got a phone call to say come and sort him out (2) So I then put on-I can veil most of the time but I can't always, "well he is going to have to come home, we gonna to have to get something to sort it", so there was a lot of barriers up at that point within school (.) especially this year one teacher, till eventually I went into the headteacher and instigated a meeting (2) and I had been in the classroom enough by that point. (.) And I hated-I-H-I turned into one of those parents I hated as a teacher, (.) but I had to be. Erm I instigated this meeting, (.) I put forward what I'd actually observed, (.) what was working what wasn't in the plan, (.) the headteacher did take it on board, (.) she'd also seen the very charming Benjamin, because he had

The demands being placed on Judith

Did she feel she couldn't say what she wanted to? Would see feel judge? Is this a way of silencing her?

Resistance to her involvement and yet she is also expected to sort things out - This feel confusing. Judith's involvement seems both wanted and not

Loss of agency – Judith turns into something she doesn't want to be because she feels she has no choice

<p>stood up for school council as year one (2)</p> <p>And he's like that ((facial expression))</p> <p>because he is very eloquent, (.) erm and cut a long story short the head did put one to one in place for year two, he had a pretty good year two, but Benjamin-but, a very experienced teacher (.) who (.) was more (.) tactile, (.) probably a bit more like my style, (.) she was more a mumsie teacher (2) And she gave-whenver he would start getting wound up, she would've just put her arm around his waist, would say "come here Benjamin let's have a look at this" and she could bring him down but there were things that came out, he used to poo himself a lot, so then we started having to go to the hospital to get that sorted (.) erm he decided to take himself to his own little table, (.) even though she had put him on a table, (.) he wanted to sit on his own, but then the girls, she used to say he had his own harem, cos of the girls ((laughing)) used to take it in turns to sit with Benjamin in a morning to read with him, (.)</p>	<p>I thought this was a different light in which to see Benjamin</p> <p>Positive view of Benjamin</p> <p>Positive association of experience – is there an implicit reference to Judith's own experience?</p> <p>Medical issues form part of the narrative and seem to contribute to the difficult experiences Judith has</p>
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and she had to put a timetable up on who is going cos there was arguments ((laughing)).

And he became the focus of attention with all these girls and still is actually (2), he loves it.

But he would walk around the classroom collecting objects and he still does that now (.) and put them on his table and the teacher just would laugh at the end of the day she says there's a big pile of objects she'd have to go and put away ((laughing)) at the end of each day and he-he still does that now at home, (.) which drives me round the bend to be honest(...), "Where is my lipstick", it is probably in Benjamin's bedroom somewhere

Scott: So, you had-you had this first teacher, who seem to be alright, the next [teacher

Judith:

[was awful and I hate to

say that about a professional

Scott: And this teacher was better

Judith: Much better yeah

Scott: And what was-what was that experience like?

<p>Judith: ((Intake of breath)) I, as a parent, I felt much better because I felt I was able to actually go into the classroom, I could work in partnership with her and I could say to her okay, and it would be almost a signal at the door (2) And she used to go ((beckoning with finger action)) ((laughing)) (3) And she would go ((whispering)) "we have not had a brilliant day ". So (.) it used to be at the door everyday (.) where she used to give me feedback and I would go in and anything that might disrupt the erm lesson or him he was out of the ordinary (.) erm I used to go in and and support him, so school trips if he had a meltdown, (.) which was quite normal, just anything so they had a like a food festival where parents came in and I supported Benjamin throughout all of that, (.) and I got to know her quite well (.) which was really, really lovely and she was very, very supportive (2) erm She wouldn't-wouldn't mince over things, she'd say he's done ABC and D, and it's like okay what can we do, cos I</p>	<p>Agency</p> <p>Perhaps the influence of working in with the Parent forum on the Charter – Partnership seems important</p> <p>Working together – partnership</p> <p>The voice of agency</p>
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am a very proactive-what can we do to actually improve this, (.) but she was also realistic in the fact, he couldn't sit on the carpet (.) but when he was walking around the classroom he was taking it in, (.) she says it-it looks like he is not listening, (.) but you ask him what he has got to do and he can tell you, (.) So she actually accept that where when he went into year three, (.) his first target, which made me laugh, was to sit on a chair still, I thought hold on getting him sat on a chair is a good target, sitting on a chair is a still is another target (2) and she says "well it is not a big target" and I said "maybe not to you and me (2) But to him", so we had a bit of a ((rubbing hands together)) at the beginning of the year ((laughing)), so I turned into a parent from hell ((whispering)), (.) and I said I want to work with you, I want to work with Benjamin, I want to be able to work in partnership, if he has been misbehaving and misbehaving and I'll jump on him (.) and I will make sure he apologises, (.) if it is his autism,

Not being heard?

A silence – the conflict is not spoken of directly
 Parent from hell
 narrative: A negative view of herself – does she feel forced into this? Lack of control over the situation
 GP/Charter reference – partnership repeated

This statement appears to reflect a disconnect

or whi-which we didn't know at that point, or

ADHD, (.) erm can we work around what is

causing the behaviour (2) And we, (.) we got

there, (.) she went on a course and he had

one-to-one (.) and I think his one-to-one

found it quite challenging (2) erm And it was

it was small things like ((laughing)), I have got

to laugh now he used to come out and he

said one day erm "can he not wear"-I got him

a very thin waterproof jacket for Summer,

and he went "can we not wear this

waterproof jacket anymore please Mrs

Parker?" and I said "why not?" and she says

"you see that bit of stitching there" I said

"yeah", he said "apparently that's his magic

shield, (.) I said "okay" and he says "he used

to press that shield and say "I've got my

magic shield on I can't hear you anymore""

(2) And wouldn't do any work because he

couldn't hear him (3) So apparently the jacket

was banned in school ((laughing)). You have

got to laugh haven't you ((laughing))

Scott: ((laughing)) It is one way around it

within the timeline of the narrative

Judith: It is. ((laughing)) And he is a stubborn little thing as well (4)

Scott: So you said "apparent from hell "and what do you mean by that?

Judith: (.) Err well this is my interpretation, when I used to be in teaching, (.) I used to-I have worked in various types of schools and it was more, and this is more me generalising, (.) your more middle class, higher socioeconomic group (.) used to coming and I used to work in Lincolnshire in a small village and it's nice big houses and lovely country school (2) And it was like (.) "why is my so and so-we've gone through all the white reading books why are they not on the pink level", "because of the comprehend-they can read but they don't understand the comprehension that is why I am keeping them on this level". "Well you're wrong, you're stopping my child progressing" (.) and my teaching was challenged all the time in that school, it did me good cos it made me challenge myself, (.) but it like oh gosh they

The stubbornness Judith refers to here could contribute to her finding things difficult

There is something of a disconnect between the things being said

<p>are here again, Mrs so-and-so is coming</p> <p>what's wrong now? What have I done? What</p> <p>have I said? (.) And they had a way of twisting</p> <p>things in that village, (.) it was lovely (.) and</p> <p>so-and it, like and I never ever wanted, and I</p> <p>said at the time I never wanted to be a parent</p> <p>like that, I wanted to work with school, to get</p> <p>the best out of your child (.), and I felt in the</p> <p>early years Benjamin's school (.) I-I wasn't</p> <p>doing that, I was complaining. (.) In the first</p> <p>two years say well-apologising first, (.) but</p> <p>then saying well why haven't you follow these</p> <p>procedures through, (.) two weeks is not long</p> <p>enough (3) erm They'd got a behaviour</p> <p>support in by this point, in school, they had</p> <p>got a learning support in, (.) and I can't</p> <p>remember the exact dates but it was all</p> <p>around year 2/3, (.) his behaviour was</p> <p>becoming more challenging he was spending</p> <p>more time in the heads office, who dealt with</p> <p>him really well, but her husband was also</p> <p>head of behaviour support in the town at the</p> <p>time (.) And he'd actually got a good</p>	<p>There is a sense of foreboding but this still being said to have been a good experience</p> <p>Smokescreen? Said to imply its opposite</p> <p>Loss of agency – Judith is forced into this position</p> <p>Want to work in partnership can't – leading to conflicts</p> <p>Judith's experience of things being difficult</p>
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<p>relationship with the headteacher Benjamin, which was positive, erm so year 3 (.) it-it felt like there were lots of obstacles put in us way (2) And it was his behaviour, cos it was Benjamin's done this, Benjamin's done that, (.) he needs to be sorted out with this (2)</p> <p>Scott: "He [needs to be sorted out]"</p> <p>Judith: [And I remember that and I said "what exactly does he need to be done?" and I started challenging it (.) and a lot of it was implied that it was our parenting skills (2) And all although I know I am not a perfect parent, nobody is I think (.) I am not doing a bad job, (.) and I think I have got a pretty good idea, (.) and I do try to bring children up respectful, (.) we do try to bring them up with decent values and respect for people (2) erm And I remember at the time thinking he should have worked with some of the parents, I have worked with in city school, believe me you'd know what bad parenting is (3) erm But we won't go there (.) So yeah, yes I felt very judged (3) And er Benjamin by that point had</p>	<p>The benefit of good relationships</p> <p>Blame and the poor parenting narrative?</p> <p>I felt that there was a menacing undertone to this statement – It reflect the difficulty and blame Judith experiences A clear sense of agency here – a resilience coming through Poor parenting narrative?</p> <p>Is this a smokescreen – this feels like a very quick move to a better time</p>
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<p>been labelled by the other parents as a “naughty boy”, (.) so I think we were pushing at that point trying to get, I don’t know if-I think they had started the procedures to go through CAMHS (2) When he was in year one, but they were changing over to Harrington Place at the time (.) and it took us three years to get a diagnosis (3) Three years of us battling (.) with school erm (.) and I remember the initial assessment, the lady came out (.) and it was things which I hadn't noticed and I did berate myself for not noticing (.) him flapping, (.) erm He got excited and he was flapping and he was jumping up on his tiptoes, but he’s like a Tigger anyway he is constantly bouncing (.) and jumping everywhere, anyway erm and running round 100 miles an hour and sliding down your hall on your knees, (.) he's that type of child, enter a supermarket on his knees ((laughing)). "up!"(instant voice imitating what she would say to him) (2) I do a lot of deep breathing ((laughing))</p>	<p>Naughty child – linked to parenting?</p> <p>There are difficult conflicts that Judith has faced</p> <p>Blame – Does Judith also feel like she has missed something because the blame narrative convinces her she is cause?</p>
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Scott: Good test of patience

Judith: But then someone told me about picking your battles and so I started doing that which improve our relationship a bit (.). With Benjamin because it felt like I was constantly on his back (.). and I did not want that type of relationship with him. (.). I'm his parent foremost (.). and I have got to discipline him, (.). but I want to give him love, I want to give him encouragement, (.). And it was turning quite negative so I stopped (.). that and tried to turn it round positively, but I said there must be a reason for all of this, and we were going through CAMHS erm (.). and I think it was in year three that he got his diagnosis, (2) Aaand I am trying to think what, what was it, oh we went down and I met a wonderful nurse in CAMHS, it was the ADHD nurse, and we were chatting things through, dead down to earth, (.). I mean we still laugh about this now and erm (.). she said at the time, er she said-you had to-you're doing your questionnaire for the different er levels of

Feels like Judith has a longing to have a different relationship and be a loving and idealised parent

Does this mean any reason or a reason which does not blame Judith?
There is an appeal to need to make sense of things related to a medical diagnosis

activity and (.) things and I did it and she phoned me back about two hours later, she says "well it's out of 100", she said "the closer to 100 it is" she says "the more he is on the ADHD". I thought "ADHD, I didn't know you were even looking for that ", (.) she says "well I just picked up on something". So er she says "are you waiting for it? School were 79/100" and-and I said "my goodness that is pretty high" (.) and so she said "yes" and I said "well what was it like at home?" she said "91" ((laughing)) (.) "Okay". She said "I think with that we can clearly see that you have got a diagnosis of ADHD". ((laughing)) (2) But we chose all the time not to erm put him on Ritalin, (.) that was partly me because I had seen a lot of bad experiences in my teaching career, (.) of children zoned out, (.) we'd also researched it quite a lot err, we were worried about the side-effects with the potential heart-I know they've got to, (.) my husband and myself had actually researched it quite a lot, (.) and we did make the decision, and the

Dilemmas – difficult choices

final one was with-it could cause bowel issues and he'd got enough problems with his tummy already, (.) so we decided to do it through behaviour management (.) which (.) on the whole it has been successful I think it's made our life a bit harder, (.) I definitely know it has made our life harder (.) and now we are looking at the moment where we do need to actually look at maybe putting him on something. (2) But I must admit there's a dilemma there for me with that at the moment (3)

Dilemma – difficult choices

Scott: Erm you said "battling with" was that with CAMHS?

Judith: Yes, (.) they-they said erm first of all they didn't even acknowledge (.) we'd-we'd seen somebody, I've forgotten is it first contact, first (.) person who comes out, I can't remember the (.) terminology now it's been a long time, (.) the first lady came out (.) then we had an initial meeting and then it went quiet and she said "oh it could be up to 6 months", and I said "it has been a year" (3) So

<p>then they eventually admitted, after we had escalated it, my husband took over and went into, (.) and he is a professional negotiator so duck ((laughing)) if he gets involved, (.) erm and it-they admitted they'd lost our papers in the move(.) so then Ryan escalated it and things got back on the ball then (.) and that's when erm we got the diagnosis for ADHD and then they went for the ASD and they did the erm gosh what's the test called (.) not A-ASOS</p> <p>Scott: ADOS?</p> <p>Judith: ADOS that's it. The ADOS test (2) an-I don't know a lot about it but I am assuming one of the social things is in there (.) and she said (.) he actually came very low on the ADOS test and I asked specifically what and she says "well he knows how to socially interact, he says good morning". I said "no, I've taught him that, I have been drilling it into him since he was three years old" (2) which affected the thing. We did have quite a battle in that meeting. I didn't particularly want him to</p>	<p>The power in professionalism</p> <p>Judith presents the need to fight to get things done and implies that it works. It is interesting how things happen when it is perceived that the parent is a professional</p> <p>Judith is making herself heard and fighting – signs of resilience?</p> <p>Battle</p>
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have a label (2) of autism, (.) however I wanted him to get the correct support if it was autism (2)

Scott: How did they respond to you saying “I’ve taught him how to do this from an early age”?

Judith: They were actually very good about it they

said it makes sense and once they knew about my background, and they knew about my husband's background as well, they actually turn round and said “we can see you are professional people” (3) erm “And we can see the input you’ve had in”. And I was very, and I-fortunately I had kept a log of everything I had tried intervention with him (3) erm I said “we've tried these sort of approaches, we’ve done family sharing, we play cards a lot, we try and play g-board games but we don't always succeed” and these sort of things and we’d-and I document it very carefully and then we got the diagnosis of autism. (.) But then you are just, as every parent says you’re just thrown out and left on your own. (2) It is like you’ve got a diagnosis,

There is a sense of wanting and not wanting – ambivalence?

Professionalism - I am struck by the power relations within this statement. It reflect the notion of professionalism as denoting trustworthiness and recognition. I wonder if perception of profession also influence interview – am I seen as a professional similar to others Judith has interacted with?

The timing of this is really interesting – identification of the professional status of Judith and Ryan in the middle of a “battle” results in a diagnosis being given

<p>you've got a piece of paper that says your child has got autism (2) Bye (4)</p> <p>Scott: How did that sort of [feel?</p> <p>Judith: [very isolating and I tell this to parents now (inaudible), I tell parents now you can go through a period of (.) like grief, (2) that you wouldn't want your child (.) to be any different because they are your child but then you grieve for them because they are not normal, (.) and I hate using that word, (.) neuro typical, (.) erm and-and it's an adjustment and it is-I can't-it's hard to explain but (.) it's that difficulty to actually think that my child is not (2) And you start worrying about what's the future for your child. (2) And every-and I think that's-it took me a while to adjust (.) at the time (.) and I think I probably got depressed as well, but it-the depressions sort of linked to me having to give up my job (.) and suddenly from being an independent woman (.) to asking for handouts off my husband, (.) which he didn't begrudge (2) but it was my own (.) self-</p>	<p>Abandonment</p> <p>Grief and loss</p> <p>"like grief" – almost indicate there is something more, something unsayable? There is a strong reaction here. I feel like there is a wanting and not wanting</p> <p>Perhaps narratives or normal are felt as judgemental and difficult to sit with</p> <p>Loss of agency – lack of control</p> <p>A big change – loss of independence – I wonder how this affected Judith's sense of herself as having agency</p> <p>Challenges to Judith's sense of self – who does</p>
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<p>esteem and change, and I recognise this now I am doing the counselling (2) And it was dealing the changes within me. So I don't know if it was Benjamin's behaviour, CAMHS, (.) the whole process (.) got me quite depressed I got quite depressed (.) and I remember behaviour at school was escalating again cos he'd moved up to a different class and they didn't handle him very well (2) And they'd removed his one-to-one support off him</p>	<p>she see herself to be throughout this narrative?</p> <p>Judith's sense of self</p>
<p>Scott: What's this after he'd got his diagnosis?</p> <p>Judith: Yes. (3) And they said he was becoming too reliant on this one-to-one support, (.) which I could see but he was just going to get general TA support in the room (.) and I knew he needed putting on task more (3) and I didn't feel he wasn't getting that. So then it-I was back to battling again, but I didn't battle with the teacher this time I went straight to the head (.) because the teacher always (.) "he's done this, he's done that, oh he's is done the other". He was constantly in fights at this point (.) with other children in his class (.) so I</p>	<p>Judith's experience and knowledge</p> <p>Not being listened to</p>

<p>was getting a lot of hassle of the parents at the gate, () “your Benjamin’s done this, your Benjamin’s kicked so and so”, I’d say “I am really sorry (2) I will deal with it and I will challenge him”, “well you ought to get him sorted”. (4) And he was being labelled the naughty bad kid, (.) which devastate me because he's not a-a bad child, (.) and I am not saying that cos I am his mum (.) but he's a good lad (.) he can be a handful, well he is a handful (2)</p> <p>Scott: So you were getting that experience of parents saying that and you felt like you were battling with [the class teacher</p> <p>Judith: (Interrupting) [school-school and parents, and my own (.) parents also didn't quite understand how to (.) err handle his behaviour. (.) And it was-it must've been about the same time, trying to think 2013 so (2) it was around that time-ish (.) it's put a big strain on our relationship, (.) erm Ryan my husband is also on the spectrum even though he is not diagnosed (.) and he finds it hard to</p>	<p>Blame</p> <p>Blame</p> <p>Bad kid – related to poor parenting? The difficult experience seems clear her with Judith applying to a truth beyond her judgement as a way of supporting herself at this time. It reflect how difficult the experience has been Good kid who is a handful – does “handful” obscure Judith’s feelings?</p>
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deal with Benjamin's behaviour, he is getting better (.) but I was the prime caretaker of Benjamin's behaviour and Ryan's approach to it (.) was to shout at him (.) because his dad had said "well I shouted at you (.) and (2) sorted you out" (.) and the worst you can do to Benjamin is shout at him because he goes ((performs action)) and then everything is boom in the air. (.) When you-you need to keep a very common approach I was told by my husband I was being too soft on him. (.) So you can imagine that it caused a lot of conflict between-in our relationship, we went to erm marriage counselling (.) and identified the conflict (.) but at that point Ryan was recognising what we were going through with Benjamin was reflect a lot on his behaviour not the challenging things but some of the other autistic (.) behaviour and he was finding that difficult to deal with. So the dynamics in the family were quite interesting at that point (4) but what doesn't kill you makes you stronger. (.) But I was learning as well with

Blame and conflict

Revision? Judith description of going to marriage counselling might suggest that things were more than "interesting" Smokescreen: this feels like a redirection away from the memory of these difficult experiences

Benjamin's behaviour (2) Constantly how to deal with it and I did lots of research, did lots of reading, (.) erm I became involved with the forum, (.) which has been the best thing I have ever done, (2) erm yeah er amazingly supportive people and I remember coming in some mornings and being like that, ((action expression)) our mornings have got easier, but (2) getting him to school-mornings were really stressful point than they are now, even getting him dressed and I've got a perfect routine so one of the things, I had to put his clothes on the floor in a certain place, in a certain way, in a certain pile (2) We'd only got to have certain types of pants, which I'd go and buy to Primark and buy 20 packs of them (2) People look at me gone out, "yeah (2) We like the pants in our house". ((Laughing)) (.) You've just got to laugh about it but unless you have got a child that's on the spectrum or has sensory issues parents don't understand (.) and I do hear "what are you got? Pants?" (inaudible). (2) See-there was quite a

I wonder if Judith things I won't understand what she is saying because I don't have a child on the spectrum. Equally I reflect on my own ability to really recognise the experience that Judith is sharing with me – I haven't experienced anything like this so wonder if this will influence my analysis

discrepancy between myself and my husband on how to deal with challenging behaviour.

(2) Erm Sitting down at a table even, having a family meal, (.) which **I thought** was a good value to have as a family, (.) he is constantly like this ((moving on chair)) on his chair, (.) then he knocked something over, then it would go all over my husband's dinner, my husband can't have anything touching his- (2) Breathe, then he'd get annoyed at Benjamin because he's being clumsy which we now know is his dyspraxia, (.) and he wouldn't sit down, he's constantly getting up and sitting back down ((action)) but the has-been thing at the dinner table, and he managed to wreck four chairs to the point they broke. (3) Yeah, so erm and he used to wreck the dining room chairs cos he was rocking on them constantly like that (.) So we ended up er buying second set of chairs (.) and keeping the-in fact we've got the table in the shed still because it was cheaper to buy a whole set rather than just the chairs. (2) **I know**, and **I**-and everyone was

complaining that Benjamin's chairs legs, his legs were all spread in different directions, so I actually went and wrote the names on the bottom of each person's chair. (2) So we all have our own chairs with our names underneath it which is really sad I know (2)

Scott: ((Laughing)) Does it work?

Judith: Yes it does, because if you just-this doesn't feel like my chair, cos I am sure my daughter is on the spectrum as well (2) Even though she's not got a diagnosis but she'll sit on a chair and (2) "This is not my chair this doesn't feel right". It is like living in the Big Bang Theory in our house I can tell you. ((laughing)) (2) Let it go. Erm so that sort of sorted it out and the ADHD bit (3) But there are lots of things erm I'm trying to think (3) What's the challenging? (2) It is change that he finds it very difficult (2) So go on (.)

Scott: Have you-have you found it since having the diagnosis things have changed at all, things been better or, do you feel better or anything like that?

I wonder if I felt that this statement was moving away from considering Judith's experience. I seem to interrupt this conversation to bring it back to her experience

Judith: Erm It helps knowing that there's a reason (2)

that, because at one point I did blame myself,

I brought him up wrong (3) I was doing a

really bad, I was blaming myself as a bad

parent, (.) erm and how come I was feeling so

miserable it when I was trying so hard and I

was successful at teaching, (.) but yet why

was I failing so badly as a parent and that

took quite a lot of (.) dealing with myself (.) so

I suppose the diagnosis did help with that and

it helped also to go to his parents and say

look he has got something called autism and

ADHD here's some information leaflets read

them, (.) Ryan's parents were a bit more

reluctant to come around (.) but they've

learnt (.) erm and they're a lot more

understanding, the fact that he sits there on

his tablet and doesn't communicate to them

or he comes up to them and just talks to

them about a car for 10 minutes (2) and

walks away and goes "you've not got biscuits I

like". (2) And then fortunately at the same

time my sister-in-law er went to be a TA and

Blame

This seems so poignant – holding together two different views: successful as a teacher and a bad parent

I wonder if there is a challenge to Judith's identity.

Judith is heard by Ryan's parents at this point

Blame

The label helps with her personal difficulties. She can say the problem is external. Does that help her sense of self at all?

she works with children with autism, so her understanding (.) increased tremendously as well and I think she's helped (.) put a bit in so actually it has helped a lot them knowing (.) he's got autism and I think Kay also, my sister-in-law, working with them she can recognise the signs in Benjamin and She'll go "Oi! Benjibob get here" (2) erm And auntie Kay is God according to Benjamin so that's okay (.) so yeah it did help and I think it helped with the school to actually say look he's got autism, (.) we've got a label here we know (3) we know what we are dealing with and I could then go away instead of googling challenging behaviour (.) I could google autism and challenging behaviour, (.)and I-I am a firm believer you self educate yourself and I love reading anyway so I was, I want more knowledge ((whisper)) (2) So yeah, yeah that did help a lot but one thing I found difficult was (.) that I can't separate the ADHD and the autism (.) and in my own mind I wanted to (.) but the two merge too much (.)

Knowing – sense making
– not blaming

Change for Judith –
developing new
knowledge

Identification of Benjamin
– Benjamin incorporating
autism and ADHD. It
feels as if these labels has
been accepted into the
identity of Benjamin. Is
this the loved son who

and I can't say that bits autism and that bits ADHD because it-it's Benjamin, (.) does that make sense? (2) And there are elements of his ADHD behaviour (.) Which (3) I don't, it (.) it explains a bit more to me (.) and I think I've become more laid-back (2) And accepting his behaviour a bit more so we were er-it was about two years ago, (.) we had to go to the incontinence service at the Children's Hospital, and we are in the out patients and the lady said, the nurses are fantastic, they are really amazing there with him, (.) but there was-we went in one day and it was a different doctor, in a different room (2) erm And I saw Benjamin's stress levels just go up through the – "Why am I in this room? This room's different, this is not the normal room mum. You're not my doctor, what are you called? Why are you not there? Why are you not my doctor?". (2) And the mum in me is like Benjamin you are being rude (2) And then I thought do I-and I says Benjamin when we talk to a person like that it sounds rude, (.) so

was lost found again?
Am I just being romantic
with the story?

Change – Laid back

she said "No, don't worry". So he said "where do I sit?", so she said "You can sit wherever you want", so he took her literally and sat on the window ledge like a Buddha.

(2) This windowsill was this high and he just ran, jumped onto the examination bed, sat on the windowsill, sat with his arms and legs crossed like that, (.) and she-she looked really taken back, and she said-and she says er "Oh". "You said I could sit where I want", and he'd just challenge her like that a lot, so you've got to be very careful with your use of language with him (.) erm and she said "well you are going to hurt yourself" and he said "Well I am not moving. You said I could sit where I wanted, this is where I want to sit".

(.) So I intervened and said "Look, I am happy (.) for him to sit up there if you're happy to do the er consultation. (.) If he falls down I will take full responsibility (.) for anything what happens". So she looked a bit uncomfortable. The nurse was killing herself behind me because she knows what he is like.

(2) She said “life is never dull with this lad around is it?”. It’s like no. (.) So we did this interview with him ((laughing)) (2) sat up on (2) ((laughing))

Scott: It is where he wanted to be

Judith: Yeah and he was quite happy and then as soon as she said “jump down” and I went “NO! ((panicked)), climb down. Can I just tell you something? Can you be a bit more careful with your choice language when you have got a child on the spectrum who takes you literally”. (2) So yes it has been things like that. I think at one point I would have got very embarrassed about that (.) now I laugh it off (.) and I just say “autism”.

Scott: So do you erm just sort of thinking about how far you have kind of come, (3) when, before you were sort of a parent (.) and does it kind of match up to your expectations of what being a parent kind of were? Do you think that it would be different or anything like that?

Judith: Erm I suppose it's quite different but this is my own sort of stuff I am carrying I was brought up on quite a strict background and had quite a dysfunctional family, (.) so I was determined-my parents divorced when I was 10 and it was just nasty. (2) So I was determined erm to get away from that working class background, (2) to educate myself and I had to battle to get through university because my parents went behind me er people like us didn't go to university. (2) And so I was determined that when I got children I was going to bring them up differently. (2) I was going to give them the opportunities that I didn't get, I was going to encourage them however small. I wasn't going to put them down like my dad put me down (.) because my dad has got narcissistic tendencies. (2) Erm So I suppose being a parent was quite different (.) and I have to a certain degree lived up to that. (3) I-I don't always get it right, I know I don't, (.) and I am the first one to hold my hands up (.) but my

Judith reflects the notion of achieving in education and moving beyond a "working class background" as important. In the process of the narrative she appears to have this loss of her professional career and the depression this brought her. I wonder if this is related to the construct of her own early childhood.

Judith has a clear sense of the kind of parent she ideally wants to be – it is contrast here with her own experience of her dad

husband is very good erm (.) he will tell me when **I am wrong**. (.) We have stopped doing it in front of Benjamin because ((mocking tone)) "daddy says you were wrong", "Yes I know". (2) An-And **I'll actually ask** to him and say to him (.) "Did I handle that right?". And we worked, since we worked through our own issues (2) and we work through the issues of how we deal with Benjamin, (2) we do do a lot of tag (.) erm which has helped and there's been once or twice **I have** actually let my husband have Benjamin more, and he realises how challenging, he finds it hard (.) and **I think** the fact that he just talks at you non-stop, (.) at least Ryan's interested in what he talks to him about, **I'm not**. He's got an obsession with cars (2) ((spoken at speed)) "Mum did you know that's a Mercedes. That first form of Mercedes was actually first brought into the country in 1979. However they change the spec of that wheel from being a so-and-so inch to a so-and-so inch and they change the component of the alloys.

Did you know also that the exhaust changed and now they use so-and-so in the car?”, “yeah”. “It is a six valve. What's yours? Yours is only a 4 valve isn't it mum? (.) 1.4 can you catch it mum?”, “No I can't darling”, “why not?”, “Because I value my licence and our lives” (.) “Oh mum you have caught it, you're brilliant mum”, “No, the traffic's caught up to it” ((Laughing)). Which it doesn't sound much but that constant rattling in your ear, and then my daughter gets annoyed and is like “shut up Benjamin! (.) We don't want to know about cars Benjamin”, and so he puts his headphones in a lot now when he's in the car and we both go ((sigh of release action)). (.) Mercedes-and you'll be having a conversation, and that's the attention bit, and he'll (.) he'll be talking about something about school and things and will say “Mercedes over there, oh wow that is a so-and-so, that is a-look at that exhaust mum”, it's like "Yes, can we go back to this please", "No I want to talk about that exhaust". (2) But I think we

Change – Laid back

have both become more a bit laid-back, and
 sometimes I'll walk in and I will just say to my
 husband you need to take over, (.) or he will
 go "you look shocking", "I feel shocking",
 "I'm going upstairs, I'm having five minutes,
 or half an hour on my own". (2) An-and I hate
 to say this but we've had to put a bedroom
 lock on our door (3) erm that if one of us just
 needs that sanctuary (.) because we-we got
 there now, we've actually got them to knock
 on the door, (.) but that has taken 11 years
 and it is not through want of trying I can tell
 you. (2) The knock does not open the door
 Benjamin. (2) But he is very clever as well
 and he'll, (.) he's always trying to outwit you,
 (.) so-and he is too smart for his own good to
 be honest (.) erm so my husband, I says he's
 on the spectrum, he's high functioning, very
 high functioning, (.) he's two points below
 being a genius and so he has told me quite a
 lot in 20 years ((Laughing)) which (.) Yeah get
 on with it and-and I think I'm fairly laid-back
 (.) and he doesn't do sport he doesn't do

I wonder if it is important
 to project a view of being
 intelligent – is it a way of
 trying to ensure she is
 believed, perhaps Judith
 feels she hasn't believe
 believed before. It is also
 used in a humorous way
 – Humour is a prominent
 feature in the interview
 Change – laid-back

anything so his ac-ac-activities-he enjoys
doing technology (.) so I just let him get on
with it and (.) it makes him happy. (2) But
everything is so high tech knowledge in our
house we can't just have a doorbell, it has got
to be a RingGo where I-even from here I can
see who comes to the front door (.) and I can
talk to them. (.) We've have got sky boxes in
four rooms and all of the skyboxes all link to
each other via the cabling through the cavity
walls so you can watch a-a sky box from the
bedroom in any other room. Why? Because
you can. (2) We had a phone system in that
you needed to press 9 to get an outside line
(laughing) like an office. You could
conference call each other, (.) and that's the
sort of environment he's been brought up in
(.) erm and Benjamin is very much like that,
(.) and him and his dad are gelling more. So
the day I moved my desk in my office and erm
he was really chuffed because he could plug
all of my monitors back in again and plug my
speakers in and (.) and set it up, and said "You

This refers to Ryan
(husband)

get better surround sound at this point”, and
I had to sit in the chair (.) and watch (.) the
aeroplane go across the screen, cross two
laptop screens, going from right to left and
see if the sound went right to left or left to
right, to make sure they had put the wires in
the right way. (2) Ten minutes of my life **I am**
not going to get back. ((laughing)) So **I think I**
am fairly laid-back ((laughing))

Scott: And that kinda-you feel that is different to
your childhood experience?

Judith: Very, and **I think** also the more understanding
I have got of autism and ADHD (.) the more **I**
can just let things go (.) and the more **I (.) find**
it easier to laugh at the situations (2)
(Inaudible) ((laughing)). He tied himself to a
lamppost last week with his bike chain. (2)
How dare **I put** the bikes on the erm-**I better**
get off in a minute-how dare **I put** the bike
chains on the bike rack err and not watch him
for a few minutes age 11? (.) And he just
comes up “mum, mum!” ((shouting)), **I was**
like “what?”, “I have tied myself to the

Being laid back is
mentioned a number of
times – is this part of the
transformation? Perhaps
Judith want stop me from
worrying that she has had
a stressful experience?

lamppost", he was laughing, I says "well get yourself untied", he said "I can't cos I have moved the digits round to the other side of the lamppost and I can't move it back round and I can't see what the numbers are", "Wally". (3) So anyway then he wouldn't let his sister undo it cos then she will know his code (2) so that-you know the fact that we live in the same house (.) and we use the same bike sheds has got nothing to do with it, but anyway that point I said to come here but he'd started panicking by that point cos he couldn't remember his code, so I am going through every code with him whilst this child is at the lamppost screaming. (2) "Hello" people walking past

Scott: Thank you so much

Judith: Is that the sort of thing

Scott: That's brilliant thank you so much for sharing that

Judith: It's alright

Scott: It's-it's great just to be able to hear people stories and to have them share them. With me I'm ever that if stranger, so yeah

Judith: And **actually he is an amazing individual to have around, life is never dull in our house, (.)** as you can probably imagine

Scott: Well yes it sounds very interesting, well thank you for sharing [that

Judith:

[it's okay, if you need anything else just shout **I am quite happy** to

Scott: Thank you. So what I will do is I am going to take all the er information I get from different people an and transcribe that and look at what I can pull out of it and then come back and have another chat with [you around that

Judith: [Yes that's absolutely fine

Scott: It will probably be after the summer (.) so it gives me time to be able to have a go at it as well. So then we will just have a chat around whether you think that yeah that is something that you think is reflected in what

Is this a revision – does it mask the complexity of the relationship and the feelings?
Positive view of Benjamin
Life is never dull seems to obscure the complex reality of the situation – it may mask the continuing times of difficulty experienced

we've said, because I am interested in (.)

what your feelings are around it

Judith: It has been interesting in actually because I go

round parent groups now and support them.

(.) I was listening to the stories of what other

parents say and they say to me (.) er "do you

find this as well?" And the thing with-we are-

find a lot of the husbands are on the

spectrum as well, undiagnosed. (.) And the

mums especially sit there and say "well how

do you handle this? (.) Or how do you handle

that?" and that peer-to-peer (.) support I

think parents find it useful. I mean I have

done a lot of reading there is a fantastic book

on asparagus-Living With a Partner With

Asperger's, (.) and that is very, very insightful

and it actually helped me understand Ryan a

bit and helped me understand Benjamin

more. (2) But I am a firm believer that if you

understand (.) you can actually, you are

halfway there to challeng-tackling it and

improving it, most times (2)

Scott: Just been able to understand it helps

Change – a new professional identity for Judith

Change – there is a new purpose for Judith

Revision – challenging to tackling

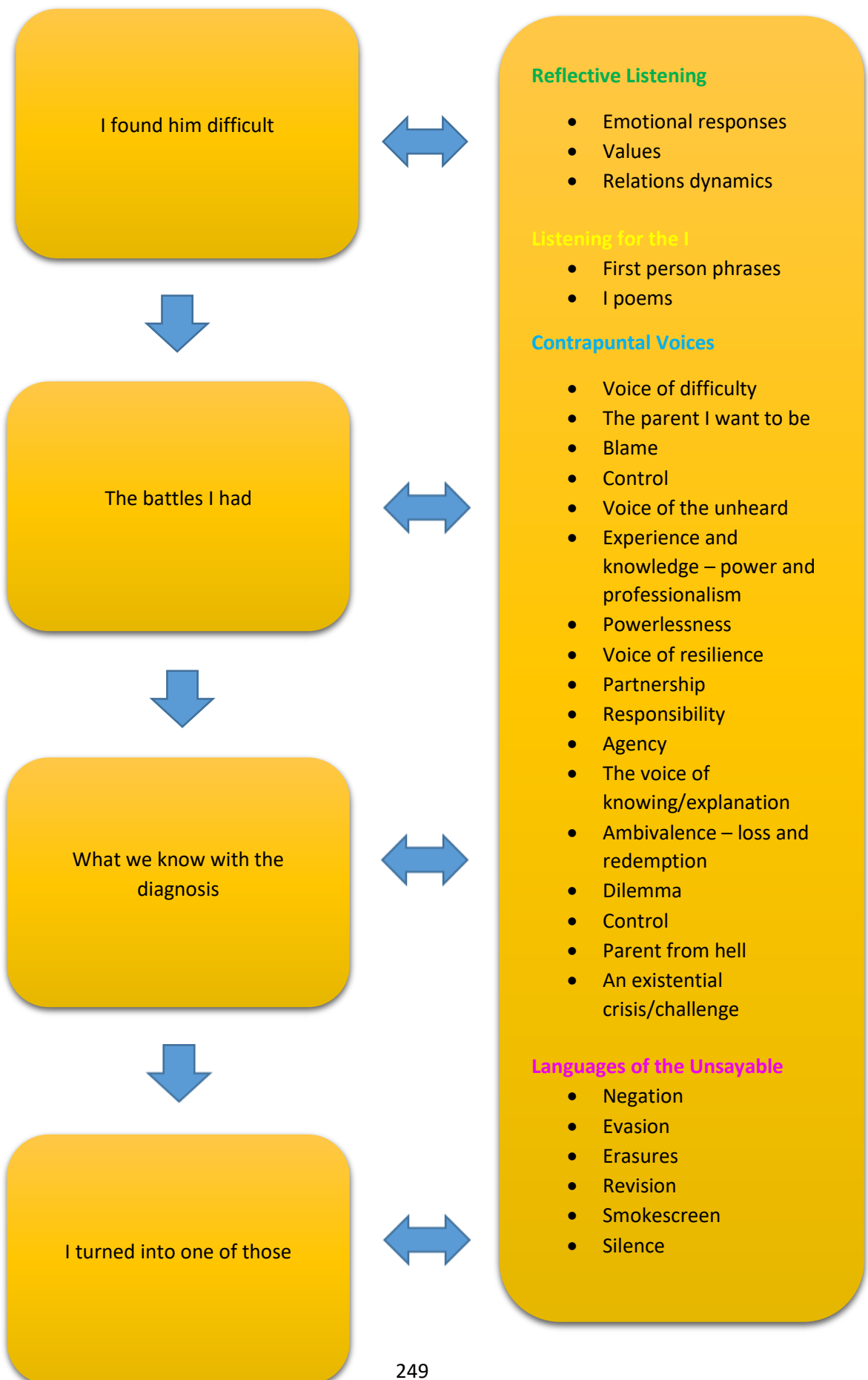
Judith: Yeah (.) You see these days where you're

coming and I'll be rocking and I say I'm gonna

kill him

Scott: Well thank you very much

Appendix F – Composition of analysis – Judith



Appendix G – Caroline Transcript

1 Scott I've only got one key question really and it's wherever we go from there erm so as I
2 say so can you tell me about your feelings and experiences of being a parent with a
3 child (.) with additional needs, (.) emotional, mental health, (.) sort of while they
4 have been in school

5 C Erm (.) it's been very, very hard, very, very hard, erm because my daughter (.) I
6 mean she was fine up till sort of year 10 (.) and then she had a bullying experience
7 (.) and then (.) she sort of went down Hill from there (.) and then wanted to go to a
8 different school (.) so (.) I moved her to another school and then that's when she
9 fell ill. (.) And err (.) it was from then on when she was diagnosed chronic fatigue (.)
10 but erm the school (.) ((deep sigh)) just wasn't (.) supportive (.) at all (.) really,
11 really, not

12 S Was that the new one or the old one?

13 C That was the new one, well the old one wasn't very good with the bullying erm (.)
14 they were just trying to sweep everything under the carpet all the time (.) and they
15 didn't treat her very-very nice either when she was in tears and upset about what
16 was happening to (.) her and erm (.) so (.) so yes so I mean getting schools to sort
17 of listen and (.) sort of do things (.) but when she moved to her other school erm
18 some of the bullying actually followed her (.) which none of us saw that one (.)
19 coming and erm (.) but that School were straight on it, the other school it was
20 pretty good with the bullying, straight away they nipped it in the bud (.) erm and (.)
21 but er as far as her actual illness (.) was concerned (.) it's actually classed as a
22 disability (.) her illness and at that stage none of us knew to what extent it was
23 gonna to affect her and how things were gonna affect her on a daily basis. (.) erm
24 But that school was very, (.) you know, it was all sort of up hill, it was all stairs and

25 things like that, which one flight of stairs and that was it that was her done (.) [even
26 just walking down a flight of stairs

27 S [Yeah

28 C and that was her done. She felt the cold quite easily (.) er (.) she wasn't very
29 comfortable er-er her joints would ache and her body would ache all of the time so
30 they offered her a different room to go to if she had a difficult (.) time and er (.) she
31 went to it but it was cold and (.) er she wasn't comfy. (.) Erm so they weren't, (.)
32 they weren't, I mean although they tried in the beginning erm it still wasn't
33 meeting her needs (.) and as a school actually they are just not set up (.) for
34 anybody with (.) those-those additional needs at all (.) from what I've seen. And
35 erm (.) As time went on it was getting more apparent that there was more (.) of a
36 mental health issue going on (.) and sometimes that is (.) linked to chronic (.)
37 fatigue (.) erm but this was over a period of time and because then she had a had a
38 lot of time off school (.) erm they wouldn't send work home (.) erm you-I'd-I had
39 meetings with them every month (.) or, you know, every three weeks or something
40 to keep them updated at one point they were going to prosecute me (.) because er
41 I couldn't get her in school erm (.) and at one point I was taking her into school just
42 one hour a day cos that's all she could manage (.) and (.) even then that was a real
43 struggle but that was a massive (.) impact on me and my husband cos we both
44 were working and trying to get an hour out to (.) take her to school, pick her up,
45 take her home erm it were, you know, s-s-so stressful (.) and erm (.) and then (.) er
46 (.) it was a case of what do you need so that I don't get prosecuted? What is it you
47 need? And at this point we'd been to the hospital and got her referred and (.) seen
48 a doctor (.) and (.) the err (.) the doctor (.) they're never very willing to give up
49 information (.) er and they rely on the secretaries and in X town in particular (.)

50 there is only her to see, there's only that one paediatrician to see kids (.) but she is
51 more rheumatoid (.) erm (.) so she still had to see my daughter but because
52 basically there were no-there were nothing else (.) for that particular ailment and
53 erm (.) so (.) she wasn't the best (.) erm but (.) I mean she tried to help us a little bit
54 and she was supposed to send the letter to school explaining (.) what was
55 happening and she didn't (.) and it was like four weeks and so when I had-I had that
56 discussion with school, (.) "Well what do you need?", "well we need proof", I said
57 "I've given you proof, (.) what else do you need?", "well a letter from your doctor
58 will do", (.) err "well errr you are supposed to have got one" (.) and er "well we
59 haven't". So I had to get the school nurse (.) involved (.) to then (.) get information
60 (.) from the hospital so I had to give her permission (.) to-to do that and (.)
61 everything-and everything that I told her she said "oh well (.) that's (.) that's quite
62 normal for a hospital really and-and surgeries and things to carry off like that,
63 you've got no control over that", I said "I know I haven't", so I said "well you tell
64 school that then". (.) So then she went back to the school and said this is all
65 perfectly normal (.) you know this is what you would expect (3) she's given me
66 permission to access notes. Anyway, so as soon as she got in touch with the
67 hospital then they got a letter (.) [even

68 S

69 [oh right

70 C though I was contacting the hospital they took no notice of me whatsoever,
71 nothing whatsoever. And that's what you feel (.) that as a parent you're actually,
72 you're absolutely powerless (.) erm there's no sort of (2) respect for you (.) at all (.)
73 erm but I find that more so at X town (.) I've got to say cos when I've had
74 experience at X City hospital, totally different story altogether. They are straight on

75 it, if there is a problem they're straight away want to solve it (.) and if I had been at
76 X city and under X city (.) like for chronic fatigue I would have had (.) erm family
77 therapy straight away, erm psychology straight away, erm physio straight away for
78 her, all those things would have been in place straightaway but at X city (...) erm
79 whereas (.) I had to kind of fall out with a few people, with that paediatrician er to
80 actually get her to (3) Well once she had given me the diagnosis which was like
81 from December to April, I got a diagnosis (.) in April. And I just got a letter and then
82 she took the month off, (.) bearing in mind she'd (.) she was giving medication to
83 my daughter to help her sleep cos (.) that is one of the things that gets turned
84 upside down (.) and erm (.) er so then no medication because she was off for a
85 month

86 Oh wow

87 Yeah so I had to fall out with (.) a few people (.) cos I had to go to my doctor and
88 say look she's given me this diagnosis, she needs medication (.) erm and he says
89 "well just contact her" and I said "you won't be able to she's off for a month", (.)
90 "well a doctor wouldn't do that, a doctor wouldn't (.) er just, (.) you know, (.) leave
91 no care (.) for that that patient". I said "well that's what she has done". (4) So me
92 and my husband had to go and sort of (.) fight for that (.) so then we got her
93 referred to (2) er (3) a chronic fatigue clinic, which is in X City, (.) which is obviously
94 it takes time so that didn't happen while in June or July (.) erm and then they
95 weren't going to see her until (.) October. All this time my daughter is sort of going
96 up, down, up, down, up, down, up, down, down, you know, down, down all the
97 time (.) and erm (.) erm and then sort off before the summer, well before July and
98 we got a holiday planned in August and her weight was fluctuating (.) but it was
99 going down gradually all the time (.) and it was just turning out that she was just

100 too exhausted (.) to actually eat (.) and erm (2) and er again I were still fighting
101 with the school, still having meetings with school erm (3) like I said she did go, she
102 did go back for a while (.) and she did like what you'd call a phased return, (.) and
103 that is because they were threatening us that she got to, she'd got to do this, erm
104 (.) which she just relapsed, it made her worse (4) erm (2) and (.) so (2) as a
105 condition on its own it was just getting worse (.) and there was no sort of (.)
106 understanding of it, you know, no sort of help or support and (.) erm an-and again
107 we were asking for work and earlier on in that period if they'd been sending work
108 home, like they said they were supposed to be doing, she would've continued with
109 some work, she would've done some (.) erm but they never did (.) erm so I was
110 fighting then for home tuition (.) and that took a long, long time, (.) that took all (.)
111 of most of last year, erm (.) from April/May (.) through to (.) August/September and
112 (.) that was a battle between school and the-the services that-that provide the
113 home tuition and er so that was going to be in place in September (2) a-a-after all
114 we got knocked back a few times because we'd got dogs (.) and they wouldn't
115 come out because we'd got dogs. (.) Erm so erm they had to come out and do an
116 assessment on my house, [make sure my house for safe (.) and erm (.) "Where
117 would you put your dogs?", so

118 S [okay

119 C: we've got a conservatory so I said "I can shut the room up completely" but I
120 couldn't explain the layout of my house (.) er because we don't shut the dogs off (.)
121 erm but I said that I would be present and that I would take the dogs with me into
122 conservatory and (2) so in the end we got it but not until about October (3) and
123 one of the teachers came, (.) they said (.) "I don't know why you haven't-you
124 haven't had this sooner cos it's not a long job, it's not a long job at all". (.) And (.)

125 they erm (2) er they said "I wasn't doing anything in (.) May and June anyway I
126 could have-I could have come out then".

127 S They weren't doing?

128 C: Yeah. They didn't have a great deal on (3) so it's not that the teachers couldn't
129 do it (.) so it was the process (.) of getting, (.) it was the school making everything
130 difficult, and it was Meadowheath provision, I don't know if you have heard of that
131 erm but once they were on board they were spot on to be honest

132 S Meadowheath?

133 C Yeah, erm they were really quite supportive erm (2) anyway like I said my
134 daughter's illness was getting (2) worse and she had this (.) weight issue (.) then we
135 went on holiday in August and she picked up, (.) she was eating fine (4) err and
136 then when we came home (.) and we started the work with chronic fatigue in X City
137 that's when she got a lot, lot worse. (.) And then it was them that pointed out that
138 there was something more sort of mental health issue going on (2) erm so (2) so
139 we started (.) er home tuition I think in October, at the end of October really, and
140 she managed to keep it going (.) up till December this is when she got extremely ill,
141 a lot worse, she lost a lot of weight. (4) Erm and this is when X city hospital was
142 concerned that she got (.) erm an eating disorder (.) and it was touch and go as to
143 whether she was going to go in hospital for anorexia but she didn't quite fit the
144 criteria (.) it was like them saying "go away and try and lose a bit more". (5) But this
145 weight thing had been going on for some time so the-the mental health issue just
146 doesn't go away unless it is treated (.) so by Christmas we had to stop all tuition, (.)
147 had to stop it altogether because everybody agreed, who was then involved, that,
148 you know, that it-it wasn't going to help. (.) So that's where (.) erm, you know,
149 everyone sort of backed off and realise that this is (.) really quite serious (.) so

150 from-from then until (.) now she's not had any schooling () err and she's not been
151 able to do exams (.) as a result of all them (.) things really. (3) I-I do believe that if
152 she had the support sort of early, early on (2) and (.) er, you know, we had the right
153 doctors and we had the right (2) procedures (.) err she might have been able to
154 carry some (.) because at that point she wasn't at the point where she was saying "I
155 can't, I can't do anything, I can't, I can't", you know, (.) that-at that point she was (.)
156 upset because she couldn't get school, she was upset because she couldn't carry on
157 with the school (.) and that she couldn't keep up with her friends and things like
158 that so all that social aspect went. Err (.) she was also struggling obviously with,
159 with the bullying (.) things as well erm (.) so there were actually an awful lot going
160 on at once (.) but just no, (2) no support in place at all. (.) Erm (.) And that is really
161 why I've come because if you want to (.) give some feedback it's that, (.) there's no
162 support, there's nothing there for parents, that's why I got involved with the
163 parents forum (.) and erm it's-and-it's been a good thing for me to [do (3) cos then
164 I've

165 S [Yeah, yeah

166 C had the support (.) it's been sort of signposting to different places, different
167 agencies, organisations (.) and just knowing that someone else is there to er (.) erm
168 that's gone through similar things.

169 S So you've talked a lot about sort of erm-using the word fight quite a lot, do you
170 think that has been your experience?

171 C Absolutely. Everything's an absolute struggle, absolutely yes, (.) an absolute fight,
172 everything. (2) You're fighting to be heard as a parent because you're talking about
173 somebody else on their behalf (.) so you are talking about a person that is reaching
174 15 and reaching 16 (2) and (3) people expect the kids to, (.) to know their own

175 mind, (.) and to be able to verbalise it (.) and that doesn't happen (.) for kids, (.)
176 but, you know, I think there are different ways, different (.) techniques and an-a-
177 certainly a different approach (.) needed er to be able to (.) get the kids to (2)
178 realise (.) erm I mean the biggest problem my daughter has even now, and she's
179 had this illness nearly 2 years now, and it is her accepting of her illness . (1) Erm
180 and if she could accept (.) that, you know at one time she was-she was an athlete
181 (2) [and now she's not (.) and accepting them changes together with (.) pressures

182 S [Right

183 C from school, pressures from peers and (.) erm all those things (.) erm I think you
184 don't realise how much (.) they're going through (.) as kids er I think they've got a
185 lot to live up to in this society, an-there is a lot pressures.

186 S So erm feeling that your daughter had had to accept erm a change in how she'd
187 been previously to and how she was now and was that something that you did as a
188 parent as well?

189 C Yeah, yeah definitely yeah because (.) essentially we've Lost a part of our daughter,
190 you know we are getting glimpses of it back now, which is great erm but, (.) you
191 know, (.) throughout it all (.) it's affected mine and my daughters relationship (.)
192 cos I've had to put pressure on her, you know, come on get ready, you need to get
193 to school, why aren't you going? (.) I know you can do this, you know, you've done
194 it one hundred times before why aren't you going? I thought it was because she
195 didn't want to go, and that's how the school treated you, like (.) you just didn't
196 want to go

197 S Right so did you feel you had put pressure on because you were told that she just
198 doesn't want to go?

199 C Yeah, yeah (.) And it wasn't a behavioural issue (.) erm yeah teenagers do dig their
200 heels in if they are pushed into corners, (.) erm that is a trait you know (.) but (.)
201 generally I think they'll, (.) I mean (.) I can talk about my daughter and I know she's-
202 she was a good student (2) erm and (1) er I know that if she could've carried on
203 with what she was doing she would have cos even to this day she still doesn't
204 accept that (.) she can't do the things that she did and she, she really struggles with
205 that. (2) I mean the other thing as well because we move from (.) one school to
206 another erm like I went to parents evening one night, but had to go without her
207 because she couldn't make it (.) erm because she-she suffers with like ongoing sore
208 throats, and tonsillitis and stuff, it is recurring (.) erm so she was feeling quite
209 poorly, So I went (.) erm (.) to one parents evening and another one she actually
210 came with me at that one (.) and there was a sports teacher, and (.) her other
211 school was a sport-a sports college, (.) so she took part in everything like a climbing
212 wall she did it from, you know, that height (.) erm and she did absolutely
213 everything cricket, (.) golf, whatever they asked her she did it, football for the boys,
214 she did it, and so she went to this school (.) and (.) they tried to get some
215 information from her old school (.) about grades and what level she was at, what
216 kind of student, and they wouldn't give her any information, (.) they just gave me a
217 sheet of paper and it was blank (.) and I said "I can't believe that". And apparently
218 they didn't know her (.) so then he had an impression that she was never (.) at that
219 school [either. (2) And

220 S [Gosh

221 C erm (.) what it was was the previous school had a different headmistress, (.) that
222 headmistress was fantastic and she come round and she'd be saying-and if, you
223 know, if parents were there she be coming up to you (.)"she is absolutely amazing,

224 she's an absolute star, she is absolutely fantastic", she'd be using positive
225 statements all the time (.) and "she's done so well and she's going to do really well
226 with us", (.) you know, stuff like that, (2) she left and then another headmistress
227 came in (.) nothing like that (2) And a lot of things changed in the school the
228 standards dropped, all those things and she-she got rid of a lot of teachers (.) and
229 she got-even though it was a sports college (.) she got rid of the sports department
230 that my daughter knew from her previous school cos it was like linked (.) so cos
231 they left, then the teachers that were left said they didn't know her, (.) because she
232 would have moved up into a new set of teachers and they didn't know her (.) so
233 nobody would give (.) a statement about her (2) so erm we got let down really with
234 that

235 S How did it feel that kind of the sense that they didn't know your daughter?

236 C Disgusted, I'm disgusted. (4) Erm I mean her art teacher actually lives in the same
237 village as me and I haven't seen her since and told her (.) and she said "I can't
238 believe that". She said "I put"-cos all her artwork, she is an excellent artist, (.) and
239 she said "they wouldn't even give her anything about her art?" And I said "no" and
240 she said "well I put her work together to send on to the school". So that's got lost.
241 (.) You know, erm the fact that she was an A star student all (.) across the board
242 with everything (.) and her effort, she got an award for effort, she got awards (1)
243 and I used to say to school (.) I know you don't believe what I'm telling you but err
244 I've got awards at home, (.) that she's had from school, (.) I said so (.) they don't lie
245 (.) [but nobody would believe that this was my child and that this school were

246 S [mmm

247 C seeing a different child (2) that was basically non-existent really (6)

248 S Wow (4)

249 C So I think we have been let down massively (4) between-between the schools. If
250 she had been at the (.) the second school from the beginning they'd have been all
251 there I think (.) I think that might have been a bit more (.) behind you, (.) but they
252 were more academic as well (.) erm and if she'd have carried on at her old school,
253 (.) she would've continuously suffered (2) to the point that she might have had to
254 accept these groups of people into her life that she didn't like (.) that were causing
255 her damage, but wanted her to behave the same way as them. (.) And she really
256 realised they were actually a lot of drugs once that headmaster-mistress had left,
257 there were a lot of drugs in school (.) erm and she saw people and (.) and she didn't
258 want to become a part of that (.) so that-that played a big (.) part on her (.) erm
259 just-just seeing that. (2) Erm so (2) I mean all those things, all those things
260 considered, I think she's, you know, tried to sort of hold her head up above water
261 with all of it really and keep a bit of her dignity (.) but wanted (.) to move away (.)
262 cos she didn't want-she didn't want that around her (4)

263 S Mmmm Mmmm Wow

264 C Yeah (5)

265 S Do you feel like she, do you think that, you mentioned her mental health do you
266 think that some of that contributed to her exp[erience

267 C [Yeah I do, yeah definitely all those things yeah
268 (4)

269 S And do you think other people recognise those mental health you know they all the
270 staff members? Or...

271 C No, (.) no, (.) I think they are very sort of ill-equipped to do that but on the other
272 hand as well as teachers (.) I think they are put under enormous pressure erm to hit
273 their goals and that seems to be more important than a child's health and a child's
274 mental health (2) erm (.) and (.) I mean I see parents (.) now that I knew (2) and
275 their-their child's probably doing fantastic in GCSE and this, that and the other, (.)
276 but they were pushing them kids, but then the school's telling them to push their
277 kid's, (.) you know telling them to (.) get down and do this kind of homework and
278 you do it with them, and you make sure (.) and all these things, so the pressure
279 that is put on the parents anyway (.) erm to make the-the child live up to
280 expectation (.) when at that age you know they've got everything going off, (.)
281 they've got all those social aspects which are more important to them (.) than any
282 grade and (.) erm (.) and they have the bigger impact (.) and I think it depends what
283 area the school was as well (.) because (.) erm (.) the first school, I mean where we
284 live there are pockets (.) of parents I suppose that (.) that don't sort of push their
285 kids (.) and don't (.) encourage the kids and they've got difficult life styles them kids
286 (.) and those kids are the ones that she saw turned to-to drugs just to get through
287 the day at school (2) And that is what she noticed (3)

288 S Gosh

289 C Yeah (4)

290 S Hmmm erm (2) When you were talking about erm there was something that you
291 mention that I just wrote down and it was related to, you know, the anorexia and
292 eating disorder stuff and you said it was like them saying go away and lose some
293 more (.) What was happening then?

294 C Erm my daughter had lost like a stone and a half she's not a big person anyway and
295 and she was always vert fit (2) erm (.) and so she had lost like a stone and a half (.)

296 but the BMI (.) criteria for her to have the help (.) for anorexia (.) she was basically
297 one (2) one mark away from it. (.) Now X town are very strict (.) and they have this
298 policy that if she's not, (.) I think BMI should've been seventeen or seventeen and a
299 half and she was eighteen and a half at one point (.) and at that point you are
300 suffering with, er well she-she was depressed, (.) obviously she was having
301 thoughts of suicide (4) erm but never acted on them (.) and unless she was at that
302 stage (.) there was nothing (3) erm which to me that was too late anyway. (2) Now
303 X City (2) said that (.) they would have admitted her (.) and that was a doctor that
304 was fighting (.) for me (.) with X Town to say she needs an assessment straight
305 away, (.) she needs help, she needs admitting, she's got an eating disorder

306 S Was that a doctor from X City?

307 C Yeah (.) Yeah (.) and this was a Gastro doctor (.) and what happens is when they (.)
308 get to that stage (.) it-he said it's very, very dangerous because she's-although she's
309 not lost more weight (.) recently (.) because she's growing it is very dangerous
310 because all the nutrients are going (.) from her bones and things like that from her
311 vital (.) organs and things (.) and that will have a massive effect on her she gets
312 older so (2) it was very dangerous for her to get to that malnutrition level which
313 she was at. (2) Erm (2) and she needed admitting cos she needed the help (.) and
314 what they would have done as a Gastro doctor is the-they like put a pipe into the
315 stomach and then they feed them through that (.) erm and that's what he
316 would've-he would've had her him in (.) because she was too exhausted to eat but
317 that didn't fit the criteria (.) for anorexia (.) and eating disorders don't always fit the
318 criteria-it's that's not always anorexia, if you've not got anorexia or bulimia or you
319 are not cutting your wrists (.) and you are not wanting to jump off a cliff or
320 something (.) then that's it (4)

321 S And how did that-that period in time make you feel as a parent?

322 C Erm (.) ((sigh)) I-I just can't put it into words (5) Just (.) helpless, (.) helpless. Just (.)
323 seeing your child (.) go from one thing to (.) this other thing (.) that was in your
324 house and you didn't know what was going off, (.) you know she was having (.)
325 screaming fits, (.) temper tantrums, (.) and she didn't know what was happening to
326 herself. (.) Erm (.) you try to help her (.) and she didn't want to go near her (.) and
327 you try to get her to drink something, you tried to get her to eat something,
328 "Getaway. I don't want you". (2) So I was absolutely (.) at my wits e-end (3) And
329 and so was my husband, (.) he couldn't function. He was still going to work at that
330 point I'd (.) had to finish my job (.) at Christmas anyway (.) and erm (.) so we were
331 both (.) at our wits end (.) phoning the crisis team all the time, phoning (.) whoever
332 I could phone, whoever I could get hold of (2)

333 S What were the responses of the people you were phoning? What was happening
334 then?

335 C Erm basically she doesn't fit into our criteria there's nothing we can do. (2) Erm but
336 (.) I'd got a referral to CAMHS, (.) but that was going to take at least another
337 month, and I'm thinking what state is she going to be in another month? (3) And
338 erm so we were longing for that appointment and tried various ways of getting it
339 move forward but that wasn't the facility to move her (.) move her into that service
340 any sooner cos that is all there is. (3) Erm So I was phoning them (.) for help and
341 support (.) all the time, what-what should I do? You know we were phoning them,
342 (.) they shut though at five so then you can only phone the crisis team (.) and then
343 you get told (.) they can't do anything (2) because for one she is not old enough,
344 there is that as well, and the other thing is they'll only take her in if she fits these
345 criteria (2) erm. If she is basically what they call in crisis. (2) But we were in crisis at

346 that time (.) and erm (.) we-we were just absolutely (.) appalled (.) and thought
347 how are we supposed to deal with this w-what are we supposed to do, (.) you
348 know. I told doctors at hospital and everything that (.) I-I feel like I'm not a parent
349 anymore, (.) I'm a therapist now (2) and I said how do you expect a parent to
350 become a therapist (2) because I am too close (.) to be able to do that and turn into
351 that, how do I know when she is going to slit-cut her wrists (3) How do I know what
352 thoughts she is having in her head and (.) what, you know, what i'd look out for (3)
353 I'm a mum (2) I am going to try and do everything I can to sort of (2) help her f-
354 what-whatever, that could have been the wrong way, (.) you know, (.) she needed
355 professional help (.) and there-there wasn't any. (3) Erm but we just kept phoning
356 CAMHS and they just kept giving us some advice over the phone (3) and that's
357 basically all we got erm. (.) I mean I did find a few other organisations (.) one of
358 which I could never get through to but apparently it is good if you can get through
359 to them but I could never ever get through to them (2) erm and erm that was
360 called Young Minds and were supposed be really good but I could never get hold of
361 them. (.) But they would have actually come out to you if they could those (2) er or
362 you would have been able to speak to a psychologist (.) and we had a psychologist
363 actually in place after a while (.) and at first she kind of helped (.) and then-but
364 through all what was happening (2) There was-there was another break of
365 communication because we were at chronic fatigue and they said "no there is a
366 mental health issue, she needs to be referred to CAMHS", so she put us back to X
367 Town to be able to do that. (.) Then, bearing in mind this doctor, this paediatrician
368 is the one that, (.) you know, we only see from one month to the next because she
369 only has one clinic (.) and she doesn't (.)she doesn't put all her attention onto these
370 cases she works more on wards (.) and (.) so (.) by the time we got to see her (.)
371 erm (.) it were, you know, it was too late (.) because we got this gap then from

372 chronic fatigue X city, back to X Town, got to wait again (2) And then (2) So (.) we
373 kept on seeing the (.) well we got back the psychologist tried to (.) to do things for
374 us even though she had not got no (.) space and wasn't (2) equipped with timeslots
375 and things and being able to come out to see my daughter and that is what we
376 really needed we needed someone to come out (.) and erm (.) but one time she did
377 (.) come out and that's when she said "do you want me to refer to CAMHS "and I
378 went "yes I do" (.) erm I said "because (2) if in a miracle she gets better she still on
379 the list (.) so we did that (.) and that's when we were waiting for-for CAMHS so in
380 between that time there wasn't anything (.) at all (.) erm we'd just go and see that
381 doctor at X Town and they just say, (.) they-they kind of threaten her and say "look
382 you will just be taken into hospital if you don't carry-If you don't eat you're gonna
383 be took into hospital" (2) And that was it (.) where as X city were sending letters
384 and saying I'm really concerned, I am really concerned about the mum, the family,
385 all of this erm (3) but you didn't get that from X town (.) and a lot of the time in X
386 town she didn't want me (.) there in that meeting (.) She tried to get rid of me (.)
387 because I'd had a few sort of battles with her not sort of all out arguments but
388 battles as in, (.) you know, I wanted you to (.) contact chronic fatigue a lot sooner
389 once you realise what diagnosis it was, (.) I want-I wanted to have medication and
390 not have it run out and seeing my daughter (.) suffer. I had to go up to the hospital
391 once and put a call out for her (2) and erm and say, (.) you know, "I've come for a
392 prescription for my daughter, she'd got one tablet left" and (2) err and I-and I said
393 to her there (.) "she's really, really poorly" I said "if I-if I could have brought her I
394 would", I said "she's so poorly" I said "I don't know what to do with her", an she
395 well she said "she will have good days and bad days". (2) That's what I got. (4) So (.)
396 all in all the experience as a mum from start to finish of all this (.) has been like I've
397 just been non-existent

398 S Right non-existent?

399 C Yeah (.) it's like, (.) you know, I've been the one that has been behind-the-scenes (.)
400 pushing it all and getting things in place and (.) hitting all the brick walls and
401 everything else (.) and sort of no support and no help (.) er but also being seen as
402 the person that's (.) overreacting erm (3) erm, you know, you don't fit this criteria,
403 you don't fit the criteria, you can't have this help, you can't have that help. () Erm
404 not wanting me in-in meetings not wanting me (.) to be present with my daughter
405 when she can't even be bothered to answer her question she is that exhausted, (.)
406 you know, and yet she wanted her to (.) put across her own (.) views and things and
407 (.) so I used to just sit there most of the time as quiet as I could to be and then I'd
408 fill her in. (.) She'd ask a question and she'd just be sat there with her head in her
409 hands and she be like that, (.) like that and I'm thinking she's going to like (.) melt
410 down in a minute (2) So I'd speak up for her and erm erm (2) she just tell her "yeah
411 I'm alright, yeah I'm okay"

412 S Right

413 C You know, (2) so (.) you know I think parents should be given a bit more (.)
414 consideration and a bit more respect than (.) than what they get

415 S So that erm (2) message you were getting that you were overreacting, was that
416 coming from lots of different people?

417 C ermm

418 S Like professionals, school?

419 C Yeah, yeah, yeah it were really erm (2) Yeah it were like you weren't believed (2) It
420 was like you were shouting but no one was listening (3) You are saying (.) Look if
421 you give my daughter this help now this is going to help you through, (.) this is

422 going to help her focus, this is going to help her feel (.) more involved, it's going to
423 help her (.) err keep along with the people that is doing (.) the same thing, she's
424 going to feel like that. And it made her feel less important because they saw that (.)
425 basically she just wasn't coming into school (.) errm so they just saw her as that
426 naughty child (3) that just didn't want to go

427 S And this was in specific conversations are you having with (2)

428 C Yeah, (.) yeah, (.) yeah (2) It was just er (.) and it was just a general sort of feeling
429 there was never any (.) consideration for what you were going through with your
430 child, there was never no (.) erm (2) Just thought for you as a human being there
431 was just nothing, (.) you know. (2) I used to speak, I mean I still speak to them now
432 at X City, chronic fatigue, and it is like (.) "oh God that must be so hard for you, this
433 is so hard for you as a whole as a family". And just having somebody say that (.) just
434 meant the world. (2) And erm so just having that experience (.) made me see why
435 aren't I getting that here? (.) Why aren't I (.) getting that support (.) here? (.) Yeah,
436 just unbelievable. I can well understand (.) why all this sort of (.) sex trafficking and
437 everything that has gone (.) on has got thrown aside (.) because, (.) you know, I
438 know of one parent that's gone through that with their daughter got groomed (.)
439 and (2) erm she was the same (.) phoning the police all the time, (.) "she's gone
440 missing, I don't know where she is, I'm afraid that she's with a group of people that
441 aren't safe", "well er she's 16 she can do what she wants", erm "But she's missing,
442 she's missing". And then I think she went missing for 30 hours once (.) and they
443 found her (.) with a day to spare before she got sent to London (.) so she could
444 have lost her that day (.) without her shouting (.) and saying "find her she's gone
445 missing" and I think she took, she's got a court case, she went to court (.) and the
446 judge actually spoke up for her (.) and said (.) "can't you see what this parent is

447 going through?", and she got treated like that, like it was a parental issue, (.) like
448 the parents were just shouting the odds and err there was nothing really going on
449 (.) and that it was just a family (.) feud, family issue, and because she is 16 she can
450 do what she wants, (.) you know (2) erm And so I know-I know it is not just my
451 experience (.) I know it is sort of wide, (2) you know (3)

452 S So you got that sense of (.) people sort of thinking this is, this is a family issue, it's a
453 parent issue?

454 C Yeah, (.) yeah, (.) yeah, (.) and you deal with it. (3) Your child is misbehaving and it's
455 a behavioural problem between you and your daughter and you, you sort it (5)

456 S And how did that kind of make you feel?

457 C (4) ((sighing)) Just, just despair, (.) just despair really. (.) It made me want to
458 become a politician ((laughing)) and make it all different. Just, (.) just makes me
459 determined really (2) to sort of do something (.) to try and change something (.)
460 but I don't know what yet (4)

461 S Oh wow (3) It sounds like it has been a real-real journey

462 C Oh absolutely, (.) absolutely (2) It really has. (.) I am just glad now it's kind of, sort
463 of (.) calmed down a bit because well I got the help with CAMHS, (.) but they
464 messed up, (.) they messed up, again they don't listen, (.) they don't listen (.) and
465 there are quite a lot of services within CAMHS that nobody knows about that they
466 do and they do a lot of good stuff, (.) you know. (.) Erm I just wished I could have
467 seen that good stuff a bit sooner, (.) cos for a start I had to wait (2) So it's like you
468 are in a queue, you know, first of all to get to see them and initially they are
469 supposed to come out to see you, (.) so you have a nurse allocated to you, a mental
470 health nurse and erm I am just looking at that poor dog over there it's suffering

471 with his joints so much (2) erm yeah erm they are supposed to come out to you (.)
472 and-which they did. That was the initial assessment (.) and they said (.) “Well
473 whatever this is, (.) this is not (.) really acceptable and we can't let you carry on like
474 this”. So that was a relief to hear that (.) and because she'd, it had just been the
475 point after where she was nearly admitted in hospital and (2) and erm (.) they er (.)
476 she said “well she's not got anorexia because she doesn't tick all of the boxes are
477 for that”. “No but” I said “there is something going on that (.) we aren't equipped
478 to deal with and she needs some help, can I get her to see a doctor”, “yeah we
479 have got some doctors, I will get her booked in”, so we got her booked in to see a
480 doctor. (2) And a erm she prescribed some medication for her only because (.) I did
481 say, (.) I said “Look I know I'm speaking for my daughter” and before now, you
482 know, I explained my situation I said (3) “I know (.) you need her to speak up” said
483 “but we are the ones that's seeing her suffer (.) and it is making us all suffer (.) so
484 (.) I need something for her”, says “She needs something”. (.) And erm so she did
485 agree (.) but she went and got backing off another doctor and he was a consultant
486 (.) so we went in to see him as well (.) and that is where it all kind of went wrong
487 because (.) she'd already gone through chronic fatigue and them saying they do like
488 rehabilitation there, well that was the point where she just spiralled down from
489 that point (.) and he was kind of trying to introduce a bit of that (.) back, and I said
490 “but we have already tried this (.) and my daughter has not been able to do it”. (2)
491 Anyway at that time (.) she just agreed to, they didn't want (.) the nurse to come
492 out to see her anymore, (.) they wanted her to come to see the nurse and the
493 doctor each week and spend some time (.) and (.) go for a walk or something like
494 that cos they wanted her to up her energy levels and her exercise (.) but this was a
495 person (2) who had not long since nearly been put in hospital for malnutrition (2)
496 and she didn't have the energy, (.) she didn't have the capacity, (.) you know, she

497 was having sort of fits on the floor, and (.) things like that and you are saying to her
498 come and have a walk, you'll feel better; do you know what I mean? (.) So to her
499 teenage mind she was like I'm not doing that, (.) so she dug her heels in. (.) Tried
500 to get her there, I got her there once, (.) couldn't get her there again, she'd just
501 blatantly wouldn't go. (2) Erm but they carried on with medication (.) and-and
502 there were-you only have so many chances with them (.) to say-to come in and get
503 the treatment, (.) you only get three chances and then they take you off the books
504 and they'll just refer you back to your own doctor (.) and I said, you know, "please
505 don't do that" I said "erm what can we do? (.) Because (.) we-we have still got to
506 deal with her, we are still having all these same issues, the same problem what-
507 what do we do? (.) How are we supposed to do it? I need some help". (.) So there
508 was a suggestion that she could have (.) a support worker to come out and get to
509 know her (.) and (.) but at-but at this point still they still stopped the nurse from
510 going out to see her. (2) Erm so she still wasn't getting any help (.) and (.) and-even
511 now she, she, she doesn't really (.) and then erm so (.) this nurse said well what is if
512 you come and see one of our family therapists (.) erm so that is what we are doing
513 now. Me and my husband go and see the family therapist in order to be able to
514 work with my daughter.

515 S Oh okay

516 C Erm And that is what we do now. (3) And (.) some of what they've said helped, but
517 I think the medications helped (.) more but then she has got a bit of her drive back
518 so she's doing it all on her own. (.) She's doing it without them anyway. (.) She's,
519 erm she's, not doing everything that she should do (.) and I'd like to get her to a
520 point where I could take her back to X city (3) and get more help there erm but
521 she's not where she was, you know, like in January, (.) thank goodness, so (.) things

522 are looking up a bit, so things have calmed down a lot, (.) there's own no more sort
523 of (.) temper tantrums and erm fits (.) and I don't know just (.) all the things going
524 off that you're not-you don't know what to do about and it is all awful to think (.)
525 that like now that's been a gap from it, there is still her attitude and her behaviour
526 as a result of everything (.) that you've got to deal with and it is hard to distinguish
527 (.) from (.) the chronic fatigue, from the eating disorder (.) I've been told now that
528 she has got a sleep disorder. ((sigh)) All these disorders erm (.) but no still nothing
529 really (.) The most support I have got is from-from this support network

530 S With the parent and carer forum?

531 C Yeah

532 S And w-what has it been like been told that your daughter has got this disorder and
533 this disorder and...?

534 C ((sigh)) (.) They're just names aren't they, they are just titles aren't they. Erm (.)
535 she-she wouldn't see, I mean even now (.) she wouldn't see that she's got an eating
536 disorder, she doesn't think she has (.) erm and she is (.) eating but only through
537 medication, (.) it-it gives her an increased appetite. (.) If we took that away we'd
538 be back to square one (...) So there's still there is still not the right (.) support there
539 (.) for her but (2) now this is where it gets really strange but—as an educational
540 thing I found out (.) through all this from October to January when she had home
541 tuition and all that, (.) I found out from getting the prospectus from college she-she
542 could have gone to college from the age of 13 (2) And I wished, I wished I knew
543 that, (.) because the college is more designed (.) to cater for all them things. (.)
544 They'd have been the one that were telling me she has got an eating disorder and
545 she is losing too much weight, they'd have been the ones that would have said “no
546 (2) she can't walk up those stairs but we've got a lift in place she can use the left. (.)

547 There's a room that she can use that's quiet she can go and eat in there, she
548 doesn't have to go out in the cold". (.) Erm there's some support workers that will
549 help her with her work, she doesn't have to worry about her work. (.) Erm I could
550 have got her (.) an educational health care plan in place for her right from the
551 beginning, they would have collected all of that information and they would have
552 told me about that (.)

553 S Mmmmm

554 C And all that those things would have now been in place and (.) things for me would
555 have been easier because people would have been coming to me and saying (.) er
556 look we are having these issues she's obviously struggling, (.) it's obviously difficult
557 for you as a parent, (.) you know we've seen other kids go through this (.) we're
558 quite equipped we'll do whatever we can. (.) The pressure would have been taken
559 off of her to do exams (.) she would have already been in place at college and
560 know-known that there were that system there. (.) The bullying would have been
561 eradicated cos they have a zero (.) policy. (.) All them issues would have not been
562 there (.) so then we could have just concentrate on (.) her chronic fatigue, (.) err,
563 err, you know, (.) her eating disorder and whatever else (.) err was going on at the
564 time, (.) but (.) I think as parents we would have had more (.) back up, more
565 support (.) and people recognising that (.) well she can't do this but we can do this.
566 (.) [That would have meant a lot

567 S [mmm

568 C to her (.) that she wasn't just put on a heap and she wasn't (.) not cared about cos
569 that is how she felt, (.) that you know she had gone from one school (.) with kids
570 that she had grown up with from being little who had lived around us (.) and all
571 those erm (.) kids she had gone to (.) primary-er to comp with, (2) they're the ones

572 that turned their back on her and didn't want to know her, so to her (.) and even
573 now she doesn't want to go outside and let-and let anybody see her (.) from where
574 we live, she wou-she wou-I mean I'd move tomorrow if I could erm (2) just to give
575 her that new-that new start erm (2) and (2) You know she finds most solace talking
576 to somebody (.) on a computer that is like thousands of miles away, they are going
577 through the same thing. She gets more (.) solace from that than she would (.)
578 wanting to reach out to the people around her that tells you a great deal (.) about
579 what is going off (.) with kids. (.) And-and I think she would have felt more normal
580 (.) cos that's what she felt like she was becoming (.) not normal, and the fact that
581 she got bullied (.) was the fact that she wasn't going along with their (.) with what
582 all the other kids were saying, (.) you know, come out with us, take drugs and stay
583 out all night and get involved in one thing and another. (.) And she was smart,
584 pretty, fit (.) and she-she tried to keep her cleverness (.) like under wraps (.) so that
585 she didn't get picked even more (2) and that is why she got isolated. (.) Erm it
586 wasn't the boys, it was the girls cos they were-they were just jealous of her (.) and
587 so that is how she sees the world now, (.) you know. (2) But she's, we're looking at
588 colleges and she is maybe hoping to try college in September. But all colleges are (.)
589 set up, you know, I've been to one college (2) again there's lifts everywhere (2) erm
590 It is all set up for them to feel independent and take a bit of control of themselves,
591 that's what they want to do when they are 16 and (.) but there's the support that's
592 (.) that's designed (.) to keep her confidence up rather than knock her confidence.
593 (.) And the support's there, they'll adapt around her (.) and if I need this health care
594 plan in place they'll-they're the ones that will collect all of that evidence (.) so, (3)
595 you know, it can only be better (.) so I wished now I'd known about all of that (.)
596 from 13 (.) and might have eradicated a few of the other issues you never know
597 ((laughing)) but we can always do that can't we, hindsight isn't it (4)

598 S Thank you so much for that. My only other main question is around what you kind
599 of expected being a parent would be like compare to how your experience has
600 been?

601 C ((Sigh)) I don't know erm (.) er I don't know, I expected, I don't know, I think you
602 expect some ups and downs with your kids (.) but I never expected what I got. (.) If
603 they were just the teenage (.) years that were difficult I could accept the teenage
604 years. (.) If it was just that that I was dealing with (.) but then when you are dealing
605 with (.) health issues that are, you know, things that aren't accepted so well (.)
606 because to look at my daughter there's nothing wrong with her. (2) Erm but if she
607 were in a wheelchair then you would realise that there was something wrong. Erm
608 (2) or if she had got a broken leg you'd realise there was something wrong. (.) But
609 (.) the issues that we've had is like, like mental health issues (.) and a physical-
610 physical issue as well (2) erm (2) have been the two most difficult things by far I
611 think. (.) So I never expected that, (.) I never expected any of that, definitely not (.)
612 erm and it's made me, (.) it has made me see er things differently (.) and it's made
613 me, (.) it's made me value things a lot more, but it has also made me (.) see things
614 more from their perspective, rather than seeing things from (.) an adult perspective
615 or a parent's perspective (2) erm cos we just think oh they can, they don't have to-
616 they can put up with that just, you know, you can put your kids through anything,
617 (.) and they love you so much and they'll do anything that you want them to do (.)
618 and it's just not like that. (.) They are their own person, their own identity (.) and
619 they have got their own things that they are dealing with in their life (.) and you're
620 the ones that are guiding them through it. (.) You are not pushing them through it
621 (.) and I actually, I mean, I-I love learning, my daughter loves learning she's a really
622 bright girl, erm she will have a bright future she will find something, erm (.) and-
623 and it is never too late to start learning the different things that she wants to do, (.)

624 but there's-there's barriers, you know, cos as she gets older (.) she can't do a
625 language and she can't (.) do certain GCSEs again (.) erm because she has missed
626 that time (.) so that's the one slot that they have got (.) so there's all that pressure
627 put on, you know, and err (.) but it's just not like that, (.) your health is more
628 important and your mental health is (.) vitally important, the most important. (2)
629 Erm without the mental health being (.) stabilised you are not going to achieve any
630 of the other things physically or anything (3) And er it's made-it's made me see
631 that. (2) And I've always wanted to help kids, you know, from the age of 13 cos I
632 had a tough time when I was 13 and I always wanted to (.) be able to do something
633 to help kids at that age (.) But now it has given me a full view, (.) you know, a full
634 birds eye view of er of what there is (.) there, out there (.) and how the
635 temptations to wonder from different-different path's (.) are just so easy (3)

636 S Mmmm so you said you had a difficult experience when you were 13 as well

637 C Yeah, yeah, yeah well I grew up in a family where (.) I was the youngest (.) and I
638 was bullied at school as well (.) erm but for me the bullying was, (.) well it was a
639 local it was on my street, you know. There was a particular girl (.) erm (.) and even
640 at school (.) one of the teachers was bullying me at school (.) err but I didn't know
641 that it was called bullying at that point you know erm and err (2) Yeah and when I
642 went up to comp I was thinking "oh thank God for that, (.) leave all that behind"
643 and I thought "oh thank goodness for that" (2) And it was just-just the growing up
644 part, at 13 I just found (.) er conflicts erm of who I actually was and identity crisis I
645 suppose (3) erm what I wanted to do, who I want to be. I've always been this
646 perfect (.) girl that grew up and did everything right, (.) please everybody, did
647 everything for everybody else (2) and I just wanted to escape from it (.) and-but I
648 suffered (2) emotionally (2) erm because I loved learning and I worked hard and I

649 was getting let down by-by the school and (.) erm our year was a bad year
650 apparently, I don't know, so we all got put in lower sets and things like that (.) but I-
651 I was the one that still kept trying, (.) was still doing everything right but got classed
652 the same as everyone else and (.) er so like maths and things like that I got held
653 back with that erm (.) erm and erm so (.) my view was different, (.) the way I
654 escaped it was that as soon as I was old enough and I could do what I wanted I
655 went travelling (.) and that is exactly what my daughter wants to do, she wants to
656 go travelling. (.) But she wants to do it differently she wants to go to different
657 places (.) but that is how I (.) sort of dealt with it (.) err and moved on from it but er
658 thank goodness I put all that behind me and I haven't got any of that nonsense (.)
659 anymore. (3) Err and er, you know, I can live my own life and I can choose my own
660 group of people (.) and so I do understand, you know, er where kids are coming
661 from and where my daughter's coming from, perfectly understand that, (.) but she
662 won't accept that I understand that ((laughing)) cos that's (.) just (.) the, you know,
663 difference between me and her she wants to have her own experiences, she
664 doesn't want to have my experiences and she doesn't want me to relate to her
665 because (.) hers are hers and she doesn't want me to impede on that. (.) So, (.) you
666 know, (3) I'm sure when she's older (.) she will (.) have a chat with me (.) and sort
667 of agree "yeah, yeah that happened to me, yeah that happened to me" (3)
668 ((laughing))

669 S And what-when you are having those kind of issues (.) at that time what-what was
670 it like with your parents and (2)

671 C Errm they didn't have a clue, they didn't have a clue any of it was going on (.)
672 especially when I was in primary (.) they didn't have a clue, (.) not a clue at all. (.)
673 They knew that this girl that lived on the street was a constant battle. (.) Er they

674 just used tell me just to walk away, you know, usual advice, (.) put your head down
675 ignore it, walk away. (.) But then when somebody is stood there and they're biting
676 your arm (.) and they are putting their teeth into your arm and they are leaving you
677 with a bruise are you supposed to walk away from that and I did, I have just stood
678 there and let it happen (.) so, (.) you know, I went through a stage at one bit where
679 I hated myself for letting someone do that to me, (.) I hated that and erm (.) erm (.)
680 but I got my own back, I got my own back one day (.) so I am pleased that I did that.
681 ((laughing)) (2) And I stopped it myself (.) and again today you can't even do that,
682 (.) you can't even advise your kids well don't put up with that (2) because you are
683 telling them to go out and (.) erm (2) assault somebody aren't they really. That's
684 what they're saying, (.) it is assault even at a young age and that you're condoning
685 it. (.) You can't even advise your kids to do that (.)erm (.) and, er (2) you know, it's
686 not a good thing for kids to be fighting is it really. (.) But I didn't-I were never a
687 fighter (.) erm (.) but I did get my own back one day definitely, yeah (.)

688 S In terms of when your daughter is going through it, you talked about the advice
689 that you gave, what kind of things did you sort of

690 C Erm well when she was going through things at comp erm (.) I thought I knew
691 everything that was going off, (.) I thought (.) I knew, again it was one particular girl
692 that was sort of a ringleader in all of this erm (2) and (.) so I thought that I knew
693 because we were so close (.) she used to tell me everything, everything that went
694 on, (.) she'd tell me. So I said right well don't do this don't do that, (.) erm stay, you
695 know, stay clear I suppose. (.) Similar advice erm

696 S Where you influenced by the advice you have received?

697 C Possibly. (.) Possibly yeah. (.) But my problem was at one point I thought what do I
698 do, do I take this more seriously, do I, do I do something more about this (.) or

699 what? (.) And a few teachers I spoke to (.) privately an said (.) “Look do you think
700 you can keep her away from this particular child as she’s having this affect?” (2)
701 erm “I think it would be good if they could (.) just have a bit of distance”, could
702 they not just sit together in every class (.) and things like that, could she sit with
703 another person, (.) things like that erm which happened some of the time (.) erm
704 but this girl always had a way of sort of worming her way back into her confidence.
705 (.) Er she was quite manipulative and she used to manipulate the girls into (.) siding
706 with her and then excluding my daughter. (.) So (.) in terms of that, you know,
707 there wasn't much advice you can give really, not much. (.) It was a case of well (.)
708 can you find some other group of girls to hang around with. (.) So she did she did
709 do that as well for a while erm but she says “mum, I can't I can't deal with it any
710 more, I can't stand it anymore” (2) erm and what hurt her, what really did it was (.)
711 there was this new girl that came into school (.) and of course because she’s knew
712 kids-everybody wants to be her friend with her (.) and that this girl was a girl that
713 sort of flitted around people and erm anyway so she is stuck to my daughter for a
714 while and she came on holidays with us, things like that. And she came on holiday
715 one year with us and at that point my daughter was just, (.) I just saw differences in
716 her (.) and as far as her energy (.) and just slight differences and I thought she is
717 just (.) feeling a bit off it but, you know, kids feel like that they are growing up. (.)
718 Anyway (.) this girl came on holiday with us when she got home (.) it was her that,
719 you know, spread rumours about her and talked about her to this other girl that my
720 daughter had been trying to keep away from all this time (.) and so she went back
721 off with her and left my daughter completely on her own and that is what broke
722 her heart (.) er cos I said to her “ Are you sure you want this girl to come with us
723 cos” I said “I'm not, (.) I'm not sure about her, (.)cos I am not sure of her motives,
724 she just using you for the holiday, cos she’s dumped you before” and things like

725 this (.) and I said "Are you sure she is not going to do that?", she said "No I am not
726 sure (.) really" and I said "Well do we still take her do we not take her", "No mum,
727 can we still take her, I'll be fine it will be okay". (2) And I remember saying to my
728 husband if she does that again to her it will break her heart. (.) And it did. (.) And
729 that was the day she broke down in school (.) and then she basically got a telling off
730 from someone for crying

731 S Wow

732 C Yeah (4) So she was absolutely terrible. (.) So (.) she came home. So then I, you
733 know, complained to her year head (.) and stuff like that and again it got "Oh well
734 what do you want me to do then?", erm so I told him (2) and err "Alright well (.)
735 erm if she need help she can come to me" (.) and that was it, that was it. I said
736 "Well she has already tried that and that's not worked" and that was it, (.) that is all
737 they did. (.) So they just, (.) the thing is with that school I think they had bigger fish
738 to (.) to deal with if you know what I mean, they have got bigger problems and er
739 my daughters problem wasn't big enough really (3)

740 S What do you think those big problems were?

741 C Well I think they had other students that were always kicking off (.) and that they
742 had to sort of control and deal (.) and er expel or send home and (.) I think they had
743 a group of kids that were a bit unruly (2) and they seemed to deal with them more
744 cos they were always expected to carry off that way so that is what they were
745 always doing. (.) And then so, you know, the kids like my daughter who wanted to
746 get along, wanted to get on with the work and it was important to her to do that,
747 and (.) she was conscientious and all those things (.) er just got left behind

748 S Yeah (2)

749 C That was the main thing. And it was the same thing in primary really, (.) they had
750 people, I think it was at a stage (.) where (.) a lot of schools weren't equipped for
751 like autism and things like that and they were trying to keep kids with those issues
752 in school, (.) in mainstream school (.) and they weren't equipped to deal with-with
753 their issues. (.) And they seemed to get the most attention (.) all the kids that came
754 from families, big families that (.) had troubles academically (.) erm got more
755 attention and more help and more support than my child that was constantly (.) at
756 a same level, but would have been at an even higher level, (.) she went in at a high
757 level, she always was at that high level (.) and didn't get that same encouragement.
758 (.) Unless she stood out, (.) unless she-she was quiet, she was shy, unless she stood
759 out, she was a bit mouthy and a bit bolshie and she got noticed and got the
760 support but the ones that are like my daughter sort of thing middle of the road if
761 you like (.) just thought "oh yes you can be sat with her and you can bring her
762 along" it was like that (.) because she was (.) able to work on her own, under her
763 own initiative, She was clever enough, and she could help somebody else along-
764 along with her as well
765 (.)And that is what happened in primary (.) to a large extent (5)

766 S Thank you

767 C I hope it is useful to you or listening to me and all my problems

768 S No, you know, I feel so privileged to do a piece of work like this because otherwise
769 you don't really get to hear peoples experiences an-and people like yourself have
770 been so (.) willing to share and share quite a lot of, you know, experiences that er
771 for me its brilliant but it's-it's a privilege to be able to do it as well so really thank
772 you for taking the time. Erm what I intend to do is spend the summer er just
773 looking through the different erm interviews that I have done and trying to do

774 some analysis of that and then what I have suggested to everyone that has taken
775 part and to you as well erm is that it would be nice if I could meet with you again
776 after the summer and just talk about erm what kind of thinking has come out of
777 that err mainly because keeping (.) you and the other people's stories at the centre
778 is really important for me cos it is your stories and I'm just privileged to be able to-
779 to listen to them and hopefully think about how we can use those to help other
780 people, services erm just think about how they might work with others the kind of
781 recommendations we might be able to pull out of the of all the different
782 experiences that people have had. So that's the plan if that's okay

783 C No yeah that's good, you know, (.) It would be nice if people did listen

784 S Yeah, yeah

785 C Definitely (2) That's what's important

786 S Absolutely

787 C Well hopefully (.) well I can't say any of it is for nothing, (.) cos it's not erm but to
788 be able to share experiences, I won't be the first person and I won't be the last (.) I
789 think as an area (.) and as schools and (.) everything, (.) you know, people need to
790 know what's going off. (.) People need to know what parents are going through. (.)
791 We've lost all that community, (.) they've been destroyed so there is no community
792 feel where people are supporting each other (.) and people are just excluding
793 people and the difference. (2) The way I know that (.) is not just from what I have
794 gone through personally (.) but when the headmistress was in that school (.) she
795 had a profound influence on the whole area (2) because before she came it was-it
796 was a bad area, a bad school. She came along and turned it all around. She had an
797 effect on the teachers, (.) she boosted them up, (2) she, she said that they were

798 fantastic, (.) they were (1) and she used to talk about the kids and she would say "I
799 know they drive me mad, and I tell them that every day that they drive me mad"
800 she says "but I love them" she says "I tell them they're fantastic every day that they
801 are". (.) And that has a massive influence on the families where (.) the kids were
802 from bigger families and they got massive issues going on as a family, (.) you know,
803 somebody had got cancer or somebody was disabled or (.) and that child was, you
804 know, probably caring for the parents (.) so what was they going to see? So what
805 was going to happen to them for the rest of their lives? And then there was this
806 headmistress that's saying that "you are really good at that. (.) Come on let's do
807 something" (.) and she'd have plays, she had plays that they did, they never did
808 them before, she got people dancing, and they never had dancing in the school
809 before, (.) she employed, she got somebody-a teacher and encouraged them to
810 carry on with their dancing skills. And they were trying to get me to get my
811 daughter to go into athletics and this teacher knew somebody in athletics, at an
812 athletics club and things like that. There were all them connections, that it was a
813 massive connection (.) and (.) when she went all that went, (.) when she was there
814 she was a strict (.) woman, she was a tough woman (2) erm but (.) the kids knew
815 that when they came in to school they were there to work and they were there to
816 have a good experience (.) and as for as bullying if she had seen my daughter crying
817 like that she'd have been straight on the phone to me, (.) she'd have been trying to
818 get to the root of it, to the bottom of it, and she would have put a stop to it, all of it
819 erm, (.) you know, all them things. (.) When my daughter saw kids then turning
820 back to drugs where they had turned away from it, (.) there were (.) there's always
821 an element of drugs everywhere isn't there (.) and (.) I think because they had such
822 a positive (.) network going off and in school (.) the kids were turning away from

823 that choice, and realising that they had got a purpose and a meaning and she saw
824 them kids (.) turning back to drugs (.)

825 S Right (.) When things had changed when the new head has gone (3)

826 C Yeah (2) cos she said one day, because they used to have a trip to Alton Towers
827 every year and it was only for the kids that had attendance and behaviour and all
828 that business, (.) well this new headmistress (.) they went no matter what, so there
829 was no criteria for it. And they would actually turn people away for their bad
830 behaviour and not let them go on this coach. (.) And it was all paid for and (2) and
831 erm anyway this erm girl that has come to the school and she said to my daughter
832 "do you think I could come round with you tomorrow cos the girls that I I am
833 hanging around with, they are wanting me to go and join them in the park (.) at 8
834 o'clock in the morning (.) er but they are all going smoking, they are all smoking
835 dope. (.) Er and she said "I don't want to be seen with them", (.) "Oh yeah of course
836 you can". And they turned up on the couch stoned and they let them go (2)

837 S Wow

838 C Yeah, (.) yeah (.) And then they were going on, you know, fairground rides, Alton
839 Towers (.) so they could have harmed themselves, they could have harmed other
840 people (.) and I don't know how they let them on because my daughter says "I
841 don't know how they could let them go" (.) she says because she noticed how they
842 were talking, slurring their words, she noticed smell that was on them (.) and you
843 could tell that they weren't-they weren't right (.) and they let them get on. (.) Now
844 the other teacher had a presence and she used to, she used to have teachers at the
845 front of school and they use to know the kids that were going smoking and er, you
846 know, if they were into drugs they used to know who they were (.) and they knew
847 who the people were who were coming and supplying them as well (3) And they

848 stood at the front of school (.) And they made their presence known in that school
849 and outside of that school. (.) So teachers there were two on the side and one in
850 entrance cos there was a drive in and erm (.) so it stopped that influence coming in
851 to school (.) and then they noticed which ones weren't going to come in that day
852 because they saw them go round the back of this building smoking. ((throat
853 clearing)) So they had an eye on who was in (2) and it was the same at end of
854 school (.) the way pupils-there were teachers there watching them out. Now when
855 that went, (.) when the headmistress went and them teachers (.) weren't there any
856 more to do that (.) my daughter noticed that there was this couple that came to
857 the school grounds (.) just stood outside gates (.) er Because it was, like I say, like a
858 drive in and drive out and they were always stood there (.) and then the kids that
859 she knew that were into drugs were going up to this couple (.) to either the man or
860 the woman (.) so she noticed that

861 S Wow gosh that's really scary

862 C Yeah it is and that's really scary to the kids isn't it (.) so that-that headmistress had
863 a massive impact on the whole area (.) because it was setting a precedent's and
864 saying you don't have to do that you've got this (.) and that you are important and
865 whatever lifestyle you've got and whatever problems you've got you can come
866 here and you can forget about it, this is what you've got here, (.) you know, and
867 they had that security (.) and somebody believing in them

868 S Sounds like she was a strong person

869 C Yeah, yeah she were, yeah (.) definitely. She went on to do erm something to do
870 with OFSTED. (.) She'd been er a teacher and a headmistress for 30 years and she
871 wanted to (.) help a different (.) area of education and so she went to OFSTED (.)
872 for helping them erm but I don't think she was allowed to come back to the area

873 that she had just worked in, I don't think so she was probably (.) in a different
874 capacity (.) but it was such a shame, (.) I nearly cried when she left ((laughing)) (2) I
875 was like oh God (.) Yeah

876 S That has got to be some kind of indictment that you know people get upset if she
877 leaves

878 C Oh yeah, yeah

879 S Erm thank you ever so much

880 C That's okay

881 S It's been really, really lovely to talk to you. And I hope things continue to get better

Appendix H - Listening Guide Stages Description – Caroline transcript

Transcription	Reflective notes
<p>S I've only got one key question really and it's wherever we go from there erm so as I say so can you tell me about your feelings and experiences of being a parent with a child (.) with additional needs, (.) emotional, mental health, (.) sort of while they have been in school</p>	
<p>C Erm (.) it's been very, very hard, very, very hard, erm because my daughter (.) I mean she was fine up till sort of year 10 (.) and then she had a bullying experience (.) and then (.) she sort of went down Hill from there (.) and then wanted to go to a different school (.) so (.) I moved her to another school and then that's when she fell ill. (.) And err (.) it was from then on when she was diagnosed chronic fatigue (.) but erm the school (.) ((deep sigh)) just wasn't (.) supportive (.) at all (.) really, really, not</p>	<p>Voicing difficult</p> <p>The hesitation and the expression "down hill from there" seem to highlight the problem from a distance – it may reflect an initial silence around the difficulties that have been experienced</p> <p>Unsupportive</p>
<p>S Was that the new one or the old one?</p>	
<p>C That was the new one, well the old one wasn't very good with the bullying erm (.) they were just trying to sweep everything under the carpet all the time (.) and they didn't treat her very- very nice either when she was in tears and upset about what was happening to (.) her and</p>	<p>Dismissed and ignored Possibly obscured</p>

erm (.) so (.) so yes so I mean getting schools to sort of listen and (.) sort of do things (.) but when she moved to her other school erm some of the bullying actually followed her (.) which none of us saw that one (.) coming and erm (.) but that School were straight on it, the other school it was pretty good with the bullying, straight away they nipped it in the bud (.) erm and (.) but er as far as her actual illness (.) was concerned (.) it's actually classed as a disability (.) her illness and at that stage none of us knew to what extent it was gonna to affect her and how things were gonna affect her on a daily basis. (.) erm But that school was very, (.) you know, it was all sort of up hill, it was all stairs and things like that, which one flight of stairs and that was it that was her done (.) [even just walking down a flight of stairs

S

[Yeah

C

and that was her done. She felt the cold quite easily (.) er (.) she wasn't very comfortable er-er her joints would ache and her body would ache all of the time so they offered her a different room to go to if she had a difficult (.) time and

This somehow seems to give a sense that it is legitimate

er (.) she went to it but it was cold and (.) er she wasn't comfy. (.) Erm so they weren't, (.) they weren't, I mean although they tried in the beginning erm it still wasn't meeting her needs (.) and as a school actually they are just not set up (.) for anybody with (.) those-those additional needs at all (.) from what I've seen. And erm (.) **As time went on it was getting more apparent that there was more (.) of a mental health issue going on (.)** and sometimes that is (.) linked to chronic (.) fatigue (.) erm but this was over a period of time and because then she had a had a lot of time off school (.) erm they wouldn't send work home (.) erm you-**I'd-I had meetings** with them every month (.) or, you know, every three weeks or something to keep them updated **at one point they were going to prosecute me (.) because er I couldn't get her in school erm (.)** and at one point **I was** taking her into school just one hour a day cos that's all she could manage (.) and (.) **even then that was a real struggle but that was a massive (.) impact on me and my husband** cos we both were working and trying to get an hour out to (.) **take her to school, pick her up, take her home erm it**

Mum has a sense that there is a mental health difficulty. It makes me wonder about how people understand constructs such as mental health which may make it difficult to communicate. Medical models or social model. Is the discourse between families and practitioners different leading to conflict?

Blamed and responsibility – needs to be prosecuted. This may set the scene for conflict to occur

There is a continuing impact on the family. Difficulty. It also appears related to being unable to change this situation.

Perhaps Caroline feels cornered to act in this way – her agency seems challenged. She is confined to respond in

<p>were, you know, s-s-so stressful (.) and erm (.) and then (.) er (.) it was a case of what do you need so that I don't get prosecuted? What is it you need? And at this point we'd been to the hospital and got her referred and (.) seen a doctor (.) and (.) the err (.) the doctor (.) they're never very willing to give up information (.) er and they rely on the secretaries and in X town in particular (.) there is only her to see, there's only that one paediatrician to see kids (.) but she is more rheumatoid (.) erm (.) so she still had to see my daughter but because basically there were no-there were nothing else (.) for that particular ailment and erm (.) so (.) she wasn't the best (.) erm but (.) I mean she tried to help us a little bit and she was supposed to send the letter to school explaining (.) what was happening and she didn't (.) and it was like four weeks and so when I had-I had that discussion with school, (.) "Well what do you need?", "well we need proof", I said "I've given you proof, (.) what else do you need?", "well a letter from your doctor will do", (.) err "well errr you are supposed to have got one" (.) and er "well we haven't". So I had to get the school nurse (.)</p>	<p>this way through fear of prosecution</p>
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involved (.) to then (.) get information (.) from the hospital so I had to give her permission (.) to-to do that and (.) everything-and everything that I told her she said “oh well (.) that's (.) that's quite normal for a hospital really and-and surgeries and things to carry off like that, you've got no control over that”, I said “I know I haven't”, so I said “well you tell school that then”. (.) So then she went back to the school and said this is all perfectly normal (.) you know this is what you would expect (3) she's given me permission to access notes. Anyway, so as soon as she got in touch with the hospital then they got a letter (.) [even

S

[oh right

C

though I was contacting the hospital they took no notice of me whatsoever, nothing whatsoever. And that's what you feel (.) that as a parent you're actually, you're absolutely powerless (.) erm there's no sort of (2) respect for you (.) at all (.) erm but I find that more so at X town (.) I've got to say cos when I've had experience at X City hospital, totally different story altogether. They are straight on it, if there

Caroline's voice is not heard. She needs someone with more power to bring about an action – the power of professionalism

This makes me think of parent voice and power. I wonder how this sits with the code of practice with families at the heart of the legislation. Is it making a difference? Dismissed and ignored These perhaps present silences to how Caroline has felt – she does not attribute them to herself Reference to a powerlessness

<p>is a problem they're straight away want to solve it (.) and if I had been at X city and under X city (.) like for chronic fatigue I would have had (.) erm family therapy straight away, erm psychology <u>straight</u> away, erm physio straight away for her, all those things would have been in place straightaway but at X city (...) erm whereas (.) I had to kind of fall out with a few people, with that paediatrician er to actually get her to (3) Well once she had given me the diagnosis which was like from December to April, I got a diagnosis (.) in April. And I just got a letter and then she took the month off, (.) bearing in mind she'd (.) she was giving medication to my daughter to help her sleep cos (.) that is one of the things that gets turned upside down (.) and erm (.) er so then no medication because she was off for a month</p> <p>Oh wow</p> <p>Yeah so I had to fall out with (.) a few people (.) cos I had to go to my doctor and say look she's given me this diagnosis, she needs medication (.) erm and he says "well just contact her" and I said "you won't be able to she's off for a month", (.) "<u>well</u> a doctor <u>wouldn't</u> do that, a</p>	<p>Battling and fighting</p> <p>Diagnosis does not bring action</p> <p>Caroline is left</p> <p>Battling/fighting fighting/battling was necessary to get support/what Lydia needs</p>
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<p>doctor wouldn't (.) er just, (.) you know, (.) leave no care (.) for that that patient". I said "well that's what she has done". (4) So me and my husband had to go and sort of (.) fight for that (.) so then we got her referred to (2) er (3) a chronic fatigue clinic, which is in X City, (.) which is obviously it takes time so that didn't happen while in June or July (.) erm and then they weren't going to see her until (.) October. All this time my daughter is sort of going up, down, up, down, up, down, up, down, down, you know, down, down all the time (.) and erm (.) erm and then sort off before the summer, well before July and we got a holiday planned in August and her weight was fluctuating (.) but it was going down gradually all the time (.) and it was just turning out that she was just too exhausted (.) to actually eat (.) and erm (2) and er again I were still fighting with the school, still having meetings with school erm (3) like I said she did go, she did go back for a while (.) and she did like what you'd call a phased return, (.) and that is because they were threatening us that she got to, she'd got to do this, erm (.) which she just relapsed, it made her worse (4)</p>	<p>Fighting/battling</p> <p>Fighting and feeling threatened</p> <p>Blaming and responsibility</p> <p>Unsupported</p>
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<p>erm (2) and (.) so (2) as a condition on its own it was just getting worse (.) and there was no sort of (.) understanding of it, you know, no sort of help or support and (.) erm an-and again we were asking for work and earlier on in that period if they'd been sending work home, like they said they were supposed to be doing, she would've continued with some work, she would've done some (.) erm but they never did (.) erm so I was fighting then for home tuition (.) and that took a long, long time, (.) that took all (.) of most of last year, erm (.) from April/May (.) through to (.) August/September and (.) that was a battle between school and the-the services that-that provide the home tuition and er so that was going to be in place in September (2) a-a-after all we got knocked back a few times because we'd got dogs (.) and they wouldn't come out because we'd got dogs. (.) Erm so erm they had to come out and do an assessment on my house, [make sure my house for safe (.) and erm (.) "Where would you put your dogs?", so</p> <p>S [okay</p> <p>C</p>	<p>Battle</p> <p>Powerless Resistance</p>
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we've got a conservatory so I said "I can shut the room up completely" but I couldn't explain the layout of my house (.) er because we don't shut the dogs off (.) erm but I said that I would be present and that I would take the dogs with me into conservatory and (2) so in the end we got it but not until about October (3) and one of the teachers came, (.) they said (.) "I don't know why you haven't-you haven't had this sooner cos it's not a long job, it's not a long job at all". (.) And (.) they erm (2) er they said "I wasn't doing anything in (.) May and June anyway I could have-I could have come out then".

S They weren't doing?

Yeah. They didn't have a great deal on (3) so it's not that the teachers couldn't do it (.) so it was the process (.) of getting, (.) it was the school making everything difficult, and it was Meadowheath provision, I don't know if you have heard of that erm but once they were on board they were spot on to be honest

S Meadowheath?

C Yeah, erm they were really quite supportive erm (2) anyway like I said my daughter's illness was

Fighting with school. Powerless to make this happen sooner. Caroline lacks agency in the situation

getting (2) worse and she had this (.) weight issue (.) then we went on holiday in August and she picked up, (.) she was eating fine (4) err and then when we came home (.) and we started the work with chronic fatigue in X City that's when she got a lot, lot worse. (.) And then it was them that pointed out that there was something more sort of mental health issue going on (2) erm so (2) so we started (.) er home tuition **I think** in October, at the end of October really, and she managed to keep it going (.) up till December this is when she got extremely ill, a lot worse, she lost a lot of weight. (4) Erm and this is when X city hospital was concerned that she got (.) erm an eating disorder (.) and it was touch and go as to whether she was going to go in hospital for anorexia but **she didn't quite fit the criteria (.) it was like them saying "go away and try and lose a bit more"**. (5) But this weight thing had been going on for some time so the- the mental health issue just doesn't go away unless it is treated (.) so by Christmas we had to stop all tuition, (.) had to stop it altogether because everybody agreed, who was then involved, that, you know, that it-it wasn't going

Criteria
Rejection

<p>to help. (.) So that's where (.) erm, you know, everyone sort of backed off and realise that this is (.) really quite serious (.) so from-from then until (.) now she's not had any schooling () err and she's not been able to do exams (.) as a result of all them (.) things really. (3) I-I do believe that if she had the support sort of early, early on (2) and (.) er, you know, we had the right doctors and we had the right (2) procedures (.) err she might have been able to carry some (.) because at that point she wasn't at the point where she was saying "I can't, I can't do anything, I can't, I can't", you know, (.) that-at that point she was (.) upset because she couldn't get school, she was upset because she couldn't carry on with the school (.) and that she couldn't keep up with her friends and things like that so all that social aspect went. Err (.) she was also struggling obviously with, with the bullying (.) things as well erm (.) so there were actually an awful lot going on at once (.) but just no, (2) no support in place at all. (.) Erm (.) And that is really why I've come because if you want to (.) give some feedback it's that, (.) there's no support, there's nothing there for parents,</p>	<p>Mum brings the experience back into the present. It is real "this is" not "this was". Perhaps it serves as a means of making me hear this is a problem</p> <p>Absence of support. Things could have been different with early help. A different outcome was perhaps possible</p> <p>Absence of support</p> <p>Absence of support</p>
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S	<p>that's why I got involved with the parents forum (.) and erm it's-and-it's been a good thing for me to [do (3) cos then I've</p> <p>[Yeah, yeah</p>	Peer support
C	<p>had the support (.) it's been sort of signposting to different places, different agencies, organisations (.) and just knowing that someone else is there to er (.) erm that's gone through similar things.</p>	Peer support Containment and connection
S	<p>So you've talked a lot about sort of erm-using the word fight quite a lot, do you think that has been your experience?</p>	I influence the narrative here. When I look back I can see that Caroline only says fighting 3 time before I mention it. It is possible that I am influenced by my experience of working with parents who indicate they have had to fight or it could reflect forms of
C	<p>Absolutely. Everything's an absolute struggle, absolutely yes, (.) an absolute fight, everything. (2) You're fighting to be heard as a parent because you're talking about somebody else on their behalf (.) so you are talking about a person that is reaching 15 and reaching 16 (2) and (3) people expect the kids to, (.) to know their own mind, (.) and to be able to verbalise it (.) and that doesn't happen (.) for kids, (.) but, you know, I think there are different ways, different (.) techniques and an-a-certainly a different approach (.) needed er to be able to (.) get the</p>	<p>communication (e.g. projective identification, transference) that other methods attempt to highlight e.g. free association narrative interviewing Battling/Fight Unheard Reflecting on the difficult of advocating for young people and hearing parent voice. Are there potential tensions?</p> <p>Power and practitioners – the power of practitioners to determine what is voice and how to elicit it</p>

<p>kids to (2) realise (.) erm I mean the biggest problem my daughter has even now, and she's had this illness nearly 2 years now, and it is her accepting of her illness . (1) Erm and if she could accept (.) that, you know at one time she was- she was an athlete (2) [and now she's not (.) and accepting them changes together with (.) pressures</p>	
<p>S [Right</p>	<p>I wonder here who mum is talking to and about. Is the "you" directed at me?</p>
<p>C from school, pressures from peers and (.) erm all those things (.) erm I think you don't realise how much (.) they're going through (.) as kids er I think they've got a lot to live up to in this society, an-there is a lot pressures.</p>	<p>Perhaps mum sees me as a representative of a group of practitioners who have not heard her before. She could be directing this statement at an other for whom I am the embodiment at the time.</p>
<p>S So erm feeling that your daughter had had to accept erm a change in how she'd been previously to and how she was now and was that something that you did as a parent as well?</p>	<p>I wondered here if this reflects how mum feels. Pressure from society or in this case schools to make her daughter conform to how they would like her to be?</p>
<p>C Yeah, yeah definitely yeah because (.) essentially we've Lost a part of our daughter, you know we are getting glimpses of it back now, which is great erm but, (.) you know, (.) throughout it all (.) it's affected mine and my daughters relationship (.) cos I've had to put pressure on her, you know, come on get ready,</p>	<p>Loss Caroline says she has lost part of her daughter but is quick to add that they are getting glimpses of her back now. Is there a haste to reassure herself at this moment as she has accepted that she lost part of her daughter – This is potentially a painful experience Compulsion This perhaps resonates with the pressure she mentioned</p>

<p>you need to get to school, why aren't you going? (.) I know you can do this, you know, you've done it one hundred times before why aren't you going? I thought it was because she didn't want to go, and that's how the school treated you, like (.) you just didn't want to go</p> <p>S Right so did you feel you had put pressure on because you were told that she just doesn't want to go?</p> <p>C Yeah, yeah (.) And it wasn't a behavioural issue (.) erm yeah teenagers do dig their heels in if they are pushed into corners, (.) erm that is a trait you know (.) but (.) generally I think they'll, (.) I mean (.) I can talk about my daughter and I know she's-she was a good student (2) erm and (1) er I know that if she could've carried on with what she was doing she would have cos even to this day she still doesn't accept that (.) she can't do the things that she did and she, she really struggles with that. (2) I mean the other thing as well because we move from (.) one school to another erm like I went to parents evening one night, but had to go without her because she couldn't make it (.) erm because she-she suffers with like ongoing sore throats, and tonsillitis</p>	<p>before. Caroline feeling pressured. Is it a justification she feels she needs to give? She had to put pressure on. I wonder if she feel a sense of guilt that she needs to defend against?</p> <p>Blame and responsibility Naughty child</p> <p>It seems like there is an influence from schools narrative about Lydia that affects the actions of Caroline. She seems to indicate that she believed what the school were telling her. Maybe she felt she had no choice as she was threatened with prosecution?</p>
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<p>and stuff, it is recurring (.) erm so she was feeling quite poorly, So I went (.) erm (.) to one parents evening and another one she actually came with me at that one (.) and there was a sports teacher, and (.) her other school was a sport-a sports college, (.) so she took part in everything like a climbing wall she did it from, you know, that height (.) erm and she did absolutely everything cricket, (.) golf, whatever they asked her she did it, football for the boys, she did it, and so she went to this school (.) and (.) they tried to get some information from her old school (.) about grades and what level she was at, what kind of student, and they wouldn't give her any information, (.) they just gave me a sheet of paper and it was blank (.) and I said "I can't believe that". And apparently they didn't know her (.) so then he had an impression that she was never (.) at that school [either. (2) And</p> <p>S</p> <p>[Gosh</p>	<p>Caroline give the impression that here daughter would be recognised and known to others as active and part of the school. It feels almost as though she is supporting a narrative of her daughter by indicating that there are people who recognise her daughter in this way</p> <p>Non-existent</p>
<p>C</p> <p>erm (.) what it was was the previous school had a different headmistress, (.) that headmistress was fantastic and she come round and she'd be saying-and if, you know, if parents were there</p>	<p>Relationships are important. The regard for others appear to have a big impact on Caroline, we see the difference when those relationships change. Recognition/recognised Building relationships through positive statements.</p>

<p>she be coming up to you (.)“she is absolutely amazing, she's an absolute star, she is absolutely fantastic”, she'd be using positive statements all the time (.) and “she's done so well and she's going to do really well with us”, (.) you know, stuff like that, (2) she left and then another headmistress came in (.) nothing like that (2) And a lot of things changed in the school the standards dropped, all those things and she-she got rid of a lot of teachers (.) and she got-even though it was a sports college (.) she got rid of the sports department that my daughter knew from her previous school cos it was like linked (.) so cos they left, then the teachers that were left said they didn't know her, (.) because she would have moved up into a new set of teachers and they didn't know her (.) so nobody would give (.) a statement about her (2) so erm we got let down really with that</p> <p>S How did it feel that kind of the sense that they didn't know your daughter?</p> <p>C Disgusted, I'm disgusted. (4) Erm I mean her art teacher actually lives in the same village as me and I haven't seen her since and told her (.) and she said “I can't believe that”. She said “I put”-</p>	<p>Non-existent</p> <p>Communication</p> <p>Difficulty</p>
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<p>cos all her artwork, she is an excellent artist, (.)</p> <p>and she said “they wouldn't even give her anything about her art?” And I said “no” and she said “well I put her work together to send on to the school”. So that's got lost. (.) You know, erm the fact that she was an A star student all (.) across the board with everything (.) and her effort, she got an award for effort, she got awards (1) and I used to say to school (.) I know you don't believe what I'm telling you but err I've got awards at home, (.) that she's had from school, (.) I said so (.) they don't lie (.)</p> <p>[but nobody would believe that this was my child and that this school were</p>	<p>The experience of loss stands out to me here. When thinking about this moment in the interviews the sense of loss was seemed to come across in how Caroline spoke, it was almost a resignation to the fact that she has had to accept this. Perhaps Caroline's difficult experience means that she feels the loss of something that is potentially positive more acutely</p> <p>I wonder if Caroline needs me to believe her. She seems to have experienced other practitioners as questioning the things she ways These rewards seem to function as a form of proof They don't lie and by association she doesn't either. Perhaps we can see Caroline's need to be believed within the interview context as she feels others have not</p>
<p>S [mmm</p>	
<p>C seeing a different child (2) that was basically non-existent really (6)</p>	<p>Non-existent</p>
<p>S Wow (4)</p>	<p>Let down – it feel like they were ignored, not visible</p>
<p>C So I think we have been let down massively (4) between-between the schools. If she had been at the (.) the second school from the beginning they'd have been all there I think (.) I think that might have been a bit more (.) behind you, (.) but they were more academic as well (.) erm and if she'd have carried on at her old school, (.)</p>	

she would've continuously suffered (2) to the point that she might have had to accept these groups of people into her life that she didn't like (.) that were causing her damage, but wanted her to behave the same way as them. (.) And she really realised they were actually a lot of drugs once that headmaster-mistress had left, there were a lot of drugs in school (.) erm and she saw people and (.) and she didn't want to become a part of that (.) so that-that played a big (.) part on her (.) erm just-just seeing that. (2) Erm so (2) I mean all those things, all those things considered, I think she's, you know, tried to sort of hold her head up above water with all of it really and keep a bit of her dignity (.) but wanted (.) to move away (.) cos she didn't want- she didn't want that around her (4)

S Mmmm Mmmm Wow

C Yeah (5)

S Do you feel like she, do you think that, you mentioned her mental health do you think that some of that contributed to her exp[erience

C [Yeah I do, yeah definitely all those things yeah (4)

S	<p>And do you think other people recognise those mental health you know they all the staff members? Or...</p>	<p>This question is attempting to elicit more information however I wonder how this question is felt? Does it sound like I am leading the narrative? I wonder if</p>
C	<p>No, (.) no, (.) I think they are very sort of ill-equipped to do that but on the other hand as well as teachers (.) I think they are put under enormous pressure erm to hit their goals and that seems to be more important than a child's health and a child's mental health (2) erm (.) and (.) I mean I see parents (.) now that I knew (2) and their-their child's probably doing fantastic in GCSE and this, that and the other, (.) but they were pushing them kids, but then the school's telling them to push their kid's, (.) you know telling them to (.) get down and do this kind of homework and you do it with them, and you make sure (.) and all these things, so the pressure that is put on the parents anyway (.) erm to make the-the child live up to expectation (.) when at that age you know they've got everything going off, (.) they've got all those social aspects which are more important to them (.) than any grade and (.) erm (.) and they have the bigger impact (.) and I think it depends what area the school was as well (.) because (.)</p>	<p>Caroline feel this is a prompt from me to say that staff in school did not understand Lydia's mental health needs I am struck here by Caroline's empathy towards teaching staff. She recognises the pressures they are under even though it is linked to a potential reason for why Lydia wasn't supported in the ways she feels she should have been. Caroline says these pressures seem to be more important than a child's health and mental health.</p> <p>The experience of pressure from with the educational system. Not only are young people put under pressure but there parents are also. It makes me begin to think about the results driven culture within which the educational system appears to be in. Narratives such as driving up standards and doing the best for young people are narrowed to as view that doing the best means ensuring they achieve the highest grades they can. Though this may help some young people achieve their further aspirations I also</p>

<p>erm (.) the first school, I mean where we live there are pockets (.) of parents I suppose that (.) that don't sort of push their kids (.) and don't (.) encourage the kids and they've got difficult life styles them kids (.) and those kids are the ones that she saw turned to-to drugs just to get through the day at school (2) And that is what she noticed (3)</p> <p>S Gosh</p> <p>C Yeah (4)</p> <p>S Hmmm erm (2) When you were talking about erm there was something that you mention that I just wrote down and it was related to, you know, the anorexia and eating disorder stuff and you said it was like them saying go away and lose some more (.) What was happening then?</p> <p>C Erm my daughter had lost like a stone and a half she's not a big person anyway and and she was always vert fit (2) erm (.) and so she had lost like a stone and a half (.) but the BMI (.) criteria for her to have the help (.) for anorexia (.) she was basically one (2) one mark away from it. (.) Now X town are very strict (.) and they have this policy that if she's not, (.) I think BMI should've</p>	<p>wonder whose needs are being served by this narrative.</p>
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<p>been seventeen or seventeen and a half and she was eighteen and a half at one point (.) and at that point you are suffering with, er well she- she was depressed, (.) obviously she was having thoughts of suicide (4) erm but never acted on them (.) and unless she was at that stage (.) there was nothing (3) erm which to me that was too late anyway. (2) Now X City (2) said that (.) they would have admitted her (.) and that was a doctor that was fighting (.) for me (.) with X Town to say she needs an assessment straight away, (.) she needs help, she needs admitting, she's got an eating disorder</p>	<p>Support Let down Empathy – Caroline presents this person as someone who understands what is going on for her Containment Supported</p>
<p>S Was that a doctor from X City?</p>	
<p>C Yeah (.) Yeah (.) and this was a Gastro doctor (.) and what happens is when they (.) get to that stage (.) it-he said it's very, very dangerous because she's-although she's not lost more weight (.) recently (.) because she's growing it is very dangerous because all the nutrients are going (.) from her bones and things like that from her vital (.) organs and things (.) and that will have a massive effect on her she gets older so (2) it was very dangerous for her to get to that malnutrition level which she was at. (2)</p>	<p>I imagine this must be a really frightening experience. Use of the word dangerous, vital organs, massive effect, malnutrition in relation to her daughters health</p>

<p>Erm (2) and she needed admitting cos she needed the help (.) and what they would have done as a Gastro doctor is the-they like put a pipe into the stomach and then they feed them through that (.) erm and that's what he would've-he would've had her him in (.) because she was too exhausted to eat but that didn't fit the criteria (.) for anorexia (.) and eating disorders don't always fit the criteria-it's that's not always anorexia, if you've not got anorexia or bulimia or you are not cutting your wrists (.) and you are not wanting to jump off a cliff or something (.) then that's it (4)</p>	<p>Criteria</p> <p>Unsupport</p>
<p>S And how did that-that period in time make you feel as a parent?</p>	
<p>C Erm (.) ((sigh)) I-I just can't put it into words (5) Just (.) helpless, (.) helpless. Just (.) seeing your child (.) go from one thing to (.) this other thing (.) that was in your house and you didn't know what was going off, (.) you know she was having (.) screaming fits, (.) temper tantrums, (.) and she didn't know what was happening to herself. (.) Erm (.) you try to help her (.) and she didn't want to go near her (.) and you try to get her to drink something, you tried to get her to eat</p>	<p>Hesitation reflecting silences – languages of the unsayable which are coupled with a distancing potentially a vialed smokescreen from the experience. “Your child” not “my child”</p>

<p>something, "Getaway. I don't want you". (2) So I was absolutely (.) at my wits e-end (3) And and so was my husband, (.) he couldn't function. He was still going to work at that point I'd (.) had to finish my job (.) at Christmas anyway (.) and erm (.) so we were both (.) at our wits end (.) phoning the crisis team all the time, phoning (.) whoever I could phone, whoever I could get hold of (2)</p>	<p>Difficulty</p>
<p>S What were the responses of the people you were phoning? What was happening then?</p>	
<p>C Erm basically she doesn't fit into our criteria there's nothing we can do. (2) Erm but (.) I'd got a referral to CAMHS, (.) but that was going to take at least another month, and I'm thinking what state is she going to be in another month? (3) And erm so we were longing for that appointment and tried various ways of getting it move forward but that wasn't the facility to move her (.) move her into that service any sooner cos that is all there is. (3) Erm So I was phoning them (.) for help and support (.) all the time, what-what should I do? You know we were phoning them, (.) they shut though at five so then you can only phone the crisis team (.)</p>	<p>Criteria</p> <p>It seems like Caroline experiences a lack of flexibility in services</p> <p>Unheard</p> <p>Crisis</p>

<p>and then you get told (.) they can't do anything (2) because for one she is not old enough, there is that as well, and the other thing is they'll only take her in if she fits these criteria (2) erm. If she is basically what they call in crisis. (2) But we were in crisis at that time (.) and erm (.) we-we were just absolutely (.) appalled (.) and thought how are we supposed to deal with this w-what are we supposed to do, (.) you know. I told doctors at hospital and everything that (.) I-I feel like I'm not a parent anymore, (.) I'm a therapist now (2) and I said how do you expect a parent to become a therapist (2) because I am too close (.) to be able to do that and turn into that, how do I know when she is going to slit-cut her wrists (3) How do I know what thoughts she is having in her head and (.) what, you know, what i'd look out for (3) I'm a mum (2) I am going to try and do everything I can to sort of (2) help her f-what-whatever, that could have been the wrong way, (.) you know, (.) she needed professional help (.) and there-there wasn't any. (3) Erm but we just kept phoning CAMHS and they just kept giving us some advice over the phone (3) and that's basically all we got erm. (.)</p>	<p>Criteria</p> <p>Identity as a parent How does this sit with the previous research?</p> <p>Uncertainty</p> <p>Possible revision –between silences (not a parents... I'm a mum)</p> <p>I feel that some of the previous research highlighted that parents had a sense of no one else knowing their child's need like them. Does this challenge that?</p>
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I mean I did find a few other organisations (.) one of which I could never get through to but apparently it is good if you can get through to them but I could never ever get through to them (2) erm and erm that was called Young Minds and were supposed be really good but I could never get hold of them. (.) But they would have actually come out to you if they could those (2) er or you would have been able to speak to a psychologist (.) and we had a psychologist actually in place after a while (.) and at first she kind of helped (.) and then-but through all what was happening (2) There was- there was another break of communication because we were at chronic fatigue and they said “no there is a mental health issue, she needs to be referred to CAMHS”, so she put us back to X Town to be able to do that. (.) Then, bearing in mind this doctor, this paediatrician is the one that, (.) you know, we only see from one month to the next because she only has one clinic (.) and she doesn't (.)she doesn't put all her attention onto these cases she works more on wards (.) and (.) so (.) by the time we got to see her (.) erm (.) it were, you know, it

Communication

Lock of support – early help

was too late (.) because we got this gap then
from chronic fatigue X city, back to X Town, got
to wait again (2) And then (2) So (.) we kept on
seeing the (.) well we got back the psychologist
tried to (.) to do things for us even though she
had not got no (.) space and wasn't (2) equipped
with timeslots and things and being able to
come out to see my daughter and that is what
we really needed we needed someone to come
out (.) and erm (.) but one time she did (.) come
out and that's when she said "do you want me
to refer to CAMHS "and I went "yes I do" (.) erm
I said "because (2) if in a miracle she gets better
she still on the list (.) so we did that (.) and
that's when we were waiting for-for CAMHS so
in between that time there wasn't anything (.)
at all (.) erm we'd just go and see that doctor at
X Town and they just say, (.) they-they kind of
threaten her and say "look you will just be taken
into hospital if you don't carry-If you don't eat
you're gonna be took into hospital" (2) And that
was it (.) where as X city were sending letters
and saying I'm really concerned, I am really
concerned about the mum, the family, all of this
erm (3) but you didn't get that from X town (.)

Unsupported –space?

Waiting

<p>and a lot of the time in X town she didn't want me (.) there in that meeting (.) She tried to get rid of me (.) because I'd had a few sort of battles with her not sort of all out arguments but battles as in, (.) you know, I wanted you to (.) contact chronic fatigue a lot sooner once you realise what diagnosis it was, (.) I want-I wanted to have medication and not have it run out and seeing my daughter (.) suffer. I had to go up to the hospital once and put a call out for her (2) and erm and say, (.) you know, "I've come for a prescription for my daughter, she'd got one tablet left" and (2) err and I-and I said to her there (.) "she's really, really poorly" I said "if I-if I could have brought her I would", I said "she's so poorly" I said "I don't know what to do with her", an she well she said "she will have good days and bad days". (2) That's what I got. (4) So (.) all in all the experience as a mum from start to finish of all this (.) has been like I've just been non-existent</p>	<p>Obscured Rejected Battling/fighting Difficult Unsupported Unheard This feels like such a powerful statement. To feel non-existent. I wonder to the extent that this experience influences the interview. Perhaps that the interview is taking place and someone is listening to Caroline give her a sense of being heard and therefore existing. I hope the experience is an empowering through having an individual attend to her story, to listen and to hear</p>
<p>S Right non-existent?</p>	
<p>C Yeah (.) it's like, (.) you know, I've been the one that has been behind-the-scenes (.) pushing it all and getting things in place and (.) hitting all</p>	<p>Agency Obscured Powerless Unsupported Criteria</p>

<p>the brick walls and everything else (.) and sort of no support and no help (.) er but also being seen as the person that's (.) overreacting erm (3) erm, you know, you don't fit this criteria, you don't fit the criteria, you can't have this help, you can't have that help. () Erm not wanting me in-in meetings not wanting me (.) to be present with my daughter when she can't even be bothered to answer her question she is that exhausted, (.) you know, and yet she wanted her to (.) put across her own (.) views and things and (.) so I used to just sit there most of the time as quiet as I could to be and then I'd fill her in. (.) She'd ask a question and she'd just be sat there with her head in her hands and she be like that, (.) like that and I'm thinking she's going to like (.) melt down in a minute (2) So I'd speak up for her and erm erm (2) she just tell her "yeah I'm alright, yeah I'm okay"</p>	<p>Though Caroline feels non-existent, when she is seen and does exist she is blamed. Is it possible that Caroline is recognised in times when others need to project their feeling out and hold her as accountable in some way for the difficulties being experienced? Obscured Rejected Muted Speaking out Speaking out – but doesn't feel heard Here we potentially see the reason why Caroline stated earlier that there needed to be others ways to elicit the views of young people. Does she feel Lydia is responding in this way because she feels she has no other choice? Does Caroline feel Lydia is being coerced and responding in the way she thinks the adults want her to? I feel there is something here for practitioners to consider when working with young people... has a young person responded how they would wish to or are they helping to say what they think the adults want to hear?</p>
<p>S Right</p>	
<p>C You know, (2) so (.) you know I think parents should be given a bit more (.) consideration and a bit more respect than (.) than what they get</p>	

S	So that erm (2) message you were getting that you were overreacting, was that coming from lots of different people?	
C	ermm	
S	Like professionals, school?	
C	<p>Yeah, yeah, yeah it were really erm (2) Yeah it were like you weren't believed (2) It was like you were shouting but no one was listening (3)</p> <p>You are saying (.) Look if you give my daughter this help now this is going to help you through, (.) this is going to help her focus, this is going to help her feel (.) more involved, it's going to help her (.) err keep along with the people that is doing (.) the same thing, she's going to feel like that. And it made her feel less important because they saw that (.) basically she just wasn't coming into school (.) errm so they just saw her as that naughty child (3) that just didn't want to go</p>	<p>Not being obscured and excluded</p> <p>Unheard</p> <p>Blame</p> <p>Naught child</p>
S	And this was in specific conversations are you having with (2)	
C	<p>Yeah, (.) yeah, (.) yeah (2) It was just er (.) and it was just a general sort of feeling there was never any (.) consideration for what you were going through with your child, there was never</p>	<p>Lack of Empathy</p>

<p>no (.) erm (2) Just thought for you as a human being there was just nothing, (.) you know. (2) I used to speak, I mean I still speak to them now at X City, chronic fatigue, and it is like (.) "oh God that must be so hard for you, this is so hard for you as a whole as a family". And just having somebody say that (.) just meant the world. (2) And erm so just having that experience (.) made me see why aren't I getting that here? (.) Why aren't I (.) getting that support (.) here? (.) Yeah, just unbelievable. I can well understand (.) why all this sort of (.) sex trafficking and everything that has gone (.) on has got thrown aside (.) because, (.) you know, I know of one parent that's gone through that with their daughter got groomed (.) and (2) erm she was the same (.) phoning the police all the time, (.) "she's gone missing, I don't know where she is, I'm afraid that she's with a group of people that aren't safe", "well er she's 16 she can do what she wants", erm "But she's missing, she's missing". And then I think she went missing for 30 hours once (.) and they found her (.) with a day to spare before she got sent to London (.) so she could have lost her that day (.) without</p>	<p>Lack of Containment</p> <p>Empathy</p> <p>Containment How things can be made better for Caroline</p> <p>Unsupported This feels like a very extreme comparison. I wonder if it serve to communicate the severity of Caroline's experience. Is she using the Sexual Exploitation discourse which has been prominent and recognised to have been a serious problem as a ways of reflecting the serious problem she has faced? Perhaps Caroline feels the need to ensure I recognise the seriousness of this experience. Perhaps she also seeks to reflect how her experience is more common that is accepted in the same sense that sexual exploitation has been shown to be in a number of areas</p> <p>Frightened The comparison appears to be a smokescreen the emotions she has experienced. There is an appeal to an authority (the police) which seems to dismiss this parents' concerns; it is possible to see parallel with Caroline's story Within this part of the narrative I wonder if Caroline</p>
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<p>her shouting (.) and saying “find her she's gone missing” and I think she took, she's got a court case, she went to court (.) and the judge actually spoke up for her (.) and said (.) “can't you see what this parent is going through?”, and she got treated like that, like it was a parental issue, (.) like the parents were just shouting the odds and err there was nothing really going on (.) and that it was just a family (.) feud, family issue, and because she is 16 she can do what she wants, (.) you know (2) erm And so I know-I know it is not just my experience (.) I know it is sort of wide, (2) you know (3)</p>	<p>is communicating her worries of losing her daughter. This alternative narrative offers a means by which to distance herself from her experience. It feels like a thin veil by which to allow her experience of loss to be spoken of.</p> <p>Dismissed and ignored</p> <p>Blame and responsibility</p>
<p>S So you got that sense of (.) people sort of thinking this is, this is a family issue, it's a parent issue?</p>	
<p>C Yeah, (.) yeah, (.) yeah, (.) and you deal with it. (3) Your child is misbehaving and it's a behavioural problem between you and your daughter and you, you sort it (5)</p>	<p>Naughty child</p> <p>Blame and responsibility</p>
<p>S And how did that kind of make you feel?</p>	
<p>C (4) ((sighing)) Just, just despair, (.) just despair really. (.) It made me want to become a politician ((laughing)) and make it all different. Just, (.) just makes me determined really (2) to</p>	<p>The injection of humour here seems at odds with the feelings being described. It is almost as if they become too much to express and the conversation is diverted into another direction. A smokescreen for the emotional experience</p>

<p>sort of do something (.) to try and change something (.) but I don't know what yet (4)</p> <p>S Oh wow (3) it sounds like it has been a real-real journey</p> <p>C Oh absolutely, (.) absolutely (2) It really has. (.) I am just glad now it's kind of, sort of (.) calmed down a bit because well I got the help with CAMHS, (.) but they messed up, (.) they messed up, again they don't listen, (.) they don't listen (.) and there are quite a lot of services within CAMHS that nobody knows about that they do and they do a lot of good stuff, (.) you know. (.) Erm I just wished I could have seen that good stuff a bit sooner, (.) cos for a start I had to wait (2) So it's like you are in a queue, you know, first of all to get to see them and initially they are supposed to come out to see you, (.) so you have a nurse allocated to you, a mental health nurse and erm I am just looking at that poor dog over there it's suffering with his joints so much (2) erm yeah erm they are supposed to come out to you (.) and-which they did. That was the initial assessment (.) and they said (.) "Well whatever this is, (.) this is not (.) really acceptable and we can't let you carry on like</p>	<p>I think the response I give here is pertinent to the conversation that has just occurred. I don't follow up the feeling of despair to investigate this further instead I offer a way to move the story on by talking about the journey Caroline has had. I wonder if I felt too uncomfortable at this time to ask more about this experience. What is the cause of this despair? Is it how people see Caroline and Lydia? Is it that she feels powerless to access support? Is it that she doesn't know how to help her daughter? Unheard</p> <p>Empathy – Caroline is heard</p>
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<p> this". So that was a relief to hear that (.) and because she'd, it had just been the point after where she was nearly admitted in hospital and (2) and erm (.) they er (.) she said "well she's not got anorexia because she doesn't tick all of the boxes are for that". "No but" I said "there is something going on that (.) we aren't equipped to deal with and she needs some help, can I get her to see a doctor", "yeah we have got some doctors, I will get her booked in", so we got her booked in to see a doctor. (2) And a erm she prescribed some medication for her only because (.) I did say, (.) I said "Look I know I'm speaking for my daughter" and before now, you know, I explained my situation I said (3) "I know (.) you need her to speak up" said "but we are the ones that's seeing her suffer (.) and it is making us all suffer (.) so (.) I need something for her", says "She needs something". (.) And erm so she did agree (.) but she went and got backing off another doctor and he was a consultant (.) so we went in to see him as well (.) and that is where it all kind of went wrong because (.) she'd already gone through chronic fatigue and them saying they do like </p>	<p>Containment</p>
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<p>rehabilitation there, well that was the point where she just spiralled down from that point (.) and he was kind of trying to introduce a bit of that (.) back, and I said "but we have already tried this (.) and my daughter has not been able to do it". (2) Anyway at that time (.) she just agreed to, they didn't want (.) the nurse to come out to see her anymore, (.) they wanted her to come to see the nurse and the doctor each week and spend some time (.) and (.) go for a walk or something like that cos they wanted her to up her energy levels and her exercise (.) but this was a person (2) who had not long since nearly been put in hospital for malnutrition (2) and she didn't have the energy, (.) she didn't have the capacity, (.) you know, she was having sort of fits on the floor, and (.) things like that and you are saying to her come and have a walk, you'll feel better; do you know what I mean? (.) So to her teenage mind she was like I'm not doing that, (.) so she dug her heels in. (.) Tried to get her there, I got her there once, (.) couldn't get her there again, she'd just blatantly wouldn't go. (2) Erm but they carried on with medication (.) and-and</p>	<p>Unheard Agency – inertness of voice Lack of power</p> <p>Power and practitioners</p> <p>Difficulty – the worry for Caroline</p> <p>Difficulty Powerless</p>
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there were-you only have so many chances with them (.) to say-to come in and get the treatment, (.) you only get three chances and then they take you off the books and they'll just refer you back to your own doctor (.) and I said, you know, "please don't do that" I said "erm what can we do? (.) Because (.) we-we have still got to deal with her, we are still having all these same issues, the same problem what-what do we do? (.) How are we supposed to do it? I need some help". (.) So there was a suggestion that she could have (.) a support worker to come out and get to know her (.) and (.) but at-but at this point still they still stopped the nurse from going out to see her. (2) Erm so she still wasn't getting any help (.) and (.) and-even now she, she, she doesn't really (.) and then erm so (.) this nurse said well what is if you come and see one of our family therapists (.) erm so that is what we are doing now. Me and my husband go and see the family therapist in order to be able to work with my daughter.

S Oh okay

C Erm And that is what we do now. (3) And (.) some of what they've said helped, but I think

I wonder if that set up a sense of desperation. I wonder what its function is compared to how it makes parents feel? Is this something that has been said to Caroline or is it how she feels she is treated – a three strikes you're out perception. From working in my EPS service I understand that other parents have experienced being discharged from CAMHS for being unable to make appointment times. Is this a common practice for CAMHS? Is it a written rule within their service? Are they flexible around this?

Powerless

Unsupport

A challenge here to a narrative of parents know best?

the medications helped (.) more but then she has got a bit of her drive back so she's doing it all on her own. (.) She's doing it without them anyway. (.) She's, erm she's, not doing everything that she should do (.) and I'd like to get her to a point where I could take her back to X city (3) and get more help there erm but she's not where she was, you know, like in January, (.) thank goodness, so (.) things are looking up a bit, so things have calmed down a lot, (.) there's own no more sort of (.) temper tantrums and erm fits (.) and I don't know just (.) all the things going off that you're not-you don't know what to do about and it is all awful to think (.) that like now that's been a gap from it, there is still her attitude and her behaviour as a result of everything (.) that you've got to deal with and it is hard to distinguish (.) from (.) the chronic fatigue, from the eating disorder (.) I've been told now that she has got a sleep disorder. ((sigh)) All these disorders erm (.) but no still nothing really (.) The most support I have got is from-from this support network

S With the parent and carer forum?

C Yeah

Diagnosis – Unsupported. The “Still nothing really” indicates a level of expectation? Is diagnosis expected to trigger support?

S	<p>And w-what has it been like been told that your daughter has got this disorder and this disorder and...?</p>	
C	<p>((sigh)) (.) They're just names aren't they, they are just titles aren't they. Erm (.) she-she wouldn't see, I mean even now (.) she wouldn't see that she's got an eating disorder, she doesn't think she has (.) erm and she is (.) eating but only through medication, (.) it-it gives her an increased appetite. (.) If we took that away we'd be back to square one (...) So there's still there is still not the right (.) support there (.) for her but (2) now this is where it gets really strange but—as an educational thing I found out (.) through all this from October to January when she had home tuition and all that, (.) I found out from getting the prospectus from college she-she could have gone to college from the age of 13 (2) And I wished, I wished I knew that, (.) because the college is more designed (.) to cater for all them things. (.) They'd have been the one that were telling me she has got an eating disorder and she is losing too much weight, they'd have been the ones that would have said “no (2) she can't walk up those stairs</p>	<p>Diagnosis Not supportive? Don't seem to offer comfort or access to help</p> <p>Communication – mum indicates she wasn't told</p>

but we've got a lift in place she can use the left.
(.) There's a room that she can use that's quiet
she can go and eat in there, she doesn't have to
go out in the cold". (.) Erm there's some support
workers that will help her with her work, she
doesn't have to worry about her work. (.) Erm I
could have got her (.) an educational health care
plan in place for her right from the beginning,
they would have collected all of that
information and they would have told me about
that (.)

S Mmmmm

C And all that those things would have now been
in place and (.) things for me would have been
easier because people would have been coming
to me and saying (.) er look we are having these
issues she's obviously struggling, (.) it's
obviously difficult for you as a parent, (.) you
know we've seen other kids go through this (.)
we're quite equipped we'll do whatever we can.
(.) The pressure would have been taken off of
her to do exams (.) she would have already
been in place at college and know-known that
there were that system there. (.) The bullying
would have been eradicated cos they have a

Wanting to be recognised

I wonder if this would have been the case? Would a college have been able to meet Lydia's needs to this extent? Is there a sense that Caroline just thinks anywhere else has got to have been better than the school her daughter was in?

zero (.) policy. (.) All them issues would have not
been there (.) so then we could have just
concentrate on (.) her chronic fatigue, (.) err,
err, you know, (.) her eating disorder and
whatever else (.) err was going on at the time,
(.) but (.) I think as parents we would have had
more (.) back up, more support (.) and people
recognising that (.) well she can't do this but we
can do this. (.) [That would have meant a lot

S

[mmm

C

to her (.) that she wasn't just put on a heap and
she wasn't (.) not cared about cos that is how
she felt, (.) that you know she had gone from
one school (.) with kids that she had grown up
with from being little who had lived around us
(.) and all those erm (.) kids she had gone to (.)
primary-er to comp with, (2) they're the ones
that turned their back on her and didn't want to
know her, so to her (.) and even now she
doesn't want to go outside and let-and let
anybody see her (.) from where we live, she
wou-she wou-I mean I'd move tomorrow if I
could erm (2) just to give her that new-that
new start erm (2) and (2) You know she finds

Support

most solace talking to somebody (.) on a computer that is like thousands of miles away, they are going through the same thing. She gets more (.) solace from that than she would (.) wanting to reach out to the people around her that tells you a great deal (.) about what is going off (.) with kids. (.) And-and **I think** she would have felt more normal (.) cos that's what she felt like she was becoming (.) not normal, and the fact that she got bullied (.) was the fact that she wasn't going along with their (.) with what all the other kids were saying, (.) you know, come out with us, take drugs and stay out all night and get involved in one thing and another. (.) And she was smart, pretty, fit (.) and she-she tried to keep her cleverness (.) like under wraps (.) so that she didn't get picked even more (2) and that is why she got isolated. (.) Erm it wasn't the boys, it was the girls cos they were- they were just jealous of her (.) and so that is how she sees the world now, (.) you know. (2) But she's, we're looking at colleges and she is maybe hoping to try college in September. **But**

all colleges are (.) set up, you know, I've been to one college (2) again there's lifts everywhere (2)

I wonder if going to college would have made a difference to Lydia and Caroline?

erm It is all set up for them to feel independent
and take a bit of control of themselves, that's
what they want to do when they are 16 and (.)
but there's the support that's (.) that's designed
(.) to keep her confidence up rather than knock
her confidence. (.) And the support's there,
they'll adapt around her (.) and if I need this

health care plan in place they'll-they're the ones
that will collect all of that evidence (.) so, (3)
you know, it can only be better (.) so I wished
now I'd known about all of that (.) from 13 (.)
and might have eradicated a few of the other
issues you never know ((laughing)) but we can
always do that can't we, hindsight isn't it (4)

S Thank you so much for that. My only other main
question is around what you kind of expected
being a parent would be like compare to how
your experience has been?

C ((Sigh)) I don't know erm (.) er I don't know, I
expected, I don't know, I think you expect some
ups and downs with your kids (.) but I never
expected what I got. (.) If they were just the
teenage (.) years that were difficult I could
accept the teenage years. (.) If it was just that
that I was dealing with (.) but then when you

Communication

are dealing with (.) health issues that are, you know, things that aren't accepted so well (.) because to look at my daughter there's nothing wrong with her. (2) Erm but if she were in a wheelchair then you would realise that there was something wrong. Erm (2) or if she had got a broken leg you'd realise there was something wrong. (.) But (.) the issues that we've had is like, like mental health issues (.) and a physical-physical issue as well (2) erm (2) have been the two most difficult things by far I think. (.) So I never expected that, (.) I never expected any of that, definitely not (.) erm and it's made me, (.) it has made me see er things differently (.) and it's made me, (.) it's made me value things a lot more, but it has also made me (.) see things more from their perspective, rather than seeing things from (.) an adult perspective or a parent's perspective (2) erm cos we just think oh they can, they don't have to-they can put up with that just, you know, you can put your kids through anything, (.) and they love you so much and they'll do anything that you want them to do (.) and it's just not like that. (.) They are their own person, their own identity (.) and they have

Caroline seems to tap into a familiar discourse around the difference between physical and mental illness. The visibility of Lydia's illness is perhaps used here as a means of making sense of her experience. That her daughter has a mental health condition rather than a physical one perhaps gives Caroline the means by which to understand the treatment she has received. I wonder it also serves to protect her from a sense of feeling that there was something personal in the way that she interacted with individuals and services?

This seem to report a change in Caroline's view of having a daughter and being a mum.

Perhaps we can see a sense of what Caroline expected being a parent to be like and how that has changed. She has a sense that children will love their parents unconditionally and do anything they are asked however she feels young people have their own difficulties. This changes

got their own things that they are dealing with in their life (.) and you're the ones that are guiding them through it. (.) You are not pushing them through it (.) and I actually, I mean, I-I love learning, my daughter loves learning she's a really bright girl, erm she will have a bright future she will find something, erm (.) and-and it is never too late to start learning the different things that she wants to do, (.) but there's- there's barriers, you know, cos as she gets older (.) she can't do a language and she can't (.) do certain GCSEs again (.) erm because she has missed that time (.) so that's the one slot that they have got (.) so there's all that pressure put on, you know, and err (.) but it's just not like that, (.) your health is more important and your mental health is (.) vitally important, the most important. (2) Erm without the mental health being (.) stabilised you are not going to achieve any of the other things physically or anything (3) And er it's made-it's made me see that. (2) And I've always wanted to help kids, you know, from the age of 13 cos I had a tough time when I was 13 and I always wanted to (.) be able to do something to help kids at that age (.) But now it

Caroline's sense of what being a parent would be like

Connection

Hope

Hope

This perhaps reflects how Caroline's own experiences influence how she feels she would like to be.

has given me a full view, (.) you know, a full birds eye view of er of what there is (.) there, out there (.) and how the temptations to wonder from different-different path's (.) are just so easy (3)

S Mmmm so you said you had a difficult experience when you were 13 as well

C Yeah, yeah, yeah well I grew up in a family where (.) I was the youngest (.) and I was bullied at school as well (.) erm but for me the bullying was, (.) well it was a local it was on my street, you know. There was a particular girl (.) erm (.) and even at school (.) one of the teachers was bullying me at school (.) err but I didn't know that it was called bullying at that point you know erm and err (2) Yeah and when I went up to comp I was thinking "oh thank God for that, (.) leave all that behind" and I thought "oh thank goodness for that" (2) And it was just-just the growing up part, at 13 I just found (.) er conflicts erm of who I actually was and identity crisis I suppose (3) erm what I wanted to do, who I want to be. I've always been this perfect (.) girl that grew up and did everything right, (.) please everybody, did everything for everybody

Connection

Connection

else (2) and I just wanted to escape from it (.)
 and-but I suffered (2) emotionally (2) erm
 because I loved learning and I worked hard and I
 was getting let down by-by the school and (.)
 erm our year was a bad year apparently, I don't
 know, so we all got put in lower sets and things
 like that (.) but I-I was the one that still kept
 trying, (.) was still doing everything right but got
 classed the same as everyone else and (.) er so
 like maths and things like that I got held back
 with that erm (.) erm and erm so (.) my view
 was different, (.) the way I escaped it was that
 as soon as I was old enough and I could do what
 I wanted I went travelling (.) and that is exactly
 what my daughter wants to do, she wants to go
 travelling. (.) But she wants to do it differently
 she wants to go to different places (.) but that is
 how I (.) sort of dealt with it (.) err and moved
 on from it but er thank goodness I put all that
 behind me and I haven't got any of that
 nonsense (.) anymore. (3) Err and er, you know,
 I can live my own life and I can choose my own
 group of people (.) and so I do understand, you
 know, er where kids are coming from and where
 my daughter's coming from, perfectly

Connection

Connection

Connection: There is a continuing sense of a similarity in experience which may serve to keep Caroline connected to Lydia. Given the sense of loss she has experienced it may serve to bring her closer to her daughter who still seems to be resistant to this relationship

Caroline reiterates her understanding of Lydia's experience but goes on to accept that her daughter does accept this understanding. It makes me feel a sense of rejection. It seems like Caroline is trying hard to keep connected to her daughter who doesn't

<p>understand that, (.) but she won't accept that I understand that ((laughing)) cos that's (.) just (.) the, you know, difference between me and her she wants to have her own experiences, she doesn't want to have my experiences and she doesn't want me to relate to her because (.) hers are hers and she doesn't want me to impede on that. (.) So, (.) you know, (3) I'm sure when she's older (.) she will (.) have a chat with me (.) and sort of agree "yeah, yeah that happened to me, yeah that happened to me" (3) ((laughing))</p>	<p>accept this. The laughter seems almost out of place in the face of this rejection, I wonder if it a means by which to move away from the experience of rejection reflected in the narrative here? Rejected</p>
<p>S And what-when you are having those kind of issues (.) at that time what-what was it like with your parents and (2)</p>	<p>There appears to be hope for a future time</p>
<p>C Errm they didn't have a clue, they didn't have a clue any of it was going on (.) especially when I was in primary (.) they didn't have a clue, (.) not a clue at all. (.) They knew that this girl that lived on the street was a constant battle. (.) Er they just used tell me just to walk away, you know, usual advice, (.) put your head down ignore it, walk away. (.) But then when somebody is stood there and they're biting your arm (.) and they are putting their teeth into</p>	<p>Reflecting on the research and the interview I am not sure that I wished to elicit with this question. Perhaps it reflects a sense of the importance of early childhood experiences in psychoanalytic theory.</p>

your arm and they are leaving you with a bruise
are you supposed to walk away from that and **I**
did, I have just stood there and let it happen (.)
so, (.) you know, **I went** through a stage at one
bit where **I hated myself** for letting someone do
that to me, (.) **I hated** that and erm (.) erm (.)
but **I got my own back, I got my own back** one
day (.) so **I am pleased** that **I did that**.
(laughing) (2) And **I stopped it** myself (.) and
again today you can't even do that, (.) you can't
even advise your kids well don't put up with
that (2) because you are telling them to go out
and (.) erm (2) assault somebody aren't they
really. That's what they're saying, (.) it is assault
even at a young age and that you're condoning
it. (.) You can't even advise your kids to do that
(.)erm (.) and, er (2) you know, it's not a good
thing for kids to be fighting is it really. (.) **But I**
didn't-I were never a fighter (.) erm (.) but **I did**
get my own back one day definitely, yeah (.)

S In terms of when your daughter is going
through it, you talked about the advice that you
gave, what kind of things did you sort of

C Erm well when she was going through things at
comp erm (.) **I thought I knew everything** that

<p>was going off, (.) I thought (.) I knew, again it was one particular girl that was sort of a ringleader in all of this erm (2) and (.) so I thought that I knew because we were so close (.) she used to tell me everything, everything that went on, (.) she'd tell me. So I said right well don't do this don't do that, (.) erm stay, you know, stay clear I suppose. (.) Similar advice erm</p> <p>S Where you influenced by the advice you have received?</p> <p>C Possibly. (.) Possibly yeah. (.) But my problem was at one point I thought what do I do, do I take this more seriously, do I, do I do something more about this (.) or what? (.) And a few teachers I spoke to (.) privately an said (.) "Look do you think you can keep her away from this particular child as she's having this affect?" (2) erm "I think it would be good if they could (.) just have a bit of distance", could they not just sit together in every class (.) and things like that, could she sit with another person, (.) things like that erm which happened some of the time (.) erm but this girl always had a way of sort of worming her way back into her confidence. (.) Er she was quite manipulative and she used to</p>	<p>Loss</p> <p>This seems really important in the context of the narrative. There has been a great deal of adversity that Caroline has overcome and it has had an impact on her relationship with her daughter. I do also wonder to what extend that is part of the experience of being a parent as your child becomes less dependent upon you and begins to focus on their friendships rather than their family relationship?</p> <p>Being seen</p> <p>Being heard Some agency to affect change</p>
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manipulate the girls into (.) siding with her and then excluding my daughter. (.) So (.) in terms of that, you know, there wasn't much advice you can give really, not much. (.) It was a case of well (.) can you find some other group of girls to hang around with. (.) So she did she did do that as well for a while erm but she says "mum, I can't I can't deal with it any more, I can't stand it anymore" (2) erm and what hurt her, what really did it was (.) there was this new girl that came into school (.) and of course because she's knew kids-everybody wants to be her friend with her (.) and that this girl was a girl that sort of flitted around people and erm anyway so she is stuck to my daughter for a while and she came on holidays with us, things like that. And she came on holiday one year with us and at that point my daughter was just, (.) I just saw differences in her (.) and as far as her energy (.) and just slight differences and I thought she is just (.) feeling a bit off it but, you know, kids feel like that they are growing up. (.) Anyway (.) this girl came on holiday with us when she got home (.) it was her that, you know, spread rumours about her and talked about her to this other girl

that my daughter had been trying to keep away from all this time (.) and so she went back off with her and **left my daughter completely on her own and that is what broke her heart** (.) er cos **I said** to her "Are you sure you want this girl to come with us cos" **I said** "I'm not, (.) I'm not **sure** about her, (.)cos **I am not sure** of her motives, she just using you for the holiday, cos she's dumped you before" and things like this (.) and **I said** "Are you sure she is not going to do that?", she said "No I am not sure (.) really" and I said "Well do we still take her do we not take her", "No mum, can we still take her, I'll be fine it will be okay". (2) **And I remember saying to my husband if she does that again to her it will break her heart. (.) And it did. (.) And that was the day she broke down in school (.) and then she basically got a telling off from someone for crying**

S Wow

C Yeah (4) So she was absolutely terrible. (.) So (.) she came home. So then **I, you know, complained** to her year head (.) and stuff like that and again it got "Oh well what do you want me to do then?", erm so **I told him** (2) and err

This is such an emotional point for mum. It makes me feel incredibly sad. I also wonder if Caroline has felt left on her own when being unable to get support

This must be such a difficult thing to experience. The emotion in the interview seemed very present at the time
Let down

<p>“Alright well (.) erm if she need help she can come to me” (.) and that was it, that was it. I said “Well she has already tried that and that’s not worked” and that was it, (.) that is all they did. (.) So they just, (.) the thing is with that school I think they had bigger fish to (.) to deal with if you know what I mean, they have got bigger problems and er my daughters problem wasn't big enough really (3)</p>	<p>Unheard</p> <p>A lack of agency to change the intervention</p>
<p>S What do you think those big problems were?</p>	
<p>C Well I think they had other students that were always kicking off (.) and that they had to sort of control and deal (.) and er expel or send home and (.) I think they had a group of kids that were a bit unruly (2) and they seemed to deal with them more cos they were always expected to carry off that way so that is what they were always doing. (.) And then so, you know, the kids like my daughter who wanted to get along, wanted to get on with the work and it was important to her to do that, and (.) she was conscientious and all those things (.) er just got left behind</p>	<p>I wonder here what Caroline’s view of those other young people is. She has spoken before about the head teacher making a difference to young people who have difficult home life situations</p> <p>Left behind – As in forgotten, not heard, not visible?</p>
<p>S Yeah (2)</p>	

<p>C That was the main thing. And it was the same thing in primary really, (.) they had people, I think it was at a stage (.) where (.) a lot of schools weren't equipped for like autism and things like that and they were trying to keep kids with those issues in school, (.) in mainstream school (.) and they weren't equipped to deal with-with their issues. (.) And they seemed to get the most attention (.) all the kids that came from families, big families that (.) had troubles academically (.) erm got more attention and more help and more support than my child that was constantly (.) at a same level, but would have been at an even higher level, (.) she went in at a high level, she always was at that high level (.) and didn't get that same encouragement. (.) Unless she stood out, (.) unless she-she was quiet, she was shy, unless she stood out, she was a bit mouthy and a bit bolshie and she got noticed and got the support but the ones that are like my daughter sort of thing middle of the road if you like (.) just thought "oh yes you can be sat with her and you can bring her along" it was like that (.) because she was (.) able to work on her own, under her</p>	<p>It seems the Caroline feels that school are not able to meet the needs of young people with special educational needs. Perhaps she would have a view regarding the development of staff or the use of specialist provisions</p> <p>Caroline makes a point of saying academically - it perhaps gives a sense that academic needs and others needs were seen differently</p> <p>I wonder if Caroline feel had Lydia received the encouragement that Caroline feels others got that Lydia may have been able to cope better in school?</p> <p>Caroline gives the impression young people were used to support others. I wonder if Caroline has a feeling that not only was Lydia missed but was also used to support others when her needs were not being met?</p>
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own initiative, She was clever enough, and she could help somebody else along-along with her as well

(.)And that is what happened in primary (.) to a large extent (5)

S Thank you

C I hope it is useful to you or listening to me and all my problems

S No, you know, I feel so privileged to do a piece of work like this because otherwise you don't really get to hear peoples experiences an-and people like yourself have been so (.) willing to share and share quite a lot of, you know, experiences that er for me its brilliant but it's- it's a privilege to be able to do it as well so really thank you for taking the time. Erm what I intend to do is spend the summer er just looking through the different erm interviews that I have done and trying to do some analysis of that and then what I have suggested to everyone that has taken part and to you as well erm is that it would be nice if I could meet with you again after the summer and just talk about erm what kind of thinking has come out of that err mainly because keeping (.) you and the other people's

<p>stories at the centre is really important for me</p> <p>cos it is your stories and I'm just privileged to be able to-to listen to them and hopefully think about how we can use those to help other people, services erm just think about how they might work with others the kind of recommendations we might be able to pull out of the of all the different experiences that people have had. So that's the plan if that's okay</p> <p>C No yeah that's good, you know, (.) It would be nice if people did listen</p> <p>S Yeah, yeah</p> <p>C Definitely (2) That's what's important</p> <p>S Absolutely</p> <p>C Well hopefully (.) well I can't say any of it is for nothing, (.) cos it's not erm but to be able to share experiences, I won't be the first person and I won't be the last (.) I think as an area (.) and as schools and (.) everything, (.) you know, people need to know what's going off. (.) People need to know what parents are going through. (.) We've lost all that community, (.) they've been destroyed so there is no community feel where people are supporting each other (.) and people are just excluding people and the</p>	<p>Loss</p> <p>Caroline's sense of loss again is prominent here. Does she feel excluded from her community?</p>
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difference. (2) The way I know that (.) is not just
 from what I have gone through personally (.)
 but when the headmistress was in that school
 (.) she had a profound influence on the whole
 area (2) because before she came it was-it was a
 bad area, a bad school. She came along and
 turned it all around. She had an effect on the
 teachers, (.) she boosted them up, (2) she, she
 said that they were fantastic, (.) they were (1)
 and she used to talk about the kids and she
 would say "I know they drive me mad, and I tell
 them that every day that they drive me mad"
 she says "but I love them" she says "I tell them
 they're fantastic every day that they are". (.)
 And that has a massive influence on the families
 where (.) the kids were from bigger families and
 they got massive issues going on as a family, (.)
 you know, somebody had got cancer or
 somebody was disabled or (.) and that child
 was, you know, probably caring for the parents
 (.) so what was they going to see? So what was
 going to happen to them for the rest of their
 lives? And then there was this headmistress
 that's saying that "you are really good at that. (.)
 Come on let's do something" (.) and she'd have

Relationships that connect

The approach of the head teacher has a profound affect in Caroline's narrative. She feels the approach of the head teacher influenced the school community. This perhaps reflect the importance of instil in an inclusive ethos from the school leaders

Connection – relationships

This approach really resonated with me as it reminded me of the relationships that I was able to build with young people when I was a teacher. I would equally tell them they were driving me mad but that I still cared about them. I felt it as was a powerful message

plays, she had plays that they did, they never did them before, she got people dancing, and they never had dancing in the school before, (.) she employed, she got somebody-a teacher and encouraged them to carry on with their dancing skills. And they were trying to get me to get my daughter to go into athletics and this teacher knew somebody in athletics, at an athletics club and things like that. There were all them connections, that it was a massive connection (.) and (.) when she went all that went, (.) when she was there she was a strict (.) woman, she was a tough woman (2) erm but (.) the kids knew that when they came in to school they were there to work and they were there to have a good experience (.) and as for as bullying **if she had seen my daughter crying like that she'd have been straight on the phone to me, (.) she'd have been trying to get to the root of it, to the bottom of it, and she would have put a stop to it,** all of it erm, (.) you know, all them things. (.) When my daughter saw kids then turning back to drugs where they had turned away from it, (.) there were (.) there's always an element of drugs everywhere isn't there (.) and (.) **I think**

Connection
Recognition

<p>because they had such a positive (.) network going off and in school (.) the kids were turning away from that choice, and realising that they had got a purpose and a meaning and she saw them kids (.) turning back to drugs (.)</p> <p>S Right (.) When things had changed when the new head has gone (3)</p> <p>C Yeah (2) cos she said one day, because they used to have a trip to Alton Towers every year and it was only for the kids that had attendance and behaviour and all that business, (.) well this new headmistress (.) they went no matter what, so there was no criteria for it. And they would actually turn people away for their bad behaviour and not let them go on this coach. (.)</p> <p>And it was all paid for and (2) and erm anyway this erm girl that has come to the school and she said to my daughter "do you think I could come round with you tomorrow cos the girls that I am hanging around with, they are wanting me to go and join them in the park (.) at 8 o'clock in the morning (.) er but they are all going smoking, they are all smoking dope. (.) Er and she said "I don't want to be seen with them", (.) "Oh yeah of course you can". And</p>	<p>Caroline gave me hope at this point that it is possible to cultivate school cultures and an ethos which can make a dramatic difference to young people. She also seems to be highlight way of approaching young people that make a difference – this could be useful for practitioners and school staff to consider. How do they communicate that they value and care for young people and their families? How can we put that message across in schools/services?</p> <p>There is a dramatic change here. Caroline indicates that it is down to boundaries. I wonder if there are other influences for feeling that there is such a change here?</p>
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they turned up on the couch stoned and they let them go (2)

S Wow

C Yeah, (.) yeah (.) And then they were going on, you know, fairground rides, Alton Towers (.) so they could have harmed themselves, they could have harmed other people (.) and I don't know how they let them on because my daughter says "I don't know how they could let them go" (.) she says because she noticed how they were talking, slurring their words, she noticed smell that was on them (.) and you could tell that they weren't-they weren't right (.) and they let them get on. (.) Now the other teacher had a presence and she used to, she used to have teachers at the front of school and they use to know the kids that were going smoking and er, you know, if they were into drugs they used to know who they were (.) and they knew who the people were who were coming and supplying them as well (3) And they stood at the front of school (.) And they made their presence known in that school and outside of that school. (.) So teachers there were two on the side and one in entrance cos there was a drive in and erm (.) so

This is an interesting notion – would presence equate to being visible? Being seen? These seem to be experiences that Caroline has not always had

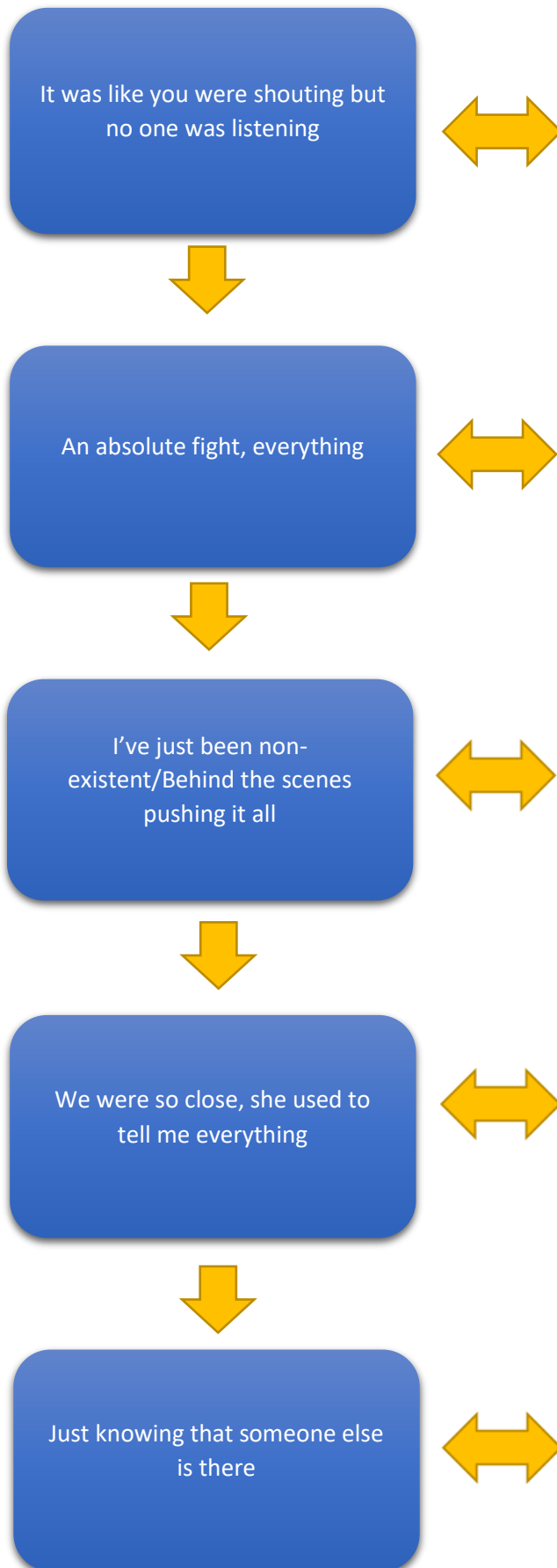
it stopped that influence coming in to school (.)
and then they noticed which ones weren't going
to come in that day because they saw them go
round the back of this building smoking. ((throat
clearing)) So they had an eye on who was in (2)
and it was the same at end of school (.) the way
pupils-there were teachers there watching them
out. Now when that went, (.) when the
headmistress went and them teachers (.)
weren't there any more to do that (.) my
daughter noticed that there was this couple that
came to the school grounds (.) just stood
outside gates (.) er Because it was, like I say, like
a drive in and drive out and they were always
stood there (.) and then the kids that she knew
that were into drugs were going up to this
couple (.) to either the man or the woman (.) so
she noticed that

S Wow gosh that's really scary

C Yeah it is and that's really scary to the kids isn't
it (.) so that-that headmistress had a massive
impact on the whole area (.) because it was
setting a precedent's and saying you don't have
to do that you've got this (.) and that you are
important and whatever lifestyle you've got and

<p>whatever problems you've got you can come here and you can forget about it, this is what you've got here, (.) you know, and they had that security (.) and somebody believing in them</p> <p>S Sounds like she was a strong person</p> <p>C Yeah, yeah she were, yeah (.) definitely. She went on to do erm something to do with OFSTED. (.) She'd been er a teacher and a headmistress for 30 years and she wanted to (.) help a different (.) area of education and so she went to OFSTED (.) for helping them erm but I don't think she was allowed to come back to the area that she had just worked in, I don't think so she was probably (.) in a different capacity (.) but it was such a shame, (.) I nearly cried when she left ((laughing)) (2) I was like oh God (.) Yeah</p> <p>S That has got to be some kind of indictment that you know people get upset if she leaves</p> <p>C Oh yeah, yeah</p> <p>S Erm thank you ever so much</p> <p>C That's okay</p> <p>S It's been really really lovely to talk to you. And I hope things continue to get better</p>	<p>Security</p> <p>This is a powerful message. Caroline perhaps thinks this is a means by which to make things better for young people. Communicating that they are valued, included and safe at school regardless of what is happening elsewhere. I remember making a note at this point in the interview reflecting on my experience of interacting with practitioners who quickly feel that cannot meet the needs of young people and that they need alternative provision. I am reminded of the work of Tom Billington on how young people are separated and excluded</p> <p>Relationships</p>
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Appendix I: Composition of analysis – Caroline



Reflective Listening

- Emotional responses
- Values
- Relations dynamics

Listening for the I

- First person phrases
- I poems

Contrapuntal Voices

- Agency
- Blame and responsibility
- Battling/fighting
- Communication
- Connection
- Containment
- Criteria and crisis
- Desperation
- Diagnosis –they are just names
- Difficulty
- Dismissed and ignored
- Empathy
- Exclusion
- Frightened
- Loss
- Marginalisation
- Muted voice
- Naughty child
- Obscured and excluded
- Pleading
- Power and practitioners
- Powerless
- Recognition
- (Being) resisted
- Security
- Supported/unsupported
- Threatened
- Uncertainty
- Unheard

Languages of the Unsayable

- Negation
- Evasion
- Erasures
- Revision
- Smokescreen
- Silence

Appendix J: Louise Transcript

1 Scott So yeah it's, it's about what your experience has been like as a parent erm
2 having a young person with additional needs while they have been in school
3 erm it can be related to other things outside of school as well it's just trying
4 to give you a specific kind of time frame in which to think erm and it it's
5 completely open it is whatever you think is (.) has been important for you
6 it's however you lead it, I will just follow I have very few questions and we
7 were just kind of go with how it comes out really is that okay

8 Louise Yeah

9 Scott So the first and major question is can you tell me about your experiences
10 and your feelings of being a parent with a young person with additional
11 needs sort of while they have been to school?

12 Louise Right, well yeah, okay Riley is due to start school in September erm this year
13 he has been at Rainbow Place nursery for the last two to two and a half
14 years, er so he is currently in the F1 provision there, they were the ones that
15 really kind of notice erm... Patterns of behaviour and of extreme responses
16 and things like that, erm and it was really them that kind of set the ball in
17 motion really obviously Riley when he was two he had-had pneumonia and
18 things and so he had not been very well, and then he acquired glue ear so
19 we thought there was a lot of problems initially around the that and, you
20 know, let's give him a bit more time, and before we knew where we were
21 the nursery were applying for extra grants for extra one-to-one erm support
22 and then there were talks of yeah of Lauren Siddal being involved, the

23 learning support service team, erm and then before we knew where we
24 were he had acquired a place (.) with an inclusion outreach worker,
25 Samantha Thornton, and from that day to this which was about 2015 kind of
26 timeframe to present day we've obviously had Sam Thornton (.) involved in
27 one way or another. It can be fun to try and contact her because it's not
28 always possible to contact her, I know there was one time when I contacted
29 her during the summer when I wasn't aware that she only worked during
30 term time because nobody had told me these things erm there has been
31 various letters that have come through from the child development centre
32 at Portis which have been ambiguous, you know, ambiguous wording, things
33 not so clear cut and obviously that has generated me to (.) phone up and
34 like with most parents of a child like Riley with additional needs or whatever
35 erm, you know, trying to speak to the right person that sent that letter is
36 almost an impossible task, so you end up phoning and then you are told to
37 phone back later and then it's a constant chain of phone calls and before we
38 knew where we were about a year or so down the line we actually got
39 invited to attend a meeting (.) cos I said I was unhappy with the service I had
40 had and they basically use this meeting as a stick to beat me with, about to
41 actually have a go at me for "draining the resources" and things, and they
42 had actively chosen to ignore some of my queries that I had and they
43 actually volunteered that to me that they had actively chosen to ignore me
44 because they thought that my questions were unreasonable and I said "well
45 would it not have been nice to maybe just have been told we are dealing
46 with that?" and there was one time that that we had got quite recently in

47 May, a TAC meeting, and no speech and language representatives erm had
48 got back in touch with me and they had had six weeks to respond so I ended
49 up generating (.) somewhere between four and six calls to say “Is Sandra
50 Benny coming? Is somebody else coming?” erm and obviously we got-we
51 went to this meeting and that's when they volunteered that they had
52 actively chosen to ignore my requests, it was not commonplace for them to
53 turn up (2) erm Me and my husband were quite upset by that, and then the
54 following day they found up to apologise that somebody would be coming.
55 So lots of contradictory sort of things (2) erm And obviously a lot of
56 unnecessary appointments like that one erm and obviously poor Ian has had
57 to take time off work for these unnecessary appointments erm and
58 obviously like today when it's a sports day for our daughter that obviously
59 doesn't have additional needs Ian can't attend because we have had to use
60 all his holidays. Obviously I recently gave up my job, that is fairly, fairly
61 recently I worked my notice, and my last day was that the 30 thirist of May
62 and I was an inclusion TA at Shipton and really with all the various
63 appointments we are having to attend, more recently with the genetic bits
64 and pieces just, just that it isn't flexibility when you are working to attend all
65 of these appointments, so fortunately I have applied for things like carers
66 allowance, we have got middle rate DLA for Riley, and lower rate mobility
67 for him from his fifth birthday and fortunately that extends to his 16th
68 birthday so that's that's an element a little bit of financial security but it is
69 not a lot, it is not a lot erm another reason was obvious Forget my job was
70 obviously the prices for Rainbow Place nursesey became a bit ridiculous they

71 were wanting £585 a month well as a-as a inclusion TA you don't get paid a
72 lot of money, you're lucky if you are walking away with kind of between
73 eight and ten grand a year so actually I wasn't walking home with any
74 money so all of us and it became silly erm for Riley to have in excess of 30
75 hours a week at the nursery so now he just has his 15 hours a week. (2) But
76 really in answer to your question the nursery are the ones that have kind of
77 orchestrated it, they are very, very supportive

78 Scott How does that feel?

79 Louise What that I'm supported? Just-just amazing (.) because obviously they've
80 picked up things that to be honest I don't know whether we had blinkers on
81 or whatever but I am pleased that they have been involved and so involved
82 with kind of sorting various bits and pieces out they have always been like a
83 shoulder to cry on because obviously they are aware that they are in the
84 industry of for want of a better word they know I suppose how me and Ian
85 feel and he is a massive, it's a massive blow to be told that your child is not
86 presenting as a typical, neuro typical child, erm but, you know, that doesn't,
87 but Riley does the most amazing things that I wouldn't want him to be (.)
88 normal, do you know what I mean because he can look at a-for example
89 quite recently erm my eldest was on her scooter outside in the garden he
90 watched for about 20/30 minutes, never attempted it before ever, watched
91 what she did, then after that extended period of time attempted it and
92 mastered it instantly, you know, that's amazing. (2) You know we can watch
93 YouTube clips, he's talked himself to count to 10, we are very good with

94 colours and addressing colours, and things like that he recently worked we
95 are kind of doing the alphabet through a YouTube song and I think we have
96 got up to kind of G or F at the moment (2) But you know we, I-I-I don't
97 remember being able to do the things with Imogen, you know at four erm it
98 wasn't until she started School that they think became interesting, I couldn't
99 get her attention with that, she just wasn't interested but Riley sorry he's
100 just got a thirst for knowledge and again this is quite contradictory with this
101 duplication 15q because, (.) you know, (2) the typical case that is that I am
102 reading about don't suggest that Riley should be able to do these kinds of
103 things really (2) erm but erm yeah obviously what we have as well as a
104 consultant Dr Hart and she has been amazing, so she was the one that said
105 obviously put Riley through a series of tests, so we established that he has
106 got a vitamin D deficient say so he has got to have medication throughout
107 adolescence, and actually since he started taking that he has been talking
108 more, I don't know where, I don't know whether there's a correlation with
109 that erm but certainly with having this vitamin D Riley is talking a lot more.
110 Erm obviously she checked his immunoglobulin, obviously eye level, you name
111 it she checked everything and wrote a very fully comprehensive report (2)
112 absolutely amazing and then obviously more recently with the the bloods
113 that were taken in March of this year they got sent off to the Uni of
114 Manchester and that is when we found out at the end of May that there
115 was a medical reason for why Riley presents the way he does they call it
116 Interstitial Duplication 15q (.)

117 Scott Catchy

118 Louise Yes erm 11.2 to 13.1. So what this means is that Riley has three cop three
119 copies, three sets off of this particular erm section on his 15th chromosome,
120 so he will have got one from me, one from Ian and then there is a spare. So
121 what we have been told is that they could've come for me, could've come
122 from Ian or it could just have been what they call sporadic. And obviously
123 that is what has caused the erm the delay with his speech and things. Erm
124 the educational psychologist that has obviously been doing various reports
125 for Riley, she's been amazing. When I have emailed her on occasion she's
126 come back to me, I appreciate people are quite busy and things, the NHS
127 SALT people (2) erm obviously on the back of the upset with going in they
128 gave me an email for the Portis CDC and when they do pick up the query I
129 do you get a good response, but just give you an example I-I-I posted a quick
130 query on 2nd of May and I didn't get a response until 23rd of May, so it took
131 them in excess of 20 days to answer that query... But when they did come
132 back to me erm they apologised and obviously then went away did some
133 research and came back to me. So it did work but I do think that everyone
134 should have the facility one way or another and I think as well that you
135 know we have got some sensory training for September this year. But we
136 had our diagnosis (.) September 2016, where was my support? There, there
137 has been no (.) counselling, there's been (3) We got given a pack (2) And
138 which I kind of found was a bit of an insult because Riley didn't come with a
139 textbook or a leaflet to when I gave birth to him, so to be given a leaflet on a
140 condition that actually wasn't really correct because obviously we have now
141 got a new diagnosis and things I I I just felt it was insensitive erm (.) I don't

142 know you are just given this blur of information and you are just thinking my
143 whole life has changed and they have given me a letter and they have CC it
144 out to doctors and (3) Health visitors and things like that, health visitors
145 have haven't wanted to know , Everything that where we are today is
146 because I'm the kind of woman that gets on the phone and you know and
147 I've sort obviously your help, the University of Newton has helped , Newton
148 Smalltalk, I have contacted the genetics department at the Uni of Newton
149 and I'm waiting for someone to come back to me, I have sourced Riley an
150 ABA program in Yorkshire with erm a charity called the Blue Door and that
151 starts in September as erm erm a Saturday school (2) erm I think that's
152 10am while 1pm and for 10 sessions it is about £250. A lot of the stuff that I
153 have found out nobody else knows about. For one reason or another it's
154 not it's not out there. In the CDC they don't know about it so I actually
155 volunteered to them, that this is available and I think they felt really
156 threatened by that. I think they are threatened as well by the way that
157 we've employed somebody as well because to be honest the input that we
158 have had from the NHS, be it two emails and a twenty minute session, it has
159 been quite good but it is not enough, (2) it is nowhere near enough and of
160 that twenty minute session when they came to Riley's nursery they spent
161 five minutes trying to wake him up. And this is another thing which I would
162 say is a bit of a bug bare is, is that when Lauren is doing her reports, when
163 Sam the inclusion outreach worker has been and done some of the reports
164 they have always come in and afternoon when Riley's typically asleep so you
165 are never going to get the best of them. I would have thought that they

166 need to get to know when the best times are cos I volunteered all of that
167 information, I volunteered what makes him tick, what motivates him and
168 nobody seems to be really interested I just feel that they are on their own
169 path and-and I feel there is a lot of conflict between parents of autistic
170 children and your multi agency professionals because ironically autism's all
171 about communication, it is about socialising, it's about interaction, yet the
172 people that I am dealing with, (.) for want of a better phrase, they don't
173 have really good communication skills. Erm the lady that gave Riley his
174 diagnosis, a lady called Sarah Clarke, I found her to be incredibly (.)
175 impersonal, abrupt. (2) I know it sounds an awful thing to say but I would
176 challenge as to whether she had problems because it was just so insensitive
177 erm and erm (.) I remember saying to her "do you know what it is like?",
178 "I've been doing this job 25 years, I know what it's like". (.) "No, do you have
179 a child that has been given a diagnosis?", "No I don't have children ". How
180 do you know? Seriously how do you know then? And I just found it quite like
181 I said abrupt and impersonal erm obviously the (2) that we pay Steph at Lets
182 Verbalise she is very supportive, (2) but then you would hope that she
183 would be because obviously I am paying her. But Wendy Rose, whose thesis
184 that we are running alongside, she's amazing she has offered us help
185 beyond September 2017 if we can access it obviously it depends on what is
186 happening with Riley's school. The school that we chose initially for Riley (2)
187 erm as I previously said were just not very supportive, they are very stats
188 driven erm there were comments on the phone and in person that "Your
189 son is going to cost me money". (.) Quite a message isn't it erm and yet this

190 is a school that promotes themselves on inclusivity (.) and erm when I went
191 erm and had a meeting on 25th of May with them they showed me round
192 where Riley's corridor would be. I don't want my son in a corridor all year, I
193 want to my son in an inclusive practice. Riley doesn't need to be in a
194 specialist provision erm and I have been and looked at specialist provision. I
195 have looked at Waterbridge, they don't take children until year three. And I
196 went and looked at Connect; the nursery who again have been amazingly
197 supportive they took me and my mum to go and have a look and I was
198 absolutely horrified, absolutely horrified. There was one child Riley's age in a
199 school of 19 and this kid is on the floor, all other eight or nine children again
200 just all independently doing their own thing no one nobody interacting.
201 Obviously you have higher ratios of staff that are talking about what they
202 had to eat last night or what they were socialising with and this one child
203 that's Riley's age was mute, on the floor, half dressed, so no T-shirt on and
204 chewing on a toy and just, erm you know, not absorbing anything and erm I
205 thought I don't want my son, we don't want our son, in a situation like that
206 if we can have void it really. Riley needs to be in a language rich
207 environment erm and that was a massive kind of eye opener and I think
208 that's kind of what people do is make you feel sometimes that if you have
209 an autistic child well why are you even looking at a mainstream school and
210 actually Riley is entitled to have mainstream education for as long as they
211 are can facilitate that and Ottoman couldn't, wouldn't really kind of, they
212 weren't prepared to do the right thing. You see if you have a sensory room
213 which sounds all absolutely fantastic but if it is outside the classroom he will

214 just gravitate to be outside the classroom, you need something like that
215 really inside. I get if he was getting distressed you'd take him out and you to
216 get him walking about and things to calm him down and things but to, to be
217 introduced that this was it going to be his corridor I just thought this is a sign
218 of things to come and obviously he got very distressed. His key worker
219 Laura, who has worked with Riley for 2 1/2 years has never seen Riley that
220 distressed and she was noticeably shook up and erm obviously the
221 conversations that followed on the phone have resulted in "well if you are
222 unhappy come and get a complaint form" do you know. Where's the
223 integrity of this headteacher, who is called Marie Trees at Ottoman and I
224 was absolutely devastated by thoughts of oh my God what have I done?
225 Because Imogen, my eldest, is in this school, we naturally assumed that he
226 would be alright and actually that was the wrong thing to do I now realise.
227 As a parent you try and do your best (.) and from a convenience factor you
228 want them to go to the same school but quite clearly I don't think it was the
229 right thing, so actually to have had that horrendous false start might have
230 actually been Riley's saving grace because we have now found a school that
231 buys into speech and language therapy a lady called Gemma Hayes she was
232 on a program called (inaudible), the Channel 4 little documentary and erm
233 erm obviously she's she's going to be working alongside Riley quite closely
234 and obviously they buy into educational psychology which are two things
235 that Ottoman school didn't want to do. (3) So then you've got the CDC not
236 really supporting you, you've got your choice of school not really supporting
237 you, you've got to various websites and things on Facebook, the parents

238 forum, Newton carers forum and you know lots of people you can interact
239 with. Erm I met one lady whose child did actually go to the same school and
240 they got managed out as well so now their child now goes to a different
241 school down the road and things. It's just seemed to be very little
242 compassion and understanding for the parents, you know, through no fault
243 of our own, that we were given a set of circumstances that were a little bit
244 challenging and we-we-we've just got to crack on with and get on with and
245 unfortunately not everybody is understanding and er, you know, you get
246 stares and points and things like that and sometimes they can actually be
247 from your friends and family. I would say that my family have supported us,
248 I would say Ian's family have supported us erm but what I am very aware of
249 is initially I think people were "Well he'll grow out of it" or "No that's not
250 right", then kind of spilling over "Oh he is never going to be alright" and just
251 an array of different comments, you know, a real spectrum of comments of
252 things and I'm thinking I have got to live with this I have got to get on with
253 this and I-I can't entertain negativity I have got to have something positive,
254 we have got to have something positive as a family. Erm (...) erm It was
255 refreshing when we contacted this other school and we send the education
256 health and care plans, Kate Whiting is absolutely fantastic, erm, erm one of
257 the multi-agency professionals that has produced this document, absolutely
258 amazing you can email her, she's been to see me, we had meetings, I just
259 can't credit this woman enough, she knows her stuff. The educational
260 psychologist she knows Riley you can tell with what she has written, she is-
261 it's an amazing report. And it is nice when the parties like Wendy Rose that

262 have looked at the reports and gone gosh isn't this really good cos we can't
263 get this in Newton, this is amazing. So it is humbling to know that this side
264 of the motorway we've got something that those in Newton can't access.
265 And equally in our town we don't have any of these fantastic like something
266 like Newton Smalltalk, we don't have that but they do so erm obviously
267 through my experiences with erm on the forum and things I have shared my
268 knowledge of where I have sourced stuff to try and pull and work together.
269 And I am aware that two other families have contacted Newton Smalltalk on
270 the back of me saying have you tried contacting this lady and that feels
271 really good to know that I have supported another two families going
272 through the same thing as what I am going through (2) I'll take a pause now

273 Scott No that's fine, thank you. (.) Lots of stuff. Is it alright if we go back over
274 some things?

275 Louise Yeah absolutely

276 Scott As we've been talking I have just been making note of a few things of the
277 kind of sentences that you have used which were just really interesting. Erm
278 and I've just-just thought I would ask you a little more about it. One of the
279 ones are used was feeling a massive blow when you were told that your
280 child is not neuro typical can you tell me a little bit more about that?

281 Louise To be honest erm I think I had a preconceived notion as to what autism was
282 is the same as every other kind of average person is that I have watched rain
283 man with Dustin Hoffman and you kind of think oh card counting and
284 socially awkward (.) and then it is like erm that is all I know, do you know

285 what I mean? And not really knowing anybody else's (.) child er that is
286 autistic that I was aware of and erm it was just devastating because you've
287 been given information and you've got, my reference point is a film, do you
288 know I mean? I don't-I don't fully understand and things and obviously and
289 my mum used to work for the child development centre in Lithgate er and
290 we regularly used to go on various day trips with erm a lot of children with
291 down syndrome so I understood what down syndrome was I understood
292 erm what additional needs meant, I understood what handicapped or
293 disabled meant I erm I-I-you know, I knew about those things, you know, we
294 used to interact with children with down syndrome, you know children-
295 children that had maybe no arms and no legs these were children that were
296 in wheelchairs but I didn't know about autism because obviously growing up
297 and thinking about it more sensibly as an adult you have your "naughty
298 children" in a classroom and actually maybe those children weren't naughty,
299 maybe those children were seeking stimuli, you know, wanting attention;
300 maybe had ADHD erm

301 Scott Did people described Riley as being naughty?

302 Louise No, no. They said that his behaviour is "challenging" and I would say through
303 the impairment with and the develop-sorry the, the, the kind of delaying in
304 your conventional speech has resulted in erm unsavoury behaviours shall
305 we put it and Riley will wallop me and will bite me if I don't-but he is talking
306 to me, this is it, there is a language underneath language sometimes and
307 because it is not terribly clear he thinks that I am ignoring him so he will

308 pinch me or he will bite me to kind of so what (3) understand what is going
309 on really which I think is quite clever actually because he is trying to get my
310 attention and things. So he's a very complex little character it's, it's, you
311 know, he is coming on lovely but yeah it was devastating because you don't
312 have a truly (2) erm clear kind of (2) notion as to what autism is, it is like I
313 said, you know, you hear a lot more about Down syndrome. I probably
314 knew more about Down syndrome than I do about autism because it was
315 not something (.) there were never any (2) because I was born in 81 so when
316 I was at infant school and junior school I didn't know anyone that was
317 autistic. I knew children that had a spina bifida erm and I knew one child
318 that had cystic fibrosis and, but yeah, you didn't hear about those things
319 and-and I did think naïvely oh is it is this the latest buzzword you know? Is
320 this like the modern version of ADHD? That kind of thing. What-what-what
321 does this mean for us and then being told that he is not always autistic just
322 in terms of certain situations and I thought hang on you're either autistic or
323 you are not because if you are Downs or if you have got spina bifida you
324 don't just switch that on and off so I-I-I-I it was really quite odd and yeah
325 and I get that is why they gave us the leaflets and stuff but I thought you are
326 giving me a massive load of information and you're going to give me a poxy
327 leaflet and the crux of the-the-the insult really is that the leaflet was
328 completely out of date. Erm there was one by the Autism Communication
329 Team saying they had speech and language therapy and I have since found
330 out that they don't have that erm and the numbers were wrong and the
331 email was incorrect so it was like this is who you need to speak to, as one

332 example, and it is completely inaccurate with all the details and stuff and
333 erm yeah, erm yeah

334 Scott Does that link into when you said so the insensitive nature of some of the
335 materials you've been given?

336 Louise Well just the insensitivity as to how to deal with things, here's an A4 green
337 folder with half a dozen leaflets, some are out of date and, you know, read
338 up on what you've got to do and I am just thinking would you do that with a
339 cancer diagnosis? And I know obviously, you know, put things into context,
340 this is not cancer, this is not serious but it could be life affecting because,
341 you know, at that point I'm thinking I'm gonna have to adjust everything I
342 know, he is never going to be independent, very selfish kind of thoughts of
343 he's never gonna get married, he's never go have children, he's never going
344 to have a job and that is what you think initially because like I said I have got
345 no reference point in real life as to what autism meant for our family (4)

346 Scott And how does it feel having that kind of experience of thinking well he's
347 never going to be independent, he's never going to get married?

348 louise It just blew my world, it blew my world completely, a lot of tears, a lot of
349 tantrums, wanting to and I think this is why we pushed the genetic thing as
350 well because I just thought there has got to be a reason why. (2) Because I
351 erm I don't know for me, I don't know maybe I've got quite a scientific kind
352 of brain, you know, (.) waters hot because I have boiled the kettle, do you
353 know what I mean? There's got to be some kind of transaction that needs
354 to take place as to why Riley was presenting in the way that he was and

355 when you look at typical symptoms of how children with autism present,
356 yeah there were some but there wasn't always and I just felt have they got
357 this wrong? I went back to the doctor, the doctor was very supportive, tried
358 to kind of reassure me, you know, and actually what he said was quite
359 profound; he said you know once upon a time people when they got a
360 diagnosis of diabetes or even asthma were absolutely devastated by those
361 things, and they can be very life affecting conditions he says but it is just a
362 label. But with asthma you have a pump or a nebuliser, with diabetes you
363 take a tablet or you have insulin and you manage your diet. What was I
364 going to do with autism? Because and then you start looking at diet and
365 then you start questioning every inoculation he ever had, is there a reason
366 why he is presenting the way he is? And my aunt who lives in Australia,
367 she's, I don't know whether the word is a homoeopath, naturopath but
368 certainly she looks at your body's natural chemicals and things and erm
369 obviously when I was pregnant with Riley I ended up having to have IV
370 antibiotics and then you are thinking have things got out of kilter, talking
371 about the gut brain connection and was that a severed gut brain connection
372 erm, you know, he was quite a low-birth-weight, I say low, 8 pound 1, you
373 know, that is not exactly low but-but his sister was 8.9 and I was kind of
374 thinking he would be bigger, don't get me wrong still noticeably a big baby
375 but not as big as Imogen, quite skinny. He had jaundice and a load of
376 treatments for things like that, also had a tongue tie, so then you are
377 thinking is the tongue-tied the reason why he's had speech problems? Is the
378 pneumonia the reason why he has had hearing problems? And you just

379 keep linking back everything that you know and, you know, and the
380 inoculations and he had this and then he behaved like this, then he had a
381 string of infections and then he developed pneumonia and you constantly
382 analyse stuff erm because of trying to find a reason why he is presenting the
383 way he is. And so for six months I am just researching gluten-free, don't do
384 this, you know, looking at gaps diet, speaking to erm naturopath's, looking
385 at movement therapies and things like that and eventually it came to kind of
386 hmmm, I don't know, I just feel like I need more insight and then obviously
387 when I then spoke with my aunt she said ask for this, this and this test, went
388 to the doctors, we arrange that erm and the (2) he's then wrote off to this
389 consultant doctor, Dr Hart, she agreed to do all those things but my GP did
390 say if you don't get these things done I will do them for you because I think
391 it is important that we get these things done. And it was nice to feel
392 supported by your family GP and we always keep going back to Dr Amrad
393 because he gets it and I don't necessarily think he has got any personal first
394 hand experience but I think he could just see the frustration that we had
395 been through as a family and just offering us the help and support that we
396 needed has been absolutely amazing.

397 Scott That's really good and is that the frustration with other services that you
398 were talking about?

399 Louise Yeah cos-cos, you know, when someone sets the bar that high, who is going
400 to be absolutely amazing, and then you've got people who don't seem to be
401 all that bothered and things, erm the health visitor initially was quite good

402 at the second year review cos obviously that with the nursery ascertaining
403 that Riley did not have his 20/50 words by a certain point was quite good
404 but from that day to this I have never seen her since erm, you know,
405 obviously we know-knew we'd kind of have a fall off at some point and
406 things but erm yeah-yeah you do you feel like you kind of have to battle a
407 little bit and er I think the reason why myself and other parents battled is
408 cos we don't-don't know enough, there's not enough out there, and if you
409 google everything-I remember getting one letter and it talked about erm
410 erm (2) anti-mongoloid slant was the terminology used in this particular
411 letter and this letter was done by Dr Hart erm and it was talking about the
412 position of the eyes and we have since found out it's not an issue, it's just a
413 (.) medical (.) terminology and stuff, but that's not been signposted (.) and
414 at this meeting that I had at the CDC where they kind of again use this
415 meeting to kind of beat me and Ian with a stick for asking too many
416 questions; how dare we ask about things that we don't know. She did turn
417 round to me and say "Why don't you google it?" and I said "So you now
418 want me to google medical conditions and you think that is a sensible thing
419 to do?" erm and a erm obviously she kind of changed her tune didn't she a
420 little bit after that and things. It was just a ridiculous (.) comment to make.
421 Why am I not allowed to have medical terminology signposted to me by the
422 professionals as to what that means? Erm There was a wood lamp test and
423 things like that and I don't know what those things are (.) and you know, I
424 don't feel that me and all the parents should have to go searching as to
425 what these things are, (.) you know, we should be told quite clearly what

426 they are and erm just have things clearly signposted to us and I think that
427 aids the frustration and aids the kind of devastating feeling because
428 everybody kind of knows what is going on but me, me as a parent I don't
429 know what's going on (3)

430 Scott That's really interesting... So that kind of sense of having to battle with
431 people and

432 Louise It shouldn't be like that, it shouldn't be like that at all

433 Scott Erm and when you were kind of in that situation where someone is saying to
434 you you are asking too many questions how did that kind of make you feel?

435 Louise It's just erm it just really upset me (.) because if-if again my child had cancer
436 (.) would I not to be entitled (.) to speak with a counsellor? Would I not be
437 entitled to kind of ask these questions about how it is going to impact my
438 family? So why is it any different with erm autism because (.) my
439 understanding of autism is that it doesn't just disappear, you acquire the
440 skill set to manage it but it doesn't disappear, (.) where erm, you know, with
441 the cancer obviously it can disappear, it can even be in remission, you know,
442 and all the rest of it and, you know, maybe I-maybe I should shouldn't be
443 comparing things to like a cancer but what I am saying is that is the kind of
444 thing that jumped to my mind that erm (.) it-it-what I think is-is it's a
445 condition and, you know, some children that have autism also do you have
446 medical implications like epilepsy and seizures and that can be very life
447 impacting, very devastating and can be quite fatal. Certainly with this
448 congenital err heart issues things like that, erm with this duplication 15 Q,

449 we have had to go and have ECG so all of a sudden it is not just autism any
450 more we are having to look into seizures, we are having to look into erm
451 congenital (.) heart issues, and things like that so er do you know I mean?
452 It's not just autism anymore, it's all the medical bits and pieces that go with
453 that (.)

454 Scott So having to look into further conditions

455 Louise Yeah, looking at further conditions and things and erm we haven't seen a
456 geneticist yet properly we've only been given, we've only been given half
457 information and you know the consultant said to us "I don't know an awful
458 lot on this" (.) and told us to join this particular forum duplicate 15 Q
459 alliance, that were in America that might be able to help you (.) but just bear
460 in mind that the case studies on here are for more extreme than what your
461 son has got. So all I have got is a reference point of the-the absolute core
462 blimey extreme and have got nothing that is kind of where Riley is at, (.) so
463 (.) that is hard as well (.)

464 S That's interesting because you said earlier about having reference points for
465 autism having an extreme example and then with this another example

466 Louise Yeah, another extreme, yeah, so I've got, we never can really dip in to
467 something and think "oh that is exactly Riley", do you know what I mean,
468 that we can pinpoint that exactly (.) so (.) I kind of feel like you have to make
469 it up as you go along kind of thing. But I've never looked at my son (.) the
470 way that I have done since May (.) checking on him, is he breathing alright?
471 Okay, there's a twitch there, is that a seizure? And then it, do you know I

472 mean, it-it becomes a bit consuming (.) and even having to let the nursery
473 know, erm you know this now could be a reality in our world (.) and it is like
474 wow, you know

475 Scott So you feel some kind of worry and

476 Louise Yeah. Totally concern and stuff but equally as well your glass is half full or
477 half empty and I-I want it to be half full that he has not touch wood (.) ever
478 had a seizure (.) erm and, you know, long may that continue. (.) But even if
479 you don't have duplicate 15 you can still have a fit, you can still have a
480 seizure, we are not exempt from having these things but erm I-I-I you know
481 I-I never, never thought for a moment (.) we would ever be looking (.) at-at
482 this and, you know, me and Ian set the ball in motion to (.) acquire this
483 knowledge (.) and sometimes you can live in blissful ignorance and could
484 you imagine if we had, you know. Would that have been better? Would it
485 have been worse? And erm I-I-I-I think it is better because all Riley as an
486 adult will-will now have to (.) look erm cos obviously he has got a 50%
487 chance of passing it on. He will have to have genetic counselling later on,
488 but when I've even researched now the things that they can do now in 2017
489 are amazing (.) so if Riley was an adult now (2) yes it would be an issue but it
490 wouldn't be too much of an issue. And can you imagine maybe 28/30 years
491 down the line? Maybe they can do something, (.) you know, there's a
492 concoction that sort you out, you know what I mean? It's-it's positive to
493 think that there are things that we can do erm but, you know, what happens
494 if we had not found out and then he had a child that had presented worse

495 than him, you would have always thought maybe there was something I
496 could have done (2) but yes you kind of open that Pandora's box you don't
497 really know what is going to happen.

498 Scott And is that a kind of experience that you've had cos this is a genetic
499 condition, that sense of with Riley if he has a kid how would you feel? Have
500 you had that experience about having Riley yourself?

501 Louise (4) How are you meaning sorry?

502 Scott Sorry

503 Louise (3) Should I have had him?

504 Scott That kind of

505 Louise I don't know ((phone begins to ring)) (2) Bear with me for just a minute

506 ((Break in recording))

507 Louise About with Riley didn't you?

508 S Yeah

509 Louise What if I'd had an insight could I have had a child like Riley?

510 Scott Yeah

511 Louise But I have had him. Riley was a very much wanted erm baby. Obviously, we
512 had Imogen, she was an absolute dream, no issues at all. She's still
513 absolutely amazing, (.) she-she knows when he is about to get upset and
514 things and is very good at reading the situation, very intelligent, very loving,
515 very caring. (.) Why wouldn't you want another child? And Riley, up until

516 about 2 to 2 and a half was very placid and he was-he was an absolute
517 dream and then the little monkey appeared. (2) And he's just highly
518 spirited, he is lovely, Riley makes you appreciate life, erm the little littlest
519 things which celebrate, the biggest things we celebrate, Riley enriches our
520 family unit, (.) erm we love him to death. To be honest apart from the
521 speech that is coming on and his little bit of unruly behaviour is, that we
522 don't pander to, I don't pander to screaming, when he gets upset and he
523 starts screaming and shouting I ignore him, make sure he is safe but
524 fundamentally we ignore him. (2) And by not pandering to him it's done in
525 five minutes (.) and, you know, what in a world where it must be really
526 confusing for him why can't he have a little five minute outburst? (.) Cos we
527 all have our things that we get upset about erm and you know it-it is no
528 different for him even at four. So absolutely I would-I would never change
529 what happened, (.) it would be nice to have a bit of hind-foresight as to
530 what things were and all the rest of it and, you know, I probably would have
531 gone about things a bit more differently. I'd have (.) pushed for Riley to
532 have a diagnosis at 2/3 rather than just turned four, cos then we would have
533 had an extra year of intervention and maybe we might have been starting
534 this year with (.)even more speech. You can beat yourself up, and I think-
535 think erm at the end of the day (.) he's very much wanted. He is loved and
536 he just brings so much to the family (.) and do you know what he is so
537 intelligent. (.) There's, you know, his speech is questionable but his ability is
538 impeccable, it's not erm it's not erm it's not under speculation. He's got a
539 fantastic memory, (.) erm fantastic recall with things, (.) you know, fantastic

540 to eat, you know, he just eats anything. He's a bit of a tinker with sleep and
541 he has to have some melatonin to help him with sleep and things, (.) so that
542 can be a bit distressing, you know. (.) If he falls asleep at six he might be
543 waking up at two and, you know, he is wanting to go and it is like I want to
544 go to sleep kind of thing. It's only those instances that you think oh God I
545 can't cope, I am worn out. (.) But he just brings so much to the family and I
546 wouldn't really have him any other way (.)

547

548 Scott ((Laughing)) so just kind of going back to some of the other things that you
549 kind of mentioned so one of the things I think that was about offering so off
550 services advice and they felt threatened by (.) So is that something that you
551 have experienced?

552 Louise I think they are threatened by it because I'm knowledgeable (.) not only
553 because I was an inclusion TA, but I was only an inclusion TA for six months
554 and things obviously (.) I have had Riley for nearly 5 years so you have to
555 kind of do your own personal research, you know: Why have we not got
556 this? Why have you not got that? Even down to the education health and
557 care plan. (2) You know, you've commented on this date, about low tone,
558 you have commented on this date about being unsteady, you've mentioned
559 about a referral. Why have you not, (.) you know, sorted the bits and pieces
560 out? And I think people find that kind of erm (2) threatening and certainly
561 when (.) erm cos I think (.) the learning support service are a bit like schools
562 with stats and, you know, no one has actually said that but I do wonder (.)

563 and obviously, as we all know, you only have to switch your TV on, the NHS
564 is stretched in every way (.) possible aren't they but I do feel that they feel
565 threatened because, you know, Riley is making headway. But Riley is
566 making headway in spite of not having any help from them so if they can't
567 claim responsibility for Riley doing really quite well (2) I don't know whether
568 they are pleased to be honest. (.) I know that sounds an awful, a weird thing
569 to say but, you know, Riley is doing well because I've put this this and this in
570 place and then you get "well maybe you are over doing it", maybe I'm not,
571 maybe I'm not at all. And then it's like and then I have got this ABA
572 programme "well why are you doing that?" And I am like well why would I
573 not be doing that? (.) So everything is kind of met with a question (.)
574 circulating, you know, why am I doing stuff. Because I've researched,
575 because you've forced me to do research, cos you won't offer me any
576 alternatives, you won't offer me any training, you aren't offering me any
577 support in any format erm other than your long winded letters that aren't
578 clearly signposted and things so (2)

579 Scott So do you feel like you have been questioned?

580 Louise Totally! I think I am totally under the microscope and erm I-I think people
581 just want to, (.) I don't know, I think they want me to be dependent on
582 them. (.) But I am not prepared to be dependent upon the service that
583 doesn't offer anything (.) to me or any other parent of an additional needs
584 child, you've only got to go onto the parents forum (.) and there are a lot of
585 people like me that just feel aggrieved, that feel angry and, you know,

586 reasonably unreasonably so (.) maybe we have too many expectations (.) all
587 I know is if I lived in America, you know, my insurance would be covering a
588 lot of these costs (.) but then you have to buy into that privatisation where
589 we don't do that over here. Erm but I just feel everything is a battle erm
590 even to try and get them, when I was working, to get appointments at a
591 reasonable time because I can't just keep leaving at 10:30 in the morning, (.)
592 you know, for like three quarters of a day, you know, while they do an
593 assessment. And erm what world do we live in where (.) you have a
594 fantastic, you know, my employer were fantastic employers but, you know,
595 they'll only let you go on so many family days and stuff and then you end up
596 not being paid erm and it's-and it's tough it's tough so, you know, the-the-
597 these were quite clearly things that weren't in their green folder, you know,
598 all this kind of upset and things

599 Scott So when you erm when you were told your son it's going to cost me money
600 what was that light?

601 Louise It was disgusting (2) He's a human being with needs, would you would you
602 would you say that if my child was in a wheelchair? (3) Would you say that if
603 my child had lost one limb? Do you know what I mean? Because it is not
604 noticeably obvious, i.e. he's got two arms, he's got two legs, he-he can walk.
605 Erm speech is just (.) erm I think it's perceived differently (.) do you know
606 what I mean? And maybe they are thinking well he's dumb, I don't want
607 him. Do you know what I mean? And that's how it was coming across and I
608 thought how dare you. You're not lucky enough to have my son, and, you

609 know, just because he has got a speech problem doesn't mean he has got an
610 ability to learn issue. My son is not thick, my son would thrive in your school
611 and your stats would look amazing with my son in it. (.) But if you are going
612 to be that ignorant and naïve (.) then you can't have my son is what I
613 thought. And you kind of have to flip it, I can get upset, I can-I can report
614 her but, you know, what am I going to get? I am just gonna get a load of
615 aggro really erm. So to have found Rockland View that, you know, the
616 headteacher Mr Kane, funnily enough I used to work with him at my old
617 school, his whole ethos erm (.) on inclusion is not that (.) erm (.) i-inclusion
618 it doesn't just mean that they are included it means that things are tailored
619 to that individual child. (.) And (.) his parents evening speech yesterday was
620 just so poignant and I just thought you've got it, you totally understand (.)
621 and me and Ian just felt so (.) at peace with the fact that he was going there
622 and that I didn't feel I was going to have to battle. (.) Erm and-and with Mrs
623 Trees at Ottoman I felt that is exactly what I was going to have to do, (.) was
624 battle to be heard, battle for-for my right-err-for my sons rights as a student
625 in that school to be able to access a fair (.) erm and kind of varied
626 curriculum, well why-why can't-not everybody learns the same (.) and you
627 might learn things slightly differently from how I learn but that doesn't
628 mean that we are autistic or-or whatever. It means (.) that, you know-erm,
629 you know, some people need more visual-Riley is quite visual (.) and erm
630 and that is the better way for him to work erm at-at this moment in time
631 and things. And erm yeah I just felt I was going to have to do battle with
632 them

633 Scott And you didn't get that experience [when

634 Louise [No, no. If anything it was what can we do? Er and it was very positive and,
635 (.) you know, nobody is making me any unrealistic promises, (.) you know,
636 well we will try and see how we get on and things, (.) er but, you know, Riley
637 will be there until year two because it is an infant school (.) erm because
638 even if he needs to access err a more specialist provision after that, (.) a lot
639 of-a lot of the provisions don't really take until year three anyway erm and I
640 have looked at Waterbridge and I like their ethos and I like the structure (.)
641 and if and it's a big if, if Riley needs that he can have that (.) and, you know,
642 there is no shame, there is no guilt, Riley is an individual and Riley will have
643 what Riley needs and we as a family will support Riley in what he needs and
644 if people want to kind of sneer and point fingers and be rude then I feel
645 sorry for them, that's their ignorance. But, you know, you can still do GCSEs,
646 you can do A-levels, you can do apprenticeships and things like that. What it
647 just means is that, (.) you know, class sizes of 8 to 10 (.) and things are a bit
648 more manageable (.) and, you know, if that's what he needs then that's
649 what he needs. But unfortunately I don't have that crystal ball yet so we
650 just have to-we just have to be positive (.) er and give Riley er lots of
651 experience of lots of language rich experiences, erm (.) just life experiences

652 Scott So your daughter is in the school that you originally took Riley too and got a
653 really negative experience?

654 Louise Yes, yes so she goes into year four in September. Erm (.) to be honest there
655 is not an awful lot to complain with-with how Imogen has gone she did

656 struggle initially with some reading (.) and (.) erm I have paid for private
657 tuition with Imogen to support her with her reading and help her maths (.)
658 and I am really proud to sit here and say (.) we do 20 minutes reading each
659 evening (.) and obviously with the reading that we do at home and the
660 reading that she does at school and the reading that she does err privately
661 Imogen has gone from being the bottom of the class (.) to the top of the
662 class, you know, she's getting 10 out of 10 with her spellings she is doing
663 really well in comprehensions, (.) still struggles a little bit with maths but
664 the-the gap there has kind of closed, you know, she's got on with it with
665 things and Imogen is a summer baby and I think that's why she initially
666 struggled and stuff but erm never really had to battle (.) erm with things and
667 they were very good at sorting things out so that is why I am just so
668 surprised (.) that (.) erm, you know, that they'll have one of them my
669 children but they won't have the other one (2) or they are certainly not
670 making, (.) no, no one has said that they won't have him but they have kind
671 of it, will cost me money and erm you, know, it might not work and, you
672 know, have you looked at anything else, maybe this isn't realistic and things
673 like that. So they are kind of managing you out before you've even got in. (.)
674 So yeah

675 Scott So when you took him there you said you had a sense of oh my God what
676 have I done, and what did you mean sort of by that?

677 Louise Erm Inasmuch as because he was so distressed from that situation it was like
678 (.) I've allowed somebody, I've allowed this headteacher (.) to orchestrate

679 her staff, (.) manage them badly (.) to have my child who is now in a
680 distressed state (.) and erm it was horrendous, but the (2) I try and look at
681 every situation with a positive flip because if I had not had that experience
682 (.) I wouldn't have moved to Riley and it might not have been until the
683 September that we realised that there was a bigger problem (.) so I am a
684 great believer everything happens for a reason (.) and by that unfortunate
685 situation taking place Riley will now have something (.) better. He is going
686 to be in an F1/F2 mixed class so they have got nine F2 children going into a
687 mixed F1/F2 provision and they also have a pure F2 class of 30 children, (.)
688 so what they have said is that well let's keep him in there, with the younger
689 F2, see how he gets on and maybe we move him over or we change the plan
690 later on and things and they are on about a reduced timetable to begin and
691 then building up. So everything is a positive. (2) So rather than just throwing
692 him in the deep end and watch him sink it is like let's put him in the shallow
693 waters and let him float and I like that-I like that

694 Scott While we have been talking have you got any other thoughts around what
695 your experience has been like how you fell as you have gone along your kind
696 of journey?

697 Louise Yeah. (.) Well obviously the journey is not ended erm it will continue (.) er as
698 to where and how it will look like (.) I can't even begin to imagine what, I just
699 feel is I have to be completely on top of my game all the time. I have to be
700 organised (.) erm and unfortunately no one else seems to share that kind of
701 (.) erm organisation and erm, erm, you know, I have had to orchestrate a

702 TAC meeting, kind of push people and say can we do this maybe on these
703 dates? Can we do this can we sort this?

704 Scott So since having Riley do you feel you have had to become much more
705 [involved?

706 Louise [I feel like I am Riley's PA, do you know I mean? You know because I am-I
707 have entered a life of appointments, meetings and things and hospital erm
708 appointments and erm I have turned into a researcher erm, a mother, an
709 educator, erm a promoter of speech and language erm a behaviourist, you
710 know it, you know, you take on a different role, you wear a different hat
711 with every situation you take with things, you know. There isn't a day that
712 doesn't go by where you think oh that appointment's soon, I need to sort
713 things erm and erm it's erm it's erm, you know, it's just, it's never ending.
714 And my husband said to me last night (.) "You won't be able to get a job yet
715 soon will you?" and I said "no" (.) and it's like I'd love to just have a job
716 where you just go in, a monotonous 9-to-5 , you just answer phones or do
717 something erm (.) because everything that I do you do has to be-has to have
718 a reason for it and, you know, there is an outcome and it is about acquiring
719 that desired outcome at the end of the day and things

720 Scott Does it feel like it has been a big transition?

721 Louise (3) Well yeah, from-from September to present day, you know, if you tell me
722 that I was going to have to, you know, you know, I have got an extensive
723 filing system all the appointments and (.) all the letters, trying to understand
724 stuff, you know, erm (.) I feel like I should work for the local Council and

725 things and erm (.) Yeah, you are-you-there are lots of little mistakes that are
726 made and you're having to constantly keep challenging little bits and pieces
727 and stuff and erm (.) even with the Education Health Care plan that arrived
728 the other day it had got someone else's (.) details in the middle of it and
729 having to phone up and say are you aware that this is here as well?

730 Scott That's not good

731 Louise No it's not and-and they are human at the end of the day and they make
732 mistakes and fortunately these documentation did go back to the right
733 people and things (.) but, (.) you know, these are not perfect people. But
734 they do feel like the gods of the situation, do you know what I mean, you
735 know, you've got to try and kind of liaise and flatter them in order to get
736 what you want, you know, erm (.) you know, (.) Even like the things with the
737 occupational therapist well let's, you know, yes he'll need that but let's wait
738 until he gets into school; right well I have got that email and I am keeping
739 that safe cos and that is going to be the next, (.) you know, trump card, you
740 know, so I can say "where's this? you've promised me this?" that kind of
741 thing. So that is why I have been so passionate about sorting out the
742 Educational Health Care plan because with having (.) insight and knowledge
743 with what I was doing in my previous job, (.) he's got to hit the ground
744 running, (.) and you don't hit the ground running with the speech problems
745 that he has got, (.) you know, with the kind of you know let's wait and see
746 approach you've got-you've got to put those interventions in place and
747 things. So yes you do you have to, (.) you do have to battle, but do you

748 know what autistic parents are strong people (.) because we have to be
749 because you either sink or swim with this and you've-and I choose to swim
750 and get on and be positive and erm (2) Yeah (.)

751 Scott Thank you

752 Louise Is that alright?

753 Scott That's amazing

754 Louise Do you think?

755 Scott For me it is such a privilege to listen to people's experience

756 Louise Oh well it might sound like I am a bit of a whinge bag really

757 Scott No, no, not at all. It's-it's really (.) interesting to hear what peoples journeys
758 been and to hopefully try and use that as a way of supporting (.)
759 engagement with practitioners schools and things like that. So that, you
760 know, what I want to try and do with that (.) the [stories

761 Louise It is scary as well because every school has a different way that they can
762 deal with things and like I said Ottoman don't buy into speech and language
763 therapy, they'll let the NHS people come in, they'll let the private people
764 come in, but they don't-they don't use their funding for that. They also have
765 a lot of children with-with educational (.) erm well not educational,
766 behavioural problems (.) and they won't employ an educational behaviourist
767 because they said they don't value (.) what they said. How can you have
768 autistic children in a school and not value what an educational psychologist
769 thinks? (.) Because we all know with autism these repetitive behaviours,

770 that you behave in such ways because you are distressed or maybe sensory
771 seeking so why would you not have (.) those basic (.) things put in place?
772 And erm the Autism Communication Team (.) don't have speech and
773 language, you know, there is a lot of (2) to be honest with you apart from
774 Rockland and maybe Chesterton and Snow Lane primary (.) I-I certainly-the
775 school that my daughter's at erm other than dealing with inner core bits (.)
776 erm, erm the-the erm the kind of help with in a core strength and making
777 her a little bit stronger and things like that, I never had to fight for that at all,
778 they seem to like-they seem to Kind of have a bit of a pick and mix, they
779 kind of choose what they want. Well they have done the NDD programme
780 because a lot of children have motor (.) problems so that seems to be more
781 socially acceptable. But not all the children have autism (.) "so why would I
782 buy into this? why would I buy into that?". And all of a sudden all of those
783 children that were autistic certainly from years F2 to about year two aren't
784 there anymore because they have been managed out (.) and there are all
785 kinds of different other schools (.) and I don't know whether this woman is
786 on a mission to just make her-her life a little bit easier before retirement (.)
787 or whether she's just that prejudiced and things and (.) the thing is with
788 autism is it's very prevalent we are hearing more and more cases of (.) of
789 autism it's not disappearing, you can't sweep it under the carpet (.)

790 Scott You sort of mentioned social acceptability

791 Louise Yeah, yeah and I think that's it. If your child looks (.) different I just don't
792 think she wants to know and you do get that with a lot of parents (.) that,

793 you know, oh, you know, that one's got some problems, and you get the
794 sneers and the looks and all the rest of it, it's like take a picture it will last
795 longer (.)

796 S And that is something you have experienced?

797 Louise Yeah, totally, totally. People do comment and I-I did find myself for a while
798 not wanting to go anywhere because I thought he is going to behave like
799 this and people are going to look (.) and I remember one lady that I have
800 met on the local Parents Forum (.) says "what do you care? Seriously if you
801 let everyone affect you you are never going to do all the fun things and Riley
802 might be missing out" and I thought yeah, (.) I've got to have this I don't care
803 ethos really (.) erm because otherwise I am going to be affected by what
804 everyone else thinks (.) and this is my family (.) and if I don't give Riley these
805 enriching experiences he's not going to develop. And so you, but it is hard
806 to block it out, it is hard to block it out and erm everybody, everyone has got
807 an opinion, everybody's got an opinion, especially friends and family,
808 they've all got an opinion, they definitely do (.)

809 Scott And friends and family's opinions what are-are they kind of around, what
810 are they like?

811 Louise "He'll grow out of it", "I knew there wasn't a problem", erm you know, or,
812 erm you know, "well we're happy to have Imogen but if we have Riley it
813 could be, you know, a little bit problematic and things". Erm (.) more
814 recently "can you not bring Riley round cos he makes a lot of noise", (.) that
815 was another family member that said that. And I said "right then, well I

816 won't to come round but you'll have to come round to me" and then it was
817 like "oh right okay". (2) Do you know what I mean? It's erm (2) they don't-
818 they don't mean it (.) erm but they-I don't think they get it, you know, when
819 Riley is kicking off and getting upset (.) the-they erm in his world there's a
820 reason why that's happening and that he is not just a naughty boy, but then
821 sometimes his behaviour is (.) very much a naughty boy, because he is like
822 looking and he is smiling and he is running away from you and things like
823 that. So it is just a real mixed bag, he's just a real mixed bag bless him. But
824 yeah, some of the people that are closest (.) to me haven't, you know, (.)
825 aren't really there, you know. To say that I have all these friends,
826 sometimes I am cruising through my phone (.) it's like there's not one
827 person that I think would understand how I feel (.) and that is why the
828 forums are so (.) useful because, funnily enough I am meeting with one lady
829 tonight and erm, you know, just-just to talk really about the same kinds of
830 experiences and I would have never thought (.) that I would meet somebody
831 off a forum (.) and, you know, she only lives locally herself and things and it's
832 erm it's nice to be able to have another reference point and how their child
833 behaves and how my child behaves and, you know, the similarities and the
834 differences and things like that. (.) But what I do find in this forum world is
835 (3) a lot of people are alright to be your friends (.) until your child starts
836 doing maybe a little bit better and then it's like yeah; isn't-isn't that parents
837 in general even (.) minus the autism it's almost like a competition, (.) "my
838 child has got this, my child has got this swimming badge" and, you know, all
839 the rest of it and it-it's just human nature so I-I take what I need from the

840 forum but equally I put back by telling people about my experiences and
841 they have asked me to write about the experiences. I am having, like
842 maybe, with yourself, certainly with Newton Smalltalk, just to give an insight
843 (.) back into what's happening (.) and erm, like I said, through doing that
844 people are able to kind of get on the phone and access some of the people
845 that I've accessed and things, (.)that's only a good thing isn't it really (.)

846 Scott So you are becoming that signed poster (.)

847 Louise Yeah, kind of other people, you know, (.) you know, instead of like don't go
848 down there because there is a dead end, it's now you can go down there
849 and turn left and there's a bit of hope at the end of that road (.) and at say
850 about (.) and this is what is so important with networking with other (.)
851 families that are in a similar situation is we have to bounce ideas off each
852 other erm we have to share what we know (.) because we can't rely on
853 other people to let us know (.) and like I said Riley got his diagnosis in
854 September, what training have they put me on? You know, and (.) not to say
855 that I need training to deal with my son but I do need training to deal with
856 the autism that affects my son (.) because, you know, you-you-you need to
857 know that you are doing the right thing by your child, you need to, you
858 know, I needed insight into his world. It's alright saying he might perceive
859 the world differently, how does he perceives that world differently? Erm,
860 you know, and it's-it's those kinds of things that you need really but erm (.)
861 I'm surprised that, (.) you know, a lot of people that I have spoken to-there
862 was supposed to be an introduction to autism course, (.) never got that. So I

863 found there was a distance learning introduction to autism, (.) NCFE level
864 two qualification, so I I've done a free qualification (.) to find out about hypo
865 and hyper sensitivity, to find about the vestibular system and to look at
866 repetitive behaviours, how to manage things (.) and that's something that
867 I've done myself, no one has told me to do that (.) because you need to up
868 skill yourself. (.) So yeah (.)

869 Scott It has been and continues to be a long journey

870 Louise Yeah it is and the thing is as well (.) my journey might be so different from
871 someone else's (.) cos it depends on (.) what you want out of it, (.) and do
872 you know what I am going to blow my own trumpet here, when I spoke to
873 Wendy Rose and she saw the Education Health and Care plan, she saw the
874 report, (.) she obviously knew what I had been accessing for Riley, she
875 turned round to me and said "you ought to be really proud of yourself", and
876 I said "why? (.) I'm not doing enough" and she said "oh my God you are
877 doing so much, you don't even realise (.) what you are doing and how you
878 make a difference to your son's (.) little world" and, (.) you know, you-you
879 just try as a parent to do (.) what you can do, but equally I now know that
880 other people won't even consider (.) doing things because they'll just accept
881 (.) what they get (.) and that's alright for some but for me (.) I've always got
882 to challenge it a little bit, (.) I've got fire in my belly (.) and I've got plenty of
883 time to challenge people

884 Scott It seems to be working well for you

885 Louise I feel it is, I feel it is and I think as well the reason I'm doing what I am doing
886 is because when we get to the end of year two (.) and if Riley does need a
887 specialist provision (.) I can say, (.) hand on my heart, that I've done
888 everything I possibly can do (.) and then the guilt has gone, do you know
889 what I mean? But if I didn't do anything and I sat in blissful ignorance, (.)
890 what am I doing really I am not helping him? I wouldn't expect a disabled
891 child to just pull themselves along the ground, I'd put them in a wheelchair
892 and I'd (.) I'd give them the equipment to help themselves with (.). Although
893 the equipment is not a physical equipment I am giving him the skills
894 equipment, aren't I, (.) to try and get the best and this is it I don't have
895 unrealistic expectations, and this is what I liked about what Rockland said as
896 well (.) that we just-just want, (.) erm he said, just wants kids at Rockland
897 View infants to be the best they possibly can be and that's all I want for
898 Riley, for him to be the best that he possibly can be given everything that is
899 on offer to him. So that is what is important. (2) But yeah there has been
900 many tears, many tantrums and perhaps just Ian and, you know, it's an
901 emotional journey. You can't say (.) autism (2) d-d-doesn't kind of instil erm
902 fear, blame, upset and then you can counter it and it's like there's a positive
903 aspect because it's exciting, it's unusual it's a bit different (.) and it's
904 amazing because, (.) you know, he can do these amazing things and it's, you
905 know, they say that children with autism have theses amazing (inaudible)
906 and stuff and Riley just seems to have an amazing ability to do bits and
907 pieces. But (.) it's always comes with the caveat that he will do it (.) when
908 he wants to do it, when you least expect it (.) and every day is different and

909 one noise one day might upset him and then the next it-it is no big deal, so
910 that's the difference that I'm noticing with other autistic families is that they
911 know instantly what triggers their child, I don't, everything changes and this
912 is probably cos of the duplicate 15 Q and all of a sudden it's not, it's not full
913 autism, it's autistic traits. (.) And I think that's another key thing as well is
914 that you slipped out of one world and you are entering into another (.) and I
915 don't know much about this one (.) and I've kind of got used to this one but
916 now it's like well (.) who-who wants us kind of thing (.)

917 Scott Erm so you mention there erm are there any specific instances where you
918 have felt that the blame?

919 Louise I think you blame yourself, you do blame yourself, I know I blame myself (.)
920 and well was it the antibiotics that I had to have cos I had like a tachycardia
921 thing and I ended up having to have a IV, I think it was penicillin (.) or
922 amoxicillin, and then you are thinking well they gave me that because I had
923 to have it so you can't argue with that and it's like (.) but then maybe I
924 should have (.) and, you know, you can ask-you can ask a million questions
925 and you get some answers and then you ask a million more kind of thing. I
926 think the end of the day (.) yes, (.) you know, it's not maybe anything me or
927 Ian have done (.) erm it may not, it may or may not be elements of
928 environment, but certainly we know now it's genetic (.) so there is a genetic
929 component there and (.) genetics dictate anything from your hair colour, to
930 your eye colour, to your behaviours (.) and so the list continues but

931 Scott And have you had experience of other people blaming, making you feel like
932 you are to blame or anything like that?

933 Louise No, not-not really, no and if-if they think that and people, you know, people
934 are allowed to think what they want no one has kind of voiced that to me.
935 (.) Obviously I think my mums expressed concerns "well if you find out
936 where it's come from how are you going to feel?" (.) and I said "right" and
937 that is kind of really where we are going with this as I think Ian would like to
938 find out (.) has it come from me or him (.) but I don't feel I need to know
939 that (.) because obviously we need to speak with the geneticist if I need to
940 work out what would be the reason really to find out (.) where it has come
941 from really, (.) is there a benefit for Riley to find out where it has come
942 from? Because (.) I don't want, (.) very selfishly, I don't want to look at Riley
943 every day thinking (.) it's my fault do you know what I mean? But (.) erm the
944 truth of the matter is that that me and Ian-he didn't come with a mark on
945 that said, you know, could have a problem on our 15th chromosome, might
946 pass it down, but the thing is Riley does have that knowledge, (.) so he can
947 use that knowledge to his advantage erm (.) but no we didn't come with a
948 stamp saying dud on it did we so you crack on don't you. But erm (2) no (2)
949 erm there's-there's always going to be feel that, you know, well we don't
950 know, but I would prefer to not know because even if I do find out it's not
951 going to change my situation. (.) What will change the situation is putting
952 the interventions in place for Riley to give him all the those experiences, to
953 love him (.) unconditionally (.) erm and all those kind of things really. Erm
954 but nobody has blamed us (.) I think people just have an expectation we are

955 to find out for the rest of the family a little bit erm and they might be a bit
956 surprised if we don't find out but erm (.) that's the power with the-the
957 information is-is that if my cousins or my brother want to have any
958 additional children then my consultant, well Riley's consultant sorry, can
959 write to their consultants and then that gives them a (.) ticket to find out for
960 themselves and stuff because (.) even if it has not come from me, even if it
961 has not come from Ian it might have come from a generation before so, you
962 know, certain conditions do jump so, you know, (.) just because it's no to me
963 and no to Ian doesn't mean it's not come from my line. So again with every
964 question you ask there is another (.) there's another question, do you know
965 what I mean? So it could be exhausting. (2) It would just be nice to have
966 quiet and not have to ask so many questions but (.) erm now I-I-I genuinely
967 feel that (.) we have this situation (.) erm and erm, you know, like I said, you
968 know, you sink or you swim with it (.) and (.) I don't think that I've been
969 given anything that I can't cope with, (.) knowing the person that I am (.) and
970 all the rest of it and (.) I'm a great believer that everything happens for a
971 reason (.) and, (2) you know, (.) my brother wouldn't be able to cope with it,
972 Ian's brother wouldn't be able to cope with it, Ian on his own wouldn't be
973 able to cope with this, so he has to be the rational one, I'm the inquisitive
974 one and that's where it works because (.) he can pacify me and I can inform
975 him and-and we bounce well together and things but erm you are only ever
976 given what you can cope with (.) and that is what I believe is that, you know,
977 (.) flip it on its head I can cope with this, we can deal with this and I can get
978 the best possible outcome I can get for Riley (.)

979 Scott Thank you

980 Louise It's alright

981 Scott Thank you it's brilliant... Thank you so much for sharing

982 Louise That's alright, I just hope it is helpful to you... I probably shouldn't mention

983 exes name so much...

984 Scott ((Me laughing)) it's all anonymized so

985 Louise No it's fine

986 Scott No one will kind of know any anything about what has been said and by

987 whom

988 Louise You can talk of a writer and they school or whatever

989 Scott Yeah

Appendix K: Louise transcript themes highlighted

1 Scott So yeah it's, it's about what your experience has been like as a parent erm
2 having a young person with additional needs while they have been in school
3 erm it can be related to other things outside of school as well it's just trying
4 to give you a specific kind of time frame in which to think erm and it it's
5 completely open it is whatever you think is (.) has been important for you
6 it's however you lead it, I will just follow I have very few questions and we
7 were just kind of go with how it comes out really is that okay

8 Louise Yeah

9 Scott So the first and major question is can you tell me about your experiences
10 and your feelings of being a parent with a young person with additional
11 needs sort of while they have been to school?

12 Louise Right, well yeah, okay Riley is due to start school in September erm this year
13 he has been at Rainbow Place nursery for the last two to two and a half
14 years, er so he is currently in the F1 provision there, they were the ones that
15 really kind of notice erm... Patterns of behaviour and of extreme responses
16 and things like that, erm and it was really them that kind of set the ball in
17 motion really obviously Riley when he was two he had-had pneumonia and
18 things and so he had not been very well, and then he acquired glue ear so
19 we thought there was a lot of problems initially around the that and, you
20 know, let's give him a bit more time, and before we knew where we were
21 the nursery were applying for extra grants for extra one-to-one erm support
22 and then there were talks of yeah of Lauren Siddal being involved, the

23 learning support service team, erm and then before we knew where we
24 were he had acquired a place (.) with an inclusion outreach worker,
25 Samantha Thornton, and from that day to this which was about 2015 kind of
26 timeframe to present day we've obviously had Sam Thornton (.) involved in
27 one way or another. It can be fun to try and contact her because it's not
28 always possible to contact her, I know there was one time when I contacted
29 her during the summer when I wasn't aware that she only worked during
30 term time because nobody had told me these things erm there has been
31 various letters that have come through from the child development centre
32 at Portis which have been ambiguous, you know, ambiguous wording, things
33 not so clear cut and obviously that has generated me to (.) phone up and
34 like with most parents of a child like Riley with additional needs or whatever
35 erm, you know, trying to speak to the right person that sent that letter is
36 almost an impossible task, so you end up phoning and then you are told to
37 phone back later and then it's a constant chain of phone calls and before we
38 knew where we were about a year or so down the line we actually got
39 invited to attend a meeting (.) cos I said I was unhappy with the service I had
40 had and they basically use this meeting as a stick to beat me with, about to
41 actually have a go at me for "draining the resources" and things, and they
42 had actively chosen to ignore some of my queries that I had and they
43 actually volunteered that to me that they had actively chosen to ignore me
44 because they thought that my questions were unreasonable and I said "well
45 would it not have been nice to maybe just have been told we are dealing
46 with that?" and there was one time that that we had got quite recently in

47 May, a TAC meeting, and no speech and language representatives erm had
48 got back in touch with me and they had had six weeks to respond so I ended
49 up generating (.) somewhere between four and six calls to say “Is Sandra
50 Benny coming? Is somebody else coming?” erm and obviously we got-we
51 went to this meeting and that's when they volunteered that they had
52 actively chosen to ignore my requests, it was not commonplace for them to
53 turn up (2) erm Me and my husband were quite upset by that, and then the
54 following day they found up to apologise that somebody would be coming.
55 So lots of contradictory sort of things (2) erm And obviously a lot of
56 unnecessary appointments like that one erm and obviously poor Ian has had
57 to take time off work for these unnecessary appointments erm and
58 obviously like today when it's a sports day for our daughter that obviously
59 doesn't have additional needs Ian can't attend because we have had to use
60 all his holidays. Obviously I recently gave up my job, that is fairly, fairly
61 recently I worked my notice, and my last day was that the 30 thirist of May
62 and I was an inclusion TA at Shipton and really with all the various
63 appointments we are having to attend, more recently with the genetic bits
64 and pieces just, just that it isn't flexibility when you are working to attend all
65 of these appointments, so fortunately I have applied for things like carers
66 allowance, we have got middle rate DLA for Riley, and lower rate mobility
67 for him from his fifth birthday and fortunately that extends to his 16th
68 birthday so that's that's an element a little bit of financial security but it is
69 not a lot, it is not a lot erm another reason was obvious Forget my job was
70 obviously the prices for Rainbow Place nursesey became a bit ridiculous they

71 were wanting £585 a month well as a-as a inclusion TA you don't get paid a
72 lot of money, you're lucky if you are walking away with kind of between
73 eight and ten grand a year so actually I wasn't walking home with any
74 money so all of us and it became silly erm for Riley to have in excess of 30
75 hours a week at the nursery so now he just has his 15 hours a week. (2) But
76 really in answer to your question the nursery are the ones that have kind of
77 orchestrated it, they are very, very supportive

78 Scott How does that feel?

79 Louise What that I'm supported? Just-just amazing (.) because obviously they've
80 picked up things that to be honest I don't know whether we had blinkers on
81 or whatever but I am pleased that they have been involved and so involved
82 with kind of sorting various bits and pieces out they have always been like a
83 shoulder to cry on because obviously they are aware that they are in the
84 industry of for want of a better word they know I suppose how me and Ian
85 feel and he is a massive, it's a massive blow to be told that your child is not
86 presenting as a typical, neuro typical child, erm but, you know, that doesn't,
87 but Riley does the most amazing things that I wouldn't want him to be (.)
88 normal, do you know what I mean because he can look at a-for example
89 quite recently erm my eldest was on her scooter outside in the garden he
90 watched for about 20/30 minutes, never attempted it before ever, watched
91 what she did, then after that extended period of time attempted it and
92 mastered it instantly, you know, that's amazing. (2) You know we can watch
93 YouTube clips, he's talked himself to count to 10, we are very good with

94 colours and addressing colours, and things like that he recently worked we
95 are kind of doing the alphabet through a YouTube song and I think we have
96 got up to kind of G or F at the moment (2) But you know we, I-I-I don't
97 remember being able to do the things with Imogen, you know at four erm it
98 wasn't until she started School that they think became interesting, I couldn't
99 get her attention with that, she just wasn't interested but Riley sorry he's
100 just got a thirst for knowledge and again this is quite contradictory with this
101 duplication 15q because, (.) you know, (2) the typical case that is that I am
102 reading about don't suggest that Riley should be able to do these kinds of
103 things really (2) erm but erm yeah obviously what we have as well as a
104 consultant Dr Hart and she has been amazing, so she was the one that said
105 obviously put Riley through a series of tests, so we established that he has
106 got a vitamin D deficient say so he has got to have medication throughout
107 adolescence, and actually since he started taking that he has been talking
108 more, I don't know where, I don't know whether there's a correlation with
109 that erm but certainly with having this vitamin D Riley is talking a lot more.
110 Erm obviously she checked his immunoglobulin, obviously eye level, you name
111 it she checked everything and wrote a very fully comprehensive report (2)
112 absolutely amazing and then obviously more recently with the the bloods
113 that were taken in March of this year they got sent off to the Uni of
114 Manchester and that is when we found out at the end of May that there
115 was a medical reason for why Riley presents the way he does they call it
116 Interstitial Duplication 15q (.)

117 Scott Catchy

118 Louise Yes erm 11.2 to 13.1. So what this means is that Riley has three cop three
119 copies, three sets off of this particular erm section on his 15th chromosome,
120 so he will have got one from me, one from Ian and then there is a spare. So
121 what we have been told is that they could've come for me, could've come
122 from Ian or it could just have been what they call sporadic. And obviously
123 that is what has caused the erm the delay with his speech and things. Erm
124 the educational psychologist that has obviously been doing various reports
125 for Riley, she's been amazing. When I have emailed her on occasion she's
126 come back to me, I appreciate people are quite busy and things, the NHS
127 SALT people (2) erm obviously on the back of the upset with going in they
128 gave me an email for the Portis CDC and when they do pick up the query I
129 do you get a good response, but just give you an example I-I-I posted a quick
130 query on 2nd of May and I didn't get a response until 23rd of May, so it took
131 them in excess of 20 days to answer that query... But when they did come
132 back to me erm they apologised and obviously then went away did some
133 research and came back to me. So it did work but I do think that everyone
134 should have the facility one way or another and I think as well that you
135 know we have got some sensory training for September this year. But we
136 had our diagnosis (.) September 2016, where was my support? There, there
137 has been no (.) counselling, there's been (3) We got given a pack (2) And
138 which I kind of found was a bit of an insult because Riley didn't come with a
139 textbook or a leaflet to when I gave birth to him, so to be given a leaflet on a
140 condition that actually wasn't really correct because obviously we have now
141 got a new diagnosis and things I I just felt it was insensitive erm (.) I don't

142 know you are just given this blur of information and you are just thinking my
143 whole life has changed and they have given me a letter and they have CC it
144 out to doctors and (3) Health visitors and things like that, health visitors
145 have haven't wanted to know , Everything that where we are today is
146 because I'm the kind of woman that gets on the phone and you know and
147 I've sort obviously your help, the University of Newton has helped , Newton
148 Smalltalk, I have contacted the genetics department at the Uni of Newton
149 and I'm waiting for someone to come back to me, I have sourced Riley an
150 ABA program in Yorkshire with erm a charity called the Blue Door and that
151 starts in September as erm erm a Saturday school (2) erm I think that's
152 10am while 1pm and for 10 sessions it is about £250. A lot of the stuff that I
153 have found out nobody else knows about. For one reason or another it's
154 not it's not out there. In the CDC they don't know about it so I actually
155 volunteered to them, that this is available and I think they felt really
156 threatened by that. I think they are threatened as well by the way that
157 we've employed somebody as well because to be honest the input that we
158 have had from the NHS, be it two emails and a twenty minute session, it has
159 been quite good but it is not enough, (2) it is nowhere near enough and of
160 that twenty minute session when they came to Riley's nursery they spent
161 five minutes trying to wake him up. And this is another thing which I would
162 say is a bit of a bug bare is, is that when Lauren is doing her reports, when
163 Sam the inclusion outreach worker has been and done some of the reports
164 they have always come in and afternoon when Riley's typically asleep so you
165 are never going to get the best of them. I would have thought that they

166 need to get to know when the best times are cos I volunteered all of that
167 information, I volunteered what makes him tick, what motivates him and
168 nobody seems to be really interested I just feel that they are on their own
169 path and-and I feel there is a lot of conflict between parents of autistic
170 children and your multi agency professionals because ironically autism's all
171 about communication, it is about socialising, it's about interaction, yet the
172 people that I am dealing with, (.) for want of a better phrase, they don't
173 have really good communication skills. Erm the lady that gave Riley his
174 diagnosis, a lady called Sarah Clarke, I found her to be incredibly (.)
175 impersonal, abrupt. (2) I know it sounds an awful thing to say but I would
176 challenge as to whether she had problems because it was just so insensitive
177 erm and erm (.) I remember saying to her "do you know what it is like?",
178 "I've been doing this job 25 years, I know what it's like". (.) "No, do you have
179 a child that has been given a diagnosis?", "No I don't have children ". How
180 do you know? Seriously how do you know then? And I just found it quite like
181 I said abrupt and impersonal erm obviously the (2) that we pay Steph at Lets
182 Verbalise she is very supportive, (2) but then you would hope that she
183 would be because obviously I am paying her. But Wendy Rose, whose thesis
184 that we are running alongside, she's amazing she has offered us help
185 beyond September 2017 if we can access it obviously it depends on what is
186 happening with Riley's school. The school that we chose initially for Riley (2)
187 erm as I previously said were just not very supportive, they are very stats
188 driven erm there were comments on the phone and in person that "Your
189 son is going to cost me money". (.) Quite a message isn't it erm and yet this

190 is a school that promotes themselves on inclusivity (.) and erm when I went
191 erm and had a meeting on 25th of May with them they showed me round
192 where Riley's corridor would be. I don't want my son in a corridor all year, I
193 want to my son in an inclusive practice. Riley doesn't need to be in a
194 specialist provision erm and I have been and looked at specialist provision. I
195 have looked at Waterbridge, they don't take children until year three. And I
196 went and looked at Connect; the nursery who again have been amazingly
197 supportive they took me and my mum to go and have a look and I was
198 absolutely horrified, absolutely horrified. There was one child Riley's age in a
199 school of 19 and this kid is on the floor, all other eight or nine children again
200 just all independently doing their own thing no one nobody interacting.
201 Obviously you have higher ratios of staff that are talking about what they
202 had to eat last night or what they were socialising with and this one child
203 that's Riley's age was mute, on the floor, half dressed, so no T-shirt on and
204 chewing on a toy and just, erm you know, not absorbing anything and erm I
205 thought I don't want my son, we don't want our son, in a situation like that
206 if we can have void it really. Riley needs to be in a language rich
207 environment erm and that was a massive kind of eye opener and I think
208 that's kind of what people do is make you feel sometimes that if you have
209 an autistic child well why are you even looking at a mainstream school and
210 actually Riley is entitled to have mainstream education for as long as they
211 are can facilitate that and Ottoman couldn't, wouldn't really kind of, they
212 weren't prepared to do the right thing. You see if you have a sensory room
213 which sounds all absolutely fantastic but if it is outside the classroom he will

214 just gravitate to be outside the classroom, you need something like that
215 really inside. I get if he was getting distressed you'd take him out and you to
216 get him walking about and things to calm him down and things but to, to be
217 introduced that this was it going to be his corridor I just thought this is a sign
218 of things to come and obviously he got very distressed. His key worker
219 Laura, who has worked with Riley for 2 1/2 years has never seen Riley that
220 distressed and she was noticeably shook up and erm obviously the
221 conversations that followed on the phone have resulted in "well if you are
222 unhappy come and get a complaint form" do you know. Where's the
223 integrity of this headteacher, who is called Marie Trees at Ottoman and I
224 was absolutely devastated by thoughts of oh my God what have I done?
225 Because Imogen, my eldest, is in this school, we naturally assumed that he
226 would be alright and actually that was the wrong thing to do I now realise.
227 As a parent you try and do your best (.) and from a convenience factor you
228 want them to go to the same school but quite clearly I don't think it was the
229 right thing, so actually to have had that horrendous false start might have
230 actually been Riley's saving grace because we have now found a school that
231 buys into speech and language therapy a lady called Gemma Hayes she was
232 on a program called (inaudible), the Channel 4 little documentary and erm
233 erm obviously she's she's going to be working alongside Riley quite closely
234 and obviously they buy into educational psychology which are two things
235 that Ottoman school didn't want to do. (3) So then you've got the CDC not
236 really supporting you, you've got your choice of school not really supporting
237 you, you've got to various websites and things on Facebook, the parents

238 forum, Newton carers forum and you know lots of people you can interact
239 with. Erm I met one lady whose child did actually go to the same school and
240 they got managed out as well so now their child now goes to a different
241 school down the road and things. It's just seemed to be very little
242 compassion and understanding for the parents, you know, through no fault
243 of our own, that we were given a set of circumstances that were a little bit
244 challenging and we-we-we've just got to crack on with and get on with and
245 unfortunately not everybody is understanding and er, you know, you get
246 stares and points and things like that and sometimes they can actually be
247 from your friends and family. I would say that my family have supported us,
248 I would say Ian's family have supported us erm but what I am very aware of
249 is initially I think people were "Well he'll grow out of it" or "No that's not
250 right", then kind of spilling over "Oh he is never going to be alright" and just
251 an array of different comments, you know, a real spectrum of comments of
252 things and I'm thinking I have got to live with this I have got to get on with
253 this and I-I can't entertain negativity I have got to have something positive,
254 we have got to have something positive as a family. Erm (...) erm It was
255 refreshing when we contacted this other school and we send the education
256 health and care plans, Kate Whiting is absolutely fantastic, erm, erm one of
257 the multi-agency professionals that has produced this document, absolutely
258 amazing you can email her, she's been to see me, we had meetings, I just
259 can't credit this woman enough, she knows her stuff. The educational
260 psychologist she knows Riley you can tell with what she has written, she is-
261 it's an amazing report. And it is nice when the parties like Wendy Rose that

262 have looked at the reports and gone gosh isn't this really good cos we can't
263 get this in Newton, this is amazing. So it is humbling to know that this side
264 of the motorway we've got something that those in Newton can't access.
265 And equally in our town we don't have any of these fantastic like something
266 like Newton Smalltalk, we don't have that but they do so erm obviously
267 through my experiences with erm on the forum and things I have shared my
268 knowledge of where I have sourced stuff to try and pull and work together.
269 And I am aware that two other families have contacted Newton Smalltalk on
270 the back of me saying have you tried contacting this lady and that feels
271 really good to know that I have supported another two families going
272 through the same thing as what I am going through (2) I'll take a pause now

273 Scott No that's fine, thank you. (.) Lots of stuff. Is it alright if we go back over
274 some things?

275 Louise Yeah absolutely

276 Scott As we've been talking I have just been making note of a few things of the
277 kind of sentences that you have used which were just really interesting. Erm
278 and I've just-just thought I would ask you a little more about it. One of the
279 ones are used was feeling a massive blow when you were told that your
280 child is not neuro typical can you tell me a little bit more about that?

281 Louise To be honest erm I think I had a preconceived notion as to what autism was
282 is the same as every other kind of average person is that I have watched rain
283 man with Dustin Hoffman and you kind of think oh card counting and
284 socially awkward (.) and then it is like erm that is all I know, do you know

285 what I mean? And not really knowing anybody else's (.) child er that is
286 autistic that I was aware of and erm it was just devastating because you've
287 been given information and you've got, my reference point is a film, do you
288 know I mean? I don't-I don't fully understand and things and obviously and
289 my mum used to work for the child development centre in Lithgate er and
290 we regularly used to go on various day trips with erm a lot of children with
291 down syndrome so I understood what down syndrome was I understood
292 erm what additional needs meant, I understood what handicapped or
293 disabled meant I erm I-I-you know, I knew about those things, you know, we
294 used to interact with children with down syndrome, you know children-
295 children that had maybe no arms and no legs these were children that were
296 in wheelchairs but I didn't know about autism because obviously growing up
297 and thinking about it more sensibly as an adult you have your "naughty
298 children" in a classroom and actually maybe those children weren't naughty,
299 maybe those children were seeking stimuli, you know, wanting attention;
300 maybe had ADHD erm

301 Scott Did people described Riley as being naughty?

302 Louise No, no. They said that his behaviour is "challenging" and I would say through
303 the impairment with and the develop-sorry the, the, the kind of delaying in
304 your conventional speech has resulted in erm unsavoury behaviours shall
305 we put it and Riley will wallop me and will bite me if I don't-but he is talking
306 to me, this is it, there is a language underneath language sometimes and
307 because it is not terribly clear he thinks that I am ignoring him so he will

308 pinch me or he will bite me to kind of so what (3) understand what is going
309 on really which I think is quite clever actually because he is trying to get my
310 attention and things. So he's a very complex little character it's, it's, you
311 know, he is coming on lovely but yeah it was devastating because you don't
312 have a truly (2) erm clear kind of (2) notion as to what autism is, it is like I
313 said, you know, you hear a lot more about Down syndrome. I probably
314 knew more about Down syndrome than I do about autism because it was
315 not something (.) there were never any (2) because I was born in 81 so when
316 I was at infant school and junior school I didn't know anyone that was
317 autistic. I knew children that had a spina bifida erm and I knew one child
318 that had cystic fibrosis and, but yeah, you didn't hear about those things
319 and-and I did think naïvely oh is it is this the latest buzzword you know? Is
320 this like the modern version of ADHD? That kind of thing. What-what-what
321 does this mean for us and then being told that he is not always autistic just
322 in terms of certain situations and I thought hang on you're either autistic or
323 you are not because if you are Downs or if you have got spina bifida you
324 don't just switch that on and off so I-I-I-I it was really quite odd and yeah
325 and I get that is why they gave us the leaflets and stuff but I thought you are
326 giving me a massive load of information and you're going to give me a poxy
327 leaflet and the crux of the-the-the insult really is that the leaflet was
328 completely out of date. Erm there was one by the Autism Communication
329 Team saying they had speech and language therapy and I have since found
330 out that they don't have that erm and the numbers were wrong and the
331 email was incorrect so it was like this is who you need to speak to, as one

332 example, and it is completely inaccurate with all the details and stuff and

333 erm yeah, erm yeah

334 Scott Does that link into when you said so the insensitive nature of some of the

335 materials you've been given?

336 Louise Well just the insensitivity as to how to deal with things, here's an A4 green

337 folder with half a dozen leaflets, some are out of date and, you know, read

338 up on what you've got to do and I am just thinking would you do that with a

339 cancer diagnosis? And I know obviously, you know, put things into context,

340 this is not cancer, this is not serious but it could be life affecting because,

341 you know, at that point I'm thinking I'm gonna have to adjust everything I

342 know, he is never going to be independent, very selfish kind of thoughts of

343 he's never gonna get married, he's never go have children, he's never going

344 to have a job and that is what you think initially because like I said I have got

345 no reference point in real life as to what autism meant for our family (4)

346 Scott And how does it feel having that kind of experience of thinking well he's

347 never going to be independent, he's never going to get married?

348 louise It just blew my world, it blew my world completely, a lot of tears, a lot of

349 tantrums, wanting to and I think this is why we pushed the genetic thing as

350 well because I just thought there has got to be a reason why. (2) Because I

351 erm I don't know for me, I don't know maybe I've got quite a scientific kind

352 of brain, you know, (.) waters hot because I have boiled the kettle, do you

353 know what I mean? There's got to be some kind of transaction that needs

354 to take place as to why Riley was presenting in the way that he was and

355 when you look at typical symptoms of how children with autism present,
356 yeah there were some but there wasn't always and I just felt have they got
357 this wrong? I went back to the doctor, the doctor was very supportive, tried
358 to kind of reassure me, you know, and actually what he said was quite
359 profound; he said you know once upon a time people when they got a
360 diagnosis of diabetes or even asthma were absolutely devastated by those
361 things, and they can be very life affecting conditions he says but it is just a
362 label. But with asthma you have a pump or a nebuliser, with diabetes you
363 take a tablet or you have insulin and you manage your diet. What was I
364 going to do with autism? Because and then you start looking at diet and
365 then you start questioning every inoculation he ever had, is there a reason
366 why he is presenting the way he is? And my aunt who lives in Australia,
367 she's, I don't know whether the word is a homoeopath, naturopath but
368 certainly she looks at your body's natural chemicals and things and erm
369 obviously when I was pregnant with Riley I ended up having to have IV
370 antibiotics and then you are thinking have things got out of kilter, talking
371 about the gut brain connection and was that a severed gut brain connection
372 erm, you know, he was quite a low-birth-weight, I say low, 8 pound 1, you
373 know, that is not exactly low but-but his sister was 8.9 and I was kind of
374 thinking he would be bigger, don't get me wrong still noticeably a big baby
375 but not as big as Imogen, quite skinny. He had jaundice and a load of
376 treatments for things like that, also had a tongue tie, so then you are
377 thinking is the tongue-tied the reason why he's had speech problems? Is the
378 pneumonia the reason why he has had hearing problems? And you just

379 keep linking back everything that you know and, you know, and the
380 inoculations and he had this and then he behaved like this, then he had a
381 string of infections and then he developed pneumonia and you constantly
382 analyse stuff erm because of trying to find a reason why he is presenting the
383 way he is. And so for six months I am just researching gluten-free, don't do
384 this, you know, looking at gaps diet, speaking to erm naturopath's, looking
385 at movement therapies and things like that and eventually it came to kind of
386 hmmm, I don't know, I just feel like I need more insight and then obviously
387 when I then spoke with my aunt she said ask for this, this and this test, went
388 to the doctors, we arrange that erm and the (2) he's then wrote off to this
389 consultant doctor, Dr Hart, she agreed to do all those things but my GP did
390 say if you don't get these things done I will do them for you because I think
391 it is important that we get these things done. And it was nice to feel
392 supported by your family GP and we always keep going back to Dr Amrad
393 because he gets it and I don't necessarily think he has got any personal first
394 hand experience but I think he could just see the frustration that we had
395 been through as a family and just offering us the help and support that we
396 needed has been absolutely amazing.

397 Scott That's really good and is that the frustration with other services that you
398 were talking about?

399 Louise Yeah cos-cos, you know, when someone sets the bar that high, who is going
400 to be absolutely amazing, and then you've got people who don't seem to be
401 all that bothered and things, erm the health visitor initially was quite good

402 at the second year review cos obviously that with the nursery ascertaining
403 that Riley did not have his 20/50 words by a certain point was quite good
404 but from that day to this I have never seen her since erm, you know,
405 obviously we know-knew we'd kind of have a fall off at some point and
406 things but erm yeah-yeah you do you feel like you kind of have to battle a
407 little bit and er I think the reason why myself and other parents battled is
408 cos we don't-don't know enough, there's not enough out there, and if you
409 google everything-I remember getting one letter and it talked about erm
410 erm (2) anti-mongoloid slant was the terminology used in this particular
411 letter and this letter was done by Dr Hart erm and it was talking about the
412 position of the eyes and we have since found out it's not an issue, it's just a
413 (.) medical (.) terminology and stuff, but that's not been signposted (.) and
414 at this meeting that I had at the CDC where they kind of again use this
415 meeting to kind of beat me and Ian with a stick for asking too many
416 questions; how dare we ask about things that we don't know. She did turn
417 round to me and say "Why don't you google it?" and I said "So you now
418 want me to google medical conditions and you think that is a sensible thing
419 to do?" erm and a erm obviously she kind of changed her tune didn't she a
420 little bit after that and things. It was just a ridiculous (.) comment to make.
421 Why am I not allowed to have medical terminology signposted to me by the
422 professionals as to what that means? Erm There was a wood lamp test and
423 things like that and I don't know what those things are (.) and you know, I
424 don't feel that me and all the parents should have to go searching as to
425 what these things are, (.) you know, we should be told quite clearly what

426 they are and erm just have things clearly signposted to us and I think that
427 aids the frustration and aids the kind of devastating feeling because
428 everybody kind of knows what is going on but me, me as a parent I don't
429 know what's going on (3)

430 Scott That's really interesting... So that kind of sense of having to battle with
431 people and

432 Louise It shouldn't be like that, it shouldn't be like that at all

433 Scott Erm and when you were kind of in that situation where someone is saying to
434 you you are asking too many questions how did that kind of make you feel?

435 Louise It's just erm it just really upset me (.) because if-if again my child had cancer
436 (.) would I not to be entitled (.) to speak with a counsellor? Would I not be
437 entitled to kind of ask these questions about how it is going to impact my
438 family? So why is it any different with erm autism because (.) my
439 understanding of autism is that it doesn't just disappear, you acquire the
440 skill set to manage it but it doesn't disappear, (.) where erm, you know, with
441 the cancer obviously it can disappear, it can even be in remission, you know,
442 and all the rest of it and, you know, maybe I-maybe I should shouldn't be
443 comparing things to like a cancer but what I am saying is that is the kind of
444 thing that jumped to my mind that erm (.) it-it-what I think is-is it's a
445 condition and, you know, some children that have autism also do you have
446 medical implications like epilepsy and seizures and that can be very life
447 impacting, very devastating and can be quite fatal. Certainly with this
448 congenital err heart issues things like that, erm with this duplication 15 Q,

449 we have had to go and have ECG so all of a sudden it is not just autism any
450 more we are having to look into seizures, we are having to look into erm
451 congenital (.) heart issues, and things like that so er do you know I mean?
452 It's not just autism anymore, it's all the medical bits and pieces that go with
453 that (.)

454 Scott So having to look into further conditions

455 Louise Yeah, looking at further conditions and things and erm we haven't seen a
456 geneticist yet properly we've only been given, we've only been given half
457 information and you know the consultant said to us "I don't know an awful
458 lot on this" (.) and told us to join this particular forum duplicate 15 Q
459 alliance, that were in America that might be able to help you (.) but just bear
460 in mind that the case studies on here are for more extreme than what your
461 son has got. So all I have got is a reference point of the-the absolute core
462 blimey extreme and have got nothing that is kind of where Riley is at, (.) so
463 (.) that is hard as well (.)

464 S That's interesting because you said earlier about having reference points for
465 autism having an extreme example and then with this another example

466 Louise Yeah, another extreme, yeah, so I've got, we never can really dip in to
467 something and think "oh that is exactly Riley", do you know what I mean,
468 that we can pinpoint that exactly (.) so (.) I kind of feel like you have to make
469 it up as you go along kind of thing. But I've never looked at my son (.) the
470 way that I have done since May (.) checking on him, is he breathing alright?
471 Okay, there's a twitch there, is that a seizure? And then it, do you know I

472 mean, it-it becomes a bit consuming (.) and even having to let the nursery
473 know, erm you know this now could be a reality in our world (.) and it is like
474 wow, you know

475 Scott So you feel some kind of worry and

476 Louise Yeah. Totally concern and stuff but equally as well your glass is half full or
477 half empty and I-I want it to be half full that he has not touch wood (.) ever
478 had a seizure (.) erm and, you know, long may that continue. (.) But even if
479 you don't have duplicate 15 you can still have a fit, you can still have a
480 seizure, we are not exempt from having these things but erm I-I-I you know
481 I-I never, never thought for a moment (.) we would ever be looking (.) at-at
482 this and, you know, me and Ian set the ball in motion to (.) acquire this
483 knowledge (.) and sometimes you can live in blissful ignorance and could
484 you imagine if we had, you know. Would that have been better? Would it
485 have been worse? And erm I-I-I-I think it is better because all Riley as an
486 adult will-will now have to (.) look erm cos obviously he has got a 50%
487 chance of passing it on. He will have to have genetic counselling later on,
488 but when I've even researched now the things that they can do now in 2017
489 are amazing (.) so if Riley was an adult now (2) yes it would be an issue but it
490 wouldn't be too much of an issue. And can you imagine maybe 28/30 years
491 down the line? Maybe they can do something, (.) you know, there's a
492 concoction that sort you out, you know what I mean? It's-it's positive to
493 think that there are things that we can do erm but, you know, what happens
494 if we had not found out and then he had a child that had presented worse

495 than him, you would have always thought maybe there was something I
496 could have done (2) but yes you kind of open that Pandora's box you don't
497 really know what is going to happen.

498 Scott And is that a kind of experience that you've had cos this is a genetic
499 condition, that sense of with Riley if he has a kid how would you feel? Have
500 you had that experience about having Riley yourself?

501 Louise (4) How are you meaning sorry?

502 Scott Sorry

503 Louise (3) Should I have had him?

504 Scott That kind of

505 Louise I don't know ((phone begins to ring)) (2) Bear with me for just a minute

506 ((Break in recording))

507 Louise About with Riley didn't you?

508 S Yeah

509 Louise What if I'd had an insight could I have had a child like Riley?

510 Scott Yeah

511 Louise But I have had him. Riley was a very much wanted erm baby. Obviously, we
512 had Imogen, she was an absolute dream, no issues at all. She's still
513 absolutely amazing, (.) she-she knows when he is about to get upset and
514 things and is very good at reading the situation, very intelligent, very loving,
515 very caring. (.) Why wouldn't you want another child? And Riley, up until

516 about 2 to 2 and a half was very placid and he was-he was an absolute
517 dream and then the little monkey appeared. (2) And he's just highly
518 spirited, he is lovely, Riley makes you appreciate life, erm the little littlest
519 things which celebrate, the biggest things we celebrate, Riley enriches our
520 family unit, (.) erm we love him to death. To be honest apart from the
521 speech that is coming on and his little bit of unruly behaviour is, that we
522 don't pander to, I don't pander to screaming, when he gets upset and he
523 starts screaming and shouting I ignore him, make sure he is safe but
524 fundamentally we ignore him. (2) And by not pandering to him it's done in
525 five minutes (.) and, you know, what in a world where it must be really
526 confusing for him why can't he have a little five minute outburst? (.) Cos we
527 all have our things that we get upset about erm and you know it-it is no
528 different for him even at four. So absolutely I would-I would never change
529 what happened, (.) it would be nice to have a bit of hind-foresight as to
530 what things were and all the rest of it and, you know, I probably would have
531 gone about things a bit more differently. I'd have (.) pushed for Riley to
532 have a diagnosis at 2/3 rather than just turned four, cos then we would have
533 had an extra year of intervention and maybe we might have been starting
534 this year with (.)even more speech. You can beat yourself up, and I think-
535 think erm at the end of the day (.) he's very much wanted. He is loved and
536 he just brings so much to the family (.) and do you know what he is so
537 intelligent. (.) There's, you know, his speech is questionable but his ability is
538 impeccable, it's not erm it's not erm it's not under speculation. He's got a
539 fantastic memory, (.) erm fantastic recall with things, (.) you know, fantastic

540 to eat, you know, he just eats anything. He's a bit of a tinker with sleep and
541 he has to have some melatonin to help him with sleep and things, (.) so that
542 can be a bit distressing, you know. (.) If he falls asleep at six he might be
543 waking up at two and, you know, he is wanting to go and it is like I want to
544 go to sleep kind of thing. It's only those instances that you think oh God I
545 can't cope, I am worn out. (.) But he just brings so much to the family and I
546 wouldn't really have him any other way (.)

547

548 Scott ((Laughing)) so just kind of going back to some of the other things that you
549 kind of mentioned so one of the things I think that was about offering so off
550 services advice and they felt threatened by (.) So is that something that you
551 have experienced?

552 Louise I think they are threatened by it because I'm knowledgeable (.) not only
553 because I was an inclusion TA, but I was only an inclusion TA for six months
554 and things obviously (.) I have had Riley for nearly 5 years so you have to
555 kind of do your own personal research, you know: Why have we not got
556 this? Why have you not got that? Even down to the education health and
557 care plan. (2) You know, you've commented on this date, about low tone,
558 you have commented on this date about being unsteady, you've mentioned
559 about a referral. Why have you not, (.) you know, sorted the bits and pieces
560 out? And I think people find that kind of erm (2) threatening and certainly
561 when (.) erm cos I think (.) the learning support service are a bit like schools
562 with stats and, you know, no one has actually said that but I do wonder (.)

563 and obviously, as we all know, you only have to switch your TV on, the NHS
564 is stretched in every way (.) possible aren't they but I do feel that they feel
565 threatened because, you know, Riley is making headway. But Riley is
566 making headway in spite of not having any help from them so if they can't
567 claim responsibility for Riley doing really quite well (2) I don't know whether
568 they are pleased to be honest. (.) I know that sounds an awful, a weird thing
569 to say but, you know, Riley is doing well because I've put this this and this in
570 place and then you get "well maybe you are over doing it", maybe I'm not,
571 maybe I'm not at all. And then it's like and then I have got this ABA
572 programme "well why are you doing that?" And I am like well why would I
573 not be doing that? (.) So everything is kind of met with a question (.)
574 circulating, you know, why am I doing stuff. Because I've researched,
575 because you've forced me to do research, cos you won't offer me any
576 alternatives, you won't offer me any training, you aren't offering me any
577 support in any format erm other than your long winded letters that aren't
578 clearly signposted and things so (2)

579 Scott So do you feel like you have been questioned?

580 Louise Totally! I think I am totally under the microscope and erm I-I think people
581 just want to, (.) I don't know, I think they want me to be dependent on
582 them. (.) But I am not prepared to be dependent upon the service that
583 doesn't offer anything (.) to me or any other parent of an additional needs
584 child, you've only got to go onto the parents forum (.) and there are a lot of
585 people like me that just feel aggrieved, that feel angry and, you know,

586 reasonably unreasonably so (.) maybe we have too many expectations (.) all
587 I know is if I lived in America, you know, my insurance would be covering a
588 lot of these costs (.) but then you have to buy into that privatisation where
589 we don't do that over here. Erm but I just feel everything is a battle erm
590 even to try and get them, when I was working, to get appointments at a
591 reasonable time because I can't just keep leaving at 10:30 in the morning, (.)
592 you know, for like three quarters of a day, you know, while they do an
593 assessment. And erm what world do we live in where (.) you have a
594 fantastic, you know, my employer were fantastic employers but, you know,
595 they'll only let you go on so many family days and stuff and then you end up
596 not being paid erm and it's-and it's tough it's tough so, you know, the-the-
597 these were quite clearly things that weren't in their green folder, you know,
598 all this kind of upset and things

599 Scott So when you erm when you were told your son it's going to cost me money
600 what was that light?

601 Louise It was disgusting (2) He's a human being with needs, would you would you
602 would you say that if my child was in a wheelchair? (3) Would you say that if
603 my child had lost one limb? Do you know what I mean? Because it is not
604 noticeably obvious, i.e. he's got two arms, he's got two legs, he-he can walk.
605 Erm speech is just (.) erm I think it's perceived differently (.) do you know
606 what I mean? And maybe they are thinking well he's dumb, I don't want
607 him. Do you know what I mean? And that's how it was coming across and I
608 thought how dare you. You're not lucky enough to have my son, and, you

609 know, just because he has got a speech problem doesn't mean he has got an
610 ability to learn issue. My son is not thick, my son would thrive in your school
611 and your stats would look amazing with my son in it. (.) But if you are going
612 to be that ignorant and naïve (.) then you can't have my son is what I
613 thought. And you kind of have to flip it, I can get upset, I can-I can report
614 her but, you know, what am I going to get? I am just gonna get a load of
615 aggro really erm. So to have found Rockland View that, you know, the
616 headteacher Mr Kane, funnily enough I used to work with him at my old
617 school, his whole ethos erm (.) on inclusion is not that (.) erm (.) i-inclusion
618 it doesn't just mean that they are included it means that things are tailored
619 to that individual child. (.) And (.) his parents evening speech yesterday was
620 just so poignant and I just thought you've got it, you totally understand (.)
621 and me and Ian just felt so (.) at peace with the fact that he was going there
622 and that I didn't feel I was going to have to battle. (.) Erm and-and with Mrs
623 Trees at Ottoman I felt that is exactly what I was going to have to do, (.) was
624 battle to be heard, battle for-for my right-err-for my sons rights as a student
625 in that school to be able to access a fair (.) erm and kind of varied
626 curriculum, well why-why can't-not everybody learns the same (.) and you
627 might learn things slightly differently from how I learn but that doesn't
628 mean that we are autistic or-or whatever. It means (.) that, you know-erm,
629 you know, some people need more visual-Riley is quite visual (.) and erm
630 and that is the better way for him to work erm at-at this moment in time
631 and things. And erm yeah I just felt I was going to have to do battle with
632 them

633 Scott And you didn't get that experience [when

634 Louise [No, no. If anything it was what can we do? Er and it was very positive and,
635 (.) you know, nobody is making me any unrealistic promises, (.) you know,
636 well we will try and see how we get on and things, (.) er but, you know, Riley
637 will be there until year two because it is an infant school (.) erm because
638 even if he needs to access err a more specialist provision after that, (.) a lot
639 of-a lot of the provisions don't really take until year three anyway erm and I
640 have looked at Waterbridge and I like their ethos and I like the structure (.)
641 and if and it's a big if, if Riley needs that he can have that (.) and, you know,
642 there is no shame, there is no guilt, Riley is an individual and Riley will have
643 what Riley needs and we as a family will support Riley in what he needs and
644 if people want to kind of sneer and point fingers and be rude then I feel
645 sorry for them, that's their ignorance. But, you know, you can still do GCSEs,
646 you can do A-levels, you can do apprenticeships and things like that. What it
647 just means is that, (.) you know, class sizes of 8 to 10 (.) and things are a bit
648 more manageable (.) and, you know, if that's what he needs then that's
649 what he needs. But unfortunately I don't have that crystal ball yet so we
650 just have to-we just have to be positive (.) er and give Riley er lots of
651 experience of lots of language rich experiences, erm (.) just life experiences

652 Scott So your daughter is in the school that you originally took Riley too and got a
653 really negative experience?

654 Louise Yes, yes so she goes into year four in September. Erm (.) to be honest there
655 is not an awful lot to complain with-with how Imogen has gone she did

656 struggle initially with some reading (.) and (.) erm I have paid for private
657 tuition with Imogen to support her with her reading and help her maths (.)
658 and I am really proud to sit here and say (.) we do 20 minutes reading each
659 evening (.) and obviously with the reading that we do at home and the
660 reading that she does at school and the reading that she does err privately
661 Imogen has gone from being the bottom of the class (.) to the top of the
662 class, you know, she's getting 10 out of 10 with her spellings she is doing
663 really well in comprehensions, (.) still struggles a little bit with maths but
664 the-the gap there has kind of closed, you know, she's got on with it with
665 things and Imogen is a summer baby and I think that's why she initially
666 struggled and stuff but erm never really had to battle (.) erm with things and
667 they were very good at sorting things out so that is why I am just so
668 surprised (.) that (.) erm, you know, that they'll have one of them my
669 children but they won't have the other one (2) or they are certainly not
670 making, (.) no, no one has said that they won't have him but they have kind
671 of it, will cost me money and erm you, know, it might not work and, you
672 know, have you looked at anything else, maybe this isn't realistic and things
673 like that. So they are kind of managing you out before you've even got in. (.)
674 So yeah

675 Scott So when you took him there you said you had a sense of oh my God what
676 have I done, and what did you mean sort of by that?

677 Louise Erm Inasmuch as because he was so distressed from that situation it was like
678 (.) I've allowed somebody, I've allowed this headteacher (.) to orchestrate

679 her staff, (.) manage them badly (.) to have my child who is now in a
680 distressed state (.) and erm it was horrendous, but the (2) I try and look at
681 every situation with a positive flip because if I had not had that experience
682 (.) I wouldn't have moved to Riley and it might not have been until the
683 September that we realised that there was a bigger problem (.) so I am a
684 great believer everything happens for a reason (.) and by that unfortunate
685 situation taking place Riley will now have something (.) better. He is going
686 to be in an F1/F2 mixed class so they have got nine F2 children going into a
687 mixed F1/F2 provision and they also have a pure F2 class of 30 children, (.)
688 so what they have said is that well let's keep him in there, with the younger
689 F2, see how he gets on and maybe we move him over or we change the plan
690 later on and things and they are on about a reduced timetable to begin and
691 then building up. So everything is a positive. (2) So rather than just throwing
692 him in the deep end and watch him sink it is like let's put him in the shallow
693 waters and let him float and I like that-I like that

694 Scott While we have been talking have you got any other thoughts around what
695 your experience has been like how you fell as you have gone along your kind
696 of journey?

697 Louise Yeah. (.) Well obviously the journey is not ended erm it will continue (.) er as
698 to where and how it will look like (.) I can't even begin to imagine what, I just
699 feel is I have to be completely on top of my game all the time. I have to be
700 organised (.) erm and unfortunately no one else seems to share that kind of
701 (.) erm organisation and erm, erm, you know, I have had to orchestrate a

702 TAC meeting, kind of push people and say can we do this maybe on these
703 dates? Can we do this can we sort this?

704 Scott So since having Riley do you feel you have had to become much more
705 [involved?

706 Louise [I feel like I am Riley's PA, do you know I mean? You know because I am-I
707 have entered a life of appointments, meetings and things and hospital erm
708 appointments and erm I have turned into a researcher erm, a mother, an
709 educator, erm a promoter of speech and language erm a behaviourist, you
710 know it, you know, you take on a different role, you wear a different hat
711 with every situation you take with things, you know. There isn't a day that
712 doesn't go by where you think oh that appointment's soon, I need to sort
713 things erm and erm it's erm it's erm, you know, it's just, it's never ending.
714 And my husband said to me last night (.) "You won't be able to get a job yet
715 soon will you?" and I said "no" (.) and it's like I'd love to just have a job
716 where you just go in, a monotonous 9-to-5 , you just answer phones or do
717 something erm (.) because everything that I do you do has to be-has to have
718 a reason for it and, you know, there is an outcome and it is about acquiring
719 that desired outcome at the end of the day and things

720 Scott Does it feel like it has been a big transition?

721 Louise (3) Well yeah, from-from September to present day, you know, if you tell me
722 that I was going to have to, you know, you know, I have got an extensive
723 filing system all the appointments and (.) all the letters, trying to understand
724 stuff, you know, erm (.) I feel like I should work for the local Council and

725 things and erm (.) Yeah, you are-you-**there are lots of little mistakes that are**
726 **made and you're having to constantly keep challenging little bits** and pieces
727 and stuff and erm (.) even with the Education Health Care plan that arrived
728 the other day it had got someone else's (.) details in the middle of it and
729 having to phone up and say are you aware that this is here as well?

730 Scott That's not good

731 Louise No it's not and-and they are human at the end of the day and they make
732 mistakes and fortunately these documentation did go back to the right
733 people and things (.) but, (.) you know, these are not perfect people. **But**
734 **they do feel like the gods of the situation, do you know what I mean, you**
735 **know, you've got to try and kind of liaise and flatter them in order to get**
736 **what you want**, you know, erm (.) you know, (.) Even like the things with the
737 occupational therapist well let's, you know, yes he'll need that but let's wait
738 until he gets into school; right well I have got that email and I am keeping
739 that safe cos and that is going to be the next, (.) you know, trump card, you
740 know, so I can say "where's this? you've promised me this?" that kind of
741 thing. So that is why I have been so passionate about sorting out the
742 Educational Health Care plan because with having (.) insight and knowledge
743 with what I was doing in my previous job, (.) he's got to hit the ground
744 running, (.) and you don't hit the ground running with the speech problems
745 that he has got, (.) you know, with the kind of you know let's wait and see
746 approach you've got-you've got to put those interventions in place and
747 things. **So yes you do you have to, (.) you do have to battle, but do you**

748 know what autistic parents are strong people (.) because we have to be
749 because you either sink or swim with this and you've-and I choose to swim
750 and get on and be positive and erm (2) Yeah (.)

751 Scott Thank you

752 Louise Is that alright?

753 Scott That's amazing

754 Louise Do you think?

755 Scott For me it is such a privilege to listen to people's experience

756 Louise Oh well it might sound like I am a bit of a whinge bag really

757 Scott No, no, not at all. It's-it's really (.) interesting to hear what peoples journeys
758 been and to hopefully try and use that as a way of supporting (.)
759 engagement with practitioners schools and things like that. So that, you
760 know, what I want to try and do with that (.) the [stories

761 Louise It is scary as well because every school has a different way that they can
762 deal with things and like I said Ottoman don't buy into speech and language
763 therapy, they'll let the NHS people come in, they'll let the private people
764 come in, but they don't-they don't use their funding for that. They also have
765 a lot of children with-with educational (.) erm well not educational,
766 behavioural problems (.) and they won't employ an educational behaviourist
767 because they said they don't value (.) what they said. How can you have
768 autistic children in a school and not value what an educational psychologist
769 thinks? (.) Because we all know with autism these repetitive behaviours,

770 that you behave in such ways because you are distressed or maybe sensory
771 seeking so why would you not have (.) those basic (.) things put in place?
772 And erm the Autism Communication Team (.) don't have speech and
773 language, you know, there is a lot of (2) to be honest with you apart from
774 Rockland and maybe Chesterton and Snow Lane primary (.) I-I certainly-the
775 school that my daughter's at erm other than dealing with inner core bits (.)
776 erm, erm the- the erm the kind of help with in a core strength and making
777 her a little bit stronger and things like that, I never had to fight for that at all,
778 they seem to like-they seem to Kind of have a bit of a pick and mix, they
779 kind of choose what they want. Well they have done the NDD programme
780 because a lot of children have motor (.) problems so that seems to be more
781 socially acceptable. But not all the children have autism (.) "so why would I
782 buy into this? why would I buy into that?". And all of a sudden all of those
783 children that were autistic certainly from years F2 to about year two aren't
784 there anymore because they have been managed out (.) and there are all
785 kinds of different other schools (.) and I don't know whether this woman is
786 on a mission to just make her-her life a little bit easier before retirement (.)
787 or whether she's just that prejudiced and things and (.) the thing is with
788 autism is it's very prevalent we are hearing more and more cases of (.) of
789 autism it's not disappearing, you can't sweep it under the carpet (.)

790 Scott You sort of mentioned social acceptability

791 Louise Yeah, yeah and I think that's it. If your child looks (.) different I just don't
792 think she wants to know and you do get that with a lot of parents (.) that,

793 you know, oh, you know, that one's got some problems, and you get the
794 sneers and the looks and all the rest of it, it's like take a picture it will last
795 longer (.)

796 S And that is something you have experienced?

797 Louise Yeah, totally, totally. People do comment and I-I did find myself for a while
798 not wanting to go anywhere because I thought he is going to behave like
799 this and people are going to look (.) and I remember one lady that I have
800 met on the local Parents Forum (.) says "what do you care? Seriously if you
801 let everyone affect you you are never going to do all the fun things and Riley
802 might be missing out" and I thought yeah, (.) I've got to have this I don't care
803 ethos really (.) erm because otherwise I am going to be affected by what
804 everyone else thinks (.) and this is my family (.) and if I don't give Riley these
805 enriching experiences he's not going to develop. And so you, but it is hard
806 to block it out, it is hard to block it out and erm everybody, everyone has got
807 an opinion, everybody's got an opinion, especially friends and family,
808 they've all got an opinion, they definitely do (.)

809 Scott And friends and family's opinions what are-are they kind of around, what
810 are they like?

811 Louise "He'll grow out of it", "I knew there wasn't a problem", erm you know, or,
812 erm you know, "well we're happy to have Imogen but if we have Riley it
813 could be, you know, a little bit problematic and things". Erm (.) more
814 recently "can you not bring Riley round cos he makes a lot of noise", (.) that
815 was another family member that said that. And I said "right then, well I

816 won't to come round but you'll have to come round to me" and then it was
817 like "oh right okay". (2) Do you know what I mean? **It's erm (2) they don't-**
818 **they don't mean it (.) erm but they-I don't think they get it,** you know, when
819 Riley is kicking off and getting upset (.) the-they erm in his world there's a
820 reason why that's happening and that he is not just a naughty boy, but then
821 sometimes his behaviour is (.) very much a naughty boy, because he is like
822 looking and he is smiling and he is running away from you and things like
823 that. So it is just a real mixed bag, he's just a real mixed bag bless him. But
824 yeah, **some of the people that are closest (.) to me haven't, you know, (.)**
825 **aren't really there, you know. To say that I have all these friends,**
826 **sometimes I am cruising through my phone (.) it's like there's not one**
827 **person that I think would understand how I feel (.)** and that is why the
828 forums are so (.) useful because, funnily enough **I am meeting with one lady**
829 **tonight and erm, you know, just-just to talk really about the same kinds of**
830 **experiences** and I would have never thought (.) that I would meet somebody
831 off a forum (.) and, you know, she only lives locally herself and things and it's
832 erm it's nice to be able to have another reference point and how their child
833 behaves and how my child behaves and, you know, the similarities and the
834 differences and things like that. (.) But what I do find in this forum world is
835 (3) a lot of people are alright to be your friends (.) until your child starts
836 doing maybe a little bit better and then it's like yeah; isn't-isn't that parents
837 in general even (.) minus the autism it's almost like a competition, (.) "my
838 child has got this, my child has got this swimming badge" and, you know, all
839 the rest of it and it-it's just human nature so I-I take what I need from the

840 forum but equally I put back by telling people about my experiences and
841 they have asked me to write about the experiences. I am having, like
842 maybe, with yourself, certainly with Newton Smalltalk, just to give an insight
843 (.) back into what's happening (.) and erm, like I said, through doing that
844 people are able to kind of get on the phone and access some of the people
845 that I've accessed and things, (.)that's only a good thing isn't it really (.)

846 Scott So you are becoming that signed poster (.)

847 Louise Yeah, kind of other people, you know, (.) you know, instead of like don't go
848 down there because there is a dead end, it's now you can go down there
849 and turn left and there's a bit of hope at the end of that road (.) and at say
850 about (.) and this is what is so important with networking with other (.)
851 families that are in a similar situation is we have to bounce ideas off each
852 other erm we have to share what we know (.) because we can't rely on
853 other people to let us know (.) and like I said Riley got his diagnosis in
854 September, what training have they put me on? You know, and (.) not to say
855 that I need training to deal with my son but I do need training to deal with
856 the autism that affects my son (.) because, you know, you-you-you need to
857 know that you are doing the right thing by your child, you need to, you
858 know, I needed insight into his world. It's alright saying he might perceive
859 the world differently, how does he perceives that world differently? Erm,
860 you know, and it's-it's those kinds of things that you need really but erm (.)
861 I'm surprised that, (.) you know, a lot of people that I have spoken to-there
862 was supposed to be an introduction to autism course, (.) never got that. So I

863 found there was a distance learning introduction to autism, (.) NCFE level
864 two qualification, so I've done a free qualification (.) to find out about hypo
865 and hyper sensitivity, to find about the vestibular system and to look at
866 repetitive behaviours, how to manage things (.) and that's something that
867 I've done myself, no one has told me to do that (.) because you need to up
868 skill yourself. (.) So yeah (.)

869 Scott It has been and continues to be a long journey

870 Louise Yeah it is and the thing is as well (.) my journey might be so different from
871 someone else's (.) cos it depends on (.) what you want out of it, (.) and do
872 you know what I am going to blow my own trumpet here, when I spoke to
873 Wendy Rose and she saw the Education Health and Care plan, she saw the
874 report, (.) she obviously knew what I had been accessing for Riley, she
875 turned round to me and said "you ought to be really proud of yourself", and
876 I said "why? (.) I'm not doing enough" and she said "oh my God you are
877 doing so much, you don't even realise (.) what you are doing and how you
878 make a difference to your son's (.) little world" and, (.) you know, you-you
879 just try as a parent to do (.) what you can do, but equally I now know that
880 other people won't even consider (.) doing things because they'll just accept
881 (.) what they get (.) and that's alright for some but for me (.) I've always got
882 to challenge it a little bit, (.) I've got fire in my belly (.) and I've got plenty of
883 time to challenge people

884 Scott It seems to be working well for you

885 Louise I feel it is, I feel it is and I think as well the reason I'm doing what I am doing
886 is because when we get to the end of year two (.) and if Riley does need a
887 specialist provision (.) I can say, (.) hand on my heart, that I've done
888 everything I possibly can do (.) and then the guilt has gone, do you know
889 what I mean? But if I didn't do anything and I sat in blissful ignorance, (.)
890 what am I doing really I am not helping him? I wouldn't expect a disabled
891 child to just pull themselves along the ground, I'd put them in a wheelchair
892 and I'd (.) I'd give them the equipment to help themselves with (.) Although
893 the equipment is not a physical equipment I am giving him the skills
894 equipment, aren't I, (.) to try and get the best and this is it I don't have
895 unrealistic expectations, and this is what I liked about what Rockland said as
896 well (.) that we just-just want, (.) erm he said, just wants kids at Rockland
897 View infants to be the best they possibly can be and that's all I want for
898 Riley, for him to be the best that he possibly can be given everything that is
899 on offer to him. So that is what is important. (2) But yeah there has been
900 many tears, many tantrums and perhaps just Ian and, you know, it's an
901 emotional journey. You can't say (.) autism (2) d-d-doesn't kind of instil erm
902 fear, blame, upset and then you can counter it and it's like there's a positive
903 aspect because it's exciting, it's unusual it's a bit different (.) and it's
904 amazing because, (.) you know, he can do these amazing things and it's, you
905 know, they say that children with autism have theses amazing (inaudible)
906 and stuff and Riley just seems to have an amazing ability to do bits and
907 pieces. But (.) it's always comes with the caveat that he will do it (.) when
908 he wants to do it, when you least expect it (.) and every day is different and

909 one noise one day might upset him and then the next it-it is no big deal, so
910 that's the difference that I'm noticing with other autistic families is that they
911 know instantly what triggers their child, I don't, everything changes and this
912 is probably cos of the duplicate 15 Q and all of a sudden it's not, it's not full
913 autism, it's autistic traits. (.) And I think that's another key thing as well is
914 that you slipped out of one world and you are entering into another (.) and I
915 don't know much about this one (.) and I've kind of got used to this one but
916 now it's like well (.) who-who wants us kind of thing (.)

917 Scott Erm so you mention there erm are there any specific instances where you
918 have felt that the blame?

919 Louise I think you blame yourself, you do blame yourself, I know I blame myself (.)
920 and well was it the antibiotics that I had to have cos I had like a tachycardia
921 thing and I ended up having to have a IV, I think it was penicillin (.) or
922 amoxicillin, and then you are thinking well they gave me that because I had
923 to have it so you can't argue with that and it's like (.) but then maybe I
924 should have (.) and, you know, you can ask-you can ask a million questions
925 and you get some answers and then you ask a million more kind of thing. I
926 think the end of the day (.) yes, (.) you know, it's not maybe anything me or
927 I can have done (.) erm it may not, it may or may not be elements of
928 environment, but certainly we know now it's genetic (.) so there is a genetic
929 component there and (.) genetics dictate anything from your hair colour, to
930 your eye colour, to your behaviours (.) and so the list continues but

931 Scott And have you had experience of other people blaming, making you feel like
932 you are to blame or anything like that?

933 Louise No, not-not really, no and if-if they think that and people, you know, people
934 are allowed to think what they want no one has kind of voiced that to me.
935 (.) Obviously I think my mums expressed concerns "well if you find out
936 where it's come from how are you going to feel?" (.) and I said "right" and
937 that is kind of really where we are going with this as I think Ian would like to
938 find out (.) has it come from me or him (.) but I don't feel I need to know
939 that (.) because obviously we need to speak with the geneticist if I need to
940 work out what would be the reason really to find out (.) where it has come
941 from really, (.) is there a benefit for Riley to find out where it has come
942 from? Because (.) I don't want, (.) very selfishly, I don't want to look at Riley
943 every day thinking (.) it's my fault do you know what I mean? But (.) erm the
944 truth of the matter is that that me and Ian-he didn't come with a mark on
945 that said, you know, could have a problem on our 15th chromosome, might
946 pass it down, but the thing is Riley does have that knowledge, (.) so he can
947 use that knowledge to his advantage erm (.) but no we didn't come with a
948 stamp saying dud on it did we so you crack on don't you. But erm (2) no (2)
949 erm there's-there's always going to be feel that, you know, well we don't
950 know, but I would prefer to not know because even if I do find out it's not
951 going to change my situation. (.) What will change the situation is putting
952 the interventions in place for Riley to give him all the those experiences, to
953 love him (.) unconditionally (.) erm and all those kind of things really. Erm
954 but nobody has blamed us (.) I think people just have an expectation we are

955 to find out for the rest of the family a little bit erm and they might be a bit
956 surprised if we don't find out but erm (.) that's the power with the-the
957 information is-is that if my cousins or my brother want to have any
958 additional children then my consultant, well Riley's consultant sorry, can
959 write to their consultants and then that gives them a (.) ticket to find out for
960 themselves and stuff because (.) even if it has not come from me, even if it
961 has not come from Ian it might have come from a generation before so, you
962 know, certain conditions do jump so, you know, (.) just because it's no to me
963 and no to Ian doesn't mean it's not come from my line. So again with every
964 question you ask there is another (.) there's another question, do you know
965 what I mean? So it could be exhausting. (2) It would just be nice to have
966 quiet and not have to ask so many questions but (.) erm now I-I-I genuinely
967 feel that (.) we have this situation (.) erm and erm, you know, like I said, you
968 know, you sink or you swim with it (.) and (.) I don't think that I've been
969 given anything that I can't cope with, (.) knowing the person that I am (.) and
970 all the rest of it and (.) I'm a great believer that everything happens for a
971 reason (.) and, (2) you know, (.) my brother wouldn't be able to cope with it,
972 Ian's brother wouldn't be able to cope with it, Ian on his own wouldn't be
973 able to cope with this, so he has to be the rational one, I'm the inquisitive
974 one and that's where it works because (.) he can pacify me and I can inform
975 him and-and we bounce well together and things but erm you are only ever
976 given what you can cope with (.) and that is what I believe is that, you know,
977 (.) flip it on its head I can cope with this, we can deal with this and I can get
978 the best possible outcome I can get for Riley (.)

979 Scott Thank you

980 Louise It's alright

981 Scott Thank you it's brilliant... Thank you so much for sharing

982 Louise That's alright, I just hope it is helpful to you... I probably shouldn't mention

983 exes name so much...

984 Scott ((Me laughing)) it's all anonymized so

985 Louise No it's fine

986 Scott No one will kind of know any anything about what has been said and by

987 whom

988 Louise You can talk of a writer and they school or whatever

989 Scott Yeah

Appendix L: Louise – Themes and colour key

From analysis of Louise’s transcript 4 key themes were identified within the text. A highlighted version of the transcript is included in appendix K in order to demonstrate where evidence towards each theme originates within the text. The following grid indicates themes and the colour used to highlight them in the transcript

Theme and colour key
Communication and contact
Support and Containment
Difference
Being positive

Appendix M: Treatment of Louise's data

Louise's interview was transcribed verbatim using the following Jefferson (2004) conventions:

Symbol	Description
(.)	Pause of less than a second
(4)	Pause length in seconds
((sigh))	Non-verbal communication
[Speech overlaps
(inaudible)	Unable to determine speech in recording

A six phase approach was employed (Braun et al, 2012) detailed as follows:

Phase	Description
1) Familiarisation	Immersing in the data through repeated readings of the transcript and making notes
2) Generating Initial Codes	Semantic codes were created to encapsulate the meaning of expressions and sections of the text. These codes began the process of interpretation of Louise's data
3) Searching for Themes	An active process of meaning making was undertaken during this phase. Coded data was reviewed to consider commonalities between them. Codes were grouped together into potential themes
4) Reviewing Potential Themes	Initial themes were reviewed in relation to the coded data and extracts from the transcript text. Five questions (taken from Braun et al, 2012; p.65) were considered during this phase: <ul style="list-style-type: none">• Is this a theme?• What is the quality of this theme?• What are the boundaries of this theme?• Is there enough data to support the theme?• Are the data too diverse and wide ranging
5) Defining and Naming Themes	A process of naming the themes was completed through consideration of the words in the text and the codes that had been created through the section stage
6) Reporting findings	Analysis of the data and the themes created are reported within the body of

	the thesis. Colour theme codes are indicated in appendix L
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