

Are parents being heard?
Parents' experiences of participating in multi-professional meetings as part of the
Education, Health and Care Plan process

by

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ABSTRACT

The recent Special Education Needs (SEN): Code of Practice (DfE, 2014) has placed great emphasis upon parents being central to the decision-making process when deciding the support needs of their child. Previous Education Acts have highlighted the importance of the parental voice with numerous frameworks and models explaining their importance, yet research suggests that parents remain frustrated, unheard and muted in their quest to be equal in the partnership with multiple professionals.

The purpose of this research was to investigate the views of parents who have participated in multi-professional meetings. This exploratory research provides insight into the experiences of parents who have recently been involved in such meetings within the Education, Health and Care Plan process (EHCP), and how they felt regarding being treated as an equal amongst a multitude of professionals.

A constructivist paradigm was adopted to explore the subjective realities of the parents. Four semi-structured interviews were conducted. An interpretative phenomenological analysis (IPA) was applied to draw out themes from the data. The findings highlighted relatively similar experiences amongst the parents with common themes including barriers to parental involvement, professional power and how the parent positioned themselves. Findings are discussed in relation to the research questions and relevant literature regarding parental and professional collaboration.

DEDICATION

In memory of my dad who taught me that life is too short

“Life begins at the end of your comfort zone”

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Chapter 1

INTRODUCTION

1.1 Recognising the child's needs

In 1944, the Education Act proposed that a child's education should be centred on the age and capability of the child. The expectation was that the child should fit the school rather than the school adjusting to meet the child's needs. The face of the education system changed with the release of the Warnock Report (DES, 1978). The report concluded that up to 20% of the school population had special educational needs (SEN), with almost 2% requiring support over and above what a mainstream school could provide. To better support our most vulnerable children the Warnock Report suggested that specialist provisions should be provided.

The Warnock Report significantly influenced the Education Act (1981), which attempted to address the support needs of vulnerable children by instructing local education authorities to identify and assess their needs and provide a suitable provision for them (Cook, 1999). This came through the introduction of 'statementing'. It was in this Act that the voice of the parent was noted as significant to assessing the child's needs. Another poignant amendment was the parental ability to challenge professional decision, allowing parents to appeal the local authority decision (Goacher, 1988)

The Education Act (1981) appeared for the first time to embody a broad belief of civil rights and recognition of the role of parents in education decision making (Russell, 2003). Russell (2003) continues that the involvement of parents will inevitably have significant implications for professionals and other agencies involved with the child. Russell's comments highlight the concerns that many professionals held following the changes in legislation and the impact

parents' input may have, which was also a common feeling through the literature at this time (Long, 1986; Macleod, 1985; Swick, 1988)

1.2 Rationale for the study

Throughout my career I have engaged with parents in supporting their child's emotional and educational needs. It is through these encounters and multi-professional meetings where I gained a sense of imbalance between the parents and professionals. I felt parents were being 'swept' along by a process and seen as unimportant in respect of a multitude of professional opinions regarding their child. The introduction of the SEN Code of Practice (DfE, 2014) appeared to create optimism to the positive engagement of parents. The parental voice is mentioned throughout the Code of Practice as being vital to supporting the child. I was keen to explore how this would transpire into practice and discover how parents perceive their position within multi-professional teams in regard to the introduction of Education, Health and Care Plans.

1.3 Researcher identity and position

My position with working with parents is liable to have an influence on my approach to this inquiry and my understanding of the findings. Working within a social care department supporting parents who felt they did not have a voice and moving into a school with a different approach to parent collaboration, I feel passionate about changing professional views on engaging parents. My core values regarding the parental voice and frustrations I have felt during my career must be acknowledged in relation to this research. Through the M.Ed. programme and the values instilled through the University of Birmingham I have developed my commitment to working collaboratively and engaging with anti-oppressive practice. The

respect for others values, beliefs and experiences are entwined through my selected area of research and the methodology I have elected.

1.4 Research Question

From this the following questions arise;

- 1) Do parents feel listened to during the Education, Health and Care Plan process?
- 2) Do parents feel confident to be central to the process?

These form the basis over the overarching research question for this study:

Are parents being heard?

Parents' experiences of participating in multi-professional meetings as part of the Education, Health and Care Plan process

Chapter 2

LITERATURE REVIEW

2.1 Historical and political perspective

SEN is a broad term that covers a wide range of difficulties, from distinct sensory and physical impairments to mild dyslexia, as well as complex behavioural and intellectual problems (O’Conner *et al.* 2005). Those who are considered to have SEN have a legal entitlement to an assessment by the Educational authorities to ensure their additional needs are met (Sanders and Rivers, 1996). The consensus view appears to be one of common presumption that children with SEN require alternative provisions from their peers in mainstream schools (Audit Commission, 2002). However, throughout literature it is well documented that children with SEN should be educated, where possible, in a mainstream school which promotes and actively encourages inclusiveness (Warnock 1978; Lehane, 2013; Garner, 2014). This statutory assessment consists of reports produced by a variety of professionals including teachers, Educational Psychologists, community paediatricians, social workers and health workers (O’Connor *et al.* 2005). This assessment will clearly identify the child’s needs; the most suitable provision, learning objectives and more recently a focus upon the child’s health and social needs will also be included (DfE, 2014).

Through government legislation, parental collaboration is expected within the assessment process (O’Conner *et al.* 2005). However, the assertion of parental involvement used throughout the literature remains abstruse. The assumption is that parents have been actively involved with the assessment process, however this does not appear to be the case, with many

parents feeling frustrated, muted and ignored throughout the statutory assessment (Murray 2000; McNab, 2010; Logsdon, 2016)

2.1.1 The Warnock Report

The parental contribution progressed following the Warnock Report (1978), which recognised the necessity for parent's involvement to ensure the needs of their child were met. This included a focus on a legal reparation to ensure all their needs were identified and plans were in place to meet these needs (Warnock, 1978). The emphasis on parents being able to legally redress appeared to cause some apprehension about the involvement of parents and sets the scene for how parents can often be viewed from a professional perspective. Warnock highlighted almost forty years ago that:

"...successful education of children with SEN is dependent on the full involvement of their parents" (DES,1978, p.150)

Warnock (1978) devotes a whole chapter within her report to the importance of parents being equal partners, which is reiterated throughout the years as being central to gaining the most suitable support for the child and fundamental to good practice amongst professionals. This key message has filtered through a succession of Education Acts and related Code of Practices (DfEE, 1997; DfES, 2001; DfES, 2004; DfES, 2005; DCSF, 2007; DCSF, 2009; DfE, 2010; Ofsted, 2011).

However, in recent years there have been concerns raised that the statutory assessment process is overly bureaucratic and costly, diverting professional resources away from meeting the needs of the child: offering little reassurance, placing excessive stress upon parents and failing to assist inclusive practices in schools (Audit Commission, 2002).

Baroness Warnock recognises these concerns in an interview with TES in September 2003 where she explains that the introduction of statements of SEN have become an obstacle to good provision (Shaw, 2003).

2.1.2 Children and Family Act (2014)

Through the recent SEN reforms cited within the Children and Family Act (DfE, 2014) the Code of Practice clearly highlights parental involvement more poignantly than previous government legislation. The underlining ideologies clearly express the significance of parental contribution:

*“Those with SEN **must** have regard to:
The views, wishes and feelings of the child or young person and the child’s parents; The importance of the child or young person, and the child’s parents, participating as fully as possible in decisions, and being provided with the information and support necessary to enable participation in those decisions; The need to support the child or young person, and the child’s parents, in order to facilitate the development of the child or young persons and to help them achieve the best possible educational and other outcomes, preparing them effectively for adulthood”* (DfE, 2014, p19)

A substantial amendment within the code is the move from Statements to EHCPs. Through this, it is essential that parents are involved and fully informed as specified by the DfE (2014, p.21)

“schools should enable parents to share their knowledge about their child and give them confidence that their views and contributions are valued and will be acted upon”

In my view, there is a concern in the affirmation of the importance of parental involvement. The point has been made over several decades, through several Education Acts, yet literature and research questions whether this practice is taken place

(Beveridge, 2005; Bone *et al.* 2015; Jansen *et al.* 2016). This fosters a discussion into how are practices changing to ensure the parental voice is central to our practice.

2.2 Concepts of parental involvement

When discussing parental involvement, there appears to be a variety of terminology adopted including partnership, empowerment, collaboration and participation (Jackson and Remillard, 2005). This language holds the premise to have positive connotations and imply that parents are welcomed into the multi-professional team (Barton *et al.* 2004; Harris and Spillane, 2008). Interestingly, much of the current debate does not share these positive associations and questions the extent in which these terms are essentially practiced or indeed are beneficial to the parent (Bastani, 1993; Dale, 1996). Furthermore, it should be recognised that ascertaining salient characteristics of the parent's involvement are inclined to be subjective by those who are defining these terms (Izzo, *et al.* 1999).

It is important to clarify what is meant by 'involvement' in the context of this research. Parental involvement is prominent in the literature on educational policies and encompasses a variety of actions that occur at school and within the home (Wood and Caulier-Grice, 2006). As defined below by Desforges and Abouchaar (2003, p.12).

“parenting, helping with homework, talking to teachers, attending school functions, through to taking part in school governance.”

Parental involvement, for this research, relates to the EHCP process and their engagement within this specific process. As suggested by Pena (2000) and Ofsted (2011) schools should take account of the realities of a child's home life and foster an atmosphere that is caring and accepting that welcomes parents and appreciates the rich information and insight they have.

Therefore, within this research the term ‘parental involvement’ is understood as a process of communication between parents and a variety of professionals, including participation and partnership within the EHCP process. Parental involvement includes engagement within the meetings between parent-school, multiple professionals ‘and the development of parental knowledge of the support that is available. It will also include how confident the parent felt in offering their opinions and wishes for their child’s support and how this opinion was received by professionals. Although providing an outline can be beneficial, this research will reflect the data collected and focus on what parents share about their experiences of involvement within the EHCP process.

2.3 Frameworks of Parental Involvement

Exploring the conceptualised framework of parental involvement in a broad sense will allow examination of the relationships between behaviours, thus giving an insight into how these interactions can be improved. Many of these frameworks appear to relate to general parental involvement within schools, however they appear to easily relate to a specific activity, in this case the EHCP process. There have been several frameworks created to understand the parent-professional functioning which may assist our understanding of the diverse perceptions and processes that may occur during these interactions (King, 2014). With the understanding that comparable characteristics may be highlighted through this research, these models will now be explored further to support understanding in this field.

2.3.1 Arnstein’s ‘Ladder of Participation’

To address the complexity of this relationship it is important to view these models as a tool for thinking rather than a blueprint for practice as each parent, every professional and each interaction with vary from each other (Gray *et al.* 2008). Arnstein’s (1969)

‘Ladder of Participation’ model appears to shape many of the frameworks used in attempt to explain parental involvement (Collins and Ison, 2006). Despite being devised almost fifty years ago, Arnstein’s model is still seen in modern day practices (Kirkbride, 2012). Arnstein’s theory could support a deeper appreciation of the distinctions between parents and professionals, and may offer a comparison with other frameworks of parental engagement that may be contemplated.

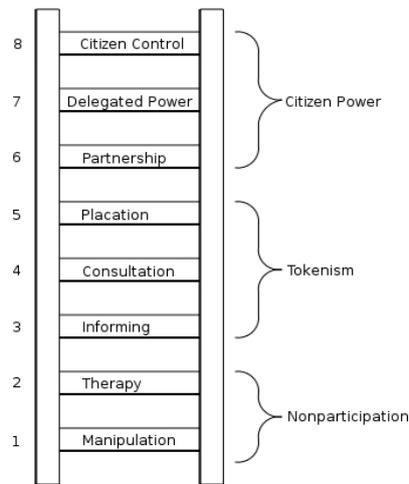


Figure 1: Arnstein’s ‘ladder of participation’ model (1969)

This ladder represents a process to demonstrate who has control when significant decisions are being created. The model offers an understanding towards the difference between ‘citizen control’ and ‘manipulation’. The bottom two rungs: manipulation and therapy are described as non-participation and have been contrived by some to substitute for genuine participation. According to Collins *et al.* (2006) the real objective is not to aid individuals to contribute in planning but to enable power holders to educate the participants. The subsequent third and fourth rungs refer to ‘tokenism’. Arnstein (1969) suggests that these allow the participants to be heard however they lack the influence to guarantee that their opinions will be heeded by those who they consider to

hold the power. The higher rungs are levels of citizen power with rising extent of decision-making power. Individuals can enter a partnership which empowers negotiation. Arnstein (1969) suggests that the top of the ladder is held by those of full managerial power. The ladder juxtaposes weak individuals with the more authoritative characters to highlight the fundamental divisions between them. In reality, neither the participants nor the power holders are consistent blocs. Each group incorporates a multitude of differing opinions and vested interests. The ladder has come under criticism over the years for its simplistically (Gallagher, 2008; Collins *et al.* 2006). Yet Ison *et al.* (2007) justifies the use of basic concepts where in most cases the participants perceive the powerful as a monolithic system and the power holders believe the participants as lesser than themselves.

Despite there being a plethora of methods and tools available to understand involvement, Arnstein's model continues to remain a 'benchmark' metaphor for describing and assessing participation which can relate quite clearly into a school context (Wilcox, 1994; Collins and Ison, 2006). Although this model opens the discussion of the purpose of participation it may be suggested that it is insufficient for making sense at a practice level. Despite being encompassed throughout the years within policies and communities, all interpretations, refinements and revisions of this model preserve a hierarchical position and encompass individuals' influence as a pinnacle of engagement. However, the lack of intricacy and its failure to acknowledge the process, outcomes nor the importance of feedback systems suggests that a subtler degree of graduation within the model is required to guide current challenges of user involvement. The extent to which collaboration takes place within schools and

understanding the tokenistic involvement may reveal some interesting views from parents.

2.3.2 Hoover-Dempsey and Sandler's (1997) model of parental involvement

With the over simplicity that the Arnstein (1969) model presents, Hoover-Dempsey and Sandler (1997) developed an alternative framework to understand the motivations for involvement. They suggest that considering psychological variables that impact upon the decision making may lead to successful parental involvement (Hoover-Dempsey and Sandler, 1997; 2005).



Figure 2: Hoover-Dempsey and Sandler's model of parental involvement (1997)

This framework delineates the complexity of the collaboration between the influencing variables as well as indicates that if areas in the initial levels are not met then effective participation will not be accomplished. Hoover-Dempsey and Sandler revised their model in 2005 placing greater emphasis upon parental involvement.

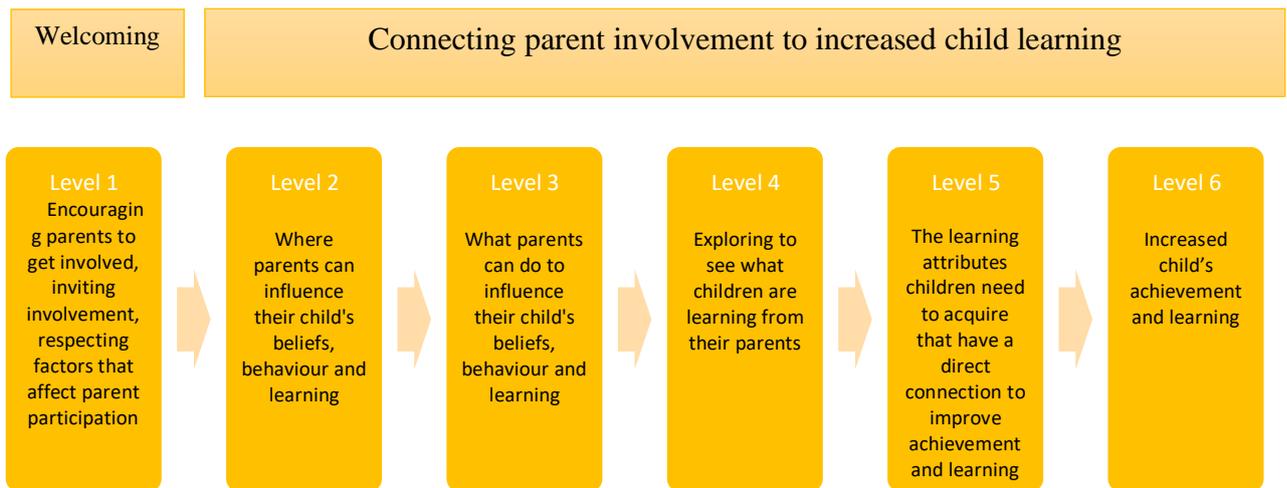


Figure 3: Hoover-Dempsey and Sandler’s revised model of parental involvement (2005)

Grounded in review of educational, developmental and social psychology research, this model presents ‘best guesses’ for why parents get involved, what form their involvement takes and how their involvement influences parents (Walker *et al.* 2005). Offering five sequential levels, the model's first level identified psychological contributors including the parent’s beliefs about what they should do in the context of their child’s education. The second level assumed that once a decision to become involved has been made, contextual factors, such as time and energy influence the parents’ choice to be involved. The following levels identify the mechanisms of parental involvements influenced through modelling, reinforcement and exploring how children learn through their parents. It appears that the first level is imperative as to whether the parents chose to become involved. What this model fails to acknowledge is the actions of those also involved with the child’s education through schools and other professionals and the influence they have upon the parents’ choice to become

involved (Sheldon, 2002). As Arnstein's (1969) model highlights if a parent feels inferior to professionals they may choose not to become involved.

It appears that even though a levelling system can be perceived as ambiguous and subjective to the professional, there is a lack of empirical evidence that would suggest where parents would place themselves within these levelling models. One would believe this would very much lie with how they perceive themselves and the confidence they have in placing themselves at a level. It would be interesting to see whether they would match those of the professional's opinions.

2.3.3 Barton *et al.* (2004) Ecologies of Parental Engagement

More recently Barton *et al.* (2004) proposed a model which tries to go beyond an action positioned description of participation, taking a more ecological viewpoint to study why parents are likely to become involved. Barton *et al.* (2004) 'Ecologies of Parental Engagement' model explains that for parental involvement to be successful it should be based upon the activity of networks rather than understanding development through a list of tasks. Barton *et al.* (2004) states that parental involvement is not an outcome of processes but rather an object which is influenced by considerations within and outside of school. It appears that this ecological perspective is in line with modern day thinking and is useful in producing alteration amongst real-life context (Cummings *et al.* 2015).

The literature highlights numerous themes that are significant to parental involvement with diverse psychological elements: connections between school and home communication, connectivity, collaboration, supporting parents to understand and

interacting positively including addressing the quality as well as the frequency of these aspects (Buchanan, 2007; Churchill and Clarke 2010; Cummings *et al.* 2015)

Pena (2000) and Barton *et al.* (2004) make specific reference to the importance of the ecological framework that underlies parental involvement that ensures all aspects of the family's 'world' is considered, conceptualising different dimensions that may affect parental involvement. Interestingly, Orrell-Valente *et al.* (1999) suggest the occurrence of engagement is based upon the relationship the parents have with school and their understanding of the relevance of the support that is being offered.

So far this literature review has focused upon the underpinning frameworks with which parents and professionals may associate when engaging in an equal working relationship. The following section will look further into deepening our understanding of this complex concept of parents becoming equal partners.

2.4 The Complexity of Parents as Partners

During the last four decades since the publication of Arnstein's model in 1969, the role of parents has developed within the decision formulating process, whereby they are seen more as a consumer of services than a passive bystander (Barton, 2004). Understanding the plethora of research surrounding this field, these parent-partnerships are exceptionally multifaceted (Samaras and Wilson, 1999; Lytle and Bordin, 2001; Childre and Chambers, 2005). As subsequent Education Acts were passed, the 1980's saw several models being produced to understand the need to include parents more. Prominent within this area was Cunningham and Davis (1985) who formulated separate models of working in partnership with parents: expert, consumer and negotiating. The expert model assumes that the professional is the specialist and

who has the control to assess the situation and solely decide what support the child will receive (Cunningham and Dale, 1985). This model does not involve the parents in the procedure nor take into consideration their feelings or opinion (Dale, 1996). This model appears to have many flaws as the parent relied on the professional's thoughts and opinions without having the confidence to question them (Hodge and Runswick-Cole 2008). Although it appears many changes have taken place over the decades with parental involvement viewed as essential, the expert model still influences the collaboration between professionals and parents.

The consumer model (Cunningham and Davis, 1985) appears to be the first approach to establish partnership at a basic level. Within this model the parent is encouraged to consider alternative solutions suggested by the professional. The professionals' role also changes with their aim to gather as much information from the parent to build a full picture (Long, 1986). This model seems to offer mutual respect, honesty and collaboration. Yet professionals retain their expert status. The predominant distinction between the expert and consumer models is that the parent is now believed to have a different expertise from the professional.

Dale (1996) proposes negotiation to be the most comprehensive model of collaboration. This model considers the power associations between both parties and deliberates that conflict as an unavoidable part of the decision-making process. It is an essential principle that professionals and parents will have different personalities, priorities and perspectives due to their differing roles within the wider context. (Gascoigne, 1995)

These models propound the idea that professionals are in control, presuming that the parent necessitates direction to support their child. Likewise, the expert and negotiating model go one step further placing the professional at the specialist level who will lead the parent into

understanding what is best for their child. It should be noted that these subtypes by their very description may not be collaborative in nature. This appears to be been similar in most researcher's description of parent-professional collaborations, such as Blamires *et al.* (1997) who outlined various types of partnership

“passive parents, parents viewed as a source of information, parents as consumers and parents as a resource to be managed by professionals” (p.22)

Harris *et al.* (2008) suggests that what these subgroups appear to be missing is an individual approach to supporting parents. To me, this insinuates that parents are expected to fit into the services provided and the professional's agenda rather than professionals adapting their approach to the needs of the families.

Along similar lines, Appleton and Minchom (1991), supported by Bethere and Pavitola (2014), argue that there may be some individuals who would favour this approach of professional contribution and may necessitate the professional to lead. The view that many of the parental involvement models assume is that the parent wishes to be involved and, in line with current legislation, would like to be treated equally within the multi-professional process. It is within my experience and support within literature that some parents may choose to be subordinate (Fylling and Sandvin, 1999; Bethere and Pavitola, 2014). However, Logsdon (2016) suggests the voice of this group of parents is often overlooked and it is imperative that the professional is creative in gaining their voice.

2.4.1 Understanding the Models in Context

Attention should be drawn to the period of when these models where first presented to understand the contexts in which they were formed. Children with SEN were treated

very differently within the 1980's, with new reforms and changes in legislation seen as radical and met with trepidation by professionals (Beveridge, 2005). The acknowledgement that parents held important information about their child and their needs increase unease amongst the education establishments (Edis and Brabazon, 1982). This may go some way to understand why models published within the 1980's still held professionals very much at the expert level. This was a time of change and inclusiveness and would take time for professionals and indeed parents to adapt (Twyo *et al.* 2007). During these times the education system has a very different approach towards children with SEN and parents were encouraged to allow professionals to take the lead and believe in what they were saying was best for their child assuming they would exercise their rights to challenge professionals if they felt the need to (Beveridge, 2005).

Twyo *et al.* (2007) argued it would take courage and confidence for a parent to challenge a professional during these times when there was little information available regarding SEN and the stigma that was attached. Throughout the 1990's further models emerged including the empowerment model (Appleton and Minchorn, 1991) and the negotiating model (Dale, 1996). A key part of these models was tasked to the professional to consider how to incorporate the parent. It is my opinion that this creates a sense of irony that still places the professional in the position of power by taking a lead in understanding how to include parents. One would assume that for an equal relationship to be formed neither should be in a position of how to try to include the other and it should be based upon agreement. Yet the concern with these models, even through the decades as they mature and become more equally based, still over-simplify a complex relationship and should be recognised as doing so (Beveridge, 2005)

Murray and Mereoiu (2016) advocate the view that these models can still be observed within professional-parent partnerships today. Due to the complexity of these relationships they do attempt to aid our understanding with guiding parental involvement. What these models do not offer is an acknowledgement into the individual personalities and differences of those involved within the process and how these interactions can help or hinder the parental involvement (Davis *et al.* 2002).

2.4.2 Parent-Professional Frameworks in today's society

The models presented tend to see the relationship from a professional viewpoint. What they fail to acknowledge is the difficulty parents may face when involved within a multi-professional situation. Engaging with a multitude of professionals through the EHCP process requires a parent to adapt their approach to each individual professional who will have their own expertise within the context (Hallgarten, 2000). Whereas professionals are trained to manage these situations, and are experienced in working with different parents. I feel that this can be forgotten when engaging a parent through the EHCP process. As Davis (2002) suggest, meeting multiple professionals can be over-whelming and daunting experience for the parent and may induce additional stress and worry upon them. It was suggested by Parsons *et al.* (2009) that parents find the statutory assessment process difficult and stressful, therefore it appears the role of professionals may be to empathise with the parent to avoid increased pressure and ensure they are supported throughout and beyond.

2.5 Parental Types

Arguably one of the most important roles for professionals during the statutory assessment process is to attempt to understand the individual parent (McNab, 2010). As previously

mentioned a 'parent' cannot be defined by a job role unlike a professional. In divergence to the multiple frameworks that have been discussed Alexander and Dore (1999) argue that understanding the 'type' of parent is more important than the framework in which we practice, as it allows professionals to alter their methods to involve parents thus increasing the likelihood of the working rapport becoming more equal.

2.5.1 Labelling Parents

Gascoigne (1995) proposed several types of parents, labelling parents as articulate and educated through to uncaring and ill-informed, recognising that some parents may have their own learning need. In my opinion, and supported by Allen (2011), that it is unfair to 'pigeon hole' parents in such a way. This model does not differentiate that parents may find themselves moving between types nor does it take into consideration the situational issues; individuals will behave differently in formal situations than they would if they were with friends (Allen, 2011). For example, Gascoigne's 'types' assume that an individual may be always 'submissive' but this may relate to only areas the parent is unknowledgeable about. Throughout Gascoigne's research the methodology is unclear in how these 'types' were deciphered. This may suggest that these are Gascoigne's own assumptions based upon her own experience rather than supported by empirical research. Although the validity of the 'types' maybe brought into question, I agree somewhat to the 'types' Gascoigne refers to yet it is through my experience that parents are fluid between these 'categories' as the process progresses; one may be submissive at the start of the EHCP process until knowledge is gained, they may become angry at times due to frustration and possibly end the process reasonably articulate about the SEN process.

2.5.2 The Parental Position

More recently McNab (2010) suggests that it may be useful to understand the position that a parent will assume within their communication and interaction with the process rather than the individual type. This appears to succour Vincent (1996; 2000) in his definition of these roles as: ‘parent as supporter’, ‘parent as consumer’, ‘parents as independent’ and ‘parent as participant’. Acknowledged by Vincent (2000) that these categories are over simplified, it does suggest that as individuals we pose a generic personality which professionals can adapt their approach to support parental involvement.

Through the literature, it appears that research has been fostered from theoretical perspectives yet parents have not been actively involved within the research process to develop the models and frameworks that have been discussed. This creates uncertainty over their reliability (Scott *et al.* 1996; Carpenter, 2003; Churchill and Clarke, 2010). What is evident is that where there is an attempt by a professional to develop an equal partnership they may still miss the essence of the parents’ wishes (Carpenter, 2003).

The aim of the present research is to understand parents’ feelings within the highly complex practice. It appears that literature portrays an unenthusiastic view on how parents feel appreciated within the progression of parental involvement (for example Keen, 2007; Gallagher, 2008; Goleniowska, 2017). In 1994, Galloway *et al.* interviewed the parents of twenty-nine children progressing through the statutory assessment process. The researchers stated that parents believed the professional assessments did not reflect their conversation that they had and that the

recommendations put forward were considered within the context of the Local Authority and of the school's limitations. Parents felt:

“reports concentrated on within-child factors such as psychometric tests that had not been discussed with parents leaving many ‘bewildered and resentful’”
(Galloway *et al.* 1994: p.24).

It is an expectation from parents that what they say is noted, communicated and acted upon. Yet when this did not happen parents felt this implied their view was not appreciated and that professionals had their own agendas based on their individual roles.

2.5.3 Parental Frustrations

This level of frustration from parents appears within the literature surrounding parental involvement (Todd, 2003; Blok *et al.* 2007; Squires *et al.* 2007). A clear example of where parents are involved and are confident to challenge can be demonstrated through Hartas' (2008) case study on a three-year-old child who was diagnosed with autism. The parents appear to have fought for support for their child yet though the case study highlighted many good practices there were numerous examples where the parents' wishes and opinions were not listened to; for example, a teacher uses a behaviour-reward chart, yet when the parents explain that the child would struggle to understand it, the teacher continues. This is an example of where a professional can assume the expert without gaining the input for the parents who feel devalued within the support for their child.

2.6 Parental Involvement with statutory assessments

For a truly integrated approach towards SEN it is essential that all parties involved with, and including, the child must be considered (Frederickson and Cline, 2002). This includes the parents as key stakeholders within this process.

2.6.1 A Collaborative Practice

The development of collaborative practice between professionals and parents appears to be of significance as inclusion continues to be highlighted within educational, governmental and social policy (DfE, 2014; DfE, 2016). As Pugh (1989) pointed out almost thirty years ago that sharing responsibility increases mutual accountability amongst the parent-professional relationships that encourage greater empowerment for parents. A critique of the mutual relationship that literature highlights comes from Vincent (2000) and Hamilton (2004). Parents are ‘clients’ and ‘consumers’ of a service in a market-oriented educational system where emphasis is placed on the idea that if the parent’s expectations are not met then they can look for reparation from the local authority (Frederickson and Cline, 2002; Posey-Maddox, 2016). In a system where currently many services are ‘brought in’ by schools through the academy structure, a commercial atmosphere will be generated.

Yet Evans and Vincent (1997) argue that parents are treated differently if their child has special educational needs and are at risk as being positioned as less influential, effective consumers (Goacher *et al.* 1988). Hornby *et al.* (1997) offers that to understand the apparent discrepancy, parents and professionals need to share their expertise to deliver the most suitable education for the child with special needs. This highlights the importance of appraising the statutory assessment process by obtaining the perspectives of the parents who have gone through the process (O’Conner *et al.*

2005). There appears to be limited research within the area of parental involvement directly with the statutory assessment process.

Interestingly, much of the positive research has been commissioned by the Department of Education which suggests that parents are pleased with the process, feel heard and understood that their wishes for their child are taken on board (Avramidis *et al.* 2000; Morley *et al.* 2005). This lays questions into the validity of these findings and the research bias that they may be looking for the positives to reflect on. Overwhelmingly, additional research not commissioned by the DfE demonstrates a very different story (Avramidis *et al.* 2000).

2.6.2 Awkward Customers?

Duncan (2010) produced a thought provoking article named ‘Awkward customers?’ for his research on how parents perceived the statutory process. Through his small-scale qualitative research, he focused upon those parents who had undergone conflict with SEN professionals. The findings of Duncan’s (2010) research were that parents found negotiating the SEN system exceptionally difficult and stressful compared to other troubling issues in their lives. As suggested by Bone *et al.* (2015) parents need to be fully informed if they are to be able to be equal within the multi-professional arena.

One of the largest studies discovered through this literature review was carried out by Parsons *et al.* (2009) who looked at the satisfaction with educational provision for children with SEN. They collected 1776 surveys from parents from across the UK. They reported a significant number of parents were satisfied with the support they and their child received. Overwhelmingly, the message they received was that information about

SEN is unclear for parents to understand making them feel unable to participate in meetings productively. Parents felt that information should be written in clear, understandable, 'everyday' language. When parents were asked if their child had a statement 12% of the parents did not know. This may however suggest that there is a body of parents who are unclear about the formal mechanisms of the SEN statutory assessment which may suggest that professionals are not explaining the processes to parents or indeed considering the parents level of understanding about the systems.

2.7 Literature Review Conclusion

Several models, theories and areas of research have been discussed within the literature review which has highlighted gaps within the literature which have shaped the intentions of this research and the research questions. The aim of this research is to contribute to the consideration of parental engagement within the multi-professional arena through gaining the parental voice of the new EHCP process. It is felt that by understanding how parents feel when positioned as being equal within a multitude of professionals will contribute to developing methods for both parents and professionals to work collaboratively for a common goal of supporting the needs of the child.

As recognised through the literature review, there appears to be little research into the topic of how parents manage several different professionals from education, health and social care each with whom may have different styles of working. Therefore, this current research will be investigative in nature, guided by the data collected. Though there will be an application of theoretical frameworks grown from the parent and professional collaboration literature to the context of the complexity of the relationships that are formed through the EHCP process. Other curious features that arise from the literature may be referred to, such as barriers to

involvement. Through relating preceding research into a new context, it is hoped that areas requiring further focus for support will be identified, as well as highlighting elements of good practice that may be applied further.

2.8 Research Questions and Aims

The present investigation has two aims:

1. To explore the current practice within the EHCP process regarding parent involvement.
2. To explore parental views on how they felt their voice was heard within the decision-making process.

The two research questions that will be applied to the current research are:

1. What are the themes that emerge from the interviews with parents about how they felt about their involvement?
2. How can these themes be used in supporting the development of parental involvement within multi-professional teams?

Chapter 3

METHODOLOGY AND RESEARCH DESIGN

3.1 Introduction

The previous chapter highlighted a mixture of research and theory into the engagement of parents within statutory educational processes. Through this there appear to be gaps in the research that focused on how parents felt about being equal partners within a multi-agency groups that the legislation has placed them in. I believe this is a worthy area to explore further. As the importance is being placed upon the ‘parents voice’ through this research, echoing the Code of Practice principles, the methodology needs to facilitate an approach that enables the parent’s experiences to be explored. This chapter aims to outline how the research questions were established along with the reasoning behind the design and methodology that will be applied to this research.

3.2 Research Paradigm

According to Doyle *et al.* (2009) the first undertaking in instituting a methodology to research is to elect a paradigm. This is a crucial component of the research progression as the future practice of data collection and exploration that emerges from the research methodology could be

“...influenced by the researcher’s theoretical framework” (Mertens, 2005. P.2).

A constructivist paradigm has been embraced as it recognises the various realities that exists and places emphasis upon an individual’s experience (Braun and Clarke, 2006). Constructivism holds its roots in phenomenology, concerning itself with the social and

psychological experiences of individuals and how they interpret the whole phenomena rather than parts of the experience (Rasmussen, 1998; Smith, *et al.* 2009) with an appreciation that no interpretation is true (Guba and Lincoln, 1994). The constructivist researcher approach is to appreciate the world of the individual's experiences (Cohen *et al.* 1994). Therefore, it seems appropriate to adopt this paradigm for this research as the aim is to explore several viewpoints relating to the EHCP process and the parent's involvement within the multi-professional groups.

3.3 Research Design

Through instructing a constructivist concept allows real-life instances of the EHCP process along with its experiences and challenges to be explored. The data aims to capture parent's experiences of engaging within multi-professional groups, assuming an insider's view to explore the parental perspectives. The constructivist paradigm lends itself well to the qualitative research method which enables me to use an exploratory approach to understand parents' experiences and avoid ascertaining a hypothesis about what may be found (Pouliot, 2007).

Although research has been carried out on parental perception of involvement through statutory assessments previously there appears to be very little literature on how the shift to parents as equal parents has impacted on the parent's views of involvement. Adopting a tentative approach compliments a solely qualitative research purpose, allowing the subjective to be emphasised.

3.4 Epistemological and Ontological issues

Understanding and recognising the epistemological and ontological position of this exploration is important, which should be aligned with my own understanding as the researcher (Pouliot, 2007). Willig (2001) suggests that within any research certain questions must be given that relate to expectations that the methodology makes about the world, what information the methodology aims to create and how the methodology assumes the researcher within the process. Therefore, the next section shall address these questions to justify the methodology adopted for the use within the present research.

3.4.1 What assumptions does the methodology make about the world?

As the constructivist methodology views reality as socially constructive, the ontological supposition accepted in this research is relativist. I acknowledge the multi-layered nature and complex reality that is specific to this area of parental engagement. However, I am also mindful that some of these realities will be similar amongst parents, interpretations and experiences will be assembled differently by individuals.

It has also been noted that constructivist methodology places emphasis on the social construction of knowledge. Therefore, I must be aware that my own position needs to be clear as I shall be assembling the information from the data and from my own experience. It must be ensured that reflexivity is preserved so I remain attentive of my own views of social reality and how this impacts on my interpretation of others.

3.4.2 What understanding does the methodology aim to produce?

Alcoff (1998) states that epistemology is the theoretical examination into

“...the nature of knowledge, what justifies a belief, and what we mean when we say that a claim is true” (p.viii)

The constructivist paradigm assumption is that information is socially constructive, subjective and transactional rather than being a reality which is objective (Pouliot, 2007). Therefore, an exploration of these multiple layered constructions needs to be understood (Tindall, 1994). In relation to this research, while theories of parental engagement are explored there is little literature regarding how the change in legislation has impacted the parent. Hence to seek understanding from multiple parental interpretations, a constructivist approach seems appropriate. For this to be successful a key aspect of the research will be elucidations, which depend on both participant's abilities to reflect upon their own perceptions of the area being researched (Mackenzie and Knipe, 2006).

3.4.3 How will the methodology theorise the researcher's role within the process?

The constructivist methodology posits that reality and knowledge are associated through social constructions of deducing the data and organising the information (Pouliot, 2007). The constructivist paradigm understands the researcher's position and the impact this may have on the formation of knowledge, and that the researcher's own interpretations of the information are also socially constructed (Siegfried, 1976). In agreement, Audi (2003) expressed the importance for the researcher to connect with their own views which may contribute to the configuration of knowledge.

3.6 Interpretative Phenomenological Analysis

For this research, Interpretative Phenomenological Analysis (IPA) has been adopted. IPA has its roots within psychology and recognises the importance of the analysis in understanding the personal experiences of the participants (Pringle *et al.* 2011). IPA applies itself to a combination of phenomenological, interpretative and idiographic elements. Smith *et al.* (2009) suggests that phenomenology offers an explanation as to how individuals interpret a phenomenon, in this case the EHCP process, within a given context, their education. Giorgi (1997) explains ideographic component examines the individual occurrences and the interpretative component is explored by capturing the experiences via interpretations of both the participant and the researcher.

Biggerstaff and Thompson (2008) advocates this view by suggesting that IPA is concerned with the elements of a lived experience. Throughout this research, I would claim that the idiographic aspect of IPA reflects the participant's experiences of being integrated into a multi-professional team.

3.7 Participants

The aim of the research was to explore how parents were involved with the multi-professional facet of the EHCP process. Therefore, parents were identified as the sample. The parents were selected from a local secondary school. A local primary school was approached however although the school gave their consent for me to contact the parents I did not receive any volunteers. By approaching the secondary school, it was assumed that parents would have been through the statementing procedure and be involved in the transfer process to EHCP's. I believe this may give a deeper understanding of how parents felt the changes in legislation had impacted on their role within the EHCP process.

3.6.1 Recruitment

I approached the school and spoke to the SENCo (Special Educational Needs Coordinator) and Head Teacher who both gave their consent for parents to be contacted. It was agreed that the SENCo would approach potential participants and explore their interest. If a parent was keen to take part my details were given and contact was made. The criteria for taking part required that the parent had been through the EHCP process within the last twelve months.

3.6.2 Sample Size

Sandelowski (1995) suggests that the appropriateness of sample size in qualitative research is relative and a matter of judging a sample as being neither too big nor too small. IPA allows the privilege to explore the individuals account and offers a different perspective from approaches such as grounded theory which uses larger sample numbers (Barbour, 2007). A small sample size maybe seen as a limitation to IPA studies, yet Smith *et al.* (2009) considers that having a smaller participant group allows a richer depth of analysis. To overcome this concern Smith *et al.* (2009) believes that if the research account is transparent and rich, then the reader will be able to assess and evaluate the transferability.

3.7 Methods

3.7.1 Data Collection: Semi Structured Interviews

A semi-structured interview (SSI) was devised. SSI were chosen to allow a level of guidance through the interviews to ensure the research question will be

addressed. The interview will be non-directive and allowed participants to explore their own experiences.

The information gained from SSIs will allow me to gain a:

“...valid knowledge and understanding by representing and illuminating the nature and quality of people’s experiences.” (Tindall, 1994, p.142)

SSI allows a level of freedom to take an exploratory approach (Robinson, 2002). Nevertheless, although the SSI incites a two-way conversational approach, interviews should be a one-way communication process to allow the researcher to remain impartial (Oppenheim, 1992).

The interview is only one part of the research method. Other stages include planning, recording, transcribing, analysing and reporting (Powney and Watts, 1987).

3.7.2 Data Analysis

Brocki and Wearden (2006), Sheldrake (2010) and Flowers *et al.* (2009) agree that immersion in the data is a key process of IPA. As the research question has foundations in *“the personal meanings and sense making in a particular context, for people who share a particular experience”* (Flowers *et al.* 2009, p.45) appears to make IPA a suitable methodology.

The data that is required for this research is based upon parent’s experiences therefore a structured approach would not have allowed the openness and freedom required for the phenomenological and interpretative element of the research question. By adopting a purely analytical methodology would not have

allowed the exploratory interpretation that was required to gain the parents experiences which are essential to an IPA study (Thomas, 2013).

McNeill (1990) and Cohen *et al.* (1997) emphasize that by attempting to gain information from an objective cause alone does not allow for a subjective analysis of the data obtained. This research accepts a qualitative structure based upon the information regarding the methodological framework. An exploratory strategy was used within the small-scale study involving four parents of children who have special educational needs and have been, or are going through the EHCP process, to provide data to investigate the RQ.

3.8 Methodology and Research Design Conclusion

In conclusion of my methodology chapter, my position regarding the paradigm and associated methodology can be summarised as:

1. The research will be exploratory in nature as there is little current research on the impact recent legislative changes has had on parental involvement. Prior research and theory will be considered however much of this is prior to the radical changes of the importance of parental engagement. Henceforth, a constructivist paradigm was assumed to understand the subject realities as well as the objectified knowledge that arises from previous investigations.
2. The data was acquired from the parent's experiences of their involvement with the EHCP process, whose perceptions are subjective and prompted by prior exchanges with professionals. None of which are valuable to explore. Subjective meanings, constructions and complex realities were gained (Allison and Pomeroy, 2000) Thus this current research has its foundations in relativist ontology.

3. Both the researcher and participants will influence the variation of the experiences from verbal data through to transcriptions and analysis. Consequently, the researcher's epistemological position will be subjective and transactional.

This section has considered the research paradigm and the related methods to investigate the research question. Elected tools and analysis methods have been deliberated and justified, and the issues regarding the quality of the data produced in qualitative research explored. By applying SSI's and an interpretative phenomenological analysis the parents' experiences can be explored and emergent themes can be compared. These themes are expected to be likened to those presented in existing research and literature with the aim to highlight areas that require further research as well as potential areas that could benefit from future development.

Chapter 4

RESULTS AND DISCUSSION

4.1 Main Themes

This section will begin to explore the findings from the interpretative phenomenological analysis. There were three emerging themes which are illustrated below.

Figure 4: Emergent themes

Barriers to Parental Involvement	Professional Power	Parental Position
Professionals' assumptions	Fight on their hands	Personal confidence to challenge professionals
Parental voice not being heard	The expert	A loss of identity within multi-professional team
Feeling rushed and unimportant within multi-professional team	Unfriendly process	Feeling a burden to professionals
Lack of trust towards professionals	Unequal balance	Being patronised

4.2 Main Theme 1: Barriers to Parental Involvement

This theme illustrates the obstacles that parents felt hindered their ability to be fully involved within the EHCP process. Referring to the literature review, and the fundamental purpose of this research, the current Code of Practice (DfE, 2014) stipulates that parents must be “*participating as fully as possible in decisions*” (DfE, 2014, p19). The parent participants suggested that there are numerous barriers that impede this process from happening. The subordinate themes reflect a negative experience for parents wishing to be involved within the multi-professional team.

Subtheme 1a: Professionals' assumptions

Each parent made comment about how they felt assumptions had been made about their child prior to their involvement. Parents felt these assumptions were untrue and unfair; this appeared to be a source of frustration.

P1 (34) when he was at school erm we wanted to hold him back ya know hold him back a year the school didn't agree they assumed he was fine so it didn't happen

P2 (592) He has severe dyslexia how do they think he is going to read it anyway a joke huh a joke they didn't get him

P3. (448) How dare I think I know my son better than them (laughs), I know what he needs I just need them to listen understand

P4 (64) I wanted him out of mainstream have done ever since he was little he needs intense support but no one listens ya know they assume they know best

It seemed that parents felt professionals had already made their decision before seeking the parental view. The sense of frustration, and at times anger, can be felt through the comments above.

Subtheme 1b: Parental voice not being heard

Ongoing with the sense of frustration, this subtheme continues with the sense of not being heard. Parents gave clear, concise examples of when they felt ignored and muted by professionals.

P1 (172) I was so cross why wasn't my word good enough for them it was only when another professional from this charity stepped in that they listened to us

P3 (44) I'm a teacher ya know (laughs) I went into C's school I felt I was talking to a brick wall I would get so angry

P4 (88) I approach the school telling them what he needed he is my son I know what he needs no one listened I'm sure they thought I was crazy

The frustration is highlighted again by how the parents felt pushed out of the process with one parent explicitly stating that the parental part of the EHCP had been written for her by professionals.

P2 (118) [When discussing the parental views on the EHCP] They had written it for me they had written it I had no part of it

A feeling of being undervalued and unimportant emerged clearly through each of the four interviews.

Subtheme 1c: Feeling rushed and unimportant

A barrier that emerged was that of feeling rushed through the process. The parents spoke about how busy professionals were referring to the amount of paperwork involved and how this may have influenced how the professionals interacted with the parents.

P1 (138) here he is just a number and not a name he's not important to them

P2 (304) I am not going to be conveyer belted I'm not going to be shoved along and ticking boxes that's not how it's going to work in B's world

One parent demonstrated empathy towards the professionals by offering an appreciation of the pressures professionals face.

P3 (136) I imagine it takes up so much time for a school to do it like I said I'm a teacher and I wouldn't have time to do all those documents and collect the evidence ya know it's a lot of work no wonder professionals are annoyed

The sense of being undervalued came through as parents felt their child was not important enough to make time for and a reason for why assumptions were made prior to parental involvement. This appears to increase the levels of frustration amongst the parents.

Subtheme 1d: Lack of trust towards professionals

The feeling of frustration appeared to influence the level of trust the parents felt towards the professionals. When parents felt that their opinion was muted, they sensed that professionals were unable to fully understand their child's needs. This seems to lead to bitterness and wariness towards professionals.

P1 (158) He [SENCo] just didn't get it... he didn't get A's needs I was so angry he is obviously in charge of all the SEN my worry was he obviously clashed with A

P1 (266) I mean I know he's somewhere on the spectrum I know he's there somewhere but professionals haven't ever really gone down that road I don't think they know what they're doing to be honest

P3 (384) (laughs) the barriers are professional attitudes to parents they are so into their own world their own job that they seem to only be interested in that part not linking it all together

P4 (222) I just don't trust them they have a job to do their own boxes to tick they do their own thing don't they

There was a sense of professionals 'going through the motions' and not fully considering the child's needs, thus leading to irritation towards the professionals involved.

4.3 Discussion around the barriers of parental involvement

The parents who participated in the research clearly felt there were several barriers in place that did not allow their views, opinions or wishes to be heard. This included: assumptions being made prior to the parent's involvement, feeling muted, and not being treated as individuals. These barriers appear to result in feelings of anger and frustration, and contributed to a lack of trust towards professionals. Davis and Hall (2005) suggest that the foundation of this frustration comes from the parent's feelings of losing control. They suggest parents develop their own strategies for coping with the stress and frustration of living with a child with SEN. These coping mechanisms can transpire into a desire to stay in control. When control is taken away, in the EHCP process for example, this can result in exasperation (which has been seen amongst the participants of the present study). The findings from this research and that of Davis and Hall (2005) appear to support Hartas (2008) research mentioned previously in the literature review. Hartas (2008) suggests that parents struggle with professionals dominating the statutory process. This is exacerbated when the professional ignore the parents voice leaving them feeling discouraged and unsatisfied.

In support, Ball and Ball (1995) identify major concerns emerging through the published literature regarding parents seeing their worries as not validated nor taken seriously by multi-professional teams. This was noted during the interviews as being important to the parents through parents feeling rushed. This is strengthened by McMaster *et al.* (2004) who suggests that many parents report negative interactions with professionals who seem to make light of their situation. The experiences of the parents involved in this research certainly appear to support the literature on parent-professional collaboration within SEN.

If the present findings were to be compared to the Hoover-Dempsey and Sandler (1997; 2005) levelling models (presented within the literature review) the first level of parental engagement, welcoming and inviting, has not occurred efficiently enough here for the parents to feel involved, leaving them unsure of their position within the team. Irrespective of the simplicity of these models the fundamental starting point has not been addressed for the parents of the present study. Cummings *et al.* (2015) argue that not accomplishing the base level will make the higher levels of collaboration futile, such as: exploring the parent's beliefs, understanding the parents influence over the child's learning, and the impact the parents influence can have on the child.

The views of the parents within this research appear to support the literature that surrounds this field. Murray (2000), McNab, (2010) and Logsdon, (2016) suggest that for the successful engagement of parents to take place, professionals should acknowledge the parents position and unique contribution to encourage their involvement. This research therefore, appears to strengthen the existing research by resonating the opinion that parents feel unimportant and ignored within the statutory process.

4.4 Main Theme 2: Professional Power

The 'Professional Power' theme was identified to describe where a professional imbalance between parent and professional had been highlighted. This included experiences, circumstances and emotions which seemed to hinder effective parent-professional interactions. They were considered barriers to the parents in how they perceived their position within the multi-professional team.

Subtheme 2a: A fight on their hands

The language adopted by all four parents appeared hostile towards the professionals and EHCP process. Key words such as 'fight', 'battle', 'at war' were some of the phrases used by the parents. This suggests that parents may have felt isolated, angered and in conflict with professionals.

P1 (220) [discussing son being allowed to do a course] I did kick off and then since then he actually has a pass now it's that one thing he could have passed without all the drama I had to fight for him

P2 (96) I said to them you can have it nice or you can have it nasty we can do this in a professional manner where B's needs are met or I see you at tribunal (pause) take your pick

P3 (70) It was from then I just thought right we are going to have a fight on our hands to get C what she deserves

P3 (78) Oh it is just feels like a constant battle on our hands to fight I had to take a term off school through stress

P4 (194) So right from that head teacher saying she wouldn't get one [EHCP] and all of the fights we had with psychologists, psychiatrists, CAMHS, school everyone it was such a fight to be heard and not be written off as just a worried mum that was hard

The description that is given by parents presents a 'them and us' situation. The parents appear to be on alert and ready to fight. The strong, hostile language that came through the interviews indicated an emotional fight that parents felt they had to go through. One parent spoke about how this perception of 'a fight' was given from the start of the process

P4 (87) as soon as they said about a statement thing I just knew I was going to have to fight right there from the start I knew it wasn't going to be easy I'd heard stories ya know I knew what was coming

The perception that the process was going to be difficult assumes that other parents have experienced a similar situation.

Subtheme 2b: The expert

The perception that the professional was the expert emerged during the interviews. Although parents felt they needed to fight to be heard they also spoke about how professionals took the stance of expert and should know what they are doing. Parents felt they were unable to question professionals due to the expert status that professionals adopted.

P1 (236) They are the experts they know what they are doing I often ya know I can sit there and think he needs visual things to learn but I assume they know that they are teachers he can't be the only one but no I haven't said anything I don't know if that's what he is already doing he doesn't tell me so

P2 (240) Yeah but I'm not a teacher I can't tell them what to do

P4 (322) No I feel the school leads...we go into the meeting they have the paper work they have the agenda I just answer their questions they know what they are doing

The underlying perception that professionals cannot be challenged presents here in the interviews. Although the parents described feelings of not being heard or views acknowledged there appears to be a barrier to be able to challenge professionals.

Subtheme 2c: An unfriendly business

Some of the parents mentioned how inimical the EHCP process was in terms of the multi-professional meetings.

P1 (188) It shouldn't be that stressful to get something your child needs well actually deserves she deserves an education

P2 (672) it's not a friendly process at all

P3 (290) sometimes I just don't have the energy to fight professionals anymore as long as C is getting the support she needs

P4 (90) I never really pushed it ya know they invited me I turn up say how things are at home and that's it I'm not welcomed

Parents appear to speak with a tone of despondence within these dialogs. The accumulation of negative emotions and difficulties within the parent-professional relationships seem to have a cumulative effect for some, leading parents to feel disengaged in the process and unable to challenge.

Subtheme 2d: Unbalance relationships

The Code of Practice (DfE, 2014) states that parents should be made to feel equal within the EHCP process. The parents' responses suggested that this was not the case. When asked to explain how they felt about this, responses were short and direct with little expansion.

P1 (318) Oh no no I couldn't lead or see myself as on par with them no certainly not

P2 (428) [when speaking about being equal to professionals] Not at all not at all its impossible

P4 (458) (laughs) it would never happen (laughs) they wouldn't listen to me

Parents appeared to find the idea of being equal to professionals unrealistic. There was the conviction that parents are not good enough to be equal with professionals with their opinion and decision making. One parent explained that she had to approach professionals in a different manner to be heard.

P3 (314) So if I want to be treated equal within these meetings then I put my professionals hat on rather than my mum hat...I have to disassociate myself from mum

This implies that by being 'mum' would not get her views heard. During this interview the parent highlighted that she would change what she wore to look more 'business like', to be taken seriously.

P3 (455) I use to wear my work clothes to meetings ya know I thought I felt professional I think it changed how I acted in meetings...I was in work mode

4.5 Discussion around the imbalance of power amongst parents and professionals

The sense of frustration continues through this theme in response to how the parents perceive professionals. All parents observed the professionals as the expert and felt they were unable to challenge although they wanted their views and opinions to be heard. Stevenson (2005) acknowledges this conflict and suggests that there is a hidden understanding that professionals are employed to be the expert and therefore an assumption is made about the professional. Stevenson (2005) noted that regardless of how the professional presents themselves, this underlying stereotype is difficult to ignore and that parents often assume a bystander role regardless of how confident they believe themselves to be. The present research appears to support Stevenson (2005) view of the unbalanced relationship. Although each parent had strong views on what support their child required they felt unable to share these with professionals. Arnstein (1969) refers to this as manipulation on the professional's part to dictate and control the process. Although Arnstein's work is nearly 50 years old, the tone of this control emerged through the parent's interviews in the present study.

To gain further insight into this conflict Dabkowski (2004) applied Maslow's hierarchy of needs (1954) to understand further how the professional power within multi-professional meetings can influence parent self-esteem. Dabkowski (2004) proposed that to have your voice heard within a group requires a level of confidence to challenge. This also requires a self-belief that what is being said is worthy of being heard. Dabkowski (2004) explains that often parents with children who have additional needs may hold feelings of guilt, alienation and embarrassment. Therefore, their feeling of self-belief may be fragile. He concluded that

professionals may use this weakness to dominate the decision-making process. This can be applied to parents interviewed in this research. Although parents appeared confident in their views during the interview their self-belief in meeting appears reduced.

Rock (2000) expands on Dabkowski's notion by stating that parents describe their experience of multi-professional meetings as traumatic, confusing and complicated which may result in parents being reluctant to ask questions or reveal their lack of understanding. They may be ill-equipped or at a disadvantage by not understanding the terminology. Rock's (2000) research may offer insight into the language that the participating parents used. By describing the process as a 'battle' and 'fight' may lend itself to Rock's description of the traumatic and complicated process. Parents will have valid views on the support their child requires yet in fear of being ridiculed they may remain quiet. In response to this, Bone *et al.* (2015) suggests that it is the role of the professionals to ensure that the parent can share their views in confidence without the fear of being derided.

4.6 Main theme 3: Parental Position

The final emergent theme relates to how the parent viewed their position within the multi-professional team.

Subtheme 3a: Confidence to challenge

As briefly discussed within the previous themes there appeared to be a lack of confidence to challenge the professionals. This subtheme explores this further. The experiences of the parents highlighted that regardless of how confident they were in their professional and home lives they felt unable to challenge professionals regarding their child's needs.

P1 (166) Maybe at the time I should of, I should have but I just thought it'll be alright and then (pause) maybe I should have took it and spoken up but well but he [SENCo], I thought he knows what he's doing he is helping with the EHCP

P2 (232) I mean I'm not blowing my own trumpet but I'm a clever confident lady not just a stupid mum as I was made to feel

P3 (228) [Discussing the support from an external charity] We were so lucky as I wouldn't have said that if we hadn't been supported by x and advised on our rights

P4 (180) So I waited, (pause) I did sort of bring it up in the next review

The parents did not feel able to challenge the professionals, often waiting until they were invited to express their views. It appears that parents felt concerned about challenging professionals during the multi-professional meetings and would hold their opinion back in the belief that, as the expert, the professional knew what they were doing.

Subtheme 3b: Loss of identity

The sense of not having an identity came through strongly in each interview. Being referred generically as 'mum' appears to add to the frustration and anger felt across all of the parents interviewed.

P1 (112) we got to the meeting and we...I had to have a word with the social worker when we got there because she called me mum

P2 (352) Ya not even called not called don't call me mum I'm Mrs X and I am not your mum and I think you'll find you're not mine (laughs)

P2 (48) Erm yeah I just just ya know I think professionals they look at you erm and the amount that call you mum oh hi this is mum erm no actually I'm not your mum I'm B's mum do not call me mum erm how dare you (laughs) because it's just patronising

P4 (180) It was all so stressful just trying to be taken seriously by professionals and not be seen as some over paranoid mum who is causing trouble...I'm just mum

Losing one's identity appears to be extremely important in how the parent is positioned in the meeting. The parents described the feeling of losing one's identity as belittling and patronising when meeting a multi-professional team.

Subtheme 3c: Being a burden

Several parents made comment about feeling a nuisance to professionals and a burden on their time.

P1 (188) So to be honest he was probably getting on Mr x nerves I just kept asking why things weren't getting done...ya know...so I kept calling (laughs) I got on his nerves but it got things done

P2 (208) I was in red on her phone though I swear she use to ignore my calls (laughs)

P2 (258) I'm a pain in their backside that's how that's how I feel

P3 (388) I do not want to be considered a nuisance to them

P3 (372) I felt like I was a thorn in their side just a constant irritant (laughs)

The parents seemed to say these phrases in jest, laughing about the annoyance they could cause professionals. All the parents noted this feeling of being a burden to professionals and feeling as if they were taking up too much of their time. The response of the professionals at these times seemed to reinforce this burden feeling.

Subtheme 3d: Feeling patronised

In line with the feeling of being ignored, misunderstood and a burden, parents also felt patronised by the professionals.

P1 (48) yeah I just ya know I think professionals they look at you as if you don't know anything

P1 (264) I felt I wasn't being taken seriously because I was just a parent

P2 (270) No no they know her best don't they I'm just her mum (laughs)

P3 (60) [discussing conversation with head teacher] She said we were lucky to get the 15 hours I said lucky we are not lucky it's what she deserves (laughs)

P4 (84) There was no need to make us feel that we were a burden or that we should be thankful that she was going to help us it was patronising.

The notion that parents should feel grateful for the professional's help came through all four interviews. This left parents feeling patronised and belittled. This suggests that the professionals did not value the parent's opinion, perhaps believing that their view is insufficient to the process.

4.7 Discussion of the Parental Position

There were two strong emergent themes that came through: a loss of identity and the feeling of being a burden on professionals. There was a sense that professionals had to adapt to accommodate the parents which parents felt was patronising and unfair.

All the parents interviewed referred to feeling inferior to the professionals within the team. There was specific reference to how parents were introduced to professionals which seemed to influence how the parent positioned themselves within the multi-professional team. Being introduced as 'mum' implied their identity as a person was inconsequential therefore setting the tone for the parent's involvement. Salembier and Furney (1997) expressed that by disregarding the person's identity by not using their name can lead to a feeling of inferiority suggesting that the parent is unlikely to give their views nor challenge others.

As discussed within the literature review, McMaster *et al.* (2004) explained that professionals tend to hold a stereotype image of parents when addressing those with SEN. McMaster *et al.* (2004) stated that professionals may assume parents of SEN children have their own additional needs and may lack understanding or be below average intelligence. Garnett (1991) discussed this stereotype as a 'manipulation' enabling professionals to ignore parent's views as they are less important and may interfere with the decision-making process. Evans and Vincent (1997) concurred with Garnett (1991) arguing that parents of SEN children are treated differently and are less influential than parents of mainstream ability. This appears to support the findings of this research as parents felt angry at not being addressed in a more professional manner which subsequently led to parents lacking confidence to challenge professionals

This emergent theme also highlighted that parents often felt a burden to professionals. The psychology around this concept is a complex construct (McPherson *et al.* 2007). The phenomenon, generally termed as ‘self-perceived burden’, has been defined as,

“empathic concern engendered from the impact on others of one’s needs, resulting in guilt, distress, feelings of responsibility and diminished sense of self.” (McPherson *et al.*, 2007, p. 425)

Goleniowska (2017) stresses that professionals must consider what parents think and want from the EHCP process. She states implicitly that parents know their child better than anyone else and therefore the burden that is felt is due to the professional’s reactions to the parent’s involvement.

Charmaz (1983) felt that this sense of burden emerged because of the discrediting felt through the loss of self. Despite Charmaz’s (1983) research taking place over thirty years ago, it appears to support the findings of this research well. Being introduced to a group of professionals as ‘mum’ discredits the person’s identity and implies that the parents do not know what is best for their child in an educational setting. This can leave the parent feeling discounted and devalued. Brenner *et al.* (2008) propounded this notion by linking the stereotype of ‘mum’ with identifying numerous social roles assumed for a parent of a child with SEN. With numerous social roles to occupy, coupled with being devalued by losing their sense of self, it is understandable that parents begin to feel as if they are a burden to professionals.

The findings from this research appear to support the existing literature surrounding how parents position themselves amongst multiple professionals. The importance appears to lie with how the parent is introduced. By being called ‘mum’ has numerous implications, typically

leading the parent to feel devalued. The feeling on being inferior can create a sense of failing and hence not challenging professionals.

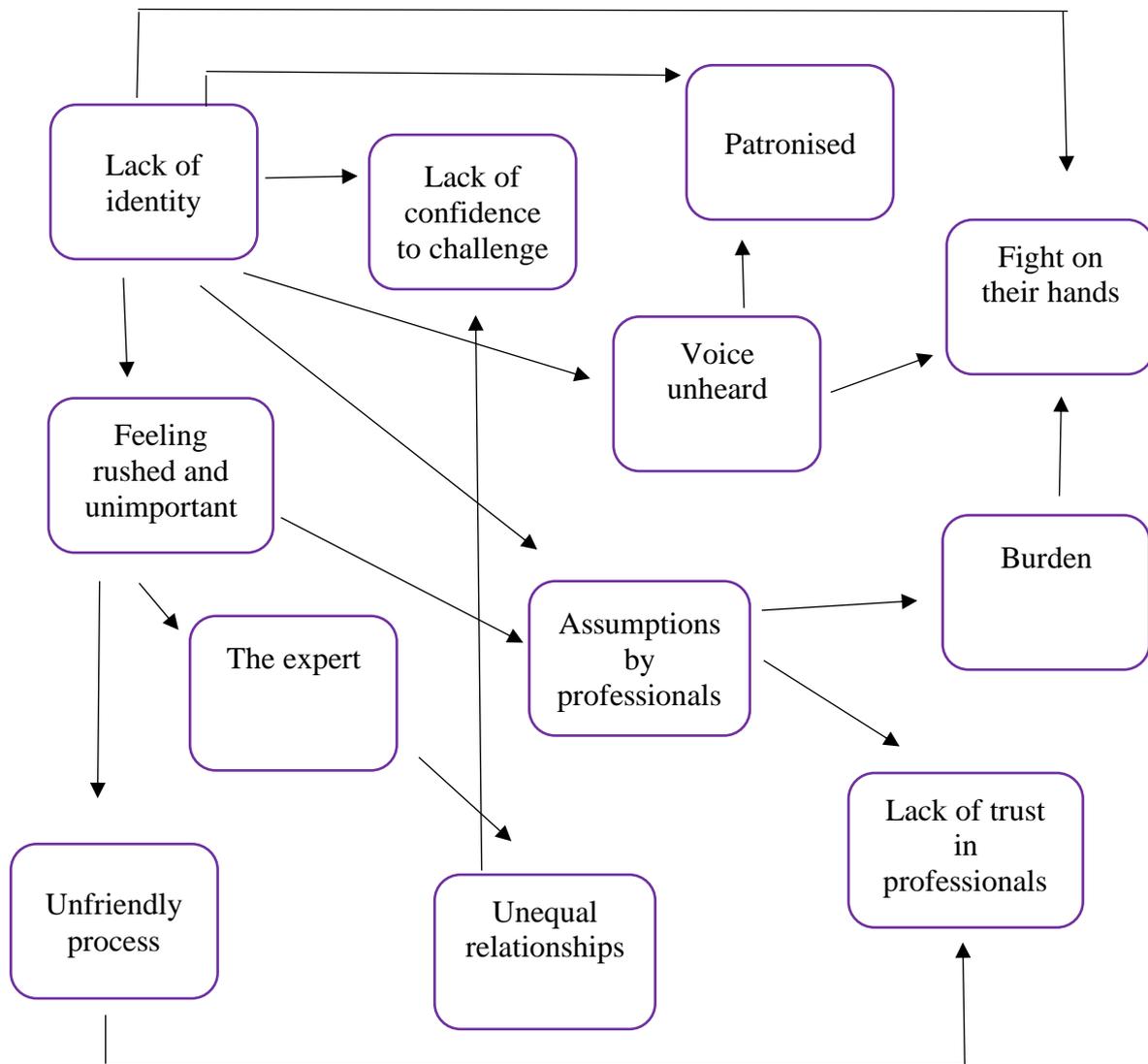
4.8 Overall Discussion

Through the IPA, three main themes were discovered demonstrating mainly negative experiences parents had regarding the EHCP process and working within a multi-professional team.

When referring to the Code of Practice (DfE, 2014) the parents voice is expected to be central to the EHCP process. It seems that from the parent's experience and supporting literature that this does not appear to be the case. Parents perceived professionals as being uninterested in their feelings and making light of their wishes and opinions. Parents felt professionals were hostile and unwilling to engage with them leaving the parents feeling angry, frustrated and belittled.

It appears that even though the main themes stand alone they seem to overlap and influence each other as demonstrated on the following page in figure 5.

Figure 5: Relationships between subthemes



The overwhelming feeling to come out of the interviews was the sense of frustration towards professionals. Parents noted that professionals are perceived as the experts therefore producing a hierarchical structure. According to Dabkowski (2004) this presents a conflict with the parent who, until this point, has been in control of their child’s support needs. Through the parents experiences it appears they found it difficult to place themselves within the hierarchy of a multi-

professional team. The sense of not belonging was experienced by all the parents interviewed regardless of their background, employment, culture or socio-economic status.

Through the interviews, it emerged that a pivotal point of whether the parents felt involved and engaged was during the introduction. As mentioned in previous models by Hoover-Dempsey and Sandler (1997; 2005), unless the parent is welcomed into the multi-professional relationship as equal to others then the parent-professional collaboration is unlikely to continue to higher, more complex levels. Through the parents' experiences this appears to have not happened with parents being referred to by a generic term and in turn losing their identity.

This occurrence can be associated with Tajfel's (1979) Social Identity Theory. Tajfel (1979) suggested that by removing the parent's identity and referring to them in a generic manner, such as using the word 'mum', divides the multi-professional group into a 'them and us' state (in this case 'professionals' and 'parent'). Social Identity Theory states that one group will attempt to discriminate against the other group, enhancing their control over the situation. Considering the parent's experiences in this research suggests that professionals may have manipulated this to move through the process quickly by discrediting the parent's opinions. However, it is my opinion through my own experience that this is neither explicit nor an intentional act.

Tajfel (1979) also refers to stereotyping which he proposes as a normal cognitive process: the tendency to group things together. However, the difficulty with stereotyping can lead to difficulties when trying to balance a parent-professional relationship. Salembier and Furney (1997) attempt to explore this further by explaining that by rejecting the person's name and inciting a generic term generates a stereotype of a mother who, in western society is gentle,

nurturing and tending to the child's needs. A stereotype of a professional is one of expertise and control. Salembier and Furney, (1997) therefore state that the hierarchy is already set before the meeting begins leaving the parent immediately at a disadvantage.

The feeling of being devalued and inferior may go some way to help explain the hostile language that each parent used whilst describing their experiences. Emotive language such as 'war', 'battle' and 'fight' were used frequently throughout the interviews. This suggests an interesting conflict within the parent. For the parent, they have assumed control of their child's wellbeing for many years: bringing the child up, caring for them, feeding them. It is somewhat understandable that allowing that control to be handed over can lead to the emotive stance that was seen amongst the parents. However, what appears interesting is that parents feel unable to voice their opinion within the meetings. There appears to be two reasons for this: (1) they are not given the chance as professionals are making assumptions and rushing parents; and (2) parents feeling devalued when invited into the meetings and therefore questioning their own judgement.

Goleniowska (2017) suggests that this barrier may be deliberately placed in front of parents to ensure the process runs smoothly and efficiently, due to the vast increase of recent EHCP referrals to local authority. The inability to share one's ideas and thoughts with professionals, according to Goleniowska (2017), demonstrates why the parent may feel a burden to professionals.

It is my opinion, through this research, that the introduction of the parent to the multi-professional team is crucial if the parent's views, opinions and wishes are to be heard and acted upon. By introducing the parent by their name, in a welcoming manner, and listening to their

views, appears to have a great impact on the success of the continued parent-professional relationship. When equal relationships have been formed successfully between parents and professionals, skills may be shared more easily and joint discussion can be made (Cunningham and Davis, 1985). The importance of this simple act could lead to the reduction in frustration and anger felt amongst parents involved in the EHCP process.

4.9 Strengths and Limitations

Consideration has already been given with regard to measures to ensure the quality of the current research in chapter 3. This section will discuss the limitations and strengths of the investigation relating purposely on the participant sample, data gathering and analysis approach.

4.9.1 Critique of the sample

It has been previously noted that the selection of participants was small. The reason for this was to draw on the personal experience of the parents: claims concerning the representativeness of the group or generalisations about the findings are not made. The approach allowed the parents' voice to be reported, which may aid professionals to commence a way forward to increasing parental engagement in multi-professional teams. Nevertheless, there are wider implications if the findings were to be generalised. The research was carried out in a suburban school within an affluent area. The parents that took part were all employed full time and lived within the local villages. Consequently, the experiences of parents in other parts of the country may not be the same.

Furthermore, the views of 'hard to reach' parents would have been interesting to gain. According to Doherty *et al.* (2004), 'hard to reach' parents can be defined into three distinct categories: minority, such as ethnic groups, travellers or asylum seekers; those who slip through the net, such as those who are unable to articulate their needs; and parents who are service resistant, suspicious and unwilling to engage. Given these definitions their views may have differed to those who partook. The parents involved in this research appeared to articulate their views and state that they would challenge professionals and fight for the support. According to Pagana *et al.* (2006) individuals who volunteer to take part in research tend to be histrionic, intrusive and overly self-confident. This suggests that the views from those who volunteered their time may differ to those who were more hesitant to be involved.

Future steps to explore this a little deeper could have been taken to think about how these parents could have been contacted and involved, this could have included engaging services who provide support to parents who feel their voice is unheard.

4.9.2 Critiques of data collection and data analysis

The use of SSI allowed the parents to share their experiences openly. The questions were planned but not rigid, which allowed parents to share areas they perceived as important without being constrained by a strict questioning structure. Yet, whilst using SSI as a collection method I needed to remain aware of the influence the parent, myself and the interaction between us had on the conversations (Cohen *et al.* 2000).

Adopting an IPA approach towards the data permitted for the identification, exploration and reporting of emergent themes. This approach to data analysis can be flexible due to

its independence from theory and therefore related to various paradigms. Nevertheless, IPA has been critiqued for being ambiguous and lacking definition (Holloway and Todres, 2003). Smith *et al.* (1999) considered that the collection of data and the consideration of stages are hazy and that the technique allows researchers to choose excerpts to reinforce the themes the researchers would like to see, therefore lessening the validity of the research. Yet, as the study was intended to understand subjective parental experiences rather than creating hypotheses about what may be discovered, findings were data-led. This allowed me, as the researcher, to understand the participant's versions of the truth (Seigfried, 1976).

In terms of the analytic procedures, the IPA process allowed for initial commenting and noting (see appendix 6). Here I wrote my initial analytical observations about the data in the margins. These initial notes were brief commentaries on the data rather than succinct coding. This initial comments allowed me to become familiar with each transcript and two levels of themes developed: emergent and subthemes. The emergent themes developed from the subthemes. Once coding and theme development was completed across all transcripts individually, I then developed the emergent themes across the dataset allowing the three main themes to be exposed.

It has been noted that the research is not bias free due to my interpretations of the parents' descriptions, and thus the validity will always be limited to a degree. However, delineating the epistemology and ontological position of this research and clarifying the process of the IPA, has made the scrutiny of the data unambiguous. Throughout this process, I was aware of how I preserved an amount of reflexivity, critically considering the impact I may have on the research process. As I adopted the position of a

constructivist researcher I acknowledged my understanding and principles which would contribute to the formation of knowledge (Siegfried, 1976; Rasmussen, 1998; Audi, 2003). Without this acknowledgment there is a risk that I would view my elucidation of the data as reality, rather than a version of reality. Barbour (2007) argues that emphasising the validity of research is vital in preserving the integrity of the study. For example, measures are taken to assure the data described embodies accurately the perceptions of the parents (Guest *et al.* 2012).

4.9.3 Influencing practice

The results from the current research have highlighted clear themes regarding the importance of how parents are welcomed and addressed within multi-professional meetings and how this helps form the ongoing relationship that develops through the EHCP process. The findings from this research can influence practice by sharing what has been found with colleagues and external professionals and how their behaviour towards parents influences the EHCP process. By informing professionals of how parents feel about the hierarchical position professionals place themselves in may create awareness of how this is perceived by parents.

Another simple change that could be made relatively quickly is raising the awareness of professionals using the parents name rather than 'mum'. Although it appears to be a common occurrence, the apparent impact of using this generic term on the parent's self-belief and confidence to be heard appears quite significant. In the wider sense the findings from this research could be applied to all professionals that engage with parents. A relatively simple change appears to be important in how the future relationship develops.

4.10 Potential implications of the findings

The findings from this research have highlighted that models and frameworks that were introduced many years ago are still not having an impact on how professionals engage parents. The findings from this current research supports this. It could be proposed that professionals be made aware of the models put forward by Hoover-Dempsey *et al.* (2005) and are supported to apply them in meetings. Professionals tend to have their own agendas that they take to the meetings yet a parent requires all the information to make decisions for their child. In today's modern world where professionals are busy and public funding is being cut, respectful changes that are made could influence the whole EHCP process.

4.10.1 Implications for Further Research

Exploratory studies are frequently used to produce hypotheses for future research (Cohen *et al.* 2000). The findings generate a picture of parental participation as being in the primary stages. Nevertheless, there is the possibility for further work to be performed. Further research comprising of larger samples would concede for a further exploration of the matters elevated in the current research with parents who may be harder to reach. The aim of the research was to understand whether the parents' voice was being heard therefore the views of differing groups of parents would be interesting to explore and compare to the findings of this current research. Additionally, research that explored professionals' approaches to working with parents and how they feel the new legislation has influenced their practice would enable a triangulation of data.

Outcomes from the present and preceding research imply a lack of lucidity around the impact of how parents feel they are represented and heard throughout schools not just within multi-professional meetings (Todd, 2003) as well as the support techniques accessible to multi-professional teams to encourage parental involvement. Therefore, future research could focus on what is needed to support professionals and parents in improving the working relationship to allow parents to have a strong voice in the decision making regarding support for their child.

4.11 Conclusion

This research has examined parents' perceptions of their involvement within EHCP-focused multi-professional meetings; a situation where there should be an emphasis on parents being central to the process. This research aimed to explore whether parents felt this process had been embedded and whether they did indeed feel central to the process.

IPA analysis of the interviews conducted looked at the lived experiences of the parents in relation to the research question and discovered three emerging themes:

1. Barriers to parental involvement (elements highlighted that impeded the process from occurring)
2. Professional power (where a professional imbalance between parent and professional was highlighted)
3. Parental position (how the parent viewed their position within the multi-professional team)

These main themes, and associated subthemes, echoed the findings of previous research and literature focused on the involvement of parents.

In relation to the research question, Theme One examined aspects of the barriers toward parents being involved. This is reflected in the literature through the work of Ball and Ball (1995) who echoed the parents' feeling that their views were not taken seriously nor validated regarding the support their child needs. McMaster *et al.* (2004) also states that professionals often make light of parent's feelings, seeing them as inferior.

The second theme highlighted professional power, specifically regarding a hierarchy and how the parent fits into this. Professionals are seen to be in control and dictating the process (Arnstein 1969); although parents were confident to want to challenge they saw this as a barrier to being involved.

The third theme examined the parental position and how the parent fitted in to the hierarchy. Parents felt their identity was lost and therefore struggled with their positioning within the hierarchy. This may have influence their self-belief, leaving them feeling alienated within the team and a burden to professionals.

The literature suggests that parents perceive the SEN world (and professionals within it) as negative. This perception is influenced through sociology, history and government policy. For decades Education Acts and government legislation have stated the impact of the parent's involvement yet it appears parents are still not feeling welcomed or equal within this process. It seems that for the participants of the present study the issue may be linked to how the parent is introduced into the multi-professional team. It seems that taking away their identity appears disrespectful and belittling towards someone who knows the child best.

The results appear to strengthen the assumptions established within the literature review. The research has shown that, for the four parents, their experience of professionals within the EHCP process has been less positive than they had hoped. As Jansen *et al.* (2016) explains, there is an assumption that parents will be welcomed into the team and empathy will be given. This was not demonstrated through this research. All parents appeared to give very similar accounts of how professionals perceived them.

That said, in the current political climate, and the continued embedment of the Code of Practice (DfE, 2014), time will tell if professional practices will change.

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APPENDICES

Appendix 1: Participants information: Social Class, age and details of their child

Four IPA participants

Parent and details of child – supported by educational files

	Age of child	EHCP new / reviewed	Details of child’s needs and parents previous experience of professionals
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Parent 1	14	Reviewed	Has a diagnosis of ASD and ADHD. Was diagnosed at 5 years old. He has managed well in mainstream school although had difficulty during transition. Parents had difficulty with middle school understanding their child's needs but feel upper school has worked well for him.
Parent 2	14	Reviewed	Has a severe learning disability and ASD. Parents have taken professionals to tribunal and have complained to local authority when they feel the child needs are not being met. Mother advocates for other parents and by her own description states she is an expert in SEN procedures at local authority.
Parent 3	15	New	Recently diagnosed with ASD, school refuser. Child has become more isolated as he becomes older due to the struggles associated with ASD. He has struggled through his education and mum has had to fight for support. Mum states she has developed in confidence to challenge professionals but only since she received the EHCP. She found this was 'proof that she wasn't a bad mum'
Parent 4	14	Reviewed	Mother is a teacher. Understands the school system and how teachers work with child with SEN. Finds it difficult to attend meetings as a 'mum' as she feels she is not taken seriously. Daughter has ASD diagnosed in early childhood.

Social Class of the Participants

Social class of the participants felt important to note as those who volunteered to be interviewed appeared confident and articulate in their views. As part of the implications for further study I feel parents who are harder to reach would be interesting to explore and compare their experiences to those in this research. The following guidance was sourced to help with this analysis.

Classes via Occupation:

Class 1. Higher managerial and professional occupations.

1.1 Large employers and high managerial occupations

1.2 Higher professional occupations

Class 2. Lower managerial and professional occupations.

Class 3. Intermediate occupations.

Class 4. Small employers and own account workers.

Class 5. Lower supervisory and technical occupations.

Class 6. Semi-routine occupations.
 Class 7. Routine occupations.
 Class 8. Never worked and long term unemployed.
 (Source: Office for National Statistics, 2008)

	Class based on parent's occupations
Parent 1	Class 4: Mother works in retail as a supervisor part time. Father works as a builder
Parent 2	Class 2: Mother works in senior leadership in a well-known company. Works full time as does father. Father works at a senior level also in a well know company
Parent 3	Class 6: did work as a carer until son began to refuse to attend school. She gave up work to support son
Parent 4	Class 3: Teacher in SLT

Appendix 2: Researchers Reflections

It is key for the researcher using IPA to be reflexive and reflective throughout the whole process of the research as the analysis involves so much subjective interpretations. Due to this it is important to acknowledge the contexts of the researcher's professional and personal identity. The notes below are informal, addressing the experiential influences of the researcher in the data collection and analysis.

Informal self-reflection notes made on the interviews and the context of the research

Context of the Researcher that is relevant to the interpretative nature of the data

I have worked within the education system for the past 12 years. This has been from an external stance working within social care as a Child and Family Practitioner where my role was to enable parents to instil boundaries and guidance for their child and allow them to have a voice during Team Around the Family Meetings. I then moved into a similar role within a large upper school in an affluent area. My specialised area was attendance but I carry a much more pastoral role in supporting the child and parents with their needs. My role often overlaps with SEN and safeguarding. From an attendance point of view gaining the parents trust and engagement is vital for good school attendance and building the relationship up between school and home.

Seeing the difference between how social care engaged parents in a very holistic manner I was surprised to find the school viewed parents very differently. Rarely speaking with parents and almost frightened to challenge parents. This had created a 'them and us' atmosphere in the school. My background of working with the parent to enable the end goal and the right support for their child, has been embedded in the school. After many years, the approach towards parents has change. It was through this process that my interest in how the parent felt involved within their child's support became an idea for further research. With the introduction of the new Code of Practice I felt this was an ideal opportunity to explore this further.

Due to the nature of my professional work I do find it easy to talk to parents. Therefore, the 1:1 interviews felt easy and natural. There were times during the interviews that the parents, all mothers, would become upset with the frustration of the processes and professionals involved. I was very aware with this and able to ease their frustration as I would if I was working in my professional role with them.

As the parents had children in the school in which I worked I had a rapport already with one parent, however I felt each interview was carried out the same and a good rapport was built with all parents who stated they wanted to tell their story and help other parents.

My own personal background is that I am a married mother of two girls, one who has had an IEP and medical concerns and therefore I have been involved with multi-professional meetings as a mother as well as a professional. This experience and empathy for the situations gave me insight into the parents within this study.

Due to the combination of professional and personal values I hold I felt it was important to explore whether parents felt their voice was heard by giving them a voice. I have become frustrated during my professional career with parents being side-lined and ignored. It is hoped that this research will offer a deeper understanding into how parents feel they are brought in and welcomed into a multi-professional team. The aim is to improve and share good practice.

Reflections on the Interviews

Parent 1: Interviewed at the school, which is familiar to both parties. Rapport was built quickly although the recording device felt uncomfortable at first. This may be due to the inexperience of myself and the device being new. Parent 1 came across as quite weak in her ability to challenge professionals although confident to speak to me about what she would have like to have said. This seemed to cause a frustration for her. Interview was uninterrupted.

Parent 2: Interviewed at the school, which is familiar to both parties. Parent 2 was very keen to get her point across about how upset she was about the system and support from the school. Parent 2 was a confident, professional woman who was very keen to be involved in the study to highlight the problems she has faced and to raise the awareness. There was lots of rich data achieved from this interview.

Parent 3: Interviewed at the school, which is familiar to both parties. Parent 3 was a teacher in an upper school and therefore knew the process of EHCP and engaged with multiple professionals regularly. However, she gave excellent data regarding the difficulty that she felt engaging with professionals and not being 'just a mum'. I could have empathised with Parent 3 as professionally working alongside multi-professionals then being the parent in front of them talking about your own child.

Parent 4: Interviewed at the school, which is familiar to both parties. I had worked with parent 4 for 12 months therefore a good rapport was already built. The interview flowed smoothly this may be due to myself being more comfortable with the parent but also understanding the interview process a bit better. I felt parent 3 was also comfortable with the interview as a lot of good data was retrieved.

Appendix 3: Consent Forms



UNIVERSITY OF
BIRMINGHAM

Individual Participant Consent Form

INFORMED CONSENT FORM

Consent to be a research participant

Purpose and Background

I am currently completing a Master's Degree in Social, Emotional and Behavioural Difficulties at the University of Birmingham. As part of this degree I am completing an independent piece of research. The focus of my research will be on the views of parents whose children have gone through the Education, Health and Care Plan process; in particular, I am interested in how you felt that your needs, views and wishes were heard by professionals.

What does it entail?

If you agree to participate in the study:

- 1, You will be asked to meet me at a time and place convenient to you.
- 2, I will then interview you for up to 45 minutes. I will ask you questions about the EHCP process: - how you felt during this process, how you felt your voice was heard, and your partnership with professionals.
- 3, I shall use a digital voice recorder to record the interview. I shall then listen to the interview and transcribe what was said. These transcripts will be handled as confidentially as possible. There shall be no individual identities used nor the school named within any of the reports or publications that may result from this study.

Questions

If you have any concerns or questions about participating in this research, you should first speak to myself, Laura Thomas on 07915 060139, via text or phone call. I am more than happy to call you back if needed. If you do not wish to do this, you may contact my supervisor Dr James Birchwood or the program lead, Neil Hall (School of Education, University of Birmingham) on 0121 414 4866.

Please note I am not employed by the Local Authority SEN team therefore your responses will not impact on the education or support your child receives nor will it influence any EHCP currently in process.

Should you feel any of the issues raised in the interview make you feel uncomfortable and you wish to discuss these further I will be happy to talk to you at any point. This, of course will not be recorded.

Please note:

- **Participation in this research is voluntary**
You are free to withdraw at any point without reason. However, a date will be given for when the research will be submitted and therefore withdrawal of your interview will not be possible. Please speak to me if you have any concerns about this. Your decision as to whether or not to participate in this study will have no influence on you present or future status.
- There will no cost implication as a result of you taking part in this research

- All information will be anonymous, however if there is a disclosure made that puts yourself, your child or any other child at risk of harm, confidentiality will be broken and the appropriate authority will be informed

You will be given a copy of this consent form to keep,
 Many thanks, Laura Thomas

 I, _____ give my consent to participate within this research
 Signature of participant: _____
 Date: _____

I give my consent to be audio-taped in this research
 Signature of participant: _____
 Date: _____

Signature of Person Obtaining Consent: _____
 Date _____

Appendix 4: Ethics Form

Ethics Form for PGT Students

This form is for all PGT students undertaking **BPhil/MEd/MA dissertations as well as the 'Special Studies in Education' Module where data will be collected.** Students should consult with their supervisor before completing this form.

Students should complete Part A of this form then pass it on to their supervisor who should complete Part B. Supervisors are responsible for checking and confirming to the ethical guidelines and frameworks of other societies, bodies or agencies that may be relevant to the student's work.

For further guidance refer to the University's Code of Ethics
<http://www.birmingham.ac.uk/Documents/university/legal/code-of-ethics.pdf> or the BERA guidelines
<http://www.bera.ac.uk/publications/Ethical%20Guidelines>

Tracking the form – Put an X in the box

Part A completed by the student

- Med/MA students submit the form with their Practitioner Inquiry in Education (PIE) assignment
- BPhil students submit the form with their Dissertation
- Students submitting a 'Special Studies' assignment should submit the form in accordance with their programme requirements

Part B completed and approved by the supervisor

Part A: to be completed by the STUDENT

NAME: Laura Thomas
PROGRAMME OF STUDY: MEd SEBD
DATE: 4th July 2016
NAME OF SUPERVISOR: Colette Sloan
PROPOSED PROJECT TITLE: Is the parents voice of special educational need children being heard in light of the new Special Educational Needs: Code of Practice (2014) legislation? An Activity Theory approach.

NOTE FOR MEd/MA STUDENTS

To avoid duplication, you can copy the relevant sections of your research study and attach them to this form. You should use the points 1 to 9 below to check that you have addressed all the ethical issues sufficiently in your PIE assignment. If you have not done so, you should complete the relevant boxes below.

NB. You should type straight into these boxes – they will expand for your text.

Do you work for or within the NHS or a Social Services Department?

If yes, contact your supervisor BEFORE filling out this form.

BRIEF OUTLINE OF RESEARCH STUDY: (100-250 words; this may be attached separately)

This research focuses upon parent's perceptions of their involvement in multi-agency teams regarding the support for their child and whether they see themselves as partners within the process. The aim is to explore whether the new Code of Practice (2014) which places parents as equal partners is taking place in practice.

I aim to interview four parents of primary school children who have been through the Education, Health, Care Plan (EHCP) process within the last 12 months. The interview will focus around how they felt their voice and opinions were listened to and their experience of the process.

I will employ the cultural historical activity theory (CHAT) as a framework to structure the interviews and analysis the data. This framework appears to consider the complexities of real-life activity, motives behind the behaviour and contradictions that take place.

MAIN ETHICAL CONSIDERATION(S) OF THE RESEARCH STUDY (e.g. working with vulnerable adults; children with disabilities; photographs of participants; material that could give offence etc.):

I shall be working with adults who may be frustrated or upset regarding the process. Discussing support for your child can be exceptionally emotive therefore consideration for how I address this is needed (signpost for support if required)

Interviews will be recorded on a Dictaphone, stored within a locked draw and destroyed after transcription.

All interviews will be anonymised

I shall not be interviewing or meeting the children nor need to see the EHCP

Please provide details on the following aspects of the research study:

1. What are your intended methods of recruitment, data collection and analysis?

Please outline (in 100-250 words) your methods and give what detail you can. However, it is not expected that you will be able to fully answer these questions at the proposal stage.

- **Methods of recruitment**

I shall inform the Head of Service within the local authority regarding my intention to study this area and propose the school I shall like to recruit parents from (local primary school). I shall then approach the local school and ask if they are willing to be involved within the research before asking a letter to be sent out to all parents who have been through the EHCP process within last 12 months.

If I do not receive all four volunteers from this school, I shall look to involve another local primary school within the same local authority.

- **Data collection**

I shall adapt the Activity Theory framework to structure my semi-structured interview. The interview will explore what the parents were working on and aiming for (object and goal), what the rules and constraints were of this, who else was involved (community), how was the work shared (division of labour) and what was used to achieve the outcome (tools).

- **Analysis**

Once data is collected and transcribed I shall then adopt a thematic analytical approach to collect themes through the transcripts and allocate them to one of the seven nodes mentioned above to compare before discussing the themes.

2. How will you make sure that all participants understand the process in which they are to be engaged and that they provide their voluntary and informed consent? If the research study involves working with children or other vulnerable groups, how have you considered their rights and protection? **[see note 1]**

After seeking support from the Head of Service I shall contact the head teacher and SENCo within the local primary school to explain my proposal. I shall explain verbally and in writing their right to withdraw. The school may be concerned about parents speaking about members of staff and their involvement within the multi-agency team however I shall explain that it will be anonymised. If the school withdraws consent, then I shall seek another local primary school.

For parents, I shall verbally and in writing explain they have a right to withdraw at any point and their recorded interview shall be destroyed. I shall also explain that names will be changed and their involvement is voluntary. Parents, head teacher and SENCo shall sign to say they understand and agree.

3. How will you make sure that participants clearly understand their right to withdraw from the research study?

I shall ensure parents are aware when they agree to take part and prior to the interview commencing that they can withdraw at any time. A date will be given to them to request to be withdrawn as once the research has been completed and handed in this will not be possible.

Parents and schools will be informed that they can withdraw without giving reason and that by withdrawing will not have an impact on the EHCP process or impact on any support for their child nor disrupt their education.

4. Please describe how you will ensure the confidentiality and anonymity of participants. Where this is not guaranteed, please justify your approach. **[see note 2]**

All transcripts will be referred to as 'parent 1', 'parent 2' etc. All names of children, professionals and others will be referred to by pseudonyms.

5. Describe any possible detrimental effects of the research study and your strategies for dealing with them. **[see note 3]**

The process of gaining support for a child with special educational needs can be emotive and this may upset some parents in discussing the process they have been through. I will ensure I am guided through the interview by their responses and signpost to the local authority or local volunteer services (Core Assets) if they require additional support regarding the EHCP process.

6. How will you ensure the safe and appropriate storage and handling of data?

The Dictaphone will be store within a locked draw within my home until transcribed. Once transcribed the recording will be destroyed and transcript anonymised. The computer and Dictaphone are my personal items and password protected where able.

7. If during the course of the research study you are made aware of harmful or illegal behaviour, how do you intend to handle disclosure or nondisclosure of such information? **[see note 4]**

I shall follow the school's guidelines which I shall request prior to conducting the research and ensure parents are aware of the process if I am concerned.

8. If the research study design demands some degree of subterfuge or undisclosed research activity, how have you justified this and how and when will this be discussed with participants?

None

9. How do you intend to disseminate your research study findings to participants?

I intend to give participants a short summary feedback sheet of my findings which will also be provided to the school (s) and Head of Service for their information. I shall offer to expand my findings further should participants, school (s), Head of Service desire.

All UK students undertaking work with pupils or vulnerable adults should give the date of their most recent Disclosing and Barring Service (DBS) check (previously known as CRB).

Date of DBS: 13/04/2015

Student's name (please print): Laura Thomas
Please send from your official University email address in lieu of signature.

Date: 04/07/2016

Part B: to be completed by the SUPERVISOR
--

Feedback from supervisor on ethics form

1 st submission
2 nd submission
Subsequent submission

1. If relevant, has the student assured you that they hold a current Disclosing and Barring Service Certificate for the participants they will be working with during their research **[see note 5]**

Yes, Not applicable

If not applicable, please state why:

2. Have you seen information and consent forms relevant to the present research study? [if not relevant at this time, please review this within 6 months]

Yes No

Student has been asked to ensure I have seen and agreed these before data collection.

Yes No

3. Is a referral to the University of Birmingham's Ethics Committee necessary? **[see note 6]**

Yes No

4. Do you require a formal letter of approval from the University of Birmingham's Ethics Committee?

Yes No Not applicable

Declaration by Supervisor

I am satisfied that I have attempted to identify the risks that may arise in conducting this research and acknowledge my obligations as Supervisor and the rights of participants. I am satisfied that those working on the research study have the appropriate qualifications, experience and facilities to conduct the research study set out above.

Print name: Colette Soan

Signature: C. Soan

Date: 22.08.16

Returning the form:

This form should be completed before any data collection:

- MEd/MA students should submit it as an attachment to their PIE assignment
-

Bphil students should submit the form with their dissertation

Students submitting a 'Special Studies' assignment should submit the form in accordance with programme requirements

The form will be kept in the student's file.

Notes for completion of form

1. Please consider the 'chains' or hierarchies of consent that may be necessary for e.g. working with children and young people. There may be a number of people / agencies /organisations who may be required to provide consent or agreement to participate. For example, a research study undertaken in a Local Authority may require agreement from members of Senior Management before agencies/organisations may be approached. Involving children may then require agreement from (eg) Head teachers and parents/carers (as well as the child/young person themselves) plus professionals from other organisations.
2. This concern may arise, for example, in experimental or quasi-experimental designs where treatment is viewed as desirable and withheld from the control group. It might also arise in unpredictable ways in other intervention designs and, for example, in interview-based studies. Harm to the researcher if, for example, working with emotionally difficult subject matter or in potentially dangerous contexts should also be considered here including the forms of support that will be made available in such circumstances.
3. This may apply in circumstances where methods involve the use of e.g. video or photographs that could identify participants or in the case of interviews where the status / job role of the interviewee will enable them to be identified by others.
4. You may wish to refer to the BERA Revised Ethical Guidelines for Educational Research, 2004; paragraphs 27 and 28, p.8 for more information about this issue.
5. When applying for a DBS make it clear whether the check is for children or vulnerable adults or both. Also, organisations/schools/ services may have different requirements for how recently a DBS check should have been completed for it to be acceptable. You are advised to check the DBS web site for further information <https://www.gov.uk/government/organisations/disclosure-and-barring-service/about>
6. Supervisors wanting advice on ethical matters should refer the student's proposal to the Head of Department in the first instance. Also, if the methods, methodology and /or participant group(s) alter substantially from those outlined in this submission during the course of the research study, continued ethical approval must not be assumed. Under such circumstances, the student may need to complete an updated submission for consideration by the Supervisor. This may be particularly appropriate for longitudinal studies where research populations and indeed content/focus can change over time.

Appendix 5: Parent interview schedule

Introduction

- Explain rationale and procedure
- Explain confidentiality and limits of confidentiality
- Obtain verbal consent and check participant has signed consent form
- Ask if the participant has any questions

Rapport building

- How long has your child been coming to the school?

[RQ1: What are the themes that emerge from the interviews with parents about how they felt about their involvement?]

Interview Schedule

- Can you tell me a little about your child and a brief overview of why the EHCP was needed?
- What information was given to you prior to the EHCP process starting?
- How involved were you in the process?
- The EHCP suggests you will be engaging with many different professionals; how did you find this aspect of the process in terms of engaging with them?
- In terms of the 2014 Code of Practice, it expresses that parents are central to the EHCP process how did you feel your voice was heard in being able to express your wishes and desires for your child?
- The Code of Practice also suggests that parents should be equal partners with professionals what are your thoughts with this suggestion?
- Can you tell me about your relationship with the professionals?
- Did you feel you required any support or advice from the professionals? Is there any information you didn't get but think would find useful?
- What do you feel has been particularly positive or a barrier during this process?

General prompts

Can you tell me a bit more about that...?

What do you mean when you say . . . ?

Debrief

Is there anything else that you would like to add?

Do you have any questions about what we've been talking about?

Thank you for your time

Appendix 6: Transcript of Parent 2

Appendix 6: Transcript of Parent 2		Researcher: LT (R)	Method Capture: Audio
Date of interview: 26/01/2017		Duration of interview: 45:53	Location of interview: Meeting room
Date of transcription: 26/01/17 and 28/01/17		Transcriber: LT	REC015.WAV
Voice	Transcription	Thread notes	Notes
R	So if we start with a little overview of your child such as why the EHCP was needed that sort of thing	1.	
P2	Ok urm X has er high functioning autism severe dyslexia and moderate learning difficulties urm physically absolutely fine urr he was diagnosed by a private ed psych when he was five and a half and we couldn't get a counsel one anywhere near him	2.	
R	Ok	3.	
P2	Urr and before that we had er he had very severe glue ear	4.	
R	Mmm mmm	5.	
P2	Which erm he they put everything down to its his glue ear so he had grommets and everything but everything was just the same	6.	
R	Hu mmm	7.	
P2	(laughs) erm he was in mainstream up until he was 16 he has just turned 17 now	8.	
R	Ok	9.	
P2	And we have mixed (laughs) experiences really urm he's been moved from two schools by me	10.	
R	Mmm	11.	
P2	Erm and then err the three other schools he was at l ya know I can't fault that them they were	12.	
R	Mmm mmm	13.	
P2	Great so he was at er x and then x then he went to x he didn't last in x very long erm he went across to x dyslexia unit coz that was still there urm x he got on really well there erm then he went off to x in x	14.	
R	Ok yeah	15.	
P2	So erm which again I can't fault them	16.	
R	Yeah	17.	
P2	And know he's at x	18.	
R	Right yeah	19.	
P2	Because ya know when he's past 16 mainstream don't want to know	20.	
R	Right	21.	
P2	Erm so and college provision is just appalling	22.	
R	Ok yeah	23.	
P2	So erm so that's kinda x (laughs) he plays football loves football plays with x him and x are great mates always playing football a lot of football together erm but yeah he had a statement when he was 7 and I've in battel with the council most years ever since (laughs)	24.	Battle with the council
R	Oh really (laughs) so when did x change over from statement to the EHCP when did that process take place	25.	
P2	Ooh that happened a couple of years ago so that would have been in his (pause) oh its difficult isn't it	26.	Fed up – difficult process
R	Yeah just roughly	27.	
P2	Yeah urm yeah so we've just reviewed his EHCP so it would have been 18 months ago when we transferred	28.	
R	So you well you seem quite frustrated by the process the whole process is not just the process but the professionals	29.	
P2	Oh yes it appalling	30.	
R	Right could you explain what you mean a little more	31.	

P2	Yes certainly its appalling I'm very well educated very articulate erm and have fortunately the means to fight people so many don't so many don't	32.	Parent type articulate, educated other parents aren't
R	Right	33.	
P2	I kick a little bit harder for those who don't I don't mean physically (laughs) obviously but I kick a little harder for all of those other parents who are not able to go up against people to say ya know	34.	Advocate for others who are weaker
R	Mmm	35.	
P2	I'm not having that written about my child erm yeah I find the whole system absolutely appalling	36.	
R	And is that do you think the staff the professionals involved or do you think it's the systems or the whole process what do you	37.	
P2	I think it's its everything	38.	
R	Yeah	39.	
P2	Ya know if you get erm ya know I've been very lucky with three of our SENCo's two of them erm I I put in complaints to erm to governing bodies about erm and them both upheld in fact	40.	Complained re: professionals
R	Right yeah	41.	
P2	So which ya know	42.	
R	Mmm mmm	43.	
P2	Erm could have been ya know three of the SENCo's of the schools the good schools you could probably work out which ones I mean (laughs)	44.	
R	Huh mmm	45.	
P2	Erm ya know they were absolutely fab definitely on the kid's side ya know they would fight for the for the kids	46.	Professionals on the kid's side
R	Yeah	47.	
P2	Erm yeah I just just ya know I think professionals they look at you erm and the amount that call you mum oh hi this is mum erm no actually I'm not your mum I'm x mum and I'm x mum but I'm not your mum do not call me mum erm how dare you (laughs) because it's just patronising	48.	Parent have no identity
R	It is patronising yes your right patronising	49.	
P2	Patronising ya know it's almost as if they can't be bothered to remember my name or have any other sort of life apart from being x's mum ya know I'm a financial planner and I'm terrible with names but I write them on the top of the documents or if I'm typing I whack them across the top so I'm never in the position of going oh don't know your name I won't forget I write their kids names down their pet names everything because its personal	50.	Patronising
R	Definitely	51.	
P2	So important	52.	
R	I agree definitely	53.	
P2	So yeah I just just I think the professionals I think are very over worked	54.	
R	Huh mmm	55.	
P2	So ya know I don't hold all of them in contempt (laughs)	56.	
R	(laughs)	57.	
P2	But I do quite a lot of them I think ya know if you don't like what you're doing go and find something else you know	58.	
R	Yeah quite	59.	
P2	Ya know if don't want to or can't give your whole work to this go and do something else	60.	
R	That's right yeah mmm	61.	
P2	X at x school was just a dream to work with	62.	
R	At the most important time in his schooling	63.	

P2	Yeah that's right such an important time for x and Mr x was just fabulous ya know when he was five they said he would never be able to read or write just just by a few points missed a GSCE in English	64.	
R	Mmm mmm	65.	
P2	Came out with distinctions in his animal care, agriculture ya know his cooking teacher use to get him to make her her pastry for her dinner parties because it was so good (laughs)	66.	
R	Oh really (laughs)	67.	
P2	He was just so good at it so by just focussing on what he can do was just fab	68.	
R	However I'm left wondering if you hadn't had pushed it so far	69.	
P2	Yeah	70.	
R	Or had just accepted that he would never read or write I wonder	71.	
P2	No he would never if I hadn't had pushed it he never would have reached where he got to	72.	
R	Yeah	73.	
P2	In fact a SENCo at x said she said to me there are two kids in this school one was x and another kid and I do know who the other child was as I knew the mum she said he will be fine because he has a tiger behind him	74.	Mum is a 'tiger' Fight for support
R	Yeah yeah mmm	75.	
P2	Who will fight every step of the way and the other one will well in fact the other one is in residential care and it's really sad	76.	
R	That is yeah mmm	77.	
P2	And if I hadn't had x I would have adopted him (laughs)	78.	
R	Well yes oh dear that is interesting through isn't it	79.	
P2	Because yeah it's just really really sad well actually worrying terrifying in fact it shouldn't be the way	80.	
R	Yeah	81.	
P2	But it's across the board yeah ya know and I do think sometimes I was a bit hard on ya but ya know what this is my son we are talking about ya know it's my boy and he need the help no one ever said to me your daughter wont achieve she won't be	82.	Fight for child's needs
R	Yeah	83.	
P2	Able to do that	84.	
R	Yeah	85.	
P2	They didn't say that to me in fact x were begging please can we have can we have her but I was like no you can't but	86.	
R	(laughs)	87.	
P2	(laughs) so you can't its very interesting it's a battle like I said I hate I hate what happens to other parents I hate it deeply and I don't hate anything in life but I	88.	Hates what happens to other parents
R	Yeah	89.	
P2	I I do think I can't take on your battle I help where I can	90.	battle
R	Yeah yeah	91.	
P2	but I can't take on your battle for you I mean some just nod along to what's being said ya know to what they are telling them their child needs and I just think no that's wrong look at what they are saying do you agree ya know	92.	
R	That's right its interesting yeah	93.	
P2	I read ya know I read the code of practice and I highlighted points in it and was like right come on then if you want battle and I've and I've even said to the council	94.	Battle
R	Yeah	95.	
P2	I said to them you can have it nice or you can have it nasty we can do this in a professional manner where B's needs are met or I see you at tribunal (pause) take your pick	96.	Mum wants to be seen as a professional in the process but feels it's a battle
R	Huh mmm	97.	

P2	And in fact when we went to x that's what I exactly said to them take your pick	98.	
R	Yeah yeah	99.	
P2	I said he's not going to x college	100.	
R	Yeah	101.	
P2	Over my dead body ya know wish it if you like but my daughter is worse than I am so (laughs) so	102.	
R	Mmm mmm	103.	
P2	Just take it any way but then in the end they were just like ya know what	104.	
R	Mmm mm	105.	
P2	X who was there at the time will take him because yep just just because we just don't want to deal with mum we'll just take him ya know because they don't want to deal with me ya do you get fed up with it it's a battle	106.	Just give in as they don't want to deal with mum
R	Sadly sometime it can be it sounds yeah	107.	
P2	It's what we have to do we have to fight its wrong we should have to be we have to fight	108.	Fight but realises they shouldn't have to
R	It's wrong	109.	
P2	Very wrong	110.	
R	Mmm mmm	111.	
P2	Well with the EHCP the first one that's what we had we got to the we got to the meeting and we I had to have a word with the social worker when we got there because she called me mum	112.	Loss of identity called mum
R	Mmm yeah	113.	
P2	So that's quite a common theme	114.	
R	Mmm mmm	115.	
P2	Yeah and they'd written it for me	116.	EHCP already written for them
R	Oh	117.	
P2	They had written it for me they had written it I had no part of it	118.	!!!! IMPORTANT !!!!
R	Oh	119.	
P2	Yeah done and I said	120.	
R	Yeah	121.	
P2	Where has this come from	122.	
R	Yeah	123.	
P2	None of this I don't recognise any of this ya know they had taken stuff from when he was seven from his first statement and ya know I'm very much like ok if as long as you get the pot of money you need	124.	Made up info on paperwork
R	Huh huh	125.	
P2	The money you need if the EHCP said you need 45 minutes of this but actually I think he needs an hour and half of this I don't care how you get the money	126.	
R	Yeah	127.	
P2	I'm not interested as long as you have got what you need	128.	
R	Yeah	129.	
P2	Erm yeah but it was written but I said its written all wrong	130.	
R	Yeah	131.	
P2	You email that to me and ill sort it out I couldn't believe it	132.	
R	Yeah yeah	133.	
P2	And they they had forgotten that I hadn't been part of that worked for a few years as he had been settled	134.	

R	Mmm	135.	
P2	They emailed it to me in a PDF	136.	
R	Oh no well that was no good for changing parts	137.	
P2	(laughs) so I put it straight through the PDF reader at work the rewriter because we have one at work	138.	
R	Yeah yeah	139.	
P2	I said I sent it through to IT and said I need this rewriting and then I sat there typing (laughs) and typing	140.	
R	And did you did you change	141.	
P2	I change swades of it loads and loads I rewrote it I challenged everything	142.	
R	Really	143.	
P2	Oh absolutely I changed the whole of it I rewrote it	144.	
R	And what was the response of the professionals when they saw what you had changed	145.	
P2	I challenged why they had wrote it for me I said I said this is absolutely nonsense and they ya know they just said this is how we do it here	146.	
R	Oh wow really mmm	147.	
P2	Well you might do it this way but you're not doing my sons this way it's wrong	148.	
R	Yeah yeah	149.	
P2	I said ya know how he was at seven is very different to how he is now at fifteen I said his needs are significantly different so	150.	
R	So I wonder why they did that	151.	
P2	Ease purely ease	152.	
R	Right	153.	
P2	Yeah ya know we didn't have an Ed Psych review although they had agreed I could use my private Ed Psych because we had all the battle with one of the Educational Psychologist	154.	Battle with professionals
R	Right yeah	155.	
P2	Who didn't recognise his autism they just didn't recognise you know obviously he has processing delay because of the autism and dyslexia and moderate learning disabilities so he takes longer to process things we actually had an Educational Psychologist say to us well I haven't got time for this	156.	Professionals unsympathetic
R	Huh huh	157.	
P2	You can go and took him on as well and he was another one who ended up at the (laughs) at the ya know (laughs) it's terrible	158.	
R	It sounds like a tough experience	159.	
P2	Oh you wouldn't believe dreadful there was lots and lots of complaints	160.	Complaints about professionals
R	Yeah	161.	
P2	I did get rid of him	162.	
R	Yeah yeah	163.	
P2	Urm yeah so they had agreed I could use my private one and I said well educationally	164.	
R	Uh uh	165.	
P2	We know where he is	166.	
R	Uh uh	167.	
P2	I said that's not the problem that's not ya know I'm quite happy	168.	
R	Yeah	169.	
P2	Not to use funds because they were going to pay for us	170.	
R	Right	171.	

P2	I'm quite happy not to use funds to er to er to get and Ed Psych assessment I said so I said this is all wrong this is all wrong what he needs so yeah I rewrote that (laughs)	172.	
R	My goodness yeah	173.	
P2	Yeah I still have it highlighted at home I'll show you it I highlighted what they put in one colour and then highlighted and in italics what the huge bit I wrote (laughs) in a different colour but ya know	174.	
R	(laughs) that's great thanks for that	175.	
P2	What I worry about is what I did that but how many other parents wouldn't do that	176.	
R	Well that's very true how many would just take what they had written	177.	
P2	Exactly its wrong	178.	
R	Yeah	179.	
P2	And the grammar was appalling (laughs) just appalling	180.	
R	Yeah yeah	181.	
P2	I was like oh come on guys put it through a spell checker for God sake	182.	
R	Oh dear that's not a great impression is it	183.	
P2	No not at all	184.	
R	Erm prior to the EHCP more so when you transferred over to the EHCP were you given much information about it what it was why it was changing that sort of thing did you know the code of practice had changed	185.	
P2	I'd done my research yeah no body had told me anything	186.	
R	They didn't give you anything	187.	
P2	No	188.	No information given – professional power?
R	No	189.	
P2	School had said bits and pieces but nothing had come out from the council not even a leaflet	190.	
R	Nothing	191.	
P2	Nothing I don't think we had anything nothing to tell us why or how things were changing it was just the case of ya know we need to transfer this to this	192.	Didn't know CoP was changed
R	Ok yeah	193.	
P2	You get offered the parent partnership	194.	
R	Yeah	195.	
P2	Which is paid for by the council	196.	
R	Yeah	197.	
P2	Or think it's an independent thing	198.	
R	Ok	199.	
P2	But ya know you work in the same building you get paid by the same people you are the same thing	200.	Services offered are all from council
R	Yah ok	201.	
P2	Yeah you're not independent are you you you meet at the coffee machine (laughs)	202.	
R	But yeah what's that's highlighting to me is if you don't know the process or what you or what you should know you could may not know what's happening	203.	
P2	Right that's totally right if you're not confident you may say oh that's nice I'll go to them not realising they are all the same thing Yeah but I'm not a teacher I can't tell them what to do	204.	

R	Ok so we have talked a little about how involved you were with the process when it actually came to the meetings and having everyone round the table was I mean well who was round the table first	205.	
P2	SENCo came, erm his assessment and monitoring officer x came who was lovely don't get me wrong x was she did she she realised that I won't I weren't going to be walked over this wasn't going to be an easy ya know she was helpful	206.	Professional realised parents weren't going to be walked over
R	Yeah yeah	207.	
P2	I was in red on her phone though I swear she use to ignore my calls (laughs)	208.	
R	Really	209.	
P2	Oh yeah like oh god it's her again	210.	
R	Oh dear	211.	
P2	so yeah SENCo, assessment and monitoring, x's social worker I think we're on number 4 now (laughs)	212.	
R	(laughs) oh	213.	
P2	Yeah since then because he urm because he urm he gets direct payments so he has a social worker	214.	
R	Right I see	215.	
P2	Yeah so that's why we have a social worker I mean why x has a social worker she's not mine	216.	
R	Ok yeah	217.	
P2	Charming social worker really (laughs)	218.	
R	Ok yeah mmm	219.	
P2	Me obviously	220.	
R	You mentioned there were no physical issues so I assume that means there was no one from the health side involved	221.	
P2	No no and we didn't get offered anyone from the health side no	222.	
R	Right	223.	
P2	He's still under Dr x urm as the paediatrician	224.	
R	Right yeah	225.	
P2	That's literally going to change	226.	
R	Yeah	227.	
P2	We've got a very much ya know if you need to ring me ring me relationship	228.	
R	Yeah	229.	
P2	Ya know	230.	
R	Yeah	231.	
P2	Ya know we don't go for meetings urm x was under CAMHS but there was only so much they could do and I'm obviously not going to have x medicated for ya know so but they err they didn't come ... I mean I'm not blowing my own trumpet but I'm a clever confident lady not just a stupid mum as I was made to feel	232.	Confident person
R	Huh huh	233.	
P2	Who else was there	234.	
R	Mmm	235.	
P2	X's LA came	236.	
R	Yeah	237.	
P2	Yeah his keyworker came erm	238.	
R	Were you given the opportunity to choose who came to the meeting	239.	
P2	No they were just all invited by the school the SENCo invited them but no that was fine I would have said all the social worker that side of it was alright	240.	Parent didn't invite professional's professionals invited professionals

R	Yeah it was alright mmm	241.	
P2	The people who needed to be there were there	242.	
R	Can I ask who led the meetings	243.	
P2	Erm it should have been the SENCO and actually the SENCO she was she did actually lead	244.	Belief senco should lead
R	So the SENCO led	245.	
P2	Yeah SENCO led with me and she was definitely on my side there was no no	246.	
R	Yeah	247.	
P2	No no doubt her looking at me and going what	248.	
R	Yeah	249.	
P2	And also because we were in a different different school in essence because I said there wasn't a school in the area that would be able to meet x needs and ill transport him	250.	
R	Yeah yeah	251.	
P2	So erm they were use to a different process from another school	252.	
R	Yeah	253.	
P2	So the SENCO going what why have they written it for you type of thing	254.	
R	Mmm mmm	255.	
P2	Because the other school doesn't write them for you do you know what I mean	256.	
R	And did you feel in those meetings that you were important did you feel you were central to it	257.	
P2	No no I'm a pain in the backside that's how that's how I feel	258.	Pain in the backside
R	Oh really ok whys that	259.	
P2	In those meetings I'm a pain because I don't go along with what they want if I don't think it right I say no	260.	
R	Ok mmm	261.	
P2	I'm not having that written down about x no	262.	
R	That's interesting that you say they see you as a pain rather than a mother looking out for her son	263.	
P2	Yeah I know I know apparently I'm a pain in their I'm a thorn in their side	264.	Thorn in their side – burden?
R	Because that's how they make you feel	265.	
P2	No that's how that's how yeah that's how they make you feel like	266.	
R	Mmm mmm	267.	
P2	This isn't going to be an easy ride	268.	
R	Mmm	269.	
P2	Obviously I don't care (laughs) No no they know her best don't they I'm just her mum (laughs)	270.	Professional assumptions made
R	Yeah yah	271.	
P2	That thick layer of skin that I've (laughs) that's built	272.	
R	Yeah yeah	273.	
P2	Think what ya like I don't care (laughs)	274.	
R	Right yeah	275.	
P2	I think they are thinking about the time they are thinking about their next meeting almost like we are on a conveyer belt	276.	No time for parents
R	Yeah huh huh	277.	
P2	And they are trying to push us through as quickly as possible	278.	
R	Yeah	279.	
P2	I know other parents feel the same ya know	280.	

R	Ok	281.	
P2	Oh ya know the amount of professionals that don't book a couple of hours in their diary for the meeting social worker was like oh really sorry got to go now	282.	
R	Yeah yeah	283.	23:38
P2	Great thanks for ya know thanks for coming were honoured you could fit us in thanks for being late	284.	Not feeling important Professional agenda
R	Yeah	285.	
P2	That drives me nuts erm and I think I did say that thanks for thanks for coming because I can be a bit sarcastic (laughs)	286.	
R	(laughs) but rightly so it seems they haven't made time to speak about x	287.	
P2	That's right ya know I'm not late and I book in well I always book in half a day out for these meetings so I know there is nothing that is going to come in the way	288.	
R	Yeah	289.	
P2	But yeah it's an interesting one isn't it	290.	
R	Certainly is	291.	
P2	Yeah	292.	
R	So the EHCP well code of practice really suggests that you will be working with lots of different professionals so I suppose what I am trying to understand is how did you find working with lots of professionals from different backgrounds	293.	
P2	Oh yeah they need to tick that box and they need to tick that box	294.	Professional agenda
R	Yeah	295.	
P2	Me personally it doesn't bother me I do it every day at work that's my that's my ya know that's my job to interact with people whether you have a learning disability or whether you are a company director of a large PLC	296.	
R	Huh huh	297.	
P2	And everybody in between	298.	
R	Yeah	299.	
P2	Urm so for me as a person it doesn't bother me who you are or where you're from erm they do as I say I am definitely a thorn	300.	Thorn
R	Mmm	301.	
P2	I am definitely the person they do not want at the table	302.	Negative view of mum
R	Mmm mmm	303.	
P2	I am not going to be conveyer belted I'm not going to be shoved along and ticking boxes that's not how it's going to work in B's world	304.	Rushed, unimportant
R	Yeah	305.	
P2	Ya know and if they've written something wrong	306.	
R	Yeah	307.	
P2	Ya know on x they put he's independent	308.	
R	Mmmm	309.	
P2	I was like he can't even clean his teeth	310.	
R	Mmm mmm	311.	
P2	(laughs) run past me what you mean by independent yeah he can walk from the house to the car doesn't need (laughs) but he's not independent (laughs)	312.	Don't understand her son
R	Well well mmm	313.	
P2	You can't be shocked it happen (laughs)	314.	
R	Well	315.	
P2	As I as I say I have no interest in who they are or where they're from because	316.	
R	Yeah	317.	

P2	They're people doing their their jobs and ya know unfortunately I'm on the other side of the table ya know in these in these reviews urm and I I go into battle mode I'm very much I walk through the door erm thinking I wonder if the boxing gloves are on or off today	318.	Uses negative words Battle
R	Yeah yeah	319.	
P2	And that's really wrong you should ya know you shouldn't it shouldn't be that way erm I can imagine a lot of parents that would erm	320.	
R	(coughs)	321.	
P2	Well in fact I know some parents that are in tears at these review meetings in terms of they come out and they cry they crumble	322.	Parents cry at reviews
R	Mmm mmm	323.	
P2	Because they ya know they are just rail roaded they don't understand and they don't understand the terminology being used	324.	Rail roaded Terminology not understood
R	Mmm yeah	325.	
P2	Erm in my world I'm not allowed to use financial terminology	326.	
R	No	327.	
P2	Ya know my regulators say you are not allowed to do that they say make sure your client understands what you are saying to them in this world it seems it's the complete opposite	328.	
R	right	329.	
P2	let's use as much terminology let's use as many big words as we possibly can to frighten that poor parent so they won't ask questions and then occasionally they get someone like me (laughs)	330.	Poor parent professionals use terminology to frighten
R	Oh right (laughs) but from what you are saying you are very much almost in the minority do you feel that	331.	
P2	Absolutely ya know I'm degree educated ya know I've been very fortunate ya know my parents pushed our education when we were younger because I'm not in that generation of that ya know but I am in the minority	332.	
R	Yeah yeah	333.	
P2	I think though ya know a lot of parents have their own need a lot of the time ya know whether its depression or a learning difficulty themselves ya know or ya know some other mental health issue very much they need care rather than a bit of a battering so someone can tick a box	334.	Parental needs learning disability etc
R	Yeah mmm	335.	
P2	It's almost like because I have a child with SEN I'm seen differently to all other parents in the school whether that's ya know less that other parents or whatever but we are seen differently	336.	
R	In what way	337.	
P2	I've said with x not so much in these later years but when we first started going into these processes I don't have a learning difficult myself don't talk to me about and I've said to people don't talk to me like I'm stupid coz really I'm not (laughs)	338.	Professionals think mum has a learning difficulty
R	Yeah yeah exactly erm	339.	
P2	My daughter said to the educational psychologist she said I have a biomedical science degree from Oxford so please don't ever speak to me as if I'm stupid again and she has that look	340.	
R	Yeah	341.	
P2	She looks at people as if to say what	342.	
R	Huh huh	343.	
P2	Are you for real (laughs)	344.	
R	Well they the professionals shouldn't assume should they	345.	
P2	They think because I'm a mum I'm stupid	346.	
R	And the code of practice is stating quite clearly that parents should be equal to professionals	347.	

P2	Definitely not no no they can't even call me by my name how can I be an equal if they are calling me mum rather than x (laughs)	348.	Can't be equal if they call me mum already playing down the role losing identity
R	Yeah	349.	
P2	Its patronising	350.	
R	Yeah	351.	
P2	Ya not even called not called don't call me mum I'm Mrs X and I am not your mum and I think you'll find you're not mine (laughs)	352.	
R	Yeah (laughs)	353.	
P2	Your behaviour would be very different if you were (laughs)	354.	
R	Yes (laughs) exactly	355.	
P2	Ya see even my daughter who is highly intelligent	356.	
R	Yeah	357.	
P2	Ya know she said well he thought I was stupid didn't he I was like let's not use the word stupid shall we darling (laughs)	358.	
R	Yeah mmm	359.	
P2	Yeah yeah so	360.	
R	So the next sort of question we have kind of answered in terms of your actually I suppose when you are round the table or when you are writing your parental contribution before arm your wishes and desires for x do you feel they are listened to do you feel they are taken on board	361.	
P2	No and I think that it's very much what is out there and what is available to him I think the professionals understand that there isn't anywhere for him there is no there is ya know no half way house between mainstream school and erm post 16 erm and I think they understand that erm but when I'm saying I'm not having him in college for	362.	
R	Mmm	363.	
P2	3 minutes a day I'm not having him in an environment like x college erm that's not the right place for him he's vulnerable	364.	Mum view not listened to professional agenda
R	Yeah	365.	
P2	Yes, he's six foot yes physically he's fine but actually he's about the age of a 10-year-old	366.	
R	Yeah yeah	367.	
P2	Maybe twelve now	368.	
R	Yeah	369.	
P2	Because we are just getting to that really stropky time (laughs)	370.	
R	Oh really (laughs)	371.	
P2	Erm I think there really is ya know maybe more x borough because we just don't have the provision for him no opportunity posts 16 erm	372.	
R	Yeah	373.	
P2	Erm yeah they are looking from it a this is going to cost us a lot of money or there isn't really anywhere for your son we know that you know that	374.	
R	Mmm mmm	375.	
P2	But you're not going to back down and say ok let him go to x college erm so I think there is a lot of erm that erm now and obviously I've not had the experience of ya know parental contribution as such from statements as you know they were very different weren't they	376.	
R	Yes of course yeah	377.	(32:14min)
P2	It's all a new document but I think that is part of it there just isn't provision	378.	New document very different from statements (P1 said they were the same)
R	Mm mmm	379.	

P2	Erm yeah I mean we were lucky we got MLD on from the statement	380.	
R	Yeah	381.	
P2	Erm because my educational psychologist knew she said he's very severely dyslexic but he does fall into the quota of moderate learning difficulties	382.	
R	Yeah	383.	
P2	We need to put it down	384.	
R	Yeah of course	385.	
P2	Or you're going to be ya know	386.	
R	Yeah	387.	
P2	On a real losing battle	388.	Play the game put things on statement otherwise won't get support
R	Yeah yeah it sounds like a game	389.	
P2	It is it certainly is a game we are playing yeah it was a game and that's because she was my private educational psychologist	390.	
R	Yeah	391.	
P2	I bet the borough council ones wouldn't have said	392.	
R	mmm mmm	393.	
P2	It makes you wonder doesn't it the targets they have they have to tick boxes don't they	394.	Professional agenda
R	You seem to feel strongly about that	395.	
P2	Yeah I do they don't care they need to tick their box	396.	
R	Mm mmm	397.	
P2	It's like the one we had from borough said x was manipulative and badly behaved	398.	
R	Oh	399.	
P2	X hasn't got a manipulative bone in his body	400.	Parent disagree with professionals
R	Mmm mmm	401.	
P2	And he he he put that on the report	402.	
R	Right	403.	
P2	Said it stood	404.	
R	Right	405.	
P2	I mean he can read he could read that and what would he he thinks ya know	406.	
R	Yeah	407.	
P2	I mean I protect him my god I protect him ya know some things he knows	408.	
R	Yeah	409.	
P2	Because (pause) you can't protect him from everything	410.	
R	No of course	411.	
P2	I'd love to I'd love to wrap him up in a big bag of cotton wool (laughs)	412.	
R	Yes, mmm	413.	
P2	And protect him from the world but	414.	
R	Yeah yeah	415.	
P2	But you can't can you	416.	
R	No as much as we would like to eh	417.	

P2	Yeah	418.	
R	But it sounds like what you are doing behind the scenes as you were is	419.	
P2	Yeah yeah I'm making sure that road is clear that road is clear for him to be successful	420.	Clearing the path for him
R	Yeah yeah	421.	
P2	Clear as we can possibly have it	422.	
R	Right yeah	423.	
P2	Mmm mmm	424.	
R	So the next question again we have kind of covered it in terms of equal partners that parents should be equal partners	425.	
P2	Yeah	426.	
R	Erm equal with professionals what do you make of that suggestion	427.	
P2	Not at all not at all its impossible	428.	Equal to professionals is impossible
R	Right what makes you say that	429.	
P2	Not in the slightest no nothing has changed for me in terms of the changes in the code of practice no I haven't seen any difference	430.	
R	Ok right	431.	Parent central to process mum made sure
P2	Because I have always been I've always ensured	432.	
R	Mmm	433.	
P2	I'm a central part to it	434.	
R	Mmm	435.	
P2	Err I don't see that they seek my opinion any more	436.	
R	No	437.	
P2	I don't think they look at it and think when they see it ya know our SENCos have been ok	438.	
R	Mmm	439.	
P2	Erm but I do tend to find the council are very much like erm er stand off-ish	440.	
R	Huh huh	441.	
P2	inconvenient	442.	Parent feel inconvenient to council
R	Right	443.	
P2	We are inconvenient how dare I have an opinion on what my son might need	444.	How dare have an opinion on needs
R	Huh huh	445.	
P2	We are interfering with their targets their budgets	446.	Professional agenda
R	Mmm mmm	447.	
P2	How dare I think I know my son better than them	448.	Excellent quote
R	Huh huh	449.	
P2	How dare I read the code of practice and know what my rights are ya know (laughs)	450.	
R	Yeah yeah	451.	
P2	Yep	452.	
R	Yeah	453.	
P2	I know a couple of parents who are like me who will stick up for themselves	454.	Stick up for themselves
R	Yeah	455.	

P2	And we support each other help each other	456.	
R	Yeah support each other yeah	457.	
P2	We fought the closure of x	458.	
R	Oh really did you	459.	
P2	Yeah my friend's daughter went there	460.	
R	Really	461.	
P2	Yeah we went there fought that and literally highlighted their policy	462.	
R	Yeah	463.	
P2	Went through their consultation document	464.	
R	Yeah	465.	
P2	It's now not lawful great	466.	
R	Mmm mmm	467.	
P2	Great I've got you	468.	Mum fighting the system
R	Yeah yeah	469.	
P2	But I shouldn't have to fight I shouldn't have to ya know	470.	Shouldn't have to fight
R	That's right you shouldn't	471.	
P2	But they play on our weakness of what we have	472.	
R	Huh huh	473.	
P2	And ya know we're busy ya know we got a full time job	474.	
R	Yep	475.	
P2	A child with learning difficulties	476.	
R	Yep	477.	
P2	That needs a lot of care	478.	
R	Mmm mmm	479.	
P2	And that's the problem everyone is really busy	480.	
R	Yeah	481.	
P2	And then all of a sudden you've got I can't say to x oh you've got a bit of homework can you get that done	482.	
R	Mmm mmm	483.	
P2	Like with x I could say to her oh darling go and get that homework done and she would go and do it and ill check it great ya know do you think that sounds right ya know	484.	
R	Yeah yeah	485.	
P2	None of that with x	486.	
R	Mmm mmm	487.	
P2	I have to physically sit with him	488.	
R	Yeah	489.	
P2	And do it with him and talk him through it ya know almost be his LA	490.	
R	Mmm mmm	491.	
P2	Ya know because he can't do it on his own	492.	
R	Yeah mmm	493.	
P2	And erm you add that into the mix and you've got and then you've got and then you add into the mix that I can't just nip to Tesco's and leave x at home	494.	
R	Yeah	495.	

P2	Like I would a normal seventeen-year-old	496.	
R	Yeah	497.	
P2	And I use normal in the the same bracket as I would class my daughter	498.	
R	Yeah yeah	499.	
P2	Ya know I'm going to Tesco do you want anything	500.	
R	Yeah yeah	501.	
P2	You can't do it so all of a sudden I've got this other stuff going on in the mix and it makes you wonder how as parent we are meant to cope in every ya know everyday life	502.	Too much to do with EHCP and look after a disabled child and be mum
R	Yeah	503.	
P2	Let a/one lead professional meetings and take a lead and tell them how to do their jobs ya know	504.	
R	Yeah yeah	505.	
P2	Its unrealistic great in theory	506.	Great in theory
R	Huh huh	507.	
P2	X is capable he is capable of learning ya know no one is incapable of learning	508.	
R	No your right	509.	
P2	And that's what I did when they said to me when he was five he will never read or write I said watch me	510.	
R	Well yeah	511.	
P2	Watch me he will learn to read and write but ya know other parents may have gone oh ok and not bother	512.	Professional power
R	Yeah yeah	513.	
P2	And ya know we use to go to the beach he loves the beach I hate sand (laughs)	514.	
R	(laughs)	515.	
P2	But he loved the beach and ya know know my parents were involved and we would write in the sand and ya know we've always read I mean I've always read to the kids since they were little	516.	
R	Mm mmm	517.	
P2	And we would read and we would read	518.	
R	Huh huh	519.	
P2	And the amount of floppy (laughs)	520.	
R	(laughs)	521.	
P2	You know mummy you've not turn the page oh sorry haven't I as I tried not to fall asleep (laughs)	522.	
R	(laughs)	523.	
P2	That's because mummy wants to sleep (laughs)	524.	
R	Yeah yeah that's right	525.	
P2	But ya know you keep going and going and going and the repetitiveness	526.	
R	Yeah	527.	
P2	Because they can learn and in fact a girl that was in erm when I first had been said his swimming teacher	528.	
R	Mmm mmm	529.	
P2	Worked for X	530.	
R	Mmm mmm	531.	
P2	I said I've just been told he'll never learn to read or write and he's got no ability to learn because I did get told that	532.	Professional power
R	Right	533.	
P2	By a teacher once he's got no ability to learn	534.	

R	Mmm	535.	
P2	I took a sharp intake of breath at that point and left the room	536.	
R	Yeah yeah	537.	
P2	Of course he has the ability to learn he's he's look at him he's swimming look he swimming up and down	538.	Professionals power not just classroom no ability to learn
R	Mmm mmm	539.	
P2	He's swimming up and down no he's not got the ability to learn rubbish	540.	
R	Mmm mmm	541.	
P2	So er well yeah incredible but	542.	
R	Well that's the word isn't it incredible	543.	
P2	Yeah it is incredible that someone could say something so cruel	544.	39:06
R	Yeah yeah	545.	
P2	I always use to by football comics because x is really into football and ya know let's get a football comic and read together ya know he would read the back of the newspaper the sport because the fact it was football	546.	
R	Yeah yeah	547.	
P2	The school said I don't care within reason (laughs) what he reads as long as he reads ya know	548.	
R	Yeah as long as he's reading something	549.	
P2	But yeah we use to do it with comics and match attack cards ya know anything	550.	
R	Yeah	551.	
P2	Git hundreds of them damn things (laughs)	552.	
R	(laughs) Right again we've kind of spoken about this already but the relationship with professionals some of them you have got on with some of them you haven't	553.	
P2	No I don't find I'm good friends with the council	554.	
R	Yeah	555.	
P2	I've had a couple of social workers that have I've got on really really well with they've got it they've got x	556.	
R	Mmm mmm	557.	
P2	Erm I've had well x had they're not my social workers probably had five now who definitely not got x	558.	
R	mmm	559.	
P2	Like I said x at assessment and monitoring like I said we had a er we had a working relationship	560.	Working relationship implies some professional could be more personal friendly?
R	Yeah yeah	561.	
P2	Ya know I'm sure she would go home and say to her husband just pour me a glass of red wine that bloody woman	562.	Burden?
R	(laughs)	563.	
P2	Erm but we had a working relationship	564.	
R	Yeah	565.	
P2	Erm x medical professionals like his paediatrician CAMHS professor x absolutely great but erm ya know found them	566.	
R	Did you ever have them come to the meetings	567.	
P2	No not really this was prior to the EHCP you could never get them involved in the meetings anyway not sure who from health could get involved with x case really	568.	Health not involved
R	Right ok	569.	
P2	Yeah the medical professionals were very good with x but they were never involved with the EHCP no	570.	

R	Yeah	571.	
P2	But ya know I kind of understand it as there is very little they can do in terms of support for him because he does suffer with anxiety very anxious erm but I don't want him medicated	572.	No health involved doesn't want him medicated
R	Yeah yeah	573.	
P2	I want to protect him from behind the scenes so he just goes to school like everybody else ya know	574.	
R	Huh huh	575.	
P2	Although they did send a letter though the other day a letter came from the borough council addressed to x to talk to him about his EHCP review	576.	
R	Oh right	577.	
P2	Yeah it's because he's over 16 but I called them and said he's a minor what are you doing you've posted this to x and in fact they put in it contact us if you haven't received the paperwork so I did because we hadn't received the paper work and also I said I said oh or should I say sorry x hasn't received the paperwork I was like what's all this about fortunately I work from home so I can get the letter before him because	578.	Professionals assumptions
R	Yeah	579.	
P2	Because he'd read it a wouldn't understand which would probably make him really anxious ya know	580.	
R	Yeah yeah	581.	
P2	Not individualised at all someone should have read his file and known that he wouldn't have been able to understand the content of the letter not just work on the fact he is now 17	582.	Not treated as an individual
R	Huh huh	583.	
P2	I know they are treating them like an adult but that's not right he can't understand ya know but mentally he's much younger than that but yeah the letters are now going to x	584.	
R	Yeah	585.	
P2	It's like ridiculous	586.	
R	Huh huh	587.	
P2	Ya know and I did say to them post it to whoever you like coz I'll be opening it	588.	
R	Yeah	589.	
P2	I said that's not a battle I'm going to fight not a battle I'm willing to take on I thought ya know this is ridiculous	590.	45:43
R	Yeah	591.	
P2	He has severe dyslexia how do they think he is going to read it anyway a joke huh a joke they didn't get him	592.	
R	Yeah yeah	593.	
P2	Which then would have made him anxious	594.	
R	Yeah	595.	
P2	So actually what they did could have had a massive impact on him	596.	
R	Yeah yeah	597.	
P2	Ya know I talk to other parents ya know we all talk and everyone has the same experience everyone	598.	
R	Oh ok yeah	599.	
P2	Ya know they they don't realise we talk	600.	
R	Mmm mmm	601.	
P2	Everyone experiences the same	602.	All parents experience the same 'them and us'
R	Yeah	603.	
P2	Its them and us	604.	

R	Ok so do you feel that you needed any support from anywhere else or feel there was anything you needed that you didn't get that would have been useful	605.	
P2	I think what would have been very useful for them to have sent out some basic documentation around the changes	606.	
R	Mmm	607.	
P2	So something that is understood by all erm with signpost of where people can go	608.	
R	Yeah	609.	
P2	Erm	610.	
R	Yeah	611.	
P2	Ya know because we are fortunate in x that we have a lot of charities that would help out and will support people	612.	
R	Huh huh	613.	
P2	Erm you kind of stumble across them almost its only when you talk to another parent who has a child with an additional need that you find out about these places and people	614.	
R	Right	615.	
P2	Ya know I certainly didn't know or ya know realise that any of these existed	616.	
R	Well yeah	617.	
P2	Because ya know I thought well I don't need financial support so	618.	Don't access support as don't need financial support
R	Yeah yeah	619.	
P2	So they're not for me kind of thing	620.	
R	Yeah	621.	
P2	There is a support agency that helps with the parental contribution called x they come out and help the parent	622.	
R	Ok	623.	
P2	Because you get such a small bit to write in	624.	
R	Yeah	625.	
P2	Parents don't realise how important their contribution is	626.	Parents don't realise they are important to the process
R	Yeah	627.	
P2	Well they give you a little box as well	628.	
R	Yeah	629.	
P2	It's kind of implying that they just want a full bullet points	630.	Small box on form implies your part isn't important
R	Right	631.	
P2	And ya know unless you like read it and go well that's not big enough for me to write what I need to write in then you start writing on the back page and add more and more pages to it	632.	
R	Huh huh	633.	
P2	Because you wouldn't necessarily know very much ya know	634.	
R	Yeah you would realise you could write more	635.	
P2	Ya know you'd probably get three or four lines in if you write small	636.	
R	Mmm	637.	
P2	Erm but its its yeah its erm not friendly	638.	Form not user friendly
R	Yeah	639.	
P2	It's not user friendly	640.	
R	Huh huh yeah	641.	

P2	And obviously there is a fine line between scaring people and getting the required amount of information but	642.	
R	Yeah	643.	
P2	You can't help but think they are working against you from the start ya know	644.	Working against from the start
R	Mmm mmm	645.	
P2	And ya know I'm going to assume they have read his file ya know	646.	
R	Yeah yeah	647.	
P2	Ya know I make that assumption that I don't need to take with me my file or write absolutely everything down in the form	648.	Unclear about amount of info assume they have read his file Personal
R	Yeah yeah	649.	
P2	Ya know I don't want to bring out the files from when he was five ya know	650.	
R	Well no	651.	
P2	But unfortunately they don't	652.	
R	Huh huh	653.	
P2	Ya know and erm they should ya know I would never go to a client looking at an old file and looking at that ya know	654.	Other professionals would know the client first
R	No no	655.	
P2	Especially from a year ago things change	656.	
R	They certainly do	657.	
P2	It's just so important for them to get it wrong time and time again I can do it in my job	658.	Professional expectation
R	Yeah	659.	
P2	They have their own targets don't they how much money they have how many they need to agree how many to turn down ya know	660.	Professional agenda
R	Mmm mmm	661.	
P2	And with manipulate without a doubt there's all of that going on and	662.	
R	Mmm mmm	663.	
P2	I understand they've got budget constraints ya know I get that but	664.	
R	Mmm mmm	665.	
P2	But that's not x fault	666.	
R	No	667.	
P2	(laughs) ya know but how many other parents are sat there going oh ok that's that then I just write a little bit	668.	
R	Mmm yeah	669.	
P2	There's a little tiny box so no its not friendly	670.	
R	No	671.	
P2	No it's not a friendly process at all	672.	No a friendly process
R	Mmm mmm	673.	
P2	I mean I can't remember the actual wording on that part but I am wondering if the language they use may even imply ya know don't write too much ya know but ya know I can't remember but I'm going to dig it out when I get home	674.	
R	Mmm mmm yeah	675.	
P2	But ya know psychologically regardless of what the words say	676.	
R	Mmm mmm	677.	

P2	If you've got a small box people will fill to that box	678.	
R	Huh huh	679.	
P2	Because psychologically you would look at it and think I've only got this small bit and other boxes on a page to put all my stuff on	680.	
R	Yeah	681.	
P2	Yeah and ya know it's it's a wordy document	682.	
R	Mmm mmm	683.	
P2	And possibly many parents aren't use to filling out forms	684.	Parents ability to fill out forms need to treat each parent individually to meet their needs to fine line / balance between patronising and supporting
R	Mmm mmm	685.	
P2	It may not be something people do on a daily basis	686.	
R	Mmm	687.	
P2	Or would assume that if you wrote something like often tired would mean he isn't going to sleep until 3am every night because he's not sleeping ya know the parent may assume professionals know that he's on melatonin and this is a really big issue but may not elaborate further	688.	
R	Huh huh	689.	
P2	Or by putting down the name of medication ya know that risperidone would assume they have anxiety which is actually his autism ya know there is a lot of assuming professionals know what you are talking about	690.	
R	Yeah yeah	691.	
P2	Or they assume you are not putting him to bed early enough and therefore you are blamed as a parent its hard	692.	Blame on parent
R	Yeah yeah	693.	
P2	But yeah I suppose it's something to get use to eh (laughs)	694.	
R	(laughs)	695.	
P2	Huh huh	696.	
R	Ok so just finally has there been any particularly positive about the process or indeed a barrier to you engaging with this process	697.	
P2	Well really x is doing really well that's a huge positive	698.	
R	Yeah of course yes	699.	
P2	Well yeah I mean x is doing well despite the process	700.	X doing well despite the process
R	Despite the process	701.	
P2	Yeah it's not the process that he he ya know he's done particularly well	702.	
R	Mmm mmm	703.	
P2	Ya know he's doing well because well because we help him to do well	704.	
R	Yeah	705.	Doing well because of parent
P2	Erm I think having the document all in one so education is there	706.	
R	Yeah	707.	
P2	Care is there erm health wise erm he he's there in terms of the anxiety and things and having it all in one is useful erm	708.	
R	Yeah	709.	
P2	Erm ya know it's probably going to be a useful tool in terms of when we transfer into adulthood and through to adult services	710.	

R	Yeah yeah	711.	
P2	Because ya know they can't argue because they have written it	712.	They can't argue as they have written it
R	Yeah yeah yeah	713.	
P2	Ya know a member of the council has written this and signed it off	714.	
R	Mmm mmm	715.	
P2	So they can't all of a sudden argue like that it was a paediatrician who's not recognised by them	716.	
R	Mmm mmm	717.	
P2	Because that irritates me	718.	
R	Mmm	719.	
P2	That ya know they don't recognise other paediatrician they want their paediatrician	720.	
R	Yeah yeah	721.	
P2	Ridiculous	722.	
R	Mmm mmm	723.	
P2	That yeah so I think that's definitely that's all in the one place erm	724.	
R	yeah	725.	
P2	Negative wise I think having it pre written it took me many hours to re write it and it went backwards and forwards backwards and forward backwards and forwards	726.	
R	yeah	727.	
P2	And I kept saying you haven't changed this bit	728.	Parents' wishes not heard document not changed
R	yeah	729.	
P2	But I was like no this has got to come out no	730.	
R	Mmm mmm	731.	
P2	You have to remove it erm I means its fortunate I work for myself	732.	
R	yeah	733.	
P2	(laughs) if I'd worked in a shop or whatever	734.	
R	yeah	735.	
P2	That would have been done at three o'clock in the morning	736.	
R	Yeah	737.	
P2	And it wouldn't have had my full attention how could have	738.	
R	Mmm mmm	739.	
P2	One time I was on a train a a a erm a close family friend past a way in France	740.	
R	Oh dear	741.	
P2	Yeah and erm I was on a train doing it on the way to Gatwick on a plane out to Toulouse and I'm re-writing this and ya know and that was about twelve months ago I was doing that	742.	Re-writing the document challenging the professionals
R	yeah	743.	
P2	You shouldn't have to	744.	
R	right	745.	
P2	It was a nightmare	746.	
R	Mmm mmm	747.	

P2	If you had read it and then looked at x and then read it again and looked back at x and gone you'd be like are you talking about the same kid	748.	EHCP was not an accurate description of the child
R	Huh huh	749.	
P2	Because it wasn't recognisable nothing was recognisable	750.	
R	Huh huh is there anything else you want to add	751.	
P2	No no I don't think so please get in touch or ping me an email if you need any more for your research	752.	
R	That's very kind thank you for spending some time with me.	753.	

Appendix 7: IPA Themes

Barriers to parental involvement	Participant and line	Parental position	Participant and line	Professional power	Participant and line
Misunderstood	P1.34, 132, 138, P2. 135, 189, 308, 312, 367, 448*, 578, 592, 596 P3.36, P3.46 P4. 364, 410	Confidence	P1.156, 166, 180, 206 P3.218, 228	Fight/battle	P1. 220 P2. 69, 96*, 510, 534, 541 P3.50, 70, 78, 176, 194 P4. 63, 136, 188, 320, 486, 510
Lack of parent's voice	P1. 150 P2. 118, P4. 122, 256	Loss of identity	P2. 112, 352 P3.156, 290, 180, 314 P4. 64, 114, 560	Unfriendly process	P2. 672 P3.60, 172, 290, 308, 90, 188
Felt rushed / unimportant	P2. 279, 304, 408 P3.136	Got on their nerves/pain in neck	P1. 188 P2.208, 258	Professionals perceived as expert	P1.78, 264, 274, 288, 322, 102, 236, 354, 240 P2. 324, 394, 446, 660 P3.270 P4. 31, 200, 276, 310, 318
Lack of trust in professionals / useless	P1. 158, 182, 254, 266, 344, 300, 306 P2.222, 240, 330, 164 P3.384, 398 P4. 328, 469	Patronised	P2.48 P3. 60, 246, 270, 84, 232, 264, 270 P4. 254	Unequal relationships	P1. 318, 320, 356 P2.428, 502, 560, 680 P4. 333
Lack of communication	P1. 210, 212	Subordinate	P1. 228, 258, 270, 320	Them 'v' us	P2.155 P3.110, 206
				Negative profession behaviour	P1. 122, 148 P3. 66,96

Appendix 8: IPA Theme Flow Chart

