



"It's the Fear of the Unknown":

An Exploration of Parents' Experiences of Early  
Education Transition for Children with Special  
Educational Needs

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Doctorate in Applied Educational Psychology

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## Dedications

*This thesis is dedicated to:*

*My parents, for always telling me I could,  
My sister, for always telling me I should,  
And my husband, for always telling me I would.*

*Thank you*

## **Acknowledgements**

Special thanks go to the parent co-researchers Caroline, Emma and Fay. Without your determination to improve education for children with special educational needs, and your passion for this project, none of this would have been possible. Your voices are truly inspirational and it was a privilege to work alongside you.

Thanks go to Wilma Barrow for your insights during this research and for introducing me to the power of dialogue. Thanks also go to Dave Lumsdon, Richard Parker and Billy Peters who all, in different ways, encouraged and supported me during this research.

Finally, thanks go to my fellow TEPs for bringing me laughter, perspective and a sense of community during the DAppEdPsy, and also to my closest friends, who offered me unwavering support throughout.

Thank you

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## Overarching Abstract

The transition into early education is recognised as an important milestone for children and their parents and a successful transition is reported to impact positively on a child's future social and educational outcomes. Whilst early education transitions are recognised as potentially challenging for all parents, literature suggests they may be particularly complex for parents of children with Special Educational Needs (SEN). This thesis aims to explore parents' experiences of the transition to early education for their children with SEN across three chapters: a qualitative literature review, a piece of empirical research and a bridging document. The bridging document connects the literature review and the empirical research and offers commentary on my philosophical position, methodological decisions and ethical considerations.

The qualitative literature review asks: What is known about parents' experiences of early education transition for children with SEN? Using meta-ethnography, seven qualitative papers are reviewed and synthesised to create a model of parent experience. The meta-ethnography suggests that power is central to how a parent will experience the transition process for their child with SEN, which will subsequently impact on a parent's emotions, important relationships with others and level of certainty.

The central theme of power that emerges from the meta-ethnography suggests that parents of children with SEN often feel excluded from the transition process by professionals. In an effort to disrupt traditional parent-professional relationships, a participatory action research framework is adopted with three parents of children with SEN in the North East of England. This empirical research explores a more specific aspect of the transition process, focusing on the parents' experiences of choosing a primary school. Data is co-constructed with the co-researchers over a six-month period and is underpinned by Bakhtinian dialogue and a narrative approach to create a rich understanding of parent experience. The dialogic interactions and the data generated then culminate in the production of individual short narratives of the parents' experience of choosing a primary school for their child with SEN.

The short narratives are coded and analysed using inductive thematic analysis and the themes constructed suggest that, whilst each individual experience is unique, the process can be overwhelming and lonely and requires significant parent effort and determination. However, the narratives suggest that this difficult process can be mediated by supportive relationships and life experience. This paper concludes that the process appears to be a stressful experience and local authorities may wish to consider how networks of group support, with Educational Psychologists well positioned to facilitate, could enhance the process of choosing a primary school for parents of children with SEN.

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# **Chapter 1. What is Known About Parents' Experiences of Early Education Transition for Children with Special Educational Needs?**

## **1.1 Abstract**

*The transition into early education is recognised as an important milestone for children and their parents and a successful transition is reported to impact positively on a child's future social and educational outcomes. Whilst early education transitions are recognised as potentially challenging for all parents, literature suggests they may be particularly complex for parents of children with Special Educational Needs (SEN).*

*This chapter offers a review of qualitative literature in the form of a meta-ethnography and asks: What is known about parents' experiences of early education transition for children with SEN? Seven qualitative papers are reviewed and synthesised to create a model of parent experience of early education transition for children with SEN. The meta-ethnography suggests that power is central to how a parent will experience the transition process for their child with SEN, which will subsequently impact on a parent's emotions, important relationships with others and levels of certainty.*

*The findings of this qualitative literature review offer a unique perspective on existing research and are therefore open to alternative interpretations. Nonetheless, it is concluded that, the balance of parent/professional power appears to have a significant influence on parents' ability to actively participate in their child's transition. It is anticipated that the model of parent experience proposed will stimulate consideration for educational professionals when seeking to work effectively in partnership with parents during early education transitions.*

## **1.2 Introduction**

Early education transitions (EET) are recognised as important milestones in a child's life (Eckert et al., 2008; McIntyre, Blacher, & Baker, 2006; Podvey, Hinojosa, & Koenig, 2010). In England, children aged three and four are entitled to pre-school education, after which they typically transition to the reception stage of primary school. This initial stage of education, between pre-school and the end of reception,

is considered the Early Years Foundation Stage (EYFS) (DfE, 2017). However, due to increases in pre-school opportunities, starting primary school is often not a child's first educational transition (Dunlop, 2017; Dunlop & Fabian, 2007a). Thus, whilst beginning school is recognised as a major event, it is also important to acknowledge earlier transitions, for example, the transition from home to pre-school (O'Farrelly & Hennessy, 2014). As such, young children between the ages of 2 and 5 may make a number of significant transitions during their early years of education (Harper, 2016). The focus of this qualitative literature review (QLR) is to explore parents' experiences of EETs when their child has special educational needs (SEN). In order to do so, I will first explore research and theory in the broad area of EET and then focus more specifically on EETs for children with SEN.

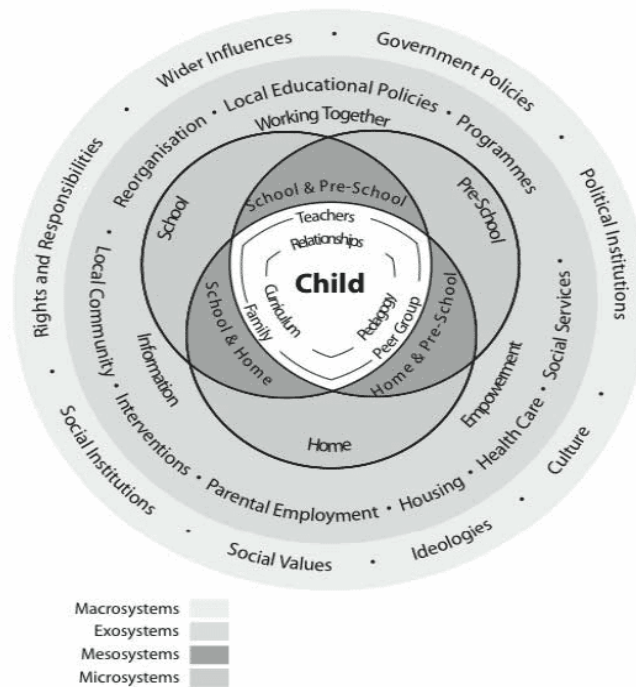
### ***1.2.1 Understanding early education transition***

Whilst there is no universally accepted definition (Dunlop, 2014) educational transition is broadly considered to be the change from one phase of education to the next (Dunlop & Fabian, 2007b; Harper, 2016; Yeboah, 2002). However, beyond this basic conceptualisation, educational transition is considered to be a socially constructed concept that is situated in a child's culture and their community (Corsaro, Molinary, & Rosier, 2002; De Gioia, 2017; Shields, 2009). Whilst attention to educational transition is considered a predominantly Western priority (Einarsdóttir, 2011; Yeboah, 2002), it is beginning to emerge as an increasingly important concept in African and Asian cultures (Kinhead-Clark, 2015; Margetts & Phatudi, 2013).

Educational transition is considered an important milestone in a child's life (Graue & Reineke, 2014; Shields, 2009), which is collaboratively constructed by and shared with those associated with the child. Educational transition is therefore often understood through the lens of ecological systems theory (Bronfenbrenner, 1977; Dockett & Perry, 2004; Dunlop, 2014; Dunlop & Fabian, 2007a; Einarsdóttir, 2014), as detailed in Figure 1. Researchers adopting an ecological perspective on educational transition (Dockett & Perry, 2004; Dunlop, 2014; Dunlop & Fabian, 2007b; Einarsdóttir, 2014) argue that children's transition experiences are inextricably linked to their social environments and are influenced by the reciprocal interplay between different systemic levels (Bronfenbrenner, 1977). When applied to educational transitions, ecological systems theory (op cit) highlights the dynamic

interplay of systems influencing a child's experience in their previous setting (home or pre-school) and the changes induced by a transition to a new microsystem (pre-school or reception class), where activities, roles and relationships are different.

**Figure 1. Transition as an Ecological System**



Whilst recognising the contribution of ecological system theory (Bronfenbrenner, 1977), educational transition literature suggests some limitations. Vogler, Crivello, and Woodhead (2008) argue that the margins of each of the sub-systems are more fluid than Bronfenbrenner (1977) suggests. Furthermore, Corsaro et al. (2002) and Vogler et al. (2008) critique Bronfenbrenner's assumption that a child is always positioned at the centre of the microsystem as it potentially neglects alternative priorities of families and professionals. Alternative theoretical perspectives put forward with regard to educational transitions include the use of Rite of Passage Theory (Corsaro et al., 2002; Van Genneep, 1960) and Border Theory (Hartley, Rogers, Smith, Peters, & Carr, 2012).

### **1.2.2 Supporting Positive Early Education Transitions**

Literature recognises that EET experiences can affect a child's future outcomes (Dunlop & Fabian, 2007b; Einarsdottir, 2011; Margetts, 2002). Experiencing a positive EET is reported to promote good social and educational outcomes, enhance

social and economic equality and promote emotional wellbeing (Dockett, Petriwskyj, & Perry, 2014; Dunlop & Fabian, 2007b; Margetts, 2009). A positive EET can be optimised by familiarising a child with their new phase before it begins: supporting them to adjust to their new relationships, activities and roles; promoting a sense of belonging; and encouraging parents to engage collaboratively with professionals to support this change (Dockett et al., 2014; Dunlop, 2003; Dunlop & Fabian, 2007b).

Considering transition from an ecological perspective highlights the interaction amongst the different systems in a child's life and recognises the influence of each of the systems involved in the transition process (Einarsdóttir, Perry, & Dockett, 2008). The home environment and consequently a child's parent(s)<sup>1</sup> are considered important in a child's educational transition. There is an emphasis in literature and policy about the importance of parental participation to promote educational success (Desforges & Abouchaar, 2003; Goodall & Montgomery, 2014; LaRocque, Kleiman, & Darling, 2011) and facilitate positive EETs (Department for Education (DfE), 2017; Dockett, Perry, & Kearney, 2011; Dunlop & Fabian, 2007b; Landmark, Roberts, & Zhang, 2013).

A child does not experience transition in isolation as transitions are rooted in the social context of school and home (Dunlop, 2003; Podvey et al., 2010; Skouteris, Watson, & Lum, 2012). Transition is recognised as a period of possible uncertainty for a child as they acclimatise to the new relationships, roles, activities and approaches in the new setting (Dunlop & Fabian, 2007b; Kennedy, Cameron, & Greene, 2012) and parents are often considered to be consistent figures during an EET (Dunlop, 2003; Einarsdóttir, 2014). However, a child's EET prompts changes for a whole family (Podvey et al., 2010) and transition is therefore recognised as a time of possible challenge for parents too (Shields, 2009), as they negotiate their changing roles and relationships and understand new approaches within the new setting.

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<sup>1</sup> It is acknowledged that 'parent' is a broad concept, and the use of the term will reflect any adult who has a primary care responsibility for a child.

### **1.2.3 Early Education Transition for Children with SEN**

Whilst transition to school is recognised as a potentially challenging process for children and families, it is suggested that it can be particularly complex for parents of children with SEN (Dockett et al., 2011; Hutchinson et al., 2014; Janus, Kopechanski, Cameron, & Hughes, 2008; Mawdsley & Hauser-Cram, 2013; Starr, Martini, & Kuo, 2016).

It is important at this stage to explicitly acknowledge and discuss the use of the term SEN here. The expression entered into education discourse in England in 1981 following the Warnock report (1979). It was originally intended as a broad concept that would transform thinking from the multiple deficit-oriented categories of disability towards a more holistic understanding of an individual child and the provision they require in order to learn. In the current context, SEN remains a dominant concept in education. The current legal Government definition can be found in Box 1.

#### **Box 1. The Current Government Definition of SEN**

The SEN Code of Practice (2014, p. 15) states that a child has SEN:

- 1. if they have a learning difficulty which calls for special educational provision to be made for them;*
- 2. if they have significantly greater difficulty in learning than the majority of children of the same age; or*
- 3. if they have a disability which prevents or hinders them from making use of educational facilities of a kind generally provided for children of the same age in schools within the area of the local education authority.*

Despite continued use of the term, SEN is increasingly considered a problematic and contested concept (Norwich, 2016; Runswick - Cole & Hodge, 2009). Whilst originally intended as a transformative term, proponents of a social model of disability argue that SEN perpetuates deficit-oriented thinking and fails to account for the contextual factors that may act as barriers to a child's learning (Thomas & Loxley, 2007). It could be argued that, by labeling certain children as 'special' and in 'need',



the current Government definition reinforces within-child discourse (Tomlinson, 2017) and has created a 'deficit super-category' for certain children in English schools (Norwich, 2016, p. 7).

Whilst acknowledging the contested nature of the term, SEN is nonetheless a dominant aspect of education discourse. Language has the power to construct experience (Foucault, 1980) and the language of SEN continues to influence the lives of children and their families. Whilst seeking to avoid essentialist conceptualisations, the term SEN is used in this paper to refer to children experiencing barriers to learning who require additional support. However, the term is considered problematic and it is hoped the alternative theoretical positions briefly discussed might encourage other considerations surrounding the term.

#### **1.2.4 Listening to Parents**

Since parents of children with SEN are acknowledged to experience more complex challenges during school transition, it is important to explore in depth their perspectives on EET. However, it appears that their voices are often lost in transition literature (Mawdsley & Hauser-Cram, 2013; Starr et al., 2016) and these parents may be subsequently subject to normative policy and education discourse (Cottle & Alexander, 2014). This meta-ethnography was conducted from a social constructionist perspective, with social reality considered a subjective concept, created through language (Burr, 2006; Moore, 2005). This meta-ethnography offers an interpretation of the selected studies and makes no claim to discover the truth (Noblit & Hare, 1988). Therefore, the purpose of this investigation is not to present an understanding of parents of children with SEN as a homogenous group but rather to give voice to their diverse expressions and construct a perspective on their experiences to better understand EET.

#### **1.3 Method**

The research question for review was: *What is known about parents' experiences of early education transition for children with Special Educational Needs?* Atkins et al. (2008) consider that the focus of qualitative research is to understand how others view their social world. Subsequently, qualitative studies were considered essential for this review given the research focus on parent experience. In order to effectively

review the qualitative research, an appropriate method of qualitative synthesis was sought. Noblit and Hare (1988) consider meta-ethnography to be an interpretivist method of comparing and analysing qualitative studies to create a new understanding on a topic. Meta-ethnography is considered a well-established method of qualitative synthesis (Britten et al., 2002) and appeared well aligned with the research objective. Noblit and Hare (1988) propose seven interrelating stages to meta-ethnography (Box 2). In this piece, stages one to five are applied as a framework to communicate the method, with stages six to seven applied to the findings.

***Box 2. Seven Stages of Meta-Ethnography***

<b>Meta-Ethnography Stages</b>
1. Getting Started
2. Deciding What is Relevant
3. Reading the Studies
4. Deciding How they are Related
5. Translating the Studies into One Another
6. Synthesising the Translation
7. Expressing the Synthesis

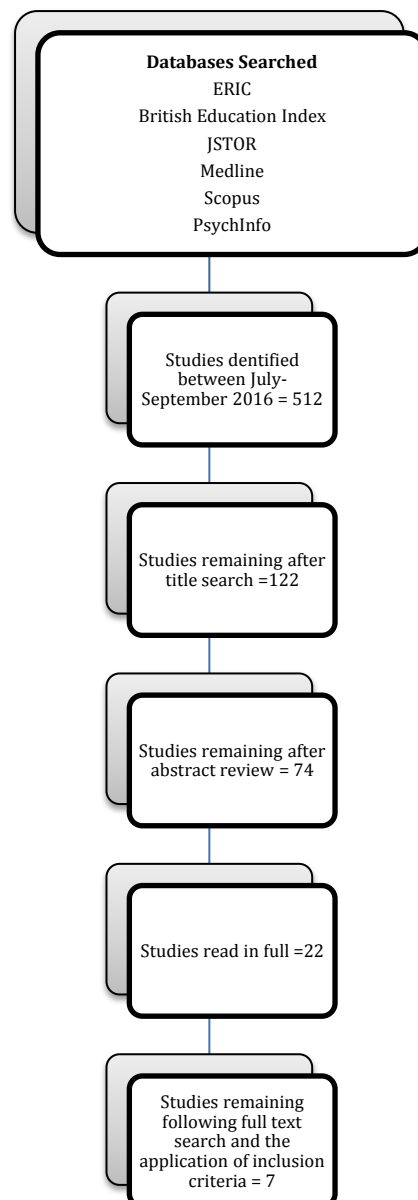
***1.3.1 Getting Started and Deciding what is Relevant***

To source studies appropriate for a meta-ethnography, Noblit and Hare (1988) suggest a focused and detailed search is undertaken relevant to the topic area; a method also endorsed by other qualitative researchers (Britten et al., 2002). To assess the range of studies available, a comprehensive search was conducted between July and September 2016. Six databases were examined including: ERIC, British Education Index, JSTOR, Medline, Scopus and PsychInfo. Whilst a number of search combinations were initially trialled, the final search criteria included the terms:

- 'special education\* need\*'
- 'transition\*' and
- 'parent\* or family'.

This initial search resulted in 512 studies. A title search was conducted to refine the studies and those deemed irrelevant to the topic area were excluded, leaving 122 papers. At this stage, a set of inclusion criteria was constructed as way of setting boundaries for the review and further refining the papers. Initially, it was anticipated that the studies would be UK specific, but it became clear that there was a very limited number of studies meeting the criteria. Subsequently, by extending the search beyond the UK, 74 abstracts were reviewed, and 22 papers were read in full. This consolidated the inclusion criteria as detailed in Table 1. The final set of inclusion criteria was applied to the 22 studies, with 7 deemed suitable for synthesis.

*Figure 2. The Literature Search Process*



**Table 1. Inclusion Criteria**

<b>Inclusion Criteria</b>	<b>Why?</b>
Related to parents' experiences of early education transition when their children have SEN	<i>In line with the research question</i>
Written in English	<i>To allow ease of access to the text</i>
Published 2004 or later	<i>To fit with a modern conceptualisation of SEN, school transition and parent participation following Every Child Matters (UK) and the IDEA Improvement Act (USA)</i>
Empirical design and qualitative methodology	<i>Suitable for meta-ethnography</i>
Parents of children with a broad range of SENs	<i>To ensure the inclusion of diverse parent experience of SEN in each of the studies</i>
Diverse parental roles, including studies with extended family members and foster parents caring for a child	<i>To ensure the inclusion of diverse parent voices</i>
Published (peer reviewed) or Doctoral Level Research	<i>Quality assurance</i>

### **1.3.2 Reading the Studies and Deciding How They are Related**

The seven papers were then read in-depth and information regarding demographics, participants, setting, method and theoretical perspectives were recorded (Table 2). To identify key concepts, the papers were read again, and details were noted for each. Included in these key concepts were the original excerpts from the participants of each paper, considered to be first order constructs. Schutz (1962) asserts that the perspectives of the original researcher are also considered data and are second order constructs. It is important to acknowledge that the first order constructs have thus been chosen then interpreted twice; once by the original researcher and again in this meta-ethnography (Atkins et al., 2008). Therefore, this process was not considered a perfect representation of the original data, but instead a collective interpretation of the findings presented in the studies. However, in line with a social constructionist epistemological position, this meta-ethnography makes no claims to

discover the truth, but instead offers only a unique perspective on previous research on the topic.

This stage constituted the initial mapping process, which subsequently supported the identification of commonalities across the seven papers, and the construction of interrelated themes. Through a process of aggregation, the recurring concepts that appeared were put together, translating the seven papers into one another to create themes (Noblit & Hare, 1988). Whilst a number of concepts arose, only those identified across two or more of the papers were taken forward as themes. It is recognised that whilst this may disregard some of the perspectives included in the studies, it was a pragmatic decision in order to manage a number of seemingly minimal constructs in the papers.

**Table 2. Demographic Information**

<b>Study</b>	<b>Type</b>	<b>Sample</b>	<b>Setting</b>	<b>Method</b>	<b>Theoretical Framework</b>
Dockett, Perry & Kearney (2011)	Published research study	24 parents (23 mothers, 1 grandfather)	Australia (New South Wales)	Conversational interviews	No pre-supposed theoretical perspective (grounded theory applied)
Hutchinson, Pyle, Villeneuve, Dods, Dalton & Minnes (2014)	Published research study	3 parents (all mothers)	Canada	Interviews	Conceptual Framework of Self-Advocacy (CFSA) (Test et al, 2005)
Podvey, Hinojosa & Koenig (2010)	Published research study	7 parents (5 mothers, 2 fathers)	USA (New Jersey)	Semi-structured interviews	No pre-supposed theoretical perspective (grounded theory applied)
Rae-Brown (2011)	Doctoral thesis	9 families (no specific information on total number of parents or their gender or status)	USA	Observations, semi-structured interviews and document analysis	No pre-supposed theoretical perspective (grounded theory applied)

<b>Study</b>	<b>Type</b>	<b>Sample</b>	<b>Setting</b>	<b>Method</b>	<b>Theoretical Framework</b>
Russell (2005)	Published research study	19 parents (no information on parent gender or status)	UK (England)	Semi-structured interviews	Ecological Systems Theory (Bronfenbrenner's, 1977)
Spencer-Brown (2015)	Doctoral thesis	20 parents (no information on parent gender or status)	USA (California)	Semi-structured interviews	No pre-supposed theoretical perspective
Villeneuve, Chatenoud, Hutchinson, Minnes, Perry, Dionne, Frankel, Isaac, Loh, Versnel & Weiss (2013)	Published research study	3 parents (2 mothers, 1 aunt)	Canada (Ontario)	Interviews and observations	No pre-supposed theoretical perspective

## 1.4 Findings

### 1.4.1 Translating the Studies Into Each Other & Synthesising the Translation

By collating the interrelated concepts and themes (Britten et al., 2002; Noblit & Hare, 1988), I began the process of 'reciprocal translation' (Noblit & Hare, 1988, p. 38). This mapping process (Appendix A) allowed me to identify the key constructs from all the papers and highlight the broader themes under which the constructs could be categorised. Wherever possible, the first order constructs of original data were recorded to maintain the voices of the participants (Britten et al., 2002). This mapping process was iterative, and a number of amendments were made throughout this stage in order to reflect my understanding of the first and second order constructs from the seven papers. By aggregating the constructs and creating themes, links were constructed, and the studies appeared to correspond and complement each other. The themes constructed from the studies are presented in Box 3.

#### **Box 3. Constructed Themes**

##### **Constructed Themes**

1. Challenges communicating with professionals
2. Feeling like an outsider
3. Being an advocate
4. Unfamiliarity with SEN processes
5. Concern for the future
6. Positive emotions
7. Unwelcome emotions
8. Supportive relationships
9. Developing trust with professionals

The reciprocal translation resulted in my personal interpretation of the first and second order construct themes. By reviewing the constructed themes, it was possible to synthesise my understanding of the studies as a whole and create a line of argument towards answering: *What is known about parents' experiences of early education transition for children with SEN?* The process of theme>interpretation>synthesis is detailed in Table 3.



**Table 3. Meta-ethnography Themes, Interpretation and Synthesis**

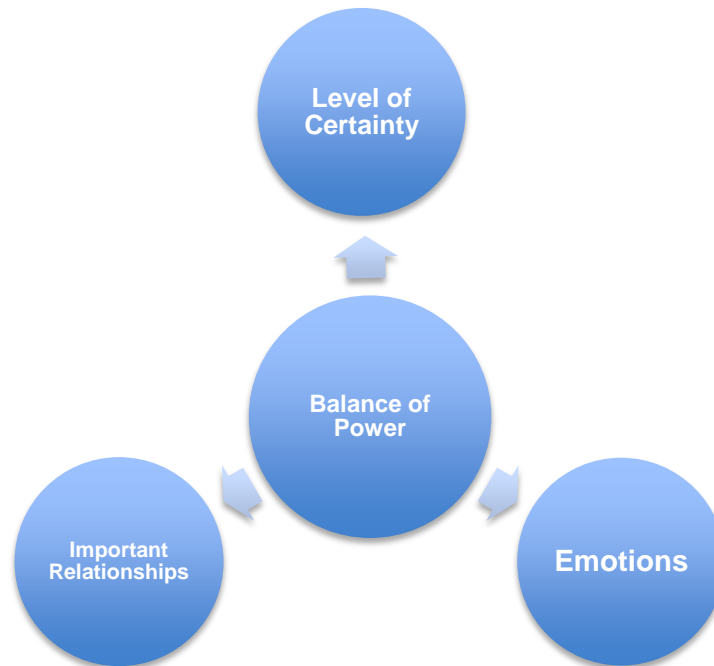
Theme	Interpretation	Synthesis
Challenges communicating with professionals	<p>Many parents experienced challenges communicating effectively with professionals during EET. Parents reported having to “prompt” professionals to respond, “fight” to make an appointment and struggled to be included in decision-making. Parents who experienced challenges communicating with professionals appeared to feel “excluded”, “frustrated” “disappointed” or dissatisfied during their child’s transition.</p>	<p><b><i>The Balance of Power</i></b></p>
Feeling like an outsider	<p>It appeared that parents’ voices were often positioned as less important than that of professionals. Parents experienced feeling “outside” when they were excluded from meetings, “left out” and “dismissed” by professionals, particularly when their perspectives were ignored. This left parents feeling “hurt”, excluded and unappreciated.</p>	
Being an advocate	<p>The parents believed they had important perspectives to share during the EET. However, it appeared that in order to have their perspectives heard by professionals, they needed to act as an “advocate”. This included extending their understanding of their child’s needs, “fighting” to be heard, pushing for information and garnering the support of influential figures. Advocating in this way was reportedly uncomfortable for some parents but was regarded as essential by most in order to participate in the EET.</p>	

Theme	Interpretation	Synthesis
Unfamiliarity with SEN processes	The parents appeared unfamiliar with the language, expectations and roles of the SEN system and this left them ill-equipped to participate in the EET. Parents were often required to self-educate on this process as professionals “assumed” they already knew. This unfamiliarity was considered “overwhelming” and left parents feeling uncertain as to their role in the EET.	<b><i>Level of Certainty</i></b>
Concern for the future	Parents appeared to experience a concern for the future during the EET. It seems their concerns centred on what provision and resources were available and what their role will be post-transition. This concern manifests in feelings of uncertainty.	
Positive emotions	Parents appeared to experience some positive emotions during their child’s transition including “excitement” and cheerful anticipation. A positive sense of “relief” was regularly experienced across a number of the studies, particularly when a child’s needs were recognised by professionals, when the EET was less troublesome than anticipated, and when parents felt included by professionals and the desired resources were secured.	<b><i>Emotion</i></b>
Unwelcome emotions	Across all the studies, parents appeared to experience unwelcome emotions such as anxiety and fear during the EET with regard to resource allocation. These unwelcome emotions appeared to intensify when parents felt “judged” or were perceived as “difficult” during their interactions with professionals or when they believed they had to “fight” to be included in the EET.	

Theme	Interpretation	Synthesis
Supportive relationships	During EET, parents experienced the benefits of supportive relationships for acquiring advice, emotional containment and backing. Often family, friends and parent support networks provided this support. These supportive relationships appeared to be particularly important at times of difficulty and they helped equip parents to participate in their child's EET.	<b><i>Important Relationships</i></b>
Building trust with professionals	Some parents experienced the benefits of building a trusting relationship with EET professionals. These relationships appeared to ease the process of EET for the parents, making it easier for them to participate in partnership with professionals.	

### 1.4.2 Expressing the Synthesis

Noblit and Hare (1988) acknowledge that the boundaries of each meta-ethnography stage are fluid, which can result in a degree of overlap. Whilst Table 3 represents the synthesis, Figure 3 further elucidates the line of argument in a visual form.



**Figure 3. A model of parents' experiences of early education transition**

Central to parents' experiences of EET is the balance of power between professionals and parents. The overarching concept of 'the balance of power' was synthesized from three sub themes, which included: challenges communicating with professionals; feeling like an outsider and being an advocate.

It appeared that the parents' experiences of the transition process were often characterised by an awareness of the power of professionals. For example, in Spencer-Brown (2015), one parent shared of her experience of difficulties communicating with professionals, stating, "I feel slightly dismissed regarding my child's issues. I need more one on one from his paediatrician and his transition team".

In addition, parents also appeared to experience a sense that they were outside of the transition, with professionals inside the transition and in control of the process. For example, in Russell (2005) one parent stated “It’s as though I’m not going to have a say in her education. Its all been mapped out for her without my consent.”

However, the qualitative studies also suggested that professional control over the transition process could be adjusted through the process of advocacy. In order to redress the balance of power between themselves and professionals, the parents engaged in the process of advocacy. For example, a parent in Rae-Brown (2011) stated, “I decided that I needed to take a look at this, and I need to research this and I need to be her advocate”.

Thus, the qualitative studies suggested that power was initially often weighted to professionals during the transition process. This made it difficult for parents to communicate with professionals and left parents feeling like outsiders. By adopting the role of advocate for their child, some parents were able to acquire the knowledge and access to their child’s transition team in order to have their voices heard.

Whilst the balance of power is a key parent experience, it also has an impact on parents’ perceived level of certainty, their emotions and the need for important relationships. The discussion explores this line of argument in greater depth, with reference to wider literature where relevant.

## **1.5 Discussion**

### ***1.5.1 The Balance of Power***

Key to my line of argument is that the balance of parent/professional power is central to parents’ experiences of early education transition. In six of the studies, parents reported challenges when communicating with professionals during their child’s transition, often feeling ignored and dismissed. The communication challenges experienced by parents appeared to result in sense of exclusion from the EET, despite their reported desire to actively participate with professionals in the process. This finding is consistent with

research by Tso and Strnadová (2017), who found that teachers often dismiss parents during times of transition.

Parent participation with schools is linked to positive education outcomes (Desforges & Abouchaar, 2003; Goodall & Montgomery, 2014; LaRocque et al., 2011), is a key quality indicator in the EYFS (DfE, 2017) and is recognised as an essential aspect of a positive transition to school (DfE, 2017; Dockett et al., 2011; Dunlop & Fabian, 2007b; Landmark et al., 2013). Parent participation is acknowledged as a complex term and may also be referred to as parent engagement, involvement and partnership. Whilst it is beyond the scope of this piece to provide an in-depth discussion (for more information, see Blackmore & Hutchison, 2010; Crozier & Reay, 2005; Hodge & Runswick - Cole, 2008; Hujala, Turja, Gaspar, Veisson, & Waniganayake, 2009; O'Connor, 2008), parent participation is considered to be a mutual relationship of respect between parents and professionals, which engenders shared expertise and collaboration towards positive outcomes for a child (Hodge & Runswick - Cole, 2008; O'Connor, 2008).

However, whilst educational research and policy may promote parent participation as good practice (DfE, 2014; OFSTED, 2010), the process involves a myriad of complex relationships and dynamics, which some have argued are oversimplified in policy and education discourse (Blackmore & Hutchison, 2010). Research suggests that schools might hold pre-defined, homogenised ideas of parent involvement, guided by normative discourses in education (Cottle & Alexander, 2014; Crozier, 2000; Fernández & López, 2017). However, parents of children with SEN have been found to have wide-ranging experiences that can be different from standardised assumptions of parent experience (Hodge & Runswick - Cole, 2008), and which may not sit comfortably alongside normative constructions of parent participation.

Akin to the parents' experience of early education transition, the balance of power has also previously been identified as a fundamental aspect of parent participation in literature (Hodge & Runswick - Cole, 2008; Todd, 2007; Trainor, 2010). From a Foucauldian perspective, power is seen to be present in every aspect of social life and acts not only to oppress but also to produce 'pleasure, forms of knowledge and

discourse' (Foucault, 1980, p. 119). Foucault (1991) argues that the intrinsic connection between knowledge and power legitimises established institutions, such as schools, to exert influence over others. Foucault asserts this institutional power, defined as governmentality, is maintained and reinforced through professional discourse, which determines rules, roles and expectations in a specific context (Fairclough, 2001). Power that is afforded to education professionals may be bound within the assumption of 'some kind of exclusive expertise' (Shumway, 1989, p. 161).

Established education discourse has been found to act as a powerful force, guiding schools' boundaries of parental participation and what constitutes the 'ideal' parent (Dahlstedt, 2009; Lai & Vadeboncoeur, 2013). Ranson, Martin, and Vincent (2004) suggest that schools may employ narrow criteria, guided by implicit structures that reinforce professional expertise and parental reverence, to determine the 'ideal parent'. Nakagawa (2000, p. 456) elucidates on this idea, stating: 'the good parent is constructed as one who takes the lead of the school, who is involved but not too involved, and who supports but does not challenge'.

In six of the studies (Dockett et al., 2011; Hutchinson et al., 2014; Podvey et al., 2010; Russell, 2005; Spencer-Brown, 2015; Villeneuve et al., 2013), it could be argued that the parents' requests for communication went beyond schools' implicitly constructed boundaries of accepted parent participation. Potentially deemed 'too involved' (Nakagawa, 2000, p. 456), it would appear that professionals may have exercised their institutional power (Foucault, 1980) by dismissing and silencing parents in order to maintain a status quo of professional control.

Dale (1996, p. 7) argues that, when engaging with parents, schools may adopt a 'professional as expert model', whereby teachers hold decision-making power and parents are afforded a pre-defined and limited role. It is acknowledged that professionals work within a context, which is bounded by policy and guidelines, which may limit the possibilities for power sharing (Hodge & Runswick - Cole, 2008). However, this approach appears antithetical to the principles of collaboration for parent partnership (O'Connor, 2008).

Interestingly, two of the papers (Russell, 2005; Spencer-Brown, 2015) contain parent reports of positive communication with professionals. Whilst this finding was thematically minimal, it appeared that good communication garnered a trusting relationship between the parents and certain professionals. In these instances, power appeared to be shared and parents felt their voices were valued during the transition process, ultimately supporting the parents' participation. This finding will be discussed in more detail in section 1.5.4.

In six of the studies (Dockett et al., 2011; Hutchinson et al., 2014; Podvey et al., 2010; Russell, 2005; Spencer-Brown, 2015; Villeneuve et al., 2013), when parents were invited to participate in their child's EET, their voices were often positioned as less valuable than the voices of professionals, ultimately leaving parents believing they were "outsiders". Runswick - Cole (2007) argues that, despite a parent's specialist knowledge about their child, professional knowledge is often privileged above that of a parent and parents are assumed to be unreliable. It seems a number of parents in the studies experienced this power imbalance, which often left them feeling excluded from participating in their child's EET.

Foucault asserts, 'where there is power, there is resistance' (1978, p. 95). In all seven studies, parents appeared to respond to a perceived imbalance of professional/parent power by adopting an advocacy role. In three studies, the term advocate was explicitly discussed (Hutchinson et al., 2014; Rae-Brown, 2011; Spencer-Brown, 2015) and, in four studies, parents or researchers alluded to the concept (Dockett et al., 2011; Podvey et al., 2010; Russell, 2005; Villeneuve et al., 2013). Whilst it is acknowledged that parent advocacy for children with SEN is a complex term (for a more detailed discussion, please see Trainor, 2010), the term is broadly defined as an empowerment and support process, which facilitates families of children with SEN to air their perspectives and potential grievances to develop solutions for their child (Wright & Taylor, 2014). Prior literature recognises the established role of advocacy for parents of children with SEN in order to secure suitable educational provision and opportunities (Bacon & Causton-Theoharis, 2013; Burke & Hodapp, 2016; Hess, Molina, & Kozleski, 2006; Trainor, 2010) and advocacy is recognised as a form of parent participation (Trainor, 2010).



In response to feeling excluded from participating, or silenced by professionals, the parents acted in resistance to redress the perceived power imbalance by speaking out, marshaling the support of influential community members and developing their expertise around their child's needs. Parent advocacy as an act of institutional power resistance is consistent with previous literature (Bacon & Causton-Theoharis, 2013; Burke & Hodapp, 2016; Trainor, 2010). However, advocacy was not always a welcomed method of participation for parents. A report in Hutchinson et al. (2014) states that a parent was required to advocate beyond what she was comfortable with to secure resources for her child. This is consistent with previous research by Leiter and Wyngaarden Krauss (2004).

It is also important to acknowledge that parental advocacy may require social capital. Influenced by Putnam (1995), Bagley and Ackerley (2006, p. 718) define social capital as: 'the form of resources such as trust, norms and reciprocity... as something which families and communities can be introduced to, helped to develop and subsequently draw on individually and collectively to positive effect'. Not all parents possess the social capital to advocate, which may potentially result in further inequalities in parents' abilities to participate in the EET process.

Thus, the balance of power appears to be central to parents' experiences during their child's EET. It seems that, due to their institutional associations (Foucault, 1980), professionals often held power and exercised it during EET. This resulted in parents experiencing difficulty communicating with professionals and feeling excluded from participating in the process. As an act of resistance, parents adopted an advocacy role as an alternative way to have their voices heard and thus participate in their child's EET.

### ***1.5.2 Level of Certainty***

Across six of the seven studies, parents appeared to feel unfamiliar with the SEN [processes with which they were engaging](#), leaving them ill-equipped to effectively participate in their child's EET. In Rae-Brown (2011), parents discussed their confusion surrounding the EET process, which subsequently led to feelings of anxiety. In Dockett et al. (2011), different advice from different professionals left parents feeling confused as

to how to move forward. It would appear that parents were left to educate themselves on SEN processes as their child's EET progressed (Rae-Brown, 2011). Parents suggested that professionals sometimes assumed they already understood SEN procedures (Russell, 2005) and therefore made little effort to enhance the parents' knowledge (Dockett et al., 2011; Hutchinson et al., 2014). A lack of information and confusion regarding transition information led to parents experiencing uncertainty about the process of their child's EET, ultimately appearing to limit the extent of their participation.

Furthermore, in three of the seven studies, parents reported experiencing uncertainty due to their concern for the future. In particular, parents appeared concerned regarding what resources and provision would be maintained or provided for their child in their new educational setting given that professionals were unable to make any assurances (Dockett et al., 2011; Spencer-Brown, 2015). Reports in Russell (2005) reflected parents' uncertainty as to what their role would be in their child's future, particularly when professionals took a leading role during the transition process.

Thus, in six of the seven studies, the balance of power appeared to impact on the parents' level of certainty, particularly when parents were uncertain of SEN processes, uncertain of the provision available for their child in the future and uncertain of their future role in their child's education. Parent partnership literature would suggest that, in order for parents to effectively participate, professionals are required to account for the individual needs of parents and make adjustments (Goodall & Montgomery, 2014; Hodge & Runswick - Cole, 2008). It appears that professionals may not have recognised the parents' need for information regarding SEN processes and provision decisions, and neglected to consider the importance of explaining potential roles to the parents. It could be argued that, by failing to recognise the parents' needs, professionals left parents in a position of uncertainty, ultimately limiting their capacity to participate in their child's EET.

### **1.5.3 Emotion**

In three of the seven studies (Dockett et al., 2011; Rae-Brown, 2011; Spencer-Brown, 2015), parents reported feeling a sense of positive emotion with regard to their child's transition. Some of the quotes reflected parents' positive emotions of excitement at the prospect of school for their child (Rae-Brown, 2011) and also reflected a sense of cheerful anticipation whereby responsibility for their child's learning was to be shared by others (Dockett et al., 2011). Whilst these findings were thematically minimal, they do appear to reflect existing literature relating to the experiences of most parents at times of EET (Dockett et al., 2014).

However, the majority of the quotes relating to positive emotion appeared to centre on the experience of relief (Dockett et al., 2011; Rae-Brown, 2011; Spencer-Brown, 2015). It appeared a sense of relief stemmed from the allocation of, what parents considered to be, appropriate resources and services. Relief was also reported when parents believed they were included as part of the transition team and when the EET was less troublesome than anticipated. Whilst the feeling of relief was constructed as a positive emotion, relief appeared to be a secondary emotional experience that stemmed from the initial unwelcome emotions of anxiety and fear.

The unwelcome emotions of anxiety and fear were reportedly experienced in all seven studies (Dockett et al., 2011; Hutchinson et al., 2014; Podvey et al., 2010; Rae-Brown, 2011; Russell, 2005; Spencer-Brown, 2015; Villeneuve et al., 2013). Parents of children with SEN have been shown to experience heightened anxieties and stress during EET due to the additional needs of their children (McIntyre, Eckert, Fiese, Reed & Wildenger, 2010; Starr et al., 2016). Excerpts from the seven qualitative studies reflected feelings of heightened anxiety, which related to SEN specific concerns such as resource allocation, provision and support. In particular, experiences of anxiety and fear appeared predominantly linked to parents' interactions with professionals, including waiting for their decisions (Dockett et al., 2011), feeling judged by professionals (Spencer-Brown, 2015), believing they were labelled as difficult by professionals (Hutchinson et al., 2014) or feeling overwhelmed by professional interactions (Dockett et al., 2011; Hutchinson et al., 2014; Podvey et al., 2010).

Thus, whilst parents of children with SEN appeared to experience the expected mixed emotions of any parent during EET (Dockett et al., 2014), they also appeared to experience an additional layer of unwelcome emotions, such as anxiety and fear, which were closely linked to professional power. Indeed, reportedly positive experiences of relief also appeared secondary to parents' initial feelings of distress. Ultimately, both positive and unwelcome emotions appeared dependent on the balance of power and the manner in which decision-making and parent participation was exercised during an EET.

#### ***1.5.4 Important Relationships***

In response to the balance of power, level of certainty and emotion, parents reported that important relationships were essential during their child's EET. In five studies (Dockett et al., 2011; Hutchinson et al., 2014; Podvey et al., 2010; Rae-Brown, 2011; Spencer-Brown, 2015) support from others was recognised as a crucial aspect of the EET. Often parents received support from their family and friends (Dockett et al., 2011; Hutchinson et al., 2014; Podvey et al., 2010), which included advice at times of difficulty or backing to prompt action from professionals and gain information. Four studies included experiences of accessing parent support networks for emotional support from other parents or for information gathering purposes (Dockett et al., 2011; Hutchinson et al., 2014; Rae-Brown, 2011; Spencer-Brown, 2015). It appeared that parents garnered support from family, friends and parent networks to adequately develop the knowledge and skills to actively participate in their child's transition.

Furthermore, in four studies, parents reported their experiences of developing a positive relationship with a trusted professional, which supported them to participate in their child's EET (Hutchinson et al., 2014; Podvey et al., 2010; Russell, 2005; Spencer-Brown, 2015). In Spencer-Brown (2015), a parent reported that a professional team made the SEN jargon more accessible and ensured that she was comfortable asking questions. In Russell (2005), a parent described her experience of spending time in her child's new classroom, which helped her to develop trust with the school team. It would appear that professionals in these instances recognised the needs of the parents, adjusted their support and gained the parents' trust. Ultimately, these power-sharing acts supported the parents' capacity to participate in their child's EET. However, again

parents' social capital appeared to be vital to their engagement in important relationships. They drew on 'trust, norms and reciprocity... to positive effect' (Bagley & Ackerley, 2006, p. 718) allowing them to actively participate in the EET.

Thus, the balance of power appeared to have a bearing on parents' experiences of important relationships. The studies suggested that support from family, friends and parent support networks were important when parents felt excluded from the EET process and they required advice and support to access information in order for them to participate. In contrast, when professionals acted to distribute power (such as making jargon more accessible, or inviting parents into the school environment), the trusting relationships that evolved supported effective parent/professional participation. This is consistent with research by Woodcock Ross and Tregaskis (2008) who, when investigating diverse parent experiences, found that augmented communication strategies can promote the inclusion of parents in professional discussions.

Furthermore, Hodge and Runswick - Cole (2008) found that professionals who are open and welcome parents' expertise often foster collaborative practice between parents and professionals.

## **1.6 Conclusions**

### ***1.6.1 Overview***

Mawdsley and Hauser-Cram (2013) suggest that little is known regarding parents' experiences of EET for children with SEN. Consequently, this small-scale QLR has proposed a model that reflects a new way to understand their experiences. At the centre of parents' experiences appeared to be the balance of power, with parent participation dependant on how this power was exercised by professionals, and with parents often needing to act as an advocate to prompt their participation in the EET. When power was imbalanced, parents experienced feelings of uncertainty about the EET process and their role with their child post transition. Parents also experienced a range of emotions during their child's transition; some positive and some unwelcome. In particular, a sense of relief was experienced when the EET professionals allocated the desired resources, when the parents felt included in the process and when the transition was less

troublesome than anticipated. However, anxiety and fear were regularly reported parent emotions and were predominantly linked to difficult professional interactions that limited parent participation. Finally, important relationships with others appeared crucial in response to the balance of power during an EET. Parents built trust with professionals when professionals acted to share power, which subsequently promoted participation in the EET. However, when parents experienced difficulties interacting with professionals, they appeared to rely on their important relationships with family, friends and influential figures.

### **1.6.2 Implications**

These findings have potential implications for research and practice. They contribute to a small body of existing research that explores parents' experiences of EET. The balance of parent/professional power appears to have a significant influence on parents' capacity to actively participate in their child's EET, and it is anticipated that the model proposed might stimulate consideration for educational professionals when seeking to work more effectively in partnership with parents. In particular, the findings of this QLR have the potential to influence the practice of Educational Psychologists, who are well positioned to query assumed educational discourse and practice and promote effective professional partnerships between multiple stakeholders during EET.

In addition, this qualitative review has highlighted an apparent gap in research literature. Whilst little attention has been paid to parents' experiences of EET, there appears to be **limited** research that explicitly investigates parents' experiences of choosing a primary school for their child with SEN. Further exploration in this area may highlight how parents could be effectively supported by Educational Psychologists and educational professionals when selecting a primary school for their child with SEN.

## **Chapter 2. Bridging Document**

### **2.1 Introduction**

Here I intend to bridge the findings of the qualitative literature review (QLR) from Chapter 1 with the empirical research in Chapter 3. Many decisions made throughout this research arose from my own philosophical perspectives and the values I espouse as a researcher-practitioner. Therefore, Chapter 2 is an opportunity to reflect on my philosophical position and justify the decisions I made during this research.

### **2.2 Personal Experience and Motivation**

My interest in school choice was initially underpinned by my experience of the Scottish education system. Having qualified as a primary school teacher in 2010, I taught in various school provisions including mainstream schools, enhanced resource bases and a specialist charity school. In these roles, I was responsible for teaching children considered to have Additional Support Needs (a Scottish term: known as Special Educational Needs (SEN) in England).

In 2015, I relocated to England where I sensed a difference with regard to how the education system approached the schooling of children considered to have SEN. In particular, I perceived a higher number of special schools. It appeared that children with SEN, whom would be taught in a mainstream school in Scotland, were often considered better placed in a special school in England. This approach was new, and I was keen to understand the underpinning rationale behind the different approaches.

My tentative understanding was initially developed through my professional practice as a Trainee Educational Psychologist (TEP). I noticed that I would often have discussions with parents of children with SEN who were experiencing difficulties during their child's early education transition (EET), particularly with regard to selecting a primary school. Often, parents would be making a difficult decision, having to choose between a mainstream and specialist primary school, and I observed them struggle to make this choice. Listening to their reasoning further developed my understanding of the English

school system, which subsequently propelled my interest in parents' experiences of EET, and more specifically, in their experiences of primary school choice for children with SEN.

### **2.3 Bridging Literature and Empirical Research**

The empirical research offered in Chapter 3 is considered to enrich the findings of the QLR in Chapter 1 in two ways. Firstly, whilst the QLR focused broadly on parents' experiences of EET, the empirical research focused on the specific aspect of primary school choice during EET. There appeared to be little research that examined the parental experience of choosing a school and no literature that focused entirely on this at the primary stage, highlighting a clear gap in existing research.

Secondly, the findings of the QLR suggested that parents of children with SEN felt excluded from the EET process due to an imbalance of power with professionals. Parents reported feeling like an "outsider" and this finding strongly resonated with me as a researcher-practitioner. The QLR brought to my awareness the potential risk that my empirical research design could potentially perpetuate parents' experiences of feeling excluded by professionals. As a way to contest the perceived exclusion of parents within the QLR, I was keen to offer a more democratic and equitable way to prioritise parents' voices and engender a parent-professional partnership during the empirical research (Stoudt, Fox, & Fine, 2012).

My search for a more democratic and equitable method for research drew me to participatory action research (PAR). PAR offered a methodological approach to facilitating a parent-professional partnership by disrupting the assumption that parents are "outsiders" by bringing them inside this research project (Kemmis, McTaggart, & Nixon, 2014). Therefore, the central theme of parent-professional power constructed in the QLR acted as a catalyst that inspired the adoption of a PAR framework.



## **2.4 Empirical Research Purposes**

It is important at this stage to explicitly set out the three distinct purposes of the empirical research. Firstly, in response to a gap in the existing literature, the empirical research sought to generate an in-depth understanding of how parents experience choosing a primary school for a child with SEN. Secondly, in response to the power imbalance constructed in the QLR, the empirical research sought to disrupt assumptions regarding traditional parent-professional relationships by adopting a PAR methodological approach. Finally, the local authority (LA) in which the research took place underwent a review of school provision for children with SEN. This research was therefore ideally placed to contribute towards this LA review of school provision.

## **2.5 Philosophical Perspectives**

My own philosophical position is central to this thesis. I approached this research from a postmodern ontological perspective, remaining critical of the scientific notion of objectivity (Robson & McCartan, 2016) and the foundational assumption that reality exists 'independently of our knowledge of it' (Grix, 2010, p. 62). Instead, understanding the world from a relational perspective, I recognised the influence of socio-political contexts in the construction of local truths (Kvale, 1995) that constitute multiple realities (Creswell, 2013). To coherently reflect my philosophical footings, I selected interpretivist approaches for both the QLR and the empirical research. However, the specific nature of my postmodern perspective has evolved throughout this research project.

Initially, I approached this research from a social constructionist epistemological position whereby I accepted the contribution of history, culture and language in the construction of human understanding and experience (Burr, 2006; Willig, 2013). Social constructionism emphasises that knowledge is dependent on social interaction and relationships, and that human experience is an entirely social process (Gergen, 2009). Subsequently, social constructionism rejects any form of inner self (Salgado & Hermans, 2005), and selfhood is understood to be multiple and varied, changing as a person's social contexts change (Gergen, 1991).

However, on reflection, I noticed that I was uncomfortable with social constructionism's understanding of self. By entirely rejecting any form of inner self, I believe social constructionism denies humans their subjective inner experience (Salgado & Hermans, 2005). It was imperative to me that the empirical study acknowledged and reflected the parents' inner subjective experiences of choosing a primary school. As such, I sought a less radical postmodern epistemological view that remained critical of foundational knowledge, and recognised the influence of social experience, but also acknowledged a human inner self that has private experiences (Salgado & Hermans, 2005). A dialogic epistemology offered an alternative to radical social constructionism, whilst remaining consistent with my relational ontology.

A dialogic epistemology is acknowledged as a complex concept to define given the many traditions that make different assumptions (Marková, 2003; Marková, Linell, Grossen, & Salazar Orvig, 2007). Nonetheless, Linell (2007, p. 2) offers a broad theoretical definition of dialogism as the combination of 'interaction, context and linguistic-communicative construction' for making meaning. Whilst researching dialogism, the specifics of Bakhtin's perspective resonated strongly with me. Bakhtin (1986) suggests that knowledge is co-constructed through language and social interaction but also states 'any utterance, whether spoken or written, that people use in communication with each other is *internally* dialogic'. Bakhtin's dialogic perspective offers an epistemological position that recognises the influence of language and interaction, but importantly, acknowledges the importance of inner self in the construction of knowledge (Salgado & Clegg, 2011).

This was important during the PAR project as it offered a way to understand how the "big stories" and the short narratives were constructed through dialogue as influenced by language, context and interaction, but also remained reflective of the subjective inner experiences of the individual parents. Linell (2009, p. 6) argues that, 'interaction with a cognitive artefact, such as a printed text, is a dialogical activity'. With this in mind, the transcribed personal narratives in this project were considered utterances. These utterances stimulated further discussion, new interactions, and inter-subjective co-construction (Jones, 2017), which created an understanding of parents' experiences of choosing a primary school for their child with SEN.

### **2.5.1 Rejecting Monologue and Embedding Dialogue**

When considering how dialogue was embedded in this research, it is important to consider how monologic discourses were rejected. Bakhtin (1986) considers monologue to be a form of discourse that is constructed when singular truths are universally accepted and there is no space for diverse ways to understand the world. Sampson (2008) considers monologue to be an authoritative force that can shape human experience and identity. Monologue has the power to silence the perspectives of those that differ from standardised assumptions and are constructed as other (op cit). I support Sampson's (2008) argument that human experience and identity can be moulded by authoritative contextual discourses, and that subsequently power is often ascribed in this way.

In order to embed dialogue, it was vital that the co-researchers and I worked to deconstruct monologic discourse during the empirical research, particularly surrounding questions of the "right" choice of primary school. This process of rejecting monologue was captured in my research journal:

*"Today, Fay was discussing why parents 'must' give their child with SEN a chance at a mainstream as she believes this gives them a chance at a "normal" life.*

*I could see Caroline was uncomfortable with Fay's perspective and I felt myself about to offer a way to bypass potential confrontation by changing the subject, but I stopped. It felt like Fay's assumption about what is "right" opened up a channel for dialogue and an opportunity for the co-researchers to acknowledge 'the other' and we all discussed this perspective further.*

*After our session, Fay pulled me aside and said, 'I've never thought of special education like that before. Caroline opened my eyes today'."*

This journal excerpt demonstrates how monologic discourse initially moulded Fay's assumption that there exists a "right" and a "wrong" school choice. By problematising and deconstructing discourse like this, the co-researchers and I shared moments where we rejected monologue and, through dialogue, constructed other ways of being and

knowing. Dialogic moments like these contributed towards the disruption of assumptions and facilitated co-researcher participation.

## **2.6 Methodological Decisions**

The knowledge constructed in this research was understood via Bakhtinian dialogic epistemology, whereby reality, knowledge and meaning were subjectively constructed as influenced by language, the socio-cultural context and social negotiation (Linell, 2007; Salgado & Clegg, 2011). To remain consistent with my philosophical position and in order to interpret the co-researchers' subjective experience of choosing a primary school, I adopted a qualitative methodology (Ponterotto, 2005). Qualitative methods aim to understand the meaning that humans ascribe to their personal experiences (MacDonald, 2012) and therefore appeared appropriate for generating an in-depth understanding of parents' experiences of choosing a primary school for their child with SEN. In addition, the empirical research sought to disrupt assumptions regarding traditional parent-professional relationships. It was therefore important that I selected a qualitative methodology that was flexible and supported the inclusion of diverse voices towards rejecting monologue and creating dialogue (Salgado & Clegg, 2011). It appeared that a qualitative PAR framework could support the stated purposes of this research.

### **2.6.1 What is it PAR?**

PAR is a qualitative method of inquiry, 'characterised by the active participation of researchers and participants in the co-construction of knowledge; the promotion of self and critical awareness that leads to individual, collective and/or social change; and an emphasis on a co-learning process where researchers and participants plan, implement and establish a process for disseminating information gathered in a research project' (McIntyre 2008, p. 5). PAR repositions those whom would have otherwise, in traditional research methods, been considered participants, as co-researchers. Co-researchers hold an active role and significant influence in a research project (Shen et al., 2017), and this can create a new understanding of the dynamic between researchers and participants (Walmsley & Mannan, 2009).

## **2.6.2 The Principles of PAR**

At its core, PAR fosters significant ethical principles. By engaging in PAR, a researcher espouses the value that all people have the right and the ability to actively participate in the process of knowledge generation specific to their lives (Van der Riet, 2008). From a philosophical perspective, PAR accepts that social actors create knowledge and meaning and the framework can provide access to locally constructed knowledge and understanding (Kemmis et al., 2014). These principles are consistent with my values and philosophical stance and therefore PAR offered a way for me to apply my values in practice.

A criticism of the PAR approach, from a traditionally scientific perspective, is that the research reflects experience rather than hard data, making the findings less generalisable, and thus they are open to challenge (MacDonald, 2012). However, the findings presented in this research make no claim to uncover the truth, but instead offer a perspective on the subjective experiences of the co-researchers by constructing local truths towards increased understanding.

The principles of PAR were therefore consistent with the purposes of the empirical research. The approach offered a flexible qualitative method that supported the construction of an in-depth understanding of parents' experiences of choosing a primary school for their child with SEN. PAR supported the inclusion of diverse parent voices, providing a platform to generate dialogue and disrupt traditional assumptions regarding parent and professional roles. Finally, PAR supported the generation of local forms of truth to contribute towards a local review of school provision.

## **2.7 Ethical Considerations**

### **2.7.1 Power and Participation**

Whilst PAR is considered to be a democratic, empowering and liberating method of research, there are highly complex ethical issues to consider. Firstly, participation is acknowledged as a problematic concept in postmodern research such as PAR (Cooke &

Kothari, 2001; Janes, 2016; Kemmis, 2006). Ospina et al. (2004) emphasise that, whilst the equitable principals of action research are straightforward in theory, they are challenging to effectively enact in practice. Critical perspectives on PAR suggest that the complexities of enacting participation are often overlooked or lack comprehensive consideration. Subsequently, this can result in a participatory paradox whereby PAR becomes tokenistic and potentially acts to reproduce the injustice which it seeks to counteract (Cooke & Kothari, 2001; Janes, 2016).

Those who assume that the ethical principles of PAR automatically enact democratic co-researcher membership may neglect to consider the impact of social, political and historical contexts and power on participation (Janes, 2016). It is therefore vital to acknowledge that power hierarchies were present and pervasive during the empirical research process and were most often associated with co-researcher roles as either 'parent' or 'professional'. I understood this power imbalance from a Foucauldian perspective (1980), whereby power is socially, politically and historically ascribed to established institutions. My position within two institutions, as both a Newcastle University researcher and a local authority representative, initially weighted power to me.

It would not be possible to claim that the power relations between the co-researchers ever became entirely equal. However, power relations were not ignored. Instead, power relations were identified, acknowledged and negotiated through dialogue and jointly problematised participation from the outset. I do not claim that this PAR research obliterated power dynamics in the research group. Conversely, by emphasising the complexity of the co-researcher power relations, I seek to dispel assumptions that PAR is a simplistic tool for participation. However, the use of continual critical reflexive questioning enabled disruptions to assumed roles and responsibilities and this worked to demonstrate that power relations are not stable but can be queried and reconstructed through dialogue (Galuppo, Gorli, & Ripamonti, 2011).

### ***2.7.2 Issues of Purpose, Ownership and Position***

As set out in section 2.4, this research had a number of purposes. This project is an example of real world research and the emergent, responsive and flexible PAR design

therefore had inherent challenges and risks (Cook, 2009). At its core, the main purpose was to construct an in-depth understanding of parents' experiences of choosing a primary school for their child with SEN. However, creating a methodological disruption to traditional assumptions of parent-professional relationships through the use of PAR was key. This empirical research also contributed towards an evaluation of school provision for children with SEN in one LA, which meant additional stakeholders, with varying priorities, held an interest in this project.

Whilst these multiple purposes were communicated clearly to all stakeholders from the outset, they added a significant layer of complexity, which had subsequent implications for how individuals perceived their ownership rights and roles during the project.

The LA held a stake in this research and, at times, suggested this project belonged to them by attempting to influence the trajectory and timeline of the project. Meanwhile, my aspiration for shared ownership with all stakeholders was often challenged by my own priority to complete the project to meet the expectations of the doctorate course. The following excerpt from my research journal provides an example of when the varied purposes of this project conflicted:

*“The email I had from X today has filled me with anxiety. He wants results before Christmas for the feedback session after the break. I could give him what we have so far, but most of it relates to project construction and initial data. There are no findings yet as the team are not due to meet again until January. I can't give findings that have not been discussed with all the parents. To be honest, I know I need to say no, but given his role, this feels really uncomfortable.”*

This excerpt demonstrates one example of when the LA's perceived rights to ownership challenged the democratic objective of this empirical research. There were no simple answers and the competing purposes and ownership challenges that unfolded required continual reflexivity and diplomacy. However, at its core, this research belonged to the co-researchers and I held on to this principle as the main priority during all ownership challenges. With this in mind, I was often required to have difficult conversations with LA stakeholders, and at times, with myself.

In addition, the co-researchers' initial ownership assumptions had implications for decision making, whereby they initially undermined their personal ownership rights by defaulting to me as the ultimate decision maker. This threatened the democratic basis of the PAR project and we initially spent a significant amount of time problematising this assumption. We did this by continually reflecting on our positions and how we positioned others through an insider/outsider framework (Dwyer & Buckle, 2009; Milligan, 2016).

An insider/outsider position model is not a novel consideration in participatory research (Milligan, 2016). Recently, however, the binary nature of either 'insider' or 'outsider' has been challenged and is now often considered to be a dynamic status that is constantly in flux dependent upon the specific context at one time (McNess, Arthur, & Crossley, 2013).

Reflection, as a research team, highlighted that we all experienced changes in our position status at some stage of the research, as influenced by emerging relationships, parent or professional role and knowledge of research methods. Rather than a binary inside or outside researcher, I often inhabited what Dwyer and Buckle (2009) describe as the space between; a dialectical position of both insider and outsider whereby my research skills and LA contacts afforded me a role in the PAR group. [Table 4](#) sets out my changing position of inside, outside and space between participation (Dwyer & Buckle, 2009) with the co-researchers.



**Table 4. My Position as Insider, Outsider and In-betweener**

Insider	Space Between	Outsider
<ul style="list-style-type: none"> <li>• I had previously been involved with all the mothers through my TEP role.</li> <li>• I had initiated the project and recruited the parents to join the research team.</li> <li>• I had experience and knowledge of SEN and school systems.</li> <li>• My professional role granted access to external participants beyond the research group.</li> </ul>	<ul style="list-style-type: none"> <li>• I had knowledge and skill in research methodology.</li> <li>• I had contacts at strategic levels of the local authority.</li> <li>• I had the skills to facilitate in-depth reflective dialogue.</li> </ul>	<ul style="list-style-type: none"> <li>• I was not a mother of a child considered to have SEN.</li> <li>• I had never chosen a school for a child considered to have SEN.</li> <li>• I held a dual professional role as Newcastle researcher and local authority TEP. This institutionalised power often positioned me as 'authoritative outsider.'</li> </ul>

My fluid positioning during the project had implications in relation to power dynamics. My dual institutional role initially positioned me as the authoritative outsider. As the co-researchers and I developed our relationship over time, I found myself more often inhabiting the space between and an insider position. However, towards the end of the project, when the co-researchers' confidence and personal relationships had developed, I experienced feeling more outside than ever. It is therefore important to acknowledge that my position was never static and my movement between positions was not linear. My experience reinforced the perspectives of McNess et al. (2013) that a researcher's position is constantly in flux and is influenced by context.

## 2.8 Qualitative Quality and Validity Frameworks

My decision to forgo the use of quality criteria frameworks is acknowledged as a potential limitation of both the QLR and empirical research. The use of quality appraisal tools for qualitative synthesis could be considered a contentious decision as there is limited agreement regarding what criteria should be sought and how measures should be applied in practice (Atkins et al., 2008). Furthermore, in applying a quality appraisal tool, I believe I would have imposed quantitative ideals regarding scientific rigour and truth upon qualitative approaches that seek to understand subjective experience (Atkins et al., 2008; MacDonald, 2012). This was antithetical to my espoused philosophical position, which acknowledges multiple forms of truth.

Furthermore, Atkins et al. (2008) state that quality appraisal tools fail to assess the quality of research, as they focus only on the content of the written report, and adopt potentially prescriptive criteria (Barbour, 2001). It is my contention that judging qualitative literature on the written report alone potentially silences the voices of participants who have shared their experiences and can alienate researchers, who are not as well versed in the traditionally academic ways of writing (such as the parent co-researchers), from contributing to a body of research. With my philosophical perspective and the acknowledged fallibility of quality appraisal tools in mind, I made a decision to forgo the application of a quality appraisal tool to those papers included in the QLR.

In a similar vein, I thought carefully with regard to the application of qualitative validity measures to the empirical research. I found Cho and Trent's (2006) transactional model of validity to be the most convincing, whereby they suggest that the use of member checking and triangulation can potentially confirm the accuracy of a participant's perspective on reality. However, when engaged in the empirical research, it became clear that due to the co-researchers' ever evolving subjective understanding of experience and personal truth through dialogue, member checks and triangulation could not fulfil the aspired confirmation of a reality. If they had been applied as validity tools, it could have resulted in endless checking for a truth that was constantly in flux, as no one-to-one correspondence between reality and interpretation appeared to exist (Lincoln & Guba, 2000). The use of a validity tool therefore appeared redundant since it was

incompatible with my philosophical perspective that truths are constantly evolving through dialogue with the self and other.

## **2.9 Summary**

This bridging document has addressed a number of my personal considerations and reflections regarding the process of conducting this research. I have discussed my personal motivation to engage in this project and my philosophical positioning. In particular, I have detailed my postmodern relational ontological perspective and the evolution of my dialogical epistemological position. My dialogical stance influenced my approach to the data, whereby I espouse that there are diverse ways to understand the world.

Furthermore, I have discussed my decision to adopt a qualitative methodology in line with my philosophical position. PAR, and the inherent complexities of the approach, has been explored with regard to this specific project. This bridging document has also discussed the ethical considerations required during this project. In particular, the issues of power, participation, purpose, ownership and positioning bore an influence on how this research was conducted. Finally, I have provided a justification for my decision to forgo the use of quality and validity frameworks in this research.

This project has been a transformational process, which has challenged my research skills. In particular, this project has extended my knowledge and understanding of participatory practice, which I am certain, will influence my on-going professional practice as an Educational Psychologist.

## **Chapter 3. How do Parents Experience Choosing a Primary School for their Child with Special Educational Needs?**

### **3.1 Abstract**

*Current political discourse emphasises the importance of parent choice when selecting a school for a child with special educational needs (SEN). School choice is more complex than a binary decision between a mainstream and special school, with additional resource provisions and dual placement options now available. As such, creating a rich understanding of parents' experiences of choosing a primary school would subsequently be important to professionals looking to provide effective support.*

*However, there appears to be a dearth of research that explicitly explores how parents experience the process of selecting a school, and no research that focuses entirely on the primary stage. In response to this identified literature gap, this chapter explores: "How do parents experience choosing a primary school for their child with SEN?" Furthermore, in response to the findings in Chapter 1, this research attempts to disrupt traditional parent-professional relationships through the use of a participatory action research (PAR) framework with three parents in North East England.*

*Data is co-constructed with the co-researchers over a six-month period and is underpinned by Bakhtinian dialogue and a narrative approach to create a rich understanding of parent experience. The dialogic interactions and the data generated then culminate in the production of individual short narratives of the parents' experience of choosing a primary school for their child with SEN.*

*The short narratives are coded and analysed using inductive thematic analysis and the themes constructed suggest that, whilst each individual experience is unique, the process can be overwhelming and lonely and requires significant parent effort and determination. However, the narratives suggest that this difficult process can be eased by supportive relationships and life experience. This paper concludes that primary school choice appears to be a stressful experience and that networks of group support,*

*with Educational Psychologists well positioned to facilitate, could enhance the process of choosing a school for parents of children with SEN.*

## **3.2 Introduction**

This research explores a specific aspect of the process of early education transition (EET) and seeks to generate an in-depth understanding of how parents experience choosing a primary school for their child with special educational needs (SEN). The central theme of power constructed in the meta-ethnography suggested that parents of children with SEN often feel [excluded from the EET process by professionals](#). In an effort to disrupt traditional parent-professional relationships, a participatory action research (PAR) framework was adopted with three parents of children with SEN in the North East of England. Firstly, the background policy, context and wider literature are explored, preceded by a review of the methodology and findings. This is then followed by a discussion within the context of relevant literature and conclusions, which outline the implications and limitations of this research.

### **3.2.1 Policy and Context**

The education of children with SEN in England has evolved significantly over the last 30 years. Signs of change began to emerge in the 1960's when, against the backdrop of the civil rights movement, policies promoting segregation came under scrutiny (Hodkinson, 2010). The Warnock Report (Warnock, 1979) and The Education Act (DfES, 1981) established the statutory role of local authorities (LAs) to identify and assess the needs of children considered to have SEN, and wherever possible, provide for these needs within a mainstream setting through the promotion of a policy of integration.

However, integration quickly appeared to be an ineffective model of practice, as it considered only the location of a child's education without due consideration for the environmental and attitudinal barriers that restricted their participation in mainstream schools (Thomas & Loxley, 2007). The Salamanca Statement (UNESCO., 1994), alongside the political principles of The New Labour Government (1997) and legislative

changes to SEN practice (1997, 1998; 1994) prompted an ideological shift towards an inclusive education policy, based on the central rights and social justice argument that all children had the right to fully participate in mainstream education (Florian, 1998; Winter & O’Raw, 2010). Alongside the inclusion of children with SEN, legislation and policy also increasingly took account of the preferences of their parents<sup>2</sup> (Bajwa - Patel & Devecchi, 2014).

Parent choice has been a key aspect of government policy since the introduction of The Education Act (HMSO, 1981). However, the initiation of The SEN Code of Practice (DfES, 1994) gave parents statutory rights to express a preference of school for their child with SEN and the right to challenge LAs should they disagree with their decision. The Special Educational Needs and Disability Act (HMSO, 2001) and the revised SEN Code of Practice (DfES, 2001) maintained an ideological push for all children to be educated in mainstream wherever possible, whilst also recognising parents’ rights to express a school preference. Barton (2003) considers this political approach a dual system, which promoted inclusion yet continued to maintain special schools.

Despite the legislation and policy that encouraged parent choice, The Lamb Inquiry (DCSF, 2009) highlighted a lack of parental confidence in the SEN system. In addition, an OFSTED SEN review (2010, p. 3) identified that ‘no one model – such as special schools, full inclusion in mainstream settings, or specialist units co-located with mainstream settings – worked better than any other’ and suggested that parents required additional support when engaging in the school choice process.

Following this, the coalition government issued a Green Paper (2011, p. 51), which recommended a transformational approach to SEN and parental choice. It stated, ‘there should be real choice for parents’ whereby ‘any bias towards inclusion that obstructs parent choice should be removed’. The discourse of this document appeared to suggest that parental choice was now placed above any political ideology on inclusion. However, despite the political rhetoric and policy rewording, the statutory rights of parents to

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<sup>2</sup> From this stage on, the term parent(s) will be used in reference to parent(s) of children with SEN.

choose a school remained unchanged in the new SEN Code of Practice (DfE, 2014). Thus, whilst political discourse currently promotes parent choice, the actual legislation merely supports a parent's right to state a preference and their right to appeal. It has been suggested that conflating these two diverse rights creates ambiguity and gives parents undue confidence in their right to choose a school for their child (Bajwa - Patel & Devecchi, 2014). This ambiguity is acknowledged when applying the term 'choice' throughout the rest of this paper.

### ***3.2.2 Factors Influencing Parents' Choice of School***

It is important, when considering parents' experiences of choosing a school, to first consider the factors that potentially influence this decision. The body of literature in this area appears to be relatively limited, and what does exist, primarily focuses on secondary school choice. Thus, the findings can provide only a tentative indication as to what might influence a parent's primary school choice and should be approached with caution.

School choice is more complex than a binary decision between a mainstream and special school, with additional resource provisions and dual placement options now available (Flewitt & Nind, 2007; Frederickson, Jones, & Lang, 2010; McAllister & Hadjri, 2013). Existing literature suggests a number of potential factors that influence a parent's choice of school. It is suggested that a key influential factor is the specific nature and extent of a child's SEN, whereby as the perceived severity of SEN increases, so does the likelihood that a parent will select a special school (Bagley & Woods, 1998; Bajwa - Patel & Devecchi, 2014; Gasteiger-Klicpera, Klicpera, Gebhardt, & Schwab, 2013; Kasari, Paparella, Freeman, & Jahromi, 2008; Leyser & Kirk, 2011; Mann, Cuskelly, & Moni, 2015). A child's age has also been identified as an influential factor, with parents more likely to choose a mainstream provision for primary school (Jenkinson, 1998; Leyser & Kirk, 2011). Byrne (2013) attributes this choice to parents' potential perceptions of increased social and academic difference between their child and their typically developing peers as they get older and the need for an increased focus on independence skills at the secondary stage.

Furthermore, the school environment appears influential. The degree of environmental accessibility coupled with class sizes, teacher skill and levels of support are recognised as significant (Bajwa - Patel & Devecchi, 2014; Hess et al., 2006; Jenkinson, 1998; O'Connor, 2007). Parents' perceptions of school ethos and staff attitudes are also reported to influence their choice (Bagley & Woods, 1998; Bajwa - Patel & Devecchi, 2014; Flewitt & Nind, 2007; Hess et al., 2006).

The perspectives of others may also influence a parent's decision. Literature suggests that parents might discuss their options with family, friends and support networks (Bagley & Woods, 1998; Flewitt & Nind, 2007; Mann et al., 2015). Parents' positive and/or negative contact with varying professionals might also be an influential factor when choosing a school (Bajwa - Patel & Devecchi, 2014; Duncan, 2003; Kenny, Shevlin, Walsh, & McNeela, 2005; Mann et al., 2015; McNerney, Hill, & Pellicano, 2015).

Thus, the process of selecting a school for a child with SEN is complex and is influenced by a number of potentially interrelated factors (Byrne, 2013).

### ***3.2.3 Parents' Experiences of Choosing a School***

From a review of the literature on school choice, there appears to be a dearth of research that explicitly explores how parents experience the process of selecting a school. Whilst it is alluded to in passing, it is often embedded within wider explorations of the factors involved in school choice. In addition, whilst Flewitt and Nind (2007) and Rose, Shevlin, Twomey, and Zhao (2017) focus on school choice for children with SEN with regard to early years, there appears to be no research that focuses entirely on the primary stage.

The literature that does exist with regard to the parental experience of school choice suggests that the process of choosing a school is stressful (Bajwa - Patel & Devecchi, 2014; Flewitt & Nind, 2007; Hess et al., 2006; Lalvani, 2012; Mann et al., 2015; McNerney et al., 2015; Rose et al., 2017; Tissot, 2011). However, I believe this research lacks a rich understanding of parents' experiences of primary school choice; a gap which this study seeks to bridge.



### **3.2.4 The Present Study**

In response to this identified literature gap, this empirical research explores ‘*How do parents experience choosing a primary school for their child with SEN?*’ The SEN Code of Practice (DfE, 2014) states that listening to and understanding parents’ perspectives is key to creating positive outcomes for children with SEN. Creating a rich understanding of parents’ experiences of choosing a primary school would consequently be important to professionals looking to effectively support parents and their children with SEN during EET, such as Educational Psychologists (EPs), school staff and local authority SEN teams. Furthermore, in response to the findings in Chapter 1, I have attempted to disrupt traditional parent-professional relationships through the use of a participatory action research (PAR) framework with three parents in North East England.

## **3.3 Methodology**

### **3.3.1 Research Context**

This research was conducted in North East England in collaboration with three co-researchers, all of whom had a child with SEN and were engaged in the primary school choice process. Additionally, at this time, the LA in which the research took place, underwent a review of school provision for children with SEN. This research was therefore ideally placed to contribute towards the LA school provision review. PAR appeared to be an effective way to foster parent-professional partnership, listen to and understand the perspectives of local parents, and facilitate an opportunity for parents to contribute towards a LA review of school provision.

### **3.3.2 Ethics**

This project was subject to an enhanced ethics assessment and subsequent approval by Newcastle University. This research also adhered to the BPS Code of Ethics (2014) and participants were issued with an information pack that detailed the aims and purposes of the research, their rights as co-researchers, how and where their data would be stored, and relevant contact information (Appendix B). However, during this

project, ethical research practice went beyond this assessment and ethicality remained central to the PAR process. A more comprehensive discussion of my ethical considerations can be found in Chapter 2, section 2.7.

### **3.3.3 Recruitment**

Criterion sampling was used to recruit the co-researchers (Cohen, Manion, & Morrison, 2013). To participate, the co-researchers had to be a parent of a child with an Education, Health and Care Plan (EHCP), making them eligible to choose a special school. Furthermore, the co-researcher's child had to be eligible to enter reception in September 2018, meaning they had recent experience choosing a primary school. To avoid any potential placement competition between the co-researchers, I recruited from various geographical areas of the LA. All the co-researchers had previously engaged with the Educational Psychology Service (EPS) where I was a Trainee Educational Psychologist (TEP). Potential co-researchers were identified through discussion with my colleagues and were subsequently approached by telephone to gauge initial potential interest. Those who registered interest were then sent further project details via email (Appendix B). Given the level of participation required, many potential parents were unable to commit to the project. However, three parents who met the recruitment criteria, agreed to participate as project co-researchers.

### **3.3.4 Participatory Action Research**

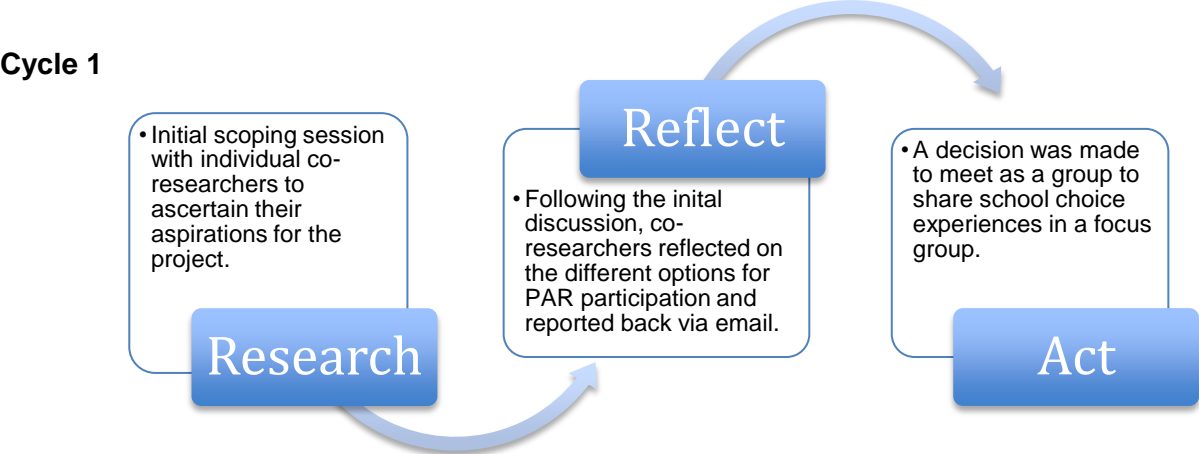
A qualitative approach was selected in order to generate a rich understanding of the co-researchers' experience (Creswell, 2013). Furthermore, this project adopted a PAR framework, which is considered 'a democratic, equitable, liberating and life-enhancing qualitative enquiry that remains distinct from other qualitative methodologies' (MacDonald, 2012, p. 34). PAR is a subdivision of action research (AR) and is often enacted through distinct phases of research, reflection and action (Kemmis et al., 2014). These phases were used to loosely frame the PAR sessions and they facilitated an approach that was responsive to the knowledge and decisions created by the co-researchers (Whitehead & McNiff, 2006), which supported their meaningful participation.

It is important at this stage to discuss the use of the term 'co-researcher' in this research. Given (2008) defines a co-researcher as a participant who makes a significant contribution to the construction and findings of a research project. MacDonald (2012) states that, due to the varied stages of a PAR project, diverse forms of leadership are required. In this project, the parent co-researchers led in the construction of the methodology and construction of the narrative data. However, given that I have authored this thesis, it is acknowledged that my voice may be more dominant in this aspect of the written work. A forthcoming LA document is in production that will detail the research findings, which will offer an opportunity for the parent co-researchers to have a more central role in the authoring of the research findings.

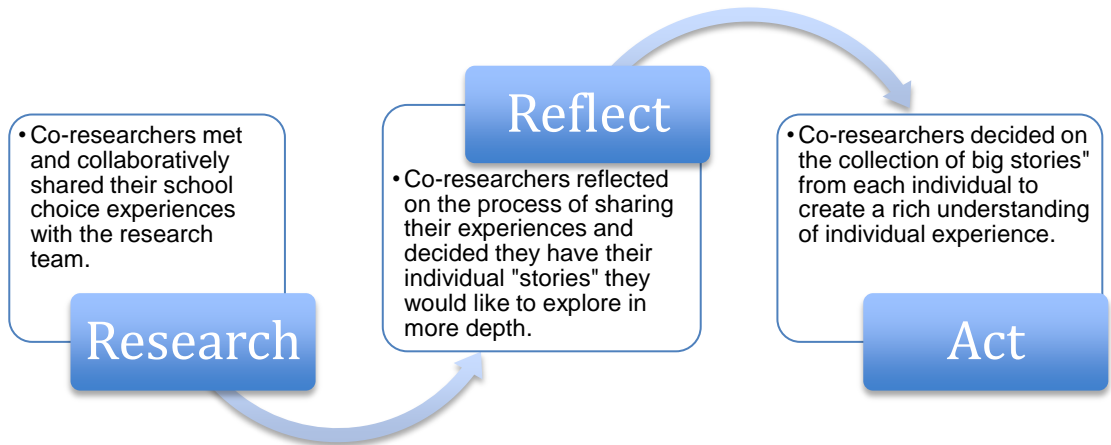
**3.3.5 Process**

Figure 4 provides a pictorial demonstration of the PAR process during this project.

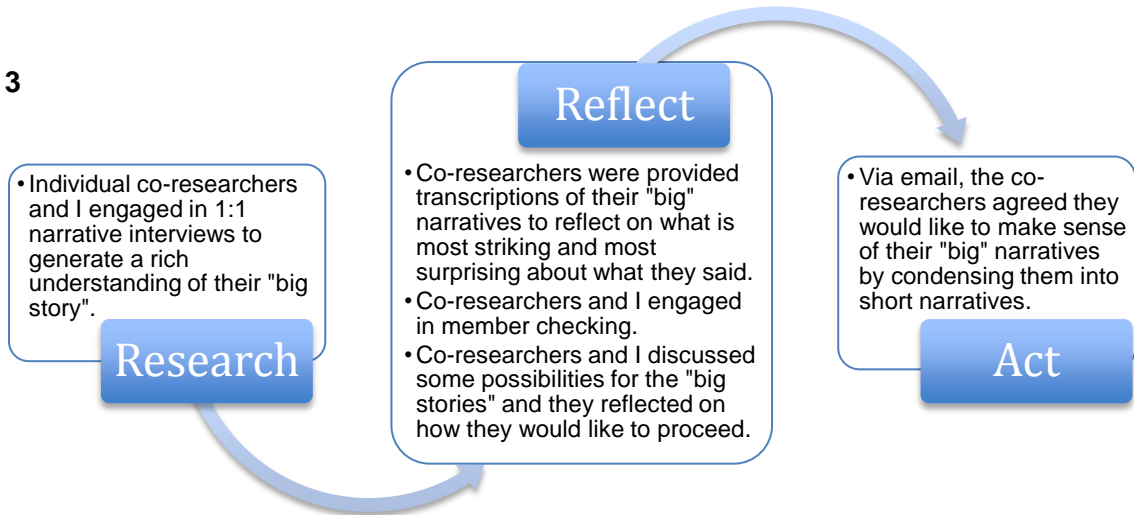
**Figure 4. A pictorial representation of the PAR process**



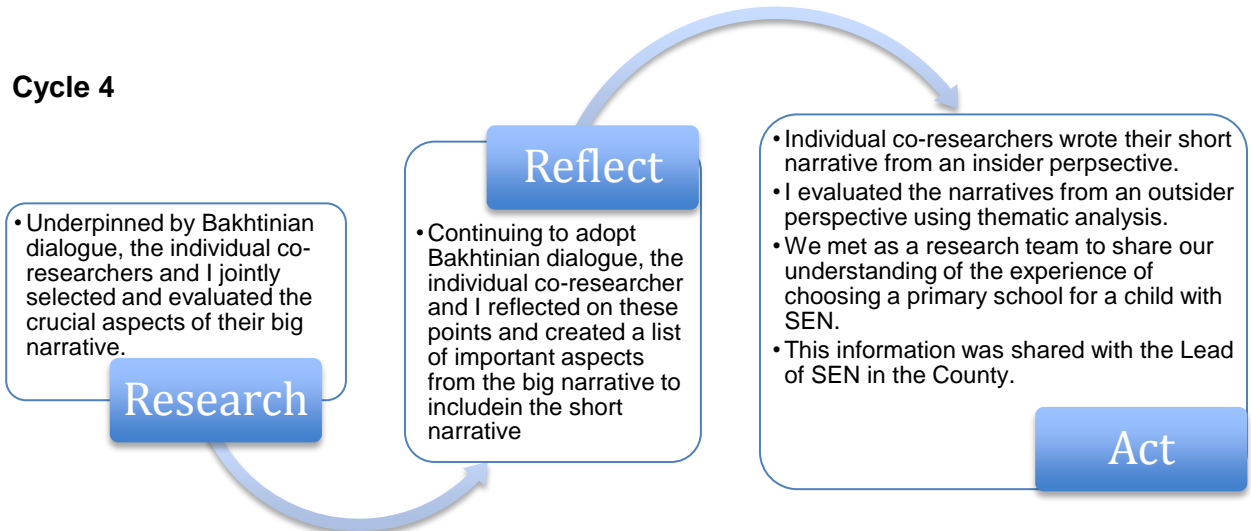
## Cycle 2



## Cycle 3



## Cycle 4



### ***3.3.6 Generating an understanding***

#### ***3.3.6.1. Cycle 1***

Cycle 1 began with individual scoping sessions with each of the co-researchers. The focus of these first sessions was to begin to develop an understanding of the co-researchers' project aspirations and to discuss their expectations for their participation in the project. Kelly (2005) suggests that a planning process is integral for establishing the focus and direction of a PAR project.

In addition, cycle 1 also prioritised the establishment of expectations regarding respect, support and confidentiality. Each member of the PAR group was introduced to the Co-Researcher Contract (Appendix C), an augmented version of Kemmis and McTaggart's 'Research Group Protocols' (2014, p. 168), and they were given the opportunity to review and later discuss the content. It is acknowledged that the Co-Researcher Contract was in no way a binding document and had very limited power for enforcing the principles it laid out. However, as noted by Kemmis et al. (2014) communicating the importance of these principles was vital in setting the tone for respect and ethicality from the outset of the project.

The discussions and email correspondence with the co-researchers in cycle 1, followed by time to reflect on this information, resulted in a collective preference to meet as a team to begin exploring their experiences of selecting a primary school.

#### ***3.3.6.2 Embedding a Bakhtinian Perspective on Dialogue***

During cycle 1, it became apparent how important dialogue was to this process. In my personal reflections, I noted how the interactions between the co-researchers and I were moulding the direction of the project. My interactions with the co-researchers generated creative project ideas that I would not have independently considered. I reflected upon this in my research journal:

*“I’ve come away from talking to Caroline today full of excitement for the project. When we were talking, she suggested she might act as the interviewer with another parent. I’ve never thought of this before and, whilst it scares me a little and I am uncertain, I wouldn’t have thought of this without her. I feel both uncomfortable yet excited by the idea.”*

This reflection emphasised the relational nature of the project and the importance of dialogue to understand how the direction of the project was co-constructed by the co-researchers. Bakhtin (1986, p. 78) states ‘what would I have to gain if another were to fuse with me?...let him rather remain outside me’. Here, Bakhtin (1986) suggests that difference creates tension, which is subsequently explored and negotiated through communication. A dialogic interpretation of this process suggests that the meeting of contrasting perspectives, where difference is held in tension, opens individuals to the alternate perspective of the other (Bakhtin, 1986; Marková, 2003). This interpretation of dialogue remained important throughout each of the cycles, whereby co-researchers were encouraged to acknowledge tensions and explore them through dialogue, generating insight, new understanding and creative directions for the project.

### **3.3.6.3 Cycle 2**

Cycle 2 began with a new research phase. The co-researchers met as a collective team, and with the overarching research question in mind, began to discuss their experiences of choosing a primary school. During this phase, the co-researchers often used the phrase “my story” or, when addressing another, “your story”. It was during this cycle that a narrative approach began to develop through the dialogue. Below is a direct quote from one of the co-researchers, taken from my research diary:

**Fay:** *“We all have our own way of seeing things, we all have our own stories”.*

A number of options for taking the project forward were discussed during this research phase, including collecting data from other parents in the same geographical area via interviews and questionnaires. During the reflection phase, these options were explored in more detail, but ultimately went beyond the scope of the immediate project due to time and resource constraints. The co-researchers decided to focus on personal

“stories” and acknowledged that their individual experiences warranted further exploration. Thus, the action phase included a collective agreement that the individual co-researchers and I would engage in a one-to-one narrative interview in order to garner a rich understanding of their individual experiences.

#### **3.3.6.4. Narrative Approaches**

As one of the co-researchers in this project, I was not separate from the process and, as described in Chapter 2 section 2.7.2, my role was that of insider/outsider/space-between (Dwyer & Buckle, 2009). As a member of the research team, I was working alongside the parents and was immersed in their experiences, and therefore inside the project. However, I also held an outsider role, where I was separate from the parents by way of my institutional memberships and my lack of experience in choosing a primary school. I often inhabited what Dwyer and Buckle (2009) describe as the space between; a dialectical position of both insider and outsider, which ultimately provided me with an element of distancing (Van der Riet, 2008). The dialogue generated during cycle 2 often returned to “stories”. From my position as outsider, this dialogue sparked a consideration that a narrative methodological approach may support an effective way to further explore the co-researchers “stories”. I fed this idea back to the co-researchers and we discussed if this had the potential to work.

The term narrative is complex and a definition is considered elusive (Dwyer & Emereld, 2017). However, a central theme of any narrative is its link to human consciousness, whereby it goes beyond mere storytelling by underpinning the way humans know, order and understand their experiences (Clandinin & Rosiek, 2007; Huber, Caine, Huber, & Steeves, 2013; Vitanova, 2013). A narrative approach to research has evolved into a prominent qualitative method in a variety of fields (Chase, 2011) and is considered a flexible method for collecting rich data based on human experience (Dwyer & Emereld, 2017). Clandinin, Pushor, and Orr (2007) also emphasise that narrative approaches situate experience within a contextual, societal and historical context and it was therefore coherent with this PAR project.

### 3.3.6.5. Layering Methodological Approaches

PAR acted as an overarching methodological framework for this research. However, within the PAR framework, the co-researchers and I also embedded a Bakhtinian perspective on dialogue and adopted narrative approaches. A visual representation of this is set out in Figure 5.

**Figure 5. A visual representation of the methodological approaches to research**



### 3.3.6.6. Cycle 3

The *research phase* of this cycle involved in-depth narrative interviews with each of the parent co-researchers. I met with each parent co-researcher individually, and through narrative questioning (Appendix D) and subsequent dialogue, we explored what came to be known by the co-researchers as their “big story”.

The “big stories” were transcribed (Appendix F) and returned to the parent co-researchers for review. Transcription is considered to be a powerful method for representing data and can impact on how the data is understood (Oliver, Serovich, & Mason, 2005). The process of returning the transcripts could also be considered as member checking, which is understood to be a contentious approach in qualitative research (Dickson-Swift, James, Kippen, & Liamputtong, 2006; Koelsch, 2013). However, given the PAR framework, member checking in this instance supported co-researcher ownership and participation whilst facilitating further research dialogue, and was therefore deemed an appropriate methodological choice (Mero-Jaffe, 2011).



During the reflection phase, the co-researchers were asked to read their “big story” and respond to a set of reflective questions (Appendix E). Lapadat (2000) suggests that a period of reflection on transcribed data can aid clarification and stimulate further dialogue on the content. Bakhtin (1986, p. 281) states: ‘any utterance, whether spoken or written, that people use in communication with each other is internally dialogic’. Vitanova (2013), adopting a Bakhtinian perspective, suggests that as an individual works to understand their own words and perspectives, they engage in a dialogic relationship with the other, either reaffirming their position or reconstructing their perspective. From my dialogic epistemological position, I had hoped that the written transcriptions and the reflective questions would stimulate internal dialogue, encouraging the co-researchers to further construct their understanding of their experience of choosing a primary school.

Following a period of reflection and correspondence on the transcriptions, the action phase included a decision that, through a shared review process, the co-researchers would (re)present their “big stories” in short narratives.

#### **3.3.6.7. Cycle 4**

Kennelly, Ledger, and Flynn (2017) suggest that given the relational nature of narrative research, the findings are a co-construction between researchers and participants. Through the PAR method, cycle 4 developed a co-construction of the co-researchers’ experiences of choosing a primary school.

Through a joint review, the co-researchers and I discussed their “big story” and shared our personal reflections on the content. The transcripts acted as an ‘atemporal object’ (Spee & Jarzabkowski, 2011, p. 1234), which visually supported a ‘distanciated’ perspective (Van der Riet, 2008). [Van der Riet \(op cit\) considers a ‘distanciated’ perspective to be a position that provides space for dialogue and the appreciation of previously unrecognised perspectives.](#) Often the co-researcher would draw attention to aspects of the transcript that surprised them. An excerpt from my research diary demonstrates one example of a moment of ‘surprise’:

*“Today Fay and I were chatting and she said, “I can’t believe I said so much about the trampoline! I read it on Google years ago! It must have stayed with me.” It was interesting to see how surprised she was by the transcript, even though they were her own words.”*

To further interrogate the transcripts, the co-researchers and I selected important excerpts. Kennelly et al. (2017) suggests that, when looking to make sense of and condense large amounts of narrative text, researchers should consider arranging and prioritising the information for reconstruction. An excerpt from my research diary demonstrates how the co-researchers and I decided to condense the “big stories”:

*“Emma suggested that we take the “big story” and talk it through together. I’ve consulted with the other co-researchers and they think this would be a good way to make the data more manageable and useful.”*

Following from this, through dialogue with each other, the co-researchers and I collaboratively selected moments of perceived particular significance, which came to be known as “critical points”. Collaboratively, the co-researchers and I then created a list of “critical points” (Appendix G). The dialogue surrounding the “critical points” encouraged the co-researchers and I to gain clarity, and at times, a new way to understand their experience of choosing a primary school emerged. Following this research phase, the co-researchers took time to reflect on their critical points list. It was decided during the action phase that the critical points list would be used to assist the parent co-researchers in writing a short narrative encapsulating their understanding of their experience with regard to choosing a primary school. The co-researchers’ short narratives (Appendix H) were subsequently utilised as the data for analysis in this project.

### **3.4 Analysis**

#### **3.4.1 PAR and Analysis**

As a preliminary consideration before discussing the approach to data analysis, it is important to acknowledge the different roles that the co-researchers and I assumed at this stage of the project. Kemmis et al. (2014) emphasise PAR’s aspiration that all

aspects of research are the responsibility of the co-researchers. In this project, the co-researchers' decisions were paramount to the direction of the project, as demonstrated in the cycles of PAR (Figure 3). However, their role in some aspects of the data analysis was reduced.

Iterative analysis was central to each cycle of this project, particularly during each of the reflection stages, whereby the co-researchers would analyse the information collected and would subsequently generate an action. Cahill (2007) considers the on-going reflective aspect of PAR to be a collaborative form of data analysis, as the dialectical analysis drives forward the participatory cycles, producing new approaches and new ways of understanding the generated knowledge. A significant level of collaborative data analysis occurred during the reflection stage of cycle 4, when the co-researchers and I analysed the "big stories" (Appendix F) and co-constructed the "critical points" list (Appendix G).

A collaborative decision was taken that I would lead the analysis of the "short narratives" from my outsider co-researcher position. MacDonald (2012) states that during PAR, the academic co-researcher may be required to take a lead on data analysis. In this project, since childcare commitments and time constraints limited the co-researchers' capacity to engage in data analysis, I was subsequently encouraged to lead on this area of the project. Kemmis et al. (2014, p. 9) acknowledge that co-researchers should 'remain open to receiving assistance from outsiders where it is useful'. Kelly (2005) acknowledges that there is no one-way to enact a PAR project and it must be responsive to the participants and their context. For this project, as I would be leading on the analysis of the short narratives, I was tasked to and provide the co-researchers with potential approaches to analysis of the data and the wider findings as a way of checking back (Cahill, 2007).

It is acknowledged that the reduced co-researcher analysis role was not ideal. However, the decision was necessarily pragmatic given the complexity of the co-researchers' childcare commitments and time constraints. This approach is consistent with previous research methodologies on PAR (MacDonald, 2012).

### 3.4.2 Data Analysis

Through discussion with my supervisor, it became increasingly important that this study would go beyond merely giving voice to the individual co-researchers (Fine, Weis, Weseen, & Wong, 2000). Therefore, after collecting the short narratives from the co-researchers, I considered what methods could help to make the most sense of the data, and these were fed back to the co-researchers. From my position as insider/outsider, the co-researchers and I agreed I would build on the individual short narratives and construct a new understanding from my slightly removed outsider position.

After considering various methods of analysis, we decided I would use inductive thematic analysis (TA) (Braun & Clarke, 2006). TA is considered a flexible method to make sense of qualitative data, and I adopted the six-phase guide for analysis as a framework to support my interpretation (Braun & Clarke, 2006), as detailed in [Table 5](#). Thematic analysis was consistent with my dialogic epistemological position (Braun & Clarke, 2006) and appeared suitable for constructing an overview of the data whilst maintaining the depths of the individual narratives (Braun & Clarke, 2013).

The TA process was guided by the six phases as set out by Braun and Clark (2006) and involved continual cycles of reflection on the data. Themes were generated, refined and presented using a thematic map (Appendix K).

**Table 5. Six Phases of Thematic Analysis (Braun & Clark, 2006)**

Phase	Process	Evidence
Familiarisation with the data	Immersing oneself with the data through a process of reading and re-reading and taking tentative notes on meaningful content.	Appendix I
Generating initial codes	Producing codes that reflect the content of the data and are of interest or are meaningful to the analyst and developing a list of initial codes.	Appendix J

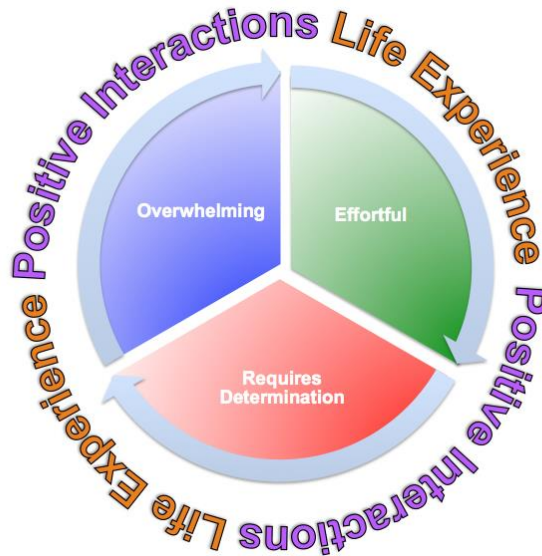
Phase	Process	Evidence
Searching for themes	From the list of initial codes, collating and combining the codes that focus on specific themes. Identifying the themes that appear most significant, and considering how all themes may be combined, refined or discarded.	Appendix J
Reviewing themes	Refining themes, potentially collapsing, discarding and diversifying them to create overarching themes and sub-themes. Producing an overview of codes and corresponding quotes into a working document.	Appendix K
Defining and naming themes	Defining the themes and providing names and definitions for each theme, ensuring each is distinct and contributes to the overall understanding of the data. Creating a clear representation of each theme from the data excerpts. Refining the thematic map, which clearly encompasses and demarcates overarching themes and sub-themes.	Figure 5 and Findings
Producing the report	Selecting the evidence from the data to succinctly provide a coherent and interesting account of the data alongside the researchers' argument regarding the research question.	Findings and Discussion

### 3.5 Findings

Through TA (Braun & Clarke, 2006), 35 initial codes were identified in the narrative data (Appendix K). The codes were reviewed and refined to create 14 basic themes, and through further detailed analysis, were subsumed into 5 overarching themes to represent my interpretation of the narrative data in its entirety. These themes included that the experience of choosing a school is overwhelming, effortful and requires determination but supportive factors such as positive interactions and life experience

can ease the process. A visual representation of this interpretation is set out in Figure 6. These findings were disseminated to LA strategic leads with a view that they would contribute towards a local review of educational provision in the area. These findings will now be explored alongside excerpts from the narrative data.

**Figure 6. Visual Representation of the Parents' Experiences of Choosing a Primary School**



### **3.5.1 Theme 1- The Process is Overwhelming**

The narratives demonstrated that the parents experienced a number of different difficult emotions when choosing a primary school. This often included feeling scared, nervous and worried:

**Emma:** *“It’s scary to think that next September Joseph will be at school and it really frightens me to think about it. He’s developmentally very young and sometimes I worry he’s not ready.”*

Furthermore, the narratives also emphasised feelings of stress and guilt. Caroline succinctly expressed how she felt during the process stating:

**Caroline:** *“If I could sum it up in one word it would be ‘stressful’.”*

Managing these difficult emotions appeared to be a lonely process at times, resulting in feeling tired and upset:

**Caroline:** *“Unfortunately there is no one else to make the decision for you and that can be lonely”*

**Emma:** *“Choosing a school for Joseph has been emotionally and physically tiring”*

The narratives also suggested that the parents experienced difficult times during the process of choosing a primary school. In particular, the times when the magnitude of the decision struck them were challenging:

**Caroline:** *“Choosing a school for your child is a big decision at the best of times but when your child has additional needs the enormity of that decision weighs heavily on parents’ shoulders.”*

Furthermore, Fay highlighted the importance of getting it right and the possible significant consequences of making the wrong choice:

**Fay:** *“if anything goes wrong it can be her life at risk and this is on a completely different scale”*

The narratives also suggested the parents experienced difficult times in their relationships with professionals, which led to frustration:

**Emma:** *“I’ve had to chase everybody else’s tail trying to find out information and I don’t feel it is my job to do this.”*

In addition, the narratives emphasised difficult times of self-doubt:

**Caroline:** *“I often doubted myself.”*

**Emma:** *“I sometimes think a special needs environment might be more beneficial to him, but I just need to see how he gets on developmentally.”*

Therefore, the narratives demonstrated that the experience of choosing a primary school was overwhelming for parents. There appeared to be a number of difficult emotions associated with the process, which were upsetting, and led to loneliness. Furthermore, there appeared to be difficult events associated with the process, including frustration with professionals, episodes of being overcome with the magnitude of the decision and periods of self-doubt. The narratives shared suggested that, in various ways, all the parents experienced feeling overwhelmed when choosing a primary school.

### **3.5.2 Theme 2 - The Process is Effortful**

The narratives suggested that the process of choosing a primary school was effortful. Often, the parents experienced the need to engage in extensive personal research:

**Fay:** *“I next did my research online and also read into Ofsted reports...Eventually I came across XXX Primary, a mainstream school a little further away from our home.”*

In addition, the narratives highlighted that parents were required to actively seek the perspectives of professionals:

**Emma:** *“The advice is there but, if I don’t ask for it, the advice will not be given.”*

The narratives also suggested that the parents experienced a sense of struggle when choosing a primary school, whereby they had to exert effort to challenge their own personal views. Fay suggested that whilst she was leaning towards a mainstream school, she also:

**Fay:** *“Put my feelings aside to make sure I was making the right choice for my children - my views aside.”*

Thus, it would appear that choosing a primary school was an effortful experience for parents. The process seemed to require an active parental role via effortful research, school visits and advice seeking. The parents also experienced the need to challenge their own personal views on provisions, which required effort.



### **3.5.3 Theme 3 - The Process Requires Determination**

The narratives suggested that choosing a primary school required parent determination. The parents' determination to get it right for their child came through strongly in each of the narratives:

**Emma:** *“Nothing will stop me from getting the best for Joseph. If that means travelling, then that will not be an issue. If I need to pack-in work or rely on taxis to get there that will not be problem as I need to make sure that the school is best suited to Joseph and his needs.”*

This determination to get it right was sometimes positioned as advocacy:

**Caroline:** *“I do what I do for her, to ensure that she has the best start to her education. I will continue to strive for the best for her...I have felt that it is my job to act as her advocate and to ensure that I strive to obtain the best for her in order to help her realise her potential.”*

In addition, the narratives suggested that it is important for parents to know what they want from their child's school. The parents discussed the importance of certain schools to them:

**Fay:** *“I think every child should be given the chance in mainstream first as all children deserve a normal life as possible and the rest of the world also need to learn more about disabilities”*

**Caroline:** *“It is precisely because Tara is bright that her father and I feel so strongly that specialist provision will give her the best start.”*

The narratives also emphasised the importance of determination when faced with perceived pressure from others. As Fay discussed, this might include pressure from professionals:

**Fay:** *“Some professionals over the years I have felt pushed me towards special school for what I believe an easy way out rather than learning.”*

Caroline described the perceived pressure she experienced from society:

**Caroline:** *“It seems to be popular at present to strive for all children to attend mainstream school and whilst I agree that no one should be excluded from this opportunity, it also needs to be recognised that some children require a specialist setting and that is okay.”*

Determination was also crucial when the parents experienced a “pushy mam” narrative from others. The parents shared:

**Fay:** *“I often feel schools etc. think I am over the top as I like to be in control.”*

**Emma:** *“I’m a bit of a pain...and an over thinker because I constantly think about the different options for Joseph.”*

The narratives suggested that parent determination was required when choosing a primary school. This appeared to manifest in a number of ways including knowing what you want, holding on to a determination to get it right and potentially advocating when faced with pressure from others.

Overall, the narratives suggested that the experience of choosing a primary school was overwhelming and effortful and required determination. In essence, this was clearly a stressful process for the parents. However, the narratives also suggested that certain supportive factors might ease this stressful process.

#### **3.5.4 Theme 4 - Positive Interactions Can Help**

The narratives suggested the stressful process of selecting a school was eased by two distinct factors. Firstly, a range of positive interactions appeared to help. The narratives emphasised that positive interactions during a school visit could ease difficult emotions:

**Fay:** *“The whole staff, every one of them were all so greeting. It was warm and inviting, the whole atmosphere was different.”*

In addition, positive relationships with others appeared to play an important role. Positive relationships with school staff supported the parents during the process, reassuring them at difficult times:

**Fay:** *“I have built up a brilliant relationship with the school: they value my knowledge of Chanel’s condition and are very happy for me to stay with her to build up staff knowledge. This has helped reassure me hugely and built my confidence up even more in them.”*

In addition to the positive relationships with school staff, positive relationships with external professionals also appeared to ease the stressful process. This included support from Portage, SEN Caseworkers and the SENDIAS family support service. Emma shared:

**Emma:** *“The parent support worker has been really important. She has been really efficient and really helpful. They go above and beyond to help him.”*

The narratives also highlighted the importance of positive relationships with family and friends during the stressful process. Caroline described how important her partner was when choosing a school their daughter:

**Caroline:** *“Andy is my absolute rock. He’s so calm about everything, he has supported me one hundred percent.”*

It would appear that a range of positive interactions, including a positive feeling about a school and positive relationships with family, friends and professionals might ease the stressful experience of choosing a primary school.

### **3.5.5 Theme 5 - Life Experience Can Help**

The narratives suggested various life experiences might ease the stressful process of choosing a primary school. Firstly, it appeared that prior experience with SEN processes could help parents manage the stressful school choice:

**Emma:** *“I’ve had a lot of experience with different professionals since having Joseph. I have learned a lot from medical professionals, health visitors and sensory support. These experiences have helped me understand what Joseph needs at school.”*

Furthermore, the narratives also highlighted that life experience associated with age might help to ease the stressful process.

**Caroline:** *“I believe my age, 43, and life experience has really helped me in this process. I am not afraid to challenge professionals or question why schools operate in a certain way. My younger self may not have been so resilient and empowered.”*

Furthermore, seminal life moments appeared to ease the stressful process, helping parents to problem-solve. For example:

**Fay:** *“A comment I heard online once has always stuck with me, it said ‘special schools usually have a large trampoline in the dining area...there is no trampoline in the real world.’”*

**Caroline:** *“The real turning point was a conversation with a relative who is a secondary school teacher.”*

Therefore, various life experiences including prior experience with SEN processes, age and seminal moments, appeared to ease the seemingly stressful process of choosing a primary school.

### **3.6 Discussion**

The overarching themes appeared to be of particular significance when considering the research question *‘How do parents experience choosing a primary school for their child with SEN?’* These themes will be discussed in turn and positioned alongside existing literature and theory.

#### **3.6.1 The Process is Overwhelming**

Arguably, the most significant experience reflected in the narratives was that the process was overwhelming. Difficult emotions appeared to dominate, with parents sharing feelings of worry, fear and guilt, which ultimately lead to experiencing stress. This finding is consistent with previous research (Lalvani, 2012; Mann et al., 2015; McNerney et al.,

2015), and Tissot (2011, p. 3) states, 'parents find obtaining appropriate education provision stressful'.

These negative emotions appeared to be stimulated by difficult events during the process of selecting a school. This included times of frustration with professionals, which appeared to be a commonly cited experience when choosing a school (Bajwa - Patel & Devecchi, 2014; Flewitt & Nind, 2007; Tissot, 2011). Parents were also overwhelmed when they were struck by the magnitude of their decision as well as when they experienced self-doubt regarding their choice. This finding is consistent with previous research by Flewitt and Nind (2007) and McNerney et al. (2015), who describe the decision as a burden.

The experience of loneliness appeared to be an interesting finding in this study. One of the parent narratives suggested the process could be isolating, as she felt she was ultimately left to make the decision on her own. However, the theme of loneliness appeared to be a significant finding in all three of the parent dialogic discussions and the narrative "big stories", with the co-researchers discussing feelings of isolation during their experience of choosing a primary school for their child with SEN. The experience of loneliness translated into only one of the short parent narratives. It is suggested that, due to the public dissemination of these narratives in the LA, some of the parents may have been reluctant to openly share this private, vulnerable emotion. Thus, it is acknowledged that the evidence in the short narratives for the theme of loneliness is sparse. However, this theme was underpinned by evidence from the PAR cycles and in the "big stories" and appeared to significantly add to the understanding of how parents might experience choosing a primary school for their child with SEN.

In existing literature, the concept of loneliness seems to only appear in Flewitt and Nind (2007), a school choice study focused on early years provisions. It is possible that, as the children were in the early stages of education, their parents had not yet had significant opportunity to develop relationships with other parents experiencing this specific primary school choice process. Consequently, this finding reflects an important practice consideration for parents' selecting a primary school. Local support networks, potentially facilitated by Educational Psychologists (EPs), schools or LA staff, which

bring parents together during the stressful school choice process could support the development of positive parent support networks and reduce potential difficult feelings of loneliness or isolation.

### ***3.6.2 The Process is Effortful***

Parent narratives suggested that the experience of choosing a primary school was effortful. This was reflected in the parents' reports of extensively researching schools via online searches, reading OFSTED reports and engaging in multiple school visits. The narratives suggested that the process of gathering information was vital for making an informed choice, though this required parents to chase information from professionals and scrutinise conflicting advice. This finding is consistent with previous research (Bagley & Woods, 1998; Flewitt & Nind, 2007; Lalvani, 2012; Mann et al., 2015; McNerney et al., 2015). The narratives gave a sense that the effortful information gathering was essential for choosing a primary school. The findings of McNerney et al. (2015) and Mann et al. (2015) suggest that this level of effort is above and beyond what is required of parents when choosing a school for a typically developing child. It is therefore reasonable to suggest that parents of children with SEN have to exert additional effort when choosing a primary school.

Further, the narratives communicated a sense of struggle, which required parental effort. In particular, the parents appeared to exert effort by placing their personal feelings about provisions aside in order to explore different schools for their child. This finding could be interpreted through the concept of cognitive dissonance (Festinger, 1962) whereby, when faced with contradictory beliefs, ideas or values, an individual may experience a sense of discomfort. The narratives suggested that each of the parents experienced cognitive dissonance regarding their personal values and what was best for their child and that battling this dissonance was effortful.

### ***3.6.3 The Process Requires Determination***

The parent narratives suggested that the process of choosing a primary school required determination. The parents all had a strong sense of what they wanted for their children,

including good support from staff who understood SEN, responded to children effectively and encouraged development and inclusion. This finding is consistent with Flewitt and Nind (2007) who found that resources, services and knowledge of SEN were important to parents when choosing a school.

The parents demonstrated a determination to hold on to these priorities when choosing a primary school, particularly when they experienced perceived external pressure. The narratives stated that the parents experienced perceived pressure from professionals during the process. Bagley and Woods (1998) propose a theoretical model of school choice based on instrumental and academic priorities. They suggest that parents prioritise social development factors when choosing a school, whereas professionals are more likely to focus on academic factors. Research suggests the academic drive of certain schools might result in professionals steering parents of children with SEN to specialist provisions in order to maintain their academic standards (Bagley & Woods, 1998; Bajwa - Patel & Devecchi, 2014; Runswick - Cole & Hodge, 2009). The parents' experiences of perceived professional pressure in this study could be attributed to the performative nature of schools and the application of market forces to education (Norwich, 2016).

In addition, the narratives suggested that the parents experienced being labelled as a "pushy mam" due to their active role in the school choice process. This is consistent with findings by Lalvani (2012, p. 482) where parents experienced being labelled as 'the mother from hell' due to their determination with professionals. This finding could be considered through a Foucauldian lens (1991), whereby challenges to perceived institutionalised power might be considered threatening to professionals.

The narratives emphasised that the experience of choosing a primary school required parental determination. Current literature often reports that parents perceive the school choice process as a battle (Bagley & Woods, 1998; Bajwa - Patel & Devecchi, 2014). The narratives in the study reflected the parents' determination, driven by their desire to choose the right school, despite adverse circumstances or perceived obstacles. The narratives often suggested that the parents adopted an advocacy role as a way of demonstrating their determination. This finding is consistent with existing literature,

which reports that parents often act as advocates for their child when choosing a school (Hess et al., 2006; Lalvani, 2012).

### ***3.6.4 The Supporting Role of Positive Interactions***

When writing about their challenging experiences of choosing a primary school, the parents suggested it was eased by various positive interactions. Of significance were their positive interactions with schools, which resulted in a good feeling about a setting. This good feeling appeared to be underpinned by positive staff attitudes and a welcoming school ethos. This finding is consistent with research by Flewitt and Nind (2007) whereby parents' feelings of anxiety were eased by positive interactions with school staff.

In addition, the narratives also highlighted that positive relationships with professionals enhanced parents in the process of choosing a primary school. In particular, positive relationships with school staff, Portage, and the SENDIAS parent support service helped the parents to manage the process. This finding is consistent with existing literature (Bajwa - Patel & Devecchi, 2014; Lalvani, 2012; McNerney et al., 2015). Interestingly, Flewitt and Nind (2007), Bajwa - Patel and Devecchi (2014) and Tissot (2011) suggest that relationships between LA representatives and parents are often reported negatively. However, the narratives suggested that SEN caseworkers were regarded as a source of support for parents in this study. This finding could potentially be explained as a result of the trusting relationships built between parents and their SEN caseworker.

Positive relationships with family and friends were also reported to be supportive, which helped the parents manage the process of choosing a primary school. The parents discussed how these positive relationships alleviated stress during the process and that parent support groups also helped. This finding is consistent with Flewitt and Nind (2007) and Bagley and Woods (1998), who all cite the positive influence of family and friends when choosing a school.

Therefore, it appeared that positive interactions with school settings; school staff, SEN professionals, family and friends helped the parents to manage the process of choosing



a primary school. This finding has particular implications for future practice, which is further discussed in section 3.10.

### ***3.6.5 The Supporting Role of Life Experience***

The narratives suggested that the stressful process of choosing a primary school was eased by various life experiences. Firstly, prior experience with SEN procedures appeared to help prepare the parents to manage the process. This finding was reflected in one parent's prior experience of choosing a primary school for an older child with SEN, and in a different narrative, through a parent's experience with different SEN professionals in the early years. In addition, the experience that comes with age was reported to have a supportive influence, helping one parent to manage the process. The supportive influence of life experience appeared to be a novel finding in the body of school choice literature. However, it could potentially be explained via self-efficacy theory (Bandura, 1982). Bandura (op cit) suggests that successful experiences in the past may act to increase a person's belief in their ability for the future. It is suggested that prior experience of successfully engaging in SEN processes and life experiences over time might act to increase a parent's self-efficacy, supporting them to manage the apparently stressful and challenging process of choosing a primary school.

Finally, the narratives intimated that seminal moments eased the challenging process of choosing a primary school. One parent reported a seminal moment after reading an online article whilst another parent discussed a seminal moment after a conversation at a party. These seminal moments of life experience appeared to support clarity and helped the parents to disentangle the school choice dilemma. Whilst this again appeared to be a novel finding in the body of school choice literature, it could be explained by double loop learning theory (Argyris, 1976). Argyris (op cit) suggests that double loop learning enables individuals to question their underlying assumptions and beliefs through dialogue in order to better understand their perspectives and resolve conflict. During the seminal moment, the parents appeared to go beyond any defensive reasoning by inviting others to challenge their views on school provisions and thus demonstrated their willingness to alter their position on a school. It is possible that this interaction produced valid feedback for the parents and helped them to generate

important information and feelings towards disentangling their school choice problem. Therefore, it could be argued that seminal moments of life experience potentially generated double loop learning, subsequently supporting parents to engage in the process of choosing a primary school.

### **3.7 Limitations**

This research had a number of limitations. Firstly, this PAR project was small and included parents from only one area of North East of England. A future project that includes parents from a range of areas in England could support the construction of a broader understanding. The parents who engaged as co-researchers were all mothers, which may have overrepresented the views of women. A future study could potentially seek to include the perspectives of fathers and broader carers in order to represent a diversity of parent voices. As previously discussed, the parents had a reduced role in the thematic analysis of the short narratives. A future study could possibly consider more flexible times for co-researchers to meet in order to facilitate childcare. Finally, this empirical research did not apply a qualitative validity tool and this is acknowledged as a potential limitation. This decision is discussed in more detail in Chapter 2, section 2.8.

### **3.8 Conclusions and Implications**

This project set out to explore a specific aspect of the process of early education transition (EET) and asked: 'How do parents experience choosing a primary school for their child with special educational needs?' In-depth understandings of three parents' experiences were generated through the use of PAR, a narrative approach and were underpinned by Bakhtinian dialogue. Thematic analysis of narrative data suggested that, whilst each individual experience was unique, the process of choosing a primary school could be overwhelming and required significant parental effort and determination. In essence, the findings of this study suggested that choosing a primary school was a stressful experience for parents of children with SEN. This is consistent with wider literature with regard to school choice for children with SEN (Bajwa - Patel & Devecchi, 2014; Flewitt & Nind, 2007; Hess et al., 2006; Lalvani, 2012; Mann et al., 2015; McNerney et al., 2015; Rose et al., 2017; Tissot, 2011).

However, whilst this study found that school choice for a child with SEN was stressful, it also found that life experience and positive interactions supported the parents to engage in the process. Prior life experience, such as familiarity with SEN procedures, and experience from age were found to bolster the parents' self-efficacy (Bandura, 1982), enabling them to engage in the school choice process. Seminal moments of life experience also provided opportunities for double loop learning (Argyris, 1976), which supported the parents to disentangle their thinking surrounding their primary school choice.

Positive interactions also helped. Social support provided by school staff, SEN professionals, family, and friends acted to ease the challenge associated with the parents' difficult primary school choice. Given that the parents in this study reported feeling lonely during the process, social support provisions appear to be an important future practice consideration for LA professionals. By establishing and facilitating networks of parent support, it is argued that EPs, school staff and LA SEN teams could generate social support between parents making the primary school choice for a child with SEN, thus combatting the potential feelings of stress and loneliness associated with this overwhelming process.

The findings of the meta-ethnography and empirical research have specific implications for the practice of EPs. In particular the activities of consultation and training, as set out in the Currie Matrix (Currie, 2002), could have a role in improving transition practices through the dissemination of good practice and structured support for schools and families.

In this study, parents of children with SEN appeared to experience a sense of exclusion by education professionals during their child's transition to primary school. Parents in both the meta-ethnography and the empirical research also discussed times when they experienced a sense of frustration with the associated professionals during their child's transition to school due to conflicting advice or a sense of perceived pressure to choose a certain type of school. Coupled with feelings of anxiety and fear surrounding the transition process, the transition to primary school was found to be a complex and stressful time for parents of children with SEN.

However, the findings of the meta-ethnography and empirical research suggest that positive communication and interactions between parents and professionals can engender trusting relationships, which can consequently support parents to effectively participate in their child's transition. It is therefore important that education professionals are equipped with the knowledge and skills to create effective partnerships with parents during the transition process.

These findings have implications for EPs, who can support the professional development of education professionals. Via training focused on parent participation theory and practice, EPs can develop education professionals' knowledge and skills to cultivate authentic parent partnerships and construct ways in which this could be enacted in their school transition processes. Furthermore, education professionals may benefit from additional input through training to refine their skills surrounding the ways in which they can support parents' in the school choice process, whilst avoiding undue pressure regarding a particular type of school choice.

EPs also engage in problem solving and re-framing during consultations with specific families and schools. In their consultation role EPs can support parents and education professionals to develop an understanding of a good school transition for those involved, discuss and address potential feelings of anxiety and construct bespoke approaches to support a positive and successful transition to school.

This small-scale study contributes to the small body of existing school choice literature for children with SEN, bridges a literature gap regarding parents' experiences of primary school choice and contributes to an on-going LA review of school provision. By researching with rather than on parents, the PAR approach adopted in this study acted as a methodological disruption to traditional parent-professional relationships and supported parents to actively contribute their experiences of school choice. These findings were disseminated to LA strategic leads and it is hoped they will contribute towards a local review of educational provision in the area. This study therefore demonstrated that, through critical consideration and power sharing endeavours, it is possible for parents and professionals to create more equitable partnerships towards insight, understanding and the continuous improvement of educational practice.



## Chapter 4. Appendixes

### 4.1 Appendix A Meta-Ethnography First and Second Order Map<sup>3</sup>

Rae-Brown (2011)	Spencer-Brown (2015)	Dockett et al (2011)	Hutchinson et al (2014)	Podvey et al (2010)	Russell (2005)	Villeneuve et al (2013)
<b>Challenges communicating with professionals</b>						
	<p><i>"I feel slightly dismissed regarding my child's issues. I need more one on one from his paediatrician and his transition team"</i></p> <p><i>"Educators need to communicate without being prompted by me."</i></p> <p><i>'Better communication skills are needed so that parents do not feel excluded.'</i></p> <p><i>"One of my biggest struggles was getting the SEN team to understand my family"</i></p>	<p><i>"She had resorted to working through an early intervention teacher to make appointments to visit schools because the school won't talk to just parents"</i></p> <p>This was the time that targeted early childhood programs ceased and when families had to navigate the unfamiliar landscape of school education and school education support.</p>	<p>One week prior to starting school, parent still unsure of supports in place "Do they have the assistant and everything lined up?"</p> <p>Parent reported having little direct contact with child's teachers and little information about child's activities in the classroom.</p> <p>Parent expressed frustration with receiving little detail about child's school day from teacher despite requests.</p>	<p><i>"Because in the beginning, we heard nothing. I would like to see more notes from the teacher, maybe just once a week."</i></p> <p><i>"I wouldn't say there's communication on the day-to-day basis..."</i></p> <p>While all families sought communication with professionals, this did not happen.</p> <p>Participants were disappointed at the difficulty they experienced in</p>	<p><i>"I have asked all the way along to be involved in every step of it. That hasn't happened."</i></p> <p>Parents experience a lack of opportunities to discuss issues such as support with school staff.</p>	<p>Parent reported expecting more following from the school after the initial transition meeting.</p> <p>Staff had no knowledge of child's 'All About Me' book at point of school change despite discussing it at initial transition meeting. "Where did all that information go?"</p> <p>All three parents found it</p>

<sup>3</sup> First order constructs are italicised font; second order constructs are standard font.

Rae-Brown (2011)	Spencer-Brown (2015)	Dockett et al (2011)	Hutchinson et al (2014)	Podvey et al (2010)	Russell (2005)	Villeneuve et al (2013)
	<i>culture.</i> "		<i>"It would be nice to get a little bit more information about what's happening with him"</i>	accessing information in a timely manner.		challenging to arrange frequent and informative meetings with teachers.
<b>Feeling like an outsider</b>						
	<p>Parent reported expecting more following from the school after the initial transition meeting.</p> <p>Staff had no knowledge of child's 'All About Me' book at point of school change despite discussing it at initial transition meeting. "Where did all that information go?"</p> <p>All three parents found it challenging to arrange frequent and informative meetings with teachers.</p>	<p>The complexity of the process was increased for some families who felt that their input into the decision was not valued and that only the voices of professionals were heard.</p> <p>For these families, there was a sense that decisions were made by others and that action would only occur when others were ready.</p> <p>Three parents outlined both actions and comments that positioned them as neither knowledgeable about the education system nor about how best to help</p>	<p>Participant describes meetings scheduled to accommodate the professionals without consulting her about her availability.</p> <p>Parent expressed the school made her "give up control" of child's health and development.</p> <p>Parent learned the school had changed support despite what she had told them.</p>	<p><i>"I'm worried about being left out of the whole thing, of giving up the control of – now she's going to be at school"</i></p> <p>Despite early expectations of remaining involved, families found that as their children transitioned to pre-school, they were much less involved in treatment.</p>	<p><i>"It's as though I'm not going to have a say in her education. It's all been mapped out for her without my consent."</i></p> <p><i>"They have held their meetings without me and then they have had a meeting afterwards to tell me what's been discussed and what is to happen."</i></p>	<p>Parent reports decisions are made for her child despite her expressed wishes.</p> <p>Parent not consulted about key decisions for her child.</p>

Rae-Brown (2011)	Spencer-Brown (2015)	Dockett et al (2011)	Hutchinson et al (2014)	Podvey et al (2010)	Russell (2005)	Villeneuve et al (2013)
		their child.				
<b>Being an advocate</b>						
<p>Families seeking information to understand their child's SEN in order to advocate for their child.</p> <p><i>"I decided that I needed to take a look at this, and I need to research this and I need to be her advocate"</i></p>	<p><i>"I still need to work on it in order to serve my child better"</i></p> <p><i>"I feel like I have to advocate for my child every step of the way."</i></p> <p><i>"My role is to advocate. I am my son's number one fan"</i></p>	<p><i>"I think by the time we got to actually apply for the funding I think [school staff] had just about had enough of me"</i></p> <p>However, one parent described marshaling the support of the child's doctor, and then the local Member of Parliament, to prompt action.</p> <p>"I'm so tired of fighting and trying to prove to people what is the matter with Walt."</p> <p>Some families consistently sought information about what was happening for their child; others provided information and pushed to have this accepted by the</p>	<p><i>"Be an advocate for your child, support them, be there for them, find answers, and see what you can do for your child."</i></p> <p>Participant identified her driven personality and her determination to do everything she could for her children as central to her advocacy role.</p> <p>Parent uncomfortable advocating but does it because it is important to ensure child "gets what he needs".</p>	<p><i>"This is how it is. And I hate to say it, the squeaky wheel gets the grease, and that's my job, and it's to bitch"</i></p>	<p>Parent reports continuing to ask the staff for information about what child is doing and what she could do to support him.</p>	<p>Parent reports researching Down's Syndrome extensively and using information to advocate for child.</p> <p>Each family described advocating vigorously for their view of inclusion for their child.</p>



Rae-Brown (2011)	Spencer-Brown (2015)	Dockett et al (2011)	Hutchinson et al (2014)	Podvey et al (2010)	Russell (2005)	Villeneuve et al (2013)
		school.				
<b>Unfamiliarity with SEN processes</b>						
<p><i>"I'm not sad, I just don't know what's going on."</i></p> <p>Parents experience anxiety due to the mystery of SEN processes.</p>	<p><i>"At the preschool/ kindergarten age the parents are still trying to figure out how the whole thing works in general"</i></p> <p>Parents felt jargon about assessments was difficult to understand and professionals failed to fully explain their language.</p>	<p><i>"You get one [set of] information from one source but you get a different lot of information somewhere else. What do you do?"</i></p> <p><i>"You don't know and it's only after you've been through it that you start getting a bit more clued up."</i></p>	<p><i>"I don't know what else you'd put on it. Is it just behavior and communication? Do academics go on that sometimes? Because it's the first time through, now at this point I'm just waiting."</i></p> <p>Parent uncertain of child's <i>"rights in the school setting"</i></p> <p>Parent reported she did not know much about the transition meeting or who would attend.</p>	<p>Transition between settings marked a lack of understanding of the new system.</p>	<p>For the majority of parents, SEN procedures were completely new. Professionals assume parents understand SEN procedures, but not all parents do.</p>	<p>Parent voiced a frequent concern of parents about "so much information" in one transition workshop.</p> <p>Mother realised that special education was new and was uncertain of what was to be included in an IEP.</p> <p>Parent unsure of how to "respond" to child's IEP.</p>
<b>Concern for the future</b>						
	<p><i>"One of the barriers I fear is that he is going to face is...he is going to lose part of his therapy and this makes me nervous."</i></p>	<p><i>. "That might not be until June next year, half way through the year...at the very best he will be 6 months behind...I can't figure this</i></p>			<p><i>"I felt my daughter's future had been taken out of my hands."</i></p>	

Rae-Brown (2011)	Spencer-Brown (2015)	Dockett et al (2011)	Hutchinson et al (2014)	Podvey et al (2010)	Russell (2005)	Villeneuve et al (2013)
		<i>whole thing out.</i> "				
<b>Positive emotions</b>						
<p><i>"I'm thrilled [at the services]. I was hoping for that. I knew she needed it."</i></p> <p><i>"I was really happy with the IEP meeting . . . they offered me services according to my concerns."</i></p> <p><i>"I'm ridiculously glad I got the assessments prior [to the meeting]."</i></p> <p><i>"I'm excited."</i></p> <p>Relief their child would be receiving services and support from the schools.</p>	<p><i>"Relief knowing that I am taking the right path for my daughter"</i></p> <p>Feeling of satisfaction when parents were valued as members of their child's transition team.</p> <p><i>"I feel encouraged and empowered."</i></p> <p><i>"It has been positive. It hasn't been easy but it has been positive."</i></p> <p><i>"Overall it has been good"</i></p> <p>Parents pleased when the transition is less troublesome than they anticipated.</p>	<p>Happy that child's needs are being recognised and additional support allocated.</p> <p>A number of parents looked forward to their children starting school as a means of accessing regular support.</p> <p>Several parents were looking forward to the notion that there were other people who were charged with responsibilities to care for and educate their children.</p>				
<b>Unwelcome emotion</b>						
All families expressed feelings of anxiety during their child's initial	<i>"Parents are vulnerable and scared"</i>	Assessments were times of tension for families, with major decisions about	Parent left feeling anxious about child's health and well-being in new	<i>"It's scary, but in the end, it's the best thing for your child"</i> Participants	<i>"After the meeting at the Early Years Centre I came out sort of feeling let</i>	Parents experience "crisis" and increasing

Rae-Brown (2011)	Spencer-Brown (2015)	Dockett et al (2011)	Hutchinson et al (2014)	Podvey et al (2010)	Russell (2005)	Villeneuve et al (2013)
transition to school. <i>"I am worried about it."</i>	<i>"I felt judged"</i>	access to specific services and educational supports based on these.  Feelings of anxiety and tension when previous support was withdrawn at the transition point.  Families sometimes felt overwhelmed by what they described as a continual fight to have their children's needs addressed.	settings.  Parent expressed she was worried about being seen as a difficult parent by professionals  Parent reports feeling overwhelmed by information from professionals because "it's hard sometimes to try and keep it all straight."  Parent very upset during child's first week of school.	described the process of transitioning from early intervention to pre-school special education as 'scary'.  Transition between settings essentially constituted a loss and a reduction in comfort.	<i>down, upset and an outsider"</i>  Parent reported feeling concern about sending her daughter to school at such a young age.	anxiety as entry to school approaches.
<b>Supportive relationships</b>						
<i>Parent discussion support group "I've learned so much from that just going through the same exact process with kids the same, exact age"</i>	<i>"I do not think I could have made it through the entire process without [Parent Network] supporting me"</i>  <i>Parents indicate the value of strong emotional support from their child's teacher and school staff.</i>	Seeking support from family members to prompt action from professionals.  <i>"Professionals are not going to necessarily come out and tell you all the information you want unless you push to find that out"</i>	<i>"We formed a moms' group ... it's moms coming together with [their] children with special needs"</i>  Parent reported relying on her sister, her friends, and a few trusted professionals for support.	Some relied on their own experience and knowledge, while others looked to knowledgeable friends and relatives for support.		

Rae-Brown (2011)	Spencer-Brown (2015)	Dockett et al (2011)	Hutchinson et al (2014)	Podvey et al (2010)	Russell (2005)	Villeneuve et al (2013)
		<p><i>or you speak to other Mums who are in the same spot”</i></p> <p>Local early intervention service that helped them develop a range of skills to support the transition.</p>	<p>Parent relied on support from familiar professionals to facilitate transition meetings.</p>			
<b>Developing trust with professionals</b>						
	<p><i>“Fortunately the team I have was kind enough to break down the language for me...I am not afraid to ask.”</i></p> <p><i>“I developed a really great relationship with his infant/toddler teachers.”</i></p> <p><i>“When I and my child see that the entire team is on board...we have done better”</i></p>		<p>Parent recognises that, over time, her and the school “share this role” of supporting the child.</p> <p>Parent reports she does not yet trust new school professionals in the same way as familiar professionals.</p>	<p>Previous experience of transition for an SEN child allowed participants to trust staff more quickly and find it easier to “let go”.</p>	<p>Parent describes spending time in the new classroom and being reassured that the staff would meet child’s care and medical needs.</p>	



## 4.2 Appendix B: Co-Researcher Information Pack

### PROJECT INFORMATION SHEET

#### Exploring Parents' Experiences of Selecting a School Provision for Their Child with Special Educational Needs

Dear Parent/Carer,

My name is Lynsey Hutcheson and I am a Trainee Educational Psychologist based in XXX. I currently work in local schools in the area and I am also in the third year of an Applied Doctorate in Educational Psychology course at Newcastle University.

I am about to begin a research project exploring parents' experiences of selecting a school for their child with Special Educational Needs (SEN). This research is being supervised by Dr Wilma Barrow and Dr Richard Parker of Newcastle University and the project has been approved by the University's Research Ethics Committee. The findings of this research will also feed in to the 'High Needs Review', an on-going local authority evaluation of provision for children with SEN in Country XXX.

#### **Invitation**

You are invited to take part in a piece of participatory action research (known as PAR). This type of research encourages researchers (me) and parents (you) to **participate** together to identify an issue and take **action** to make changes through **research**. Those who wish to participate will be part of a small group of researchers who will collectively decide what specifically we will study, how we will collect and analyse the information we find and how we will present it to the High Needs Review team in County XXX.

#### **What will happen?**

You will be asked to take part in a series of sessions taking place at the Education Development Centre (EDC) in XXX. The nature and outcome of these sessions will depend on the decisions of you (a co-researcher) and the collective research group.

However, the sessions will be loosely structured around a process of investigation, reflection and action on the topic of 'school selection for children considered SEN'.

In the initial sessions, you will be asked to contribute your experiences of selecting a school for your child with SEN with the research group. Following group reflection and negotiation, you may be asked to take part in focus groups and interviews or interview other local parents in County XXX (to name a few possible research activities).

However, the utmost sensitivity will be given to ensure you are comfortable with any research activity you are asked to engage in.

Should it be required, you will be provided with the appropriate training that reflects the group's chosen research methods. This training may focus on developing questionnaires, interview techniques or analysing information (possible examples). This training will be delivered in a small group setting and will be responsive to the needs of you and the collective research team.

### **Time commitment**

Given the nature of this project, the time commitment will depend on the agreed actions negotiated by the collective research group. However, individual sessions should last no longer than 1 hour each. It is envisaged the minimum time commitment to the project will be five hours across a three-month period.

### **Participants' rights**

You may decide to stop being a part of the participatory action research project at any time without explanation. You have the right to ask that any data you have supplied to that point be withdrawn until the results are submitted. You have the right to omit or refuse to answer or respond to any question that is asked of you. You have the right to have your questions about the procedures answered. If you have any questions as a result of reading this information sheet, please ask me before the research project begins.

## **Benefits and risks**

Whilst the benefits of this project are currently unknown, it is hoped the research findings will provide new insights regarding local parents' experiences of selecting a school for their child with SEN. In turn, the results of the research project will contribute to the outcomes of the High Needs Review in County XXX. Furthermore, it is hoped the PAR approach will promote the inclusive and democratic engagement of local parents and develop their knowledge and skills in research methods.

It is unlikely that this research project will present any known risks to participants. However, there may be some mild discomfort if discussing sensitive issues relating to your child's SEN during potential focus groups or interviews. I am confident that any emerging issues will be dealt with sensitively and supportively. There may also be some mild discomfort with potential audio recording. This is a very normal response and any self-conscious moments will be accepted and acknowledged and those taking part in audio recording will be reassured. Should your participation in the research elicit any issues, a member of the County XXX SENDIAS team will be available for support.

## **Confidentiality and anonymity**

By consenting to participate in this project, your identity and contributions may be known to members of the High Needs Review group in County XXX. Furthermore, fellow co-researchers on the research team will know your identity. Given the nature of PAR, there may be instances where you are identifiable in reports or publications (e.g., in footnotes or in the 'acknowledgement' sections of reports of published accounts of the research). By consenting to participate in this research you agree your decisions regarding the degree of confidentiality and anonymity will be considered in all phases of the project. Furthermore, you agree to act with discretion so co-researchers confidentiality/anonymity wishes can be appropriately safeguarded.

Should you deem it appropriate, you may be acknowledged by name (e.g., in footnotes or in 'acknowledgements' sections of reports of published accounts of the research). However, you have the right to request anonymity in any published accounts of this research until the point of submission.



Non-gender specific pseudonyms (e.g., for direct quotes) will be used in the main text of accounts so that it is difficult for readers to attribute particular comments to you. Should, through the course of the project, the research group collectively decide it beneficial to name members (beyond general acknowledgements), further individual consent will be sought. However, the naming of individual members must be of benefit to the individuals, Newcastle University and XXX County Council.

The research group will take all decisions regarding what information is and is not shared collectively. All voice-recorded data will remain confidential beyond the parameters of the research group. Any data generated during the course of this research will be stored securely in paper or electronic format by the Newcastle University researcher (Lynsey Hutcheson). This data will be retained for a minimum of 12 months following data collection or the minimum time required by law. Typically this may be six, to twelve years or longer. Data will be stored safely and securely via encryption on the laptop of the Newcastle University researcher (Lynsey Hutcheson).

The data collected may be used for the purposes of presentation at conferences or publication. All data will be anonymous unless you have individually consented to be named. Any account excerpts used in presentations will not identify participants or their children by name.

### **For further information**

If you have any questions about this research project at any time then please contact me by telephone 07908020360 or email [L.A.Hutcheson2@newcastle.ac.uk](mailto:L.A.Hutcheson2@newcastle.ac.uk)

Alternatively, if you have any questions that you would prefer to direct to my research supervisor at Newcastle University, please contact please contact Dr Wilma Barrow on [w.barrow@newcastle.ac.uk](mailto:w.barrow@newcastle.ac.uk)

Thank you very much for taking the time to read this information.

### **4.3 Appendix C: Co-Researcher Contract**

#### **Participatory Action Research Group Protocols: Ethical Agreements for Participation**

Participants (to be known as as Co-Researchers) in the \_\_\_\_\_ participatory action research project group agree to participate in accordance with the following protocols:

##### **Respect and Open Communication**

1. Group members agree to communicate respectfully and openly with one another throughout the project. In particular, this means that they agree, individually and collectively, and sincerely to seek (a) agreement about the ideas and language used, (b) mutual understanding of one another's points of view, and (c) unforced consensus about what to do under the circumstances that exist when a decision about what to do is needed.
2. Each group member agrees to respect the rights of others to withdraw from the study at any time, or to decline participation in particular aspects of the study, or to have information they have provided removed from any reports emanating from the study. Group members agree to respect the right of any group member to withdraw from the group, the study, or part of the study.
3. Group members agree to be open with other group members if they think the research is having a negative impact on the group, or on them personally.

##### **Access to Empirical Material**

- All group members will have access to empirical material/transcripts that are generated or collected within the context of the group meetings (that is, as 'common empirical material').

- Access to material that is collected outside of group meetings, but that directly involves group members (for instance in observations or face to face interviews with parents) will be restricted to those collecting the information and those about whom it is collected, unless the group members concerned negotiate for such material to be released to the group for the purposes of analysis or discussion (for example, at a group meeting) or in reports or publications. Group members agree that where others are involved (such as participating parents who may appear in audio-recorded interviews), such release of empirical material to the group will occur only with the consent of those involved.
- Group members agree that if they wish (for their own publications and/or research purposes) to use common empirical material generated within this project, they need to negotiate that with members of the group.

### **Identifiability in Reports and Publications**

- Group members understand that there may be instances where they may be identifiable in any reports or publications on the participatory action research project (e.g., in footnotes or in 'Acknowledgement' sections of reports of published accounts of the research). Group members agree that this needs to be considered in all phases of the project and agree to act with discretion so that the group members can be appropriately safeguarded.
- Considering the conditions outlined above, group members agree that:
  - it is appropriate to acknowledge the group members by name (e.g., in footnotes or in 'Acknowledgement' sections of reports of published accounts of the research); but that
  - non-gender specific pseudonyms (e.g., for direct quotes) are to be used in the main text of accounts so that it is difficult for readers to attribute particular comments to particular people; and

- if, through the course of the project, the group members collectively decide that the naming of the group members in accounts of the research (beyond general acknowledgements) would be beneficial to both the individuals concerned and the institution, and not harmful to others, then individual written consent to be named would be obtained from each of the group members before anyone is named.

### **Reflecting on the Research Process**

- In order to ensure that the research process does not compromise the integrity of the group, or impact negatively on those involved, group members agree to periodically review (as a group) how the research is unfolding and impacting on the group and the individual group members.

### **Changes to Group Membership**

- Group members agree that, if new members join the group during the project, the new members will be invited to take part in the research and written informed consent will be obtained before they become involved. Group members agree that the new group members will be required to agree to these group protocols.
- Group members agree that if one or more of the group members no longer wish to be involved in the study, then other group members respect that group member's right to determine what of his or her previous statements can be used in the research.

### **Representation**

- If not directly involved in the writing of reports about the initiative, group members will be given an opportunity to check that the work and comments of the group are fairly, relevantly and accurately represented in any reports of the research.
- Group members agree that, if they feel that representations relating to them are not fair, relevant or accurate, they will negotiate with the authors of the report, and with

other members of the group, to resolve the issue, keeping in mind the principle of respect and open communication.

- The authors of any reports about the work of the group will notify the group about the writing and the existence of the reports, and will give group members access to the report and, so far as is practicable, will make copies available to group members on request.

### **Mediation**

- In the very unlikely event that there is conflict/relationship breakdown (between group members) that cannot be resolved and that is detrimental to the project and/or well-being of group members, group members agree that \_\_\_\_\_ [a credible and neutral person] will be asked to act as mediator to help those concerned work through the issues.

### **Certification of agreement**

We, the undersigned, collectively, individually, and voluntarily give consent to our participation in the critical participatory action research initiative \_\_\_\_\_.

In providing our group consent, we agree that:

- We have each read an outline of the proposed initiative, discussed it, and understand the purpose, methods, potential risks and benefits of the research.
- We agree that our participation will be of value to us as parents of children considered to have Special Educational Needs, reflecting on our decisions about school provision for our children, beneficial to the discipline and profession of education in XXX County Council, and likely to contribute to the development of participatory action research as a research approach.
- We regard the study as an extension of and contribution to what we are already committed to doing in our involvement with XXX County Council's 'High Needs

Review' group. We see the study as an addition to our established process of collective self-reflection.

- We undertake individually and collectively to participate in the study in accordance with the group protocols above, and in keeping with the values of respect, justice and beneficence.
- Each of us recognizes that we have a right to withdraw without penalty at any time. If a group member withdraws, we respect the group member's right to determine what of his or her previous statements can be used in the research.
- We understand that not everyone will be able to attend every meeting dedicated to the research project and assume that evidence will continue to be gathered in a group member's absence.
- We understand that if we have any complaints, concerns, conflicts or disputes about this research we can contact the person identified below, who has agreed to mediate if a complaint, concern, conflict or dispute arises in the course of this critical participatory action research initiative:

Co-Researcher 1:

Name: \_\_\_\_\_ Position: \_\_\_\_\_

Address: \_\_\_\_\_

Contact Number: \_\_\_\_\_ Email: \_\_\_\_\_

Name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date : \_\_\_\_\_

#### 4.4 Appendix D: Narrative Interview Questions

*Parents Experiences of Selecting a Primary School for Their Child with SEN, based on Morgan (2000).*

1. Can you please tell me about X and what it is like to be her Mum?
2. What does being a Mum of a little girl with special needs mean to you?
3. What ideas do you have about what a “good” school would look like for X?
4. How did you develop these ideas?

-Can you please tell me what it has been like to choose a school for X?

-What do you see as your role in choosing a school for X?

-Can you tell me about the role of other people in choosing a school for X?

1. What did it take in order to decide a school for X?
2. Can you tell me about how choosing a school for X made you feel?
3. Can you tell me about how you have managed this time?
4. What impact has choosing a school had on the life of you and your family?
5. Can you tell me about how choosing a school for X has impacted on how you think of yourself as a parent?
6. What do you think choosing a school for X says about your abilities, skills and knowledge as a parent?

#### **4.5 Appendix E: Transcription Reflection Questions**

- What were your first impressions of the text?
- What parts of the text stood out to you?
- Did anything surprise you in the text?
- Is there anything you disagree with in the text?
- Would you change anything about your interview transcription?



#### **4.6 Appendix F: Excerpt of a Transcription/”Big Story”**

**Caroline:** Oh incredibly rewarding. I do [pause] I am conscious that she gets far more attention than her sister. And I do try and make special time for Charlie, so I’ll take her out, just the two of us. But I can see in Charlie’s behaviour, and this is no bad behaviour at all, there’s sufficient age gap with her being ten for her to...she understands, she doesn’t appreciate, but she understands. But I notice...Charlie’s always been talkative, but she’s- she now talks over peo...she will get louder and louder and louder, and talk, just ramble about anything. And I think it’s just her way of saying I’m here too.

**Lynsey:** Yeah.

**Caroline:** And that breaks my heart a little bit...

**Lynsey:** It’s tough.

**Caroline:** ...because I just think I know I’m not letting her down cos I do- I do Guides with her, which I really haven’t got time- time or energy for, I really haven’t.

**Lynsey:** No, that sounds tough.

**Caroline:** I really haven’t, but you know, it’s some...I need to be doing things for her as well that’s- that’s just about her. So like if- if I was just dealing with Tara, that’s one thing, but when you’re trying to...

**Lynsey:** yeh

**Caroline:** ...you’re trying to be a good mum to the other one as well, it is...

**Lynsey:** mmmm

**Caroline:** It is hard work.

**Lynsey:** Yeah, yeah.

**Caroline:** It is hard work.

**Lynsey:** Thank you. So I wonder if this is...this might be...it's a similar question... but it's slightly different in that what- what I'd like to know is what's it like to be a mum of a little girl who's considered to have special educational needs, what does...?

**Caroline:** [Pause] I guess for me, I- I just feel very strong...I need to be her advocate. So I don't want Tara put in a box, you know, special educational needs we- we're very good aren't we, at giving...it's like cerebral palsy, we give a term to something and it kind of tidily puts somebody in a box of they're in this group. And actually, every single child and person with special needs is completely individual. Y- you know, there are some wonderful professionals working with Tara, but they're working with lots of children. They've got enormous caseloads and they haven't got time to. So I have to be her advocate, or me and her dad, have to be her advocates, and that's what it's about for me, more than- more than her having a special need. We can work with that, that's- that's fine, there's all sorts we can do to support her. We've just got to make sure we keep pushing. I know that sounds, I don't mean pushing in a- in a negative way, I just mean, you know, making sure that she's getting the best so that she can achieve the best really.

**Lynsey:** So it sounds like you're saying two things there. First of all special...the term or the label or whatever we want to call it, special educational needs, isn't really a super important term for you, it's more about what individually Tara needs.

**Caroline:** Yeah. Yeah, absolutely. I mean if- if before I had her someone had said oh, you're gonna have a child with special needs, I would have been in a panic, oh my god, oh my god, it sounds terrifying. It sounds really scary, but actually the reality is you've got this wonderful little person who just needs to go about certain tasks differently than what's considered normal. So yeah, that bit really doesn't...and I remember when she was...we first knew there was something not quite right, and my sister said oh, will she have to go to a special school. And my first reaction was, [sharp intake of breath] no. And yet here I am, I have fought [laughter] tooth and nail to get her into special school. Because it's like well actually, that's- that's how she's gonna achieve her best.

**Lynsey:** Yeah. Okay, so there's- there's the kind of the label aspect, which doesn't sound like it's too important, it's more about what she needs and what's going to be best for her.

**Caroline:** Yeah, definitely.

**Lynsey:** And there's also the- the- the aspect of what you feel that you have to be the advocate.

**Caroline:** Yeah.

**Lynsey:** You're the advocate.

**Caroline:** Definitely.

**Lynsey:** her champion.

**Caroline:** Yeah.

**Lynsey:** Yeah.

**Caroline:** Yeah, absolutely.

**Lynsey:** So and I'm- I'm just gonna lead on from that question slightly. What does the term special needs even mean to you? And I suppose maybe you've kind of already answered that already, but.

**Caroline:** Yeah, I [sighs] I guess broadly it suggests to me that somebody- somebody has a condition be it physical, mental, emotional, whatever it maybe, you know, a huge spectrum. That means in order for them to achieve in all aspects of life basic independence or educationally, or socially, or whatever, they just need to go about things differently than those of us who haven't got those challenges. And that's all it means to me. I really do believe that it- it's [sighs] before having Tara if- if somebody had said to me special needs, I guess in my head I'd have one extreme in my mind.

Whereas now I realise actually it's- it's so huge, isn't it, it's so broad and actually we've probably all got special needs to some...haven't we, really?

**Lynsey:** Yeah. Well we do. Yeah, we all have needs, don't we? So...

**Caroline:** Exactly, and you know...

**Lynsey:** Whether we consider them special or not.

**Caroline:** Yeah, exactly. And yeah. So I don't know if I've answered your question [laughs].

**Lynsey:** That's perfect. That's absolutely perfect. Okay, so this is a slightly different topic, and I'm sure you'll be able to tell me this in great detail. I know you...so what ideas do you have about what a good school would look like for Tara?

**Caroline:** Okay. Well in an ideal world where a county council has got infinite pots of money, that they can just keep spending [laughter]. Exactly, so in cloud cuckoo land [laughter] somewhere I guess where they can look at her as an individual, say right where are we now, where do we want to get to in whatever, be it six months, be it a year. And ultimately where- where are we looking to get to and how can we tailor out activities with Tara to help her reach those goals, I guess, in simple terms.

**Lynsey:** Yeah, so that's a quite succinct way. So what is it about then the provision, and you've chosen a specialist provision for Tara. What is it that you feel that a specialist provision can do over and above that of one the...?

**Caroline:** The- the biggest thing for us has been about Tara's communication and the fact that she is non-verbal. And that we feel, the best will in the world in a mainstream environment, even if they bring people in who, you know, know Makaton or whatever, we just feel that most of the staff in the special school, I'd say the majority of the staff in a special school will be able to communicate well with her. In a mainstream school you might have her individual support staff who can communicate with her, but she'd still be kind of separated. And I kind of feel in special school she'll be fully integrated. You

know, they've all got their challenges. Everybody working there understands that. If she has a meltdown about something, they're used to dealing with that on a daily basis. She's not gonna be labelled troublesome, even unofficially, you know, somebody's mainstream teacher said oh [sighs, laughs]. And I'm not, you know I'm not...I know schools are great, and they...I...just for me I know how busy a mainstream primary school can be, and best will in the world, unless they could absolutely look me in the eye and guarantee me that Tara would get one to one support every minute of every day, with a consistent person, and that's the key with Tara, is having the consistency of the- the people. Then it's- it's a no goer.

**Lynsey:** Yeah, yeah.

**Caroline:** Really, but it's mainly her communication. Cos she's- she learns really quickly. She learns, she's bright, she is so bright. And I guess some people may think well if she's really bright she doesn't need a special school. Well for me that's all the more reason for her to at least start off in a school where they know how to build that communication for her, you know. And then if that develops and it comes, and the speech is coming. So it maybe two, three, four, five, however many years down the line. They may be coming to us and saying well look, do you know what, we think we could start talking about transitioning her to mainstream. Then we'd be open to looking at that, but we've got to give her the best start.

**Lynsey:** Yeah, okay. So there's a couple of things you mentioned there. I think communication and- and the ability to support Tara's communication...

**Caroline:** Yeah.

**Lynsey:** ...is really important.

**Caroline:** Yeah.

**Lynsey:** Consistency of staff seems really important.

**Caroline:** Yeah.

**Lynsey:** And that you're open to other options, but at this present time that feels like what- what a good school would be like for Tara.

**Caroline:** Yeah.

**Lynsey:** Are there any other things that you feel are...that a specialist provision or what you would consider a good school for Tara would I...would have in it, or would look like?

**Caroline:** Well with her [sighs] physical disability, the- the environment, you know, I mean I- I look at Charlie's current primary school, and there's steps here and there's steps there. And I know they'd put in ramps, I know that. You know, and they- and they pull out ramps when we come to visit. Oh here comes Tara, let's pull out a ramp for her wheelchair, you know. But just generally, the environment, the classroom space was more open, flat, wide, things at a low level, as well as a higher level, just everything's ready for children with different abilities.

**Lynsey:** Yeah, so accessibility is something really important to you.

**Caroline:** Yeah, yeah, that's the word. Yeah, definitely.

**Lynsey:** Good. Thank you. Lovely. Okay, so what I'm interested to know now, is cos you've got really...a really clear idea it sounds like of what's good for Tara, and you're a mum so we would expect that. How do you think you came about developing these ideas about what a good school would be like? What's supported you to- to come to that decision about what a good school for Tara will be like?

**Caroline:** I think it probably started when we- we started going to a portage group. So before she was getting the home portage service, cos there was quite a long waiting list, we went along to a group in [inaudible 17:25] on a Thursday morning. And it was just that- that was my first real interaction with other children with additional needs. And there was a- a huge range of different needs and different abilities. And I guess that was the first...that sort of started [sighs] reducing the, the word keeps coming into my head is fear, I guess fear of- of the disabled and special needs children. And, you know, the- the

fact that [pause] that sounds terrible, but it was. I- I guess there was a- a fear, it's fear of the unknown, isn't it?

**Lynsey:** Yeah.

**Caroline:** And [pause] yeah, so really through- through portage and that kind of taught me an awful lot about other disabilities and other conditions that children might ha...or people, not just children, but they all happened to be children [laughs] might have. And chatting to other parents and carers, and there was, you know, a- a couple of foster carers would go and- and they specialise in fostering additional needs children. And just conversations. And then we were actually a- a family christening, and Tara must have been about two, and one of my relatives has just recently, relatively recently changed professions into teaching. And during his teacher training he spent time and worked in a special school. And he was saying in the current school he's in now, some of the biggest challenges he has is dealing with- with children who are in mainstream, who have got ability, but struggle in that mainstream because the classes are so big, and- and they just struggle. And that as a teacher he hasn't got the time. He knows that if he could give them that bit more time and support, they can achieve just as well as the others. But because he hasn't got the time to give them that focus they start lagging behind. That really struck a chord with me.

**Lynsey:** Yeah, absolutely.

**Caroline:** Really, really struck a chord with me. And then Andy and I just talking about what we wanted for her, and did we want her to be normal in inverted commas, or did we want her to be the best she can be at whatever she wants to do. And to give her...and I mean at that stage as well, we didn't know...I mean to me at the minute I feel like the future looks bright for Tara, it really does. But at that point we didn't really have a definite diagnosis. We didn't really know what...whether she had a learning disability or not. We didn't know, you know, is she gonna develop, is she gonna stay at, you know, certain cognitive level for- for...we just didn't know. And it was really about well we want her to, whatever her best is, we've...we need her to achieve that best.

## 4.7 Appendix G: Example Excerpt of a “Critical Points” List

### Caroline- Dialogic Discussion

*From the review of the transcript and a dialogic discussion, these are the agreed critical points of Caroline’s experience of choosing a school for Tara.*

- Caroline is strong and she is Tara’s advocate;
- It is important that Tara’s individual needs are recognised and she is more than a label;
- Professionals are pushed, its up to Caroline and Andy to advocate for Tara and push to get it right for her;
- Choosing a special school was not an immediate choice just because of Tara’s needs;
- Caroline has “fought tooth and nail to get her into a special school”;
- A good school is one that looks at Tara as an individual and sets appropriate. holistic targets to help her reach her goals;
- Tara’s communication is her biggest barrier and creating a total communication environment is essential. Staff in the special school can do this, it is much more difficult in mainstream. It is also important for Tara to be able to communicate with other children using Makaton and for her to be included with other children and adults.
- Due to this, Tara may be isolated in a mainstream setting whereas she would be fully included in communication at special school due to their Makaton rich environment;
- Staff at sp sch will understand Tara’s “meltdowns” but in a mainstream she may be labelled as “troublesome”. This narrative would be due to a lack of understanding about the frustrations Tara sometimes experiences;
- Tara will get lots of support at sp sch and this support will be consistent;
- OVERALL SP SCH offers- communication/staff knowledge & experience/understanding of needs and behaviours/consistent support and the environment is accessible;
- Tara is very bright and sp sch can give her the best start to establish her communication;
- Tara may not always go to a sp sch, this may change for Caroline. This will depend on circumstances and Tara’s progress. This choice is not set in stone.
- Caroline first began to develop ideas about the best school for Tara at portage group;
- Interacting with children with additional needs showed her this was not scary. The portage group opened Caroline’s eyes to children with additional needs and taught her to “look past the disability and focus on the individual child”.
- Caroline met with and chatted with other parents in the same boat as her about school;
- A discussion with a trusted relative who is a teacher “really struck a chord” with Caroline. This was a tipping point at which Caroline felt sp sch would support Tara to achieve her best. This discussion was highly influential in Caroline’s decision;



## 4.8 Appendix H: Parent Short Narratives

### Caroline's experience choosing a school for Tara

My name is Caroline and my daughter Tara, now 4 years old, was diagnosed at age 2 with Schizencephaly, diplegic cerebral palsy and delayed development. From Tara being very young I have felt that it is my job to act as her advocate and to ensure that I strive to obtain the best for her in order to help her realise her potential. For me knowledge is power and therefore I research...everything! If I have done my research and feel confident that I know what I need to do, I believe that I can truly help Tara. It is as though despite not being able to control her condition, I can control how we deal with it as a family and how she will learn to live with her diagnosis rather than be defined by it. It has always been vitally important to me that Tara is treated as an individual and not labelled or 'put in a box' due to her condition. Choosing a school for your child is a big decision at the best of times but when your child has additional needs the enormity of that decision weighs heavily on parents' shoulders – at least that is how it was for me. If I could sum it up in one word it would be 'stressful'. At first, when coming to terms with Tara's diagnosis, I didn't really consider Special School. I had an image of specialist provision being a place where children who had no ability to learn or achieve were sent. It was through Portage group however and subsequent discussions with other parents and carers that I started to consider specialist provision as a potential route for Tara. But the real turning point was a conversation with a relative who is a secondary school teacher. He was relating his experiences of teaching in a Special School during his training and comparing it to his current role in a mainstream setting. What struck a chord with me was that he was expressing his frustrations in not being able to support all his students in the way they needed. He explained that there were a few of his students who had additional challenges and were they in a specialist educational setting he felt sure they would 'fly' but in mainstream they struggled. Tara's main barrier is her lack of verbal communication. She signs using Makaton and relies on others around her to understand what she is signing. When she is not being understood Tara can become extremely frustrated which can result in her having a meltdown – lashing out at others, biting, scratching etc. I never want Tara's frustrations to be misinterpreted by others as naughty behaviour. I do not want her labelled as the naughty girl. I do not want her to

be always on the edge of friendship groups because of her communication difficulties. Specialist provision is used to dealing with these frustrations but more importantly they are equipped with the specialist communication experience to enable Tara to achieve her best. Classes are small with a high Staff:pupil ratio. She is a bright little girl who loves to learn so for me placing her in an environment where the focus will be on her abilities rather than her disabilities is vital. In spite of the fact that I researched all the provision available and feel sure that a specialist route is right for Tara, I have often doubted myself. I have often been asked by professionals if I have considered mainstream provision for Tara and this has been a huge source of frustration for me, as though choosing Special School is wrong. It is precisely because Tara is bright that her father and I feel so strongly that specialist provision will give her the best start. She will be able to flourish in an environment that is geared to her needs. It seems to be popular at present to strive for all children to attend mainstream school and whilst I agree that no one should be excluded from this opportunity, it also needs to be recognised that some children require a specialist setting and that is ok. One size does not fit all. 'Equality is not the same as equity'. Unfortunately there is no one else to make the decision for you and that can be lonely. My husband Andy is my absolute rock. He's so calm about everything, he has supported me one hundred percent. There have been many occasions when I have wished there was a parent support group for people going through this process. A place where parents and carers can share experiences and sound off. No one can take the decision away from us but it is always helpful to know you are not alone. In the end I believe my age, 43, and life experience has really helped me in this process. I am not afraid to challenge professionals or question why and how schools operate in a certain way. My younger self may not have been so resilient or empowered. Ultimately it is Tara who has kept me focussed. I do what I do for her, to ensure that she has the best start to her education. I will continue to strive for the best for her and if, in time, we feel that she should transition to mainstream then that is something we will look into. Tara is not static and neither should our approach to her education be.

## **Emma's Narrative**

My name is Emma and I have two children called Charlie and Joseph. Charlie is 11 and goes to a local comprehensive school in XXX. Joseph will be 4 on his birthday but I would say developmentally he's not quite 1 year. He has CHARGE Syndrome and has visual and hearing difficulties and some growth differences. He is completely deaf in one ear and has moderate hearing in the other. He also has delayed development and he can't yet walk or talk. Having a child with special needs has taken a very long time to accept but I do accept that he is different and he needs extra time.

Having a child with additional needs can be disheartening but when I look at him now compared to last year his progress is amazing and he's doing really, really well. I don't like the term special needs and prefer the term additional needs because Joseph does need additional help. It is important to me that Joseph is treated the same as everyone else. There will be things that he maybe can't do and things that he won't do but overall I want Joseph's school to treat him the same as all the other kids and I don't want this SEN status to limit him.

The most important thing for me when choosing a school for Joseph is communication and it is right at the top of my list. I have had bad experiences communicating with professionals in the past and there is no room for error when knowing about Joseph's needs. I've had to chase everybody else's tail trying to find out information and I don't feel it is my job to do this. That is why good communication is so important to us. Now I make sure that professionals know I'm not taking any shit from anybody.

When I was choosing a school for Joseph, I looked at the school environment. I want Joseph to continue to have a one-to-one like he has had in nursery. Joseph is unsteady on his feet and he wears a helmet for protection. I need a school that has lots of support for Joseph and one that is going to prioritise his safety. I think all schools should be adapted for additional needs with wider doors, changing areas and sensory rooms but this does not need to be a special needs environment. When choosing a school for Joseph I saw different schools but I really didn't want to be looking around with a chaperone. I wanted to get a true honest picture but I thought it was quite staged. I really

like honesty from schools and I want to see the good and the negative parts so I could get a feel for the place.

I've had a lot of experience with different professionals since having Joseph. I have learned a lot from medical professionals, health visitors and sensory support. These experiences have helped me understand what Joseph needs at school including lots of different sensory experiences and resources and somebody who knows how to sign.

I have chosen mainstream to start with to give him a shot and see how he is. He's done really, really good in his mainstream nursery. The staff in his nursery are lovely and the kids are nice and he gets lots of help. The parent support worker at the mainstream school has been really important. She has been really efficient and really helpful. They go above and beyond to help him. They do research into signs and I'm really happy with the support he has got at nursery. The mainstream school is attached to the nursery and is convenient so it is handy for when I go back to work as my mum lives close by for if he is poorly. All our family have gone to that school, so why wouldn't Joseph? I sometimes think a special needs environment might be more beneficial to him but I just need to see how he gets on developmentally. He might need a school that's more equipped or with people more experienced with additional needs. If that is what Joseph needs, I'm not going to compromise.

It's scary to think that next September Joseph will be at school and it really frightens me to think about it. He is developmentally very young and sometimes I think he's not ready. Choosing a school for Joseph has been emotionally and physically tiring as I worry about everyone else's attitude to him. The attitude of the school is really important to us because they need to understand Joseph. I also worry about the behavioural side of things as Joseph might be naughty and I need the school to understand that he is just frustrated.

Choosing a school for Joseph has been down to me. It's definitely my responsibility to pick a school but I talked to Joseph's Dad about it if I needed to. I would say I've been alone in making this decision for Joseph and it's solely my decision. The advice is there but, if I don't ask for it, the advice will not be given. If I am honest I am probably socially

isolated but I'm not as bad as I used to be. Nothing will stop me from getting the best for Joseph. If that means travelling then that will not be an issue. If I need to pack in work or rely on taxis to get there that will not be problem as I need to make sure that the school is best suited to Joseph and his needs.

I genuinely care where my son goes to school and getting it right is very important to me. Joseph needs a school that is going to adapt to his needs and where he is going to get extra support. When choosing Joseph's school I looked in to the ins and outs of every possibility, as I do like to know the ins and outs of everything. I'm not just putting him into mainstream because it is easier and my decision is not just on a whim, its something I've looked into in great depths. The experience has taught me that I'm a bit of a pain and that I am an over thinker because I constantly think about the different options for Joseph.

For me, giving Joseph a chance at mainstream is important because the world is not equipped for special needs and I want Joseph to learn how to manage the world. I think special needs schools keep children in a bubble and when they leave school it is a massive shock. If he does need a special needs school in the future, it will take me time to accept and will upset my family as we might feel we have taken a couple of steps back. But if a special needs environment is what Joseph needs, then that is the route we will have to go down.

## **Fay's Final Narrative**

My name is Fay and together with my husband Micheal we have three children who each in their own ways have helped make me into the person I am today. Chase 8 has Autism and multiple sensory disorders, Cole is 5 almost 6 and Chanel 4 was diagnosed antenatally with Hypoplastic Left Heart Syndrome and an Intact Atrial Septum. To date Chanel has undergone 23 operations and procedures including 4 open heart surgeries, the first being at birth making her the Worlds Youngest Open Heart Surgery Patient. She also had a major stroke at 17 days old leaving her with poor movement in her left side and resulting in Cerebral Palsy. Chanel also developed left vocal cord palsy and has been tube fed since birth. Given very low statistics for Chanel surviving and being told she would not see the age of two - she is now 4 years old (the oldest ever living in the UK with the combination of her condition) although she will eventually need a heart transplant she has beat every odds against her and I know she will continue to do the same. She is inspirational and the bravest person I know, I feel extremely lucky to be all three of their mums. We probably are not your typical family but we know no different to the medical problems we deal with daily so our lives are our 'normal'. We have been told before what a difficult hand we have been dealt but we know there is always worse. It is up to you how you view a situation. You can be dealt with a difficult, rare and high risk situation and feel unlucky or you can choose to see how you were dealt with a difficult, rare and high risk situation and overcome it, beating every odds along the way and that makes you the luckiest person in the world. I hope my children see that too as I don't want them to dwell on what they cant do but instead live life to the full and know that anything is possible.

Chanel is due to start Reception Class at Seaview Primary in September 2018 which is a mainstream school. It was a lot easier for me to know what I wanted for Chanel and where I wanted her to go through already having gone through the process of choosing a school for a child with SEN once with Chase. Although the word SEN means very little to me as I believe every child/family has something that makes them 'different'. The first time I chose a school for Chase we had a horrendous experience when we choose a school that was simply the closest to where we live. The staff had very poor understanding of his condition but I believe how he was treated shouldn't happen to any

child never mind one with extra needs. This experience left a lasting impression on me and I still to this day feel very guilty for not seeing how poor the school was and for trusting someone with my child and it going terribly wrong. If it wasn't for this I would more than likely have done the same with Chanel - went to the nearest school, trial and error.

With having a bad experience of a school I next did my research online and also read into offstead reports. Mainstream has always been very important to me as I believe it gives children skills they need to live as 'normal' life as possible. Im quite firm on this fact and a comment I heard online once has always stuck with me, it said 'special schools usually have a large trampoline in the dining area so children who find it hard to cope with the dinner time routine can use this to help soothe themselves but what about when you and your family go for a meal at the weekend or go on holiday? Restaurants in the 'real' world cant put a trampoline in for you attending, there is no trampoline in the real world. And this is so true! Of course there is some circumstances and children who do very well in special schools but I think every child should be given the chance in mainstream first as all children deserve a normal life as possible and the rest of the world also need to learn more about disabilities so society in general can learn about all types of people and needs not hide them away or separate them.

With the above being said I still did look at multiple special schools (and even took Chase to visit one) and put my feelings aside to make sure I was making the right choice for my children - my views aside. But it did only confirm my feelings and wasn't for us. Eventually I came across Seaview Primary a mainstream school a little further away from our home. As soon as I visited the school the difference from his last was immense! The whole staff, everyone of them were all so greeting. It was warm and inviting, the whole atmosphere was different. The children all seemed at home and happy and the way the staff spoke to the children was different. They were soft, calm and caring. The headteacher is lovely and has halved all year groups into two sperate classes making smaller groups, with each class a teacher and teaching assistant. Making four teaches to each year group (that is without SEN children and their one to ones) which means all children are a lot more supported.

Chase has had wonderful years now at this school and because of this I wouldn't have wanted Chanel anywhere else because I already know how amazing they are. This made choosing a school this time round quite simple. However Chanel's needs are quite different to Chase's and if anything goes wrong it can be her life at risk and this is on a completely different scale so I am the most nervous for her transition. As well with Chanel's condition and how fragile she was in her earliest years we never let ourselves think too far into the future so this also feels like a huge and emotional milestone. The school have been absolutely amazing though and I actually don't think they could have done more to both help reassure me or be more prepared to care for Chanel in every way. They have done everything from structural work all ready in time for her to letting me be involved in choosing her one to one and helping with teacher training. I have built up a brilliant partnership with the school, they value my knowledge of Chanel's condition and are very happy for me to stay with her to build up staff's knowledge. This has helped reassure me hugely and built my confidence up even more in them.

I do like to do a lot of research so this along with brilliant support from my husband enables us to come to decisions between the two of us although I do feel I have had brilliant support from the school especially the SENCO and headteacher, our SEN caseworker, Portage and SENDIAS over the years. Some professionals over the years I have felt pushed me towards special school for what I believe an easy way out rather than learning but the professionals I have just spoke about supported me in what I wanted and felt best for my children as well as helping me being well prepared for Chanel starting school and her having an EHCP from the age of two. I do often feel schools etc think I am over the top as I like to be in control by nature anyway but especially when it comes to my children and having so many special needs I am very overprotective but once you get to know me I hope they see it's just having my children's best interests at heart as I do also not want them mollycoddled at the same time as I am trying to prepare them to cope and gain skills to live with their conditions not just at school but through the rest of their lives.

I appreciate everyone's situations are different and acknowledge my views may even change when it comes to choosing a secondary school but all I can give is my views and families experience so far...





#### 4.10 Appendix J: Thematic Map

##### Initial Thematic Map

Code	Source	Evidence
Battling challenges (not specific to the question)	Fay Emma	<p><i>"Given very low statistics for Chanel surviving and being told she would not see the age of two - she is now 4 years old"</i></p> <p><i>"Having a child with special needs has taken a very long time to accept but I do accept that he is different and he needs extra time."</i></p>
Strength (collapse with empowered) <b>(Determination)</b>	Fay Caroline Emma	<p><i>"We have been told before what a difficult hand we have been dealt but we know there is always worse. It is up to you how you view a situation. You can be dealt with a difficult, rare and high risk situation and feel unlucky or you can choose to see how you were dealt with a difficult, rare and high risk situation and overcome it, beating every odds along the way and that makes you the luckiest person in the world."</i></p> <p><i>"I am not afraid to challenge professionals or question why and how schools operate in a certain way."</i></p> <p><i>"Now I make sure that professionals know I'm not taking any shit from anybody."</i></p>

Code	Source	Evidence
<p>Prior experience (Life experience)</p>	<p>Fay Emma</p>	<p><i>"It was a lot easier for me to know what I wanted for Chanel and where I wanted her to go through already having gone through the process of choosing a school for a child with SEN once with Chase."</i></p> <p><i>"we had a horrendous experience when we choose a school that was simply the closest to where we live."</i></p> <p><i>"Chase has had wonderful years now at this school and because of this I wouldn't have wanted Chanel anywhere else because I already know how amazing they are."</i></p> <p><i>"I believe my age, 43, and life experience has really helped me in this process."</i></p> <p><i>"I have had bad experiences communicating with professionals in the past and there is no room for error when knowing about Joseph's needs."</i></p> <p><i>"I've had a lot of experience with different professionals since having Joseph. I have learned a lot from medical professionals, health visitors and sensory support. These experiences have helped me understand what Joseph needs at school including lots of different sensory experiences and resources and somebody who knows how to sign."</i></p>

Code	Source	Evidence
Staff attitudes	<p><b>Fay</b></p> <p><b>Emma</b></p>	<p><i>“The staff had very poor understanding of his condition”</i></p> <p><i>“The whole staff, everyone of them were all so greeting. It was warm and inviting, the whole atmosphere was different. The children all seemed at home and happy and the way the staff spoke to the children was different. They were soft, calm and caring. The headteacher is lovely.”</i></p> <p><i>“I never want Tara’s frustrations to be misinterpreted by others as naughty behaviour. I do not want her labelled as the naughty girl.”</i></p> <p><i>“The staff in his nursery are lovely”</i></p> <p><i>“I also worry about the behavioural side of things as Joseph might be naughty and I need the school to understand that he is just frustrated.”</i></p>
Guilt (Overwhelming)	<b>Fay</b>	<i>“This experience left a lasting impression on me and I still to this day feel very guilty for not seeing how poor the school was”</i>

Code	Source	Evidence
<p>Effort (Effort)</p>	<p>Fay Caroline Emma</p>	<p><i>“With having a bad experience of a school I next did my research online and also read into offsted reports”</i></p> <p><i>“Eventually I came across Seaview Primary a mainstream school a little further away from our home.”</i></p> <p><i>“I do like to do a lot of research”</i></p> <p><i>“I have felt that it is my job to act as her advocate and to ensure that I strive to obtain the best for her in order to help her realise her potential.”</i></p> <p><i>“In spite of the fact that I researched all the provision available”</i></p> <p><i>“I’ve had to chase everybody else’s tail trying to find out information and I don’t feel it is my job to do this.”</i></p> <p><i>I really didn’t want to be looking around with a chaperone. I wanted to get a true honest picture but I thought it was quite staged.</i></p> <p><i>“The advice is there but, if I don’t ask for it, the advice will not be given.”</i></p> <p><i>“Nothing will stop me from getting the best for Joseph. If that means travelling then that will not be an issue. If I need to pack in work or rely on taxis to get there that will not be problem as I need to make sure that the school is best suited to Joseph and his needs.”</i></p> <p><i>“When choosing Joseph’s school I looked in to the ins and outs of every possibility, as I do like to know the ins and outs of everything.”</i></p> <p><i>‘I’m not just putting him into mainstream because it is easier and my decision is not just on a whim, its something I’ve looked into in great depths.’</i></p>



Code	Source	Evidence
<p>Knowing what you want</p> <p><b>(Determination)</b></p>	<p><b>Fay</b></p> <p><b>Caroline</b></p> <p><b>Emma</b></p>	<p><i>"Mainstream has always been very important to me"</i></p> <p><i>"I think every child should be given the chance in mainstream first as all children deserve a normal life as possible and the rest of the world also need to learn more about disabilities"</i></p> <p><i>"the professionals I have just spoke about supported me in what I wanted and felt best for my children as well as helping me being well prepared for Chanel starting school"</i></p> <p><i>"but once you get to know me I hope they see its just having my children's best interests at heart"</i></p> <p><i>"I do also not want them mollycoddled at the same time as I am trying to prepare them to cope and gain skills to live with their conditions not just at school but through the rest of their lives."</i></p> <p><i>"It has always been vitally important to me that Tara is treated as an individual and not labelled or 'put in a box' due to her condition."</i></p> <p><i>"I do not want her to be always on the edge of friendship groups because of her communication difficulties."</i></p> <p><i>"She is a bright little girl who loves to learn so for me placing her in an environment where the focus will be on her abilities rather than her disabilities is vital."</i></p> <p><i>"It is precisely because Tara is bright that her father and I feel so strongly that specialist provision will give her the best start."</i></p> <p><i>'It is important to me that Joseph is treat the same as everyone else. There will be things that he maybe can't do and things that he wont do but overall I want Joseph's school to treat him the same as all the other kids and I don't want this SEN status to limit him.'</i></p> <p><i>When I was choosing a school for Joseph, I looked at the school environment. I want Joseph to continue to have a one-to-one like he has had in nursery.</i></p> <p><i>"I need a school that has lots of support for Joseph and one that is going to prioritise his safety."</i></p> <p><i>"I think all schools should be adapted for additional needs with wider doors, changing areas and sensory rooms but this does not need to be a special needs environment."</i></p>

Code	Source	Evidence
<p>Determined <b>(Determination)</b></p>	<p><b>Fay</b> <b>Caroline</b> <b>Emma</b></p>	<p><i>"I'm quite firm on this fact"</i></p> <p><i>"I have felt that it is my job to act as her advocate and to ensure that I strive to obtain the best for her in order to help her realise her potential."</i></p> <p><i>"I do not want her to be always on the edge of friendship groups because of her communication difficulties."</i></p> <p><i>"It is precisely because Tara is bright that her father and I feel so strongly that specialist provision will give her the best start."</i></p> <p><i>"I do what I do for her, to ensure that she has the best start to her education. I will continue to strive for the best for her"</i></p> <p><i>'It is important to me that Joseph is treat the same as everyone else. There will be things that he maybe can't do and things that he wont do but overall I want Joseph's school to treat him the same as all the other kids and I don't want this SEN status to limit him.'</i></p> <p><i>"He might need a school that's more equipped or with people more experienced with additional needs. If that is what Joseph needs, I'm not going to compromise."</i></p> <p><i>"Nothing will stop me from getting the best for Joseph. If that means travelling then that will not be an issue. If I need to pack in work or rely on taxis to get there that will not be problem as I need to make sure that the school is best suited to Joseph and his needs."</i></p>

Code	Source	Evidence
Turning point <b>(Life Experience)</b>	<b>Fay</b>  <b>Caroline</b>	<p><i>“a comment I heard online once has always stuck with me, it said ‘special schools usually have a large trampoline in the dining area.. there is no trampoline in the real world.’”</i></p> <p><i>“But the real turning point was a conversation with a relative who is a secondary school teacher.”</i></p> <p><i>“What struck a chord with me was that he was expressing his frustrations in not being able to support all his students in the way they needed.”</i></p>
Challenging own views <b>(Effort)</b>	<b>Fay</b>  <b>Caroline</b>  <b>Emma</b>	<p><i>“I still did look at multiple special schools... and put my feelings aside to make sure I was making the right choice for my children - my views aside.”</i></p> <p><i>“In spite of the fact that I researched all the provision available”</i></p> <p><i>“I sometimes think a special needs environment might be more beneficial to him but I just need to see how he gets on developmentally. He might need a school that’s more equipped or with people more experienced with additional needs. If that is what Joseph needs, I’m not going to compromise.”</i></p> <p><i>But if a special needs environment is what Joseph needs, then that is the route we will have to go down.</i></p>
Scary <b>(Overwhelming)</b>	<b>Fay</b>  <b>Emma</b>	<p><i>“if anything goes wrong it can be her life at risk and this is on a completely different scale so I am the most nervous for her transition.</i></p> <p><i>we never let ourselves think too far into the future so this also feels like a huge and emotional milestone”</i></p> <p><i>“It’s scary to think that next September Joseph will be at school and it really frightens me to think about it. He’s developmentally very young and sometimes I think he’s not ready.”</i></p>



Code	Source	Evidence
Magnitude of the decision <b>(Overwhelming)</b>	<b>Fay</b> <b>Caroline</b> <b>Emma</b>	<p><i>“if anything goes wrong it can be her life at risk and this is on a completely different scale so I am the most nervous for her transition.”</i></p> <p><i>“Choosing a school for your child is a big decision at the best of times but when your child has additional needs the enormity of that decision weighs heavily on parents’ shoulders”</i></p> <p><i>“I genuinely care where my son goes to school and getting it right is very important to me.”</i></p> <p><i>‘I’m not just putting him into mainstream because it is easier and my decision is not just on a whim, its something I’ve looked into in great depths.’</i></p>
Daunting <b>(Overwhelming)</b>	<b>Fay</b> <b>Emma</b>	<p><i>“if anything goes wrong it can be her life at risk and this is on a completely different scale so I am the most nervous for her transition.</i></p> <p><i>we never let ourselves think too far into the future so this also feels like a huge and emotional milestone”</i></p> <p><i>“It’s scary to think that next September Joseph will be at school and it really frightens me to think about it.”</i></p>

Code	Source	Evidence
<p>Good relationships with school</p> <p><b>(Positive relationships)</b></p>	<p><b>Fay</b></p> <p><b>Emma</b></p>	<p><i>“The school have been absolutely amazing tho and I actually don’t think they could have done more to both help reassure me or be more prepared to care for Chanel in every way. They have done everything from structural work all ready in time for her to letting me be involved in choosing her one to one and helping with teacher training. I have built up a brilliant partnership with the school, they value my knowledge of Chanel’s condition and are very happy for me to stay with her to build up staffs knowledge. This has helped reassure me hugely and built my confidence up even more in them.”</i></p> <p><i>“The staff in his nursery are lovely and the kids are nice and he gets lots of help. The parent support worker at the mainstream school has been really important. She has been really efficient and really helpful.”</i></p>
<p>Support from family and friends</p> <p><b>(Positive relationships)</b></p>	<p><b>Fay</b></p> <p><b>Caroline</b></p> <p><b>Emma</b></p>	<p><i>“brilliant support from my husband enables us to come to decision’s between the two of us”</i></p>

Code	Source	Evidence
Support from professionals  <b>(Positive relationships)</b>	<b>Fay</b>  <b>Caroline</b>  <b>Emma</b>	<p><i>"I do feel I have had brilliant support from the school especially the SENCO and head teacher, our SEN caseworker, Portage and SENDIAS over the years."</i></p> <p><i>"the professionals I have just spoke about supported me in what I wanted and felt best for my children as well as helping me being well prepared for Chanel starting school"</i></p> <p><i>"It was through Portage group however and subsequent discussions with other parents and carers that I started to consider specialist provision as a potential route for Tara."</i></p> <p><i>"The parent support worker at the mainstream school has been really important. She has been really efficient and really helpful. They go above and beyond to help him. They do research into signs and I'm really happy with the support he has got at nursery."</i></p>
Professional Pressure  <b>(Determination)</b>	<b>Fay</b>  <b>Caroline</b>	<p><i>"Some professionals over the years I have felt pushed me towards special school for what I believe an easy way out rather than learning"</i></p> <p><i>"I have often been asked by professionals if I have considered mainstream provision for Tara and this has been a huge source of frustration for me, as though choosing Special School is wrong."</i></p>
"Pushy mum" narrative  <b>(Determined)</b>	<b>Fay</b>  <b>Caroline</b>  <b>Emma</b>	<p><i>"I do often feel schools etc think I am over the top as I like to be in control"</i></p> <p><i>"I am very overprotective but once you get to know me I hope they see its just having my children's best interests at heart"</i></p> <p><i>"I'm a bit of a pain and that I am an over thinker because I constantly think about the different options for Joseph."</i></p>

Code	Source	Evidence
Advocate <b>(Determined)</b>	<b>Fay</b> <b>Caroline</b> <b>Emma</b>	<p><i>"I am very overprotective but once you get to know me I hope they see its just having my children's best interests at heart"</i></p> <p><i>"I have felt that it is my job to act as her advocate and to ensure that I strive to obtain the best for her in order to help her realise her potential."</i></p> <p><i>"I am not afraid to challenge professionals or question why and how schools operate in a certain way."</i></p> <p><i>"I do what I do for her, to ensure that she has the best start to her education. I will continue to strive for the best for her"</i></p> <p><i>"Now I make sure that professionals know I'm not taking any shit from anybody."</i></p>
Being in control (Collapse with pushy mum?) <b>(Determination)</b>	<b>Fay</b> <b>Caroline</b> <b>Emma</b>	<p><i>"I like to be in control by nature anyway"</i></p> <p><i>"despite not being able to control her condition, I can control how we deal with it as a family and how she will learn to live with her diagnosis rather than be defined by it."</i></p> <p><i>"When choosing Joseph's school I looked in to the ins and outs of every possibility, as I do like to know the ins and outs of everything."</i></p>
Stressful (Overwhelming)	<b>Caroline</b>	<p><i>If I could sum it up in one word it would be 'stressful'.</i></p>

Code	Source	Evidence
<p>The influence of others (collapse supportive relationships)</p> <p><b>Positive relationships</b></p>	<p><b>Caroline</b></p>	<p><i>“It was through Portage group however and subsequent discussions with other parents and carers that I started to consider specialist provision as a potential route for Tara.”</i></p> <p><i>“But the real turning point was a conversation with a relative who is a secondary school teacher.”</i></p> <p><i>“What struck a chord with me was that he was expressing his frustrations in not being able to support all his students in the way they needed.”</i></p>
<p>Worried <b>(Overwhelming)</b></p>	<p><b>Caroline</b> <b>Emma</b></p>	<p><i>“When she is not being understood Tara can become extremely frustrated which can result in her having a meltdown – lashing out at others, biting, scratching etc.”</i></p> <p><i>“I never want Tara’s frustrations to be misinterpreted by others as naughty behaviour. I do not want her labelled as the naughty girl.”</i></p> <p><i>“I worry about everyone else’s attitude to him.”</i></p> <p><i>“I also worry about the behavioural side of things as Joseph might be naughty and I need the school to understand that he is just frustrated.”</i></p>
<p>Frustration with professionals <b>(Overwhelming)</b></p>	<p><b>Fay</b> <b>Caroline</b> <b>Emma</b></p>	<p><i>“Some professionals over the years I have felt pushed me towards special school for what I believe an easy way out rather than learning”</i></p> <p><i>“I have often been asked by professionals if I have considered mainstream provision for Tara and this has been a huge source of frustration for me, as though choosing Special School is wrong.”</i></p> <p><i>“I’ve had to chase everybody else’s tail trying to find out information and I don’t feel it is my job to do this.”</i></p>

Code	Source	Evidence
Self-doubt <b>(Overwhelming)</b>	<b>Fay</b> <b>Caroline</b> <b>Emma</b>	<p><i>"I still did look at multiple special schools... and put my feelings aside to make sure I was making the right choice for my children - my views aside."</i></p> <p><i>"I have often doubted myself"</i></p> <p><i>"I sometimes think a special needs environment might be more beneficial to him but I just need to see how he gets on developmentally. He might need a school that's more equipped or with people more experienced with additional needs."</i></p>
Sense of a struggle <b>(Effort)</b>	<b>Fay</b> <b>Caroline</b> <b>Emma</b>	<p><i>"I still did look at multiple special schools... and put my feelings aside to make sure I was making the right choice for my children - my views aside."</i></p> <p><i>"I have often doubted myself"</i></p> <p><i>"I sometimes think a special needs environment might be more beneficial to him but I just need to see how he gets on developmentally."</i></p> <p><i>"I'm a bit of a pain and that I am an over thinker because I constantly think about the different options for Joseph."</i></p>
Societal pressure <b>(Determined)</b>	<b>Caroline</b>	<p><i>"It seems to be popular at present to strive for all children to attend mainstream school and whilst I agree that no one should be excluded from this opportunity, it also needs to be recognised that some children require a specialist setting and that is ok."</i></p>
Lonely <b>(Overwhelming)</b>	<b>Caroline</b> <b>Emma</b>	<p><i>"Unfortunately there is no one else to make the decision for you and that can be lonely"</i></p> <p><i>"I would say I've been alone in making this decision for Joseph and it's solely my decision."</i></p> <p><i>"If I am honest I am probably socially isolated but I'm not as bad as I used to be."</i></p>

Code	Source	Evidence
Wanting support <b>(Positive relationships)</b>	<b>Caroline</b>	<i>"There have been many occasions when I have wished there was a parent support group for people going through this process. A place where parents and carers can share experiences and sound off." "</i>
Experience with age <b>(Life Experience)</b>	<b>Caroline</b>	<i>"I believe my age, 43, and life experience has really helped me in this process." "My younger self may not have been so resilient or empowered."</i>
Empowered <b>(Determined)</b>	<b>Caroline</b> <b>Emma</b>	<i>"I am not afraid to challenge professionals or question why and how schools operate in a certain way." "My younger self may not have been so resilient or empowered." "I do what I do for her, to ensure that she has the best start to her education. I will continue to strive for the best for her" "Now I make sure that professionals know I'm not taking any shit from anybody."</i>
Maintaining good progress (Outlier)	<b>Emma</b>	<i>"when I look at him now compared to last year his progress is amazing and he's doing really, really well."</i>
Convenience (outlier)	<b>Emma</b>	<i>"The mainstream school is attached to the nursery and is convenient so it is handy for when I go back to work as my mum lives close by for if he is poorly."</i>
Tradition <b>(Determined)</b>	<b>Emma</b>	<i>"All our family have gone to that school, so why wouldn't Joseph?"</i>

Code	Source	Evidence
Tiring (Overwhelming)	Emma	<i>“Choosing a school for Joseph has been emotionally and physically tiring”</i>
Upsetting (Overwhelming)	Emma	<i>“If he does need a special needs school in the future, it will take me time to accept and will upset my family as we might feel we have taken a couple of steps back.”</i>



#### 4.11 Appendix K: Refined Themes

##### Code Map

Codes (35)	Themes (14)	Over-Arching Theme (5)
Battling challenges	Not specific to the question so disregarded.	N/A
Strength <i>Strength links closely with empowerment and is thus collapsed.</i>	N/A	N/A
Prior experience with SEN processes	Prior Experience with SEN	Life Experience
Staff attitudes (hmm)		
Guilty	Difficult emotion	Overwhelming
Effort	Parental Effort	Effortful
Knows what she wants	Knowing what you want	Determined
Determination to get it right for their child	Determination to get it right	Determined
Seminal moment	Important experience	Life experience
Challenging their own views	Parental Effort	Effortful

<b>Codes (35)</b>	<b>Themes (14)</b>	<b>Over-Arching Theme (5)</b>
Scared	<b>Difficult emotion</b>	<b>Overwhelming</b>
Magnitude of the decision	<b>Difficult times</b>	<b>Overwhelming</b>
Daunting	<b>Collapsed with 'scary' to</b>	<b>Overwhelming</b>
Good relationships with school	<b>Positive relationship with the school</b>	<b>Positive interactions</b>
Support from family and friends	<b>Positive relationships with family and friends</b>	<b>Positive interactions</b>
Support from professionals	<b>Positive relationships with professionals</b>	<b>Positive interactions</b>
Professional Pressure	<b>Pressure from others</b>	<b>Determined</b>
"Pushy mum" narrative	<b>"Pushy mam" narrative</b>	<b>Determined</b>
Advocate	<b>Determination to get it right</b>	<b>Determined</b>
Being in control (Collapsed with "pushy mam" narrative)	<b>N/A</b>	<b>N/A</b>
Stressful (Overwhelming)	<b>Difficult emotion</b>	<b>Overwhelming</b>
Worried	<b>Difficult emotions</b>	<b>Overwhelming</b>
Frustration with professionals	<b>Difficult times</b>	<b>Overwhelming</b>

<b>Codes (35)</b>	<b>Themes (14)</b>	<b>Over-Arching Theme (5)</b>
Self-doubt	Difficult time	Overwhelming
Sense of a struggle	Sense of a struggle	Effortful
Societal pressure	Pressure from others	Determined
Lonely	Difficult emotion	Overwhelming
Wanting support	Positive relationships with family and friends	Positive interactions
Experience with age	Important experience	Life experience
Empowered	Knowing what you want	Determined
Maintaining good progress	Code appears to be an outlier, disregard	N/A
Convenience	Code appears to be an outlier, disregard	N/A
Tradition	Knowing what you want	Determined
Tiring	Difficult emotion	Overwhelming
Upsetting	Difficult emotion	Overwhelming

Themes (14)	Overarching Theme (5)
<ul style="list-style-type: none"> <li>• Knowing what you want</li> <li>• Determination to get it right</li> <li>• Pressure from others</li> <li>• “Pushy mam” narrative</li> </ul>	<b>Requires determination</b>
<ul style="list-style-type: none"> <li>• Difficult emotions</li> <li>• Difficult times</li> </ul>	<b>Overwhelming</b>
<ul style="list-style-type: none"> <li>• Parental effort</li> <li>• Sense of a struggle</li> </ul>	<b>Effortful</b>
<ul style="list-style-type: none"> <li>• Prior experience</li> <li>• Important experiences</li> </ul>	<b>Life experience</b>
<ul style="list-style-type: none"> <li>• A positive feeling about the school</li> <li>• Positive relationships with the school</li> <li>• Positive relationships with family and friends</li> <li>• Positive relationships with professionals</li> </ul>	<b>Positive interactions</b>

## Chapter 5. References

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