# Exploring mothers' experiences when their disabled child starts school: An interpretative phenomenological analysis.

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# Abstract

## Exploring mothers’ experiences when their disabled child starts school: An interpretative phenomenological analysis.

Most disabled children in England start school within a mainstream primary school environment. Research demonstrates that starting school is an important life stage for children and their families in terms of internal family dynamics and relationships with the wider community. However, there has been limited research about this experience for families with a disabled child, particularly within the English context, following the 2014 Children and Families Act. To extend the evidence base, this research explored the experiences of five mothers with disabled children as their child began mainstream primary school. The researcher adopted an insider researcher perspective, herself the mother of a disabled child. The interviews were analysed using Interpretative Phenomenological Analysis (IPA). The mothers’ experiences are interpreted and organised around four patterns across themes: Starting school as a life stage process, ‘The System’, change and growth and belonging and rejection. The analysis focused on the mothers’ idiographic accounts and some of the patterns across accounts, both convergent and divergent, were explored. The findings indicate that starting school was a significant experience for these mothers and their families, not least negotiating the statutory processes to secure additional support. The process involved a significant investment of time and emotional labour. Mothers experienced frustration, uncertainty and power imbalance. They also shared positive changes such as new relationships, acquisition of knowledge and confidence, changed understandings and involvement in supporting other families. The findings are contextualised within relevant paradigms including the Family Life Cycle, post-crisis growth, Bordieuan capital and Bronfenbrenner’s Ecological Systems Theory. Opportunities for professional reflection, implications for educational psychology practice and possibilities for future research are considered.

# Acknowledgements

With thanks to the five mothers who shared their experiences and made this research possible. And in acknowledgement of all parents who strive for their disabled child.

Also, thanks to my research supervisor, Dr Rachael Green and to colleagues, family and friends for their support.

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# 1: Introduction

## 1.1 Overview

This chapter outlines the reasons why this research took place and the aims of the study. It introduces my professional interest in the topic and my research position. The chapter locates the phenomenon of disabled children starting school within national and local contexts. It explores the phenomenon of starting school in terms of models of school readiness and within the broader theoretical context of transition to school. This information forms the conceptual framework in which some of the key ideas used in this study are located, identifying questions which are then explored in the literature review and through which the findings are understood. The chapter provides an outline of some ways of understanding disability and locates this research within my own understanding.

## 1.2 Research Rationale

In 2009 The Lamb Disability and SEN Information Review (Lamb, 2009) presented its findings to the Secretary of State for Education. Despite evidence demonstrating that more positive outcomes are achieved when families and schools work together (Harris & Goodall, 2008), the Review presented a bleak picture of *“an underlying culture in which parents and carers of children with SEN can too readily be seen as the problem”* (p. 2). The Review found that, faced with a lack of information and a system in which their views were side-lined, parents lose confidence, and distrust and conflict arises. Lamb proposed that the system be overhauled to place the parent-school relationship at the heart of the support process, with a focus on the views and aspirations of the child and family. The Review meant that the focus on reforming the SEN system gained momentum, ultimately leading to the 2014 Children and Families Act. The Act emphasises engaging and involving parents in their child’s support, especially at points of transition. The focus of this research is to listen to the experiences of mothers whose children are at a point of transition. There is extensive research around starting school, from numerous theoretical perspectives. However, the evidence around families affected by disability, especially within this policy framework, is much more limited. This research intends to address this limitation, by exploring experiences and considering the implications for professional practice.

### 1.3 My Interest in the Research Topic

I began my professional life as a Reception teacher and watched with curiosity and anticipation as, each year, children and their families made the transition from preschool to ‘big school’. As the year went on, I witnessed families develop new relationships with teachers and one another, celebrate achievements and negotiate the practical and emotional challenges that arose. Since becoming an educational psychologist, I have worked alongside families of disabled children, and the schools educating them, often with a focus on starting school. As my interest and professional skills in working with diverse families has grown, I again watch with curiosity as families negotiate this transition. I am struck by the ordinariness of the process as parents take that treasured ‘first day at school’ photo, and the extraordinariness, as this first day might follow months of legal wrangling or planning accessibility with teachers. I wanted to know more about how this process is experienced from the inside, listening to mothers’ experiences of the people and processes that facilitated, or hindered, their family’s start to school life. My professional interest overlapped with personal experience, when, some years before completing this study, my disabled son started school. Again, experience, this time of a personal nature, piqued my curiosity about the experiences of others, and I became an ‘insider researcher’, alongside my professional role.

This study references theoretical frameworks and psychological perspectives which influence my professional practice and how I view the findings. My training in applied systemic practice has provided a lens through which I consider the multifaceted complexities of transition and family life. Key influences include systemic models, such as Carter & McGoldrick’s (1989) Family Life Cycle, resilience focused models such as post-crisis growth (Tedeschi & Calhoun, 2004), ecosystemic models, such as Bronfenbrenner’s Ecological Systems Theory (1979), and sociocultural understandings, such as Bourdieu’s (1986) cultural capital.

### 1.4 Educational Psychologists working with parents: An evolving role

My interest in working with families sits within my professional role as an educational psychologist. Dunsmuir, Cole & Wolfe (2017) state that, for practitioner psychologists, working with parents is central to good practice. They state that professional practices are changing in terms of how we view our work with parents and the methods used to engage families. McQueen & Hobbs (2017) propose that professional practice should employ approaches that accommodate the complexities of diverse and marginalised families. Hodge & Runswick-Cole (2008) suggest that professional practices focused on ‘supporting parents’ imply an imbalance of power and knowledge and that there should be a shift towards understanding and respecting individual and diverse complexities in family life. This is perhaps a challenging shift for professionals and one which requires a continuing reflection of both our ontological understanding and everyday practice. It is within this changing professional practice context, with a growing interest in engaging with the individual experiences of diverse families, and with a desire to engage critically with what is currently understood and enacted within my own profession around disability, parenting and starting school, that this research was realised.

## 1.5 National Context for this Study

### 1.5.1 Disabled children starting school in England: Processes and Policy

In England, the arrangements for children starting school are clarified in the Schools Admissions Code (Department of Education, 2014). All maintained schools are required to comply with this mandatory code, and non-maintained schools are required to comply as part of their funding agreement. English children start school before almost all others. In France, the USA and Australia, children start school aged six. In Scandinavia, the school starting age is seven. Children are required to attend school or to receive education elsewhere on a full-time basis from the term after they turn five. Children whose additional needs necessitate an Education, Health and Care plan (EHCP) are admitted outside the normal admissions arrangements, as outlined in the Children and Families Act (2014). When a child has an EHCP, their family can request the child attends any maintained or non-maintained school and the Local Authority must name the school on the child's EHCP if it is suitable for the child.

According to recent data (Department of Education, 2018) 253,680 children in England have an EHCP. About half of these children (47%) attend state-funded, mainstream schools. According to this data, 2% of four-year olds and 3% of five-year olds have an EHCP, which suggests that only a relatively small proportion of children beginning mainstream primary school have an EHCP.

### 1.5.2 Support for Children with Special Educational Needs and Disabilities in Schools

Following the Lamb Review (2009), The 2014 Children and Families Act overhauled the provision and processes available to children and young people identified with special educational needs. The Act introduced a co-ordinated assessment process and the introduction of EHCP's. The Act states that any child or young person identified with a special education need might require an Education, Health and Care Needs Assessment which might lead to an EHCP being issued. For many disabled children, this process will be undertaken prior to starting school and assessment is likely to be an important context in which a child's needs are understood and planned for (Nettleton & Friel, 2015). The SEN Code of Practice (2014) emphasises strategic planning at all phases in education, involving the child and family to ensure that the child's needs are understood, and their aspirations are planned for. The purpose of an EHCP is to identify needs, through a co-ordinated assessment process and to outline the provision required to meet these needs. The educational provision in an EHCP is enforceable in law. It is the Local Authority's duty to ensure that the provision is implemented. In the context of the current research, it can be understood that the great majority of children who have an EHCP are disabled in some way and it is the children with the most complex support needs who possess an EHCP (Nettleton & Friel, 2015).

### 1.6 Local Context of this Study

The participants in this study had children attending school in the same Local Authority. The Local Authority is the second largest non-metropolitan authority in England, with 1.4 million residents, of whom 26% are children and young people. A Joint Strategic Needs Assessment of SEN provision undertaken in 2015 (Essex County Council, 2015) indicates a 30% increase in the number of children with identified SEN in the past decade. Most of these children attend mainstream schools. The Assessment identifies a smooth transition for young people with SEND as a key strategic priority.

## 1.7 Starting school: Key concepts

### 1.7.1 A key transition

Starting school is a big day for a child and their parents. It is a big day because a child makes a **transition** from being one thing (a pre-schooler, mostly at home with the family and/or in day-care) to another (a 'big school' child, with a life and social world apart from their family). Pianta & Cox (1999) describe this process as *'a key life cycle transition, both in and outside school'* (p. 367). They observe that starting school is important for a child because it is a rite of passage, associated with increased status and a turning point in their life. In this research, I use the term 'starting school' to refer to the transition of a child and family from their 'prior to school experience' to their 'school experience'. In educational contexts the word *transition* is generally used to refer to a move from one stage of education to another. However, it has been argued that this understanding does not convey the complex and multifaceted process of a life transition. Rogoff (2003) defines transition as a time in which '*individuals change their role in their community's structure'* (p. 150). Rogoff locates transitions within societies and cultures, in which tensions, judgements about preparedness and sources of support differ between contexts. Rogoff (2003) suggests that transition is not a one-way change located within an individual but a deeply socially and culturally embedded process.

### 1.7.2 The importance of a good start to school life

Bowes, Harrison, Sweller, Taylor & Nielson-Hewitt (2009) argue that transition, as an important time in family life, is critical in establishing the foundation for a positive long-term experience of schooling for families. Berlin, Dunning & Dogoel (2011) found that a positive start to school, as perceived by parents, is associated with better social and academic outcomes for the child. Supporting a positive transition is not just helpful, it might make a material difference to the attainment and achievement of young children. Janus, Kopechanski, Cameron & Hughes (2008) state that a positive transition is especially important for families with disabled children, though more complex and challenging. Rosenkoetter, Hanmuins & Fowler (1994) argue that transition is a key aspect of early intervention support for disabled children moving from pre-school into mainstream education and that it is important that transition should be a focus of targeted support for these children.

### 1.7.3 School Readiness

Petriwskyj, Thorpe & Taylor (2005) state that traditional understandings of starting school have focused on **‘school readiness’**, related to a child’s individual preparedness for school. In 2006, the OECD study ‘Starting Strong’ (OECD, 2006) outlined understandings of school readiness across cultures. Notably, between **pre-primary** and **social pedagogical** understandings of school’s readiness.

### 1.7.4 Pre-primary models

Moss (2013) states that the pre-primary model of school transition dominates discourse around starting school in England. The OECD (2006) reports that pre-primary approaches are characterised by a focus on *‘knowledge and skills useful for school viz. literacy, math and scientific thinking’* (p. 14). Moss (2013) argues that that current systems of early childhood education in England are aligned with *‘a dominant narrative of normativity and performativity in which the purpose of education is conformity to predetermined performance criteria’* (p. 5). Indeed, the power of this perspective within the political arena, can be heard from policymakers themselves. Michael Gove, then Secretary of State for Education stated that:

> *‘If children arrive in school unable to sit, listen and learn, and then disrupt the learning of others, their lives are already* blighted’ (Gove, speech at the Durand Academy, September 2011)

This model poses a challenge for those tasked with including children whose developmental trajectories do not meet Gove’s criteria for a successful start to school life. Evans (2013) argues that the model fails to embrace complexities faced by some families, meaning that inclusive understandings of school readiness are subjugated in favour of a within-child skills-focused approach. This discourse, despite the aspirations of the 2014 Act, presents a challenge to those seeking a more inclusive understanding of the needs of *all* children starting school.

### 1.7.5 Social Pedagogical model

The OECD (2006) report identifies social pedagogy as characteristic of Nordic and Central European education systems. These models foreground a whole-child and relational approach, in which learning environments are collaborative contexts, with shared and mutually beneficial value. Bennett (2012) states that, within the social pedagogical model, school is considered a broad social-educational service, supporting the whole-child’s and whole family’s development as a continuous process. While social pedagogical approaches identify broad developmental goals set for each child, there is less focus on assessing school readiness through acquired skills and less of a defined leap between pre-school and school-based activities. It is evident that the social pedagogical perspective, in contrast with pre-primary approaches, allows for a more nuanced understanding of starting school, which incorporates the familial, cultural and emotional needs of each child, moving towards the interactionist understandings presented below.

### 1.7.6 Interactionist Perspectives

When understandings of starting school include experiences of parents and educators, they move towards an **interactionist** orientation which accommodates the complexities and contradictions of individual experience. Dockett & Einarsdottir (2017) researched the school starting experiences of diverse families. Drawing on Rogoff (2003), they conclude that starting school involves both continuity and change, and that '*these emphases are consistent with the conceptualisation of transition as a process, generating changes in role, status and identity'* (Dockett & Einarsdottir, 2003, p.259). Dockett & Perry (2013) apply an interactionist framework which incorporates not just the readiness of a child to make the transition, but the readiness of the school and the family**.** Dockett, Griebel & Perry (2017) assert that starting school is a key family life transition. Their research indicates that parents experience this time as transitive in terms of their changing role, obligation to fulfil the duties and expectations that school life places on them, and diminished agency in the choices and actions made in their child's everyday life. While the English term 'transition' indicates a one-way, individual and sequential movement from one place to another, words used in other cultures describe starting school with more nuance. Describing their Aboriginal community's understanding of starting school, Clancy & Simpson (2001) provide a compelling example:

> *'We not only use 'transition' which can imply a one-way journey towards something better, but also the term fire-stick (an Aboriginal stick that is kept alight to ensure the availability of fire). This highlights the way in which culture is not something to be left behind… the 'fire-stick' period equates to the time needed to learn how to navigate between home and school cultures' (p. 57).*

This understanding of starting school provides a more complex account of the factors that influence this key life event. Transition is a time of continuity and change for all involved. While the school, family and community influence the child's start to school life, the child's experience also impacts on how others experience this transition. In short, starting school does not just happen *to* a child, it happens *with* a child. Starting school is a family, school and community event.

### 1.7.7 Ecosystemic and Bordieuan Perspectives

As understandings of starting school shift from a normative 'school readiness' model, towards frameworks which consider the interplay of relationships and environments, researchers have conceptualised the process within multidimensional frameworks that give consideration to how each layer of the transition system interacts and influences the process.

Gioia (2017) applied Bronfenbrenner's (1979) **Ecological Systems Theory** to explain how the microsystem of family life and cultural practice interacts with the mesosystem (society and the school community) when children from diverse families start school. She suggests that dominant discourses around 'normality' within the mesosystem of school can disadvantage some families. There is a further indirect impact of the macrosystem, through government policies and practices, and societal attitudes to difference. At this level, a child's transition to school can be affected by funding issues, professional skills and attitudes, and the opinion of the wider community towards a child starting school. This is demonstrated in research which indicates that, while parental engagement is a strong predictor of success, *'the reality is that disadvantaged families are less likely to be involved and listened to in school environments'* (Bernard van Leer Foundation, 2007, p. 4).

Gioia (2017) considers how a multisystemic understanding of transition can be understood in the context of Bourdieu's (1986) **cultural capital**. From a Bordieuan perspective cultural capital forms the foundation of societal belonging. Capital is not just economic but social and cultural, developed through shared experiences, values and activities. These elements work together to form a dominant shared identity and Bourdieu cites this as a source of inequality and powerlessness for those who are perceived as 'other'. Gioia (2017) explains that when starting school, families are generally able to build social capital within the dominant culture through group membership and connection with the school. However, diverse families (by way of ethnicity, refugee status or disability) might experience a more 'othering' context in which they share fewer experiences and through which less social capital, and therefore voice, is accumulated.

### 1.8 Understanding Terms

This research concerns mothers' views of their **disabled** child starting school. I have chosen this word intentionally and after considerable thought, aware of the cultural, power and ethical implications when using the word 'disabled'. My own use of term evolved over the course of this project and here I explore the process by which I came to use this term, drawing on key themes from critical disability theory and on the writings of disabled academics and activists. I am grateful for the time given by

Professor Katherine Sang (Professor of Inclusive Employment, Herriot-Watt University and a disabled researcher) in supporting my understanding of these complex issues. The term ‘disabled’ was introduced in this research as I became more aware of the considerations given to language in critical disability studies and as my research increasingly drew on this area of research, both in terms of my ontological and axiomatic understanding and perspective on data analysis. While at the time of the interviews, I used the term ‘special educational needs’, and referred to ‘children with an EHCP’ to describe the children in this study, below I describe why I have chosen to use a different term in the final thesis.

### 1.8.1 Special Educational Needs or Disability?

As a psychologist working in schools, the term ‘special educational needs’, and associated terms such as ‘additional needs’, are very familiar to me and I used them often, both when speaking with parents and in written reports. They are terms that, before completing this research, I assumed to be unproblematic. However, in considering the language used in this research, I now have a different understanding, drawing on perspectives from academic research and activism.

In England, Special Education Needs (SEN) is the term commonly used in legislation and educational settings to describe children who have a *‘difficulty or disability that means that learning is harder for them than for other children of their age’* (Children and Families Act, 2014). It is evident from this description that ‘SEN’ is a term that might include disabled children. However, as an umbrella term, it also includes children who have different needs, such as children requiring a reading booster program because of time off school. The children spoken of in this research have significant and long-term conditions, such as Down Syndrome and autism, which could more accurately be described as a disability. Because of my recruitment strategy, they all accessed a facility which describes itself as supporting ‘children with disabilities and their families’. Additionally, the definition of the term SEN above focuses on difficulties with ‘learning’. Interactionist perspectives around starting school (e.g. Dockett, Griebel & Perry, 2017) focus not just on learning, but on cultural, systemic and relational factors which impact on a family’s experiences of starting school, all of which are touched by disability, when this is situated in the social-relational model of disability described below.

In the process of my research, I have become aware of criticism of the term ‘special needs’, particularly by disability activists and critical disability theorists. Gernsbacher, Raimond, Balinghasay and Jilana (2016) describe the term ‘special needs’ as an ineffective euphemism for disability. The authors state that many disabled people dislike the term special educational needs, and their own research has found that members of the public, even those with a personal connection to disability, viewed characters in vignettes more negatively when they were described as having ‘special needs’ rather than ‘disabilities’. The authors go on to assert that the use of euphemistic language suggests avoidance of a shameful or stigmatising term, whereas many disabled people view their disability as an inherent, and at times positive part of their identity. While this research occurred in an American context, similar objections exist within UK disability activism. A survey of disabled people conducted by the BBC found that ‘special needs’ ranks forth in a list of terms considered offensive (Ouch! 2003). Campaigns led by disabled people have lobbied to remove the terms ‘special needs’ and ‘special educational needs’ from the public and professional lexicon. For example, Josh Reeves (a disabled TV personality) has gained considerable following using the Twitter hashtag #don’tcallmespecial (Reeves, 2015). In 2007, Barnes and Sheldon, pioneers in the field of emancipatory disability research, launched a campaign in the UK to replace the term ‘special educational needs’ with ‘unmet educational needs’. They argue that the former focuses on a within-child problematising, with a focus on special resources a child uses rather than in terms of their universal right to appropriate education. They argue that the term ‘special educational needs’ is drawn from the within-child, medical model, in which it is the child’s ‘deficiencies’ which create barriers to progress and inclusion, rather than accessibility being prevented by physical and societal barriers. Kailes (2010) argues that phrases which use the word ‘special’ connote segregation of disabled people. He cites ‘special programs’, ‘special Olympics’, ‘special school’ and ‘special educational needs’ as terms which are used to foreground segregation, rather than accessibility.

While I am satisfied that I have chosen to use the word ‘disabled’ for good reason, I am also aware that this might not be the preferred term for the participants in this study. Gernsbacher, Raimond, Balnghasay and Boston (2016) state that parents and professionals are not always as comfortable using the term ‘disabled’ as disabled people themselves. There is limited formal research about parents’ preferred terms, and this raises an ethical issue about the language I chose to use.

### ***Using the word ‘disabled’ ethically***

The parents in this study are likely to be familiar with both terms (special educational needs and disability/disabled) in relation to their child. In the recruitment advertisement I use the terms ‘additional needs’ and ‘disabled child’. They all accessed a resource centre which states that it supports ‘children with disabilities and their families’. However, I do not know for sure that this is their preferred term to describe this part of their child’s identity. I am aware that as the researcher and author, I have chosen to use a particular term, and that this choice evolved over time as I learned more about disability activism and the central role of language. This reflects a power imbalance within the researcher-participant relationship, in that the researcher chooses their preferred terms, which might not hold the same meaning for the participants. However, I have also become increasingly aware that some commonly used terms are seen as unethical and problematic, particularly by disabled people themselves. In making my choice, I referred to the British Psychological Society Code of Ethical Practice (2018) and specifically the Principle of Respect. This states that in following the principle of respect, psychologists should be clear that their practice avoids manipulation or exploitation, and that they should consider both the individual and the broader social and systemic perspective of their choices. While I am aware that my use of the term disabled carries some inherent ethical issues, I am satisfied that, in choosing to use the word, I have considered both the implications for the participants in this study, their children and the broader social implications.

### 1.8.2 Understanding disability

Having chosen to use the words disability/disabled in my research, it is important to outline the different ways in which this term can be understood, particularly, perspectives developed by disabled people themselves. Beaudry (2016) states that a distinction can be made between individual (medical) and social models.

The **medical model** of disability presumes that a ‘normal’ state exists, from which those with disabilities deviate and that ‘normality’ is the desired state of being (Oliver, 1990). Disability is located within the individual. Rees (2017) states that the medical model has been influential in education and cites the teaching of children with profound and multiple disabilities, where there might be a focus on developing a child’s physical and cognitive skills over building relationships. Reid and Valle (2004) criticise the use of the medical model in education, as perpetuating a ‘within child’ model of deficit, emphasising what a child cannot do and with the responsibility of failure to learn residing within the child.

It has been a focus of the disabled people’s movement since the 1970’s to shift the way that disability is talked about, acted upon and thought about in everyday life (Oliver, 1993). From this campaigning, the **social model** of disability emerged. For social modelists, disability not something people *have*, but something that is *done to* people with impairments. People with impairments are disabled by poor access to public places where ordinary life happens and by unwelcoming attitudes (Barnes, 1994). In the **social relational** model of disability, Thomas (2004) moves beyond the idea that disability is purely socially constructed. She views impairment as separate to disability but the reality of the lived experiences of disabled people are acknowledged. While societal barriers are foremost, challenges experienced by the individual, for example, chronic pain, are also acknowledged. While this model acknowledges the objective reality of ‘impairment’, it also emphasises the extent to which social and educational environments have the potential to dismantle the barriers impacting on disabled children and their families. In considering my understanding of disability, I adhere to the social, and towards the social relational model of disability and it is important that my language reflects the axioms of this model.

### *‘Disabled’ or ‘with disabilities’?*

In this research I have chosen to use the term ‘disabled children’ rather than ‘children with disabilities’. Below I explore why I have chosen the former term, and how it is consistent with my understanding of disability. When I was training as a psychologist, I was encouraged to use ‘person-first’ language’ i.e. *‘William is an 8-year-old boy with a disability’*. Person-first language is based on the premise that everyone is a person first and should not be defined by their disability. However, social modelists have challenged this convention (Heaton, 2014). They argue that, in the presence of social barriers, disability is not something that people *have* but something that is *done to them.* Therefore to describe a person as ‘disabled’ is more affirming. Furthermore, debate has arisen over the potentially stigmatising possibilities of person-first language, compared with identity-first language, which disabled people sometimes favour. Increasingly, people assert that ‘disabled’ is an inherent part of their identity, like ‘young’, ‘gay’ or ‘British’ and that language related to this fact should be considered no less stigmatising. Dunn and Andrews (2015) state that psychologists should use identity-first language when talking about disability. This includes the term ‘disabled’, but might also include other identity-first language that is gaining prominence, such as ‘autistic’ and ‘deaf’, particularly when this is the preference of the person being spoken about. Gerschbacher (2017) writes that adopting identity-first language around disability might be of particular importance in scholarly writing about disabled children. She found that, while writing about disabled adults has shifted towards identity-first language, person-first terms continue to dominate in scholarly writing about children, particularly those with the most stigmatised disabilities, such as learning disabilities. She argues that this practice, while well-intentioned, might perpetuate stigmatising attitudes towards certain disabilities. With these arguments in mind, I have chosen to use the term ‘disabled’ to describe the children spoken about in this research. This reflects both my social-relational view of disability and the fact that I use the term disabled without any implication of within-child deficiencies or stigma, as any other adjective about a child’s identity might be used.

### 1.8.3 Parents' understanding

Cologon (2016) explored the views of parents of disabled children about different models of disability. She found that the views of parents varied widely. Some adhered to the medical model of disability, with a strong internal construct of 'normal' and their own child's variance from this. She found that most parents in this study reflected a social model understanding of disability, especially when thinking about their own child. Cologon (2016) observes that parents reflect on disabling social and environmental barriers for their child, while being aware of the individual impairments their child experiences. Cologon argues that parents' perspectives are most often consistent with Thomas's (2004) social relational model of disability and she argues that it is important that service providers, who might unintentionally present a different perspective, are aware of and respectful towards parents' views about their child. I understand that parents understand their child's disability in different ways, and it is important to remain curious and respectful of this.

### 1.8.4 Mothers and disability research

The title of this study refers to **mothers'** experiences. I did not intentionally recruit only mothers. I was interested in parents' experiences and this is how my research was first described. Only mothers volunteered to participate in this study, and this has implications for the outcomes of the study, hence my specific use of the term. It is important not to assume that mothers' experiences are parents' experiences. Considering Trausdottir's (1991) warnings about the pitfalls of 'gender blind' disability research, in which maternal experiences tend to be described as parental experiences, this specificity becomes important. Mothers of disabled children have a socially and culturally gendered experience of parenting their children (Ryan & Runswick-Cole, 2008) and this is likely to be relevant to the themes discussed in this study. Additionally, the experiences of fathers of disabled children is an under researched area, and it is important that their absence in the research literature is not overlooked. Therefore, this study carefully and intentionally uses the word ‘mothers’ to describe the participants.

## 1.9 Conceptual framework

Miles & Huberman (1994) propose that the conceptual framework sets out the researcher’s understanding of the research themes and what is to be explored. This introduction has identified several key themes around the process of disabled children starting school and how this intersects with being a parent of a disabled child. Key concepts have been developed into a visual conceptual framework. This framework, illustrated in *Figure 1*, aided development of the literature review questions and provided a flexible referential framework through which to discuss the findings.

***Figure 1: Conceptual framework***

## 1.10 Literature review questions

This introduction has outlined the key theoretical frameworks relevant to the process of disabled children starting school, drawing on social pedagogical and interactionist paradigms to understand starting school as a significant and stage in the lives of all families. The process and policy contexts relevant to the experiences of families of disabled children has been outlined and I have considered my choice of language in the context of current understandings of disability. In the literature review that follows I examine the published literature to consider how these themes come together in research exploring the experiences of parents when their disabled child starts school. Drawing on the key themes outlined in this introductory chapter, I ask the following questions of the literature:

1. ***What are the key events and processes that parents report when their disabled child started school***?
2. ***How do parents describe their relationships with professionals?***
3. ***What factors do parents report contributed to success or difficulties when their child started school?***
4. ***What impact do parents report the transition had on family life and on their own life as a parent?***

# 2: Literature Review

## 2.1 Overview

This chapter outlines the process I undertook to review the literature related to my research. It relates this literature to the questions presented at the end of Chapter 1 and synthesises the literature, leading to the formation of my research question.

## 2.2 Purpose and Aims

Robinson & Lowe (2015) state that the **purpose** of a systematic literature review is to answer a precise question, or questions. It applies inclusion and exclusion criteria to select papers, usually fewer than fifty and sometimes fewer than ten in number. They state that a good literature review leads to clear outcomes for the next steps in a piece of research.

To facilitate a clear, systematic and relevant literature search, I developed the following **aims**:

- To identify studies that have been carried out about parents' experiences of their disabled child starting school.
- To identify insights the studies provide, ensuring relevance by answering the literature review questions.
- To evaluate the strengths and limitations of these studies, in terms of their design and relevance to this piece of research.
- To consider what conclusions can be drawn from these studies and identify gaps in research.

## 2.3 Literature review process

To fulfil these aims, I adopted a three-stage review process:

**Stage 1**: Systematic search of current literature using clear inclusion and exclusion criteria. This allowed me to select relevant studies to explore in greater depth.

**Stage 2**: Critical evaluation of selected literature to assess the quality, reliability, validity and relevance.

**Stage 3:** Use of information from the selected studies to answer the literature review questions. This enabled me to assess what is already known and to identify gaps in the current literature, from which to develop my research question.

## 2.4. Stage 1: Systematic literature review

### 2.4.1 Inclusion and Exclusion Criteria

Clearly defined inclusion and exclusion criteria, as illustrated in *Table 1*, ensured that the literature included was relevant to this research and answers, as far as possible, the literature review questions.

| **Included** | **Excluded** |
|---|---|
| International studies published in English | Studies not published in English |
| Studies that focus on disabled children | Studies without a specific focus on disabled children |
| Studies that focus on starting school | Studies that focus on transitions between other school phases |
| Studies that focus on the views, evaluations and insights of parents | Studies with a focus on information from other sources (e.g. teachers) |
| Studies published in peer-reviewed journals | Unpublished studies, such as theses |

***Table 1: Literature review inclusion and exclusion criteria***

### 2.4.2 Reasons for inclusion and exclusion criteria

I included studies published in English because, as an English speaker, it was not possible for me to access studies in other languages. However, I chose to include studies from any part of the world. While I was aware of the limited relevance because of cultural, procedural and legislative differences, I judged that these studies could provide relevant information. Including only studies focusing on disabled children ensured that the studies involved research relevant to my intended participant cohort. I decided, in considering the scope and nature of the available research, to limit my review to research focusing on parental views, evaluations and insights. While it is acknowledged that information from other sources, such as teachers, might provide some information, I judged that this would not be relevant to a study such as this, with an exploratory and experiential focus. I chose to limit studies to those which focused on starting school, rather than transition to other phases of schooling. This was because the research evidence (e.g. Griebel & Niesel, 2003) has identified starting school as a distinct and significant event in family life. The final criterion was to include studies which had been published in peer-reviewed journals. Consideration would also be given to relevant theses, but no relevant theses came up in the search. I judged that that the reliability and validity of such research was more assured, following review by academic peers. While this criterion adheres to Creswell's (2012) assertion that research in peer reviewed journals should be given primary consideration, it does raise an issue of study publication bias. Joober, Schmitz, Annable & Boska (2012) assert that because positive studies are more likely to be published, omitting unpublished studies risks not fully scoping the breadth of perspectives and research findings. While there was no formal time limit on studies, the relevance of older studies was to be carefully considered before inclusion. In fact, no studies before 2003 were identified in the search.

### 2.4.3 Literature Search Process

The final literature search was conducted in March 2019. The search took a systematic approach as advocated by Aveyard (2010).

#### *Databases*

I searched for literature using the Tavistock and Portman NHS Trust Discovery search facility, which searches all available databases. This included the following psychology and education databases: PsychINFO, Pep Archive, The Psychology and Behavioral Sciences Collection, PsycArticles, PsychBooks, Autism Data, Education Source and ERIC.

#### *Search Terms*

I used a single Boolean search to find relevant literature, with the search terms detailed in *Table 2*. This allowed me to search for literature using several phrases (search terms) for each search name, and ensured that search terms were considered in each possible combination. Provided the parameters of a single search are precisely defined, it is not necessary to conduct multiple searches of the same terms.

*Appendix 1* contains a detailed summary of the search. The additional appendix contains full search results.

| SEARCH NAME | SEARCH TERMS |
|---|---|
| Disabled Children | Special Educa*tional Needs<br>SEN<br>Special Needs<br>Disab* |
| Starting | Start*<br>Transition* |
| School | School |
| Family | Parent*<br>Mother*<br>Family |

* all words with this at the beginning were identified.

***Table 2: Literature review search names and search terms***

### *Search Limitations*

Every effort was made to ensure the search strategy was robust and thorough. However, some limitations are acknowledged. Despite efforts, it was not possible to obtain a copy of one of the papers identified (Stoner, Angell & House, 2007). I took the following steps to obtain the paper:

1. Searching the databases available at the University. Only the abstract was available.
2. Searching Google scholar and a general Google search. Again, only the abstract was available.
3. Emailing the authors to request a copy of their paper. I did not receive a reply to my emails.

4. Emailing another researcher who had cited this study in her research. She had worked from a paper copy and had not retained a copy.
5. Considering purchasing a copy of the paper from the publisher. The paper was available to purchase but at considerable cost (over $90 for full access).

It is unfortunate that one study meeting the inclusion criteria could not be obtained and I acknowledge that this omission impacts on the reliability and trustworthiness of the literature review, in the absence of this relevant data.

### 2.4.3 Selection Strategy

A three-stage process was undertaken to select papers for review. An initial trawl of papers by title was conducted to exclude those which clearly did not fit the inclusion criteria. For the remaining papers, I read the abstract to determine whether the papers met the inclusion criteria. When this was not clear, I read the full article to assess their suitability. Studies meeting the inclusion criteria moved to stage 2.

## 2.5 Stage 2: Critical Evaluation of selected studies

All papers included in the literature review were systematically evaluated for quality. I applied the Critical Skills Appraisal Programme Checklist (2013) to evaluate research using a qualitative methodology. Mixed methods research was also evaluated using the McGill Mixed Methods Appraisal Tool (2018). Below I provide a critical review of the seven selected studies, based on the evaluation tools used. I later synthesise these papers in the context of the literature review questions, exploring what is currently understood and identifying gaps in knowledge.

### 2.5.1: Study 1

### Investigating the Transition of Young Children with Intellectual Disabilities to Mainstream Classes: an Australian Perspective (Kemp, 2003)

#### *Overview*

This study, part of a larger longitudinal project, investigates the transition of 33 children with intellectual disabilities to mainstream school in Australia. Data were gathered using structured telephone interviews with teachers, principals and parents, conducted by the researcher. Participants were asked to select the statement that best described their experience of transition and to comment on the factors that might have contributed to a more positive transition. Spearman-rank correlations were calculated to compare perceptions of integration success and difficulties by each set of participants. Descriptive data were organised in tabular form.

#### *Critique*

The author does not state the aims of the study, nor the research questions, so it is difficult to assess how study fulfils the intended aim. It can be deduced from the method of reporting that the study was evaluative in purpose. This study does not illuminate parents' experiences in depth because the interviews are structured around a questionnaire, from which parents could only choose limited responses. It is difficult to see what the interview process adds. A postal questionnaire might have produced similar data in less time. The small number of participants in each category raises an issue with the rigour of the correlational data. The author observes that the number of participants made more in-depth data gathering impossible. I think that this is unfortunate because, in this varied group of participants (parents, teachers and principals), this represents a missed opportunity to acquire comparative experiential data. The study does not consider parents' different interpretations of 'success', instead relying on this judgement through a yes/no answer. There is no information about the role of the researcher in relation to the participants or other ethical considerations. The limited presentation of data means that only limited conclusions can be drawn from this data. The authors' research takes place in a specific transition program, and so it is not possible to generalise this data to other contexts. Because of the context-specific nature of this data set, and the small number of participants, the author is right to draw only tentative conclusions from the study, broadly concluding that parents often receive good support prior to transition, but that this dwindles as their child moves to school-age services. However, the study raises some interesting possibilities for future research, such as the influence of parent-teacher relationships on transition success.

### 2.5.2 Study 2

#### In Transition: Experiences of Parents of children with Special Needs at School Entry (Janus, Kopechanski, Cameron & Hughes, 2008)

***Overview***

This Canadian study explored parents' perception of the quality of care and the impact of disability on family life prior to and post transition. Two groups of twenty participants (pre- and post- transition) were recruited purposively. The research is described as exploratory, with a mixed-methods design. Data were gathered through one semi-structured interview per participant and standardised self-report measures, relating to impact on family life, perception of care and their child's adaptive behaviour. Descriptive qualitative data and statistical comparisons were reported for each group.

### *Critique*

This study has clearly defined aims and purposes. The researchers appropriately selected a mixed-method design because of the cohort size. The authors propose a hypothesis, which they discuss further following data analysis. The quantitative measures are robust and appropriate to the study aims. The authors do not share the schedule for the semi-structured interviews but provide information about how the data were analysed and validated for inter-rater reliability. The authors justify the purposive sampling method based on challenges in finding participants. Informed consent was obtained, but the researchers do not report consideration of other ethical issues, such as the impact of participation on service access. This study gathers a wide range of qualitative and statistical data, taking place in a specific context, so data cannot be easily generalised. The authors consider the quantitative findings and use the qualitative findings to triangulate and enrich these data. This means that the experiences are reported in a thematic way, rather than with deeper interpretation. Further exploration of individual experiences might have provided richer data. This study is robustly designed, and the authors highlight the limitations of their study.

## 2.5.3 Study 3

### Experiences of parents whose children with autism spectrum disorder (ASD) are starting primary school (Connolly & Gersch, 2016)

### *Overview*

This small-scale Irish study purposively recruited five parents through a multidisciplinary therapeutic team. The study explores the experiences of parents of autistic children who are in the process of transitioning to school. Children were due to begin school in the September, after the interviews took place. This qualitative study uses Interpretative Phenomenological Analysis (IPA) as a research framework.

### ***Critique***

The aims of the research are not stated, nor do the authors state the gap in knowledge to be addressed. The authors make a good case for using a qualitative methodology (IPA), based on their critical realist epistemological understandings and the exploratory research focus. The authors argue that use of a purposive sampling method improves homogeneity of participants, which is considered important in IPA. One interview featured two parents together. The authors do not address this anomaly, nor consider how this might have affected the interview process or the data acquired. This is a limitation in their research method and means that the data should be interpreted more cautiously. The authors do not discuss ethical concerns and do not address the relationship between the participants and researchers. Because of the sample size, the authors state correctly that these data are not generalisable beyond the parents interviewed but claim that learning can be drawn from the data to assist professional practice. A significant limitation is that, while this research is stated to be about children starting school, the interviews took place before the children had started school. Therefore, only part of the transition is described. Additionally, this research focuses on children with a specific diagnosis and some of the experiences described in this study might be specific to parents of autistic children. While this study is interesting for the in-depth, idiographic focus, there are significant design limitations which mean that the data need to be viewed with caution.

### 2.5.4 Study 4

### Starting School with Special Needs: Issues for Families with Complex Support Needs as Their Children Start School (Dockett, Perry & Kearney, 2011)

#### *Overview*

This grounded-theory study was conducted in Australia, in a program for families with diverse needs. Twenty-four families were purposively recruited for their social economic and geographical diversity. The research design was qualitative, using case study and Grounded Theory approaches. Data were gathered through conversational interviews. Data analysis was conducted according to Grounded Theory protocols, validated between two researchers. Case studies aimed to reflect uniqueness and commonalities between families, including case studies of six families with complex support needs, whose strengths were considered in-depth.

#### *Critique*

The authors state that the purpose of their study was to 'shed light' on the experiences of families by describing the key features of their school starting experience and theorising this in the context of intersecting factors. The study is therefore exploratory and appropriate to a Grounded Theory study. The purposive sampling method is justified because the authors aimed to reflect the diversity of their communities, including families with the most complex support needs. The conversational interview style is appropriate in providing flexible interactions and allowing stronger relationships between participants and researchers. The data analysis phase is described in detail. The authors discuss ethical issues related to working with vulnerable families; that research can marginalise families even further when it unconsciously reinforces stereotypes or highlights vulnerabilities. The authors state that they chose to focus on strengths and resiliencies shown by families. Although this approach could be criticised for being excessively interpretative, I agree that it is appropriate in the context of the aims of this study. While not as 'objective' as some of the other studies selected, this research provides another perspective and, in common with much research from the critical disabilities studies canon, challenges the prejudicial or 'tragedy' narratives sometimes evident in mainstream social research (Oliver, 1992). The Australian context means that it is not possible to make direct comparisons to English policies and systems. However, a strength of this study is the focus on experiences of diverse families, paying attention to their resiliencies and complexities, providing rich experiential data.

### 2.5.5 Study 5

#### Experiences of parents of children with special needs at school entry: A mixed methods approach (Siddiqua & Janus, 2017)

#### *Overview*

The stated aims of this Canadian study were to further explore parents’ experiences using a mixed methods approach. A convenience sample of thirty-seven families came from a pre-school support program and were interviewed before and after transition to school. Quantitative data came from standardised questionnaires and qualitative from semi structured interviews, analysed using software. A thematic analysis emerged and is reported, as well as quantitative results, using cross comparison between groups and with qualitative findings.

#### *Critique*

The researchers provide a rationale for their choice of method. This study focuses on comparative quantitative data to test a hypothesis. However, the small sample size, raises the possibility of a type 2 (false negative) error in analysis. While ethical consent was obtained, parents who did not speak English at home and those with ‘cognitive impairments’ were excluded from the study, which raises both ethical and methodological concerns in terms of the extent to which this data includes those with more complex experiences and can be generalised. The authors state that the qualitative data provided richer information that could not have been learned through quantitative measures, with five themes emerging. These are presented somewhat descriptively, with little consideration of more in-depth analysis. The researchers claim some degree of generalisability, although I think that this is questionable given the small sample size. However, this is a useful study in its generation of key themes, which reflect some of the themes in other studies and as reference point when considering more phenomenological and in-depth studies.

### 2.5.6 Study 6

### School Transition within the lifespan of People with intellectual Disabilities: Perceptions and Recommendations of Ageing Mothers (Strnadova & Evans, 2013)

#### *Overview*

This study differs from others in this literature review. It uses retrospective accounts to consider transitions, including starting school. This study used a qualitative research design and methodology, described as a ‘life history’ method. The authors used interviews to elicit a first-person narrative, suggesting an exploratory purpose. Twenty Czech and Australian mothers participated through multiple semi-structured interviews. Mothers were purposively recruited through disability support organisations. The data were coded using 'systematic thematic analysis' and were compared across cultures and individual participants. Data were analysed and coded by two researchers to promote inter-rater reliability.

### ***Critique***

The life history method, while unusual, is appropriate to the aims of the study. It allows detailed exploration of life events. Multiple interviews allow rich data to be gathered and cross-cultural individual comparisons to be made. Ethical consideration includes confidentiality of both participants and their (adult) children, informed consent of parents and their children, and sensitive reporting of data. The authors argue that a significant limitation of the life history method is that the information is collected retrospectively. This means that it can be misremembered, and that it is interpreted through the lens of parents' later experiences, which challenges the reliability in terms of the veracity of the events, but not in terms of parents' interpretations. An additional limitation is that the Czech interviews were then translated before analysis. This raises the possibility that the data is compromised in terms of the extent to which language and cultural meanings can be reliably translated into another language, and means that the data is interpreted through the linguistic 'lens' of the translator. Because of the idiographic and specific contextual nature of this research, which relates to experiences long past, there is extremely limited scope to generalise this data in contemporary contexts, although it does provide an interesting context for comparisons.

### 2.5.7 Study 7: Starting School: the importance of parents' expectations (Russell, 2005)

***Overview***

The author states that this study aims to be exploratory, participatory and emancipatory. She states that nineteen parents of disabled children starting school in England were to be active participants in the research process. A ‘research participation group’ of other parents of disabled children assisted in the research design and analyses. Parents engaged in the ‘statementing’ process were purposively recruited. Data were gathered through semi structured interviews across the transition process, stopping just before children started school. Parents were asked to compare the expectations of starting school with those of other parents interviewed. The parents' advisory group assisted the author in organising the data according to themes and the author then organised the data using the framework of Bronfenbrenner’s Ecological Model (1979).

***Critique***

This study has clearly stated aims, one of which is to explore the use of a new participatory research methodology. It aims to explore the experiences of parents of disabled children, making appropriate use of semi-structured interviews. Thematic analysis is an appropriate method of data analysis but allows more limited scope for interpretation of data than other techniques, such as grounded theory or IPA. However, it is appropriate to the purpose of this study. The use of collaborative parent researchers is an innovative research approach, inspired by the work of disability researchers (for example, Oliver, 1992). As a method created, in part, by the researcher for the purpose of this piece of research, it is difficult to judge whether this is an appropriate design. However, it does appear to fulfil the researcher’s participatory purposes. A purposive recruitment strategy was appropriately used because of the specific nature of the experience of all participants. The data gathering method is clearly described. It is quite complex, involving several processes, and would be challenging to replicate. The organisation of the final data into categories based on Bronfenbrenner's ecological model (1979) is clear and makes good sense. The author describes being the parent of a disabled child and has considered the implications of her position. She gives no explicit consideration to ethical issues that may be raised by her research design. There are issues of confidentiality and consent when sharing data with other parents acting as collaborating researchers.

This study is the only one of the studies reviewed to have taken place in a UK context. It has relevance to my study because it is possible to make tentative within-context comparisons. Russell consciously uses her position as an insider researcher, and actively involves other insider researchers. While this approach can be criticised as being a threat to subjectivity and validity of data (Greene, 2014), it does provide a different perspective to the other research I have reviewed. It can also be advantageous in terms of the empathy, quality of interactions and system knowledge the researcher brings to the role (Greene, 2014). This study uses a relatively large cohort for a qualitative study and looks at the data in-depth. In this sense I think that it is an appropriately designed study for the stated aims. A significant limitation is that the data gathering stopped prior to children starting school. Therefore, while the research provides useful data in relation to the process of transition to school, it does not fully explore the experience of transition.

## 2.6 Stage 3: Answering the literature review questions

When reading each study, I focused on key areas of relevance identified in the introductory chapter and by considering the literature review questions.

### 2.6.1 What are the key events and processes that parents report when their disabled child started school?

#### *Support before and following transition*

Each of the studies report that most parents were offered support for transition that took their child's additional needs into account. However, the nature and duration of the support varied widely. Kemp (2003) found that three quarters of parents surveyed felt that they had received 'adequate' support before starting school but only a small minority received support after transition. Transition preparation included meeting school staff, visiting the school and having a say in the school their child attends. This experience of reduced support following transition is echoed in Siddiqua & Janus's (2017) study which found that parents had a more positive perception of services before transition.

#### *Information sharing*

Siddiqua & Janus (2017) found that most parents did visit their child's school and meet with other professionals in advance of their child starting at the school. However, these visits were often initiated by the parent and a significant minority of parents had no contact at all with their child's future school. The authors report that information sharing processes were a key issue for parents. They found that parents described a spectrum of communication between services, and the extent to which parents were included in this communication varied. Parents generally perceived pre-transition services, such as day-care providers, to be active information sharers, both with families and schools. While parents reported some positive stories of school information sharing, such as through communication books, it was common for parents also to experience a perceived lack of information from teachers.

### *Communication about support available*

As well as issues with day-to-day communication, some studies point towards a relative lack of information sharing, either formal or informal, about the support a child would receive once in school. A key finding in Siddiqua & Janus' (2017) research was that only about half of parents knew about the support planned for their child and that only three parents felt that their child received the support they needed from the school, suggesting either a lack of communication between parents, schools and outside services, or a lack of structure for clarifying and recording the support a child receives in school. This is a finding echoed by Dockett, Perry & Kearney (2011), who also noted that parents reported reduced contact with services once their child began school, especially around support available. They reported confusion about the nature of the support planned for their child, especially when support and access criteria varied between settings. Parents sometimes reported that support which they had been active in planning with authorities did not materialise once their child began school. Siddiqua & Janus (2017) found that parents experienced delays in service provision when their children started school. Individual Education Plans took too long to be issued, leading to delays in service provision, especially from healthcare professionals.

### *Finding the right school*

Connelly & Gersch (2016) identified the 'fight' some parents experienced in trying to find the right school for their child. They observed that this pressure sometimes came from the perceived missed educational opportunities following delay in the diagnosis of their child, and that this experience caused stress and worry. Connelly & Gersch (2016) observed that, while parents were generally satisfied with their choice of school, they reported a lack of available information about suitable schools for their child. This finding is echoed by Dockett, Perry & Kearney (2011) who reported that the process of finding a match between school and child was complex and challenging, with many factors needing to be considered. They observed that some families with complex support needs had little choice of school because of financial and transport limitations. Other families experienced being ‘turned down’ for one school, having to start the process again, or even to move to a new house to find suitable placements. In their study, parents describe the process of finding a suitable school as a lengthy, complicated and sometimes demoralising process.

### ***Experiences of professional involvement***

Russell (2005) reported that, in the UK context, parents sometimes reported not reading or not understanding much of the written information produced by professionals about their children. As a result, Russell (2005) surmised that parents’ expectations were based on incomplete knowledge of the system they were expected to negotiate. Dockett, Perry & Kearney (2011) explored parents' experience of the assessments required to ascertain their child’s needs prior to starting school. Parents reported this process to be dominated by professional voices and that the labels assigned to their children for them to access special education services (such as ‘severely delayed’) were insensitive and upsetting. Others reported that their children were not considered disabled ‘enough’, leading to withdrawal of services upon beginning school, which made them feel very anxious.

### *Intersecting systems*

Parents found that access to support was often process-driven and that they received conflicting advice from health and education services. Dockett, Perry & Kearney (2011) highlighted the intersecting factors when a disabled child starts school. A choice of school can have significant financial implementations on families who already experience poverty. Other parents struggled to negotiate the process of starting school while they have their own care needs. It is evident from the body of research explored that parents' experience of the processes around starting school vary widely both between and within studies but that key themes emerge around the importance of information sharing, sensitive assessment and the complex, time-consuming process of choosing an appropriate school.

### 2.6.2 How do parents describe their relationships with professionals when their child starts school?

### *Building relationships*

The nature of relationships with professionals, especially schoolteachers, is a key theme emerging from the studies that took an exploratory perspective on parent's experiences. Siddiqua & Janus (2017) found that parents most commonly had broadly positive perceptions about members of school staff, using terms such as 'understanding' and 'competent'. Some reported instances of the school taking the initiative to build a relationship, such as introducing a home-school book. However, other parents reported that schools did not attempt to initiate communication, meaning that the parent themselves took on this role, or that there was little effective communication prior to a child beginning school. Russell (2005) reported that parents sometimes felt disappointed because, while they were encouraged to visit schools prior to transition, communication diminished once their child began school.

### *The importance of including parents*

For parents in several studies, being actively included and listened to in meetings and events to do with their child was considered important. Russell (2005) found that parents experienced frustration about being left out of meetings, despite continually requesting to be involved. The importance for parents of being sensitively included in such events is highlighted by Connolly & Gersch (2016). They found that parents felt that their role as advocate for their child adversely affected their perceived relationship with school staff. When disputes did occur, school staff were described as ‘quite intimidating’, with parents talking about the need to develop a ‘thick skin’. This research suggested that parents were very keen to communicate with teaching staff, but worried about being perceived as a ‘pushy parent’. This perceived advocacy role also appears in Dockett, Perry & Kearney’s (2011) research, which reported parental experiences as advocates for their child. While some families felt confident about seeking information and stating their preferences, others, especially those with additional support needs, were less confident in advocating for their children. Russell (2005) found that it was very important to parents that professionals shared information with them, so that they could develop a shared understanding of their child's needs, and so that parents knew that professionals thought that their child could make progress in school. Looking back at their experiences, mothers in Strnadova & Evans’ (2013) study reflected on the important role some education professionals had played in helping parents to address their doubts and fears. Mothers recounted how educators had helped them to address their fears about their child starting in a special school program. Other mothers in this study reported developing trusting relationships with members of staff which allowed parents to give their child more independence, such as going on school trips.

### ***Parental perceptions of judgement and blame***

Connolly & Gersch (2016) found that relationships with professionals were sometimes affected by the parents' belief that they were being judged for their child's needs. Parents in Dockett, Perry & Kearney's (2011) study reported a similar perception, indicating that parents sometimes felt blamed by professionals for their child's special needs. A related theme of prejudgement and stigma towards their disabled children arises in Strnadova & Evans' (2017) work, in the context of education services more than a decade ago. They reported mothers feeling pressured to move their child to special education services, with low expectations from staff. Mothers reported needing to find reserves of strength and conviction to pursue a path of high expectations for their child.

### ***Professional expectations of parents***

A key finding in Dockett, Perry & Kearney's (2011) research is the theme of 'school expectation', whereby parents felt expected by the school to take on certain roles because their child had special needs. For example, parents were expected to be available if a child needed to be sent home early or to stay at school with the child when a teaching assistant was not available. The researchers commented that relationships between parents and professionals appeared to be influenced by power differentials. Parents in their study reported actions and comments that positioned them as not knowledgeable about the system or their child's best interests.

### *Support from peers*

While most studies focused on relationships with professionals, Kemp (2003) observed that several parents cited other parents of disabled children as a source of support. This resonated with Dockett, Perry & Kearney's (2011) research which indicated that families valued informal support when their child started school, especially from those who had already 'been there'.

It is evident from these studies that parents perceived their relationship with their child's teachers and other professionals, as well as fellow parents, as an important factor when a child begins school. However, a varied picture emerges, ranging from parents who experienced caring and thoughtful support to those who did not always feel listened to or felt judged. The differential power dynamic between parents and school staff, especially when parents have support needs of their own, can lead to parents feeling unheard and disempowered.

## 2.6.3 What factors do parents report contributed to success or difficulties when their child started school?

### *Collaboration and communication*

In evaluating a transition program for disabled children, Kemp (2003) asked parents what they would want to change. Parents sometimes felt that they had insufficient opportunity to take part in orientation visits and suggested that visits to their child's future school should be earlier, more varied and more frequent. They felt that a greater degree of collaboration with the school, such as increased exchange of information and a clearer school transition policy, might be effective in ensuring a smooth transition. Some parents suggested that improving their child's school readiness in terms of social skills would have been helpful. Once children began school, Kemp

(2003) found that parents wanted better communication with the school and between the school and outside professionals. A key factor highlighted was the willingness of the school to receive advice from expert professionals.

### ***Professional attitudes and expectations***

Kemp (2003) found that parents considered the class teachers' attitude to be an important factor. This was considered much more important than the attitude of support staff or senior leaders. Parents considered the specific skills and training of their child's teacher to be important, but this was outweighed by the perceived importance of the teacher's attitude and willingness to support their disabled child. A similar story is reflected in Strnadova & Evans' (2017) research, exploring the experiences of mothers looking back at their child's transition. Mothers sometimes encountered prejudice and stigma towards their disabled child. However, in other cases children experienced a successful transition to school because of the perceived skills and positive attitudes of teachers. Russell (2005) found a similar theme and wrote that parents found varied professional attitudes. While some professionals and schools were willing to be flexible to accommodate the needs of disabled children, others were not.

### ***Complex needs: Intersecting factors***

Dockett, Perry & Kearney (2011) moved beyond describing parents' experiences and introduced a model which explores the complex interplay of parent support needs and their child's special educational needs. They assert that the interplay of multiple factors can position families in a way that reinforces rather than reduces their difficulties. For example, a parent with mental health needs was uncomfortable about asking for advice from teachers and therefore enrolled her child in a school that did not meet her needs. Dockett, Perry & Kearney (2011) found that parents' choices of school sometimes led to financial difficulties, of which the school was unaware. This placed pressure on parents to earn additional income at a time of enormous change. For example, school expectations for parents to buy uniform, resources or to cover the cost of transportation, led to financial stress and impacted on parents' perception of the success of the child's transition.

In exploring the literature, it becomes apparent that, for parents, the importance of the perceived attitudes of professionals toward disabled children is a key factor in a successful transition. While financial resources, skills and administrative processes were mentioned, 'hearts and minds' were central. Parents report the importance of professional collaboration with families in achieving success, and valued opportunities for orientation visits and open communication. Parents report both positive and negative experiences and while some schools appear willing to accommodate a child's individual needs, others were less flexible. Research from an interactionist perspective indicates that while there exist other, sometimes hidden, factors which also make a difference to parent's experience of the child starting school and that these can interact as part of a complex system, characterised by differentials of power and influence.

### 2.6.4 What impact do parents report the transition had on family life and on their own life as a parent?

#### *Organisational challenges*

Dockett, Perry & Kearney (2011) explored this question in some detail. Families described the process of preparing for transition as time-consuming. Parents reported visiting and researching numerous schools to find the right place for their child. While parents sometime prioritised proximity and convenience, often other factors, such as their child's safety or provision of specialist resources, overrode considerations of convenience. Some parents even moved area to access an appropriate provision, which had financial, employment and relationship implications. In Kemp's (2003) study, parents reported taking on organisational responsibilities to ensure their child found the right school. She reported that parents were given limited information about the options and it was expected that they would research and arrange visits to schools themselves, which impacted on their time and work practices. This experience is reflected in Connelly & Gersch’s (2016) research in which parents reflected on the time taken to find, visit and arrange appropriate educational placements for their child. Parents in this study also reported putting considerable time and effort into ensuring professional services correctly identified their child’s needs to ensure appropriate educational support. Again, parents described this process as emotionally draining and time-consuming. When diagnosis was delayed, or arrived just prior to transition, parents reported that this could have a life-changing impact on their child and themselves. Some parents spoke of how, through the process of assessing their child's needs and planning for appropriate support, they experienced feelings of shock, especially when expected to consider provisions, such as special schools, that had not previously been suggested.

### *Emotional impact*

When asked to consider how their role as parents had changed during their child's transition to school, Dockett, Perry & Kearney (2011) received varied responses. Whereas some looked forward to sharing the responsibility of caring for their child with other people, others felt judged to be poor parents and anticipated time apart from their child with anxiety. The theme of the emotional impact of 'letting go' is reflected in Strnadova & Evans’ (2013) study. Here, one mother reflects on her dread of 'letting her go' and how she was grateful that this was managed sensitively by her daughter’s school. Others described the impact that the process of transition had on their own emotional well-being. This was particularly the case when parents were told that their child was not able to access resources or attend a preferred school. Janus, Kopechanski, Cameron & Hughes (2008) used qualitative methods to assess the emotional impact of the transition to school on parents. Following administration of the Impact of Family scale, they found a significant effect size for both social-familial and personal strain. Suggesting that the process of transition to school had placed additional strain on parents’ personal well-being.

### ***Changing understanding***

Russell (2005) reported that over the course of their child’s first year in school, parents developed a changed understanding of their child. Their expectations of what they felt their child was able to achieve were different, with parents sometimes reporting that they had a better understanding of their child's needs and challenges because of their time in school. A positive change impacted on parents’ sense of wellbeing and their hopes for the future, both for themselves and their children.

### ***The wider family***

While the effect of transition to school on parents is the aspect most widely reported in this literature, Dockett, Perry & Kearney (2011) also acknowledged the impact on other family members. They report that siblings took on additional responsibilities at school, 'looking after' their disabled brother or sister. Additionally, the financial and transport impacts that school placements had on families meant that siblings sometimes missed out on activities and experiences, especially when parents felt exhausted.

### *Advocacy role*

Siddiqua & Janus (2017) reported that some parents identified a changing role and new skills, stemming from their experience of advocating for their child. Some parents formalised this role by taking on new roles within the wider community, such as becoming school councillor (governor) or becoming involved in parent advocacy organisations. Parents described taking time to advocate for services on behalf of their child and other disabled children. Dockett, Perry & Kearney (2011) also found that parents frequently adopt an advocacy role for their child. This is described as a time intensive and challenging task, as parents researched support options and provided information to the school. Parents who identified their advocacy role described feelings of responsibility when something did not go to plan, such as missing out on a school place because of missing paperwork. Parents described feeling overwhelmed by a continual struggle to have their children's needs addressed. This feeling is also reflected in Siddiqua & Janus's (2017) study in which parents reflected upon the emotional toll of maintaining continuity of services following transition and the uncertainty of not knowing which services will continue to be available for their child. Strnadova & Evans (2013) use mothers’ retrospective accounts to explore their changing role. They reported that mothers frequently remember their child starting school as a time of stress and reflect that the stress was amplified by factors outside their control. Like the parents in Dockett, Perry & Kearney's (2011) study, parents report that changing processes and bureaucratic expectations are a source of stress, especially when a resource, such as a school place, that seems secured is then lost. The mothers in Strnadova & Evan's (2013) study also reflected on the role they adopted in challenging prejudice and stigma against their child in school. Mothers describe developing a new inner-strength and conviction enabling them to fight for their child to access a wider range of opportunities and to challenge the low expectations of education professionals. Connolly & Gersch (2016) reported a similar experience, with parents describing the need to become more assertive when fighting for their child's interests, changing how they present themselves and interact with professionals. Connolly & Gersch's (2016) research reflected Srnadova & Evans' (2017) findings around parents assuming a role in challenging disability stigma. They found that parents sometimes felt the need to grapple with schools' pre-conceived ideas about their child, which focused on their diagnosis and report feeling fearful that their child would face exclusion based on this diagnosis.

### ***Intersecting challenges and resilience***

Dockett, Perry & Kearney (2011) acknowledged the ways in which other factors, such as poverty, parental disability and domestic abuse intersect to bring additional challenges to a difficult process. They found that parents living in already challenging situations did not always feel that they had the power to effect change, and that this impacted on how they responded to their parenting role during the transition process. Dockett, Perry & Kearney (2011) found that transition to school had a considerable financial impact on some families and that this added to the stress of starting school. For some parents in poverty it was extremely important that their child had the correct school uniform so that they did not stand out to other children, parents or staff. Others faced financial challenges because of the cost and work time lost when transporting their child some distance to school. When parents were compelled to work longer hours to pay for the additional costs, this impacted upon time spent at home with their child. Janus, Kopechanski, Cameron & Hughes (2008) used quantitative measures to demonstrate an adverse financial impact on families when their disabled child began school. They found that, according to the Impact on Family scale, starting school produced a moderate adverse financial effect on families, greater than that of other families. While Dockett Perry & Kearney (2011) reported considerable challenges for families, they emphasise the importance of recognising familial strengths and the extent to which families were able to build capacity in this situation. Dockett, Perry & Kearney (2011) identified a growing repertoire of advocacy, administrative and time management skills in the families they met, and the researchers admired the families' aspirations for their children.

## 2.7 Synthesis

Evident from this literature review is the diversity of parents’ experiences and the extent to which experiences differ across educational systems, cultural contexts and personal circumstances. The absence of one research paper identified as meeting the inclusion criteria is likely to have impacted on the reliability and depth of this information. However, it is possible to draw out some key themes and events apparent in the literature. These are identified below and have been used to consolidate my research questions:

- Parents received **varied levels of support for transition**. Greater support was generally associated with a more positive parental experience of transition.
- Parents often report that **professional voices and 'expertise' dominate** the transition process and they can experience feeling judged.
- They **value communicative relationships** with individual professionals who know their child and have positive expectations for transition.
- In school, parents sometimes take on an **advocacy role** in ensuring their child gets the support they need. They feel that this is sometimes expected of them, but their ability to do so depends on their confidence and skills.

- Support offered varied widely, and successful transitions are characterised by a **flexible and sensitive approach**.
- Starting school has **time, financial and emotional implications** for the wider family, and these differed between families depending on circumstances. Measures indicate that the process is generally more demanding for families of disabled children than for other families. When a disabled child transitions to school there are additional complexities in relation to **parents' emotions, well-being and identities**, both positive and negative.

### 2.8 Gaps Identified

The research evidence is often evaluative in nature and often focused on specific projects and contexts.

There is a limited amount of evidence which focuses on gathering in-depth experiential data, especially research with an idiographic and interpretative focus.

While there is some research in the English context, there is no research which looks at this phenomenon following the changes to policy and practices brought about by the 2014 Children and Families Act.

### 2.9 Research Question

Because of the lack of any published research evidence in the context I am researching, indicating a significant gap in the literature, I chose to ask a broad and exploratory research question:

***What are parents' experiences when their disabled child begins mainstream school?***

In the next chapter I explain the selection, design and realisation of the method selected to answer this question.

# 3: Method

## 3.1 Overview

This chapter is presented in two parts. **Part One** outlines the aims and research questions I developed following the critical literature review. Part One also considers the ontological and epistemological framework within which the research is positioned and examines the choice of methodology. **Part Two** presents the research design and method, including how the research was carried out, ethics and researcher reflexivity.

## Part One

## 3.2 Purpose, Aims and Research Questions

The **purpose** of this research is **exploratory** because there is a gap in existing knowledge about the phenomenon being examined. I intended to explore in greater depth the under-researched area of mothers' experiences of their disabled child starting school, which the literature review indicated is an important experience for families. Denscombe (2010) describes an exploratory investigation as attempting to collect information which describes how things are, as opposed to explaining or evaluating information.

While predominantly exploratory in purpose, this research also has **descriptive** and **emancipatory** elements. Through the qualitative approach used, mothers were asked to describe *their* experiences of the phenomenon. The research could be considered emancipatory because it gives mothers the opportunity to share experiences in their own words.

## 3.3 Aim

The **aim** of this study is to give voice to mothers of disabled children who are just beginning mainstream primary school. The literature review identified themes of frustration, tensions in professional-parental relationships, hopes and fears for the future, and the wider impact of a child starting school. This study aims to explore further the experiences of mothers of disabled children starting school within a UK context, considering how this significant life event impacts on their lives.

## 3.4 Research Question

Following a systematic review of the current literature and identification of gaps in knowledge, this **research question** is asked:

***Research question:***

***What are parents' experiences when their disabled child begins mainstream school?***

The research question has been kept intentionally broad. This is congruent with the epistemological framework of the study, the method selected and the aim of hearing the experiences of mothers, in their own words. In *Figure 2* I outline my theoretical orientation and epistemological assumptions, providing a rationale for my selected methodology, based on these philosophical underpinnings.

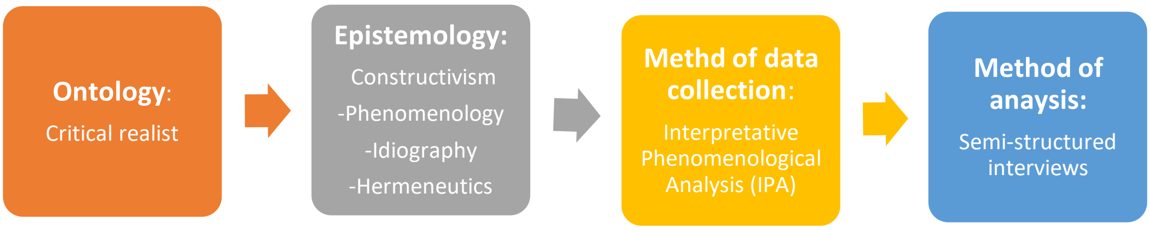

***Figure 2: Philosophical underpinnings of the research***

### 3.5 Philosophical Orientation

Cresswell (2012) writes that it is important for a researcher to understand the philosophical assumptions underlying their research. He states that they shape how the researcher formulates their research questions and affects how they evaluate other research literature. Below, I examine my ontological and epistemological assumptions, based on my beliefs as a researcher and practitioner and explore how these have guided my choice of methodology.

#### 3.5.1 Ontology

Willig (2008) states that ontology is concerned with the nature of the world, asking *'what is there to know'* (p.13). Ontological positions can be located on a realist-relativist continuum. Realism maintains that the world consists of structures and objects that have a clear and consistent cause and effect relationship with one another. Thus, reality exists in the outside world, separate from human thought. In contrast, relativist ontologies question the assumption that reality exists in a law-bound and consistent external reality. Relativist ontologies emphases the diversity of interpretations that can be applied to what happens in the outside world, which are entwined with the meaning individuals make of their life experience. Ontologically, this study sits somewhere between realism and relativism and could be described as drawing on critical realist ontological assumptions. Critical realism is a postmodern ontological perspective proposed by Bhaskar (2008). For critical realists, fundamental features exist independently in the world but our approach to examining these features is a socially and culturally mediated activity. Taking this ontological position into account, my research methodology is situated within a **phenomenological** framework. Phenomenology is concerned with the interpretation experience. It assumes that what is known is understood through individual experience. Phenomenological research draws on the work of Husserl, who argued that phenomena can be understood by exploring individual perception and meaning making, embedded within the context of politics, relationships, language and culture (Moran & Cohen, 2012). A critical realist stance can provide the underlying ontological/epistemological framework for phenomenological research such as IPA because it acknowledges both the real and the perceived nature of the world (Mertens, 2010). In exploring people's experiences, the researcher assumes that there are experiences or phenomena to be elicited (ontological realism), and that these can be accessed and interpreted in multiple ways (epistemological relativism).

### 3.5.2. Epistemology

Epistemology is '*the branch of philosophy concerned with the theory of knowledge*' (Willig, 2008, p. 2). Epistemology concerns itself with *how* we can know. In modern social science, a tension has emerged between two epistemological stances. **Positivism** is epistemologically informed by the pure sciences. Positivist epistemologies maintain that the goal of research is to discover objective knowledge, and that this can be achieved through following empirical research methods, essentially an experimental, hypothetico-deductive approach. Kirk & Miller (1986) explain that positivist epistemologies assume that:

> '*the external world itself determines absolutely the one and only correct view that can be taken of it, independent of the process or circumstances of viewing*' (p. 14).

With the paradigm-shift towards **postmodern** philosophy, social scientists began to critique the utility of positivist epistemologies, arguing that it is impossible for a researcher to position themselves outside the subject matter, because they will have some experience of, or relationship with, the phenomenon studied (Haraway, 1988).

**Constructivism** is an alternative epistemology. Creswell (2012) writes that, from a constructivist perspective, *'individuals seek understanding of the world in which they live and work. They develop subjective meaning of their experiences'* (p. 24). Instead of starting with a hypothesis that they seek to test, researchers use information inductively to find patterns, meaning and complexity. Constructivism acknowledges that realities are produced over time and within social contexts (Willig, 2008). Researchers seek to explore the meaning people make of their experiences and acknowledge that the contexts in which people live and work will shape their worldview, which the researcher subsequently interprets through *their* own perspective.

As a practising psychologist, I have come to understand that the same event can be experienced in multiple ways, coloured by language, culture and power. I believe that I cannot view a situation with complete objectivity because I bring my own assumptions and experiences to bear on it. Social constructivism therefore reflects my epistemological beliefs.

Once I had established my philosophical framework, I sought a **methodology** congruent with my epistemological position, which allowed reflexive exploration and acknowledgement of the complexities of individual experience.

### 3.6 Choice of Methodology

This section examines the **philosophical orientation of Interpretative Phenomenological Analysis (IPA)** and explains why this was an appropriate methodology to use for this research.

#### 3.6.1 IPA

IPA is a phenomenological methodology '*concerned with exploring experience in its own terms*' (Smith, Flowers & Larkin, 2009, p. 2). IPA researchers intend to listen actively to the experience of a participant to hear an insider's perspective of the phenomenon. Furthermore, IPA researchers interpret the shared experiences of participants, to obtain a better understanding of what it might mean for an individual (Reid, Flowers & Larkin, 2005). In conducting a piece of research that sought to explore the experiences of a small number of individuals, these intentions fit with my research aims. I have a professional interest in post-modern and systemic educational psychology practice, which foregrounds the individual experience and the role of the practitioner within the system. To demonstrate the compatibility of IPA with my research, I have examined the key philosophical understandings of the approach: phenomenology, hermeneutics and idiography.

### ***Phenomenology***

Phenomenology is a philosophical position formulated in the early twentieth century by Edmund Husserl. It is concerned with the world as it is experienced by people. Husserl acknowledged that, while we tend to organise experiences within our pre-existing understanding, it is valid simply to describe the experience (Smith, Flowers & Larkin, 2009). Phenomenology concerns itself with **individual experience** within contexts, rather than statements about the world in general (Willig, 2008). Moustakas (1994) explains that, from a phenomenological perspective, '*self and world are inseparable components of meaning*' (p. 28). If perception *is* the experience, rather than an interpretation of the experience, this explains how people can perceive the same event in different ways. I acknowledge that each parent's perception of their child starting school will depend on their social, relational and educational experiences.

Phenomenology, as espoused by Husserl, intends to present a framework that allows researchers to explore a phenomenon while **bracketing** aside what they believe they already know about that phenomenon (Moran & Cohen, 2012). This requires a phase of contemplation referred to as ***epoche,*** requiring the suspension of assumption so that what is before us can be viewed (Moustakas, 1994). Willig (2008) states that, while few researchers would claim to suspend wholly their assumptions, phenomenology provides an opportunity for the researcher to engage in a critical examination of their ways of knowing that phenomenon.

### ***Hermeneutics***

As phenomenology advanced, Heidegger (1962) proposed a model that incorporated **hermeneutics.** Hermeneutics is the branch of philosophy that is concerned with interpretation, for example, of text, discourse and events. IPA methodology is influenced by Heidegger’s hermeneutic version of phenomenology. IPA is a process of interpretation, whereby the researcher undertakes exploratory work to elucidate a phenomenon (Smith, Flowers & Larkin, 2009). The interpretative process in IPA involves a **double hermeneutic** process. This process assumes that the '*the researcher is making sense of the participant, who is making sense of x*' (Smith, Flowers & Larkin, 2009, p. 35). IPA acknowledges the dual role of the researcher in that they are understanding the experience through both the participant's telling and their own experiential lens. Smith, Flowers & Larkin (2009) describe this as first and second order meaning making. The hermeneutic nature of IPA acknowledges that the researcher's knowledge, experience and assumptions influence the research process. Smith, Flowers & Larkin (2009) suggest the researcher adopts a '*spirit of openness*' (p. 27), integrating researcher **reflexivity** as an essential part of the IPA process.

### ***Idiography***

IPA is an **idiographic** methodology, in which insights are formed from intensive and detailed engagement in individual cases, seeking to discover how that phenomenon is experienced for individuals. While attention and analysis initially focus on the individual case, in studies with more than one participant the researcher can explore similarities and differences between cases. Smith, Flowers & Larkin (2009) argue that establishing a corpus of individual case studies can shed new light on the nomothetic research literature.

### 3.6.2 Rationale for Selecting IPA

Having explored the philosophical underpinnings of IPA, and the processes of data collection and analysis, I was confident that IPA suited my research purpose, aims and question. The focus on **exploring** individual experience before moving onto tentative generalisations would allow my research questions to be explored with accuracy and depth. Reid, Flowers & Larkin (2005) assert that IPA is *'particularly well-suited to researching in 'unexplored territory''* (p. 23). In researching a relatively unexplored topic, the inductive process used in IPA allows an interactive approach; whereby, instead of acquisition of hypothesis-driven data, themes can be identified progressively, as the data is further explored Smith, Flowers & Larkin (2009).

The facility of the **double hermeneutic** is important to me in the role of professional practitioner and 'insider researcher' in enabling a reflexive critique of the research process. IPA literature values **ethical** integrity. Smith, Flowers & Larkin (2009) are clear that *'Ethical research is a dynamic process which needs to be monitored throughout the data collection and analysis'* (p. 53). I believe that IPA is a fundamentally ethical and respectful methodology, which supports my ethical research practices. Once I had established my ontological and epistemological position, I was committed to carrying out a piece of research with appropriate **rigour and quality**. As a novice researcher, I was reassured to follow a clearly structured and established methodology, which nonetheless allowed for some flexibility of approach (Smith, Flowers & Larkin, 2009).

### 3.6.3 Limitations of IPA

Willig (2008) states that, while the introduction of IPA into applied psychology has enabled those without a background in philosophy to access phenomenological methodology, it is important to be aware of the conceptual and practical limitations. One criticism of IPA relates to the role of language. In working with texts (transcripts, diaries, other accounts), language is the way in which participants communicate their experiences with the researcher. Therefore, IPA researchers must assume that language is a valid means through which to communicate experiences. However, some social psychologists, influenced by the philosophical ideas of Wittgenstein and Foucault, such as Gergen (1989), argue that language is not a reliable way for one person to communicate to another what is ‘in their mind’. Rather, linguistic discourse is a social act in which all participants have a stake. Willig (2008) explains that, because there are multiple ways of describing an event, the language that the participant chooses adds meaning within the social context in which they find themselves. For example, a participant might use different words to describe their experience depending on the gender or professional role of the researcher. As a reflexive researcher, it is also important to acknowledge the role that the researcher-participant power dynamic might play in what the participant chooses to describe, and the language they use to do this. Willig (2008) states that, in good qualitative research, the role of the researcher in shaping the object of inquiry needs to be considered. Tuffour (2017) identifies a second issue with language as a way of eliciting experience. He states that while phenomenology as a philosophical endeavour relies on introspection, phenomenological research relies on communication, through the accounts of participants and the experiences of researchers. Willig (2008) suggests that the linguistic and communicative limitations of participants and researchers might constrain their ability to convey their experience. In this sense, again influenced by Wittgenstein, their argument is that the language available to participants precedes their ability to conceptualise and convey their experience. Tuffour (2017) raises concerns that this argument could be viewed as elitist, potentially suggesting that IPA be available only to the most eloquent participants. However, he does acknowledge that it is important that researchers consider this limitation and are attentive to obtaining the richest data possible.

A further criticism of IPA concerns its descriptive nature, which allows only limited scope for deeper interpretation or theorising. Tuffour (2017) acknowledges that IPA can produce rich experiential data. However, he argues that the analysis does not purport to theorise or explain events. He goes on to question whether this data, in the absence of a deeper, explanatory perspective, provides sufficient insight into a phenomenon to develop understanding. While this might be less of an issue in a small-scale study, I appreciate that researchers exploring a topic on a larger scale, or over a greater period of time, might seek a methodology that allows them to develop broader theoretical interpretations of their data.

## Part Two

## 3.7 Research Design and Implementation

### 3.7.1 Participant Recruitment

#### *Sample Size, Selection and Homogeneity*

This research is a small-scale, in-depth, exploratory study and consequently required a **small sample size.** Smith, Flowers & Larkin (2009) propose that between four and ten interviews is a reasonable sized sample for a qualitative doctoral research study, due to the intensity of analysis of each case. My intention was to recruit five participants for the main research, and a further participant for a pilot interview. In fact, five participants were interviewed, and all data is included in the research, both for its inherent value and as an acknowledgement of the time and effort of the participants.

Smith, Flowers & Larkin (2009) state that IPA requires a **purposive** sample. This ensures that participation is based on the insight people can offer into a certain experience. IPA studies seek to recruit a **homogeneous sample**, to ensure that convergence and divergence between participants can be identified, whist maintaining a focus on the individual (Smith, Flowers & Larkin, 2009). Sampling factors might include gender, location, age, education and ethnicity. Smith, Flowers & Larkin (2009) acknowledge that the possibility of recruiting a homogeneous sample is dependent on the frequency of occurrence of the phenomenon studied. In this study, inclusion criteria, outlined in *Table 3* were implemented to assist with homogeneous sampling and to ensure that the selected participants were able to provide meaningful insight. Similarly, clarifying exclusion criteria were applied, which are outlined in *Table 4*. This study does not claim homogeneity of sample characteristics, but of shared experience of a phenomenon.

| **Inclusion Criteria** | **Rationale** |
|---|---|
| Parents of a disabled child | Parents were selected as it was considered that they could provide the best insight into their own experience |
| Parents of a disabled child with an education, health and care plan (EHCP) issued before starting school | Ensuring the process of transition can be discussed in the context of the 2014 SEN Code of Practice, through which the statutory process of issuing an EHCP takes place. |
| The child started school in September 2018 and attends school at the time of the interview | The has had sufficient time in school for parents to have experienced the transition process and that they are all experiencing transition into a reception class. |
| The child attends a mainstream primary school | The type of school each child attends is similar in terms of the educational and support context. |
| The child attends school within x local authority | This places the research within a geographic and administrative context. |

***Table 3: Participant inclusion criteria***

| **Exclusion Criteria** | **Rationale** |
|---|---|
| Parents of a child with no EHCP in place | While a child with complex needs might start school with no EHCP, it is more difficult for the |

| | |
|---|---|
| | researcher to ascertain whether the child is disabled. Parents would not have experience of the EHCP needs assessment process relating to transition. |
| Parents with a child in a special school, an independent school or who is home-schooled | These are different educational contexts, with different systems in place. |
| Parents whose disabled child is not in reception class | This study focuses on children of school starting age. |
| Child attends a school maintained by a different Local Authority | This study is interested in the experiences of parents with children at school within one Local Authority area. |

***Table 4: Participant exclusion criteria***

### *The Recruitment Process*

This research explores the experiences of mothers with disabled children in school. The most direct recruitment method would have been to contact parents via local schools. As an educational psychologist I visit several local schools who indicated that they would have been willing to facilitate recruitment. However, I chose not to contact parents through schools. My literature review pointed towards parents' experiences of difficult interactions with professionals and schools. I felt that it might be easier for parents to be open in a neutral space away from situations perceived to be problematic. I also made it clear to parents that I did not work for the Local Authority in which their child attended school and that participation in this research would have no influence on their child's schooling.

While this research concerns mothers’ experiences, I did not intend to recruit only mothers. However, the volunteer participants were all mothers. Trausdottir (1991) observes that the gender of parent participants is relevant in critical disability research and for this reason, gender has been referred to in the research title and the discussion chapter.

I contacted parents through an inclusive nursery school and resource centre, which supports *‘children with disabilities and their families’*. Potential participants were informed of the research through the organisation’s social media platforms. The organisation invited parents to contact me for more information. Parents who indicated they were interested in taking part were provided with a participant information sheet, which detailed the purpose of the study and how they could be involved. Those who chose to participate signed a consent form (see *Appendix 6*). Of the nine parents who contacted me, five were interviewed, three did not meet the inclusion criteria and one chose not to take part in the study.

### 3.8 Method and Procedure of Data Collection

To acquire data, I chose to conduct **semi-structured interviews**. Jamshed (2014) describes semi-structured interviews as ‘*those in-depth interviews where the respondents answer pre-set open-ended questions’* (p. 88). Smith, Flowers & Larkin (2009) describe such interviews as conversations with a purpose. This requires a balance of two elements. Conducting an interview that, while conversational, is focused enough to provide answers to the research questions. Secondly, conducting an interview whilst maintaining a curious stance, open to the unexpected (Kvale, 1996).

I developed an **interview schedule** (see *Appendix 8*) which provided a framework for discussing the broad areas I wished to explore, based on my research question. The schedule asked broad questions with the aim of covering the span of the starting school process, from asking parents about their first steps in finding a school to their child's first day in school, and beyond. My schedule was influenced by some of the qualitative studies identified in my literature review, especially Dockett, Perry & Kearney (2011) and Connolly & Gersch (2016) and questions touched on several of the themes identified in these studies, such as forming relationships and effects on family life.  The purpose of the schedule was not to limit responses, but to allow participants to describe key issues and events from the perspective of their own experience. I developed ten open questions to ask each participant, with some additional supporting questions to encourage elaboration. However, as the interviews focused on the experience of each participant, the interview schedule was not fixed and the conversation flowed as best elucidated the participant's experience, through use of follow-up questions and empathic listening techniques. In developing my interview schedule, I followed Smith, Flowers & Larkin's (2009) suggestions for asking open questions of various types, such as narrative questions (for example, '*can you tell me how you came to choose Tom's school?*') and more structured, information-giving questions (such as, '*can you please describe the process you went through to get to the stage of an EHC needs assessment*?'). While some participants preferred to elaborate 'free form' from open questions, others felt more confident with providing shorter answers to more structured questions, such as providing adjectives to describe a key event. A key task for me was to be responsive to a participant's preferred way of exploring key events, allowing them to comfortably express these individual experiences. During the interviews, I drew on my skills as a psychologist, especially my training in systemic conversations, to encourage participants to provide rich, information. For example, I sometimes used circular questions, to encourage the participant to reflect on how their experience might have appeared to others e.g. '*I wonder what the school SENCO might have felt if they knew how stressed you were about that meeting?*' Such questions enabled me to explore relational aspects of the experience, considering how mothers interpreted their own experience in relation to the feelings and motivation of others and within the context of a complex system.

Once the interview schedule was drafted and participants identified, I undertook the **first interview** with an identified participant (Paulina), who was aware that she was the first participant the study. Following the first interview, and a brief reflective discussion with Paulina at the end of the interview, small changes were made to the interview schedule, including the re-ordering of some questions.

At the start of each interview, I used my skills as a psychologist to build **rapport** and to talk through the information-giving and consent procedure, taking appropriate steps to make this accessible to all participants. Participants were made aware that their interview would be audio recorded and of how their data would subsequently be used. The interviews took place in a meeting room at a local resource centre, the environment was made warm and comfortable, with refreshments, before the interviewees arrived at the venue. I asked a descriptive 'ice breaker' question with the intention of putting the participants at ease, and participants were reassured that there were no right or wrong answers, I was just interested in hearing about their personal experience, whatever that may be.

I used a professional service to **transcribe** the interviews. Whilst this was convenient and time efficient, I acknowledge that it does represent a lost opportunity to fully immerse oneself in the data, which made the reading and re-reading process important. I wrote reflective notes following each interview, which attempted to capture the unspoken experiences of the interview and my reflections about the process.

## 3.9 Reflexivity

One reason I selected IPA as a methodology was because of the acknowledgement that the data collection and analysis is an interpretative process, for the participant and the researcher. Smith, Flowers & Larkin (2009) emphasise the importance of maintaining reflective practices in IPA, throughout the data gathering and analysis stages. The process of reflection and critically evaluating one's own experience is referred to as reflexivity (Etherington, 2007). Willig (2008) states that reflexivity is an important part of the qualitative research process because it encourages the researcher to focus on how they personally affect the process of research and its findings.

To further understand my role in the research it was important to consider the factors that might influence how I conducted the research. I did this through creating a pen portrait of myself as researcher and examining this using Burnham's Social GRACES reflexive model (Burnham, 1993). The social GRACES reflexive tool allows a practitioner to reflect on their own prejudices, assumptions and influences because of the privileges or oppressions they experience. By separating out aspects of our lives, we can more fully explore the parts that might have a dominant presence or be sometimes unnoticed when we consider our interactions with others. The GRACES I identified as being potentially influencing factors are identified below in *orange italics*.

*I am a white (ethnicity), British (geography) 40-year-old (age) woman (gender identity). I am well educated (education, class), financially comfortable (economics) and straight (sexuality). I live with my husband, daughter and son. I have a good network of social support.*

*In my professional life, I work as an educational psychologist (education). I work in schools but independent of the Local Authority. I have previously been employed by the Local Authority in which the research was conducted.*

*I have a disabled son (ableism/disablism). He has an education, health and care plan. My son attends a mainstream primary school.*

***Figure 3: Pen portrait as myself as researcher***

In my reflexive diary, I further considered how my experiences and position might have influenced my interpretation of the experiences voiced to me, to acknowledge and, where possible, **bracket off** my own prejudices and assumptions.

As the parent of a disabled child who has started school with an EHCP I have experienced the same phenomenon as the participants in this study. This means that I am an ***insider researcher***. Hoffman & Barker (2017), in examining Hoffman's experience as an insider researcher (in a study of type 1 diabetes), state that reflexivity is especially important in this situation. While experiencing a phenomenon one gives experiential knowledge (Borkman, 1990), it may lead to overidentification with the participants. Hoffman (Hoffman & Barker, 2016) reflects that her experience means that she had knowledge of the medical condition and rarely needed to seek clarification. She also believed that her experience meant that she was more empathetic and less judgemental of participants. However, Hoffman (Hoffman & Barker, 2016) cautions that insider experience could lead to a risk of 'assumed similarity' with participants and difficulties bracketing off researcher assumptions.

An important decision for an insider researcher is whether to disclose their position to participants. I made the decision to mention my experience in the participant information sheet but not to provide detail. Finlay (2012) argues that, assuming the role of detached observer creates a false power differential between participant and researcher, which may compromise research data and is difficult to justify ethically.
In the *Table 5*, I have outlined the opportunities and risks in my own role as an inside researcher, which I identified before conducting the research.

| **Opportunities** | **Risks** |
|---|---|
| Participants speak more freely without need for clarification of processes. | Wrongly assuming I know what participants are ‘going through' based on my personal experiences |
| Drawing on my experience and knowledge to empathise with the participant | Risk of bringing up difficult emotional experiences for the researcher |
| Helps to build up rapport with the participants, who might see me as less judgemental about their compromises or difficult experiences | Difficulties bracketing off own pre-existing assumptions, based on personal experience |

***Table 5: Opportunities and risks of insider researcher role in this study***

Some issues did arise in the research process, and my reflexive log was useful in recording and reflecting on them. I was surprised about the strong emotional response I experienced when speaking with some of the participants about their frustrations and challenges. Finlay (2012) emphasises that reflexivity is not just about being aware of issues, it requires critical evaluation of the researcher's interpretation and reactions. During the research process I accessed supervision with my research supervisor and fellow researchers, to reflect critically on my pre-existing assumptions and attempts to bracket these. I also contacted another parent insider researcher (Professor Katherine Runswick-Cole, from the University of Sheffield) who kindly provided thoughts and encouragement about this process.

When reviewing the transcripts as part of the IPA process, I chose to add an additional **reflection stage**, to consider my interactions and interpretation, based on my own pre-existing assumptions. I attempted to be aware of where my personal experience interrupted the process of data gathering and analysis (Etherington, 2007).

### 3.10 Ethical Considerations

Ethical approval was sought from the Tavistock and Portman NHS Foundation Trust Research Ethics Committee (see *Appendix 2*). In the document supporting this request, ethical considerations and risks were outlined (see *Appendix 4*) and the research was granted full ethical approval (see *Appendix 3*).

This research followed the ethical principles outlined in the **British Psychological Society Code of Ethics and Conduct** (2018), which provides a framework for applied psychology research. Using this framework, key ethical issues are considered below.

### 3.10.1 Respect

I treated all participants with respect and maintained an awareness of the importance of anti-oppressive practice, appropriate to my professional role. I attended to the balance of power during this research. I used Burnham's Social GRACES (1993) model as a context in which to reflect upon how imbalances of power and influence might prejudice the participants and affect the research.

Participants were asked if they required any **adaptations** to access the interview. One participant informed me that she is partially deaf and asked that we conduct the interview in a quieter room, with a minimum of background noise. To facilitate this access requirement, we conducted the interview in the centre manager's office.

In designing the study, I reflected on how I could minimise **power imbalance**. I interviewed participants with whom I had no professional involvement and parents were made aware that their involvement in the study would in no way impact on their child’s educational provision. Interviews took place in a 'neutral' and welcoming venue to assist the participants in feeling at ease.

Participants **provided informed** consent before the interview was conducted. Participants were provided with an information sheet which gave an explanation of the aims of the research, the nature of their participation and how their data would be processed. A known family worker was available to read forms with participants if this was required. I offered to answer any questions or talk through the form on the day of the interview. Participants were informed of their right to withdraw from the research at any time, up to the point of thesis submission.

**Gathering and processing of research data** was compliant with the requirements of the General Data Protection Regulations (Information Commissioner's Office, 2018), which provides statutory guidelines for how professionals treat information they hold about individuals. The TREC data protection guidelines were also followed. As principal researcher I was responsible for data collected in connection with the research. In keeping with the Data Protection Act (1998), data was kept for no longer than necessary. No names, dates or other information about participants has been recorded. Interviewees were given a pseudonym in all notes.

Data was gathered through **audio recordings** and participants explicitly consented to this. The recordings, alongside their paper transcripts and consent forms, were stored in a locked filing cabinet and on a password protected computer, which only the researcher had access to. The audio files were deleted from the voice recorder as soon as they had been uploaded onto the computer. To maintain confidentiality, interview data was de-identified, prior to transcription. Any identifying data such as names, schools and places were removed and replaced with a pseudonym. Participants understood that this process could not guarantee complete anonymity. Participants were informed about how their data would be processed, including sharing de-identified data as part of research supervision and in the thesis. Participants understood that data would be disclosed if professional or legal obligation arose.

### 3.10.2 Competence

I followed the British Psychological Society *Code of Ethics and Conduct* (2018) in to ensure that ethical issues were understood and acted upon. **Ethical issues** were discussed in research and peer supervision sessions. This discussion reflected appropriate standards of professional supervision (Dunsmuir & Leadbetter, 2010) and enabled me to draw on colleagues' experiences and observations to reflect on ethical issues.

### 3.10.3 Responsibility

The TREC ethics application required me to identify **physical and psychological risks** to myself and participants. I ensured that the interviews were conducted in a safe, public place and a risk assessment was completed (see *Appendix 4*).

My risk assessment did not identify any significant risks of physical or psychological harm. I remained aware that I was speaking with parents about a sensitive experience, and their emotional wellbeing was paramount. Participants understood that their participation was voluntary and that they could withdraw at any time. In acknowledging the potential emotional impact of the interviews, the information sheet informed participants about how to seek follow-up support.

### 3.10.4 Integrity

The information letter provided accurate and honest information about the nature and purpose of the research and participants were invited to ask any questions.

I chose not to interview participants with whom I had professional involvement. The recruitment process and interviews took place outside the school system and parents understood that their participation did not influence their child’s educational provision.

### 3.11 Ensuring Quality

Willig (2008) states that the application of quality assurance criteria used in quantitative research, such as large sample sizes, replicability and inter-rater reliability, is of little use in qualitative research. Researchers have developed several structures to ensure quality in qualitative research. According to Creswell (2012) such processes use qualitative terms that parallel their quantitative equivalents, employing postmodern perspectives. In this research, I have used Yardley’s (2000) four broad principles for assessing the quality of research.

I have addressed each of Yardley’s four principles in turn to demonstrate how I ensured the quality of my research:

#### 3.11.1 Sensitivity to context

Yardley (2000) states that sensitivity to context can be demonstrated in several ways. My interest in this research came about through professional and personal experience. I developed further sensitivity to the context through pursuit of a systematic review of the literature, which deepened my understanding of the phenomenon and the theoretical frameworks within which the topic is situated. Sensitivity to context in this research is also demonstrated through selection of IPA as the research methodology. Smith, Flowers & Larkin (2009) state that IPA can demonstrate sensitivity to context when it is selected to engage closely with participants. I remained sensitive to context during the interview and data analysis stages. During the interviews I explained the process to participants and built rapport through sensitive questioning. Part of the reflexive process involved developing an awareness of the socio-political and power context in which this research occurred. Using reflexive models, such as Burnham's (1993) Social GRACES, I monitored the potential power imbalance of the researcher-participant relationship and considered how my biases might affect the research.

### 3.11.2 Commitment and Rigour

Smith, Flowers & Larkin (2009) argue that commitment is evidenced by the:

> *'…degree of attentiveness to the participant during data collection and the care with which the analysis of each case is carried out'* (p. 181).

I developed my interview skills by attending tutorials and reading about IPA interview techniques before carrying out an interview and I also completed a pilot interview. For Yardley (2000), rigour is exemplified by completeness of data analysis as well as the thoroughness of the study, in terms of design and sample. I developed inclusion and exclusion criteria to select a homogeneous sample of participants who were well-placed to answer my research questions. IPA is a process which requires immersion in the interview data which demonstrates commitment to the research project. IPA moves beyond the descriptive, towards deeper idiographic insights and allows the researcher to demonstrate rigour through their own reflexive engagement with the data.

### 3.11.3 Transparency and Coherence

Yardley's (2000) transparency criterion refers to how clearly the research process Is described. My write-up describes honestly the process of designing and implementing this research project, including the challenges and pitfalls. Smith, Flowers & Larkin (2009) state that Yardley's (2000) coherence criterion is reflected in the quality of the research write-up. I have endeavoured to produce coherent arguments, through rigorous and immersive data analysis. Coherence can relate to the extent to which the research undertaken fits the underlying theoretical assumptions of the methodology. I have considered the philosophical assumptions and values I bring to research and my reasons for using IPA are detailed in this chapter.

#### *Impact and Importance*

These criteria relate to the extent to which the study is interesting, important and useful. This professional doctoral research is intended to enrich and extend professional understanding and practice. While a positivist research design would assess impact by considering generalisability, this phenomenological study considers the illumination of individual experience to be paramount. Smith, Flowers & Larkin (2009) suggest that, rather than thinking of IPA studies in terms of generalisability, impact can be assessed through considering theoretical transferability. A quality IPA study should allow the reader to make links between *'the analysis in the IPA study, their own personal and professional experience, and the claims in the literature'* (p. 51). I hope that, through publication of my findings, professional practice advances and practitioners reflect on their professional practice in relation to this phenomenon.

### 3.12 Data Analysis Process

The data analysis followed the process for IPA studies recommended by Smith, Flowers and Larkin (2009). Each stage, with examples, is presented in *Figure 4*.

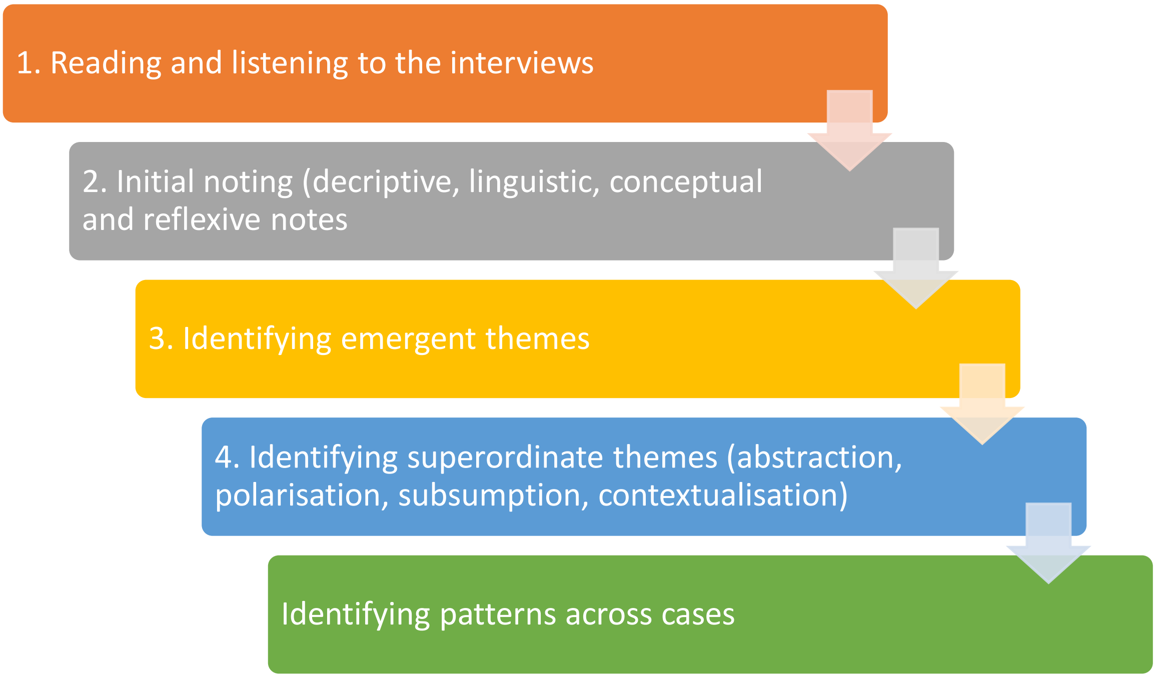

***Figure 4: Data analysis five-stage process***

#### 3.12.1 Reading and Listening to Interviews

Each transcript was read through twice, whilst listening to the audio recording. I identified errors or omissions in the transcription process and noted interesting elements of the interview such as tone of voice and pauses. I endeavoured to keep the participant as a central focus, slowing down and listening carefully for meaning.

#### 3.12.2 Initial Noting

The initial noting phase involved four forms of notetaking. Smith, Flowers & Larkin (2009) outline three forms. However, I added a further reflective/reflexive stage with the aim of reflecting on my response to the interview, and to ‘wonder aloud’ about responses, questions and process. I judged that this additional reflexive stage was particularly important for me as an insider researcher and formed part of the process of ‘bracketing off’. The transcript was formatted into a table, with line numbers. The initial notes were colour coded according to their categories:

- **Descriptive comments**
- **Linguistic comments**
- **Conceptual comments**
- **Reflective/ reflexive comments**

### *Descriptive Comments*

This stage focused on summarising and clarifying the participants or questioner’s meaning. For example, where local terms for statutory processes were used, this was clarified.

### *Linguistic Comments*

These comments focused on use of language. I identified and considered choice of words or metaphors, use of pronouns, adjectives, and changes in tense.

### *Conceptual Comments*

Conceptual comments took a more reflective view of the participants’ individual experiences. Rather than exploring the outward meaning, conceptual comments explore the implicit meaning behind comments.

### *Reflective/ reflexive notes*

This final stage formed part of the process of considering the double hermeneutic. I identified my reactions to the language, ideas and experiences conveyed and reflected upon the significance of these to interviewee and interviewer. I used this phase to consider the influence of my presence in the interview process and to ‘wonder aloud’ about other aspects of the interview.

### 3.12.3 Identifying emergent themes

Smith, Flowers & Larkin (2009) state that:

> *‘themes are usually expressed as phrases which speak to the psychological essence of the piece and contain enough particularity to be grounded and enough abstraction to be conceptual.’ (p.87).*

This stage was the beginning of identifying these psychological essences. I read the transcripts alongside initial notes to identify themes. Emergent themes were noted in a column next to the original transcript and the corresponding transcript excerpt was highlighted. While identification of emergent themes was seen in part as a process of abstraction, relevant parts of the original transcript were identified to remain connected with the original data and the complexities and interconnections therein.

### 3.12.4 Identifying superordinate themes by grouping emergent themes

This stage involved clustering of emergent themes into superordinate themes for each participant. This was a lengthy manual process, which required cutting up the emergent themes list and arranging and rearranging them into clusters, until I judged that they cohered sufficiently. Superordinate themes were identified according to four techniques suggested by Smith, Flowers & Larkin (2009).

#### *Abstraction*

A superordinate theme, which links some of the emergent themes, can sometimes be identified through the process of abstraction. For example, anecdotes about specific events can be identified as linked to a more abstract concept, such as ‘identity’ or ‘agency’.

### *Subsumption*

Subsumption occurred when a superordinate theme was taken directly from an emergent theme, with other emergent themes then linked to it. For example, an emergent theme such as ‘a journey’ might be identified several times, thus leading to development of a superordinate theme.

### *Polarisation*

Polarisation occurred when seemingly opposing or ambivalent themes were clustered together. For example, a theme of ‘belonging and acceptance’ encapsulates not only experiences of acceptance and belonging, but also contrasting experiences of rejection and refusal.

### *Contextualisation*

Temporal, narrative and cultural aspects were clustered within themes. This included noting and grouping occasions where events or processes were discussed, and considering the thematic threads running through these retellings of events.

To organise the themes, they were colour tabulated and colour coded. Superordinate themes were named and their corresponding emergent themes, and related transcript excerpts, were organised.

### 3.12.5 Repeat for transcripts 2-5.

Each stage was repeated for each participant. Smith, Flowers & Larkin (2009) recommend that each transcript is analysed discreetly so that the idiographic nature of each transcript is honoured, and the individual themes can emerge. To support this element of the bracketing process, I left at least one week between analyses. However, in reflecting critically on this process, it is important to acknowledge the element of the double hermeneutic which means that I, as researcher, cannot wholly bracket each experience and that each analysis built, intentionally or unconsciously, on my previous experience. This was not resisted as I judged it important to be aware and consciously reflective of this process. At times, my initial notes document my awareness of this process and reflections on it.

A transcript excerpt is provided in *Appendix 10*. Full transcripts are in the additional appendix.

### 3.12.6 Patterns Across Cases Identified

Once all transcripts had been analysed individually a process of identifying patterns across cases began. This was a lengthy and dynamic process in which superordinate themes combined and were again arranged and rearranged into clusters which appeared to relate conceptually. I judged that a pattern would be identified when similar superordinate themes were present in 3-5 of the transcripts, so they were representative of the group. To facilitate clearer writing up of the data, patterns and themes were organised into subthemes. This is not a stage identified by Smith, Flowers & Larkin (2009). However, because of the large amount of data within each pattern, I used this method to sort the material into more manageable groupings, as well as allowing a further stage of identification of similarities, discrepancies and themes between individual participants.

### 3.12.7 Reflections on Data Analysis

While data analysis could at times feel like an exercise in pattern seeking, it was important for me to hear the individual voices contained within the data. While it was tempting to ‘standardise’, for example the superordinate themes, using consistent language across the interviews, I was aware that this would lose some of the individuality and complexity contained within the data, such as the voices and language used by each interviewee. Therefore, while I have created overarching themes through which individual voices are, to some extent, brought together, I consider these tentative and sometimes overlapping. They are not intended to provide perfectly ordered data which reflects the reality of a conversation about a complex and emotionally challenging event. I did not base inclusion of superordinate themes on frequency of occurrence, because, for me, this process might fail to reflect the whole experience of the mothers and did not account for the intensity or significance of the identified theme for individuals. My intention was that the analytic process and narrative generated, conveyed in the Findings chapter that follows, communicates the complexity of each experience, complete with contradictions both within and between interviewees.

# 4. Findings

## 4.1 Overview

This chapter aims to provide a comprehensive account of findings following the Interpretative Phenomenological Analysis (IPA) of the five interviews, which sought to answer the broad research question:

***What are mothers' experiences of their disabled child starting mainstream school?***

This chapter begins with pen portraits of each of the mothers who took part in the study. I then provide an overview of the themes identified for each mother. For the presentation of findings, these themes have been organised according to patterns across the individual themes (hence called 'patterns across cases'). The intention is not in any way to standardise or homogenise the idiographic accounts, but to provide a means to consider patterns, similarities and contrasts within and between accounts. Each mother's account is colour-coded so that the voice of each one stands out in the presentation.

## 4.2 The Participants

In keeping with the hermeneutic cycle, I begin by presenting some biographical information about the mothers, as I know them. I hope that this information helps the reader to form a sense of how the parts of the interview, later presented thematically, form a whole and to 'hear' the findings in the context of the mothers' experiences. These short, selective biographies perhaps bring to light some of the contextual factors and provide an indication of how my experience of the mothers influenced my subjective analysis of their interviews. Each participant’s superordinate themes are represented pictorially below their pen portrait.

### Paulina

Paulina lives with her husband, and sons John Paul (4) and Alejandro (2). She explained that John Paul has autism and other developmental needs. John Paul attends a ‘hub’ for autistic children in a local mainstream primary school. Paulina does not work outside the home and her husband works full-time. Paulina is originally from South America and her family speaks English and Spanish at home. Paulina was the first mother to reply to my request for participants. During the interview I perceived her to be an energetic and positive woman who was keen to share her experiences. She brought Alejandro to the interview and her interactions with her son and towards me were characterised by gentle humour and warmth. Starting school has been an important time for her family, and she described developing a (at times tentative) sense of belonging in the school and an empathy towards other parents. Paulina vividly described her son’s first school day, following months of preparation, waving him off with his backpack as he got on the bus. Her pride for John Paul shone through and she is now enjoying spending more time with Alejandro. Perhaps the most striking aspect of Paulina’s interview is the positivity with which she speaks of the professionals she encountered during her son’s Education, Health and Care Needs Assessment (EHCNA), and her resolve to make a success of school life and to form positive relationships, even when she encounters challenges along the way. The superordinate themes identified in Paulina’s account are shown in *Figure 5*.

*Figure 5: Paulina's superordinate themes*

## Sarah

Sarah lives rurally with her husband and daughter Sasha (5), who has Down Syndrome. Sasha attends her local primary school, alongside her friends from preschool. Sarah appealed the Local Authority's refusal to carry out a statutory assessment, commissioning solicitors and expert witnesses. Sarah has two adult children, who live nearby, and she recently became a grandmother. Sarah was a teacher for twenty years, becoming a Deputy Headteacher. She does not now work outside the home. When listening to Sarah, it was striking that she had already thought a great deal on the process of finding appropriate educational support for Sasha as she began school and that this was an emotional topic for her. I perceived her to be an articulate woman who reflected thoughtfully on her own experiences and on the structural inequities of the system within which her daughter's needs were identified and supported. Sarah was influenced by her teacher identity and is driven to help other families, particularly those less able to advocate for their child. Sarah's description of the process as she negotiated her daughter's school starting experience is characterised by frustration, her drive to advocate for Sasha and others, her pride in Sasha's achievements and her uncertainty as she wonders what the future might hold for her daughter. The superordinate themes identified in Sarah's account are shown in *Figure 6*.

***Figure 6: Sarah's superordinate themes***

## Laura

Laura lives with her daughter Emily (4) and her two secondary-aged children. Emily is diagnosed with developmental delay. She does not yet speak and attends a speech and language unit in a mainstream primary school. Laura's son also has special needs, and this was Laura's second experience of statutory assessment in the context of starting school. Laura does not work outside the home. Laura at first seemed quieter and more reticent than the other mothers. However, she was an engaged interviewee, arriving early for our meeting. Laura spoke in detail and with conviction about the lengths she had undergone to secure support for her daughter and to advocate for her daughter in school, despite the systemic challenges she faced. She spoke of the impact of starting school on family life and of her continued frustration when seeking support. For Laura, Emily's needs are not yet fully understood, her placement is precarious and the future uncertain. The superordinate themes identified in Laura's account are shown in *Figure 7*.

***Figure 7: Laura's superordinate themes***

## Lisa

Lisa was very keen to take part in this interview and was proactive in organising an interview date. Lisa lives at home with her husband, older daughter and son, Tate (5). Tate has autism and attends a local mainstream primary school. Tate had a shaky start to education; the pre-school repeatedly excluded him for 'poor behaviour'. It took several months for Tate's EHCNA to be finalised and Lisa chose to defer his school entry for a year. Lisa is an articulate woman who, when speaking about her journey, conveys strength and wisdom alongside vulnerability and uncertainty. Lisa has worked hard to ensure a place at her preferred school and to ensure that they understand the support Tate needs. For Lisa, a couple of understanding professionals and parent groups on social media were of great support. Lisa resolved to learn as much as she could about Tate's condition and the system in which he will be educated and aspires to use this knowledge to help others, as well as her son as he moves through school. The superordinate themes identified in Lisa's account are shown in *Figure 8*.

***Figure 8: Lisa's superordinate themes***

## Vicky

Vicky was the last mother to be interviewed. She had heard about the project from another mother and asked to become involved. Vicky lives at home with her husband and son, Toby (4), who has autism and learning difficulties. Before becoming a mother, Vicky worked in housing support and domestic abuse services. Toby now attends a unit for children with learning difficulties in a mainstream school. Vicky appealed his initial Education, Health and Care Plan (EHCP) and asked for a placement in a special school, but her relationship with the school broke down. Vicky experienced significant organisational and emotional challenges while securing Toby's school place. Her own experiences of changing identity, belonging and rejection come across strongly in her interview. Vicky now works as a preschool family support worker with families with disabled children. She comes across as a friendly, warm woman, who feels passionately about generating something positive from her experience. She was exceptionally open during the interview, sharing not only her positive experiences and pride in herself and her son, but the feelings of inadequacy and trauma that accompanied parts of the process. The superordinate themes identified in Vicky's account are shown in *Table 9.*

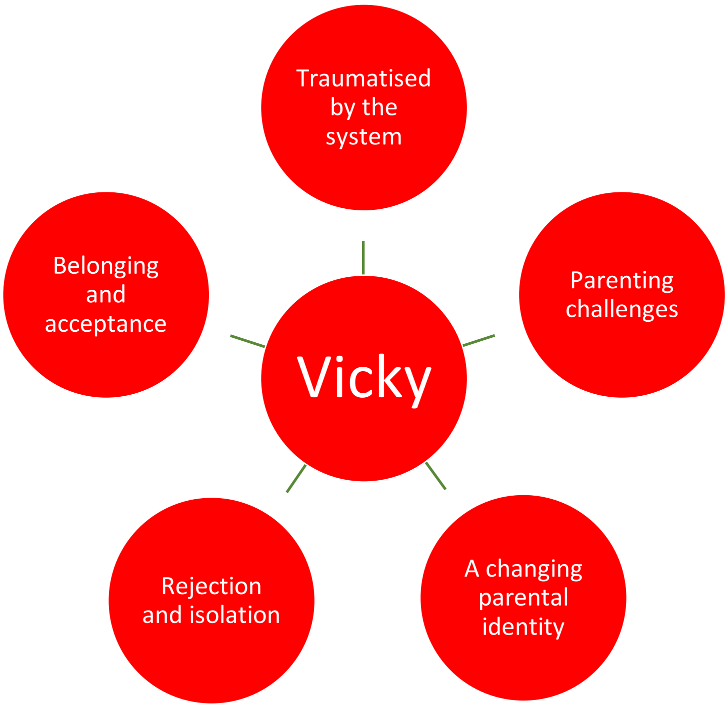

***Figure 9: Vicky's superordinate themes***

Arranged thematically and colour-coded, key excerpts from the individual interviews are presented alongside my interpretation, to bring to light individual voices and to maintain the phenomenological core from which my interpretations arose.

## 4.3 Patterns across cases

Four key patterns emerged from cross-case analysis of the transcripts and themes generated. These were:

- Starting school as a life stage process
- 'The System'
- Personal change and growth
- Belonging and rejection

I searched for patterns by grouping participants' superordinate themes. Because of the individual nature of each analysis and the idiographic interpretation, the participants' themes are broad and do not map precisely onto each other, either conceptually or linguistically. Rather they are similar in concept or content and provide a platform from which to consider, compare and, at times, contrast each voice. Each participant has been assigned a colour, to allow for the individual voices to be more easily heard in the cross-case analysis. *Table 6* shows the superordinate themes identified in each participant's account, grouped into patterns across cases.

| **Pattern across cases** | | **Sarah** | **Laura** | **Lisa** | **Vicky** | **Paulina** |
|---|---|---|---|---|---|---|
| | **Transition as a life stage process** | **A step on a long journey** | **An important point** | **Bumpy road** | | **A long and continuing journey** |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | | | | A family experience |
| | 'The System' | Battling bureaucracy | Lost in the system<br>Hear my voice | People and processes | Traumatised by the system | Communication and preparation |
| | Change and growth | Mothering: A complex role | | Gaining and sharing knowledge<br>Parent and advocate | Parenting challenges<br>Changing parental identity | Being a 'special needs' parent<br>Power and agency |
| | Belonging and rejection | A place for us | A place for us | Isolation and community | Belonging and acceptance<br>Rejection and isolation | Knowing my child |

***Table 6: Participants' superordinate themes grouped into patterns across cases***

Because of the broad nature of the patterns across cases and the large amount of data contained in each pattern, I have chosen to subdivide the patterns to make them easier to report and read. These relate to participants' superordinate themes grouped within each pattern and were developed from a process of grouping and regrouping, rather than precise thematic grouping or mapping. The divisions are intended to allow for a more coherent and ordered reporting of patterns, while still ensuring that the individual experiences are voiced. The patterns and their divisions are presented visually before a narrative account of the findings for each pattern.

## 4.4 Pattern across cases 1: Starting school as a life stage process

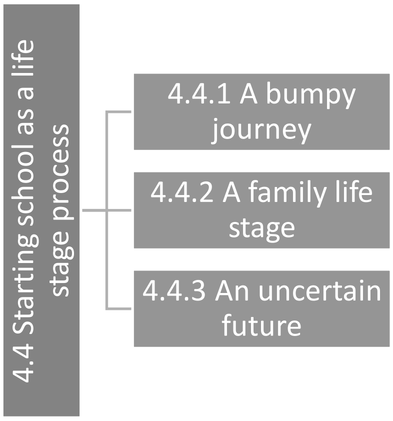

***Figure 10: Pattern across cases: Starting school as a life stage process***

The theme of starting school as a life stage process, as outlined in *Figure 10*, is taken to express the significance of a child starting school as a key event in the mothers' life course and in family life. Each of the mothers describes a different journey in understanding their child's additional needs, through statutory assessment and into starting school. This process includes joining school systems, changes to family life and consideration of future transitions. I understand this event as a life stage process not only for each child, but for the mothers and the family as whole. The concept of a life-stage *process* rather than a life-stage *event* is important here, as we hear of their months-, and sometimes years-long journeys. For these mothers, starting school has no clear beginning or endpoint, and there are many ups and downs along the way.

As Paulina tells us, about the start of her journey:

*I told my husband, he needs more help, I think his needs will be more.* (121-122)

### *4.4.1 A bumpy journey*

When each of the mothers speak about their child starting school, they describe a lengthy and convoluted process. For these mothers, starting school does not begin or end with their child walking through the door of the Reception class for the first time. That day was preceded by months of assessments, meetings, and relationship-building. Each mother conveyed a sense that starting school for a disabled child required more parental time, effort and emotional labour. For each mother, in one way or another, her journey was a ‘bumpy’ one, characterised by highs of success and pride, and lows of disappointment and rejection, as we can hear from each account below.

Lisa’s story conveys this sense of a bumpy journey as she recalls the ups and downs, she experienced as Tate started school. She loses and then regains her ability to choose for her son, as her choice of school is rejected and then agreed. Even now, in his first term at school, the process of settling in and relationship building continues. Lisa and Tate have yet to reach an end point in the transition process:

*So, we couldn’t get the school we wanted him in, so we deferred for a year…and then we were able to choose the school. We chose LC. He’s settled in quite well, yeah, he’s getting there* (4-7)

Paulina describes how, for her, John Paul starting school brought about not just a change in circumstances, but a changing understanding of his needs and changed expectations for his life course:

*Yes, and the hopes and dreams they have changed a lot since all this autism journey began, because in the beginning to make friends, you know they were too idealistic. Now I want him to be able to communicate in whatever means* (248-251)

Paulina goes on to speak of the pain she experienced during the assessment process, prior to John Paul starting school. She describes a ‘secret hope’ she has for her son.

Not a hope that she shares with professionals, but perhaps a fantasy for him, as his mother:

*It’s like that secret hope you have, no he’s not that autistic* (139-140)

For Paulina, this ‘secret hope’ was dashed as professionals communicated their opinions of John Paul’s needs. Paulina had hoped that he would be able to join the mainstream class and she describes this as a sad point on her journey:

*It was kind of choking when they told me his needs were too high* (163)

Perhaps for the first time, Paulina experienced how her son’s special needs would be viewed by those in systems outside her family and felt understandably sad.

I was struck by the mothers’ use of language and metaphor related to travel to describe their experiences of starting school, which prompted my own description of this process as a journey. The images and descriptions related to obstacles and of roads with twists and turns.

Sarah, like Lisa, talks about the obstacles placed in the way as she sought to ensure that Sasha’s needs were understood and met. She describes encountering ‘*a brick wall from the other side’* (332) when she attempted to communicate the complexity of her daughter’s needs to the Local Authority. Following tenacious advocacy for Sasha this frustration was eventually resolved by a legal process:

*I’ve just constantly been at them the whole time, and in the end, which is why we had to go to the solicitors* (282-284)

Lisa too describes a series of challenges, like an obstacle course, that just keep on coming:

*So, it just seems to be you get over one hurdle and then you have to get over another one* (73-74)

For Lisa, these hurdles included broken promises, mix-ups and a need to constantly ‘chase’ for decisions from education officers. Here she describes the statutory assessment process:

*…a nightmare. It was chasing all the time, so we applied for it March time, we got rejected, we appealed, it stopped. So, from the March to the December. It took that long, and then obviously getting everything with the school. So, it was 13 December last year that the school actually made a decision to make a place* (272-274)

Lisa and Tate’s school starting journey became a race against time, eventually sped along by Lisa’s proactive approach.

Laura experienced similar disruptions and delays in the assessment process, and describes an unrelenting journey:

*It’s exhausting when you just have to keep going* (604)

For Laura, the journey was not just long, but confusing and convoluted, as reflected in her retelling of the statutory assessment process. I admit to feeling confused by her retelling of the process, which reflects perhaps both Laura’s own frustration and the complexity of the process. For example:

*I had to apply again at Easter. But applying at Easter it would have gone well past September* (261-263)

*And that is now, it went on until the middle of November* (165-166)

*...and then it would have been on a Sunday when they gave the decision. So, I phoned on the Friday and they said they hadn’t made a decision yet.* (219-220)

It is perhaps understandable therefore that while Emily's school placement is not perfect, Laura describes feeling:

*…relieved because it had been a long while to get there* (392)

### *4.4.2 A family life stage*

Each mother spoke with pride about their child's first day in school. The vividness with which they recalled that moment, whether waving their child off onto the bus, or handing them over to a teacher, reflected the importance and significance of that day to their child, to themselves and as a family; the sense of finally achieving what had taken so long.

Paulina paints a positive picture of an excited family awaiting her son's first day:

*The first morning of school, well we were all very excited, but he was waiting by the door.* (339-340)

For Sarah, Sasha starting school was an important family day, made into a special occasion:

*My husband took the day off as well because we thought that it would be nice for us all* (423-424)

While the image of children being happily waved off by their family is heart-warming, it is important to remember that this is not the endpoint in these mothers' journeys and that starting school continues as a process beyond the first day. Laura reminds us that in the days and months that follow, starting school can have longer term and negative effects on family life. She describes how starting school has brought about Emily's reluctance to join in family outings:

*…if we say we're going out anywhere, she's* [Laura shakes her head] *… it's either school or home* (366-367)

### *4.4.3 An Uncertain Future*

Reflecting on their journey, several mothers suggested that the process of their child starting school had changed their view of what the future might hold, raising uncertainties about their future education and future challenges in ensuring their child's needs are met. For these mothers, whose children are likely to need support and care for the rest of their lives, starting school seems a staging post on a long and uncertain life journey.

For Laura, difficulties when Emily started school evoked feelings of uncertainty about Emily's future:

*So, I don't know what's going to happen for her future and that's a worrying thing, especially with the shaky start we've had.* (664-665)

For Sarah, thinking about Sasha's future requires balancing uncertainty and hope. But in contrast to Laura's worry, she frames this uncertainty more positively:

*I mean, I've always thought, or hoped, that she would stay in mainstream, for as long as she can. I mean we've always kept an open mind* (408-409)

Lisa talks of learning to take a similarly open-minded approach to considering the future, because she has learned from past experiences:

*With Tate you never know what it's going to be so I tend not to think, you know, this is going to happen, this is going to happen, because nine times out of ten the exact opposite happens.* (431-432)

For Paulina, a similarly flexible approach to the future perhaps guards against disappointment:

*I have learned with autism that you have to be more relaxed in life because autism is hard to live with. So, you have to compensate, to find a way not to lose your mind.* (490-493)

However, key, too, for Paulina is hope that the future can be a positive one. In describing watching other children in the school take part in a performance, she reflects:

*…and that gave me hope that one day, you know, JP could be there, giving this.* (297)

Finally, Laura contrasts her own responsibilities as a mother, with those of the professionals involved in the process, poignantly describing the lifelong responsibility that she alone feels:

*And when they go home at the end of the day, we have these children all the time and this is their and our future* (655-656)

## 4.5 Pattern across cases 2: 'The System'

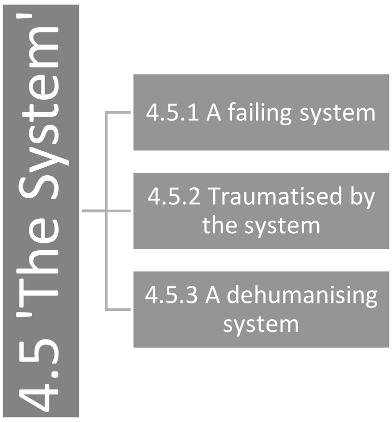

***Figure 11: Pattern across cases: 'The System'***

‘The System’ as outlined in *Figure 11*, is significant for these mothers, involved with two systems. Firstly, in common with all parents, they encountered the school system, which their child eventually joined. Unlike other parents, they encountered a second system – the Local Authority administering their child’s statutory assessment. In discussing their child’s start at school, the mothers devoted considerable time to discussing systemic and bureaucratic issues, which were focused on their experiences of the statutory assessment process and the involvement of Local Government officers responsible for administering this system.

Paulina describes a largely positive experience of the statutory assessment process, led by supportive professionals. She valued the way that professionals, such as the specialist teacher and educational psychologist had taken time to get to know her and John Paul:

*And they were talking about a little boy that they’ve actually spent time with…* [pause] *Yes, and it was lovely. We really felt that overwhelmed by listening to all these people talking about our son in that caring way* (232-236)

However, the other mothers report a more problematic experience, characterised by delays and poor communication. Lisa expresses her frustration that the promises of ‘the system’ do not reflect its realities:

*I mean it was, when you look through the* [names Local Authority] *Local Offer and …You just think, excuse my language…bullshit, they don’t even do that! It’s nothing like it. I mean they say all within 20 weeks we’re going to do this, but they don’t.* (288-290)

### 4.5.1 A failing system

Four of the five mothers expressed their frustration and distress about a system that, as Lisa relates, does not support families in the way it espouses. Four mothers had, to some extent, experienced a 'fight' for their child to be assessed and for their needs to be recognised before entering school. This included Laura's numerous phone calls, asking for support and chasing deadlines:

*I was always pushing against their delays really* (298-299)

Vicky's difficult experience of finding a school place resulted in a formal appeal. She describes an upsetting process which left her son without a school place. In her words:

*It all went hideously, horribly wrong* (147)

Lisa expresses her frustration about professionals, who she felt prevaricated when she sought support for Tate:

*I just said to her 'he's going to need help when he goes to school' and she's like 'leave it with us, leave with us' but nothing got done* (165-167)

For Laura, once the assessment was secured, her frustration continued as she encountered a system which she perceived as disinterested in her views and the long-term needs of her daughter. She describes a cumbersome and process-led system, in which her own and her daughter's voices became lost:

*But the way the meeting is set up, my views wasn't, they didn't ask me enough. I don't think for my views to be put on the EHCP* (287-288)

For Laura, professional disinterest and delay failed her and her daughter:

*She's a bit of a victim of their business and got a bit lost in the system* (627-628)

This led to a disappointing experience when Emily entered school:

*I expected her to go in with the EHCP, for her to go in with a one to one.* (488)

*That's what I expected and that's not what happened.* (492)

This story is echoed by Sarah who, when asked how the statutory assessment process had supported her daughter's start to school life, replied simply:

*It didn't really, not for Sasha* (209)

Vicky, Laura, Sarah and Lisa, all of whom told of their struggle with 'The System', had each adopted a proactive role in seeking the support their children needed. Despite her experience in education, Sarah, an ex-Deputy Headteacher, found this a laborious and challenging process:

*Every deadline was missed by them, I have just constantly been on their backs*. (269)

She describes how she *'just completely lost faith in them'* (284)

Perhaps aware of the power differential between parents and those administering the assessment, Sarah became concerned that her view of her daughter's needs would not be believed in school:

*I really began to panic that, I wasn't sure, you know whether people would believe what this is* (308- 309)

These mothers use strong language to describe feelings of disappointment, anger and disillusionment at a failing system that did not support their children in the way they had hoped.

For Lisa:

*It was a nightmare for me* (258)

Vicky’s language is even stronger:

*No, because it’s disgusting that any of this should happen* (179)

### *4.5.2 Traumatised by the system*

The strength of feeling, that Vicky portrays above, begins to make sense when we hear her story of a start to school life that she perceives as not just upsetting, but traumatic. For Vicky, the struggle to find support for her son intersected with the existing trauma of living with her son’s disability:

*K- So this was almost a cumulation* (sic) *of a five-year journey?*

*V- Pretty much of trauma*

*K- And would you describe this experience as trauma?*

*V- Absolutely. Yes. Because I think it certainly ticked a lot of the boxes for a lot of the triggers for my PTSD* (310-315)

For Vicky, a painful aspect of the assessment process was the extent to which it impacted on family life. She describes an all-pervading experience that violated privacy of family life:

*It felt very intimate, intrusive, not quite in a gynaecological sense, but certainly in the sense of… [Vicky does not complete this sentence]* (326-327)

While other mothers do not go as far as to use the word *trauma*, the strength of feeling with which they describe their individual experiences reflects similarly strong emotions. Lisa describes a *‘nightmare’* (258) and Sarah tells us:

*The whole process was a nightmare, an absolute nightmare* (268)

In hearing these accounts, there is a temptation to focus on the challenges and traumas. However, each mother, in her own way, spoke of her resilience and the ‘fight’ they found to advocate for their child in the face of a system that, at times, let them down. As the mothers describe the challenges they faced, they reflected upon the strength they found, their ability to assert themselves and their tenacity to continue in the face of confrontation and challenge:

*Fortunately, I am a bloody fighter* (180)

Lisa describes developing *‘confidence, awareness’* (445) and then goes on to describe how her experience has meant that she has developed a more assertive side:

*I can be a bit of a bitch at times, because I know I need to for Tate* (445-446)

And Laura, who came across as a quiet and at times nervous person, speaks of finding tenacity and strength to challenge the system and to advocate for Emily:

Maybe they hoped I wouldn’t stick with it, but I knew what had to be done (255-256)

Some of the mothers focused on the combative nature of process of seeking support for their child. This was not what they expected when they initially sought support, and some mothers reflected on how their vulnerability was highlighted when faced with a daunting system. Lisa describes a system characterised by power imbalance, which left her feeling vulnerable and isolated. Where she was hoping for support, she found dispute:

*Yeah, you are really vulnerable. You just want someone. You’re not looking for a fight, it was horrible*. (315-316)

At this point in the interview, Lisa, a woman whose confidence and humorous approach to life shone through, became tearful and quiet. We paused the interview before she confirmed that she wished to carry on. It was evident to me that her experience was emotionally charged and the challenges she encountered continued to affect her.

Similarly, in talking about her experiences of Sasha's statutory assessment, Sarah describes experiencing a process characterized not by support, but by confrontation:

*And it just becomes a battle, rather than supporting* (541-541)

While those mothers who describe a 'battle' to get support for their child undoubtedly found the process challenging and upsetting, they reflect, with humour and pride, on the strength, assertion and knowledge they developed to persist. Reflecting on her experiences, Sarah wryly communicates her growing ability to navigate 'The System':

*I'm a bit of a pro now!* (417)

And when Vicky looks back on her experiences of a process that, for her, *'went hideously, horribly wrong'* (147), she reflects with pride on her personal growth:

*Absolutely, it's an opportunity to realise your strength and often through life we don't always have reasons to look about ourselves and think 'Wow! Look at what I've achieved'.* (349-251)

### *4.5.3 A dehumanising system*

A striking aspect of these interviews is the impact of the quality of communication and relationships with professionals administering the statutory assessment process. Paulina describes a process in which professionals took time to get to know her and her child, enabling her to feel included and valued:

*Yes, everyone could have their say, what they thought was important to include in there* (230)

In contrasting accounts, the other mothers described encountering professionals who did not always demonstrate an interest in getting to know the parents or their views. Far from being a person-centred process, the system is described as anonymous, led by process and paperwork. Sarah describes the local government professionals she encountered:

*no…these people are just names to me* (288)

Sarah describes the demanding nature of the statutory assessment process. She shares her disappointment that the EHCP did not reflect important information about her daughter, such as the fact that she has Down Syndrome. She told me that she did not meet any of the professionals involved in the assessment process. Sarah goes on to describe an imagined meeting:

*I know that I will never meet that person, but I would just like to see them across the table. My husband would like to…* (292-294)

Strikingly she does not finish her sentence. But her strength of feeling, about the anonymous and impersonal nature of this bureaucratic process, comes across very clearly.

A similar sentiment is reflected by Laura, who describes how her daughter became lost in the paperwork that was supposed to reflect her needs:

*It just looks so formal and there's not much about the child in there. It's not really them on that piece of paper* (298-299)

Lisa describes errors in paperwork that suggested to her that Tate was not at the centre of this process:

*It was, well, silly things, like when we were coming to the outcomes meeting, Tate was 'he' then 'her' then there was something else that shouldn't have been in there*. (305-307)

Vicky, who describes a difficult statutory assessment process, defined by dispute and legal appeals, shares similar views. For Vicky, the process is impersonal, not just for parents but for professionals, leading to them favouring process and bureaucracy over their shared humanity:

*I would like them to remember that they're human beings before professionals* (439-440)

However, even within this process-driven system, some mothers identified individuals who made efforts to get to know their child and who worked hard to offer support and to make a difference. For some mothers, these individual relationships were vital in advocating for the families and enabling them to advocate for themselves.

For Lisa, this person was Bernie, the advisory support teacher, with whom she developed a close and trusting relationship:

*I could just text. I still keep in contact with Bernie* (147)

This is a contrast to her experience of other professionals, who she characterized as driven by bureaucratic processes, rather than their children's best interest:

*And a lot of them are just like, just filling in tick boxes or not answering the phone.* (319-320)

So, in Lisa's experience, finding support comes not from a consistent and efficient process, but the luck of the draw in finding engaged professionals open to developing constructive relationships. Lisa reflects:

When I spoke to some of the other mums, they had really good caseworkers. I think that perhaps we were just unlucky that we got one who was not so good. He was hopeless. (320-323)

Perhaps this ‘luck of the draw’ goes some way to explaining Paulina’s much more positive experience, during which she felt that her participation was valued. In contrast to Sarah, who had not met the professionals involved in Sasha’s assessment, professionals visited Paulina’s house and took time to get to know the family:

*…and we gathered information from everybody who knows him. What do you like and admire of JP? So that gave us a lot of a bigger future of him* (190-192)

*Well I think that people know JP, the people that were there. They knew him very well, from their different points of view*. (227-228)

Contrasting Lisa and Paulina’s experiences, we hear how important it is for parents to feel that they are listened to, and for parents to know that professionals who are making plans for their child’s future both know and, perhaps as importantly, like and admire their child.

### 4.6 Pattern across cases 3: Personal change and growth

A key theme for four of the five mothers was how planning, choosing, and experiencing their child’s start to school life impacted on their own identities, both as mothers and in other aspects of life. This pattern is described as ‘personal change and growth’, as shown in *Figure 12*. The mothers spoke of their growing understanding of their child and of using their acquired expertise to advocate for their child. For some mothers, as their identity as parent of a disabled child grew, this led to a desire to support others in a similar position.

***Figure 12: Pattern across cases: Personal change and growth***

### *4.6.1 Changing Understanding*

As the mothers told their stories, from their realisation that their child needed more support to their child beginning school, a key feature was their own change and growth. They described gaining knowledge, of their child and of the system, which allowed them to navigate processes and to integrate their understanding of their child's needs into their own life journeys.

Paulina describes vividly her growing understanding of John Paul's needs through her 'autism journey'. At first, she held a secret hope for her son:

*It's like the secret hope that you have, no, he's not that autistic* (140)

Paulina describes this as a reason for choosing mainstream school for her son:

*It gave us a kind of hope that being in a normal school, he would become normal, so that was kind of, you know, a secret hope we had.* (104-105)

In describing her changing understanding of John Paul's needs, Paulina talks of developing different hopes for the future:

*Yes, and the hopes and dreams, they have changed a lot since this autism journey began* (248)

As Paulina describes John Paul's first term at school, she has evidently formed a shared identity with other parents of disabled children, talking about meeting other mothers:

*…who I think are special needs parents too* (448)

And when she describes her growing understanding of her son's disability, she reflects on the insight her experience has given her:

*We kind of…we have an eye for autistic children.* (156)

Similarly, Vicky shared that, at first, her inexperience was a barrier to choosing a school for her son. She describes her relative naivety when she began the process, which compromised her ability to make an informed decision. Here, Vicky employs the term 'lay parents', which I have taken to mean parents with no particular expertise in the education system.

*…as lay parents… the things that you can compare between schools are the concrete things that you can see.* (64-66)

However, on her journey, she also describes a growing understanding of her son's needs, which stood her in good stead when discussing the provision Toby would need in school:

*Without trying to sound pompous, they were really impressed with how we knew and understood what Toby's needs were.* (216-217)

Lisa describes being very proactive in choosing to learn about her son's condition and the education system. For Lisa, knowledge is power. She presents her acquisition of knowledge, about autism, about her son and about the system as critical in achieving a successful start to school life. Like Vicky, Lisa describes her initial lack of awareness:

*I mean I just didn't understand it. I mean, this is a big learning curve for us* (173-176)

And she then goes onto to describe an intentional process of seeking advice, information and support from sources available to her:

*And then I looked at courses like the Good Beginnings course. I've been on other such courses at various organizations and then I read Tony Attwood's book and heard him speak. That was really interesting* (158-161)

Key for Lisa was learning from other parents. Social media played an important role in this. Lisa describes establishing a Facebook group, with over 100 members, which allowed her and others to share:

*All sorts of things. Just exchange information, you know…we went and saw this person and that sort of thing* (173-175)

For Lisa, this knowledge and information sharing was transformational. It brought about a new-found confidence in negotiating the system to find support for Tate:

*From that point onwards, I felt a lot more confident in doing the things I was doing* (299)

Lisa tells us how she chose to adopt a proactive and assertive role in addressing frustrations such as professional procrastination. Lisa describes initiating support plans (which she calls 'One Plans') in nursery, researching appropriate schools and starting a parental request for statutory assessment. She describes making sure the process retained momentum, ensuring Tate got the support he needed:

*I didn't have any One Planning**. *I didn't even know what One Planning was. So literally in the course of two or three weeks, we did the One Plan and the one-page profile* (225-27)

**One Planning* is the term used to describe individual SEN support in this county.

For Lisa, Paulina and Vicky, the process of starting school was one of discovery. Not only of schools and processes, but of their child's needs and of their ability to achieve their aspirations. This is perhaps encapsulated in the pride Vicky expresses when taking about Toby's successful transition into school:

So, in part it's about the school being really good, but in part it's also that we wouldn't have achieved it if I hadn't been really good (257-259)

### *4.6.2 Solidarity*

While the mothers' focus was, of course, on their own experience, it is striking that each related this to the wider system. Each made some mention of a system that left some families unsupported or disappointed, acutely aware of, and sympathetic to, the challenges faced by more vulnerable families. My sense is that this resonates with their own developing identity as mother of a disabled child, and their evolving understanding of the systemic and societal challenges facing families affected by disability.

Sarah, an ex-Deputy Headteacher, described her struggle to have Sasha's needs met and contrasts this with the plight of vulnerable families:

*I mean it's daunting to me, but it must be impossible. Yes, so, to some families* (341-462).

Similarly, Paulina, contrasts her good fortune in getting her son into their desired school with the difficulties of parents who have not had this:

*because I've spoken to other parents who want their child to get in there but can't go this year*. (253)

Sarah, Lisa and Vicky each describe their motivation to use the knowledge and confidence they have acquired to help others. In each case, their motivations relate to their awareness of the systemic power imbalance, the vulnerability of parents and their desire that other parents should not struggle in the way they have.

Sarah is understanding that she has a privileged understanding of the system, and this motivates her to help others:

*That's another reason I'm doing it as well, for families that can't do it* (342-343)

Similarly, Lisa hopes to use her knowledge to support other parents and to show them they are not alone:

*Because I never want other mums to go through, you know. You know that because, you know, when we were going through the process of the EHCP and having problems with the preschool it was really isolating…* (461-464)

She speaks about her desire to support a friend whose child has autism:

*I want to just, you know, offer some support and see how they do…* (490-491)

Vicky describes how her experiences help her to empathise with families, which she uses in her professional role as a family support worker. Reflecting on overlap between her personal and professional roles, she talks of striking a balance between supporting parents through her acquired knowledge, and understanding that their experiences are unique:

*I do get how scary this is and to be able to relay that without sort of burdening them with your experience* (405-407)

### *4.6.3 The mothers as experts and advocates*

In describing the process of starting school, the mothers identify their role in advocating for their child. They each describe advocating for their child at different stages in the process, particularly when they believed the EHCP did not reflect the help their child would need in school. Consistent with the change and growth we have already encountered, there is a contrast to be made here between the advocacy role each mother eventually undertook, and their initial *'stumbling around in the dark'* (Lisa, 565-567). Following her decision to learn as much as possible about Tate's condition, Lisa describes how her knowledge and confidence enabled her to support the school in understanding Tate's needs:

*And then in the afternoon is Mrs. S and she was saying to me 'well, what do I do?'* (84-85)

For some of the mothers, this role proved essential to their child, in ensuring their safety and that their basic care needs were met. Emily is non-verbal and so Laura advocated for her by sharing information and interpreting her behaviour for members of staff in school:

*Emily hadn't said she needed a wee or a nappy change, and I said 'well, she won't- she's non-verbal'* (456-457)

In this short anecdote, I sensed Laura's frustration that she needed to share, and then reshare, basic information about her daughter's needs. It is understandable therefore that Laura feels a unique responsibility for Emily, as the person who understands her best. Laura reflects that this advocacy role is unique to parents of disabled children and draws a contrast with her experiences of starting school with her other two children:

*I was on at them all the time; in a way you don't need to be with other children* (467-468)

The mothers' experiences of parenting their child, and the way in which they and others perceived them, sometimes powerfully intersected with other aspects of self.

For Vicky, the challenges of supporting Toby in school, within what she perceives to be a failing system, threatened the very core of her identity as an adequate mother:

*When we couldn't find a school for him, I felt like an inadequate mother. I felt that the harder I tried to make this better, it was making things worse* (319-321)

Sarah describes the knowledge that her previous role as a teacher has given her. In the extract that follows, Sarah contrasts the expertise she knows she possesses with the lack of respect afforded by those who view her in her parenting role. In describing a telephone conversation with a Local Government officer, she tells us:

*'oh, you're her mum', and I just had this, he obviously had this vision of a little mummy at home* (545-546)

I wonder if here, Sarah is reflecting both on the way she perceives that professionals within the statutory assessment system viewed her, but, given the awareness she shows of the systemic issues facing families, is also reflecting upon a more general observation regarding the gendered and subjugated way in which the role of mothers of disabled children might be understood by some within the system. In her empathy with other families, Sarah shows that she understands the challenges of power differentials within this system and I certainly sensed a glint in her eye as she explains her next step:

*Right, I'm not going to actually tell you that I've been in education for 20 years and I do have some insight into it.* (548-549)

However, Sarah is aware that drawing on her own professional experience could cause difficulties. She describes striking a delicate balance between her teacher and parent roles. Her experiences have made her aware of the challenges faced by schools and she is sensitive to this in how she speaks with teachers about Sasha:

*I have been on the other side where I've been in school and you have a parent of a child with additional need and they're constantly saying 'you need to do this, you need to this', so I'm wary that I'm trying not to do that.* (529-533)

While Sarah reflected on the intersection of parent and professional roles, Vicky describes questioning how her current position as a mother of a disabled child in school could possibly fit in with her desire to pursue a career:

*Oh my God. Well, that's one of the frustrations for me, as a woman.* (386)

Vicky goes on to describe enjoying a twenty-year career in challenging roles, working with young offenders and in domestic abuse services.

She then reflects:

*How can I do that, with the sort of life we have now**?*** (392)

Vicky's dilemma, which she frames in gendered terms, reflects the emotional and logistical complexities experienced by a mother of a disabled child as she navigates a dual role. However, for Vicky, who had previously worked with vulnerable groups in housing and mental health roles, her experience of supporting Toby into school provided new and unexpected opportunities. Vicky now works for an organization supporting families with disabled children, and she describes how her advocacy for Toby caught the attention of the manager:

*She said, "I've admired the way you've handled all of this, and when this is all over, I'd like you to take over from me so that I can retire"* (382-384)

For Vicky, this happy outcome gives meaning to the challenges she faced, perhaps the beginning of a resolution to the trauma she describes. Here, Vicky describes not only her sense of purpose in her new role, but also her belief that the experience of supporting Toby into school, despite the challenge and trauma, has had some positive outcomes, both personally and professional:

*And it was another way of thinking this whole experience has been for a reason, because actually my role at [Names Nursery] is to support parents through the transition from nursery to school.* (397-399)

While Vicky has taken up a new job, other mothers described how their children starting school provided them with time and psychological space to pursue new interests and consolidate important relationships.

Sasha’s time in school means that Sarah has the time to explore her new role as a grandmother:

*My elder daughter already has a child, so I manage to spend more time with him* (354-355)

For Paulina, John Paul’s time in school gives her an opportunity to develop her relationship with Alejandro, away from the demands she feels when John Paul is at home:

*well, more time to be with Alejandro, to do more things and more toddler related routine…because when he was here, I had nothing, he came back home at 1 and I have to be constantly vigilant*. (308-312).

This perhaps contrasts with Lisa, for whom the challenges of combining work and home life with a disabled school-aged child, unable to access before-school care, is proving too much:

*At the moment, I'm struggling with work. I only work two days a week and I can't get to work on time and it's a bit of an issue.* (353-355)

Lisa goes onto explain that she is considering giving up work so that she can focus on helping Tate with his schoolwork to allow him to continue to access the school curriculum.

## 4.7 Pattern across cases 4: Belonging and rejection

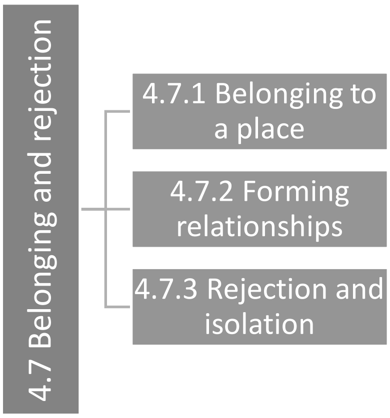

***Figure 13: Pattern across cases: Belonging and rejection***

The final pattern, shown in *Figure 13* relates to the mothers' experiences of developing a sense of belonging to the school community that their child joined. A contrasting thread running through the accounts describes incidents in which some mothers felt isolated, or marginalised, as the parent of a disabled child. Each mother, to some extent presents a picture that features both belonging and feelings of difference or isolation.

### *4.7.1 Belonging to a place*

In speaking about their child starting school, the mothers often reflect the process of developing a sense that they and their child belonged within the school community. They often illustrated their reflections with reference to specific events. It is notable that these stories often recall their experience of what we might consider emblematic, if quotidian, rites of passage in school life: the harvest festival, or ‘pick-up time’. In sharing their stories, the mothers make observations both about the events themselves and about the physical environment and the words used by others, all of which add to the sense of the event’s significance.

Sarah and Laura each chose to send their daughters to their local primary schools. Sasha attends a small village school and for Sarah, the process of belonging to the school community began with Sasha’s presence within her wide community before she even began school. She had already established friendships in preschool and the children, parents and school staff knew about Sasha:

*They know Sash so it wasn’t, you know, she’d be doing odd things that children, they just know that that’s Sasha* (120-121)

This gives us a sense that the transition to school, was, for Sarah and Sasha, part of the much longer process of developing relationships and joining a wider community. Starting school in this sense, is perhaps understood by Sarah as being both a point in time and a continuous experience, a next step on a life journey within that community.

Similarly, Emily attended the school that had been attended by her three siblings and Laura reported a similar sense of continuity. While starting school was a new event that brought about challenges, Laura gives us the sense that Emily, in the local school, with family connections, already, in a way, belonged. Laura tells us that Emily was:

*Comfortable walking about the school and the people there looked comfortable with her* (133-134)

For some of the parents, the sense that their child can or does belong to a place relates not to proximity of community membership, but to something less tangible, a 'hunch' that this is the right place for them. Paulina's son attends a school some distance away from home. While it was not her first choice, she describes her instinctive reaction that her son could belong there:

*After visiting… we completely changed our minds. It felt right*. (178)

In describing her son's school, Vicky speaks of a similar 'feeling', which relates to the ethos within the school:

*'You can't see it; you can't touch it'* (109)

She later goes on to reflect that, while the facilities were not ideal, a particular approach made all the difference to the welcome she received:

*I think it's about an attitude. It's about an openness of attitude. It's about a, of gosh, this sounds awful, but a sense of kindness* (111-112)

Here Vicky touches on the powerful idea that it is not just physical location, facilities or espoused practice that ensures inclusion, but something cultural and attitudinal, something akin to 'hearts and minds.'

The others spoke at some length about the process of planning their child's school start. This involved numerous meetings, sometimes instigated by the parents.

However, when these were initiated by schools, mothers tended to appreciate this and recalled the steps taken which helped them to feel reassured and listened to.

For Sarah, the reassurance that she and Sasha would fit in well began with initial meetings with the school, with the language and physical environment of the school pointing towards a welcoming and accepting ethos:

*We sat in the chairs with a little coffee table and things. It was less formal. You know, they could have made it quite imposing to a parent but, no, it wasn't'* (137-139)

Similarly, Laura describes an encouraging initial meeting with Emily's school, in which the SENCO puts her mind at ease by containing Laura's concerns that she would be out of place. Laura describes her feeling after the meeting:

*I didn't feel like she would be out of place there, and that they would accept her as she was and they wasn't bothered about anything. Nothing phased them at all'* (91-93)

Vicky's experience of finding a school was turbulent. She describes feeling an enormous sense of relief in her discussions with a second school:

*They were lovely, they were warm and engaged with us, they were interested in asking our opinion. What did we need? What would they do? We can do this…we can do this.* (218-220)

For several of the mothers, it was important that schools had been proactive in getting to know their child before they began attending. It is evident from listening to their accounts that this process involved much more than simply reading paperwork or referring to the EHCP.

Sarah was impressed by the lengths to which school staff members went to get to know Sasha before she began school:

*The preschool met with the class teacher; the class teacher had several sessions over at the preschool* (144-145)

*They had a story together and again, very relaxed. Not very formal* (166)

Toby’s teachers were similarly proactive, and Vicky appreciated that they were interested in getting to know the family and in learning from the special knowledge she had about her son:

*The school had clearly listened to what we had said about how we did things. (287-288)*

### *4.7.2 Forming relationships*

For each of the mothers, starting school was a time of new relationships, which required careful negotiation, sometimes in challenging circumstances. While the relationships with teachers are important, so are relationships with support staff, and other parents. Additionally, in several of these accounts, the mothers speak of the value of the positive relationships formed between adults in school and their children. As we have heard above, to these mothers it is important that their child is known as an individual.

Paulina speaks of how taking time to get to know John Paul has helped teachers to support his learning:

*I think they are tuned into his needs, his character, yes. His personality. I think they know him* (72-73)

However, Laura describes a different experience. She shares the difficulties she experienced in leaving Emily in a learning environment in which adults had not taken time to get to know Emily, her needs and her ways of communicating:

*It was the first term, where they hadn't really got know her* (466-467)

Understandably, for Laura, this was a time of great worry. Because of Emily's disability, the staff's failure to know and understand her needs led to concerns that her basic safety and care needs could not be met.

*It was just sending her into school and not knowing who was going to be looking after her* (133-134)

Unfortunately, these worries were grounded, as Laura shares that, in her view, the failure of the school to understand what Emily needs and how she communicates her needs, led to care failings:

*Yeah because they weren't keeping her safe* (384)

*Her nappy wasn't changed once when she came out of school and it was like hanging out bulging* (454-455)

Laura describes her role in advocating for Emily, and in helping members of the school staff team to understand more about her daughter's needs. She explains that this eventually led to a better understanding of Emily's special needs amongst those working with Emily:

*They realised it was because Emily was telling children not to run and because they were still running, she hit them* (479-480)

Other mothers also speak of playing a proactive role in communicating their child's needs to members of staff. While misunderstandings and difficulties arise, teachers showing an interest in their points of view helped the mothers to feel valued and that their child's individual needs were being met.

Paulina describes her communications with John Paul's teachers:

*Open, constant, yes. I use the communication book a lot and, well, they have noticed that I am a motivated parent in saying things and asking things. So, I feel there is a good communication. I receive good feedback from them, and they ask me things* (93 - 96)

Similarly, Lisa described the teachers using her unique knowledge of Tate's needs to support their working with him:

*But they are pretty good and out of the five days I'm called into the classroom at least three of them.* (523-524)

Sarah provides a positive account of working with the professionals at Sasha's school to share information and understand her needs:

*So yes, we're working together, basically, and the teacher's lovely too and very sort of open to ideas.* (199-200)

For Sarah, it has been the opportunity to develop this positive working relationship with members of staff in school that has been key to Sasha's successful start to school life:

*It's been the relationship that we've had that's making the difference.* (321)

Sarah speaks of a genuine partnership having developed between Sasha's family and her school, with open and positive lines of communication:

*I can speak to the TA whenever I need to know and also, they give me that feedback at the end of the day.* (510-11)

However, Sarah is also aware of walking a line between offering helpful advice to the school and coming across as pushy or overbearing. This concern is, in part, from her own professional experience:

*And I’m sort of gently offering because I don’t want to go steaming in.* (196)

This suggests that, while Sarah has formed positive relationships, she understands these to be delicate, with potential for conflict or misunderstandings.

Alongside their experience of negotiating relationships with members of staff, some mothers shared the significance of the relationships formed between their children and adults in school.

For Sarah, this is spoken of in wholly positive terms. Again, the work of developing this relationship began before Sasha started school. As Sarah explains:

*I think she did three or four sessions, so she was observing Sasha, working with Sasha, obviously speaking to the SENCO* (147-149)

And Sarah is now pleased with the quality of the relationship:

*I think they’ve got a very good relationship* (554)

These positive relationships with adults outside the family home, for some mothers, took on a significance when thinking about their child’s future. Vicky speaks of the significance of Toby’s relationships with adults in school from the perspective of his future life trajectory. She is aware that he is likely always to need additional help and shares her sense of relief that his first steps towards independence from his family went well:

*The fact that he can attach to somebody else so quickly is hugely reassuring to me* (275-276)

*I need Toby to attach and connect to other all sorts of people; otherwise what kind of life is he going to have?* (278-279)

Again, this illustrates starting school as both a transitional process, in which new relationships are forged and also a point along a more continuous journey, in which the relationships allow mothers to consider how their child's future might look in terms of their interactions with others and future care needs.

Mothers expressed differing and, at times, ambivalent feelings about the relationships they developed at the school gates. Sarah, already known within the school community, shared how she enjoyed being able to join in with the other mums, enjoying relaxed chats:

*I can sort of step back and be one of the Mums and just chatter and things* (386-387)

Lisa's feelings about relationships formed at the school gates are more complicated, and she approached them with caution:

*Speaking from, like when Tia went to school, all the like cliques and stuff. I thought like 'I'm going to keep myself to myself and not get involved with anyone'* (402-404)

Lisa's trepidations perhaps indicate complexity of negotiating these relationships as the parent of a child whose needs and behaviour differ from other children. Perhaps linked to her strong feelings of solidarity with other families with disabled children, she found understanding and support from families in a similar situation to her own:

*Yes, there's these two nans and we sort of gravitated to each other. One of them, she is caring for her grandson. And her son has got ADHD, so she realizes.* (409-410)

So, for Lisa, support has come from sharing experiences across generations, and with others who understand, through their own experiences, the complexities of her own.

### *4.7.3 Rejection and isolation*

While mothers shared their positive experiences and their growing sense of belonging within the school community, this was often accompanied by experiences of rejection and isolation.

In Paulina's interview, generally characterised by positive retellings of her son's start to school life, there is a striking anecdote she chose to share, communicating how a mother's experience of their child's exclusions can be deeply affecting. Paulina sets the scene, describing her excitement about attending John Paul's first harvest festival. However, when the class appeared, he was not part of the performance:

*I didn't see my child. That I didn't like* (295)

John Paul's teachers later explained that they did not think that John Paul would cope with the event. Despite her disappointment, Paulina's priority was finding a way that the situation should not arise again. She approached John Paul's teachers to suggest a way to include her son:

*I was like, come to me for the next time, because I would like to see JP taking part somehow* (296-297)

Paulina goes onto reflect on how John Paul's exclusion has brought about another 'secret hope'. Seeing the other children performing made her yearn for this normality for John Paul:

*So that gave me hope that one day John Paul could be there, you know giving this* (284-285)

This bittersweet optimism is typical of Paulina's approach throughout her interview, in which she shows an ability to take positive ideas from difficult experiences.

Similarly, while Lisa describes Tate as happy and well-included in his school environment, she describes an excluding experience that shook her confidence early on:

*They did a parent open night and basically, he… well we weren't invited because they forgot about us.* (49-50)

Lisa goes onto explain that this situation arose because of the different admissions practices for children with an EHCP. This meant that her son's name was not on the list of children joining the school and indicates how exclusionary practices can inadvertently arise because of bureaucratic and systems failures. While Lisa understood this as an administrative error, she uses this to illustrate how parents of disabled children can be unintentionally isolated.

Feelings of rejection are a persistent theme as Vicky shares her story. While she felt let down by the Local Authority and tribunal system, her sense of rejection by the school she had requested for her son is particularly uncomfortable:

*The school wouldn't support us, they didn't want to take another child, they were full. So, we were left without a school.* (153-154)

And so, for Vicky, the experience of the school's rejection of her son is accompanied by an experience of abandonment, as she is left, at that time, with no school for her son to attend. Vicky goes on to explain that the failure of either the Local Authority or the SENDIST tribunal service to resolve this dilemma brought about a difficult realization:

*It became clear to me that, well, there's nowhere right for him* (164-165)

At this stage in the interview Vicky communicates the despair she felt that her son might never belong. This perhaps explains, in part, the gratitude she later feels towards the ‘good man’, the headteacher of a school who found Toby a place.

The sense of a school place being tenuous and uncertain arises for Laura and Sarah. For Laura, who had significant concerns about the school’s ability to safeguard her daughter, the possibility of her child being able to continue to attend the school is in doubt. Laura shares that she is pleased with how Emily has settled:

*I thought it would be her hitting people and to be not liked, but she’s made loads of friends* (68-69)

However, others, notably the headteacher, have communicated to Laura that Emily’s place at the school is by no means certain:

[the headteacher says] *she can’t see her being there long term with the needs she has* (322-323)

Laura goes on to share that the headteacher has encouraged Laura to look at other schools. This has unsettled Laura and it is another way in which she now worries about what the future might hold for their family:

*If she has to go to the special needs school, I don’t know what we’ll do* (609-610)

While this superordinate theme has focused predominantly on the ways in which parents, schools and others worked to find a place for families and children within the schools, the theme of belonging and isolation demonstrates that this is a complex process. All parents spoke positively about aspects of their child’s inclusion, but each had stories which also reflected rejection, isolation and/or the tenuous nature of their child’s belonging within the school community.

## 4.8 Summary

This chapter provides an account of each mother's experience, presented through the lens of my interpretative phenomenological analysis. From the broad research question: *'What are mothers' experiences when their disabled child begins mainstream school?*', I developed a thematic account of each mother's experiences and synthesised these to consider the patterns, similarities and differences in each individual account. The next chapter contextualises these findings in current research literature and considers key points within the context of relevant psychological paradigms.

# 5: Discussion

## 5.1 Overview

In Part One of this chapter, I discuss and critique the findings reported in Chapter 4, in relation to the original research question, the literature previously identified, relevant broader psychological paradigms and considerations for professional educational psychology practice. Part Two forms a critical evaluation of the study, including the methodology, quality and limitations. The implications of the research for educational psychology practice, and on wider policy frameworks in relation to disabled children starting school, is discussed and the distinct and unique contribution of this study is identified.

## Part One

### 5.1.1 Relating research questions to the findings

Following review of the gaps in existing knowledge, this research set out to answer the following research question:

***What are mothers' experiences when their disabled child begins mainstream school?***

To answer this question, I conducted a small-scale qualitative study, using a phenomenological methodology, which produced idiographic findings structured around four patterns across individual themes:

- **Starting school as a life stage process**
- **'The System'**
- **Personal change and growth**
- **Belonging and rejection**

Each of these themes contributes to answering the research question in a different way. In the section that follows they are discussed in turn, in relation to the research question and existing research literature about the topic. I then widen my analysis to place the findings in the context of psychological models which enable a broader paradigmatic understanding of the findings and their implications.

### 5.1.2 Interacting systems

In researching transition to school from an interactionist perspective, researchers have considered how key findings relate to the multiplicity of systems that interact in the process (Dockett, Perry & Kearney, 2011). Gioia (2017) and Russell (2005) located these systemic interactions within Bronfenbrenner's ecosystemic model (1979). With the mothers and their families located at the centre of the model, I have adapted this approach to place each theme within the model, and to consider interactions between systems within each pattern across cases, considering the impact of relational and interactional factors within the findings. A summary is provided in *Figure 14*:

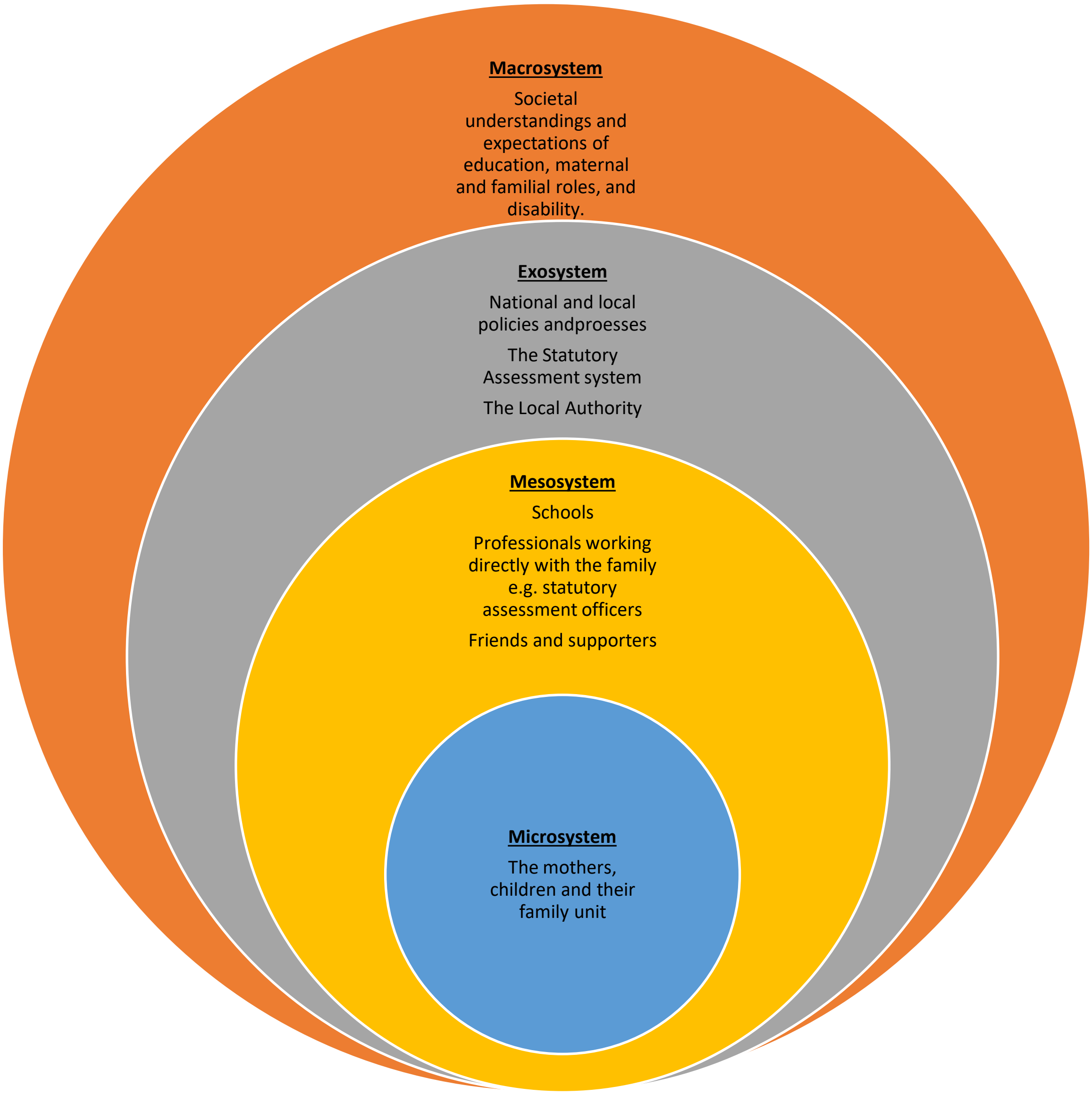

***Figure 14: The interacting systems described in the data, contextualised in Bronfenbrenner's ecosystemic model (1979).***

### 5.1.3 Theme 1: Starting school as a life stage process

#### 5.1.3.1 Ecosystemic Context

This theme is very personal to each mother. It relates to events at the **microsystemic** level, as the mothers consider the changes that have occurred in family life when their child started school. However, it is evident that **mesosystemic** factors, such as school expectations, as well as **exosystemic** and **macrosystemic** factors, such as delays and uncertainties about future provision, also influence changes to family life during this process.

### 5.1.3.2 A life stage process

This theme captures the experience of starting school as a key event in the lives of mothers, their children, and the family unit. Congruent with the mothers' descriptions of their experiences, I have chosen to use the word *process,* rather than *event,* to describe starting school. This is intended to convey the sense of continuity and change that mothers reported, as the preparation and eventual commencement of school took place over several months. This process resonates with the 'firestick' metaphor of dual belonging, introduced in Chapter One (Clancy, 2001), relating to the two-way process of change and continuity, that families keep 'glowing' as their child makes the transition to school.

### 5.1.3.3 Familial changes

The term *process* perhaps conveys the complexity, ambivalence and, at times, quite fundamental relational and psychological transformation that mothers reported as they reflected on their experiences of their child starting school. That, as a mother of a disabled child, starting school is a step along a long-life journey, with an uncertain future. As Lisa shared, *'It just seems to be you get over one hurdle and then you have to go for another one'* (73 – 74). In their individual ways, starting school was a bumpy journey for each of the mothers, with successes and setbacks along the way. While the mothers acknowledge the huge change for their child, changes were experienced by other family members. Paulina's family unit experienced a positive change, because John Paul's starting school allowed her to spend relaxed time with Alejandro: *'more time to be with A, to do more things and more related to toddler routine'* (308-

310). Whereas for Laura, Emily's starting school brought about difficulties for the whole family, with her increased reluctance to leave the house: 'If we say, we're going out anywhere…she's…it's either home or school' (366-368. While the mothers' stories are unique in terms of the changes that occurred, each of the mothers conveyed the starting of school as a highly significant event for their child, themself, and the family system.

### Context within existing research

#### 5.1.3.4 A significant life event

Rogoff (2003) describes the process of starting school as often the first opportunity for a child to experience a life outside home. As such, it is often an event of deep significance to a family. For these mothers of disabled children, who *'are even more likely than other mothers to engage in complex, skilled and prolonged aspects of care'* (Runswick-Cole, 2013, p. 107), we can hear in their accounts the deep significance of their child starting school, as they share achievements, frustrations, ambivalence and hopes.

#### 5.1.3.5 Changing understanding of needs

In describing their journey, some mothers describe the process of realizing their child's needs would be greater, and their growing understanding that finding the support their child needed might be a long and difficult process. In describing her experience of this process, Paulina begins her story by telling us *'I told my husband; he needs more help, I think his needs will be more' (*212-122). Connolly & Gersch (2016) report a similar 'bumpy journey' for the parents involved in their interpretative phenomenological analysis (IPA) study. Here, parents discussed the significance of diagnosis and subsequent realisation that their child's education needs would be different. In exploring parents' expectations of their child starting school, Russell (2005) found that parents reported developing a clearer understanding of their child's needs through the process of starting school.

### 5.1.3.6 A bumpy journey

Each of the mothers in this study describe the highs and lows of their child's start to school life. The parents in Russell's (2005) study describe a similar trajectory of ups and downs, sometimes feeling let down or disappointed and having to 'chase' professionals for information. Russell reports how parents described visiting prospective schools as an emotional experience. Parents also noted an, at times, frustrating process, expending considerable time and emotional labour into securing their child's educational placement. Parents relate the emotionally exhausting nature of the process, often describing 'hitting a brick wall'. It is striking that some mothers in this study also make use of similes and metaphor related to travel to illustrate their journeys. Sarah expresses her frustration when she encounters *'a brick wall from the other side'* (332) and Lisa encounters similar obstacles in the road, *'Yeah, and then all of a sudden you think you are getting somewhere and then…yeah…that was difficult'* (64-65).

### 5.1.3.7 A stressful time

The stressful nature of the process of their child starting school is evident in some of the mothers' accounts. It is important to note that the pressures experienced are both substantively different and experienced differently between each mother. For example, for Laura, stress is experienced in terms of worry about her daughter's safety in school. For Vicky, stress is experienced in terms of an invasive process which retriggers her PTSD. Dockett, Perry & Kearney (2011) reflect similar parental stress in navigating the system when a child begins school. The phenomenological nature of their research enabled these researchers to investigate the complexity of individual family experiences. Using Grounded Theory, they were able to theorise around how intersecting factors, such as poverty and mental health needs, can impact on the complexity of family's school starting experiences. The researchers discuss the 'emotional drain' experienced by parents as promises are made and then not kept. While parents describe a tiring process of fighting to demonstrate their child's higher needs before they can take the next step in the process. Similar experiences also featured in this study.

#### 5.1.3.8 The future

In this study, a key theme for parents was the part of the journey significant in their minds, but untrodden: The future. This transition was perhaps a first glimpse into what the future might hold for their family. As Laura shared, *'so I don't know what's going to happen for her future and that's a worrying thing. Especially with the shaky start we've had'* (664-665). Connolly & Gersch (2016) found that parents had hopes for the future; but for some parents the potential success of educational placements were not yet certain. While the parents in this study expressed similar views, some went a step further and shared their uncertainties about their child's longer-term future and that of themselves in terms of the continued need to advocate for their child.

### Broader theoretical understandings

#### 5.1.3.9 Family Developmental Psychology

Broadening out to the wider literature around families starting school, the mothers' experiences reflect some of the patterns within existing research. Griebel & Nielsel (2009) researched the familial impact of starting school on family life. In their model, which draws on Cowan’s (1991) Family Developmental Psychology model, transitions are viewed as complex biographic processes of change that take place not just at the individual level, but at the level of interactions and familial processes. In this study, we observe this reflected in Paulina’s relief at spending uninterrupted time with her toddler, Vicky’s return to work and Laura’s growing understanding of the challenges that she and Emily might face in the future.

### 5.1.3.10 The Family Life Cycle (Carter & McGoldrick, 1999)

To further understand transition as a whole family experience, it is helpful to consider the Family Life Cycle model (Carter & McGoldrick, 1999). This model proposes that families develop according to patterns and rhythms, with common challenges along the way. Points of change within the family, such as birth, death, or joining and leaving extrinsic systems, represent points of challenge and transformation for the family. For Griebel & Nielsel (2009) a child starting school represents a significant point of change within the family life cycle. While families with disabled children generally experience cohesive and positive familial relationships, stress can be higher at certain times in family life, especially around transition and change (Dyson, 1993). DeMarle & Roux (2001) hypothesise that, when a family has a disabled child, important family life cycle stages can be elongated or missed. This brings with it a unique set of challenges for families. Thomas, Thomas & Trachtenburg (1993) suggest that, while each family develops along a trajectory, themes might deviate from socially constructed family life cycle ‘norms’ for families with a disabled child. DeMarle & Roux (2001) conclude that, rather than focusing on this deviation and difference, families and professionals are supported to understand the family’s unique trajectory and to celebrate their resilience as they move through family life.

#### *5.1.3.11 Opportunities for professional reflection*

- *How can educational psychologists (EPs) contribute to making the starting of school a family-centred process?*
- *How can EPs help to alleviate the organisational and administrative implications of transition processes for families?*
- *What tools could EPs employ to identify family strengths during this process?*
- *Consider how the process will be experienced in the context of the child and family's whole life journey. Does this process give families positive hope for the future?*
- *How can EPs gain parental confidence as the parents' understanding of their child's needs evolve?*

### 5.1.4 Theme 2: Personal change and growth

#### 5.1.4.1 Ecosytemic context

This is perhaps the most personal of the patterns across cases, relating to each mother's description of the process of change and personal growth they experienced as their child started school. Whilst this transformational process occurs at the individual level within the **microsystem,** the mothers describe a two-way process in which their personal change transforms how they understand the **meso-, macro-, and exo-systemic** factors they experience**.**

#### 5.1.4.2 Similar and different parenting experiences

Part of the change encapsulated in this pattern across cases relates to the mothers' understanding of themselves as a mother of a disabled child, and the intensely personal experience of what this might mean in the context of their child starting school. While the mothers describe many of the trials and joys experienced by all parents, there is also a sense of something different, together with the uniqueness of their individual experience in parenting their child. As Sarah shares, comparing this school starting experience to those of her older children, *‘with Sasha I was a bit more apprehensive’* (422-423).

### 5.1.4.3 Gaining knowledge

As they prepared for their child beginning school, the mothers developed expertise in the administrative processes and their own children’s needs. Starting from a position of uncertainty, as described by Vicky, *‘at the point we still didn’t really have any idea because we’re lay people’* (64-65), each of the mothers, in their own way, described gaining knowledge and expertise. As Sarah tells us, ‘*I’m a bit of a pro now!*’ (417). In critiquing accounts of parenting disabled children, Barnes (2006) writes that stories are often associated with themes of passivity and disempowerment. This pattern across cases perhaps offers a counterbalance to this. While the mothers’ accounts at times spoke of anguish, power imbalance and confusion, several mothers also expressed their pride, in themselves and their child.

### 5.1.4.4 Advocacy and Activism

Some of the mothers identified their new-found expertise, understanding and resilience as an opportunity to advocate and work for social justice for others. Some mothers spoke about how the complex experience of negotiating their disabled child starting school had led them to reflect on how this experience might affect others, especially those more vulnerable. I had the sense that, for some mothers, the experience was catalytic in their understanding of the challenges faced by other families in this position. This empathy can be heard when Sarah reflects on using her own professional expertise to advocate, not just for Sasha, but for other parents less able to do so: *'I mean, it's daunting to me it but it must be impossible yes, so to some families'* (461-462). For one of the mothers, her emerging role as advocate and activist seems to give meaning to the challenges faced along the way. In describing her new job as a family support worker, Vicky shares, *'it was another way of thinking this whole process has been for a reason'* (397).

## Broader theoretical understandings

### 5.1.4.5 Personal growth experiences

Personal change and growth of parents is a topic that is not addressed in most of the research studies identified in the literature review. I think that this absence relates to the research design and focus, rather than an anomaly in the findings in this study. Indeed, some of the more in-depth, phenomenological studies do touch on the topic. The parents in Dockett, Perry & Kearney's (2011) research report gaining confidence to advocate for their children and an understanding of their strengths and resiliencies as a family. Connolly & Gersch (2016) found that parents spoke again about developing the confidence to advocate for their child and in sharing their expertise about their child. However, these studies do not speak in-depth about parents' wider reflections of personal change, or the implications of this. While the research around growth experiences of mothers of disabled children starting school is limited, researchers have identified personal growth experiences at other important life stages. Weizbad-Botov, Yehonaten-Sohan & Gold (2019) explored the personal growth experiences of mothers of autistic children across childhood. The mothers reported similar experiences of participating in advocacy for their children, offering advice and support to other parents. Just as Vicky describes, '*It has given me insight into the intricacies of these experiences'* (392), the mothers in Weisbard-Botov, Yehonaten-Sohan and Gold's (2019) study describe developing self-confidence and their feelings of strength manifesting in a wish to help others. Similarly, Ooi's (2016) narrative research found that, while parents of disabled children experience increased stressors, in comparison with other parents, they also described themselves as having become more self-confident, less judgmental and as having a stronger sense of social justice. Ryan (2009) explored mothers' roles as disability advocates and activists. She found that, while almost all mothers adopt an advocacy role, many mothers, as their awareness and knowledge increases, move into broader advocacy and activist roles. She proposes a continuum between individual advocacy and traditional activism, which is experienced by many mothers.

#### 5.1.4.6 Ambivalence and uncertainty

For some mothers in this study, starting school was a time of ambivalent understanding, about themselves and their child. Starting school provided challenges to their expectations for their child, changing their hopes, dreams and perspectives. For Paulina, this appeared to form part of a process of acceptance: *'Yes, and all the hopes and dreams, they have changed a lot since all this autism journey began'* (248-249). For Laura, the experience raised new uncertainties about her own and Emily's future: *'So I don't know what's going to happen for her future and that's the worrying thing'* (664-665). In exploring the process following their child's diagnosis, Marvin and Pianta (1996) describe ambivalence and uncertainty, leading to an eventual resolution and acceptance, which enabled parents to replace aspirations to 'normalise' their child with different hopes. Moving towards a theoretical understanding of change and growth when a child begins school, we can view these events through the process of crisis related growth.

#### 5.1.4.7 Crisis related growth.

Crisis related growth (in psychiatry sometimes referred to as posttraumatic growth) is a paradigm which is interested in the opportunities for growth that emerge following challenging or traumatic events. Calhoun & Tedeschi (1999) found that when people experience a stressful event (including caring for a sick or disabled child) the reports of growth experiences far outnumber those of serious distress. It is important to point out that consideration of the mother's accounts in the context of this paradigm is by no means intended to side-line the genuine challenges they faced. Indeed, Vicky describes her experience of a process *'pretty much of trauma'* (326) which *'ticked a lot of the triggers for my PTSD'* (315-316). However, Vicky also describes a process of growth as she emerged from this challenge: *'Absolutely it's an opportunity to realise your strength and often through life we don't have, we don't always have reasons to look about ourselves and thing wow look what I've achieved'* (257 – 259). In acknowledging the expertise and resilience she has gained, coupled with her awareness of the struggle other parents endure, Lisa describes how she now has the confidence to use this transformational experience to help and support others: *'Because I want to…you know that I can sort of pass it on. You've got to'* (482-483). Calhoun & Tedeschi (1999) identify the juxtaposition of strength and vulnerability as a key paradox within the process of crisis related growth. That whilst an individual has experienced great vulnerability, they may also discover a capacity for resilience and strength to prevail. The mothers in this study spoke of how the experience of their child starting school, and especially the challenges they faced, led to them looking at their child, and themselves in different ways. Paulina tells us (about living with her child's disability): *'so, you have to compensate, find a way that you don't lose your mind and trust. Trust all the work you've done to take him there'* (490-483). Paulina's re-evaluation, of her views of herself and her parenting style, reflect a central process in crisis related growth. Tedescshi & Calhoun (1999) propose that the emotional and cognitive engagement of an individual in a 'seismic' event brings about upheaval that may lead to a re-evaluation of how individuals see the world and their place in it, questioning their fundamental beliefs and values. They report that people sometimes report increased capacity for challenge and a perceived increase in compassion for others. As we have seen, these changes are very much reflected, in individual ways, in the accounts of the mothers in this research and again provide a counterbalance to the challenge, vulnerability and frustration they also describe.

#### *5.1.4.8 Opportunities for professional reflection*

- *How can educational psychologists have conversations with parents about their hopes and dreams which recognise experiences of ambivalence or confusion?*
- *When might it be appropriate for educational psychologists to discuss mothers' own changed lives, in the context of assessment or casework? What benefit might an understanding of this process provide in carrying out a holistic assessment for a family?*

### 5.1.5 Theme 3: 'The System'

#### 5.1.5.1 Ecosystemic Context

This pattern explores the mothers' experiences of the systemic factors that impacted on their child starting school. This is perhaps the theme that is most bound within a certain cultural and legislative context. The mothers refer to **exosystemic** factors, such as statutory assessment processes and policies. However, it is interesting to see how these interact with **mesosystemic** factors, which mothers speak about the roles and attitudes of individual professionals within the system and the impact of attitudes and processes on the **microsystem** of family life. Mothers at times hint towards the broader, **macrosystemic factors**, such as societal expectations of mothers that impact on the functioning of 'The System' they describe.

### 5.1.5.2 Mothers' experiences of 'SEN' systems

In this research 'The System' is taken to describe the processes and policies that have been put in place at a national and local level to formalise support arrangements for children with SEN. It is evident from listening to the mothers' accounts that, in the context within which this research was conducted, the Statutory Assessment process played an important part in the experience. There is a sense of 'The System,' both as a collection of individuals (SEN officers, educational psychologists, specialist teachers) and as a bureaucratic monolith. When accounts of individuals in the system emerge, these are sometimes positive. For example, when Paulina speaks about the professionals *'talking about a little boy they've actually spent time with'* (232-233) or in Lisa's account of Bernie, the specialist teacher who went out of her way to support Tate. However, at other times, mothers describe frustrating interactions with individuals who appear to follow bureaucratic processes, giving little consideration to the needs of the individual child. For example, Lisa describes how officers are *'just, like, just filing in tick boxes, or not answering the phone'* (319 – 320). For some of the mothers, there is a strong sense of 'The System' as monolithic, with individuals, both professionals and families, subsumed. Laura describes her child being lost in bureaucracy, so that her 'paperwork' no longer represents the little girl her mother knows her to be, *'it's not really them on that piece of paper'* (299). However, it is not just the children who become lost in this system. While some of the mothers, notably Paulina, describe professionals who provide an individualised approach, other accounts are notable for the anonymity of professionals who are designated to offer support. For Sarah, *'these people are just names to me'* (288). Vicky goes a step further in identifying the dehumanising process that leads her to ask professionals to *'remember they're human beings before professionals'* (439). For four of the mothers, 'The System' is associated with failings, such as delays and difficulties securing a school place. These mothers each described the steps they took in finding a voice within 'The System', to fight for their child's needs to be met. The mothers variously describe their vulnerability and the challenges they faced. However, there is pride to be found in overcoming the challenges of this 'System' and in achieving appropriate support for their child.

#### 5.1.5.3 Context within Existing Research

This pattern across cases relates to the policy and legislative context within a Local Authority and is difficult to compare directly with the existing research. Consideration needs to be given to the process of Statutory Assessment within the English context, following significant legislative changes. However, while there might be differences at the meso- and macro- systemic levels, it is interesting to reflect on how common factors and challenges are found across 'Systems' and contexts. In looking back at their experiences, the mothers of adult children in Strnadova & Evans' (2013) study voice their frustration about a constantly changing system which was challenging to understand and negotiate for their children. Dockett, Perry & Kearney (2011) found that starting school involved a complex process of planning for the parents of disabled children, with a need to initiate contact with professionals and frustrating experiences of delays. Connolly & Gersch (2016) identify similar experiences within the Irish context, with parents needing to ‘battle’ for their child’s needs to be identified and to access the appropriate support. In the English context Russell (2005) identified that while parents valued the contributions of individual professionals, which helped them to further understand their children’s needs, they did not always have a complete knowledge of the statutory assessment system, placing them at a disadvantage in seeking support for their children. The delays to assessment and implementation of support described by mothers in this study were echoed in a Canadian context by Siddiqua & Janus (2016) and in an Irish context by Connolly & Gersch (2016). In each of these studies, parents voiced their concerns that delays in the process led to inappropriate or inadequate support for their children when they began school and led to unnecessary stress within the family. In several studies, parents report advocating for their child. This is explored at some length by Connolly & Gersch (2016), when parents describe striking a balance between flighting for their child and their fear of being perceived as a ‘pushy parent’. Dockett, Perry & Kearney (2011) described parents sometimes being placed in a position of deficit during assessment processes, leading to the dominance of professional opinions in judging appropriate placements for their child. These findings are used by the researchers to contextualise the experiences of individual parents within a broader ecosystemic context, which provides a helpful understanding of how interacting factors influence parents’ experiences of their disabled child starting school.

### 5.1.5.4 Parental experiences of the Statutory Assessment system

While not focused on starting school, Adams, Tindle, Basean, Dobie, Thomas, Robinson & Corina (2017) carried out a wide-ranging qualitative study of parents’ experiences of Education, Health and Care Needs assessments, which relates to ‘The System’ largely referred to in the pattern across themes. Several of the themes identified are reflected in my research. Like Paulina and Lisa, some of the parents in their study describe how support form just one or two engaged professionals, who considered their family's individual needs, made a difference to their confidence and trust in 'The System'. Their study also reflects the lack of accessible information and transparency within the process. Just as Laura describes her daughter being 'lost' in the process, these researchers report that parents experienced the assessment process as holding little scope for parental involvement or possibilities for engaging their child. Some parents, like some of the mothers in this study, experienced the process as adversarial, reporting that they needed better communication with the Local Authorities, and more proactive communication when delays and errors occurred.

#### 5.1.5.5 'The System': Ecosystemic and Bordieuan perspectives

In broadening out to a wider theoretical understanding, Bronfenbrenner's (1979) ecosystemic model provides a theoretical underpinning for understanding the interplay between interacting systems within the context of starting school and how these impact on individuals within the system. Todd & Jones (2003) assert that mothers of disabled children are increasingly drawn into professional networks, where, in Bronfenbrenner's terms, the microsystem meets and is impacted by those exterior systems. While these systems might be characterised by professionals as bringing benefits for the families, such as 'assessments' or 'support', they can be perceived by mothers as containing risks of judgement, misunderstanding and the stress of the 'professional gaze'. Runswick-Cole (2013) argues that in their encounters with systems and authorities, mothers of disabled children experience disablism by proxy, and that this systemic disablism characterises their encounters with 'The System'. Gioia (2017) explored the school starting experiences of marginalised families using

Bronfenbrenner's ecosystemic model. Here, I have considered some of the perspectives voiced by the mothers in this research within these theoretical frameworks.

### 5.1.5.6 Bronfenbrenner's Ecosystemic model (1979)

Mothers live within microsystems of their families. These are characterised by the familial and cultural practices and values enacted within this system. When a child has additional needs, within the English education context, their family's interactions bring together at least three interconnecting systems: the family, the school and the local authority. According to Bronfenbrenner (1979) the number and nature of the interactions that the family initiate with other systems will depend, in part, on the sense of power and confidence they perceive in their situation. Previous research (e.g. Russell, 2005) has demonstrated that parents can find the formal processes around a disabled child starting school opaque and confusing which is likely to influence a mothers' confidence in achieving a voice within the mesosystem of schools and the Local Authority. Within a complex system, which can, at times, be characterised by delays and miscommunication (Adams et al. 2017), it becomes evident how interactions between the microsystem of the family, and the meso- system of the Local Authorities and schools, can become a source of frustration, confusion and stress. In considering this experience for mothers, we must then factor in macrosystemic factors. For example, prejudice towards mothers of children with disabilities at a societal level (Runswick-Cole, 2017) and the challenges of facing an education system that is geared towards 'age related expectations'.

#### 5.1.5.7 Social capital

Bourdieu's (1986) Theory of capital proposes that individuals (or families) exert differing levels of power and influence based on their possession of capital as espoused by the dominant culture, through education, labour and social networks. Critical Disability Theorists (e.g. Oliver, 1990) have argued that disability diminishes capital by virtue of the privileging of bodily 'normality', and success in work and education, in our dominant culture. It could be considered that these expectations place families of children with disabilities in a position of diminished capital, which impacts on their ability and confidence to achieve influential interactions with 'The System'. Each interaction between the mothers and individual professionals, or 'The System', occurs within an education and cultural macrosystem which implicitly promotes a dominant culture of 'normalcy' (Cooper, 2013). Therefore, when the mothers in this study speak about their experiences of 'vulnerability' and their child's voices being lost, we can perhaps hear a reflection of their diminished capital, contextualised within a macrosystem in which cultural narratives privilege normalcy and marginalise disabled people, and, by proxy, their families and advocates (Oliver, 1990).

#### *5.1.5.8 Opportunities for professional reflection*

- *What steps could educational psychologists take to develop a genuinely respectful and collaborative relationship with each family?*
- *What are the questions educational psychologists should ask of their own privilege and practice each time they work with a new family?*
- *How can educational psychologists balance their role as both part of, and independent of, 'The System'?*

- *How can educational psychologists offer assessments and interventions that are sensitive to the cultural and other individual needs of each family?*
- *What steps can educational psychologists take to recognise (dis)ableism in their own practice?*

### 5.1.6 Theme 4: Belonging and rejection

#### 5.1.6.1 Ecosystemic context

This pattern across cases explores the mothers' experiences of the process of their family joining the school community. It refers to the two-way interaction and relationship that develops predominantly between the family **microsystem** and the school **mesosystem**. While macro- and exo-systemic factors exert some influence, it is striking that this process is described as a more intimate experience, certainly when compared with mothers' descriptions of the statutory system. The mothers refer to building relationships with individuals and their sense of belonging or estrangement within the school community. The anecdotes mothers use to describe their experience of belonging, rejection and isolation are notable for their unremarkable nature, referring to typical day-to-day events in school life, but seen through the unique lenses of the mothers with a disabled child.

#### 5.1.6.2 Belonging and rejection

This pattern across cases identifies the significance ascribed by the mothers of developing an involvement in their child's school and a sense of belonging located in a physical place and community. Mothers valued opportunities to visit their child's school, and it was through these visits that they sometimes began to develop a sense of 'fit' for their child. As Paulina shares, *'it felt right'* (178). Some of the mothers describe their initial visits as important opportunities to judge the culture and values of the school: *'you can't see it, you can't touch it'* (Vicky, 109). Mothers understood when schools had taken steps to show an interest in the child, and to help the family feel at ease, such as the comfortable furniture in Sasha's headteacher's office. A key aspect of this experience for each of the mothers was the process of forming relationships with members of school staff. Some mothers valued the efforts of members of staff to get to know their child as an individual, becoming *'tuned into his needs'* (Paulina, 72). However, for Laura there were concerns that the school had failed to get to know her child beyond their 'paperwork' which was a cause of great worry, as she felt that the school were not *'keeping* [Emily] *safe'* (479). Several of the mothers described developing a genuinely collaborative partnership with members of school staff, offering advice and support when needed. For Sarah, this dynamic allowed Sasha to settle into school successfully: *'It's been the relationship we've had that's made the difference'* [226]. Some mothers valued their child's positive relationships in school. For Vicky, whose son might need care across his lifespan, she found this first experience of Toby building relationships outside the home *'hugely reassuring'* (276). While the mothers shared positive accounts of collaboration and relationship building, a second thread ran through their narratives. This was most notable for Laura, who had perhaps experienced a bumpier start to school life than the other mothers. While Laura felt her daughter had now settled in, there remained uncertainty about whether she truly belonged to the school community because of some things the headteacher had said: *'she can't see her being there long term with the needs she has'* (32-323). Lisa and Paulina shared more everyday experiences which suggested that, while their family had been welcomed into school, this belonging was perhaps more tenuous than that experienced by other children. Paulina's anecdote is striking in this respect. John

Paul was excluded from taking part in the school harvest festival because his teachers feared he ‘wouldn’t cope’. John Paul’s exclusion was hurtful for Paulina, but what is also notable is how she describes picking herself up and explaining to the teachers that next time, they could solve this problem together.

#### 5.1.6.3 Context within existing research

The evaluative nature of some of the existing research means that parents’ experiences of belonging are sometimes communicated in terms of their satisfaction with certain school processes, rather than in terms of the psychological and social processes at work. For example, Janus, Kopechanski, Cameron & Hughes (2008) found that whilst parents received additional support from schools on transition, there was often uncertainty about the level of support their child would receive, and a lack of appropriately trained personnel to support their child. Siddiqua & Janus (2016) identified lack of communication between families and schools as a key source of dissatisfaction for parents when their child entered school. They found that parents were expected to take the initiative in developing relationships and communicating with members of school staff, leading to parental dissatisfaction with school services, compared to those in preschool. From a phenomenological perspective, Stradova & Evans (2015) found that mothers retrospectively reported developing relationships with members of school staff as of key importance in the transition process. Trusting relationships allayed mothers’ concerns about their child’s safety and education but some mothers (like Laura) experienced ongoing uncertainty about the stability of their child’s mainstream placement. Dockett, Perry & Kearney’s (2011) research also found that parents valued school visits to develop a sense of the school culture and ‘fit’ for their child. Parents gave mixed reports about the quality of communication between home and school. While some families received proactive communications, others found that they need to make contact and felt frustrated by delays in replies. A key finding, which is not identified in this project, is the role of school expectations. Parents in Dockett, Perry & Kearney's (2011) study found that schools expected parents to adopt certain roles as their children started school, such as being available to collect their child at short notice. This expectation of responsibility for their child's care was viewed as a source of stress for parents. In another experiential study, Connolly & Gersch (2016) found that parents sometimes did not feel heard and believed by staff in school and could perceive school staff as intimidating. Parents reported that communications were not always open and the sense of collaboration with school staff was undermined by their parenting skills being called into question. Participants were at times reluctant to initiate communication for fear of being considered 'pushy parents', a view we hear echoed in Sarah's account.

#### 5.1.6.4 Home-school connections

Broadening this out, a literature search revealed very little research into familial belonging in school communities. However, it is evident that family participation has a positive impact on broader education outcomes (Barnard, 2004). Some research has focused on improving school outcomes by improving connections with families, including those from groups experiencing additional challenges (Pomerantz & Moorman, 2010). To this end, various models of family involvement have been developed. One of the most influential is Epstein's framework of six types of family involvement (2011). This model asserts six ways in which schools can encourage families to become engaged in their children's education:

1. *Parenting*
2. *Communicating*

3. *Volunteering*
4. *Learning at home*
5. *Decision making*
6. *Collaborating with the community*

In this research, when mothers speak about the process of becoming involved in school life, and developing a sense of engagement, perhaps the most important step for the mothers is communicating. While Epstein's model focuses on school to home communication, it seemed important for the mothers in this study that communication flowed both ways. Mothers valued opportunities to share their unique knowledge about their child, and recognised when the school listened to this. In Laura's case, where she felt that she had not had the opportunity to communicate in this way, she felt concern for Emily's safety and wellbeing. A second important area for the mothers in this study is around decision making. This is perhaps particularly important for parents of disabled children, whose children might well need different decisions made about the support they receive compared with others in the school. In this study, where mothers felt they had the agency to be involved in genuinely collaborative decisions and decision making (such as when Vicky reports the school's genuine interest in how they did things are home) they felt appreciated and positive. Paulina's experience of her son's exclusion from the school harvest festival demonstrates how wounding a decision, although made in good faith, that does not involve the family, can be. While models of parental involvement, such as Epstein's, can be a useful framework for evaluating school practice, this research indicates occasions where parents have felt a sense of exclusion related to experiences that were not policy, but attitudinally-driven. For example, Paulina's interpretation, of the experience of her child being excluded from the harvest festival, related to the teacher's perception of what her child could ‘cope’ with. Laura’s experience of the headteacher questioning whether Emily could remain in mainstream schooling, related to her doubts about the school’s ability to ‘cope’ with a child ‘like’ Emily. Therefore, perhaps as well as the importance of formalising inclusionary policies (such as Epstein’s six-step model), it is important for schools to consider the trickier and more nebulous concept of school culture. As Vicky shares, when she speaks about realising her child would belong in a particular school: ‘you can’t see it, you can’t touch it’. Research has attempted to explore inclusionary/ exclusionary practices in schools and to consider the practice implications (Baars, Shaw, Mulcahy & Menzies, 2018). However, this research has not considered pupil or parent perceptions of belonging and this is a gap ripe for further exploration.

#### *5.1.6.5 Opportunities for professional reflection*

- *How can educational psychologists work with schools to foster a sense of belonging among parents of disabled children?*
- *Should EPs and schools develop evaluative tools to consider how school culture fosters a sense of belonging?*
- *When a parent talks of feeling a sense of rejection, how can educational psychologists work collaboratively with schools to overcome and learn from this?*

### 5.1.7 Synthesis

This part of the discussion has considered the key findings of the research, organised into thematic patterns across cases, as interpreted through IPA. While it is interesting to explore the extent to which this research resonates or contrasts with existing research, the relative lack of research in these areas, particularly of a phenomenological nature, limits this process somewhat. However, it is evident that some of the key themes of this research, such as the importance of establishing positive relationships and being welcomed by schools, the significance of starting school for families, and the administrative and emotional challenges on families of disabled children when they begin school, are reflected. Broadening the perspective, key themes can be linked to established paradigms in psychology and critical disability theory, which enables the phenomenon of mothers' experience of their disabled child starting school to be located within a broader understanding of experiences of disability for parents, families and within educational and broader societal contexts.

## Part 2

## 5.2 Critical evaluation of research: Limitations, reflections, implications and next steps for research.

In part two I critically examine the limitations of this research and my role as researcher, before considering possibilities for future research in this area.

### 5.2.1 Limitations of research

In considering the findings of this study, it is important to consider the limitations relating to methodology and method and the implications for the research findings.

### 5.2.2 Suitability of the method and methodological limitations

I chose to use the IPA method to gather and interpret my data. This method was selected because I intended to explore individual experiences and IPA offers an appropriately idiographic and phenomenological approach to conducting research. Semi-structured interviews with participants, and following IPA protocols to analyse interview data, enabled me to gather *'rich, detailed, first person accounts of their experiences'* (Smith, Flowers & Larkin, 2009, p. 15) and this was in keeping with the aims of the study. IPA enabled the experiences of individual participants to be explored in depth, while also allowing some pattern finding between cases, in search of convergence and divergence. Whilst I maintain that IPA was an appropriate method for this research, there are some limitations to this method, consistent with the underlying epistemological framework. Firstly, because of the small sample size and purposively homogeneous sample, this study offered only a snapshot of mothers' experiences in a specific geographic, cultural and time context. The small and homogeneous sample limits the applicability to other contexts. Consistent with its idiographic intentions, this study elicits the voice of the individual, rather than establishing wide-ranging conclusions that answer hypotheses. Given the small sample size and the specific research context, while the method itself is transparent and replicable, there should be no assumption that methodological replication would produce themes that are similar in content or intensity to those elicited in this study. As Smith, Flowers & Larkin (2009) observe, IPA does not set out to make generalisations to a wider population but offers a different way of drawing together shared experiences: *'It locates them in the particular, and, hence, develops them more cautiously'* (p. 29). The small number of participants and the context in which this study was conducted mean that any extrapolation or learning taken from these findings are tentative and cautious. I avoid making generalisations but do consider the findings in the context of relevant psychological theory and existing research, which I believe adds to the depth of the analysis. While the data is not generalisable in a nomothetic sense, when considered within the 'patchwork' of other phenomenological research about experiences in similar contexts, and within relevant psychological frameworks, the findings might contribute to our broader understanding around mothering, disability and starting school.

Consistent with the IPA approach, the sample recruited was intentionally homogeneous and purposive. Participants were selected based on homogeneity of experience, according to inclusion and exclusion criteria. In practicality, there was a limited ‘pool’ of parents from which to recruit. This presented three challenges. Firstly, when planning this study, I did not include gender in the inclusion criteria. However, only mothers came forward and this has implications for the findings of this study. In light of Trausdottir’s (1991) findings about the pitfalls of ‘gender blind’ research, in which maternal experiences tend to be extrapolated to parental experience, I have considered this demographic difference in my analysis. I acknowledge that mothers of disabled children have a socially and culturally gendered experience of parenting their children (Runswick-Cole, 2013) and that this is likely to be relevant to the themes discussed in this study. Selection of participants in IPA studies relates to homogeneity of experience (Smith, Flowers & Larkin, 2009). Between participants within the group, experiences and demographics were quite diverse. Mothers came from different cultural and educational backgrounds. Another factor to consider, in terms of the sample characteristics, is that mothers were all highly engaged in services, including the family centre through which they were recruited. Each of these mothers were motivated interviewees, some even approached me to take part in the study. Each had the confidence and skills to seek outside support and to advocate for their child, and to share their story. While this does not affect the rigour of this ideographically focused study, it does raise possibilities for future research. Dockett, Perry & Kearney (2011) identified how intersecting demographic factors influence parents’ experiences of their disabled child starting school. They raised the question of how risk factors intersect to impact on family’s experiences at this time. It is important to remember that complex, intersecting factors influence parents’ experiences, and these were not explicitly identified in the current study, raising possibilities for future research with diverse groups of parents. Another limitation of this study is that the homogeneity of the group's experience was not considered in the context of their child's disability, either in nature or severity, except insofar as each child had an EHCP. This was intentional and congruent with my ontological orientation towards the social-relational model of disability (Thomas, 2004). The social relational model places disability within disabling environments and relational contexts, rather than focusing on individual (medicalised) conditions.

### 5.2.3 Reflexive critique

Here, I examine my role as researcher and the implications for this research, considering my research skills, role and influence as a novice, insider researcher. I found my research diary invaluable for reflexively considering my position in the research, excerpts of which are in *Appendix 12*.

#### 5.2.3.1 Novice researcher

Smith, Flowers & Larkin (2009) set out clear protocols for conducting an IPA study. They suggest that this stepped approach makes IPA a good method for novice researchers. However, I appreciate that the experience of the researcher is likely to influence the analysis of findings, the themes generated, and the patterns identified. While I am confident that I followed the IPA protocol, as I understood it, it is important that I accept that my own relative inexperience in conducting research is a potential limitation of the study and its findings.

#### 5.2.3.2 Insider researcher

A thread running through this project has been my position as an insider researcher. I have experience of the phenomenon explored. This position has meant that it has been necessary for me to find out about the advantages and issues for insider researchers and to consider the limitations this imposes on this study.

#### 5.2.3.3 Role Duality

A key consideration is role duality. Much professional doctorate research has some level of role duality, because practitioners often work with the groups researched, or within the research context. I had an additional duality to consider, that of researcher and mother. DeLyser (2001) observed that role duality can be difficult to balance, and that there is a risk that the process of research and analysis can be excessively swayed by personal experience. The IPA model, with roots in phenomenology, acknowledges the subjective role of the researcher in interpreting phenomena. Smith, Flowers & Larkin (2009) argue that, because we are not necessarily aware of our preconceptions and biases, reflective processes, and a cyclical approach to bracketing off our assumptions, are important. I spent considerable time reflecting on this. Smith's (2010) description of noticing one's biases and preconceptions in the context of the hermeneutic circle provided a helpful guide. Here, the researcher moves from one-point in the circle, the 'whole' of their experiences and preconceptions, to the 'part', a meeting with another individual. At this point the focus is on their story, and preconceptions and biases are bracketed off (insofar as is possible), before moving back to the 'whole' point in the circle, when the participants' accounts are considered in the context of the research as a whole and the researcher's own biography.

#### 5.2.3.4 Using the Double Hermeneutic

As an insider researcher, the double hermeneutic, which situates the researcher as both similar and different to the participant, became even more important. The idiographic focus of IPA allowed me to incorporate the understanding that, while I might espouse to have ‘experienced the same thing’, this was never really possible because each person’s experience is situated in diverse social, cultural and biographic contexts.

### 5.2.3.5 Using Researcher Reflexivity

As part of this process, I introduced a final stage in the data analysis. **The reflection/ reflexive stage** enabled me to consider the personal resonances of the particular words and stories, inevitable comparisons and instinctive feelings. I found this step to be helpful, allowing me to take the IPA analysis a step further. Using Burnham’s social GRACES model (1993), I was able to reflect on my response in the context of social and cultural similarities and differences. Within this stage I sometimes drew upon psychoanalytic understandings that I use in my professional practice, which enabled me to reflect on the psychological processes that might be at work as I undertook the task of making sense of the participants’ stories.

Through my research diary and in supervision sessions, I have given considerable thought to how my experiences impacted on the research and subsequent analysis. I related to some of the stories in terms of feelings of hope, doubt and frustration, as well as pride. However, there were times when their stories did not echo my own, and it was at these points I became particularly aware of the importance of ensuring the mothers’ own voices were heard. For example, the intensity of Vicky’s description of trauma stood alone, but also said something important about the particular challenges she faced. While I was prepared for my responses as a parent, I was surprised at times by how often my emotional responses came from my professional position. I was taken aback sometimes by the extent to which mothers felt dismissed by professionals and let down by a system to which I have contributed. At times, I found myself considering the perspectives of the professionals mentioned, and needed to consciously bracket off this line of thinking. Again, I was aware of the relevance of the double hermeneutic, as I considered how my professional experience and identity influenced what I heard of the mother’s accounts.

#### 5.2.3.6 Personal reflections on the analysis

Professional and personal experience had shown me that beginning school is a transformative time in family life. I was surprised to discover, during my literature review, that while there is a great deal of research around traditional ideas of ‘school readiness’, there is still limited understanding about starting school at a deeper experiential level in the UK context. The research literature around disabled children and their families was even more limited. My professional involvement in supporting disabled children starting school indicated that this is a complex process, involving multiple professionals and complex bureaucratic systems. On a personal level, I had also become aware that the process, even for those who know the system, can be challenging to navigate. However, I was mindful of bracketing off this prior knowledge as I conducted the interviews and undertook analysis.

During the analysis, I found the process of continually reading and rereading the interviews meant that my interpretations evolved incrementally. At first, I was interested in the words used and in events recalled. As the process continued, particular themes began to form a backdrop for the words and events. I observed that I became drawn into the linguistic style of each participant, and that, with this familiarity, I began to infer possible intended meaning and emotional context. I found the process highly iterative. Despite intentions to bracket off assumptions as I approached each interview, similarities and discrepancies, both from my own professional and personal experience and those of other participants, appeared. The reflections section of the analysis allowed me to voice these, and to then put them aside for later consideration. It was here that the double hermeneutic turn of the IPA model became relevant, as I became aware of how my own experiences shaped my interpretations of language and meaning.

#### 5.2.3.7 A personal and professional challenge

This research project represented a personal and professional challenge. Working as an applied psychologist, my research experience had been limited to small scale action research projects. The rigours of academic writing, critiquing research and implementing an ethical and thorough study were considerable. This was my first experience of IPA, and it helped to have supervisors and peer researchers to assist in designing appropriate research questions and construct my methodology. In considering my role as an insider researcher, I sought out and received helpful advice from academics who also position themselves in this role, as parents of disabled children. I felt that my strengths were in planning and completing interviews and developing positive rapport with interviewees. The responsibility of data analysis felt more challenging. I was aware that I had interpretative choices to make and that this would affect how the mothers' experiences would be understood by readers. Ryan (2009) observed that research into mothers' experiences can emphasise passivity, powerlessness and struggle. However, inspired in part by Dockett, Perry & Kearney's (2011) research, I aspired to pursue a more nuanced account in the analysis and subsequent discussion.

### 5.2.4 The mothers' experiences

The mothers who took part in my research invested considerable resources in this research, both in terms of their time, and their thoughts and feelings. Each of the mothers revealed deeply personal information about their hopes, relationships and struggles and in the months of interview analysis I developed a deep, if one-sided, relationship with their words. I felt it would be ethical and courteous, but also interesting, to feedback the IPA to the mothers and chose to do this in a short email. Each of the mothers responded, and three provided more detailed responses, including an update on their child's progress. One mother commented that the research would 'sound familiar to lots of parents.' Another told me that, since her child started school, she had 'got smarter and wiser.'

### 5.2.5 A Unique and Distinctive Contribution

In doing research of this kind, it is useful to have knowledge of the educational and statutory processes within which starting school occurs, as well as some understanding of the relevant psychological processes at an individual, familial and systemic level. As an educational psychologist, I have been able to apply my knowledge, research skills and experience to produce a research project that explored this area at an experiential level, which I hope provides a useful contribution to my professional community. As far as I am aware, this is the first in depth, phenomenologically oriented study that explores parents' experiences of their child starting school with an EHCP.

#### 5.2.5.1 New perspectives

This study reflects some of the findings of the research examined in the literature review, highlighting the significant impact of starting school for parents. This study found that choosing and starting school is a complex and multi-layered process which, at times, requires both time and the emotional labour of the parents. Starting school is an important time in family life, in which parents get to know their children in different ways, think about the future and develop new senses of belonging. Parents, like those in some other studies, advocated for their child and often wanted to help others. My interpretation of the mothers' accounts also led me to consider their child starting school as a time for personal change and growth. This aspect has not featured strongly in previous research, but does feature in research around other significant life events (Ryan, 2009). My research is congruent with interactionist perspectives, which understand starting school as an important time in life, and accommodates the complexities involved for a family with a disabled child. The research highlights the complex systems in which the process occurs, and the frustration and powerlessness felt by some parents. However, in each of these accounts there are also stories of resilience, change, gaining knowledge and of wisdom. While there can be a focus on what goes wrong, it is important for researchers to acknowledge the positive changes that this time can bring, for children, schools and parents, and to think about how this can be built upon. While at times the mothers despaired of the systems they encountered and of professional disinterest and disorganisation, there were also accounts of committed professionals who made a real difference for their families.

#### 5.2.5.2 Practice Implications

In section 1 I considered some ways in which I, and other educational psychologists, might use this research to reflect on their practice. These are by no means prescriptive 'how-to' tips, but convey some of the key themes that the mothers shared in their interviews, and consider ways in which educational psychologists might respond.

While a shift in practice is perhaps the aim of any professional research, equally important is the possibility that this research, building on other phenomenological research in my professional field, encourages us to think differently about the people we meet as part of our work. That (in Vicky's words) 'nightmarish' mothers encounter us following experiences of trauma and obfuscating professionals. That when we take time to build a relationship with a parent and to get to know their child (like Paulina), this is reassuring and meaningful. That a formal system in which we are intimately involved, which policy makers and bosses tell us is here to help, can be experienced by families as inconsequential or even hostile. That, echoing Runswick-Cole (2013), we need to be mindful of what we really mean when we offer 'support'. Are we, as professionals, able to accept questioning, challenging and genuine collaboration with the families we meet? Can we, with professional humility and an open mind, recognise that the knowledge, the resilience, and the potential sits with the person across the table? And that, even if we meet them and their child just once, it is our professional obligation to patiently hear their story, hoping to be taught something new, about their family and about our job?

#### 5.2.5.3 Sharing my research

I hope to disseminate my research findings in several ways. Firstly, these will be shared with the family centre which facilitated this research, and to local professionals through the SENCO network I attend. When possible, I hope to share this research through a professional journal article and have applied to host a seminar at a (virtual) professional development event. I hope that this research will provide a unique and distinctive perspective which will prove an interesting starting point for discussions between professionals and with parents.

#### 5.2.5.4 Next steps for research

This study identified a lack of research about the experiences of parents of disabled children at this important stage in life, especially in the UK. Because of this, I developed intentionally broad aims and a wide-ranging research question. Now that some information is available, it would be interesting to begin to explore further the factors that impact on parents' experiences. There is a growing understanding of the impact of intersecting risk and resilience factors on individuals' experience of the same phenomenon (Liasidou, 2012). It would be interesting to explore how socio-economic factors, education, health and gender intersect to impact on parents' experiences. This study was conducted from the perspective of mothers and it provides an unapologetic 'warts and all' account of the process of starting school, and the concurrent EHC assessment, from their perspectives. I am conscious that those professionals who work within the statutory system, seen as a source of frustration and disappointment at times, rarely have a voice beyond their 'corporate' role. It would be interesting to hear their contrasting perspectives and to explore how these different perspectives fit together into a more holistic narrative about the process and the systems described in this study.

### 5.2.7 Summary of Research and Practice Implications

As an IPA research project rooted in phenomenology, it is not easy to supply 'take home' messages, for educational psychologists to 'copy and paste' into their practice. The focus of this research was on individual experiences, which were as notable for their differences, as their similarities. However, I have throughout this chapter provided some key points for reflection which practitioners might wish to consider in relation to their own work. I have found opportunities to discuss some of these points in professional supervision sessions to be helpful in my own professional work.

With the caveat above, I believe there are some key points that have emerged from this research which resonate with similar research and further our knowledge in the contexts of the paradigmatic frameworks, such as Bronfenbrenner's (1979) bioecological model and Carter and McGoldrick's (1993) Family Life Cycle model, within which they are located. Some key findings are described below:

- The process of starting school with a disabled child is not a simple 'transition' form one environment to another, as it has traditionally been viewed. **It is a complex and significant event in family life**, involving multiple and interacting systems functioning at the individual, familial, social and cultural levels. It is important that psychologists understand and respond to this complexity in working with families and schools to plan and facilitate this process.
- While an educational psychologist might be involved for only a short period, **it is important that we 'get it right' in terms of our communications with families**. Mothers remembered, and were at times deeply affected by professional actions both positive and negative. Commenting on a child's strengths or recognising a family's skills and knowledge can make a big difference to their confidence in the process.
- When we listen to these mothers, it is evident that **'The System' can be understood as ineffective and oppressive for disabled children and their families.** Mothers reflected hearing negative, apathetic and outdated messages about their disabled child's right to an appropriate education. While it is perhaps unrealistic to expect individual educational psychologists to effect

cultural change, it is important that we challenge these views where we hear them and position ourselves as allies of disabled people, even when this involves difficult conversations with colleagues.

- It is important for educational psychologists to understand that the long process of starting school can be a **time of stress for families** who have already experienced trauma and change. This can include financial, relationship and work stresses as well as the emotional factors that come with a big life change. Educational psychologists, working through an interactionist and whole-family lens, should not be afraid to spend time exploring this with families.
- For mothers, **developing a sense of belonging**, for themselves and their child within the school community appears to be very important. Mothers were sometimes acutely aware of events which signalled a school's acceptance or rejection of their child, beyond formal systems and processes. Perhaps educational psychologists have a role to play in engaging with schools to understand some of the cultural, relational and environmental factors that can promote a sense of belonging for families. These changes can be as simple as allowing meetings to take place in an informal seating area, or inviting a parent to share their knowledge with a teaching assistant.

### 5.2.7 How this research has changed my practice

Like many EP's (Dunsmuir, Cole & Wolfe, 2017), my work increasingly involves working closely with families. Both the findings of this research, and my experience of insider research has furthered my interest in this aspect of my professional role. In the process of completing this research, I have reflected in professional supervision and through casework on the 'points for EP reflection' made in this chapter. Here are some of the ways in which I have noticed my practice evolve:

- I have looked at **'transition' work through a more interactionist lens**, reflecting on the multiple systems that work together to help or hinder the process of a child starting school.
- **Developing an awareness of my role, however transient, in the life journey of families**. For me, this includes recognising the small acts, such as commenting aloud on a family's resilience's or a child's strengths, that can make a difference to how parents view the assessment process and their child's potential future.
- Inspired by the advocacy and support roles adopted by these mothers, I have given thought to **ways in which I can advocate for disabled children and** their families, including making links with voluntary groups.
- **Seeing my practice through a critical disability theory lens** has allowed me to explore how my assessments, reports and actions might perpetuate oppression or facilitate emancipation of the disabled people I work for and with.
- Following this research, I continue to **make links with other insider researchers and those who also see their work through a critical disability theory lens**. I have presented a seminar about insider research for some graduate research students at Herriot-Watt University. I have recently been asked to collaborate on a project exploring the in-work experiences of carers, working from a social-relational model.
- **This research project has enhanced my skills as a reflexive and reflective practitioner.** Using models such as Burnham's (1993) social GRACES, I have become very interested in the role of self in professional educational psychology practice and am interested in exploring this aspect of practice further.

## 5.3 Conclusions

This study has contributed new knowledge through an in-depth exploration of the experiences of mothers when their disabled child starts school. While the phenomenological nature of this research means that is not generalisable to a broader population, it has allowed consideration of the psychological and systemic processes that relate to this experience and the implications for professional educational psychology practice and future research.

It is my hope that practitioners working with families at this important point in their lives will use some of the insights gained from this research. I hope that professionals, especially educational psychologists, will remember the upheaval, frustration and disappointment this process sometimes involved for the mothers, and the uncertainties it raised for their child’s future. I hope that practitioners will also remember the difference that a few committed, kind, professionals made in empowering mothers to have their voices heard. Finally, it is hoped that we, as professionals working with families, can come to identify and celebrate the successes that can be enjoyed when we work collaboratively with families; and can learn from the resilience they demonstrate and the insights they share.

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Trausdottir, R. (1991). ‘Mothers Who Care: Gender, Disability and Family Life’. *Journal of Family Issues*. *11* (2), 24–38.

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# Appendices

## Appendix 1: Literature search details

**Literature Review – Search Record**

*Databases:*

ERIC (via Shibboleth)

EBSCO (via Shibboleth)

PsycINFO

PsycARTICLES

Psychology and BEhavioral Sciences

PEP Archive

Education Source

ERIC

*Limitations:*

Peer Reviewed Journals only

Publications after January 2000

*Search Strings:*

| | **Search Strings** |
|---|---|
| 1 | (special educational needs) + (start* school) + (parent*) |
| 2 | (SEN) + (start* school) + (parent*) |
| 3 | (disab*) + (start* school) + (parent*) |
| 4 | (special educational needs) + (school transition*) + (parent*) |
| 5 | (SEN) + (school transition*) + (parent*) |
| 6 | (disab*) + (school transition*) + (parent*) |

*indicates prefix search.  For example, PARENT* will retrieve PARENT, PARENTS, PARENTAL

***Search Results***

*Boolean Term:*

***(special educational needs OR SEN OR special needs) AND (school) AND (start* OR transition*) AND (parent* OR family)***

## Total number of results: 513 (377 results following removal of exact duplicates)

Full search results are provided in compressed file in additional appendix.

**Inclusion criteria:**

| Included | Excluded |
|---|---|
| International studies published in English | Studies not published in English |
| Studies that focus on disabled children | Studies without a specific focus on disabled children |
| Studies that focus on starting school | Studies that focus on transitions between other school phases |
| Studies that focus on the views, evaluations and insights of parents | Studies with a focus on information from other sources (e.g. teachers) |
| Studies published in peer-reviewed journals | Unpublished studies, such as theses |

### Studies meeting inclusion criteria

1. Connolly, M. & Gersch, I. (2016). ‘Experiences of parents whose children with autism spectrum disorder (ASD) are starting primary school’. *Educational Psychology in Practice*, *32* (3), 245 – 261.

2. Dockett, S., Perry, B. & Kearney, E. (2011). ‘Starting School with Special Needs: Issues for Families with Complex Support Needs as Their Children Start School’. *Exceptionality Education International*, *21* (2), 45–61.

3. Janus, M., Kopechanski, L., Cameron, R. & Hughes, D. (2007). ‘In Transition: Experiences of Parents of Children with Special Needs at School Entry’. *Early*

*Childhood Educational Journal*, *35* (5) 479–485

4. Kemp, C. (2003). ‘Investigating the Transition of Young Children with Intellectual Disabilities to Mainstream Classes: an Australian perspective’. *International Journal of Disability, Development and Education*, *30* (6), 403–432.

5. Russell, F. (2005). ‘Starting School: The importance of parents’ expectations’. *Journal of Research in Special Educational Needs*, *5*(3), 118–126.

6. Strnadova, I. & Evans, D. (2013). ‘Schooling Transitions Within the Lifespan of People with and Intellectual Disability: Perceptions and Recommendations of Ageing Mothers’. *The Australian Journal of Special Education supplement: Transitions for Students with Special Educational Needs*. *37* (1), 64–98.

7. Siddiqua, A. & Janus, M. (2016). ‘Experiences of parents of children with special needs at school entry: A mixed methods approach’. *Child: Care, health and development.* 43 (4), 566-575.

## Appendix 2: Application for ethics approval

The Tavistock and Portman NHS
NHS Foundation Trust

# Tavistock and Portman Trust Research Ethics Committee (TREC)

## APPLICATION FOR ETHICAL REVIEW OF RESEARCH INVOLVING HUMAN PARTICIPANTS

**This application should be submitted alongside copies of any supporting documentation which will be handed to participants, including a participant information sheet, consent form, self-completion survey or questionnaire.**

Where a form is submitted and sections are incomplete, the form will not be considered by TREC and will be returned to the applicant for completion.

For further guidance please contact Paru Jeram (academicquality@tavi-port.nhs.uk)

## PROJECT DETAILS

| | | | |
|---|---|---|---|
| **Current project title** | Exploring parents' experiences when their child with an Education, Health and Care Plan (EHCP) begins mainstream primary school | | |
| **Proposed project start date** | 01/02/18 | **Anticipated project end date** | 01/01/19 |

## APPLICANT DETAILS

| | |
|---|---|
| **Name of Researcher** | Kathleen Gayton |
| **Email address** | kathleengayton@hotmail.com |
| **Contact telephone number** | 7795154881 |

## CONFLICTS OF INTEREST

**Will any of the researchers or their institutions receive any other benefits or incentives for taking part in this research over and above their normal salary package or the costs of undertaking the research?**

**YES** ☐ **NO** ☒

If **YES**, please detail below:

**Is there any further possibility for conflict of interest? YES** ☐ **NO** ☒

If **YES**, please detail below:

| |
|---|
| |

**FOR ALL APPLICANTS**

| | |
|---|---|
| Is your research being conducted externally* to the Trust? (for example; within a Local Authority, Schools, Care Homes, other NHS Trusts or other organisations).<br>*Please note that 'external' is defined as an organisation which is external to the Tavistock and Portman NHS Foundation Trust (Trust) | **YES** ☐ **NO** ☒ |
| If **YES**, please supply details below:<br>Interviews will be carried out with parents within a specified Local Authority area, but I do not work for a Local Authority. As an independent practitioner, I am not carrying out this research in the context of another organisation, and I therefore do not need to seek external ethical approval from another organisation. I do not have an external sponsor for my research and local approval is not needed. | |
| Has external* ethics approval been sought for this research? **(i.e. submission via Integrated Research Application System (IRAS) to the Health Research Authority (HRA) or other external research ethics committee)**<br>**External ethics approval is not needed for this research.**<br>*Please note that 'external' is defined as an organisation/body which is external to the Tavistock and Portman Trust Research Ethics Committee (TREC)<br>If **YES**, please supply details of the ethical approval bodies below **AND** include any letters of approval from the ethical approval bodies:<br>Please see above. | **YES** ☐ **NO** ☒ |
| If your research is being undertaken externally to the Trust, please provide details of the sponsor of your research?<br>My research is not being undertaken externally and I do not have a sponsor for this research | |
| Do you have local approval (this includes R&D approval)? | **YES** ☐ **NO** ☒ **Not needed** |

**COURSE LEAD**

- Does the proposed research as detailed herein have your support to proceed?
  **YES** ☐ **NO** ☐

| | |
|---|---|
| **Signed** | |
| **Date** | |

**APPLICANT DECLARATION**

I confirm that:

- The information contained in this application is, to the best of my knowledge, correct and up to date.
- I have attempted to identify all risks related to the research.
- I acknowledge my obligations and commitment to upholding our University's Code of Practice for ethical research and observing the rights of the participants.
- I am aware that cases of proven misconduct, in line with our University's policies, may result in formal disciplinary proceedings and/or the cancellation of the proposed research.

| | |
|---|---|
| **Applicant (print name)** | Kathleen Gayton |
| **Signed** | Katey Gayton |
| **Date** | 07/01/18 |

**FOR RESEARCH DEGREE STUDENT APPLICANTS ONLY**

| | |
|---|---|
| **Name and School of Supervisor/Director of Studies** | School of Child, Community and Educational Psychology<br>Dr Rachael Green/ Dr Brian Davis |
| **Qualification for which research is being undertaken** | Professional Doctorate in Applied Child and Educational Psychology<br>DedChPsych |

**Supervisor/Director of Studies –**

- Does the student have the necessary skills to carry out the research?
  **YES** ☐ **NO** ☐
- Is the participant information sheet, consent form and any other documentation appropriate?
  **YES** ☐ **NO** ☐
- Are the procedures for recruitment of participants and obtaining informed consent suitable and sufficient?
  **YES** ☐ **NO** ☐
- Where required, does the researcher have current Disclosure and Barring Service (DBS) clearance?
  **YES** ☐ **NO** ☐

| | |
|---|---|
| **Signed** | |
| **Date** | |

**DETAILS OF THE PROPOSED RESEARCH**

- **Provide a brief description of the proposed research, including the requirements of participants. This must be in lay terms and free from technical or discipline specific terminology or jargon. If such terms are required, please ensure they are adequately explained (Do not exceed 500 words)**

I intend to investigate the experiences of parents of a child with an Education, Health and Care Plan (EHCP) when their child begins mainstream primary school. An EHCP is a statutory plan that outlines educational and other provision for children with the most complex additional needs within their school setting. I intend to carry out a single in-depth interview with a small group of participants (5) and a pilot interview. The participants will be parents of a child with an EHCP currently in their reception (first) year at mainstream school. Participants will take part in a semi-structured interview which will last for about an hour. This will be audio recorded. The interview will take place at a convenient, private and safe venue, such as the family room at a local children's resource centre )PARC) or in the child's school. During the interview participants will be asked about their experiences in the lead up to transition from pre-school to school, transition planning and their child's first few months in school. The research will use an Interpretative Phenomenological Analysis (IPA) methodological framework, and the interview planning and implementation, and data analysis will adhere to IPA research principles.

- **Provide a statement on the aims and significance of the proposed research, including potential impact to knowledge and understanding in the field (where appropriate, indicate the associated hypothesis which will be tested). This should be a clear justification of the proposed research, why it should proceed and a statement on any anticipated benefits to the community. (Do not exceed 700 words)**

Starting primary school is considered one of the most important transitions in a child's life and a key point in the family life cycle (Fabian and Dunlop, 2006).Ghaye and Pascal (1989) found that initial success leads to a cycle of achievements and can be a critical factor in determining future progress. There is a body of research into the experiences of children starting school, predominantly voiced through parents and teachers (e.g. Rimm-Kaufman and Pianta (2000). Research into the parents' own experiences suggests that starting school brings about change for the whole family (Dockett and Perry 1999). However, much more limited research exists about the particular experiences of parents whose children have additional needs, such as disabilities. Most of the existing research in this area has been undertaken in other cultural and policy contexts e.g. Dockett, Perry and Kearny (2011) in Australia and Janus, Copechanski, Cameron and Hughes (2008) in Canada. The research data indicates that, while parents of children with additional needs experience some of the same hopes and anxieties as other parents, their lived experience of their child starting school can be very different; more isolating, challenging and more complex. (Janus et al. ibid.). A detailed literature review indicated that very limited published research exists that focuses on this phenomenon in the UK educational context. Additionally, the overhaul of the UK SEN system, brought about by the implementation of the 2014 Education Act, means that the way in which children with additional needs and their parents should be supported has changed significantly in recent years.

My research, building on the body of research evidence about the significance of starting school from a whole family perspective, aims to explore the experiences of parents' of children with additional needs starting school, within the UK context. I will focus on parents of children with an EHCP because this serves a proxy indicator that their child has complex needs, and also so that parents' experience within this relatively new statutory framework can be explored. The research, in giving voice to parents experiences, is congruent with the 2014 SEN Code of Practice which emphasises the importance of professionals working in partnership with parents and listening to their hopes and aspirations. While some literature about the experiences of parents of children with SEN starting school in the UK does exist (e.g. Russell, 2005), this research could now be considered out of date because of the huge changes that have taken place within the SEN system over the past few years. To date, I have not been able to find research relating to UK parents' experiences since the Code of Practice was implemented and this represents a gap in our understanding of how parents experience transition to mainstream primary school.

My research aims to answer the following broad research question:

**How do parents in the UK context experience the process of their child with an EHCP starting school?**

Why should this research take place?

As outlined above, there is a robust body of research evidence that demonstrates that beginning school is an important life stage for children, and a significant event in family life. There is also evidence to demonstrate that parents of children with additional needs have different and more complex experiences, in comparison with other parents. At present, there is very little research about this experience within the UK educational context, and my literature review indicates that none has been collated or published since the 2014 Code of Practice overhauled the SEN assessment and transition process. My proposed research would be an important first step in gathering information about parents' experiences in this context. It is hoped that by answering these research questions, the following contributions to professional practice could be made:

Highlighting individual, lived experiences within a context that has not been explored before, and in which there is a gap in research knowledge.

Enabling parents to have a voice about their experiences of this important life event.

Exploring the extent to which parents' experiences of this event in this context are similar to the published research data in other cultural and administrative contexts, and critiquing any important similarities or differences.

Use of this data to place parent's voiced experiences within existing theoretical contexts; with consideration of how such theoretical contexts enrich the data, and how the data might enhance or challenge existing theory about starting school.

Helping educational psychologists to understand the experiences of the parents they work with, and how it might be understood within existing psychological and systemic theoretical frameworks. Using this information to develop professional knowledge, training and practice, especially around how educational psychologists work and communicate with parents when their child begins school.

- **Provide an outline of the methodology for the proposed research, including proposed method of data collection, tasks assigned to participants of the research and the proposed method and duration of data analysis. If the proposed research makes use of pre-established and generally accepted techniques, please make this clear. (Do not exceed 500 words)**

This research is exploratory, seeking to give voice to parents of children with additional needs. It is qualitative and sits within an phenomenological framework exploring individuals' experiences and the meanings attached to these. It does not aspire to be objective, but acknowledges the pre-conceptions of the researcher and the participant in influencing what is told and how this is interpreted.

I have chosen to use Interpretative Phenomenological Analysis (IPA) as my research methodology and my method of data collection and data analysis will be congruent with IPA methodologies. Qualitative data will be gathered through semi-structured interviews, which are the most common form of data analysis used in IPA (Flowers and Larkin, 2011). I believe that a face-to-face meeting is the most reliable and respectful way to elicit this type of personal story. An interview schedule with some pre-determined questions will be constructed. However, as this is a semi-structured interview and aims to respond to the participant, this will not be strictly adhered to, with questions being adapted to remain appropriate and engaging for the interviewee.

I intend to carry out one pilot interview, to practise my interview technique and questions, and will gain feedback about this from the participant. In particular, this will develop my skills in asking questions appropriate to an IPA research methodology, such as ensuring questions are non-assumptive.

Once recruited, participants will be required to take part as follows:

- Reading (or otherwise accessing) the participant research information form and consenting to take part in the research and for their de-identified data to be stored securely for the duration of the research.

- A one-off semi-structured interview. During this time participants will answer questions about their experiences. It is envisaged that this interview will last about an hour. The interview will take place in a private place to ensure confidentiality. In order to minimise risk to both researcher and participant, this will be in the family room at PARC (a resource centre in the local area). If it is not possible for a parent to attend this venue, an alternative safe, private venue will be sought, such as an office at their child's school.

The interviews will be audio recorded. This data will be held in line with the requirements of the Data Protection Act (1998). Data will be de-identified and stored on a secure computer for the duration of the research. It will then be deleted. I will fully transcribe each interview before the data is analysed.

The data will be analysed according to best practice in IPA research. While this is not prescriptive, and depends on the nature and quality of the data, I intend to draw on the following techniques:

- I will fully transcribe interviews, helping me to gain an initial understanding of their content
- Line by line reading and re-reading will further immerse me in the data-collection
- Then descriptive (*what happened*), linguistic (*how is language used?*) and conceptual (*what might this mean for the participant*?) comments by the participant will be noted and exploratory comments related to these recorded.
- Emergent themes will be developed from each participant's data. These reflect both themes that are present across the data, and also the researcher's interpretation of these. From this, clusters of themes will be formed.
- This process will take place sequentially, one participant at a time.
- Finally, I will look for patterns across cases. This will allow an exploration of both the uniqueness of each case, but also qualities shared by each piece of datum. Super-ordinate themes will be illustrated visually, with reference to how these are present (or not) for each of the participants.

I intend to use the data analysis software MAX-QDA to analyse this data. However, I will also have hard copies of the transcripts available for ease of recording and cross-comparison.

## PARTICIPANT DETAILS

- **Provide an explanation detailing how you will identify, approach and recruit the participants for the proposed research, including clarification on sample size and location. Please provide justification for the exclusion/inclusion criteria for this study (i.e. who will be allowed to / not allowed to participate) and explain briefly, in lay terms, why this criteria is in place. (Do not exceed 500 words)**

This is a small-scale, in-depth, exploratory study. I intend to interview one participant in the pilot interview, and a further five participants for the main research. My choice of methodology (IPA) means that it is important that participants have had the same experience and that this is experience being studied. Homogeneity of research sample in IPA relates to homogeneity of experience, other individual differences within the sample are acceptable. All participants will be parents of a child with an EHCP who is currently in reception at a mainstream primary school. My inclusion and exclusion criteria have been developed to allow for a sufficiently homogeneous sample, while still being practical in terms of recruiting participants.

Inclusion criteria:

*Parents of a child who has an Education, Health and Care Plan (EHCP) issued before they started school.* This is so that the process of transition in the context of the 2014 SEN Code of Practice can be explored, and the EHCP serves as a proxy indicator that the child has complex SEN, requiring a significant level of support.

*The child must have started school in September 2018, on a full or part-time basis and should be attending at the time of the interview.* This ensures that the child has had sufficient time in school for parents to have experienced the transition process and their child's first few months in school (the starting school process)

*The child is in their second term of their reception year in a mainstream, maintained primary school.* This research will be carried out between February-March 2018.

*Parents live within the same Local Authority area (this is both for practical reasons and to ensure the homogeneity of the sample).* This means that this research is placed within a particular geographical and administrative context.

Parents will not be eligible to participate if they:

*Have a child with SEN who does not have an EHCP in place.*

*Have a child at a special school, in an independent school or who is home-schooled.* This is because these are very different education contexts, with different systems in place. This would affect the group homogeneity.

*Have a child with an EHCP who has just started school in a different year group.* This research focusses on a child's first year in school.

*Live outside the pre-designated Local Authority area.*

I do not intend to recruit parents through schools, because, as this needs to be done through school staff members and it might bias the sample towards those who have had a positive experience. I intend to recruit parents through a local voluntary organisation which supports parents of children with special needs. I have had an initial meeting about this, and the organisation is happy to help, following ethical approval. They are also able to provide a safe and private venue for interviews to take place. My request for participants will go out in their e-newsletter and will be shared on their social media platforms. Parents will be invited to make direct telephone or email contact with me to get more information, before deciding to take part.

- **Will the participants be from any of the following groups?*(Tick as appropriate)***

☐ Students or staff of the Trust or the University.
☒ Adults (over the age of 18 years with mental capacity to give consent to participate in the research).
☐ Children or legal minors (anyone under the age of 16 years)[1]
☐ Adults who are unconscious, severely ill or have a terminal illness.
☐ Adults who may lose mental capacity to consent during the course of the research.
☐ Adults in emergency situations.
☐ Adults[2] with mental illness - particularly those detained under the Mental Health Act (1983 & 2007).
☐ Participants who may lack capacity to consent to participate in the research under the research requirements of the Mental Capacity Act (2005).
☐ Prisoners, where ethical approval may be required from the National Offender Management Service (NOMS).
☐ Young Offenders, where ethical approval may be required from the National Offender Management Service (NOMS).
☐ Healthy volunteers (in high risk intervention studies).
☐ Participants who may be considered to have a pre-existing and potentially dependent[3] relationship with the investigator (e.g. those in care homes, students, colleagues, service-users, patients).

☐ Other vulnerable groups (see Question 6).
☐ Adults who are in custody, custodial care, or for whom a court has assumed responsibility.
☐ Participants who are members of the Armed Forces.

[1] *If the proposed research involves children or adults who meet the Police Act (1997) definition of vulnerability[3], any researchers who will have contact with participants must have current Disclosure and Barring Service (DBS) clearance.*

[2] *'Adults with a learning or physical disability, a physical or mental illness, or a reduction in physical or mental capacity, and living in a care home or home for people with learning difficulties or receiving care in their own home, or receiving hospital or social care services.' (Police Act, 1997)*

[3] *Proposed research involving participants with whom the investigator or researcher(s) shares a dependent or unequal relationships (e.g. teacher/student, clinical therapist/service-user) may compromise the ability to give informed consent which is free from any form of pressure (real or implied) arising from this relationship. TREC recommends that, wherever practicable, investigators choose participants with whom they have no dependent relationship. Following due scrutiny, if the investigator is confident that the research involving participants in dependent relationships is vital and defensible, TREC will require additional information setting out the case and detailing how risks inherent in the dependent relationship will be managed. TREC will also need to be reassured that refusal to participate will not result in any discrimination or penalty.*

- **Will the study involve participants who are vulnerable? YES** ☐ **NO** ☒

For the purposes of research, 'vulnerable' participants may be adults whose ability to protect their own interests are impaired or reduced in comparison to that of the broader population. Vulnerability may arise from the participant's personal characteristics (e.g. mental or physical impairment) or from their social environment, context and/or disadvantage (e.g. socio-economic mobility, educational attainment, resources, substance dependence, displacement or homelessness). Where prospective participants are at high risk of consenting under duress, or as a result of manipulation or coercion, they must also be considered as vulnerable.

Adults lacking mental capacity to consent to participate in research and children are automatically presumed to be vulnerable. Studies involving adults (over the age of 16) who lack mental capacity to consent in research must be submitted to a REC approved for that purpose.

**6.1. If YES, what special arrangements are in place to protect vulnerable participants' interests?**

If **YES**, the research activity proposed will require a DBS check. *(NOTE: information concerning activities which require DBS checks can be found via https://www.gov.uk/government/publications/dbs-check-eligible-positions-guidance)*

I have an enhanced, clear DBS check and am on the DBS update service. This is necessary when visiting PARC and schools. Both schools and PARC will be encouraged to take a copy of my DBS check (or use their update service) and professional registration information.

- **Do you propose to make any form of payment or incentive available to participants of the research? YES** ☐ **NO** ☒

  If **YES**, please provide details taking into account that any payment or incentive should be representative of reasonable remuneration for participation and may not be of a value that could be coercive or exerting undue influence on potential participants' decision to take part in the research. Wherever possible, remuneration in a monetary form should be avoided and substituted with vouchers, coupons or equivalent. Any payment made to research participants may have benefit or HMRC implications and participants should be alerted to this in the participant information sheet as they may wish to choose to decline payment.

- **What special arrangements are in place for eliciting informed consent from participants who may not adequately understand verbal explanations or written information provided in English; where participants have special communication needs; where participants have limited literacy; or where children are involved in the research? (Do not exceed 200 words)**

Participants will be provided with the information form and consent forms prior to the interview date, so that they can take time to read the form, or ask an assistant to read this with them. I have spoken to the organisation through which I hope to recruit participants and they have offered to make a family worker available to support participants in accessing information, if needed.

I will also offer to go through the information form on the day of the interview and will give participants the opportunity to answer any questions.

Where participants have special communication needs, these will be adapted for, where possible, with arrangements made prior to the interview date (e.g. sign language interpretor, translator). Participants will be asked if they have communication support requirements when the interview is being arranged.

## RISK ASSESSMENT AND RISK MANAGEMENT

- **Does the proposed research involve any of the following?** ***(Tick as appropriate)***

☐ use of a questionnaire, self-completion survey or data-collection instrument (attach copy)
☐ use of emails or the internet as a means of data collection
☐ use of written or computerised tests
☒ interviews (attach interview questions)
☐ diaries (attach diary record form)
☐ participant observation
☐ participant observation (in a non-public place) without their knowledge / covert research
☒ audio-recording interviewees or events
☐ video-recording interviewees or events
☐ access to personal and/or sensitive data (i.e. student, patient, client or service-user data) without the participant's informed consent for use of these data for research purposes
☐ administration of any questions, tasks, investigations, procedures or stimuli which may be experienced by participants as physically or mentally painful, stressful or unpleasant during or after the research process
☐ performance of any acts which might diminish the self-esteem of participants or cause them to experience discomfiture, regret or any other adverse emotional or psychological reaction
☐ investigation of participants involved in illegal or illicit activities (e.g. use of illegal drugs)
☐ procedures that involve the deception of participants
☐ administration of any substance or agent
☐ use of non-treatment of placebo control conditions
☐ participation in a clinical trial
☒ research undertaken at an off-campus location (risk assessment attached)
☐ research overseas (copy of VCG overseas travel approval attached)

**Please see the risk assessment attached.**

- **Does the proposed research involve any specific or anticipated risks (e.g. physical, psychological, social, legal or economic) to participants that are greater than those encountered in everyday life? YES ☐ NO ☒**
  If **YES**, please describe below including details of precautionary measures.

- **Where the procedures involve potential hazards and/or discomfort or distress for participants, please state what previous experience the investigator or researcher(s) have had in conducting this type of research.**

I am an educational psychologist with 12 years experience working with children and families. I have also undertaken a year of additional training in systemic practice and family therapy. In my professional role I have worked extensively with parents of children with EHCP's and complex needs. This has included regularly meeting parents to talk about their child's needs and their own experiences. Therefore, I have experience of eliciting information from parents of children with special needs in a sensitive way, taking into the account the individual needs of each family. From professional experience and reading into this area of research, I have a good knowledge of some of the sensitive areas that might be discussed and I will ensure that I have contact details for professionals and organisations who might be able to offer follow-on support if needed. These are detailed later in this form.

I have received recent safeguarding training.

The participant information sheet clearly states that this research is voluntary and that the participant can withdraw at any time, even after they have been interviewed. I will reiterate this when I meet the participant.

**For more information, please see the attached risk assessment form.**

- **Provide an explanation of any potential benefits to participants. Please ensure this is framed within the overall contribution of the proposed research to knowledge or practice. (Do not exceed 400 words)**
  **NOTE:** Where the proposed research involves students of our University, they should be assured that accepting the offer to participate or choosing to decline will have no impact on their assessments or learning experience. Similarly, it should be made clear to participants who are patients, service-users and/or receiving any form of treatment or medication that they are not invited to participate in the belief that participation in the research will result in some relief or improvement in their condition.

This research aims to give a voice to parents of children with an EHCP who have just started school. My literature search indicates that this will be the first research about this topic undertaken within the context of the new SEN Code of Practice framework. It is hoped that, through exploring parents' lived experiences, practitioners can begin to consider how their practice contributes to making parent's experience of their child's school start positive and how training and practice might be adapted.

The research into parents' experiences of their child with SEN starting school indicates that parents sometimes feel that they are not listened to and that they do not have sufficient opportunity to communicate with professionals. I hope that, albeit in retrospect, this research might be beneficial to participants in giving participants an opportunity to voice their experience, knowing that, through this research, their perspectives will be communicated to professionals. Participants might feel that taking part in this research, which will be communicated to the professional community, might help to change professional practice and help other families.

- **Provide an outline of any measures you have in place in the event of adverse or unexpected outcomes and the potential impact this may have on participants involved in the proposed research. (Do not exceed 300 words)**

Any upset or distress expressed by participants during this research will be addressed as detail in question 11 above.

There are limited possibilities for this research to have adverse outcomes, as it is asking for participants to voice an experience, rather than taking part in experimental research or an intervention. Because I do not work for any organisations that might be spoken about in the research, or have professional involvement with the organisations, school or participants, I have no interest in the data being 'positive' or 'negative' and I hope that I will be able to ensure that the data is analysed and presented fairly and is reflective of the participant's lived experiences.

All participants will be de-identified as far as possible (considering the small sample size). The Local Authority area or organisations will not be named, to assist with anonymity. This should minimise any potential adverse consequences of participants taking part in the research (for example, upsetting members of staff in their child's school).

**Please see attached risk assessment for more information.**

- **Provide an outline of your debriefing, support and feedback protocol for participants involved in the proposed research. This should include, for example, where participants may feel the need to discuss thoughts or feelings brought about following their participation in the research. This may involve referral to an external support or counseling service, where participation in the research has caused specific issues for participants. Where medical aftercare may be necessary, this should include details of the treatment available to participants. Debriefing may involve the disclosure of further information on the aims of the research, the participant's performance and/or the results of the research. (Do not exceed 500 words)**

This is answered in some detail in questions 10 and 11 above.

To summarise:

1. If any issues are raised for participants because of taking part in this research, they will be signposted to an appropriate professional or organisation with whom to discuss this. I have professional experience in this area and the ability to signpost them to the appropriate organisation. I will have telephone numbers and email contact details of relevant organisations available on a printed sheet. These include:
    - The child's school (e.g., the SEN coordinator)

  - Special Needs and Parents (SnaP), Play and Resource Centre (PARC) or another local voluntary organisation.
  - Families in Focus (FiF) or another local parent advocacy group

I might also signpost parents to a more specific source of support such as:

  - An organisation such as the National Autistic Society (NAS) which works with families affected by a particular condition.
  - Their family doctor for medical or psychological onward referral or support

- I will ask participants at the end of the interview if they have any questions or if they would like to know anything else.

I plan to feedback my research to participants. Participants can choose to provide me with an email address so that I can send a summary of my research.

## PARTICIPANT CONSENT AND WITHDRAWAL

- **Have you attached a copy of your participant information sheet (this should be in *plain English*)? Where the research involves non-English speaking participants, please include translated materials. YES** ☒ **NO** ☐

  If **NO**, please indicate what alternative arrangements are in place below:

- **Have you attached a copy of your participant consent form (this should be in *plain English*)? Where the research involves non-English speaking participants, please include translated materials.**
  **YES** ☒ **NO** ☐

  If **NO**, please indicate what alternative arrangements are in place below:

- **The following is a <u>participant information sheet</u> checklist covering the various points that should be included in this document.**

☒ Clear identification of the sponsor for the research, the project title, the Researcher or Principal Investigator and other researchers along with relevant contact details.
☒ Details of what involvement in the proposed research will require (e.g., participation in interviews, completion of questionnaire, audio/video-recording of events), estimated time commitment and any risks involved.
☒ A statement confirming that the research has received formal approval from TREC.
☒ If the sample size is small, advice to participants that this may have implications for confidentiality / anonymity.
☐ A clear statement that where participants are in a dependent relationship with any of the researchers that participation in the research will have no impact on assessment / treatment / service-use or support.
☒ Assurance that involvement in the project is voluntary and that participants are free to withdraw consent at any time, and to withdraw any unprocessed data previously supplied.
☒ Advice as to arrangements to be made to protect confidentiality of data, including that confidentiality of information provided is subject to legal limitations.

☒ A statement that the data generated in the course of the research will be retained in accordance with the University's Data Protection Policy.
☒ Advice that if participants have any concerns about the conduct of the investigator, researcher(s) or any other aspect of this research project, they should contact Simon Carrington, Head of Academic Governance and Quality Assurance (academicquality@tavi-port.nhs.uk)
☒ Confirmation on any limitations in confidentiality where disclosure of imminent harm to self and/or others may occur.

- **The following is a consent form checklist covering the various points that should be included in this document.**

☒ University or Trust letterhead or logo.
☒ Title of the project (with research degree projects this need not necessarily be the title of the thesis) and names of investigators.
☒ Confirmation that the project is research.
☒ Confirmation that involvement in the project is voluntary and that participants are free to withdraw at any time, or to withdraw any unprocessed data previously supplied.
☒ Confirmation of particular requirements of participants, including for example whether interviews are to be audio-/video-recorded, whether anonymised quotes will be used in publications advice of legal limitations to data confidentiality.
☒ If the sample size is small, confirmation that this may have implications for anonymity any other relevant information.
☒ The proposed method of publication or dissemination of the research findings.
☒ Details of any external contractors or partner institutions involved in the research.
☒ Details of any funding bodies or research councils supporting the research.
☒ Confirmation on any limitations in confidentiality where disclosure of imminent harm to self and/or others may occur.

## CONFIDENTIALITY AND ANONYMITY

- **Below is a checklist covering key points relating to the confidentiality and anonymity of participants. Please indicate where relevant to the proposed research.**

☐ Participants will be completely anonymised and their identity will not be known by the investigator or researcher(s) (i.e. the participants are part of an anonymous randomised sample and return responses with no form of personal identification)?
☐ The responses are anonymised or are an anonymised sample (i.e. a permanent process of coding has been carried out whereby direct and indirect identifiers have been removed from data and replaced by a code, with no record retained of how the code relates to the identifiers).
☒ The samples and data are de-identified (i.e. direct and indirect identifiers have been removed and replaced by a code. The investigator or researchers are able to link the code to the original identifiers and isolate the participant to whom the sample or data relates).
☐ Participants have the option of being identified in a publication that will arise from the research.
☒ Participants will be pseudo-anonymised in a publication that will arise from the research. (I.e. the researcher will endeavour to remove or alter details that would identify the participant.)
☒ The proposed research will make use of personal sensitive data.
☐ Participants consent to be identified in the study and subsequent dissemination of research findings and/or publication.

- **Participants must be made aware that the confidentiality of the information they provide is subject to legal limitations in data confidentiality (i.e. the data may be subject to a subpoena, a freedom of information request or mandated reporting by some professions). This only applies to named or de-identified data. If your participants are named or de-identified, please confirm that you will specifically state these limitations.**

**YES** ☒ **NO** ☐

If **NO**, please indicate why this is the case below:

**NOTE: WHERE THE PROPOSED RESEARCH INVOLVES A SMALL SAMPLE OR FOCUS GROUP, PARTICIPANTS SHOULD BE ADVISED THAT THERE WILL BE DISTINCT LIMITATIONS IN THE LEVEL OF ANONYMITY THEY CAN BE AFFORDED.**

## DATA ACCESS, SECURITY AND MANAGEMENT

**Will the Researcher/Principal Investigator be responsible for the security of all data collected in connection with the proposed research? YES** ☒ **NO** ☐

If **NO**, please indicate what alternative arrangements are in place below:

- **In line with the 5th principle of the Data Protection Act (1998), which states that personal data shall not be kept for longer than is necessary for that purpose or those purposes for which it was collected; please state how long data will be retained for.**

☒ 1-2 years ☐ 3-5 years ☐ 6-10 years ☐ 10> years

**NOTE:** Research Councils UK (RCUK) guidance currently states that data should normally be preserved and accessible for 10 years, but for projects of clinical or major social, environmental or heritage importance, for 20 years or longer. (http://www.rcuk.ac.uk/documents/reviews/grc/grcpoldraft.pdf)

- **Below is a checklist which relates to the management, storage and secure destruction of data for the purposes of the proposed research. Please indicate where relevant to your proposed arrangements.**

☒ Research data, codes and all identifying information to be kept in separate locked filing cabinets.

☒ Access to computer files to be available to research team by password only.

☐ Access to computer files to be available to individuals outside the research team by password only (See **23.1**).

☐ Research data will be encrypted and transferred electronically within the European Economic Area (EEA).

☐ Research data will be encrypted and transferred electronically outside of the European Economic Area (EEA). (See **23.2**).

**NOTE:** Transfer of research data via third party commercial file sharing services, such as Google Docs and YouSendIt are not necessarily secure or permanent. These systems may also be located overseas and not covered by UK law. If the system is located outside the European Economic Area (EEA) or territories deemed to have sufficient standards of data protection, transfer may also breach the Data Protection Act (1998).

☐ Use of personal addresses, postcodes, faxes, e-mails or telephone numbers.

☒ Use of personal data in the form of audio or video recordings.

☐ Primary data gathered on encrypted mobile devices (i.e. laptops). **NOTE:** This should be transferred to secure UEL servers at the first opportunity.

☒ All electronic data will undergo secure disposal.

**NOTE**: For hard drives and magnetic storage devices (HDD or SSD), deleting files does not permanently erase the data on most systems, but only deletes the reference to the file. Files can be restored when deleted in this way. Research files must be overwritten to ensure they are completely irretrievable. Software is available for the secure erasing of files from hard drives which meet recognised standards to securely scramble sensitive data. Examples of this software are BC Wipe, Wipe File, DeleteOnClick and Eraser for Windows platforms. Mac users can use the standard ‘secure empty trash’ option; an alternative is Permanent eraser software.

☒ All hardcopy data will undergo secure disposal.

**NOTE:** For shredding research data stored in hardcopy (i.e. paper), adopting DIN 3 ensures files are cut into 2mm strips or confetti like cross-cut particles of 4x40mm. The UK government requires a minimum standard of DIN 4 for its material, which ensures cross cut particles of at least 2x15mm.

- ◦ **Please provide details of individuals outside the research team who will be given password protected access to encrypted data for the proposed research.**

**None**

- ◦ **Please provide details on the regions and territories where research data will be electronically transferred that are external to the European Economic Area (EEA).**

**None**

## OVERSEAS TRAVEL FOR RESEARCH

**Does the proposed research involve travel outside of the UK? YES** ☐ **NO** ☒

- Have you consulted the Foreign and Commonwealth Office website for guidance/travel advice? http://www.fco.gov.uk/en/travel-and-living-abroad/ **YES** ☐ **NO** ☐
- If you are a non-UK national, have you sought travel advice/guidance from the Foreign Office (or equivalent body) of your country? **YES** ☐ **NO** ☐ **NOT APPLICABLE** ☐
- Have you completed the overseas travel approval process and enclosed a copy of the document with this application? (For UEL students and staff only) **YES** ☐ **NO** ☐
  Details on this process are available here http://www.uel.ac.uk/qa/research/fieldwork.htm
- Is the research covered by your University's insurance and indemnity provision? **YES** ☐ **NO** ☐

**NOTE:** Where research is undertaken **by UEL students and staff** at an off-campus location within the UK or overseas, the Risk Assessment policy must be consulted: http://dl-cfs-01.uel.ac.uk/hrservices/documents/hshandbook/risk_assess_policy.pdf.
For UEL students and staff conducting research where UEL is the sponsor, the Dean of School or Director of Service has overall responsibility for risk assessment regarding their health and safety.

- Please evidence how compliance with all local research ethics and research governance requirements have been assessed for the country(ies) in which the research is taking place.

- Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs? **YES** ☐ **NO** ☒

## PUBLICATION AND DISSEMINATION OF RESEARCH FINDINGS

- **How will the results of the research be reported and disseminated? *(Select all that apply)***

☒ Peer reviewed journal
☐ Conference presentation
☐ Internal report
☒ Dissertation/Thesis
☐ Other publication
☒ Written feedback to research participants
☒ Presentation to participants or relevant community groups
☐ Other (Please specify below)

## OTHER ETHICAL ISSUES

- **Are there any other ethical issues that have not been addressed which you would wish to bring to the attention of Tavistock Research Ethics Committee (TREC)?**

**None identified**

## CHECKLIST FOR ATTACHED DOCUMENTS

**Please check that the following documents are attached to your application.**

☐ Letters of approval from ethical approval bodies (where relevant)
☒ Recruitment advertisement
☒ Participant information sheets (including easy-read where relevant)
☒ Consent forms (including easy-read where relevant)
☐ Assent form for children (where relevant)
☒ Evidence of any external approvals needed
☐ Questionnaire
☒ Interview Schedule or topic guide
☒ Risk Assessment (where applicable)
☐ Overseas travel approval (where applicable)

- **Where it is not possible to attach the above materials, please provide an explanation below.**

## Appendix 3: Confirming ethics approval

The Tavistock and Portman NHS
NHS Foundation Trust

Quality Assurance & Enhancement
Directorate of Education & Training
Tavistock Centre
120 Belsize Lane
London
NW3 5BA

Tel: 020 8938 2699
https://tavistockandportman.nhs.uk/

Kathleen Gayton

**By Email**

4th June 2018

Dear Ms Gayton,

**Re: Research Ethics Application**

***Title:*** Exploring parents' experiences when their child with an Education, Health and Care Plan (EHCP) begins mainstream primary school

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

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

I am copying this communication to your supervisor.

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

Yours sincerely,

Best regards,

**Paru Jeram**
Secretary to the Trust Research Degrees Subcommittee
T: 020 938 2699
E: academicquality@tavi-Port.nhs.uk

Cc: Course Lead, Supervisors, Research Tutors

# Appendix 4: Risk assessment

**Kathleen Gayton TREC January 2018**

## Risk Assessment for Research

This document identifies any risk, both physical and psychological, that might arise as a result of undertaking my doctoral research. It examines the likelihood of the risk occurring and makes a plan to manage and mitigate the associated potential outcome.

| Identified Risk | Likelihood | Potential impact or outcome | Risk management plan and mitigating factors |
|---|---|---|---|
| **Travel risks associated with visiting participants:**<br>**Road accident**<br>**Physical assault** | Low | Physical harm to the researcher | • Travel will be well planned and carefully timed.<br>• Aware of options for travel.<br>• Aware of physical environment e.g. travelling on safest rural roads.<br>• Researcher to be aware of health and safely policies of any location travelled e.g. location of exits.<br>• I carry out similar visits on a daily basis in my professional role and have an awareness of the risks and safety measures necessary when travelling to visit clients. |
| **Meeting with unknown participants** | Low risk | Physical injury or psychological harm to researcher | • Interviews to take place in an identified safe location (family meeting room at PARC) or at a pre-organised meeting in the child's school. There will be other people in the building.<br>• Researcher to familiarise themselves with health and safety policies and procedures at interview location.<br>• Participants will be recruited through, and known by, a local organisation supporting families with children with |

| | | | |
|---|---|---|---|
| | | | disabilities.<br>- Room will be private but with glass panels and close to the PARC (or school) office.<br>- Visit location prior to data collection to assess possible risks with the built and physical environment.<br>- Staff at location to be aware of the meeting and estimated finish time etc. so that they can 'check in' if concerned.<br>- Researcher to have two identified contacts (one EP colleague and a family member). Contacts to know location, start and finish time. Researcher to make contact at agreed time. If no contact made, identified contact will phone research venue.<br>- I have extensive experience of meeting with new people in my professional role and of the associated risks and appropriate safely measures. I have also received training in this area. |
| **Discussion about a potentially sensitive topic in an interview has potential to cause distress to the participant.** | Medium | Psychological stress and emotional distress to the participant<br>Anxiety about managing the stress and distress for the researcher | - Offer to cease interview.<br>- Provide a debrief to participants if needed.<br>- Offer to signpost participants to appropriate support organisations (as detailed in the ethics form).<br>- I discuss sensitive and distressing topics with families as part of my professional role and have training and experience in supporting families to talk about these subjects and how to support them in this.<br>- I will seek support about any issues that have caused me anxiety in my research supervision sessions. |
| **Safeguarding** | Low | Immediate, urgent | - Ensure all verbal and written |

| | | | |
|---|---|---|---|
| **concern: Research participant or vulnerable adult or child in danger of harm to self or others** | | or prompt response may be required by safeguarding organisations (e.g. social care services or police) | information about research indicates intended research response to indication of danger of harm to self and others. Please see ethics form and attached information documents.<br>• Ensure professional standards and professional practice requirements are followed.<br>• I have received recent safeguarding training and am aware of the steps to follow should a disclosure be made. |

## Appendix 5: Recruitment advertisement

### <u>Recruitment advertisement:</u>

**Has your child with additional needs recently started primary school?**

Kathleen Gayton is a practising educational psychologist. She is seeking parents to participate in a research study exploring parents' experiences of their disabled child with starting mainstream school. The is part of her research work at the Tavistock Clinic. Kathleen hopes that this research will help to develop the understanding of professionals about this important time in family life.

You will be asked to take part in one-hour long interview, at a time convenient to you. The interview can take place at xxxxxxx Centre.

If you are interested in taking part, please get in touch for more information: xxxxxxxxxxx

If you would like to take part, or find out more please send me an email: xxxxxxxx

## Appendix 6: Informed consent form

The Tavistock and Portman NHS
NHS Foundation Trust

### Consent to Participate in a Research Project

**Research Study Title: Exploring parents' experiences when their child with an Education, Health and Care Plan (EHCP) begins primary school.**

I have read the information sheet relating to the above research in which I have been asked to participate and have been given a copy to keep. The nature and purpose of the research have been explained to me and I have had the opportunity to discuss the details and ask questions about the information. I understand what is being proposed and the research procedure in which I will be involved has been explained to me.

In particular, I understand that:

- I will take part in one audio-recorded interview, lasting no more than an hour.
- Identifying information (such as my name) will not be used in the final research, although the small sample size means that anonymity cannot be completely assured.
- This research might be published in peer-reviewed, professional journals. Anonymised direct quotes might be used.
- Information relating to safeguarding and/or potential harm of children or vulnerable adults will be referred to the appropriate bodies, in line with the researcher's professional obligations.

I understand that my involvement in this study, and the particular data from this research, will remain strictly confidential. Only the researchers involved in this study will have access to the data. It has been explained to me what will happen to the data once the research has been completed.

I freely and fully consent to participate in the study which has been fully explained to me. Having given this consent, I understand that I have the right to withdraw from the programme at any time without disadvantage to myself without being obliged to give any reason.

Participant's name (BLOCK CAPITRALS)

…...........................................................................................................

Participant's signature

…...........................................................................................................

Researcher's name (BLOCK CAPITALS)

…...........................................................................................................

Researcher's Signature

…...........................................................................................................

## Appendix 7: Participant information sheet

The Tavistock and Portman NHS
NHS Foundation Trust

## Participant Information Sheet

**Research Study Title: Exploring parents' experiences when their child with an Education, Health and Care Plan (EHCP) begins school.**

**Researcher:**
Ms Kathleen Gayton, Educational Psychologist
c/o The Tavistock and Portman NHS Foundation Trust,
120 Belsize Lane,
London, NW3 5BA

Contact details:xxxxxxxxxxxxxxxx Tel:xxxxxxxxxxxxxxxxxx

I would like to invite you to participate in this project, which is about your experiences of being the parent of a child with an Education, Health and Care Plan (EHCP) who has recently begun attending primary school. This research has received formal approval from the Tavistock and Portman NHS Trust Research Ethics Committee (TREC).

**Why am I doing this research project?**
I am a practising educational psychologist, running a small independent practice and this project is part of my doctoral research at The Tavistock Clinic (part of the Tavistock and Portman NHS Trust). My doctorate is validated by the University of Essex. I have worked with lots of families with a child with an EHCP and I hope that this project will further our understanding of parents' experiences when their child begins school. It is hoped that this information can be used by professionals to reflect upon and develop their practice when working with parents.

**What will you have to do if you agree to take part?**
You will take part in a single interview, which will last for about an hour. I will ask you questions about your experiences of your child starting primary school. We will arrange a time to meet, which is convenient for you, when your child is at school if this is easiest. The interview can take place at xxxxx Centre.

When I have completed the research project, I will produce a summary, which I am happy to send to you. This research might also be published in professional publications and will be shared with local professional and parent groups. I might use anonymised direct quotes in publications but will not use identifying information.

**Do you have to take part?**
Your participation in this project is completely voluntary at every stage. You will be given a consent form to sign which explains this. You are free to withdraw your consent and stop being part of this study at any stage, even when you have done the interview. You will not be asked about why you have withdrawn your consent and there will be no adverse consequences for withdrawing your consent.

**Will your participation in the project remain confidential?**
Data generated in the course of this research will be retained in accordance with the University of Essex Data Protection Policy and the GDPR. Any identifying information will remain

confidential to myself. Your name, your child's name and any other identifying information (such as school names and where you live) will not be will not be used in the project or disclosed to other parties.

I will audio record the interview with you and the audio recording and typed transcript will by kept securely in a locked cupboard and information will be stored on a secure computer. The typed transcripts will not have any identifying information on them. Only I will be able to identify the interview, from the number I allocate to it. I will erase the audio recording and destroy other information relating to the interview when my research study is submitted.

Your responses to the questions will be used for the purpose of this project only. The exception to this is if you tell me something that raises a safeguarding concern (for example, about the safety of your child), which I am professionally obligated to report to the appropriate safeguarding agencies, or if disclosure of data is required by a Court of Law. Every effort will be made to ensure that you are not identified in the research, but because this is a small-scale and local study, your anonymity cannot be totally guaranteed.

**What are the advantages of taking part?**
You may find the project interesting and might enjoy sharing your experiences about your child's move to primary school. Once the study is finished it could provide information to other parents and to professionals to help improve their practice.

**Are there any disadvantages of taking part?**
It could be that you are not comfortable talking about your child's move to primary school. You can choose to stop taking part at any time, even during or after the interview.

If you feel upset or distressed as a result of the interview, I will use my skills as a qualified psychologist to debrief you and offer further support. I can signpost you to local and national organisations who can offer further support.

If you have any concerns about any aspect of this research project or the conduct of the researcher, please contact Simon Carrington, Head of Academic Governance and Quality Assurance (academicquality@tavi-port.nhs.uk)

If you would like to take part in this project, please get in touch with me:

**email:** xxxxxxxx

**tel:** **xxxxxxxx**

**Appendix 8: Interview Schedule**

## Interview Schedule

This schedule follows the methods outlined in Smith, Flowers and Larkin (2012) *Interpretative Phenomenological Analysis: Theory, methods and research.* The interview will be followed by prompt questions, if needed. However, it is acknowledged that *'the interview will be led, in part; by the participant's concerns'* (p.58) and the questions are open to adaptation.

| Research Question | Interview Question | Prompt questions |
|---|---|---|
| **What are parents' experiences when their child with an Education, Health and Care Plan (EHCP) begins mainstream primary school?** | Can you please tell me a little about your child and where they go to school? | What sorts of things does your child enjoy doing?<br>How would you describe their needs?<br>How would you describe the school?<br>Who are the key people in your child's life, at home and school? |
| | Can you tell me about the process of planning your child's transition to school? | What sorts of things did you needs to consider?<br>How did you decide to send your child to this school?<br>Who was involved in the planning?<br>What helped or hindered the process?<br>Can you please describe the role you and your family had in planning X's transition to school? |
| | Tell me about the role of the EHC needs assessment in planning your child's school start | What did you understand about the needs assessment process?<br>Can you please describe your participation in the EHC needs assessment?<br>How did the needs assessment fit in with the start of schooling?<br>Was the assessment process what you expected? In what way? |
| | What have been the main changes since your child started school? | What have been the changes in and out of school?<br>What have been the main changes for you as a parent?<br>What do you think the main changes are for your child? |
| | Can you describe your child's first day | What happened? Who did you |

| | | |
|---|---|---|
| | at school, from your own perspective? | meet? What happened afterwards? |
| | Was the experience of your child starting school how you expected it to be? | How was it the same?<br>In what was it different?<br>Did anything surprise you about your child starting school? |
| | Tell me about the new people involved with your child now they are in school. | In what ways are they involved?<br>How would you describe the role and contribution of this person?<br>What is your relationship with these people |
| | What words or phrases would you use to describe your experience of your child starting school? | What emotions words might you use to describe the experience?<br>What pother life experiences is it most like? |
| | What would you want professionals to know about your experiences of your child starting school? | What might they be surprised to hear? |
| | Is there anything you would like to have been different about the process? | Is there anything you would want the school to have done differently?<br>What changes would have made the process better? |

## Appendix 9: Example thematic table

## VICKY EMERGENT AND SUPERODINATE THEMES

In this process, patterns begin to be identified between emergent themes leading to super-ordinate themes for that interview.

**Parenting challenges Belonging and Acceptance Traumatised by the system Changing parental identity rejection and isolation.**

| Possible super-ordinate theme | Transcript | |
|---|---|---|
| ***Rejection and Isolation***<br>***Emergent Themes*** | | |
| **'brilliant' placement not able to meet child's needs.** | as brilliant as they are, they weren't entirely able to meet Toby's needs | **6-7** |
| **Rejection by school**<br>**Left without support** | school wouldn't support us, they didn't want to take another child, they were full. So we were left without a school. | **153-154** |
| **Child belongs nowhere.** | it became clear to me that well there's nowhere right for him | **164-165** |
| ***Parenting challenges***<br>***Emergent Themes*** | | |
| **Proactive parents** | So our decision was that we would seek a nursery placement at X as they were more used to SEN children | **20-21** |
| **Parents moving process forward.** | We started the EHCP process, but it was very delayed getting started, we wanted to do it quite quickly | **33-34** |
| **Seeking information and clarification** | we weren't getting feedback with regards to what Toby's actual needs were, what they were putting in place, whether it was working or not. | **41-43** |
| **Identify as proactive parents.** | So he was only there three days a week, and so we were being quite proactive parents | **45-46** |
| **Seeking to support child at home.** | Also wanting to seek their guidance on what we could be doing better at home to support Toby | **47-49** |
| **Lack of knowledge and lack of support** | at that point we still didn't really have an idea because we're Ley people, were not professionals, as to actually what Toby's needs really were | **64-66** |
| **Seeking information** | And we still were sort of trying to get information from the school as to how do you assess him, what methods, what needs does he have | **71-73** |

| | | |
|---|---|---|
| **Inexperienced parent, difficult decisions** | so from, the things that as a lay parent who is inexperienced, the things that you can compare between schools are the concrete things that you can see | **87-89** |
| **Challenge of making the right school choice.** | I also, you know, sort of, was very aware of this common difficulty in really knowing what a school is going to be like. | **105-107** |
| **A journey thwarted** | So that was the route that we were taking. | **145** |
| **Proactive in problem solving.** | so I arranged to have a meeting with EB, and they had said that they couldn't take Toby until the following September. | **167-168** |
| **Finding strength** | fortunately I am a bloody fighter | **180** |
| **Aware of challenges for others** | We actually had a lot of information which so many parents wouldn't have had access to | **190-191** |
| **Systemic challenges for parents** | I knew friends who's children attended EB, in the unit, so I was again picking their brains and also trying to think | **200-201** |
| **Support from other parents** | without trying to sound pompous they were really impressed with how we knew and understood what Toby's need were | **206-207** |
| **Stigma of fighting your corner.** | And to engage with parents who have been portrayed as nightmarish parents, who are never satisfied | **216-217** |
| **Professionals acknowledging challenges.** | they acknowledge the stress and strain of this whole experience on us as parents. | **234-235** |
| **Child's new life, outside home** | 'there's no oh there's another woman in his life' you know. It wasn't like that. | **276-277** |
| **Facilitating what child needs for future.** | I need Toby to attach and connect to other all sorts of people, otherwise what kind of life is he going to have | **279-278** |
| **Freedom and oppression** | We were liberated as a family because we'd been living under that cloud | **295-296** |
| **Feelings of parental inadequacy** | When we couldn't find a school for him, I felt like an inadequate mother...<br>the harder I tried to make things better, it was making things worse. That I couldn't protect him, | **319-321** |
| **Recognising own successes** | So in part it's about the school being really good, but in part it's also that we wouldn't have achieved that had I not been really good as well. | **257-259** |
| **Recognises challenges for other parents.** | I do get how scary this is | **405-406** |
| **Pride in having overcome challenges.** | Pride. In him and I as well actually, I'm so proud of him that transitioned so well, I could never have expected that | **420-421** |
| ***Traumatised by the system.*** | | |

| *Emergent Themes* | | |
|---|---|---|
| **A long and complex story of placement breakdown** | And it, yes like I say he went there, and it deteriorated very, very rapidly, for lots of reasons, which I could elaborate on but would take for ever, and you could obviously ask me further questions if you need more information about that. | **29-33** |
| **Terrible deterioration in process** | and it all went hideously, horribly wrong | **147** |
| **Taken to the brink** | absolutely brought me to my knees that experience was horrendous | **150-151** |
| **Disgusted by the system.** | No because it's disgusting that any of this should happen | **179** |
| **Transition is likened to previous traumas.** | So when Toby was a year old, I was diagnosed with post-natal depression and PTSD, and then we started the process of discovering that actually Toby has additional needs. | **309-311** |
| **Transition viewed as traumatic.** | Absolutely. Yes. Because I think it certainly triggered, or it ticked a box for a lot of the triggers for my PTSD | **315-316** |
| **Transition is an intrusion.** | It felt very intimate intrusive, not quite in a gynaecological sense, but certainly in the sense of…. | **326-327** |
| **Emotional detachment from process** | Intruding into family life, and it's not entirely healthy, I should be talking to you and be in tears but part of what I've had to do it detach the pain and the emotion of it otherwise it would cause me to literally collapse, internally anyway | **329-332** |
| **Anger lives on** | Anger. There is some anger there as well I think, I'm hopefully channelling that into constructive things, but it does make me angry | **422-424** |
| **Dehumanised professionals** | I would like them to remember that they're human beings, before professionals | **439-440** |
| ***Belonging and Acceptance***<br>*Emergent Themes* | | |
| **Importance of school ethos** | actually the ethos of schools is completely different, and its only by being in that school for a period of time that you really get to know that | **99-101** |
| **School ethos** | You can't see it; you can't touch it. | **109** |
| **Kindness is key to belonging.** | I think it's about an attitude. It's about an openness of attitude. It's about a, oh gosh this sound awful, but a sense of kindness. | **111-112** |
| **Recognises importance of school ethos.** | he basically said but it's not about the facilities it's about the people, it's about the attitude and the ethos. Now I can meet Toby's needs. If there are things that Toby | **208-211** |

| | | |
|---|---|---|
| | needs, that we don't yet have in place we can put them in place. | |
| **Staff attitude important for belonging.** | The willingness to want to support this child who on paper is a tricky case | **215-216** |
| **Warmth, engagement**<br>**Welcoming ethos** | They were lovely, they were warm, they were engaged with us, they were interested in asking our opinion, what did he need, what could they do, we can do this, we can do this. | **218-220** |
| **School advocating for child** | And the school pushed for it and said no, he needs it, we have to have it. | **225** |
| **Responsive to needs of parent.** | as far as EB were concerned we could do it at our pace, that they would bend over backwards, that they would facilitate whatever it was that we needed to do | **232-234** |
| **'good people'** | He was a 'good' man as well. He's lovely. | **241** |
| **Relationship building** | Yes, very quickly she was involved. We met with the deputy head as well, was very involved as well. | **244-245** |
| **Warm and welcoming attitude** | And they were very welcoming, they were very warm, they really were, they were brilliant at it. | **249-250** |
| **School engaged and interested.** | They were really wanted to know, tell us, how do we get to know Toby. | **252-253** |
| **Mutual respect** | Yes, they were clearly respectful of us as parents, they clearly were just so interested in Toby, despite the pages, reams of paperwork they had, they wanted to get to know him. | **257-258** |
| **Child feels comfortable.** | I'm sure is part of, or that actually Toby really felt comfortable. | **271-272** |
| **Child forms positive relationships** | The fact that he can attach to somebody else so quickly is hugely reassuring to me, massively | **275-276** |
| **School listens** | The school had clearly listened | **287-288** |
| **Needs are normalised.** | And they talk about autism all the time at that school, it's just something normal, like wearing glasses | **290-292** |
| **Relief of belonging.** | And I just, it felt ok. It just did. I mean I was really emotional when I picked him up | **369-370** |
| **Reassurance from school** | They popped back when I was having my coffee and said, he's alright. | **374-375** |
| **Acceptance matters** | because getting a child into the right school with the right provision and the right support will determine.... what am I saying?.... | **442-444** |

| ***Changing parental identity***<br>***Emergent Themes*** | | |
|---|---|---|
| **Ambiance about 'power struggle'** | Position of some power here. This is horrific, I hate this. And I don't say this with any relish or.... | **175-177** |
| **Gaining in confidence** | had we not had that sort of guidance and support we wouldn't have been in the position of feeling confidence to say what we wanted | **195-197** |
| **Life experience as a key to facilitating child's needs.** | I recognise I'm a really resilient person and that I have a lot of strength and I have a lot of abilities or skills which my life experience had given me which had enabled me to do this | **342-344** |
| **Discovered new strengths as a person.** | Absolutely, it's an opportunity to realise your strength and often through life we don't have, we don't always have reasons to look about ourselves and think wow look what I've achieved. | **349-351** |
| **Pride in strength found.** | Look what I overcame. Look what I've managed to do. | **353** |
| **Process has revealed hidden strengths.** | rather than being broken by something I will be damaged by it, but I will also be made stronger by it, and I think that that's sort of what's happened here | **355-357** |
| **Recognising own success** | So in part it's about the school being really good, but in part it's also that we wouldn't have achieved that had I not been really good as well. | **357-359** |
| **New opportunities from experience** | when Carol the founder at Steppingstone said to me, "when this is all over, I need to retire, I've been needing to retire for about two years, I need to retire" but she said, "I've admired the way you've handled all of this, and when this is all over I'd like you to take over from me so that I can retire" | **380-384** |
| **Professional identity intersects with parenting identity.** | Oh My God. Well this was one of the frustrations for me as sort of a woman, was I worked for sort of almost 20 years before having Toby, I'd worked in therapeutic communications with adolescents with behaviours problems. I'd worked in housing projects with young offenders. You know I'd worked Mental Health and things like that, and I couldn't go back to any of that. How can I do that with sort of the life that we have now? | **386-392** |
| **New professional identikit from the experience** | And it was another way of sort of thinking this whole experience has been for a reason, because actually my role at Steppingstone is | **397-399** |

| | | |
|---|---|---|
| | to support parents through the transition from nursery to school. | |
| **A deeper professional understanding** | but it'd given me an insight into the intricacies of these experiences | **404-405** |
| **Greater professional motivation to 'do a good job'.** | to be able to relay that without sort of burdening them with your experience but to be able to properly identify with them and for them to hopefully feel that you can be trusted that you will do a good job for them. | **406-409** |
| **Recognises complexity of experience on self.** | one of those things that I've always look at my life and thought 'would I change it'? Would I? I don't know. It's a really difficult one because in the moment you go, I'd do anything to change this, I'd give my right arm to not be in this situation but often life does that doesn't it. | **430-434** |

## Appendix 10: Interview transcript excerpt

### LAURA TRANSCRIPT

| Emergent Themes | Line no. | Transcript | Notes |
|---|---|---|---|
| | 1. | **K - Kathleen Gayton** | |
| | 2. | **L – Laura** | |
| | 3. | K – so starting the interview, perhaps you could tell me a little bit about | |
| | 4. | Emily and where she goes to school now? | |
| A special place for her child | 5. | L.- Yeah Emily is now five, she's five in October and she goes to C | He attends the same mainstream school as her siblings, which has an additionally resourced unit.<br>'we' suggests that both he and We are experiencing the education process. Suggest that L is an active participant in the process. |
| | 6. | Academy like her brothers and sisters did. We've got a speech and | |
| | 7. | language unit, which is why I wanted, her, well she's non-verbal and we're | |
| | 8. | doing the speech and language unit. | |
| | 9. | K - And so she goes to the speech and language unit now? | |
| | 10. | L - Yeah. | |
| | 11. | K - How many kids are in the speech and language unit? | |
| | 12. | L - There's space for nine, but they used to be in one classroom together | While she is part of the 'unit', E's education is predominantly in a mainstream class. |
| | 13. | and go into like the mainstream equivalent through the day, but now they're | |
| | 14. | in the mainstream class all day and go out for therapy. | |
| | 15. | K - Ok, so it works a bit differently now, so she's in mainstream reception | |
| | 16. | most of the time. | |
| | 17. | L - Yeah. | |
| | 18. | K - Ok. So what sorts of things does Emily enjoy doing? | |
| Child cannot speak for herself | 19. | L - Messy play, play water. She's terrible with water. Running. That's it. Um. | 'terrible with water, this quickly moves L's thinking on for the things she enjoys, to her neds, or the things that are problematic.<br>E is described as an energetic, playful girl, who enjoys physical activities.<br>It is interesting how quickly L moves from describing what E enjoys to talking about her needs. In wonder if this is the question, she is used |
| | 20. | To look at you wouldn't think that she's has so much difficulty because she's | |
| | 21. | just into everything and always willing to do everything but she just can't | |
| | 22. | communicate. She really finds that a struggle. | |

| | | | |
|---|---|---|---|
| | | | sed to being asked? A focus on a deficit.<br>Medicalised model of describing her child.<br>She has significant speech and langue needs. |
| | 23. | K - OK. And how would you describe Emily's needs? What would you say | |
| | 24. | her main needs are? | |
| Child's voice cannot be heard | 25. | L - She's got, she's still in nappies, she's got no awareness of needing the | Her care needs are high, she needs a lot of support.<br>'obviously' she can't talk. Why is this obvious? |
| | 26. | toilet. She'll hold the mobile but obviously can't talk, but she can understand | |
| | 27. | everything | |
| | 28. | K - Ok so she understands what people are saying but she can't | |
| | 29. | communicate back? | |
| He needs to be known to be heard | 30. | L - Yeah. She tries, she'll try Makaton, she'll try using her hands, or try | Again, she is decreed as needing a lot of care, and people around know her needs.<br>L; s first mention of how important it is to have someone who 'knows' her. That this is central to E having voice and he need being met. |
| | 31. | some words, but yeah it really needs someone to know her to understand | |
| | 32. | what she is talking about, and she's got no awareness of danger at all, | |
| | 33. | people roads, anything. | |
| | 34. | K. Right. And does she have any diagnoses? | |
| | 35. | L - Only Global Delay. | 'only' is interesting. I wonder if L feels that this diagnosis is somehow inadequate in defining her needs, or in some other way not meaningful.<br>I wonder why she uses the word only? this struck me as incongruous with that diagnosis and the needs she describes, but the word only makes more sense to me when she talks about the lack of support offered and 'minimising' she has experienced from education and health professionals- perhaps this is her first indication of that. |
| | 36. | K – Global Delay, ok. And who are the main people in Emily's life at home | |
| | 37. | and at school? | |
| | 38. | L - At home she's got three older brother and sisters. | |
| | 39. | K - Oh wow, a big family then. | |
| | 40. | L - Who are 18, 13 and 11. And then at school, now we've got a 1:1 but she | A big family, with a wide age spread. L is the main carer at home. |
| | 41. | didn't at the start. | |
| | 42. | K - Oh really? | |
| | 43. | L - No. | |
| | 44. | K - So she went in with no 1:1 support. | She started school without one-to-one support, 'proved them wrong' an interesting hint into where Laura sees the power dynamic perhaps. |
| | 45. | L - Yeah, they said she didn't need one. But there's a few incidents that | |

| | | | |
|---|---|---|---|
| A place with appropriate support<br>Support needs a continuous process | 46. | have proved them wrong, that yeah, she's does need one, so there's one in | It sounds like there were some issues at the start, with insufficient support provide. This meant that things didn't always go 'right' at first.<br>'proved them wrong' suggest that L knew in the first place that this was not going to work.<br>L describes a process of needing to 'prove' that E had the needs and needs the support she now has. Suggests a system that looks out for children failing before putting the support in place. |
| | 47. | place after October half term. Probably a couple of weeks into November | |
| | 48. | she started getting one. | |
| | 49. | K - So I guess that's a key person at school? | |
| | 50. | L - Yeah. | |
| | 51. | K - So let's think a bit about the process of planning Emily's transition to | |
| | 52. | school. When you started thinking about… when did you start to become | |
| | 53. | aware that she might need something extra for school? | |
| A surprising journey | 54. | L – Probably when she started at the nursery, she couldn't walk when she | L knew for a while that E had additional needs and would need some extra support in school.<br>L does describe the things that We cannot do again, but this time it is juxtaposed with the surprise people felt when she achieved walking.<br>Suggests agency to surprise and achieve on Emily's part and the idea pf people's expectation for her having the potential to surprise.<br>Evidence of the progress she has made, E's development has surprised people before. |
| | 55. | started nursery and she started walking a month before her third birthday | |
| | 56. | when she started nursery. Literally she was coming in as a non-walker then | |
| | 57. | she just come in walking it surprised everybody. It was then I knew she | |
| | 58. | needed support when she went to school. | |
| | 59. | K - You realised she was later to develop those skills | |
| Planning ahead, anticipating needs | 60. | L - and when it was she was in nursery a year and we starting looking into | L is clear about the provision she wants for her child, and her reasons for wanting this.<br>Interesting constructs her of special neds and mainstream schools and children. The idea of children in the mainstream school as the best models for Es learning. |
| | 61. | thinking, planning ahead. Yeah, she was about, just turned four when we | |
| | 62. | applied for the EHCP. | |
| | 63. | K - And when you were thinking about the plan for going into school, what | |
| | 64. | sort of things did you consider? Thinking about where she was going to go, | |
| | 65. | what you needed for her? | |
| Sense of family belonging. | 66. | L - I didn't want a special needs school, because I think that would have just | 'you're' –interesting use of direct speech. as if she is talking to E when she says this. Alternatively, I wonder if she's using 'you're too suggests general expertise, perhaps a ore reflexive and iterative role- interpreting her choices in a more general context of the roles of mainstream- special ed. |
| | 67. | held her back, because she's, if you met her, she's just full of confidence | |
| | 68. | and she loves learning off other people, so I thought if she does to a special | |
| | 69. | needs school with other children that can't talk you're not going to be able to | |
| | 70. | develop your own speech. So yeah, I wanted a mainstream school for her, | |
| | 71. | and I knew I've got other children that went to C Academy as well and I | |

| | | | |
|---|---|---|---|
| | 72.<br>73. | knew they had the speech unit as well which I thought was the best place for her. | She made an intentional decision for C academy, based on the facilities available and her past experience of the school. |
| | 74. | K - Anything else you thought about when you were thinking about school? | |
| Parent knows child's needs best.<br>Child's voice is limited.<br>Changing people changes the story | 75.<br>76.<br>77.<br>78.<br>79.<br>80. | L – Well I went to speak to the SENCO last year and she said if she started tomorrow, and listed all her difficulties and all this is going to have to be in place, like nappy change, and she can't communicate with people and you won't know what is wrong with her when she's upset and yeah, I listed all the difficulties and then they said they'd work with me up till we started. Then the SENCO left. | Initially a very positive reaction, reassuring and suggestive of professional competence and containment. |
| | 81.<br>82.<br>83. | K - Ok. And how did the SENCO respond to that, when you first when to the mainstream SENCO and kind of said Emily's got these needs, what was her...? | |
| Child 'fits in', not seen as a problem | 84.<br>85. | L - Oh she was fine with it. She was saying we've had other children here with other difficulties, everything I said wasn't a problem at all. | |
| | 86. | K - Oh really? | |
| | 87. | L - They just said that's what they needed to do to suit Emily's needs. | A child-centred response, about doing what's right for E's needs.<br>At this point L appears to feel listened to.<br>The response of the SENCO appears very containing, like they had this in hand and could manage it- to do with having space and belonging, |
| | 88. | K - So would you say that their response was positive? | |
| | 89. | L - Yeah. | |
| | 90. | K - How else would you describe it? | |
| Belonging, the right place<br>Acceptance<br>Containment | 91.<br>92.<br>93. | L - I didn't feel like she would be out of place there, and that they would accept her as she was and that they weren't bothered by anything, nothing phased them at all. | Important for L that E is accepted and that adults are not 'phased' by her, that they have the competence and skills to meet her needs.<br>Talk about not being out of place' and 'wasn't bothered' seems quite a negative or neutral way of framing E's inclusion in the school- there's nothing positive said about it. |
| | 94.<br>95. | K - So they'd accept Emily for who she was? Ok, and how was that for you, when you had that meeting? | |

## Appendix 11: Stage 6 Identifying patterns across themes

**Photo of process of grouping participant superordinate themes into patterns across themes. Each colour text corresponds to an interview participant.**

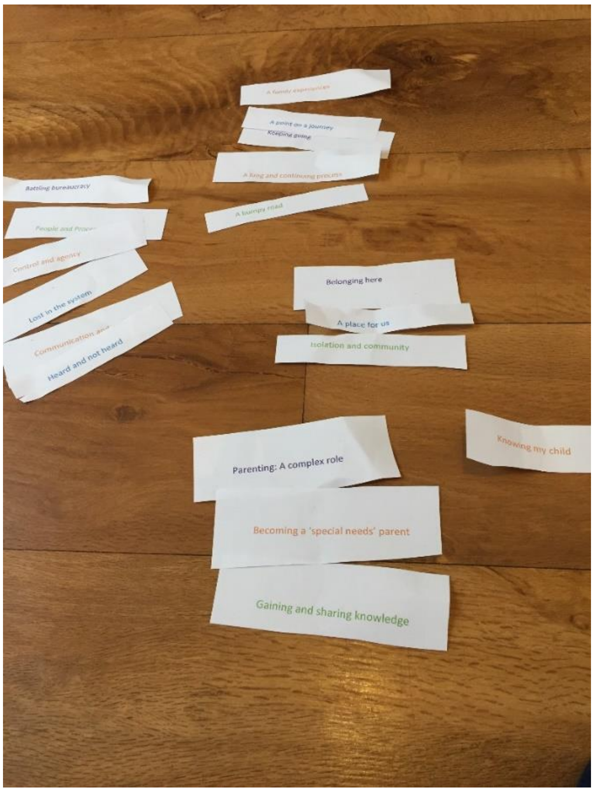
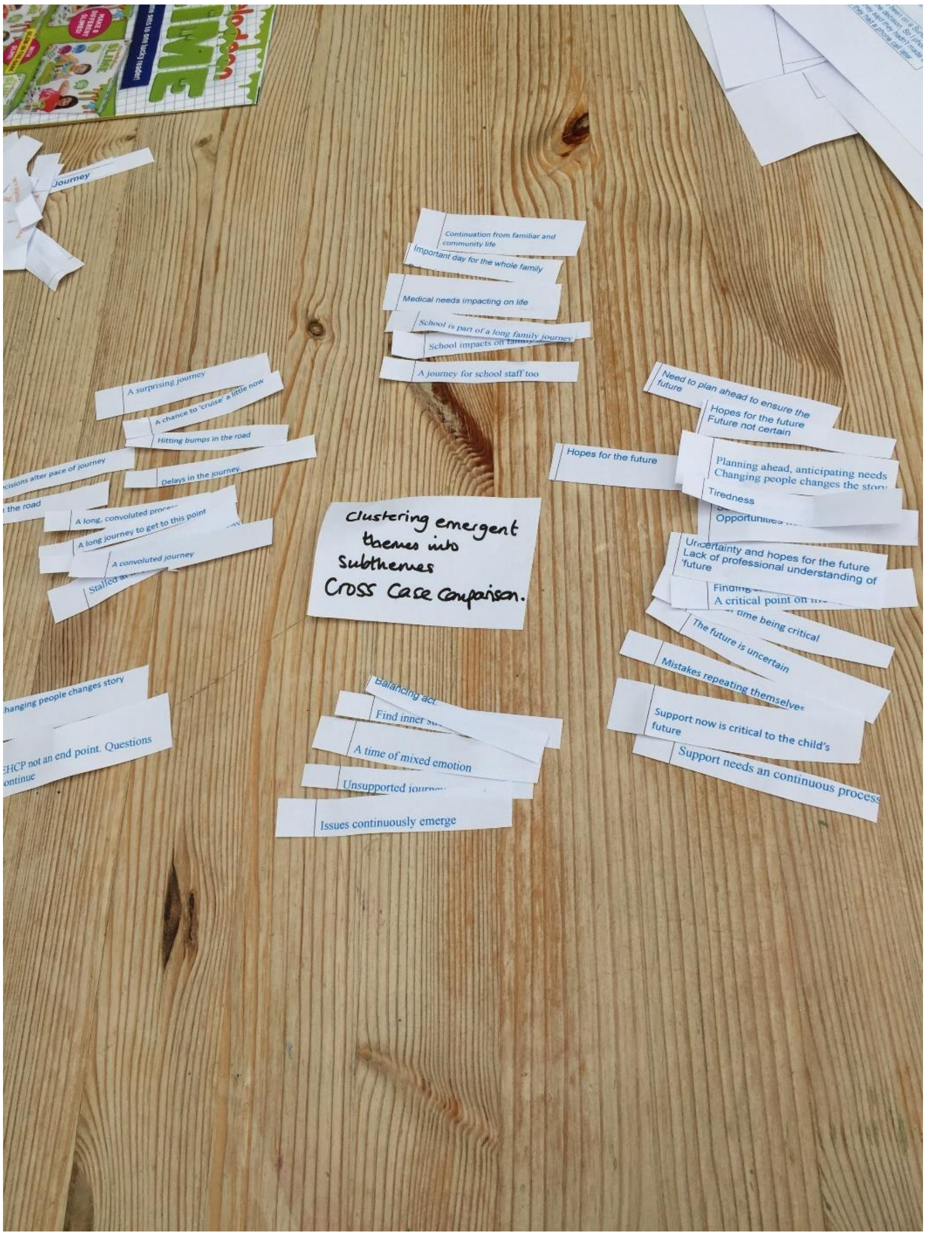


**Table of patterns across themes and corresponding superordinate themes for each participant**

| Pattern Across Themes | Participants | | | | | |
|---|---|---|---|---|---|---|
| | | **Sarah** | **Laura** | **Lisa** | **Vicky** | **Paulina** |
| | **Transition as a life stage process** | A step on a long journey | An important point | Bumpy road | | A long and continuing journey<br>A family experience |
| | **'The System'** | Battling bureaucracy | Lost in the system.<br>Hear my voice | People and processes | Traumatised by the system | Communication and preparation |
| | **Change and growth** | Parenting: A complex role | | Gaining and sharing knowledge<br>Parent and advocate | Parenting challenges<br>Changing parental identity | Being a 'special needs' parent<br>Power and agency |
| | **Belonging and rejection** | A place for us | A place for us | Isolation and community | Belonging and acceptance<br>Rejection and isolation | Knowing my child |

**Organising overarching themes into subthemes: cross-case comparisons (Sarah and Paulina)**



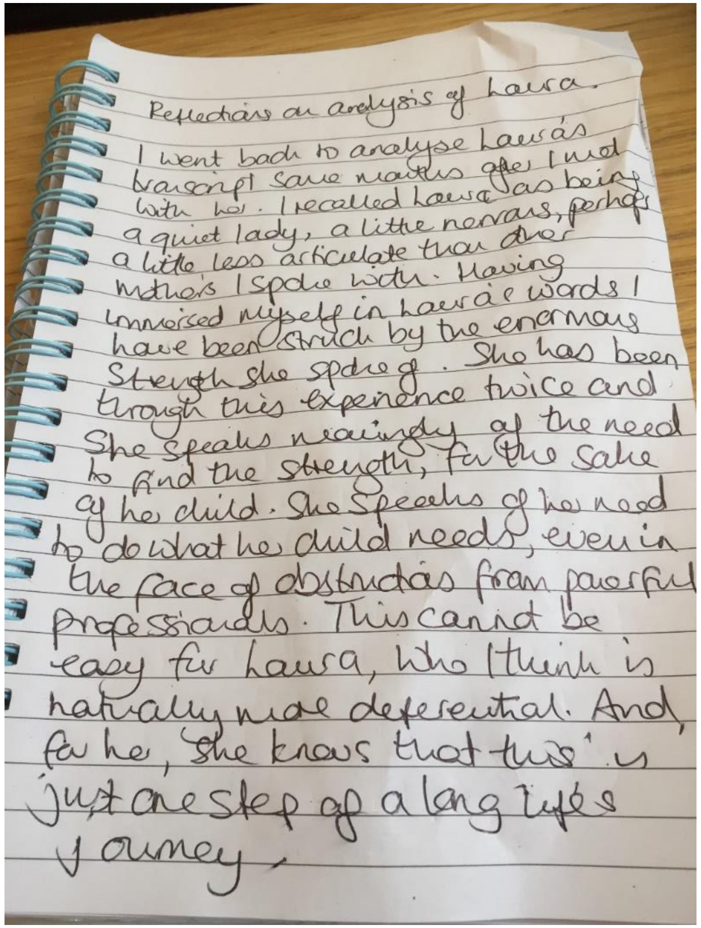
Clustering emergent themes into subthemes to identify patterns across cases.

| | Subthemes | | | | | |
|---|---|---|---|---|---|---|
| **Overarching Themes** | | | | | | |
| | **Transition as a life stage process** | A bumpy journey | A family life stage | Now impacts on later | An uncertain future | |
| | **'The System'** | Systemic failings | Challenge and trauma | Unheard voices | Power and agency | Faceless bureaucracy |
| | **Conceptualisations of self** | Identity as an 'SEN' parent | Solidarity | As a woman and worker | Strength and vulnerability | |

| | | | | | | |
|---|---|---|---|---|---|---|
| | **Belonging and rejection** | Belonging to a place | Forming relationships | Rejection and isolation | | |

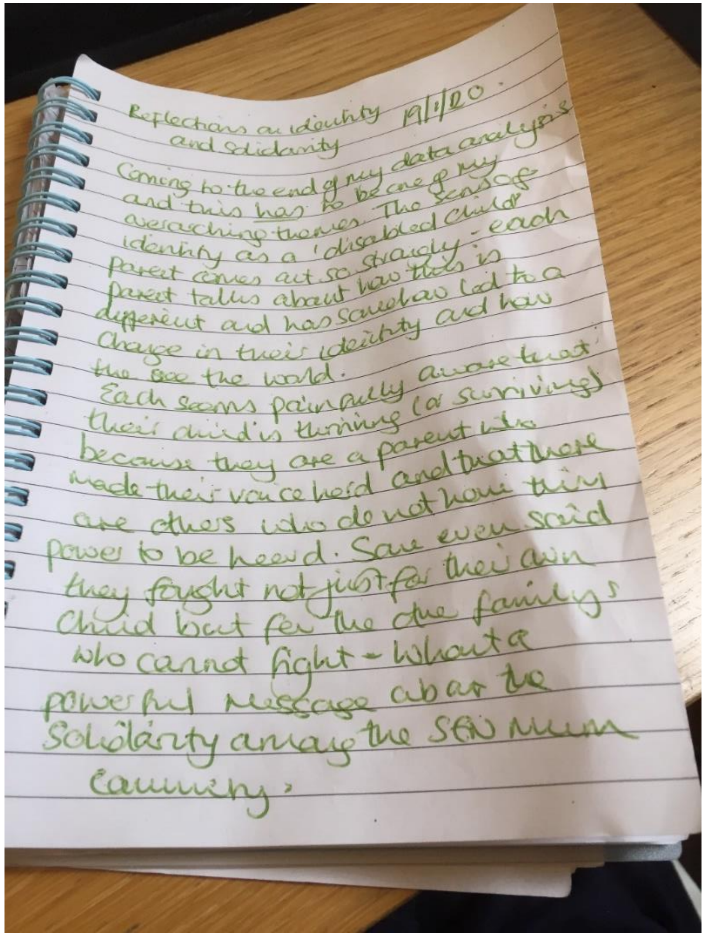
Clustered emergent themes in patterns across cases (used to organise patterns across cases into subheadings)

## Appendix 12: Reflective Diary excerpts



Reflections on analysis of Laura.

I went back to analyse Laura's transcript some months after I met with her. I recalled Laura as being a quiet lady, a little nervous, perhaps a little less articulate than other mothers I spoke with. Having immersed myself in Laura's words I have been struck by the enormous strength she spoke of. She has been through this experience twice and She speaks movingly of the need to find the strength, for the sake of her child. She speaks of her need to do what her child needs, even in the face of obstructions from powerful professionals. This cannot be easy for Laura, who I think is naturally more deferential. And, for her, she knows that this is just one step of a long life's journey.



Reflections on identity and solidarity 19/1/20.

Coming to the end of my data analysis and this has to be one of my overarching themes. The sense of identity as a 'disabled child' parent comes out so strongly - each parent talks about how this has led to a different and has somehow change in their identity and how they see the world.

Each seems painfully aware that their child is thriving (or surviving) because they are a parent who made their voice heard and that there are others who do not have this power to be heard. Some even said they fought not just for their own child but for the other family's who cannot fight - what a powerful message about the solidarity among the SEN Mum community.