

**WHAT DO FAMILY NARRATIVES REVEAL ABOUT PARENTAL PERCEPTIONS OF SOCIETAL
ATTITUDES TOWARDS AUTISM AND HOW DOES THIS IMPACT UPON FAMILY
FUNCTIONING?**

by

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Abstract

Relatively little is understood about the lived experiences of parents who have a child with a dual diagnosis of autism and learning difficulties (autism and LD). Understanding these experiences is important, as parents are pivotal in influencing the quality of life and longer-term outcomes for their children. One dimension of parental experiences, where there is a gap in UK research, is societal attitudes towards autism. A qualitative study was conducted with Interpretative Phenomenological Analysis (IPA) to explore the experience of eight parents of children with autism and LD and other co-occurring conditions, living in Southeast England. Semi-structured interviews were used with parents to collect data at two different points in time. In the first interview, parent narratives were captured about their daily experiences and individual stories were co-constructed. In the second interview, parental perceptions of attitudes towards autism were explored.

This study used a conceptual framework, which drew upon the Bio-ecological systems theory, this situated the parent/child dyad in their world to understand the societal impacts on their experiences. A drawing of the conceptual framework was used as a visual tool in both interviews, enabling parents to visualise their interactions. From this, parents decided which individuals or organisations, for example grandparents, they wished to explore in relation to their experiences of attitudes. Parents gave examples of how unsupportive and supportive attitudes presented in these contexts.

The findings provide insights into the unique experiences of parents in this group.

Unsupportive attitudes were identified as having a significant effect on family life, which

often compounded parents feelings of loss for their expected child. Attitudes were often subtle or hidden. Parents particularly highlighted how grandparents' attitudes were related to social expectations. Notwithstanding these challenges, parents also conveyed their experiences of supportive attitudes, these contribute towards a positive model of attitudes. Implications for practice include the need for professionals to better understand autism and how unsupportive attitudes impact upon families, and for providers of autism training programmes to find ways of engaging grandparents.

DEDICATION

This thesis is dedicated to Charlie, my shining star.

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CHAPTER 1: INTRODUCTION TO THE THESIS

1.1 Background to research

This study arises from my own interest in the perspectives of families of children with autism, but also from my parenting position, as a mother to fraternal twin boys. One of my twins, Charlie, has a dual diagnosis of autism and learning difficulties. Charlie's diagnosis took me on an unexpected journey in a pursuit of knowledge and better understanding of autism.

In these early days, I was desperate to learn more about autism and I began enrolling on parent training courses, including the NAS Early-Bird course and Hanen More Than Words. Parent training courses were helpful, but I was left with many unanswered questions, and I wanted to learn more. By chance, another parent informed me of the autism courses at the University of Birmingham. I initially embarked on the PG certificate in autism and then continued to the MEd in autism children.

I became curious to understand how other parents of children with similar profiles to my own coped. This was the motivation for my MEd final year dissertation study, which explored how four mothers of children with autism coped and considered what constitutes good parental support. Findings from this study indicated parent coping was finely balanced. Two families from this study, felt that they had no alternative than to move their child into residential care. This was a last resort option. This was a small study and it left unresolved questions. Why were the outcomes so different? Why did some parents of children with similar autism profiles

seem to cope, whilst others reached a tipping point unable to continue to have their child living at home? Whilst my motivations to study autism were initially for personal reasons, my interests developed into a broader aspiration to improve societal understandings of autism, with the aim of enhancing the quality of life and outcomes for other autistic individuals and their families.

1.2 Rationale for terminology

There is a lack of consensus across the autism community about preferred language for referring to individuals with autism (Kenny et al. 2016). My own preference is to simply use the term autism, although I am acutely aware that there are other preferences, for example 'on the autism spectrum' or autism spectrum disorder (ASD) (Kenny et al. 2016). My decision to use the term 'autism' reflects my view of respecting autism as a difference and avoiding deficit loaded language such as 'disorder'. I believe the 'disorder' word is unhelpful to parents and other family members, as it contributes to a way of thinking where autism is framed in the negative, albeit perhaps sometimes unconsciously. This is not to underplay the individual difficulties and challenges for the child with autism and their family. In this study, some of the parents referred to their children as having ASD, this is their choice, which is reflected in some of the parent quotations used.

I mainly refer to children with autism, this also includes babies and teenagers. I also occasionally refer to children with other special educational needs, for other diagnoses without autism. I use the terms neurotypical or typical when referring to children or adults without autism. I also refer to parents and occasionally carers. Some parents identified as both. The focus of this study is upon parents of children with a dual diagnosis of autism and

learning difficulties. This terminology is my preference, although I use learning difficulties or learning disability interchangeably. As the phraseology is a rather unwieldy for the reader, I have chosen to use the shortened acronym autism and LD.

My preference is to use person-first language, not the condition or disability. For example, a child with autism or autism and LD or a parent of a child with autism or autism and LD.

Occasionally to help with the flow of writing I use the condition-first terminology 'autistic child' or 'parents of autistic children'. I am aware that many within the autism community, particularly autistic adults, dislike person-first language and would rather others use the terms 'autistic' or 'Asperger syndrome' (AS) (Kenny et al. 2016). My struggle with this language is partly personal, I never warmed to the idea of talking about my son as 'autistic'. If he had been able to communicate his preference, I would have naturally respected this. However, in the continuing absence of knowing his wishes, I prefer to view 'autism' as being part of him, rather than dominating my view of his identity. The other issue is that the condition-first terminology is a challenge for communicating learning difficulties. It is difficult to imagine saying that the child 'is learning difficulties'. Some parents talk about their child as being '*learning disabled*'. However, as stated above, I prefer child with autism and learning difficulties (autism and LD).

Some children with autism and LD will have significant verbal communication difficulties. In this case, my preference is to use the term limited or no spoken language. I prefer this to saying they are non-verbal, as this term suggests that children can either speak fluently or not at all. There is no clear delineation, and some children may develop spoken language

much later. Non-verbal might also infer children have no other augmentative systems to communicate their needs (Prizant and Fields-Meyer, 2015).

Some authors have chosen to define autism through the functioning labels, *high (HF)* and *low functioning (LF)* or mild or severe autism (Gray, 2002a; Broady, Stoyles and Morse, 2015). '*LF autism*' has become synonymous with children who have little or no spoken language (Kenny et al. 2016). I have tried to avoid using these terms as they are thought of as '*misleading*' and '*disrespectful*' (Prizant and Fields-Meyer, 2015, p.221). Moreover, according to Kenny et al. (2016) these terms have never been included in the autism diagnostic manual. Rather, the diagnostic manual DSM-V stipulates a diagnosis of autism needs to be specified, with or without an intellectual impairment (APA, 2013). Thus, I felt it was right to differentiate between those with autism with and without additional LD. Whilst I will use HF and LF when referring to an author's work, I will use my preferred term autism or autism and LD respectively, throughout my own narrative and interpretation of the work of others. For a further in-depth discussion around the specific issues of terminology of autism and LD, see literature review (section 3.2.1)

1.3 Rationale for this research

Whilst this PhD research was conceived from the findings of my MEd study, it was also informed and further developed from identifying gaps in the literature. I begin this section by explaining these gaps, which provides the rationale for research exploring the lived experiences of parents of children with autism and LD, with a specific focus on societal attitudes to autism.

1.3.1 Exploring the experience of parents of children with autism and learning difficulties

The existing autism literature is heavily focused around the perspectives of parents, particularly mothers (see for example, Preece, 2014). This has created a tension within the autism community, that research has privileged the views of non-autistics, who sit outside of the world of autism. Thus, research is the wrong way around, from the outside in (Williams, 1996). That said, much less is known about the specific experiences of parents of children with autism and LD. This remains a largely under-researched and forgotten group of parents (see for example, Bessette Gorlin et al. 2016; Fairthorne et al. 2014). Yet there are thought to be some distinct challenges for this group, versus the wider population of autism parents (Jordan, 2001). In the next section, I will seek to delineate some of these issues, which underlines the need for this research.

For parents of children with autism and LD, their child's communication difficulties are likely to be greater than within the general autism population (Jordan, 2001), particularly for those whose children have limited or no spoken language (Norrelgen et al. 2015). Thus, in these circumstances parents have a special role as advocates for their children, particularly when their children are unable to tell their own stories (Hacking, 2009b).

A significant challenge for parents of children with significant communication difficulties is recognising when their child is unwell or in pain (Bessette Gorlin et al. 2012). From my own experience, I recall others not realising my son had broken his arm, as he did not appear to be in pain. In these circumstances, parents rely on close observation and instinct to know when their child is unwell.

Children without spoken language are often supported to use visual communication systems. For example, the Picture Exchange Communication System (PECS) can enable children to build simple sentences, to make choices and express comments (Bondy and Frost, 2002). Makaton or objects of reference are alternative methods for supporting communication (Jordan, 2001). Parents often become more aware of the effect of their own spoken language upon their child and learn to adjust and reduce this (Jordan, 2001). To help support their child's communication, parents therefore often spend considerable time attending parent workshops and training (Jordan, 2001). These opportunities and the associated time commitment, have reflected my own experience of parenting a child with autism and LD.

Another issue that may be more pronounced for parents of children with autism and LD is child safety (Lutz, Patterson and Klein, 2012). The tendency of children to abscond means parents need to focus on the security of their homes, locking their doors and windows (Bessette Gorlin et al. 2012, Fairthorne et al. 2014). Some have recounted stories of their child escaping, when visitors have forgotten to close the gate (Fairthorne et al. 2014). This example highlights how despite parents' efforts to be vigilant; they are dependent upon the compliance of others.

Another issue is the care needs of children with autism and LD. Studies confirm how extra support is needed for feeding, dressing and toileting (Lutz Patterson and Klein, 2012) and how independent toileting can be a particular challenge for children with autism and LD

(Bessette Gorlin et al. 2016; Cicero and Pfadt, 2002). This functional skill may be delayed or with other physical difficulties full independence is never achieved (Jordan, 2001).

The difficulties for parents of children with autism and LD are likely to continue into the teenage years and beyond. Versus typical children, children with autism and LD are likely to struggle to fill their leisure time and be dependent upon their parents for entertainment (Jordan, 2001). Consequently, at a time when parents generally find they have more freedom, the opposite happens for parents of children with autism and LD.

A stressor for parents of children with autism is their concern for their children's future (DePape and Lindsay, 2014). However, the stage of life when children leave home, described by DePape and Lindsay (2014, p.570), as '*launching children*', is likely to be different for parents of children with autism and LD. This group are likely to be more closely dependent on parents to support their needs and as adults they are unlikely to live fully independently (Jordan, 2001), with support expected to be lifelong (IASSIDD, 2013). Thus, parents often worry about the long-term care of their children (Bessette Gorlin et al. 2016) including burdening siblings (Lutz, Patterson and Klein, 2012).

In the next section I briefly outline how autism can also present with other co-occurring conditions.

1.3.1.1 Other co-occurring conditions

Alongside learning difficulties, autism sometimes presents with other co-occurring conditions, including, Epilepsy, Chromosome Disorders, Cerebral Palsy, Down syndrome, Hearing Impairment, Tuberous Sclerosis (TS), Tourette's syndrome, attention deficit hyperactivity disorder (ADHD) and anxiety disorders, such as obsessive-compulsive disorder (OCD), Social Anxiety Disorder and Selective Mutism (Ghaziuddin, 2005). The combination of autism and other co-occurring conditions is likely to magnify the issues outlined above and add further complexities to parents lives (Jordan, 2011). Moreover, some autism approaches, which tend to favour visual methods, may be unsuitable for children with a visual impairment (Jordan, 2011).

1.3.2 Exploring societal attitudes towards autism

The UK report, a Future Made Together (Pellicano, 2014) confirms little autism research funding has focused upon how societal issues impact upon people with autism and their families. Parents have particularly emphasised the failure of others to understand the realities of their lives. Findings from a recent report, The Autism Dividend (Lemmi, Knapp and Ragan, 2017) also identify a significant gap in our understanding of autism stigma and discrimination and make recommendations for more UK based research. Recent reviews of the relevant literature also confirm this gap, highlighting most autism stigma studies have been conducted outside the UK (Mazumder, Thompson-Hodgetts, 2019). Notable exceptions include a recent UK study examining the experiences of African immigrant mothers (Munroe, Hammond and Cole, 2016) and a UK study exploring the stigmatization of having an autism diagnosis (Russell and Norwich, 2012). Furthermore, most studies have either

focused specifically upon parents of children with autism without LD (Gray, 2002a; Broady, Stoyles and Morse, 2015) or have covered a range of autism diagnoses (Kinnear et al. 2016).

Most studies have also focused solely upon exploring negative attitudes (Gray, 1993; Kinnear et al. 2015; Broady, Stoyles and Morse, 2015), rather than considering a range of attitudes. One exception is a recent study of the Aboriginal and Torres Strait islander communities in Australia, where both negative and inclusive attitudes were explored (Lilley, Sedgwick and Pellicano, 2020). This study also highlights the importance of understanding the experience of specific and forgotten groups within the autism community.

1.4 Overall aims

In view of the gaps in the literature and issues discussed above, there are two main aims of this research. First, through a broad lens the aim is to explore the lived experiences of parents of children with autism and LD. This approach is intended to avoid limiting the scope of what parents may want to share, thus respecting their experiences as unique and individual. The second aim is more focused and seeks to understand parent perceptions of societal attitudes to autism, both unsupportive and inclusive attitudes. The reason for focusing on this aspect is borne from identifying a gap in the literature, but also from my personal experience of encountering unsupportive attitudes about my son. Reflecting upon the times I have encountered both judgmental looks and verbal criticisms about my son's behaviour from members of the public, has instilled me with a passion and motivation to explore the experiences of other parents and to expose this societal issue. However, in the light of balance, I also wish to explore parents experience of supportive attitudes.

1.5 Research questions

Main research question:

What do family narratives reveal about parental perceptions of societal attitudes towards autism and how does this impact upon family functioning?

Subsidiary research questions:

RQ1. What is unique about the everyday lived experiences of parents whose children have a dual diagnosis of autism and learning difficulties?

RQ2. What do parents feel their relationships/interactions with individuals and service providers reveal about societal attitudes to autism?

RQ3. How do attitudes towards autism help or hinder parents' ability to care for their children?

RQ4. What are parents' perceptions of attitudes towards autism from wider society?

1.6 Conceptual framework

This research project is underpinned by a conceptual framework. This drew upon

Bronfenbrenner's Bio-ecological systems theory (Bronfenbrenner, 2005). This theory was adapted to situate the parent/child dyad in their world and understand societal impacts on their experiences. Although the framework was not intended to be directly applied to parents of children with autism, there is evidence in the literature to show how this has been used in other related studies (McLinden et al. 2016). I return to discuss this in more detail in chapter 2.

1.7 Methodology

This qualitative study explores the lived experiences' of eight parents of children with autism and LD and other co-occurring conditions, living in Southeast England. This research used a phenomenological methodology with Interpretative Phenomenological Analysis (IPA). The parental voice was central to the research. As advocates for their children, parents were positioned as experts on their experience. Also from an '*insider*' position, my researcher role was to interpret this experience.

This study was conducted using semi-structured interviews with two points of data collection. In the first interview, a broad lens was used to explore parents lived- experience. This was an active process involving myself working with the parents to reflect upon their experience. This approach enabled parents' specific perspectives to be fully acknowledged and revealed how parents felt there was little understanding of their realities. Individual stories were co-constructed. As part of this process, member checking was used with parents to ensure that the words in the stories truly reflected their individual experiences. This was part of ensuring the credibility and trustworthiness of the data (for more details see section 4.2). The individual stories became research products. In the second interview, through a narrower lens, I examined parental perceptions of societal attitudes towards autism, both unsupportive and inclusive attitudes.

1.8 Organisation of thesis

This thesis is presented in six chapters as follows:

Chapter 1- provides an introduction.

Chapter 2- provides an overview of the conceptual framework, which sits at the heart and is referred to throughout this thesis. The framework was developed through an iterative process, which involved making connections between Bronfenbrenner's Bio-ecological systems theory (2005) with the literature. This chapter also explains how the framework was used to structure the literature review and influenced the evolution of the research questions.

Chapter 3- is the literature review, which was conducted in two phases. This chapter begins by outlining the methods used for searching the literature. The literature review is written in sections which correspond with the structure of the conceptual framework. The chapter ends with a summary of the gaps in the literature which helped to inform the research questions.

Chapter 4- explains the methodology. This chapter begins with an overview of my philosophical position and choice of methods. This is followed by an exploration of my own positionality in relation to this research, which I return to throughout the chapter. Next, I provide the rationale for using Interpretative Phenomenological Analysis (IPA), as well as exploring the limitations. I then outline the ethical considerations and approval. Afterwards, I outline the choice of sample and procedure for collecting the data. Finally, I explain how the data was analysed, and the process of working out the themes.

Chapter 5- is the findings and discussion. This chapter begins through using the conceptual framework as a lens for understanding the superordinate themes (see fig.1 below). This is used as a structure for the discussion of the findings in relation to the literature. The complexities of this decision are also explained. Key findings and the contribution from the research are outlined.

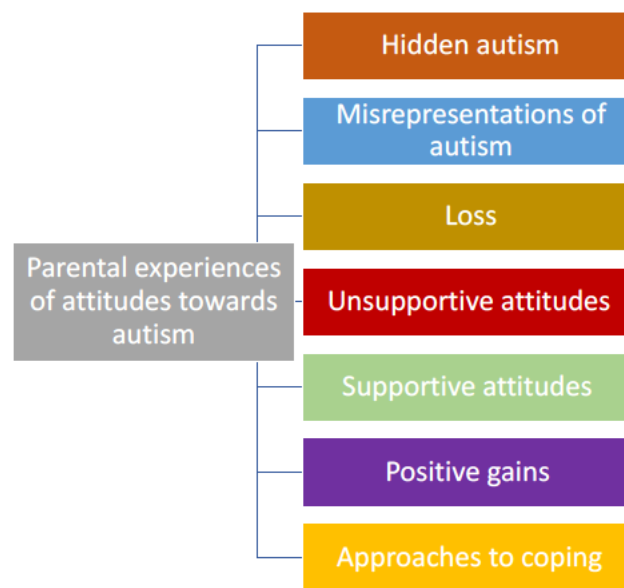


Figure 1: Superordinate themes

Chapter 6- provides an overview of the whole thesis. This begins with a summary of the study and research contribution. The research questions are addressed in this chapter and then the implications, recommendations and contributions of the research are discussed. Finally, the limitations and suggestions for future research are considered. An overview of full structure of the thesis is shown on the next page (see fig. 2).

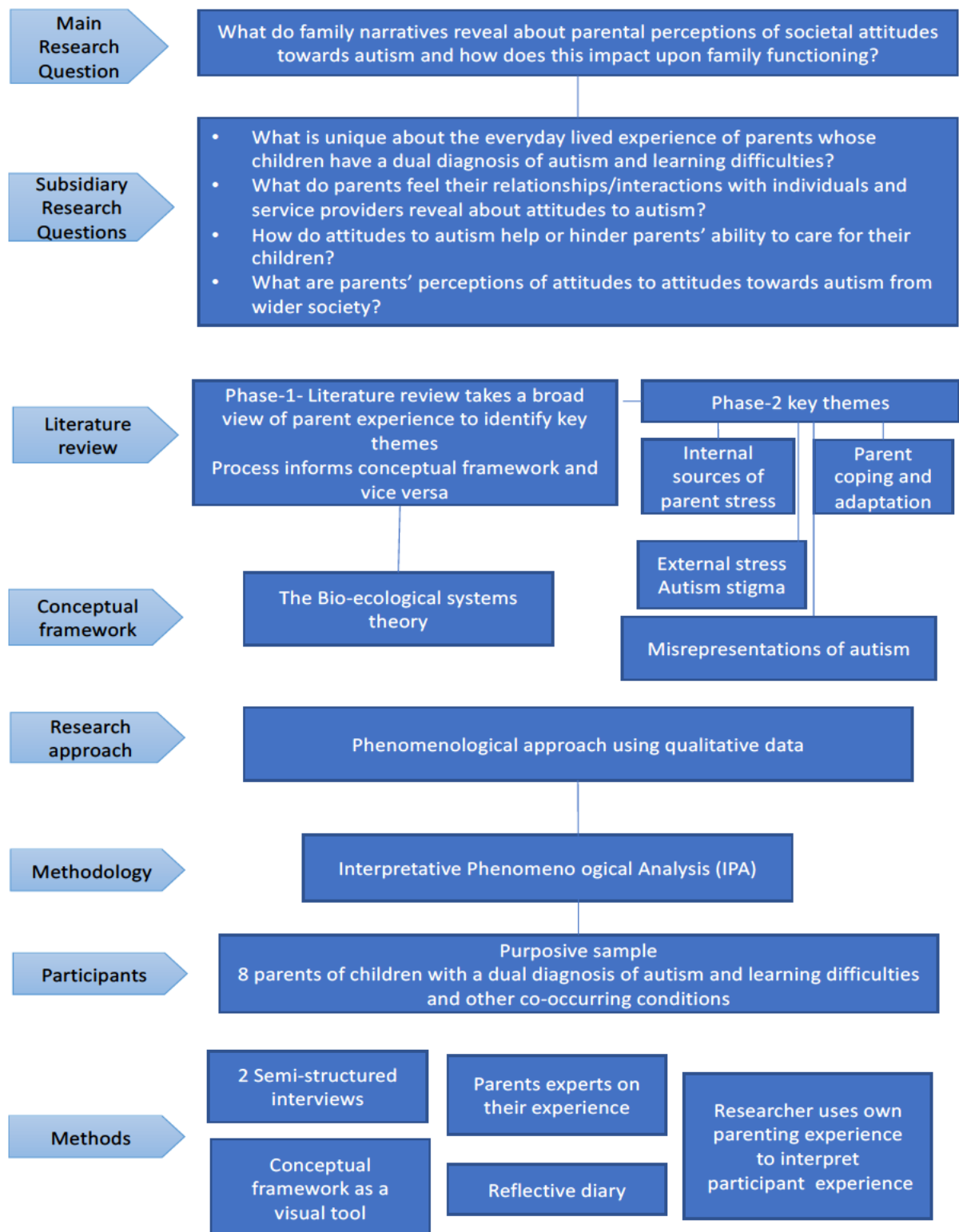


Figure 2: Design frame

2 CHAPTER 2: CONCEPTUAL FRAMEWORK

2.1 Introduction

At the heart of this research project is a conceptual framework, which was developed drawing upon Bronfenbrenner's Bio-ecological systems theory of human development (Bronfenbrenner, 2005). This theory evolved from the original ecological systems theory (Bronfenbrenner, 1979).

In the next sections, I first outline the purpose of the conceptual framework. Second, I summarise the Bio-ecological systems theory (Bronfenbrenner, 2005). Third, I outline the justification for using this theory to develop a conceptual framework for the current study of parental experience. I also draw upon other related studies which have successfully applied this framework. Fourth, I explain how I adapted this framework to produce an autism specific model. This was intended to help structure parent experiences and understand the connections between the quality of relationships, attitudes and family adaptability. Fifth, I consider some of the limitations.

In further sections, I explain how as my own thoughts about the focus of the research project changed over time, the conceptual framework both informed the research questions and enabled a further development of the model. I also explain how the framework was helpful as a lens for organising the literature.

2.2 Purpose of the conceptual framework

In this section I outline the purpose of the conceptual framework. The aim was to develop a conceptual framework for helping to understand the lived experience of parents of children with autism and LD, through the lens of the parent/child dyad. I sought to do this by conceptualising two aspects. The first of these was to identify the relationships between the parent/child dyad with others in their environment and to explore parents' perceptions of the quality of these interactions and attitudes towards autism. Second, I wanted the framework to help conceptualise how parents might adapt their lives to accommodate the needs of their children with autism.

Nicholas et al. (2016) asserts the literature often presents parental experiences in an overly simplistic manner, as either negative or positive, which fails to take account of the subtle complexities. Thus, the aim was to use the conceptual framework as a lens to reflect the complexities and contradictory aspects of this experience (Larson, 1998; Myers, Mackintosh, Goin-Kochel, 2009; Nicholas et al. 2016) and to reflect a wide range of parental perspectives (Preece, 2014). In summary the conceptual framework was intended to sit at the heart of the research informing each stage, from how I organised the material in the literature review to the findings and analysis.

2.3 Bronfenbrenner's Bio-ecological systems theory of human development
Bronfenbrenner's model is concerned with child development. It examines how the interactions between the child and the different aspects of their environment, impact on child development. The Bio-ecological model (Bronfenbrenner, 2005) builds upon the original 'ecological' systems theory (Bronfenbrenner, 1979) which conceptualises a series of concentric circles, described as:

'A set of nested structures, each inside the next, like a set of Russian dolls.'

(Bronfenbrenner, 1979, p.3)

The model begins with the child at the centre of the microsystem, which might be the home or classroom. Taking the microsystem as the home, this system examines how the interactions between the child and their parents impacts upon the child's development. In considering this relationship, Bronfenbrenner proposes:

'If such parties are absent, or play a disruptive rather than supportive role...like a three-legged stool, it is more easily upset if one leg is broken...' (Bronfenbrenner 1979, p.5)

In other words, Bronfenbrenner is saying the quality of parent interactions with the child, will impact upon the child's development. The microsystem also considers how the interactions between the child and any siblings, impact upon their development.

Later, Bronfenbrenner acknowledged that his 'ecological' model was too focused on how the environment affected the developing child. Thus, the '*Bio-Ecological*' model incorporated the active role of the developing child at the centre of the model in shaping their own

development (McLinden et al. 2018). Moreover, he also recognises how the developing child is affected by the personality of closely related others:

‘and containing other persons with distinctive characteristics of temperament, personality and systems of belief.’ (Bronfenbrenner, 2005, p.148)

The model then shifts outwards from the microsystem to the next concentric circles, first the meso and then the exo system (Bronfenbrenner, 1979). In the mesosystem the interactions between the child and other people they are in contact with on a daily or weekly basis are considered. For example, the interactions between the child and their teacher at school and between the child and their peers. The mesosystem also examines the relationship between the parents and the child’s teacher and how these impact upon the child.

The exosystem differs from the micro and meso systems as the child is not present in this environment. However, their development is significantly affected by indirect decisions. For example, the child may be impacted from a parent working long hours or working away from home. Note, both the meso and exo systems remained unchanged in the later *‘Bio-Ecological’* version (Bronfenbrenner, 2005).

In the outer layer, the macrosystem represents the cultural values, political system and how the economy might impact upon the child’s development (Bronfenbrenner, 1979). In his later *‘Bio-Ecological’* version Bronfenbrenner refers to how cultures are embedded in the wider macrosystems, describing this as:

‘a societal blueprint for a particular culture, subculture, or other broader social context.’ (Bronfenbrenner, 2005, p.150)

For example, social class or ethnicity is emphasised as influencing child development (Bronfenbrenner, 2005).

Finally, the notion of time and how this might result in changes to the child and environment, is included in Bronfenbrenner’s *‘Bio-Ecological’* framework through the inclusion of the *‘chronosystem’* (Bronfenbrenner, 2005, p.119). This is reflected through the words *‘throughout the life course’* (Bronfenbrenner, 2005, p.107). See below (fig.3) for Bronfenbrenner’s Bio- ecological systems theory of human development.

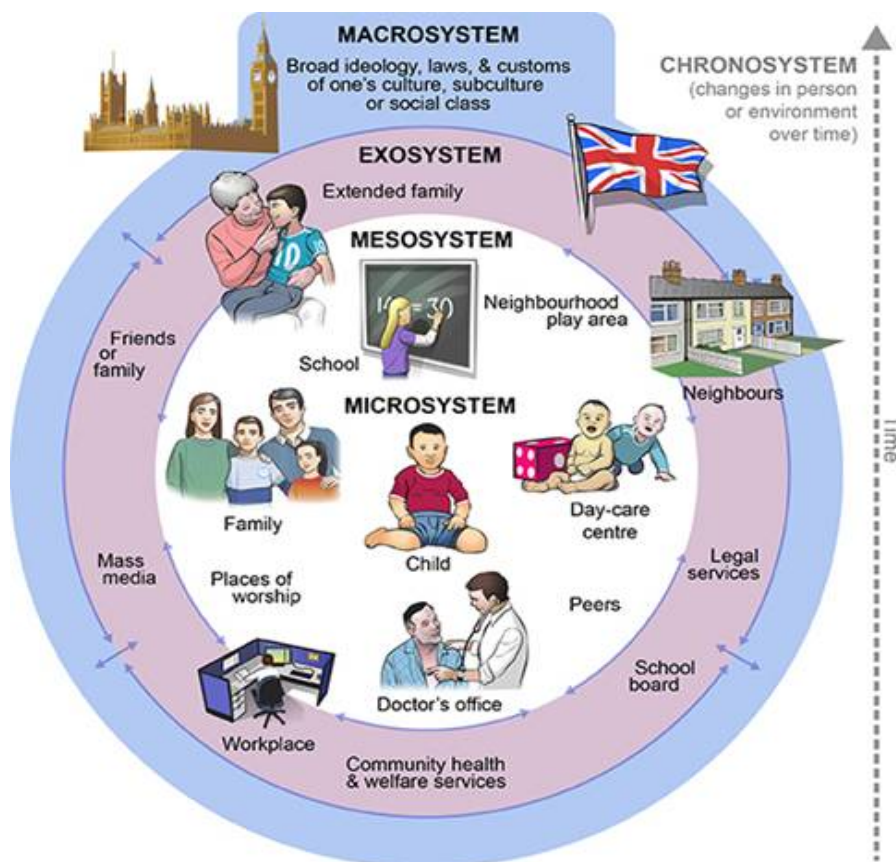


Figure 3: Bronfenbrenner’s Bio-ecological systems theory of human development

In terms of this study of parental experience, the above theoretical framework may not appear, to the reader, to be immediately relevant. After all the framework relates to child development. However, I was drawn to visual presentation of the Bio-ecological systems theory. I could relate to this from my knowledge of parental experience. I could see that the different systems of the framework would be helpful for visualising the different levels of interactions between the parent/child dyad with others. I also identified that the framework would be helpful for visualising where the parent/child were mostly situated, to shed light upon their level of inclusion in society and why? For example, if the parent/child struggled to access the community, they would be mostly situated in the microsystem, which might indicate a risk of social isolation. In the next section, I continue to explain the rationale for using this framework and locate my research in relation to the literature.

2.4 Justification for choice of framework

As mentioned above, I had identified that the framework from the Bio-ecological systems theory would be useful for mapping different levels of parent experience. For example, the microsystem was useful for conceptualising parents experience of living with the child seen in the context of the home. The Bio-ecological systems theory also helps to illustrate how different levels of parent experience do not exist in isolation from one another, but they are overlapping and are interconnected.

The value of drawing on this framework can also be seen through examining the related literature. Bronfenbrenner's framework has been used flexibly across a wide range of educational and disability studies, including autism and vision impairments (Connolly and

Gersch, 2016; Hebron and Bond, 2017; Melvin et al. 2019; Ravindran and Meyers, 2011; McLinden et al. 2016; McLinden et al. 2018; Cullen and Lindsay, 2019; Akbayrak and Douglas, 2021). Moreover, many of these authors have taken Bronfenbrenner's framework and developed this flexibly, using it as a lens for their own research. For example, McLinden et al. (2018) developed the Bioecological Model of Inclusive Early Childhood Development. Whilst, Melvin et al. (2019) created the Kids and Teens at School (KiTeS) framework to explore the issue of children's school attendance. Also, studies have used the framework to explore the experience of both children and their parents (Hebron and Bond, 2017; Connolly and Gersch, 2016; Cullen and Lindsay, 2019). Some studies have concentrated upon specific levels of the framework. For example, Cullen and Lindsay (2019) identified the 'exosystem' as the part of the framework where decisions are made by the SEN system affecting the child's development, but which parents do not have direct influence over.

In summary, this framework have been used across a range of related studies, which adds to the justification for using it in the present study. In the next section I explain how I developed the conceptual framework; this is followed by a consideration of some of the limitations.

2.5 Developing the conceptual framework

In this section I outline how I developed an autism specific conceptual framework through drawing on the Bio-ecological theory systems theory, (see fig.4). However, I begin with outlining some background information.

The path that led me towards considering the suitability of Bronfenbrenner's framework emerged from both reflecting on my own experiences of living with my son with autism and LD and consulting the relevant literature. Early in my search of the literature, a Japanese study, Kimura, Yamazaki and Mochizuki (2010) was particularly influential in introducing me to the idea of a framework for mapping how interactions between different factors might impact upon parent experience. During their analysis, these authors drew a map for each of the participants, to help conceptualise the relationships between the background of the participant, family relationships, social support and severity of disability and how these might impact upon the mothers' decision-making. In capturing this idea, I became interested in the Bio-ecological systems theory. The structure of concentric circles resonated as helpful for conceptualising the interactions between the parent/child dyad with others in their world. Other related studies validated the value of the interactional aspects of the framework, see for example, Melvin et al. (2019) and Connolly and Gersch (2016).

I also re-visited some data from an interview conducted for my MEd with a mother of a child with autism and LD. In this interview, I had explored parent coping strategies and support. In applying this data to the framework, I made further connections. I realised with some adaptations the framework would be useful for helping to understand the experience of

parents of children with autism LD and other co-occurring conditions. I assert that these other diagnoses are likely to alter the child's development and add other complexities to the relationship between the child and the people closest to them. Kimura, Yamazaki and Mochizuki (2010) also offered insights about how external culture may impact upon the lives of parents of children with autism. Through the '*culture or subculture*' aspect of the macrosystem (Bronfenbrenner, 2005, p.149), I began to see how the model would be helpful for conceptualising cultural factors which might influence how well parents adapt to having a child with autism. In the next sections, I conceptualise how I used the different systems from the framework.

2.5.1 Microsystem

I conceptualised that the microsystem would be used to represent the parent/child home environment. This mirrors a related study which also positioned the parent/child dyad in the microsystem (Connolly and Gersch, 2016). Contrastingly, I included all other immediate family members in the microsystem and other added factors related to diagnosis. These included, communication difficulties, toileting/self-care, sensory differences, restricted diet, sleep difficulties and other behaviours that challenge.

2.5.2 Mesosystem

Moving outwards, I used the structure of the mesosystem to conceptualise the interactions between the parent/child dyad with other individuals or service providers occurring on a daily or regular basis, for example interactions with the child's school.

2.5.3 Exosystem

The exosystem was used slightly differently from Bronfenbrenner's theory. This system included a mix of direct and indirect interactions. It was used to situate direct interactions with significant individuals or service providers the parent/child had contact with on a less frequent basis, for example visits from the child's social worker. At the same time, it was used to situate indirect factors, such as decision making about a child's care packages or an application for a specialist school placement. In a similar vein, Cullen and Lindsay (2019) identified the 'exosystem' level of the framework could be used to represent decisions made within the SEN system about the child. This decision making is usually removed from parents at panel meetings behind closed doors, and communicated back to parents, via a social worker or case worker. In the conceptual framework, both direct interactions and indirect decision-making have impacts upon the lives of families of children with autism and LD.

2.5.4 Macrosystem

Bronfenbrenner's theory uses the macrosystem to represent how a country's cultural values through its political system and economy, might impact upon the child's development. By contrast, I used this part of the structure to represent how these factors might impact the experience of parents of children with autism and LD. For example, how policy decisions might impact upon the provision of autism specific services. Moreover, the '*culture or subculture*' aspect of the macrosystem (Bronfenbrenner, 2005, p.149), was helpful for conceptualising how beliefs about autism may permeate the other systems (Ravindran and Myers, 2011) and influence how parents adapt and cope to parenting children with autism and LD.

2.5.5 Chronosystem

Bronfenbrenner's model uses the chronosystem to represent how time is likely to result in changes to the child and the environment. By contrast, I used the chronosystem to represent how parent experience may change over time. This system acknowledges as parents of children with autism and LD become more experienced, they are likely to interact differently with the systems across the framework.

To summarise the conceptual framework drew upon Bronfenbrenner's Bio-ecological model, using the interactional aspects between the parent/child dyad and the different layers of their environment, including cultural aspects of how parents make changes to adapt to autism (see fig.4 below).

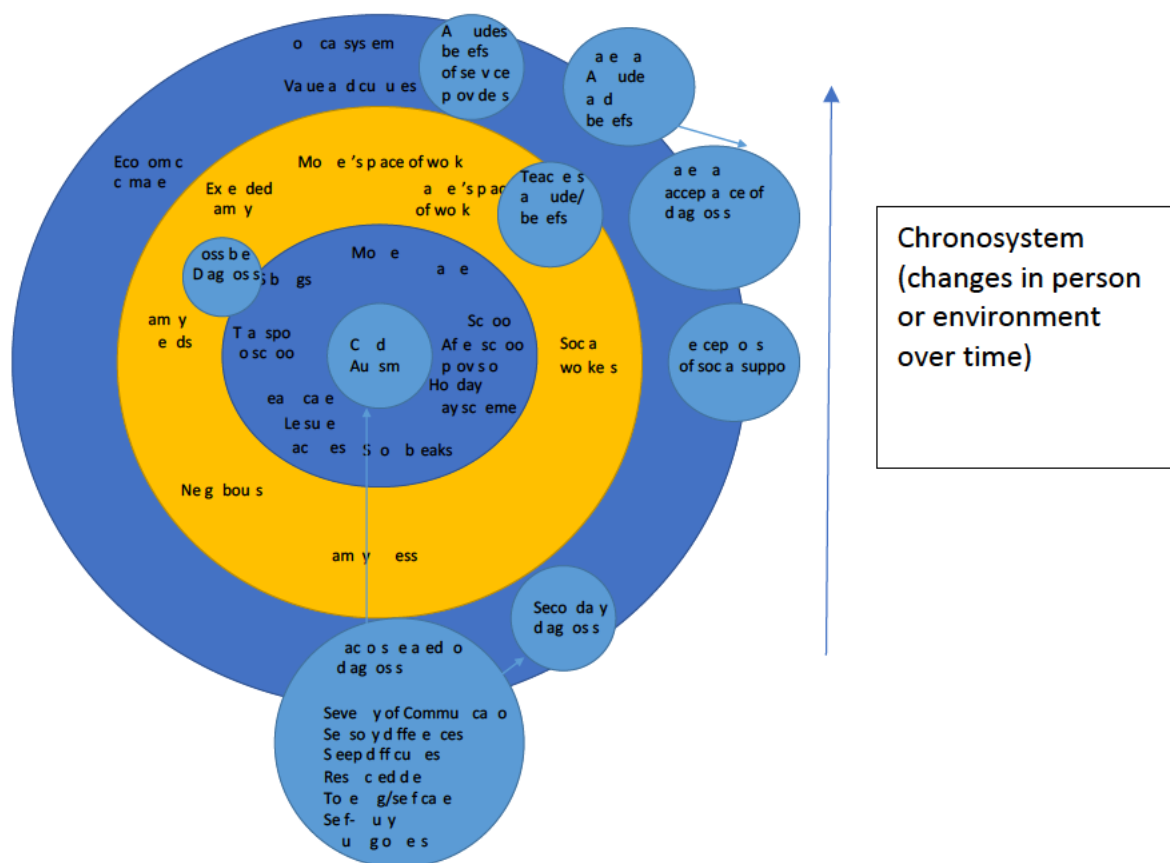


Figure 4: Adapted conceptual framework, autism specific

2.5.6 Limitations of the framework

In this section I highlight the limitations of using Bronfenbrenner's theory for the conceptual framework. I also underline some of the challenges of using these frameworks for organising the literature review for the next chapter. In chapter 5, I also return to discuss these challenges for organising the findings and discussion.

The weaknesses of Bronfenbrenner's theory for use in this study as a conceptual framework mainly relate to the original 'ecological model'. Thus, these were largely addressed by adopting the revised 'Bio-ecological' theory. First, Bronfenbrenner's original ecological

framework did not include a chronosystem. Time was an important element, as I needed the conceptual framework to represent how parents' experiences may change over time, as parents adapt to autism. However, the 'Bio-ecological' theory incorporated the chronosystem into the framework.

Second, the original ecological model did not consider the active role of the child upon their own development (Rosa and Tudge, 2013). This might not appear relevant, but translating this across to parent experience, I needed the conceptual framework to reflect the active role of parents. In other words, parents are likely to actively support their children (see section 25.5). However, Bronfenbrenner (2005) acknowledges his early model was focused more on the effect of the environment on the developing child and therefore incorporated the role of the child in shaping their own development in his later '*Bio-ecological*' model.

Third, is an issue related to how culture was dealt with in the framework. Understanding culture is important as this plays a role in determining how families and children with disabilities live their lives (Ravindran and Myers, 2011). Likewise, cultural aspects were relevant to the present study, as societal culture shapes attitudes towards autism and family culture influences how parents or other relatives view the child with autism and LD. There are different views of how well Bronfenbrenner managed to encompass culture in his framework. Ravindran and Myers (2011, p.313) refer to how '*influences at one level flow naturally into the other levels*'. In other words, these authors contend that the interrelated systems of Bronfenbrenner's framework are sufficient for understanding societal cultures. I agree that wider societal culture can be depicted in the macrosystem (Bronfenbrenner,

2005) as permeating the different levels of the system (Ravindran and Myers, 2011).

However, at the same time, I suggest that parents' specific experience of attitudes towards autism might be better depicted through their daily interactions between the micro and meso systems. Likewise, how they adapt and cope with having a child with autism and LD would be better situated in micro and meso aspect of the framework. Similarly, Velez-Agosto et al. (2017) suggests that the cultural aspects of Bronfenbrenner's framework were misplaced in the macrosystem and that the focus of culture should have been part of the microsystem. However, equally the interrelatedness of the different systems in the framework can not be disregarded.

Finally, I underline some of the challenges of using these frameworks for organising the literature review on parent experience. One issue was each system of the framework was seen as interacting with others, with key themes often overlapping and interrelated. The merging across these different systems was inevitable given the interactional nature of the framework. Therefore, the literature did not fit neatly into the different systems, and I had to make some practical decisions about where to discuss certain sections. For example, the micro and meso systems had some overlapping themes, such as the theme '*child behaviour*' was situated in the microsystem, but overlapped into the mesosystem under the theme of '*Parent experience of autism and stigma*'. Although this made organising the literature messy, it also reflected Bronfenbrenner's evolving view of his framework, that the micro and meso were closely related systems (Bronfenbrenner, 2005). It is also worth noting, that I used the microsystem to organise the literature relating to parent internal stressors.

However, Bronfenbrenner (2005) may well have viewed these as external factors (see section 2.6).

To summarise, even with some of the above limitations I found the conceptual framework, with some adaptation, a useful instrument for approaching this research. This informed every aspect of my work, from how I organised the material in the literature review, shaping the research question, as well as illuminating the findings and analysis.

2.5.7 How the conceptual framework informed the research question
I reflect upon how the research question developed iteratively. As I moved between thinking about the conceptual framework and reviewing the literature, the research question became sharper and more focused. Societal attitudes to autism are one aspect of parents' experience and I began to problematise how attitudes might impact on families of children with autism. I realised whilst the framework was suitable for mapping parent interactions, it might also help more specifically to illuminate parents' perceptions of societal attitudes towards autism, often thought of as stigma. I identified that the framework could help with visualising how the different levels of the systems influence attitudes. I began to consider a cascading effect of attitudes from the macrosystem through to the exosystem and mesosystem. Related studies also confirm the value of the framework for understanding multi-layered influences (McLinden et al. 2016, Coleman, 2013; Rogoff, 2003). Rogoff's (2003, p.45) reflection that Bronfenbrenner was interested in factors that both '*foster and undermine development*', particularly resonated with me. Even though this is in relation to

child development, it is possible to translate this across to using the framework to map and understand how attitudes both help and hinder family functioning.

Accordingly, first the framework was developed to conceptualise the quality of relationships/interactions between the parent/child dyad and others. Second, it was used to explore what this revealed about societal attitudes to autism. Similarly, I explored how the quality of parent/child dyad interactions, represented in the framework by the mesosystem and exosystem could through understanding parents' experiences reveal more about their perceptions of societal attitudes to autism. As the research question evolved to focus on parents' perceptions of societal attitudes to autism, I simplified the framework to use with parents, as part of the data collection, see methodology chapter (section 4.9).

Similarly, Connolly and Gersch (2016) found the framework helped to illustrate parental experience of stigma. Several related studies have also explored the issue of inclusion in education and adopted Bronfenbrenner's framework (McLinden et al. 2018; Hebron and Bond, 2017; Akbayrak and Douglas, 2021; Melvin et al. 2019; Cullen and Lindsey, 2019).

Overall, perceptions of attitudes are significant for parents of children with autism and LD, as this helps to pinpoint how well this group is included or excluded in society. The use of the Bronfenbrenner's theory or adaptations of this, in the above studies adds to the rationale for also using the framework in the present study.

2.5.8 Further development of the conceptual framework

As I progressed with the research and reached the stage of analysing data from the parent interviews, I began to make further connections between the data and the conceptual framework, (see fig.5 below). I propose that when parents recognise a change in their identity or approaches to coping from being the parent of a child with autism, that this in turn may cause a change to the relationships within the Bio-ecological system. For example, parents might decide to relax social expectations. If extended family accept this and do not judge the child or parents, then I suggest that this will contribute to more positive family functioning. Contrastingly, if family members are unsupportive, this can result in potential frictions and parents may feel excluded from family gatherings or in some cases decide to self-exclude themselves.

For example, one of the participants described the grandparents' expectation of the family sitting down for Sunday lunch. However, their son was not able to cope with sitting at the table and he would roam around the house, until one day he broke a cheval mirror. His parents quickly recognised this could have resulted in serious harm to their son. Their overriding priority was to keep their son safe. Thus, from this point onwards the parents decided to refuse to conform with the grandparents' wish of both adults remaining seated for Sunday lunch. The participant explains:

'it was from then on I kicked into mother mode and I kicked into right we're carers, he's disabled and we will never sit down to Sunday lunch again.'

This turning point reduced the frequency of visits and contact with the grandparents. This is conceptualised with the position of grandparents shifting outwards from the model, illustrating a less supportive relationship.

This further development of the conceptual framework for this study, also meshes with the evolution of Bronfenbrenner's theory from *ecology* to *bioecology* (Rosa and Tudge, 2013). To put this another way, Bronfenbrenner's later work recognised the active role of the child in shaping their own development. This maps on to my experience and the literature, albeit in relation to parent experiences. That is, parents are likely to be advocates for their children and seek to inform themselves about autism (Altieri and von Kluge, 2009). Also, parents may actively challenge the services or individuals they interact with, seen in the systems of the framework. Similarly, in the above example the participant was willing to challenge grandparents' social expectations.

Interaction between the three components reveals attitudes to autism which impacts upon family functioning

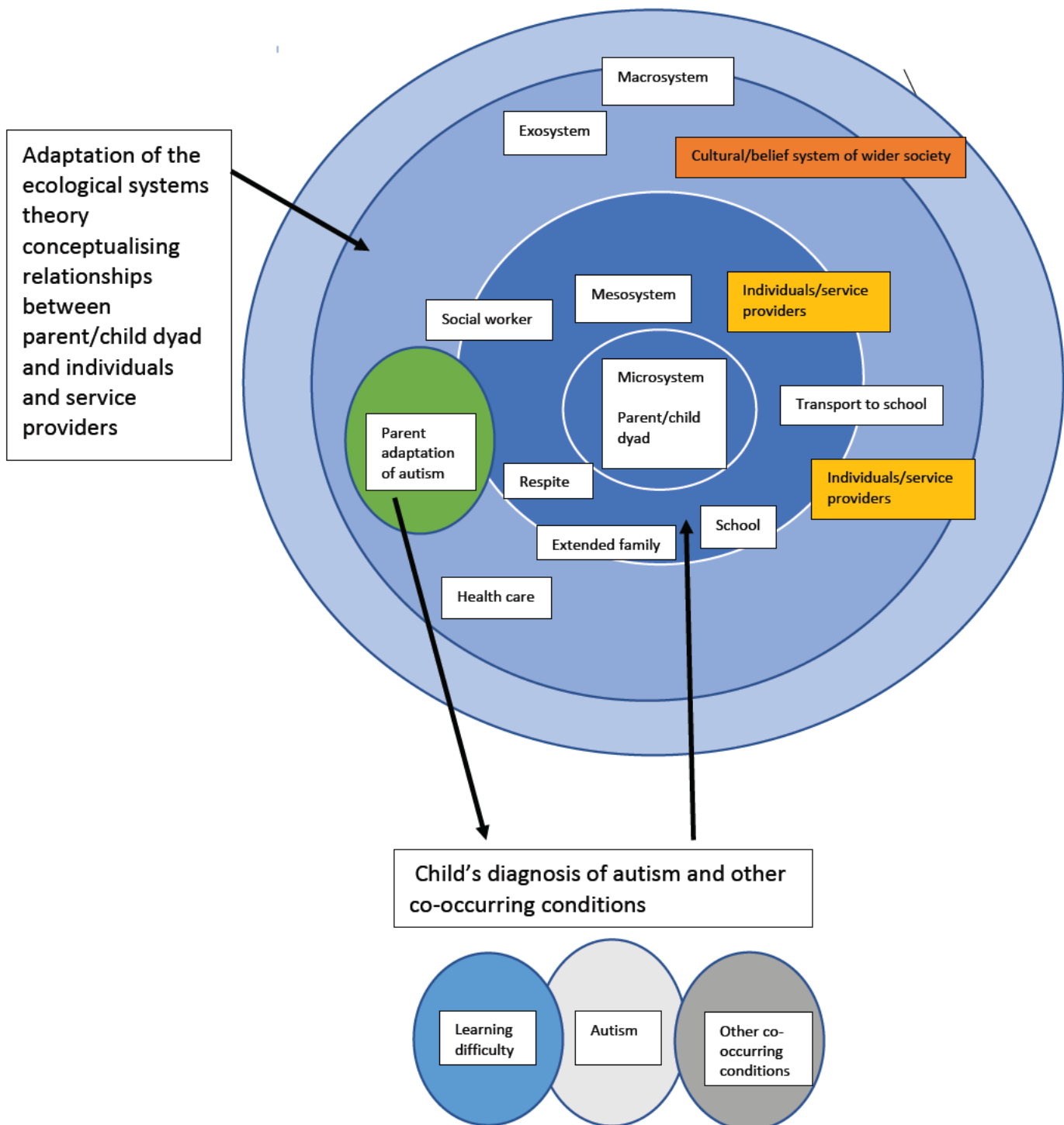


Figure 5: Conceptual framework showing 3 interacting components

2.5.9 Reflection- conceptualising the extent of inclusion for the parent/child dyad
The interactions between the parent/child dyad in the microsystem and the mesosystem helps to reveal the extent of inclusion in their community. In other words, if the parent/child dyad spent most of their time at home, this might not be from choice, but more reflective of an unsupportive or a perceived unsupportive community. However, another explanation for exclusion may be sensory sensitivities, illustrated by drawing on an example from a study which describes one parents' reality:

'My life is very closed...I can't take him to a lot of places because of crowds and noise, so we spend a lot of time at home...' (Myers, Mackintosh and Goin-Kochel, 2009 p.674).

Another reflection circles back to the stressors and challenges parents encounter in the microsystem. Parents may come to terms and make adaptations in their lives to accommodate the needs and differences of children with autism. However, it is clear from the literature that stressors in the form of external judgements/stigma and lack of understanding, represented in the mesosystem, are the most intractable form of stress for parents (Ludlow, Skelly and Rohleder, 2011). In relation to the framework, I conceptualise that coming to terms with the stressors of child behaviour in the microsystem, is perhaps easier than learning to cope with a lack of understanding from others in the mesosystem.

2.6 The conceptual framework as a structure for the literature

The review of the literature was structured around the conceptual framework and organised according to key theme areas, relating to parents' experience (see fig. 6 below). The parts of the framework helped to construct a map of how the literature presents the experiences of parents of children with autism. Below, I outline the organisation of the literature within the framework.

Moving from the general to the specific, I begin with macro and exo systems on the outer concentric circles of the framework, which represent how outside influences impact on societal understandings of autism. In the macrosystem I explore models of disability. This aspect flows into the exosystem, where I explore the debates of how autism has been (mis)represented and how these aspects have influenced societal misconceptions of autism. The literature across these two systems is closely related and overlapping.

I then moved inwards to consider the concentric circles of the meso and micro systems. As both systems help to conceptualise the literature on parent stressors or challenges, it seemed more logical to explore the internal stressors first in the microsystem and then move on to the external stressors in the mesosystem.

The microsystem primarily symbolises the home environment and the interactions between the parent child/dyad at the centre of the framework. This also represents the interactions with immediate family living in the family home. Treating the microsystem as the family home, differs from how it is conceptualised in the Bio-ecological systems theory, but it made

more sense to organise the literature in this way. As, in my view, the parent/child dyad does not exist in a bubble outside of the immediate family. Adopting the distinction made in the literature between sources of internal and external stress for parents (Ludlow, Skelly and Rohleder, 2011), I conceptualised parents' stress or challenges in the microsystem to arise from internal factors, such as the extra care demands from looking after a child with autism and LD. Thus this literature is organised by key themes primarily related to parent stress. Some of these themes are connected and or link to other parts of the conceptual framework. For example, child behaviour and sensory differences are interrelated themes. The microsystem is also used to conceptualise the position of the parent/child dyad in relation to the whole framework. For example, a parent who lives in a fully supportive community may feel able to spend more time with their child outside of the family home/microsystem, interacting with other aspects of the community.

By contrast, the mesosystem represents parents' experiences of interacting with the community and how this relates to stress and challenges. Thus I structure the literature pertaining to parents' experiences of stress, originating from external stressors in the mesosystem. This diverges slightly from the Bio-ecological systems theory, albeit in relation to child development where internal factors specifically relate to the child, whilst factors within the immediate family are viewed as the external environment. Ludlow, Skelly and Rohleder (2011) assert the literature has largely neglected the contribution of external sources of stress, in relation to the experiences of parents of children with autism. Moreover, Nicholas et al. (2016) contend parent stressors are further compounded by a lack of understanding by others. In other words, stressors originating in the microsystem may be

made worse by a lack of understanding from others cascading down from the mesosystem. Accordingly, both the microsystem and mesosystem aspects of the conceptual framework need to be considered together to understand the experience of parents of children with autism. Thus, in this section, I also include the literature related to how parents might cope and adapt to both internal and external stressors depicted in the microsystem and the mesosystem. The interconnectedness of these two systems has been emphasised:

‘the mesosystem is not a layer outside the microsystem but a relationship between or among microsystems.’ (Rosa and Tudge, 2013, p.255)

Finally, the chronosystem helps to represent the literature on how parents perceptions of their experience might change over time and how parents make positive sense of their experience. The chronosystem also meshes with the literature about parent coping strategies. In view of the temporal aspect, this literature in the chronosystem appears towards the end the literature review chapter.

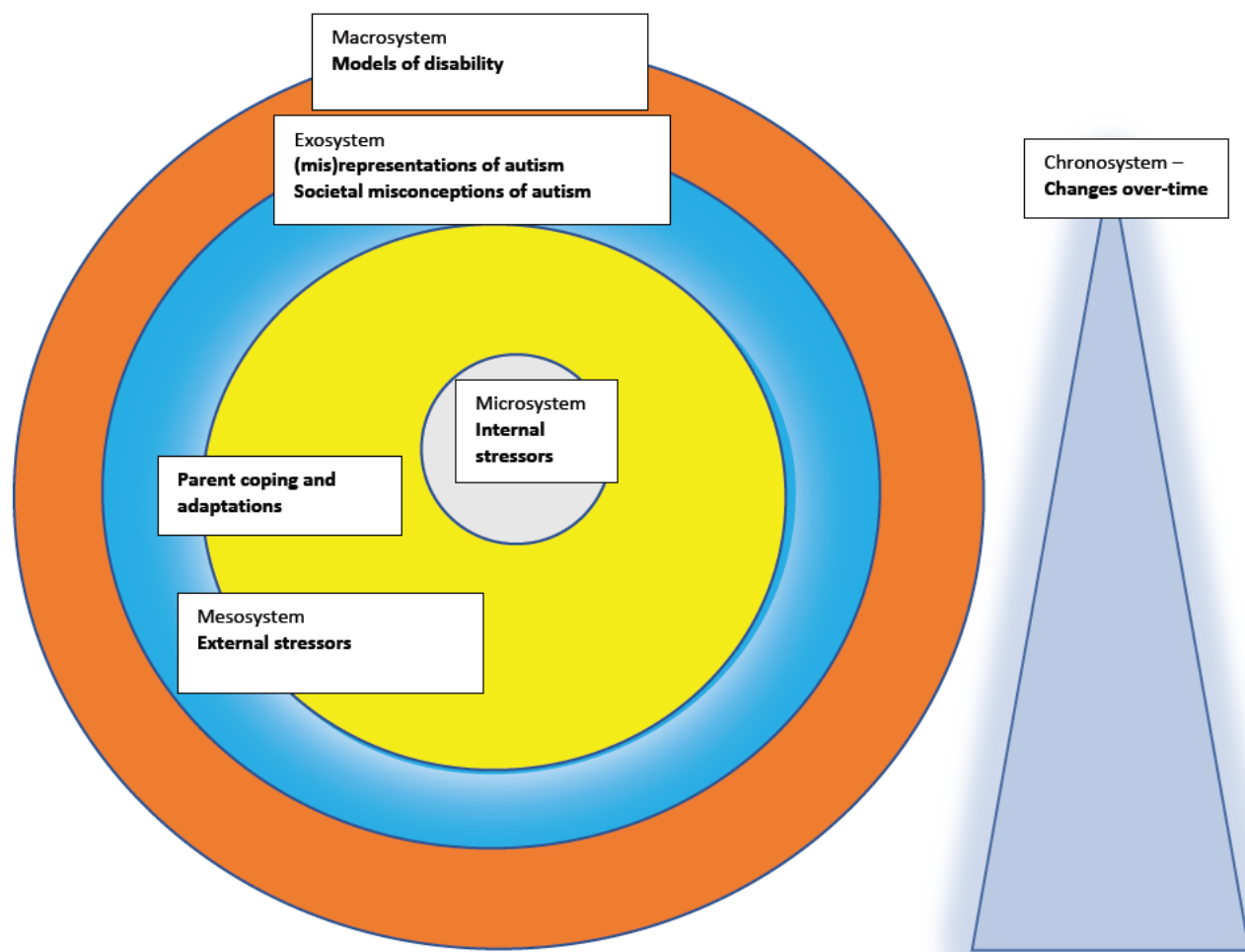


Figure 6: Organising the literature within the conceptual framework

3 CHAPTER 3: LITERATURE REVIEW

3.1 Overview of the approach for reviewing the literature

To explain my approach for reviewing the literature it is important to reiterate that my PhD research project was conceived as a natural progression from my MEd study, which left unanswered questions (see section 1.1). Through carrying out this study, I had also developed a foundation of knowledge about the literature and parents of children with autism. The literature seemed confusing and contradictory, as parents are described as experiencing stress (Estes et al. 2009), but also developing resilience (Bayat, 2007). For more details of this literature (see section 3.2.1). In view of this confusing picture, my PhD project began with a broad focus to understand the factors that might influence how parents sustain caring for their children with autism at home. From the outset of the project, I used the following working title: What factors enable families to sustain caring for children with autism within the family home?

3.1.1 Method for searching the literature

There were two phases to my search. In Phase-1, I took a broad approach to searching the literature of parent experience of autistic children. My rationale was that I did not want to limit my search to a specific area of the literature and potentially risk overlooking important and interesting aspects of parent experience. In view of this, I will explain why I decided not to use a systematic or scoping review of the literature. Systematic reviews use a structured approach and clearly defined criterium to search the literature, with inclusion and exclusion criterium (Munn et al. 2018). These authors confirm systematic reviews are a robust and trusted method. Thus, in following the same process, it is expected that the exact findings could be replicated by someone else. Contrastingly, scoping reviews aim to map out the

landscape of the literature, establishing the scope. They allow the exact focus of the research to stay undefined and can sometimes be used prior to a systematic review (Munn et al. 2018). Akin to systematic reviews, scoping reviews also use a structured approach that can be replicated. Ultimately, both systematic and scoping reviews seek to narrow the focus of the literature review (Munn et al. 2018).

It became clear from my own early exploratory attempts to research relevant electronic databases, that with a broad topic these approaches would generate vast numbers of articles, unless strict criterium were used to narrow this. To further illustrate this point, I draw upon the literature and provide two examples where authors have used structured approaches for reviewing the literature. DePape and Lindsay (2015) conducted a meta-synthesis of the qualitative literature, focusing upon the broad topic of parents' experiences of the benefits and/or challenges of caring for a child with autism. Using several databases and key words to identify potential articles for inclusion, 4,148 articles were captured. Specific inclusion criteria were then applied to reduce this number, including studies needed to include a child of 18 years or younger living in the parental home, a primary diagnosis of autism, not including any co-morbid diagnosis. Articles focused solely on quantitative data were also excluded. Through reviewing the titles and abstracts, this number was further reduced to 125 articles, which were reviewed in full and reduced finally to 31 articles for inclusion.

Another example, Bonis (2016) used a structured review of the literature, focusing on parents of children with autism and stress. A two-stage approach was used for searching

data bases, using the key words 'autism', 'parents', 'experience' and 'stress' to get a broad overview of the literature and then focusing in-depth on key themes. This search captured 1615 articles, which was narrowed to 132 articles for inclusion. Articles were included that focused upon parental experiences of caring for a child with autism. Articles were omitted if they included other diagnoses and were not autism specific. The author identified that a source of parent stress was judgements and criticisms about the autistic child and their behaviour. They noted that only one study, Neely-Barnes et al. (2011), mentioned how parents responded to these judgements, inferring the possibility of a gap in the literature. However, from my own searches of the literature, relating to the theme of autism and stigma, it is clear that there are other studies which have captured how parents respond to judgements (see Harandi and Fischbach, 2016; Broady, Stoyles and Morse, 2015).

In summary, I propose reviews with defined criteria may have limitations in terms of overlooking the broader and related aspects of the literature. I therefore concluded that maintaining a breadth of focus and open mind for reviewing the literature was more appropriate for my study. This also aligned with using an interpretative and phenomenological methodology and my parenting position being central to the interpretation of this research.

In view of the above considerations, in Phase-1 of my search of the literature I sought to maintain a broad approach. This process included re-visiting known authors from my MEd literature and reassessing key papers on the broad experience of parents of children with autism, for example Australian studies conducted by D.E Gray (1993, 2002a, 2002b, 2006)

and Woodgate, Ateach and Secco (2008). I examined relevant reviews of the qualitative literature (see DePape, Lindsay, 2015) and large-scale studies investigating understandings of parent experience (see for example, Myers, Mackintosh and Goin-Kochel, 2009). As parent experiences are not always fully transferable across different cultures, I also considered smaller scale studies carried out in the UK, for example Preece (2015) and Ludlow, Skelly and Rohleder (2011). Furthermore, I took a broad view of how parent experience has been presented, through exploring relevant books (see for example Randall and Parker, 1999; Silberman, 2015; Prizant and Fields-Meyer, 2015).

These papers and books helped to map out the landscape of the literature and challenge preconceptions from my MEd and from my own personal experience. I also carried out searches through the University of Birmingham tool, Findit @ Bham, using key words for example, 'Lived experience' and 'Parents of Children with Autism'. I set up alerts to relevant literature, via ScienceDirect, Mendeley and Goggle Scholar and followed key authors through the same mechanisms. Furthermore, I contacted academics directly via email who had conducted research in my focus area for guidance to other literature (for example, Dr David Preece, Dr Miyako Kimura and Dr Chris Papadopoulos). These papers acted as signposts to key themes in the literature and provided references to other relevant papers, which I searched manually.

Throughout this process, I saved copies of all relevant papers to my computer. I made handwritten notes in a book, recording any interesting ideas or themes, which I could return to. Papers which I determined were especially interesting or essential to my topic, were printed

as hard copies and labelled as 'A' papers. Coloured highlighter pens were used to emphasise key sections and were re-visited multiple times for further review. I also created an annotated spreadsheet of the literature, to keep track of emerging themes and differences. In the early stages of my search, I found I was regularly returning to themes related to the social implications of child behaviour and stigma. Limitations on family life and social isolation was a related strong emerging theme. In conjunction with my Phase-1 search, I developed a conceptual framework and worked iteratively between this and the literature.

The Phase-1 search strategy enabled key themes in the broader literature to be identified. To develop more in-depth understanding, in Phase-2 I carried out focused searches for each of the key themes. Where possible I utilised systematic or scoping reviews, focusing upon specific segments of the literature, related to these key themes (see for example, Bonis (2016) review of stress; Liao and Li (2019) review of economic burden; Papadopoulos et al. (2018) review of autism stigma and risk to carers of mental health problems).

Although I did not apply the exact principles of conducting a systematic review (e.g., the PRISMA guidelines), I used several criterium to determine which reviews to examine. These needed to be written in English, published in a peer reviewed journal and focused upon the experiences or perspectives of parents or carers of children with autism and related to a key theme. Reviews were excluded if they related to the perspectives of autistic individuals or other family members, or if the research did not relate to parent experience. Finally, reviews were excluded if they related only to specific geographical regions. Other searches were carried out using the University of Birmingham tool, Findit @ Bham and other databases

including Web of Science, SAGE journals, ScienceDirect and Mendeley, using key words to capture the key academic papers on these theme areas. I looked at relevant papers published up until 2021.

3.2 Review of the literature

In this section I first present an overview of what is already known in the literature about the experience of parents of children with autism, through key theme areas related to the conceptual framework. Second, I turn to consider the rationale for conducting research with a particular focus upon the experiences of parents of children with autism and LD. Finally, I summarise the main findings in the literature, describe the research gaps and explain the research aims. Throughout I will weave in my own experience and positionality in connection to autism. Consistent with this style, I will write using the first-person pronoun.

3.2.1 An overview: The lived experiences of parents of children with autism

Traditional studies exploring the experiences of parents of children with autism have accentuated the stress and burden of parental caring (Sivberg, 2002; Woodgate, Ateach and Secco, 2008; Estes et al. 2009; Quintero and McIntyre, 2010). Contrastingly, other research has found evidence of parental resilience and life-changing effects of parenting children with autism or disabilities (Huws, Jones and Ingledew, 2001; Bayat, 2007; King, Zwaigenbaum, Baxter, 2006; Scorgie and Sobsey, 2000; Cashin, 2004; Fleischmann, 2004, 2005). Another strand tries to reconcile this, through asserting parents experience both the stresses and restrictions of living with children with autism, whilst also recognising positive aspects. Examples of relevant studies include '*My greatest joy and my greatest heart ache*' (Myers, Mackintosh and Goin-Kochel, 2009) and '*The embrace of paradox*' (Larson, 1998) where

mothers had seemingly contradictory perspectives of both loving their child, whilst wanting to remove their disability. Given this confusing and contradictory picture of the literature, I will use the conceptual framework as a structure to illuminate the landscape of parent experience and draw attention to the interrelated aspects.

In the review of the relevant literature, I also acknowledge two aspects. First, studies are heavily dominated by mothers' perspectives (Ludlow, Skelly and Rohleder, 2011; Dillenburger et al. 2010; Nicholas et al. 2016; Lloyd, Osborne and Reed, 2019). In view of this, authors have recommended that a broader range of family perspectives is needed (Nicholas et al. 2016; Lloyd, Osborne and Reed, 2019). Some authors have also tried to give better representation to fathers (Johnson and Simpson, 2013; Preece, 2014).

Second, authors use different terminology to describe children with a diagnosis of autism and LD. One of the issues is the designated categories have changed overtime. For example, Wing (1996) describes autism as '*co-existing with a learning disability*', meanwhile Jordan (2001) adopts '*dual diagnosis of autism and severe learning difficulties*'. Other authors refer to '*classic autism*,' Lutz, Patterson and Klein (2012), which is autism associated with a cognitive delay (Volkmar et al. 2014). Furthermore, the DSM-V uses three autism levels, for example *Level 3 'severe autism'* refers to autism with the highest level of need, describing children as '*requiring very substantial support*' (APA, 2013). The DSM-V also stipulates a diagnosis of autism needs to be specified, with or without an intellectual impairment (APA, 2013).

Differences in diagnostic labelling makes it challenging to navigate the literature and isolate relevant studies related to the experience of parents of children with autism and LD. For example, a recent study of lived experience, refers to children with '*severe autism*,' but does not confirm whether children had LD (Besette Gorlin et al. 2016). Since this study is post DSM-V, this is surprising. These authors explain how they used a functional challenges questionnaire, to help identify a sample of children with 'severe autism'. The criteria characterised children as needing: (1) 24-hour supervision, (2) help with personal care and (3) often having speech delays. In view of this, it seems likely the children also had LD.

Often studies have used samples without specifying, if any of the parent's children also had a LD (Myers, Mackintosh and Goin-Kochel, 2009; Nicholas et al. 2016). The existence or not of a LD is equally opaque in a recent systematic review of the qualitative literature concerning the lived experience of US parents of children with autism (Corcoran, Berry and Hill, 2015). Furthermore, another review of the qualitative literature chooses to focus specifically upon the experiences of parents of children with a primary diagnosis of autism, not including other co-occurring conditions (DePape, Lindsay, 2015). These authors acknowledge the gap in the literature about parental experience related to other segments of the autism community. Similarly, smaller scale studies have focused upon parents whose children have a diagnosis of autism (Woodgate, Ateach and Secco, 2008), autism or AS (Cashin, 2004; Ludlow, Skelly and Rohleder, 2011) or specifically AS (Gill and Liamputtong, 2011).

Only a small number of studies exploring parental experience have indicated a focus upon children with autism and LD. Munroe, Hammond and Cole, (2016) and Bessette Gorlin et al. (2016) refer to *autism and a learning disability*, whilst Fairthorne et al. (2014) mention *autism and intellectual disability*. Like Bessette Gorlin et al. (2016), Werner, DeGrace (2004) refers to '*severe autism*', whilst Lutz, Patterson, Klein (2012) mention '*classic autism*'. Reflecting on these differing terminologies, my interpretation is they are referring to children with additional LD.

3.2.2 The problem of terminology for describing the autistic child and their behaviour
Authors differ in their terminology when referring to the autistic child and their behaviour. For example, Gray (1993, 2002a) uses the terms 'disruptive behaviour' and 'inappropriate public behaviour', whilst other studies refer to 'difficult child behaviour' (Dillenburger et al. 2010), 'socially inappropriate and difficult behaviour' (Farrugia, 2009) or 'behaviour problems related to autism' (DePape and Lindsay, 2015).

My own view is whilst these terms may appear to be helpful descriptors, they are problematic, as they imply specific behaviours can be identified as autistic. I echo the position there is only behaviour, and no single behaviour is an autistic behaviour (Prizant and Fields-Meyer, 2015). In my view, behaviour needs to be understood in its specific context, as different inputs from the social environment will impact and influence this. The underlying reasons for behaviour should be seen through a lens of emotional regulation. Moreover, I assert that as behaviour is viewed according to one's own perspective, it is highly subjective. Thus, people will have different attitudes, related to culture and settings, which in turn will influence tolerance levels and reactions to behaviour.

An alternative term '*challenging behaviour*' (CB) has become widely used (Bonis, 2016; Lloyd, Osborne and Reed, 2019; Myers, Mackintosh and Goin-Kochel, 2009; Ludlow, Skelly and Rohleder, 2011; Clements and Zarkowska, 2000; Clements 2005). Clements and Zarkowska (2000) believe behaviour may qualify as a CB if there is a significant cost to the individual or others around them. Clements (2005) explains CB can be defined as physical, social, lifestyle, financial and emotional costs, with the cost of a specific behaviour determined by the frequency and risk. Moreover, the 'Challenging Behaviour Foundation' (Formal Definitions of Challenging Behaviour), argues the term CB was introduced with the aim of 'describing the behaviour as challenging to services', rather than positioning behaviour as a problem within the person. They acknowledge CB has wrongly been used 'as a diagnostic label', resulting in stigma and exclusion.

Having considered the differing terminologies, throughout this review I have decided to use the authors' term to describe behaviour, when referring to their work. However, as these terms do not represent my own views, I will use my preferred term 'behaviour that challenges' (NICE, 2015), or the shorter term 'behaviour', throughout my own narrative and interpretation of others' work. The term 'behaviour that challenges' is reflective of the position that behaviour should be viewed as 'a challenge to services, family members and carers and may serve a purpose to the individual' (NICE, 2015). I believe 'behaviour that challenges' is a clearer term than CB, as it pointedly re-positions behaviour as something challenging for others. As such, the challenge is for the individual who perceives the behaviour to be irritating or annoying, rather than the other way around. This terminology respects that behaviour may serve an important purpose for the individual and may be

harmless. Other terms I endorse are '*Behaviours of Concern*' (McDonnell and Deveau, 2018, p.21) or '*indicators of distress*' (Martin et al. 2019, p.131). However, in my view these terms may exclude behaviour that may be harmless or even be beneficial to the individual, but at the same time perceived by others as challenging.

In the next sections I use the different systems from the conceptual framework as a structure to organise and explore the relevant literature. Moving from the general to the specific, I begin with outer layer of the framework in the macrosystem and explore the literature on models of disability.

3.3 The Macrosystem

In this section I outline the literature on models of disability, namely the medical and social models in relation to autism and their limitations. I then suggest some possible alternatives more appropriate to autism.

3.3.1 Models of disability

Many within the autism community contend negative perceptions of autism are underpinned through the medical model, where the terms '*deficit*' and '*disorder*' are used to describe autism (Milton, 2019, p.3). This model pathologizes the autistic person is a problem to be fixed or cured. This is synonymous with the view autistic people are a passive group who require treatment or therapies, so they can become '*normal*' to fit with the rest of society. This is at odds with the belief autistic individuals should be respected as the '*expert on their autism*' (Woods, 2017, p.1093). Ultimately, autism is framed as a problem, as an autism diagnosis is presented as a medical condition (APA, 2013). The DSM-V also highlights

how autism is often accompanied by other medical diagnoses, described as co-morbidities, which helps to perpetuate a medicalised view of autism (Anderson-Chavarria, 2021). This is problematic as it has encouraged professionals to situate autism in terms of behaviour and cognitive deficits (Milton, 2019), rather than considering '*defects*' in the social environment (Marks, 1997, p.87) and how these are disabling for autistic people (Milton, 2019). A focus on negative and '*pathologizing*' aspects is also perpetuated by an education system, where funding to support needs and a formal diagnosis are entwined. Professionals act as '*gatekeepers*' for accessing autism services and disability benefits, which encourages parents to focus upon deficits (Marks, 1997, p.88).

An alternative to the medical model is the social model of disability (Oliver, 1990). This model rejects the negative focus on deficits (Anderson-Chavarria, 2021). Disability shifts from the individual to being a social construction and the fault of the social environment (Marks, 1997). Inaccessible societal institutions are blamed for creating disability (Anderson-Chavarria, 2021). Also, the role of negative attitudes in contributing to difficulties is acknowledged (Jordan, 1999). A key distinction in the social model is separation of impairment from disability (Anderson-Chavarria, 2021). Through the lens of the social model, '*so called autistic*' behaviours are viewed more favourably as alternative behaviours for coping with the environment (Anderson-Chavarria, 2021).

Ostensibly the social model seems to address many of the issues of the medical models. However, authors have highlighted its limitations both in the wider and relevant autism literature. Woods (2017) argues whilst the social model has been effective for those with

physical and sensory impairments, it is less relevant for autism. Likewise, Marks (1997) highlights how making changes, such as dropping kerbs for wheelchair users, may make life more difficult for others.

Hacking (2010) argues that in presenting autism as a spectrum, a linear view has developed, which has failed to fully capture the diversity of autism. He describes autism as:

‘a complex and ill-understood manifold of differences’ (Hacking, 2010, p.636).

In other words, it is diverse and not well understood, at least by neurotypicals.

Thus, Anderson-Chavarria (2021) proposes through the lens of *‘the predicament model’* (Shakespeare, 2006), autism can be best understood as a *‘predicament of neurodiversity’*.

This model rejects the notion of autism *‘as a spectrum’* and the related high or low functioning labels and acknowledges how autism experience differs for individuals and varies depending on the specific context and environment (Anderson-Chavarria, 2021).

An alternative is the bio-psycho-social insider model (Guldborg, 2020), which does not attempt to entirely discard the medical and social models. Rather, this author considers how biological, psychological and social aspects are ultimately interlinked and provide a viewpoint for understanding individual perspectives of autism. Later, I return to models of disability (see findings and discussion chapter, section 5.2.2). For the next section of this review, I move inwards from the macrosystem to explore the literature relating to the exosystem.

3.4 The Exosystem

In this section I build upon models of disability and explore (mis)representations of autism.

Thus, I consider how autism autobiographies and parent biographies have contributed to sometimes misrepresenting autism. How the media, TV, films and fiction have depicted autism is also examined. I then explore the controversy of the puzzle piece imagery and autism. Finally, I consider how these (mis)representations of autism have contributed to societal misconceptions of autism.

3.4.1 Autobiographies and parent biographies

Autobiographies and parent biographies have contributed to views of autism. Before the rise of autism autobiographies, beliefs were mainly informed and sometimes misinformed by parental accounts (Prizant and Fields-Meyer, 2015). This was considered the wrong way around, from the outside in (Williams, 1996). Thus, the autism community hit back and autistic authors, such as Temple Grandin, Donna Williams and Daniel Tammet published their own accounts of their experiences (Hacking, 2010). These personal insights helped to create a new language of autism (Hacking, 2010), which re-informed our views of autism (Prizant and Fields-Meyer, 2015).

However, it is asserted some of these autism autobiographies presented a distorted view of autism, as 'high functioning' (Hacking, 2009a). This is likely because these autistic autobiographers were able to articulate their experiences, making their collective voice stronger. This is in comparison to those with autism and LD who are more likely to have limited spoken language. Equally, some parent biographies have also been criticised for

perpetuating a myth that the autistic child has special talents, maybe a '*computer geek*' or the misleading suggestions of a cure (Hacking, 2009b, p.511).

In essence, I suggest whilst both autistic autobiographers and parent biographies sit in different positions within the autism community, they have played their own parts in misrepresenting autism. Moreover, there has been a tendency to overlook the experience of parents of children with autism and LD, who have described their brutal reality:

'Autism isn't genius, it's not different ability. It hurts' (Bessette Gorlin et al. 2016 p.587).

3.4.2 TV, films and fiction

In this section I consider how the films and fiction have misrepresented autism.

Whilst the film '*Rain Man*' holds a significance for helping to establish a public awareness of autism (Hacking, 2010), there are differing views on whether it has helped or hindered our understandings. On the one hand, it is claimed to have presented a distorted view of autism, one associated with savant skills (Hacking, 2010), or the brilliantly clever and talented (Bessette Gorlin et al. 2016). However, a different interpretation is '*Rain Man*' provided an accurate depiction of an autistic savant (Treffert, 2014). Nevertheless, this author concedes this led to incorrect assumptions about autism and savants:

'Not all autistic persons are savants, and not all savants are autistic' (Treffert, 2014, p.565).

Draaisma (2009, p.1476) defends *'Rain Man'* for trying to educate us about autism. He reminds us of how the film used *'a white-coat scene'* and a psychiatrist to educate the audience about autism and savant skills. Contrastingly, it is claimed later films such as *'Snow Cake'* missed these valuable opportunities, assuming public knowledge of autism and thus contributing to perpetuating stereotypes (Draaisma, 2009, p.1476).

Draaisma (2009, p.1477) is also critical of films which have failed to accurately portray a diversity of autism characters, presenting as extremes, either savants or individuals with *'diminished capacity'*, examples include *'Mozart and the Whale'* and *'Mercury Rising'*. This author contends these images do not correlate with Asperger's case histories, as these did not describe savant skills, only special talents or abilities. Moreover, Draaisma (2009, p.1477) argues films, such as *'Mercury Rising'* often portray savants with exceptional computer skills, akin to machines, which suggests autistics have no feelings.

Autism has also been depicted in fiction. Whilst it is argued that families may derive some comfort from reading about fictional autistic characters being portrayed with special talents, this misconception is likely to be more damaging (Hacking, 2010). As a parent, I echo this thinking as I believe it is not helpful for others to distort the reality of our real lives.

3.4.3 Autism as a puzzle piece

Any discussion about how autism is represented would not be complete without touching upon the debate surrounding the use of puzzle imagery. There are several reasons why it is

thought to misrepresent autism (Smukler, 2005) and shunned by autistics and many parents and practitioners (Brook, 2016).

First, the imagery suggests autistic individuals are a problem to be solved or a missing piece to be found (Pellicano et al. 2018). The missing piece infers a deficit view (Smukler, 2005) with the implication autistic individuals need to be cured (Pellicano et al. 2018; Smukler, 2005; Grinker and Mandell, 2015). Second, the puzzle has been criticised for suggesting autistic people are not really human (Brook, 2016). Likewise, Smukler (2005) argues the puzzle represents the notion of the real child, that is the neurotypical child, being somehow removed by autism. This author is particularly critical of Park (1982, p.12) and her description of her daughter being '*stolen away*' by fairies. Whilst I see his point, I suggest that Park's choice of words should be considered in context of the time and I echo those who defend Park's overall view of autism (Prizant, Fields and Meyer, 2015). Third, the puzzle has been rejected as jigsaw puzzles are generally associated with childhood, encouraging a view that autism does not extend beyond childhood. Yet people with autism spend most of their lives, not as children, but as autistic adults (Pellicano et al. 2018).

Another claim is that the puzzle imagery is imposed by people who think they know best (Brook, 2016). That is, autism organisations, practitioners and academics, who are not autistic, yet position themselves as experts in the field. This brings the discussion full circle to the positioning of different voices within the autism community and the argument that we should not privilege any single voice and make autism research a '*shared endeavour*' (Pellicano et al. 2018, p.82).

Responding to these controversies, some autism organisations changed their logos. In 1963 the National Autistic Society (NAS) (formerly the Society for Autistic Children), was the first to introduce the puzzle piece as their logo (Pellicano et al. 2018, Brook, 2016). However, this has been updated to avoid any negative associations with the puzzle image (Grinker and Mandell, 2015). Until recently the research journal 'Autism' also encompassed the puzzle piece as its logo, but after listening to those offended by the imagery and consulting with the autism community (Brook, 2016), it too changed its logo (Pellicano et al. 2018). Given the diversity of autism, the appropriateness of symbols for autism has also been questioned (Brook, 2016).

Despite these criticisms, some organisations and authors continue to embrace the puzzle imagery. It continues to have close links with Autism Speaks, which uses a blue puzzle piece as its logo and the Autism Society of America, which has a ribbon depicting puzzle pieces (Gernsbacher et al. 2018). Furthermore, numerous authors in the autism literature have chosen to incorporate the word 'puzzle' into their titles, for example '*Solving the Autism Puzzle a Few pieces at a Time*' (Schaaf and Zoghbi, 2011) and '*Another Piece of the Autism Puzzle*' (State, 2010). Similarly, authors have described parents' experience of searching for the cause of autism, as a '*piece of the puzzle*' (Altieri and von Kluge, 2009, p.148).

Advocates of the puzzle argue it increases autism awareness and improves advocacy (Grinker and Mandell, 2015). These authors claim it represents the autistic individual and their relationship to society, represented by the whole puzzle. The image helps to portray

the feeling of not fitting in or they should not try to fit in with the rest of society, but it also suggests a sense of social isolation (Grinker and Mandell, 2015).

Finally, to touch on my own reflections of the puzzle image, my sympathies rest with those who reject the image. I suggest that the puzzle represents an admission by neurotypicals of not knowing. Or perhaps it is an unwillingness to try to understand the unique perspectives of those with autism. As a parent, I concede that I once viewed my son as a puzzle, though on reflection this was due to my own lack of understanding. Through careful observation I have tried to step inside his world, to try to see things from his perspective, as far as this is ever possible. I view him as an individual using a range of creative coping strategies to try to manage his environment.

3.4.4 How (mis)representations of autism have created societal misconceptions of autism

Building on the misrepresentations of autism explored through autobiographies and parent biographies, TV, films and fiction and autism as a puzzle piece, I now explore how these have trickled down to shape societal misconceptions.

Studies point to a variety of societal misconceptions or myths about autism (Huws and Jones, 2010b; John, Knott and Harvey, 2018). Some of these relate to perceptions about social interaction, including misconceptions that autistic individuals lack interest in social relationships, do not notice social rejection, dislike being touched and are introverts (John Knott and Harvey, 2018). A slightly related misconception is the unhelpful notion of autism as a shell with a normal person waiting to get out (Jordan, 1999). Others have also described

autism as being '*trapped*' (Huws and Jones, 2010b, p.341; Harkness et al. 2007, p.375). This image has compounded a view that autistic individuals are unlikely to live independently (Huws and Jones, 2010b).

Studies confirm that a commonly held societal view is autistic individuals have high levels of ability or savant skills (John, Knott and Harvey, 2018; Huws and Jones, 2010b). Using focus groups to explore myths about autism, John et al. (2018) described participants' beliefs that '*savant*' was associated with being good at drawing, maths skills or being a talented guitar player. Whilst savant skills do exist, these are rare (Jordan, 1999) and thought to only relate to about 15 percent of autistic individuals (Prizant and Fields-Meyer, 2015).

Another myth relates to perceptions of autistic individuals with challenging behaviour, which is seen as dangerous or aggressive (John, Knott and Harvey, 2018). Autism is also mistakenly seen as a mental illness (John, Knott and Harvey, 2018), like depression or schizophrenia, which can result in discrimination (Huws and Jones, 2010b). This may be due to a lack of appropriate alternative language to describe autism (Huws and Jones, 2010b). Thus, I suggest the misuse of the word mental illness is unintentional and more likely reflective of poor public awareness and education.

The literature suggests there is parental confusion about the causes of autism. Whilst many understand the genetic links (Mackowiak, 2000), other studies have highlighted a persistent misconception that vaccinations lie at the root of autism (Mitchell and Locke, 2015). In particular, the Measles, Mumps and Rubella vaccine (MMR) has been blamed (Huws and

Jones, 2010a; Altieri and von Kluge, 2009), despite this linkage being refuted (Knopf, 2021). Studies have also revealed religious related misconceptions, such as autism is '*an act of God*' (Huws and Jones, 2010b, p.340) or conversely the child with autism is '*your gift from God*' (Huws, Jones and Ingledew, 2001, p.574).

A common misconception is the notion of autism as a unified form (John, Knott and Harvey, 2018), rather than acknowledging autism presents differently in different people. Draaisma (2009) suggests Kanner created a single view of autism, describing it in terms of aloneness, insistence on sameness and islets of ability. This may in part explain this misconception. Another false belief concerns the longevity of autism. Autism is not '*transient*' (Hacking, 2010, p.640), it is a life-long condition, though improvements can be made with the right support and education (Jordan, 1999). Despite this, a misconception of autism as a childhood condition has prevailed, which according to Jordan (1999) can be traced to Kanner's diagnostic label of '*early infantile autism*' and suggestions of curing autism (Kaufman, 1994). It is proposed that any illusion of children '*outgrowing autism*' is more likely due to a misdiagnosis of autism (Treffert, 2013, p.564).

There are differing findings regarding the stability of autism beliefs. For example, John et al. (2018) found some participants were inclined to change their thinking about autism after hearing alternative views. Contrastingly, Huws and Jones (2010b) highlighted some participants held definitive views of autism, even though many of these were inaccurate. Circling back to the notion of autism as a puzzle, there are suggestions this imagery encourages negative public perceptions of autism (Gernsbacher et al. 2018). Likewise, a

study exploring how school children conceptualised the causes of LD, revealed a perception that neurodevelopmental disabilities, such as autism, were caused by:

‘a puzzle piece missing in the brain’ (Nowicki, Brown and Stepien, 2014, p.77).

This example highlights the insidious effects of misrepresentations of autism. In the next sections, I explore the literature related to the microsystem at the centre of the conceptual framework. I then move onto the mesosystem.

3.5 The Microsystem: Parent experience of internal stressors

Using the microsystem, I explore the impact of internal stress factors associated with caring for children with autism within the home environment. Stress factors relate to the internal family dynamics of spouse/partner and siblings and family challenges, for example behaviour that challenges. Other relatives such as grandparents are excluded from the microsystem (and positioned in mesosystem), unless residing in the same home, as they are situated outside of parents’ daily reality. This interpretation is informed from the literature, my MEd data analysis and personal experience. It is worth stressing that parent experience is not always easy to discretely isolate, as aspects are often interrelated

Stress is by far the most dominant theme in the relevant literature (Myers, Mackintosh and Goin-Kochel, 2009; Bonis, 2016). Parents of children with autism are thought to experience more stress versus those of typically developing children (Quintero and McIntyre, 2010; Sivberg, 2002). This group also experiences more stress than parents of children with other developmental disabilities (Gray, 2006; Estes et al. 2009; Schieve et al. 2007; Olsson and Hwang, 2002; Quintero and McIntyre, 2010; Khanna et al. 2012). Studies suggest

perceptions of stress differ with gender, with mothers reporting more stress than fathers (Hastings et al. 2005; Little, 2002).

Stressors for these parents emanate from several sources (Bonis, 2016) and are thought to correlate with the severity of the child's impairment (Tobing and Glenwick, 2002). A distinguishing feature of autism, versus other physical disabilities, is its invisibility (Lloyd, Osborne and Reed, 2019) and it can be especially difficult, particularly in the early days, for parents to make sense of their child's atypical development (Altiere and von Kluge, 2009).

Another source of stress is coping with behaviour that challenges (Gray, 1993; 2006; Lounds et al. 2007; Ekas and Whitman, 2010; Lloyd, Osborne and Reed, 2019). Parents report how their child's behaviour can pervade many aspects of family life (Myers, Mackintosh and Goin-Kochel, 2009). Parents have described experiencing emotional stress from their child's meltdowns and tantrums, particularly if self-harming puts their child's safety at risk (Nagib and Williams, 2018). For example, parents have described needing to stop the car as their child became so distressed, they were physically harming themselves (Lloyd, Osborne and Reed, 2019). Parents have also reported their child banging their head into hard surfaces (Celia et al. 2019) or hurting siblings (Nagib and Williams, 2018; Myers, Mackintosh and Goin-Kochel, 2009). Another aspect of physical behaviour is breaking items in the home (Nagib and Williams, 2018) or insisting on shutting all doors or knocking down all upright objects, such as lamps (Altiere and von Kluge, 2009). Parents have also reported how their child's behaviour cannot always be predicted (Ludlow, Skelly and Rohleder, 2011). Thus, they become preoccupied by anticipating possible behaviours (Nicholas et al. 2016). Couples can

also have conflicting ideas about how to respond to their child's behaviour, which creates inconsistency (Johnson and Simpson, 2013).

The above studies have provided examples of behaviours that parents find challenging. However, the underlying reasons for behaviours should also be considered. Schaaf et al. (2011) found behaviour was often a response to sensory inputs from the environment, relating to the child's needs and sensitivities. Likewise, Bogdashina (2016) views behaviours are compensatory reactions to sensory experiences. Behaviour can also be a response to time-related demands, for example getting ready for school, which generate sensory overload (Schaaf et al. 2011). Mealtimes are another sensory-related area. Some children have sensory sensitivities related to food texture, or have difficulty remaining seated at the table, which can be problematic for parents wishing to have a family meal (Schaaf et al. 2011).

Parents have explained that behaviour that challenges is more manageable at home, as they have more control over the environment (Schaaf et al. 2011). Beyond home the external environment is less easy for parents to predict and requires on-going surveillance of potential difficulties (Nicholas et al. 2016). Some parents may even be fearful of their child running in the road when they open the front door. These issues place restrictions on families (Dillenburger et al. 2010) which can make them socially isolated (Celia et al. 2019).

A related aspect concerns the need for maintaining set routines (Ludlow, Skelly and Rohleder, 2011), for example when visiting to a shopping centre, following the same route

and using the escalator (Nicholas et al. 2016). However, these routines can be difficult to maintain, for example the escalator may be out of use, and the disruption to the routine can cause extreme distress to the child (Nicholas et al. 2016). Parents have also reported the need to maintain routines, such as ensuring their child gets on the bus for school, to avoid a pattern of refusal (Ludlow, Skelly and Rohleder, 2011). Contrastingly, some parents prefer to view these as challenges rather than restrictions (Dillenburger et al. 2010).

It is my interpretation, that my son's behaviour is best understood through viewing his experience through a sensory lens. My understanding of his behaviour is that it is often a response to sensory sensitivities, such as hypersensitivity to certain noises, which can quickly create overload. Other behaviours such as seeking the pressure of lying under a heavy blanket and the need to jump and move around, seem to be hyposensitivities related to the need for tactility and vestibular inputs (Bogdashina, 2016).

Another stressor for parents relates to social communication difficulties (Dillenburger et al. 2010; Gray, 2006). Parents first concerns often arise from observing their child has no spoken language, versus their peers (Lloyd, Osborne and Reed, 2019), which makes it challenging to understand their needs (Myers, Mackintosh and Goin-Kochel, 2009). Interpreting non-verbal behaviours, such as body language, can also make parenting stressful (Gray, 2006).

Care demands are another stressor, deemed far greater than parenting typical children (Nicholas et al. 2016). Parents in one study estimated that an extra 60 hours per week was

needed to care for their children (Järbrink, Fombonne and Knapp, 2003). Other studies describe caring as 'a 24-hour, 7-day-a-week task' (Altieri and von Kluge, 2009, Myers, Mackintosh and Goin-Kochel, 2009).

Parents also report the need to constantly supervise their children to keep them safe (Nagib and Williams, 2018). As children tend to abscond, all exterior doors may need to be locked (Myers, Mackintosh and Goin-Kochel, 2009; Celia et al. 2019). This level of vigilance, described as being in '*a continuous fight or flight mode*,' inevitably puts parents under a high level of stress, as well as affecting other family members (Celia et al. 2019, p.6). After school, parents report spending much of their time interacting with their child (Nagib and Williams, 2018; Preece, 2014). Parents also explain the extra time required to provide therapy for their child or to attend appointments, for example Occupational Therapy (OT) (Myers, Mackintosh and Goin-Kochel, 2009). Time during the weekend and holidays is also reported to place extra demands on parents, in particular single parents (Preece, 2014).

Dillenburger et al. (2010) found having children with limited self-help skills and sleep issues made life particularly stressful. Parents have conveyed the cleaning tasks involved with looking after children who are not toilet trained (Nagib and Williams, 2018) and the problem of children smearing faeces (Altieri and von Kluge, 2009; Myers, Mackintosh and Goin-Kochel, 2009). Care demands are also increased when parents need to engage in prolonged bedtime routines (Nagib and Williams, 2018; Preece, 2014), exacerbated when children have episodes of night waking, which impacts parents' sleep (Nicholas et al. 2016; Myers,

Mackintosh and Goin-Kochel, 2009). This is further compounded if the child is inclined to self-harm (Celia et al. 2019).

One consequence of these extra care demands is parent exhaustion (Nicholas et al. 2016; Celia et al. 2019; Lloyd, Osborne and Reed, 2019). Mothers explain how struggling to function becomes a normal part of reality (Nicholas et al. 2016). They also have less energy for household tasks and have emphasised the '*never-ending*' (Ludlow, Skelly and Rohleder, 2011, p.706) and overwhelming feeling that comes from '*the burden of constant care*' (Myers, Mackintosh and Goin-Kochel, 2009, p.674). Not surprising these parents often report suffering health problems (Myers, Mackintosh and Goin-Kochel, 2009; Ludlow, Skelly and Rohleder, 2011) and are at a higher risk of developing mental health issues (Papadopoulos et al. 2018; Dillenburger et al. 2010; Ludlow, Skelly and Rohleder, 2011; Celia et al. 2019). Low self-esteem often results from feeling like failed parents (Ludlow, Skelly and Rohleder, 2011).

Extra care demands are also deemed to impact other family members (Dillenburger et al. 2010). Parents report having less time with their other typically developing children (Altieri and von Kluge, 2009), with some not able to devote enough time to their other children with special needs (Preece, 2014). Siblings sometimes complain about their autistic brother or sister, due to lack of privacy or having personal items broken (Myers, Mackintosh and Goin-Kochel, 2009). Parents describe the sacrifices siblings make (Lloyd, Osborne and Reed, 2019) and how they feel guilty (Dillenburger et al. 2010), for example sacrificing trips out and going away on holiday (Gray, 1993). Mothers have also expressed guilt about their dependence on

older children for support (Preece, 2014). Contrastingly, some parents have suggested positive aspects, siblings have matured and understood others with disabilities (Gray, 1993). Overall, whether impacts upon siblings are positive or negative seems to be variable (Gray, 1993; Dillenburger et al. 2010, Ludlow, Skelly and Rohleder, 2011).

Extra care demands are also thought to affect marital relationships (Altiere and von Kluge, 2009; Lloyd, Osborne and Reed, 2019). Some mothers report fathers being less involved with parenting (Preece, 2014), which leads to feelings of relational isolation (Nicholas et al. 2016; Woodgate, Ateach and Secco, 2008). The strain of parenting is cited for some couples divorcing (Myers, Mackintosh and Goin-Kochel, 2009; Nagib and Williams, 2018). Thus, studies highlight significant numbers of single mothers caring for children with autism (Bromley, Hare, Davison, Emerson, 2004; Preece, 2014). In some cases, grandparents may offer help to lessen the care burden (Prendeville and Kinsella, 2018). Contrastingly, Lloyd, Osborne and Reed (2019) found few parents mentioned divorce and that their experience strengthened their relationships (Myers, Mackintosh and Goin-Kochel, 2009; Preece, 2014).

3.6 The Mesosystem: Parent experience of external stressors
The stressors for parents of children with autism are not isolated to the family home, these challenges continue to unravel through the interactions between the parent/child dyad with others in their community (Gray, 1993). I define the challenges related to these interactions as external stressors (Ludlow, Skelly and Rohleder, 2011). External stressors arise from specific negative interactions between the parent/child dyad and relatives, friends, neighbours or strangers. External stressors may also occur from difficult interactions with

service providers, such as schools or health providers. These may also contribute to issues related to employment for parents.

From reviewing the literature, I determined that parents' experience of external stressors is best explained through the broader theme of autism stigma (Gray, 1993; Gray, 2002a; Kinnear et al. 2015). Thus, a discussion of autism stigma will be central to this section. Through exploring the relevant literature, I became more aware of the meaning of autism stigma and I developed my own preference for the alternative term '*unsupportive attitudes to autism*'. However, throughout this review I will continue to refer to '*stigma*', as this word is used by most authors. I will explain more about my preferred terminology in the discussion chapter (see section 5.6.1).

In the next section I begin by briefly outlining how a lack of understanding of autism contributes to parent stress (Woodgate, Ateach and Secco, 2008), which relates to the wider theme of autism stigma (Gray, 1993; Gray, 2002a; Kinnear et al. 2015). Second, I provide a more wide-ranging discussion examining stigma. This begins with how stigma has been conceptualised in the wider literature and how stigma has been conceptualised in relation to parents of children with autism. Third, I consider the distinction between felt and enacted stigma for parents. It is worth re-stating that UK studies on parents' experience of autism stigma are limited (see for example, Munroe, Hammond and Cole, 2016; Preece, 2014; Ludlow, Skelly and Rohleder, 2011; Papadopoulos et al. 2018), thus I mostly draw on literature from outside the UK. However, to keep this as relevant as possible to the experience of UK parents, I have tried to focus upon studies which describe parent

experiences from within western cultures. Fourth, I consider the challenges of employment and extra financial costs for parents of children with autism. Finally, I explore the literature on parental coping strategies and how parents make adaptations to autism. Later, I return to the topic of parental coping, where I explore specific strategies for coping with stigma (see findings and discussion chapter, section 5.9).

3.6.1 Lack of understanding of autism

A lack of understanding of autism and how this contributes to parent stress, emerges as a key theme in the literature (Woodgate, Ateach and Secco, 2008). Parents report how some family members lack autism understanding (Woodgate, Ateach and Secco, 2008; Ludlow, Skelly and Rohleder, 2011; Broady, Stoyles and Morse, 2015, Lutz, Patterson and Klein, 2012; Safe, Joosten and Molineux, 2012) and can be unwilling or able to offer practical help (Woodgate, Ateach and Secco, 2008; Safe, Joosten and Molineux, 2012; Farrugia, 2009). Contrastingly, some parents have reported how family members provide support (Woodgate, Ateach and Secco, 2008). Likewise, the role some grandparents play in caring for their autistic grandchildren has been emphasised, although this mostly relates to maternal grandparents (Ludlow, Skelly and Rohleder, 2011; Prendeville and Kinsella, 2018).

Studies indicate how parents of neurotypical children can lack understanding about autism (Lloyd, Osborne and Reed, 2019; Safe, Joosten and Molineux, 2012), which makes parents feel isolated (Safe, Joosten and Molineux, 2012). Thus, parents often seek social connections with other autism parents, who share the same experiences (Lloyd, Osborne and Reed, 2019). Parents also describe difficult interactions with service providers (Woodgate, Ateach

and Secco, 2008; Myers, Mackintosh and Goin-Kochel, 2009). For example, parents have reported experiences of unsupportive education and health care professionals, who lacked autism knowledge (Woodgate, Ateach and Secco, 2008). They experienced difficult interactions with schools, fighting for resources and dreading phone calls about their child's behaviour (Myers, Mackintosh and Goin-Kochel, 2009). Studies point towards the issue of schoolteachers judging behaviour, due to a lack of autism knowledge (Broady, Stoyles and Morse, 2015) and understanding of sensory considerations (Safe, Joosten and Molineux, 2012). Nicholas et al. (2016) sums up the issue for parents' of the lack understanding of their experience:

'you can explain and explain, but unless you live the life...you can't really understand it' (p.929).

3.6.2 Conceptualising the meaning of stigma
Several authors have offered definitions for stigma. Goffman (1963) conveys that an individual becomes stigmatised when they are:

'reduced in our minds from a whole and usual person to a tainted, discounted one.

Such an attribute is a stigma, especially when its discrediting effect is very extensive; sometimes it is also called a failing, a shortcoming, a handicap' (p.2).

Later, Link and Phelan (2001, 2006) conceptualised stigma as a process with five related components. First, people identify and label differences. Second, the different characteristics of the labelled group are stereotyped. Third, the group are separated from others, such that they become a stigmatised group. Fourth, the stigmatised group are discriminated and suffer a loss of status. Finally, it is emphasised that for the process of

stigmatisation to occur, there must be an exercising of power over the individual. These authors assert through the process of stigmatisation, individuals feel rejected and excluded.

Goffman (1963, p.30) also proposed the notion of '*courtesy stigma*'. This term describes a situation where those with close associations to a stigmatised individual are also perceived by society as stigmatised. Scambler and Hopkins (1986) distinguish between courtesy stigma experienced as either felt or enacted stigma. Felt stigma is regarded as the feelings or perceptions of shame or embarrassment, whilst enacted stigma is deemed to be overt hostility, verbal abuse and blame.

3.6.3 Understanding the stigma process for parents of children with autism
Building upon conceptualisations of stigma, some authors have attempted to identify why stigma is an issue for parents of children with autism. Gray (1993) conducted an Australian study exploring the perceptions of stigma among 32 parents of autistic children. Gray (1993, p.102) proposes three aspects. First, parents experience reactions from the public, in relation to the behaviour of their children, including damage to property, difficulties understanding personal space, socially inappropriate behaviour and issues around toileting. Second, '*the normal physical appearance of autistic children*' with autism compounds this, as families can often pass for '*normal*'. Third, a lack of public knowledge and understanding of autism, versus other disabilities such as Down syndrome.

Moreover, it is the child's '*disruptive behaviour*' in public situations, viewed by others as unexpected, which compounds negative reactions (Gray, 1993, p.113). Thus, parents

experience a courtesy stigma that is '*discreditable*' (Gray, 1993, p.111). Nicholas et al. (2016) also found that parents perceived they received less empathy than parents of children with Down syndrome or Cerebral palsy. In a later study, Gray (2002a, p.742) noted that '*discreditable*' stigma was likely to be a greater issue for parents of children with '*HF autism*', whose autism is possibly more hidden.

More recently authors have proposed models for identifying the stigma process for parents of children with autism (Kinnear et al. 2015; Broady, Stoyles and Morse, 2015). Building on the work of Link and Phelan (2001, 2006), Kinnear et al. (2015) proposes a pathway for conceptualising stigma. Correlating with Gray (1993), Kinnear et al. (2015, p.944) suggest the first component is the '*child's autism-related behaviors*'. Second, others misinterpret the child's behaviour and make assumptions that it relates to bad parenting. Third, the child's behaviour is stereotyped. Fourth, this leads to rejection. These authors highlight the rejection aspect particularly increases the risk of wider social isolation and exclusion for parents. A further aspect of their stigma model is the degree to which parents internalise and accept stigma. This links to the key aspect of Link and Phelan's (2001, 2006) model, which is the notion of exercising of power over the individual for stigma to occur. Kinnear et al. (2015) tested their model in a large quantitative study using phone interviews with 502 parents in the USA and Canada. Their findings confirmed the stigma process was underpinned by stereotyping of child behaviour, rejection and exclusion.

Contrastingly, Broady, Stoyles and Morse (2015) conducted a smaller qualitative study in Australia using interviews with 15 carers of children with '*HF autism*'. These authors propose

a stigma pathway of four interrelated components. First, a lack of autism knowledge resulted in carers feeling judged about their child. Second, judgements made carers feel rejected. Third, feeling rejected led to carers feeling unsupported. Both Kinnear et al. (2015) and Broady, Stoyles and Morse (2015) used different methodological approaches and conceptualise stigma slightly differently, yet there are clear similarities with how judgements and rejection contribute to stigma for parents and how this leads to isolation.

3.6.4 The distinction between felt and enacted stigma for parents of children with autism
Studies have also explored the distinction between felt and enacted stigma (Scambler and Hopkins, 1986). For example, Gray (2002a) conducted interviews with 53 parents of children with ‘HF autism’ to explore both felt and enacted stigma. Felt stigma was identified as parent assumptions of others’ negative thoughts. Most parents indicated they perceived felt stigma, mostly experienced as embarrassment in public places, illustrated by the example below:

‘he called me an idiot in front of all those people, and swearing started to come out, and everybody just freezes. Everybody is just embarrassed’ (Gray, 2002a, p.740).

Other examples of felt stigma included, feeling their parenting was questioned and not feeling accepted.

Broady, Stoyles and Morse (2015) also explored the experiences of carers of children with ‘HF autism’, identifying both felt and enacted stigma. Carers experienced felt stigma across four different contexts, schools, in public, family and friends. Felt stigma related to a lack of

support from schools and practical and emotional support from family and friends. This was underpinned by a lack of autism knowledge.

In comparison, enacted stigma related to parents identifying tangible behaviours, indicating judgements (Gray, 2002a; Broady, Stoyles and Morse, 2015). Gray (2002a) found this was mostly recognised as avoidance, for example parents not being invited to parties or out to dinner. Authors have also found enacted stigma is encountered in public situations, where parents either experience extreme staring from strangers, due to their child's perceived (Gray, 2002a), or hear critical comments (Broady, Stoyles and Morse, 2015). Whilst not referring to enacted stigma, other studies have also reported parents' experiences of strangers staring at their children in public places (Myers, Mackintosh and Goin-Kochel, 2009; Nicholas et al. 2016) or being overtly critical of their behaviour (Preece, 2014).

Broady, Stoyles and Morse (2015, p.5) also found that despite trying to explain to family and friends about their child's diagnosis, they experienced judgements, as if they were '*bad parents*'. Echoing Gray (2002a), this was thought to be due to misunderstandings of viewing the autistic child's behaviour '*through a lens of what was considered normal*' (Broady, Stoyles and Morse, 2015, p.5). Broady, Stoyles and Morse (2015) framed these judgements as enacted stigma, whilst as above Gray (2002a) seemed to consider these felt stigma. Thus ostensibly, there appears to be a lack of consensus about how authors view stigma. Broady, Stoyles and Morse (2015) found judgements, particularly from family and friends, caused carers to withdraw from social occasions and to become isolated, which created feelings of felt stigma. This underlines the possibility of a double effect of felt and enacted stigma. Gray

(2002a) also acknowledges the methodological limitations of making a distinction between felt and enacted stigma. Thus, parents experienced a merging of these categories, which Gray (2002a) concluded overstated instances of enacted stigma.

A UK study conducted by Ludlow, Skelly and Rohleder (2011) explored the challenges faced by 20 parents of children with autism. These authors deviated from the terms felt and enacted stigma and used the alternative terms, either '*perceived*' or '*more concrete scenarios*' to categorise parents' experiences of judgements (Ludlow, Skelly and Rohleder, 2011, p.705). Perceived judgements were deemed to relate to parents being made to feel their children were naughty, having their parenting skills questioned and had failed as parents. Hostile staring and feelings of embarrassment were also deemed to be perceived judgements. Whilst parents' experiences of negative comments were categorised as more concrete scenarios. Whilst these distinctions do not clearly map on to the descriptions of felt and enacted stigma discussed above, they highlight the overlapping fuzziness of descriptions in the literature and the difficulty of trying to pigeonhole parent experience into discrete categories.

In summary, the literature on understanding the stigma experiences for parents of children with autism has some significant features. First, most studies have been conducted outside of the UK. Second, most of these studies have focused upon the stigma experiences of parent/ carers experiences of autism or '*HF autism*', rather than autism and LD. Third, these studies have not tended to explore parental experiences of supportive or inclusive attitudes

towards autism. Finally, these studies have used either medium sized samples or larger scale studies.

3.6.5 Challenges of employment and extra financial costs
Financial burden is another key stress theme (Bonis, 2016). This is a relationship between autism stigma and financial burden, which in turn leads to a greater risk of social isolation for carers of autistic individuals (Papadopoulos et al. 2018). To this end, this author proposes a theoretical framework to help explain the relationship between mental health and autism stigma.

A systematic review of the literature examining the economic burden for this group, concluded that parents experience both increased financial costs related to caring for children with autism and indirect costs related to employment (Liao and Li, 2019). Extra financial costs can arise due to medical care and extra transport costs (Liao and Li, 2019) or paying for the child's therapy (Safe, Joosten and Molineux, 2012). Whilst indirect costs may relate to paid employment and the impact on career progression, arising from extra care demands (Liao and Li, 2019; Järbrink, Fombonne and Knapp, 2003; Dillenburger et al. 2010; Nagib and Williams, 2018; Preece, 2014; Lloyd, Osborne and Reed, 2019). Studies estimate that caring for a child with autism results in the loss of opportunity for paid employment of 22 hours per week (Järbrink, Fombonne and Knapp, 2003) and 14% loss of annual income (Montes and Halterman, 2008). Likewise, Dillenburger et al. (2010) found more than half of parents were not employed in paid work. Broady, Stoyles and Morse (2015) also highlights how parents perceive being rejected by some employers and thus having difficulty securing work.

Studies also indicate that mothers are more likely to give up work or reduce their working hours (Liao and Li, 2019; Myers, Mackintosh and Goin-Kochel, 2009; Preece, 2014; Hill et al. 2015, Gray, 2003). For these mothers, the change to their working status can be difficult to cope with, not only because of loss of income and related impacts to lifestyle, but also because it can result in a feeling of '*altered identity*' (Nicholas et al. 2016, p.929). Gray (2003) found that whilst some mothers accepted this situation, others resented the impact to their career. Contrastingly, in other studies mothers were more willing to prioritise the needs of their child (Joosten and Safe, 2014), or viewed parenting a child with autism as a career (Nicholas et al. 2016). Having said this, some mothers have also reported needing to work to pay for autism services (Nicholas et al. 2016).

Hill et al. (2015) outlined the barriers to paid employment for mothers of children with autism, including struggles with finding suitable childcare and issues with asking relatives for child-care support (see also, Ludlow, Skelly and Rohleder, 2011). Other obstacles included a lack of understanding amongst work colleagues about how caring for an autistic child impacted their lives, such as feeling sleep deprived and the longevity of support for their children, likely to continue into the teenage years and beyond. Inflexible organisational policies also made it difficult for time off work. Hill et al. (2015) found that public sector organisations were often the most understanding and flexible around the needs of these parents.

Joosten and Safe (2014) also identified barriers preventing mothers from engaging in full-time employment. These included concerns employment would disrupt their child's usual

routines and cause distress. Likewise, mothers felt employment could not be balanced with the extra time needed to support their child with therapy, with this need increasing as their child got older. Gray (2003) found compared to mothers, fathers' careers were less likely to be affected. However, research also suggests that if mothers give up work, fathers may work longer hours to compensate (Myers, Mackintosh and Goin-Kochel, 2009; Preece, 2014). Although, Kinnear et al. (2015) found over half of spouses, who were mainly fathers, needed to reduce working hours to help support their children. Gray (2003) found some fathers used work as an escape from spending time with their autistic child. However, this author suggests that many fathers still suffered stresses from the responsibility of an autistic child, for example restrictions to their career from being unwilling to take risks or move away. In view of families overall employment restrictions and extra costs, parents often report suffering financially, with some going into debt (Myers, Mackintosh and Goin-Kochel, 2009).

In the specific case of mothers of children with autism and intellectual disability (ID), Fairthorne et al. (2014) echoes some of the same barriers to employment. These include inflexibility from employers and difficulty finding suitable childcare. However, Saunders et al. (2015) found evidence that the impact to this group was greater in terms of paid employment and financial costs, versus parents of children with autism or ID alone. Similarly, Zablotsky et al. (2014) contended that financial costs related to health care are greater for parents of children with autism and additional co-morbidities, such as ID. Moreover, as children with autism and ID get older, they are likely to continue to be dependent on their parents to support their needs (Jordan, 2001), thus the related impacts to employment and financial costs for this group may also continue beyond childhood. Contrastingly, Järbrink

Fombonne and Knapp (2003) found parents of children with autism reported higher losses of income, versus those with autism and additional ID. I assert that it is difficult to be certain of findings, as studies have collated data according to parents' subjective calculations of costs. Furthermore, it is worth noting that findings from some of the above studies, particularly related to health care costs and education are not always generalisable to the experiences of parents in the UK, as the funding and parent expectations of these provisions may differ.

Another financial stressor for some parents of children with autism relates to accessing financial disability benefits, for example Disability Living Allowance (DLA) (Dillenburger et al. 2010). Despite autism being recognised as a life-long condition, parents periodically spend many hours filling in forms, to re-apply for Disability Living Allowance (DLA) (Dillenburger et al. 2010). Also, Hill et al. (2015) found some parents fell into a trap of having to limit their working hours to avoid losing DLA. From my experience, I suggest that these parents were referring to the risk of losing Carer's Allowance, which is related to being in receipt of DLA. DLA is not currently a means tested or taxable benefit (Rayner and Coxon, 2013). It is worth noting that, except for children under 16 years of age, Personal Independence Payment (PIP) has replaced DLA (Rayner and Coxon, 2013).

3.6.6 How parents cope with stressors
As parents of children with autism play a pivotal role in determining the quality of life and longer-term outcomes for their children (Jordan, 2001), it makes sense to understand how they cope. A useful starting point is to consider the research conducted by Hastings et al. (2005), which breaks down how these parents cope into four main categories. First, active

avoidance coping, includes efforts to escape the stress and self-blame and venting. Second, problem-focused coping, includes planning and social support. Third, positive coping includes humour, positive reframing and acceptance. Finally, there is religious beliefs or denial coping.

A general distinction is made between problem-focused and emotion-based coping strategies (Pepperell, Paynter and Gilmore, 2018). Problem-focused strategies essentially mirror the description above, although authors also include other examples such as parents seeking knowledge about autism from the internet or books (Pepperell, Paynter and Gilmore, 2018; Kuhaneck et al. 2010). Some studies also refer to parents seeking solutions (Altieri and von Kluge, 2009), or using routines and structure to support their child (Joosten and Safe, 2014; Schaaf et al. 2011; Kuhaneck et al. 2010), which closely relates to problem-focused coping. Another problem-focused strategy is having time away from their child, described as '*me time*' (Kuhaneck et al. 2010, p.344). Contrastingly, emotion-focused coping strategies include, crying or venting to others (Pepperell, Paynter and Gilmore, 2018), therefore mirroring active avoidance coping.

A recent systematic review of coping strategies for parents of children with autism (Vernhet et al. 2018) confirms earlier findings that parents use more active avoidance coping versus those parents of typically developing children (Sivberg, 2002). However, this is problematic for parents, as active avoidance strategies can generate more stress and mental health issues (Hastings et al. 2005). Some authors contend that parents may benefit from their religious faith (Tarakeshwar and Pargament, 2001; Altieri and von Kluge, 2009). However,

others disagree (Kuhaneck et al. 2010), including Munn et al. (2005) who asserts that religious coping and denial increases mental health issues.

In comparison, problem-focused coping, which also includes social support, is thought to reduce stress levels (Vernhet et al. 2018; Hastings et al. 2005). Similarly, support from professionals such as school staff, paediatricians and other organisations may help parents to cope (Ludlow, Skelly and Rohleder, 2011), as well as spousal support (Kuhaneck et al. 2010). However, in relation to autism support groups, some parents may prefer to have individual friendships (Joosten and Safe, 2014). This last point underlines how social support may be nuanced. Furthermore, another issue is that as not everything can be planned for or anticipated (Safe Joosten and Molineux, 2012), problem-focused coping may not be as effective as it seems (Pottie and Ingram, 2008). A hidden aspect of problem-focused coping is also the time and cognitive effort required by parents for planning and maintaining structure for their children (Safe, Joosten and Molineux, 2012). These authors found the emotional and time demands on mothers, reduced opportunities for them just to 'be' (p.300), resulting in exhaustion and impacts to their overall health. Another consideration is that the focus of problems or solutions is likely to be influenced by beliefs about the causes of autism (Altieri and von Kluge, 2009), some of which may be misguided. For a more detailed discussion about the confusions about causes of autism (see earlier section 3.4.1).

The third category of coping described by Hastings et al. (2005) as positive coping or positive reframing, has likewise been portrayed by authors as '*Recognizing the Joys*' (Kuhaneck et al. 2010, p.346) or celebrating developmental milestones (Ludlow, Skelly and Rohleder, 2011).

This coping is seen as most useful for parents coping with high levels of stress (Hastings et al. 2005; Hastings and Taunt, 2002). The use of comparisons between the parent's child and others has also been found to be helpful (Ludlow, Skelly and Rohleder, 2011). However, maintaining a positive mindset can be difficult for parents, particularly when faced with negative attitudes (Safe, Joosten and Molineux, 2012). This last point underlines how parent coping is entwined with societal attitudes towards the autistic child and their behaviour (Ludlow, Skelly and Rohleder, 2011). Additionally, Kuhaneck et al. (2010, p.344) proposes that '*me time*', particularly the opportunity to do exercise is the most effective coping strategy for these parents.

Another strand in the literature focuses upon gender as a factor in parent coping (Gray, 2003). Hastings et al. (2005) found a difference across genders, with women more inclined to use emotion-focused strategies. However, these authors also point to the contextual factor that mothers are likely to spend more time with the child, exposing them to higher levels of related stressors. Another suggestion is that mothers may have a different perception of their child's disability and find judgements more stressful (Hastings et al. 2005; Gray, 2003). The impacts to fathers may come more indirectly, because of the mothers' stress (Gray, 2003).

More recent studies also indicate that the gender factor is not clear-cut. Pepperell, Paynter and Gilmore (2018) found mothers used a wider range of strategies than fathers, both emotion-focused and problem-focused strategies. These authors found whilst fathers reported using only problem-focused strategies, mothers felt that fathers were reluctant to

disclose their use of emotion-focused strategies. Indeed, some mothers have revealed how husbands or partners have struggled to accept and come to terms with their child's autism diagnosis, trivialising their child's difficulties (Ludlow, Skelly and Rohleder, 2011). I return to this topic again later, where I explore parental strategies for coping with unsupportive attitudes (see findings and discussion chapter, section 5.9).

3.7 The Chronosystem: How parent experience changes over-time

In this section, I explore the literature on how parental experience changes over time.

Inevitably this section is entwined with some of the literature covered in other sections, where appropriate I have included signposts. I begin with outlining some of the methodological limitations of the literature.

Few longitudinal studies have explored how parents' experiences change over time. Key examples, often cited in the literature are Gray's studies (2002b, 2006) which explored the experiences of families of children with autism over a ten-year period. Whilst most parents felt they were able to cope better, others struggled due to issues with their child's '*aggressive*' behaviour and a lack of appropriate services (Gray, 2002b). Parents were also found to use less problem-focused coping, relying more on religious faith and emotion-focused coping Gray (2006). Recently, McGrew and Keyes (2014) carried out a longitudinal study to see if caregiver stress changed during the year after the child's diagnosis. The study found parents had begun to access more social support and developed more positive perceptions of their child, however little changed in terms of their stress levels. It is likely that more time is needed post diagnosis for parents to view their experiences differently.

Contrastingly, most other studies are cross-sectional and rely upon parents memory (Altiere and von Kluge, 2009).

The literature has tended to position the experience of parents of children as a journey which alters with the passing of time (Nicholas et al. 2016; Ludlow, Skelly and Rohleder, 2011). The beginning of the journey is depicted as the time in or around the child's diagnosis, when parents feel grief or anger (Myers, Mackintosh and Goin-Kochel, 2009; Altieri and von Kluge, 2009; Lutz, Patterson and Klein, 2012; Lloyd, Osborne and Reed, 2019) or even denial (Ludlow, Skelly and Rohleder, 2011). For some parents, not all, there is a tranche of time before this, '*the first 12-18 months*', when they perceive their child is developing '*normally*' (Altiere and von Kluge, 2009, p.144). Contrastingly, other parents have reflected having early concerns about their child, for example their child not appearing to notice when their parents called their name or not starting to talk (Altiere and von Kluge, 2009). Other parents have reported a regression in their child's development, related to verbal functioning (Altiere and von Kluge, 2009; Bessette Gorlin et al. 2016).

One aspect which complicates a parents' journey is when health professionals are slow to recognise and diagnose autism (Altiere and von Kluge, 2009; Flesichmann, 2005; DePape and Lindsay, 2015; Lloyd, Osborne and Reed, 2019; Celia et al. 2019). They have been known to dismiss parents' concerns, offering platitudes or sending children for hearing tests (Altiere and von Kluge, 2009). These alternative explanations have encouraged a sense of parental denial (Altiere and von Kluge, 2009). Even after a diagnosis is secured, parents report feeling lost, unsure how to help their child (Celia et al. 2019). For some parents, grief is mixed with

relief, the diagnosis is recognition that their concerns were real (DePape and Lindsey, 2015; Celia et al. 2019).

Gray (2002b) found over time most parents saw an improvement in their lives, including finding their relationships with relatives, in particular grandparents got better. Also, Fleischmann's (2004) depiction of *'The Hero's Story'* is a key example of parents coming to terms with their child's diagnosis autism and finding positive meaning from their experience. Likewise, there are plenty of other cross-sectional studies which indicate parental resilience (see earlier section 3.2.1). Altieri and von Kluge (2009) also found parents began to recognise positive aspects from their experience including developing more patience, making new friends and receiving more support from relatives.

Finding positive meaning is thought to be supported by several aspects, including parents increasing their autism knowledge through attending conferences and support groups (Altieri and von Kluge, 2009; Ludlow, Skelly and Rohleder, 2011). Hence, parents develop better understandings of supporting their child's needs (Altieri and von Kluge, 2009). Likewise, some parents start to view their child as a teacher of autism (Fleischmann, 2005). Parents also found the support of other parents in the same situation helpful, as this enabled them to cope with judgements (Ludlow, Skelly and Rohleder, 2011). Contrastingly, some authors suggest a more contradictory picture of parent experience, simultaneously highlighting the positive and negative (see earlier section 3.2.1). Similarly, Safe, Joosten and Molineux (2012, p.297) highlight how mothers experience *'A paradox of emotions'*. Rather

than viewing their experience in a wholly positive light, mothers developed an altered view of what they envisaged the future would look like for their child.

Another segment of the literature examines whether parents' experience of stigma alters over time? Some authors report that parents continue to experience stigma, regardless of the time since their child's diagnosis (Broady, Stoyles and Morse, 2015). Some also suggest it gets worse as children get older (Neely-Barnes et al. 2011). Contrastingly, Farrugia (2009, p.1016) in referring to Goffman's concept of '*spoiled identity*', proposes that parents use the child's diagnosis to adopt a medicalised position and justify their child's '*socially inappropriate and difficult behaviour*'. In this way, parents reinterpret their position shifting from '*spoiled*' to '*unspoiled*'.

3.8 The interrelatedness of parental experience

It is evident from the review of the literature that the systems of the conceptual framework have provided a helpful lens for seeing the interrelatedness of the experiences of parents of children with autism. It is impossible to understand this parental experience without recognising the interactions between the various systems. For example, the experience of parental stress does not exist in isolation in the microsystem, rather these challenges are entwined with parental interactions in their external environment in the meso system. Likewise, one of the aspects depicted in the macrosystem is how wider societal views of autism are created through how autism is often framed through the 'medical model'. The view that autism is something that is intrinsically 'broken' has a trickle down effect through the systems and feeds into the meso system and how parents experience autism stigma.

3.9 Main findings from the review of the literature and identifying gaps in knowledge:

There is an abundance of literature about the parental experience of children with autism, with mothers' perspectives dominating this. Many studies focus upon experiences of stress, although this is thought to improve over time as parents eventually attach some positive meaning to their experiences. Despite the plethora of these studies, mothers still perceive their experiences are poorly understood. This lack of understanding of their reality is concerning, as the quality of life and outcomes for autistic children are seen as intertwined with their parents' wellbeing. Furthermore, studies indicate how views of autism have been misrepresented and how this has led to a failure to capture the full diversity of autism. There appears to be a relationship between misrepresented views and societal misconceptions of autism. Societal misconceptions seem to be related to shaping societal attitudes to autism, including stigma.

It is evident from the literature there are the following gaps. First, although many studies have been conducted about the parental experience of autistic children, the specific experience of parents of children with autism and LD, including other co-occurring conditions has been somewhat neglected and forgotten (see DePape and Lindsay, 2015, p580). Yet these are parents whose children often have a higher level of care need. Second, although the topic of autism stigma is well established in the literature, the issue of societal discrimination and exclusion continue to persist. This is problematic as it puts parents at risk of social isolation. Underpinning this issue is a lack of societal knowledge of autism and misunderstandings about the autistic child and their behaviour. Third, most studies exploring autism stigma have been conducted outside the UK, as such there are recommendations for

more UK based research to explore this issue (Lemmi, Knapp and Ragan, 2017). Returning to my first point, these autism stigma studies have also focused upon the experiences of parents of autistic children, often described in the literature as (*HF autism*), excluding the experience of parents of children with autism and LD. Fourth, these studies have tended to have medium size samples or been large-scale studies, which has highlighted a methodological gap requiring smaller scale in-depth approaches. Finally, few studies have also considered parental experience of inclusive attitudes.

3.10 Overview of the aims of this research

Building upon the existing work and the above gaps in the literature, I will outline the main topics to be covered in this research. First, through a broad lens this research aims to explore the everyday lived experiences of parents of children with autism and LD and other co-occurring conditions. Through focusing upon this group of parents, this study seeks to add another layer of insight about parental experience. Second, a further aim, through a narrower lens, is to examine parental attitudes towards autism. However, this research extends the focus to include both aspects of attitudes, the negative and inclusive. It therefore seeks to achieve a balanced view of parental perspectives and a wider view of how attitudes impact families' lives. In contrast to much of the relevant literature, this research will be an in-depth small-scale study, using methods designed to capture rich data. I return to these methods and layout the specific research questions in the next chapter.

4 CHAPTER 4: METHODOLOGY CHAPTER

4.1 Introduction

As explained in the introduction this research explored the lived experiences of parents of children with a dual diagnosis of autism and LD (for more details, see section 1.7). In the next sections, I provide an overview of the methodology, including explaining the phenomenon. I also explore the subject of researcher positionality and I reiterate the research questions. I return to my researcher position throughout this chapter, providing reflections upon how I perceive my researcher position supported the research, as well as some of the limitations.

4.2 Philosophical position and overview of methods

The methodological direction for this research is underpinned by my philosophical world view, which has developed from my own experiences of parenting my own child with autism and LD. Over the years I have learned to appreciate that autism takes many forms and that the different perspectives of parents of children with autism and LD are shaped by their different experiences. Preece (2014, p. 88) takes this position further emphasising that:

‘...a range of perspectives exist within families and between family members.’

It is my position that there is not one single truth or reality regarding parents’ experiences, which can be contrasted with the positivist view of a one truth (Walliman, 2001). I view parent’s perceptions are socially constructed from their subjective experiences and consequently my epistemological position is interpretivist.

Smith, Flowers and Larkin (2022, p 27) describe the situation of personal experience going beyond the ordinary:

‘Where ordinary everyday experience becomes ‘an experience’ of importance as the person reflects on the significance of what has happened.’

Likewise, the parents in this group do not have ordinary parenting experiences. Rather parenting a child with this dual diagnosis and other co-occurring conditions, is highly pervasive experience which impacts upon their daily lives in ways which are often difficult for others to fully comprehend.

Consistent with my philosophical position, I decided that qualitative methods for collecting data in words would best suit my own exploration of parent’s in-depth experiences. As qualitative methods are well established in the literature for research concerning the experiences of parents of children with autism (DePape and Lindsay, 2014). I chose to use a phenomenological methodology with IPA to collect this qualitative data from parents via two semi-structured interviews. The specific focus of the phenomena in this study was the exploration of the perceptions of parents who have a child with autism and LD, in relation to societal attitudes towards autism. This was informed through considering the interaction between the parent/child in the microsystem with others in the meso and other systems of the conceptual framework.

To reiterate, the data was captured from meeting with parents individually and conducting interviews at two separate times. The first set of data collection was aimed at capturing an understanding of the broader aspects of parental experience and using this data to co-

construct parent stories. As part of the process, I checked back with parents to ensure that the words in the stories truly reflected their individual experiences. In the qualitative literature this process of ensuring that participants are happy with how the researcher has portrayed their experience is described as member checking (Candela, 2019). According to Birt et al. (2016)

‘member checking, also known as participant or respondent validation, is a technique for exploring the credibility of results’ (p.1802).

In other words, it helps to support trustworthiness in the data, through avoiding researcher bias, but also enables the researcher to show the participant that their perspective is fully respected (Robson, 2011).

The data collected via the second interviews was intended to build upon the first set of data. In this interview, the aim was to capture in more detail parental perceptions of attitudes towards autism. A further aim was to consider how attitudes both positively and negatively impacted family functioning. The conceptual framework was also used to identify parents’ experiences of interactions, which suggested positive or negative attitudes towards autism. I return to discuss the rationale for choosing IPA later in the chapter (see section 4.5).

4.3 Researcher positionality

In research that uses interpretative methodologies, understanding the researchers’ experiences and how this positions them in relation to the research and the participants is important, as this inevitably influences the nature of their interpretations (Thomas, 2013;

Corbin Dwyer and Buckle, 2009). In the next section, I first touch upon the *'insider-outsider'* debates and then move onto explore my own researcher positionality.

4.3.1 Making a distinction between insider and outsider status
Much of the debate over the position of the researcher in qualitative research has centred upon the notions of the researcher as an *'insider'* or *'outsider'*, determined by locating the position of the researcher within the researched group (Gair, 2012). A researcher is defined as an *'insider'* if they have a shared experience, shared characteristics or have the same role as the participants (Corbin Dwyer and Buckle, 2009; Griffith, 1998). Whilst an *'outsider'* refers to researchers not sharing this experience or any of these features (Corbin Dwyer and Buckle, 2009). Consequently, it is asserted that the *'outsider'* researcher produces different knowledge, as their work is not informed by an *'insider'* knowledge of their participants (Griffith, 1998). In other words, the *'outsider'* researcher is likely to conduct their research with a different emphasis, collecting data that may differ from that collected by an *'insider'* researcher. Accordingly, both researcher positions are also likely to lead to different interpretations of the data.

Contrastingly, several scholars have contended that there is not a clear dichotomy between researchers as *'insiders'* or *'outsiders'*. One stance is that researcher position is more fluid and can only be understood by considering personal experiences and engaging in a process of reflexivity (O'Connor, 2004; Couture, Zaidi and Maticka-Tyndale, 2012). In conjunction to engaging in reflexivity, Couture, Zaidi and Maticka-Tyndale (2012) assert that an intersectional approach of understanding the different identities of the researcher is needed. This acknowledges how the multiple aspects of the researcher's identity, for

example, ethnicity, religion, age and gender intersect and impact upon the researchers' insider/outsider position (Couture, Zaidi and Maticka-Tyndale, 2012). Similarly, Hockey (1993, p.203) introduces the notion of the researcher as a '*partial insider*', as factors such as having a higher level of education, gender or age may separate the researcher from their participants and this may weaken their insider position.

Adding to the insider/outsider debate, Hellawell (2006, p.484) conceptualises researchers sit on a series of '*insider-outsider*' continua throughout the research process, sometimes as an '*insider*' and sometimes as an '*outsider*'. Contrastingly, some authors have suggested researchers can occupy a dual position of being both an '*insider*' and an '*outsider*' at the same time (Griffith, 1998; Corbin Dwyer and Buckle, 2009). This is particularly evident with researchers who have left their country of birth and have subsequently returned to conduct research with their home communities (Yakushko et al. 2011). Hellawell (2006) also challenges the notion of who qualifies as an '*insider*'? He asserts that providing the researcher has an intimate knowledge of the research group, they can be an '*insider*'.

4.3.2 Exploring my own researcher positionality
I propose my own parenting position was central to the interpretation of this research, as I have an extensive lived experience of supporting my son with autism and LD. I also have experiences of participating in parent autism training programmes, such as the NAS Early-Bird, navigating the special education system, healthcare system and experiences of having a social worker and accessing local short-break provision.

I suggest the recognition of my *'insider status'* is closely connected with feelings of identity. Shortly after my son's diagnosis I attended a class for parents of recently diagnosed children with autism and I reflect upon a sudden realisation of my own change of identity. I recall the course leader referring to parents in the group rather negatively, as *'belonging to the club no-one wanted to belong to'*. There after, the challenges of accessing support for my son only reinforced this connection. With regards to this research, I suggest identification with this group enabled a clearer recognition of my *'insider' status*.

I recognise my *'insider'* position worked at several levels of *'familiarity'* with the participants (Gelir, 2021). Unsurprisingly I had more in common with some participants than others (this is described in section 4.7.2). It is also important to acknowledge my academic experiences of studying for my MEd and my PhD research contributed to developing and altering my thinking about autism, arguably reducing my *'insider'* position to a *'partial insider'* (Hockey, 1993). Thus, I conclude that my researcher positionality is not definitive, I am an *'insider'* and sometimes inevitably an *'outsider'* (Corbin Dwyer and Buckle, 2009). Nevertheless, I believe there was still sufficient common ground to bring me close enough to the parents' own reality, to enable me to empathise with their lives, make sense and to provide an interpretation of their experiences. Later in the chapter, I return to my positionality as a main instrument for conducting interviews (see section 4.8.1)

4.4 Research questions and choice of methods

In this section I first reiterate the research questions, which aim to address the gaps in the literature (see section 3.9). Second, I provide a more detailed rationale for my choice of IPA. I also outline some of the limitations and consider what alternative methods could have been used.

4.4.1 Main research question

What do family narratives reveal about parental perceptions of societal attitudes towards autism and how does this impact upon family functioning?

4.4.2 Subsidiary research questions

RQ1. What is unique about the everyday lived experiences of parents whose children have a dual diagnosis of autism and learning difficulties?

RQ2. What do parents feel their relationships/interactions with individuals and service providers reveal about societal attitudes towards autism?

RQ3. How do attitudes towards autism help or hinder parents' ability to care for their children?

RQ4. What are parents' perceptions of attitudes towards autism from wider society?

4.5 Interpretative Phenomenological analysis (IPA)

IPA is concerned with exploring how participants make sense of a major life experience, which involves drawing on the individuals' reflections of why the experience is significant (Smith, Flowers and Larkin, 2009). In other words, IPA is concerned with exploring a phenomenon, but for the experience to be a phenomenon it must be a significant life experience. To reiterate, the phenomenon in this study was the exploration of the perceptions of parents who have a child with autism and LD, in relation to societal attitudes towards autism.

Smith, Flowers and Larkin (2009) assert that IPA is a qualitative, experiential and psychological approach, shaped by three main philosophical underpinnings, which I will explore below. The first commitment of IPA is phenomenology, which is concerned with the participants' perceptions (Smith, 2004). The philosophy of phenomenology originates with the work of Edmund Husserl. Husserl's phenomenology is a method of reduction which requires the '*bracketing*' of preconceptions, aimed at isolating the unique components of the phenomena or experiences under analysis, through attending to how people perceive and talk, rather than describing the phenomenon (Pietkiewicz and Smith, 2012).

The second commitment of IPA is that it positions the contributions of both the researcher and the participants as essential components of the research process. Participants are situated as experts on their experience (Reid, Flowers and Larkin, 2005). IPA also has an underlying commitment to viewing individuals as cognitive and linguistic (Smith and Osborn, 2008), which means it is assumed that research participants can effectively articulate their

experiences through language. IPA's strong commitment to hermeneutics or interpretation, recognises the central role of the researcher in making sense of the participants' experience (Smith, 2004). Thus, the aim for the researcher is to try to stand in the shoes of the participant and to understand their experience from their perspective, whilst also acknowledging that this is not entirely possible (Pietkiewicz and Smith, 2012). IPA equally recognises the double hermeneutic in the process of IPA analysis. This means that whilst the participant is trying to make sense of their experience, the researcher is trying to make sense of the participant, making sense of their experience (Smith and Osborn, 2008).

The third commitment of IPA is that it is idiographic, which contrasts with more usual nomothetic approaches to psychology. IPA's idiographic commitment is characterised by research projects with small samples, which focus on an in-depth examination of the meanings of experience for each participant. Likewise, a detailed analysis of each participants' experience is examined one at a time and only when all cases have been examined, can the analysis move on to looking across cases for convergence and divergence (Smith, 2004). It is only then that any general statements about the data can be made (Pietkiewicz and Smith, 2012). Another feature of IPA is that it takes an inductive approach, '*bottom up*' rather than '*top down*' which tries to prove or disprove a hypothesis (Reid, Flowers and Larkin, 2005). In other words, with IPA the research emerges from the participants' experience. In the next section I explore some of the weaknesses of IPA.

4.5.1 Limitations of IPA

One of the perceived weaknesses of IPA's approach relates to the underlying commitment of viewing individuals as cognitive and linguistic (Smith and Osborn, 2008). This means that it is assumed that research participants are effective at articulating their experiences through language. It relies heavily on the ability of the participants to describe their experiences through language in a way that fully captures the richness of their experience (Willig, 2008). I acknowledge this weakness and I sought to manage this through carefully selecting a purposive sample of parents who were willing and able to articulate their experiences. This is described in more detail in the discussion on the choice of sample, (see section 4.7).

Another criticism is the linguistic aspect of the IPA methodology. Words are seen as constructing rather than describing the reality of participants. Thus, interview transcripts tell us more about participants use of language, than their actual experience, which makes it difficult to have direct access to the reality of participants (Willig, 2008). Whilst IPA describes experience, it does not help us to understand why individuals have this experience and why there are differences between participants' experience (Willig, 2008). Another perception of IPA is that it is sometimes viewed as descriptive qualitative methodology. It is thought that this impression has arisen because some IPA studies have been carried out badly (Larkin, Watts and Clifton, 2006). In these instances, analysis is too easily satisfied at the level of description, lacking the required deeper levels of interpretation. Different levels of interpretation in IPA are discussed more in the section on analysis.

4.5.2 Why IPA and not Grounded Theory?

In considering whether to use IPA, I reviewed the alternative method, grounded theory, which is seen as sharing a number of similarities with IPA. Willig (2008) confirms grounded theory and IPA both aim to produce a cognitive map, presenting the individual or groups view of the world. Second, they both use a systematic process to identify themes and categories. Third, they both start with individual cases, moving to looking at the data across cases, eventually using a system of reduction. Fourth, both methods use shared analytic language, such as themes and categories that emerge from the analysis. In both cases the process of analysis is also iterative.

However, I assert that grounded theory differs in ways that makes IPA a more appropriate choice. First, grounded theory seeks to develop theory. This is incompatible with IPA's focus upon gaining understanding into the participants world (Willig, 2008), but without trying to generalise these findings. Likewise, another difference relates to the sampling, as grounded theory usually works with larger samples than IPA. Pietkiewicz and Smith (2012) confirm that large samples are not appropriate for IPA, as the aim is to carry an out in-depth analysis of the phenomenon and generally not to generate theory. Likewise, Smith, Flowers and Larkin (2022) reflect that typical sample sizes for IPA are becoming fewer, as researchers realise the benefit of focusing on quality over quantity. Overall, IPA was a better fit for this research, as it uses a more interpretative approach than grounded theory, through its commitment to the double hermeneutic.

4.5.3 Rationale for using IPA

IPA has traditionally been used for studies within health psychology (Reid, Flowers and Larkin, 2005; Pietkiewicz and Smith, 2012). However, the appeal of IPA as a methodology for examining participant experience has begun to surge into other fields, including autism. A recent study, Howard, Katsos and Gibson (2019) confirms that IPA is suitable for researching the experience of autistic individuals. These authors assert that an attractive feature of IPA is that participants are viewed as experts on their experience, creating an equality between the participants and the researcher. IPA has also been used to explore the experience of parents of children with autism or other developmental disabilities (Kimura and Yamazaki, 2013; Martins, Walker and Fouché, 2013; Tansley, 2014; Stewart et al. 2017) and the experience of parents of autistic adults (Griffith et al. 2012).

Some autism studies exploring lived experience have used alternative, but closely related phenomenological methods. For example, Woodgate, Ateach and Secco (2008) and Schaaf et al. (2011) both used the hermeneutic phenomenology described by Van Manen (1990). Woodgate, Ateach and Secco (2008, p.1075) sought to describe '*the essence*' of the experiences of parents of children with autism, whilst Schaaf et al. (2011) explored how sensory-related considerations affected family routines. However, whilst IPA may be considered a close relative to this phenomenological method, it is considered distinct as it is both a descriptive and interpretative methodology (Pietkiewicz and Smith, 2012).

Overall, it is evident that other related studies have successfully used IPA or other phenomenological approaches. This provides a sound rationale for using IPA in this research

to explore the phenomenon of the experiences of parents of children with autism and LD. In addition, the interpretative role that IPA assigns to the researcher fully utilises my positionality and interpretation of other parents' experiences to help illuminate meanings. Similarly, IPA's idiographic focus aligns well with my focus and commitment to examining parents' in-depth experiences individually.

In this chapter so far, I have provided an overview of the methods for collecting the data and how this is entwined with my researcher position. In the next section, I consider the ethical considerations for working with parent participants and the ethical issues related to my researcher position.

4.6 Ethical considerations and approval

There are many ethical considerations to consider throughout conducting research with parents of children with autism, particularly given the sensitive nature of collecting parental narrative experiences. The BERA (2018) guidelines were followed throughout every aspect of the research process. To proceed with the data collection for this project I needed to seek approval from the Ethics Committee of the University of Birmingham. As detailed in the Application for Ethical Review (see Appendix 1), some minor revisions were made to minimise risks and full approval was granted (Ref. ERN_17-0071). In the sections below, I outline some of the ethical considerations, some of my reflections about the challenges and the effect of my researcher position.

4.6.1 Being transparent about my researcher position

From the outset, I was transparent with parents about my positionality. This is documented in the parent information sheet (see Appendix 2). In this research, I felt that disclosing my position would help to build rapport and enable parents to be more open about their experiences (O'Connor, 2004; Smith and Osborn, 2008), particularly pertaining to those experiences which they might otherwise feel embarrassed to share with others. However, I tried to be cautious about sharing too much of my own experiences. I continued to remind myself that the interviews were about the other parents' experiences, not about my own. Contrastingly, some authors suggest that it is better for the researcher to not disclose their researcher position until at the end of the interview, as participants prior knowledge can result in their responses being biased (Smith and Osborn, 2008).

4.6.2 Mitigating conflict of interest with recruiting participants

The Ethics Committee of the University of Birmingham highlighted that there could be a conflict of interest if parents whose children attended the same school as my son, were to participate in the study. However, finding appropriate parents to interview, who had a child with autism and LD and were willing to find time and to talk openly about their experiences was potentially difficult. To find sufficient participants, I proposed to the Ethics Committee that I would only recruit parents from the lower/primary part of my son's school, mitigating any potential conflict of interest, as at the time my son was in the secondary department of the school. The Ethics Committee gave clearance for this.

4.6.3 Informed consent, confidentiality and right to withdraw

All interested parents were sent a parent information sheet (see Appendix 2). This explained the purposes of the research, the criteria for inclusion in the study, the process involved and how their data would be used. Parents were advised that interviews would be conducted sensitively and the potential risks of being involved in the research were explained. Parents were also assured that anonymity of themselves and family members and any other individuals or organisations would be protected by de-identifying their names and assigning appropriate pseudonyms. Parents were sent a consent form before the interviews took place, for their consideration (see Appendix 3). In practice, parents signed the consent form in person before the interviews commenced. They were reminded that their participation was voluntary and that they could withdraw from the study.

4.6.4 Reducing the risk of emotional distress for participants
I wanted to reduce the risk of emotional stress for parents. Therefore, I felt that it was appropriate to exclude from the study any potential parents who had received their child's diagnosis less than two years before. I judged this to be important, as these families could still be coming to terms with their child's diagnosis (Bayat, 2007) and I needed to safeguard as far as possible from adding additional pressure during this period of adjustment. Another factor that I thought would reduce the risk of emotional distress was being a parent of a child with autism and LD. As such, I felt I was well-positioned to be empathetic and conduct the interviews with parents sensitively. The parent information sheet (see Appendix 2) provided participants with information about support agencies, where they could seek further advice.

4.7 Choice of sample
My focus was upon capturing rich in-depth data about the experiences of parents of children with autism and LD. This I believed could only be achieved by using a purposive sample. As data in qualitative interviews is highly dependent on participants' willingness to talk, I aimed to select parents who, I perceived, would be willing to speak openly and honestly about their experiences (Thomas, 2013). Moreover, the research topic needed to be meaningful to those who participated (Pietkiewicz and Smith, 2012). These characteristics of the sample were critical to the research design. Since, if parents were not interested or felt unable to share their experiences openly, this would likely impact upon the depth and quality of the narrative data collected. Thomas (2013, p.137) proposes that a purposive sample can also be called '*non-probabilistic*', as it is not trying to be representative.

Authors have recommended a sample size of ten participants for IPA studies (Smith, Jarman and Osborn, 1999). However, to reiterate more recently Smith, Flowers and Larkin (2022) have observed a reduction in sample sizes. My aim was to have a sample of six parents with two points of data collection, which I felt aligned with the idiographic commitment of IPA. However, I had concerns about the potential for participant attrition over the data collection time (Thomas, 2013). Therefore, I decided to recruit an additional parent to try to de-risk the research project. Note, eight parents were in the final sample, as two were a couple (see section 4.7.2).

Smith (2004) suggests that if the data is particularly rich, IPA can be conducted on a single case. Although, this was an interesting possibility, I did not believe I could predict how rich the data captured from the experiences of a single parent would be. Also, it was not possible to rule out the possibility of a single parent withdrawing their data from the project, (see parent information sheet, Appendix 2).

To find a homogenous sample of parents (Smith, 2004), I defined a set of criteria:

(1) Each parent needed to have minimum of one child with a diagnosis of autism and LD.

Given this diagnosis, I anticipated that some children would have no or limited spoken language and other co-occurring conditions. Parents of children with autism, without LD, often described by parents as having Asperger's syndrome or 'HF' autism, were excluded unless one of their other children had a dual diagnosis.

(2) As stated above (section 4.6.4), a main diagnosis of autism needed to have been in place for at least two years.

(3) The child must have been attending an autism specific or special school and residing at home with the family.

(4) The parent needed to be the main carer and to be willing to talk openly about their experiences.

(5) All parents needed to be living within a sensible distance of my home, for time and financial reasons

(For more details, see ethics form in Appendix 1)

4.7.1 Approaching and recruiting participants

An overriding advantage of my researcher '*insider*' position was this provided invaluable access to potential parent participants (Blythe et al. 2013). Through attending parent training programmes and accessing short breaks for my son, I had over many years built a network of parents of children with autism. Moreover, I suggest that these shared experiences engendered unique feelings of trust and common purpose enabling the recruitment of parent participants. However, it should be noted that despite having this ready-made network of parents, for ethical reasons I was limited in terms of which parents I could recruit from my son's school (see ethics section 4.6.2). Whilst I fully appreciated the ethical considerations, it was nonetheless frustrating to realise that my '*insider*' position had created these limitations.

I proactively started the process of identifying and informally contacting potential parents early into my research project via email. I used email as a means of avoiding putting pressure on the parents, to gauge their willingness of participation and to make it easy for them to

change their minds about participating. With those who expressed an interest, I sought confirmation that parents fulfilled the defined criteria (see section 4.7). I sent a parent information sheet, providing full details of the project, (see Appendix 2). I kept in regular contact with parents via email, to build and maintain rapport (Thomas, 2013).

At this stage, I had identified five participants, but I still needed two more. I began to explore alternative methods for finding parents. First, I tried to proactively locate parents through attending a school coffee morning, which was more challenging than I expected. At the coffee morning, several parents initially expressed an interest in contributing, but most of the follow-up emails that I sent to parents, providing more information about the project, were ignored. Disappointingly, the 'coffee morning approach' only succeeded in recruiting one parent. I reflect that it did not help that the parents did not know me. Moreover, given the nature of their children and their care needs, they were already having to juggle a lot of other demands. Taking part in my research project, involved two interviews and it was therefore a sizeable time commitment. On reflection, I think having two interviews was off-putting and perhaps more parents might have been interested in participating in a single interview (Flowers, 2008).

Second, I tried to find a suitable participant through contacting local service providers. I anticipated that they would have an '*insider*' knowledge which would enable them to connect me with other autism parents. I initially contacted two leaders of a local play scheme for disabled children. Even though they were willing to try to help locate suitable participants, it proved difficult to find any parents willing to participate in the research. This

highlights some of the challenges of participant recruitment. I finally resorted to contacting the CEO of the same organisation, who was able to connect me with one suitable parent. Despite the challenges, I assert that being an *'insider'* gave me access to parent participants. I suggest that being an *'insider'* also engendered a feeling of trust and common purpose between myself and the parent participants and that this encouraged an on-going commitment, reducing the probability of participant attrition.

4.7.2 Details of the participants

I recruited a purposive sample of eight parents (seven mothers and one father, two parents were a couple), of children with a minimum of one child with a diagnosis of autism and LD, attending a special school. I assert that my *'insider'* researcher position connected me to parents at several levels of *'familiarity'* (Gelir, 2021). (1) Six of the parents were already known to me through my autism parenting network, but not personal friends. Two of these parents had previously participated in interviews for my MEd study and they had expressed a willingness to take part in my PhD research. (2) I was also a parent of a child with autism and LD. (3) Gender, except for one father, all the other parents were mothers. (4) As a mother of twins, I was connected to Ella (a mother of triplets), through our experience of multiples. I assert these levels provided an *'insider'* status that was a significant enabler in securing willing participants. I felt a strong sense that parents were willing to give up their precious time to contribute to this research project for the collective good of trying to improve understanding of the realities of their lives.

Whilst there were commonalities across the parents, the sample was also diverse. One parent had two children with autism and LD, whilst others had another child with autism, but without LD or another developmental disability (DD). One parent had a son and a daughter, both originally diagnosed with autism and LD. Although it was felt the LD diagnosis no longer applied to the daughter. Another parent had triplets, two with a diagnosis of autism and LD. Some children also had other co-occurring conditions. The children attended a wide range of different special schools from around the county. Table 1. below provides an overview of the sample. The diagnosis, communication and types of school were the parents own descriptions. (Post interview reflections about the sample can be found in section 4.9.2).

Table 1: Details of sample

Pseudonym names for parents	Children with autism diagnosis	Names of children/(age)	Diagnosis and age	Communication	Type of school	Other siblings
Jayne	2 boys	Tim (13) Felix (11)	Classic infantile autism & SLD 2 years and 3 months autism/Aspergers (HF) 8 years	Pre-verbal (PECS) Verbal (2-year delay)	autism specific school Mainstream	None
Helen and Charles	1 boy	Owen (13)	autism, epilepsy, DD & SLD 4 years (West syndrome was the initial diagnosis)	Single words gesturing	autism specific school	2 brothers one with ADHD, anxiety and SLD
Ella	2 boys from set of (triplets)	Jacob (6) Harvey (6)	Both autism & LD 2 years and 4 months	PECS PECS (earlier stage)	Both SLD special school with autism specific class	1 brother from set of (triplets) 1 older brother
Diana	1 girl 1 boy	Zara (13) Sam (11)	autism & LD 2 years Severe autism & LD PDA features & severe anxiety disorder 3 years	Very verbal Verbal	autism specific girls school autism specific school	None
Ana	2 boys	Matthew (12)	autism & LD, ADD and Tics 2 years	Verbal	autism specific school	Brother diagnosed aged 10 with autism (currently disregarding diagnosis) several step siblings
Iona	1 boy	Gabriel (12)	Epilepsy, Tuberous sclerosis (TS), SPLD and sensory processing 2.5 years	Vocalisations	autism specific school and complex needs	Younger sister
Becky	1 boy	Joshua (15)	autism & LD (moderate) 2.5 years	Verbal	SLD special school & autism	2 older brothers

4.8 Overview of procedure

In this section I will provide an overview of the procedure for the data collection. To demonstrate rigour, a systematic process was used (Robson, 2011). Two, face to face, semi-structured interviews were conducted with parents. After the first interview, a process of member checking was used with parents to ensure the credibility and trustworthiness of the data (Robson, 2011). For more details, see section 4.2.

Using a location where parents feel most comfortable is widely acknowledged as critical in eliciting rich in-depth data (Thomas, 2013). With one exception, the interviews took place at the parents' home addresses, during the daytime when their children were at school. One parent preferred for both their interviews to be conducted at my own home on a Saturday. The first interviews took place between May and July 2017 and ranged between just over 1 hour - 1 hour and 47 minutes in length. The second interviews took place between March and June 2018 and ranged between 1 hour and 20 mins- 2 hours long. All the interviews were audio recorded with consent from parents and later transcribed verbatim. I kept a reflective diary and after each interview took place, I noted down my initial thoughts and ideas to use during the analysis.

4.8.1 Design of instruments

In this section I will provide an overview of the design of the instruments for the data collection, as well as highlighting potential issues. As a fellow parent of a child with autism and LD with *'insider'* knowledge, I was the main research instrument for conducting the interviews. Being an *'insider'* brings obvious benefits, as this improves the ability of the

researcher to establish rapport, which in turn provides the opportunity to extract more in-depth data (Corbin Dwyer and Buckle, 2009). However, there are also potential pitfalls. For example, shared experience can result in an assumed understanding between the researcher and the researched (Blythe et al. 2013) These authors identified spoken phrases, for example '*You know what I mean*', which indicated that the participant felt it was too obvious to mention. This sense of sharing the same reality, undoubtedly creates a warm feeling between the researcher and the participant. However, participants may fail to share important information and if the researcher assumes too much and does not probe for further details this can be compounded (Blythe et al. 2013). Thus, in conducting the interviews, I needed to be aware of these potential issues.

Interview schedules was another instrument for the data collection. The interview schedules for both the first and second semi-structured interviews (see Appendix 5 and 11) were informed from the literature and the conceptual framework. The data collected in the first interviews also helped to inform the second interview schedule and subsequent refinements were made. As the aim of the first interview was to ask parents to share their stories, positioning them as experts on their experience (Sherwood and Nind, 2014), the interview schedule was prepared only as a guide and aide memoire. Reflecting on both my experiences of conducting interviews for my MEd and being participant in interviews for other researchers, I anticipated that a pre-prepared interview framework, might help parents to organise their thoughts. An informal piloting of the first interview schedule was carried out with a parent of a child with LD, who was not a participant, to assess the suitability of the questions. Some refinements were made. An additional short form was also

designed for gathering profile information about the parent's child, for the beginning of the first interview, (see Appendix 4).

A unique instrument for supporting the data collection was a blank version of the conceptual framework, designed as a visual tool, to help parents map out their interactions with others in relation to their child. A pack of coloured stickers, red, amber and green was also used to help parents to think clearly and identify the quality of their relationships. Utilising the completed frameworks, parents were asked in the second interviews to share their experiences about attitudes towards autism. I argue that the conceptual framework contributes an innovative approach, highlighting the benefits of using visual tools in interviews for capturing parental experience (for more details, see section 4.9).

4.9 First interviews- Data collection

At the start of each interview, I explained to each parent the background to the research including my journey so far from MEd to PhD. I reiterated the purpose of the study and that I was interested in understanding more about their experiences of living with a child with autism, in particular autism and LD, as this segment of parents is less researched. I reminded parents how long the interviews would take, and that there would be a second interview. I also explained that the focus of the second interview would be upon their experiences of attitudes towards autism. I also touched upon some of the ethical considerations, double checking that parents were happy for the interview to be recorded and reminding them about their right to withdraw from the study. Each parent was asked to sign a consent form before the interview proceeded.

I proceeded with taking some brief profile information about the child's diagnosis and overview of the family, (see Appendix 4). Afterwards, there were two parts to the interview. First, to capture a narrative account of the parents' experiences. Then and in preparation for the second interview, to use the conceptual framework to understand parent interactions with others. My original thought was to conduct the interview in this order. However, after some reflection I decided to do this in reverse for several reasons. First, the conceptual framework task would provide an opportunity for the interview to warm up. It would also give me some information about the parents' experiences and an opportunity for me to be a little more prepared for what to expect from the parent's narrative. I was also conscious of not having enough time and did not want the conceptual framework aspect of the interview to be rushed and squeezed into the final part of the interview.

Overall, I used a flexible approach during the interviews, first discussing the conceptual framework and then moving onto the parent story and back again as parents thought of other ideas to add to the framework. I think this approach worked well as on several occasions, parents thought of aspects to add to the conceptual framework. I explained to each parent that the conceptual framework was intended to represent their parent/child world. I showed them the example below (see fig. 7).

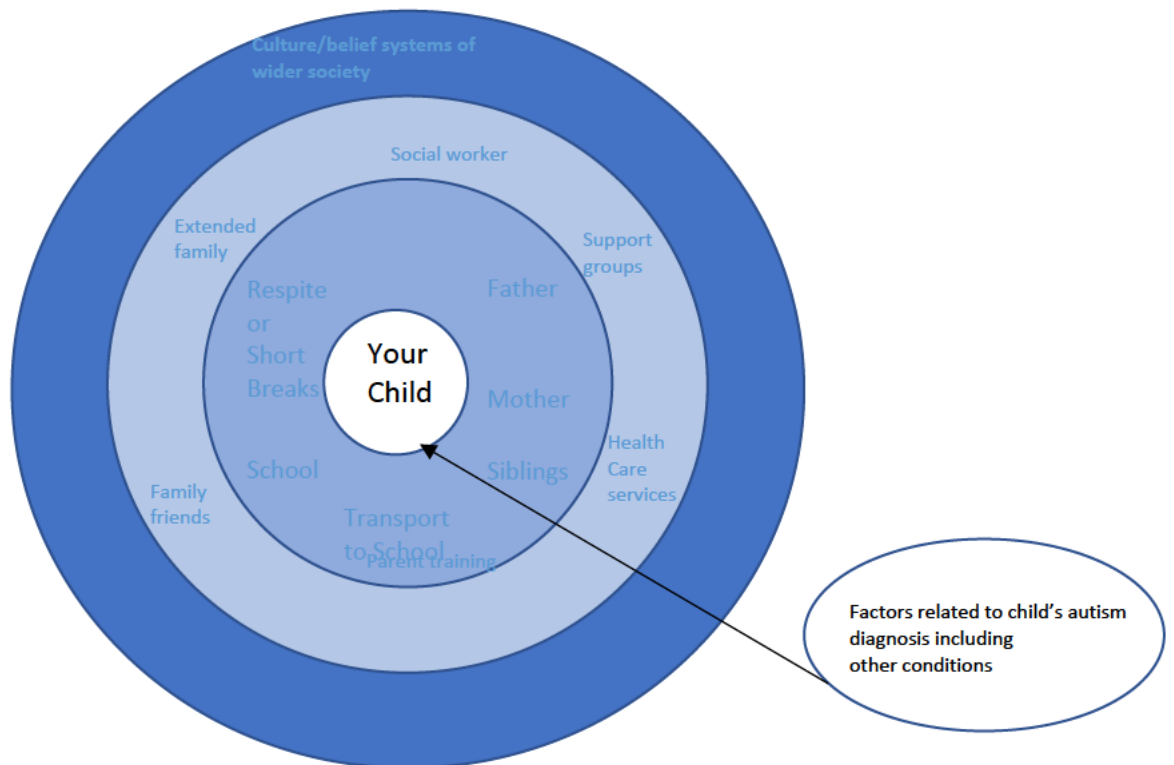


Figure 7: Simplified framework for use in parent interviews

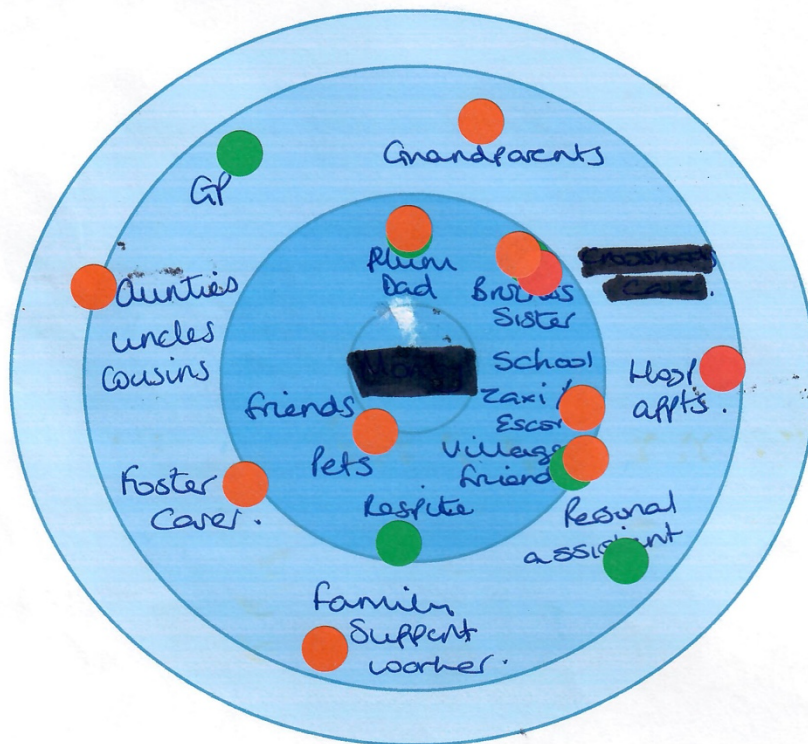
I systematically asked parents to tell me about the individuals, or organisations that they encountered on a regular basis and less frequent basis. Then I provided a blank framework for them to map their interactions related to their child with others onto the framework. Moving outwards from the child/parent dyad in the microsystem, this began with plotting immediate family members and other significant daily contacts they had interactions with, such as the child's school, transport to school and respite services. Less frequent contacts such as, extended family, social worker or healthcare services were usually assigned to the next concentric circle. The different layers of the framework and distance from the parent/child dyad, denoted the relative daily importance of these interactions.

When this process had been exhausted, parents were then asked to think about how supportive or unsupportive each of the interactions was and to assign coloured stickers (red/amber/green in the form of a traffic light system) to each of their entries on the framework. With red denoting unhelpful/unsupportive relationships and green the opposite, I propose that the visual representation was a useful method that facilitated parents to be able to identify individuals and service providers in their child's world. It also worked at the beginning of the interview as an icebreaker, enabling rapport. Virtually all parents decided to spontaneously talk about their experiences of grandparents' attitudes. As little is known in the literature about the topic of grandparents' attitudes, I assert that the framework was instrumental in uncovering and elevating this important aspect of parent experience. See fig. 8-14 below, for photographs of the completed parental frameworks. These have been redacted to protect all identities.



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Blank conceptual framework



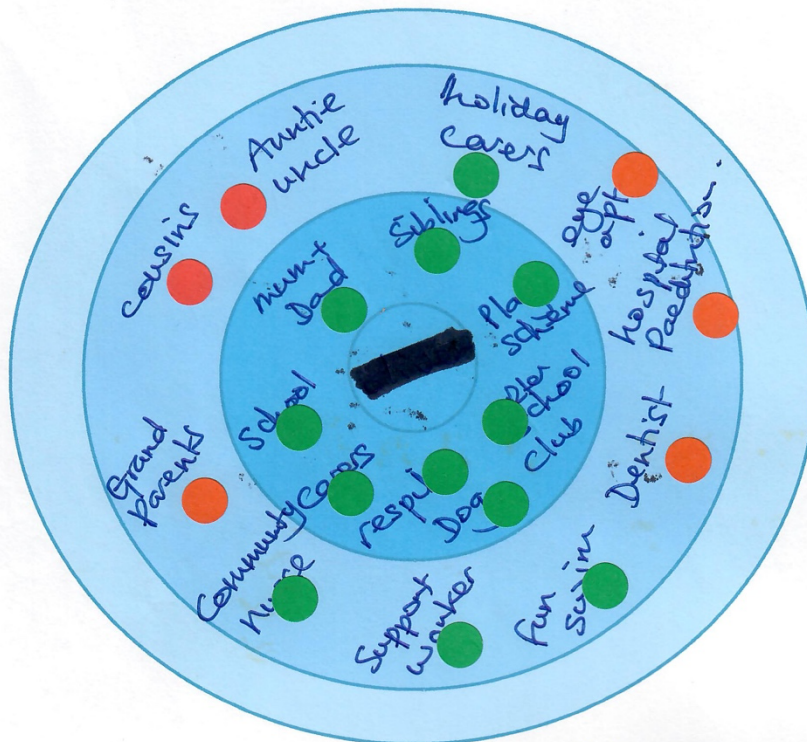
1. GP
2. Grandparents
3. Siblings.

Figure 8: Completed framework for Ana



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Figure 9: Blank conceptual framework



(C) →

All red.

Parent training
sister

→ shifted out. ●

~~Parent~~ Grandparents
(H)

Centre → shifted out.
not able to cope

careers changed — because they couldn't
cope

Friends →

Figure 9: Completed framework for Charles and Helen



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Blank conceptual framework

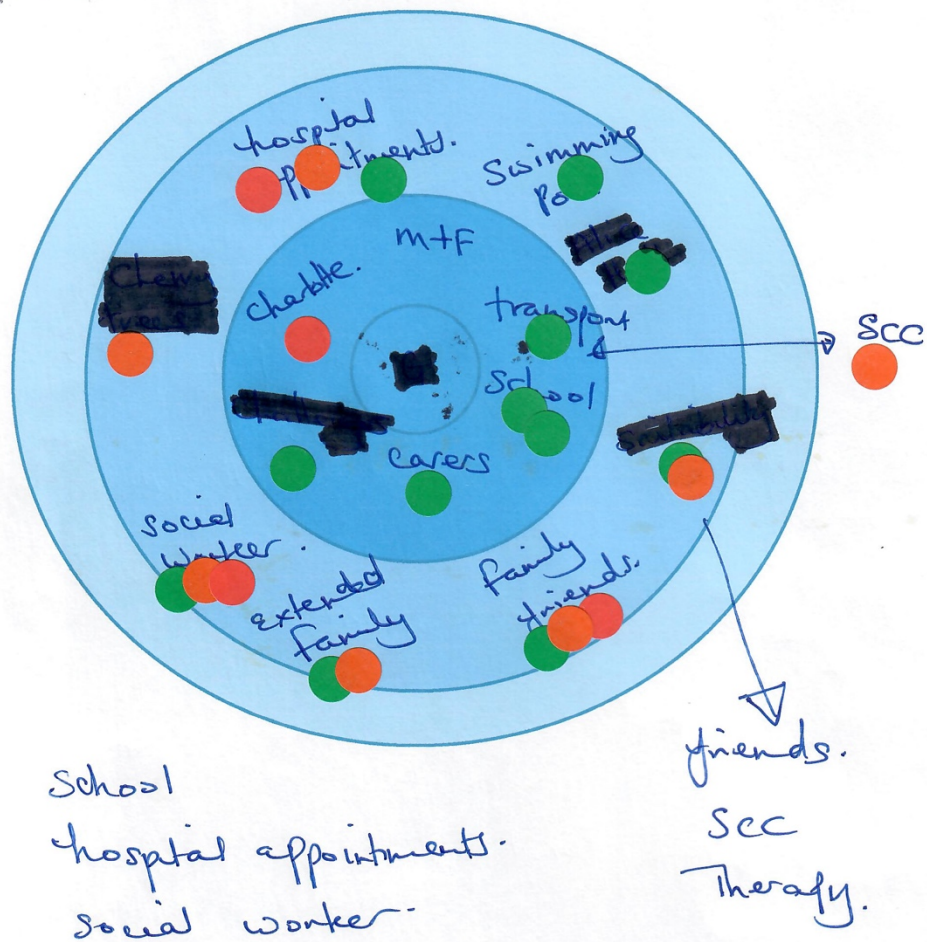


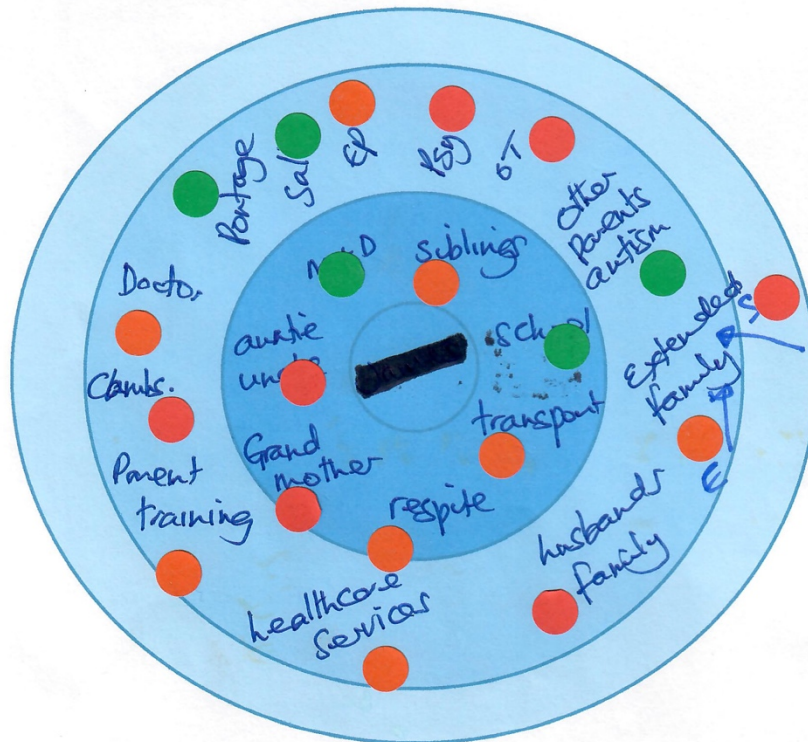
Figure 10: Completed framework for Iona



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Becky

Blank conceptual framework



Teachers
extended family
siblings

Figure 11: Completed framework for Becky

1. Grandparents
 2. Strangers
 3. Uncles
 4. Teacher



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Blank conceptual framework

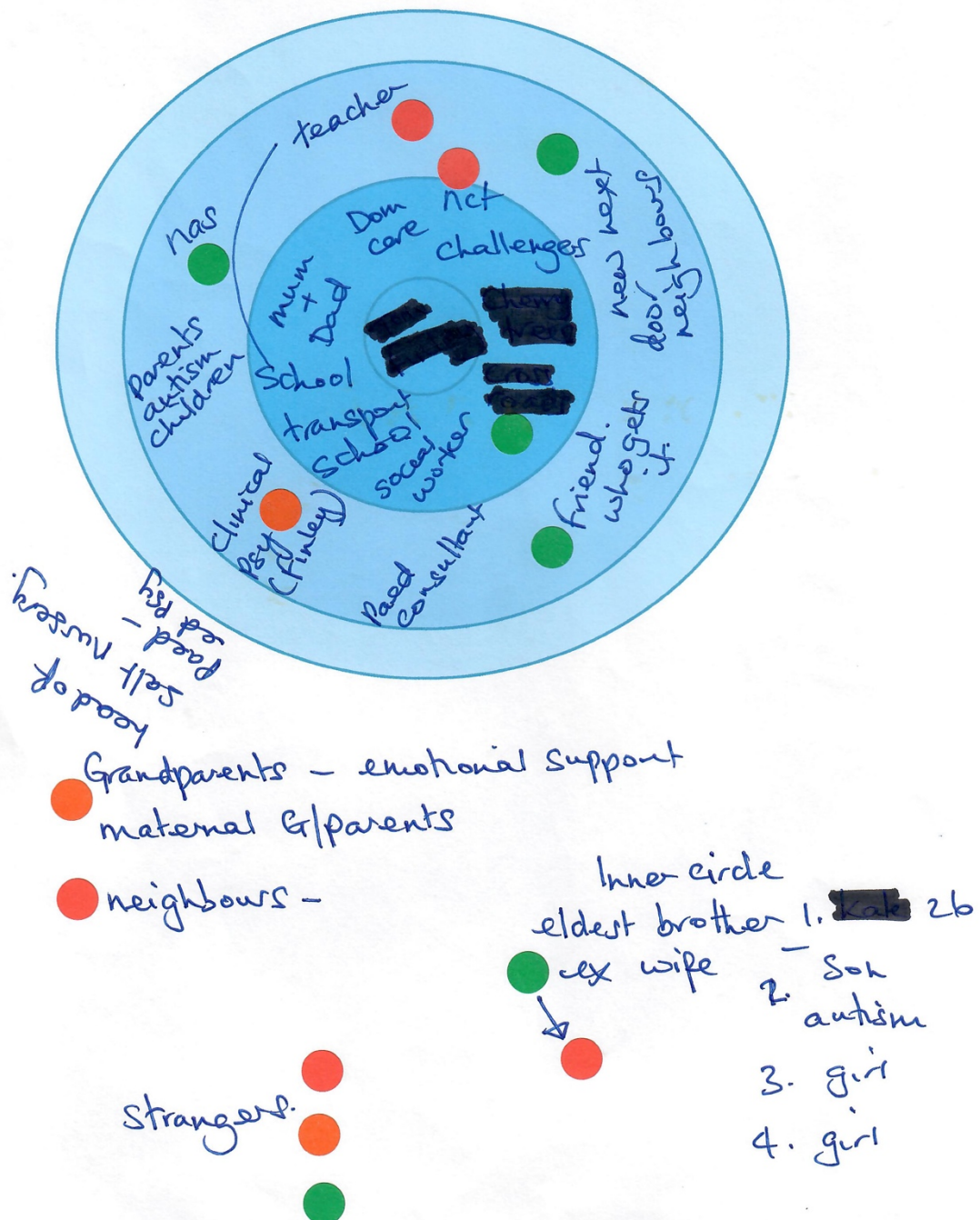
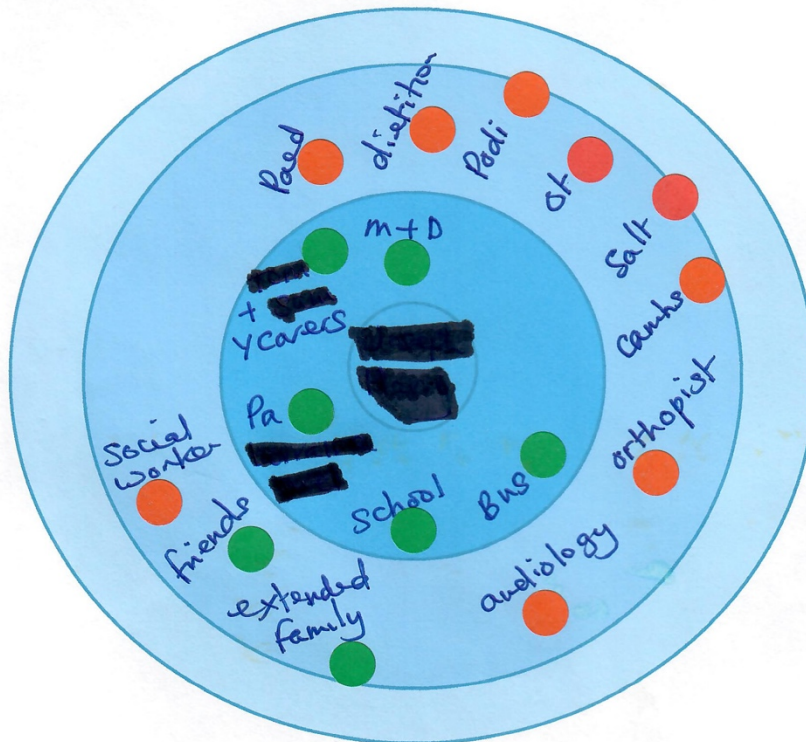


Figure 12: Completed framework for Jayne



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Figure 13: Blank conceptual framework



1. Friends (distance)
3. SW Salt
4. Pa.

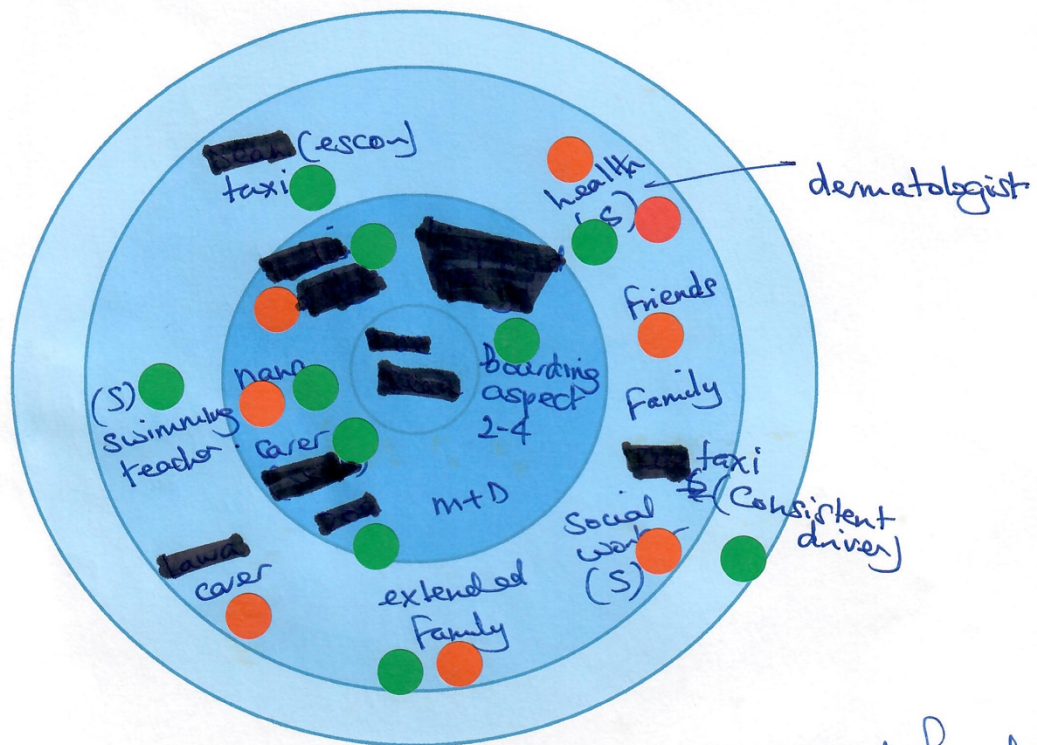
2. ~~challengers~~
~~Cherry trees~~
parents
(absent) ●

Figure 13: Completed framework for Ella



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Blank conceptual framework



- Social life
 - ● Parent training - ta
 - ● Learning disability - ta
 - ● S breaker refused to go
 - ● S - family link - Boarding at school
 - S - Refusal.
 - 2 - outgrown.
1. Extended family
 2. Swimming teacher
 3. ~~taxi~~ school.

Figure 14: Completed framework for Diana

After completing the conceptual frameworks with each parent (as above), I felt that they were more at ease and in a good position to openly tell me about their experiences. This part of the interview involved capturing a narrative account of the parents' experiences of living with a child/ren with autism. I explained that I would write their story, but they would have the opportunity to reflect on this version and propose revisions, until they were happy that the account reflected their experiences.

In asking parents to tell their story, a general open-ended question was used to frame the interview as follows:

- **Tell me about your experience of parenting your child with autism?**

It was left entirely for the parent to decide what they wanted to share. I tried to impress upon each parent that they were free to tell me their story in their own way and as such what they told me could be different from another parent's story. Moreover, they should not think that there were right or wrong answers and I needed them to be honest as possible. However, I anticipated that the question may be too open and that parents may wonder where to begin? Consequently, I scaffolded this with further questions following a timeline, going back in time, to the present and then looking to the future.

Parents were asked to:

- **Tell me when you first had concerns about your child**
- **Tell me about the diagnosis and life afterwards**
- **Tell me about finding a suitable school**
- **Describe a typical school day and non-school day**
- **Thoughts about looking to the future**

The above questions were an aide memoire and could be completely disregarded (Thomas, 2013). This approach was intended to give a voice and a level of control to the parent, reducing the traditional expert position of researchers (Sherwood and Nind, 2014). I believe this approach for collecting parents' personal and sensitive data respected the individual nature of their experiences.

From the outset before parents began with their story, I explained that I was going to try to say as little as possible, as my words might disrupt the flow of what they were trying to say and not to misread my silence to suggest a lack of interest in what they were saying. I found this to be a difficult balance, deciding when to step in to try to show support and encouragement versus remaining silent. There were times when parents seemed to be ashamed or embarrassed about some of their experiences. Often these were things that I could identify with, and I found myself slipping into a natural empathy of explaining that I had experienced the same or felt the same. I feel this encouraged parents to feel less embarrassed or ashamed and they began to relax and reveal more. For example, a parent told me about her child's narrow range of eating and episodes of their child absconding.

There were other times when a parent might pause asking for reassurance checking that what they were saying was helpful. Some parents became emotional and quietly weepy during the interviews. I was obviously conscious of my ethical responsibilities to each of the parents and I did not want to cause any upset. I tried to carefully monitor these situations and when appropriate I paused the interview for a time to give the parent time to re-set or I moved on to another question (Smith, Flowers and Larkin, 2009). Interestingly many of the parents commented that the process of reflecting across the whole of their autism experience and co-constructing their stories, was therapeutic. Likewise, parent narratives as a form of catharsis have been noted in previous research (Fleischmann, 2005; Altieri and von Kluge, 2009).

In the next two sections, I offer some reflections about parents understanding of the conceptual framework and the recruiting participants.

4.9.1 Reflection on parents understanding of the conceptual framework
Parents listened and mostly understood my explanation of the purpose of the conceptual framework. However, one parent immediately assumed she knew all about it. She described the concentric circles as '*ring of support*' and explained that this was a term her social worker had used to try to determine the family's informal support. This prior assumption was a surprise and I had to think carefully about how to manage the situation. I decided to explain the full purpose of the framework to the parent to ensure that there were not any misunderstandings. Some months later, I coincidentally attended an information day about Education, Health and Care (EHC) plans (my own son, who had Statement of Education

Needs was going through the transition of moving to an EHCP and I needed to understand the process). I became aware that determining a family's '*ring of support*' constitutes one part of the EHCP process. If I had been aware of this before I conducted the interviews, I would have been more prepared.

4.9.2 Post interview reflection about recruiting parent participants
Except for Ana, I had met all the other parents before the first interview. Being unacquainted with Ana, I reflect that I found this first interview challenging. Unlike with the other parents I felt like an '*outsider*'; there was no instant warmth and shared empathy, maybe even a suspicion about my motives. This interview was the shortest, lasting for just over an hour. I was left wondering if Ana had refrained from revealing her experiences as openly as the other parents. Thus, my experience correlates with the view that rapport and acceptance is not a given and may take time to develop (Yakushko et al. 2011). Having said this, during the second interview I felt that a rapport with Ana had started to develop, resulting in a longer interview of almost 1 hour and 30 minutes. Overall, I was relieved that I had met all the other parents before the interviews.

4.10 Reviewing the data and co-constructing parent stories

In this section I explain the process of co-constructing parent stories. My approach involved working actively with parents to co-construct their individual stories (Sherwood and Nind, 2014). The aim of collecting parent narratives was to provide a background picture of each parent's experience. It was also an important foundation for the second set of data.

The process of reviewing the data began with transcribing the interview transcripts verbatim. I re-listened to the recordings several times again, also noting any laughter, emotional upsets, or significant pauses. With so much data, this proved to be a long-winded task. Whilst I could have considered getting someone else to do the transcribing, persisting with this task alone provided an opportunity to fully immerse myself in the data. Listening to each audio-recording again, I could completely visualise myself in the interviews sitting in front of the parent again. I felt that each interview came alive, which seemed to make it easier to make sense of my interpretations. Through double and triple checking the audio-recordings, I frequently realised that I had missed words. Sometimes these were critical words, which altered my interpretation of the sentence, or I had misinterpreted what the parent meant. This links with appreciating the different levels of the hermeneutic circle, for example single words can change the meaning of a sentence (Smith, Flowers and Larkin, 2022). Thus, I reflect that even with an audio-recording of an interview, without sufficient checking it is possible to miss important meanings.

After fully transcribing each interview transcript, I focused upon one interview at a time. I carefully re-visited each recording again, until I was fully immersed in the story. Sherwood

and Nind (2014) describe revisiting the audio-recordings six times. As I listened to each parents' individual story, I reflected that they were often telling several stories that were related to each other. However, these stories tended not to be told in chronological order, as the parent moved back, and forth as new thoughts occurred to them. In this way the sequence of events became jumbled. In reviewing the transcripts, part of my task was to restore some order to the stories. For each transcript, I began to organise the data drawing out the themes that appeared important for individual parents through a mapping exercise (Thomas, 2013). For each of the stories, I created a mind map with tentative themes to help organise my thoughts, (for example, see Appendix 8). Initially, I utilised the software package Nvivo to help manage this. However, overtime I found constructing simple mind maps for each parent, using Microsoft word or Power Point, was more helpful for organising my thoughts and visualising the interconnections between themes. I also kept a reflective diary. Sherwood and Nind (2014) stress that identifying themes is worthwhile, but rather than seeking similarities and differences in the data, they propose that it is important to ensure individual parent experiences are maintained in the co-construction of their stories.

I approached the writing of each of the parent stories through following the structure of the interview, but with flexibility. I chronologically reconstructed the stories, with the individual and significant themes weaved throughout (for example, see Appendix 9). Each of the stories began with an introduction, to provide background about the parent, key information, such as the age of child and diagnosis was highlighted in bold in the text, so this could be quickly picked out by the reader. Next, the early days prior to the child's diagnosis was explored, which flowed into the parents' experience of the diagnosis and finding a

suitable school. The stories then moved to the present-day, exploring topics such as what a typical day looked like, what made life challenging and what it was like taking the child out into the community. Stories were written in the first person, so that they read as if the participant had written the story themselves. I tried to imagine stepping into the same shoes as each of the parents, immersing myself in their world, as far as this is possible, to write the story from their perspective. Although it was my interpretation of their experience, I wanted the parents to feel that the narratives reflected their story.

After I had completed drafts of all the stories, I provided parents with a copy of their story via emails. I wanted to check back with parents to ensure that the words in the stories truly reflected their individual experiences. This draft version was my interpretation of their experiences and was not the end of the process. I then arranged to meet parents for second interviews. During these interviews, I discussed face to face with each parent the revisions that they wanted to make. Parents were reminded that this was their story, they were the expert on their experience and thus to be critical of my account. Riessman (1993) confirms the importance of asking participants for their comments.

Five parents requested revisions to the stories. These revisions included correcting errors in the accuracy of their child's diagnosis and changing wording to reflect stronger emotions, from '*cross*' to '*angry*'. One parent wanted a change of wording to reflect that the special school they had selected for their son, was not really a choice and should therefore not be viewed as a '*preference*'. This parent felt that versus mainstream schools, there was a limited range of choice of special schools. Changing words is significant as it links back to the

hermeneutic circle (Smith, Flowers and Larkin, 2022). In other words, parents seemed be conscious that changing a single word in a sentence could completely change the tone and meaning of what they wanted to convey.

Each of these stories were reworded carefully and sensitively. This required listening to the parent comments in the sections of the audio recordings multiple times. This was an iterative process requiring me to continue to reflect upon my interpretations of each story, in order to make the revisions. The amended stories were re-sent to the parents for any further comments or approval. The process only concluded when the parent was completely happy with the re-writings of the story. The final stories were co-creations between parent and researcher (Sherwood and Nind, 2014) and reflected a double hermeneutic (Smith, Flowers and Larkin, 2022). In other words, there were different layers of interpretation. Parents had verbally provided an interpretation of their experiences, in turn I had interpreted their words and produced a written account, which parents had critiqued. I suggest that this process of member checking minimised the limitations of my own biases and interpretations and thus increased the credibility and trustworthiness of the study (Robson, 2011). I also assert that the active co-construction of parent stories was an ethical process, as it helped to re-position the parent and researcher as equals. I propose that the finished stories are, in their own right, research products (Koch, 1998) and added another layer of richness to the research. Parents were pleased and grateful to have a written account of their experiences to keep and reflect upon. Many commented that they found it emotional reading their story. (See section 4.10.1 below, for an example of a co-constructed story. See Appendix 10 for the other 6 stories).

4.10.1 Example of co-constructed story – Ella’s narrative

Introduction

Ella is the mother to three little boys. Ella’s boys are **non-identical triplets** and they are **six years old**. Harvey and Jacob, **two of the triplets, have a diagnosis of autism and severe learning difficulties. Their diagnosis was received when they were two years and four months old**. They both attend the same special school and are in the same class. Sebastian is the remaining triplet. He is typically developing and attends a mainstream school. In addition, Ella has an older son, Theo who is nearly 20 years old. Ella’s narrative, told in the first person, tells the story of living with her children, through the early days and getting a diagnosis for Harvey and Jacob and the challenges beyond. Although, her story is centred around her two children with autism, she also describes the challenges of supporting and balancing the needs of her other triplet son and likewise her older son.

The boys are natural triplets. They were born eight weeks early by emergency C section and spent ten weeks in special care. Harvey and Jacob were the first to come home, whilst Sebastian remained in hospital. Pretty much straight away I knew that there was something not quite right with Jacob. He had only been home for a day and he became very agitated. He popped a hernia and was admitted to hospital to have an operation, but it was in a different location to where Sebastian was. It was absolutely awful having my three babies in three different places. Harvey was at home, Sebastian was still in special care and Jacob was in a different hospital. Even though Jacob was healing, I started to have a feeling that something wasn’t right, he wasn’t a happy baby. I remember sharing this with my husband,

that I couldn't put my finger on exactly what it was, but my gut instinct was telling me at the time that something wasn't quite right. It wasn't just eye contact, he was never very settled, quite agitated and miserable. A couple of months later, I started to have similar feelings about Harvey. He wasn't agitated like Jacob, but he was very quiet, almost in another world. At the time I didn't know it was autism, but I knew that something just wasn't quite right. I recognised that something was wrong with Jacob at four months and then with Harvey a couple of months later.

When the boys were nine or ten months old we decided to move to the South East of England, my husband was based there for work and had been commuting. We decided that we wanted to be together as a family, including Theo. In the meantime, I had seen my health visitor and expressed my concerns about the boys, yet nobody really took much notice. Harvey and Jacob were having some difficulty with their necks, as a result of the position that they had been in the womb when I was pregnant. Consequently, each week they were having some physiotherapy to help improve the movement of their necks. When we moved to this area, their treatment transferred and a lady visited from the local NHS clinic. Initially, I decided to not to say anything, to see if she noticed anything about the boys. Within a few minutes she asked me if I had any concerns and I explained that I did. It had also become clear to me that there was not a lot of social element to anything they were doing and they were behaving quite differently to Sebastian. I don't think it was necessarily obvious to anyone on the outside, they just looked like three little boys toddling around. However, as I was with them all the time I could see the difference. The lady from the clinic visited again with her manager and they used a tick box questionnaire to review all the things the boys

could do and couldn't do. We were referred almost straight away to see the paediatrician. It was at this appointment that autism was first suggested as a possible diagnosis, the boys were 14 or 15 months old. We were given some literature to read and it was suggested that we went away and got used to the word autism. I was just so thankful that someone else could see it.

At this time Jacob and Harvey had begun to regress and key words such as 'mum mum' and 'dad dad' had gone by the time they reached 18 months. I also began to have dietary issues with Jacob and Harvey. In the beginning they would practically eat anything, my three boys would be in a row, munching away. However, Jacob and Harvey started to reject foods and their foods quickly diminished to three or four key foods. By contrast, Sebastian continued to eat a wider range of foods. By two years and four months, even before receiving the formal autism diagnosis, we knew that they were autistic. My husband and I had read lots and spoken to the National autistic society (NAS). We knew that this was the diagnosis, they ticked every box; from the social element, to being non-verbal. They couldn't understand any verbal instructions, they had issues with food, weren't able to use a knife and fork and still can't now. There were also sensory differences, they did not want to be around loud noises and with lots of people. They were babies and even now they are still babies.

When we received the formal diagnosis we began to get more support, I opted to have a social worker for the boys, so that I would hopefully have their support for sorting out schooling. I also attended an autism course at the hospital and I came in contact with parents with older children, who had only recently received their child's diagnosis. They

were literally on their knees with their children. Their experiences motivated me to find out as much as I could to help my boys. I thought, I am never ever going to let my children suffer unnecessarily, for the sake of what my family or friends might think.

Finding a suitable school was a stressful experience. The boys are not very good with travelling and they find it stressful in traffic, so we looked at two special schools and a mainstream school with a special needs unit attached, all within a 20 mile radius of home. We also looked at the boys' current special school and immediately got a good feeling, it isn't a large school and there are small numbers of children in each class. The environment is low distraction, plain painted walls and everything is very calm and the children in the school seemed to be very happy. We made the decision that that we would like this school for the boys. However, I never envisaged that our children would go somewhere like this, it broke my heart. It wasn't that the school was awful in anyway, it's just that I was probably a bit naive thinking that these sorts of schools full of children didn't exist. I was also concerned that in choosing a special school we might be putting an extra label on the boys. Yet, I knew in my heart that as the boys are so vulnerable, this school would be more suited to them, where they would make progress and be able to cope. I knew that they needed to be in a small class with a lot of 1:1 support, as they were not independent at all and still in nappies. Also, the noise levels in mainstream school would have been too much for the boys and I felt that it would have been terrible with the bullying.

At the time that we were looking at schools, the boys started having Portage (home visiting educational service) once a week. They also had speech therapy, but this was very limited

and everything was shared. We were not in a position to fund anything ourselves as it would have cost thousands of pounds. The boys needed some pre-school provision, so we applied for the pre-school autism nursery attached to the boys' current school. However, the boys didn't get a place, no alternative places could be found and so the boys had no provision, prior to them reaching school age. Furthermore, the boys were at home with me day after day and I had no help with them. I was almost totally cut off, isolated from the outside world. Other than putting the three of them in the buggy and walking around, I was stuck in the house. I used to walk miles every day, never really seeing anyone and just waiting to see my husband or Theo come home, so that I could have a conversation with someone. The boys needed some provision, so my husband and I decided to escalate the matter with the Director of Education for the area. She visited us at home and we insisted that something was done to provide some schooling for the boys. We were quite willing to be flexible and suggested that the boys shared some provision, perhaps with one doing a morning and the other doing an afternoon, just as long as they had something.

The social worker made an assessment of our family situation. When my husband was at work, she would come out in the community with me and spend time at home with me. I wanted to demonstrate to her what it was like day to day. It felt so bad, I honestly felt like I was doing a prison sentence. I recall saying to my husband that I felt I would be probably be having a better life if I'd murdered someone! The social worker could see how desperate things were. The necessary paperwork was completed by March of the next year and the boys were offered a place to start at the autism nursery at the school for the September. They had one year in the nursery, the following year they went into the reception and now

they are in the class above. As they were of school age when they started at the nursery, this has in effect put them behind a year.

In the interim, before the boys started at nursery, funding was provided to enable the provision of carers to help me with the boys. They were provided through social services via their preferred supplier. This was the beginning of a series of horrendous events. One day whilst I was taking Sebastian to see his new school, my husband had gone to the park with the boys and one of the carers. He was pushing Jacob on the swing and the carer was looking after Harvey and he turned around to find that the carer had disappeared with Harvey. My husband was going out of his mind, asking everyone had they seen Harvey and half an hour later the carer reappeared with Harvey. On a different occasion a carer was helping me with the boys at home and my wedding rings disappeared never to be found again. This was really upsetting as my rings are things I can't replace. I was not only trusting these people with the house, but I was trusting them with my children. At other times carers arrived at my house still drunk from the night before and others couldn't get here, as they were due in court for failing to pay their council tax or they had lost their driving licences through drunk driving. In this case, I ended up needing to go and collect them from home. I felt almost like a Samaritan on top of having three little boys, trying to get them ready to leave the house and no help. During the summer, a couple of weeks before the boys were due to start at school the caring provider could no longer provide any staff. I contacted my social worker and explained that I couldn't go on like this, I needed some decent help. I honestly felt like putting my coat on and walking off the end of a cliff...

I decided that the only option was to supply my own personal assistants (PA's) through direct payments. I put adverts at a couple of the schools, through Netmums and a local agency, but it was difficult to find the right people. I set strict criteria for who I would take, as they needed to be right for the boys. Some of the people who contacted me about the positions seemed worse than what had gone before, it felt like hell. Eventually, I found a male PA and in the beginning this worked well. However, he started to be unreliable. By now the boys were at school and fortunately a staff member from the boys' class offered to help with them. They were obviously already familiar with her and I also found a staff member from another local special school to help. The PA's alternate working for in two hour slots, during the week and also at the weekends. They help me to take the boys out and get them home safely, we go to the park, feed the ducks, throw stones, go swimming and soft play. It helps to break up a very long day and the boys get a bit of fresh air and exercise. I don't ask my PA's to do anything too difficult, they are just my second pair of hands and eyes, but it works. However, it's taken three years to finally sort this all out and get help.

At the beginning of last year, I decided I was determined for the boys to be toilet trained. I worked really hard, it took six months and now they are both toilet trained. If they haven't emptied their bladders, they still sometimes need to wear a nappy at bedtime. I'm so proud of them, it's such an achievement, a year ago I would never have thought the boys would have accomplished this, especially for Harvey as he is non-verbal. Harvey has found his own ways of communicating that he needs the toilet. At school he exchanges the toilet symbol and at home he taps on the door or the lid of the toilet if he needs some help from me. I make a big point of celebrating the achievement every time the boys use the toilet. Toilet

training the boys has enabled them to be more independent, they can go out to places such as soft play and not stand out as different from other children. I also felt that it was important for Sebastian to not have to cope with other children commenting that his brothers wore nappies. Likewise, I celebrate other milestones, such as when Harvey picks a pen up and goes to write with it.

Living with the boys has resulted in many challenges and restrictions to our lives. Over time things have probably improved a bit, but it's almost like taking two steps forward and one back. Diet is an on-going challenge. It was very difficult to move the boys on from drinking their baby bottles of milk and they are still not interested in holding a spoon or a fork. They eat a very limited range of foods and won't eat foods if they are mixed together. Every day they eat sausages. Harvey likes his with M&S gravy and mash and Jacob likes his with fries. They both eat dried bread, dry Cheerios, crisps and organic rice cakes. A lot of foods are gluten free, not because they need to be, but because they just like them. They also like baby organic biscuits and digestive rich tea biscuits. Harvey also likes Hula Hoops and the inside of custard creams, but he literally picks the cream out. Whilst, Jacob likes Bacon Frazzles, Fig Rolls and Garibaldi biscuits, but he wouldn't eat a broken one. They eat yoghurts and custard, but I have to spoon feed these. In between, they drink lots of fluids and often need to use the toilet.

Taking the boys out is challenging. If Jacob is desperate for the toilet he will go behind a tree, but Harvey will only use a toilet. So we take a portaloos with us in the boot of the car, which is really quite big. The boys don't like going out for too long at a time and so we are limited

by the length of time we can do things for and this dictates everyone's life. We can't go to the cinema and we can't eat in a restaurant, as the boys won't sit down. We can't go to the beach, because one of the boys doesn't like sand and the other doesn't like the water and we'd probably need ten people to help us keep track of them.

We are really limited with spending time with people or it makes it awkward and I can't relax, because I am thinking we're ruining somebody else's day. If we meet up with friends we never get to sit down and socialise, because we can't turn a blind eye for a second with the boys. We are also often the first to leave to get home to give the boys their meal. The boys don't eat a lot and won't eat outdoors. Sometimes friends have suggested meeting for a picnic, however our children won't sit down to eat a picnic and won't eat picnic food. In addition, when we go to see family, we can't see them all at once, as it would be too overwhelming for the boys. In addition, they can't come at lunchtime or during the boys evening meal, as the boys need peace and quiet to eat. A further challenge is not having family locally who will help with the boys. My husbands' parents live locally, but since the boys' autism diagnosis, they have rarely wanted to see the boys. My parents are supportive, but live far away. When they visit they help us with the boys and perhaps twice a year we go to the cinema, but we don't have a social life.

If the boys are ill, this just compounds all the other challenges. They don't cope at all well, especially Jacob, it's like 'Hell on Earth' and I really wish I could be ill for them. Also, if my husbands' shifts change, sometimes I don't see him for two or three days. If he calls from

work to speak to the boys on the phone, this can upset them as they want him to be at home. These things all have an impact and I'm not always able to make things ok and happy.

Even though Jacob and Harvey both have autism and learning difficulties, they are mostly very different from one another. There are some similarities, they both find noise and hustle and bustle difficult to cope with. They are also both very flappy boys with hand gestures and hand movements, more when they are anxious and more so with Jacob. Otherwise they are both very different. Jacob is more advanced with his communication than Harvey. He has some school friends who are able to talk and I think this has helped with the development of his speech. He uses the Picture Exchange Communication System (PECS) to make requests. He can construct a full sentence and use key words, which means I can work out what has happened in his day. However, some days he hardly says anything to me. By comparison, Harvey is currently completely non-verbal and uses PECS, but at the stage of just exchanging simple symbols, with an adult. He is very quiet, he'll say a word and it's fantastic, but then he might never say it again. Conversely, Harvey's play skills are more advanced than Jacob's. He has got very fine motor skills and lots of patience for building and doing puzzles. He will sit and finely turn the bricks and likes everything lined up. His play is quite imaginative and he likes to play with toys, such as the barn and the horses. He also likes his dinosaurs and will sort them into piles of Triceratops and T-Rexes. He'll play with them and almost find a mummy and a daddy and make them kiss and then make them fight. If he is playing with horses, he'll get a figure to ride the horse and he will gently make the horse walk. Alongside, we will make the 'clip clop' noises, to try to encourage him with his speech. Jacob is the opposite and has not patience for these toys. He's almost at the baby stage of learning how

to play and he will go 'bang bang bang' with the horse, so he's playing. He'll also take Woody and Jessie from Toy Story and throw them down the stairs. Harvey likes to look at things from high up, so he will climb on the cupboard and look down at the cars on the floor, whereas Jacob will look at things more at eye level, from different angles. Harvey is a loner and likes peace and quiet. He often takes himself off and doesn't like you in his space, touching his things. I spend a lot of time trying to encourage him to come out of himself and spend time with us. There are times when he wants a big cuddle and a squeeze. He's a very loving boy, but he can pull your hair, bite you and he'll get excited and go to hit you, as he doesn't know how to control his feelings. By contrast, Jacob doesn't hit out at me, but he can be sitting quietly and then in a split second he'll get up and hit Sebastian or throw himself to the floor and he'll also make high pitch noises. Jacob suffers from quite bad anxiety and we have a programme in place at the moment to try to understand the reasons for some of his behaviour. So I always try to encourage a calm vibe in the house and keep a good routine. Sometimes this doesn't happen and it feels like utter bedlam...

Alongside the needs of Jacob and Harvey, I have to also consider the needs of Sebastian and Theo. It has been important to try to create some normality for Sebastian, because living with Jacob and Harvey obviously affects him. Sebastian has homework to do and I need to spend some time with him. Likewise, when Theo was in the middle of his A levels he wanted me to test him or ask me to look through something. He's just had some other exams and I'm really wanting to support him and yet there are not enough hours in the day.

On a school day, getting the boys ready is non-stop from the minute the boys get up. Everything has to stay in a routine and I try to keep everything calm. If my husband is at work, one of the PA's comes to help, before they go to work. The boys like to see their clothes and pack lunches ready and their bags with their names on. Clothing presents challenges for the boys and they no longer wear school uniform. Harvey is very sensory and has difficulty tolerating his clothes, so it can take 20 minutes to get him dressed. There are times when his clothing gets ripped. At the moment he will only wear Crocs on his feet. Likewise, Jacob sometimes takes his socks and shoes off two or three times before he settles. For breakfast Jacob eats dry bread and yogurt and Harvey likes yogurt and dry Cheerios. They have the iPad for 20 minutes and afterwards we brush their teeth. However, Jacob needs a two-minute countdown to support this and sometimes he'll throw himself on the floor. Afterwards, they use the toilet and are ready for the bus coming. I talk through the routine with the boys and show them a picture of the bus. There are days when they don't want to eat breakfast and I have a fight getting them to use the toilet. I really need to know if the bus is going to be late. Fortunately I have a good relationship with the staff on the bus, they tell me when they are a few minutes away, so that I can put on the boys' shoes and coats. If the bus is late, I try to distract the boys and we sing a song or play a game. The boys also take a favourite toy to school on the bus. Furthermore, I have to get Sebastian ready for school and he suffers from quite bad separation anxiety. There can be tears as he misses his brothers. He wishes he was autistic, so that he could go to the same school. It's about 9.15am, when I finally have the boys at school and I can breathe. The boys are making progress at school, but I am never one to shy away from the challenges. I will always try to work with the school to find strategies and keep good communication with everyone. It

remains a constant battle trying to secure support for the boys, whether it's Occupational Therapy (OT) or Speech and Language Therapy (SALT). I believe it's up to me to speak up for my boys, to get them everything that they need. I can't give up because they would have nothing.

In the afternoon, I collect Sebastian from school. There is no opportunity for Sebastian to walk home from school with friends, as we only have about 10 minutes to get home before Jacob and Harvey get home. After getting home, for the first half an hour the boys like their own space. Then they have snacks, use the toilet and play with the iPad, cars or trains. We also do music and dancing and try to encourage them to pick a musical instrument.

Sometimes it can be lovely and other times Harvey wants to be on his own. I also try to take them out and I give the boys a choice of where we go. It might be the park, soft play, swimming or feeding the ducks. As part of the programme for supporting Jacob's anxiety he makes the choice. Harvey will pretty much go along with whatever Jacob wants to do, he's very easy going.

At the weekend or during the school holidays, the boys find it more difficult to cope. I show them a picture to help explain that there is no school. Everything has to remain in a routine and the boys need to know what our plans are for the day. My husband and I often try to spend individual time with the boys. He recently took Sebastian to Legoland on an inset day. This weekend he took Harvey swimming on his own and then took Jacob, and I do similar. If my husband is working, one of the PA's comes to help a couple of times during the day, to enable me to do something with the boys in the morning and then again after lunch. They

like to go into town on the bus, around the shopping centre and up and down the escalator, it's the same way every week. We go to McDonalds and Sebastian has a happy meal, whilst the boys have their snacks. Then we come home on the bus, it's like 'Groundhog Day'. If we take the boys to the park, often one of them will decide that they only want to stay for ten minutes, so we often have to split up and bring one home early. Some days the boys argue and fight all day, but just as siblings often do. The difference is that Jacob and Harvey are a lot stronger than Sebastian, so I have to supervise them all the time. On other days it's a pleasure being with the boys and I can have a couple of good days. However, when this happens, I know there's going to be a bad day soon.

I have respite from the boys whilst they are at school and I can now get on with the other things. I help at the boy's school running a parents group, to help support the school with things like fundraising. I also spend time with some of the older children, going out with them into the community. If I can learn anything to help the boys it will be worth it. It also helps me to visualise what my own boys might be like when they are older. I can see how independent they try to make the children, getting them to do their own shopping. Going out with the children is very rewarding, but also a reminder of how vulnerable they are. In addition, I've become good friends with some of the other mums in Jacob and Harvey's school. It's more relaxed being with people already in your position as you haven't got to explain and apologise for things. I can't imagine what some mainstream parents would say if they were in our shoes for a day, as they haven't had our experience.

So this is our life. The boys have completely changed everything and it's so busy that I could never envisage being able to go back to a full-time job. I am very much in tune with my boys and it's become my job to understand what they want. It's still really, really tough, but I try to remember how far we have come and that it can't be any worse than having no help. I worry about the future and who is going to look after the boys when I am not here. I just hope that in time, as the boys get older they relax a bit more and have more understanding, the challenges will become less, but they are never going to disappear.

4.11 Second interviews-Data collection

To reiterate, the phenomenon for this study concerns the perceptions of parents of children with autism and LD of societal attitudes towards autism. The second interviews were focused upon parents' choices of the individuals/organisations, they had identified using the framework from the first interview, (see Table 2. for parent choices). Focusing upon what was important to the parents aligns with the thinking that interviews should be broadly participant led, positioning parents as experts on their experience (Smith, Flowers and Larkin, 2009).

Each interview schedule was individualised and included some further general questions, (see Appendix 11). I reminded the parent what they had started to say in the first interview. For example, Ella had spoken about her parents-in-law. To refresh her memory, I reiterated a section of her words from the first interview transcript and asked her to tell me more about it:

'they have nothing to do with us...I think the last time the boys saw them was just before Christmas for maybe 10 minutes and we've decided to cut ties because it's one less hassle one less strain...' [Ella]

This provided a starting point for parents to tell me about their experiences.

In the next sections, I first provide a reflection about using two interviews in this research and then I move forward to providing an overview of the IPA analysis.

	Family members/friends	Social care	School	Healthcare	Respite/support	Others
Helen and Charles	Grandparents	Support worker			Short break provider	
Diana	Grandparents Extended family		School			Swimming teacher
Ana	Grandparents Siblings			GP		
Iona		Social Worker	School	Hospital		
Jayne	Grandparents Uncles					Strangers
Ella	Grandparents Friends				PA's	
Becky	Grandparents Extended family Family		School			

Table 2: Shows parent choices of individuals/organisations, for exploring societal attitudes towards autism

4.11.1 Reflection about conducting two interviews

Flowers (2008) acknowledges that multiple phases of interviews help to build rapport and provide opportunities to re-visit any ambiguities of understanding. Likewise, having two interviews in the research may have contributed to the length of the interviews, as except for one parent, rapport and trust were established with parents. I observed that in the second interview some parents spoke more candidly, sharing more. Having said this, the potential attrition of the parent participants was an area that continued to haunt me. I could not rest until both interviews had been carried out, all the data had been collected and parents were comfortable with the final versions of the co-constructed stories.

4.12 Overview of IPA analysis

The data from the second interviews was analysed using IPA. In this section I begin by referring to Smith, Flowers and Larkin (2009) and I outline the basic method for IPA analysis. This is intended as a guide and starting point for researchers. At times I also refer to the 2nd edition of their book, which proposes some revisions to this process (Smith, Flowers and Larkin, 2022). Following Smith, Flowers and Larkin (2009) guidance the steps are as follows:

Step 1- In the case of interview data, the researcher takes one interview transcript and should be focused upon '*immersing*' themselves in the data through '*reading and re-reading*' the transcript and listening to the audio-recording.

Step 2- Involves the '*Initial noting*', which comprises of three aspects of exploratory comments. These notes can be made on a separate column of the interview transcript. First,

the researcher describes anything the participant feels is interesting. Second, any significant linguistic aspects are isolated which might bring further depths of meaning, for example words spoken with particular emphasis or emotion, words that were repeated, hesitations or the use of metaphors. Third, conceptual comments are made, which involves combining descriptive meanings and linguistic comments and provides the researchers interpretation of the important meanings for the participant.

Step 3- This stage concerns reviewing the exploratory comments from Step 2 and identifying chunks of data or phases that become emergent themes.

Step 4- The researcher considers how the themes relate or cluster together and determines a table of superordinate themes. It should be noted that in the 2nd edition (Smith, Flowers and Larkin, 2022, p.76), the term emergent themes was replaced by '*experiential statements*' and these are clustered to form '*Personal Experiential Themes*' (PET), rather than superordinate themes.

Step 5- The researcher repeats the Step 1-4 process individually with all the other transcripts, or alternative data. However, staying true to IPA's idiographic commitment, it is important for the researcher to '*bracket off*' their thoughts from the analysis of the previous transcript (Smith, Flowers and Larkin, 2009).

Step 6- Involves looking at patterns across all the cases and creating a structure showing superordinate themes for the group.

Smith, Flowers and Larkin (2009) and Larkin, Watts and Clifton (2006) emphasise how IPA is a flexible approach. This naturally encourages the researcher to consider innovative ways of adapting the methodology to suit their need. Furthermore, IPA is an interpretative methodology, which recognises the central role of the researcher in making sense of the participants experiences (Smith, 2004). In the spirit these two aspects, in the next section I explain how I chose to deviate from the basic guidance for carrying out the IPA analysis for this study. I also chose to adapt the methodology to connect both sets of data, (see sections 4.12.1 and 4.12.3 respectively).

4.12.1 Outline of my approach to the IPA analysis

In this section, I will outline my approach to IPA, how this partly deviated from the guidance in the above section but remained true to the philosophical commitments, which underpin the methodology. It should also be noted, I excluded the first section of the audio recording, approximately 10 minutes, from the transcriptions for the second interviews, as this covered reviewing the parent stories. Also, I use the older IPA terminology '*emergent*' and '*superordinate themes*' (Smith, Flowers and Larkin, 2009). This reflects the time that I carried out the analysis, rather than an indication of preference.

Even before I formally began to analyse the data, I felt familiar and engaged with it, due to the prolonged time that it took to transcribe the interview data. I began the process of analysis following Step 1 and Step 2 described above (Smith, Flowers and Larkin, 2009).

Staying true to the idiographic commitment, I focused upon the analysis of one interview transcript at a time, beginning with the last interview I had transcribed, as this was still fresh

in my mind. Following a prolonged time checking and re-checking the accuracy of the transcript against the audio recording, I then spent further time re-listening to the audio recording and re-reading the transcript, until I felt fully present in the world of my parent. I added a column to each side of the transcript for my own comments. Working through the transcript I initially began highlighting text that seemed important to the parent and made free notes in the right-hand column of the transcript.

In the next stage, to make the volume of data more manageable, I used an approach which deviated from the usual Step 3- of reviewing the exploratory comments and identifying chunks of data or phases that became emergent themes (Smith, Flowers and Larkin, 2009). Rather, than following this inductive method (Reid, Flowers and Larkin, 2005), I decided upon an iterative combination of top down and bottom-up approaches. I suggest this aligns with the view that IPA can be used flexibly (Larkin, Watts and Clifton, 2006; Smith, Flowers and Larkin, 2009; 2022).

I took a broad overview of the whole transcript to identify the possible superordinate themes that might be emerging from the data. Going through the transcript, I identified certain aspects of the transcript which strongly indicated important parts of the voice of the parent and an emerging superordinate theme. I highlighted these sections of the transcript in different colours for each superordinate theme and noted the theme name in the left-hand column. I then returned to the data and used an inductive approach, focusing upon each of these sections of the transcript in great depth, making detailed exploratory

comments in the right-hand column of the transcript, following the three-part process described in section 4.12 (Smith, Flowers and Larkin, 2009).

To remain focused upon the data, throughout the process I recorded any additional thoughts and ideas in a reflective diary, knowing that I could refer to them. I also took regular breaks from the analysis, to slow down my thinking and return to looking at the data refreshed. Subordinate themes related to the superordinate themes began to emerge from the exploratory notes and these were also noted in the left-hand column. My approach continued to be iterative, for example to organise and re-order my thinking I arranged the superordinate and subordinate themes in a mind map, (See fig.15 below for example of Ella's mind map).

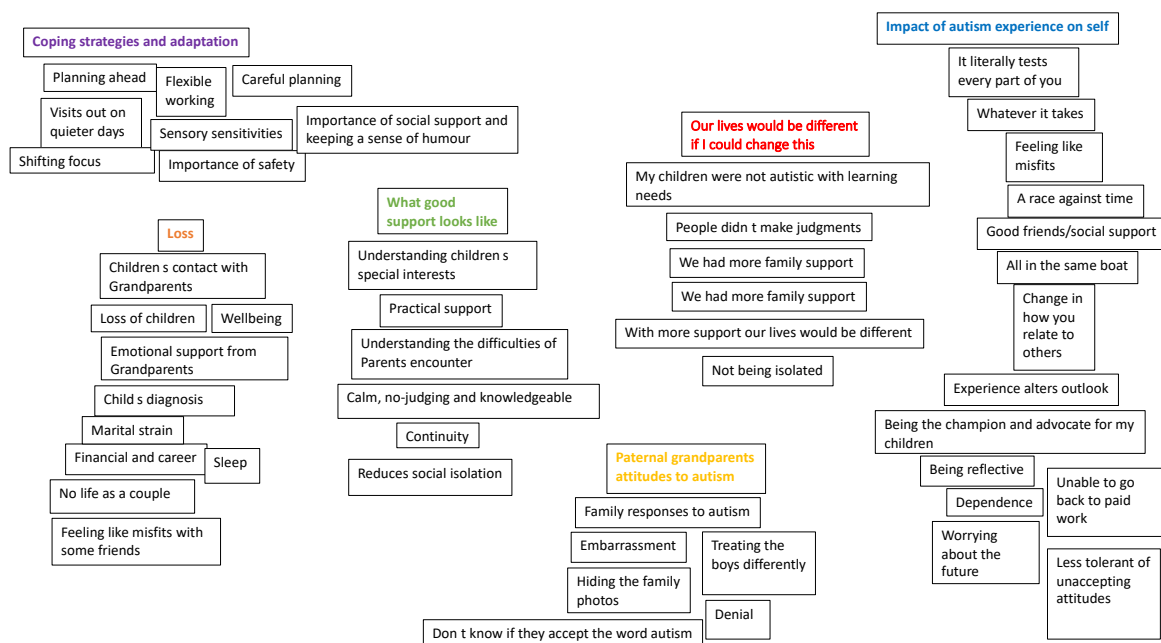


Figure 15: Mind mapping for Ella with superordinate and subordinate themes

Mind-mapping enabled me to take a fresh view of how the themes clustered together and to see the connections and overlaps between them. Through this process, the positions and names of the superordinate and subordinate themes were revised or refined. In establishing my interpretations, I followed IPA's commitment to the hermeneutic circle (Smith, Flowers and Larkin, 2009; 2022). I not only looked at the individual words/parts of the section of the transcript, but also considered my interpretations in the light of the whole of the transcript and in reverse throughout the process.

As I moved onto follow the same process with the next interview transcript and subsequent ones, I also inevitably took with me new ideas and interpretations from carrying out the analysis of the previous transcript/s into the process of the next (Smith, Flowers and Larkin, 2022). In a similar way, it is important to acknowledge that my thoughts had also been shaped by the data collected from the first interviews and the process of writing the individual parent stories about their experience. As part of this earlier process, I had needed to try to position myself as if I was the parent to try to write their story from their perspective and inevitably, I took this experience and carried these interpretations with me. It was important to be aware of all these prior assumptions and try to bracket them off. Consequently, I used the reflective diary to record my thoughts, so that I could try to remain focused upon the present data. For example, of IPA analysis, (see Appendix 12).

4.12.2 IPA analysis across the group data

In this section I outline how the analysis moved onto examine the data at a group level. The purpose of this stage was to identify patterns, similarities and differences (Smith, Flowers and Larkin, 2009). A further step was to determine which superordinate themes would best

illustrate what was most important to this group of parents of children with autism and LD. It was essential that themes were grounded in the extracts from parents' individual transcripts, to retain the idiographic level of the analysis and remain true to the philosophical principles of IPA (Smith, Flowers and Larkin, 2009).

First, I collated the superordinate themes from all separate analyses into a master list of themes. The recurrent superordinate themes from across the group data were clustered together, (see Appendix 13). Next, the superordinate themes which applied to half or more of the parent participants were selected for closer examination, following guidance (Smith, Flowers and Larkin, 2009). Superordinate themes were deliberately worded broadly, to capture a wide range of closely related parent experience. For example, '*Approaches to coping*' captured a range of different strategies that parents use to cope.

4.12.3 IPA analysis- connecting both sets of data collection
In this section, I explain the rationale for innovatively looping the analysis back and encompassing the first interview data. It is worth re-stating that IPA is a flexible approach and emphasises the central role of the researcher in making sense of the participants experiences (Smith, Flowers and Larkin, 2009; Larkin, Watts and Clifton, 2006). Thus, one aspect of my role as researcher was to critically reflect on the methodological approach that I was using to analyse the data. It was important to determine if something was missing or needed to enrich my interpretation of the participants experience. I reflected that the two points of data collection were well connected, as the first interview acted as a foundation and springboard into the collection of second interview data. However, I needed a way of

bringing both sets of data together. To resolve this, I decided to use the superordinate themes as a lens to re-interpret the initial data in the parent stories. In other words, I turned the data on its head, re-examining the initial data through the themes that had emerged from the preliminary IPA analysis. The superordinate themes became the bridge to reconnect both sets of data, ensuring nothing significant was missed, thus providing robustness to the final set of findings.

Methodologically, this was a different way of approaching IPA. However, I assert that my approach was in keeping with IPA's philosophical commitments. First, in terms of the hermeneutic circle (Smith, Flowers and Larkin, 2009), re-visiting the initial set of data was in effect circling back to consider my interpretations in the light of the whole data. Second, applying the IPA in this way enriched my interpretation of the initial data and helped to highlight the individual voices in the data. Their importance could therefore be preserved in the findings, thus abiding by IPA's idiographic commitment.

Thus, although superordinate themes were all grounded in the second interview data, the first interview data played a role in validating these choices. This is because the parent stories contained some sections of rich in-depth data, describing parents' experiences of attitudes towards autism. In this way the analysis retained its commitment to the hermeneutic circle (Smith, Flowers and Larkin, 2009). Themes that were of particular importance to an individual participant were used to illuminate this experience in other transcripts or to reveal contrasting experiences. For example, for Ella 'Loss' was a strong superordinate theme. Further analysis across the group data revealed that 'Loss' was a

stronger underlying theme, than I first thought, for many of the other parents. Conceptual comments were re-examined to assist with this process.

For each of the selected superordinate and their related subordinate themes, a separate table was used to help organise the data. Subordinate themes were colour coded for each participant to emphasise similarities and variations in the data at an idiographic level, (for example, see Appendix 1). Using this approach also helped to highlight particularly strong or weak themes for each participant and to make connections across the data.

Using the example of *'Parent coping'*, the following 6 subordinate categories emerged from looking at the data across cases (*'Problem-focused coping'*, *'Avoidance coping'*, *'Ignore staring'*, *'Time out'*, *'Social support'* and *'Positive re-framing'*). Categories were determined through my own interpretation and knowledge of these terms from the literature.

'Approaches to Coping' was interpreted to be a suitable final superordinate theme, with the subordinate themes nested beneath. Although *'Approaches to Coping'* was interpreted as a strong recurrent theme across the group data, the wide variance in the subordinate themes demonstrates how the analysis sought to both reveal an understanding of parent experience at a group level, whilst drawing attention and seeking to preserve parents' individual and specific experience.

The analysis across the group data helped to reveal the interconnectedness of the themes.

Analysis of the theme *'Hidden autism'* not only shed light upon the similarities and differences of how parents experience of autism is hidden. However, through deeper

analysis (Smith, Flowers and Larkin, 2009), it became evident that *'Hidden autism'* overlapped and underpinned many of the other superordinate themes, helping to illuminate these further. For example, *'Parents' experiences of unsupportive attitudes to autism'* is better understood through its overlaps with *'Hidden autism'*. The data revealed a pattern of hiddenness. For example, social expectations and control were often hidden inside families. In addition, parents' experience of feeling judged by strangers and others in society was often subtle, unseen by others and thus hidden from view. Likewise, a lack of inclusion was often subtle and hidden.

A final set of group level superordinate themes and their subordinate theme categories are represented through the diagram on the next page (see fig. 16). The themes shed light on parents' experience of unsupportive attitudes (indicated in red) and supportive attitudes (indicated in green) and other aspects that may underpin and help to illuminate this experience.

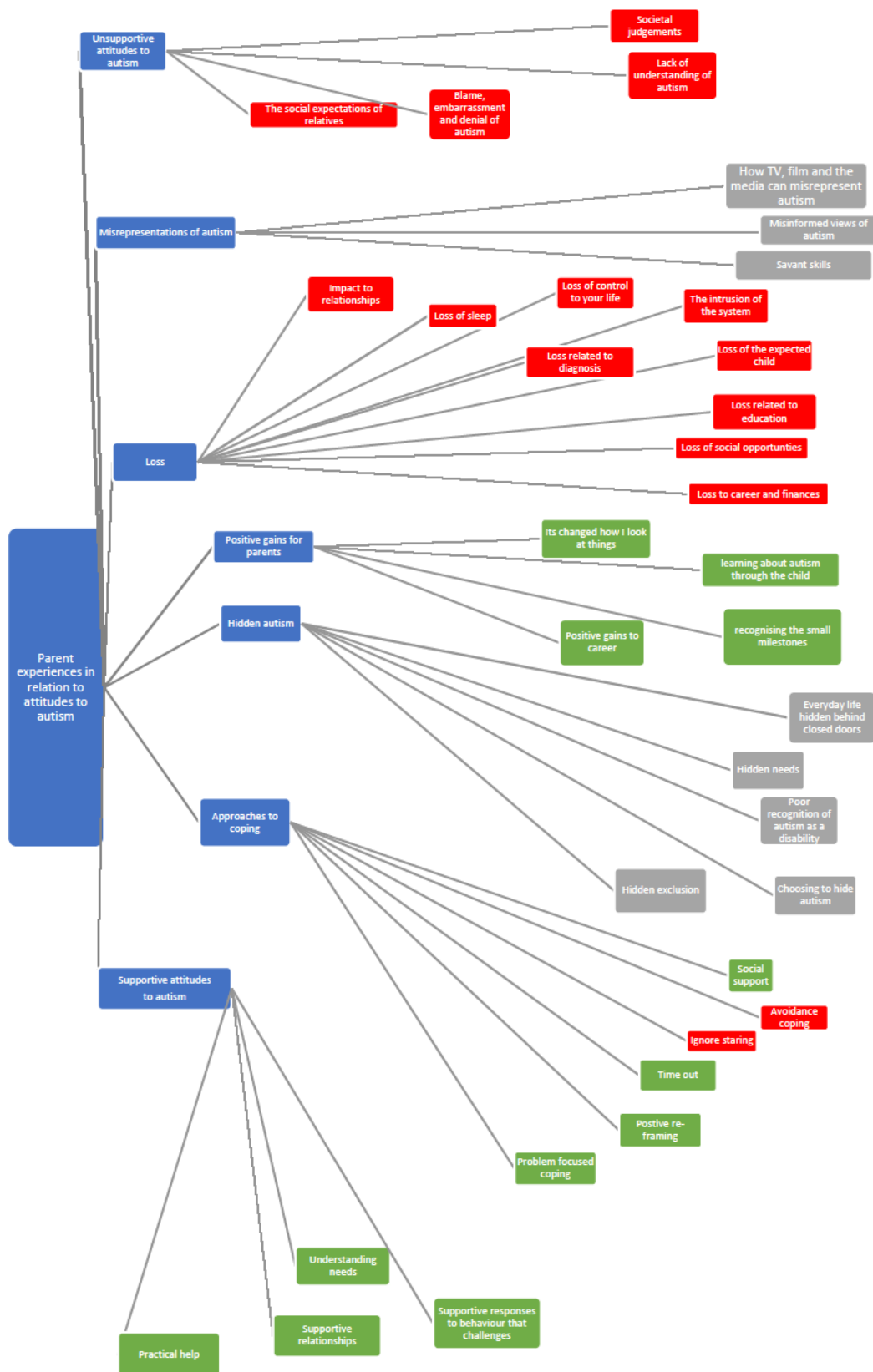


Figure 16: Group level superordinate and subordinate themes

In the next sections, I include some reflections about the richness of second set of data and some of the challenges of using IPA across the group. I then move onto explain how the themes emerged from the data.

4.12.4 Reflection on the richness of the second set of data
Two factors helped to facilitate the capture of rich data. First, using two interviews helped me to build a greater rapport with parents than perhaps would have otherwise been possible, resulting in more in-depth data. Second, I believe my '*insider position*' also supported this. For example, in two of the interviews the mothers revealed that they had never shared some of what they told me with anyone else. This correlates with other findings in the literature on the advantages of having an '*insider status*' (Corbin Dwyer and Buckle, 2009).

4.12.5 Reflections on the limitations and challenges of carrying out IPA analysis across the group
At first glance this sample of parents of children with autism shared certain key characteristics and appeared largely homogenous. However, although the children all had a dual diagnosis of autism and LD, some also had other co-occurring conditions. This undoubtedly added variance to the parental experiences. Although the key focus of the interviews was upon perceptions of attitudes towards autism, parents made choices of which individuals or service providers they discussed in relation to this topic. In view of this, some similarities, but also different experiences emerged.

Despite these differences, it was possible to identify a set of themes that were sufficiently recurrent to present the shared experience for the group. There were instances where a theme, although dominant at an idiographic level, was too weak to be considered a theme at the group level. For example, for Charles and Helen the issue of the safety of their children was a dominant theme, key to understanding all the layers of their experience. Whilst safety featured in the narratives of other parents, it was not sufficiently strong across the group to warrant being included in the final structure of superordinate themes for the group. Nevertheless, the issue of keeping children safe is included within the discussion of some of the themes. Contrastingly, whilst ‘Loss’ was an especially strong theme for Ella, it also helped to illuminate how this theme applied to other parental experiences. Therefore, this was included as a final superordinate theme.

4.13 Details of how superordinate themes emerged from the data
In this section, I explain how each superordinate theme emerged from the group data. I also signpost the reader to some of the overlaps between these themes.

4.13.1 Superordinate theme: Hidden autism
‘*Hidden autism*’ was seen through the experience of all parents in the study. Some parents specifically used the term ‘*hidden*’ and others used related language such as ‘*closed doors*’ or ‘*they needed to see it*’, this language enabled me to make links between their experiences. The literature largely attributes the hidden aspects of autism to the stigma process. However, I use caution around this term as not all parents will identify with stigma. Rather, I consider the hidden aspects of autism as contributing to a negative or unsupportive attitudes towards autism, which I assert is a more encompassing term.

From the analysis, I approached hidden autism from the perspective of any hidden aspect of parent reality or where a hidden aspect of autism might help to explain a lack of autism awareness. To illustrate this, I provide some examples of what I mean by hidden autism, in the context of this group of parents. One example relates to the current process for accessing disability benefits, such as Disability Living Allowance (DLA), Personal Independence Payment (PIP) and eligibility for a Blue Badge (for disabled parking). The system for applying for these is structured in a way that favours physical disability over autism, as questions on the application forms are designed from the perspective of physical disabilities. The wording of the questions does not take account of the hidden difficulties or needs of someone with autism, such as sensory sensitivities. Likewise, a societal focus on physical disability means that many community facilities, such as swimming pool settings, focus upon disability as physical and tangible. Accordingly, as the needs of children with autism are more hidden and less tangible, these can be overlooked. In essence, the hidden needs of autism are only hidden insofar as there is often a failure to understand and recognise these as needs. Likewise, parents only perceive their realities as hidden, as others fail to understand their family's needs and provide appropriate supports. The theme of *'Hidden autism'* reappears throughout the next chapter, as it overlaps with the other themes.

4.13.2 Superordinate theme: Misrepresentations of autism
'Misrepresentations of autism' was a significant theme for virtually all parents. Clues to this as an emerging theme were evident through the word's *'naughty'*, *'misunderstanding'* and *'special talent'*. Misunderstandings about behaviour also emerged as a relevant aspect. This is explored in the findings through the subordinate theme *'Lack of understanding of autism'*

(see section, 5.6.1). At an idiographic level, *'Misrepresentations of autism'* emerged as a particularly significant theme for Charles, Helen and Jayne through their experiences of how TV and film were felt to distort views of autism. In addition, this theme is evident through Diana, Becky and Ana's experience that assumptions about autism should be challenged. It was also evident that most parents viewed their experiences through a lens of autism and LD and other co-occurring conditions. Whilst the issues parents encountered differed in relation to their children's different needs, typically their concerns included supporting basic functional skills, making sure their homes were safe and trying to secure sufficient breaks from caring. For some supporting their child's medical needs was also a main priority. These characteristics were relevant as they inevitably shaped parental views of how autism was misrepresented. These parents often felt disconnected from other autism parents, whose priorities and concerns often did not always correlate with their own.

4.13.3 Superordinate theme: Loss
Although presenting differently, *'Loss'* developed as a significant theme for all parents. *'Loss'* was pervasive, seen in multiple layers cascading across their experiences. For some, this theme was clear in the early stages of the IPA analysis. For example, for Ella *'Loss'* was a particularly strong superordinate theme, underpinning the whole of the analysis. Likewise, for Helen and Charles *'Loss'* was clearly visible through their experiences with how autism had impacted relationships and how they viewed autism as *'debilitating'*. Looking through the lens of Ella's experience and then re-examining the individual analysis of the other parents across both sets of data, helped to shine a light upon how loss was also entwined within their experience. Although, this sometimes took me longer to recognise and locate, it

was nonetheless present for all parents. This process also illuminated the temporal aspect of how the theme often emerged and re-emerged at different stages of the parenting journey.

4.13.4 Superordinate theme: Parents' experiences of unsupportive attitudes
As the focal point for the collection of data in the second interviews was upon parents' experiences of supportive and unsupportive attitudes to autism, it was not surprising that these two opposing themes emerged strongly. All parents shared their perceptions of '*Unsupportive attitudes to autism*'. In the context of this study, this is parental experiences of difficult interactions or poor-quality relationships with others in relation to their child. Inevitably this term captures elements that contribute to the stigma model, but without the assumption that parents felt stigmatised (for more details, see section 5.6.2). Parents reflected upon their difficult encounters with a wide range of different individuals or settings, including health workers, school staff, social workers, short-break provision, transport to school, strangers and other parents. In addition, virtually all parents chose to share their experiences of their relationships with grandparents and other family members. Parents also highlighted their perceptions of the underlying reasons for the persistence of these attitudes. The issue of unsupportive attitudes also overlapped with exclusion.

4.13.5 Superordinate theme: Parents' experiences of supportive attitudes
All parents shared their perceptions of '*Supportive attitudes to autism*' and how these presented. This emerged as a divergent theme to '*Parents' experiences of unsupportive attitudes to autism*'. Parents provided examples of a range of individuals, service providers, including family members, whose actions indicated a supportive or inclusive attitude.

4.13.6 Superordinate theme: Positive gains for parents of children with autism
'Positive gains from autism' emerged as a contrasting theme to *'Loss'*, albeit much less

dominant. This was not unexpected given the associated challenges for these parents.

Nonetheless, this important theme helped to convey how parents were eventually able to attach positive meaning to their experiences and reflected the temporal aspect of parental experience.

Notably, parents tended to convey these positive gains towards the end of their narratives, as they reflected upon and tried to make sense of their whole experience. Although all parents shared some positive gains, some were more tangible. For example, Becky and Ana both emphasised how their careers had benefitted from having a child with autism.

4.13.7 Superordinate theme: Approaches to coping
This theme relates to how parents managed the daily challenges associated with parenting their children, including how they coped with unsupportive attitudes towards autism. Many stressors were triggered by the interactions between the parent/child dyad and other individuals, including their relatives. Some of the parenting approaches were proactive, such as anticipating stressful situations and taking action to prevent the source of stress or limit its effects. Other coping strategies were more reactive or avoidant. There was also a temporal aspect to parents coping, whereby over time parents all found ways of attaching positive meaning to some of their experiences.

The approaches parents used for coping seemed to naturally cluster together into groups.

Once I had identified each of these groups, I re-visited the literature as a form of sanity

checking. Overall, six groups of coping approaches were identified as subordinate themes. Parent coping strategies were also a lens to view parent perceptions of how grandparents and other relatives coped with having a child with autism in the wider family. Some grandparents responded to the needs of their grandchild proactively, mirroring parents' problem-focused approaches or positive coping strategies. Contrastingly, other grandparents and other relatives were more disconnected appearing to avoid engaging with autism.

In the next chapter I return to the above superordinate themes and their related subordinate themes. Through the themes, I explore the main findings from this study across the group of parents and discuss these in relation to the literature.

5 CHAPTER 5: FINDINGS AND DISCUSSION

5.1 Introduction

In this chapter I have drawn together the main findings from the study. These both build on the literature and contribute new knowledge about the experiences of parents of children with autism and LD in this study. The findings are structured through seven superordinate themes, which emerged spontaneously from the data analysis, (see fig.17). I first consider how the superordinate themes map on to the conceptual framework. I also explore some of the complexities of using the conceptual framework as a structure to discuss the findings in relation to the extant literature. Parent quotations are used throughout to illustrate the themes. Whilst there were common features for the parents in the study, this was not a homogenous group. Thus, some findings are more specific to individuals or a small number of parents. This reflects both the idiographic aspects and the commonalities of parental experience across this group.

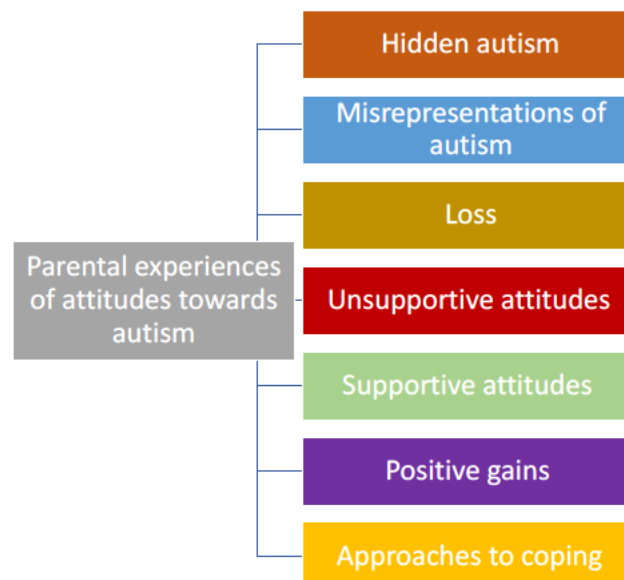


Figure 17: Superordinate themes

5.2 The conceptual framework as a lens for understanding the superordinate themes

In viewing parental experience as a journey it initially felt appropriate to begin the discussion of the findings through exploring the theme of 'Loss'. This also seemed to make sense as 'Loss' emerged as the strongest superordinate theme in the findings. However, as I thought about how the themes related to the conceptual framework, I decided it made more sense to continue the thread of using the framework as the structure, mapping each of the superordinate themes onto the different systems. Situating parental experiences within the conceptual framework was important as a lens for trying to understand their world. I also envisaged that this would provide a novel way of presenting the discussion of the findings, thus providing a new methodological contribution.

The process reinforced how there was a significant amount of overlapping between the superordinate themes, which stemmed from the interconnectedness of the data (see fig.18). At times this almost resembled spaghetti and made the organisation of this chapter challenging. However, recognising the different levels of connectedness across the data enabled the uncovering of deeper interpretations. In keeping with the underlying philosophy and methodological approaches of this research, I tried to keep an open mind and allow the data to speak for itself. This illustrated how parental experience across the group data was wide-ranging and multi-layered. For signposts of where the themes overlap and how this has been organised, see the previous chapter (see section 4.13).

Most of the themes were clustered across the micro and meso systems, conceptualising the interactions between these structures. This was not surprising, given that this research was

focused upon parental perceptions of societal attitudes towards autism. Parents recognised the attitudes of others, both negative and inclusive attitudes, through their interactions with individuals or service providers, in the mesosystem/outside community. As the mesosystem/outside community was closest to parents, this most directly impacted parents lives daily. Not surprisingly, the exo and macro systems had fewer superordinate themes, reflecting the relative remoteness of these systems from parent daily lives. This is not to suggest that these were not significant, as they still indirectly influenced the mesosystem.

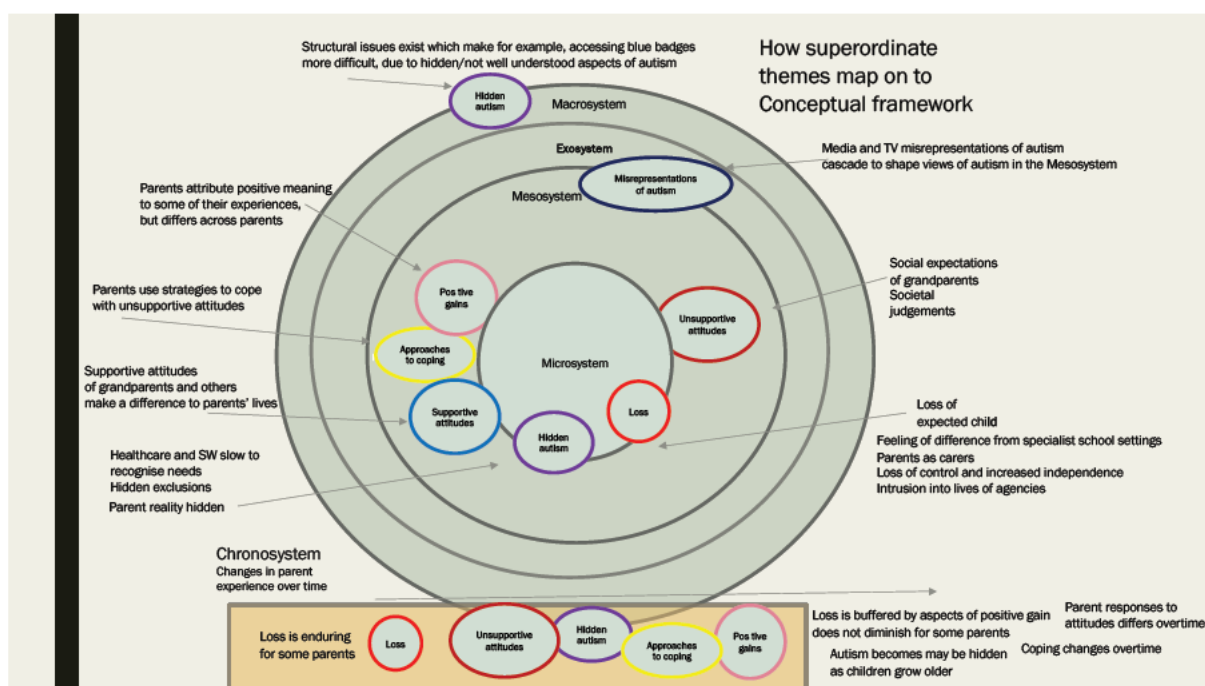


Figure 18: How superordinate themes map onto the conceptual framework

Nevertheless, there were some complexities from using the conceptual framework as the structure for this chapter, as it was difficult to isolate themes to specific systems. This issue was ultimately mitigated through viewing the conceptual framework as a set of open

systems interacting with each other, reflecting The Bio-ecological systems theory (2005). In other words, for organisational purposes I have assigned each theme to a system, but in reality some of the themes also appear across other systems.

I have organised this chapter beginning at the outer edge of the conceptual framework with the macrosystem and then moving inwards within the framework. Thus in the macrosystem, I begin with a discussion of the superordinate theme of *'Hidden autism'*. This reflects the existence of structural policy issues at a societal level. For example, hidden issues of autism, related to applying for a Blue Badge. *'Hidden autism'* was also the most recurring theme across the framework. Being a general theme, it naturally intersected reflecting the interactions between the systems and helped to illuminate the other more specific themes. Thus, whilst I mainly discuss *'Hidden autism'* in the macrosystem, I return to it throughout the chapter, particularly in the mesosystem in relation to how the subordinate theme of *'hidden exclusion'* intersects with parental experiences of grandparents attitudes towards autism.

In the exosystem, I situated the superordinate theme of *'Misrepresentations of autism'*, although this intersected across both the exo and meso systems. Reflecting the interactions between these systems, this general theme cascades downwards to the mesosystem, shaping the impressions relatives and others had about autism.

In the microsystem, I discuss the theme of *'Loss'*, although these parental experience are better understood through seeing the interaction of this theme in the microsystem with the

mesosystem. I then move on to mesosystem to consider '*Unsupportive attitudes towards autism*' and '*Supportive attitudes towards autism*'. Similarly, these themes are best understood through seeing this as a two way interaction between the meso and microsystems.

Whilst this study was not intended to be longitudinal, parents reflected across the breadth of autism parenting journey. Many of the overlapping superordinate themes in the micro and meso systems thus resurfaced in the chronosystem, conceptualising how parents' experience changed over time. I decided to use the chronosystem to more specifically discuss the two remaining themes, '*Postive gains*' and '*Approaches to coping*'. These themes capture aspects of how parents adapt to having a child with a diagnosis of autism and LD. Likewise, they also feature through the interactions in the meso and microsystems. Overall, I felt that this was the most appropriate way of using the conceptual framework to structure the themes. However, I accept that this could also have been approached differently.

In the next sections, this chapter takes each system from the conceptual framework in the order described above and I discuss the findings for each of the relevant superordinate themes in relation to the literature. The main points are summarised at the end of each section.

5.3 The macrosystem – Hidden autism

In this system I discuss the findings in relation to the superordinate theme of '*Hidden*

autism'. This theme is explored through five subordinate themes seen below in (fig. 19). At

the end of this section I provide a summary of the key findings for this theme.

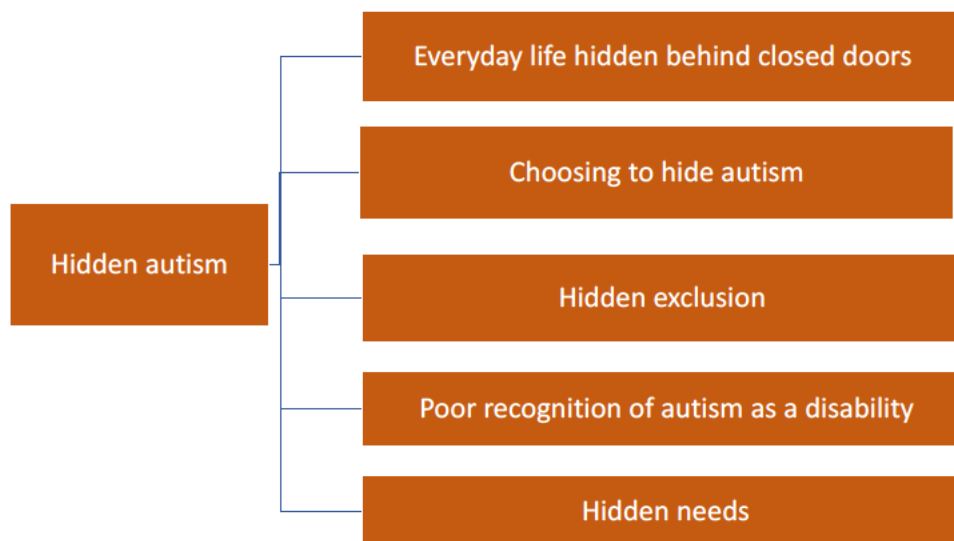


Figure 19: Hidden autism

5.3.1 Everyday life hidden behind closed doors

A starting point for exploring this theme is to examine the notion that the everyday life of parents of children with autism and LD is hidden. Jayne conveys this:

'So probably the day-to-day behaviours that you get in the home, no one will ever know, its behind closed doors...' (Jayne)

The image of '*behind closed doors*' is striking as it reflects Jayne's feeling that others have a poor understanding of her reality. Through the conceptual framework this can be depicted

through the parent in the microsystem feeling that others situated in the mesosystem (extended family, friends and service providers) are on the outside of their reality.

Likewise, this feeling of parental reality not being understood is mirrored by (Nicholas et al. 2016). However, whilst this study concerned the experiences of mothers of children with autism, the findings of the present study highlight, through Jayne's experience, issues that may be more pronounced for parents of children with autism and LD:

'inside you're dealing with the toilet issues, the eating issues, the sensory crumbling food issues, hoovering every day.'(Jayne)

Another aspect of this hidden reality related to parents trying to keep their children safe within the home, as Helen and Charles explained:

'Both boys need constant supervision and its particularly difficult looking after them at home by yourself. As they are getting bigger, its getting harder as Owen and Fergus can reach the top shelf of the cupboards and everything is more accessible to them. They don't have an appreciation of danger.' (Helen and Charles)

The issue of keeping autistic children safe in the home has also been confirmed in the literature (Nagib and Williams, 2018). However, these authors indicate that parents were able to manage the issue by keeping items out of reach of their children. By contrast, a difference in the present study was that Helen and Charles struggled with this as their children could reach to the top of the cupboards.

Similarly, Jayne spoke about the issues of making sure that her son could not escape from the house:

'Tim can be very unpredictable and inclined to try to abscond from the house. It is lock and key, deadlocking the doors and double locking the windows to keep him safe.'

(Jayne)

Both of these examples highlight the need for constant vigilance which can be seen through the parent/child dyad in the home/microsystem aspect of the conceptual framework. The significance is that the issue of safety for parents of children with autism and LD goes beyond what is typical for most parents. I return to the issue of safety again in various sections of this chapter (see sections: 5.3.3, 5.54, 5.56, 5.5.8, 5.6.1).

Another element of parental experience that is hidden was seen through parents describing how their children had little or no spoken language and used alternative communication systems, such as visuals. Ella's experience highlights how parents must ensure that appropriate pictures/visuals are readily available to support communication with their child. For example, she explained how the boys understood that it was not a school day:

'I show them a picture to help explain that there is no school.' (Ella)

This finding is significant as Joosten and Safe (2014, p.257) have proposed more research to understand the '*hidden work*' of mothers of children with autism. Thus, the preparation of visuals underlines a specific hidden area of work for parents of children with autism and LD.

A further aspect of everyday life that was hidden related to Becky reading negative comments in her son's home to school diary. This is covered later in the chapter (see, section 5.5.9).

5.3.2 Choosing to hide autism

Another feature of hidden lives, related to deliberately choosing or trying to hide aspects of reality. This particularly related to Jayne, who tried to hide the toileting and food issues described above (see section, 5.3.1) to show things at their best:

'you do try to present we're ok.' (Jayne)

Likewise, when visiting someone else's home, she tried to hide the reality of Tim's toileting issues:

'they don't see really the toileting issues...in somebody else's house...again we cover up, we deal with it quietly, discreetly. We don't say oh come and look at all the poos smeared all around the loo...we open the window and don't say a word...' (Jayne)

Jayne's experience highlights how parents of children with autism and LD may hide aspects of their child's behaviour they find embarrassing to avoid judgements and 'loss of face' (Yang, 2015).

The embarrassment around toileting is likely to arise from perceived social expectations that, by a certain age, children should be able to use the toilet independently. Moreover, it looks likely that Jayne's desire to conceal and show things at their best, indicates a tendency to internalise perceived judgements, associated with self-stigma (Mitter, Ali and Scior, 2019; Ali et al. 2012). In addition, Lawson (2020, p.522), discusses how autistic people often have a

desire to fit in, which he describes as '*adaptive morphing*'. Whilst findings from the present study relate to non-autistic parents, there are similar parallels with Jayne's need to hide aspects of her reality to fit in with perceived social expectations. Therefore, it is likely that non-autistic parents of children with autism, may also be susceptible to '*adaptive morphing*', to escape societal judgements. I return to the notion of self-stigma later in the chapter (see section, 5.6.2).

Another strand of '*Choosing to hide autism*', related to the invisibility of autism. Jayne admitted to taking advantage of those moments when her son would walk down the road and his autism was largely invisible to strangers and to feel '*normal*':

'If Tim is walking down the street beautifully, no one would ever know and we can have a four-minute moment...of everything presenting quite normal and we can feel very calm, relaxed and happy and no one would know.' (Jayne)

Accordingly, this was a conscious decision to conceal autism, which is probably underpinned by a lack of parental acceptance of autism. This form of avoidance correlates with the description in the literature of '*passing*' (Goffman, 1936; Gray 1983, 2002a). Like Jayne, I confess to have used the strategy of '*passing*' with my own son. There seem to be parallels between '*passing*' and the coping strategy of concealing mess to avoid perceived judgements.

No other parents conveyed enjoying times when they knew child's autism was not noticeable to others, so it is difficult to know if this consciously happened or not.

However, it is evident from Helen and Charles' experience of visiting a park with their children that *'passing'* might not be an option for all parents of children with autism and LD (see section, 5.6.2). This correlates with Gray (2002a) who suggested that the behaviour of children with LF autism may be more evident. Moreover, Jayne, conceded that as her son had got older, his autism was more obvious to others:

'as he's older and he's fourteen and he's twiddling his scarf, he's wearing his ear defenders...its more obvious...I don't have to explain it as much.' (Jayne)

Whilst it seems the opportunity for *'passing'* had diminished, Jayne felt there was increased acceptance of her son's behaviour. By contrast Ryan (2005, p.70), found parents reported there was less tolerance for older children, as they *'become more odd to the public'*.

In summary, the findings suggests that the opportunity to conceal or *'pass'* may vary across this group of parents. For some this opportunity may diminish as their children get older and their differences become more obvious, whilst for others their child's *'perceived socially inappropriate'* behaviour may mean this is never possibility.

5.3.3 Hidden exclusion

Another strand of hidden autism related to parents' experiences of exclusion. In this context, exclusion was a lack of acceptance of their child's differences or awareness of environmental issues, such as sensory sensitivities or safety issues. Exclusions were not always overtly obvious to outsiders; they were subtle or hidden behind closed doors. In this section, I mainly focus on hidden exclusion in the context of schools. However, I return to *'Hidden*

exclusion' later in the chapter in relation to the social expectations of grandparents (see section, 5.6.4).

In the context of school, parents encountered '*Hidden exclusion*'. Schools were found to either exclude the child or try to exclude them from activities. Becky reflects how her son who attended the unit of a mainstream school, was excluded from many activities:

'they wouldn't include them with whole school activities and things like that, so which is a real shame really because some children in year six could have gone on a night, stay overnight residential...they weren't included in assemblies, they weren't included in erm lots of things.' (Becky)

Similarly, Ana highlights how the special school that her son attended tried to exclude him from an inter-school sports tournament. However, the reason for the exclusion was as a safeguard from meeting a child who had inappropriately touched him, rather than providing a proper solution. Ana recalls what the school said:

'maybe it means that Matthew can't go to these tournaments.' (Ana)

Despite the school's discouragement, Ana insisted that an extra member of staff should be there to keep Matthew safe, so that he was not excluded from the tournaments. The example suggests the possibility of subtle school exclusions which are hidden and may routinely occur. There are parallels with positioning the problem with the child, rather than taking responsibility and providing appropriate support.

Ana explained that she felt the safeguarding risk to Matthew was not taken seriously because the incidents had occurred between two boys with autism and LD:

‘if it had been a girl that this boy had touched, I think it would have been different and I think if they both hadn’t had autism, it would have been different...there’s something in the fact that there’s a learning disability and ASD involved and that it was boy on boy, that as a society, its disregarded as not being a problem.’

The finding highlights the issue of insufficient awareness of some of the potential safeguarding risks for children with autism and LD. More needs to be done to protect this group of children across all settings.

Contrastingly, a situation of wider social exclusion is conveyed by Charles. He explained that it was not safe for his children to go out into the community:

‘they have quite a sort of closed existence because they’re not able to sort of access you know the wider community, in some respects they’re always here with us, er or they’re at school with teachers and assistants and stuff like that...’ (Charles)

Accordingly, Charles highlights the reality of parents where safety risks and concerns over perceived judgements about behaviour that challenges, become barriers to inclusion. Above all, this can deter parents from using community facilities.

5.3.4 Poor recognition of autism as a disability
A common complaint amongst many parents was that there was a poor recognition of autism and LD as a disability. Parents particularly highlighted the hidden aspect of autism, which meant that this was not well recognised versus physical disabilities or conditions such

as Down syndrome. Whilst, Down syndrome is mainly associated with an intellectual or learning disability, it may have identifiable physical features. Likewise, this parental experience is reflected in the literature (Gray, 2002a). Jayne made a direct comparison between the lack of compassion and recognition of autism versus how she felt children with Down syndrome were treated by society:

'if Tim was Downs and people could see it...people just...you know you see a Downs child and immediately are 'Ah anything I can do or help?'...it's the sign round their neck, the way they look...' (Jayne)

Jayne's insight is significant as she feels if her son had Down syndrome, she would get more help and understanding. The implication is that parents forgo the opportunity to provide an explanation for their autistic child's behaviour, the chance to educate and potentially change the viewpoint of others.

Parents also emphasised that society's focus on physical disabilities was a key barrier to their children accessing activities in the community. For example, Iona explained that on a Saturday Gabriel went sailing with a local sailing club, organised by volunteers for children with disabilities. As much as Iona was grateful to the volunteers for giving up their time, she was frustrated that they had little understanding of Gabriel's communication difficulties. For example, they would ask Gabriel to help them or to wait his turn and these things were difficult for him to understand. Iona conveyed the issue:

'their understanding of disability is around physical disability, more than learning disability and they need to do more to understand people with autism.' (Iona)

This example reveals that a minority of specialist settings may still fail to understand the needs of children with autism and LD, and highlights a training need to improve understanding of hidden disabilities.

Likewise, Diana who took her son to swim at a local leisure centre and was frustrated about societal understandings of disability:

‘disabled doesn’t mean you need all the bits that they put around the toilets and all the handholds, actually sometimes all you need is a quiet space, and I don’t think society is set up for that in many places. You know I would hate to take Sam to the [leisure centre] when it was at capacity.’ (Diana)

Charles also explained how poor recognition of autism and LD as a disability was a barrier to accessing support. For example, justifying the need for a *blue parking badge*, so that he could take his children out into the community:

‘stuff like getting blue badges, it’s really hard erm because you know they can walk, they can get about, not that you want them to, not safely...but if they were in a wheelchair and that, you’d get that sort of thing straight away...’ (Charles)

Charles felt that the wording of questions on these application forms was inherently biased towards physical disabilities. Thus the hidden presentation of autism and other co-occurring conditions seemed to underpin the issue. This is perhaps because attitudinal barriers remain which prevent the full recognition of the needs of children with hidden disabilities.

The significance of the finding is that more needs to be done to improve societal understanding of the alternative reasons why someone with autism and LD might find a blue badge for parking helpful. For example, in car parks that are frequently very busy, where waiting for a space to become available might be necessary, the availability of a blue badge space can help to reduce anxiety and sensory overload and make visiting the community easier. It is worth noting that recent changes to guidance (DfT, 2019) have expanded the eligibility criteria for awarding blue badges to include hidden disabilities. This means that theoretically more people with autism should now qualify for a blue badge.

Contrastingly, an interesting side finding was Iona's view that versus TS, autism was a much better-known condition:

'whilst people don't understand TS, when you mention autism they have some level of understanding.' (Iona)

Gabriel's autism diagnosis was thus more of an enabler in accessing support, than his TS diagnosis alone:

'the diagnosis opened up avenues of support and helped to shape Gabriel's school provision.' (Iona)

5.3.5 Hidden needs

Another issue for parents was the difficulty or slowness of professionals in recognising their child's needs, the extent of the parents' caregiving burden and the impact to family functioning. This seemed to be a particular problem in the early days, often shortly after diagnosis, when parents most needed help. It also seemed to be a particular issue for

parents with multiples or more than one child with additional needs. These parents felt that they had to demonstrate and prove these needs to social workers, so that they could access a care package of support.

As Helen and Charles explained:

'I think in the early days we-we struggled a little bit, in terms of getting them to understand...our needs erm.' (Charles and Helen)

Consequently, the social worker needed to visit them at home, as Helen and Charles explained:

'I think we went through a period where they did house visits and stuff like that and they kind of saw things and I think it quickly became apparent.' (Helen and Charles)

Similarly, Ella recalls the social worker visits to prove her need:

'she would come out into the community with me and spend time at home with me. I wanted to demonstrate to her what it was like day to day. It felt so bad, I honestly felt like I was doing a prison sentence. I recall saying to my husband that I felt I would probably be having a better life if I'd murdered someone!' (Ella)

This finding is significant as it builds upon the literature which found that parents felt like 'prisoners' in their own homes, due to the issues of keeping their autistic children safe (Nagib and Williams, 2018, p.51; Celia et al. 2019, p.6).

In addition, Helen and Charles explained what the social worker saw when they visited and how they finally started to understand the difficulties of trying to juggle two children with special needs:

'the madness the needs the...you had to be on...you had to have eyes on the children at all times...probably didn't appreciate how hard it was and if you are with one child something else is happening, with the other one.' (Helen and Charles)

Whilst Iona had secured care package for her son, her experience highlights the hidden issue of having to prove to a social workers you are in a crisis before they would increase care package support:

'you shouldn't have to demonstrate that you're in crisis, when you're in crisis they should be able to see that for themselves.' (Iona)

Likewise, Iona explained how she felt judged for having a nice home which seemed to blind the social worker from seeing Gabriel's needs:

'I think because you know we're lucky enough to have a nice house, a nice garden, I think she would come here and think perhaps that you know that we didn't need help... rather than seeing our son and the fact that we needed help.' (Iona)

The findings from this example are important as they underline how family needs may change over time. Social workers should be engaged with families to be able to understand how well parents are coping.

The above examples illustrate how the theme of hidden autism re-emerges and helps to explain the curious situation where children's needs were significant and obvious to parents, but somehow hidden from the understanding of social workers, unless they could see it with their own eyes. Ultimately, there will always be limited resources which will restrict the funds available for care packages. However, it is likely to be more cost-effective to fund

support for parents to sustain caring for their children at home, rather than children being placed in residential settings, often as a last resort (Tansley, 2013). Policy makers should therefore be aware of taking a short-sighted view and not limiting support for parents of children with autism and LD who need it. These findings are significant as they support other studies which point towards families of children with disabilities needing to reach a crisis point, before support is offered (Cullen and Lindsey, 2019). Likewise, the findings reinforce the recent Independent Review of Children's Social Care (2021), which discovered:

'the children's social care system too often focuses its efforts on investigating and assessing parents rather than providing the help that families need' (p.11).

A related aspect of *'hidden needs'* was the endless form filling to prove need, to access financial benefits. This is an issue for any parent of a disabled child, navigating the system at both a local level to access care package support from social workers and at a national level to access financial benefits. However, for parents of children with autism and LD, this process seems to be more complicated, as parents are likely to have more difficulty proving their child's hidden needs.

Helen and Charles conveyed the effort and emotional aspect of having to fill in all of the forms for their two children with additional needs:

'You know carer's allowance, disability living allowance all this sort of stuff...and its emotionally draining, putting yourself through all that...' (Helen and Charles)

Likewise, the emotional effects and precious time taken to fill in long-winded and poorly designed application forms has been confirmed in the literature (Dillenburger et al. 2010).

However, Helen and Charles experience was compounded by needing to make separate applications for their two children with special educational needs, and then at regular intervals having to reapply. These parents also felt that they needed to amplify their child's difficulties to access these benefits, which links back to the issue of the system which determines eligibility through the lens of the medical model (Marks, 1997).

5.3.6 Key findings

'Hidden autism' emerged as an important theme for parents in this study overlapping and underpinning much of their experiences. The data revealed a pattern of hiddenness, beginning with the challenges for parents of caring for their children which were largely unseen and not understood as they were *'Hidden behind closed doors'*. For one parent, some of this hiddenness was a deliberate attempt to *'save face'*, to keep her reality hidden from family and friends. This was driven by embarrassment of her autistic child's behaviours. The findings also highlighted the problem of *'hidden exclusion'*. In terms of schooling, this was evident when children were attending a specialist unit attached to a mainstream school. However, there was also the example of a special school trying to manage a safeguarding issue through exclusion, rather than tackling the matter directly. A specific finding was also the concern that some children with autism and LD seemed to live a *'closed existence'* spending little time in the community due to issues around safety. When children did access the community, parents felt that there was still too much societal focus upon physical disabilities and thus a lack of compassion for children with autism seemed to prevail. A focus on physical disabilities was also cited as a barrier to children with autism getting enough support to be able to access community activities. The lack of focus on hidden disabilities

was also seen to make navigating the system of disability benefits more challenging. A particular key finding was also the slowness of social workers to recognise the needs of children with autism and LD, which resulted to delays to parents accessing support. Another key finding of this study was that the above issues of accessing support were amplified for parents with more than one child with autism and LD or other additional needs.

5.4 The exosystem- Misrepresentations of autism

In this system I discuss the findings in relation to the superordinate theme of

Misrepresentations of autism. This theme is explored through three subordinate themes

seen below in (fig.20). At the end of this section I provide a summary of the key findings for this theme.

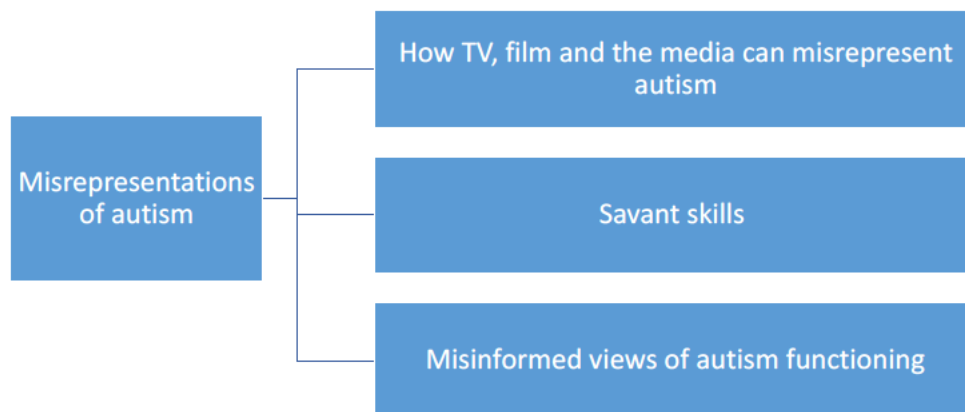


Figure 20: Misrepresentations of autism

5.4.1 How TV, films and the media can misrepresent autism

Parents conveyed how their experience of autism, which was wrapped up with their child's learning difficulties, differed from how autism is generally portrayed in society. Several parents talked about the role of TV, films and the media in either informing or misinforming others about autism. On the one hand Ella described a written article in the media which presented autism in a disparaging light:

'I read an article the other day when they basically you know, the feedback was, people just make up this label of autism. It's just because their children can't be controlled and they are naughty, all this kind of thing. And it really does get my backup... our children haven't got the mental age...it's not just that they're being naughty or silly or cheeky. My children don't speak to be cheeky to me, they throw themselves on the floor and people are standing there and they will tut and they'll judge and they'll say things.' (Ella)

Ella's words are powerful as they highlight the anguish and frustration of hearing disrespectful comments about autism. Her experience particularly highlights the societal assumptions which tend to position the behaviour of children with autism and LD as 'naughty'. Later in the chapter, I return to this issue (see section, 5.6.2).

On the other hand, Charles was critical of the role of TV and the media for distorting views of autism:

'a lot of people don't really understand what autism is and even when you talk to them, if they know something about it, they've generally picked it up from films or TV, or the media or what have you.' (Charles)

Jayne also conveyed this issue:

'autism is a real disability, when it's as severely affected as Tim is and of course people see autism on the telly and it's not like that...the full-blown classic autism, that Tim has...because they generally see autistic people talking quite articulate, holding themselves together and they don't see the real...' (Jayne)

Jayne makes the point that it is becoming more usual for autistic people to appear in TV programmes and that this is broadly a good thing:

'there's certainly nothing wrong with showing the autistic gardener and things like that.' (Jayne)

However, the problem is that sometimes images of autistic people do not necessarily correlate with any meaningful understanding of what life is like for parents of children with autism and LD. This can be seen through the conceptual framework where there is the potential for portrayals of autism to have a cascading effect from the exosystem into the mesosystem and result in societal misunderstandings of autism and LD.

The issue for parents in this group is that their children often have little or no spoken language (Norrelegen et al. 2015). Thus it is left to parents to be this voice and to try to influence societal views (Hacking, 2009b). Jayne grappled with this concern of improving knowledge about autism and LD:

'it's almost how can you raise awareness?' (Jayne)

Jayne felt that there was a need for more TV programmes and films that presented images of children with autism and LD:

'but more showing the other end, more showing neuro-disabled.' (Jayne)

She reflected that the film *'After Thomas'* successfully captured this reality of autism.

'It was on Boxing Day one year; Tim was only just diagnosed, and the little boy was having a meltdown in the middle of the road and people [in cars] were beeping [their horns]. I wish they'd play that again...because it showed a very autistic little boy, non-verbal.' (Jayne)

It appears that these images in the film were meaningful for Jayne, as they validated aspects of her own reality of autism. The significance of the findings is the parental plea for more images of children with autism and LD to be included through these mediums reflecting their realities.

In essence, Jayne concluded that to improve understanding of autism and LD:

'You've got to keep talking about it, keep showing different types of autism on TV.

Like The A Word.' (Jayne)

Ella also felt this TV drama offered a helpful glimpse into the lives of parents like herself and as a tool for helping to educate relatives. Albeit unsuccessfully, she tried to encourage her parents-in-law to watch it:

'I'd say you know record that tonight and watch it.' (Ella)

The variety of autism portrayed through images of able and articulate individuals seems to be more visible, accessible, and comfortable for society to accept, than perhaps autism with additional learning difficulties. Accordingly, this seems to underpin Ella's difficulty with engaging her parents-in-law with *'The A Word'*. This group of parents shine a light upon the question of whether society relies too heavily upon media, films, and TV to provide knowledge to society about autism? A key finding is that the absence of sufficient formalised autism education across all segments and settings in society, is likely to mean that autism and LD will remain largely invisible and poorly understood by many.

5.4.2 Savant skills

Some parents felt that there was a persistent societal view that autism was associated with special talents or as depicted in the film *'Rain Man'*. Although, Diana felt that autism awareness autism had improved:

'everyone seems to know someone who's autistic now.' (Diana)

She reflected that there was a gap in real understanding of what autism is like:

'I think they're idea of what autism actually is differs from what it actually is day to day, because when they think of an autistic kid, quite often they are thinking of either Rain Man or a high functioning autistic child who's struggling a little bit in school.'

(Diana)

Diana's experience reveals that understandings of autism are too often based upon stereotypes of autism, which distorts parents' true reality. Likewise, the association between autism and *'Rain Man'* is confirmed in the literature (Joosten and Safe, 2014; Hacking, 2010; Draaisma, 2009; Treffert, 2014).

Similarly, Charles reflected that his stepfather had a stereotypical view of autism:

'his impression of autism again, it's this classical thing, what's his special talent then, type of thing? And it's that not understanding what it's all about, type of thing.'

(Charles)

My interpretation was that some grandparents favoured the stereotype of *'special talents'*, as it is a more palatable way of viewing autism, rather than having to face the reality of having a grandchild with autism and LD. The significance of the findings is that it brings into sharp focus the emotional vulnerability of parents of children with autism and LD. This

seemingly harmless remark can be especially hurtful for parents whose children may be struggling to achieve basic independence skills, as it fails to take seriously these challenges and suggests a lack of empathy. Broady, Stoyles and Morse (2015) also found that carers experienced the most emotional hurt from family and friends, who lacked understanding. However, the significance of the current study was that parental experiences of grandparents dominated the findings.

5.4.3 Misinformed views of autism functioning

A few parents had children who were able to communicate verbally. However, these parents articulated that other people tended to overestimate their children's overall ability to function. Diana conveyed this issue:

'if children are verbal they are judged as being able and that isn't necessarily the case. You know obviously Sam's verbal ability is above his understanding and people really do not get that. It's like, well if he can talk he can understand.' (Diana)

Likewise, family members and close friends tended to also draw the same conclusion. Becky recalled holding a party in her garden to celebrate her son's confirmation. She remembered Joshua making a speech:

'Oh, and I'd like to thank the academy for being here.' (Becky)

Becky explained:

'Everyone laughed, but the problem is that people assume he's quite intelligent, but I know he uses it to mask everything, rather than having a normal conversation.'
(Becky)

In addition, Ana reflected upon the attitude of the teaching staff at her son's previous school:

'I think they wrongly assumed that because Matthew was verbal, he must therefore have the ability to say what he was feeling.' (Ana)

In the above examples, parents felt that assumptions about autism needed to be challenged. The belief that their child's spoken communication was seemingly matched with the same level of understanding was a clear frustration for these parents. Parents were also irritated when others did not realise that their children could not express their feelings verbally.

A related finding concerned schools focusing upon student's academic ability to determine class groups, rather than considering the importance of shared special interests to support learning. Diana explained how Sam's school had previously placed him in a class of children with a similar academic ability:

'Sam felt that he didn't have anything in common with the other students. Whilst academically he might have been on a par with them all...but the fact that their interests were here [at an older level] and he's still liking 'In the Night Garden' down here [at a younger level], he felt that he had no interests.' (Diana)

Diana's experience highlights that schools need to incorporate children's special interests into both learning and planning class grouping. Some older children with autism and LD may continue to be interested in TV characters, usually aimed at younger children. These

characters may be familiar, calming and reassuring and may positively help support their coping and emotional regulation.

5.4.4 Key findings

Parents highlighted the issue of how TV, films and media can distort societal understandings of autism. Parents made a plea for more TV programmes and films that present images of children with autism and LD. A key finding is that the absence of sufficient formalised autism education across all segments and settings in society, is likely to mean that autism and LD will remain largely invisible and poorly understood by many. The misassumption that others thought their children must have a special talent or be especially clever was highlighted by parents. A key finding was that this was particularly hurtful when grandparents failed to take seriously the challenges for their grandchildren with achieving basic independence skills. For children with spoken communication, the assumptions that was seemingly matched with understanding was also a clear frustration for parents.

5.5 The microsystem- Loss

In this system I discuss the findings in relation to the superordinate theme of *Loss*. I explore the similarities and variations in how parents in this study experienced loss through the nine subordinate themes below (see fig. 21). At the end of this section I provide a summary of the key findings for this theme.

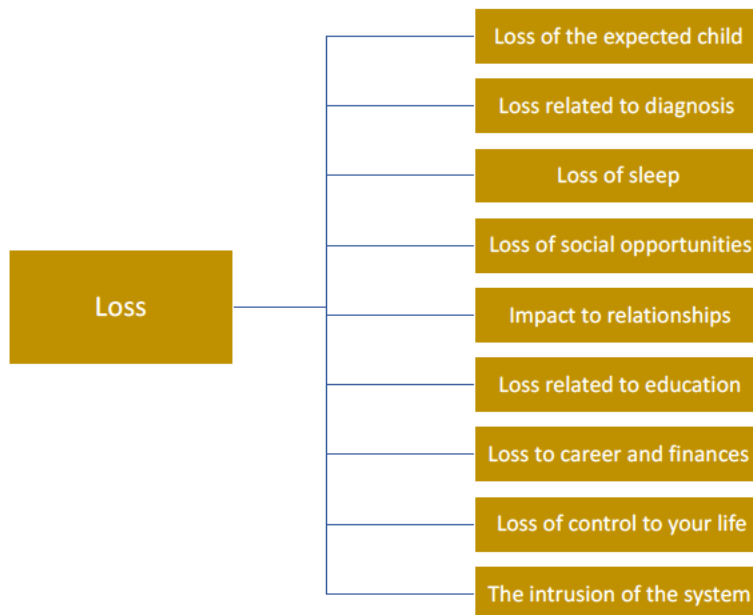


Figure 21: Loss

5.5.1 Loss of the expected child

Echoing the literature, for most parents in this study loss appeared as a journey in time, reflecting the temporal aspects of their experiences (Nicholas et al. 2016; Ludlow, Skelly and Rohleder, 2011). Loss first emerges towards the beginning of their autism journey, as an

awareness began to grow of the differences in their child's development, versus their peers. All parents in the study shared experiences of having early concerns about at least one of their children, who were later diagnosed with autism. In these instances, it was virtually always the parents who recognised that something seemed to be a miss, rather than health professionals, friends or other family members. Ultimately, parents felt lost, unsure how to help their child (Celia et al. 2019).

Three parents in the study reflected about these early days and had similar concerns of their child's endless crying:

'It started with the crying, crying, crying, day and night and I couldn't turn it off.'
(Jayne)

'He was so different from my other babies, the minute he was born he started crying, but he was constantly crying, he was screaming.' (Becky)

'Matthew was a very unsettled young baby. He would cry for what felt like days, but it was probably just hours.' (Ana)

Also Ella had concerns about two of her triplet boys, Jacob and Harvey, shortly after they were born:

'Pretty much straight away I knew there was something not quite right about Jacob. He had only been home for a day and he popped a hernia and was admitted to hospital. [After he came home from the hospital] Even though Jacob was healing, I started to have a feeling that something wasn't right, he wasn't a happy baby...A

couple of months later, I started to have similar feelings about Harvey. He wasn't agitated like Jacob, but he was very quiet, almost in another world.' (Ella)

A common feature of this finding was it related to parents who had baby boys. By contrast, Diana did not recall having any early worries about her daughter Zara. Rather, Diana dismissed her behaviour as expected:

'She was my first child and I just thought she was going through the 'terrible twos.'
(Diana)

Mirroring the literature about grandparents, it was Diana's mother who noticed something unusual about her granddaughters' development (Prendeville and Kinsella, 2018). However, unlike the grandparents in the Prendeville and Kinsella (2018) study, she chose not to alarm Diana by mentioning her concern. In the end, it was the staff at Zara's nursery school who raised their concerns with Diana. This led to her diagnosis of classic autism at two years old. In another study parents also had concerns about their children's development, only retrospectively recognising that something was different (Fleischmann, 2005).

In the current study, naturally parents who had concerns about their children, sought advice from health professionals, such as their GP, health visitor or Paediatrician. However, it is evident from the findings that health professionals did not always agree with parent's disquiet about their child's development and parents felt they were not taken seriously. These difficult interactions are depicted in the conceptual framework between the parent/child dyad in the microsystem and health professionals in the mesosystem. This had the effect of amplifying the parental experience of loss.

For example, Becky describes the response that she had from the doctor about her son's crying:

'She dismissed my concerns as Joshua just having wind. So, I bought lots of Infacol, but nothing worked.' (Becky)

Ella also felt ignored:

'I had seen the health visitor and expressed my concerns about the boys, yet nobody really took much notice.' (Ella)

Mirroring the literature, several parents recalled being concerned that their child was not starting to talk (Lloyd, Osborne and Reed, 2019) or their development had started to regress (Altieri and von Kluge, 2009; Bessette Gorlin et al. 2016). Their concerns were not imagined, they were real. For example, Ella recalls how:

'Jacob and Harvey had begun to regress and key words such as 'mum mum' and 'dad dad' had gone by the time they reached 18 months.' (Ella)

Similarly, Jayne remembers being worried as:

'Tim's peers were beginning to utter their first words, but Tim did not have a single word...At his 15 months check with the health visitor, I expressed my concerns about his speech, but these concerns were dismissed.' (Jayne)

Jayne recalls that even her friends misguidedly tried to offer reassuring words that Tim's speech would catch up with his peers:

'Everyone talks eventually.' (Jayne)

The opinions of health professionals often left parents feeling lost. Not knowing how to help their children, they began to develop doubts about their parenting. For Iona, her self-doubts began when she struggled to breast feed Gabriel:

‘the health visitor made me feel that I couldn’t feed my child, rather than looking at other possibilities’ (Iona)

Contrastingly, not all parents had difficulty securing a diagnosis for their children. Jayne, Becky and Ella received their child’s diagnosis relatively early, probably because their children had no spoken language and were showing other signs of developmental delay. In other words, the issues were visible.

Despite having an existing experience of an older child already diagnosed with autism, both Jayne and Diana had their concerns of autism in their second born children dismissed. Jayne remembers the initial appointment where she discussed her concerns about Felix:

‘the clinical psychologist belittled me.’ (Jayne)

After the full multidisciplinary team had assessed Felix, a diagnosis of autism was denied. However, when Felix was 8 years old, with the support of his school, he finally received a diagnosis of autism.

Similarly, Diana recalls:

‘the Paediatrician did not think there was an issue with Sam and conversely suggested that there was an element of copied behaviour.’ (Diana)

Likewise, with the support of the teaching staff at Sam's preschool, he was eventually diagnosed with autism.

Overall, these findings are largely consistent with studies in the literature which have also found that health professionals were slow to recognise and diagnose autism (Huws, Jones and Ingledew, 2001; Altieri and von Kluge, 2009; Fleischmann, 2005; DePape and Lindsay, 2015; Lloyd, Osborne and Reed, 2019; Celia et al. 2019)

However, perhaps most worryingly, and a key finding of the study, was that health professionals failed to recognise other co-occurring conditions, such as epilepsy and TS. The experiences of Charles and Helen and Iona were strikingly similar. It is notable that these parents instinctively knew that something was 'wrong' with their babies. Yet when they tried to describe this to health professionals, they failed to recognise that these babies were having seizures. As Charles and Helen explained, the issue seemed to be that their son's symptoms were so subtle:

'his eyes would roll up, just for 10 seconds or so.' (Charles and Helen)

Similarly, Iona recalls that Gabriel started having odd movements:

'a bit like when your child's head suddenly drops, and they fall asleep and then they wake up.' (Iona)

In ignoring parent's genuine concerns about their child's development, I assert that health professionals positioned themselves as the experts (Sherwood and Nind, 2014), inferring parental instincts were wrong.

An uneasy feeling continued to fester in the minds of these parents, they could not sit back and ignore what their instincts were telling them. Eventually parents found other ways of being heard. Charles and Helen conveyed:

'it was so difficult to articulate and describe. It was only when we decided to make a video of these instances and we took it to show to the doctor, that we were taken seriously. Owen was immediately admitted to hospital.' (Charles and Helen)

Owen received a diagnosis of West syndrome.

Contrastingly, Iona recalls:

'I did some online research, which is how I came across 'infantile spasms'. When I read about these, I realised that it was very serious and it was such a close description to what was going on with Gabriel. That's when we got our Paediatrician friend to talk to her colleagues and we went back to the GP and he agreed to speed up the Paediatrician referral.' (Iona).

However, even this was not enough and eventually Iona's husband contacted the hospital:

'He spoke to the right person at the hospital who knew what 'infantile spasms' were.'
(Iona)

Eventually Gabriel was admitted to hospital and received a diagnosis of TS and epilepsy.

From the descriptions above it is evident that parents and their children were denied support at a time of heightened need. These parents were left in limbo, questioning their instincts and parenting abilities. The significance of the finding is that whilst parental loss was initially related to a loss of their expected child, this loss was compounded by a lack of

support and acknowledgment that parental concerns were genuine. I assert that this was a *'double'* loss.

In some cases, the absence of a diagnosis and support prevented access to the right educational support and or medical care, thus impacting long term health and educational outcomes. A willingness to see parental concerns as real, might have reduced the *'double'* loss effect and supported better long-term health and educational outcomes for their children. The government's recent autism report (Department of Health and Social Care and Department of Education, 2021) is timely as this acknowledges more needs to be done to improve the diagnosis process.

5.5.2 Loss related to diagnosis

The theme of loss continues to unravel through the parental narratives. Consistent with the literature, for some parents the period when they received their child's diagnosis was entwined with a sense of *'Loss of their expected child'* and this was experienced as a form of grief (Huws, Jones and Ingledew, 2001; Altieri and von Kluge, 2009; Myers, Mackintosh and Goin-Kochel, 2009; Lloyd, Osborne and Reed, 2019; Celia et al. 2019).

Jayne recalls her feelings at the time:

'It was impossible to escape my own mini grief, trying to come to terms with losing part of my little boy.' (Jayne)

The language that Jayne uses conveys that the diagnosis confirms her worst fears. It is almost as if she feels that autism is responsible for stealing away part of her son. This seems to mirror Park's (1982) description of her daughter, Elly:

'The fairies had stolen away the human baby and left one of their own' (p.12).

Thus, Jayne is left trying to come to terms with a child who she feels is unlikely to develop as she had hoped and expected.

Contrastingly, for Ella receiving a diagnosis of autism for her boys was initially experienced as a relief, as finally her earlier concerns were acknowledged. However, much like Jayne she also reflects upon her grief at this time, mourning the loss of not having the children that she and her husband expected:

'it does feel like you mourn your children even though they haven't died, which sounds awful I know, but I don't really know any other way to explain it.' (Ella)

Likewise in the literature, grief was mixed with relief, as parental concerns were finally recognised (DePape and Lindsey, 2015; Celia et al. 2019).

This parental grief can be seen through the conceptual framework with the parent/child dyad in microsystem/home. The theme of *'Misrepresentations of autism'* also intersects and amplifies this loss in relation to their child's diagnosis, as parents felt that their realities did not align with the societal view of individuals with autism as able and articulate (see section, 5.4). Also the theme of *'Hidden autism'* in the framework reveals how this grief is largely hidden within the family/microsystem and goes unnoticed by the outside world.

Conversely, Becky's feelings of this loss were entangled with feelings of blame. Whilst pregnant with her son, she experienced an allergic reaction to Penicillin. She believed that her husband's delay in getting her medical help, resulted in her son being born early:

'If he had taken me to the hospital sooner, then they might have done something sooner and maybe Joshua might not have been so special' (Becky)

For Becky, her loss of her expected child, seems to be related to her own beliefs about why her son developed autism.

Research suggests that overtime parents move on from feelings of loss and become more hopeful about their child's development (Altiere and von Kluge, 2009). Similarly, Fleischmann (2004) using the analogy of 'The Hero's Story', depicts how parents eventually come to terms with their child's autism diagnosis. By contrast, a U.S study of parents of children with autism, who probably also had LD (Bessette Gorlin et al. 2016, p.587), described autism as *'it hurts'*. This seems to align more with the present study where several of the parent narratives depicted a rather negative picture of their child's autism and other co-occurring conditions, viewing this as pain and suffering:

'Our experience of autism...it is so debilitating...because it's wrapped up in learning difficulties and wrapped up in epilepsy and stuff like that.' (Charles)

These parents were eager to point out that they wanted to eradicate their child's conditions:

'of course, I would, I mean its debilitating for Owen, I don't know what his future is going to be? Yes, I'd want to take everything away from him if I could, if I had that wish.' (Helen)

At the same time, parents in the present study would not have changed their children:

‘you wouldn’t change them as a person as in looks and so on, but you would not want them to be autistic with learning needs of course you wouldn’t...’ (Ella)

In this sense, parents seemed to view their children as a slightly separate entity from their actual diagnosis. In addition, these parents had a self-awareness of their negative view of autism, which was at odds with the seemingly opposite views held by other autism parents. As Helen explained:

‘I’ve read a lot of parents with a child with autism say that they would never, they won’t want to change their child, that’s-that’s the way they are...’ (Helen)

With this came an awareness of not belonging and feeling disconnected from the autism community. It seems likely that autism and LD together with possible other co-occurring conditions, such as epilepsy created a different experience for these parents, setting them apart from other autism parents, as if living in a different reality. Having more than one child with additional needs, such as Ella who had triplets, was another complicating factor.

Many within the autism community contend that the real issue and what underlies negative perceptions of autism, is that a medical model view of autism continues to prevail, where the terms *‘deficit’* and *‘disorder’* are used to describe autism (Milton, 2019, p.3).

Furthermore, this author argues that viewing autism in terms of behaviour and cognitive deficits, fails to take account of the disabling effects of society.

Looking at this through the conceptual framework, this view of autism can be seen as originating in the macrosystem. As the DSM-V positions autism as a medical condition

accompanied by other possible 'medicalised' co-occurring conditions (APA, 2013). In turn, this view of autism can be seen as having a trickle-down effect through the conceptual framework, including the mesosystem. A recent UK study confirms the preference amongst professionals for the term '*person with autism*' (Kenny et al. 2015, p.442). However, my experience is that the term '*a diagnosis of ASD*' also continues to be widely used by professionals throughout schools, health and social care. This might be related to some of the support that is associated with children with a diagnosis of autism and LD and other co-occurring conditions. For example attending a special school and having a care package. However, ultimately this choice of language, which is focused upon impairment is likely, even subconsciously, to help to perpetuate a view of child with autism as '*disordered*' and '*challenging*'.

Continuing this cascading effect, in the microsystem this can have the potential to influence parental perceptions of autism, as a condition of impairment and deficits. Parents may naturally have a tendency to follow the lead of these professionals and refer to their child's condition through their medical diagnosis of ASD, rather than 'just' autism. If they are misguided, it is through no fault of their own. Another reason why parents may use deficit language is that emphasising the negative is likely to be needed to be able to successfully access disability benefits (Kenny et al. 2015). This is likely to be more a reflection of the difficulties of navigating the disability system, than the views of parents. Overall, the potential over use of medicalised language in relation to autism is significant as it may amplify the parental experience of loss.

Another view is that there has been a concerted effort to move away from specific references of ASD, in favour of the wider term '*special needs*' (Russell and Norwich, 2012, p.240). These authors suggest that the use of this term is intended as to replace deficit language with a focus on positives or '*special*'. However, I contend that there is a vagueness about the blanket term '*special needs*' *because* there is no signpost to what these needs might be and or how significant they are.

Having made these points, I contend that parents who held negatives view of autism, did so not because of 'impairment language', but because they genuinely felt, much like Bessette Gorlin et al. (2016), that their child was suffering. Many autistic adults disagree with the notion of a '*person who suffers from autism*', as the language implies that '*separating the person from their autism is damaging, as it reinforces opinions about autism being a 'thing' that can be removed*' (Kenny et al. 2015, p.448). This relates back to autism being viewed through the medical model. However, an important distinction of these parents was that their child's diagnosis of autism and LD, and for some other co-occurring conditions, was responsible for creating a different parental experience. Thus, I would argue that the origins of their child's '*suffering*' were biological, but were no doubt compounded through unsupportive interactions with others, including professionals and family members (see unsupportive attitudes towards autism, section 6.3).

To be clear, parents seemed rooted in the 'real' reality of autism as lifelong, which contrasts with a persistent view amongst some parents, albeit misguided, that autism is curable (Lloyd, Osborne and Reed, 2019). I would speculate that if these had been parents of autistic

children, without LD and other co-occurring conditions, they would probably have held more positive views. I contend that the lives of these parents lives were ultimately '*inter-dependent*' with their children, due to their higher level of needs (Giri et al. 2021, p.103). Thus, this made their experience different to parents who have a child without a dual diagnosis. This translated to for example, their children attending special schools, accessing disability benefits and services via a care package. Also the continuation of their caring role extending well into their child's teenage years, with impacts to paid employment and other restrictions to opportunities. Differences between how parents of children with a dual diagnosis might experience life, is also discussed in the further sections below and later in this chapter about societal judgements (see section 6.3.2).

Whilst the theme of parental stress dominates the relevant literature (Myers, Mackintosh and Goin-Kochel, 2009; Bonis, 2016; Ludlow, Skelly and Rohleder, 2011), the findings from this study propose that there are other parental experiences which might be better understood through the prism of loss. In the next sections through the remaining subordinate themes, I continue to explore the theme of '*Loss*' through its multiple layers.

5.5.3 Loss of sleep
'*Loss of sleep*' emerged as a common theme. Especially in the early days, every parent spoke of their child's sleep difficulties. Consequently, parents felt constantly sleep deprived, beyond what most parents of young children experience.

For Becky the difficulties of having to cope with a child who did not sleep, were also compounded by his screaming:

'He also never slept, all night long he would scream, and I would get myself into such a state, it was just too much.' (Becky)

Jayne reflected on how her family were unable to appreciate what sleepless nights felt like for her:

'They'll never feel the pain of that, of that tiredness and how it really impacts upon your day to day.' (Jayne)

In this case, there is a real sense of the absence of any family empathy.

The strain of disturbed nights was more intense for parents who had more than one child with autism and LD or other children with developmental issues. Charles and Helen explained how they had sleep issues with both their boys:

'Fergus didn't sleep right from the start, whilst with Owen sleep difficulties developed when he became a toddler.' (Charles and Helen)

Likewise, two of Ella's triplet boys with autism and LD had sleep issues:

'I've got two up through the night. For instance, yesterday, they were both up at 5 o'clock in the morning. So, I'm literally still living on 4 hours sleep some nights, so that's pretty tough.' (Ella)

For Jayne the accumulation of insufficient sleep eventually took its toll on her health:

'My body couldn't carry on any longer and one day I suddenly felt that I was having a mental and physical breakdown.' (Jayne)

These examples highlight how caring for a child with long term sleep issues can impact upon parental wellbeing and their ability to function. Likewise, other studies confirm the issue of loss of sleep and how this eventually impacts upon parental health and wellbeing (Myers, Mackintosh and Goin-Kochel, 2009; Altieri and von Kluge, 2009; Ludlow, Skelly and Rohleder, 2011).

For most parental loss of sleep persisted into their child's teenage years. For example, Ana explained how Matthew still frequently woke up in the middle of the night and would not resettle:

'Sometimes he can be awake from 3.30am and then he's up for the day, he doesn't seem to need the sleep.' (Ana)

Some parents resorted to using medication to support their children's sleep. Diana explained that her son could still not go to sleep without this help:

'Sam still can't sleep without Melatonin, and he also takes a sedating antihistamine.'
(Diana)

Overall, it is evident that the issue of loss of sleep was an enduring one for these parents. It is unclear whether this directly associated with their child's dual diagnosis, though long-term issues with sleeping have also been identified in a similar study (Bessette Gorlin et al. 2016). Another factor which amplified the issue was that some parents, such as Ella who had triplets, had more than one child with additional needs who had difficulty sleeping.

5.5.4 Loss of social opportunities

Echoing the literature, virtually all parents identified that having a child with autism and LD had limited their social opportunities (Myers, Mackintosh and Goin-Kochel, 2009; Altieri and von Kluge, 2009; Preece, 2014). These studies suggest that a loss of social opportunities mostly relates to stigma, originating from judgements and stereotypes about their child's behaviour (Broady, Stoyles and Morse, 2015; Kinnear et al. 2015; Ludlow, Skelly and Rohleder, 2011; Cashin, 2004). In comparison, whilst the findings from the present study suggest a relationship between judgements about behaviour and loss of social opportunities, there were a range of other reasons why parents experienced a loss of social opportunities.

For Helen and Charles, the main factor that prevented them from visiting the homes of friends or family were their own concerns for their children's safety. Other people's houses were insufficiently secure to prevent their children from absconding:

'Whenever we went to someone's house, we were always worried about what they could do, could they escape?' (Helen and Charles)

Likewise, in the literature the issue of children absconding is confirmed (Celia et al. 2019).

Charlie explained how the underlying issue was that friends or relatives seemed to fail to understand that safety was a real issue for their family:

'you can talk about things, and you can describe things, but quite often people don't really get it, so security and that, you know locking the front door, making sure all the back doors are locked...' (Charles)

Parents were also reluctant to visit the homes of friends and family as their children were inclined to break items and hurt themselves (Celia et al. 2019). This is evident through Jayne's depiction of Tim, who when momentarily was unsupervised, broke the glass in his grandmother's antique cheval mirror.

'suddenly there's a big crash and upstairs he's pulled over grandmothers swivel cheval mirror, it.. we all run upstairs, this mirror has shattered in half and a huge chunk of glass has slid off, it could have cut his leg off or anything, so of course we're mortified that he's damaged something, we're horrified that actually it was a huge jolt for us...' (Jayne)

Helen and Charles felt that the need for constant vigilance meant that, unlike parents of typically developing children, they were on tenterhooks the whole time. Consequently, they started to make conscious decisions to self-exclude themselves from visiting others:

'we stopped going to friends' houses as well.' (Helen and Charles)

In these circumstances as parents begin to lose out on social opportunities there is a risk of them becoming isolated from friends and family.

The difficulty for parents of keeping their children safe and how this affected their social opportunities can be seen through the conceptual framework. As vigilance was not enough to ensure their children's safety, the parent/child dyad is seen to shift inwards to spending more time in their home in the microsystem, rather than visiting the homes of others in the mesosystem. A key finding from this study was that the issue of safety continued into their child's teenage years and this issue was exaggerated for parents with more than one child with autism and LD or other special educational needs.

A related issue for some was their children had no or limited spoken communication. If they got lost, they were particularly vulnerable, unable to ask for help or give their name and address. Yet to strangers without an understanding of autism, these children appeared like typical children. Drawing on my personal experience of my own son absconding, I suggest that these events become indelibly etched in parental minds. Being vigilant becomes second nature to the way we live our lives.

Having a child with a developmental delay also resulted in parents limiting social opportunities. For Helen, visiting friends who had typically developing children highlighted her own child's developmental delay. These direct comparisons were unhelpful and compounded her feeling of loss.

'I used to meet up with friends from my anti-natal group, but as Owen's condition began to unravel, it became difficult to bear being around others in the group with typically developing children.' (Helen)

Studies indicate how parents of neurotypical children can lack understanding about autism (Lloyd, Osborne and Reed, 2019; Safe, Joosten and Molineux, 2012). Moreover, feeling self-conscious of having a child with a developmental delay and having to deal with overt comparisons from parents descriptions of typically developing children is confirmed elsewhere in the literature (Canning and Beryl, 2021; Bessette Gorlin et al. 2016). In this circumstance, Helen chose to self-exclude herself rather than being excluded. This became a means of self-preservation, an avoidance of having a light shone upon their child's missing development and family reality.

Another related issue was how sensory sensitivities restricted family opportunities in the community. Ella gave an overview of how difficult it was to take her boys out into the community because of their sensory sensitivities:

‘we are limited, the boys don’t like to do too much and then there’s the noise, we can’t do any queuing and its got to be all very familiar. We do struggle in the winter because Harvey still only wears crocs on his feet.’ (Ella)

The challenges of managing the sensory differences of children with autism is also confirmed in the literature (Schaff et al. 2011). Similarly, the issue of living with restrictions and lack of spontaneity, which places parents at risk of social isolation has been reported (Myers, Mackintosh and Goin-Kochel, 2009; Ludlow, Skelly and Rohleder, 2011; Schaff et al. 2011). By comparison, the significance of Ella’s experience is that it highlights a greater sense of restriction for parents of multiples or those with more than one child with autism and LD or other additional needs. The reality for these parents is likely to go largely unnoticed by the rest of society. Parallels can perhaps be found with the Covid-19 pandemic and the restrictions imposed upon our normal freedom of movement. However, there is an important distinction. Whilst these restrictions related to the pandemic are perceived as temporary measures, for families of children with autism and LD, they are likely to be more enduring. Later in the chapter, I return to how Ella found ways of adapting to her boys sensory sensitivities, so that they could have opportunities to access activities in the community (see section, 5.9.1).

5.5.5 Impact to relationships

Virtually all parents talked about loss from the perspective of how parenting a child with autism and LD, had impacted their relationships with their relatives and friends.

Most parents spoke at length about a challenging relationship, with at least one grandparent. Some parents also echoed similar difficulties in their relationships with other relatives and friends. Parents were also often consciously aware of how differently grandparents seemed to treat their neurotypical grandchildren versus their own child/ren with autism and LD, which amplified their sense of loss. Later in the chapter, I return to discuss more about grandparents through the theme *'The social expectations of grandparents'* (see section, 5.6.3).

Exploring Ella's experience brought to light a strained relationship with her parents-in-law.

Ella explained that overtime this relationship had worsened and her parents-in-law had become less involved with her children, eventually losing all contact. She explained the awkwardness of having to explain to her other triplet son (without learning difficulties), why they were excluded:

'It's kind of heart-breaking really because what do I say to S? You know, there's no pictures of me and my brother's, why don't granny and grandad do that with me?'
(Ella)

This loss of involvement of the paternal grandparents, sat in stark contrast to their engagement with their other grandchildren, as Ella explained:

'But she'd have all the other children over and they would build dens and tents in the garden.' (Ella)

This strained relationship resulted in an absence of both emotional and practical support, even though they lived locally. This had a cascading effect deepening Ella's sense of loss and weakening her family's ability to cope. Loss followed loss into other aspects of their life. For example, there was a negative impact to their finances (see section 5.5.7, loss to career and finances). Furthermore, the strained relationship with the paternal grandparents and lack of support had a deleterious impact to their marriage, which Ella explained came close to ending:

'It's nearly cost us our marriage because that's the point that I was at, I just thought I was, I can't do this anymore.' (Ella)

Ella's experience highlights how a difficult relationship with grandparents added to the family's weight of vulnerability. She conveyed how she was pushed to the edge of loneliness:

'when you're at that point, and you haven't got any support and you're being treated like outsiders, you feel so isolated, I can't even put it into words how dark a place you're at, it's very lonely you know.' (Ella)

Contrastingly, Charles conveys a caring image of the relationship between his parents and their two children with learning difficulties, but nonetheless one that lacked physical warmth:

'There isn't that sort of connection, erm they are quite caring, and they always ask and want to know what's happening and this and the other, but they're not physically there.' (Charles)

It is evident that Charles felt a profound sense of loss that his children were missing out on what he felt were normal interactions with their grandparents.

For some parents, having a child with autism had also had a negative impact on their friendships. Friends drifted away, or friendships became damaged, as friends did not take seriously parental concerns about their child's development. This is clearly depicted in Jayne's account of trying to share Tim's diagnosis with a close friend:

'I explained and I explained, and I explained for about two hours and then she leant into me and said, 'Jayne don't worry about him, all children do that, my child does that and I went...and I flipped, and I used swear words...' (Jayne)

Cashin (2006) also found parental social contacts diminished, with their worlds becoming smaller. As friends were not always aware of the effects of insensitive comments, I suggest there is a hidden aspect to this experience.

Overall, a key finding was that loss was pervasive, worsened by other conditions, but also exacerbated by societal attitudes. Parents' loss of their expected child was compounded by a loss of support from relatives, including grandparents. The pervasive nature of parents' experience of loss is reflected through multiple interconnected layers, seen through each of the subordinate themes.

5.5.6 Loss related to education

All parents in this study were advised that their children's educational needs would be best met in specialist settings. Depending upon an assessment of the child's needs, parents were either encouraged to visit specialist nursery and school settings or directed towards specialist units attached to mainstream schools. Therefore, a specific feature of this study was that all parents had at least one child attending a specialist school. This is significant as

most children with a diagnosis of autism (70%) in England, are educated in mainstream schools (DfE, 2021).

As parents visited the potential schools for their children, the theme of loss re-emerges as entering this world of special education was unplanned and unexpected. Together with her husband, Becky visited her son's future school. This shone a light on a new reality, that her son had special needs:

'My husband and I went to visit the specialist centre and I recall that he was quite shocked at seeing the children with physical difficulties, as it wasn't just children with autism, I therefore realised that my child was special needs.' (Becky)

Equally, Ella admitted that she was shocked to realise there were special schools full of children with special needs:

'I never envisaged that our children would go somewhere like this, it broke my heart.' (Ella)

For these parents the sight of other children with disabilities, some of these physical, was a harsh projection into a new reality of special needs. This is a notable finding, as these descriptions of visits to specialist provisions seemed to suggest that parents were re-living the feelings of loss for their expected child.

Having said this, after coming to terms with her children attending special school, Ella was ultimately grateful that her children were in a protective bubble, away from the possibility of being bullied in a mainstream school:

'I knew in my heart that the boys are so vulnerable, this school would be more suited to them...I knew that they needed to be in a small class with a lot of 1:1 support, as they were not independent at all and still in nappies. Also, the noise levels in mainstream school would have been too much for the boys and I felt it would have been terrible with the bullying.' (Ella)

Parents also found they had a limited choice of preschools and schools for their children.

Iona felt that there was no real choice at all:

'We had been offered two choices of specialist nursery provision and neither of these provisions were perfect.' (Iona).

Furthermore, the recommended school placement for Becky's son caused a tension within the wider family, as they had wanted him to go to a Catholic school:

'My mum wasn't happy that Joshua wasn't going to a Catholic school.' (Becky).

Parents also described feeling rather disconnected from other autism parents, whose children attended mainstream schools, as their priorities and concerns did not always correlate with their own. This was particularly the case for parents whose children who had additional medical conditions. For example Helen describes attending a local NAS support group:

'I went to some of the coffee mornings, but I didn't find them very helpful either. The sort of parents who attend seem to have children who are probably more Asperger's.'
(Helen)

This sense of difference may have been magnified by specialist schools being located a distance away from their homes. In consequence, rather than taking their children to nursery or school themselves, parents used the provided transport by the local council. This finding raises the question of whether their children's attendance at special educational settings was initially more of an issue for the parents than for their children?

Several parents also spoke of how school settings failed to support their child's needs. For Iona whose son also had TS and epilepsy, getting the right educational support felt like a race against time to support his development. She felt that any lost learning could not be made up.

'it was kind of wasted time that he was not getting the learning that he could.' (Iona)

Iona recalls fighting with the educational authority to secure a more suitable setting for her son, that would meet his needs.

Similarly, Becky was dissatisfied with her son's schooling. Joshua attended a unit attached to a mainstream school for his primary education and she felt that he was not learning:

'Horrible it made me feel awful, absolutely awful, but I couldn't do anything about it, there was nowhere else for him to go.' (Becky)

In contrast to Iona, she could not see any possibilities of finding a more suitable school.

Recognising that her son was so unhappy and not able to learn, compounded her feelings of powerlessness to change the situation. It is my interpretation that the pain of knowing that her child was so unhappy, hit at the core of Becky's emotions. However, these intense

feelings did not enable Becky to change the situation. Joshua's secondary school placement was in a special school.

Parents also gave other examples of their child losing education, either because a suitable placement could not be found, a school exclusion or anxiety which made attendance difficult. Diana recalls how her son's behaviour was challenging for school staff and he was frequently excluded:

'the school would call me at least once or twice a week, to ask me to collect him. I believed that this was an illegal exclusion...' (Diana)

Diana felt Sam's exclusion was unjustified and that his experience of school had been traumatising, resulting in his diagnosis of severe anxiety disorder. Diana believed that Sam had been:

'Controlled by fear.' (Diana)

Sam was finally offered a place in an autism specific school, but the staff were not aware of the historical issues around him absconding. Diana explained that he was subsequently excluded again, until the school could put adequate safety measures in place:

I think the issue at the beginning was when he was dropped in the school, they didn't have that knowledge and they didn't have a fob system or any way of keeping him safe, it was almost like it was setup to fail...But once they put the things in place and ironically now, he walks round with a fob opening the doors that were all put in place to keep him safe.' (Diana)

It is evident from Diana's experience that inadequate safety is a potential common factor for children with autism and LD, losing time in school and social opportunities outside of the family home.

Contrastingly, Iona's experience of her son, whose main diagnosis was initially TS, contributes an interesting side finding. She explained that her son's autism diagnosis had opened a vital door. At school the diagnosis gave him a place in an autism class, focused on supporting communication. Iona explains that without the diagnosis, the school would have disregarded his communication needs and only focused upon:

'Health, walking and physio.' (Iona)

Overall, the findings indicate that parents also experienced a specific loss in relation to their child's education, either through a loss of choice, inadequate provision or through their children being out of school, due to exclusions or anxiety. These findings bring into focus the wider debate around inclusion and whether children with autism and LD should be educated in more local mainstream schools or continue to be placed in specialist provisions? However, Iona's experience highlights how despite the various aspects of loss for parents, they were sometimes also able to pinpoint positive gains from their experience. This is discussed more later in the chapter (see section, 5.8).

5.5.7 Loss to career and finances

Beginning in the early years, several parents recognised that their role as parent also extended to being a carer for their children. Jayne acknowledged that looking after Tim required:

'24-hour care...' (Jayne)

For parents, their caring responsibilities also continued into their child's teenage years as it was always necessary to have a responsible adult available at home to look after their children.

Ella explained that she was unable to go back to paid work after having her triplets, as all her energy was taken up with their additional caring needs:

'this house wouldn't manage if I wasn't here and I couldn't commit because I don't have enough sleep or have enough in me to commit to it, do you know what I mean?'
(Ella)

The family finances were further impacted when her mother-in-law decided she could no longer help with the children. This meant Ella's husband had to arrange flexible working hours, so that he could help more with the children:

'That affected the money that he earned, that affected us in lots of different ways, that was a knock-on-effect to us.' (Ella)

Likewise, the impact of caring on parental careers and finances is well documented in the literature (Liao and Li, 2019; Myers, Mackintosh and Goin-Kochel, 2009; Järbrink, Fombonne

and Knapp, 2003; Dillenburger et al. 2010; Nagib and Williams, 2018; Preece, 2014; Lloyd, Osborne and Reed, 2019; Ludlow, Skelly and Rohleder, 2011).

Contrastingly, Diana's concerns about loss of career related to her concerns for the future, rather than the present. She worked as a teaching assistant in a special school, utilising her autism experience and she was also trying to advance her career through studying for a degree. However, Diana felt uncertain that she would be able to continue to work and fulfil her future career aspirations because of Sam's care needs:

'When Sam finishes school at 19, he's probably not going to have a full-time placement and that's scary, because you're thinking I'm never going to be able to get a career. Where does that leave me with what I want to do?' (Diana)

The above findings are significant. First, these parental experiences underline the longevity of needing to juggle the care needs of their children as they become young adults, whilst also trying to balance their career and family finances. At a time when most parents of typically developing older children find themselves with relatively more freedoms to focus on their careers, the perceived increase in the burden of care for some parents of young adults with autism and LD presents a paradox. Giri et al. (2021) also highlights the issue of many parent carers of adults with a learning disability being unable to have a paid role. Second, the findings highlight that returning to work is likely to be more challenging for parents with multiples or more than one child with LD.

5.5.8 Loss of control over your life

Parents conveyed how parenting their children placed limits and restrictions to everyday life, that went beyond what parents of typical children usually expect. Several parents overtly articulated this sense of loss of control over their lives, but in different ways.

For Ella this loss related to feeling dependent. Before having her triplet boys, Ella had had a successful career. However, after the boys were born prematurely, two of them with autism and LD, she did not go back to paid work. She reflects back to her career and the feeling of independence this provided:

‘because I had a good job and a nice car...’(Ella)

Ella’s feeling of independence was further diminished, as the additional caring needs and safety of the boys meant that she needed help from carers to carry out simple daily routine tasks with the boys. This was further compounded by the daily worries and an uneasiness of how she would manage if one of the carers was sick and could not work:

‘we are solely dependent upon these two ladies to help us you know and if that doesn’t work, because one of them is off sick or one of them can’t cover, it leaves me in a right predicament.’ (Ella)

Contrastingly, as explained above, Becky’s experience of loss of control related to feeling unable to find an alternative school placement for her son (see section 5.4.6).

For Iona, this loss is seen through her view of the social worker, who she describes had considerable influence over the funding of her son's care package which affected her family:

'it's a really difficult thing to accept that someone can have that much influence over your life, erm and erm without you having control over it really.' (Iona)

Iona conveys her feeling that social workers did not necessarily always work in the best interest of families:

'it's your life that they've got in their hands.' (Iona)

Iona's words reflect a strong sense of feeling controlled by the system, which in turn indicates her own loss of control and unwilling dependence.

The above examples underscore that there are some distinct features of experience for parents of children with autism and LD and higher care needs. These were parents who prior to having a disabled child probably felt that they had a high degree of control over their lives. These were parents who unexpectedly found themselves entwined in a system of support, with social workers, care packages and PA's. These aspects ultimately made parents feel uncomfortably dependent and less in control of their lives. The findings also highlight how Ella's experience of triplets compounded this feeling of dependence.

Finally, in this section I discuss below *'The intrusion of the system'* which also serves to highlights the pervasive nature of the theme of *'Loss'*.

5.5.9 The intrusion of the system

For parents in this study, the system for accessing support, for example social care, communicating with schools and navigating the system of disability benefits was inherently intrusive. This can be seen through the conceptual framework with the interactions between the parent in the microsystem and the systems of support in the mesosystem or macrosystems.

Virtually all parents had a social worker, which correlates with previous research of children with autism who attend special schools (Preece and Jordan, 2007). Most parents accepted that regular visits from a social worker to their home was normal for families like them. This was part and parcel of what was needed to justify their children's needs to access support services, as Charles confirmed:

'you had to almost sort of prove to them, you know...you know these are the sorts of behaviours, these are the learning difficulties.' (Charles)

Likewise, Ella spoke of a social worker joining her out in the community with her triplet boys to get an understanding of their families' needs (see section, 5.3.5). There was an inevitable intrusive element to these social workers involvement, although this was most evident in Iona's narrative.

Iona conveyed the reality, that regular home visits meant sharing lots of personal information. She felt that versus education or health care providers interactions with the social worker were the greatest intrusion into her life:

‘Social care can potentially reach out into anything, and they come to your home and it’s quite invasive, there are a lot of personal questions to get an understanding of your erm family life.’ (Iona)

Social worker visits are depicted through the conceptual framework as physically permeating the parent/child’s environment in the microsystem. The intrusion into Iona’s life and the loss of privacy conceded to access services created a sense that the space between public and private lives was disregarded. This slightly resonates with Canning and Robinson (2021, p.5), description of the notion of the *‘blurring of the boundaries’*, where home *‘as a safe place’* is invaded by outside agencies. These authors describe the Covid-19 pandemic and the issue of autistic children feeling that accessing schooling at home, invaded their home space.

However, this notion seems relevant for parents in the present study. It is notable that if parents had not had children with LD, that their lives would probably not have been entwined with the social care system. In essence the findings suggest a paradox that if parent/child needs were better understood, then it is likely that the system of accessing support would be less intrusive.

A distinct feature for parents of children with autism and LD in this study was that their children travelled to special schools or a specialist unit attached to a mainstream school via transport. A home to school-diary is the main communication tool used between school and parents of children with autism and LD, to provide daily information about the child’s day. Becky revealed how she hated reading her son’s home to school diary as it usually contained negative comments about his behaviour. This was upsetting as she felt judged and blamed, yet this experience was hidden:

'I was dreading reading that every day, which is awful.' (Becky)

Anticipating the negative messages and reading these at home, there was a sense that the written words transcended the page in the book, intruding her thoughts and personal space.

5.5.10 Key findings

Mirroring the literature, parental experience of loss was seen as a journey in time (Altieri and von Kluge, 2009) and this begins with the theme *'Loss of the expected child'*. However, *'Loss'* continued to emerge and re-emerge across their experiences. Although, this sometimes presented differently, reflecting both their child's diagnosis and the individual nature of their experiences. Whilst a key theme in the literature is stress, the findings from the present study suggest that parental experiences might be better understood through the theme of loss.

For some parents their experience of *'Loss'* was compounded by delays in health professionals recognising and diagnosing autism. A key finding was that health professionals also failed to recognise other co-occurring conditions, such as epilepsy and TS, seemingly disregarding parental descriptions of their babies' seizures. Some social workers were too slow to recognise the child's significant needs and they were slow to grasp the full implications of how this impacted upon family functioning. Parents felt their child's needs, which were obvious, had to be demonstrated to social workers through home visits and accompanied visits into the community. This issue was amplified for parents of multiples or for those with more than one child with special educational needs. Parents felt that the hidden presentation of autism and other co-occurring conditions seemed to underpin the

underestimation of needs. The findings highlighted a system that is inherently biased towards physical disability. Moreover, navigating systems of support was inherently intrusive, as boundaries were crossed into personal and emotional space. In summary, the above examples illustrate how the systems intended to support parents also negatively intruded upon their lives and impacted their emotional wellbeing.

5.6 The mesosystem- Parents' experiences of unsupportive attitudes

In this system I discuss the findings in relation to the superordinate theme

Parents' experiences of unsupportive attitudes. This is explored through four subordinate themes seen below, (fig.22). At the end of this section I provide a summary of the key findings for this theme.



Figure 22: Unsupportive attitudes

5.6.1 Lack of understanding of autism

In the present study a '*Lack of understanding of autism*' was conveyed by all parents as

being at the root of '*Unsupportive attitudes to autism*'. A '*Lack of understanding of autism*'

was seen across a range of individuals, including relatives, friends and professionals.

Parents indicated how others failed to recognise their child's needs and often used phrases such as, *'they get it'* or *'they don't get it'* to encapsulate whether they felt people understood autism. Likewise, in the literature studies have found that family members can lack autism understanding (Woodgate, Ateach and Secco, 2008; Ludlow, Skelly and Rohleder, 2011; Broady Stoyles and Morse, 2015; Lutz, Patterson and Klein, 2012; Safe, Joosten and Molineux, 2012). Whilst this theme often features in relation to the literature about parental stress (Woodgate, Ateach and Secco, 2008), it has also been identified as a component leading to stigma (Broady, Stoyles and Morse, 2015).

As detailed in the literature review, authors have proposed different models for identifying the stigma process (see, Kinnear et al. 2015; Broady, Stoyles and Morse 2015). However, one issue with these stigma models, is the degree that parents internalise and accept stigma might differ (Kinnear et al. 2015). The differences in parental perceptions of stigma are significant, as it correlates with Link and Phelan (2001) who assert:

'that for stigmatization to occur, power must be exercised' (p.363). That is, the individual needs to accept the stigma for them to be stigmatised (Lilley, 2013). In view of this, in the present study I did not assume that parents felt stigmatised. Rather than stigma, my preference was to use the broader term *'Parents' experiences of unsupportive attitudes'*. However, in discussing my findings in relation to the literature, I will use the terms stigma and negative or unsupportive attitudes interchangeably.

One example of a '*Lack of understanding of autism*' related to autistic children absconding and others not understanding the importance of keeping their children safe. Charles particularly conveyed that regardless how much you tried to explain:

'People don't really get it.' (Charles)

The failure of others to take their children's safety seriously, led Charles and Helen to self-exclude themselves from visiting many of their family and friends. In turn, the issue of child safety meshes with a '*Lack of understanding*' of the reality of parents' lives. This feeling of not being understood is also mirrored by Nicholas et al. (2016)

'you can explain and explain, but unless you live the life...you can't really understand it' (p.929).

There were also misunderstandings about behaviour. Parents highlighted how relatives and others thought their children were '*naughty*'. Helen conveyed this:

'I think that erm probably especially [my father-in-law], that he thinks the boys are naughty still, you know if they do something wrong.' (Helen)

Likewise, Diana emphasised the persistence of the '*naughty label*':

'I think society needs to recognise people are having issues, stop thinking it's behavioural difficulties, I think a lot of people just think oh it's a naughty child and I think we need to almost lose the naughty label.' (Diana)

Another assumption was the association between autism and violence. Jayne explained how her close friend and neighbour dismissed Tim's diagnosis, because he did not display any violent behaviour.

'this women who knows nothing about autism, said to me the mother of an autistic child, she said 'He can't be autistic...severely autistic, he's not violent.' (Jayne)

Parents also conveyed how family members did not understand that their autistic child struggled being too close to others. For example, Diana's mother failed to accept that Sam could not cope with travelling to school beside other children on the bus:

'she thinks it's now absolutely abhorrent that he is going in solo transport to school, she thinks that he should be on a bus with others and should just get on with it...'
(Diana)

Relatives also failed to understand how an autistic child might appear to be able to carry out a simple task, but struggle at another time due to anxiety. Ana expressed frustration that Mathews' siblings did not appreciate this:

'people just seem to think that he does it on purpose...they don't have that level of understanding that says because you've done this once that you're [not] necessarily going to be able to repeat that.' (Ana)

The assumption that behaviour must be deliberate, was also reflected in Becky's experience of Joshua's teachers:

'her attitude was negative, very negative about children with autism. She'd say, 'Oh he's just doing that on purpose, or to get attention...' (Becky)

Becky went on to explain how the school responded to this behaviour:

'He'd be sent out of the classroom, made to stand in a corner erm for talking, so quite old-fashioned punishments really.' (Becky)

School staff also lacked understanding of how sensory sensitivities contributed to behaviour.

For example, Joshua had a sensory sensitivity which made wearing some items of school uniform uncomfortable, yet his school had a strict uniform policy:

'he had great trouble wearing the uniform. He'd get really upset with the labels; he just didn't like the feeling of it.' (Becky)

Another important finding was in relation to a *'Lack of understanding'* from health care professionals. Whilst some worked hard with parents to support the needs of their children, others lacked the understanding or willingness to try to understand autism, positioning themselves as experts and disregarding parental knowledge. Iona highlighted the issues of accessing hospital care for her son, who had Tuberous sclerosis (TS). She recalled a traumatising experience of Gabriel being in hospital for surgery on his leg. She explained that various things were going wrong, as hospital staff did not seem to have the skills to support Gabriel:

'so, we had things like, you know some junior doctor trying to get a cannula into Gabriel and she couldn't get the cannula into him and she tried several times and there's blood pouring out and Gabriel was beside himself and we were restraining him and there was blood everywhere on the floor...' (Iona)

Iona explained that when she and her husband complained to the hospital, the matron in charge of the service apologised:

‘It’s totally unacceptable and this shouldn’t have happened’

‘so at least it was recognition that-that-that you know what we went through should never have happened.

What she said is: ‘They were not equipped to deal with children like Gabriel.’

Which is when you think about [name of hospital] is the tertiary hospital, they should know how to deal with children like Gabriel...so you kind of think, well where are we supposed to go then?’ (Iona)

The significance of Iona’s experience is that it brings to light a hidden issue that accessing treatment in hospital for children like Gabriel is particularly challenging for the parent and child. It is difficult to communicate to the child what is happening and so this increases fear and anxiety. Whilst specialist hospitals may have expertise of medical conditions, they do not always have sufficient understanding and the skills to support the communication needs of children with autism and LD and other co-occurring conditions. This example also underscores how a *‘Lack of understanding’* feeds into the issue of inclusion.

Overall, the finding from Iona’s experience is significant, as it supports the view reflected in the government’s autism strategy (National strategy for autistic children, young people and adults: 2021 to 2026, 2021), which acknowledges the need to improve health and care staff’s understanding of autism. Moreover, the recent Health and Social care Act (2022) insists that learning disability and autism training should be mandatory for health and care

staff and reasonable adjustments made. These include, taking account of sensory needs and supporting communication with visual aids.

5.6.2 Societal judgements

In the literature, judgements are viewed as a component contributing to autism stigma or courtesy stigma for parents of children with autism (Gray, 1993; Kinnear et al. 2015; Broady, Stoyles and Morse, 2015). By comparison, in the present study parents were asked about their experiences of being judged, but it was not assumed, that they identified with stigma. It is also worth reiterating that whilst the above authors use the terms '*high functioning*' (HF) or '*low functioning*', these do not represent my own views. However, I have made the decision to use the authors' terms when referring to their work (for more details section 1.2.).

All parents shared experiences of '*Societal judgements*' in relation to the behaviour of their autistic child. Parents also felt judged about their parenting and spent time worrying and anticipating judgements. Judgements originated from a plethora of different people, including professionals and service providers, other parents, and strangers. Parents also felt judged by their relatives. This is explored below through the separate subordinate theme of '*The social expectations of grandparents*'.

Authors have tended to position stigma as a particular issue for parents of children with '*HF autism*' (Gray, 2002a; Broady, Stoyles and Morse, 2015; Kinnear et al. 2015). This comes from the perspective that these families spend more time in social settings, they have more

exposure to stigma opportunities and also due the largely invisible presentation of autism (Gray, 2002a).

Contrastingly, Gray (2002a) considered stigma to be a secondary issue for parents of children with '*LF autism*' as:

'the markedly bizarre nature of its symptoms would often lead others to suspect a disability' (p.742).

In view of the above, the findings of the present study are notable as they indicate that judgements are also a significant issue for parents of children with autism and LD. Moreover, Mitter, Ali and Scior (2019) conducted a recent systematic review of the literature, which also confirmed that autism stigma is an issue for family members of those with an intellectual disability (ID), including autism. Nonetheless, it should be noted that most studies in this review were conducted outside the UK, where different cultural settings may make some family members more susceptible to stigma.

In comparison to the relevant literature, whilst there are similarities there are also some distinct differences about parental experiences of judgements. In the present study some of these are context related. First, every parent in this study had at least one child with this minimum diagnosis, attending a specialist school. Most parents reported how staff in specialist schools had supportive attitudes and therefore they felt their children were largely protected from judgements. In comparison, in the relevant literature children mostly attended non-specialist schools and their parents encountered judgements (Gray, 2002a;

Broady, Stoyles and Morse, 2015). That said, one important finding from the present study was the feeling of difference that specialist settings created, amplifying the parental realisation that they had a child with special needs and feeling of loss (see section, 5.5.7). The implication is that whilst specialist settings may shelter children and their parents from judgements, the protective bubble of these settings can bring a wider sense of societal exclusion.

Contrastingly, some parents, namely Becky and Diana also had 'earlier' experiences of their child attending a unit attached to a mainstream school. In these less specialist settings these parents encountered judgements from school staff, regularly receiving phone calls concerning their autistic child's behaviour. For example, Becky recalled the phone calls criticising her son's behaviour:

'in the playground you know, and then can I speak to him, because he was pushing a child over. Of course, I spoke to him, but I wasn't expecting those phone calls...I blamed myself, or you know I'm not a very good parent.' (Becky)

Similarly, Diana recalls that Sam was often excluded from school due to his behaviour and she would also receive phone calls asking her to collect him from school:

'Sam was presenting with extremely challenging behaviour at school. He was at risk, as were the other children and adults in the unit. As a result, Sam was frequently out of school. He didn't attend every Wednesday and the school would call me at least once or twice a week, to ask me to collect him.' (Diana)

Likewise, parents have reported dreading phone calls from school about their child's behaviour (Myers, Mackintosh and Goin-Kochel, 2009). The issue of schoolteachers judging behaviour, due to a lack of autism knowledge is also well known (Broady, Stoyles and Morse, 2015). However, when parents experience these judgements, there is a potential to view their autistic child's behaviour as other people do, seeing yourself as a bad parent (Neely-Barnes et al. 2011) and perceiving the child's behaviour to stem from poor parenting (Farrugia, 2009).

It is my interpretation that Becky internalised these judgements, this is evident from how she describes her feelings of blame. Self-blame and feeling at fault seems to correlate with the notion of self-stigma (Mitter, Ali and Scior, 2019; Ali et al. 2012). It is also likely that Becky's feeling of blame was entwined with a wider blame culture from within her family (see section, 5.6.4). Becky's experience also seems to correlate with the literature about mothers being more likely to report feeling stigma (Gray, 1993; Neely-Barnes et al. 2011). Similarly, Gray (2002a) found most mothers identified with enacted stigma, whilst only a minority of fathers recognised this. Possibly this is because mothers tend to be primary carers and may feel responsible for their child's autism, suggesting a possible link between perceived responsibility and felt stigma (Gray, 1993). Mothers are also likely to spend more time in the community with their child, increasing opportunities for negative interactions (Gray, 2002a).

By contrast, it is less clear whether Diana experienced self-stigma, as she seemed more consciously aware that the school were wrongfully excluding her son:

'I believed this was an illegal exclusion, but the school insisted that they could not guarantee his safety.' (Diana)

However, even after Diana's son moved to an autism specific school, she described her on-going worry and anticipation that Sam's school would call her:

'literally sitting by the phone waiting for it to ring.' (Diana)

Thus, it seems likely that Diana carried forward a sense of trauma from her earlier experience. It is unlikely that schools are aware of how their own communications with parents impact upon wellbeing, thus these parental experiences are essentially hidden. The implication of the findings is that rather than blaming parents, school staff should consider the potential triggers for behaviour, for example sensory sensitivities to noise or being touched.

Another context for potential judgements for parents in this group came from the complexities of their children using transport to school. Whilst most parents had a good experience of the transport staff who they felt tried hard to support their children, there were contrasting examples. For example, as Diana explained, her son could not cope with the taxi to school collecting him half an hour earlier than usual and he was judged for his behaviour:

'He could not cope with the change at all. You know he started by doing everything right, he kept saying 'stop picking me up early.' And then the behaviour started escalating and while he is anxious, he does swear...But they didn't treat him right,

they were just don't swear. You don't swear on this bus and telling him off for that...'

(Diana)

Diana's experience illustrates the issue of adults disregarding a child's communication, this can trigger behaviour that challenges. Thus, parents are left to cope with their distressed child, compounded by feeling judged about their child's behaviour. The key learning is rather than criticising the child for not complying, we need to look beyond the surface of the behaviour to see the underlying reasons and to view unwanted behaviour as communication or a clue to a loss of wellbeing.

Another distinguishing feature of parents in this study was that virtually all had a social worker and a care package. This entailed having regular meetings with their social worker and navigating an overly complex system of support. They shared a range of experiences of social workers, the good and the bad. Iona's experiences of a specific social worker's judgements particularly stand out. For example, the social worker criticised Iona for giving her son paracetamol rectally:

'she told us we should stop giving Gabriel paracetamol suppositories, because in her view it wasn't the right thing to do.' (Iona)

This is significant as social workers are supposed to be a source of support for parents and underlines that when professionals take an expert position, they disregard parental knowledge of their children (Jordan, 2001). Likewise, Iona felt that social workers' held the purse strings to care packages and forced parents to reach a crisis point before they would review support. In other words, they had control over funding decisions and therefore did not necessarily always working in the best interest of families. This finding is significant as it

underlines the need to appropriately fund care packages to support families of disabled children, so that they can have sufficient breaks from their caring responsibilities and avoid reaching a crisis point.

Another related feature was that parents in this group used respite or short breaks. In these contexts, staff work in proximity to children and have a duty to raise any safeguarding issues with parents. However, Helen's experience of being wrongly judged underlines that staff should use sensitive approaches with parents. Emotionally Helen recalled how staff at a local play-scheme quizzed her about her son's bruises:

'they were on the phone to me, telling me they'd phoned social services and reported me...and I just shouted at her and bursted [burst] into tears and put the phone down, I was just all a bit taken aback with it all.' (Helen)

Helen's experience highlights that versus most other families, parents of children with autism and LD are subject to levels of scrutiny and intrusion that can feel like a blinding spotlight.

Most parents also shared their experiences of feeling judged by strangers, which supports the findings from Mitter, Ali and Scior (2019). These judgements mostly related to staring and negative body language. Mirroring the literature staring occurred in settings such as the doctors waiting room, parks and supermarkets (Broady, Stoyles and Morse, 2015; Ludlow, Skelly and Rohleder, 2011). For example, Ana instantly recognised when strangers in the doctors waiting room were judging her about her son's behaviour:

'It was just the looks on their faces...nobody looked particularly sympathetic.' (Ana)

No comments were verbalised, but she could feel the judgements:

'You could sense it; you could feel it...like somebody had climbed on your back...very heavy it felt.' (Ana)

Similarly, Jayne shared her experience of how strangers staring made her feel:

'I feel its rude on their part...and it makes me feel very conscious...I suppose I'm shocked that people can judge...that people can't work out, somethings not quite right...where's the I won't stare, where's the I'll give them space...' (Jayne)

Anticipating unspoken judgements was also a concern for parents. In public spaces, such as playgrounds, parents anticipated judgements from other parents about their child's behaviour. For example, Helen anticipated that strangers in the park would react badly to Owen touching them:

'if we go out to the park or whatever, was always on edge could never relax, even if it was a secure park, you'd just worry about other children or other adults not understanding and Owen's always been a bit inappropriate by running up and kissing people and hugging people and stroking their hair.' (Helen)

Other studies have also identified the issue of inappropriate touching (Ryan, 2005) or 'violations of personal space' (Gray, 1993, p.111). The nature of these judgements is best explained by considering the distinction between stigma that is discredited and discreditable (Goffman, 1936). In the case of the former, stigma might be a physical disfigurement that is visible, whilst in the later stigma is deemed to be more hidden. In the light of this, Gray

(1993, p.111) asserted that the public are sympathetic to the behaviour of a young child, but the issue becomes more complicated as children get older, as behaviour becomes judged as '*discreditable*'. In other words, parents are judged about their autistic child's behaviour because on the surface their child looks '*normal*'.

This correlates with Helen and Charles' experience. Similarly it was the lack of public sympathy and fear of judgements that deterred them from visiting their local playground with their children. The significance of this finding is the paradox that playgrounds are normally perceived as family friendly, inclusive settings. Yet this parental experience highlights that due to the unspoken social rules, families are encouraged to effectively hide away their children. Likewise, studies also confirm how parents have avoided going out in public, due to feeling blamed for their '*child's behaviour*' (Broady, Stoyles and Morse, 2015). However, conversely this compares to studies where parents have reported forcing greater acceptance of their autistic child, by increasing their presence in the local community, through going to church or visiting restaurants (Neely-Barnes et al. 2011), or attempting to gain public sympathy by using their child's diagnosis to justify '*socially inappropriate and difficult behaviour*', thus avoiding stigma (Farrugia, 2009, p.1016).

It is notable that the parents of children with autism and LD in this study spent most of their time in non-mainstream settings, attending special schools and respite care. This means that they were largely invisible to the outside community. I assert that this can create a vicious circle in not promoting greater societal acceptance of autism and LD.

Whilst parents mostly conveyed that these judgements were recognised through staring and negative body language, sometimes verbal judgements were cited. For example, Jayne remembered walking with her son in a buggy at a National Trust Garden and hearing two women comment very loudly:

'That child is too old in be in a buggy.' (Jayne)

Though Jayne was upset for being judged, she also conceded that it was difficult for the women to have known that Tim had autism:

'So that's quite tricky because they don't know autism's involved, they just see a big boy in a buggy and think it's wrong.' (Jayne)

Likewise, Ella regularly encountered negative comments from strangers:

'we will be out and parents will comment and their children will comment ...and they don't know anything about the situation...people are always quick to comment and then say things and they've never stepped in your shoes for a day.' (Ella)

Ella's experience reveals that the attitudes of parents can also be reflected downwards to their children, who make the same judgements.

Mirroring the literature, overall it seems likely that children were judged through a typically developing lens (Broady, Stoyles and Morse 2015; Ryan, 2005). Judgements in these public settings seem to be underpinned by a societal lack of understanding about autism, social expectations around behaviour and intolerance of difference. Avoidance of judgements in public places was one of the reasons why some parents chose to utilise disability play schemes for their children. In a relaxed safe and secure environment, Charles and Helen felt

their children could play and be supported by staff who understood their needs (Ryan, 2005). However, the warm glow that these parents enjoyed from using these services was also a reminder of that their children ultimately lived a '*closed existence*' (see section 5.3.3, about hidden exclusion).

5.6.3 The social expectations of grandparents
The literature on parental experiences of grandparents' attitudes to autism remains limited. Most studies refer to parents' experiences of relatives or family members, but specific references to grandparents are few (see for example, Gray, 1993; Huws, Jones and Ingledew, 2001; Myers, Mackintosh and Goin-Kochel, 2009; Ludlow, Skelly and Rohleder, 2011; Broady, Stoyles and Morse, 2015; Kinnear et al. 2015; Neely-Barnes et al. 2011). One exception is a recent Irish study which did explore the perspectives of grandparents and parents (Prendeville and Kinsella, 2018). However, this study captured their perspectives together, which I suggest could have deterred participants from being honest about each other. The authors also suggest that those with negative perspectives were less likely to have taken part in the study.

Most of the literature has highlighted the positive contribution of grandparents, in particular maternal grandparents (Glasberg and Harris, 1997; Prendeville and Kinsella, 2018). The theme '*strengthening the family system*', depicts how grandparents adapted their lives and provided support to parents, although most conceded that they had sacrificed their retirement plans (Prendeville and Kinsella, 2018, p.743). In the present study, there were also some examples of positive support from maternal grandparents (Ludlow, Skelly and

Rohleder, 2011; Prendeville and Kinsella, 2018). This is discussed later in this chapter in section 5.7. However, overall grandparents were much less involved with families and seemed less willing to make personal sacrifices. Thus the differences between Prendeville and Kinsella (2018) and the present study, highlight the issue of trying to generalise findings across different cultures.

There is also a broader body of literature about grandparents' experiences of children with disabilities. However, these studies have usually been taken from the grandparents' perspective and they have largely taken a positive view of their contribution (see recent scoping review of the literature, Novak-Pavlic et al. 2021). Furthermore, with a few exceptions (Moffatt, Tse Laurence, Pennington, 2019; Hastings, 1997; Margetts, Le Couteur and Croom, 2006), these studies have largely been conducted outside of the UK. Accordingly, the following findings from the current study about parental experiences of grandparents' attitudes, helps to fill a gap in an under-researched area of the literature.

In the present study one of the key distinctions was also the use of the conceptual framework as a tool within the interview, which helped to draw out experience that was especially important for parents. The significance of using the framework was it was a spontaneous and individual choice for parents to share their experiences of grandparents. Similarly, Broady, Stoyles and Morse (2015) also confirms the importance of relationships with relatives, but did not specifically isolate grandparents.

All parents, except Iona, shared their experiences of strained relationships with relatives, mostly grandparents. A distinct finding was that judgements about their child's behaviour were related to social expectations. Broady, Stoyles and Morse (2015, p.5) also reported that parents felt grandparent's viewed their autistic grandchildren's behaviour, as *'just naughty children'*. However, the findings from the present study reveal more about the context of grandparents' attitudes and their social expectations. Social expectations related to children being expected to behave in socially appropriate ways. For example, it was difficult when Ana's parents-in-law visited, as her father-in-law was intolerant of Matthew making any noise. She recalls him shouting loudly at her son:

'will you be quiet!!' (Ana)

Despite disagreeing with her father-in-law's outburst, Ana felt that she could not react as the situation would have ended badly:

'my father-in-law would have either sulked, he would have said he couldn't hear me or [my husband] would have probably died on the spot.' (Ana)

Ana's example of her father-in-law's behaviour shines a light on how parents can feel powerless to challenge the social expectations of grandparents. To avoid wider conflict, Ana felt that she had no choice than to remove her son from the house:

'I said come on Matt, we'll go up to the village club, I'll take you up there.' (Ana)

This experience reveals how parents can experience a subtle form of hidden exclusion which is related to grandparents' social expectations and intolerance to the behaviour of their autistic grandchildren.

Not all parents articulated quite the same experience of their autistic children's behaviour being judged by grandparents. For Charles, there was more of an awkwardness in the way his parents reacted to their behaviour:

'I guess not quite sure how to act...cos you know their [the children's] behaviours often quite inappropriate...' (Charles)

For this reason, his parents struggled to engage and play with the children:

'they tended to step back a bit, erm so then they never sort of erm interacted.'
(Charles)

This example brings into sharp focus that grandparents may simply feel lost, unable to find ways of connecting with their grandchildren. Similarly, Johnson and Simpson (2013) found that a lack of support from grandparents may be due to not knowing how to care for children with autism. Nonetheless, Charles felt the pain and sadness from this parents lack of emotional connection with his other two children.

Social expectations also related to grandparents envisaging that their grandchildren should be able to cope with attending formal occasions or meals, such as a family Sunday lunch or birthday dinner. Parents described how their children could not conform with these social norms and expectations, for example being expected to sit still at the table or eat the same food as everyone else. Jayne conveyed that it became difficult to visit her parents-in-law for Sunday lunch:

'they liked sitting round the table for Sunday lunch and for both my boys that's the most hideous awful...' (Jayne)

Similarly, Becky's mother was always critical of Joshua's behaviour and food preferences:

'She'll say to him, why are you sitting like that?...but why doesn't he try chicken, why doesn't he try meat?...you should make him, I used to with you.' (Becky)

Becky attributed her mother's attitude to:

'Just old-fashioned views...' (Becky)

Nevertheless, parents found the lack of understanding of autism difficult to cope with.

Family gatherings at Christmas may be particularly difficult for parents, when their child eats a restricted range of foods, as these occasions may amplify their child's limited diet, inviting criticisms from relatives.

Ella also explained how her parents-in-law would invite them to their parties with their children. However, these events were impossible for them to attend, due to their rigid social expectations. Ella explained how this made her feel:

'they obviously think we're misfits. You know we don't quite fit in with the social group, we can't go to parties that they invite us to because of the situation with the boys.' (Ella)

When social expectations make parents feel uncomfortable or prompt them to exclude their children, or exclude their whole family, this can be seen as a subtle form of hidden social exclusion. Ostensibly, the notion of '*misfit*' is closely associated with rejection, thought of as part of the stigma process (see, Kinnear et al. 2015; Broady, Stoyles and Morse, 2015).

Without doubt Ella felt rejected, but the findings suggest that she refused to accept the grandparents' view of her family. From this example, I contend that family rejection is

nuanced and it should not be assumed to lead to parents feeling stigmatised (Broady, Stoyles and Morse 2015).

Whilst most experiences of attitudes around social expectations related to grandparents, there were also similar attitudes from other close relatives. For example, Jayne recalls Sunday lunch at the grandparents' house, when Tim was struggling to sit still at the table. She was shocked by his uncle's outburst:

'to have someone opposite you at the Sunday lunch shouting at your child.' (Jayne)

Also, Becky explained how her son who worked as a nutritionist was critical of his brother's diet:

'He'll say well he should learn to eat salads...so it's really hard, it's harder than normal because he's a nutritionist.' (Becky)

In this last example, the friction created between Becky's nutritionist son, who is still living at home, over Joshua's diet is significant as this is seen directly in the microsystem/home part of the conceptual framework, rather than between the meso and microsystems. Although well meaning, the brother shows a lack of understanding of autism and the reasons why Joshua might have certain preferences for foods and dislike others, which may be sensory related.

A key finding and another element of the social expectations of grandparents were the differences between how grandparents treated their grandchildren. The findings indicate

hidden exclusion, as grandparents were seen to favour their neurotypical grandchildren over their autistic ones.

For example, Ella's experience of grandparents' favouritism highlighted two aspects of symbolic exclusion. First, Ella's parents-in-law wrote different messages in her autistic son's birthday cards, versus their other triplet brother:

'they wrote something different in Harvey's and Jacob's cards, which was nothing along the lines of they missed them and that kind of thing, so again the was that split straightaway just reading them cards, Sebastian's says one thing and Harvey's and Jacob's were identical and said something else.' (Ella)

These grandparents' actions point towards a favourism for their more able grandson, thus indicating an aspect of emotional exclusion.

The second aspect of symbolic exclusion related to family photographs. Ella explained how her parents-in-law displayed photographs of all their extended family, including their grandchildren. However, Ella began to realise that they deliberately removed the photographs of her family, only displaying them during planned visits. Ella recalls how on an unplanned visit to her parents-in-law's house, when she immediately noticed that photographs of her children had been hidden away:

'so, when we got there and of course they were miles away, none of the photos were out. And the only photo of [husband] and our children at our wedding was hidden behind the curtain, that you would never have known it was there. And it really upset me, so all the other children are on display.' (Ella)

Ella's experience of the hidden family photographs, highlights how attitudes can be subtle and symbolic. Family photographs are visual symbols of acceptance, pride and celebration and so selectively removing photos of certain family members, is a hidden form of exclusion and rejection.

Contrastingly, Charles explained how his parents behaved differently with their younger neurotypical son, compared to his two children with autism and/or LD:

'they act very differently...they treat him differently, because they can talk, they can interact, they can play games, this that and the other, its more stuff that they know about.' (Charles)

Huws, Jones and Ingledew (2001, p.578) also cite an example of a grandfather ignoring his autistic grandson, yet *'actively'* playing with his neurotypical granddaughter. However, Charles' description differs as he suggests that his parents simply felt more comfortable with their neurotypical grandchild. Compared also to Ella's experience, there is nothing to suggest they were acting out of intentional favouritism. No doubt this was familiar territory, something which felt known to them.

Another element of social expectations, which revealed *'Hidden exclusion'* related to a grandparents' view about access to education for children with autism. Diana explained how both her autistic children travelled to their special schools via transport. She conveyed her concerns to her mum about how budget cuts could result in transport assistance being withdrawn:

'I've said to my mum, what would I do if I lost boarding and I lost transport? [for Zara] and she's like well, Sam would have to drop out of school wouldn't he?' (Diana)

Her mum's view was that Zara's educational needs were more of a priority than Sam's, as he was more academically able and more likely to become an independent adult. Diana had an altogether opposite view:

'And I said actually no, Zara would have to drop out of school and go to mainstream...she's closer to mainstream than Sam, Sam's education [setting] is far more specialist.' (Diana)

Thus, Diana's experience reveals how grandparents may discriminate between their autistic grandchildren with regards to schooling. Likewise, Ravindran and Myers (2011, p.314) highlighted that in some cultures sending disabled children to school is viewed as *'a waste of money'*. However, Diana's mothers' view of education, that is autism and LD should be de-prioritised over children with autism, suggests that these attitudes may be more subtle and nuanced. These attitudes towards accessing education may be underpinned by outdated views, which precede the introduction of the Education (Handicapped Children) Act, (1970), which gave rights to education for all children with a disability.

Diana's experience also draws attention to a specific issue that many children with autism and LD travel significant distances to attend special schools. This is often only possible if transport assistance is provided. The potential for this support to be withdrawn is an additional stress for many parents in this group. These issues also contribute to a wider debate about whether more children should be included in more locally based mainstream schools and whether attitudinal barriers pose a problem to achieving greater inclusion?

Overall the findings about the social expectations of grandparents' reveals a picture of attitudes associated with old fashioned parenting views, which in part might be a generational issue. Families would benefit from grandparents learning more about autism and being more flexible around the needs of their autistic grandchildren. (See section 5.9, for how parents cope with grandparents' social expectations).

5.6.4 Denial, Embarrassment and Blame

Understanding *The social expectations of grandparents* (see the above section 5.6.3) can be further illuminated through the theme of '*Denial, Embarrassment and Blame*'. Two parents particularly underlined how their relatives had responded negatively to their child's autism diagnosis, through denial, blame or embarrassment.

From quite early, Ella knew the boys were probably autistic:

'we knew at 18 months from first seeing the Paediatrician and she kind of said then, it's all signs of autism. Go away join the National Autistic Society, gave us these massive great big books to read, we gave then to [my husband's] parents to look at.'
(Ella)

Yet they dismissed this possibility:

'it was poppycock you know, this couldn't possibly be...you know they are probably just a bit slow because they were premature...not kind of listening to all the things that I'd said up until that point. All the people that had been involved and just couldn't understand that anyone would be slightly different.' (Ella)

Denial was evident as the grandparents refused to accept that their grandchildren were likely to be autistic. This lack of acknowledgement and validation of what is happening can make parents feel very alone and isolated at a time that they need lots of family support. The finding is significant as by contrast, Prendeville and Kinsella (2018) found grandparents were often the first to express concerns about their grandchild's development.

After their diagnosis was confirmed, Ella tried hard to try and engage her parents-in-law to learn about autism:

'they'd be programmes on telly and I'd say you know record that tonight and watch it. And it was 'The A word'...after the series was finished and we were chatting on the phone...it was something like, she found it compelling or something like that?...and [father-in-law] said something really similar...they're now lying to me...they obviously haven't watched it.' (Ella)

Ella also tried to give them opportunities to learn about autism and visit the boys at school:

'we've offered them to come [on] all courses with us, you know they've been invited to things at [the boy's school]. And you're almost 'squeaming' for them because you can see how awkward they feel about it.' (Ella)

Ella believes the grandparents were embarrassed of the boys autism diagnosis:

'I kind of think, they think of it as an embarrassment...because they don't know how to handle it. But they would never ever admit that. But like what else could it possibly be?' (Ella)

Goffman (1963, p.19) refers to this '*discomfort*' around disability and the difficult interactions it creates as '*stickiness*'. This is likely to be borne out of '*guilt, fear and uncertainty*' (Mark, 1997, p.86).

Ella also confessed that her husband has struggled to come to terms with his autistic boys delayed development:

'Harvey and Jacob they don't use a knife and fork or spoon they still use a bottle, they can't talk you know, he takes Sebastian out to play football and Harry and Joe are only just learning to kick a ball, although we practice the last few years, but it's been one of those things, are they ever going to get it?...I think he buries his head because he's heartbroken really you know, with the situation that we're in...he says I see other people with their children and I think he feels quite envious at times, that you know they've got a normal life...' (Ella)

Ella words are powerful and reveal how her husband feels he is missing out, unable to fully engage his boys in 'normal' family activities such as football. Ella goes on to explain:

'I think it's linked to the fact that he doesn't get the support from his parents and he's only got me to lean on.' (Ella)

Thus it is evident that her husband's struggle with his family situation can be linked to a lack of support from his parents, driven by their attitudes towards their autistic grandchildren.

In Becky's account of this issue, denial, embarrassment and blame related to her husband and grandparents. However, these issues were also entwined across other family members.

This began at home with her husband's refusal to engage with her concerns about Joshua:

'I knew that something was wrong, but nobody else could see it. Instead of feeling understood and supported, I felt abandoned. My husband thought it was all in my imagination, but he was in denial.' (Becky)

Becky explained her husband's reaction when the Paediatrician formally diagnosed Joshua with autism:

'My husband was really angry, he was not happy at all, he was in complete denial and didn't accept the diagnosis for years.' (Becky)

Within the family, denial was interwoven with embarrassment, as Becky explained how her mother tried to conceal her grandson's diagnosis from their relatives in Spain:

'My mum felt embarrassed about Joshua's autism and told me not to tell anyone in Spain.' (Becky)

Becky also describes how her own sister avoided talking about Joshua's autism diagnosis:

'she doesn't mention it, its swept under the carpet.' (Becky)

Becky's account of her experiences also strongly indicated that a family culture of blame extended across the wider family. When she visited her relatives in Spain they avoided talking about autism:

'they don't mention it, nothings said, it's swept under the carpet again, nothings said at all...That's it, so it's totally ignored.' (Becky)

Another interpretation is that relatives used avoidance coping, because they did not want to engage with Joshua's diagnosis. (For more about avoidance coping, see section, 5.9.2)

Becky conveyed what happened when she tried to talk to her Spanish relatives about her son's diagnosis of autism:

'and they listen to me, but I know deep down they're thinking, 'Oh it's in the genes, I wonder who else in the family has got it?' (Becky)

In Becky's view these disapproving opinions were fuelled by her relatives using alternative negative language for autism:

'in Spain they do call it retarded, which is quite insulting.' (Becky)

Becky explained that Joshua's diagnosis had generated an atmosphere of blame throughout the family:

'My mum blamed my husband's side of the family, whilst my mother-in-law blamed my side of the family.' (Becky)

It is also likely that the inherent family blame culture also contributed to Becky's tendency to blame herself for her autistic son's behaviour at school (see section above, 5.5.7).

The experiences of both Becky and Ella illustrate how the issue of denial frequently presents around the time of diagnosis. These tensions are often hidden and extend across different family members, leaving parents feeling alone and isolated. This issue has been identified in

the autism literature (Gray, 1993; Huws, Jones and Ingledew, 2001; Broady, Stoyles and Morse, 2015; Neely-Barnes et al. 2011).

Overall the findings from the present study in relation to *Denial, Blame and Embarrassment* build upon the existing autism literature. However, they also provide insights into the specific experiences of parents of children with autism and LD, particularly illuminating grandparent's attitudes. The findings also underline how the unsupportive attitudes of grandparents towards their autistic grandchildren can negatively impact the emotional wellbeing of fathers.

One reason for grandparent denial might have been that these grandparents were unaware of the issues with their grandchild's development, and thus they began on a different pathway from parents, possibly then leading to a denial of their grandchild's diagnosis. The unwillingness of these grandparents to learn about autism could also be interpreted as avoidance coping (see section 5.9.2). Becky and Ella's experiences also indicate that grandparents may feel autism carries a stigma by association (Gray, 1993), which can lead to an avoidance of disclosing the grandchild's diagnosis. This probably reflects a wider issue of lack of acceptance of difference. These attitudinal barriers perpetuate a lack of understanding of autism. Likewise, the response of hiding and concealment suggests denial, that given time, the child's diagnosis might not turn out to be real or the child '*would grow out of it*' (Broady, Stoyles and Morse, 2015, p.5). Whilst this is untrue, I suggest the hidden aspect of autism makes this delusion easier.

The lack of engagement of these grandparents in the present study, can be contrasted with other UK research where grandparents were keen to educate themselves about their grandchild's condition (Moffatt, Tse Laurence and Pennington, 2019). However, ultimately there might be reasons for the differences in the findings between this research and the present study. First, the study conducted by Moffatt, Tse Laurence and Pennington (2019) was taken from the grandparents perspective. Thus, it is reasonable to expect that grandparents who are willing to engage in research are more likely to be more involved with their disabled grandchildren. Second, the exact diagnoses of the disabled children were not clear and thus this might have also influenced the grandparents engagement.

An Irish study, Prendeville and Kinsella (2018) found that grandparents were active in informing relatives about the child's autism diagnosis, therefore playing a significant role in supporting parents. However, the possibility of differences between family culture for Irish and English grandparents should be considered as a factor in explaining the differences between Prendeville and Kinsella's research and the present study. It also underlines the broader issue of generalising findings across cultures and beyond a sample of parents or grandparents. Overall, the implication from the findings of the present study is that more needs to be done to engage grandparents both prior and during the diagnosis process, so that they acknowledge that autism is present and can support parents in the post diagnosis process.

5.6.5 Key findings

This study builds upon the related autism stigma literature, extending knowledge about the specific experiences of parents of children with autism and LD and other co-occurring conditions and strongly indicates the prevalence of the issue of unsupportive attitudes. These attitudes are underpinned by a lack of knowledge and understanding of autism and deepened by the hidden nature of autism. A key finding was that unsupportive attitudes towards autism were entwined and compounded parental feelings of loss.

Unsupportive attitudes were perceived across multiple settings and some of these were seen to be subtle or hidden. There appeared to be a clear dichotomy between parental experiences of attitudes of staff in special schools versus non-specialist provisions, the latter showing insufficient understanding and knowledge of autism (Ludlow, Skelly and Rohleder, 2011). The findings also point towards an inconsistency of supportive attitudes across other service providers, such as healthcare.

The current study contributes knowledge about parental perspectives of grandparent's attitudes towards autism. A key finding was that grandparent's attitudes were associated with social expectations and these were often hidden. For example, autistic children should be able to cope with attending formal meals and social occasions. These rigid expectations did not take account of different dietary preferences, sensory sensitivities or issues with anxiety. Grandparents were seen to favour and have greater emotional connections with their neurotypical grandchildren or more academically able autistic children. Another key findings was that parents used coping strategies to navigate these social expectations (see,

section, 5.9). The social expectations of grandparents were also related and further illuminated through grandparents denial, blame or embarrassment of autism. In relation to this, some grandparents probably experienced autism stigma by association with their grandchild. Overall, a picture emerged of social expectations being associated with old fashioned parenting views, which in part might be a generational issue.

5.7 The mesosystem - Parents' experiences of supportive attitudes

Within this system, I secondly discuss parents' experiences of unsupportive attitudes. The findings for this theme are explored through four subordinate themes below, (see fig.23). At the end of this section I provide a summary of the key findings for this theme.

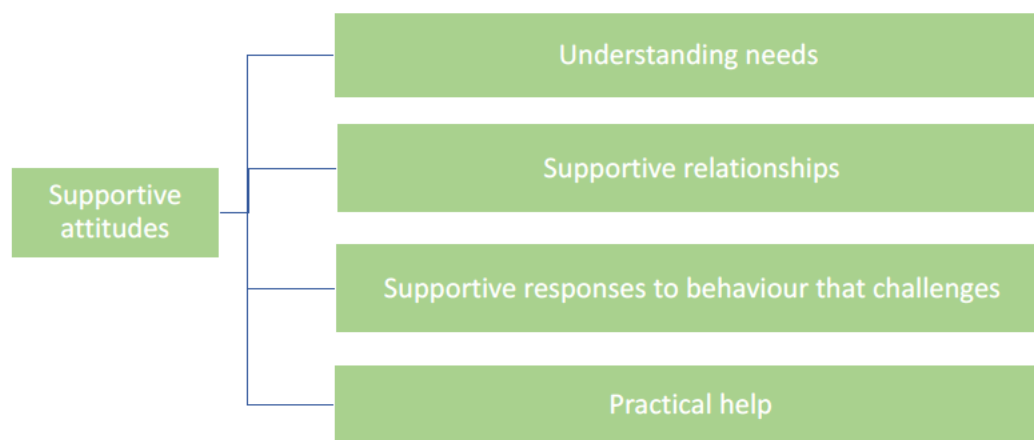


Figure 23: Supportive attitudes

5.7.1 Understanding needs

Whilst parents spoke about the issue of a *Lack of understanding of autism* (see section, 5.6.1), '*Understanding needs*' emerged as a divergent theme and a key attribute of supportive attitudes to autism. Parents shared their experiences of professionals, service providers and family members who through their actions, indicated a good understanding of their child and family needs. This was contrasted with professionals who were either too slow or failed to recognise their needs. Some parents also shared their experiences of shop workers and strangers, who seemed to have an innate understanding of what would help.

Parents spoke of others recognising the following areas of need: safety, respite and family support from PA's, changing needs, healthcare, not making assumptions about autism, understanding sensory sensitivities and supporting special interests.

Safety was a significant issue for several parents. In this regard, some parents shared their positive experiences of professionals, service providers and complete strangers who seemed to understand the importance of keeping their children safe.

For Helen, the support package arranged by the family support worker reflected an understanding of the high level of support needed to keep their children safe in the community:

'Well putting the great care plan [in place]...understanding that we need...the boys need 2:1.' (Helen)

Another need related to having access to supportive non-judging environments that were also safe. Charles and Helen spoke of their visits to a play centre for disabled children. This was a safe and secure space where parents could relax whilst their children explored, knowing that no one would pass judgement about their behaviour:

'you just felt safe-safe and secure erm even if you didn't have them in your sight, within sort of reach all of the time, erm they could just sort of go off and explore and it helped them as well to-to be a little bit more independent...all the normal stuff that children do...' (Charles)

Likewise, Charles and Helen stressed the importance of designated swimming sessions for disabled children and their families, where they could take their children:

'we do the [play-scheme] swimming...they love it...' (Helen)

'there are no other people in the pool other than [children with] disabilities or relations and that and so they all get it, so you don't need to worry, so it immediately removes the stress.' (Charles)

For these parents, it is evident that if they had gone to community settings alongside typical families, that they perceived that they would have been judged about their children's behaviour. Therefore, reflecting upon the position of the '*social model of disability*' (Oliver, 1990), I suggest the notion of '*disabled children*' needs challenging. In this context, the issue is rather a '*dis-ability*' to behave according to social norms and a weariness amongst parents of feeling judged and blamed for their parenting. In essence the existence of segregated settings reflects a parental need, due to on-going attitudinal issues and insufficient inclusion in society, underpinned by a lack of understanding and tolerance. Moreover, some children with autism and LD may have little or no sense of danger and therefore need access to safe environments during leisure time.

Respite and support from PA's was an important need for parents in this group. Overall parents had mixed experiences of social workers. However, some spoke warmly of their social worker or family support worker for supporting them with a care package of support and offering helpful ideas. There was also an appreciation that family needs were likely to change overtime.

Charles confirmed that the support worker offered ideas of respite options, that might work for their family:

'they came up with ideas erm about things that we could try like [other respite provisions], you know things that we probably wouldn't have thought about.'

(Charles)

Similarly, Iona commended her social worker for understanding their family's changing needs, especially after her second child was born and they felt under more pressure. He was always willing to listen and, at this challenging time, offered slightly more help to support the needs of Gabriel:

'we could share with him how we felt...I just felt that at least he could see when things were going wrong, erm so to me he was doing his job as a social worker.'

(Iona)

For Diana, the need for respite intersected with issues about Sam's safety. She recalls a period when Sam was temporarily excluded from his new school, whilst the school improved security, and the social worker organised some respite:

'With Sam out of school, I remember that the social worker was pretty supportive.

She organised for Sam to go to a local respite centre for a couple of hours in the day, when no other children were there.' *(Diana)*

Iona and Diana's experiences underscore that social workers have a vital role in both recognising families' changing support needs and offering alternative support when children

are excluded from school. Having a supportive attitude and providing appropriate support so that families can continue to function represented a lifeline to these parents.

Accessing healthcare for their children was another important area. Some examples were provided of health professionals who had a clear understanding of their child's needs, including an awareness of sensory sensitivities and sensory overload.

For example, if Ana needed to take Matthew to the doctors, they were really understanding and appreciated that waiting was difficult for him:

'I can ring them and ask if the doctor's running late...and they'll say don't bother coming up for 5.30pm, come up for getting here at 5.50pm' (Ana)

Similarly, the doctor knew it was difficult for Matthew to cope with being with other patients in the waiting room, offering another room for them:

'the doctor came out within a minute and said:

You can wait in here, it's fine.' (Ana)

Contrastingly, Iona's experience of accessing healthcare for her son Gabriel who had TS and significant medical needs was mixed :

'you go into hospital and you know, you're not there for fun, you know you've got a need and erm you're totally dependent on-on who you're going to meet.' (Iona)

However, she had begun to recognise good health professionals who were able to support Gabriel's needs:

'over the years when it's things are non-critical, we've built a team around Gabriel of people that you know that erm we think are the right people...' (Iona)

This strategy of surrounding themselves with those who looked after their family's best interests, is depicted in the conceptual framework through the movement of the right people into the mesosystem and those without the right attitudes outwards. Iona's experience alludes that the recognition of supportive attitudes, is likely to develop from a bitter experience of those with unsupportive attitudes. However, she was clear to point out that in an emergency the experience of accessing treatment for her son was unpredictable:

'If there's an emergency, then you know, you just have to deal with whoever's there and it's-it's completely dependent on who you meet and the problem is...you'll come across a chain of people during your time in hospital and you're going to have one really good experience at one point in time and two hours later it's a different nurse or a different consultant and then suddenly your experience, which was going well at that point, is not going well.' (Iona)

Other examples of understanding needs, including an awareness of possible sensory sensitivities and sensory overload. Also not making assumptions about what children with autism want. For example, Diana explained that the new escort in Sam's taxi to school had asked her, whether Sam would like her to talk to him on the journey to school:

'Does he want me to be chatty or does he want me to be quiet?'

Diana conveyed how this made her feel:

'I thought that's really nice to get that understanding and I'm like yes he'd like you to chat, but if he doesn't want you to talk, he will say stop talking now.' (Diana)

Diana's experience draws attention to the importance of keeping an open mind and understanding that all autistic children are different, rather than making assumptions about needs.

Similarly, Becky emphasised the importance of schools having a low distraction teaching environment. She praised her son's current school for their understanding of sensory needs:

'Special school, complete understanding...minimal distraction.' (Becky)

Likewise, Diana explained how Sam's swimming teacher seemed to be acutely aware of his noise sensitivity and when he might feel overloaded. The swimming teacher could also be relied upon to advocate for her son, if the pool environment was becoming uncomfortable:

'if he feels that something is happening in the pool, that's too noisy, you know that shouldn't happen, so he will say something to management, try not to overload the pool all the time...' (Diana)

These parental experiences underline how understanding the specific sensory sensitivities indicates a supportive attitude to autism.

Supporting a child's special interests was also highlighted as another important indicator of understanding needs. Parents praised some of their family members, for engaging in their child's special interests. Diana explained how her sister, who was also a teacher, made an interactive version of the book *Bear Hunt* to help Zara and Sam to engage with the story:

'She gave us a book and then she had all these visuals that she's made, so she'd made a [piece of] grass and she'd got a little teddy bear...so from that you can understand that she does get it, you know and she understands, what floats their boats...' (Diana)

Likewise, Becky explained how one of Joshua's brothers supported his enjoyment of playing Yu-Gi-Oh:

'he will take Joshua specially to...the Game Shop...where they do... Yu-Gi-Oh tournaments on a Friday night.' (Becky)

Ana's experience highlights the importance of grandparents understanding needs. Her mother understood the importance of supporting Matthew's interests and made preparations before he went to her house to stay:

'She'll get the telly set up for him, so that he can watch Worzel Gummidge, because he likes that. All those little things that she'll put in place, make sure she's got the bubble bath that he likes, or a bath bomb or something, so that he feels relaxed.'
(Ana)

Ana's mother also realised the importance for Matthew of knowing what to expect when he stayed:

*'So, when he stayed at her house...she called up and said:
Could you let Matthew know I've got cottage pie for tea...and that we'll go to the [name of café] in the morning for breakfast and then I'll take him for a haircut, so he knows.'* (Ana)

It is plausible that grandparents developed an understanding of their grandchild's needs through mirroring the *'Problem-focused coping'* strategies adopted by parents, (see section, 5.9.1).

Parents also applauded others for supporting their child's special interests. For example, Ella described the actions of her PA's, who understood how upsetting it was if Harvey could not find his toy animals.

'If I need anything, like Harvey's animals are missing, he's got this rhino and an elephant, so I've asked Megan this morning could she pop into class at some point and try and look for them...she knows how important they are to Harvey, because he keeps going in this bucket and they're not there and he gets really upset.' (Ella)

Similarly, Becky praised the staff at Joshua's special school for supporting children's specific areas of ability:

'if a child achieved academically in one particular area, they would create a new little class for them, for those particular children, even if it was only three children...'
(Becky)

In essence, these parental experiences highlight how family members, PA's and school staff tried to understand and support the special interests or specific areas of ability of their children. Likewise, a positive attitude of respecting special interests, rather than regarding these as obsessions has also been discussed in the literature (Prizant, Fields, Meyer, 2015).

5.7.2 Supportive relationships

Despite examples of strained and lost relationships, several parents also spoke of enjoying supportive relationships. The findings indicate that *'Supportive relationships'* was another important attribute of supportive attitudes, which was seen across different contexts. This correlates with a theme in the literature *'the growing accepting of autistic differences'* (Lilley, Sedgwick and Pellicano, 2020, p.1).

Parents were actutely aware of those individuals and service providers who they had developed supportive relationships with. For example, parents asserted the importance of health professionals and school staff respecting their parental knowledge and working with them to achieve the best outcomes for their children (Sherwood and Nind, 2014). Iona conveyed how some health professionals in hospitals worked closely with parents:

'it's having that open mindedness about understanding that...the parents know the child better...you know taking the attitude that we're working together for the best outcome, rather than coming from the point of, well I'm the expert, so I'm going to tell you how it's going to be done...' (Iona)

By the same token, Iona explained how school staff worked together with parents:

'they work with you as parents, with the child and with their knowledge...they try and find the best way for your child and...because every family's got different...slightly different ways or priorities.' (Iona)

Iona's experience highlights the importance of schools using individualised approaches to support the child, which flexibly consider the home and needs of other family members.

Similarly, Diana commented about the importance of school staff working together with parents:

'The school have come to realise the importance of working together as a team and having a consistent approach.' (Diana)

Despite these examples of good practice, it is important to reiterate the findings that parental experiences were also mixed with experiences of judgements from school staff and

health professionals (see section, 5.6.2). Overall, a key finding from this study is that respecting the views of parents of children with autism and LD is especially critical, as these children often have significant communication difficulties. Those without spoken language are particularly reliant on their parents as advocates.

Another context where parents developed supportive relationships was with the transport staff who took their children to school. Ella emphasised the importance of these relationships:

'I have a good relationship with the staff on the bus. They tell me when they are a few minutes away, so that I can put the boys' shoes and coats on.' (Ella)

This finding is significant as it offers a glimpse into the morning routine for parents of children with autism and LD. It is often a difficult for children with autism and LD to cope with the time pressure of getting ready for school and thus this becomes a challenge for parents to navigate. Moreover, this is compounded for parents with more than one child with autism, or as seen in the example of Ella, being a parent to triplets. In view of this, it was often these small gestures of help, such as good communication from transport staff, that made the most difference to these parents. The finding also highlights that the children attended specialist schools, which given the distance from home, necessitated using transport to school.

In addition, parents also spoke of the building supportive relationships with PA's who helped to support their children. Diana described finding a suitable PA to work with her son and the personal characteristics she had been looking for:

'half the reason I chose her is that she's young and full of energy and absolutely nutty and that's the kind of person that Sam quite often bonds with...I do think the younger and the more open-minded you are the better...' (Diana)

Likewise, Ella described the supportive relationships she had developed with her PA's:

'always willing to help, always willing to say to me, oh I've been on a course and I've learnt this...I can ask them something and they are very informative' (Ella)

Jacob had recently been assessed for Pathological Demand Avoidance (PDA) and Lucy, one of the PA's, had accessed some training about PDA through her school and was able to share her knowledge:

'Lucy was able to spiel it off to me, explain a lot more about it, give me some instances where she's been involved with that kind of thing.' (Ella)

Ella also explained the benefit of having continuity as her other PA, Meghan, worked in the boys' class at school:

'at school, if they need to know something, like oh Harvey's doing this today and she'll say well yes...he does that at home.' (Ella)

This finding about developing supportive relationships from PA's is important, as again, it highlights another distinct feature for parents in this group. This is, their children's needs were significant and therefore most were in receipt of a care package, often provided as direct payments to pay for PA support.

Parents also conveyed the importance of these relationships so that their children could access activities outside of the home. For example, Helen was touched by the work and understanding of the support workers at the play-scheme, which provided short-breaks for families of children with disabilities:

‘I found them really understanding, I mean young girls and boys erm that got it...They weren’t scared to get stuck in with the boys...and it was lovely seeing the relationships grow...the boys just loved them to bits...’ (Helen)

Moreover, Helen found it a little surprising that support workers, often still in their late teens, seemed to have such an innate understanding of her children. She felt this was born from their experiences of family members with disabilities:

‘most of them came from families with a connection...their brother or sister or cousin or whatever erm and they got it...’ (Helen)

The notion Helen uses of the support workers ability to ‘to get stuck in’ stands in stark contrast to Charles’ description of his own parents relationship with their autistic grandchildren. (For more details, see section 5.5.5).

Overall, the finding that young support workers, often with a connection to autism through their own family, positively supporting children with autism and LD is significant. This is because it seems evident that early exposure to others with autism seems to shape supportive attitudes.

Similarly, Diana shared her experience of her son’s swimming teacher and the supportive relationship that he had managed to build with Sam:

'he is just amazing with Sam, he's built the relationship and Sam yeah just absolutely adores swimming with him.' (Diana)

Visits to the swimming pool for his weekly lesson, made a huge difference to Sam, particularly during the time that he was temporarily excluded from school. The continuity of this supportive relationship was a particularly key support. Likewise, the continuity of relationships is also important for children with autism and LD who have significant communication difficulties, particularly for those with little or no spoken language.

5.7.3 Supportive responses to behaviour that challenges
Another element of supportive attitudes related to how others responded to the behaviour of autistic children. For example, Ella conveyed how her PA's were always calm around the behaviour of her children:

'they both just got that natural way about them, they're very calm, very laid back and don't ever seem to bat an eyelid with anything that goes on behaviour wise.' (Ella)

Responding to behaviour in this way, also correlates with *'the growing accepting of autistic differences'* (Lilley, Sedgwick and Pellicano, 2020, p.1).

Similarly, Becky shared examples of how Joshua's current school responded to behaviour:

'If someone's screaming in the classroom, they'll deal with it completely differently, because Joshua has told me. They would use a high motivator to try to get them to calm down, iPad whatever.' (Becky)

Whilst, the use of motivators may act as a form of distraction, the underlying reasons for behaviour need to be fully explored and understood to effectively support children with autism.

Occasionally, parents experienced supportive responses from strangers in relation to behaviour. Diana recalled the extraordinary kindness of two ladies, who stepped in to help her with Sam:

'he had a huge meltdown in the middle of the [shopping centre] and basically I was just holding on to him, because he was trying to run and we just sunk into the corner...and he was screaming and shouting at me...then these two came over...they were both MAPA trained and they helped going back to the car. And I was just like, thank you so much, because that could have been a situation that ended very badly.'
(Diana)

This example highlights the challenging situation of when children with autism and LD become distressed or overwhelmed, shining a light upon the vulnerability of this parent/child dyad. Sometimes the child may have little sense of danger and behave in ways that seem unpredictable, requiring the support of two adults in the community. Diana's experience also underscores the importance of others responding to behaviour that challenges without judgement. Moreover, it points to the value of educating society, so that autism understanding, and acceptance are embedded in our culture.

5.7.4 Practical help

The findings revealed that *'Practical help'* was another feature of supportive attitudes.

Whilst parents mostly cited the absence of *'Practical help'* from grandparents, a few waxed lyrical about the invaluable help grandparents provided. It was notable that this only related to the maternal side. For example, in the early years Helen's parents were a major source of support. They took the children out on trips into the community. They did all they could so that Charles and Helen could visit them safely with the boys. Helen conveyed the practical changes her parents made to the outside of their house, securing the boundary of their home so their grandchildren who were susceptible to absconding could safely visit:

'they put gates on the front...they made it safe...they put a big gate on, they put side gates on...'(Helen)

Similarly, Nagib and Williams (2018) highlighted how parents have reported the importance of modifying their home environment with locks and gates to keep their autistic children safe. By contrast, the example from the present study is significant as it was grandparents who were willing to make modifications to the outside space of their home to make it safe for their grandchildren with autism and LD to visit. These practical steps can also be seen to mirror the problem-focused coping strategies used by parents (see section, 5.9.1). In terms of the conceptual framework, securing the boundary of their home, enabled Helen's family to leave the microsystem, in effect creating another safe place in the mesosystem. However, in one sense the grandparents' home is perceived as a microcosm of the community or mesosystem, as the children are never fully integrated.

However, overtime as Helen's parents aged, which coincided with Owen and Felix becoming older and bigger but not more independent, they were no longer able to cope with taking the boys on their own. For Helen and Charles this was another loss, as they found themselves without the family support for their two children with LD. Charles was emotional when he conveyed his feelings about his parents-in-law losing this contact with the children:

'You do feel a bit, I guess they're losing something.' (Charles)

It was apparent that Charles thought his parents-in-law had missed out on time spent with their grandchildren. The missed time is contrasted with the time that they used to spend with the boys. However, this is brought into sharper focus, as he reflected that they were still able to spend time with H, their youngest typically developing son:

'seeing them with H is lovely cos they've got that sort of relationship with H.' (Charles)

Another example of the '*Practical help*' provided by grandparents is seen in Ana's example of how her mother supported them on holiday. She shared a bedroom with Matthew and helped him with personal care tasks:

'She'll come on holiday with us and she'll share a bedroom with him.

She'll say, just go and get yourself off to bed and I'll sort him out. So, she'll do all of that, she'll help him in the shower, all those sorts of things.' (Ana)

Whilst studies confirm how some parents with autistic children are unable to go on holidays (Myers, Mackintosh and Goin-Kochel, 2009), the finding from the present study is significant as it shows how support from grandparents with personal care for children with autism and LD, can make family holidays more viable. This is notable as it differs from Moffatt, Tse

Laurence and Pennington (2019) who found practical support related to grandparents liaising with services to try to secure support for their grandchildren. It is worth noting the above examples related to maternal grandparents, which echoes the literature (Ludlow, Skelly and Rohleder, 2011; Prendeville and Kinsella, 2018). However, by contrast in the present study not all maternal grandparents were supportive.

By contrast, Ella was very clear that she relied upon her PA's for practical support, rather than this coming from her parents-in-law:

'Not family, it's my PA's.' (Ella)

Ella powerfully describes the importance of their help:

'we've got two really good PA's and if it wasn't for them Lynda, I wouldn't be able to do anything, you know they are my lifeline. We would be isolated; we would be indoors a lot.' (Ella)

Her portrayal of needing help, simply to be able to take her triplet boys out into the community safely, is striking and underscores the need for practical support, especially for parents who have more than one child with autism & LD or other special educational needs. The implications for parents of children with autism and LD, who do have practical help is that this can ameliorate the issue of keeping their children safe and they are more able to access the community reducing the risk of social isolation. This can be seen through the conceptual framework with the parent child dyad shifting outwards from the micro to the mesosystem/community.

Whilst practical help was seen as vital, it also compounded parental dependence. This can be seen through Ella's description of being consciously aware that her PA's might decide to leave at anytime:

'but I do know that that could all change you know and I can't be solely reliant on them, because at some point they will decide they want to go and do different things, or their personal lives change.' (Ella)

In addition, parents also emphasised the practical support their child's special school provided. Iona highlighted the help provided for her son with toileting:

'when he was nine years old, his teacher thought we should try. They sat him on the toilet and the toilet became the classroom. When he did a wee, they would give him lots of reward and take him back every 15 minutes and this continued for a week. I couldn't have done it without the help of school.' (Iona)

This is significant as having an older child wearing nappies brings the extra complexity of needing to find appropriate changing facilities in the community. It is also more challenging to take part in leisure activities, such as swimming. One implication of achieving this developmental milestone is that it removes these barriers to accessing wider society.

Jayne's son's school also focused upon teaching skills for helping the children to navigate the wider community:

'The class go on weekly outings, which are a huge part of their integration into society. They go to the supermarket, use the self-service checkouts or to Burger King, just to get used to coping in the world.' (Jayne)

Jayne's experience highlights the important role of school in helping children with autism and LD to develop functional independence skills, which are likely to have more practical value than the curriculum offered in mainstream schools.

5.7.5 Key findings

Whilst the subject of unsupportive attitudes towards autism or stigma has been widely covered in the literature (Gray, 1993; Kinnear et al. 2015; Broady, Stoyles and Morse, 2015), the opposite theme of '*Supportive attitudes*' has received less attention. One exception, is a recent Australian study which explored both negative and inclusive attitudes towards autism in the Aboriginal and Torres Strait Islander communities (Lilley, Sedgwick and Pellicano, 2020). The findings from the present study are important as they both build on this study and provide specific insights about parental experiences of supportive attitudes to autism in the UK, including some positive experiences with maternal grandparents. Four closely related attributes of supportive attitudes emerged, including '*Understanding Needs*', '*Supportive Relationships*', '*Supportive Responses to Behaviour that Challenges*' and '*Practical Help*'. These attributes are significant as they build upon the '*positive model of support*' proposed by Lilley, Sedgwick and Pellicano (2020, p.1). They contribute to a societal vision and underscore how supportive attitudes enable parents and their autistic children to be accepted and better understood.

5.8 The chronosystem- The experience of positive gains for parents of children with autism

The findings are explored through four subordinate themes below, (see fig. 24). At the end of this section I provide a summary of the key findings for this theme.

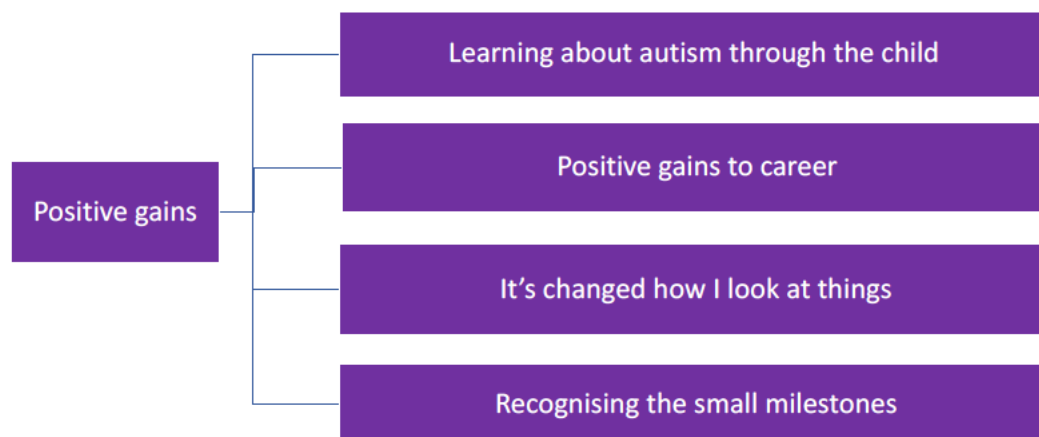


Figure 24: Positive gains

5.8.1 Learning about autism through the child

Returning to parent experience as a journey. In the literature, the early years around the child's diagnosis are portrayed as a time of '*loss for parents*', which diminishes overtime as parents become more positive about the future (Altiere and von Kluge, 2009, p.150).

Moreover, there is evidence that parents develop resilience and experience life-changing effects from parenting children with autism or disabilities (Huws, Jones and Ingledew, 2001; Bayat, 2007; King, Zwaigenbaum and Baxter, 2006; Scorgie and Sobsey, 2000). Similarly, in the present study two parents conveyed an overriding sense that despite their parenting challenges, having a child with autism had been personally enriching.

Overtime, Becky reflected positively about how much she had learned from her child:

'in a way, I'm glad he is on the spectrum, because it's taught me so much.' (Becky)

Likewise, Ana was upbeat about the impact of her child on the family:

'Mathew has definitely changed our lives for the better.' (Ana)

In this sense it seems that these parents viewed their child as a teacher of autism, perhaps challenging their world view and helping them to seek out new perspectives (Fleischmann, 2005). I suggest that this is likely because their children were probably functioning at a slightly higher level than most of the others in the group, for example they could both communicate with spoken words. On the face of it, these examples appear to support previous research which suggests that parental experience resulted in *'transformational outcomes'* (Scorgie and Sobsey, 2000, p.200). Having made this point, I am slightly uneasy with assuming this perspective. Whilst the notion of *'transformational outcomes'* seemed to fit for Ana, for Becky it seemed more of an aspiration than a reality. Whilst Becky's autistic son had taught her so much about autism, the notion of her experience as *'transformational'* was marred by the attitudes of her relatives. Negative attitudes to autism were set against a family culture of blame. Becky's narrative captures how she felt emotionally abandoned by relatives, who did not understand autism and failed to understand her son (see section, 5.6.4). This example illustrates how the experiences of parents are entwined with the attitudes of relatives.

For the remaining parents in the group their experience was more akin to survival than being *'transformational'*. This is probably as their children had more difficulties communicating

and had other co-occurring conditions. In consequence, a key finding is that in comparison to the literature, most parents in this study ultimately did not view their experience as *‘transformational’*.

5.8.2 Positive gains to career

Whilst some parents were unable to combine their parenting roles with paid work (see loss to career and finances section 5.5.7), Becky and Ana were able to make tangible links with how autism had benefitted their careers.

Becky acknowledged that through her child, her knowledge of autism had helped her find a job as a teacher in a special school, that she really enjoyed:

‘You know, I’ve got the best job in the world, because of my son.’ (Becky)

Similarly, Ana’s experience of autism, through her son, had changed the direction of her career for the better:

‘I wouldn’t have taken the career path I’ve taken without him. It has opened my eyes to so many differences and possibilities...’ (Ana)

Whilst these parents perceived that autism had enabled their careers, Diana’s experience highlights a notable contrasting issue. Diana’s experience of autism had provided her with knowledge which had enabled her to work as a teaching assistant in a special school.

However, she expressed deep concerns that when Sam finished school, he would not get a full-time college placement and her caring responsibilities would increase, limiting her career ambitions (see section, 5.5.7).

Overall, the findings highlight that the experience of being able to make *'Positive gains to career'* from parenting a child with autism and LD is variable. Certainly, prioritising a career may be more difficult for parents who are unable to leave their teenage children with autism and LD at home on their own, even for short periods of time. Also, particularly for those with more than one child with autism or SEND.

5.8.3 It's changed how I look at things
In comparison to the literature, most other parents continued to experience more challenges than positive gains. They did not view their experience as transformational (Scorgie and Sobsey, 2000). Nonetheless, overtime their parental experiences had changed how they looked at things and they too were able to positively re-frame some aspects of their experience (Fleischmann, 2005; Altieri and von Kluge, 2009).

Whilst Ella's experience was predominately centred around various aspects of loss-related experience, she was still able to reflect upon some positive aspects. For example, she felt parenting had helped to re-define her view of children with special needs:

'before I probably wouldn't have given a lot of time and notice to people with special needs, just because it's never been part of my family or anything I've had to deal with. But now I definitely judge things differently, I wouldn't be quick to label anything or I'm probably more patient and more understanding.' (Ella)

Ella's experience of positive meaning was significant, as it was entwined through the circumstance of parenting triplets and magnified her challenges and losses. Her unique

insights contribute to knowledge about the specific experience of families of multiple births and autism. Ella's parenting journey was also one of self-development, seen through increased patience and self-awareness of others with special needs. This may seem difficult to reconcile, when seen against the backdrop of her narrative dominated by loss. However, it further validates existing studies which have also found parent experiences to be contradictory (Myers, Mackintosh and Goin-Kochel, 2009) and paradoxical (Larson, 1998). Moreover, it perhaps points to something more intrinsic about how parents of children with autism and LD, learn to adjust and adapt to a different parenting experience. Similarly, in the literature parenting an autistic child was seen to result in a change of self (Cashin, 2004). However, this author also found patience was not always a conscious choice, but more imposed by circumstances.

Contrastingly, Diana reflected upon her own experience, but almost in reverse. She was aware that she was so immersed with autism, both as a parent of two autistic children and from her experience of working in a special school, that this had obscured her thinking of non-autistic children:

'it's kind of interesting that I am exploring my understanding of what typical kids are like'. (Diana)

Jayne's view of autism was coloured by her experience of Tim's autism and LD. She took a different view of her younger autistic son Felix as he did not have additional LD:

'And then Felix ironically with his autism, because you know I forget that he's autistic Felix, he's on the spectrum, but you see, I don't see that as autism, I just see he's got

some strong character traits that are on the autism spectrum, but I don't see him as autistic, so that's just my-my...because Tim is so.' (Jayne)

Jayne's differing views of two autistic children, shines a light on how parents direct experiences are likely to shape their understandings of autism.

5.8.4 Recognising the small milestones

For some parents in the present study, the development of their child's independence skills, such as toilet training were particularly challenging. Consequently, when their children achieved these developmental milestones, parents considered these major achievements.

Iona expressed her delight when Gabriel learnt this life skill:

'Gabriel is now toilet-trained, I'm so proud of him, because it's such a huge achievement.' (Iona)

Iona described the difference this made:

'It's been transformational for us...' (Iona)

In this context, I suggest that this was an islet of transformational experience, rather than an overall transformation.

Likewise, Ella was overjoyed when her boys managed this:

'I'm so proud of them, it's such an achievement, a year ago I would never have thought the boys would have accomplished this, especially for Harvey as he is non-verbal.' (Ella)

Previous studies have also identified how parents recognise small milestones (Fleischmann, 2005). However, Cashin (2004) found these milestones also brought an aspect of sadness for parents, as they were reminded that their child was different. Similarly, studies have found as children reach birthday milestones, parents can feel a sense of loss due to their development delay (Lutz, Patterson and Klein, 2012; Wayment, Al-Kire and Brookshire, 2019). By comparison in the present study there is nothing to suggest that the achievement of developmental milestones or birthdays brought with it anything other than celebration.

Ultimately for parents in this study, *'Recognising the small milestones'* needs to be understood in the context of *'Loss'* (see section, 5.5), which was far more dominant than their experience of *'Positive gains'*. Whilst it is evident from the examples above that parents tried to positively re-frame their experiences, it is important to be clear that unlike the literature most of these parents did not view their experience as transformational (Scorgie and Sobsey, 2000). Rather they remained in a survival mode. Ultimately these were parents of children with a diagnosis of autism and LD and also other co-occurring conditions, such as epilepsy. Parents genuinely saw the extent to which their children struggled to cope with being in everyday ordinary environments (see section, 5.5.2). In other words, eventually the positive gains for parents were limited by their child's diagnosis, how this affected their child and the impact upon the family.

5.8.5 Key findings

The theme of *'Positive gains from autism'* emerged towards the end of the parent narratives, as they tried to make sense of the whole of their experience, reflecting a

temporal aspect. The findings confirm that all parents were eventually able to attach some positive meaning to their experiences. However, whilst a key theme in the literature is parental resilience and autism as a transformational experience (Huws, Jones and Ingledew, 2001; Bayat, 2007; King, Zwaigenbaum, Baxter, 2006; Scorgie and Sobsey, 2000; Cashin, 2004; Fleischmann, 2004, 2005), it is my interpretation that, with possibly the exception of Ana, parents did not identify with this. Rather, most seemed to remain in a survival mode and they continued to experience more challenges than positive gains from parenting their children with autism and LD.

5.9 The chronosystem- Approaches to coping

This theme is explored through the six subordinate themes below (see fig. 25). At the end of this section, I provide a summary of the key findings for this theme.

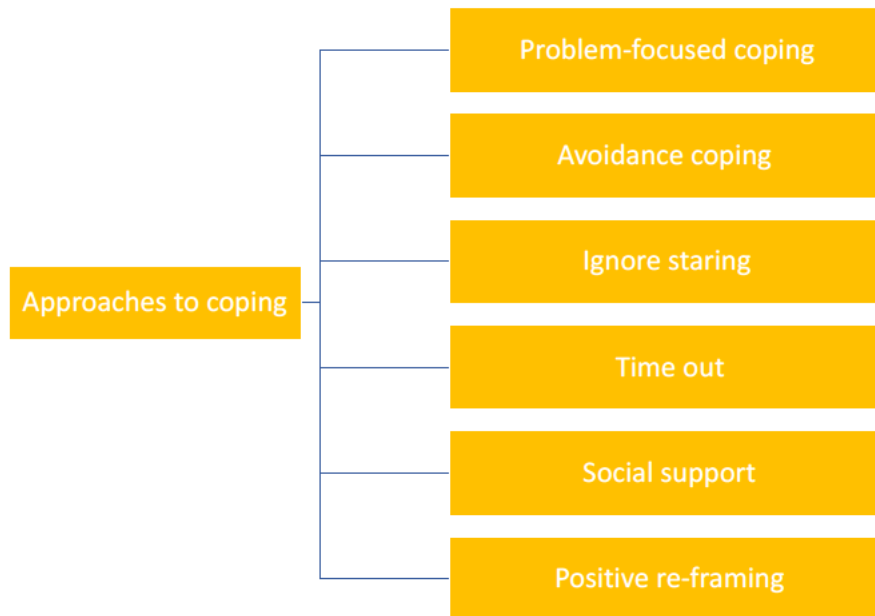


Figure 25: Approaches to coping

5.9.1 Problem-focused coping

There was a clear sense that parents anticipated situations that would be difficult for their children. Virtually all parents gave examples of planning ahead for these possible scenarios. From the relevant literature of how parent coping has been conceptualised (Hastings et al. 2005; Pepperell, Paynter and Gilmore, 2018), I interpreted these approaches as '*Problem-focused coping*' (for more details, see section, 3.6.6).

The regular and widespread parental use of these strategies reflected two characteristics. First, parents drew on previous experiences and realised that a lack of planning did not work. Thinking ahead had become an essential component for survival. Second, a strong reliance on problem-focused coping strategies, underscores how their lives lacked spontaneity. Ella confirmed this reality:

‘Living with the boys has resulted in many challenges and restrictions to our lives.’
(Ella)

Jayne conveyed a virtually identical picture:

‘Living with Tim’s autism has placed many restrictions and pervaded every aspect of our family life.’ (Jayne)

Several *‘Problem-focused coping’* approaches emerged. The first of these was managing the safety risks for their children. Some parents emphasised that keeping their homes secure was critical, so that children could not abscond. Charles conveyed this reality:

‘with our house, we are very sure that they can’t escape, we’ve got that in place and we’ve got this in place...’(Charles)

Charles was referring to the fencing around the perimeter of the garden and the electronic gates at the front of their home.

It is evident that parents used problem-focused strategies to make their home environments safe and secure. However, this was often less predictable when visiting friends or relatives resulting in a constant need for vigilance (see earlier section, 5.5.4).

Another element of *'Problem-focused coping'* related to parents planning for worst-case scenarios. Ella explained:

'I like to know all the facts and just tell me what is [the] worst-case scenario and I will find a way to get through it.' (Ella)

Similarly, Diana coped through trying to anticipate the unexpected:

'It's just one thing stops, and another thing starts, I think every special-needs parent feels like this. It's like last night our PA's like:

I don't think I can work for you anymore.

So, you're looking for another PA and luckily, I've got someone in mind...' (Diana)

Using routines was a further *'Problem-focused coping'* strategy. Jayne explained that getting her two autistic children ready for school in the morning was the most difficult routine. It required the utmost skill to avoid one of her boys getting distressed and upsetting his brother:

'I try to gently manipulate both boys, keeping them happy to get them ready for school. I have become a master of doing this and I don't even know that I'm doing it half the time.' (Jayne)

Similarly, parents conveyed the importance of keeping routines on days when their children were not at school:

'On a non-school day everything remains very routine driven from Gabriel. Activities include spending time in the garden or going to the train station. He loves to watch the trains and we'll also watch a lot of trains on YouTube...he also likes water, so the

paddling pool or swimming occupies a lot of his time. It's always the same things.'

(Iona)

Ella also confirmed the importance of these routines:

'At the weekend or during the school holidays, the boys find it more difficult to cope. I show them a picture to help explain that there is no school. Everything has to remain in a routine and the boys needs to know what our plans are for the day.' (Ella)

Parents also used '*Problem-focused coping*' strategies to help manage their children's sensory sensitivities.

'so to go out and about he uses his disability buggy and I wrap blankets around him, because obviously he's got no shoes and socks on.' (Ella)

Another aspect related to careful planning and timing. Ella conveyed how they visited places at times when it was likely to be quieter:

'we've been to the zoo and we kind of do things on inset days, when other children would be at school and ours are off, they like the Sea Life Centre...we do soft play and stuff normally at the beginning or end of the day, when it is quieter.' (Ella)

Ella's experience reflects an awareness of knowing, probably through bitter experience, that busy environments increase sensory overload and are difficult for her children to cope with. The adaptations of these parents, shines a light upon their resourcefulness. Overall, these findings are important as they build on the exisiting literature, which also found that parents coped through '*routines and structure and pre-planning*' (Joosten and Safe, 2014, p.255).

In this study parents also used a range of specific strategies to cope with unsupportive attitudes across a range of individuals and service providers. These findings contribute to the existing literature, both in-depth qualitative studies (Gray, 2002a; Gray, 1993; Farrugia, 2009; Neely-Barnes et al. 2011; Preece, 2014; Ludlow, Skelly and Rohleder, 2011; Broady, Stoyles and Morse, 2015; Munroe et al. 2016) and larger scale quantitative studies (Kinnear et al. 2016; Harandi and Fischbach, 2016) of how parents of children with autism cope with autism stigma. The importance of understanding these parental strategies can not be underestimated, as the stigma process is closely associated with wider social isolation and exclusion and parents have been found to be at risk of developing mental health problems (Papadopoulos et al. 2018). This is also important as families have a significant influence upon the mental health of autistic individuals (Papadopoulos et al. 2018). Furthermore, Papadopoulos (2016) problematises that because society stigmatises mental health problems, it thus follows carers who experience autism stigma may endure a double-stigma effect. In view of this, in the next sections I include some focus upon the strategies that parents used for coping with unsupportive attitudes.

In the present study one of the key findings was that parents used '*Problem-focused coping*' strategies to navigate the social expectations of grandparents. For example, parents made separate arrangements for their autistic child, so that they did not have to visit grandparents or attend formal social occasions. Ana's experience illustrates this, she explained the expectation that they attended a formal birthday celebration for her mother-in-law. However, it was too much to expect Matthew to cope with. Consequently, she made

arrangements for him to stay overnight with her own mother, whilst the rest of the family attended:

'We've adapted ourselves to around them. So, the last party that they had...we dropped Matthew off at my mum's. He stayed with her overnight and we went up to their birthday celebration...we made the call of what he can't cope with and sitting in a big dining area with a four-course meal, wasn't going to happen.' (Ana)

In the literature parents have also confirmed how they have to be flexible around the sensory needs of their autistic children (Schaff et al. 2011). In view of this, Ana's description of *'we've adapted ourselves around them'*, reveals an interesting paradox. Rather than grandparents also being flexible around the needs of their autistic grandchildren, it was parents who felt the need to be flexible to satisfy their *'social expectations'*.

Similarly, Jayne spoke of the grandparents' expectation of her family attending formal meals, and their eventual decision to make other arrangements for Tim:

'we get a carer, we get a babysitter and we don't bring him.' (Jayne)

Jayne was clear that this was an assertive decision, one which her parents-in-law were probably unhappy about:

'we took control then...we were telling them, it was not up for negotiation.' (Jayne)

Charles and Helen also explained that they stopped visiting his parents with their children from quite an early age:

‘we had a few instances with Owen in particular...when we stayed there, sort of broke a few things...some things rather valuable...and that didn’t go down very well...’

(Charles)

At home, parents tend to manage the issue of precious items being broken by removing them from the reach of their autistic children (Nagib and Williams, 2018). However, this is often less possible when visiting relatives or friends. As Charles and Helen felt embarrassed about their children’s behaviour they became uncomfortable with continuing these visits.

Another key finding was that some parents utilised their valuable respite allocation so that their children could be looked after. For example, Charles and Helen described staying with his parents along with their younger typically developing son:

‘you know we have gone and stayed there, just the three of us, when the other two have been in respite.’ (Charles)

When parents feel compelled to make separate arrangements for their autistic children, this could be viewed as partial self-exclusion. Moreover, one issue with utilising valuable respite for visiting grandparents is that it reduces the time available for other purposes, such as supporting their wellbeing.

Similarly, Broady, Stoyles and Morse (2015) found that carers withdrew from family gatherings, because their relatives were unwilling to accommodate their autistic children. However, the findings of the present study differ, as grandparents did not actively encourage this exclusion. Rather, parents self-excluded their own children due to embarrassment about their behaviour or they felt their children could not cope with the

social demands. The implications from these findings is that it would be better if grandparents were more accepting of their autistic grandchildren and willing to accommodate more informal meal arrangements.

5.9.2 Avoidance coping

It was clear from the findings that parents often tried to cope through avoiding difficult interactions or minimising conflict. From how parent coping is conceptualised in the literature, I interpreted these approaches as '*Avoidance coping*' (see section 3.6.3). Although there were examples of parents using '*Avoidance coping*' with professionals and friends, a key finding was that most examples related to grandparents. Rather than rejecting these difficult relationships entirely, parents tried to escape from grandparents' unhelpful attitudes or minimise conflict. For instance, when Ana's son was making noise and upsetting her father-in-law, Ana took him out of the house (see earlier section 5.6.3).

In addition, Diana described the times when she avoided talking to her mum, as she could not cope with her unhelpful remarks about her parenting of Sam:

'She knows when I get cross, and I go off and I lick my wounds and I don't talk to her for a couple of weeks.' (Diana)

Diana's choice of language suggests that it is most hurtful when family members have negative attitudes. She continued to try to manage this less-than-ideal relationship, as her mother was the only remaining grandparent. In both examples, avoidance coping can be seen through the parent/child dyad temporarily shifting back into the microsystem to avoid contact.

Research indicates that parent personality is a factor in determining how parents cope. Glidden, Billings and Jobe (2006) suggests that neuroticism (characterised by feelings of anxiety, worry and anger) is associated with avoidance coping. Avoidance of difficult situations is also seen as a passive response (Harandi and Fischbach, 2016). Contrastingly, it is suggested that extraverts (characterised by enthusiasm and assertiveness) are more likely to use problem-focused coping strategies. Personality type may have been a factor in determining how the parents coped in this study. However, I suggest that parents tendency to use avoidance coping may also have been context driven. For example, as discussed above Helen and Charles stopped taking their disabled children to see their paternal grandparents due to judgements about their behaviour (see section, 5.9.1). Also, Becky reluctantly tried to cope with a lack of understanding from her relatives through emotional distancing (see section, 5.5.5).

I assert that as grandparents are close relatives, the context for coping with unsupportive attitudes to autism is different to how one might respond to difficult encounters from strangers. This might be because there is no permanence or relationships attached to these interactions. Overall, the significance of the avoidance coping in the context of grandparents, was that it was a last resort strategy, often to minimise conflict and avoid long-term damage to these relationships. Parents need to judge for themselves and assess the impact and potential long-term damage to these relationships, if they decide to respond proactively to unsupportive attitudes to autism.

Contrastingly Ella's estranged relationship with her parents-in-law, provides an example of permanent avoidance coping, as they continued to refuse to treat their triplet grandsons equally:

'[my husband] and I have just decided that they're either all included or not....and they've never really given an answer to that, so we've just moved on... and I've just decided that I don't want anything to do with them.' (Ella)

In this example the relationship is discarded, such that her parents-in-law are seen to move outside the mesosystem and beyond the framework. Ella's rejection of this relationship suggests a clear refusal to accept and identify with stigma. Whilst this may be perceived as a beneficial response to unsupportive attitudes, the loss of support from these grandparents contributes to the pervasive nature of loss and sense of social isolation for Ella, (see section, 5.5.5).

Parents also shared examples of other family members, where it was evident that they used 'Avoidance coping'. For example, Becky avoided conflict with her dietician son, as he was always critical of Joshua's diet:

'if his brother is criticising the food that he eats, I just blank it out, I ignore it and I think Joshua has to be happy and I give Joshua a hug and I say you know. And I just know that that helps me to get through it really. I'm constantly fighting everyone really!' (Becky)

Overall, Becky spoke about her feelings regarding her relatives' lack of understanding:

'Just after a while, they don't exist in that respect, in that bubble of being with Joshua, you just get on with it, but they don't realise what you, what you go through.'

(Becky)

Becky's use of a bubble metaphor encapsulates her sadness about the lack of emotional support from her relatives, leaving her feeling cast adrift and left to cope alone.

Beyond the family, some parents gave examples of '*Avoidance coping*'. For example, Iona recalled a particularly stressful time when Gabriel had undergone surgery. She could not cope with her social worker's negative attitude:

'I just couldn't cope with it at the time, so I decided not to have any dealings with her...whilst Gabriel was having his [surgery], you know that awful time.

I just said. 'I can't you know, I can't deal with you, I can't you know.

I just-just didn't communicate with her until that bit with Gabriel was mostly over.'

(Iona)

Iona's experience highlights the paradox that social workers should be a source of support for families and yet in this instance the social worker was perceived as doing more harm than good. It is important for parents to recognise the damage of unhelpful interactions with others and learn how to cope with these, particularly at times when they are feeling vulnerable. In this context '*Avoidance coping*' is probably a sensible means of self-preservation.

Parents also indicated using more subtle forms of avoidance with friends. These were conscious decisions to avoid conversations about their autistic or other children with special

needs. Thus, there is a hidden aspect to this. However, in the beginning parents had not felt like this. They had tried very hard to educate their friends and family about their child's autism. These parents had wanted to dispel misassumptions about autism and widen understanding about children with additional learning difficulties. Jayne conveyed how in the beginning she wanted to tell everyone about autism:

'I wanted to raise awareness, I wanted to explain [about] Tim so that people would understand it. Some people hear autism again and they just think they're a little bit mis-wired and I do use the word mentally handicapped sometimes because it just hits home a bit more...because Tim is classically fully blown classically autistic...to me autism is somebody who is not mainstream school, you know just learning life skills...'
(Jayne)

Likewise, Ella tried to engage her parents-in-law with TV programmes about autism, such as *'The A Word'* (see section, 5.6.4).

However, educating friends and family proved to be problematic. Parents came to realise that these interactions had a deleterious emotional effect. Helen confirmed this:

'I don't really talk about Owen or Fergus too much to my friends, who don't have children with special needs.' (Helen)

Charles explained why this was:

'people can be very sympathetic, but they don't really understand, they don't get it. They don't appreciate the difficulties and how hard it can be to cope.' (Charles)

Gray (1993) also noted how parents avoided asking about the well-being of a parents' autistic child. Thus, it is likely that parents without personal experience or knowledge of autism may struggle to know what to say to parents of autistic children or be conscious of saying the wrong things. It is possible that this uneasiness is traced to societal negative perceptions of autism, seen through the medical model, synonymous with '*deficit*' and '*disorder*' (Milton, 2019). The perceived absence of understanding can make parents feel that their child is not accepted and becomes a subtle form of social exclusion.

Likewise, Jayne realised that no one could really appreciate what it was like for her:

'I'm banging my head against a brick wall...people don't listen, they don't want to know. So, it was a defining moment, I'm wasting my time, so-so I don't talk about it so much.' (Jayne)

She considered why her thinking had changed:

'Could I perhaps say that, as I've got older with the diagnosis, I've got used to it, I've stopped trying to make it make sense to everybody...I don't think people want to hear it all the time...its complex and its invisible...they don't get it and when I say things, they think gosh she's exaggerating.' (Jayne)

Jayne's narrative depicts a journey of self-reflection. In coming to terms with her son's diagnosis, she learnt to relinquish the need for acceptance from others. Overall, it is not clear whether educating friends and family was a problem for these parents, or whether it is wider UK issue, as other studies have shown that parents are successful in informing family and friends about autism (Lilley, Sedgwick and Pellicano, 2020).

5.9.3 Ignore staring

Another approach to coping was to *'ignore staring'*. Ana recalled the glaring looks on the faces of patients in the doctors waiting room, because of Matthew's behaviour:

'the people were a lot older, they were definitely in their 60s and 70s, so I don't know whether this made a difference?' (Ana)

Ana explained how these looks made her feel:

*'Well personally, I don't give a s***...but it's not very comfortable either...I don't care what they think, but I'd rather that they didn't ...because you get this sort of heavy feeling, I don't want that, you can have it back...but I don't get defensive or anything.'*
(Ana)

Whilst Ana insisted that she did not care, her language reveals a depth of feeling, highlighting both mental and physical impacts from perceiving non-verbal judgements.

By slight contrast, Iona and Diana both asserted that it was necessary to develop a *'thick skin'* to cope with strangers staring. Iona explained why strangers tended to stare at Gabriel:

'Gabriel's really noisy and now he's hitting puberty, he's making some quite loud noises...they can be scary noises, if you know what I mean? So, they kind of turn and they're a bit worried and they frown...so we get a lot of that...but you know people always find difference difficult to cope with, but on the whole...you have to have a thick skin to be out and about.' (Iona)

Diana also described her regular encounters with strangers staring, which happened during the weekly routine of taking Sam to the leisure centre for his swimming lesson. Sam had a

blue badge for parking and so Diana would park the car in a disabled bay. Although this was perfectly valid, it seemed to trigger staring:

'I get looks, as I rather obviously put up the blue badge, so that's kind of my way of dealing with it, but you do think people question...yeah and you can tell they're judging...yes and I know it's really sad, but you just have to learn to be thick skinned.'
(Diana)

In the literature mothers describe having *'to put on a brave face'* to cope with judgements when their children were having *'meltdowns'* in public places (Joosten and Safe, 2014, p.256). This approach appears to correspond closely with Iona and Diana's experience of needing to develop a *'thick skin'*. However, findings in the present study provide rich insights about the contexts where this was deemed necessary. Parents used a *'thick skin'* specifically in relation to strangers staring when their child made *'loud noises'* or because they had parked in a disabled parking bay. Unlike Joosten and Safe (2014, p.256) these parents did not suggest that their children were having *'meltdowns'*. Overall, the findings highlight how members of the public are sometimes fearful of children whose behaviour does not fit with social norms (Marks, 1997). Similarly, Diana's experience points to an on going societal perception that blue badge parking spaces are only intended for those with mobility issues. Both examples highlight a lack of societal exposure to children with autism and LD and a lack of understanding of hidden disabilities.

Some parents in the present study had made efforts, albeit unsuccessfully, to educate their friends and family about autism (see section, 5.9.2). However, one aspect which was unclear

was why parents avoided using direct approaches to try to educate strangers about autism? This may be related to the tendency of the UK public to avoid verbalising criticisms and perhaps parents did not want to upset their autistic children by inviting an argument. Their approach differs from the literature where parents have tried to educate strangers about autism (Harandi and Fischbach, 2016; Neely-Barnes et al. 2011 and Broady, Stoyles and Morse, 2015; Safe, Joosten and Molineux, 2012), for example some parents have given cards out to strangers to communicate their child's autism (Farrugia, 2009).

5.9.4 Time out

Some authors propose that positive coping or reframing is the most useful strategy for parents of children with autism, who are coping with high levels of stress (Hastings et al. 2005; Hastings and Taunt, 2002). By contrast, Kuhaneck et al. (2010, p.344) insists that '*me time*', particularly exercise is the most effective coping approach. Likewise, Joosten and Safe (2014, p.254) reported that parents tried to find '*me time*'. In view of this, it is perhaps unsurprising that all parents highlighted their need to have time away from their child. As parents of children with autism and LD, a distinguishing feature of this study was that most parents had formal help, via a care package for their children. This enabled them to pay for carers/PA's or have access to respite services, also known as Short-Breaks.

Whilst it was evident that Charles and Helen needed a break from their caring role, Charles acknowledged how they had initially struggled to realise this:

'I think one of the things, I think we've struggled on-going is erm recognising when we need a break and we need respite.' (Charles)

Sending the boys to a local playscheme for children with disabilities, was their first step along this respite journey:

'It was our first real sort of baby steps in terms of understanding that we need-we need to recharge, we need you know to cope, we need respite we need to erm something other than just full-time caring.' (Charles)

Overtime the family became much at ease with using respite:

'we're much further along now and Owen and Felix have nights away and things like that, so we are nice and comfortable with that now that they are much older.' (Charles)

Similarly, Jayne explained that overnight respite services gave them time with their other autistic son without LD:

'We regularly make use of local respite services and use this opportunity to take Felix out. Tim goes away on respite overnight every other Friday night.' (Jayne)

Ana talked about the support the care package provided on a typical weekend:

'On every other Sunday Matthew goes to a carer's house and in between times he goes to a playscheme.' (Ana)

Contrastingly, Ella used her care package to pay for PA hours. However, rather than enabling her to take a break herself, this simply translated to having extra hands to help with her triplet boys:

'respite, we have none of that. It's me, myself and I...' (Ella)

Thus, Ella's experience differed from other parents in the group, who used their care packages to have a break themselves or spend time with their other children.

Becky's experience also deviated from the other parents in the group. She was the only parent who did not receive formal support via a care package, yet she still recognised her need for a break. Particularly when Joshua was younger, Becky recalled asking her mother to look after Joshua, so she could have a break:

'I was struggling to cope with him, as he was always screaming so much...I just needed to get away...I would often ask my mum to collect Joshua from nursery, whilst I went skating.' (Becky)

There was a distraught tone to the way that Becky described needing to get away, which may indicate avoidance coping. However, another interpretation is that she simply needed some time out.

Some parents viewed school as a form of respite. This was especially the case for Ella who only got a break from her caring responsibilities when her boys went to school:

'I have respite from the boys, whilst they are at school.' (Ella)

Iona's experience particularly highlights the additional dimension to caring for a child with medical needs. During the time that Gabriel was recovering from a hospital procedure and had a leg wound, school became a source of respite. Iona praised the school for allowing him to attend and their flexibility for accommodating his extra needs:

'there were all sorts of things they had to do to keep him safe...and they did it.' (Iona)

Iona was resolute that the school's support at this particularly difficult time, had enabled her to cope:

'I don't know how we'd have coped having Gabriel at home the whole time.' (Iona)

It is evident that the attitudes of school staff were a critical factor in supporting her son, so that he could attend school. This example underscores how school is an essential respite, enabling parents to take a break from their caring responsibilities.

For some parents, it was evident that going to work was a form of time out and coping mechanism. Becky revealed how she had returned to work as a teacher:

'I needed to go to work, I wanted to do something, I wanted to get my life back on track.' (Becky)

Becky's feelings suggest that work fulfilled her need to both contribute something beyond being a parent and to restore a sense of her former self and identity.

Diana also found that working had a positive impact upon her wellbeing:

'you know you do gain a lot of positives from working, you know its not about the money, its about you know the interactions that you have with people at work and that makes you feel a lot happier and a lot more secure.' (Diana)

Diana also found that her job distracted her from worrying about how Sam was coping during his school day:

'Initially it took a lot to step back, I found it really hard and that's one of the reasons why I took the job at [name of school] because I would sit here and worry about what

he would do, if he had gone off anxious or he had done that, and I was literally sitting by the phone waiting for it to ring, because that was what it had been doing.’ (Diana)

In both cases these parents seem to have been left traumatised by phone calls from their children’s previous school, related to their behaviour. Yang (2015) who found parents who defined themselves through multiple roles, coped better with stigma. It is also likely that Becky and Diana found working gave an escape, which provided the opportunity of finding perspective, enabling them to cope better with judgements.

By contrast, the caring responsibilities of other parents, namely Helen and Ella made finding paid work unrealistic. This is a significant finding, as caring responsibilities are not only barriers to paid employment, but they also potentially exclude parents who might find working a helpful coping mechanism. For these parents access to respite services to get a break from caring is probably essential. Despite these limitations, Ella conveyed how she had carved herself a role through contributing to her children’s school. It is evident that this also helped her to cope:

‘I obviously do a lot at the school, chair the friends group... I think that’s kind of for my sanity to be doing something else and be giving something else back.’ (Ella)

5.9.5 Social support

Some authors have tended to categorise ‘*Social support*’ as a form of problem-focused coping (Hastings et al. 2005; Glidden, Billings and Jobe, 2006). However, I decided this would be clearer if discussed as a separate theme. Virtually all parents conveyed that having a child

with autism had had an adverse effect on their relationships with some family members and friends. Despite these broken relationships and echoing the literature, several parents emphasised how social support had helped them to cope (Ludlow, Skelly and Rohleder, 2011; Broady, Stoyles and Morse, 2015). Some parents were able to make new friends with other parents of children with autism and LD and other special educational needs. As Helen explained:

'we have ended up building new networks of special needs parents. I've got a good network of friends from Fergus's school and we meet regularly and exchange stories and laugh about them. We can because there is understanding.' (Helen)

Likewise, in the beginning Ella had conveyed how desperately lonely she felt, but this changed when her boys started school and she made friends with other parents:

'Since the boys have been at school and we're all parents in a similar boat, so we do things together, if it doesn't work out and it's hell and all bedlam, but that's just how it is, no one's there to judge and fall out with and off we go, tomorrow will be a better day, you know they are my friends.' (Ella)

Mirroring the literature, these parents found social and emotional support through aligning themselves with other parents in the same situation (Ludlow, Skelly and Rohleder, 2011; Broady, Stoyles and Morse, 2015). The nature of these friendships underscores how these parents often recognise the similarities in their experiences, described in the literature as *'walking in our shoes'* (Mackintosh, Myers and Goin-Kochel 2006, p.50). This also reflects an awareness of shared reality or *'universality'* (Huws, Jones and Ingledew, 2001, p.579).

Likewise, the gravitation of this group of parents towards others in the *'same boat'*, points towards a possible deficiency in their relationships with some relatives and friends. In turn this may result in some parents choosing to self-exclude themselves from some social opportunities with family or friends.

Parents also spoke of a range of significant others, for example, staff on their child's transport to school, PAs and playscheme support workers, all of whom provided practical support (see section, 5.7). Parents adapted to the situation and adopted these *'others'* who became part of the families' bubble of support. This finding seems to slightly parallel the *'hybrid families'*, described by Bessette Gorlin et al. (2016, p.591), but differs as these bubbles of support were extended families and friends. A significant finding is that for some parents, namely Ella, these compensatory relationships, often reflected a deficiency in support absent from grandparents and other relatives or friends.

By contrast, some parents did benefit from *'Social support'* from their families. Whilst Ana's mother provided her with practical help, it was the emotional support and reassurance that made the biggest difference. Ana conveyed how what her mother would say when she was having a difficult day:

'just don't worry about it, it doesn't matter.' (Ana)

Similarly, Yang (2015) found self-compassion was a coping strategy. An interesting finding was that Ana indicated this support also had a moderating effect upon the unsupportive attitudes of the paternal grandparents. However, whether the emotional support of

grandparents', as close relatives, is a particularly effective source for buffering unsupportive attitudes is difficult to generalise from the findings.

5.9.6 Positive re-framing

In this section I consider how well parents were able to positively-reframe their experiences of everyday life and also judgements.

For example, for Ella it was evident from how she conveyed sharing her experience with other parents of children with autism and LD, humour was a coping strategy,

*'people are in a s*** place like we are, you haven't got to hide anything from these people, we're all in the same boat... never had a night off from our children...and we kind of laughed it off, because you've got to, you know.'* (Ella)

This finding highlights the important role of humour in managing to cope for parents in this group. It also builds upon the literature about the importance of seeking social connections with other autism parents, who share the same experiences (Lloyd, Osborne and Reed, 2019).

In addition, Becky's experience underlines how the strength of love for her son helped her to cope:

'I think I've coped because I love Joshua so much, that nothing, nothing could tear me away from him. I think the overall love for a child is what keeps you going.' (Becky)

With regards to judgements, Diana reflected that how she coped depended upon her emotional state at any time:

'if I'm emotionally quite happy and everything is going smoothly, then quite often I'm not really affected by negative attitudes and I usually brush them off, but if I'm feeling low that's when they get me and that's when problems happen.' (Diana)

In comparison, despite many years of encountering judgements, Jayne still found these experiences difficult:

'I'm used to it...and its oh another one, another judgement call...yeah I don't feel any less...its painful.' (Jayne)

Jayne's experience seems to align with Gray (1993) who found that it was parents of younger children or those with more severe symptoms who were more likely to be susceptible to stigmatisation. It is probable that this author was referring to parents of children with autism and LD. Conversely, this author also found that parents of older children reported becoming more desensitised to the negative reactions of the public and so over time they were less concerned by judgements. This differs from both Jayne and Diana, whose experiences portray a more nuanced picture, where the ability to positively re-frame judgements may be variable and situation dependent.

5.9.7 Key findings

Parents used a range of strategies to cope with unsupportive attitudes across a range of individuals and service providers. A major finding was how parents used strategies to navigate the social expectations of grandparents. Parents often made other arrangements

for their autistic children, seen as '*Problem-focused coping*', so that they could attend formal occasions. They also used '*Avoidance coping*' strategies, for example removing their child from the company of grandparents or distancing themselves to minimise conflict. The findings suggest that social expectations were associated with hidden exclusion. Another finding was that going to work helped some parents in this group to cope. However, this opportunity was unrealistic for others and ultimately highlights the caring responsibilities for parents of children with autism & LD.

5.10 Summary

In this chapter I have discussed the findings in relation to the experiences of parents whose children had a diagnosis of autism and LD. Unsupportive attitudes were identified as significantly impacting on family life, which often compounded parental feelings of loss. Parents particularly highlighted how grandparents' attitudes were related to social expectations. Attitudes were often subtle or hidden. Notwithstanding these challenges, parents also conveyed their experiences of supportive attitudes, these contribute towards a positive model of attitudes. Overall, these findings are significant as they provide insights and contribute to increasing knowledge about the unique experiences of an often-overlooked segment of the autism community (DePape and Lindsay, 2015). In the final chapter, I present an overview of the study and address the research questions.

6 CHAPTER 7: OVERVIEW

In this chapter, I begin by re-stating the aim of this research and I provide an overview of the methods. Next, I summarise the key findings and contributions of this research. I then address how the findings answer the research questions. This is followed by the implications of this research and recommendations. Throughout I make links to the conceptual framework. Finally, I consider the strengths and limitations and suggest ideas for future research.

6.1 Overview of study and methodology

This research explored the lived experiences of eight parents of children with a dual diagnosis of autism and LD and other co-occurring conditions, living in Southeast England. Understanding these experiences is important, as parents play a pivotal role in determining the quality of life and longer-term outcomes for their children. This study is significant as the experiences of this group of parents is an under researched area. Moreover, knowledge of these parents' experiences of societal attitudes towards autism, also known as stigma, is limited. Thus, this study makes a distinct contribution to improving understanding.

This qualitative study used a phenomenological methodology with Interpretative Phenomenological Analysis. As advocates for children with limited spoken language, parents were positioned as experts on their experience, enabling their voices to be heard. As a parent of a child with autism and LD, my researcher position was also central to this study. Although I could not directly share other parents' experiences, I assert that my reality was close enough to be able to interpret their experiences. Furthermore, at the heart of this research project, a conceptual framework was developed which drew upon the Bio-

ecological systems theory. This theory was adapted to situate the parent/child dyad in their world and understand the societal impacts on their experiences.

This study was conducted using two semi-structured interviews with parents. In the first interview, a broad lens was used to explore parents' lived- experience. This was an active process involving myself working with the parents to reflect upon their experience.

Individual stories were co-constructed, which became research products. This approach enabled parents' specific perspectives to be fully acknowledged and revealed how they felt there was little understanding of their realities. In the second interview, through a narrower lens parents' perceptions of societal attitudes towards autism were examined, both unsupportive and inclusive attitudes. As most studies have focused upon exploring negative attitudes, also known as stigma (Gray, 1993; Kinnear et al. 2015; Broady, Stoyles and Morse, 2015), the current study contributes a wider perspective.

6.2 Addressing the research questions

In this section I consider how the findings help address the research questions, drawing upon the conceptual framework.

6.2.1 RQ1 What is unique about the everyday lived experiences of parents whose children have a dual diagnosis of autism and learning difficulties?

I assert that trying to situate what is unique about the experiences of parents whose children have a dual diagnosis of autism and LD, versus parents of children without

additional learning difficulties, is problematic. The central issue is that autism is ultimately a

heterogeneous condition (Jordan, 2019), thus it is difficult to simplify this experience. In the context of the present study, all parents had at least one child with a dual diagnosis of autism and LD, yet their children presented differently. For example, this is seen from parents' descriptions of child's spoken language. Some described their children as verbally articulate, albeit not matched with the same level of understanding, whilst others described them as having little or no spoken language.

In addressing this research question, it is important to reiterate that '*Loss*' emerged as the strongest superordinate theme in the findings. It was also pervasive, seen in multiple layers cascading across parental experiences. Thus, significant aspects of these parental experiences need to be understood through the prism of loss (see section 5.5). Whilst cautioning against making generalisations, I will try to draw together the findings which reveal what is unique about the experiences parents of children with autism and LD.

First, returning to children's spoken language, the findings reveal that parents whose children had little, or no spoken language used alternative communication systems, such as visuals. Ella's experience highlights how these parents needed to plan to ensure that appropriate pictures/visuals were readily available to support communication with their child. This extra preparation underlines another area of their lives which is largely hidden. Whilst parents of typical children may be afforded the opportunity to relax some of their routines during weekends or school holidays, for this group of parents these routines were enduring.

Second, some of the parents in this study had children with other co-occurring conditions, which added other dimensions to their experience. A key finding was that health professionals initially failed to recognise these co-occurring conditions, such as epilepsy and Tuberous Sclerosis (TS), seemingly disregarding parental descriptions of their babies' having seizures. This lack of recognition that their instincts were right, led parents to doubt their parenting. Despair was also compounded by the loss of their expected child and feelings of loss at the time of their child's diagnosis (see sections, 5.5.1 & 5.5.2)

Third, all the children in this study attended a specialist school (although some had previously attended units attached to mainstream schools). This compares to most autistic children with an autism diagnosis (70%) in England, who are educated in mainstream schools (DfE, 2021). Becky and Ella's descriptions of their visits to specialist provisions and the sight of other children with disabilities, suggest a re-living of the loss for their expected child (see section 5.5.6). Some parents also described feeling rather disconnected from other parents, whose autistic children attended mainstream schools, as their priorities and concerns did not always correlate with their own. This was particularly the case for parents whose children had other co-occurring conditions.

Also, communication between the child's school and parents was often via a school diary, which came home in the child's school bag. Whilst this was an adequate system for some parents, for Becky it was a source of stress to be continually bombarded with negative comments about her son's day:

'I was dreading reading that every day, which is awful.' (Becky)

Fourth, all the children in this study had to travel a distance to get to school, in some cases this was considerable. For parents, using home to school transport to get their child/ren to school, added an extra complexity to the morning routine. Not only because of bus timings, but because a lot depended upon the quality of the relationships with the transport staff. On the one hand parents shared some good experiences:

'I have a good relationship with the staff on the bus. They tell me when they are a few minutes away, so that I can put on the boys' shoes and coats.' (Ella)

By comparison, Diana had to contend with a difficult situation with transport staff whose attitude clearly contributed to her son's anxiety and behaviour. Some parents managed the issues of being remote from their child's school, by forming social support groups with other parents of children attending the same special school.

Fifth, except for Becky, all parents had a care package and an allocated social worker or family support worker. This reflected their child's high care needs and absence of family support. However, the process of securing this support took time. In some cases, social workers were slow to recognise their child's significant needs and to grasp the full implications of how this impacted upon family functioning. Parents felt their child's needs, which were obvious, had to be demonstrated to social workers through home visits and accompanied visits into the community. This issue was particularly amplified by parents with more than one child with additional needs. Parents felt that the hidden presentation of autism and other co-occurring conditions seemed to underpin the underestimation of these needs.

The findings highlighted a system that is inherently biased towards physical disability. Care packages, once agreed, provided respite also known as short-breaks, overnight stays or PA support. Some parents chose to have money paid to them as direct payments, which they used to employ a PA. Whilst this option provided most flexibility for parents, it also left parents with the responsibility of finding the right person and managing the financial aspects of this arrangement. The continuous apprehension of having to think through worst case scenarios, always trying to be one step ahead, added extra parental strain.

For these parents the vital support provided by care packages, also came with '*strings attached*'. Having an allocated social worker meant regular communications and home-visits which were inherently intrusive, as boundaries were crossed into parents' personal and emotional space, which Iona highlighted:

'Social care can potentially reach out into anything, and they come to your home and it's quite invasive, there are a lot of personal questions...' (Iona)

Whilst other parents seemed more resigned to the involvement of social workers in their lives, it is also likely that they recognised this intrusive aspect of accessing support.

Finally, all the parents' children had relatively high care needs, although these differed across the group. Several parents recognised how their role and identity extended beyond parent to also being carers. One parent described the needs of her son as:

'24-hour care...' (Jayne)

Achieving independence with toileting was described as happening much later, than is typical. Schools or disability nurses were often involved in supporting this process. Most

children continued to need support with their personal care needs, such as showering, hair washing and teeth brushing. Even as children reached their teenage years, parents did not feel that their children could be left alone at home. Safety was a particular concern, for parents whose children had a history of absconding. For some parents the care needs of their children limited their opportunities for paid employment or future opportunities. For example, Diana highlighted how her son's care needs might impact her own longer-term career aspirations.

'When Sam finishes school at 19, he's probably not going to have a full-time placement and that's scary...Where does that leave me with what I want to do?'

(Diana)

In summary, although not all the above issues applied equally to parents, these insights suggest some unique aspects about this group of parents in comparison to the wider autism community.

6.2.2 RQ2 What do parents feel their relationships/interactions with individuals and service providers reveal about attitudes to autism?

The findings have shown that through reflecting on their relationships or interactions, parents were able to identify specific attributes of attitudes towards autism. These are explored in detail through the superordinate themes of unsupportive attitudes and supportive attitudes to autism, with related subordinate themes (see findings and discussion chapter, sections 5.6 and 5.7)

Parents perceived unsupportive attitudes across a variety of settings and individuals. The different contexts and nature of these relationships/interactions, seen through the conceptual framework, sheds light upon how unsupportive attitudes were experienced. Attitudes from strangers presented differently from all other interactions. Parents described how they felt judged about their child's behaviour or their parenting. These attitudes presented as judgements, which were mostly non-verbal staring looks. Occasionally parents also overheard verbal criticisms or negative comments. It is likely that strangers perceived these autistic children as typically developing, thus expecting them to conform with behaviour around social norms. Parents felt that these judgements stemmed from a lack of understanding of autism and a lack of recognition of hidden disabilities.

Attitudes from service providers differed from strangers, as for example with school staff there was a formal relationship,. As with strangers, parents described the same experiences of feeling judged about their child's behaviour or their parenting. However, judgements were more tangible, for example receiving phone calls from school staff, complaining about their child's behaviour. Parents felt school staff perceived their child as '*naughty*' and needed to be taught how to behave. They felt school staff failed to understand the underlying reasons for their child's behaviour, thus the notion of '*naughty*' underscored this attitude. As for parents being criticised, Iona recalled how her social worker disapproved of her administering paracetamol suppositories for her son. The social worker seemed to take an expert position, disregarding the parent's knowledge of their child. Findings from this research support other studies where parenting competence is questioned (Myers, Mackintosh and Goin-Kochel, 2009; Nicholas et al. 2016).

Attitudes from relatives, particularly grandparents, differed from the examples above, due to the familiar aspect of these relationships. Grandparents often positioned themselves as senior family members, who knew best. Grandparents' unsupportive attitudes were associated with rigid social expectations. For example, fixed ideas that their grandchildren should behave quietly, they should be able to attend formal occasions or meals and sit still eating the same food. Parents explained that compliance with these social expectations was difficult and traumatic for their children. Sensory sensitivities or anxiety contributed to the issue for their children.

The findings showed that some parents felt these attitudes were related to blame, denial or embarrassment. For example, Becky described a systemic blame culture within her family, where everyone sought to blame everyone else for her son's autism. Similarly, Ella explained how her parents-in-law were in denial of the likelihood that their grandchildren were autistic. Similarly, embarrassment of her grandson's autism caused Becky's mother to try to conceal this diagnosis from relatives. It is my assertion that grandparents who were embarrassed were experiencing stigma by association. Overall, these attitudinal issues seemed to be underpinned by old-fashioned parenting ideas, a lack of understanding of autism and acceptance of difference.

Contrastingly, parents also perceived supportive attitudes to autism across a variety of settings and individuals. Parents were able to identify clear attributes of supportive attitudes including, '*understanding needs*', '*supportive relationships*', '*supportive responses to*

behaviour that challenges’ and *‘practical help*’. These attributes were overlapping and emerged across settings and individuals.

Some parents also recalled occasions when they were touched by the kindness of complete strangers. For example, Diana recollected how two ladies in a shopping centre had intervened to help her support her son back to the car when he *‘had a huge meltdown*’. The strangers were teachers who worked in a special school and had experience of supporting autistic children. This example, underscores how having autism knowledge enables others to understand needs.

Parents gave examples of service providers, including health care professionals, schoolteachers and other service providers, who had a good understanding of their child’s needs. For example, they were open minded, aware of sensory differences and respected special interests, rather than viewing these as obsessions (Prizant and Fields-Meyer, 2015). Parents cited school staff and health workers who worked in partnership respecting parenting knowledge (Sherwood and Nind, 2014), to achieve the best outcomes for their child. The findings show that respecting parents’ knowledge is likely to be more critical when children with significant communication difficulties rely on their parents as advocates.

Parents spoke of the supportive relationships they had developed with transport staff, PA’s and play scheme support workers. It was often the small gestures of help that made the most difference to parents. Rather than reacting and judging behaviour through a traditional

lens of *'naughty'*, parents described how these individuals showed understanding and were not fazed. For example, Ella described her PA's as:

'don't ever seem to bat an eyelid with anything that goes on behaviour wise.' (Ella)

Some parents also shared their experiences of relatives and grandparents' supportive attitudes. Supportive attitudes were more positively correlated with maternal grandparents Helen and Ana provide good examples (see section 5.7.4), although this did not reflect everyone's experience. The attributes of supportive attitudes were much the same as discussed above, though practical help was also significant. The practical help offered by grandparents underscored the issues of keeping children safe and extra challenges of going on family holidays. One parent also spoke of how her mother provided emotional support.

To summarise this study contributes new knowledge about the unsupportive attitudes of grandparents, which were associated with rigid social expectations and blame, denial and embarrassment. Overall, attitudes seemed to be underpinned by old fashioned parenting ideas, a lack of understanding of autism and acceptance of difference. Contrastingly, attributes of supportive attitudes, which were seen across a variety of settings and individuals included, *'understanding needs'*, *'supportive relationships'*, *'supportive responses to behaviour that challenges'* and *'practical help'*.

6.2.3 RQ3 How do attitudes towards autism help or hinder parents' ability to care for their children?

I begin with this question in relation to how attitudes hindered parents. Parents found the unsupportive attitudes of some health professionals were a hinderance. Parents cited how their concerns about their children were often disregarded, resulting in a later diagnosis. This had detrimental effects, including delays to accessing medication to manage epilepsy and wasted time without access to the right educational support. On many occasions health professionals seemed to position themselves as experts, in effect inferring parental instincts were wrong. Some parents began to doubt their parenting. The significance of this finding is that these factors have an impact upon the life outcomes for children with autism and the wellbeing of their parents.

Parents found the unsupportive attitudes of some social workers were a hinderance. Parents cited how social workers were much too slow to recognise their child's significant needs. They were slow to grasp the full implications of how these needs impacted upon the functioning of their family. Parents felt that needs, which should have been obvious, had to be demonstrated to social workers through home visits and proving that there were safety issues with going out into the community. This was particularly for parents who had more than one child with additional needs. Parents felt that the hidden presentation of autism and other co-occurring conditions, versus Down syndrome, seemed to underpin this issue.

Parents found some grandparents' attitudes a hinderance. Parents described how social expectations and the pressure to attend formal family occasions, which their children could

not cope with, negatively impacted their family. These parents felt they had no option than to make alternative arrangements for their autistic children, so that they could still attend. The implication of making separate arrangements was that parents had the added extra pressure and complexity of making these arrangements. Moreover, respite time was sometimes used for this purpose, rather than being prioritised to support wellbeing.

Parents found strangers' attitudes a hinderance. The anticipation of judgements meant that some parents were reluctant to take their children out into the community. There was a sense that going out into the community was an unpredictable '*journey into the unknown*'. Parents could not predict how their children might behave and how strangers would react. The significance of this findings is that parents who encounter or perceive attitudes are likely to feel discouraged from spending time in in the community, increasing their risk of isolation. Avoidance of judgements in public places was also one reason why some parents chose to utilise disability play schemes and respite. In essence, for parents to feel comfortable in accessing the wider community, they need to feel supported rather than judged (Lutz, Patterson and Klein, 2012).

I move on to address the opposite question of how supportive attitudes helped families to function? Practical help possibly made the biggest difference to parents' lives, particularly for those with more than one child with additional needs. For example, practical help, via a care package, enabled Ella to employ PA's to help her take her triplets out into the community safely. Without this support the family would have been isolated. However, Ella's description of her two PA's as her '*lifeline*' underscores that whilst parents appreciated

this support, they were left feeling uncomfortably dependent. Similarly, Iona conveyed how support, via her care package, was needed to provide sufficient breaks from caring.

However, the perceived power that social workers had over funding care packages made Iona feel that *'it's your life that they've got in their hands'*. Parents also spoke of grandparents joining them on holiday to provide practical help with their child's personal care needs or securing their garden so that grandchildren could visit safely. Without this help, holidays and visits would have been less viable.

Supportive relationships also made a difference to parents' lives. A good example was the relationship that the swimming teacher had developed with Diana's son. This enabled him to learn to swim. Moreover, these regular swimming sessions at the local leisure centre provided continuity and routine, particularly during the time that Sam was temporarily excluded from school. Similarly, supportive non-judging environments, such as specific swimming sessions for disabled children and their families, gave children leisure opportunities and their parents time when they could relax without worrying about being judged.

Supportive relationships also made a huge difference to parents whose children needed to access health care. Some health professionals tried hard to understand their children's needs and difficulties. They were willing to work in partnership with parents to find the best approaches, so that healthcare could be accessed more comfortably. In these circumstances, parents felt listened to.

Supportive relationships from school staff also made a huge difference to parents. For example, when Becky's son moved to a special school, the staff were able to support his needs and he was happy. Thus, Becky was able to go back to work as a teacher, without feeling that she would be interrupted during the working day, with phone calls about her son's behaviour.

To summarise this study contributes new knowledge about how attitudes both hindered and helped parent's ability to care for their children. The expectation of attending grandparents' formal family occasions, meant parents often made alternative arrangements for their autistic children, sometimes using formal respite to prioritise family expectations, rather than using respite for their own wellbeing. Practical help possibly made the most difference to helping parents, particularly for those with more than one child with additional needs. However, with this support, parents were left feeling uncomfortably dependent, conscious of the lack of control over their lives.

6.2.4 RQ4 What are parents' perceptions of attitudes towards autism from wider society?

This question considers parental experiences of how factors in wider society contribute to societal attitudes to autism. This is seen through the outer layers of the conceptual framework of the macro and exo systems. The data captured from parents was limited as most spoke of their experiences of attitudes, related to their immediate environments of the micro and meso systems. However, some did spontaneously contribute their thoughts about wider aspects of society, seen through the overlapping superordinate themes misrepresentations of autism and hidden autism.

The study highlights how structural societal issues contribute to attitudes. Parents shared their frustrations of trying to navigate a system for accessing social care and disability benefits, designed and biased towards physical disabilities rather than autism. It was harder to prove their child's needs as these were often invisible. Furthermore, form filling was long-winded and their child and family needs, which they felt were obvious, had to be continually proved with regular requirements to re-apply for support.

It is evident from the findings that the societal bias towards recognising physical disability had a trickle-down effect into parents' experiences of taking their children out into the community. For example, a parent had to contend with strangers staring at her when she parked her car in a blue badge space. The leisure centre swimming pool was often overcrowded and noisy and lacked a quiet space for children to retreat to, enabling them to calm down. In comparison, there were toilets with handholds to support those with physical disabilities.

Some parents talked about how autism was misrepresented through the media, films and TV. They particularly mentioned the issue of autism being associated with able and articulate individuals, having '*special talents*'. Contrastingly, some parents asserted that the TV series, '*The A Word*' had succeeded in portraying their reality, though they felt more was still needed to level up coverage of autism and LD. Parents also spoke of the persistent use of the word '*naughty*' to describe the behaviour of autistic children. This was a frustration for parents, as this view failed to take account of possibility of sensory sensitivities and anxiety as possible factors underlying their child's behaviour.

To summarise this study contributes new knowledge about parents' perceptions of attitudes towards autism from wider society. Parents felt there was not enough focus on understanding autism and LD and that the realities of their daily lives and challenges were not well understood. Even from within the autism community, for example their local NAS, they felt rather disconnected from the issues that concerned other parents of autistic children who attended mainstream schools. In addition, one parent felt that issues of safeguarding, when they involved incidents between two children with autism and LD, were disregarded.

6.3 Implications, recommendations and contributions of research
The experiences parents shared about attitudes towards autism highlight some practical implications from this research. Several recommendations are suggested. In addition, contributions to methodology and theory are explained.

6.3.1 Recommendation One: For health care professionals
Health professionals should respect parents' instincts and knowledge of their child. They should consider the implications on the parent and child's wellbeing from dismissing these concerns. Parents with an existing child with an autism diagnosis, are likely to be best placed to notice signs of autism in younger siblings. Professionals assessing the appropriateness of an autism diagnosis should therefore consider parents' existing knowledge and experience of autism. Health professionals should also listen to the views of parents and work together to find the best way of supporting children before they undergo medical treatment.

The findings that led to this recommendation are as follows:

In virtually all cases, parents were the first to recognise that something was different about their baby. However, health professionals dismissed their concerns. Perhaps more worryingly, health professionals were also slow to recognise co-occurring conditions, for example epilepsy and TS. In these cases, access to much needed medication was delayed. Children without any spoken language, whose developmental delays were more obvious were more likely to receive an early autism diagnosis. These children were also more likely to be allocated a place in a specialist school. However, with second born children, health professionals were dismissive when parents suggested that they might also be autistic. As these children had spoken language, it is likely that their difficulties were less obvious or easier for health professionals to ignore. The findings revealed that a delayed autism diagnosis was significantly damaging to the child's educational experience. Prior to their diagnosis, they were not given an appropriate school placement and support. For parents these experiences caused untold distress, as they began to question their parenting instincts. Ultimately this is significant, as Jordan (2001) asserts that the quality of life of children is intertwined with the quality of life of their families.

Iona's experience particularly underscored the inconsistency of experience of accessing hospital treatment for her son. On the one hand, she gave examples of health care professionals working brilliantly as a team with parents, to try to achieve the best outcome for their child. On the other hand, there were occasions when health professionals were unwilling to listen, positioning themselves as experts and disregarding the knowledge of parents. This resulted in unnecessary suffering for the child and the parents and child were left traumatised from the experience.

The findings and recommendations lend support to the government's autism strategy (National strategy for autistic children, young people and adults: 2021 to 2026, 2021), which acknowledges the need to improve health professionals understanding of autism and improve the process of diagnosis. Also, the recent Health and Social Care Act (2022), which has insisted that learning disability and autism training is mandatory for health and care staff.

6.3.2 Recommendation Two: For social workers
The recommendations from these findings are that social workers should pay particular attention to providing early support to parents in this group, to avoid the possibility of families reaching a crisis point.

The findings that led to this recommendation are as follows:

Parents reported that social workers were too slow to recognise the care needs of their children. Delays in accessing care packages was a particular issue for parents caring for more than one child with an autism diagnosis, multiples or other children with special educational needs. Parents spoke about the additional care burdens, practical issues and safety considerations of looking after more than one child. According to the Independent Review of Children's Social Care (2021, p.11), rather than providing support to families, too much time is spent '*assessing and investigating*'. This finding is mirrored, as parents spoke about social workers insisting upon spending time with them at home or out in the community, to be able get an understanding of the family's needs. Parents felt that the extent of their needs should have been obvious. Parents believed that the hidden nature of autism and other co-occurring conditions was a barrier to accessing support, versus having a child with a physical

disability. In addition, Iona spoke of her social workers' refusal to increase her son's care package to reflect his changing needs. She felt that her family literally needed to be '*in crisis*' before anyone would take any notice. Resources will always be finite, but it is likely to be more cost-effective to fund support for parents to sustain caring for their children at home, rather than children being placed in residential settings, often as a last resort. These findings are significant as they support other studies which point towards families of children with disabilities needing to reach a crisis point, before support is offered (Cullen and Lindsey, 2019).

Iona also described the '*invasive*' nature of having a social worker visiting her home and asking lots of personal questions. Other parents seemed to mostly accept having a social worker was part of the process of accessing support services, but this does not mean that it was not intrusive. Whilst the true extent of this finding is unclear, it lends support to the Independent Review of Children's Social Care (2021), which found the processes that social workers have in place are '*costly*', (p.30) and '*overly intrusive for families*', (p.39). It is worth pointing out that in another life, without a disabled child, the lives of parents in this group would probably never have crossed into the social care system. Social workers should therefore build trust and be cognizant of how their involvement may feel intrusive.

6.3.3 Recommendation Three: For providers of parent training programmes
Providers of parent autism training programmes, such as NAS EarlyBird (Palmer et al. 2020) and Barnardo's Cygnet programme (Stuttard et al. 2013), should consider differentiating their programmes for parents of children with autism and LD and other co-occurring

conditions. They should also be aware of the issue of attitudes towards autism. They should support parents with strategies to cope with unsupportive attitudes from friends, relatives and others. Providers should extend autism training to include grandparents, with the aim of increasing grandparents' engagement and understanding autism.

The findings that led to this recommendation are as follows:

Some parents felt disconnected from issues concerning other parents of autistic children without LD. This is reflected in a recent study which found parents felt not all aspects of the NAS EarlyBird programme were relevant to their children (Palmer et al. 2020). This further underlines that autism is a heterogeneous condition (Jordan, 2019). From the findings it is clear parents encountered issues with unsupportive attitudes and used a variety of coping strategies. Grandparents' unsupportive attitudes were particularly difficult to cope with.

6.3.4 Recommendation Four: For shaping local and national policy
To simplify the system of accessing disability benefits and support for parents of children with autism and LD whose caring role is often significant. Campaigns at both national and local levels are recommended to improve societal understanding and acceptance of autism and change attitudes.

The findings that led to these recommendations are as follows:

Parents reported that navigating the system for disability benefits was overly complicated, time consuming and a drain on their energies. Efforts were duplicated when parents had more than one child with additional needs. Systems at national and local levels were not joined up. Thus, needs that were proved at a local level, through diagnosis, attendance at a

special school and having an EHCP, did not result in any automatic qualification for a blue parking badge or disability benefits.

Judgements from strangers, safety and sensory issues were barriers to families accessing community facilities. The implication is that parents may feel discouraged from spending time in their local community, increasing their risk of social isolation. More supportive environments for families of children with autism should be available. For example, properly secured playgrounds and enclosed spaces. Leisure centres should provide quiet changing spaces for families of children with autism. They should also schedule specific times for these families to have sole access to swimming pools, so that they are protected from the potential judgements.

6.3.5 Contribution to methodology

This study contributes to methodology. The emerging superordinate themes from the IPA analysis from the second interview data, was also used innovatively to re-visit the initial data from the co-constructed parent stories. The effect was to enrich my preliminary interpretations. In consequence, this study contributes new methodological ideas, which may be adopted by future researchers interested in using phenomenological approaches. This study also highlights the benefits of using flexible approaches to contribute to ensuring robust research.

6.3.6 Contribution of conceptual framework

This research which focused upon parental experience, utilised the Bio-ecological systems theory of child development for the conceptual framework. The conceptual framework was

a central component of the research project and underpinned every stage. A unique instrument for supporting the data collection was a blank version of the conceptual framework, designed as a visual tool, to help parents map out their interactions with others in relation to their child. A pack of coloured stickers, red, amber and green was also used to help parents to think clearly and identify the quality of their relationships. Utilising the completed frameworks, parents were asked in the second interviews to share their experiences about attitudes towards autism. Virtually all parents decided to spontaneously talk about their experiences of grandparents' attitudes. As little is known in the literature about the topic of grandparents' attitudes, I assert that the framework was instrumental in uncovering and elevating an important aspect of parental experience. Overall, the conceptual framework contributes an innovative approach, highlighting the benefits of using visual tools in interviews for capturing parental experience (for more details, see section 4.9).

6.3.7 Strengths and limitations

The strength of this study was that it captured in-depth, the unique perspectives of parents of children with autism and LD. Each of these parents were willing and able to articulate what it was like to live with a child with autism and LD. They also shared their perceptions of societal attitudes towards autism. Each parent devoted significant time from their busy lives to meet with me twice, which was a considerable commitment, given their care demands and pressures.

As a parent of a child with autism and LD, my researcher position was also central to this study. Although I could not directly share other parents' experiences, I assert my reality was close enough to be able to interpret their experiences. However, my positionality inevitably influenced and shaped my interpretations of the data. With the same set of data, it is likely that another researcher, particularly someone living without an autistic child, would have reached some different conclusions about the meaning of these parental experiences. They may also have probed or have asked different follow up questions, thus capturing slightly different data.

One limitation was that this was a small-scale study, and the findings are mostly biased towards the perspectives of mothers. The dominance of mothers reflects that they were the main carers and the difficulty of finding suitable participants able to commit to two phases of lengthy interviews. The dominance of mothers perspectives has been identified in the literature and studies have tried to include the perspectives of other family members (Johnson and Simpson, 2013; Preece, 2014). A further limitation was the focus upon the perspectives of parents only, seen through the conceptual framework at the microsystem level. Furthermore, the findings mostly relate to parents' interactions with their external environment at the mesosystem level, and what this indicates about attitudes towards autism. Overall, the parents in this group cannot be considered representative of all parents of children with autism and LD. Thus, findings cannot therefore be generalised beyond this group of parents. However, some of the parental' insights pinpoint areas of interest for further research.

Another constraint of this study was that parents were asked to recall their experiences, reflecting over a prolonged period, often more than ten years. The reliability of this data is inevitably dependent upon the accuracy of parent memory, which cannot be absolutely known. At times parents conveyed how their experiences had changed their outlook and ways of doing things, but again this was dependent on parent memory. A longitudinal study would have provided a more accurate view of these changes; however, this was impractical given the timeline for completing this PhD.

Another weakness was each parent confirmed their child's diagnosis of autism and LD, but this was not externally verified. Furthermore, in conducting the interviews it became increasingly evident, from how parents spoke of their children, that the range of abilities of the children was wider than I had anticipated. I had expected virtually all the children to have no or limited spoken language. An issue that emerged was that it was difficult to isolate findings, which could be applied across the full group of parents. However, some of the most interesting findings related to one or a few parents. In addition, the variations in the diagnostic labelling used by different authors across the literature for example '*severe autism*' (Besette Gorlin et al. 2016) made it challenging to situate my own research, in relation to other studies that have focused upon the lived experiences of parents of children with autism and LD.

6.3.8 Suggestions for future research

A future study could consider whether the emotional support of grandparents', as close relatives, might be a particularly effective source for buffering unsupportive attitudes.

Rather than relying on parental reflection, future research could use a longitudinal study to determine how parent experience might change over time. A greater balance between the voices of mothers and fathers should also be considered. A more homogenous group of parents of autistic children might be captured through using specific terminology, which might be meaningful to potential participants, for example '*severely autistic*' or '*autism with severe learning difficulties*'.

6.3.9 Concluding comments

In summary this study has illuminated the experiences of parents of children with autism and LD. It has highlighted how unsupportive attitudes continue to persist in society, but are often hidden. The conceptual framework and choice of methodology particularly helped to amplify parental experience of loss. Parental loss was also entwined and exacerbated by attitudes towards autism. The findings and recommendations seek to support improvements in acceptance and understanding of autism, creating a kinder and more inclusive society. A society tolerant of difference, supporting better health outcomes and happiness for autistic individuals and their families.

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8 APPENDICES

8.1 Appendix: 1 Application for Ethical Review

UNIVERSITY OF BIRMINGHAM APPLICATION FOR ETHICAL REVIEW

Who should use this form:

This form is to be completed by PIs or supervisors (for PGR student research) who have completed the University of Birmingham's Ethical Review of Research Self Assessment Form (SAF) and have decided that further ethical review and approval is required before the commencement of a given Research Project.

Please be aware that all new research projects undertaken by postgraduate research (PGR) students first registered as from 1st September 2008 will be subject to the University's Ethical Review Process. PGR students first registered before 1st September 2008 should refer to their Department/School/College for further advice.

Researchers in the following categories are to use this form:

1. The project is to be conducted by:
 - staff of the University of Birmingham; or
 - postgraduate research (PGR) students enrolled at the University of Birmingham (to be completed by the student's supervisor);
2. The project is to be conducted at the University of Birmingham by visiting researchers.

Students undertaking undergraduate projects and taught postgraduate (PGT) students should refer to their Department/School for advice.

NOTES:

- An electronic version of the completed form should be submitted to the Research Ethics Officer, at the following email address: aer-ethics@contacts.bham.ac.uk. Please **do not** submit paper copies.
- If, in any section, you find that you have insufficient space, or you wish to supply additional material not specifically requested by the form, please it in a separate file, clearly marked and attached to the submission email.

- If you have any queries about the form, please address them to the Research Ethics Team.

☒ **Before submitting, please tick this box to confirm that you have consulted and understood the following information and guidance and that you have taken it into account when completing your application:**

- The information and guidance provided on the University's ethics webpages
(<https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Ethical-Review-of-Research.aspx>)
- The University's Code of Practice for Research
http://www.as.bham.ac.uk/legislation/docs/COP_Research.pdf

UNIVERSITY OF BIRMINGHAM APPLICATION FOR ETHICAL REVIEW	OFFICE USE ONLY: Application No: Date Received:

1. TITLE OF PROJECT

What do family narratives reveal about parental perceptions of societal attitudes towards autism and how does this impact upon parents' ability to sustain caring for children with autism at home?

2. THIS PROJECT IS:

University of Birmingham Staff Research project ☐
 University of Birmingham Postgraduate Research (PGR) Student project ☒
 Other ☐ (Please specify):

3. INVESTIGATORS

a) PLEASE GIVE DETAILS OF THE PRINCIPAL INVESTIGATORS OR SUPERVISORS (FOR PGR STUDENT PROJECTS)

Name: T t e / frst name / fam v name	Dr Karen Guldberg
Highest qualification & position	Director of the Autism Centre for
School/Department	Research (ACER) at the School of
Telephone:	of Birmingham and Senior Lecturer in
Email address:	[REDACTED]

Name: T t e / frst name / fam v name	Dr Despina Papoudi
Highest qualification & position	Lecturer in Autism in the Department of
School/Department	Inclusion and Special Needs/DISN at the
Telephone:	Education. University of Birmingham
Email address:	[REDACTED]

b) PLEASE GIVE DETAILS OF ANY CO-INVESTIGATORS OR CO-SUPERVISORS (FOR PGR STUDENT PROJECTS)

Name: T t e / frst name / fam v name	
Highest qualification & position	
held:	
School/Department	
Telephone:	
Email address:	

c) In the case of PGR student projects, please give details of the student

Name of Course of study:	Lynda Smith	Student	
	Doctor of Philosophy degree in	Email address:	
Principal supervisor:	Dr Karen Guldberg		

Name of Course of study:		Student No:	
		Email address:	
Principal supervisor:			

4. ESTIMATED START Date: March 2017 **OF PROJECT**

ESTIMATED END OF Date: 2021 **PROJECT**

5. FUNDING

List the funding sources (including internal sources) and give the status of each source.

Funding Body	Approved/Pending /To be submitted
Not applicable self-funded	

If you are requesting a quick turnaround on your application, please explain the reasons below (including funding-related deadlines). You should be aware that whilst effort will be made in cases of genuine urgency, it will not always be possible for the Ethics Committees to meet such requests.

6. SUMMARY OF PROJECT

Describe the purpose, background rationale for the proposed project, as well as the hypotheses/research questions to be examined and expected outcomes. This description should be in everyday language that is free from jargon. Please explain any technical terms or discipline-specific phrases.

Purpose of this research:

To explore the everyday lived experiences of parents of children with autism and to develop greater understandings about attitudes in society towards autism.

Rationale:

The literature presents a mixed view of the everyday experiences of parents of children with autism. Many studies traditionally emphasise the stress and burden of parental caring, whilst other more recent studies have emerged focusing upon the strengths, positives and potential gains from parenting children with autism. However, my recent dissertation study for my MEd in autism (children) has helped to inform me of families who look like they are coping, but under closer scrutiny are at or near breaking point, often related to their child's behaviour. Sometimes parents are unable to continue to care for their son or daughter at home and a residential placement is sought, but often as a last resort (Tansley, 2013). However, in other instances parents seem to carry on, despite the many challenges. The focus of my PhD research is upon the ordinary, sometimes just about managing families, who continue to care for their children at home. The rationale for this research is the gap in the literature revealing a need for more understanding of in-depth parental experiences, in order to help explain what enables parents to sustain caring for children with autism at home. One aspect of trying to understand these experiences is exploring more about societal attitudes towards autism. Findings from a recent report, The Autism Dividend (Lemmi, Knapp and Ragan, 2017), make a recommendation for more UK based research to understand stigma and discrimination. This highlights the need for more understanding of attitudes and validates the focus of my research. However, my research will go further than this, exploring both the negative and positive aspects of attitudes towards autism. In addition, few studies have been conducted by researchers who are themselves parents of children with autism, thus sharing the same reality. As a parent of a child with autism and learning difficulties, I have first-hand experience of this reality, how my son's differences are not always obvious and understood by others. My own perspective and experience will add further depth to this research, whilst helping to interpret and make sense of the experiences of other parents.

Main research question:

What do family narratives reveal about parental perceptions of societal attitudes towards autism and how does this impact upon parents' ability to sustain caring for children with autism at home?

Sub questions:

1. What are parents' perceptions of the quality of the relationships/interactions that they have with individuals or service providers related to caring for their child with autism?
2. What do they feel these relationships/interactions reveal about attitudes towards autism?
3. How do these attitudes towards autism help or hinder parents' ability to care for their children?
4. What are parents' perceptions of attitudes towards autism from wider society, including the impact of how the media, films and TV portray individuals with autism? How does this impact upon families?
5. Do attitudes play a significant role in whether families can sustain caring for children with autism at home?

Expected outcomes:

I expect this research to make a contribution to knowledge and practice. It will add to the existing literature on the lived experiences of parents of children with autism. It will help to increase understandings of parents' experience of attitudes towards autism and how these might help or hinder their ability to care for their child with autism at home. Additionally, this research should make a practical contribution by providing valuable parental insights, which may inform and shape local autism strategy. It may also provide knowledge to professionals in close contact with parents, for example social workers. Understanding the effects of attitudes will provide professionals with better awareness of the social influences that can affect families of children with autism, both positively and negatively. This knowledge may help to identify potentially vulnerable families, with possibly weak social support networks and provide more focused support, enabling better outcomes for children with autism and their families. This research may also be of interest to other service providers such as, learning disability nurses, teachers, home to school transport and short breaks providers.

7. CONDUCT OF PROJECT

Please give a description of the research methodology that will be used

The method used for collecting data will be semi-structured interviews, in two phases. The interviews will be conducted with six parents of children with autism. These will be individual, face-to-face interviews, designed to collect in-depth and rich qualitative data about their experiences, through broad open-ended questions. As the interviewer I will be the instrument for collecting the data, which will be audio recorded. Interviews will take place at a time and place convenient to the participant. I will draw on my own experience as a fellow parent of a child with autism and learning difficulties and I will avoid conducting interviews too close to (what I expect to be) busy times and where there is increased pressure for families, for example just before the end of school term or beginning of the new school term school holidays. I anticipate that interviews will take place at the participants' home, in order to reduce the impact upon the participants' time and energy and hopefully where they will feel most at ease. However, some parents may feel that being interviewed at home is intrusive and so other suitable locations could be used, such as the child's school. The interviews will be conducted at separate times, with each lasting between 1 hour and 1 hour 30 minutes. I will be careful to keep within these times, out of respect for parents' precious time. For each phase I will use a prepared interview schedule (see Appendix 5). This will be piloted in advance with at least two individuals to ensure that the questions are clear and understandable. Changes will be made to the schedule as needed. In addition, to the audio recordings, handwritten notes will be made to take account of data undetectable on an audio recording, such as body language will be made during each interview.

In the first interview I will talk to parents to capture background information about their daily experiences of caring for their son or daughter with autism. I will then use the conceptual framework as a guide (see figure 1.) to help structure and identify individuals and organisations or service providers who are significant, provide support or services within the parent/child's world. I will ask the parent to identify two or three individuals or service providers and locate them on the blank conceptual framework (see figure 2.) for further discussion in the second interview. I want to find out about the quality of these relationships/interactions and what this reveals about attitudes towards autism. After the first interview I will transcribe the audio recording verbatim and write an account from the background information, which will aim to reflect the participants' story. This will be my interpretation of the participants' story and I will send the narrative to the participant for them to add further comments to and make any changes to. The participant will also have the opportunity to reflect on the interview and provide further information. Changes will be made to the narrative as needed until the participant is happy that it clearly reflects their experience. In this way each narrative will be co-constructed using the interpretations of the participant and

myself the researcher. The narrative accounts from the interviews will be analysed using narrative analysis. The data collected relating to the conceptual framework will also be transcribed. I will use this information to refine or revise questions for the second interview.

Parents will be contacted and arrangements made for a second interview. This interview will take place at a location of the participants' choice and audio recordings and shorthand written notes will be made. During this interview further opportunity will be given for the participant to reflect on the narrative account constructed from the first interview and any changes will be documented and made. This interview will then focus upon the two or three areas identified on the conceptual framework in the first interview. These might relate to a member of their extended family, the child's transport to school, a neighbour or complete strangers. However, it will be up to the individual parents to determine these. I will ask the parent to talk about the quality of these relationships/interactions and what they perceive to be the attitudes of the individual/organisation towards autism. I will seek to find out if this impacts positively or negatively on their daily lives of caring for their child with autism. Additionally, I will discuss parents' perceptions of attitudes towards autism from wider society. This will include how the media, films and TV portray individuals with autism and how this impacts upon their daily lives of caring for their child with autism. After the interviews I will transcribe the audio recordings verbatim. The transcripts will be analysed using Interpretative phenomenological analysis (IPA) and the data finally reduced to common themes. IPA is concerned with how people make sense of a major life experience; this can be negative or positive. It involves drawing on the individuals' reflections of why the experience is significant for the individual (Smith, Flowers and Larkin, 2009).

8. DOES THE PROJECT INVOLVE PARTICIPATION OF PEOPLE OTHER THAN THE RESEARCHERS AND SUPERVISORS?

Yes ☒ No ☐

Note: 'Participation' includes both active participation (such as when participants take part in an interview) and cases where participants take part in the study without their knowledge and consent at the time (for example, in crowd behaviour research).

If you have answered NO please go to Section 18. If you have answered YES to this question please complete all the following sections.

9. PARTICIPANTS AS THE SUBJECTS OF THE RESEARCH

Describe the number of participants and important characteristics (such as age, gender, location, affiliation, level of fitness, intellectual ability etc.). Specify any inclusion/exclusion criteria to be used.

The participants will be six parents with at least one child with a diagnosis of autism living in the SE of England. My preference is for parents who have a child with a dual diagnosis of autism and learning difficulties, typically with limited or no verbal communication. The rationale for focusing on this segment of autism, is that many existing autism studies have tended to focus upon autism in general or cases of individuals with high functioning autism, rather than specifically autism and learning difficulties. There is a gap in the literature and a need for more understanding of the in-depth experiences of parents of children with autism and learning difficulties. Additionally, this is my main area of interest, as I am a parent of a child with autism and learning difficulties. My own perspective and experience will also help to interpret and make sense of the experiences of other parents. Mothers or Fathers may qualify as participants, but they will need to be the primary caregiver of the child with autism. I deem this necessary as extensive daily experiences of interactions with others, whilst in the presence of their child, will be needed for there to be sufficient experiences for parents to draw upon easily. The diagnosis of autism for the child must have been in place for a minimum of two years. I judge this to be important as families of children with a recent diagnosis may still be coming to terms with a diagnosis. I need to safeguard as far as possible from adding additional pressure to families who may be going through a period of adjustment. The son or daughter must be residing at home with the family and must be attending school during the day. I expect this to be a special school or autism specific provision in the local area. As data in qualitative interviews is highly dependent on participants' willingness to talk, I will also aim to select participants who I perceive to be willing to talk openly about their experiences.

10. RECRUITMENT

Please state clearly how the participants will be identified, approached and recruited. Include any relationship between the investigator(s) and participant(s) (e.g. instructor-student).

Note: Attach a copy of any poster(s), advertisement(s) or letter(s) to be used for recruitment.

Finding appropriate parents to interview, who have a child with autism and learning difficulties and are willing to talk openly about the experiences is potentially difficult. I will therefore recruit participants for the interviews purposively through the network of parents already known to me. None of the parents would be personal friends, more acquaintances. Other parents will be recruited via a snow ball effect. I anticipate recruiting a mix of parents from the autism specific schools in the county. To find sufficient numbers, I consider it necessary to include parents from my child's school. However, as my child is in the upper/secondary part of the school, I will only recruit parents from the lower/primary part of the school, mitigating any potential conflict of interest. Parents will be contacted individually through email. This approach is intended to avoid putting pressure on parents who may not wish to participate. Parents will be provided with an information sheet (see Appendix 2). This will explain the purposes of the research, the process involved, why their participation is being requested, how their data will be used and an explanation of the potential risks from being involved in the research. Those who indicate their willingness to participate will be reminded of their right to withdraw from the study at any time. Measures to mitigate researcher objectivity are written into the research design of this project. In the first phase of interviews and data collection, parent narratives will be co-constructed by myself and the parent. I will interpret the parents' experience and write this into a narrative account, they will be asked to review this and make changes, so that it reflects their story. Further, the transcripts from the second interviews will be analysed using Interpretative phenomenological analysis (IPA). IPA uses a double hermeneutic to interpret individuals' lived experiences. In addition, throughout the process, I will keep a reflective diary, to record thoughts about the interview process and be aware of my impact on the interview process.

11. CONSENT

a) Describe the process that the investigator(s) will be using to obtain valid consent. If consent is not to be obtained explain why. If the participants are minors or for other reasons are not competent to consent, describe the proposed alternate source of consent, including any permission / information letter to be provided to the person(s) providing the consent.

Participants will be offered the opportunity to take part in the research, but they will not be pressured to do so. Voluntary informed consent will need to be secured via a signed consent form (see Appendix 3) from each participant before interviews can take place.

Note: Attach a copy of the Participant Information Sheet (if applicable), the Consent Form (if applicable), the content of any telephone script (if applicable) and any other material that will be used in the consent process.

b) Will the participants be deceived in any way about the purpose of the study? **Yes** ☐ **No** ☒

If yes, please describe the nature and extent of the deception involved. Include how and when the deception will be revealed, and who will administer this feedback.

Not applicable

12. PARTICIPANT FEEDBACK

Explain what feedback/ information will be provided to the participants after participation in the research. (For example, a more complete description of the purpose of the research, or access to the results of the research).

After the first interview participants will be provided with a written account of their individual story and given an opportunity to make changes or provide further information. A summary of the findings of the research will be provided at the end of the research project.

13. PARTICIPANT WITHDRAWAL

a) Describe how the participants will be informed of their right to withdraw from the project.

Information advising participants of their right to withdraw from the project will be provided in the consent form letter, which will be sent to each of the participants. They will be assured of their right to decline to answer any of the interview questions, without needing to offer a reason. Participants will also be assured of their right to withdraw from the study. However, there will be a deadline for this withdrawal of three weeks (in the first phase of the study) after they have received the written narrative account, thus providing opportunity for them to review the written narrative. Further, after the second interview (second phase of the study), there will be a deadline of three weeks, for withdrawal of data. In each phase of the study, after the respective three week deadlines, I will not be able to remove their data from the study. This will be clearly stated in the letter.

- b) Explain any consequences for the participant of withdrawing from the study and indicate what will be done with the participant's data if they withdraw.

If a participant withdraws from the study within the specified time, they will be assured that there will be no further collection of data, no further analysis of any data initially collected and any existing data from the records will be removed and destroyed. However, there would be obvious consequences to my research project. As families of children with autism live with considerable daily pressures, an unexpected event may make it difficult to continue to participate in the study. In anticipation of this, I propose including an additional participant in my study.

14. COMPENSATION

Will participants receive compensation for participation?

i) Financial

Yes ☐

No ☒

ii) Non-financial

Yes ☐

No ☒

If **Yes** to **either** i) or ii) above, please provide details.

If participants choose to withdraw, how will you deal with compensation?

Not applicable

15. CONFIDENTIALITY

a) Will all participants be anonymous?

Yes ☒ No ☐

b) Will all data be treated as confidential?

Yes ☒ No ☐

Note: Participants' identity/data will be confidential if an assigned ID code or number is used, but it will not be anonymous. Anonymous data cannot be traced back to an individual participant.

Describe the procedures to be used to ensure anonymity of participants and/or confidentiality of data both during the conduct of the research and in the release of its findings.

I will ensure the anonymity of all the participants, family members and any other individuals or organisations discussed by de-identifying their names in the transcripts and assigning appropriate pseudonyms. All written data will be kept confidential and securely kept in my home and all electronic data will be saved on to my computer and password protected.

If participant anonymity or confidentiality is not appropriate to this research project, explain, providing details of how all participants will be advised of the fact that data will not be anonymous or confidential.

Not applicable

16. STORAGE, ACCESS AND DISPOSAL OF DATA

Describe what research data will be stored, where, for what period of time, the measures that will be put in place to ensure security of the data, who will have access to the data, and the method and timing of disposal of the data.

Informed consent will be obtained in order to obtain, hold and use the personal data relating to each of the participants. In the event that a participant decides to withdraw from the study, data will be destroyed immediately. In order to comply with the legal requirements in relation to the storage and use of data as stated in the Data Protection Act (1998), all interview transcripts in both paper and electronic form will be kept securely in my home, either locked away or computer password protected. All memory sticks or electronic files will also be password protected and will not be erased or reused, but kept in their original form. I will have access to all the data and this will be made available only to my supervisors upon request. In line with University ethical guidelines all data will be kept for 10 years and then destroyed.

17. OTHER APPROVALS REQUIRED? e.g. Criminal Records Bureau (CRB) checks or NHS R&D approvals.

☐

YES

☒

NO

☐

NOT APPLICABLE

If yes, please specify.

I have investigated the requirement for a DBS check. I will be visiting parents in their own homes, where children may be present, however I will not be caring for or working with children or working in a school. The eligibility criteria indicate that I do not qualify for DBS. I am awaiting a formal confirmation and will take further action if

18. SIGNIFICANCE/BENEFITS

Outline the potential significance and/or benefits of the research

Contribution to knowledge

I expect this research to make a contribution to knowledge by building on the existing work in the literature on the lived experiences of parents of children with autism. It will help to increase understandings of parents' experience of attitudes towards autism and how these might help or hinder their ability to care for their child with autism at home. As a fellow parent of a child with autism sharing the same reality, I will be able to interpret these experiences with insider knowledge.

A voice for parents and contribution to practice

This research will also provide a voice for ordinary parents of children with autism to share their experiences, which they may find therapeutic. Furthermore, if outcomes are to be improved, parental views' as key stakeholders should be central to research. Taking account of these insights should be fundamental in raising public awareness of the needs of families, in shaping local autism policy and prioritising the provision of limited resources. This research may also be helpful for professionals working in close contact with parents, for example social workers. Comprehension of the effects of attitudes will provide professionals with better insights to recognise the social influences that can affect families of children with autism both positively and negatively. This may help to identify potentially vulnerable families, who perhaps have weak social support networks and provide more focused support, enabling better outcomes for children with autism and their families. This research may also be of interest to other service providers such as, learning disability nurses, teachers, home to school transport and short breaks providers.

19. RISKS

a) Outline any potential risks to **INDIVIDUALS**, including research staff, research participants, other individuals not involved in the research and the measures that will be taken to minimise any risks and the procedures to be adopted in the event of mishap

Risks to the research participants

The interviews will explore the participants in depth feelings about their experiences of living with their child with autism. There is the potential for this to trigger some emotional responses from the participants. Some parents may discover in the course of the interview that they have unresolved issues for example to do with coming to terms with their child's diagnosis. I have tried to mitigate this as far as possible by avoiding recruiting parents who are only recently post diagnosis. As a fellow parent of a child with autism I hope that I will be highly sensitive and have a heightened awareness of the upset and distress that may be caused from the nature of my interview questions. Since my own child's diagnosis, I can recall occasions whilst talking to others about my child that I have experienced an emotional response, which can sometimes feel quite unexpected. During the course of the interview, if I sense that a participant does not wish to be probed further on a particular question, I will be sensitive and move on to the next question. However, if a question triggers an emotional response I will take appropriate action including, pausing the interview and stopping the audio recording to give the parent time to calm down, moving on to another topic or stopping the interview completely. If aftercare is required by the parent, I will provide an appropriate contact for further support such as, The National Autistic Society Helpline or The National Parent Partnership. If I feel that a parent appears to be depressed or anxious, I will suggest that they consider talking to their GP. In addition, before the interview I will explain to the parent that I will be following the University's risk assessment eligibility guidelines. As such, if the parent discloses anything illegal or concerning, such as they or their child is at risk of abuse, I will have a duty to share this information with my supervisors.

Risks to the researcher

I will be visiting the participants in their own homes on my own. This carries a potential risk to my own physical safety. To mitigate this risk, I will advise my husband where I will be, I will have my mobile phone with me at all times and I will text him when I arrive and again when the interview has been completed. He will also be able to identify my location with the facility 'find my iPhone' as this will be enabled. I will travel to the interviews by car and expect the interviews to take place during the working day, whilst children are at school. In addition, my experience from conducting parent interviews for my MEd has informed me that listening to the experiences of others can be distressing, thought provoking and very emotional draining. This has the potential to affect my own emotional well-being. I will plan to conduct only one interview a day and provide myself time to rest, relax and reflect on the interview experience. On weeks when I have carried out one or more interviews, I will contact my supervisors by email. They will be available if any debriefing is needed.

- b) Outline any potential risks to **THE ENVIRONMENT and/or SOCIETY** and the measures that will be taken to minimise any risks and the procedures to be adopted in the event of mishap.

20. ARE THERE ANY OTHER ETHICAL ISSUES RAISED BY THE RESEARCH?

Yes ☐ No ☒

If yes, please specify

21. EXPERT REVIEWER/OPINION

You may be asked to nominate an expert reviewer for certain types of project, including those of an interventional nature or those involving significant risks. If you anticipate that this may apply to your work and you would like to nominate an expert reviewer at this stage, please provide details below.

Name
Contact details (including email address)
Brief explanation of reasons for nominating and/or nominee's suitability

22. CHECKLIST

Please mark if the study involves any of the following:

- Vulnerable groups, such as children and young people aged under 18 years, those with learning disability, or cognitive impairments ☐
- Research that induces or results in or causes anxiety, stress, pain or physical discomfort, or poses a risk of harm to participants (which is more than is expected from everyday life) ☐
- Risk to the personal safety of the researcher ☐
- Deception or research that is conducted without full and informed consent of the participants at the time study is carried out ☐
- Administration of a chemical agent or vaccines or other substances (including vitamins or food substances) to human participants. ☐
- Production and/or use of genetically modified plants or microbes ☐
- Results that may have an adverse impact on the environment or food safety ☐
- Results that may be used to develop chemical or biological weapons ☐

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

	ATTACHED	NOT APPLICABLE
Recruitment advertisement	☐	☒
Participant information sheet	☒	☐
Consent form	☒	☐
Questionnaire	☐	☒



23. DECLARATION BY APPLICANTS

I submit this application on the basis that the information it contains is confidential and will be used by the University of Birmingham for the purposes of ethical review and monitoring of the research project described herein, and to satisfy reporting requirements to regulatory bodies. The information will not be used for any other purpose without my prior consent.

I declare that:

- The information in this form together with any accompanying information is complete and correct to the best of my knowledge and belief and I take full responsibility for it.
- I undertake to abide by University Code of Practice for Research (http://www.as.bham.ac.uk/legislation/docs/COP_Research.pdf) alongside any other relevant professional bodies' codes of conduct and/or ethical guidelines.
- I will report any changes affecting the ethical aspects of the project to the University of Birmingham Research Ethics Officer.
- I will report any adverse or unforeseen events which occur to the relevant Ethics Committee via the University of Birmingham Research Ethics Officer.

Name of principal investigator/project

Date:

Please now save your completed form, print a copy for your records, and then email a copy to the Research Ethics Officer, at aer-ethics@contacts.bham.ac.uk. As noted above, please do not submit a paper copy.

8.2 Appendix: 2 Parent information sheet

Name of researcher: Lynda Smith

Title of research: What do family narratives reveal about parental perceptions of societal attitudes towards autism and how does this impact upon parents' ability to sustain caring for children with autism at home?

What is the purpose of the research?

This research is about the experiences of parents of children with autism. The research is to find out about the everyday lived experiences of parents of children with autism and to develop greater understandings about how attitudes in society towards autism impacts upon their lives.

Who is conducting out this research?

My name is Lynda Smith and I am a student carrying out this research in partial fulfilment of my PhD, under the supervision of Dr Karen Guldberg and Dr Despina Papoudi at the University of Birmingham. I am also the parent to my son with autism and learning difficulties.

Parent criteria for inclusion in the research

I am looking for parents who have a minimum of one child with a diagnosis of autism and learning difficulties. Your child's diagnosis must have been in place for a minimum of 2 years. You will need to be the primary caregiver and your child must be currently residing at home with you. Your child must be attending school; this is likely to be a special school or autism specific provision in the local area. You will need to be willing to talk openly about your experiences.

How will you be involved in the research?

I plan to meet with you for two interviews, where I will ask you to answer various questions about your experience as a parent of a child/children with autism. The information that I collect will be audio recorded. The interviews will each last between 1-1/2 hours and will be completed at a time and place convenient to you. I can travel to your home or wherever you feel most comfortable. After meeting you for the first interview, I will write up a narrative account of your experiences, which you will have an opportunity to comment on. At a later time, I will revisit you for a second interview to discuss aspects of the first interview in more depth.

Time required

[Approximately 1- 1 ½ hours]

Are there any benefits?

Sharing your unique experiences will provide valuable insights that will help to improve understandings of what it is like to parent a child/children with autism. Your insights may

also help to inform and shape local autism strategy and provide knowledge to professionals in close contact with parents.

Are there any risks?

The interviews are intended to be in-depth and will require you to talk about your own personal experiences of parenting your child/children with autism. It is possible that some of the questions may provoke difficult emotions. I will try to minimise this risk as the interview will be conducted sensitively and you can discuss with me any concerns. We can move on from any questions you would rather not talk about.

What will happen to the results of the research project?

You will have opportunities to comment upon my written narrative account from the first interview. At the end of the research I will also send you a summary of the whole study. The results of the study will be published in my thesis. However, please be assured that you and other family members will not be identifiable in the information that I keep.

Voluntary participation:

Participation in the study is voluntary and participants are free to withdraw. However, there is a deadline for withdrawal of your data. This will be three weeks after you have received the written account from the first interview. After the second interview, there will also be a deadline of three weeks, for withdrawal of data. In each phase of the study, after the respective three week deadlines, I will not be able to remove your data from the study. However, before this time, your data will be removed and destroyed and there will be no further data collection. There will be no other consequences for your withdrawal.

What about confidentiality?

The anonymity of all participants, family members and any other individuals or organisations will be assured by de-identifying their names in the transcripts and assigning appropriate pseudonyms. All the data collected will be stored securely. I will have access to the data and this will be made available to my supervisors upon request. The data will be disposed of in accordance with the University of Birmingham Ethical Review procedures.

My contact details:

Should you require any further information, please do not hesitate to contact me, using the details below:

Name of researcher: Lynda Smith

Email address:

Mobile number:

A grey rectangular box redacting the email address and mobile number of the researcher.

Supervisors contact details:

Dr Karen Guldberg

Director of the Autism Centre for Education and Research (ACER) at the School of Education, University of Birmingham and Senior Lecturer in Autism studies



Dr Despina Papoudi

Lecturer in Autism in the Department of Disability, Inclusion and Special Needs/DISN at the School of Education, University of Birmingham

**Support agencies:****The National Autistic Society**

Contact: autism.org.uk

Autism Helpline- 0808 800 4104

Lines are open 10am-4pm Monday-Thursday
and 9am-3pm on Fridays

Surrey SEND Information, Advice and Support Service (SSIASS)

Contact: ssiass@surreycc.gov.uk

Helpline by phone: 01737 737 300

8.3 Appendix: 3 Consent form for parents

Name of researcher: Lynda Smith

Title of research: What do family narratives reveal about parental perceptions of societal attitudes towards autism and how does this impact upon parents' ability to sustain caring for children with autism at home?

- I confirm that I have read and understood the information sheet for the above project and the researcher has answered any queries to my satisfaction.
- I consent to being audio recorded as part of the project.
- I understand that information that is audio recorded will remain confidential and no information that identifies me, family members, other individuals or organisations will be made publicly available.
- I consent to the use of direct quotations being used and included in the written report of the project.
- I understand that any direct quotations used in the written report will not identify me, family members, other individuals or organisations.
- I understand that my participation is voluntary and that I am free to withdraw from the project at any time, up to the specified deadline, without giving a reason and without any consequences. After this time, I understand that my data will not be removed from the study. Before this time, my data will be removed and destroyed and there will be no further data collection. There will be no other consequences for your withdrawal.

Agreement:

I consent to being a participant in the research study as described above and I agree to the conditions:

Print Name:

Signature of Participant:

Date:

8.4 Appendix 4: Child profile information

Profile information

Name of parent

.....

Name of child

.....

Diagnosis

.....

Age at Diagnosis

.....

Siblings with/without diagnosis

.....

.....

.....

Type of school

.....

Means of communication

.....

.....

.....

8.5 Appendix 5: First Interview schedule

Name of parent:.....

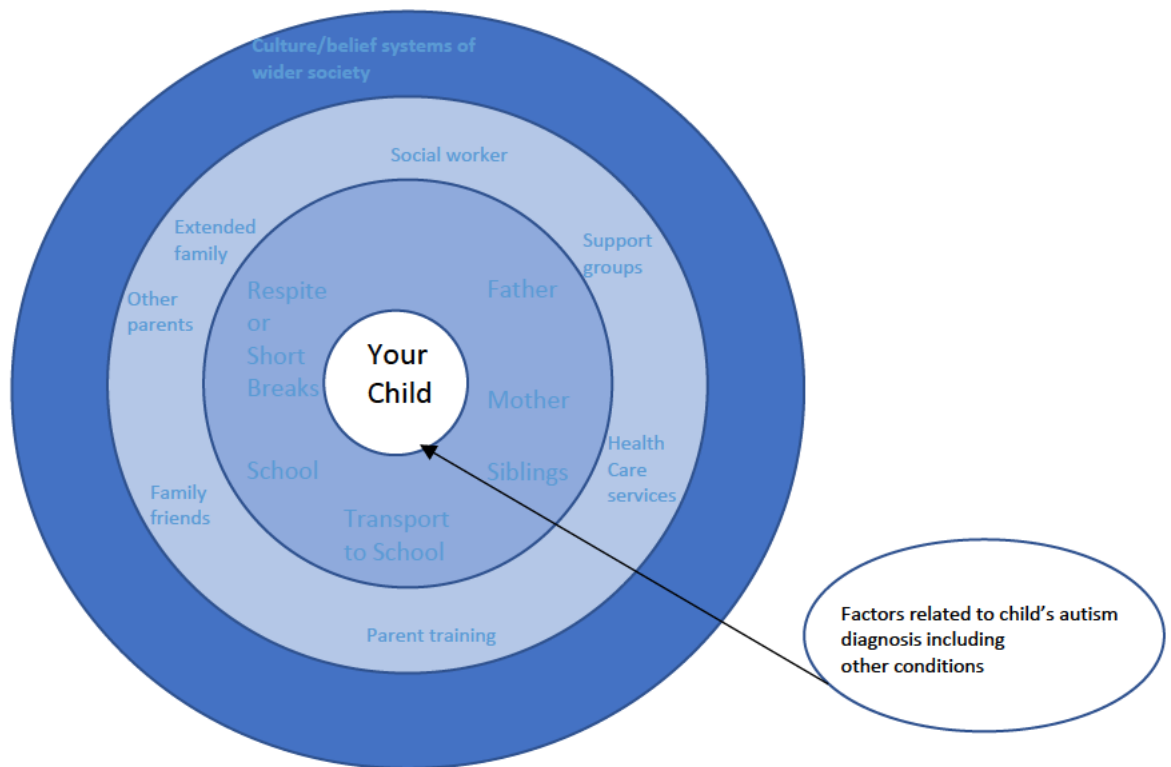
Name of child/children:

Part 1a- The background to your child/children

1. Tell me who is in your immediate family?
2. Tell me about your child, when did you first have concerns?
3. Tell me about their diagnosis, any secondary diagnosis or other factors?
[restricted diet, sleep difficulties, behavioural routines]
4. Tell me about the early days, post diagnosis/finding a suitable school?

Part 1b- The present time

5. Tell me about where your child goes to school?
6. Tell me what a typical school day looks like for you and your child?
Tell me what a typical non-school day looks like for your child?
7. Tell me about their personality - likes/dislikes strengths/interests/difficulties?
8. Are there difficulties that make family life challenging?
9. Tell me about what is it like when you take your child out into the
community/outside home/visiting friends/family? [specific examples]
10. Tell me about any support/respite that you access?
11. Anything else?



Conceptual framework

Part 2- Conceptual framework

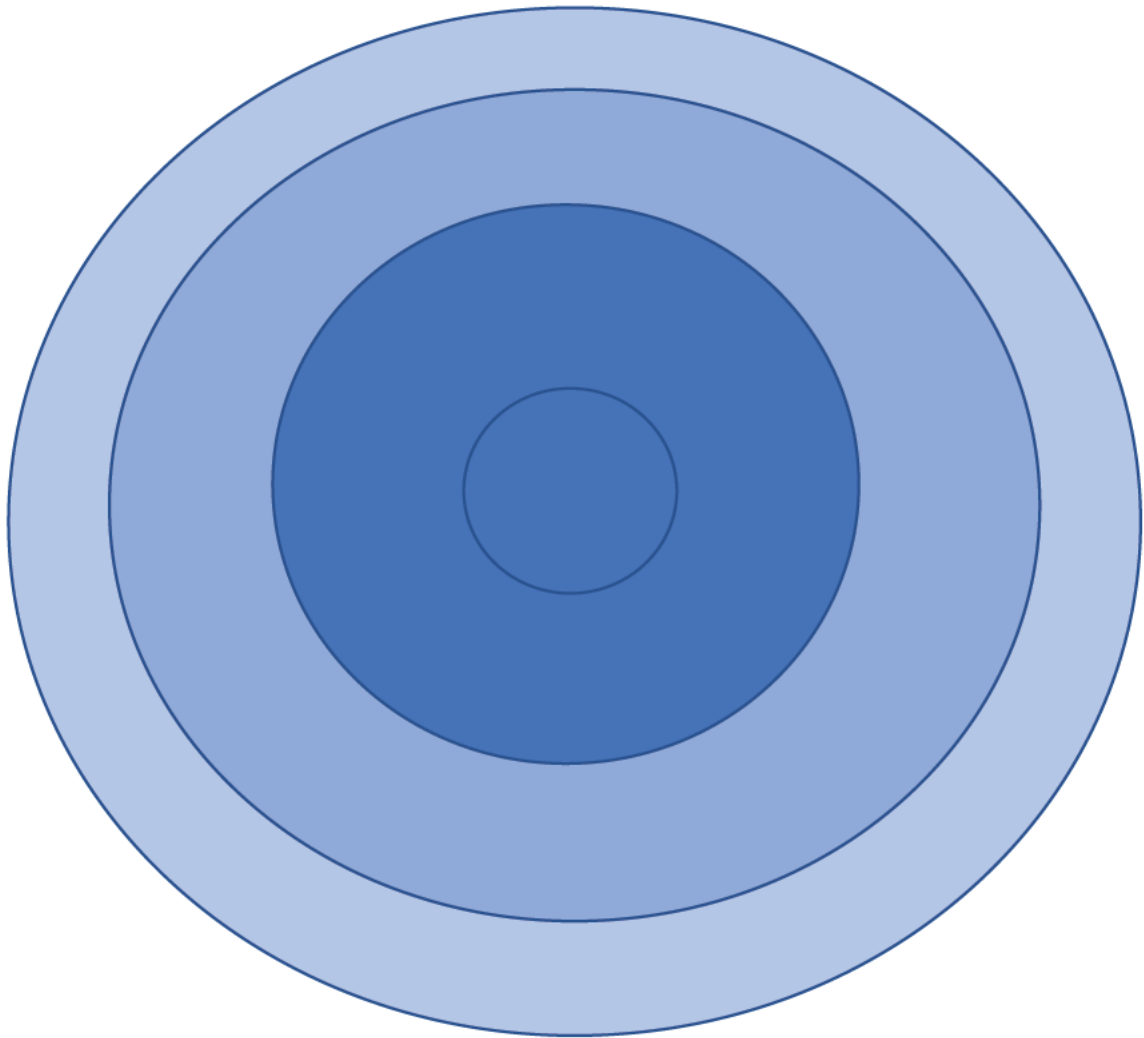
I will explain the conceptual framework and use this as a structure to explore attitudes towards autism

1. Using the blank framework (see Appendix 6)
 - A) Ask the parent to identify people/service providers relevant to themselves and their child.
 - B) locate them on the framework

[most significant/those you have most contact with in the inner concentric circles]
 [prompt] Transport to school, school, play scheme, short-break, social worker, friends, extended family, neighbours, strangers
2. Colour code them, in terms of the quality of the interaction/relationship [Green for supportive] [Red for unsupportive] [Amber for neutral]

3. Are there people, including family members and friends or service providers who would have appeared, but are now absent. Explain why you might not see them anymore or might not use their services.
4. Choose 2 or 3 people, including family members and friends, organisations or service providers that can be discussed further in the second interview. **This might also include those who are absent.**

8.6 Appendix 6: Copy of blank framework used in interviews



8.7 Appendix 7: Reflections from first interviews

Helen and Charles

I am apprehensive about doing this interview. Not only is it the first one, but also interviewing a couple was not really in my original plan. The fact that H doesn't want to be interviewed alone concerns me somewhat and I wonder whether I will find having C present intimidating. I met him a couple of times years ago on a parent training course and didn't warm to him too much. I am also concerned about whether they will find my research relevant to them and worthwhile.

The interview went well much better than expected. Instead of finding the husband-and-wife team intimidating I found it useful and worthwhile having both to contribute to the interview. I appreciate the contribution that they both made. Often one would start of saying something and the other would fill in useful gaps about their shared experience. I had been a little apprehensive about whether they would find the research topic relevant, but I need not have worried, I came away feeling that it was totally relevant. There were times in the interview when I found myself talking too much, trying to offer empathy that I could understand their situation, that I had had similar experiences of my own. I felt there were times when H almost felt embarrassed about admitting something and I was keen to assure her that she was not alone. However, in doing so I couldn't decide if I had talked about my own son's autism too much.

Jayne

I have interviewed Jayne before so had a good idea of what to expect. This interview in many ways feels like an opportunity to develop in greater depth some of the subject material that has been touched on before. This interview was interesting as I hadn't realised the journey that they had been on to get their 2nd child's diagnosis. I hadn't realised that they felt he should have been diagnosed from such a young age, but their early concerns had been dismissed by professionals. There was one aspect of the interview when J got quite tearful when describing the time when her niece died and how the timing was linked to the diagnosis of her 1st son. With hindsight I felt I had probed too much and wished I had not. It was revealing how raw the emotions still were about the death of her niece even though this was not a recent event. I don't think J was overly concerned that the discussion had led in this direction. I think she thought it was only to be expected that there might be tears and strong emotions, it was all about being honest about the situation

Ella

I have only met Ella once and don't exactly know what to expect. She has triplets, so there is already hopefully an element of empathy as I have twins. It was initially difficult to remember the names of the 3 boys and their individualisms. After a while this became more comfortable as I began to build up individual profiles in my mind. Ella was a joy to listen to, her stories were funny and could break your heart at the same time and I found myself almost in tears, which I found rather unexpected. I think I could really empathise with her

situation, as far as anyone can, but it did stir genuine emotions in me. Again, the research topic felt really relevant, and it was easy to get her to decide on topics for discussion in the 2nd interview

Diana

In one sense I expected this interview to be straightforward. I've interviewed D before about one of her children, this time it would be both, but I had some background already, including that S was thought to have PDA. Not knowing much about PDA, I had spent some time reading about it, so at least I could avoid asking the wrong questions. This interview is a perfect example of expect the unexpected. Firstly, I was absolutely on time and wished I'd been a bit later as D wasn't back from work and D's husband who answered the door looked a little surprised that I was coming. However, D soon arrived home, but then D's mother arrived. Although it was expected that she would not sit in on the interview, which I made clear that I was recording, she sat through the entire interview, making contributions here and there. This made the interview which should have been between D and I tricky to manage and keep in track, though I did the best I could to do this whilst trying to remain polite. This interview was also an important lesson in terms bring clear about communicating the point of the conceptual framework. D instantly thought she'd done this before with the social worker and that the framework referred to 'ring of support'. So, I felt the need to ensure full understanding and explained that it went further than support and was a framework for looking at the interactions between herself and her children and the outside world and therefore the quality of the relationships. However, I think perhaps this was interpreted slightly differently from what I had intended. So, I took this as a caution and in subsequent interviews tried to be as clear as possible about its purpose.

Ana

This was the only interview where I hadn't previously met the parent. It was difficult to know what to expect, but I didn't expect to conduct an interview in a room with so much chaos, due to building work being carried out. This ended up being an interesting interview, though not knowing the family I struggled at times to make sense of all the family members. I thought A just had 2 children, but then there were mentions of other siblings and it was immediately clear that they were in fact half brothers and sisters. M was also one of the most able children of the families I have interviewed. He is very verbal, whilst other children in other families have virtually no speech and are not fully continent. This made me realised that the term autism and learning difficulties is a catch all term. Maybe I should have been more specific and focused on children with the highest levels of need? However, this would have restricted the families who would have fulfilled my criteria. So, maybe a wider interpretation of the term was just as well. The term foster carer was also used to refer to a carer and the term foster was confusing, and I needed to clarify this. I also felt at least initially that perhaps A was not able be fully open with me. She seemed to relax as the interview progressed, as she realised, I too had encountered similar experiences. It may have been in my imagination, but her face seemed to visibly soften the further the interview progressed. With hindsight and listening to the transcript this interview seemed to go better

than I felt during it, if that makes any sense. I certainly felt that A had lots she would be willing to share with me in a second interview on attitudes towards autism.

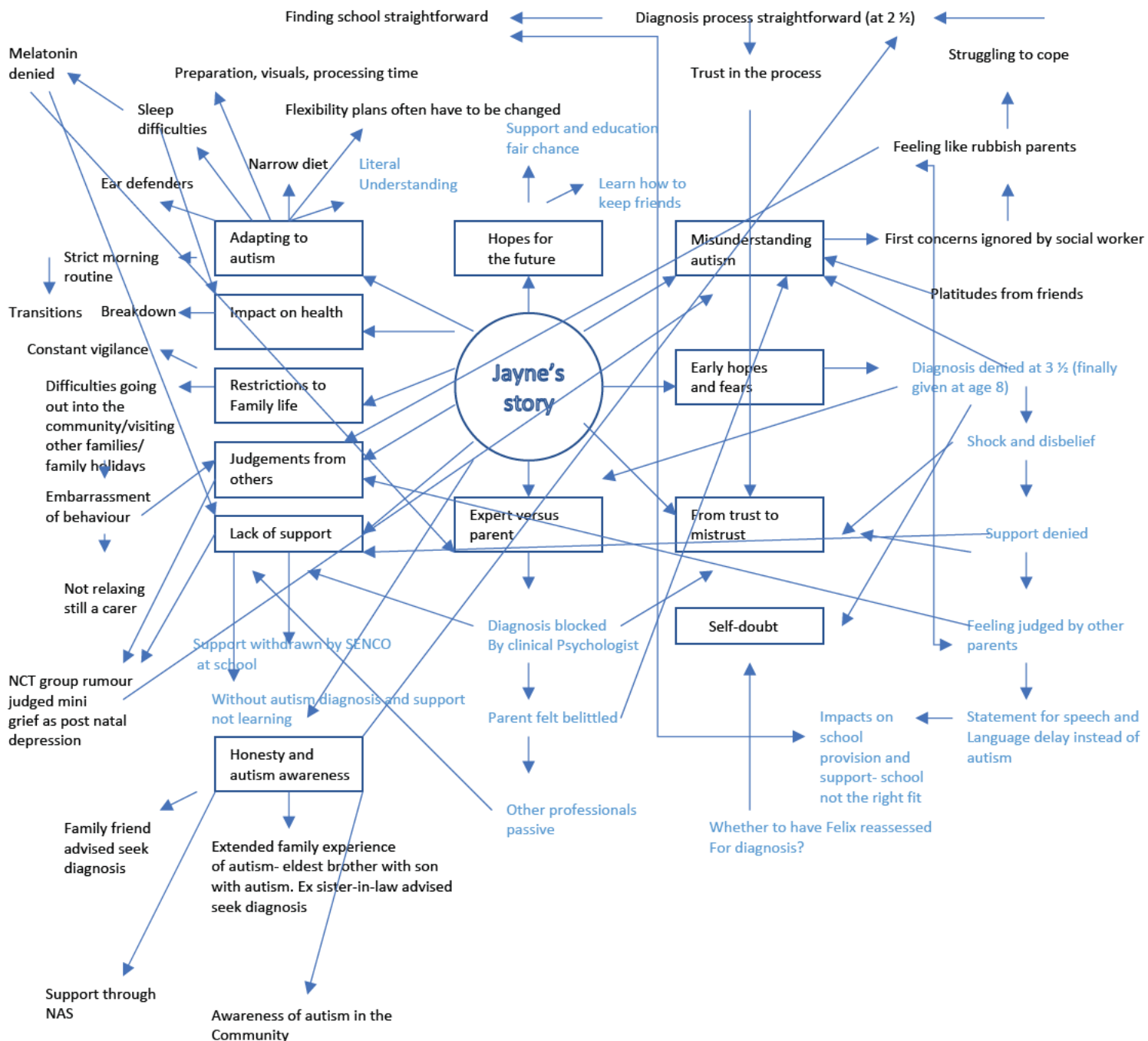
Iona

I don't know her all that well. I've only met her I think twice and so I was slightly apprehensive about how this would go. I know that G has TS as well as autism and so I read a little about TS so I would have some background at least. This interview ended up being one of the most interesting ones to me. Lots of fascinating insights were shared. Iona is French and was able to make comparisons of her experience of being with G here in the U.K and contrast this with France, sharing that it was her experience that in the U.K we are far more accepting and tolerant. As the interview progressed, I sensed that the opportunity to talk about G and the many years of caring for him was quite therapeutic and I thought that her face softened. I think that this will be a fascinating story to write up and tell and I will have plenty more to share in terms of talking about attitudes to autism in a second interview.

Becky

This was the final interview. I was initially a little unsure about this one, as J is described as having M learning difficulties and was clearly more able than most of the other children in my study. I also wondered how relevant B would find my study. However, this proved to be a fascinating interview and I couldn't have been further away from my initial reservations and B was willing to provide as much information as possible and I was pleased to include this one. I think B found it a therapeutic opportunity to think back over her experience of living with J, from pre-diagnosis to the present time. Clearly B had felt judged about her son on so many occasions and I was so absorbed in the story and felt for B that I wasn't far from tears. I think B will have lots of share in terms of attitudes towards autism in the second phase.

8.8 Appendix 8: Example of mind mapping from Jayne's narrative



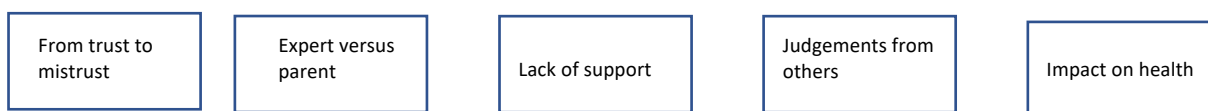
8.9 Appendix 9: Example of structure used for writing Jayne's parent narrative, including individual emerging themes

Introduction

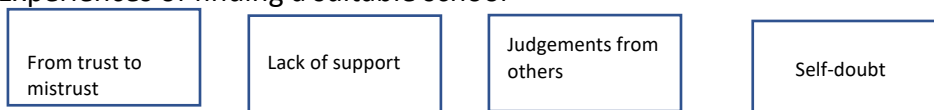
Part 1a - Early days/pre diagnosis



Part 1b -Experiences of diagnosis and beyond



Experiences of finding a suitable school



Part 1c-The present time

Experiences of a typical school day and non-school day



Experiences outside the home/difficulties that make life challenging



Part 1d - Anything else



8.10 Appendix 10: Co-constructed parent stories

8.10.1 Diana's narrative

Introduction

Diana is the mother to both a **daughter and a son with autism. Zara her daughter is 13 years old, she was diagnosed at two years old with classic autism.** In the early days, Zara was considered to be 'low functioning', but has made substantial progress moving across the school system. Zara started at a school for children with severe learning difficulties (SLD), but now attends an autism specific school for girls. **Sam her son is 11 years old, he was diagnosed at three years old with autism and also has learning difficulties.** Sam started school in mainstream provision, but now attends an autism specific school. Additionally, at seven years old, **Sam received a diagnosis of severe anxiety disorder and his autism diagnosis was clarified to include demand avoidance features.** Written in the first person, Diana's story describes two very different experiences of living with her children, going through the diagnosis process and navigating the education system. Her story describes the positive support that she has received for her daughter and subsequent progress made, contrasted with the battles that she has endured to have her son's autism recognised and supported with suitable schooling. Diana touches upon the day-to-day challenges of parenting two children with autism with very differing needs. Diana also explains how recent budget cuts have impacted upon school overnight provision.

In the beginning I didn't really have any concerns about Zara. She was my first child and I just thought she was going through the 'terrible twos'. However, Zara had started at a little pre-school group and the staff were really struggling with her. At this stage, I couldn't understand what was going on, as I didn't know anything about autism. My extended family were also concerned about Zara, but at this time they didn't voice these concerns. It was only when I visited the health visitor for Zara's two-year check-up, that she looked at Zara and explained that she would make a referral to the clinic. I didn't understand what the issue was.

When we finally had an appointment with the Paediatrician, Zara was pretty much diagnosed straight away with autism. We had a triage meeting and I was given information about autism. It was like reading the book about Zara, everything matched what she was doing, she was literally doing everything. Zara was lucky because support was put in place straightaway and I think this helped. She was placed at an autism assessment nursery and got lots of support. The Speech and Language Therapist (SALT) also made regular visits to our home and taught me how to use the Picture exchange communication system (PECS) with Zara. I could see the progress straightaway and this was very motivating for me. I did my best to learn as much as possible and I attended parent training programmes, such as EarlyBird to help support Zara. I could see that she was reaping the rewards from all the support, early intervention really worked. It's always been the case that if you ask Zara to do something correctly, she will do it.

During the time that Zara was at the autism assessment nursery we started to think about schools for Zara. Oak Ridge school, which was attached to the autism nursery, was about to add autism specific classes to its provision. I was always led to believe that these classes would be on a level equivalent to the other autism specific schools in the county. The school was also 'on our doorstep' so we decided to make a preference for Zara to start at Oak Ridge school in the September. We also looked at two other autism specific schools in the area. I didn't like one of the schools and maybe this was telling. Waterford school, was the other school and had a history of taking more-able kids with autism. It immediately felt right, but we made it our second choice because it was some distance from our home. Zara started at Oak Ridge and she just flew, it was the right provision. Progress was such that when Zara was in year 3 at school, my sister (who is a teacher) gave me some SATs papers for her to complete. My sister scored the papers and Zara was achieving level ones and twos. Zara had become too able for her school and it was time for her to move on. Ironically, the head teacher didn't believe that Zara could possibly be capable at the time of achieving these SATs levels. However, Zara's class teacher believed it to be true and it was eventually deemed appropriate for her to move school. She secured a place at Waterford school, for more-able pupils. At the beginning of year 6, Zara also began to board for two nights per week.

Zara continued to progress and eventually also became too able for Waterford school. She moved again to her current provision, Westwood School. This a more academic school for girls with autism. She is doing really well and I don't have any worries, she's happy and she's learning. Zara has a natural thirst for knowledge, so if you teach her in an autistic way she will learn. She is now incredibly verbal and in order to keep on task with her work, all she needs is a list. Her academic levels are increasing rapidly and when the school identify an issue they work to support it. At the moment I'd still say that Zara has a learning disability, but by the time of her GCSE year she may have outgrown this. As the school is a long distance from home, Zara boards for two nights per week. This is soon to increase to four nights per week.

In comparison to Zara, When Sam was born everyone thought that he was very sociable. However, my mother disagreed. I recall thinking that I would stop worrying about Sam when he started to point, but this didn't happen. Consequently, I started to raise my concerns with the health visitor, who acknowledged the matter and made a referral for Sam to be seen by the Paediatrician. However, the Paediatrician did not think that there was an issue with Sam and conversely suggested that there was an element of copied behaviour. Sam was kept under review by the Paediatrician, but after subsequent appointments, a diagnosis was still felt to inappropriate. Sam started to attend a preschool, attached to the local infant school. As part of the on-going review process the SALT visited to observe Sam. After her visit, she called me to explain that she felt she could see some issues. Observing Sam in a setting away from Zara, it was impossible to conclude that this was copied behaviour. As a result, we had a meeting to reassess whether a diagnosis was appropriate for Sam. Staff from the preschool were very supportive and also attended. At the meeting we went through all the criteria for a diagnosis of autism and Sam pretty much ticked every area and was accordingly diagnosed

with autism. I had already attended all the autism parent training courses for Zara, so there seemed no point doing it all again. However, second time around with Sam, I recall feeling more isolated and a little more out on a limb.

In the early days, all the professionals thought that Sam would benefit from attending mainstream school. It was felt that Sam needed to be at school around positive role models. Zara was attending a school alongside children with severe learning difficulties (SLD) and was deemed to be a poor role model for Sam. Looking back, I don't feel that this was the priority, Sam needed more nurturing, more care and more support. Accordingly, when he attended mainstream pre-school provision, he would come home distraught or upset or didn't want to go. Sam was also allocated two afternoons a week at the same autism assessment nursery that Zara had attended and by contrast he was noticeably happy there. For this reason, I wanted Sam to go to a special school. At this time, Zara was still attending Oak Ridge school and I was focused on trying to secure a place there for Sam too. However, the head teacher considered Sam was too cognitively able and thought it was the wrong school for him. The Educational Psychologist also had a similar viewpoint and recommended that he should go to a unit attached to a mainstream school. In this area, once an Educational Psychologist has made a recommendation, you can't fight back and it becomes written into the statement of educational needs. At the time she was the expert and she deemed Zara's needs to be more severe than Sam's. However, she certainly didn't know Sam. Ironically, sometime later the head teacher of Oak Ridge school also didn't accept that Zara was too able for the school.

I went to visit Sam's proposed school and I recall even at this time, that it didn't feel right. I was also worried that Sam was going to escape. Consequently, I managed to fight and get the LA to provide Sam with one-to-one support. Unfortunately, this was not enough, they used all the wrong strategies with him such as, 'time out' and the teachers used to shout a lot. It just really upset him, it was just all wrong. However, there was no way that I was going to be able to fight my case in a tribunal, I knew that I was up against a losing battle. With the benefit of hindsight, I think I was having the wrong battle, I wish I had fought harder for Sam to get a place at one of the other two local autism specific schools.

To be honest I think Sam's early experiences of school have harmed him. Sam is still traumatised by the experience of the infant school with the unit, he was controlled by fear. He still talks negatively about it and he still can't drive past the school. We had to write a social story, because I think some of his current behaviour is linked to what happened at the school. By the time he moved to the unit attached to the middle school, he had been diagnosed with severe anxiety disorder. Sadly, there was no documented evidence via school to get him placed anywhere else. I would describe this time as a very bitter battle with the LA. It took a whole year to move Sam from this school to Waterford school, his current autism specific provision. By Christmas, I had already called for an emergency annual review, which the LA didn't even bother to attend. Sam was presenting with extremely challenging behaviour at school. He was at risk, as were the other children and adults in the unit. As a result, Sam was frequently out of school. He didn't attend every Wednesday and the school would call me at least once or twice a week, to ask me to collect him. I believed this to be an illegal exclusion, but the school insisted that they couldn't guarantee his safety.

We had a further emergency annual review and this time we managed to get the Area Special Needs Manager to attend. It was agreed that Sam would be placed at Waterford school for the beginning of year 4. Just after this meeting when I was about to leave, the school staff advised me that Sam was not having a good day and I was asked to come and calm him down. I went into the unit and Sam had pulled a fire extinguisher off the wall and he was throwing it around at both adults and children. As the Area Special Needs Manager was still there at the time, he was fully aware of these behaviours. However, the nature of Sam's behaviour was not communicated to his new school. When he started, he was automatically placed him in a class of ten pupils. By the beginning of December that year, the school explained that they couldn't cope with him. It was too dangerous for him and the other students and staff. Sam was taken out of school and stayed at home all over Christmas. I don't hold the school responsible for what happened, I hold the LA responsible, particularly the Area Special Needs Manager. He knew of Sam's behaviour and Sam had been left to fail again...

With Sam was out of school, I remember that the Social Worker was pretty supportive. She organised for Sam to go to a local respite centre for a couple of hours in the day, when no other children were there. I thought for a Social Worker this was pretty good. Meanwhile, the head teacher of Waterford school improved security around the school and she explained that support would be put in place for Sam to return to school in the January. He wouldn't go back in class, but he would have a room on his own. One day after Sam returned to school, the head teacher sat with Sam and played with him. She explained to me that she had been able to successfully engage with him through play. He spent the rest of the year out of the classroom in his own room, with at least one to one support. The effects of Sam being sent home from his previous school continued. He kept pushing to see what it would take, before Waterford school would send him home. Even today, he still thinks his school will send him home if he behaves really poorly. Sam is now back in a class of other pupils, but he still goes out of the class a lot too, into a quiet room and he has his own individualised timetable.

The school use milestones to measure learning. Sam is now in year 6 and his school consider that he is equivalent to reception or year 1, so there is definitely an issue with accessing learning. Although he is verbal and he can read, there is certainly a learning difficulty. At home I often write down the words for him on a white board, as he is visual. He also responds to structure and social stories. Sam has struggled a lot this year, as just before Christmas his class teacher was signed off sick, causing a bit of upheaval. Sam can't cope with any change whatsoever and his school now recognise that this is difficult for him and have tried to manage the situation as well as possible. By March, they had found a new teacher, but only for two days a week. On account of this, the assistant head stepped in to cover the remaining days. His teacher returned to work again, but was off sick once more. At this time, Sam began to think that this was his fault, as he had been violent towards her. I don't think this was actually the case. I think his anxiety presents in such a way, that he always feels that everything is his fault. The school have come to realise the importance of working together as a team and having a consistent approach and having complete honesty. For example, Sam had been incredibly violent at school, so we told him there would be

consequence of this behaviour and he wouldn't be able to have his Xbox at night. After about a month, this started to work.

When Sam was younger he acted autistic and his school would comment that he was quite reserved. However, we didn't see this reserved behaviour at home and it became clear that there was different behaviour at school. As Sam has got older, it has become more obvious that he is demand avoidant. After he started at Waterford school, I talked to the head teacher about the possibility of Sam having Pathological Demand Avoidance (PDA). She agreed that it was very likely, but explained that he wouldn't be able to get a diagnosis. However, with my knowledge and the school on board it has made a difference knowing how to tackle Sam.

Over the years there have been many other challenges, but one in particular has been the children sleeping and how they have impacted each other. In the early days, we were so frightened of Zara waking up in the night. If she woke up, she'd be awake for hours. For this reason, Sam learnt from quite a young age that he would get attention from us if he made a lot of noise at night. Eventually, we started to give Zara Melatonin at night and this got her into a good sleep cycle. These days she's pretty good at sleeping and doesn't often need any Melatonin to help her sleep. I only give it to her if we are away in the caravan and she's keeping everyone awake with her talking. At home, I often hear her in her room late at night and she's talking to herself. She has explained to me that she just doesn't get tired. If she wakes up in the night, I know she will just talk to herself, which is ok as long as she is not too loud. I don't have to worry anymore that she is going to walk out of the house. By contrast, Sam still can't sleep without Melatonin and he also takes a sedating antihistamine. At the moment his medication is stable and we are in a good sleep cycle.

If I think about a typical morning when both my children are at home. Zara has to get up very early, as the taxi arrives to collect her at 7.20am. It's just a question of keeping her on task to get her out of the door on time, as she can dress independently. After Zara has left the house, I am free to wake Sam up and I give him breakfast and his medication for his anxiety. On a school day Sam does not dress independently and he refuses to wear school uniform. It's about resetting expectations and accepting this, you pick your battles and this one can wait. I have to keep things as calm as possible, until his taxi arrives at 8.15am. Towards the end of the week, I find that he tends to be calmer about getting in his taxi. Even so, I still find that I need to use strategies, including some low level Management of Actual or Potential Aggression (MAPA). When Sam is in the taxi, I also have to hold the door closed until the driver is able to lock the doors and then he'll go off to school. Sam returns home at about 4pm and is usually fairly calm. He likes to play on his Xbox, but he'll get upset about being told to come off it. Sam understands that Zara sometimes boards at school, as she has now been doing this for three years. However, he idolises her and misses her when she is not around. Zara is back at about 4.25pm on the days that she does come home. She's a bit of a butterfly at school, so by the time she gets home she has done all of her socialization. She is more aloof around Sam and just wants to be on her own and play on her computer for an hour or do homework. Whereas, Sam doesn't socialise much at school. He cuts himself off from the other children, so he wants to be with her. There can be a conflict, as sometimes

she rejects him and this upsets him. For example, on Friday night he was annoying her, he was just being a younger brother and she hit him.

On a non-school day, Zara likes to spend a lot of time in her room. She's very technically minded, interested in computing, the Xbox and also likes music. These days she is open to trying new things. Zara now goes to Guides, it's nice that she is able to do a mainstream activity. She also likes to go to the cinema, we can take her out to dinner and she loves to try lots of different types of food. Whilst she might say afterwards that she didn't enjoy it, she'll at least now try it. In the early days, diet was a really big challenge for Zara. She was a really, really fussy eater and wouldn't eat anything. However, the special schools that she has attended, have always been very supportive and tried to extend her range of foods. She's no longer scared of new food and it's amazing how much she has progressed. There are some things that Zara is still rigid about. For example, she will insist on sitting on the right hand side of the car. In addition, sometimes she will insist that she can't do things because she is autistic. She will try to use her disability as an excuse, or she will explain that she can't do things because she has got Obsessive Compulsive Disorder (OCD). I have to remind her that she hasn't been diagnosed with OCD and is just being lazy, at the moment this is the biggest joke. Zara has also become quite obsessive about what a diagnosis means and will ask me why she just has autism?

I think the biggest issue that we have are the differences between Zara and Sam. This presents lots of challenges to our family life. Sam differs from Zara because he is very closed to trying new things. He likes to know what we are doing and wants to be in control of it. There is also a difference of ability between them and they therefore won't agree on the activity. Likewise, Sam can't cope with doing as many things as Zara can. Thereby, we have to bring everything down to his level, which frustrates Zara. Sam struggles to cope with loud noises and can't cope with going to the cinema and so I thought ear defenders might help him. However, Zara told me about a girl from her school who also can't cope with the cinema. She explained that it kind of overwhelms the senses, the screen is too big, it's too loud, it's too bright. This might explain why Sam doesn't like going. However, Sam is unable to voice why he can't cope and it takes a more verbal autistic child to explain this. Furthermore, Zara likes to go clothes shopping, but Sam can't cope because it's loud and presents similar sensory challenges as the cinema. Sam likes to be outside and still loves going to the park, however Zara generally feels she is too old to go to the park. I find that Sam is much calmer in the summer when he can get outside more, though he won't go outside in bad weather and will just stay inside. Sam loves theme parks and roller coaster rides. Unfortunately, when we took him to Disney he couldn't cope, as a lot of the rides were inside and acoustically they sounded very different. Furthermore, Sam used to go to a local play scheme. However, they rebuilt the play centre and the new building is now very noisy and very small. Whilst previously, there had been lots of smaller rooms, now there isn't any respite from the noise and that's why we won't go. He's been put off being left anywhere and he's become overly attached to me, because he is anxious.

Sam likes swimming and is good at it. However, on a recent holiday abroad he didn't want to spend very much time in the swimming pool. When I reflected back to try to understand why

this might be, I realised that the pool was busy and it didn't have any slides or anything else fun. For Sam it was a boring pool and it wasn't motivating him to go and use it. I think this explains why he was withdrawing and spending a lot of time in the apartment. He wasn't happy at the beach either, because his eczema was bothering him and of course that caused problems because Zara wanted to go scuba diving and snorkelling. With anything we do, we've got to analyse where the difficulty is going to be and what support is going to be needed. For example, at the weekend we had a family party and we knew that Sam wouldn't be able to cope with much of it, so we took our carer. This enabled Sam to dip in and out of the party. However, sometimes we just have to decide not to take Sam. All too often, we end up splitting the family and doing completely different things.

Reflecting back, Zara has received more early support and intervention than her brother. The LA have pretty much given me everything I've asked for. Zara has responded well to learning and has continued to make significant progress. Waterford school have always promoted independence and so even before moving to her current school, Zara benefitted from the opportunity to board at school. As an existing boarder, even with current budget cuts, her boarding provision has been protected. Looking to the future, I expect that she will take GCSE's and in the end achieve full independent living. Conversely, I have had nothing but fights with the LA over Sam's education and I always felt that Sam has suffered. He hasn't always attended a special school and did not have the same early intervention as his sister. Sam remains the one with the more lingering issues. He is now of the age when Waterford school would have previously offered over-night boarding. However, the budget cuts have affected provision and the school has reduced the number of beds that they can offer. I also think the school are aware that if Sam would need extra support to board. Without doubt, the school offers more to those students who are more-able and can access facilities easier. Even so, I don't think it's fair that the less-able don't always get the same opportunities. Sam has not been offered overnight respite anywhere else that is suitable for him. He needs to be where there is consistency and an existing relationship with the staff. Some children can cope with lots of different places, but this is not good for Sam. I continue to believe that he needs to board at his school. When schools are able to offer boarding, they stay in control and there's the same ethos through the whole offering. I believe that there needs to be complete consistency running through everything and this is currently lacking in the provision offered to disabled children.

Introduction

Helen and Charles are parents to three sons. **Owen their eldest son is 13 years old and has a diagnosis of epilepsy, autism, XYY chromosome, developmental delay and severe learning difficulty. He was also initially diagnosed with West syndrome**, which is an epileptic syndrome (Ghaziuddin, 2005), **but this is no longer deemed to be present**. Owen is described as being at the bottom of the autism spectrum in term of functioning and he has limited verbal communication. He attends an autism specific school. Fergus is 11 years old and is Helen and Charles' second child. He also has a learning difficulty and attends a special school. His special needs are completely unrelated to Owen's and he does not have a diagnosis of autism. Their third and youngest son is typically developing and has no special needs. He attends a mainstream school. Helen and Charles' story is mostly centred around their experiences of Owen, owing to his diagnosis of autism. However, they also talk about their experiences of Fergus as he has a high level of need, requiring substantial support and this impacts significantly upon family life. Helen and Charles' story also touches upon how the demands of caring for Owen and Fergus reduces the time they are able to spend with their youngest son.

Helen and Charles told me their story together and equally contributed to the content. Where possible I have combined their voices and written their story in the form of 'We'. However, there are sections of the story where I have felt it more appropriate to write in the first person. I have denoted the beginning of these sections told through the voice of Helen or Charles with their respective name in brackets, to avoid upsetting the flow of the story.

In the beginning Owen was an easy baby and he slept a lot. From six months on wards he started having seizures, although we didn't recognise this was at the time. However, we had begun to notice was that he wasn't doing things that other babies were doing. For example, he didn't sit up or walk, he didn't have a pincer grip. At the time we talked to the health visitor and the doctor, but we didn't feel we got too much attention. Nobody else could see the seizures, perhaps they weren't happening regularly enough. However, we knew that something was wrong, but it was happening in such a subtle way; his eyes would roll up, just for ten seconds or so. It was so difficult to articulate and describe. It was only when we decided to make a video of these instances and we took it to show the doctor, that we were taken seriously. Owen was immediately admitted to hospital and we received the West syndrome diagnosis. West syndrome is a very serious condition, not just life limiting, but life expectancy is expected to be quite short. So, our world came crashing down a bit...

We started to research West syndrome on the internet and we found that it is linked to autism, so we knew it would go the autistic way or he'd have a very serious type of epilepsy. We initially focused on trying to help Owen's epilepsy. He had all sorts of tests and we needed to sort out the right anticonvulsant, at the right levels. The medication seemed to work quite quickly, but the on-going challenge has been trying to manage the right dose, as

he has grown. Over time the other aspects of Owen's condition became the main focus and West syndrome became sort of de-emphasised. So, whether he had West syndrome or just a mild version is not certain.

(Helen) As we got the diagnosis for Owen, I also found out that I was pregnant with Fergus. I had a very traumatic time when I was pregnant with Owen. I have a condition which makes my blood clot and so I have to inject myself with Heparin blood thinner. Consequently, during my pregnancy with Fergus I had my own health issues going on, whilst we were trying to look after Owen with his additional needs. We also began to worry about whether our second baby might develop the same condition as Owen and questioned whether there was anything about Helen's treatment that had been a contributory factor. (Charles) My way of coping is to find out about things, so I was reading and trying to understand all about Owen's condition, including autism. Then Fergus was born and we had a really difficult time. He weighed 5 ½ pounds, but then he wasn't feeding very well and his weight dropped. He had to be tube fed and we were in and out of hospital for the first six months of his life. It was a very difficult time; staying up all night trying to feed Fergus, whilst having to cope with Owen, it was overwhelming. We also had sleep issues with both boys, which we needed to cope with too. Fergus didn't sleep right from the start, whilst with Owen sleep difficulties developed when he became a toddler. Having two children to look after with completely unrelated conditions, brought with it a further dimension, which has made our lives very difficult.

Spending time with people socially began to present its own challenges. (Helen) I used to meet up with friends from my anti-natal group, but as Owen's condition began to unravel, it became very difficult to bear being around others in the group with typically developing children. All the other children were doing things and Owen was just sitting there or laying there and you could see the difference and it was really hard to cope with. Likewise, the boys' have cousins and we had friends with similar aged children and we began to see a big development gap appearing between their children and ours. Other people can be very sympathetic, but they don't really understand, they don't get it. They don't appreciate the difficulties and how hard it is to cope with the emotional side of things, it's a very isolating feeling. (Helen) I don't really talk about Owen or Fergus too much to my friends who don't have children with special needs. Furthermore, gaps have also been driven between long-standing friends who we just don't really see anymore. So we have ended up building new networks of special needs parents. I've a good network of friends from Fergus's school and when we meet up regularly and exchange stories and laugh about them. We can because there is understanding.

One of the difficulties is having to remain constantly vigilant to keep our children safe. This has become part of our everyday lives, in a way that other people take for granted. For a number of years, when the children were very young, we went on holiday as a big group with my (Helen's) parents, my sister and some friends. However, we had an incident when Owen ran off and we lost him for 20 minutes, it was horrific. We eventually found him naked running down a single track in the middle of nowhere. Since then, we have never gone away again like this. We began to realise that with such a big group, with such a lot of children, it's

very distracting. We can't absolutely rely on the others to keep an eye on the children, just for a moment to go the toilet or something like that. We have tried going on holiday on our own with the boys, to a holiday cottage in the UK, which was supposed to be 'autism friendly'. We also took a carer with us. However, we didn't find it secure enough and this made it very stressful. Consequently, we haven't been on a family holiday for a long time. Even at home we have to constantly supervise the children, we can't really relax. They need constant one to one support in a way that parents with mainstream children just don't understand. Similarly, with Grandparents, they are sympathetic, but they don't really understand what is needed to keep our children safe and we have found that isolating.

Unlike some other children with autism, Owen didn't have lots of skills and then suddenly lose them. He didn't go through that classical regression phase that is talked about, so we've never viewed him as being classically autistic. It was difficult from early on and it has always been a struggle. (Charles) I joined the National Autistic Society (NAS) for the information, but I didn't find anything relevant to Owen. They seem to concentrate on more capable individuals with autism. Owen is more on the lower ability end of the spectrum, where he can't do so much and the NAS seem less able to provide support. Owen is auditory, he is also quite visual and uses the Picture Exchange Communication System (PECS), but he's never been very good at Makaton and Sign Language. We also went to some autistic conferences at the local University. These were interesting, but again not very applicable for Owen. The NAS also hold local support groups and (Helen) I went to some of the coffee mornings, but I didn't find them very helpful either. The sort of parents who attend seem to have children who are probably more Asperger's. Similarly, we tried to engage with the Epilepsy Society, but we had the same sort of experience. The autism and severe learning difficulty aspects of Owen's condition, has meant that information and support from the Epilepsy Society hasn't really helped. He hasn't really fitted into one group, it's almost like we've got a foot in both camps and none of it helps.

Before Owen started school we were trying to find ways of encouraging his development. When he was 3 years old we began to use Portage (home visiting educational service). Owen had Portage for a year and then Fergus took it over. Owen was also attending a private mainstream nursery school. It was a lovely place and in the beginning he seemed to cope, he was in a really nice room. However, as he got older he moved into an environment that was more open, this was just totally unsuited for him and he couldn't cope. It became quite sad seeing him there. The staff were very good, quite flexible and wanted to understand, but they couldn't cope with him. Consequently, after attending some meetings at Owen's nursery, it was recommended that Owen should go to the local autism assessment nursery. The year before school, he started at the specialist nursery and during this time he formally received his diagnosis of autism. Owen's time at the nursery was great and a big relief for us. We were also offered transport for Owen, but we didn't use it in the beginning. (Helen) I didn't want my 3-year-old, to go all that way on his own in transport, I just couldn't do it. As time went on though, I had to concede to using the transport. I couldn't cope taking him back and forth each day to nursery, as the additional demands of looking after Fergus were becoming too much.

During the year that Owen attended the autism assessment nursery we needed to find a suitable school for the following year. He could have continued on in the special school attached to the autism assessment nursery, as an autism specific stream was about to be introduced by the school. However, the school was in the process of transferring to a new site and the new school building had not been finished. It was difficult for us to visualise things, we couldn't see the building and it had no history or track record of autism, beyond the work it was doing in the autism assessment nursery. We looked at three other special schools and discounted two of them. One autism special school was too far away and we had the impression it was suited to more-able children. Another special school just didn't feel right and it wasn't secure enough as Owen is a bit of escapee. In the end we choose and secured a place at a local autism specific school. The building was new, purpose built and secure. In the September Owen started school and travelled from home to school by transport each day. However, we went through a period of lots of transport problems. There was no continuity with the taxi and it changed almost every month and this made things difficult for Owen. He would get used to the taxi people and then they would change. However, it was more than a lack of continuity. We also had difficulty communicating with the taxi people, because they couldn't understand English and there was a lack of understanding of Owen's needs.

Looking at the present-day, a typical school day usually begins very early, this morning Owen was awake from 2.30am. Whenever Owen wakes up he thinks it is the morning and he goes downstairs to get something to eat. However, as it was very early this morning, (Helen) I managed to get him back upstairs to bed and after about an hour and a half he went back to sleep. He slept until 7am and then went to the toilet. He has been able to use the toilet since he was seven or eight years old, but he still needs support. He needed to wear night-time pants for a while and even now we still have occasional accidents. He continues to need prompting and help him to wipe his bottom, reminding to wash his hands and to flush the toilet. He loves water, he loves showers and he loves swimming, but with washing his hands it's different. When he turns the tap on to wash his hands, he hesitantly moves a finger towards the running water, almost as if he's scared of it. It's a sensory thing, he'll scream if you try to put his hand underneath the running water and he'll resist. After using the toilet, Owen will come downstairs with his iPad and he helps himself to a frozen waffle from the freezer. He then sits in the TV room and just nibbles away on it watching his iPad. Sometimes he will spontaneously ask for other food, such as pasta or maybe sausages.

The mornings are an extremely busy time. (Helen) I have to make sure that Fergus is ready for school for 7.30am and also have Owen ready for his bus arriving at about 8.10am. Everything is hard work; getting Owen dressed, giving him his medicine and brushing his teeth. He doesn't like having his teeth cleaned and he screams, it's the same thing every day. Getting Owen dressed is also challenging and he can get very easily frustrated and upset. He is able to undress himself, but he is unable to get dressed, so I do this for him. He's not very coordinated and so if an item of clothing doesn't go on easily, if I don't put a sock on properly straight away, he'll get frustrated and take it off and I won't be able to put it on again.

(Helen) I prefer Owen's bus to arrive at a set time, so I can have him ready near to the door. I support this transition by verbalising single words: 'Bus', 'School' and then 'Home' and 'After School Club.' This prepares him for what is happening in the day and he remembers it. The terms 'Now' and 'Next' also work well with him. I have tried using picture sequences with him, but I don't think he needs them. He understands as long as I use simple words. Just before the bus is due to arrive, I sit him on the stairs, put his shoes on and he sits with the iPad waiting. I can't leave him, even for a moment, as he will run off and get undressed. The actual transition on to the bus is quite difficult. Owen sits on to the bus and I give him his iPad as a distraction, whilst we sort out his 'Houdini' harness. Owen frequently screams at a high pitch, regardless of whether he's likes something or not, is happy or has hurt himself. Even though I do a countdown to support this transition, he still screams when I take the iPad away from him. It has been like this for ten years, it never changes. As soon as the bus goes off, I'm busy getting my youngest child ready for school.

Some days Owen comes straight home from school and on other days he goes to an after school club. When he gets home he goes straight to the fridge, to find something to eat, even if he's eaten at the after school club. At home, he occupies himself a lot of the time with his iPad. In the summer months he likes to go outside into the garden and he balances his iPad, whilst playing on the swing. He will stay outside for hours, until we ask him to come inside. If his iPad has a problem; it won't load or it runs out of power, he'll sometimes get frustrated with it. On occasions he will discard it in a hedge or a bush, it depends on his mood. At other times he brings it inside to tell us that it's not working and then takes someone else's iPad as a replacement. As Owen is getting older he is going to sleep a lot later, around 8.00pm or 8.30pm. At bedtime he takes Melatonin to help him to go to sleep and sometimes he also has a shower before bed. He usually takes himself upstairs when he feels tired, but at other times falls asleep downstairs. For when Owen has times of night waking, he's recently been prescribed Phenergan. This is just to get him back into a better sleep routine again, but we don't use it every night.

During term time Owen is busy at school and going to after school clubs, so at the weekend he often spends a lot of time at home and is happy to chill out. The weekend is always a juggle with children, but we find it particularly difficult with our situation to go out as a family. Our youngest son goes to football on a Saturday and without a lot of extra support, we usually can't both go and watch him. The exception is once or twice a month when Owen goes to a play scheme on a Saturday, which means at times we are both able to go. During the school holidays Owen has lots of days when he goes out with his carers. He goes swimming, to the Cinema, the Cathedral or to a theme park.

Living with Owen and Fergus places lots of restrictions on us as a family and as parents as well. Both boys need constant supervision and it is particularly difficult looking after them at home by yourself. It also impacts on our youngest son, we have less time to help him with his homework and it's always rushed. He loses out because we are busy trying to keep the other two safe. As they are getting bigger, it is getting harder as Owen and Fergus can reach the top shelf of the cupboards and everything is more accessible to them. They don't have

an appreciation of danger and they have problems with basic coordination, like pouring milk onto cereal.

If we go out with Owen and Fergus, they both need 2:1 support and we normally need to organise two carers to come with us. Consequently, everything needs to be planned in advance and so family life is devoid of the usual spontaneity that other people enjoy. As Owen has got older, it's definitely become harder for us to take him out, due to a combination of inappropriate behaviour and lack of danger. I (Charles) used to be able to take Owen swimming at the weekend by myself, but it's got much more difficult. He's very touchy feely, very attracted to women and girls and their long hair and he likes to kiss them. He can approach someone very quickly and our experience is that people are generally accepting of a toddler approaching them to give them a hug, but with an older child they are much wary. Consequently, we feel we can only go to places where people are accepting of this sort of behaviour. We regularly go to the fun swim that runs monthly for families of disabled children, because everyone's very accepting and so we feel comfortable going there.

Likewise, as Owen has become taller and stronger it's become more difficult to take him for a walk. (Charles) I used to take Owen out walking the dog on my own, as we have a very safe route that's enclosed all the way from the road. However, even this can be difficult now because he can decide that he doesn't want to walk and he'll throw himself to the ground. I can't physically get him up. It's getting a bit scary for me too as (Helen) I am on my own a lot these days for appointments and I'm concerned about not being able to cope with him, he's just so unpredictable. Furthermore, we don't visit family very often because we are concerned about the boys escaping or breaking things and so it's quite stressful. Also, travelling by car in a confined space is difficult with the boys. We have occasions when Owen throws things around the car and the boys start fighting. Amongst other challenges is managing all the administration and bureaucracy that goes with having children like ours. It's a huge effort and very time consuming to compile all the required information to apply for things like disability payments and for a blue badge to assist us with parking. It's also a huge battle to fight and secure these.

At the present time, Owen continues to find it difficult to cope with so many little things in life, like a hair out of place or he doesn't like you crossing your legs. He occasionally gets angry, which is probably the worst time because you can see the frustration. By contrast, one of the positive developments is that Owen has become more flexible to bigger changes. He now copes with going on lots of different buses, on a weekly basis, to respite and after school club. Likewise, he's become quite adaptable to big changes like moving house. He's also got a lovely personality, he's very cheeky, has a sense of humour and he's got a wicked smile.

As we look to the future, one of the difficult things to talk about is the emotional aspects of living with our children. We are starting to think about our children's future choices and life chances. In particular, we worry about what will happen when we are no longer around? We made our Will a few years ago and looking at provision, we wonder who would look after

Owen and Fergus, it's really difficult? We have lived through a process of them growing up and we are more capable that we were compared to ten years ago. However, to drop someone in that situation, if we weren't around' doesn't really bare thinking about, it's quite scary. We have friends who have two special needs children, but this is with the same condition. For us it is different, we have two children with very severe special needs that are totally unrelated. We often ask ourselves why? Perhaps, it's because we are parents who can cope? However, it's also a case of, if you put people in a situation where they have to cope and have no choice in the matter, you just have to get on with it!

8.10.3 Iona's narrative

Introduction

Iona is the mother to her son Gabriel. He is **12 years old, has a diagnosis of Tuberous Sclerosis (TS) epilepsy, severe learning disability and autism**. Gabriel attends a school for children with autism and complex needs. TS is a genetic condition that causes benign tumours in organs of the body, such as the skin, kidneys, heart and brain. Those with the condition often have a learning disability and epilepsy (Ghaziuddin, 2005). Iona also has a younger daughter who is typically developing. Written in the first person, Iona's story describes her experiences of living with Gabriel, including the early days pre diagnosis, coping with Gabriel's health challenges and also the practical difficulties of accessing healthcare with a child with autism and learning disability. Iona also describes her journey to find suitable educational provision for Gabriel.

Gabriel had a rare form of epilepsy. Most GP's don't come across this in their lifetime, so it was difficult as we were parents for the first time to recognise that something was wrong. I wish that Gabriel had been my second child, as I could have spotted the signs of his epilepsy earlier. In the early days Gabriel appeared lively, but at other times he just wasn't quite reacting normally. When he was three or four months old we were seen by a Paediatrician because Gabriel had a big head, but she reassured us that it was all fine. However, Gabriel started failing distraction tests and at six months he also wasn't feeding. Initially the health visitor made me feel that I couldn't feed my child, rather than looking at other possibilities. I was getting more and more worried and it became more obvious that there were other concerns. The health visitor referred Gabriel for speech and language therapy and a hearing test. As there were now two different referrals, we were referred to the multidisciplinary Paediatrician. Moreover, at about nine months, Gabriel began to have really odd movements. It was a bit like when your child's head suddenly drops and they fall asleep and then they wake up. I remember thinking that's really, really odd. It was just getting worse and happening more often, but my husband wasn't seeing it as much as I was, so he wasn't as worried. I also did some online research, which is how I came across 'infantile spasms'. When I read about these, I realised that it was very serious and it was such a close description to what was going on with Gabriel. That's when we got our Paediatrician friend to talk with her colleagues. We also went back to the GP and he agreed to write to speed up the Paediatrician referral. However, nobody was taking it seriously enough and so this was when my husband contacted the hospital. He spoke to the right person at the hospital who knew what 'infantile spasms' were and it was suggested that Gabriel's symptoms warranted urgent action. Gabriel was admitted to the hospital and was diagnosed in 24 hours and that was the start of Tuberous Sclerosis (TS) and epilepsy.

The epilepsy was the worst bit in the beginning. Gabriel's rare type of epilepsy damages the brain. Initially it looked like Gabriel's epilepsy was becoming controlled with the medication, but then his condition deteriorated. There is a lot of trial and error with epilepsy drugs and they don't always work. So you try other drugs and they don't necessarily work either. The other problem with these type of seizures is that they are very subtle and hard to detect. They go on and damage the brain and the awful thing is that you don't necessarily realise

this is happening, because it's very gradual. The quicker you can treat and stop the seizures, the better the outlook, but it also depends on the number of tumours you've got on your brain and Gabriel had lots. We realised that he was getting worse and we were getting worried. Gabriel was actually like a ghost, his body was there, but his mind wasn't. He wasn't smiling, he wasn't looking, he wasn't reacting, his brain was totally shut down. Consequently, Gabriel was prescribed a high dose of steroids, which somehow can reboot the brain and Gabriel slowly came back again. It was one of the worst times of our lives because your child's not there and without the steroids it was as if Gabriel had died. Unfortunately, in the process we lost some of Gabriel, there were things he could do before, that he couldn't do afterwards. He could no longer shake maracas together and his eye contact and interactions diminished. Epilepsy was a big thing for the first years of Gabriel's life. It was all about controlling the seizures and he had all sorts of different seizures over the years as he got older. There was such a lot to learn and we spent a lot of time online, email, networks and forums trying to learn as much as possible and trying to understand how best to help him. With the added involvement of all the health professionals it just took over our life.

Gabriel also had other health challenges. When Gabriel was seven or eight years old, we had a really difficult period as he had a tumour on his leg. It was getting bigger and bigger and was starting to rub against his clothes and cause discomfort. We went to see a surgeon about it, who gave us plasters to put on his leg. However, it materialised that they were live plasters and we couldn't remove the plasters. The tumour had become purple and was full of blood. It was oozing and bleeding and started to look like it was infected. Gabriel had to have surgery to remove it and it was expected to be a 10-day recovery. However, as Gabriel isn't a child who will stay still, the wound reopened. We had to go back to hospital and we had the most horrendous experience, as the hospital staff couldn't deal with Gabriel, thinking about it is just awful. He had two more surgeries and the tumour had become so big it was down to the bone, so there was nothing that we could do than let it close up on its own. He was in a lot of pain and for his medical care, awful things were being done to him and we were having to hold him down to do these awful things. Understandably Gabriel was very assaultive at the time. It took four months and Gabriel had to be bandaged and it was summer and 33 degrees outside. During this time, he wasn't able to do all the things he loved doing. He wasn't able to go to playgrounds or on a climbing frame and he wasn't able to go swimming and he was used to going twice a week. It was difficult to occupy a child who is so very lively and active, because how do you do it? In spite of this, his current school were very supportive and whenever we sent him to school, they took him without question. Without that, I would have completely fallen to pieces. Everything was so unpredictable, I would wake up in the morning and have no idea what was going to happen that day. For example, Gabriel contracted a severe case of chicken pox and he had to be injected with antibiotics and then he sliced the back of his feet and so for three weeks he had one leg in a full bandage and the other in a plaster. You just couldn't make stuff up like that. Another challenge was having Gabriel and my daughter sharing the same space. When she was a baby it was easier, but by this time she was a toddler and would come into Gabriel's space. She was noisy and he couldn't cope with this, so we couldn't have them in the same room together. She didn't understand be quiet or don't go near your brother, so for her own

safety and for Gabriel's functioning we kept them apart and that was really tough for us. It was a really, really tough time, we were also very sleep deprived and the anxiety was just taking over.

The most challenging aspect of caring for Gabriel is when his behaviour is assaultive, when he is aggressive and we have physical behaviour. At this point Gabriel was pretty extreme and yet we had an horrendous social worker who didn't realise that we were in crisis. My view was that as Gabriel got bigger, it was going to get worse and we weren't sure if we could carry on looking after Gabriel and he would end up in residential care. For this reason, we were asking for a lot more help, we wanted more funding to pay for carers at home. However, the social worker did not understand and made our life even more difficult than it was. In the end we decided to use a barrister to help support our case. He told us to get supporting evidence of Gabriel's needs and he sent a couple of letters to social care with this extra evidence. They knew that we would have pursued this legally and that they would have to in the end provide the extra help. Consequently, they conceded to provide the extra help for us to continue to look after Gabriel at home. I think social services realised that it was going to cost an awful lot more if Gabriel had to go to a residential school, and that's the only thing they understand. The experience has made me more cautious and more afraid because I just can't go back to that awful time.

With all of this happening we had postponed some of Gabriel's health checks. His next check on his kidneys indicated a large growth, which was life threatening. We had to decide whether to proceed with open surgery or consider an experimental drug for TS and kidneys. We decided to proceed with the drug and it was fantastic and shrunk the tumour by 80 percent. Gabriel has now been on the medication for three years and we think there have also been some other positive effects. He is a lot calmer, less impulsive, sharper, reacts more quickly and so he is quicker at processing instructions. These improvements are very significant for us at home. Gabriel is much easier for us to look after as his behaviour is easier to manage. One thing I have learnt from this experience is when Gabriel is really aggressive, he is in pain. I had thought that maybe it was frustration or the autism manifesting in aggressive behaviour. However, when it's really intense and it goes on, I know that it is pain related. It has been great to realise this.

50 percent of kids with Gabriel's condition typically have autism. Accordingly, it was very likely that Gabriel would have autism, as well as his initial diagnosis of TS and epilepsy. On account of this, when Gabriel was two and a half years old we decided to pursue a diagnosis. We felt it would be helpful to know for sure and it would enable us to access support for Gabriel. Whilst people don't understand TS, when you mention autism they have some level of understanding. Furthermore, there are special schools for children with autism and therapies which are more targeted, than just speech and language. Whereas there aren't any specific services for children with TS. We were referred to the Paediatrician and she gathered information about Gabriel. She was very pragmatic and made a working diagnosis of autism. The diagnosis opened up avenues of support and helped to shape Gabriel's school provision.

At this time Gabriel was attending the nursery at Willow Tree school, attached to a special school. Compared to mainstream provision, we weren't given a lot of choice for Gabriel. We had been offered two choices of specialist nursery provision and neither of these provisions were perfect. However, we felt that Willow Tree school, which was further away than the nearest option, was the slightly better of the two. The nearest provision was an interesting model, it was a mixture of normal kids and special needs kids on the site of a mainstream school. However, we were really shocked by the lack of interaction and they didn't seem to care about the kids. Sometimes you go and look somewhere and you just go no no no.... accordingly, we ruled this school out and sent Gabriel to Willow tree school. Willow Tree school had two streams of nursery provision. One for children with profound and multiple learning disabilities (PMLD) and the other for children with autism. Each with a different focus, PMLD is focused upon health; walking and physio, whilst the autism stream is focused on communication, interaction and behaviour management. Gabriel's autism diagnosis enabled him to move into this class. As Gabriel got older the autism stream became more appropriate, with support for his communication, using for example the Picture Exchange Communication system (PECS). In addition, as this was the nearest autism nursery, Gabriel also qualified for transport to school. Furthermore, it gave me access to parent training programmes, such as EarlyBird and other training with the National Autistic Society (NAS). It was nice to be able to find ways of helping Gabriel.

The next step was to think about schools for Gabriel. We looked at a two autism specific schools. It was obvious with the first school that they preferred kids with more of an autism profile, rather than learning disability, health and other diagnoses. Gabriel was definitely not welcome there. Furthermore, the second autism specific school seemed suited to more-able kids. So it was an obvious decision for Gabriel to continue on from the autism nursery into Willow Tree school. Notwithstanding this, when Gabriel started at school we were unhappy with the support he was receiving in class. He wasn't engaged in his learning. Likewise, we were frustrated by the lack of speech and language therapy (SALT) offered by the school. In his statement Gabriel was supposed to have half an hour of SALT a week and this wasn't happening. In the end the local authority (LA) agreed to fund our own SALT, to go into Gabriel's class, which we had been privately funding. In the beginning this worked well, however the following year the class teacher refused to have the SALT coming into class. I think she felt threatened. Gabriel had to be collected from outside the classroom and also none of the recommendations were being acted upon in class. Likewise, we were frustrated that the Occupational Therapy (OT) was mostly equipment related, rather than sensory processing. So we had a traumatic time battling with the LA to secure a more suitable school for Gabriel. I was also pregnant with my daughter and I really wish that I had been able to enjoy my pregnancy and the early days after her birth. However, it was completely dominated by the fight with the LA. We were expecting to have to go to a tribunal, but luckily in the end the LA gave on everything. Gabriel was six years old when we were offered a place at his current school. His school is for children with autism and complex needs and is also an Applied Behaviour analysis (ABA) school.

Looking at a typical school day, Gabriel usually gets up at 7.30am. He'll be awake before this, but he's now quite good at staying in bed. Most of the time I look after my daughter and

take her to school, whilst my husband looks after Gabriel and then he goes to school on transport. Although on days that I work we have a carer to come and help in the mornings as well. After school it varies. One afternoon a week I'm on my own with both children, which is quite challenging. On the days I work Gabriel goes to a play scheme after school and two days a week we've got a carer who comes to help me. When Gabriel comes home he has a snack and the main focus is getting him to take his medication. When he was about eight or nine years old he became more aware and wanted to assert control. He would decide that wasn't going to have his drink, as he knew the medication was in it. Taking his medication is so important because if he doesn't he can have a seizure. It used to be a really huge challenge as he used to have his medication both morning and evening, but now it's only in the evening it's a little more straightforward. So now we can put all of his medication in one dose and it still takes time, but it is easier. In the evenings Gabriel sometimes goes to visit the train station and look at the trains with Daddy. He goes to bed between 8pm and 9pm.

On a non-school day everything remains very routine driven for Gabriel. Activities include, spending time in the garden or going to the train station. He loves to watch the trains and we'll also watch a lot of trains on YouTube. He's very sensory and likes coloured kinetic sand, playing with lentils or rice, foam and paint. He also likes water, so the paddling pool or swimming occupies a lot of his time. It's always the same things. He used to love playgrounds, but now he only plays in the dirt and mud, which is again all sensory. This is a shame as it's stopped him from doing things like climbing. On a Sunday we usually have a carer to help and she'll take Gabriel out or we'll go and do things together, again it's all the same things. We are fortunate that we seem to be able to keep our carers. I think that's because Gabriel has a lovely personality, he's very cheeky, has good sense of humour, he likes his own jokes and he's got a great smile.

In the summer on a Saturday morning Gabriel goes sailing at a local lake. It's amazing to have the facility and we are grateful because they're all volunteers. However, their understanding of disability is around physical disability, more than learning disability and they need to do more to understand people with autism. Hence, they will ask Gabriel to wait his turn or ask for his help with something and it's hard for Gabriel to understand these things. Also sometimes on a Saturday Gabriel goes to a play scheme. The local centre is great, the leader is fantastic and really supportive. She always knows what Gabriel has done, how much he's eaten and I totally trust her. Looking back to when we were going through that awful time, we started to think about starting overnight care, so sometimes Gabriel goes to a respite centre. We started with day care there, however we've never got to the point where we are comfortable with leaving him overnight. They are nice people, but they don't really understand autism. They don't understand that Gabriel needs to be more active. They're surprised when he gets assaultive because he's bored or hasn't used up enough energy.

We have had many challenges with Gabriel, but also celebrate milestones. Gabriel used to be really difficult with food and it was always a big stressor, particularly on holiday. However, his current school did the 'Talk Tools' program with him and this helped to expand his range of foods. He progressed from eating five things, to eating more widely now than

my daughter does. Despite this, he is still particular about how food is presented, for example cheese needs to be given to him in a particular way. Additionally, Gabriel's medication can sometimes affect his appetite. Sometimes he eats a lot of food and at other times he doesn't eat as much.

Gabriel is now toilet trained. I'm so proud of him, because it's such a huge achievement. We didn't think he'd do it, as for a long time he wasn't showing any signs that he was ready. However, when he was nine years old his teacher thought we should try. They sat him on the toilet and the toilet became the classroom. When he did a wee they would give him lots of reward and then take him back every 15 minutes and this continued for a whole week. I couldn't have done it without the help of school and I don't think many schools can give that level of support. There were obviously a lot of accidents at first, but he was dry in the day within a few months and then about a year ago we were able to take his nappy off at night. It's been transformational for us, because changing Gabriel's nappy was pretty hard work. The problem we have now is that Gabriel is very particular about which toilet he will use and he tends to hold on all day and not use the toilet until he comes home. Obviously it's not comfortable and it might be even painful and we have some challenging behaviour associated with that. Whether he has emptied his bowels or going to the toilet dictates how his behaviour is going to be. Others who look after Gabriel, have taken some time to realise that you can take Gabriel to the toilet ten times, but he won't necessarily do a wee, even though he really needs the toilet.

Gabriel has difficulty coping with unfamiliar places. My mother and father-in-law recently moved closer to us and we regularly visit. So, Gabriel has got used to going there and even though we don't go for long, he is comfortable there. However, if it's somewhere new, he often won't get out of the car or go into the house and he'll be very upset. So, I suppose we just build our life to go to the places where he is comfortable. If we need to take him somewhere new, we try to plan as much as possible. I prepare photographs and I will often visit first on my own. We didn't travel with Gabriel on holiday for quite a long time because it was so difficult. However, this is the second year we've been to Portugal. We flew from one of the smaller airports and took him to the airport before to we travelled. I prepared and showed him lots of photographs of where we were going. However, on holiday he regresses with his toileting, he won't use the toilet and is back in nappies. He also doesn't drink for the first 24 hours and might not necessarily eat well. Eating, drinking and not going to the toilet are all symptoms of when Gabriel is not comfortable, when he's not in his own environment. Obviously as a consequence, if he doesn't take his medication he has seizures. Eventually as the holiday progresses everything starts to settle down, apart from the toileting. Towards the end of the holiday he will start to do a wee in the toilet, but he'll still not empty his bowels.

I think overall considering Gabriel's level of need at the moment things are probably as good as you can hope really. We are having a period of time with no health crisis and I tell people things are stable. That's as good as it gets, because TS has a way of having something for you round the corner... Looking forward, I have both hopes and worries for Gabriel's future. It would be wonderful if Gabriel could use the toilet every time he needs to. I think we'll get

there. One of the difficult things remains the interaction between my daughter and Gabriel. When we are out in the car we have to separate them, because otherwise he'll reach out and grab her and scratch her. We have to keep her safe, but we also want her to have positive experiences around Gabriel. It would be lovely if they could just be like normal siblings. Moreover, going forward the impact of Gabriel's autism and learning disability on accessing on-going medical care worries me. When you're struggling to give him medical care, but you're not able to, what that might mean for him? If he wasn't able to cope with having treatment, I'd be concerned about the serious long-term consequences. In addition, through my experience I have found that you are always so dependent on the staff, with a procedure you go through a chain of people and not everyone is going to be supportive. We've had great people who work with us, but we've also had doctors not being able to do what they're supposed to do and those not working with us. In the healthcare system there's lots of health workers from countries where disability is hidden and the doctor or nurse knows best. We've had the best experiences with doctors who have had exposure to kids like Gabriel or are older and are confident. They don't need to reassert themselves as they've had enough experience and they know it is best to work in partnership with the parents.

Several months later:

The changing nature of TS is that you never really know what is around the corner... several months later, as I had predicated, this was about to change.

For a few years Gabriel's epilepsy had been generally well controlled. We had a few instances of seizures, but generally there was a reason for it, such as he hadn't taken his medication or he wasn't well. In January he was on really good form and so there wasn't any trigger and yet he had a series of seizures. He went from one seizure and he seemed to recover, but probably didn't, then he had a second seizure and a third seizure. Following protocol, we administered emergency medication, but this didn't take effect. He was taken to hospital, but on the way his condition deteriorated quite rapidly and he stopped breathing. They had to call the crash team, they struggled to stabilise him, but eventually he stabilised and he was intubated and given lots of drugs to keep him safe. Eventually after a period of time, they were able to take the tube out and he was able to start breathing again on his own. Gabriel made a very good recovery after that, but he had never had a life threatening seizure before, so that was a really big shock and it just came out of nowhere.

Introduction

Jayne is the mother of **two sons both with a diagnosis of autism. Tim the eldest has a diagnosis of classic infantile autism, is preverbal and has severe communication difficulties.** Tim attends a local autism special school and is in a class of children with very high needs. He uses the Picture Exchange Communication System (PECS) to help communicate his needs. By comparison, his younger brother **Felix has a diagnosis of higher functioning autism and is verbal**, though his speech was delayed. He attends a mainstream school and is about to transition to a local secondary mainstream school with an autism unit. Jayne's story told in the first person, describes her experiences of living with her children with autism. Jayne begins with recalling the early days prior to Tim's diagnosis, the process of his diagnosis and beyond. This is contrasted with her very different experiences of navigating the system with Felix. Jayne also talks about the present day and looking forward.

If I start at the beginning when Tim was a baby, I would say he was happy and content and I thought I was doing fine as a Mum. Then suddenly at about eight months, virtually out of nowhere, this all changed. It started with the crying, crying, crying, day and night and I couldn't turn it off. At first I thought it was teething and in part I think it was, but it was more than that. At this time Tim's peers were beginning to utter their first words, but Tim did not have one single word, he just babbled. At his 15 months check with the health visitor I expressed my concerns about his speech, but these concerns were dismissed. On reflection I should have put in a complaint, as we didn't get the support I now know we needed. I began to look for an explanation for our little boy's absence of words and began to blame myself. At this time friends tried to reassure me that Tim would be fine, they proposed to me that everyone talks eventually and cited that Einstein didn't talk until he was three. This I now feel was ironic and it is now clear that they didn't understand about autism. However, at the time I wanted to believe them, but inside I knew things were not going right. By contrast, I remember clearly that two people were brave enough to raise their concerns about Tim. One was my sister-in-law, who herself had a son with autism and the other was a friend who ran a Montessori nursery. They both encouraged me to seek a diagnosis for Tim and I admire them for their honesty.

The process of Tim's diagnosis happened when he was 2 ½ years old and was straightforward. However, this coincided with a horrible episode in the lives of our family. My little niece who was only 4 ½ years old, had been battling with cancer and very sadly died. We had gone to the hospital for a consultant meeting about Tim, not really realising that we would be given the diagnosis. In the afternoon was her funeral, little pink coffin. So we had to compartmentalize that day. Overall, Tim's diagnosis brought with it mixed feelings, relief and upset at the same time. It was impossible to escape my own mini grief, trying to come to terms with losing part of my little boy. At around the same time my father suffered a stroke and never spoke again.

My experience of social support at the time was very mixed. My sister-in-law had experience of autism through her own son and helped get me on the right path, such as guidance with some of the form filling and advice of not to fear social workers. However, she couldn't be there as much as she would have liked too, as she was still grieving for her daughter. By contrast, there were people who were unsupportive and I found quite judgemental. I had a neighbour who thought she knew more about autism than I did. She wouldn't accept that Tim could be severely affected because he wasn't violent. There was also my NCT group. I had tried to explain to the others in the group about Tim's autism diagnosis, hoping they could try to understand what we were going through. However, one of the girls spread a rumour that I had postnatal depression and I didn't, I was just trying to cope. So, you soon find out those people who want to learn about autism with you and those who literally turn their back and walk away.

Tim was so badly affected that in the months that followed his diagnosis, all of the educational support fell into place. I found a place for him at a local nursery and Tim was also placed at an autism assessment nursery for a couple of days a week. So, he did a split between the two nurseries. We thought that socially it was important for him to stay at the local nursery. The staff at the autism assessment nursery literally took over and were fantastic. They helped with all the paperwork, practically did the forms that were needed to secure a suitable school for Tim. We were very much on a conveyor belt and were offered a place at an autism specific school for Tim. He has continued to attend this school, travelling back and forth in a mini bus each day.

By comparison, my journey with Felix was quite different. One of the greatest challenges has been to have Felix's needs recognised with a diagnosis and the struggle to secure appropriate educational support. When Felix was born we had early hopes that he wouldn't have autism, but we knew that there was a 25 percent chance that he could be affected and we were obviously fearful of this happening. My experience of Tim had meant that I had attended lots of autism parent training courses. I had also read numerous books, so there were things that I was looking out for. Though, when Felix was eight months old, he said his first word in context and I reassured myself that he would be fine. However, there were little things that began to stand out overtime, things that my husband and I both recognised as possible signs of autism. I think in the end we both knew he would have a foot on the autism spectrum somewhere. However, because our gauge was so severe with Tim, it felt like nothing.

Caring for both boys, in the months and years that followed became exhausting for me. In particular, Tim wasn't sleeping at night and I was feeling hugely sleep deprived. At this time, I tried to cope by sleeping during the daytime, when Felix was having his nap. I knew that melatonin would have helped with Tim's chronic sleep disorder. However, because of the cost of it, the community nurse had refused to provide, a case of professionals thinking they know best. When Felix was coming up to his third birthday, we secured a place for him at the local state run nursery as we were already flagged up as a family with an existing child with significant needs. We had to wait until the term after Felix was 3 years old for him to start, due to the rules at the time. With hindsight, I should have found another nursery for

him, which he could have started at already. In the gap between his third birthday and eventually starting nursery in the September, he had started to drop his daytime naps. This meant that I could no longer catch up on my sleep during the daytime. The cumulative effect finally began to take its toll and impacted on my health. My body couldn't carry on any longer and one day I suddenly felt that I was having a mental and physical breakdown. However, what happened to my body and mind that day gave me the confidence to suggest to the paediatric consultant that being denied Melatonin for Tim was neglect. She agreed to prescribe it and within six weeks of giving Tim Melatonin, he said his first word.

In September Felix began at the state nursery. It was clear from the outset that Felix would need some support, but we were not sure what. The SENCO, who was experienced, suggested that we tried to get a statement of speech and language delay for Felix straightaway. The alternative would have been to wait and see. However, I feared that we might miss the boat on getting support and I felt it was better to try to get support and then drop it if it wasn't needed in the end. So we applied and Felix was given the statement. A little later when Felix was about 3 ½ years old, the nursery had gathered sufficient evidence and suggested that we tried to get an autism diagnosis. Everybody felt it was the right thing to do, to get him supported with early intervention. Obviously, I had been through the process already with Tim and I assumed that if the diagnosis was deserved it would be given. Looking back, I think I was probably a little too trusting of the professionals. Felix was assessed through a multidisciplinary process by various professionals. One of the initial appointments was with the clinical psychologist. I recall sitting in the room feeling exhausted as Tim wasn't sleeping very much at the time. I remember Felix was with me, sitting banging his foot against the radiator, which was annoying me. I had a headache and the clinical psychologist belittled me, telling me I couldn't concentrate. She sat there as the expert with her professional hat on and made me feel quite small in her presence. After the full multidisciplinary team had assessed Felix, we attended a panel meeting to determine if Felix should be given a diagnosis. The diagnosis was denied. I think at the time they'd been told not to give a diagnosis until about age seven. However, I had always trusted them and so it came as a complete shock. I should have spoken up at the meeting and said I disagreed, but I had no fight left in me. So I suppose after that my trust went down.

The next step was to find a suitable school for Felix. This was a very painful experience because for the next five years, I had no diagnosis to support this process. Of course Felix still had a statement of speech and language delay, which was something. It was therefore recommended that we placed him in a school which had a specialised speech and language unit. We took the place as it felt like the right thing to do at the time. Ironically his speech improved quite a lot over the summer and in the end it wasn't quite the right fit for him. The other children in the unit had more severe speech and language problems. Consequently, Felix was integrated back into the mainstream class, still linked to the unit. After this year it was felt the specialised unit was no longer needed and he moved to his local primary school. He still had his statement and one to one support in the mornings and for the first year this worked well. However, in his second year a new SENCO decided to withdraw Felix's support as he had coped so well the previous year, so the crutch was taken away. At the same time Felix ended up having a supply teacher, who had an old fashioned

approach to teaching. Felix had no support and his behaviour deteriorated. It was not fair, looking back I feel what they did in denying Felix's diagnosis was wicked. Without a diagnosis and the support that went with it, I became the parent of the child who was hitting and kicking other children, misbehaving in the playground. I had to cope with all the judgements from other parents. I was the parent with the child running away, hiding under the coats, not able to learn. If the diagnosis had been in place from the outset, Felix would have been supported. When he had felt overwhelmed, he would have been able to take a little break and leave the class, he could have coped. In the months and years that passed after Felix's diagnosis was refused, I was on a rollercoaster, constantly self-judging myself, questioning whether Felix had autism or not. It was obvious that he did, but the denial of his diagnosis had caused me to doubt myself. I feel looking back, in discussions with the school SENCO that I was portrayed as a dithering mother. Finally, I could bear it no longer and Felix was reassessed. At 8 years old Felix finally received a diagnosis of autism, but the experience that had gone before had caused me to mistrust the system.

At the present time, in order to give some idea what it is like living with my boys, I will describe what a typical day looks like. If it's a school day, the hardest part of the day is the beginning between 7am and 9am. I try to gently manipulate both boys, keeping them happy in order to get them ready for school. I have become a master of doing this and I don't even know that I'm doing it half the time. Tim is the first to go out to school, by mini bus and so the first hour of the day is focused upon getting him out of the door. The second hour is about getting Felix to school. Looking back to the early days it was very hard, trying to keep Felix away from Tim because both boys were cry-babies and could easily upset one another. I would do everything in my power to make sure Tim didn't get upset, so I could get him on the minibus. I would have food and drink ready for Felix, so he wouldn't cry and I'd keep both boys apart. Even now the transition of getting on the mini bus can be difficult for Tim, even just getting his feet over the last threshold. His foot goes over, his foot comes back, both feet go over and then one foot comes back, as he processes moving into the next part of his day. By comparison the end of the school day is generally not too bad. Tim is usually happy when he arrives home, he wears ear defenders now which has helped him to cope a lot better. I have food ready for Tim and both boys play on their iPads. Tim also loves the garden, he loves then swings and he loves the trampoline. At weekends and during the school holidays the alarm clock is switched off and everything is much more relaxed. However, there is unpredictability every day and often plans need be changed. If we are planning to go out and Tim has not slept, we often have to cancel our plans at short notice. Or if we are due to visit family and Tim doesn't want to go, we don't all go. If it's my family, I might go with Felix and my husband will stay at home with Tim or is it's my husband's family, he might go with Felix and I stay at home with Tim. It splits the family.

Living with Tim's autism has placed many restrictions and pervaded every aspect of our family life. We have learnt to adapt to accommodate his needs and differences, but also to have time to ourselves. We regularly make use of local respite services and use this opportunity to take Felix out. Tim goes away on respite overnight every other Friday night, so we can literally book a Travelodge and go away for the night or go to the cinema. Sometimes we are all exhausted and we just stay at home, without having to care for Tim.

Tim's restricted diet is one aspect of family life that needs to be accommodated. Over the years, Tim's diet has become very, very limited. He no longer eats any cooked meals or dairy, meat or vegetables. On recommendation from the dietician, he has 19 slices of bread with calcium a day and iron supplements. Luckily he will drink the iron supplements in his water. He mostly only eats toast with butter or he mixes honey and marmite together and rice cakes. He will also eat quite a lot of cakes and biscuits and crisps. If I think back to the beginning, he started off normally, weened normally and ate pretty much everything that I put in front of him. However, slowly over the years, literally up until now, he has just dropped foods and once this has happened he never eats the food again.

Needing to be constantly vigilant is another restriction to our family life. Tim can be very unpredictable and inclined to try to abscond from the house. It is lock and key, deadlocking the doors and double locking the windows to keep him safe. We've lost Tim five times, once he got on the road and it was almost catastrophic, fortunately the neighbour spotted him and brought him home. Taking Tim outside the home is also unpredictable. I am so fearful, that my anxiety spikes and I generally avoid taking him out at all costs. It can be physically difficult and he can get very distressed. For example, we would never think of putting Tim on an aeroplane and going on holiday. I think we might get him there, but we might never get him back home. We also don't really like to visit anybody's house with Tim. If anyone invites us and tries to reassure us about bringing Tim, we'll explain that we'd rather not come, because we know we will be there as Tim's carer. I've had some mixed experiences taking Tim out to a small local supermarket. About six months ago, I took him out on my own and we went to buy him Pringles and Wotsits, which he likes and some biscuits for Felix. I remember he was bouncing up and down like a boxer dog and I was trying hard to keep him calm and I have having to steer him quite a lot, because the aisles are quite narrow and he tends to bump into little old ladies. However, we managed it, it was a good experience and I'm very proud of that. By contrast, on another day I went to the same supermarket with Tim and his carer. It was very difficult and I don't know why and I felt everyone was judging me. Everyone was looking at us and I was embarrassed, I don't mind admitting it, it embarrasses me. So you have to decide is it worth it for everyone involved. These days, going to the dentist or for a hospital appointment is generally the only time that I take Tim out and this can also be difficult. About a year and a half ago, I needed to take him to the hospital. His eye had reacted badly and he needed to be treated. It was unfortunate timing because for some reason the paediatric area, which he is used to, was closed off and we were waiting in the adult area. He wasn't used to not being in paediatrics and although he seemed to be coping for a while, he then flipped. He was like a wild animal scratching me and trying to get out. His size has matched my physical strength now, so it was very traumatic experience. Eventually a nurse offered Tim a DVD and he calmed down a bit and eventually we were able to sit in paediatrics as it was open again.

Thinking about the present and looking forward. Tim is currently 13 years old and continues to have high support needs. He attends the same autism specific school, but is now in the secondary part of the school. The staff are generally very proactive, very thoughtful and the children get to spend time out in the community. The class go on weekly outings, which are a huge part of their integration into society. They go to the supermarket, use the self-service

checkouts or to Burger King just to get used to coping in the world. By comparison, Felix is classic Asperger's. He continues to be very literal in his understanding, so I have to warn people that he says it as it is. I hope in life he can learn to be more as he would like others to see him, instead of just behaving as he wants to behave. I feel this is something he needs to learn, if he's going to keep friends. Since Felix's diagnosis he has received more support at school and at 11 years old is about to transition to a secondary school with an autism unit. I believe that if everyone communicates and does the right thing, this can be a success story and he has a fair chance to come out fairly well.

Introduction

Ana is the mother of two sons. **Matthew** her younger son is **12 years old**. He has a **diagnosis of autism and learning difficulties** and currently attends a special school. He also has with **Attention Deficit Disorder (ADD), Tics and anxiety. Although Matthew is verbal, he is very literal in his understanding.** For many years Matthew was placed in a non-specialist school until he was finally offered a place at an autism specific school. Following on from experience of Matthews' diagnosis, Ana's elder son was also diagnosed with autism at the age of ten years old. However, he later questioned the appropriateness of his diagnosis and at 16 years old requested a reassessment. Ana also feels that there are other family members with undiagnosed autism, including Matthew's older half-brother. Written in the first person, Ana's story focuses upon her experience of Matthew, from her early concerns about his development, to securing a diagnosis and navigating the education system. Ana also talks about how Matthews' anxiety impacts upon his functioning. Ana stresses the importance of consistency and preparation, so Matthew knows what to expect, which in turn reduces his anxiety. Ana also shares the frustration and difficulties of spending time with extended family, who don't really understand autism.

Matthew was a very unsettled young baby. He would cry for what felt like days, but it was probably just hours. When he was about 18 months old, I noticed that his speech was very limited. He also wasn't walking and there was other behaviour that was a bit bizarre. It was unlike what I could remember with my older son. I decided to take him to see the Doctor and I explained that he wasn't talking, but I was told not to worry about it. However, I was worried as Matthew didn't have any words at all. I went back to see the Doctor a couple of times and eventually we were referred to Paediatrics. By this time, Matthew was two years old and he still wasn't talking. I recall at the appointment, that the Paediatrician got all these toys out for Matthew to play with and he was babbling and ran off. The Paediatrician started to try to make sense of what he was saying and I asked her if she thought Matthew was autistic? She agreed that he was and explained that she had been about to talk to me about that. She gave me a leaflet on autism, but explained that she didn't have any full information to give to me. She explained that I would receive a letter confirming the diagnosis in the post. That was it, off we went, nothing else...

Even though I had already thought that Matthew had autism, the appointment left me feeling a bit shell-shocked. We didn't hear anything about receiving any support for three months after that and it felt like complete abandonment. It's a long time to wait for help when your child can't do the things that you would expect them to do, at that age. Matthew was completely own agenda led and I just had no idea what to do. I searched the internet for information, in fact at the time, the internet was my saviour really. Eventually we received an appointment for an initial speech and language therapy (SALT) appointment, to see if Mathew was a match for a group therapy session that was going to be run. I recall on the day of the appointment, that it was the tail end of a gale storm. There were trees falling down in the wind and I remember thinking that I needed to get to the appointment, as it was the only one that we had been offered. He managed to get to the appointment and

Matthew was asked to do some activities, including brushing the dolls hair. Matthew wouldn't do this and the SALT also asked him questions. I knew that he couldn't answer the questions, so I started to answer the questions for him. The SALT told me not to talk for him and I remember thinking that Matthew was hardly going to be able to answer as he didn't have any language. Eventually, we received a letter to confirm that Matthew had been accepted for the SALT group therapy. A Women from Portage (home visiting educational service) also visited Matthew at home for a term. She would come, set up a little table and bring out toys for Matthew to play with. As Mathew had one to one attention from her, he was absolutely fine and he would sit and play with her. I also did the EarlyBird course, which was when alarm bells started ringing about our older child and he was subsequently diagnosed with autism. Matthew was also put forward for a place at a local assessment nursery. However, Matthew was already settled at the local nursery and he was happy, so I didn't know why he needed to go to a specialist nursery. The local nursery also felt that they could meet his needs and Matthew wasn't running off or anything. However, I was told that if Mathew didn't attend the assessment nursery, he wouldn't be considered by the panel for a specialist school placement. At this time, it felt as if they were speaking a foreign language to me, I didn't understand what any of it meant. I felt we had no option, so Matthew attended the specialist nursery and had to travel by taxi to get there. We were never offered the opportunity for Matthew to do a split placement between the two nurseries, but it might have been that I needed to know to ask for that. As a parent you don't know what you don't know! It's difficult when you are still in the post diagnosis stage to ask the right questions.

Matthew stayed in the assessment nursery for a year and we were told to start looking at schools. We didn't really know what that really meant and so we were advised to look at schools with unit places. We were never advised by either the nursery or the Local Authority (LA) to go to look at autism specific schools in the area. Much later, the advice to look at specialist schools came via another parent. So at this time, we looked at two local schools with units. We didn't particularly like either of them, but decided to request the nicer of the two schools. We were left waiting on the outcome, as the panel didn't meet to decide on these school places this until July, which I felt was very late. However, Matthew was given a place at our requested school with the unit.

When Matthew started at the school with the unit, we started to have quite a few challenging behavioural incidents, for example he would spit at the teachers. I wasn't happy with the teachers' approach to managing this behaviour, as she would shout at him a lot. We were also seeing some quite extreme behaviour at home, it was worse than at school. For example, he squirted washing up liquid into the aquatic tank and killed all the fish and he would pee on the plug sockets or urinate out of the window. He was all over the place and he needed one to one support all the time. We needed help, we needed support and I remember going into school and explaining that I was really struggling. I asked if they have any ideas or could they make any suggestions about what I could do? Whilst I was standing there, the teacher merely stood and told Matthew off for his behaviour at home. I remember thinking that he didn't need telling off like that. Likewise, the school struggled to understand how to teach Matthew and how to find motivators to support his learning, they

assumed he wasn't able to learn. By comparison, at home Matthew was able to recite twenty letters of the alphabet and count to twenty in an exchange for a reward. When I tried to explain that he could learn with motivators, the school dismissed my efforts and told me that this was not real life. It was exasperating! We tried to remove Matthew from the school, but the school kept saying that they could meet his needs. I knew that they were not meeting his social emotional and mental health needs. He was crumbling, he was tearing his hair out and kicking the walls. Matthew was also presenting with violent behaviour during his taxi journey to school. At this time, we went through four escorts in his transport. They wouldn't take him to school because of his behaviour. Furthermore, two taxi companies barred him from their taxi and so the LA had to find another provider. All the time, I knew that Matthew was communicating something about going to school, yet every morning I had to put him in the taxi and then watch him go off. I was horrible it was horrific and yet I couldn't get him out of the school, because they kept saying that they could meet his needs.

Matthew was at the school with the unit for the three years, until it was time to move on to Junior school and we managed to secure a place at Somerset school. Somerset school was a special school, but it wasn't autism specific. Matthew spent four years altogether, the first two years were good and then the last two years were not so good. In year 3 and year 4 Matthew had quite empathetic teachers, who really understood him. However, in year 5 the teacher couldn't cope with the class, she was also off sick for a long time and ended up leaving halfway through the school year. I don't know whether she had ill health or couldn't cope? Whenever I went to visit the school, it certainly looked like that. In the teachers' absence, Matthew had teaching assistants and substitute teachers. In year 6, Matthew had a teacher with a terrible attitude, similar to the teacher in the school with the unit. For example, one day I had a meeting at the school as I wanted some support to help manage difficult behaviour at home. The teacher was telling me that they didn't see the sort of behaviour that I was describing at school. I found them to be very patronising, I think they wrongly assumed that because Matthew was verbal he must therefore have the ability to say what he was feeling. I suggested that they gave Matthew pictures and visual support, but they didn't believe that he needed it. At school Matthew had seen that other children in his class with visual support and he thought that it helped them, so he believed it was going to help him. I tried to explain to the school, how having visual support would make him feel less anxious, more safe and it would enable him to access the curriculum more. I suggested to the school that they try this for two weeks to see if it made a difference, but they wouldn't.

We eventually managed to get Matthew a school place at Woodside school, his current autism specific school, for the start of secondary. However, the journey to get to secure this was not at all straightforward. We had started to look at secondary schools and we visited two autism specific schools. We had already looked at Woodside school, when Matthew was around 6 years old and I recall remembering that I loved it then. This was the place where he needed to be, it was absolutely perfect for him. However, at the time it seemed to be too far away from home. The other autism specific school seemed to be very poor at communicating. I found it very difficult to get in contact with them, or at least this was my experience, but it was closer to home. I made this our preference on the application form

and sent supportive evidence, an Educational Psychologist report and some other reports, all by the given deadline of 7th November. The reports stated that Matthew needed an autism specific school, not mild learning difficulties (MLD). However, the LA did not act on this information and offered Matthew a place at Eastside school, a school for MLD students. I was feeling very emotional, as I did not want Matthew to go to that school. I posted the form back to the LA rejecting the place at Eastside school and asked them to sort it out. I also asked for the results of the forum meeting which allocated the special school places. The forum results indicated that Eastside school had been awarded on 30th October, before the official deadline for evidence. From this time, it took four months until finally we were asked if we would consider a place for Matthew at Woodside school. I checked the mileage and found that it was actually the same distance as the other autism specific school. We were offered the place and accepted it. Matthew started at Woodside school at the beginning of year 7 and the change in him has been amazing. The school use appropriate honesty with him, they explain things, give him as much information as he can deal with and generally no-one shouts. It's been the making of him!

If I think about a typical day with Matthew, well there isn't really a typical one, at the moment he has been getting up at 6.30am. He can dress himself, but he needs a lot of encouragement and I still put his socks on for him, even though I know he can do it at school. I have to coordinate everything as he's not at the stage of getting his school bag ready or anything. He comes down stairs and has his breakfast. He sits there and allows me to do it all for him, partly because he's got autism and partly because he's a boy. Then we wait for the taxi, which comes about 8.10am. The end of the school day is different depending on which day it is. On a Wednesday and Thursday, Matthew goes to an after school club straight from school and sometimes on a Friday he is collected by a carer. On the other days when he comes straight home and goes upstairs for about an hour to de-stress. Then he will have a snack and sometimes we go swimming or we might play a board game, such as Monopoly. However, we have to play by his rules and I have to lose all the time and he has to win, otherwise he gets quite stressed. If you get Mayfair or Park Lane in Monopoly, you might as well just go and hang yourself, really it's not worth playing otherwise. We have tried to teach him that you can actually win the game by buying other properties, but it's a slow process.

On a non-school day, sometimes he can be awake from 3.30am and then he's up for the day, he doesn't seem to need the sleep. He's definitely more tired on a school day, which is when we tend to get more sleep, but not always. He also sleeps more in the summertime and less in the winter, as he's scared of the dark and quite likes it when its light outside. He'll stay in his bedroom more when its light outside, whereas in the winter he gets quite traumatised. He's not actually able to tell us this, but through trial and error we've worked it out. When he was a lot younger and would be awake during the night, I used to have get up with him and stay with him, because he was unsafe. These days if he is awake early, he will go on his iPad and stay in his room or sometimes he'll come into our bed. When he gets hungry he'll go downstairs and get something to eat and watch TV for a while. At weekends, on every other Sunday Matthew goes to a carer's house and in between times he goes to a play scheme. At other times, he will take the dogs for a walk with me. However, his anxiety can

prevent him from walking very far and he often just wants to stay at home. He loves the dogs, he licks their ears and he sucks them too, which is disgusting, but they don't seem to mind.

In terms of his interests, at Christmas time Matthew likes Christmas lights and we have a huge display of at home. He always likes being in control and so is interested in padlocks, security systems and key pads. He likes anything to do with school that makes him feel safe, as feeling safe is his ultimate aim. If he feels safe, he's a pretty chilled kid, but it's difficult to get him to that point. By contrast, he doesn't like people being in his house, so if someone unknown was here when he got home from school he would be very cross. He enjoys talking to people, but sometimes asks people random questions. For example, if we are shopping in Sainsbury's, Matthew might suddenly ask someone if they have got an eight-inch hammer drill. I wish he would check with me first, as I could explain that they are not going to sell it here. Furthermore, when he is here we have to be so careful about what we say about anything, as he zones into certain aspects of our conversations at home. For example, I had recently bought a lottery ticket and I was having a conversation with my husband about the pointlessness of gambling on the lottery and he had taken it all completely out of context and concluded that I was a gambler. His head is like a 'belisha beacon' on alert for anything. I think it's because having anxiety creates a heightened sense, so that you hear more, see more and smell more. Also with his autism, he has an acute sense of hearing and so he hears things that he shouldn't hear, that aren't designed for him, or he actively comes out to listen as well.

Matthew is extremely verbal, but that doesn't always mean he's very able, it depends on his level of anxiety. Over the years Matthew has suffered with his anxiety to such an extent, that there have been times when in coping with his autism, his anxiety has increased to such a point that he couldn't even leave the house. This is really sad because if he had had the correct education to start with, he might not be at the autism specific school now. He might have managed at a different school and we might have been able to do it the other way around. So, I'm angry about all that really. His anxiety can be so really debilitating and so he has cognitive behavioural therapy (CBT). However, he has to go to London for the hospital appointments and since the terror attacks he doesn't like going up to London and gets highly anxious.

Living with Matthew, makes it difficult for us to go out socially. We don't go to parties and very rarely go to family events. Our family don't really get autism and so they don't make any allowances for Matthew. For example, when we do see family, it would be so much easier if they would tell me in advance what they are making for dinner, so that I can decide if Matthew will eat it. However, they like dinner to be a surprise and they don't seem to realise that surprises are difficult for Matthew to cope with. Another example of the difficulty of spending time with family happened over the New Year period. We decided to go away with my parent-in-laws to stay in a cottage. However, they were not tolerant of Matthew being noisy and they had certain expectations for mealtimes. It was a huge cottage and so there was plenty of room for everyone. However, on New Year's eve my parent-in-laws decided that they would sit in the children's lounge and watch TV altogether. They

wanted to watch programmes, such as National Geographic and Country File, which didn't interest Matthew. He soon became bored and started to make a noise, getting louder and louder and they kept telling him to be quiet. It became so difficult that in the end I decided to take Matthew off in the end into the kitchen, to keep him entertained for a while play snakes and ladders. My parents-in-laws had made a casserole for dinner, but I knew that Matthew wouldn't eat this and so I explained that I would cook some sausages and mash for Matthew instead. They couldn't understand why Matthew wouldn't want the casserole, so I tried to explain that we've all got different tastes. My parents-in-laws expected that we would all eat at 8pm in the evening. This was too long for Matthew to wait, so I explained to my parents-in-laws that I would give Matthew his food a little earlier and then he could join us at the table for his pudding. My parents-in-laws accepted this and so Matthew joined his at the table for his pudding. However, a while later he started to get bored and so I let him leave the table. Despite this, his grandad insisted that Matthew came back to sit at the table, but I told Matthew that it was ok for him to go. A while later Matthew returned to the table and started to get louder and louder and my father-in-law got very annoyed and angry about the noise, explaining that he'd had enough of it. There was a deathly quiet, it was horrible atmosphere and I didn't want to be there any longer, I really wanted to go home. It was really upsetting for Matthew too. I managed to calm Matthew down and eventually we all went back to the table to have dessert. Everyone else had got over the upset, but I was still seething.

Looking to the future, I think it is crucial that the LA understand the importance of more consistency and keeping things the same for our kids. Matthew currently goes to an established play scheme, which is perfect for him. The transition into the centre is handled well by the staff. We just wait in the car and one of the play workers comes and collects Matthew from me. However, the LA plan to withdraw the play scheme and replace it with another provider. When this happens we will lose one of our main respite opportunities. Matthew won't go to the new provider because he's had a bad experience there, he screams at the door and you can't get him in, as he doesn't feel safe. I can't leave him there, as it's meant to be respite, so I feel a bit bitter about that.

My final thoughts are that Matthew has definitely changed our lives for the better. It has definitely been challenging, but he is hilarious and I wouldn't have taken the career path I've taken without him. It has opened my eyes to so many differences and possibilities, how thin skinned people or thick skinned are, not in my backyard kind of thing, whilst being challenging and irritating at the same time. You know, you sort of reach the depths of despair and then the heights of euphoria.

Almost a year later:

Ana's elder son had previously questioned the appropriateness of his diagnosis, actively resisting it. However, he has now accepted and recognises the diagnosis. He is also more willing to engage about it and now accepts that it makes his life a bit easier.

8.11 Appendix 11: Example of individualised interview schedule

Parental second interview schedule:

Part 2- Exploring the perceptions of parents of children with autism of their experiences of attitudes towards autism

Probes

- Why?
- How?
- Can you tell me more about that?
- Tell me what you were thinking?
- How did that make you feel?

Parents-in-law

You said in the 1st interview *'they have nothing to do with us...I think the last time the boys saw them was just before Christmas for maybe 10 minutes and we've decided to cut ties because it's one less hassle one less strain...'*

Can you tell me more about that?

- How does that make you feel?
 - Do you feel misunderstood/judged/stigmatised in some way?
1. Could you tell me how often you see them?
 2. Do you feel the way they behave hinders your life in anyway?
 3. Could you tell me what you perceive about M's parents' attitudes to autism?

Friends (who are no longer friends)

You said in the 1st interview *'people who we would maybe no longer maybe associate ourselves with and we've seen a difference in and their attitude towards us or the fact that they've completely shun away from us...'*

1. Can you tell me more about that?
 - How does it make you feel?
 - Do you feel misunderstood/judged/stigmatised in some way?
2. Do you see them anymore?
 3. Do you feel the way they behave hinders your life in anyway?
 4. Could you tell me what you perceive about 'these friends' attitudes to autism?

Social worker or SALT

You said in the 1st interview (SW) *'we don't see her much...as much as I'm quite grateful for the things that we've had put in place, I do feel that if you're not sort of telling them you're going to jump off a bridge today...'*

You said in the 1st interview (SALT) *'I'm normally aarr inside because I've got all this going on with SALT and OT and you're fighting for something else...I can't give up because they'd have nothing if I do...'*

1. Can you tell me more about them?
 - How does that make you feel?
2. How often do you see them?
 3. Do you feel the way they behave hinders your life/child's life in anyway?
 4. What do you perceive about their attitude to autism?

PA's

You said in the 1st interview (M and L) *'my PA's are my lifeline...they sort of alternate when M' at work just to help me get out and about really because I literally can't leave the house without a second pair of hands... even on days I could do with a third pair of hands, you know you just think should I even leave the house today? They help me support the boys to go out and about and make sure they are safe, they have a drink and a snack and we all get back safely...'*

1. Can you tell me more about that?
2. How often do you see them?
3. Can you describe how their support helps you?
4. What do you perceive about their attitude towards autism?

Final further questions:

5. Could you tell me (the people who you have talked about) how their attitude towards you and your child with autism impacts overall upon your family's ability to function?
6. Or perhaps you think there are other more significant factors? (Please give examples and explain in detail)
7. Anything else about general attitudes in society to autism?

8.12 Appendix 12: Example of IPA analysis for Ana, with superordinate and subordinate themes

IPA analysis for Ana

Ana is the mother of two sons with a diagnosis of autism. Her boys also have half-siblings from her husbands' first marriage. The focus of the interview is upon her younger son Matthew, who has additional learning difficulties. Matthew is verbally very able, but he suffers from high levels of anxiety. Matthew's schooling began when he attended the special needs unit attached to a mainstream primary school. At the time of this interview Matthew was attending an autism specific school. The analysis covers Ana's experience of a range of supportive and unsupportive attitudes to autism. It mainly focuses upon Ana's mostly positive experiences of the attitudes of her local GP surgery, this is followed by contrasting experiences of the attitudes of grandparents and siblings. Ana also touches upon the attitudes of a playscheme provider and Matthew's current school with regards to ignoring the safeguarding needs of children with autism and learning. She also talks about the related experiences of subtle exclusion.

Two of the superordinate themes, **What unsupported attitudes to autism look like** and **How judgements about autism makes me feel** encompass Ella's experience of unsupportive attitudes to autism. The superordinate theme **Supportive attitudes to autism** explores the positive support from the GP surgery and the positive ways that Ana's mother helps to support Matthew. The superordinate theme **Coping with unsupportive attitudes to autism** explores what Ana does to manage difficult attitudes and how the support from her mother has a moderating effect. The final superordinate theme **What needs to change going forward** brings to light some of Ana's view that there needs to be more autism training and more awareness to consider the possible underlying reasons for behaviours about autism. However, she feels that parents also have a responsibility to challenge their children to learn to respect boundaries, rather than using autism as an excuse. Her final thoughts are that that we should strive for genuineness in society.

Superordinate and subordinate themes for Ana

Supportive attitudes to autism

The GP surgery don't keep us waiting

The importance of knowing what to expect

Understanding that his needs are genuine

Practical help

What unsupported attitudes to autism looks like

Why is he behaving like that?

'Will you be quiet!'

Feeling you can't challenge the views of family members

They think he does it on purpose

Thinking exclusion is the solution
The hidden safeguarding risks for children with autism and a learning disability

How judgements about autism makes me feel

I know when people are judging
You could sense it, you could feel it
I feel angry and resentful
It feels unjust because other people have choices

Coping with unsupportive attitudes to autism

We've adapted ourselves around them
Having to take your child out
Coping with glaring looks
Support from my mum

What needs to change going forward

Keep autism training up to date for GPs
Autism shouldn't be an excuse to say whatever you like
Focus on what's causing the problem
We need genuineness

Supportive attitudes to autism

The GP surgery don't keep us waiting

That they get us in pretty quick for an appointment if I have to take Matthew with me

Ok ok

Literally just last week I had to go to the doctors myself and I'd forgotten to tell Matthew in the morning that he would have to come with me, so when he got home from school

I said 'Look Matt really sorry, I've got to go to the doctors, you need to come with me, here's some chocolate, just can you go with it please'.

And he wasn't having any of it, and we got there and he's giving all the other patients the middle finger, and making it very clear about how he feels about being there and effing and blinding

And this is in the waiting room?

In the waiting room

Ok ok

And the doctor came out within about a minute and said 'You can wait in here, it's fine, they are brilliant'

Exploratory comments

Ana explains if she needs to take Matthew with her to the doctors that the surgery are very quick to give her an appointment. Ana describes the difficulties of taking Matthew with her but how the doctor offered another waiting room for them to sit in and also how quickly they were seen.

'pretty quick' 'within a minute' 'you can wait in here' – language indicates supportive attitudes

'forgotten'- language infers that it was a mistake to not give Matthew advance warning
'I've got to' 'you need to' 'some chocolate' 'just can you go with it please'- persuasive language, chocolate is an incentive or distraction
'he wasn't having any of it' – not wanting or able to comply
'he's giving the other patients the middle finger'- language indicates that Matthew isn't happy

'effing and blinding' – language indicates that he is swearing

The analysis highlights that parents of teenage children with autism and learning difficulties are not able to leave their children at home on their own even for short periods of time. This is usually not the case for parents of typical teenage children and also perhaps some teenage children with autism and no learning difficulties

In view of this, the additional challenge for this group of parents when needing to carry out routine tasks, such as to attend a doctors highlights a further burden for these families.

Some parents might need to attend appointments for themselves whilst their child is being cared for by another family member or by someone else

The analysis also highlights the importance of preparing children with autism so that they know what to expect and the difficulties that often arise when springing unexpected events on them

It is evident that the doctors surgery recognise the difficulties of attending appointments for parents like Ana and are very accommodating, providing appointments quickly and ensuring that there is a quiet space to wait

However, is it an understanding of autism or is the bad language that triggers support. Would the same support be forthcoming for a parent with a child with autism, with no spoken language, whose needs may be less visible?

The importance of knowing what to expect

Oh she would forewarn Matthew beforehand

What would she forewarn him of?

So when he stayed at her house

Ok

She called up and said 'Could you let Matthew know that I've got cottage pie for tea

Ok, ok

and that we'll go to the [name of café] in the morning for breakfast and then I'll take him to get his haircut, so he knows'

What to expect

Actually she'd probably do haircut and then [name of café]

Yeah yeah

So that he gets it as a reward

So it's that taking away the surprise and

Yeah

And understanding that that that's important

Yeah and she'll get the telly set up for him so that he can watch Worzel Gummidge, because he likes that

Yeah [laughter]

All those little things that she'll put in place, make sure that she's got the bubble bath that he likes, or a bath bomb or something, so that he feels relaxed

Exploratory comments

Ana describes the preparations that her mum puts in place for Matthew before he goes to stay with her.

'forewarn' 'beforehand' 'could you let Matthew know' 'so he knows' – language indicates the need for planning

'cottage pie for tea' 'Café in the morning for breakfast' 'haircut' 'telly set up' 'bubble bath'

'bath bomb' – language indicates planning and working with interests

'then' – structures things in an order, so you know what to expect

'reward' – determines order of things

'those little things' – irony that little things often make the biggest difference

'she'll put in place' – organised

'feels relaxed' – focus on happiness

The analysis highlights that it is important for children with autism to know what to expect.

Parents/carers will often put in place lots of pre-planning to support their children. It is evident that Ana's mum is trying to do all she can to keep Matthew happy during their time together and understands the importance of Matthew knowing what to expect.

The analysis also reveals the importance of knowing the child's interests

Many children with autism and learning difficulties may benefit from visuals to help structure day and support their understanding of what to expect

Understanding that his needs are genuine

And why do you think she's like that?

Because she's a nice person

Yeah, ok

But, because she gets it! She's seen the flip side, when these things don't happen. She doesn't see it as a erm spoilt child getting their own way

Yeah

She sees it as a genuine

Yeah

If things, if we try fit a square peg into a round hole

It's not going to work

You are going to get problems.

Exploratory comments

Ana explains why her mum is so supportive of Matthew. She understands the effect on Matthew if the right things are not put in place and she does not view him as a spoilt child.

'nice person' – tone of language if slightly flippant

'she gets it' – the phrase encapsulates understanding of what it is like

'seen the flip side' – has experience of the opposite

'when these things don't happen' – refers to if planning ahead does not happen

'spoilt child' – refers to behaviour

'sees it as genuine' – views needs as real

'square peg into a round hole' – common phrase used to describe individuals with autism not able to fit in with the neurotypical world

Through exploring the grandmothers' view of Matthew's autism, the analysis highlights that Ana does not think that everyone else is as supportive and understanding of her son's needs

The references to 'spoilt child' versus 'sees it as genuine' draws attention to this. There is a wider issue of societal misconceptions and misunderstandings of behaviour as originating

from 'bad parenting' rather than reflecting the underlying often unmet need or anxiety of children with autism

Practical help

Well she'll come on holiday with us and she'll share a bedroom with him

Ok

And she'll say 'Just go and get yourself off to bed and I'll sort him out'

Yeah

So she'll do all of that, she'll help him in the shower, all those sorts of things

Exploratory comments

Ana explains that her mum will come on holiday with the family and help with Matthew.

'on holiday' 'share a bedroom' 'shower'- language depicts tangible aspects of help

'go' 'off to bed' 'I'll sort him out' – language emphasises how the grandmother takes the responsibility

'all of that' 'all those sorts of things' – suggests she also provides lots of other help

Having practical help is important for families of parents of children with autism and learning difficulties, in order for them to sustain their caring role. Going on a family holiday can be difficult for these families, but having help from a close family member can sometimes make this possible

The analysis also draws attention to the reality that children with additional LD often need on-going support with personal care tasks, such as bathing, teeth brushing and toileting.

These aspects of care continue to be needed on family holidays.

What unsupported attitudes to autism looks like

Why is he behaving like that?

I think if we get a locum sometimes they don't get it

Ok ok so there are occasions when, when it's not quite as good as it could be

Yes, because they're kind of like, why is he behaving like that?

Ah ok ok

Well it's because he has autism and he's really anxious and he doesn't want you looking at his stomach or his willy or whatever you've looking

Exploratory comments

Ana explains that if the surgery has a locum doctor on duty, that they don't always understand about autism and question why Matthew is behaving as he does. Ana tries to explain that Matthew has autism and gets anxious and does not want to be examined.

'they don't get it'- language represents understanding or not understanding of autism

'they're kind of like'- strongly implied

'why is he behaving like that'- suggests behaviour is not in line with usual expectations

'really anxious'- language emphasises how uncomfortable the situation is for Matthew

More training may be needed for GPs and locums, so that parents have a more consistent experience

All health professionals should have a good understanding of autism and you should not be left feeling that you need to explain about your child's behaviour

Unsupportive attitudes make accessing healthcare more difficult for individuals with autism and LD, this effects long-term health outcomes. An unsupported attitude becomes a subtle form of unintended exclusion

‘Will you be quiet!’

And there's a room next door, that if they don't like it

They could go in there

They could go in there, but they didn't and [my husband's] going ‘Matthew be quiet’ And I'm come on Matt, come over here and we'll make some jellies and then he came into this area and there was something on the telly that and [husband's] dad went ‘will you be quiet!!!’ [said very loudly] and it's just like no, not in my house.

Exploratory comments

Ana recalls that her parents-in-law were staying and Matthew was being noisy. She was trying to distract him by encouraging him to help make some jellies. There was another quiet room that her parents-in-law could have gone to sit in to avoid the noise, but they stayed and then the grandfather got annoyed and shouted very loudly ‘Will you be quiet’. Ana was not happy about this outburst.

‘if they don't like it’ ‘they could go in there’- language emphasises options for the grandparents to avoid noise

‘Matthew be quiet’ – tone of father is calmer than the grandfather

‘come on’ ‘come over here’ ‘we'll make some jellies’- distractions

‘will you be quiet’ – Outburst, tone of voice is very loud and angry

‘it's just like no, not in my house’- language reflects that Ana feels that shouting at Matthew is completely wrong

Ana's recollection of the tone of the grandfathers indicates a negative attitude to autism.

Some family members need to do more to understand and support the needs of their relatives with autism

The analysis indicates that both parents felt pressured to try to manage the situation and suggests that they both did not want to upset the grandfather. Ana tries to use distractions, whilst her husband asks Matthew to be quiet, but in a calmer tone than his father.

Having an alternative room for family members to go and sit in will provide some space for everyone, but this will only work if everyone respects the needs of children with autism

There is a sense that the grandfather thinks that his needs come first and Matthew should be able to comply with requests to be quiet, out-dated views

The grandfather is being inflexible, opposite of what is needed for children with autism

Feeling you can't challenge the views of family members

if I had challenged him, he would have, my father-in-law would either have sulked, he would have said he couldn't hear me or [my husband] would have probably died [not literally] on the spot

Exploratory comments

Ana explains did she did not feel that she could have challenged the behaviour of her father-in-law

‘challenged him’ – been critical of her father-in-law's reaction

‘sulked’ ‘couldn't hear me’ – expected responses

'would probably have died on the spot'- feeling very embarrassed

The analysis indicates that Ana felt that the expected repercussions of challenging her father-in-law's behaviour did not make it an option

Expected repercussions based upon previous experience of father-in-law (see 1st interview data)

I suggest that this make parents feel powerless and unable to change the situation going-forward

Specific need to target awareness of autism to grandparents and older generation, to increase understanding and change attitudes

They think he does it on purpose

people just seem to think that he does it on purpose

Ok

'You know, I know he can do it, I've seen him do it before'.

But it doesn't mean that he can do it this time

Yeah, when you say people who do you mean?

The brothers and sisters

The brothers and sisters, yeah yeah

They will say things like 'Yeah well I know he understands'

It does not mean to say he can do it though, just because he understands

And is this [brother] or half siblings?

This is all of them

This is the half siblings

Yes, they just don't have that level of understanding that says because you've done once that you're necessarily going to be able to repeat that

Exploratory comments

Ana expresses her frustration that the brothers and sisters think that just because Matthew has been able to do something before that he can do it again.

'just seem to think'- not really thinking

'does it on purpose'- intentional and being difficult

'he can do it, I've seen him do it before'- Language emphasises the view that because someone has been able to do something, they are able to do it again

'this time' – at this point in time feelings and anxiety may be different from last time

'It does not mean to say he can do it though, just because he understands'- understanding something is not the same as being able to do it

'level of understanding' – siblings no not have enough in-depth understanding of Matthew's autism

The analysis highlights how there is sometimes a gap in real understanding of autism amongst family members. It is important to look for the underlying reasons in order to understand the reasons for behaviour

Thinking exclusion is the solution

so I went back to the school and I said to the police 'look can you speak to the school please, on my behalf because they are not listening to me, this can't happen again, they have to have a risk assessment.'

Yeah, yeah, yeah

And the school's said 'maybe it means that Matthew can't go to these tournaments.' No it means, that Matthew can go to the tournaments, but you need an extra member of staff

Exploratory comments

Ana explains about a safeguarding issue that occurred which involved Matthew being inappropriately touched by a child from another school. She perceived that he would be at risk if he came into contact with the child at an inter-school sports tournament. She had asked the police to talk to Matthews school about having a proper risk assessment. The schools' attitude was that Matthew would not be able to go to the tournaments, whilst Ana's view was that an extra member of staff should be there to keep Matthew safe.

*'on my behalf' 'they are not listening to me' – language emphasises that Ana feels ignored
'can't go' – view of the school exclusion*

'can go' – view of Ana inclusion

Case of power distancing, the school ignoring the concerns of the parent

The analysis reveals an example of a school using exclusion as a way of safeguarding a pupil, rather than providing a proper solution. Are schools always aware that some decisions are examples of exclusion? In this case, it positions the problem as the child, rather than trying to find a solution that does not involve exclusion. There are parallels here with viewing behaviour, as challenging behaviour, that is the problem is within the child

The hidden safeguarding risks for children with autism and a learning disability

if it had been a girl that this boy had touched, I think it would have been different and I think if they both hadn't had autism, it would have been different

Ok

So I think there's something in the fact that there's a learning disability and ASD involved and that it was boy on boy, that as a society, it's disregarded as not being a problem

I see

There's definitely something that were missing and even his school are missing it

Exploratory comments

Ana explains that she thinks the risk to Matthew was not taken seriously by anyone because the incidents happened between two boys with a learning disability and autism.

'touched'- inappropriate touching

'it would have been different' – repetition emphasises Ana's view that LD and autism are not taken seriously enough

'I think there's something in the fact that there's a learning disability and autism' – language emphasises that this segment of children are overlooked

'disregarded' 'not being a problem'- ignored

There seems to be insufficient awareness of some of the potential safeguarding risks for children with a learning disability and autism

Whilst we need to do more to improve the health outcomes for people with learning difficulties, we also need to do more to raise awareness and improve safeguarding for this segment of society across settings and ages

How judgements about autism makes me feel

I know when people are judging

Oh definitely, there's no doubt

And in what way could you describe that they were judging you?

It was just the looks on their faces

Ok

Nobody looked particularly sympathetic

Ok ok

But then I'm not sure, I would look very sympathetic if somebody was giving me the middle finger, when all I was doing was waiting to see the doctor

Yeah

If I didn't have the knowledge I've got

Exploratory comments

Ana recalls her experience of being in the doctors waiting room and being judged by others about Matthew's behaviour.

'definitely' 'there's no doubt'- language reflects feeling of certainty

'looks on their faces' 'nobody looked particularly sympathetic' – perception of people's faces reflecting their thinking

'I'm not sure'- doubts about whether people should be sympathetic or not

'knowledge'- Having knowledge may alter how you perceive behaviour

Parents often experience unspoken judgements from strangers in public places, these are sometimes so subtle that they go unnoticed by others.

When strangers do not verbalise their judgements, this gives parents less opportunity to respond with an explanation for their child's behaviour and takes away the chance to educate and potentially alter the viewpoint of others

In these situation there is the potential for parents to experience felt-stigma

In anticipation of encountering judgements in public places, parents may choose to isolate themselves, for example avoiding doctors' appointments. Possible impact to health outcomes if you feel unable to access healthcare

You could sense it, you could feel it

Ok ok, so it was nothing that anybody said?

I didn't hear them if they did

It was more the looks that you get off people

You could sense it, you could feel it

Ok that's interesting

Yes it was definitely, almost like a erm like, like somebody had climbed on your back

Yes that's interesting

Very heavy it felt

Exploratory comments

Ana was not aware of anyone making a comment about Matthews behaviour, but she could feel the judgements.

'I didn't hear them'- Not aware of any spoken comments

'sense it, feel it' 'like somebody had climbed on your back' 'very heavy it felt' -language reflects knowing you are feeling judged

Ana describes how she can sense and feel that she is being judged about her son's behaviour. It's is her perceptions that she was being judged that matter.

It is possible that some parents may have an over-developed sense that they are being judged. This may be in anticipation of their children's behaviour and based upon previous experiences of when they have felt that they were judged. However, unless a stranger verbalises their judgement, we can make misassumptions

Potential for felt-stigma

I feel angry and resentful

Angry

You were angry

Yeah I was very put out that [name of husband] didn't say something

Yeah yeah, and that you were left having to manage the situation

After I'd bloody cooked for them all sodding week as well

Exploratory comments

Ana explains that the attitude of her parents-in-law makes her feel angry. She also feels let down by her husband, as he did not challenge his parents. Ana is also upset because she had been doing all the cooking all week for the family.

'angry' 'very put out' – language reflects feeling unsupported

'Didn't say anything'- the inference is that he should have challenged his parents

'bloody cooked' 'all sodding week' – indicates that Ana took on all the responsibility for cooking

'as well'- language indicates that doing all the cooking added to the unfairness of the situation

The analysis reveals that feeling unsupported by grandparents and spouse in the context of having child with autism makes Ana you feel angry and resentful

Ana's husband appears to behave with a deference to his parents, putting their needs before those of Ana and Matthews for fear of upsetting them

It feels unjust because other people have choices

It feels unjust

It feels unjust ok, yeah

Because other people have choices

Exploratory comments

This part of the transcript relates to Ana's parents-in-law coming to stay. She feels it is unfair that her parents-in-law, in particular the grandfather, are intolerant of Matthew's noise, expecting him to be quiet rather than deciding to go and sit in another room away from the noise.

'feels unjust'

'other people have choices'

The reference to it feeling 'unjust' suggests a power divide between the grandparents and the rest of the family, but it is also 'unjust' because neurotypical members' of the extended family can make a 'choice' to behave differently or more flexibly. This would make a huge difference to both children with autism and their family.

Underlying this attitude is probably a lack of understanding of autism, which means that they do not recognise the need to make allowances for children with autism. They may have an expectation that they should be able to behave according to social norms and fit with their needs and expectations, rather than offering to be flexible by moving into another room. The analysis points to the possibility that Matthew is feeling overloaded and is making noise to try to take back some control over his environment.

Coping with unsupportive attitudes to autism

We've adapted ourselves around them

But we've adapted ourselves to around them. So the last party that they had, which was earlier on this year, erm we dropped Matthew off at my mum and dad's, at my mum and dad's, at my mum's

At your mum's?

He stayed with her overnight and we went up to their birthday celebration

So rather than take him with you

Yeah. We made that call of what he can't cope with and sitting in a big dining area with a four-course meal, wasn't going to happen

Exploratory comments

Ana explains how they manage when there are family special occasions. She recalls how Matthew went to stay overnight with her mother, whilst they attended the birthday celebration for her mother-in-law.

'we've adapted ourselves'- language reflects that Ana's family are being flexible around the need of the grandparents, rather than the reverse

'at my mum and dad's' – perhaps out of habit, instead of mum's

'stayed with her overnight'- reflects the support of her mum

'their'- rather than 'the' tone of language suggests something the grandparents wanted, rather than the whole family

'that call' – judgement

'can't cope with' – increases anxiety

'big dining area' 'four-course meal'- language reflects aspects that Matthew would find difficult

'wasn't going to happen' – language reflects that Ana was clear on the decision

The analysis reveals a paradox, that Ana's family are the ones having to be flexible around the needs of the grandparents in order to attend the family gathering, rather than the reverse. This indicates that the grandparents are unsupportive of the needs of Matthew. In contrast to the support that Ana's mother provides through looking after Matthew and having him to stay at her house. There seems to be a clear division between the support provided by the maternal grandparent versus the paternal grandparents.

The analysis also reveals that Ana is being realistic about what Matthew can cope with and a social occasion with a four-course sit down meal would be too difficult for him. Why does she think this? I suggest that her view is drawn from previous difficult experiences and perhaps also what Matthew has told her himself

Family gathering can be difficult social occasions for families of children with autism to navigate. Difficult choices may have to be made, such as asking the extended family to consider a different setting that may be more supportive of their child's needs and more informal meal arrangements. Or choices may have to be made where the whole family decide to either self-exclude themselves from attending or make other arrangements and selectively- excluding their child with autism

Do families feel supported enough to make the right choices in these circumstances, or do they feel pressured to attend family occasions and then left to cope with the fall-out? Do families feel able to manage any potential criticisms when they make a choice not to attend

or selectively exclude themselves from family occasions? Do professionals need to provide support and reassurance?

Having to take your child out

So then I said come on Matt, we'll go up to the village club, I'll take you up there

So you took him out in the end, that was the only way of managing the situation?

Yes, because if I had challenged him, he would have, my father-in-law would either have sulked, he would have said he couldn't hear me or John would have probably died [not literally] on the spot, erm so what I chose was to take Matthew out and then to have a chat with Matthew and say that sometimes grown-ups do things, erm that they shouldn't do and it feels really unfair

Exploratory comments

Ana explains that in order to get Matthew away from annoying her parents-in-law, that she decided to take him out to the village club

'come on' 'we'll go up' 'I'll take you up there' – language reflects the need to remove Matthew

The analysis reveals an instance of subtle form exclusion which is hidden within some families which becomes a coping mechanism unsupportive attitudes to autism from some family members

Reflects an unwillingness to challenge the attitudes of some family members

This subtle form of exclusion can become normalised within families as a means of managing the behaviour that challenges related to the child, rather than looking more widely at the unsupportive attitudes and other family members

There is the potential to view your child's behaviour as other people do, seeing yourself as a bad parent/self-stigma

Coping with glaring looks

But the people were a lot older they were definitely in their 60s and 70s, so I don't know whether that made a difference?

So these were the people that you felt were being...

Glaring

More glaring at you. And how does that make you feel in that environment, where people are sitting and glaring at you?

Well personally I don't give a s***

Ok, ok that's honest yeah

But it's still not very comfortable either

Would...

I don't care what they think, but I'd rather that they didn't either

Yes ok

because you get this sort of heavy feeling, I don't want that, you can have it back

Yeah ok ok

But I don't get defensive or anything

Exploratory comments

Ana explains that she experienced glaring looks from some of the other patients in the waiting room at the doctors and she explains that they were older people. Ana conveys how she felt about the staring.

'definitely in their 60s and 70s'- language reflects that these were older people

'don't know whether that made a difference?'- difference refers to is the attitude of older people different?

'glaring' – very obvious disapproving

*'I don't give a s****' 'still not very comfortable either' 'I don't care what they think, but I'd rather that they didn't' 'you get this sort of heavy feeling, I don't want that, you can have it back'*

– feelings about the staring seem to slightly mixed and contradictory

'heavy feeling' – physical reaction

'I don't get defensive or anything' – not trying to justify behaviour

The analysis explores how Ana copes with glaring looks from strangers related to her

Matthew's behaviour

She conveys an overriding message that she doesn't care about the staring, but the depth of feeling reveals a more contradictory picture. Perhaps she does not want to care, does not think she should care

The analysis highlights mental and physical impacts from perceiving non-verbal judgements from others

Support from my mum

Yeah I think so and sometimes if I'm having a day where I'm being more sensitive and she is with us she will say 'just don't worry about it, it doesn't matter'

Yeah, so how does that make you feel having a mum that's....

Oh it's brilliant

Yeah

It does make such a difference

Yeah, and how does that make you feel when she, what you just said when you're not having a very good day and she says don't worry about, how does that then make you feel?

Erm, I just appreciate it

Yeah

I appreciate that I don't have to make allowances, I don't have to explain myself, I think that's what we want most of the time

Does that counterbalance some of the difficult aspects of having to cope with the other side of the family with your parents-in-law that aren't like that?

Definitely, my husband finds it hard, because I think he wishes that his parents were more like my mum

Exploratory comments

Ana explains that if she is having a difficult day that her mum will reassure her and tell her not to worry, she does not feel that she needs to explain herself or make any allowances.

Her husband wishes that his parents were like her mum.

'more sensitive' – feeling more vulnerable

'just don't worry about it, it doesn't matter' – reassuring language

'brilliant' 'such a difference' 'just appreciate it' – language reflects feeling supported

'I don't have to make allowances, I don't have to explain myself' – not wanting to feel judged for what we do

'finds it hard' – contrasting experience of husband and his parents

The analysis highlights the importance of having good social support as this can act as a moderator to counteract the effect on well-being of unsupportive attitudes

What needs to change going forward

Keep autism training up-to-date for GPs

Just if they could all be like that, it would be great!

Yeah

You know they need to keep that autism training up-to-date, definitely erm

Exploratory comments

Ana explains that it would be great if all GP were as supportive and that it's important for on-going autism training

'if they could all be like that' – all be supportive

The analysis highlights that parents need to be able to anticipate a consistently good experience of supportive attitudes when visiting their GP

Autism isn't an excuse to behave however the hell you like

I don't expect everybody to you know sort of smile nicely and wave, if he's got the hose pipe over the fence, soaking the family dog, because that sort of thing, I would expect somebody to be a bit cross about that

Yes ok

And even if I was say 'I'm really sorry, my son's got autism'. It might be 'I don't care what he's got, we were just walking up the road to church and he's soaked us.'

So yes

Does that make sense?

It does, yes it does

So we still need to be challenged

We still need to be challenged, yes

About, you know I think it's boundaries, it's attitudes, you know autism isn't an excuse to behave however the hell you like

Ana explains that she does not expect other people to be overly tolerant of her son's behaviour. She thinks there should be limits and in the end everyone needs to be challenged and learn to respect boundaries

'sort of smile nicely and wave' – false response to behaviour

'hose pipe over the fence, soaking the family dog' – behaviours that challenge

'we were just walking up the road' – language reflects that you should be able to carry out ordinary routines

'would expect' 'be a bit cross' – should not tolerate

'challenged' 'boundaries' – behaviour should not be just tolerated

'autism isn't an excuse to behave however the hell you like' – language powerful sums up that behaviour should be challenged

The analysis highlights the need to try to support learning boundaries

Whilst this is a good aim, I suggest that this may be easier for some children than others, depending on cognitive function and level of understanding. It might be better to seek an understanding of the underlying reasons and motivations for behaviour that challenges and try to support this, perhaps with alternatives. Whilst we all need to learn to co-exist, the onus should be placed upon people who can be more tolerant and flexible to support the needs of children with autism and their families

Some families will have children with autism whose behaviour challenges in ways that they feel they have little influence over. Without sufficient support and tolerance, these are the families who may feel unable to interact with the community and are at great risk of social isolation, potential loss of well-being and risks to mental health

Focus on what's causing the problem

I was observing a boy with autism and he had his shirt hanging out and he went up to the teacher and the teacher said to him 'How many times, how many times do I have to tell you to tuck your shirt in?' And afterwards I went to see the teacher at the end and I said 'You're

probably have to keep telling him loads, unless you've got something up in the class that says 'Shirts need to be tucked in' or you find out why he untucks it, you know what might be going on?

Yeah, yeah

Is it sensory, is there a label there that's really irritating him

Yes absolutely, yeah yeah

So I said 'You know, rather than blaming him for it, let's look at what's causing the problem

Exploratory comments

Ana was doing some observations in a school classroom and explains that the teacher could not understand why a boy with autism would not tuck his shirt in

'find out why' 'what might be going on' 'look at what's causing the problem' – language reflects the need to take an open-minded exploratory approach

'is it sensory' 'label' 'irritating him' – clothing sensitivities

'blaming him for it' – represents an attitude

Schools need to have an open mind and explore the possible underlying reasons for behaviour that challenges, rather than adopting a blame mentality. I suggest a blame mentality reflects a lack of knowledge and awareness of autism

Sensory sensitivities to clothing are a common issue for children with autism and wearing school uniform can be difficult. Schools should adopt a flexible school uniform policy, in order to support the needs of children with sensitivities

We need genuineness

No I think attitudes is important, acceptance is more important

Yeah yeah

But to be able to accept you've got to have a good attitude

Yes, yeah yeah

If you've got a poor attitude then you're not going to be anywhere near to acceptance

So if you sort of turned it around and you sort of imagined a world where everybody was like your mum, in terms of your kind of experience with your boys and everywhere you went everybody was very understanding and accepting, going to the doctor's and everyone sitting in the waiting room didn't sort of bat an eyelid and were sympathetic

That would be amazing wouldn't it [laughter] It would be amazing

It would be amazing

But would we grow from it as well, because we grow from experiences

Yeah, do you want to say any more about that?

Well I wouldn't have learnt half of what I've learnt, if everyone was nicely accepting.

Ok, ok

I certainly wouldn't have had my own exploration of self-awareness

Yeah, yeah

So I think there are two sides to it really. I think some of it depends on your own experiences growing up, I wouldn't want everyone being nice all the time, it would drive me mad

Ok ok, it would would it? ok ok

Well I think it would wouldn't it [both laughter] it would be very 'Stepfordy' really, because you wouldn't be genuine

Yeah yeah

So I think if you could have genuineness

Yeah, yeah

It's better than attitudes

Exploratory comments

Ana explains that she thinks acceptance is more important than attitudes, but to get to acceptance you need to have a good attitude. However, she doesn't think too much acceptance is good, as we would not learn from our experiences. She thinks we need people to be genuine.

'important' 'more important' – both attitudes and acceptance are important, but the latter is more so

'to be able to' – enables

'not going anywhere near' – not going to be possible

'Amazing wouldn't it' 'it would be amazing'- tone infers that this is a good thing

'would be grow'- tone is reflective

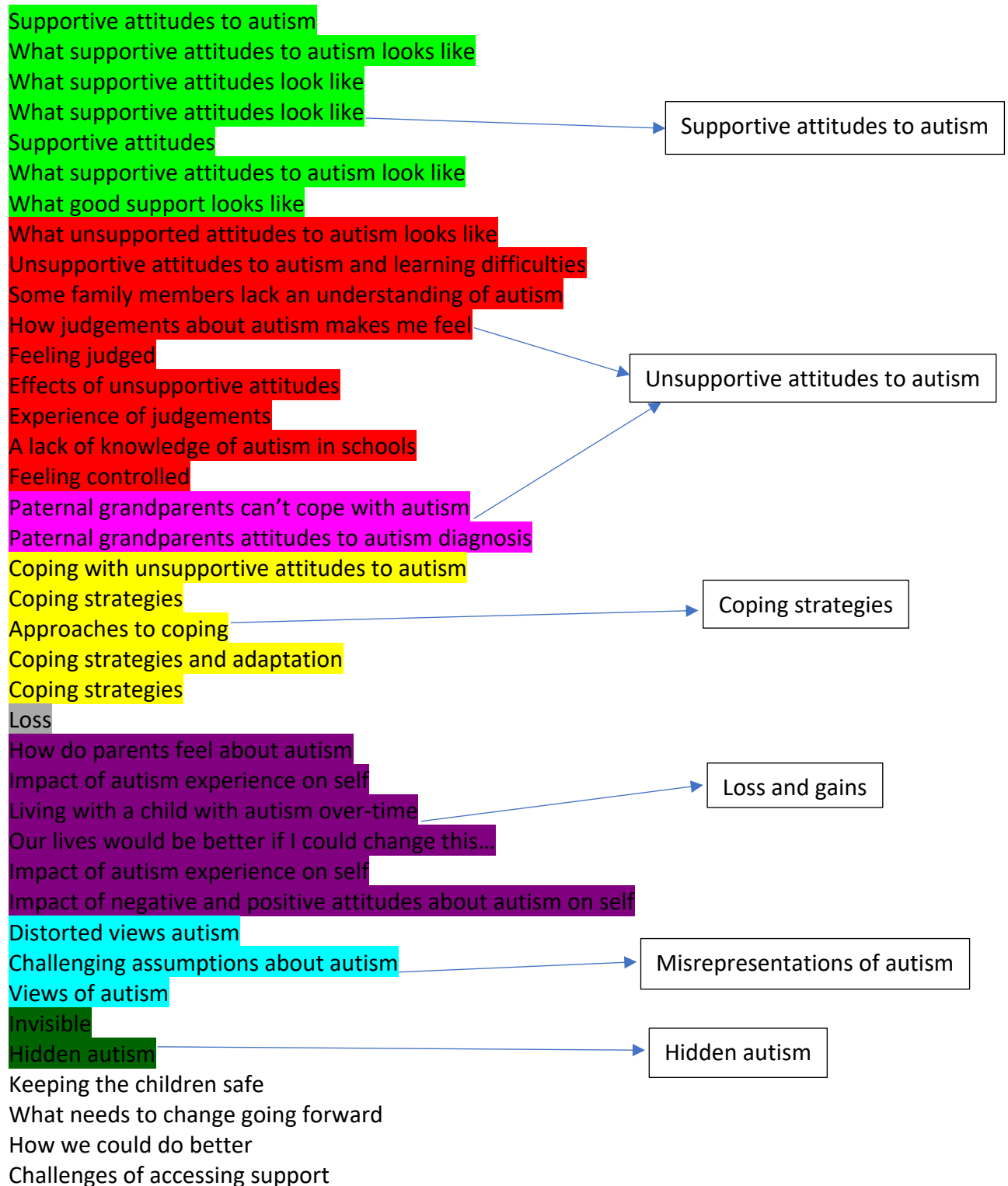
'grow from experiences'- tone is reflective

'nicely accepting' – the use of nicely, infers that being too accepting is not something we should strive for

'Stepfordy' – reference is to the film 'The Stepford Wives' and means too compliant

Ana's view is that a good attitude is essential for acceptance. However, being too accepting could be almost too compliant and not healthy for anyone. She thinks we all need to be challenged more and strive for genuineness in society

8.13 Appendix 13: Master listing of superordinate themes organised into clusters



8.14 Appendix 14: Example of analysis across cases

		Final superordinate theme: Approaches to coping					
		How subordinate themes clusters at group level data					
Group level subordinate theme clusters		Social support	Problem-focused coping	Time out	Avoidance coping	Ignore staring	Positive re-framing
	Parent						
Idiographic level Subordinate themes	Ana	Support from my mum	We've adapted ourselves around them		Having to take your child out	Coping with glaring looks	
	Diana	My sister is my advocate	Always thinking ahead	Interactions with people at work	Avoidance	Being thick skinned	
	Ella	The importance of social support and keeping sense of humour Making friends with parents in a similar boat	Being flexible and problem focused Careful planning Adapting to sensory sensitivities				
	Iona	The right team of people		School as respite	Avoidance	Needing to have a thick skin	
	Becky	I started to live my life		Going to work	Ignoring negative comments		My love for my child keeps me going Focusing on the positive gains from understanding autism
	Jayne		Re-defining family expectations		Moving on from trying to explain autism to everyone		
	Helen and Charles	Maternal grandparents adapting to autism	The need for constant vigilance Maternal grandparents adapting to autism				