Falling into an abyss: An Interpretative Phenomenological Analysis of the lived experiences of the parents of autistic daughters in the UK

Thesis submitted in accordance with the requirements of the University of Chester for the degree of Doctor of Professional Studies in Psychological Trauma by Lucy Chantrey

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Declaration

I declare that the material being presented for examination is my own work and has not been submitted for an award at this or any other Higher Education Institute

1st November 2021

Dedication

This thesis is dedicated to my family. To my husband Julian for his constant love, support, encouragement, and belief in me, particularly in the more challenging times when I was earnestly questioning the wisdom of my decision to undertake this study. And to our three wonderful boys Robert, William, and Nicholas, for patiently humouring a sometimes distracted and occasionally exasperated mother.

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I would like to thank the parents who took part in this study for their generosity, bravery, and determination to change for the better the future for the parents of autistic girls. Each time I read your heartfelt words, I am reminded of your strength and resilience.

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Abstract

Whilst research increasingly focuses on autism in girls, there is a dearth of literature around the experience of parenting an autistic daughter in the UK, with the few studies that do focusing only on mothers. The data was gathered through in-depth semi-structured interviews that explored the lived experience of parenting an autistic daughter for six mothers and two fathers, from their first concerns, through to the diagnosis, with life in-between and beyond. Their daughters were aged between eleven and seventeen at diagnosis and were diagnosed within the UK. IPA was used to analyse the data. Five superordinate themes were identified: Journey to diagnosis; Negotiating systems; Psychological impact; Living with an autistic daughter; and Reflections. The research demonstrates that the parents of autistic daughters find themselves seeking professional advice and support for a pervasive condition that, whilst better known for its familiar male presentation, appears invisible in its female form to all but those in their close family. The impact of the ensuing struggle to have their concerns believed and to obtain her autism diagnosis often has profoundly negative consequences, leaving families in crisis, chaos in daily life, and parents' mental and physical health compromised. The subsequent delay in diagnosis means that their daughter remains unsupported in her education and social life, with the adverse ramifications of this reverberating throughout her family. The findings of this study have implications for parents, professionals, and the field of research in terms of the need for a better recognition and understanding of female autism, an apposite educational setting, and a holistic approach to family support.

Keywords

Autism, Autism Spectrum Condition, female autism, autistic, gender, gender bias, parents

Abbreviations

ASC- Autism Spectrum Condition; NT- Neurotypical

Table of Contents

Chapter 1: Introduction

1.1 Reflexive positioning statement

The role of my 'self' is integral and inseparable from the qualitative research process (Smith et al., 2009; Willig, 2013). It is therefore appropriate to give an account of my own positioning in relation to this study. I already belong to the autism community, having a son with a diagnosis of ASC. What follows is not a self-indulgent, narcissistic 'confessional tale' (Pillow, 2003) of my story, with my voice as the researcher dominant in the process (Pillow, 2003; Pillow, 2010). Rather, it is a transparent account of my personal experience of autism parenting, and the role this has played in my decision to research the lived experiences of the parents of girls with autism. The second thread that is entwined throughout this study is that of my professional experience of working with autistic girls and their families, both pre- and post-diagnosis, as a child and adolescent psychotherapist. The bringing together of these two facets of my experience almost feels like a symbiotic relationship; a continuum. My personal experience as a parent of a child who, as part of his condition, has ongoing mental health issues, underpinned my decision when training as a psychotherapist, to specialise in working therapeutically with young people. This professional work then brought me into contact with autistic girls and their families. As I attested to their everyday lived experiences and saw some parallels to those of mine, I became acutely aware of a different undercurrent to their process, taking their experiences in quite another direction.

When my son was diagnosed with autism at the age of seven, the actual diagnosis came as something of a relief (Siklos & Kerns, 2007). This is a statement that would have been unconscionable when I first became a mother; indeed, a diagnosis of autism in one of my children was one of my greatest fears. So why did I feel relieved? My son was an enchanting baby, with huge brown eyes and a very ready smile; he was also generally very placid. There were, however, some concerns around his physical development, and he seemed to be quite floppy with joints that clicked and clunked when he was picked up. This placed him on the radar of the community paediatricians; only later would I recognise how important this step was. In toddlerhood, it became obvious that some of his behaviours were more extreme and unusual than should be expected. I was not concerned as I was sure that he would outgrow his tantrums and funny ways, much as his older brother had done; however, he did not follow this trajectory. Additionally, at the age of three, he still only had a handful of words in his

vocabulary. As he entered the playgroup years, his need for ‘sameness’ became more marked, in particular when he was around his peers. He did not seem to be too concerned with the social side of play and was quite happy in his own world.

I remember feeling complete despair, and a sense of isolation, when I went out to a new park with other mums, and he spent the entire time on the far side of the field trying to empty a dustbin and eat the contents, while my older son was watched by my friends, who’s own children were playing happily together with him. That was the first time that I recall experiencing what I now know to be subtle, yet definite judgement from other parents (Harandi & Fischbach, 2016). Life at home with him was getting more challenging too (Gill & Liamputtong, 2013; Lutz et al., 2012), as he would only eat a very restricted diet, and would have explosive tantrums if I unknowingly made some small change. He would scream when I dressed him in certain clothes, in particular waterproofs. He could fall and cut himself badly and would not appear to register any pain. The greatest challenge was that he was unable to communicate what was upsetting him other than to scream. I spoke to the health visitor about my concerns, and despite me having an apparently well-adjusted older toddler, she suggested that a parenting course might be helpful. I found her tacet suggestion that somehow, *I* was causing his odd behaviours to be deeply hurtful; the focus seemed to be on me not my son.

However, it was when he started school that his obvious differences and difficulties began to make him the target of bullies, with their behaviour seemingly condoned, even encouraged by their parents; it’s just ‘boys being boys’. He would come home with bruises around his tummy, and scratches down his neck; coming out of school only just managing to hold in his tears and exploding with rage when he got home. I spoke to teachers who just shrugged and said, ‘he seems fine when he is here’, implying that I was making up what I was seeing at home. It became distressingly clear that although he was in a year group of just eight children, he was the only child not to be invited to birthday parties; he was unaware, but I felt brutally hurt, both personally and on his behalf. A young girl came up to me and said, ‘why is he so *weird*?’ Her mum looked faintly embarrassed and rushed her away from my strange child. Another parent asked me if I’d had a ‘difficult’ birth with him. No one knew how isolated I felt, or of the struggle behind closed doors at home, because to confide this would have been to admit that something *was* wrong (Gill & Liamputtong, 2013), with the inevitable conclusion was that it was in some way my fault.

I now know how fortunate I was that my son was referred to a wonderful consultant paediatrician who had worked with many similar children. She gave me hope; she listened and believed me. She gently gave me a possible reason for our difficulties; she mentioned autism, and this did not frighten me. She said that whatever label he was given through diagnosis would not define him and his potential. I remember being so worried that he *wouldn't* be diagnosed with autism, because if it was not that then what was wrong? I was worried that we could not then use his diagnosis as a starting point for help and support. And his 'label' has not defined him; indeed, it has opened doors to much more support and understanding. He is an intelligent and popular boy, thriving in school, with a good group of friends, and a highly promising future. How starkly the experiences of some of the parents of girls with autism who I have worked with, have contrasted with my own. Although undoubtedly, some of my experiences mirror those of the parents of autistic girls, my professional insight tells a different story. Autism was not an unexpected diagnosis for my son, because he was a boy; I did not have to fight to have my concerns addressed. It was on the diagnostic radar from quite early on.

The different presentation of girls with autism, and the pervasive deficit of knowledge of autism in girls among the key gatekeepers to referral and diagnosis (Bargiela et al., 2016) means that frequently, for their parents, there is no relief by way of a diagnosis; a reason for the daily struggles that they are experiencing, yet that are frequently unseen outside the home. Professionals involved with my son both recognised and validated my concerns because they were typical and well researched; I was believed. But what if I had been imploring people to understand and recognise my daily struggles, and they simply had no diagnostic box to neatly fit them in to, so dismissed them in disbelief? Witnessing such experiences in my professional capacity formed the basis of my previous research into the parental perceptions of autism in girls (Chantrey, 2017). Findings from this study, with an implicit urge from participants to make their struggles known, has led to this current doctoral study. I have set out to give a voice to those who have previously been unheard and disbelieved (Chantrey, 2017).

Through my position as not simply a researcher, but as a member of the autism community, I am approaching this study as an insider, and whilst acknowledging the potential implications of this position (Section 1.4), feel that this is likely to engender a trust and rapport that might not otherwise be possible. Taylor (2011, p.19) accurately sums up my sense of straddling the

two worlds that come together in this thesis; my professional life, and that of parenting an autistic son: "…the field is not only my site of work and learning, but it is my place of personal belonging, comfort, trust, friendship and love".

1.2 Context of the research

Autism Spectrum Condition (ASC) is a neurodevelopmental condition that is typically underscored by difficulties in social communication and reciprocal behaviour, sensory processing, and rigidity of thought (American Psychiatric Association, 2013). Individuals with ASC often experience a challenging gamut of emotional, social and behavioural difficulties (Eggleston et al., 2019). Whilst ASC is widely considered to be a predominantly male condition (Cridland et al., 2014; Loomes et al., 2017), this is a misconception that is perpetuated by Hans Asperger's now revised assertion that the autistic children he observed were exclusively male (Frith, 2008). Despite an emerging body of research that refutes the persistent view that autism is predominantly a male condition, there remains a clear male gender bias (Duvekot et al., 2017), in particular amongst those who are the gatekeepers to referral and diagnosis (Bargiela et al., 2016; Rynkiewicz et al., 2016). This gender bias is perpetuated by the frequent exclusion of females in autism research studies, influenced by the assumption that numbers are too low to be of clinical significance (Kreiser & White, 2014). Girls with autism frequently exhibit fewer stereotypical repetitive and restrictive behavioural characteristics than their male counterparts (Frazier et al., 2017; van Wijngaarden-Cremers et al., 2014). However, because diagnostic tools for assessment are based around research studies, these being dominated by male participants (Duvekot et al., 2017), the subtly different presentation of girls with autism is frequently missed, leading to late diagnosis, if diagnosed at all (Bargiela et al., 2016). Girls with autism frequently slip beneath the diagnostic radar (Begeer et al., 2013; Carpenter et al., 2019; Halsall et al., 2021; Ratto et al., 2018).

Studies suggest that many parents report difficulties in having their initial concerns around development and social/communication behaviours validated by professionals, finding themselves labelled as over-protective and neurotic (Factor et al., 2018; Karst & van Hecke, 2012). Research highlights frustration with the convoluted pathway to diagnosis once referred, with parents citing lengthy delays and waiting lists (Ho et al., 2014). Another significant facet of these challenges is the impact on parents of day-to-day life (Bozkurt et al.,

2019). Research overwhelmingly highlights the negative impact on parents and carers, documenting increased levels of anxiety, stress, depression and burn out when compared with those of parents of children with other developmental conditions (Falk et al., 2014; Zablotsky et al., 2013a; Zablotsky et al., 2013b).

Whilst there is a widely acknowledged recognition of general dissatisfaction with obtaining a diagnosis of ASC (Crane et al., 2016, 2018), this is particularly highlighted where individuals do not quite fit the recognised criteria for current autism diagnostic tools (Gould, 2017). The challenges faced by the parents of children with ASC are well documented, highlighting the adverse impact and toll on parents of raising a child with ASC (Bonis, 2016; Hayes & Watson, 2013; Ho et al., 2018). Although the evident difference in the presentation of ASC in girls is becoming more widely acknowledged (Kanfiszer et al., 2017), from a thorough review of the literature, there would appear to be sparse research into the lived experiences of raising a daughter with ASC, within the UK.

1.3 Aims and philosophical positioning

Although there have been many global studies that have explored both the diagnostic experiences of parents with an autistic child (Crane et al., 2016; Ho et al., 2014) and their lived experiences (Bozkurt et al., 2019; Falk et al., 2014), few of the studies to date explore experiences with autistic children of a specified gender. Research clearly demonstrates that there is a general overall dissatisfaction with the diagnostic pathway with many studies citing lengthy delays and a convoluted process from initial concerns to assessment (Ho et al., 2014; Siklos & Kerns, 2007). More recently, Little et al. (2017) have suggested that gender might impact upon the age and type of concerns that are raised, with this study developing suggestions that the time between first concerns and diagnosis is marginally longer for girls, concurring with Begeer et al. (2013). Their findings, however, contradict an earlier study by Horovitz et al. (2012), that suggests a far lengthier wait for diagnosis for girls. In further exploring this diagnostic gender inequality, it is clear that the ability of autistic girls to mask their social and communication struggles has a significant role to play in this delay (Duvekot et al., 2017; Gould, 2017; Tierney et al., 2016). Studies around the diagnostic experiences of parents clearly demonstrate a lower degree of parental dissatisfaction when diagnosis is straightforward and made in a timely manner (Crane et al., 2016; Crane et al., 2018). Girls with autism frequently ‘hold it together’ in school (Bargiela et al., 2016) and present with a

quite different persona to that seen at home (Chantrey, 2017). Along with diagnostic tools being skewed towards the male presentation of autism (Duvekot et al., 2017), this innate ability of girls to hide their autistic traits (Dean et al., 2017) means that diagnosis is made late, if at all (Bargiela et al., 2016).

This study focuses on the lived experiences of eight participants who are parents of an autistic daughter; the aim and purpose being to explore their lived experiences, and the objective to give them a voice where often they go unheard (Chantrey, 2017). Examination of the literature around the experiences of parenting a child with ASC highlights that both quantitative and, to a lesser extent, qualitative methods have been used in research studies. Quantitative approaches have generally been used with high numbers of participants, looking at a broad overall experience (Crane et al., 2016; Howlin & Moore, 1997); whereas qualitative methods have been more commonly used when exploring more detailed personal experiences (Cook et al., 2018; Sproston et al., 2017).

It is imperative that the methodological approach that is used for this in-depth study incorporates sensitivity and flexibility. A qualitative, phenomenological approach is the most appropriate method of exploring the participants' lived experiences; such a perspective seeking to ascribe meaning to and understand their experience (McLeod, 2011). Finlay (2011) alludes to phenomenological approaches as elucidating situations and events that often go unnoticed, and this feels to be highly pertinent when exploring the lived experiences of those who so often *do* go unheard (Chantrey, 2017). As a reflexive researcher, concerned with exploring the lived experiences of the participants, Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009) has been chosen as the methodology most appropriate for this study.

In practising as a pluralistic psychotherapist, striving to be alongside clients, seeking to understand their world, it is important to be mindful that much as it can be tried to bracket them off, their world is interpreted through the lens of personal experience (McLeod, 2011). This awareness bridges onto reflexive research in as much as being the parent of a child with autism, what is known cannot be 'un-known' (Creswell & Poth, 2018). Reflexive journalling throughout the research process allows an openness to, and an acknowledgement of any preconceptions (Larkin et al., 2006). It is hoped that through such reflection, it will be less likely that the common trap is encountered in phenomenology, whereby knowing too much

about the phenomenon being researched leads the researcher to interpret the nature of the phenomenon, before they have even embarked upon understanding the significance of the phenomenological question (van Manen, 2016).

1.4 Parent and researcher

Creswell & Poth (2018) suggest that a research question often arises from a personal problem or position. As a researcher, transparency with the participants has been paramount from the outset, taking the position to some extent as an 'insider' rather than an 'outsider' in the research process (Band-Winterstein et al., 2014; Dwyer & Buckle, 2009, 2018). As the parent of an autistic child, researching parents of an autistic child, albeit of the opposite gender, there are both advantages and disadvantages to this approach. Participants might feel a greater level of rapport, trust and openness with the researcher if she is transparent about her own experiences of the subject being researched (Etherington, 2017). Insider research has the potential to enhance the depth of the exploration of the participants' experiences through establishing an open and trusting rapport (Kirpitchenko & Voloder, 2014), and through this deepened trust, facilitate the emergence of data that might not be accessible to an outsider researcher (Mitchell, 2008). Indeed, Greene (2014) writes extensively on the benefits of being an insider researcher, suggesting that participants are likely be happy to talk, and welcome the opportunity to explore their issues with someone who understands. Researching from within the perspective of living the experience and being part of the community brings a valuable validity that might not otherwise be possible.

However, there is equally the suggestion that such an approach might instigate a raised level of researcher subjectivity that has the potential to detrimentally impact upon data collection and analysis (Dwyer & Buckle, 2009). It will be through the 'phenomenological attitude' outlined by Finlay (2011), alongside the rigorous use of reflexive journalling that, in striving to ensure that the participants' voices remain uppermost in the research, any potential for over-subjectivity will be mitigated against (Ortlipp, 2008). As a practising psychotherapist, the British Association for Counselling and Psychotherapy (BACP) advice on equality, diversity and inclusion remains of paramount importance (BACP, 2018). That is that even if similar characteristics in terms of personal lived experience are shared with the client or participant, each experience is unique, so whilst this might be helpful, it is of paramount importance in the process to establish *their* individual experience.

1.5 Research question

This study seeks to address two main research questions:

(i) What are the lived experiences of parents who have a daughter with a diagnosis of Autism Spectrum Condition?

(ii) What, if anything, might have made a difference to these experiences?

These two questions underpin the interview questions to be covered, in the participant information sheet (Appendix B)

1.6 Originality of the research

There are numerous studies world-wide that explore the parental experience of an autism diagnosis (Chamak et al., 2011; Fewster & Gurayah, 2015; Goin-Kochel et al., 2006; Mitchell & Holdt, 2014), however, these all explore the experiences of the parents of both males and females. UK studies quantitatively researching both genders document evident parental dissatisfaction with both the pathway to, and the obtaining of, a diagnosis (Crane et al., 2016; Crane et al., 2018). In a qualitative study using parent YouTube interviews, Lloyd et al. (2019) explore the daily challenges endured by the parents of autistic children. In Ireland, Rabbitte et al. (2017) have conducted a study into the parental experiences around the diagnosis of autism in their daughter, although this predominantly addresses the practical aspects of diagnosis, rather than offers an exploration of the more emotional side of everyday life. There has been research into the maternal experiences of parenting a daughter with autism (Anderson et al., 2020; Fowler & O'Connor, 2020; Mycroft, 2017; Navot et al., 2017), however these studies overlook the often-marginalised paternal aspect (Paynter et al., 2018). Indeed, even the studies that set out to recruit both mothers *and* fathers (Kseib, 2018; Senior, 2019) recruited no fathers, supporting the suggestion that there is a female gender bias in research around parenting an autistic child (Burrell et al., 2017; Paynter et al., 2018).

Given the clear difference in the presentation of girls with autism (Kanfiszer et al., 2017), there is a significant gap in the literature, with little research into the lived experiences of the parents of *solely* girls with a diagnosis of autism in the UK, and at the time of writing, none

that include the experiences of their fathers. The notion that girls are highly adept at masking their autistic traits and difficulties (Tierney et al., 2016) is well established, and the consequential delay in diagnosis and therefore timely access to support (Bargiela et al., 2016) is well known. Along with the recognised toll taken on the mental health and overall quality of life for the parents of both genders in raising a child with autism (Bonis, 2016; DePape & Lindsay, 2015; Due et al., 2018), it would appear that few studies address the unique lived experiences of the parents of autistic girls within the UK.

1.7 Structure of thesis

This introduction clarifies the context and aims of the research, as well as the reflexive positioning of the researcher. It also outlines the methodology, research question, and its originality.

Chapter **two** explores the current literature around autism, autism in girls, the diagnostic process, and the lived experiences of the parents of *both* genders of autistic children.

In chapter **three** the ethical considerations and the rationale behind the choice of methodology are discussed, along with the methodological process.

Chapter **four** is a presentation of the data from the semi-structured interviews with the eight participants. This is presented as superordinate and subordinate themes through the process of data analysis according to IPA methodology.

Chapter **five** is an analysis and discussion of the findings, and these are explored alongside the current literature. The discussion expands upon how these findings and the current literature relate to the research question. The implications for research, parents, professionals and autistic girls are discussed, along with the strengths and limitations of the study.

Chapter **six** concludes with a summary of the research, and a closing reflexive section, 6.2.

1.8 Summary

This introduction has set out to provide an overview of the study, outlining the rationale and background to the research question. The researcher's personal positioning as the parent of a son with autism, as well as a being a practising psychotherapist working with autistic young people their families has been clarified. The literature review follows on from this chapter.

Chapter 2: Literature review

2.1 Introduction

This literature review sets out to comprehensively explore the available literature around the research question: What are the lived experiences of the parents of girls with autism? The chapter encompasses a review of the existing literature[1] and sets out to provide an in-depth theoretical context within which to locate this study (Booth et al., 2016). Following a general overview of autism, that through its evolution demonstrates the origins of the under-diagnosis of autistic females, there are two threads that, when seen together in context, expose a clear gap in the research with regard to the lived experiences of the parents of autistic girls in the UK. The first section addresses why and how girls are likely to be under-identified as being autistic. The second is an exploration of the lived experiences of parents of an autistic child, and unless specified, this makes no differentiation as to the gender of the child.

In this writing, the term 'autism spectrum condition' (ASC) is used rather than 'autism spectrum disorder' (ASD) as it is felt to set out the importance of conveying the strengths of those on the autism spectrum as well as their challenges. The autism community prefer this term, feeling it to be less pathologising (Bargiela et al., 2016; Kenny et al., 2016). The terms 'girl and female' are distinct binary expressions and for the purposes of this writing, are used to discuss those assigned a female gender at birth.

2.2 Search strategy

Initial online searches were conducted in order to access journals via sites including Google Scholar, EBSCOhost, Science Direct, Scopus, Pub Med, and ProQuest. A 'snowballing' action was then utilised whereby references in online journal articles were then searched for using the above methods.

[1] The literature in this review is world-wide, unless referring to UK systems and procedures, where this is explicitly stated.

2.3 Evolution of autism

Although this does not directly relate to the research question, it is important to outline the evolution of autism as it demonstrates the roots of male bias in autism research and diagnosis. It also sheds light on how the progressive versions of diagnostic criteria have perpetuated this bias and, in turn, further decreased the likelihood of an autistic female receiving a diagnosis.

Autism Spectrum Condition (ASC) is a neurodevelopmental condition that is characterised by impairments in social communication and reciprocity, flexibility of thought and sensory processing (APA, 2013). Unlike the diagnostic criteria for many health conditions, ASC has taken a more convoluted path to the current description in the Diagnostic and Statistical Manual of Mental Disorders DSM-5 (APA, 2013). Autistic individuals frequently experience emotional, social and behavioural difficulties (Eggleston et al., 2019).

When Leo Kanner, an Austrian-American psychiatrist, first described autism in 1943, he described it as a highly stigmatising condition. He observed that children with the condition possessed a distinct autistic aloneness and an obsessive desire for sameness, often being highly intelligent (Kanner, 1971). However, although grounded in the thinking of his day, this did mark the beginning of autism awareness (Blacher & Christensen, 2011). A year later, when Hans Asperger identified autistic psychopathy, he was only interested in males, thinking that females were unaffected by the condition (Frith, 2008).

In the 1950/60s, blame for the condition was placed on 'refrigerator mothers' (Bettelheim, 1967), with their cold and distant parenting style; a concept that was disproved in the 1960/70s as research began to focus on biological underpinnings, rooted in brain development (Baker, 2013). In accordance with Kanner's perspective, DSM-2 (APA, 1968) classified autism as a psychiatric condition: a subset of childhood schizophrenia underscored by a detachment from reality (Mintz, 2017). However, it was not until the publication of DSM-3 (APA, 1980) that autism was finally given its own classification and labelled a pervasive developmental disorder, distinct from schizophrenia (Baker, 2013).

Then, with the publication of DSM-4 in 1984 (revised in 2000), autism was first categorised as a spectrum (Baker, 2013). However, it was the latest edition DSM-5 (APA, 2013) that

created significant controversy in the autism community, as it was decided to dispense with the term 'Asperger's syndrome', instead defining autism as an all-inclusive spectrum, from mild to severe (Baker, 2013). Additionally, the three diagnostic criteria from DSM-4 were collapsed from abnormal functioning in social interaction, language in social communication and lack of symbolic or imaginative play, down to deficits in social interaction and communication, and demonstrating repetitive and restrictive behaviours in DSM-5 (van Steensel et al., 2015).

Part of the controversy around the changes in DSM-5 was concerned with people already diagnosed with Asperger's syndrome, fearing that its removal might take away their sense of belonging and reason for their challenges with a resultant loss in their identity (Giles, 2014; Mogensen & Mason, 2015). A recent study by Smith & Jones (2020) into self-identity of people with Asperger's post DSM-5, found mixed results, with one of the findings being that the gender of the participant might have some impact on this. The females in the study, although far outnumbered by males, suggested that for them the removal of 'Asperger's' could be viewed positively as being more part of human variation than a disability.

However, there is a growing body of evidence that suggests that the revised criteria of DSM-5 *do* exclude those with milder, or atypical traits, in particular females (Haney, 2016; Mayes et al., 2014). Although DSM-5 is a widely used guide in the UK and many other countries, the International Classification of Diseases, currently ICD 11th revision (ICD-11, 2019), is frequently used. This differs from DSM-5 in certain features, most pertinently in recognising that females have a clear ability to mask their autistic traits (Al-Jadiry & Al-Jadiri, 2019; Smith & Jones, 2020). The range of diagnostic tools used in the UK all assess against a set of criteria found in DSM-5 and ICD-11. This would seem somewhat of a scatter-gun approach to female autism diagnosis given that it is acknowledged that autistic girls are disadvantaged by the changes to DSM-5 that reduce the likelihood of their more subtle presentation being picked up (Haney, 2016).

2.4 Under-identification of autism in females

When Hans Asperger first identified autistic psychopathy in 1944, he described the autistic personality as an extreme variant of male intelligence (Frith, 2008), finding it fascinating to remark that the children he observed were almost exclusively male (Frith, 1991). While, over

time Asperger revised his thinking, autism remains a condition that is predominantly associated with boys and men (Gould, 2017). There is now an increasing awareness that girls and women with autism are being missed, with diagnosis being made late, if diagnosed at all (Bargiela et al., 2016). A study by Fombonne (2005) suggested that boys were four times more likely to receive an autism diagnosis than girls, with this estimate increasing further to 6-8:1 where the participants were of average IQ or higher. Although more recent research has found a much lower ratio, with suggestions that it is about 2-3:1 (Lai et al., 2015a), such findings are disputed with other studies suggesting that females are still far less likely to receive an ASC diagnosis than males when referred for evaluation (Bargiela et al., 2016; Wilson et al., 2016).

2.4.1 Gender bias in research and diagnosis

This discrepancy raises the question of how gender bias in autism diagnosis both might be created and perpetuated. It is increasingly recognised that boys are more likely to be diagnosed with autism than girls (Duvekot et al., 2017; Frazier & Hardan, 2017); however, it would appear that the reasons behind this are multifactorial (Gould, 2017).

The majority of extant research into autism has been conducted with a predominance of male participants (Kreiser & White, 2014), with the expectation that female numbers are too low to be of clinical significance (Dworzynski et al., 2012; Loomes et al., 2017). At the very most, 'male-like' girls might be captured due to their more male presentation (Andersson et al., 2013). Therefore, the current understanding of autism and the criteria, in terms of recognised traits used to make a diagnosis, are based on those in DSM-5 (APA, 2013), and hence are inherently skewed towards the typical male presentation (Duvekot et al., 2017; Rynkiewicz et al., 2016); research around autism is founded in male-biased samples (Geelhand et al., 2019). In turn, this creates a domino effect, whereby the gatekeepers to onwards referral and diagnosis are influenced by the prevalence of confirmatory gender bias in research and practice (Bargiela et al., 2016; Leedham et al., 2020b). This bias is evidenced in studies where the ratio of male to female in non-referred studies is approx. 2-3:1 (Zwaigenbaum et al., 2012), whereas in participant samples derived from autism diagnostic services, this increases to 4:1 and even higher (Bargiela et al., 2016; van Wijngaarden-Cremers et al., 2014). Furthermore, the development of diagnostic tools is based upon such research, so it is

quite plausible that the gender bias in such studies translates into 'gold-standard' assessments that simply miss the subtly different presentation of autism in girls at an early stage (Begeer et al., 2013). Although there are preliminary ventures into creating a diagnostic test more geared towards the female autism presentation (Brown et al., 2020a; Hull et al., 2019; Ormond et al., 2018), it could be argued that without the gatekeepers to referral being aware of the different presentation of ASC in girls when compared with boys, such tests will do little to address the under-diagnosis of autistic girls.

Although clearly evident in autism research and diagnosis, consideration as to whether gender bias exists across other mental health conditions is worthy of further exploration. Possibly, societal expectations of female behaviour are such that females need additional symptoms, such as behavioural difficulties and intellectual impairment, over and above the standard traits of ASC and other associated developmental conditions, in order to receive a diagnosis (Jamison et al., 2017). The World Health Organisation certainly suggests that implicit gender bias exists across *all* mental health disorders (WHO, n.d.). A study by Wilson et al. (2016) found that women were notably less likely to receive an autism diagnosis than their male counterparts after being referred for assessment. This finding mirrors those of studies into Attention Deficit and Hyperactivity Disorder (ADHD), with suggestions that girls require more extreme behaviours to be exhibited and are at risk of a delayed diagnosis, when compared to their male counterparts (Quinn & Madhoo, 2014; Walters, 2018). With respect to psychopathology in general, Keenan & Shaw (1997) argue that girls adapt their social skills development, learning to internalise their psychopathology, which in turn inhibits the expression of traits; a suggestion that appears to be borne out in studies that explore why girls with ASC often hide in plain sight (Hull et al., 2017; Hull et al., 2020a).

2.4.2 Challenges in identifying ASC in girls: Masking

The gender bias around ASC in girls is further compounded by a female camouflaging or 'protective' effect of their autistic traits (Jacquemont et al., 2014; Lai et al., 2017). A growing body of research suggests that adolescent autistic girls develop elaborate social coping strategies, such as imitation and masking to help them to navigate complex social relationships (Baldwin & Costley, 2016; Gould, 2017; Tierney et al., 2016).

Biogenic theories, such as the 'extreme male brain' (Baron-Cohen, 2002) have been proposed in order to explain why females with autism are driven to camouflage their difficulties. Males are portrayed as having a brain that prioritises rule-bound systemising over empathising, whereas females possess superior empathy and emotional sensitivity; hence males, being more predisposed to autistic traits, are more likely to be on the autistic spectrum (Tierney et al., 2016). Whilst this theory ascribes a strong determinant risk for ASC as a result of biological factors, it could be argued that this downplays the influence of equally valid non-biological factors (Krahn & Fenton, 2012; Ridley, 2019).

It is perhaps better explained through research focussing on social factors as the driving force (Kreiser & White, 2014; Parish-Morris et al., 2017; Ratto et al., 2018). Similarly, social cognitive theories around gender expectation suggest that gender-appropriate behaviour is learned through modelling the social behaviour of other same gender people (Bem, 1981; Bussey & Bandura, 1999). Davis & Wilson (2016) use the example from such theories, where boys are conditioned to be strong and dominant, whereas girls are expected to be nurturing and passive. It therefore follows that if girls are expected to demonstrate greater relational sensitivity, then their perception of negative feedback as a result of non-conforming behaviours might be regarded more powerfully than for boys and may consequentially lead them to suppress their autistic characteristics by way of modelling more gender appropriate behaviour (Kreiser & White, 2014).

This camouflaging or masking hypothesis (Dean et al., 2017; Dworzynski et al., 2012) means that, in order to adhere to perceived social norms, girls with ASC go to elaborate lengths to conceal their deficits. One such coping strategy might be to make great effort to hide behaviour that may be deemed socially unacceptable (Hull et al., 2020b), or to artificially adopt more neurotypical (NT) social behaviour; to 'pretend to be normal' (Willey, 2014). Autistic girls might learn to make eye contact, and practice pre-prepared jokes, and learned phrases (Lai et al., 2017); mimicking facial expressions and gestures (Hull et al., 2017). Although such camouflaging might be seen as superficially helpful in order for girls with autism to blend into their social environment, the reality is that masking is an emotionally exhausting business (Gould, 2017). It is suggested that the sheer cognitive effort of repressing and masking autistic behaviours is so gruelling (Leedham et al., 2020b), that this is likely to be an underlying cause for subsequent mental health disorders in autistic females (Cage &

Troxell-Whitman, 2019; Gould & Ashton-Smith, 2011), even causing her to lose her true identity (Bargiela et al., 2016).

Autistic female masking therefore perpetuates an insufficient acknowledgement of how autism might present both in a qualitatively and quantitatively different way in females from the more male dominated concept of autistic traits (Lai et al., 2015a). This ability to conceal and compensate for their autistic traits is cited as one of the main reasons that autism is so much more challenging to detect in females (Baldwin & Costley, 2016; Hull et al., 2017). The impact of masking has the potential to resonate through the whole process from referral to diagnosis (Tierney et al., 2016). However, it could be argued that this is only partly true; the suggestion that parents are therefore unlikely to pick up on signs of autism in their daughter (Lai & Baron-Cohen, 2015) is starkly at odds with the finding of Chantrey (2017), who found that parents were often *more than* aware that something was wrong, it was simply that those to whom they then turned for advice did not recognise the subtly different signs of female autism. It follows therefore, that there exists the real potential for diagnosticians to also miss the signs of camouflaging, taking superficially typical non-verbal and social skills as evidence to exclude an autism diagnosis (Dean et al., 2017; Goldman, 2013); a scenario that professional experience would suggest is all too common.

2.4.3 Social communication and friendships

The camouflage hypothesis is usually discussed in relation to social interaction (Baldwin & Costley, 2016). Empirical evidence suggests that girls with autism manifest with greater social motivation and an enhanced capacity for friendships than their male counterparts (Cook et al., 2018; Head et al., 2014; Sedgewick et al., 2018a). A recent study by Foggo & Webster (2017) suggests that adolescent autistic girls largely feel that friendships are important, fundamentally valuing loyalty, trust and mutual understanding. This finding supports earlier studies that established that levels of social motivation are similar for both NT and autistic girls (Bauminger et al., 2008; Sedgewick et al., 2016). Research into adolescent autistic female friendships (Backer van Ommeren et al., 2017; Foggo & Webster, 2017) surprisingly found similar feedback to those of NT children (Graber et al., 2016), in that participants valued reciprocity in their relationships with their best friend. However, it was not clear whether those girls went on to engage in reciprocal friendships. It is perhaps therefore clear to understand why autistic girls have been further disadvantaged by changes to

DSM-5 (APA, 2013), as one of the diagnostic traits that remains prominent is that of difficulty in managing and understanding social relationships, and social reciprocity.

This is not to say that autistic girls find friendships straightforward when compared with those of autistic boys. Difficulties with social communication for autistic girls are likely to be internalised (Duvekot et al., 2017), manifesting as anxiety and depression (Oswald et al., 2016; Solomon et al., 2012) rather than the externalising problems displayed by boys, such as aggression and behavioural issues (Hiller et al., 2014; May et al., 2016). However, although clearly autistic girls are impacted upon by difficulties that fall outside the core ASC domain (Duvekot et al., 2017), studies such as those cited are few in number with inconsistent results dependent upon the informant used. Additionally, as only a few studies use comparison groups, it is unclear as to whether the differences are only applicable to autistic individuals.

Adolescent female relationships demand intricate and complex social skills, necessitating the ability to recognise subtle social nuances, such as eye rolling and body language; skills in which girls with ASC are likely to be deficient (Dean et al., 2013). Twinned with an apparent increasing impairment in the social and communication skills of autistic children that adolescence brings, autistic girls are highly vulnerable to relational conflict (Cook et al., 2018; Sedgewick et al., 2018a). Despite their efforts to fit in with NT friendship norms, autistic girls may still struggle with the more subtle non-verbal elements of communication, leading to accusations of outright violation of unwritten social rules, and subsequent conflict and social exclusion (Dean et al., 2013). Research into NT adolescent relationships highlights clear differences in how adolescent boys and girls manage conflict, with boys tending to exhibit clearly aggressive behaviours and girls displaying more subtle ways, such as gossiping and exclusion (Card et al., 2008). However, whilst this view is supported by Sedgewick et al. (2018a), they go further in discussing how such differences might manifest in female autistic adolescents, finding that they tend to blame themselves, and attempt to resolve the dispute, even if not responsible. The difficulty comes in their fundamental lack of understanding into how the conflict has arisen in the first place, and attempts to make amends and appease often result in an escalation of conflict and exclusion (Dean et al., 2013).

Despite a prevalence of studies that recognise that girls with autism have a clear ability to hide their social difficulties (Hull et al., 2017; Kanfiszer et al., 2017; Tierney et al., 2016), professional experience would suggest that although girls are known to mask, it is *how* this

masking is manifested that remains under-recognised. Perhaps insight into the challenge of identifying autistic girls within the school setting might be found in the word 'camouflage', with much closer observation into how autistic boys and girls blend with their social environment (Dean et al., 2017). They suggest that it might be easier to pick up on autistic behaviours with boys, as the play of NT boys is typically structured and rule-bound, with physical interaction. A boy with autism is likely to stand out as alone and isolated from the group, whereas given her efforts to blend and fit in, an autistic girl might be more difficult to identify.

Interestingly, building on findings by Bargiela et al. (2016), the study by Dean et al. (2017) found that although social communication deficits of autistic girls were picked up on by NT peers within friendships groups, they remained concealed from teachers and playground assistants. From a distance, autistic girls *appeared* to be involved in joint engagement, however more careful observation would reveal this to be interspersed with frequent episodes of solitary time. It could however be argued that this study creates something of a binary distinction, and one that only serves to blur an already complex area around gender identity and autism; side-lining the significant minority of autistic individuals who identify as gender-fluid or non-binary[2] (Cooper et al., 2018; Dewinter et al., 2017). Parents of girls with autism frequently report that their daughters are tomboys, preferring to hang out with male counterparts (Cridland et al., 2014), finding their company less complex and socially demanding (Bargiela et al., 2016; Chantrey, 2017).

2.4.4 Behaviours

Repetitive and restricted behaviours and interests (RRBI) can be considered to go some way in explaining the sex differences in ASC diagnostic rates (Duvekot et al., 2017; Frazier et al., 2013). As a symptom of RRBI, DSM-5 (APA, 2013) includes restricted behaviours, stereotyped behaviours, repetitive play, insistence on routine, circumscribed interests, and self-injurious behaviours. More recent literature suggests that higher levels of RRBI are more predictive of an autism diagnosis for males than females (Halladay et al., 2015; Mussey et al., 2017). Others have gone further, arguing that autistic females present with lower levels of both frequency *and* severity of RRBI than their male counterparts (Rubenstein et al., 2014;

[2] Although gender identity and autism are of increasing interest in research, this study investigates the experiences of parents of a girl who was assigned female gender at birth.

van Wijngaarden-Cremers et al., 2014). This might, however, overlook the possibility that females with autism present their RRBIs both quantitatively and qualitatively differently than autistic males (McFayden et al., 2020). Further compounded by current autism diagnostic tools being designed and validated using predominantly male participant samples, it could be argued that the RRBIs of autistic females are simply invisible when viewed as one assessment score, with intricate differences in sex-specific domains being missed by taking such a global view (Antezana et al., 2019).

A recent study in the USA found that autistic females demonstrated higher levels of compulsive, restricted and self-injurious behaviours than males, but scored lower on stereotyped behaviours and interests (Antezana et al., 2019). Their study is both novel and significant in that it highlights the possibility of a missed female autism diagnosis where the RRBI of females may be masked or hidden (McFayden et al., 2020). This further supports the view that current diagnostic tools are largely developed using predominantly male samples (Duvekot et al., 2017; Kreiser & White, 2014), and are therefore likely to miss females with autism (Bargiela et al., 2016).

Research has found that autistic females, right across developmental stages, demonstrate lower levels of motor stereotyped behaviour, such as playing with toys repetitively in the same way, or flapping their hands (May et al., 2016; Rojahn et al., 2016), with decreased rates of preoccupation with routine (Antezana et al., 2019) relative to their male counterparts. Autistic females also have lower levels of repetitive play such as lining up toys, when compared with autistic males (Fulceri et al., 2016; Hiller et al., 2014; Schroeder et al., 2014). Additionally, research by Knutsen et al. (2019) has established reduced levels of RRBI in young, high-functioning autistic females. Although recognised as more frequent in female adolescents (Zetterqvist, 2015), autistic females frequently engage in non-suicidal self-injurious behaviours (NSSI) such as hair-pulling and scratching (Antezana et al., 2019). However significantly, such behaviours are often not included under the RRBI umbrella (Maddox et al., 2017). However, as the study by Zetterqvist (2015) was not explicitly considering participants who were neurodivergent, it is possible that autistic females were unknowingly captured in their study, and therefore their results were potentially skewed by the higher prevalence of NSSI in autistic females (Antezana et al., 2019). Therefore, although clearly present in autistic females, such behaviours are not captured by current diagnostic measures (McFayden et al., 2019).

Of recent interest is the role of circumscribed interests (an intense and all-consuming hobby or interest that occupies the individual's time, such that it interferes with social or family life) in the sex discrepancy around an autism diagnosis (McFayden et al., 2020). Results from parent/teacher interviews suggest that females have fewer such interests when compared with their male counterparts (Beggiato et al., 2017; Hiller et al., 2014; Solomon et al., 2012), and those that they have might be less intense (McFayden et al., 2019). Adding to the argument that the play and interests of young autistic females might be overlooked as normal, is the suggestion that an intense interest in babies and dolls might be mistaken for pretend play, and thus exclude a diagnosis of autism (Halladay et al., 2015). Another subtle difference in restricted interests in autistic females is in the nature of the interest; females typically showing more interest in social content such as other people, or animals (Grove et al., 2018; McFayden et al., 2019; Nowell et al., 2019), whereas males lean more towards mechanical topics and computers (Grove et al., 2018; Nowell et al., 2019). These findings are consistent with an earlier study by Anthony et al. (2013) into parent-reported interests which suggested that girls with autism tended to have interests related to music and maths whereas boys preferred Lego and video games. Females with ASC also tend to use less factual knowledge around their interest (Mandy et al., 2012), so that their interests appear more socially appropriate in the way they relate to them (Bitsika et al., 2018; Frazier et al., 2013).

It is clear that autistic females *do* express differences when compared to autistic males in terms of RRBIs. The challenge in identifying females with autism lies in the gender-sensitivity of the diagnostic measures against which they are assessed (Mandy et al., 2012). Until the female phenotype of autism is better captured by diagnostic tools, it is likely that the odds will continue to be stacked against them in terms of autism identification (McFayden et al., 2020).

2.4.5 The impact of a delayed diagnosis

Were assessment more informed as to potential gender bias, many autistic females would have had a timelier diagnosis, likely to have resulted in earlier intervention and support (Bargiela et al., 2016), with research suggesting that late diagnosed autistic females are historically disadvantaged by inaccurate or delayed diagnosis (Baldwin & Costley, 2016). The majority of participants in a study into the experiences of women who were diagnosed

late with autism, stated that their lives would have been so much easier had their diagnosis been made in adolescence; except for one participant, all spoke of severe clinical anxiety and distress (Bargiela et al., 2016). Diagnosis can bring relief in providing a framework through which to explore long-standing social and interpersonal difficulties; making sense of the feeling of always being on the margins of social interaction (Lai & Baron-Cohen, 2015). However, not all shared such feelings of relief with some autistic girls reacting with ambivalence (Fowler & O'Connor, 2020), down to those who really did not want to hear their diagnosis (Fowler & O'Connor, 2020), to those who reacted negatively, rejecting the concept of being 'labelled' (Chantrey, 2017).

Reflecting the importance of early diagnosis for autistic females, Baldwin & Costley (2016) suggest that where women are diagnosed post-18 years old, they are likely to have missed crucial years of social skills support that might have helped them navigate complex social territory. Participants in their study spoke of appearing capable to teachers and achieving good marks, although showing clear signs of needing support, yet none was forthcoming, amplifying complications arising from the efforts of masking (Baldwin & Costley, 2016). Undiagnosed autistic females are frequently the target of victimisation both by teachers and peers (Bargiela et al., 2016). Adolescent girls with autism would appear to experience a 'double whammy' as they strive to manage the increased complexity of peer relationships, aware of their social and communication shortcomings yet with inadequate awareness of their unique social skill needs; the majority of intervention is still based on the needs of adolescent autistic males (Jamison & Schuttler, 2017). The impact of a delayed diagnosis affects not just the autistic girl, but her family too (Gould & Ashton-Smith, 2011).

2.4.6 'Jekyll and Hyde'

A further impact of female autistic masking is that parents' reports of their daughter's struggles at home are frequently met with disbelief from teachers who know her at school (Chantrey, 2017; Tierney et al., 2016); their daughter being a conscientious model student, but with frequent meltdowns and controlling behaviours at home. This supports results from a study into sex-differences in pre-diagnosis concerns (Hiller et al., 2016), where a surprise finding was that carers reported increased levels of externalising behaviours (aggression and violence) in girls than boys, which was the opposite to that reported by teachers. The autistic girl's efforts in masking her social and sensory difficulties at school, with conflicting

experiences of parents and teachers, only serves to further reduce the likelihood of referral for assessment (Hiller et al., 2016).

Parents in many studies use the expression 'Jekyll and Hyde' to describe a lovely, caring, and model student at school, a 'teacher's dream' (Kreiser & White, 2014), but as violent, unpredictable and controlling in her behaviour at home (Anderson et al., 2020; Chantrey, 2017; Sturrock & Goldsack, 2019; Sutherland et al., 2017; Volkers, 2018). As she attempts to appear 'normal' and fit in, constantly monitoring and imitating the behaviour of her NT peers, and trying to respond appropriately, she becomes progressively more exhausted and burnt out; her mind full at the end of the day (Halsall et al., 2021; Zener, 2019). It is only at home that she can let her 'mask' slip (Anderson et al., 2020), dropping her social 'persona' and showing her true 'self' (Tierney et al., 2016). In a study into the experiences of late-diagnosed autistic women (Bargiela et al., 2016), one participant spoke of being a model student at school, yet 'unbearable' with her mother at home. The brunt of these meltdowns is experienced behind closed doors at home, and professional experience hints at an unspoken shame felt by parents, reluctant to seek support, perhaps imputing a parental failing.

Despite the acknowledgement that autistic girls mask their struggles in the school environment (Dean et al., 2017), there is little research into their experiences. Research suggests that autistic girls lack the appropriate support at school because the staff do not understand their needs, with parents finding themselves locked in a battle for a suitable placement (Moyse & Porter, 2015; Sproston et al., 2017). Despite the recommendations for changes to support the inclusion of autistic girls in school, a more recent study into how autistic girls experience their school life (Goodall & MacKenzie, 2019) suggests that little has changed. The challenges at school outlined by late-diagnosed autistic girls (Bargiela et al., 2016) remain depressingly unchanged.

2.5 Parental experience

2.5.1 Initial concerns and pursuing a diagnosis

The distress manifested by parents relating to autism usually precedes any formal diagnosis (Factor et al., 2018; Karst & van Hecke, 2012), as concerns around behaviours and social/communication gradually emerge (Carlsson et al., 2016). Although clear guidelines

have been developed, clarifying the importance of taking the concerns of parents seriously (NICE, 2011), research would suggest that parents are still sometimes labelled as over-protective and neurotic for raising such concerns (Chantrey, 2017; Legge & Tickle, 2019). Although studies suggest that parents often recognise unusual development in their child, usually at an earlier stage than health professionals (Carlsson et al., 2016; Fewster & Gurayah, 2015), they are often met with dismissals and premature reassurance over their concerns (Richards et al., 2016; Ryan & Salisbury, 2012). Parents frequently receive inappropriate and dismissive reassurance that their child will outgrow their idiosyncrasies (Fewster & Gurayah, 2015).

To date, there have only been a handful of large-scale studies into the diagnostic experiences of UK parents around an autism diagnosis (Crane et al., 2016, 2018; Howlin & Moore, 1997). These studies are quantitative in their methodology, and largely focus on the diagnostic experience rather than the preceding events. However crucially, they do not differentiate between males and females. What is clear, however, is that the process of obtaining a diagnosis, both in the UK and abroad, is almost universally experienced as a protracted and stressful process (Chamak et al., 2011; Crane et al., 2018; Crane et al., 2016; Ho et al., 2014; Moh & Magiati, 2012). Despite some of these studies having been written almost ten years ago, experience suggests that very little has changed and that even with these insights, the provision of ongoing support services remains woefully inadequate. Many studies suggest that time spent both negotiating referral and on the waiting list for assessment, increases the levels of parental stress (Chao et al., 2018; Eggleston et al., 2019; Höfer et al., 2019).

Several smaller scale qualitative studies into the pre-diagnosis experiences in the UK of the mothers of autistic daughters (Kseib, 2018; Mycroft, 2017) further support these findings. Delays in accessing an autism diagnosis would appear to be lengthier and more convoluted for children who are more cognitively and verbally able (Crane et al., 2016; Howlin & Asgharian, 1999), in particular for those individuals with an atypical presentation, such as women and girls (Gould, 2017; Milner et al., 2019). What appears to be critical here is that when clinicians have more information pre-diagnosis, so the length of the diagnostic process is reduced (McKenzie et al., 2015). It could be argued that the lack of understanding of not just autism in general (Foley et al., 2018), but more specifically of the different presentation of autism in females (Bargiela et al., 2016; Milner et al., 2019), itself creates confusion in pre-diagnostic concerns. This is partly driven by autistic females' ability to mask, with the

suggestion that the likelihood of both a referral and subsequent diagnosis is partly dependent on whether, within her assessment time slot, she is 'performing' so well that no traits are seen (Fowler & O'Connor, 2020; Milner et al., 2019).

Interestingly, although research by Horovitz et al. (2012) found that the age that concerns were first raised was significantly younger for girls than boys, a later study by Ramsey et al. (2018) found no difference at all. Suggestions by Messinger et al. (2015) who argue that because both autistic and NT boys demonstrate more readily observed behaviours, parents' concerns are likely to be greater and overshadow such concerns for girls, further evidence the differences in RRBI between the genders (McFayden et al., 2020). Mothers of autistic girls often question their own parenting before suspicions of an autism diagnosis (Anderson et al., 2020; Fowler & O'Connor, 2020), supporting the suggestion that young girls with autism may not present with behaviours that are particularly concerning or salient to their parents (Little et al., 2017). However, parents of autistic girls often know that something is not quite right (Chantrey, 2017), but in the face of a lack of awareness of the female presentation of autism among professionals (Kanfiszer et al., 2017; Lai & Baron-Cohen, 2015), the likelihood is that that she will be referred for assessment for other mental health conditions before a consideration of autism (Baldwin & Costley, 2016; Gould, 2017).

2.5.2 Parental sentiments around a diagnosis

The general dissatisfaction with obtaining an autism diagnosis is well documented in research on a global level, with frequent findings of a confusing, convoluted process (Ho et al., 2014), and lengthy delays to assessment (Chamak et al., 2011; Crane et al., 2016; Siklos & Kerns, 2007). Such frustrations are particularly marked for those who are verbally and cognitively able (Crane et al., 2016), or for those whose presentation does not fit the standard criteria for current autism assessment tools (Gould, 2017; Mandy et al., 2012). However, the parental emotional response to their child's diagnosis is frequently overlooked by professionals in the diagnostic process (Nicolaidis et al., 2015; Unigwe et al., 2017).

Studies into how parents feel on receiving an autism diagnosis for their child frequently result in mixed responses (Alqahtani, 2012; DePape & Lindsay, 2015; Desai et al., 2012; Lutz et al., 2012). Many speak of an overriding sense of relief, often that there is finally a label, and a meaning for the challenging behaviours that parents have experienced (Lloyd et al., 2019;

Ooi et al., 2016). Parents speak of diagnosis as providing a form of legitimacy, with absolution from being bad parents (Anderson et al., 2020; DePape & Lindsay, 2015; Ooi et al., 2016). However, although expressing relief, most also allude to contradictory sentiments alongside, as parents process the implication of their child's diagnosis (Bonis, 2016; Gill & Liamputtong, 2013; Navot et al., 2017). Many parents speak of an immediate fear of what would happen with the care of their child when they were no longer alive (Karp & Kuo, 2015; Potter, 2017).

One of the overriding sentiments around diagnosis was one of loss and grief (Altiere & Von Kluge, 2009; Begeer et al., 2013; Fernańdez-Alcántara et al., 2016; Navot et al., 2017). It has even been described as being so overwhelming that it has been likened to a death in the family (Altiere & Von Kluge, 2009; Cheuk & Lashewicz, 2016; Fernańdez-Alcántara et al., 2016); suggesting that the word 'autism' is in some way linked to the 'loss' of the healthy child they had known up to that point (Burrell et al., 2017; Fernańdez-Alcántara et al., 2016; Mitchell & Holdt, 2014). Some parents report being in shock and denial (DePape & Lindsay, 2015; Fernańdez-Alcántara et al., 2016); others talk of guilt and blame (Burrell et al., 2017; Mulligan et al., 2012; Rasmussen et al., 2020). Mothers sometimes blame themselves, wondering whether they have done something wrong in pregnancy or afterwards, such as not breastfeeding, to cause autism (Alqahtani, 2012; Fernańdez-Alcántara et al., 2016; Lutz et al., 2012). Fathers, on the other hand, whilst wondering about the aetiology, tend to focus not only on what has caused the autism, but whether it can be 'fixed' (Hannon & Hannon, 2017). First time mothers appear to be particularly negatively impacted upon, in their sense of guilt for not recognising the early indicators of autism (Herlihy et al., 2015), in stark comparison to mothers with older typically developing children who, knowing they had already raised a well-adjusted child, did not feel to blame for their child's diagnosis (Gill & Liamputtong, 2013).

The theme of 'loss' also extends to the loss of the future hoped for their child (DePape & Lindsay, 2015; Karp & Kuo, 2015), including shattered hopes for a career and marriage (Hock et al., 2012; Lutz et al., 2012). Several studies liken the diagnosis of autism in their child to a 'process of grief' (Kübler-Ross & Kessler, 2005), moving through cyclical stages (Fernańdez-Alcántara et al., 2016; Frye, 2016; Mitchell & Holdt, 2014). However, this is a process that eventually leads to acceptance (Altiere & Von Kluge, 2009; Burrell et al., 2017), personal growth (Lloyd et al., 2019) and a search for 'the next steps' (Cridland et al., 2014;

Fowler & O'Connor, 2020); occasionally the discovery of a sense of empowerment (Anderson et al., 2020; Ooi et al., 2016). It is important, however, to acknowledge that sometimes, acceptance is not a positive concept whereby the individual can just 'move on', with a struggle to come to terms with loss being one of the main reasons that a mother seeks psychiatric support post autism diagnosis (Gatzoyia et al., 2014; Karp & Kuo, 2015).

It is, however, important to recognise that in studies around the experiences of parents of an autistic child, mothers outnumber fathers by 8:1 (Potter, 2017), with fathers generally underrepresented (Braunstein et al., 2013; Burrell et al., 2017). How might the impact of the diagnostic process and the diagnosis itself be felt by the father? Research suggests that fathers often have similar sentiments to mothers around the diagnosis, with expressions of relief and devastation, along with guilt and blame (Frye, 2016). However, arriving at the stage of acceptance differs for fathers compared with mothers; fathers reported needing to move beyond the stage of anger and frustration (Burrell et al., 2017), whereas for mothers it was more often the case of moving beyond sadness (Navot et al., 2017). The stage at which their child was diagnosed also made a difference for fathers, with a later diagnosis marking a clearer path to acceptance; a reason behind the challenging behaviours (Burrell et al., 2017; Potter, 2017). Similarly, to that reported of mothers (Nicholas et al., 2016), fathers of children diagnosed at an earlier stage, acutely felt the loss of the child they had assumed was normally developing, the one they had prepared for, only to find them replaced by a 'monster' (Burrell et al., 2017). Possibly mirroring the relative absence of research into paternal sentiments around their autistic child, fathers also spoke of feeling marginalised, and not sufficiently included in the diagnostic process (Potter, 2017)[3], feeling it was all about mum and how she was feeling. Perhaps the reason that fathers find it more difficult than mothers, to come to terms with their child's autism diagnosis, is grounded in this sense of exclusion from the diagnostic process (Legge & Tickle, 2019).

An interesting aspect emanating from a study of mothers raising autistic daughters (Fowler & O'Connor, 2020) was the finding that mothers who, through the process of assessment and diagnosis, recognised autistic traits within themselves, and used this affinity to develop a sense of empowerment in familial pride around their identity as autistic females. This finding

[3] Although fathers are present less often than mothers during the diagnostic process, there is a sense that even if they were present, resources are targeted predominantly at the needs of mothers.

contradicts the assertion of Pohl et al. (2020), that autistic mothers are at considerably higher risk of mental health difficulties when compared to their non-autistic counterparts. Although a thorough search of the literature elicits very little specific research into this area, one study around fathers' experiences of autism diagnosis suggested that fathers are usually keen to explore the potential that autism is likely to have a significant genetic component (Hannon & Hannon, 2017). It is possible that for fathers, there is less stigma attached to nature-based than nurture-based conditions, hence the importance to them of uncovering potential genetic links.

It must be added that although the overwhelming reaction to an autism diagnosis is negative, whilst not specifying time since diagnosis, there are positive outcomes reported as well (Kayfitz et al., 2010; Lloyd et al., 2019; Waizbard-Bartov et al., 2019). One of the most commonly discussed themes is that of empowerment (DePape & Lindsay, 2015), and being able to make sense of their situation and use the diagnosis to move ahead (Potter, 2017); bringing with it a new confidence in the ability to parent (Anderson et al., 2020), and allowing for more understanding and patience (Fernańdez-Alcántara et al., 2016). Positive first experiences around diagnosis set up the foundation for parents to feel empowered in their drive to advocate for their autistic child (Boshoff et al., 2016; Boshoff et al., 2018). They suggest that self-education is one of the most important aspects of enabling parents to advocate for their autistic child at all stages of their journey. A further finding was a parental sense of celebration and acceptance following the autism diagnosis (Lloyd et al., 2019).

However, research overwhelmingly suggests that such positivity in the hope that the diagnosis might then open the door to further support is depressingly short-lived, with many parents discovering that resources and funding are severely limited if offered at all (Crane et al., 2016; Crane et al., 2018; Legge & Tickle, 2019; Mitchell & Holdt, 2014; Potter, 2017). One of the key reasons that parents pursue an autism diagnosis is in the hope that it will enable their child to access appropriate support (Crane et al., 2018; Eggleston et al., 2019; Potter, 2017). However, the reality of a dearth of post-diagnostic support would appear to be a global experience (Chamak et al., 2011; Crane et al., 2018; Eggleston et al., 2019; Hannon & Hannon, 2017; Ho et al., 2014; Mitchell & Holdt, 2014); 'a diagnosis and a handshake' (Chantrey, 2017).

2.5.3 The lived experiences of parents of autistic children

There is an abundance of research that acknowledges the parenting of autistic children to be an exhausting business, both physically and mentally (Argumedes et al., 2018; Bozkurt et al., 2019; Factor et al., 2018). Indeed, the stress experienced in parenting an autistic child is widely reported to be more significant than that of parenting a child with other mental health conditions such as ADHD or Down's syndrome (Biondic et al., 2019; Hayes & Watson, 2013; Seymour et al., 2017). Parents of autistic children are overwhelmingly reported as leading 'tormented lives' (Sukmak & Sangsuk, 2018) and longing for normality (Altiere & Von Kluge, 2009). Nicholas et al. (2016) report that mothers frequently feel that life would be lighter without an autistic child, with '150%' of their time being taken up with the process of daily life with their autistic child. Fathers talk of being 'battlefield fathers', fighting against bureaucracy and systems that are seemingly loaded against them (Burrell et al., 2017).

Many studies find raised levels of stress and depression in parents of autistic children (Hayes & Watson, 2013; Lai et al., 2015b), with the inevitable outcome of poor parental mental health (Bonis, 2016; Sukmak & Sangsuk, 2018). One of the most overriding themes over the past few decades of research into the mothers of autistic children has indeed been the increased levels of depression, anxiety and stress that they experience (Bitsika et al., 2013; Falk et al., 2014; Nicholas et al., 2016). Owning to the predominance of mothers in such research, the mental health of fathers is less often explored (Potter, 2017). However, fathers are not exempt from having elevated stress levels, although these often centre on the child's behaviour (Ooi et al., 2016; Paynter et al., 2018). Studies around depression coming from parenting an autistic child often find that mothers have higher levels than fathers (Estes et al., 2013; Jones et al., 2013; Ozturk et al., 2014). However, a study by Rivard et al. (2014) suggests that fathers have higher levels than mothers, while Craig et al. (2016) found no difference. It is likely that such discrepancies are accounted for by the small sample sizes of fathers in autism research around parents in general (Seymour et al., 2017). However, despite the abundance of research into these adverse impacts on parents, it would appear that the provision of accessible and appropriate support to parents and families is hard won, if available at all (Lai et al., 2015b; Nicholas et al., 2016; Potter, 2017).

Because autism is an invisible yet extremely pervasive condition, unless it exists comorbidly alongside a physical disability, there are no outward characteristics to explain inappropriate behaviours (Bonis, 2016; Gill & Liamputtong, 2013). This can result in the 'shopping experience' (Neely-Barnes et al., 2011), where public meltdowns and age-inappropriate behaviours are viewed critically (Iadarola et al., 2019; Lloyd et al., 2019), with less understanding from the public than if the child was in a wheelchair (Nicholas et al., 2016). Parents frequently feel stigmatised and judged for being ineffective in their parenting (Gill & Liamputtong, 2013; Paynter et al., 2018; Reddy et al., 2019). This can in turn lead to self-stigma where parents internalise public stigma and blame themselves (Chan & Lam, 2018; Liao et al., 2019).

Parents' experiences of stigma, both public and self, associated with their child's autism is a significant cause of their emotional stress (Corcoran et al., 2015; Kinnear et al., 2016; Tilahun et al., 2016), evidenced through hurtful and tactless open criticism (Harandi & Fischbach, 2016; Kenny et al., 2016). It is likely that public ignorance, and a lack of the social acceptance of autism is at the root of such experiences (Harandi & Fischbach, 2016), with the stigma founded in parents' experiences of rejection, social exclusion and stereotyping (Kinnear et al., 2016). This is particularly hurtful when their child has a self-injury, leading to parents fearing that *they* will be accused of harming them (Fodstad et al., 2012; Nicholas et al., 2016). Worryingly, criticism and parent-blaming for the autistic behaviours is also suggested to emanate from professionals involved in the care of the child (Gill & Liamputtong, 2013), with accusations that parents pathologise their child's condition rather than admit to their bad parenting (Chantrey, 2017).

Fear of public criticism often results in parents avoiding social situations (Nicholas et al., 2016), in turn, leading to feelings of intense loneliness and isolation (Lloyd et al., 2019; Lodder et al., 2019). Parents talk of finding that even close family do not understand their struggles (Ekas et al., 2016; Griffith et al., 2012), with many finding their child criticised by *their* parents and compared to a NT child (Bonis, 2016). Due to an overall lack of knowledge of the challenges of autism parenting, they would also prefer not to burden their friends with their difficulties (Iadarola et al., 2019). However, it would appear that parents who are struggling with their child's challenging behaviours frequently find great support and solace from other parents of autistic children, whether through an active local community or through online advice (Lloyd et al., 2019). Nicholas et al. (2016) write of mothers of autistic children

being less judgemental of each other, imparting a sense of 'experiential authenticity'. Although Lloyd et al. (2019) suggest that mothers are more likely to value this solidarity between other parents than fathers, this finding contradicts a study by Paynter et al. (2018) who found that fathers of autistic children very much sought and valued the support of other fathers; perhaps suggesting an affinity with the same gender parent for support.

Most studies into the social experiences of autistic girls (Sedgewick et al., 2018a; Tierney et al., 2016) do not locate the parent's experience alongside that of their daughter. However, in a recent study around the social motivation of autistic girls involving parent-daughter dyads (all but one were mother-daughter), it was the parent who felt most sensitive towards social rejection and isolation by their daughter's peers, rather than the daughter herself (Cook et al., 2018), perhaps amplifying the mother's overall feelings of social exclusion (Kinnear et al., 2016). Anxiety in autistic children is widely acknowledged and researched (Rodgers et al., 2016; van Steensel et al., 2011; van Steensel et al., 2015), and in girls, is likely to represent the manifestation of their social and communication difficulties (Oswald et al., 2016; Solomon et al., 2012). However, there are very few studies that explore the impact of this anxiety on parents, and those that do make no differentiation in anxiety between boys and girls (Adams et al., 2019; Adams et al., 2020).

Research suggests a 28-fold increase in suicidal behaviour in children and adolescents with autism compared to their NT counterparts (Hannon & Taylor, 2013; Howe et al., 2020; Stewart et al., 2017), and an overall increase in self-harming behaviours (Hosozawa et al., 2020), with studies into recently diagnosed autistic adults finding that 66% had contemplated suicide and 35% had planned or attempted suicide (Cassidy et al., 2018). Crucially, none of these studies differentiate between males and females, yet recent research by So et al. (2021) suggests that autistic females are at a much greater risk of significant self-harm than males. However, whilst there are studies around the negative impact on parents of child self-harm (Curtis et al., 2018; Ferrey et al., 2016), these make no reference to autism, let alone autism in girls. It could therefore be argued that not only are autistic girls overlooked in research, but by extension their parents too.

Mothers parenting a child with a developmental disability (not specifically ASC) are likely to believe that their child is vulnerable and at risk of harm (Thackeray & Eatough, 2015). A study by Hodgetts et al. (2013) suggests that other family members are also felt to be at risk

of harm *from* the autistic child. However, there would appear to be very little, if any, literature around how the parent experiences such behaviours; what it is like to witness your child hurting other family members.

Possibly supporting the lack of paternal engagement in the diagnostic process, mothers typically leave work in order to manage the extra care, and support their child's needs, both pre and post diagnosis, with school-related issues and additional health appointments (Bonis, 2016; Jones et al., 2013; Lutz et al., 2012). They talk of their new life as being a fulltime job, 'living and breathing' autism (Nicholas et al., 2016), although with the additional stress of no delineated hours (McAuliffe et al., 2019). This has an immediate financial impact that in turn exacerbates already strained family relationships (Bonis, 2016; Harandi & Fischbach, 2016; Ten-Hoopen et al., 2020), and pushes the mother further into social isolation through loss of her self-identity associated with her work outside the home (Gill & Liamputtong, 2013). The round the clock role of mothers to autistic children (Nicholas et al., 2016) means that although they are frequently exhausted, pervasive worry and concern for their child's safety and wellbeing means they find it hard to switch off (Gill & Liamputtong, 2013), with mothers often feeling that they are expected to 'run the ship' (McAuliffe et al., 2019). Interestingly, identifying themselves as the breadwinner, fathers of autistic children also found their working lives strained by lack of flexibility from their employers when needing to attend appointments, although cited support from their work mates as being very important (Paynter et al., 2018), in contrast to the isolation felt by mothers in their new found role (Gill & Liamputtong, 2013).

Although violence and aggression by an autistic child towards their family is acknowledged to create significant parental stress (Del Pozzo et al., 2018; Hodgetts et al., 2013; Sabapathy et al., 2016), there would appear to be very limited research into the lived experiences of such parents. It is possible that this dearth of research is in some part due to parents being unwilling to acknowledge their struggles, instead blaming themselves for being unable to manage their child's behaviours (Lai et al., 2015b). Research suggests that parents frequently adopt avoidant coping mechanisms, preferring to pick their battles and ignore the offender (Nealy et al., 2012), although both parents (Hodgetts et al., 2013), and siblings (Yacoub et al., 2018) have been on the receiving end of aggression from their autistic child/sibling.

Although this section of the literature review focuses on the lived experiences of parents of an autistic child, it would seem relevant to briefly discuss the impact on the often-overlooked siblings, given the recognition that the whole family unit is affected by a member having autism (Leedham et al., 2020a). One of the most common themes is that of the NT sibling feeling that their own needs are overshadowed by their autistic sibling (Bonis, 2016; Lovell & Wetherell, 2016; Ward et al., 2016a). Parents similarly feel guilty that they cannot give the NT sibling enough of their time, adding to their feelings of inadequacy and stress (Corcoran et al., 2015; Lloyd et al., 2019). However, on a positive note, a study into the impact of challenging autistic behaviours on siblings found that NT siblings quite often feel that their parents compensate in other ways for the challenges that they face (Yacoub et al., 2018). It is clear, however, that the shift in family routines that is necessitated by an autistic child has a significant impact on family functioning (Boyd et al., 2014), with frustrations expressed around the limitations placed on the NT siblings, in terms of family activities that can be enjoyed (Paynter et al., 2018).

A lack of knowledge about the features and causes of autistic behaviours within a household can exacerbate family tensions, leading to eventual breakdown of relationships (Lloyd et al., 2019; Mandell et al., 2010). Increased levels of stress are placed on parents around managing their child's anxiety (Adams et al., 2020). Additional stressors in parental relationships come from chronic fatigue due to disrupted sleep, that is common in autistic children (Fewster & Gurayah, 2015; Malow et al., 2014; Veatch et al., 2015), with up to 80% of autistic individuals experiencing some degree of insomnia (Kirkpatrick et al., 2019). Difficulty in knowing what behaviours can be attributed to autism, and which cannot, leads to conflicting approaches to discipline (Aylaz et al., 2012; Harper et al., 2013; Hill-Chapman et al., 2013), contributing to the subsequent deterioration of the parental partnership (Zablotsky et al., 2013b). Although the degree of autistic behaviour might be considered to have an impact on the extent of parental relationship stress, studies have shown inconsistent results (Lai et al., 2015b). Some studies demonstrate a positive correlation between parenting stress, and the severity of autistic behaviours (Mori et al., 2009; Wang et al., 2011), whilst a study by Huang et al. (2014) found more parental stress with children with mild to moderate autistic behaviours.

Such discrepancies are perhaps better answered by exploring the common perception that divorce rates are higher among parents of autistic children than those of typically developing

children (Freedman et al., 2012; Kousgaard et al., 2018). Whilst it is clear that strain on marital relationships can be intensified by the extra time and effort needed to care for an autistic child (Pozo et al., 2014), family-focused research around the well-being of parents is predominantly based on data gathered from mothers (Hayes & Watson, 2013; Saini et al., 2015). When asked their views on their input into their autistic child's life, fathers often report feeling side-lined and disregarded (Potter, 2017), and an 'after-thought' (Burrell et al., 2017). Overlooked in many studies (Hayes & Watson, 2013), one of the greatest stressors for fathers of autistic children was their concerns over the impact on their partner (Paynter et al., 2018). Furthermore, it is suggested that an additional relationship strain might be seen when one or other partner shows autistic tendencies themselves (van Steijn et al., 2012), possibly having a significant impact on their ability to co-parent (Saini et al., 2015). However, this should be balanced against the relief felt when through their child's autism diagnosis, the recognition of autistic traits in a parent can explain a lot of longstanding marital misunderstandings (Gill & Liamputtong, 2013).

A search of the literature around parental coping mechanisms elicits some contradictory findings. A systematic review of the literature around coping styles in parents of an autistic child (Vernhet et al., 2019) suggests that overall, parents tend to use more avoidant coping strategies, such as self-blame, expressing negative emotion, and the use of alcohol/tobacco, as well as prescribed medication, than those of typically developing children. However, this was not an absolute finding with Wang et al. (2011) positing that parents of autistic children were less likely to use avoidant coping mechanisms than the parents of typically developing children, although Lai et al. (2015b) and Pisula & Kossakowska (2010), suggest the opposite. Many studies suggest that problem-focused coping mechanisms such as pre-empting behaviours, adapting family life, and creating a supportive structure within the home, reduce parental stress levels (Cappe et al., 2011; Dabrowska & Pisula, 2010; Wang et al., 2013), with both mothers and fathers engaging equally in such strategies (Pepperell et al., 2018). However, interestingly, a more recent study by Ang & Loh (2019) found that whilst in agreement with much of the literature, in that avoidant coping styles increase parental stress and depression, they found that problem-focused coping strategies *did not* predict better outcomes for parental mental health.

Some studies suggest that there are gender differences that impact upon the use of coping strategies (Meléndez et al., 2012; Pozo et al., 2014). It could be argued that the significant

under-representation of fathers in autism research (Brown et al., 2020b; Burrell et al., 2017; Vernhet et al., 2019) overlooks the potential for mothers and fathers to cope in different ways. Whilst it is acknowledged that a lack of social support drives increased levels of stress for mothers of autistic children (Zaidman-Zait et al., 2017), it is important to recognise that fathers often feel like 'after-thoughts' (Burrell et al., 2017) where social support is concerned. It is possible that mothers and fathers seek such social support from different sources. Lloyd et al. (2019) attempt to discern such differences, and found that mothers are more likely to value solidarity with other parents of autistic children than fathers, although this finding is contradicted in other research around fathers of children with autism who found that fathers highly value talking to other fathers of autistic children as a means of support (Burrell et al., 2017; Paynter et al., 2018).

It could be argued that wellbeing support for parents of autistic children is more focussed on the needs of mothers (Paynter et al., 2018) in part due to the relative dearth of fathers in autism research (Vernhet et al., 2019). In contrast, Pepperell et al. (2018) found that both mothers and fathers were comparable in number in their use of social media forums as a means of gaining support through increased knowledge around autism and linking up with other parents to gain advice and importantly to hear their success stories. Research suggests that social support via online media for parents of autistic children represents a shift towards more accessible and less judgemental social support (Saha & Agarwal, 2015). Social media support groups for the parents of autistic children help them to make sense of and search for meaning around their experiences, and to seek support through mutual experience (Huws et al., 2001; Reinke & Solheim, 2015). It is also likely that through such groups, parents can pick and mix the support they need, rather than have to adapt to the 'one size fits all' approach to parent support that Clifford & Minnes (2013) suggest is particularly unhelpful.

However, it is interesting to note that in a study researching the use of Facebook groups for autism support (Abel et al., 2019), just over 10% (approx. 50 groups) were directed at mothers, yet only two groups were specifically for fathers. This supports the assertion of Paynter et al. (2018) that the needs of fathers are often overlooked in autism support for parents. Although Cole et al. (2017) found that parents welcomed the inclusion of professionals on such groups, personal experience would concur with Abel et al. (2019) in suggesting that parents in such closed groups often value a safe place to explore negative

experiences and resent this space being monitored by anyone not sharing their parenting journey.

However, even though the literature overwhelmingly paints a very negative picture, there are some positive parental experiences (Lloyd et al., 2019; Markoulakis et al., 2012), although possibly these are underrepresented in previous research that predominantly focuses on parental stress and poor mental health (Gill & Liamputtong, 2013; Sukmak & Sangsuk, 2018). Indeed, it should be noted that relationships can also be strengthened through autism diagnosis, with parents united by a common goal (Iadarola et al., 2019), and although perhaps set apart from other families by their child's diagnosis, brought together as a couple through their mutual experience and commitment (Hock et al., 2012; Markoulakis et al., 2012). Parents sometimes find that a diagnosis acts as a catalyst in deepening the parent-child relationship, as they not only come to accept, but to celebrate the uniqueness of their autistic child (Lloyd et al., 2019). An increase in patience and understanding is also a reported benefit that can come with an autism diagnosis (DePape & Lindsay, 2015).

2.6 Summary and the context of the current study

As is clearly evidenced, girls with autism present quite differently to their male counterparts (Gould, 2017; Lai et al., 2015a) and, although there are early signs of a more female-based assessment (Brown et al., 2020a), the diagnostic tools remain geared towards capturing the male presentation (Duvekot et al., 2017; Mandy & Lai, 2017). Many females with autism are mis-diagnosed, diagnosed late, or are not diagnosed at all (Bargiela et al., 2016). There are many global studies that explore the parental experience of an autism diagnosis (Chamak et al., 2011; Fewster & Gurayah, 2015; Mitchell & Holdt, 2014; Moh & Magiati, 2012). There have been a few large-scale UK studies all with over 700 participants (Crane et al., 2016, 2018; Howlin & Asgharian, 1999; Howlin & Moore, 1997), although all are analysed using quantitative methodologies; alongside a more recent smaller qualitative study that recruited participants via You Tube (Lloyd et al., 2019). Such studies clearly evidence an overall dissatisfaction with the both the diagnostic process and post-diagnostic support, along with the day-to-day challenges faced by parents of children with autism in the UK. There are many more non-UK studies that further document such challenges with the lived experiences of the parents of autistic children (Gill & Liamputtong, 2013; Lai et al., 2015b; Sukmak &

Sangsuk, 2018). However, these all explore the experiences of the parents of autistic males *and* females.

There are several UK studies that explore specific aspects around the parental perspectives of their autistic daughter's life such as school life (Sproston et al., 2017), and friendships (Cook et al., 2018; Sedgewick et al., 2018b). An Irish study by Rabbitte et al. (2017) explores the diagnostic experiences of the parents of an autistic daughter, and although fleetingly touching upon the emotional impact, it focuses predominantly on the actual diagnosis and post-diagnostic support. There have been a few UK studies into the lived experiences of the mothers of girls with autism (Anderson et al., 2020; Kseib, 2018; Mycroft, 2017; Senior, 2019), however, these fail to acknowledge the highly pertinent, yet often overlooked views of fathers (Potter, 2017). Given the recognised impact on the parental relationship, of raising an autistic child (Lai et al., 2015b), it would seem highly relevant to explore the lived experiences of both mothers and fathers.

There is a breadth of research around the evident difference in the presentation of autistic girls (Duvekot et al., 2017; Kanfiszer et al., 2017), the clear ability of girls to mask their struggles (Tierney et al., 2016), to hide in plain sight (Dean et al., 2017), and the wider impact on the parents of a delayed or non-diagnosis (Bargiela et al., 2016). Paired with the clearly documented toll taken on the quality of life and mental health of parents in raising an autistic child (Bonis, 2016; DePape & Lindsay, 2015; Due et al., 2018), there would appear to be a significant gap in the literature, with, at the time of writing, no in-depth research into the lived experiences of both mothers *and* fathers of an autistic daughter within the UK. This study sets out to address this evident gap in the research: that of exploring the lived experiences that are unique to the parents of autistic girls.

2.7 Reflexive statement

Throughout the writing of this literature review, I have become uncomfortably aware of an increasing frustration that, much as there is a growing body of research around autism in girls, some dating back several years, this knowledge still fails to be implemented in practice. Even in recent studies, females are clearly under-represented, and until this balance is redressed, the persistent male bias in autism research will continue to be perpetuated in practice.

Chapter 3: Methodological choices and methods

3.1 Introduction

In this chapter, methodological choices and methods are set out, demonstrating how these are influenced by ethical considerations and issues that have emerged throughout the research process. The research questions that this study seeks to answer are:

- What are the lived experiences of the parents of adolescent autistic girls, within the UK?
- What, if anything, might have made a difference to these experiences?

3.2 Theoretical positioning of the research study

In order that the research question (Section 1.5) was best addressed, the overall approach to the design of the study necessitated a methodology that would be both the most appropriate for the capture and exploration of the fine detail of the under-researched area of the lived experiences of the parents of an autistic daughter, but one that would also remain true to the rationale and aims of the study (Silverman, 2014). In endeavouring to give a voice to those previously unheard (Chantrey, 2017), quantitative approaches have been discarded. Indeed, qualitative research is felt to be the more appropriate choice when studying under-represented and unheard individuals (Willig, 2013), such as the parents of autistic girls. In agreement with Lincoln & Guba (1985), the positivist approach that underpins quantitative methodologies, if used with human participants, overlooks the essence of humanity and is therefore wholly unsuitable for this study. Rather, the qualitative approach is one that seeks to "…develop an understanding of how the social world is constructed" (McLeod, 2011, p. 3); the notion of the world as being 'constructed' implying that we live in a relational, political and social world, both layered and complex, and acknowledging that multiple versions of reality co-exist.

Being ontologically and epistemologically positioned in the interpretivist-constructivist paradigm as defined by Taylor & Medina (2013), this paradigm represents a worldview consistent with the position of the research question (Denzin & Lincoln, 2017). This underlines the requirement to engage in interpretative research in order to deepen

understanding. The study assumes a phenomenological perspective and is situated in an interpretivist-constructivist paradigm, as this best exemplifies the overarching ontological and epistemological positionings that underpin IPA. This is shown in figure 1 (below) which is based upon the writing of Ponterotto (2005) on qualitative paradigms.

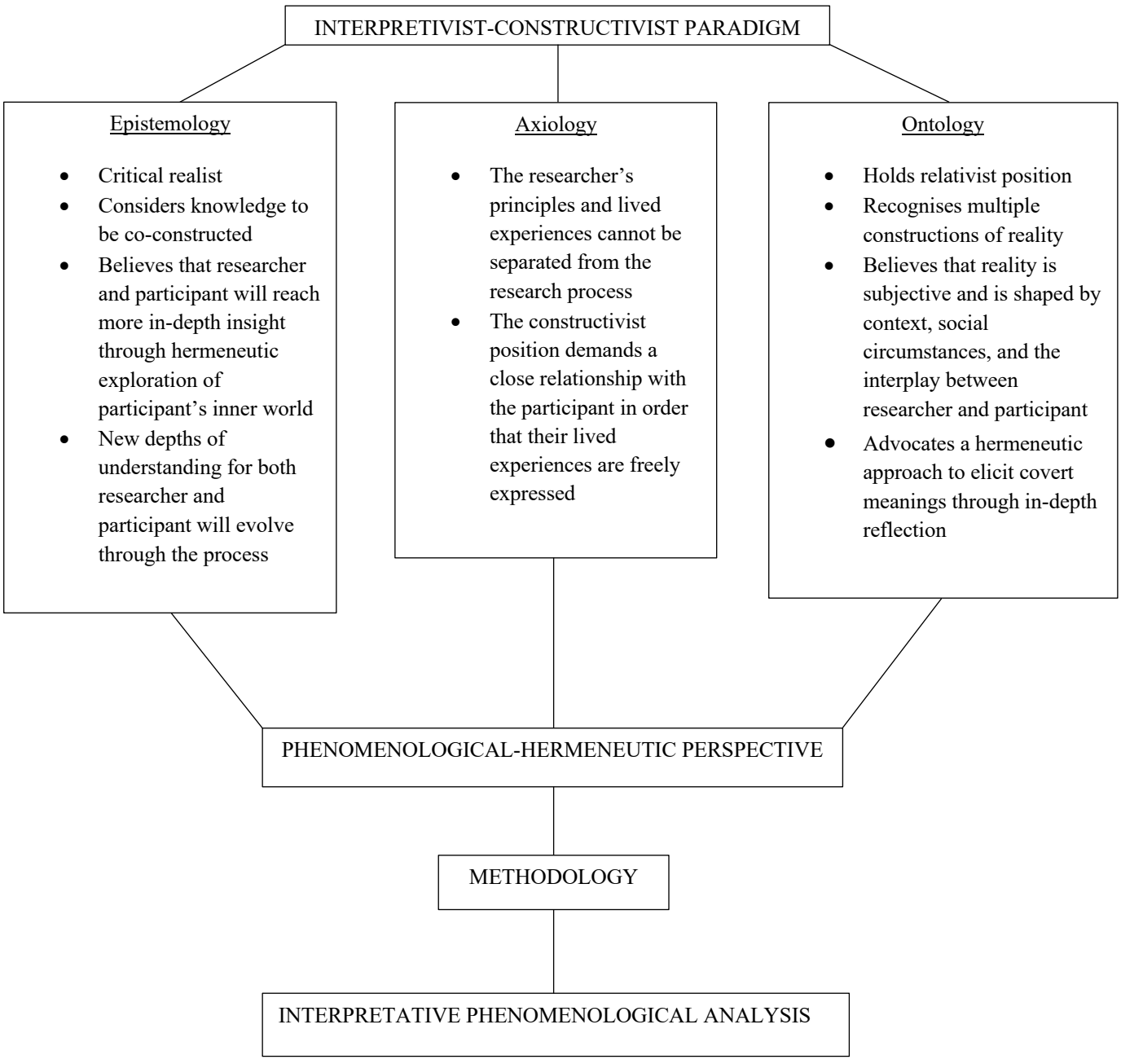

Figure 1: Positioning the research in an interpretivist-constructivist paradigm (Ponterotto, 2005)

Holding a critical-realist epistemological stance, the position taken is that the language used by participants reflects their experience. This approach fits with the concept of the data being

understood through the ‘double hermeneutic’ where the experience is first refined through the participant’s perception, and then further through that of the research position (Smith et al., 2009). The critical realist stance acknowledges that this filtration is occurring, whilst accepting that the perception is connected to the reality of the experience (Oxley, 2016).

In weighing up the most appropriate methodology for this study, Foucauldian Discourse Analysis (FDA) was considered, as it would identify the political and social context in which the experience of parenting an autistic daughter is framed (Willig, 2013). In seeking to understand the participant’s worldview, and being unable to look into their experience, it was felt that the exploration of language might be a means through which to understand how they represent themselves. FDA differs from other types of discourse analysis in that it is founded on the assertion that social structures and practices are dictated by discourse, specifically that language is a mechanism through which to provide meaning (Willig, 2013). Power is regarded as a core element of discourse and indeed is one of the main reasons that individuals partake in discourse (Foucault & Rabinow, 1991).

Thematic Analysis (TA) (Braun & Clarke, 2006) was also considered, although after extensive reflection, it was discarded. It would undoubtably have been useful in capturing the commonalities in participant experience. However, this study was focused on the in-depth lived experience of the participants, and it was felt that the analysis needed to go further than simply eliciting broad themes. West (2013) describes TA as a less intense and rich method in comparison to other qualitative approaches, although this opinion is strongly contradicted by Clarke & Braun (2018), who argue that TA can deliver a rich analysis of data when their approach is followed. As a methodology previously used by the researcher (Chantrey, 2017), it is not disputed that rich and valuable data can be uncovered; however, that study involved the analysis of thirty detailed questionnaires, whereas the current project is looking more in-depth into the lived experiences of eight parents of autistic girls.

After reflecting on Interpretative Phenomenological Analysis (IPA) it was also felt to be an appropriate possibility as a choice of methodology. It is concerned with the exploration of lived experience and draws on a collation of theoretical strands from phenomenology, including the emotional, cognitive and embodied experience of the phenomena (Smith et al., 2009). Perhaps, part of the appeal of IPA lies in the researcher’s work as a psychotherapist. Denzin & Lincoln (2017, p. 11) describe qualitative researchers as ‘quilt-makers’, in that they

work with the participant and their data to patch together an in-depth account of their lived experience. This has parallels with the pluralistic psychotherapist's role, in seeking to come alongside the client and understand their world, whilst holding an awareness that this can only be an *interpretation* of that world. The epistemological position is also in some part shaped by the researcher's insider position as the mother of an autistic son, as it concerns the lived experience; one shared in part with the participants. This 'insider' role is a powerful and reflexive position that can support more in-depth engagement and insight into the participant's making sense of their lived experience (Cooper & Rogers, 2015).

In the very early stages, FDA was initially marginally favoured over IPA, although there was no firm decision. However, following the first interview it became clear that IPA would be a more appropriate choice of methodology; a decision that was not felt to preclude the situating of the findings in a social and political context. Although the research question would have been adequately addressed through using FDA, it was felt that IPA was more complimentary with the principles that underpin the researcher's work as a pluralistic psychotherapist and as a practitioner-researcher; that is that both focus of the 'life-world' *(Lebenswelt)* (Husserl, 1964) of the individual, through co-constructed meaning-making, rooted in a socio-cultural and relational context (Fischer, 2006; Strong et al., 2008). Cultures are, in effect, frameworks for the making of meaning (Much, 1995). Therefore, while IPA has the main focus on understanding experience, Smith et al. (2009) posit that IPA is already always entwined with culture and language. It could be argued that both IPA and FDA have shared links within how context is enmeshed in the experiences of the individual (Smith et al., 2009); with IPA focusing on the experiential story of the individual's involvement in the context, whereas FDA provides a critical analysis of the framework of the context itself. Certainly, Johnson et al. (2004) suggest that IPA and FDA have many features that make them compatible, notably that there are different ways of constructing the same phenomenon.

Whilst such semantics can be contextualised in the advice of Silverman (2014): that it is not necessary to define the researcher's philosophical position to the extent that the essence of good qualitative research suffers as a result, the paramount reason for using IPA rather than FDA lies in the significant lack of research into the lived experiences of the parents of an autistic daughter. The first level of research to be undertaken should be phenomenological; exploring the lived experience. This can then later be further explored through the lens of discourse (Section 5.4). Although the inherent struggle to explicate the reasons for choosing

IPA is evident, the choice has been made because its clear theoretical foundation allows for innovation and creativity, yet the sound methodology, founded in an appropriate philosophical tradition makes it applicable to the research question (Harper, 2012). From the outset, it has been paramount that the methodology chosen allows the participants' voices to come to the fore, whilst the perceptions made through the interpretation of the data are transparent for the reader. IPA fulfils these requirements in allowing the researcher to "stand alongside the participant, to take a look at them from a different angle, ask questions, and puzzle over things that they are saying" (Smith et al., 2009, p. 36).

3.3 Interpretative phenomenological analysis

Developed in the 1990's by a British psychologist, Jonathan Smith (McLeod, 2011), IPA is a qualitative methodology, frequently used in research within the field of health, psychology, and psychotherapy. Although IPA is experientially focused, it is acknowledged that the researcher is only able to capture an understanding of the participant's experience through what is said, being unable to directly partake in that experience (Oxley, 2016). Therefore, two 'filters' are created between the participant's experience and the research: the participant reflecting on their experience through language, and the researcher interpreting what has been said, thus creating a triangulation of interpretation (Smith, 2018a). The challenge in this is acknowledged and becomes part of the methodological stance of IPA that positions individuals as 'meaning-makers' (Peat et al., 2019). This is described by Smith et al. as the means by which 'the meaning, which is bestowed by the participant on experience, as it becomes an experience, can be said to represent the experience itself' (Smith et al., 2009, p. 33). IPA is underpinned by theory that is founded in phenomenology, hermeneutics and idiography (Oxley, 2016; Smith et al., 2009).

Phenomenology is a movement of philosophy, first outlined by the German philosopher Edmund Husserl in the late nineteenth century and focuses on the study of 'being' (Hefferon & Gil-Rodriguez, 2011); his primary objective being to establish a means of discovering the ultimate truth (Husserl, 1931/2012; McLeod, 2011). His main emphasis was in interacting directly with the phenomena itself, arguing that the researcher should 'go back to the things themselves' (Smith et al., 2009, p. 12). As IPA is influenced by the core concepts from several philosophical positions on phenomenology, it sets out to form these into a practical research methodology (Oxley, 2016). IPA makes no attempt to carry out the 'reductions'

suggested by Husserl, but rather emphasises capturing the unique lived experiences of a unique subset of people (Hefferon & Gil-Rodriguez, 2011).

As IPA places emphasis on the interpretative element, it is underlined by hermeneutics, or the theory of interpretation. In recognising that humans are 'meaning-making' individuals, IPA accepts that efforts in making sense of an experience will be reflected in the accounts that they give. Additionally, it is acknowledged that access to their experience will depend on the participant's recounting of that experience, and that the researcher then needs to interpret that story in order to understand the experience (Smith et al., 2009). A double hermeneutic is then said to be engaged as the researcher is actively "…trying to make sense of the participant trying to make sense of what is happening to them" (Smith et al., 2009, p. 3). To support this meaning-making process, IPA requires that the researcher engages with the 'hermeneutic circle'; an iterative process of moving between the smaller and larger units of meaning (Peat et al., 2019). Within this circle, the researcher uncovers challenges to their preconceptions as they engage with the data (Oxley, 2016).

Unlike the reductions proposed by Husserl, the phenomenology of hermeneutics recognises that it is not possible to separate the researcher's views of the world from their interpretation of the participant's data: the two are too entwined (Oxley, 2016). For this reason, IPA researchers are urged to maintain a continually reflexive stance (Finlay, 2002; Finlay & Gough, 2003; Goldstein, 2017); a reflexive 'dance' where the researcher glides and twists through an ongoing iterative struggle in bringing to awareness and then managing pre-existing assumptions and habits, in the hope of a finale of fresh insights (Finlay, 2008).

Whereas in traditional phenomenology, the approaches tend to focus on the essence of an experience or phenomenon of a specific group of people, IPA is different in that it is 'idiographic' (Smith et al., 2009). That is, that it explores the convergence and divergence of experiences of a homogenous sample of individuals (Allan & Eatough, 2016; Pietkiewicz & Smith, 2014); the experience of *that* individual and the sense *they* are making of their experience (Smith, 2011). An IPA study involves examining each participant's experiences individually, and important in their own right, then searching for distinct and common themes across the group of participants' cases (Willig, 2013).

Although a highly popular methodology, in particular for health psychology and social science research (Brocki & Wearden, 2006; Pringle et al., 2011), there remain criticisms of IPA that are important to reflect upon, in particular as a practitioner-researcher. Van Manen (2017) refutes the notion that a psychotherapist can hold the dual role of phenomenological researcher, arguing that whilst a psychotherapist might be in the business of helping their client to make sense of challenging life experiences because that is what they do, it is not what a phenomenological researcher does. He asserts that Smith et al. (2009) place too much emphasis on understanding the personal experiences of the participant, at the expense of focusing on the phenomenon itself. Reiterating the insinuation of Giorgi (2010) that IPA has been set up with no indication as to how it relates to philosophical phenomenology, van Manen (2017) implies that although IPA research sets itself out as being inspired by phenomenology, because it fails to pursue a phenomenological outcome, it should instead be regarded as a psychological research study. He goes on to suggest that in his desire to promote IPA as a suitable methodology to those hoping to use a phenomenological approach, Smith et al. (2009) erroneously regard psychology and phenomenology as being mutually compatible. However, this suggestion that phenomenology and psychology are mutually exclusive constructs is rebutted by Smith (2018b) who argues that they act on different levels. He rightly maintains that rather than the therapist being needed to bring about 'sense-making' in the participant, it is simply an inherent and natural response in humans when faced with unforeseen life events.

3.4 Ethical practice

Ethical approval was sought from and granted by the University of Chester Ethics Committee through their ethics application process (Appendix A). The application form also contained the relevant consent forms and information sheets (Appendices B&C). As a practising psychotherapist and researcher, and a member of the British Association for Counselling and Psychotherapy (henceforth BACP), it was considered imperative to uphold the same values in research as in practice; those of autonomy, informed consent, and confidentiality, alongside beneficence and non-maleficence as outlined in the BACP Ethical Framework (BACP, 2018). Correspondingly, in the research, the BACP Ethical Guidelines for Research (Mitchels, 2018) were adhered to, alongside the Chester University Research Governance Handbook (University of Chester, 2019).

The wellbeing and safety of the participants was of the utmost importance throughout the research process (Bond, 2004), and remained at the core of every research decision that was made. Confidential documents, such as electronically signed consent forms, digital recordings, interview transcripts and reflexive post-interview notes were stored securely in accordance with the Data Protection Act (2018), and the University of Chester requirements. Data was stored on the university OneDrive system and backed up on a USB pen, with both the computer and the USB being password protected. At all stages, the participants were made aware of their right to withdraw, from initial interest in the research to the interview stage, and within a specified period post-interview. No participant requested to withdraw. All participants, their daughters, and any other family members or friends were ascribed pseudonyms in accordance with the participant information sheet in order to preserve anonymity. Place names were replaced with '*****' to reduce the possibility of identification by deduction.

Although it had initially been intended to conduct either face to face or video interviews, this choice for the participant was removed by the onset of Covid-19. Therefore, every stage from sending out participant information sheets and consent forms through to conducting the interviews, was carried out electronically. Similarly, it had originally been intended to limit the geographical area of travel to interviews for logistical and financial reasons, but this change enabled the recruitment of participants from the wider geographical area of the entire UK. Covid-19 did however create potential additional ethical issues, in that the participants (parents of an autistic daughter) might find it more challenging to find a private space in which to conduct the interview with the closure of schools. The participant information sheet (Appendix B) highlighted this potential issue, with the invitation to reschedule, if the initial interview time was no longer appropriate. In the event, all the interviews took place either during school hours, when schools were open, or in the evening when their child was being cared for by a family member.

3.5 Participant recruitment and purposive sampling

Although an enthusiastic uptake by participants was anticipated given previous research into the parental perspectives on their autistic daughter (Chantrey, 2017), the initial plan to recruit via closed Facebook support groups for the UK parents of autistic girls (two were identified), was backed up by the intention to recruit through local National Autistic Society groups,

were there not to be a sufficient response from the Facebook groups. Any back up plans soon proved to be unnecessary, as was the plan to use a second Facebook support group. Inclusion criteria for participation was that their daughter was aged between 12 and 18 at diagnosis (or within one year), was diagnosed within the UK in the past 10 years and was assigned female gender at birth. It was requested that anyone interested did not 'tag' friends who they thought might want to participate, in order to maintain confidentiality.

In adolescence, the subtleties of social interaction increase in complexity, so autistic girls, with their acknowledged deficits in social communication, typically begin to more overtly struggle around this age (Gould, 2017). This notion supports the suggestion that the impact of autistic traits on social functioning may not be evident until the pressure from demands for new social adaptation emerge across developmental transition stages (Hsiao et al., 2013). Autistic girls are often socially immature, and in their primary school years, are frequently 'mothered' by their peers (Gould & Ashton-Smith, 2011). However, this protective effect seems to disappear in the transition to secondary school. The complex and intricate social skills that are necessary to manage and maintain adolescent female relationships are manifestly lacking in autistic girls, as social communication becomes less overt and more non-verbal (Dean et al., 2013). In order to hide their social struggles, autistic girls develop elaborate coping strategies, imitating the behaviours of their NT peers, learning to mask their social deficits, superficially appearing to fit in (Anderson et al., 2020; Tierney et al., 2016). However, 'pretending to be normal' (Willey, 2014) is emotionally exhausting and leads to meltdowns that are frequently only seen at home behind closed doors (Bargiela et al., 2016). This transitional age also often coincides with puberty, which brings particular challenges for autistic females that are likely to enhance their overall feelings of sensory overwhelm (Mademtzi, 2018). Therefore, the ages of 12-18 were felt likely to coincide with autistic difficulties becoming more marked, and an appropriate range in order to capture similarity of experience.

Diagnosis within the last 10 years and in the UK was important in order that participants had been part of a similar diagnostic and social system. The assignation of female gender at birth was specified, as clinical evidence suggests that there is an over-representation of gender dysphoria among autistic adolescents (Janssen et al., 2016; May et al., 2016). Although both studies suggested that the difference between males and females was insignificant, a later study by Cooper et al. (2018) found an increased prevalence of gender dysphoria in autistic

females over autistic males. Therefore, the requirement for natal autistic females was felt to be important in order to support the view that autism manifests differently according to biological gender (Lai et al., 2013). Additionally, it was required that participants must be able to engage with the English language to such a degree that they were able to consent, understand questions and give sufficient answers to engage with and reflect on their experiences.

Potential participants were excluded if the age of their daughter was more than a year outside the specified age range or she was not assigned the female gender at birth. Another important exclusion was that of dual relationships. Although having a son, not a daughter with autism, in belonging to the closed Facebook groups, there existed the possibility that a participant might be known online. In the event, one participant was familiar to the researcher having met at a presentation. Although she was keen to participate, and this had been the only meeting or correspondence that they had had, after discussion, her partner, their daughter's father, felt that he would very much like to participate instead. None of the remaining participants were otherwise known.

The administrator of one of the Facebook groups was contacted via private message, to request that the recruitment advertisement might be placed on their members' page of the group forum (Appendix D). This was agreed and the advert went 'live' shortly afterwards. Within less than a day sixteen emails were received expressing an interest in taking part. The advertisement was updated to pause recruitment due to the response received, with a concern that over subscription was likely to become an issue; IPA studies of this size usually need about eight participants (Brocki & Wearden, 2006; Smith et al., 2009). However, two further replies were received asking if they could go onto a backup list; both were acknowledged, thanking them for their interest and letting them know that they would be contacted if numbers allowed. Replies were sent to all sixteen, thanking them for their interest, and confirming that further details would be sent shortly. Given that only eight participants were needed for the study, further emails were sent to the first eight responses, in chronological order of their email expressing interest, and provided that their daughter was aged between 12 and 18 (or within one year) at diagnosis, as outlined in the recruitment advertisement. This email included the consent form and participant information sheet (Appendices B&C) and requested a reply within seven days. As all of the interviews were to take place online, consent forms could either be signed digitally, or the email reply could confirm consent, as

not all participants were familiar with digital signatures. Consideration for the potential emotional impact on participants in discussing a sensitive and personal topic was felt to be important, so the participant information sheet also included a short list of support service resources.

Within that time, four completed consent forms (or email consent) were sent back, and interview times and dates were mutually agreed. On the morning of the day that details were due to be sent to the remaining eight respondents, an email was received from one of those who had replied initially, but whose daughter was slightly outside the age range specified. She was clearly upset at not yet having been sent further information regarding participation, and assumed that she was no longer needed, and requested that information such as her email address was deleted from any records. An email was sent apologising and confirming that any identifying details would be deleted, although explaining that it was planned to email her that day to invite her to participate, explaining the reasons for the delay; she did not reply. From the remaining seven emails that were sent out, a further four replies with consent were received, and the remaining four interviews were arranged at mutually convenient times.

3.6 Data collection

All eight interviews were semi-structured (Table 1) and conducted via the online video platform Zoom. Owing to restrictions being in place due to Covid-19, there was no option for face-to-face interviews. Before the start of each interview, it was ensured that the participant was still happy to go ahead, an approximate time that the interview would last was given, and it was ensured that they were aware and happy that the interview was to be audio recorded, and that they were aware of their right to stop the interview, and/or withdraw at any point. The participant was given the opportunity to ask any questions, with the instigation of engagement in pre-interview conversation in order to build rapport and trust between interviewer and participant (Smith et al., 2009).

Several participants mentioned that it was helpful to have been informed in advance, via the participant information sheet, the questions upon which the interview would be based. This supports the suggestion that participants value having access to the interview questions prior to the interview (Denscombe, 2010; Smith et al., 2009). The interviews took place over approximately four weeks and lasted between 43 and 76 minutes. They were spaced out to

ensure self-care of the researcher, acknowledging the emotional demands created through conducting research into an area in which there is known personal involvement (Etherington, 2004; Kumar & Cavallaro, 2018; Rager, 2005). It is not known whether the parent had consulted their daughter prior to taking part, although it was emphasised that the study was seeking the experience of the parent and not their daughter, or her perspective.

Although all eight interviews were conducted using the video function of Zoom, only the audio element of the recording was saved, to ensure ethical practice in not over-collecting data. The open-ended questions around which the semi-structured interviews were guided are shown in Table 1. After the interview had ended and the recording function had been switched off, each participant was allowed some time for a debrief. Although all felt that it was very important to take part, several reflected that they knew that it would be an emotional process. All participants were then sent a follow up email thanking them for their participation. They all replied, many expressing thanks for the opportunity to take part, with three participants also asking if they could be sent details of any publication resulting from the study. One participant replied with further reflections around emotions that she found hard to express in the interview. One of the interviews was experienced as being particularly moving and emotionally demanding, therefore, supervisory support was sought as soon as the interview was over. Even though research supervision was regularly accessed, this one interview resulted in significant feelings of upset, not uncommon when collecting data of a personally sensitive nature (Rager, 2005).

Table 1: Interview questions

Background:

- Age of daughter now?
- Age at diagnosis?
- When was the diagnosis made?

Questions:

- Can you tell me about what you noticed, and why you were first concerned that your daughter was different from a neurotypical girl?
- Was it you who first raised the concerns?
- If so, who did you first approach about this, and how do you feel that your concerns were received?
- How did you experience the diagnostic process?
- What are your reflections on her day-to-day life?
- Can you tell me about your experiences of parenting your daughter?
- What, if anything, would you change about your experiences?
- Do you have any other comments that you'd like to add?

3.7 Transcription and ethical considerations

The interviews were all transcribed verbatim by a General Data Protection Regulation (GDPR, 2018) compliant external transcription service, and all names, both of parents and their daughter (and in some cases, siblings or other relatives) were ascribed pseudonyms. Any identifying dates or locations were also obscured to eliminate the risk of disclosure through deduction. Interview audio recordings were uploaded via a secure transfer service that was used by the transcriber, and all documents held by the transcriber were deleted after 30 days.

Several weeks had passed between the interviews taking place and the recordings being transcribed. The participant information sheet had not suggested that transcripts would be returned to the participants for member checking, however, the option of whether or not to return transcripts was one that was considered in depth before arriving at this decision. This is discussed in more detail in Section 3.9.

3.8 Data analysis IPA

In order to analyse the data (Chapter 4), the steps laid out by Smith et al. (2009) were followed, with the acknowledgement that although perhaps 'following steps' suggests somewhat of a unidirectional approach, IPA data analysis is in fact a multi-directional process involving a continual shift between the different analytic processes (Willig, 2013).

Pietkiewicz & Smith (2014) liken the process to cooking with only a basic recipe; the finished product is the result of the researcher's expertise, flair and creativity, with guidelines simply illustrating *possible* ways of analysing the data and only becoming fixed through the process of writing up (Smith et al., 2009). There is no single 'right way' to conduct IPA analysis, merely one analytic focus; that is paying attention to patterns within participant experiences, examining the ways in which the participants make sense of those experiences, and then interpreting those experiences within a theoretical and social context (Miller et al., 2018).

The first step in the process was to read and re-read each transcript and this was done whilst listening to the audio recording of that participant, in order to reconnect with their story as it was told. This was important in order that the subtle intonations could be captured and checked against the transcripts. This facilitated the role of the researcher as 'quilt maker' (Denzin & Lincoln, 2017) through immersion in the transcribed text, sifting through the layers of meaning, noting the words used to tell their story, alongside pauses, intonations and long silences, in order to begin to move through the process at the end of this first step, of eliciting emergent themes. However, it should be noted that the process of transcription is not totally neutral, in that orthography cannot truly replicate the spoken word, as even if it is verbatim, it removes the paralinguistic features that profoundly shape the meaning of what is being said (Bailey, 2008).

Initial notes were made on the transcripts (Appendix F), and these were expanded upon and added to through re-reading. The use of a reflexive journal, although important throughout the research process (Finlay & Gough, 2003), was invaluable at this stage, as it in some part mitigated against superficial reading of the text and finding only what was expected, supporting efforts to bracket off familiar research knowledge in the field.

The data was analysed using a combination of paper-based analysis, and NVIVO computer analysis software (Bazeley & Jackson, 2013; Leech & Onwuegbuzie, 2011). After the initial reading and line by line notation on paper, it was intended that NVIVO would only be used for the analysis from that point. However, although undoubtedly useful in terms of the organisation and accessibility of extracts of the text (Bazeley, 2007), the continued use of NVIVO beyond this was felt to hinder the process of ordering the emergent themes into superordinate and subordinate themes. Although Jackson et al. (2018) refute the criticism that

qualitative data analysis software (QDAS) programs, such as NVIVO, create a barrier between the researcher and the data, preventing a closeness and familiarity, it became frustratingly evident that this was precisely what *was* being experienced. Perhaps the suggestion of Bonello & Meehan (2019), that such programs are best learnt by 'doing' simply supports the notion that technological advances do not suit the style of every researcher, in particular a novice researcher. Therefore, a combination of paper copies of the transcripts and the printed codebook produced by NVIVO was used, to maximise the analysis of the rich data from the interviews (Appendix F).

3.9 Qualitative Research Integrity

Unlike quantitative research, where there is generally a clearly defined set of criteria by which to assess validity, although not absent, this is more of a challenge in qualitative research. One of the main criticisms of qualitative research is that to a greater or lesser extent, because findings evolve through the researcher's active engagement with the data, then any findings are likely to bear the mark of their approach to interpretation (McLeod, 2011). However, although it is accepted that within the qualitative paradigm, outcomes will vary depending on the worldview of the researcher and their approach to interpreting the data (Denscombe, 2010; McLeod, 2015), it is none the less important that the verification of a qualitative study can withstand scrutiny and ensure integrity (Birt et al., 2016; Denscombe, 2010).

Smith et al. (2009) argue that the four principles for evaluating the quality of qualitative research proposed by Yardley (2000) can be satisfied for IPA studies: sensitivity to context; rigour and commitment; coherence and transparency; and impact and importance. Sensitivity to the context is demonstrated throughout the study, through reflexive positioning and acknowledging a similar identity to the participants as the parent of an autistic child and the sensitivity around the area being researched. This is particularly important where the researcher might be deemed as the research expert but the participant is the experiential expert. Sensitivity can also be demonstrated through an in-depth awareness of the existing literature, with this orientating the study and the findings relating to this.

Rigour and commitment are demonstrated by the care taken towards the participant both before and during data collection and this is continued with meticulous attention to the

participants' words throughout the analysis of the data. Conducting an in-depth IPA interview is an intense experience and one that requires considerable personal effort and commitment from the researcher. According to Smith et al. (2009), rigour, in the context of IPA, pertains to the thoroughness of the study, in terms of the comprehensiveness of the analysis carried out. In some ways there can be seen to be overlaps between rigour/commitment and sensitivity to context, in that it can be argued that good quality IPA research is, by its nature, sensitive to the data (Mjøsund et al., 2017).

Transparency relates to clarity around all the stages in the research process and how this is demonstrated in the writing up. In this study, transparency is evidenced throughout from the formation of the research question, through the data collection and analysis to the writing up of the findings, and these are all consistent with IPA methodology. To support transparency, excerpts of interview transcripts with annotations are presented in appendix F. A clear account and rationale for the choice of research question and the criteria for participant inclusion is given, along with ongoing reflexive research statements. Attention to coherence has been paramount from the outset, with a clear rationale evidenced throughout the literature review, through to a logical and coherent presentation of themes and sub-themes. Additionally, Yardley (2000) posits that coherence can also apply to the degree of fit between the underlying theoretical assumptions of the methodological approach being used, and the research question being addressed. For this study, the findings and discussion ally closely throughout with the underlying principles of IPA.

The final principle is that of impact and importance. Yardley (2000) stresses that no matter how well a study is researched, the true test of its validity lies in whether it presents novel, interesting and useful information to the reader. Chapter 2 demonstrates the gap in the literature and emphasises the clear need for, and importance of, the research. It is hoped that through giving a voice to the previously unheard parents of autistic girls (Chantrey, 2017), that such research is used to promote recognition, and the need for support, not just of the girls themselves, but also their parents.

Member checking is often considered a fundamental requirement in qualitative research (McGaha & D'Urso, 2019), with the process usually involving taking the data and the interpretations back to the participant in order that they can confirm the credibility of the information and the narrative of the researcher's account (Miller & Creswell, 2000). It is

often the ‘go-to’ validation tool of choice for the IPA researcher (McGaha & D’Urso, 2019). It can take the form of returning the interview transcript to the participant, or the interpretation can be returned (Thomas, 2017). However, this view is widely challenged in the literature. Although Lincoln & Guba (1985, p. 314) state that member checking is “…the most critical technique for establishing credibility”, qualitative research has evolved, and methods / participants have changed. One of the main concerns is that interpretation might be modified depending on the context within which it is viewed (Madill & Sullivan, 2018; McConnell-Henry et al., 2011). The participant might be perceiving the data in an entirely different context from when it was gathered at the first interview. A further concern is that it hands control over to the participant for a major component of the research study, potentially creating a role-reversal between participant and researcher (Hallett, 2013), risking the participant wanting to change their story, or in the worst case, no longer participate (Lanzara, 2016; Varpio et al., 2017). Furthermore, Iivari (2018) suggests that member checking has the potential to have a negative influence on the participant’s understanding of their lived experience, raising further ethical concerns.

However, in this study, one of the greatest concerns was around the potential for distress in the participant in revisiting what was recognised to be, and in several cases experienced as, a highly sensitive and emotive subject. Much attention is given to the potential for psychological distress to participants during the collection of the data (Dempsey et al., 2016), yet this degree of concern is rarely afforded to the participant member checking, when the support through the research relationship is likely to be absent (Birt et al., 2016). Additionally, the very essence of an IPA study is to explore the lived experience of the participant as expressed in the moment in the interview process, so to then ask the participant to review this, risks them potentially invalidating the interpretative work of the researcher (Thomas, 2017). Although perhaps helpful in certain epistemological approaches, member checking is less relevant for interpretative-constructionist research (Willig, 2013). In supervisory discussion the decision was therefore made that member checking was not appropriate, and indeed might even be unhelpful in this study.

Smith et al. (2009) support the suggestion of Yin (2009), that in order to assess the validity of the researcher’s study, an indepenedent audit can be carried out. This requires that the data is filed in such a way that anyone could follow the trail of evidence from the initial notes made

to the final write up. In the context of an IPA study, this would include the research proposal, the interview schedule with questions, annotated transcripts, themes, and sub themes, and both the draft and final write up. For the purposes of this study, in order to ensure transparency, some excerpts of these are included in Appendix F.

3.10 Summary

This chapter has explored the ethical issues considered and has outlined how these have been addressed. It has clarified the researcher's ontological and epistemological position and has discussed how this has shaped the decision to use Interpretative Phenomenological Analysis (IPA) as the methodology for this study. The next chapter will present the findings.

3.11 Reflexive statement

At the outset of my studies, I struggled with the concepts of ontology and epistemology, and although I can now write about these with confidence, and understand their relevance and importance, it has not been a straightforward process. Whilst not anticipating difficulties in recruiting participants, I was taken aback by the extent of interest, and found it an unexpected challenge to have to manage the disappointment of potential participants when sufficient numbers were reached. I have also been struck by the enormity of the personal responsibility that I have felt through the participants entrusting me with their deeply personal experiences. Several participants spoke of a moral duty to share these in order to improve outcomes for the parents of autistic daughters going forward, and it has been frustrating to have been unable to include all of the data due to very tight word limits.

Chapter 4: Findings

4.1 Introduction

This chapter presents the IPA analysis of the lived experiences of parents of an autistic daughter. Due to the nature of dialogue, there will inevitably be some overlapping of superordinate and subordinate themes, as the researcher creates her 'quilt' (Denzin & Lincoln, 2017). However, every effort has been made to minimise this, and links between subordinate themes are included where relevant. They are presented using five superordinate themes (see table 3): *Journey to diagnosis; Negotiating systems; Psychological impact; Life with an autistic daughter; Reflections,* and 31 subordinate themes. The order in which the superordinate and subordinate themes have been set out has been felt to fit with the phenomenological approach to this study. The participants all lived in England or Wales. The pseudonyms ascribed to the participants and their daughters, as well as age at diagnosis and at the time of the interview are presented in table 2. The interviews lasted between 43 and 76 minutes.

Because of the significant amount of rich data that the participants shared and the restrictions of the word limit of the thesis, further excerpts pertaining to the subordinate themes can be found in Appendix E. These will be numbered in **green** in the text, so that the relevant excerpt can be found in Appendix E. Table 3 provides an overview of the superordinate and subordinate themes that emerged from the data provided by the participants. Each superordinate theme represents all of the participants' experiences, however, not all eight participants are represented in each of the 31 subordinate themes. Due to the interpretative nature of IPA, it is acknowledged that the researcher views the data through her own 'lens' and that another researcher might elicit different themes; however, that does not invalidate the findings of either.

Table 2: Participant and daughter details
(* pseudonym)

Participant's name *	Daughter's name *	Age now	Age at diagnosis
Simon	Bella	17	13
Sally	Freya	17	15
Daisy	Olivia	22	17
Sophie	Jasmine	17	11
Megan	Kate	16	13
Thomas	Charlotte	17	16
Becky	Maisie	19	14
Julia	Emily	15	12

4.2 Superordinate and subordinate themes

Table 3: Superordinate and subordinate themes from the data provided by the participants

Superordinate themes	**Journey to diagnosis**	**Negotiating systems**	**Psychological impact**	**Life with an autistic daughter**	**Reflections**
Subordinate themes	Noticing the signs	Girls aren't autistic	Being on my own	Daily life	Reflections on diagnosis
	Falling apart	Family in crisis	Impact on the inside	Impact on family & relationships	Reflections on parenthood
	Trying to make sense	Us v them	Exhaustion and burnout	Impact on career	If only…
	Unheard and unseen	Seeking support	Impact of the outside	Learning as I go	Loss & grief
	Looking in the wrong place	Unhelpful 'help'		Wearing a mask	Support networks
	Breakthrough	Broken systems		New normal	Walk a mile in my shoes
	Obtaining the diagnosis				Social justice
					Personal growth

4.2.1 Superordinate theme 1: Journey to diagnosis

This superordinate theme summarises the experiences of participants from first becoming aware that something was not quite 'right' through to obtaining the diagnosis.

4.2.1.1 Subordinate theme 1.1: Noticing signs

With post-diagnostic hindsight, all eight participants could reflect back on noticing early signs. One of the most frequent observations was that their daughter was extremely bright (Daisy, Sally, Simon, Megan, Thomas, and Julia), almost to the point of being developmentally precocious (Sophie). Perfectionist traits particularly around homework were noted by Becky and Sophie. Simon and Thomas both reflected on their daughters being highly strung, needy, and dominant within their families, noting the difficulties that this created. Simon said that around toddlerhood, his daughter developed a strong sensitivity to clothing and around noise. Sophie noted a lack of imaginative play. Unusual communication was mentioned by Sally (talking non-stop, but only with adults, rarely with children), and Daisy (that she spoke very fast and ran her words together). Megan found that her daughter preferred the company of boys.

However, across all of the interviews, these were generally not considered as being anything other than the usual difference in personalities. Although at times challenging, such differences were regarded as being part of the trials of parenthood, and not suggestive of anything else.

> *"She was very bright, very inquisitive, asked really good questions, clearly intelligent. She had one trait which I tried to persuade people to take seriously, but nobody was very interested. And looking back, it was it was an indicator. There was something about the way she ran her words together when she was speaking. She would pick up on the end of one word and run it into the next word" (Daisy)*

> *"And I was at the time not too worried about that, I just thought children are different, they all do different things. She's blatantly as bright as a button, she'll come to in time" (Megan)*

> *"When she was about six, I started to notice she didn't communicate in the same way that her friends did. I mean, she talked, she talked nonstop, but to adults, but not to other children" (Sally)*

"As she got from sort of toddlerhood into school age, she started becoming much more sensitive. And so around food, around clothing, it was always a bit of a joke, you know she would just wonder around the house in just her underwear. And we just thought oh you know, it was one of those things that we never really thought about" (Simon)

One participant reflected that she saw nothing unusual in her daughter's behaviours because she was exactly like that as a child, although with hindsight, this is because she too is autistic:

"So, they didn't strike me as so very different, they were just having understandable difficulties with the world, which I didn't know at the time of course was because both of us are autistic" (Megan).

For several participants, the first time that they knew something was wrong, was when their daughter had a complete breakdown (see subordinate theme 1.2).

For all participants, there were definite signs, although often these were only evident in hindsight. Although clearly challenging, parents attributed these to the range of 'normal' development, in some cases having no comparison.

4.2.1.2 Subordinate theme 1.2: Falling apart

Several participants only came to realise that anything was wrong when their daughter reached crisis point. Becky recalled her daughter coming to her one day at the age of 9 and telling her that she wanted to kill herself. Daisy said that the first she knew was when her daughter jumped out of her bedroom window. Simon spoke about significant self-harm:

"It started with self-harm, and the first we knew about it was when she jumped out of her bedroom window. Then we discovered she'd been cutting…" (Daisy)

"I just couldn't understand what was going on with her and then she came to me when she was 9 and said Mam, I want to kill myself. And I said, have you got a plan and she told me her plan" (Becky)

"And she got into a really bad state, self-harming, we ended up in A&E one evening" (Simon)

Several participants (Becky, Julia, and Simon) became aware of problems when their daughter suddenly started to refuse to go to school, having previously had full attendance:

"She had 100% attendance, like in primary school. 100% attendance in Year 7. And she just said to me I'm not going to school, and I was like sorry, I think you probably are going to school. And she went no, no I'm not going to school" (Julia)

"Because I would say, well we're going to walk to school, you know if you won't get in the car, we will walk, and I would take her down the road. And then she'd kick her shoes off, and I'd say well look you've kicked your shoes off, what are the hell are you doing that for? We'll walk in bare feet in, but you are going to school. Understanding now…you know this wasn't you know because at the time, because we didn't understand where all this was coming from, you go down the principle well this is behavioural. This is just you know, me and her butting together and I need to show her who's boss because you can't behave like that in the real world just because you don't want to do something. Unless there's a reason why you can't" (Simon)

All eight participants said that at some point, their daughters' difficulties eventually meant that they were no longer able to manage to attend school, despite often wanting to attend:

"Every day was a battle to get her to go to school really, for her as well, you know, it was a battle for her. She wanted to go, but it was anxiety was the issue that we thought at the time" (Thomas)

"She said that to me one time, she'd been there for about a year, and she said, 'Mummy I really like school, I just don't like being there'…" (Megan)

"I was literally just getting Jasmine into school. You know it was only just working, it felt like it was all being held together with sellotape; so fragile. And then when Jasmine went back in September last year, she lasted a month or so and over that sort of month or 6 weeks, Jasmine would last perhaps an hour in school, and they'd be phoning me to go and get her" (Sophie)

"In the November I just asked her if she would get out of bed, and she would get really aggressive…so I went straight to the school and I said look she's refusing to come to school" (Becky)

For many participants (Becky, Sophie, Julia, Sally[1], and Thomas) this coincided with starting high school, with two parents feeling that social relationships were at the root of their daughter's difficulties:

"I prepared her for secondary school like you do, by then she was starting to completely refuse school at all. There was nothing I could do" (Becky)

"They did a little bit of transition work between primary and secondary, not a huge amount. And it was just a disaster really from the moment it started" (Sophie)

"So it was only more, it was secondary school where she suddenly started having massive problems with anxiety" (Thomas)

"And in that time, she completely crashed so from, say in the February being able to do pretty much everything that an 11-year-old could do, she became housebound pretty much. Self-harming, not eating, just on the sofa all day, not washing. So, she had a complete collapse" (Julia)

"I think it was just that, you know, when social relationships became difficult as a teenager, I mean, teenage girls are foul, really, aren't they? When relationships became more complicated, she wasn't coping with that, and she turned it all in on herself" (Daisy)

"That's where the school refusing started because I think at that point, she was starting to feel that she couldn't speak up in class, because it made it feel uncomfortable. She was struggling with interpersonal relationships within school" (Simon)

This was also felt to be accompanied by a marked decline in mental health (Simon and Daisy):

"She wasn't able to function in the school environment any longer and the self-harm became worse until she was eventually sectioned under Mental Health Act for her own safety" (Daisy)

"And what then happened was Bella's mental health really started to tank…ultimately, she, her mental health and the anxiety which then led to sort of depression and self-harm and all kinds of really horrible stuff" (Simon)

Megan reported that her daughter regressed to babyhood when struggling to attend school, and that her anxiety frequently manifested with physical illness:

"Every night she would come home put on a onesie and crawl around the floor like a baby. If you gave her a cup that didn't have a sippy spout on it, she would spill the drink all over herself. It was baby language or no language at all for most of the time" (Megan)

It seems important here to recognise and look behind the difficulties that all participants expressed in their daughters struggling to attend school. The demands placed on these girls, both academically and socially, would appear to have a significantly detrimental impact on their mental wellbeing.

4.2.1.3 Subordinate theme 1.3: Trying to make sense

Sally and Simon had both raised concerns around behaviours with professionals but, having been reassured, felt a sense of relief that it probably meant nothing:

"I felt at first I was euphoric that they said there's nothing... because I didn't want there to be anything, you know, you don't want to be anything wrong, do you? And, you know, I put it all to bed for maybe a year or so" (Sally)

"When she said, no, no, she's not autistic, if she was autistic I would know, and we just sort of thought well okay, we'll just take that as her opinion, because we knew no better. And when you're paying somebody that amount of money for expert advice, and they say no definitely not, you kind of take their advice" (Simon)

Thomas hoped that his daughter would outgrow her behaviours:

"I think we just felt that she was going to grow out of it, I think that was the big issue, that the big thing throughout those years, you always felt that she would just grow out of it. And I always remember thinking that, you know, she's been hard work as a child, she's been highly strung little girl, but when she becomes a teenager, she'll do really well, she'll grow out of it sort of thing. And, you know, so it was something that she never grew out of really" (Thomas)

Julia, Sally, and Thomas remarked that they had no one to compare with as for Thomas, he had an older son, she was Sally's only child, and for Julia, her daughter was her older child:

"I mean, she always seemed as a small child, just like a very highly strung little girl, really. I mean, little girls can be like that. And it wasn't anything that we were concerned about it just with having a boy before her, and we just thought just, you know, she's just different to him and that's just the way she is" (Thomas).

Several parents (Julia, Simon, Daisy, Sophie, and Becky) said that they really had no idea what was wrong [2]:

"And we had no idea what was, genuinely no idea at all what was going on, because her attendance had been so good up to that point and it was really weird that it had gone haywire, and we couldn't work out why" (Julia)

"So, we'd go through all the whole, has somebody said something to you, no, are you being bullied, no, are you physically worried about something, is there something that's happening?" (Simon)

"This went on a for months, with me sort of checking with school, are you sure she's okay, because you know I started to see her then becoming aggressive at home. Where she'd just hit you or kick you for no reason, we just didn't know why" (Becky)

Megan was so confused by her daughter's ongoing stress-induced illnesses that she feared that her daughter was seriously ill:

"She was having all these illnesses which at the time, I remember walking home from dropping off in the morning on one day crying the whole way home thinking has my child got leukaemia or what's wrong with her. You know I couldn't see why she was so ill" (Megan)

Three parents (Sally, Simon, and Thomas) concluded that their parenting was to blame:

"I would find because everyone was saying to me that there was nothing wrong with her and I had decided that it was my bad parenting skills, well, that's what I decided" (Sally)

"Where have we gone wrong, how have we ended up with you know, a child in our family who's effing and blinding and throwing things around and swearing and being disobedient and all of the rest of it" (Simon)

"That's the hardest part I think the expectation of, it's that whole thing of blaming yourself, what are we doing wrong?" (Thomas)

All the participants [3] except Sophie, felt that they could not have known what was wrong, as they had no knowledge of autism. Sophie had an older son with autism, and although recognising how different her son and daughter were, felt that she considered it at quite an early stage:

> *"Well, we realised that you know Jasmine had a couple of autistic traits I guess when she was young" (Sophie)*

> *"Coming from a place of no knowledge of autism whatsoever, I didn't, I just thought it was something she would grow into" (Sally)*

> *"It was anxiety was the issue that we thought at the time. We hadn't got the full picture when it comes to autism" (Thomas)*

The lack of an obvious reason for their daughters' struggles left all the participants, at one stage or another, feeling at a complete loss as to which way to turn. This led to several parents turning inwards and looking to themselves for an answer.

4.2.1.4 Subordinate theme 1.4: Unheard and unseen

As gatekeepers to onwards referral, their GP was the first port of call for several participants (Julia, Megan [4], Sophie, and Becky). However, all experienced a dismissal of their concerns, even when in some cases, having done their own research, they shared their suspicion that their daughter might be autistic:

> *"I went to the doctor and said look this is what's happening with her, oh she's depressed leave her there, no referral to CAMHS or anything like that, no sort of help" (Becky)*

> *"The GP spoke to her for about 5 minutes and came out and said no she's not autistic. And so, she wouldn't refer us to CAMHS" (Julia)*

"I said I believe Jasmine might be on the spectrum could you make a referral. And the GP said she's making eye contact, I'm not making a referral" (Sophie)

"I took her to a doctor when she was about eight, maybe even younger, who sat down and said, well, she makes perfect eye contact, so I can't see what you're concerned about" (Sally)

"We went into the doctor, told them you know how anxious Jasmine was and the response was well you need to bring them back when they are self-harming. You know the thresholds for access to the CAMHS Service were so high and are so high, that even though Jasmine was unwell, she wasn't actually unwell enough to access the service" (Sophie)

This sense of having concerns dismissed extends to other professionals encountered on their journey, with several participants feeling that this stems from an underlying ignorance of autism in girls [5]:

"I just thought well if you're telling me you're not seeing it, I think that's because you can't see it. You are not trained enough to be able to spot these difficulties that my daughter is having" (Sophie)

"I didn't really know where to go to, so the first child psychologist that I saw, she recommended someone a private ed psych who apparently did, who would do a diagnosis. But that all fell through because she, I don't think she understood autism in girls very well" (Julia)

In a similar vein, even when parents approached school with their concerns, these too were dismissed. This often left parents wondering if they were imagining their problems. Many participants (Becky, Simon [6], Sophie, Thomas [7], Julia, and Sally) suggested that school considered their daughter to be a model pupil:

"So, the first thing I did then was go to the school and say look is there something going on in school that is worrying her because I thought she's

been having trouble getting into school and no, she's fine, her grades are fine, she's a more than able and talented student. No, she's fine, quiet as always, but fine" (Becky)

"And it would be like, surely not, that's not Bella, she's not like that in school. She's an absolute lamb…I mean, if we were doing something wrong, we'd be getting letters home from school about how she'd beaten somebody up or she'd spat at a teacher or something" (Simon)

"But of course, that was not an issue for anybody because they were really happy because they've got this really bright little girl" (Sophie)

"But she was always very well behaved. So, they never, she was never disruptive, so they never thought she was anything else but a sort of shy, quiet" (Julia)

"When I spoke to the teachers at school, they told me I was barking up the wrong tree" (Sally)

Megan and Sophie both felt that their daughter's school became quite hostile and unhelpful when they clearly had significant concerns. Sophie's son was autistic, and she felt that this made the situation worse. Megan was threatened with being fined for her daughter's poor attendance:

"I said I'm concerned, I think Jasmine might be on the spectrum, you know, and she said look your son has left school, he was autistic, Jasmine is not on the spectrum so sort of get over it. You know, it was almost you're not having any more attention from us" (Sophie)

"That maths teacher was telling me that they had been lenient with us. They stopped doing that, after that any more fines are authorised, and I thought but I've just told you here's some evidence of something that has been affecting her. Anyway, so that was really horrible being told, we're not

listening to you what you're saying really, you have been a bad parent. Any more time off school and you're going to be…" (Megan)

Both Becky and Sophie felt that school only listened when their academic work was impacted, and for Sophie the school's rationale seemed quite contradictory:

"They just saw nothing in school out of the ordinary, so only when her grades started to drop did they actually believe that anything I was saying. It's never nice to not believed as parent" (Becky)

"It was contradictory, you know, and Jasmine was on their more able and talented register. Didn't really need any help academically, but they were saying that they couldn't manage her social and emotional needs in school" (Sophie)

Megan, Sophie, and Simon both expressed frustration that no one at school either wanted to hear, or might understand what was going on [8]:

"I guess but it was frustrating, I think because it was very difficult to describe what was happening and why. You know for the most part, it was nobody else would have had even the merest clue that stuff was going absolutely, stuff was horrendous in the home" (Simon)

"And they clearly don't want to know what we're doing at home, I've tried to explain can you, this is what we're doing at home, they didn't want to know. And then when you know full well that your child needs you to do, be something, and that the school isn't really listening, it's not on their radar. I rang up the school on the third day when she was off school and asked to speak to the pastoral lead and they never phoned back, nothing there was nada. So, I just thought okay, that's it, I'm not being listened to at all now" (Megan)

Sally described her great hope when her daughter was finally referred to CAMHS, only for these hopes to be dashed:

"Eventually we got to CAMHS, and I was so relieved that we had a CAMHS appointment because they would be able, I believed, be able to tell me what was going on. And basically, they said she didn't meet the criteria and we'd waited 2 years; I think we waited 18 months for the appointment. And it all built up to this one big day and I walked away so deflated thinking I'm actually back to square one, I don't know what to do and how to help her" (Sally)

Reflecting on being told that she didn't meet the criteria for an autism assessment, Sally said:

"In my mind, them saying she didn't meet the criteria, what I heard was there's nothing wrong with her. But actually, what I didn't listen to was she didn't meet the criteria" (Sally)

Daisy recalled that she had to plead with professionals to help her to keep her daughter safe:

"We've had lots of incidents, but one that comes to mind is that she actually asked for help. She actually said she didn't feel safe. I took her to A&E and she met with the psych team who said, no, she's fine. There's no bed for her. Take her home. We got a psychiatrist in who said the same thing. I begged psychiatrists to do something because I knew that I couldn't keep her safe that night. You know I could see it in her eyes, you know, you can see when she's just in another place and she's just distressed hugely" (Daisy)

The experience of feeling unheard and unseen would appear to be universal for the participants.

4.2.1.5 Subordinate theme 1.5: Looking in the wrong place

For several participants, their raising concerns about their daughter resulted in blame on them, both direct and indirect. This manifested in their own mental health being questioned with Sophie being accused of being an over-anxious parent [9]:

"I generally think that, yes looking for a problem that isn't there perhaps you know, I think probably a number of parents would report that professionals believe it's perhaps the anxiety of the parent" (Sophie)

"I went and collated my own evidence, because they were trying to say I had a psychosis at one point, I didn't. I had, so I had to go to my doctor you know and things like that to get evidence for that. No, I had reactive depression, which I feel is quite normal for a family like that" (Becky)

Simon and Megan both had the impression that they were regarded as being overindulgent and 'soft'. Sally, Megan, and Sophie all felt that the attention was focused on them as parents, and not on their daughters' difficulties [10]:

"I was put on a parenting course, and I was like, now I look back, I think, oh, my God, they invested in me, but not in her, which is where they should have put the investment. Basically, they put me on a course, a parent workshop. And no one ever looked at why she couldn't sleep and why she was anxious. They were all looking at you as a parent" (Sally)

"And their standard procedure was to see what the parents did with the child to rule us out or in as good parents. The system seems to be, you rule out all the relevant things before you go for the nugget of truth in what may be happening" (Megan)

"You know the dilemma you're faced with as a parent, as I'm sure you'll understand if you have a child, and they threaten that they're going to hurt themselves or put their life in danger. And you're known to Social Services, you have to take steps to evidence that you have mitigated that risk" (Sophie)

Several participants (Becky, Megan, Sophie, and Sally) felt that they were being accused and placed under suspicion:

"Oh, my God. I had all sorts of questions. What's going on at home? How's your relationship? School came round to make sure that everything was all right" (Sally)

"And he said, now Mr & Mrs Jones, no one is making any accusations here, but he said something about, it may be that there's somethings that you can learn. He thinks that we're bad parents anyway, so he referred her as a case" (Megan)

This accusation went further for Becky and Sophie who found themselves under investigation by Social Services [11]:

"So even though I'd asked Social Services to be involved when she 11, they eventually got involved when she was 12 because of the violence. They immediately came in and said that it was my fault and what was I doing to cause it. And so, by the time she was 13, still, by this time because of all this and because nobody was sort of looking at Maisie in any other way, they were put on the at-risk register. It was sort of, well we're not seeing you know, you must be doing something" (Becky)

"You know my husband is one of the gentlest people you'll ever meet. But Jasmine went into school, they had specific type of assembly which I can't even remember what it was, but it moved Jasmine to the point of feeling emotional and she broke down and made a disclosure to one of the staff in school that she'd had this incident with dad at the home. That she was concerned that mum was at risk when mum came back because dad had made a threat" (Sophie)

Many participants felt that the tables turned when they expressed their concerns, finding themselves under the spotlight, with the focus on them as parents.

4.2.1.6 Subordinate theme 1.6: Breakthrough

Feeling brushed off and having their concerns dismissed, several parents (Julia, Simon, Becky, and Megan) took matters into their own hands, and started on their own investigations. Three people had suggested autism to Becky which was the turning point for her undertaking her own research [12].

> *"And I thought well three people have said that now, let's have a look into this myself. And it fitted because the girls present differently, and it just fitted that actually could be the answer" (Becky)*

> *"I began learning about autism in girls. We got highlighter pens, I started off with one highlighter to highlight Kate's stuff, but ended up with 2 more, Bryony's and mine because all 3 of us blatantly as little girls had done all these. Different mixture of different things, not the same as each other but I said this is clearly a family thing isn't it and she said yes" (Megan)*

> *"And around the time, I was doing a bit of reading around like you do and I'd come across some research that was done by Simon Baron-Cohen, about extreme left male brain syndrome and all of this sort of stuff. And one of the things that came up in that was you know there's a kind of a, there's a genetic element to autism and that's definitely what they'd identified from his research was a pre-disposition in families where one or more of the grandfathers was an engineer, and both of Bella's grandfathers are engineers, my dad is a marine engineer and Sue's dad is a chemical engineer. I'm a software engineer and Sue is a water engineer. So, it's kind of what are, what are the chances you know?" (Simon)*

Sally, Julia, Megan, and Sophie all spoke of the relief that they felt when a professional finally listened to them, after many years of fighting to have their concern taken seriously [13]:

> *"And they did manage to get Jasmine onto a waiting list at that point because this paediatrician said well hello, she's got autism in the family. Mum is*

seeing difficulties, you know let's get her on the list, but that list was 2 years, it was a 2-year waiting list" (Sophie)

"Then the child psychologist said who had seen her a few times, well I'm not sure but you know I'll do some basic rudimentary stuff with her and see if it maybe. And she came back, and she said yes I'm pretty sure she is autistic" (Julia)

"She said to me there's an elephant in the room Mrs Jones, I don't know how to say this but I think your daughter might be autistic. And I said yes, we'll look into that, funnily enough. So, it was good that somebody independent had raised it without having heard anything of the history. It wasn't even me, my daughter had just been doing her own thing, telling this person about what made her anxious and then the person that thought normal folks don't get anxious about this" (Megan)

4.2.1.7 Subordinate theme 1.7: Obtaining the diagnosis

The participants expressed mixed experiences around the diagnosis. Except for Thomas, all the participants described a convoluted and frustrating route to diagnosis. In some cases, this involved bypassing the usual routes, and seeking a private assessment. Although most had described a challenging and fraught journey to that point, for Thomas the process was smooth, as his daughter was already under CAMHS for other mental health issues, and they suggested that she might be autistic:

"Well, she was going to CAMHS with anxiety. She was going to CAMHS, so the CAMHS worker there was speaking to her, a psychologist was speaking to her and she gradually sort of come to a point where in January we had the diagnosis" (Thomas)

Similarly, Simon moved from suspecting that his daughter was autistic, to the actual diagnosis, and didn't suggest that the actual diagnostic process had been difficult:

"...Right actually we need to go down the route and start trying to understand what's going on her. So that's how we got to where we were with the autism diagnosis" (Simon)

Having firstly decided to go down the route of a private autism assessment, Julia struggled to know who to approach, so she also waited for a CAMHS assessment, but found the whole process to be very distressing:

"There was no support, I would ring CAMHS, I was crying down the phone saying when are we going to get an appointment. Oh, we're very busy, it was, so we didn't know that she was autistic at that point, it was just a guess" (Julia)

Julia and Sophie both spoke of very long waiting lists, leading them both to seek a private diagnosis:

"The GP still wouldn't do anything, so I had to get a private letter that cost hundreds of pounds including all the sessions from the psychologist. She had to write a letter for the GP before the GP would accept that she might refer her to CAMHS. And unfortunately, so that happened so I think we got the referral in about May, that went in, but it was incredibly stressful because CAMHS at that point was just and still is, just overrun" (Julia)

Sophie's daughter herself decided that she might have autism, and Sophie found it very hard having to explain how long and convoluted the process might be, and ultimately sought a private diagnosis:

"We were on holiday, and she came to me said mum I think I've got autism. I read about it in this book, it sounds a lot like me, this is how I'm feeling, can you take me to the doctor and get me a test. And that felt crushing because I had to say to Jasmine, I'm sorry love it's not that straightforward...but that list was 2 years, it was a 2-year waiting list" (Sophie)

Sophie also expressed a concern that in going privately, she was perhaps 'buying' a diagnosis, although chose this route as she feared that her daughter's possible autism might be missed through lack of awareness:

> *"One of the issues we had is that everybody recognised our son and his difficulties, I wasn't confident that they would pick up on my daughter's subtleties in their presentation at that time. And I also didn't want to feel like I was buying a diagnosis" (Sophie)*

4.2.2 Superordinate theme 2: Negotiating systems

This superordinate theme focuses on the challenges faced when seeking support both pre and post diagnosis. Participants describe many hurdles and pitfalls that they had to negotiate, with varying levels of success.

4.2.2.1 Subordinate theme 2.1: Girls can't be autistic

Sophie described an awareness that autistic boys are offered support, and it does not appear to be needed to be fought for [14]:

> *"Then in direct sort of comparison to our experience with Jasmine, my son Ben has virtually had everything handed on a plate. You know people have sought me out, what can we offer him, how can we help" (Sophie)*

Julia stated that her experience of her nephew being autistic was at odds with her own, suggesting that her daughter's school did not believe that girls could also be autistic:

> *"And they said they'd never had an autistic girl at the school, because girls aren't autistic are they…So, when someone said that Emily was autistic everyone was going no, really. Whereas when they said that James was autistic, they were like yes, I can see that" (Julia)*

4.2.2.2 Subordinate theme 2.2: Family in crisis

Simon reflected that the only way to bring his family's crisis to the attention of social services was to call the police. Both Becky and Simon recalled having to call the police, because the level of violence became too dangerous:

> *"We were possibly forcing the issue somewhat because we couldn't get support from anybody. It was you know having the police come around and file a report was actually one of the ways that we were able to kind of get some visibility from Social Services and other people that actually we were a family that was pretty much in crisis at this stage" (Simon)*

> *"The violence went straight up quite badly, when I had to call the police, I don't know how many times. So even though I'd asked Social Services to be involved when she 11, they eventually got involved when she was 12 because of the violence" (Becky)*

> *"There were occasions where the behaviour was so bad, the violence was just unmanageable. We would end up having to get, we'd have to call for support from the police…For the most part the police were very, they handled the situation very well and really helped to kind of calm things down to an extent" (Simon)*

Daisy similarly recalls the police being supportive when she felt that no one else would help with her suicidal daughter:

> *"The police then talked to the A&E staff who still insisted that she didn't need to be in hospital. I begged the police to do something. Police have always been fantastic, and the police could see that this young girl was not going to be safe" (Daisy)*

4.2.2.3 Subordinate theme 2.3: Us v them

Several participants recalled the exhaustion of the constant fight for support, feeling that they were in an ongoing battle against professionals and service providers:

> *Like awful, everything is a fight, everything is a battle, everything is a chore, everything is difficult. I mean we have just everything has been a fight. Like to get a paediatrician was a massive battle…It was horrific and then you're trying to do the education thing as well you're battling for all this stuff with the NHS and with the schools and all the rest of it. You're also trying to look after a very poorly girl who is not averse to having plenty of violent melt downs" (Julia)*

> *"It's been very wearing, it's been hugely time consuming, you know hours and hours on the phone, sending letters, writing emails, begging for services that are supposed to be provided, that are supposed to be available, and you sort of meet thresholds. You meet criteria on paper, but then trying to get professionals to make those services available it's been really hard work" (Sophie)*

> *"I need to battle every day… if your child had cancer, I don't think you would be expected to do all that battling" (Julia)*

While being under suspicion from social services, Becky spoke of feeling that they were selective in what they wanted to hear, in order perhaps to fit with their own interpretation:

> *"She'd get violent, but none of this was reported with the report that came out, nothing at all. But no, she was even violent with staff in the home, but that was never recorded anywhere. They just ignored everything anybody had ever said. According to them I wasn't going to visit her, I wasn't staying in the flat with her, I wasn't making her doing family therapy, all of these things which just wasn't true, at all. That was really upsetting that was, I was thinking where has all this come from. I really don't understand, it was like they were talking about a completely different family" (Becky)*

Julia felt that she had to instigate everything in her quest for an answer and support:

> *"No one ever said no, but no one ever suggested it either, until it was like, everything had to come from us about everything"* and that she has had to become the expert: *"Oh God in everything and it's so wrong. You know you're going into a panel meeting for an EHCP and everyone in there is a professional, and yet their knowledge is so limited" (Julia)*

Becky recalled her shock, when in the midst of her fight with social services, the social worker decided that her case was too stressful for him:

> *"I remember one social worker saying to me, over the phone and he was a senior social worker and he said I've dropped your case, it's too stressful for me. I just thought what, pardon and he said again, and I was like well how do you think it is for me then, you're supposed to be supporting a family" (Becky)*

Sally spoke of having to prove everything, and that without this degree of scrutiny, she wasn't believed:

> *"And, you know, one of the things I had to do when she was off school, I had to prove that she was ill. So, I had to get a doctor's, like some evidence. I had to... every time she was prescribed something, I had to give it in to school, like a copy of the prescription. Every time she was off, I had to take her to the doctors, and prove that I'd taken her to the doctors" (Sally)*

However, Becky, Megan [15], and Julia all spoke of a turning point where they started to fight back:

> *"Suddenly I went into that kind of warrior mother again that I've forgotten a little bit what I was like. And I sent an email that was like so, I mean I complained everywhere, I complained about the service she got from the NHS. It's exhausting, so I had to send this email and I looked at it afterwards and I thought oh my God, this is like scary email lady. You just go into that*

mode of like, I don't give a crap what you think, this is my daughter, she is going to get seen you know" (Julia)

Becky was aware that in fighting back, it was she who had all to lose, but felt driven by the risk of losing her children:

"I knew a lot about it myself by then and I thought no you're not having me anymore, I've had enough, this is it. And I went and collated all my own evidence, put it all together in a report, bound it and made it look as professional as possible and we went into this one meeting now. And it was a review to whether they stayed on the at-risk register or not. And I sat her down and I said there we go, there's my answer, all the things you've ever said. And it just kind of turned a corner, it was like to say oh hang on then, she's fighting us back now at her own game, we don't kind of like this. We don't like it very much, but the evidence was there, so they actually apologised, took us off the register and gave us a disability social worker which is what we should have had all along" (Becky)

4.2.2.4 Subordinate theme 2.4: Seeking support

In order to access an appropriate school, an EHCP (education, health and care plan) is usually needed, although the experience of accessing these was described as a fight by Simon and Julia:

"We were going down the EHC because after the diagnosis, we were going down the EHC plan route. And there were all kinds of headaches with that, we eventually got the EHC plan…" (Simon)

"Then once we got her diagnosis in the Spring of 18, we were then going into the whole battling EHCP process which is another complete nightmare…" reflecting that the process is so hard that parents are set up to fail *"the fact that you can't understand what the hell this EHCP form is trying to get you to say. They create everything to be so difficult, you know they create it, so you fail" (Julia)*

Finding the right school placement was felt to be crucial by several participants, and although the path was not always easy, it brought great relief both to the parents and daughter [16]:

> *"Eventually came to the point where she decided, we decided perhaps home education was the way forward. But she had, that was never going to work. She was too much, too anxious about working. She needed to be in some kind of school because she became very anxious about being self-motivated and doing it herself, and that became a big problem, so that didn't work. And then she got a place at a special school, where, you know, we saw some progress. It's not been easy…" (Thomas)*

> *"Sort of 3 years down the line, we've got her in a school, got Emily in a school that's, it couldn't be better, you know it's a brilliant school. She's managing to go for 3 afternoons a week which you know at one point I never knew whether she'd ever be able to go back to school ever again" (Julia)*

> *"And we had a meeting with the Head Teacher…they just listened, and I came out of that session almost crying with relief, I couldn't quite believe that that was what we were getting" (Megan)*

Daisy hoped that a diagnosis would equal support:

> *"And once the diagnosis was made, part of me thought, that's fantastic, you know, we now have something to work with. Now we'll get the support, now she'll not be going into hospital anymore. Now, and clearly, that wasn't what happened…" (Daisy)*

4.2.2.5 Subordinate theme 2.5: Unhelpful 'help'

Simon described a misplaced assumption that having managed to get an autism diagnosis for his daughter, then support would follow:

"Well that all came to an end, and we were sort of kind of left high and dry really. So although we'd continued to see CAMHS, it wasn't really in any…there wasn't really a lot they could do, I think this was the thing that I found, we both found really frustrating going through the sort of neuro-diagnostic pathway, is we had to wait for ages and then we got to see doctor, I can't remember her surname now, we got the diagnosis and then we were given some kind of post-diagnostic sessions, where we sat in a drafty school room and were basically told your child has an autism diagnosis, it's going to be a bit shit. That was it…" (Simon)

Simon and Thomas both felt that parenting advice missed the mark, with this coming from both professionals and other parents:

"And you just think well this is really hard because as a parent I'm being given sort of advice about how to handle the situation which is actually the opposite of what we needed rather than the kind of well you know, show them whose boss, let them know what's what. And actually, that was the complete opposite of what she needed at the time" (Simon)

"All you're dealing with is your behaviour at home, really. So, and her behaviour at home was extremely challenging. But you're very much on your own with that, and you're completely alone with that. And it just becomes like... well, parents give advice, but it's more general parenting advice that does not work in this situation. You were trying to apply these things, this advice out of desperation but they don't work either because it's not…" (Thomas)

Julia, Simon, and Sophie all spoke of therapy that was not just unhelpful, but for Simon, actually made his daughter's difficulties worse. For these participants, there was a sense that professionals were going through a process and ticking boxes without addressing the therapeutic relationship, and more specifically being mindful, or even aware of, how to respond appropriately to her communication needs [17]. There was a sense that those who were supposed to be helping really had no understanding of female autism, and in the case of

Simon, the male-based approach taken was actually harmful and the advice given made their situation far worse:

> *"But they said well I can only see you for 6 sessions and I'm like Jasmine doesn't talk to anybody, let alone new people. You know she might say hello to you by the 6th session, this is going to be a waste of time, you know for you and me. So, they closed the case down. Jasmine managed, I think we did two sessions of the six sessions at CAMHS. Again, it was like very well-meaning professionals trying to deliver some sort of therapeutic support but without any relationship" (Sophie)*

> *"They recommended that we participate in a programme called positive parenting, which is, it's for kids who are kind of going off the rails and need very supportive, assertive parenting and that actually set us back. Because we were being led to believe that part of the problem was because we were being a bit soft. Letting her get away with things and we needed to put kind of that structure and say it's very kind of I need you to do this and if you don't do it, you won't get…Very sort of assertive and demand led and it was the worst thing that we had been given and we ended up going on 2 of, we ended up going on 2 of these courses. And they really set us back, because they kind of, particularly for myself, embedded a particular mindset that this was, you know, this is the way that we need to be. And it was, like pouring petrol on the flames" (Simon)*

Julia similarly spoke of a psychiatrist who was thoughtless in how he approached her daughter:

> *"Emily was on the sofa with the duvet over her head and he came in and he said to her like so Emily can you tell me your deficits please. And I was like what deficits, I don't think, that's not the way that you approach anybody, never mind a 14-year-old child who is obviously in distress, he was just beyond. I mean like they just don't get it…" (Julia)*

Megan and Sophie both reflected on the damage done by the approach that school had taken:

> *"There were times after that she has had a sort of, she's had a quite ins and outs at the school. Mostly caused by all the school trauma that she now has stuck in her system" (Megan)*

> *"And the sort of negative experience Jasmine had in year 6 which prompted you know a professional ringing the police effectively Jasmine has not trusted anybody since then. Why would you tell somebody your feelings if you can't trust what they will do with that information?" (Sophie)*

4.2.2.6 Subordinate theme 2.6: Broken systems

There was a clear gender bias suggested by two participants (Simon and Julia), with systems, particularly in schools, being more geared to supporting autistic boys [18]:

> *"And then you've got the whole kind of awareness from the teachers who are kind of first line of defence in all this kind of stuff. Just thinking we've got a really compliant child here; we haven't got a kid that just sits in a corner, stacking things up in order and you know is obviously classic autism syndrome" (Simon)*

> *"There are some schools in ***** but they're very focused on boys; they're boys' schools and a lot of them are more fitted for someone with learning disabilities as well" (Julia)*

Many participants (Simon, Megan, Daisy, Julia, and Sally) found that they encountered a system where diagnosis was the end point; there was no post-diagnostic support [19]:

> *"It was basically this is the kind of thing that's probably going to be hard. And then you will never be able to do this, and this is difficult, and that is difficult and off you go, off you toddle. So, and it was almost like, CAMHS, you know they're entitled Childhood & Adolescent Mental Health Services. It was basically yes, we've got you, you have a problem, but we can't do*

anything about it and it's up to you now, you need to kind of support yourselves, that's it. And it was almost like yes, we were discharged on the spot literally" (Simon)

"And I think even if you had all endless money, you still don't know, there's so little support out there for people that really understand" (Julia)

"Because you get diagnosed with autism that's it goodbye, no more services, we can't do anything about your sensory differences which she had. Sensory things were a big thing but there is no sensory integration help here in our area on the NHS. That was it, there clearly needs to be some sensory follow up and there wasn't any. And you know here's a list of local organisations that you might get some help from, but that was it…" (Megan)

"By then we'd had her diagnosis and they said, you know, that's part of her condition and there's nothing we can do to help you" (Sally)

Daisy, Sally, Sophie [20], and Julia all described an overrun, broken system that was essentially seen as not fit for purpose where services for autistic girls and their families were concerned:

"I'm not suggesting that some professionals aren't brilliant, they are, they're just all worn out and knackered and exhausted. And they haven't got the capacity to do anything when it comes to something that's not dead obvious" (Julia)

"My experience all the way along has been that the NHS is completely rule driven and jobsworth and tick boxes" (Daisy)

"Well, it's broken, isn't it? It doesn't, I mean, as a system, how can a system pay for, invest in me to make me a better parent and not invest in Freya who needs the help and support" (Sally)

Sally and Julia both felt that the system might work, but only if you knew how to play it:

> *"You know, what I also realise is that the system, is only there to support severely, why? I don't even think it supports severely autistic children. I think it's not made to support families. It's kind of... you only get something out of it if you know how to play the system. That's how I feel, I didn't learn how to play the system. And if I'd had my time again, I'd be so much wiser and know how to play the system" (Sally)*

> *"We are massively privileged, massively, we're educated, we're confident, I work in the sector, I've worked with children and young people services. I know to a level the way the system works, as I said I've had long conversations with the people who created the autism pathways. And still, it's a nightmare…" (Julia)*

Julia felt that the system might work, and that the staff do their best, but that it is held back by lack of funding:

> *"I work in the third sector, I know what the money's like, I know the funding situation. No one's there to try and be malicious, I get that. The CAMHS worker we've got now is very good, I can see how you know, how she could be a very good CAMHS worker for lots of kids, but they haven't got the funding or the capacity to be able to do anything for Emily" (Julia)*

4.2.3 Superordinate theme 3: Psychological impact

This theme highlights the psychological impact on parents as a result of their lived experiences.

4.2.3.1 Subordinate theme 3.1: Being on my own

Feeling isolated and abandoned was a significant theme for Sally, and one that was woven throughout her interview. In some cases, this was others abandoning her, but in others, she chose to isolate herself [21]:

"You know, when she was younger, we used to go on holidays with people. People don't invite us anymore. We only go if there's more than a crowd, you know if there's more than just us, it's because we've instigated it. I used to be a chief when, you know, in our social life, I would be the chief organiser, and over the years, I realised that people stopped joining in and joining us"

"I have three really good friends. Between us we have five children all the same age, have all known each other their whole lives and they don't get it. They don't understand it. And you know, we used to do things together, and when Freya got to about 13, they all dropped her, which I found heart-breaking. I walked away from them for a little while…" (Sally)

Sally's feeling that her friends don't 'get it' is echoed by Julia:

"It's really rubbish, people don't get it. I mean I've got fantastic friends and so has my husband. But like I have tried to, I do talk to them about it, but like they're the loveliest people and they feel terrible, but they don't understand" (Julia)

Becky and Daisy both found themselves abandoned by their daughters' fathers:

"I'm a single parent so and you know their dad still hasn't sort of, I wouldn't say come to terms, he's just blinkered, doesn't see it. Doesn't see all this behind you know this going on and I suppose I would like to have had a bit of support from him in that these are your children as well, type of thing. Because when he, when we got divorced it was very much, you're not my responsibility anymore. He has always been good financially; you know pays that way. But when it comes to support and love for the children, that doesn't happen" (Becky)

"…that's the one person in the world who ought to have been, understood what I was going through and gone through it with me. Whether we were together or not, he is still her father. She's got two parents, why is only one of them here for her?" (Daisy)

Even within her marriage, Sally expressed a sense of isolation in the way her husband responded:

> *"Her dad, bless him, he is of the opinion that whatever we do can't help her. And what will be will be. And so, he doesn't feel it in the same way I do, in fact, he buried his head in the sand rather than doesn't feel it" (Sally)*

Becky, Daisy, Sophie, and Simon relayed a sense of powerlessness, both through meeting dead ends in their quest for answers, but also in their feelings of impotence in the face of all-powerful decision makers:

> *"It was huge, huge part of me that's who I was, and it was just taken from under your feet…because well issues I suppose and shared decisions being made by the powers that be" (Becky, on being forced to give up teaching after her children were placed on the at-risk register)*

> *"It was just such a horrendous experience, you know, just having this woman tell me to take her home and begging her to do something and having her refuse and telling her I can't keep my daughter safe and having her not care" (Daisy)*

> *"A kind of sense of powerlessness and failure as well. Because I think there's, particularly when Bella was younger and prior to getting the diagnosis. You know when we saw her behaving in ways which were really not kind of within the bounds of what you expect. You know there is a lot of kind of chaotic and violent and out of control behaviour and you sort of think to yourself, what does that say about us as parents" (Simon)*

> *"You know I forget it was the shame of it. That was sort of the main feeling, and just I guess that sense of power that other people have over your life. That part was quite scary" (Sophie)*

Becky felt that she was regarded as being completely worthless in the eyes of the authorities:

> *"It's heart breaking how you can't say they make you feel that way because it's your reaction to it, but they're so strong because they are powerful, and they can take your kids away and they do lots of things that hurt. They do make you feel like this, tiny, you know you don't know anything and you're a worthless piece of muck on the bottom of their shoe. And you know, how dare you have your own opinion about something" (Becky)*

4.2.3.2 Subordinate theme 3.2: Impact on the inside

Feeling guilty was an emotion that many participants mentioned (Julia, Sally, Daisy, Sophie, Megan, and Thomas). However, there were several reasons given for this.

Sophie spoke of feeling guilty when she wanted to take a break:

> *"I've had to work on being able to give myself permission to have time away. It is and it's the reality of doing it and not feeling guilty" (Sophie)*

Julia, Sally, and Thomas all spoke of their guilt when they looked back at what they had 'forced' upon their daughters, ignorant of what was going on:

> *"I feel terrible, you know with hindsight, I just feel like we threw Emily into a fire pit without realising" (Julia)*

> *"Oh God, constant guilt that I didn't pick up…and actually I now know that once she got there, she was in absolute panic mode, and I just forced her to do something that was pretty awful for her" (Sally)*

> *"The impact, I'd say a lot of frustration, exhaustion, but a real sense of guilt about that. Because actually it wasn't her fault and I could have, her childhood or her life to this point could have been so much easier if I'd have...not if she'd have acted differently, but if I'd have acted differently" (Thomas)*

Sally also felt an acute sense of guilt that she had been naïve and believed everyone when they said that nothing was wrong:

> *"There is guilt on my part that I didn't push. I believed everyone, and so I didn't push hard enough, and I just let everyone walk all over us (crying)" (Sally)*

Julia spoke of feeling guilty that her younger daughter had been side-lined due to Emily's challenges:

> *"So, I feel, that's another thing that you know just to add to the list of emotional stuff. The guilt…" (Julia)*

Similarly, Megan had not noticed that her older daughter was feeling suicidal:

> *"I would never notice this because I'm always too busy dealing with much more needingly obvious, needy child two. And so, I was glad that she took this to see the doctor and I was horrified to hear that she'd been having these suicidal thoughts. I got to hear what was in her head and it was really quite scary as a parent. This poor child has had all this going on and I haven't really been paying attention to it, or not been seeing it, she's been hiding it" (Megan)*

Daisy felt guilty for reacting in what she felt was the wrong way, coming from a place of, at that point, not understanding:

> *"I got it wrong, I did things, you know, I'd get, I'd feel stressed when she was stimming and I'd shout at her to stop, because it was stressing me and I was worried, and I thought it was making it worse, actually it was making it better, but I didn't understand it. That's all part of the guilt, that's all part of the, OK, if she can't cope, it's my fault because I got things wrong" (Daisy)*

Fear and terror were emotions that were spoken about by Becky, Sophie, and Daisy. Becky and Sophie both spoke of the fear that they would lose their children through the involvement of social services:

> *"It had a number of impacts really. Initially I was frightened, I was going to lose my children, that was my biggest fear" (Sophie)*

> *"And it was just an awful, awful time in our lives for a couple of years. Just constant sort of not being believed, being watched, afraid to blow your nose type of feeling you know" (Becky)*

Daisy spoke about the fear she felt while trying to keep her daughter from hurting herself:

> *"Along the journey, we've gone through times when I have, you know, I've slept on the landing outside her bedroom door, because I have, her modus operandi was just to run if she was stressed and it could happen any time, no triggers necessary, she would just run, bare feet, pyjamas out the door" (Daisy)*

Anger appeared to be an intense emotion felt by Daisy, Megan, and Sally. For Daisy, this was directed at her ex-husband as she had no support from him:

> *"I was very angry because that's the one person in the world…I progressed because I went from seriously contemplating how would it be to spend my life in prison after I murdered him, because I, that was the level of my anger, to actually I just hope he gets run over by a bus. Well, that's as far as I'm ever going to get, I think with that one (laughing)" (Daisy)*

For Megan and Sally, it was anger that they had not been believed:

> *"In that awful 5 weeks the school ignored me, and my child was regressing to babyhood - and I had a bad chest infection. It was anger. I was angry that they explicitly doubted my integrity. Anger that it was pointless to express*

because the school had invalidated my word. So instead, I coughed and coughed and barked out my feelings" (Megan)

"…and actually, at the time I went along with it and now I think, well, bloody cheek, you know, who are they to tell me? That effectively, they're accusing me of lying" (Sally)

Daisy, Julia, Becky, and Sophie all spoke of having been traumatised in various ways. For Daisy, this was the trauma of having no choice but to aid her daughter's self-harm. Sophie spoke of the trauma of being interviewed over her daughter's disclosure [22]. Julia described the trauma of watching her daughter fall apart:

"And she actually asked me if I would get her a razor blade (crying). And on one occasion I did, because I decided that was the lesser of two evils. And it was the most, I mean, it's hard to describe giving your daughter something that you know, she's going to harm herself with and, you know, afterwards cleaning up the blood and, and I allowed, I facilitated that. I still think it was probably the right thing to do on that day. But the impact of having done that, it is never going to go away. There weren't any good options" (Daisy)

"When you see your child just breaking down in front of you, burning out, breaking down, it's horrific. So, she just really crashed, and it was awful, truly awful. You're watching your daughter decline literally in front of your eyes, like getting worse every day" (Julia)

Becky found her trauma almost too much to bear:

"I was in that situation in hospital which is traumatic in itself, and you come home 2 hours later, you're hit with another trauma, and you know and you think, 'no' this is too much. You know it builds up and builds up and builds up and I really think that's when you know, you'll see a parent with a breakdown, or you know they're in the hospital with a big illness because their body has said 'no'" (Becky)

The impact of the trauma on Daisy and Julia at times left them feeling overwhelmed and suicidal:

> *"And I definitely felt suicidal definitely over the situation. Not in the way that I would ever do it. Pretty much, I can't cope, I can't do all this on my own. But I mean I never would have done it, but it's definitely crossed my mind. And it's only because of this, it's not because of anything else, it's because of all the battling that you have to do, to try and get your child an education and support for their neurology. You know I'm just doing things that are really normal, I'm not asking to win the lottery or live in a castle. I'm just wanting basic education and basic health care" (Julia)*

For Daisy, this feeling was both driven by a feeling that she wouldn't be able to live with the guilt if her daughter took her life, and through despair at trying to keep her daughter alive [23]:

> *"The number of times I made the conscious decision that if she lost her life, I would kill myself, because (cries) that helped me cope, because I couldn't bear the idea of losing her life and still being here, so if that happened, I would just follow her because that would be the easier thing for me to do. Staying around would be too hard. I think before when it was just her and me in *****, if she'd gone, it would have been my fault. I would have, there would have been something I should have done differently. I could have, it was my fault, my responsibility. So, I think basically it comes down to the fact that it would have been guilt. I wouldn't have been able to live with the guilt because I would have felt responsible when she was living under my roof and there was only her and me, if she'd killed herself, that would have been on me" (Daisy)*

> *"And she took her drip out because she said she just didn't want to go on. And I sobbed, and I begged her, and I think in that moment well, I said, well, come on then let's go and find a tall building because we'll just go if that's what you want to do" (Daisy)*

Daisy then spoke of reaching a place of no longer feeling suicidal, but more reflected a sense of hopelessness:

> *"It's the hope that kills you. The more I start to believe that maybe we're, maybe it's not going to happen again (cries), maybe, and then it does and it's harder each time. It hits you harder each time when you've been in that place, where you've thought maybe my gorgeous girl isn't going to hurt herself again, maybe she's maybe she doesn't need to do that. But she still does…" (Daisy)*

Sally spoke several times about a deep sense of hurt and rejection, that caused her great sadness, at the breakdown of her relationship with her daughter:

> *"I said to her, do you want to talk about it? And she just said to me, we don't have that sort of relationship. I don't think I'll ever be able to talk to you about how I feel about anything. And it wasn't done in malice or, it was just as a matter of fact. That's how she feels our relationship is, and that I feel incredibly sad about" (Sally)*

> *"It was the first day of that part of her life where I didn't know everything about her anymore, and it's always been like, sorry (crying). She just completely shut down" (Sally)*

Daisy [24] and Sally both spoke of feeling jealous of parents with neuro-typical children:

> *"At the moment, they're all looking at universities and they're worried because their children's predicted grades might not get them into the university they want. And I think, oh my God, they just don't know how lucky they are. When lockdown started, I felt our life didn't actually change. In fact, it was quite a relief that everyone else was going through it. Because then I didn't feel different" (Sally)*

4.2.3.3 Subordinate theme 3.3: Exhaustion and burnout

Several parents spoke about the impact of their struggles on their own mental health [25]:

> *"I realized that I was struggling. I was absolutely, I needed a crutch. I was absolutely flailing. So, I started taking Sertraline, which did help somewhat, I've had beta blockers, which I can pop in stressful situations that stopped me panicking. So, I suppose my mental health has suffered. It's been up and down…" (Daisy)*

> *"I'm not sort of taking any medication myself but that is something I've considered at times. The feeling of thinking am I feeling anxious, you know am I going to feel better about this, knowing really frustratingly that a lot of it is circumstance driven. It's outside influences you know. But lots of parents are on medication with their mental health you know" (Sophie)*

Becky and Sally both spoke of the physical impact on them:

> *"I lost two stone in about four weeks and had to go for counselling for three months" (Sally)*

> *"Well, I had a break down, complete and utter break down. I just remember thinking, I have nothing, I have nothing to give you today, just literally nothing. And I had to phone my mother and say Mam, I can have sympathy with her, but I've just got nothing to give her. I'm out; completely depleted. I don't even know how to explain it, you're just empty and I honestly haven't felt like that before. It's just like really, my body had obviously said that's enough for now, you need to stop, you know and deal with or recover from lots of things that have already happened this year… I'm exhausted, I'm emotionally exhausted, I just need a little bit of a break and you can't have one, because you have to carry on" (Becky)*

4.2.3.4 Subordinate theme 3.4: Impact of the outside

Megan [26], Thomas, Simon, Becky, and Daisy[27] all spoke of a sense of feeling judged:

> *"There's heaps of advice other parents can give you when you're dealing with difficult children, maybe, and a lot of that can be a kind of a... at the root of it can give you a sense of sort of blaming yourself for it. We've not done this right, or we've been too soft in this way, or we haven't, you know. You know, other people's experiences of parenting are very different to yours, so therefore, you know, it's. They can sort of say, oh, well, if you do, you know, well I wouldn't put up with that, you know that kind of attitude, but they didn't have to put up with that" (Thomas)*

> *"So, when my mum would come and stay or when Sue's parents would come and stay, there would be a sense of you know you're letting her get away with blue murder" (Simon)*

> *"I don't know I think it's everyone's attitude out there, as well as sort of the us and them" (Becky)*

> *"It's other people's attitudes as well you know and even your friends say now, well I wouldn't have done that, I wouldn't have given her that, I wouldn't have done it" (Becky)*

Linking in with the sense of being traumatised (Section 4.2.3.2), Megan felt so vulnerable when recognising how reliant she was on good communication with her daughter's new school, that when an email wasn't returned, she realised how out of control this made her feel:

> *"I realised that trauma happens to parents as well, and I thought I couldn't control myself, I was out of control. It felt like somebody had put a big claw, yanked it in my intestines and pulled them sideways, that's how it felt… I still find it hard to trust in schools" (Megan)*

Similarly, Sophie reflected on not liking feeling vulnerable, fearing that showing this would be seen as a weakness:

> *"It's like my vulnerability because of previous experience. I don't want to feel vulnerable particularly. You don't want to feel like you're expressing that you're not coping or that you're not managing, or your mental health is suffering. Because again you know then you get met with well, we're not here to look after you, we're here to look after Jasmine" (Sophie)*

Becky too felt that it was counterproductive if she showed emotion:

> *"The moment you show any emotion, they switch off, they're not going to listen to you ever again then, you know. You've got, and you can't help showing emotion because it is emotional. They're just like I'm not going to listen to her, she's just emotional now. And you can sort of feel the attitude change" (Becky)*

Sally described how acutely she felt the side-lining of her and her daughter within their family, feeling invisible and hurt by favouritism. This led her to feel very resentful towards her family [28]:

> *"And at the point my parents stopped looking after Freya when I was working, they have not done anything because they don't know what to do, so they don't do anything. And I feel they've forgotten her. But we all went on a family holiday this year. So, there was my brother and his family, my parents and us, we got a cottage, and my brother and his family were leaving a day early because they were going somewhere else on holiday. And my mum in front of Freya, gave Rachel £20 for her holiday. And about a week later, she said to me, oh, I was thinking about this, I should have given Freya some money as well shouldn't I" (Sally)*

> *"I resent my parents. I have resented my parents for about 10 years, which and you know, I come from a very loving family. I resent everybody. I'm jealous and I was never like that before. I'm sorry (crying)" (Sally)*

4.2.4 Superordinate theme 4: Living with an autistic daughter

This theme explores the experiences of living with their autistic daughter.

4.2.4.1 Subordinate theme 4.1: Daily life

Sally and Becky both spoke about having no respite, no break:

> *"…like I could do with a weekend away and my mother might say well then go, you know. But you know when you come back, before you go it's going to be hell, when you come back it's going to be hell. And you just think, I don't want to go" (Becky)*

> *"I find myself thinking about her situation all the time…I can't see an end to it" (Sally)*

For Becky, this desperation for a break meant that she found herself not wanting to be discharged from hospital following an operation:

> *"But I was thinking to myself I wish I was back in hospital, that's what I was thinking you know, I was thinking I was back there. Even though in the hospital they had the Covid outbreak there. I was thinking, I'd just be back there now. You know I was thinking of even, at that point I was thinking maybe my stitches will break and I can go back in. After I'd had my op, I sat there for two whole days in the room on my own, the telly wasn't on, because the nurses kept saying shall I put the telly on, I was like no I'm enjoying the peace. I was just sitting there you know, in my own world, just watching the goings on and I didn't need the noise, I didn't need people phoning me or calling into to see me, I just sat…" (Becky)*

Daisy talked about the brief respite afforded to her when her daughter was admitted to hospital:

> *"So, she ended up back in hospital, which was just a massive relief because for a little while it wouldn't be my problem. For a little while I could actually relax and sleep at night" (Daisy)*

Several participants described feeling trapped and unable to step back [29]:

> *"She went through a… unsurprisingly a massive anxiety of me leaving. So, most of 2017 and 2018, I could really only leave the house for work, she wouldn't let me, if I was going out with friends or anything like that. She just couldn't bear to see me go out, so she'd have massive melt downs with the idea of me leaving. So, you know she's jumped on the bonnet of my car when I'm trying to go somewhere to see my friends. Or she has just been physically holding onto me so I can't leave the house" (Julia)*

> *"And I thought I've just got to have some time away from this child, I've got to have some minutes in the day where I'm not with her" (Megan)*

Sally spoke of never being able to make plans:

> *"What I realised throughout our whole journey with Freya, is we constantly change our plans to accommodate, you know, we in fact, we don't plan. All our plans are last minute…" (Sally)*

Sally, Sophie, Daisy, and Thomas [30] all talked about their daughter's high level of dependence on them:

> *"Well, it's just felt like having a new-born baby, in terms of level of care I've had to provide for Jasmine" (Sophie)*

> *"You can't just tell them not to do something and know that they're not going to do it, can you?" (Sally)*

"It has meant that she is a much, much bigger part of my life than a 22-year-old daughter would normally be…" (Daisy)

Simon, Daisy, Becky, and Megan described the experience of living on tenterhooks, with Megan likening this to being on a rollercoaster:

"I would wake up in the middle of the night thinking…it's like a rollercoaster, here I go again, and I don't suppose it's ever going to stop" (Megan)

"I realised it was it was just massive anxiety, and anxiety isn't a word I had ever used before. But I came to realise that I'd been living with low level anxiety constantly, and I still am; the level changes, but it never goes away" (Daisy)

For Becky and Simon, their anxiety stems from not knowing what will set their daughter's mood off:

"You have to breathe and keep and calm because if you don't say the right things at the right time, if this isn't done at the right time you know. Really silly things, kind of sort of set it off, where she will say right, I'm not going now, and she won't go because she's already in a panic and if you've used the wrong tone when you say Maisie your coffee is ready. Slightly wrong tone you don't even know you've done, so you're just always on edge" (Becky)

"You know we were all kind of pussy footing around her, just kind of thinking what's the next thing that's going to set her off, what have we done wrong now? What's been moved, what's not been moved?" (Simon)

Daily life for Sophie and Thomas [31] was described as becoming caught up with their daughters' autistic behaviours:

> *"By that point Jasmine had become very anxious, so didn't want to leave the house, when we did, if I managed to get Jasmine in the car, she'd hide in the footwell because she was convinced that people were looking at her" (Sophie)*

Managing their daughters' sleep habits was mentioned by Julia, Megan, Sophie, and Sally:

> *"We ended up having to put a double bed in her bedroom because we would sleep with her, until, you know, we would go to bed with her eight or nine or whatever time she was going to bed, she couldn't be on her own in her bedroom. And so, one of us would sleep with her. So, in the end, we just got a double bed because we were falling asleep and having to get up at three o'clock in the morning to get back into our bed" (Sally)*

> *"So, then the night scaries started and she slept awfully after that…" (Megan)*

> *"From at that point year 7 her sleep just completely screwed. So, she'd be up all night, awake all day, asleep all day and it would just move…" (Julia)*

The impact of violence was spoken about by Becky, Simon, and Julia. Julia likened this to having to endure abuse that she would not have tolerated within her marriage:

> *"I've had a lot of my hair pulled out; I've been beaten up quite a lot by Emily. You know there is stuff that I've taken from Emily that I would never in a million years have taken from a partner. You know like because you love them and because they're your child and because they're vulnerable and they're young and all the rest of it. Like if a partner had ever treated me in a tenth of the way that Emily treated me. I'd have walked years ago, but you can't do that, because they're your kids" (Julia)*

For Julia, Becky and Simon, this violence was also directed at their other children, as well as themselves:

> *"We've had situations where Amelia's had to, we've had to open windows to get her out of the house, or she had to lock herself in the car and Emily has been throwing logs at the car, trying to get to her and it's awful" (Julia)*

> *"Molly was the one who bore the brunt of it or had to see things that you know a small child really shouldn't see and felt very threatened because when Bella when she was at her worst, there would be knives flying around and sharp objects being thrown around. And a huge amount of screaming and shouting and violence and quite oppressive behaviour, which try as we might to sort of shield them from that, it wasn't always easy or even feasible at times when you've got somebody kicking off like that" (Simon)*

Sophie and Sally both briefly mentioned their daughter's gender identity. Sally reflected that she felt that it was just her daughter trying to fit in:

> *"Freya has now decided that she's transgender and I have to say, I've run out of things to be shocked about. So, I haven't processed that at all. I actually don't believe it. I think what she's doing is fitting in with a social group of people that she's met online who are all transgender. She was such a girly girl…" (Sally)*

> *"Changing my pronouns because at the moment Jasmine is identifying as non-binary. Which she wasn't" (Sophie)*

4.2.4.2 Subordinate theme 4.2: Impact on family / relationships

The impact on siblings was a theme brought up by Megan, Daisy[32], Julia, Thomas, and Simon. For Megan, Julia, and Daisy, they reflected on the lack of time they had been able to give their other child/children:

"She seems to have…she seems biased as well like, how much time do you spend with Emily, how much time do you spend on her, whilst she gets ignored. It's really hard and I do feel for Amelia because you know she'd had to go through a load of crap that people her age haven't had to" (Julia)

On discovering that her older daughter had been feeling suicidal, Megan said:

"She will be the person who will speak up last, so when they weren't there suddenly, she'd be telling me things and I got to hear what was in her head and it was really quite scary as a parent. This poor child has had all this going on and I haven't really been paying attention to it" (Megan)

For Julia (Section 4.2.4.1) and Simon, it was also around the impact on the sibling of the violence:

"It has been really, really difficult for her and I think she bears a lot of kind of psychological scarring as a result of that. Because as I say, when you're a small person you're very vulnerable and you certainly don't want to be. You know at the stage where you're coming home from school just thinking well you know I'll open the door and what fresh hell awaits me. When I come and sit down and try and have my tea and I'm yelled at because something's not where it's supposed to be" (Simon)

Thomas spoke about the frustration felt by his other children over the impact of their sister's behaviour:

"And it has a ripple effect on the other siblings where they start to…we get frustrated, they start to blame her and everyone sort of, she feels that everyone is blaming her for spoiling a day or a holiday or a situation" (Thomas)

This was echoed by Simon:

> *"There was a sense that you know she would express that as she got a bit older, wish I didn't have those around you know because if they weren't there, basically I would have had you all to myself. But I think it was, as she's grown up, it was a more a sense of if we, if we hadn't had to accommodate her younger siblings, life would have been so much easier. Because there wouldn't have been so much compromising and the fact that you know oh well, Toby wants to do this and Bella is not feeling well, so we can't go out" (Simon)*

Sally spoke about the impact on her marriage, adding that she felt that the impact on their lives was invisible to others:

> *"You know, we went through a very sticky patch as a couple because he would tell me I was soft. That I let her off school too much, that she was playing me and that I needed a bit of tough love. And yet he also was involved…" (Sally)*

> *"Nobody else seemed to be able to see it, but it was massively affecting her life. In fact, all our lives. Because all our lives stopped, basically" (Sally)*

The impact on the wider family was mentioned by Sally, Daisy, and Becky, although this varied. Daisy and Becky both drew support from their own parents. For Becky, she felt the need for their support as witnesses that she was not hurting her daughter:

"I moved in with my parents so that I had a witness…I was glad I was living with my mother because they would have been taken away at that point" (Becky)

Daisy's parents moved closer in order that they could support her:

> *"I mean, my parents are very supportive. My parents moved from ***** down to ***** where I moved to, where I am and where Olivia is and where Georgia is, so I mean they're supportive" (Daisy)*

However, this was not the experience of Sally:

> *"I had decided to go back to work, and so my parents looked after Freya. I worked part time and they would look after her one or two days a week, and by the time she got to about three... no, she was much older than that probably by the time she got to about six, they told me that they couldn't do it anymore because she was too much like hard work" (Sally)*

4.2.4.3 Subordinate theme 4.3: Impact on career

All the participants except Simon spoke about the impact that their daughter's autism had had on their working life. Megan, Daisy, and Sophie all spoke of putting their lives on hold:

> *"It all looked completely crackers, and I just thought to myself I don't think I can take a child out of school and do that and have a business. So, the business had to virtually die, almost completely snuff it out, which I didn't enjoy doing. It was a horrible decision to have to make and I became ill, physically ill with the pressure" (Megan)*

> *"Every time Jasmine has had a breakdown, I feel like I've had to put my life on hold…" (Sophie)*

> *"…so exhausting, it was…and eventually I gave up work" (Daisy)*

For Becky, the reason for this was taken out of her hands when social services placed her children on the at-risk register:

> *"I lost the ability to be a teacher anymore, obviously that's changed now, but because when they were put on the at-risk register, I wasn't allowed to teach. I lost my livelihood as well and that changed me because I wasn't me anymore, because I'm very much one of those people that live to work, rather than work to live and that was a huge part of me" (Becky)*

The turning point where Daisy decided she could no longer manage to work came through another suicide attempt by her daughter:

> *"Eventually I came home from work one day to find that she was in an underpass near where we were living. I'd bought a house up there by then, we planned to settle there, and she was in an underpass, having gone to Sainsbury's, having bought razorblades and paracetamol, taken a load of paracetamol, cut, and she was lying in an underpass. And I thought there is really no point in me earning money to pay a mortgage to have a house, and I haven't got a daughter…so I stopped work" (Daisy)*

Julia reflected that although her employers were very understanding, it was hard to manage to attend meetings for her daughter:

> *"I'm trying to be a manager of a charity as well. So, you know, I'm lucky that my charity is incredibly flexible, and my trustees have been brilliant. Because how most people carry on a job is beyond me, I don't know how most people, well I know that a lot of people don't, a lot of people have to give up work" (Julia)*

She went on to reflect that no consideration for her own professional needs were afforded to her, with an assumption made that they were doing her a favour:

> *"I'm Julia and I'm a professional as well; you might be a professional, but you are getting paid for this. I've had to take time out of work to come to this meeting that you've set at some weird stupid hour, in the middle of the day, you know I had to come out of work to attend this meeting" (Julia)*

Although Thomas worked from home, this still presented challenges for him:

> *"Oh, it was incredibly challenging, you know, because, when you're both busy, both working. I mean, it was just, she was home, at home a lot. I mean I work, not in the house, but, you know, sort of my farm is outside of the*

house, so I was able to pop in and out and see her when she's at home. And, so it was just, yeah, that was very difficult, actually" (Thomas)

Sally said that she had to change her career to accommodate her daughter's needs:

"All of our lives stopped basically. You know, I changed my career for her" (Sally)

4.2.4.4 Subordinate theme 4.4: Learning as I go

Several participants talked of learning and understanding as they went along. For Simon [33], this was around adapting his approach as he viewed his daughter's behaviours through the lens of Pathological Demand Avoidance (PDA):

"So, we had to massively change the way that we dealt with her and the way that the kind of expectations that we had on her in the home environment. So that, it was the change in the way that we tried to kind of manage Bella in the home that made a big difference. Because you know when they can't express what they need or how they're feeling, you know it's kind of natural to just lash out. To communicate, kind of shout and scream and it's only when she talks about people being behaviour detectives, it's actually kind of go under the surface, look at why is your child behaving in a particular way, what it is they're actually trying to get out of the situation. And that was a big game changer for us" (Simon)

Similarly, Becky began to understand the need for low demand:

"You felt like you had a set of guidelines in which to manage her behaviour and you know, you sort of looked at other ways and you understood why you know any sort of demands on her she couldn't cope with. She would just shut down and just lots of little strategies really that helped and that you know, you knew that's why she's shutting down, that's okay I can deal with that, that's fine. I do think she's got tendencies towards partial pathological demand avoidance. And I've learnt my lesson now, if I just keep trying to

persuade and everything it just gets worse and worse and worse, so I know I can't." (Becky)

Thomas said that although life wasn't necessarily easier, they were learning how to stop problems from escalating:

"I suppose it hasn't got any easier really, we just know how to deal with certain issues better, really, and not make them worse" (Thomas)

Becky also spoke of feeling that it was her job to keep learning and understanding:

34 *"You know when you're tired or she's been off it for sort for like hours and hours and you don't make a mistake then sometimes, you might not say the right thing or because you're not focusing completely because you're tired. Because it's tiring, it's all headwork. And you can see then the difference, oh right okay, I shouldn't have said it that way and you try and remember for the next time and there's always something to remember for the next time" (Becky)*

Daisy talked about learning to accept that her daughter needed to self-harm, although recognised that she didn't understand it:

"She doesn't really want help with it. She doesn't really want to stop self-harming. I hope one day she will but at the moment she still sees that as a coping mechanism that works for her…I've accepted, I mean, we did have one time when she was living at home, when I come to understand that it was either she would just run off and be in danger or she would go into the bathroom with a razor blade…I respect her and I respect her decisions, and I don't always agree with them and I don't always understand them, but she's a very clever girl, and she deals with things the way she needs to deal with them" (Daisy)

4.2.4.5 Subordinate theme 4.5: Wearing a mask

Several parents spoke of masking. However, although this was often their daughters hiding their problems, this was also about parents having to hide their difficulties.

Julia, Simon [35], Daisy, Sophie [36], and Thomas all spoke about their daughters masking. Julia and Simon likened this to a swan swimming:

> *"With hindsight that just shows me that whilst she was in the middle all through primary, it was very much like a swan. So, she was kicking the feet very hard and reaching a standard that was absolutely fine" (Julia)*

> *"But obviously under the surface you know she's… her legs are going, and it was only much later in her time at primary school where things really started to surface" (Simon)*

> *"I think sometimes I mean, some kids, some parents know very early, and I think with Charlotte it was hidden behind… but didn't, you know, didn't rock the boat, didn't behave badly in school and wanted to go to school" (Thomas)*

> *"She seemed to be coping well with it and clearly she wasn't…" (Daisy)*

> *"She can mask for a little while and people say what do you mean, there's nothing wrong with her…and that's really hard to explain to someone that she's acting" (Becky)*

However, Simon, Becky [37], and Thomas spoke about what happened when the mask slipped:

> *"At this stage Bella's behaviour was starting to become much more challenging, difficult to manage and in school she was managing okay, but we would find quite often she's come back from school, and we'd have this sort of what we know with hindsight, it's the classic coke bottle effect" (Simon)*

"I suppose if her behaviour was, she was acting out in school with disruptive, difficult behaviour, then you would have someone coming to you and sort of, you know, we'd be able to, you know, sort of have a consensus of...as adults about what she's doing and why she's doing this and what's, what's triggering this, whereas when you're just, you've got a child that never, you know, never does anything to draw attention to herself at school. All you're dealing with is your behaviour at home, really. So, and her behaviour at home was extremely challenging" (Thomas)

Becky felt that she had to hide her emotions from social services:

"The moment you show any emotion, they switch off, they're not going to listen to you ever again then, you know. You've got, and you can't help showing emotion because it is emotional. They're just like I'm not going to listen to her, she's just emotional now. And you can sort of feel the attitude change" (Becky)

Similarly, Sophie didn't feel that she could let on how she was feeling:

"I don't want to feel vulnerable particularly. You don't want to feel like you're expressing that you're not coping or that you're not managing, or your mental health is suffering" (Sophie)

4.2.4.6 Subordinate theme 4.6: New normal

When asked to reflect on her journey and life now, Daisy described it as:

"Falling gradually into a big black hole, from the moment that she jumped out the bedroom window, realising something wasn't right, and that was the moment. A sort of slippery slope down into the abyss. I think at the bottom of the hole, eventually a tunnel appeared. And I'm close to the light, I think I see the light and then it goes again and again and, you know, being out there

in the fresh air at the end of it thinking it's over, is not going to happen. That's what I'd like to happen, but it's not going to happen" (Daisy)

Similarly, Megan felt that this was her new normal:

"It's like a rollercoaster, here I go again. And I don't suppose it's ever going to stop" (Megan)

Sally spoke about the change in her life:

"I'm a complete extrovert and I love going to parties and I love socialising. Not that we do that anymore because that's all part of the fallout from all of this…" (Sally)

For Sophie, her focus for the future was that her daughter (and son) to live sheltered but independent lives:

"If Jasmine can work on independent living skills, can work on just overcoming social anxiety, being able to access a community. I mean we're sort of preparing our home, we're having an extension at the moment, to make it bigger thinking that we'll probably you know have adult children living with us for a long time, which we don't mind" (Sophie)

4.2.5 Superordinate theme 5: Reflections

This theme encompasses the 'looking back' aspects of the participants' journeys.

4.2.5.1 Subordinate theme 5.1: Reflections on diagnosis

There were many different views expressed by parents about their daughters' diagnosis. Sally and Sophie both felt that autism should not be viewed negatively:

"It's disappointing I think how systems are set up in this country to make you feel like you're less if you don't meet those expectations" (Sophie)

"...not that I want to call what she has a problem" (Sally)

In a similar vein, Simon [38], and Thomas both felt that the diagnosis brought a sense of self-understanding to their daughters:

"She does embrace it as a, having it as a title for what she you know, her challenges, really, so it's a very helpful thing to her" (Thomas)

Diagnosis was also seen to bring a sense of understanding too, both for parent and daughter:

"I suppose with us, being able to give it a diagnosis and then explain that to siblings, it sort of makes, makes it easy for all of us, really, I think. But there is also a sense of knowing who she is, you know, and understanding now that comes through that diagnosis, that is very helpful in moving forward and getting the best out of situations, and helping her to understand herself as well" (Thomas)

However, for Simon and Sally [39], the delay in obtaining the diagnosis was felt to be frustrating:

"If I'd have had that diagnosis a lot earlier and we would deal with every situation, would have been dealt with differently, and our expectation of things would have been very different, which would have been a lot more, you know, a lot more helpful to her" (Simon)

"And that know we were seeing this behaviour, but you know Bella's other siblings were not behaving in the same way. If it was a parenting problem, and that wasn't the case and I think if the people who we were dealing with. They become a bit more switched on, maybe they would have been more aware of, we might have been able to turn things around more quickly" (Simon)

Daisy and Becky both felt that the diagnosis was just the beginning, and made little difference to their daughters' mental health:

> *"Really, once we had the diagnosis, there wasn't any support, it didn't really make a difference. It may well have made a difference in the way the hospital dealt with her while she was an inpatient. But she went on to be an inpatient in another CAMHS ward and then on an adult ward. So, you know, it's not, that was not the end of it by any means. I mean, she had been diagnosed with borderline personality disorder, emotionally unstable personality disorder" (Daisy)*

> *"So, she did eventually get it diagnosed but things didn't really stop there. It was still no help for her suicide attempts and that's still going on now" (Becky)*

For Daisy, the diagnosis was a surprise:

> *"To be honest, the diagnosis was a surprise to me…" (Daisy)*

For Sophie, it was felt to be bittersweet:

> *"Sort of yes just for thinking oh wow, somebody else is seeing what I'm seeing you know. It was lovely having that affirmation that yes, I have been right to think that there was something different happening with her. But then I was also nervous of what that might mean for Jasmine, just in terms of future need" (Sophie)*

Both Thomas and Megan spoke about how the diagnosis had brought with it funding for support:

> *"Also, I think it opens up, obviously funding and sort of things and help" (Thomas)*

For Megan, it was when her older daughter was diagnosed on the back of her younger daughter's diagnosis, that support was provided:

> *"It's been a way forward, my elder one is now at university, she has had, she's in a university that knows what they're doing with autism. She's had support to get on with things and is doing very well with the support, it's been huge…" (Megan)*

Through both of her daughters being diagnosed with autism, Megan, recognising parallels with her own younger life, also started her own assessment and subsequent diagnosis of autism. She felt that many of her questions around her own way of being could be answered through diagnosis, and that it was important in self-understanding at whatever stage of life.

> *"From my point of view, I'm aware that there have been times in my life when I thought to myself, I just need some help, something is weird about the way my brain works. So, I thought to myself I'm doing it, I don't care how long it takes and I was on the waiting list for about a year and a half. But I looked into it more and more and I just want to know now and what's more my young people have had this looked at. They've been through this process, I think I should be, I see too many of these traits in me. This business of being assessed isn't just something that's just done to young people" (Megan)*

4.2.5.2 Subordinate theme 5.2: Reflections on parenthood

Sally talked about her dreams of motherhood, and how she now reflected upon this:

> *"I'm an older mum; I was 39 when Freya was born, and I craved having a baby so much, and I couldn't believe when she was born how much I loved this little tiny thing. And I thought, right, I'm not going to put all my hopes and dreams on her, because that's not fair, that's, you know she's got to live her own life and obviously there'll be challenges on the way. And I fully accepted that that was going to happen…I realised that I don't enjoy being a mum at all, it's too hard. And that's just awful because that's not what it should be at all" (Sally)*

Daisy spoke about her intensity of feelings towards her daughter and the impact of what she then experienced:

> *"I mean, before I had children, I had no idea what it meant, and I'm not sure anybody ever does. That immediate I would lay down my life for these small creatures. It just hits you like a ton of bricks and there's just no getting around it. It's not logical, and I'm a logical person. You know, my brain works in a very list orientated, task orientated way. And yes, you're right to have this massive emotional side of it, was like 'waah'" (Daisy)*

Sally talked about the realisation that her daughter is almost a stranger to her. She went on to reflect that it was through her not understanding that her daughter was struggling that their relationship has broken down. Her distress at the broken relationship between she and her daughter was a theme that was woven throughout the interview:

> *"She was a master at masking, and I feel like she is, you know, she's a stranger to me, you know, she's been in my life nearly 18 years and I don't actually know her" (Sally)*

> *"I mean, I have to say that our, my relationship with her is quite broken. Sorry, I'm very upset (crying). I think probably that's where our relationship started to break down a little bit was when she started going out with... in fact, I do remember there was a time where I was taking her to school. I walked her up to school and she was begging me not to make her go. And I now know the language that I used probably belittled her situation…*[40] *And, you know that absolutely destroyed our relationship" (Sally)*

Sally then spoke about her feeling that her daughter will just walk out of her life:

> *"I worry now that when she comes to the stage where she wants to leave home that I will never hear from her again unless she wants some money, because she's rubbish with money" (Sally)*

Daisy, however, talked of the strengthening of the relationship with her daughter throughout their journey, arriving at a place of mutual accord:

> *"Now, I can say that it's made me stronger, and it's strengthened my relationship with Olivia. So, we have a really good relationship because it's based on spending quality time together and not based on me trying to look after her and keep her safe. And I'm just happy that we have a good, I believe we have a good relationship now, and she will talk to me about some things and not about others. And that's fine because she's 22 and she can make those choices. I believe she knows that me and my new husband are there for her. I believe she knows that if she you know well, she's done it. If she phones in the middle of the night, says, I need you, I'm there" (Daisy)*

Becky and Sally both found themselves questioning why they were parents of autistic children:

> *"I've always been a believer in life is what you make it, and the last ten to twelve years, I've actually thought life just isn't fair (crying). And why her, and why us?" (Sally)*

Becky, although questioning 'why me?' also went on to reflect that it was because she was strong enough to cope:

> *"I often think to myself, I'm not a religious person but I think, when I found out the two children were autistic, I was like really God two? You couldn't just give me one, you had to give me two? And now I'm very much well you gave them to me because they needed me, they needed somebody like me, only and that's why you gave them to me. I'm not so resentful" (Becky)*

4.2.5.3 Subordinate theme 5.3: If only…

Many parents reflected that had they known what they do now with the benefit of hindsight, they would have done things differently:

"Daily challenges could have been so much easier if we'd have understood. The way we deal with things now, if we'd done that, then we would have had a lot, she would have had a lot more success and we would have a lot more success with her really…I would just understand... I'd have that diagnosis a lot earlier and we would deal with every, every situation would have been dealt with differently, and our expectation of things would have been very different" (Thomas)

"I think the one thing that would be different would be, we would have been able to see that the kind of low demand, low sensory diet type of approach was you know, would have been transformational" (Simon)

For several parents, this feeling was centred around school, and their attempts to get their daughter to attend [41, 42] (also see 3.2):

"We worked really hard to try and get her in and at that point again very naively, you know we didn't know what to do or what was wrong. So, we did things like putting her in the car in her pyjamas and just awful things that with hindsight I would never do again" (Julia)

"And you know, with hindsight again you know there was some of the tactics and strategies that I deployed that were probably you know, were quite cruel. And she would now come back and allude to some of these and just so you know that was a really horrible thing that you did" (Simon)

"I mean when I look back, I realise that she must have been struggling" (Becky)

"She would beg me not to make her go to school, but I'd already put to bed all the ideas that she was autistic" (Sally)

Sally and Simon both spoke about naively making her problems worse:

> *"I used to try and second guess what was going on in her day, and I probably said things to her that reminded her that she was having a crap time at school because I was trying to get the information out of her" (Sally)*

> *"You've got your child; you love them you want to do the best for them. And actually, what we were doing, a lot of the time, we were actually making things worse for her not better, a lot harder rather than making it easier" (Simon)*

Sally spoke about regrets; feeling that she let people walk all over her:

> *"I believed everyone, and so I didn't push hard enough, and I just let everyone walk all over us…And I think it's because I never listened to her, I listened to everybody else telling me I was wrong. And trying to fit us into the mould of I don't know, the perfect family or the family. I must be really thick, is the best way to describe it, but I allowed other people to tell me I was wrong…I can't believe that very first time I went to CAMHS, if that had been a different outcome, I think her life and our relationship would be completely different. You know, they should have given her a full evaluation at that time, and they didn't" (Sally)*

Simon spoke about the emotional damage to his daughter, through not being understood:

> *"From Bella's perspective it has been quite, really quite damaging, emotionally because you know she's been forced to do things and the difficulty that she's faced wasn't able to explain what was going on…as an early teenager, she was just a morass of up there and what she needed and I think that's really, that's really saddening as a parent" (Simon)*

4.2.5.4 Subordinate theme 5.4: Loss and grief

Thomas spoke about how he felt a sense of loss when he reflected on her desire for friends, and her relationship with them; sentiments shared by Sally with regard to her own daughter's relationships:

> *"She'd have a friend for a sleepover or friends come up for the day and then, and it wouldn't be too long before maybe she would come to us and say she wants us to take them home, because it's, because it's become too much for her, so that then we'd have to make some excuse for taking them home and make it, make out, oh, we've got to go to town now. So, we need to go now, and we need to take you home. And which is a bit odd to them, why they were suddenly prematurely going home. So, its little things like that gradually start to affect friendships, I guess…it makes you feel, I suppose it's like a grief really" (Thomas)*

> 43 *"…And Freya went to college and met somebody very inappropriate who was rude. Basically, it's somebody who is transgender, who was trying to be, I suppose what he thought a boy should be, and he treated Freya really badly, so I went from the guilt feelings when she went out with the first boy, how lovely he was, how he treated her, I felt almost relief that she could have a relationship with someone that was normal or that's not the right phrase, but you know what I mean. Somebody who saw through her flaws and still adored her and how she could prefer to go out with someone who treated her so badly and was rude and arrogant and... messed her about and I had a breakdown. Because I went from relief to horror all in the space of a week" (Sally)*

Thomas described his experience as one of grieving:

> *"…like you grieve for, you feel a sense of loss for the person that she wants to be, that she could be without these sorts of restraints upon her…and then there is that loss of that life she could have had. And then so that's extremely*

sad for her and it's sad for us to watch, really. I would say probably there's a real sense of loss there, I think, and grief…I mean, how I imagined this stage of our life back then when she was a little baby to, is a very different picture of what the reality is. So, it does come back to that sense of loss, and grieving for what you, because it's not... it's not like you're, in a way, you're sort of, you're not disappointed in, that she isn't the child you wanted, you're disappointed in the fact that she can't be the child, the adult that she wants to be. I'm not saying, oh, it's a really bad thing, it's just that, you know, there is definitely that sense of loss" (Thomas)

Sophie similarly describes a sense of sadness:

"It's been a bit of a contention for me, you know it's beautiful watching other people's successes, but then you think I want that so badly. You know, I'd really like to have that…" (Sophie)

Julia talked about 'lost years':

"For a lot of years and this is sad as well that we've never been able to sort of see what the real Emily, because it's just been covered in sadness and aggression and shut down and illness" (Julia)

Sally mourns the loss of family relationships:

"I'm very sad that my parents don't have the same relationship with her that they do with my with their other granddaughter" (Sally)

Sophie and Sally speak of missing the child they once had:

"I do wish when she was younger, she was a very loving, affectionate child and I really miss that, I really miss, I miss her…and psychologically, on a parent, God, that's just awful" (Sally)

"We see glimpses of how Jasmine was before the breakdowns, but she's never really been fully restored to the young, vibrant person she was when she was 11" (Sophie)

Daisy feels sad about the lack of relationship between her daughter and her ex-husband:

"Olivia doesn't have a relationship with him now because he got married last year and told her not to come…I mean, he's seen so little of her since we split up that he doesn't know her, and he doesn't understand that she will make decisions" (Daisy)

Another loss for Sophie was that of her reputation, when the police were investigating her daughter's disclosure:

44 *"But I was also concerned about reputational damage for myself and my husband. You know, people say there's no smoke without a fire. We were interviewed in the school staff room and Jasmine's name was on the board, was on the whiteboard in the room with detail of what was happening and I just, my heart sank, and I thought so every person who has come in this staff room is going to have seen that. Anybody that is going to have come into this room, so it really doesn't even matter that we have been completely exonerated, during this meeting. It will be left with that impression of us" (Sophie)*

Sally spoke of her worries about the future for her daughter:

"My big fear, the trouble is I stopped looking forward a little bit. I look forward to her life moving forward and I don't see, it's not going to be easy, but I worry when me and her dad aren't here anymore. Who's going to advocate for her?" (Sally)

4.2.5.5 Subordinate theme 5.5: Support networks

Sally, Daisy, and Julia all spoke of the importance of the support of other parents of autistic daughters. They all felt alone, and were reassured when they discovered that in fact, they were very much not alone:

> *"I think I thought she was unique. I thought our situation was unique. And it's only relatively recently that I've sort of come across Facebook groups, the one I saw you on in fact, and I've come to realise that there are a lot of people out there with daughters in hospital, often with personality disorder diagnosis, who are actually autistic. And it's actually a well-trodden route" (Daisy)*

> *"I tended not to talk with those friends about it and where I find a major source of support is through Facebook; that's where I got the support and the understanding. I realised that we weren't alone, so that, that was massively important. I feel for anyone 20 years ago that was going through the same thing when those channels weren't available, because that was totally, that was kind of 100% my support base" (Julia)*

This sense of not being alone was very important:

> *"And you know, knowing that you're not the only one and knowing that you can get support…going back go Facebook that's why it is such a massive support because you know that there are families like you across the country" (Julia)*

Similarly, Sally only discovered quite latterly that support was out there:

> *"Actually, during lockdown, I discovered a lot of Facebook groups, and I think, God, I wish I would have... if I'd have discovered these beforehand…" (Sally)*

4.2.5.6 Subordinate theme 5.6: Walk a mile in my shoes

Becky, Sally, Simon, and Thomas [45] all spoke about feeling judged (Section 4.2.3.4), stating that unless you've lived it, you cannot truly understand:

> *"I think for somebody to truly understand they have to have gone through it themselves, you know they have to have some sort of experience of seeing it, whether it be a sibling towards their own parents perhaps" (Becky)*

> *"I couldn't talk to my friends because I was like a stuck record, and I could tell I was like a stuck record, and I think unless you have a child on the spectrum yourself, you actually have no idea what it's like" (Sally)*

> *"It would be a question of, walk around in our shoes and you might see things differently" (Simon)*

Becky talked about wishing that the path before her had been more well-trodden:

> *"I would have liked a bit more support, rather than finding things out for myself, you know and constantly searching for information and the right way to do things and testing things out" (Becky)*

4.2.5.7 Subordinate theme 5.7: Social justice

Several participants reflected on the importance of, and need to tell their 'story':

> *"It's nice to be able to share it with somebody independent who isn't going to be upset by it or give me advice or be involved in any way. It's quite nice just to have that platform to say, this was our journey and hope that something of what I say may be of help to someone somewhere along the line" (Daisy)*

> *"I do feel rubbish... but that is a small price to pay if research going forward will help future parents of autistic girls" (Julia)*

"Before I came across you with what's going on with her now. It sounds stupid, but I felt so strongly, that I was going to… I wrote basically from her life every kickback and knockback we've had through the system and what we've had to pay for privately. I thought about writing to Boris just to tell him how broken it is!" (Sally)

"Even though it's difficult to speak about, this is why I think your area of research is so important" (Sophie)

Julia and Becky both expressed a sense of injustice, speaking about those not able to stand up to the system:

"And for other parents as well because there are other parents that wouldn't be able to stand up for themselves and I think they are having an even worse time from certain sides, maybe even doctors, school, social services anybody who is involved really, you know. I don't like that because there's parents who can't stand up for themselves, they need help, and they shouldn't be treated like that in the first place" (Becky)

"This is what gets me the worst, is that the people, you know what happens to these people, if you don't happen to know people in the council and people in children & young people's services. What happens if you're not working with an educational psychologist, you know what happens to those people, how the hell do they get help? And just knowing, you know but there will be so many families out there, that don't even know DLA exists or that they qualify for it. So many families who just fill the forms and they get rejected because they didn't fill the forms in the right way" (Julia)

4.2.5.8 Subordinate theme 5.8: Personal growth

Becky and Daisy both spoke about their sense of becoming reconciled to their situation:

"I think, I know that I'm being supported to do everything I possibly can for Olivia. I don't feel that I'm failing her anymore, that before, I was failing her, whereas now, it would be her choice. I'm doing everything I can for her…that that makes me feel better. Feeling I can do something. I can give her support. I can give her a solid foundation. I can give her something she can rely on and be sure of, that's what keeps me going" (Daisy)

"As the years go on, you deal with things, and you're put through things and you're having to sort of grow and look after yourself and mature. Be the one that is strong for everyone, you just have to find a way to deal with it yourself, don't you? You have to find a way to reconcile in your own head" (Becky)

Becky speaks of the importance of rebuilding herself, not only for herself, but also to demonstrate this to her daughter:

"It wasn't a choice you know, and I've had to build myself back up from being on the floor because well issues I suppose, and shared decisions being made by the powers that be. And you know I fought to get myself back where I am now. But I also felt that I needed to do that for Maisie to see that it can be done" (Becky)

Similarly, Sophie spoke about the importance of thinking positively, and empowering young autistic individuals:

"You just have to think well, I just have to keep going and keep thinking that there's still time for something good to happen. I am a firm believer that people with autism don't always tick the boxes and meet the milestones that society say you have to do things by a certain age" (Sophie)

In reflecting on their personal growth through adversity, Becky and Daisy both spoke about an awareness of this resulting from their experiences. For Daisy, this inspired a new career that she loves:

"As the years go on, you deal with things, and you're put through things and you're having to sort of grow and look after yourself and mature" (Becky)

"My life is fantastic, I'm so, so lucky I'm doing a job that I love. I'm working as an advocate. I do mental health advocacy on the wards because I met an advocate through Olivia. So, I feel like I'm turning things into a positive, and I'm doing some good" (Daisy)

She went on to reflect that her daughter was also proud of her:

"And she really admires what I'm doing work wise, the fact that I'm helping other people that are where she used to be. Though that's, that's the fact that she is proud of me for doing that. And she knows that it's because of her, it's because of what we went through, we've got this thing going on" (Daisy)

Sophie was driven by her experiences to create a charity, although she did add that this still creates mixed feelings:

"I really don't think there is much care for the parents. And that's what's driven me really with the charity that we run. One of the main aims of that is to care for parents and carers, because I just feel the more that they're supported and given information and given help…"

"I volunteer with the charity usually a couple of days a week. So, I'm still the chairperson of it but even that has been a source of guilt for me because feeling well I'm helping all of these other families, and my own daughter is like really struggling" (Sophie)

Daisy spoke about her role in her daughter's life keeping her going, reflecting that she would no longer want to die if her daughter took her own life, feeling that she is now doing all that she can:

"You know, that's never going to change. And that makes me feel better, feeling I can do something. I can give her support. I can give her a solid

foundation; I can give her something she can rely on and be sure of, that that's what keeps me going…Now, I think, what's hard for me now is that I think that probably I wouldn't do that. I wouldn't follow her. I'm not sure what's changed, but I wouldn't follow her, and that's really hard, that's hard in its own way… I won't have to live with the guilt, I mean, don't get me wrong, it would be the worst thing ever. But I won't have the guilt because I'm doing what I can. I'm supporting her the best way I can" (Daisy)

Thomas, Julia [46], and Simon all spoke of life getting easier, although not perfect:

"She's thriving at school, and you know although at home, it can still be a bit spikey and sometimes a bit treading on eggshells, it's a lot less stressful particularly for her siblings" (Simon)

"We're in a better… you know, things have improved in some ways, although still a daily challenge" (Thomas)

Becky, Megan [47], and Julia all spoke about using humour as a way of getting through:

"And you know people come here and they say you are mad you are, but I've got to be!" (Becky)

"I work in death, I work in bereavement and that has seriously been my light relief for the last 4 years, so I think that gives you a kind of indication of how horrific…it's just beyond really. I wouldn't recommend it as a 3-year process!" (Julia)

4.3 Summary

This chapter has presented an analysis of the rich data from the parents of autistic daughters. The following chapter will discuss these findings in relation to the research question, comparing and contrasting the findings with the existing literature.

4.4 Reflexive statement

Having started the analytical process feeling utterly swamped by the extensive data I was holding, and the intense responsibility that I felt in having been entrusted to make sense of the participants' heartfelt words, I experienced a mix of relief and excitement when clear themes and subthemes finally began to emerge. I had set out to use NVIVO but as I was using a MacBook, the functions that it offered were far more limited than had I been using a Windows computer. This caused a real hiatus that, at the time, only served to deepen my sense of feel overwhelmed. It was only as I developed a 'to and fro' between NVIVO and pen and paper, that I started to really appreciate and utilise the benefits of both.

My research position as an 'insider', as the parent of an autistic son (Sections 1.1 & 1.4), has played a key part in both capturing and interpreting the lived experiences, many deeply painful and private, that were shared by the participants. The trust that several participants expressed through the assumption of shared experience along the lines of, "you know what it's like", was felt to really enable the expression of deeply traumatic experiences that in some cases they had never before felt able to articulate. In being regarded as an insider, one of their own, rather than a detached researcher, the depth and intensity of the interpretation of these findings are set apart from the few studies that explore the lived experiences of parenting an autistic daughter.

Chapter 5: Discussion

5.1 Introduction

The aim of this phenomenological study is to address the research questions set out in section 1.5 of this thesis: namely, to explore the lived experiences of eight parents of autistic daughters and to question what, if anything, might have made a difference to their experiences. This chapter relates the findings from chapter 4 to the extant literature that was reviewed in chapter 2. Although this chapter is arranged broadly around the five superordinate themes, due to the overlapping and duplicative nature of the themes, some aspects of discussion will pertain to more than one theme.

Although the findings are discussed in relation to the relevant literature, an important caveat is that studies rarely differentiate their findings on gender, and if they do, they refer to boys. Therefore, unless explicitly stated that the literature refers to autism in girls, it can be assumed to either talk about autism in males, or to be unspecified with reference to gender.

5.2 Lived experiences

5.2.1 Journey to diagnosis

The findings from superordinate theme one, and the associated subordinate themes revealed many insights for the participants, when looking back on their journey to the diagnosis. All participants felt that with hindsight, the signs that they had noticed were significant. However, at the time, they were instead attributed other causes, such as differences in character from other siblings, or, in the cases where other siblings were boys, just how girls are.

Consistent with the literature around early behaviour as an indicator of possible autism in girls (Hiller et al., 2016; Tierney et al., 2016), many participants noted controlling and dominant behaviours in their daughters, with the need for everything to be perfect and for life to generally go their way. Similarly, Megan stated that her daughter preferred the company of boys; this finding concurring with extant literature (Bargiela et al., 2016; Chantrey, 2017; Cridland et al., 2014). However, at the time, none of these behaviours, although challenging,

seemed to be anything other than variations of normal development. The only participant to note that her daughter's play was lacking in imagination, a known indicator of autism in general (Harrop et al., 2015), already had a son who was diagnosed with autism. It is possible therefore, given her knowledge, that she was already more alert to signs in her daughter. Simon stated that his daughter's interests were concerned with well-known figures in the news, supporting the suggestion that the restricted interests of autistic girls are often hidden by the social content of their interests seeming normal (Grove et al., 2018; McFayden et al., 2019; Nowell et al., 2019). Interestingly, Megan commented that initially she saw nothing unusual as she saw herself as a young child in her daughter's behaviour. It was only when she witnessed the real struggles that her daughter was having that she became aware of deeper problems.

Nevertheless, for many participants, the first they knew of any real problems was when their daughter could no longer hide her difficulties; she was no longer able to camouflage her struggles. Although, for many participants, this manifested in a refusal to attend school, overwhelmingly, this took parents by surprise, as they had not been made aware of any problems by teachers. This finding supports the conclusion of the study by Dean et al. (2017), who suggest that the social communication deficits of girls, although picked up on by peers, leading to internalised distress (Sedgewick et al., 2018a), usually remain hidden from teachers and playground staff. Simon said that his daughter was described as being 'like a lamb' at school, fitting with the description of the 'teacher's dream' (Kreiser & White, 2014), yet she was volatile and aggressive at home.

For two participants, their daughters' masking was maintained to such an extent their daughter became suicidal before they became aware of any problems. Although there is research around the masking of autistic symptoms in girls (Dean et al., 2017; Hull et al., 2017; Lai et al., 2017), it would seem crucial to focus not just on the fact that masking conceals autistic traits, but the exhausting impact of masking on the girl herself (Cage & Troxell-Whitman, 2019; Gould & Ashton-Smith, 2011; Leedham et al., 2020b). However, the knock-on effect on parents of this impact is further overlooked in the few studies that explore the parental perspectives of having an autistic daughter (Anderson et al., 2020; Cridland et al., 2014; Mademtzi et al., 2018).

Except for one participant, Thomas, whose daughter was already under CAMHS (Child and Adolescent Mental Health Service), all the participants found themselves met with disbelief, with their concerns dismissed when they approached professionals. Although studies that establish the premature reassurance and general dismissal when parents first express concerns around unusual behaviours are few in number, they predominantly fail to differentiate between boys and girls (Fewster & Gurayah, 2015; Richards et al., 2016; Ryan & Salisbury, 2012). Given that on average females receive an autism diagnosis at a later stage than males (Begeer et al., 2013; Kirkovski et al., 2013; Rutherford et al., 2016), it is likely that the overwhelmingly dismissive and negative response encountered by the participants reflects the general lack of awareness of autism in girls, amongst the very professionals who are the gatekeepers to onwards referral for assessment.

Many participants spoke about their GP dismissing their concerns and refusing to make an onwards referral for autism assessment, because she could make 'good eye contact' or she 'didn't seem autistic', therefore not appearing to fit their knowledge of autistic presentation. However, this raises the question of how much GPs know about autism in general, specifically autism in girls. Although a study of self-reported GP accounts around autism awareness by Unigwe et al. (2017) found that, despite a frequent lack of formal training in autism, many GPs felt themselves to have a good awareness of the key features of autism; the fact that making eye contact and not seeming autistic remained key indicators for the participants' GPs, suggests that there is clear lack of awareness of the female masking effect. Concurring with findings from a study into the perspectives of the parents of autistic girls (Chantrey, 2017), many participants were all too aware that something was wrong. However, the professionals, from school to medical to whom they turned for advice, were simply unaware of the female presentation of autism (Kanfiszer et al., 2017; Lai & Baron-Cohen, 2015). Consistent with the literature (Baldwin & Costley, 2016; Gould, 2017; Gould & Ashton-Smith, 2011), as a result of this lack of awareness of female autism, several participants said that their daughters were diagnosed with other mental health conditions, when these were in fact hiding the underlying diagnosis of autism.

Despite studies conducted almost a decade ago, that highlighted the importance for parents of being included as a 'co-expert' on their child, feeling heard with open and transparent communication (Braiden et al., 2010; Moh & Magiati, 2012), such research has clearly failed to be implemented in practice. Worryingly for the participants in this study, their experiences

more supported the outdated concept of the professional being the 'expert' in autism (De Clercq & Peeters, 2007). Indeed, several participants spoke of having to become experts on autism themselves, before having their concerns taken seriously. If autistic features are persistently viewed through the skewed lens created through years of male bias in autism research (Duvekot et al., 2017; Geelhand et al., 2019; Rynkiewicz et al., 2016), then girls with autism will remain underdiagnosed.

Most participants felt that their daughters' difficulties really started to outwardly manifest around the time of their transition to high school. Daisy and Simon both remarked that they felt that the issues were around their daughters' challenges with the increased demand at this age of social interaction. This is entirely consistent with current literature that suggests that although difficulties would likely have been present before this, it is the subtle shift in adolescent female communication around this age that necessitates more intricate and complex social competence; skills that are lacking for autistic girls and that lead to unbearable tension (Dean et al., 2017). However, although there is research around school refusal in autistic children, this predominantly focuses on bullying as the underlying reason, and crucially fails to address potential differences in the experiences of autistic girls (Bitsika et al., 2021; Ochi et al., 2020). Many participants, when faced with their daughter refusing to attend school, asked her if something was wrong at school, and she could give no reason. This perhaps implies a far more complex and layered landscape for these girls, where their struggles are not binary and simply cannot be put into words. Although difficulties with relational aggression for autistic girls have been researched (Cook et al., 2018; Sedgewick et al., 2018a), with Cook et al., finding that autistic girls have higher rates of absenteeism, there are no studies that look at the bigger picture as to *why* girls with autism struggle to attend school.

Faced with no clear reason for their daughter's behaviour and the subsequent challenges experienced, many participants looked within themselves for the answer, questioning their own parenting, and in some cases concluding that they must be to blame. This is consistent with the findings of two studies that explore a mother's experience of their daughter's autism (Anderson et al., 2020; Fowler & O'Connor, 2020). However, the two male participants, Simon and Thomas, both spoke about questioning their own parenting, highlighting the importance of including the experiences of fathers as well as mothers in autism research; an acknowledged imbalance (Burrell et al., 2017; Potter, 2017). Simon's questioning of how

they have ended up with a child who is *'effing and blinding and throwing things around'* mirrors the findings of Burrell et al. (2017), a study into father's experiences of autism parenting. Of note, for two participants, this sense of being at fault did not just come from within, but through the experience of finding themselves accused of harming their daughter. Although the literature acknowledges the fear of being accused (Fodstad et al., 2012; Nicholas et al., 2016), this does not appear to extend to the actual experience.

Consistent with the literature from studies into diagnosis within the UK (Crane et al., 2016; Crane et al., 2018), most participants encountered lengthy delays in waiting for an autism assessment. However, although these studies made no differentiation between males and females, the complex and convoluted road to diagnosis for most of the participants in this study corroborates the findings of Gould (2017) and Milner et al. (2019), who argue that the path to diagnosis is more tortuous yet for those with an atypical presentation such as females. The root cause of the delay described by most of the participants, aside from the acknowledged unacceptably long waiting lists in the UK (British Medical Association, 2020; Crane et al., 2019), would seem to be exacerbated by the underlying lack of knowledge of the presentation of female autism among professionals as suggested by Kanfiszer et al. (2017) and Milner et al. (2019). Faced with waiting list of up to two years, several participants opted to pay privately for an autism assessment. In all cases, this decision was brought about through parents witnessing the marked deterioration in their daughter's mental health while waiting for assessment.

Although the long-term impact on mental health through delayed autism diagnosis is highlighted in recent research (Crane et al., 2019; Rutherford et al., 2016), little would seem to change for autistic females. No matter how the challenges around the long waiting lists for autism assessment in the UK are addressed, unless the gatekeepers to referral both accept that females can be autistic, *and* are trained in the female presentation of autism, the dire situation outlined by most of the participants will remain unchanged. The situation is compounded further still by the use of diagnostic tools that remain set up to capture the more male-based presentation of autism (McFayden et al., 2020). This fear of her daughter's autistic traits being overlooked through ignorance of the female autism presentation, drove one participant to seek not just private assessment, but assessment by a professional who had a good awareness of this.

5.2.2 Negotiating systems

The general perspective from most of the participants was that autism was regarded as a predominantly male condition; a view considered to be held by both the public and professionals, from school staff to medical services. In part, this misconception persists due to the 'extreme male brain' theory proposed by Baron-Cohen (2002); a theory mentioned by Simon in his search for the origins of his daughter's behaviour. Although for Simon, this was helpful in that it took him down the route of recognising the strong genetic component to autism, it is a theory that has been widely disputed (Krahn & Fenton, 2012; Ridley, 2019) and one whose impact continues to overshadow the recognition of female autism. Interestingly, Simon was the only participant to express the importance of the potential genetic link, concurring with the assertion that this is an important aspect of a father's journey (Hannon & Hannon, 2017). From the participants' accounts, it is clear that despite research around the experiences of autistic females in the UK school setting (Cook et al., 2018; Goodall & MacKenzie, 2019; Moyse & Porter, 2015; Tomlinson et al., 2020), their parents and teachers (Halsall et al., 2021), and including one study that was delivered to additional learning needs staff (NASEN, 2016), there remains not just a lack of awareness that girls can be autistic, but more worryingly, how this might manifest.

As discussed in sections 5.2.1 / 5.5, this lack of knowledge of female autism is not just limited to school staff, but to medical and support services as well. Therefore, many participants spoke of finding themselves seeking support and advice for an unknown and invisible condition, embarking on a relentless and exhausting fight to be heard and understood. Although the participants' descriptions of battling and fighting for support are consistent with the literature (Bonis, 2016; Gill & Liamputtong, 2013; Nicholas et al., 2016), their experiences seemed to go further, causing them to feel absolutely desperate; a depth of despair that is not picked up on in the literature. It is likely that the description of autism as a condition that is invisible, yet extremely pervasive (Bonis, 2016; Gill & Liamputtong, 2013), making no differentiation between males and females, underplays the experiences of the parents of autistic girls; parents whose daughters are known to be adept at masking their autistic behaviours until behind closed doors at home. Indeed, several participants spoke of resorting to calling the police in the hope of bringing their family crises into the open, in their quest for support.

The participants' accounts of the constant battle for support and fighting systems are entirely consistent with the literature around the all-consuming impact of having an autistic child (Lloyd et al., 2019; Nicholas et al., 2016). Interestingly, one mother described herself as going in to 'warrior mother' mode; a description that closely aligns to that of 'battlefield fathers' (Burrell et al., 2017), with the constant fight against systems that are stacked against them. Although there is very little research around the experiences of the parents of autistic girls, the findings of Fowler & O'Connor (2020), and to a lesser extent Anderson et al. (2020), concur with those of this study, suggesting that the parents' fight for recognition of their daughter's diagnosis is simply replaced by the fight for appropriate support and school placement.

As discussed in section 5.2.1, the struggles of autistic girls often begin to outwardly manifest around the transition to high school. It is likely that the school environment has a large part to play in this. Most participants spoke of their daughter being unable to articulate their reasons for finding school unbearable, consistent with the findings of Rodgers et al. (2016), who suggested that unlike NT children, the anxiety around school for autistic children is more complex and multifaceted. Concurring with the literature around the 'invisibility' of adolescent autistic girls within the classroom (Halsall et al., 2021; Hendrickx, 2015; Hiller et al., 2014), parents spoke of their daughter being regarded as a model pupil, hard-working and conscientious, with no externalised behaviours to bring them to the attention of school staff. However, it is likely that there is no one single cause of their difficulties, with participants alluding to a combination of a lack of understanding of their support needs by teachers, an inappropriate sensory environment, and a rigid and inflexible approach to their inclusion both within the classroom, and during unstructured time, concurring with studies by Sproston et al. (2017) and Goodall & MacKenzie (2019).

Consistent with research by Sproston et al. (2017), many participants highlighted the battles faced in searching for and securing an appropriate school for their autistic daughter, citing the need for everything to be suggested or instigated by themselves. They spoke of the positive difference that finding the right school setting made, although in most cases this was not within the mainstream education system, but specialist schools, and in some cases a PRU (Pupil Referral Unit). However, in several cases this was not without problems, as they were again found to be more geared towards managing the more externalised autistic behaviours of boys (Duvekot et al., 2017). Although their study focuses on school exclusion for autistic

girls, rather than refusal, Sproston et al. (2017) discussed the helpful 'experience' driven curriculum in PRUs and special schools for autistic girls, rather than one that strives for academic excellence.

Several participants felt that the pressure placed by teachers on their clearly bright daughters, had a large part to play in her breakdown and subsequent inability to attend school. Likewise, the positive difference to their daughter through finding the right school was noted. Also in this context, parents felt that schools did not differentiate between the needs of their autistic daughter and those of a typically developing child, placing the bar too high, and setting her up to fail, entirely consistent with the findings of Sproston et al. (2017). Concurring with a study by May et al. (2016), parents spoke about the adverse impact on their daughter of being misunderstood by teachers as being detrimental to her mental well-being, with several parents, suggesting that this had a knock-on effect on their own mental health (Section 5.2.3).

Several participants either had a son or nephew with autism, and their impression of the readiness with which support was offered, and did not need to be fought for, perhaps underlines the pervasive lack of awareness of autism in girls. However, the literature, although not distinguishing between males and female, overwhelmingly paints a bleak picture that although many parents hope that a diagnosis will lead to support, this is rarely the case (Crane et al., 2016; Crane et al., 2018; Legge & Tickle, 2019). The participants' experiences are undoubtably consistent with the literature; however, given their experiences of the relative ease with which boys seem to be offered support, it is likely that girls are yet further disadvantaged by the underlying lack of awareness of female autism. In contrast to the findings in these studies, the limited research that explores mothers' experiences of their autistic daughters (Anderson et al., 2020; Fowler & O'Connor, 2020) found that post-diagnosis support was quite readily accessed. However, consistent with the experiences of participants who *did* manage to access support, these studies found that even though support was offered, it was felt to be geared towards the needs of autistic boys; perhaps echoing the adolescent equivalent of the male bias in adult autism support (Tint & Weiss, 2018).

Many participants spoke about the advice they as parents received, and the support offered to their daughter as being not just inappropriate but actually harmful. There is a dearth of literature around the negative impact on autistic girls and their parents, of inappropriate therapy, with only the anecdotal reports of late-diagnosed autistic women describing how

misunderstood they felt when those trying to 'help' inadvertently made their problems worse (Bargiela et al., 2016; Kanfiszer et al., 2017). Simon said that the advice given to him was based on 'assertive parenting', which he felt focused on confronting behaviours in a very demand led and assertive manner more suited to the externalising behaviour of autistic boys. In hindsight, he recognised that this was the opposite of the low-demand approach needed for autistic girls who are likely to be demand avoidant (Fidler, 2019), likening this to 'pouring petrol on the flames'. As long as the difficulties faced by autistic girls are viewed through a male-biased lens, then the advice given to parents is likely to be based upon the more externalised behaviours typical of autistic boys (Hiller et al., 2014; May et al., 2016), not the internalised difficulties of girls (Oswald et al., 2016; Solomon et al., 2012).

Although social impairment is a recognised deficit for autistic individuals, the majority of social skills research and school-based intervention is still modelled around the needs of autistic males (Jamison & Schuttler, 2017). Evidenced by the accounts of several participants, the support that their daughters were offered not only missed their female-specific social communication challenges but left them feeling misunderstood and unheard. These girls already inhabit a world where they are aware of feeling like social misfits (Bargiela et al., 2016). The experiences related by several participants of their daughter being misunderstood by the very professionals who should support them, was felt to leave her with a deep sense of frustration that she found hard to place, only serving to add to her sense of isolation.

It was also clear from the participants' accounts that the challenges in obtaining post-diagnostic support for their daughter extended to the whole family. There is an abundance of literature that highlights the intense stress that an autistic child places on not just parents, but the functioning of the family unit (Hayes & Watson, 2013; Lai et al., 2015b; Nicholas et al., 2016; Sukmak & Sangsuk, 2018), yet little changes in the real world of these parents. Moreover, these studies make no differentiation between autistic boys and girls, and given the under-representation of girls in autism research (Geelhand et al., 2019; Rynkiewicz et al., 2016), and the invisible daily struggles that both they and their families encounter, it is likely that such studies will fail to reflect the all-consuming stress faced by the families of autistic girls.

5.2.3 Psychological impact

There is an abundance of literature around the adverse psychological impact on parents of raising an autistic child (Argumedes et al., 2018; Bozkurt et al., 2019; Factor et al., 2018). However, there are very few studies that explore this impact on the parents of autistic girls, with those that do exploring the experiences of mothers, not fathers (Anderson et al., 2020; Fowler & O'Connor, 2020).

Feelings of loneliness and isolation among the parents of autistic children are widely recognised (Lloyd et al., 2019; Nicholas et al., 2016). As alluded to by several parents in this study, this frequently emanates from a fear of public criticism (Nicholas et al., 2016), leading to parents imposing isolation on themselves. Concurring with the findings of Kinnear et al. (2016), several participants expressed feelings of isolation, not only self-imposed, but also finding themselves excluded from events with family and friends. It is clear from the participants' sense that people 'just don't get it', that their experiences are consistent with studies that allude to an underlying ignorance of the challenges of parenting an autistic child (Ekas et al., 2016; Griffiths, 2017). Consistent with a study by Iadarola et al. (2019), several parents spoke of preferring not to burden their friends; one describing herself as 'sounding like a broken record'. Sally's sense of isolation within her marriage, describing her husband as 'burying his head in the sand' perhaps reflects the multifactorial coping styles of parents with an autistic child (Lai et al., 2015b), with different coping mechanisms employed by mothers and fathers (Dabrowska & Pisula, 2010). It also underlines the impact on parental relationships (Aylaz et al., 2012; Harper et al., 2013; Hill-Chapman et al., 2013), where different approaches to discipline can have an adverse impact on the parental partnership (Zablotsky et al., 2013b).

In concurrence with the literature (Gill & Liamputtong, 2013; Harandi & Fischbach, 2016; Kinnear et al., 2016; Tilahun et al., 2016), many participants felt unfairly judged by both professionals and friends over their daughter's behaviour and how they managed this. However, their experiences were subtly different from studies around parents' experience of stigma and judgement over public meltdowns (Iadarola et al., 2019; Lloyd et al., 2019; Neely-Barnes et al., 2011). Due to the ability of autistic girls to mask their behaviours in public (Anderson et al., 2020; Hull et al., 2017), meltdowns were frequently only witnessed behind closed doors, so judgement was often felt to come from within their inner circle of

friends and family. Consistent with the literature (Bonis, 2016; Ekas et al., 2016; Griffith et al., 2012), for several participants, judgement from the very people to whom they might turn for support, was felt particularly keenly, only serving to enhance their sense of isolation.

Although as discussed in section 5.2.1, there is a substantial body of literature that acknowledges the frustratingly complex and lengthy journey to diagnosis, these studies overwhelmingly understate the sense of powerlessness expressed by the participants in this study. For the participants who felt disempowered, this was mainly felt to stem from finding themselves under suspicion of causing their daughter's behaviour, with an implicit sense of not being believed. Intense anger was expressed by two participants, who felt that their integrity was doubted, adding to their sense of impotence. This experience of not just being disbelieved but rather accused had a deep and lasting impact on the parents, and this is simply not captured by the descriptions of frustration with a general lack of autism awareness (Carlsson et al., 2016; Crane et al., 2018). There is a far more sinister sense of powerlessness in the face of accusation, with the inherent ultimate threat that contrasts starkly with the parents' very reason for seeking support: their concerns over the well-being of their child. The feeling of vulnerability and dependence on outside agencies expressed by several participants only enhances this sense of worthlessness and impotence; an experience that is not picked up on in the literature.

The sense of guilt expressed by participants stemmed from several different aspects of their experience. Research around the guilt felt by the parents of autistic children is predominantly focused on mothers (Courcy & des Rivières, 2017; Lopez et al., 2018; Sousa, 2011), with many references to the outdated concept of the 'refrigerator mother' as the cause of autism in their child (Bettelheim, 1967). Concurring with this literature, many parents spoke of feeling guilty that they could have done more or were doing too much. Similarly, some participants talked of feeling guilty when they complained about their situation, with several feeling the need to add that it 'could be worse', consistent with the findings of a study by Courcy & des Rivières (2017). Corresponding to research by Herlihy et al. (2015), the participants who expressed a retrospective sense of guilt at not recognising their daughter's autism were either the parent of an only child, the autistic child was their oldest child, or their other children were male. Another significant cause of guilt was in looking back at how they had managed their situation when they had no knowledge of autism. Although, perhaps skewed by the under-representation of fathers in autism research (Potter, 2017), the few studies that

highlight the father's guilt around responding inappropriately, thus making the situation worse (Burrell et al., 2017), are echoed by both Simon and Thomas in their sense of wishing they had acted differently.

Although Daisy's account of the fear that she felt, in trying to keep her suicidal daughter alive, superficially concurs with research on parental sentiments around self-injury in autistic individuals (Celia et al., 2020), there is a visceral intensity in the depth of her fear that is not captured here, or elsewhere in the literature. Both Daisy and Julia were themselves driven to consider suicide in the depths of their despair. Despite research suggesting that the incidence of suicidal behaviour in autistic adolescents is twenty-eight fold over their neurotypical peers, (Stewart et al., 2017), with a significant increase in self-harm (Hosozawa et al., 2020), these studies fail to recognise the psychological impact on parents. While suicidality in autistic youth is well researched (Howe et al., 2020; Storch et al., 2013), and there is an acknowledged adverse impact on parent mental health (particularly mothers) of parenting an autistic child (Bonis, 2016; Falk et al., 2014), there is only one study around suicidality in the parents of autistic children (Jahan et al., 2020). This highlights not only the ongoing lack of support for the parents of autistic children, despite many studies alluding to the need, but in the case of this study's participants, the exacerbation of this lack of support by a sense of their experiences and needs being invisible.

Several participants spoke of their trauma, and although a common thread, there were different reasons behind this. The multi-factorial nature of the participants' traumatic experiences, induced by parenting their autistic daughter, is accurately captured in the literature (Schnabel et al., 2020; Stewart et al., 2017; Zhang et al., 2015). These studies build upon previous similar findings (Hayes & Watson, 2013; Lai & Oei, 2014), and although none of these studies differentiated according to the child's gender, little appears to have changed from these findings. Given the invisibility of their daughter's autism outside the home, it is likely that the trauma experienced by the participants is greater still; exacerbated by their sense that they are totally alone in their unique situation (Section 5.2.5).

Several mothers talked about the impact on their mental and physical health. Interestingly, this was not mentioned by the two fathers in the study. Although many studies suggest an adverse impact on parental mental health (Bonis, 2016; Hayes & Watson, 2013; Lai et al., 2015b), these do not differentiate between fathers and mothers. The findings of this study

concur with the literature around the adverse impact on maternal mental health (Gill & Liamputtong, 2013; Karp & Kuo, 2015; McAuliffe et al., 2019; Nicholas et al., 2016). Consistent with the literature (Estes et al., 2013; Jones et al., 2013; Ozturk et al., 2014), it was only the mothers who spoke of seeking support for their mental health. However, the two fathers in the study, although not alluding to poor mental health, both expressed a deep sense of frustration, focused on their daughter's behaviour; a finding that concurs with the suggestion that fathers do experience elevated levels of stress, but it is more based on their child's behaviour (Ooi et al., 2016; Paynter et al., 2018).

Consistent with the literature (Altiere & Von Kluge, 2009; Nicholas et al., 2016), several participants, when reflecting on the ongoing support that their daughter is likely to need, expressed feelings of jealousy towards the parents of NT children. At a time when most parents are both envisioning the freedom that their children leaving home will bring, and their pride at witnessing them forge their independent identity in the world, there was a sense of sadness, yet a reluctant acceptance, that their daughter was likely to need their support for many years to come. This in turn led several participants to express a nagging concern about the future, and who might advocate for her when they were no longer around; a finding that concurs widely with the literature (Karp & Kuo, 2015; Nicholas et al., 2016; Potter, 2017).

5.2.4 Living with an autistic daughter

Although Adams et al. (2020) recognise that separation anxiety has an impact on parents, their study fails to capture the intense sense of feeling, expressed by several participants, of being trapped by their daughter's anxiety. In this study, the feeling was only expressed by the mothers, and interestingly, one participant reflected that she resented the fact that for no obvious reason, her daughter, although close to her father, only refused to be separated from her. It is likely that this intense attachment stems from the mother, in all cases becoming the primary carer, either leaving or adapting their work, in order to provide the extra care needed to support their daughter, as suggested in the literature (Cridland et al., 2014; Lutz et al., 2012; Nicholas et al., 2016). Although several participants spoke about the impact of their daughter's over-dependence on them, rather than simply acknowledging this, as was the case with the mothers, Thomas described this as a 'challenge', reflecting the importance alluded to by Burrell et al. (2017), that their child learning independent skills would seem to be afforded a higher priority by fathers over mothers.

Challenging behaviours in autistic children are well researched and acknowledged to represent a significant stressor for parents (Bonis, 2016; Craig et al., 2016; O'Nions et al., 2018). Tensions within the home were mentioned by several participants, as they tried to manage their daughter's volatile moods, likening this to constantly 'walking on eggshells'; a description used in several studies around living with an autistic child (Bekhet & Matel-Anderson, 2017; Schnabel et al., 2020). Although not inherent, outright violence is nonetheless recognised as being *an* aspect of autism (Del Pozzo et al., 2018; Hodgetts et al., 2013). However, as such studies either exclusively research autistic males, or make no differentiation in gender, it is likely that the violence noted is an extension of the tendency for autistic males to externalise their symptoms (Duvekot et al., 2017). Therefore, the paucity of literature that might concur with the participants' experiences of, in some cases, extreme violence towards them and their other children, is likely to stem from the overall bias in autism research against females. Additionally, given that autistic behaviours in females are most often experienced by their families behind closed doors, it is possible that the self-blame that parents feel when unable to manage their child's challenging behaviour (Lai et al., 2015b), plays a role in this under researched area.

Although the literature suggests a strong link between gender variance and autism in general (Strang et al., 2014; van der Miesen et al., 2018), with a predominance in autistic females over autistic males (Cooper et al., 2018), this was only mentioned fleetingly by two participants. It is possible that while the literature focuses on the significance of gender identity for the autistic individuals themselves, it is perhaps of less significance to parents. Certainly, in this study, one participant only mentioned it when she found herself correcting the pronouns that she was using, whilst the other dismissed this as just another 'phase' that her daughter was going through; there was no sense of wishing to further expand on this area. One of the few studies into parental response to their autistic child's gender variance (Kuvalanka et al., 2018), although not differentiating between girls and boys, found that parents' main concerns were around bullying and standing out. It is possible that the parents in this study had already been through these experiences, as their journeys to this point had been fraught with challenges of this nature; they were 'battle weary' (Celia et al., 2020).

Insomnia is common in autistic children (Kirkpatrick et al., 2019). Consistent with the literature (Fewster & Gurayah, 2015; Malow et al., 2014; Veatch et al., 2015) several participants spoke of the chronic fatigue resulting from their daughter's insomnia. However,

although many studies focus on the stress that this places on parent relationships, this was not touched upon by the participants (only mothers) who discussed sleep. They all spoke of a weary acceptance that insomnia was just part of the autism package.

Except for Sally, all the participants had more than one child. Having to consider the needs of the siblings, the parents found themselves facing complex dilemmas that impacted both upon the functioning of the family unit (Boyd et al., 2014) and added to their sense of guilt (Lloyd et al., 2019) (Section 5.2.3). Consistent with the findings of Yacoub et al. (2018), three participants spoke of fearing for their other child's safety faced with their autistic daughter's violence. Similarly, their expression of feeling torn between the needs of their other children and those of their daughter, is accurately captured in literature around the impact of autism on siblings (Bonis, 2016; Lovell & Wetherell, 2016; Ward et al., 2016a). Interestingly, both fathers in this study spoke about their frustration over the impact of their autistic daughter's needs on family activities, echoing the literature around fathers' experiences of autism parenting (Paynter et al., 2018). Although the mothers in this study reflected negatively on the impact of autism on the daily life of their other children, unlike the two fathers, they did not talk about the limitations imposed on family functioning. The different way that mothers and fathers respond to the impact of the autistic daughter on her siblings seems to correlate to research by Jones et al. (2013) into gender-specific coping styles of parents of an autistic child.

Informal social support from family is regarded as having a positive impact on the quality of life for autism parents (Goedeke et al., 2019; Marsack-Topolewski & Church, 2019; Pepperell et al., 2018). However, for the participants in this study, those that spoke about this had mixed experiences of having that support. Becky and Daisy deeply valued the unconditional support offered by their own parents, whereas for Sally, she felt hurt and abandoned by her parents, with any early support withdrawn. It is not possible to know how much of this difference in experience was attributable to existing relational dynamics, but it was clear that when given, informal family support was not just helpful, but in the case of Becky, essential in maintaining the functioning of her family unit. It is likely that another reason for the different experiences is that of an acceptance and understanding of autism by those offering the support (Pepperell et al., 2018).

The literature suggests that mothers typically have to change or end their career to meet the care and support needs of their autistic daughter (Bonis, 2016; Jones et al., 2013; Lutz et al., 2012). Although several participants (all mothers) did have to stop or adapt their work, it was not clear from the two fathers whether this was the case for their partners. Certainly, several mothers gave varying reasons why their daughter's autism impacted their career, and in some cases, these were consistent with this literature. However, most studies tend to focus on the extra daily needs that arise from parenting an autistic child, and although clearly relevant, they do not address the experiences of some of the participants in this study who had to stop work simply to keep their daughters safe and alive. Although there are multiple studies demonstrating that autistic adolescents are at a considerably higher risk of self-harm or suicide (Hannon & Taylor, 2013; Howe et al., 2020; Liu et al., 2019; Oliphant et al., 2020), there is no distinction made according to gender. However, a recent study by So et al. (2021) suggested that autistic girls *were* at a much higher risk of significant self-harm or suicide. Therefore, although there are studies that recognise the negative impact on parent carers of child self-harm, (not specifically autism-related) (Curtis et al., 2018; Ferrey et al., 2016), the paucity of literature around the experiences of the participants in this study further highlights the persistent male bias in autism research (Geelhand et al., 2019; Kreiser & White, 2014).

One disturbing impact of the general ignorance of autism in females, perpetuated by this male bias in research, was highlighted by the situation in which Becky found herself, when rather than being supported, she found herself accused of hurting her children (Section 5.2.3), so they were placed on the 'at-risk' register. This was incompatible with her career as a teacher, so she was forced to abandon the career that represented the essence of who she was. Although the limited research into mothers' experiences of parenting an autistic daughter clearly highlights the impact on her career through the demands of having to meet her daughter's needs (Anderson et al., 2020; Fowler & O'Connor, 2020), these simply fail to capture the shattering experience of having your career 'taken from under your feet'. However, several parents, including Becky, used their necessitated career change to positive effect, and this is discussed in section 5.2.5.

Although the literature on parents' experiences of their child's self-harm (Hughes et al., 2017; Stewart et al., 2018; Whitlock et al., 2018) generally concurs with the participants' need to make sense of their situation, it makes little, if any, reference to a parent's acceptance of such behaviours necessitating the aiding of their child's self-injury, as described by Daisy.

It is likely that the impetus for adolescent autistic females to self-harm, is too complex for the generalised literature around this area. Daisy was so closely attuned to her daughter's needs that not only was she required to learn to accept her daughter's self-harm, but she also recognised that at times, although deeply traumatic (Section 5.2.3), she needed to actively facilitate this through adopting a positive risk-taking approach, as discussed by Stewart et al. (2018).

While masking is well researched and acknowledged as being a key feature of female autism (Hull et al., 2017; Tierney et al., 2016; Willey, 2014), most participants only realised in hindsight that this was what their daughter had been doing. Consistent with the literature (Bargiela et al., 2016), several felt that this was the reason that no one outside their immediate family recognised or believed the extreme challenges faced at home. The participants' impression of the emotional effort involved in masking and the consequences of the 'coke bottle effect' (described by Simon), are well documented (Cage & Troxell-Whitman, 2019; Gould & Ashton-Smith, 2011; Leedham et al., 2020b). However, mothers (not fathers) also spoke of having to knowingly mask their own feelings. They sensed that if they showed how they felt, then they were judged as being unstable. This is not reflected in the limited literature around maternal parenting of an autistic daughter, and perhaps highlights the fundamental difficulties faced by women being labelled as 'emotional', through gender bias in medical research (Samulowitz et al., 2018).

Consistent with the literature (Cappe et al., 2011; Dabrowska & Pisula, 2010), many participants, although still acknowledging that life was far from straightforward, had learnt how to employ positive coping mechanisms, although this was through 'learning on the job' rather than through external support. For some participants, it was by experiencing 'unhelpful help' given through such support (Section 5.2.2) that they had worked out what *not* to do, when trying to adapt their approach to create a supportive and calm home life. Concurring with Pepperell et al. (2018) both mothers and fathers spoke of using problem-focused strategies to pre-empt challenging behaviours and adapt family life around their daughter's needs. However, the 'new normal' that several participants described, although recognised to be better than at the outset, was spoken with tacit sense of reluctant acceptance rather than an outwards embracement, concurring with the findings of studies of both mothers and fathers (Burrell et al., 2017; Fowler & O'Connor, 2020; Nicholas et al., 2016).

5.2.5 Reflections

Studies around parental responses to their child receiving an autism diagnosis often result in mixed responses, and this was the case for the participants in this study. Consistent with the literature (Lloyd et al., 2019; Ooi et al., 2016), most parents felt relieved, regarding the diagnosis as giving a 'label' to the challenging behaviour, with an unspoken sense of absolution over the insinuation, whether external or internal, that their bad parenting was to blame (Anderson et al., 2020; DePape & Lindsay, 2015; Ooi et al., 2016). As described by Anderson et al. (2020), this was helpful in that viewing behaviour through the lens of autism brought a sense of renewed patience and understanding. Two participants spoke of their daughter using their diagnosis as a 'title', and the starting point for forging a new identity as an autistic female, as discussed by Bargiela et al. (2016).

Interestingly, echoing findings by Fowler & O'Connor (2020), one participant recognised her daughter's autistic traits within herself and her older daughter, and both went on to be diagnosed autistic. Although research suggests that autistic mothers are at an increased risk of developing their own mental health difficulties (Pohl et al., 2020), in this case, the participant expressed a sense of familial pride and affinity with her daughter, as suggested by Fowler & O'Connor (2020). Whilst not denying the clearly negative impact of autism on daily life, several participants were also keen that it should not be viewed as a problem; reflecting the changing views of the autism community (Kenny et al., 2016), that autism should be regarded as a difference rather than a disorder. Concurring with previous studies (Gill & Liamputtong, 2013; Karp & Kuo, 2015; Potter, 2017), several participants spoke of their concern around the implications of the diagnosis for her future needs, and a fear for who would support her when they were no longer alive (Section 5.2.3).

However, consistent with an abundance of studies, both in the UK (Chantrey, 2017; Crane et al., 2016; Crane et al., 2018; Potter, 2017), and abroad (Eggleston et al., 2019; Hannon & Hannon, 2017; Ho et al., 2014; Mitchell & Holdt, 2014), most participants spoke about their initial relief at diagnosis turning to deep frustration, when faced with the utter dearth of post-diagnostic support. This disappointment was felt particularly keenly, as all but one of the participants had faced not only lengthy waiting lists, but a huge battle even getting their daughter referred for assessment (Section 5.2.1), echoing the findings of the few studies

around mother's experiences of parenting autistic daughters (Anderson et al., 2020; Fowler & O'Connor, 2020).

Although for most participants diagnosis answered questions and resolved self-doubt, the impact of the overall delay in diagnosis was felt to have created many unnecessary obstacles, and in some cases, made things much worse. Frustrations with accessing a diagnosis are well documented in the literature (Section 5.2.1), however studies into the impact of this delay make no differentiation between girls and boys, therefore, given the predominance of male participants in autism research (Kreiser & White, 2014), it is likely that these do not reflect the intensity of the "if only…" sentiments for the participants in this study. Whilst the limited studies into maternal experiences of parenting an autistic daughter (Anderson et al., 2020; Fowler & O'Connor, 2020) acknowledge the lengthy and frustrating diagnostic process, they do not address the impact of this delay. In this study, it was the two fathers who spoke most about their frustration, yet not only are fathers frequently under-represented in general autism research (Burrell et al., 2017; Potter, 2017), they would appear to be excluded in research specifically around parenting an autistic daughter. This is perhaps better answered by the different process that fathers undergo on their journey to acceptance (Burrell et al., 2017).

Much of the research into the impact of a delayed diagnosis for autistic females is anecdotal and is reported by women diagnosed in late adolescence and early adulthood (Baldwin & Costley, 2016; Bargiela et al., 2016; Cridland et al., 2014). Although relayed by parents, not the girls themselves, the participants' retrospective reflections on situations that they naively imposed on their daughter, mirrors those of the autistic girls in the literature, particularly around their unmet needs in school (Bargiela et al., 2016). Because her difficulties within the school environment were expertly masked (Section 5.2.4), and were therefore unseen by teachers, participants spoke of using what they now see as not just unhelpful, but harmful tactics to manage her refusal to attend school. The sadness and regret expressed by the participants around their hindsight is not captured by the literature, yet further underlines the pervasive consequences of the fundamental lack of awareness of autism in girls.

The multidimensional sense of loss and grief expressed by many participants is consistent with the literature that explores parents' feelings about an autism diagnosis (Altiere & Von Kluge, 2009; Fernańdez-Alcántara et al., 2016; Mulligan et al., 2012; Navot et al., 2017). Although not likening his feelings of grief to a death, one participant nonetheless described

his sense of grieving for the loss of the life she could have had, supporting the notion of the 'loss' of a once healthy child (Burrell et al., 2017; Fernańdez-Alcántara et al., 2016; Mitchell & Holdt, 2014). Some parents spoke of the loss of their hopes and dreams for their daughter's future, consistent with previous research (DePape & Lindsay, 2015; Hock et al., 2012; Karp & Kuo, 2015). Whilst not blaming herself for causing her daughter's autism through something she did in pregnancy (Fernańdez-Alcántara et al., 2016; Lutz et al., 2012), throughout her interview, Sally spoke of feeling guilty that in some way her daughter's autism was her fault. She was a first (and only) time mother, and her sentiments more reflect the findings of Herlihy et al. (2015), where first time mothers are often particularly negatively affected by feelings of guilt, forming part of the grieving process on the path to acceptance. Absent from the literature, the intense sadness that she articulated around her shattered dreams of motherhood were captured by her words…' I don't enjoy being a mum at all, it's too hard'.

Whilst studies into both fathers and mothers suggest that acceptance is the end point of this grief process (Altiere & Von Kluge, 2009; Burrell et al., 2017), for several participants in this study, their sense of ongoing sadness, hopelessness and guilt suggests that their journey was more complex than those reported in the literature. Although undoubtedly having clear parallels with the feelings of loss and grief expressed by other parents of children with autism, the unresolved depth to some participants' experiences further highlights the difference in the lived experiences of the parents of autistic girls and boys, and the challenges perpetuated by the lack of research around female autism.

Whilst feelings of loss and grief around a child's autism diagnosis are widely researched, the loss of reputation outlined by two participants is not captured by the literature. The impact of being falsely accused of harming their children was deeply pernicious and encompassed not only their sense of impotence and powerlessness (Section 5.2.3), but a loss of reputation that could never be recovered. They were accused because the very professionals they approached to help them failed to recognise that their daughter's behaviours were caused by her autism. This further supports the pervasive and prejudicial impact of the lack of awareness of female autism (Section 5.2.1) that is driven by the exclusion of females in autism research (Geelhand et al., 2019; Kreiser & White, 2014).

Consistent with the literature around the sense of feeling judged (Section 5.2.3) (Gill & Liamputtong, 2013; Iadarola et al., 2019; Lloyd et al., 2019), several participants spoke of needing to walk in their shoes to truly understand their journey. In describing the isolation felt on this journey, some parents spoke of the relief at discovering that they were not alone, and as reported in the literature (Lai et al., 2015b), conveyed a sense of solidarity with other parents of autistic children. Burrell et al. (2017) suggest that fathers often feel like 'after thoughts' in their social support needs, and although Simon did refer to being put in touch with other parents, this was felt to represent professionals moving him on after diagnosis, rather than being something he sought out and valued. It is likely that Simon's experience of inappropriate support concurs with the suggestion that a 'one size fits all' approach to parent support is unhelpful (Clifford & Minnes, 2013).

Although Pepperell et al. (2018) found that mothers and fathers were comparable in their use of social media for support, with studies suggesting that fathers highly value talking to other fathers (Burrell et al., 2017; Paynter et al., 2018), in this study, it was three mothers who spoke about the transformative impact of finding social media support groups for the parents of autistic girls. This supports the suggestion that mothers and fathers use different coping strategies (Meléndez et al., 2012; Pozo et al., 2014), and seek social support from different sources (Lloyd et al., 2019). However, given that the participants for this study, including two fathers, were recruited through one such Facebook group, it is likely that, whilst not discussed, fathers also use social media as a means of support, although perhaps for a subtly different purpose. It is also possible that social media support groups are more targeted towards supporting mothers than fathers (Abel et al., 2019). The vital role of social media suggested by these participants, concurs with the literature around the use of such groups as a source of accessible and non-judgemental support (Ammari et al., 2014; Ammari & Schoenebeck, 2015; Cadwgan & Goodwin, 2018), and more specifically around the needs of the parents of autistic children (Cole et al., 2017; Reinke & Solheim, 2015). Consistent with a study by DeHoff et al. (2016), such support was also felt to empower the parents in seeking further help for their daughter.

Whilst many findings from this study paint a somewhat negative picture, although not a path they would have chosen, several participants reflected on their sense of personal growth. In some cases, an enforced change of career (Section 5.2.4) led mothers (not fathers) towards a new career that was inspired by their experiences. Consistent with studies around personal

growth in maternal autism parenting (Fowler & O'Connor, 2020; Markoulakis et al., 2012), these mothers spoke of rebuilding their lives, with new careers forged from their experiences. One became an advocate for autistic girls in mental health services, and two others set up, or became involved in, charities supporting the parents of autistic children. Concurring with findings by Fowler & O'Connor (2020), they spoke of the importance of doing this not just for themselves, but crucially to empower their daughters and other young autistic girls. Neither of the fathers in the study spoke of a significant impact on their career, perhaps supporting the notion that fathers identify as the main breadwinner (Paynter et al., 2018), and it is mothers who have to give up work to care for their autistic child (McAuliffe et al., 2019; Nicholas et al., 2016).

For most participants, there was a sense of having arrived at a point where although far from perfect, life had become less stressful with their increasing knowledge and experience. Consistent with the literature (Cridland et al., 2014; DePape & Lindsay, 2015; Lloyd et al., 2019), these parents felt that the diagnosis brought with it increased understanding and patience. In one case, having found herself contemplating suicide in her darkest moments, one mother reflected not just on a deepening bond between herself and her daughter, but a shift that in knowing that she was doing all that she could, she reached a place of reconciliation with the struggles she had faced. This concurs with previous studies that have identified the acceptance of challenging autistic behaviours as a marker for parental personal growth (Altiere & Von Kluge, 2009; Jones et al., 2014).

Whilst not specifically asked in the interview, several participants felt driven to relate the importance of telling their story in taking part in this study, and although recognising that this might be upsetting, articulated a sense of duty to speak out where perhaps other parents were less able to do so. Although the literature accurately refers to autism parents as 'embattled' and fighting unhelpful systems (Burrell et al., 2017; DePape & Lindsay, 2015; Lloyd et al., 2019; Nicholas et al., 2016), it fails to capture the sense expressed by the participants that their fight is for *all* parents of autistic girls. Whilst these participants had undoubtably felt compelled to educate themselves in order to advocate for their daughter (Boshoff et al., 2016; Boshoff et al., 2018), the literature does not extend to the drive to advocate for other parents too. This highlights the unique battle that they have fought, and the intensely lonely path that they have trodden, implying a deep need for social justice for those who, unlike the self-

selecting participants, are not able to speak out; a drive to empower not just autistic girls, but their parents too.

5.3 Original contribution to research

This study makes several original contributions to the field of research around the lived experiences of the parents of autistic daughters.

- Explores the lived experiences of mothers and fathers of autistic daughters in the UK
- Highlights significant deficits in the UK mental health services for autistic girls both pre- and post-diagnosis
- Focuses on the need for the provision of female-specific advice and support for parents of autistic girls
- Discusses the impact of parenting an autistic daughter on parent mental health
- Enabled through the insider position of the researcher, a focus on a depth and intensity of lived experience that has not been captured in the few studies to date in this area of research

However, the original contribution of this study is more extensive than these headlines and sits in the application of the research across different parameters. These will be discussed in turn.

5.4 Implications for further research

Revisiting the literature review, there are both quantitative and qualitative methods used in research around autistic girls. In using IPA, this study supplements these findings. As has been discussed (Section 3.2) there is value in looking at parent experiences through the lens of discourse analysis. Diagnosis and the experiences pre and post are not free from social and political injustice.

The need for better understanding of the presentation of autism in girls, and support for their families, is highlighted in this study. Although a growing awareness of the importance of research around autism in girls is evidenced by the ongoing increase in such studies, the lived experiences of their parents remain woefully disregarded. There are a handful of studies into maternal experiences of parenting an autistic daughter (Anderson et al., 2020; Fowler &

O'Connor, 2020; Navot et al., 2017), although as far as can be ascertained, at the time of writing, there are no studies that include the fathers of autistic girls.

In this study, the differences in the lived experiences of mothers and fathers, although in some aspects subtly different, were not remarkable. However, given the under-representation of fathers in autism research, future research might explore the lived experiences of the fathers of autistic daughters. Mothers outnumber fathers in autism research by 8:1 (Potter, 2017), yet the ratio of mothers to fathers in this study, where participants self-selected, is reduced to 3:1, suggesting that fathers too have a need to talk about their experiences. Fathers of autistic children often feel disregarded and an after-thought in the diagnostic process (Burrell et al., 2017; Potter, 2017), yet very few studies explore their experiences of parenting. Therefore, any support needs that are identified through research focus on the needs of mothers, and as evidenced in this study, in certain aspects these are different from fathers. Research should therefore focus not only on the specific support needs of fathers of autistic children, but within that the needs of fathers of autistic daughters. Moreover, given the level of interest in participating in this small-scale study (Section 3.5), and the dearth of literature, there is a clear need for further research into the lived experiences of the parents of autistic girls.

5.5 Implications for professionals

The findings from this study suggests that autistic girls and their families are failed on every level, from the moment parents express their concerns, through the diagnostic process, to accessing the appropriate provision both in education and support in their home life. Although some of the aspects of seeking support are not unique to the parents of autistic girls, the pervasive lack of awareness of the presentation of autism in girls, driven by the under-representation of girls in autism research simply maintains the momentum of a vicious cycle. This cycle then feeds into the parents' lived experiences with their autistic daughter.

5.5.1 Medical practitioners

At a training level, the different presentation of autism in girls from the recognised male presentation needs to be disseminated, so that all involved, from mental health services to GPs, are fully aware of this gender difference. It is evident from the participants' accounts

that when they approached their GP, most parents found their concerns dismissed, because their daughter did not fit the more widely recognised male-based signs of autism. Whilst GPs largely regard themselves as having a good awareness of autism presentation (Unigwe et al., 2017), a more recent review uncovered significant obstacles to aiding better autism awareness (Coughlan et al., 2020), although most GPs conceded that autism training should form not just part of their basic training but be enhanced through CPD programmes.

It is clear that knowledge around autism is mixed with a worrying number of GPs thinking that autism is always accompanied by learning disability (Altay, 2019), and a survey of UK GPs finding that 6% thought that autistic individuals could not talk (Unigwe et al., 2017). Suggestions that the criteria for autism assessment should be widened have been discussed (Fenikilé et al., 2015), however, this also highlighted GPs' concerns around over-diagnosis. Given the worrying findings of Unigwe et al. (2017), not only should medical training include far more awareness of autism in general, but more specifically, autism gender differences within that training. However, although the recent systematic review of the literature around GPs' autism awareness (Coughlan et al., 2020) raised salient issues for autism training, they failed to uncover any studies that discussed gender difference in autism awareness. The suggestion that UK GPs are already struggling with an excessive workload (Baird et al., 2016), whilst undoubtedly likely, does not absolve them from their duty to the autistic community to equip themselves with not only in-depth but up-to-date awareness of autism. However, it is imperative that such training underlines the gender differences in autism presentation.

It is evident from the participants' accounts that even when eventually referred to, and seen by mental health services, including CAMHS, clinical psychologists, and psychiatrists, in many cases they were diagnosed with other mental health conditions and their autism was missed. From professional experience, this finding was not surprising, and underlines a systemic male bias and what appears to be a real reluctance to even consider autism in females. Girls are referred time and again for anxiety, eating disorders, self-harm, and other issues yet, in part due to the pressures on under-resourced and overloaded systems, the lack of continuity in her care means that any insights that one practitioner might have, are lost with frequent staff changes. Adolescent mental health services need increased funding to help to reduce what are accepted within the profession to be unacceptably long waiting lists (Rutherford et al., 2016), and to increase staffing levels so that young people can access

continuous and timely support. Moreover, the requirement to train all levels of professionals in the female-specific presentation of autism should be given the utmost priority when allocating funding and resources.

Studies into autism awareness in relevant health care professionals (psychologists, psychiatrists, paediatricians), elucidate concerning discrepancies around assessment and diagnostic procedures (Taylor et al., 2016; Ward et al., 2016b). Recent research into UK psychiatrists' own view of their autism awareness (Crane et al., 2019) largely found that they regarded themselves as having good knowledge, however, this increased further still if they had personal experience of autism. That personal insight *might* improve their knowledge suggests this to be lacking. Additionally, there is no mention of their skill at diagnosing those with an atypical presentation such as females. Clinicians also need to be aware of the female camouflaging effect (compensating for and masking their autistic characteristics) when using standard diagnostic tools (Mandy & Lai, 2017). Although still in its infancy, there are signs of the development of assessment tools that allow for this female camouflaging effect (Hull, et al., 2020a; Ormond et al., 2017) but as yet these are not used in practice.

5.5.1.1 Post-diagnostic support

There is a manifest lack of support for both the autistic girl and her family post-diagnosis. Unsupported parents are not well placed to support their autistic daughter. Having already negotiated a hazardous journey to her diagnosis, for medical professionals to consider this as the 'endpoint' is to disregard the heartbreak that parents have endured and leaves them feeling adrift and utterly lost as to where to turn. Although clearly not only an issue for the parents of girls (Legge & Tickle, 2019; Potter, 2017), the support needs around the receipt of a diagnosis that profoundly impacts on parents and families, not only around their sense of 'loss', but in how it alters their family dynamics, needs to be urgently addressed. Although written resources are usually handed out by way of support, there needs to be gender-specific information available for parents. Any support offered to the autistic girl must be tailored to her unique needs, as, evidenced by the participants' accounts, the wrong support (mainly set up to meet the needs of autistic boys), can do more harm than good.

5.5.2 School staff

Although the need for an appropriate school environment is discussed in section 5.2.2, school staff need to be educated in observing the autistic girl who is camouflaging her struggles and is flying under their radar (Halsall et al., 2021; NASEN, 2016). Whilst it is recognised that mainstream school places progressively more complex demands on autistic students (Brede et al., 2017), the hidden needs of autistic girls in the curriculum (Moyse & Porter, 2015) are disregarded. A recent review of trainee teacher autism awareness by Vincent & Ralston (2020) concluded that, in the same vein as GPs and psychiatrists, teacher awareness of autism was self-reported as being stronger through personal experience. This suggests that training programmes not only fall short in teaching autism awareness, but with no mention of the difference in male and female presentation, again fail to equip teachers with the essential knowledge needed to support the covert struggles of these often 'model pupils'.

Whilst from 2018, it has been compulsory for teacher training to include autism awareness (Sackville-Jones 2019), this only covers the basics and as is evident from the male bias in research, such training is likely to generalise, and overlook the specific presentation of autistic girls. Although a step in the right direction, training needs to be updated to educate teachers in the atypical female presentation, as with more skilful observation, these girls and their families might be saved from years of distress and heartache, were they referred for timelier assessment. Moreover, the female specific autism signs should be incorporated in qualified teacher CPD, ideally, given the precious commodity of time for many teachers (Ho et al., 2016), delivered through accessible e-learning.

5.5.3 Counselling services

School counsellors are often a first port of call for teaching staff, when experiencing what they regard to be problems for, as yet undiagnosed autistic girls, in attending school and coping with daily life. Although desirable, there is currently no requirement in the UK for counsellors to undergo further training to work in schools. Therefore, all counsellor training should incorporate not only awareness of neurodiversity, but also gender specific traits within this. This is essential in order that school counsellors can both recognise potential signs, such as high levels of anxiety and school refusal, and so consider referring her for assessment, and to enable them to understand and accommodate her needs within the counselling room.

It was evident from participants' accounts that it was of paramount importance to their daughter that the person offering her support 'got' her autism, so she did not need to explain it. The managers of counselling services need to understand the difference in female autism from the general male-based view. She might struggle to convey her feelings as she camouflages her struggles, and in a time-limited service, might need more sessions to build trust with her therapist. The counselling environment may need to be adapted to suit her sensory needs, and consideration given to different types of approach such as pet or play therapy. The siblings of autistic girls may also attend for therapy, as they might be impacted upon by their volatile home environment, along with parents who are less able to attend to their needs due to the increased demands on their time.

Counsellors working with the parents of autistic girls need to understand the trauma that their client might be experiencing behind closed doors. One participant likened this to domestic violence that she would never have tolerated from her spouse, yet she had no choice but to live in fear of the next violent outburst, although this was hidden from view for anyone outside the immediate family. These parents have often been disbelieved and even accused of harm, because of the fundamental lack of awareness of female autism. If counsellors have a greater awareness, then they will gain helpful insight into the tormented life their client might be living. Additionally, supervisors of counsellors need to be able to access specific training around female autism, in order that they can support supervisees who might be working either with an autistic girl, or her parents.

5.6 Implications for parents

All participants alluded, in some way, to a negative impact on their mental health and wellbeing, that highlights their need for support (Desmarais et al., 2018). There is little, if any, meaningful post-diagnostic support for autistic girls and less still for their families. However, this study established that parent-to-parent support through social media groups is an invaluable asset, both in sharing experiences and resources, and imbuing a sense of solidarity in the face of often overwhelming challenge. This sense of belonging can be invaluable in promoting parent knowledge and self-confidence in order that that they are empowered to persist in their quest for answers and eventual diagnosis.

Several participants had got involved in or set up their own charities to support parents of autistic children. There needs to be a greater awareness of these charities and groups, so that parents can be signposted to immediate and relevant support. Post-diagnostic literature should be available for the parents of autistic boys and girls, and not simply written as though the parent support needs are the same, and additionally should include information regarding parent support services at both national and local level.

5.7 Implications for autistic girls

This study highlights the need for autistic girls to be able to access appropriate resources to help them to understand and make sense of their feelings of being different. It is clear from some of the parent reports that their autistic daughters welcomed a reason for their difficulties and took pride in belonging to the autistic community. However, it was also evident that many of their struggles were caused by both the environment being hostile to their needs, and they themselves not being able to place their feelings of being different. An increased awareness of female autism, through channels that young people are likely to access, could empower these girls to speak out and voice their needs, rather than have to mask their struggles, with the ensuing impact on their own, and their families' lives. Autistic girls are clearly good at identifying their needs, although less good at conveying them to those around them. This can be achieved through social media campaigns, and web resources, that will not only catch the attention of autistic girls, but also the wider public, promoting the concept of autism as being a difference, not a disability.

5.8 Strengths and limitations

This study has several fundamental strengths. The participants were gathered through a non-clinical setting, from an under-researched cohort. Additionally, due to the required use of video interviewing, participants were introduced from a geographically diverse sample. The phenomenological approach used facilitated an in-depth and rich analysis of the lived experiences of this often-excluded population. The semi-structured interviews were conducted loosely with the emphasis on flexibility, to allow the participants' voices to be heard, enabling the data to emerge according to the information *they* judged to be important to them, rather than be dictated by predefined research questions.

However, there were limitations which need to be discussed. The sample was small and self-selecting, which although ensuring participant motivation, might have biased the findings towards those with more negative experiences. As the inclusion criterion for age of their daughter was within one year of 12-18 years old, the results cannot provide insight into those whose daughter's age falls outside this age range and remains undiagnosed. It also leaves the voices of the girls themselves unaired. Acknowledging the importance of transparency in qualitative research, the 'insider' position of the researcher was made known to the participants at the recruitment stage but may have had an impact on what was shared and how this was interpreted. This is discussed in the following reflexivity section, 6.2.

5.9 Summary

Although rarely focussing explicitly on the lives of the parents of autistic girls, much of the current literature does relate to some elements of the participants' experiences. However, what sets the findings apart from the extant literature (around the parents of both genders), is the sense of 'invisibility' to the parents' process. This permeates every stage of their lived experience and highlights the pervasive lack of awareness of autism in females.

In this chapter, the lived experiences of the parents of autistic daughters have been presented and compared with the limited available literature. This has identified significant gaps in the literature, and highlighted these, along with the implications for parents, professionals, autistic girls, and research. These have addressed the 'so what' question (Denscombe, 2010) in terms of the significance and purpose of this research.

5.10 Reflexive statement

Having related the findings of this study to the existing literature and discussed in depth the implications for all involved, I have become acutely aware of an absolute duty to the participants to publish these findings. It would be disingenuous to complete a study of this profoundness with findings of this significance, and not present these to the very professionals and policymakers who can formulate the changes that are vital, in order that the outcomes for both autistic girls, and their parents improve dramatically.

Chapter 6: Conclusion

6.1 Answering the research question

This study set out to address two main research questions. Firstly, to explore the lived experiences of the parents of autistic daughters; and secondly, to ask what, if anything, might have made a difference to these experiences. Autism in girls is frequently missed, and if assessed at all, is often attributed to other mental health conditions. As the first known study to explore the lived experiences of both mothers *and* fathers of autistic daughters within the UK, this research has revealed deep insights into the challenges that parents face from having their first concerns addressed, through the exhausting process of obtaining a diagnosis, to their daily lived experiences both up to and beyond diagnosis. The superordinate themes that emerged: Journey to diagnosis; Negotiating systems; Psychological impact; Living with an autistic daughter; and Reflections, encompass an in-depth analysis that answers both parts of the research question.

The second part of the research question is further answered in the implications for parents and professionals (Sections 5.5 & 5.6). The research found that parents of autistic girls are failed on every level. There is an evident need to address the significant lack of awareness in professionals of how differently autistic girls present from their more well-known male counterparts, and beyond this, their different support needs. This gap in professional knowledge encompasses the education system, medical and mental health services, through to therapeutic services. Additionally, it highlights the frequently overlooked need to support the parents and family of the autistic girl.

As outlined in Section 2.1, this thesis is based around two threads. Firstly, that of the presentation of autism in girls, under-diagnosis, and the challenges around identifying autistic females; and secondly the lived experiences of the parents of an autistic child (both genders). The recommendations reached through analysis of the findings using IPA, and the subsequent discussion have been developed and related to the lens through which the parents view their daughters' experiences. The lived experiences of the parents are driven by the pervasive and widespread lack of knowledge and acceptance of female autism.

6.2 Reflexive statement

Van Manen (2016) suggests that researchers are often drawn to their research question by an inquisitiveness borne out of their own experience. Whilst not the parent of an autistic daughter, having in-depth experience of autism with my son, I found myself comparing this with my professional encounters working with autistic girls and their families. Although participants were aware of this from the outset, and as was evident throughout the interview process, this introduced a sensitivity toward the participants' situation that engendered their trust in me, with comments along the lines of 'you must know what it's like'.

When I commenced this doctoral process, although highly motivated, I lacked confidence in my ability to study at this level. I had started my original master's study without having attended university as an undergraduate for reasons outside my control and left that course at the end of the first year, having gained a PGCert. The final words of my course tutor were to the effect that I was not academically up to that level of study. I then started another master's course at a different university, and despite having almost no supervisory guidance in the final year, I gained a distinction in my MA, with my research forming the basis of this study. Throughout this research process, with positive and supportive supervision, I have gained independence, authority and confidence, evidenced as I have embraced the opportunities and challenges that this study has presented. I have taken ownership of this process and have grown in my confidence to articulate the findings from this novel study.

Having reached the end of the research process, I have been left feeling humbled by the resilience and determination shown by the participants, in the face of adversity that, at times, left me without words. In the post-interview debrief, several participants spoke of feeling compelled to partake in this study, knowing that it would be emotionally arduous. Having walked alongside them as they told their story, I feel an implicit obligation to reflect their heartfelt words and use them to influence and shape future policy.

> *"I do feel rubbish... but that is a small price to pay if research going forward will help future parents of autistic girls" (Julia)*

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Appendix A

Ethical approval letter

University of Chester

Department of Social and Political Science

sps@chester.ac.uk
Direct Line 01244 512040

22nd April 2020

Mrs Lucy Chantrey

Dear Lucy 1123356 SPS EA53

RE: ETHICS APPLICATION

The Department of Social and Political Science Ethics Committee has considered your application for ethical approval for your research for the following study: *No title as yet*

The committee considers that minor amendments are required before the application can be approved, and details are noted on the returned application form.

After making amendments, please ensure that the completed new application form is submitted to your supervisor for approval after which it should be resent to SPSEthics@chester.ac.uk.

I wish you all the best in conducting this study.

Yours sincerely,

Dr Holly White
Chair of Social and Political Science Departmental Ethics Committee
Deputy Head of Department

Cc: Student email address
Supervisor

Appendix B

University of Chester

Participant information sheet

An Exploration of the Psychological Impact of Raising a Daughter who has a Diagnosis of Autism

Dear

Thank you for indicating that you are interested in taking part in this research. This Information Sheet will hopefully explain what is involved, but if you need further clarification, then please do not hesitate to contact me using the contact details below.

What is the purpose of the study?
This research is part of a Professional Doctorate in Psychological Trauma that I am undertaking at the University of Chester. I am interested in finding out about the psychological impact on you as the parent/guardian, of raising your autistic daughter. I would be interested in exploring your view on, and experience of this. Please take time to discuss the information with relatives and friends and to ask questions of the researcher.

What will happen to me if I take part?
To enable this, if you decide to take part, I will arrange a time to interview you at your convenience, via Skype, FaceTime, Zoom or similar video interview platform. You will need to set aside up to 1.5 hours and identify a quiet room where you will be free from interruption or disturbance. Your written consent will be obtained through the enclosed consent form which can be digitally signed. The interview will be digitally audio recorded and last about an hour. The interview data will then be transcribed by an external transcription service.

The interview will be semi-structured and be focussed around the following questions:

Background:

- Age of daughter now?
- Age at diagnosis?
- When was the diagnosis made?

Questions:

- Can you tell me about what you noticed, and why you were first concerned that your daughter was different from a neurotypical girl?
- Was it you who first raised the concerns?
- If so, who did you first approach about this, and how do you feel that your concerns were received?
- How did you experience the diagnostic process?
- What are your reflections on her day-to-day life?
- Can you tell me about your experiences of parenting your daughter?
- What, if anything, would you change about your experiences?
- Do you have any other comments that you'd like to add?

Once the interview is complete, the digital recording will be transcribed by an external transcription service. Your transcript will be allocated a pseudonym or code to protect your anonymity, and any identifying features in the data will be deleted.

Interview environment with Covid-19 situation

With the current Covid-19 conditions, it is possible that you might find it more difficult to conduct the interview in a confidential space away from interruption or being overheard. This might mean that the planned interview schedule is no longer suitable. In this case, the interview can be rearranged to allow for the above conditions to be met.

Your right to withdraw without prejudice
You have every right to withdraw from the research at any time, without prejudice, for 14 days after the date of the interview. After this point, it will be impossible to remove your data as it will be aggregated, making your data more difficult to identify.

What are the possible disadvantages and risks of taking part?
If, for any reason, personal issues are stirred for you, I have provided a list of resources where you can access support.

What are the possible benefits of taking part?
The experience will give you time to reflect on your work, and to share your thoughts. This may contribute to something greater at research and policy level.

What if something goes wrong?
I will do everything within my ability to ensure your safety and confidentiality. However, if you are not happy with any aspect of the research process, please raise it with me. If you are still not happy, you may raise it with the Chair of the Ethics Committee Email: SPS.Ethics@chester.ac.uk

In the unlikely event that a participant is harmed by taking part in the research, there are no special compensation arrangements. Accordingly, the University does not accept liability for harm which does not result from its negligence. In the event that something does go wrong, and a participant is harmed during the research and the harm sustained is due to the negligent acts of those undertaking the research, then the participant may have grounds to bring legal action. Anyone bringing such legal action may incur legal costs.

Will my taking part in the study be kept confidential, and how will my data be stored?
The fact that you are taking part in the research, and everything that you share, will remain confidential. In the unlikely event that Child Protection issues are raised, I may have to alert Social Services or Police, but otherwise, what you share will form part of the data which will be anonymised by use of a pseudonym or code. The data will be stored securely in locked premises and kept encrypted on a password protected computer. Only I, and my Research Supervisor, will have access to the data. The data will be destroyed (shredded or electronically deleted) after ten years, in keeping with the data protection act. Participants should note that data collected from this project may be retained and published in an anonymised form. By agreeing to participate in this project, you are consenting to the retention and publication of data.

What will happen to the results of the research study?
The completed research will be stored (bound and electronic) at the University of Chester. The research may be disseminated in future publications and at conferences.

Whom may I contact for further information?
I, the researcher, am Lucy Chantrey
My contact details are: 1123356@chester.ac.uk

Support service resources

Counselling Directory: https://www.counselling-directory.org.uk
National Autistic Society: https://www.autism.org.uk/services/helplines/parent-to-parent.aspx
Child Autism: https://www.childautism.org.uk/for-families/autism-helpline/

Thank you for your interest in this research.

Appendix C

University of Chester

Consent form

An Exploration of the Psychological Impact of Raising Girls with Autism

Name of Researcher: Lucy Chantrey Please initial box

1. I have read and understood the participant information sheet and have had the chance to ask questions, and that the answers provided are satisfactory. ☐
2. I agree to the research conversation being audio recorded. ☐
3. I understand that my participation is voluntary and that I am free to withdraw my data within 14 days of the interview date. ☐
4. I agree to take part in this study. ☐
5. I understand that the data will be written up as part of a thesis and I will not be identifiable in the thesis. ☐
6. I understand that the data may be included in any presentation or publication of the research, but that my anonymity will be protected. ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Researcher	Date	Signature

Appendix D

Participant recruitment advertisement

Exploring the psychological impact on parents/guardians of raising a daughter with Autism Spectrum Condition

I am a postgraduate student researching for a Doctor of Professional Studies in Psychological Trauma qualification at the University of Chester. I am also the mother of two boys with a diagnosis of Autism Spectrum Condition.

I am carrying out a research project exploring the psychological impact on parents/guardians of raising a daughter with Autism Spectrum Condition.

I am looking for participants who have a daughter diagnosed with Autism Spectrum Condition, fulfilling the following criteria:

- Aged between 12 and 18 at diagnosis
- Diagnosed in the UK
- Received her diagnosis within the last 10 years
- Assigned female gender at birth

Participation will involve a one-hour online, audio-recorded interview, via Skype, FaceTime, Zoom or similar

If you feel that someone you know might be interested in taking part, please could I request that in order to maintain confidentiality, you do not tag them, or mention their name on this post

If you are interested in taking part, and would like to find out more, please contact me on:

1123356@chester.ac.uk

Thank you

Lucy Chantrey

Invitations to participate in this research will close after 30 days from the date of posting

Appendix E

Participant data not included in chapter 4

4.2.1.2 Falling apart

1: *"...then she started senior school and it just all went hideously wrong for her. There were two hundred children in her year group and on the first day, they only have seven go in and she came home, she was so excited, and by day 2, the rest of the school, go in. And she came home that day, and she was... I just remember her not being able to tell me what was happening" (Sally)*

4.2.1.3 Trying to make sense

2: *I mean, I am a coper. I was an army officer for seven years. I'm used to problem solving and I couldn't solve this one. And there's just no logic to it, you know, if I could have worked out the pros and cons and made a plan and made a decision and talked her through it, but I just, I didn't know what was going on. I didn't understand…" (Daisy)*

3: *"It wouldn't be fair on us to look back and say oh we should have known. Because there's no way, really, other than a few, and as I say a few allusions that had come in from family history" (Simon)*

4.2.1.4 Unheard and unseen

4: *"I took her to the one of the newer GPs and he said the same thing and he said it in front of Kate. And he said well, the answer to this is just to get on and go to school, just go there. And I said well, I don't think it's as simple as that… 'no, no this will cure it'" (Megan)*

5: *"For the first 45 minutes she spent with Freya, she had no idea what we were seeing, and it was only maybe the last 15 minutes that she spent with her, and I think blimey, no wonder no one sees it, if all you're going to do is spend an hour with somebody" (Sally)*

6: *"Cognitively absolutely brilliant, really compliant in class, really voluble, participated in absolutely everything. I think it was because when she was out and about at school, you know we would, we'd sort of talk about how things were with staff and so on at school" (Simon)*

7: *"I suppose if her behaviour was, she was acting out in school with disruptive, difficult behaviour, then you would have someone coming to you and sort of, you know, we'd be able to, you know, sort of have a consensus of...as adults about what she's doing and why she's doing this and what's triggering this, whereas when you're just, you've got a child that never, you know, never does anything to draw attention to herself at school" (Thomas)*

8: *"Well, when you are trying to tell you know an education professional, like this is urgent, this is my daughter's mental health. You know they're in a position where they're feeling, they'd actually prefer to start hurting themselves than to come to school. You know at that point you know I'm still trying to work with school, I'm still trying to make a way, like work with me…And what was I going to say, so when he sort of turned around and said he didn't have space in his diary for all those weeks, I just thought, this is not a priority for you. You really don't care, you haven't heard me" (Sophie)*

4.2.1.5: Looking in the wrong place

9: *"I don't know, I just thought to myself they think I'm crackers and I feel crackers because I am that wound up by this whole business. So it was just horrible" (Megan)*

10: *"They didn't know how to put it, but I think they thought we were being soft or some other kind of delusion; it started to feel unpleasant" (Megan)*

"I suppose by the time she got to about 7 or 8 there was a sense that we would kind of feel that we were indulging her a bit and she was being a bit spoiled" (Simon)

11: "*To the point where I moved in with my parents so that I had a witness that you know that I wasn't hitting my daughter or hurting her or neglecting her in anyway. I thought hang on now I contacted Social Services myself and asked for help because I knew this wasn't right. And I didn't know what to do about it and now you're turning it all around saying I'm doing something wrong" (Becky)*

"I was off one day, left my husband at home preparing, getting everything ready for school, getting the children off to school and Jasmine had got ready for school eaten some breakfast, spilled the breakfast on them. And my husband was stressed because he couldn't find any more school uniform. You know I'd left everything ready for that morning, I hadn't left extra supplies. So, he commented you wait until your mother gets home, I can't believe she's left us in this situation, you know you're going to have to go to school messy, this sort of thing" (Sophie)

4.2.1.6: Breakthrough

12: "*And again, said to my friend who lives in *****, who is a SENCo and said do you have any information about autism in girls, she said not much but I'll post you what I've got. I looked at my elder daughter, I said you should read this" (Megan)*

"...she was on Lorraine talking about how she'd only been diagnosed as an adult, but these are the kind of the way that she presented. And I swear if I hadn't watched that programme, we could still, not know that she was autistic. So, we watched that programme, a few of the things that Laura said kind of rang a few bells with them. So, I started doing research and no one thought it was right, and no one said you're wrong, but it was on no one's radar" (Julia)

13: *"And she said to me straight away, if you can't get into CAMHS immediately, go and get a private diagnosis, because I see what you see. I was really relieved that somebody saw what I was seeing. Then getting feedback from the lady at the autism centre at school, they were able to see some of the stuff that I see" (Sally)*

4.2.2.1: Girls can't be autistic

14: *"…so and then there were like ironically, just really recently we found that on the day Emily started school there was another girl who started with her who has got the same birthday as Emily and they're both autistic. So that class had at least 2 girls in its class of 16 kids, were who autistic and neither of them were spotted until secondary school" (Julia)*

4.2.2.3 Us v them

15: *"The wheels were grinding very slowly with city council because they really didn't want to pay for the kind of service which they knew full well she was going to need. And we took solicitors to them and did everything that middle class parents with a bit of income can do and to get her in there via tribunal" (Megan)*

4.2.2.4: Seeking support

16: *"So that's the school that she goes to, it's ***** in *****and it's a specialist school, specialist setting for children and young people who are academically capable of school, cognitively are kind of able to cope with things but because of their autism, they just massively struggle in a mainstream, busy, challenging environment. And she took to it like a duck to water" (Simon)*

4.2.2.5: Unhelpful 'help'

17: *"She would only go into the room with the Occupational Therapist if I sat outside the door, the idea was sort of do a cooking activity and then do work around feelings and anxiety and social anxiety and things like that. Of course, she's really smart, so she knows that there's always an end game, you know to things. She would be quite happy to do the cooking and the moment they said, oh let's talk about feelings, the first time she went under the table. And they were sort of calling me to go in and get her and then the second time she bolted past me out of the door and ran out of the hospital. So, we had to sort of get, stop her but they very quickly decided that like those sessions were not working" (Sophie)*

"School has an Occupational Therapist who kind of did really bad stuff with Emily like saying if you set an alarm clock then you'll be able to get up for school. You know is it magic and with the feeling stuff it's not that she doesn't feel safe to express her feelings, it's that she can't express her feelings because that's part of her neurology, that she just doesn't have that ability and she has very different ways of expressing her feelings and sort of understanding her feelings. It's nothing to do with feeling safe. So, they just don't get it" (Julia)

And this was like, I'm very aware of what an alarm clock is, that wasn't the issue. It's like she wasn't aware of what an alarm clock did, it was the fact that she, you know the Occupational Therapist didn't get it at all. And they'd say stuff like Emily needs to, by July 2020, Emily will have found a trusted adult who she can share her emotions with. Or she will have got the confidence to go to the corner shop and buy a packet of sweets. But like there's no, how do you get to that point in it at all." (Julia)

4.2.2.6: Broken systems

18: *"It's a difficult one actually because looking back now, with the research that's just been done. You know because I think it's a really, emerging area. How autism presents in girls and how to diagnose it and the different, you know and there's all kinds of stuff now saying well you know the diagnostic instruments that they've got are very much weighted toward identifying autism in boys, and much less in girls" (Simon)*

19: *"And really, once we had the diagnosis, there wasn't any support, it didn't really make a difference. And for a lot of people, you know, whether it's mental health or whether it's autism, which has led to mental health, is a massive, massive, gap. You leave hospital, you've got 24-hour support from professionals, and then you're discharged, and even if you're seeing CAMHS once a week, that's nothing; it's a small investment in terms of keeping people back out of hospital because they will, they will be back" (Daisy)*

20: *"I really don't think there is much care for the parents. And that's what's driven me really with the charity that we run. One of the main aims of that is to care for parents and carers because I just feel the more that they're supported and given information and given help. Because we are like running a marathon looking after these children, it's not like a little sprint. If we hold our breath and smile for the next 100 metres, we'll like make it through. You've got to be able to dig in for the long term you know" (Sophie)*

4.2.3.1: Being on my own

21: *"With the best will in the world, none of our extended family are involved in her no matter how hard I've tried to get them to include her. She's got cousins that are slightly older*

than her, they all hang out together, they all go shopping together. They don't include her, and I've tried every which way" (Sally)

4.2.3.2: Impact on the inside

22: *"It was enough to get the police to school. So that was hugely traumatic. I can talk about it now almost without being tearful. But this is you know and even though it's difficult to speak about, this is why I think your area of research is so important. You know because I think this is part of the issue of our girls, sometimes our boys being understood. And the difficulty with child protection really, because sometimes when a person on the spectrum says something, you need to be able to tease out a bit more detail to understand what's happened. And obviously with child protection you just record what the child has said, and you have to take that information at face value and pass it on to services. It was probably one of the worst things we've ever been through, it was awful for Jasmine, she was absolutely terrified. You know it was, as quickly as it flared up it also resolved within 24 hours" (Sophie)*

23: *"So, I really shared that information with a couple of friends and they both steered me towards a GP, and I said, no, no, this is, this is, this is right for me, this is how I need to think, this is this is what's getting me through the days. I will never have to live without her, so, I'll never have to feel the guilt of not having saved her" (Daisy)*

"We were in the hospital, she'd taken a lot of paracetamol and she had a drip. And obviously, that was trying to protect her liver, save her liver from the damage that would be done and in the middle of the night, we're in a corridor as you are in hospitals, it was the start of Covid" (Daisy)

24: *"I feel quite envious of people who have two daughters like Georgia. Because their life must be so, so different from mine. But yeah, imagining that both of my daughters are out there in the world doing their thing, having relationships, holding down jobs, moving forward with their lives. And that I don't have to… I've got an app on my phone that I check every night to see where Olivia is, I check every morning to see where Olivia is. It's just part of my daily routine that keeps me going. And the idea of a life where I wouldn't have to do that is just, you know, I know everybody has their problems, nobody's life is perfect, I get*

that. But sometimes I just get a bit envious of people that don't have to worry about their children the way that I do" (Daisy)

4.2.3.3: Exhaustion and burnout

25: *"I'd go to the GP and said you know, it's awful and all they can do is prescribe anti-depressants. So, I went on 3 anti-depressants, none of which even touched the sides because that's not, I wasn't chemically imbalanced type depression. I know because it's exactly the same with bereavement. You know if you've been bereaved, a pill might take the edge off, but it's not going to change the situation. It's the same with this, taking a pill isn't going to change the fact that I need to battle through it, diagnosis, that I need to battle for an EHCP, that I need to battle for a dentist that I need to battle for a paediatrician" (Julia)*

4.2.3.4: Impact of the outside

26: *"Where the school was, was an area where there happens to be, it's a very, very upper middle-class zone, some doctors, and lawyers and dentists living there. So, this primary school was like a hotbed for those who didn't quite want to pay for private school…these children would come, and their parents would say where's Kate and the kid would say she hasn't been in, and they'd say that's a sickly child" (Megan)*

27: *"I suppose I worry that people will feel I'm getting it wrong; I'm doing too much and doing too little, I think I'm getting it right and therefore I don't welcome anybody else's opinion on that. And so, advice is not, I'll ask for advice if I need it, otherwise I don't want it…I don't need to be judged. It's my journey and I am where I am and I'm as comfortable as I can possibly be with where I am" (Daisy)*

28: *"I have a niece and she's lovely and she's gorgeous and she's bright and she's funny, and she gives so much, and Freya doesn't. She's serious and she's, she doesn't give anything. So, since Rachel was, this is my niece, since she was born, my mum and dad have had her every holiday, every Tuesday since she was born, basically, they have done something with her, pick her up from school, take her to school, in the holiday she's been with them, throughout her whole life" (Sally)*

4.2.4.1: Daily life

29: *"Jasmine wasn't diagnosed with it, but sort of suffering with separation anxiety, didn't want to leave me, didn't want to be away from me. I've had several periods over the last five years where we've had to set up a bed in, in my and my husband's bedroom for Jasmine. So, Jasmine could sleep next to us because at its worst Jasmine was having night terrors, she'd be crying. So, we'd literally have to sleep holding her hand, because she couldn't bear to be apart from me" (Sophie)*

30: *"You know, they're getting to an age where they should be sort of, your expectation of them is more independence, less sort of intervention from us when it comes to daily needs, and instead of sort of more independence, you get less independence. And so that's quite challenging" (Thomas)*

31: *"(She) became obsessed by certain things, just her whole sort of needing to have things in a certain way. To achieve anything and to function, really. It was incredibly challenging, you know, because, when you're both busy, both working and you've got other children as well and other challenges with them that come up as well, it's really hard when, when one of, you know, one child has very, I suppose, extreme sort of needs when it comes to just daily functions, really, you know, just things that should be done very quickly and very easily without an awful lot of hassle become massively stressful" (Thomas)*

4.2.4.2: Impact on family/relationships

32: *"It's been hard. I mean, I know that my daughter, Georgia, she's twenty-five. She hasn't had as much attention as I would to have given her…she hasn't had as much of me as she should have had" (Daisy)*

4.2.4.4: Learning as I go

33: *"It was around this time I think that we discovered a local network of people from the Pathological Demand Avoidance society, the PDA Society. And that made a big difference to us because through understanding about PDA and low demand and what, how young people manifest that and how…we realised that actually the low demand, the low stimulus approach*

was the only way that we were going to be able to help Bella manage her own behaviour. We also realised that the kind of demands that we placed on her were part of the reason why she was getting stressed" (Simon)

34: *"I don't know everything, there's loads of stuff I don't know. I'm always researching, always reading books, always you know looking to get involved so I can learn things. I still do it wrong" (Becky)*

4.2.4.5: Wearing a mask

35: *"She was almost always good as gold when anybody else was around. You know she'd be able to put the mask on and keep it altogether, but yes, as soon as somebody else's back was turned she'd be…" (Simon)*

36: *"You know for the most part Jasmine was masking in school…they said to Jasmine oh you're doing so well, do you want to go to lessons without support. So of course, Jasmine wanting to please, wanting everything to be right, said yes, I'll go to lessons without support. Well by the December, Jasmine was out of school again, had been missing days, all this anxiety starting to school refuse" (Sophie)*

37: *"If you sort of take her out somewhere social or somebody meets her for the first time, she's masking then, she'll mask her behaviour. She'll pretend that she can sort of be social, but she's absolutely shattered after" (Becky)*

4.2.3.1: Reflections on diagnosis

38: *"Anything and everything you wanted to know about autism, Bella can tell you, she's read all the books, she knows everything that's going on. It became one of her, you know after Dr Who, it's kind of her special interest that and Donald Trump. She really likes to read about and kind of double down on it. And she was, she herself, she's brilliant, she worked it out for herself how she could get various you know, contacts online from various support groups" (Simon)*

39: *"That's my fourth dealing with CAMHS. I'm like, why didn't you tell me that the first time? Why wait till now? Because she could have been supported through school with that. And it might have had a different outcome with her GCSEs because basically she wanted to do A-levels but didn't make the grade" (Sally)*

4.2.5.2: Reflections on parenthood

40: *"…you know, I was saying, oh, you'll be fine once you're in there…so I tried shock tactics with her. I tried you know, if you do this, if you don't do that, you don't go to school, I'm going to take your phone off you for a week. You know, all of those but I was always the bad cop" (Sally)*

4.2.5.3: If only…

41: *"I thought about home-schooling, but I actually decided against that and if I could have my time again, I think I would actually go down that route" (Sally)*

42: *"Of course, knowing what I know now to change her environment and put her in a new school and all that, at that time. Would I do that again? No, of course I wouldn't. But hindsight's a wonderful thing" (Daisy)*

4.2.5.4: Loss and grief

43: *"Freya met and started going out with a very lovely boy and she was very honest with him. She just had a diagnosis, and she was very honest with him about what was going on for her and for the first time in her life, I saw her have a meaningful relationship with somebody, umm, somebody who, basically he put her on a pedestal. And it was very, very lovely, and very sweet. And then at the end of last summer, they broke up and they broke up about a week before she started college" (Sally)*

44: *"I was then worried that when they interviewed the children and I wasn't present would something else be said or interpreted incorrectly, you know. So that was a big fear and obviously I'd, the children were the main overriding factor" (Sophie)*

4.2.5.6: Walk a mile in my shoes

45: *"I mean, the only problem with autism is it just plays out so differently in different.... you know, people will tell you that their child is autistic and that they do this and that and struggle with this and that and it can be very different to our experience" (Thomas)*

4.2.5.8: Personal growth

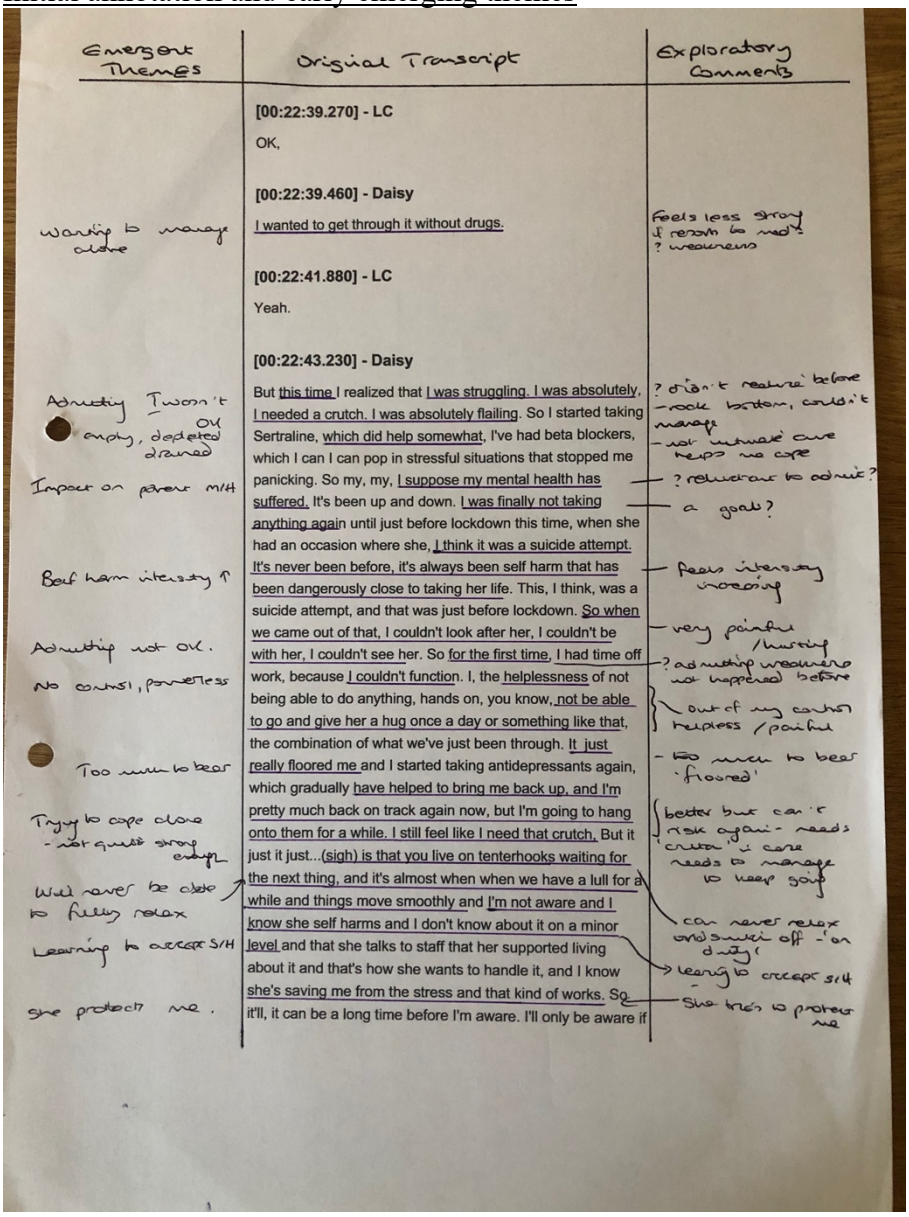
46: *"She's managing to go for 3 afternoons a week which you know at one point I never knew whether she'd ever be able to go back to school ever again. But obviously we still have massive blips like this afternoon…" (Julia)*

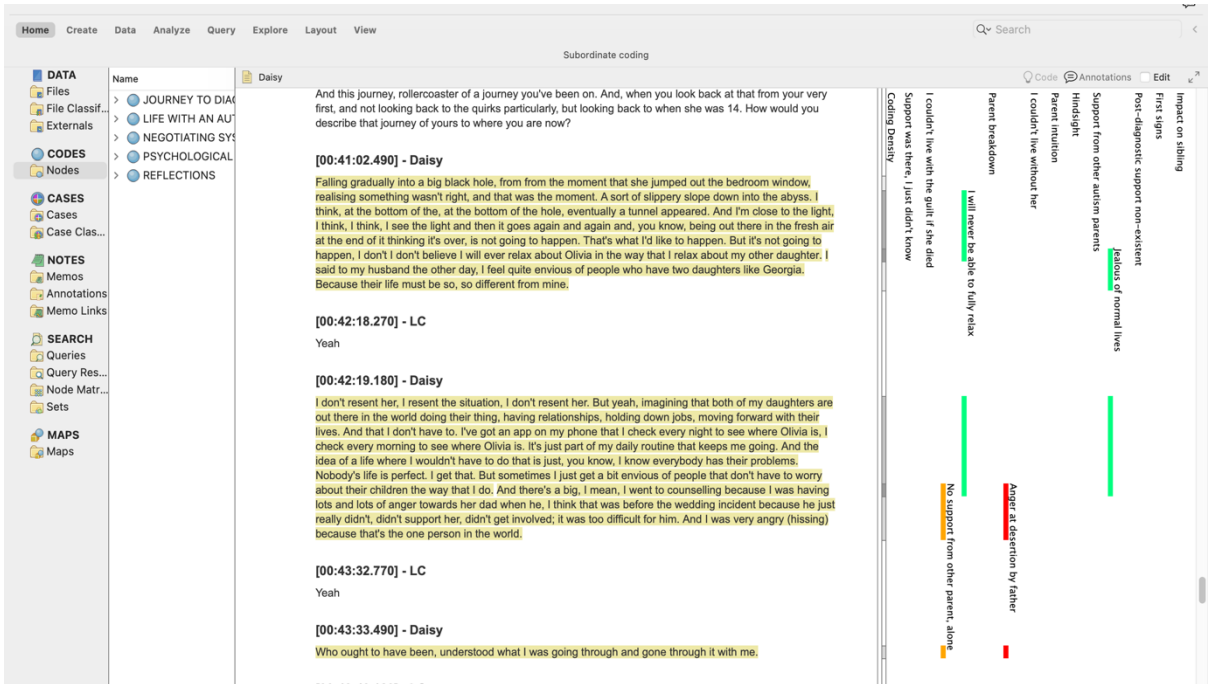
47: *"I laugh at this because it's the only way of dealing with it…" (Megan)*

Appendix F

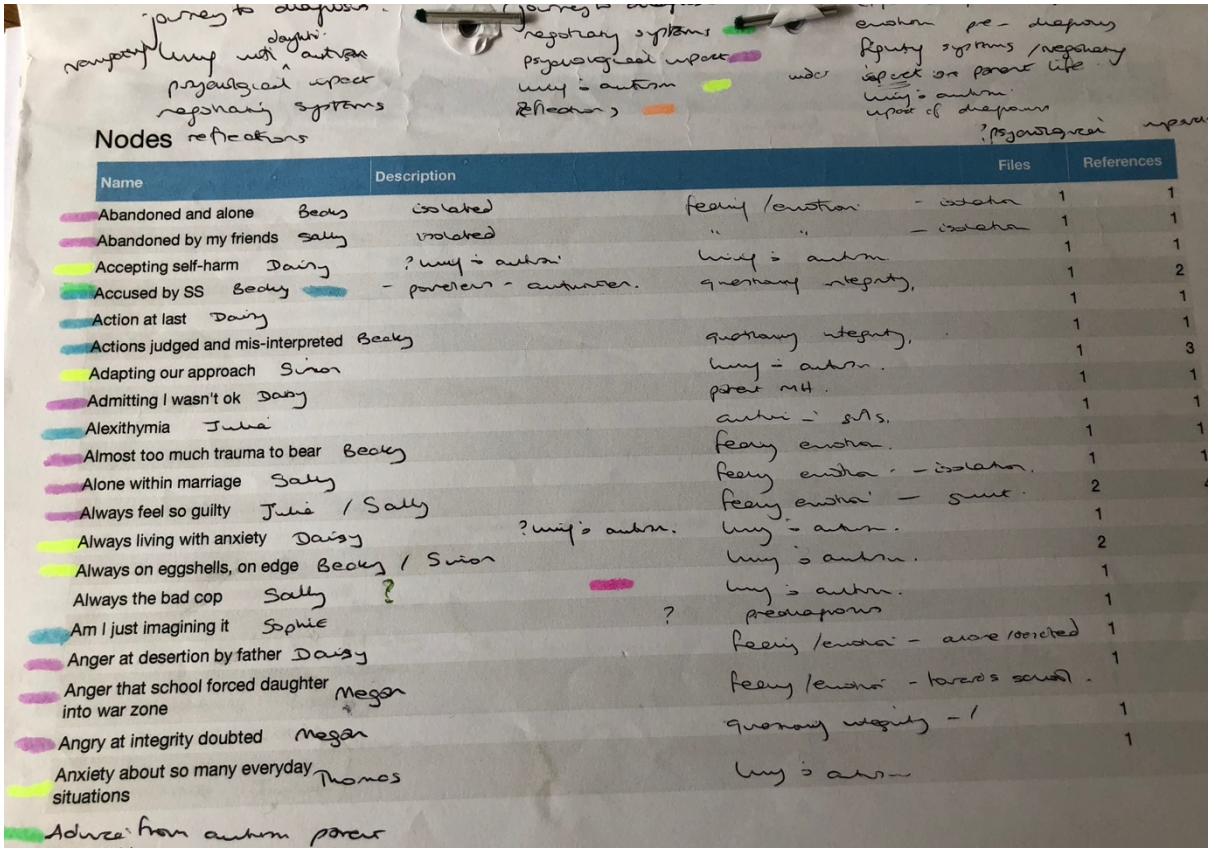
Analytic process, paper based and NVIVO

Initial annotation and early emerging themes

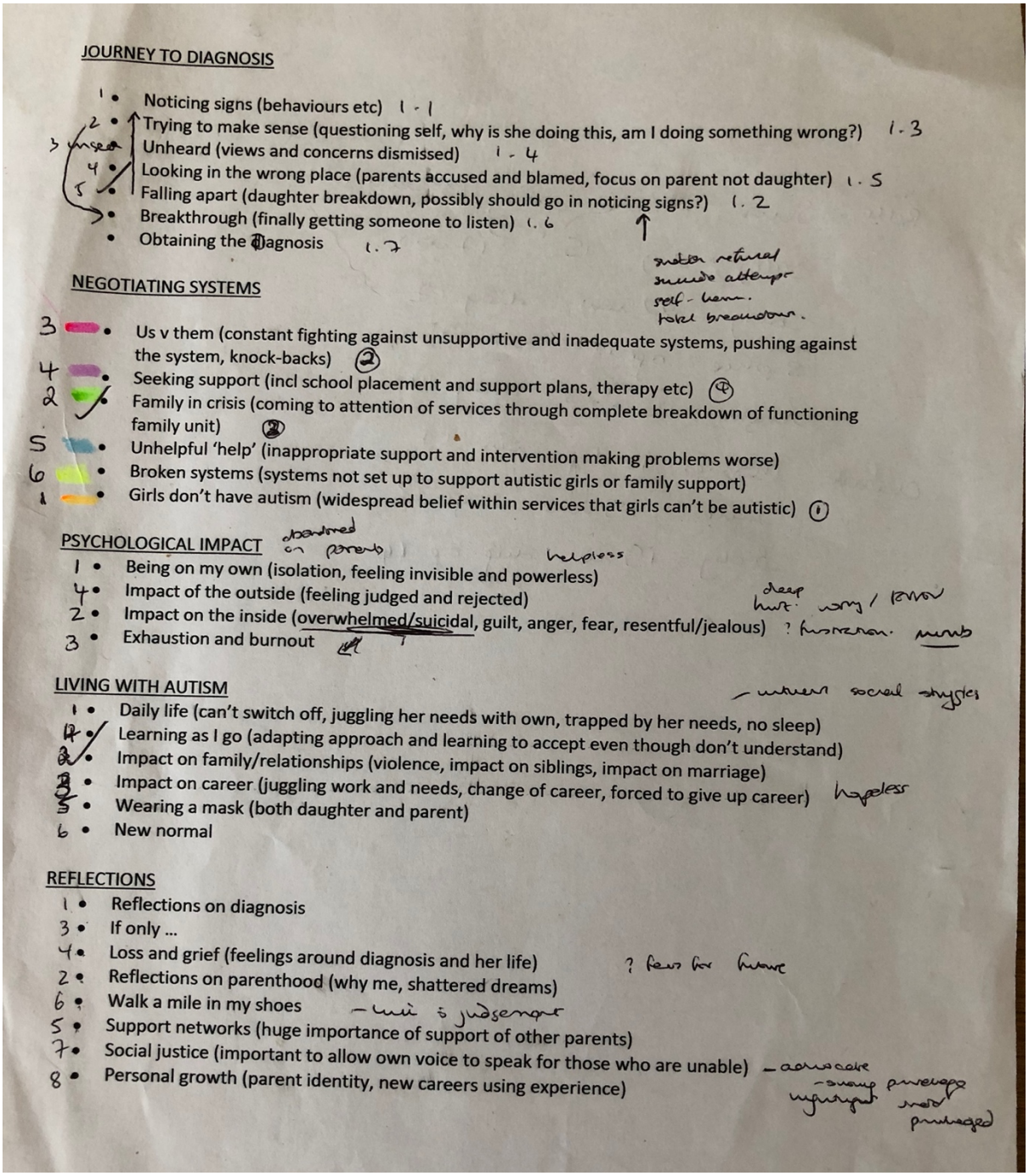




NVivo coding process



Organising subordinate themes into superordinate themes



JOURNEY TO DIAGNOSIS

- Noticing signs (behaviours etc)
- Trying to make sense (questioning self, why is she doing this, am I doing something wrong?)
- Unheard (views and concerns dismissed)
- Looking in the wrong place (parents accused and blamed, focus on parent not daughter)
- Falling apart (daughter breakdown, possibly should go in noticing signs?)
- Breakthrough (finally getting someone to listen)
- Obtaining the diagnosis

NEGOTIATING SYSTEMS

- Us v them (constant fighting against unsupportive and inadequate systems, pushing against the system, knock-backs)
- Seeking support (incl school placement and support plans, therapy etc)
- Family in crisis (coming to attention of services through complete breakdown of functioning family unit)
- Unhelpful 'help' (inappropriate support and intervention making problems worse)
- Broken systems (systems not set up to support autistic girls or family support)
- Girls don't have autism (widespread belief within services that girls can't be autistic)

PSYCHOLOGICAL IMPACT

- Being on my own (isolation, feeling invisible and powerless)
- Impact of the outside (feeling judged and rejected)
- Impact on the inside (overwhelmed/suicidal, guilt, anger, fear, resentful/jealous)
- Exhaustion and burnout

LIVING WITH AUTISM

- Daily life (can't switch off, juggling her needs with own, trapped by her needs, no sleep)
- Learning as I go (adapting approach and learning to accept even though don't understand)
- Impact on family/relationships (violence, impact on siblings, impact on marriage)
- Impact on career (juggling work and needs, change of career, forced to give up career)
- Wearing a mask (both daughter and parent)
- New normal

REFLECTIONS

- Reflections on diagnosis
- If only ...
- Loss and grief (feelings around diagnosis and her life)
- Reflections on parenthood (why me, shattered dreams)
- Walk a mile in my shoes
- Support networks (huge importance of support of other parents)
- Social justice (important to allow own voice to speak for those who are unable)
- Personal growth (parent identity, new careers using experience)

Ordering themes for structuring the analysis