

‘Hindsight is a wonderful thing’:

**An exploration of how mothers make sense of
their experiences of their daughters’ early
development and behaviours preceding a
diagnosis of autism in later childhood**

by

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Dedication

For my parents Terry and Rose Swales, for their constant love and support, always being there, believing in me and encouraging me towards my aspirations.

For my husband Ian, for his limitless optimism, understanding, love and infinite support.

For Kate, Sarah and Joe, for their patience and understanding whilst I have been studying (for what seems like forever) including, all your encouragement keeping your mum on track at times when I thought the end was an impossibility.

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Abstract

As research identifying a 'missing' population of autistic girls and women is gathering momentum, it is now being recognised that cognitively able girls with autism are diagnosed later in childhood or as adults and the number of girls with autism is significantly underestimated (Hendrikx, 2015; Happe, 2018). There is limited research on the experiences of mothers raising a daughter before there was any consideration that she was autistic.

This research aims to provide a greater understanding of the experiences of mothers. Six mothers of cognitively able daughters with autism took part in semi-structured interviews. Interpretative Phenomenological Analysis was used to analyse the data. Three superordinate themes emerged: 'Mum's unconditional love,' 'Who is my daughter?' and 'An unexpected destination.'

This study enhances existing knowledge including, the contribution of the early experiences directly related to being a mother raising a daughter who is diagnosed with autism later in childhood and additionally heightens insight into how girls with autism present. Key findings which add to the literature on this under-researched topic are described and implications are discussed with particular reference to understanding of the under-identifications of autism in girls from the mother's perspective and implications of the role of professionals to facilitate optimal outcomes for mothers of cognitively able girls who are diagnosed with autism in later childhood.

Underpinning these recommendations is an emphasis on the significance of listening to and hearing the voice of parents who know their daughters best and have something important to say.

"I just think people's eyes need opening and that people need to listen. Nobody knows a child better than their parent". (Vroni, research participant)

List of Abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
AEP	Association of Educational Psychologists
ASD	Autism Spectrum Disorder
BPS	British Psychological Society
DfE	Department for Education
DSM	Diagnostic and statistical manual of mental disorders (Arabic/Roman numerals indicate the edition; the suffix R indicates a revised version)
CAMHS	Child and adolescent mental health service
C&YP	Children and Young People
EP	Educational Psychologist
EPS	Educational psychology service
GP	General Practitioner
HCPC	Health and Care Professions Council
ICD	International statistical classification of diseases and related health problems (Arabic numerals indicate the edition)
IPA	Interpretive phenomenological analysis
NASEN	National association of special educational needs
NAS	National Autistic Society
RRIBs	Restrictive, Repetitive Interests and Behaviours
SC&I	Social communication and social interaction
SEND	Special educational needs & disability
SENDCO	Special educational needs & disability co-ordinator
UK	United Kingdom

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Chapter 1

1.0 Introduction

1.1 Background and Research Focus

Chapter 1 provides an overview and a brief synopsis of the purpose of the current research. A diagnosis of autism in girls is under identified and they are frequently overlooked or misdiagnosed (Atwood., 2006; Gould & Ashton-Smith, 2011; Dworzynski et al., 2012; Kirkovski et al., 2013). The literature instead reveals autism as being perceived as a predominantly male condition (Bargiela et al., 2016; Navot et al., 2017) and the number of autistic girls is considerably underestimated (Hendrikx, 2015; Happe, 2018).

This retrospective study seeks to create new knowledge in an area which has been previously under researched by exploring the lived experiences of mothers raising their intellectually able daughters prior to a diagnosis of autism in later childhood. It is envisaged and hoped that this study will contribute to the literature on mothers making sense of their daughter's early development, behaviours and experiences before autism was a consideration.

1.2 Terminology

1.2.1 Autism

There are many ways of describing 'autism' and there is continual disagreement about how it is termed (Kenny et al., 2016). Autism Spectrum Disorder is the official way of describing autism (Diagnostic and Statistical Manual of Mental Disorders-5th edition (DSM-5), American Psychiatric Association (APA), 2013). However, many autistic people and their families feel that the term 'disorder' is too negative for everyday use and prefer to describe autism as a difference rather than a disorder (Kenny et al., 2016). Kenny et al., considered all the preferred terms for how autism is described. They received 3470 responses from their survey of a UK sample and concluded that the preferred terms were 'autism' or 'autism spectrum'. The participants in the current research without exception used both terms throughout their narratives but, mostly 'autism'. The researcher has considered the options and has chosen to use the term 'autism' which was the participant's preference in harmony with the research and the recommendations from the National Autistic Society (2016) and NHS England (2018). Where other research literature has been quoted or referenced the terminology for autism will stay true to those authors.

1.2.2 Gender

For the purpose of this thesis the terms 'girls' refers to females and 'boys' to males aged 0 to 18 years.

1.2.3 Cognitively Able Girls

The definition of cognitively able girls for the purpose of this research includes those girls who do not have a language delay or a learning disability for whom a diagnosis of autism would not be an obvious conclusion under the age of three or four years of age. Eaton's (2012) research concluded that the average age of diagnosis for cognitively able girls was eight years. Therefore, the age of eight years and up to eighteen years was the range chosen for girls included in this study.

1.3 Autism and Gender

Autism is a neurodevelopmental condition describing individuals as having difficulties with social interaction and communication, in addition to restricted and repetitive behaviours, activities and interests (American Psychiatric Association, APA, 2013).

Autism spectrum disorder (ASD) is one of the most common childhood-onset neurodevelopmental disorders. In the UK, the estimated prevalence in adults is about 1.1%, with relative consistency across studies.

Approximately one percent of the population are diagnosed with autism and males are more frequently diagnosed than females and often at an earlier age (Buckley, 2017; National Autistic Society, 2018). Characteristics identified in girls are often discounted because they conflict with those more commonly associated with boys who have autism (Fombonne, 2009; Russell et al., 2011).

In the current climate the focus on girls and autism is still in its infancy however, it is gathering momentum. In 2015, The Autism and Girls Forum was established with the aim of raising the profile of girls on the autism spectrum. In 2016, the National Association for Special Educational Needs (NASEN) produced 'Girls and Autism: Flying Under the Radar,' as one of their mini-guide series. This guidance was written by members of the Autism and Girls Forum. One of the aims of the guidance was to share family, professional and academic perspectives to identify key issues for girls with autism.

Traditionally there has been an assumption that autism is predominantly a male disorder and professionals have been less likely to diagnose girls with autism even when symptoms and behaviours are evident (Wing, 1981; Russell et al., 2011). Many questions have been raised and the traditional position that statistically, autism affects more boys than girls has been challenged (Gould & Ashton-Smith 2011). Very few studies to date have disagreed with the typical strongly male biased ratio and current figures suggest that it affects on average four times as many males as females (Fombonne, 2009; Lai et al., 2015; Halladay et al., 2014). However, more recent research is beginning to contest the accuracy of the gender ratio. Baron-Cohen (2015) postulates that once detection of autism in girls improves there will still be a male bias however, he suggests that it will be less marked and more like 2:1.

The most recent large-scale population studies have suggested a ratio of approximately three males to every female (e.g., Baxter et al., 2015; Loomes et al., 2017). This also fits in with the growing body of research exploring and reflecting a growing awareness of the female - specific phenotype (e.g., Hull et al., 2017 & 2019; Lai et al., 2015; Lai et al., 2017).

Researchers and clinicians are in addition questioning differences in numbers with a diagnosis across the range of intellectual ability (Lai, et al., 2015; Dworzynski et al., 2012). There is speculation that a number of girls are missing from the figures because cognitively able girls with autism are rarely referred for diagnosis (Ehlers & Gillberg, 1993; Wing, 1981 and Attwood, 2000). This is very much aligned to more recent research that suggests, as a result of a bias towards males, statistics are missing these girls (Gould & Ashton Smith, 2011; Lai et al., 2015; Carpenter et al., 2019). This current thinking is very much in agreement with Bazelon (2007) who concluded in her studies that girls with autism have been greatly underrepresented.

Girls are possibly misdiagnosed, diagnosed later than boys or missed completely (Lai et al., 2015) because many of them are less likely presenting with 'classic autism' that is often identified in boys. This often results in girls being diagnosed with an alternative condition, consequently many girls are diagnosed later in their lives which often has a detrimental impact on their educational and adult outcomes and experiences (Hendrickx, 2015).

The literature is beginning to recognise that there may be girls in schools with autism whose needs are not recognised or understood and significantly less likely to be diagnosed with autism compared to the boys with equal levels of traits (Baldwin & Costley, 2015).

1.4 Parents and Raising Girls with Autism

While the research understanding gender disparity and how autism presents in these intellectually able girls is growing, including how they look different from more typical autistic boys, there remains a paucity in research from the perspective of parents who raise their daughters.

Parents of girls with a later diagnosis of autism when interviewed often say that they knew their daughter was different from an early age (Eaton, 2012). Frequently their daughters have visited many health professionals before autism is recognised (Fisher Bullivant 2018; Gould & Aston-Smith, 2011) and the diagnosis process often starts when the parent expresses a concern about their daughter (Eaton, 2012). Parents are often aware of the difficulties their daughters may be experiencing with sleep, food or anxiety. However, they would not necessarily associate them with autism (McCann, 2019, in Hebron & Bond, 2019). Raising a child with autism is challenging for all parents. Nonetheless evidence currently available suggests the challenges are magnified for parents raising girls (Eaton, 2012). It is not uncommon for mothers to experience not being believed by professionals and this resonates with Simone's (2010) findings where mothers were identified as part of the problem rather than being part of the solution.

Historically, mothers have been blamed for their child's autism. Bettelheim, (1967) described mothers of autistic children as cold and heartless, a view that has since been discredited, nevertheless, it has left an effect on mothers and some researchers suggest that the impact of Bettelheim still exists (Stace, 2010). Instead, the available research is proposing that this is far from the truth and mothers of children with autism are proactive, they seek information and show an incredible strength (Anderson, 2020; Montes & Halterman, 2007; Kuhn & Carter, 2006 and Mansell & Morris, 2004). There is some growing evidence that mothers of children with autism experience more stress (Bristol, 1984, in Eaton,2012) and they blame themselves more for their child's behaviour (Anderson, 2007, in Eaton ,2012). However, mothers of girls with autism are often described as over anxious by professionals when seeking a diagnosis (Grinker, 2007). Eaton (2012) reported that the greatest difficulties for mothers was the

hidden nature of the autistic condition including the various explanations for their daughter's difficulties. In terms of a time frame the research about girls with autism is described as being still in its infancy and there needs to be more clarity and consensus so that girls are recognised to enable them to have a fulfilling future.

The current research had hoped to explore a mother and fathers' perspective of raising their daughters however, only mothers volunteered to participate so the experiences of mothers became the focus. The research will address a gap in the literature by directly exploring the nature of the early lived experiences of mothers who raised an intellectually able daughter who was diagnosed with autism later in childhood.

1.5 Relevance to Educational Psychology Practice

Although professionals working in education have increased awareness of autism it is only relatively recently that girls with autism have been highlighted (NASEN, 2016).

Nevertheless, given the significant prevalence of children with autism within mainstream primary and secondary schools (DfE, 2014) it would appear vital to understand the role that educational psychologists (EPs) might play. The Special Educational Needs and Disabilities (SEND) Code of Practice (DfE, 2014) identifies that children and young people with autism are likely to experience barriers to their education and are likely to have particular difficulties with social communication and interaction.

EPs are in a unique position within the education system as they are members of the Health and Care Professional Council (HCPC) and they observe stringent ethical and professional standards in line with the role of the EP (Woods, 2012 & 2016, in Hebron & Bond 2019). EPs are required to keep up to date with research while supporting others to apply psychological knowledge and skills to make a difference for all the children and young people they work with. EPs are widely involved in research and evaluation, and they have a distinct role and work with children and young people (CYP) aged 0-25 years.

EPs assess and support the educational, social and mental health needs of children and young people they work with. EPs may work with children and young people with autism pre-diagnosis or post-diagnosis, and they can also be involved in the diagnostic process. EPs are in a fortunate position to promote marginalised voices of parents and children and young people (Fox, 2016).

In England, EP practice is underpinned by the Children and Families Act 2014 and the SEND Code of Practice (CoP, DoE, 2014). The Children and Families Act 2014 stresses the importance of gathering the views of parents and CYP themselves during assessments and when planning interventions. The CoP (DoE, 2014) also places a strong focus on capturing the views, wishes and feelings of the CYP and their parents ensuring that they are at the heart of the decision-making processes.

As the recognition and understanding of girls with autism increases (NASEN, 2016) EPs may be in a unique position to raise the awareness of this group of CYP. EPs could help improve the understanding of girls with autism and how their difficulties present. This could include how the difficulties they experience can affect the children and young people themselves and their families.

As new knowledge becomes available it is important for EPs to find ways to talk about the girls and how their autism may present. EPs can talk about how these girls can be identified including the concerns, needs and hopes of girls with autism which will provide more informed and effective support for those living or working with autistic girls. They are also in a position where they can help to identify communication barriers between parents and school. For example, in schools where parents are seeking support for their daughters and school are not recognising the difficulties these girls are experiencing.

1.6 Outline of the Remainder of the Thesis

This research will report on a study of the lived experiences of mothers making sense of their daughter's early development and behaviour before autism was a consideration. Chapter two begins with a narrative exploration, an overview of autism including exploring gender findings. This is followed by an understanding of how autism is identified in girls including the development of the female phenotype that is being alluded to in the research. Finally, an exploration of the understanding of the contribution that mothers are able to provide towards the identification of a diagnosis of autism for their cognitively able daughters.

The third chapter will describe the methodology of the research including an outline of the ontological and epistemological position of the researcher. This section provides details of the participants, the ethical considerations that the study raised and how these were dealt with. Chapter three also outlines the process followed, including how data was gathered and

analysed. The fourth chapter presents the research findings, as interpreted using Interpretative Phenomenological Analysis (IPA). A discussion of the outcomes of the research is provided in the fifth chapter including a discussion of the findings with reference to the literature review. The final chapter will discuss the strengths and limitations of the research together with considerations for the implications of the role of the EP in their forthcoming work supporting the recognition of girls who have autism including, promoting the voice of the parents who have raised their girls. Finally, recommendations for future research and a conclusion reflecting on the current study and its findings is provided.

Chapter 2

2.0 Literature Review

2.1 Introduction

The literature review begins with setting the context of the research to provide an understanding of girls with autism in a world where it has often been predominantly thought of as a 'male' disorder. The literature discussing differences is gathering momentum and it is recognising a female population that has previously been neglected. As the knowledge cascades to clinicians and professionals they will become more skilled at identifying these girls who are often described as being 'under the radar'. While the media continues to portray autism as a male disorder and until clinicians become more skilled at recognising autism in girls when a parent raises a concern about their daughter and her social struggles, autism will not be a considered conclusion (Happe, 2012; Gould, in Hendrickx, 2015).

Rationale for a Narrative Literature Review

The researcher fundamentally selected a narrative literature review for this study because it was able to capture the development of the understanding of autism in girls over time, including summarizing and synthesizing the body of work on this topic. The narrative literature review allowed the researcher the opportunity to tackle broader and more abstract questions (Baumeister & Leary, 1997). In addition, this type of literature review is deemed to be better at appreciating and using methodological diversity. The literature review is initially focused on a broad topic that is narrowed down to address the more specific research questions. It also identifies some of the unresolved issues, questions and identifies areas that remain to be studied which are important to inform the direction of future research. Finally, the researcher can be confident that there is proven data and a body of existing knowledge that supports the current study (Grant et al., 2009).

This narrative review will be conducted to provide an appraisal of the research landscape to critically understand the context of girls in the autism research including the identification of the gaps in the research. It will be presented in three parts. Part 1 begins with a historical overview, relevant theories including a broader understanding of the gender disparity and a synopsis of the diagnosis process. Part 2 considers the probable emerging female phenotype and how traits in girls with autism may differ from boys. This section will also deliberate how

girls are diagnosed using the current diagnostic criteria. Finally, Part 3 will consider the relevant research that explores the literature linked to the knowledge and experiences of parents and in particular mothers raising children with autism.

In summary, this narrative approach explores theoretical and contextual perspectives pertinent to the research including:

- A historical overview of autism including how the knowledge and understanding of autism has developed
- theories and explanations of autism including how the awareness of girls with autism has developed and gathered momentum
- the present position on autism and gender
- an understanding of how autism manifests itself in cognitively able girls by examining the research to support the current understanding of the characteristics of autism in these girls including the diagnosis of their autism and to reflect on differences from their male peers
- a critical examination of existing research that focuses specifically on the perspective of mothers raising cognitively able girls who are later diagnosed with autism.

The review of literature leads into a justification for the current research study and the research questions to be explored. The researcher does not go into great detail with regards to theoretical concepts and behaviour except where they are specifically relevant to girls.

2.2 Key Sources:

A thorough literature search was undertaken in order to find UK policy documentation, legislation and guidance at national level to understand girls with autism and the role of the EP. Electronic database including ERIC, Psych Info and Psych ARTICLES using the library catalogue and the electronic journal resource at Cardiff University and the World Wide Web, was also utilised using the same research terms. These sources were chosen to include a variety of empirical research articles available in peer-reviewed journals and publications. Hand searching relevant journals was also a valuable source of finding specific documents. These included Good Autism Practice, Educational Psychology in Practice and Autism. The search terms used include 'Autism,' 'Autism Spectrum Disorders,' 'Autism Spectrum Condition,' 'Gender ratio', 'Boys and Girls,' 'Diagnostic criteria', 'Parents', 'Parenting autistic

children and young people', 'Fathers' and 'autistic daughters/sons/children' and 'Mothers and autistic daughters/sons/children' were used.

Throughout the searching process relevant literature was filtered using the following inclusion criteria:

- for practical reasons the researcher only used papers published in the English language
- including children or young people both male and female with a documented diagnosis of autism
- the literature in relation to the experiences of mothers raising girls before autism was a consideration was scarce and therefore the search was widened to include parents raising children who had an autism diagnosis both within the UK and internationally.

This search provided an opportunity to identify literature to be reviewed that was relevant to the questions that the researcher was pondering.

What does the literature say about -?

- the gender disparity and how existing research captures the girls?
- autism traits and characteristics in cognitively able girl - is there a female phenotype?
- the experiences and impact of parenting a child with autism prior to the consideration that they could be autistic?

Part 1 -An Overview of Autism

2.3 Definition of Autism

Individuals who are described as having autism are commonly understood to experience difficulties with social communication and to have an inflexible style of thinking (APA, 2013). The autism diagnostic process in the UK is a service led by the National Health Service (NHS), whereby professionals involved, compare a person's behaviours against a behavioural checklist (NICE, 2011) as a consequence medical language and terminology tends to be used when describing autism.

The definition of autism is still embryonic, and a number of definitions are proposed in the research literature, the more popular ones include:

- The National Autistic Society (NAS)

'a lifelong, developmental disability that effects how a person communicates with and relates to other people, and how they experience the world around them' (NAS, 2020, p.1).

- The ICD 10 defines autism as

'a pervasive developmental disorder defined by the presence of abnormal and/or impaired development that is manifest before the age of 3 years, and by the characteristic type of abnormal functioning in all three areas of social interaction, communication, and restricted, repetitive behaviour. The disorder occurs in boys three to four times more often than in girls' (ICD-10 Version: 2010, Chapter 5, F84.0).

N.B. Since this research was carried out the ICD 11 has superseded the ICD 10 however, there is nothing in it which substantially alters the argument in this thesis.

The definition of autism has changed over the years and it is still evolving. Capturing a definition from the different sources examined can be summarised by the description of autism as a life-long pervasive developmental disorder which is characterised by difficulties in communication, understanding of social situations together with a deficit in being able to think flexibly.

2.4 Causation

The majority of experts in the field of autism consider that there isn't one single or specific 'cause' for autism and it is an area that continues to be investigated and reviewed, (NAS,

2020). Research suggests that autism develops from a combination of genetic and non-genetic or environmental influences. Like autism itself there are a diverse range of theories that try to capture what autism is. There are theories that endeavour to capture and explain the autism traits at a genetic level, others look at variations in brain activity and some have a focus on the psychology of the condition. Evidence is in addition accumulating to suggest that autism can be caused by a range of different physical factors, all of which effect brain development. There are a number of different cognitive and psychological thoughts emerging that capture the autism symptoms (Silberman, 2015; NAS, 2020). Original proposed theories that considered emotional deprivation or the way a person has been brought up could cause autism have been discounted (Bettelheim, 1967). Kanner (1943) regarded autism as a cognitive disorder and thought of in terms of a 'deficit model' which is focused on causation and treatment. In a similar manner the work of Simon Baron-Cohen sits within this cognitive deficit model (Baron-Cohen, 2002 & 2003).

On the other hand, new beliefs developed which explain the autism symptoms as a result of genetic influences. Happe (2018) recognises that there is little agreement, even among top autism researchers, about causation. She states that the 'holy grail' of autism research seems to be identifying the genes that cause autism or knowing which parts of the brain are affected. No single gene for autism has yet been identified. There is also some growing recognition of environmental influences including a number of controversial ideas like the effect of age of parents, exposure to drugs or toxins invitro, diet and vaccines on the development of autism symptoms (Grabruker, 2012).

In the UK between 2007 and 2011, £21 million was spent on research with a major focus on projects to support reducing autism symptoms and identifying causes of autism (Pellicano et al., 2014). In reality, what is becoming more evident as research continues is that scientists believe there are a number of causes of autism, involving both genes or the environment, or a combination of the two.

2.5 National Context

Autism is classified as a disability under the Equality Act (2010). The Autism Act was passed in England in 2009 and this has helped to embed autism into the local commissioning of services. This act guaranteed the rights of autistic adults in England and it is England's only law aimed at improving support for people with one particular disability. The Autism Act (2009) was

designed to bring about changes in the way adults with autism were treated by local authorities and NHS organisations. This Act is the only condition-specific legislation of its type in England and although references adults, has been used in many areas to campaign for 'All-age Autism Strategies'. The Act provides full statutory guidance here for Local Authorities (LA) and NHS organisations to support the implementation of the Adult Autism Strategy

The UK Government has also published an autism strategy for adults (Department for Health (DH), 2010), which was updated in 2015 (DH, 2015). The strategy set out a number of key actions and recommendations for central Government as well as for local authorities, the NHS and Jobcentre Plus, and it focused on five key areas:

- increasing awareness and understanding of autism
- Grant
- improving access to the services and support people need to live independently within the community
- employment
- enabling local partners to develop relevant services to meet identified needs and priorities.

The Autism Act (2009) is supported by 'Think Autism', (April, 2014) which is a strategy for meeting the needs of autistic adults in England. The Department of Health and Social Care (DHSC) and the Department for Education (DfE March 2019) have been reviewing their autism strategy to include children and adults and the review has recently been published in July 2021. The All-Party Parliamentary Group (APPGA) on Autism has met to consider:

- what has worked well?
- what hasn't worked well?
- what needs to change?

The APPGA aimed to review the current state of care and support for autistic children and adults and to secure additional support and funding.

2.6 Prevalence of Autism

A review of the research found that the estimated global prevalence of autism is 1.04%, equivalent to 700,000 autistic people in the UK (Baron-Cohen et al., 2009). Recent UK estimates indicate an increasing trend, estimating 1 in every 100 children have ASD (Baird et al., 2006; Baron-Cohen et al., 2009). These conclusions are based on a sample of school-aged

children in the UK. It is recognised that patterns in incidence of autism may be dependent on the local system of assessment and the diagnostic criteria used. In a recent study where there was a re-examination of all studies on gender ratio it was reported that autism is thought to be three times more common in men than women (Loomes et al., 2017). Researchers have suggested that autism may be under-diagnosed in adults, females, gender-fluid and non-binary people, and those from ethnic minorities (UK Parliament, 2020).

2.7 A Historical Overview of Autism

Eugene Bleuler, a Swiss psychiatrist, originally used the term 'autism' to denote a state of social withdrawal (Bleuler, 1911, in Kanner, 1943). During the 1940's, Kanner an American psychiatrist identified five key diagnostic elements based on observable behaviours which were used to describe the condition (Kanner, 1943). Kanner described autism in children as appearing not to be engaging with their external environment (Evans, 2013). Kanner's theory resulted in a very narrow definition of autism and Wing and Gould (1979) identified a group of children who did not fully meet Kanner's criteria, and they revolutionised the understanding of autism and described the 'triad of impairments.' Their seminal work defines autism as experiencing a difficulty in; social communication, social interaction and restricted interests and repetitive behaviours (Russell et al., 2011). The concept of the triad of impairments was helpful as it provided a recognisable and classifiable structure with which a diagnosis could be reached (Cashin & Barker, 2009). Wing and Gould (1979) at this time, focused attention on the work of Hans Asperger (1944) who described the variation in areas of difficulty individuals with Asperger syndrome experienced. This broadened thinking and Wing et al., described the triad of difficulties that encompassed autism as a spectrum of difficulties. Asperger also recognised that there was a familial link to the condition effecting adults as well as children and that it occurred across the intellectual ability range (Chown and Hughes, 2017). Whilst Asperger's definition of the condition recognised that individuals with autism could have strengths and unique skills, both his and Kanner's autism models were based on a deficit, medicalised model of the condition.

The concept of the triad of impairments was helpful as it provided a recognisable and classifiable structure with which a diagnosis could be reached (Cashin and Barker, 2009). It formed the basis of a revised version of the Diagnostic and Statistical Manual of Mental Disorders 3 - Revised (DSM 3, APA 1987). At this time Asperger's was considered as a separate

diagnostic category. The most recent version of the DSM 5 (APA, 2013), now incorporates Asperger's Syndrome under the autism umbrella. Kanner's perspective of autism came to dominate mainstream autistic theory and this early exploration of the condition still underpins the current diagnosis of autism as outlined in the DSM 5 (Coury, 2013). The DSM 5 describes a substantial review of the diagnostic criteria based on just two overarching criteria that are the areas for an autism diagnosis. The two areas described are namely social communication and social interaction difficulties and restricted, repetitive patterns of behaviours or interests. This inclusive diagnosis has caused controversy amongst the autistic population as it is perceived as being very broad. The new diagnostic criteria have also influenced the increased prevalence rates (Russell et al., 2014).

2.8 Theoretical explanations of autism

Since the conception of autism by Leo Kanner (1943) many theories have developed to explain the confusion behind this disorder. There have been various attempts to provide causal models to explain the wide range of traits presented by those with autism. In education, understanding from a cognitive perspective provides the basis for many interventions. Various theoretical concepts to explain the impact cognitive dysfunction has on autism have been developed and three of these will be discussed briefly. Baron-Cohen et al., (1985) proposed that a lack of Theory of Mind (ToM) was the central deficit found in autism. ToM is described as an ability to read the beliefs, intents and desires, of themselves and others and to have an understanding that other people have beliefs, desires, intentions, and perspectives that are different from their own. ToM is thought to occur in typically developing children around the age of three (Baron-Cohen et al., 1985). Not understanding others have thoughts different to their own, can create challenge in social communication and interaction skills. Central Coherence theory offered by Frith (1989) centres around an information processing style associated with autism. Some children and young people who are diagnosed with autism demonstrate relative strengths or special abilities, for example being able to memorise by rote. Frith (1989) proposed that these patterns of relative strengths among difficulties can be explained by weak central coherence. This theory suggests a limited ability to see the "big picture". This can present as a strength in processing details but it makes it difficult for those with autism to understand a wider context. Executive Dysfunction a theory proposed by Ozonoff (1997) where executive functions are those skills responsible for planning,

monitoring, inhibiting and selecting different actions. Ozonoff proposed executive dysfunction as a central cognitive defect in autism and suggests it offers an explanation for behaviours such as rigidity, repetitive behaviour and difficulties with change (Ozonoff, 1997).

Cognitive theories have successfully explained the typical abnormal behaviour seen in autistic children. Conversely, cognitive theories have their weakness in explaining the whole picture of autism. Also, the deviance in the autistic characteristics between different children effected by autism could not be explained by these cognitive theories. A further limitation of using cognitive theories to explain autism as a fixed cognitive impairment instead of considering a developmental approach to understand autism differences.

The historical assumption that autism is predominantly a male disorder (is being challenged current research is challenging the narrow-stereotyped view that autism mainly effects males) DELETE, is now being challenged (Starke, 2018; Gould, 2017). The assumptions are influenced by later theories including the 'extreme male theory' of autism proposed by Baron-Cohen (2003) which attempted to address the gender disparity in autism. This theory suggested that brains in both sexes were functionally and structurally more masculine than expected (Baron-Cohen 2002). Baron-Cohen argued that people with autism match an extreme of the male profile with an intense drive to systemise and a low drive to empathise. This leads him to propose that the male brain is more 'autistic' and therefore autistic females have 'male' brains This theory has been challenged by others who suggest that this theory may inadvertently favour boys when autism is diagnosed. Bird and Viding (2014); Krahn and Fenton (2012) argue that if this theory was correct, it could have detrimental consequences for treatment and services for females with autism. An alternative theory that has received support from a number of studies is the 'female protective effect' (Skuse,2000). This theory argues that females require a higher 'load' of the factors that cause autism before they show diagnostic signs. Robinson et al., (2013) considered a number of studies that tested for the female protective effect to consider autism or numbers of autism traits in girls versus boys. Robinson argued that if girls have a larger genetic load than boys it is more likely their siblings may be autistic compared to the siblings of boys and concluded this was the case in the studies reviewed. Messinger et al., (2015) found this not to be the case and found no similar associations in his studies. Furfaro (2019) suggests despite discrepancies that there is currently more evidence in support of the 'female protective effect'. Many traditional

theories help to maintain the status quo of autism as a male disorder and it is crucial to look beyond these theories when considering the female population.

2.9 Diagnosis Process

The autism umbrella is vast in its range of abilities and disabilities. It is a fluid diagnosis that does not have a definite beginning or a certain end point, (Holliday-Willey, 1999). Autism is possibly one of the most misunderstood developmental disorders. There is neither a definitive test nor a standardised assessment format for autism. The outcome of the assessment process is therefore subjective and reliant on the quantity and quality of the evidence and the experience of the clinician. Wing and Gould proposed that autism is characterised by a 'triad' of symptoms following their 1979 epidemiological study, carried out in London (Wing & Gould, 1979). For many years this was reflected in the two main diagnostic manuals, International Classification of Diseases, 10th Edition (ICD-10. World Health Organisation [WHO], 1992) and Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM 4. American Psychological Association [APA], 2013), which provided a diagnosis of 'Childhood Autism' and 'Autistic Disorder' respectively. A number of other terms namely, Asperger's Syndrome (AS) and Pervasive Developmental Disorder (PDD) were used for those who met some of the characteristics described by Wing (1981). The most recently published criteria for diagnosis appears in DSM 5 (APA, 2013). There is now a single diagnostic category of 'Autism Spectrum Disorder', and all other subdivisions have been dropped.

In 2013, new criteria were published in the DSM 5 for Autism Spectrum Disorder which encompassed each of the previous subgroups (APA, 2013). These criteria are split into two main areas for consideration:

- Deficits in social communication and social interaction-including social-emotional reciprocity, nonverbal communication and developing relationships
- restricted, repetitive patterns of behaviour-including insistence on sameness, fixated interests and hyper/ hypo activity to sensory input.

These two all-encompassing diagnostic categories are frequently referred to as the "dyad of impairment" and highlight the structural nature of autism (Lai et al., 2014, p. 896).

Lai et al., (2014) maintains to meet the DSM 5 criteria for autism spectrum diagnosis, an individual must display 'persistent deficits in social communication and interaction', (p. 896)

and 'restricted or repetitive behaviours and interests', (p. 896). These 'symptoms' need to have been present during the child's early development and must be causing 'clinically significant' impairment of the individual's functioning (APA, 2013). The World Health Organisation, International Classification of Diseases (ICD-10) (WHO, 1992) has similar diagnostic criteria to DSM 4 (Hassall, 2016). Autism can be diagnosed alongside learning difficulties (LD) and other medical disorders and conditions (NICE, 2011). Notably, the sensory needs of those with autism (Bogdashina, 2003; Leekam et al., 2007) have been included in the DSM 5. The DSM 5 also provides three levels of severity descriptors with the purpose of establishing support needs. In the UK the ICD-10 is more frequently used, it is assumed that these criteria will also be revised in the ICD -11 to reflect the changes in the DSM-V, (The ICD-11 is currently a consultation document, and it is due for clinical use in January 2022).

In the UK today autism in children and young people (CYP), is currently diagnosed by a multi-agency team in a clinical setting; this team will usually include health professionals but can also include educational psychologists (NICE, 2011; Brown and Paterson, 2013). The diagnostic procedures vary depending on the local health pathway. Assessment will usually include a discussion with parents, including a developmental history, and observations of the child or young person (NICE, 2011). It is only relatively recently that sex differences have been considered when using the commonly used diagnostic criteria in the DSM and the ICD, (Gold & Ashton Smith, 2011 and Lord et al., 1982). The updated DSM 5 mentions sex differences for the first time. The DSM 5 suggests that girls without intellectual disability will not be recognised by current criteria as having autism. Mandy (2013) argues that this has provided an arena for researchers to consider the characteristics for the recognition of a female phenotype and Frazier (2014) suggested sex-specific norms for some of the diagnostic processes may be helpful.

Part 2 - Autism and Girls

2.10 Gender Disparity

Traditionally autism has always been considered as a predominantly male disorder and cognitively able females have been missed from the statistics. Lorna Wing in her 1981 paper on sex ratios in early childhood autism, found that among people with 'high-functioning autism' or Asperger's Syndrome there were fifteen times more men and boys than women and girls, while in autistic people with learning difficulties, the ratio of men and boys to women and girls was closer to 2:1. The diagnosis was based on behaviour including difficulties in social communication and interactions in addition to repetitive and rigid behaviour and interests.

During the last decade as a consequence of an increased awareness to understand why girls have been missed from the autism statistics a number of studies have explored differences in the gender balance. The research is beginning to explore the diagnosis process in response to the 1:4 gender bias. The diagnostic tools used primarily to make a diagnosis of autism have been predominantly based on data that has been gathered from studying boys (Evans, et al., 2018; Mandy et al., 2016; Head et al., 2014).

The research understanding the imbalance between the male and female representation advocates that the girls are 'research orphans' (Shefcyk, 2015, p.131), meaning that they are frequently underrepresented in the research. Often when girls are included, the statistics may be skewed towards girls with more severe difficulties (Kreiser & White, 2014). The cognitively able girls are more frequently diagnosed at a later age and this can offer further explanation for their absence from research literature (Rutherford et al., 2016; Begeer et al., 2013; Siklos & Kerns, 2007).

While evidence remains relatively sparse in terms of the under-recognition of girls with autism it is growing and the challenges in the literature are often because:

- there are only a few small-scale studies that have been published focused on females with autism (research studies prior to 2007 rarely had more than 25 female participants enrolled and/or spanned a large age range)
- the girls included in studies are of mixed ages and IQs
- there are only a few comparisons to neuro-typical development in girls

- assessments are limited to diagnostic tools that are male biased
- there are no specific language or communication assessments.

To date regardless of the rise in interest in gender difference there remains insufficient awareness of knowledge about how autism presents in intellectually able girls and women which prevents the correct diagnosis (Eaton, 2018). Existing research that explores autism in females is beginning to provide explanations and an understanding as to why girls have been missed from the statistics. Researchers are beginning to recognise that the girls are presenting differently from the boys which could be considered as a contributory factor towards professionals previously under diagnosing the female population unless they have additional cognitive deficits (Lai et al., 2015). Current studies suggest that there are many girls who are described as cognitively able who are frequently unidentified. Happé (2012) found that when girls and boys displayed similar autism-spectrum traits, girls had to either exhibit more behavioural problems or have significant intellectual disability, or both, in order to be diagnosed (Szalavitz, 2016). Traditional developments in the field of autism subscribe to the belief that in line with a range of developmental disorders males are inherently more likely to have autism. In the existing research a predominant theme across disability categories is that the average girl with a given diagnosis generally has a lower IQ than the average boy with the same diagnosis (Arms et al., 2008; Mandavilli, 2015).

Recent trends in research are beginning to challenge the autism imbalance and are questioning the presentation of autism in females, which is making it more complex to diagnose and consequently when girls do receive a diagnosis it is at a later age than boys. (Giarelli et al., 2010; Eaton, 2012; Begeer et al., 2013; Hurley, 2014; Hiller et al., 2014; Mandaville, 2015; Duvekot et al., 2017). Frequently these girls are often misdiagnosed and/or identified with another disorder prior to being diagnosed with autism. Evidence is expanding steadily and gender variance studies are increasingly documented both in the UK and internationally (Rubenstein et al., 2015; Strang, 2014 & 2018). These studies are proposing a range of hypotheses and theories to offer explanations to why girls are less frequently diagnosed with autism. Researchers believe that previously, many girls were being missed because their symptoms look different and the current definition of autism and how it is diagnosed, is based on a male-centric presentation that does not accurately reflect the disorder in girls, (Sutherland et al., 2017; Pelphrey 2015; Dworzynski et al., 2012; Gould and

Ashton-Smith., 2011). Together with the descriptors of behaviours in the International Classification Systems, these explanations have been deemed as being responsible for gender stereotyping by professionals (Gould & Ashton-Smith., 2011). Saris (2015) suggests that the gender ratio would be different if diagnostic tests and medical practitioners sharpened their focus on autism in females.

There is increasing awareness that girls who meet the criteria for autism are undiagnosed or misdiagnosed, often with other mental health conditions (Lai and Baron-Cohen, 2015). Nichols et al., (2009) suggest that the older the girl, the more alternative diagnoses she is likely to have been given prior to an autism diagnosis. This is particularly evident in girls with intelligence in the average or above average range (Yull-Smith, 2008; Gould & Ashton-Smith., 2011; Hiller, 2014; Baldwin & Costley, 2015; Mandaville, 2015; Szalavitz, 2016). Researchers and clinicians are beginning to recognise that often these alternative mental health diagnoses for example, anxiety, depression and anorexia nervosa can be a barrier for a girl not getting the recognition that she has autism. Many of these girls are described in the literature as 'internalising' their difficulties and it is these difficulties that underpin the emotional and mental health difficulties that they are experiencing (Livingston et al., 2019; Duvekot et al., 2017; Hull et al., 2017; Baldwin & Costley 2015; Rubenstien et al., 2015; Corocombe et al., 2006, p.15 in Eaton, 2018), and it is argued that autism is frequently missed as their primary diagnosis. The literature on gender differences particularly during the last ten years has demonstrated an increasing awareness that statistics have missed out women and girls with autism. It is important to appreciate why girls have been missed including gaining an understanding of the presentation of autism in cognitively able girls so they are understood and identified more accurately. Research in both the UK and the USA shows that girls are significantly less likely to be diagnosed with autism than their male peers even though they have similar levels of characteristics (Baldwin and Costly, 2015; Cheslack et al,2012).

2.11 Identifying Autism in Girls

While the increasing research is considering differences in males and females including the existence of a female phenotype it is also clear that some autistic females may present similarly to autistic males. Consequently, distinguishing between the characteristics in males and females with autism is a complex and challenging process. The majority of research data is based predominantly on male samples and the tools developed, have mainly been designed

to identify the autistic males and they are possibly not sensitive enough to recognise the differing female traits (Loomes et al., 2017; Lai et al., 2013).

While there continues to be a debate about whether there is a fixed female phenotype both actual and perceived distinguishing characteristics are beginning to be more accurately recognised in the literature. These traits are contributing towards the evidence supporting the increased recognition of those girls who are cognitively able (Dworzynski et al., 2012; Lai et al., 2013). Even though specific areas are identified the overlap between them is evident and despite an attempt to separate them there are times when they are intrinsically interlinked. Those most frequently identified in the literature include:

- Language and communication
- Restrictive and Repetitive Behaviours and Interests (RRBIs)
- Social play
- Friendships
- Camouflaging and masking
- Mental Health

These will be discussed in turn to consider their pertinence to cognitively able girls.

2.11.1 Language and Communication

Girls with autism are described as having a greater skill for language acquisition, better communication skills (Andersson et al., 2013) and can appear more socially motivated than their male peers and appear to want to fit in with the neuro-typical world. These girls are often described as having fewer communication and social difficulties and are often less extrovert in their behaviours providing explanations for the under recognition of autism in females (Mandy et al., 2012; Lai et al., 2011).

It is already believed that differences in language development exist between typically developing males and females (Weiss et al., 2006). Additionally, there may be crucial differences in the development of all boys and girls with autism and that the evidence in the differences in the acquisition of early language skills can assist in the understanding of what protects girls from autism (Burger-Caplan et al., 2016). However other research comparing early social skills and language development in boys and girls have described them as equivalent (Hartley & Sikora, 2009; Andersson et al., 2013; van Wijngaarden-Cremers et al.,

2014; Harrop et al., 2015; Reinhardt et al., 2015). Some studies have found some evidence of greater early language problems in girls (Hartley & Sikora 2009) and others have identified better core language in girls, particularly at later ages (Hiller et al., 2016; Halladay et al., 2015; Messinger et al., 2015; Goddard and Howlin, 2014). These findings are supported by other studies including Lai (2011); Eriksson (2012); Cheslack-Postava and Jordan-Young (2012) Goddard and Howlin (2014) Hiller et al., (2015) who report that the language ability including verbal fluency and reciprocal conversation of cognitively able females is inclined to be higher than those in boys. These arguments add to the research literature providing insight into why girls with average and above language development in line with peers can be missed or not considered in terms of autism.

Social communication skills are often described as deficient when a diagnosis of autism is being considered. Holtmann et al., (2007) looked for and identified clear differences between girls and boys in their social communication skills and described girls with autism as being better at using non-verbal communication. Hiller et al (2016) later demonstrated while this is true these girls with autism struggle more to interpret non-verbal communication and signals. Mandy (2018) describes a group of girls whose social difficulties may not be presenting until adolescence and argues that it is not yet clear why these problems escalate during adolescence. Mandy suggested that it possibly relates to the increasing social complexities in the social environment for them at this crucial time in their lives. Georgiades (2018) supports Mandy's findings concluding that increasing social demands around the adolescent years exceed capacity, particularly for females and the challenges increase. Gould (2017) also examined language differences when diagnosing autism in females compared to males.

Gould (2017) discusses differences in diagnosing autism in girls compared to boys. Gould compares Asperger's use of the term 'little professors' i.e. those boys with excessive knowledge about obscure subjects to her description of girls with autism as 'little psychologists', who show fascination in the minds and the behaviour of people around them. Many of the cognitively able girls captured in the research to date are described as having profuse speech and are advanced in terms of vocabulary and quantity and this positive skill can potentially add to the reasons why these girls may be overlooked or under diagnosed (Sturrock 2020; Boorse 2019; Atwood 2011-2013).

Girls are described as having language strengths in terms of being able to have more verbal interactions and their eye gaze is described as less problematic compared to boys with autism. In terms of language linked to social complexities the middle school years for girls can be especially revealing and challenging. Being an atypical girl in the often-ruthless environment of girls when growing up can be very painful, it is often difficult enough for many teenage girls who are neuro-typical. Language has always been part of the diagnostic criteria but it has been dropped from the new DSM-V criteria in terms of it as a distinct measure which could be a further challenge when considering an autism diagnosis for girls.

2.11.2 Restrictive, Repetitive Interests & Behaviours (RRIB)

The evidence in the literature with a focus on gender differences referencing restricted and repetitive interests that would contribute towards a diagnosis of autism is mixed. The familiar autistic mannerisms that have been identified in the research about boys and autism are linked to primarily studying boys with autism and include boys lining up toys, an interest with spinning wheels or parts of objects, or fascination with trains, motors, video games, or mechanical objects. Researchers including van Wijngaagden-Cremers et al., (2014); Frazier et al., (2014); Mandy, (2012); Zwaigenbaum, (2012) have suggested they are present in the girls to a lesser extent. Hiller et al., (2014 & 2015) identify that girls' obsessions and interests are different from those of the boys for example, girls are less likely to organise in categories or to line things up and their interests are more similar to those of their peers. Equally, while the research suggests that the girls with autism seem to have fewer RRIBs than boys there is always a debate that it is possible that some of the behaviours go unrecognised because girls are doing something that may be more invisible or hidden. Hiller et al., (2015), identified that girls appear to have more random obsessional interests from a young age through to teenage years. Conversely, because their interests are more similar to those of typically developing girls and they do not create a barrier or get in the way of family life, they are often missed. In a similar way Sutherland et al., (2017) identified the girls' interests in fashion, hair, nature and soap operas as being very different and more mainstream than the boys whose interests included pylons, trains and space. As a consequence, these obsessions and rituals do not show up as obviously in girls because they appear to be less unusual, intense or disruptive in nature so they are not identified by the usual screening tools (Lai & Baron-Cohen, 2015; Hiller et al., 2014; Mandy et al., 2012; Zwaigenbaum et al., 2012; Kopp & Gillberg 2011; Hartley & Sikora

2009; Kopp & Gillberg 1992; Lord et al., 1982). Jamison et al., (2017) reviewed the experiences of clinicians including gathering their opinions and perceptions of how severe symptoms of autism in both females and males are presenting at key stages in their development. The findings in this research were consistent with previous research findings showing that increased differences were found in restricted and repetitive behaviours and less differences for social communication features. Evans (2018) identified that girls had to have more severe social communication difficulties than boys to be diagnosed with autism, the study found no differences in the restrictive and repetitive interest between the boys and girls. Gould and Ashton-Smith (2011), Mandy et al., (2012); Sutherland et al., (2017), recognised that girls with autism have interests that are not dissimilar from their neuro-typical peers, and they have been found to show less repetitive behaviours. The significant difference in girls is that they pursue their interests with an autistic intensity.

In summary, girls with autism are considered to have fewer or less intense restricted and stereotyped behaviours than males with a diagnosis however they can demonstrate similar levels of routines, stereotyped movements and preoccupations (Muggleton et al., 2019; Hiller et al., 2015; Mandy et al., 2012). Their special interests appear more socially typical and less idiosyncratic and can go unnoticed by professionals or parents (Attwood, 2007). The literature is recognising that what is becoming more noticeable is that the RRIBS can be similar to those of their peers but different in the level of intensity. Currently these differences in presentation of autistic symptomatology mean that females with autism do not fully fit the model of autism proposed within the triad of impairments and the observational diagnostic toolkits and criteria on which a diagnosis is based suggesting that their difficulties in these areas can be missed by clinicians and professionals.

2.11.3 Social Play

There is a growing body of evidence to advocate that females with autism have a greater level of motivation to develop compensatory skills which makes them appear socially typical (Attwood, 2007, Lai et al., 2011; Mandy et al., 2012). The research examining social play concludes that girls with autism are more effective at masking their social challenges and their social interactions are qualitatively unlike those of boys with autism. Autistic girls are being described to be more focused on social interactions when compared to autistic boys but what is apparent, these girls tend to be not as successful using their social skills when in the vicinity

of their peers (Dean 2017). Girls with autism are reported to demonstrate different play skills compared to boys and their neuro-typical peers and observation of girls with autism in play has shown that they will often appear to have more passionate imaginative play skills acting out scenes from home or television (Grant,2018, in Carpenter et al., 2016).

Autistic girls are reported to have intense interests in animals and people rather than objects and they may be similar to those interests of their neuro-typical peers (Atwood et al 2007; Hiller et al., 2014) so therefore appear to fit in better and are not perceived as having unusual interests. Kickmeyer et al., (2008) identified there is more pretend play in girls and that the imaginative play of girls with autism is more like their neuro-typical female peers. Girls have a preference to play with girl toys and choose gender typical play (Harrop et al., 2016; Dean et al., 2014; Hiller et al., 2014) and autistic girls have been observed to spend less time in play and they demonstrate symbolic play in their activities (Harrop et al., 2016). Dean et al., (2017) reported that cognitively able girls with autism appeared on the surface as not unlike their neuro typical peers, instead they mask or camouflage their traits. This is supported by Sedgwick et al., (2019) whose study proposed that when observed more closely girl's play skills can be superficial and offer explanations about how their autism can be missed or not be a consideration. In the research the girls were described as struggling with being able to maintain shared interactions with their peers, and they were unable to identify and make sense of the non-verbal social interactions (e.g., rolling of eyes, sharing glances, giggling, or smirking) resulting in girls regularly misreading the emotions of their peers. While there is some agreement amongst researchers there continues to be a need for further clarification to understand if social play traits are an amplification of subtle pre-existing traits in early childhood or is it the case that girls genuinely develop these difficulties later in life. Typically, gendered play is often encouraged by parents and girls are encouraged to engage in co-operative pretend play and more active physical play is encouraged for the boys, a possible predicting factor in developing friendship and play patterns. Girls are also recognised as reaching complex linguistic and social development earlier than their male peers which may contribute to their ability to form relationship-based play or co-operative play and reciprocal conversation more readily than boys (Barbu et al., 2011). Gould (2017) is in agreement that differences in social communication including their interactions could coincide with

challenges girls face when they reach adolescence and these findings have been replicated by Mandy et al., (2018).

2.11.4 Friendships

Girls may appear to develop social relationships, but it may be with one individual replicating a maternal attachment and someone who is 'safe' (Attwood, 2007, p.59). The sources to date propose the research is identifying girls as having different friendship and social skills to boys (Holtmann et al., 2007; Lai et al., 2011). The research outcomes for girls with autism suggests that they are more likely to have some friendships (Head et al, 2014; Hiller et al., 2014; Mandy et al., 2012) but, what is becoming more apparent for these girls, is the nature of the friendships. The literature has highlighted that the quality of these friendships may be a challenge for the girls particularly as they may not recognise or be aware of the changes in the social climate and dynamics and this could be why girls would tend to be described as 'neglected', rather than 'rejected', by their peers (Dean et al., 2014, p.7). Head (2014) also noted girls as being more responsive to friends than their male peers with autism but, less responsive to friendships than their neuro-typical female peers. Data from a number of studies have noticed that often friendships for girls with autism are with older peers who will take on a mothering role with them or they form friendships with younger peers who they then are in charge of and where they can control games and activities they play. Studies have also concluded that the social expectations are reduced in friendships for the girls with autism who are likely to have fewer friends and become over reliant on particular friendships (Tierney, 2016; Dean, 2014 Hiller, 2014; Atwood 2007). Often a difficulty identified for girls with autism in previous studies is they have to work hard to maintain and make friends (Dean et al., 2014). It is also reported in a number of studies that girls are often less able to recognise aggressive social behaviour in friendship groups, they struggle to recognise that they have arguments with friends during the interviews even though they reported them in the questionnaires (Sedgwick, 2016). Girls with autism are reported to have more difficulties interpreting others. They may find friendships and relationships more complex when they reach adolescence which coincides with the development of their sexual identity. Additionally, at this time there are changes in social groups with a movement to secondary education and social expectations begin to change (Tierney 2016). Sedgwick (2016 & 2019) established that girls with autism displayed comparable social motivation and friendship

quality to girls without autism however, positive friendships were more important to girls with autism than the right friendship. The girls in this particular study were found to be able to make appropriate conversations that were central to friendships compared with the boys with autism and they were described as struggling more with resolving conflict which often resulted in social isolation. While there is a vast volume of research on bullying there continues to be a deficiency of research on bullying that particularly includes cognitively able girls including adolescents with autism. Adolescence is a time of changing social dynamics and expectations and for girls with autism who experience difficulties in negotiating social environments and relationships, this can be a particularly challenging period (Nichols et al., 2009). There are a few studies that discuss conflict with friendships including 'relational aggression', 'relational bullying' or 'relational conflict' (Nichols et al 2009), including issues about gossiping, inferring in relationships, excluding individuals socially and 'stealing' friends. Research to date has interestingly highlighted that there are gender differences in friendships and the autistic girls are more likely to experience relational conflict compared to autistic male peers in the same way as neuro-typical girls are more likely to experience relational conflict compared to their neuro-typical male peers (Bowie, 2007). Sedgwick and Pellicano (2019) described adolescent girls with autism as often having supportive and close friendships nevertheless, these same girls can be subject to bullying, which parents report compromises their mental health. Sedgwick also identified the role of social media and online interaction being equally as important to autistic girls and their peers. The social media can often act as a positive concrete reinforcement of friendships because it is allowing for written interactions including more processing time when there are online conversations between friends.

Stereotyping could influence the gender debate when considering autistic characteristics in girls because of the social expectations amongst clinicians and parents when considering the differences in relation to friendship skills between boys and girls (Goldman, 2013

). This is supported by the recent research that argues that girls would need to experience significant social impairments and difficulties with friendships to be considered for a diagnosis of autism when compared to male peers (Evans, 2018). For many autistic girls and young women there is growing evidence that they will have an increased risk of experiencing issues with friendships, relationships, bullying and harassment. These difficulties may well contribute towards their significant mental health problems (Eaton, 2018).

2.11.5 Camouflaging and Masking

Camouflaging has become a term linked to girls with autism to describe how they hide their autistic difficulties, and it has recently become a popular term in the literature and an understanding of the purpose of camouflaging may reveal why girls have been missed from the statistics. 'Camouflaging' is described as using learnt strategies to conceal social difficulties, Hull et al., (2017). It is a term that has become associated with describing a behaviour in cognitively able girls whose autism traits and characteristics are hidden. Clinicians and researchers are increasingly describing camouflaging in females, in contrast to males, with autism (Mandy, 2018; Attwood, 2006; Gould and Ashton-Smith, 2011; Kopp & Gillberg, 1992; Lai et al., 2015; Marshall, 2015). A number of research studies have found that females with autism and their parents consider camouflaging as one of the major reasons females often go under-recognised until they can no longer compensate and mask their difficulties, (Ernsperger & Wendel, 2007; Hendrickx, 2015). Bargiela et al., (2016) & Dean (2017) suggested that camouflaging behaviour by its very nature, is often not obvious to observers. Dean et al., demonstrated that girls with autism mask or camouflage their difficulties in different ways and these girls are similar in many ways to their neuro-typical peers. Mandy et al., (2016) described the effort of pretending to be neuro-typical as wearing and disorienting, and several women thought that it was a factor in the lateness of their diagnosis. It is becoming more established in the research that women often 'camouflage' their autism however, it is not just specific to females and males can be also described as camouflaging their difficulties. Stark (2018) suggests that perhaps camouflaging is explained by social motivation to fit in with peers rather than being a distinguishing feature between genders. Mandy (2018) suggested that camouflaging becomes more significant with the increasing complexities of adolescence and suggested that in younger girls camouflaging masks any childhood characteristics that had been apparent.

A number of studies demonstrate that clinicians and other professionals find it more difficult to identify the difficulties in social communication and interaction in able girls because of their masking and camouflaging which reduce the visibility of their symptoms (Dean et al., 2017; Lai et al., 2017). Dean et al., (2017) and Tierney et al., (2016) reported that many girls with autism don't want to stand out and getting life right can be extremely challenging for them. Research describes the cost of camouflaging for many females including the effort and desire

to fit in with the neuro-typical world creates anxiety and stress which often results in mental health difficulties and missed autism diagnosis (Krahn and Fenton, 2012). The need to mask and imitate behaviours is a major contribution to the exhaustion girl's experience. For many of these girls the consequence is described as a 'meltdown' at home following an exhausting day in school, camouflaging for these girls can be socially debilitating, (Livingston et al., 2018).

To date a number of studies including Livingston, (2019); Crane et al, (2018); Hull et al, (2017) maintain that camouflaging within the social environment has contributed to the under recognition and diagnosis of autism in females. A recent research study has proposed a tool that could help identify camouflaging strategies which could further facilitate the identification of masked symptoms and difficulties in these girls that will in the future support their more timely diagnosis, Livingston et al., (2020). Conversely, Fombonne (2020) describes camouflaging as one of a number of coping strategies and proposed the understanding of camouflaging and its links to autism is still in its infancy and there needs to be some caution when making a link specifically to females with autism. Fombonne argues that the evidence remains sparse because studies to date have been based on small sample size and involved females who have been diagnosed later in adult life. Further research is necessary to justify if camouflaging is specific to females with autism. A further understanding of camouflaging and its impact is necessary to understand how it influences and effects those who have a diagnosis of autism (Lai et al., 2020).

2.11.6 Mental Health

There is a high incidence and prevalence of mental health problems being identified for girls with autism. The implication is for these girls that they are often missing out on receiving much-needed diagnosis and subsequent support, resulting in negative effects on their mental health and well-being, (Crane et al., 2019). As the research increases the number of studies show that able girls with autism tend to experience depression and anxiety more often than boys with autism, (Hartley & Sikora 2009) or typically-developing girls, which still is being explored to understand why it is the case for girls (Solomon, Miller, Taylor, Hinshaw & Carter, 2012). As understanding of autism in cognitively able girls is growing and the research is providing further evidence that additionally recognises that for these girls there is an increased risk of mental health difficulties (Crane et al., 2018; Simonoff, 2008) if autism in girls is not identified or there are delays in receiving a diagnosis. Rogers et al., (2016) stated that

people with autism are at increased risk of anxiety, and fifty percent of autistic adults and children with autism experience this incapacitating mental health condition. Females with autism are often described as suffering with alexithymia which is the inability to describe their own emotions within the situation they are in which is a further barrier for them (Lawson, 2017). Girls are frequently described as being more passive–aggressive and will often avoid situations rather than cope with increased demands placed on them (Bird et al., 2014 & Lawson, 2017). Yaul & Smith (2008) and Wild, 2019, in Carpenter et al., 2019) argue that the masking and camouflaging suppresses typical social reactions, and it can result in mental fatigue, social isolation and increased anxiety. Wild concludes that anxiety can be a significant characteristic for many if not all girls with autism. Girls with autism may be more concerned with how they are viewed by their peers and the failure to connect with people outside of their immediate family could lead to severe anxiety or clinical depression, (Bazelon, 2007). Research is illuminating that it is often the case that late-diagnosed individuals experience concurrent mental health difficulties related to the stress of continually having to adjust to daily life in a society that demands social proficiency, is full of confusing sensory experiences, and requires people to ‘fit in’ (Lai & Baron-Cohen, 2015). Girls with autism in school are often described as unable to cope with the demands of the classroom and may begin to become school refusers or their behaviours can cause exclusion from school (Sproston et al., 2017). Alternatively, they become the passive, quiet anxious girls at the back of the classroom concealing or masking their complex worries so are missed by their teachers in terms of having difficulties (Tierney, 2016). The emotional disorders are being recognised as being different to those displayed by boys and the girls are described as internalising their behaviours. The immense pressure this puts on the girls with autism over time contributes to their emotional vulnerability and mental health problems including alternative diagnoses for example, anxiety, self-harm, depression, personality difficulties and eating disorders (Hull et al., 2017; Baldwin & Costly, 2016; Russell, 2016; Rubenstein et al., 2015). The evidence is accumulating to indicate that autism may be the cause of many of these underlying diagnoses and the consequences of these difficulties for those with autism is complex and a concern. Research is identifying that individuals diagnosed with autism are more likely to experience stress and anxiety (Simonoff, 2008). Joshi et al., (2013) found a high incidence of psychiatric comorbidity in adults who were diagnosed with autism. Wilkinson (2017) concludes that clinicians and other professionals should consider the possibility of autism when girls are

referred with internalizing disorders including, anxiety or depression. Recent evidence from eating disorder clinics is a realisation that there are links between autism and eating disorders. Westwood et al., (2017) reviewed the existing studies linking autism in girls and Anorexia Nervosa with the intention to examine the most recent research in this area to identify gaps in existing knowledge, ways forward and implications for treatment. Of particular interest was the identification that twenty three percent of girls hospitalised for anorexia met the cut off on autism diagnostic tools and further evidence is necessary to understand if the autism predated the eating disorders and if it is part of a repetitive behaviour rather than an intention to starve (Milner et al., 2019).

Another area that is capturing the interest of the researcher concerns identification and gender identity issue which is a sensitive topic. Gender identity is defined as one's personal experience of one's own gender and can correlate with gender assigned to an individual at birth or it can differ from it completely. Research suggests that women and girls with autism may have more masculine or androgynous neurological profiles (Baron-Cohen, 2002; Berjerot et al., 2012). There is also evidence that 25% of youth gender referrals have significant autism symptoms (Shumer et al., 2015; Skagerberg et al., 2015) and more than five percent of autistic youths have the "wish to be the other gender" (Strang et al., 2014; Janssen et al., 2016). Lawson (in Hendrickx, 2015) states that twenty percent of the autistic population live with gender dysphoria which is a condition where a person experiences discomfort or distress because there is a mismatch between their biological sex and their gender identity. She stresses the importance of sensitivity and respect when working with people with autism.

While cognitively able girls with autism are not as readily diagnosed as their male peers the research is recognising that these girls are more vulnerable because they are more likely to conceal and internalise their problems, and in addition more likely to experience anxiety, depression and eating disorders. There is an increasing awareness of the importance of a timely diagnosis, effective support, and understanding needs, as more about autistic girls is uncovered (Baldwin and Costley, 2016; Hull et al., 2017).

2.12 Capturing the Girls – The Diagnostic Criteria

The diagnosis of autism in England and Europe is captured using the International Statistical Classification of Diseases and Related Health Problems, 10th revision (ICD 10) and the Diagnostic Statistical Manual of Mental Disorders Version 4 (DSM 4). These diagnostic criteria

were originally based on the triad of impairments (Wing and Gould, 1979). In 2013 the DSM 4 was revised by the American Psychiatric Association and the DSM 5 replaced it. The ICD 10 has recently been revised and the ICD 11 reflects changes similar to those in the DSM 5, but it will not be in circulation and use until 2022. The intention of creating the current the DSM 5 was to provide an improvement in the diagnosis of autism. This included moving away from some of the inconsistencies that the DSM 4 had created. Researchers are now considering whether girls and women have found it harder to get an autism diagnosis under the new criteria. Wing, Gould and Gillberg (2011) in their research paper concluded that the DSM 5 criteria may make it more challenging for girls to meet the criteria for a diagnosis.

The DSM 5 dropped language problems as a domain and instead it is captured as part of the social communication requirement. This change means that all aspects of language involving social communication needs to be gathered under this new criterion. The quality of the language used by those being assessed needs to be considered including, the integration of verbal and non-verbal interactions within the social communication domain in the DSM 5. The DSM 5 criteria is recommended to be used as a guide, rather than a hard and fast requirement. Klin (2017) recommends that clinicians should not be expecting girls with autism to behave like boys.

For the first time the acknowledgment of how gender shapes autism has been featured in the DSM 5 which is already six years old. This could potentially provide some clear evidence about the gender ratio which is starting to emerge as being closer to 1:3 supporting speculation that girls, particularly those who have not got an intellectual disability are under diagnosed. The explanation to support the under recognition of girls suggests it is because of the more subtle presentation of their social and communication difficulties and often these girls are not presenting to clinicians with significant social difficulties until adolescence (Mandy et al., 2018). Mandy argues that it is important that the information stated in the DSM 5 is recognised and that the implications for girls are developed to enable diagnosticians to apply the diagnostic criteria in a manner that is sensitive to the presentation of autism in girls. Evidence supporting the gender difference in diagnosis and the under recognition of girls has been challenged by previous diagnostic criteria. A further proposal expressed in the DSM 5 is that autism characteristics may not be as apparent at a younger age and instead it is as social demands intensify that the difficulties become more obvious. The DSM 5 now includes a

statement that although “symptoms must be present in the early developmental period,” these may be “masked by learned strategies in later life,” is harmonious with the broader principle in the DSM 5 that early traits that are no longer obvious can count toward a diagnosis. The evidence in the recent literature suggests that this is particularly relevant to cognitively able girls (Mandy et al., 2018; Dovekot et al., 2017; Bargiela et al., 2016; Sedgewick et al., 2016 Hiller et al., 2015).

A further consideration in the DSM 5 criteria is the examination of “highly restricted, fixated interests,” the diagnosticians often consider male interests, and as a consequent the interests of girls are not recognised, and a diagnosis may be missed. It is becoming more transparent that special interests of the girls are reported to be more mainstream (Gould & Ashton Smith 2011; Kopp & Gillberg, 2011; Jamison et al., 2017; Sutherland et al., 2017). Nevertheless, it is not necessarily the special interests which could differentiate the girls from their peers but instead the quality, detail and intensity of these including the length of time spent engaged in these interests. It is recommended that careful questioning on interests and routines is important (Gould & Ashton Smith 2012), particularly when considering if the girls meet the diagnostic criteria. Mandy et al., (2018) argue that diagnostic tools are biased against the female and if tools have not been adapted or changed the argument could be that the wrong information has been captured, and this will challenge the diagnostic criteria. Until the revision of the DSM 5 in 2013, there was no mention of unusual responses to sensory stimuli. By not including this within the diagnostic criteria, there is perhaps further reason for the reduced numbers of females with a diagnosis. Lai et al., (2011) noticed that females with autism experienced increased sensory issues.

The acceptance amongst researchers, clinicians and professionals that there is a great variation in how autism presents in individuals is becoming more evident. Nonetheless, what is less acknowledged is that autism can change over a lifespan and there are differences in males and females. Mandy et al., (2018) credit the DSM-5 for recognising and encouraging more sensitivity from clinicians towards these differences. Once female differences are fully acknowledged clinicians will be more accurate in their evidence-based understanding of female characteristics in their diagnosis in line with the DSM-5 criteria which will contribute to a more accurate gender picture. Muggleton (2019) concluded that while the current

diagnostic criteria offer fitting attention for the core features of autism, it does not necessarily capture everything about gender difference.

2.13 Concluding Comments:

Part 2 has considered the gender debate and the attributes of cognitively able girls with autistic traits to endeavour to understand why girls, when they are experiencing these difficulties, continue not to be diagnosed with autism in a timely manner. Lai et al., (2015) concluded that autism 'symptoms' seem more subtle in females without learning difficulties. The difficulties are often more difficult to identify because the girls have more desire to be sociable and have friendships. However, the literature is beginning to recognise that this is because difficulties can be superficial in girls. Recognition that cognitively able girls have been missed from the autism statistics has caused a surge in interest and the research during the last ten years has provided a greater understanding about how girls present including differences and similarities with their autistic male peers. The evidence base compared to boys continues to be described as small, nonetheless, it is helping clinicians to become more skilled in recognising girls and they are beginning to be identified more frequently. Autism in able girls is more diverse than was originally thought and new research is helping establish the difficulties girls experience and this is helping towards a more accurate picture of these girls and in turn a timelier diagnosis. It is vital that if the girls are going to continue to be recognised and diagnosed with autism the way in which girls and boys differ has to be shared so that there is clarity when girls are considered for a diagnosis. Skuse (2014) maintains that frequently clinicians and professionals don't recognise the female traits because they are looking through a male prism, when considering an autism diagnosis.

The DSM 5 diagnostic criteria used to diagnose autism while not gender specific does capture girls and it is recognised that the girls meet the criteria for an autism diagnosis differently to the boys. Several researchers advocate that detecting the female autism phenotype in girls with average intelligence may continue to be problematic until the research literature is in agreement and there is further consistency in the recognition of intellectually able girls (Lai et al., 2015; Dovekot et al., 2017; Mandy, 2013 & Jamison, 2017). As the body of research is growing, numerous explanations are being put forward to elucidate why autism may be difficult to detect in girls. The masking and camouflaging offer some explanation to understanding why girls appear to be functioning better than they are. Researchers suggest

that there may not be a need to change diagnostic criteria rather a need to learn to apply them in a way that is sensitive to the developing female autism phenotype. The recent interest in girls who are not intellectually impaired, the presentation of their differences and the recognition of autism suggests that professionals are beginning to develop a better understanding of how autism in girls can be identified. This is reinforced with evidence in a number of studies that endorse a range of theories supporting the different indicators of autistic behaviour in cognitively able girls, (Hurley, 2014; Dworzynski et al, 2012; Gould & Ashton-Smith, 2011; Head, McGillivray & Stokes, 2014; Mandy, Chilvers, Chowdhury, Salter, Seigal & Skuse, 2012; Giarelli et al, 2010; Kopp & Gillberg, 1992). Experts in the field are beginning to recognise that a number of shared characteristics are emerging (Dean et al., 2017; Szalavitz, 2016; Lai, Lombardo, Auyeung, Chakrabarti, & Baron-Cohen, 2014). Autistic girls are being additionally described as having similar core characteristics to the boys but, their presentation is considered to be more understated (Hartley & Sikora, 2009, Brugha, 2009 and Gould et al., 2011). While concerns remain, that autistic females are being missed, diagnosed later than males or misdiagnosed (Loomes et al., 2017; Giarelli et al., 2010; Holtmann et al., 2007), it is anticipated as awareness accelerates, being a girl should not be a barrier. The evidence for girls receiving a diagnosis of autism is clearer when it is

“viewed through the lens of autism rather than viewed through a lens that believes girls don’t have autism” (Hendrikx 2015, p.74).

Part 3 - Autism from the Perspective of Parents

2.14 Background Information

Part 3 draws on the sparse body of literature regarding the experiences of parents whose daughters subsequently receive a diagnosis of autism in later childhood, specifically the lived experiences of mothers who raise cognitively able girls, a population who appear to be invisible within the academic literature (Eaton, 2012). Therefore the literature capturing the experiences of all parents raising a child with autism has been included. In recent years more cognitively able girls are being identified with autism than previously (Gould & Ashton-Smith, 2012) and as the research increases professionals are recognising the complexities in reaching a diagnosis including the increasing implications for parents raising these girls. A number of studies that focus on parents' day-to-day lives conclude that parenting a child with autism is widely reported to be more stressful than raising a typically developing child (Vasilopoulou & Nisbet, 2016; Firth & Dryer, 2013). Historically, mothers have been blamed for their child's autistic condition, they have been described as cold and unfeeling (Bettelheim, 1967) and whilst this view has been discredited these theories have had an impact on mothers, making it difficult to ignore them and Stace (2010) argues that mothers are still fighting to correct these theories. The majority of recent research available contradicts these findings and instead propose that these parents are found to show remarkable strength, they are described as proactive and seek information (Kuhn & Carter, 2006). A further challenge for parents in general raising daughters is a cultural bias which is offered as an explanation in the literature because the girls in Western society are expected to have greater skills in interpersonal relationships than boys and reach higher levels of competence. Holtmann et al., (2007) suggested that there was an unfairness because parents anticipate more socially desired behaviour from daughters than from sons. More recent advances in research has emerged supporting the findings identifying social and relationship differences between genders, including the importance of friendships that impact on their daughters' quality of life (Dean et al., 2014; Lai, 2015; Bargiela et al., 2016; Sedgewick et al., 2016 & 2018a). Many parents recognize raising their daughters present them with numerous challenges together with many unique joys and rewards (Eaton, 2012).

2.15 Key Sources:

A thorough literature search was undertaken at the beginning of the project in order to find UK policy documentation, legislation and guidance at national level to understand girls with autism and the role of the EP. Electronic database including ERIC, Psych Info and Psych ARTICLES using the library catalogue and the electronic journal resource at Cardiff University and the World Wide Web, was also utilised using the same research terms. The electronic search ended December 2020. Hand searching was also utilised.

The search terms used initially were narrowed down to explore Part 3 of the narrative literature review which aimed to explore parents, particularly mothers' perceptions and understanding of raising a cognitively able daughter pre and post a diagnosis of autism.

The terms search included in part 3: 'mothers raising a daughter with autism' fathers raising a daughter with autism' 'parents raising children with autism prior to diagnosis' 'mothers raising girls prior to an autism diagnosis' 'parents of girls with autism' 'mother of girls with autism' 'fathers of girls with autism' 'mothers and fathers of children with autism' autism'. This initial literature review which returned 400+ references was determined to be too broad so relevant literature was filtered using the following inclusion criteria:

- for practical reasons the researcher only used papers published in the English language and western studies were selected. The selection of only Western studies was considered to be an important factor because of parenting styles, cultural bias and experiences are relevant when raising a child. Cultural factors including myths can impact on how autism is understood, interpreted and accepted in different communities. The difference in knowledge about cognitively able girls who eventually receive a diagnosis of autism is diverse even within the Western world and would certainly raise culturally sensitive issues outside of the Western world.
- The specific topic under research generated so few studies the area of research was widened to include parents, mothers and fathers of children or young people both male and female prior to and following a diagnosis of autism
- all items that did not reference any of the project aims within the abstract were discarded, for example, some articles just relating to boys with autism.

- only peer reviewed articles were included, because peer-reviewed articles are considered to be a highly reliable source of data as a result of the rigorous process they go through before publication.

This search provided an opportunity to identify literature to be reviewed that was relevant to the initial questions that the researcher was initially pondering.

What does the literature say are the experiences and impact of parenting a child with autism prior to the consideration that they could be autistic?

Since the thesis is primarily concerned with an examination about mothers understanding of behaviours when raising a daughter prior to any consideration that they were autistic the final studies selected were chosen because they were related to raising an autistic girl. The researcher was keen to focus on some of the most current relevant research data that fitted in with the researchers' key questions including links to the gaps in the literature the researcher had identified in the topic being explored. The final studies the researcher selected provided an opportunity to offer a critical and analytical summary of the current literature that guides the readers through the central theme of the topic being researched.

Table 1 illustrates a selection of studies from the key sources have informed the literature research in Part 3.

Table 1: Summary of key sources which have informed the literature research in Part 3

Author & Country	Year	Topic	Research method	Findings	Limitations /Gaps
Eaton (UK)	2012	Under the radar and behind the scenes: the perspectives of mothers with daughters on the autistic spectrum	Qualitative study	<p>The views from mothers on diagnosis, needs and services and the demands and rewards of having daughters with autism.</p> <p>The mothers experienced several difficulties related to the hidden nature of the condition which left maternal skills in question and highlights the strengths of a mother.</p>	The research identified the need for further research to identify support and services for girls with autism and their families.
Cridland, Jones, Caputi & Magee. (Australia)	2014	Being a girl in a boys' world: investigating the experiences of girls with autism spectrum disorders during adolescence	Qualitative study	This study highlights an important research area and is a preliminary step towards understanding the experiences of adolescent girls with ASD and their families. The implications for professionals and clinicians include a need for appropriate support to be provided for the girls and their families.	Future research needs to look at a comparison with boys and look at the cognitive range of ability in boys and girls.

Author & Country	Year	Topic	Research method	Findings	Limitations /Gaps
Crane, Chester, Goddard, Henry & Hill. (UK)	2015	Experiences of an autism diagnosis: a survey of over 100 parents in the UK with autistic children.	Mixed methods	The stress factors associated with the diagnostic process and satisfaction with post-diagnostic support. Post-diagnosis, the support (if any) that was provided to parents was deemed unsatisfactory.	Future research could address more social, cultural and ethnical demographics to give a wider perspective for all parents.

Author & Country	Year	Topic	Research method	Findings	Limitations /Gaps
Hiller, Young & Weber. (UK)	2014	Sex differences in pre-diagnosis concerns for children later-diagnosed with autism spectrum disorder	Mixed methods	<p>Carers of boys and girls diagnosed with autism spectrum disorder from school age completed an online survey addressing concerns regarding the child's development during the pre-school years (pre-diagnosis).</p> <p>Findings suggest, from carer perspective, that girls who went on to be diagnosed with autism spectrum disorder presented differently when compared to boys in some areas.</p> <p>Results have demonstrated the importance of both the understanding that girls with autism are likely to present with less concerning behaviours in the school-environment, and that underlying impairments in social understanding may not manifest in behaviours considered typical of the male-centric presentation of autism.</p>	The results highlight the importance of continuing to explore further how the female profile may differ, particularly to aid the identification of how and why core deficits may present differently in cognitively able girls, and thus improve earlier identification.

Author & Country	Year	Topic	Research method	Findings	Limitations /Gaps
Crane, Chester, Goddard, Henry & Hill (UK)	2016	Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom	Qualitative	Capturing parental views about the diagnostic process	The research was largely based on a sample of mothers in the UK, therefore, had little cultural diversity. The numbers of parents who took part from different areas in the United Kingdom was small, so it was not possible to reliably analyse regional variations.
Vasilopoulou & Nisbet (UK)	2016	The quality of life of parents of children with autism spectrum disorder: A systematic review	Systematic Review	This review aimed to systematically examine studies measuring the quality of life among parents of children with autism (<18 years) and to investigate parental, child-related and circumstantial related factors. The findings showed a poorer quality of life for parents with autistic children.	The research identified some of the gaps and limitations in previous research.
Little, Wallisch Salley & Jamison (USA)	2017	Do early caregiver concerns differentiate girls with Autism Spectrum Disorders?	Qualitative	The findings suggest that girls with autism have characteristics that may go unrecognised in every day family life	A limitation of the study was a lack of consistency of cognitive scores for all participants.

Author & Country	Year	Topic	Research method	Findings	Limitations /Gaps
Navot, Jorgenson & Webb. (USA)	2017	Maternal experience raising girls with autism spectrum disorder: a qualitative study	Qualitative study	This study highlighted the impact of gender on the maternal experience of raising a daughter with autism and contributed to a better understanding of the needs of both mothers and daughters. These results can help providers support the mother–daughter dyad by recognizing gender-specific challenges.	The information was just taken at one point in time and information over different time periods would be valuable. Fathers' perspectives would in addition have provided a richer picture.
Sproston; Sedgewick & Crane (UK)	2017	Autistic girls and school exclusion: Perspectives of students and their parents. Autism & Developmental Language Impairments	Qualitative study	Themes and subthemes that emerged from the interviews were not unique to autistic girls and were similar to those raised by parents of autistic boys	The results highlight that more needs to be done to positively influence the direction of the girls' educational journeys.

Author & Country	Year	Topic	Research method	Findings	Limitations /Gaps
Sutherland, Hodge Bruck, Costley & Klieve. (Australia)	2017	Parent-reported differences between school-aged girls and boys on the autism spectrum	Qualitative	The surveys provided insights regarding the characteristics of boys and girls (as perceived by parents) as well as some demographic information.	Research in the future is needed to investigate the behaviours that differentiate girls with autism to provide further understanding of underestimation of autistic characteristics for autistic females which in turn reduce the likelihood of a clinical diagnosis.
Crane, Batty, Adeyinka, Goddard, Henry & Hill. (UK)	2018	Autism Diagnosis in the United Kingdom: Perspectives of Autistic Adults, Parents and Professionals	Qualitative methods	It has provided a unique and detailed exploration of the autistic diagnostic process in the UK (highlighting both strengths and weaknesses) and made recommendations for future practice.	Future research is needed to more fully explore the unique factors effecting the autism diagnostic process across genders. In addition it is suggested to replicate this research in future to ascertain if recommendations identified have made a difference to clinical practice.
Sedgewick, Hill & Pellicano. (UK & Australia)	2018	Parent perspectives on autistic girls' friendships and futures	Quantitative	This study sought to examine parents' perspectives on the friendships and social difficulties of their autistic daughters, and their views and concerns about their daughters' futures.	Parents have rarely been asked to comment on the friendships of their daughters with autism – huge implications to keep them safe in the future because of their vulnerability. Mostly views of mothers – capturing views of fathers is a gap.

2.16 Raising an autistic child

There are typical challenges for all parents including stress which is an expected and normal experience when it comes to caring for a child. However, much higher stress levels have been found in parents of children with autism than for parents caring for and raising a child without developmental disabilities (van Steijn et al., 2014). Existing studies have highlighted that learning that a child has autism can be very difficult to accept and dealing with the reality of the situation can be a complex journey for the parents, for some families who have no idea it can come as a complete shock and feel like the end of the world at first, (Hendrickx, 2015; Bonis, 2016). In a similar manner coming to terms with autism is a challenge in itself. While there are a number of factors that contribute towards stress, worry and anxiety among parents and carers notwithstanding, the mainstream social attitudes about autism have an impact on them, (Bonis,2016; Zaidman-Zait, Mirenda, Duku et al., 2017). In addition, parents feel judged because all too frequently an autistic child often displays behaviour that's considered as "disturbing", "unusual", and "annoying" by the neuro-typical general population (Myers, Mackintosh & Goin-Kochel, 2009 ; Bonis,2016). Regardless, the research available does demonstrate that parents in particular mothers, experience substantial stress and they are considered to be to blame for their child's behaviour more than other significant adults (Anderson, 2007). It has been proposed that while the differences in presentation of females is still under-recognised and the current observational and parent – report measures are not accurately capturing the more subtle presentation of autism in cognitively able girls, parents continue to face significant challenges (Duvecot et al., 2017; Little et al., 2017).

Research that focuses on the challenges faced by parents who are raising cognitively able girls with autism is limited however, the studies that have a focus on the autism diagnostic process additionally capture the stress factors for parents and families. The majority of research available predominately includes the parents of children with intellectual disability across a wide age range. Studies that have included mothers raising autistic children have highlighted their substantial stress experiences (Bristol & Schopler, 1984; Gray, 1994) including, often being blamed for their child's behaviour (Anderson, 2007). Accessing an autism diagnosis is often a key milestone for an individual and their family, Crane et al, (2018). The literature reports copious amounts of research with regards to parents' dissatisfaction about receiving a diagnosis of autism.

Crane et al., (2016); Siklos and Kerns (2007); Wiggins et al., (2006) conclude that parents experience lengthy delays in accessing an autism diagnosis. Crane et al., (2016) argue that this is a particular challenge for children and young people who are verbally and cognitively able. These children and young people can cause additional stress for parents including an impact on their physical and emotional well-being as well as their marital relationships (Anderson, (2020); Desmarais, (2018); Crane et al., 2016; Siklos and Kerns 2007) and can influence their initial responses when they receive a diagnosis for their children (Wiggins et al., 2006). The research identifies that all parental stress levels rise with the increase in delay in the diagnostic process however, this is often further increased for cognitively able girls who are diagnosed at an older age. This later diagnosis is further linked to an acknowledgment that the needs of girls that are not understood or recognised and often parents are not felt to be believed by the professionals making the diagnostic process even more stressful. Cridland et al., (2014) reported that the mothers of daughters with autism reported more stress with the diagnosis process than other parents in the research. Crane et al., (2017) in a UK study, examined the views and experiences of ten autistic adults, ten parents of children on the autism spectrum, and ten professionals involved in autism diagnosis. Interviewing these thirty respondents' identified aspects of the diagnostic process that are working well, and areas in which improvements are needed. The study provided a unique and detailed exploration of the diagnostic process highlighting both strengths and weaknesses including the need to support families during all stages of the process to help reduce stress factors. Parenting a child with autism is reported to be more stressful than parenting a typically developing child including a lower quality of life for these parents (Bonis, 2015; Vasilopoulou & Nisbet, 2016). A recent longitudinal American study that considered the stress levels of parents of young children prior to a diagnosis of autism found that parents of children with autism concerns reported consistently higher levels of stress compared to parents of children with other developmental concerns and parents of children with no concerns (DesChamps, Ibañez, Edmund, Dick & Stone, 2020). To date few studies have specifically investigated the predictors of parental stress in school children with autism without intellectual disability, or 'high functioning'. The research available is not conclusive in terms of whether the stress of the diagnostic process falls entirely towards the mother because the data available from the research does highlight raising a child with autism has an impact on mothers more

than fathers. Vasilopoulou and Nisbit (2016) explored research from a number of countries and found the quality of life for mothers was significantly below that of fathers. These authors concluded with caution because the sample size of fathers was relatively small. There was concern about the mental and physical health of nine out of twelve mothers in their studies. Bitsika et al., (2013) supported these findings in their study, they used the Zung Self Rating Anxiety and Depression Scales, and reported mothers as being “stretched beyond their resources” (p.1) more frequently than fathers. They found no statistical differences between parent’s stress index but they did however comment on a mother’s role within the family as taking on more day-to-day involvement in their children’s lives and the fathers take on different roles. O’Halloran et al., (2013) reported in their small-scale qualitative study involving nine fathers parenting children with autism that they generally did not always know the finer details of the diagnostic journey and they would refer to the mothers for the information. An exception to these findings includes an Irish qualitative study of eleven mothers who were reported to be mostly happy and satisfied with the process (Braiden et al., 2010). A further stress factor for many parents is their reported frustration with the lack of support they are offered post diagnosis (Crane et al., 2016; Siklos and Kerns, 2007; Howlin and Moore 1999), they are often left alone with their child’s diagnosis and have to manage access to services (Carlsson et al., 2016) which is a further challenge because the autism diagnosis is frequently only the start of a journey for parents and families (Crane et al., 2018).

The literature while remaining limited is beginning to capture the cognitively able girls with autism (Gould & Ashton Smith, 2011). However, there are still gaps in understanding the maternal and paternal experiences, relationships and interactions when raising a child with autism based on gender. There remains little research literature on the mother-daughter relationships and as the primary care provider mothers will often have a direct impact on their daughter’s development. Rich (1976) argues that the most profound relationship in a female’s life is the one between mothers and daughters. Traustadottir, (1991) suggests that mothers are expert witnesses and need to be recognised for their knowledge and experience. These findings were replicated by Ryan, Runswick-Cole, (2008), Rocque, (2010) and O’Halloran et al., (2013) whose studies highlighted the importance of listening to parents and their initial concerns regarding their child's development and functioning. To date there is a particular lack of literature that has a focus on raising an intellectually able daughter

before autism was a consideration. As part of a qualitative study Navot et al., (2017) investigated the mother-daughter relationship from the perspective of mothers who are raising girls with normal intelligence and functional verbal communication with an autism diagnosis and concluded that there is a need to support the interactions between mothers and daughter. The research acknowledged the importance of recognizing the gender-specific challenges and identified that the mother-daughter relationship started with an early expectation of a close and intimate relationship that overtime transformed. This was a consequence of the challenges they faced, the mother's competency and expectations were restructured which created a different bond between the mothers and daughters. The research literature on the mother-daughter relationship and mothers as the primary care provider is limited. Navot et al., (2017) findings were consistent with previous research and the focus on raising a cognitively able girl with autism decreased their perception of their parenting competence. Their concerns included the lack of understanding about symptoms and challenges their daughters experienced. Following a lack of recognition of their daughter's difficulties by paediatricians and following a diagnosis they reported experiencing disbelief from family members and friends (Eaton, 2012; Navot et al., 2017). These relationships with family and friends are further challenged by the influence of society's expectations and beliefs around females and femininity and has an impact on a mother's perception of how female autism presents (Kreiser & White, 2014). However, Navot (2017) argued that for many mothers the reality of raising a daughter with autism was very different from their expectations which were reshaped and a different bond between mother and daughter was created. The limited research on girls with autism may also result in parents attributing their daughter's difficulties to their parenting skills rather than understanding the behaviour as being linked to autism (Navot et al., 2017). Despite the more recent increase in awareness of girls with autism the voices of their mothers are rarely heard and the hardest part for parents to understand are the challenges of not being believed and convincing professionals about their concerns. In addition, they report disbelief from others, including family members regarding their daughter's diagnosis and finally the lack of information available about girls with autism (Eaton, 2012; Cridland et al., 2014; Navot et al., 2017).

2.17 Parents Intuition - Early Signs in Cognitively Able Girls

There is a paucity of research literature that contributes to the understanding of parental views, concerns and knowledge about raising girls who do not have a learning disability or language delay and where autism is not an obvious conclusion. In the few cases, where parents' views have been elicited they demonstrate that parents try to concentrate on communication and friendship skills to support their autistic children (Loomes et al., 2017). Questions have inevitably been raised to whether comparable results are found for autistic girls which has resulted in a minority of published studies that have elicited parents' views about their daughters' friendship skills and these views have been captured incidentally in the context of discussions about their education (Milner et al., 2019; Sproston et al., 2017; Cridland et al., 2014). Where studies have had a focus on girls' outcomes parents reported mixed feelings towards a diagnosis. In addition the parents suggest that these girls have encountered significant challenges throughout puberty including concerns about their daughters' ability to maintain relationships and with their emerging sexuality and romantic interests (Cridland et al., 2014).These studies were in agreement about the complexities in their abilities to maintain successful relationships and propose that autistic girls acquire greater linguistic and communicative skill levels at an earlier age than boys (Goddard et al., 2014). However, recent evidence confirms a link has been made between this apparent communicative competence and greater social difficulties in many girls, which has demonstrated that their peers respond to their verbal skill rather than their deeper social understanding (Mandy et al., 2018; Sedgewick et al., 2016). Sedgewick et al., (2016) interviewed twenty parents of autistic adolescent girls, aged between eleven and eighteen years, on the topics including friendships, conflict and thoughts about adulthood and the future. Research results demonstrated that parents of girls often have significant involvement in their daughters' social lives and friendships. The benefits and pitfalls of their daughters' peer interactions highlight the perceived negative influence of these interactions on their daughters' mental health. Most parents in existing research had significant concerns about their daughters' futures, either about their ability to live independently, or their potential vulnerability to exploitation. Despite concerns raised about their daughters and sexual relationships, parents reported that they avoided raising these issues with their daughters (Sedgewick et al., 2016). Other studies which have explored subtle gender specific differences reported by parents

including problems with socialising, puberty, accessing a diagnosis, receiving a later diagnosis and access to appropriate interventions, support these findings (Mademtzzi, Singh, Shic, Koenig, 2018). Parents recognise that their girls have some different behaviours including, being absorbed in their own play (Riley-Hall, 2012) and this is often interpreted by others as the girls just being 'shy', (Kreiser and White, 2014). The under identification of girls is increasingly being highlighted and arguably, the challenges faced by parents of intellectually able girls are possibly more complex than those of raising boys with autism.

Very few studies that have examined parent/carer perspectives about their children's early development for example, the identification of skills used in social situations including restrictive, repetitive behaviours. In those few cases where parents' views have been elicited parents describe being faced with numerous barriers and challenges from professionals when explaining unusual behaviours that concern them however, parents report that when they are told there is nothing wrong with their daughters they would start to believe them (Walker, 2012). Constantino (2013) advocated that doctors are looking at girls through boy-coloured glasses. Little et al., (2016) proposed that the role of gender, and how it could impact parents' first concerns and early identification of signs of autism, remains mostly unexplored.

Hendrickx (2015), argued that there can be a tendency to ignore family and self-reporting, instead the clinicians prioritise only what they see. Hiller et al., (2015) argued that medical professionals very rarely identified autism in intellectually able girls following parent/carer initial concerns. Conversely, it is reported in Sweden there is an appreciation that parents often recognize problems in their child's development earlier than health professionals (Carlsson et al., 2016). Hendrickx (2015) suggested observations that may have caused parents concern at the time about their children's atypical behaviours are often made with hindsight. A diagnosis of autism would not be an apparent conclusion for girls who do not have a learning disability or language delay before the age of three or four years (Dworzynski et al., 2012). The research evidence suggests that if these girls receive a diagnosis of autism it would come at a later age (Mandaville, 2015). Hendrickx (2015) argues that for the parents of these girls there is often nothing that they can define as 'wrong' with their daughters that would need a medical intervention. These mothers still described a 'nagging sense of something

different that they can't put their finger on' (Hendrickx, 2015, p.49). Hendrickx proposes that parents' intuition is often accurate, and the voice of parent's could provide valuable evidence towards their daughter's future autism diagnosis.

Halliday et al., (2015) summarise research studies about gender differences including the age of diagnosis and concluded that differences in autism characteristics in males and females are not always apparent in toddlerhood. Holtmann et al., (2007) when examining sex differences in autism advocate that results in their study are interpreted with a bias from parents who may expect more socially desired behaviour from daughters than from sons. Other studies have reported that toddler boys and girls with autism do not show any differences in behavioural features, suggesting that the differences in symptoms may not show up until later childhood (Reinhardt et al., 2014; Postorino et al., 2015). Equally research has concluded that the young girls with autism may demonstrate behaviours that are not particularly salient or concerning for parents. The girls in these studies who went on to be diagnosed with autism at a later age presented differently when compared to boys, suggesting they were not autistic at an earlier age. Giarelli et al., (2010) and Russell et al. (2011) argued that despite the identification of similar difficulties boys were diagnosed at an earlier age. Eaton (2012) identified that the average age for a diagnosis for girls is about eight years. The complexity of a diagnosis of autism in cognitively able girls is further challenged by understanding differences in cognitively able girls with autism reported in existing studies (Young & Weber, 2016; Little et al., 2016; Sutherland et al., 2016; Hiller et al., 2015; Mandaville, 2015; Pelfrey, 2015; Hurley, 2014; Gould et al., 2011; Mandy et al., 2012). The research reports first concerns were more likely to be recognised by parents when externalizing behaviours which were exhibited by their daughters rather than difficulties in their early development (Hiller et al., 2015; Little et al., 2016).

In 2015, Hendrickx retrospectively gathered information anecdotally from parents whose girls had received a diagnosis of autism however, Hendrickx noted that the information was not always female specific. The research identified the following more specific early indicators reported by parents in babies and toddler girls that contributed to their later diagnosis:

- *“Parents feel they have a sense of detachment from the baby or young child – often this cannot be further articulated by the parent; it is just a feeling of the baby or child ‘being in a world of their own’*
- *atypical eye contact (either unusually limited or staring)*
- *a lack of attention paid specifically to people’s faces- interest in people is not prioritised over objects*
- *limited interest and/or response to people stimuli (smiling voices, peek-a-boo games)*
- *limited reciprocal social facial expressions and social cues (smiling, pointing)*
- *limited reciprocal seeking out of people and responses from people*
- *very placid, silent and peaceful babies.*

Or

- *very anxious, distressed and clingy babies – ‘Intense emotions, especially distress, and an inability to be comforted by affection.’ (Attwood,2012)*
- *sensory preferences and intolerances*
- *small temperature tolerance range, which can result in febrile convulsions*
- *clothing – texture and touch*
- *physical touch – distressed by being cuddled*
- *specific strong food preferences and dislikes*
- *food and other intolerances and allergies,” (Hendrickx, p.50).*

Information gathering tools are beginning to mirror information reported. Attwood (2013) has developed a screening tool for girls, to be used by clinicians, so an accurate profile can be provided by parents. This screening tool is not a diagnostic test but allows supplementary information to be gathered. Marshall (2013) has also developed a female profile that is able to reflect a broader range of traits in females compared to those traditionally gathered. Research suggests that traditional tools and measures of autism are male biased supporting evidence that girls were less likely to receive a diagnosis of autism based on the standardised diagnostic instruments and they recommended that these tools needed to be adapted to capture the girls more accurately. For instance, they suggested special interests which they reported are similar to those of typically developing girls and therefore may not be recognised as unusual for example, animals, horses and classical literature however, the variance is in the quality and intensity of these interests that differentiate the autistic girls (Gould & Ashton-Smith, 2011). More

recently studies are reporting that it is the ability, skill and knowledge of clinicians to recognise autism in girls that is the challenge,

‘researchers theorize that girls are better than boys at camouflaging their symptoms, particularly during highly structured interactions such as a clinic visit,’ (Bishop, 2016).

There are a number of diagnostic tools currently available however researchers, clinicians and professionals need to consider the measures available and how these can be applied rather than becoming reliant on one tool or one measure to assess autism

A review of literature highlighted that only a limited number of studies have examined the parent’s concerns about the early development of their intellectually able daughters who were diagnosed with autism in later childhood. In these studies, various methodologies have been used to collect and examine data. Mandy et al., (2012) used direct observation and information reported by parents and professionals to look at comparisons in toddlers with autism. The study included three hundred and twenty-two participants including fifty-two girls all of whom were cognitively able and went on to be diagnosed with autism. In the study parents reported less repetitive stereotyped behaviour in the girls compared to the boys. Teachers however, reported males with autism as having greater externalising and social problems than females. The study reported more stable female characteristics across the age range in the sample and hypothesised that milder characteristics reported in girls could contribute to their under recognition in reports from their parents and carers. Hiller et al., (2015) provided similar insight into why autism may be more difficult to detect early in cognitively able females compared to males. In the study carers of ninety-two boys and sixty girls diagnosed with autism who were of school age completed an online survey addressing concerns regarding their child's development during the pre-school years (pre-diagnosis). The findings from carer perspective, recognised that the girls who went on to be diagnosed with autism presented differently when compared to boys. Carers in addition identified girls using more ‘active’ strategies to manage social situations and additionally presented with different types of restricted interests, both of which may alter the more typical presentation of autism therefore, making it difficult to recognise potential early signs. Sutherland et al., (2017) undertook a qualitative study which involved distributing a survey via social media to parents whose children had an autism diagnosis. This study included one hundred and seventy-one parents of girls and one hundred and sixty-three

parents of boys. Again, the surveys provided insights and perceptions of parents regarding the characteristics of boys and girls as well as some demographic information. However, there were fewer differences reported regarding strengths and difficulties in communication and social skills in boys and girls with autism. There appeared to be an equal number of special interests reported in the boys and girls however, significant differences were found in the types of special interests with boys and girls showing generally interests along traditional gender lines. Further analysis of the data from parents of girls identified them as masking or hiding their difficulties and this was not reported to be the case for boys. Little et al., (2016) reviewed and analysed medical records of children. The study examined the carer's concerns prior to a diagnosis of autism or other developmental disability. Parents reported that while they celebrate their daughter's developmental milestones, there were concurrent concerns about unusual and puzzling behaviours. The limited studies to date, gathering parent and carers views, highlight the importance of continuing to explore how the core deficits may present differently in cognitively able girls, and thus improving earlier identification of autism in these girls. Parents of children with autism report increased stress and difficulties compared with parents of typically developing children. The analysis of the data in available research studies, while providing valuable insight into understanding differences in characteristics of boys and girls as perceived by parents, remains in its infancy and there remains a lack of information about girls with autism (Cridland et al., 2014; Navot et al., 2017). Research literature currently available capturing knowledge and understanding of how autism presents in cognitively able girls is currently limited, and parents of these girls are described as experiencing challenges when raising their daughters that are linked to the lack of understanding about autism in particular its presentation in cognitively able girls, their use of masking and how male based theories complicate existing autism literature (Anderson et al., 2020).

2.18 Summary

"When you start to raise a family, for many it is your first full-time experience of children so noticing differences is not even on your radar. It is not until your child starts school, and teachers begin to take you to one side, that you realise that perhaps your child is not the same as other children" (Grant,2018, in Carpenter, 2019, p.26).

The emerging research to date agrees that a missed or late diagnosis can result in girls being socially isolated, rejected by their peers and receiving grades below what would be expected for their ability and at greater risk of mental health and behavioural challenges including anxiety and depression during adolescence and adulthood. It argues that when girls present with a combination of social immaturity, restricted interests, limited eye gaze, repetitive behaviours, social isolation, and are viewed as “unusual” or “different” by parents, teachers and peers, the possibility of autism should be given consideration (Wilkinson, 2017).

While the evidence base is still in its infancy there appears to be agreement between authors that the gaps in the current diagnostic processes may be as a result of its insensitivity to detecting girls on the spectrum (Halladay et al., 2015; Kirkovski et al., 2013; Loomes et al., 2017). It is evident that contributing factors including gender differences in autism characteristics, traits and the coping strategies of cognitively able autistic girls are not being readily recognised by clinicians and professionals who are using male based diagnostic criteria to make decisions and judgements. Intellectually able girls are potentially missed because they are internalising behaviours and they often mask or camouflage their difficulties to fit in with neuro-typical expectations, (Livingston, 2018). When parents present their experiences to convince professionals including clinicians regarding their concerns about their daughters they are often dismissed which adds immense strain on their parenting. The mothers ‘ability to fight’ to protect and support their daughters out of necessity often results from maternal instinct including their confidence in knowing their daughter’s needs Rocque (2010). The existing research demonstrates the lack of information available about raising cognitively able girls before there was a consideration that the girls were autistic. Little is also known about the mother–daughter relationship in babies and very young children. Both the qualitative and quantitative studies available are predominantly based on males however, they do support the challenges of raising children and young people with autism (Hayes et al., 2013). The findings of parental experiences in these studies often report negative feelings including grief, frustration, incompetence and stigmatization. Still, there is some limited research that describes more positive experiences of mothers including their resilience and personal growth (Eaton, 2012). The maternal experiences reported when raising a girl suggests that parents’ stress levels are higher than those parents who raise boys with autism. The studies available

are highlighting differences, albeit, subtle at times between girls and boys with autism from both parent and professional perspectives (Sutherland, 2017; Little, 2016; Hiller, 2014; Mandy, 2012). Again this research presents a distinct challenge because of the intersection of autism symptoms with the cultural expectations of female identity development (Kreiser & White, 2014). Ernsperger and Wendel (2007) propose that prior to receiving a diagnosis parents of girls describe feeling that they have spent their daughter's early years on an emotional roller coaster.

2.19 The Contribution of the Present Study

2.19.1 Rationale

Part 3 of this narrative review has examined existing research related to the phenomena being explored in this research and the rationale for the current research is constructed with reference to areas deficient in the existing research base. The foregoing literature review has identified several issues that are consistent and indicate a need to increase parental involvement in order to obtain a better understanding of their unique experiences of raising their daughters before autism was a consideration. The literature available has highlighted the significant lack of knowledge and understanding about maternal lived experiences of raising their cognitively able daughters throughout their infancy and early childhood and how they made sense of these behaviours and development in later childhood when their daughters were diagnosed with autism. Additional information and knowledge would be helpful in furthering professional understanding of cognitively able girls with a later diagnosis of autism to both increase the chance of a successful outcome, as well as valuing and empowering the status of parents. The present study aims to contribute to the body of research, by specifically focusing on the lived experiences and viewpoints of the under-researched area, specifically mothers raising their daughters throughout infancy and early childhood before autism was a consideration in later childhood. Given that mothers are frequently the main caregivers they may have useful insights into the experiences of raising daughters and are very much 'expert witnesses' as they have direct impact on their daughter's development and it is important their knowledge and experiences are valued, (Traustadottir, 1991; Anderson et al., 2020). Moreover, at present, the researcher's initial literature search has revealed that no research has been conducted

in the United Kingdom (U.K.) that directly explores early lived experiences of mothers whose cognitively able daughters were diagnosed with autism in later childhood.

Therefore, the aim of the current study is to gain an in-depth understanding of the reported sense making of mothers' early experiences of their daughter's development and behaviours following their subsequent diagnosis of autism later in childhood.

Based on the examination of existing research, the key research questions in this study will be:

Primary Research Question:

- To explore how mothers make sense of their experiences of their daughter's early development and behaviours preceding their subsequent autism diagnosis.

Secondary Research Question:

- How might the experiences of these mothers help professionals have a clearer understanding about the difficulties cognitively able girls with autism experience?

Chapter 3

3.0 Methodology

3.1 Summary of Chapter 2

The literature examined in the critical review did not focus explicitly on eliciting mothers' perspectives and experiences in an in-depth manner. This gap in the literature is one which the present study aims to address. The research findings from this study will be presented in Chapter Four.

3.1.1 Introduction to Chapter 3

The first section of this chapter provides a summary of ontology, epistemology and methodology. The second section clarifies why a qualitative research method was chosen. There will be an explanation about other quantitative methods that were considered before being rejected followed by a justification about the decision to use Interpretative Phenomenological Analysis (IPA) to answer the research question. IPA is defined by three theoretical structures - phenomenology, hermeneutics and idiography and they will be précised in this section. The limitations of using IPA as a methodology are also deliberated. The third section specifies details of the participants, ethical considerations, participant well-being, processes and procedures for the gathering and analysis of the data collected. Table 2 below summarises the researcher's framework.

3.1.2 Summary of Research Framework

Table 2: Summary of research framework

Ontological Position	Subjectivism
Epistemological Position	Interpretivism
Methodology/research paradigm	Qualitative - Interpretative Phenomenological Analysis
Theoretical perspectives	Phenomenology, hermeneutics, idiographic
Data Collection	Semi-structured interviews
Participants	6 mothers whose cognitively able daughters received a diagnosis of autism after the age of eight but before eighteen years.

3.2 Ontology and Epistemology

3.2.1 Introduction to Ontology and Epistemology

It was critical that thought was given to “the philosophical base of the chosen research to ensure coherence of the study design in terms of its ontological, epistemological and methodological levels of enquiry” (Proctor, 1998, p.74).

The term philosophy in this research refers to the development of knowledge and the nature of that knowledge (Chetty, 2016). The researcher’s view regarding the world is important when deciding the philosophical approach and this will in turn determine the research strategy and the methods employed to implement them in order to inform the research design which enables the research to be rationalised. It is therefore important to understand the ontological and epistemological stance taken by the researcher.

The researcher’s philosophy is based on the development and understanding of knowledge that defines the philosophical perspective. This is based on the researcher’s perspective of the world including the practical considerations taken when deciding the research topic, (Saunders, Lewis & Thornhill, 2009). Individual researchers have different perspectives and practical considerations about their views of the world depending on their chosen method to answer the research question. In simple terms it would depend on whether the researcher is concerned with gathering facts or feelings. Depending on the choice of perspective, strategies and methods used by the researcher outcomes will also differ.

3.2.2 Ontology

Ontology is concerned with identifying the overall nature of existence of a particular phenomenon. When we seek answers to our research questions, we are referring to a particular type of knowledge that exists external to the researcher.

Ontology is a belief system that mirrors an interpretation by an individual about what establishes a fact. i.e., “What exists in the world, to the nature of reality” (Punch, 1998, p.170).

Ontology is linked to a central question of whether social entities should be viewed as objective or subjective. Consequently, objectivism (or positivism) and subjectivism (also known as constructionism or interpretivism) can be specified as two key characteristics of ontology.

Objectivism portrays the position that reality is independent of human perception and cognition, and a single reality can only be researched by applying a thorough scientific methodology to find a direct relationship between observations and events. This is in contrast to subjectivism which, observes that social phenomena are seen as interactions between the object and the subject (Crotty, 1998).

This researcher has adopted the ontological stance of subjectivism because of its emphasis on social phenomena that are created from the perceptions and subsequent actions of people. Subjectivism is a social phenomenon that has been constantly reviewed through continuous social interactions of people and the world they live in. In line with the beliefs of subjectivists the researcher believes that human participants interpret a situation based on their perception of the world and through their interaction with their environment. Therefore, to find out about factors influencing the participants' experience it was important for the researcher to understand the subjective reality of the participants and their actions in a meaningful way. A qualitative methodology was applicable to support the philosophy embraced by the researcher whose research was concerned with the 'lived' experience of the participants (Smith, Flowers, & Larkin, 2009) while recognising that our experiences can be interpreted in numerous ways (Willig, 2008). The primary aim of an IPA based research study is "focused on the subjective meanings people assign to events rather than attempting to record or represent objective events" (Flowers et al., 1999, p486), and this is echoed in this researcher's study.

3.2.3 Epistemology

Epistemology is theoretically related to ontology and is centred on assumptions of how an individual might acquire and interpret knowledge about the world and reality. It is concerned with questions such as, 'how do we know what is true?' Epistemology is internal to the researcher and it is about how they see the world around them, (Carson et al., 2001, p. 6).

The nature of this research advocated that it would be valuable for the researcher to adopt an interpretivist epistemology, as it recognises there are numerous ways of construing the world. It believes that the knowledge is relative to the researcher and in turn interpretivists work with others as they make sense and meaning from events and create their realities in order to understand their points of view, and then to interpret

these experiences based on the researcher's academic and life experiences (Hatch & Cunliffe, 2006). As a consequence of interpretivist philosophy, two people may provide very different constructions of the same incidence, for example, a meeting between teacher and parent, without either being privileged as the true or superior account (Willig, 2008). Adopting this stance would embrace the research aims where the concern is not with what happened so much as how the participants experienced what they perceived to have happened.

Interpretivism reflects the researcher's philosophical stance because the researcher is described as a 'feelings' researcher who is keen on observing, interpreting and analysing human behaviour including emotions, their social role and interpreting them in line with the researchers own set of perspectives and meanings about life. A qualitative approach has been applied where the researcher interacted with individuals in order to collaboratively construct a meaningful reality (Rowlands, 2005). The researcher chose open ended questions in a semi structured interview to gather data and views from the participants who volunteered to take part in the research. An interpretive paradigm is more likely to be employed in qualitative research, it argues that the world is interpreted by those engaged with it. This perspective is aligned with a qualitative approach, where researchers are concerned to understand people's perceptions of the world (Taylor et al, 2006).

It was the goal of this interpretivist researcher to understand and interpret the meanings of human behaviour rather than to generalize and predict causes and effects. It is therefore important for the interpretivist researcher to understand motives, meanings, reasons and other subjective experiences bound by time and context (Hudson and Ozanne, 1988; Neuman, 2000). Carson et al, (2001), summarised interpretivism as capturing the stance adopted by the researcher whose aim was to concentrate on understanding and interpretation including, an ability to feel the experience of what is being studied while allowing feeling and reason to govern actions. This researcher is permitted to partially create what is studied, the meaning of phenomena so recognising the importance of some pre-understanding of the occurrences being studied. The researcher has the knowledge that the distinction between facts and value judgements can have less clarity and accepts influence from both science and personal experience

which directed the researcher to the choice of a qualitative method to address the research question.

Consequently, these factors influenced the researcher who chose to take an interpretivist stance as the epistemological position. The researcher came to the research topic with some sort of prior insight of the research context but, made the assumption that this was insufficient to be able to develop a fixed research design due to the complex, multiple and unpredictable nature of what is perceived as reality (Hudson et al., 1988). The researcher was open to new knowledge throughout the study and let it develop with the assistance of the participants. The researcher believes that using such an evolving and collaborative approach is consistent with the subjectivist beliefs that humans have the ability to adapt, and that no one can gain prior knowledge of time and context bound social realities (Hudson et al., 1988).

In conclusion, as a consequence of both the researcher's own beliefs and opinions and, because the research was concerned with understanding the early 'lived' experiences of parents (Smith et al., 2009),

- a subjectivist ontological stance was taken, recognising there are numerous ways of interpreting our experiences of the world (Willig, 2008), and
- an interpretivist epistemology was embraced arguing that interpretations of experience are shaped through the language used to discuss them (Burr, 2015).

3.3 The Researcher's Position

It is important that the reader gains an initial understanding of the researcher's personal and professional position, along with the reasons why this particular research topic was chosen. Research psychology is integral to the profession and 'reflectivity' is a constant within the context of the current qualitative research including an awareness and honesty of one's own feelings and emotions, (Shaw, 2010).

The researcher is a mature married woman living and working in the North West of England. She has three grown up children, two daughters and a son and returned to her career as an educational psychologist having raised her children to school age.

The researcher has had a lifelong interest in special educational needs and has worked with many children and young people with autism. She has worked with and supported many families and their children and young people with autism throughout her

experience as both a teacher and an educational psychologist. As a result of these experiences, the researcher noticed inconsistencies in the access to diagnosis, interventions and strategies that support the children, young people and their families. She recognised that parents understand and know their children best and their contribution is important. This long held interest has influenced her exploration of what may be improved for these children, young people and their families.

At the time of carrying out the research, the researcher was a local authority educational psychologist with a specialist practitioner post in language and communication including autism. She led a multi-agency team of professionals in developing a neurodevelopment pathway. Having followed the process of the pathway with colleagues it was reviewed after four years. Interestingly girls were coming forward for a diagnosis where previously a girl was rarely seen however, in many cases these girls were not receiving a diagnosis unless they had additional learning difficulties. It was noticed that some of the patterns in the girls who did not receive a diagnosis were remarkably similar, they were often described as anxious, school refusers and struggling with friendships by schools and their parents.

At this time research identifying able girls and women with later autism diagnoses was beginning to emerge and particularly from women who were diagnosed early in adult life including, Temple Grandin (1995), Donna Williams (1992), Claire Sainsbury (1988) and Ros Blackburn (2011) who have told and written their inspirational stories. Their stories have challenged, inspired and raised the researcher's awareness of cognitively able girls and women with autism.

The researcher had an opportunity to reflect on the position that girls were being more frequently referred to the autism pathway with a wide range of needs however, these girls were not receiving a diagnosis of autism. Instead in many cases an alternative diagnosis was given because they did not meet the autism 'criteria'. This sparked an interest, and the research provided an opportunity for the researcher to understand more about these girls.

When embarking on this thesis research, the researcher was aware that she needed to appreciate these girls better. The researcher reflected on this at length to uncover her underlying beliefs regarding able girls with autism. This research has supported her

ability to shape her understanding of cognitively able girls who are diagnosed later in their childhood.

Good quality qualitative research includes transparency of the researcher's values and assumptions brought to the collection, analysis and interpretation of data (Yardley, 2007). Reflexivity is the process of increasing awareness and acknowledging the researcher's influence on the subject being explored. Within qualitative research it is recognised that the researcher's beliefs and assumptions will have an impact upon the analysis of the data collected. It is therefore important for the researcher to be honest about their personal perspective. The researcher was interested in hearing first person accounts, this research would therefore be qualitative and would fit within the constructivist paradigm. The researcher wanted to carry out individual interviews with a relatively small sample of participants and IPA was the method best allied to these research aims.

As part of conducting qualitative research, the researcher kept a reflective journal and recognised an understanding of bracketing was essential. The aim of bracketing is to objectify and amplify the researcher's awareness of their own assumptions and experiences (Finley, 2008 p.4). Husserl suggested that the researcher needs to put to one side or 'bracket' the world that is taken for granted so that they are able to focus on their perception of that world, (Smith et al, 2009 ; Watts, 2014).

Husserl (1927) claimed that to access human experience we should 'bracket off' our assumptions, ideas and opinions about the world.

'Putting it in brackets shuts out from the phenomenological field the world as it exists for the subject in simple absoluteness; its place however, is taken by the world as given in consciousness (perceived, remembered, judge, thought, valued etc.)', (Husserl,1927: para.3, in Smith et al., 2009, p13).

The researcher's own expectations for mothers' involvement in raising their children, childcare and their relationship with their children were noted and discussed, (Appendix 25 - An excerpt from reflective diary summarising the researcher's thoughts in terms of bracketing). In this research, the researcher was involved in finding out about people's experiences of raising an intellectually able daughter who was diagnosed with autism in later childhood. The researcher was aware of their role as an attentive, empathic listener

who wanted to hear what participants had to say and was mindful of, and endeavoured to put aside, their preconceptions and assumptions. During the parental interviews, the researcher identified with Kvale and Brinkmann's (2009) reflectivity 'miners' metaphor, in that they approached knowledge in their study as pre-existing. The researcher sought to find out about people's (pre-existing) experiences and attempted to explore these experiences as factual phenomena in their own right. Reflexivity is reflection on the influence of the researcher on the study (Yardley, 2000).

3.4 Reflectivity

Reflexivity is the procedure in the research process where the researchers are 'conscious of and reflective about' the ways in which their methods and own subject position might impact on the psychological knowledge which is the end product of the research process (Langdridge, 2007).

Husserl's work has helped IPA research to focus primarily on the process of reflection, setting the scene for attentive and systematic examination of the content of consciousness and lived experiences, Smith et al., (2009). In qualitative research reflectivity can be referred to as "disciplined self-reflection" (Wilkinson, 1988, p.493) and refers to the examination of the way in which the researcher's own values and assumptions shape their research. A self-reflexive researcher acknowledges their role in the research process, throughout the process of structuring of the research "problem" to the reporting of the research findings; the researcher is deliberately aware of their involvement and considers the implications of this during their research (Pillow, 2003).

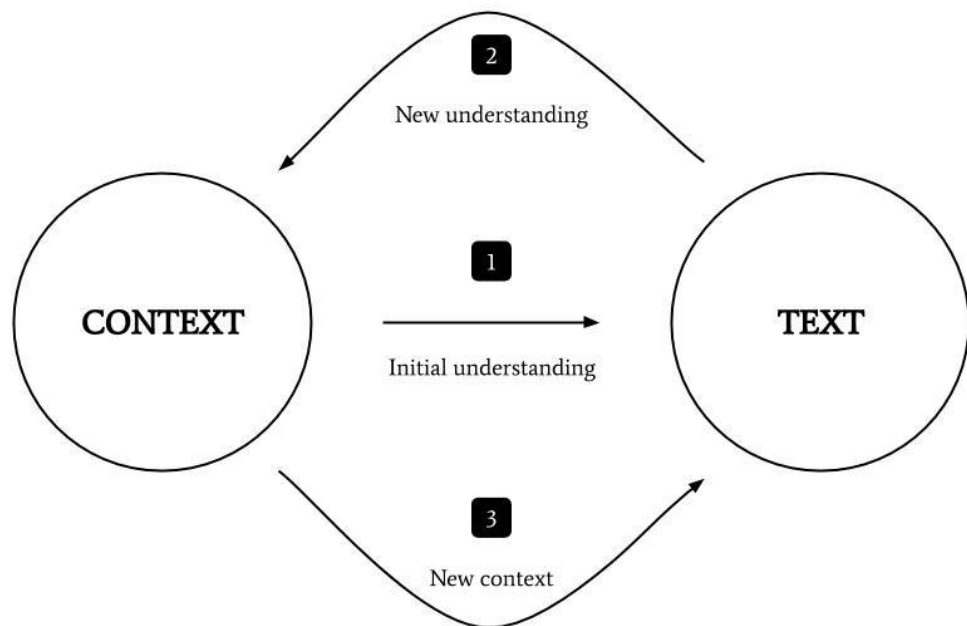
As part of conducting qualitative research, the researcher kept a research diary to capture thoughts and findings throughout the research process. This continual reflexive approach in addition facilitated the researcher to reflect on their role, data collection and the analysis process. Willig (2013) describes this personal reflexivity as involving 'reflecting upon the ways in which our own values, experiences, interests, beliefs, political commitments, wider aims in life and social identities have shaped the research. It also involves thinking about how the research may have effected and possibly changed us, as people and as researchers' (Willig, 2013.p.10)

The diary led the researcher to reflect and problem solve systematically to ensure their confidence in the choices that were made throughout the research process and hence

reinforcing the importance of the IPA researcher adopting a continually reflexive attitude. The researcher in addition acknowledges that any pre-existing knowledge and pre-conceptions are brought to the research process. Hermeneutic phenomenology recognises that the researcher's view of the world is 'inextricably intertwined' with the way in which they interpret the participants' experiences (Oxley, 2016).

The concept of the hermeneutic circle was conceived by German philosopher Martin Heidegger in 1927 in his book *Being and Time*, (Le Cuff, 2020). The idea of the hermeneutic circle is to imagine a whole in terms of how the parts interact with each other, and how they interact with the whole.

Figure 1: Le Cunff, (2020) diagrammatically captures the complex interaction of the hermeneutic circle



Oxley (2016) views reflexivity as an ongoing process because unconscious pre-conceptions can come to light throughout the research process and describes the hermeneutic circle as

'The relationship, in which the researcher discovers challenges to their pre-conceptions as they engage with the data' (Oxley, 2016, p57).

Oxley (2016) in addition describes two 'filters' between the researcher and the direct experience for example, the participant expressing their perception of the experience and the researcher interpreting what the participant has said. Smith et al., (2009)

advocate that the researcher's interpretation may 'shed light' on an aspect or aspects of the experience which the participant does not visibly share, that is, it is concealed and only surfaces through the researcher's interpretation of the data. The researcher's primary concern was with the participants and their experiences of raising their daughters before there was any concern that their daughter's had autism. During the research process the researcher kept a reflective diary in order to aid and illustrate reflexivity and the diary informed the reflexive boxes that are incorporated into Chapter 4.

'IPA aims at giving evidence of the participants' making sense of the phenomena under investigation and, at the same time, document the researchers' sense making'.

(Hefferon & Gil-Rodriguez, 2011, p11).

3.5 Research Design

3.5.1 Qualitative Approach

The theoretical viewpoint that underpins this research is phenomenology, which is the study of experience from the first person's point of view rather than the belief that a phenomenon can be condensed to an appropriate number of identifiable variables, which can be tested. Phenomenology was developed largely from the work of Edmund Husserl (1859-1938) a philosopher who believed that experience should be examined in the way that it occurs and in its own terms (Smith et al, 2009). Husserl's ideas were further developed by the philosopher Heidegger, who felt that people's engagement in the world was a characteristic of their ability to communicate with and make sense of each other and so the interpretation of people's meaning-making activities are central to phenomenological inquiry in psychology (Smith et al, 2009). More simply stated phenomenology is the study of an individual's experience of the world and Finlay clarifies phenomenology researchers' aim for fresh, complex, descriptions of phenomena as concretely lived (Finlay, 2013).

This research employed a qualitative design utilising Interpretative Phenomenological Analysis (IPA, Smith, 1996). The study's main focus exploring the lived personal and social experiences of mothers raising a daughter diagnosed in later childhood, with the aim of gaining meaningful insights and perspectives, makes IPA an appropriate methodology (Smith, sample of parents 1996; Smith & Osborn, 2007). This approach is

in keeping with the researcher's ontological and epistemological positions. IPA was the methodology chosen to enable the researcher to gain a deeper understanding and exploration of the of the research questions which are focused on the participants' personal experiences and views of the world. This research is concerned about how mothers made sense of their experiences of raising their daughters before autism was a consideration which aligns with a qualitative research methodology which "tends to focus on meaning, sense-making and communicative action" (Smith et al., 2009, p. 45) and is concerned with lived experiences and realities (Shaw & Frost,2015). The researcher chose to use IPA because gaining an in-depth understanding of the meaning attributed to a small experience was of interest. A quantitative approach could have been used and would have provided information from a larger pool of participants but would not have captured information about the depth of 'lived' experiences. To date significant amounts of autism research tends to be more from a quantitative viewpoint than a qualitative one. In particular, little has been heard from parents with daughters who received a diagnosis of autism in later childhood. Dallos and Vetere (2005) advocate that qualitative methods: "emphasize rich descriptions of a phenomenon and allow participants' voices to be heard, for example, by providing contextualised verbatim quotes from participants" (p.50). A qualitative methodology was deemed to be the most appropriate for addressing a research question exploring the idiographic experience of members of a particular group, Barbour (2001) argued that qualitative research can help to expose the mechanisms involved in particular phenomena by exploring the explanations and accounts of the relevant individuals. This research was concerned with uncovering the richness and detail of the individual's experience of being a parent raising a daughter who was diagnosed with autism in later childhood including the meanings given to their experiences. IPA is therefore a suitable method of data analysis because the researcher sought to gain a rich and detailed picture of the experiences mothers had raising their daughters including their relationships, the meaning they attributed to them and the sense they made of their experiences. However, all knowledge gained can be described as provisional and relative because the same phenomena can be understood in a variety of ways and is dependent on the unique perspective of the person, Madill et al., (2000). The research data can provide an opportunity to understand individual points of view, conversely, these views can only be related to a particular person, in that particular context at that particular time hence,

research findings are dependent on the context the data is collected and examined, (Madill et al, 2000; Larkin et al, 2006). This therefore highlights the active contribution that the researcher inevitably has in the research process.

Assessing the quality of qualitative research is paramount. The quality of methods, data and of data analysis need to be carefully considered when undertaking research (Silverman, 2005). The researcher stayed close to the guidelines set out by Smith (2011) in order to conduct IPA on the research data in addition to evaluating its quality. The researcher wanted to ensure that the data collected was of excellent quality and the views and experiences of the participants were represented and well-defined in line with the guidelines for IPA. The researcher's interest is in human perception and how people make sense of their experiences including a need to understand another person's relationship with the world (Smith et al., 2009). IPA does recognise the researcher's own perspective to contextualise participants' experiences in the framework of theory and research in relation to the phenomenon under exploration. Finally, IPA was selected because of its belief in focusing on effect and cognition, and the explicit stance it takes on the role of the researcher in interpretation, which aligns with the researcher's background in educational psychology.

3.5.2 Consideration of Alternative Approaches

Examining the lives and experiences of others, in order to foster a shared understanding of their motives, beliefs and values, is a fundamental principle of psychology. It is important for research methodology to have strong theoretical and philosophical underpinning to provide a sense of vigour and purpose, Pringle et al (2011). The researcher is in agreement, but, also recognises that there are a number of highly regarded qualitative methodologies that would capture this preliminary prerequisite, and two of these will be discussed in turn in relation to this research. The focus on lived experience was the initial aim of this research and IPA is only one phenomenological approach which aims to do this and is in fact a relatively new approach.

The researcher reflected on alternative qualitative research methodologies before selecting IPA. Both Narrative and Thematic analysis are qualitative methods that were considered and then discounted for the purposes of this research study.

Narrative analysis is focused on how a person's timeline of life events navigates them to their current state. IPA, on the other hand, assesses how people viewed or view their

life and past experiences which can raise inherent perspectives the individual has over their life. Although both approaches are qualitative in their methods, they differ in the nature of data they are trying to measure. A narrative analysis is going to find an objective level of analysis to understand the person's life experiences whereas IPA advocates the subjective nature of the measurements capturing each individual's unique perspective of their own life. Narrative analysis assumes that the subjectivity of the person is measurable in a qualitative way and it can additionally depict quantitative analysis for example, it may also capture social trends. IPA however, assumes subjectivity and is rooted in the philosophies of phenomenology and hermeneutics the study of interpretation. Phenomenology is the study of perception a methodology, developed by Giorgi, making an attempt to describe phenomena (rather than interpret) and aims to capture the constant, underlying structure of an experience (Giorgi, 1992). Narrative analysis can be described as a method of making sense of the world by exposing the participant's story and examining how they "imposes order on the flow of experience to make sense of events and actions in their lives" (Riessman, 1993, p.2). Narrative analysis was reflected on as a research method as it appealed to the researcher because of the focus on content and on how a story is structured, alternatively it may look at the narratives which occur in society or the stories we tell ourselves (Smith et al., 2009, p.44). The researcher wanted to explore the structured elements of a story and carefully considered a narrative approach, as this approach could fit the information to be explored. While it might have been interesting to explore the mother's narratives about raising their daughters who were later diagnosed with autism, it was felt that this approach could be inappropriate to meet the research aims or answer the research questions to be explored. Narrative analysis was rejected because it was unable to provide the researcher with the thoroughly structured data analysis protocol including wanting to capture how people perceive, organise and experience their daily lives that could be provided by an IPA approach.

Thematic Analysis (TA) was also considered as an appropriate approach by the researcher for identifying, analysing and reporting themes within qualitative data in rich detail (Braun & Clarke, 2006). TA is known as one of the most popular methods of qualitative analysis (Howitt & Cramer, 2008). Similarly, to IPA, TA requires the researcher to identify a number of themes which capture the original data. This process usually involves coding the data and from these codes, the researcher attempts to identify

themes that relate to the data. The researcher considered using TA because it is a useful research tool because of its flexibility and its ability to provide a rich and detailed account of data (Howitt & Cramer, 2008). TA is a method where the researcher closely examines the data to identify common themes, topics, ideas and patterns of meaning that come up repeatedly. A risk of a thematic analysis approach is the reliance of the creation of codes by the researcher which do not always remain true to the data and can divert from the quality of the individual experience (Willig, 2013). However, this current research was exploring a 'lived' experience and TA does not examine the experiences to the same depth and complexity as IPA. In contrast to IPA, TA has often been criticised as purely a description of an event rather than an exploration of a person's understanding and perceptions of reality in greater detail, to get a greater understanding of a particular phenomenon (McLeod, 2001). Smith et al., (2009) highlight the fact that sample size is contextual and must be considered on a study-by-study basis. This research was interested in analysing rich data from a small number of participants. Thematic analysis as a qualitative method of data analysis was thought as too broad an approach for this research, and it would not allow for the quality and depth of analysis of the 'lived' experience that the researcher wanted to capture, individually and as a group. TA was not considered to be a suitable method of analysis for the current research because of its restricted interpretative power as its methods are not based in an existing theoretical framework where the analytic claims are made (such as hermeneutics of suspicion, which involves more in-depth explanations to challenge the superficial accounts of the data) (Smith et al., 2009).

IPA was selected rather than narrative or thematic analysis due to the focus on rich psychological interpretation of meaning emerging from the participants' data.

3.5.3 Interpretative Phenomenological Analysis (IPA)

"IPA is a qualitative research approach committed to the examination of how people make sense of their major life experiences" (Smith et al., 2009, p.1).

IPA is a relatively new qualitative approach that aims to encapsulate and explore the meanings that individuals assign to their own experiences. At the heart of IPA is the perception of individuals as 'self-interpreting beings' (Taylor, 1985, in Smith & Eatough, 2006). IPA recognises the part that the researcher plays in understanding the individual's experience. IPA also acknowledges that the analysis of the individual's experience may

be effected by the researcher's own beliefs and thoughts which could influence access to the participant's individual experiences. Smith and Osborn (2003) have described it as 'the participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world' which is of a complex personal nature. IPA describes this phenomenon as a "double hermeneutic" (Smith et al., 2009, p.35). In IPA, the role of the researcher is made explicit (Shinebourne, 2011) through this process of the double hermeneutic, the researcher reports the process of making sense of the participants' sense-making. It is argued that IPA is an appropriate method of analysis where conversational approaches focus on how an object of interest is being construed through an analysis of language, social interaction and/or through the identification of patterns of discursive action. IPA is an interpretation of the meaning for a person in a particular context (Smith et al, 2009). IPA is accepted as an established method in clinical, health and social psychology, which offers a position and protocol for the analysis of experiential qualitative data (Reid et al., 2005; Smith & Osborne, 2003; Smith et al., 2009). In using IPA, the researcher seeks to understand in detail how an individual experiences an event from a particular perspective within a specific context and it is concerned with ways in which people make sense of their experience and attach meaning to their life events (Smith et al., 2009). Reid et al., (2005) describe IPA as an exploration of lived experience combined with a personal and reflective process of interpretation. Any implications taken from the information are done so cautiously and with an awareness of the context within which the study is undertaken. IPA is essentially a subjective research approach, so two analysts working with the same data may come up with different interpretations, (Smith et al., 2009; Brocki & Wearden, 2006). However, despite this subjectivity, Smith et al., (2009) argue that IPA is dialogical, methodical and rigorous. IPA captures a considerably detailed understanding and a comprehensive account of unique lived experiences of a small group of participants that is unique to IPA as a method of data analysis. Smith et al., (2009, p. 45) describe quantitative research as tending to try and measure "what happens at one remove, by inferring mental events from observations of behaviour". Whereas qualitative research "tends to focus on meaning, sense-making and communicative action" (Smith et al., 2009, p. 45).

IPA appeared to be the method best suited to this research: "IPA is a qualitative research approach committed to the examination of how people make sense of their major life

experiences” (Smith et al., 2009, p. 1), in this case, their cognitively able daughters being given an autism diagnosis in later childhood. The researcher is interested in participants’ reflections on the significance of something that is a life changing experience. Larkin, Watts and Clifton (2006) talk about the potential of IPA to “properly explore, understand and communicate the experiences and viewpoints offered by its participants”, (Larkin et al., 2006, p. 103).

This research is a retrospective study in terms of studying the phenomena of looking back at events that have already happened (Hulley, Cummings, Browner et al., 2011). While this can be described as a disadvantage because it can be prone to bias, in this study the nature of the sample selected for the research included a need to know that the girls had received a diagnosis of autism in later childhood. For the parents in the current research the outcome has already occurred, the girls discussed in the research had already received a diagnosis of autism at the time the research was conducted and had therefore already been exposed to those early experiences in raising their cognitively able daughters.

“The interest is in how the participant experienced situations even if they come through memorial modes, because the manner in which situations stand out in memory is psychologically revealing” (Giorgi & Giorgi 2003, p.47).

In addition to the overall benefits of cohort studies, a retrospective cohort study can be more cost effective and less time consuming. A major advantage of a retrospective study is that it allows the investigation of rare phenomena without having to use a very large sample size which is a key component of IPA methodology. A distinctive element of IPA is its commitment to a comprehensive interpretative account of the cases included and many researchers recognize that realistically this can work best with a very small sample. The suggestion for small numbers in IPA is that the researcher is sacrificing breadth for depth (Smith & Obsborn, 2012). IPA was additionally chosen as the method of analysis to address the research question to be answered by this research because it advocated smaller numbers of participants. The small number of participants to be examined in greater depth emphasises IPA’s commitment to idiography. It was first suggested by Reid et al.,(2005) that less is more in IPA. Smith et al., (2009) highlighted the fact that sample size is related to the context and needs to be considered for each individual study. Smith et al., (2009) encourages a focus on comparing one dimension in a single

group, thereby conserving a deeper level of examination with a more interpretative focus. IPA's focus on convergence and divergence within a participant group's experience of a phenomenon naturally requires comparisons at the individual level (comparing case to case). IPA allows the researcher to gain a phenomenological account of participants' experience, identifying their perceptions of their social world. These will be subjective and could be in-depth accounts. Conrad (1987) calls this an "Insider's perspective" (p2).

However, it is difficult to do this directly or completely. The process is dependent on the researcher's own conceptions which are required so that sense can be made of that other personal world through a process of interpretative activity. In IPA this is a two-stage interpretative process, or a double hermeneutic. The researcher is trying to make sense of the participants making sense of their world. IPA is therefore cognitively connected to hermeneutics and theories of interpretation, (Packer and Addison, 1989). Thus, consistent with its phenomenological origins, IPA is concerned with trying to understand what it is like, from the point of view of the participants, to take their side.

IPA researchers are advised to explore the semantic content and language used at a number of levels: descriptive (taking explicit meanings at face value), linguistic (for example, noting metaphors) and conceptual (taking a more analytic approach), Finlay, (2014). The chosen methodology is that of interpretative phenomenological analysis (IPA) which has its theoretical basis in hermeneutics, phenomenology and idiography (Smith et al., 2009).

3.5.4 Phenomenology

The feature that differentiates phenomenological research from other qualitative research approaches is that the subjective experience of the participant is at the centre of the inquiry (Mertens, 2009). Smith (2004) describes the 'characteristic features' of IPA: idiographic, inductive and interrogative, and considers the different levels of interpretation which are possible with IPA. Langdrige (2007) talks of a "family of methods with a common phenomenological philosophical foundation." (p. 7) and describes the different approaches to phenomenological psychology. In IPA the phenomenological requirement is a commitment to understand and 'give voice' to the concerns of participants from a psychological perspective (Larkin et al., 2008). Phenomenology is constructed on the thinking of philosophers such as Husserl (1859 –

1938), Heidegger (1989 – 1976), Merleau-Ponty (1908 – 1961) and Sartre (1905 – 1980) who all conducted philosophical investigations of consciousness. “IPA is influenced by core ideas from a number of different philosophical perspectives on phenomenology and aims to translate these into a practical research methodology.” (Oxley, 2016, p56). Husserl was mainly concerned with first person processes, individuals conducting phenomenological inquiry in regard to a person’s own experiences. Husserl was concerned about understanding human experience and seeks to understand the participant’s ‘life world’. The aim of applying phenomenological philosophy to psychology is to focus on ‘lived’ experiences more explicitly, people’s perceptions of the world they live in and what this means to them, (Langdridge, 2007). Merleau-Ponty was also interested in understanding our ‘being’ in the world and was interested in context and argued that humans see themselves as different from everything else in the world however, individuals can never share another person’s experience. Merleau-Ponty talked about the ‘lived’ experience shaping the fundamental character of our knowing about the world (Smith et al., 2009). Sartre emphasised the developmental aspect of human beings and stressed that people are constantly developing and becoming themselves. According to Sartre an individual’s perceptions of the world is shaped by the presence of others and the schemes that they engage with (Smith et al., 2009).

The origins of IPA is based upon phenomenology – the philosophical study of “anything that presents itself” (McConnell-Henry et al., 2009, p8), whether this is an object, event or experience. Predominantly, it is the study of what the experience of being human is actually like (Smith et al., 2009). Phenomenology argues that human experience is worthy of detailed examination. Phenomenology is the study of conscious, lived experience in detail and depth, the aim of which is to get as close to understanding as possible, (Shinebourne, 2011). As researchers we focus upon the person in context, and that person’s relatedness to the phenomena at hand Larkin et al., (2006). IPA is not ‘simply descriptive’; it is vital that the researcher presents an interpretive account of what it means for participants to have such experiences, within their particular context (Noon, 2018).

3.5.5 Hermeneutics

Another hypothetical underpinning of IPA is hermeneutics, which is the theory of interpretation. IPA requires the researcher to pay attention to the participant’s ‘lived’

experiences and then develop interpretations which help to explain what it is like to be that person in a particular situation. Smith et al., (2009) précised the theoretical descriptions of the understanding of hermeneutics by a number of theorists including Schleiermacher, Heidegger and Gadamer, which IPA embraces as part of its theoretical and methodological underpinnings. Hermeneutics places emphasis on contextual meanings (Oxley, 2016). This involves what Findlay (2008) refers to as the 'dance' between reduction (bracketing out the researchers' preconceptions) and reflexivity, where the researcher is building interpretations and at this stage of the process must acknowledge the researcher's own perceptions, always going back to the participant's words to ensure that the interpretations are grounded in the participant's life world, or the 'return to the thing itself'. Interpretation is dynamic and iterative, necessitating some interplay between the parts and the whole, and between the interpreter and the object - the hermeneutic circle (Smith et al., 2009). Smith et al., (2009) provide an example, the meaning of a word only becomes clear in the context of the whole sentence and the meaning of the sentence is dependent on the meaning of individual words.

IPA utilises an iterative process of analysis which allows the researcher to see the viewpoint of the participant whilst also being aware that their own view can effect the way they understand the participants' accounts. It is therefore imperative that the researcher remains aware of their own predispositions as much as possible by constantly referring to the raw data and being influenced as little as possible by their own assumptions. IPA recognises that analysis always involves interpretation and is strongly connected to hermeneutics in its recognition of the investigator's centrality to analysis and research (Brocki & Wearden, 2006). A researcher recognises that attempts to understand the nature of the participant's relationship to the world, or to aspects of the world, is interpretative. Hermeneutics is the theory of such and is concerned with interpretation and IPA is said to involve a double hermeneutic (Smith & Osborn, 2008). Interpretations are therefore constrained by both the participant's capacity to articulate their experiences, and the researcher's ability to separate them. Indeed, the phenomenon is there, ready to "shine forth, but detective work is required by the researcher to facilitate the coming forth, and then to make sense of it once it has happened" (Smith et al., 2009, p. 35). As this process is unvaryingly influenced and made more problematic by the researcher's own biases (Heidegger, 1962), IPA recognises that

it is unpractical to gain access to the exact personal world of another, completely or directly. The objective is, therefore, to obtain an account which gets as 'close' to the participants' view as is possible (Larkin et al., 2006).

Without the phenomenology, there would be nothing to interpret, [and] without the hermeneutics the phenomenon would not be seen' (Smith et al., 2009, p. 37).

3.5.6 Idiography

Finally, IPA is underpinned by idiography which stresses the value of studying the individual, suggesting this can be important as "a means of troubling our assumptions, preconceptions and theories" (Smith et al., 2009, p.30). IPA is in contrast to popular 'nomothetic' research is idiographic in nature, which means the aim is to focus on personal perspectives and the experiences of particular individuals rather than completely losing these accounts in order to make group level claims (Smith, 2004). In IPA studies the selection of participants is on the basis that they can access the phenomenon being examined (Smith et.al. 2009). Since IPA is idiographic and very concerned with in depth examination of the phenomena the sample sizes are usually small. Participants are purposively recruited to present a homogeneous sample in terms of the particular research topic. The homogeneity of the researcher's sample is based on the researcher finding a closely defined participant group for which the research question will be significant and meaningful. (Smith, 2008). IPA is dependent on idiography, which means that the researcher will have a focus on the 'particular' rather than the universal (Smith et al., 1995). In this research 'the particular' is represented in IPA's commitment to understanding a particular experience, in this case, that of the experiences of mothers with a daughter who is later diagnosed with autism. Whilst the participants are linked to each other they hold unique perspectives of phenomena and the emphasis is on the individual's experience and what it was like for them and what sense it made to that person. The researcher is able to make specific statements about the individual participants because the researcher's analysis is based upon a comprehensive case exploration. An IPA researcher will equally and attentively examine each individual participant resulting in individual case studies. This idiographic commitment is unusual even among qualitative methodologies. The researcher wants to examine a group of individuals and will move between key themes generated in the analysis and illustrate them with individual narratives demonstrating how stories were

told by individual participants, showing similarities and differences. 'The fundamental principle behind the idiographic approach is to explore every single case before producing any general statements' (Pietkiewicz & Smith, 2014, p 8). Throughout its subsequent cross-case analysis, IPA remains faithful to the individual, illustrating both the life world of respondents who have recounted their experiences, and elucidates how they align with more general themes (Smith & Eatough, 2006). In this research, the idiographic commitment will also be represented in the analysis write up by including transcript extracts for each individual in order to highlight individual experiences.

To summarise a strength of IPA is its ability to draw upon these three main existing theoretical philosophical frameworks namely, phenomenology, hermeneutics and idiography "through the two complimentary commitments of IPA – 'giving voice' and 'making sense', thus allowing researchers to 'seek to attain an 'insider perspective' of lived experiences" (Noon,2018, p.1).

3.5.7 Limitations of IPA

Whilst IPA is described as a forward-looking research approach that adopts a flexible and versatile design to understand people's experiences, Tuffour (2017), argues that like any qualitative research methodology it has limitations. IPA has been criticised for being riddled with uncertainties as well as lacking standardization (Giorgi, (2010). It is also argued that IPA is frequently described as more descriptive and not necessarily sufficiently interpretative (Hefferon, Gil-Rodriguez, 2011). Tuffour, (2017) deliberates in his critique of IPA that the methodology suffers a number major conceptual and practical limitations.

IPA in line with a number of other phenomenological studies gives insufficient recognition to the fundamental role of language according to Willig, (2008). Questions are often raised as to whether IPA can precisely capture the experiences and meanings of experiences rather than opinions of it. In their negation of this criticism, the critics accept that making sense of the meaning takes place in the context of narratives, dialogue and comparisons and whilst it remains the primary purposes of IPA to gain insight into experience, it is continuously interwoven with language, (Smith et al., 2009). This is also reinforced by Burr (2015) who argues that language used to describe events influences the interpretations of experience.

Phenomenology as a research approach relies on the accounts of participants and the experiences of researchers. The researcher additionally used a timeline at the beginning of the interview process to support the participants' memory of times events occurred in their lives while raising their daughters. Its criticism is that IPA is elitist and that there is a reliance that participants and the researcher have the right level of fluency and communication skills which suggests that phenomenological research is suitable with the most eloquent individuals (Willig, 2008). Nevertheless, language plays an important role in IPA and the researcher has to analyse participants' language so that they are able to understand how they are making sense of their 'lived' experiences. However, it is argued that it is important that the researcher is aware of this criticism and pays extra attention to collect rich and exhaustive data from participants, (Tuffour, 2017). It is imperative that the researcher takes this into consideration and is able to be active in the role of supporting the participants' exploration of their experiences and interpreting responses both, verbal and non-verbal. In addition, throughout the analysis process the researcher details judgements made by the research, including the use of reflexivity, which addresses this potential criticism, (Smith et al., 2009).

It can be argued that IPA is similar to other phenomenological explorations because it has a focus on perceptions. This can also be a problem and limit understanding, because phenomenological research seeks to understand the lived experiences but, does not explain the cause or origin of the experiences that participants describe. It could, therefore, be debated that the explanation might be located in past events and this could therefore restrict a researcher's understanding of phenomena (Willig, 2013). However, Smith et al., (2009) have reasoned that IPA uses hermeneutic, idiographic and contextual analysis to understand the cultural position of the experiences of people. IPA is additionally criticised because its association with cognition is identified as problematic. Mainly, because some characteristics of phenomenology are not attuned with cognition and the role of cognition is not accurately understood, (Langdrige, 2007; Willig, 2008). However, Smith et al., (2009) reject this by proposing that the IPA's requirement of sense-making and meaning-making which includes conventional reflection obviously resonates with cognitive psychology. Of interest is the increasing number of publications identifying the theoretical, methodological and philosophical underpinnings of IPA (Smith et al., 2009), criticisms are gradually being refuted.

It was IPA's focus on the 'particular' (Smith et al., 1995) that appealed to the researcher most, because some diversity was anticipated between the experiences of parents being interviewed and IPA is a methodology that would capture the individual parent's voices as well as those experiences that were mutual (Smith et al., 2009). A further advantage was that such an approach allows for the emergence of unanticipated findings (Barker, Pistrang & Elliott, 2002). IPA is a research approach committed to the examination of how people make sense of their major life experiences (Smith et al., 2009, p. 1): in this case, the mothers early lived experiences including the understanding of the development and behaviours of their daughters who are given a diagnosis of autism in later childhood. The researcher is interested in the participants' reflections on the significance of something that is presumably important or central to their lives.

3.6 Method

3.6.1 Design

The researcher engaged in a qualitative research design to consider the recounted experiences of mothers raising cognitively able daughters who subsequently received a diagnosis of autism in later childhood. In keeping with IPA principles participants were selected "purposively" (Smith et al., 2009, p.48) using a selection criterion to ensure recruitment of a fairly homogenous sample of participants. In order to address IPA's exploratory approach a series of individual semi-structured interviews (see Appendix 6) were undertaken with parents. They were recorded using audio technology and then transcribed verbatim prior to applying IPA analysis (Smith & Osborn, 2008; Smith et al., 2009).

3.7 Participants

3.7.1 Recruitment of participants

The research took place in the North West of England and in terms of adhering to data protection legislation (General Data Protection Regulation (GDPR), 25th May 2018), the appropriate sample was recruited via a local autism support group.

The researcher then provided the required number of information leaflets (see Appendix 3a & 3b) and consent forms (Appendix 2b) and stamped self-addressed envelopes to the group facilitator. The researcher did not receive any details regarding potential participant's whilst awaiting receipt of the participants' consent. The

researcher was reliant on the group facilitator to disseminate the information pamphlets and consent forms to the identified participants.

3.7.2 The Sample

IPA researchers seek to generate a purposive, fairly homogeneous sample; to make sure the research holds relevance and personal significance to participants, enabling the researcher to capture detail on an exact group of individuals who have experienced a particular phenomenon. In this study the participants have all raised a cognitively able daughter who was diagnosed with autism in later childhood (Noon, 2018). The researcher recruited 6 participants who volunteered to take part in the research. IPA was selected because it allowed for small numbers of participants. IPA as a qualitative approach advocates smaller sample sizes because it aims to reveal the unique life and lived experiences in detail of each individual within a specific situation. IPA is documented as an idiographic approach (Smith et al., 2009), concerned with understanding a unique occurrence in particular contexts, therefore the study uses of a small, select, purposive sample size. The age and gender of participants are both unknown factors however, they are not deemed relevant in this research.

The inclusion criteria in terms of the participants were parents who met the following criteria:

- Mothers or fathers who were parents since the birth of their daughters (it was important that they have very early knowledge and experience of their daughter's development.)

N.B. Both parents were able to take part in the research if desired as they will both have had 'unique' experiences of raising the same girl. Both parents were offered individual interviews. However only mothers volunteered.

- The parent's daughter received a diagnosis after the age of 8 and before 18 years. This was in line with research which proposed that cognitively able girls receive a later diagnosis than girls with a learning disability or language delay (Begeer et al., 2013; Rivet and Matson, 2011). Eaton (2012) concluded that the average age of cognitively able girls was eight years when they received their diagnosis. Therefore, for the purpose of this research the age of 8 years was chosen.

- For the purpose of this research cognitively able girls were described as those girls who did not have a language delay or a learning disability and for whom a diagnosis of autism would not have been an obvious conclusion before the age of three or four years of age. The girls were also ‘cognitively able’, to the extent that they had been able to attend a mainstream school and access a mainstream curriculum at least prior to their diagnosis. This appears to be a particularly evident description for girls who receive a diagnosis at a later age, (Giarelli et al., 2010).
- Prior to their diagnosis their daughters were in a mainstream school.

In terms of the exclusion criteria, parents who met the following criteria were excluded from the research:

- Parents who had a daughter who had been only educated in a special school
- Parents who had not been with their daughter from birth
- Parents of girls who received a diagnosis before the age of 8 years

Table 3 provides a summary of demographic and contextual information that was gathered interview.

Table 3: Background information on the participants

Mothers Names	Daughters names	Age at diagnosis	Age at time of research	Source of diagnosis	Mother with birth father	Siblings/parent with diagnosis
Jane	Jodi	9.6 years	12 years	private & NHS	No	brother
Emily	Jas	10 years	13 years	private	No	brother
Vroni	Anna	9 years	12 years	private	No	stepbrother
Betty	Danni	16 years	17 years	NHS	No	brother & sister
Abbie	India	9 years	18 years	private	Yes	
Jennie	Molly	12 years	14 years	NHS	Yes	father

3.7.3 Interviews

Gathering good-quality data for IPA asks for a more open-ended interview maintaining a careful balance between guiding and being led, (Hefferon & Gil-Rodriguez, 2011. p.757) Thus, the interview schedule designed for this research was relatively short and it started with broad, general questions that allowed the participant to set the parameters of the topic, rather than the other way around. This was to avoid the

researcher imposing their understanding of the phenomenon on the participant's account (Smith et al., 2009). The research data was gathered using semi-structured interviews lasting between ninety minutes and two hours and thirty minutes. The participants were considered as "experiential expert[s]" (Smith et al., 2009, p.64), and 'open' interview questions were designed to encourage participants to talk at length with minimum interruptions.

Semi-structured Interviews

IPA research was employed to elicit rich, detailed, first person accounts of the experiences of participants in regard to the phenomena under investigation. Semi-structured, one to one interviews are the most popular method for conducting IPA research (Hefferon & Gil-Rodriguez, 2011, p.46). Open-ended interview questions were designed to encourage participants to talk at length with minimum interruptions. The interview questions (Appendix 6) were rehearsed, practiced, memorised and followed in a flexible manner so participants frequently guided the flow of the conversation and allowed the participant to focus on the parts of their experience they chose to discuss in depth. The semi-structured interview schedule contained a number of main questions, with supplementary questions and prompts that could be used with participants as necessary. The interview schedule was used flexibly, in order to allow further questioning in unforeseen areas that emerged. During a semi-structured interview, the researcher and participant have the opportunity to engage in dialogue. Semi-structured interviews additionally offer 'space and flexibility' for any unexpected issues to arise and be subsequently investigated (Hefferon & Gil-Rodriguez, 2011). The semi-structure interview questions aided the exploration of the participant's experiences of raising their daughters before an autism diagnosis was given. Autism was explored in terms of knowledge of autism prior to their daughter's diagnosis and their experiences following their daughter's diagnosis were explored.

The nature of this study was a retrospective study, and the researcher was aware that asking mothers about their memories pre-diagnosis is fraught with confirmation bias type difficulties and could lead to data that in effect serves to support mothers' perspectives now that their children have been diagnosed, especially given the group being lobbied are active in an autism support group. To address difficulties to reduce the conformation bias the researcher started the interview with a timeline to support

the parents visually whilst enabling them to think about their early experiences of raising their daughters. The timeline was to scaffold their thinking and recall through the various stages in their daughter's life. The timeline was initially marked with four initial key times in their daughters' life, (Appendix 4).

- Birth
- Pre diagnosis
- Age at diagnosis
- Post diagnosis.

The parents were also invited to bring if they wished a few photos of their daughters to the interview to act as prompts at different ages.

Some demographic and contextual information was gathered including: daughter's age when diagnosed, sibling's ages, age of daughter at the time of interview and date when mothers joined the support group. These were established on the timeline. (Table 3)

3.8 Ethical Considerations, Participant Welfare and Protocols

3.8.1 Consent

A gatekeeper letter (Appendix 1) and consent form (Appendix 2a) were sent to the group. The group facilitator gave the information about the research (Appendix 3) to the parents of girls who attend the group to find out if they would be interested in taking part in the research. The information provided highlighted the purpose of the research and the researcher's contact details if participants had any questions. The information provided additionally explained that not all participants who agreed to participate would be selected due to the limited number of participants needed for this research.

3.8.2 Informed Consent

Prior to approaching the participants, the researcher asked the group facilitator to inform the parents who attend the group about the nature of the research. It was explained that the researcher was a qualified, practicing and experienced Educational Psychologist.

Following the initial gatekeeper letter, a consent form and participant information leaflet explaining the nature of the research and their ethical rights was sent to parents who volunteered to participate. They were asked if they are happy to be interviewed by the researcher and if they were, they were asked to sign the consent form and provide

their contact details. The consent form ensured that each parent could make an informed decision about whether to participate in the research before volunteering to be interviewed. The consent form included details of the researcher, the researcher's university supervisor (and the Cardiff University School of Ethics Committee Secretary) if any of the participants required further information or clarification about any parts of the research. Prior to individual interviews the researcher made sure that the participants understood the information leaflet (Appendix 2a), which included information about the purpose of the research, what taking part would involve, who would have access to the data, the right to refuse to answer questions or to ask for data to be deleted until it was anonymised and how it would be stored. Informed consent to participate was ensured by the researcher providing and talking through the consent form (Appendix 2b) with the participants to check their understanding before they were to sign if they wanted to continue being involved in the study. A signed copy of the consent form was given to each participant and a second copy was kept by the researcher.

During the Ethics Approval Procedure, the researcher was asked to make some slight amendments firstly: a clearer definition to how the selection of 'cognitively able' girls were identified. In addition, it was brought to the researcher's attention that it could be problematic that the participants would need to rely on their memories to recall information about their daughter's early years. The researcher therefore provided some memory prompts including the use of a timeline and an invitation to bring a selection of photographs as their daughters were growing up as an aide memoire (Appendix 4).

3.8.3 Anonymity and Confidentiality

The interviews were voice recorded and subsequently transcribed, the data was kept confidentially and, on a password, protected electronic device. Once the data was transcribed the voice recordings were deleted. The data was held anonymously, and it would not be possible to trace the data back to individual participants. If personal data, such as names of professionals were mentioned in the transcripts they were anonymised.

Participants were fully informed about confidentiality and its limits. They were made aware that professional transcription services might be used, and that any such services would have signed confidentiality agreements. Participants were also made aware that

all identifying information about themselves and their daughters would be removed from the transcripts and pseudonyms would be used. They were also made aware that academic supervisors and examiners would have access to anonymised transcripts. Prior to the interviews the researcher explained the situations when confidentiality would be compromised including a situation when the participant or another individual was at risk of harm or any indication of illicit activity was disclosed. In accordance with the Cardiff University Safeguarding Children and Vulnerable Adults Policy 2010, as soon as practically possible the researcher would then notify the researcher's supervisor and the safeguarding contact in the school.

3.8.4 Objectivity

The researcher avoided ethical conflict by selecting participants from a support group that had no professional or personal links to the researcher, therefore endorsing the researcher's objectivity.

3.8.5 The Right to Withdraw from the Study

The right to withdraw from the study was made clear to the participants via the information leaflet and letter (Appendix 3a & 3b) and they were additionally reminded prior to their interview. If the parents who volunteered to be involved in the research changed their minds they had the right to inform the researcher of their decision and to withdraw up until the point that the data was transcribed and anonymised, this was agreed to happen within two weeks of the interview, after this date it was not possible to identify their data. Whilst the researcher did not anticipate that the interviews would cause any distress to any of the participants, at times this may be unavoidable because the researcher was aware that a semi-structured interview was being used and it was difficult to predict the exact nature of the dialogue between the researcher and the participants. The participants also had the right to decline to answer any question during the interview. Participants likewise had the right to withdraw from the interview at any time. Before each of the interviews the participants were briefed regarding what to expect within the interview and the sheet they had previously accessed was shared again (Appendix 3b). The contact details of the researcher were also provided in the original information so that participants could register their interest and have an opportunity to contact the researcher about any potential questions or concerns about taking part in the research.

3.8.6 Pseudonyms

All the participants were notified of the procedure regarding how data would be collected and stored including the use of pseudonyms throughout the transcriptions and in the Thesis.

3.8.7 Ethical Approval

Ethical approval was obtained from the Cardiff University School of Psychology Ethics Committee. The research project commenced in October 2018 following receipt of ethical approval and finished in January 2022.

3.8.8 Interview Times and Locations

Parents were offered an interview during the summer and autumn terms 2019 at the venues provided by the local support group. A Friday was selected as a day that suited each parent and the researcher. While parents selected a date in advance flexibility was built in to allow for a date change if unexpected events arose. The final parent interview was at a different destination because of unexpected circumstances of the parent who wanted to be included in the research. The parent had another child whose health issues required the parent to not be too far away from her home. A local university was able to offer a room for the interview. All interviews were completed between April and September 2019.

3.8.9 Debrief

The researcher highlighted to participants the importance of their physical and psychological welfare, during the research process, and to support this a protocol had been prepared in advance to support them if it was needed (BPS Code of Human Ethics, 2014). The participants received a full debrief at the end of the interview process (Appendix 5). The information given to the participants at the beginning of the interview process highlighted both the purpose of the research and information about contacting the researcher with any questions they may have had about the research. The participants were given information signposting them to their local support group and the National Autistic Society (NAS) if they felt that further support was required as a result of their participation in this research.

3.8.10 Data protection

The research data was collected with agreement of the participants (BPS, 2009) using audio recording and notes. The data was stored in accordance with the Data Protection

Act (1998). The transcripts were password protected and accessible only by the researcher. All consent forms, recordings prior to transcripts and timelines were kept in a locked filing cabinet.

3.8.11 Data Collection

Smith, Flowers and Larkin (2009, p.56) wrote that for a successful data collection method “IPA is best suited to one which will invite participants to offer a rich, detailed, first person account of their experiences”. Therefore, the current study devised in-depth semi structured interviews to encourage participants to share their views of their lived experiences of their daughter’s early development, experiences and behaviours prior to a subsequent diagnosis of autism in later childhood, which according to Smith et al., (2009) is implicit in the IPA data collection events which is designed to elicit detailed stories, thoughts and feelings from the participants. Reid, Flowers, and Larkin (2005) state that semi-structured, one-to-one interviews have been a popular and preferred method for collecting such data. Smith and Osborn (2007) and Thomas (2009) agree that this practice of interviewing allows the researcher and participant to engage in a dialogue whereby initial questions can be adapted in the light of the participants’ responses and the researcher is able to probe and ask follow up questions in important areas as they arise.

3.8.12 Pilot Study

The researcher conducted a pilot interview with one parent in order to validate that the questions asked were logical and effective in drawing out valid and relevant information in connection with the research.

The pilot study was helpful in terms of timings of the interview process from meeting the participant to the debriefing process. In addition, it was useful in terms of rehearsing the interview questions and making any necessary amendments. During the pilot study, the researcher was aware of the use of the tape recorder for the participant and reassurance in subsequent interviews was helpful. Unexpected emotional responses during the pilot allowed the researcher to provide tissues as part of the resources available to the participant during the interview process. The pilot study was not included as part of the final data collection.

3.8.13 Data Analysis of Interviews Using IPA

IPA involves the detailed analytic treatment of each case followed by the search for patterns across the cases. Where this is done, the best IPA studies are concerned with the balance of convergence and divergence within the sample, not only presenting both shared themes but also pointing to the particular way in which these themes play out for individuals (Smith, 2011 p. 9).

IPA provides a set of flexible guidelines which can be adapted by individual researchers according to their research objectives (Hefferon & Gil-Rodriguez, 2011). The IPA analysis process involves a sequence of steps that allow the researcher to identify themes for the individual participants and to then look for common experiences and meanings across the group of participants. Smith et al (2012), state that they do not provide a definitive account and have not prescribed a single method for the breakdown of data. This allows for some flexibility in analysis while staying true to the model described by Smith et al., The researcher followed the guidance set out in Smith et al., (2009). They suggest six stages that researchers should follow in order to analyse and interpret data (table 4).

Table 4: 6 Stages of Analysis

Stages of Analysis
Stage 1: Reading and re-reading - close examinations of the transcript.
Stage 2: Exploratory commenting - examining the content on a very exploratory level by making notes.
Stage 3: Developing emergent themes - focusing on discrete chunks of text in order to identify what has been learned through exploratory commenting.
Stage 4: Searching for connections across themes - identifying subordinate themes with related emergent themes.
Stage 5: Moving to the next case - analysing each transcript in turn using the same method.
Stage 6: Looking for patterns across cases - subordinate themes are drawn.

IPA (Smith & Osborn, 2008; Smith, Flowers & Larkin, 2009) was the approach used to analyse the data. The model has been applied in turn to each of the interviews undertaken and an example of each has been included in the appendices. Smith et al

(2009) outline a number of stages involved in data analysis and these were used flexibly to help guide the process. The analysis process involved moving from a focus on the individual to a more shared understanding and from a descriptive level to a more interpretative one (Smith et al, 2009).

3.9 Stages of Analysis

3.9.1 Stage 1: Reading and re-reading - Listening, Checking Transcript, Reading and Re-reading

The First stage required the researcher to become immersed in the data from the individual participants. This process requiring the researcher to read and re-read the written transcripts while simultaneously listening to the audio-recording, which assisted with the analysis of the data. During the process the researcher was able to access the chronological accounts of the individual interviews which provided an understanding of the overall structure of the interview. At the same time the researcher was immersed in an active engagement with the data. The re-reading additionally provided the researcher with an understanding of how the accounts embedded within the script were bound together in different sections of the interview. This allowed the researcher to recognise the flow of the genetic story as well as the specific individual events. The immersion in the data in this way allowed the researcher an appreciation of how the rapport with the participant built up and that trust became more evident throughout the conversations as both parties became more comfortable. The researcher noted that as the participants became more comfortable, the flow and the rhythm of the interviews became more relaxed as they progressed. (Sample script Appendix 7).

3.9.2 Stage 2: Initial noting

This time-consuming step had a focused analysis on the semantic content and language use on an intense level of exploration. The researcher, while remaining open minded, noted comments of interest. This step added depth to the knowledge gained in step 1 and demonstrated how the two steps often merge. In the style of IPA described by Smith et al., at this stage there are no rules about what the researcher chooses to comment on, and the research ended up with a detailed set of comments and notes on the interview with each parent. Smith et al., make suggestions as to how this may be undertaken but comment that their suggestions are not exhaustive rather the importance is the use of a fluid process to engage with the data in detail thus allowing

the researcher to push the analysis of the data to an interpretative level. The process involved the researcher capturing a clear phenomenological focus close to the account and explicit meanings provided by the parents. The researcher's intention throughout this step was to capture those things that are important to the parents including relationships, places, events and values including the meaning they attach to these things. The process was supported by the researcher's focus on the language used by the parents in their accounts of their lived experiences which was helpful for the researcher and allowed the identification of the more abstract concepts when making sense of the parents making sense of their experiences.

The researcher individually focused on the:

Descriptive comments- Focused on describing the content of what was said and highlighting the objects which structure the participants' thoughts and experiences.

Linguistic comments- Focused upon exploring the specific use of language including aspects such as pauses, repetition, metaphor and tone.

Conceptual comments- Focused on engaging at a more interrogative and conceptual level. This is about asking interpretative questions to develop an understanding of the key messages.

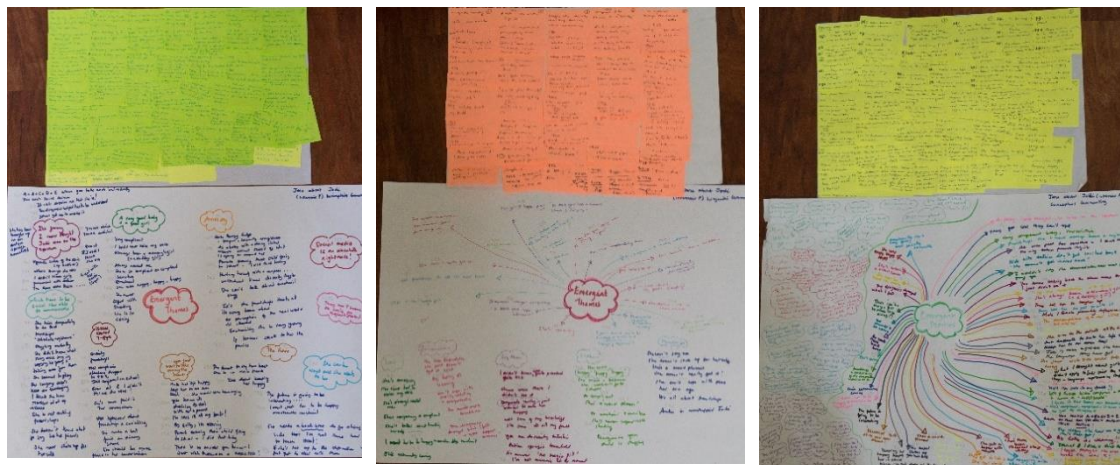
These steps of exploratory commenting are not meant to be exhaustive but a useful analytical tool, (Smith et al., 2012). A visual representation of these 3 systems of commenting was designed by the researcher to support the researcher's focus and ability to apply each type of comment individually (Figs.2-4).

As recommended by Smith and colleagues this analysis was completed on a hard copy of the transcript with additional margins on the left-hand and right-hand sides of the transcript for the exploratory comments initially, and then again in step 4 providing emergent themes. For each of the six scripts the researcher used two additional steps to support the descriptive, linguistic and conceptual commenting.

To distinguish descriptive, linguistic and conceptual the researcher used different coloured post it notes to pick out comments (Figs: 2, 3 & 4) and then developed mind maps for each section before highlighting the comments onto the landscape script, (sample annotated script Appendix 8).

Figure 2-4: additional steps included by the researcher

Figure: 2 Descriptive comments concerned with the content of the data (Full photo Appendix 9 a & 9b)
Figure: 3 Linguistic Comments - concerned with the language used (Full photo Appendix 10a & 10 b).
Figure: 4 Conceptual Comments - concerned with interpretation (Full photo Appendix 11a & 11b)



This assisted the researcher’s preferred method of working with a script particularly as IPA was a new method of analysis.

3.9.3 Stage 3: Developing Emergent Themes:

Guided by Smith and colleagues the researcher applied a multi-sensory process to support capturing the data, identifying and developing the emergent themes. While this additional step extended the process of analysis it supported the researcher’s visualisation of the components of the process. These steps provided the researcher with an extensive data set that was used for the next step of analysis - developing the emergent themes.

Figs: 2, 3 and 4 demonstrate how the researcher was able to reduce the volume of data, while maintaining its complexity to enable an analysis of the exploratory comments allowing for the identification of the emergent themes. This process involved breaking up the narrative flow of the interview and re-organisation of the data. At this stage in the process the original interview becomes a ‘set of parts’ while the analysis is undertaken however, these parts come together in another ‘new whole’ at the end of the analysis during the write-up (Smith et al., 2009)

3.9.4 Stage 4: Connection across Emergent Themes

The researcher established a set of themes within the transcript which were ordered chronologically following the sequence of the interviews. The next step applied by the researcher was to develop a map of how the themes fit together.

Again, the model allowed the researcher to be creative in the representation of this step to allow the exploration and organisation of the analysis. The researcher discarded some of the originally identified themes during this process so that themes were reflecting the research question and were representing the lived experiences of parents raising a daughter who is diagnosed with autism in later childhood. The researcher was able to draw together the emergent themes and provided a structure which was able to capture the most interesting and important accounts of the parent's dialogue. The researcher captured this using the mind mapping task see Appendix (9b, 10b & 11b).

Elements within this step which Smith et al., suggest are important, are considered as helpful when identifying patterns and connections between emergent themes in the IPA model.

3.9.5 Stage 5: Moving to the next case

Stage 5 involved moving onto the next transcript and repeating the process.

The researcher was rigid in applying the same approach to each of the interview transcripts, so the method used to analyse the individual interviews was consistently applied (stages 1-4 were adhered to) for each participant, (Appendix 14 & 19) and for participant super-ordinate themes.

It was important to approach each case "on its own terms, to do justice to its own individuality" (Smith et al., 2009, p. 100). During this process, the researcher considered it inevitable that the analysis could be influenced by findings from the previous accounts however, strived to bracket the ideas that may have emerged from earlier transcripts.

Each interview transcript was analysed individually and all six had been analysed before a comparison with other cases was made. This allowed the researcher to respect and value the worth of the findings from each participant.

3.9.6 Stage 6: Patterns across the cases:

This stage involved identifying the patterns across cases. The researcher achieved this by drawing up a list of themes for the group and then grouping them into master themes

that represented shared higher ordered themes. The master table of themes for the group is shown in Figure 5 in chapter 4. Adhering to the closeness of the data by understanding each participants' words and perspectives was imperative (Smith et al., 2012).

However, in IPA research, "fewer participants examined at a greater depth is always preferable to a broader, shallow and simply descriptive analysis of many individuals" (Hefferon & Gil-Rodriguez, 2011, p.756).

The analysis leads to writing a narrative account for the research which, involves writing about each theme in turn. Each theme is described with examples of extracts from the individual transcripts and followed by analytic comments from the researcher. The researcher needs to look at the data through a psychological lens and interpret it with the application of psychological concepts and theories (Hefferon & Gil-Rodriguez, 2011).

To complete stage 6 of the analysis the researcher took each of the parent's sub themes (examples, Appendices 14-19) and physical cut them up and organised them into a number of repeating themes and the process was repeated several times until the researcher felt satisfied the chosen superordinate themes had captured the narratives told by the mothers individually and collectively. Each of the individual tables of superordinate themes were cut up and arranged into themes – this process underwent a number of steps before the group themes were arrived at (Appendix 20-24). A number of superordinate themes had emerged for participants but the repetition of the process and the reviewing of individual themes from the participants finally brought the researcher to the final three superordinate themes (Fig.5).

3.10 Quality of the Research

3.10.1 Validity and Reliability

It has been established that evidence from qualitative research should not be evaluated using the same criteria as that used in quantitative methodology and a number of guidelines have been developed to assist with the process. Smith (2011) argues that it is important that qualitative researchers take the question of quality and validity seriously and presents guidelines for specific elements that capture good IPA research. Qualitative methodologies are diverse in nature because they are based on having differing epistemological standpoints and a specific set of criteria when evaluating

validity. Smith, Flowers and Larkin (2009) are in favour of the Yardley (2000 & 2008) guidelines and have described how they apply them to an IPA study. The researcher adopted Yardley's four broad principles for evaluating a qualitative approach.

3.10.2 Sensitivity to Context

Being sensitive to context can be demonstrated in the developing of the research question in the context of the existing literature and in making connections with the analytical findings surrounding topics under examination. The social context between researcher and participant is very important; therefore, Yardley (2000) recommended reflexivity around the researcher's actions and characteristics. The researcher's awareness of the balance of power between researcher and participants in the study is important. Smith et al., (2009) argued that IPA researchers demonstrate sensitivity to context in their choice of IPA as a method, concerned as it is with the idiographic and the particular context of the participant. The researcher's analysis of the data which is immersed in the participants' lived experiences demonstrates sensitivity in context because it stays close to the narrative in the analysis. The interviews were organised to accommodate the mother's commitments to avoid an impact on their daily routine.

3.10.3 Commitment and Rigour

Commitment, in Yardley's conceptualisation, refers to the researcher's engagement with the topic and method used as well as their competence and skill in using the method. Rigour refers to the quality of the data collection and analysis. In interpretative methods, this refers to the quality, completeness and complexity of the interpretation. The principles of commitment and rigour are integral to IPA as a methodical and comprehensive method of data collection and analysis. The commitment is shown by the researcher's sensitivity, concern and attention provided for each of the participants during the interview. In addition to this was the dedicated time taken to analyse their interviews. The development of the researcher's understanding of the underlying theoretical principles and commitment to the method is demonstrated through the reflection and in-depth engagement that is demonstrated at each stage of the research analysis process. The rigour is evident in the research's analytic stages where, while still following the six stages recommended by Smith et al., (2009), the researcher put in additional steps (Appendix 9a & b, 10a & b, 11a & b, 1-19) to ensure a thorough understanding of the interviews. Each of the stages were followed in an identical

manner for each participant. The researcher followed the guidelines provided by Smith (2011) and selected extracts that depicted convergence and divergence, representativeness and variability, to support the in depth representation of the participants contributions.

3.10.4 Transparency and Coherence

Transparency and coherence have been observed throughout. Yardley (2000) proposed that transparency and coherence are important factors in how qualitative research is presented. The narrative should be clear, convincing and meaningful to readers. This can include how data and analysis are presented and described, and the degree to which all relevant aspects of the research process are detailed. The researcher provided participants with clear information and consent forms (Appendix 2b, 3a&3b) which provided a clear explanation of the aims of the research and how the findings would be used. The parents were also given the opportunity to ask further questions before the data collection to ensure transparency. The analysis process followed a unique path staying true to IPA to identify themes and the researcher attempted to create a clear, comprehensive and accurate account of the research process followed. Transparency and coherence were adhered to by keeping an electronic, photographic and paper trail of all stages of the research process, particularly during the analytic journey, which is available for independent audit. Transparency is additionally evident in the methodology and analysis sections of the research including direct quotes from the participants to illustrate the themes. These have been clearly referenced by line and number following the extract used throughout the research findings chapter. A research diary supported the journey of the researcher throughout the project. They demonstrate the descriptions of the origins of the idea and direction of the research. The researcher has captured reflections, ideas and thoughts from a reflective diary in the 'Reflection Boxes' in Chapters 4 and 6.

3.10.5 Impact and Importance

Yardley (2000) considered impact and importance to be decisive criteria by which any research is judged. Yardley argued that qualitative research needs to have both theoretical and practical impact (Yardley, 2000). Impact and importance are critical aspects of research because it explains to the reader that something is interesting, of value, useful or important.

Yardley (2000, p.223) argues that, “the decisive criterion by which any piece of research must be judged is, arguably, its impact and utility”. The impact may be made on theoretical understanding, socio-cultural understanding and/or practical use for the community, policy makers and other professionals. It is anticipated that the rich analysis will provide an improved understanding of how raising a cognitively able daughter who is later diagnosed with autism is experienced by their mothers. It is hoped that this may shine some light on the factors within this life event and will therefore help in some way to assist all professionals working with girls with autism to work more effectively together to improve the outcomes for these girls and their parents. In this respect the researcher is of the opinion that particular research could have both a theoretical and practical impact within Educational Psychology practice and more generally within Autism Services. These areas are to be discussed further by the researcher in the discussion section in Chapter 5.

Smith et al., (2009) maintained that the IPA researcher should be aiming to tell the reader something “interesting, important or useful” (p. 183).

3.10.6 Summary

The contents of this chapter has stated the purpose of the research, and the research orientation or epistemology. The IPA methods of data collection which was selected to address the research questions are outlined for all phases of the research in line with a pragmatic position. The IPA design is described, in detail capturing the qualitative design of the research including the analytical strategies and steps employed by the researcher. The researcher has remained true to the IPA process including the recognition of the importance of the researcher’s role being central to a procedure that is all about the participant. It was vital to ensure that the researcher embraced the lived experience of the parents and captured the significance of the I and the P in the methodology of the IPA, (Smith et al., 2012).

The next chapter will provide information on the six mothers who participated in this research. There will be a presentation of both the superordinate and subordinate themes generated from the interview data using IPA which have captured the parent’s original words and the researcher’s understanding and reflection of them, in other words, the researcher’s interpretation. Quotations from the participants will illustrate their lived experiences.

Chapter 4

4.0 Research Findings

4.1 Introduction

Chapter three described the theoretical underpinnings of IPA which are embedded in phenomenology and hermeneutics; phenomenology being the study of the individual's perceptions of phenomena (Smith et al., 2009) and the hermeneutic circle referring to the role of interpretation in the perception of phenomena (Smith & Eatough, 2006). In an IPA study, each participant interprets their own experience in their own particular way, in the context of their personal history. This chapter aims to provide a rich picture of the experiences of mothers raising a cognitively able daughter who is diagnosed with autism in later childhood by presenting the emergent themes drawn out during the analytic process. Their accounts are presented and draw solely on the interpretative analytic process described in Chapter three and aim to capture the quality of the participants 'shared' experience. The findings from the transcript data employed IPA due to its relevance in addressing the research questions:

4.1.1 Primary Research Question:

- To explore how mothers make sense of their experiences of their daughter's early development and behaviours preceding their subsequent autism diagnosis.

4.1.2 Secondary Research Question:

- How might the experiences of these mothers help professionals have a clearer understanding about the difficulties cognitively able girls with autism experience?

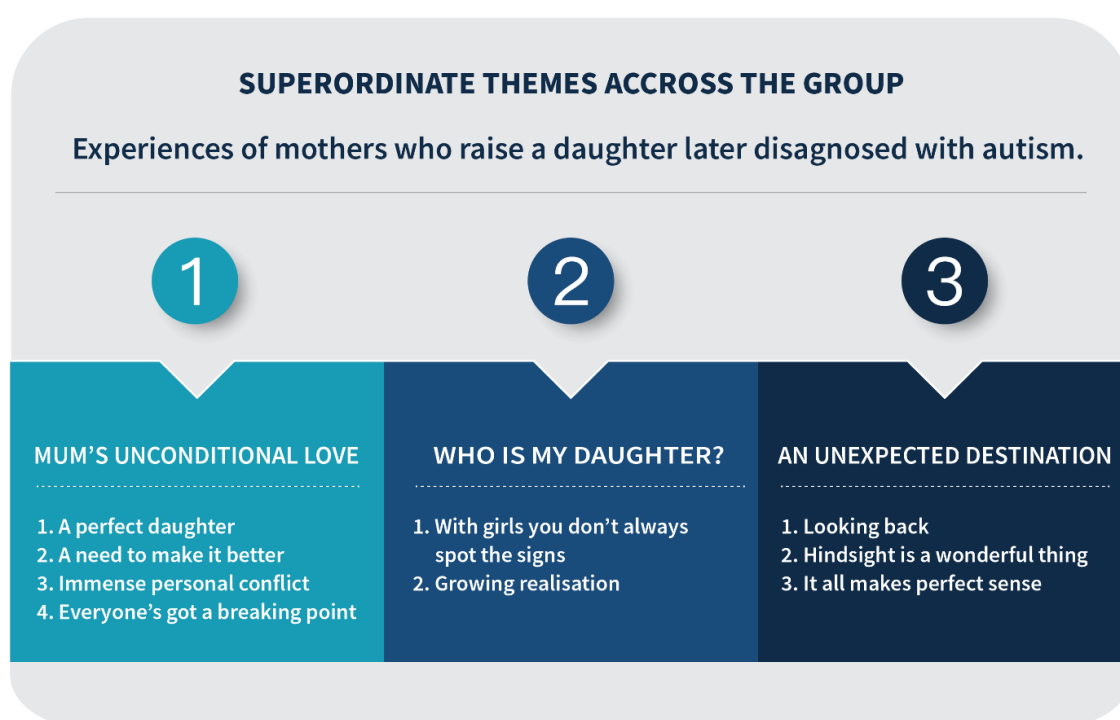
The primary research question relates to the overall lived experiences of mothers raising a daughter before there was any consideration that she was autistic. The secondary research question is concerned with how the mothers' lived experiences contribute to the professionals' understanding of how autism presents in cognitively able girls.

It was evident to the researcher throughout each individual interview that the mothers had not considered autism as a diagnosis for their daughters when recalling and reflecting on their early development and behaviour. Most of the mothers began their story tentatively however, as the interviews progressed, more introspective accounts of the challenges they experienced with their daughters surfaced. The superordinate

themes that have emerged represent the researcher’s interpretation of the reflective journey taken by each participant which was meaningful to them. The lived experiences of each mother were as a result of multi-layered interactions between their daughter, their immediate and wider families, professionals and the intertwined social systems around them.

When final themes were identified they were relevant to each of the mothers throughout their narrative accounts about raising their daughters and thus the themes are presented to reflect this. The researcher aims to present the themes to capture the lived experiences at a time when there was no consideration of autism for their daughters and at a time when their daughters had a diagnosis and sometimes these are distinctive and at others the boundaries are more blurred.

Figure 5: Superordinate themes across the group



Superordinate and subordinate themes were identified for each participant as well as the group collectively. The individual experiences are captured through a detailed interpretative exploration via extracts of text which are presented and discussed. During the IPA analytic process described in Chapter 3 the three overarching superordinate themes which best relate to the research questions being explored emerged as:

- Mum’s Unconditional Love - reflecting how each of the daughters were clearly loved and accepted for who they were,

- Who is my Daughter? - capturing the intensity for the mothers needing others to know their real daughter.
- An Unexpected Destination - captures an understanding of how the journey the mothers were on with their daughters changed and they ended up in a different place.

These themes aim to provide a rich representation of the patterns and connections between the emergent subthemes, and the shared experiences of these mothers raising a daughter who was diagnosed with autism in later childhood. A visual representation of the themes is presented in Figure 5. Each superordinate theme includes a number of subordinate themes and they will be discussed in the context of the research questions. The findings for each superordinate theme in turn will be discussed, including direct quotations from participants. Reflections on each interview, comments on participants' communicative style and an interpretive summary for each participant can also be found in the Appendices (Appendix 14-19). It is crucial in IPA that interpretation is recognised including the researcher's interpretation of what was said rather than a supposedly impartial analysis (Smith et al., 2009). The theme labels identified are mainly derived from parental quotes however, they remain the researcher's preference. While the researcher has separated the themes throughout the process of data analysis, many of the themes remain interrelated and this is clear throughout the narrative account. The researcher has aimed to illustrate each of the mother's voices by using their direct quotes uniformly where possible across individual participants so that their unique experiences are illustrated. The extracts from at least half of the participants who related to each subordinate theme will be included to support the claims made (Smith, 2011). Throughout the narrative it has been the researcher's intention to explore and capture complexity of individual distinctive experiences while highlighting collective shared experiences. Themes are discussed with supporting quotes and areas of convergence and divergence are considered where appropriate throughout the process. Each of the superordinate and subordinate themes are discussed before the diagnosis was a consideration and secondly following their daughter's diagnosis

4.2 Superordinate Theme 1 - Mum's Unconditional Love

This superordinate theme represents the mother's immense love they had for their daughters from the moment they were born and throughout their lives. Almost from

nowhere the mothers in the research were challenged by aspects of their daughter's behaviour that they tried to make sense of and this took them on a 'roller coaster' of an emotional journey which included their daughters being diagnosed with autism and beyond. The intensity of the love each mother had for their daughters remained no matter what they were going through themselves to support their daughters and at times making things right so their daughters could be understood. These experiences could be all consuming and extreme and there were times when the mothers took a knock to their own confidence and their sense of self-worth.

The researcher asked each mother to share their daughter's story from the moment they were born, throughout their early years and into their childhoods and beyond. It was evident to the researcher from the moment each mother spoke about their daughter how much they loved them from the moment they met them. The construct of 'Mum's unconditional love' is taken to express the intense and on-going experience of love, described by all the mothers. Each of the girls were immensely loved and as their difficulties developed they were just accepted for who they were by their mothers. The theme of unconditional love emerged and dominated every participant's narrative. This superordinate theme 'mum's unconditional love' captures how the mothers in this research made sense of the intensity of their love for their daughters and illustrates their intense love and total acceptance of their daughters at different times and stages throughout their lives. The theme 'mum's unconditional love' was a golden thread throughout the entire analysis of the narratives and was captured by the researcher during the analysis of the scripts as each of their stories unfolded, in the language used and in the emotion the mothers portrayed throughout their interviews which added to the demonstration of how much love there was for their daughters. Without an exception the researcher's interpretation of the participants narratives captures the way each of the mothers interviewed demonstrated their love for their daughters. As narratives unfolded the love remained constant despite the personal challenges the mothers encountered as their daughters grew up and eventually received an autism diagnosis and beyond. The subordinate themes within this superordinate theme capture the mothers' recognition of their daughters amazing positive qualities and strengths despite what they were dealing with throughout their childhood. In addition, while they coped with their own conflict and challenges, these mothers strived to protect and help their daughters as they grew up and their needs changed.

The superordinate theme **Mum’s unconditional love** – was identified as a construct and was supported by the emergence from the data of the creation of four distinctive subordinate themes from the mothers’ accounts:

- A perfect daughter
- A need to make it better
- Immense personal conflict
- Everyone’s got a breaking point

Table 5 below captures the inclusion of each of the mothers within the subordinate themes.

Table 5: subordinate themes for superordinate theme 1 - Mum’s unconditional love

Subordinate themes	Jane	Emily	Vroni	Betty	Abbie	Jennie
<i>A perfect daughter</i>	√	√	√	√	√	√
<i>A need to make it better</i>	√	√	√	√	√	√
<i>Immense personal conflict</i>	√	√	√	√	√	√
<i>Everyone’s got a breaking point</i>		√	√	√	√	√

Each mother was asked to talk about what it was like for them raising their daughter from birth, including their experience of their daughter’s early childhood and their development journey as they were growing up. All the mothers identified with the birth of their daughters and the love they had for their daughters. When each of the mothers were discussing their understanding of having a daughter who was diagnosed in later childhood with autism it was evident in each of the narratives that in the early years there was little or no recognition that there was something not right with their daughter’s development and behaviour. This was more surprising because most of the mothers had first-hand experience of autism within their families, including one mother who had another daughter with autism. Another mother who had no direct family members with autism had worked in a school setting with children and young people with autism. However, as the years progressed for different reasons the mothers talked

about gradually becoming aware that something was not quite right, and this became more of a concern and evident as their stories unfolded and their daughters were growing up.

The subordinate themes capture themes that overlap into both pre and post diagnosis stages and they have been presented to demonstrate this.

4.3 A perfect daughter

4.3.1 Pre-diagnosis

Each mother talked in their narratives about the intense love that they had for their daughter from the moment they were born and throughout their lives to date. It did not matter where they were in their own personal journey, each of the participants highlighted the love they have for their daughter who were in their eyes just perfect and their recognition of their daughter's amazing talents, characteristics and strengths throughout their lives was so clear in each of the narratives.

All the daughters were described by their mothers, particularly in their early years, as being faultless, beautiful, well behaved, adored and almost without imperfections. The language and the words used by the mothers was almost harmonious at times and there was no reason why they would be looking for faults or difficulties.

..... **'just loved'** (378) Emily

..... **'Danni is beautiful, Danni is bright, Danni can talk, Danni can walk, Danni can read'**, (942), Betty.

..... **'a little angel'** (1231) Betty

..... **'she would just be a ray of sunshine, just always happy, always cuddly'** (148) Jennie.

..... **'because I never had to tell her off, she never did anything wrong'** (80) Jane

..... **'she was... you know she was quite easy really'** (174) Abbie

..... **'I don't know easy really'** (376) Emily

The words used by the mothers capture each of their reminiscences and reflections of their daughters as babies and in their early years were so positive and suggested that they had no knowledge or reason to believe their child was going to have any struggles in life. However, what was clear to the researcher as the mothers spoke, these feelings and sentiments were also current and captured in the language they used and in their emotions and expressions throughout each of the interviews.

Each of the mothers in the group described their love for their daughters and this continued to be equally expressed a number of times throughout the transcripts. Every mother spontaneously talked about their daughter in a loving and positive way and any difficulties were felt by the researcher to be almost played down as if they wanted their daughter's perfection to shine through. They were proud of their daughters as they talked about their emotional strengths and their abilities and what others had noticed too. Most of the mothers expressed surprise when others noticed positive qualities in their daughters. Vroni felt that she didn't expect other people to see her daughter's strengths in the same way as she was able to. Vroni captured a quote from one of her daughter's teachers,

'Anna is honestly the most loving affectionate child you'll ever meet, and she wows... even the teacher said to me this week, she was like 'How does she know what she knows?' (2781) Vroni

Vroni was proud and moved emotionally by the recognition by her daughter's teacher that she also saw her as this loving, amazingly clever child. Vroni was able to share that she knew her daughter had strengths however, she did not realise until Anna's teacher spoke to her that others recognised her daughter's strengths. While Vroni was overwhelmed by her daughter's ability, affection and honesty she spoke of how she was more amazed that other recognise these qualities. The qualities recognised by her teachers suggested she had superior knowledge that surprised her teacher, at this point it was very much recognised as a strength. Vroni spoke about not stopping to consider how her daughter knew the things that would take people by surprise, she had no reason to question or think how her daughter was able to acquire the knowledge she had for her young age. Vroni's love and appreciation of the strengths of her daughter was so evident just from the way she spoke the words and the emotion portrayed in her voice.

Abbie was also stunned by her daughter's nursery teacher telling her about her daughter's ability and how she amazed them, and she was ahead of her peers. As her mother she knew she was clever but she was surprised that other people saw her strengths. She decided to put her into nursery early where she was so happy. She was so delighted that her talents were recognised.

'She was so focussed. (umm) And so we... we went for parents evening and the teacher was just saying 'I've never known a child like it! She's got this amazing concentration!'(274) Abbie

Jennie thought that while her family thought Martha was a bright girl she didn't realise just how clever until she was told by her school teacher and she expressed that it was lovely and emotional to hear somebody else talking about Martha's strengths.

'Yeah, she... (sigh) schoolwork was brilliant, absolutely no issue. I remember in year one, (umm) the teacher really got [Martha] and she said '[Martha] is outstandingly intelligent and she'll be able to do whatever she wants in life'. Which was such a lovely thing to hear'. (247), Jennie

Emily reflected on her friends noticing how easy her daughter was at toddler group and how she had reached all her milestones quickly.

'she seemed to keep up with all of her peers and everything like that. Nothing stood out at all, but she was just sort of... I don't know easy really. Just... I remember my friends saying 'You've got a really easy baby, why haven't...?'(375), Emily

For these parents, they felt reassured that their daughters were developing well and they implied that at these times they had no reason to be concerned about the little girls they were raising. In the early years, as the mothers in this study described their daughters there was almost no room for them to consider any difficulties or imperfections their daughters may have. However, when recalling raising their daughters they did reference some difficulties they were experiencing, but these were often dismissed at the time or not recognised as an issue until perhaps a later point in their daughter's lives. The researcher felt as if these mothers were almost in denial of any difficulties when they occurred. However, because the interviews were retrospective in terms of their daughters' diagnosis of autism there were moments when they talked about challenges they had experienced which they now understood were linked to autism

In the context of the secondary research question this theme is captured in turn as the mother's experiences of raising their daughters was explored.

4.4 A perfect daughter

4.4.1 Post-diagnosis

It was plain at times, particularly when their daughter's unexpected difficulties emerged, including when behaviours became more complex and challenging, their mothers still found so many positives to focus on. At times throughout the years their daughters were growing up, they recognised that their daughters were struggling with aspects of their lives and they feared that their daughters were different, they were able to still see their 'perfect' daughter. Even at times when they were speaking about the difficulties and challenges for their daughters they demonstrated in their verbal and non-verbal language the emotions of laughter, sadness and tears which reinforced their adoration of their daughters. Before their daughters were diagnosed with autism some of the mothers talked in a manner that was interpreted by the researcher as they had 'lost' their daughter. In a similar way following their diagnosis they described 'finding' their daughters again. The mothers while acknowledging the difficulties their daughters were experiencing always tried to understand and talk about their daughter's positive qualities. Even following many difficult and challenging times these mothers didn't want the autism to take away from who their daughters were in their eyes.

One parent following the diagnosis talked about wanting her daughter to be

'defined by her strengths' (2534) Betty

She did not want people to see the autism first and then her daughter.

And Vroni despite her diagnosis described her daughter

'But yeah all these pictures... and she is... she's the most amazing little girl ever. She's so clever. So clever.'(3553),Vroni

However, prior to her diagnosis she described her 'lost' daughter re-emerging following her move to a school where her difficulties were recognised and understood and when she finally got her diagnosis and they celebrated her differences and her strengths with an autism party.

'I finally... I feel like I've got my little girl back. You know likes she's a happy... she has struggled in year six, don't get me wrong, and she's clashed with the teacher, it hasn't been easy' (2365) Vroni

'And we said we were going to have an autism party when we got home to celebrate her differences' (2265) Vroni

Each mother talked throughout the narratives about their daughters in a favourable tone and manner, even at those times when life became more complex and there were difficult challenges. It was clear from the way in which the mothers described raising their daughters their strengths shone through even at the darkest times. At a time when her daughter had attempted suicide three times and her older daughter was very poorly in hospital, Jennie found positives about her daughter. However, at the same time she was trying to understand why her daughter was struggling with life so much. She was always astounded by her daughter's talent and skills even at times when she did not appear to be coping with her own life. Jennie was trying to understand and make sense of what was happening while her daughter was struggling and hurting so much, she wanted to understand how did she still have the strength to do the most amazing things.

'She did an amazing cake for Emma when she last came out of hospital.'(2220)

'And it was absolutely stunning this cake. And she hadn't followed a pattern, she'd just done it herself and it... it tasted amazing and looked amazing,' (2256), Jennie

In the same way when Vroni's daughter was struggling, her strengths would come to the forefront,

'She's unbelievable, the things that she sees that you wouldn't see. This is just an example for a competition she's done recently. (umm) A writing competition, and the language in there unbelievable,' (3607), Vroni

It was clear in the narratives of these mothers that when their daughters started to struggle with events in their lives at different stages they wanted to just make everything right. At a time before autism was a consideration despite the perfectionism of each of their daughters there were clearly times that were tricky or difficult for them. These mothers without exception just wanted to make everything better for their daughter and the subordinate theme *'a need to make it better'* captures this.

4.5 A need to make it better

4.5.1 Pre-diagnosis

The love these mothers expressed for their daughters was highlighted in their need to make everything better for them. In particular, if they faced any challenges in or out of school their mothers were there for them to fight their battles in terms of putting things right. As the narratives unfolded the researcher interpreted from the mothers' voices and body language that their ability to recognise and face the reality that their daughter had difficulties was really tough. Each mother had an intense need to make everything better for their daughters which is what most mothers want for to do for their children. The language they used together with expression in their voices reinforced how they viewed their connection with their daughters particularly at times when life was more turbulent. Their love and fears of how vulnerable their daughters were prompted a further sense of needing to protect their daughters from distress and harm. Prior to any consideration of a diagnosis when teachers or other adults did acknowledge behaviour or anxiety issues they were mostly sympathetic and could identify problems for these girls. In addition the mothers always indicated their gratitude when they felt others acknowledge difficulties and they were able to put strategies in place meaning that the experiences their daughters were having in school were going well or better than they had been.

'you just want to take the hurt away' (750), Jane.

'because I'm all about removing that anxiety' (955), ***I don't want her to be any more anxious than she already is'*** (962), Betty.

The mothers individually and collectively recognised a need for others to understand their daughters' experiences in school when they were not going well, before autism was a consideration. One mother explained,

'she's been failed' (3178) Vroni and added ***'it hasn't been that easy'*** (2404), Vroni.

'I'm responsible for making her feel better' (1642) Emily.

Abbie felt she was always making excuses for her daughter with her grandparents who looked after her after school. For example, she would say, she was tired and she had had a hard day at school. However, one day Abbie's father was exhausted with his granddaughter and he commented that the family needed professional help. A referral

was made to CAMHS and were told it was poor parenting and as parents they really did not feel this was the case.

'So we went to CAMHS... went to the GP, both of us went, (umm) explained the situation, what we'd been told, he said well it just sounds like bad parenting! (laugh) Which I... I didn't... if he hadn't have said it, you just... you know you read about these things and you just think no surely not!' (612), Abbie

Jennie's daughter was so clingy to just her from very young and even though she loved her father and Granddad she would not let them approach or cuddle her. This spilled over into family events and Jennie felt she would make excuses for her behaviour.

'And all these people had come to see her. (umm) And other than eating the odd strawberry, she just cried, and I had to go and put her back to bed.' (142), Jennie.

Jennie felt she wanted to protect her daughter and she struggled to see her being so distressed, so she resolved the situation by putting her back to bed and making excuses to their visitors.

Another parent was a teacher, and she didn't want her daughter to be judged as the naughty teacher's child. She was trying so hard to get it right as a mum and as a teacher. She expressed her determination to make sure her daughter behaved herself especially in public.

'you know my child's never going to be naughty, I know exactly what I'm doing here, I'm going to have a really good child. I've been that judgy teacher with other people's kids and you know well they behave for me, why don't they behave at home? And here I was with this little two year old so sat on the steps and getting up and... you know just wasn't having any of it.' (407), Emily

Vroni felt she was always defending her daughter at school and she was always being called in and made to feel that no other child did anything that was wrong. She laughed at times because she felt so embarrassed recalling the situations she found herself in. She expressed that she just wanted to understand why the teachers were picking on her daughter and she would always try to make excuses for her daughter while trying to understand why her teachers picked up on the things they were discussing with her.

'No, not really' I said, 'Oh right, so I've got a special child then!' (laugh) You know because she made it out like my child was the only child in the world that would do something like that and be naughty! And you know I just felt... I did feel like I had a naughty child then like 'Here comes the naughty girl's mum!' You know! (laugh)'. (779), Vroni

It is appeared so difficult for these mothers to see their daughters struggle and they just wanted to make things right for them and this would be the response of any parent who found themselves in similar situations. Parents want to protect their children and it is difficult when somebody else is saying negative things about your child. At the point these events happened autism was not on any one's radar.

4.6 A need to make it better

4.6.1 Post-diagnosis

Following their daughter's diagnosis of autism there was still an intense need for mothers to make things better for their daughters. The mothers recognised that having a diagnosis was and could be helpful but they did not necessarily all want or expect the diagnosis for their daughters. They wanted to make life better at home, in extended families, in school and the community. At the point where things had reached crisis point for them as mothers, they were aware of needing other support for themselves and their daughters. They were grateful for the support from others when it was there for them. Some of the mothers also recognised that this was not an easy thing to do and they acknowledged the lack of understanding in the world around them for their daughters who were finding life challenging. There was a need to want *'it'* (the autism) to go away were words spoken by one mother who was almost speaking her thoughts out loud and then she was reflective and added

'there isn't a magic pill' (975) Jane.

Jane talked about the need for a 'magic' tablet that would take away the autism for her daughter and then life would be so much better for her.

Some mothers expressed that there did seem to be an understanding from some of their work places that their daughters required them at times to be there for them and this could be unexpected and their availability needed to be flexible and they were grateful that they did not need to have to explain, they were just understood.

'So, I just had to say to my boss 'I'm really sorry, but I've got to go home'. So (sigh) I went home, and she was still under the bed and... and eventually we unravelled that Queen Victoria had said that all children had to go to school... and so that was... that was the... the problem.'(916), Abbie

On one occasion Abbie's daughter was really struggling to go to school and her Dad had run out of ideas to help her so her mother came home, and she was able to take charge of the situation. The children were learning about the Victorian times and she was scared of Queen Victoria.

There was an acknowledgement from all the mothers that the difficulties these girls were facing was often linked to school or a situation that was away from their home. The mothers expressed that there was a need for teachers from school to support the girls and recognise the challenges and difficulties these girls were facing at different times throughout their childhood. What often made things more difficult were the times when school did not see the struggles and it was the behaviour at home that indicated to the mothers that school was causing some challenges for their daughters. The mothers suggested that they were being 'fussy' parents but acknowledged that they just wanted the best for their daughters, and when it was acknowledged by others and when their girls were supported there was an overwhelming feeling of relief for the mothers.

'But they understand it and they've put the support in place. They know she's going to struggle with transitions, so they put her pack in place and take pictures and take her to the class and do an extended transition', (3210). 'So they spend that time with her and do debrief sessions with her now and you know in the afternoons and things. So... and do you know she's a happy little girl', (2320), Vroni.

'So it basically meant that for the whole year, T got one-to-one support as well as India. Yeah. Worked... worked brilliantly. And it... India came out with all 5s and just was... you know really... happy and you know settled and... and I think you know coming to terms with... with things,' (1090), Abbie.

'So (umm) they... they're putting some more stuff in place for her (umm) as far as emotional support is concerned,' (608), Jane.

The mothers felt their daughters struggles were been acknowledged by school staff and the sense of relief for the mothers was acknowledged and the mothers indicated that

there was some recognition for their daughters difficulties which made such a difference.

One parent had given up work because of the complexities in her family and she needed to be able to drop everything and be there for her children when they needed her. In some ways she felt she was the only one who really understood her children. Betty expressed her children were her life and she needed to be always there for her children she stated,

'I have given up my career and my life,' (1889) Betty.

As Abbie's daughter's behaviour became more unpredictable her mother found it easier to give up her job because she had more control and was able to manage complex situations as they arose and trying to manage a job at this time was almost impossible.

'So I mean as I'd given up work long before... by that stage because she was just so unpredictable as to when we could get her in,' (1193) Abbie

Every mother put their daughters first and this was very clear in the narratives as they unfolded. There was a need to protect their daughters before and after there was a diagnosis and as their stories unravelled they often explained that even close family members did not understand and that made life a further struggle. They wanted to protect and make it right for their girls and wanted their extended families to understand their daughters and accept their difficulties. One parent talked about the struggles for her daughter's Granddad who she described as really struggling to understand his granddaughter even though he knew that she had a diagnosis of autism.

'He struggled for a long time with her swearing. But I would just say well you know I don't like her swearing either. But she only does it at home and that is her release. And actually, when she starts swearing then I know that that's the precursor to a meltdown! And actually, we just need to back off and... and leave her alone,' (1381), Abbie.

4.7 Immense Personal Conflict

4.7.1 Pre-diagnosis

This subtheme captures how all the mothers in this research made sense of personal conflict and their endurance with the challenges as their daughters grew up. They fought

with themselves in particular with making sense and accepting why their daughters were struggling particularly at those times before any one including themselves had ever considered they may be autistic. The researcher asked a question regarding the parents understanding of autism and many of the responses that represent this sub theme emerged. Of interest to the researcher when discussing their experience of autism was that each of the mothers interviewed had realised they had already significant knowledge about autism but, it was not at the forefront of their thoughts or even a consideration that they could be raising a daughter with autism. Each of the interviews were tinged with pain and guilt in the mother's voices when they talked about their experiences or knowledge about autism.

The mothers who had other children with autism or even knowledge of autism questioned themselves asking themselves why they had not realised the difficulties their daughters were experiencing were linked to autism. This theme interrelates with their questioning of themselves as mothers to their daughters and at times in their daughter's lives they were unable to protect them from their challenging environments. The mothers all revealed throughout each of the narratives that the responsibility for the upbringing of their daughters even when a father was present, typically fell to them. While parental relationships were not specifically discussed in the research the mothers alluded to some of the additional challenges they were experiencing within immediate and extended families as well as with other professionals.

One parent expressed that life would be easier if it was just her and her daughter,

'things would be a lot easier - if it was just me and her' (197), Jane.

Each parent with one exception had struggles in their relationships with their partner and only two mothers lived with their daughter's father. One mother lived apart from the father but stated they were together in so many ways for the children. For Jane she just felt dealing with her daughter was complex enough without living with another adult who did not understand the situation. She claimed her daughter's father just complicated their lives to the point she expressed it would be better if she did not have to consider him at all.

The personal challenges the mothers faced individually and collectively made them question their own ability as a parent and often they felt isolated in their battles to get

it right. Two of the mothers stated that they felt like the worst mothers in the world, when they described how they felt when their parenting was positively acknowledged or negatively judged by others, at a real or imagined level.

'other people think I'm the worst mum in the world. To look at it, it looks like you're being really nasty.'(1610), Betty.

Another mum explained,

'Yeah, cannot cope at all. Yeah. I'm the worst. The worst mum in the world!' (1200), Emily.

'Then you have the judgement of everybody else of you know,' (1783), Emily.

The immense personal conflict these mothers were facing prior to there being a consideration that their daughters were autistic reflects their experiences of struggling for others to take their concerns seriously including being repeatedly turned away by professionals. These were mothers who clearly loved and protected their daughters throughout the ups and downs of their lives. The feelings of incompetence and worries experienced by the mothers were exacerbated by the judgements made by other people either within the family or in the community including school staff, medical staff and other professionals.

4.8 Immense Personal Conflict

4.8.1 Post-diagnosis

The mothers were already caught up in their own personal conflict and they were relieved once they recognised that their daughters' difficulties could be explained by autism but the diagnosis process and the time following the diagnosis highlights an increase in the personal conflict they were dealing with individually and as a group of mothers.

Another source of personal conflict was that the mothers expressed feelings of guilt and failure because they had retrospectively missed the signs of their daughters' autism. One parent with a son who had autism felt that because of her vast experience she should have recognised her daughter's autism. The pain she experienced was heard in her voice as she explained that she should have recognised the autistic traits and questioned herself as a parent because she had missed them.

I just didn't see it at all because it... she's so different to how my son presents with being on the autism spectrum. They're the opposites of a coin,' (58), and '... that the clues were there, but I just didn't see it,' (133), Jane.

Another parent felt guilty as she explained that her daughter was her third child and said:

'to be honest with you I didn't even think that Danni would have had any traits or anything, up until I would say the age of seven, coming to eight, like that quite big transition from primary' (160), 'we used to laugh actually saying we got it right third time around because she seemed to much more settled and so much more neuro-typical' (168), Betty.

Abbie realised during the interview she had worked in a unit for children who had autism and she commented:

'So while... so even... this is before India's diagnosis. So there wasn't anything that I saw there that made me think oh... you know.'(736), Abbie.

Her comments were reflecting her job in the unit.

Another mother with a son diagnosed with autism worked in schools and she explained she only knew that boys had autism. Her daughter explained to her one evening that she thought she was like the boy in the book her mum had just read to her brother, her daughter was recognising autism in herself.

'Boys! (laugh) Yeah. And in teaching I think everyone that I'd come across was... was a boy.' (815), Emily.

Abbie on the other hand had been through the diagnosis process with her husband which had come out the blue following a radio programme that she had heard about autism and she felt the programme was very much describing her husband.

'How autism came into my life really was my husband (umm) has always been quirky as well and I always say the phrase high maintenance.'(565), Abbie.

Once her husband progressed through the process of being diagnosed she started to realise that her daughter was similar in many ways to her father. This brought with it its

own stress and anxiety for Abbie because she was trying to work out how to tackle the situation she had found herself in.

'A massive worry. With her being so young and what struggles is she going to have? And to me the biggest thing was that high school was looming.' (605), Abbie.

Vroni had not really considered that she had any first-hand knowledge of autism however, while she was chatting she revealed her experience with her stepson who was diagnosed with autism. At the time he had stayed with her she did not understand about autism. She felt able to explain why but she was left feeling really guilty that it had not seemed important at the time.

'I was a bad stepparent you know. I mean... you know looking back now and she'd said... she'd touched on things and said 'Oh he's (umm) been assessed for autism and whatever' and I didn't really think much of it. I didn't really research it and its bad really. But I was really, really young and... (umm) and she said things like (umm) it was a very important thing that we have pizza on a Thursday night because that's what they have at home, its pizza night. So we just adapted that, I didn't really ask questions, I just did pizza on a Thursday night because that's what he had at home. And he has his teddy bear for bed, so then I used to make sure he had his teddy bear for bed and I kind of listened to mum what she wanted and we used to do it. (umm) But I never really questioned it, I just accepted that this is what mum had said and this is what we did. And I never really... so I'd heard of autism in that way, but I didn't really know what it was,' (1921), Vroni.

Further problems challenged Jane who recognised that different family members had views different from hers and this added to her personal conflict and concerns. She did not feel comfortable with having to challenge and explain how things were different for her daughter and how other family members were treating her daughter was exhausting and she felt she was left to pick up the pieces.

'Her dad's family don't understand autism (umm) there's... there are no allowances made (umm) so they... they do tell her that she needs to toughen up, (umm) and she needs to stop being so ridiculous and (umm) you know there's quite a lot of negativity and I then have to spend the whole week (umm) bringing her back up emotionally

(umm) because (umm) they'll just tell her to get on with it. (umm) But that's the difference between parenting isn't it?' (153) Jane.

The paths for each of these mothers of raising a daughter who was later diagnosed with autism had ups and downs and this was particularly evident in terms of their inner self-doubt and personal conflict of their abilities as a mother despite their amazing admiration and undoubting love for their daughters. The conflict with their already acquired knowledge of autism was an added disadvantage because there was no correlation between their previous experiences and those experiences they were having while raising their daughters. Once their daughters had received an autism diagnosis there was an expectation they would receive the help they needed for their girls professionally but, as some of the mothers identified this was not necessarily the situation and often more frustration and challenge followed for them at a time help would have been so important. The mothers described how their emotions especially their anger and frustration escalated because other professionals left them so exasperated and they felt alone trying to get things right for their daughters.

'And I also feel that Molly was an alien to them,' (1131).' They could not deal with her. No. The SENDCo was new into the role, she'd clearly had very, very little training, and she didn't know the basics of autism. I had to beg for anything to be put in place. (umm) That was very, very upsetting' (1140) Jennie.

I was fuming! (laugh) So I went to see my MP and I just said 'Look, it's not good enough'. I said 'This child has been failed time after time throughout the education, throughout the NHS'. I said 'You know she's been pushed from person to person to person, nobody's listened, I said 'It's just not good enough' (2276), Vroni.

'She's been failed. All I can say all along the way, this is what I kept saying to the HCP and I cried in the end when I phoned them and I lost it with... and I'm a patient person. (cough) It was a couple of weeks ago and I said 'Enough is enough!' I said 'You've lied to me, you've missed deadlines' (3093), Vroni.

One parent heard from her daughter (who had overheard a conversation her teacher was having) that her (Abbie's) aspirations for her daughter's education were too ambitious, India reported what she had heard to her mother,

'I think the teachers think that you have unrealistic expectations! So I laughed, I said... she said 'Yes' she said I was on a beanbag and I overheard the teachers talking about you'. And I just thought this was so low aspirational....' (1221), Abbie.

Abbie was absolutely furious with school at this point and they were the specialists, she withdrew her daughter from the school at this time. She knew her daughter was bright and capable and that her autism was such a barrier, and it was holding her back from achieving.

While parents talked about their experience there were tears of laughter alongside tears of grief, sadness and fury. They also 'burst' into an almost nervous laughter during the interview almost as a relief and to express that they could not believe what others were saying to them when their daughters were experiencing failure from the education and diagnostic systems. This included the times when the professionals did not understand the reasons why their daughters were experiencing these difficulties. The individual paths these mothers were on prior to their daughter's diagnosis of autism were often challenging in themselves. To then get the point of a diagnosis was not straight forward and they felt furthered compromised by professionals which was another significant barrier for them. The mothers had frequently done their own research online and by contacting autism support organisations who helped them understand what was going on for their daughters and it felt at times for most of them as if they were telling the professionals what was causing the difficulties at times.

'left to pick up the pieces' (1280), Jennie.

Another parent commented

'I just lost the plot. You know when you've had enough. Because they promised me...' (3368), Vroni.

The mothers in the research despite the adversity they were dealing with day to day demonstrated their amazing personal resilience and strengths throughout their challenges and the barriers they were confronted with while raising their daughters so that their daughters' needs could be met.

4.9 Everyone's got a breaking point

4.9.1 Pre-diagnosis

All the parents with the exception of Betty who had raised two autistic children described getting to a 'crisis point' and there were times they did not think they could continue with the various challenges and battles they were faced with. Betty was more laid back in her approach and she reflected on her experiences of raising her older children who had already received a diagnosis of autism. She was more relaxed with her third child and this was evident in her responses. This subtheme is making sense of how particular situations caused upset and conflict for the mothers when they were just seeking the best most positive outcomes for their daughters and these encounters often left them feeling not listened to, alone and isolated. The physical expressions and tears of sadness emphasised how these mothers were feeling by recalling their experiences that supported the theme of 'everyone having a breaking point' they reached a point when they did not think they could take much more. Prior to their daughters being recognised as having autism there were points in their lives where they felt so let down and sometimes by themselves as well as other people. This theme mainly captured a time when there were concerns and some mothers had some early battles prior to autism being a consideration.

'But the school were... very adamant that actually there wasn't anything wrong.'

(690)Abbie

'You know and that's very draining (umm) to have to deal with as a parent'. (umm) (435), Jane.

The parents expressed that they were often facing a lonely battle to make sure their daughters were successful in school and this was often at the expense of their own mental health, and often it was complicated by others not believing or understanding their daughter's diagnosis.

'I was so angry. So disappointed' (804) 'just accepted that school had nothing to give, it made no sense, I just felt... I just thought we're in for a battle here'. (808), Jennie.

'I was so frustrated because I just felt that you know... (sigh) I... I think it was just one of those things. That I knew what the rest of the evening was going to be like, you

know it would... I... I was frustrated that they hadn't phoned me, that she was clearly... had got herself so distressed'. (973), Abbie.

'And... I... I regret what I said to her that led up to the overdose because I challenged her behaviour for the first time in a long time. I'd been following the strategies recommended' (1823), Abbie.

The narratives were scattered with examples of when life became tough for the parents and there was that feeling of being frantic with what was happening however, there was also evident a determination from each parent that even at each crisis point when they themselves faced an all-time low they had a battle they needed to win so their daughters were supported.

4.10 Everyone's got a breaking point

4.10.1 Post-diagnosis

Following the diagnosis, the parents expressed in the narratives they felt the worst was over, but for a number of them, they themselves were struggling emotionally. The recognition that the daughters have some challenges additionally puts pressure on family life which causes further distress for the mothers. For one parent whose daughter was going through the diagnosis process the challenges from school were so frustrating for her and she recognised that she was not the only parent facing such battles.

'But you have to fight every step of the way and I feel for parents...' (3447), Vroni

Parents waiting for phone calls and advice that were vital to support them moving forward in supporting their daughters were challenged by delays or the wrong answers added to their struggles when all they wanted was the best possible education and support for their daughters.

'I cried in the end when I phoned them and I lost it with... and I'm a patient person (cough) It was a couple of weeks ago and I said 'enough is enough!'(3094), Vroni.

'That's... if I could say anything to any teacher, that's what you need. You know it's just... this has happened, right what can we do, how can we help? You know not a lecture or... you know.'(1457) Emily.

Emily was waiting for a call from school so that she could help her daughter sort out a difficult situation that had occurred during the day. She explained, instead of offering

her some support or words of comfort and understanding, they started to lecture her about what she should be doing for her daughter. Vroni felt that even when people were listening they did not always hear what she was saying and while she wanted help for her daughter she felt she was also asking for help and some direction for herself particularly about how difficult things had become.

'You're pulling your hair out, you're not sleeping, you're being pulled in by the school, this child's crying, they don't want to be here anymore and you are actually at breaking point...'(3298),Vroni.

Abbie just wanted some help for her daughter and she did not feel she was being unreasonable in her requests.

'Well it's not fair that India should have something that other children don't have'. You know and our point was we're not asking for something that other children don't have' (1273), Abbie.

Experiencing autism for these parents is evidently all-consuming and extreme, and so different in each daughter which represents how the unique presentation of autism relates to the experience of parenting and how it impacted on each mother's sense of self.

Reflective Box

It has been my choice to follow academic convention in this thesis and I refer to myself as the 'researcher'. I acknowledge that this can be a tension in a qualitative enquiry however the claims made throughout my work are from my perspective as 'the researcher'.

As a mother of two daughters and a son, the understanding of the unconditional love each of these mothers had for their daughters no matter the difficulties they experienced was so real. Having raised a child who developed some unexpected difficulties with their mental health as a young adult was difficult at the time for me a mother and I was conscious not to allow this to influence me. The importance of being able to 'bracket' my own thoughts and preconceived ideas was crucial. It was vital that I was able to see the world through the eyes of each of the participants rather than being influenced by assumptions and pre-judgements (Finley, 2008 p.4).

4.11 Superordinate Theme 2 Who is my daughter?

This superordinate theme reflects participants' experiences of observing their daughter camouflaging within her surroundings, having increased social awareness, and the impact of social expectations on gender roles. This theme captures how the mothers made sense of the increasing conflict they experienced as the girl they were raising began to change as she became older and particularly the social challenges that impacted on so many different areas of their lives. The mothers began to recognise there were diverse and changing constructs about their daughters who behaved differently in school and at home and because they were becoming skilled at hiding their challenges and their needs were often unidentified. The confusion for their girls predominantly meant the mothers had to deal with the 'fall out', and often this was in terms of how the challenging behaviour presented in a variety of ways. The mothers recognised that gaining a diagnosis enabled changes in the way their daughters were understood and how they as parents could respond, and how this made a difference to the mother's confidence and sense of self-worth.

Two subthemes emerged:

- With girls you don't always spot the signs
- Growing realisation

Table 6 below captures the inclusion of each of the mothers within the subordinate themes.

Table 6: subordinate themes for superordinate theme 2

Subordinate themes	Jane	Emily	Vroni	Betty	Abbie	Jennie
With girls you don't always spot the signs	√	√	√	√	√	√
Growing realisation	√	√	√	√	√	√

The mothers did feel that they were responsible for making everything alright at those times their daughters had a struggle in life but what they also started to identify was that others also needed to take some responsibility when things were not going well

particularly at school. The mothers were able to recognise that the daughter who was at school did not always present with the challenges and difficulties mothers were recognising they were having. They described at times a distinctive pattern throughout the transcripts that each of the girls, as they grew up, presented differently at home and at school and this made it a further challenge and it was as if there were two different girls. Again subordinate themes are captured pre and post diagnosis.

4.12 With girls you don't always spot the signs

4.12.1 Pre-diagnosis

This subordinate theme represents how the mothers made sense of their daughters' behaviours when they began to realise that they appeared to be different girls depending on their environments. Before autism was a consideration the mothers were trying to make sense of what was happening for their daughters. The mothers identified that their daughters did seem to be concealing behaviours socially and in school and they interpreted this as a coping strategy. The mothers seemed to have insight into their daughters' behaviours, and they were able to explain that this camouflaging behaviour gave the illusion that their daughters were functioning well. The mothers recognised that their daughters wanted to fit in with their peers to a point, but they could see that it was exhausting for their daughters. Before many of the girls were diagnosed their mothers were also able to recognise that some these behaviours meant that the daughter they knew did not seem to be the daughter others met. They were trying to work out how this could ever change, and if anyone would know who their real daughter was. This was exhausting and puzzling for the mothers. As younger children the mothers were not considering that their daughters were autistic, and they expressed their reasons.

Betty a mother to older children both with autism was frustrated that she did not realise her third child as presenting with autism and it was not until she reached nearly eight years old that she considered her daughter might have autism. Betty had knowledge of girls and boys with autism and she referred to the term 'under the radar' which is more recent phrase in the literature used to describe cognitively able girls whose difficulties are not identified because the girls are masking them so well and because she already had an older daughter with autism, she was able to demonstrate some of her knowledge in the field. As a mother of two autistic children, including a girl, she was upset that she

had not recognised autism in her third daughter, and she was making sense that her daughter's strengths were helping to hide the difficulties in her opinion.

'To be honest with you I didn't even think that Danni would have had any traits or anything, up until I would say the age of seven, coming to eight, like that quite big transition from primary.'(159) Betty.

'it was just little things like that initially with Danni. And also she excelled in so many other areas, she's gifted and talented in creative writing and would write these like amazing poems with amazing adjectives in and things like that from a very young age. But in all honesty until she was seven or eight, I didn't think she had any difficulties with her processing and everything, it's just that it seemed to be while you learn through play she could manage and was under the radar,' (241),Betty.

In a similar way Emily, Abbie, Jane, Jennie and Vroni explained their daughters did not stand out at school and even some of the professionals found it difficult to understand why they had received a diagnosis. It also added to their explanations of why autism had not been an obvious diagnosis for their daughters when they were younger.

'They... they've not been great to be honest because I think because on the outside she's very... you know does her work, ticks the boxes.' (989), Emily

Emily did not think that school were seeing the difficulties that Emily was experiencing at home with her daughter, and she was talking to school about her daughter's difficulties and they were listening to her and making adjustments for Emily prior to her diagnosis.

'I think because she achieves at school, you know she got expected level across the board, she's not a behaviour problem, there's no challenging behaviour. It's just... she's not a problem for them if you know what I mean.' (1035) Emily

In school Abbie's daughter demonstrated no significant externalising behaviours and the teachers often only saw the model student she appeared to be. While Abbie was pleased her daughter behaved in this manner in school she was also extremely frustrated because she recognised from the behaviours she experienced with her daughter, school was challenging for her and this was stressful for her mother.

'She's been... she's come from a school where she was... you know in a lot of ways the model student.' (1187), Abbie

Jane was beginning to see that her daughter had autism and she began to seek professional help however, the reports from the school described a different girl who teachers recognised as being compliant, but these positive behaviours became more of a barrier to her diagnosis.

'But like everything, (umm) I think after two meetings with the paediatrician, I was getting frustrated because they had all the paperwork, (umm) but they wouldn't... they wouldn't agree it. (cough) Because in the school setting (umm) she's so compliant,' (291), Jane

Vroni had a similar experience to Jane but with professionals in school who suggested that she was making up all the issues with Anna and this made her feel intimidated and she felt the whole world was against her. Life was at this point very complex at home with Anna and not having support from the school left Vroni feeling threatened and as if she was not doing the right thing for her daughter.

'Anna doesn't have a diagnosis'. I said 'I know she doesn't have a diagnosis however, she's been waiting to be assessed for autism'. 'But that's your word against theirs, it's just your word, it's your opinion'. This is what the head teacher said to me! And I said 'I understand that' and this head teacher had a way of always intimidating you and always making you feel like (umm) you didn't know what you were talking about.' (2037), Vroni

Vroni was then further challenged by the professionals when they refused to diagnose her daughter with autism because school had not provided any evidence to suggest that autism could explain Anna's difficulties. Instead they suggested her daughter had ADHD which Vroni did feel they said that because they did not really know what to say. Vroni felt very compromised because she did not think the diagnosis was right for her daughter, but she explained they were the professionals.

... 'This is entirely down to you know, you can either... which is my advice, you cannot discuss her autism diagnosis and move forward, you know and just go with the ADHD'. This is what she kind of advised. And just keep that... you know on a backburner kind of thing... to yourself or... you know... 'Or you can go with that if you want, but you

know...’ So basically she was saying to me, going forward, we don’t actually believe she’s got ADHD... (umm) autism or... or maybe because she wasn’t...’ (2950), Vroni.

The mothers were understanding that their daughters were struggling and there was an awareness that something was not right and they were realising that other professionals were also not understanding why these girls were different depending on their situation. The mothers found this exhausting and an added stress because they recognised that others did not understand or even truly know the daughter they were raising.

4.13 With girls you don’t always spot the signs

4.13.1 Post-diagnosis

Some of the mothers described a prevailing sense of something being ‘different’ but most did not arrive at autism as the explanation for this difference. Some mothers also described that they were the only ones to witness that certain behaviours only appeared to happen at home. However, each parent in turn recognised that their daughter was not easily identified as being so different from her peers and they were starting to do their own research to try to make sense of why others were often seeing a different girl than they were seeing at home. The mothers reported disbelief and some scepticism from others that their daughter had autism and this was a particular challenge prior to the diagnosis and at different times once their daughters were diagnosed with autism. Some of the reasons they described included a lack of understanding of how autism presents in girls, and that their daughters did not look like they had autism. Some of the mothers identified that it was mental health difficulties such as anxiety, self-harm, and grief that brought their daughters into contact with services. There was a sense of feelings from the mothers’ experiences that some of the core characteristics of autism were secondary to mental health concerns and this was additionally because they were not looking for autism. There was a sense of guilt that emerged because of the struggles their daughters had experienced and this was intensified by the lack of understanding about cognitively able girls who were autistic.

‘... you know it’s taken a... it’s been a difficult journey because I think it is... I think with girls, you... you don’t always see it. And then they mask so much that actually it’s... I feel now with India that... there probably was so much (umm) anxiety going on that maybe we hadn’t realised that,’(1320), Abbie

The theme 'with girls you don't always see it' emerged throughout the transcripts and at times parent's awareness was additionally masked by their lack of knowledge and understanding of what was going on for their daughters. This was further complicated because their daughters' difficulties were not always visible to, recognised, identified or acknowledged by school and health professionals which added to the complexities, issues and struggles the mothers were having with their daughters at home. At this point the mothers were starting to research the problems they were experiencing while raising their daughters and reaching their own conclusions about autism. The mothers identified that their daughter was able to hold a conversation, make eye contact and blend in, ultimately making it difficult to tell that she may have autism, which was an added difficulty when school were asked about the problems the girls may be experiencing.

Emily described that she understood where her daughter was coming from in terms of wanting to be like her peers, rather than just being herself. She could sympathise however, while she was keen to make everything right so her daughter could fit in with her peers but she felt this had to be balanced with a sense of not spoiling her and letting her have everything she wanted. This was difficult for her and she felt guilty because at times she felt to have a peaceful life it would be easier just to give in to her daughter.

'It's hard I guess that she can't be herself and you know you're seeing this... very sort of fake version of herself. But I guess I understand a bit because I think all... all of us have been there trying to fit in and... and I guess I try and help her, but I don't want to spoil her so I'm not just going to go and buy her everything. But I guess I understand a little bit where she's coming from' (1192), Emily

Betty described her daughter as wanting to be like everyone else but as Betty recognised that while she might want to be like everyone else she can see that she isn't. Her daughter's vulnerability is stressful for her and she worries that her differences could cause difficult situations if other people are unable to understand her.

'Danni cares because Danni wants very much to be like everybody else, because she is aware that she's different. But she's trying to mask it and doesn't want to admit it, she sees it as some sort of I don't know... they're very negative, very negative. But it's like... she doesn't have... she doesn't have the same emotions about things. She... she could get... she did get upset recently when she went to see the new Mary Poppins movie'

because it was nothing like the other one and she is a mad like... she could pick things out by watching Disney things. I know that's kind of... 'And that picture in that background is in that film you know mum!' She couldn't... she sees very much in things like that, yeah. Now she could get upset over that, but she's never got upset over like a family pet, dying or family member or... she doesn't...,' (590), Betty

In trying to make sense of her daughter's difficulties Betty expressed that her daughter was a complex girl which made life more problematic for her. As her mother Betty was finding it difficult to understand her daughter at these times which made it harder to make sense of her needs.

.' But none... none of her traits sort of match to make up a whole person if you know what I mean. It's like there's a bit of this, there's a bit from that, there's a bit... she's very,'^(umm) (613), Betty.

Abbie's daughter had other issues and she found everyday things difficult. Abbie's time was taken up with professionals resolving these difficulties and she did not recognise how anxious her daughter was at the time and she started to recognise that her anxiety could have been masked because her physical issues had taken centre stage. The more she understood about girls with autism it helped her appreciate her daughter's hidden difficulties more clearly and this helped her reassure herself.

'And I think it's taken... you know it's taken a... it's been a difficult journey because I think it is... I think with girls, you... you don't always see it. And then they mask so much that actually it's... I feel now with [I] that... there probably was so much (umm) anxiety going on that maybe we hadn't realised that now you know she still had a lot of constipation problems, she has really poor muscle tone. So if she had to walk far, you know she really... complains about it. (umm),' (1320), Abbie.

Jane blamed herself for missing her daughter's autism because she was having major difficulties with her autistic son but, as her knowledge of autism in girls increased she recognised that her daughter could have been hiding her difficulties rather than her original thinking that her son's behaviour could have an influence on her daughter.

'Yeah. Because... also with me, I'm probably fairly unique in that because I've already got an older child diagnosed with autism, that she's been brought up in an autism specific household and I think that has masked a lot of her issues.'(554), Jane.

Jenni's husband had been diagnosed with autism and she had read a lot about it and was starting to understand that girls can hide their autism. She was devastated when school rang her to explain they could provide no evidence to support her daughter who they described as doing just what other children were doing. However, at home Jennie was dealing with the consequences including her daughter's unpredictable behaviour which was having a significant impact on her and the rest of the family. Jennie felt that no one was listening to her and understanding how complex her life was dealing with her daughter.

'And then I was at work one day and the headmaster phoned and said 'I've been given this form to fill out for Molly', he said 'There is no evidence. Molly is a perfectly normal, happy school child'. And I said 'But there's been the instances!' 'Oh, that's just normal, that's what children do'. And I said 'But her behaviour at home is a problem, even if it isn't at school'. And he said 'I'm sorry [J], but there is no evidence I can put down'. But now I know so much more about it, that she was just masking at school all day because girls are much better at masking. That it would just come out at home as an absolute explosion. We had weeks of it being explosions and then weeks of it being in her bedroom and both were a massive worry.' (623), Jennie

The worry for Vroni was her embarrassment for the situations her daughter put herself in without the awareness of what she was doing. As a mother Vroni struggled because it was her job to protect her daughter. She was unable to do this at the times she was not with her.

'She did a lot of like masking and learning and copied behaviours. She used to have like... she used to say things and you used to cringe sometimes. So I'd said to [S] or I'd said to her 'No! ^(umm) We do not put our hands in the toilet'. You've got to be very direct with her and very specific. So then she would go to school and if somebody dropped a pen on the floor, 'No! We do not drop a pen on the floor!' You know copy, mimic. So she will copy whatever I've said and she'd do it at school. Sometimes we were out somewhere and I'd like cringe. I'd like be oh!! Sometimes I have cringed in situations with her and it's just been like when she's done things that just are not socially acceptable or like the norm, you're just like... I want to die for her, you're just like...!',(2864),Vroni

4.14 Growing realisation

'Growing realisation' captures how all the mothers in this research made sense of their awareness that the difficulties their daughters were experiencing as they were growing up were linked to autism. The theme reflects how the mothers recognised that their daughters were autistic during the period of time prior to their diagnosis. This was a particular challenge for many of the mothers because while they all had varying degrees of experience of autism they had not particularly made the connection to their daughters. This caused so many feelings of guilt and self-blame because they thought they had missed the signs. The mothers retrospectively were additionally beginning to identify differences, behaviours and issues that they experienced with their daughters during their early years alongside later social issues and their daughters ability to cope with a range of life experiences as they were growing up. The impact of the mothers thinking back caused them to have a sense of guilt because some of their daughters' early difficulties could now be explained as autism. However, they also considered that alone these difficulties could not necessarily be explained by autism. It was only as their girls were growing up and social situations became more complex that their difficulties became more apparent and the mothers recognised that it was more than just anxiety that described their daughters' difficulties.

While all the mothers recalled and talked about their daughters' different degrees of general emotional regulation and social anxiety, Emily and Jennie were able to vividly recall their daughters' early anxiety. However, they explained that when their daughters were very young they had not thought that it was linked to autism and it was part of their personality, which of course it was, but they were realising there was more to these earlier anxieties. The anxiety was often an explanation that was given for the reason the girls behaved as they did.

'And then up until her first birthday, other than that, she met all her milestones. Nothing unusual. But it's always stuck in my mind and... I've already thought age one is too early to sort of show signs of social unhappiness.'(127), Jennie.

'And now looking back I... I just wonder whether that was social anxiety.'(166), Jennie.

Emily's daughter from an early age sought reassurance from her and other adults and she just thought her daughter wanted to make sure that she got everything right.

'but (umm) she used to check everything. So it was like free to go to the toilet, but she... I remember she used to go up to the nursery teacher and be like 'Can I go to the toilet?' and they'd be like 'You don't have to ask'. And then she'd go back to them and be like 'Did you say yes?' and they'd be like 'Yes, we said yes'. And then she'd be like 'Can I paint? Can I put... shall I put an apron on?' She had to check everything about three times.'(194), Emily.

'(laugh) Yeah. So yeah she started reception, (umm) similar thing just checked everything, was really... really good, well-behaved, (umm) used to get not told off, but used to skip everywhere. So would be (umm) it would be 'walk J'! (laugh) And then she'd skip again. So I wonder now if that was a bit like stimmy with her,' (240), Emily.

All the mother's recalled increased anxiety and complex emotional regulation as their daughters were growing up. Often as a result of their own research and knowledge they were able to make links to 'social' anxiety which they would explain as their daughters' struggle to fit in as the social rules became more complex. Each of the parents would make their own sense of why their daughters had these difficulties with anxiety. Vroni's daughter had lost her grandfather and school was causing her some unhappiness, Jane felt it was because there were so few girls in class, Betty felt her daughter's anxiety was down to her co-ordination difficulties.

'You know that I can tick for Anna and I just thought somethings not quite right. So then she was finally referred to CAMHS, they said they wanted to do (umm) an anxiety workshop because she was very anxious, she'd lost grandpa, she was hating school by this point, she was about seven and they wanted to do an anxiety workshop.' (1884), Vroni

'And I'd get so frustrated, she'd get so frustrated, there wasn't a lot to do. (umm) And then we went to CAMHS, she had this (umm) anxiety which was ok. You know it... it worked and we did lots of things... activities that we both had to do at home and then take with us and everything.' (1958), Vroni.

'So from a... from about the age of eight is when (umm) we... I started getting quite a lot of issues with her (umm) as far as (umm) anxiety was concerned, (umm) friendships (umm) have and continue to be an absolute nightmare.' (65), Jane

'The friendships thing started at (umm) becoming an issue and it just gradually increased (umm) with anxiety,' (106), Jane

'Yeah. Yeah, she was saying that (umm) you know (umm) she didn't understand what they were saying, the girls and (umm) when they had to choose people to be in their team and she was never picked and (umm) it... there was a lot of (umm) anxiety around the friendships at school. Because it was a small village school, there was only eight children in each class at [A]. (umm) When this (umm) other girl left, (umm) it just changed the dynamics of that... those girls in the class.' (2017), Jane

'And didn't want me to take her again. It caused her more anxiety going to learn how to use a knife and fork, and it's like I've been one of these parents that have been like very... you know sitting at the high chair, stabbing, doing... oh she prefers finger foods. And then she's just masked it because the things that she will eat while she is out with her friends could be a burger and chips.' (1705), Betty

'And I think it's taken... you know it's taken a... it's been a difficult journey because I think it is... I think with girls, you... you don't always see it. And then they mask so much that actually it's... I feel now with India that... there probably was so much (umm) anxiety going on that maybe we hadn't realised,' (1310), Abbie

'You know the anxiety ... I always thought she was really anxious, but then it was like there's something more to this anxiety and stuff. And then I think the penny just started dropping,' (1310), Emily.

'Molly was showing signs of anxiety and problems with eating,' (1103), Jennie.

The growing realisation developed for the mothers in their recognition of their daughters' struggles with friendships as they progressed through school. Social anxiety in terms of relationships and friendships was a golden thread that wove through the narratives and as the mothers grasped that it was potentially that these difficulties linked to autism that were impacting on their girls' behaviour. They made references to 'social anxiety', a term that is identified in the literature, which made sense because the mothers themselves had been doing their own research and were trying to understand their daughters. The mothers were able to recognise that the social skills their daughters

had acquired did not appropriately support their friendship skills so they were not on par with other girls.

'She'll go from one friend to another. (umm) She's always struggled in threes which I get. But yeah, all through... probably the first six months at high school there was somebody different coming home all the time but, like when I was young you'd go and play out. And she used to do that (umm) and she made lots of different friends, she was happy to play with people older than or younger than and boys, girls... (umm) go around to people's houses for tea or they'd come to us. And that was just great. But I think that was because it wasn't intense.' (1007), Jennie.

'Because she has changed... I can see that she is trying to become somebody else to fit in, this is showing me that she is struggling. And then when you put it together with the not sleeping anymore and you put it together with the can't stand still on a kerb, and you put it together with the you have to scaffold every social activity that she does and be there... and you're the one that takes her and her friends and picks them up because she wouldn't ask anybody else for a lift or... anything like that. Even now.' (1146), Betty.

'It's the friendship. Yeah. That's all it is. (umm) It's all it's ever been. You know (umm) certainly from the age of going to school.' (706), Jane.

'But as she moved up into probably year one and two, she would form very close friendships with one particular friend at a time. And she would get very upset if somebody else tried to take that friend. 'They're stealing my friend' or they're hogging them, she used to say, hogging my friends. So she'd have like this really close friendship with somebody and if anybody else tried to get in there, 'they're hogging her'. She hated it.' (754), Vroni.

'Yeah, friendships will remain a real issue with India. She... (sigh) she finds friends tiring and so she doesn't really put the effort in, and she's got quite a few... so there's quite a few of her friends that... so when she went to college there was one friend that used to keep phoning her. But I think she gave up in the end because it... India's not good at reciprocating.' (1461), Abbie.

'She had friends, never had a best friend, has always struggled to have a really close friendship with one person. She's always been a bit of a flitter between groups and still is.'(272), Emily.

The mothers' realisation that there was more to their daughters' anxiety as they were growing up was evident throughout the narratives. It was as their daughters matured and the mothers' knowledge increased they were all able to recognise and make sense of their daughters' social anxiety even though they were not always able to understand the complexity and unpredictability of it. When their own recognition and knowledge about their girls' difficulties was possibly linked to autism increased, they were able to make even more sense of why their daughters were struggling with social issues predominantly friendships which particularly exacerbated their anxiety. The social anxieties linked to the difficulties with friendships the girls experienced were identified as significant by their mothers. Their own research increased their understanding of how autism effected girls and this was another part of the complex picture they were building to understand who their daughters were.

Reflective Box

Following the analysis of the first interview with Jane I wrote a note to myself 'be prepared to expect the unexpected'. This was so important for me as a professional and from a personal viewpoint because some of the delicate information the mothers shared was so powerful. I felt more prepared in particular for the power of the emotions the mothers expressed throughout their interviews. They were surprised at times how they coped with the challenges their daughters were facing as they were growing up before they suspected autism and again once they realised there were some difficulties emerging. Even though each story was so different there was such sensitivity with each of them. The increased anxiety they expressed as their daughters' social environments became more complex was evident. In each narrative even without knowing that their daughters were autistic there was a growing awareness in different ways that their daughters were struggling so much with social expectations in society. They were aware that their girls were 'masking' or 'camouflaging' without knowing they were describing traits of autism. Each parent encountered some similar experiences with their daughter but, in so many different ways. Some of the mothers described their concern that nobody would ever know the 'true' girl that was their daughter because they were

'hiding' themselves so well to fit in. Some of the mothers wondered if they actually knew their own daughter at all at times.

In terms of bracketing my own experiences I found myself asking why it was not obvious to professionals that these girls were showing signs of autism. However, I realised as the narratives were analysed it was my own knowledge that highlighted the awareness of the difficulties the girls were experiencing in terms of them being linked to autism and it was not obvious to the mothers and in many of the narratives to other professionals involved with their girls either. The researcher was reminding themselves that there is still a need to cascade training and understanding about how cognitively able girls might be presenting in ways that are different to the boys with autism.

What was clear was that each of the mothers felt the sense relief following their daughter receiving a diagnosis of autism and it helped them understand and make sense of their daughter's struggles in everyday life.

4.15 Superordinate Theme 3:

4.15.1 An Unexpected Destination

The third superordinate theme "an unexpected destination" makes sense of the unfolding journeys the mothers were experiencing raising their daughters who from birth and throughout their early years did not appear to have issues that were of significant concern. The mothers were making sense of the journey they thought they were on with their daughters which had taken another direction and took them to another place. The mothers described the diagnosis as helpful as it enabled them to make sense of and understand their daughters' unexpected actions and behaviours. In hindsight they were all able to reflect on some of the former behaviours that they had identified in their daughters' early development and at the time the mothers described them as 'just who they were' and now they could consider these as possible indicators of autism. On reflection they recognised that all was not what it seemed but at the time these unusual behaviours were dismissed or explained in a way that made sense and helped them understand their daughters. There was a sense of relief that the difficulties they witnessed with their daughters had a reason and a purpose. These mothers wanted to make sure their daughters were supported in the future and some mothers recognised that they needed to focus on preparing their daughter for the realities of their future in the world.

This theme additionally captures how the mothers, on reflection, made sense of the unique personalities and characteristics their daughters were demonstrating including, some of the day to day challenges they were having with them were because their daughters were autistic. While the diagnosis was an initial shock, the realisation that there was an explanation for their daughters' behaviours gave them a sense of relief, partly because they realised they were not to blame for their daughter's difficulties. Finally they could understand and provide scaffolding in terms of care to protect and support their beautiful daughters. This theme emerged as a result of their daughters' eventual diagnosis and reflects the period of time post diagnosis.

Three primary subthemes emerged from the mother's accounts:

- Looking back
- Hindsight is a wonderful thing
- It all makes perfect sense

Table 7 below captures the inclusion of each of the mothers within the subordinate themes.

Table 7: subordinate themes for superordinate theme 3

Subordinate themes	Jane	Emily	Vroni	Betty	Abbie	Jennie
Looking back	√	√	√	√	√	√
Hindsight is a wonderful thing	√	√	√	√	√	√
It all makes perfect sense	√	√	√	√	√	√

4.16 Looking Back

It was clear from the outset of each interview with the mothers that they had no awareness that their daughters were autistic from birth and throughout their early years. It was later in each of the childhood journeys that the clearer clues began to emerge and they were starting to make sense of what was happening. When their daughters early childhood journey ended up at an unexpected destination all of the mothers identified a significant sense of emotional relief. The individual pieces of an

unknown puzzle came together when each of their daughters were diagnosed with autism, one parent's words summed this up,

'It's not until you're in that situation that you realise you know A plus B plus C plus D equals E. You know when you take each individual thing separately you don't automatically think oh that's autism.'(368), Jane.

Another parent also explained

'But none... none of her traits sort of match to make up a whole person if you know what I mean. It's like there's a bit of this, there's a bit from that,' (613), Betty.

However, as the mothers looked back over their daughters' early years they could later recognise that there were subtle signs and they could now make sense of these. But at the time these signs did not suggest autism, and while each mother had some knowledge and experience of autism – it was mainly about boys with autism. The exception was Betty whose oldest daughter was diagnosed with autism at the age of 21. Betty explained that her daughters were just so different nothing like each other so why would she think Danni was autistic.

'But I was thinking... Danni... we used to laugh actually saying we got it right third time around because she seemed to much more settled and so much more neuro-typical.'(167)

'because you don't automatically think when your child's going through the stages of development, what is wrong with them? You know you're not looking for it.'(665), Betty.

For other mothers their daughter was their first born or their first girl and they explained:

'So because Anna was our first, we hadn't... I hadn't done it before so I didn't quite know... I don't have anything to compare it to or like... know it wasn't... wasn't the norm.'(284), Vroni.

Looking back at their daughters' early years including some of the unique behaviours and experiences mothers had witnessed they felt at the time it was just a difficult phase so it did not register as being different and they certainly did not consider autism.

However, when they were thinking about how autism could explain early behaviours they reflected on their thoughts at that time.

'But one thing I did noticed is that she really didn't... you know W as a baby would... would soil his nappy every day, and she didn't. (umm) And because I'd only had one before, I didn't really kind of think that much about it really,'(171), Abbie

'Nothing stood out at all, but she was just sort of... I don't know easy really. Just... I remember my friends saying 'you've got a really easy baby, why haven't...?' You know she didn't really demand a lot or need a lot,' (376), Emily.

'you know you sort of think that you know she'll grow out of it,'(1434), Abbie

In their own way the mothers were making sense of their daughters' behaviours in terms of their diagnosis, Jennie explained

'The not being cuddled by anyone but me, and the... what happened on her first birthday, and the slurry language that she grew out of, she slurs again now... but that's common with autism. But it wasn't an issue for years. Those... I never thought oh that explains why she was so difficult because she just wasn't. It explains why she devoured so many books and why she was so good at jigsaws', (2525) Jennie

Some of the mothers interviewed while positive about the diagnosis were still understanding and surprised that their daughters were autistic and this could have been influenced by how long it was since they received the diagnosis at the time of their interview. Therefore these mothers had had less time to come to terms with their daughter's diagnosis and while they knew it made sense it was still a shock and a 'loss' of the daughter they thought they were bringing up.

'But it still surprises me that she is!' (318), Jane.

4.17 Hindsight is a wonderful thing

Once the mothers understood about autism in their daughters and they talked about their early and younger years even though they had not been looking for any explanations for their daughters' differences they could see that maybe some of their quirky and unique strengths and difficulties were because they were autistic. At the time when they were raising their daughters autism was not even a consideration and as the narratives were analysed the mothers were explaining reasons for these differences for

themselves. However, as in any situation when there is an unexpected outcome there is often that analysis and questioning. This was the same for these mothers who questioned themselves - should we have seen it earlier? did we miss the signs? It was only as they made sense of their experiences including their daughters' subsequent diagnosis including increased knowledge of autism in girls, they did start to see early experiences from a different perspective.

'Just I think... just that she's always been a bit of a worrier and a bit you know... I think we look back at the times we were in the public toilets with the hand driers and she was like... you know and... (umm) smells and things and smelly places and busy places and... sensory things.' (1469), Emily

'I wouldn't say she communicated very well (umm) even from a young age. (umm) (sigh) You know looking back, (umm) yeah probably that... that the clues were there, but I just didn't see it.'(130), Jane

'So because Anna was our first, we hadn't... I hadn't done it before so I didn't quite know... I don't have anything to compare it to or like... know it wasn't... wasn't the norm. But I'm... looking back now things that stand out, that's like actually we should really have known. I remember being in a moses basket by the side of the bed and every time I sneezed or like coughed loud she would wake up and scream, cry absolutely hysterical. Now this... I never did that, you know with a loud noise, a sudden notice she would cry hysterical. (umm) (cough) And its really bizarre', (284),Vroni

'So this teacher that had mentioned these things throughout nursery and reception, when you don't really know you're not sure, nothing comes up... autism hadn't even crossed my mind. I just thought ok I've got the naughty child. You know and I just thought why is she so hard work at times?' (856),Vroni

'... yes, I mean you know I think she's clearly (umm) always been autistic, but we just didn't... I think had she not had the... the (umm) processing delay, I think that was a curveball. (umm) She didn't... she didn't get cars and line them up, you know she didn't do those sorts of things.' (1424), Jennie

'I never thought oh that explains why she was so difficult because she just wasn't. It explains why she devoured so many books and why she was so good at jigsaws.'(2527), Abbie.

'it was just little things like that initially with Danni And also she excelled in so many other areas, she's gifted and talented in creative writing and would write these like amazing poems with amazing adjectives in and things like that from a very young age. But in all honesty until she was seven or eight, I didn't think she had any difficulties with her processing and everything, it's just that it seemed to be while you learn through play she could manage and was under the radar.'(241), Betty.

One mother recalled with hindsight how literal her daughter was. She saw this as a difficulty however, she decided she would write a book herself to capture all the quirky things her daughter had said over the years and she had decided to name her book '****' which would capture why her daughter was so difficult to diagnose. She suggested it was possibly because of her strengths particularly her academic ones.

'Yeah, oh she's very literal. I've got... I'm going to write a book one day. All the things she's come out with, over the years...,' (2749),Vroni

*'It's hysterical and it's going to be called something random like '*****' or something really random,'* (2774),Vroni

Once the mothers understood what autism could look like in cognitively able girls each mother was able to look back and they realised retrospectively that their daughters were showing some early signs or traits of autism but they were all in agreement, unless you were looking for it you would not be thinking that at the time. Each daughter had a different journey and different experiences but, each were diagnosed with autism.

4.18 It all makes perfect sense

The mothers in the research while raising their daughters were unaware from birth throughout those early formative years that any exceptional positive or negative behaviours were because they had a daughter with autism. However, once they recognised that the autism diagnosis could explain their daughters' unique characteristics and behaviours they could start to comprehend and make sense of their daughters' life journeys. Nevertheless, getting a diagnosis was neither easy nor

straightforward because these girls were not presenting in a manner that fitted with their understanding of autism.

As Emily explained when her daughter got her diagnosis

'I think everything made sense and I think it kind of made me think ah right that's... that's why it was perhaps trickier and... and harder and more rocky than I expected it to be,' Because you kind of think I've got all of these skills as a teacher and you know I've always been really interested in inclusion and stuff like that. And then I've got this child that kicks me and jumps out of windows and runs up the road and... you know it was kind of like actually this isn't my fault and you know... (921) Emily

'... it still took two years to get her diagnosed through the NHS (umm) and I wish that had been an easier process (umm) because she's so (umm) complacent, compliant and what have you (umm) it was difficult to get that diagnosis. But these are all (umm) symptoms of autism,' (360), Jane.

'It was only because she was struggling so much in school and there were some any issues with the friendships, the social communication. (umm) I've never thought that she was literal until (umm) about the age of nine or... or something where (umm) she'll come out with comments and you think my God, you're obviously... you are autistic! (laugh),' (382), Jane.

'so that was the summer that we had the hell and they wouldn't give her a diagnosis. And by the Christmas I had already contacted AXIA for a private assessment... (umm) really frustrating,' (2146), Vroni.

Vroni explained her daughter Anna was also at a point in her own life where she was recognising her own differences which were still invisible to so many others.

'Anna felt relieved, you know she always knew she was different, she used to say to me...when she was going through this really difficult time in school (umm) 'I just don't feel like I fit in this world mummy, I just don't feel like I fit in, I'm not like everybody else or'... even 'I don't belong in this family' she came out with once (umm) you know really sad things! That she felt different but she didn't know why,' (2246), Vroni

Following her diagnosis Vroni explained she and her daughter were both reassured and things were making sense. They were able to understand why Anna was struggling

'Anna felt a sense of relief when she found out. (umm) And we said we were going to have an autism party when we got home to celebrate her differences,' (2264), Vroni

Jennie had a similar experience with her daughter. The waiting and extreme amount of time getting a diagnosis was a struggle and often the mothers in the research had put the pieces together themselves. They gained their own knowledge in understanding why it was difficult for cognitively able girls to be diagnosed with autism. They found it even more difficult when professionals lacked knowledge and or experience to recognise the difficulties that these girls were having were linked to autism.

'Yeah, so they put the paperwork in in the September. And it took until the July for her to get her diagnosis. (umm) The diagnosis was just a farce really,' (1685), Jennie

'And if you looked at... like a little princess and yet she is so. And its... it doesn't match, but that's where you see the spikes you know in the behaviours, the patterns, the not... they're not right.'(1826), Betty

But I... I'm wondering whether... we would have noticed sooner really. But I... I think... I think because of the... because there was the... the processing delay and the speech, then I think that... and then I think because of the health issues... it all... the fact that she would get frustrated and she would be (umm) have control issues, all sort of made... made perfect sense.'(1430), Abbie

'So I think it's good. You know I would always... I'm glad that we got the diagnosis and I'm glad we told her.'(1413), Abbie

'But she's not... it's not in a bad way, she's very, very good at masking and then like I said when she went to high school... she was put in all the top sets 'at first and then halfway through year eight she seemed to be really, really struggling. I pushed for a diagnosis, she finally got diagnosed at sixteen.'(329), Betty

So for each parent and their daughter the diagnosis made sense and it as able to help the mothers understand their daughters' behaviour. The mothers additionally were relieved for their daughters that they could understand themselves better. Each of them want the best for their daughter and had dreams and ambition for them and while they did understand that the autism could at times be a barrier they were not going to let it define their daughter.

Betty the mother with two autistic daughters commented that the hardest thing about having a daughter with autism is that you may never know who they truly are.

‘That’s what... that’s the hardest thing I think about parenting with autism. You don’t... you don’t ever really, really, really know who they are.’(1792), Betty.

While Betty was referring to her journey she captured in this quote the essence of how the other mothers were making sense of their daughter’s journeys. These daughters had unique traits while being very able and they all excelled in different areas of their lives. Their anxieties manifested in many diverse ways and they masked who they were and copied so well that their difficulties remained hidden from view from their families and a range of professionals. Often they were very different at home and school. These mothers demonstrated their acceptance, love and persistence which enabled them to understand and protect their beautiful daughters for who they were. As the mothers explained in their words their daughters were also seeking out their own answers to understand who they were for themselves and their mothers enabled this to happen.

One mother explained that her daughter had more insight into herself than the adults around her and she commented:

‘I think she has a lot more insight into herself and what she needs,’ (199) Abbie

Jennie’s daughter recognised that she needed her diagnosis and it could help her get on with her life and help her understand why she does what she does which was a sense of relief for her mother who described her daughter’s journey as being so frustrating.

‘By this point, she had accepted that she had Asperger’s and she actually wanted the diagnosis. Because we do all the paperwork, to do it all again and she kept saying to me ‘When am I going to get my diagnosis?’ (1301), Jennie

While the mothers acknowledged the relief to understand that their daughters’ strengths and difficulties were because they were autistic, they still did not want them to be defined by their autism but realised life was always going to be a challenge for their girls.

‘She can be whatever she wants to be,’ (732), Jane.

The mothers were very positive about their aspirations for their daughters but while they spoke positively their comments also unearthed worries about their daughters’

futures. Jane felt so positive that her daughter could do whatever she wanted to do but then worried that the diagnosis would change her dreams for her daughter.

'I think the diagnosis kind of changed (umm) what I felt (umm) because (umm) you know when you're little and you talk about what you want to be when you grow older and all the rest of it, (umm) there was no recognition at that time that she wasn't going to be able to do anything. (umm) So that's your hopes and dreams isn't it and of course then you get your diagnosis and you... and you look at the educational psychologist report which talked about her being two and a half years behind in some of her (umm) processes (umm) and her capability... and (umm) and you think well she's not going to be able to do that or what have you,' (umm) (sniff), (981), Jane

Jennie, Abbie and Betty reflected in a similar way and recognised that their daughters' autism would regrettably cause struggles for them in the future. The mothers recognised they are still on the journey with their daughters and they want the best outcomes in life for them and they are still making sense of the autism diagnosis and its impact on their daughters' lives.

'Molly most certainly won't be able to do what she wants in life necessarily because... There's all the social stuff to hold her back. (umm) But yeah amazing creative writing. (umm) And amazing artwork as well. (umm) Yeah, extremely artistic. Well she makes me sick actually because I'm not! (laugh) She certainly gets that from [C], he's very artistic,' (258), Jennie

'No, they don't. But I... I'm wondering whether... we would have noticed sooner really. But I... I think... I think because of the... because there was the... the processing delay and the speech, then I think that... and then I think because of the health issues... it all... the fact that she would get frustrated and she would be (umm) have control issues, all sort of made... made perfect sense. So we weren't looking for an explanation, we felt that we'd already found it. (umm) We just hadn't... you know hadn't appreciated that it would (umm) you know it would... it would be so long... you know you sort of think that you know she'll grow out of it. So I think that was the... the hardest bit. And I think that was really... that didn't really hit me until (umm) I was reading that Aspergirls book. And I remember just reading it in bed one... (laugh) one night and... that... you know that really felt like (umm) a... you know a real hammer blow of... of kind of... gosh she is... is going to struggle for you know the rest of her life

with this. I think... whereas previously we just thought you know she'll... you know as she gets older she'll grow out of it. (umm) But you know... but having said that... that is just so who she is. (umm),' (1430),Abbie

'Yeah. Because it's like in order to get the best out of Danni,

she is going to need some intervention. But I think it's only going to last as far as sixth form. If she goes to uni, then yes we are going to have to go down the route of having some form of support whether that'll just be someone to check in with once or twice a week to break things down and make sure she's staying on track. She's going to need some sort of support, but I am wondering is the idea of maybe having the support thing that's putting her off going to further education,'(2282),Betty

While recognising they had come on a journey with their daughters and they had experienced reaching a different destination they continued to recognise their daughters for their strength's. However, they realised their daughters were going to need support thought their lives and it continued to be the role of their mothers to understand what their daughters were going to need. These mothers were still coming to terms with having an autistic daughter and they were able to articulate that they had become an expert about their daughters' needs and wanted to learn as much about autism to ensure their daughters' best interests were met.

Reflective Box

What I noticed about all of my participants was their honesty, a willingness to talk openly about difficult experiences. They were able to reflect about a period of time when autism had not been a consideration in terms of their daughter's difficulties. They all talked about problems their daughters were experiencing but within the context of their 'whole child' and none of the mothers focused on their daughters' difficulties specifically and for each of these mothers there were some very tough and extremely challenging times. They all knew their daughters so well and they all wanted the best for them. The diagnosis was a surprise in that the daughter they were raising from a baby was not presenting with difficulties they recognised for varying reasons as having signs of autism. When they identified that autism was a possible diagnosis for their daughters it was often then a fight for them to persuade other professionals why they thought their daughter had autism. For each of the girls their anxiety was a huge

area of concern and it was a factor influencing each of the mothers. Asking each of the mothers to look back over their daughters' early experiences and development in terms of if they raised their daughters again and with the knowledge they now have about autism would they recognise the difficulties as autism. The mothers reflected about not being sure what they would do because their daughters were who they were because of their experiences. They suggested with hindsight they might see things differently but it is not so straight forward because for most of them the real issues or problems they recognised developed as their daughters grew up. Each story is so individual and reflects the mother's experience of raising a cognitively able daughter who was diagnosed with autism in later childhood however, the researcher while bracketing their own thoughts and reflections could not help but recognise some common threads in the experiences of these mothers. Each of the mothers wanted to talk and tell their stories. For a number of different reasons three of the mothers had personal challenges which meant they had to rearrange their interview dates and for one it was dependent on a change of venue which the researcher was able to accommodate. However, they expressed to the researcher their need to talk about their daughter and have a chance to reflect about what had happened in their journey. They did also recognise that there is a lack of knowledge and understanding about girls with autism and they wanted to help put that right and telling their personal stories may help another mother or family.

4.19 Summary

IPA has been used to explore the lived experiences of mothers raising cognitively able daughters before there was any thoughts that she was autistic.

The analysis of the narratives in this study identified three central, interrelated themes:

- A mum's unconditional love
- Who is my daughter?
- An unexpected destination

These themes highlight the complexities for each of the mothers raising their daughters including the turmoil, interpersonal factors and psychological suffering in the development and progression of their understanding of their daughters' unexpected behaviour particularly when the social environment became more challenging. The themes also represent efforts to celebrate their daughters' successes and achievements

together with their attempts to resolve their distress and frustrations when professionals could not understand the complexities of difficulties their girls were experiencing and at times they felt personally alone on their journey. Finally, the mothers expressed a sense of relief when they had worked out why their daughters struggled in aspects of their life as they were growing up.

The following chapter considers the research questions, they are examined and the results have been discussed in relation to the literature review.

Chapter 5

5.0 Discussion

5.1 Overview

The overall aim of the present study was to explore the early lived experiences of mothers raising daughters who are diagnosed with autism later in childhood. It was anticipated that these mothers would provide professionals with valuable information about girls with autism.

This chapter will discuss the research questions in relation to the findings and previous research literature. In particular, these findings will be examined to create a richer understanding of the first hand experiences provided by these mothers. The unique contributions of this research will be highlighted. Where unanticipated findings emerged through the interpretative analysis the researcher introduces relevant new literature. Lawson (2017) argued that changing the long held attitudes of professionals takes time as there are many misconceptions about how autism 'shows', this is getting in the way of recognising autism and how it effect different genders.

5.2 Key Findings in Relation to the Research Questions

The qualitative findings elicited from this IPA study are discussed in relation to the following broad research questions:

Primary Research Question:

- To explore how mothers make sense of their experiences of their daughter's early development and behaviours preceding their subsequent autism diagnosis.

Secondary Research Question:

- How might the experiences of these mothers help professionals have a clearer understanding about the difficulties cognitively able girls with autism experience?

The research questions were initially viewed as two separate questions by the researcher. However, as the results presented themselves it became evident that the two questions were intrinsically linked. It was when the diagnosis of autism became the purpose for each of the mothers who were trying to understand who their daughters

were that there was a recognition that their daughters' early development and experiences were significant and made more sense to them. The research questions were relevant to the mothers' lived experiences both pre and post diagnosis and they are prominent throughout the themes that emerged. In particular, these research findings will be related to systemic thinking to argue that the complexity issues for the mothers raising a daughter before autism was a consideration arose not only because of the lack of knowledge about cognitively able girls with autism but from factors inherent in the school and health systems.

Narrative accounts were generated from mothers with direct experience. This study supports the researcher's view that providing the context to individuals' experiences of raising their daughters together with emphasising the subjective meaning of their experiences, can improve the understanding of how very complex the identification of autism in cognitively able girls is. While acknowledging this complexity, important patterns in individual and shared varied experiences emerged. Three super-ordinate themes emerged as a result of the analysis of the data, these were:

- Mum's unconditional love
- Who is my daughter?
- An unexpected destination.

The superordinate themes captured the journey each mother was on when raising their daughter, particularly how they made sense of raising their cognitively able daughter who was eventually diagnosed with autism. There is a particular focus on systemically linking the findings to argue that while raising their daughters often amidst personal conflict, each mother demonstrated their love and a recognition of their daughters' strengths. These mothers revealed their own personal challenges with their daughters and their need to want to make things right while loving and protecting them. As the mothers were confronted by emerging unexpected positive and negative behaviour patterns in their daughters' development, as they were growing up, there was a necessity to understand who their daughters were. Finally, their unexpected destination namely the change in their daughter's life journey as they were subsequently diagnosed with autism, while it made perfect sense it was not without its trials and tribulations.

The experiences of a mother raising a daughter who is diagnosed with autism in later childhood is profound, meaningful and life changing. It challenges mothers to consider

their own core belief systems and values to determine what is most important to them when raising their daughters to provide them with the scaffolding they need to grow and develop. In this respect, the findings from the present study reflect previous outcomes in the literature concerning raising a girl who is diagnosed with autism later in childhood. However, the present study also makes an original contribution to knowledge as there is no existing literature that precisely explores a mother's understanding of their experiences of their daughter's early development and behaviours before there was any consideration that she was autistic, using a phenomenological approach.

5.3 'Mum's Unconditional Love'

The intensity of the mother's love for their daughters was an unanticipated finding in the current research. Such findings are a feature associated with IPA methodology, (Smith et al, 2009). The unexpected direction IPA research can lead to is as a result of the inductive nature of open ended questions and interviews being led by the participants (Eatough & Smith, 2008). Smith et al., (2009) argued that such unanticipated outcomes are often the most valuable features of interviewing: 'on the one hand they tell us something we did not even anticipate needing to know; on the other, because they arise unprompted, they may well be of particular importance to the participant' (p.58).

5.4 'A perfect daughter'

The mothers in the current research were not looking for problems in their daughters' early development and behaviour not to mention a diagnosis of autism, in fact the opposite, they each described 'a perfect daughter,'

'she would just be a ray of sunshine, just always happy, always cuddly' (148) Jennie.

The mothers were able to provide reasons to explain to themselves or to others when there were concerns or when unexpected incidents arose with their daughters,

'because you don't automatically think when your child's going through the stages of development, what is wrong with them? You know you're not looking for it.' (665), Betty.

Without exception at these times, the mothers did not think there was something wrong with their daughters. The mothers were all so proud of their daughters' strengths, skills

and talents. They described their daughters' idiosyncrasies or differences as the things that made them just who they were. These findings concurred with Riley Hall who described her daughters before they were diagnosed with autism as girls with all the 'quirks and spirit of ordinary children' (p.24, 2012). The strengths these mothers recognised in their daughters was consistent despite the many challenges they were experiencing and it may be a consideration that these are overlooked and not captured by professionals considering an autism diagnosis for girls.

5.5 'A need to make it better'

The mothers felt that they had to be a strong advocate for their daughters and these feeling intensified as their girls grew up and were diagnosed with autism. The mothers interviewed wanted to make everything right for their daughters, they didn't want to see their daughters' struggle. They talked about wanting to take the hurt away, remove the autism, and they just wanted to make everything better. They wanted to make sure they could make things okay for their daughters now and in the future. This was captured in the theme 'a need to make it better'.

'you just want to take the hurt away' (750), Jane. *'there isn't a magic pill'* (975), Jane.
'I'm responsible for making her feel better' (1642), Emily.

The intensity of the relationship between the mothers and their daughters was evident throughout each of the dialogues. The theme 'mum's unconditional love' clearly captured the love these mothers had from the moment their daughter was born. They protected them, loved them and cared for them intensely. The mothers continued to describe their intense support including their fight to make sure their daughters got what they needed to enable them to cope with their complex lives. Once they realised their daughters were autistic they recognised the intensity of the challenges they were experiencing when dealing with professionals on their journey to make things better for their daughters. Navot et al., (2017) captured the mother-daughter relationships. Their study described early intense close and intimate relationships which are similar to those reflected in the current research. In addition, they referred to the changes in these relationships as the girls grow up which challenged maternal competence echoed in this study i.e. theme of immense personal conflict which reflected the difficulties the mothers faced as they recognised difficulties their daughters who they loved so much were experiencing. Navot et al., (2017) described the mothers as reshaping their

expectations and in doing so the mother and daughter bond changed. While this was not a specific area of focus in the current research there is a sense that this is captured in the journey of each of the mothers and they described how their role changed in relation to recognising their daughter's future needs.

'you sort of can't live a kind of normal life, you have to adapt your life to their needs,' 1862(Betty).

'I felt really bad for her because I just thought it doesn't matter... I... I know that autism effects every single aspect of her life,' (1265), Abbie.

The mothers maintained their unconditional love throughout the conflict and turmoil as their daughters were growing up which was combined with their relief they experienced when they were later diagnosed with autism. While the current research did not focus on changes in the mother-daughter relationships, these relationships may be significant when professionals are recognising and understanding the early indicators in cognitively able girls.

5.6 'Immense personal conflict'

In the theme 'Immense personal conflict' the mothers talked about their guilt because the majority of them had pre-existing knowledge about autism however, they mainly knew of boys and they did not recognise autism in their daughters.

'Boys! (laugh) Yeah. And in teaching I think everyone that I'd come across was... was a boy.' (815), Emily.

I just didn't see it at all because it... she's so different to how my son presents with being on the autism spectrum. They're the opposites of a coin,' (58), Jane.

While each of the mothers reported having some relatively accurate knowledge of the characteristics associated with autism, they were in agreement that they thought autism was more frequently linked to boys.

It was later in their daughters' lives that the mothers in the current research recognised associations to autism at a time when their daughters were struggling socially particularly, as the societal challenges became more complex. It was only retrospectively or when the mothers looked back and reflected on anything that stood out in their daughter's early development that they recognised that some of their early behaviours

could be attributed to autism. However, at the time these were not thought particularly relevant by the mothers. The current research echoes studies including Marshall, (2013); Attwood (2012); Happé (2012) who advocated that the observations that parents make about their children's behaviour are often made with hindsight, their studies report even when parents have worries at the time they have kept them to themselves, so they were not at risk of being told they were overanxious.

A common thread that the mothers in the research experienced was the personal conflict that they encountered when they met with education and health professionals at a time when they raised concerns about their daughters' behaviour, even before there was any consideration that they may be autistic. There was a recurrent pattern of the maternal frustrations and feelings of not being listened to by the many professionals they met on their journeys. They visited their GPs and spoke to their daughter's teachers, and they felt frustrated with responses they received from school.

'But the school were... very adamant that actually there wasn't anything wrong,' (690), Abbie.

Or their GP who,

'just accepted that school had nothing to give, it made no sense, I just felt... I just thought we're in for a battle here,' (808), Jennie.

5.7 'Everyone's got a breaking point'

The emerging theme 'everyone's got a breaking point' captured the conflict and confusion experienced by the mothers, recounting experiences with professionals as being particularly difficult and challenging. Their daughters were often reported as not having any noticeable difficulties at school so warning signs were not recognised or acknowledged, a concern that has received increased attention in the existing research, (Dworzynski et al., 2012). The parents reported that they felt disbelieved and the professionals made them feel that they did not know their own daughters and ultimately they did not feel they had been listened to, which was a finding in Simone,2010; Eaton,2012 and van Tongerloo et al., 2015, studies. Not being heard or believed was one of the most difficult experiences for the mothers who were dealing with their often-distressed daughters which, added to their own personal stress levels. The mothers in this current research described their feelings of guilt, grief, frustration and

incompetence replicating a number of the existing findings (Woodgate et al., 2008; Corcoran et al., 2015). Existing research does indicate raising a child with autism is challenging and their parents report higher levels of personal mental health problems, (Hayes & Watson 2013; Corcoran et al., 2015).

These mothers at times, while bringing up their daughters, were desperate to understand them, particularly their behaviour. They had done their own questioning, learning and research leading to them becoming informed about autism in girls including an understanding that with bright girls there were often fewer obvious signs when they were younger. Consequently, they were understanding their daughters' needs at a time when they felt challenged by a lack of professional knowledge and insight into how autism presents in cognitively able girls.

'So we went to CAMHS... went to the GP, both of us went, (umm) explained the situation, what we'd been told, he said well it just sounds like bad parenting! (laugh) Which I... I didn't... if he hadn't have said it, you just... you know you read about these things and you just think no surely not!' (612), Abbie.

Professionals with whom they came into contact because of concerns they raised about their daughters, made the mothers feel guilty at times, for example, professionals blamed poor parenting for their daughter's difficulties, concurring with Simone (2010) who argued that mothers were often considered to be part of the problem rather than part of the solution to their daughter's difficulties.

More recently in the literature clinicians have begun to document and refine diagnostic tools to capture the female traits, (Atwood, 2013; Marshall 2013). However, it may be that not all practitioners who complete diagnostic assessments are as up to date as they should be, in particular about girls and their presentation, (Crane et al., 2016; Pellicano, 2017). It's only relatively recently that autism research is emerging that looks more specifically at the female profile. (Gould and Ashton-Smith, 2011; Sedgewick, 2016; Livingston, 2019).

5.8 'Who is my Daughter?'

The mothers' suspicions about autism appeared to coincide with a time in their daughters' lives when social expectations became more complex. The mothers

described recognising that their daughters were struggling with social aspects of their lives including their friendships and relationships.

The theme 'who is my daughter' identified the mothers describing their daughters making a considerable effort to be like their peers physically and socially and it was exhausting for them. They recognised these masking characteristics in their daughters including some ability in 'pretending to be normal,' (Holliday-Willey 2014). This was consistent with previous studies where the mothers have awareness that their daughters were hiding their social difficulties and using masking behaviours, (Cridland et al., 2014; Hurley, 2014; Mandy et al., 2012). However, for some mothers in the current study there was a real concern that no one would ever really know her 'real' daughter.

'That's what... that's the hardest thing I think about parenting with autism. You don't... you don't ever really, really, really know who they are.' (1792), Betty

It was very much the mothers recognising the masking and the camouflaging rather than the professionals. The mothers were very clear about their daughters having a need to fit in with their peers at school, which is very much society norms for girls and this was another factor that made the autism so difficult to detect. The experience of these mothers replicates existing research. Livingston, (2019); Crane et al, (2018); Hull et al, (2017) maintain that camouflaging within the social environment has contributed to the under recognition and diagnosis of autism in females. However, the mothers in the research had noticed the masking as a dominant issue for their daughters creating so much of their anxiety. The negative effects of masking in school when daughters returned home are in line with previous research Hiller, (Bargiela et al., 2016; Nevot et al., 2017; Young, & Weber, 2014; Dworzynski et al., 2012; Mandy et al., 2012). Disbelief and scepticisms from other professionals about recognising autism in girls was possibly more evident because the masking can make the girl's difficulties appear more invisible and consequently makes autism more difficult to diagnose.

The current research highlighted that it was often more obvious to the mothers that their daughters were struggling socially as they grew up, and to others, including family members and professionals, their daughters' difficulties were often invisible. The mothers were often made to feel they were to blame for their daughters' difficulties as they felt judged by other family members

'other people think I'm the worst mum in the world. To look at it, it looks like you're being really nasty.'(1610), Betty,

'Then you have the judgement of everybody else of you know,' (1783), Emily.

5.9 'With girls you don't always see the signs'

The invisibility of their daughters' difficulties are evident in the theme 'with girls you don't always see the signs'. At this time in their daughters' lives many of the mothers did their own research to try to understand why their daughters behaved in the way they did and this is when each of them started to unravel that their daughters could have autism. A further challenge for these mothers was that when they raised their concerns about their daughters' difficulties with the teachers their views were different. On these occasions their daughters were usually not considered to be having any difficulties in school. The mothers found it hard at these times to make sense of what was happening.

'she's not a behaviour problem, there's no challenging behaviour. It's just... she's not a problem for them if you know what I mean.' (1035) Emily

'She's been... she's come from a school where she was... you know in a lot of ways the model student.' (1187), Abbie

Often mothers recognised that their daughters were trying to fit in with expectations at school which made seeking support and recognition from professionals very difficult.

'But like everything, (umm) I think after two meetings with the paediatrician, I was getting frustrated because they had all the paperwork, (umm) but they wouldn't... they wouldn't agree it. (cough) Because in the school setting (umm) she's so compliant,' (291), Jane

The first professional the mothers often communicated their concerns about their daughter to was their teacher. They often felt they were not understood by these teachers. However, as these girls progressed through primary school the behaviours that became worrying to the mothers were interpreted as being linked to increased social pressures and these difficulties were more evident in their daughters' behaviour at home. The mothers all identified that friendships were a challenge for their daughters particularly as the social environment became more complex. At these

times their daughters' challenges with their peers were described by the mothers to be significant in their autism journey. These findings replicated the work of Tierney et al., (2016) who reported that girls with autism are more socially driven to fit in with their peers.

'It's the friendship. Yeah. That's all it is. (umm) It's all it's ever been. You know (umm) certainly from the age of going to school,' (706), Jane.

'She had friends, never had a best friend, has always struggled to have a really close friendship with one person. She's always been a bit of a flitter between groups and still is,'(272), Emily.

As difficulties with friendships increased there was a recognition by mothers of how hard their daughters were working to fit in with their peers.

'It's hard I guess that she can't be herself and you know you're seeing this... very sort of fake version of herself. But I guess I understand a bit because I think all... all of us have been there trying to fit in and...' (1192), Emily

To fit in with their peers the mothers were aware of their daughters masking or camouflaging behaviours which, are reported in previous studies (Cridland et al., 2014; Hurley, 2014; Mandy et al., 2012). This was significant in terms of how the mothers in the current study noticed their daughters in different situations and described at times they were seeing two different girls and they reported that this was not often evident to others. This replicated the findings of Baldwin and Costley (2015); Cridland et al., (2014), who described girls in their research as putting on a mask and pretending to be neuro-typical. It was evident as the narratives unfolded that while mothers identified these characteristics in their daughters they understood that they had the ability to mask their difficulties at school which, they later understood from their own research into autism was typical in many able girls with autism. The mothers could also recognise that the result of pretending, masking camouflaging in school all day resulted in considerable exhaustion including, externalising behaviours at home possibly because this is where they felt safe. Their girls would not necessarily want to talk, they needed their own space and increasingly for some of the girls going to school was becoming a challenge. This links to existing research which describes the desire to fit in as being exhausting with negative consequences on mental health, (Livingston et al., 2019). The

mothers in the research were often left fatigued themselves having dealt with the fallout from their daughters' stressful days at school resulting in 'melt-downs' at home ,they wanted to protect their daughters and keep them safe and away from judgement of others. Bearden, (2014) & Mandy et al., (2012) found more frequently that parents of girls report that their child manages to hold it together at school, but then comes home and has to release the pressure built up during a day of pretending to be someone else. They additionally describe girls as being more likely to control their behaviour in public including they were less likely to have public meltdowns or make socially inappropriate comments or speak too loudly which suggests they are hiding their autism. The mothers recognised that trying to blend in becomes a significant contribution to autism not being a consideration. Hiller et al., (2014; 2015) argues that when professionals and parents have vastly different impressions of a girl's behaviour it becomes a barrier and as a consequence girls are frequently undiagnosed and untreated.

The lack of awareness of autism traits in girls was particularly pertinent because the mothers in the current study had researched their daughter's difficulties and were already recognising that their daughters were autistic so the added pressure of feeling disbelieved by professionals put them under further unnecessary pressure. The contribution that mothers can offer professionals, to support the diagnostic process, may be significant to support their daughter's outcomes. Existing research literature identifies that tools that measure symptoms in girls are not refined enough to capture the subtler indicators that these intellectually able girls are presenting with (Dovekot et al, 2017; Little et al., 2017). The girls in the present research all eventually received a diagnosis of autism. Leading up to their daughters' autism diagnosis there were increased stressful challenges for the mothers. This was frequently as a result of the professionals' lack of awareness of autism traits in girls. This is captured in the literature as a contributing factor towards the under diagnosis of girls (Hiller et al., 2014; Lai et al., 2015; Jamison et al., 2017).

The hidden traits in girls is captured in the analysis of the theme 'with girls you don't always spot the signs' which, mirrors the literature which often describes girls as hiding in plain sight (Saris, 2015). The theme 'hiding in plain sight' has in the existing research been linked to describing those girls without intellectual disability and it suggests that these girls appear potentially to have less severe symptoms than boys. These girls are

described in the literature as being more able to mask and camouflage their social challenges at school. Camouflaging has also been proposed as an explanation for the missed or late diagnosis of females with autism, as part of the female presentation (Gould and Ashton-Smith 2011; Kirkovski et al., 2013; Lai et al., 2015; Livingston, 2019). It was a difficult time for many of the mothers because they could see their daughter as being able to hide, mask and pretend in other situations as if she was someone else however, professionals and family members were unable to acknowledge these concerns, and this echoes the findings of Hiller, (2015); Hull, (2017).

5.10 'Growing Realisation'

The theme in the current study 'growing realisation' captured how the mothers began to recognise that there was something amiss as their daughters' struggles increased as they grew up and as they progressed through school, in particular, their social conflicts including, their misunderstandings and confusion with relationships and friendships. The behaviours that were seen at school for some of their daughters were more frequently identified as challenging difficulties rather than being linked with autism even when the parents pursued their concerns. Support and information from online research together with local support groups appear to be important and useful resources which enabled the mothers to connect with other parents. They were provided with support and were able to increase their understanding of their daughters' autism pre and post diagnosis. These experiences were consistent for the mothers in the current research and they may be able to contribute to professional knowledge which may ease the diagnostic journey for other girls.

5.11 'An Unexpected Destination'

The mothers followed their instinct to seek a diagnosis for their daughters when they became concerned about unexpected and unusual behaviour that they needed to make sense of. While still in its infancy the growing evidence about signs of autism in cognitively able girls are often missed or misinterpreted which makes the diagnostic process more of a challenge. This was very much the experience of the mothers in the current study. Research indicates that even when or if parents recognise initial signs of autism there are often barriers to accessing an autism diagnosis (Gould and Ashton-Smith 2011; Crane et al 2017). It would therefore, be important to focus research efforts on exploring early knowledge-seeking behaviours amongst parents and carers

(Mandy et al., 2012, Hiller et al., 2016). Mothers in the present research were not considering any unusual or difficult behaviours as part of their early experiences raising their daughters as a problem at the time however, as their knowledge of autism in cognitively able girls increased they recognised that some of the early indicators were evident and these could provide valuable information for the clinicians. While there has been a rise in numbers, autism still remains less common in girls, because symptoms may be less obvious and or less likely to occur in girls, which often results in the misdiagnosis and or under recognition, (Gould, 2017; Eaton, 2018).

All the mothers were determined to make sure that their daughters' needs were met and long term there was a recognition that their daughters may need help into their adult lives. The narratives in the current research captured a sense that the mothers managed better themselves when their daughters were coping with social and life experiences. However, there was the recognition that their daughters' autism was not going to go away.

... 'is going to struggle for you know the rest of her life with this. I think... whereas previously we just thought you know she'll... you know as she gets older she'll grow out of it. (umm) But you know... but having said that... that is just so who she is. (umm),'(1430),Abbie

5.12 'Looking back'

While the mothers in the current study did not recognise the difficulties their daughters experienced during their early development as traits of autism they did however recognise something was not right as their daughters' social situations became more complex. Despite this their first thoughts were often not about autism and some of these mothers reflected this as they looked back over their daughter's development. One parent explained,

'But none... none of her traits sort of match to make up a whole person if you know what I mean. It's like there's a bit of this, there's a bit from that,' (613), Betty.

Yet, as the mothers looked back over their daughters' early years they could later recognise that there were subtle signs, and they could now make sense of some of their daughters' behaviours. These mothers also expressed that looking back at their daughters' diagnostic journey and discussing their daughters with professionals that it

takes someone with knowledge and understanding of the aspects of female autism to piece the clues together. In line with existing research the age these girls were diagnosed with autism spanned from nine to sixteen years, each mother experienced challenges from professionals and other explanations were suggested before autism was often thought about, (Eaton, 2018).

5.13 'Hindsight is a Wonderful Thing'

It was only later when the mothers in the current study looked back over their daughter's lives that they realised that any unusual and or quirky behaviours were in hindsight possible indicators of autism. These findings do contradict some of the existing research. Hendrickx (2015) proposed that parents reported it was just instinct and they said they 'just knew' that something was different about their child as a baby or early in childhood, and McCann (2019) who described parents as having a nagging sense of that something is different, but they can't quite put their finger on it. The mothers in the current research talked instead in 'hindsight' when they were looking back they realised that some of the behaviours and challenges they experienced with their daughters could retrospectively be described as being linked to autism.

'I wouldn't say she communicated very well (umm) even from a young age. (umm) (sigh) You know looking back, (umm) yeah probably that... that the clues were there, but I just didn't see it.' (130), Jane.

The mothers' comments suggested that if they brought their daughters up again they possibly would not have seen indicators of autism in their early years because they were not looking for any difficulties with their daughters. These mothers were able to justify their thoughts and were able to describe how they vindicated any difficulty their daughters experienced. They explained that their daughter was their first child or their first girl or just thought their children were different from their older children (who had difficulties of their own) but, they did not consider early development and unusual behaviours they saw as a problem or as their daughter having 'something wrong' with them. These findings reflect those of Gould and Ashton-Smith (2011), who reported that it may not be easy to identify signs of autism in very young children (especially for first-time parents) or in those who may not 'fit' the standard descriptions of autism, such as adults who do not have intellectual disabilities, or women and girls.

In terms of 'looking back' and 'hindsight is a wonderful thing', these themes capture information about the early experiences of the mothers raising their daughters at a time when the quirky or unusual behaviours had no particular significance for the mothers. It was often the anxiety recognised by the mothers that would be recognised and addressed but, at the time it was not linked to autism. These mothers were also recognising anxiety in their daughters at a very young age but often retrospectively.

'And now looking back I... I just wonder whether that was social anxiety.'(166), Jennie.

It was only when their daughters subsequently received the diagnosis that they realised the relevance of some of these behaviours. While there were some apparent signs of autism in the early developmental years and while these girls were growing up they were not significant at the time. However, if captured they could inform the research to enhance understanding about how early traits in cognitively able girls may be recognised and contribute to a timelier diagnosis. The mothers in the current research recognised albeit often later in their daughters' childhood years and before the professionals that their daughters had difficulties linked to autism which is very much reflected in the literature demonstrating that cognitively able girls frequently receive a diagnosis in later childhood (Giarelli et al., 2010; Eaton, 2012; Begeer et al., 2013; Hurley, 2014; Kenworthy, 2017; Dovekot et al., 2017).

In the current research the distinctive behaviours that link to an autism diagnosis appear to be more evident in the later childhood behaviours and they appear to be more pertinent in terms of concerns raised by the parents about their daughters. The existing literature established that first concerns were more likely to be recognised by parents when externalizing behaviours were exhibited by their children, Hiller et al., (2015), rather than specifically in their early development Little et al., (2016). Once there was a recognition that their daughters may have autism their experiences of waiting for a diagnosis were reported by the mothers to be comparable to those captured in the existing literature.

'But you have to fight every step of the way and I feel for parents...' (3447), Vroni.

These mothers who had been waiting long periods of time for the diagnosis of autism which they felt was the more accurate one, recognised that autism could explain the significant social difficulties and anxieties their daughters were experiencing together

with their strengths and talents. For each mother at this time there was also a sense of relief. Rivet and Matson (2011) concluded that cognitively able girls with autism have a tendency to experience greater delays in receiving a diagnosis. However, receiving a diagnosis did not prevent the mothers experiencing confusion including a sense of relief, acceptance and hope entwined with sadness, guilt and anger often as a result of the time it had taken to get their diagnosis (Eaton, 2012; Hendrickx, 2015). These mothers recognised that while they had arrived at an 'unexpected destination' the diagnosis was only the beginning of the journey and not the end (Hendrix, 2015), which was important because they accepted that their daughters will continue to need support in their everyday lives. The mothers reported that their continuing role of being an advocate and coordinator of services for their daughters was often a constant battle. Despite the toll it took on themselves at times once their daughters got the support or resources they needed they felt vindicated which mirrored previous research (Desmarais et al., 201; Nicholas et al., 2016).

The theme an 'unexpected destination' portrayed the emotional reactions of the mothers when their daughters finally received their diagnosis including feelings of relief that they were right in pursuing the diagnosis along with worries for their daughters' futures. The mothers' mixed reactions to the diagnosis are consistent with previous research (DePape & Lindsay, 2015; Ooi et al., 2016). The mothers identified a feeling of reduced guilt as the diagnosis freed them of thinking of themselves as being bad parents.

'Anna felt a sense of relief when she found out. (umm) And we said we were going to have an autism party when we got home to celebrate her differences,' (2264),Vroni.

These experiences fit other parents' reports of feeling vindicated after their child received a diagnosis of autism (Ooi et al., 2016). The unconditional love the mothers maintained throughout all their emotional journeys with their daughters concur with previous research which reported that having positive perceptions about your child may preserve the psychological well-being of parents, despite the diagnosis of autism, such as the joy and love parents expressed for their children (Kayfitz et al., 2010;Eaton,2012).

5.14 'It all makes perfect sense'

Receiving a diagnosis of autism, for the mothers in the research, helped them make sense of their daughters' behaviours as they were growing up, particularly, as socially, life became more complex. They were released from the blame that the behaviours were their fault as a result of poor parenting skills. The diagnosis gave the mothers a new positive sense of direction (Eaton, 2012; Hendrickx, 2015). This feeling of relief for the mothers was conversely often tinged with grief because they realised that their daughters were going to face a variety of challenges into and throughout their adult lives. While parents did not want the autism diagnosis to be a barrier for their daughters, they did have concerns about their daughters' futures and the support they may need.

'She can be whatever she wants to be,' (732), Jane.

'Molly most certainly won't be able to do what she wants in life necessarily because... There's all the social stuff to hold her back. (umm) But yeah amazing creative writing. (umm) And amazing artwork as well. (umm) Yeah, extremely artistic. Well she makes me sick actually because I'm not! (laugh) She certainly gets that from [C], he's very artistic,' (258), Jennie.

This paralleled Navot et al., (2017) who identified mothers as reporting how they worried about their daughter's futures following a diagnosis of autism and their ability to cope with the social pressures of life including, their friendships and relationships. As awareness of how autism presents in cognitively able girls continues to increase, it is anticipated in the future that autism will be recognised more accurately so cognitively able girls receive their diagnosis in a timelier manner.

5.15 Summary

Autism was not the automatic conclusion reached by each mother as an explanation of their daughter's behaviours. This may emphasize a lack of recognition of the presentation of autism in girls. These findings enhance the growing evidence of an autism gender bias which is linked to the view that autism is a male condition (Baron-Cohen, 2002; Bargiela et al., 2016; Nevot et al., 2017). The mothers in the current study recognised autism in their daughters nevertheless, they were failed by professionals who did not recognise the more subtle autism presentation associated with females. The mothers in the current research reported atypical behaviours and

anecdotal evidence in their infants and toddlers that related retrospectively to characteristics and early signs of what they later understood to be autism. These issues included early signs of anxiety, issues with friendships and masking and camouflaging. It was the mothers who understood that their daughters were 'different' depending on their environment which contributed to their daughters' stress levels significantly. These findings add to the growing evidence of the gender bias in autism and the failure to recognise the more subtle signs of autism associated with girls. Instead, autism continues to be perceived as a male condition which is consistent with previous studies (Bargiela et al., 2016; Nevot et al., 2017). Constantino (2013) advocated that when professionals are considering an autism diagnosis they are frequently missing the girls because they are looking at the girls through 'boy coloured glasses', (in Saris, 2015).

The current research findings suggest parents' knowledge about their understanding of their daughters' early behaviours could contribute to professionals' awareness of how autism presents in cognitively able girls when they are growing up. In particular how cognitively able girls present with autism.

The love each of these mothers demonstrated towards their daughters was regardless of the numerous personal challenges they faced not only from their daughters but, from their families and the professionals they met on their individual journeys. Each daughter was at the centre of their mother's world together with a recognition of the challenges their daughters faced. This included the mothers' own personal experiences of getting the diagnosis right for their daughters. The mothers felt a sense of relief as they started to recognise that the difficulties their daughters were experiencing were linked to autism however, it was getting others to understand their daughters which became more of a significant challenge. All the mothers identified a feeling of personal emotional conflict during their daughters' experiences of junior and secondary school years. These encounters added to a culture of self-blame including questioning their own skills as a mother as unexpected twists and turns emerged while their daughters were growing up. It was only when the mothers had time to reflect on their daughters' early experiences and development that they were able to recognise that some of their behaviours were linked to their later autism diagnosis. Each of the mothers identified positive aspects of having a daughter with autism and the mothers continued to appreciate their daughters,

which is captured in previous research involving mothers of children with autism (Cridland et al., 2014; Nicholas, et al., 2016). The mothers in the current research had the awareness of their daughters' ability to camouflage social difficulties and their use of masking behaviours. In addition, they identified that their daughters presented differently depending on their environment. They recognised their daughters' social and friendship challenges as the social environment became more complicated for them. These mothers were challenged by the lack of information available about autism in cognitively able girls and this was a further barrier when they met professionals who only understood how autism manifested in boys. The impact for these mothers of their lived experiences was not just the complexity of the diagnostic process itself but navigating the school systems where their daughters' difficulties became more apparent and then within the health systems when they first sought help. These mothers have a wealth of knowledge and could enrich professionals' knowledge about how autism presents in cognitively able girls.

Finally, even though their daughters' early childhood journey ended in an unexpected destination all the mothers identified a significant sense of emotional relief as the pieces of the puzzle came together and their daughters were diagnosed with autism. One parent summed this up:

'it's not until you're in that situation that you realise you know A plus B plus C plus D equals E. You know when you take each individual thing separately you don't automatically think oh that's autism,' (367) Jane.

While there is an increased awareness of autism in girls and women, in particular there has been an increase in information available which has been written by autism organisations and autistic women themselves however, more awareness is still needed.

This chapter has considered how the research questions for the present study have been reflected in the findings and in particular it has explored points of difference and similarity with the existing research.

The following chapter is concerned with offering conclusions to the study, including identifying strengths and limitations of the present research, making recommendations for future directions and it addresses possible implications for

practitioners including educational psychologists. The chapter concludes with the researcher's final reflections.

Chapter 6

6.0 Conclusion

6.1 Introduction

Many parents of girls on the spectrum experience an “emotional rollercoaster”. While they are excited and celebrate their daughters’ developmental milestones, they become increasingly concerned and anxious over puzzling behaviours, (Ernsperger, 2017, p.1).

This study aimed to gather information from the perspectives of mothers by capturing their first-hand accounts of raising their daughters to improve current understanding of autism in cognitively able girls, (Milner et. al., 2019). It additionally aimed to add to the existing important body of qualitative research about understanding and identifying the presentation of autism in these cognitively able girls at an earlier age. It was anticipated that by gaining accounts from these mothers including their insight into raising a daughter before there was a concern that she was autistic could contribute towards the understanding and knowledge about these girls to improve the under-recognition girls with autism.

The data gathered, including the small glimpses into the lives of the mothers raising autistic girls highlight the question of how their experience can contribute to future research, clinical practice, and ultimately give mothers with autistic daughters the opportunity to share their understanding about their daughters’ early development and behaviour. While it is not possible to generalise the findings of this research across all mothers who raise a cognitively able daughter who is diagnosed with autism in later childhood, it is the researcher’s intention to offer insights into the experiences of these six mothers. The researcher provided these mothers an opportunity to tell their stories and opportunity to share their often-ignored voices. Findings in this study reflected what has been said in the literature and have added to what has been found previously.

6.2 Key Findings

This research adds to the small cluster of studies exploring mothers' early lived experiences of raising a daughter with autism. The use of IPA, based on the lived experience of participants, limits the transferability of these findings however, it has highlighted how mothers coped and the challenges they faced while raising their cognitively able daughters as each of them was diagnosed with autism in later childhood.

It is remarkable that some of the key issues highlighted in this study were being raised ten years ago (Attwood, 2006) and it appears that not a lot has changed during the last few years. However, there has been an increase in the awareness of cognitively able girls with autism. Nevertheless, more recognition is still needed.

The findings of this study provide insight and understanding of the unique experiences and challenges of parenting a daughter before the mothers knew that they were autistic. The challenges the mothers faced are somewhat related to the lack of understanding around how autism manifests in females including, how the male-based theories and empirical studies dominate existing autism literature. There is, a scarcity of research surrounding female autism and how it presents differently or similarly compared to males across a variety of contexts. The current study enriches knowledge about girls with autism pre and post diagnosis together with implications for clinical practice and future research. New knowledge is needed in order to provide increased understanding of autism in cognitively able girls including knowing how to support these mothers and their daughters. The current research explored both primary and secondary research questions which the researcher noticed became intrinsically interlinked as the mother's accounts unfolded.

The research primarily aimed to explore how mothers make sense of their experiences of their daughter's early development and behaviours preceding their subsequent autism diagnosis. It was clear from the narratives that the mothers who took part in this research did not recognise any of their daughter's early behaviours as being linked to autism. This was despite five of the six mothers having direct knowledge and or experience of boys with autism. Little et al., (2016) proposed that the role of gender could impact parents' first concerns and early identification. By including what the mothers in this study have to say about what they noticed when raising their

daughters, particularly their observations of how masking and camouflaging strategies present in different social settings, could help overcome some of these issues. Collectively the mothers did comment on the strengths, unusual or distinctive characteristics and the social challenges their daughters experienced in their early years and as they were growing up which at the time they did not connect to autism. Instead, it was only later in their daughters' childhoods particularly when their social environments became more complex and challenging for their daughters to circumnavigate that they understood their daughters' difficulties to be linked to autism. They each reached a **point of crisis** in their daughters' lives at different ages and this was when they started to seek explanations and answers. The mothers additionally recognised the lack of knowledge that both educational and health professionals had about girls and autism. This deficit added to their complex experiences of raising their daughters including their own recognition that their daughters' complicated and challenging behaviours could be explained by autism.

The researcher's secondary research question is reflected by the experiences of these mothers individually and collectively these experiences could help professionals have a clearer understanding about cognitively able girls with autism. The mothers themselves researched reasons why their daughters behaved in the manner they did and reached the conclusion of autism for themselves. These mothers were often left in a position where they understood their daughters better than professionals from whom they were seeking answers and explanations. In addition, it was often after months and in some cases years before assessments were completed and autism was confirmed. The girls in the study had often received alternative diagnoses prior to autism. It was only when they were looking back over their daughters' lives in particular, their early years that these mothers appreciated that the autism diagnosis could account for some of the earlier unexpected behaviours and difficulties their daughters experienced. Despite the majority of mothers in the study having knowledge about autism it was not obvious to them that this was a condition their daughters could have.

All the mothers suggested that if they were to raise their daughters again, they may not necessarily make the association of the difficulties their daughters experienced at an earlier age to a diagnosis of autism. The research additionally highlights the stress

and challenges both in the immediate and long term for the mothers while their girls were growing up in a world where medical, clinical and education professionals were not always identifying or understanding why their daughters were finding life challenging. However, unless the clinicians and professionals become more aware of how autism presents in these girls their difficulties may not be considered relevant and these intellectually able girls could continue to be missed, not be diagnosed until a later age, not diagnosed at all or receive a misdiagnosis (Happé, in Carpenter, 2019; Eaton, 2018; Lai et al., 2015).

The current research identifies that increased attentiveness and dissemination regarding gender differences in autism presentation is needed. Clinicians also need to consider how the diagnostic process may be biased towards males and be aware of gender bias when using standardised autism measures as part of the diagnostic assessment (Mandy & Lai, 2016).

As the narrative accounts of each of these mothers unfolded amongst the positive experiences their daughters brought was the intensity of the mothers' personal emotional journey which could be likened to an 'emotional rollercoaster', (Ernsperger 2017). While there were similarities for these mothers it is also important to acknowledge that there are also many distinctive aspects to their individual journeys, girls and families. The research supports existing literature recognising that a parent's intuition is often accurate and the voice of the parent could actually provide a valuable contribution towards their daughter's future autism diagnosis (Hendrickx, 2015; Wilkinson, 2017). Arguably, this is an area that could be addressed by professionals including EPs. Halliday et al., (2014) emphasise the importance of an accurate and timely diagnosis in both sexes but, particularly for girls and women whose difficulties were traditionally under-recognised, and suggest that women and girls will need support throughout their lives.

It could be argued that these research findings provide a valuable and personal insight into the world of mothers raising a cognitively able girl who is in later childhood diagnosed with autism. The mothers wanted to share their experiences through telling their stories to the researcher and they voiced that they wanted other parents and professionals to hear their stories to ensure other girls were understood and

recognised as having autism with less of an emotive experience for both the parents and the girls.

Implications for Educational Psychologists (EPs)

The researcher's reflections are highlighted in terms of implications for the role of EPs in this section. Smith et al., (2009), advocate caution in terms of practitioners using IPA to guide understanding of the explored experience into their professional practice rather than generalising the findings. Notably only one of the six participants mentioned EP involvement, suggesting that EPs have not featured strongly along their journeys. However, from the research findings it is suggested that there are key things to consider in relation to the role of the EP.

EPs in their day-to-day work often explore hypotheses based on psychological knowledge and these findings are interesting in relation to this process particularly when gathering information from those adults who know the children and young people (CYP) best. The mothers met professionals whose knowledge about girls with autism was inadequate. EPs are in a position to share knowledge and research about girls with autism and how their presentation differs from boys including how girls present and manage their behaviour in different environments. It was evident in the current findings that this lack of understanding from professionals created a barrier for the mothers.

It is important that while on their individual journeys the mothers are listened to and provided with an opportunity for their voice to be heard and not judged as being 'just difficult' parents. EPs can be supportive when there appears to be increased communication barriers for parents. This could change the culture for mothers who need a support system where they are understood and believed and not blamed for their daughter's difficulties. For mothers having a child who has grown up with no perceived identified difficulties and then almost suddenly appearing to be so different is a challenge for any parent however, it is made more difficult when what they have to say is not believed by professionals causing them to doubt their own parenting abilities.

A diagnosis of any medical condition is hard enough however, for these mothers it was a further shock because it had come when their daughters were older, and it had been

unanticipated. The guilt and confusion together with their concerns about how their daughters would cope as they were growing up was already challenging them. The need for the mothers in this study to make everything better for their daughters was powerful and the importance of being listened to, believed and understood by professionals was vital. EPs have a role in actively listening to parents, CYP and professionals, and are in a position where they could facilitate opportunities for parents to come together to learn and share their experiences raising a cognitively able girl with autism. It is argued that this could provide a therapeutic opportunity for parents, it would also provide the opportunity for parents to support other families.

6.3 Strengths and Limitations

Using an IPA approach allowed the researcher to produce a rich in-depth account of the participant's experiences and in addition, the associated use of semi structured interviews permitted the participants to guide data-collection rather than the researcher deciding significant areas for discussion were strengths of this study. This approach permitted for a thorough examination of the impact of the experiences of the mothers raising a daughter before there was a consideration that she had autism. A further strength is the process of reflectivity used by the researcher. The phenomenological approach calls for 'bracketing' by the researcher which "involves a deliberate and conscious attempt to set aside ones' personal and theoretical assumptions, expectations and proclivities before commencing data analysis." (Watts, 2014, p. 3) and the researcher has embraced this by the use of reflective boxes to capture their own experiences, thoughts and reflections to enable a more rigorous bracketing process.

This study used IPA to explore early lived experiences of mothers raising cognitively able daughters who were diagnosed subsequently with autism in later childhood. It has provided noteworthy interesting insights into developing an understanding of the self-perceptions of parenting when mothers recognised the intensity of the journey and a change in direction when they recognised their daughters had autism. While the researcher has highlighted these strengths in the study a number of limitations have been also identified and will be discussed.

The initial invitation was open to all parents who attended a local parent support group and who met the research inclusion criteria however, only mothers chose to

volunteer for the research. Despite some consistency of the findings in the current research the interpretations that have been made are limited to the small, homogeneous group of mothers who were interviewed (Smith et al., 2009). The researcher additionally acknowledged that it was only the mothers making sense of their early lived experiences that was explored. Inevitably as in many phenomenological interview-based studies the group consisted of those mothers who were self-selecting and wanted to share their stories in a coherent and reflective manner. The current study is therefore only representative of mothers' perspectives and consequently the recommendations are offered with caution, (Watts, 2014).

The selection process adhered to in this study could have potentially biased the sample towards mothers who have had more challenging times and/or have more proactive coping styles. A further limitation relates to mothers who might be systematically excluded. This study relied on parents from a local support voluntary group open to families from all cultural and socio-economic backgrounds. However, the mothers who volunteered to participate were all white British from higher socio-economic group so only these mothers are represented in the study.

The interviews occurred only at one point in time and relied on the mothers' memory of their retrospective accounts, which may have been skewed by their current perceptions and later experiences. The girls in the current research gained their diagnosis between the ages of 9 and 16 years. At the time the data was collected some of the girls were as young as twelve years old and the oldest was eighteen and they had received their autism diagnosis at different ages, (Chapter3, table 4). It is maybe noteworthy, that the period of recall for each mother varied and was dependant on the age of their daughter both when they were diagnosed and at the time of interview. It is therefore important to acknowledge that the accuracy of the recall of events may be subject to error because individual retrospective recall has taken place over time and within different time scales. Therefore, caution is necessary when interpreting results (Smith et al., 1999). The researcher reflected on these issues and aimed to strengthen early recall and memories for the mothers by using a timeline (Appendix 4) and by asking the mothers to bring photos of their daughters at different ages to help with their earlier memories. The data collection and analysis were systematic and

rigorous, and the themes represented the perceptions of the mothers who participated.

6.4 Suggestions for Future Research

The present study revealed several areas that would be worthy of future research. The mothers in the study spoke at length about their experiences with their daughters including their involvement with educational and health professionals they encountered, which added an additional layer of interpretation to the “double hermeneutic” of IPA (Smith et al., 2009). The triangulation of the constructions of the views of the mothers together with those of their daughters and the professionals would seem a logical next step in terms of future research.

Furthermore, duplication of this research to capture the experiences of fathers raising a cognitively able daughter before autism was a consideration, would be valuable.

6.5 Conclusion

In summary, the findings of this study provide insight and understanding of the unique experiences and challenges for mothers raising a daughter prior to any consideration she was autistic and subsequently following her diagnosis. Many of the challenges the mothers encountered related to a lack of understanding of autism and its presentation in cognitively able girls. There is, indeed, a scarcity of research surrounding autism in cognitively able girls and how it displays differently or similarly compared to males across a variety of contexts. While this study enriches knowledge about these autistic girls it also highlights that there are significant gaps in the understanding of these girls by educational and clinical practitioners.

It is argued that appreciation of the impact of the experiences of raising a cognitively able girl with autism on mothers can improve the way that professionals who meet and work with these families engage with them and are able to offer support more effectively.

Finally, this research has provided a unique understanding of the perceptions of mothers who were making sense of the life journey they had embarked on from the moment their daughters were born becoming one that was overwhelmingly meaningful and life changing.

Reflective Box

Engaging in this research and exploring an area of interest has been personally and professionally motivating and rewarding. I feel I have used my knowledge and research skills within a theoretical framework to improve my educational psychology professional practice. Nevertheless, I have also found it quite challenging at times (particularly during the analysis process). I would relate the emotional impact of hearing and re-reading the narrative accounts to the “emotional rollercoaster” that many of the mothers appeared to be riding. I wanted to make sure I was able to do justice to their in-depth insight and lived experiences that they shared with me. My professional interest in the importance of the views of parents continued to gain momentum throughout the research process and continues to progress throughout my EP practice. I feel fortunate to have had the opportunity to have met these mothers who raised their daughters before anyone considered they were autistic. The opportunity of sharing their first-hand knowledge has reinforced the importance of listening to parents particularly as they provide tremendous insight and vital information. I believe I now have an even better understanding of the importance of supporting parents and therefore hopefully improving the outcomes for their autistic daughters from the point that their unique characteristics, strengths and difficulties are recognised.

The importance of training for health and educational professionals in understanding and recognising the early indicators of cognitively able girls with autism is paramount. Finally, I have had the opportunity to increase my personal knowledge and understanding about the girls who are missing from the autism statistics.

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Appendices

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Appendix 21: Example of Emergent Subordinate Themes

Appendix 22: Example of Emergent Subordinate themes

Appendix 23: Example of Emergent Subordinate themes

Appendix 24: Emergent Superordinate and Sub themes

Appendix 25: An exert from reflective diary summarising the researcher's thoughts in terms of bracketing

Appendix 1: Gatekeeper letter



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June, 2018.

Dear Mrs G,

My name is Win Little and I am an experienced and practicing Educational Psychologist. I am a postgraduate student in the School of Psychology, Cardiff University undertaking a Doctorate in Educational Psychology. I am required to undertake a thesis. I have chosen to explore the experiences of parents of raising a daughter who is diagnosed with Autism Spectrum Condition (ASC) later in their childhood.

I am writing to enquire whether you would be willing to share the attached information regarding this research.

Under the supervision of Dr Ian Smillie, course tutor, this research will explore experiences of parents with daughters who have a diagnosis of ASC.

In particular, I am interested in understanding the experiences of parents with a daughter who

- has attended mainstream school
- was not given a diagnosis of ASC before the age of 8 or after the age of 18 years

(Both parents are welcome to take part in the research if desired but will be offered individual interviews).

In order to do this, I will ask participants to take part in an interview, which will be arranged at their convenience. The interview should take no longer than 90 minutes.

Participation in this study is entirely voluntary and participants can withdraw at any time without giving a reason. A risk assessment of the study has suggested there are minimal potential risks involved in participation. Before, during and after the study, participants will be free to discuss any concerns about this research with Win Little, or with her supervisor Ian Smillie, at Cardiff University.

All data resulting from the study will be kept confidentially and will not be accessible by anyone other than the researcher. Data will be anonymised and as such will not be traceable to any individual.

This research will be conducted using open questions through individual semi-structured interviews which will last up to ninety minutes with a minimum of 6 participants. Once your consent has been granted, I would ask that you distribute the participant information leaflet so that potential volunteer participants can be informed about the research and make contact with myself.

All of the participating parents will have the project carefully explained to them including the rationale, recording of the interview, confidentiality, anonymity and the transcription process, the right to not answer a question and withdrawing of their data. Participants will also be made aware that findings may be published or presented at conferences, but only in the anonymised state.

The volunteering parents will be asked for their consent and will be chosen at random to be participants; this process will also be explained.

Furthermore, the confidentiality and anonymity of the participants that take part in this research is assured, no one will be identified within the write up or in any work that may follow from this research. This research is conducted with the appropriate ethical approval and is supervised by a member of the university doctorate course.

Thank you for your consideration of this project.

Please let me know if you require further information. Furthermore, if you wish to discuss this research with the ethics committee the contact email psychethics@cardiff.ac.uk.

Regards,

Win Little
Postgraduate Student
School of Psychology
Cardiff University
Tower Building
Park Place
Cardiff
CF10 3AT
Tel: 029 20875474
Email: LittleWM@Cardiff.ac.uk

Ian Smillie
Tutor
School of Psychology
Cardiff University
Tower Building
Park Place
Cardiff
CF10 3AT
Tel: 029 20875474
Email: Smillie@Cardiff.ac.uk

Appendix 2a: Gatekeeper consent form



Consent Form

- I give permission for Win Little to speak with members of this group.
- I understand that this research will involve individual interviews with parents of girls with a diagnosis of Autistic Spectrum Condition (ASC) in relation to their early experiences of raising their daughters.
- I understand that participation is voluntary.
- I understand that information will be confidential and held securely up until it is transcribed, at which point it will be anonymised.
- I understand that the information collected will be used to write a report for the university and may be used for publication purpose, but only in an anonymous form.

I.....consent to participate (name)

Signature.....

Date.....

Appendix 2b: Participant consent form



Participant consent Form

The aim of this research is to explore the experiences of parents of raising a daughter who is diagnosed with Autism Spectrum Condition (ASC) later in their childhood. You have been asked to participate in this research as you are a parent of parents with a daughter who

- has attended mainstream school
- was not given a diagnosis of ASC before the age of 8 or after the age of 18 years.

There are no direct or instant benefits to you from taking part in the study. However, gathering an understanding of the experiences of raising a girl who is later diagnosed with autism can benefit professionals who support them. There are no foreseen risks from participating in the research.

If you do consent to participate:

I understand that my participation:

- Involves completing an interview with the researcher.
- Will take a maximum of ninety minutes.

I understand that:

- My participation is voluntary;
- I do not need to answer any questions that make me feel uncomfortable;
- I can withdraw at any time from the interview without giving a reason;
- I am free to ask any questions;
- I am not being asked to comment on any named others but may choose to use examples from my own experiences in order to answer the researcher's questions.
- The information I give is held in strict confidence and all data will be made anonymous;
- I can withdraw my data to the point of anonymity (two weeks from the date of the interview);
- That the interview will be audio recorded for purpose of transcribing the interview. Once the interview has been transcribed (up to two weeks after the interview date), the recording will be destroyed and the anonymous transcript will be kept indefinitely, in accordance with the policy of Cardiff University;
- The recording tapes will be kept, encrypted and only accessible to the researcher (Win Little).

If issues arise during or following the interview, a participant can seek support from one of the following:

- Parent Support Group(*anonymised*)

- National Autistic Society - <http://www.autism.org.uk/get-involved/about-us/contact-us.aspx>

Consent to participate

Name

Signature.....

Date:

Appendix 3a: Parent information leaflet

Thank you taking the time to read this leaflet.

If you need any further information or have any questions please don't hesitate to contact me on the details below.

Win Little, Educational Psychologist
Email: littlewm@cardiff.ac.uk

Ian Smillie, Research Supervisor
Email: smillie@cardiff.ac.uk
Tel: 02920 874 007

N.B: If you email personal information please be aware that the email addresses are not secure.


Privacy Notice:

The information provided will be held in compliance with GDPR regulations. Cardiff University is the data controller and Matt Cooper is the data protection officer (mcooper@cardiff.ac.uk). The lawful basis for processing this information is public interest. This information is being collected by Win Little.


The information on the consent form will be held securely and separately from the research information. Only the researcher will have access to this form and it will be destroyed after 7 years.

The research information you provide will be used for the purposes of research only and will be stored securely. Only Win Little & Dr Ian Smillie will have access to this information. After 14 days the data will be anonymised (any identifying elements removed) and this anonymous information may be kept indefinitely or published.

Exploring parents' experiences of raising a daughter who is later diagnosed with Autism Spectrum Disorder



“Autism can’t define me. I define autism.”
- Kerry Magro



Information for parents and carers

Who am I?

My name is Win Little and I am a qualified and practicing Educational Psychologist as well as a post graduate student in The School of Psychology at Cardiff University.

A requirement of my course is to undertake a thesis and I have chosen to explore the experiences of parents who have a daughter with Autism Spectrum Disorder.

In particular, I am interested in understanding the early experiences of parents with a daughter who has attended mainstream school and was given a diagnosis of ASD between the age of eight and eighteen years.

Why have you been invited?

You have been invited to participate in this research as you are the parent of a daughter who attended a mainstream school and was given a diagnosis of ASD between the age of eight and eighteen years.

It is your choice as to whether you would like to be considered as a participant for this research. Participants will be selected randomly, so it is possible that you might not be selected.

What will you need to do?

If you agree to participate in this research, and are selected, you will be asked to take part in an individual interview.

The questions asked during the interview are designed to gain insight into your experiences of raising your daughter. There is no right or wrong answers and this research is not concerned with assessing individuals.

You have the right not to answer any questions you feel uncomfortable with and you are able to withdraw from the interview at any time.

The interview will last a maximum of 90 minutes and will include time for a debrief.


What will happen to the information that is collected?

Information and confidentiality:
All information will be held confidentially and no one will have access to it other than myself. On completion of the study, the information will be anonymised and no one will be able to trace the data to yourself or your family.

It is important for you to know that once your information is anonymised it cannot be withdrawn. The results of the research will be made available to you in the form of a summary sheet. The researcher will also be contactable to discuss the outcome of the research with you.

Consent:
If you would like to withdraw your consent to take part in the study, then you can do so at any time. Please contact me or Cardiff's School of Psychology (all contact details are provided overleaf).

Complaints:
If you have any complaints or concerns about the research please contact the School of Psychology Research Ethics Committee by emailing psychethics@cardiff.ac.uk.



Appendix 3b: Participation information letter



Participant information letter

Thank you in advance for your possible interest in this research. My name is Win Little and I am a qualified and practicing Educational Psychologist who is also post graduate student at Cardiff University. A course requirement is that I undertake a thesis. I have chosen to explore the experience of parents of raising a daughter who is diagnosed with Autism Spectrum Condition (ASC) later in their childhood.

I am writing to enquire whether you would be willing to take part in this project.

In particular, I am interested in understanding the experiences of parents with a daughter who

- has attended mainstream school
- was not given a diagnosis of ASC before the age of 8 or after the age of 18years

(Both parents are welcome to take part in the research if desired but will be offered individual interviews).

This research will involve asking open questions through an individual interview. The questions are designed to gain insight into your ideas and experiences around bringing up a daughter who receives a diagnosis of ASC in later childhood. Clearly there are no right or wrong answers and this research is not concerned with assessing individuals but rather understanding their experiences. You will have the right not to answer any questions. You can withdraw from the interview process at any time. The interview will last a maximum of ninety minutes which will include time for a debrief.

The interview will be confidential and you will have the right to withdraw your data up until the point of transcription (a maximum of two weeks from the date of the interview) after that the data will have been anonymised and cannot be withdrawn. The findings of the research will be made available to you in the form of a summary sheet. The researcher would also be contactable to discuss the outcome of the research. The researcher appreciates your time in considering whether you might like to be a possible participant. Participation is completely voluntary and participants will be selected randomly so it is possible that you might not be selected.

If you feel that would like to be considered as a participant or require further information please contact me using the information below. You may also like to contact the professional university supervisor involved with this research and/or the ethics committee. The contact information for each is also listed.

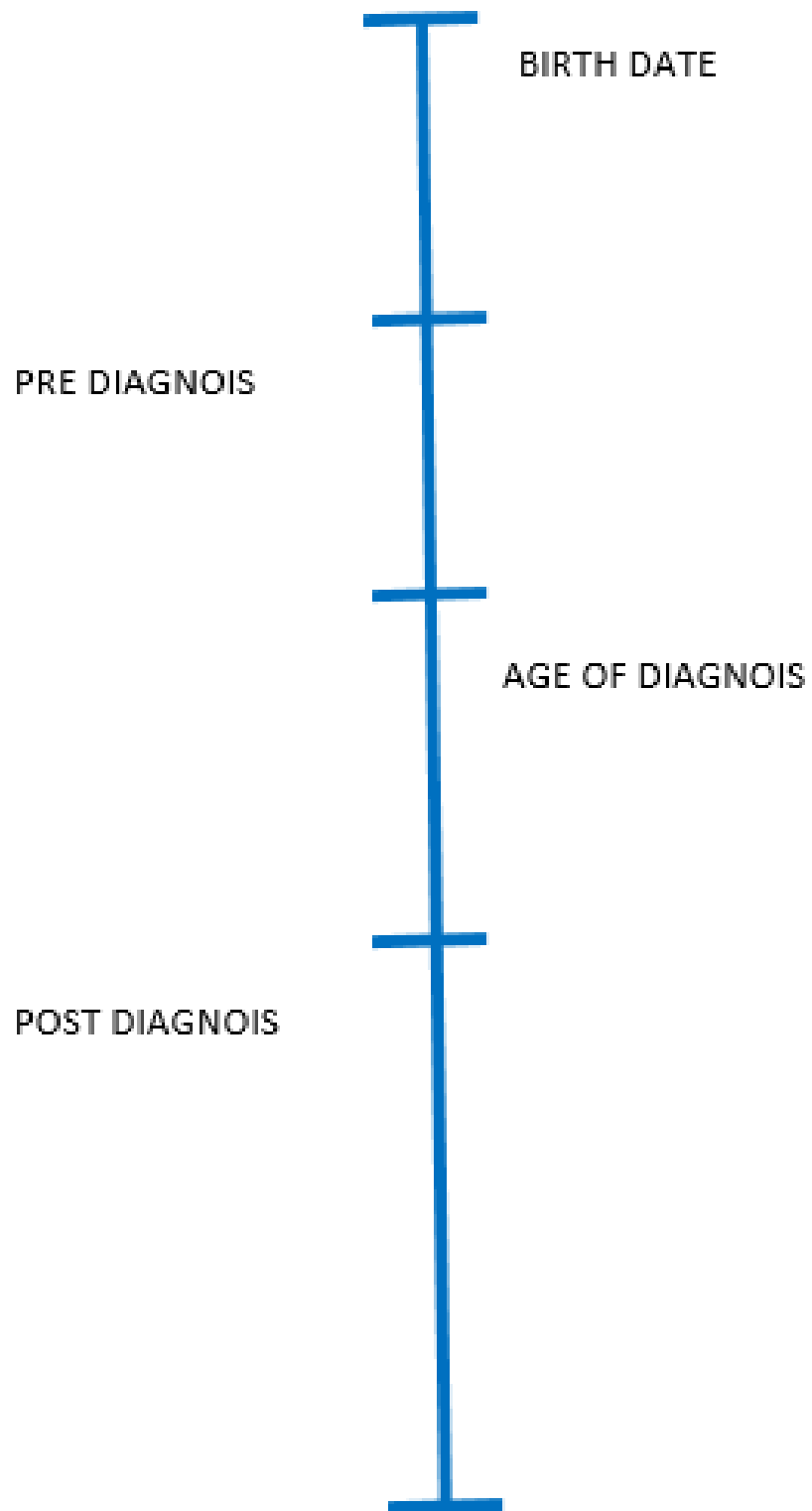
Win Little: LittleWM@cardiff.ac.uk

Ian Smillie: Smillie@Cardiff.ac.uk or 029 20875474

The Ethics Committee: psychethics@cardiff.ac.uk

N.B: If you email personal information please be aware the email addresses are not secure

Appendix 4: Timeline



Appendix 5: Debrief



School of Psychology, Cardiff University

Debrief Form - Anonymous data

Dear Participant,

I would like to thank you for your participation in a recent study exploring your experiences of raising a daughter who is diagnosed with Autism Spectrum Condition (ASC) later in their childhood. For further information on girls and ASC research, please find the following articles as suggested reading:

- Eaton, L. (2012). Under the radar and behind the scenes: perspectives of mothers with daughters on the autism spectrum, *Good Autism Practice*, 13, (2), 9-17.
- Hiller, R.M., Young, R.L. & Weber, N. (2016). Sex differences in pre-diagnosis concerns for children later diagnosed with autism spectrum disorder. *Autism*, 20(1): 75–84.

If issues arise following the interview, a participant can seek support from one of the following:

- Parent Support Group (*anonymised*)
- National Autistic Society - <http://www.autism.org.uk/get-involved/about-us/contact-us.aspx>

The information provided in participants' interview manuscripts will be analysed. Neither the information you have supplied nor will the research findings be used to inform future policy or practice, but findings may be published or presented at conferences however, the information will not be traceable to yourself or anyone mentioned during the interview process.

The information provided in the interviews was gathered confidentially and will be anonymised 14 days later. This information will be stored securely by Cardiff University before being destroyed after a period of 5 years. Information gathered during the interviews - including all notes and audio recordings- will be anonymised and will be stored securely by Cardiff University for five years before being destroyed.

If you would like to learn more or would like to complain about any aspects of this research project, please find the contact details of the Secretary of the Ethics Committee below. If you would like to contact the researcher or their supervisor about this study, please also find their contact details below.

Once again, your participation in this study was much appreciated.

Yours sincerely,

Win Little	Ian Smillie
Postgraduate Student	Tutor
School of Psychology	School of Psychology
Cardiff University	Cardiff University
Tower Building	Tower Building
Park Place	Park Place
Cardiff	Cardiff
CF10 3AT	CF10 3AT
Tel: 029 20875474	Tel: 029 20875474

Email: LittleWM@Cardiff.ac.uk

Email: Smillie@Cardiff.ac.uk

Appendix 6: Interview Schedule

Before commencing interview:

Introduce myself more fully and explain about the interview -

I'm interested in your early experiences linked to you raising your daughter and your thoughts and feelings towards their early development and behaviour prior to you having knowledge that they may have ASD preceding the time they received their diagnosis of ASD. I will aim to ask you questions that will explore your feelings, experiences and the meaning different things had for you. Give the participant an opportunity to re-read the consent form, and explain the limits of confidentiality.

- Give the participant the opportunity to ask any questions that they may have.
- Inform the participant that there are no right or wrong answers to questions and that I am interested in their story, views and experiences.
- Check it is still OK to record the interview and that I may note things down during the interview that I'm interested in, to come back to.
- Inform participants that they may take a break at any time if they wish to, and that they are free to stop the interview and withdraw from the study at any time, without providing reason, up to the point of transcription. Provide estimated date of transcription.

Plan for Interview:

The general plan for the interview – the areas I hope to cover:

I was wondering if we could begin by drawing a timeline and adding key events etc. onto the timeline which we can then refer to throughout the interview as we talk about specific parts of your timeline.

We can use your photographs and place them on key places on the time line.

Explain it is helpful to use the timeline and or the photographs so they can identify or think back to their early lived experiences/ the time before they knew that their daughter had ASD

Would that be OK?

Using A3 paper to draw a timeline: mapping out key events on timeline in order to refer to it throughout the interview: birthdate, key milestones and events birth of siblings, starting nursery, starting school, and date of diagnosis.

Possible questions:

1. Please tell me about your daughter growing up and about her early childhood?
Possible prompts what were your thoughts and feelings during these years? Make reference to key events on time line for example, What about when her brother/ sister was born? Moved house etc. What's was she like with family and friends? What was she like going out to the shops?
2. What was it like when your daughter was attending pre-school/ nursery, school?
Possible prompts: What were your thoughts and feelings at this time? What was it like for you? the family ? and what about when was attending school? The move to juniors what was that like? And now?
3. Can you tell me about your thoughts/ knowledge/ understanding or experience of ASD prior to your daughter's diagnosis?
Possible prompts: did you have any prior knowledge, thoughts or feelings about

ASD? Did you have any thoughts that your daughter could have ASD before she was diagnosed?

4. How did your daughter's diagnosis of ASD come about?

Possible prompts: how has your daughter's diagnosis effected you? If it has how? At the time it happened? And now? What did it mean to you? What about the involvement of professionals prior to and/or since your daughter's diagnosis? In what way(s)? Did you feel listened to by the professionals?

5. Do you think there are the positive outcomes in terms of your daughter's diagnosis?

Possible prompts: What did it feel like when your daughter received her diagnosis? What would you thoughts and feelings at the time? And now?

6. Looking back have you any thoughts about your daughter's early years since she has had a diagnosis?

Possible prompts: In what way(s)? Do you think about the way she behaved differently now she has a diagnosis? Looking back did you change how you thought and felt about her early years? What do you mean by...? Have you changed/adapted the way you behave towards your daughter over time? In what way(s)? Did these changes help? Have they continued to help since her diagnosis?

7. Have you thought about the future? How would you describe your hopes and dreams in terms of your daughter's future – her adult life /education/work life/ independence?

Possible prompts: What are your thoughts and feelings about her future? In what way are your hopes/dreams different because of your daughter's ASD diagnosis at the time? And now?

Generic prompts to build on every question:

How? How did this feel? What did that mean to you? Can you tell me more about this? Can you tell me how you were feeling? Can you tell me what you were thinking? Can you say more about this? What was that like? What do you mean by...?

End of interview:

I do not have any other questions to ask you. I would like to thank you for your time today and I wish you and your family the very best. Do you have any questions you would like to ask me?

Refer participant to relevant support service / services if needed (Parental support Group (*anonymised*) / National Autistic Society (NAS)).

Appendix 7: Transcript (Abbie)

INTERVIEW STARTED

Interviewer: Yeah, ok. So just tell me about [I] growing up and about her early childhood, so very earliest memories.

Participant: Well she was born in [S], so we had moved there with my husband's work. And she was a planned caesarean because of the problems that we had with [W]. (umm) So we... we knew we were going in and we were having her, so she was (umm) I'd ended up having an emergency caesarean with [W]. (umm) So I was in labour for a long time, but with [I] it wasn't, it was... it was (umm) scheduled to have the (umm) have the caesarean and she was very jaundiced and we were in hospital at the time... we had it all planned, [S]'s mum was coming over and [S] was going to stay with me at the hospital with her. And then I was (umm) had had... he'd had meningitis and encephalitis when he was eleven months old. So he'd been very poorly and then the night that she was born, he... had another (umm) febrile convulsion, well I think he was just too hot. But so he got rushed to another hospital and my husband went... obviously went over there. So I was in the hospital with [I] (umm) and she was then very jaundiced and they wouldn't let [W] visit because obviously they didn't know quite what the problem was. So after a few days they put... decided to put her in the special care baby unit just to kind of have a Billie blanket on really. So [W] could then come into the hospital for a couple of hours. (umm) And she... [I] wasn't... wouldn't feed, I had a real nightmare to get her to feed. (umm) But I felt at the time that... the way that the procedure was in [S] is that if you... as soon as you've given birth, they take the baby away and they take you to intensive care where you have a team that monitor you. (umm) And then you can't actually go... so that took me to sort of lunchtime and then there was nobody around to take me. So it was quite some time having had her before I got down to the ward where... you know back to the room where she was. So they had tried feeding her with a cup in the meantime. She really didn't feed very well... and she was jaundiced. (umm) And obviously we just wanted to... to get home (umm) I wasn't very well. (umm) But anyway eventually we... they did allow us to come home and... while we waited for the blood test on the understanding that we would take her back in if the results weren't ok, but they were. So we got her home. (umm) And she was... it took a bit to get her feeding, (umm) but apart from that she was generally (umm) quite an baby really, she was very alert, you know would sort of have her head up from being really young. And you know they say don't they about smiling.

Interviewer: Yeah.

Participant: It was six weeks and... and she would smile, very young. I mean it... when my sister came over to visit and she was about three weeks old (umm) so she... she was always very alert and we always had a problem trying to get her to sleep in the pushchair because she was just watching all the time. You know [W] even... you know even older, you would drive in the car and he would always sleep. Well babies do, don't they?

Interviewer: Yeah.

Participant: But... but she didn't... at all and she...

Interviewer: if all else fails...

Participant: But she... yeah, she slept badly generally (umm) through the night. It took her to about a year before she slept through the night. (umm) But one thing I did noticed is that she really didn't... you know [W] as a baby would... would soil his nappy every day, and she didn't. (umm) And because I'd only had one before, I didn't really kind of think that much about it really.

My ^(umm) but so... so you know we had like... we had a... eighteen months is quite close age. I was at home. ^(umm) And she was... you know she was quite easy really. She... she would pull herself up and then not bother and then sit down and she had an eighteen month old that would run around after her...

Interviewer: And get all...

Participant: Getting her toys, she didn't really... and she just smiled, she just... she just had a beaming smile all the time. So she was... she was very ^(umm) you know all this just typical of her, she would just always... had a...

Interviewer: Yeah, she's lovely.

Participant: ^(umm) You know having a... she just adored him. This is when she was very first... first born, so very... very jaundiced. But she... she always had a smile on her face. ^(umm) And he would just... yeah, just doted on her. And he would just bring anything for her. ^(umm) And so as she got a little bit older, but she just ^(umm) she was just happy. You know a very happy baby. But she wasn't anywhere near as vocal as [W] had... had been.

Interviewer: Right.

Participant: And she... she did start to go to a preschool, so [W] went to an English speaking preschool and we used to... she used to come with me, we'd go and she just wanted to stay all the time. So... we then said she could do *(sigh)* you know she could stay there for two mornings. ^(umm) And on the other mornings, when she wasn't staying, she'd... she would just *(laugh)* have a complete tantrum and... she... she just loved being there and just smiling all the time and... sort of... yeah, she was just generally happy. ^(umm) Very self-sufficient. If she wanted something, she would go to the cupboard and she would get it. She could put her big thick] snowsuit on ^(umm) *(sigh)* I don't... twelve months? You know I was there... eleven months, you know I was having to help [W] put his on and we turned around and she'd got hers on so...

Interviewer: Yeah.

Participant: So very independent and we were very aware that her speech wasn't as developed, but every time you tried to... you know you would ask her something, [W] would answer for her. ^(umm) And we did wonder whether being in [S], you know whether that... the other language was just a little bit further of a delay.

Interviewer: Yeah.

Participant: ^(umm) So that was sort of the only thing really. She... she would be... sometimes if I... I used to run ^(umm) with another lady an English speaking playgroup, which she loved. But I did use to have to watch her all the time because she was very... she was very huggy ^(umm) and so even like... I mean she was late to walk really, she would... she would walk a little bit and then not do anything for three months. ^(umm) And my sister was getting married and [I] was going to be a bridesmaid at... so she would have been eighteen months and we really didn't think she'd be able to walk down the aisle! *(laugh)* But she ^(umm) but you know she did and she got there in the end, but she didn't do... she was quite happy... she would do things that she wanted, if she wanted to get a drink she would go and do it. But if... she was quite happy just sitting, playing with her toys.

Interviewer: What did she like to play with?

Participant: ^(umm) She would play with anything really. She wasn't really into sort of dolls, but she would play with Lego, ^(umm) and she used to watch [W] a lot. ^(umm) And she... I mean I

remember once he had all of his Lego, all lined up and it was all Bob the Builder Lego. And she would just watch and she'd be quite happy just sitting observing and then she just pounced and she pinched Bob and ran off. And of course he was just beside himself, but... and she just killed herself laughing, she just thought that was really funny. ^(umm) So... and that's... was a very early incident of many of which you know she sort of knows sort of... they're... really... but she likes to... she had a long concentration span when she'd like watching other people. ^(umm) As she got... as she got older, so when she was two, we moved to [A] and...

Interviewer: So is that after her diagnosis?

Participant: Yes. So then the diagnosis was in the November and we then started everything in the January. And a friend of mine had ^(umm) requested the same thing for her son, but it got rejected because the school hadn't demonstrated that they had used their level one funding. So we went in and said you know basically 'Where is the evidence of you using your level one funding?' And they... the school had got quite badly criticised by the council for not using... so... so immediately they then concocted all of these hours and... started doing some ^(umm) speech and language sessions or some social skills sessions with ^(umm) there were four of them. ^(umm) But they didn't really know... they were a bit rubbish. But I'd brought some ^(umm) Model Me DVDs from [A] that were quite good and so I'd lent her those and she used to play those for the... in these Friday sessions. So we were trying to get all of the paperwork together and the school were still saying that there wasn't an issue. ^(umm) And we... we knew that there was and... so sort of time went on a little bit, I was at work, I was in the lift with my vice president going up in the lift to the office and my husband phoned and he just said 'I've got a really important meeting and she's under the bed and she won't come out and she'd said Queen Victoria is an f-ing bitch!' And it was like...

Interviewer: Wow!

Participant: Where on earth has this come from? And then we tried to unpick everything because it's like... well I don't know where that level of language and anger has come from, she's not doing the Victorians because she's... she did that last term. So he just... *(sigh)* you know and he just said 'Well look you know I've got to have this meeting'. So I just had to say to my boss 'I'm really sorry, but I've got to go home'. So *(sigh)* I went home, and she was still under the bed and... and eventually we unravelled that Queen Victoria had said that all children had to go to school... and so that was... that was the... the problem. So *(sigh)* we had told her after the diagnosis...

Interviewer: Did she have a diagnosis at that point?

Participant: She'd had... she had the diagnosis at that point and we had...

Interviewer: So how did you feel sort of at that point when you went home to her and she was so distressed?

Participant: Well... yeah, I think... I mean we... we had told her that we thought that her brain worked the same way as [J]'s.

Appendix 8: Annotated Script (Jennie)

Interview Started

Key	Commenting
Yellow	Initials & Chat about other children
Green	Descriptive
Blue	Linguistic
Pink	Conceptual

I: Oh, ok. So I mean it was just as a prompt for you really, but no that's absolutely fine. So really what I'm interested in is in your raising your daughter, raising [M] sort of her very, very early days to now, but particularly interested in before anybody even considered that you know she might have autism and what her sort of time growing up was before that diagnosis happened. So probably you'll do lots of the talking and I've got a series of questions, but sometimes you'll automatically answer those without me asking them. But I might, as I said before, dip in and out say oh you mentioned that, I'm interested in knowing a little bit more about that. So yeah, so just really I would like you to tell me about her growing up from her very early childhood, from her birth really and just tell me about what that was like for you.

P: If I waffle or go off on a tangent, just pull me back because... I do just waffle! So...

I: No, it's really your opportunity to tell me about you know just about [M] really, about how it was for you really, I'm interested in your feelings and thoughts. So I might prompt you at times, how did that make you feel so... that sort of interruption I'll do as and when.

P: Ok.

I: Ok?

<p>Attachment</p> <p>Exhausting</p> <p>Tricky</p> <p>Good baby</p>	<p>P: ^(umm) [M]'s birth was a very fast one. [E]'s before her, three and a half years before it has been very long and painful and difficult. But [M]... sums her up really, she came out in a rush! Impatient. ^(umm) Yeah, after I'd given birth, I remember saying to [C] 'It just doesn't feel like I've given birth'. There was... I think I was only in pain for forty-five minutes. I woke [C] up at half five and she was born at quarter past six.</p> <p>I: Gosh!</p> <p>P: ^(umm) So it was just like oh... (<i>sigh/laugh</i>) she's here. Whereas with [E], it was twenty-four hours and... so that was... that was a bit of a shock really, but she was really easy to settle. [E] before her... I don't like to compare them, but you can't help but do that. [M] seemed to settle at night much easily, more easily. ^(umm) But what we did notice is (<i>cough</i>) she wasn't happy for other people to cuddle her.</p> <p>I: Right.</p> <p>P: I could cuddle her non-stop and she was breastfed. And if [C] tried to cuddle her she cried, if granddad tried to cuddle her she cried. ^(umm) And that was actually really hard especially for [C], for me as well actually because I didn't get much of a break.</p> <p>I: Yes.</p> <p>P: But for [C]... it... it was hard because he was her dad. And [E] had been completely different and he did so much for her, changed her nappies, bathed her from birth, trimmed her nails. But he just couldn't do that the same with [M].</p> <p>I: And you said it made you feel exhausted. But how else did you feel about that, did you feel?</p> <p>P: ^(umm) I was ok about it. It just meant that she was kind of permanently glued to me. ^(umm) But she wasn't difficult other than that. I can remember being able to get out of the house on time to get [E] to preschool.</p> <p>I: Right.</p> <p>P: And she... she was good.</p> <p>I: Ok.</p> <p>P: Didn't make... yeah, she was. She'd sleep, have her good naps. But it was for [C] that it was difficult for really.</p> <p>I: Right.</p>	<p>Mum making sense of her daughters quick arrival</p> <p>Also early recognition only Mum could cuddle her in the early days</p> <p>Hard on Dad who wanted to be involved as he was with older sibling</p>
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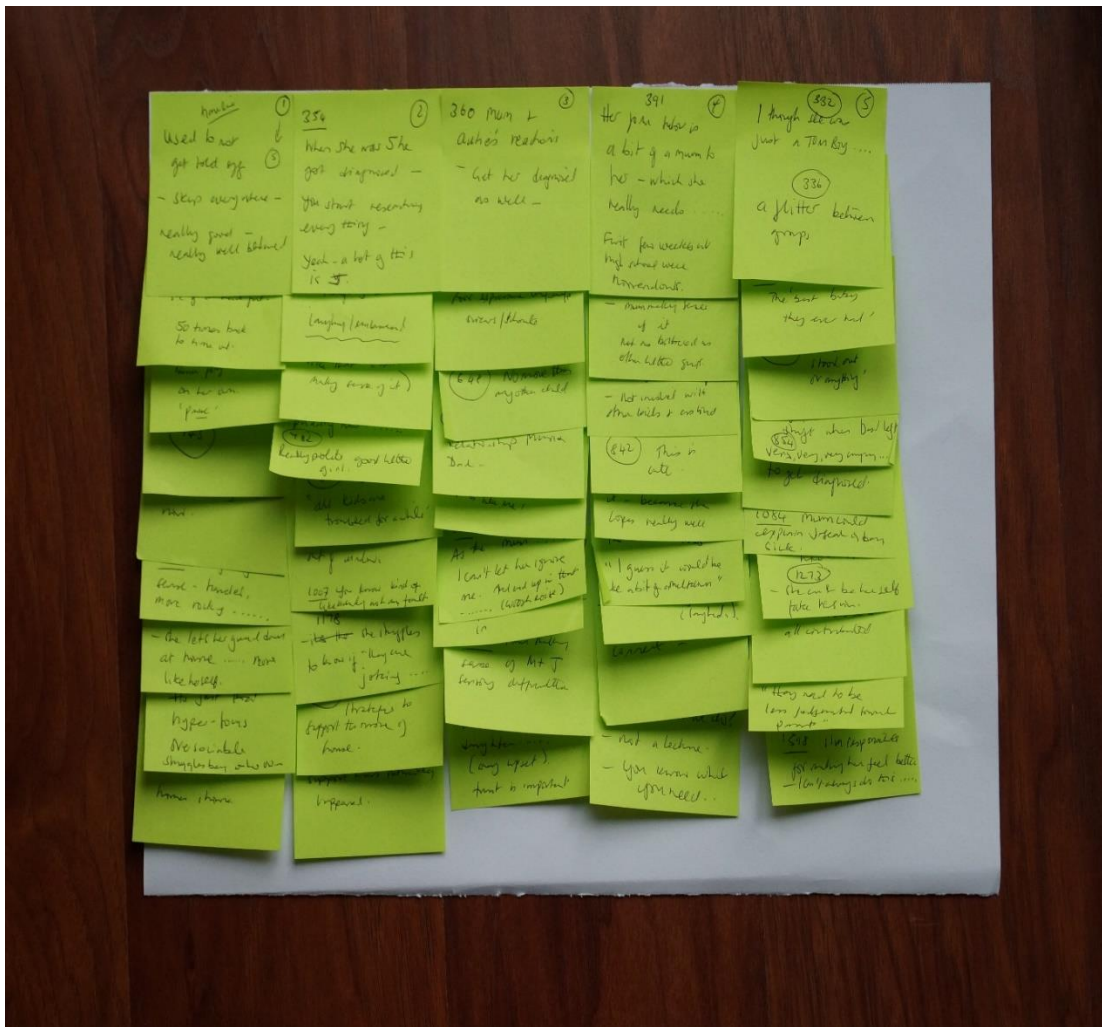
<p>Normal</p> <p>Anxiety</p> <p>unhappy</p>	<p>P: And then up until her first birthday, other than that, she met all her milestones. Nothing unusual. But it's always stuck in my mind and... I've already thought age one is too early to sort of show signs of social unhappiness. But ^(umm) we planned her first birthday party just for family, ^(umm) it was a really hot day so we had it all outside, we put plenty of shade up, we had a chocolate fountain. ^(umm) And there were probably fifteen people, which is the most we've ever had in... at our house for a get-together. ^(umm) And we'd planned it so that everyone came when she'd have had her nap, midday nap and I put her down a little bit early so if she needed a longer sleep, she could have it. ^(umm) And it got to the time of the party and I thought gosh she's slept for such a long time, I'm going to have to go and wake her up because everyone's here to see her. So I went and woke her up and she just wanted to sleep, but I brought her down and like granddad was there and normally by one she was really happy to see granddad, not so keen about the cuddles. But she was having none of it, she just cried.</p> <p>I: Right.</p> <p>P: ^(umm) And all these people had come to see her. ^(umm) And other than eating the odd strawberry, she just cried and I had to go and put her back to bed. So she probably was in the garden with everyone for about fifteen minutes. And then I went and put her back to bed and she slept. And I just thought oh she must have been a bit under the weather. But I just wondered did she sense something was going on because there were preparations and then... she came downstairs and all these people are in her garden... and wanted to say hi to her. But it was bizarre, so yeah her first birthday party was a bit...</p>	<p>Mum trying to make sense of her behaviour</p>
<p>excuses</p>	<p>I: But significant for you to remember that? And can you remember your thoughts at the time, was it more that she was poorly or did you have any other thoughts at that time?</p> <p>P: No thoughts, at all. Certainly nothing to do with autism at all.</p> <p>I: Yeah.</p> <p>P: I just thought it's a hot day, she's really tired and she just needs a big sleep.</p> <p>I: Yeah.</p> <p>P: And then when I woke... well she woke up later on that afternoon, everyone had gone and it was just back to normal. I checked her temperature, everything was absolutely fine.</p> <p>I: Gosh!</p>	<p>Mum realised it was out of character even at 1 years old</p>

<p>Wondering anxiety</p>	<p>P: (<i>sigh</i>) And now looking back I... I just wonder whether that was social anxiety. I: Right. So after her first birthday, how was she then? P: No different. Really good with her eating, ^(umm) she was happy going to preschool, sorry toddler group at that stage. She went to toddlers from a... quite an early age just so I could chat with other mums. She mixed really well, she'd share toys. She was really happy. ^(umm) And I always said that if ever I was feeling a bit down and if the weather was bad, [M] would always cheer me up. I: Oh! P: Because she would... she would just be a ray of sunshine, just always happy, always cuddly, ^(umm) just always doing silly things to make us laugh.</p>	<p>Trying to understand it looking back – recognition it could have been social anxiety even then</p>
	<p>I: And what about with her sister, how was she with her sister? P: She wasn't happy being cuddled by [E], but she wasn't happy being cuddled by anybody. I: What's the age gap? Did you say about three and a half years? P: Three and a half years, yeah. I: Yeah.</p>	
<p>Good behaviour Milestones on time Slurred speech</p>	<p>P: But very soon ^(umm) you could tell she really looked up to her big sister and trusted her and would play with her. ^(umm) She was always good at turn taking when she was very little, playing board games, no problems. She'd make it through the game. ^(umm) Her speech was quite slurred, she wasn't slow to speak or walk or anything, ^(umm) and I could understand her and [C] could and [E] could, but other people really struggled to understand her language. And I can remember at maybe up until the age of four, one of my friends said 'I really do struggle to understand [M]'. And ^(umm) my friend is French. I: Right.</p>	<p>Slurred speech – family understood her so not overly concerned – friend was french</p>
<p>Good friends Nothing identified</p>	<p>P: And I just thought she's just struggling because [M]'s speech is a little bit slurred and English is her second language. But when I look back... my then... my friend [S] is so experienced with children that she must have just noted [M] was a bit different in that respect. I: Right. But preschool didn't pick it up? P: No, absolutely fine going into preschool. She had ^(umm) really good group of friends. ^(umm) I: They didn't comment on her speech? P: No. I: No, so other people could understand her?</p>	<p>Nothing unusual at</p>

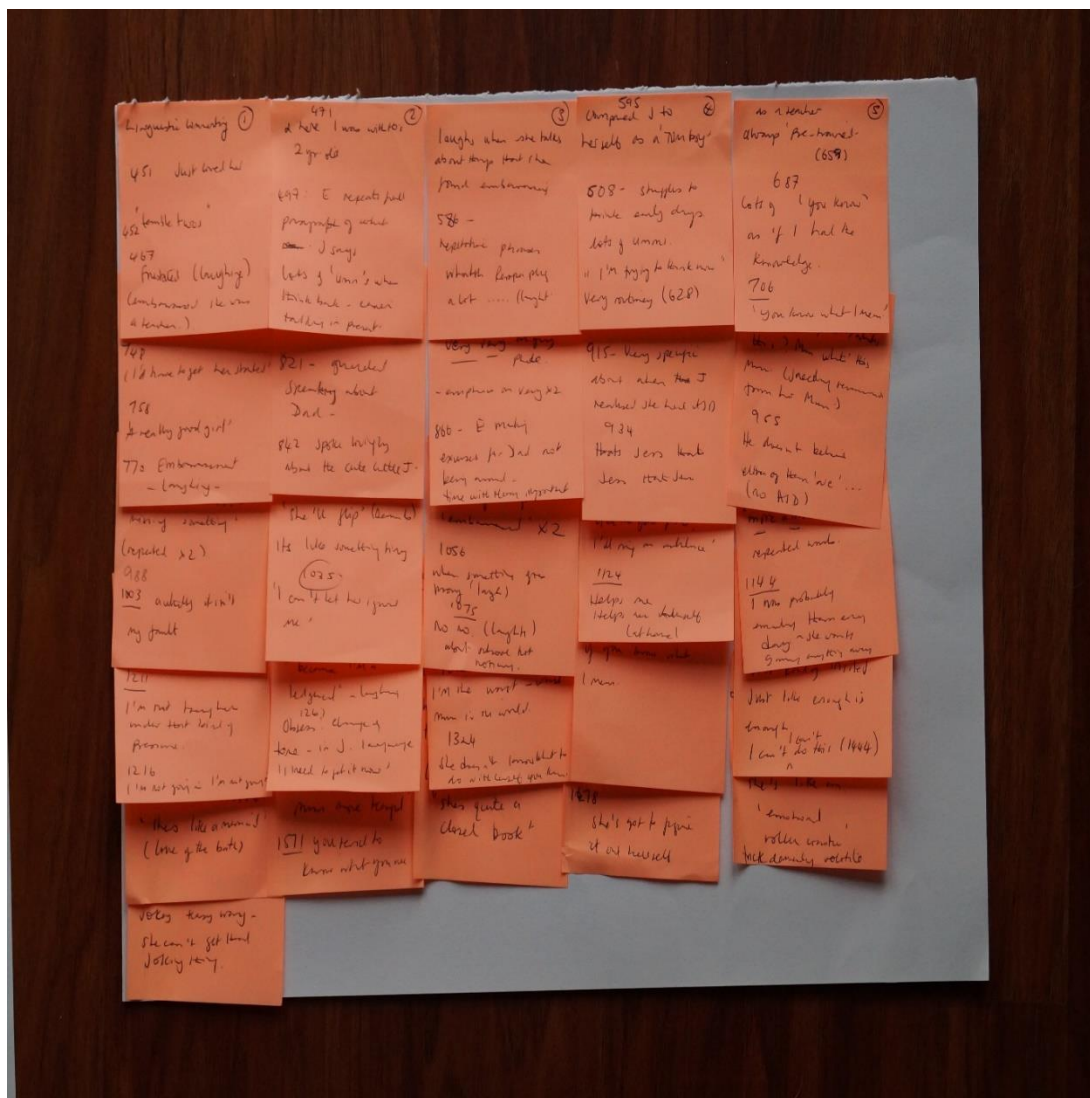
No issues attachment	<p>P: I looked back at her little book that she had from preschool and nursery actually, ^(umm) and there was nothing like that, no development issues. I do remember that it... it's been the same throughout preschool, primary school, high school, she kind of latches onto one favourite person.</p> <p>I: Right.</p> <p>P: Yeah, definitely at ^(umm) nursery. I went back to work when she was one, she had one definite favourite ^(umm)</p>	Looking back from birth her daughter always latched onto one adult
attachment	<p>I: And how did that present? How did you know that that was the case?</p> <p>P: She only ever talked about that particular grown-up. ^(umm) she would run straight over to her, when we picked her up she was always with her. ^(umm) And I think she kind of just followed her around! <i>(laugh)</i> And that stuck right through nursery. And at preschool? Preschool was a bit different because they... they were given a key worker so that was less obvious. ^(umm)</p>	
Normal behaviour Same as others	<p>I: How did she cope for the move from preschool to nursery? Was there any different then or did she just transition as normal?</p> <p>P: ^(umm) she probably cried for the first three sessions, but only a little bit. Which to me was perfectly normal.</p> <p>I: Yeah. Nothing unusual.</p> <p>P: Whereas [E]... [E] didn't cry at all, she just moved from... building to building, person to person, absolutely fine with no tears. So [M] cried a little bit, but not a lot, there was no ^(umm) separation anxiety or anything like that. To me it was just what the normal children did, just being away from their mum for a few hours.</p> <p>I: Yeah. And also she'd lost her key person hadn't she I suppose?</p> <p>P: Yeah. Yeah.</p> <p>I: In that respect.</p> <p>P: But she soon settled. ^(umm) We had a rota at preschool where the ^(umm) parents would just be an extra adult and do the snacks. ^(umm) And I'd always watch because you just wouldn't you? And she was just happy, same as... same as the others.</p>	Mum observed her daughter at pre-school and she just saw a 'normal' happy child

<p>Very academic</p> <p>Bright</p> <p>Well behaved</p> <p>avoided it</p> <p>Fun</p> <p>Quirky</p>	<p>I: So then moving to school? Was there any?</p> <p>P: Primary school was absolutely great until year six. ^(umm) She had a good group of friends, one best friend that she stayed with until the end of primary school. ^(umm) Looking back at all her reports, very, very academically strong, extremely bright, extremely well-behaved, no... no behavioural issues, no friendship issues. ^(umm) If ever girls fell out, she would just stay out of it. If there was an argument with her friendship group, she would sometimes talk to me about it, but she always just stayed out of it. Which <i>(laugh)</i> is great... to her credit is the right thing to do.</p> <p>I: Right.</p> <p>P: ^(umm) Yeah, absolutely nothing. But she was quirky, ^(umm) yeah, I've written that down there and her... her best friend's mum said she saw [M] at preschool and said 'I want [M] to be best friends with [M] because she's... she looks fun' and she used the word quirky as well.</p> <p>I: Right.</p> <p>P: Yeah, just <i>(sigh)</i> I can't really put my finger on it. Yeah, just quirky. I can't... I can't really describe it. Fun, I guess.</p>	<p>Mum just saw all the positives – she did not consider it was more unusual to not be involved in friendship dynamics at that age</p>
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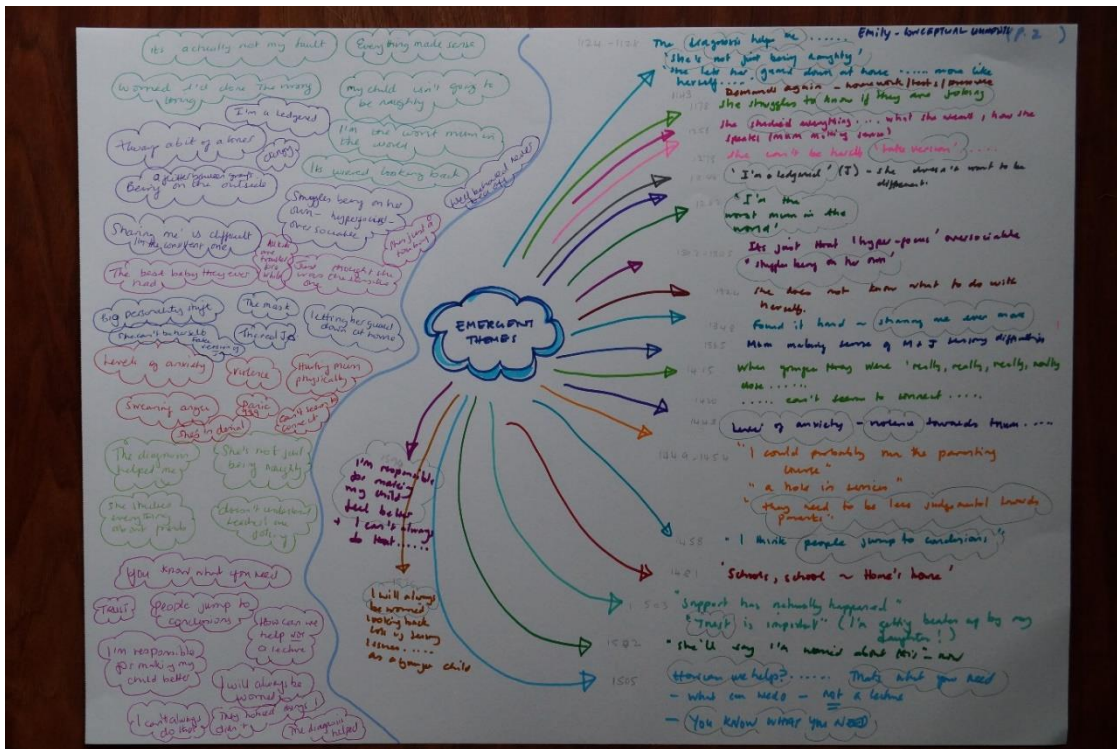
Appendix 9a: Descriptive Comments Jane



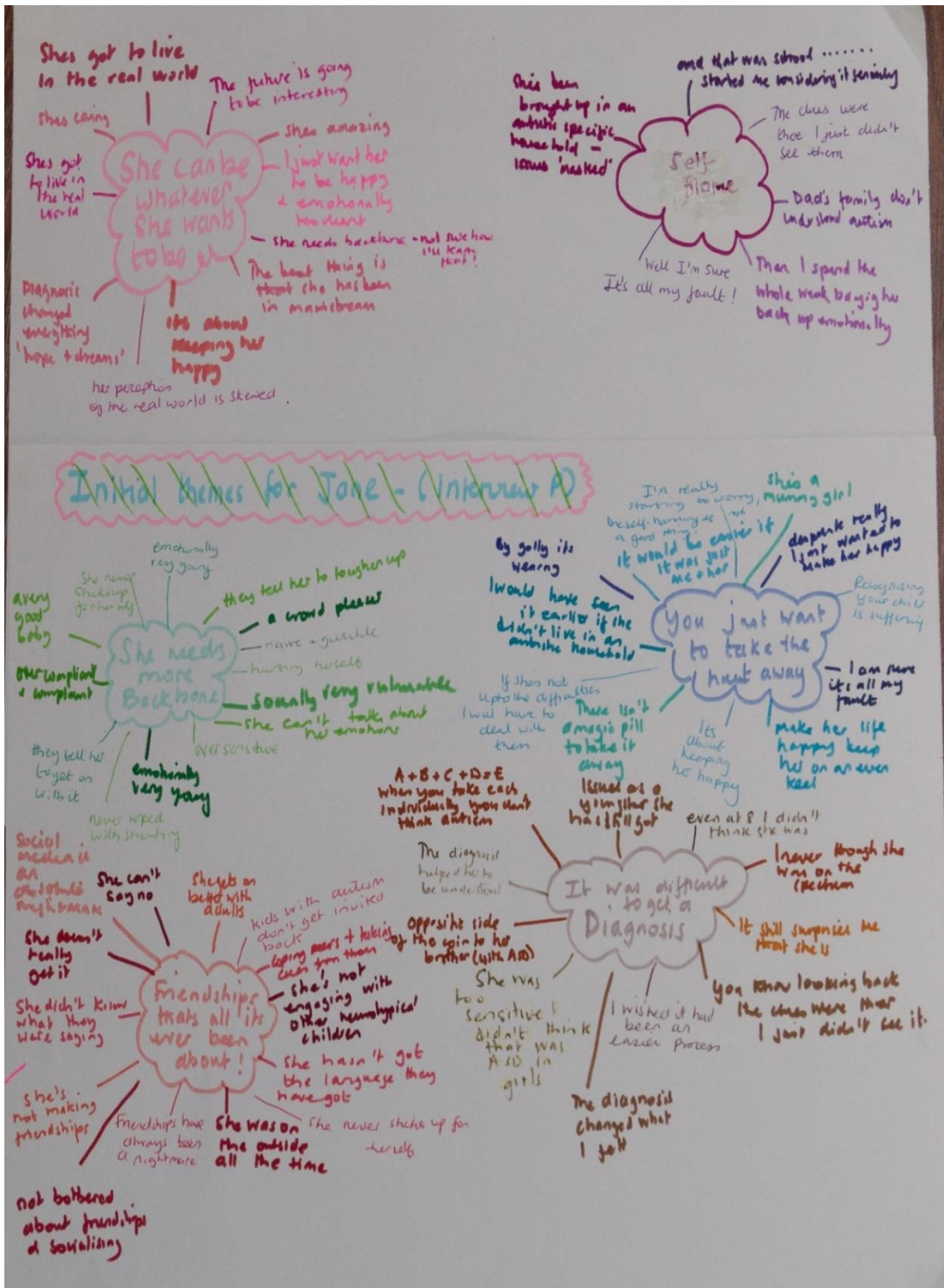
Appendix 10a: Linguistic Comments Jane



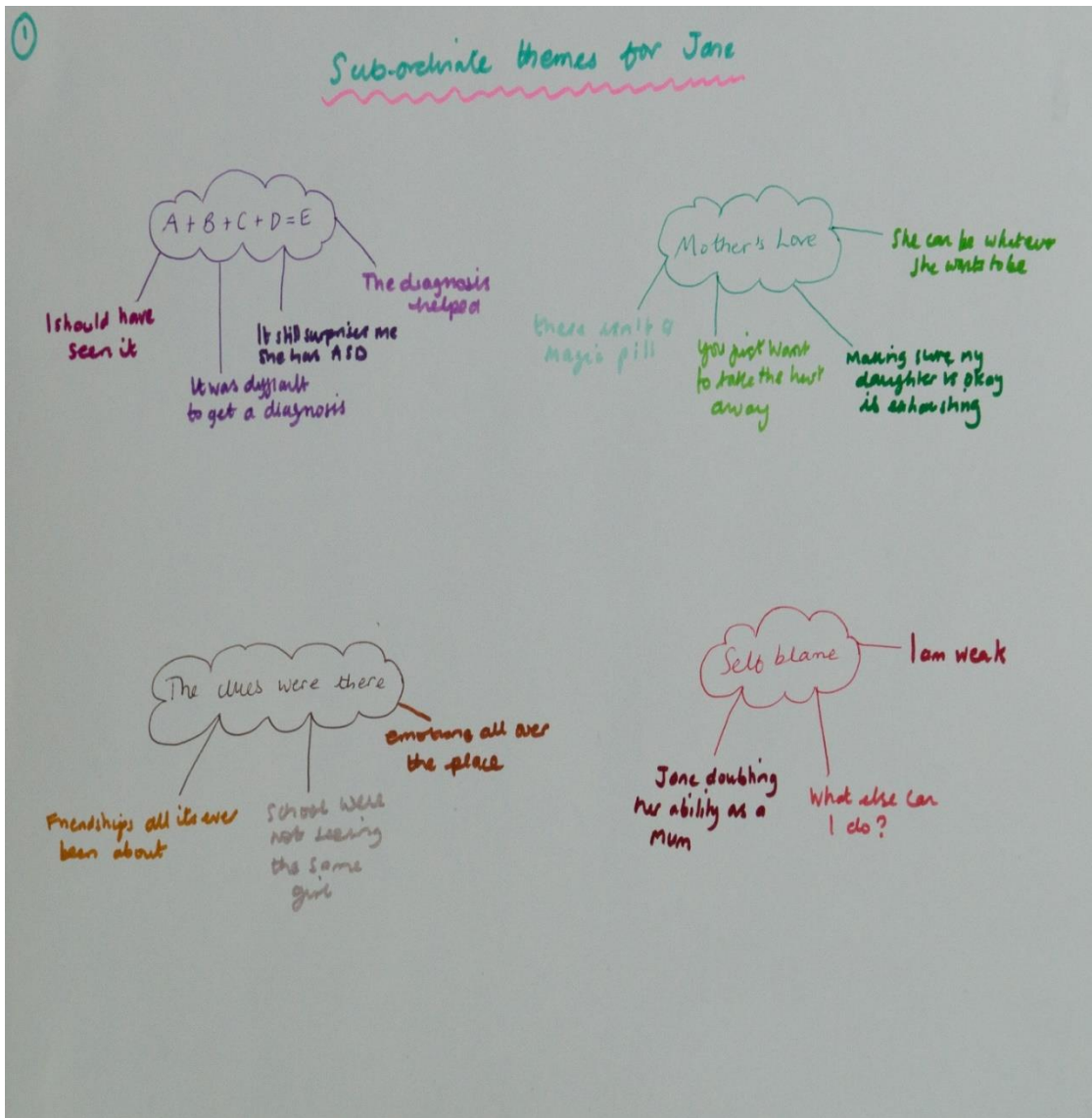
Appendix 11b: Conceptual Comments Mind Map



Appendix 12: Subordinate emerging themes Jane



Appendix 13: Reduced Sub-Ordinate Themes Jane



Appendix 14: Table of super-ordinate themes from Jane in the autism daughter's project

Themes	Line	Key words
A + B + C + D = E		
<i>I should have seen it</i>	133	Looking back
<i>It was difficult to get a diagnosis</i>	370	That's autism
<i>It still surprises me that she has autism</i>	383	I didn't think she was
<i>The diagnosis helped</i>	982	Changed what I felt
Mother's love		
<i>there isn't a magic pill</i>	975	Make it go away
<i>You just want to take the hurt away</i>	750	Want her to be happy
<i>Making sure my daughter is okay is exhausting</i>	197	Easier if it was just me and her
<i>She can be whatever she wants to be</i>	732	The future
Self-blame		
<i>Jane doubting her ability as a mum</i>	58	I just didn't see it
<i>What else can I do?</i>	376	It's wearing
<i>I am weak</i>	328	My fault
The clues were there		
<i>Friendships is all its ever been about</i>	873	Needs more backbone
<i>School were not seeing the same girl</i>	631	Crowd pleaser
<i>Emotions are all over the place</i>	254	Fluttery

Appendix 15: Table of super-ordinate themes from Emily in the ASD daughter's project

Themes	Line	Key words
Looking Back		
Just loved her	378	Didn't demand
Nothing stood out	376	really easy
A bit of a sensitive one	304	always a worrier
Very routiney	697	checking
Everything made sense	922	More rocky
Enough is enough		
I'm getting immune to it	1796	I didn't hurt you
Judgement from everyone else is hard	1812	don't understand
It's like exhausting	1768	self-destruct
You know what you need - not a lecture	1458	help
Who is my daughter		
That card never comes down	1619	the mask
She wants to be the same as everyone else	1170	I'm a legend
Social hangover	1825	friends
Fake version of herself	1178	obsess
I'm the worst Mum		
I'm responsible for making her feel better	1642	diagnosis
My child won't be naughty	406	frustrated
This isn't my fault	807	consistent

Appendix 16: Table of super-ordinate themes from Vroni in the ASD daughter's project

Themes	Line	Key words
The signs were there		
<i>Nothing to compare</i>	589	Normal toddler
<i>Everything on her terms</i>	2001	Strong willed
<i>When will she get it</i>	2162	Oh my days!
<i>I didn't really think much of it at the time</i>	387	Jump & cry
<i>Autism hadn't even crossed my mind</i>	425	Hard work
<i>I knew she was different</i>	2311	relieved
Everyone's got a breaking point		
<i>Frustration</i>	482	Never got it
<i>Enough is enough</i>	3160	Patient
<i>It's not good enough</i>	2342	Failed
<i>I could cry</i>	3368	Lost the plot
<i>Everything's a fight</i>	2671	It's shocking
Self-blame		
<i>The worst Mum</i>	1594	Not nasty
<i>I gave up</i>	1424	Didn't work
<i>Not believed</i>	2127	Label your child
<i>Can't cope</i>	2166	Not happy
<i>She's been failed</i>	3178	Promised
I've got my little girl back		
<i>'****'</i>	2846	She wows
<i>Amazing relationships</i>	2039	Best friend
<i>She was happy</i>	1124	Wanted to be a princess
<i>Autism party</i>	2331	Celebrate differences
<i>It hasn't been easy</i>	2404	Amazing

Appendix 17: Table of super-ordinate themes from Betty in the ASD daughter's project

Themes	Line	Key words
Intensity of Mum's Love		
<i>You don't automatically look for things that are wrong</i>	680	So different
<i>I want her to be defined by her strengths</i>	2534	Fabulous
<i>She didn't even know she was so ill</i>	637	Can't tell me
<i>I've given up my career and my life</i>	1889	Find a balance
<i>I'm never cross with her just frustrated!</i>	2562	Patience very stretched
Disbelief		
<i>Just seemed neuro-typical</i>	170	More settled
<i>That's teenage girls</i>	1819	Hard to read
<i>Nothing like them</i>	510	Emotionally intelligent
<i>It didn't occur to me</i>	155	On target
<i>Thought we'd got it right 3rd time</i>	169	More settled
The perfect daughter		
<i>Just seems happy to be here</i>	1229	No emotion
<i>To me she's beautiful and bright</i>	909	Looks the part
<i>I embrace that</i>	428	Different/unique
<i>Maximum impact, minimum effort</i>	1957	Not bothered
<i>Please other people</i>	898	Time to overthink
<i>A little angel</i>	1231	Dead placid
A need to make it better		
<i>She's hard to read</i>	1821	Nothing, she's solid
<i>Can't do the social bit</i>	789	Comfort zone
<i>I'm fine ,I'm fine</i>	1669	Stop annoying me
<i>Getting ill as she gets older worries me</i>	630	Never cried
<i>She can't make choices and decisions</i>	1464	No clue
<i>I'm all about removing that anxiety</i>	960	Quite normal
What does autism look like?		
<i>Slightly under the radar</i>	262	Following instructions
<i>The face is all that matters</i>	557	Nothing like them
<i>You never really, really know your child with autism</i>	1792	The hardest thing
<i>A bit of this and a bit of that</i>	614	A whole person
<i>She wants to be like them</i>	585	She has learnt
<i>Does she look like she's autistic?</i>	2314	Hate that

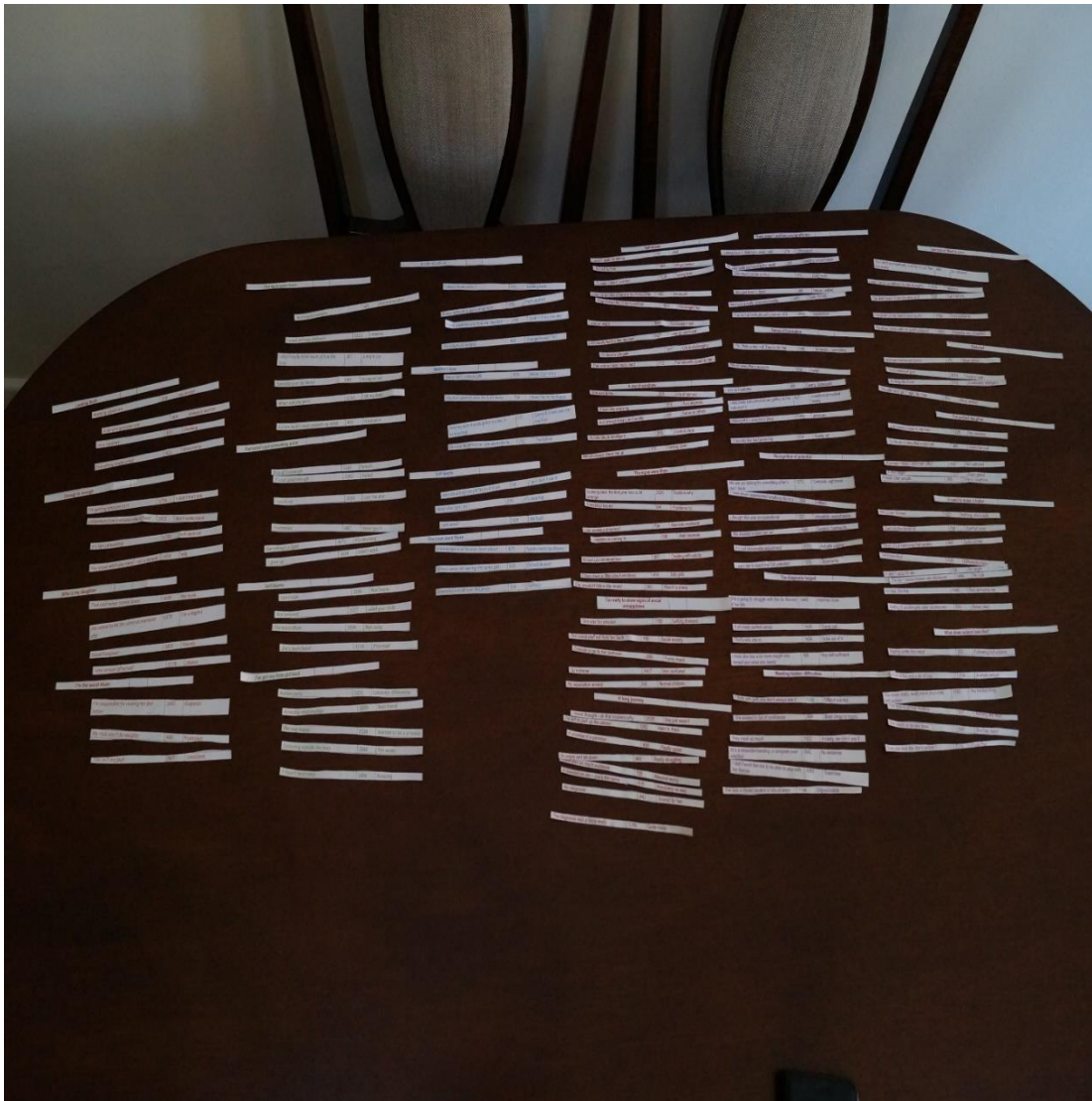
Appendix 18: Table of super-ordinate themes from Abbie in the ASD daughter's project

Themes	Line	Key words
There wasn't anything wrong with her		
<i>Looking back it didn't ring alarm bells</i>	274	focussed
<i>We were quite confident in the result</i>	263	Amazing concentration
<i>She would just be smiling</i>	175	Easy really
<i>She just loved it there</i>	360	Happy, settled
<i>We have a really close relationship</i>	1465	Open, honest
<i>You sort of think she will grow out of it</i>	1444	explanation
Sense of frustration		
<i>You think surely not! Thanks for that</i>	608	Behaviour, controlling
<i>We did everything possible</i>	1230	Awful
<i>I was so frustrated</i>	986	Clearly distressed
<i>I was more concerned about getting to the bottom of it</i>	607	Complicated medical history
<i>Hindsight's a wonderful thing</i>	1163	pressure
<i>It sounds like bad parenting</i>	614	Surely not
Recognition of potential		
<i>We are not asking for something other's don't have</i>	1273	Complete nightmare
<i>I have never experienced anything like this</i>	1289	Entitled
<i>I thought this was so aspirational</i>	1221	Unrealistic expectations
<i>We decided to take her out</i>	1069	Support, backwards
<i>It's just reasonable adjustment</i>	1313	Actually coping
<i>I want her to reach her full potential</i>	1265	Opportunity
The diagnosis helped		
<i>She's going to struggle with this for the rest of her life</i>	1449	Hammer blow
<i>It all made perfect sense</i>	1435	Curve ball
<i>That's who she is</i>	1454	Grow out of it
<i>I think she has a lot more insight into herself and what she needs</i>	199	Very self-sufficient
Masking hidden difficulties		
<i>She walked in full of confidence</i>	484	Boys clingy to mums
<i>They mask so much</i>	1322	Anxiety, we didn't see it
<i>It's a misunderstanding, a complete over reaction</i>	1042	No evidence
<i>I didn't want her not to be able to play with her friends</i>	1063	Supervise
<i>She was a model student in lots of ways</i>	1194	Unpredictable
<i>I think with girls you don't always see it</i>	1310	Difficult journey

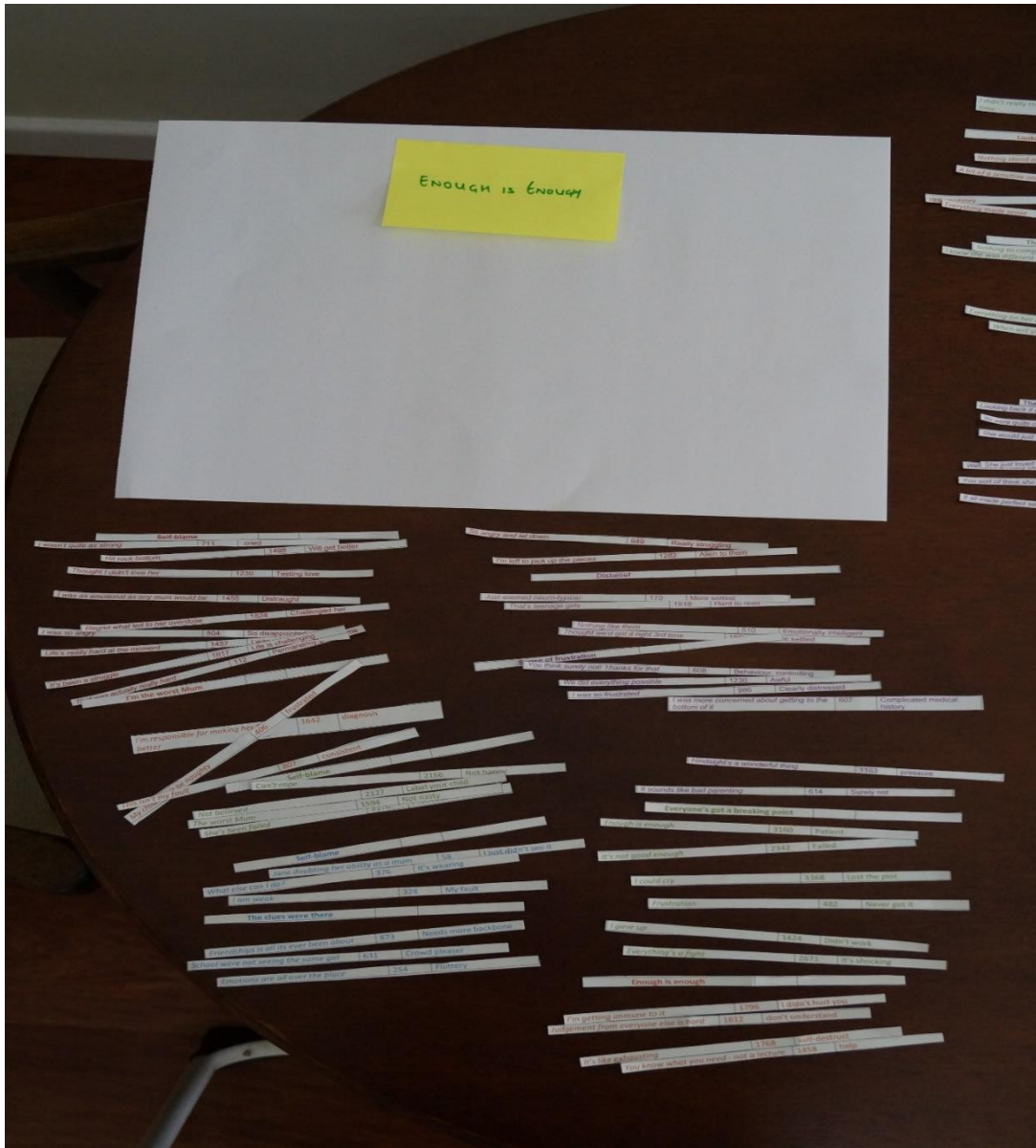
Appendix 19: Table of super-ordinate themes from Jennie in the ASD daughter's project

Themes	Line	Key words
A ray of sunshine		
<i>Just always happy and cuddly</i>	252	Same as others
<i>Would always cheer me up</i>	173	Feeling down
<i>Absolutely amazing</i>	558	Avid interests
<i>Outstandingly intelligent</i>	295	Lovely to hear
<i>She was funny</i>	288	Lots of humour
The signs were there		
<i>Looking back the first year was a bit strange</i>	2525	Explains why
<i>Friendship issues</i>	344	Problems hit
<i>Just masking at school</i>	754	Absolute explosion
<i>Grown up conversations</i>	287	Chatting with adults
<i>Obsessions coming in</i>	558	Avid interests
<i>Close down a little about emotions</i>	414	Silly girls
<i>She wouldn't follow the crowd</i>	285	Wasn't a sheep
Self-blame		
<i>I wasn't quite as strong</i>	711	cried
<i>It's been a struggle</i>	1817	Life is challenging
<i>I was as emotional as any mum would be</i>	1455	Distraught
<i>I was so angry</i>	804	So disappointed
<i>That was actually really hard</i>	112	Permanently glued to me
<i>Life's really hard at the moment</i>	1457	I was so emotional
<i>Thought I didn't love her</i>	1239	Testing love
<i>Hit rock bottom</i>	1498	Will get better
<i>Regret what led to her overdose</i>	1824	Challenged her
Too early to show signs of social unhappiness		
<i>The social stuff will hold her back</i>	166	Social anxiety
<i>She was too anxious</i>	1769	Getting stressed
<i>Explode or go to her bedroom</i>	699	Funny mood
<i>So extreme</i>	1417	Very confused
<i>No separation anxiety</i>	240	Normal children
A long journey		
<i>I never thought - oh that explains why</i>	2528	She just wasn't
<i>I'm left to pick up the pieces</i>	1282	Alien to them
<i>A promise is a promise</i>	458	Really upset
<i>So angry and let down</i>	949	Really struggling
<i>There was so much evidence</i>	755	Massive worry
<i>It dawned on me – she's the same</i>	616	Absolutely no way
<i>No diagnosis</i>	842	Scared for her
<i>The diagnosis was a farce really</i>	1785	Quite ironic

Appendix 20: Emerging themes from all participants



Appendix 21: Example of Emergent Subordinate Theme



Appendix 22: Example of Emergent Subordinate themes

HIDDEN FROM PLAIN SIGHT

I didn't really think much of it at the time | 187 | June 8 cry
 Looking back |
 Nothing about it | 176 | Loudly noisy
 A lot of a normal one | 158 | Always a scene
 I remember | 167 | Searching
 Everything was normal | 167 | Most rocky
 The signs were there | 158 | Sudden toddler
 Nothing to point out | 158 | Sudden toddler
 A huge 360 view difference | 231 | relieved

Everything on her face | 200 | Being weird
 When was she girl at | 213 | Oh why does
 A+B+C+D+E |
 I was confused to get a diagnosis | 231 | Looking back
 I don't work | 238 | That's autism
 Autism hasn't even raised my mind | I still surprises her that she has ASD | 153 | I don't think she was
 The diagnosis helped | 143 | Changed what I look

There wasn't anything wrong with her |
 Looking back it didn't cry when fed | 274 | focused
 She was quite confident in the road | 253 | Amazing concentration
 She would just be smiling | 175 | Easy really
 | 300 | Happy, settled
 She just burst in there | 145 | Open hearted
 She social relationship | 145 | Open hearted
 She sort of think she will grow out of it | 144 | Impatience
 I all kinds perfect people | 143 | Curve ball

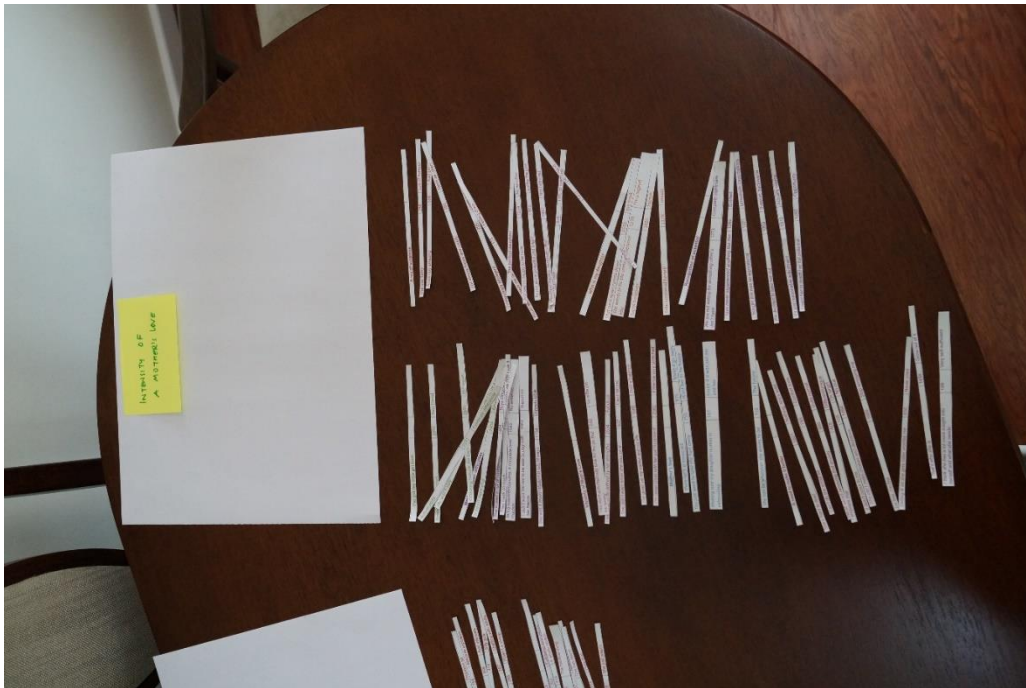
Too early to show signs of social unappiness
 She was too anxious | 179 | Getting stressed
 She social stuff and had her back | 156 | Social anxiety
 Cried or go to her bedroom | 169 | FURRY YETU
 | 147 | Very confused
 Her appearance anxiety | 246 | Normal children

The signs were there
 Looking back the first year was a bit strange | 232 | Explains why

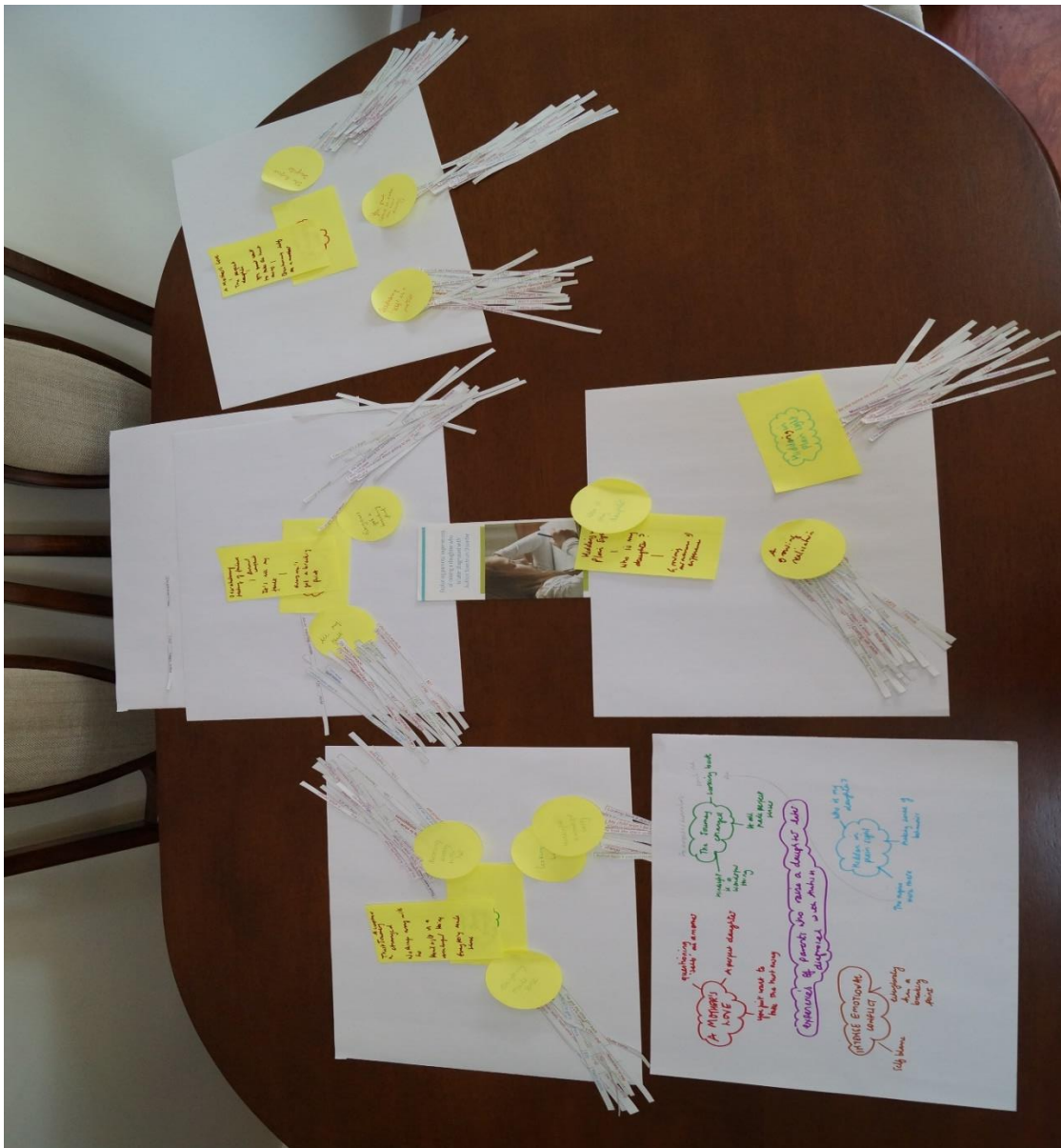
Emotional issues | 144 | Problems fit
 Not looking at school | 156 | Absolute nightmare
 | 158 | Ask interests
 | 174 | Only one
 | 187 | Chatting with adults
 | 226 | I wasn't a thing

What does autism look like?
 Tightly under the radar | 253 | I followed instructions
 I lot of love and a lot of fear | 174 | A whole person
 You really really really know your child | 152 | That's the thing
 She was a bit of a mess | 157 | I was
 She wants to be like them | 155 | She has more
 | 118 | I was a girl
 She was like she didn't smile | 155 | I was a girl
 She was angry - Oh that explains why | 232 | She got angry

Appendix 23: Example of Emergent Subordinate themes



Appendix 24: Emergent Superordinate and Sub themes



Appendix 25: An exert from reflective diary summarising the researcher's thoughts in terms of bracketing

