



“Being an autism parent”

Mothers’ experiences from initial concerns about their daughters to a diagnosis of autism spectrum disorder: An interpretative phenomenological analysis

Doctorate in Educational Psychology

2017

Janet Mycroft

Acknowledgements

I would like to thank my research supervisor, Dr Dale Bartle, for his guidance and encouragement and for asking more questions than he answered.

My love and thanks of course go to Martin who has been a constant source of support despite the completion of a thesis not being the best start to married life. Most of all I would like to thank the mothers who gave their time and shared what were often difficult and personal stories. Each time I read their words, I am moved by their strength and eloquence.

This thesis is dedicated to the memory of my own mother who saw the beginning of my DEdPsy journey but not the end. She would have been very proud.

“It’s really hard being an autism parent, because you have all these feelings that you manage about your child. All your worries about them and some of your own feelings. About injustice, about services that they’re offered and things that should be in place to meet their needs that aren’t. And you have to be able to regulate yourself, so that you don’t vent that on all the people that you meet with and wreck the relationships and them wanting to help you.” (Claire)

Summary

This thesis consists of three parts: a major literature review, an empirical study and a critical appraisal.

In Part One, the literature review begins with a brief introduction which outlines the importance of the topic, in particular the disparity in diagnosis rates for autism spectrum disorder (ASD) in girls compared to boys and possible causes and consequences. This is followed by an overview of the development of the diagnostic criteria for ASD and a critical exploration of a range of explanations for this disparity, suggesting some under-identification of symptoms in girls. This is followed by an overview of research into the experiences of girls and their parents during the diagnostic journey, including evidence for a later and longer diagnostic process, the prevalence of comorbid psychiatric diagnoses and evidence for the impact on mothers particularly. Finally, the literature review is summarised in order to provide the rationale for this thesis and to lead into the research questions.

In Part Two, following a brief overview of the literature, the empirical study provides a detailed account of the research undertaken. This includes an outline of the methodology and method and presents an interpretative phenomenological analysis of semi-structured interviews with five mothers of daughters with diagnoses of ASD, exploring their diagnostic journeys in the broadest sense. This analysis is explored in relation to psychological literature, particularly systemic thinking, before a discussion of the implications for future research and for educational psychology practice.

Part Three, the critical appraisal, consists of two parts: firstly, a critical account of the research process is given from inception through to completion including ontological, epistemological and ethical considerations as well as difficulties encountered; secondly, a more detailed discussion of the findings is offered in relation to psychological literature and the contribution to knowledge and educational psychology practice.

Contents

Declaration	ii
Acknowledgements	iii
Summary	v
Contents	vi
List of Tables	xi
Abbreviations	xiii
PART ONE: MAJOR LITERATURE REVIEW	1
1 Introduction	2
1.1 Introduction	2
1.2 A Social Model of Disability	4
1.3 A Note on Terminology	5
1.4 Description of Key Search Terms and Literature Sources	6
2 Development of the Diagnostic Criteria for ASD	7
3 The Female Phenotype	11
4 Explanations for the Disparity in Diagnosis Rates	13
4.1 Biological Explanations	13
4.2 Historical Explanations	15
4.2.1 Diagnostic criteria	15
4.2.2 Diagnostic tools	16
4.2.3 Research orphans	17
4.3 Behavioural Explanations	17
4.3.1 Social communication and interaction	18

4.3.2 Restricted, repetitive patterns of behaviour	21
4.3.3 Externalising behaviours	23
4.3.4 Internalising behaviours	26
4.4 Sociocultural Explanations	28
5 Girls' Diagnostic Experiences	29
5.1 Later and Longer Diagnostic Process	30
5.2 Other Diagnoses	33
5.3 The Impact of the Diagnostic Process on Parents	37
6 Rationale for Thesis.....	41
6.1 Rationale	41
6.2 Research Questions	42
7 References.....	44
PART TWO: EMPIRICAL STUDY.....	57
Abstract.....	58
1 Introduction	59
1.1 The Current Thesis	61
1.2 Aims and Research Questions.....	61
2 Methodology.....	62
2.1 Ontology and Epistemology.....	62
2.2 Methodology	62
3 Method.....	62
3.1 Selection and Recruitment	62
3.2 Participants.....	63

3.3 Interviews	64
3.4 Ethical Considerations	64
3.5 Analysis of Data	64
4 Results and Analysis	66
4.1 Superordinate Theme: “ <i>DIAMOND-SHAPED DAUGHTERS</i> ”	68
4.1.1 Subordinate theme: “ <i>Very Much a Swan</i> ”	69
4.1.2 Subordinate theme: “ <i>So Uncomfortable</i> ”	70
4.1.3 Subordinate theme: “ <i>Going to Pieces</i> ”	71
4.2 Superordinate Theme: “ <i>JUST GETTING NOWHERE</i> ”	72
4.2.1 Subordinate theme: “ <i>Fighting on My Own</i> ”	72
4.2.2 Subordinate theme: “ <i>Who’s Got the Key?</i> ”	74
4.2.3 Subordinate theme: “ <i>Pain in the Arse</i> ”	75
4.2.4 Subordinate theme: “ <i>What the System Needs</i> ”	76
4.2.5 Subordinate theme: “ <i>Hauled Over the Coals</i> ”	78
4.2.6 Subordinate theme: “ <i>Breaking Point</i> ”	79
4.3 Superordinate Theme: “ <i>THIS THING CALLED ASPERGER’S</i> ”	80
4.3.1 Subordinate theme: “ <i>Surely That’s Boys</i> ”	80
4.3.2 Subordinate theme: “ <i>A Process of Discovery</i> ”	82
4.3.3 Subordinate theme: “ <i>The Life I Wanted</i> ”	83
5 Discussion	84
5.1 The Research Questions	85
5.2 Previous Research	86
5.3 The Female Phenotype	86
5.4 Systemic Thinking	87
6 Contribution to Knowledge	89

7 Strengths and Limitations of the Research	90
8 Suggestions for Future Research	91
9 Implications for Educational Psychologists.....	91
10 Conclusion	91
11 References	93
PART THREE: CRITICAL APPRAISAL.....	99
1 Critical Account of Research Practitioner	100
1.1 Rationale for Thesis	100
1.1.1 Inspiration	100
1.1.2 Initial literature search.....	101
1.1.3 Personal position	102
1.2 Methodological Considerations	102
1.2.1 Ontology.....	102
1.2.2 Epistemology	102
1.2.3 Interpretative phenomenological analysis.....	103
1.2.4 Alternative methodologies	104
1.2.5 Semi-structured interviews	105
1.3 Selection and Recruitment of Participants	105
1.3.1 Inclusion and exclusion criteria	105
1.3.2 Mothers	107
1.3.3 Recruitment	107
1.4 Data Collection	108
1.5 Analysis of Data.....	108
1.6 Other Ethical Considerations	109

1.6.1 Informed consent.....	109
1.6.2 Anonymity	110
1.6.3 Harm.....	110
2 Contribution to Knowledge.....	110
2.1 Contribution to the Literature	110
2.2 Contribution to Future Research	113
2.3 Contribution to Professional Practice	115
2.3.1 Within educational psychology services.....	115
2.3.2 Within schools.....	116
2.3.3 Within the classroom	118
2.4 Personal Practice	119
2.5 Conclusions	119
3 References.....	120
Appendices	125

List of Tables

Table 1 Research into age at diagnosis and length of diagnostic process	31
Table 2 Details of participants.....	63
Table 3 Key to symbols and styles used in quotations	65
Table 4 The six steps of IPA	66
Table 5 Recurrent superordinate and subordinate themes	67
Table 6 Recurrence of themes across participants	68
Table 7 Illustrative quotations for Very Much a Swan.....	69
Table 8 Illustrative quotations for So Uncomfortable	71
Table 9 Illustrative quotations for Going to Pieces	72
Table 10 Illustrative quotations for Fighting on My Own	73
Table 11 Illustrative quotations for Who's Got the Key?	74
Table 12 Illustrative quotations for Pain in the Arse	75
Table 13 Illustrative quotations for What the System Needs	77
Table 14 Illustrative quotations for Hauled Over the Coals	78
Table 15 Illustrative quotations for Breaking Point.....	79
Table 16 Illustrative quotations for Surely That's Boys	81
Table 17 Illustrative quotations for A Process of Discovery	82
Table 18 Illustrative quotations for The Life I Wanted	83
Table 19 Participant inclusion and exclusion criteria	106
Table 20 Fundamental principles of the Code of Practice.....	119

Abbreviations

ADHD	Attention deficit hyperactivity disorder
ADOS	Autism diagnostic observation schedule
ASD	Autism spectrum disorder
BMI	Body mass index
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
EP	Educational psychologist
GP	General practitioner
ICD	International statistical classification of diseases and related health problems (Arabic numerals indicate the edition)
IPA	Interpretive phenomenological analysis
RRB	Restricted, repetitive patterns of behaviour
SC&I	Social communication and social interaction
SENCO	Special educational needs co-ordinator
TEP	Trainee educational psychologist



“Being an autism parent”

Mothers’ experiences from initial concerns about their daughters to a diagnosis of autism spectrum disorder: An interpretative phenomenological analysis

PART ONE: MAJOR LITERATURE REVIEW

(Word Count: 9988)

1 Introduction

1.1 Introduction

The ratio of males to females diagnosed with autism spectrum disorder¹ (ASD) and related conditions is typically estimated at about 4:1 (see, for example, Fombonne, 2003; Hinkka-Yli-Salomäki et al., 2014; Whiteley, Todd, Carr, & Shattock, 2010). When Asperger's² syndrome (AS), a form of ASD without intellectual or language impairment, is considered separately, this ratio increases to 10:1 (Attwood, 2006). Although some UK- and Ireland-based studies have reported both wider and increasing ratios (Webb et al., 2003; Whiteley et al., 2010), others have reported the converse, narrower and decreasing ratios (Latif & Williams, 2007). What remains consistent among these figures, however, is that girls are several times less likely than boys to receive a diagnosis of ASD and that this ratio is possibly twice as high among people with AS.

Some of the proposed explanations for the disparity in diagnosis rates, particularly those predicated on a biological etiology (see, for example, Baron-Cohen et al., 2011; Carter, 2007) suggest that the disparity reflects, in part at least, a genuine difference in incidence. Other, not incompatible, research suggests that the disparity also reflects a male-centric bias in the way ASD is described and diagnosed (Gould & Ashton-Smith, 2011; Hiller, Young, & Weber, 2016) and, therefore, the difficulties associated with ASD are not being recognised in cognitively able girls (Van Wijngaarden-Cremers et al., 2014). As a consequence, the needs of this group are not being met (Attwood, 2015; Gould & Ashton-Smith, 2011).

As well as being diagnosed less often, research also suggests that girls

¹ The choice of terminology will be discussed below.

² *Asperger's* is used in preference to *Asperger* as this was the term used by most participants.

receive diagnoses of ASD later than boys, particularly those without intellectual disability (Begeer et al., 2013; Goin-Kochel, Mackintosh, & Myers, 2006; Rutherford et al., 2016; Siklos & Kerns, 2007).

A consequence of the disparity in diagnosis rates is that relatively little research focuses on girls and women with ASD (Baldwin & Costley, 2016; Solomon, Miller, Taylor, Hinshaw, & Carter, 2012). Where girls are included in research along with boys, their numbers may be so relatively small that results for girls and boys are sometimes not considered separately and the experience of girls is subsumed into a boy-dominated statistical norm (see, for example, Hammond & Hoffman, 2014; Mayes & Calhoun, 2011; Mazefsky, McPartland, Gastgeb, & Minshew, 2013)³; when comparisons are made between girls and boys, there is a risk that gender differences will not be identified as the relatively small number of girls can mean that studies lack statistical power to detect group differences unless the effect size is large (Mandy, Chilvers, et al., 2012).

This literature review will begin by briefly outlining the development of the diagnostic criteria for ASD within the various editions of the *Diagnostic and statistical manual of mental disorders* (DSM) published by the American Psychological Association (APA) and in the *International statistical classification of diseases and related health problems* (ICD) published by the World Health Organization (WHO). This will help to provide a contextual background for the thesis, showing how autism is an evolving social construct. Following on from this brief history of diagnosis, research related to the known differences between girls and boys with ASD will be explored in order to show how little is known for certain

³ Hammond & Hoffman (2014), for example, acknowledge that “males represented most of the sample (92.9%)” (p.251); this meant just one girl in their sample of 14 adolescents.

about the female phenotype.

Next, this literature review will explore a range of explanations for the disparity in diagnosis rates. These will include historical, biological, behavioural and sociocultural explanations and help to give an indication of the relative difficulty of identifying ASD in cognitively able girls given current diagnostic criteria and tools. This will also highlight how disparities in diagnosis rates might reflect both a genuine difference in underlying prevalence as well diagnostic bias.

Finally, research related to the diagnostic experiences of children and their parents will be outlined. This will include evidence for longer and later diagnosis in cognitively able girls and evidence of what might be either comorbidities or misdiagnoses. Evidence for the impact of the diagnostic process on parents will also be explored in order to provide a broad understanding of the experiences of parents.

1.2 A Social Model of Disability

This thesis is underpinned by a social model of disability which distinguishes between impairment and disability (Oliver, Sapey, & Thomas, 2012)⁴. *Impairment* is acknowledged as part of the individual and is not denied (Oliver, 2013). By contrast, *disability* is seen as arising from a range of barriers within society, for example physical, structural and attitudinal, which limit opportunities for individuals to engage as fully as they might wish in that society (Hughes, 2010). One of the earliest descriptions of a social model was proposed within the context of social work and, as such, was intended as a pragmatic tool to encourage thinking that focused on the removal or lessening of identified barriers (Oliver et al., 2012).

A social model of disability can be contrasted with a *medical model* where the focus might be on identifying and treating impairment within the individual

⁴ The model was originally described in the first edition of this book in 1983.

(Hughes, 2010). Although both models might take an individual's goals and aspirations into account, these are more central to a social model (Hughes, 2010).

The two models can be seen as complementary rather than contradictory. However, within the context of this thesis, and in relation to the role of the educational psychologist, a social model is emphasised in acknowledgement of its potential for encouraging a focus on the identification and removal of barriers to children and young people with diagnoses of ASD participating as fully as they might wish in mainstream education. Thus, a social model of disability will recognise, for example, that the social difficulties that a child with a diagnosis of ASD might encounter within the school environment might be addressed by changes to the environment itself rather than being seen as requiring only social skills training or as being intractable.

1.3 A Note on Terminology

Autism has many names both “official” and cultural, with different people favouring different terms (see, for example, Kenny et al., 2015). As the current research focuses on the experiences of mothers whose daughters have been given a diagnosis, the current diagnostic terminology of DSM-5 (APA, 2013) will usually be used, namely autism spectrum disorder (ASD). However, within the literature review, the vocabulary will also reflect usage in the articles under discussion. Where children and young people are referred to as “with ASD”, this is to be understood as having a diagnosis of ASD.

This thesis is concerned primarily with girls who might be considered to fit an *Asperger's profile*, that is those without a clinically significant delay in language or cognitive development. Within the literature, the latter criterion is variously described as an absence of intellectual disability or impairment and, where

quantified, is taken to be an IQ score of at least 70. As the purpose of this literature review is neither to assign diagnoses nor infer IQ scores, this group will be referred to as *cognitively able*⁵ unless referring to terms used within the literature.

1.4 Description of Key Search Terms and Literature Sources

Initially, the following electronic databases were searched for literature relevant to this thesis: *PsycINFO* and *Web of Science*. Combinations of the following sets of search terms were used: autism⁶, Asperger's; diagnosis, diagnostic and statistical manual; diagnostic bias, differences, gender gap, human sex differences, sex differences; boys, females, gender, girls, human females, human males, sex, women; comorbidity; phenotype; caregiver, family, fathers, mothers, parenting, parents; coping, mental health, quality of life, wellbeing. An additional search was conducted on the *Educational Resources Information Center (ERIC)* using combinations of the following search terms: autism, diagnosis, educational psychology and school. Chosen literature was restricted to that published in English, in peer-reviewed journals, since 2006, that is the previous ten years. Details of searches are given in Appendix A. In addition, a hand search was conducted of the journal *Autism* from 2006 onwards as research has suggested that electronic searches alone are unlikely to identify all important sources (Greenhalgh & Peacock, 2005).

Exclusion criteria included: articles focused on preschoolers or adults; articles related to co-morbidity other than mental health; articles related solely to diagnostic experiences in non-Western cultures. Literature on diagnostic criteria, apart from historical overviews, was restricted to that relating to actual rather than proposed DSM-5 criteria. Literature related to comorbidities was restricted to that

⁵ This definition is used by Hiller et al. (2016).

⁶ Not all variations of search terms, e.g. autistic/autism, are listed here.

relating to children described as having diagnoses of Asperger's syndrome or high-functioning autism.

The literature review was restricted to research focusing on Western cultures as Kreiser & White (2014) draw attention to research suggesting that the core symptomology of ASD can differ between cultures, and between genders within cultures, due to differences in child-rearing practices (Amr, Raddad, El-Mehesh, Mahmoud, & El-Gilany, 2011). Further, the difficulty of utilising Western diagnostic instruments and the influence of cultural practices at a local level has been highlighted (Shefcyk, 2015) suggesting that the application of any research conducted outside the UK to the UK was problematic. Norbury & Sparks (2012), for example, highlighted the differences in diagnostic rates in the UK and Denmark, despite many superficial similarities between the two countries, as well as the differences in prevalence rates in different states of the USA.

The literature search was an iterative process in that literature identified as relevant to this thesis was used to refine the search terms. As suggested by Greenhalgh & Peacock (2005), further relevant literature was also found using the reference lists of identified articles. In total, 102 references are included in the literature review.

2 Development of the Diagnostic Criteria for ASD⁷

Infantile autism first appeared as a recognised diagnosis in the third edition of the DSM (APA, 1980) under the newly-coined class of *pervasive developmental disorders* (PDD). It presented a much more restricted concept of autism than current

⁷ This historical account draws on Barahona-Correa & Filipe (2016) and Volkmar & McPartland (2014).

definitions, requiring amongst other things, a “pervasive lack of responsiveness to other people” and “gross deficits in language development”. It also required onset before 30 months of age. In the revised third edition (APA, 1987), infantile autism was re-termed *autistic disorder* and, whereas previously all six diagnostic criteria had to be met, the idea of a triad of impairments was introduced where eight criteria had to be met from a total of sixteen across three categories: reciprocal social interaction; verbal and non-verbal communication; and restricted repertoire of activities and interests. This edition also introduced examples of such behaviours, such as talking about train schedules and spinning the wheels of toy cars; the implications of this will be discussed below.

In addition to the category of autistic disorder, the fourth edition of the DSM (APA, 1994) introduced the diagnosis of *Asperger’s disorder* and the concept of autism as a spectrum disorder. The three categories of impairment for autistic disorder remained broadly the same, although renamed, but the examples given of behaviour were fewer. The requirement for eight symptoms was reduced to six and the latest age at which symptoms must become apparent was extended slightly to three years. The new diagnosis of Asperger’s disorder used the same list of symptoms but required just two of the symptoms from the list of impairments in social interaction and one from the list of restricted repetitive and stereotyped patterns of behaviour with no overall additional threshold number of symptoms beyond these. Further, a diagnosis of Asperger’s disorder did not include the category of communication impairment and instead required that there was no clinically significant delay in language or cognitive development; no age was given by which impairment should become apparent. This edition also included the classification of *pervasive developmental disorder not otherwise specified* (PDD-

NOS) which included “‘atypical autisms’ – presentations that do not meet the criteria for autistic disorder because of late age of onset, atypical symptomatology, or subthreshold symptomatology, or all of these.” The criteria for *childhood autism* in ICD-10 (WHO, 1992) are broadly the same as those for autistic disorder in DSM-IV (Esler & Ruble, 2015) and ICD-10 similarly includes a classification of “atypical autism” (Brukner-Wertman, Laor, & Golan, 2016).

The fifth, and most recent, edition of the DSM (APA, 2013) replaced the concept of PDD with that of *autism spectrum disorder*⁸ whilst removing the specific diagnoses of autistic disorder, Asperger’s disorder and PDD-NOS as well as other less common diagnoses that fell within the PDD classification. The categories of social interaction deficits and communication deficits were merged into one, *social communication and social interaction* (SC&I), recognising the interrelation between these domains (Buxbaum & Baron-Cohen, 2013). Although this reduced the triad of impairments to a dyad, individual symptoms remain largely unchanged (Esler & Ruble, 2015) with the category of *restricted, repetitive patterns of behaviour* (RRB) now including sensory behaviours. In addition, a series of five descriptors was introduced that might be applied to a diagnosis: known etiological factors; severity; presence of intellectual impairment; presence of language impairment; and presence of catatonia. A new diagnosis of *social (pragmatic) communication disorder* was added to the DSM-5 which includes difficulties with pragmatic language and the social use of both verbal and non-verbal communication but does not include RRB.

Justifications for the more recent changes include the view that disentangling social and communication deficits was problematic at a clinical level (Volkmar & Reichow, 2013), a belief supported by studies using factor analysis which suggest

⁸ Esler & Ruble (2015) note, however, that the term was first proposed by Happé & Frith (1991).

that symptoms could not reliably be grouped into three categories (Harstad et al., 2015; Mandy, Charman, & Skuse, 2012). It has also been argued that the subtypes of PDD outlined in DSM-IV could not be reliably defined and had limited value in either predicting a child's needs or in suggesting ways to meet those needs (Esler & Ruble, 2015). A further argument in favour of the changes, which might be particularly pertinent to girls, is that the removal of a deficit or delay in expressive language as a symptom to be replaced by a descriptor, reflects the heterogeneity both of language skills and the development of those skills in children with ASD (Grzadzinski, Huerta, & Lord, 2013).

These changes to the diagnostic criteria are not without their issues, with some concerns having particular implications for cognitively able girls in terms of diagnosis and in terms of developing our understanding of the spectrum. Hiller, Young, & Weber (2014) found that children who met the criteria for PDD-NOS under DSM-IV were the group most likely not to meet the new diagnostic criteria⁹. Although they did not find a statistically significant difference between the rate at which girls and boys were affected, they suggest this might have been because the research lacked statistical power, a perhaps not uncommon problem given the relatively small number of girls in many studies. As will be discussed below, this might arise from the way in which the diagnostic criteria for both SC&I (Head, McGillivray, & Stokes, 2014; Hiller et al., 2014) and RRB (Dworzynski, Ronald, Bolton, & Happé, 2012; Kreiser & White, 2014) are applied to girls.

If children with a particular profile no longer meet diagnostic criteria despite difficulties, this may compound the broader issue of the visibility of girls more

⁹ DSM-5 criteria state that those with a "well-established" DSM-IV diagnosis should automatically be given an ASD diagnosis under DSM-5 so this would only affect new diagnoses.

generally within autism research (Shefcyk, 2015), and cognitively able girls in particular. Although broadly welcoming the changes in DSM-5, Buxbaum & Baron-Cohen (2013) note that “high-functioning individuals with *superficially* very good social skills” (p.11, emphasis added), a group likely to contain a disproportionate number of girls (Dworzynski et al., 2012) are at particular risk of not meeting diagnostic criteria despite genuine difficulties (Hiller et al., 2014; Turygin, Matson, Beighley, & Adams, 2013). It could be argued that this will continue to make it difficult for cognitively able girls to stand out from the statistical noise of the entire spectrum, where generalisations about ASD, whilst statistically true, may not reflect their behaviours or experiences. See, for example, Linton, Kreck, Sensui, & Spillers (2014) who state that children “typically receive initial diagnoses” under the age of six (p.68), a statistic that does not reflect the experience of cognitively able girls, and Bauminger, Solomon, & Rogers (2010) who include just four girls in a sample of seventy-seven children. It may also have a deleterious effect on individuals and their families if this leads to their needs not being met (Buxbaum & Baron-Cohen, 2013).

A further, not unrelated, point of view is offered by Linton et al. (2014) who argue that the removal of Asperger’s as a diagnosis has important implications for identity in cognitively able populations, if the typical person with a diagnosis of ASD is seen as either a boy, or a girl with intellectual disability.

3 The Female Phenotype

It has been argued that ASD has a distinct female phenotype (Kopp & Gillberg, 2011; Mandy, Chilvers, et al., 2012; Van Wijngaarden-Cremers et al., 2014) and that “most of what we believe we know about autism is actually about males with autism” (Thompson, Caruso, & Ellerbeck, 2003, p.351, cited in Haney,

2015). However, this apparently distinct female phenotype may be difficult to describe as girls often form a minority of research participants or are excluded from research altogether (Head et al., 2014; Mandy, Chilvers, et al., 2012). The difficulty of describing the female phenotype compared to the male is further compounded by changing definitions of ASD (Honda, 2013), the heterogeneity of children and young people with the diagnosis (Dworzynski et al., 2012; Giarelli et al., 2010; Solomon et al., 2012) and the heterogeneity of both participants and methodologies across studies (Mandy, Chilvers, et al., 2012). Not only might participants in one study differ from those in another on dimensions such as age and cognitive ability but, frequently, research pertaining to younger age groups tends only to include those who have been diagnosed at a young age thus potentially presenting an incomplete account (Hiller et al., 2016). This makes it difficult to describe the female phenotype with any certainty and difficult to evaluate contradictory findings.

Given these limitations, this section aims to provide a brief summary of the reported differences between girls and boys with ASD. The implications of these differences in relation to diagnosis rates will be discussed below and it should be remembered that these findings typically relate to children and young people with diagnoses of ASD and might exclude more undiagnosed girls than undiagnosed boys.

In a review article, Rivet & Matson (2011) suggest that one of the most consistent findings is that girls with ASD typically have lower IQ scores than boys. Although this is perhaps not surprising given that the ratio of boys to girls with ASD is higher amongst cognitively able children, the finding also holds good when those with and without intellectual disability are considered separately.

In terms of core symptomology, two other commonly-reported findings are

that diagnosed girls have fewer difficulties in SC&I than boys (Mandy, Chilvers, et al., 2012; Solomon et al., 2012) and either a lower incidence of, or less severe, RRBs (Hiller et al., 2014; Mandy, Chilvers, et al., 2012). As research explored below will show, however, this might reflect, amongst other things: a misunderstanding of the social interactions of girls with ASD; a male-centric bias in assessment instruments; and different social expectations about, and hence socialisation of, girls and boys more generally. This is not to deny the existence of a distinct female phenotype, however, only to suggest that the subtleties of this might be lost if explored at the level of current diagnostic criteria and using current diagnostic tools.

4 Explanations for the Disparity in Diagnosis Rates

It could be argued that explanations for the disparity in diagnosis rates between girls and boys form their own spectrum. At one end are explanations predicated, in part at least, on the idea that different diagnosis rates reflect a “genuine” difference in the prevalence of ASD in girls and boys and which tend to explore biological factors; at the other end are explanations suggesting that, for cultural and historical reasons, behaviours associated with ASD are under-identified in girls. These two ends of the spectrum are not mutually exclusive and in between lies a range of explanations, such as those based on differences between girls and boys in social communication and interaction, where biological and cultural factors perhaps interact.

4.1 Biological Explanations

A detailed overview of evidence for a biological basis to ASD is beyond the scope of this literature review. However, one theoretical model will be briefly outlined together with evidence for the role of genetics in gender differences in ASD

to highlight the complexity of biological explanations.

Baron-Cohen et al. (2011) have proposed the concept of the extreme male brain. This model suggests that, typically, males have a tendency to systematise and females to empathise. Further, in ASD, the tendency to systematise is exaggerated and the tendency to empathise reduced making males more likely to show behaviours associated with ASD. Both genetic and hormonal factors have been explored as explanations for this (for example, Carter, 2007; Ingudomnukul, Baron-Cohen, Wheelwright, & Knickmeyer, 2007; Szatmari et al., 2012).

Two genetic models provide explanations of the mechanism by which genetic factors might lead both to the discrepancy in diagnosis rates between girls and boys and to the tendency for girls who are diagnosed to be more severely affected. On one hand are models suggesting that females require a greater genetic load to be affected; on the other hand models suggesting that greater genetic variability in males allows for more common but milder symptoms (Solomon et al., 2012). These explanations are not incompatible. In effect, biological factors might protect girls from ASD (Hiller et al., 2016) but when the genetic load is sufficiently high, they are disproportionately affected (Solomon et al., 2012).

The evidence for greater genetic loading in girls is mixed. Szatmari et al. (2012), for example, reasoned that if girls with ASD carried a greater genetic load than boys, it followed that a boy with ASD in a family with girls with ASD would, on average, share that greater genetic load. They hypothesised that, as a consequence, boys with ASD in families with girls with ASD would have higher scores on measures of ASD symptoms than boys with ASD who were not in a family with girls with ASD. Their findings bore this out for repetitive behaviour but not for social reciprocity, lending some support to the theory but also suggesting that there

is more to ASD than genetics.

However, taking a different approach, Goin-Kochel, Abbacchi, & Constantino (2007) found no greater incidence of ASD in the families of girls with ASD compared to the families of boys with ASD as might be predicted from the idea that girls carry a greater genetic load. However, their data were based on parental report of familial incidence or suspicion of ASD and such judgements might have been influenced by the presentation of ASD in their own child. Thus, parents of children with less severe difficulties, where girls are less represented, might have been more likely to find similarities between their children and close relatives than parents of children with more severe difficulties, where girls are more represented.

Given current understanding, biological factors are perhaps too complex, and ASD itself too variable, to provide a definitive explanation of sex differences in diagnosis rates. As Dworzynski, Ronald, Bolton, & Happé (2012) note, there are currently no biomarkers which can aid diagnosis of ASD. Therefore, such explanations are, from an educational psychology perspective, interesting more than useful and leave open the possibility of other explanations, which can both challenge and complement these biological insights.

4.2 Historical Explanations

Before exploring some of the behavioural explanations for the discrepancy in diagnosis rates, it is important to explore historical explanations as these provide a useful context in which to evaluate the validity of available research.

4.2.1 Diagnostic criteria

Several researchers cite the fact that Kanner's early work describing cases of autism included just three girls and Asperger's none (Goldman, 2013; Gould & Ashton-Smith, 2011; Van Wijngaarden-Cremers et al., 2014). Further, however,

Haney (2015) notes that Asperger's original cases were referred for externalising behaviours: "overtly aggressive behaviors, opposition to authority, and inappropriate conduct in school and at home" (Asperger, 1991, cited in Haney, 2015, p.398), thus excluding those with more passive behaviours. Despite revisions to the diagnostic criteria, it has been argued that the original focus on boys whose behaviour presented difficulties continues to lead to ascertainment bias (Hiller et al., 2014; Van Wijngaarden-Cremers et al., 2014) as study of those who are already identified as having ASD is typically used to refine the diagnostic criteria further (Andersson, Gillberg, & Miniscalco, 2013; Constantino & Charman, 2012; Dworzynski et al., 2012; Head et al., 2014). Prior to DSM-5, for example, symptoms had to have been present before the age of three, a requirement now removed (Esler & Ruble, 2015). This might have reflected the symptomology of easier-to-diagnose children, that is girls with intellectual disability and boys, and perpetuated some under-recognition of ASD in cognitively able girls. This fact is seemingly acknowledged in the DSM-5 suggestion that impairment might be masked through, for example, compensation strategies (Esler & Ruble, 2015; Head et al., 2014).

4.2.2 Diagnostic tools

A corollary of the male-centricity of diagnostic criteria is that diagnostic tools also reflect the presentation of ASD in boys and are validated through research on boys (Haney, 2015; Kreiser & White, 2014). Kreiser & White (2014) argue that *The Autism Diagnostic Observation Schedule* (ADOS, Lord et al., 2000), for example, might lack sufficient sensitivity to detect conversational difficulties obvious in more complex social interactions and that girls particularly may have sufficient ability in basic conversation to appear not to struggle.

It is argued that diagnostic criteria and tools influence the expectations of

both clinicians and those in a position to refer children to clinicians (Dworzynski et al., 2012; Gould & Ashton-Smith, 2011; Kreiser & White, 2014). Thus, the inclusion of “train schedules and spinning the wheels of toy cars” in DSM-III-R might continue to lead clinicians to look for these and similar examples and overlook other relevant behaviours.

4.2.3 Research orphans

As noted above, it is argued that these factors combine to mean girls are at risk of becoming “research orphans” (Shefcyk, 2015, p.131), that is under-represented in research. Hiller et al. (2014) argue that this can explain why few behavioural differences between girls and boys are reported in studies which only include children already diagnosed. Further, where girls are included, they may not be representative of all girls with diagnoses as the clinical samples often used are skewed towards girls with more severe difficulties (Kreiser & White, 2014).

As will be discussed below, cognitively able girls might be likely to be diagnosed later than boys (Begeer et al., 2013; Rutherford et al., 2016; Siklos & Kerns, 2007) and this is also likely to mean their absence from research literature focusing on younger children (Hiller et al., 2016).

4.3 Behavioural Explanations

As noted above, ASD is diagnosed on purely behavioural characteristics (Dworzynski et al., 2012; Lai, Lombardo, Chakrabarti, & Baron-Cohen, 2013; Tanguay, 2011). This section will discuss how differences in the actual or perceived behaviour of girls and boys extend our understanding of the female phenotype and might lead to under-identification of relevant behaviours in girls. It will first consider

behaviours related to diagnostic criteria¹⁰ and then other behaviours.

As will become apparent, there are two common difficulties in interpreting this research. Firstly, the female phenotype is itself heterogeneous. Although cognitively able girls are the focus of this thesis, their numbers are small compared to girls overall with ASD whose numbers are in turn small compared to all children with ASD (Latif & Williams, 2007; Whiteley et al., 2010). Van Wijngaarden-Cremers et al. (2014) note that, relatively speaking, girls with low IQ scores are over-represented in ASD research compared to cognitively able girls. As intellectual disability is associated with greater severity of both SC&I and RRB, isolating findings related solely to cognitively able girls can be difficult.

Secondly, as noted above, research is only as sensitive as the research instruments used and some may not be sensitive to the behaviours seen in cognitively able girls (Andersson et al., 2013; Constantino & Charman, 2012; Dworzynski et al., 2012; Head et al., 2014). So when, for example, Holtmann, Bölte, & Poustka (2007) report that “no note-worthy differences exist between males and females with high-functioning autism in respect to autism core symptoms” (p.365), this might reflect a male-centric bias in the standardised measures employed.

4.3.1 Social communication and interaction

Typically, where differences are reported in the social communication and interaction (SC&I) of girls and boys with ASD, girls are found to have superior skills, particularly if cognitively able. Research reports, for example, that girls are more likely to initiate friendships (Head et al., 2014); to have a best friend (Kopp & Gillberg, 2011); and to be more pro-social (Dworzynski et al., 2012; Mandy,

¹⁰ This distinction is somewhat subjective in that research cited may refer to earlier diagnostic criteria or to none at all. Equally, a given behaviour may not neatly fit just one category.

Chilvers, et al., 2012). However, other research has found no statistically significant differences (Holtmann et al., 2007; May, Cornish, & Rinehart, 2014; Mayes & Calhoun, 2011; Solomon et al., 2012; Szatmari et al., 2012). Hiller et al. (2014) concludes that “evidence of sex differences in the social and communication domain have [sic] remained inconsistent” (p.1382).

However, the debate is more complex than simply deciding whether or not a difference exists. The notion of a distinct female phenotype for ASD suggests a third alternative: the profile of SC&I in girls with ASD is different from that of boys. This position argues that concluding that girls’ skills are either superior or identical risks contributing to the disparity in diagnosis rates (Mandy, Chilvers, et al., 2012).

Where no differences are identified, it has been suggested, as outlined above, that the tools used might lack the refinement to detect subtle differences and difficulties in girls’ social behaviour. Williams et al. (2008), for example, proposed adding questions to *The Childhood Autism Spectrum Test* (CAST¹¹, Scott, Baron-Cohen, Bolton, & Brayne, 2002) to explore difficulties such as “anxiety in unpredictable social situations” (p.1736) to increase its sensitivity to difficulties experienced by girls. A further suggestion is that although girls and boys might score similarly on a given criterion, they might meet the criterion in the different ways. Hiller et al. (2014) compared girls and boys with a DSM-IV diagnosis of autism against DSM-5 criteria, finding that being able to engage in typical reciprocal conversation meant a child was 14 times more likely to be a girl. This has implications both for the diagnosis of girls and for our understanding of the female phenotype. However, as Hiller et al. (2014) note, merely comparing girls and boys only tells us how they differ, it does not itself lead to a description of the female

¹¹ This was originally named the Childhood Asperger Syndrome Test (Dworzynski et al., 2012).

phenotype: only 17% of the girls in their sample were able to engage in typical reciprocal conversation so although it represented a difference at a statistical level, it was not typical of the female phenotype. Research which focuses on girl/boy differences, however robust the findings, risks inadvertently promoting a view of the female phenotype as a variant of the male and somehow atypical.

It has further been suggested that when differences are reported, which as noted above typically suggests girls are less affected, this might mask genuine difficulties. Kopp & Gillberg (2011), for example, report that in a clinical sample girls were less likely than boys to lack a best friend. They note that this could reflect the typical gender patterns of ordinary childhood friendships which make it easier for a girl to have a single friend rather than having to negotiate group friendships as boys might. This, they argue, might overlook the difficulties girls could have within that friendship, such as a need to be in control and a lack of reciprocity.

The difference in the way girls and boys socialise is also evident at a motivational level. There is evidence that girls with ASD are more likely to want to fit in than boys, with carer reports indicating that girls have a greater desire to be liked by peers and are less likely to isolate themselves (Hiller et al., 2016). More social contact would afford girls more opportunities to practise strategies such as mimicking which is a commonly-reported social strategy in cognitively able girls (Attwood, 2006; Buxbaum & Baron-Cohen, 2013; Hiller et al., 2016).

There is a range of research evidence supporting the idea of girls having superficial skills that either deliberately or inadvertently mask difficulties. Head et al. (2014) found that the gap between children's friendship skills as measured by the *Friendship Questionnaire* (Baron-Cohen & Wheelwright, 2003) and parental reports of their friendship skills is greater for girls with high-functioning autism than for

boys, with all children with ASD typically rated as having poorer friendship skills by parents. The questionnaire assesses what children think they should do rather than actual behaviour, suggesting that girls might have a theoretical understanding of friendships without the ability to put this into effective practice (Head et al., 2014). Complementing this finding, it has been reported that girls can have social skills which they are unable to apply in different contexts (Haney, 2015) and that they might, for example, be able to use social gestures but not be able to understand and interpret them (Hiller et al., 2014). These findings could suggest that girls' communication difficulties might be less noticeable to adults and explain why teachers in one study were found to be three times less likely than clinicians to have concerns about girls' conversation skills (Hiller et al., 2014).

The evidence presented here, which includes the overt behaviour of girls, motivational factors, imitation and masking, the transferability or otherwise of skills across contexts and discrepancies between espoused and practical knowledge of friendship skills, provides a complex picture of ways in which girls' SC&I might be different from that of boys. These differences appear to be at a systemic level rather than just at the level of individual symptoms and behaviours and suggest that a male-centric view of ASD might lead to an under-identification of relevant behaviours in girls.

4.3.2 Restricted, repetitive patterns of behaviour

Arguments for the way that understanding of restricted, repetitive patterns of behaviour (RRB) might contribute to diagnostic disparities are similar to those for SC&I although the evidence for differences in the presentation of girls and boys in this domain is perhaps more consistent. This section will focus mainly on one of these behaviours, "highly restricted, fixated interests" (APA, 2013).

In a study matching diagnosis and comparing behaviour, boys with ASD have been found to have higher *scores* of RRB than girls which included unusual preoccupations, circumscribed interests, repetitive use of objects or interest in parts of objects (Szatmari et al., 2012); this finding of greater severity is supported by a meta-analysis (Van Wijngaarden-Cremers et al., 2014). Boys with ASD have also been found to have a higher *incidence* of RRB in terms of repetitive motor movements (May, Cornish, & Rinehart, 2016). Using *The Developmental, Dimensional and Diagnostic Interview* (3Di)¹², Mandy, Chilvers, et al. (2012) also found higher incidence of RRB in that boys were more likely to “have a large store of factual information” and line up toys (p.1308), with the latter finding supported by ADOS observations.

As with SC&I, critique of these findings has highlighted the dominance of the male phenotype in the development of diagnostic criteria, such as the example of “spinning the wheels of toy cars” in DSM-III-R, and questioned the validity of available screening tools in relation to the female phenotype (Van Wijngaarden-Cremers et al., 2014). Solomon et al. (2012) note that the *Repetitive Behavior Scale-Revised* (Bodfish, Symons, & Lewis, 1999), a screening tool used with parents suggests “trains, dinosaurs, and toy cars” (p.55) as examples of fixed interests, suggesting, perhaps uncontroversially, that these are stereotypical male interests.

Both anecdotal accounts (Attwood et al., 2006; Simone, 2010) and research suggest that girls typically have restricted interests which differ from those of boys. Interests that have been noted include animals, rocks, books, stickers or pens (Hiller et al., 2014); and drawing, science fiction novels and dolls (Kreiser & White, 2014).

¹² This is a computerised method of interviewing parents based on the *Autism Diagnostic Interview-Revised* (ADI-R, Lord, Rutter, & Le Couteur, 1994).

This appears to support the suggestion that the interests of girls are likely to be similar to those of typically developing girls (Gould & Ashton-Smith, 2011) and is perhaps also related to the observation that toys are made available to children by their parents (Kreiser & White, 2014) potentially limiting the opportunities of girls to become fixated on trains, dinosaurs and toy cars. It might also mean that whereas boys have, as Mandy, Chilvers, et al. (2012) report, a store of factual information, girls might instead have a store of information related to, for example, fictional characters (Attwood, 2015).

As with SC&I, the pattern of RRB in girls might contribute to the disparity in diagnosis rates in several ways: it might reflect lesser difficulties; it might reflect a bias against noticing fixated interests in girls; it might reflect the male bias in the description of the supposedly gender-neutral phenotype.

4.3.3 Externalising behaviours

Although the behaviours above reflect the core criteria for a diagnosis of ASD, it is recognised that the phenotype encompasses a wider range of behaviours (Mandy, Chilvers, et al., 2012) which might influence whether a child is referred to a clinician and whether that clinician explores the possibility of an ASD diagnosis (Hiller et al., 2016).

The evidence on externalising behaviour in girls with ASD suggests this may be a significant factor in determining whether a girl is referred to a clinician and whether she meets diagnostic criteria. In a study of British children, Dworzynski et al. (2012) found that teachers reported significantly more concerns about hyperactive behaviour for girls with ASD diagnoses compared to girls who scored similarly highly for autism traits on the CAST but had no diagnosis. The same pattern was not evident for boys where teachers reported similar concerns about externalising

behaviour for those both with and without diagnoses. Further, when comparing diagnosis rates among girls and boys with similarly high scores, they found girls were less likely than boys to meet DSM-IV diagnostic criteria for ASD unless they had additional intellectual or behavioural problems. This again suggests the possibility outlined above of gender biases in diagnosis criteria and screening tools (Dworzynski et al., 2012; Head et al., 2014) which will not be repeated here.

However, two further interpretations of these apparent behaviour differences have been proposed: one first suggesting how they might contribute to girls' difficulties going unrecognised; the second suggesting how they might explain genuine differences in prevalence.

Firstly, it has been argued that findings such as those of Dworzynski et al. (2012) noted above, that girls whose behaviour is a concern to teachers are more likely to have an ASD diagnosis than girls with similar CAST scores whose behaviour is not a concern, reflect the extent to which a child's struggles are recognised when the child becomes difficult for an adult to manage (Mandy, Chilvers, et al., 2012). This possibility is supported to an extent by Hiller et al. (2016) who retrospectively explored the pre-diagnosis concerns of parents whose children later received a diagnosis of ASD. Perhaps unsurprisingly, however, their results are somewhat nuanced as they found that externalising behaviours in social settings had been a parental concern for half the girls but only a quarter of the boys. This suggests at least two factors additional to the child's behaviour: the adult judging the behaviour and the setting in which the behaviour is judged, and hence whether a referral is made. Thus, social expectations about how girls do or should behave perhaps influence whether perceived behaviour is seen as problematic (Hiller et al., 2016; Holtmann et al., 2007) with identical behaviour in girls and boys

perhaps being judged as more or less manageable or acceptable according to social norms.

A second way in which the apparent behaviour differences might contribute to discrepancies in diagnostic rates is the extent to which they might reflect a genuine ability on the part of cognitively able girls with high levels of autism traits to cope in different settings (Dworzynski et al., 2012). This might limit a teacher's inclination to refer a girl, particularly given the finding noted above that teachers are typically less concerned about girls' language difficulties than parents, and might also limit the likelihood of clinicians considering ASD given the DSM-5 criterion that behaviours be evident across different settings. However, if it represents a genuine ability to cope, it could be argued that this is not problematic given the diagnostic criterion that symptoms cause significant impairment (Volkmar & McPartland, 2014). Thus it might be regarded as an explanation for different rates of prevalence.

However, Dworzynski et al. (2012) do not assert that girls are coping, only that it is a possibility and they recommend an exploration of mental health difficulties in similar populations to ascertain whether this is the case. It might also be relevant that Dworzynski et al. (2012) used data collected when participants were eight years old and it could prove valuable to look also at adolescent populations as it has been suggested that the apparently superior ability of girls to cope during the primary school years is lost towards the end of primary school when girls' social relationships become more complex (Attwood, 2015), a fact apparently acknowledged in DSM-5 criteria which state that symptoms may not be apparent until "social demands exceed limited capacities" (APA, 2013). A difficulty then potentially arises for girls if that ability to cope is lost quite suddenly and leaves

parents and teachers, and the girls themselves, without an understanding of what their needs are.

A further issue regarding coping is highlighted by Mandy, Chilvers, et al. (2012) who found that conduct scores derived from parental reports did not show the difference between girls and boys found in teacher reports. Mandy, Chilvers, et al. (2012) suggest this is because boys “have greater difficulties adapting to the school environment than do girls” (p.1311). However, in light of their finding that parents reported higher levels of internalising problems for girls, which will be discussed below, an equally reasonable conclusion is that boys and girls express their difficulties in adapting to the school environment in different ways.

4.3.4 Internalising behaviours

Internalising behaviours are common in adolescents with ASD (Mazefsky, Conner, & Oswald, 2010). Girls are perhaps at higher risk, although the arguments for why this might be so appear less developed than for other differences reported between girls and boys with ASD. How this might contribute to differences in diagnostic rates is also less clear.

Looking specifically at girls and boys with high-functioning autism¹³ in a matched-pairs design, Holtmann et al. (2007) found parental reports gave higher scores to girls for thought problems, social withdrawal and social problems although the groups did not differ in terms of core symptomology. Although they suggest their finding might reflect gender bias in parents if they have different expectations for girls, other recent research, using both parental- and self-report, has found similar results: cognitively able girls with ASD were found to be at elevated risk of

¹³ Defined here as an IQ \geq 70.

internalising psychopathology in adolescence¹⁴ (Solomon et al., 2012) and greater depressive symptoms in early adolescence¹⁵ (Oswald et al., 2016) than either boys with ASD or neurotypical girls, a finding that held good in both studies even where girls and boys showed identical levels of ASD symptoms.

Given the foregoing discussion on the potential under-identification of ASD behaviours in cognitively able girls, it is not clear whether these findings reflect the profile of girls with ASD *traits* compared to boys or the profile of girls with ASD *diagnoses* compared to boys. A comparison of girls above and below the diagnostic threshold in the manner of Dworzynski et al. (2012) is likely to be informative as this could suggest that internalising problems distinguish between girls who are and are not diagnosed as Dworzynski et al. (2012) originally found with intellectual and behavioural problems. However, it is equally possible that girls without diagnoses show identical or elevated levels of internalising behaviours.

It has been argued that internalising behaviours in girls can be overlooked in school (Esler & Ruble, 2015; Hiller et al., 2014), what Mandy, Chilvers, et al. (2012) describe as “the well-known phenomenon” (p.1311) that parents are better at detecting the internalising behaviours of their children than are schools. As such, although recognition of internalising problems could prompt referrals for girls, it is equally possible that a failure to recognise needs contributes to internalising behaviours. Kreiser & White (2014), for example, suggest that internalising may be the result of repeated experiences of failure arising from girls’ stronger desire to fit in, whilst Buxbaum & Baron-Cohen (2013) note that superficially good social skills of cognitively able girls can be used to “mask inner suffering” (p.11) both of which

¹⁴ Defined here as 12-18.

¹⁵ Defined here as ages 12-14 with *late adolescence* defined as 15-17.

could suggest unrecognised needs. These arguments are not incompatible, however, and the evidence for neither is currently strong.

4.4 Sociocultural Explanations

Sociocultural explanations have been implicit in much of the above discussion in terms of the expectations for how girls and boys with and without ASD diagnoses typically behave. However, there are additional arguments which suggest that these expectations are not only in the eye of the beholder as they judge specific incidents of behaviour but permeate social environments in ways which influence the phenotypic expression of ASD (Kreiser & White, 2014). This has implications for the discrepancy in diagnosis rates.

It has been suggested that the expectations parents have of social and communication skills in girls compared to boys means they are socialised in different ways. In deference to DSM-IV, Cheslack-Postava & Jordan-Young (2012) term this the *pervasive developmental environment* to emphasise the extent to which it permeates a child's life. They cite research suggesting, amongst other things, that girls and boys are provided with different toys, are exposed to different level of mutual eye-gaze from birth and are given different levels of encouragement to socialise, suggesting that this latter factor particularly might lead to girls developing better social skills which mask their ASD symptoms relative to boys. It could equally be argued, however, that greater pressure on girls to behave in a socially acceptable way (Begeer et al., 2013) would operate much as a social skills programme that might be put in place for a child and genuinely enable them to cope better, particularly in the early years when social demands are fewer (Attwood, 2015). Kirkovski, Enticott, & Fitzgerald (2013) note how the influence of cultural expectations on the ASD phenotype is highlighted by Amr et al. (2011) who found

different patterns of SC&I and RRB in girls and boys with ASD from three Arab countries from that reported in the Euro-American literature, a fact that they attribute to different cultural practices in relation to expectations of children's behaviour.

Kreiser & White (2014) note that sociocultural influences come from other children as well as adults and might contribute to less severe or different symptom presentation in girls. Kreiser & White (2014) suggest, for example, that girls with ASD may demonstrate less factual information because their peers do not like it, thus masking "interests that are abnormal in intensity" (APA, 2013). Further, Gould & Ashton-Smith (2011) propose that some girls might be "mothered" (p.35) by their peers whereas boys might tend to get bullied, again making it more difficult for adults to recognise girls' struggles and providing girls with opportunities to learn and practise masking and coping skills.

It is evident that sociocultural factors might provide protective factors for girls leading to fewer diagnoses but might equally contribute towards the masking of difficulties. It is also possible that some of those protective factors become less effective as social demands increase, contributing to later onset of difficulties and, hence, diagnosis.

5 Girls' Diagnostic Experiences

As outlined above, there are several reasons to suspect that behaviours associated with ASD might be under-identified in cognitively able girls. This section will explore evidence to suggest that cognitively able girls are typically diagnosed later than boys and that the process can take longer. It will also look at evidence that girls are more likely to be diagnosed with other psychiatric disorders than boys. Finally, evidence for the impact on parents will be examined. Although it might be

tempting to suggest a causal link to the explanations for the disparity in diagnosis rates outlined above, it is not possible to do so.

5.1 Later and Longer Diagnostic Process

Although there is some evidence that girls with intellectual disability are diagnosed at an earlier age than boys (Begeer et al., 2013; Giarelli et al., 2010), this does not appear to hold true among cognitively able girls. Precise figures are, however, difficult to obtain as much depends upon the ages of children in any given study: children who have not received a diagnosis by that age will not, by definition, be included and this might disproportionately affect girls. Further, published research either does not distinguish data for cognitively able children or perhaps lacks the power to detect a statistically significant difference. However, results from five published studies considered together suggest that, for cognitively able girls, the diagnostic process might take longer and that diagnosis might be made at a later age. These findings are summarised in Table 1; where possible, data are extracted that refer only to children with diagnoses of Asperger's. All data reflect statistically significant differences between girls and boys.

Table 1 Research into age at diagnosis and length of diagnostic process

Reference	N	Age of Participants	Mean age of diagnosis [Mean length of diagnostic process]		Population
			Girls	Boys	
Goin-Kochel et al. (2006)	101	Mean = 8.3 ¹⁶	8.9 [n/a]	7.0 [n/a]	Children with diagnoses of Asperger's from 5 countries including the UK
Siklos & Kerns (2007)	56	Mean = 7.98	6.1 [4.2]	4.8 [2.2]	Children with diagnoses of autism in Canada
Giarelli et al. (2010)	1497	8 year olds	No statistically significant differences in mean age of diagnosis or length of process		Children with diagnoses of autism in the USA
Begeer et al. (2013)	306	Range = 0-18	9.7 [2.2]	7.9 [1.4]	Children with diagnoses of Asperger's in the Netherlands
Rutherford et al. (2016)	31	Range = 10-18	15.4	14.2	Adolescents with diagnoses of ASD in Scotland
			[No statistically significant difference in length of process]		

A common limitation of this research relates to children who might be systematically excluded. Three of the studies, Goin-Kochel et al. (2006), Siklos & Kerns (2007) and Begeer et al. (2013), relied on voluntary recruitment via autism support groups which might have excluded particular socio-economic groups. This is pertinent to the present thesis as Goin-Kochel et al. (2006) found that higher levels of parental education and income were associated with higher satisfaction with the diagnostic process. Therefore, were the children of parents with lower educational attainment and income excluded, results might not be representative of the full range of diagnostic experiences. Begeer et al. (2013) acknowledge that their research did not include information on the socio-economic status of respondents and it is debatable whether the opportunity they offered to win a €50 book prize would be equally motivating to all potential participants.

¹⁶ This is the mean for all participants including those with diagnoses of autism and PDD-NOS.

This difficulty of excluding some groups was obviated by the more systematic sampling from clinical records used by Giarelli et al. (2010) and Rutherford et al. (2016). However, a number of factors suggest that the findings of Giarelli et al. (2010) are of limited relevance to cognitively able girls. Firstly, their sample includes only 8 year olds and therefore excludes those who will go on to receive diagnoses as older children. Secondly, it is noteworthy that their broader study included children without diagnoses of ASD who demonstrated behaviours consistent with DSM-IV criteria. This undiagnosed group was disproportionately female, 46% of all girls in the study compared to 41% of all boys, although the authors do not say whether this was statistically significant. Lastly, their data include children with cognitive disability and it is not possible to separate out those without such disability which might mask gender differences for the cognitively able group.

The study most relevant to the current research is perhaps, therefore, Rutherford et al. (2016). This research used a stratified random sample of diagnostic services across Scotland, inviting 16 of these to submit data on up to 10 of their most recent cases, and distinguished in the findings between those with autism and Asperger's diagnoses. Although there were only 31 adolescents in the Asperger's group, of whom just 11 were girls, it is noteworthy that the authors were still able to demonstrate a statistically significant difference in the age of diagnosis which in practical terms amounted to girls, on average, being diagnosed just over a year later than boys. The authors suggest that the lack of a statistically significant difference in length of process between girls and boys, which contradicts other research, may reflect an adherence to clinical guidelines and policy. This might suggest that, without such guidelines, girls are perhaps apt to be treated differently.

Although it is impossible to reach firm conclusions, these findings suggest that cognitively able girls are often diagnosed later than similar boys. Analysis of these studies also highlights the difficulty of obtaining precise data for cognitively able girls.

5.2 Other Diagnoses

A high incidence of psychiatric comorbidities is widely-reported in children with ASD relative to typically developing children. A recent study of general psychiatric co-morbidity among Finnish children and adolescents with higher-functioning autism spectrum disorders found that 68% had an additional psychiatric diagnosis compared to 12% in a typically developing control group (Reinvall et al., 2016).

The range of co-morbid conditions reported is broad. Compared to typically-developing controls, research using a range of measures including self-, parental- and teacher-report among children with Asperger syndrome or high-functioning autism, has reported higher rates of emotional disorders, attention deficit hyperactivity disorder (ADHD) and tic disorders (Reinvall et al., 2016); higher anxiety scores (Farrugia & Hudson, 2006); and higher levels of anxiety and depressive symptomology (Hammond & Hoffman, 2014). Taken individually, it is difficult to assess how far these findings can be generalised to wider populations of young people with diagnoses of ASD. These three studies combined assessed just 103 children and adolescents with ASD diagnoses, of whom only 16 were girls. Participants were recruited via a variety of services including clinics (Reinvall et al., 2016), support services (Hammond & Hoffman, 2014), and support groups and special schools (Farrugia & Hudson, 2006), and it is possible, therefore, that the children and young people represent those with higher levels of psychiatric

symptoms for which they or their parents were seeking help.

Little information is available on the general prevalence of co-morbid psychiatric conditions among cognitively able girls with ASD specifically. However, there is a limited amount of evidence that suggests girls are possibly at greater risk of some comorbid diagnoses than boys and might have more severe symptoms than boys. Among 9 to 16-year-olds with diagnoses of Asperger's or high-functioning autism in Finland, Mattila et al. (2010) reported at least one current co-morbid disorder in 74% of children and noted that the general functioning of girls, as measured by the Children's Global Assessment Scale (CGAS, Shaffer et al., 1983), was significantly lower than that of boys. This study has the strength of including a community-based, as well as a clinic-based, sample, the former identified by screening 81% of the 5484 eight-year-olds in the local hospital district. However, in common with many studies, the final number of participants was small with just four girls and six boys unique to the community-based group¹⁷. It is not possible to determine from the figures reported how many children were diagnosed as a result of this screening process so it is not possible to know how representative these ten children might be of a wider community sample.

A Dutch study exploring differences between clinically anxious children with and without diagnoses of high-functioning ASD (van Steensel, Bögels, & Dirksen, 2012) illustrates the difficulty of reaching firm conclusions about gender differences from small-scale studies. Overall, girls both with and without diagnoses of ASD scored higher than equivalent boys for total anxiety, specific phobia, and posttraumatic stress disorder symptoms but girls with ASD diagnoses were less likely than equivalent boys to meet the DSM-IV-TR criteria for a diagnosis of

¹⁷ A further two girls and six boys were in both community- and clinic-based groups.

generalised anxiety disorder. In addition to the possibility of lacking power to detect some gender differences, this study utilised a clinical sample. Given research discussed above highlighting the sub-clinical internalising behaviours of girls (e.g. Holtmann et al., 2007; Solomon et al., 2012; and Oswald et al., 2016), it is not clear that this would be equally representative of girls and boys with ASD diagnoses who are struggling with such symptoms.

Rather than comparing girls and boys with ASD diagnoses, other research has compared girls with ASD with typically developing controls suggesting that cognitively able girls with ASD are at greater risk of some disorders. Among 56 adolescent girls with Asperger syndrome, Kalyva (2009) reported significantly more eating problems than among controls as measured by both self- and parental-report. The number of participants was larger than many studies which include adolescent girls with Asperger syndrome and participants were matched for age and body mass index (BMI) with girls from among their own classmates.

Although Kalyva (2009) reported that her findings were consistent with studies conducted in the 1990s, it is not clear that the measure used, the Eating Attitudes Test-26 (Garner, Olmstead, Bohr, & Garfinkel, 1982), is as valid for those with diagnoses of ASD as it is for those without. For example, items on the test such as “cut my food into small pieces” and “take longer than others to eat my meals” may not be indicative of eating problems in people with ASD to the extent that they are in populations without ASD. As Kalyva (2009) noted, the controlled eating habits of anorexia can resemble the rigidity of ASD and this difficulty of distinguishing between disorders is also highlighted by Hammond & Hoffman (2014) who point out that the repetitive behaviours typical of ASD resemble those of anxiety. However, the findings of Kalyva (2009) do highlight the difficulty of

assessing with any certainty the extent to which children with ASD are misdiagnosed with other disorders, as alternative diagnoses prior to a diagnosis of ASD might reflect a co-vulnerability to these disorders (Mazzone, Ruta, & Reale, 2012).

There is a limited amount of both anecdotal and more formal empirical evidence to suggest misdiagnosis could be higher in girls. Gould & Ashton-Smith (2011), for example, suggest that girls and women referred to *The Lorna Wing Centre for Autism* for ASD assessment are typically referred via mental health services with diagnoses including obsessive compulsive disorder, eating disorders, personality disorders, selective mutism, anxiety and depression. They suggest some of these are misdiagnoses. They do not offer, however, an indication of the incidence of these disorders in girls and women or a suggestion of how this compares to boys and men. Similarly, Aggarwal & Angus (2015) explored psychiatric symptoms in older adolescents and young adults referred for assessments for ASD, noting that among a small sample of twenty young people, females were disproportionately represented, an observation they suggested was due to the “unmasking” (p.122) of girls and young women as a result of their psychiatric symptoms. However, neither article provides evidence of the likely incidence of misdiagnosis amongst girls and women with ASD more widely.

More systematic findings are offered by Hiller et al. (2014) who looked at a much younger sample: children with a mean age of 8. Among 69 girls and 69 boys with high-functioning ASD, they found girls were significantly more likely to have been diagnosed with anxiety disorders, 32.5% of girls compared to 7.0% of boys, and less likely to have been diagnosed with ADHD or significant behaviour problems, 25.0% compared to 74.4%. This might not reflect incidence in the UK as the children had all been referred to a private clinic in the US for ASD assessment.

However, it suggests a useful area of further research.

Given the possibility of later diagnosis of ASD in cognitively able girls and the increased risk of internalising behaviours in girls, it has been suggested that other diagnoses might reflect the consequences of some girls not having their needs recognised which might be compounded by undiagnosed girls not having an explanation for their difficulties (Kreiser & White, 2014). Further, where other disorders are diagnosed, incorrectly or otherwise, girls are unlikely to be offered treatments adapted to their needs if difficulties associated with ASD are not recognised (Kreiser & White, 2014; van Steensel et al., 2012).

Although the evidence presented here is consistent and accords with what is known about internalising behaviours in girls with ASD, much of it does not represent general populations of children with ASD; and it is not clear whether it represents cognitively able populations. However, it does provide some evidence that girls with ASD have a high incidence and level of comorbid psychiatric symptoms.

5.3 The Impact of the Diagnostic Process on Parents

Parenting a child with autism is widely reported to be more stressful than parenting a typically developing child (see, for example, Firth & Dryer, 2013; Foody, James, & Leader, 2014; Montes & Halterman, 2007; Vasilopoulou & Nisbet, 2016). However, these studies focus on parents' day-to-day lives. The limited research that focuses on the diagnostic process tends to include the parents of children with intellectual disability across a wide age range. However, it is possible to distinguish, within this research, a number of factors associated with being a cognitively able girl with ASD that are also associated with higher levels of stress for parents during the diagnostic process.

Two large-scale studies have explored diagnostic experiences of parents in the UK (Crane, Chester, Goddard, Henry, & Hill, 2016; Howlin & Moore, 1997). In the most recent of these, exploring the views of 1012 parents recruited via the National Autistic Society and autism-related services, 56% rated the process as ‘very’ stressful and 28% as ‘quite’ stressful (Crane et al., 2016, p.158). The overall figure is not dissimilar to the 82% who found the diagnostic process for ASD stressful in a Canadian study (Siklos & Kerns, 2007), although the latter was a much smaller study comprising just 56 parents.

It is difficult to quantify “stressful” as measured as part of a wide-ranging questionnaire, rather than a standardised tool, and “very stressful” could possibly include a broad range of experiences. However, several more objective factors have been associated with parental stress. Crane et al. (2016) found that parental satisfaction with the diagnostic process was inversely associated with levels of stress during the process and increased stress was, in turn, associated with delays in diagnosis and the increased age of the child. The authors suggest that the parents of children with Asperger’s syndrome might be particularly at risk of later and delayed diagnosis but report that identifying them reliably within a questionnaire survey is problematic due both to the reliance on parental report and to changes in diagnostic practice and criteria. Elsewhere, an association between earlier diagnosis and increased parental satisfaction has been reported (Sansosti, Lavik, & Sansosti, 2012; Siklos & Kerns, 2007). However, both studies were small scale and in the case of Sansosti (2012) only included children aged seven and under. Therefore, it is again not possible to differentiate the experiences of parents of cognitively able children, whether girls or boys. However, as both delays and increased age at diagnosis are associated with cognitively able girls, this suggests that their parents may be at risk

of finding the diagnostic process more stressful. There might also be a link with a perceived lack of support if girls' needs are not understood.

Other factors that might make the diagnostic journey stressful have been reported in a qualitative study in Australia which explored the more general experiences of five mothers of daughters with ASD diagnoses using semi-structured interviews (Cridland, Jones, Caputi, & Magee, 2014). All mothers were reported to have found the diagnostic process “challenging” (p.1264), with four of the five believing this was more so for girls. Interestingly, some of the factors identified by the mothers as contributing to making the diagnostic process stressful reflect the arguments presented above for the possible under-identification of behaviours associated with ASD in cognitively able girls¹⁸: “presentation of symptoms, imitation of social behaviour, higher incidence of ASD in boys, misdiagnosis, and reluctance from health professionals [...] to provide a formal diagnosis” (p.1264). By using semi-structured interviews to explore experiences within a qualitative design, Cridland et al. (2014) gave participants the opportunity to control the direction of the research to an extent, rather than relying on the preconceived ideas of the researcher, and to elaborate answers.

Research suggests that the stress of parenting a child with a diagnosis of ASD might fall disproportionately on mothers. In a review article exploring research from the USA, Europe, Australia, the Middle East and Asia, Vasilopoulou & Nisbet (2016) found that, in nine out of twelve studies included, the quality of life of mothers, in terms of a range of factors including mental health, bodily pain, difficulties with work and participation in social activities, was significantly below

¹⁸ Cridland et al. (2014) do not report specifically on the cognitive profile of the daughters in their study. However, three had diagnoses of Asperger's, one a diagnosis of ASD and one of PDD-NOS.

that of fathers although the authors acknowledge that the sample sizes of fathers tended to be relatively small. These findings are supported by an Australian study of 73 mothers and 35 fathers where it was reported that mothers had significantly higher anxiety and depression scores than fathers, as measured by the Zung Self-Rating Anxiety and Depression Scales, and mothers reported being “stretched beyond their resources” more frequently than fathers (Bitsika, Sharpley, & Bell, 2013, p.533). Bitsika et al. (2013) did not report a statistically significant difference in the resilience score of mothers and fathers and suggest, therefore, that the differences in anxiety and depression scores might reflect traditional gender roles with mothers being responsible for more day-to-day involvement in their children’s lives whilst fathers take on other roles.

Although a lack of research means it is not clear whether the stress of the diagnostic process also falls disproportionately on mothers, this might be reflected anecdotally in a qualitative study of nine fathers’ experiences of parenting children with ASD in Ireland where “broadly speaking, fathers were not able to relate the minute details of their journey to a diagnosis and would often defer to their spouse if the investigator needed more clarification” (O’Halloran, Sweeney, & Doody, 2013, p.209). It should be noted, however, that not all parents find the diagnostic process stressful. In a qualitative study in Northern Ireland, a majority of the eleven mothers were reported to be “happy and satisfied with the diagnostic process” (Braiden, Bothwell, & Duffy, 2010, p.382). However, the children’s ages ranged from five to eleven, suggesting that, for some of the children at least, difficulties would have been apparent quite early; the gender of the children is not reported.

6 Rationale for Thesis

6.1 Rationale

The foregoing literature review has identified several issues related to the identification of behaviour associated with ASD in cognitively able girls. Although there is evidence for a biological basis to ASD (Baron-Cohen et al., 2011; Szatmari et al., 2012), it is diagnosed at the level of behaviour (Dworzynski et al., 2012) and there is strong evidence that both the diagnostic criteria and the diagnostic instruments derived from these have tended to reflect a phenotype of ASD associated with boys (Van Wijngaarden-Cremers et al., 2014; Williams et al., 2008).

There is evidence that the female phenotype differs from the male in sometimes subtle ways (Hiller et al., 2014). However, research on differences has often used existing diagnostic tools which may not capture the subtlety of these differences (Kopp & Gillberg, 2011). It also means that understanding of the female phenotype is sometimes developed in reference to the male: however, a statistically significant difference between girls and boys on a particular behaviour does not necessarily mean that this behaviour is typical of the female phenotype (Hiller et al., 2014). Therefore, the female phenotype is not well understood and the nature of girls' difficulties is sometimes not recognised by teachers (Hiller et al., 2014; Mandy, Chilvers, et al., 2012) or clinicians (Kreiser & White, 2014).

The difficulties in identifying ASD in cognitively able girls might be contributing to girls' needs being identified and understood at a later age (Begeer et al., 2013; Goin-Kochel et al., 2006; Rutherford et al., 2016) and the process of diagnosis sometimes taking longer (Begeer et al., 2013; Siklos & Kerns, 2007), both factors associated with increased parental stress (Siklos & Kerns, 2007). There is also evidence that this stress might be falling disproportionately on mothers (Bitsika

et al., 2013; Vasilopoulou & Nisbet, 2016).

In general, there is a lack of research that focuses on cognitively able girls with ASD. Further, although teacher reports are often included in studies related to the symptomology of ASD (Dworzynski et al., 2012; Hiller et al., 2014; Mandy, Chilvers, et al., 2012) and the importance of gathering information from schools is recognised (Posserud, Lundervold, & Gillberg, 2006), there is perhaps limited understanding of the role of schools in contributing to the diagnostic process.

This thesis aims, therefore, to explore the diagnostic experiences of mothers of cognitively able daughters with ASD in a broad sense that might include the school system. In particular, it is concerned with the quality of those experiences and what they might mean for participants.

6.2 Research Questions

The National Institute for Health and Care Excellence (2011) recommends the establishment of local pathways for the diagnosis of ASD and provides flowcharts mapping the process of diagnosis from the point at which parents first contact health professionals. However, this thesis is concerned not so much with a narrowly-defined clinical *process* of diagnosis as with what happens in the wider school and home environments where concerns might become apparent and where an educational psychologist might become involved in the search for solutions. Therefore, the term *journey* is used to emphasise the idiographic nature of mothers' experiences.

The research questions are:

- How do mothers of girls in mainstream schools experience the diagnostic journey of their daughters from initial concerns to a

diagnosis of ASD?

- How do mothers experience the outcomes of this diagnostic journey?

7 References

- Aggarwal, S., & Angus, B. (2015). Misdiagnosis versus missed diagnosis: Diagnosing autism spectrum disorder in adolescents. *Australasian Psychiatry*, 23(2), 120–123.
- Amr, M., Raddad, D., El-Mehesh, F., Mahmoud, E., & El-Gilany, A. (2011). Sex differences in Arab children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5, 1343–1350.
- Andersson, G. W., Gillberg, C., & Miniscalco, C. (2013). Pre-school children with suspected autism spectrum disorders: Do girls and boys have the same profiles? *Research in Developmental Disabilities*, 34(1), 413–422.
- APA. (1980). *Diagnostic and statistical manual of mental disorders (3rd edition)*. Washington, DC: American Psychiatric Publishing.
- APA. (1987). *Diagnostic and statistical manual of mental disorders (3rd edition revised)*. Washington, DC: American Psychiatric Publishing.
- APA. (1994). *Diagnostic and statistical manual of mental disorders (4th edition)*. Washington, DC: American Psychiatric Publishing.
- APA. (2013). *Diagnostic and statistical manual of mental disorders (5th edition)*. Arlington, VA.: American Psychiatric Publishing.
- Asperger, H. (1991). Autistic psychopathy in childhood (U. Frith, Trans.). In U. Frith (Ed.), *Asperger and his syndrome* (pp. 37–92). Cambridge: Cambridge University Press.
- Attwood, T. (2006). The pattern of abilities and development of girls with Asperger's syndrome. In T. Attwood & T. Grandin (Eds.), *Asperger's and girls*. Arlington, Texas: Future Horizons, Inc.
- Attwood, T. (2015). *The complete guide to Asperger's syndrome (Revised)*. London:

Jessica Kingsley Publishers.

Attwood, T., Faherty, C., Wagner, S., Wrobel, M., Bolick, T., Myers, J. M., ...

Grandin, T. (2006). *Asperger's and girls*. Arlington, Texas: Future Horizons, Inc.

Baldwin, S., & Costley, D. (2016). The experiences and needs of female adults with high-functioning autism spectrum disorder. *Autism*, 20(4), 483–495.

Barahona-Correa, J. B., & Filipe, C. N. (2016). A concise history of Asperger syndrome: The short reign of a troublesome diagnosis. *Frontiers in Psychology*, 6, 1–7.

Baron-Cohen, S., & Wheelwright, S. (2003). The Friendship Questionnaire: An investigation of adults with Asperger syndrome or high-functioning autism, and normal sex differences. *Journal of Autism and Developmental Disorders*, 33(5), 509–17.

Baron-Cohen, S., Lombardo, M. V, Auyeung, B., Ashwin, E., Chakrabarti, B., & Knickmeyer, R. (2011). Why are autism spectrum conditions more prevalent in males? *PLoS Biology*, 9(6).Bauminger, N., Solomon, M., & Rogers, S. J. (2010). Externalizing and internalizing behaviors in ASD. *Autism Research*, 3, 101–112.

Begeer, S., Mandell, D., Wijnker-Holmes, B., Venderbosch, S., Rem, D., Stekelenburg, F., & Koot, H. M. (2013). Sex differences in the timing of identification among children and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 43(5), 1151–1156.

Bitsika, V., Sharpley, C. F., & Bell, R. (2013). The buffering effect of resilience upon stress, anxiety and depression in parents of a child with an autism spectrum disorder. *Journal of Developmental and Physical Disabilities*, 25(5),

533–543.

Bodfish, J. W., Symons, F. J., & Lewis, M. H. (1999). The repetitive behavior scale-revised. *Western Carolina Center Research Reports*.

Braiden, H.-J., Bothwell, J., & Duffy, J. (2010). Parents' experience of the diagnostic process for autistic spectrum disorders. *Child Care in Practice*, 16(4), 377–389.

Brukner-Wertman, Y., Laor, N., & Golan, O. (2016). Social (pragmatic) communication disorder and its relation to the autism spectrum: Dilemmas arising from the DSM-5 classification. *Journal of Autism and Developmental Disorders*, 46(8), 2821–2829.

Buxbaum, J. D., & Baron-Cohen, S. (2013). DSM-5: The debate continues. *Molecular Autism*, 4(1), 11.

Carter, C. S. (2007). Sex differences in oxytocin and vasopressin: Implications for autism spectrum disorders? *Behavioural Brain Research*, 176, 170–186.

Cheslack-Postava, K., & Jordan-Young, R. M. (2012). ASD: Toward a gendered embodiment model. *Social Science and Medicine*, 74(11), 1667–1674.

Constantino, J. N., & Charman, T. (2012). Gender bias, female resilience, and the sex ratio in autism. *Journal of the American Academy of Child and Adolescent Psychiatry*, 51(8), 756–758.

Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism*, 20(2), 153–162.

Cridland, E. K., Jones, S. C., Caputi, P., & Magee, C. A. (2014). Being a girl in a boys' world: Investigating the experiences of girls with autism spectrum disorders during adolescence. *Journal of Autism and Developmental Disorders*,

44(6), 1261–1274.

Dworzynski, K., Ronald, A., Bolton, P., & Happé, F. (2012). How different are girls and boys above and below the diagnostic threshold for autism spectrum disorders? *Journal of the American Academy of Child and Adolescent Psychiatry*, 51(8), 788–797.

Esler, A. N., & Ruble, L. A. (2015). DSM-5 Diagnostic criteria for autism spectrum disorder with implications for school psychologists. *International Journal of School & Educational Psychology*, 3, 1–15.

Farrugia, S., & Hudson, J. (2006). Anxiety in adolescents with Asperger syndrome: Negative thoughts, behavioral problems, and life interference. *Focus on Autism and Other Developmental Disabilities*, 21(1), 25–35.

Firth, I., & Dryer, R. (2013). The predictors of distress in parents of children with autism spectrum disorder. *Journal of Intellectual and Developmental Disability*, 38(2), 163–171.

Fombonne, E. (2003). Epidemiological surveys of autism and other pervasive developmental disorders: An update. *Journal of Autism and Developmental Disorders*, 33(4), 365–382.

Foody, C., James, J. E., & Leader, G. (2014). Parenting stress, salivary biomarkers, and ambulatory blood pressure in mothers of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 8(2), 99–110.

Garner, D. M., Olmstead, M. P., Bohr, Y., & Garfinkel, P. E. (1982). The Eating Attitudes Test: Psychometric features and clinical correlates. *Psychological Medicine*, 12, 871–878.

Giarelli, E., Wiggins, L. D., Rice, C. E., Levy, S. E., Kirby, R. S., Pinto-Martin, J., & Mandell, D. (2010). Sex differences in the evaluation and diagnosis of autism

- spectrum disorders among children. *Disability and Health Journal*, 3(2), 107–116.
- Goin-Kochel, R. P., Mackintosh, V. H., & Myers, B. J. (2006). How many doctors does it take to make an autism spectrum diagnosis? *Autism*, 10(5), 439–451.
- Goin-Kochel, R. P., Abbacchi, A., & Constantino, J. N. (2007). Lack of evidence for increased genetic loading for autism among families of affected females: A replication from family history data in two large samples. *Autism*, 11(3), 279–86.
- Goldman, S. (2013). Opinion: Sex, gender and the diagnosis of autism: A biosocial view of the male preponderance. *Research in Autism Spectrum Disorders*, 7(6), 675–679.
- Gould, J., & Ashton-Smith, J. (2011). Missed diagnosis or misdiagnosis? Girls and women on the autism spectrum. *Good Autism Practice*, 12(1), 34–41.
- Greenhalgh, T., & Peacock, R. (2005). Effectiveness and efficiency of search methods in systematic reviews of complex evidence: Audit of primary sources. *British Medical Journal*, 331, 1064–5.
- Grzadzinski, R., Huerta, M., & Lord, C. (2013). DSM-5 and autism spectrum disorders (ASDs): An opportunity for identifying ASD subtypes. *Molecular Autism*, 4(12).
- Hammond, R. K., & Hoffman, J. M. (2014). Adolescents with high-functioning autism: An investigation of comorbid anxiety and depression. *Journal of Mental Health Research in Intellectual Disabilities*, 7(3), 246–263.
- Haney, J. L. (2015). Autism, females, and the DSM-5: Gender bias in autism diagnosis. *Social Work in Mental Health*, 14(4), 396–407.
- Happé, F., & Frith, U. (1991). Is autism a pervasive developmental disorder? Debate and argument: How useful is the “PDD” label? *Journal of Child Psychology*

- and Psychiatry*, 32(7), 1167–1168.
- Harstad, E. B., Fogler, J., Sideridis, G., Weas, S., Mauras, C., & Barbaresi, W. J. (2015). Comparing diagnostic outcomes of autism spectrum disorder using DSM-IV-TR and DSM-5 criteria. *Journal of Autism and Developmental Disorders*, 45(5), 1437–1450.
- Head, A. M., McGillivray, J. A., & Stokes, M. A. (2014). Gender differences in emotionality and sociability in children with autism spectrum disorders. *Molecular Autism*, 5(19).
- Hiller, R. M., Young, R. L., & Weber, N. (2014). Sex differences in autism spectrum disorder based on DSM-5 criteria: Evidence from clinician and teacher reporting. *Journal of Abnormal Child Psychology*, 42(8), 1381–1393.
- 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.
- Hinkka-Yli-Salomäki, S., Banerjee, P. N., Gissler, M., Lampi, K. M., Vanhala, R., Brown, A. S., & Sourander, A. (2014). The incidence of diagnosed autism spectrum disorders in Finland. *Nordic Journal of Psychiatry*, 68(7), 472–480.
- Holtmann, M., Bölte, S., & Poustka, F. (2007). Autism spectrum disorders: Sex differences in autistic behaviour domains and coexisting psychopathology. *Developmental Medicine and Child Neurology*, 49(5), 361–366.
- Honda, H. (2013). How can epidemiological studies contribute to understanding autism spectrum disorders? *Brain and Development*, 35(2), 102–105.
- Howlin, P., & Moore, A. (1997). Diagnosis in autism: A survey of over 1200 patients in the UK. *Autism*, 1(2), 135–162.
- Hughes, R. (2010). The social model of disability. *British Journal of Healthcare*

Assistants, 4(10), 508–511.

Ingudomnukul, E., Baron-Cohen, S., Wheelwright, S., & Knickmeyer, R. (2007).

Elevated rates of testosterone-related disorders in women with autism spectrum conditions. *Hormones and Behavior*, 51(5), 597–604.

Kalyva, E. (2009). Comparison of eating attitudes between adolescent girls with and without Asperger syndrome: Daughters' and mothers' reports. *Journal of Autism and Developmental Disorders*, 39(3), 480–486.

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E.

(2015). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 55–59.

Kirkovski, M., Enticott, P. G., & Fitzgerald, P. B. (2013). A review of the role of female gender in autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 43, 2584–2603.

Kopp, S., & Gillberg, C. (2011). The Autism Spectrum Screening Questionnaire (ASSQ)-Revised Extended Version (ASSQ-REV): An instrument for better capturing the autism phenotype in girls? A preliminary study involving 191 clinical cases and community controls. *Research in Developmental Disabilities*, 32, 2875–2888.

Kreiser, N. L., & White, S. W. (2014). ASD in females: Are we overstating the gender difference in diagnosis? *Clinical Child and Family Psychology Review*, 17(1), 67–84.

Lai, M. C., Lombardo, M. V., Chakrabarti, B., & Baron-Cohen, S. (2013).

Subgrouping the autism “spectrum”: Reflections on DSM-5. *PLoS Biology*, 11(4).

Latif, A. H. A., & Williams, W. R. (2007). Diagnostic trends in autistic spectrum

- disorders in the South Wales valleys. *Autism*, 11(6), 479–487.
- Linton, K. F., Krcek, T. E., Sensui, L. M., & Spillers, J. L. H. (2014). Opinions of people who self-identify with autism and Asperger's on DSM-5 criteria. *Research on Social Work Practice*, 24(1), 67–77.
- Lord, C., Rutter, M., & Le Couteur, A. (1994). Autism Diagnostic Interview-Revised: A revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders*, 24(5), 659–685.
- Lord, C., Risi, S., Lambrecht, L., Cook, E. H. J., Leventhal, B. L., DiLavore, P. C., ... Rutter, M. (2000). The Autism Diagnostic Schedule – Generic: A standard measures of social and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders*, 30(3), 205–223.
- Mandy, W., Charman, T., & Skuse, D. H. (2012). Testing the construct validity of proposed criteria for DSM-5 autism spectrum disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, 51(1), 41–50.
- Mandy, W., Chilvers, R., Chowdhury, U., Salter, G., Seigal, A., & Skuse, D. (2012). Sex differences in autism spectrum disorder: Evidence from a large sample of children and adolescents. *Journal of Autism and Developmental Disorders*, 42(7), 1304–1313.
- Mattila, M. L., Hurtig, T., Haapsamo, H., Jussila, K., Kuusikko-Gauffin, S., Kielinen, M., ... Moilanen, I. (2010). Comorbid psychiatric disorders associated with Asperger syndrome/high-functioning autism: A community- and clinic-based study. *Journal of Autism and Developmental Disorders*, 40(9), 1080–1093.
- May, T., Cornish, K., & Rinehart, N. (2014). Does gender matter? A one year

- follow-up of autistic, attention and anxiety symptoms in high-functioning children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 44(5), 1077–1086.
- May, T., Cornish, K., & Rinehart, N. J. (2016). Gender profiles of behavioral attention in children with autism spectrum disorder. *Journal of Attention Disorders*, 20(7), 627–635.
- Mayes, S. D., & Calhoun, S. L. (2011). Impact of IQ, age, SES, gender, and race on autistic symptoms. *Research in Autism Spectrum Disorders*, 5(2), 749–757.
- Mazefsky, C. A., Conner, C. M., & Oswald, D. P. (2010). Association between depression and anxiety in high-functioning children with autism spectrum disorders and maternal mood symptoms. *Autism Research*, 3(3), 120–127.
- Mazefsky, C. A., McPartland, J. C., Gastgeb, H. Z., & Minshew, N. J. (2013). Brief report: Comparability of DSM-IV and DSM-5 ASD research samples. *Journal of Autism and Developmental Disorders*, 43(5), 1236–1242.
- Mazzone, L., Ruta, L., & Reale, L. (2012). Psychiatric comorbidities in Asperger syndrome and high functioning autism: Diagnostic challenges. *Annals of General Psychiatry*, 11(16), 1–13.
- Montes, G., & Halterman, J. S. (2007). Psychological functioning and coping among mothers of children with autism: A population-based study. *Pediatrics*, 119(5), 1040–6.
- National Institute for Health and Care Excellence. (2011). Autism spectrum disorder in under 19s: Recognition, referral and diagnosis. Retrieved January 7, 2017, from <https://www.nice.org.uk/guidance/cg128/resources/autism-in-under-19s-recognition-referral-and-diagnosis-35109456621253>
- Norbury, C., & Sparks, A. (2012). Difference or disorder? Cultural issues in

- understanding neurodevelopmental disorders. *Developmental Psychology*, 49(1), 45–58.
- O'Halloran, M., Sweeney, J., & Doody, O. (2013). Exploring fathers' perceptions of parenting a child with Asperger syndrome. *Journal of Intellectual Disabilities*, 17(3), 198–213.
- Oliver, M. (2013). The social model of disability: Thirty years on. *Disability & Society*, 28(7), 1024–1026.
- Oliver, M., Sapey, B., & Thomas, P. (2012). *Social Work with Disabled People* (4th ed.). Basingstoke: Palgrave Macmillan.
- Oswald, T. M., Winter-Messiers, M. A., Gibson, B., Schmidt, A. M., Herr, C. M., & Solomon, M. (2016). Sex differences in internalizing problems during adolescence in autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 46(2), 624–636.
- Posserud, M. B., Lundervold, A. J., & Gillberg, C. (2006). Autistic features in a total population of 7-9-year-old children assessed by the ASSQ (Autism Spectrum Screening Questionnaire). *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 47(2), 167–175.
- Reinval, O., Moisio, A.-L., Lahti-Nuuttila, P., Voutilainen, A., Laasonen, M., & Kujala, T. (2016). Psychiatric symptoms in children and adolescents with higher functioning autism spectrum disorders on the Development and Well-Being Assessment. *Research in Autism Spectrum Disorders*, 25, 47–57.
- Rivet, T. T., & Matson, J. L. (2011). Review of gender differences in core symptomatology in autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5(3), 957–976.
- Rutherford, M., McKenzie, K., Johnson, T., Catchpole, C., O'Hare, A., McClure, I.,

- ... Murray, A. (2016). Gender ratio in a clinical population sample, age of diagnosis and duration of assessment in children and adults with autism spectrum disorder. *Autism*, 20(5), 628–634.
- Sansosti, F. J., Lavik, K. B., & Sansosti, J. M. (2012). Family experiences through the autism diagnostic process. *Focus on Autism and Other Developmental Disabilities*, 27(2), 81–92.
- Scott, F. J., Baron-Cohen, S., Bolton, P., & Brayne, C. (2002). The CAST (Childhood Asperger Syndrome Test): Preliminary development of a UK screen for mainstream primary-school-age children. *Autism*, 6(1), 9–31.
- Shaffer, D., Gould, M. S., Brasic, J., Ambrosini, P., Fisher, P., Bird, H., & Aluwahlia, S. (1983). A children's global assessment scale (CGAS). *Archives of General Psychiatry*, 40(11), 1228–1231.
- Shefcyk, A. (2015). Count us in: Addressing gender disparities in autism research. *Autism*, 19(2), 131–132.
- Siklos, S., & Kerns, K. A. (2007). Assessing the diagnostic experiences of a small sample of parents of children with autism spectrum disorders. *Research in Developmental Disabilities*, 28(1), 9–22.
- Simone, R. (2010). *Aspergirls: Empowering females with Asperger syndrome*. London: Jessica Kingsley Publishers.
- Solomon, M., Miller, M., Taylor, S. L., Hinshaw, S. P., & Carter, C. S. (2012). Autism symptoms and internalizing psychopathology in girls and boys with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 42, 48–59.
- Szatmari, P., Liu, X. Q., Goldberg, J., Zwaigenbaum, L., Paterson, A. D., Woodbury-Smith, M., ... Thompson, A. (2012). Sex differences in repetitive

- stereotyped behaviors in autism: Implications for genetic liability. *American Journal of Medical Genetics Part B*, 159B, 5–12.
- Tanguay, P. E. (2011). Autism in DSM-5. *American Journal of Psychiatry*, 168(11), 1142–1144.
- Thompson, T., Caruso, M., & Ellerbeck, K. (2003). Sex matters in autism and other developmental disabilities. *Journal of Learning Disabilities*, 7(4), 345–362.
- Turygin, N., Matson, J. L., Beighley, J., & Adams, H. (2013). The effect of DSM-5 criteria on the externalizing, internalizing, behavioral and adaptive symptoms in children diagnosed with autism spectrum disorder. *Developmental Neurorehabilitation*, 16(1), 38–43.
- van Steensel, F. J. A., Bögels, S. M., & Dirksen, C. D. (2012). Anxiety and quality of life: Clinically anxious children with and without autism spectrum disorders compared. *The Journal of Child Psychology and Psychiatry*, 41(6), 731–8.
- Van Wijngaarden-Cremers, P. J. M., van Eeten, E., Groen, W. B., Van Deurzen, P. A., Oosterling, I. J., & Van der Gaag, R. J. (2014). Gender and age differences in the core triad of impairments in autism spectrum disorders: A systematic review and meta-analysis. *Journal of Autism and Developmental Disorders*, 44(3), 627–635.
- Vasilopoulou, E., & Nisbet, J. (2016). The quality of life of parents of children with autism spectrum disorder: A systematic review. *Research in Autism Spectrum Disorders*, 23, 36–49.
- Volkmar, F. R., & McPartland, J. C. (2014). From Kanner to DSM-5: Autism as an evolving diagnostic concept. *Annual Review of Clinical Psychology*, 10, 193–212.
- Volkmar, F. R., & Reichow, B. (2013). Autism in DSM-5: progress and challenges.

Molecular Autism, 4(13).

Webb, E., Morey, J., Thompsen, W., Butler, C., Barber, M., & Fraser, W. I. (2003).

Prevalence of autistic spectrum disorder in children attending mainstream schools in a Welsh education authority. *Developmental Medicine and Child Neurology*, 45(6), 377–84.

Whiteley, P., Todd, L., Carr, K., & Shattock, P. (2010). Gender ratios in autism,

Asperger syndrome and autism spectrum disorder. *Autism Insights*, 2, 17–24.

Williams, J. G., Allison, C., Scott, F. J., Bolton, P. F., Baron-Cohen, S., Matthews,

F. E., & Brayne, C. (2008). The Childhood Autism Spectrum Test (CAST): Sex differences. *Journal of Autism and Developmental Disorders*, 38, 1731–1739.

WHO. (1992). *International statistical classification of diseases and related health problems (10th edition)*. Geneva: WHO.



“Being an autism parent”

Mothers’ experiences from initial concerns about their daughters to a diagnosis of autism spectrum disorder: An interpretative phenomenological analysis

PART TWO: EMPIRICAL STUDY

(Word Count: 5902)

Abstract

It has been suggested that a male bias in diagnostic criteria for autism spectrum disorder (ASD), and in the diagnostic tools derived from them, has contributed to the under-recognition of symptoms in girls and thus to the gender gap in diagnosis rates, particularly among cognitively able children. This may lead to a later, and perhaps longer, diagnostic journey with girls' needs going unrecognised and with more associated stress for parents. Using semi-structured interviews, this thesis aimed to explore how five mothers of daughters in mainstream secondary schools with diagnoses of ASD experienced the diagnostic journey from first concerns to the present day. Using interpretative phenomenological analysis, three superordinate themes are described: DIAMOND-SHAPED DAUGHTERS; JUST GETTING NOWHERE; and THIS THING CALLED ASPERGER'S. Analysis suggested that a social construction of ASD based on a male phenotype typically impeded the participants' journeys: within school, within the NHS and in their own and their daughters' growing understanding. A failure to recognise daughters' needs in school was associated with perceptions of fragmentation which was often followed by crisis. Systems were seen to respond to challenge by focusing on their own needs, becoming rigid and failing to communicate effectively, thus mirroring the symptoms of ASD. Mothers felt attacked and belittled. One participant offered a divergent perspective suggesting that a difficult journey was not inevitable although concerns around systems prioritising their own needs remained. Implications for future research and for educational psychology practice are discussed.

1 Introduction

The ratio of males to females diagnosed with autism spectrum disorder (ASD) is typically estimated at about 4:1 (Fombonne, 2003; Hinkka-Yli-Salomäki et al., 2014; Whiteley, Todd, Carr, & Shattock, 2010). When Asperger's syndrome (AS), a form of ASD without intellectual or language impairment, is considered separately, this ratio increases to 10:1 (Attwood, 2006).

It has been argued that this discrepancy in diagnosis reflects a biological etiology in which girls are generally protected but subject to greater impairment when affected (Baron-Cohen et al., 2011; Solomon, Miller, Taylor, Hinshaw, & Carter, 2012). However, there is evidence that the discrepancy might also reflect different patterns of internalising and externalising behaviours in girls and boys and a focus on the male phenotype in diagnostic criteria and the diagnostic tools derived from these (Van Wijngaarden-Cremers et al., 2014; Williams et al., 2008).

It is commonly reported that girls with ASD have higher levels of internalising behaviours than both typically-developing peers and boys with ASD (Oswald et al., 2016; Solomon et al., 2012) and lower levels of externalising behaviours than boys with ASD (Dworzynski, Ronald, Bolton, & Happé, 2012; Head, McGillivray, & Stokes, 2014). It has been suggested that this leads to girls' difficulties going unrecognised by teachers in particular (Hiller, Young, & Weber, 2014; Mandy et al., 2012). It has been suggested that failure to recognise girls' struggles can exacerbate internalising behaviours and that this might in some cases be leading to misdiagnosis (Aggarwal & Angus, 2015; Gould & Ashton-Smith, 2011).

There is also evidence that the female phenotype differs from the male in more subtle ways. For example, girls with ASD have been reported to be more likely

than boys to engage in reciprocal conversation (Hiller et al., 2014) and less likely to lack a best friend (Kopp & Gillberg, 2011). Although neither characteristic is typical of girls with ASD, this can lead to difficulties going unrecognised (Mandy et al., 2012) particularly as cognitively able girls are widely-reported to mimic in social situations (Linton, Krcek, Sensui, & Spillers, 2014).

These difficulties in recognising girls' symptoms can be compounded at a clinical level where diagnostic tools reflect a male phenotype: Solomon et al. (2012) note, for example, that the *Repetitive Behavior Scale-Revised* (Bodfish, Symons, & Lewis, 1999), suggests "trains, dinosaurs, and toy cars" (p.55) as examples of fixed interests; whereas girls might be more typically interested in fictional characters (Attwood, 2015). Further, it is suggested that diagnostic tools might not reflect girls' experiences and Williams et al. (2008) have proposed adding questions to *The Childhood Autism Spectrum Test* (Scott, Baron-Cohen, Bolton, & Brayne, 2002) to explore difficulties such as "anxiety in unpredictable social situations" (p.1736) to increase its sensitivity to the presentation of ASD in girls.

The dominance of a social construct of ASD based on the male phenotype might be contributing to the needs of cognitively able girls being identified and understood at a later age (Goin-Kochel, Mackintosh, & Myers, 2006; Rutherford et al., 2016) and the process of diagnosis sometimes taking longer (Begeer et al., 2013; Siklos & Kerns, 2007), both factors associated with increased parental stress (Siklos & Kerns, 2007) in addition to the day-to-day stress associated with parenting a child with ASD (Firth & Dryer, 2013) and there is some evidence that this stress might be falling disproportionately on mothers (Bitsika, Sharpley, & Bell, 2013; Vasilopoulou & Nisbet, 2016) perhaps due to traditional gender roles (O'Halloran, Sweeney, & Doody, 2013).

In general, there is a lack of research that focuses on girls with ASD (Pellicano, Dinsmore, & Charman, 2014). Further, although teacher reports are often included in studies related to ASD symptomology (Dworzynski et al., 2012; Hiller et al., 2014; Mandy et al., 2012) and the importance of gathering information from schools is recognised (Posserud, Lundervold, & Gillberg, 2006), there is perhaps limited understanding of the role of schools in contributing to the broad diagnostic process.

1.1 The Current Thesis

There are many gaps in the literature relating to girls with ASD. One of these is a detailed understanding of what is happening to delay the recognition of difficulties related to ASD in cognitively able girls. This thesis aims, therefore, to explore the diagnostic experiences, in a broad sense including the involvement of the school system, of mothers of cognitively able daughters with ASD. It is concerned with the quality of those experiences and with what they might mean for participants. This has implications for the role of educational psychologists (EPs) in supporting both schools and parents to find solutions to perceived problems and in promoting understanding of girls' needs.

1.2 Aims and Research Questions

Although this thesis aims to provide detailed insights into the experiences of mothers of girls with diagnoses of ASD, it is concerned not so much with a clinical *process* of diagnosis as with what happens in the wider school environment where concerns might become apparent and where an educational psychologist (EP) might become involved. Therefore, the term *journey* is used to emphasise the idiographic nature of mothers' experiences.

The research questions are:

- How do mothers of girls in mainstream schools experience the diagnostic journey of their daughters from initial concerns to a diagnosis of ASD?
- How do mothers experience the outcomes of this diagnostic journey?

2 Methodology

2.1 Ontology and Epistemology

As this thesis is concerned with lived experience (Smith, Flowers, & Larkin, 2009), a relativist ontological stance was taken, recognising there are multiple ways of interpreting our experiences of the world (Willig, 2008). A social constructionist epistemology was also adopted which argues that interpretations of experience are created through the language used to discuss them (Burr, 2015).

2.2 Methodology

In keeping with these ontological and epistemological positions, the chosen methodology is interpretative phenomenological analysis (IPA) which has its theoretical basis in hermeneutics, phenomenology and idiography (Smith et al., 2009). IPA involves a *double hermeneutic* (Smith & Osborn, 2008) whereby participants interpret their own experiences through the accounts they give and the researcher then interprets these accounts. As the researcher's interpretative role is acknowledged, the researcher's position is outlined alongside the assumptions on which IPA is based in Part Three.

3 Method

3.1 Selection and Recruitment

In line with the principles of IPA, participants were recruited “purposively”

(Smith et al., 2009, p.48) with selection criteria devised to ensure a “fairly homogenous” group. Participants were mothers of daughters who had been given a diagnosis of ASD within the last five years, were of secondary school age, had attended mainstream state schools and did not have additional needs as the result of another diagnosis. Participants were recruited via educational psychology services (EPSs) in England and Wales. Full inclusion and exclusion criteria are discussed in Part Three.

3.2 Participants

Participant details are provided in Table 2. All daughters lived in authorities where transfer to secondary school is at the end of Key Stage 2.

Table 2 Details of participants

Mother's pseudonym	Claire	Elaine	Fiona	Olivia	Tracy
Daughter's pseudonym¹⁹	Charlotte	Emily	Rachel	Alice	Sophie
Participants' early concerns	Academic anxieties	Stomach aches	Not mixing with other children	None	Reluctance to attend school
Daughter's school year at diagnosis	End of Year 6	Year 9	Year 8	End of Year 3	Year 8
Daughter's school year at interview²⁰	Going into Year 8	Going into Year 10	Going into Year 9	Going into Year 8	Going into Year 11
School placement	Moved to ASD base in another secondary	Original secondary although alternatives explored	Withdrawn from secondary in Year 7	Original secondary school	Moved teaching groups in secondary

¹⁹ These pseudonyms have been used throughout to avoid repetition of ‘her daughter’ and the ambiguity of ‘she’. It is also hoped that it gives a better sense of the girls as individuals.

²⁰ As interviews were conducted during the summer, this reflects the year group for each girl as of September of that year.

3.3 Interviews

Data were gathered using semi-structured interviews lasting between seventy minutes and an hour and fifty minutes²¹. As participants were regarded as “experiential expert[s]” (Smith et al., 2009, p.64), interview questions were designed to be open and encourage participants to talk at length with interruptions kept to a minimum. The interview schedule (Appendix B) was memorised and followed flexibly so participants frequently guided the flow of the conversation and chose which aspects of their experiences to discuss.

3.4 Ethical Considerations

Ethical approval was obtained from the Cardiff University School of Psychology Ethics Committee. Procedures followed for recruiting participants and conducting research in line with ethical practice are detailed in Part Three.

3.5 Analysis of Data

Interviews were transcribed verbatim broadly following advice for orthographic transcription by Braun & Clarke (2013); pseudonyms were used and some personal information was changed or redacted. A full key to the interview transcripts is given in Appendix C; symbols and styles pertinent to quotations within the body of the thesis are shown in Table 3.

²¹ The shortest ended early as the room was unexpectedly required. The participant had, however, described her experiences both before and after diagnosis.

Table 3 Key to symbols and styles used in quotations

Style	Meaning	Style	Meaning
()	Round brackets indicate words, pauses, noises etc. of the participant	[]	Square brackets indicate the researcher's explanatory comments/observations
XXX	Redacted words/ very brief phrases	[...]	Longer redacted or edited passages
(.)	Very short pause typical of connected, flowing speech	((pause))	A longer pause
?	Used to indicate a questioning tone ²²	!	Used to indicate an exclamatory tone
<u>underlining</u>	Used to indicate emphasis	dash-	Cut-off speech

Analysis followed the steps outlined by Smith et al. (2009): reading and re-reading; initial noting; developing emergent themes; searching for connections across themes; moving to the next case; looking for patterns across cases. Further details are given in Table 4. In practice, these steps were iterative (Eatough & Smith, 2011) and necessitated a repeated return to transcripts and recordings to keep interpretations grounded in the data.

In keeping with the principles of IPA, with the exception of the section on the development of the diagnostic criteria for ASD, the literature review was written after data analysis.

²² Given that judgement of tone is subjective, question and exclamation marks are not used in the transcripts. However, they are occasionally included in the body of the thesis for clarity.

Table 4 The six steps of IPA

Step	Description
Reading and re-reading	Recordings were listened to and transcripts read through at least twice to increase familiarisation.
Initial noting	The first transcript was read through carefully and notes made of anything interesting or significant (Smith & Osborn, 2008). Smith et al. (2009) note that this is “the most detailed and time consuming” (p.83) stage of analysis and can be done at three levels: descriptive, linguistic and conceptual. For earlier interviews, each of these stages was done in turn to encourage closer analysis; for later interviews, when the technique was more familiar, they were done in parallel. An example is shown in Appendix D.
Developing emergent themes	Initial notes on the first transcript were explored at a higher level of abstraction, mindful of the initial notes that had been made on the transcript as a whole, and emergent themes were recorded. An example is shown in Appendix D.
Searching for connections across emergent themes	A list was made of emergent themes within the first transcript, together with key quotations. These were reordered to establish links, patterns and contrasts and eventually grouped into superordinate themes at a further level of abstraction. An example is shown in Appendix E.
Moving to the next case	This process was repeated with each subsequent transcript whilst being mindful of the way in which on-going analysis of each transcript was changing the researcher’s preconceptions. This and other reflection were recorded in a diary to enable them to be “bracketed off” (Smith et al. 2009) Extracts from the reflective diary are shown in Appendix F.
Looking for patterns across cases	Themes were compared between participants, leading to a re-ordering of themes until a set of super- and subordinate themes was developed to represent the transcripts as a whole. This re-ordering continued to a minor extent throughout the writing of the results and analysis. The participants’ own words were used to label the themes to reflect their often emotional experiences in preference to using more neutral labels.

4 Results and Analysis

This section explores super- and subordinate themes recurring in at least three interviews: these are summarised in Table 5. Table 6 shows the recurrence of each theme across participants. It is recognised that these are the researcher’s interpretation of what was said rather than a hypothetically neutral analysis (Smith et al., 2009); theme labels are derived from quotations but remain the researcher’s choice.

Table 5 Recurrent superordinate and subordinate themes

Superordinate themes	Subordinate themes	Illustrative quotations
DIAMOND-SHAPED DAUGHTERS	• Very Much a Swan	she wears the most fantastic mask (.) you don't know what's going on underneath (.) she's very much a swan (Tracy)
	• So Uncomfortable	she didn't want to be different (.) she didn't want to be weird (Tracy)
	• Going to Pieces	she was (.) she was (.) in bits (.) the way she thought people (.) thought of her (.) how she viewed herself (Fiona)
JUST GETTING NOWHERE	• Fighting on My Own	I was on at them <u>all</u> the time (.) all the time I was on at them (.) so I was angry thinking (.) <u>all</u> the times I went down there (Fiona)
	• Who's Got the Key?	we'd been back and forth to the GP (Elaine)
	• Pain in the Arse	a pain in the (.) arse [...] I think they used to cringe (.) if they see me coming (Fiona)
	• What the System Needs	"we only need her to be level four and she's already a level six and a level seven (.) what's the problem?" (Claire quoting school)
	• Hauled Over the Coals	we had an awful time with the educational welfare officer (.) I was really made to feel (.) I was the bad parent (Elaine)
	• Breaking Point	it became when the OCD-type behaviours came in and got worse and worse and worse (.) and it ruled everything in the end (Tracy)
THIS THING CALLED ASPERGER'S	• Surely That's Boys	I was naïve enough to think it didn't happen to girls (Tracy)
	• A Process of Discovery	she's got really really poor theory of mind (.) really poor (.) it's like wow! (Olivia)
	• The Life I Wanted	couldn't see how (.) she would have the life that I wanted her to have (Olivia)

Table 6 Recurrence of themes across participants

Superordinate themes	Subordinate themes	Fiona	Olivia	Tracy	Elaine	Claire
DIAMOND-SHAPED DAUGHTERS	<ul style="list-style-type: none"> • Very Much a Swan 					

qualities and the suffering caused when needs were not recognised.

4.1.1 Subordinate theme: “*Very Much a Swan*”

Very Much a Swan reflects the contrast between participants’ positive constructions of their daughters and their hidden struggles. It also reflects the contrasting ways daughters were constructed by participants and through school.

Table 7 shows illustrative quotations for each participant.

Table 7 Illustrative quotations for Very Much a Swan

Participant	Quotations
Claire	<ul style="list-style-type: none"> • always very keen to learn • she was really trying (.) to manage all the anxiety on her own (.) she wasn’t telling anybody • the other girls had changed over the summer [...] they’d matured
Elaine	<ul style="list-style-type: none"> • quite gifted in things like literacy and maths • she has tended to internalise it which I think is then (.) added to mental health issues later on • we had people over for tea and stuff (.) although that wasn’t always reciprocated we noticed
Fiona	<ul style="list-style-type: none"> • she’s lovely (.) she’s just lovely • Rachel hadn’t said anything (.) just didn’t want to go to school • I got upset seeing how upset she was (.) because it’s the way (.) other children seen her as well (.) they just sort of seen her as strange
Olivia	<ul style="list-style-type: none"> • enormously imaginative • she’s quite easy to ignore (.) in terms of needs • they were really supportive and (.) they were very (.) erm ((pause)) brotherly and (.) I’d say protective of her when she was in the village school
Tracy	<ul style="list-style-type: none"> • very intelligent (.) very musical ((pause)) very determined and very much a perfectionist • she’s very much a swan ((pause)) and it’s only when you sit down quietly with her and listen to the things that are coming out • [she] was referred to as rude [...] and I’d never had her called rude

All participants described their daughters positively, seeming to see these positive qualities as the essence of their daughters. These qualities did not appear to flourish in school as when Fiona compared Rachel at home to in school:

“totally relaxed (.) totally different”;

and when Claire described recently seeing Charlotte as she was before “[academic] pressure jump[ed] up and (.) grab[bed] her”:

“we had this like glimmer of how she was (.) and she was happy”.

For both participants, school seemed to have taken away their real daughter.

Participants described their daughters' struggles as hidden, sometimes deliberately.

Realisation of daughters' difficulties appeared to come slowly through comparison with other children or through the reaction of other children, signs that sometimes seemed easy to dismiss:

“she has some (.) social signs that she’s different [...] but hey everybody does” (Claire).

Participants described how peers or teachers seemed to view their daughters, which sometimes appeared to shock them:

“[other children] just sort of seen her as strange” (Fiona).

Elaine described realising the extent of the suffering associated with Emily's stomach aches when Emily hit out, “desperate” to be allowed home from school:

“she actually physically hit me [...] and that shocked me”,

her use of “actually physically” suggesting continued shock as though expecting “hit” to be understood metaphorically without these modifiers.

4.1.2 Subordinate theme: “*So Uncomfortable*”

So Uncomfortable reflects the apparent mismatch between participants' daughters and the school environment. Table 8 shows illustrative quotations for each participant.

Table 8 Illustrative quotations for *So Uncomfortable*

Participant	Quotations
Claire	<ul style="list-style-type: none"> Charlotte could not cope with the behaviour of the other pupils she come up with a code word (.) she would say hopscotch (.) teacher would know Charlotte needs to get out
Elaine	<ul style="list-style-type: none"> [Emily] was finding drama lessons really traumatic to help her cope with that if she needed time out and working in a quiet area she'd be allowed to do that
Fiona	<ul style="list-style-type: none"> she just did not want to do [PE] (.) and it's because of the changing (.) and couldn't change quick enough so Rachel [was] moved out of his class
Olivia	<ul style="list-style-type: none"> noise (.) that's the thing [Alice] finds the hardest one of the L.S.A.s (.) had come up with this idea that she could use a stress ball if she was getting wound up
Tracy	<ul style="list-style-type: none"> some mornings was literally get her by the hand and drag her along [to school]

All daughters were reported to find school challenging, either socially, due to the environment or because of particular lessons. Elaine and Claire reported their daughters leaving the classroom temporarily to help them “cope”. Their use of “cope” suggests their daughters just tolerated school and there is a sense daughters had to identify and manage their own needs at an early age. This was also evident for Alice, despite Olivia saying she generally enjoyed school:

“break and lunchtime (.) she goes to a quiet room (.) so I think that she needs that time out in order to cope”.

Elaine, Fiona and Tracy also reported their daughters being moved more permanently within school:

“they have put [Emily] in a lower set (.) than she could work at” (Elaine);

and both Fiona and Claire removed their own daughters permanently from their original secondary schools.

4.1.3 Subordinate theme: “*Going to Pieces*”

Going to Pieces is related to *So Uncomfortable* and reflects the psychological and physical consequences of unrecognised needs. The two themes are distinct in that *Going to Pieces* was not inevitable as Olivia’s experience showed. This theme is

also separate as it reflects often acute reactions to the chronic stressors reflected in *So Uncomfortable*. Table 9 shows illustrative quotations for each participant.

Table 9 Illustrative quotations for Going to Pieces

Participant	Quotations
Claire	<ul style="list-style-type: none"> she was very graphic (.) “it’s going to be this arm (.) I’m going to do it with a knife (.) I’m going to do it here”
Elaine	<ul style="list-style-type: none"> she had such terrible pain and I when I went to pick up her face looked awful (.) you could tell she was in excruciating pain
Fiona	<ul style="list-style-type: none"> she didn’t think she deserved to be around
Tracy	<ul style="list-style-type: none"> half an hour to an hour of kicking (.) screaming (.) throwing things (.) head-butting walls (.) kicking walls (.) she’s cracked the wall in the bedroom ((pause)) um ((pause)) she nearly took the hinges off the door

Metaphors suggesting daughters were breaking apart were frequent:

“broken down (.) breaking her heart” (Claire),

appearing to reflect how incompatible constructions of the girls fragmented their sense of identity:

“[Rachel] was (.) in bits (.) the way she thought people (.) thought of her (.) how she viewed herself” (Fiona).

Relating these experiences was difficult for participants who often spoke quietly at these times. This appeared to reflect the immediacy of their emotions as when Claire used the present tense to describe Charlotte after her ASD assessment interview:

“she is like (.) a wreck (.) she can’t even walk (.) she wants to sit down (.) she just (.) totally drained”.

4.2 Superordinate Theme: “JUST GETTING NOWHERE”

This superordinate theme reflects participants’ experiences interacting with school and health systems. For Olivia, these interactions appeared to be mainly the routine conversations parents have with school; for other participants these interactions were motivated by a desire to find solutions for their daughters’ difficulties.

4.2.1 Subordinate theme: “Fighting on My Own”

Fighting on My Own reflects participants' experiences of struggling to find someone to take their concerns seriously and being repeatedly turned away by professionals. Table 10 shows illustrative quotations for each participant.

Table 10 Illustrative quotations for Fighting on My Own

Participant	Quotations
Claire	<ul style="list-style-type: none"> I feel I could run and be president of America because I ran such a campaign ((laughter)) to get Charlotte diagnosed “there are no post-diagnosis services (.) so you’ll have to go back to your GP (.) um (.) but it’s not really worth going back to your GP” [quoting CAMHS]²⁴
Elaine	<ul style="list-style-type: none"> I (.) had to keep bashing on at them [...] at this point I was going hammer and tongs this is what’s been so difficult along the process is getting professionals to be with you
Fiona	<ul style="list-style-type: none"> I had many a dust-up with her it’s like ((pause)) find the help yourself kind of thing (.) <u>that</u>’s what I found difficult
Olivia	<ul style="list-style-type: none"> sometimes we need a bit of guidance on what to do
Tracy	<ul style="list-style-type: none"> what’s the most awful (.) [Sophie] said is she was diagnosed on the twenty-eighth (.) and discharged from CAMHS on the second of May (.) same week ((pause)) you get your diagnosis thank you very much goodbye

Elaine and Fiona’s use of violent metaphors, “bashing”, “dust-up”, to describe interactions perhaps reflects many failed attempts and feelings of exhaustion. Exhaustion also seemed psychological in Fiona’s description of bracing herself for the effort involved in accessing services:

“I needed breathing space myself so I give it a couple of days and I rung back”.

Claire, too, seemed to brace herself, with the anticipated impact perhaps linked to how she felt herself perceived in school:

“I don’t care what anybody says or what I’m accused of (.) when she goes back to school [...] this is going to be different” (quoting past thoughts).

Elaine described her effort in terms of the resources employed to support her views:

“full-blown research (.) reading books (.) looking at papers [...] recording all the evidence [...] I sent [CAMHS] a twelve-page report (.) with referenced evidence (.) of why I thought she had Asperger’s”.

²⁴ Child and Adolescent Mental Health Service

All participants referred to the lack of post-diagnostic services, suggesting feelings of abandonment. This also seemed evident when Tracy described ASD being mentioned in school:

“and I’m supposed to do what with this information?”;

a feeling apparently shared by Sophie:

“you’re told to get out and go in the big wide world and deal with it” (Tracy quoting Sophie).

4.2.2 Subordinate theme: *“Who’s Got the Key?”*

Who’s Got the Key? reflects the difficulty of gaining entry to what Claire called “a locked cave somewhere” to start the process leading to diagnosis. It is separate from *Fighting on My Own* as finding the key-holder did not always require a struggle and did not necessarily end the struggle. Table 11 shows illustrative quotations for each participant.

Table 11 Illustrative quotations for Who’s Got the Key?

Participant	Quotations
Claire	<ul style="list-style-type: none"> the GP was hopeless (.) so I basically wrote a begging email to [a known] paediatrician they all thought that she probably had Asperger’s (.) but of course nobody can say it (.) until a clinician has
Elaine	<ul style="list-style-type: none"> I mean we saw we saw three different GPs (.) we saw a nurse practitioner and in the end I took her to A&E I just happened to chat to her at a market stall that was on at the conference (.) it was actually to do with toddlers and pre-schoolers
Fiona	<ul style="list-style-type: none"> I’m sure it was year five I asked for an educational psychologist to get involved (.) didn’t happen
Olivia	<ul style="list-style-type: none"> within a month [the school] said “we think she’s got Asperger’s”
Tracy	<ul style="list-style-type: none"> so [a consultant I knew] said “go to your GP (.) get a letter of referral from your GP to me” [Sophie] reminded [the headteacher] so much of her nephew

Participants seemed to feel chance contacts helped their journey. Claire and Tracy used personal contacts whilst Elaine described how a chance encounter encouraged her to seek a second opinion:

“I just happened to chat to her”.

Tracy appeared to feel fortunate Sophie's headteacher suggested ASD:

"it was only that I [worked there] that [she] felt comfortable enough to say anything";

Elaine, however, suggested that school's reluctance to mention ASD, despite implementing suitable strategies, wasted time:

"we'd have been a year or two ahead of where we are now".

For Claire, perceived reluctance extended to an unwillingness to implement strategies:

"can't just treat her as if".

Fiona did not report chance acquaintances and only found the key-holder after taking radical action:

"if I hadn't pulled Rachel out of school (.) I'd still be fighting".

4.2.3 Subordinate theme: "Pain in the Arse"

Pain in the Arse reflects how participants felt education and health systems viewed them. The label was chosen over less pejorative alternatives as it captures how participants appeared to feel belittled and a nuisance. Table 12 shows illustrative quotations for each participant.

Table 12 Illustrative quotations for Pain in the Arse

Participant	Quotations
Claire	<ul style="list-style-type: none"> ruining all of the relationships that I've set up because I've now become this pest of a mother
Elaine	<ul style="list-style-type: none"> I think [CAMHS] were getting a little bit sick of me by that stage probably being the nuisance parent (.) keep ringing up "well we don't always know why people have heart attacks do we?" (quoting CAMHS)
Fiona	<ul style="list-style-type: none"> I'm I'm (.) well (.) practised at that now with the schools (.) made a nuisance of myself instead of just making me feel like I was a paranoid mother (.) because that's what they (.) made me feel like "she'll be fine (.) they adapt" (quoting school)
Tracy	<ul style="list-style-type: none"> was I given a diagnosis to get rid of us?

Participants' descriptions suggested they felt condescended to: "pest", "nuisance",

“paranoid”. This appeared to happen when they were interrupted or concerns were apparently normalised:

“before [the teacher] would let me say anything else (.) she shut me down”
(Claire);

“[school] said [the children] were all terrified about going to high school”
(Tracy).

Claire described feeling like “a parent with an opinion” and Elaine seemed to share this feeling when she justified her concerns, as though her worry about Emily’s hallucinations would not be self-evident:

“we had dizziness (.) we had hallucinations [...] I knew it wasn't something that could just be brushed under the carpet”²⁵.

This feeling seemed to be reflected in Elaine’s reluctance to seek a second opinion despite disagreeing with Emily’s diagnosis of “anxiety”:

“I thought ooh (.) well I don’t really like to do that”,

as though disagreeing with but respecting the system.

4.2.4 Subordinate theme: “What the System Needs”

What the System Needs reflects school and health systems apparently prioritising the needs of the system in terms of aims, processes and communication. Table 13 shows illustrative quotations for each participant.

²⁵ The ellipsis in this quotation represents some two hundred words in which Claire describes some of Charlotte’s hallucinations. Ellipses in all other quotations are considerably shorter.

Table 13 Illustrative quotations for What the System Needs

Participant	Quotations
Claire	<ul style="list-style-type: none"> • “we only need her to be level four and she’s already a level six [...] what’s the problem?” [quoting school]
Elaine	<ul style="list-style-type: none"> • “we have to have something in writing” (.) now even though they had spoken on the phone to health professionals (quoting school) • it all got very complicated (.) no one could agree on who should do the referral [...] finally (.) I think the GP was allowed to refer me but had to get permission
Fiona	<ul style="list-style-type: none"> • it was easier [for school] just to say well Rachel should never have been taken into school • “oh no no no no (.) you’ve got to have an appointment” he said “you can’t go in” (quoting school) • I’m like “w-w-w-w-?” [when given diagnosis]
Olivia	<ul style="list-style-type: none"> • she’s getting fifty in her exams (.) she’s passing ((pause)) she’s not squeaking (.) so she’s not getting oiled
Tracy	<ul style="list-style-type: none"> • “Sophie has to agree (.) and consent to the assessment” [quoting CAMHS] • [the psychiatrist] said “having looked at all your paperwork Sophie [...] I can tell you that (.) you do fit the criteria” (.) and she said “what do you mean?” • I don’t remember half the conversation from the rest of the day

Participants appeared to feel schools only became concerned over academic issues: “missing some school”; “time management” rather than mental health needs. Claire described school not understanding Charlotte’s anxieties as she was high-achieving and Olivia suggested Alice was allowed just to do minimally well. The system’s needs were also apparently experienced as bureaucratic: Elaine described school wanting written confirmation of Emily’s illness despite having spoken to the hospital, apparently making school part of the problem as reflected in Elaine’s “incredible” relief at a clinician linking Emily’s stomach aches to ASD:

“I finally had a letter (.) that I could take into school”.

Tracy appeared frustrated at the Child and Adolescent Mental Health Service (CAMHS) deciding that Sophie was “Gillick competent”, contrary to Tracy’s own belief:

*“she’s twelve and a half why how can she possibly be Gillick competent”.*²⁶

²⁶ In keeping with the ontological position of this thesis, what matters here is not whether Sophie was or was not “Gillick competent” but Tracy’s experience in the context of believing that Sophie was not “Gillick competent”.

Participants also seemed to feel systems prioritised their own perspective in communications, overlooking participants' knowledge and mental state. Fiona reported not being warned of the possibility of a diagnosis of ASD; both Tracy and Elaine reported the difficulty of absorbing new information when shocked, with Elaine also describing an apparently intimidating meeting:

“we went into this meeting (.) in shock (.) from what they'd just said (.) plus having to work out this big meeting with the school and the GP and everything”.

4.2.5 Subordinate theme: *“Hauled Over the Coals”*

The subordinate theme *Hauled Over the Coals* reflects participants' descriptions of feeling attacked by the system when seeking help. Table 14 shows illustrative quotations for each participant.

Table 14 Illustrative quotations for Hauled Over the Coals

Participant	Quotations
Claire	<ul style="list-style-type: none"> • “you have just taken our lives apart” (.) you know (.) “and like hauled us over the coals” (.) you know ((pause)) um it was such a traumatising experience [reporting comments made to the police and a social worker] • we had to account for everything you know ((pause)) um ((pause)) and ((pause)) what was I going to say to you ((pause)) my mind is like ((pause)) which bit do I say next ((pause))
Elaine	<ul style="list-style-type: none"> • because it had gone through complaints procedures now the boss was there to protect her doctor • we had an awful time with the educational welfare officer (.) I was really made to feel (.) I was the bad parent
Fiona	<ul style="list-style-type: none"> • “but please don't think you're going to come into my home (.) and tell me (.) I have to put my daughter back into school” [speaking to children services]
Tracy	<ul style="list-style-type: none"> • it sort of got twisted back the other way that Sophie was in the wrong • the psychologist said she didn't want to see us anymore (.) because we'd complained (.) I hadn't complained

Participants appeared to experience systems as attacking and defensive. Sometimes this appeared as a counter-attack when participants sought help:

“it sort of got twisted back the other way” (Tracy).

Claire described her experience as “traumatising” and Fiona's description suggested she felt her home was being violated:

“please don't think you're going to come into my home (.) and tell me”.

Tracy seemed to feel that defensiveness cut off help for Sophie in school and the health service:

“the psychologist said she didn't want to see us anymore (.) because we'd complained (.) I hadn't complained”.

Similarly, it appeared that Elaine experienced defensiveness when she challenged Emily's diagnosis, rather than the reconsideration she sought:

“now the boss was there to protect her doctor”.

It appeared that expectation of a counter-attack was so strong for Fiona, that she described her shock when children's services wanted to help rather than attack her:

“I said oh that took the wind out of my sails a bit”.

4.2.6 Subordinate theme: “*Breaking Point*”

Breaking Point reflects the sense that, for all participants except Olivia, one or more crisis points were reached before progress was made. Table 15 shows illustrative quotations for each participant.

Table 15 Illustrative quotations for Breaking Point

Participant	Quotations
Claire	<ul style="list-style-type: none"> • [Charlotte] planned to start cutting herself (.) you know (.) she's like “I just can't take this (.) anymore” • I had to just like cradle her in my arms (.) until we got home (.) um (.) and [my husband] thought we were going to have to have her committed • they'd started child protection proceedings ((pause)) so by the time I got home (.) the police were involved (.) social services were involved
Elaine	<ul style="list-style-type: none"> • I came to the session distraught with my daughter on one time • the hallucinations [...] that's what prompted a referral to the mental health team
Fiona	<ul style="list-style-type: none"> • [Rachel] didn't think she deserved to be around ((pause)) • that morning when I decided [to withdraw Rachel from school] I'm like “just get your uniform off”
Tracy	<ul style="list-style-type: none"> • the head teacher [...] noticed that I (.) ((laughs)) I'd got to the point (.) it was breaking point • it became when the OCD-type behaviours came in and got worse and worse and worse (.) and it ruled everything in the end • my husband walked out (.) he came back (.) but he stormed out one night (.) he just couldn't cope with it any further

It appeared that crises, as participants and their families no longer felt able to cope,

were experienced by daughters, “she planned to start cutting herself”; by participants, “it was breaking point”; and by the family more widely, “my husband walked out”. This appeared to result from not knowing how to respond to the daughters’ behaviour. In this respect, the system can also be seen to be in crisis as it failed to cope when a comment made by Charlotte in school was misinterpreted, leading to the initiation of child protection proceedings. Tracy and Elaine reported the crisis precipitated progress with CAMHS; Fiona gained access to an educational psychologist. Despite making progress after crisis, however, participants also appeared to experience negative long-term consequences: Fiona and Claire reported school placements breaking down; Emily had a reduced timetable; Tracy reported “very difficult” relationships at home whilst Claire described Charlotte’s difficulty trusting adults:

“it’s just wrecked relationships for her”.

4.3 Superordinate Theme: “THIS THING CALLED ASPERGER’S”

This superordinate theme reflects different and changing constructions of ASD and the effect of these on understanding the present, past and future and the self.

4.3.1 Subordinate theme: “*Surely That’s Boys*”

Surely That’s Boys reflects the impact social constructs of ASD, whether participants’ own, their daughters or those of professionals, had on participants’ journeys. Table 16 shows illustrative quotations for each participant.

Table 16 Illustrative quotations for Surely That's Boys

Participant	Quotations
Claire	<ul style="list-style-type: none"> lovely (.) always like polite (.) kind [...] and those were also the things that made me think she couldn't be autistic I really felt the school were kind of (.) well this [a boy] is autism (.) this is what it looks like [the GP] just said "she doesn't have Asperger's syndrome (.) she's not autistic (.) she's just sat and talked to me"
Elaine	<ul style="list-style-type: none"> I had only recently heard of autism anyway the fact that she could have a conversation with the clinician (.) they didn't think she had autism "you've totally missed this is a <u>girl</u> you're looking at not a boy (.) I <u>don't</u> feel you've been asking the right questions" [response to CAMHS]
Fiona	<ul style="list-style-type: none"> she's like the other end of the ASD scale I guess
Olivia	<ul style="list-style-type: none"> I always used to think of it as classical autism which is so closed in (.) so ((pause)) so closed off from the world
Tracy	<ul style="list-style-type: none"> I was naïve enough to think it didn't happen to girls "and you think I'm like <u>him</u>?" [quoting Sophie]

Participants reported preconceptions of ASD that influenced both their likelihood of suspecting ASD and their expectations about the future when ASD was mentioned.

Fiona's comment is particularly interesting:

"she's like the other end of the ASD scale I guess (.) that's why it come as a bit of a shock".

By not specifying what this "other" was in relation to, Fiona perhaps reflects an understanding that Rachel did not fit many people's preconceptions about ASD which seemed to be reflected in participants' experiences with schools and clinicians. For Claire and Elaine particularly, this seemed to create feelings of frustration that they had come to know more about ASD than apparent experts:

"I'm surrounded by ignorance!" (Claire, said with mock indignation);

and there was a sense they were having to challenge these preconceptions to make progress:

"you've totally missed this is a girl you're looking at" (Elaine reporting conversations with CAMHS).

Claire reported school having preconceptions based on boys and Tracy described how Sophie understood ASD through knowing a boy at school and refused to be

assessed:

“and you think I’m like him!?” (quoting Sophie).

4.3.2 Subordinate theme: “*A Process of Discovery*”

A Process of Discovery reflects participants evolving knowledge of ASD and of their daughters. Table 17 shows illustrative quotations for each participant.

Table 17 Illustrative quotations for A Process of Discovery

Participant	Quotations
Claire	<ul style="list-style-type: none">• she’s not able to show empathy (.) but she is one of the most compassionate people you’ll ever meet• just feeling like I’m getting to know (.) my daughter (.) and I’m really having to learn what autism is like for girls
Elaine	<ul style="list-style-type: none">• she has to choose the textures which actually (.) in hindsight (.) fits back to when she was a baby• [Emily] kind of had to clarify with me (.) “will it ever go away? (.) will the Asperger’s ever go away?”
Fiona	<ul style="list-style-type: none">• well of course it all slots (.) together now (.) everything just makes so much sense now• I just feel so sorry for her that she must have been suffering• I think it was as if “hah! there’s a reason why I’ve been feeling like ((gesture indicating unspoken swear word))” [describing Rachel’s reaction]
Olivia	<ul style="list-style-type: none">• she’s got really really poor theory of mind [...] it’s like wow
Tracy	<ul style="list-style-type: none">• you read things that say (.) that say people on the autistic spectrum can’t do that (.) well she’s just done it• I’ve had since how much [the bullying] really did happen (.) and how much was it her interpretation (.) and very much different people trying to brush it under the carpet (.) because now she has ASD how much of it was her interpretation and did it really happen at the time• she doesn’t hear the blended sound (.) she hears each individual part (.) which is phenomenal for somebody doing music

Participants frequently spoke about understanding their daughters better since diagnosis. Fiona experienced this as a realisation of Rachel’s past suffering; Olivia as a realisation of Alice’s present struggles. Tracy described others reinterpreting the past too, casting doubt on Sophie’s experience of bullying:

“because now she has ASD how much of it was her interpretation”.

However, Tracy also described learning about strengths such as how Sophie, a keen musician, hears choirs:

“she doesn’t hear the blended sound (.) she hears each individual part”;

and recognition of strengths appeared important for many participants, particularly looking towards adulthood:

“I don't know what she's going to end up being but it's going to be great”
(Olivia).

Participants also spoke about their daughters challenging their understanding of ASD by not fitting stereotypes:

“you read things that say (.) that say people on the autistic spectrum can't do that (.) well she's just done it” (Tracy).

Tracy appeared to see this as challenging stereotypes but also suggested she sometimes doubted Sophie's diagnosis. Daughters' self-understanding appeared important for participants as Elaine poignantly described:

“[Emily] kind of had to clarify with me (.) “will it ever go away? (.) will the Asperger's ever go away?”

4.3.3 Subordinate theme: *“The Life I Wanted”*

The subordinate theme *The Life I Wanted* reflects participants and their daughters coming to terms with the diagnosis. Table 18 shows illustrative quotations for each participant.

Table 18 Illustrative quotations for The Life I Wanted

Participant	Quotations
Claire	<ul style="list-style-type: none"> we (.) totally (.) changed our family dynamic (.) of (.) being a family (.) um (.) that (.) is lots of fun (.) that have lots of jokes (.) with each other “I'm not being part of a base” (.) you know (.) she said “I don't want to be known as the freak kid who comes into mainstream” [quoting Charlotte]
Elaine	<ul style="list-style-type: none"> she's quite happy to tell all her friends (.) you know she's (.) she's fine about that (.) she doesn't necessarily want me to tell friends' parents
Fiona	<ul style="list-style-type: none"> and I I went back with that form ((pause)) and she ((pause)) I'll never forget it (.) I will never forget it (.) cos I'm sat in the chair (.) and she goes “you all right (.) I said “yeah fine” [describing receiving diagnosis] I'm bawling my eyes out
Olivia	<ul style="list-style-type: none"> I thought oh God is she not going to have the life ((pause)) and uh (.) you make assumptions about your kids and then I just you know kind of got my act together and it was fine (.) and it's been fine ever since
Tracy	<ul style="list-style-type: none"> like a brick in the stomach it's like her guilty secret (.) that she mustn't tell people

Fiona, Olivia and Tracy were all presented with the idea of ASD quite suddenly and

their initial reactions seem to reflect this, Tracy's violent metaphor, "a brick in the stomach" suggestive of incapacitation by physical assault. Fiona spoke vividly in the present tense of Rachel's diagnosis weeks earlier, perhaps reflecting her continued experience of these feelings. Olivia described her reaction in cognitive terms as her assumptions about the future appeared swept away:

"a bit similar to when um somebody comes out (.) as gay [...] it takes people a little while (.) to (.) rewrite the plans they have",

suggesting ASD was equal but different and perhaps reflecting a deliberate decision to think positively. For others, coming to terms appeared harder. Claire described practical adjustments as her family dynamic changed, as if changing their identity:

"because that is just who we are";

and identity appeared important for daughters who had to decide whether to tell others of their diagnosis, described by Tracy as Sophie's "guilty secret". Adjustment was also on-going for Claire who spoke broadly, and eloquently, about the day-to-day emotional impact and the difficulty of managing these feelings whilst fighting for her daughter:

"it's (.) really (.) hard being an autism parent (.) because you have all these feelings (.) that you manage about your child (.) all your worries (.) about them (.) and some of your own feelings about you know injustice (.) about services that they're offered (.) and (.) things that should be in place to meet their needs that aren't (.) um (.) you know (.) and you have you have to be able to regulate yourself (.) so that you don't vent that (.) on all the people that you meet with (.) and wreck the relationships and them like wanting to help you".

5 Discussion

This thesis aimed to explore the lived experience of mothers of daughters in mainstream secondary schools with a diagnosis of ASD in terms of the diagnostic journey and their perceptions of the outcome of this journey. This section will

discuss the research questions in relation to previous research, using psychological theory to propose tentative links between themes. In particular, these findings will be related to systemic thinking to argue that the difficulty of participants' journey arose not solely from a lack of knowledge about girls and ASD but also from factors inherent in schools and CAMHS as systems.

5.1 The Research Questions

In general, participants experienced the journey as long, difficult and somewhat lonely as illustrated by the subordinate themes *Fighting on My Own* and *Who's Got the Key?*. The school and health systems they were negotiating apparently focused on their own interests and participants sometimes felt attacked and belittled as illustrated by *What the System Needs*, *Hauled Over the Coals* and *Pain in the Arse*. Their daughters' experiences within schools were similarly difficult as illustrated by *Very Much a Swan* and *So Uncomfortable* and in both cases this was followed by crisis as illustrated by *Breaking Point* and *Going to Pieces*. Throughout, competing social constructs of ASD made the journey more challenging as illustrated by *Surely That's Boys*. Participants' constructs of ASD and of their daughters evolved as illustrated by *A Process of Discovery* and this subordinate theme offers a backdrop to the journey as participants came to terms with their evolving understanding as illustrated by *The Life I Wanted*.

Continuing the analogy of a journey, diagnosis did not appear to represent the destination; instead it appeared to signal that participants and their daughters had found the right platform from which to start their travels although in some cases they had perhaps missed their train and wondered if the next one would get them where they wanted to be. Diagnosis did not bring immediate changes for participants and the subordinate themes within *JUST GETTING NOWHERE* reflect participants'

experiences both before and after diagnosis.

5.2 Previous Research

This analysis is consistent with much previous research, both quantitative and qualitative, which indicates that parents do not feel listened to (Van Tongerloo, Van Wijngaarden, van der Gaag, & Lagro-Janssen, 2015); that they are given limited information and left feeling like bad parents (L. A. Osborne & Reed, 2008); that it is difficult to find support (Safe, Joosten, & Molineux, 2012); that schools and primary care doctors do not recognise the symptoms of ASD in girls (Aggarwal & Angus, 2015); and that difficulties are not recognised if they do not cause a difficulty for schools (Dworzynski et al., 2012). In addition, the style in which participants spoke, at times vivid and in the present tense, recalling small details and precise dialogue, speaking in whispers, echoes research describing French parents' experiences of being told of a diagnosis of ASD in which participants' accounts were likened to those of parents receiving diagnoses of life-threatening illnesses:

“every word in detail, the expressions, the manner and the style of delivery”
(Chamak, Bonniau, Oudaya, & Ehrenberg, 2011, p.94).

5.3 The Female Phenotype

Consistent with previous literature, the male phenotype of ASD as reflected in *Surely That's Boys* appeared to dominate thinking among professionals and impede participants' journeys (Haney, 2015; Head et al., 2014). This appeared to arise, in part, from an understanding of ASD as a fixed concept rather than a social construct (Connor, 2013; Huws & Jones, 2013) as was apparent in the way discussion was curtailed by professionals. This can be contrasted with participants' own understanding which recognised the differences between their own daughters and stereotypes of ASD and highlights the importance of female narratives in

challenging dominant discourses (Connor, 2013; Gould & Ashton-Smith, 2011).

Further, even when daughters had diagnoses of ASD, the dominant social construct of ASD, which does not acknowledge that it is a social construct (Connor, 2013), appears to reify ASD, leading to the positioning of the problem within the child rather than between the child and her environment. This is perhaps illustrated by Claire's experience of school expecting Charlotte to be like boys with a diagnosis:

"school were kind of (.) well this is autism (.) this is what it looks like".

However, experiences reflected in *Surely That's Boys* did not only impact on participants' journeys by delaying recognition of their daughters' difficulties, the self-doubt this appeared to engender seemed to contribute to the negative experiences reflected in *Pain in the Arse* which occasionally dissuaded participants from taken action.

Participants' experiences also highlighted the negativity of the dominant stereotype with the emphasis on deficit which, as Connor (2013) has argued, has a negative impact on identity and self-understanding and is reflected in *The Life I Wanted*.

5.4 Systemic Thinking

Although poor understanding of the female phenotype pervaded many aspects of participants' journeys, it may not be sufficient to explain how participants found themselves constructed through the system and how they appeared to internalise aspects of these constructions. These aspects of participants' experiences can be illuminated by exploring elements of systemic thinking and their interaction with the dominant construct of ASD.

The experiences reflected in *What the System Needs* suggest that a

fundamental difference existed between the way in which schools and participants constructed the “problem” just as *Very Much a Swan* reflected the contrast between the way schools and participants constructed the daughters. Participants raised concerns about their daughters’ well-being as reflected in *So Uncomfortable* and *Going to Pieces*; however, schools appeared to reframe these in terms of academic concerns. Gameson & Rhydderch (2008) argue that the construction of a problem will have a reciprocal relationship with the construction of the expected solution which is perhaps reflected in Tracy being offered literacy and numeracy catch-up for her academically able daughter and, thus, agreement could not be reached on solutions.

As participants appeared to threaten the school’s coherence (Dowling, 1994) by disputing the school’s construction of the problem, or suggesting that a problem existed that the school could not recognise, schools seemed to respond by resisting change and maintaining homeostasis (E. L. Osborne, 1994). Thus, when participants’ daughters were removed from the classroom to enable them to “cope”, this could represent a quick fix rather than a systemic solution which requires the system to adapt and which Gameson & Rhydderch (2008) suggest may be necessary for lasting change. Therefore, it seems, experiences reflected in *So Uncomfortable* persisted. This may have implications for whether the adaptations offered by schools can be said to be inclusive rather than integrative (Rodriguez & Garro-Gil, 2015) and this will be discussed in Part 3.

Further, by schools asserting their role as experts, as perhaps occurred when Tracy’s use of “terrified” was appropriated, when participants were not allowed to express their concerns and when concerns were apparently normalised, they seemed to force participants into the role of *Pain in the Arse* as participants felt they had to

keep “bashing on” in order to be heard but were seemingly not allowed the space to have coherent discussions as when Fiona was literally denied access to her daughter’s school. Thus participants’ behaviour is perhaps maintained through a process of circular causality (Beaver, 2011) and they might therefore become part of the problem, as perceived by school, rather than part of the solution and, hence, mothers’ experiences of being *Hauled Over the Coals*.

A similar pattern of rigidity in which a closed system sought to assert its role as expert in response to threat can perhaps be seen when Tracy and Elaine challenged decisions made by CAMHS. Tracy reported Sophie’s therapy being terminated by CAMHS when she questioned Sophie’s Gillick competence and Elaine described language apparently used to curtail rather than enable dialogue when she asked why Emily should be anxious without an underlying cause:

‘well we don’t always know why people have heart attacks do we?’ (Elaine quoting CAMHS).

In trying to rigidly maintain the coherence of their soft systems (Gameson & Rhydderch, 2008), such as form period and Gillick competency for Sophie and 100% attendance for Emily, as well as being closed to the participants’ perspectives, it can be argued that the schools and health service came to mirror the symptoms of ASD that they did not recognise in participants’ daughters. Only in response to a *breaking point* were the patterns of circular causality apparently broken and change achieved.

6 Contribution to Knowledge

This thesis brings together many ideas reflected in the literature and places them within the context of mothers’ lived experiences and within the context of their interactions with the school system, where their daughters’ differences and

difficulties often became apparent and where they often first sought help, and within the health system. Within this context, this thesis extends understanding of how dominance of the male phenotype in the social construction of ASD can pervade the experiences of mothers and daughters not just in the diagnostic process but also in school.

By using IPA to analyse in-depth, personal accounts of mothers' experiences, this thesis offers detailed understanding of the potential impact, immediate and long-term of girls on the autism spectrum being educated in a system that neither recognises nor meets their needs. It also suggests how systemic factors can perpetuate rather than alleviate what the foregoing analysis suggests it would be appropriate to call suffering.

7 Strengths and Limitations of the Research

A strength of the current research was the use of IPA both to produce a rich account of participants' experiences and through the associated use of semi-structured interviews to allow participants to guide data-collection rather the researcher deciding important areas for discussion. This allowed for a detailed examination of the impact of the diagnostic journey on participants and their daughters. However, in keeping with the principles of IPA, the research findings presented here are ideographic and cannot be generalised (Smith et al., 2009); also, analysis remains subjective (Smith, 2004).

A further limitation arose from using five participants, producing an abundance of data. Analysing the experience of five participants within a short report risks losing much of the detail and it requires a particularly attentive reader to appreciate the individuality of each participant's experience.

8 Suggestions for Future Research

Although participants' accounts reflected much of their daughters' experiences, this added an additional layer of interpretation to the “double hermeneutic” of IPA (Smith et al., 2009): it would be valuable to explore in detail daughters' accounts of their diagnostic journeys and school experiences. In addition, schools have not had a voice here and it would seem that their role is an important one. An exploration of the perspective of special educational needs co-ordinators (SENCOs) and pastoral heads, that examined processes as well as knowledge and understanding, would be informative.

9 Implications for Educational Psychologists

The work of EPs is often about exploring hypotheses based on psychological knowledge (Beaver, 2011) and in this respect these findings are useful. In addition to disseminating knowledge about girls and ASD, it is important for EPs to find ways to talk about the girls that schools do not tell us about, perhaps those whose parents are “pests” and “paranoid”, and to help identify barriers to communication. Even where the diagnostic journey appears relatively smooth there remains a role for EPs in helping schools support parents on that journey.

10 Conclusion

This thesis aimed to explore in depth the experiences of mothers with daughters in mainstream secondary schools who had been given a diagnosis of ASD. These personal accounts showed that participants' experiences could be highly stressful with long-term negative consequences. Schools and the health service could be perceived as not listening and focused on their own interests. However, the

divergent perspective offered by Olivia suggests that, when needs are recognised, girls with ASD can be helped to thrive in mainstream schools.

11 References

- Aggarwal, S., & Angus, B. (2015). Misdiagnosis versus missed diagnosis: Diagnosing autism spectrum disorder in adolescents. *Australasian Psychiatry*, 23(2), 120–123.
- Attwood, T. (2006). The pattern of abilities and development of girls with Asperger's syndrome. In T. Attwood & T. Grandin (Eds.), *Asperger's and girls*. Arlington, Texas: Future Horizons, Inc.
- Attwood, T. (2015). *The complete guide to Asperger's syndrome* (Revised). London: Jessica Kingsley Publishers.
- Baron-Cohen, S., Lombardo, M. V, Auyeung, B., Ashwin, E., Chakrabarti, B., & Knickmeyer, R. (2011). Why are autism spectrum conditions more prevalent in males? *PLoS Biology*, 9(6), e1001081.
- Beaver, R. (2011). *Educational psychology casework: A practice guide* (2nd ed.). London: Jessica Kingsley Publishers.
- Begeer, S., Mandell, D., Wijnker-Holmes, B., Venderbosch, S., Rem, D., Stekelenburg, F., & Koot, H. M. (2013). Sex differences in the timing of identification among children and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 43(5), 1151–1156.
- Bitsika, V., Sharpley, C. F., & Bell, R. (2013). The buffering effect of resilience upon stress, anxiety and depression in parents of a child with an autism spectrum disorder. *Journal of Developmental and Physical Disabilities*, 25(5), 533–543.
- Bodfish, J. W., Symons, F. J., & Lewis, M. H. (1999). The repetitive behavior scale-revised. *Western Carolina Center Research Reports*.
- Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide*

- for beginners*. Los Angeles: SAGE.
- Burr, V. (2015). *Social constructionism* (3rd ed.). Hove: Routledge.
- Chamak, B., Bonniau, B., Oudaya, L., & Ehrenberg, A. (2011). The autism diagnostic experiences of French parents. *Autism, 15*(1), 83–97.
- Connor, D. J. (2013). Kiss my Asperger's: Turning the tables of knowledge. *International Journal of Inclusive Education, 17*(2), 111–129.
- Dowling, E. (1994). Theoretical framework: A joint systems approach to educational problems with children. In E. Dowling & E. L. Osborne (Eds.), *The family and the school: A joint systems approach to problems with children* (2nd ed.). London: Routledge.
- Dworzynski, K., Ronald, A., Bolton, P., & Happé, F. (2012). How different are girls and boys above and below the diagnostic threshold for autism spectrum disorders? *Journal of the American Academy of Child and Adolescent Psychiatry, 51*(8), 788–797.
- Eatough, V., & Smith, J. A. (2011). Interpretative phenomenological analysis. In C. Willig & W. Stainton-Rogers (Eds.), *The SAGE handbook of qualitative research in psychology* (pp. 179–194). Los Angeles: SAGE Publications Ltd.
- Firth, I., & Dryer, R. (2013). The predictors of distress in parents of children with autism spectrum disorder. *Journal of Intellectual and Developmental Disability, 38*(2), 163–171.
- Fombonne, E. (2003). Epidemiological surveys of autism and other pervasive developmental disorders: An update. *Journal of Autism and Developmental Disorders, 33*(4), 365–382.
- Gameson, J., & Rhydderch, G. (2008). The constructionist model of informed and reasoned action (COMOIRA). In B. Kelly, L. Woolfson, & J. Boyle (Eds.),

Frameworks for practice in educational psychology: A textbook for trainees and practitioners. London: Jessica Kingsley Publishers.

- Goin-Kochel, R. P., Mackintosh, V. H., & Myers, B. J. (2006). How many doctors does it take to make an autism spectrum diagnosis? *Autism, 10*(5), 439–451.
- Gould, J., & Ashton-Smith, J. (2011). Missed diagnosis or misdiagnosis? Girls and women on the autism spectrum. *Good Autism Practice, 12*(1), 34–41.
- Haney, J. L. (2015). Autism, females, and the DSM-5: Gender bias in autism diagnosis. *Social Work in Mental Health, 14*(4), 396–407.
- Head, A. M., McGillivray, J. a., & Stokes, M. a. (2014). Gender differences in emotionality and sociability in children with autism spectrum disorders. *Molecular Autism, 5*(1), 19.
- Hiller, R. M., Young, R. L., & Weber, N. (2014). Sex differences in autism spectrum disorder based on DSM-5 criteria: Evidence from clinician and teacher reporting. *Journal of Abnormal Child Psychology, 42*(8), 1381–1393.
- Hinkka-Yli-Salomäki, S., Banerjee, P. N., Gissler, M., Lampi, K. M., Vanhala, R., Brown, A. S., & Sourander, A. (2014). The incidence of diagnosed autism spectrum disorders in Finland. *Nordic Journal of Psychiatry, 68*(7), 472–480.
- Huws, J. C., & Jones, R. S. P. (2013). I'm really glad this is developmental: Autism and social comparisons: An interpretative phenomenological analysis. *Autism, 19*(1), 84–90.
- Kopp, S., & Gillberg, C. (2011). The Autism Spectrum Screening Questionnaire (ASSQ)-Revised Extended Version (ASSQ-REV): An instrument for better capturing the autism phenotype in girls? A preliminary study involving 191 clinical cases and community controls. *Research in Developmental Disabilities, 32*, 2875–2888.

- Linton, K. F., Krcek, T. E., Sensui, L. M., & Spillers, J. L. H. (2014). Opinions of people who self-identify with autism and Asperger's on DSM-5 criteria. *Research on Social Work Practice, 24*(1), 67–77.
- Mandy, W., Chilvers, R., Chowdhury, U., Salter, G., Seigal, A., & Skuse, D. (2012). Sex differences in autism spectrum disorder: Evidence from a large sample of children and adolescents. *Journal of Autism and Developmental Disorders, 42*(7), 1304–1313.
- O'Halloran, M., Sweeney, J., & Doody, O. (2013). Exploring fathers' perceptions of parenting a child with Asperger syndrome. *Journal of Intellectual Disabilities, 17*(3), 198–213.
- Osborne, E. L. (1994). An educational psychologist's perspective. In E. Dowling & E. L. Osborne (Eds.), *The family and the school: A joint systems approach to problems with children* (2nd ed.). London: Routledge.
- Osborne, L. A., & Reed, P. (2008). Parents' perceptions of communication with professionals during the diagnosis of autism. *Autism, 12*(3), 309–324.
- Oswald, T. M., Winter-Messiers, M. A., Gibson, B., Schmidt, A. M., Herr, C. M., & Solomon, M. (2016). Sex differences in internalizing problems during adolescence in autism spectrum disorder. *Journal of Autism and Developmental Disorders, 46*(2), 624–636.
- Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism, 18*(7), 756–70.
- Posserud, M. B., Lundervold, A. J., & Gillberg, C. (2006). Autistic features in a total population of 7-9-year-old children assessed by the ASSQ (Autism Spectrum Screening Questionnaire). *Journal of Child Psychology and Psychiatry and*

Allied Disciplines, 47(2), 167–175.

Rodriguez, C. C., & Garro-Gil, N. (2015). Inclusion and integration on special education. *Procedia - Social and Behavioral Sciences*, 191, 1323–1327.

Rutherford, M., McKenzie, K., Johnson, T., Catchpole, C., O'Hare, A., McClure, I., ... Murray, A. (2016). Gender ratio in a clinical population sample, age of diagnosis and duration of assessment in children and adults with autism spectrum disorder. *Autism*, 20(5), 628–634.

Safe, A., Joosten, A., & Molineux, M. (2012). The experiences of mothers of children with autism: Managing multiple roles. *Journal of Intellectual and Developmental Disability*, 37(4), 294–302.

Scott, F. J., Baron-Cohen, S., Bolton, P., & Brayne, C. (2002). The CAST (Childhood Asperger Syndrome Test): Preliminary development of a UK screen for mainstream primary-school-age children. *Autism*, 6(1), 9–31.

Siklos, S., & Kerns, K. A. (2007). Assessing the diagnostic experiences of a small sample of parents of children with autism spectrum disorders. *Research in Developmental Disabilities*, 28(1), 9–22.

Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, 1(1), 39–54.

Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis. In *Qualitative psychology: A practical guide to research methods* (2nd ed.). London: SAGE Publications Ltd.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. Los Angeles: SAGE.

Solomon, M., Miller, M., Taylor, S. L., Hinshaw, S. P., & Carter, C. S. (2012).

- Autism symptoms and internalizing psychopathology in girls and boys with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 42, 48–59.
- Van Tongerloo, M. A. M. M., Van Wijngaarden, P. J. M., van der Gaag, R. J., & Lagro-Janssen, A. L. M. (2015). Raising a child with an autism spectrum disorder: “If this were a partner relationship, I would have quit ages ago.” *Family Practice*, 32(1), 88–93.
- Van Wijngaarden-Cremers, P. J. M., van Eeten, E., Groen, W. B., Van Deurzen, P. A., Oosterling, I. J., & Van der Gaag, R. J. (2014). Gender and age differences in the core triad of impairments in autism spectrum disorders: A systematic review and meta-analysis. *Journal of Autism and Developmental Disorders*, 44(3), 627–635.
- Vasilopoulou, E., & Nisbet, J. (2016). The quality of life of parents of children with autism spectrum disorder: A systematic review. *Research in Autism Spectrum Disorders*, 23, 36–49.
- Whiteley, P., Todd, L., Carr, K., & Shattock, P. (2010). Gender ratios in autism, Asperger syndrome and autism spectrum disorder. *Autism Insights*, 2, 17–24.
- Williams, J. G., Allison, C., Scott, F. J., Bolton, P. F., Baron-Cohen, S., Matthews, F. E., & Brayne, C. (2008). The Childhood Autism Spectrum Test (CAST): Sex differences. *Journal of Autism and Developmental Disorders*, 38, 1731–1739.
- Willig, C. (2008). *Introducing qualitative research in psychology: Adventures in theory and method* (2nd ed.). Maidenhead: Open University Press.



“Being an autism parent”

Mothers’ experiences from initial concerns about their daughters to a diagnosis of autism spectrum disorder: An interpretative phenomenological analysis

PART THREE: CRITICAL APPRAISAL

(Word Count: 5982)

1 Critical Account of Research Practitioner

1.1 Rationale for Thesis

1.1.1 Inspiration

Inspiration for this thesis developed out of my experience as a teacher and trainee educational psychologist (TEP). As a TEP, I had become aware of the apparent emotional impact on some mothers, who I met far more frequently than fathers, as they negotiated a path between education and health services in a quest to find solutions for their children's difficulties in school. Secondly, as both teacher and TEP, I had noticed what seemed a paradox in the treatment of a number of girls with diagnoses of autism spectrum disorder (ASD): although acknowledged to have difficulties with social skills, they were sometimes isolated from same-sex peers in placements or intervention groups where they were the only girl, a situation which Wagner (2006) argues is unlikely fully to meet their needs. Further, I was sometimes told by schools that, because of ASD, the girls did not mind.

These thoughts came together when I read an informal account of several high-achieving women who had struggled to get a diagnosis of Asperger's or ASD in adulthood (Townsend, 2015). This led me to reflect on my own tendency, encouraged by the Doctoral in Educational Psychology course, to question the usefulness of labels and diagnoses in meeting the needs of children in schools (Lauchlan & Boyle, 2007) and the impact of these on children (Taylor, Hume, & Welsh, 2010). It appeared that a diagnosis was important for these women in understanding themselves and I wondered what impact a late diagnosis might have on girls' experiences in school, particularly if their needs were not being met.

This prompted me to consider a number of informal questions including: whether research had explored the experience of mothers in the diagnostic journey;

whether the longer diagnostic journey impacted on their daughters' experiences in school; what the role of educational psychologists (EPs) was in this journey; what were "we" collectively, as professionals, doing to these mothers; and, most importantly, what could be learned that might help an EP contribute towards making the journeys and the school experiences better.

1.1.2 Initial literature search

An initial literature search revealed that research exploring diagnostic experiences focused on the clinical process (e.g. Rutherford et al., 2016) with the length of the process measured from the first point of contact with a health professional (Crane, Chester, Goddard, Henry, & Hill, 2016): this excluded exploration of what happens in school which from the perspective of a TEP excluded the place where first concerns might be raised by parents. A further gap was that qualitative research into the diagnostic process often used thematic (Braiden, Bothwell, & Duffy, 2010) or content analysis (Osborne & Reed, 2008) which highlighted important aspects of the process with limited exploration of what this might mean to participants.

Therefore, I felt there was a gap in the literature both in exploring the diagnostic journey from the earliest concerns, which I anticipated would include school, and in doing so from a more experiential perspective. This will be discussed below in relation to the ontology and epistemology of the thesis.

This gap in the literature helped to narrow and refine my informal questions into the research questions:

- How do mothers of girls in mainstream schools experience the diagnostic journey of their daughters from initial concerns to a diagnosis of ASD?
- How do mothers experience the outcomes of this diagnostic journey?

1.1.3 Personal position

My interest in daughters with diagnoses of ASD is purely professional. However, I came to this research with a number of preconceptions based on my professional experience which it is important to acknowledge. I expected that participants would have had negative experiences, particularly in trying to get their daughters' needs recognised, and that this would have been an emotive issue for them. I did not anticipate the extent to which it would remain an emotive issue.

1.2 Methodological Considerations

1.2.1 Ontology

Witnessing the apparent distress of mothers, suggested to me that it would be valuable to adopt a relativist ontology, acknowledging there are multiple ways of interpreting the world. Thus, two people may provide very different constructions of the same phenomenon, for example a meeting between teacher and parent, without either being privileged as the true or superior account (Willig, 2008). This is in keeping with the overall research aims and a concern not with *what* happened so much as *how* participants experienced what they perceived to have happened.

As Maya Angelou may or may not have said, “I’ve learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel.”²⁷

1.2.2 Epistemology

Given the relativist ontology, a social constructionist epistemology was adopted. This recognises that phenomena are constructed through the language used to discuss them (Burr, 2015). Further, these constructions are influenced by the

²⁷ Reflecting the ontological position, this is presented without reference as no objective fact is claimed about whether Maya Angelou said this. The only claim is that some people might think she said it.

cultural and social setting in which they occur (Gergen, 2015). Thus, within this thesis, it is acknowledged that the accounts given by participants will be influenced by their experience of talking to the researcher. This epistemological position allows for the possibility that participants' constructs of their experiences may change over time and context, contain contradictions and perhaps conflict with apparent "facts".

An alternative epistemology that was rejected was that of constructivism. Although this has similarities with social constructionism in that both positions challenge the idea of an objective reality, constructivism places the construction of meaning within the individual (Gergen, 2015). This position did not appear to fit with my experience in which mothers' experiences appeared to be influenced by the way they were spoken about in school.

1.2.3 Interpretative phenomenological analysis

In keeping with the research aims of exploring individual lived experiences (Smith, Flowers, & Larkin, 2009; Willig & Stainton-Rogers, 2008) and the ontological and epistemological positions outlined above, the chosen methodology is that of interpretative phenomenological analysis (IPA) which has its theoretical basis in hermeneutics, phenomenology and idiography (Smith et al., 2009)²⁸.

Phenomenology argues that human experience is worthy of and admits of detailed examination. It posits that experiences do not exist as independent objective entities but become phenomena in the sense-making processes that people bring to them. Thus, *what* happened is less important from a phenomenological perspective than the *experience* of what happened. A tenet of phenomenology is that we bring our embodied selves to our experiences which "shapes the fundamental character of our knowing about the world" (Smith et al., 2009, p.19).

²⁸ The following outline of these theoretical underpinnings is derived from Smith et al. (2009).

Hermeneutics is concerned with interpretation and IPA is said to involve a *double hermeneutic* (Smith & Osborn, 2008) whereby participants interpret their own experiences through their accounts and the researcher interprets these accounts. A key assumption of IPA is that we bring preconceptions to the phenomena we interpret: as researchers, we cannot know the entirety of these preconceptions and must engage in a cyclical process of reflection, reflexivity and re-engagement with the phenomenon to increase our awareness of preconceptions and minimise their impact on our interpretations. Following this process, it is argued that the researcher is able to bring insights to the participants' experiences through detailed analysis, sometimes of multiple cases, and through consideration of psychological theory.

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).

1.2.4 Alternative methodologies

An alternative methodology considered was narrative theory which, like IPA, draws on phenomenology, is compatible with a social constructionist epistemology and seeks to explore lived experience (Crossley, 2000b). To an extent, narrative theory has been positioned in relation to IPA, with Crossley (2000a) arguing that IPA risks perpetuating a “romanticist” (p.40) view of the self and experience and ignoring the power relations and the availability of dominant narrative structure within and through which self and experience are constructed. However, narrative theory appeared to emphasise “the study of self and identity” (Crossley, 2000b, p.527) and “personal narratives” (Crossley, 2000a, p.70) which I felt was not compatible with my research questions as it would shift the emphasis from the experience to the self in society.

Having returned to thinking about narrative theory, it is apparent that it would have been an interesting methodology to apply to the broad topic of this thesis. Power relations between participants and the school and health systems appeared to shape participants' experiences and there was a sense in which participants were cast into the role of *pain in the arse* with implications for their journeys. However, these findings were not foreseen and a narrative approach might not have enabled exploration of the experiences reflected in *Diamond-Shaped Daughters*, which did not seem directly related to participants' sense of self and identity.

1.2.5 Semi-structured interviews

The ontological and epistemological stance of this thesis, together with the theoretical underpinnings of IPA, suggested semi-structured interviews as an appropriate method of data collection. These enable a dialogue between researcher and participant (Smith & Osborn, 2008), acknowledging the social construction of meaning. They also allow participants to guide discussion, encouraging a focus on what is of "significance to the person" (Smith et al., 2009, p.33) rather than the choice of questions being solely guided by the researcher. However, by the researcher identifying key areas to cover, it allows a focus on the research questions and for comparisons to be made across participants.

1.3 Selection and Recruitment of Participants

1.3.1 Inclusion and exclusion criteria

The full inclusion and exclusion criteria for participants are given in Table 19.

Table 19 Participant inclusion and exclusion criteria

Criteria
Mothers were recruited who met the following criteria:
<ul style="list-style-type: none"> • Had a daughter who had been given a diagnosis of ASD, or a closely-related disorder such as Asperger's syndrome, in the UK within the last five years; • The daughter was under the care of the same health authority for her entire diagnostic journey; • The daughter was in secondary school;²⁹ • The daughter had mainly been educated in mainstream state schools; • The daughter did not have additional educational needs as the result of another diagnosis.

All criteria were used to ensure that participants were a “fairly homogenous” group (Smith et al., 2009; Smith & Osborn, 2008). However, there were other considerations. As the literature suggested there were particular problems recognising the symptoms of ASD in cognitively able girls it was their mothers I hoped to interview. Given the timing of interviews, focusing on girls already in secondary school who had been diagnosed within the previous five years, gave a potential minimum age at diagnosis of 6 years and 11 months compared to the mean age of diagnosis for Asperger's syndrome of 6.6 years reported in a UK and Ireland sample (Whiteley, Todd, Carr, & Shattock, 2010). Focusing on girls who had experienced the transition to secondary school was informed by evidence suggesting this transition could lead to social difficulties becoming more obvious (Rivet & Matson, 2011), perhaps through a combination of the changing nature of girls' peer-group relations and the change from one environment to another (Attwood, 2015; Gould & Ashton-Smith, 2011)³⁰.

‘Cognitively able’ was difficult to codify in a way that would be both meaningful to potential participants and practical. This was captured to an extent by

²⁹ Principal Educational Psychologists were asked to only send the letter to mothers whose daughters were in secondary school although this criterion was not specified in the letter.

³⁰ Although Mandy et al. (2016) reported no increase in difficulties as measured by the *Strengths and Difficulties Questionnaire* (Goodman, 1997) following the transition to secondary school, their sample included just three girls among their twenty-eight participants.

focusing on girls in mainstream schools although it is recognised that many children with IQ scores below 70 are educated in mainstream schools; it was also reflected in the criterion that girls not have additional learning needs as the result of another diagnosis which was again difficult to codify. However, in keeping with the social constructionist epistemology, any additional diagnoses the participants' daughters had were not privileged as having any objective status; instead, participants themselves were allowed to determine whether they experienced these diagnoses as giving rise to additional educational needs.

1.3.2 Mothers

The decision to focus on mothers arose partly as the result of my experiences as a TEP. In addition, mothers have formed the majority of respondents in several questionnaire-based surveys of children with ASD (May, Cornish, & Rinehart, 2014; Siklos & Kerns, 2007). This is supported by research suggesting fathers might sometimes be less involved in the diagnostic process (O'Halloran, Sweeney, & Doody, 2013). Research also suggests that men and women can sometimes be treated differently by healthcare professionals with women's concerns being taken less seriously (Chapman, Kaatz, & Carnes, 2013). Therefore, the lived experience of mothers possibly differs from that of fathers and focusing on mothers was in keeping with the IPA principle of homogeneity of experience (Smith et al., 2009).

1.3.3 Recruitment

Gatekeeper letters (Appendix G) were sent to Principal Educational Psychologists in twenty local authorities in England and Wales over a period of six weeks. Twelve authorities agreed to pass letters (Appendix H) and information sheets (Appendix I) to mothers who met the selection criteria.

Participants were recruited via EPSs to enable confirmation of diagnosis. It

also enabled me to recruit gradually to limit the number of women invited to participate. Recruitment via an on-line forum could have potentially attracted too many participants and made it difficult to confirm diagnosis. I was concerned that recruitment via EPSs would give them control over who was invited to participate. This was an ethical rather than methodological consideration as the sample was not intended to be representative. However, this had to be weighed against ethical concerns about over-recruitment.

1.4 Data Collection

At the start of interviews, participants were reminded of their right to withdraw at any point and to decline to answer any questions; they were reminded that transcripts would be anonymised and then asked to read and sign the consent form (Appendix J).

During interviews, account was taken of participants' reactions and topics were not probed if participants appeared uncomfortable or upset. At the end of each interview, participants were fully debriefed. The debrief sheet (Appendix K) also signposted participants to their GP and national and local organisations that support the parents of children with ASD if they felt the need for this.

1.5 Analysis of Data

The biggest difficulty was analysing the large amount of data as this was a time-consuming process for which there are no short cuts. The richness of data also meant that not every aspect of participants' accounts could be included in the final analysis. This partly arose due to my inexperience in using IPA. However, I concluded that it was more important to attempt to analyse a focused part of their stories well. I decided, therefore, to focus analysis on the mothers' experiences and their perceptions of their daughters' experiences. This meant excluding, for example,

the wider family impact. On reflection, I could have included fewer participants and did consider stopping at four. However, I feel it adds to the value of the research that the same themes were reflected in different ways in each account.

Even though the focus was narrowed, themes could not be explored in as much detail as I would have liked. A particularly interesting strand of the findings for me was the way dialogue within schools, and also within CAMHS, seemed to be controlled by the system and to create perhaps unintended outcomes such as the positioning of mothers as *pains in the arse*. It would have been interesting to explore this in more depth. However, I decided that this would necessitate a greater focus on the superordinate theme *Just Getting Nowhere* at the expense of the other two. I felt *Diamond-Shaped Daughters* added an important context to participants' experiences by provided an understanding of participants' concerns; similarly, *This Thing Called Asperger's* provided an informative context in terms of participants' developing understanding which helped me make sense of the experiences reflected in *Just Getting Nowhere*.

1.6 Other Ethical Considerations

The proposal for this thesis was written with the British Psychological Society (BPS) ethical guidelines in mind (British Psychological Society Ethics Committee, 2009) and ethical approval was obtained from the Cardiff University School of Psychology Ethics Committee. However, BPS guidelines acknowledge that ethical practice involves on-going decision-making in changing contexts.

1.6.1 Informed consent

Although I followed the procedures for informed consent agreed with the Cardiff University School of Psychology Ethics Committee, I became aware that participants arrived at interview unsure of the level of detail they would be asked and

wondering if they should have prepared. I therefore decided to tell participants when telephone contact was made prior to interview what they would be asked and to reassure them that I wanted to know about aspects of their stories that they felt were important.

1.6.2 Anonymity

Anonymity was of paramount importance in writing this thesis. As I had recruited via EPSs, it was conceivable they knew who had or might have taken part. Biographical details that might have identified participants to those who suspected their involvement were excluded from quotations. This occasionally influenced the choice of quotations but not so as to alter the analysis.

1.6.3 Harm

Speaking about their daughters' struggles was an emotive experience for some participants. Although I felt it was important not to ask probing questions when participants appeared upset, I also thought it important not to seem to ignore their distress or to seem to prevent them from talking about these aspects of their experience. I found this quite difficult in the first interview. However, I found subsequently that asking a closed question, for example "Do you know what that was?" in response to Tracy's discussion of bullying, gave space for her to give more details rather than asking her to do so.

2 Contribution to Knowledge

2.1 Contribution to the Literature

This thesis has contributed to the literature by taking a broader perspective on the diagnostic journey such that participants' experiences within the school system were explored from the time that concerns were first raised, which could be years

before contact was made with a health professional. This thesis has also focused on *how* participants experienced the journey rather than *what* they experienced, giving a rich picture of the impact on mothers and their daughters and sometimes a glimpse of the impact on their wider families. Equally importantly, the focus of the thesis has taken a narrower perspective in focusing on the experiences of the mothers of cognitively able girls which previous research suggests might be quite distinct from the experiences of parents of boys or of girls with cognitive disability (Begeer et al., 2013; Bitsika et al., 2013). Finally, the research offers a British perspective to complement the qualitative research reflecting French and Australian perspectives offered by Chamak, Bonniau, Oudaya, & Ehrenberg (2011) and Cridland, Jones, Caputi, & Magee (2014) respectively. Thus this thesis is unique in taking a broad view of the diagnostic journey with a narrowly-defined, and often neglected, group of children on the autism spectrum and exploring their mothers' experiences through an in-depth interpretative phenomenological analysis within the context of the UK school and health systems.

This thesis builds on previous research by highlighting how the dominance of the male phenotype is not just a potential problem at the diagnostic stage, as indicated in the research literature, but can perhaps affect almost every aspect of participants' journeys including schools' perceptions of ASD:

“the school were kind of (.) well this [a boy] is autism (.) this is what it looks like” (Claire);

interactions with health professionals:

“she’s not autistic (.) she’s just sat and talked to me” (Claire quoting her GP);

participants' own understanding of ASD:

I was naïve enough to think it didn’t happen to girls (Tracy);

and their daughters' sense of identity:

“and you think I’m like him!?” (Tracy quoting Sophie).

It has also highlighted how, despite the limited amount of peer-reviewed research into cognitively able girls on the autism spectrum, ASD is often perhaps reified, rather than recognised as a social construct, potentially closing off dialogue between parents and professionals.

This thesis complements previous research into diagnostic experiences which has tended either to be quantitative (Crane et al., 2016); to focus solely on experiences within the health service (Osborne & Reed, 2008); or to include diagnosis among the daily stresses of parenting a child with a diagnosis of ASD (Cridland et al., 2014). Thus, the experiences reflected in *Who’s Got the Key?* and *What the System Needs* complement the findings of Osborne & Reed (2008) by suggesting how the dissatisfaction they report in conversations with clinicians might be paralleled in the smaller and more frequent interactions that might take place in school. This thesis also offers a more experiential exploration of these conversations with school and CAMHS and, by providing an analysis informed by systemic thinking, suggests ways in which these interactions influence the course of the diagnostic journey as well as parents’ satisfaction with it. This is perhaps evidenced in the myriad ways conversation was shut down. This seemingly occurred as the result of interruptions:

“before [the teacher] would let me say anything else (.) she shut me down”
(Claire);

dismissive responses:

“well we don’t always know why people have heart attacks do we?” (Elaine, quoting CAMHS);

controlling when conversations occur:

“oh no no no no (.) you’ve got to have an appointment” he said “you can’t go in” (Fiona, quoting school);

and determining the format of conversations:

“we went into this meeting (.) in shock (.) from what they’d just said (.) plus having to work out this big meeting with the school and the GP and everything” (Claire).

This thesis also provides a unique perspective into the way that systemic factors, within schools particularly, appear to influence the broad diagnostic journey. The analysis shows how schools and health services have the potential to control priorities in interactions with parents, deciding *what the system needs*. This complements findings that schools are less likely than parents to identify internalising behaviours (Esler & Ruble, 2015; Hiller, Young, & Weber, 2014) to show how, by adopting the role of expert, services have the potential to position mothers as *pains in the arse* and to maintain their behaviour as such by controlling dialogue through setting the time, place and manner of discussion. Schools, in this expert role, may also inadvertently close down or reframe dialogue that does not reflect *what the system needs*. Thus, through interactions which might seem trivial, and well-meaning, to a school, mothers may come to feel that they are *fighting on their own*, unable to find *who’s got the key* and perhaps heading towards *breaking point*.

2.2 Contribution to Future Research

The experiences explored in this thesis emphasise the very real need for further systematic research into the female phenotype of ASD, particularly amongst cognitively able girls, which needs to be mindful of the limitations of current screening tools and recognise that the female phenotype exists in its own right rather than just as an ‘atypical’ variant on the male.

This thesis has touched on the quality of interactions between participants

and schools. Further useful research could explore the experience of those interactions more fully to investigate how they function from a systemic perspective.

It would seem to be important that the present findings are complemented by qualitative research exploring girls' own perspectives of aspects of their broad diagnostic journeys within school and the health service. This may serve to complement the experiences reflected in *Diamond-Shaped Daughters* and, given the experiences of mothers reflected in *A Process of Discovery*, may also offer fresh insights. These may both enhance understanding of the female phenotype at a more theoretical level and also suggest practical ways that the needs of girls can be met in school and during diagnosis.

A further area where the voices of girls themselves are important is within the experiences reflected in *A Process of Discovery* and *The Life I Wanted* which suggest that constructs of ASD have an impact of girls' self-image and are perhaps largely negative. Understanding of girls' constructs of ASD may suggest ways that those constructs can be modified to highlight the strengths participants saw in their daughters rather than only the struggles.

None of the foregoing analysis and discussion is meant to imply that individuals within schools are deliberately neglectful of the needs of girls with ASD and it is recognised that these individuals are operating within a system as much as are parents. However, individuals in schools, particularly special educational needs coordinators (SENCOs) and pastoral heads, often appeared to respond as parts of a system, and an exploration of their perspective would be informative. An important focus might be how SENCOs, and others who act as key-holders, understand their decision-making processes and how, perhaps, soft systems within school affect these processes. This may provide a different perspective on the experiences reflected in

What the System Needs and in *Just Getting Nowhere* more broadly.

2.3 Contribution to Professional Practice

It is neither possible nor desirable to make claims of generalisability for the findings of this research. This is in keeping with the ontological and epistemological basis of this thesis, together with the theoretical bases of IPA in hermeneutics and idiography particularly. Therefore, it is not claimed that the experiences of these participants are representative of all mothers of daughters with a diagnosis of ASD. However, as Yin (1989, cited in Smith et al., 2009) noted, a case study “is intended to demonstrate existence, not incidence” (Smith et al., 2009, p.30). So it is not important that 80% of participants had a poor experience but that four individuals did.

At the same time, however, it could be argued that this research is not just about girls or mothers or ASD but in some respects reflects wider issues concerning the journeys parents make to receive help for their children in schools. As such, the issues raised possibly concern all children with additional needs.

However, the experiences reflected in this thesis do not, generally, provide examples of good practice. Therefore, the contribution to professional practice can be at the level of encouraging reflective practice, through which it has been suggested we can move from the position of novice to that of expert (Tarrant, 2013).

Although this might have implications for schools, EPSs and health services, my professional practice only covers the first two so my recommendations will be restricted to those.

2.3.1 Within educational psychology services

It is evident that EPSs have a role in increasing schools’ understanding of girls with ASD. Although the female phenotype of ASD is not well understood

(Mandy et al., 2012) and it seems unlikely that training alone would enable relevant staff in schools to identify the needs of every girl in school who might meet the criteria for a diagnosis of ASD, EPs are in a unique position in having regular contact with schools and being trained to doctoral level in research methods. Further, as the foregoing discussion has suggested, systemic factors can be important in determining the ease of a parents' interactions with school. It is recommended, therefore, that educational psychology services:

- Contribute to research exploring the expression of the female phenotype within school environments.
- Provide training to schools that includes, among other things: the poor understanding of the female phenotype; typical friendship patterns; the impact of rigid/logical thinking on academic anxiety; the nature of sensory/social overload; ways to meet/reduce these needs.
- Promote understanding of a social model of disability within schools that de-problematise the child and focuses instead on outcomes and the removal of barriers to inclusion.
- Create opportunities for informal/anonymous discussions with schools/SENCOs about concerns raised by parents in order to build capacity within schools to identify and meet additional learning needs.

2.3.2 Within schools

Given that so much of the analysis in this thesis has focused on experiences within schools, it is useful to reflect on its findings in relation to the fundamental principles of the Special Educational Needs Code of Practice for Wales (Welsh

Assembly Government, 2004).³¹ These are outlined in Table 20.

Table 20 Fundamental principles of the Code of Practice

Fundamental Principles
• A child with special educational needs should have their needs met.
• The special educational needs of children will normally be met in mainstream schools or settings.
• The views of the child should be sought and taken into account.
• Parents have a vital role to play in supporting their child's education.
• Children with special educational needs should be offered full access to a broad, balanced and relevant education, based on the National Curriculum.

It would appear that participants' experiences frequently did not reflect these principles, particularly with respect to children having their needs met, the importance of the views of the child and the vital role of parents. It is recommended, therefore, that schools:

- Be aware of power and knowledge imbalances both within meetings with parents, and in the scheduling and format of such meetings, and give parents opportunities to bring advocates and/or indicate who they would like to attend.
- Adopt a person centred approach in respect of all children, for example through the use of one page profiles, both as a way of seeking the views of children and parents and of identifying and recording individual needs.
- Acknowledge the importance of social/non-teaching times in schools for all children by providing quiet, relaxing environments that any child can access.
- Provide quiet working spaces that some children can access during lesson time.
- Provide all children with social communication difficulties with

³¹ Although not all participants lived in Wales, the principles discussed here are similar to those in the Code of Practice for England (DoE, 2015).

access to an autism-aware member of staff who can give trusted advice should misunderstandings arise and advice to prevent misunderstandings from arising.

- Help children with diagnoses of ASD, and their parents, to develop their own solutions to perceived problems.

2.3.3 Within the classroom

Rodriguez & Garro-Gil (2015) explore the notion of integration and inclusion, with the former about the provision of designated spaces within schools for children with additional needs, perhaps in parallel to other children, and the latter about the provision of classrooms built around the needs of all pupils regardless of whether they have additional needs. The subtheme *So Uncomfortable* suggests that frequently classrooms and other spaces in school were not experienced as inclusive as leaving or being removed was often used as a strategy to help the girls “cope”.

The experiences reflected in this thesis, where girls sometimes had to identify their own needs and know when to remove themselves, suggest that the move from integration to inclusion as a model of meeting additional learning needs (Rodriguez & Garro-Gil, 2015) will not always meet the needs of girls with ASD, particularly if the environment itself is problematic. It is recommended, therefore, that class teachers:

- Provide written instructions for homework tasks that set clear parameters about what is expected, in terms of time, effort and content, in order to avoid both underachievement and excess effort.
- Oversee the movement of children between the classroom and other quiet working spaces such that children with ASD are not expected to monitor their own anxiety and comfort.

Help children with diagnoses of ASD to develop their own solutions to perceived problems.

2.4 Personal Practice

In the process of completing this thesis, I have increasingly reflected on three aspects of my personal practice. Firstly, it has made me reflect on the meaning for parents of apparently small interactions with professionals, such as a casual normalising of concerns, within the context of a parent's on-going relationship with a school. Secondly, it made me reflect on the conversations that do not happen, the parents who do not try again and do not challenge decisions. Finally, it made me reflect on the children who do not have resourceful, articulate and determined parents to advocate on their behalf.

2.5 Conclusions

This thesis aimed to provide in-depth and ideographic accounts of the lived experiences of mothers with daughters in secondary school who had been given a diagnosis of ASD. It has shown how the diagnostic journey can be perceived as long, difficult and lonely. Schools and health services do not always recognise the symptoms of ASD in girls and are, at times, perceived as self-serving; when challenged they can be perceived as hostile. It is suggested that systemic factors play an important role in this. This can be associated with crises for daughters, mothers and wider families with sometimes long-term negative consequences.

3 References

- Attwood, T. (2015). *The complete guide to Asperger's syndrome* (Revised). London: Jessica Kingsley Publishers.
- Begeer, S., Mandell, D., Wijnker-Holmes, B., Venderbosch, S., Rem, D., Stekelenburg, F., & Koot, H. M. (2013). Sex differences in the timing of identification among children and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 43(5), 1151–1156.
- Bitsika, V., Sharpley, C. F., & Bell, R. (2013). The buffering effect of resilience upon stress, anxiety and depression in parents of a child with an autism spectrum disorder. *Journal of Developmental and Physical Disabilities*, 25(5), 533–543.
- Braiden, H.-J., Bothwell, J., & Duffy, J. (2010). Parents' experience of the diagnostic process for autistic spectrum disorders. *Child Care in Practice*, 16(4), 377–389.
- British Psychological Society Ethics Committee. (2009). *Code of Ethics and Conduct. Ethics*. Leicester: British Psychological Society.
- Burr, V. (2015). *Social constructionism* (3rd ed.). Hove: Routledge.
- Chamak, B., Bonniau, B., Oudaya, L., & Ehrenberg, A. (2011). The autism diagnostic experiences of French parents. *Autism*, 15(1), 83–97.
- Chapman, E. N., Kaatz, A., & Carnes, M. (2013). Physicians and implicit bias: How doctors may unwittingly perpetuate health care disparities. *Journal of General Internal Medicine*, 28(11), 1504–1510.
- Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism*, 20(2), 153–162.

- Cridland, E. K., Jones, S. C., Caputi, P., & Magee, C. A. (2014). Being a girl in a boys' world: Investigating the experiences of girls with autism spectrum disorders during adolescence. *Journal of Autism and Developmental Disorders*, 44(6), 1261–1274.
- Crossley, M. L. (2000a). *Introducing narrative psychology: Self, trauma, and the construction of meaning*. Buckingham: Open University Press.
- Crossley, M. L. (2000b). Narrative psychology, trauma and the study of self/identity. *Theory and Psychology*, 10(4), 527–546.
- DoE. (2015). *Special educational needs and disability code of practice: 0 to 25 years*.
- Esler, A. N., & Ruble, L. A. (2015). DSM-5 Diagnostic criteria for autism spectrum disorder with implications for school psychologists. *International Journal of School & Educational Psychology*, 3, 1–15.
- Gergen, K. J. (2015). *An invitation to social construction* (3rd ed.). London: SAGE Publications Ltd.
- Goodman, R. (1997). The Strengths and Difficulties Questionnaire: A research note. *Journal of Child Psychology and Psychiatry*, 38(5), 581–586.
- Gould, J., & Ashton-Smith, J. (2011). Missed diagnosis or misdiagnosis? Girls and women on the autism spectrum. *Good Autism Practice*, 12(1), 34–41.
- Hiller, R. M., Young, R. L., & Weber, N. (2014). Sex differences in autism spectrum disorder based on DSM-5 criteria: Evidence from clinician and teacher reporting. *Journal of Abnormal Child Psychology*, 42(8), 1381–1393.
- Lauchlan, F., & Boyle, C. (2007). Is the use of labels in special education helpful? *Support for Learning*, 22(1), 36–42.
- Mandy, W., Chilvers, R., Chowdhury, U., Salter, G., Seigal, A., & Skuse, D. (2012).

- Sex differences in autism spectrum disorder: Evidence from a large sample of children and adolescents. *Journal of Autism and Developmental Disorders*, 42(7), 1304–1313.
- Mandy, W., Murin, M., Baykaner, O., Staunton, S., Hellriegel, J., Anderson, S., & Skuse, D. (2016). The transition from primary to secondary school in mainstream education for children with autism spectrum disorder. *Autism*, 20(1), 5–13.
- May, T., Cornish, K., & Rinehart, N. (2014). Does gender matter? A one year follow-up of autistic, attention and anxiety symptoms in high-functioning children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 44(5), 1077–1086.
- O'Halloran, M., Sweeney, J., & Doody, O. (2013). Exploring fathers' perceptions of parenting a child with Asperger syndrome. *Journal of Intellectual Disabilities*, 17(3), 198–213.
- Osborne, L. A., & Reed, P. (2008). Parents' perceptions of communication with professionals during the diagnosis of autism. *Autism*, 12(3), 309–324.
- Rivet, T. T., & Matson, J. L. (2011). Review of gender differences in core symptomatology in autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5(3), 957–976.
- Rodriguez, C. C., & Garro-Gil, N. (2015). Inclusion and integration on special education. *Procedia - Social and Behavioral Sciences*, 191, 1323–1327.
- Rutherford, M., McKenzie, K., Johnson, T., Catchpole, C., O'Hare, A., McClure, I., ... Murray, A. (2016). Gender ratio in a clinical population sample, age of diagnosis and duration of assessment in children and adults with autism spectrum disorder. *Autism*, 20(5), 628–634.

- Siklos, S., & Kerns, K. A. (2007). Assessing the diagnostic experiences of a small sample of parents of children with autism spectrum disorders. *Research in Developmental Disabilities, 28*(1), 9–22.
- Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis. In *Qualitative psychology: A practical guide to research methods* (2nd ed.). London: SAGE Publications Ltd.
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. Los Angeles: SAGE.
- Tarrant, P. (2013). *Reflective practice and professional development*. London: SAGE Publications Ltd.
- Taylor, L. M., Hume, I. R., & Welsh, N. (2010). Labelling and self-esteem: The impact of using specific vs. generic labels. *Educational Psychology, 30*(2), 191–202.
- Townsend, L. (2015). How The Bridge's heroine became a role model for women with autism - BBC News. Retrieved December 20, 2016, from <http://www.bbc.co.uk/news/disability-34995327>
- van Steensel, F. J. A., Bögels, S. M., & Dirksen, C. D. (2012). Anxiety and quality of life: Clinically anxious children with and without autism spectrum disorders compared. *The Journal of Child Psychology and Psychiatry, 41*(6), 731–8.
- Wagner, S. (2006). Educating the female student with Asperger's. In T. Attwood & T. Grandin (Eds.), *Asperger's and girls*. Arlington, Texas: Future Horizons, Inc.
- Welsh Assembly Government. (2004). *Special educational needs code of practice for Wales*. Cardiff: Welsh Assembly Government.
- Whiteley, P., Todd, L., Carr, K., & Shattock, P. (2010). Gender ratios in autism, Asperger syndrome and autism spectrum disorder. *Autism Insights, 2*, 17–24.

Willig, C. (2008). *Introducing qualitative research in psychology: Adventures in theory and method* (2nd ed.). Maidenhead: Open University Press.

Willig, C., & Stainton-Rogers, W. (2008). *The SAGE handbook of qualitative research in psychology* (2nd ed.). Los Angeles: SAGE.

Yin, R. (1989). *Case Study Research: Design and Methods* (2nd ed.). Beverly Hills: Sage.

Appendices

Appendix A – Details of Electronic Literature Searches.....	126
Appendix B – Semi-Structured Interview Schedule.....	127
Appendix C – Key to Interview Transcripts	128
Appendix D – Example of Initial Comments and Emergent Themes.....	129
Appendix E –Example of Development of Super- and Subordinate Themes	130
Appendix F – Extracts from Reflective Diary	131
Appendix G – Gatekeeper Letter	134
Appendix H – Letter to Mothers.....	136
Appendix I – Participant Information Sheet	138
Appendix J – Consent Form.....	140
Appendix K – Debrief Sheet	142

Appendix A – Details of Electronic Literature Searches

PsycINFO searches included the terms listed as *keywords* and as *subject headings* where available; Web of Science searches included the terms as *topics*; for ERIC searches, no restriction was placed on field. The literature search was conducted between September 2016 and April 2017. The figures below are approximate as they were taken from recreated searches in July 2017. Given the high number of articles returned by these searches, titles and abstracts were read to identify the most relevant articles.

Search Terms	Articles
PsycINFO Searches	
(autism OR asperger*) AND diagnostic and statistical manual	831
• of which published since 2013 ¹ AND in peer reviewed journals AND in English	199
(autism OR asperger*) AND (diagnostic bias OR differences OR gender gap OR human sex differences OR sex differences) AND (boys OR females OR gender OR girls OR human females OR human males OR sex OR women)	1532
• of which published since 2006 AND in peer reviewed journals AND in English	954
(autism OR asperger*) AND phenotype	1614
• of which published since 2006 AND in peer reviewed journals AND in English	1141
(autism OR asperger*) AND (caregiver OR family OR fathers OR mothers OR parenting OR parents) AND (coping OR mental health OR quality of life OR wellbeing)	1134
• of which published since 2006 AND in peer reviewed journals AND in English	544
(autism OR asperger*) AND comorbidity	1441
• of which published since 2006 AND in peer reviewed journals AND in English	885
Web of Science Searches	
(autis* OR asperger*) AND diagnostic and statistical manual	314
• of which published since 2013 AND in peer reviewed journals AND in English	116
(autis* OR asperger*) AND (diagnostic bias OR differences OR gender gap OR human sex differences OR sex differences) AND (females OR gender OR girls OR human females OR sex OR women)	2285
• of which published since 2006 AND in peer reviewed journals AND in English	1778
(autis* OR asperger*) AND phenotype	278
• of which published since 2006 AND in peer reviewed journals AND in English	248
(autis* OR asperger*) AND comorbidity	1015
• of which published since 2006 AND in peer reviewed journals AND in English	693
ERIC Searches	
(autis* OR asperger*) AND diagnosis	1642
• of which published since 2006 AND in peer reviewed journals AND in English	1261
(autis* OR asperger*) AND (educational psychology OR school)	2138
• of which published since 2006 AND in peer reviewed journals AND in English	1750

¹ The year that DSM-5 was published.

Appendix B – Semi-Structured Interview Schedule

1. I've got a lot of questions that I could ask you, but I'd prefer you to choose what you think is important to tell me. First of all, it would be helpful to know a little bit about you and your family such as who lives with you and your daughter, whether you work ... anything that you think is important.
2. Imagine I don't know anything about your daughter or ASD. Tell me about her. Her personality; what she likes doing; anything at all.
4. I'd like you to think back to the time when you first had concerns about your daughter/name. Can you tell me about that?
5. Can you tell me about the time when you first told someone about your concerns.
6. (If not already covered) And what about the first time you spoke to a professional? Tell me about that?
7. (If not already covered) When was ASD first mentioned?
8. (If not already covered) Tell me about your daughter's experiences in school before the diagnosis.
9. Moving onto the present, how do you think things have changed or stayed the same since your daughter's diagnosis?
10. Can you tell me about the person - professional, friend, family member, anyone - who's had the most positive impact on your daughter up till now?

Appendix C – Key to Interview Transcripts

Transcription broadly followed the advice for an orthographic transcript suggested by Braun & Clarke (2013). All names of people, places and organisations have been changed; other biographical details have been changed or redacted if these risk identifying participants.

Key

- Round brackets () are used to indicate the words, pauses, noises etc. of the participant; square brackets [] are used to indicate my own explanatory comments/observations.
- Brief non-verbal sounds– e.g. um – are spelt as best seemed to suit each occasion; for longer non-verbal sounds, an indication is given of what the sound was felt to convey.
- Abbreviations pronounced as a string of letters are separated by full stops (e.g. C.B.T.); those pronounced as words are not (e.g. SENCO).

Style	Meaning	Style	Meaning
(.)	very short pause typical of connected, flowing speech	XXX	redacted words/ very brief phrases
((pause))	a longer pause	[...]	longer redacted passages
((laughs))	the participant laughing	Typewriter	reported speech of mother
((laughter))	both participant and interviewer laughing	Segoe	reported speech of daughter
((unclear))	a word or very brief phrase that was unclear	Chalkboard	reported speech of father
<u>underlining</u>	indicates emphasis	Marker	reported speech of sibling
dash-	cut-off speech	Marker	reported speech of others
<i>italics</i>	book titles etc.		

Appendix D – Example of Initial Comments and Emergent Themes

Emergent themes		Initial comments
341 hostility of school - actively	and my daughter ((pause)) <u>she needed friends</u> and I think other children (.) <u>I was in the yard one day</u> when (.) children were making fun of her (.) in the primary school ((pause)) um (.) and you weren't allowed to see the teachers (.) you <u>had to ring</u> and make an appointment <u>and all this</u> and they were clearly (.) taking the mickey out of her and it was something to do with her shoes (.) right (.) and she had brand-new trainers on (.) there was nothing weird about these trainers (.) but they were (.) and it was obvious (.) and she felt so uncomfortable so I thought 'yeah <u>I'm not having this</u> ' and I thought 'I can't say anything to these kids' (.) so I walked down and I'd seen the deputy head at the time and I said 'can I go in and see Mrs Williams' which was her teacher at the time (.) <u>oh no no no no (.)</u> you've got to have an appointment' he said 'you can't go in in the morning' (.) so I said <u>right okay then?</u> (.) I said 'I'm going to take Rachel home with me (.) and when she's got time to fit me in' I said 'give me a ring' I said 'and I'll bring her	comp as a hostile place witnessing daughter being bullied seen by others unable to speak to teachers pointless procedures actions of others what's seemingly OK daughter's feelings of discomfort trying to sort out bullying barange of refusal/obligation having to follow school system having to accept this making school time with removing child from sch not feeling like a priority repetition of 'I said' - emphasising of strength/balance/challenge
342		
343		
344		
345		
346		
347		
348		
349		
350		
351		
352		
353		
354		
355		
356		
357		
341 procedures barriers to communication		
342		
343		
344		
345		
346		
347		
348		
349		
350		
351		
352		
353		
354		
355		
356		
357		
discomfort of daughter - fish out of water		
sense of snapping / breaking point		
issue of refusal		
not feeling a priority		
radical action to get help		

Appendix E –Example of Development of Super- and Subordinate Themes

Superordinate Theme	Subordinate Theme	Emergent Theme	Line No	Quote
Fragmented Daughter	Constructed through peers	Daughter as different from her peers	174	Rachel seemed quieter than all the other children (.) didn't want to get in the thick of it
Fragmented Daughter	Constructed through peers	Daughter's social isolation	191	I said I was a little bit concerned because she didn't seem to play with many children
Fragmented Daughter	Constructed through peers	Isolation of daughter from peers	194	I'm going <u>past</u> the school and I can see that she's by herself
Fragmented Daughter	Constructed through peers	Daughter not playing in groups	197	she'd have one friend (.) but if there was a crowd of them (.) she wouldn't be with them
Fragmented Daughter	Constructed through peers	Daughter suffering in a group	226	it was she couldn't tolerate (.) in a big group ((pause)) it it had to be one on one
Fragmented Daughter	Constructed through peers	Catalogue of daughter's difficulties	274	she would just be really upset (.) and nobody liked her (.) she had no friends
Fragmented Daughter	Constructed through peers	Daughter maturing slowly/being left behind	339	just her maturity
Fragmented Daughter	Constructed through peers	Seeing daughter through other's eyes	360	I got upset seeing how upset she was (.) because it's the way (.) other children seen her as well
Fragmented Daughter	Constructed through peers	Daughter as an outsider	362	they just sort of seen her as strange and that's why they didn't want to be her friend ((pause))

Appendix F – Extracts from Reflective Diary

Date: / /

Sense that deficit in social communication is two-way - grandmother judges her granddaughter by her own standards → so she fails to understand → am I going to be touching on something Foucaudian here?
→ dominant narratives?

↓
Would this approach enable my thesis to be useful to EPs or would it become an intellectual exercise?
(philosophical/political)

↓
certainly interesting but of limited practical value → how is this thesis going to stay grounded in what can help me to be a better EP?

When does participant use 'right okay'?

- assimilating information
- disagreeing but not reacting

Judgements - both ways - based on personal evaluation (i.e. evaluation of person) rather than an evaluation of the circumstances FTD

Date: / /

Are the time references indicative of trauma? suggestive

Is there an issue of interpreting if I think mother is on the spectrum

→ I don't think they are but there's the issue of detail → does it really mean something about the experience or reflect the participant's standard interactional style?

A sense of participant having done everything possible - bloody nuisance - and still it wasn't enough. Yet still needing to justify being a nuisance: → cognitive dissonance here

↓
What are the psychological consequences of this?

[Makes me think of stonewalling experiences I feel I've had and the feeling that eventually it will make you 'mad' - echoes of the double bind.]

Datum / Date:

Paradox of a system that insists on procedures but fails to follow procedures - the school can get away with it but the mother can't

Massive paradox of a spectrum and yet the girls either have it or they don't.

↓
And qualitatively rather than quantitatively different

System in which all information flows to the top (unless blocked)

Diagnostic system can't believe school system didn't get it but where is the dialogue between them?

13.11.16

Concise - where are the sticking points - why can't these mothers bring about change.

- Don't know what change issues are
- No review of process
- No intention to change
- No reframing → rigid thinking
- Hypotheses → not related to problem
- Ability to change → irrelevant
- Facilitate change → of dyslexia - even who can that not happening promote this?
- Evaluate ?

It's the core! → But how related to research questions?

326

Datum / Date:

7.11.16

What does 'right okay' convey?

- uncertainty
- lack of understanding
- attempts to assimilate new information
- attempts to contain reaction - to assimilate before responding
- disagreement

When she says 'a bit draining to be honest' does this suggest that she doesn't normally say this, that she'd normally say 'I'm fine'?

12.11.16

Sense of being reluctant even now to make a proper fuss.

Mismatch between containment (right on) and release (bawling eyes out)

Lots of clichés → do these point to the 'obvious' 'common sense' responses of Mum. There's a sense that no rational adult could think otherwise

* Suddenly realised that the daughters (at least the first) don't do anything - she is passive as the world responds to her. → they're reacting to her existence not her actions

327

Datum / Date:

Frequent repetition when describing daughter's struggle

Sense that for the school this is never about the daughter ... it's about the label. They have standard education, they have dyslexic education but never child-centred education ↓

The needs of the school and other systems seem paramount.
 gradually given

Paradox of mum having to explain dyslexic perspective to an apparently dyslexia-aware school

Seeing the multi-disciplinary process ~~and~~ as a background for professionals rather than a collaborative process.

Sense of intense emotional response to diagnosis being irrational / over the top / unjustified.

Paradox of seeing ADOs as 'proof' and yet still seeing need to justify ~~the~~ diagnosis.

21/11

So much scanning when describing daughter's difficulties ... "it it ..." as though mum feeling the anxiety herself?

22/11

Datum / Date:

16/11 Unconscious incompetence

20/11
Sense that the pervasiveness extends into the family and the effect upon relationships

P1/263
"just really draining" - puts me in mind of WOI and men in observation balloons - stress of powerlessness

Sense of mum having done everything reasonably possible but with no positive outcome

Sense that without diagnosis Mum unable to help in the past because she didn't understand the past - couldn't understand why friend seemed difficult

Language of P1 seems so much more hesitant when she's fighting her corner. It flows when she is making progress.

Contrast between how mother views her daughter and how others see her.

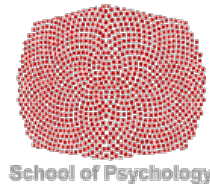
Simultaneously discrediting yet if going with not getting diagnosis of dyslexia → over reliance
→ asking to use their gut feelings to assume not ASD but not willing to use gut feelings
↓
to go with dyslexia as a working hypothesis
other children

23/11

Appendix G – Gatekeeper Letter

**School of Psychology
Cardiff University
Cardiff
CF10 3AT**

email: psychenquiries@cardiff.ac.uk



11th July 2016

Dear PEP,

Educational Psychology Research: Daughters with autism spectrum disorder

I am studying for the doctorate in Educational Psychology in the School of Psychology, Cardiff University. I have just completed my second year and collecting data for my thesis research.

I am interested in exploring mothers' experiences of obtaining a diagnosis of autism spectrum disorder (ASD) for their daughters from their initial concerns until diagnosis and beyond. As you might imagine I am particularly interested in girls due to the greater prevalence of diagnoses amongst boys, particularly amongst children with higher functioning autism or Asperger's syndrome. I am interested in recruiting mothers whose daughters have a diagnosis of ASD, and who attend a mainstream school, to take part in semi-structured interviews about their experiences. My research is supervised by Dale Bartle, Professional Tutor in the School of Psychology at Cardiff University and has been approved by the Cardiff University School of Psychology Research Ethics Committee who may be contacted should you have any concerns (Secretary of the Ethics Committee, School of Psychology, Cardiff University, Tower Building, Park Place, Cardiff CF10 3AT. Tel: xxx xxx xxx. Email: psychethics@cardiff.ac.uk).

I am writing to enquire whether you would be willing to allow Educational Psychologists within your service to pass letters to the mothers of girls in their schools with a diagnosis of ASD to request that they take part in semi-structured interviews. Further, would it be possible to use space within the educational psychology service (EPS) to conduct the interviews given that I anticipate recruiting a maximum of one or two participants in any one service?

A report of my findings will be submitted to Cardiff University as part of my research portfolio and might also be submitted for publication. It will also be made available to participating EPSs on request. However, neither the service nor any individuals will be identifiable in the report.

Mothers who volunteer are asked to contact me directly. They may if recruited elect to have the interview conducted away from the EPS to ensure anonymity. They will be interviewed individually. They will be asked to set aside an hour and a half for this although the actual interview will not take more than 70 minutes. I will need to make an audio recording of the interviews which will be destroyed when I submit my thesis in the Spring of 2017.

Many thanks in advance for your consideration of this project. Please let me know if you require further information.

Yours sincerely,

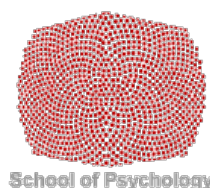
Janet Mycroft.

Janet Mycroft
DEdPsy Student
School of Psychology
Cardiff University
Cardiff
CF10 3AT
Tel:
Email: mycroftj@cardiff.ac.uk

Dale Bartle
Professional Tutor
School of Psychology
Cardiff University
Cardiff
CF10 3AT
Tel:
Email: bartled@cardiff.ac.uk

Appendix H – Letter to Mothers

School of Psychology
Cardiff University
Cardiff
CF10 3AT
email: psychenquiries@cardiff.ac.uk



12th July 2016

Dear Parent,

Educational Psychology Research: Daughters with autism spectrum disorder

I am studying for the doctorate in Educational Psychology in the School of Psychology, Cardiff University. I have just completed my second year and am conducting research for my thesis.

I am interested in speaking to mothers who have a daughter who has been diagnosed with autism spectrum disorder (ASD) or a closely related disorder about their experiences of obtaining a diagnosis. As you may be aware, many more boys than girls have a diagnosis of ASD and I am interested in hearing about the process mothers go through for their daughters. I am interested in speaking specifically to mothers as their experience might be different from a father's.

If you can say Yes to all the following questions, I might be interested in talking to you:

- Has your daughter been given a diagnosis of ASD, or a closely related disorder such as Asperger's syndrome, in the UK within the last five years?
- Was your daughter under the care of the same health authority for the whole of her diagnostic journey?
- Is your daughter in the equivalent of Year 13 or below?
- Has your daughter mainly been educated in mainstream state schools?

As I want to speak to mothers who have had broadly similar experiences, I'm sorry that I can't include mothers whose daughters have additional educational needs as the result of another diagnosis such as Down's syndrome. However, I can include mothers whose daughters have additional diagnoses such as ADHD (attention deficit hyperactivity disorder) or anxiety disorder as these are commonly associated with ASD. If you wish to take part and are uncertain whether you are suitable, please feel free to contact me to discuss it.

I would like to meet mothers face-to-face on an individual basis to talk about their experiences. This would take place in a quiet public space that we agree on such as an office in a council building. The session would last a maximum of 90 minutes and would be a semi-structured interview: this means that I have some ideas about the things we might talk about but I am more interested in letting the mothers decide what they want to tell me.

I would need to make an audio recording of the interview. I would then make a written copy of this, taking care to change any names so that you and your daughter can't be identified. Both the recording and the written copy will be stored securely.

My research is supervised by Dale Bartle, Professional Tutor in the School of Psychology at Cardiff University and has been approved by the Cardiff University School of Psychology Research Ethics Committee who may be contacted should you have any concerns (Secretary of the Ethics Committee, School of Psychology, Cardiff University, Tower Building, Park Place, Cardiff CF10 3AT. Tel: xxx xxxx xxxx. Email: psychethics@cardiff.ac.uk).

A report of my findings will be submitted to Cardiff University as part of my research portfolio and might also be submitted for publication. However, data will be anonymised meaning it won't be possible to identify either you or your daughter from the report.

If you are interested in taking part, I would ask you to contact me directly via email or phone to help ensure anonymity. Many thanks in advance for your consideration of this project. Please let me know if you require further information.

Yours faithfully,

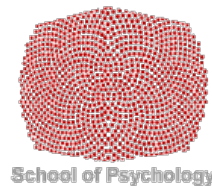
A handwritten signature in dark ink that reads "Janet Mycroft."

Janet Mycroft
c/o Dale Bartle
Professional Tutor
School of Psychology
Cardiff University
Cardiff CF10 3AT
Tel:
Email: mycroftj@cardiff.ac.uk

Dale Bartle
Professional Tutor
School of Psychology
Cardiff University
Cardiff
CF10 3AT
Tel:
Email: bartled@cardiff.ac.uk

Appendix I – Participant Information Sheet

School of Psychology
Cardiff University
Cardiff
CF10 3AT
email: psychenquiries@cardiff.ac.uk



PARTICIPANT INFORMATION SHEET

Mothers' experiences from initial concerns about their daughters to a diagnosis of Autism Spectrum Disorder

Invitation to participants in a research study

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask the researchers if there is anything that is not clear or if you would like more information. Take your time to decide whether or not you wish to take part.

Who I am:

I am studying for the Doctorate in Educational Psychology at Cardiff University, working under the supervision of Dale Bartle, Professional Tutor in the School of Psychology. My research has been approved by Cardiff University School of Psychology Research Ethics Committee who may be contacted should you have any concerns (Secretary of the Ethics Committee, School of Psychology, Cardiff University, Tower Building, Park Place, Cardiff CF10 3AT. Tel: xxx xxxx xxxx. Email: psychethics@cardiff.ac.uk).

What is the purpose of the study?

My research aims to investigate mothers' experiences of obtaining a diagnosis of ASD for their daughters from the time they were first concerned about their daughters until they received their diagnosis.

Who I am looking for:

I hope to speak to mothers whose daughter attends/attended a mainstream state school (up to Year 13) and received a diagnosis of in the past 5 years in the UK.

What the study involves:

The study involves a semi-structured interview which will last a maximum of 90 minutes: this means I have some ideas of the questions I'd like to ask but will be guided by the things you tell me. An audio recording of the interview will be made. An anonymised transcription (a written copy) will be made and the recording destroyed as soon as my report is finished. The interview can take place at an agreed public place such as council offices.

What are the benefits and risks:

Many more boys than girls are diagnosed with ASD and therefore people who work with children often know more about boys with ASD than they do about girls with ASD. This means that the process before diagnosis can be different for girls and boys. The findings may help improve understanding of mothers' experiences and the needs of mothers seeking diagnoses and/or help for their daughters.

You will possibly be speaking about a sensitive topic but will not have to answer any questions that you do not wish to answer.

What will happen to my information?

All data collected will be confidential. Recordings will be kept under lock and key. When transcribed, all identifying information will be removed. Anonymous data will be kept indefinitely but will not be traceable to any individual neither you nor your daughter will be identifiable in any report or publication that arises from this study.

Contact details of researchers:

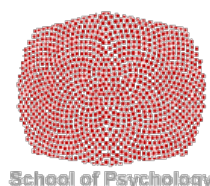
Janet Mycroft, DEdPsy Student, c/o Dale Bartle
Professional Tutor, School of Psychology, Cardiff University, Cardiff, CF10 3AT
Tel: ; Email: MycroftJ@cardiff.ac.uk

Dale Bartle, Professional Tutor
School of Psychology, Cardiff University, Cardiff, CF10 3AT
Tel: ; Email: BartleD@cardiff.ac.uk

Thank you for reading this information sheet.

Appendix J – Consent Form

School of Psychology
Cardiff University
Cardiff
CF10 3AT
email: psychenquiries@cardiff.ac.uk



Consent Form - Confidential data

Mothers' experiences from initial concerns about their daughters to a diagnosis of Autism Spectrum Disorder

I understand that my participation in this project will involve a semi-structured interview about my experience of obtaining a diagnosis of ASD for my daughter from the time I first had concerns about her. An audio recording will be made of the interview. The session will last a maximum of 90 minutes.

I understand that participation in this study is entirely voluntary and that I can withdraw from the study at any time without giving a reason. I can decline to answer any of the questions during the interview.

I understand that I am free to ask any questions at any time and I am free to withdraw at any time. I can discuss any concerns or complaints about this research with either Dale Bartle at the address given below or the Cardiff University School of Psychology Research Ethics Committee (Secretary of the Ethics Committee, School of Psychology, Cardiff University, Tower Building, Park Place, Cardiff CF10 3AT. Tel: xxx xxxx xxxx. Email: psychethics@cardiff.ac.uk).

I understand that the audio recording of the interview will be held confidentially, such that only the researcher can trace this information back to me individually. I understand that the recording will be transcribed and anonymised and the recording destroyed when the report is submitted and that after this point no one will be able to trace my information back to me. The anonymised information will be retained indefinitely. I understand that I can ask for all or part of the information I provide to be deleted/destroyed at any time up until the data has been anonymised and I can have access to the information up until the data has been anonymised.

I also understand that at the end of the study I will be provided with additional information and feedback about the purpose of the study.

[PTO]

I, _____(NAME) consent to participate in the study conducted by Janet Mycroft School of Psychology, Cardiff University with the supervision of Dale Bartle.
Signed:

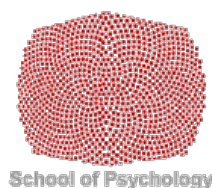
Date:

Janet Mycroft
c/o Dale Bartle
Professional Tutor
School of Psychology
Cardiff University
Cardiff, CF10 3AT
Tel:
MycroftJ@cardiff.ac.uk

Dale Bartle
Professional Tutor
School of Psychology
Cardiff University
Tower Building
Park Place
Cardiff
CF10 3AT
Tel:
BartleD@cardiff.ac.uk

Appendix K – Debrief Sheet

School of Psychology
Cardiff University
Cardiff
CF10 3AT
email: psyquenquiries@cardiff.ac.uk



DEBRIEF SHEET

Mothers' experiences from initial concerns about their daughters to a diagnosis of Autism Spectrum Disorder

Thank you very much for giving up your time to take part in this study.

As many more boys than girls are diagnosed with ASD it is possible that professionals are used to spotting the signs in boys rather than in girls. This possibly makes the experience of getting a diagnosis more complex for girls. This means it can take longer and girls can take longer to get help. Also the help available can sometimes appear more relevant to boys' difficulties and boys' interests.

As educational psychologists (EPs) can become involved early on with difficulties in school and can have a role in advising and training teachers, I am interested in finding out if there is anything EPs can learn from mothers' experiences.

The recording of this interview will be stored securely and will be transcribed, excluding any details which might identify you or your daughter. The recording will be destroyed as soon as the report is finished. Until that point, you have the right to withdraw all or part of your data without explanation. Afterwards it will not be possible due to the anonymising of the data.

Today's talk may have touched upon some sensitive areas for you. If you have been affected by today's discussion, please consider talking about it to a friend or contacting one of the following advice organisations:

The National Autistic Society:

Web: www.autism.org.uk or Tel: 0808 800 4104

Local autism charity:

Web: www.XXXXXXXXXXXXXX.org.uk or Tel: XXXX XXX XXX

Local SEN charity:

Web: www.XXXXXXXXXXXXXX.co.uk or Tel: XXXX XXX XXX

The Special Educational Needs (SEN) Team at XXXXXXXXXXXX Council also offer advice, support and signposting for parents/carers – Email: sen@XXXXXXXXX.gov.uk or Tel: XXXX XXX XXX.

If you continue to experience distress, you might want to make an appointment with your GP.

If you have any concerns or complaints about this research you can contact either Dale Bartle at the address given below or the Cardiff University School of Psychology Research Ethics

Committee (Secretary of the Ethics Committee, School of Psychology, Cardiff University, Tower Building, Park Place, Cardiff CF10 3AT. Tel: xxx xxxx xxxx. Email: psychethics@cardiff.ac.uk).

Thank you again for giving up your time which is very much appreciated.

A handwritten signature in black ink that reads "Janet Mycroft."

Janet Mycroft
c/o Dale Bartle
Professional Tutor
School of Psychology
Cardiff University
Cardiff, CF10 3AT
Tel:
MycroftJ@cardiff.ac.uk

Dale Bartle
Professional Tutor
School of Psychology
Cardiff University
Tower Building
Park Place
Cardiff
CF10 3AT
Tel:
BartleD@cardiff.ac.uk